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*Portfolio submitted in fulfilment of the requirements for the
Professional Doctorate in Counselling Psychology*

Relating within Neuropsychology:

“The unfamiliar becomes familiar” (Jumisko et al, 2008, p. 2277)

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List of Abbreviations

ABI- Acquired brain injury
GCS- Glasgow Coma Scale
GT- Grounded Theory
IPA- Interpretative Phenomenological Analysis
PTG- Post-traumatic growth
PTSD- Post-traumatic stress disorder
RTA- Road traffic accident
TA- Thematic Analysis
TBI- Traumatic brain injury

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Finally I wish to thank my dedicated colleagues. Your support and with have made both my research and my training entertaining throughout. I look forward to many more enjoyable times with you all in the future.

III. Declaration of Power

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IV. Preface to the Portfolio

Relating within Neuropsychology: “The unfamiliar becomes familiar” (Jumisko et al, 2008, p. 2277)

“The unfamiliar becomes familiar” resonated with my own personal experience during my journey to becoming a qualified counselling psychologist. At the start of my journey the world of clinical practice seemed unfamiliar. By my second year, I had a sense of my own strengths, and as I now complete my training I feel ready to embrace my new identity as a qualified practitioner with a keen sense of the challenges ahead. Throughout the process of writing this portfolio I was struck by the considerable parallels in my journey towards becoming a counselling psychologist and that of my clients and research participants. While I wouldn’t assume to have experienced the same level of trauma, I too have emerged from the process with a new identity and a new relationship to the field of psychology.

Relating by definition means to establish a connection. This portfolio represents a culmination of various connections throughout the three years of my training. ‘Relating’ in this context specifically reflects the dynamic nature of change within myself, with my clients, and my identity as a counselling psychologist. As noted, this personal process also mirrored the journey of my clients, following their neurological conditions, in how they related to themselves, others and the wider world. To quote one of my research participants, “I’ve still got traits of the old me, but I’m not the same person,” (Simon, L1582).

Although ‘relating’ was the theme that I connected most with and will be the focus of this preface, there are a number of interrelated themes connecting me, my practice and this portfolio. For instance, social constructionism, systemic practice and narrative exercises have been influential at various points throughout the portfolio and my own personal journey. Both systemic practice and social constructionism have been approaches that I have been drawn to in my clinical and research work respectively. Bowen et al (2010) highlighted the important perspective systemic therapy and its epistemological stance brings to the field of neuropsychology. Systemic practice transcends difficulties in communication, conversations, narratives, systems and community ideas in order to “promote curiosity, difference and change” (p.308) in the lives of clients. Throughout life my own curiosity about how humans relate to and cope with adversity in such different ways has led me, to always question and seek alternative explanations or theories. In fact, this innate curiosity and way of relating in the world is what drew me to a career in counselling psychology in the first place. I have been lucky in my clinical placements to have worked alongside various systemic practitioners and this has enhanced my understanding of working with this model within a neurological setting. For me, both systemic practice and neuropsychology sit comfortably alongside one another.

However, even more than that, systemic practice has offered insight into how I understand, relate to and interact with the world both professionally, with my clients in sessions and as a counselling psychologist in the wider context.

Narrative exercises were a significant part of this portfolio as evidenced primarily in the combined case study and process report and in the design changes necessary in the thesis. Narrative therapy was developed by White and Epston (1993) and is grounded in a social constructionist epistemological stance. It has grown in popularity as an effective intervention in understanding how individuals construct and relate to their life experiences in order to create meaning. Narrative therapy has been utilised effectively in the field of systemic practice and more recently in the field of brain injury (Chow, 2015). Narrative therapy takes the position that the “problem” is separate to the individual’s life and that through a process of deconstructing the narrative, re-authoring the narrative and then thickening the narrative we as psychologists can support individuals to utilise and relate to their own strengths to effect change. Its relevance to this portfolio lies not just in the aim of narrative therapy but in the secondary gain that it can re-address power imbalances through valuing the client and their own skills above all else. For me, this was an essential part of the portfolio work within this area, since clients often felt powerless following neurological illness, relating more to their brain injury or illness than to moving forward.

The role of counselling psychology within neuropsychology is still developing with no clear guidance on what it should look like but with a clear commitment to involvement within this field. This was further acknowledged in the review of the HCPC Standards of Proficiency for Practitioner Psychologists (2015). My interest in neuropsychology and brain injury in particular was established prior to engaging with my doctorate. I have been privileged, in that for the last three years, individuals who have experienced ABI have trusted me to support them on their journeys, at times, when they were dealing with significant difficulties. However, I was not anticipating how much learning about myself I would experience from my work within this field and how I would establish my identity as a counselling psychologist. Both my own journey and that of my clients and research participants has reinforced my belief in the resilience of individuals to direct their own paths in life and to adapt in the most challenging of circumstances. This is also fundamentally at the heart of what counselling psychologists believe about an individual’s capacity for growth.

This portfolio comprises three parts: Section A: Doctoral Thesis, Section B: Combined Case Study and Process Report and Section C: Publishable Paper. I intend to demonstrate the ongoing theme of ‘relating’ in neuropsychology and show how relating as it weaves through, links these pieces of work.

Section A: Doctoral Thesis

This doctoral research explores the experience of acquired brain injury (ABI) from a young adult's perspective utilising Thematic Analysis. Ethical considerations were at the forefront of my research design from the outset which involved significant consideration of the role of different relationships in the research process. Having been on placement within the organisation for three years as a trainee counselling psychologist, I had to reflect on both my own and the participants' prior relationships during the research process. In my opinion, the relationships that I forged over time, in fact strengthened the research process by allowing participants to open up, discuss their experience more comfortably and thus reduce the ethical risk to my clients.

As Bury and Strauss (2006) suggested, "we do not want research to diminish the significance of experiential material by forcing it into an empirical mode" (p. 122). It was imperative for me, that I recognised their experience and that participants benefited from the research. This was achieved through the inclusion of the narrative exercise, which allowed previously discounted participants (due to cognitive or communication issues) to be included in a meaningful way, giving voice to their experience and connecting with the meanings which they attached to their experience. Chow (2015) explained that the narrative exercises are therapeutic in this sense, since they provide balance. Narrative exercises enable the client to turn a problem saturated narrative into a more adaptive way of thinking about the "problem" and in doing so, "facilitate the creation of a new perspective" (p. 324) or rather, a new way of relating to their ABI.

Section B: Combined Case Study and Process Report

"The essence of our work as therapists is in striving to help our clients lend meaning to their own personal stories," (Bury & Strauss, 2006, p. 120). This resonated significantly within the combined report. As therapists and within the systemic model we do this through connecting to the client's feelings, thoughts and actions in order to make sense of their relationships with others and with the systems they are involved (Hedges, 2005). This client work was dynamic as well as set within a challenging context. Relating to each other was a key focus in order to balance issues of power inherent within the client's narrative.

Furthermore, it was crucial to consider my relationship within the wider systemic context in order to develop this therapeutic work. For example, I considered both my client's and my own role within the team and more broadly our roles in relation to the presenting issues, namely, a potential neurological diagnosis. I was therefore able to recognise my own perspective within my clinical practice and constantly challenge my view of the situation. What I aimed to evidence in this combined report was the often subtle challenges in the work that we as

counselling psychologists are engaged with. I wanted to provide an example of a therapeutic relationship where I was challenged, not just with a client presentation, but with other multifaceted systemic issues including ethical challenges. Negotiating these systems brought me not only closer to the client but also gave me a better understanding of my role and what it meant to be a counselling psychologist. As Bury and Strauss (2006) noted, “not only do we learn within a context of a single case conceptualization, but also we continually build a body of knowledge that informs all of our work as scientist practitioners” (p. 121).

Section C: Publishable Paper

This paper was produced as a result of presenting various research posters at a number of neuropsychology conferences during my training. An earlier version was accepted by the Counselling Psychology Review and is due to be published in late 2017. Initially the attendance at conferences was suggested as part of our own professional development, but I gained significantly more than this. I was excited to meet many of the academics whose papers are quoted within this portfolio and it allowed me to learn about the current research and the direction of overall practice within the field. It provided the opportunity to network, establish links and engage in discussions with other psychologists within the areas of both neuropsychology and counselling psychology. It led me to realise that much of the research continues to focus on quantitative methods and gives little voice to the experience of the individual. This re-ignited my passion and determination to give something back to my participants and to make a difference by pursuing this publishable article.

The conferences also allowed me to meet individuals, families, carers and practitioners working within the field and to engage them in discussions about my research. This feedback and insight into their lives were crucial in influencing my perspective about the importance of the topic and of disseminating the findings more widely. Ultimately, the cycle of scientist-practitioner and reflective-practitioner was supported through these conversations and led me to make the vital changes in my research design following the focus group. The reasoning behind these changes is reflected in more depth throughout this paper and in the thesis itself.

Counselling Psychology

Counselling psychology has much to offer the field of research within neuropsychology since, “at its core, counselling psychology privileges respect for the personal, subjective experience of the client over and above notions of diagnosis, assessment and treatment, as well as the pursuit of innovative, phenomenological methods for understanding human experience,” (Bury & Strauss, 2006, p. 113). Engaging with and relating to my clients, my research participants and other practitioners solidified for me, the relevance to counselling psychology, with its more

phenomenological approach, within the world of neuropsychology and specifically acquired brain injury. It was also crucial in terms of advocating for the usefulness, advantages and benefits counselling psychologists can offer within a more clinically dominated field.

Concluding Comments

In conclusion, my intention was to demonstrate that this portfolio evidences the mutual benefits of 'relating' and 'connecting', that counselling psychologists and clients can glean from working closely together in both a therapeutic and research setting. In my experience counselling psychologists are valued for the different approaches they bring to working with clients in the research field. Frankland and Walsh (2005) share some of the challenges that counselling psychologists face when working within the NHS model however, "part of the fundamental essence of counselling psychology is about negotiating between various models and ways of seeing the world," (p. 34). This was a key element in bringing together the portfolio presented. In fact, we have many additional aspects to our training, knowledge base and philosophy which I think enhances practice within this field and ultimately helps to provide more rounded services to people with neuropsychological issues. A key aspect of learning for me is the recognition of the profound contribution that I myself and Counselling Psychologists generally can make to this field.

Moreover, as I move onto the next stage of my development I finally have a strong sense of identity and can define my practice more confidently, as seen through the combined case study and process report. Counselling psychology is fundamental to my practice and professional development. I intend to continue my learning within the exciting field of neuropsychology to engage with further training in systemic practice whilst simultaneously enhancing my own levels of self-awareness in my evolving relationship with myself.

"I long, as does every human being, to be at home wherever I find myself," (Maya Angelou, (n.d.) cited in Conrad, 2014).

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Section A: Doctoral Research Project

Young Adults' Experience of Acquired Brain Injury:

Implications for Counselling Psychology

1. Abstract

Background and Aims: An estimated 275 per 100,000 individuals (UK) sustain an acquired brain injury (ABI) requiring hospital admission. Survivors may suffer from; depression, anxiety, post-traumatic stress disorder (PTSD) and an increased risk of suicide. From 2002/3- 2011/12, UK admissions for head injuries have risen by 33.5% with traumatic brain injury (TBI) considered the most common cause of disability and death in young adults aged 18-25yrs. The aim of this research was to gain insight into the lived experience of young adults with an ABI and to consider the implications for counselling psychologists.

Methods: The research was split into two parts. Stage one: data was collected from five participants (aged 18-30yrs) who had experienced an ABI; this formed the focus group. The focus group participated in eight semi-structured questions, broadly exploring the lived experience of ABI which informed the development of stage two. Stage Two: data was collected from nine different participants (aged 18-30yrs) who had experienced an ABI. They took part in individual interviews involving a narrative exercise called the 'Train of Life' followed by four semi-structured questions which provided stage two of the results.

Results: Thematic Analysis was utilised for both stage one and stage two of the research process. Focus group emerging themes were- negotiating relationships; growing stronger; and experience of self in the world. Individual Interviews generated the master themes- hidden consequences; discovering a different world; and piecing together a new narrative. Master themes comprised of eleven sub-themes - making sense of what could have been; change as a challenge; coping strategies; person in context; identity; connecting; rejection; surviving in a hostile world; moving beyond ABI; appreciating life and the paradox of survival.

Conclusions: Young adults with ABI more frequently access general psychological services. To effectively work within this field, counselling psychologists should have an increased awareness of ABI and its consequences in planning services, policies and work practices.

Key words: Acquired brain injury; young adults; Thematic Analysis; narrative exercise and lived experience.

2. Chapter One: Review of Literature

2.1. Introduction

This chapter will explore the literature surrounding young adults' experience of acquired brain injury (ABI). The term acquired brain injury or ABI will be used throughout this study with the exception of quoting directly from the literature. The chapter will move on to discuss the specific demographic details of prevalence age, gender and ethnicity. In exploring the literature, particular attention is given to the assessment, management, consequences, psychological support and impact on young adults, their families and wider community. It will then broadly describe the qualitative literature in ABI with themes relating to the subjective psychological experience and identity. It will explore some current issues identified with the young adult ABI population before establishing a developmental perspective of young adulthood. Following this it will reflect on the current research focusing on young adults with ABI specifically and the increasing role of social media in the ABI community. An important part of this review is to identify limitations in the literature past and present and therefore recognise gaps. The chapter concludes by establishing a fuller rationale that provides evidence for design recommendations.

Much of the current research in this area is dominated by quantitative studies whether that is focusing on pathology and dysfunction or by evaluating methods of rehabilitation and recovery from ABI. Few papers have focused on the perspective of the brain injured individual themselves. Fewer still have considered qualitative accounts of ABI in young adults. Throughout the chapter the following research questions should be kept in mind:

1. How do young adults make sense of their ABI?
2. How does their context; specifically age, impact on their experience of ABI?
3. What are the implications and significance to counselling psychology as a profession?

Implications for therapeutic intervention must be considered since various setbacks appear to occur over the life span for young adults with ABI (Robertshaw, 2013). In particular, the financial implications and service provision, to meet the needs of this population throughout the numerous periods of transition still to come. Anticipating these needs, being sensitive to individual journeys and learning from such research, may mitigate further adverse life experiences.

2.2. Aims

The primary aim of this study was to gain insight into the meaning of living with an ABI for young adults aged 18-30 years, in order to better support them, not only in the immediate recovery phase but in their future lives. The secondary aim was to consider the implications for counselling psychology in both service delivery and at an individual practice level. A third aim was to provide recommendations for future research.

2.3. Background

2.3.1. Definition of acquired brain injury

The term Acquired Brain Injury (ABI):

“Implies damage to the brain that was sudden in onset and occurred after birth and the neonatal period. It is thus differentiated from birth injuries, congenital abnormalities and progressive or degenerative diseases affecting the central nervous system.”
(Scottish Needs Assessment Programme Report, 2000, p. 7).

This research study focused on ABI which encompasses a wide range of disorders that can be sub-divided into two types of injury; traumatic brain injury (TBI) and non-traumatic brain injury (Kloet et al, 2013). Traumatic brain injuries are externally caused by; road traffic accidents, domestic accidents, industrial accidents, sport injuries or physical assaults. Non-traumatic brain injuries are triggered by internal events such as brain tumours, cerebrovascular accidents (strokes) or infections such as, meningitis or encephalitis. Even within these groups there is variation in aetiology.

2.4. Demographics

2.4.1. Prevalence

Approximately 275 in every 100,000 individuals within the UK are estimated to sustain an ABI that requires hospital admission (Royal College of Physicians, 2003). However, this statistic might not be an accurate reflection of the prevalence within the population, since it is thought that 25% of individuals with a subsequent diagnosis of mild-moderate brain injury do not seek initial medical attention (Langlois et al, 2006).

Over the last decade, UK admissions for head injuries have risen by 33.5% (excluding superficial injuries of the face) and between 10,000-20,000 severe traumatic brain injuries per year in the UK in 2011-2012 (National Health and Social Care Information Centre, 2012; Headway, 2012). In England and Wales 5% of those attending hospital for head injuries are scored within moderate to severe categories using the Glasgow Coma Scale (GCS) (Teasdale & Jennett, 1974) and 0.2% of these are fatal (National Clinical Guideline Centre, 2014). The most common causes of ABI are traumatic brain injuries, like falls, assaults and road traffic accidents with variations across age ranges (Williams, 2012).

2.4.2. Age

Traumatic Brain Injury (TBI) is considered to be the most common cause of disability and death in young adults aged 18-25yrs (Fleminger and Ponsford, 2005; National Health and Social Care Information Centre, 2012) with ten million injured worldwide each year (Gould & Ponsford, 2014). Harrison et al (2012) suggested that young people were at a significantly higher risk when living rurally. In a report commissioned by the Scottish Prison Service, pre-injury factors such as punitive parenting, other adverse life events and reduced supervision, along with socio-economic status were predictors of TBI (McKinlay et al, 2009). In another study, alcohol and drugs played a factor in brain injury with adolescents and young adults (Williams, 2012). Powell (2004) an author and clinical psychologist in the field of neurorehabilitation stated that; “a large percentage of survivors were adolescents and young adults with relatively normal life expectancies”, (p. 6). This finding was confirmed by Koponen et al, (2002). Thornhill et al (2000) determined the frequency of disability in young people and adults admitted to hospital with head injury through a case study analysis. 47% of the individuals were still considered to experience disability one year after injury.

2.4.3. Gender

With respect to gender, in all age groups, males are twice as likely to sustain traumatic brain injuries as females (Royal College of Physicians, 2003; Powell, 2004; Headway, 2012). The National Clinical Guideline Centre (2014) published that between 70-88% of people who sustain a head injury are male. Perron and Howard (2008) in a US based study focusing on a “delinquent youth” population found no demographic differences in TBI other than gender.

2.4.4. Ethnicity

Langlois et al (2006) stated in a brief article that focused on the epidemiology and impact of TBI in the US, evidenced that white ethnic children and adolescents were more likely to seek medical attention in comparison to African- American or other ethnic groups. The authors were

unable to determine in their results, whether this was due to an increased prevalence of ABI within specific ethnic groups or due to economic or cultural differences across ethnic groups. It was postulated that medical services were more inaccessible to African- Americans living in the USA. Other US studies evidenced the greater incidence of TBI in non-white ethnic groups (Corrigan et al, 2010; Thompson et al, 2006; Ownsworth, 2014). There were no UK studies that investigated differences in ethnicity and ABI.

2.5. Assessment and Management of ABI

Head injuries usually occurred in various stages over a period of time. It was not only the injury itself, but also the lack of oxygen to the brain and any subsequent bleeding, bruising and swelling, that required essential observation and assessment over time. Injury severity was most commonly assessed via the GCS, with scores ranging from 3-15 with a low score correlating to severity of injury. This took account of the depth and duration of the coma along with the duration of amnesia post-injury. Rehabilitation began immediately following injury and involved specialist services provided by doctors, nurses, physiotherapists, occupational therapists, psychologists (generally clinical), social workers and speech and language therapists. See care pathway diagram detailed below:

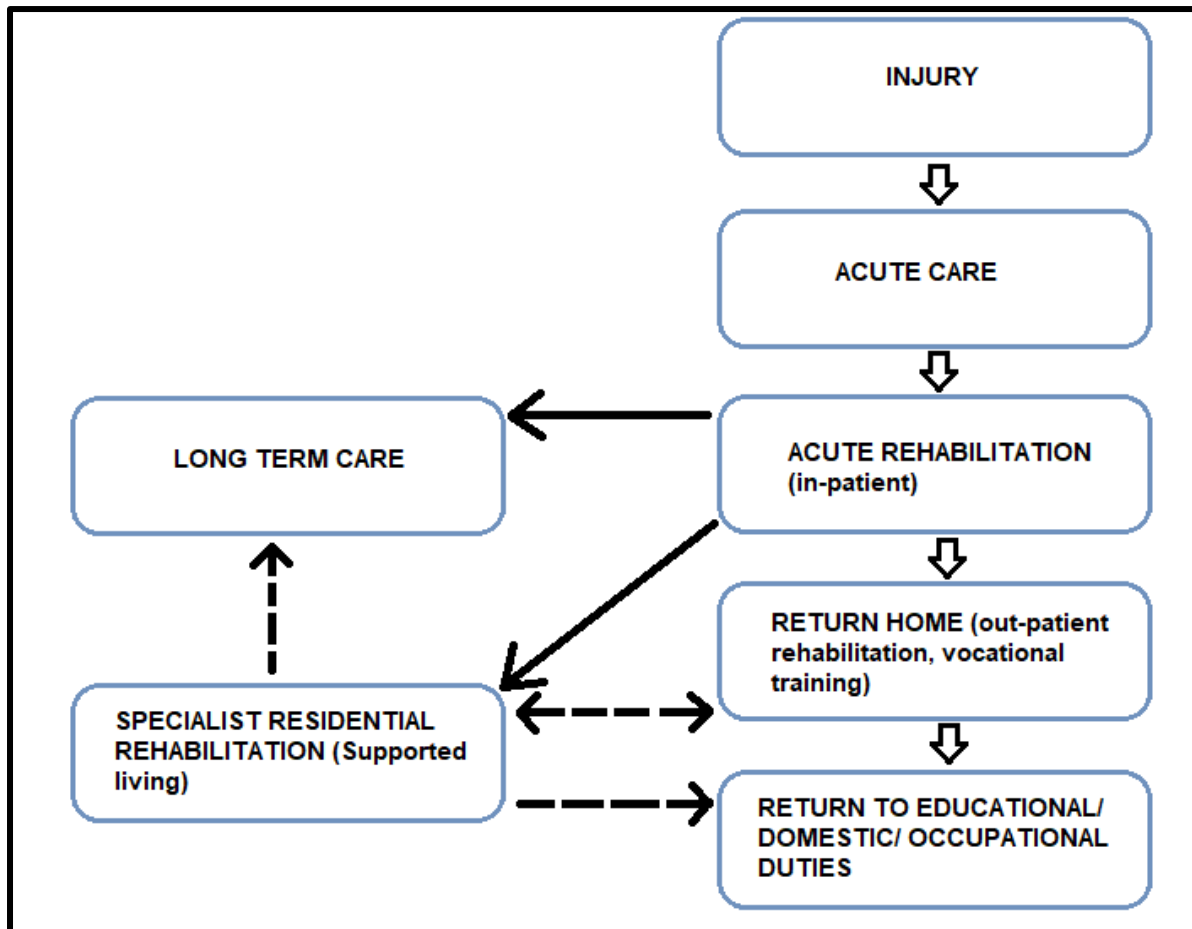


Figure 1: Care Pathway Following Acquired Brain Injury (Powell, 2004, p43).

Long term condition guidelines (Royal College of Physicians et al, 2008), although applied to general neurological conditions, laid out important points for the care of individuals following ABI. In addition the Royal College of Physicians and British Society of Rehabilitation Medicine (2003), have made recommendations which focused on improving the quality of life of individuals following ABI, through the promotion of co-ordinated care between multidisciplinary teams in both health and social care. This involved working towards clear goals aimed at reducing morbidity, restoring function and improving participation.

2.6. Consequences of Acquired Brain Injury

2.6.1. Impact

“Survivors are faced with the sudden and unexpected need to adjust to life post-injury, which can result in the onset of secondary difficulties, including depression and anxiety,” (Ralph, 2012, p. 12).

The majority of recovery occurred within the first two years post-injury but could continue for up to 5-10 years post-injury (Fleminger & Ponsford, 2005). Jumisko et al (2005) commented that, “literature also shows that people with TBI needed a great deal of support for a long time after the injury in order to manage their lives,” (p. 43). Long-term difficulties were reported as; cognitive deficits, sensory disturbances, communications difficulties, physical disabilities and behavioural issues in addition to personality changes.

As early as 1959, Kurt Goldstein noted the emotional impact of brain injury. The impact was much more complicated and subtle, with long lasting emotional effects far greater than initially realised. ABI had a major impact on social interaction leading to increased isolation and emotional distress (Couchman et al, 2014). Soo & Tate (2007), in their systematic review of psychological treatment of anxiety in a TBI population, reported that between 30-70% of their participant sample, were likely to experience significant psychological difficulties. Although these results were wide ranging in their responses, this reflected the complications inherent in ABI research such as participant awareness of pre and post-injury mental health. Likewise, Hesdorffer et al (2009) found in a review of literature, that ABI survivors were more likely to suffer from; depression, anxiety, post-traumatic stress disorder (PTSD) and were at greater risk of suicide than the general population. Long-term psychiatric disorders; depression, anxiety and substance misuse, in some individuals persisted at 30 year follow up meetings (Koponen et al, 2002). Whitnall et al (2006) evidenced levels of disability in young people and adults in a 5-7 year period post head injury, that were significantly more related to psychological distress, than to physical impairment.

Additionally, the impact of ABI was not limited to the individual themselves but the consequences were felt by family, friends, carers and the wider communities. Family and carers were found to have increased their responsibility to the individual with the ABI negating their own needs and desires (Robertshaw, 2013). But more importantly, Vangel et al (2011) evidenced that wellbeing and satisfaction of family members had shown a positive effect on the survivor of ABI. Conversely family dysfunction was linked to higher levels of depression (Schonberger et al, 2010; Weddell, 2010).

2.6.2. Public perception of acquired brain injury

Living with an ABI has been reported, as akin to living with an ‘unseen’ disability (Cloute et al, 2008), where individuals regularly dealt with, “not being believed, being forced to struggle for understanding, and having a feeling of being offended” (Jumisko et al, 2005, p. 44). In her doctoral thesis investigating the public’s understanding of ABI and the survivors perceptions of stigma, Ralph (2012) suggested that individuals with an ABI were more likely to conceal

their injury from others. Moreover, withdrawing from society and having increasing feelings of isolation due to their anticipation of discrimination were recurring themes.

Several studies have shown that survivors of brain injury felt that those around them; family, friends and professionals did not understand the meaning and impact that a brain injury had on their lives (Darragh, Sample & Kreiger, 2001; Swift & Wilson, 2001). Paterson & Scott-Findlay (2002) and Greenwood et al (2015) have recommended areas for further consideration when conducting research within the ABI population. This included but was not limited to having an awareness of the impact of fatigue and distress in participants, conducting pilots with interview questions and developing interview schedules with those who had experience in working with individuals following ABI.

Kovareky et al, (2007) found that the language used by therapists could deepen an individual's feelings of being "damaged goods". In addition to this, Ylvisaker et al (2008), found that "therapists unintentionally contributed to a post-injury identity that is the opposite of that which holds the potential to support active engagement in the construction of a compelling new life", (p. 717). This was important because multi-disciplinary rehabilitation can at times focus on a deficit model, in other words, on the individual's impairments, and as a consequence interfere with identity reconstruction following ABI. Ylvisaker et al (2008) argued that in order to balance these views, clinicians must have appropriate training to engage and support clients with these discussions. Furthermore they must show a willingness to work in collaboration with young adults. Critically, this has implications to future research investigations; we must be sensitive to the inadvertent consequences of research, such as heightening feelings of being "damaged". From the outset, we must listen to those who have an ABI, in order to gain insight into their world.

2.6.3. Cost of care and treatment of young adults

While it was not the scope of this research study to account for NHS and social care spending priorities, it was interesting that in a detailed analysis Beecham et al (2009) calculated the projected costs of health and social care for young adults following ABI. The majority of young adults following ABI returned home with no need for further medical or social care input. However, the projected costs to health and social care budgets for those who had subsequent disabilities were in excess of £47.2 million per year. Beecham et al (2009) cautioned that this could have been an under-estimate of the true costs due to under-reporting of ABI. Moreover due to informal and unpaid care provided by family and friends, this figure could have been significantly higher. Finally they warned that these costs were reflective of the current and actual costs of service provision and not necessarily a reflection of the ideal support that would "promote the best outcomes for young adults with ABI," (Beecham et al, 2009, p. 37).

2.7. Review of Acquired Brain Injury literature

2.7.1. Current qualitative trends

Vitally, there is a growing body of qualitative research shedding light on the different perspectives of ABI. This increasing investigation into the experience of ABI is raising awareness of the ongoing and long term consequences beyond the traditional rehabilitation phase. This is informing and changing practice within the field leading to new insights, treatments and importantly understanding for the therapeutic work completed with survivors of ABI.

Jumisko et al (2007) focused on the experience of treatment, as narrated by individuals and their carers. They utilised semi-structured interviews and thematically analysed the transcripts of twelve individuals with moderate to severe TBI and eight of their carers identifying two themes; being excluded and missing confirmation. These findings highlighted the negative role services played in the wellbeing of their participants following ABI. The researchers called for services to recognise their role and actively address the systemic barriers within the organisations reflected in the poor experiences participants stressed.

A few key features of this study heightened its relevance to this research field. Firstly, unlike much of the qualitative research to date, it directly involved those with more severe TBI who were most regularly discounted from research. Furthermore, for a qualitative piece of research this study used a relatively large sample size, therefore improving the likelihood of being able to reliably generalise its findings. However, it should be noted that this study was conducted within Sweden and so cultural differences perhaps limited its application to a UK population.

Jumisko et al (2008) then explored the experience of 'feeling well' for eight participants following ABI. A phenomenological hermeneutic model of analysis was applied to research interviews leading to the themes of; finding strength, regaining control over everyday life, being close to someone and being good enough. A strength of this study was that the researchers made significant effort to remain close to the 'meaning' provided by the participants through using their own language and checking understanding of the lived experience. This lent itself to the credibility of the research process. Initial limitations of the study were the relatively small sample size, along with the authors' acknowledgement of the cultural bias within the participant population. For example, the researchers mentioned that their participants' experience of 'feeling well' was conceptualised through a western perspective thus not easy to generalise to the wider population of individuals impacted by ABI.

Identity itself has been a key feature of much of the qualitative research to date. Gracey et al (2008) utilising a Thematic Analysis approach focused on how people constructed their self-concept following brain injury. Using structured small group exercises, they asked thirty-nine participants to explore a variety of post-injury areas with a focus on past, present and future self. Analysis revealed nine themes of which the three most prominent were; 'experience of self in the world', 'basic skills' and 'experience of self in relation to self'.

A strength in using a group based model is that it enabled participants to support each other through sharing their experiences. Conversely, however, it also isolated those who did not agree or 'fit in' with the majority in their experience sharing. Most importantly, what this study evidenced was that following ABI individuals searched for meaning in their lives through engagement with social and practical activities, which Gracey et al (2008) later recommended as a remit for rehabilitation. However, like much of the qualitative research under scrutiny a key limitation of Gracey et al's (2008) study was that the participant sample did not take into consideration those where the cognitive or communicative deficit was more pronounced or where participant's self-awareness was reduced. Arguably these factors are necessary in order to participate in group conversations in a meaningful way. Regardless, this paper provided an insight into the difference between how rehabilitation is currently provided and what it a more prominent focus for the individuals themselves, following ABI.

Uprichard (2010) explored the process of adjustment to brain injury for six participants following ABI as part of her doctoral thesis. Critically, she discovered that participants were often driven to make sense of these changes and that they continued, to want to play a valued role in society despite perceived barriers. Interestingly, she identified a role for professions in supporting individuals to move towards 'hope for change' and away from the traditional reductionist explanations, lending reinforcement to the argument of balance in research. Another key finding in reviewing this study was that, Uprichard (2010), asked participants how they experienced the research interviews. Participants advised that they were content to have been involved and that they had received some therapeutic benefit from being able to explore their experience. This is so important, as it emphasised the readiness for participants to engage with the topic and share their experience in a meaningful way. This highlighted the reciprocal nature of research and the importance of research, itself, effecting positive change for the participants involved in these studies.

Cocks et al (2014) conducted an in-depth qualitative analysis of eight individuals with a dual diagnosis of ABI and mental illness along with two family members and five support workers. This culminated in determining five key themes namely; loss, personal development, occupation, family and services, listed in order of perceived importance to the researcher.

Significantly, although some limitations were evident, such as utilising a small sample size and potentially weak generalisability of findings, however, it was thought that key recommendations outweighed these weaknesses and were indeed more stressed. Findings included greater emphasis on the long-term impact of ABI, increased awareness of the impact of ABI in the wider public, greater sensitivity and support for families and care givers, more emphasis on establishing meaningful occupations and increased provision of appropriate accommodation. The implications of these findings for young adults is clear; these issues are extremely important when considering the longevity of their life post-injury and the need to establish a clear mandate for further action on a policy level.

In a small scale qualitative study, using an interpretative phenomenology analysis (IPA), Howes et al (2005) investigated six women's experiences of brain injury. Key themes were identified, namely; awareness of change, emotional reaction, struggle to make sense and adaptation & acceptance. They "faced a new existence in the world as a person they didn't recognise and in some circumstances had no desire to," (p. 139). Participants felt isolated due to a combination of unemployment and physical impairment. They experienced common reactions to loss such as anxiety, anger, depression and fear. Interestingly, Howes et al (2005) found that participants with a greater post-injury period were less emotionally intense, made fewer comparisons with others and were less fearful of how others might react. This gave further weight to the changing perspective of ABI over time and raised questions about the correlation between time since injury and adjustment, especially when planning for therapeutic service delivery.

While gender differences were significant given the prevalence of males within the ABI population, it was not a particular focus of the current study. Nevertheless, it was important to consider how this was reflected upon within the qualitative literature. Firstly, the similarities in themes identified and secondly in the challenges that males, in particular, have in accepting therapeutic input. Katzer (2010) examined males' experiences of undergoing a traumatic close head injury using IPA, finding similar results to Howes et al's (2005) IPA exploration of women's experience, thus lending weight to support corroboration in the research. Individuals felt that they had little opportunity to discuss the psychological or emotional impact of their head injury. They had feelings of low self-esteem, worth and self-confidence. They experienced disconnect from their situation, withdrew from social interaction, experienced loss of relationships and felt uncertain about their future. These findings were duplicated in a study by Freeman et al (2015) exploring men's experiences of self within the social world using Thematic Analysis. Despite gender, common themes were stressed across all of the studies. This had implications for participant recruitment in the current study as the group were most likely to be male in this young adult population.

Bamford (2007) conducted an interpretative phenomenological analysis (IPA) of six semi-structured interviews and focused on the individuals' experiences of living with an ABI as an inpatient. Four main themes emerged namely; piecing together of the past and being aware of the present, transition from the old self to the new self, sources of strength and survival and experiences in rehabilitation. Positive and negative experiences emerged with post-traumatic growth (PTG) developing as an overarching theme. These findings were and still are controversial since current debate exists regarding whether survivors of ABI can in fact experience PTG. Some studies argued that it is difficult or impossible due to cognitive deficit (Maihau et al, 2005; McGrath, 2004) whereas others argued that even those with severe ABI can experience aspects of PTG (Collicutt, McGrath and Linley, 2006).

Bamford (2007) raised key limitations of her own research related to the population under investigation. She identified various risks relating to the participant group, namely; the time limitations of the study and the emotional toll of retelling their stories, which could have triggered the need for further support. Despite this, the quality of information gleaned from this study added to the argument of Collicutt McGrath & Linley (2006) and importantly for professionals, provided insight into the first few months of recovery. It supported our understanding of the issues and most importantly for the individuals themselves who face "psychological struggle to adapt to their new identity and come to terms with their cognitive and physical deficits" (Bamford, 2007, p. 183).

More recently, Robertshaw (2013) explored the experiences of individuals' journeys to acceptance following TBI through semi-structured interviews with eleven participants utilising a Grounded Theory approach. Five themes emerged; understanding limitations, changed perspectives, confirmation of prognosis, adapting and overcoming injury and finally barriers to acceptance. Robertshaw (2013) summarised how participants narratives attempted to understand their interactions with others, what supported them to move towards achieving acceptance and the barriers that prevented this journey. Most notably each journey was not a progressive or fluid model of recovery but one which had various setbacks along the way.

More than one limitation was significant from this study. These were identified again within the participant population, in that individuals differed in terms of time since injury and thus Robertshaw (2013) surmised that they also differed in their 'stage of recovery'. We noted from Howes et al (2005) that there is an inverse relationship between reductions in negative outcomes as the time since injury increases. Consequently the homogeneity of the participant group could have been affected by the length of time post-injury, therefore producing variable results. Additionally, some participants elected to have support present during the interview process while others did not. Whilst this could have enhanced the interview process, for

example by assisting with communication difficulties, it could also have led to bias, as participants could monitor what information they decided to share. Interview dynamics must be considered carefully in research design development.

Frazier and Kaler (2006) argued that research was more broadly focused on the negative aspects of life after ABI, failing to take account of the 'positive' changes that can develop. In response to this perceived negative perspective, a positive psychology movement developed that focused on the strengths of the individual, in order to improve wellbeing and minimise psychological distress (Seligman & Csikszentmihalyi, 2000; Collicutt McGrath, 2008; Silva et al, 2011).

Studies over a considerable period of time have reported that individuals describe positive outcomes of acquired brain injury such as an increased sense of self, new perspectives and re-evaluating values (Lennon et al, 2014). In an interpretative Thematic Analysis results highlighted that individuals utilised coping strategies to support the reconstruction of positive self-narratives, as they continually changed and evolved. This emphasised the importance of considering both positive and negative aspects of ABI since neglecting to acknowledge positive change, reduces the depth of understanding of the lived experience which is an essential aspect of the current research study.

Of critical importance was that the researchers believed in the positive aspects of recovery and post-traumatic growth (PTG). Hayes et al (2007) suggested that, "traumatic life events may also serve as a catalyst for growth that goes beyond an individual's level of pre-trauma psychological functioning" (in Silva et al, 2011, p. 94). Collicutt McGrath & Linley (2006) in a small scale cross sectional study of twenty-one participants showed a reduction in depression with an increase in PTG. Whilst Silva et al (2011) in a quantitative study of sixty participants on discharge from an inpatient unit were recruited to investigate post-traumatic growth using various measures. The results evidenced that there was a greater appreciation of life at six months post-discharge. Even more surprisingly, there was a significant increase in the level of PTG around the ten year post-injury follow up, when there was a negative association between PTG and symptoms of depression. This revelation in both Collicutt McGrath & Linley (2006) and in Silva et al's (2011) findings, was that it emphasised the need for more longitudinal research into life following ABI, since the impact of the ABI continued to evolve over time and was not limited to the immediate years following injury. These findings were further substantiated in a recent systematic review and meta-analysis of 744 published studies (Grace et al, 2015). The changeable nature of each individual's journey indicates the need for further research into the consequences of time-limited therapy so that services and practitioners can become more effective in supporting young adults with ABI.

Critics of positive psychology biased studies, on the other hand argued that, such positive psychology studies, did not consider those who were struggling with their brain injury and unable to consider positives (Lazarus, 2003; Evans, 2011). Schrank et al (2014) summarised concerns cited in Norem and Chang's (2002) paper that positive biased studies could cause individuals to avoid areas of necessary therapeutic processes "defensive pessimism can help people deal with anxiety, adapt and perform better than strategic optimists," (p. 96). This also concurs with La Torre's (2007) views.

2.7.2. Critical issues for young adults

It has been well documented that initial episodes of mental health issues are experienced during early adulthood (Jones, 2013; Kessler et al, 2007). McGorry et al (2011) in reviewing the literature found 75% of mental illness emerged by age 25, although it was not until later that individuals sought treatment. There were various reasons provided for this including; lack of education about mental health, stigma, early diagnosis and access to care being key issues. They found this was heightened for hard to reach populations which related to the ABI population. We know from the literature (Powell, 2004) that as individuals with ABI transition out of their initial stages of recovery contact with services reduced. Therefore we are relying on the young adults themselves to recognise and seek appropriate support in order to gain treatment for co-morbid mental health issues. A lack of education on the part of both professionals and individuals about the impact of ABI on mental health, compounded by impaired self-awareness, could also have played a role in hindering early diagnosis and access to care even more so for a young adult ABI population.

2.7.3. Developmental perspectives of young adults

Young adulthood is a period of experimentation and formation of identity where individuals then transition into adulthood, form mutual relationships and develop their self-image. Adulthood is typified by more stability and responsibility whereas change and transition are more common in young adulthood.

Erikson's (1963) model characterised the period of young adulthood (18- 40 years) by the internal conflict of intimacy versus isolation. During this time, he believed personality and identity became more concrete and that the individual's sense of self was more defined. In Erikson's model, "crisis occurs when a person cannot establish a clear and stable identity" which he believed could lead to further conflict. Arnett (2000) in his paper on emerging adulthood (ages 18- 25 years) in American young adults, described three main criteria of this period as; "accepting responsibility for one's self", "making independent decisions" and

“becoming financially independent” (p. 473). Like Erikson’s stage theory (1963), Arnett’s theory of emerging adulthood and identity formation relied on the resolution of these aspects.

Lenz (2001) in an article based on her doctoral thesis developed a theoretical framework for managing the transition from adolescence into young adulthood within the nursing profession, suggesting that adolescence was a period of identity formation. During this transition she asserted that physical maturation occurred simultaneously with social and emotional development. Whilst experiencing a heightened sense of self-consciousness this period of development then provided opportunities for young adults to identify with peers as well as embracing their own uniqueness.

2.7.4. Research into acquired brain injury in young adults

In an article for the British Medical Journal (BMJ), Fleminger and Ponsford (2005) advised that head injuries in people aged 15-24 years often disrupted important developmental processes impacting on the young person’s ability to develop independence from parental support, complete further education, employment or training and form social networks. This led to loss of self-esteem, social isolation, and family uncertainty. In fact, this highlighted the ongoing need for practitioners to have an awareness of the co-morbidity of ABI, further complicated by mental health issues.

In a large quantitative study, Thornhill et al (2000) analysed 2962 individual patient case records from across five hospitals looking at the impact of ABI on young adults. Specific problems were noted in all cases, such as increased dependency or unfit for work. However, it was not determined in the scope of this research if any of these issues were present prior to injury. Of significance, however, this study evidenced that the incidence of disability in those admitted to hospital following ABI was greater than expected. The implications being that disability was not easily assessed immediately following injury but something that emerged over time.

McMillan & Laurie (2003) surveyed characteristics, level of disability and services received by young people and adults living in nursing homes across Glasgow. Of ninety-two participants identified with an ABI, sixteen individuals were under the age of 40 years old and four participants were in their 20’s. 20% of participants were found to have a mild-moderate disability, no severe language impairment, no diagnosis of dementia and therefore no clear reason for placement within a nursing home. A review of the service provision is required in relation to young adults as services are often not designed to meet the needs or demands of this age group. Such a review could provide insight into why issues such as isolation are more prevalent following ABI.

Viguier et al (2001) investigated the relationship between cognitive, behavioural, depressive and self-awareness disorders in adolescents and young adult inpatients, following TBI. Two participant groups were studied; those with traumatic pathology and head injury and those with traumatic pathology but without head injury. Findings showed a higher incidence of depression but not anxiety and a greater use of prescribed medication in the group with head injury. However, limitations noted were that the age of the participants in the TBI group was lower and that there was a delay between the accident and the evaluation. Crucially, the questionnaires relied on self-reporting and there was a noticeable difference between the participant and clinician reports, which the researchers reasoned was explained through a lack of awareness on the part of the participants.

More recently and following the commencement of the current research study, Schrover (2014) investigated the impact of ABI on young adults aged 18-40 years old. Through Thematic Analysis of eight semi-structured interviews with young adults following ABI, she gave insight into their lived experience. Key findings were; impact of brain injury, inclusion/exclusion and dealing with consequences and support. This research, also considered issues pertaining to the chosen method and the challenges of analysing data where communication difficulties are apparent. It identified a clear and important finding in that young people with a brain injury are left to negotiate their lives in relative isolation and for the most part without support following ABI. This left young adults with significant feelings of exclusion from society and their wider networks, findings also supported within the wider literature reviewed. Therefore, supporting young adults with ABI to connect to their wider social context, in a way that feels right for them is essential. This needs to be a key focus for therapeutic input throughout the remainder of the young adults' lives. Whilst similar to the current study, Schrover's (2014) study did have limitations most notably, that methodological reflections were only considered in relation to rigour and validity and not more generally within the research design. For example, there was no clear evaluation of the difficulties which individual interviews posed for participants following ABI.

Whilst it was not the purpose of this research study to focus on any specific young adult population, it was a significant finding in the review of literature that "delinquent youth" populations were consistently reported, over the last twenty years, to have further increased risk of TBI (Perron & Howard, 2008; Miura et al, 2005; Rantakallio et al, 1992). Harrison et al (2012) evidenced that 60% of young offenders were estimated to have TBI. "Delinquent youths frequently exhibit high risk behaviours that can result in serious injury" (Perron & Howard, 2008, p. 243). In a cross-sectional study of 720 participants, Perron & Howard (2008) found that "delinquent youths" showed higher levels of psychiatric distress, early onset of criminal and substance using behaviours, more substance abuse issues and suicidality. However, it

was unclear and therefore could not be determined; whether this higher incidence of TBI was due to risky behaviour, for example, impulsivity and fearlessness in the population, or whether young people were at risk of offending due to the ABI.

1.4.1. The role of social media and ABI

More recently there has been research into the role of social media within the ABI field, for example, people engaged with online support groups, accessing resources and sharing information relevant to ABI (Vaccaro et al, 2007; Todis et al, 2005). It was noteworthy that various studies have highlighted both positive and negative aspects of social media engagement. Advantages suggested were; increased social connectedness, less intrusive ways of engaging with others, ability to control levels of disclosure and use for it as a memory aid (Baker & Moore, 2008; Todis et al, 2005). Negative impacts of social networking included; cyber bullying, harassment, privacy concerns (Boyd & Ellison, 2007) or feelings of disconnect and exclusion (Kilov et al, 2010). Easton and Atkin (2011) have commented that, “the internet has given millions of people access to new ways of not just exploring their health conditions, but also recording and sharing them with other people,” (p. 36). Young adults of today who have grown up using social media may have a different experience post-ABI than the pre-social media ABI cohort.

2.8. Limitations of the Literature

Having reviewed the literature it is evident that most of the quantitative studies gathered data retrospectively from hospital samples. While it was extremely difficult to achieve fully homogenous participant samples, many were not representative of the general population of young adults with ABI, since those individuals with mild symptoms were treated by local doctors and never recruited. Other weaknesses in methodology occurred when there was significant delay between the accident occurring and the evaluation of data. This has been a main criticism of the majority of ABI research to date (Newby & Groom, 2010). Some studies were limited by the nature of the sample used, as participants were at different stages of recovery (Robertshaw, 2013). Effort must be made in order to ensure that there is clear guidance around the inclusion criteria for participants to reduce the issues related to population samples.

Early reasoning for the gap in literature surrounding individuals' experiences of brain injury postulated that, participants themselves did not easily fit into existing models of therapy (Judd & Wilson, 1999). Qualitative accounts of ABI until recently, were from carers or clinicians'

perspectives. A major flaw in all quantitative research is that, in the main, it failed to acknowledge the personal experience as reported by the brain injured individual themselves. This current research study therefore aimed to gain insight into the lived experience of ABI for young adults with a wide variety of backgrounds and experiences, and not be bounded by those who had increased levels of communication and cognition.

Researchers involved in rehabilitation were generally more focused and involved with individuals who had problems in coping with their lives (Nochi, 2000).

“Poor self-awareness, memory difficulties, perceptual problems and impairments of language functions were thought to pose insurmountable obstacles to the clinician working with brain-injured persons,” (Coetzer, 2007, p. 39).

Others had concerns that cognitive impairments led to a skewed view of the brain injury (Brown et al, 2006). Many studies relied on self-reported measures; a method purported to be ineffective with this population as participants lacked the self-awareness to give accurate representations of the issues (Viguier et al, 2001). Other studies highlighted issues of self-awareness in relation to the injury that led to an underestimation of disability or impact (Thornhill et al, 2000; Bamford, 2006).

Characteristically, there were two main issues featured around data collections; firstly there was no way of ensuring that the difficulties, self-reported post-injury, had not existed pre-injury and secondly that self-awareness of difficulties may have led to the underestimation of the actual disability. These were common difficulties raised across the literature reviewed in using such measures. Again this finding had implications for the current research, in working alongside experienced others and in selecting participants who could engage meaningfully in the research.

In general the quantitative research that focused on young adults, sometimes referred to the same population as young people. On the other hand it should be noted that whilst, in general, many papers on ABI may include participants that ‘fit’ the young adult population, because of the age range disparity (for example age zero to 25 for childhood/ adolescent populations or eighteen to eighty for adult populations) the findings can not be specifically applied to young adults. Various significant life transitions happened within this age range and the impact of an ABI differed greatly depending on the age and stage at which it occurred. For example, those injured in young adulthood and who returned home to parents would have significantly different challenges to those injured during their forties who were married with children or those injured in their seventies whose partners may have passed away. This made it very

difficult when reviewing the literature, to obtain true consistency in any of the findings across the ABI population.

Qualitative research, in contrast, was sparse. Fundamental to qualitative research of this nature is “how people make sense of the world and how they experience events,” (Willig, 2013, p. 8). Gracey et al (2008) stated that qualitative research supported the development of depth in understanding of people or groups who have been excluded or disregarded in the research field. To create this ideal structure in qualitative research design is very difficult to achieve, and was not an easy route to take, but necessary in order to gain more in-depth knowledge of what young adults thought and felt.

More recent qualitative research within ABI has started to shine a light on these first hand experiences allowing the research process to be more person-centred. Medved and Brockmeier (2008) argued in their discursive approach to qualitative research involving participants with severe memory loss that, to not include individuals’ accounts in the research assumed that individuals were without agency and involvement in their own lived experience. This opinion has been widely held across the ABI research for a number of years (Paterson & Scott-Findlay, 2002; Brown et al, 2006; Uprichard, 2010; Freeman et al, 2015; Greenwood et al, 2015) and thus should not be ignored. In order to understand the experience of ABI fully, it was essential to include those with ABI and necessary to adapt to meet their needs, regardless of the challenges that posed the researcher.

Challenges to the literature review also existed and were noteworthy in relation to the current study. Firstly there was well documented evidence signalling the difficulties in developing an appropriate search strategy in relation to ‘qualitative research’ and ‘ABI research’. In particular the ambiguity of titles, the recording of indexing of qualitative research and the variety of terminology used to explain similar concepts for example; ABI, TBI, head trauma and brain injury when they were all used interchangeably. This posed difficulty in both the scope and relevance of the search. The present research study overcame these issues through utilising both specific and broad terminology (Flemming and Briggs, 2007) in the search strategy (See section 4.1.1 and 8.1.1).

2.9. Relevance to Counselling Psychology

Powell (2004) stated that during the initial stages of recovery, input from therapeutic and health services were intensive but as the individual recovered, these services generally reduced. Most rehabilitation teams have a psychologist, typically a clinical psychologist, who assessed

and advised on treatment as part of that rehabilitation process. Therapeutic intervention focused on the emotional problems involved in adjustment and coping with the ABI. The reintegration period has been highlighted as a key period of adjustment and acceptance of people with ABI (Ownsworth et al, 2011; Turner et al, 2011, Silva et al, 2011).

Bearing in mind that ABI and its consequences are enduring, often across the individual's life span and involve the wider social context specifically family, carers and friends, Judd and Wilson (1999) commented that;

“organic brain damage needs to be conceptualised within a framework which acknowledges the effects upon both the physical, and the non-physical aspects of being; as such the organic damage and the psychological damage are inseparable,” (p. 5).

They go further and suggested a framework which counselling psychologists could utilise to enhance their skill set. With its focus on the phenomenological experience namely understanding therapy through the client's own experience, counselling psychologists are appropriately placed to therapeutically meet the needs of individuals with ABI. Counselling psychologists;

“understand diagnosis and the medical context to mental health problems and work with the individual's unique subjective psychological experience to empower their recovery and alleviate distress” (BPS, n.d., <http://www.bps.org.uk/>).

Moreover the HCPC (2015) Revision of the Standards of Proficiency for Practitioner Psychologists have suggested that counselling psychologists show increased commitment to issues relating to “neuropsychological processes”, “adaptation and resilience to adverse circumstances and life events”, and “the nature of relationships throughout the lifespan” (pp. 15-23). This provides counselling psychologists with a clear mandate for supporting individuals following ABI and it is surprising therefore, that counselling psychology does not currently have a significant presence in this field. Furthermore, individuals with ABI, more frequently access general psychological services, namely Improving Access to Psychological Therapy (IAPT) services, where counselling psychologists are more prevalent in comparison to ABI services. Therefore to effectively work with individuals following ABI increased knowledge within this field and an awareness of ABI is crucial.

2.10. Rationale for the Current Study

Although information about brain injuries has increased over recent years there still remains widespread misconceptions, for example, the speed of recovery, a lack of understanding and negative attitude towards the individual with the brain injury.

Few research studies have focused on the perspective of the brain injured individual themselves. This is particularly important in creating truly client centred services and in addressing any power imbalances between client-therapist within the counselling relationship (Darragh, Sample & Kreiger, 2001; Swift & Wilson, 2001).

Although some qualitative research has highlighted the value in understanding the individuals' experience of ABI, research remains dominated by quantitative accounts. Moreover, most of the research to date has not discriminated in age. There is limited literature that has focused on young adults and even fewer studies that have taken a qualitative approach to their reported experiences. Evidence has shown that young adults are at the greatest risk of acquiring a brain injury and have a higher incidence of mental health issues. Both developmental theorists and mental health specialists recommend early psychological intervention with this age group.

The heightened level of stigma and discrimination that individuals experience following ABI, within their wider community and society has been well documented. Since it causes increased social isolation and likely increased incidence of mental health difficulties, it is an area which should be further addressed in research, to better inform practitioners. These issues have far reaching consequences to the support services involved in social and health care.

Cultural difference has implications for the current study particularly in reflecting on the researchers own background and the assumptions that she may bring to the research process. Most importantly however Jumisko et al's (2008) research underlined the, "importance of professionals carefully investigating the needs and wishes of the person they care for and on the basis of this, together with the person with TBI, finding the solutions that support the person's feeling of wellbeing," (p. 2279).

Rehabilitation too, while specifically focused on the individual, must take account of the impact the wider context has on the individual's recovery. This has been an important recommendation of the Royal College of Physicians and British Society of Rehabilitation Medicine (2003) that recognised the importance of family within the rehabilitation process.

Social media has led to a cultural shift since the start of the 21st century. This includes platforms such as Facebook, Twitter, blogs or online dating sites. It has changed the way that individuals interact and establish and maintain relationships. Therefore it would be apt to take into account the opinions of young adults with ABI and their use of social media to aid recovery

Linking all of the above reviewed literature back to Beecham et al (2009) we should consider how the long term financial implications of care for young adults with ABI would be reduced on a policy and practice level. For example, when reflecting on the co-morbidity of young adults with ABI who suffer from mental health issues, we should consider how investment in education and training, targeting this population, could reduce the incidence or severity of mental health issues. Much investment targeting the young adult population early on could support the reduction of long term care costs. This is particularly important since medical advancements mean that young adults are surviving longer following ABI.

A robust, qualitative research study is therefore required to close the gap in the literature, to move academic understanding forward and provide informed recommendations for professions and practitioners. Crucially, new research must include and enable young adults with ABI, in the context of their daily lives, to express their views and give voice to their needs. An essential principle in carrying out this research is to listen to the young adults discuss important aspects of their lives and how they make sense of their ABI post-injury.

3. Chapter Two: Methodological Overview

3.1. Introduction

The principle research aim was to investigate the lived experience for young adults who had an acquired brain injury (ABI). This chapter considered the research paradigm and provided critical consideration of the research methodologies and methods available within the quantitative and qualitative research field. This ensured that appropriate and relevant methodology and methods were selected and would reflect the young adults' views about their lived experience. Therefore this section provides a theoretical critique and explains the rationale for decisions taken throughout the research process.

3.2. Qualitative versus Quantitative Perspectives

For the past 150 years a positivist model has dominated the field of Psychology (McGrath & Johnson, 2003; Willig, 2008) emphasising objectivity rather than subjective experience (Wolfe et al, 2003). More recently, psychology research has acknowledged the benefits of qualitative research. "Qualitative researchers tend to be concerned with the quality and texture of the experience rather than with the identification of cause-effect relationships," (Willig, 2013, p. 8). Qualitative research has focused on individual meanings created and attributed to the events, adopting a more in-depth exploration.

Much of the current quantitative investigations in the area of acquired brain injury (ABI) is dominated by research that focus on pathology, dysfunction or comparative studies evaluating methods of rehabilitation and recovery from ABI. Notably the benefits are in terms of expanding our knowledge of ABI, identifying those at highest risk and considering preventative measures in reducing the incidence of ABI.

Within qualitative research there are several approaches including, amongst others, discourse analysis, grounded theory and phenomenological investigations. Whilst these approaches share a common purpose; particularly in holding the participants' experience central (Elliott et al., 1999; Starks & Brown Trinidad, 2007), they differ in philosophical standpoint. No qualitative researcher will produce the same results due to their differing approaches and philosophical stances, posing difficulties in validity and generalisability.

3.3. The Research Paradigm: Philosophical Underpinnings

In choosing an appropriate research method it was essential to first consider the research paradigm. Guba (1990) argued that paradigms between ontology, epistemology and methodology inform the researcher's perspective of the world and thus the approach to research.

3.3.1. Ontology

Ontology is a continuum from realism to relativism. Realism assumed reality exists independent of thoughts and beliefs, resulting in a cause and effect reaction (Ponterotto, 2005). Realism lends itself to more quantitative research as it is based on the premise that reality is measurable. However relativism assumed that reality is socially constructed and thus only understood through interpretation.

Along this continuum lies critical realism (Bhaskar, 1975, 1989, 2011) suggesting that there is a stable and enduring reality separate from human thought. Personal perceptions of that reality would differ based on an individual's values and beliefs (Finlay, 2006). It argued that, "while experience is always the product of interpretation and, therefore, constructed (and flexible) rather than determined (and fixed), it is nevertheless 'real' to the person who is having the experience," (Willig, 2013, p. 12). Critical realism acknowledged an individual's inner subjective knowledge that differed in perspective but was equally valid. It is more attuned to the counselling psychology philosophy which has a more phenomenological focus with the researcher seeking to understand how individuals define their own reality from the beliefs and thoughts attached to their experiences.

This research was also ontologically founded in critical realism; it assumed the reality of ABI is true and not constructed. It also assumed that the lived experience of ABI will differ for the individual based on their interpretation of their experience. This was in keeping with the researcher's role and practice as a counselling psychology trainee within the organisation.

3.3.2. Epistemology

Finlay (2006) advised that the researcher should choose an epistemological stance; one which reflects the researcher personal views, beliefs, values, professional practice and in this case, as students with academic demands. In keeping with critical realist ontology, this study was epistemologically grounded in the social constructionist stance. "Social constructionist inquiry is principally concerned with explicating the process by which people come to describe, explain or otherwise account for the world, including themselves, in which they live within," (Gergen, 1985, p. 266). It maintains that there is no single truth but that knowledge is

determined by both the participant's and the researcher's social, cultural, moral, ideological and political views. In other words, knowledge is a construction of both the internal psychology and the external reality. These in turn influence the interpretation of data (Braun & Clarke, 2013). This position assumed that all knowledge is perspective dependent, where differing perspectives provided insight into the same phenomenon (Willig, 2001).

3.3.3. Methodological considerations

The terms method and methodology are often used interchangeably however the latter is more directly informed by the researcher's epistemological stance (Willig, 2008). Method refers to the specific technique or model for data collection/analysis whereas methodology refers to a theoretically informed framework (Silverman, 2005). The methodological approach applied to this research paper was Phenomenology (Husserl, 1970). Phenomenological research aims to draw out the lived experience, "thematized through language and refracted through philosophical, theoretical, literary and/or reflexive lenses," (Finlay, 2011, p. 79). Phenomenological investigations are interested in asking questions about lived experiences and can be either descriptive or interpretative in essence. Husserl believed that there were universal aspects to human lived experience which the researcher could access once they bracketed their biases and presuppositions (Ashworth, 1999; Lopez & Willis, 2004). His approach was essentially a descriptive phenomenological methodology.

Husserl's concept was furthered by Heidegger (1962) who introduced the role of hermeneutics namely, looking for meaning hidden within interpretation of narratives within the context of the social, cultural and historical environments (Dermot, 1999). Husserl and Heidegger's models differed in that Heidegger did not believe it possible to erase the influence of the researcher from the data. He reasoned that social, cultural and historical influences were inherent in the processes of creating meaning (Owen, 1995). This was true of both the participant experiencing the phenomena and the researcher listening to the participants account.

Various different phenomenological frameworks have been developed, namely; lifeworld approaches, Interpretative Phenomenological Analysis (IPA) or hermeneutic phenomenology. This research specifically took the view of hermeneutic, interpretive phenomenology. It did not demand the use of any specific method but it emphasised the application of the hermeneutic circle. This is a cyclical process by which the researcher understands the data as a whole with reference to the individual accounts and understands the individuals' accounts with reference to the whole of the data (Finlay, 2011). This encapsulated the idea that the researcher's interpretations, the participant's interpretations and the context of the research were intertwined in the understanding of the phenomenon under investigation. Hermeneutic phenomenology takes the view that both structural and textual information are analysed

through the data but that there is a shift towards interpretation rather than a purely descriptive analysis. Moreover the context is of utmost importance in conceptualising the results.

There are four key principles to hermeneutic phenomenology;

- a) A commitment beyond science towards the human condition.
- b) Explicit use of interpretation of the illicit meanings whether they be implicit or hidden.
- c) Reflexive acknowledgement of the researcher's involvement to enable further understanding of the interplay between the researcher, participant and the phenomenon under investigation.
- d) Attention being paid to expressive writing using myth and metaphor namely focusing on the way findings are communicated in order to elicit the lived experience.

Finlay (2011) suggested that this methodology was particularly suited to social or human sciences. This framework also sat well with the epistemological stance of this research.

3.4. Methodologies

This study was initially conceptualised with the intention of using an Interpretative Phenomenological Analysis (IPA). As such the initial focus group questions were broad and open, designed with IPA in mind. Reflections following the focus group, and prior to any analysis raised the issue that due to participants' limitations, such as memory loss and cognitive difficulties, many had struggled to engage in a semi-structured interview schedule with the depth of insight required for a doctoral research project.

In discussion with my university research supervisor we considered the various implications of continuing to pursue an IPA research project. Due to the level of prompting and encouragement required by the researcher, it was felt that IPA was no longer the "best fit" for the research project. The researcher was unable to remain as bracketed as required. Actively engaging in the interviews throughout the research process and specifically in the co-production of the narrative exercise was essential in gaining the depth and richness of data required for this study. This was consistent with a social constructionist position in that analysis will be influenced by what the researcher brings to the data. However, bracketing was important in this instance as the researcher also held a clinical role within the organisation which included holding personal information about the participants. This required the researcher to balance the roles since it could potentially have influenced the direction of the interviews. Furthermore, information gleaned from the video recording of the focus group, for example, body language and expression or emphasis, proved essential in understanding the

context in which the information was presented and gathered. Failing to take account of this early on, may have resulted in the analysis not reaching the necessary depth of inquiry required in a thorough doctoral research project. Nor did it do justice in my opinion to the participants lived experience and their needs.

Both methodology and method were adapted in order to maximise the analysis of the information. It was paramount that whatever methodology and method selected, that it was aligned with the researcher's ontological and epistemological stance and was in keeping with the aims of the research. Therefore after much investigation hermeneutic phenomenology and Thematic Analysis were selected as being most suitable in both meeting the research aims and providing a rigorous and credible approach to the research analysis. In addition, Thematic Analysis provided flexibility in addressing design issues when stage two of the research project was adapted, (as discussed in sections 5.1 and 5.3).

3.4.1. Thematic Analysis

Thematic Analysis (TA) was selected as the most suitable research method because it was consistent with the ontological, epistemological and methodological position of this research. TA is a widely used method of qualitative analysis. It seeks the identification, synthesis and reporting of patterns that emerge as being significant to the described phenomenon (Daly, Kellehear & Gliksnam, 1997). Braun and Clark (2006) argued that these themes must be comprehensible, substantial and grounded in the data. Boyatzis (1998) argued that TA goes beyond the reporting of patterns but interprets the findings within the research. Interpretation was important to this study, in acknowledging the participants' subjective views but also the context within which these views were constructed and researched (Horsefall et al, 2001; Leininger, 1994).

Aspects of TA have underpinned many of the different qualitative research methodologies such as Grounded Theory (GT) or Interpretative Phenomenological Analysis (IPA) which both rely heavily, on line by line coding, in order to identify meaning in the data (Willig, 2013). Consequently TA has only gained recognition as an independent method more recently (Braun & Clarke, 2006).

There are many styles of Thematic Analysis namely; inductive (Frith & Gleeson, 2004), theoretical/ deductive (Boyatzis, 1998; Hayes, 1997), experiential (Roulston, 2001; Aronson, 1994) and constructionist (Braun & Clarke, 2006). This study was most aligned to the experiential Thematic Analysis that focused on the participants' standpoint; specifically how they experienced and made sense of the world. Experiential TA fitted well with the methodological framework of hermeneutic phenomenology. Unlike IPA or GT, TA is a method

for data analysis and not a methodology, making it flexible in philosophical background and research design. The most cited approach of TA is Braun & Clarke's (2006). This is a systemic, multistep, rigorous process which used an inductive process to explore the data. Specifically, TA was well suited to the current research as it allowed opportunities for the nuances of ABI to be explored, which was particularly significant given the complex participant group under investigation.

3.4.2. Reflexivity

Most qualitative approaches acknowledge the impact of the researcher's influence on the research, thus reflexivity is a requirement in all qualitative work (Willig, 2008). Actively evaluating the researcher's interpretations occurs throughout the research, "so as to move beyond the partiality of our own previous understandings and our investment in particular research outcomes" (Finlay, 2003, p. 108). It acknowledges that the researcher is never impartial from the research process but an involved and active agent within. Indeed the interview transcript is viewed as a product of reflection and collaboration between participant and researcher (Smith, 1997). For example; I acknowledged that my own values and beliefs along with my training as a counselling psychologist guided my interest within this area of research. These factors influenced the entire research process, from philosophical underpinnings and the research focus through to the analysis and discussion. Finlay (2011) warned against becoming too absorbed by the 'self' and one's own emotions during the research process; leading to losing sight of the participant's voice and the potential to skew results. Contrastingly, reflexivity promotes methodological evaluation since the researcher may have to admit to choosing the wrong strategy therefore exploring and adapting the research process, as happened in this case.

3.4.3. General Thematic Analysis: Strengths and limitations

The development of the TA method aligns closely with psychological concerns (Braun & Clarke, 2006; Crabtree & Miller, 1992) which have evolved with the increase in service-user led research (Joffe, 2012). More recently it was used in the field of mental health (Gilburt et al, 2008; Allen et al, 2009; Johnston, 2000). Critically its flexibility provided researchers with an opportunity to be creative in its application. This was essential within the ABI population where engaging in complex interviews were difficult. TA is situated within a context that allows for issues of the phenomenon to be considered within the changing political, social climate, for example, within the disability movement or in response to benefit reforms. It was worth noting the inherent tension between methodological flexibility versus consistency and coherence in research (Holloway & Todres, 2003).

The application of TA to different research designs has also generated debate. Whilst many argue positively about TA's flexibility, this can be problematic. Firstly, themes may be more generalised with some individuals' voices overwhelming others and by default minimizing some important views. This also challenges the continuity and contradictions within individual accounts (Braun & Clarke, 2013). Furthermore with a level of subjective interpretation in analysis it also raises questions about findings being grounded within the data. To mitigate this effect, researchers must highlight clear examples of how the interpretation has evolved with direct reference to the transcripts. Conflicting concerns have also been put forward, where TA is seen as an easy method of analysis. Consequently, without an existing theoretical framework, it was essential that research, like this study moved beyond describing the basic data. Otherwise the results remained no more than a description of the phenomena. This was achieved at various points throughout the research process from 'real time' interpretation during interviews to including an interpretation of body language or indeed the images created through the narrative exercises. For example, one participant separated the internal experience from the external experience of ABI. This was not vocalised but instead was interpreted from the narrative exercise through his organising of key words relating to these experiences on opposite sides of the 'train tracks'. The analysis was also discussed with both of the researcher's supervisors for further agreement on the findings and finally, the findings were cross checked against the raw data to ensure that the interpretation of themes was grounded in the data.

Validity was important in producing accurate and reliable data (Golsworthy & Coyle, 2001). Notably no two researchers will interpret the data in exactly the same way; therefore robust data analysis was required to ensure accuracy of results. Several ways of correcting this issue in TA research have been suggested (Braun & Clarke, 2013; Fereday & Muir Cochrane, 2006) namely; having 10-20% of the overall data analysed by another academic or external person to cross check findings (Joffe, 2012), checking data with the participants following analysis or checking the data with participants who were excluded by the criteria. Further suggestions to enhance efficacy include being aware of code representation across the data set including deviant cases (Seale & Silverman, 1997) and triangulation (Denzin, 2011). To ensure rigour, checking the data with participants was key to this context, where a cognitive deficit might encourage the researcher to depend on their own interpretation. This was monitored throughout the research design as both focus groups and semi-structured interviews allowed for the participant to challenge the researcher's understanding of the data through a process of feedback.

Although reflexivity has been addressed earlier in relation to qualitative research as a whole, it was worth considering the specific limitations of TA in its positioning of the researcher. With

no clear guidance about the role of reflexivity, Taylor and Ussher (2001) warn that the account of the findings may ignore the active role that the researcher has in identifying and pursuing themes emerging from the data. It was prudent that the researcher, in this study, responded to this criticism by being more explicit about issues pertinent to reflexivity throughout the whole research process. This research was grounded within a hermeneutic phenomenological framework and as such provided clearer guidance about the role of the researcher within the research. Steps were taken to ensure the transparency in the analysis of the data such as, by keeping a reflective diary (Smith et al, 2009) or documenting assumptions and actions throughout the research process (Pidgeon and Henwood, 1997) in order to increase reflexivity and lessen the impact of assumptions.

3.5. Critical Comparison of Other Methodologies

Due to the scarcity of qualitative research with this participant sample, other methodologies were considered equally valid in exploring this subject. One such consideration was Grounded Theory (Glaser & Strauss, 1967) and another was Interpretative Phenomenological Analysis (Smith et al, 2009) due to their similarity with TA in the coding of data.

3.5.1. Grounded Theory

“Grounded theory generally sets out to generate a theoretical-level account of a particular phenomenon,” (Smith et al., 2009, p. 43). Grounded Theory (GT) is embedded within sociology emphasising social processes and change. It has particular relevance and fruitful application to the field of counselling psychology (Ponterotto, 2005).

Since its initial conception GT has evolved with versions offering different perspectives on how to approach or analyse the data and take account of the position of the researcher within this process. Constructivist GT’s stance (Charmaz, 2000) diverged from Glasser’s model in that “it assumes the relativism of multiple social realities, recognises the mutual creation of knowledge by the viewer and viewed, and aims towards an interpretive understanding of subjects’ meanings,” (Charmaz, 2003, p. 250). This method emphasises the study of the phenomenon rather than method of studying it. This constructivist approach to GT argues that meaning is contextual and therefore not one ‘true’ reading of the data (Braun & Clarke, 2013). It acknowledges the role of the researcher in this process and that the emergent theory is shaped by the researcher’s perspectives and background.

Grounded Theory was not aligned with the current research question, since it would have analysed data with a view to identifying emergent theory, and thus it would not have sought to

elicit the individual's experience of ABI. For this current investigation, the focus on the relationship to 'meanings' as understood by the young adults was deemed more significant than developing a theory of the experience. Moreover, GT is formulaic in its approach to research providing a prescriptive application to data analysis. Whilst this has been viewed positively in validating findings, it would not have allowed for as much flexibility or creativity in the current design or analysis. Whilst Charmaz's (2000) GT approach was philosophically in keeping with the current study neither it nor Glasser and Strauss's (1967) model of GT were compatible with the current research due to their differing aims. In order to accommodate the complexity of the participant sample and considering this area is under-researched it was felt that GT could not meet the aims of exploring the phenomenon in question. Flexibility was key and thus GT's formulaic approach was felt too rigid to access the relevant depth and richness of data required for a doctoral thesis. TA was therefore viewed more preferably particularly within the field of ABI where the researcher was required to respond more openly to the data gathering.

3.5.2. Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) (Smith et al, 2009) was initially considered for this study, as a preferred method due to the richness and depth of information gleaned from interviews. IPA is both phenomenological and interpretative in nature. It is interpretative as it accepts that the researcher can never fully understand each participant's experience. IPA is specifically a structured hermeneutic version of phenomenology. Hermeneutics refers to the method of interpretation that can be applied to written, verbal and non-verbal communication. IPA adopts a process of double hermeneutics in that the researcher "is trying to make sense of the participant trying to make sense of what is happening to them," (Smith et al, 2009, p. 3). It ascribes an idiographic sensibility namely, understanding the phenomena within the individual's context and analysing every case individually, then highlighting individual and shared themes. IPA is described as an inductive process achieved through the development of broad research questions to be explored. "IPA studies tend to focus on significant life experiences that often have implications for our identities, as they unfold in particular contexts," (Braun & Clarke, 2013, p. 181).

IPA was deemed appropriate as it shared the same research paradigm as the current study. Furthermore, IPA was both a methodology and method which provided more structure and guidance about its application from question development through to analysis. IPA encouraged the use of broad questions where there was less expectation about what may emerge from the data leading to a more open analysis with more weight on interpretation.

The main conflict in using IPA was the incompatibility of the narrative exercise utilised in the semi-structured interviews to support discussion of the phenomenon in question. The narrative exercise was considered a necessary addition as it tapped into story telling memory, rather than recall memory which had previously been a limitation of research with this user group (Paterson & Scott-Findlay, 2002). "Narratives are an integral and important element in communication and can assume particular significance in understanding how people make sense of health and illness," (Easton & Atkin, 2011, p. 39). Incorporating the narrative exercise challenged the idiosyncratic nature of IPA by providing prior knowledge (narrative exercise informed by the focus group data) and more frequent prompting from the researcher. The questions were therefore more structured around this experience and not as broad as would be expected for an IPA directed study. Adapting the research to meet the needs of the participant group was more appropriate from the British Psychological Society (BPS) Code of Conduct (2009) and was in keeping with the researcher's clinical work and the ethos of the organisation from which participants were selected. Due to the challenges of working with the ABI population, IPA was not considered compatible with the research design, and this ultimately influenced the decision to apply TA.

On principle, gaining insight into an individual's experience was necessary to further understand the implications for counselling psychology and subsequent clinical practice.

3.6. Appraisal of Thematic Analysis within the Specific Research

More recently, TA has been applied effectively in acquired brain injury research (Couchman et al, 2014; Lennon et al, 2014; Cocks et al, 2014) and traumatic brain injury research (Gendreau & Sablonniere, 2014; Jumisko, 2005, 2007, 2008; Hagger, 2011). However, as in depth interviews depend on the participant being able to engage with the topic and nature of the questions, this raised some challenges in conducting research within this young adult ABI population.

An advantage of TA was its creative application (Braun & Clarke, 2006). This also allowed for more than one interview with each client, thus accommodating for physical impairment such as fatigue during interviews, which was prominent within this ABI sample population. This creative flexibility in research design allowed for participants who may have previously been excluded in research to be considered. Data collection was catered for in various formats from individual interviews, focus groups, participant generated textual data or secondary sources. Paterson & Scott-Findlay (2002) advocated the use of a focus group to pilot questions and check for suitability. This also lent itself to research rigour in that it allowed for method and

design reviews at an early stage. However it is worth noting that the lack of set procedure can be challenging for researchers and must be accounted for.

Paterson and Scott-Findlay (2002) investigated the challenges associated with interviewing individuals with ABI recommending, “direct interview questions that prompt participants’ script knowledge, rather than those typically used by qualitative researchers to prompt free recall” (Paterson & Scott-Findlay, 2002). Due to the adaptable nature of TA this allowed questions to be tailored to meet the needs of this client group whilst in keeping with the richness and depth of data gathering. Although this study was designed to be inclusive of certain deficits and while TA’s flexibility lent itself to creative applications, there were inevitable draw backs inherent in any research that is dependent on the coding and analysis of transcripts, given the severity of some participants’ cognitive and communication limitations.

Key to TA is that it requires a level of homogeneity in the participant sample. This is to ensure validity since sampling facilitates generating themes in small groups. ABI incorporates a variety of aetiologies leading to a range of cognitive and physical impairments posing complexities in participant selection and inclusion criteria. Due to the variation in aetiology of ABI it was acknowledged that the participants’ subjective experiences could have differed despite the common factor of ABI. Despite these differences, the sample was considered homogenous because participants all shared the experience of having an acquired brain injury and all had physical and/or cognitive deficits as a result of their brain injuries. “Homogeneity can be defined in different ways depending on the requirements of the study, from obvious socio-demographic factors such as sex and age, or factors relating to key elements of experience,” (Braun & Clarke, 2013, p181).

A challenge in using TA was linked to the participant population. Braun and Clarke (2013) recommended 10-20 individual interviews for a UK doctoral research study. A smaller sample size could have been an issue since the complex presentations of ABI do lead to greater participant exclusion; for example due to severe communication difficulties or cognitive impairment. The research sample in this study comprised nine participants (eight males and one female) who participated in individual interviews. Also when considering participant recruitment, it was worth noting, the impact that a predominantly male group, as is commonly the case in ABI, could have had on the research sample and consequent findings. Whilst this sample is not representative of gender equality it is reflective of the general population of young adults with ABI which tends to be male dominant. The results have been sensitive to the lone female participant and have detailed where her views may not have been consistent with the majority.

3.7. Summary

Thematic Analysis (TA) was selected as the most suitable research methodology as it was consistent with the main aim of the research, namely to gain insight into the lived experience for young people with an ABI. This research methodology has been applied effectively in brain injury research (e.g. Couchman et al, 2014; Lennon et al, 2014; Cocks et al, 2014).

4. Chapter Three: Overview of Research Design

The current chapter discusses the scope of the research and its design including; conceptualisation, ethical issues and other considerations. Many of these topics are expanded upon throughout other chapters of the research study. The research design remained fluid in an attempt to meet the participants' varying needs and thus evolved significantly from its conception. Initially the research study proposed a similar two stage process where the method of analysis was intended to be Interpretative Phenomenological Analysis (IPA). However following the focus group stage, it was recognised that participants struggled with the semi-structured style of questioning. As such the design was reviewed and a narrative exercise was devised and included to support participants to explore their experience in more depth. The method of analysis was also changed to Thematic Analysis (TA) to allow for more flexibility in the design framework and analysis of results. The design framework is detailed below (see *Figure II*).

4.1. Scope

4.1.1. Search strategy

As mentioned there were numerous challenges to the search strategy in selecting appropriate literature to inform the research study. This applied to both qualitative research and ABI research. This was due to the ambiguity and interchangeability of terminology. For that reason the following search strategy utilised both broad and specific terminology related to the topic (see section 8.1.1). This incorporated:

1. Terms relating to acquired brain injury (e.g. ABI, TBI, head injury and brain damage)
2. Terms relating to specific causes of brain injury (e.g. stroke, brain tumour, hypoxia, haemorrhage and encephalitis).
3. Terms relating to development (e.g. young adult, young people, early adulthood)
4. Terms relating to the study methodology (e.g. qualitative, semi-structured interviews, focus groups and Thematic Analysis).

These search strategies were repeated over the life time of the research to ensure that the literature was current. No data restrictions were used and each abstract was examined for relevance. Relevant articles were included in the literature review. The reference section of each relevant article was also examined for further pertinent literature.

4.1.2. Design framework

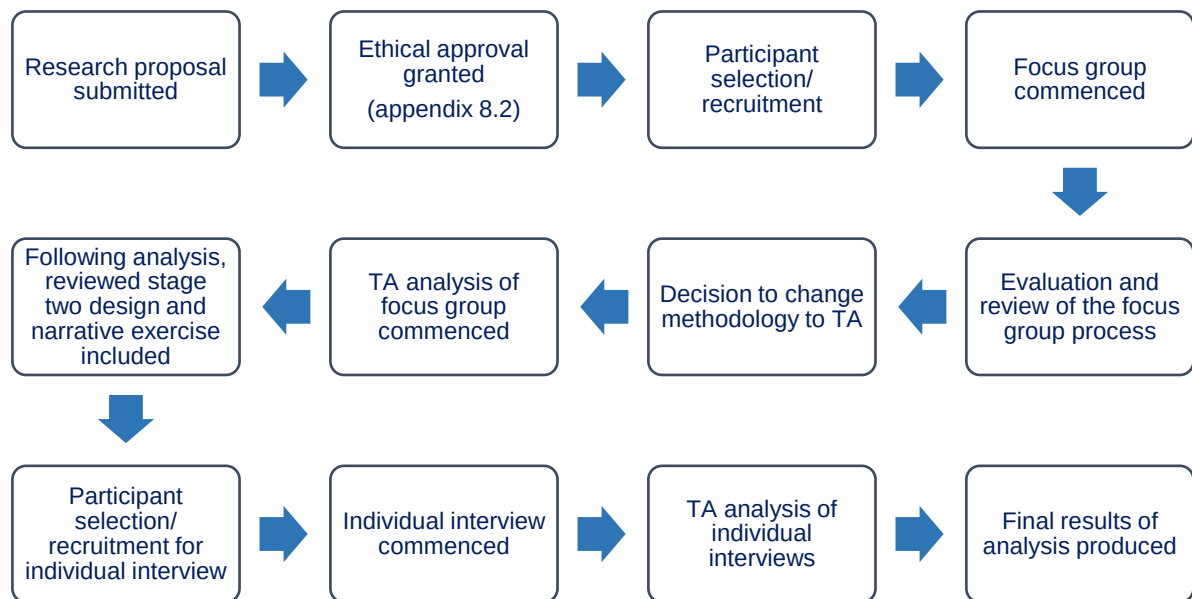


Figure II: Design Framework

4.2. Design

4.2.1. Setting

The research was conducted using participants from a third sector charitable organisation which supported individuals and their families following ABI. Individuals who attended the service were referred to as members and attended for 1-2 days per week which was usually funded through social care. Other individuals engaged with the outreach services which included a weekend social group and a support worker service. The participant sample was recruited from both day service and outreach service. Further details of the organisation and its underpinning approach can be found in appendix 8.3.

The research topic was discussed and approved by the organisation in July 2015. It was agreed that, in return for participation, group therapy would be offered based on the findings of the research. Research participants were invited to attend this group on a voluntary basis. Although not a formal incentive to participate, it was acknowledged that group therapy might be of benefit to those participants who were not as able to access wider support.

4.2.2. Research sample

Stage one of this study comprised a focus group of five participants (see appendix 8.4) followed by stage two, which gathered in-depth qualitative data from a narrative exercise and concluded with four semi-structured questions involving nine participants (see appendix for 8.5). Although both samples were dominated by a male population it was not felt by the researcher that this impacted on the quality of the data collected. In fact the participant sample was representative of the general population of individuals with ABI.

4.2.3. Recruitment

Advertising through the use of posters or flyers was not appropriate with this particular participant sample due to the nature of ABI. This was because some participants did not have the self-awareness, comprehension or ability to retain details of the study over time, for example, topic, time and date of study or what had been discussed in previous information sessions. The selection process was an in-depth nuanced process of matching participants to the inclusion criteria. This was supported via consultation with the organisation. The young adults' key workers were approached with a briefing of the study. The key workers then approached individuals whom they deemed to have capacity, and obtained informed consent for participation in the research. It was important that participants were not approached by the researcher directly, to minimise feelings of compliance in agreeing to participate. Key workers were also able to assure participants that they had the right to refuse to attend and that this did not affect their service provision.

It was noted that the researcher also held a trainee position within the organisation so it was crucial that participants be able to recognise the different roles and boundaries that the researcher held and act accordingly. Furthermore some participants may have met the inclusion criteria but due to the impact of their brain injury be unsuitable for participation. For example one individual considered was unable to maintain personal boundaries and would ask inappropriate questions during almost all conversations with the researcher. Whilst it is important to give voice to his experience it was felt that his ability to engage in an interview would be severely impacted. Sargeant (2012) states that to ensure quality in qualitative research participants must be appropriately identified to, "be able to inform important facets and perspectives related to the phenomenon being studied," (p. 1). Therefore whilst some participants may have met the inclusion criteria they were excluded for the purpose of this study.

4.2.4. Participant inclusion and exclusion criteria

Inclusion criteria included:

- Participants would all have an acquired brain injury.
- Participants would be between the ages of 18-30years old **or** acquired their brain injury within this age bracket and identify within the young adult's group (up to and including aged 32 years). Arnett (2000) argued that emergent adulthood (18-25yrs) and young adulthood (26-30yrs) were distinctly different periods of development. They were characterised by multiple life transitions, identity exploration and development. Emergent adulthood covers leaving school education, for example, moving out of the parental home, a change of legal status such as voting or drinking. Young adulthood was one step beyond this where identity, employment and financial stability was more common (Arnett, 2000). Using this age bracket was considered inclusive for all participants in this study who belonged to both the emergent adult and the young adult groups within the organisation's structure.
- Participants would be more than two years post-injury, since the majority of recovery occurred within the initial two years. Therefore participants would have, had time to regain any cognitive or physical skills and had the opportunity to reflect on their experience of living with an ABI.
- Participants would be able to speak English or able to communicate their experiences of their brain injury.

Exclusion criteria affected those:

- Where due to the nature of their ABI and while able to meet all other criteria, were unable to agree to the focus group rules, for example, respecting other members' participation.
- Where the cognitive deficit was too severe that they were unable to process their experience of ABI.
- Who were deemed to lack capacity to consent. This was assessed using the five principles of the Mental Capacity Act 2005.

Based on the inclusion/exclusion criteria some young adults did not meet the criteria to participate in the study. Whilst it was hoped that participants were carefully selected based on the strict criteria listed, it was recognised that variables could not be fully controlled.

The Mental Capacity Act 2005 aims to protect people who lack capacity, maximising their ability to make decisions. Capacity is assessed on a decision specific basis. Capacity to

consent was assessed in advance of the focus group by the key worker. It was further, separately assessed with each participant in advance of the individual interviews, by the researcher. If participants were deemed to have the capacity to consent to participate, they were then provided with the relevant research consent forms (appendix 8.7). The researcher also had an awareness of an individual's capacity difficulties and any other issues likely to impact on the participant's engagement on the day of the interviews.

At the next stage of recruitment key workers engaged with participants, to explain the research in an accessible way (appendix 8.6). Various versions of the participant information and consent forms were made available, this met with the guidelines of the Scottish Accessible Information Forum (2014). These accessible guidelines were developed for individuals with a variety of difficulties and disabilities. Participants were provided both sets of forms and were then allowed to choose which ones to engage with. Four of the five focus group participants chose the standard participant information forms however chose to sign the accessible consent form. Six of the nine individual interview participants chose the standard forms with half choosing to sign the accessible consent forms. Outreach versions were provided to those who utilised the service for community based support. Key workers then supported the participants by answering questions, support with reading or explaining the content of the forms to ensure that the research aims and participation was understood. Any questions which the keyworkers were unable to answer were referred back to the researcher. Based on the individual's need, the key worker gauged interest and followed up by reminding and showing participants where to attend.

This sample was considered on the evidence that young adults were at the greatest risk of acquiring a brain injury and of experiencing incidences of mental ill health. Due to medical advancement, the survival rates of individuals following ABI is increasing. With much of their life ahead of them, these young adults have the potential to make a valid contribution to society, provided the right policies, support and resources are in place.

4.3. Procedure

4.3.1. Stage 1: Focus group

Due to ABI, Paterson and Scott-Findlay (2002) advised that group interviews can sometimes lead to stimuli overload. Therefore the seven semi-structured interview questions (appendix 8.8) were listed in priority of importance prior to conducting the focus group. The focus group was limited to a maximum of 2hrs. The researcher was aware of issues of fatigue, and was

sensitive to participants' wellbeing, so adjusted the interview accordingly. Breaks were offered as appropriate.

4.3.2. Stage 2: Individual interviews

Following the initial focus group the design of the research study was reviewed. Participants noticeably struggled with broad open ended questions and required more input from the researcher than an IPA study would generally suggest. Although this did not impact on the quality of the data collected, the researcher decided that another design format would lend itself to the depth and richness required for qualitative research. The method of analysis was changed to TA prior to the focus group analysis in order to allow for flexibility in the research design.

Paterson and Scott-Findlay (2002) advocated the use of an active interviewing approach as a method which could avoid pitfalls inherent in interviewing individuals with an ABI specifically due to their cognitive needs and the diversity within ABI samples. Although an active interviewing approach was considered its focus tends towards "the procedures and resources used to apprehend, organise and represent reality" (Holstein & Gubrium, 1995, p. 16). The researcher felt that a narrative exercise was also sensitive to these needs and provided a rich source of utilising different forms of communication including both visual and auditory data from which to analyse. Furthermore the focus of the narrative exercise was more aligned with the research aims of exploring the phenomenon in question. As such, stage two involved a narrative exercise called the 'Train of Life' and four semi-structured interview questions (appendix 8.9). Where participants were perhaps not as able to verbally communicate, they could do so through the picture/ diagram they were constructing (appendix 8.10). For other participants where visual difficulties or mobility issues were an issue they were able to verbally discuss their experience and use the prompts provided from the focus group to support their account. The prompts and visual diagram also supported memory difficulties in that it acted as a visual representation of the participants account allowing them to move back and forth between memories as they occurred, minimising the chances of forgetting what they may wish to explore. Interview length was limited to ninety minutes and participants were monitored throughout by the researcher for signs of fatigue and offered breaks where necessary.

4.4. Ethics

4.4.1. Ethical approval

Approval for the research study was granted on the 6th of July 2015 by City, University of London Ethics Committee (appendix 8.2). The organisation from which the participants were recruited also granted approval in July 2015. Recruitment and discussions with the organisation with regards to timetabling began in August 2015 and stage one of the research namely the focus group commenced in October 2015.

4.4.2. Ethical considerations

This topic had the potential to raise some difficult issues which the participants might not yet have explored, such as identity or loss. Consideration was therefore given to the participants inadvertently using the focus group, or individual interview, as a form of therapy to address any emotional reactions to the topic. The researcher, the researcher's supervisor (a registered BACP psychotherapist) and the participants' key workers were therefore available throughout the data gathering process, should the participants have wished to discuss any aspect of the research further.

Participants also had access to their key workers and support in line with the organisation's policy and duty of care. Participants were debriefed following their involvement (appendix 8.11). If issues were raised during this research, or if participants wished to engage in formal therapy, then therapeutic services were made available through the organisation. Participants' key workers were aware of the referral process and forwarded counselling requests using the relevant procedures. Of note, only two participants contacted their key workers and the researcher following the individual interviews. Both individuals were provided with support and encouraged to follow up with more formal therapeutic intervention to deal with the issues raised. Neither participant wished to engage in formal counselling at the time. So after following organisational policy, participants were provided further contact details should they have changed their minds. The key workers involved provided ongoing support on a regular basis to ensure that any issues raised were addressed appropriately.

The researcher's internal supervisor organised group therapy based on the findings of this study. Participants had the option of joining to explore any issues further. More importantly and despite the potential for risk, this study provided the opportunity for participants to have a voice and to contribute to the research. It also provided the opportunity for clinicians and relevant professionals to better understand this client group's experiences.

Finally it was worth paying attention to the researcher's role within the wider service context. The researcher was a trainee counselling psychologist on placement within the organisation and thus was known to the participants. The researcher at the time of collecting data was not engaged as a therapist with any of the participants, although she had worked with one of the participants previously. Participants accessed key workers throughout the research process who provided additional support to deal with issues arising from the research process.

4.4.3. Data confidentiality

In order to assist the researcher in transcribing, the focus group was audio-recorded using an Olympus Digital Voice Recorder VN-733P and video recorded using a Sony Handycam N50-HDRCX220. The individual interview questions and design evolved from the data gathered at the focus group stage. The individual interviews were audio-recorded only on an Olympus Digital Voice Recorder VN-733P. All data was immediately transferred onto an Acer Aspire V5-122P laptop computer which was password protected and held in an encrypted password protected file. Paper copies of consent forms and other sensitive data were kept in a locked filing cabinet at the researcher's home address.

4.5. Other Considerations

4.5.1. Originality

Since January 2015, key database searches of the current literature were completed namely; Psychinfo, PubMed, EThOS, Psychsource, and Taylor Francis. Combinations of multiple search terms were used namely; acquired brain injury (ABI), traumatic brain injury (TBI), identity, young adult, qualitative research and Thematic Analysis (TA).

During the individual interview analysis stage, it became known to the researcher that another unpublished thesis (Schrover, 2014) had recently been added to EThOS which showed similarities to the current study. Caution was taken in reviewing the paper to ensure that the current study was not influenced by the analysis of Schrover's (2014) findings. The researcher's supervisor reviewed the papers to ensure that duplication had not occurred. Although this finding was initially disappointing to the researcher, after discussion with the researcher's supervisor, it was felt that the two research studies differed significantly enough to ensure that duplication was not an issue. Similarities were noted within the participant sample; both involved young adults and with the method of analysis being Thematic Analysis. However, it was felt that the research design and the methodological approach in the current research demonstrated important original differences. Furthermore the current research was

deemed to build on the recommendations of Schrover (2014) and therefore lent further depth and knowledge to the topic under investigation.

4.6. Summary

This design model was selected to gain maximum benefit for both the young adults with acquired brain injury who took part and to capture their lived experience in a meaningful way for professionals seeking to understand the impact and improve services long-term.

5. Chapter Four: Analysis and Results

In this chapter, I have provided an overview of the research design and presented the main findings of the research. This chapter commences with a discussion and presentation of stage one, namely the focus group, in light of the general challenges within this participant group and its implications specific to this study. These findings acted as a guide to the development of stage two of the research project; namely the individual interview analysis. Stage two findings are then presented and reflections are offered throughout, in relation to the different areas of analysis. Consideration is also given to the research quality with reference to the relevant literature. Finally a full analysis of the findings is presented.

5.1. Overview of Stage One: Focus Group Findings

The focus group comprised of five participants, including 3 males and 2 females (appendix 8.4). All participants had sustained an acquired brain injury (ABI) between the ages of 18-32 years old and were recruited a minimum of two years post-injury. The participants self-identified some of the following difficulties: communication, physical and cognitive difficulties such as speech difficulties, word finding difficulties, visual impairments such as distorted vision, mobility issues leading to difficulties with co-ordination and dexterity, fatigue, poor concentration and memory impairments. For further details of difficulties see appendix 8.4. The purpose of the focus group was to explore the topic more broadly prior to individual interviews. As it was recognised that participants with ABI find difficulty engaging with research interviews (Paterson and Scott-Findlay, 2002), the focus group had the secondary purpose of gauging any practical difficulties the researcher had during the semi-structured individual interviews. As such the smaller sample size was not. The resulting analysis then informed the format of the individual interviews and specifically allowed more in-depth questioning of the research topic. It was noted that both communication and cognitive difficulties often resulted in shortened responses with incorrect wording or grammatical errors.

5.1.1. Reflexivity

Early in the process, I wished to address the issue of reflexivity. Interview questions were initially developed with the view to using an Interpretative Phenomenological Analysis (IPA). Thus the IPA guiding principles were considered when phrasing the questions. During the initial stages, it became apparent that the participants required slightly more prompting than anticipated which consequently changed the format of the interview. Therefore a retrospective decision to apply Thematic Analysis to data allowed a richer depth of analysis and enabled

the use of multiple sources to be analysed alongside the transcript. The focus group was video-recorded and so body language, intonation and non-verbal communication was also utilised as a source of information.

The researcher's positioning within the organisation was also poignant to reflecting on the focus group interactions. As a trainee counselling psychologist on placement within the organisation, I had worked with several of the participants on various projects within the centre and in one case I had completed work as their therapist six months previously. This had implications in that the clients were familiar with me and I had intimate knowledge about a particular client, which as a researcher I would not normally be privy too. With this came a cost and a benefit and I judged the risks accordingly.

5.1.2. Focus group analysis

Exploring attitudes to a particular topic from a relevant sample is often a key advantage of using focus groups as a methodology (Powell & Singer, 1996; Morgan, 1997) and is widely advocated as a methodology to inform exploratory studies (Kvale, 2007). Crucially focus groups can help to increase participant involvement specifically of marginalized groups (Barbour & Kitzinger, 1999; Barbour, 2007) by asking for their views about aspects of the investigated topic (Dunne & Quayle, 2001); in this case, young adults' experience of living with ABI.

As mentioned, the focus group was videotaped for the purpose of providing a fuller analysis, this included the analysis of non-verbal cues such as body language. This was crucial where communication may have posed more difficult for participants following brain injury or where participants may not have felt comfortable enough to vocalise their experience or opinions within the context of the group setting. As Opdenakker (2006) asserts, "social cues, such as voice, intonation, body language etc. of the interviewee can give the interviewer a lot of extra information that can be added to the verbal answer of the interviewee on a question," (p. 3). Examples of non-verbal cues included leg shaking, nods of agreement or disagreement but also included agitated or excited presentations which gave more emphasis to the strength of the points being made. The interpretation of such body language was in keeping with the methodological stance of the research however, caution should be applied to the analysis of non-verbal cues as they may be misinterpreted by the researcher (Burnard, 1994) and thus may then misdirect the line of questioning (Opdenakker, 2006).

5.1.3. *Thematic Analysis*

This analysis utilised the 'six stages' process outlined by Braun and Clark (2006). Thematic Analysis is a flexible approach to qualitative analysis that aims to identify key ideas or patterns within complex data sets. As this study was exploratory with a focus on subjective experience it was selected as the most appropriate analysis. Within this Thematic Analysis there were a number of distinct stages, which were iteratively cycled between identifying themes within the data, and then interpreting these themes in a way which accurately describe the phenomenon under investigation. The first phase of analysis called familiarisation, involved becoming immersed in the data through reading each transcript and listening to a selection of the recordings. During the second phase of analysis, codes were generated from the data transcripts and collated. These codes were then compared and contrasted. Similar ideas and concepts were grouped together into initial sub-themes during the third stage. Grouping these initial themes into potential master themes provided a structured thematic framework. From the original mind map (appendix 8.13) it was noted that many of the master themes had an underlying tone of relationships as well as many overlapping themes. On reflection it was felt that this might be have been related to the researchers own interests and reading of the topic. The themes, therefore, were reviewed at stage four, minimising overlap between themes to be more objective (appendix 8.14). In stage five of analysis the transcript was revisited to ensure that the proposed sub-themes and master themes were evident in the focus group account, and collated illustrative quotations provide evidence for each theme. This final examination of the transcript allowed each theme to be further refined (appendix 8.15), ensuring that relevant contradictions, nuances and exceptions were captured. The final stage of TA was the write up of the analysis presented below.

5.2. **Results**

Thematic Analysis generated eight themes which were grouped into three master themes (Table I). Findings and themes are presented as a narrative account of the data (Braun & Clarke, 2006). Participant pseudonyms are provided within the quotes to denote the speaker. Quotations are provided throughout the narrative to ground the results and enable evaluation of the fit between the data and the interpretation of the results (Fossey et al, 2002). When part of a quotation is omitted, to remove non-relevant data, it is denoted by '...'. All themes are positioned across the focus group data and therefore the amount of analysis presented for each theme does not represent prevalence.

Table 1: Master and Sub-themes of the Focus Group

Master Themes	Sub-Themes
Negotiating Relationships	<i>Relationship to Self: Acceptance</i> <i>Relationship to Help</i>
Growing Stronger	<i>Creating a Positive Narrative</i> <i>Re-defining Goals and Grabbing Opportunities.</i> <i>Seeking Meaning</i>
Experience of Self in the World	<i>Hidden Disability</i> <i>Discrimination and Stigma</i> <i>Where do I Fit?</i>

5.2.1. Narrative account of results

Participants' names have been anonymised and assigned pseudonyms.

5.2.1.1. Theme one: Negotiating relationships

This study provided insight into how participants understood themselves following ABI. Participants discussed the stages of self-discovery over time. This included relationship to self through the process of acceptance and relationships to help which included both services such as the benefits system or housing and formal or informal family support. Understanding how participants conceptualised themselves following ABI was crucial to any therapeutic relationship.

5.2.1.1.1. Relationship to self: Acceptance

Clear within all the participants' accounts were the links between time since injury and acceptance. Participants discussed a chronology in relation to the pre-injury, immediately post-injury, rehabilitation, assimilating back into life, present and then projections to the future. Participants did not identify any moments of change or acceptance but reflected that it was an ongoing journey of recovery. They used phrases such as "in the beginning" or "at the start" or "after". Different challenges to identity and acceptance were linked to different stages of recovery.

Both Liam and Yasmine discussed their developing awareness of 'self' and understanding of their brain injury being an evolving process. Liam later linked this to building confidence in his new identity which was ultimately part of the acceptance process.

"After my brain injury at the start, I was very uncomfortable...but now, sort of learned to accept my brain injury. I'm quite confident now, I'm a confident person...I never used to <tell people about ABI> I used to hide it." (Liam, L622- 629)

Several participants described a feeling of 'acceptance of self' being affected by other people's perceptions of them; in particular when interacting with others and specifically family and friends. Yasmine highlighted the impact of other people's perceptions on her self-confidence. Crucially for Yasmine, however, having a physical reminder of her brain injury was key to keeping perspective on her situation and reflecting on how far she had come in the process, irrespective of other people's perceptions of her. How the participants dealt with the ways in which they were perceived or treated by others differed significantly and was potentially linked to their stage of the acceptance process. What was strongly evident in all the accounts was the feeling of being viewed differently.

"People don't treat you the same...before I used to feel frustrated but not so much now 'cause I got used to it." (James, L5-8)

"they were making decisions for me all the time. It's getting better now, I'm doing a lot more for myself." (Liam, L447-448)

"I'm still proving myself to my family and friends." (Yasmine, L528)

Many of the participants discussed the wider impact on the family of developing an identity and their awareness of the changes for all involved. Here Veronica described the idea that life had been suspended whilst in hospital, but with the re-entry into the “real world” she was faced with new challenges.

“I suppose at the beginning cause I’d just come out of hospital it was <different>. And I was away for quite a while, maybe a year and then come back and stuff, in to the real world”. (Veronica, L479-480)

It suggested a tentativeness in relation to adjustment and the idea that identity was not just their own but part of a wider context. There was also a sense of responsibility in negotiating this role and keeping others in regard;

“For me, I’d say people don’t understand your life. Basically you’re starting again from the life you had and personally, I think it’s more hard for the person that gone through it as much as your family...and that’s where I thought the frustration comes from”. (Yasmine, L57- 69)

For the most part many of the participants positively discussed their challenges to forming identity and adjustment. However one participant described the struggles he felt in accepting the more noticeable disabilities following brain injury, particularly those linked to ease of daily activities. When discussing how to overcome this challenge Tony stated,

“Well obviously I just have to get used to it and that. Make myself who I am”. (Tony, L154)

Although this might suggest a lack of agency, it again reinforced the idea of ‘time’ correlating to acceptance. In particular, Tony’s last statement suggested that he felt that he will regain his sense of identity in the future.

5.2.1.1.2. Relationship to help: Services.

Discussion about support was tentative with an underlying conflict between accepting support and establishing independence as young adults. This was particularly salient when discussing family support;

“You feel like you’re being awful sometimes ‘cause you just kinda like. Well I personally snap at them and say like, “I don’t want this help” kind of thing. And I feel like I’m being awful to them but I’m not like fed-up ‘cause you feel like everyone keeps doing it all the time”. (Veronica, L46-48)

More prominent was the link to a feeling of powerlessness. Many of the young adults acknowledged the difficulties for family systems adapting to the injury as being just as difficult an adjustment for them. They made reference to small decisions, such as people making cups of tea, to larger life decisions about what care they should receive or when they should move into their own accommodation, or start a family. Many of these decisions became a collective decision between family, services and the young adult rather than a private individual matter. This conflict was often seen as coming from a caring position but the young adults reported feeling less able to challenge this.

“... natural reaction is to help you and knowing that you’re not as normal, not as mental normal as you was. They all naturally want to help you to what they assume or (that) you need to be helped”. (Tony, L37- 40)

“But I don’t know how it would be. My mum would probably kill me”- when talking about starting a family. (Veronica, L757)

Participants were more vocal about their dissatisfaction about services. Perhaps the facelessness of services reduced the participants’ cautiousness, or diplomacy in voicing their opinions. They perceived themselves as a number within a system rather than a person and were active in comparing the differences in packages of care received in different boroughs. Suggested services were seen as inadequate to meet their needs. They voiced that decisions about care were often funding related and not based on individual needs.

"I was left in a hospital bed for months until I even got any money to be able to go to any rehabilitation centre...So I didn't have to go to rehab before my case (worker) could confirm that I could get money for rehab and things...The first rehab was £1800 a day with this in my throat (tracheostomy). But for some reason I was coughing a lot on that day and I coughed my tracheostomy up out my throat a tiny bit and the doctor saw this and came and looked at it and decided to remove it there and then...And we reapplied for funding and it went down to £900 a day, innit. Like a week later it was accepted and I got moved to the rehab." (Tony, L338- 351)

Although easier to vocalise their discontent they felt powerless to effect change in the system. The system was perceived as a threat to any future decisions. This theme of support being a 'double edged sword' was strongly defended by all of the participants. Acceptance of support was seen as giving up agency in their life but having the choice to reject support was often not an option.

"I'm currently living in a rehab place which ended up like a care home and...for the past four years, em, I've actually was meant to be there for six months but it's been 4 years now...and I've been trying my best for the past two-three years to actually move out of that place. And just explore what's out there and even though I've been telling them, "this is what I was, that is what I want," I'm still in this place after three years." (Yasmine, L409- 416)

5.2.1.2. Theme two: Growing Stronger

"Positive psychological change experienced as the result of the struggle with highly challenging life circumstances" (Tedeschi & Calhoun, 2004) encapsulated this finding. This study of young adults with ABI included three crucial sub-themes namely; creating a positive narrative, redefining goals and seeking opportunities and finally seeking meaning following ABI.

5.2.1.2.1. *Creating a positive narrative*

On several occasions participants raised some of the challenges they had experienced post-injury. However when discussing this, the group often reframed the topic and co-created the discussion with a more positive narrative. This was clearly seen when discussing the changes in friendships;

“Veronica- I don’t know what the negatives are. There’s probably loads eh?”

Liam- See who your friends are.

James- Yeah that’s one.

Veronica- Yeah but is that a positive?

Liam- Yeah it’s sorta both isn’t it?

Veronica- It’s both...

Liam- I think, I think for me it was a bit of a positive cause, you know, like you don’t want people like that around you.

Interviewer- OK

Liam- So, it sort of, I didn’t, I wasn’t going to give my time to them if they weren’t going to give any time to me.” (L230- 248)

Participants were keen to hold on, or strengthen positives, post-injury. One consideration during analysis was the participants’ awareness of the impact of brain injury. From participants’ accounts, it was clear that they chose to view their situation positively as opposed to dwelling on the negative impact of their injury. This could be seen when Veronica considered the life her sister may have had and the enormity of choosing to become her carer;

“She’s changed a lot as a person. She had to grow up at 17 and all of her friends were going out and stuff. And then she had to change and not do any of that. And she could have but she didn’t...Em, ‘cause she was there for me and now obviously being my carer. She’s younger than me, she’s only 21 now. But she’s my carer. A lot of people at 21 are not cares for their sisters you know”. (Veronica, L552- 556)

Participants also spoke about the depth of their developing self-awareness post-injury. Conversation became more existential, highlighting the idea of progressing over time.

“It’s still a journey and I’m still learning from it. I’m still seeing things I don’t know, I’m just completely different from who, when I was before my injury to now”. (Yasmine, L992-993)

Although there was a shared experience of the phenomenon, the impact was variable. This quite often reflected the idea of becoming ‘someone’ in conjunction with learning about their own capacity. It changed their account from being potentially limiting to being transformative.

“I’m kind of glad my brain injury happened because I’m, I’m still fighting for what I want and working with my brain injury, it taught me a lot more. If that makes sense?” (Yasmine, L986- 988)

5.2.1.2.2. Redefining goals and grabbing opportunities

Discussions were initially focused on change but quickly became goal oriented. Many of the participants spoke about the new opportunities that had arisen following the brain injury using such terms as “opened more doors” and doing “more than I would’ve done before”. For some, this discussion involved recognising what was meaningful pre-injury and trying to regain that by redefining or changing the goals, whereas for others it was a “starting from scratch”. Although participants recognised certain limitations post-injury this was not considered a barrier, rather, a challenge to overcome using phrases such as; *“(I) just took a different path”* (Veronica, L204) or *“but you just take a different like kinda route.”* (Liam, L207). For one person returning to her pre-jury stage, life was seen as a backwards step, while adapting to her current needs was more empowering.

Overall the participants showed an awareness of change. When aligning their goals with their change in needs, self-care was a high priority. Participants were creative in ways to seek this out, instead of fitting back into what would have been more mainstream life;

"I don't want to go back to working for someone. 'Cause obviously I volunteer which volunteering is quite enough for me. I don't want to, I don't like other people being in charge of me...I don't know or want someone owning me...So like if it was a family business. I'm really close to my mum and sister anyway that I can just say "no" when I want to. Well I couldn't with someone else, I'd have to go through everything".
(Veronica, L972- 978)

Throughout much of the discussion about future goals was the underlying tone of being given a second chance. Participants voiced that they had taken opportunities to change and re-evaluated the meaning of life and prioritised what was important.

"I've got back to studying last year. Started last year but it's just, it's was a case of ignoring everyone saying I couldn't do this and I just please like have to be strong and be brave. No complain because this is actually my, what would you call it? My decision so I brought this to myself". (Yasmine, L926- 928)

5.2.1.2.3. Seeking meaning

Although not obvious in all of the participants' accounts the concept of seeking meaning or the wider implications of the ABI was present. For some it was about changing a current life plan that was not meaningful; for others it was safeguarding a potential life journey that was heading off course. Essentially, timing of the injury and 'why me?' together with considering the stage of development and how the injury happened, was central to redefining the 'self';

"first off I was a young girl then and it came at the right time, at my teenage years. And that's the time that you actually, you're trying to go out there and be a person".
(Yasmine, L167- 169)

For others it was less about why it had happened and more linked to what it had taught them. A sense of fulfilment, of bettering of self, was noticeable. Some phrases such as being a better

person, feeling healthier and learning about oneself may have been used more than if the ABI had not been experienced.

5.2.1.3. Theme three: Experience of self in the world

The Sub-Themes of “hidden disability”, “discrimination and stigma” and “where do I fit?” generally moulded the participants’ subjective experience. Having an awareness of changes and how these were perceived by others was crucial to their sense of self in the world. Barriers hindering the move to acceptance included feeling judged by others and withdrawing from social integration. In this study each journey was not a progressive or fluid model of recovery but one which had various setbacks along the way, for all participants.

5.2.1.3.1. Hidden disability

Participants were quick to involve discussions about hidden disability. Throughout their accounts many referred to recent news stories or social media posts which had highlighted the issue of hidden disabilities. This was an area the participants connected to very easily and many gave examples of how their ABI challenged them. For one participant the ABI had left more visible injuries and her experience was different. The more obvious disability led to more obvious discrimination and reduced control over her life, such as, where she felt comfortable to go. For the majority however the hidden disability led to issues of fear of being misunderstood. It set them apart from their general communities and led to more feelings of isolation. When talking about using her walking stick:

“I suppose with my balance quite a lot but it is as well for other people to know that. Cause they’ll just, like I’ve got asked if I’m em drunk when I didn’t have the stick...People don’t care if you’ve got a stick, they just want to know that you’ve got something wrong other than that you’re drunk”. (Veronica, L682- 686)

In managing any anxiety the participants spoke of discussing their injury early on in the relationship forming stages. Alternatively, using strategies such as, making their ABI more visible by using a walking stick when on public transport, or having close friends to support provided more reassurance. Participants felt that the general public had more understanding

when the disability was more visible and this managed any potential conflict. The participants reported that their disability led to initial rejection and they felt they had to explain themselves or their actions before feeling accepted:

“It used to be that you could see it (the brain injury) a bit more so it was, not alright but like people then would give you like more say leeway. Whereas now like they look at me and then, so I have to tell them, I have to”. (Veronica, L699- 701)

5.2.1.3.2. Discrimination and stigma

The discussion around this topic was interesting as discrimination and stigma were concepts that heightened anxiety and fear. It was often perceived as something that filtered down from establishments rather than directed at the young adults by individuals alone. They felt that flaws in the system perpetuated wider discrimination;

“I just wish the government or whoever doesn’t actually know that the brain injury doesn’t just stop in one position. It’s not the day from you are who you are but it carries on throughout your life. And they seem to think it stops but it doesn’t.” (Yasmine, L1175- 1177)

For two of the participants the idea of discrimination had far reaching implications on their decision to have a family. In particular, one participant felt this right had been taken away from her. Her decision to have a child, she felt, would lead to increased scrutiny and removal of that child, due to the perceived view that she couldn’t look after it as a consequence of her ABI.

Overall the participants felt that an ABI was lifelong and should have been recognised as such. They felt it should have been worked with and that any services, organisations and systems who discriminated, in fact misunderstood the impact of ABI;

“See I’m always going to have my brain injury but well yeah, you’re still always gonna have the brain injury so we should get that (freedom pass) for life. And I just don’t know, like why do they put an expiry date on it then... You’re still always going to have the disability”. (Veronica, L1051- 1056)

However conversation was not dominated by negativity as participants were quick to offer solutions, such as education or increasing visibility of ABI within the general populations.

5.2.1.3.3. Where do I fit?

For the most part the participants felt they were more confident about who they were. This view however, was challenged when trying to assimilate this into others' perceptions of their identity; within their own family system, the wider community or social grouping. In order to stay congruent with their view of self they discussed strengthening their voice, developing more resolve and challenging the status quo;

"A couple of weeks ago I had an, I had an assessment to move out of where I live and em. The assessor actually said to me, "no you're not going to come out of this place yet because you won't meet the needs", if that makes sense?...after she went the manager said to me, "why can't you just pretend like you can't do anything?" and I'm like, "no I'm not going to do that because I want. I'm not going to lie (about) who I am and pretend cause at the end of the day I am who I am". (Yasmine, L1079- 1090)

Key for the participants was the concept of being valued despite their ABI. This was generally salient during discussion of the term "normal" which provoked conflicting views about its usefulness. What was apparent was the underlying need for 'sameness'. As Liam suggested;

"I'm a normal person at the end of the day." (Liam, L656)

5.3. Summary of the Findings

5.3.1. Focus group reflections

It was noted that many of the quotes came from female members, possibly due to these members being more articulate and vocal during the group discussion. The researcher was

also of similar age to the female members of the group, and this could therefore have allowed them to feel more at ease in her presence and possibly more able to open up during discussions. Female dominance in the conversations was obvious and the reverse effect noted with the male respondents. On many occasions however, the male members were in agreement, indicated through their non-verbal communications. This necessitated the inclusion of analysis of non-verbal cues. Throughout the narrative of this paper the quotes included were, in the main, agreed by multiple members, so that findings were representative of the majority. Additionally, any conflicting findings were highlighted as it was important to capture opinions that were not representative of a majority (Barbour & Kitzinger, 1999).

One such participant (Tony) left the group approximately half way through the session. Reflecting on the discussion, it was difficult for him to explore his story surrounded by a more generally positive account. He appeared to be at an earlier stage in his recovery, while many of the other participants were more used to exploring their experience through participation in various groups. He generally chose a more reserved role within the organisation. This participant may not have been as able to discuss these difficulties. Or that he had not, had as much space to reflect on his injury and gain insight into its impact. Being at the stage of young adulthood, perhaps finding a voice within the young adults group could have caused this participant to feel exposed by sharing his story.

Reflecting on his decision to leave acknowledged the positive way in which he was able to show agency. It was important to remain mindful and to respect his decision due to the underlying theme of powerlessness which was apparent in much of the latter conversation. His return, on the other hand, at the end of the session could have reflected his desire to remain part of the group and an indication that he did not want to be forgotten. This participant was debriefed individually and no risks were identified.

5.3.2. Ethical considerations and limitations

Ethical challenges and limitations were frequently considered throughout the study from initial conceptualisation to interpretation of results and these were often interrelated. Studies that focused on the importance of understanding the individual's lived experience have provided little guidance on how to take research forward. Issues of adaptability and accessibility led to all written aspects adhering to accessibility guidelines (Scottish Accessible Information Forum, 2014). Consent to participate posed some difficulties and was assessed using the Mental Capacity Act (2005) principles. Video and audio recording of interviews were beneficial as it allowed tracking of conversations and analysis of body language, key to analysis, when social norms and cues were more disinhibited or difficult to understand. However this raised issues around storage and possible identification of participants' data.

Considerations around interviewing included wheelchair access and mobility challenges, with interview times arranged around support provision or fatigue levels. Where understanding communication was challenging; paraphrasing, reflecting and prompting were used to clarify meaning and interpret in real time. 'Meaning' would have been lost if relying solely on recordings post focus group and proved crucial to further analysis leading to more active participation by the researcher. On balance this more active role led to more depth of enquiry in the moment.

5.3.3. Challenges to the analytical process

While the flexibility of Thematic Analysis allowed those who previously would have been excluded in research to be considered, participants in this study were often unable to answer more abstract or conceptual questions. This was possibly due to their cognitive deficit, communication difficulties or a difficulty in being more exposed in front of their peers. During the analysis phase agreement was sought on the interpretation of participants' accounts when transcribing was more difficult due to speech impediments. Agreement was also sought when considering the resultant emerging themes. Overall, it was more important to have facilitated access and included participants by adapting accordingly than to have included only those that "fitted" easily into a pre-existing research template.

5.3.4. Production of an individual interview schedule

The findings were gathered and discussed with the research supervisors. Before making decisions about the design of the semi-structured individual interviews, the challenges of using this format were considered. Possible ideas were cross referenced with the literature regarding the impact of ABI on engagement within the research process. This assisted decision making around the design of the individual interviews and resulted in the inclusion of a narrative exercise accessing more story telling memory (Paterson and Scott-Findlay, 2002). Furthermore this included the decision to ask more focused questions, avoiding more difficult free recall questions (Paterson and Scott-Findlay, 2002).

5.3.5. Consideration of credibility

After discovering the extent of the difficulties participants had with the focus group questions it was crucial to judge the credibility of the research. This was carried out prior to analysing the findings and informed stage two of the research study. In doing so the credibility was judged using a pragmatic approach to assessing validity recommended by Chioncel et al, 2003. Focus groups are ultimately underpinned by the hermeneutic circle in keeping with the methodological considerations, whereby, "people's views and understandings are shared,

debated, challenged and changed” (Field, 2000, p. 324). Chioncel et al (2003) suggested an eleven point criteria by which to judge focus group credibility and this was applied to the focus group data.

This study produced an outline of research schedules including both introductions and debriefs (appendix 8.8, 8.9 and 8.10). Although the questions included were semi-structured they were all worded and agreed in advance. This ensured the replicability of the focus group although the discussion itself was fluid and evolving. The research questions were ordered by importance to the research aims. Questions were spaced evenly across the focus group however depending on how animated the participant group was; some questions had more time for discussion across the interview.

Participant recruitment was detailed (section 4.2). All six participants recruited to the focus group were deemed competent to answer the questions, in keeping with recommendations, (Morgan, 1997). However one could not attend due to ill health on the day, leaving a total of five individuals. Participant gender was also considered; although the majority were male this was representative of the overall population of young adults with ABI and thus was deemed appropriate. Group dynamics were considered so as to ensure that even those participants who did not agree were represented in the analysis. This ensured no bias was applied to the research. The smaller sample size was also not considered to impact on the validity of the findings at this stage since the purpose of the focus group was to inform the individual interviews. The role of the researcher was considered particularly in relation to dealing with inappropriate behaviour in the focus group and impact this had. Throughout the focus group the researcher fed back her understanding to check for accuracy and clarity of the participants’ points. This furthered the reliability as it checked understanding in real time and allowed the participants to correct any interpretative mistakes.

5.4. Conclusions of Stage One

The focus group was audio and video taped and process notes were kept throughout the focus group in order to maximise data collection and assist analysis. The coding and interpretation of the data followed the methods recommended by Braun and Clarke (2006). As the analysis was contextual in nature, “the quality of the responses and their association are more relevant than their frequency,” (Chioncel et al, 2003, p. 504). However reference back to the research question was kept in mind, respecting both theoretical and interpretative validity of the analysis. At this stage the report construction and reviewing the findings with participants was

not appropriate. Finally research findings were discussed with both internal (University) and external (Organisation) supervisors to ensure validity and agreement of the findings.

5.5. Overview of Stage Two: Individual Interviews

This section presents the analysis and findings following the final stage of the doctoral research namely, the individual interviews; the purpose being to explore the topic in more depth, following on from the insight gathered at the focus group stage.

5.5.1. Individual interviews

Nine participants, one female and eight males, were interviewed for between 60-90 minutes. The participants self-identified various cognitive, physical and emotional difficulties following ABI. For further details of difficulties see appendix 8.5.

As it was recognised that participants with ABI find difficulty engaging with research interviews (Paterson and Scott-Findlay, 2002), the individual interviews took the form of completing an initial narrative exercise exploring each participant's experience, followed by four semi-structured questions (appendix 8.9). This narrative exercise was adapted from the 'Train of Life' (Chow, 2015) which was recently evaluated and found to be effective in exploring an individual's lived experience of stroke. For an example of the narrative exercises see appendix 8.10. The following interview questions were semi-structured in nature in order to provide prompts to guide the conversation about specific areas of interest not yet covered by the narrative exercise (Petty et al, 2012).

This analysis gave insight into the meaning of living with an ABI and was accessible to meeting the needs of the participant group. It was noteworthy that both communication and cognitive difficulties often resulted in responses being short with incorrect wording or grammatical errors. As with the focus group body language and non-verbal cues were noted throughout the interview so as to add to the strength and richness of the data gathered. This included when participants intonation and presence changed, for example, when one participant was discussing a particularly difficult topic his demeanour became more agitated and he gesticulated more forcefully along with the rhythm of his speech becoming faster and his pitch increasing slightly. This was therefore interpreted as a point in the interview which elicited emotions of anger and the point being made as having more weight although this was not verbally expressed. As mentioned the interpretation of body language and non-verbal cues is in keeping with the methodological stance of this study.

5.5.2. *Thematic Analysis*

As with the focus group analysis all interviews were analysed using Thematic Analysis and specifically the 'six stages' process outlined by Braun and Clark (2006). Thematic Analysis is a flexible approach to qualitative analysis that aims to identify key ideas or patterns within complex data sets. Therefore it was deemed an appropriate tool for analysis of both a narrative exercise and semi-structured interview questions. This allowed discussion content, body language and the evolving visual exercise to be considered as sources of data collection. It was also in keeping with the researcher's epistemological and ontological stance.

5.6. **Research Quality**

Recommendations relating to quality in qualitative research were adhered to throughout the study, referring to guidelines by Elliott, Fischer, and Rennie (1999) and Yardley (2000). This included consideration of the following areas:

5.6.1. *Ownership of the research*

The theoretical orientations underpinning the research have been described in statements about ontological and epistemological stance (section 3.3). The impact of the researcher's background, values and assumptions was considered throughout the process of the research.

5.6.2. *Reflexivity*

I addressed reflexivity throughout this study as appropriate to each stage of the research. However in considering my epistemological stance as one of social constructionist along with my chosen methodology namely, hermeneutic phenomenology, it was worth addressing what I brought to the topic more generally.

I am a 32-year-old white British trainee counselling psychologist. My interest in the topic stemmed from working on a placement during my training with young adults who had an acquired brain injury. Since systemic therapy also approaches knowledge from a social constructionist stance, this influenced the way in which I approached the analysis. I took into account how an issue, such as being known to the participants prior to the research interviews, could have made the interview process more challenging.

I acknowledged that my own culture and gender was often significantly different from the majority of the participants and so maintaining sensitivity while moving alongside their

experience was important to me. As such, I acknowledged the influence of my own views and experiences and remained open-minded to new stories when conducting the study.

It was crucial to take this knowledge, my own awareness and learning into consideration as I proceeded with developing the research. Of particular note, my interest guided me to a paper evaluating the use of narrative therapy following stroke (Chow et al, 2015), which encouraged me to incorporate a narrative exercise, enabling the participants to engage more in-depth during stage two of the data collection.

What emerged was the difference between how services were developed or responded to these young adults and what the young adults themselves felt were their needs and priorities. These experiences and specifically my interest in systemic therapy and its application to neuro-rehabilitation settings led me to feel passionate about the type of support, specifically psychological support, which individuals received throughout their life cycles.

I have reflected further on personal-professional beliefs and the potential impact of these on the research within the discussion (section 6.5).

5.6.3. Situating the sample

Recommendations suggested that authors provide an adequate description of participants to enable readers to understand the findings within the limitations of generalisability (Elliott, Fischer, & Rennie, 1999). However this was bounded by the terms of the ethical approval, which specified that participation data should only include de-identified samples. Therefore no identifiable personal information has been made available about the participants. General demographic information about the participants is contained in appendix 8.4 and 8.5. Furthermore a description of the context in which participants were recruited is contained in appendix 8.3.

5.6.4. Grounding in examples

Data extracts are provided throughout to illustrate concrete examples of themes and ideas used at each stage. Examples of initial codes and the process of developing themes are appended (Tables II and III) to illustrate how the analysis was undertaken.

5.6.5. Rigour and validity

The researcher conducted the analysis in a way that captured the subjective experiences of the participants. The researcher's placement supervisor, a systemic psychotherapist with 15 years of experience working in the field of acquired brain injury and with a full understanding of Thematic Analysis, scrutinised an extract (10% as recommended by Joffe, 2012) of the raw

data from the individual interviews to act as an additional analytical 'auditor' (Elliott, Fischer, & Rennie, 1999, p. 222). Throughout the analysis extracts of coding and examples of themes were shared with, both placement and university research supervisors, who provided verification about the interpretation of data. Data extracts were provided throughout the result sections that enabled readers to review the analytical process. This ensured that biases were minimised in the interpretation of data and crucially, it also made sure that the content was sensitive to the experiences of young people living with ABI.

5.6.6. Coherence

The results were presented in a narrative format to enable readers to better comprehend how data was interpreted. The description of the data was organised into broad categories or themes, with sub-themes which highlighted the nuances of the participants' discussions.

5.6.7. General versus specific results

An additional consideration pertained to the generalisability of the findings to different contexts. The current research focused on the experience of ABI from a young adult's perspective. Due to the potential heterogeneous nature of the participant group and the context in which the participants were recruited, it is important to be mindful of these factors when considering the applicability of the results of the current study.

5.7. Results Summary

Thematic analysis generated eleven themes which were grouped into three master themes. Findings and themes were presented in both, table format with illustrative samples of the data (Tables II and III), and as a narrative account (Braun & Clarke, 2006) to allow the reader to easily evaluate the fit between the data and the interpretation of the results (Fossey et al, 2002).

As with the focus group results participant pseudonyms were provided within the quotes to denote the speaker. Within the quotations, non-relevant data was removed and denoted by '...'. Excerpts are included from across the breadth of the data and to this extent do not necessarily represent frequency of response.

Table II: Master and Sub-themes of the Individual Interviews

Master themes	Sub-themes
Hidden Consequences	<i>Making Sense of What Could Have Been.</i> <i>Change as a Challenge</i> <i>Coping Strategies</i> <i>Person in Context</i>
Discovering a Different World	<i>Identity</i> <i>Connecting</i> <i>Rejection</i> <i>Surviving in a Hostile World</i>
Piecing Together a New Narrative	<i>Moving Beyond ABI</i> <i>Appreciating Life</i> <i>The Paradox of Survival</i>

Table III: Illustrative Quotations of the Individual Interviews

Master theme, Sub-theme, Illustrations
1. Hidden Consequences 1.1 Making Sense of What Could Have Been <i>"You know it's crazy but you just don't expect it to happen when you're young. You think you're going to live forever." (Simon, L688-689)</i> <i>"You had this path that was all set out for you and life would have been easier, it would have been sweeter if you had just followed it." (John, L664-665)</i> 1.2 Change as a Challenge <i>"It's not exactly a choice that you take, it's the choice that you've been given." (Louise, L558-559)</i> <i>"I've realised in my journey some people don't even make it this far and em, and if we do we're still on the journey of stability and realness...I don't think I'll ever be normal again." (Juan, L777-781)</i> <i>"Cause it's not rebuilding my life because there's no foundation to build on." (Simon, L1075-1080)</i> <i>"Just as I turned 21 and life was good. Not even with rose tinted spectacles, my life was really good...And then this happened and I was dehumanised in just like every way really. I was put in this awful situation and it was a nightmare, an absolute nightmare." (John, L303-307)</i> 1.3 Coping Strategies <i>"For a good while I resorted to drink, I'll be honest. You know I was drinking 20 cans a day and that just kinda just dumbed it down a bit...shaved it off a bit." (Simon, L294-302)</i> <i>"The only thing that I've got in my life that I can actually say keeps me ticking over is probably the smoking." (Simon, L1549-1550)</i> 1.4 Person in Context <i>"I think he's always been a little bit more reserved sort of how to act around me a little bit, cause he's nervous if he does something that I'll have a fit around him or something." (Louise, L167-168)</i> <i>"I was coming to terms with the fact that I'm in what I know to be normal life...because normal is a word that I do not like...cause people take, get that, get the whole definition of that completely</i>

wrong...you know to them feeling normal is being 100% healthy with no health issues. But that's not the case. Everyone's got their own different...version of normal." (Simon, L398-408)

"Once you are in that grey area you are forgotten about." (Simon, L1373)

2 Discovering a Different World

2.1 Identity

"Although I was aware, the total, total recovery was still half there, half not there. I wasn't able to feel myself or know what myself was. So then I didn't really know how to em "be" myself...But now, now I'm strong enough to find myself." (Juan, L437-446)

"I think that's the way it often is in your early 20's. You are so, like being a late teenager you're forming your identity aren't you? And getting on with your own life that's what we are doing." (John, L265-267)

2.2 Connecting

"You know, I know what it feels like, I've been there myself and could explain to him how it feels and what you go through." (Simon, L1230-1231)

"A friend is someone who, who will be there for you." (Mark, L191)

2.3 Rejection

"You just can't seem to connect with other human beings it seems." (Charles, L170)

"They need something from me. Like if I'm alright everyone would be two or three of them would turn up. Afterwards no-one turned up, it was only my mum and dad and brother was there." (Ashan, L97-99)

"She obviously want to be there for the good times and hopes that maybe I'll come back but I won't." (Simon, L1106-1107)

2.4 Surviving in a Hostile World

"The people there you know, it's just like they love making your life hell. It's really bad and you know you'll explain something like, 'I've got dyspraxia and I've got a brain injury and I've got dyslexia'. And they'll say, 'oh you used that excuse the last time'." (Charles, L487-490)

"I feel like a ticking time bomb." (Simon, L1171)

"I was really secure there and now I don't have that." (John, L611)

3 Piecing Together a New Narrative

3.1 Moving Beyond ABI

"I was going out and drinking. I was wasting time not doing things properly and not looking after myself. And now that I've removed that from my whole formula of life, I can live more and see more." (Juan, L273-276)

"It's life changing and it is what it says on the tin." (Simon, L1901)

"It's the end thing of I'm noticeably different without being crude...It is subtle granted, it is subtle. The movements, sound of my voice they're a little slightly altered and I think that...I don't want to compromise, settle for less." (John, L169-173)

3.2 Appreciating Life

"I am powerful in many ways but I don't know how to put it...influential." (Prabir, L525-528)

"I'm thankful because I could have been still alive and not been able to do the things I've done...I've actually managed to pick myself back and had that chance. I've had that opportunity so I want to use it the best I can and get myself back out there and live, you know? And be able to have it as a distant memory and a story and just be able to say, 'I went through this'." (Simon, L1783-1791)

"I'd never have been able to do that otherwise. I mean that's a very different life." (John, L408-410)

"The brain injury and me, it's the same thing now." (John, L895)

3.3 The Paradox of Survival

"To see the rainbow you have to see a storm." (Simon, L443)

"Because lucky is such a tale of two halves." (John, L807)

5.7.1. Narrative accounts of the results

5.7.1.1. Theme one: Hidden consequences

Many participants described their expected consequences of ABI as adjustment, change and adapting. However, subtly underlying these broader topics were 'hidden consequences'. For many of the participants these were outcomes that couldn't be planned or prepared for, including 'making sense of what could have been', 'change as a challenge', 'coping strategies' and 'person in context'. These often evoked the most emotional responses during interviews and were discussed most passionately. Although the individuality of these hidden consequences was apparent the frequency and impact of this was moving.

5.7.1.1.1. Making sense of what could have been

Each of the participants described the idea of the past before the ABI being the starting point of making sense of what had happened. This was triggered by the shock of the event for many;

"I sound crazy but you wake up and why have I done nothing that I care about so why have I lived?" (Brian, L477)

This quickly moved towards 'hitting rock bottom' where the losses became more apparent both in relation to the self and in relation to others. A common theme for many of the participants was the naivety of their assumptions pre-injury, for example, taking life for granted became a barrier to the 'sense making' process. The enormity of this was highlighted by one participant;

"I was just happy go lucky and just living every day as it comes. You know when I think about it as well, I never thought of myself as getting ill, having a disability. None of that, none of that ever occurred to me. I never, ever thought that could happen. I always thought I would be fine, I'll always be healthy you know." (Simon, L672-678)

Participants discussed the chronology of this process, moving on from internal reflections towards external reflections of difference, using examples of assimilating back in to life. There

was a clear sense of 'transitions' with participants using words such as 'before', 'in the beginning' or 'at the start'. Whereas others were more direct in their accounts by stating the permanency of the changes;

"I've sort of never really got back to whatever I was before sort of." (Louise, L57)

"From the start realising that I wasn't on that same level anymore...I have been set back many years." (Juan, L209-211)

"And there is nothing I can do cause you can't bring the person back or put your life back in and rewind the clock". (Simon, L138-139)

Finally this period was concluded with the resolution of what had happened. For many of the participants this was an individual process depending on when the injury happened, how the injury was acquired and the severity of the outcomes. For one participant it was about the loss of a transition in life from adolescence to adulthood. She commented that this stage was "robbed";

"I never really got to finish that part of life." (Louise, L190)

She went on to discuss the changes and the future she could have had with the sense of this being an unresolved ending. For another however timing was key to resolving the past as he felt he had lived his best years prior to the ABI and so he accepted the accident, allowing him to leave behind any feelings of regret;

"I look back and I don't regret it because I had my time at that time. I don't regret it, it's the best years of my life before my accident." (Prabir, L270-272)

"I didn't live up to my expectations...I might not have been higher but that was good enough. I was happy. What I accepted before my accident was what I accepted". (Prabir, L802-804)

For a few where the ABI had been a result of trauma (e.g. assault or car accident) retribution was a key issue in making sense of what had happened. An acknowledgement by others of the part they played in causing the ABI, as well as, a sense of their recognition of the life changing nature of ABI, together with an acceptance of the young adult's lack of control over the accident, may have allowed them to feel resolution;

*"No amount of punishment could ever give me back what I lost anyway but nonetheless it would have made me feel better to have known that at least someone had seen it".
(Simon, L904-906)*

5.7.1.1.2. *Change as a challenge*

Many participants discussed the focus initially being on rehabilitation but that it was post-discharge when the 'real work' began. For one this was highlighted by feelings of elatedness as they felt discharge was the major hurdle achieved but then they hinted at the dawning reality of their situation;

"Immediately after coming out of hospital I've never been more happy in my life. I was, you know, just really positive about everything...I mean I was like, 'I got hit by a bus and eh, I've lived! Oh there must be a God'...And then as time went on and things got really shit, I was like, 'yeah God kept me alive for his own sick personal amusement'. And then as time went on I was like, 'there is no God at all'." (Charles, L393-394)

"Em, yeah it wasn't all about walking it was more like psychological effects on your brain really but repair speech and everything, you know?" (Mark, L38-39)

Some participants discussed the idea again of change being a process over time; only through discovery could the extent of the injury be appreciated. Many described change itself, as being a challenge with the continually evolving nature of treatment and the ABI (e.g. transitioning from hospital to rehabilitation to home or balancing emotions in maintaining hope). Some participants felt that it took time for the change to become apparent;

“Until you’ve actually experienced what it’s like to have a brain injury over the course of a few years, you’re not going to know just yet what sort of problems it, you know, presents.” (Charles, L696-698)

“I’d say recognition and acceptance aren’t the same because I had realised what had happened to me but I didn’t really accept it until I went to. Until I heard that the nurses told me I wouldn’t walk again. Cause then I really thought, shit, it was worse than I thought.” (Mark, L298-302)

This noticeably included how others adapted to the changed individual, highlighting differences within the peer group. For example many spoke of wanting to ‘fit in’ but having to remain vigilant. Often over thinking decisions meant that they couldn’t relax and act spontaneously, therefore setting them apart from their peers;

“Sometimes I have this little impulsiveness of ‘hey it’s only once and it won’t make a difference to me’. But even once will have consequences for me.” (Juan, L562-563)

“Alcohol em, is not good now so I’ve been told by doctor’s em, do not drink, it’s so bad for your brain and blah blah blah. And em, I think alcohol is bad for anyone. That’s a fact but to be told you can’t drink on top”. (Brian, L178-180)

“[They] say, ‘yeah let’s have a drink on a Friday and let’s have a late night on a Saturday’. They see that as normal. And I really can’t really do that now because it doesn’t really work for me.” (Juan, L280-282)

This theme also extended into discussions around relating to professionals as challenging, where their changing demands or expectations often left participants confused;

“I don’t know what on earth I’m supposed to be doing now.” (Louise, L124-125)

“As much as I really criticise it, it did the psychological treatment at the hospital it was pretty much what I needed in some ways. The harsh reality to myself.” (John, L447-448)

For many the adjustment into 'normal' or the 'old' life was when the stark reality of the change was realised. For many it was small changes that held the greatest consequences;

"You know I can't have a bath. I have to shower...and it's just the simple things like that. There's nothing that I would love more than just to get in the bath and sit in it and soak." (Simon, L1282-1291)

For others change was not about something to overcome but that life was just more difficult;

"You can be an intelligent guy but still have lots of difficulties with you now just, just normal mundane kind of things that people take for granted really. That come easy to everybody else but might not come so easily to someone with a brain injury." (Charles, L686-688)

Others described a feeling of being trapped by the ABI. Every time they adapted to the change another challenge would appear or evolve so that the participant was continually under pressure to adjust. This was reflected when a participant described the ABI as being similar to a spiders web;

"And it's like basically you are trying to detach yourself from all the strings you are attached to but it's like the strings you're trying to detach to they're not detaching or they keep being reattached by something else. And it's always one thing after another." (Simon, L1493-1497)

5.7.1.1.3. Coping strategies

Coping strategies were an emerging theme present in all participants' accounts. The theme was interpreted in two ways with the emergence of various coping strategies post-injury along with the injury being used as a coping strategy for managing general life.

Addressing the first element of coping strategies, participants mentioned initially more extreme or maladaptive methods of coping. These involved suicidal ideation, self-harm, gambling, alcohol and drug misuse;

"Not just feeling a bit down it's really, really, really wanting to fucking top yourself."
(Charles, L413).

"Before my injury I was King but after my accident, the day after this cut (indicates to self-harm)." (Ashan, L127)

Exploring these further it was apparent that many of the participants did not rely on these strategies to cope with everyday challenges, prior to the injuries. Now, however, they were strategies that for them could be easily accessed and acceptable post-injury. However, as these coping strategies evolved and participants' journeys moved beyond the ABI, their accounts changed too. For one participant this was a moment of recognition;

"But I realised that I couldn't keep doing it (drinking) ...I've got self-respect for my body."
(Simon, L294-303)

Putting in boundaries and admitting to there being a problem was the first sign of re-establishing control. However, for others it was about changing direction, managing expectations and normalising their experiences. Some participants named various different strategies they had developed post-injury;

"I keep my expectations low because then that way I don't become disappointed."
(Simon, L725)

“We all have days where sort of we’re all there and life is horrible.” (John, L592)

“Numbness that’s towards it...I’ve got an extra layer of skin now.” (John, L869-877)

Whereas others commented more specifically using or seeking services for further support and becoming more proactive in managing the consequences of ABI. One participant reflected;

“Also my psychologist, knowing that I’ve got that back-up. That pillar to lean on, its stability there cause it gives me the confidence.” (Juan, L117-118)

At this point many of the participants gave examples of where the ABI itself became a coping strategy. In particular one participant felt it gave him more freedom to be himself and commented that it;

“gives me an excuse for anything”. (Brian, L265)

This idea of excuses also protected the participant from feeling the full force of others’ judgement;

“If someone says something, criticises, then I can say I’ve had a head injury, leave me alone”. (Brian, L261-262)

5.7.1.1.4. Person in context

Layers of change from the impact on family and friends to the impact of services such as housing were cited. Some participants mentioned more systemic barriers where they felt consequences of ABI were further complicated by gender and discrimination. Whilst there was an element of the journey being individual, participants were clear that the impact was far

reaching and not in isolation. One participant felt her family had to make major adjustments to the changes. She talked about the change in relationships;

“It has actually become sort of more intense really because she’s not just my mum she’s my full time carer now.” (Louise, L77-78)

Whilst this change was perceived positively, she spoke of it being imposed on the family, adding complex emotions such as guilt and feeling a burden. Whereas for some the ABI drew them closer to others; many reflected that the breakdown of relationships led to more complex feelings including loneliness and isolation. Further consequences of ABI led to compounding health issues adding to further levels of complexity of context;

“It’s been very deceiving...that individual might look alright but really what’s he feeling? That happened to me.” (Juan, L690-696)

“Yeah it’s just everything else that’s come behind it as well. It’s fell on top and I’ve had to deal with so much”. (Simon, L53-54)

“All of it is hidden, you can’t see what I’ve got now. No-one can see the epilepsy, no-one can see that the nerves are damaged.” (Simon, L1151-1152)

A few participants commented on how systems perceived young single males creating additional barriers over and above the ABI. When discussing moving on from rehabilitation two participants mentioned homelessness and employment being specific barriers.

“Because I’m single, housing refused to class me as vulnerable...you know and that’s just because of the gender I was born.” (Simon, L1028-1030)

However this was closely linked to feelings of powerlessness; participants felt that services or systems did not understand ABI, leading to further levels of discrimination that they had not initially anticipated;

“And I remember just one day when I just been absolutely everywhere being told no by absolutely everyone and it’s just, it got to the point where I just burst into tears at the end of the day. I just fell to bits. I just felt it was so stressful.” (Charles, L365-368)

“That makes you feel disempowered because obviously you feel powerless because you’re in a position where you want to get better and work, you’re still employed but you know full well in your head you can’t.” (Simon, L1270-1272)

5.7.1.2. Theme two: Discovering a different world

Many of the discussions were relational in content with participants, firstly, making sense of themselves followed by, making sense of themselves in relation to others and finally themselves in relation to the wider context. Identity was one of the most open and easily discussed themes throughout the interviews as were social groups and relationships following ABI. Relationships were described as ever changing, where they were not seen as fixed in time but instead fluctuated and changed along the journey. The young adults revealed a deep sense of fear and rejection when discussing how they felt their perception of the world and their place within it had changed as a result of their ABI. It was clear that issues were very current for participants. Unlike the first theme which was more resolved these themes still had a tendency to elicit an emotional response, indicating the significant challenges the participants continued to experience.

5.7.1.2.1. Identity

Identity was a key theme in all participants’ accounts. Again this was described as a fluid process. Participants used key phrases such as ‘before’, ‘early stages’ and ‘now’ to evidence this evolution. Participants identified moments of perceived change in identity to connecting to the new self then to resolving the new self, which included developing a positive self-concept, through to ‘becoming me’. For some participants it was letting go of the past self and developing a completely new identity whilst for others it was merging the past identity with the present;

"I have two me's but even the second me isn't a bad person." (Prabir, L330)

"I've still got traits of the old me but I'm not the same person." (Simon, L1582)

*"You realise that you have to leave the old you behind and get used to being me."
(Mark, L370-371)*

'Resolution of the self' involved a key period of questioning where the participants discussed not having a clear sense of who they were. This struggle of identity came in two parts with one external and one internal process. The first stage involved coming to terms with the injury and telling others. Some participants discussed, 'telling people', provided a therapeutic value enabling them to come to terms with the ABI. However for others this was a more difficult process as they preferred to reject the labels or negative associations of ABI. This was highlighted in the accounts;

"I wouldn't say I'm someone who changed status since the brain injury...it's difficult as I had always firmly denied it...and got a bit defensive." (John, L71-75)

*"I don't want to say anything about a brain injury but em it, to me it sounds worse".
(Brian, L603)*

"I was really brain damaged and that took a long time to say." (John, L316)

However the physical evidence of the ABI often challenged participants to address the issue of their changing self;

"Because it's real, I had changed". (Juan, L637)

"I don't want to tell people that I've had a head injury but I seem to be addicted to saying it. Look at this, look at this, this scar in my head that this thing is in my head, there's a piece of titanium". (Brian, L613-615)

The second challenge to identity was an internal conflict. Participants used words such as 'broken' and 'damaged' to emphasise how they felt about the enormity of the issue. Many suggested that there was a long period of uncertainty in dealing with this experience and the isolating nature of the journey;

"You break up inside and you know nobody can actually see your pain." (Simon, L1640)

"You try piecing them back together but you never ever repair the damage because the cracks are always still going to be there. That lives with you for the rest of your life." (Simon, L1644-1646)

Key to moving on appeared to be acceptance of self. Participants spoke of recognising that the ABI was something which would always be part of them. One participant emphasised this when discussing the transition from adolescence to adulthood;

"Just as you're coming on to be adult and then you actually become an adult, you become an ill adult". (Louise, L500-501)

She went on to discuss how it had changed her experience of adulthood. This was echoed in other participants' journeys where they felt they were not able to experience a particular stage of life in a similar way to their peer group. This connected to the idea of "change as a challenge".

During this shift towards acceptance of their present identities, there was also a change in narrative where the participants began to reframe their experience of their ABI. This was highlighted when using words with more positive connotations such as 'strong', 'resilient' and 'appreciative';

"I think those changes were meant to happen for me to become the me that I was supposed to be." (Simon, L625)

"I'm not completely dead but to me, I see the old me as being dead. Because the old me was going round the same cycle day in day out. Not thinking as much as I am now and not, not even felt pain or anything real. I've experienced real stuff, real life and that's the best way I can put it real life. You know it doesn't get any more painful." (Simon, L1690-1693)

"Whereas now I love it. I'm a sucker for a, call me cliché but it's like em, the whole journey of life. I'm fully accepting that this injury is also going to be a permanent factor of my life." (John, L80-82)

For others this change signified a shift in focus from being more internally focused on the change to an outwards focus on life;

"It's unfortunate but the normal me now, she's an epileptic but that's part of me... but really you've just got to keep going with it because life's still going ...cause there's a life out there." (Louise, L562-569)

However it was worth noting that for one participant the ABI tainted his sense of identity. Despite being able to discuss positive changes in his life since the ABI he was less able to reframe his account.

"I don't see that as achieving because it's not what I wanted for me." (Prabir, 354)

5.7.1.2.2. Connecting

Connecting was a strong feature in all the interviews. It took various forms, from connecting to others, ways of connecting, to being included. Participants listed the importance of a variety of connections for example friendships, sexual relationships and identifying with similar others with an ABI. Participants all felt that the experience of ABI had provided them with an opportunity to reflect on the connections they had. This often led them to recognise the inevitable changes in relationships re-defining what relationships meant and being more forthcoming about their own relationship needs;

“The experience of having a brain injury or anything like life changing experience where it teaches you who your real friends are. It teaches you not to use the ones I do see. Because like I said friends really are just friends, people that will be there if you need them.” (Mark, L214-216)

Although many felt that this was natural following a life changing experience one participant felt this was a reflection of their stage in life;

“I suppose it cemented friendships in a lot of senses. But at the same time it’s not to say my friends are the same because you always get new friends.” (John, L58-59)

For another two participants this was seen as an opportunity to explore new friendships in different contexts;

“But you know I think that when you get old you got years of wealth and experience. Maybe you’ve got an unusual or interesting point of view, maybe you’ve got something funny to say. I would rather hear that than sit in silence”. (Brian, L141-143)

“They’re all friends that I’ve met in rehab or met in places like this (organisation).” (Mark, L159)

Most of the participants discussed using social media as a platform for staying connected in the early days when perhaps friends were less accessible. One participant highlighted that social media acted as an aid for memory difficulties allowing them to remember past events and people;

“Cause things like Facebook were there and for a while I would, I was saying yesterday, I would forget names and names to faces...say hi or keep tabs on what’s going on basically”. (Brian, L162-172)

“Social media that has actually been throughout...Positively completely because it gave me the validation. It allowed me to tap back into my life...I had a sort of voice on social media.” (John, L530-539)

Many participants spoke of the difficulties in establishing romantic relationships following ABI. In particular they raised the issue of not knowing how to communicate and found that social media ‘apps’ provided a medium for opening conversations, without the same fear of rejection caused by people seeing their physical changes post ABI. Many participants discussed numerous unsuccessful relationships as they tried to make sense of what had “gone wrong”. However, two participants who did establish longer term romantic relationships felt this area had been neglected by support services, and even themselves. Although very complex, they stressed that it had been essential to them when integrating back into society;

“She em, she taught me everything. She knows everything, she didn’t mind. She just helped me with changing my mind, changing my thoughts and everything.” (Ashan, L231-233)

“I’ll sound a bit weird but it’s like I’ve lost my virginity again. Cause I mean after the accident I was in the hospital. Obviously I’m not going to get much sex while I’m in. It’s, it’s em, obviously I remember a bit about sex but it’s really, it’s nice to have sex again”. (Brian, L530-532)

For other participants it was a more difficult area to address but one which they felt the full impact of and was often in the forefront of their minds;

“It’s just fucking shit, I’ve got no friends, no girlfriend, you know? I’ve gone through, I’m turning 30 next year which means next year, it means- well I guess this was last year when I was turning 29 and I said so which means I’ve gone through the whole of my 20’s without one single relationship.” (Charles, L247-250)

Finally 'connection' raised the idea of being included. In particular, many participants felt the idea of leading by example gave them a chance to share their stories of what they had learned from their experiences. For one participant with children this was essential in giving him as sense of purpose and achievement;

"It's good to still have that in my life [children] and know that I've actually done something right in my previous life." (Simon, L1576-1577)

For others it was related to passing on advice or knowledge gained through the ABI experience. This involved acting as a role model and connecting with similar others at different points in their journey and with the wider society in general.

5.7.1.2.3. Rejection

Closely aligned with stories of connection were the numerous stories of rejection. Participants were quick to give examples of both subtle and overt rejection. This was most obvious when discussing the breakdown of relationships. Many reflected on how it was not only themselves who had changed but people's perceptions and reactions to them. Some discussed how a perceived increased vulnerability caused people to react in two ways, either withdrawing or becoming overly protective;

"She left me because I was disabled...and I had no money or anything...she became reduced and I embarrassed her." (Ashan, L222-227).

"I think as a general people would be more protective just because I would be more vulnerable. There's no, there's no two ways about it." (John, L235-236)

Others were more open about their experience of rejection. They noticed a change over time namely; friend's no longer maintaining the level of support that had initially been offered. One participant responded bluntly;

“Because in the beginning the waiting room was banging out with people coming to see me. But I think they just wanted to see me die or something. Cause it was a little bit of excitement in their lives or whatever.” (Mark, L153-156)

Many also felt that this change reflected their changing circumstances at no longer being able to offer their friends the same relationship they had previously. One person reasoned that this reflected more about his previous relationships with certain friends rather than internalising the blame;

“When I was in my prime and I was doing well and I had something to offer people they were there...but when that all went away, they weren’t there for me. And that really doesn’t resemble who I am, that doesn’t define who I am. That defines who they are, and they were obviously no good in my life.” (Simon, L836-840)

For some participants, rejection was at a wider or societal level. Some felt that the focus of rehabilitation, although positive, did not focus on the elements that enabled them to reintegrate into society, instead focused solely on physical and psychological recovery. Following discharge participants felt issues such as homelessness, employment and benefits posed barriers to the life they previously engaged with and thus disconnected them from others;

“I think rehabilitation is not just about em, I think a lot of rehab is like feeling equal in society. Like I want to be given the same chances as everybody else.” (Mark, L414-416)

“I feel a bit more marginalised in society, they can talk to me, they can relate to me a bit because they see that I’m not one of them but I’m just a plain book.” (John, L906-908)

Managing others’ expectations was a further factor that participants felt isolated them from their community, specifically the length of time to recovery and the expectation of a full

recovery. They felt that others' empathy and patience were often time limited which was at odds with the advice they were given professionally. One participant felt that due to his ongoing compensation case, people also regarded him with less empathy. Rather than recognising the challenges or difficulties he faced, he felt that they lacked empathy due to the perception that he now had financial wealth.

5.7.1.2.4. Surviving in a hostile world

This theme surfaced at various points throughout all the participants' accounts. For some the threat was linked to the impact of the ABI but for others it was a result of external influences. Trust was an issue which spanned both internal and external elements. Many participants had lost the ability to trust themselves first and foremost. Some spoke of the certainty of their pre-injury sense of self and raised this mostly with reference to their health;

*"Whatever happened I was just broken. Like I eh, can't trust my life, I can't trust me".
(Ashan, L359-360)*

"Life is unpredictable. Life is something you can't predict". (Prabir, L841)

"Cause I mean I don't worry about the future. I don't look at the future...I don't even know if I'm going to wake up tomorrow when I go to sleep tonight." (Simon, L1176-1182)

This uncertainty transferred to the world in which the participants lived. They perceived their own increased vulnerability as due to the ABI and thus were more acutely aware and primed to identify threats. For one this was about being able to rely on others for support if she experienced a period of ill-health, compared to others for whom it was about more actively avoiding situations that could have posed a threat;

"I can't always rely on the support that there is out there for you." (Louise, L147-148)

"I'd say you need to listen to others but don't trust other people...you have to trust yourself". (Ashan, L787-789)

"I found the challenge to be independence. It's scary like getting on the bus or getting on the tube. Remembering how to get to places again or how to remember roads, look left or look right." (Juan, L505-507)

Interestingly all the participants had an awareness of this change in sense of vulnerability with one participant commenting;

"It's made me more em, it's made me act a little bit, not paranoid but em this brain injury has really affected my way of reading, of reading the world, of living in this world and perceiving things." (Juan, L753-755)

Vulnerability was further heightened when many of the participants discussed the ABI being a hidden disability. This was also found in the focus group analysis emphasising and reinforcing its importance. Many commented that the lack of visible disability had led to numerous incidents where assumptions had wrongly been made. One participant highlighted how this level of discrimination was experienced when one benefits' officer stated;

"You know, you look fine, you are an intelligent guy so there's obviously nothing wrong with you." (Charles, L512)

Whilst another gave an example of a recent interaction with police;

"They thought I was to blame cause I was speaking a bit funny or my accent or my words or I was stumbling a lot in my vocabulary or whatever." (Juan, L141-142)

All participants expressed a lack of power in addressing this issue. They felt that dealing with their own safety was their responsibility rather than depending on services adapting to help them cope with their own vulnerability.

5.7.1.3. *Theme three: Piecing together a new narrative*

This theme was more about 'going forward', so future-oriented, with participants discussing moving beyond the ABI, personal growth and the irony of ABI. For many this was about making plans, appreciating the journey they had already been on, whilst acknowledging the journey to come. Many participants were able to direct more empathy inwardly and spoke of their hopes and goals. Overall this theme was a combination of the more positive aspects of life in general rather than being overtly influenced by the ABI. Many participants felt the ABI was a contradiction. Whilst they would not wish for the ABI they did appreciate the positive change and growth the experience of the ABI had brought them.

5.7.1.3.1. *Moving beyond acquired brain injury*

Although not explicitly asked in the individual interviews all participants discussed their future. Many spoke of a 'journey', 'stages' and 'moving on'. This was epitomised by the idea that the focus was no longer on the ABI itself but on the individuals' lifetime priorities. Within this was the acknowledgement of the ABI, its impact and recognition that it would always be part of their lives. One participant summarised this when he stated;

"No-one comes out with a brain injury unscathed." (Simon, L1916-1917)

Many participants reflected that moving on was almost like 'taking a leap of faith' and going 'solo'. They clearly expressed that advice was no longer helpful at this point as they acknowledged the uniqueness of their injury. Participants commented that around this point they no longer felt the need to tell their story, but acknowledged that having an awareness of their needs and being able to convey this to others had been crucial in finding their way;

"The sense of being aware and recognising what you need at that certain point and being comfortable at admitting it." (Juan, L849-850)

Some likened this awareness to the feeling of clarity about life; no longer reacting emotionally or impulsively to situations but having a clearer path or level of control over their options. This too included an element of knowing what options were available to them;

"I wanted to find eventually find a role where I could actually support others who have gone through the same thing." (Simon, L1247)

There was a sense of responsibility which contrasted with previous discussions where the raw emotion of the ABI was directed outwardly and recovery was something imposed on the participants. Instead the participants were now open to the idea that for positive change to happen then they themselves had to believe in themselves to make this happen. Many used words such as 'power' and 'purpose' to exemplify this point;

"Well you haven't really got a choice, you've got to keep going with what you've got really." (Louise, L534-535)

"I don't want to risk my life. I don't want to live scared of life". (Ashan, L252-253)

"I'll carry it but not let it carry me, I mean it's there but I don't feel the need to expose it necessarily." (John, L940)

There was also a noticeable empathy towards themselves within their accounts. Whilst previously the participants had focused on telling their stories, now when speaking of the future, participants recognised their achievements and the positive qualities they had retained;

"I should give myself more credit sometimes actually cause you are still going through it and you are still trying and you're not as bad as you think you are sometimes." (Louise, L588- 590)

"I'm still very capable." (Simon, L1354)

Finally there was acknowledgement of the journey continuing and that future change was most likely. Interestingly, this also signified a change in pace where participants arrived at a sense of peace. This too was in contrast to earlier stages where there was a sense of urgency surrounding recovery;

“Now I’m happy just to live how it is.” (Prabir, L591)

“It’s going to take the rest of your life, you’re going to be getting better for the rest of your life.” (Mark, L711-712)

5.7.1.3.2. Appreciating life

‘Appreciating life’ is used to describe positive change occurring following the experience of a negative life event. It was a key feature in the accounts of all the participants linked to ‘Moving beyond ABI’. For many it signified a point of change where accounts were less deficit saturated and where participants searched for the meaning of why the ABI happened. In listening to the participants discuss this sense, I couldn’t help but make a link to ‘hope’. It was alluded to when participants used phrases such as ‘gaining perspective’, ‘re-evaluating’ and ‘second chances’;

“I want to inspire other people. Because some people think about, look at his accident he’s no-one. He can’t walk; he can’t run, after his accident he’s nothing. So I want to, I want to do some big thing to inspire other people as they do things. Look at this, he’s done this, he came back...I came back to life.” (Ashan, L486-491)

“I always say I’m not disabled. I’ve got limited ability.” (Mark, L699)

Many discussed how these life events, regardless of how unexpected they were, had led to positive change. Many found that their previous lives were perhaps not as fulfilling or did not meet their needs in the way they had originally thought. Some felt that the ABI had given them an opportunity to re-evaluate their lives and make more conscious decisions about their future;

“Before the accident I was basically advising, doing a job I didn’t care about and now I get a second bite, a second crack”. (Brian, L554-555)

“So the stuff I’m doing now is very in tune with what I am really.” (John, L674)

Some spoke of the ways in which the injury had changed how they now felt about themselves or provided increased self-esteem. That they were in some way able to move beyond their capacity pre-injury towards personal growth, something that without the ABI may not have occurred;

“Before I’m alright. Now I can be better.” (Ashan, L581)

“And then basically accepting it, that’s when you become you, cause then you love yourself for all the pain and everything you’ve been through and how strong you’ve stood and fought your way through to become yourself.” (Simon, L651-654)

“I quite like that label and be with that quite nicely, I don’t mind being eccentric.” (John, L687)

There was the idea of the ABI having a greater meaning or purpose. One linked this to his religious beliefs whilst another two discussed the idea of fate. Several participants explored the possible meaning behind the ABI within a positive account. One participant felt that although the meaning may never be clear to him, the security in knowing that there was meaning to his experience provided a way of dealing with the adversity;

“Considering I survived you know what could have killed me. I’ve got to look at it as you know what, I’m still here. I must be here for a reason and there must be a purpose. I don’t know what that is yet. I might never find that out. Who knows but I’m here for a reason.” (Simon, L305-307)

Finally it was noteworthy that all participants’ discussions surrounding this theme regularly contained an element of motivation or inspiration;

"I would rather try it and fail rather than not to try and fail anyway." (Simon, L1765)

"Carry it rather than let it carry you." (John, L88)

"Never allow yourself to resign yourself to anything." (John, L886)

5.7.1.3.3. *The paradox of survival*

I felt that it was crucial to give voice to the 'paradox of survival' although a much smaller sub-theme underlying the "Piecing together of a new narrative". Many spoke of the words 'luck' or 'lucky' as being particularly controversial. They mentioned that it was commonly used by others to explain their relief at the situation. However participants felt this undermined the experience of the ABI and their journey. Many had conflicting emotions when they heard this term and spoke passionately of their dislike for it;

"Oh you're lucky, just appreciate you're really lucky. I think no! I'm not lucky am I to have this...How am I lucky? How can this ever be constructed as lucky? Having been through what I've been through." (John, L814-818)

Many in the narrative exercise struggled with whether to include 'lucky' and 'unlucky' as part of their experience. One participant preferred the term 'paradox' as a better way of describing ABI. Although many experienced this conflict of balancing both their survival with the negative changes they perceived, they did re-frame this sense more positively. The use of metaphor in their accounts was an example of re-framing this conflict;

"I've recognised that sometimes in life you've got to go through the hard and the badness to get to those ups and bigs." (Juan, L891-892)

"But there is pain and gain". (Ashan, L321)

"To see the rainbow you have to see a storm." (Simon, L443)

Finally a few participants compared their experiences to others in order to manage this paradox. The idea that their situation regardless of how difficult it was and that it could have been 'worse', appeared to create more balance within their accounts, which ultimately for most participants was what survival was about;

"You've got to stay positive and remember that no matter how bad it is for you there's always someone worse...You've got to remember that there's still good things about your life. And that's important, try and remember what's good." (Mark, L598-602)

5.8. Conclusion

Overall the analysis highlighted the individuality of every journey following brain injury even though some shared key stages and themes developed. While age in itself was not an emerging theme, the participants' responses reflected age-related interests and priorities that could have challenged every group of young adults, irrespective of ABI. Although many of the participants reflected on themes found elsewhere in the literature, it was noticeable that age played a role in the findings. For example, they referred to how the ABI had shaped or influenced their context including social life, culture and relationships, particularly friendship groups. Some made reference to changes experienced as being "normal" to this stage of life whereas others explored the idea of how life could have been different should their injury have happened earlier or later in life. Of most importance however, was the fact that life after brain injury was a complex balance between letting go of the past and defining a new role within the wider context of family, friends, community and survival.

The changes made to the design allowed me as the researcher to better explore the participants' experience in depth and through analysis, summarise this lived experience in a way which was accurate and sensitive to the individual participants. Critically it allowed greater depth of investigation into an under-represented population.

6. Chapter Five: Discussion

In this chapter, the findings of the research project are drawn together and considered within the context of the research aims. This chapter reviews the aims and areas of interest of this study and then follows on with a summary of the findings giving consideration to both current literature already discussed and introduces new literature where unexpected themes emerged. Having explored the themes, the clinical implications and the methodological considerations of the research are presented. Future research suggestions are discussed and finally in keeping with the ethos of qualitative research, the researcher's own personal reflections of the research process are put forward.

In review, the primary aim of this study was to gain insight into the experience of living with an ABI for young adults aged 18-30 years. The secondary aim of the research was to consider the implications for counselling psychology in light of the research findings, in order to better support young adults following ABI, not only in the immediate recovery phase but in their future lives. A third aim was to provide recommendations for future research.

The following areas of interest were explored:

- The experience of gaining awareness of change including physical, emotional, behavioural and personal.
- The process of losing an old identity and adapting to a new identity.
- The impact on relationships with friends and family.
- The use of social media in life post brain injury.
- The positives and negatives of living with an acquired brain injury

6.1. Summary of the Findings

6.1.1. Hidden consequences

Participants began by discussing the idea that pre-injury was the starting point for making sense of where they were presently. Indeed, Skell et al (2000) found that pre-injury cognitive functioning has been shown to positively impact on post-injury distress and the effectiveness of coping strategies. When considering age and stage of the participants it was worth deliberating how this had impacted on the participants' experience and resilience post-injury in dealing with the challenges of ABI.

One of the challenges mentioned by all participants was the experience of loss. Participants were clear that loss touched upon various aspects of life including past, present and future goals, dreams and even sense of self. This was consistent with the literature where Nochi (1998) reported three types of loss namely, loss of clear self-knowledge, loss of self by comparison and loss of self in the eyes of others. Whilst these themes were all relational it seemed appropriate to consider that loss was often, “mediated by many factors, such as other people’s attitudes and actions” (p. 875) towards the individual. Uprichard (2009) cautioned that as practitioners we should be sensitive in applying any grief framework as it could imply that the past self is “dead” and is irretrievable. The theme of identity was discussed in more depth (section 6.1.2) however it was important to consider participants’ perspectives and views of identity prior to offering any therapeutic intervention.

All participants focused on coming to terms with change. This linked closely with loss and was identified as part of their accounts early on in the recovery process. Participants were emotional when discussing this theme and the permanency of it. For a few who were younger at the time of the injury, this loss was felt more deeply as they felt a stage in life had been removed from their life experiences. For others, who were injured later within this young adulthood stage, the timing provided more resolution. Reflecting back on findings by Skell et al (2000) within the context of this developmental stage, it was interesting that timing caused such different feelings and impacted in different ways for the participants. Potentially the more experience young adults had, the more able they were to utilise coping strategies and reconcile the past. Wiklund (2000) stated that reconciliation took place when the individual was able to face their suffering and challenge the shame, distress and rejection that ABI imposed. We could therefore hypothesise that the more positive coping strategies the individual had the more able they would be to reconcile the past.

The only contradiction to this idea was where the ABI resulted from trauma. Participants discussed how difficult it was to find resolution when the result was ‘unfinished’ namely, where there was a sense of injustice in the outcome or others did not take responsibility for their role in the trauma. This too was consistent with the literature where unresolved issues such as ongoing litigation, led to feelings of persecution and an overwhelming sense of helplessness, (Raskin and Stein, 2000) further compounding the loss experienced. For practitioners we must take into account the impact of stressful and ongoing litigation on all therapeutic intervention used with young adults, by supporting and encouraging them to express these feelings too.

A few long term investigations have suggested that following ABI 20% of young adults continued to have significant disabilities (Beecham et al, 2009). Participants felt that in the initial stages they had little insight into the impact of the ABI post-injury. Many participants

focused on the physical side of recovery. This was a key criticism of rehabilitation which tended to be more task or skill orientated rather than addressing the psychological changes. However, Martin et al (2014) found that “even for those with severe memory impairments, life is purposeful and life goals can be articulated and discussed,” (p. 6). The current study found that change was a process over time and it was only through experience and engagement with activities that participants realised the extent of their injuries. Martin et al (2014) recommended and I commend this view, that as practitioners we must be aware that physical integration in activities does not necessarily lead to a sense of belonging or social integration and could in fact be a source of distress to individuals.

Furthermore, medical experts’ reliance on the brain being the cause of difficulties often left participants feeling hopeless and indeed, created a barrier to moving on (Uprichard, 2009). At such times participants felt separated from their wider systems which they attributed solely to their newly acquired disabilities. Multiple studies have found that following discharge there was an increase in unmet need (Fleminger & Ponsford, 2005; Beecham et al, 2009). This was at a critical time when participants stated that they required more support, as awareness of the impact became more visible and the individuals’ insight was greater. Beecham et al (2009) found that over half of her participant sample would have liked additional support at this time and specifically from therapeutic services.

Participants emphasised the need to ‘fit in’ with their peer group at this time. A few participants reflected how the changes set them apart from their peer group as they struggled to accept these changes following ABI. These included social drinking against advice of their medical doctors or being impulsive without accounting for potential adverse consequences. Putting these factors into context, it was difficult to affirm what was linked to accepting the ABI and what was a natural stage of development within this age range. However, in other research it had been suggested that individuals needed to have a period of rejecting their disability in order to incorporate their disability into their self-image later in the recovery process (Nochi, 2000). This could be extended to individuals following ABI. “Fitting in” becomes important when we define ourselves by those we associate with and rejection or not “fitting in” could in turn have adverse effects on self-esteem (Tod et al, 2010; Jones et al, 2011; Hagger, 2011). “Fitting in” was a key element of this stage of development.

Evidence suggests that following ABI individuals are more self-critical particularly when things go wrong (Ashworth, 2014; Freeman et al, 2015). Thus the rejection of disability in order to ‘fit in’ may have been a key coping strategy for these young adults as they made sense of the challenges of their ABI. Unfortunately this was never completely possible since the physical reminders of ABI and its consequences were never far from their minds as shown when the

participants discussed feeling trapped or having to remain somewhat vigilant even during times of “rule breaking”.

Coping strategies were also discussed by all the participants at various stages of the interview. As previously mentioned, coping strategies appear to be more effective based on pre-injury cognitive functioning. Brown et al (2006) commented that individuals relied on a wide range of coping strategies to “make sense of their experiences during their ongoing recovery,” (p. 943). Participants seemed to identify key emerging coping strategies at different points throughout their journey. Initially suicidal ideation, self-harm, gambling, alcohol and drug misuse seemed to feature in the earlier stages post-injury. It is worth mentioning the role of gender in selecting these coping strategies. Although the sample was representative of the general population of young adults with ABI there may have been gender differences in selecting coping strategies (Howes et al, 2005; Katzer, 2010).

It has been suggested that growth following ABI is a combination of both the positive and negative effects of trauma (Karagiorgou et al, 2017). The absence of negative effects may have led to ineffective coping strategies such as denial or avoidance. Rogan (2013) postulated that maladaptive coping strategies served as a motivational purpose in the early stages of recovery. When this was considered in light of the correlation between feelings of control over the ABI and adaptive coping strategies mentioned in this study, we could reason that for example self-harm, suicidal ideation, gambling, and so on, all provided a level of controllability over the situation. In feeling more powerful the participants were then afforded the opportunity to utilise more positive adaptive coping mechanisms.

By normalising their difficulties further into their journey, participants were able to dispel any ‘false beliefs’ about the consequences of their ABI’s, allowing them to reframe their experience within the context of their life stage. In other words, they perceived self-harm or alcohol misuse as a normal stage in their development as young adults, and as an appropriate risk taking behaviour, separate from the ABI and its consequences. Again this could have provided a sense of “controllability” over the ABI. (Rogan et al, 2013, p 652). Participants were clear that establishing boundaries, seeking support and admitting to there being a “problem” in relation to gambling, alcohol or drug misuse was a turning point in accepting change. At these times participants felt utilising the support offered was crucial in moving forward. Counselling psychologists are frequently involved in dealing with addictive behaviours and thus if they had an increased knowledge of the impact of ABI this would benefit any engagement they may have with survivors.

Many participants discussed how the ABI itself became a coping strategy for the discomfort that they experienced. It supported them to ‘fit in’ or allowed them to make excuses for their

perceived deficits (Sabat, 2001; Brown et al, 2006). Participants argued that since the ABI was all encompassing during the early stages, they had been able to detach themselves from the responsibility of their actions through using the ABI as an excuse for any socially undesirable behaviour. If this excuse was then deemed valid then the individual's self-esteem and position was somewhat preserved. It was important to acknowledge this in relation to the participant's stage of development where the heightened fear of rejection and the importance of 'fitting in' with their peer group during young adulthood, along with solidifying identity were of paramount importance (Lenz, 2001).

In considering the theme of 'hidden consequences' it was important to reflect on the sub-theme of 'person in context'. New difficulties were often experienced on discharge from hospital. Atkin et al (2010) in an ethnographic study of encephalitis identified that medical practitioners knew the general impact of life following encephalitis however were often unable to provide specific answers to the questions individuals sought. Furthermore they found that participants were unable to reconcile what the medical professionals were telling them with what they experienced. For many of the current study's participants, returning home was a time of great challenge. Patterson et al (2001) found that relatives rarely retained information about the ABI from medical professionals. This led to further anxiety and distress for the young adult in light of their ongoing memory deficits. "Individuals are not passive recipients of their symptoms but...actively interpret them," (Nochi, 1998, p. 869).

Whilst one participant specifically mentioned the impact on family, six of the participants mentioned complex feelings of guilt and feeling a burden also reflected in the literature (Bamford, 2007). Overall these findings have also been represented in research involving caregivers where feelings of burden have added to feelings of stress, anger and reduced life satisfaction with contributing factors linking to reduced income, inability of the injured individual to empathise with the carer and the impact of neurobehavioural deficits (Wells et al, 2005; Marsh et al, 2002). However, interestingly one finding by Wells et al (2005) found that caregivers were generally able express more positive feelings about their role and perceived ability to cope, suggesting a potential disconnect between participants and caregivers experiences. The importance and significance for this young adult group was that they had experienced a sense of autonomy prior to the injury. Following their injury their aspirations to be independent were lost. Therefore, feelings of guilt and of being a burden developed from both this loss of aspirations and their return to dependence on their caregivers. The impact being that young adults in particular and family carers were denied their rights and freedoms to move on. As a consequence, the young adults with ABI found adjusting and relating in their new roles more difficult. On the other hand, for parents and carers, this caregiving role was already familiar and one which they could perhaps easily fall back into, hence their positive

feelings about fulfilling this role. For this young adult population, the consequences were greater, since they might not be as able to develop the new skills required to become more independent as they transition into adulthood whilst being cared for by family. This could have explained the heightened feelings of loss and increased experience of isolation described by the participants.

This feeling of being a burden was not restricted to personal relationships but also experienced in the wider systemic context. This often led to participants feeling discriminated against and powerless. Lennon et al (2014) commented that following ABI this was often coupled with a loss of autonomy, meaning more dependence on the systems they felt a burden to. Systems, on the other hand, treated survivors as an object or only in terms of their medically related health diagnosis (Jumisko et al, 2007).

A lack of knowledge about ABI served to drive a gap between the survivors and others. Further education in general but specifically to service providers may, in future, lessen this gap. This was also a suggestion of the focus group. For example, it could be incorporated within existing training around disability and/or mental health or as part of induction training for new staff. Linden and Boylan (2010) found that whilst visible signs of trauma may assist services in recognising when someone has experienced an ABI, those who were more able to identify survivors without the need for visible signs can have greater depth in their understanding of the daily challenges of life after ABI. Regardless, involving individuals with ABI in the discussions regarding their care should be a starting point for redressing this power imbalance.

6.1.2. Discovering a different world

Identity was a major theme which has been well documented in the literature (Nochi, 2000; Gracey, 2008, Gendreau et al 2014; Walsh et al, 2017). As early as 1984, more than three quarters of survivors of ABI felt that they had changed as a person (Tyerman & Humprey, 1984). Changes reported by the current research participants included; physical and cognitive difficulties, loss of autonomy, loss of skills, uncertainty of self and memory deficits.

However, there have been various opposing theories explaining why this may be. This was reflected in the participants' accounts as some described the creation of a new identity whilst others felt it was a continuation of self but with differences. In some research individuals readily acknowledged the experience of a changed self but fundamentally felt the same person (Medved and Brockmeir, 2008; Uprichard, 2009). Individuals were also found to retain the same value base and goals but changed how they achieved them (Uprichard, 2009). In the present study participants gave examples of changed behaviour, for example, increased aggressiveness or frustration, yet alongside this, they listed their interests or political views as

remaining the same. This was in keeping with findings from Gelech and Desjardin (2011) who stated that, “the past self is ‘new’ only in the sense that it differed from what existed before the injury, not in the sense something that pre-existed had been totally lost or wholly replaced,” (p71).

However Muenchenberger et al (2008) rejected the idea of reaching a stable identity arguing instead that identity was a balance between the ‘contraction’ of self; sense of difference, reliance of others or situational avoidance and the ‘expansion’ of self; a purposeful journey, working towards goals or future thinking. This balance was hinged on self-doubt, unease between past and present along with the tensions related to control versus compliance. This was reflected in the current study where participants’ accounts in particular, struggled to strike a balance between making allowances for the changed identity and fitting in with the peer group. A good example was noted around assessing risk and whether to engage in risk taking behaviours.

Gendreau and Sablonnière (2014) discussed the cognitive processes involved in identity reconstruction. They found that in the initial categorisation stages there was an emphasis on the difference between pre and post-injury self with the pre-injury self being seen as prized and highly valued. Whereas moving on (compartmentalisation stage) brought about more connections between the old self and how individuals understood their current presentation, although they still remained polarised. The final stage brought about more resolution between the old and new self. Again this was a stage based model suggesting that progression from one stage depended on resolution of the previous stage. Some participants in this study did discuss stages of recovery and differences in how they perceived identity at different stages. However, this journey towards resolution did not appear to be as linear, rather, more dynamic and fluid. Change was reported to pose challenges to identity continuously and participants suggested the need for constant reflection and adaptation. What was clear was that following ABI, identity was affected and adjustment was difficult but required. Bennett and Raymond (1997) commented that “once an individual has achieved a point in his or her life at which he or she recognises, accepts and adjusts to the limitations resulting from the brain injury, then a more favourable level of adjustment can occur. This altered sense of self helps the individual to build a new life around a realistic view of his or her strengths and limitations,” (p. 61). In addressing the participant who felt unable to find positives regarding his identity, it was worth considering that Lennon et al (2014) found that negative themes concurred with negative views of self, particularly when individuals were unable to utilise previous identity roles. This was confirmed in research on disability (Yoshida, 1993) although to date little existing literature has specifically focused on this area.

Nochi (2000) researching self-narratives found five categories of self which overlapped with this study's accounts. Most relevant to the current study was "the grown self", "the recovering self" and "the self, living in the here and now". He proposed that these identities could co-exist concurrently, explaining participants experiencing 'self' linked to stages of recovery, often switching between pre, post and future narratives.

When considering the participants in this research study and more generally the young adult population following ABI, we must be mindful of how this identity resolution process may be hindered. Due to circumstances such as disability, many may not be able to explore aspects of their identity without restrictions. For example, following their ABI many individuals continued to rely on the support of caregivers, rather than developing the autonomy required to engage in activities on their own. This in turn restricted their ability to develop a sense of self including risk taking behaviours, if carers were frequently present providing basic care (Arnett, 2000) and establishing relationships (Yildirim & Demir, 2015). It is my understanding that these challenges resulted in the participants feeling a sense of separateness from their peer group, where they struggled to establish their place in the world and felt uncertain about their future.

Regardless of how identity is constructed post-injury, one consideration was how individuals adjusted to their changed identities in different situations and how they, then assimilated the feedback that they received. Some insight was provided in research investigating how individuals chose to disclose their ABI. This was something which the current research participants cautiously touched upon when they discussed their reticence to tell others about the ABI preferring to attach themselves to the individual health consequences of the injury such as memory loss or epilepsy. Hagger (2011) found that individuals following ABI would often manage impressions through playing down the extent of the impact. Alongside this plan, others would strategically place themselves in relation to others that supported a more positive self-narrative (Lennon et al, 2014). One consideration for us as practitioners is how we meet this obvious vulnerability. Particularly where there are more constraints both financially and on time within the NHS, a resource most individuals following ABI rely heavily on. We need to be aware of the underlying story to what is being presented and more importantly how we react to this. In these instances therapeutic group work could be utilised to deal with the financial and time constraints. Ownsworth (2014) commented that, "identifying with others in a group can provide a positive means to redefine self after brain injury and motivate people to modify their behaviour and support others," (p. 144). This may be a less intimidating setting within which to share this vulnerability more openly. Furthermore acknowledging the idea of multiple identities at any one time may serve to develop new possibilities for clients as they adjust to what is their 'new normal'.

The themes of connection and rejection were interlinked. Connection took various forms in the current research study from connecting to others, being included, to ways of connecting. The first noticeable comment by participants reflected that relationships had changed and most often broken down. These findings have been replicated in the research (Ashworth et al, 2014) with ABI leading to social isolation and social stigma (Hagger, 2011; Haslam et al, 2008). Many participants hinted at their disappointment at being let down by others, however, interestingly they reconciled this by reframing this loss as a positive, stating that it allowed them to re-evaluate their friendships. This was also noted by Jumisko et al (2007) and Bamford (2007). Some participants reconciled with this through normalising changes in friendship as an appropriate stage of development within their life, which Erikson (1982) coined "intimacy versus isolation". They felt it was typified by transitions such as leaving school, going to further education or employment. Others reasoned that this was part of their life changing experience and so resigned to accepting the change. However, with literature confirming that this change in relationships was a source of distress for individuals it is something that should never be taken for granted in supporting survivors. As mentioned previously, rehabilitation would benefit from considering how to support these transitions alongside the skill based rehabilitation process. As a way forward this could perhaps include more family or systemic therapeutic work with the individuals and their wider network. Alternatively, more active engagement within education and training establishments to assist in the transition from rehabilitation back into areas of life that generally have emphasis on relationships. For example, by linking work related friendships, individuals could be enabled to find more meaningful participation or activities to be involved in and thus establish a sense of self more readily. This has the secondary benefit of educating the wider system regarding what they should expect from individuals following ABI and how best to support and include them in specific areas of their lives.

Gracey (2008) investigated sixty-four individuals recovering from ABI and found that feeling part of things was most important in supporting resolution in the changes that had occurred. Part of this was connecting with similar others and sharing experiences. Participants in the current research study discussed this as being important for two reasons. Firstly in connecting with similar others and sharing experiences they were afforded the opportunity to be accepted completely by others who had knowledge or understanding of their situation. "Being confirmed by someone and confirming someone seemed to help the participants understand that, in spite of their limitations, they were still of worth," (Jumisko et al, 2008, p. 2278). Secondly, for the young adults, linking the idea of multiple identities, this allowed for participation in multiple groups thus expanding the social network and potentially reducing their isolation and loneliness.

It has been suggested that multiple group membership could also result in an internalisation of identity (Douglas, 2012). Walsh et al (2017), suggested that identifying with ABI groups supported participants to engage meaningfully with a shared identity, thus experiencing, “personal continuity, integrity and wholeness,” (p. 7). Haslam et al (2008) reported that belonging was a fundamental part of the change process. As psychologists we need to ensure the provision of not just individual therapy in coming to terms with life after brain injury but also group therapy to help to promote this sense of shared identity and belonging. This is a key area where counselling psychology in particular may be of benefit since engaging in group therapy is often a key skill of counselling psychologists.

Understanding how participants conceptualise themselves following ABI is crucial to any therapeutic relationship. Our relationship to self is often intertwined through interactions with the environment. In this case the current research participants were engaged with a charitable organisation that promoted positive engagement for people following ABI. Therefore we could postulate that the current participants were more positive in relation to self-image because of this context and support. Conversely, for individuals with an ABI, living in more isolated circumstances or less able to engage with society, this may not be the case.

Being mindful of findings from Mealings and Douglas (2010) it was suggested, that individuals only saw change as successful when included in developing strategies and when they felt the professionals supporting them understood them. I believed this acted as a clear message for any professional involved in supporting individuals following ABI. It is my view that by engaging individuals in the decision making process it provided a platform of trust, respect and empowerment. This in turn maximised the possibilities for positive change in behaviour to bring about more recovery and connectedness for the current participants.

Much of the literature surrounding the experience following ABI suggested that maintaining social networks was problematic and often resulted in a variety of negative consequences. It was therefore not surprising, that at a stage when peer groups were significant and meaningful as during young adulthood, why this would be a priority for participants. Social media, in this case, however, became a resource where many participants could stay connected. Many reported that the benefits of staying connected in this way were positive, however for one who was unable to use social media he felt that it further acted to isolate him from his peers, a finding replicated by Kilov et al, (2010).

Romantic relationships were also highlighted as a priority for participants. All mentioned romantic relationships at some point whether this was the breakdown of relationships or their desire to have a relationship. This too may have been linked to age and stage given that this period is a key time in exploring romantic connections and often about preparing for the future

such as marriage or children. Erikson (1982) suggested that the successful resolution of this stage “intimacy versus isolation” depended on the strength of relationships, whilst failure resulted in isolation. It was also worth considering that Erikson believed within his staged model that in order to achieve intimacy you must first have resolved the stage of “identity versus confusion”. When considering changes following ABI this stage was likely to be ongoing for many individuals.

Following ABI many gave examples of failed relationships. This may have been linked to the participants’ need to disclose their ABI or be about feelings of heightened vulnerability or to being exposed in revealing their fears. Chaudoir and Fischer (2010) suggested that to disclose the ABI may cause longer term effects on self-esteem and wellbeing. Furthermore fear of disclosing may also serve to alienate or reduce the chances of forming romantic relationships since a level of self-disclosure is required to establish and maintain close relationships (Graham et al, 2008; Hagger 2011). Romantic relationships featured briefly in the review of literature (Bamford, 2007; Murray & Harrison, 2004) and have been investigated from the views of both the uninjured partner and the individual themselves (Godwin et al, 2011; Gill et al, 2011 and Gosling & Oddy, 1999). Findings have detailed the impact physically and emotionally on both parties with communication emerging as a key finding (Gill et al, 2011). However there has been no in-depth research, to my knowledge, into the experience of romantic relationships following ABI specific to a young adult population.

From more general literature about romantic relationships it was interesting to note that young adulthood was typified by relationship break-up. Although causing distress these relationship break-ups served as a learning process since they informed the individual about interpersonal learning, problem solving strategies and what they wanted from future relationships (Yildirim & Demir, 2015). There was also evidence that those young adults who ruminated on why their relationships had broken up and those who experienced a reduced social or support network following a break-up, generally did not adjust to the relationship breakup (Yildirim & Demir, 2015). This was important for the young adults in this research study since they often attributed the relationship breakdown as being a result of their ABI instead of it being normalised as part of their age and stage. Furthermore it was found that self-worth was reduced following a break-up with increased depression and decreased self-esteem (Ayduk et al, 2001; Perilloux & Buss, 2008). For the young adults following ABI in this study, these feelings were experienced more severely and therefore, the opportunity to use the break-up as a learning opportunity may not have been maximised. Practitioners should seek to support individuals following ABI, particularly with relationship breakdown, by shifting the focus from allocating blame to the ABI, to normalising the experience and the positive learning that can be gleaned from it. That is to say young adults who meet with the emotional consequences of the relationship break-up

could be offered different and potentially more adaptive explanations. Practitioners should be ready to explore this in their therapeutic work with clients, starting from the client's perspective.

Rejection was also a prominent theme within 'discovering a different world' sub-theme and also in research pertaining to this developmental stage. All participants reported rejection in various ways. In initial stages this was epitomised by feelings of shame regarding their changed presentation, which then turned to frustration and anger. Many reported being misunderstood by others which on reflection was perhaps due to their lack of informed knowledge. Lack of social relationships was a reliable predictor of depression in adults with TBI (Douglas and Spellacy, 2000). It is worth acknowledging the long-term care implications for the current participants and all future ABI young adults. The need for early intervention or focus on connectedness to address or prevent future mental health issues and specifically for the services who support them.

Within the literature 'rejection' was conceptualised in two ways. More overt rejection by society was found often where people with disabilities raised feelings of anxiety and discomfort in others (Imrie, 1997). This may have been important given that this peer group of young adults may not have had the exposure or life experience to support them, to manage or overcome such feelings. People behaving differently towards those following ABI have been consistently documented. Jumisko et al (2007) reported that perhaps the demands of the individual with the ABI and their family were too great and therefore over time the wider support network felt unable to meet these expectations. This was consistent with these participants', who reported having lots of support initially which then reduced over time.

Conversely, the literature has also investigated the role of the individual with ABI initiating the rejection. Jumisko et al (2005) suggested that even though participants were longing for a relationship they would sometimes choose loneliness, avoiding situations where there could be a risk to self, such as making a fool of themselves. This was reflected by one of this study's participants who discussed being selective about where he chose to socialise, for example, bars instead of clubs due to communication difficulties. The literature concurred finding individuals who felt misjudged or mistrusted by others, undermined their own self-confidence (Jumisko et al, 2007). Fear of negative reactions from others and a wish to avoid emotional upset led to individuals becoming more avoidant of social situations (Hagger, 2011). On the other hand it was also worth reflecting that young adulthood is a period where feeling misjudged, lower self-confidence and fear of negative reactions can affect "relating" in every sense. Never the less it is crucial in considering how the interplay of both others' reactions and the individual's behaviour might perpetuate isolation and create barriers to connecting and therefore relating. With these feelings being more salient for individuals following ABI in

general, it is not surprising that rejection played a significant part in reporting mental health issues, such as anxiety and depression. Thus we could postulate that this participant group of young adults with an ABI are at further and increased risk of isolation and mental health issues due to their heightened sensitivity.

Robertshaw (2013) summarised how participants attempted to understand their interactions with others, moved towards acceptance and the barriers that prevented this journey. She discovered that, having an awareness of how 'change' was perceived by others, was crucial to the sense of self in the world. Barriers hindering the move to acceptance included, feeling judged by others and withdrawing from social integration. In the present study each journey was not a progressive or fluid model of recovery, but one which had various setbacks along the way, for all participants. Participants viewed these challenges as inherent in their personal journey and necessary to overcome in order to form a more cohesive sense of self. The narrative exercise in particular supported participants to view both the highs and the lows of their journey so far. Often due to memory deficit the impact of their journey was lost, however when drawn out on paper, this provided a visual aid to support memory deficit. This was in keeping with the HCPC Standard of Proficiency for practitioner psychologists which states that counselling psychologists specifically should, "understand how empathic understanding can be helped by creativity and artistry in the use of language and metaphor," (p. 10).

Understanding how individuals experience the external world is crucial in appreciating how they conceptualise themselves. Vulnerability was a factor which changed the way that participants understood their world. Following ABI they commented that their world had become more threatening in a way that was noticeably different from before. Chronic illness research suggested that the fluctuations between feelings of illness and wellness impacted on individuals' confidence and self-belief (Paterson et al, 2001; Muenchenberger et al, 2008). These changes left participants feeling vulnerable and exposed within this now hostile world. Furthermore participants also suggested a mistrust of self as they could no longer rely on their 'healthy' bodies as they once had. Both Corbin (2003) and Jumisko et al (2005) found that participants were afraid of being injured again and retained uncertainty over their health. This was also vocalised by participants in Atkin et al (2010) where uncertainties were created by trying to reconcile the extent to which the individuals had recovered and were still recovering. The current participants discussed the impact of changes to health specifically in making plans for the future. Considering the implications, this could explain why individuals following ABI have difficulty in engaging with future planning as an adaptive coping strategy in the initial stages. Focusing on the present was an easier task as they learned to reconnect with their own body. We should take this into account in pacing sessions.

Finally within this 'hostile world' participants raised the issue of systemic discrimination. Particularly a wider lack of knowledge and understanding of ABI and its consequences leading to feelings of stigma and persecution. Participants raised this in relation to a wide range of services from social care and housing to law enforcement. All raised feelings of frustration and anger.

Research into the public's understanding of ABI found that society was more accepting where disability was more visible, whereas those with mild-moderate, emotional, behavioural or cognitive difficulties were not given as much consideration (Linden and Boylan, 2010). Furthermore, Linden and Crothers (2006) found that the general public held less positive views of survivors with ABI whereas younger generations generally held a more positive view. Despite this, it was noted that participants had previously found it more difficult to integrate with their peer group. Significantly there was a divide between what the research suggested and what the young adults in the current study experienced. It was unclear why this might be. It is my understanding from the individual interviews that it could have been a direct result of the peer group experience itself in this case, or a fear of rejection within the individuals themselves, or most likely a combination of the two. The young adults had undoubtedly changed which had impacted on their relationships. Whilst the young adult population as a whole appeared to be more accepting of 'difference' the individual relationships, did not withstand this change. This could have been due to increased anxiety about relating to an individual with ABI, increased demands of the individual with the ABI or the individual themselves choosing to withdraw from the relationship. Further research could enable these issues to be addressed and in turn identify what we as professionals need as guidance about how to address the wider lack of knowledge and understanding that participants have discussed.

Regardless, in all the literature and from analysis of both stage one and two of the results in this study, the request, from young adults for more dissemination of knowledge and awareness of ABI is called for. Linden and Boylan (2010) commented that the media portrayed an unrealistic picture of life following ABI often depicting physical disability and not acknowledging the spectrum of severity. Little has been done to address this from a policy perspective and therefore more needs to be done given the prevalence of ABI in the young adult population, the longevity of their life span and the compounding consequences of their injury. This will not only support the individuals themselves but has long term financial incentives (Beecham et al, 2009). Interestingly despite these findings, the young adults continued to feel a sense of personal responsibility over their care instead of feeling dependent on those services aiming to support them. There was no apparent expectation, from the participants, that services would change or adapt to meet their growing needs. It was surprising that participants did not feel

more impassioned about this issue and it perhaps reflected the feelings of powerlessness that they experienced by depending on services. One consideration for the future may be to strengthen the role of advocates for individuals following ABI to ensure that their rights or wishes are heard and the difficulties they experience are challenged appropriately. This too has implications for therapeutic intervention. In my experience of dealing with the difficulties individuals experienced with the system, it often triggered significant anxiety and distress, impacting on their ability to pursue the goals or aims of the therapeutic input. As such, knowing where to signpost individuals, understanding the structures and functions of UK service providers and working as part of a wider multi-disciplinary team are within the remit of all practitioner psychologists (HCPC, 2015, pp. 11-13).

6.1.3. Piecing together a new narrative

This section represented a turning point in the participants' accounts. The ABI and its impact were recognised but not the focus of the journey any longer. Over time the unfamiliar life and its challenges following ABI had become familiar to the participants. At such times the research suggested that the individual had resolved the issues relating to identity, acknowledging that they were neither a patient any longer nor the healthy person whom they used to be (Muenchenberger et al, 2008). Over time this resulted in a value shift that potentially opened up opportunities to recognise this change for being neither good nor bad but different, and so a new account was pieced together. The ABI was viewed by the participants in an existential light, as something without which, they would not have evolved into the person whom they were in the present. In some cases this was described as being a better person, being more caring or being more knowledgeable about human suffering. Although not desired, the ABI itself now had some positive connotations and enabled the identification of characteristics that attached value. Nochi (2000) described this as the "grown self", (p. 1801). This was consistent with the accounts of other individuals following disability.

Jumisko et al (2007) argued that relative dignity was formed both socially and culturally and although following illness could be lost, crucially it could be re-gained. This idea resonated with the participants' accounts as they spoke of responsibility over their lives. They discussed a fear of the ABI overwhelming them and losing their way or what they once had. The recognition that positive change was something which they held the key to was then a transition point. Ylvisaker et al (2008) commented that the process of negotiating meaning provided a new perspective from which to view the ABI. In doing so it contributed to the healing process following ABI. This may have indicated why at this stage of recovery accounts began to change, new perspectives were born and a way of moving forward developed. Participants who had previously felt that they lacked control over their lives were now able to identify areas

which were within their control. For professionals involved at this key time of transition, facilitating positive change in the accounts and lives of individuals with ABI will not only be critical in supporting them to move forward, but also in working preventatively to reduce future mental health issues.

As mentioned, participants began to show themselves more compassion and empathy at this stage. They were also able to identify more positive aspects about themselves following their ABI. Both Jumisko et al (2005) and Bamford (2009) found that the participant's 'will to live' had increased over time and that they continued to show both courage and strength in the face of adversity. In particular, Jumisko et al (2005) suggested that this was due to participants finding meaning when faced with suffering as they realised that they had developed as human beings. This linked to the present participants' desire to mentor, or connect with others in a meaningful way and share their stories. Furthermore, it linked to the idea of the change being a process or journey and that as awareness and insight developed, so too did the ability to recognise positive aspects of life as evidenced in the current findings.

However as the participants stated, the journey did not have a foreseeable end point and there was an acknowledgment of the distance still to be travelled. Jumisko et al (2005) again linked this to the idea of retaining hope of returning to full health. "Full health" may not be the same definition as for those without an ABI. As described, a growing understanding of the ABI as time progressed, gave participants the opportunity to judge their experiences and place within the world against their new sense of 'normal'. However, rather than react to this with distress as they experienced previously in their journey, participants now met this information in a new and inspired way. The ability to "feel well" following ABI requires the ability to think positively and focus on opportunities despite the limitations of ABI (Jumisko et al, 2008, p. 2278).

Considering the timing of the injury for the current participants it was worth considering whether this view had enabled them to move forward. Focusing on the longevity of life with an ABI may have felt like a daunting task. From my experience with this particular population it would have been more difficult for these young adults. They were seeking to redefine who they were and negotiate their new position within their context, while their life was going through a period of instability and resources available to them were decreasing. "Identity formation involves trying out various life possibilities and gradually moving towards making enduring decisions," (Arnett, 2000, p. 473). Participants might have been able to reconcile and look more favourably on the future if this was more positively framed. Positively reframing their experience whilst knowing that their journey of recovery was life-long, with no clear resolution, could have served to protect participants from ongoing distress. "Anyone with illness must relinquish something, understand something new and reconcile all with one's

mission in life,” (Jumisko et al, 2008, p. 2278). Therefore paying attention to the richness of life, seeing the positives regardless of the limitations, may be a form of self-treatment (Gadamer, 2003) in allowing participants to continue with their journey.

Post-traumatic growth (PTG) has been widely addressed in the literature although not specifically addressing young adults following ABI. PTG refers to psychological developments that extend beyond pre-trauma functioning and include recognition of new possibilities, increased personal strength, deepened spirituality, and enhanced appreciation of life and closer relationships (Tedeschi & Calhoun, 2004). Consistent with the participants’ accounts, PTG appeared to serve the ‘meaning making’ process by protecting the individuals’ sense of self in regaining control of their lives. Ownsworth (2014) discussed that people strive to feel good and restore their self-esteem through social interaction and active participation, closely correlating with long term adjustment. She commented that positive ‘meaning making’ and adjustment to ABI can act as a “catalyst for personal growth” (Ownsworth and Flemming, 2011).

Silva et al (2011) confirmed a greater appreciation of life at six months post-discharge, with a significant increase in the level of PTG around the ten year post-injury follow up. The authors noted a negative correlation between PTG and symptoms of depression. Sawyer et al (2010) also reported that in the early years, PTG aided the reduction of negative effects but as time passed it, in fact enhanced wellbeing. PTG enabled the current participants to be more engaged while living a fuller, more satisfying life and holds the potential to reduce their future incidence of mental ill health.

Yeates et al (2007) found that drawing on both pre-injury and post-injury discourse helped individuals make sense of their present lived situation. Similarly in the current paper accounts changed, becoming more positive as participants sought to find meaning in their experience. However it is thought that, “positive change may take longer to develop in this population as it is consistent with gradual increase in understanding of long-term consequences after discharge from rehabilitation,” (McGrath & Linley, 2006, p. 771). Finding new purpose, in this case, worked to increase self-esteem consequently relating to the search for goals and increased participation in activities and events. Recognising and comparing their previous life gave an understanding of how in their present situation their needs were not met.

In considering stage of development, Grace et al (2015) found that older people reported greater levels of PTG than younger people. This finding was inconsistent with the general literature which posited that following trauma or illness younger people experienced more PTG. In this present study all the young adults were injured during a formative stage of development. This could have meant that they were not as able to access a pre-injury

comparative point from which to compare their post-injury self. One participant mentioned that they were in an unfulfilling job which became apparent following his injury. Two others mentioned the idea of having a second chance at life, one that was more valued. For most of the participants, they were not engaged in employment opportunities where they could re-evaluate. Thus we could hypothesise that those who did not have an established identity prior to the injury may have found it more difficult to compare pre and post-injury identities. Despite striving to feel well, for these young adults the development of PTG could be delayed. Critically, all the participants positioned themselves as part of a “bigger picture”. This ability to provide upward comparisons (Arenth, Corrigan & Schmidt, 2006) created a feeling that they were better off in some ways and led to hope, which motivated these participants in moving forward beyond the ABI. Establishing reasons for this in future research, would provide more secure insight into the difficulties young people with ABI experience in developing a more positive sense of self.

Overall, it was worth noting that PTG leads to less depression with a positive effect on relationship status, employment status, longer duration in education and training and more positive beliefs about injury (Grace et al, 2015). This was also verified in the current study's findings since generally developing a new account gave participants the opportunity to appraise their life, leading to a more positive perspective of a life-altering experience. As practitioners seeing one's own practice in a new light, not just to address the issues relating to the brain injury, but as one of supporting young adults to find meaning in their lives, may serve a secondary purpose of alleviating the “suffering” of young adults following ABI (Jumisko et al, 2005).

“The paradox of survival”, although a smaller sub-theme comparatively, was laden with emotion as participants passionately spoke of the consequences of their ABI. Paradox refers to something that combines contradictory features or qualities. Brain injury encapsulated this sense. Participants spoke of the conflict of the negative experience of being injured in the first instance, versus the relief experienced in surviving albeit with life changing injuries. They felt this conflict was most often vocalised when others described their situation as “lucky”. This too has been anecdotally reported in the literature (Powell, 2004). Participants felt this reflected being misunderstood by others, although the essence of truth within the use of the word ‘lucky’ also made them feel disempowered. One way of dealing with this was to reframe their accounts to reflect this paradox, usually through the use of metaphor. Coetzer (2007) found that the use of metaphor in working with adolescents and adults following ABI allowed participants to understand more difficult or challenging concepts. Ylvisaker et al (2008) also commented that on a cognitive level metaphors were more easily processed by “concrete thinkers” (p. 13) a common outcome following ABI. This again lent weight to the idea that

following ABI, metaphors and exercises that utilised visual metaphors could allow young adults to access information that was not readily accessible in a way that allowed them to explore the issues in more depth.

Recognising this paradox involved “downward comparison” (Couchman et al, 2014, p. 826). This is a process where participants compared themselves to others who were in “worse off” situations. This most regularly involved comparisons to others who had experienced ABI but it also compared their own situation and how they could have been “worse off”. This comparison led to seeing themselves in a more favourable light. Balancing their account through reframing their experience again enabled participants to move on from their ABI. Possibly, this also linked to their stage in development as the participants attempted to find their place within the world and become reconciled with their experience. Future research and therapeutic input would benefit from utilising this information with survivors of ABI in terms of understanding both the function of downward comparisons and the use of reframing as a coping strategy in regulating emotional distress following ABI.

6.2. Methodological Considerations

6.2.1. Strengths

The strengths of this research lay in the research design and method of analysis. Having a stage one focus group provided an opportunity to review the challenges of the initial methodology/ method, especially the use of the semi-structured interview schedules with the participant group. Firstly, the focus group stage allowed the researcher to work through the interview questions and to identify the particular difficulties participants had with broad open-ended questions. Although it was regularly cited as a difficulty in research (Paterson et al, 2001; Uprichard, 2009; Schrover, 2014) with this specific participant group little had been done to actively adapt research styles to address these challenges.

Recommendations in the use of visual aids to facilitate were not known about at the time of conceptualising this research (Lorenzo, 2010; Schrover, 2014). However it was later suggested that using visual aids would support memory deficits and could enable participants to explore their experience following acquired brain injury. It would be prudent to reflect on the impact that any cognitive impairment may have had on the ability of the participant to engage with the narrative exercise. For example where participants may have a visual impairment then the narrative visual aid would not have supported the participant’s account. Indeed those with memory deficit may not have felt any more able to engage with this narrative exercise

than an interviewing style. Finally engaging with such an exercise may have challenged those with executive functioning difficulties. In deciding to pursue the inclusion of a narrative exercise advice was sought from individuals with extensive knowledge of the area as to the appropriateness of this approach to the research. As Lorenz (2010) suggested, “participatory visual research approaches that generate visual metaphors of lived experience may be particularly appropriate for use by brain injury survivors, given the cognitive and communication challenges endemic to their injury,” (p. 219). This decision was confirmed in the current research where even those individuals with more moderate ABI’s were able to participate in a meaningful way. Easton and Atkin (2011) highlight that listening to an individual’s account alone may have benefit to the individual. Additionally feedback from the participants regarding this research noted that they found it had been both an enjoyable and meaningful exercise for them to engage in and they particularly valued the inclusion of the narrative exercise. “Writing one’s narrative could provide an uninterrupted opportunity that more fully illustrates the person’s experience as they see it and over which they have more control” (Easton & Atkin, 2014, p. 7).

The changes to the design also affirmed the chosen methodology in that “visuals that are metaphors bring emotions and life experience in to the research conversation” (Lorenz, 2010, p. 219). This was in line with hermeneutic phenomenology which shows commitment to the use of metaphor as a form of communication in order to elicit the lived experience. It also aligned with the HCPC Standards of Proficiency (2015) for counselling psychologists; standard 8.17 (p. 10). Furthermore it evidenced a commitment beyond science towards the human condition using interpretation to extract meanings that were both implicit and hidden. This added to the credibility of the research project as a whole.

A significant strength was choosing to include this narrative exercise when some may argue that the findings as such, become a collaboration of both the researcher and the participants. The researcher’s role in completing a narrative exercise was certainly more involved; however, one would argue that all qualitative research findings are ‘collaboration’. This is in keeping with the hermeneutic cycle of the research methodology, namely, the idea that the researcher’s interpretations, the participant’s interpretations and the context of the research are intertwined in the understanding of the phenomenon under investigation. Furthermore for most qualitative research, the researcher is not an innocent bystander to which the research unfolds but instead an active agent within the process (Smith et al, 2009). Holstein and Gubrium (1995), as with this research, take this one step further arguing that, “socially constructed meaning is unavoidably collaborative...All participants in an interview are inevitably implicated in meaning making,” (p. 18).

6.2.2. *Limitations*

There were various limitations to this study that are worth commenting on further. With regards to the population sample and in relation to my own role within the research. As a trainee counselling psychologist on placement where the participants were sourced the researcher was known to the participants. However, in this specific situation, it was an advantage, since having already established a relationship of trust; it gave the participants with more significant memory deficits the opportunity to retain who the researcher was over a period of time.

Holding knowledge regarding the setting and the individual participants, allowed the researcher to understand and more importantly, interpret the data in a way that was sensitive to the context the participants were recruited from, again showing a commitment to the quality of the research (Yardley, 2000). However it is worth considering the consequences of having a pre-existing relationship more broadly, namely; some participants may not have fully explained their experience within the interview process. The perception that knowledge of their situation was already known to the researcher could have influenced this decision. Although this is not believed to have been the case in the current study this could have resulted in findings not being as deep or in line with the individuals' meaning.

Due to time constraints, themes and findings were not checked with the original participant group. This is an additional level of rigour suggested by Yardley (2000) and would have added to the credibility of the research. It would have additionally addressed any perceived power imbalance between the researcher and participants, truly viewing the participants as the 'expert' and central to the experience of brain injury.

Finally participants were selected in collaboration with the organisation. This meant that additional knowledge was incorporated into the selection process potentially leading to selection bias. Due to the under-researched nature of the participant group, issues relating to behavioural, cognitive and memory deficits, it was pertinent to consider as much background knowledge as possible. This ensured that participation was both meaningful and positive for participants and met the research aims as closely as possible.

In relation to the organisation from which the participants were sourced; as mentioned in appendix 8.3 this organisation is based on an ethos of co-production. This meant that the organisation recognised and capitalised on people's ability to do useful things for each other and themselves in a positive way. This may have impacted on the experience that these young adults in particular explored in the current study. Although it was felt that the participants provided a balanced view of both positive and negative aspects to life following brain injury, their engagement with the research may have been connected to having a more secure base

from which to explore their experience. As previous research mentioned, engagement in meaningful activities positively impacts on wellbeing, mental health and connectedness. Atkin et al (2010) caution that “those joining such organisations might be assumed to have a strong identification with the condition” and thus be more able and willing to discuss its impact. As such, including young adults in research from a variety of backgrounds and services is essential in future investigation.

Another limitation of the study was that this research only acknowledged the cultural expectations of young adults within a Western culture. Arnett (2000) commented that “young adulthood” is culturally defined. Although all the participants in this research study were either born in the UK or had spent a significant period of time (childhood and adolescence) within the UK, some were from different ethnic backgrounds and thus their family and societal expectations differed from white British culture. Future research may wish to consider how identity formation is perceived differently for those raised within culturally different families.

Finally, due to cognitive, memory and communication difficulties it was not always possible to understand the transcription from which the analysis emerged. As such some of the meaning and experience may have been lost in translation. However, the depth of the data as a whole was enough to provide a rich account and the emergence of similar themes across participants’ accounts leading the researcher and supervisors to agree that the quality of the research was not compromised.

6.3. Clinical Implications

6.3.1. Counselling psychology

Many have advocated for the integration of psychotherapeutic approaches within ABI rehabilitation (Wilson et al, 2009). Currently, recovery usually focuses separately on a variety of different issues. Therefore using an integrative therapeutic model could more holistically meet clients’ needs. Counselling psychology’s strength is its flexibility in being applied alongside existing rehabilitative input. Counselling psychologists are required to understand models relating individuals’ adaptive responses to difficult life contexts (HCPC, 2015, p. 15). In reality, survivors of ABI require treatment at various key stages of recovery or when life changes become more challenging, for example, transitions to home or work. This was paramount for young adults recovering, where a multitude of life transitions or stages were yet to be addressed, namely living independently, establishing a family, engaging in employment or further study and should be no less important or undervalued due to ABI. Supporting young

adults and “drawing on knowledge of developmental, social and neuropsychological processes across a lifespan to facilitate adaptability and change” (HCPC, 2015, p. 23) is a key remit of counselling psychologists.

Recommendations for Clinicians:

1. Involve young adults with ABI in the development of strategies to best support them within their overall care plan. This recognises the uniqueness of each individual and each brain injury and views the world from their standpoint. As Lorenz (2010) cautions, “the greater danger is to see brain injury survivors merely as victims, and not as thinking, feeling actors on a journey similar to our own, who want to find meaning and purpose in life,” (p. 222).
2. Have a specific focus on connections including romantic relationships at the same time as skills based rehabilitation within the rehabilitation stage as described in Gill et al (2011).
3. Increase awareness of the co-morbidity of ABI and other complex mental health presentations rather than seeing them as solely a consequence of ABI.
4. Consider more systemically orientated interventions, for example, couples therapy (Backhaus et al, 2006), family/ group therapy (Couchman et al, 2004) or narrative therapy (Chow, 2015), to include the wider support context of the individual with the ABI and its far reaching consequences.
5. Consider the purpose of coping strategies including those initially felt to be maladaptive and their role within the recovery journey. This should include the introduction of alternative coping strategies for those who may have had limited life experience or opportunity to build resilience pre-injury.

6.3.2. *Wider social context*

Participants in both focus group and individual interviews made reference to increasing the knowledge base of the general public, services and policy makers involved in the lives of people following ABI. Findings of previous research (Jumisko et al, 2007; Linden and Boylan, 2010) highlighted the importance of others having knowledge about ABI to reduce stigma and isolation but also in terms of having a positive influence on recovery following ABI. Indeed Atkin et al (2010), although specific to encephalitis, found that professionals conceptualised encephalitis as an acute time limited event and ended with resolution of the primary insult. Yet participants felt the chronic impact of the encephalitis far beyond the acute stage. This experience was echoed in the current study. Cocks et al (2014) stated that with no clear policy or guidance on how to deal with complex presentations such as ABI and other mental health issues, services could pose more barriers and lead

to an overwhelmingly negative experience post-injury for the individual. Although this finding was within an Australian sample, it was supported by the findings of this research. Recommendations from Cocks et al (2014) are still relevant today and included; more emphasis on long-term and life-long needs assessment, ongoing education and training of staff within support services (namely police, housing and social care), greater support for carers and families and greater emphasis on meaningful engagement with activities including training, education and employment (Cocks et al, 2014, p. 420). The significance of neglecting to take these factors into account must not be underestimated. I believe the young adults in this study have reinforced that all of these points are of paramount importance when we consider the age at which young adults are injured. We must also emphasise the potential positive contribution these young adults will continue to have in society for the remainder of their life span.

Further General Recommendations:

1. Provide increased psychological input after the initial two year recovery period, as social care and health support generally reduces around this time, yet the individual has greater insight.
2. Consider the need for continued medical explanation of the ABI and its consequences, in a more accessible format, to reduce the young adult's dependence on family and carers to retain information. Services need to develop specialised aids including visual, auditory and easy read formats or communication forums with specialist practitioners, available through the various platforms young adults access most frequently, like internet or social media rather than traditional written leaflets such as www.healthtalkonline.org. Therefore increasing the likelihood of young adults being better informed to make decisions or ask questions about, for example, understanding the medical implications of alcohol use, so they can make an informed decision about their drinking choices.
3. Increase awareness that ABI is life-long and enduring and the need for a broader remit to the application of specialist psychological intervention, thus recognition that survivors may require to access specialist psychological input throughout their life span and across life transitions.
4. Develop policy further, to increase levels of education and training, particularly but not specifically to services that support ABI survivors such as housing, social care and law enforcement to enable them to better understand the impact of ABI.
5. Provide wide spread awareness-raising with the general public with a view to reducing discrimination, stigma and isolation. Consideration should be given to the role of the

media and in particular social media (a preferred platform of young adults) to promote this information and dissemination.

6.4. Suggestions for Future Research

Reflecting on the direction of future research as a whole, there are still many barriers to overcome. For example, there is still a view that individuals following ABI lack insight and awareness into their experience. This research rejected these assertions and evidenced that individuals engaged in a meaningful way. This can be achieved by thoughtful planning and preparation along with ensuring appropriate resources, such as a narrative exercise, are in place to support them. This is in keeping with the government's National Service Framework (DoH, 2005) showing a willingness to engage in furthering work with these young adults. Furthermore Uprichard (2009) stated that "participants valued being able to take initiative, identifying their needs and working towards meeting them," (p. 141).

Specific to young adults with ABI there remains a gap in the research. There are currently few studies exploring the lived experience of young adults following acquired brain injury, due in part, to the difficulty in accessing such a population. More focus could be given to the different contexts in which young adults live following ABI. For example, most research has used urban populations of young people. Therefore with access to services and isolation being a key finding of this study, it would be appropriate to explore more young adults with ABI living more rurally, to compare whether the issues raised in this study continue to be meaningful.

As the population of young adults with ABI is more male dominated it would be worth investigating whether the issues raised in the present research are as meaningful to young women following ABI. The issue of deciding to have children was raised by two of the women in the focus group study as an issue for concern. This was not a gender specific issue since one participant in the individual interview discussed ongoing concerns of being involved in the care of his children. It would be of interest to know whether having and caring for children would raise similar or different issues for males and females with ABI. Research has already flagged the difference between genders (Howes et al, 2005; Katzer, 2010) thus further investigation is required looking specifically at young adults with ABI, with a view to developing ideas and strategies to best support males and females.

Finally a longitudinal study would be beneficial given that due to medical advances young adults' survival rates are increasing post-injury. Again this could be a key role for counselling psychologists in working with this user group given their focus on understanding "different

theories of lifespan development,” along with understanding, “the social and cultural contexts and the nature of relationships throughout the lifespan”, (HCPC, 2015, p. 16). The investigation of long-term implications related to consequences would enable policy development around best practice and service development to be established, so that young adults do not find themselves in services that do not meet their changing needs.

6.5. Overall Reflections of the Research Process

As I embarked on this process I was enthusiastic about the research study. My curiosity increased about what young adults felt were the key issues and messages that needed to be heard following ABI. Initial challenges included my ability to bracket my own assumptions from therapy sessions with clients. However, through working with this population as a whole, my search for knowledge and appreciation about life following ABI has grown significantly.

The research process has been challenging throughout. As the researcher I have commented on the issues as they have arisen. However it is worth considering my reflections of the research as a whole. The evolving nature of this research I believe resonated with the journey relating to the participants’ lives. Having the opportunity to discuss this with both university and placement supervisors, provided me with deeper insight and understanding of the research process. My hope for this research is that it continues to be as useful to me, other practitioners and the participants themselves. This may be through tailoring the therapeutic interventions following ABI, or by being more mindful of the most important issues that they report as experiences in their lives, or in providing information so that a variety of services feel more willing and able meet the wider needs of young adults with ABI without “specialist knowledge”. The most important learning point however has been listening to the views of individuals following ABI and giving a voice to their experiences. Greater opportunity must be given to young adults to be involved fully in all decisions that affect them.

A concern was that my commitment and passion for the topic could have led me off course, therefore, losing sight of the aims of the research. This was something that I continually worked with and reflected upon. Throughout the research I made judgements that as I developed as a practitioner my training would guide the thesis in a particular direction. However, my interest and training actually supported the development of the research. Without more insight into systemic practice, for example, I may not have chosen to include a narrative exercise and had the opportunity to present my work in the early stages. Furthermore, I now feel more assured of my ontology and epistemology and I believe that this is reflected in the social constructionist approach to my practice too.

A final consideration was that by working with a vulnerable population there was the potential for re-traumatising these young adults. Easton (2012) does caution that whilst involving oneself in an individual's narrative can be positive this is not always the case for everyone. Having a robust risk assessment and plan for how to support these individuals during and after the research was something of increasing importance to me. The support of the organisation was also paramount and I cannot thank them enough for their time and commitment to my research along with their continued commitment to the individuals with whom they work.

6.6. Highlights of the findings specific to young adults with ABI

Young adults with ABI may find post-injury challenges difficult to contend with. The current research has highlighted that those individuals who adapt more easily are those who have more positive coping strategies and those who are able to utilise and compare established pre-injury identities. This may be less likely in those suffering a brain injury during a formative period of their life. Due to the consequences of ABI (such as cognitive impairment or disability) they may not be as able to develop these skills or coping strategies. Beyond this, requiring care or support from carers or family may limit young adults' access to important ways of developing a post-injury identity such as through relationships with others or group participation.

The current research has also highlighted the difficulties young adults face in striking a balance between making allowances for the changes versus fitting in with their peer group. Normalising some behaviours as "age appropriate" allows the young adults to separate themselves from the ABI thus perceiving themselves as "fitting in". However in some cases, difficulties such as relationship breakdown, are seen as the "fault" of the ABI and thus reduce the opportunities for valued learning and socially normal experiences. At such times maladaptive coping strategies such as rejecting disability, engaging in self-harm or suicidal ideation may provide a level of control for young adults; thus, affording them the opportunity to develop more positive coping strategies and in the process learning about themselves and their identities.

Finally, young adulthood is a period of feeling low in confidence, being misjudged and fearful of negative reactions. These are heightened following ABI and could lead to a higher risk of isolation and mental health issues. Most importantly following ABI and with their full lives ahead, this study highlighted the difficulty young adults face in dealing with the uncertainty over how far they have recovered and how far they have still to recover. Uniquely this study has found that metaphors and visual exercises allow young adults to access information in a way that allowed them to explore this in a more in-depth way despite the consequences of

their ABI. Most inspiring however is that the young adults, regardless of what may appear to be unsurmountable challenges, continue to engage with life after ABI.

6.7. Conclusion

Although many of the findings were not new within the existing body of the literature or exclusive to young adults, there were subtle differences of emphasis. For example struggling and coming to terms with change in identity, managing coping strategies, 'transitions' and moving forward, recognising the differences in people's reactions, acceptance and talking about having romantic relationships were very prevalent throughout. Clear within the results was the message that the participants felt safer, more connected and involved when included in any decision making processes particularly around their recovery and future lives. Understanding the consequences and by listening to their experiences first hand, of living with an ABI, should help health care services and professionals to be more proactive in response to their needs (Leith et al., 2004).

There is a strong foundation, I believe, for replicating this research, so that more young adults benefit from being supported by counselling psychologists who can bring their skills to therapeutic settings and as a consequence, more knowledge to the forefront of research into the impact of acquired brain injury for young adults.

7. References

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8. Appendices

8.1. Search Strategy

Search Term	Number of article identified					
	Psych info	PubMed	EThOS	Psych source	Taylor Francis	City University Library
Acquired brain injury	1,883	82,665	152	1,499	36,790	122,755
Traumatic brain injury	18,101	40,362	224	1,325	30,095	184,825
Head injury	7,749	159,471	185	751	108,881	701,496
Brain damage	155,841	144,622	402	981	90,503	737,708
Stroke	2,669	16,050	73	11	15,711	180,021
Encephalitis	238	1,629	3	1	2,523	21,120
Hypoxia	330	28,223	27	8	5,160	76,030
Brain tumour	56	14,380	10	4	14,109	159,773
Haemorrhage	1,010	12,828	31	1	9,612	90,770
+ Young adult	155	377	3	23	8,056	41,815
+ Young People	20	2	6	23	7,770	33,169
+ Early adulthood	2	152	0	25	10,661	14,021
+ Qualitative research	46	546	22	7	3,902	21,592
+ Semi-structured interview	42	89	16	33	1,476	2,948
+ Focus group	30	234	8	29	13,738	46,596
+ Thematic analysis	24	68	7	2	4,074	5,405
+ young adults + qualitative research	7	7	1	0	2,040	13,378

8.2. Ethics Approval (City University of London and Headway East London)



Psychology Research Ethics Committee
School of Social Sciences
City University London
London EC1R 0JD

20th July 2015

Dear Erin Seeto

Reference: PSYCH (P/F) 14/15 218

Project title: The experience of living with an Acquired Brain Injury from a young adult's perspective: the implications for Counselling Psychology.

I am writing to confirm that the research proposal detailed above has been granted approval by the City University London Psychology Department Research Ethics Committee.

Period of approval

Approval is valid for a period of three years from the date of this letter. If data collection runs beyond this period you will need to apply for an extension using the Amendments Form.

Project amendments

You will also need to submit an Amendments Form if you want to make any of the following changes to your research:

- (a) Recruit a new category of participants
- (b) Change, or add to, the research method employed
- (c) Collect additional types of data
- (d) Change the researchers involved in the project

Adverse events

You will need to submit an Adverse Events Form, copied to the Secretary of the Senate Research Ethics Committee (), in the event of any of the following:

- (a) Adverse events
- (b) Breaches of confidentiality

(c) Safeguarding issues relating to children and vulnerable adults
(d) Incidents that affect the personal safety of a participant or researcher
Issues (a) and (b) should be reported as soon as possible and no later than 5 days after the event.
Issues (c) and (d) should be reported immediately. Where appropriate the researcher should also report adverse events to other relevant institutions such as the police or social services.

Should you have any further queries then please do not hesitate to get in touch.

Kind regards

Karen Hunt
Departmental Administrator
Email: [REDACTED]

Katy Tapper
Chair
Email: [REDACTED]



Supporting people affected by brain injury

Headway East London

Timber Wharf

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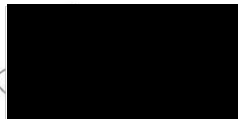
Friday 12th June 2015

To whom it may concern,

I am writing to inform you that Headway East London have granted permission for Erin Seeto to conduct her doctorate research on her placement with us.

Please do not hesitate to contact me if you would like any further information.

Kind regards,



Tina Greenhill MSc, BSc, MBACP (Accred)

Specialist Counsellor/Psychotherapist and Systemic Practitioner

Headway East London - Registered Charity No. 1083910. Company No. 3998925 Affiliated to Headway - the brain injury association - a registered charity



8.3. Service Context

The participants were recruited from a local Third Sector organisation designed to meet the needs of individuals following acquired brain injury. The service expectations are that everyone coming to the day service; members, staff, volunteers and visitors will work towards the following universal goals:

1. Feel accepted and welcomed at the day service
2. Be positively engaged in service community
3. Take responsibility for the maintenance and progress of the service community
4. Support and help other people who are involved in the service community

The service is founded on the principles of co-production. Co-production means recognising and capitalising on people's ability to do useful things for each other and themselves—abilities that are often missed by professionals and professional organisations. Other things include: social networks, mental and physical health, purposeful occupation and self-esteem.

Co-production was deemed a necessary way of meeting some of the unmet needs of people who have long-term disablement or mental illness—the kind of problems that typically make the 'community' inaccessible to them. People in this situation are often isolated and undervalued. Co-production creates a way for them to be involved with and valued by the community again. The principles of co-production are also closely aligned with current Department of Health policy. The Commissioning Framework for Health and Well-being (2007), The National Institute for Mental Health in England (NIMHE) (2005) and National Social Inclusion Programme (also part of NIMHE), (Seebohm and Gilchrist, 2008):

The service aims to use co-production as a model for service development and delivery. This means:

- 1) Helping people take responsibility for developing and managing their own programmes and activities at the centre.
- 2) Encouraging people to do what they are good at and what motivates them.
- 3) Including people in decision-making—those with brain injuries and those without, people who get paid to work at the centre and people who do not; having conversations before decisions are made.

4) Recognising that people who have brain injuries are experts, that they have the ability to teach and help others—both professionals and people who have been through similar experiences.

5) Involving people with disabilities in delivering the crucial work of the centre: assessments, mentoring and advice, reviews, public relations, lobbying, fundraising, therapies, teaching and training, administration and recruitment.

6) Expecting people to take responsibility for the centre and its up-keep.

7) Letting people share ownership of the centre.

8) Saying thank you when a person does something helpful; acknowledging the contribution of each person to the community.

Amended by E. Seeto (2017) based on information provided in Graham (2009) and Headway East London (n.d.).

8.4. Focus Group Participant Demographics

Participant Name	Gender	Aetiology of ABI	Self-reported areas of difficulty	No. of years post-injury	Year of Birth	Year of Injury	Age at Interview	Age at time of Injury
James	M	Hypoxia	Memory, information processing, concentration, word finding.	5	1989	2009	27	20
Liam	M	Other*	Mobility, memory, word finding.	7	1993	2011	23	18
Tony	M	TBI- RTA	Speech, mobility, concentration.	5	1984	2010	31	26
Veronica	F	Brain tumour	Mobility, visual, memory, anxiety/ depressions, fatigue.	4	1992	2012	24	20
Yasmine	F	Other*	Mobility, word finding, speech, fatigue.	6	1990	2010	26	20

NB: Other* denotes conditions which may lead to the identification of participants.

Average time since Injury	5 years
Average age at time of injury	21 years
Average age at interview	26 years

8.5. Individual Interview Participant Demographics

Participant	Gender	Aetiology of ABI	Self-reported areas of difficulty	No. of years post-injury	Year of Birth	Year of Injury	Age at Interview	Age at time of Injury
Simon	M	TBI- assault	Memory, dexterity, fatigue, irritability, depression, epilepsy.	3	1985	2013	31	28
Mark	M	TBI- assault	Speech, mobility, dexterity, epilepsy	6	1987	2010	29	23
John	M	TBI- RTA	Speech, memory, information processing, mood.	3	1985	2013	31	28
Brian	M	TBI- RTA	Aphasia, language and understanding, mood, impulsiveness.	6	1989	2010	27	21
Prabir	M	TBI- RTA	Mood, motivation, concentration and fatigue.	11	1988	2006	29	18
Ashan	M	TBI- assault	Fatigue, memory, speech, mood.	12	1986	2004	30	18
Juan	M	TBI- RTA	Motivation, impulsiveness, mood, reasoning, memory, disinhibition.	5	1985	2011	31	26
Charles	M	TBI- RTA	Memory, mood, concentration, fatigue, impulsiveness.	3	1986	2012	29	26
Louise	F	Encephalitis and other*	Memory, fatigue, epilepsy, other*.	6	1991	2009	24	18

NB: Other* aetiology denotes conditions which may lead to the identification of participants.

Average time since Injury	6 years
Average age at time of injury	23 years
Average age at interview	29 years

8.6. Information Leaflet (Long/ Accessible/ Outreach Versions)



Long version

Title of study: The experience of living with an acquired brain injury from a young adult's perspective: The implications for counselling psychology.

You have been approached by your key worker because we would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with your key worker if you wish. Ask the researcher or your keyworker if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

Various studies have shown that survivors of brain injury felt that those around them, including professionals did not understand the meaning and impact a brain injury had on their lives. The aim of this study is to try and understand the experience of living with an ABI for young adults, like you. This is to better support you, not only in recovery but throughout life.

This research is part of a Doctorate in Counselling Psychology and will be submitted as part of the researcher's final piece of work at City University, London. This research may also be published in an academic journal in future.

Why have I been invited?

- You have been invited to take part because you have an acquired brain injury.
- You are also between the ages of 18-30 years old. **Or** you acquired your brain injury within this age bracket and identify within the young adult's group (up to and including aged 32 years).
- You may also be part of the young people's group at Headway House.
- You also speak English or are able to communicate your experiences of your brain injury.

You have been selected by your keyworker because he/she thinks that you will be able to talk about your brain injury and you would be interested in participating in this research. The research will be in two parts:

1. In the first part of this research is a focus group will last 1-1:30hrs. This group will have between 6-8 participants.
2. The second part of the research will involve an individual interview which will last about 1-1:30hrs.

Do I have to take part?

Participation in the research is voluntary, and you can choose to participate in part or all of the project. You can also withdraw at any stage of the project without any consequences. Your service at Headway House will not be affected by your decision to participate or not.

If you do decide to take part you will be asked to sign a consent form. Even if you sign the consent form you are still free to withdraw at any time and without giving a reason.

What will happen if I take part?

- The research will take part in two stages: first during the focus group in October 2015 and second during an individual interview from January- March 2016.
- You are only consenting to participating in the focus group at this time. You do not need to participate in both stages and you are free to withdraw at any time.
- At a later date you may be asked to participate in an individual interview.
- You may see the researcher at Headway House throughout the year in her role as the volunteer counsellor.
- Each time you meet the researcher it should last between 1-1:30hrs.
- At the focus group the researcher will ask some general questions about having a brain injury.
- At the individual interview the researcher may ask you more in-depth questions about your experience specifically.
- The research will take place in the morning at Headway House on your usual day of attendance (Friday).

What do I have to do?

- Stage 1: Focus group- you will be asked 6-8 general questions about your experience of living with an acquired brain injury.
- Stage 2: Individual interview- you will be asked to complete a narrative exercise called the "train of life" and then answer 4 questions about your experience of living with an acquired brain injury.

What are the possible disadvantages and risks of taking part?

This research may raise some issues which you may not yet have thought about. The researcher and the key workers will be available following both the focus group and individual interviews should you need to discuss any aspect of the research further. If you wish to talk more about your personal issues raised during this research then counselling is available at Headway House. Your keyworker can make a referral to this service and you would be put on the waiting list.

What are the possible benefits of taking part?

Not many people have written about young adults with brain injuries and how it affects their lives. This research will give you the opportunity to discuss your experience and opinions about your brain injury and how people can better understand or support you.

Headway House will be organising some group therapy which you have the option of joining to discuss any issues further. This will begin in the weeks following the focus group and you can speak to your key worker if you would be interested in joining.

What will happen when the research study stops?

Once the research study is finished all data will be kept for 18 more months. This is in case the researcher needs to refer back to the original data for either amending the research or for publishing reasons. Once the time has lapsed then the data will be deleted from the relevant computer files and hard copies will be shredded and destroyed through confidential waste disposal bins.

Will my taking part in the study be kept confidential?

- The researcher will have access to the data prior to it being anonymized. Following analysis it will be anonymized and only the researcher's supervisors at City University or Headway East London may have access to the data.
- Audio/video recordings will be kept in an encrypted file on a password protected laptop computer. These will be deleted 18 months after completion of the research.
- Data will not be forwarded to other parties nor will it be used for any purpose other than those stated.
- Confidentiality will be respected except in the following circumstances – e.g. reporting of violence, abuse, self-inflicted harm, harm to others, criminal activity. Total confidentiality cannot be promised in the focus group.

What will happen to the results of the research study?

The study may take up to 2 years to complete. Afterwards, it will be marked by an exam board and an electronic copy will be held on an online database. The research may also be published in an academic journal. All data will be anonymised and so you will not be identifiable in the finished paper.

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

Your participation is voluntary, you can choose not to participate in part or all of the project, and you can withdraw at any stage of the project without being penalized or disadvantaged in any way. Your service at Headway House will not be affected.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: Young adults' experience of living with an Acquired Brain Injury: implications for Counselling Psychology.

Anna Ramberg
Secretary to Senate Research Ethics Committee
Research Office, E214
City University London
Northampton Square
London
EC1V 0HB
Email: [REDACTED]

City University London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Who has reviewed the study?

This study has been approved by City University London Psychology Department Research Ethics Committee, PSYCH (P/F) 14/15 218.

Further information and contact details

If further information is required about this study please contact either your key worker or the researcher: Erin Seeto at [REDACTED]

If you wish more information about the university course or research project you can email the research's supervisor: Kate Scruby at [REDACTED]

Thank you for taking the time to read this information sheet.

Accessible version

Title of study: The experience of living with an acquired brain injury from a young adult's perspective: The implications for counselling psychology.

You have been approached by your key worker because we would like to invite you to take part in a research study. Please read this information and discuss it with your key worker if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

Various studies have shown that survivors of brain injury felt that those around them, including professionals did not understand the meaning and impact a brain injury had on their lives. The aim of this study is to try and understand the experience of living with an ABI for young adults.

Why have I been invited?

- You have been invited to take part because you have an acquired brain injury.
- You are also between the ages of 18-30 years old. **Or** you acquired your brain injury within this age bracket and identify within the young adult's group (up to and including aged 32 years).
- You may also be part of the young people's group at Headway House.
- You also speak English or are able to communicate your experiences of your brain injury.

What do I have to do?

The research will be in two parts:

1. The first part of this research is a focus group will last 1-1:30hrs. This group will have between 6-8 participants. The focus group will take place in the morning at Headway House on your usual day of attendance (Friday).
2. You may be asked to participate in the second part of the research will involve an individual interview. This will last about 1-1:30hrs.

Do I have to take part?

Participation in the research is voluntary, and you can choose to participate in part or all of the project. You can also withdraw at any stage of the research without any consequences. Your service at Headway House will not be affected by your decision to participate or not.

If you do decide to take part you will be asked to sign a consent form. Even if you sign the consent form you are still free to withdraw at any time and without giving a reason.

The researcher and the key workers will be available should you need to discuss any of the research further. If you wish to talk more about your personal issues raised during this research then counselling is available at Headway House. Your keyworker can make a referral to this service and you would be put on the waiting list.

What are the possible benefits of taking part?

This research will give you the opportunity to discuss your experience and opinions about your brain injury and how people can better understand or support you.

Headway House will be organising some group therapy which you have the option of joining to discuss any issues further. This will begin in the weeks following the focus group.

What will happen when the research study stops?

Once the research study is finished all data will be kept for 18 more months. Once the time has lapsed then the data will be destroyed.

Will my taking part in the study be kept confidential?

- The researcher will have access to the data prior to it being anonymized. Following analysis it will be anonymized and only the researcher's supervisors at City University or Headway East London may have access to the data.
- Confidentiality will be respected except in the following circumstances – e.g. reporting of violence, abuse, self-inflicted harm, harm to others, criminal activity. Total confidentiality cannot be promised in the focus group.

What will happen to the results of the research study?

The study may take up to 2 years to complete. Afterwards it will be marked by an exam board and an electronic copy will be held on an online library database. The research may also be published in an academic journal. You will not be identifiable in the finished paper.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. Your key worker can support you to do this.

Thank you for taking the time to read this information sheet.

Outreach version

Title of study: The experience of living with an acquired brain injury from a young adult's perspective: The implications for counselling psychology.

You have been approached because we would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with your key worker if you wish. Ask the researcher or the Headway staff if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

Various studies have shown that survivors of brain injury felt that those around them, including professionals did not understand the meaning and impact a brain injury had on their lives. The aim of this study is to try and understand the experience of living with an ABI for young adults, like you. This is to better support you, not only in recovery but throughout life.

This research is part of a Doctorate in Counselling Psychology and will be submitted as part of the researcher's final piece of work at City University, London. This research may also be published in an academic journal in future.

Why have I been invited?

- You have been invited to take part because you have an acquired brain injury.
- You are also between the ages of 18-30 years old. **Or** you acquired your brain injury within this age bracket and identify within the young adult's group (up to and including aged 32 years).
- You may also be part of the young people's group at Headway House.
- You also speak English or are able to communicate your experiences of your brain injury.

You have been selected by the researcher because he/she thinks that you will be able to talk about your brain injury and you would be interested in participating in this research. The research will be in two parts:

3. In the first part of this research is a focus group will last 1-1:30hrs. This group will have between 6-8 participants.
4. The second part of the research will involve an individual interview which will last about 1-1:30hrs.

Do I have to take part?

Participation in the research is voluntary, and you can choose to participate in part or all of the project. You can also withdraw at any stage of the project without any consequences. Your service at Headway House will not be affected by your decision to participate or not.

If you do decide to take part you will be asked to sign a consent form. Even if you sign the consent form you are still free to withdraw at any time and without giving a reason.

What will happen if I take part?

- The research will take part in two stages: first during the focus group in October 2015 (**complete**) and second during an individual interview from January- March 2016.
- You are only consenting to participating in the focus group at this time. You do not need to participate in both stages and you are free to withdraw at any time.
- At a later date you may be asked to participate in an individual interview.
- You may see the researcher at Headway House throughout the year in her role as the volunteer counsellor.
- Each time you meet the researcher it should last between 1-1:30hrs.
- At the focus group the researcher will ask some general questions about having a brain injury. (**complete**)
- At the individual interview the researcher may ask you more in-depth questions about your experience specifically.
- The research will take place at Headway House on a weekday.

What do I have to do?

- Stage 1: Focus group- you will be asked 6-8 general questions about your experience of living with an acquired brain injury. (**complete**)
- **Stage 2: Individual interview- you will complete a narrative exercise called the “train of life” and be asked 4 questions about your experience of living with an acquired brain injury.**

What are the possible disadvantages and risks of taking part?

This research may raise some issues which you may not yet have thought about. The researcher and the Headway staff will be available following both the focus group and individual interviews should you need to discuss any aspect of the research further. If you wish to talk more about your personal issues raised during this research then the Headway staff/ researcher can make a referral to your local NHS Counselling service and you would be put on the waiting list.

What are the possible benefits of taking part?

Not many people have written about young adults with brain injuries and how it affects their lives. This research will give you the opportunity to discuss your experience and opinions about your brain injury and how people can better understand or support you.

Following the research Headway House will be organising some group therapy which participants will have the option of joining. This will begin 2016 and you can speak to the Headway staff if you would be interested in joining.

What will happen when the research study stops?

Once the research study is finished all data will be kept for 18 more months. This is in case the researcher needs to refer back to the original data for either amending the research or for publishing reasons. Once the time has lapsed then the data will be deleted from the relevant computer files and hard copies will be shredded and destroyed through confidential waste disposal bins.

Will my taking part in the study be kept confidential?

- The researcher will have access to the data prior to it being anonymized. Following analysis it will be anonymized and only the researcher's supervisors at City University or Headway East London may have access to the data.
- Audio/video recordings will be kept in an encrypted file on a password protected laptop computer. These will be deleted 18 months after completion of the research.
- Data will not be forwarded to other parties nor will it be used for any purpose other than those stated.
- Confidentiality will be respected except in the following circumstances – e.g. reporting of violence, abuse, self-inflicted harm, harm to others, criminal activity. Total confidentiality cannot be promised in the focus group.

What will happen to the results of the research study?

The study may take up to 2 years to complete. Afterwards, it will be marked by an exam board and an electronic copy will be held on an online database. The research may also be published in an academic journal. All data will be anonymised and so you will not be identifiable in the finished paper.

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

Your participation is voluntary, you can choose not to participate in part or all of the project, and you can withdraw at any stage of the project without being penalized or disadvantaged in any way. Your service at Headway House will not be affected.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: Young adults' experience of living with an Acquired Brain Injury: implications for Counselling Psychology.

Anna Ramberg
Secretary to Senate Research Ethics Committee
Research Office, E214
City University London
Northampton Square
London
EC1V 0HB
Email: [REDACTED]

City University London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim

compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Who has reviewed the study?

This study has been approved by City University London Psychology Research Ethics Committee, PSYCH (P/F) 14/15 218.

Further information and contact details

If further information is required about this study please contact either your key worker or the researcher: Erin Seeto at [REDACTED]

If you wish more information about the university course or research project you can email the research's supervisor: Kate Scruby at [REDACTED]

Thank you for taking the time to read this information sheet.

8.7. Consent Forms (Long/ Accessible/ Outreach Versions)



Consent to participate in a Focus Group (long version)

Title of Study: The experience of living with an acquired brain injury from a young adult's perspective: The implications for counselling psychology.

Ethics approval code: PSYCH (P/F) 14/15 218

Please initial box

1.	I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records. I understand this will involve: • Participating in a focus group facilitated by the researcher • allowing the focus group to be video-taped/audiotaped	
2.	This information will be held and processed for the following purpose(s): • to be transcribed into written text for analysis • to be analysed using Thematic Analysis. I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation. I understand that my name and personal information relating to me will be anonymised as far as possible to protect my identity from being made public. I understand that data will be stored in either a locked filing cabinet or held on a laptop computer which is both password protected and the file encrypted.	

	I understand that I have given approval for Headway East London to be named in the final report of the project, and future publications. I understand that confidentiality cannot be guaranteed for information which I might disclose in the focus group(s)/group interviews(s). I consent to the use of sections of the videotapes or audio tapes in publications.	
3.	I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalized or disadvantaged in any way.	
4.	I agree to City University London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.	
5.	I agree to take part in the above study.	

Name of Participant

Signature

Date

Name of Researcher

Signature

Date

When completed, 1 copy for participant; 1 copy for researcher file.

Note to researcher: to ensure anonymity, consent forms should NOT include participant numbers and should be stored separately from data.

Consent to participate in Focus Group (Accessible version)

Title of Study: The experience of living with an acquired brain injury from a young adult's perspective: The implications for counselling psychology.

Ethics approval code: PSYCH (P/F) 14/15 218

1. I confirm that my keyworker has given me a copy of the participant information sheet and has explained the research project to me including what I will need to do, issues of confidentiality and data storage/ usage.
2. I understand that this will involve participating in a focus group for approximately 1hr to 1hr 30mins.
3. I understand that this focus group will be video and audio taped.
4. I understand that the data will be transcribed and my comments will remain anonymised so that people cannot identify me.
5. I understand that the researcher will treat all information confidentially and it will be held securely by the researcher.
6. I understand that the research may be published and that Headway East London may be mentioned in the research paper.
7. I understand that my participation is voluntary, that I can choose not to participate in part or all of the project. I understand that I can withdraw at any stage of the project. This will not affect the service that I receive.

I agree to take part in the above City University London research project.

_____	_____	_____
Name of Participant	Signature	Date
_____	_____	_____
Name of Researcher	Signature	Date

When completed, 1 copy for participant; 1 copy for researcher file.

Note to researcher: to ensure anonymity, consent forms should NOT include participant numbers and should be stored separately from data.

Consent to participate in Individual Interviews (long version)

Title of Study: The experience of living with an Acquired Brain Injury from a young adult's perspective: the implications for Counselling Psychology.

Ethics approval code: PSYCH (P/F) 14/15 218

Please initial box

1.	I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records. I understand this will involve: • being interviewed by the researcher for approximately 1-1:30 hour. • allowing the interview to be audiotaped.	
2.	This information will be held and processed for the following purpose(s): • to be transcribed into written text for analysis • to be analysed using Thematic Analysis. I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation. I understand that my name and personal information relating to me will be anonymised as far as possible to protect my identity from being made public. I understand that data will be stored in either a locked filing cabinet or held on a laptop computer which is both password protected and the file encrypted. I understand that I have given approval for Headway East London to be used in the final report of the project, and future publications. I consent to the use of sections of the audiotapes in publications.	

3.	I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalized or disadvantaged in any way.	
4.	I agree to City University London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.	
5.	I agree to take part in the above study.	

_____	_____	_____
Name of Participant	Signature	Date

_____	_____	_____
Name of Researcher	Signature	Date

When completed, 1 copy for participant; 1 copy for researcher file.

Note to researcher: to ensure anonymity, consent forms should NOT include participant numbers and should be stored separately from data.

Consent to participate in Individual Interviews (Accessible version)

Title of Study: The experience of living with an Acquired Brain Injury from a young adult's perspective: the implications for Counselling Psychology.

Ethics approval code: PSYCH (P/F) 14/15 218

1. I confirm that my keyworker has given me a copy of the participant information sheet and has explained the research project to me including what I will need to participate in, issues of confidentiality and data usage.
2. I understand that this will involve participating in an individual interview for approximately 1hr to 1hr 30mins.
3. I understand that this individual interview will be audio taped.
4. I understand that the data will be transcribed and my comments will remain anonymised so that people cannot identify me.
5. I understand that the researcher will treat all information confidentially and it will be held securely by the researcher.
6. I understand that the research may be published and that Headway East London may be mentioned in the research paper.
7. I understand that my participation is voluntary, that I can choose not to participate in part or all of the project. I understand that I can withdraw at any stage of the project. This will not affect the service that I receive.

I agree to take part in the above City University London research project.

_____	_____	_____
Name of Participant	Signature	Date
_____	_____	_____
Name of Researcher	Signature	Date

When completed, 1 copy for participant; 1 copy for researcher file.

Note to researcher: to ensure anonymity, consent forms should NOT include participant numbers and should be stored separately from data.

Consent to participate in Individual Interviews (Outreach service)

Title of Study: The experience of living with an Acquired Brain Injury from a young adult's perspective: the implications for Counselling Psychology.

Ethics approval code: PSYCH (P/F) 14/15 218

1. I confirm that the researcher has given me a copy of the participant information sheet and has explained the research project to me including what I will need to participate in, issues of confidentiality and data usage.
2. I understand that this will involve participating in an individual interview for approximately 1hr to 1hr 30mins.
3. I understand that this individual interview will be audio taped.
4. I understand that the data will be transcribed and my comments will remain anonymised so that people cannot identify me.
5. I understand that the researcher will treat all information confidentially and it will be held securely by the researcher.
6. I understand that the research may be published and that Headway East London may be mentioned in the research paper.
7. I understand that my participation is voluntary, that I can choose not to participate in part or all of the project. I understand that I can withdraw at any stage of the project. This will not affect the service that I receive.

I agree to take part in the above City University London research project.

_____	_____	_____
Name of Participant	Signature	Date
_____	_____	_____
Name of Researcher	Signature	Date

When completed, 1 copy for participant; 1 copy for researcher file.

Note to researcher: to ensure anonymity, consent forms should NOT include participant numbers and should be stored separately from data.

8.8. Focus Group Schedule

Today you have been invited to participate in research about your experience of having an acquired brain injury. As you may know, I will be recording today's group on both an audio and video recorder. All audio/video recordings will be held securely by me on an encrypted file on a password protected laptop. The audio/video recordings from today will be transcribed by myself and then anonymized so that you will not be individually identifiable in the research paper. Data will not be forwarded to other parties nor will it be used for any purpose other than those stated in the participant information sheet.

Various studies have shown that survivors of brain injury felt that those around them, including professionals did not understand the meaning and impact a brain injury had on their lives. The aim of this study is to try and understand the experience of living with an ABI for young adults, like you. This research is part of my Doctorate in Counselling Psychology and will be submitted as part of my final piece of work at City University, London. This research may also be published in an academic journal in future. Your participation is voluntary, and you can choose not to participate in part or all of the project. If you wish to leave at any point you are free to do so however I ask that you do this as quietly as possible so that it does not disturb the rest of the group.

Before we start I would like to have some group rules. It is important that everyone who wants to say something has the chance to do so. Not everyone may share the same experience so respecting others opinions even if you do not agree is important. As part of respecting each other, I would prefer that we do not speak over one another. If at some point I feel someone is not getting the chance to speak I may step in to make sure that they get the chance to give their experience also. Some people may share information that is very personal to them. In the spirit of respect to each member, I would prefer if we could agree not to discuss outside the group information people have disclosed.

So I have a few questions to ask you about your experience of living with an ABI but I wondered where you think would be a good place to start?

1. Can you tell me how life had changed since your brain injury? Prompt- How do you feel about those changes?
2. How do you feel about yourself following your brain injury? Prompt- your body, your mind, your identity?

3. What are the positives and negatives of your brain injury?
4. What impact has your brain injury had on relationships? Prompt- How do you feel about those changes? Prompt- with family, children or friends?
5. Has your future goals or plans changed as a result of your ABI? Prompt- How do you feel about those changes?
6. Do you tell people about your ABI? Prompt-How do you feel when/about telling them? Prompt- on a night out, when meeting new people, on social media?
7. What do people need to understand about the impact of ABI on people's lives? Prompt- what advice would you give.

8.9. Individual Interview Schedule

The first part of the interview is a bit more creative and called the train of life. We're going to map out the story of your brain injury and what life has been like since. It will take about an hour and afterwards I'll ask you some questions. Does that sound ok?

The train will represent you and you can pick as many carriages as you would like.

The track will represent your life. There are different track designs, choose one which you feel represents your life journey or you can draw your own. The track starts when you wake up from your brain injury or from whenever your memories begin.

The passengers are the significant people that may have come in or out of your life since your brain injury. You can put them in the carriages or along the tracks. If you have any you would like to add you/ I can write them down.

The stations are the transition points since your brain injury. These may be particular places or moments of change. Choose as many "stations" as you want and place them around your track.

The barriers represent the challenges since your brain injury. Place the barriers along your track wherever you think appropriate.

I also have some of the feelings or words mentioned by the focus group participants about their brain injury. Pick any that are relevant and you can place them wherever you prefer along your journey. Again if you have any you would like to add you can write them down.

Can you tell me a bit about your picture, why did you choose this track? Tell me about who you have chosen as passengers? What transitions or stages do stations represent? What barriers or challenges have you faced since your brain injury? Tell me a bit about the emotions you have chosen? Overall how would you describe your experience?

Questions

1. What has your brain injury taught you about yourself?
2. How do you tell people about your brain injury?
3. What do people need to understand about the impact of your brain injury?
4. Given what you know now. What advice would you give someone else who has just suffered a brain injury?

The mind map is a hand-drawn diagram with a central circle labeled "Me". Radiating from this center are several lines, each representing a different aspect of the person's life. The lines are labeled with various terms and phrases, some of which are highlighted in yellow or green. The lines are connected by a large, irregular black outline that resembles a person's silhouette. The lines are labeled as follows:

- Top Left:** Support worker, Sad, Down, Tension, Negative, Changed xious, focusing on imperfections, Weakness, Frustrated, Physical disability, Recovery, Disappointed, Psychologist, Mental Health, Stress, Home, Cognitive impairment, Queen's Square, Becoming me, Finding myself, Making unwise life choice / decisions, Thinking patterns unhelpful, Emotions, Comfortable with myself, Healthy, New self, Normal, Adjustment, Confident, Happy, Feeling that I've got failures, Challenge, Independence, Inner strength, Routine, Headway, Moving on, Support group, Key worker.
- Left:** Nurse, Rehab, Doctor, Physio, Unsure, Independence, Memory, O.T., Cousin, Uncle, Aunt, Old self, connecting.
- Right:** Friend, Brother, Mum, Sister.



8.11. Participant Debrief Forms (General/ Outreach versions)

Today you may have discussed some personal information about your experience of living with an acquired brain injury. I'm aware that this may have raised some difficult issues. If you feel you need to talk to someone about these issues then please come to speak to me. Alternatively, you can talk to your keyworker.

If you feel you need more support to discuss how you may be feeling then you can be referred to the counselling service here at Headway House. You can speak to your keyworker about this and they will be able to complete the referral form for you.

Once this research project is completed I will hold a further group to go through what the research found. You do not have to attend this group, it is only if you are interested. Thank you for taking time out of your day to participate in this research and share your experience with me.

This study has been approved by City University London Psychology Department Research Ethics Committee, PSYCH (P/F) 14/15 218.

Further information and contact details

If further information is required about this study please contact either your key worker or the researcher: Erin Seeto at [REDACTED]

If you wish more information about the university course or research project you can email the research's supervisor: Kate Scruby at [REDACTED]

Thank you for taking the time to read this information sheet.

Participant Outreach Debrief

Today you may have discussed some personal information about your experience of living with an acquired brain injury. I'm aware that this may have raised some difficult issues. If you feel you need to talk to someone about these issues then please come and speak to me. Alternatively, you can talk to the Headway staff.

If you feel you need more support to discuss how you may be feeling then you can be referred to your local NHS Counselling service. You can speak to the Headway staff about this and they will be able to complete the referral form for you.

Once this research project is completed I will hold a further group to go through what the research found. You do not have to attend this group, it is only if you are interested. Thank you for taking time out of your day to participate in this research and share your experience with me.

This study has been approved by City University London Psychology Department Research Ethics Committee, PSYCH (P/F) 14/15 218.

Further information and contact details

If further information is required about this study please contact either your key worker or the researcher: Erin Seeto at [REDACTED]

If you wish more information about the university course or research project you can email the research's supervisor: Kate Scruby at [REDACTED]

Thank you for taking the time to read this information sheet.

8.12. Initial Focus Group Coded Transcript (sample)

Patience & tolerance with slower speech

Not being heard
Individual as expert
- J2 V listening

E- OK and you find that really frustrating?
Y- Yes, just the frustrating part because you know what you want and you've told them that's what you want 10,000 times but that's they still end up doing something else. And, em, I'm saying that because em, I'm currently living in a rehab place which ended up like a care home and
E- OK
- Powerlessness
- T beginning to disengage.

Being forgotten
Y- For the past four years, em, I've, I've actually was meant to be there for 6 months but it's been 4 years now
E- Hmm
Unheard
L- Yawning.

Moving on & being stuck.
Y- And I've been trying my best for the past 2-3 years to actually move out of that place. And just explore what's, what's out there and even though I've been telling them "this is what I want, that is what I want", I'm still in this place after 3 years and so...
E- Hmmm so you're not being listened to
Y- Its just I'm not being listened to so
E- I guess that's a really important point. V you've raised it in terms of your family were worried about you being moved somewhere inappropriate. And Y you're saying that you are somewhere you don't want to be and you can't move out of there
Both- Yeah
E- Yeah <pause> Powerlessness
Fighting the system

Not being seen as a person.
E- That decision is not being made by me. It's being made by someone who is probably sitting in the office. That's never seen me. In that's the frustrating part because, the person that's making decisions doesn't even know me, let alone what to say what I can or can't do. Unheard. Mood - low.
E- I guess that links quite well into not being seen as a person just being dealt with in a system.
Y- Yeah, I think that.

Obstacles to being heard even in supported places.
T- It sounds a little bit like people are coming across a lot more obstacles in actually fighting for your view and your voice to be heard. Nodding
L- Yeah
Multiple levels of barriers not to recover in terms of being back to where were but in striving for a better future for selves.

Reticence to share or talk about impact.
T1- Is it more difficult to be heard than it was maybe perhaps before your injury?
L- Yeah
E- What about em? What about the relationships you have? What is... What impact has your brain injury had on relationships that could be...? You've mentioned a bit about friends about finding out who your real friends are. But you've talked a bit about parents as well. And I guess carers too. How has it impacted on relationships? Mood lower.
L- em, I don't know. It affect it a little bit. But then I think it, after a while it finds its way back to normal. Tentative
E- Ok, so you feel it's back to normal now? Back to normal.
L- Yeah, well yeah. T- standing up and getting ready to leave.
Naming it might make it an issue not to be ignored so almost covering this by saying getting back to normal. (Syrus talks)

E- What about, well you've mentioned that parents will make decisions for you and you've kinda got to argue a bit with them about making decisions for yourself.

L- Yeah

E- So I guess I'm wondering a bit about you being 22 and parents making decisions. How, how do you feel that's changed since your brain injury?

Again
menhounding
getting
better

L- Em... I mean at the start it was like, they were making decisions for me all the time. It's getting better now, I'm doing a lot more for myself.

E- Hmm, ok

L- So yeah

E- So you're doing a lot more. I we talked about your parents

J- It's like my dad. When I first had my accident he seemed angry with me.

E- Angry with you?

J- Yeah

E- OK

V- Who?

J- My dad, yeah. But was because em just before my accident I used to have a phone bill. I used to have a phone and it was on contract

E- OK

J- And it came really expensive just before my accident

E- OK

J- But then I had my accident and you

E- And you thought he carried that forward?

J- Yeah but now it's just normal with me.

E- So I guess you mentioned that your mum used to, initially would make lots of decisions

J- Yeah

E- But now she kind of lets you live your life?

J- Yeah, yeah

E- I'm wondering I guess about things like moving out?

<pause> V you just laughed

V- Me moving out is kind of... no

E- No?

- Inherent deflection to what parents may want. Again sense that what V want's doesn't matter because what parents wants goes and acceptance of that

→ Unable to grow up exaggerated body movements
Life choices not theirs.

remaining the child

Moving out influenced by others - lack of independent decision making.

Transition stages

Family roles.

Concept of doing a lot more. independence/proving ability causes a reduction in parental control?

Tom leaves & noise level from outside increases. J more animated now & mood shifts slightly.

Awareness
↳ Still a child?

Changes in roles of family. Mum = carer
sister = carer

↳ Other relationships adapt to dual role or are neglected/drift as a result.

transient V- I don't know. Well because my mum and well my sister are my carers. And I was... I don't know. I just couldn't see that. Well it will happen but it'll be with someone. It'll be with my boyfriend, that's in years to come. But... Moving from one dependent relⁿ to another.

E- Well, what about your relationship with your boyfriend has that changed?

Defensive

V- No

E- Still the same?

Stages of change

V- It had, I suppose at the beginning cause I'd just come out of hospital and it was. And I was away for quite a while, maybe a year and then come back and stuff. In to the real world. And yeah, so I suppose it changed for the first few months but then...but now it's, it's still there. hand gestures

E- Ok

V- I suppose. Other than that obviously there is some little things but, no...

E- I guess like what? I'm guess I'm wondering if you're.... We've had a few discussions before about him, looking out for you more, being a bit more protective.

V- Oh yeah

E- So I'm wondering a bit about things like that

V- Definitely stuff like that but I think he's learned that from my family.

E- Ok

V- Like they are, like my sister is. But he's really close to my sister and my cousin. But he's learnt that from them. And my mum and dad I suppose

E- Ok so you think your family after your brain injury became a lot more protective of you?

V- Yeah, and then

J- Yeah

V- He just followed them. But eh, if like he sees them, like my mum. If I walk round like Romford or whatever, em now and then he has to kinda see that for then to...otherwise he won't let me do that when I'm with him. Cause I'm in kind of his care, a bit.

E- So there's still this kind of feeling that people are caring, they think they're caring for you

V- Yeah and I just let them get on with it to be honest.

E- Ok, so you'll let them have that...

V- Yeah, I do yeah

E- Ok. What about the rest of you, have you found that? That parents still act in a kind of caring role?

All- Yeah definitely

E- Yeah

J- Yeah especially my mum

E- In what way? Do you want to explain that a bit more?

Not mention
stuff said
before.

Criticism of
group as
in not safe
or comfortable
enough
rather than
say.

detached.

life suspended in hospital(?)

Prompt

family being the lead example
what about ability to
challenge this.
Yoki nodding

enmeshed.

Them & me. Boundaries.

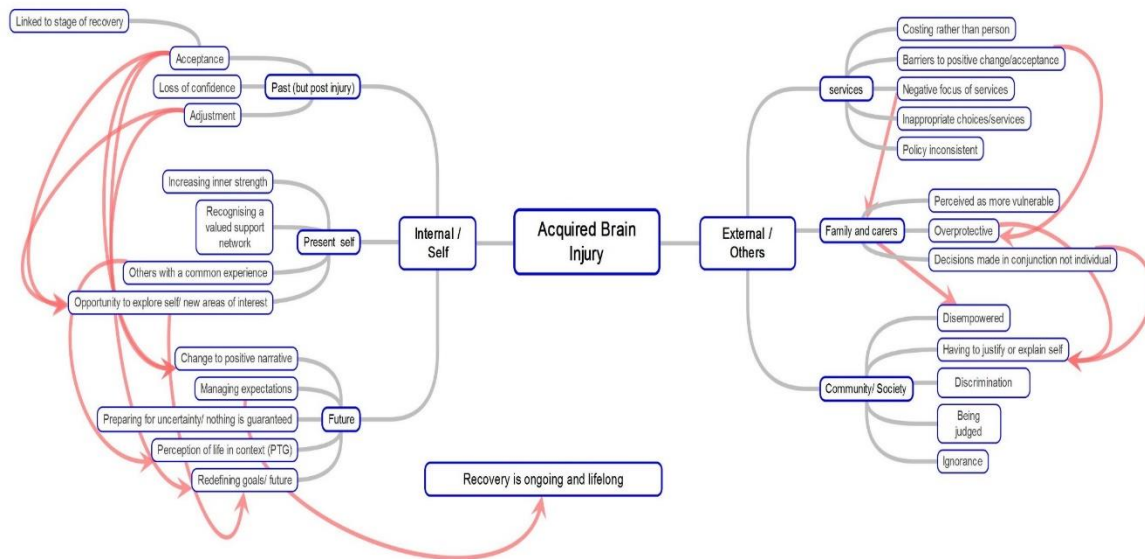
Boyfriend = carer. Boundaries & relⁿ

Acceptance of dual role.
rather than challenge it.

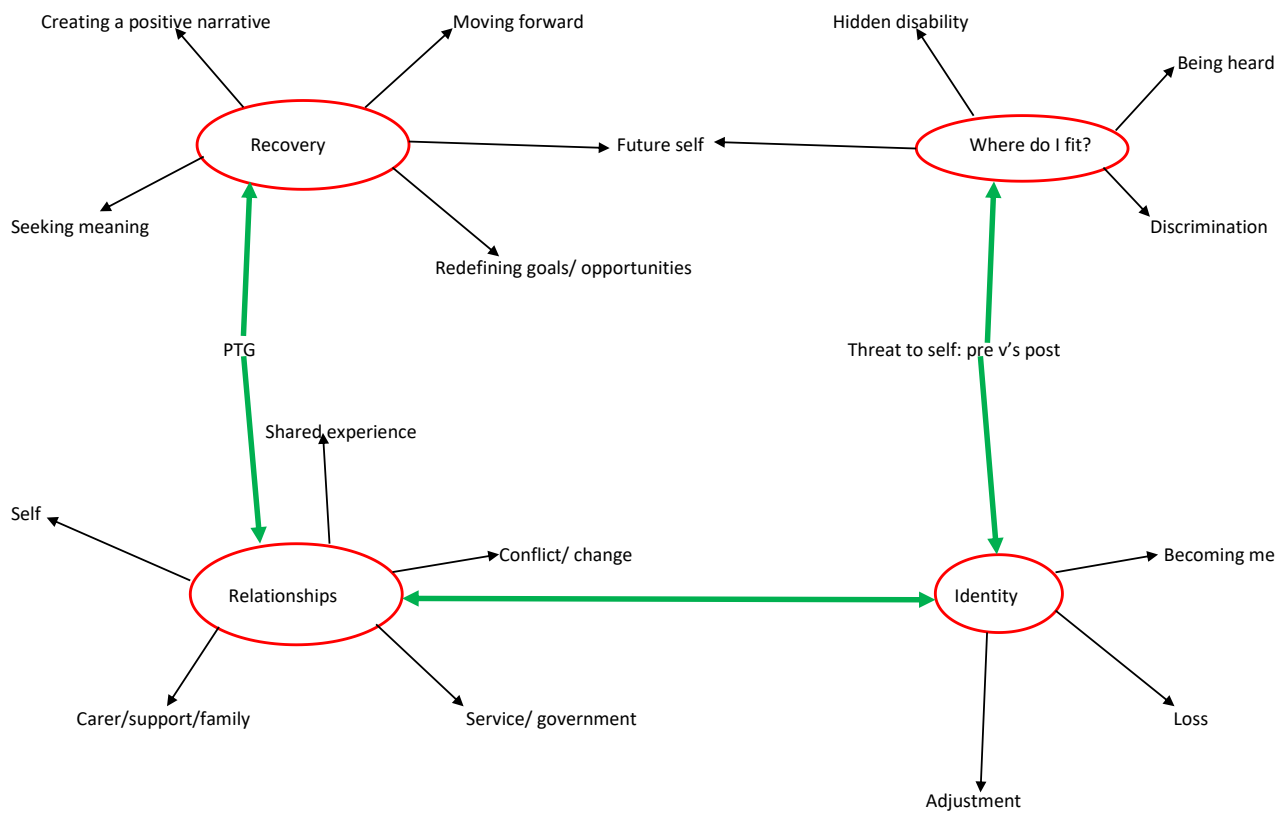
↑
powerlessness

Dual role common if living
at home. Skill dependency

8.13. Initial Map of Coded Themes



8.14. Revised Map of Themes and Sub-themes



8.15. Final Map of Themes and Sub-themes



8.16. One Individual Interview Full Transcript

- 1 R- So as I explained the first part of the interview was back in September and that was me
2 asking a group of young people about their experience. So I asked them a few questions and
3 then based on that story or what they told me about their experience we developed this
4 exercise. It's called the train of life, so it's about exploring your experience since you had your
5 brain injury up until now.
- 6 P- Uh huh
- 7 R- Em, and what I might do is add in some bits of paper that represents some of the stuff
8 came out of the focus group and if there's anything missing you can let me know and I'll add
9 that into the bits of paper. So this is a bit creative and this will take about, probably about
10 50mins or so
- 11 P- Ok
- 12 R- Em, so the idea of this is that the train tracks will represent your journey. So it will start
13 with either when you wake up in hospital after your brain injury or your first memory after
14 your brain injury. OK? Whatever you prefer, you can start wherever you want.
- 15 P- Ok. It's probably sort of when I was in the coma.
- 16 R- Ok so you can start there then and then it goes right up until today.
- 17 P- Yeah
- 18 R- Now you can, I've drawn out various different train tracks here. That all have different
19 patterns. You can choose whichever one you want. If you want to have a flick through them
20 now. If you have a look.
- 21 P- Em
- 22 R- Or you can draw your own
- 23 P- I think, if you've got a standard line.
- 24 R- A standard line, like this one?
- 25 P- Yeah, it does the job really.
- 26 R- Ok...ok. So the train is going to represent you and you can choose however many
27 carriages you want to add to the train.
- 28 P- I suppose if I'm doing the attempted sliming world, I'm best to...uh...it's just me (indicating
29 no carriages)
- 30 R- Just you (both laugh) so you want one carriage or just you just want the train.
- 31 P- Em probably the thing

32 R- One carriage?

33 P- Because of this as well (indicating to the board)

34 R- Yeah...yeah

35 P- Yeah

36 R- Ok, so the train will represent you and the carriages is just whatever you bring along with
 37 you in life. So as we're going through if you think there has been things that have been
 38 particularly important not just at one point of the track, then you can add it to the carriage
 39 and bring it. And it could be people or it could be places that have been important to you.
 40 OK? (Indicating examples as going along)

41 P- Ok

42 R- So, em. The passengers are going to represent the significant people in your life. So I
 43 would like you to have just a think about from when you woke up and your journey until now.
 44 Have there been particular people who have been important to you? And I guess just tell me
 45 a little bit about them?

46 P- Well it's mainly my family really.

47 R- Your family? OK so I've got some em, names and people here who came from the focus
 48 group. So you can pick through some of these or we can go through them. Whatever you
 49 prefer? Em, and if you just place them along the track where they've been important. So I
 50 guess I'm thinking about things like em, people like the OT or the doctors or the nurses
 51 might have been more important when you were in hospital initially but maybe not as
 52 important now? Or that might be wrong? Em, so if you just place the people...

53 P- It's more like stages since I've recovered.

54 R- Yep

55 P- And em, more sort of like became more of myself.

56 R- Became more of yourself?

57 P- I've sort of never really got back to whatever I was before sort of.

58 R- Uh huh, OK.

59 P- And then it's family quite a big bit. Because she had to give up a job for looking after me
 60 and becoming a full time carer.

61 R- Yeah so your mum is really important? Do you want to put your mum along the tracks or
 62 is she in the carriage with you?

63 P- She's probably in there with me.

64 R- She's in the carriage. Ok so you said she gave up her job to look after you?

65 P- Yeah, she was a dinner lady and I feel so robbed because she really enjoyed her job. And
 66 I sort of feel that I've robbed her of it and her best mate but

67 R- Hmmm Ok. Does she enjoy looking after you?

68 P- She said she's always says, "I don't mind you're a pleasure to look after, you're really nice
69 and that". And I'm like "well yeah, but I feel like I've robbed you of your best mate". And I feel
70 like, how would I feel if someone had taken away my best friend?

71 R- Ok, so you put yourself in her shoes?

72 P- Yeah and I am just sort of thinking if I had to do any job at my local primary school sort of
73 thing, Well not local primary school...and quite enjoying being a dinner lady and all that. And
74 you didn't mind the job too much, and you kind of enjoyed getting on with it. Then you sort of
75 think actually taking away the nice bit of like female company you enjoy like

76 R- Has your mum, has your relationship with your mum changed?

77 P- It has actually become sort of more intense really because she's not just my mum she's
78 my full time carer now and sort of like, if anything the epilepsy happens really she has to be
79 like, on hand. Seeing to me in person to like sort of be the person looking after me.

80 R- Ok

81 P- And it's quite difficult I would say but she says, "I don't mind doing it, sort of like as a carer
82 because that's what my job is."

83 R- Uh huh. Do you mind it? Do you mind your mum being your carer?

84 P- Well nah. Because I'm a little baby really, because the person you want most in your life
85 looking after you most of the time is always your mammy. Cause you want someone who
86 you don't mind giving a cuddle at the end sort of.

87 R- Ok so she provides kind of emotional support as well as doing the day to day caring stuff
88 with your epilepsy?

89 P- Yeah

90 R- Ok. Do you like...would you ever want anyone else to be your carer?

91 P- If it was, I would always feel a little bit more worried about who's, who's going to be my
92 carer. Like would they understand all the different things with the family because they're not
93 one of them? They wouldn't really understand it.

94 R- Hmm ok

95 P- So...

96 R- OK, so that's your mum has that extra level of support that someone else couldn't
97 provide? Are their pros and cons to it?

98 P- There are to a certain extent because when you want sort of a thing to offer on the
99 outside of it you sort of think, "I can't remember, I can't ever really get away from my
100 disability thing with my carer and that is always some, someone to ride home with me"

101 R- So em, if you can't have alone time with friends or that sort of thing...as much because
102 you're mum has to come with you?

103 P- To a certain extent because if we're meeting she'd have to sort of say sort of like, give me
 104 a time, what sort of time are you coming back to and all the rest

105 R- Yeah

106 P- It's a bit of a bugger really cause with my epilepsy and that it's...

107 R- Hmm ok

108 P- I don't really see as much of my friends now. And it's sort of when it's this sort of ages
 109 they are now it's, they're more sort of uni and off starting their first steps into life really. And
 110 seeing what, starting off little properties with their friends and so...

111 R- So they're moving out?

112 P- Or boyfriends and that. Sort of like, they branched away from their homes, they're sort of
 113 like, almost sad cause that's the bit of life that you've been robbed of a bit.

114 R- Ok, you feel robbed of, of moving out and starting up something on your own or with a
 115 boyfriends or with friends?

116 P- Yeah cause you sort of haven't really done your own sort of branch away from the
 117 schools and that into the older generational thing and then become an adult. Because all I've
 118 become since I was 17 and got ill. Now you haven't just got into adulthood, you've come into
 119 or going into it as an ill person adult sort of.

120 R- Ok, Ok, so rather than kind of progressing in a very linear way you've had to take a
 121 different, it's different because of the illness?

122 P- Yeah

123 R- Do you still feel like an adult now?

124 P- I do to a certain extent but it's just...you know I sort of think, I don't know what on earth
 125 I'm supposed to be doing now. And there is more sort of youth group and support for young
 126 people with brain injury in my area and that. And then you sort of think well, that really with
 127 the government and that there's not much, much support that there is, than there should be
 128 for young people and sort of young adults with a brain injury which I would come under now.

129 R- Yeah do you feel there's not enough support out there for you to be able to get on to that
 130 kind of ladder and follow the same journey as your friends?

131 P- Not exactly. It's not too bad because I got to a young local em youth group and things like
 132 that for young people with a brain injury. And it's a nice day out but it's just sort of...I always
 133 feel like you're putting on some of it and its difficult. You also worry has the centre got
 134 enough money for it, do they need another fund raising event or something?

135 R- So you are worried about it being taken away?

136 P- To a certain extent and then you sort of think. I don't exactly know what party I should
 137 vote for and that, because I don't exactly know who would, what would twist it to make a
 138 better world and so you just kind of stick where you are.

139 R- Ok so that idea of not really knowing who's there to support you, who can make the
140 changes that will make you a priority? Or young adults a priority?

141 P- Yeah, as you sort of branched into, as you started growing up from being 17 to the age I
142 am now, you start to thinking how did you? What...? Since then what support is there for
143 older people with a brain injury and things like that to...

144 R- So do you think it's brain injury as a whole that's kind of not prioritised or is it specific age
145 groups within brain injuries?

146 P- Eh, cause there is some things for young people with brain injuries and that there is to a
147 certain extent but then you sort of think but I can't always rely on the support that there is out
148 there for you.

149 R- Hmmm, ok, so you don't know what there is out there to be able to access it?

150 P- Not really cause then you sort of think once it gets past your local borough covers then
151 you sort of think well if I get older and I move somewhere then what will it be like in that area
152 and how is it all going to develop sort of thing?

153 R- Hmm. Ok. Can we go back to the people in your life? So is there anyone else here that
154 you would put on your journey that have been really important in your journey?

155 P- Eh to start with it was my mum and my dad and em

156 R- Your dad as well, would you put him on the train or at the start of the journey?

157 P- Probably in the train really because they've always been my support really

158 R- Uh huh

159 P- Mum had to give up her job and then sort of my brother's there because he's sort of

160 R- I think I've got one for brother. Would you put brother in the train with you or would you
161 put him along the journey?

162 P- He's in the journey but he's, he can be a grumpy sod sometimes though. He's just...
163 (Laugh)

164 R- So you want to put him half in half out?

165 P- Yeah cause he, he'll only sort of be in when he has to be sort of stuff.

166 R- Hm, ok has your relationship with your brother changed since you had your brain injury?

167 P- I think he's always been a little bit more reserved sort of how to act around me a little bit,
168 cause he's nervous if he does something that I'll have a fit around him or something. I mean
169 I'm not in charge of when I have them, they're in charge of when I'm having it. You know?

170 R- Uh huh. Ok. So it's more the epilepsy side of things that he's a bit more wary of?

171 P- To a certain extent yeah cause he sort of thinks how will I know when she's just going to
172 have one. Well it's not exactly up to me it's you know it does it on me.

173 R- Hmm ok, is there anyone else you would add in?

174 P- Probably yeah. We live near my grandad and

175 R- Oh I don't think I've got one for grandad. How about I write it and I'll add it?

176 P- It's just with him being an elderly relative it sort of like

177 R- Yeah. So where would you put your grandad?

178 P- Em

179 R- Would he go on the train or would he go? Has he been more important at a certain point?

180 P- Em, he's been sort of helpful sometimes taking me to art class and sometimes bits like

181 that so I suppose in the train.

182 R- Uh hmm in the train. Ok.

183 P- Since he's been a little bit more ill recently he's just sort of. Cause he's got Parkinson's

184 and he's quite worried about it. He's sort of like, he doesn't know what use. It's quite sad

185 because he feels he's sort of "what use am I to you guys as I can't exactly help you when

186 you need help yourselves".

187 R- Ok. You mentioned friends, I think I have one for friends where would you put them?

188 P- Well since I came out of sixth form and that...cause I was ill and that. I have never really

189 got off or back with them. Cause they've all bounced off in their ways and go off to uni and

190 that and I never really got to finish that part of life.

191 R- So were they very early on? Did they come and visit you in hospital?

192 P- Quite a few cause they were a little worried for me to a certain extent that I was going to

193 die. But then when I survived and then they were all sort of happy and being nice and

194 coming to see me a couple of times and that. But you just feel a little bit more worried of

195 wary for them because then you sort of think, well I'm not in charge of when I have a fit or

196 that cause it's in charge of me sort of.

197 R- So you're worried about now they'll react to you having seizures?

198 P- Yeah cause one or two have seen them and always been really worried because they just

199 don't know if I'm going to next time drop down dead or something.

200 R- Uh huh. So what do you do to (pause) resolve that worry for them?

201 P- My mum's usually at home and she'll just say "don't worry" you know, "she's just having a

202 fit. Just leave her in the corner and she'll be alright"

203 R- OK. So your mum kind of steps in and makes sure that you're alright?

204 P- Yeah.

205 R- OK. So do you see your friends often or not as much anymore?

206 P- Not as much since my sort of school days cause I. Since coming out of school and mum
 207 going to the uni side of things it's never really been as much of a thing really.

208 R- Hmm. And what about friends. I mean you've mentioned the art class and your support
 209 group. The young people's group near to your house and you've got Headway here as well.
 210 What about the friendships here?

211 P- I've got like mates who I talk to here and that and it's.

212 R- Do you see them outside the centre or...?

213 P- No, just mainly on Fridays really

214 R- OK, OK. What about anyone else I guess there's some support workers here, there's
 215 support group? When did you start going to the art class support group?

216 P- Erm, not exactly sure about that

217 R- Maybe put that

218 P- I'm not really good with dates

219 R- Yeah, yeah. What about anyone else have you been involved with any? I guess there's
 220 things like mental health or psychology or OT or SWK

221 P- I think I did a little bit of the psych em what is it the em.

222 R- Psychologist?

223 P- O em

224 R- Physio?

225 P- Nah what is it? Em? I think maybe my aunties and uncles are always in on it as well
 226 cause my mum is from quite a big Irish family and so there's quite a lot of them.

227 R- OK So you see them quite a lot?

228 P- Yeah cause I've got loads of cousins so it's

229 R- Yeah. So is that ongoing would you put them on the train or would you put them just on
 230 the board somewhere?

231 P- On the board probably

232 R- OK

233 P- Because we're always going to sort of see them and what they're up to sort of.

234 R- OK cool. Is there anyone else you would add? Do you want me put cousins there?

235 P- Yeah cousins really cause I've got quite a few. So...

236 R- OK. So anyone else you would add or is that it?

237 P- We're always seeing doctors.

238 R- Yeah are they an ongoing part of?

239 P- Yeah I think only sort of annual check-up or some more regular check-ups if we are trying
240 to do something to the epilepsy.

241 R- Yeah so is that like an epilepsy nurse that you'll see and then the doctor? Do they play
242 around with your medications?

243 P- Yeah they try and resolve it so that I em have less fits and they're trying to fix it but em it's
244 not worked as in reducing, which is tough on me. But it doesn't really stop your epilepsy
245 you're still suffering from it so it's quite a serious illness you got quite a bit.

246 R- Uh huh so they're not been able to find drugs that works at the moment?

247 P- Exactly, I've got ones that sort of make it more, so if I'm under certain medications I'll
248 hopefully not have fits and that but

249 R- Uh hm and what impact does the epilepsy have on your life?

250 P- It's quite a big one cause it's, I've never been able to go for a driving licence or things like
251 that I've always. I've got a freedom pass.

252 R- Hmm

253 P- From having it but it's just eh (pause) on me getting better scale I've never really been
254 there or greatest form sort of thing. It's...

255 R- OK, so you're never really felt like you're in like you were saying improved enough

256 P- Nah not really cause as soon as you just sort of feel better then you just catch a cold and
257 then probably have another fit and then you're in trouble again.

258 R- OK so it's affected by lots of different things?

259 P- Yeah

260 R- And did you have epilepsy before the brain injury?

261 P- No, I was fine before

262 R- And what impacts more the brain injury or the epilepsy?

263 P- That's been the one that impacts most since the brain injury. It's sort of like a life time
264 brain injury, the epilepsy is in general and

265 R- Ok, so the epilepsy continues to impact on the brain injury that (pause) is that what you
266 were saying?

267 P- Nah, it's just that since I've been here it's like been a catch thing since I've had it. Since I
268 got ill.

269 R- So you can't kind of tease out either they're both impacting on your life just as much as
270 each other.

271 P- Pretty much because them both do impact and stuff. One leads into the other.

272 R- Ok, I'm going to clear some of these away and we're going to look now at the stations. So
273 the stations, the idea of the stations is that they are the transition points in your story. So
274 maybe the key moments where you realised things were different, things were good, things
275 were bad. Em (pause). They might be particular places or they might just be moments of
276 change, things that you realised. So these are the ones that the focus group came up with
277 but as I mentioned feel free to let me know if there's any others that. Like your grandad's so
278 if there's any others you feel have been important then let me know and I can write them up
279 as well. Some of these won't apply to you but some of these will so just pick any and you
280 can put them around your journey as well. Around the train tracks.

281 P- OK. I wanted to put wanting to sort of getting a job at some point.

282 R- So is that kind of a goal for the future then or...

283 P- Yeah cause I wouldn't mind being able to pay my own way sort of thing. And em...

284 R- Ok, if we put that there then that can be kind of the future plans. Something you're looking
285 at. What else, what else strikes you? I guess you've spoken about becoming more me
286 (pointing to the card). When do you feel you became more you again?

287 P- Erm, when I first got out of the hospital and that and em and then the youth groups and
288 things for young people with brain injuries in my area and that it was eh, helping me to sort
289 of like open up new things in the future that the way it could make the difference for yourself
290 now.

291 R- OK. So that, I guess that sounds quite like adjustment. You were adjusting and I'll put
292 them around the support group. It sounds like you're kind of saying you were adjusting to
293 how the brain injury is and how life is for you now. I've put "goals" beside "employment", as it
294 sounds like that is your goal.

295 P- Yeah

296 R- What else? What else is relevant to you? Do you think?

297 P- Eh, eventually when I'm a bit older I wouldn't mind eventually moving on. Moving out of
298 home.

299 R- Ok. So moving out and having your own place, yeah?

300 P- Yeah but that was more, more in to the future because I've, well I've still got the epilepsy
301 and that and still quite

302 R- Well would it be worth bracketing that off then if I just put that in a cloud here. You can put
303 goals in there.

304 P- Well I'm not sure but it is a goal at the moment cause I've joined slimming world cause I
305 wanted to lose a bit of weight.

306 R- Are you becoming a bit more healthy?

307 P- Attempting to. I wasn't bad healthy before but it's just em, I've got a sweet tooth as a
 308 demon and it's sort of cakes just appear and I suddenly find the wrong one.

309 R- Yeah how are you finding it?

310 P- It's not bad cause, eh, it's quite nice just switching to like a low calorie recipe and things
 311 or trying to be more. Em, it helps my mum as well cause she's diabetic and it

312 R- Ok so your, is she doing it as well?

313 P- Not, she's not joined especially but once she's making the recipe and things she's sort of
 314 has a bit of it.

315 R- So she's eating different foods. Yeah, yeah. OK. So was that a conscious decision to do
 316 something like that to also help your mum or was it mainly for you initially.

317 P- Nah it was mainly for me. Because I wanted to actually join a real group as a thing that I
 318 could sort of like work on and eventually keep up. Sort of thing.

319 R- OK, so you wanted to join a group that wasn't associated with ABI that was something
 320 that could give you goals to work on.

321 P- Yeah cause if it's just about what you weight you'd be more, sort of, like that side of it.

322 R- So is it the social side of it as well then, the being part of something?

323 P- It's part of that because some of the people going are really nice and supportive

324 R- Ok

325 P- It's nice kind of swapping recipes and that and my mum goes to the group to take me
 326 there and she'll sort of bring recipe ideas from a couple of people and that.

327 R- OK

328 P- She don't mind.

329 R- So it's much more sociable then, the swapping of the recipes and trying out new things
 330 and talking about how it's going... Yeah great

331 P- Yeah

332 R- Ok so em, do you want to put that on the board then? What shall we put it under? Do you
 333 want to just put it under slimming world? Does that sound about right?

334 P- Em, I suppose.

335 R- Yeah. Cause it seems like that's a different type of group. Or do you want me just to write
 336 social group. Is that better?

337 P- It is a type of social group.

338 R- Yeah. And do you think that being part of this sort of group changes you in any way?

339 P- Em

340 R- What meaning does it have?

341 P- Nothing much really it's just really seeing if you've lost some that week and you can still
342 try.

343 R- That idea of challenge. It challenges you?

344 P- Yeah and cause it's something to do.

345 R- Is there anything else you think applies to the slimming world?

346 P- I guess so partly trying to change the old self and into a healthier (points to card saying
347 new self).

348 R- New self? Do you want me to put healthier in as well then? It seems like that is important
349 too. Being healthier.

350 P- To a certain extent

351 R- Yeah

352 P- Which is never on Fridays really cause I'm only allowed to smoke on Friday.

353 R- You're only allowed to smoke on Friday? So you've given up smoking as well then?

354 P- No, I've never really used to smoke much before really but it's just a...

355 R- What triggered the smoking? Why did you take it up?

356 P- Oh that was years ago. My old mate was always on the fags. And I thought well

357 R- So it was something that helped you fit in with your friends.

358 P- It was never really needed to fit in with them. It was just something to do really because. It
359 was just quite nice and relaxing because you can just come out of a really horrible lesson
360 with a grumpy old teacher and you could just chill with a fag.

361 R- Yeah, yeah. And how have you found giving up? Has it been difficult or has it been ok?

362 P- Well I haven't really because I'm back on them on Friday.

363 R- Yeah. But only on Friday is still quite an achievement.

364 P- Em yeah. I'm trying to keep it as only a Friday that I'm allowed. And my brother goes mad
365 at me, "you were never allowed to and wasting your life" (inaudible grumbling).

366 R- Does your brother smoke?

367 P- No he's asthmatic so I used to always worry.

368 R- Ah ok.

369 P- Cause we made my dad give up years ago cause he used to be a really bad smoker and
 370 he used to. But he's under cancer treatment at the moment and he'll say it's quite a big thing
 371 sort of.

372 R- Yeah so you made him give up smoking for the cancer treatment or before the cancer
 373 treatment.

374 P- Oh, no, no that was years and years before.

375 R- But it feels

376 P- And he gave up eventually by himself

377 R- Yeah

378 P- Because he kind of thought that he probably couldn't afford to do it nowadays.

379 R- Ok, so he was motivated but now I'm sorry to hear he has cancer.

380 P- Yeah the amount of people who have nowadays

381 R- And how are you dealing with that? How are you feeling about it?

382 P- It's always worrying cause you always want your dad to be about but I mean you just sort
 383 of like hoping that it's eh, it's a couple of years as a non-smoker he'll be better for it. And that
 384 hopefully his health will improve.

385 R- Uh huh

386 P- But you never know what the next medical thing is going to be because it's always such a
 387 history.

388 R- Yeah, is medical or has medical things become more important in your family?

389 P- Well they've always been pretty medical cause my uncle trained as a pharmacist years
 390 ago and my aunties a blood genius.

391 R- OK. I guess what I was thinking is that you've been talking about your grandad having
 392 Parkinson's, you were talking about your dad now has cancer and then you've talked about

393 P- My Dad's got the onset of Parkinson's too, which he's really worried about. He loves his
 394 music and he's very worried to lose that side of him with it. And I really hope he doesn't get
 395 really bad Parkinson's because he really, really enjoys his music and that.

396 R- How did hearing about all those things change the family dynamics? Did it change at all?

397 P- Not too much. Just eh always trying to sort of keep with the "what lot we've been given".
 398 So we have to just power through

399 R- OK

400 P- Don't, it's never the most cheerful but it's just sort of life and we'll just keep trying.

401 R- Is that what your family do? They kind of survive through things?

402 P- Yeah cause it's always just. Well we've been given a raw deal but we'll all just have to
403 keep going and that's all we can do

404 R- And has it changed anything between you and your mum with your dad now being ill too?

405 P- She's a little bit more worried about what to do sometimes with him and em. And she's a
406 bit worried about certain things like well, "what should I do?" Like you get worried about will
407 he be too ill to do this or that and I'm just like "mum you need to just give him a break, you
408 know, relax".

409 R- OK so the tables have turned a bit because you're now reassessing her about how to
410 manage your dad being ill

411 P- Yeah cause she's always the one sort of taking care of us. And now it's sort of like she's
412 had to be taken care of them. Hmm, ok. Are there any other one's you would include as
413 transition points that have been significant? Em, just trying to think of coming out of hospital
414 since the brain injury.

415 R- So coming out of hospital was that sort of a key point, going home after hospital

416 P- Mainly and then eh (pause)

417 R- How did you feel about going home?

418 P- I was quite happy. Cause I was well mainly not enjoying it and was happier out of it

419 R- You weren't enjoying hospital?

420 P- Not massively

421 R- What part of it? What about the hospital?

422 P- I didn't mind it, really, but most of it was comatose so I didn't exactly know

423 R- OK, so when you know you were going home what did that mean?

424 P- I just would be going home with my family so

425 R- OK, so getting home to them was your focus

426 P- Yeah and it was like, I'm back where was best for me sort of

427 R- OK, I'll move some of these out of the way. Em, I'm going to put, can I put headway there
428 as well because you're talked about groups and that was one where it's named specifically
429 Em. Do you know which hospital you were in?

430 P- Em I think it was Kingsbarn its East Enfield

431 R- OK

432 P- For most of it

433 R- OK. So the next part we're going to talk about is the barriers. So the barriers represent
434 the challenges since your brain injury. These are some of the ones that the focus group
435 came up with so they might be specifically about the brain injury but some of them I think are
436 about how other people approach people with brain injuries and some of them are about the
437 government and that side. But have a look through and tell me any that you think have been
438 important to your story.

439 P- Well dependence is quite important on my end because my mum had to give up her job.

440 R- OK, so is that something that's been key all along and should go in the train or would you
441 put that somewhere specifically along your journey

442 P- Well I would have thought along the journey because since I've come out of hospital she's
443 had to give up her job to become a full time carer

444 R- OK. Do you want me to write carer then as well? Having to have a carer? What do you
445 think?

446 P- Em I think that might because I think covers what she has too, that's her career now that's
447 what she does

448 R- So I'll write carer and mum. And then you talked as well earlier on, some of this might be
449 a bit out of order because you mentioned some stuff earlier on about freedom. You kind of
450 said that freedom has been more than a barrier as well. That you've not had as much
451 freedom because of your epilepsy and because you need to have your mum with you.

452 P- Yeah, because em of I'm usually stuck in or I don't go out unless it's me and my mum

453 R- OK

454 P- I'll only ever go into youth group things for my local young brain injury group and em yeah

455 R- Can I write not able to because an adult because you mentioned that at one point. Yeah
456 because that's quite a big part of what my development has sort of had to become.

457 P- Yeah, OK.

458 R- What? You also mentioned illness, do you want me to write illness down? Because I think
459 you used the word illness when you were referring to both your epilepsy and your brain
460 injury.

461 P- Yeah because if I ever get a cold then my mum's always really worried with what next sort
462 of thing am I going to have so?

463 R- OK So there's the worry about em, even small things like having a cold whether that will
464 be something bigger?

465 P- Yeah

466 R- OK I'll write that down as well if that's OK, So em, small health issues becoming bigger

467 P- Yeah. It just gets on my nerves in the summer because I get the worst hay fever and I'm
468 streaming and my brothers panicking next to me. And I'm like for goodness sake hurry up
469 and get to the end of this snotty one (laughs)

470 R- It sounds like there has been a bit of a change in relationship between you and your
471 brother as well.

472 P- Yeah because he sort of, well now he feels a lot more as the older brother because

473 R- Is he younger than you?

474 P- No he's my older brother

475 R- OK. So is he having to take more responsibility then?

476 P- Yeah, like he had to take me to Headway today cause dad had ...

477 R- So he's picking you up today, later on this afternoon?

478 P- Yeah

479 R- OK. So em what will I wrote. Brother taking more responsibility? But also more nervous?

480 P- Yeah, because he hasn't done it before and don't exactly know what to expect.

481 R- But you said that it will be even small things like your hay fever and sneezing that he
482 worries about you having a fit

483 P- Yeah

484 R- OK. Is there any other ones? I mean you've talked about a bit about the government
485 about funding and things like that as well. Has that been a specific issue for you?

486 P- Oh, the government usually is at home because with my brother he's got a politics degree
487 and he's. It's always with family a massive argument. I mean "Oh, God's Sakes" I couldn't
488 give a toss about half of it but

489 R- What about funding because you'd mentioned funding as well about projects you're
490 involved in like the youth project and stuff.

491 P- Yeah like my local arts centre and that. And places, local places for young people with
492 brain injury or people in general with brain injury. It's been a worry for eh which way should
493 we vote that would change or how it would change the future for them.

494 R- Uh hm. Em I'm trying to think. Is this to do with losses or would you say not being able to
495 become an adult not having as much freedom being stuck inside and small health issues
496 becoming bigger. Do you think that?

497 P- Yeah I think that about covers it.

498 R- Ok and then also when you talked about freedom that was to do with independence
499 wasn't it.

500 P- Yeah cause when you get ill just as you're coming on to be an adult and then you actually
501 become an adult, you become an ill adult. It's more of a <pause>

502 R- Yeah and what about specifically to do with your brain injury with things like memory or

503 P- Yeah the memory is always a bummer because em I can't remember the slightest and it's
504 a worry more if family aren't out with me. And I usually have to have family with me cause it's

505 R- Ok so that's kind of tied in to that loss of freedom is that the fact you can't always
506 remember. I mean what is it like with your memory, can you describe it?

507 P- Em, it's like trying to remember something that's a massive, massive thing of text but for
508 someone who doesn't have their glasses kind of job. Cause it's a struggle trying to fish their
509 way through it.

510 R- Ok. So you're trying to find your way through all the text but also trying to remember it but
511 you just end up not being able to.

512 P- Yeah, that's the trouble of it.

513 R- Yeah? Ok. And that impacts. And because of that, it impacts on your freedom and
514 memory and because of that you're stuck in and because of that you're not as able to be the
515 adult? Is that right? (Summary of train)

516 P- Yeah

517 R- Is that how you would describe it? Like that (drawing). Ok. What about any of the other
518 ones – do any of these ones do think?

519 P- Oh I would of thought that covers it mainly

520 R- Yeah. Ok, I'll tidy these ones away. So the last bit is that I have some feelings and some
521 key words that were important to the people who were in the focus group talking about their
522 brain injury. And I would like to just see whether any of these apply to you also. It might be
523 that some do or maybe they don't so you can just let me know if there's any you want to get
524 rid of. <pause> And again some are in relation to how they see themselves, some are about
525 how other people see them. <Pause> Do any of these ring any bells for you?

526 P- I would say to a certain extent quite a few people have been through the disappointment
527 in the way they feel that they are themselves now.

528 R- Uh hmm. Is that how you feel? Disappointed?

529 P- Not really cause I just sort of think well I'm being judged or given the hand I've been given
530 so

531 R- Ok

532 P- So keep running with it sort of.

533 R- Ok so is that more positive then?

534 P- It's more just em, seeing sense and saying well you haven't really got a choice, you've got
535 to keep going with what you've got really

536 R- Can I add that line in - "seeing sense"? That's a good way of describing it

537 P- Cause I could understand being really upset and being really low or upset or depressed
538 about it but just seeing how that doesn't exactly help at all. You've got whatever you've got to

539 deal with already. Why wouldn't you just keep going with what you've been given and keep
540 running really, that's all that you can?

541 R- Ok. So you think some of the... Do you think you've changed since you've had your brain
542 injury?

543 P- Eh. I wouldn't really know. Really cause I've only ever been myself so...

544 R- Ok. So you said feeling sad or down or angry don't really apply?

545 P- Well they do to a certain extent cause you feel you're always bummed when you sort of
546 had another fit or you've just done something you're upset about it. But then you just sort of
547 think with all the joys of that I've got another day to go so.

548 R- Ok so you balance things again? Would that be right?

549 P- I try

550 R- Eh so trying to see the positive

551 P- Yeah

552 R- Or re-framing would that be a good word? You re-frame how things are, change them to
553 feel a bit better

554 P- Yeah, cause you can't keep being upset about it cause that doesn't solve any of it. So
555 <pause>

556 R- Ok. Would you add any other one's in? Would you say that you've accepted your brain
557 injury?

558 P- Em, I would have said but only because it's not exactly a choice that you take, it's the
559 choice you've been given sort of job

560 R- Ok. So it's not really about accepting it's about that being the hand that you've been dealt.
561 So it's normal being you? It's normal too?

562 P- Yeah and it's unfortunate but the normal me now, she's an epileptic but that's part of me

563 R- Ok so you treat it as the brain injury and the epilepsy are part of you

564 P- Yeah when I might not like it but it's the thing you've got to keep going with <pause>
565 cause I can really see where people get upset or depressed about it all and then you just
566 sort of think well yeah it's not nice that you have fits or you've had all this or that but really
567 you've just got to keep going with it because life's still going so

568 R- Yeah, so keep going and live

569 P- Yeah cause there's a life out there though

570 R- Hmm it's a very positive way of viewing it

571 P- Well yeah cause if you tried to keep putting yourself so you think like that when you're
572 feeling bummed and just want to be upset about it you think, well that won't solve it, why
573 don't you just keep going and live.

574 R- Ok would you add anything else? Or is that about it?

575 P- Em, that's about it really

576 R- Ok. Is there anything else you would like to say about, I guess about what it's like to be a
577 young adult with a brain injury?

578 P- It's most difficult mainly because it's something you'd never even have though you would
579 ever have and then since you've got it you've just had to live it. So it's difficult and it's not the
580 easiest but try and get the support that you can around you, and keep going as best you
581 can.

582 R- Ok. Em, I've got four questions that I'd like to ask you if that's okay.

583 P- Yep

584 R- And then that will be the interview finished. So the first question is; what has your brain
585 injury taught you about yourself?

586 P- Em

587 R- What has it taught you or what have you learned about yourself?

588 P- That I've got a really great family around me and support. And that I should give myself
589 more credit sometimes actually cause you are still going through it and you are still trying
590 and you're not as bad as you think you are sometimes

591 R- Uh huh, so it's taught you that you've got, that you're a lot more able than you give
592 yourself credit for

593 P- Yeah

594 R- Yeah? Anything else?

595 P- Nah, not really. Not that I can really remember.

596 R- Em how do you tell people about your brain injury?

597 P- Well I usually say, "unfortunately I'm someone with epilepsy".

598 R- Ok so you tell them about your epilepsy first

599 P- Not really, no. Only really if we're going to group or something. Or we're doing something

600 R- Ok

601 P- And most people I hand around with nowadays are either people I already know from
602 school and they all know that I've been ill and that. And that I'm not going to be exactly as I
603 was.

604 R- Uh huh. Ok. So with new people you'll only tell them if you have to?

605 P- Eh, I do to a certain extent. I don't mind sort of like admitting to the epilepsy cause it's a
606 thing I've got but.

607 R- Uh huh. Em. What do people need to understand about the impact of your brain injury?
608 What do other people need to understand?

609 P- How sort of massive it can be and impacting on people's lives. And that we're not in
610 charge of it, the people who suffer from it because unfortunately we do suffer from it but we
611 don't decide when it comes on us it decides itself. And then

612 R- You sound like you're saying it's got a life of its own almost

613 P- It does. Because then when you get the brain injury – you think “Oh god, I'm in charge of
614 my brain could it just play a game and stop pissing about”

615 R- Ok so you get frustrated when your brain is not doing what you want it to?

616 P- Yeah cause when it's not playing ball you've just sort of “come on can you just behave!”

617 R- Yeah, it sounds frustrating.

618 P- Yeah cause you sort of think come on man will you just do your job

619 R- Yeah

620 P- Be a brain, in a good way, behave! I didn't ask to be Stephen Hawking's or nothing just
621 come on

622 R- Ok <both laugh>. Given what you know now. What advice would you give to another
623 young person who has just suffered a brain injury?

624 P- Oh I would say, take an interest in their local areas and their support groups and things
625 running in the local areas that would be useful for them.

626 R- Ok. So take advantage of the services that are around.

627 P- Yeah cause it's open for young people just like yourselves so it would be best. It's
628 somewhere best that they can get advice from similar sufferers of what you may have.

629 R- Ok so that idea of having someone else who understands?

630 P- Yeah cause they're in it themselves and it's best because it might be the same
631 generations. They may be only a few years older or that and they would understand more of
632 your sort of age.

633 R- Ok so that idea even of getting advice from people who are older than you just to see
634 what they've been through and the different stages of life for the future.

635 P- Eh yeah. Not just that but for there will be younger people as well so that there will be
636 people your generation so you would enjoy it on that side.

637 R- Ok. Anything else that you think would be important for another young adult to know
638 about having a brain injury?

639 P- Apart from taking as best you can from all the services they offer. That's about it really.

640 R- Yeah? Is there anything else you want to add in general about your life and how it's been
641 for you?

642 P- Em, that's about that really

643 R- Covered everything? Okay thank you very much.

8.17. Initial Individual Interview Coded Transcript (sample)

Theme - Work in progress

1648	Because up until now. My memory is not great. My long term memory is OK. My short term	Change	1680	How would you summarise that experience?	
1649	memory is practically non-existent.	Adjusting	1681	Dreadful.	
1650	Ok yeah		1682	Is that the one that you were saying is shit?	
1651	But the thing is its like. Those things that happened in the earlier stages from when I woken	Reliving	1683	That's dreadful. That's the side that has been shit.	
1652	up from the comma are still <u>fresh in my mind</u> . I still remember the first day I woken up.	trauma	1684	OK	
1653	Hmm		1685	This side however, as much as in the early stages it was difficult and painful. It then	Stages of
1654	And that will never leave. That will always be there. And I never will forget how others were	Trauma	1686	progressed and when I got that transition of change, that's when I then accepted myself and	recovery
1655	towards me. All the things I've had to go through, how it's <u>affected</u> me along the way and		1687	became the person I am today. And that has been, the new me, is the better version of the	
1656	how I feel even up until now.		1688	old me.	
1657	How would you summarise your journey?		1689	OK	
1658	(Inhales loudly and laughs). Can I swear?		1690	So it's like, <u>I'm not completely dead</u> . But to me, I see the old me as being dead. Because the	Re-evalu
1659	Yeah		1691	old me was going round the <u>same cycle day in day out</u> . Not thinking as much as I am now	ating self
1660	Shit. (Laughs) In point blank terms it's been <u>shit</u> .		1692	and not, not even felt pain or anything real. I've experienced really stuff, real life and that's	
1661	It's been shit?		1693	<u>the best way I can put it real life: You know it doesn't get any more painful</u>	(S)
1662	Yeah		1694	So you experience has been real life.	
1663	Can we separate out how you would summarise your internal journey?		1695	Yeah that's right and if anything I kind of look at it as if, you know what I'm kind of grateful for	
1664	Yeah		1696	this experience because it's made me who I am today	
1665	And how we would summarise your circumstances and everything that happened as a result		1697	OK	
1666	of it?		1698	So...	
1667	Yeah we can we can.		1699	So that's a bit more positive	Process
1668	Cause you kind of separated them out ... (interrupted)		1700	Oh yeah definitely	Changing / Fluid Self
1669	I can separate the two.		1701	And this is a <u>work in progress</u>	
1670	On either side of the track.		1702	Yes	
1671	That's right.		1703	A difficult work in progress	
1672	Yeah yeah		1704	Pff, really difficult and you have to <u>fight for everything</u> .	Challenge
1673	Don't get treading on this side.		1705	Yeah yeah	
1674	So tell me about this side of your journey first?	Imposed	1706	IN a situation like that where you're going through enough as it is with yourself. Trying to get	
1675	This side all external entities. That's <u>beyond my control</u> .	Powerlessness	1707	yourself to adjust, and get yourself back and you're going through changes.	
1676	Yep ok.		1708	Hmm	
1677	I can't fix that. That's you know, for all the situations I've spoken about. That's all out of my		1709	You don't need cause you're trying to <u>adjust</u> to that. And that's <u>painful enough as it is</u> .	Change
1678	reach, out of my control. I'm not in charge of that. That's because of what <u>others have done</u>		1710	Hmm	Hardship
1679	and how everything else in this life.		1711	And then you go from that <u>pain</u> to all of this lot.	Transition

Key words - 'fresh in my mind', affected, not in charge, done to me, dreadful, early stages, progressed, 'same cycle day in day out'; work in progress

Theme - Surviving within a harsh world
 "try it and fail rather than not try and fail anyway"

1712 So all the external stuff is still impacting

1713 Yeah

1714 At different points on your internal journey of becoming you?

1715 That's right. And it's still up to the present.

1716 OK

1717 You know and obviously I'll move this along. Future, it's like that.

1718 Future is a blank space?

1719 Uncertain. Uncertainty.

1720 Ok. Can I move that into here then?

1721 Yeah yeah that's a good one.

1722 Because the future is uncertain.

1723 Yeah uncertain. Cause the thing is especially living in, living in London. Things are getting so much more difficult in London, it's unreal. Social housing is difficult to get into and like I say you've got the discrimination side of things.

1726 Hmm

1727 And not only that it's just the whole how the system has worked out but there's nothing you can do about that.

1729 Uh hmm

1730 But the thing is the house prices and rental prices are going up and the thing is the benefits you are getting are basically fuck all.

1732 Uh hmm

1733 Sorry about my language

1734 No no

1735 But I have to tell it like it is.

1736 Yeah

1737 It's nothing. Because every two weeks, I get ESA. £250 for two weeks is nothing. Right, I used to earn every week without fail on the buses. Near enough £400 near enough £500 a week.

1740 Hmm

1741 You know if I done extra

1742 So it was a big big drop?

1743 Considerable drop.

1744 And you're managing?

1745 I have to and luckily I don't have any debt or anything. But if I had debts, if I had a mortgage or anything, I wouldn't be able to cope.

1747 Can I move on a bit from this and just ask

1748 Of course you can, of course you can.

1749 You the last few questions. Because I'm aware I'm trying to time keep so we've got about 20 minutes left.

1751 That's fine that's fine go for it.

1752 So I guess one of the big ones, they're all kind of connected to your journey anyway but one of the big things I wanted to know was, what has your brain injury taught you about yourself?

1754 To love me. I am precious

1755 To love you?

1756 To love me, yeah. And that, do you know what? Anything is possible.

1757 Yeah

1758 As long as you put your mind to it, you can do it, you can achieve.

1759 Yeah

1760 That's, that's what it's taught me. And I'm living proof of that. Like I said, when I left the hospital, I could barely walk, my arm did nothing, my hand did nothing.

1762 Yeah

1763 They were just there and I didn't have it much belief in myself at the time.

1764 Yeah

1765 But, I thought, I would rather try it and fail rather than not to try and fail anyway.

1766 Yeah

1767 At least if you failed, if you tried and you fail. At least you tried. And that's all you can do is try and push yourself more. And that's what I did and look at where I am today.

1769 Yeah

1770 It's not so bad you know. Like people will moan and complain about things. People complain about the most trivial of things that not even I will complain. The reason why is that I could have been in a much worse state than what I am now.

1773 Uh hmm

1774 I could have been in a vegetative state, I could have been dead.

1775 Hmm

53

"try it & fail rather than not try and fail anyway"
 Key words - present; future; uncertainty; unreal; anything is possible; put your mind to it you can achieve; living proof; belief in self; vegetative state; dead

No choice but to survive

Climate of change - political leading to uncertainty

powerlessness

Surviving within a harsh world

Try you can succeed

Hope Nothing to lose

Pride

Comparison to others suffering

1776 I mean out of the two I would rather be dead than a vegetable but luckily I, none of those two
 1777 things happened to me. I've got my bearings back. I've been, come back as the old me but
 1778 just with more of the old traits of me but a new me and I've adjusted and worked trusted in
 1779 my life.

Adjusted
 Same but different

1780 It sounds like you appreciate life a lot more now.

1781 I do I do I do I do appreciate life

Meaning

1782 Hmm

1783 And the thing is its like, I'm thankful because my I could have been still alive and not been
 1784 able to do the things I've done. There's people who go through a lot worse than what I've
 1785 been through

Part 53

1786 Hmm

1787 And they're living with that for the rest of their lives.

1788 Uh hmm

1789 I've actually managed to pick myself back and that that chance. I've had that opportunity. So
 1790 I want to use it the best I can and get myself back out there and live, you know. And be able
 1791 to have it as a distant memory and a story and just be able to say I went through this and
 1792 blah blah blah.

Recovery
 Reframing

1793 Hmm

1794 And it means nothing. You know, it's just like, to me it's like water off a duck's back. And
 1795 people will be like, "you went through all of that?" (Laughs) You know and they'll be shocked
 1796 you know.

1797 Hmm. My second question kind of buys into other people. How do you tell other people
 1798 about your brain injury?

1799 How do I tell em, hmmm, that's an interesting one? Em, well I just, I just tell em. Like, you
 1800 know, I don't get into a conversation about it but if I'm talking, or someone's talking to me
 1801 about something

1802 Uh hmm.

1803 And I say go off track and they complain or about this or that. I say "it could be worse" and
 1804 then I would say you know

1805 OK

1806 And then I'll tell them "yeah this is what happened to me". And I'll show them the scars

1807 Yeah

1808 And then say this happened to me. I went through this and that. I might not tell them as in
 1809 depth as I have here

1810 Yeah in here

1811 But I'll give them a basic idea. Like, and what I tend to do actually, funny enough you should
 1812 say that. I just remembered all these messages. (Laughs) Oh forget it. I tend to carry this
 1813 with me as well em, where is it (looking through phone) no no no no. Oh pressed the
 1814 wrong things sorry

1815 That's ok

1816 Bear with me. Ah there we go. It's loading. I carry that with me. That's the article on me
 1817 They got my age wrong

1818 OK

1819 I was 28 at the time, not 29

1820 Ok ok

1821 But it gives you the general gist of what happened. You know, I just show people that and
 1822 there you go.

1823 OK so you, it's important for you to have that kind of snippet

1824 That's correct

1825 Of you?

1826 That's right

1827 And be able to show people this is what you've been through

1828 People. And it saves me talking about it all the time. (Laughs)

1829 OK

1830 As well you know because then I can say this is basically what happened without going too
 1831 in-depth

1832 OK

1833 With what happened with me

1834 OK

1835 You know like for something like Headway and everything I don't mind telling my story
 1836 because I'm sure there's been many people who've been through it. I would similar, not
 1837 exactly the same but similar to what I've been through

1838 OK

1839 And for them to hear I've been through it as well and then they can relate and then they can
 1840 see how I got through it

1841 Yeah

1842 It might help them 'sharing is caring'

1843 Yeah yeah

connecting
 - sharing with others
 importance
 - defining

Difficult to discuss
 - distance without
 depth

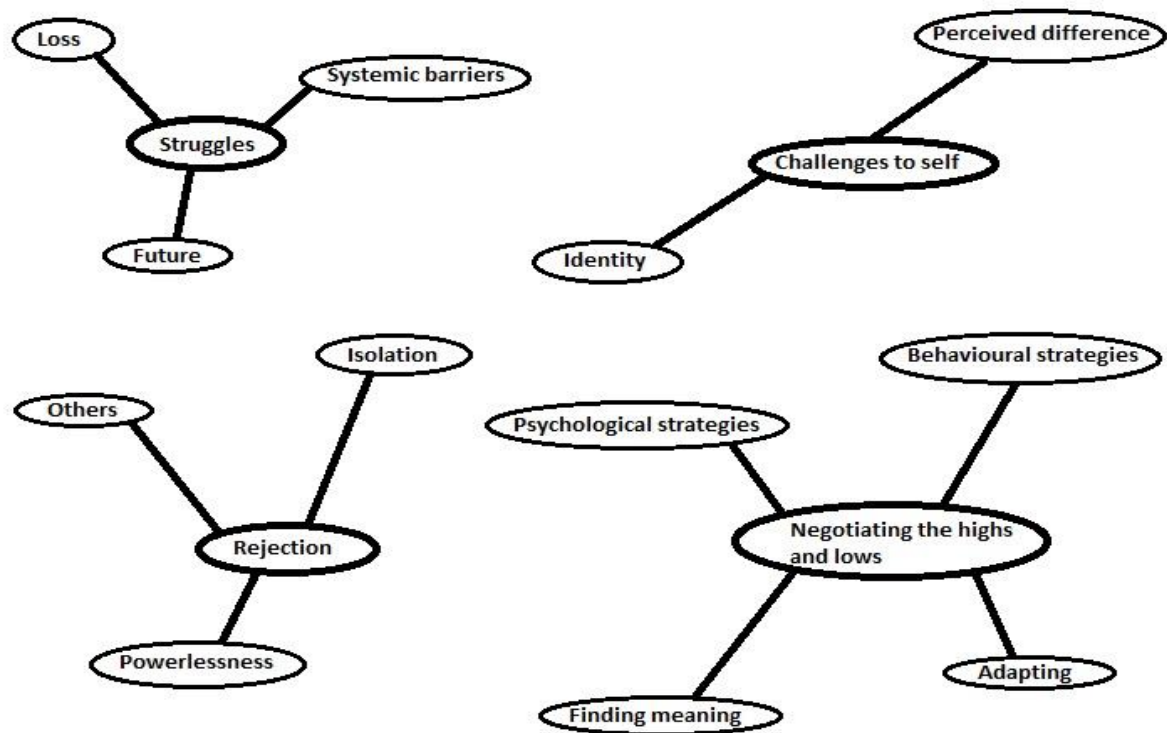
Role
 modeling

Solidarity
 Role
 model

connecting
 - solid
 - role
 - sharing

Key words - bearings back⁵⁵; opportunity; thankful; water off a duck's back⁵⁶

8.18. Sample of Coded Themes of Two Individual Participants



Participant 1: Map of themes and sub-themes



Participant 6: Map of themes and sub-themes

8.19. Cross Participant Map of Themes and Sub-themes

