DClinPsy Portfolio

VOLUME 1

The Constructions and Experiences of Males with an Acquired Brain Injury (ABI)

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A thesis submitted to the University of Hertfordshire in partial fulfilment of the requirements of the degree of Doctor of Clinical Psychology

June 2016

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Acknowledgements

I would like to thank the group of men that participated in this research: Derek, Bruce, Lance, Percy, Dean and Robert. It was a privilege to have heard their stories.

I would also like to thank my research supervisors Anna Green, Professor David Winter and Dr Scott Ferguson for their advice, guidance and support throughout. In addition, I would like to thank the organisations that supported me with the recruitment for this research.

I would also like to thank my family for the ongoing love, patience and support they have shown me. I would particularly like to thank my sister for believing in me every step of the way. I also want to thank Sapna and the ‘misfits’ for sustaining me throughout this process, your support has been invaluable. Finally, I would like to say a special thank you to Tushar, who has without fail ‘validated my core structure’ throughout the ups and downs of the training process.

Abstract

Acquired brain injury (ABI) is predominantly experienced by males and younger populations in the United Kingdom (UK). Although some research exists exploring the experiences of individuals living with an ABI, no research exists in the UK specifically exploring the lived experiences of males with an ABI. This study aimed to explore the lived experience of males with a mild to severe ABI, and understand the construing that underpinned the meaning they gave to their experiences. A mixed methods design was used, combining the use of repertory grids and Interpretative Phenomenological Analysis (IPA) of data collected via semi-structured interviews. Six working-age males with a moderate to severe ABI participated in the study. Five themes emerged from the data, including invisibility, painful relationship with society, post-injury growth, a vulnerable mind and importance of others in recovery. Repertory grids found commonalities within constructs, a predominantly tight process of construing as well as commonalities within the structure of construing. Repertory grids were also found to be a helpful method in supporting the research process. The clinical implications of this study were discussed, highlighting the need for further psycho-educational and psychological support. Recommendations for further research were suggested, including exploration of the experience of individuals with difficulties engaging with narrative form research, or from ethnic minority backgrounds in the UK.

1.0 Introduction

This chapter will begin with a personal introduction to the researcher. The aim of this is to provide insight into the researcher and what brought them to the topic of exploring the male experience of Acquired Brain Injury (ABI). It is necessary to reflect on how personal thoughts, feelings and beliefs may impact how researchers understand the experiences of others (Shaw, 2010). In light of this, an introduction to the researcher will be provided for transparency, so the reader is made aware of how these personal experiences may go on to impact the research. This section will be written in first person as recommended by researchers using qualitative methods (Elliott, Fischer & Rennie, 1999; Lichtman, 2013), and to make the subjective nature of interpretive research more explicit for the reader (Lichtman, 2013).

Following the introduction to the researcher, this chapter will go on to provide an overview of what ABI is and how it may impact on people’s lives, including definitions, prevalence and key policies. It will then present the main areas of research focusing on ABI, including the lived experience of ABI, and more specifically the lived experience of males with ABI. This chapter will then present a systematic review and a critique of the existing literature. Following this, the research rationale and aims for this study will be presented.

1.1 Personal Reflections on ABI

1.1.1 Introduction to the Researcher

I am a 31-year-old British-Indian woman who was born in the United Kingdom (UK). I am from a small Sikh Punjabi family, and have lived in East London for the vast majority of my life. I am a Trainee Clinical Psychologist and have worked within mental health and psychological services for five years, with the inclusion of my time spent engaging in clinical psychology training at the University of Hertfordshire. As part of my clinical experience I have worked within health psychology, as well as having undertaken separate postgraduate studies within the area of health psychology.

I have no personal or familial experience of cognitive difficulties or brain injury. I have not experienced any major difficulties or losses with my health, however I have experienced the relational, emotional, psychological and practical consequences of long-term health conditions within my family. I explicitly note this for the reader as a potential bias to the way in which this research may have been approached, as well as to reflect the process of self-reflexivity I engaged in during the early stages of considering this research topic.

1.1.2 Epistemological Position

I align myself with the epistemology of social constructionism at a personal level, however professionally I align myself to pragmatism. I have held the view that there can be multiple meaningful perspectives or realities (Andrews, 2012) throughout my life, however, I have only come to label this as social constructionism during my clinical psychology training. My social constructionist position does not mean that I am unable to engage with the positivist research paradigm, instead I view this as one of many ways in which we may understand and take a 'snapshot' of an individual’s reality.

I take a pluralist theoretical orientation, valuing the use of a range of models and theories. I am unable to list the theories and models I value most, as for me this is a situational process dependent on the value of a particular theory or model for the situation at hand. In light of this, as a practitioner I view myself as a pragmatist, using what appears to be the most helpful and workable in a given situation.

1.1.3 Interest in the Topic of ABI

My interest in this topic has come from a combination of personal curiosity of what it is like for others to live with a health condition (due to my personal experiences), as well as an interest in cognitive impairment. My interest in cognitive impairment started during my first placement in clinical psychology training within dementia services. The placement encouraged a curiosity as to the lived experience of loss in cognitive function.

This chapter will now go on to present an overview of ABI, its impact and prevalence, as well as key policies. There will be a return to writing in the third person format for the rest of this chapter.

1.2 Setting the Context

1.2.1 Defining Acquired Brain Injury (ABI)

An acquired brain injury (ABI) is an injury acquired to the brain that alters brain functioning, is non-degenerative and occurring after birth (Headway, 2015). Alteration in brain functioning includes a period of loss or decreased consciousness, loss of memory for events before or after the injury, neurological deficits (e.g. balance, vision, sensory loss etc.) or an alteration in mental state at the time of injury (Menon, Schwab, Wright & Maas, 2010). ABI can occur as a result of health events such as strokes, brain infections, cerebral tumours or hypoxic brain damage (Wilson, 2008). ABI can also occur as a result of an alteration in brain function caused by the brain undergoing an external force. External force can occur through an acceleration/deceleration movement, the head being struck by an object, the head striking an object, a foreign body penetrating the brain or forces from events such as blasts (Menon et al., 2010; Struchen, Davis, McCauley & Clark, 2009). This nature of injury is referred to as a traumatic brain injury (TBI). For the purposes of this study, ABI will refer to both traumatic brain injuries and those acquired through health events.

Various methods of classifying the severity of an ABI exist. The severity of an ABI can be classified as mild, moderate or severe based on the level of consciousness (measured using the Glasgow Coma Scale) (Teasdale & Jennet, 1974) or by using morphological criteria based on computed tomography investigations (Zhu, Wang & Liu, 2009). Post-traumatic amnesia can also be used to classify the severity of brain injury, with an interval from injury to the patient becoming orientated measured (Davis, Sander, Struchen, Sherer, Nakase-Richardson & Malec, 2009). Research has found imperfect correlations between classification measures and outcome (Parker, 2012), suggesting an unpredictability in determining outcomes from these measures.

1.2.2 Prevalence of ABI

Acquired brain injury has increased in prevalence and affects a predominantly younger population (Tennant, 2005). In the UK admissions to hospital with ABI (both head injuries and strokes) have increased by 10% since 2005, with 348,934 reported admissions of brain injury between 2013 and 2014 (Headway, 2015). Of these numbers, 194,734 admissions were male, who were found to be 1.6 times more likely than females to require hospital treatment for a brain injury. Although female admissions have been reported to be increasing (Headway, 2015), it appears that there is a greater propensity for ABI cases to be male.

1.2.3 Recovery following ABI

Recovery after an ABI can vary and is impacted by a number of factors. Examples of these factors include the nature of the injury (e.g. anatomical extent of damage, locus of damage), pre-morbid intelligence, pre-injury personality (e.g. resilience, motivation or persistence in learning) (Parker, 2012) age, general health, social environment and length of post-traumatic amnesia (Raymont, Greathouse, Reding, Lipsky, Salazar & Grafman, 2008). The timeline for recovery indicates that the most progress takes place within the first five months after the acquisition of an injury, and can then continue for up to two years or more (Barnes, 1999; Khan, Baguley & Cameron, 2003). The extent of recovery and length of time taken for progress will also vary across individuals, and good outcome may not mean recovery back to pre-injury baselines (Ratnasingam, Lovick, Weber, Buonocore & Williams, 2015).

1.2.4 Key Policies in the area of ABI in the UK

Research into the epidemiology of ABI by Tennant (2005) informed the development of the National Service Framework (NSF) for Long Term Conditions (DOH, 2005b). This was written as a tool for delivering the government's plan to support individuals with long-term health conditions, including brain injury. A review of this framework was due in 2010, but as a result of governmental changes placing the responsibility of health services with NHS England and Public Health England, this did not go ahead, and no updated government-led national plan exists (DOH, 2015).

In the place of a governmental strategy on the treatment of long term conditions (including ABI), there are now areas for action set out by NHS England, utilised in partnership with Clinical Commissioning Groups and local government to plan for and provide care. As part of this, one area identified was the 'house of care', a strategic framework for integrated care for people with long-term conditions (Coulter, Roberts & Dixon, 2013).

1.2.5 The Biopsychosocial Impact of ABI

Acquired brain injury sequelae are categorised in four core domains: physical, behavioural, emotional and cognitive (Lorenz, 2010). Physical difficulties can include somatosensory and motor difficulties (Wilson, 2008) such as headaches, sleep disturbances and reduced motor function (Hibbard, Uysal, Sliwinski & Gordon, 1998). Behavioural difficulties are also common, including impulsivity (Busch, McBride, Curtiss & Vanderploeg, 2005), socially inappropriate behaviour (e.g. swearing, sexual disinhibition) (Kelly, Brown, Todd & Kremer, 2008) or aggression (Rao, Rosenberg, Bertrand, Salehinia, Spiro, Vaishnavi & Cornwell, 2009).

Emotional and psychosocial issues can also be caused by neurological factors post injury (Gainotti, 1993) and may exacerbate cognitive difficulties, and vice versa (Wilson, 2008). Research has found that following an ABI, there is a high incidence of psychological difficulties, including depression and anxiety disorders (Hackett, Yapa, Parag & Anderson, 2005; Morton & Wehman, 1995; Tyerman & King, 2004), aggression (Baguley, Cooper & Felmingham, 2006), interpersonal difficulties and substance misuse (Corrigan, Rust & Lamb-Hart, 1995; Kreutzer, Wltol, Sander, Cifn, Martvitz & Delmonico, 1996; Struchen et al., 2009).

Cognitive deficits are commonly experienced following an ABI (Wilson, 2008). This can include memory (Dikmen, Machamer, Fann & Temkin, 2010; Nochi, 1998), attention (Ponsford, Willmott, Rothwell, Cameron, Kelly, Nelms & Ng, 2000) communication, visuoperceptual (Rabinowitz, Li, McCauley, Wilde, Barnes, Hanten & Levin, 2015) and executive functioning impairments (Millis, Rosenthal, Novack, Sherer, Nick, Kreutzer & Ricker, (2001). Deficits in attention and memory have been described as particularly difficult, as impairments in these domains can cause or exacerbate additional deficits in other domains (Arciniegas, Held & Wagner, 2002).

Alongside the above, sexual, financial, social, functional and employment difficulties are also common (Elliott & Biever, 2009; Kosciulek, 1994; Temkin, Corrigan, Dikmen & Machamer, 2009; Van Velzen, Van Bennekom, Edelaar, Sluiter & Frings-Dresen, 2009). In light of the impact of an ABI described, life following an ABI can present many challenges and difficulties. Researchers have applied psychological models to understand the experience of ABI, which will now be discussed.

1.3 Models Examining Adjustment to ABI

Three models have predominantly been applied in research focusing on adjustment to living with an ABI. The Kubler-Ross Model of Grief (1969), the Theory of Stress and Coping (Lazarus & Folkman, 1984) and the 'Y' Shaped Model (Gracey, Evans & Malley, 2009). The applications of these models will be briefly described below.

1.3.1 Kubler-Ross Model of Grief (1969)

The term 'chronic sorrow' has frequently been used to describe the experience of grief felt by individuals with a chronic illness, injury or disability such as an ABI (Burke, Hainsworth, Eakes & Lindgren, 1992). The Kubler-Ross Model of Grief (1969) was developed to better understand the emotional process of terminally-ill individuals but later was applied to individuals with chronic health difficulties (Kubler-Ross, 2011). The model outlines five stages of grief that individuals move through during emotional adjustment. These consist of denial, anger, bargaining, depression and acceptance. Kubler-Ross described the process of acceptance of chronic illness as a state where a stage of peace and acceptance is reached. This model suggests that the process of adjustment is a linear one.

One criticism made of the application of this model to understanding the adjustment process after injury has been on the basis of self-awareness. Ownsworth and Clare (2006) state that due to damage to specific neural systems, individuals with a brain injury may not have full awareness of changes to the self and their abilities during recovery. In light of this, the Kubler-Ross model is unable to broadly capture the movement of individuals to adjustment, as this movement may be hidden from the individuals themselves, with no place in the model to highlight this. Kingsbury (2000) also criticised the appropriateness of this model, arguing that understanding an individual's adjustment from their point of view was of greater importance than categorising their experiences. This argument highlights the heterogeneous nature of ABI, and their sequelae, suggesting the need for more person-centred conceptualisations of adjustment.

1.3.2 Theory of Stress and Coping (Lazarus and Folkman, 1984)

Lazarus and Folkman (1984) defined coping as an ‘individual’s constantly changing cognitive and behavioural efforts to manage specific external and internal demands that are appraised as taxing or exceeding their resources'. The theory sets out that a situation is perceived as stressful by the individual's appraisal of it, leading to emotional distress when the demands are appraised as exceeding personal resources. In light of this appraisal of stress, individuals are said to utilise problem or emotion-focused coping strategies. In the context of this model, an individual's emotional adjustment to brain injury is a response to their symptoms and losses attributable to their neuropsychological difficulties, mediated by individual coping skills, insight and social support (Godfrey, Knight & Partridge, 1996).

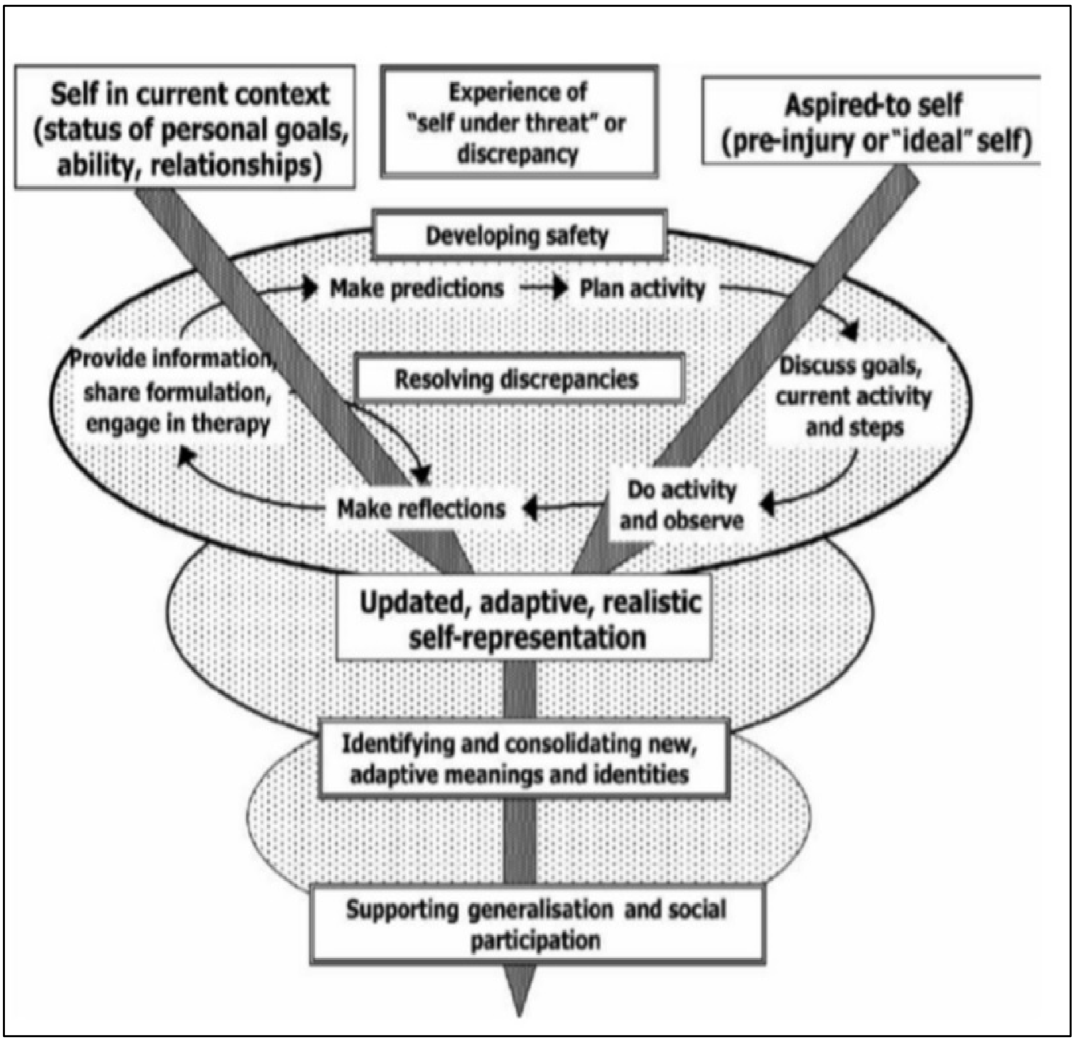
In reviews of the literature examining this model in the area of ABI, mixed outcomes were reported. Godfrey, Knight and Partridge (1996) and Kendall and Terry (2009) found strong support for the application of the model to aid understanding of emotional adjustment after an ABI. Additional support for the framework was highlighted by Kendall and Terry (2009), which found a small effect size for the relationship between personal resources and emotional well-being in the short and long term. These resources included self-esteem and financial security, which predicted emotional well-being via their effect on perceived threat, with higher levels of these resources related to lower levels of perceived threat. A more recent study evaluating this model, however, did not find support for its use as a framework to predict adjustment after an ABI (Rutterford & Wood, 2006). A recent review also found that many studies used a variety of coping measures, no definition of coping and the psychometric properties of the measures used were not detailed (Donnellan, Hevey, Hickey & O’Neill, 2006). It appears that the research base of this model is varied in regards to its understanding of the application of this model to understanding adjustment after an ABI.

1.3.3 'Y' Shaped Model (Gracey, Evans & Malley, 2009)

The ‘Y’ Shaped model was developed taking into consideration the complex mixture of biopsychosocial factors and their interaction to determine the consequences of ABI (Gracey, Evans & Malley, 2009). The model states that increased social and personal discrepancies can be encountered by individuals during adjustment after an injury. Social discrepancies were described as including reduced social contact and closeness of relationships (as well as their quality), poor family functioning and social stigma. Personal discrepancies refer to awareness of undesired comparisons of functioning before and after injury. The model proposes that a 'threat to self' is created by the discrepancies described above, placing individuals at risk of emotional distress. Figure 1 presents further information about this model.

Although not specifically testing the model described above, Ponsford, Kelly and Couchman (2014) found that self-concept may be lowered after an ABI, which was related to negative emotional consequences in their sample. In light of their results, they suggested that psychotherapeutic input focusing on self-concept might support emotional adjustment to ABI, as proposed by the 'Y' shaped model. Studies are required to test the applicability of this model to adjustment to living with an ABI.

Figure 1. Diagram of ‘Y’ Shaped Model taken from Gracey, Evans and Malley (2009)



1.4 Research on the Experiences of ABI

1.4.1 Extent of ABI Research

The research area for ABI is extensive. This may reflect the nature of acquired brain injury itself, with it commonly resulting in a variety of difficulties including but not limited to somatosensory, motor, cognitive, behavioural, emotional and interpersonal issues (Wilson, 2008). The degree of research exploring these areas is highlighted by the number of reviews that have been conducted. Reviews have focused on physical phenomena following brain injury such as pain (Dobscha, Clark, Morasco, Freeman, Campbell & Helfand, (2009)) and fatigue (Mollayeva, Kendzerska, Mollayeva, Shapiro, Colantonio, & Cassidy, 2014), as well as psychological and emotional phenomena such as depression (Lepage, Yuan, Leon, Marshall, Labelle & Ferland, 2016), anxiety and PTSD (Moran, Fletcher, Calvert, Feltham, Sackley & Marshall, 2013). Treatment approaches for behavioural or psychosocial difficulties have also been the focus of reviews (Cattelani, Zettin & Zoccolotti, 2010; Snell, Surgenor, Hay-Smith & Siegert, 2009). There are also systematic reviews focusing specifically on research looking into the family experiences of ABI. This includes studies exploring the support offered to them (Coco, Tossavainen, Jaaskelainen & Turunen, 2011; Rietdijk, Togher & Power, 2012) and interventions for carers (Victor, 2009). The reviews listed are not exhaustive but a brief demonstration of how extensive the research base is. In light of this, this chapter will not attempt to provide an overview of the sequelae of ABI, but instead focus specifically on research looking at the experience of living with an ABI reported in research thus far.

1.4.2 Research Exploring the Experience of ABI

Research has been conducted looking at the individual experience of ABI in two particular areas; (1) self and identity, and (2) post-traumatic growth. This section will look to summarise the research within these areas.

Impact on Self

There has been keen interest in the exploration of the self following an ABI. Beadle (2016) recently conducted a systematic review appraising the evidence for changes to the self, specifically looking at the literature on the impact of a traumatic brain injury (TBI) on the self. Fifteen studies were appraised, and evidence of negative changes to self-concept were found predominantly. One 'negative' change to self-concept that has been explored in the literature is the loss of self.

A 'loss of self' following an acquired brain injury has been reported within the qualitative literature on experiences of ABI (Nochi, 1998). Nochi (1998) interviewed four females and males who had experienced a brain injury, and analysed data using a grounded theory methodology. Three main themes reflecting the way that ABI mediates loss were identified. These included the loss of self knowledge due to memory, loss of self via comparison of pre and post injury self, and the loss of self in other’s eyes. Gelech and Desjardins (2011) also found reports of a lost or shattered self, with particular reference to this loss being of the public aspects of the self. An example of this loss included reduced social participation.

Studies using a quantitative methodology also appear to have found evidence for the loss of self following an ABI. Tyerman and Humphrey (1984) explored the nature of changes in self-concept after brain injury using the Head Injury Semantic Differential Scale (HISD). They found discrepancies between how people with a brain injury rated themselves, with their ratings found to be more negative in the present in comparison to the past and future. Ellis-Hill and Horn (2000) conducted a similar study with stroke survivors, and also found negative views of the current self, compared with the pre-stroke self. From these studies it can be hypothesised that a loss of self, relative to the pre-injury self, has been a common experience for individuals following an ABI.

Research has also suggested that following experiences of loss within the self, there is a process of reappraisal and revision. Trulsson, Johansson, Jansson, Wiberg and Hallberg (2003) highlighted the struggle of the participants interviewed to find a new self, who described a reappraisal of life expectations and dreams as becoming impossible to reach. Nochi (2000) also reported a process of revision of self-narratives through changing the way in which past, future or environments were construed. Muenchberger, Kendall and Neal (2008) attempted to capture the process of self-reconstruction that takes place following an ABI, describing this as a non-linear journey consisting of contraction and expansion of the self. Contraction of the self was defined as a process of adopting an 'illness script' or becoming defined by difficulties. Expansion of the self conversely consisted of factors such as focusing on short-term goals, taking positive meanings from their experience or weighting social norms of success as less important than inner success.

Research within this area has also reported the construction of a new self by individuals’ post-injury. Gelech and Desjardins (2011) described a process of the development of a new 'personhood' that combined elements from participants’ old and new selves. They found that via the loss and ‘de-legitimisation’ of the public self, referring to a sense of others refuting their personhood and experiences, participants found a new inner moral growth. Gelech and Desjardins (2011) also found that individuals were able to maintain a sense of a stable inner self through their ABI journey, despite threats to the self via ‘de-legitimisation’ by medical professionals and impersonal others.

Positive changes to the self have also been reported by a recent study. Lennon, Bramham, Carroll, McElligott, Carton, Waldron and Benson (2014) reported that individuals described the acquisition of positive attributes to their sense of self following brain injury. This included having greater insight into the inner workings of others, increased emotional strength, or personality changes such as calmness. However, individuals also described acquiring negative views of the self post injury, including becoming defined by their difficulties, or feeling like a burden to others.

The impact of ABI on social identity has been explored within the research literature also. Gelech and Desjardin's (2011) qualitative study found that individuals reported resistance of change to previous social identities. They described a sense of striving to retain their pre-injury self by re-establishing aspects of these identities, such as being a ‘contributing member of society’ by returning to work. Lorenz (2010) published a case study outlining one individual's experience of identity change after ABI, supporting the idea that people will seek to restore parts of their old identities. A narrative of identity was described for 'Judy', who was reported as having formed a 'chorus of voices' constructed of multiple identities through which she spoke. These identities consisted of both former and new identities, such as brain injury survivor or self-advocate for example. Carroll and Coetzer (2011) conducted a quantitative study exploring perceived identity change after a brain injury, and found a positive association with depression and grief, and a negative association with self-esteem and awareness. This study suggested that changes to identity are related to poorer psychological outcomes, but due to the small sample used for the nature of analysis conducted (n=29), these results should be interpreted with caution.

Post-injury Growth

As interest has grown within the area of positive psychology and psychological strength for well-being, researchers have in turn begun exploring a phenomenon referred to as 'post-traumatic growth' (PTG). PTG refers to the experience of positive change following experiences of trauma, loss or struggle, which may be experienced in a variety of ways, such as a richer spiritual life, relational gains, growth in personal strength and change within individual meaning or purpose (Tedeschi & Calhoun, 2004). PTG has been distinguished as separate to the return of long standing personal attributes an individual may have had. Instead it is described as a growth that goes beyond the individual’s level of pre-trauma psychological functioning, as opposed to a return to a former baseline (Collicutt McGrath, 2011; Silva, Ownsworth, Shields & Fleming, 2011).

Within the area of ABI various studies have found positive relationships between PTG and a variety of factors. These factors include high levels of anxiety, longer length of time living with an ABI (McGrath & Linley, 2006), greater functional consequences (Silva et al., 2011), greater perceived social support (Warren, 2008) and coping styles (positive cognitive restructuring, downward social comparisons and denial) (Gangstad, Norman & Barton, 2009). One long-term study has investigated long-term PTG in individuals with a TBI and identified positive psychological changes in 165 individuals (Hawley & Joseph, 2008). This study found psychological PTG in over half the sample, although a negative relationship was found between PTG and anxiety and depression.

Reviews of the research literature on PTG have been conducted to understand better what is known about this topic thus far. A meta-analysis of 87 studies covering a variety of traumatic events found that PTG was related to gender (females reported higher PTG), age, intrusive thoughts and coping variables (e.g. acceptance, denial, reappraisal) (Hegelson, Reynolds & Tomich, 2006). Better psychological outcomes were also found to be related to PTG, including lower levels of depression and greater positive well-being. It also found that PTG was unrelated to anxiety, quality of life, global distress and subjective reports of physical health. A meta-analysis reviewing studies on PTG within ABI specifically has also recently been conducted. Grace, Kinsella, Muldoon and Fortune (2015) reviewed eight studies covering 554 participants and found reports of PTG across all of these. This study also found relationships between PTG and employment, longer time spent in education, subjective beliefs about change post-injury, relationship status, older age, longer time since injury and lower levels of depression. In addition, this review found a very small effect size for the relationship between anxiety and PTG. It is important to note however that this review used a small number of studies, therefore the results may need to be considered cautiously.

It appears from the research base that PTG has been reported within the experience of ABI, and is related to a number of factors. It is unclear whether there is a relationship between anxiety or depression and PTG however, as there have been inconsistent findings (Grace et al., 2015).

1.5 Research on the Lived Experience of ABI

Studies on the impact of ABI on individuals have recommended listening carefully to service users, and trying to view the world from their standpoint in future research (Nochi, 1998). Howes, Benton and Edwards (2005) reiterated this point further, highlighting that the service user's relative or carer continued to remain the focal point in research. There now appears to be a change in focus, with some researchers beginning to explore the lived experience of ABI from the point of view of the individual affected. Much of this research has focused on specific areas such as living with the impact of ABI on daily functioning, including daily occupation (Erikson, Karlsson, Borell & Tham, 2007; Klinger, 2005; Parsons & Stanley, 2008; Turner, Ownsworth, Cornwell & Fleming 2009), adaptions for daily life (Larsson Lund, Lövgren-Engström & Lexell, 2011), participation in activity (Haggstrom & Lund, 2008) and return to work (Oppermann, 2004; Roscigno & Swanson, 2011). Studies have also explored the lived experience of inpatient rehabilitation (Fleming, Sampson, Cornwell, Turner & Griffin, 2012), as well as the transition to independent living (McColl, Davies, Carlson, Johnston, Harrick, Minnes & Shue, 1999).

There is a paucity of research examining the broader experience of individuals living with an ABI. It was planned that this section would provide an overview of research on this topic, followed by a literature review exploring gender-focused research. This however will not be possible in light of the lack of research exploring the experience of individuals living with an ABI, including the male experience. This section will therefore briefly provide an overview of the little literature available on the experience of ABI with particular reference to males, followed by a systematic review on the lived experiences of individuals with an ABI.

1.5.1 Gender and the Lived Experience of ABI

There are a very small number of studies exploring the experience and understanding of living with an ABI through a gender lens. Although brain injury is most prevalent in males (Headway, 2015), and most studies use samples including males unless otherwise specified, these studies have not conducted research with the intentional aim to explore the male experience. One study was recently conducted to understand the nature of self and experiences after an ABI in this sample (Freeman, Adams & Ashworth, 2015). Nine males were interviewed, with two themes emerging from the data. The first theme was identified as ‘the self in the social world’ and consisted of four sub themes: ‘abnormality’, ‘hidden’, ‘the old-me-new-me’ and ‘others treat me differently’. The second theme focused on the ‘experience of distress’, consisting of three sub-themes: ‘self-criticism’, ‘need to be as others want me to be’ and ‘withdrawal’. One other study was conducted in 2011 also exploring the experience of males with a brain injury, with a specific focus on the nexus between masculine identity and participation. Jones and Curtin (2011) found that males in their sample had a movement from traditional male gender roles to non-typical roles following an ABI. They found that the individuals in this study moved from typical masculine roles, such as the 'breadwinner', to non-typical roles such as the 'carer' or taking responsibility for activities in the home.

There is additional literature that has also commented on the experiences of males with ABI. Gutman (2000) discussed the experience of ‘gender strain’ described by four males after an ABI. ‘Gender strain’ was defined as the restricted availability of socially acceptable roles in culture and society allowing men to express masculine identity (Pleck, 1995). Gutman described how the four males experienced gender strain following their ABI, and highlighted that this experience was more common for the males who had previously utilised traditionally male gender roles and activities to express their male identity. This account of the experience of living with an ABI via a gender lens is helpful, however it must be considered cautiously due to its small sample, which included a mixture of adult and adolescent males.

Some research has also been conducted exploring the experience of living with an ABI using personal construct methods, which will now be discussed.

1.6 Personal Construct Methods for the Exploration of the Experience of ABI

Personal Construct Psychology (PCP) has been described as an approach that facilitates understanding the experience of individuals, but also which supports a respectful sense-making of the way one behaves and the choices they make, including the behaviour and choices of individuals with cognitive impairment (Morris, 2004). Morris (2004) cautions that an illness or health difficulty can pose the threat of becoming ‘a patient and nothing but a patient’, but using a PCP approach can help bring the person to the centre of one’s understanding. Personal construct psychology (PCP) was developed by George Kelly to create a perspective consisting of a humanist orientation alongside quantifiable methods (Kelly, 1955). A main feature of PCP is the premise that all individuals actively interpret their experiences, which leads to the formation of dichotomous constructs that are hierarchically organised (Morris, 2004). Constructs develop for situations, events and people, with new experiences being made sense of by using constructs formed based on past experiences.

Some research examining service user experience of ABI using Personal Construct methods has been conducted. Gracey, Palmer, Rous, Psaila, Shaw, O'Dell and Mohamed (2008) used personal construct methods and thematic analysis to explore and capture how service users construe themselves after brain injury. Their brain injury was discussed in small group exercises based on a personal construct approach, with constructs elicited through comparison of pre-injury, current and ideal selves. Nine themes were found, with the highest proportion of constructs falling into the theme “experience of self in the world”, followed by “basic skills”, which included cognitive, sensory, physical and social skills, and “experience of self in relation to self”. The authors concluded that following brain injury service users construe themselves in light of the “meanings and felt experiences of social and practical activity”.

The existing research suggests that there is a growing interest in understanding the experience of living with an ABI from the point of view of the individual. There does appear to be a gap in existing literature however, with a need to explore the experiences of the most prevalent group of individuals affected (males) highlighted. The next part of this chapter will focus on exploring the research currently available on the experience of living with an ABI.

1.7 Systematic Review of Literature on the Lived Experience of ABI

A search was carried out to investigate whether any systematic reviews had been conducted on existing literature focusing on the experience of individuals with an ABI, from the point of view of the individual. The Online Cochrane Database of Systematic Reviews, DARE database, EBM Reviews Database via Athens and the NICE website were used to conduct this search, and did not yield any results. As such, there is an absence of known systematic reviews to date on this topic. With this in mind, the following has been identified as the topic of interest to be explored via this systematic review:

'What does research literature know about the experience of adults living with an Acquired Brain Injury'.

This review aims to meet the following objectives:

1- To investigate the convergences of experiences reported by adults with an ABI.
2- To investigate the divergences of experiences reported by adults with an ABI.
3- To investigate the quality and methodological limitations of research exploring the experiences of adults with an ABI.
4- To suggest potential future research and direction needed in the area of ABI.

1.7.1 Method

Search Techniques and Terms

A review of available literature on ABI from the initial stages of the research study design was used to inform the search terms utilised during this review. Combinations of the following terms were used to search literature:

- Brain Injury terms- Brain Injury(+ies), Head Injury(+ies), ABI and TBI.
- Individual's perspective focused terms- Experience and meaning.

- UK: The initial search conducted used 'UK' as a search term, but few studies could be identified from the United Kingdom. In light of this, this search term was not continued, and a broader search was conducted looking at studies from the UK, Europe, USA and Australia.

Study Inclusion and Exclusion

Studies were selected based on the most appropriate nature of evidence suitable for the question being asked. As the question sought to explore the lived experience of individuals with an ABI, qualitative research was deemed to be the most appropriate evidence to explore the topic of this systematic review. In light of this, the following study types were included:

- Qualitative, or mixed method studies, looking at lived experiences
- Peer-reviewed studies
- Studies readable in English (due to linguistic and research fund constraints for translation)
- Studies exploring the experiences of working age adults: The experiences of working age adults may differ significantly to older adults, due to change in roles, responsibilities and transitions. In light of this, one specific age range was selected for in-depth exploration.

The following study types were excluded:

- Fictional accounts
- Periodicals or newspaper articles
- Dissertations: Although doctoral dissertations can add to research areas that are scarce, they are not peer-reviewed in the same nature as published journal articles and therefore considered unsuitable for research at doctoral level. In light of this, dissertations were excluded.
- Case studies: Although case studies can enrich systematic reviews of qualitative research, these were not included on the basis of the hierarchy of qualitative research outlined by Daly (2007). Daly (2007) states that single case studies are the least likely studies to produce good evidence for practice, and therefore they were excluded.
- Studies looking at experiences or views of living with ABI within specific areas (e.g. military, sports, rehabilitation unit, education, work or occupational): To ensure this

research was exploring the experiences of a client population that would be seen by clinical psychologists, as well as experiences not specific to a particular context, research conducted in specific contexts was excluded.

- Reviews or meta-analyses: As the aim of the systematic review was to gather research findings as opposed to reviews that have already summarised the research area, reviews and meta-analyses were excluded.
- Medical research (biomedical, medication studies): This nature of evidence was excluded due to the focus of the systematic review on lived experience as opposed to medical interventions for people with brain injuries.
- Intervention research: This nature of evidence was excluded due to the focus of the systematic review on lived experience as opposed to specific interventions for people with brain injuries.
- Epidemiology research: This nature of evidence was excluded due to the focus of the systematic review on lived experience as opposed to the frequency, cause and distribution of brain injury in populations.

Literature Search Strategy

Electronic searches of PubMed, PsycARTICLES, CINAHL and Scopus were carried out. These databases were selected based on a search of frequently used journal databases by systematic reviews within brain injury, as well as the availability of the resource. Studies ranging from the earliest available to the present date were searched.

Literature Search and Sifting Process

Once literature was found through the above-named databases, it was evaluated on the basis of the inclusion and exclusion criteria. The remaining studies were then examined for relevance to the topic, this was done by reading the title and abstract followed by the paper if necessary. Studies were retained if they focused on gathering a qualitative understanding of how individuals with an ABI view their brain injury and their life. Duplicates were then identified and removed. The literature search process can be seen in Table 1 and Table 2.

Table 1. Stage one of Search for Papers

Stage one- Using search terms: ((((((brain injury[Title/Abstract]) OR brain injuries[Title/Abstract]) OR head injury[Title/Abstract]) OR head injuries[Title/Abstract]) OR abi[Title/Abstract]) OR tbi[Title/Abstract]) AND experience[Title/Abstract]				
Dates searched: 1966 (or earlier alternative) to present date				
Databases	**PubMed (inc. Medline)**	**PsycARTICLES**	**CINAHL**	**Scopus**
No. of records	2444	8252	28262	9548
After application of inclusion/ exclusion criteria	114	119	185	214
After assessing paper for relevance to review topic	1	0	1	2
No. of duplicates	0	0	0	0
After removal of duplicates	1	0	1	2
Duplicates across databases	1			
Total after removal of duplicates	3			

Table 2. Stage Two of Search for Papers

<table>
<tr><td colspan="5">Stage two- Using search terms: ((((((brain injury[Title/Abstract]) OR brain injuries[Title/Abstract]) OR head injury[Title/Abstract]) OR head injuries[Title/Abstract]) OR abi[Title/Abstract]) OR tbi[Title/Abstract]) AND meaning [Title/Abstract]</td></tr>
<tr><td colspan="5">Dates searched: Earliest to 10/02/2016</td></tr>
<tr><td>Databases</td><td>PubMed (inc. Medline)</td><td>PsycARTICLES</td><td>CINAHL</td><td>Scopus</td></tr>
<tr><td>No. of records</td><td>132</td><td>617</td><td>28,901</td><td>574</td></tr>
<tr><td>After application of inclusion/ exclusion criteria</td><td>9</td><td>2</td><td>188</td><td>50</td></tr>
<tr><td>After assessing paper for relevance to review topic</td><td>2</td><td>0</td><td>4</td><td>5</td></tr>
<tr><td>No. of duplicates</td><td>0</td><td>0</td><td>0</td><td>0</td></tr>
<tr><td>After removal of duplicates</td><td>2</td><td>0</td><td>4</td><td>5</td></tr>
<tr><td>Duplicates across databases</td><td colspan="4">4</td></tr>
<tr><td>Total after removal of duplicates</td><td colspan="4">7</td></tr>
</table>

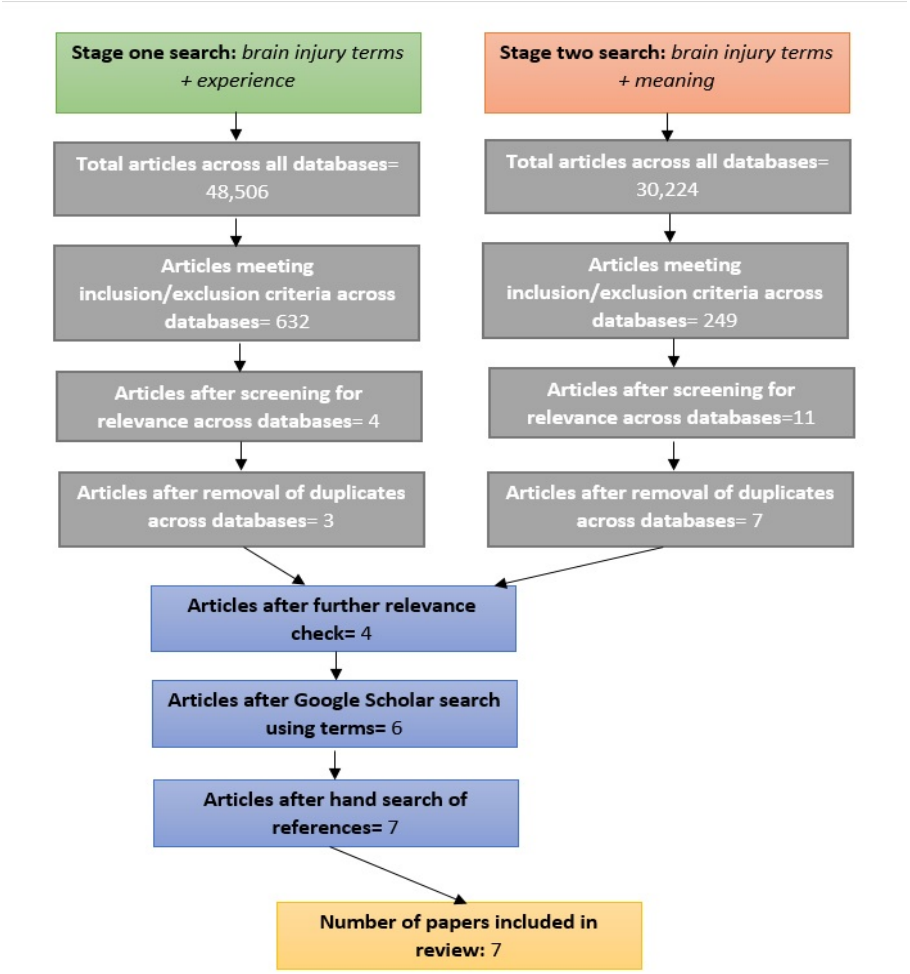
The papers collected through both levels of the searches were then combined and duplicates were removed leaving a total of seven papers. These papers were then read in more depth to check for their relevance further. At this stage, two papers were removed due to their focus on occupational therapy as opposed to lived experience more broadly, and one paper was removed due to its case study format. This left four papers. A Google Scholar search was also completed using the two levels of search terms. From this two further papers were identified using the experience search. There was an absence of papers found using the meaning search which left a total of six papers.

References Hand Search

The final process of the search was conducting a hand search of the references from the research articles identified during the searches. One paper was found via this process, bringing the total of papers to seven.

A total of seven papers were identified for the review (see Appendix 1). The overall search process is summarised in Figure 2.

Figure 2. Flowchart representing systematic review search process



1.8 Literature Review of Research on the Lived Experience of ABI

Although there is a great deal of research focusing on the lived experience of particular aspects of rehabilitation, from a systematic search of the literature it was clear that there is a dearth of research focusing on the broader experience of living with an ABI. There was also a lack of research focusing particularly on the male experience, with an absence of any studies from the UK. It is important to note that during the process of finding relevant literature, a number of theses were found exploring the male experience both in the UK and internationally. As these studies were not published in a peer-reviewed journal, it was not possible to include them due to these studies not meeting the inclusion criteria. It is noteworthy however that there is a clear interest in exploring this topic.

The literature found consisted of qualitative research conducted on mixed samples composed of both males and females, with the majority of the research conducted outside of the UK (five studies were from Sweden, Australia and USA). Seven studies were found, which will be discussed in depth now. The studies will also be critically appraised using Yardley's (2008) evaluative criteria in light of the qualitative nature of the studies.

Disruption to Life

Studies have explored the impact of the sudden nature of ABI. Crisp (1993) conducted a qualitative study exploring the experience of ten males and females living with a brain injury acquired through trauma, and the meaning it had for them. All individuals were reported as having described an abrupt transition in their life as a result of their injury.

Jumisko, Lexell and Söderberg (2005) also appeared to describe a form of disruption. This study examined the experiences of twelve people living with a traumatic brain injury, and found a theme emerging from the data reflecting a sense of participants feeling they had lost their way. A sub-theme within this appeared to describe how individuals described waking up to the unknown all of a sudden, reflecting a sense of sudden disruption to their understanding and way of living.

Nilsson, Jansson and Norberg (1997) similarly found a sense of disruption within their qualitative study exploring the experiences of individuals’ post-stroke, using Erikson's theory of crises as a lens. From their data they interpreted that the organisation of the whole self, consisting of the balance between the body, mental processes and cultural organisation of interdependence, had been impacted across all individuals. They reported that the balance between these three factors listed were provoked by the experience of brain injury, demonstrated by a number of descriptions alluding to developmental crises within the interviews. Dowswell, Lawler, Dowswell, Young, Forster & Hearn (2000) also studied the experiences of 30 males and females recovering from a stroke, and found reports of life having changed overall, with the majority of this change seen in an overwhelmingly negative way in comparison to life pre-injury.

Brewin and Lewis (2001) explored the impact of cognitive difficulties after a brain injury across different aspects of life, including personal, domestic, training and education, work, hobbies and communication within a sample of nine men and women. Deficits in functioning were seen across all areas, where functioning had been adequate pre-injury. These deficits were linked back to participants’ cognitive difficulties. It appears from this study that the ABI had disrupted all aspects of individuals’ lives.

From the studies described above it appears that individuals with an ABI experienced their sudden change in health as both disruptive to life direction and functioning.

Deterioration of Social life and Relationships

The studies reviewed also appeared to find reports of changes within the social domain, including the closeness of relationships. Nilsson, Jansson and Norberg (1997), described above, found examples of developmental crises within the area of 'intimacy vs. isolation'. They found examples of isolation, the opposite pole of social intimacy, within the data. Social intimacy appeared to have been mostly within friendships or neighbours, however isolation was identified within spousal relationships. Examples of isolation included not speaking about the situation of living with a stroke or difficulties in expressing feelings to spouses directly as a result of the ABI. Some divergences were also found, with some individuals within the sample describing feeling cared for or having caring feelings towards their partners.

The social life of individuals with an ABI was discussed more broadly in the following papers. Dowswell et al. (2000) found different experiences of social lives after a stroke, including some individuals having a deterioration within this domain, while others remained ‘ferociously independent’ or busy. Some areas of individuals’ social lives were altered due to the loss of the situation that would normally have brought them social opportunities or due to their circumstances (e.g. lack of access, energy, stamina). Reduction in social life also appeared to be as a result of worries and discomfort with individuals’ 'disabled' states, and concerns about burdening others with their post-stroke 'new selves'. Jumisko, Lexell and Soderberg (2005) also found that individuals worried about social interactions, and 'shaming’ themselves in front of others. They also reported losing social contacts due to loss of situations that gave social opportunities, such as work, as well as loss of friendships more broadly. Individuals also spoke about trying to establish safe social contact, such as through patient unions.

Brewin and Lewis (2001) similarly found a deterioration of social lives after the acquisition of a brain injury. This study found that cognitive difficulties such as attention led to withdrawal from socialising. It was hypothesised that this was due to difficulties with being able to attend to conversations or activities due to noise. Cognitive changes were also found to have led to some individuals withdrawing from social roles, such as looking after family members. Alongside this many individuals described forgetting who people were, or to call people back, making it difficult to maintain social contact with prior social networks.

From these studies it appears that social deterioration has emerged as a significant experience after brain injury, in the form of losing closeness in relationships, as well as loss of relationships or social contact and activity. It appears that both situational factors, such as opportunities to socialise, as well as personal factors including social worries contribute to this phenomenon. Studies report some differences to this however, with some individuals maintaining close relationships, keeping busy social lives or establishing safe contact through other means, such as patients groups and unions.

Difficulties within Recovery

Studies also reported on the emotional difficulties related to recovery. Dowswell et al. (2000) found that individuals reported criticising their progress to recovery, and feeling dissatisfied with how they were doing in comparison to the goals they were trying to reach. The realisation that recovery may only occur to a certain extent appeared to be difficult for all individuals, with some having difficulty accepting that a complete recovery may not be possible. This was demonstrated by suicidality and difficult emotions reported during interviews. Others found a way of adjusting to this realisation, but this also made way for non-optimistic perceptions, such as there being ‘nothing more that could be done’ for them. Jumisko, Lexell and Söderberg (2005) also found that some individuals reported painful feelings when others did not believe in their ability to recover, especially when participants had been unable to attain goals they had set for themselves.

Guilt as an emotional experience as part of recovery was also reported in some studies. Jumisko, Lexell and Söderberg (2005) found that individuals reported difficult emotions in regards to their recovery, for example, guilt for not being better. Nilsson, Jansson and Norburg (1997) also saw reports of guilt emerge from their data. They reported that participants felt guilty when they saw only small signs of improvement, leading to an imbalance within the developmental crisis 'initiative vs. guilt'.

Grief

One study found an overwhelming experience of grief within individuals. Chamberlain (2006) explored the experiences of 59 individuals that were living with a brain injury. They found that one-year post-injury these individuals experienced complex grief as a result of losses to friendships and occupation. The feeling of grief was also found to be a daily occurrence, with reminders of loss experienced every day, leading to what the authors described as a 'never-ending cyclic experience of grief'. This was described by much of the mild to moderate sample, but it was noted that it had been difficult to establish whether this had been an experience within the severely injured individuals, who had struggled with the narrative nature of the research. Recommendations for research with this group of individuals were provided, suggesting further exploration of their experiences via a non-narrative form.

Difficult Feelings about Health Services

Studies found a number of descriptions of emotionally difficult experiences of health services from individuals. Chamberlain (2006), described above, reported that one theme that emerged from their data reflected a sense of insensitivity from health professionals specifically. Individuals reported distress due to a lack of empathy from health professionals, which was particularly salient in regards to 'invisible' symptoms. 'Invisible' experiences were described as being met with distrust, with professionals deemed to assume individuals were 'malingering'. This study also found that individuals reported feeling abandoned by services due to a lack of transition, with a strong sense of anger about this reported. Some individuals reported experiencing sudden realisations during hospitalisation that once they left they would be 'on their own'.

Identity

Identity changes were reported in a number of studies. Nilsson, Jansson and Norberg (1997) reported descriptions by participants alluding to an imbalance between the developmental crisis of 'identity vs. identity confusion'. The authors noted that there had been few explicit statements about identity by participants, but they hypothesised that this may have been due to difficulties in expression due to cognitive deficits. This experience of identity disruption was instead interpreted from various examples of individuals describing looking backwards to their pre-injury selves to attempt to strengthen their current identity. Dowswell et al. (2000) reported that individuals reported difficult emotions about their identity more explicitly. Individuals reported a sense of frustration due to having a change of longstanding roles within their life, for example going from being the 'giver' to becoming the 'receiver' within close relationships.

Jumisko, Lexell and Soderberg (2005) also found descriptions of loss of self and identity within interviews. Individuals reported struggling to know who they were and wondering about whether they were the same people as before their injury, describing a sense of loss that could not be named. Individuals described listening to stories about themselves through others, and observing others of the same age to help them rebuild their identity.

Feeling Well

One study specifically focused on the experiences of living with brain injury and feeling well. Jumisko, Lexell and Soderberg (2008) explored the experience of eight men and women, focusing specifically on the meaning of feeling well with an ABI. It emerged from the data that feeling well was composed of a number of aspects, branching across psychosocial domains. Psychological factors included feeling reconciled with the circumstances of their life, forming a new entity from it, taking responsibility to succeed with goals, thinking positively and focusing on possibilities. Social factors included getting help and support from others, being involved in others’ lives and having connections that made them feel loved and popular.

Striving to Find Understanding

One study also seemed to describe experiences of trying to find understanding. Jumisko, Lexell and Söderberg (2005) found that individuals reported seeking information and explanations about their injury and who they were. They reported using medical journals to gain further information or listening to others’ stories about their lives.

Striving to Find Autonomy

Nilsson (1997) reported that individuals struggled with the developmental crisis of 'autonomy vs. shame' due to a loss of independence. 'Shame' and dissatisfaction was reported as a result of their perceived lack of ability, and individuals struggled to regain mastery over their lives. Jumisko, Lexell and Soderberg (2008) also described the importance of regaining control and mastery, and how that individuals felt it was necessary in everyday life to feel well.

Differing Experiences Across Individuals

One study took a typological approach to explore the experience of individuals as closely as possible, while also attempting to understand it within their personal and social situations more specifically. Crisp (1993) explored the experience of ten males and females living with a brain injury acquired traumatically, and ordered their experiences across four typologies summarised in Table 3.

Table 3. Table Summarising Typologies Identified by Crisp (1993)

Type	**Characteristics**
Type one	- Strong sense of loss, self-deprecation, powerlessness and social isolation. - Valued intelligence, appearance and achievement. When these domains were not congruent with personal standards, this created distress and personal threat. - Experienced a sense of devaluation by disability. - Few satisfying relationships outside of their family.
Type two	- Strong sense of powerlessness, struggle to overcome losses and experienced a sense of failure. -Self-worth based on socially defined success. -Experienced a sense of devaluation by disability. -Experienced a loss of friends but also established new relationships.
Type three	-More satisfied, striving to be independent and felt mastery over life with support from others (e.g. financially and social). -Found intrinsic satisfaction from productivity and relationships with others. -Found satisfying relationships that provided tangible support. -Hoped for decreased disability but were not left feeling devalued by it.
Type four	-Strong sense of self-worth. -Accepted disability as part of them. -Saw self as psychologically intact. -Gained intrinsic satisfaction from productivity and relationships with others. -Continued having satisfying relationships and regular social support. -Saw disability as part of self with no expectation of it to change.

1.8.1 Quality Appraisal of Studies

The above seven studies were assessed for quality using Yardley's (2008) evaluative criteria. A summary of Yardley's criteria and the application of this to the studies can be found in

Appendix 2 (a and b).

1.8.2 Summary of Papers

Overall the papers reviewed appeared to focus on understanding what living with an ABI is like from the point of view of the participant. This was done using a variety of analytical methods, such as the application of Erikson's theory of developmental crises, grounded theory or narrative methods. Although different methods were utilised, the papers seemed to outline similar experiences described by individuals across the following areas: disruption to life, deterioration of social life and relationships, difficulties within recovery, grief, difficult feelings about health services and identity. Some study findings did not fit these areas however, with some studies reporting experiences of feeling well, as well as striving for understanding or independence. Although further literature is needed to elaborate on the experience of individuals living with an ABI overall, it may be that well-being, understanding and independence are areas that may need further exploration in particular.

In light of the evaluative criteria set out by Yardley (2008), some methodological limitations were found across the papers reviewed. The papers broadly lacked adequate reference to context and researcher reflexivity, with glimpses seen of these two processes but not consistently throughout any of the studies. In regards to reflexivity, it must be noted that this may not always feel appropriate due to the international dissemination of research studies, and potentially personal information in turn (where relevant). These areas are however important aspects of qualitative studies, and required to bring depth and transparency to the interpretation of experience, and therefore the interpretations given would need to be considered cautiously.

Adequate sample sizes were used across all but two studies, where larger study samples were used (n=59, n=30). No details were given regarding the rationale for this, or if this amount was required for saturation, therefore it is difficult to assess the adequacy of these samples. This assessment of sample size was made following guidance from Baker, Edwards and Doidge (2012), which suggests sample sizes should be selected in light of factors such as the research paradigm, time availability and saturation.

The research was rigorous in other ways however, with consistent monitoring of interpretation using other methods such as discussions with peers, or credibility checks with participants. Transparency of methods and analysis were also consistent across studies. In addition to this, these studies all contributed to the research base due to the lack of studies in this area, with some recognising further areas in need of exploration and elaboration.

1.8.3 Gaps in Literature

The literature that was reviewed had broadly contained mixed-sex samples making it difficult to unpick and understand the male experience in depth. All studies utilised mixed-sex samples, except one where this information was not detailed, suggesting this is another area of need in regards to future research. Some studies also struggled to gain information on the experiences of living with ABI due to the level of cognitive deficits of participants. It appeared that participants struggled at times with narrative expression, suggesting that future research would need to be tailored to supporting individuals to be understood, as well as understand the experience of severe ABI better. Other studies not covered within this review due to restriction by the inclusion and exclusion criteria have highlighted a variety of methods to engage individuals (e.g. Photovoice, a combination of written and spoken narratives), which may be important to consider.

1.9 Rationale for this Research

In light of the above literature review, the main area highlighted where further research is needed is the following:

-focused exploration of the male experience of living with an ABI
-exploration of individual’s experiences using methods to support the research process.

In line with these gaps, this research will aim to explore the experience of males living with an ABI, as well as gain an insight into the way in which they have interpreted their lives at a cognitive level. To do this, it appears it may be necessary to employ multiple methods to support individuals to engage in the research process. Therefore, the aims and objectives of the research are:

1- To explore the lived experience of males with an ABI.
2- To explore the construct systems of males with an ABI in order to understand the meaning they have given their experience. The exploration of construct systems will include the content of constructs, how these are applied and which are the most important to understand the nature of participants’ construing.

Alongside this, the researcher will also endeavour to support individuals to engage in the research process via alternative methods of exploration.

2.0 Method

One aim of this study is to capture a snapshot of the construing and lived experience of individuals with an acquired brain injury (ABI) at one point in time. A mixed methods design was used to investigate and meet this aim. Repertory grids were used quantitatively to understand the nature of participants' construct systems, and qualitatively to elicit constructs for further use as a point of reference and basis for interviews. Semi-structured interviews were then used qualitatively to explore the lived experience of ABI and were analysed using Interpretative Phenomenological Analysis (IPA). This section will outline the study design used in more depth, including the rationale for methods used by this study, and the analysis process used.

2.1 Design

2.1.1 Mixed Methods Research

There has recently been a growing interest in mixed methods research. Mixed methods research consists of studies that are undertaken using a combination of methods (O'Cathain, Murphy & Nicholl, 2007), which may take differing epistemological, theoretical or philosophical perspectives (Crotty, 1998). A number of benefits have been described from using a combination of methods, including confirmation of data heightening confidence in findings and completeness, and adding richness to the understanding of concepts being explored (Cresswell & Plano Clark, 2007; Halcomb & Andrew, 2005; Turpin, Dallos, Owen & Thomas, 2009). Researchers using mixed methods also argue that using a combination of methods enables a degree of triangulation, enhancing the validity of the study (Symonds & Gorard, 2010). As a result of the above benefits, several researchers have encouraged qualitative study of participants involved in randomized controlled trials, to triangulate and validate data and arguments (Midgley, Ansaldo & Target, 2014).

There are however criticisms of combining different methods, especially when these may differ due to their assumed epistemological positions, referred to as the 'incompatibility thesis'. It has been argued that philosophical and epistemological differences between research methods can make them incompatible (Symonds & Gorard, 2010). As a result, mixed method theorists have instead developed separate philosophical foundations to differentiate this style of research. Theorists propose that the most appropriate epistemology for mixed methods is pragmatism (Jonson & Onwuegbuzie, 2004; Tashkakkori & Teddlie, 2003).

Pragmatism proposes that practical activity is the foundation and test of knowledge, with knowledge being judged according to its action based consequence, and sets one up to question whether knowledge serves our purpose (Rorty, 1999) as opposed to reflecting underlying reality (Cornish & Gillespie, 2009). Pragmatism has also been described as being pluralist in nature, and acknowledges the variety of knowledge and interests (Cornish & Gillespie, 2009). It is also non-relativist, with evaluation of knowledge taking place on the basis of whether it has led to successful action (Cornish & Gillespie, 2009). For the researcher what this means is that rather than selecting personally or academically privileged methods, methods are selected on the basis of achieving a particular goal (Baert, 2004). As a clinical psychology trainee, taking a pragmatic approach feels in line with learning experiences thus far, as both clinical psychology training and practice can be pluralist in nature, with trainees expected to learn and apply a breadth of models and formats in their work.

2.1.2 Combination of Methods Used

Repertory Grids

The repertory grid technique originates from Personal Construct Psychology (1955). It is a structured interview technique developed by Kelly (1955) used to examine the relationship between an individual’s constructs, by comparing the way they apply to events or people, otherwise referred to as 'elements' (Burr & Butt, 1992). The repertory grid is a tool derived from George Kelly's role construct repertory test (1955), used to elicit one’s views, or 'constructs' through the comparison of how two things may be alike, but different to a third. The network of constructs elicited can be viewed as ‘representations of individuals' own truth of their world' (Ashleigh & Meyer, 2012). Once constructs are elicited, including both poles of each construct, elements are rated in light of the constructs. The grid is then analysed using statistical methods to understand the interrelationship between constructs, between elements, and between constructs and elements, as well as to elucidate the structure of the construct system (Bannister & Fransella, 1986). Repertory grids can also be used qualitatively, with the content of constructs providing vital qualitative information (Bell, 2005; Caputi, Bell & Hennessy, 2012), and therefore are a tool that can be used across research paradigms. Repertory grids are epistemologically constructivist in nature, with knowledge being seen as constructed actively by individuals, and ontologically seen as a relativist method.

The benefits include the technique's ability to access how an individual construes in their words, as well as how the process supports reflexivity and 'thinking about thinking'. Researchers have also highlighted that repertory grids address potential problems of interviewing individuals with brain injury, which includes using open questioning, providing structure and allowing for the expression of personal perspectives in one's own terms (Gracey et al., 2008).

Interpretative Phenomenological Analysis

Interpretative phenomenological analysis (IPA) is a form of analysis that aims to explore and understand the lived experiences of individuals in depth, and understand how people make sense of their personal and social world (Smith & Eatough, 2007). The foundation of IPA is built up of three main theoretical assumptions; phenomenology, hermeneutics and idiography:

- **Phenomenology:** Phenomenology is concerned with capturing an individual's personal perception of the topic at hand, as opposed to trying to present an objective statement of the topic (Smith, Jarman & Osborn, 1999).
- **Hermeneutics:** IPA highlights that research is a dynamic process within which the researcher plays an active role, trying to get an intimate view of the participant's world although unable to do so completely (Smith & Osborn, 2007). The researcher’s process in accessing and making sense of the participant's personal world is impacted by their way of seeing the world and assumptions, and through this lens they are attempting to participate in a process of interpretative activity (Smith & Osborn, 2007). This two-stage interpretive process is referred to as 'double hermeneutics' (Smith & Eatough, 2007).
- **Idiography:** Traditionally research studies in psychology have been nomothetic in nature, focusing on the analysis and constructing arguments at a group level. IPA in contrast to this takes an idiographic approach, seeking to understand and make statements at the individual level. IPA also concerns itself with understanding a group of individuals, with themes across individuals also explored. IPA however begins with a focus on understanding individuals case by case initially (Smith & Eatough, 2007).

IPA studies use small sample sizes due to their idiographic focus, as opposed to assuming an average across a large sample. A sample of five to six participants has been recommended for student studies (Smith & Eatough, 2007), using a sample that is as homogenous as possible, closely defined by for whom the topic is significant. IPA analysis is conducted mostly on data collected using semi-structured interviews, where the interview schedule guides rather than dictates the interview (Smith & Osborn, 2007). IPA takes a critical realism epistemological position, positing that a stable and enduring reality exists that is independent of human understanding, but that the meanings attributed to experiences are different due to individuals experiencing different parts of reality (Fade, 2004). Ontologically IPA is phenomenological in nature.

IPA has been criticised on the grounds of reliability. Drummond, Hendry and Dip (2011) argue that there is a high risk of variance in the interpretation of themes emerging from the text, as each reader may interpret findings differently to the researchers. Finlay (2009) also has argued that claims made on the basis of data analysed using IPA may never be credible as the researcher's interpretation may also change over time. The benefits include the ability to access both an idiographic and group viewpoint on a topic. Alongside this, IPA can also transparently address factors such as researcher bias by bringing into discussion the researcher's lens through which they understand the participant's experience.

2.1.3 Suitability of Grids and IPA

Both repertory grids and IPA share the common goals of attempting to capture an individual's own meaning of the personal and social world, with the individual's responses not becoming lost by averaging the understanding across a group (Smith, 1995). Repertory grids seek to do this quantitatively, although they can also be used qualitatively, and IPA does this qualitatively. By combining the two, it is possible therefore to gain a thorough and 'complete' understanding of an individual's understanding of their personal and social world, by using each method to contribute a different aspect towards answering the research question at hand (Coyle, 2007). Repertory grids have been used in combination with IPA of interview data by researchers previously to gain a focused exploration of how participants make sense of and think about health experiences (Turpin et al., 2009; Smith, 1992). Repertory grids can also contribute a different dimension to understanding the experience and meaning-making of individuals when combined with other methods, by contributing insight into the structure of an individual's belief systems (Turpin et al., 2009).

2.1.4 Rationale for use of Combined Methods for Current Study

This study took a pragmatic stance and used repertory grids to elicit constructs to capture individuals' views of important people and events in relation to their ABI, followed by an elaboration of these constructions and the important experiences that have contributed to them, using semi-structured interviews. Data from these interviews were then analysed using Interpretative Phenomenological Analysis. This combination of methods was selected for the following reasons;

-To scaffold participants with cognitive impairments to take part in the research. Grids have been found to be helpful in providing structure for individuals who may struggle due to cognitive deficits in areas such as memory, planning or attention (Gracey et al., 2008). Through using grids, it was possible to support participants to find a frame of reference that they could discuss during the interviews.

-To capture not only the meaning participants have ascribed to their experiences, but also how they construe.

2.1.5 Alternative Methodologies Considered

Other qualitative approaches were considered in place of IPA, specifically Thematic Analysis. Thematic analysis is a method that aims to identify, analyse and report patterns, or themes, within data (Braun & Clarke, 2006). This method was considered as an alternative method but was rejected as the method focuses more on reporting patterns across participants, as opposed to both idiographically as well as at a group level, which IPA was able to provide.

2.1.6 Summary of Design

A mixed methods design was used. Repertory grids were used to elicit constructions participants held about themselves and their lives, and semi-structured interviews were employed to explore the development of these constructions within the context of participants' experiences, using Interpretative Phenomenological Analysis.

2.2 Participants

2.2.1 Recruitment

A purposive sample was recruited from two non-statutory services based in Hertfordshire and Bedfordshire. These services were third sector organisations that provided slow stream community rehabilitation to individuals that had sustained a brain injury. These services provided multi-profession interventions instructed by local health commissioners as well as support and skills groups. Third sector organisations were selected as an initial option, with NHS services considered for a further stage of recruitment if necessary, but a large enough sample was found without need for this. The organisations selected were used as they could provide access to individuals with mild to severe brain injuries. Field supervisors provided details for key links at the services, who were then contacted in regards to helping in the recruitment of participants to this study. The research study was reviewed by staff members working within the services, and following this verbal and written permission to recruit via these organisations was provided (see Appendix 3).

2.2.2 Participant Inclusion and Exclusion Criteria

The inclusion and exclusion criteria were selected on the basis of ensuring participants were appropriate for the aims of this study and created a group as homogeneous as possible. The criteria are summarised in Table 4.

Table 4. Inclusion and Exclusion Criteria

Include	**Rationale**
Adult males.	This criterion was selected in line with the aims of this research to focus on the lived experiences of males.
Have an ABI classified as mild, moderate or severe.	A wide injury range was used as the physical, emotional and psychological experience of brain injury can vary based on numerous factors (e.g. nature of structural changes in the brain, pre-morbid history or level of functioning). This can make it difficult to recruit a homogeneous group (Vakil, 2005).
Working age (18-65).	Life stages, such as childhood, adolescence, adulthood and old age are separate developmental phases that are characterised by biological, psychological, and social processes and transitions (Mintz, 1993). It was expected that a brain injury may have a widely different impact on an individual due to the context of their life stage, therefore a specific age range was selected.
>1 year and <10 years since ABI was sustained.	Within the first year after an ABI, typically a natural recovery may take place as well as social adjustment. In light of this, this criterion was selected to ensure the sample recruited were cognitively and emotionally able to engage in the research.
Sufficient ability to communicate in English.	This was selected as it was not possible to provide interpreter services due to research fund constraints. Therefore, a language understood by both researcher and participant was selected.
Exclude	**Rationale**
Ongoing unresolved physical health issues, significant untreated mental health problems, substance disorder issues or severe anxiety or depression.	This was selected to ensure the individuals recruited were emotionally able to engage with the research.

The inclusion and exclusion criteria were determined using a mixture of neuropsychological tests, psychometric tests, notes from service user records kept at the organisations and direct questioning. The use of these measures was overseen by a Clinical Psychologist and Neuropsychologist. The following measures were used:

- Addenbrooke's Cognitive Examination III (ACE-3) (Hsieh, Schubert, Hoon, Mioshi & Hodges, 2013) was used to assess for cognitive impairment in domains of memory, language, verbal fluency, attention and visuospatial skills.
- Mayo-Portland Adaptability Inventory (MPAI) (Malec, Kragness, Evans, Finlay, Kent & Lezak, 2003)) was used to assess for physical, cognitive, emotional, behavioural and social difficulties.
- Glasgow Coma Scale (GCS) (Teasdale & Jennett, 1974) score. Information on the length of time spent unconscious and structural changes to the brain following injury was collated from records. This information was then used to assess brain injury severity.
- Patient Health Questionnaire 9 (PHQ-9) (Kroenke, Spitzer & Williams, 2001) to assess for mood difficulties.
- Generalised Anxiety Disorder 7 (GAD-7) (Spitzer, Kroenke, Williams & Löwe, 2006) to assess for difficulties with anxiety.

The remaining criteria were assessed using notes from records or direct questioning. The ACE-3, MPAI, PHQ and GAD were scored using standardised scoring and administration guidelines.

According to the MPAI and ACE-3 tests, all participants had some level of cognitive difficulty, as well as physical, emotional or social difficulties. This indicated that these individuals had experienced an injury large enough to lead to a change in their functioning and met the study criteria. According to the PHQ, the most difficulty experienced with mood was 'Mild', and according to the GAD, the most difficulty experienced was 'None'. No participant reported current or historical severe or enduring mental health difficulties, or issues with substance abuse. In light of information collected regarding mood, anxiety and mental health, all participants met the criteria to take part in the study. A summary of participants’ assessment scores from the above measures can be found in Appendix 4.

According to data collected on injury severity, four of the research participants had a brain injury that could be classified as severe, and therefore met the criteria to take part in the study. There was no documented data available for two participants regarding the severity of their injury. These participants told the researcher directly that they had been told they had sustained a moderate to severe brain injury, and this had led to their referral from NHS services to the non-statutory services. These participants still met the criteria to take part in the study, as they had between a mild to severe brain injury. The information collected to classify the severity of participants' brain injury can be found in Appendix 5.

2.2.3 Sample

A sample size of four to six individuals was aimed for, with six participants recruited. A smaller sample size can be used when using qualitative methods of analysis, due to the focus of this method being on obtaining an in-depth understanding of a small set of individuals. The characteristics of participants who were recruited and took part in the research have been summarised in Table 5. They were also anonymised by giving them the following names: Derek, Bruce, Lance, Percy, Dean and Robert.

Table 5. Summary of participant characteristics

ID	**Age**	**Years since injury**	**Nature of injury**	**Presence of cognitive, physical or social difficulties**	**ACE- 3 Score**	**MPAI Score**	**Presence of mood, mental health or substance difficulties**	**Injury severity**	**Ethnicity**	**Marital status**	**Employment status**
Derek	44	7	Accident (fall)	Yes	63	49	Mild classification on PHQ (8)	Severe	Indian	Married	Unemployed
Bruce	41	7yrs 10months	Assault	Yes	94	12	None	Severe	British Asian (Indian)	Single	Unemployed
Lance	57	8yrs	Stroke	Yes	87	34	Mild classification on PHQ (5)	Mild to Moderate	British White	Separated	Unemployed
Percy	59	5yrs	Road traffic collision	Yes	91	41	None	Severe	British White	Married	Unemployed, voluntary work
Dean	44	6yrs and 3.5 yrs.; 2010 and 2012	Assault and accident (fall)	Yes	91	34	None	Severe	British White	Married	Unemployed
Robert	65	5yrs, 2 months	Myocardial infarction	Yes	85	66	None	Mild to Moderate	British White	Single	Unemployed, voluntary work

2.3 Ethical Considerations

2.3.1 Ethical Approval

Research ethics approval was applied for from the University of Hertfordshire University ethics boards in August 2015, with approval granted in September 2015. An amendment was sought in November 2015 to extend the location of where the research could be conducted, which was approved in December 2015. A further amendment was sought in January 2016 to change the focus of the study to the male experience, which was approved in January 2016. Ethics approval notifications can be found in Appendix 6.

2.3.2 Confidentiality

Informed and written consent was sought from all participants, which included a statement about confidentiality (see consent form and information sheet in Appendix 7). It was explained to participants (and relatives if present) that all data collected would be kept confidential using locked storage for hard data (e.g. paper forms completed) and password protected documents for soft data (e.g. audios, scanned versions of forms). They were also informed that any information that may identify them would be removed from all documents, including transcripts and excerpts used within the thesis. The research process also took place in a private space, either in the participant's home or at one of the services, where others would not be able to listen in without permission.

2.3.4 Informed Consent

The recruitment stage was carefully navigated, with consideration of how consent had to be transparently acquired with a group of individuals who may have difficulties or a lack of capacity to give full considered consent. Therefore, the following stages were followed:

- Potential participants who fitted the study criteria were approached by a member of the service whom they knew. They discussed the research with them, with consideration of particular scaffolding they may need to think about this decision due to cognitive difficulties.
- Participants who gave consent to the member of staff had their details passed to the researcher. The researcher then met them face to face or spoke to them, or a family member, and the research information sheet was discussed together (see Appendix 7 for information sheet), with room for questions given. During this discussion the following criteria were also considered to determine whether they had the capacity to make an informed decision to take part (Mental Capacity Act, 2005):
    - Were they able to understand information?

- Were they able to retain information long enough to make a decision?
- Were they able to weigh up information relating to the decision?
- Were they able to communicate their decision?

If individuals were able to do the above in relation to the information given and invitation to participate, capacity was assumed, and a consent form was given for the participant to complete (see Appendix 7 for consent sheet) with or without the support of a carer, relative or member of staff. This support included helping potential participants with reading the material, asking questions relevant to their needs and considering practical factors (e.g. time and availability).

2.4 Data Collection

2.4.1 Materials

Repertory grids

Elements were selected based on previous studies using repertory grids to explore the constructs held by individuals with brain injury or conditions that impact cognitive and physical abilities (Brumfitt,1985; Gracey et al., 2008). The aim to elicit participants' current views of their lives and self were also considered alongside this. In light of this, the following elements were selected for the repertory grids (see Appendix 8 for repertory grid):

- Self before brain injury ('Me before my brain injury')
- Current self with brain injury ('Me now with a brain injury')
- Ideal self ('Me as I'd like to be')
- Expected self ('Me as I expect I will be in the future')
- Social self ('Me seen by others')
- Self as Patient ('Me as a patient')
- People with a brain injury ('A typical person with a brain injury')
- People without a brain injury ('A typical person without a brain injury')
- Important individuals in the individual's life ('Partner' and 'Child')

Elicited constructs as opposed to provided constructs were selected to obtain the participants' own frame of reference, in line with the idiographic and phenomenological approach. These constructs and information about their construct system were uses to scaffold participants during the interview, and as the basis of the semi-structured interview. In a similar way to the repertory test (Kelly, 1955), participants were asked to select triads based on how two were alike (the emergent pole), and how the other one was different to these two (implicit pole), to elicit constructs. All participants struggled to give both poles of constructs and required prompts. All participants therefore had to be asked to state what the opposite pole was for each construct. This was asked using prompts such as 'so if this is one end, what would be the exact opposite of this?'. To facilitate this method, flashcards of the elements were also used to support participants to remember which elements they could select for the triads, or had selected by physically separating them from the others. All participants used these during the elicitation process. Participants were then asked to rate the elements on the constructs elicited using a 7-point Likert scale. The scale was drawn out visually for participants to see to support them to remember the construct poles, as well as estimate their rating visually to help them identify what this would be numerically.

Interview

A semi-structured interview focusing on discussing the grid results further was conducted on a one to one basis with each participant. All interviews were audio taped, with written consent for audio recording obtained (see information sheet and consent form in Appendix 7). An interview schedule was developed but questions were asked in a flexible order to support the flow of conversation (see Appendix 9 for interview schedule).

2.4.2 Other materials

Consent and information sheets were constructed for use with this study (see Appendix 7). Demographic, social status, injury history, treatment history and eligibility information were also collected using a proforma sheet created for this study (see Appendix 10). Areas of information to be collected were selected using recommendations by Maas, Harrison-Felix, Menon, Adelson, Balkin, Bullock & Robertson (2011) on the standardisation of data collection in brain injury research. Service user consultation was sought to review the accessibility of information and consent sheets that were used. Positive feedback was given for the sheets, with no changes recommended. The consultation also suggested that the use of repertory grids may be helpful due to their idiographic nature, with the participants’ own words used via the elicitation of constructs.

After conducting each session, a diary entry about factors that may have impacted participants that day, the research process and researcher were made (see Appendix 11 for an excerpt). This was done to guide future interviews as well as the interpretation of data during the analysis, as suggested by Yin (2015).

2.5 Procedure

Staff members from the services, a manager and an occupational therapist, approached potential participants who fitted the study criteria and invited them to take part in the research. They were given an information sheet (see Appendix 7) to use within this discussion. The staff members discussed the research with them, and if participants consented to be contacted, their details were given to the researcher via the staff member. The researcher then met the participant, or a relative or carer they had asked to be contacted on their behalf, either face to face or in a telephone call. The research information sheet was discussed, and questions were answered. During these conversations participants were assessed for their capacity to give informed consent, which is detailed above in the recruitment section of this thesis. Once written consent was given, the research proforma sheet and neuropsychological and psychometric tests were conducted alongside direct questioning to see if participants fully met criteria. If the participant met the study criteria, the repertory grid was then conducted. The data collected by the grid was then analysed using the software Idiogrid, and this data and a graph summarising their grid were discussed with participants to confirm, disconfirm and elaborate on the results of the grid. Following this, a semi-structured interview was conducted.

2.6 Location of Data Collection

The location of data collection, from the consent procedure extending to the interview, was discussed with all participants. Participants were given the choice to take part in the research either in their home (if there were no known risks to others identified by service team members), or at the service locations they usually attended. Participants were made aware that the whole research process would take place in approximately two sessions. It was proposed that the first session would be used to complete the ACE-III, MPAI, PHQ, GAD, proforma sheet and complete the repertory grid. Participants were told that the second session would be spent discussing the results of the repertory grid, and conducting a semi-structured interview. Participants were informed that each session would last between forty-five to sixty minutes, although this could be changed to suit their cognitive and physical needs, such as by meeting for shorter periods but across more sessions. The semi-structured interviews were audio taped and then transcribed outside of the session.

2.7 Transcription of Interviews

Five interviews were transcribed by a professional service, and one was transcribed by the researcher. A confidentiality agreement was signed by the service before being given access to the audio interview data (see Appendix 12). Although transcription can support the analysis process through immersion, it was not possible to transcribe more than one interview due to time constraints. All patient identifying data was removed from transcripts in order to protect anonymity.

2.8 Data Analyses

Data analysis methods used for the repertory grids and interviews will be outlined separately in this section.

2.8.1 Repertory Grids

Each repertory grid was analysed individually using the software package Idiogrid (Grice, 2002). A Slater Analysis (single grid) was conducted on each individual's repertory grid. As part of the Slater Analysis, the following analyses were selected for each grid: descriptive statistics for the elements and constructs, standardised Euclidean distances and principal component analysis (PCA). Alongside this a graph plotting elements and constructs was also selected. The graph, as well as data output for all analyses, were printed out and discussed with participants. The discussion was used to confirm, disconfirm or elaborate on the validity of the data output. Table 6 summarises the above analyses, based on Winter (2013).

Non-statistical analyses were also conducted on data collected from the repertory grids. All constructs elicited by the repertory grids were described and defined. The meaning of each construct elicited was described by the participant during administration of the repertory grid, and this data was used by the researcher to create a definition. The definitions summarise the meaning of each construct, describing psychological concepts or processes where relevant.
A data-driven content analysis was also conducted to find commonalities between constructs. This method was used, as opposed to applying predetermined categories from categorisation systems, to make sure that the analysis was idiographic and led by the data.

Table 6. Repertory grid data output provided by Idiogrid, based on Winter (2013)

Analysis	**Information elicited**	**Interpretation of this Information**
Descriptive statistics for elements and constructs	Description of constructs and elements, including percentage sum of squares accounted for by an element or construct.	The higher the sum of squares score: - the more salient the element is - the more superordinate the construct is.
Euclidean distances (standardised)	Level of similarity or difference between elements.	Distance is understood on a scale of 0 to 2: 0= elements seen identically 1= distance expected is by chance 2= elements seen as very different.
Principal Components Analysis	Percentage of variance accounted for by each component, representing the tightness or looseness of participants' construct systems.	-The higher the percentage of variance accounted for, the more tightly organised and unidimensional the construct system is. -The lower the percentage of variance accounted for, the more loosely organised and multidimensional the system is.

2.8.2 Interviews

Semi-structured interviews were analysed in line with the IPA approach outlined in Smith and Osborn (2007). Each transcript was analysed individually in detail case by case, in line with the idiographic approach, before moving to a general categorization of all cases (Smith, 1995). The following procedure was used:

- *Case by case analysis*: Each interview transcript was repeatedly read to become intimate with the account, as well as gain new insights (Smith & Osborn, 2007). This was done until no new insights or reflections could be made. The initial readings were also done to remove identifying data such as names or locations. Further readings were then used to heighten familiarity and record initial thoughts, connections, interpretations and ideas. Annotations were then recorded in the right margin. Following this each transcript was re-read, and emerging themes were noted in the left margin (see audit trail under Appendix 13). During this process transcripts were referred to frequently to ensure that the themes were grounded in the data.

- *Connecting the themes within each case:* Emergent themes noted in the transcript were listed in chronological order and connections were made on an analytical and theoretical basis to organise themes in clusters. This process was done by printing the themes on paper, cutting them out, and then visually clustering them. Once clustered, each set of themes was given a name, becoming the superordinate themes. Excerpts that were considered to represent themes well were taken from the transcripts to create a table of superordinate themes, the clusters of themes represented by the superordinate themes and related quotations (see Appendix 13). This and the previous stage were repeated for all six interviews. A short period of time was left between analysing each interview to support a position of curiosity and openness to new ideas (Smith & Osborn, 2007).

- *Analysis across Cases:* This stage involved creating a final table of superordinate themes, bringing together themes from all six of the interviews (see Appendix 13). Themes were selected based on the richness passages brought to certain themes, as well as how these themes highlighted other areas of the account (Smith & Osborn, 2007). This table of themes was then used to create a narrative account explaining the themes, supported with verbatim extracts from the interview transcripts.

Alongside the above, supervision for the analysis of the semi-structured interviews using IPA was provided by a member of the research team at the University. This included providing feedback on the analysis of one transcript using IPA.

2.9 Quality Assurance

Measures to ensure the quality of this research in line with current qualitative research standards were also taken. A number of guidelines to assess the quality of qualitative research are now available (Elliott, Fischer & Rennie, 1999; Spencer, Ritchie, Lewis & Dillon, 2003;

Yardley, 2008). For this research project the guidelines described by Yardley (2008) were used. These guidelines propose four principles to assess qualitative research: sensitivity to context, commitment and rigour, coherence and transparency, and importance and impact. Definitions of these principles and the strategies used in turn are summarised in Appendix 2 (a).

Alongside the above the quality of this study as a mixed methods piece of research was also considered using the 5 P's framework (Cameron, 2011). Cameron (2011) proposes five principles to assess mixed methods research; paradigms, pragmatism, praxis, proficiency and publishing. These principles and the strategies used to ensure these were considered are summarised in Table 7.

Table 7. Mixed method quality measures (Cameron, 2011) and corresponding strategies

Principle	**Description**	**Strategies**
Paradigm	The researcher needs to position themselves paradigmatically.	The paradigmatic stance taken was discussed in the design section of this chapter.
Pragmatism	The researcher needs to discuss literature and debates in mixed methods, and provide a rationale for choices made.	1) Literature and key criticisms and advantages have been discussed in the design section of this chapter. 2) A rationale for the use of mixed methods has been given in this chapter.
Praxis	Researchers need to integrate methods well across design, sampling, data collection strategies and analysis and inference quality. Mixed methods also need to be sufficiently justified.	1) Both methods have been integrated well at the procedural level, and play separate but complementary roles, as discussed in the design section. 2) Both methods have been integrated well across design (with each playing a complementary role to collect data), with the sample and data collection appropriate to both methods. Analysis will be done systematically, covering repertory grids first to establish constructs and construct systems, and IPA to elaborate on these constructs. 3) A rationale for the use of mixed methods has been given in this chapter.
Proficiency	Researchers need to be competent in both qualitative and quantitative methods, including knowledge and practice.	1) Supervision has been provided for both repertory grids and IPA, to support the use of these methods for data collection and analysis. 2) Supervision has been provided for the introduction section covering the existing knowledge base for both methods.
Publishing	Researchers need to navigate the difficulties of publishing mixed methods research, due to dominant paradigmatic views.	1) Stange, Crabtree and Miller (2006) will be referred to when planning dissemination of the study's findings via publication.

3.0 Results

Six male individuals with an acquired brain injury (ABI) took part in this research. Their names were changed to ensure anonymity. They will be referred to by the following names: Derek, Bruce, Lance, Percy, Dean and Robert. Repertory grids were used to elicit an understanding of how these individuals construe their lives with an ABI, and used as a basis for semi-structured interviews that were analysed using Interpretative Phenomenological Analysis (IPA) to understand more broadly their lived experience of having an ABI. This section will present both the constructs and nature of construing of these six male individuals with an acquired brain injury (ABI), as well as their reported experiences of living with their injuries.

The constructs elicited by the repertory grids for each individual will be presented first. Following this, the results of a Slater analysis conducted on repertory grid data for each individual will be presented, outlining the nature of their construing systems. Finally, the results of the IPA of the six individuals will be presented.

3.1 Results of Repertory Grids

Repertory grids were used to elicit constructs held by individuals in regards to different aspects of their life, represented by elements (a list of these elements is detailed in the method chapter). The constructs were then rated between 1 to 7, and this data was analysed using the software Idiogrid. This section will detail the results of this analysis, including the bipolar constructs elicited from each individual and details about the nature of their construing.

3.1.1 Constructs Elicited by Repertory Grids

The constructs elicited by repertory grids will be outlined in this section. Repertory grids were administered and completed for all six of the individuals that participated, an example of one individual's grid can be found in Appendix 14 (as part of a full Slater analysis data output). The tables below will outline each pole of the constructs elicited, and a definition of the constructs.

Derek

Five constructs were elicited from Derek. Derek appeared to struggle with eliciting constructs using the triadic approach, both without and with the use of flashcards to support him. He asked to stop at five constructs, which was adhered to. The constructs that were elicited can be seen in Table 8.

Table 8. Table summarising Derek's constructs

Construct		**Definition of construct**
Emergent pole	**Implicit pole**	
Well	Unwell	This construct referred to the presence and absence of physical wellness.
No physical problems	Physical problems	This construct referred to the absence or presence of physical problems, such as mobility issues, not physical illness.
Understanding	Not understanding	This construct referred to the presence or absence of empathy.
Easy life	Hard life	This construct referred to the difficulty level of one's life.
Positive thinking	Negative thinking	This construct referred to the nature of one's thinking style.

Bruce

Ten constructs were elicited from Bruce. The constructs that were elicited can be seen in Table 9.

Table 9. Table summarising Bruce’s constructs

Construct		Definition of construct
Emergent pole	**Implicit pole**	
Determination	Lazy	This construct referred to the presence and absence of determination to achieve an aim.
Motivated	Unmotivated	This construct referred to the extent to which one has internal or external rationales to do something.
Achieving	Boring	This construct referred to how much one endeavours to try to achieve something.
Positive attitude	Depressing attitude	This construct referred to one’s general disposition on a daily basis.
Occupied	Uninterested	This construct referred to the extent to which one kept oneself busy.
Satisfaction	Unsatisfied	This construct referred to the presence or absence of pleasure one felt with their life.
Progressing	Can't develop further	This construct referred to the extent to which one can develop at a personal level (cognitive and physical self).
Happy	Depressed	This construct referred to one's emotional disposition.
Independent	Reliant	This construct referred to the level of dependence one has on others.
My life	Someone else's life	This construct referred to the level of agency one has over making life choices.

Lance

Eleven constructs were elicited from Lance. The constructs that were elicited can be seen in Table 10.

Table 10. Table summarising Lance's constructs

Construct		Definition of construct
Emergent pole	**Implicit pole**	
Realistic	Unrealistic	This construct referred to how practical one is.
To look after	Failing	This construct referred to how well one can meet the needs of significant people.
Being successful	Failing	This construct referred to whether one is able to achieve a desired result.
Independence	Physical reliance	This construct referred to physical independence.
In control	Reliant	This construct referred to the extent to which one had the ability to influence one's own life
Coherent	Incoherent	This construct referred to the extent to which one's actions make sense.
Being normal	Different	This construct referred to the extent to which one is able to conform to social expectations.
Employable	Unemployable	This construct referred to the extent to which one was suitable to work.
Understood	Misunderstood	This construct referred to the extent to which one feels one is perceived accurately by others.
Being accepted	Standing out in the crowd	This construct referred to the extent to which one feels accepted by others.
Confidence	No self esteem	This construct referred to the extent of one's self belief.

Percy

Ten constructs were elicited from Percy. The constructs that were elicited can be seen in Table 11.

Table 11. Table summarising Percy's constructs

Construct		Definition of construct
Emergent pole	**Implicit pole**	
Insular	About everyone	This construct referred to how much focus is on an individual.
Insight	Lack of knowledge	This construct referred to the amount of understanding one has about oneself.
Normal	Abnormal	This construct referred to the extent to which one is seen as conforming to social expectations.
Passing off as typical (being dishonest)	Being honest	This construct referred to the extent to which one tries to appear being like the average individual.
Managing	Struggling	This construct referred to the extent to which one is able to manage one's day to day living.
In control	Out of control	This construct referred to the extent to which one felt one had influence over their life.
Individuality	Cloning	This construct referred to the extent to which one is their authentic self, or like others.
Freedom of choice	Autocracy	This construct referred to the extent to which one has power of choices in one's life.
Idealistic	Realistic	This construct referred to the extent to which one has a false sense of belief in what one is able to do.
Treated the same	Treated differently	The construct referred to the extent to which one is treated equally to others, or as an individual.

Dean

Ten constructs were elicited from Dean. The constructs that were elicited can be seen in Table 12.

Table 12. Table summarising Deans' constructs

Construct		Definition of construct
Emergent pole	**Implicit pole**	
Realisation	Not moving forward	This construct referred to how much awareness an individual had of their difficulties, enabling them to progress.
Easier life	Harder life	This construct referred to the ease of one's thought process.
Truthfulness	False	This construct referred to the extent to which what they said was truthful.
Positivity	Negativity	This construct referred to the general disposition one has.
Difficulties are physically invisible	Difficulties can be seen by people	This construct referred to how visible one's brain injury related difficulties were.
Understanding	Making conclusions	This construct referred to how much awareness one has of others.
Flexibility	Thinking things through	This construct referred to how much planning one needed to do.
Make choices	Not able to choose	This construct referred to whether one could make choices in their lives for themselves.
Learning	Ignorant	This construct referred to how much one was learning.
Improving	Remaining the same	This construct referred to whether one wanted to develop as an individual.

Robert

Ten constructs were elicited by Robert. Information on these can be seen in Table 13.

Table 13. Table summarising Robert’s constructs

Construct		Definition of construct
Emergent pole	**Implicit pole**	
Enjoying life	Wading through treacle	This construct referred to how much enjoyment one had from their life.
Being everything I want to be	Being useless	This construct referred to the extent to which one felt able to be their preferred self.
Achieving	Failing	This construct referred to how much one was making progress.
Getting on with life	Being held back	This construct referred to how able one was to do things one wished to do.
Being in control	Control in someone else's hands	This construct referred to how much control one had over making decisions.
Independent	Reliant	This construct referred to the level of dependence one has on others.
Feeling important	Not important	This construct referred to how needed and wanted one felt by others.
Reliable	Unreliable	This construct referred to how consistent one saw oneself as.
Being trusted	Being untrustworthy	This construct referred to how much one could be relied on.
Feeling lost	Happiness	This construct referred to how much one knew about what direction one was going in.

Commonalities Across Constructs

Common topics were found underpinning constructs across cases, which were within the area of control, reliance, positivity, moving forward, nature of life, realism, achievements and truth.

These have all been summarised in Table 14.

Table 14: Commonalities in constructs across cases

Topic of construct	Construct Poles	
Control	Being in control	Control in someone else's hands
	In control	Out of control
	In control	Reliant
Reliance	Reliant	In control
	Reliance	Dependence
	Independence	Physical reliance
Positivity	Positivity	Negativity
	Positive thinking	Negative thinking
	Positive attitude	Negative attitude
Moving forward	Improving	Staying the same
	Progressing	Can't develop further
	Getting on with life	Being held back
Normality	Being normal	Different
	Normal	Abnormal
Nature of life	Easy life	Hard life
	Easier life	Harder life
Realism	Realistic	Unrealistic
	Realistic	Idealistic
Achievements	Achieving	Failing
	Achieving	Boring
Truth	Being honest	Passing off as typical (being dishonest)
	Truthfulness	False

Construing of 'Me now with a brain injury'

Commonalities within the construing of the element ‘Me now with a brain injury’ were also explored. The construing of this element was found to have predominantly negative connotations across cases, and these constructions have been summarised in Table 15.

Table 15. Construct Poles with Negative Connotations Applied to the Self with ABI

Individual	Constructs
Derek	'Hard life', ‘unwell' and' not understanding'.
Lance	'Unemployable', 'failing (to look after others)', 'standing out in the crowd' and 'physically reliant’.
Percy	'Treated differently'.
Dean	'Harder life', 'ignorant' and ‘not able to make choices’.
Robert	'Held back' and 'wading through treacle'.

3.1.2 Results of Slater Analysis of Repertory Grid Data

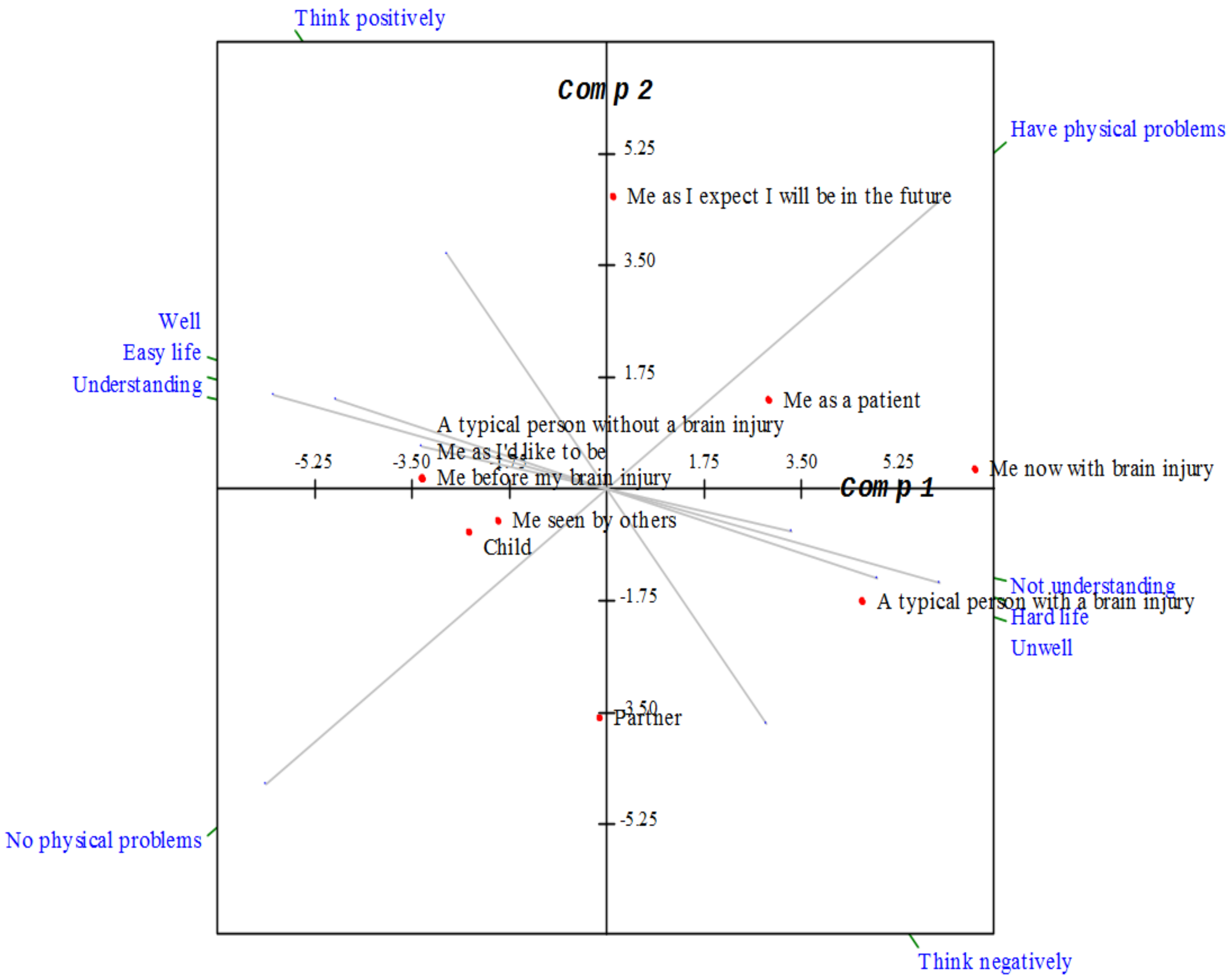
Slater analyses were conducted on the data obtained using repertory grids. Data from one individual’s Slater analysis can be found in Appendix 14.

The results of these analyses will be presented now for each individual below to outline the understanding captured about the nature of their construct systems. Each analysis will commence with a plot presenting the loadings of elements and constructs on the first two components identified by a principal components analysis for each individual’s grid. The first component is represented by the horizontal axis and the second component is represented by the vertical axis. Following this the loadings of constructs on the two components will be described. Then there will be a description of the construing of elements, using Euclidean distances where relevant to highlight interesting similarities and differences. After this will be a description of the tightness or looseness of the construing system, using data from the principal components analysis. Finally, there will be a description of the salience of elements and superordinancy of constructs within individuals’ construct systems.

Derek's construct system

Figure 3 visually represents the way Derek construes himself and others in regards to the elicited constructs.

Figure 3. Plot representing Derek's construing



The first component accounts for 64.72% of the variance, and contrasts people who are well, have no physical problems, are understanding and have an easy life with people who are unwell, have physical problems, are not understanding and have a hard life. The second component accounts for 21.97% of the variance, and contrasts people who think positively with people who think negatively.

From the plot it appears that 'A typical person with a brain injury' is construed as not understanding, having a hard life and as unwell, as this element is plotted closest to these construct poles. The plot also suggests that 'Me as I expect I will be in the future' is construed at an extreme level, which can be seen by its position on the plot, which is further out relative to the majority of other elements.

The element 'Me now with a brain injury' is construed at an extreme level, as seen by its extreme position on the grid. It appears Derek construes the element 'Me now with a brain injury' as unwell, having a hard life and not understanding, due to its close positioning to these construct poles on the graph. This element is also in contrasted positioning to 'Me before my brain injury' and 'Me as I'd like to be', suggesting that 'Me now with a brain injury' is different to these elements, which is supported by the Euclidean distances (1.59 and 1.59). The Euclidean distances also highlight a difference between ‘Me now with a brain injury’ and ‘A typical person without a brain injury’ (1.59), suggesting Derek construes himself as different to a non-brain injured individual.

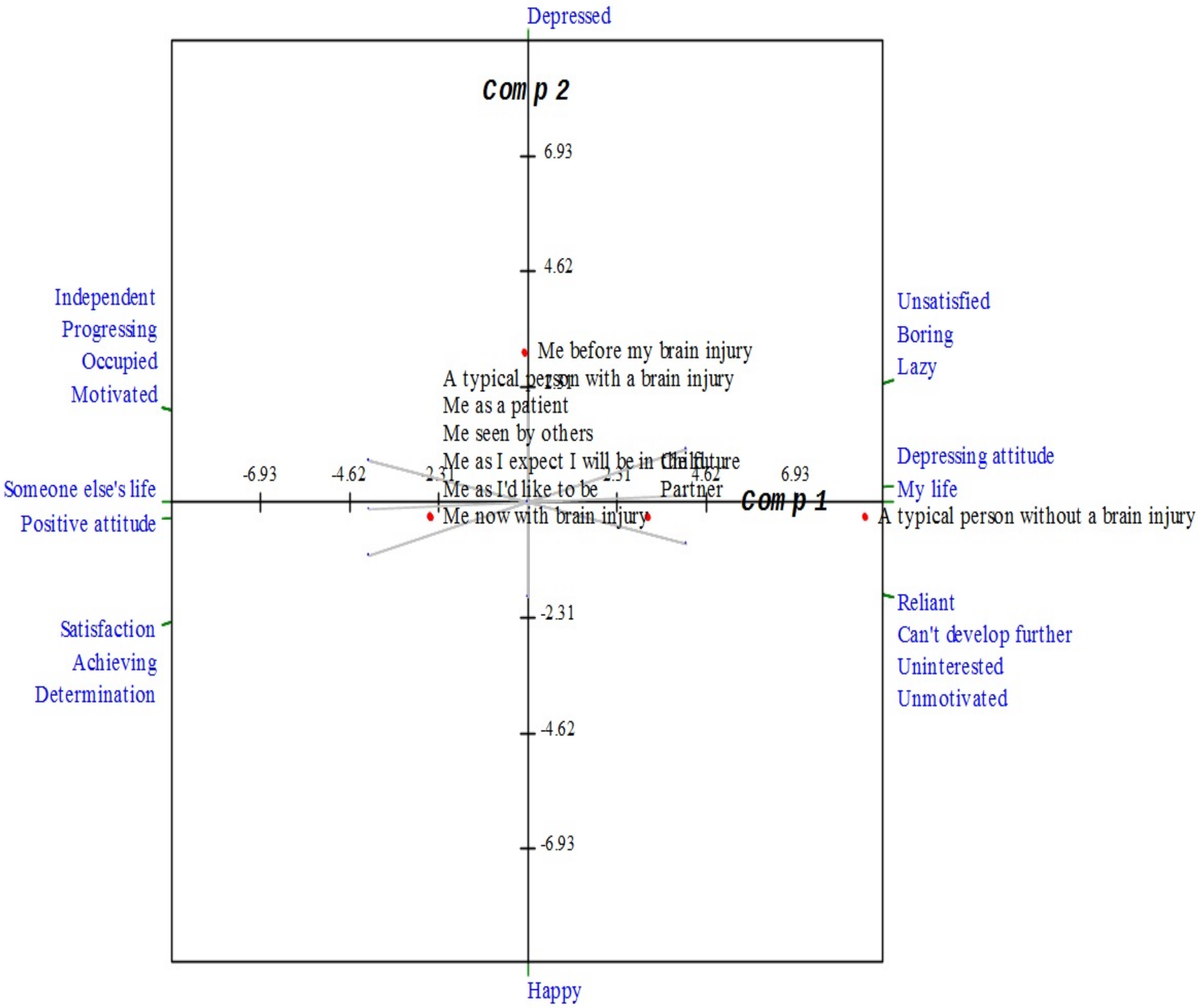
The principal components analysis of the repertory grid also provided data on the tightness or looseness of Derek's construing. The application of eigenvalue decomposition found that the first principal component could explain 64% of variance in the data. In light of a sample of 'normal' participants, where the percentage of variance of the first component was 39.4% (Ryle & Breen, 1972b), Derek's construct system can be interpreted as tight and unidimensional, although in this particular sample he is one of the least tight.

The analysis of Derek's repertory grid data also elaborated on the salience of the elements from the grid for him. The data suggests that the elements 'Me now with a brain injury', 'A typical person with a brain injury' and 'Me as I expect I will be in the future' accounted for the majority of the variance in the data (25.74%, 14.53%, and 13.42%, explaining 53.69% of the variance). From this it can be interpreted that these three elements were the most important from the grid for him. The analysis also elaborated on the superordinancy of the constructs. The data suggests that the constructs 'no physical problems-physical problems', 'easy life-hard life' and 'well-unwell’ accounted for much of the variance in the data, (33.8%, 22.4% and 19%, explaining 75.2% of the variance). From this it can be interpreted that these three constructs are the most superordinate within his construct system, and therefore the most important to him.

Bruce's construct system

Figure 4 below visually represents the way Bruce construes himself and others in regards to the elicited constructs.

Figure 4. Plot representing Bruce's construing



The first component accounts for 93.25% of the variance, and contrasts people who are determined, motivated, achieving, had a positive attitude, were occupied, had satisfaction, were progressing and were independent with people who were lazy, unmotivated, boring, had a depressing attitude, were uninterested, were unsatisfied, couldn't develop further and were reliant. The second component accounts for 6.75% of the variance, and contrasts people who are happy with people who are depressed.

The plot also suggests that 'A typical person without a brain injury' is construed at a more extreme level than other elements. This can be seen by its position on the plot, which is further out relative to other elements. From the plot it appears that 'A typical person without a brain injury' is construed as having a depressing attitude and life is construed as their own, as this element is plotted closest to these construct poles. It is positioned far from 'Me now with a brain injury', 'Me as I'd like to be', 'Me as I expect I will be in the future', 'Me seen by others', 'Me as a patient' and 'A typical person with a brain injury', suggesting that Bruce construes 'A typical person without a brain injury' as different to the elements listed. This hypothesis is supported by the element Euclidean distances, which show a large difference between the element 'A typical person without a brain injury' and 'Me now with a brain injury' (1.90), 'Me as I'd like to be' (1.90), 'Me as I expect I will be in the future' (1.90), 'Me seen by others' (1.90), Me as a patient' (1.90) and 'A typical person with a brain injury (1.90).

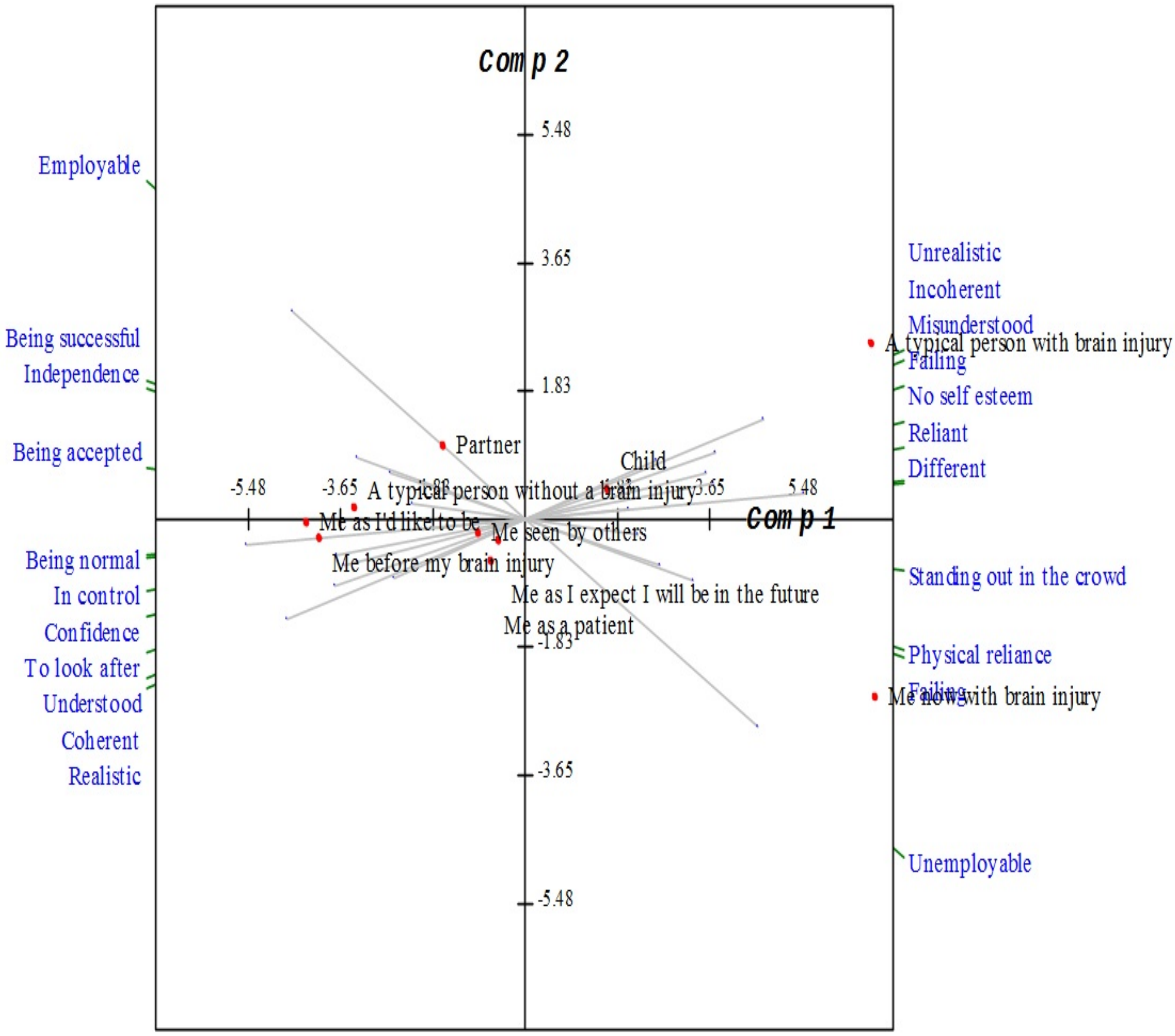
The principal components analysis of the repertory grid also provided data on the tightness or looseness of Bruce's construing. The application of eigenvalue decomposition found that the first principal component could explain 93% of variance in the data. In light of 'normal' participants (Ryle & Breen, 1972b), Bruce’s construct system can be interpreted as tight and unidimensional.

The analysis of Bruce's repertory grid data also elaborated on the salience of the elements from the grid for him. The data suggests that the element 'A typical person without a brain injury' accounted for the majority of the variance in the data (53.56% of the variance). From this it can be interpreted that this element was the most important from the grid for him. The analysis also elaborated on the superordinancy of Bruce's constructs within his construct system. Seven of Bruce's constructs appear to account for 12% of the variance in the data each. From this it can be interpreted that none of his constructs can be considered to be superordinate within his construct system.

Lance's construct system

Figure 5 below visually represents the way Lance construes himself and others in regards to the elicited constructs.

Figure 5. Plot representing Lance’s construing



The first component accounts for 79.61% of the variance, and contrasts people who are realistic, able to look after, being successful, have independence, in control, coherent, being normal, employable, understood, accepted and confident with people who are unrealistic, failing (both to look after or be successful), physically reliant, reliant, incoherent, different, unemployable, misunderstood, standing out in the crowd and have no self-esteem. The second component accounts for 7.77% of the variance. From the construct loadings it appeared that no constructs loaded highly onto component two.

From the plot it appears that 'A typical person with a brain injury' is construed as incoherent, failing (unable to look after), having no self-esteem and misunderstood, as this element is plotted closest to these construct poles. The plot also suggests that 'A typical person with a brain injury' is construed at a more extreme level than other elements. This can be seen by its position on the plot, which is further out relative to other elements. It is positioned in stark contrast to 'Me before my brain injury' and 'Me as I'd like to be' and 'A typical person without a brain injury', suggesting that Lance construes a typical person with a brain injury as very different to how he used to be, would like to be and what a person without a brain injury is like. This hypothesis is supported by the element Euclidean distances, which show a large difference between the element 'A typical person with a brain injury', and 'Me before my brain injury' (1.75), 'Me as I'd like to be' (1.78) and 'A typical person without a brain injury’ (1.64).

The element 'Me now with a brain injury' is construed as unemployable, failing (to be successful), standing out in the crowd and physically reliant, again which can be seen by the element's close position to these construct poles. Again, this element can be seen as positioned in stark contrast to other elements on the plot, and therefore very different to these elements. For example, 'Me now with a brain injury' is visibly situated far from 'Me before my brain injury', 'Me as I'd like to be' and 'A typical person without a brain injury'. This again is supported by the element Euclidean distances (1.75, 1.80 and 1.67). This suggests that Lance construes himself now with a brain injury as far from how he used to be before the injury, how he would like to be, and what a person without a brain injury is like.

'The elements 'Me as I’d like to be', 'Me before my brain injury' and 'A typical person without a brain injury sit closely on the plot, suggesting that Lance would like to return to being as he was before his injury, which is similar to those without a brain injury. This is supported by the element Euclidean distances, which show small distances between 'Me as I'd like to be', and 'Me before my brain injury' (0.16) and 'A typical person without a brain injury (0.31). The elements 'Me seen by others', 'Me as I expect I will be in the future' and 'Me as a patient' are close to the origin of the plot, suggesting that Lance's views of these are less elaborated.

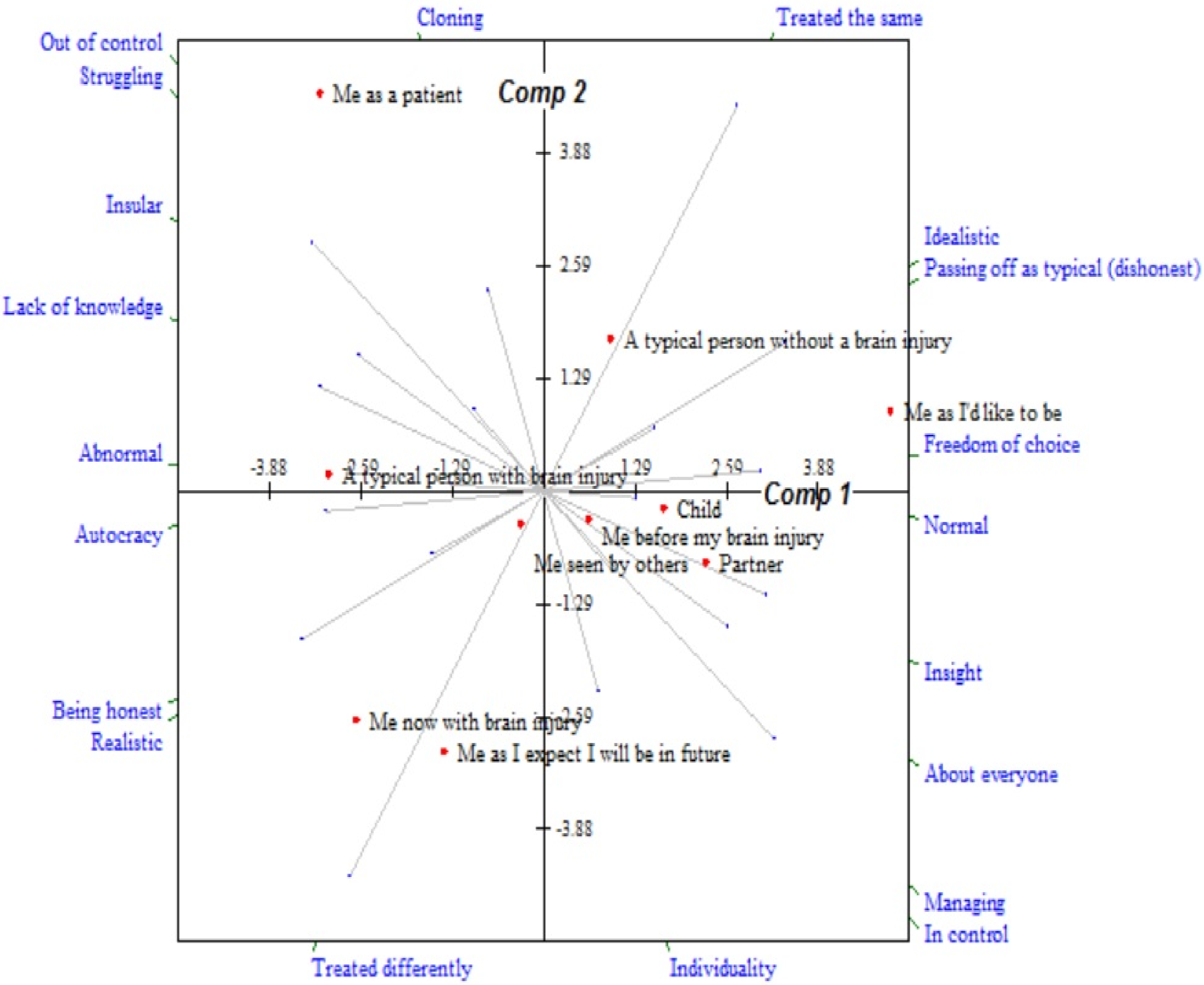
The principal components analysis of the repertory grid also provided data on the tightness or looseness of Lance's construing. The application of eigenvalue decomposition found that the first principal component could explain 79.61% of variance in the data. In light of a sample of 'normal' participants (Ryle & Breen, 1972b), Lance's construct system can be interpreted as tight and unidimensional.

The analysis of Lance's repertory grid data also elaborated on the salience of the elements from the grid for him. The data suggests that the elements 'Me now with a brain injury' and ‘A typical person with brain injury' accounted for the majority of the variance in the data (29.72% and 28.97%, explaining 58.69% of the variance). From this it can be interpreted that these two elements were the most important from the grid for him. The analysis also elaborated on the superordinancy of the constructs. The data suggests that the constructs 'being normal-different', 'employable-unemployable' and 'coherent-incoherent’ accounted for much of the variance in the data, (17.1%, 16.2% and 14.4%, explaining 47.7% of the variance). From this it can be interpreted that these three constructs are the most superordinate within his construct system, and therefore the most important to him.

Percy's construct system

Figure 6 below visually represents the way Percy construes himself and others in regards to the elicited constructs.

Figure 6. Plot representing Percy's construing



The first component accounts for 41.69% of the variance, and contrasts people who are insular, lack knowledge, are abnormal, are being honest, live with autocracy and are realistic, with people who are about everyone, have insight, normal, passing off as typical (dishonest), have freedom of choice and are realistic. The second component accounts for 27.76% of the variance, and contrasts people who are managing, in control, have individuality and are treated differently with people who are struggling, out of control, part of cloning and are treated the same.

From the plot it appears that 'Me as I'd like to be' is construed as having freedom of choice, being normal and passing off as typical (dishonest) as this element is plotted closest to these construct poles. It is positioned in contrast to 'Me now with brain injury', which appears to be construed as being honest, realistic and being treated differently. The contrast between these two elements on the plot suggests that Percy construes these elements differently. This hypothesis is supported by the element Euclidean distances, which show a difference between these two elements (1.50). The Euclidean distances also show a difference between ‘Me as I’d like to be’, and ‘Me as a patient’ (1.60) and ‘A typical person with brain injury’, suggesting Percy’s ideal self is different to how he was as a patient and others with a brain injury.

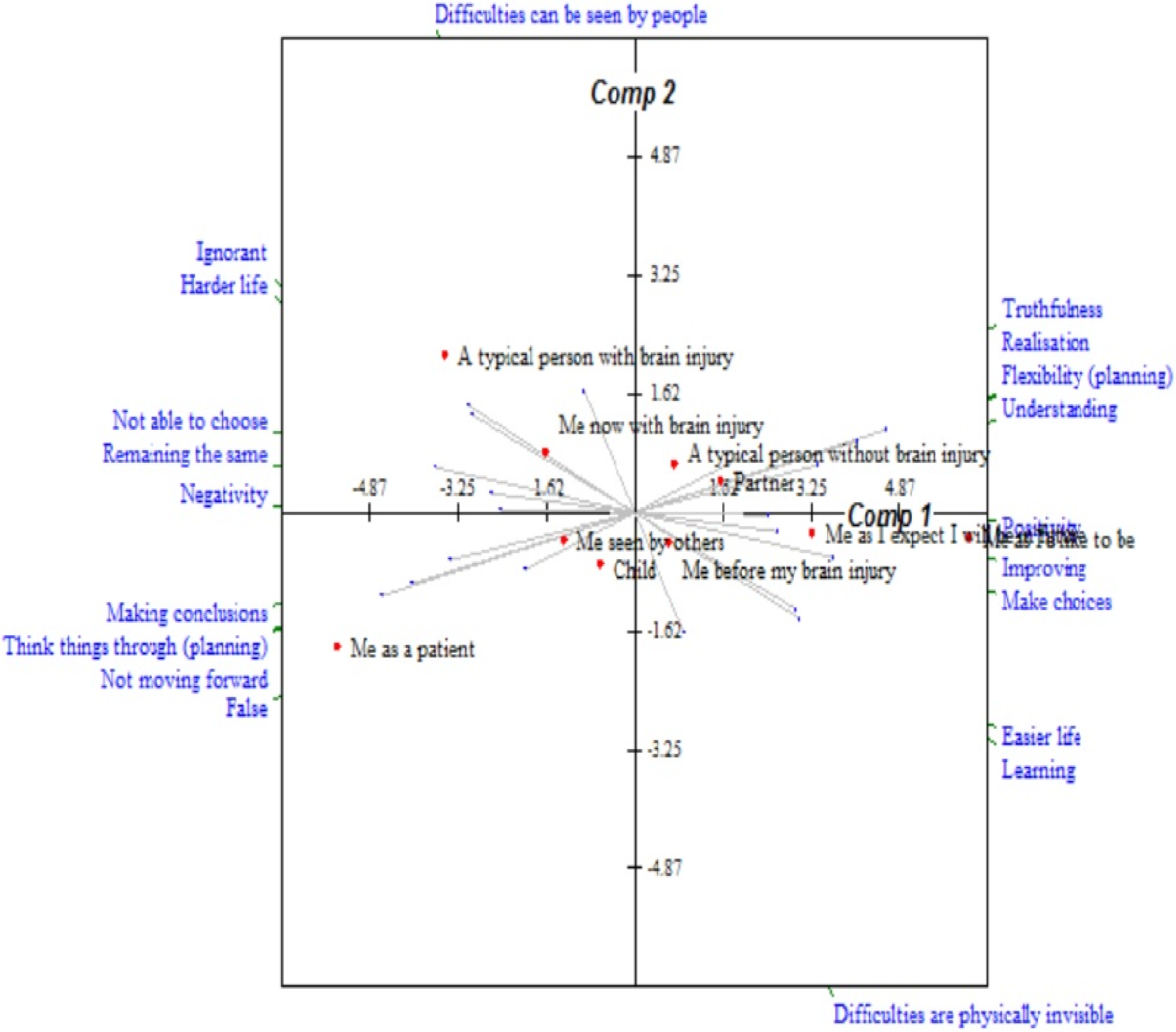
The principal components analysis of the repertory grid also provided data on the tightness or looseness of Percy's construing. The application of eigenvalue decomposition found that the first principal component could explain 41.69% of variance in the data. In light of 'normal' participants (Ryle & Breen, 1972b), Percy's construct system can be interpreted as what would be expected from a 'typical' individual, with his construing appearing to be not overly tight or loose.

The analysis of Percy's repertory grid data also elaborated on the salience of the elements from the grid for him. The data suggests that the elements 'Me as a patient’, ‘Me as I'd like to be' and 'A typical person with a brain injury' accounted for the majority of the variance in the data (22.4%, 19.51% and 13.58%, explaining 55.49% of the variance). From this it can be interpreted that these three elements were the most important from the grid for him. The analysis also elaborated on the superordinancy of the constructs. The data suggests that the constructs 'treated the same-treated differently', 'managing-struggling' and 'idealistic-realistic' accounted for much of the variance in the data, (20.8%, 16.2%, and 12.2%, explaining 49.2% of the variance). From this it can be interpreted that these three constructs are the most superordinate within his construct system, and therefore the most important to him.

Dean's construct system

Figure 7 below visually represents the way Dean construes himself and others in regards to the elicited constructs.

Figure 7. Plot representing Dean’s construing



The first component accounts for 80.03% of the variance, and contrasts people who have realisation, an easier life, truthfulness, positivity, are understanding, have flexibility (planning), make choices, learning and are improving with people who are not moving forward, have a harder life, are false, have negativity, make conclusions, have to think things through, are not able to choose, are ignorant and are remaining the same. The second component accounts for 8.37% of the variance, and contrasts people whose difficulties are physically invisible with people whose difficulties can be seen by people.

'Me seen by others', 'Child' and 'Me before my brain injury' appear to be elements that Dean may not have an elaborated construal of, which is reflected in their close position to the origin of the plot. From the plot it appears that 'Me now with brain injury' is construed as having a harder life, being ignorant and not able to choose, as this element is plotted closest to these construct poles.

The plot also suggests that 'Me as I'd like to be' is construed at a more extreme level than other elements, which can be seen by its position on the plot, which is further out relative to other elements. It is positioned at some distance from 'Me as a patient' and ‘A typical person with a brain injury’, suggesting that Dean construes these elements as very different to each other. This hypothesis is supported by the element Euclidean distances, which show a large difference between these elements (2.24 and 1.92).

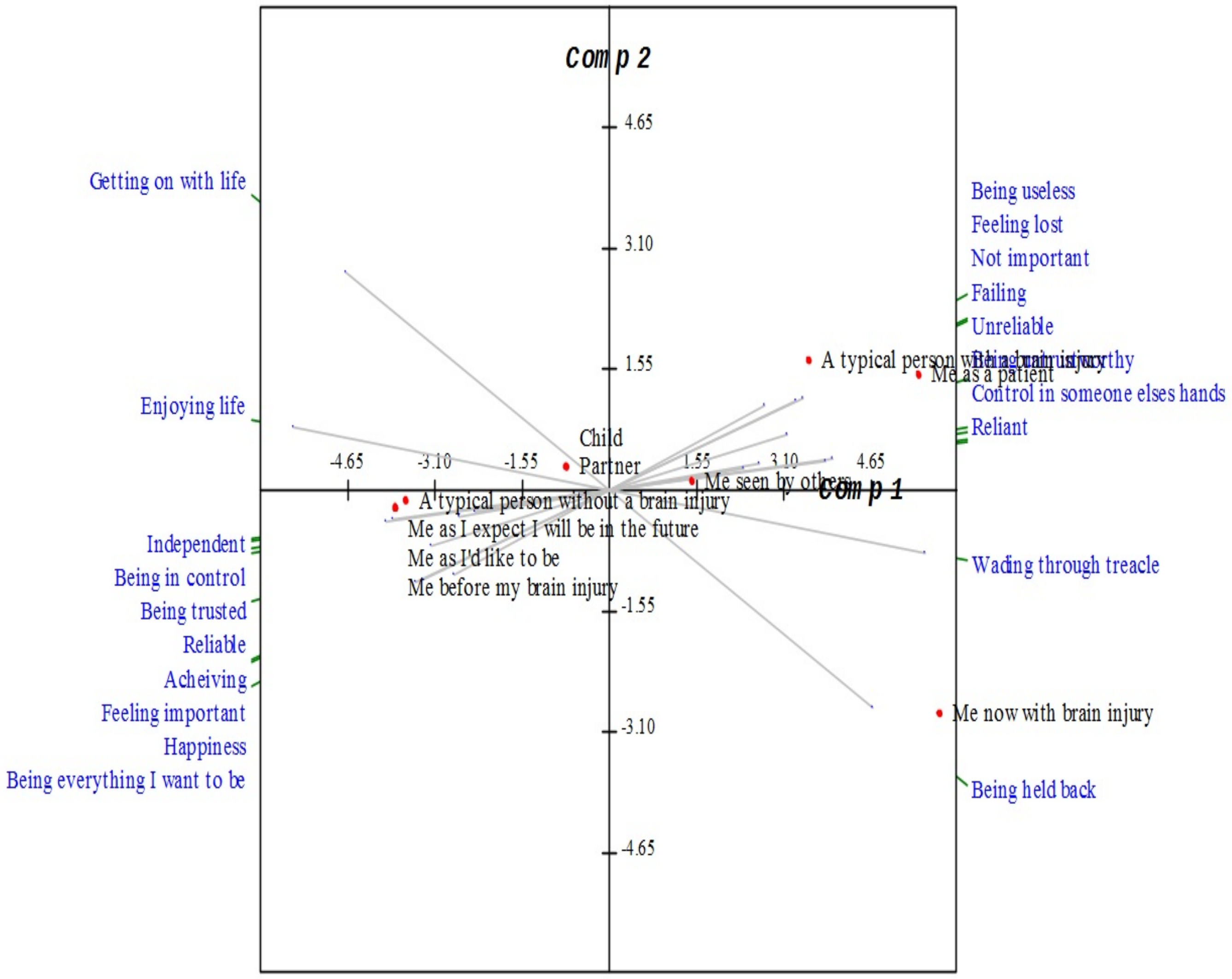
The principal components analysis of the repertory grid also provided data on the tightness or looseness of Dean's construing. The application of eigenvalue decomposition found that the first component could explain 80.03% of variance in the data. In light of 'normal' participants (Ryle & Breen, 1972b), Dean's construct system can be interpreted as tight and unidimensional.

The analysis of Dean's repertory grid data also elaborated on the salience of the elements from the grid for him. The data suggests that the elements 'Me as I'd like to be', 'Me as a patient' and 'A typical person with brain injury' accounted for the majority of the variance in the data (31.52%, 27.16% and 13.75%, explaining 72.43% of the variance). From this it can be interpreted that these three elements were the most important from the grid for him. The analysis also elaborated on the superordinancy of the constructs. The data suggests that the constructs 'realisation-not moving forward' and 'flexibility-think things through' accounted for much of the variance in the data, (26.4% and 18%, explaining 44.4% of the variance). From this it can be interpreted that these two constructs are the most superordinate within his construct system, and therefore the most important to him.

Robert's construct system

Figure 8 below visually represents the way Robert construes himself and others in regards to the elicited constructs.

Figure 8. Plot representing Robert's construing



The first component accounts for 86.95% of the variance, and contrasts people who are enjoying life, being everything they want to be, achieving, getting on with life, being in control, independent, feeling important, reliable, being trusted and have happiness with people who are wading through treacle, being useless, failing, being held back, control being in someone else's hands, reliant, not important, unreliable, untrustworthy and feeling lost. The second component accounts for 8.51% of the variance. Construct loadings showed that no constructs loaded onto the second component.

The plot also suggests that 'Me as a patient' is construed at a more extreme level than other elements. This can be seen by its position on the plot, which is further out relative to other elements. It is positioned in stark contrast to 'Me before my brain injury', 'Me as I'd like to be' and 'Me as I expect I will be', suggesting that he construes 'Me as a patient' differently to the listed elements. This hypothesis is supported by the element Euclidean distances, which show a difference between the element 'Me as a patient', and 'Me before my brain injury' (1.61), 'Me as I'd like to be' (1.61) and 'Me as I expect I will be' (1.61).

From the plot it also seems that 'Me now with a brain injury' is construed at a more extreme level than other elements. This can be seen again by its position on the plot, which is further out relative to other elements. It is positioned in stark contrast to 'Me before my brain injury', 'Me as I'd like to be' and 'Me as I expect I will be', suggesting that he construes 'Me now with a brain injury' very differently to the listed elements. This hypothesis is also supported by the element Euclidean distances, which show a difference between the element 'Me now with a brain injury', and 'Me before my brain injury' (1.70), 'Me as I'd like to be' (1.70) and 'Me as I expect I will be in the future' (1.70). From the plot it appears that 'Me now with a brain injury' is construed as being held back and wading through treacle, as this element is plotted closest to these construct poles.

The principal components analysis of the repertory grid also provided data on the tightness or looseness of Robert's construing. The application of eigenvalue decomposition found that the first principal component could explain 86.95% of variance in the data. In light of 'normal' participants (Ryle & Breen, 1972b), Robert's construct system can be interpreted as tight and unidimensional.

The analysis of Robert's repertory grid data also elaborated on the salience of the elements from the grid for him. The data suggests that the elements 'Me now with brain injury', Me as a patient' and A typical person with a brain injury' accounted for the majority of the variance in the data (27.35%, 21.85% and 10.9%, explaining 60.1% of the variance). From this it can be interpreted that these three elements were the most important from the grid for him. The analysis also elaborated on the superordinancy of the constructs. The data suggests the constructs 'enjoying life-wading through treacle' and 'getting on with life-being held back’ accounted for much of the variance in the data, (34.4% and 30.4%, explaining 64.8% of the variance). From this it can be interpreted that these three constructs are the most superordinate within his construct system, and therefore the most important to him.

3.2 Results of Interpretative Phenomenological Analysis

Following the elicitation of constructs, and analysis of the grid data, the data output reported above was discussed with all six individuals taking part in the study to see if they were in agreement with what had been found. They were then interviewed using a semi-structured interview based on the constructs elicited. A plot graph and grid from the repertory grid data analysis was given to all individuals outlining their constructs and system of construing as points of reference for support. Interpretative Phenomenological Analysis (IPA) was used to analyse the semi-structured interview data obtained from the individuals.

IPA was used to gain in-depth accounts of the lived experiences of males with an ABI. From this analysis, five master themes emerged, which have also been summarised in Table 16 (along with the subordinate themes that emerged):

- Invisibility
- Painful relationship with society
- Post-injury growth
- A vulnerable mind
- Importance of others in recovery

It is important to note that although this account attempted to understand the reality and lived experience of having an ABI, this account represents the experiences of six particular individuals at this point in time. This account also strives to represent the experiences of these individuals using themes emerging from my personal interaction with the data collected (Smith, Jarman & Osborn, 1999). I am aware that the themes and organisation of themes that have been constructed are as a result of my own construing of others’ construing, and in line with Kelly's philosophical assumption of constructive alternativism (Burr & Butt, 1992), are open to alternative construing by others. In light of this, I present this account not as a definitive account of the experience of living with an ABI, but instead one based on my experience of the experiences of six individuals with an ABI.

The rest of this section will be presented as a written narrative account based on the master and subordinate themes, using extracts from the interviews to retain the voice of the individuals whose experiences are being explored (Smith & Pietkiewicz, 2014). This account will highlight convergences of experiences across the dataset, while also indicating divergences between individuals. The rest of this section will now be written in the first person to support the researcher to present reflections and make subjective interpretations more transparent through the use of reflexivity (Elliot et al., 2009; Lichtman, 2013).

Table 16. Master and Subordinate Themes

	Master themes	**Subordinate themes**
1	Invisibility	*Hidden injury*
		Social invisibility
2	Painful relationship with society	*Feeling unable to meet perceived expectations*
		Unwanted labels and perceptions from society
3	Post injury growth	*Relational gains*
		Personal growth
4	A vulnerable mind	*Loss in thinking skills*
		Emotional and psychological fragility
5	Importance of others in recovery	*Learning and rehabilitation*
		Psychological encouragement through others

3.2.1 Invisibility

This theme reflected a sense of invisibility described by all of the men interviewed and appeared to be an invisibility experienced at two separate levels. Invisibility was described at the injury level, focusing on the invisible nature of acquired brain injuries, and at the social level focusing on a sense of individuals with ABI and their family members becoming invisible to others.

Hidden Injury

A theme that emerged from the interviews was about the invisible nature of ABI. Some individuals described their personal view of brain injuries as something not visible to the eyes:

> *Wouldn't be able to see that I've had that or understand that I've had an ABI. (Lance)*

> *I’m walking here and there whatever but I’m, you wouldn’t necessarily know straight away there was something wrong with me. (Dean)*

It appeared that these individuals were aware of some level of superficial 'normality' that did not outwardly identify them as having experienced an injury to their brain. I interpreted this as being a recognition of the outward appearance of brain injury, where appearance may not typically indicate an injury has occurred. One individual elaborated on the sense of invisibility of ABI becoming apparent to him during social situations with others:

> *Everyone else don’t actually know what’s happened to me. For example, the football club. Walk in there, no-one knows me, well people know me but not from my accident, they don't know I had an accident or anything. So they look at me a lot differently. And if I can’t do something they like why can’t you do that, why can’t you talk, why can’t you do things. (Bruce)*

It seemed that Bruce had become aware of the invisibility of ABI through interactions with the public, and from experiencing their surprise when he was unable to perform in some way. I interpreted this similarly to the above, that there appeared to be a superficial blending in with others. It seemed that his injury remained invisible until particular tasks, or expectations, could not be met within the gaze of others. One individual reported about the invisibility of particular difficulties related to brain injuries:

> *As people with a brain injury, it is a hidden injury, that some difficulties they have as mine which is fatigue, doesn’t show itself up automatically, nor would you notice, until such time as it took a dramatic turn for the worse. (Percy)*

It appeared that again there was a shared sense of a brain injury being invisible, or hidden, with this invisibility also extending to some related symptoms. I also wondered about the individual's use of the term 'hidden injury'. I interpreted this as perhaps an aspect of post-injury education he had been involved in, having heard and seen this term spoken about frequently within the organisation from where he had been recruited. I interpreted his use of this term as congruent with the preferred personal identities he spoke about within his interview, as an 'educator' or 'teacher'. In line with these, it appeared that he wished to pass on the education he had received to others, teaching them about the 'hidden injury'.

Social Invisibility

The second theme that emerged from the interviews linked to invisibility was about a sense of social invisibility that was experienced by individuals:

> *No, my friends, all of my friends left me, after my injury, before injury 14/15 of us, every day we get together, but after injury nobody comes to say hello even (pause). It's painful, painful for me. (Derek)*

Derek recognised the loss of his social circle, and was aware that he had gone from a regular full social life to the extreme opposite. He also appeared to be recognising a more general loss of connections, suggested by his statement of not even having basic interactions with others. I interpreted this not as just a loss of interactions, but of his social existence, where even the smallest polite gesture of acknowledging someone's presence had gone, leaving him with a painful sense of social invisibility. Another individual spoke of particular social interactions he had encountered:

> *Say somebody says to me… you know… "how are you?" … (pause) …I suppose…(pause)…the easy…answer is – and the one that everybody wants to hear is – "I'm absolutely fine!". Yeah, and…big smile and, and they, and they're- they're happy. (Robert)*

Robert's experience of some social interactions with an ABI appeared to be based on him going through the motions to present a social mask that hid the difficulties that having an ABI brought to his life. I interpreted this social mask as something that not only made his difficulties invisible, but also made invisible the real Robert (with the inclusion of his ABI) from social interactions. Other individuals spoke about a different level of invisibility:

> *None was given to those that were supporting me that were the hidden people, that were injured and that the bombshell dropped on them. (Percy)*

Percy described an invisibility of those who supported him, who were hidden from the gaze of health services. I was struck by his use of the words 'injured' and 'bombshell', and saw this as the people who cared for him as having experienced some type of vicarious trauma. However, according to Percy these people had not been offered support in the way he thought was important, leaving them as hidden and invisible, and part of the collateral damage from his injury. Another individual also spoke about how he felt that those that had cared for him, such as his family members, had been left unnoticed:

> *You lose sight of the fact that your people around you go through that as well. Ok they're not going through the illness but they're getting all the bad stuff and no good whatsoever. (Lance)*

Lance also described a sense of invisibility of those who had cared for him, although he included himself as one of the people who had been part of the process of making them invisible. An alternative interpretation also considered was that perhaps Lance had lost track of other people due to reduced awareness as a result of cognitive deficits, such as with executive function. Another individual spoke about social invisibility, but at a broader level:

> *But having said that, I had a brilliant meeting the other day with xxxxxx ok, and er, and I've, well I stressed a point too, I thought about brain injuries, what needs to happen about it is not everybody knows about it, you'd be surprised at the number of people who really know about it at all, and they've actually said that and I am in a way aware of that. I said "you know what, needs to happen", "what's that", I said "social awareness", and they said "well right how would you do that" and I said "I've got an idea". I said "if you for example were a good author, write a good book". (Dean)*

Dean appeared to describe ABI as a health phenomenon that was partially invisible at a societal level, requiring the re-education of the public via his recommended intervention of disseminating a book.

3.2.2 Painful Relationship with Society

This theme reflects the difficult and emotionally painful relationships described within the interviews between these individuals and society. This theme appeared to be describing two similar yet separate levels of experiences. The first was describing the experience of feeling unable to meet perceived social expectations across a number of roles, including work, fatherhood and gendered expectations of the male as the provider. The second was the experience of painful labels individuals perceived society was placing on them.

Feeling Unable to Meet Perceived Expectations and Norms

A theme that emerged from the interviews was feeling unable to meet perceived social norms and expectations within society. One individual spoke of his inability to work a 40 hour working week:

> *A normal person would be able to work 40 hours a week; I can't. (Percy)*

Percy had realised that he was no longer able to work in the way that he felt people expected him to. I interpreted what he told me as his ABI having made it difficult for him to meet the societal requirements of being a working man. I also found it interesting how he described himself in relation to normality. His statement making a comparison to a 'normal person' appeared ‘othering’, positioning himself as abnormal by default. I understood this as perhaps a reflection of how his difficulty meeting societal expectations had left him feeling, like he was now abnormal. One individual spoke more broadly about social normality:

> *Interviewer: And that unawareness that people from your culture might have towards a brain injury and what comes with it, does that help or hinder you in any way?*
> *Lance: Just think every day being accepted with that, within normal life I would say.*

Lance felt that a lack of social awareness of ABIs stopped him from feeling accepted by others. I interpreted this similarly to Percy's experience, with both Percy and Lance defining themselves as the opposite to 'normality', and left feeling a sense of not being able to meet social expectations. Like Percy, another individual spoke about being unable to work:

> *She doing hard work, I’m not able to do anything. (Derek)*

Derek spoke about how, in contrast to his wife, he was unable to work. I interpreted his comparison as being related to perhaps feeling like he had been unable to meet perceived expectations of him as a male, namely to work and provide. Derek came from a similar ethnic and cultural background to me, which he also acknowledged:

> *Derek: You Indian yeah?*
> *Interviewer: I am, yes.*
> *Derek: Then you know about the culture.*

The interpretation of this experience Derek described was perhaps contributed to by the sameness in the culture we shared. I was aware that within Indian culture there was an emphasis on both males and females taking traditionally gendered roles within relationships and families, with males working and females taking on the responsibility of looking after the home and family. I also felt my personal experience of growing up in an Indian family where there had been a similar role reversal as a result of health difficulties also contributed to my understanding of the experience Derek described. In light of this, there was an interpretation of possible emotional pain as a result of the reversal of roles and difficulty in meeting cultural expectations. One male also spoke about his experience of possible fatherhood:

> *That’s a really good question, it’s a hard question to answer, oh dear, dear, dear, how do I put this. We’ve had this discussion; we feel the problem is with this one, this is what I’m trying to say about this acceptance thing, cos something major has happened, it will be, we could have children ok, it could be the case that wife will have to look after the baby and I would as well, but and I’m thinking, that could set my recovery right back (laughs). (Dean)*

Dean described a sense of worry about the impact of having a child in the future in light of his ABI. It seemed that Dean was worried about fatherhood perhaps negatively impacting his ABI recovery, but conversely also the possible impact of his ABI on his ability to be a good enough father. I wondered whether there was a particular societal narrative of fatherhood that he was worried about being unable to meet because of his ABI. Another individual spoke more about his interests and activities:

> *I still can't play football (laughs). But everything else I am getting better. So I reckon I will play football. (Bruce)*

Bruce recognised that he had been unable to regain his ability to take part in his interest of football, but appeared certain this would change. I interpreted this as not only hope to regain his sports skills but also to regain his sense of masculinity. I wondered whether he hoped to fulfil expectations of him as a working age British male, in light of football having played a large role in British 'lad' culture. I also wondered whether his striving was also as a result of decreased self-awareness due to cognitive deficits, such as with executive function.

Unwanted Labels and Perceptions from Society

The second theme that emerged from interviews linked to society was about the difficult nature of the labels individuals felt society was placing on them. This theme was concerned with specifically wider views of society, the general public or others that were not defined as sharing close relationships with the individuals, such as friends, colleagues or close family members. The account by Derek highlighted one particular label he felt he had been given:

Derek: (pause) You know Punjabi language?
Interviewer: I do, yes.
Derek: I can’t explain in English.
Interviewer: Ok, you can explain in Punjabi if you want.
Derek: Yeah?
Interviewer: Yeah.
Derek: Like this they think oh he’s not working he’s “bichara”, you understand “bichara”?
Interviewer: I do, yes.
Derek: He’s not working from last seven years. They think like that.
Interviewer: And how do you feel about someone seeing you as a “bichara”?
Derek: Very bad.

Derek reported being labelled as a 'bichara', a Punjabi term that can be closely interpreted as a 'poor thing', a term he was not happy to be given. This term does not refer to the financial aspect, of being poor due to not working, but is usually used as a term of sympathy or pity. Unlike the other individuals, there was a sense of overwhelming pain experienced during this conversation about the label given. This may not seem apparent from Derek's use of the words 'very bad', but I wondered whether his exact feelings were hard for him to get across in English, but were captured in his use of the word 'bichara', painting a picture of someone whom society now pitied. I also wondered whether this experience was interpreted as overwhelmingly painful as a result of this conversation being reminiscent of my own familial experiences.

Two other individuals, Lance and Percy, talked about their experience of being labelled, this time with the label of disability:

In this country they pay people just to be disabled, they write them off. And I think they still have a lot to give and I think could, trying to think of the word, (pause), they’ve still got things to invest in this country. (Lance)

Because I don’t see myself as having a disability, although as I say I'm registered disabled.

(Percy)

Lance's use of the words 'write off' particularly struck me and appeared to create an image of being perceived as damaged or something that could no longer work, like a written-off piece of machinery. I interpreted this alongside his description of being paid for being disabled as a type of ‘pay off’, due to him no longer being 'workable' in society. Percy also spoke about disability, and how he had been registered as disabled. I interpreted the registration as a label having been placed on him, to fit him in a category socially. It appeared from both Lance’s and Percy's interviews that they rejected the disabled identity that was being placed on them, with Percy stating this more clearly as a way he did not see himself, with Lance more subtly offering alternatives that he would prefer.

One individual did not report specific labels, but perceptions of them that were inaccurate and unwanted:

Presume you’re drunk, presume you’re this, presume you’re that. (Dean)

For example, go out, I don’t know, when the balance on that day wasn’t brilliant someone would say “oh look at you, you been like on the piss, you been drinking beer or something”, right, I’d say “no, balance is down blah blah blah” and they would still be taking the mick or something like that. (Dean)

Dean had experienced his injury related difficulties as being presumed to be related to being drunk. I interpreted his use of repeating words (e.g. 'presume you're this, presume you're that', 'blah, blah, blah') as a way of portraying how often he had experienced this, perhaps again and again. I also understood his use of the words 'taking the mick' as him stating that he felt ridiculed by others’ perceptions of him.

Divergences from Master Theme

Across this theme one individual did not appear to report feeling unable to meet societal expectations, feeling particularly difficult feelings about others’ perceptions of them. Robert reported:

I think that…(pause) most people I think would probably see me as somebody who struggles to

> *find the words to have a conversation or remember anything. Erm, not much else really, um. It's difficult to, to, to tell. (Robert)*

I interpreted this statement by Robert as uncertainty of how others construed him. I wondered if this was perhaps due a lack of insight as a result of cognitive deficits, as he appeared to reach to concrete examples to illustrate his way of construing how others may construe him. At other points however I wondered whether Robert held a sense of anxiety about how others may see him:

> *You know… down at (organisation name), there are lots of groups of people with learning disabilities…and… it's a challenge to get to know them. You know, because…they don't behave…as you'd expect a person to behave (laughs). You're probably thinking "ahh…just like (own name) (laughs). (Robert)*

Robert was recognising that perhaps elements of his behaviour may at times not fit social norms. I interpreted his statement about my construing of him being followed by humour as a way of describing his anxiety about people seeing his behaviour as different, but following this with a defence mechanism to ease the potential pain of stating this, or the answer he may receive. It seemed from Robert's interview that he was perhaps still working out what others may think of him, as well as trying to manage his anxiety about this, but he did not state particular views or labels that had been given to him or people with an ABI.

3.2.3 Post-injury Growth

This theme reflects the experience of positive changes or gains following the acquisition of the brain injury described within the interviews. Two subordinate themes emerged for this theme. The first was describing the experience of having found improved interactions with others, or improved relationships. The second theme was reflecting the experience of having gained personal attributes or characteristics that were not present before the brain injury, and were construed as being positive changes.

Relational Gains

The first theme of relational gains was concerned with the experience individuals described of having changed relationships, new ways of interacting with others, or gaining particular factors that supported relationships or interactions. Five out of the six individuals highlighted improvements:

My relationship with my children and grandchildren is much better, so the answer is that I am richer after my accident than I was before. (Percy)

Percy described having better relationships after his accident, which I interpreted from his statement about feeling 'richer' now in contrast to pre-injury. The use of the word 'richer' also made me wonder whether Percy was assessing the amount of value he now had to his life, with the outcome being that it was of greater value now. Bruce also described having experienced a positive change in relationships:

I must admit, my family's changed completely now. Because now they're not coming cos they have to, they're coming cos they want to, so three or four of them will come down every three/four months just make sure I'm ok. (Bruce)

Bruce also recognised having changed relationships. It seemed from his description that his family were now meeting not due to social or cultural expectations, but instead because they wished to, bringing a sense of a new authenticity to their relationships.

Others spoke about finding that the nature of interactions they shared had changed:

I seem to get along with a lot of people easier than I did before possibly. (Lance)

I would say I was a much more controlling person before and knew what I wanted and it wasn't up for question, that was the way it was going to be, and I think out of all of this, the person I am now in that respect is a very big positive point in my life. (Lance)

Dean: Right ok, ok yeah, right and this takes a bit of getting your head around really, I can, how do I put it. Start being respectful to others.
Interviewer: Ok, can you tell me more about that?
Dean: Yeah (laughs) cos when you've been through, for example you have a major injury which I've been through, I think you might get to a certain point where you think "oh sod all you lot, you don't understand". But then obviously you thank god I'm out of that now. Then you get to a certain point where acceptance comes into play.

Lance and Dean recognised that their interactions with others had improved. Lance appeared to have recognised a new easier interaction process with others since his brain injury, in contrast to his pre-injury controlling way of being with others. He was able to make the link between this change and the sense of positivity this had brought him. Dean also had recognised having a change in the nature of his interactions; however, this had been something that had emerged as part of a journey of recovery after his ABI. I interpreted his statement as reflecting a journey in light of his reference to different perspectives at different points of his recovery. It seemed that as a result of this journey he had become more accepting, and in turn was able to have more respectful relationships.

Robert also described having experienced gains in a way that impacted his life positively:

> *What I, what love about my life now… is… having more time… for people. (Robert)*

I understood Robert's statement as recognition of having gained a more practical factor, time. This factor appeared to make it more possible in turn to have relationships, which he experienced as a highly valued change.

Personal Growth

The second theme of personal growth reflected the changes or new aspects to self described by the individuals interviewed, such as personal characteristics or attributes. These changes were all described in positive ways, and in contrast to the individual's construing of their former selves (before their brain injury). Five out of the six individuals reported some level of change or newness:

> *I feel I can be more understanding now than I was before and more tolerant. (Lance)*

Lance described a recognition of a change to himself from his former non-injury self. This did not appear to need further interpretation, with Lance himself identifying these changes as becoming more understanding and tolerant, and their contrast to his former self. Bruce also reported changes, this time to his emotional disposition:

> *I don't know, I didn't actually know I'd be happy though. I just (pause)...I just turned out to be*

happy and content. (Bruce)

Bruce described finding himself to be happy and content. It was difficult to interpret this statement separately to the awareness I had of Bruce's life experiences pre-injury that he had informed me of, which included a long period of depression. In light of this information, I interpreted this statement as a recognition of a new happier self he had found after his injury, although this is not directly observed in his statement. Another individual described an improved spiritual life:

Which is not a lot of financial benefit but is it spiritual benefit, far outweighs that and 64,000 dollar question is would I want to go back, turn the clocks back five years to before my accident and then have that kind of life to what I have now? My spiritual life is much better. (Percy)

Percy spoke about an improvement to his spiritual life, although noting this as not being financially beneficial. I interpreted this as perhaps an assessment process of how valuable his spiritual life may have been. It seemed that although his life now may not have been financially valuable, Percy recognised its value to him as a person at a spiritual level. I also interpreted his statement that his spiritual life was better as an answer to the $64,000 question, that he would perhaps choose his life now over his pre-injury life. Another individual spoke of his new-found interest in gardening:

It's just so nice to… put a little seed in the ground…and…(Pause) to see it grow…and then… you know…it grows into a vegetable. (Pause) That, that's really good, I enjoy that. I get a lot of…a lot of pleasure from that. (Pause) Which is…it's a new side of me I guess. I don't, I mean I don't remember ever being like that and…(pause) people who…knew me…when I…in my previous life… said that, you know… I'd be boring them to tears, talking to them about computer programs (laughs)! (Robert)

Percy also recognised a new aspect to himself that was different to his former pre-injury self, and recognised the pleasure it brought to him, which I interpreted as making this a positive and wanted change. I was also struck by his observations of watching a seed grow, and interpreted this as a metaphor perhaps for how he had also observed himself growing and developing, and finding pleasure in this process of finding new insights into himself.

Divergences from Master Theme

One individual did not report experiences that were in line with others' experiences of either relational or personal growth. He, in contrast, reported a number of losses within his relationships:

> *Derek: My married life is not good after my injury.*
> *Interviewer: So that's become quite difficult?*
> *Derek: Yeah, we just live together, that's it, nothing else.*
> *Interviewer: Was it different before your brain injury?*
> *Derek: We talked to each other and laugh.*

Derek recognised a change in his relationship with his wife from how their relationship was before his injury. I interpreted his statement 'we just live together, nothing else' as signifying some kind of loss of intimacy and closeness in their relationship, changing their relationship from a marital one to becoming relative lodgers in the same home. His statement about previously talking and laughing added to this interpretation, and seemed to describe a loss of both communication and a connection.

> *No, my friends, all of my friends left me, after my injury. (Derek)*

Derek also described a loss of friendships. I was struck by his use of the term 'left me', and I interpreted this as more than a loss of friends for him in light of another section of his interview where Derek told me about his closest family living outside of the UK:

> *Interviewer: Not in England? How about outside of England?*
> *Derek: My sister, my father.*

In light of this information, the loss of these friends was interpreted as perhaps like the loss of a surrogate family that had been formed in the place of his blood-related family, who were not in the UK.

3.2.4 A Vulnerable Mind

This theme reflects the aspects of individuals’ experiences described in the interview relating to non-observable phenomena typically and commonly related to the mind, including cognition, thoughts and feelings. Two subordinate themes emerged, the first relating to a perceived loss in thinking skills due to deficits within cognitive domains and abilities, such as memory or concentration, that appeared to leave the individual interviewed vulnerable. The second theme related to psychological or emotional difficulties that individuals appeared to be trying to protect themselves from, suggesting a vulnerability or fragility requiring protection.

Loss of Thinking Skills

This theme was concerned with a loss in thinking skills related to and as a result of cognitive deficits that individuals had experienced since their brain injury. One individual discussed their difficulties taking part in occupational activities:

> *I couldn’t run a business now, I don’t think I have the acumen or the intellect to do that and be able to make the right decisions to do that anymore. (Lance)*

Lance described being unable to run a business now. I interpreted his description of his difficulties with running a business due to his 'intellect' as him understanding his change in functioning to be a result of cognitive deficits that had impacted his thinking. I interpreted ‘intellect’ as reference to cognitive abilities because one’s intellect is usually measured on the basis of performance on certain tasks that require a number of different cognitive skills to be successful. From Lance's statement, it appeared he was describing a loss of ability to perform tasks across different cognitive domains (e.g. memory, concentration etc.) that are required to run a business, as a result of his ABI.

Dean and Derek both also described experiencing a change in their thinking skills due to cognitive difficulties:

> *Because with brain injuries I would say, which I found, was the way I found it, how do I put it, I think with, if you like, I’ll put it simply, with your computer being all messed about (laughs) which it has been. Ok, it makes it a lot, lot, lot, lot harder to think about things straight. (Dean)*

> *My brain doesn’t understand what to do now. (Derek)*

Dean recognised that since his brain injury he found it harder to think. I interpreted his reference to thinking as him alluding to cognitive performance, specifically the cognitive deficits he had experienced since his brain injury. Derek, in contrast, referred to having difficulties with understanding, linking this to a physical source (his brain). Although Derek referred to a physical source, I wondered still whether he was describing cognitive deficits he had experienced within particular domains. I wondered whether the nature of language used in everyday conversations had an impact on his way of describing his experiences. As cognition is a term not frequently used in everyday conversation, it was hypothesised that this was a word he may not necessarily have used, but instead alluded to through the use of more typical terms used in day to day conversations.

Other individuals referred more directly to particular cognitive abilities:

> *You would only know that they had a brain injury if you knew the common denominators related to brain injury which are concentration and memory and working memory as well, working memory in particular because that's what we all suffer with and what we are familiar with. (Percy)*

Percy appeared knowledgeable about the cognitive domains that individuals with a brain injury may commonly have impairments in. I interpreted Percy's reference to working memory being something 'we all suffer with' as a statement of both others' and his difficulties with this particular cognitive domain and thinking skills in turn. Other individuals' cognitive deficits were more apparent during the interview:

> *You need quite a bit of memory and brain power to do it. Because, is very much a…a… concentration of memory and focus, because you're (pauses and laughs). Sorry, I've forgotten my words. (Robert)*

Robert also was knowledgeable about the nature of cognitive abilities necessary for particular activities, which he also appeared to struggle with during the interview. Throughout Robert's interview his thinking difficulties were apparent at different points:

> *I was going somewhere and it was like… it's completely gone. (Robert)*

Sorry, I've forgotten my words. (Robert)

I interpreted these moments as demonstrations of cognitive deficits, such as decreased memory and word-finding difficulties, but also experienced them as quite exposing. These moments seemed to leave him quite embarrassed and vulnerable, unable to present himself in a way he may wish to due to his cognitive difficulties. I was aware that there had been similar moments with other individuals too:

And, oh no I've lost the thread now, I can't remember what the question was. (Percy)

Sorry what's your name? I forgot. (Derek)

There had also been a lot of repetition of answers and lack of depth at times. This all led me to wonder whether there was a subtle self-protection of not extending beyond a certain point, this time to avoid the risk of exposing one's cognitive vulnerability. Alongside this interpretation, I also considered an alternative way of construing these difficulties. I wondered whether their cognitive difficulties had simply made it hard to answer some questions, perhaps due to a lack of insight.

Emotional and Psychological Fragility

This theme was concerned with difficult psychological and emotional experiences that individuals appeared to describe, or try to protect themselves from, during the interviews. One individual spoke openly about his fears:

I can't walk around to the town on my own because I am scared. (Derek)

Derek stated feelings of fear about walking around by himself and named his feelings as being 'scared', revealing a fragile emotional aspect of himself. Others however avoided speaking about topics that were emotionally or psychologically painful:

I'm not really spending too much time (laughs) dwelling on this one because of nothing, I don't want things to screw my head up as well (laughs). (Dean)

I interpreted this as Dean avoiding the question asked to protect himself from difficult feelings. I interpreted this from his refusal to think further about the question, and understood this as a form of protection of his psychological self from something confusing, in light of his statement about not wanting to 'screw' his head up.

Others appeared to protect themselves in different ways:

> *My perception of someone with a brain injury, not proud of what I say was someone maybe slumped over at dinner table with dribble you know from the mouth and unable to do anything for themselves, you know like in a vegetative state more so, it never really occurred to me that someone with a brain injury, and as I said to you, people that I meet at xxxxxx are all very intelligent. They have attributes that they're either academically (pause) gifted or clever or smart. (Percy)*

I was struck by Percy's extreme change in constructions about individuals with brain injury from 'vegetative' to 'all very intelligent'. I initially wondered whether his change in constructions was as a result of having experienced something different to what he had anticipated based on his former constructs. Eventually I came to understand this as a form of self-protection. I interpreted Percy's change in construing as a way of rationalising to defend himself from the painful anxiety or fear that he may be viewed in a similar way to his previous constructions, as 'unable to do things' and unintelligent. Another individual also appeared to be using defence mechanisms to protect himself from worries:

> *Because… they don't behave… as you'd expect a person to behave. (laughs) You're probably thinking: "ahh… just like (own name)!" (laughs). (Robert)*

Robert's statement appeared to recognise social norms in relation to behaviour, as well as reflect on his own behaviour relative to this. I saw his use of humour after stating how his behaviour may not be as expected as a form of self-protection, to defend against and cope with the uncomfortable possibility that his behaviour was in reality breaking expectations. Bruce also appeared to be defending himself psychologically:

> *No, no, no, nah, nah, nah, nah. So what I can't play football. But again, I reckon I will play football again. If for example my, I'm partially blind, I can see to the left, right I can't see anything. But I tell my doctors, they've both said my nerves have been damaged. I can't see again. But I reckon I will see again. (Bruce)*

Bruce was aware that due to physical damage there were abilities he may not be able to regain. I was struck by how despite his current difficulties, and medical advice, Bruce did not accept any limitations. I interpreted his repetitive use of 'no', 'nah' and 'I reckon I will' as perhaps a form of denial, trying to convince himself and block thoughts about the opinion that he would be unable to do those activities through the repetition. I wondered if this was a type of blind faith to protect himself from the possible painful reality he felt unable to cope with emotionally. An alternative interpretation of this was that perhaps he was not trying to protect himself from painful feelings but instead was unaware of these as a result of a lack of insight, perhaps due to cognitive deficits in his executive functioning.

3.2.5 Importance of Others in Recovery

This theme reflects experiences reported by individuals about the importance of others within their journey to recovery. Two subordinate themes emerged for this master theme. The first reflected learning and teaching from others, some of this part of formal rehabilitation, and some experiences of less formal learning through close others. The second subordinate theme reflected the importance of interactions with or being around others in gaining psychological encouragement.

Learning and Rehabilitation

This theme reflected experiences of others playing a significant or important role in learning as part of individuals' recovery. Two individuals referred to specific experiences through formal services to highlight the importance of others to their recovery:

> *Derek: Bit better. Around like three years ago, my occupational therapist, she's from, comes from (organisation name), something like that.*
>
> *Interviewer: Ok.*
>
> *Derek: She take me out, she comes every week, comes to me every week once a day, once a week sorry, once a week for one/two hours, she takes me to the shopping market (pause) that's very helpful for me. I walk properly, she teach me, "(own name) don't do this, don't do this, like that yeah", she teach me, do that, don't do that, like that, it's useful.*

> *Mmm, er yes I would say, well for help, erm as regards, how do I put this, taking on board and listening to what others have got to say, I'm talking for example (organisation name) for example, what I've learned from (organisation name), which has been absolutely brilliant erm, and taking those points on board and taking them in, erm that has been yeah that has been a major plus. (Dean)*

Derek appeared to be referring to one to one input on physical and social rehabilitation that had been provided to him. I interpreted Derek's assessment of this help as 'useful' as having been an important aspect of recovering his physical abilities. Dean also spoke about having learnt important aspects from formal services (the name of the service has been taken out for anonymity), which he assessed as 'brilliant'. One individual referred to the importance of both formal and non-formal learning they had experienced through others:

> *If it wasn't for xxxxxx picking up, which is a charitable organisation, then god knows, I would never have made unless well I say would never have made, I would probably have made some progress because of (wife)'s knowledge on that side because she's worked with severely she calls them children with severe learning difficulties, brain injuries and so on, so she, her field specialises in that or should I say her knowledge, she has a vast amount of knowledge which would, what's the word, would be used to assist me so the impact on me would not be so bad. (Percy)*

Percy recognised that the progress he had made in his recovery had been due to the help he had received from formal services. He also appeared to recognise however that his wife's knowledge and support had also contributed to his progress in some way, and could have potentially played a larger role had formal services not been able to provide support. Bruce also highlighted the contribution of both health services and friends' contributions to his recovery:

> *Bruce: Health services have been brilliant to me.*
> *Interviewer: Yeah?*
> *Bruce: Yeah, they taught me how to speak, how to read, taught me how to write. Took me to physio, so yeah. Yeah, yeah, yeah. With hospital for six weeks they were brilliant to me and then I went up to xxxxxx hospital, they were brilliant to me.*

> *Two of my best friends, they sorted the (hospital name) for six weeks and then once a week*

> *used to come to (other hospital name) and every time used to come then teach me something else. (Bruce)*

Robert spoke of the contribution of being around others more generally having an important impact on him:

> *By getting out and… getting involved in other people's ways of being… you… I, I feel that that, that helps, as much as…doing other, erm, things like cog metal (COGMED) or something like that. (Robert)*

Robert seemed to describe that informal learning, through being with others, was of equal importance to formal learning via community rehabilitation programmes. I understood this as Robert acknowledging how important social support had been for him in his recovery, with it taking an equal position to formal rehabilitation.

Psychological Encouragement Through Others

This theme was concerned with reflecting the experiences of interactions with others playing an important role in giving individuals psychological encouragement. This nature of encouragement was less about an intentional encouragement given by others, but a perceived encouragement by individuals interviewed via the interaction or knowledge of the other. Some individuals found encouragement through comparison to other 'patients' they had met:

> *Other patients, they bad from me yeah, bad condition from me, I'm thinking about them, then I think "(own name) you are better than that, better than Them, you should be alright, go through it". (Derek).*

Derek found encouragement and motivation to keep progressing (interpreted from his use of the words 'go through it') by looking at others' difficulties. I construed Derek's use of self-talk as a form of motivation or encouragement in reaction to comparing himself to others. One other individual also seemed to look to others for encouragement:

> *So important yeah, so important and success for me, but not just me, other people; wife, family, friends, everyone. (Dean)*

During a conversation about needing determination to be successful in recovery, Dean highlighted the need to be successful not just for himself but as also being important to others. I interpreted from this that he seemed to look to others to encourage himself to pursue success, having more than one reason to continue trying to be successful (his family, friends and wife). Other individuals looked more to the interaction with others:

> *I think when I see people a month afterwards and they say you said that, that and that, that makes me realise that, that means next month I'll pick up some more words and I'll be able to read a lot more. (Bruce).*

It seemed through others bearing witness and reflecting on Bruce's progress, he in turn recognised his own progress. From his description of gaining insight on his own recovery through others, and using this to mean that his progress would continue, it seemed these interactions with others gave him a sense of motivation to keep striving for progress. Hearing others' alternative ways of construing difficulties during interactions also appeared to be helpful for other participants:

> *They very often will be discussing something and will say well "no, look at this way (own name), you've had a brain injury, you haven't done this on Purpose", whereas I come at it as if I wanted to have a stroke and wanted to have this brain injury, you know. They paint a different picture which I can understand, so I accept things a bit better and keep going. (Lance)*

Lance described hearing others' alternative ways of construing what had happened to him as important in both accepting changes, as well as giving him the motivation to continue with his recovery. I interpreted a sense of motivation from his statement about how through these interactions he found better acceptance and the will to 'keep going'.

4.0 Discussion

This section will begin with a discussion of the major findings. The findings will then be considered in light of the nature of the sample that participated, as well as the context of the research. The chapter will then focus on methodological limitations and strengths, and discuss the clinical implications of the findings as well as provide recommendations for further research.

Although typically new material is not introduced in the discussion section, this chapter will include some further studies. Qualitative approaches can lead to discoveries of new ideas or themes that had not been expected (Richards & Schwartz, 2002), and therefore it is important to address these within the context of the research literature available. As can be seen from this section so far, there will also be a return to writing in the third person.

4.1 Main Findings

Two aims were identified for this research: to explore the lived experience of males with a mild to severe ABI, and explore their construct systems to understand the meaning they have given their experience. Alongside this, the researcher also hoped to support individuals to engage in the research process using alternative research methods. The two aims will be discussed separately below, along with reflections on what this data overall suggests about the experience of males with an ABI. Following this, reflections will be given on the use of repertory grids.

4.1.1 Exploration of the Lived Experience of ABI

To explore the lived experience of males with a mild to severe ABI, semi-structured interviews were conducted that were analysed using Interpretative Phenomenological Analysis. From this analysis five themes emerged reflecting the lived experience of the individuals interviewed: invisibility, painful relationship with society, post-injury growth, a vulnerable mind and importance of others in recovery.

Invisibility

In this study a sense of invisibility was described by all the individuals interviewed. The invisibility described was experienced at two different levels - an invisibility of the injury and an invisibility at the social level - which included both the individual and their family members.

The sub-theme of ABI being recognised as an invisible injury resonates with previous research. Jumisko, Lexell and Soderberg (2005) described experiences of living with a traumatic brain injury as living with a 'hidden handicap', a phenomenon that held them back but could not be seen. Buck, Laster, Sagrati and Kirzner (2012) also conducted a qualitative study of health professionals, who also discussed the invisible nature of brain injury, and discussed it describing the “unseen” injury. They also highlighted how the invisible nature of brain injury put individuals at risk of experiencing suspicion from employers, family, friends and health professionals about the extent of their injury. No published studies are available however where the problematic ‘invisible’ or ‘hidden’ nature of brain injury is explicitly stated by participants, such as found in the current study. This new knowledge not only helps to contribute to understanding the way individuals construe the nature of brain injury, but also provides support for previous research describing the invisible nature of brain injury.

The emergence of invisibility at the social level is also similar to previous research findings, such as Nilsson, Jansson and Norberg (2000). This study described how individuals experienced an imbalance within the developmental crisis 'intimacy vs. isolation' after their injury, with the balance here tipping towards isolation. Individuals in the current study also described losses of social connections such as friends, which again is similar to previous studies (e.g. Dowswell et al., 2000). The current study also found that individuals with a brain injury discussed the invisibility of important others, who were not living with a brain injury but had been personally affected. Again elements of this are consistent with previous research where family members reported their experience as the 'hidden' victims of injury due to the impact on their family dynamics, caring and adjustment (Degeneffe & Olney, 2010). No previous studies could be identified where individuals had identified the impact of their ABI on others, highlighting this as a contribution to the existing literature.

Within the sub-theme of invisibility at a social level, a lack of social visibility of brain injury as a health difficulty was also alluded to. This theme was similar to findings from previous research, including a study by Swift and Wilson (2001), which interviewed people with a brain injury and their caregivers to explore their experience of the UK general public and professionals. They found descriptions of experiences of the public and professionals having inaccurate and inadequate understandings of brain injury, and hypothesised that this was due to a lack of awareness of brain injury. More recent studies of the UK public also show similar findings about a lack of understanding of brain injury, such as about the extent of difficulties and vulnerability (Chapman & Hudson, 2010).

Painful Relationship with Society

A difficult and emotionally painful relationship between individuals and society was described during interviews. This included the experience of feeling unable to meet perceived social expectations such as traditional expectations of males, a finding that again resonated with previous research. Jones and Curtin (2011) found that males described a movement away from traditional male roles, including 'the breadwinner', something that was similarly interpreted about the experiences described by individuals in the current study. Jones and Curtin (2011) however reported that individuals experienced a change from the traditional gender roles to traditionally female roles such as caring, which was not described in the current study. Interestingly the findings from this study are also congruent with those from a qualitative study of women living with a brain injury. Haag, Caringal, Sokoloff, Kontos, Yoshida and Colantonio (2016) found that women described a sense of difficulty fulfilling traditional gender roles, such as caregiving or as home-makers. This suggests that the experience of difficulty meeting social expectations is one that may be experienced by both males and females, although further research is required to explore this.

The current study also found individuals described being unable to fulfil occupational and employer expectations due to their injury making it difficult to work, which is also congruent with previous research. Gilworth (2008) found that continuing symptoms affecting an individual's ability to do their job was reported by participants. Greenspan, Wrigley, Kresnow, Branche-Dorsey and Fine (1996) also found that failure to return to work was related to reduced cognitive function after brain injury. This study also found that failure to return to work greatly increased when individuals also had motor limitations, which was experienced by three out of the six people in the current study.

The second sub-theme found within the theme of painful relationship with society was in recognition of the individuals' perception of society placing labels on themselves that they deemed undesirable. Culture-specific perceptions of having a brain injury were reported by one individual within the current study from an ethnic minority background. A previous study conducted in Australia found that individuals from an ethnic minority background experienced shame and stigma, and the label 'brain injury' itself was understood in some languages as a type of shameful madness (Simpson, Mohr & Redman, 2000). The current study found similar themes, with one individual describing being labelled in an unwanted and difficult way by people from within the same culture. However, it is important to note that the perceived labels and explanations given in Simpson, Mohr and Redman (2000) were from differing cultural backgrounds to those within the current study. There is an absence of studies focusing on the perception or construing of individuals from ethnic minority backgrounds with brain injury living in the UK at this time, making this aspect of the current study an original contribution to the research in the UK.

Individuals in the current study also spoke about being labelled with terms that held negative connotations, such as the term ‘disabled’, which is consistent with previous literature. Nochi (1998) found that individuals reported terms that were used to describe them that they perceived to have negative connotations of abnormality, or that placed them within traditionally stigmatised groups such as those with learning disabilities and mental illness. Similar misperceptions by the public have also been reported by individuals with a personal, familial or professional experience of brain injury in one other study. Swift and Wilson (2001) found that the public frequently misidentified individuals with brain injury as either having learning disabilities or being mentally ill.

Post-injury Growth

The current study revealed a theme reflecting the experience of positive changes or gains following brain injury within interactions or relationships, as well as personal attributes or characteristics. These findings were also similar to previous research that has found post-injury changes across the personal and interpersonal domains (McColl, Bickenbach, Johnston, Nishihama, Schumaker, Smith & Yealland, 2000). It is also consistent with Gelech and Desjardins (2011), who recognised a post-injury 'moral growth process' for the self. The current study found post-traumatic growth described by five out of the six individuals who took part in the study, all of whom had PHQ scores categorised from none to mild, and GAD scores categorised as non-clinical. Previous research findings have been inconsistent, with some studies suggesting a negative relationship between anxiety, mood and PTG (Hawley & Joseph, 2008), whilst others suggest an absence or a non-prominent relationship between anxiety and PTG (Grace et al., 2015; Hegelson et al., 2006). As this study is not correlational or exploring relationships it is unable to contribute to the debate regarding the relationship between these factors. It can however contribute that within this sample, PTG was experienced by individuals who also reported to have minimal emotional well-being difficulties. The one individual who did not report PTG had higher scores on the PHQ (8), but this was still within the category of mild depression.

The individuals in this study had a range of years since injury between five to eight years. One systematic review of studies found a medium effect size (ES^r=0.38) for the relationship between years since injury and growth following injury (Grace et al., 2015), suggesting that people with an ABI experience more growth over time. In light of this, it is hypothesised that perhaps the PTG reported could be a reflection of the stage that individuals in this study were at in regards to living with their injury and recovery.

A Vulnerable Mind

This study also found a theme reflecting difficulties with cognitive abilities, or thinking skills, such as memory and concentration, that appeared to leave individuals vulnerable or unable to do what they used to. This finding was consistent with Brewin and Lewis (2001), which found different aspects of life impacted by cognitive difficulties, leaving individuals with decreased functioning at work, within the social domain or at a personal level.

The current study also found moments of vulnerability that the individuals appeared to try to psychologically protect themselves from. Studies have been conducted examining the relationship between maladaptive and adaptive coping styles with adjustment and functioning (Anson & Ponsford, 2006; Gregório, Ponds, Smeets, Jonker, Pouwels, Verhey & Heugten, 2015), but there is no qualitative research outlining a similar sense of vulnerability. This finding could be understood in light of the Theory of Stress and Coping (Lazarus & Folkman, 1984). It is hypothesised that perhaps individuals used emotion-focused coping strategies, such as avoidance or humour, in light of an appraisal of the challenges within their life with ABI being emotionally difficult and requiring management using internal (psychological) resources. An alternative construction of this finding was that the lack of insight due to cognitive deficits could also have accounted for their difficulty in elaborating on parts of our discussions.

Importance of Others in Recovery

The final theme found by this study reflected the importance of others within the individuals' journeys to recovery, such as through supporting their learning. A second sub-theme (as part of this theme) recognised an unintentional motivation provided by others via interaction. The literature reviewed in Chapter One of the current study found predominantly negative impacts of ABI within relationships, such as losses of these connections or a new lack of intimacy, and therefore this theme is inconsistent with the research reviewed. One hypothesis of this finding is that perhaps this theme may be connected to a sense of having a greater connection with and appreciation for others, which has been reported as part of PTG in previous studies (Grace et al., 2015). It could be that this sample of individuals, with the exception of one, may have commented on the importance of others in their recovery as a result of a new or increased appreciation for others as part of their PTG.

Summary

The main findings appear to be predominantly consistent with previous research. Aspects of social invisibility, feeling unable to meet perceived expectations, unwanted labels and perceptions from society, PTG (both relational and personal) and cognitive vulnerability have all been described in previous research. There were also some findings not yet seen in previous research, such as explicit examples of the ‘invisible injury’ and ‘hidden people’ from the point of view of the brain injured person. Alongside this, cultural perceptions of brain injury were highlighted by one person. The appreciation of others as being important to recovery was also reported. In addition, PTG was found in this study and can contribute to understanding the relationship between PTG and depression and anxiety, by contributing further perspectives to the existing research. The next section will go on to discussing the results from the repertory grid analyses.

4.2 Nature of Construing Underpinning the Interpretation of Experience

Repertory grids were used to understand better the way in which individuals construe their experience, through gaining insight into their construct system. From this analysis, common areas were found within the content of constructs as well as the process and organisation of construing.

Content of construing: The constructs

Common topics were found underpinning constructs across cases within the following areas: control, reliance, positivity, moving forward, nature of life, realism, achievements and truth.

Gracey et al (2008) used a personal construct approach to examine the constructs of individuals with an ABI, and found the themes 'experience of self in the world', followed by 'basic skills', which included cognitive, sensory, physical and social skills, and 'experience of self in relation to self'. Some constructs that were consistent with this research were found within all three themes. The current study found constructs about physical and cognitive problems, consistent with the theme of 'basic skills'. It also found constructs similar to the theme of 'experience of self in the world'. Finally, this study also found constructs that fit into the theme of 'experience of self in relation to self' within the areas of control and motivation. The current study also found constructs not consistent with those found by Gracey et al. (2008). These constructs fell within the domains of the experience of life with an ABI more broadly (e.g. easier life- harder life), self-actualisation (e.g. improving-staying the same), positivity (e.g. positive thinking-negative thinking) and visibility (e.g. difficulties are physically invisible-difficulties can be seen). Therefore, it appears that the current study not only has found some consistent aspects in light of previous research, but also some new areas to contribute to personal construct research within the area of ABI.

Process of Construing: Tightness and Looseness of Construing

The process of the individuals' construing was also examined. Commonalities were found across cases, with four out of five individuals found to construe tightly. The four individuals were found to be tight construers relative to a sample of 'normal' participants (Ryle & Breen, 1972b), where the average percentage of variance accounted for by the first principal component of the grid was 39.4%. The tight construers in the current study were significantly above this, at 93.25% (Bruce), 79.6% (Lance), 80.03% (Dean) and 86.95% (Robert). Tight construing leads to unvarying predictions, suggesting that these individuals may see their experience in one certain way with little room for alternative constructions. Derek was also a tight construer (64.72%), but due to the small number of constructs elicited on his grid which can lead to exaggerated results, this must be interpreted with caution. One individual was found to have construing closer to 'normal' construing (Ryle & Breen, 1972b), with a percentage of 41.69% found for Percy.

There is no previous research on the process of construing of individuals with ABI to refer to, but reflections from the interview will be made instead. It appeared apparent at times during the semi-structured interviews that the tight construers found it difficult to consider certain topics from another perspective. Alongside this, these individuals would return to specific hypotheses and understandings that they repeated frequently. A critique of this hypothesis however would be that the repetition observed and difficulty expressing alternative perspectives may have been due to cognitive deficits related to their injuries, such as memory, cognitive inflexibility or rigidity and poor insight. Cognitive deficits within the domain of executive functioning (e.g. perseveration and self-monitoring of communication) may have also contributed to this.

Organisation of Construing: Salience and Superordinancy

Commonalities across the structure of construing were also examined, specifically the hierarchical structure of construing to examine the most commonly salient elements and the most extremely construed elements.

The salience of elements was examined. The element 'A typical person with a brain injury' was found to be highly salient as a superordinate construct within the construct systems of five individuals (Derek, Lance, Percy, Dean and Robert). Following this, 'Me now with a brain injury' was found to be the next most frequently salient element for three individuals (Derek, Lance and Robert), as well as 'Me as a patient' (Percy, Dean and Robert).

The organisation of constructs was also examined. Although individuals had varying personal constructs as these were elicited from each individual, some similarities could be seen. There were three superordinate constructs for different individuals all relating to a theme of being restricted ('enjoying life-wading through treacle' (Robert), 'getting on with life-being held back' (Robert) and 'realisation-not moving forward' (Dean)). There were also two superordinate constructs placed as most superordinate relating to difference ('being normal-being different' (Lance)) and 'treated the same-treated differently' (Percy)). Alongside this, there were also two superordinate constructs relating to ABI sequelae ('no physical problems-physical problems' (Derek)) and 'flexibility-thinking things through' (Dean)). There is no previous research on the structure of construct systems of individuals with ABI. It is hypothesised, however, that the topics reflected by individuals’ constructs were a reflection of the areas experienced as most impacted following their injuries, which has also been found by previous research (Chamberlain, 2006; Nalder, Fleming, Cornwell, Shields & Foster, 2013; Wilson, 2008).

Construing of 'Me now with a brain injury'

The construing of the element ‘Me now with a brain injury’ was found to be predominantly negative, with terms used that would traditionally have negative connotations. The negative construing of the element 'Me now with a brain injury' is consistent with previous research, which has also reported descriptions of overwhelmingly negative changes post-injury (Dowswell et al., 2000).

One individual out of six construed the element 'Me now with a brain injury' differently to the above individuals, and reported being happier, with post-injury construed more positively. This finding was consistent with one previous study (McColl et al., 2000). Further research is required within this area to elaborate on and understand these findings.

4.3 Reflections on the Experience of Males with an Acquired Brain Injury

The researcher aimed to understand the experience of males with an ABI. Speculations can be made about the impact of an ABI on males, however it is important to note that this research did not aim to obtain a generalized understanding, but instead took an idiographic and phenomenological approach to understand the experience of one particular set of males. In light of this, it is helpful to consider the speculations below as hypotheses that may be transferable to understanding males with an ABI within a similar context.

Previous research has described how following an ABI, males and females report feeling unable to meet perceived social and gendered expectations (Jones & Curtin, 2011:Haag et al., 2015). Similar experiences were described in this study. Percy reported being unable to work ’40 hours a week’, which appeared to be a reference to a social norm or expectation of one’s working life. Another participant, Derek, reported being ‘not able to do anything’ in comparison to his wife. Although he did not explicitly state this as difficult within the context of his gender, his reference to his personal context as a male within Indian culture was suggestive of his experience as not meeting expectations of him as an Indian male, such as being the breadwinner or provider (Shah, 2013). Another participant avoided the topic of culture and religion, with Bruce stating that his mother was a ‘Hindu’ but this was not how he saw himself. Again, although not explicitly stated, it was hypothesized this avoidance was perhaps as a result of feeling unable to tolerate speaking of the dissonance between his current capabilities and what would be expected of him within the Hindu religion and Indian culture.

In light of the above it is hypothesized that the impact of an ABI may be at a deep psychological level, perhaps impacting one’s core constructs. Core constructs and construction of the male identity take place within a social and cultural context, and following the transition caused by a life-changing health event such as an ABI, one may experience a dislodgement from their core constructs (referred to as ‘guilt’ by the personal construct psychology perspective). These core constructs may be based on or contributed to by cultural or societal expectations, and being unable to act in the world in line with these may cause emotional distress, and a loss of or undermined identity. Emotional distress and a loss of the male identity as a result of the impact of mental health events on the ability to work has been documented before in research (Norris, 2016), and may be applicable to the impact of physical health events on males also.

For males whose identities are based heavily on traditional views of the role of the male, the impact of a health event on their view of themselves may be large. Recent research identified that men that are unable to meet a masculine ‘gold standard’, which includes having employment and acting as the breadwinner for one’s family, are placed at greater risk of suicide (Wyllie, Platt, Brownlie, Chandler, Connolly, Evans, Kennelly, Kirtley, Moore, O’Connor & Scourfield, 2012). This research did not look at the impact of both physical health and unemployment difficulties on males however. Based on the above, it is hypothesized that perhaps the impact of an ABI can have an impact on one’s sense of who one is. This may be important for clinicians providing emotional or psychological input to consider in their work.

4.4 Research Methods for Participant Engagement: Reflections on the Use of Repertory Grids

The researcher aimed to utilise a research method supporting individuals with an ABI to engage in the research process. This was done by using a combination of both repertory grids and semi-structured interviews, using the repertory grid data and its related plot as a point of reference to guide individuals if needed during the interview.

The repertory grids were used by five out of six individuals without difficulties. They were observed to use the grids during the interviews at times when it had been difficult to express a point, with individuals looking for terms that they felt summarised what they were trying to express. An example of this was Bruce looking to his grid to summarise his experiences related to his continuous movement towards recovery as being due to 'determination', a construct on his grid. One individual however found the process of eliciting constructs difficult and asked to stop after five, although the rating of these was free from difficulties. As five out of six individuals utilised the repertory grids as points of reference with little difficulty, it is suggested that this is a helpful research method to use for individuals with cognitive difficulties.

Previous studies reported difficulties supporting individuals with severe injuries who struggled to express themselves in the narrative form (Chamberlain, 2006). Although this study has used repertory grids to support reporting in the narrative form via interviews, the individuals in this study did not have apparent difficulties with verbal expression or comprehension that impacted the research process. In light of this, it is difficult to assess whether repertory grids would be helpful with individuals who struggle with the narrative form. This study does however acknowledge the utility of repertory grids in supporting individuals with cognitive difficulties to engage in the narrative aspects of research.

4.5 Further Context to the Findings: Cognitive and Physical Deficits

The physical and cognitive deficits experienced by individuals may also provide important context to the findings of this study. From the MPAI the domain of participation appeared to show that across cases there were two individuals experiencing little difficulty with participation (range= 1-7), and four individuals who were experiencing mild to moderate difficulties (range= 10-19). Although particular individuals reported difficulties in relation to employment or transport, it is hypothesised that perhaps participation was not reflected within themes and constructs, as these individuals were well supported to access other forms of participation (e.g. voluntary work, groups at the organisation they were recruited from).

The domain of adjustment appeared to show that across cases there was one individual experiencing little difficulty with adjustment (score= 0), three individuals with mild to moderate difficulties (range= 11-16) and two individuals with severe difficulties (range= 26-28). Again it is hypothesised that the range in adjustment seen here may have had an impact on the themes and constructs found. The individual reporting 0 adjustment difficulties, also was found to construe his life now as 'happier', as well as to report PTG. The remaining individuals experienced mild to severe difficulties across the domain of adjustment, and it is hypothesised that this may have impacted the social nature of themes that emerged from the data (e.g. feeling unable to meet social expectations and norms, perceived unwanted labelling by society, social invisibility).

The domain of ability showed that across cases there were five individuals experiencing mild to moderate difficulties (range= 10-18) and one individual experiencing severe difficulties (score= 31). Cognitive difficulties were also examined further using the ACE-III, which found that one individual's cognitive difficulties had been highly impacted (63/100), whilst others had less difficulties (range= 86-94/100). This suggests that perhaps the findings from this study may not be helpful to understand the experience of individuals post-injury where they have acquired a higher level of cognitive deficit.

4.6 Methodological Considerations

This section will now discuss the strengths and limitations of this study, focusing specifically on the credibility, transferability, dependability and confirmability of the findings (Shenton, 2004). The strengths and limitations of the methodology used will also be discussed.

4.6.1 Transferability of Findings

The aim of qualitative research, and IPA in particular is to explore the individual and personal lived experiences of participants in detail via a phenomenological approach, using an idiographic mode of inquiry (Smith, 2007). The repertory grids were also used due to their phenomenological approach, and utilised to understand each individual's construct system, again taking an idiographic approach. The idiographic approach seeks to understand the individual's experience as opposed to a general understanding, traditionally taken by the nomothetic approach (Smith et al., 1995). In light of this, it is difficult to make generalised statements about the wider population of males following a mild to severe brain injury, but it provides one understanding of a group of individuals from this population at this point in time. Instead an attempt will be made to draw the boundaries around the research topic, as suggested by some researchers (Shenton, 2004).

4.6.2 Settings

The individuals in this study were recruited from two branches of a brain injury charity that provides slow stream community rehabilitation to individuals with an ABI. This is in the form of advice, education and guidance about physical, cognitive and emotional difficulties. As a result of this input, the experiences of the individuals who participated in this study may be different to those of individuals who have not engaged with non-statutory or voluntary agencies after discharge from medical care or inpatient rehabilitation. It could also be that the individuals who are more cognitively and physically restricted to engage with these services, and this research in turn, may have been missed by this research.

4.6.3 Sample

It is important to consider the nature of selection biases that could have impacted this study. The individuals who took part in this study were selected at the first stage of recruitment by a staff member working in the organisations, with an aim to ensure individuals who had capacity and were of low risk to others were selected. This criterion itself would have had an impact on the nature of individuals selected, with individuals with more severe executive functioning or behavioural difficulties not being selected. The organisations may also have selected individuals known to have had better experiences at those services, due to concerns about how the opposite could reflect on the organisation. This would have had an impact on the research in turn, with some experiences being missed.

Once individuals were identified as being potentially appropriate to participate in this research, they were invited to meet with the researcher. Volunteer bias could have therefore had an impact, with the sample containing individuals who had chosen to participate

(Callahan, 2007), as opposed to random sampling representing the wider population of males with an ABI.

In line with the idiographic approach, this research aimed to recruit a homogenous sample in order to capture an in-depth understanding of the experience of one set of individuals. Due to the unique physical, emotional and psychological impact of an ABI, and how this can vary according to the individual in light of their pre-morbid abilities, it is difficult to obtain a homogenous sample of individuals with an ABI (Vakil, 2005). This can be seen in this study, with the six participants varying in regards to their cognitive, physical and social difficulties reflected by their ACE-III and MAPI-7 scores. The sample also varied in regards to ethnicity, marital status, and the severity of the ABI. The age range of the sample was also wide, with the youngest member aged forty-one and the oldest aged sixty-five. The sample was however homogenous in other areas, such as employment status, level of psychological difficulties (reflected by the PHQ and GAD scores) and with all participants having lived with their ABI for between five to eight years.

Individuals' time since injury may also have had an impact. In light of the study by Grace et al. (2015) discussed earlier in this chapter, the participants in this sample may have reported different experiences to those earlier on in their recovery, impacting the nature of findings. The research itself also was reliant on using the narrative form to collect data via interviews, which could have restricted individuals with deficits within the area of language to take part.

4.6.4 Credibility

Credibility checks are an important aspect of the interpretation process within qualitative analyses, to ensure the findings are congruent with reality. One way of assessing credibility is using member checks to determine the accuracy of interpretations. Some researchers describe member checks as the most important aspect of ensuring credibility (Shenton, 2004), but others argue against these due to concerns that they lead to confusion (Yardley, 2008). Member checks were not possible to do due to time constraints, but other credibility checks were carried out. These included peer scrutiny of data analysis stages by peers and supervisors, including those familiar with the methods used. Findings from this study were also considered in light of previous research to assess for consistency, and potential researcher biases were highlighted at the beginning of this thesis.

Credibility was also considered specifically in regards to how elicited constructs were defined in the results section. Elicited constructs were elaborated on by participants, and this data was then used by the researcher to create a definition summarising the construct and any psychological concepts or processes the constructs alluded to. One criticism of this process is that the definitions were not subject to peer scrutiny to assess the congruence of the definitions with how participants understood their constructs. A way in which this could have been overcome is by using verbatim descriptions given by participants, which may have been more aligned with the idiographic, phenomenological and person-centred approach used by this research.

4.6.5 Dependability

Dependability of the research conducted was also considered, not to enable future researchers to gain replicable results, but as Shenton (2004) suggests, to understand the context of the research and research approach taken. To do this, the research method employed has been described in detail, along with the materials used. Alongside this, interpretations have been contextualised as far as possible as seen earlier in this chapter.

4.6.6 Confirmability

Confirmability is the extent to which the findings can be corroborated with others, and are not as a result of the researcher’s own beliefs, values or interests (Shenton, 2004). Personal reflections on interpretations being made were given within the narrative account, as well as a statement of position at the beginning of the thesis, to provide transparency to support the reader and researchers to assess for confirmability. Alongside this an audit trail is also available in Appendix 13.

One criticism of the confirmability of the research method used is in regards to way in which the data-driven content analysis to find commonalities between constructs was conducted. Data driven analyses include a stage of independent peer scrutiny to ensure confirmability. However, this was not possible due to a lack of time and resources.

4.6.7 Methodology: strengths and limitations

Neuropsychological Measures

The ACE-III and MPAI-7 were used to screen for whether a participant met the inclusion criteria of having an ABI. A strength of this method is that it is unbiased, with these methods relying on standardized administration, scoring and interpretation. A limitation however was the length of time and effort required to administer the tests, with some participants requiring one and a half hours to complete these measures alone. Another limitation is that despite the commitment of time needed to administer these, they were not able to give further meaning to the research, other than whether the participant met the research criteria. Although the ACE-III AND MPAI scores were used to contextualise the results in the discussion chapter, they could not be applied further than this. An alternative method that could have been used was liaison with participants' General Practitioners, or obtaining their medical records, to access information on their health status that already existed. This would have contributed the same information in regards to whether a participant met the criteria, but taken less time, and less effort from participants.

Use of Mixed-Methods Approach

A mixed-methods approach was taken in order to meet the aims of this research, using a combination of repertory grids and semi-structured interviews analysed using IPA. A strength of combining these methods is that it allowed for a deeper exploration of the individuals' experiences, covering their conscious meaning-making via semi-structured interviews, and what may at times be more unconscious meaning-making using the repertory grids. This combination of these methods was also complementary, with the repertory grids helping to bring structure with constructs that could be used as a frame of reference, which the semi-structured interviews were not able to provide due to their open nature. A limitation of using a mixed-method approach however was that an overwhelming amount of data was collected, with little time to use the data to its fullest. As a result, it was not possible to spend time triangulating the data further than what has been covered in the discussion section, which could have been done with more time. There also was too little time to conduct a group-level analysis of the repertory grid data beyond the data driven content analysis of constructs, due to the time commitment required for the group-level analysis of the interview data. As a result, it was difficult to analyse the data collected in depth, and to go beyond separate analyses of the two sets of data.

4.7 Clinical Implications

The clinical implications of the findings described above have been considered and suggest that further support is required by individuals with an ABI. The findings indicate that individuals with ABI may benefit from access to greater psycho-education and psychological support through the recovery pathway. This is recommended based on themes found in this research, including the impact of perceived societal expectations and the sense of social invisibility described. Psychological input in the form of specific models that focus on challenging the impact of problematic societal, cultural or familial narratives may support people with ABI to adjust to the social world post-injury. This could include the use of therapeutic models such as the narrative model. Collective narrative work with individuals with an ABI has been conducted and reflected on positively within research previously (Butera-Prinzi, Charles & Story, 2014; Lorenz, 2010).

In light of the experiences described by individuals regarding loss of connections and a sense of invisibility, again psychological support and input may be helpful. Systemic, family or collective narrative family work may help to support individuals and close others to rebuild alliances and connections, and adjust to changes experienced post-injury. Alongside this, carers support groups may also be another way to provide support to the individuals highlighted by people in this study as ‘hidden’.

The individuals in this study were recruited from non-statutory services providing community rehabilitation, including input with cognitive difficulties. Despite this input there were many descriptions from individuals in regards to the negative impact of cognitive difficulties on their lives. The effects of an ABI can be on-going and longstanding, however it appeared that despite the programmes these individuals were accessing, they were struggling to manage these difficulties. This suggests that further psycho-education and input with managing cognitive deficits may be required to help individuals adjust to life post-injury in the community. It may therefore be helpful for clinical and neuropsychologists to provide consultation in the development of cognitive rehabilitation programmes used in the community.

Finally, it may also be important to provide education to the general public to increase the awareness and understanding of ABI, in light of individuals reporting a lack of social awareness. It may be helpful therefore for local councils and charities to work in conjunction to build awareness within communities.

4.8 Recommendations for Future Research

There is a paucity of literature on the lived experiences of individuals with an ABI, and with particular reference to the experiences of males. This study has provided an in-depth account of the lived experience of one group of males with a severe ABI; however further studies within this area are recommended. This would be helpful to build further understanding of the experience of this group of individuals more broadly, as well as put the existing research into context.

Research on the experiences of individuals with a severe brain injury with difficulties engaging in the narrative form was also found to be lacking. Some research has been conducted exploring the use of different research methods supporting the narrative form and has found these helpful (Egan, Chenoweth & McAuliffe, 2006; Lorenz, 2010). It would be interesting and contributory to the research available therefore to utilise these, or other methods, to learn further about the experience of ABI.

During the literature search the sparsity of literature examining the experience of individuals from diverse cultural backgrounds was highlighted. Culture can have an impact on various aspects of an individual's understanding and experience of their health, expectations and interactions with health professionals (Simpson, Mohr & Redman, 2000). It can also impact the understanding of health problems and rehabilitation (Diaz, 2013). Although some research exists examining the experience of individuals from ethnic minority backgrounds, the samples in these studies are not representative of the ethnic makeup of the UK. The findings from the current study may bring some insight, however, further research is needed examining the experiences of individuals from diverse backgrounds. This could help to understand the experiences of these individuals better, and develop culturally competent services (Lequerica & Krch, 2014).

5.0 Conclusions

Through the use of IPA, this study has captured the experiences of six males living with a mild to severe ABI. An in-depth account of the experience of these individuals highlighted the experience of living with an injury invisible to the eye, as well as a sense of becoming invisible to others in the world. This account has also captured the painful relationship formed between these individuals and society, in light of feeling unable to meet social expectations and perceiving the world to have labelled them in unwanted ways. Alongside this, experiences of growth were also captured at both a relational and personal level. This account also highlighted the vulnerability experienced by these individuals, in regards to both cognitive abilities as well as psychological and emotional aspects. Finally, this account also captured the importance of others for recovery, both in the learning and teaching of skills, but also unintentionally providing motivation through interactions. The findings from this aspect of the study have contributed to a lacking area of research, both in regards to the lived experience of ABI, as well as the experience of males with an ABI.

This study also aimed to explore the way in which individuals construed their experience of brain injury. Using repertory grids, the construct systems underpinning the way individuals interpreted their experiences were also captured. Commonalities were found across the content of constructs, with specific topics found across cases including independence, reliance and difference. Commonalities were also found in the process of construing, with five of the six individuals found to construe tightly. Finally, the organisation of construct systems also found similarities, with 'A typical person with a brain injury' found to be the most salient element for the vast majority of participants. Commonalities were also found within the organisation of constructs, with the majority of individuals found to have superordinate constructs within the area of restriction. Finally, similarities were also found in the construing of 'Me now with a brain injury', with this predominantly construed in a negative way. The findings from this aspect of the study again contribute to a lacking area of research, with only one published study having explored the area of ABI using personal construct methods. Finally, this study also explored the use of repertory grids to support individuals with an ABI to engage in the research process. Although this method was found to be helpful in engaging these individuals with the research process, the limitations of understanding this method as a way of overcoming aspects of cognitive deficits such as language were discussed.

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7.0 Appendices

APPENDIX 1. Table summarising papers identified for literature review

	Author	**Year**	**Title of paper**
1	*Crisp*	1993	Personal responses to traumatic brain injury: a qualitative study.
2	*Nilsson, Jansson and Norberg*	1997	To meet with a stroke: patient's experiences and aspects seen through a screen of crises.
3	*Dowswell et al.*	2000	Investigating recovery from stroke: a qualitative study.
4	*Brewin and Lewis*	2001	Patient's perspectives of cognitive deficits after head injury-related.
5	*Jumisko, Lexell and Söderberg*	2005	The meaning of living with traumatic brain injury in people with a moderate or severe traumatic brain injury.
6	*Chamberlain*	2006	The experience of surviving traumatic brain injury.
7	*Jumisko, Lexell and Soderberg*	2008	The meaning of feeling well in people with moderate or severe traumatic brain injury.

APPENDIX 2. Principles, definitions and application of Yardley's (2008) evaluative criteria (a) AND Application of Yardley's (2008) evaluative criteria to papers as part of literature review (b)

Principles, definitions and application of Yardley's (2008) evaluative criteria (a)		
Principle	**Description**	**Strategies used in current study**
Importance and impact	This principle is concerned with assessing if qualitative research is contributing new, important or interesting information.	1) Clinical and research relevance of undertaking this study has been considered within both the introduction and discussion section of this thesis.
Commitment and rigour	This principle highlights the importance of commitment to the research, as well as thoroughness and completeness of the study.	1) The data collection process was conducted with attention to the physical and cognitive needs of participants, with considerable time committed to this aspect. 2) An in-depth analysis was conducted of interview data collected, which required a large time commitment. An audit trail is available in the appendix. 3) The IPA element of this study was developed with the support of a consultation with Jonathan Smith by telephone and email, to ensure the design was appropriate for the use of IPA. Criteria to ensure homogeneity of the sample, sample size, study design and study schedule were discussed. 4) The repertory grid element of this study was developed in consultation with a supervisor experienced in the use of this method.
Coherence and transparency	This principle proposes that the stages of qualitative research process should be clear when written up, and that the arguments presented are coherent and logical.	1) All aspects of the research design and analysis have been described step by step for transparency, and an audit trail has been provided (see appendix). 2) I attended a peer supervision group for trainees conducting qualitative research studies using IPA. This was done to check the transparency of analysis, and that emerging themes

		were grounded in data through comparison of how peers analysed the same transcript, and to bring alternative perspectives. 3) I kept a researcher journal, which I completed after each session with a participant (Yin, 2011), to highlight areas that my impact my interpretation of data collected and the interview process. This has been referred to within the narrative account in the results section.
Sensitivity to context	This principle highlights the importance of demonstrating that context has been considered throughout the study.	1) Existing literature has been reviewed and used to underpin the research aims and objectives. 2)Material gathered from individuals taking part in this study were used to evidence themes in the IPA analysis. 3) The impact of the personal beliefs and experiences of the researcher on the interpretation of data were explicitly stated in the analysis. The impact of the researcher's personal beliefs and expectations on the development of this study were also considered in the introduction and earlier in the method section.

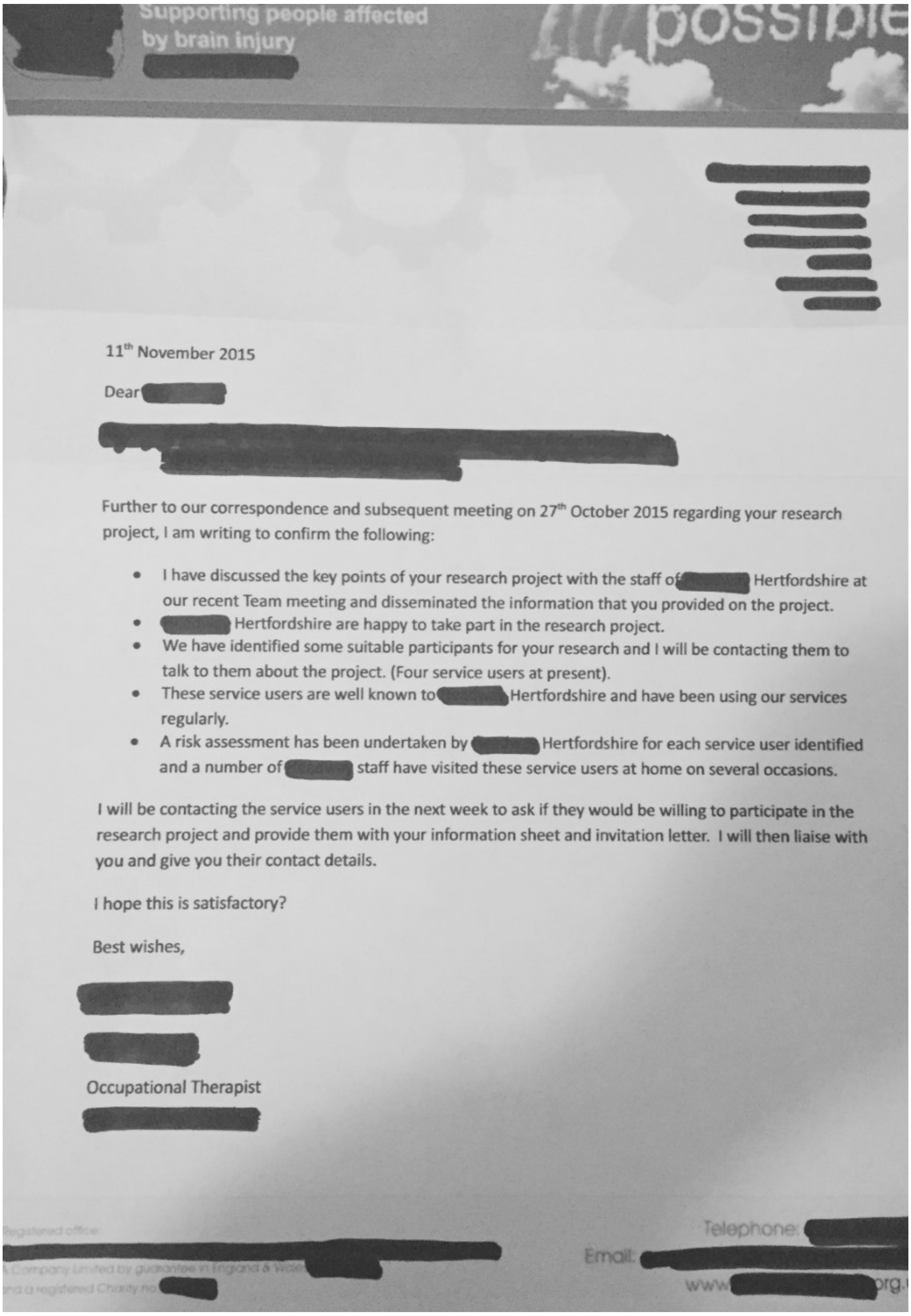
Application of Yardley's (2008) evaluative criteria to papers as part of literature review (b)

Title, author and year	Critical appraisal
-Personal responses to traumatic brain injury: a qualitative study. -Crisp (1993)	*Sensitivity to context:* Personal and social context brought through use of typologies, however little description of this in the text. No acknowledgement of impact of researcher on interpretation. *Commitment/Rigour:* Good sample size for qualitative analysis (n=10). *Coherence/Transparency:* Transparency of interviewing (examples of questions and follow up questions) and analysis technique. No member checks. *Importance/Impact:* Brought depth to literature as little on the experience of ABI. Brought depth to different styles of experience, useful for clinical application.
-To meet with a stroke: patient's experiences and aspects seen through a screen of crises. -Nilsson, Jansson and Norberg (1997)	*Sensitivity to context:* No acknowledgement of impact of researcher on interpretation. *Commitment/Rigour:* Homogeneous sample and good sample size (n=10), appropriate for qualitative analysis. *Coherence/Transparency:* Transparency of data collection methods and analysis stages. No member checks conducted. *Importance/Impact:* Helped understand experiences of stroke in early stages, and variety of experiences at psychological level.
-Investigating recovery from stroke: a qualitative study. -Dowswell et al. (2000)	*Sensitivity to context:* Stated awareness of purposive sample as part of wider RCT, and needing interpretation to be read in light of this. Reflexivity lacking throughout analysis and narrative account. Some information on impact of researcher relationship to participant on interpretation in discussion section. *Commitment/Rigour*- Credibility checks done via discussions with other researchers, and triangulation of coding. No member checks. *Coherence/Transparency*- Addressed research questions well with method used. Large sample (n=30) adequate size for study. Transparency of methods and analysis. *Importance/Impact*- Adds richness to RCT previously done using same participants. Gave further understanding of context to recovery, which had not been covered by quantitative studies.

-Patient's perspectives of cognitive deficits after head injury-related -Brewin and Lewis (2001)	*Sensitivity to context:* Reported context of returning home. No discussion of social context in interpretation. Peer discussion for reflexive purposes (and credibility), however no evidence of reflexivity in narrative account. *Commitment/Rigour:* Good sample size (n=9) for qualitative study. Member checks conducted. Lack of interpretation of data at times, very concrete examples taken from interviews. *Coherence/Transparency:* Transparency of data collection and analysis method. *Importance/Impact:* Built on quantitative research, added richness and confirmation of what was known from these.
-The meaning of living with traumatic brain injury in people with a moderate or severe traumatic brain injury. -Jumisko, Lexell and Söderberg (2005)	*Sensitivity to context:* Some acknowledgement of researcher impact on interpretation. *Commitment/Rigour:* Homogeneous group, appropriate for qualitative method used. Transparency of interviewer and coding process. Gender/sex of participants not detailed. Use of peer interpretation and triangulation. Attempts to bracket off known understandings of interviewees also made. No credibility checks conducted. *Coherence/Transparency:* Transparency of data collection methods and analysis stages. No member checks conducted *Importance/Impact:* Contributed to lacking qualitative literature base.
The experience of surviving traumatic brain injury. -Chamberlain (2006)	*Sensitivity to context:* Discussed power imbalance between individuals and health professionals, as well as others in wider society. Some reflexivity evidenced in limitations sections, acknowledged impact of having built relationships with participants. *Commitment/Rigour:* Very large sample (n=59), unclear if this was for saturation or for other reasons, inappropriate size for qualitative study. Query whether it was possible to look at this amount of data in depth. *Coherence/Transparency:* Transparency of method and analyses. *Importance/Impact:* Adds to lacking data on experience of recovery and living with injury, as well as considering grief within this for non-severely injured. Identified where more research on grief is needed with severely injured individuals, and need for non-narrative or creative emphasis. Triangulation of theming process reported.

The meaning of feeling well in people with moderate or severe traumatic brain injury. -Jumisko, Lexell and Soderberg (2008)	*Sensitivity to context:* described awareness of being one Western sample so not applicable to other settings. Participant's context not really elaborated or referred to in analysis. Very few statements of reflexivity during interpretation. *Commitment/Rigour:* good sample size (8). Peer supervision to triangulate and bring different perspectives. Bracketing of what was pre-known. *Coherence/Transparency:* No member checks. Transparency of methods and analysis. *Importance/Impact:* Contribution to lacking literature base.

APPENDIX 3. Permission letters from recruitment sites



[redacted]
Supporting people affected
by brain injury
[redacted]
possibl

[redacted]

11th November 2015

Dear [redacted]

[redacted]

Further to our correspondence and subsequent meeting on 27th October 2015 regarding your research project, I am writing to confirm the following:

- I have discussed the key points of your research project with the staff of [redacted] Hertfordshire at our recent Team meeting and disseminated the information that you provided on the project.
- [redacted] Hertfordshire are happy to take part in the research project.
- We have identified some suitable participants for your research and I will be contacting them to talk to them about the project. (Four service users at present).
- These service users are well known to [redacted] Hertfordshire and have been using our services regularly.
- A risk assessment has been undertaken by [redacted] Hertfordshire for each service user identified and a number of [redacted] staff have visited these service users at home on several occasions.

I will be contacting the service users in the next week to ask if they would be willing to participate in the research project and provide them with your information sheet and invitation letter. I will then liaise with you and give you their contact details.

I hope this is satisfactory?

Best wishes,

[redacted]

[redacted]

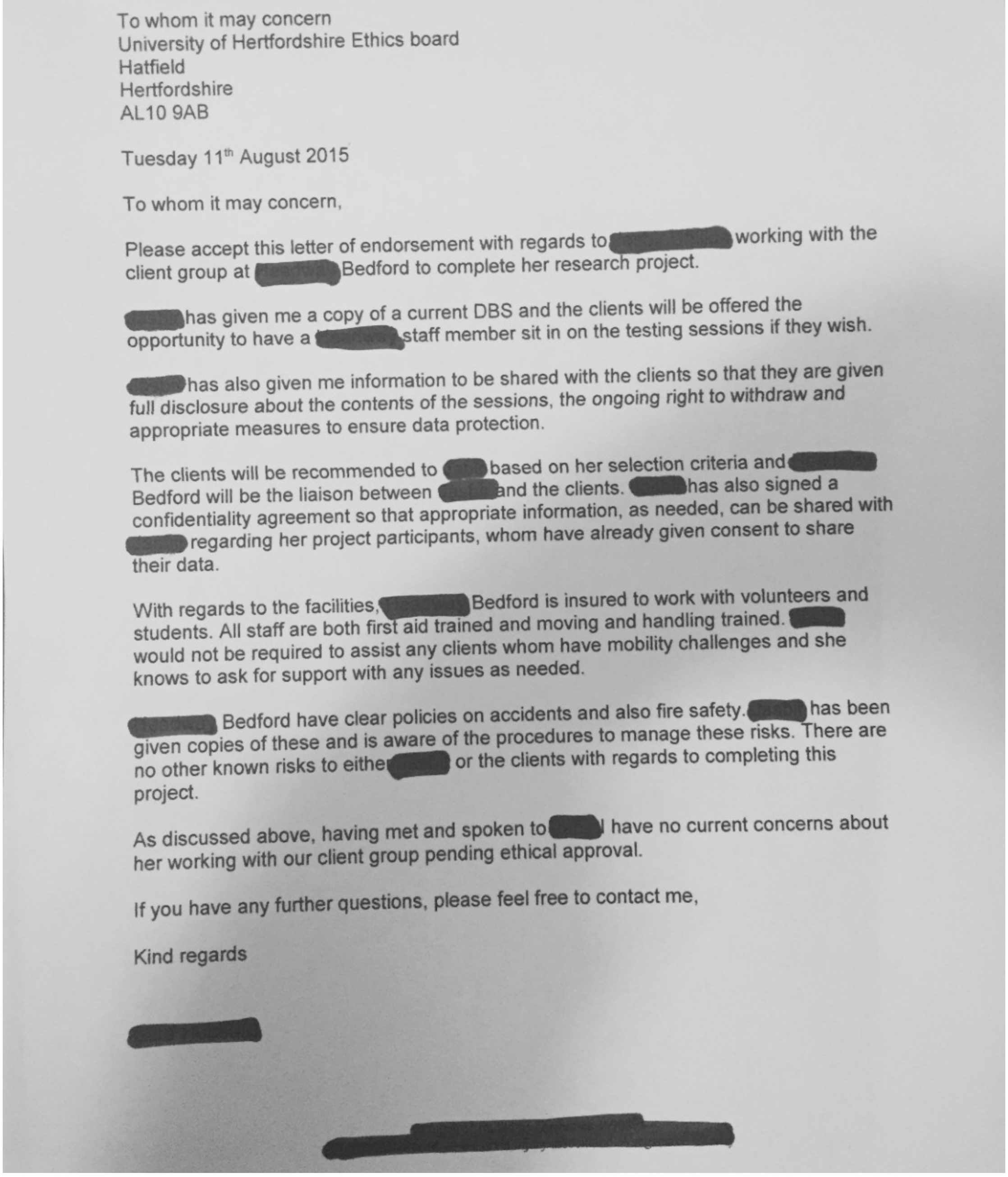
Occupational Therapist

[redacted]

Registered office:
[redacted]
A Company Limited by guarantee in England & Wal [redacted]
nd a registered Charity no [redacted]

Telephone: [redacted]
Email: [redacted]
www [redacted] org.

APPENDIX 3. Permission letters from recruitment sites



To whom it may concern
University of Hertfordshire Ethics board
Hatfield
Hertfordshire
AL10 9AB

Tuesday 11th August 2015

To whom it may concern,

Please accept this letter of endorsement with regards to [redacted] working with the client group at [redacted] Bedford to complete her research project.

[redacted] has given me a copy of a current DBS and the clients will be offered the opportunity to have a [redacted] staff member sit in on the testing sessions if they wish.

[redacted] has also given me information to be shared with the clients so that they are given full disclosure about the contents of the sessions, the ongoing right to withdraw and appropriate measures to ensure data protection.

The clients will be recommended to [redacted] based on her selection criteria and [redacted] Bedford will be the liaison between [redacted] and the clients. [redacted] has also signed a confidentiality agreement so that appropriate information, as needed, can be shared with [redacted] regarding her project participants, whom have already given consent to share their data.

With regards to the facilities, [redacted] Bedford is insured to work with volunteers and students. All staff are both first aid trained and moving and handling trained. [redacted] would not be required to assist any clients whom have mobility challenges and she knows to ask for support with any issues as needed.

[redacted] Bedford have clear policies on accidents and also fire safety. [redacted] has been given copies of these and is aware of the procedures to manage these risks. There are no other known risks to eithe[redacted] or the clients with regards to completing this project.

As discussed above, having met and spoken to [redacted] I have no current concerns about her working with our client group pending ethical approval.

If you have any further questions, please feel free to contact me,

Kind regards

[redacted]

[redacted]

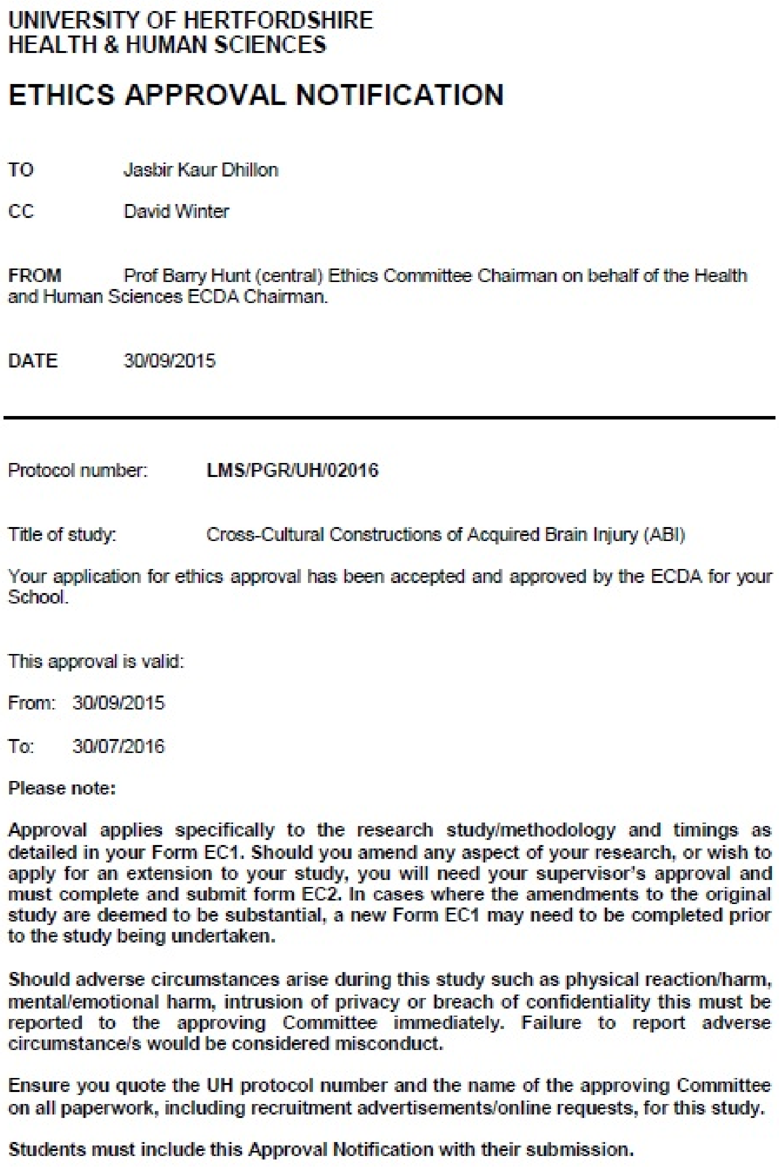
APPENDIX 4. Table of PHQ, GAD, MPAI and ACE-III scores

ID	PHQ-9	GAD-7	Mayo-Portland			ACE-III	
				Score	**T-Score**		**Score**
Derek	8 (MILD)	1 (NONE)	Ability:	18	42	Attention:	16
			Adjustment:	20	43	Memory:	10
			Participation:	19	43	Fluency:	6
						Language:	22
						Visuospatial:	9
			Total:	*49*	*54*	*Total:*	*63*
Bruce	0 (NONE)	0 (NONE)	Ability:	11	37	Attention:	18
			Adjustment:	0	-4	Memory:	25
			Participation:	1	10	Fluency:	11
						Language:	24
						Visuospatial:	16
			Total:	*12*	*38*	*Total:*	*94*
Lance	5 (MILD)	3 (NONE)	Ability:	18	42	Attention:	18
			Adjustment:	11	37	Memory:	19
			Participation:	7	32	Fluency:	11
						Language:	26
						Visuospatial:	13
			Total:	*34*	*49*	*Total:*	*87*
Percy	4 (NONE)	1 (NONE)	Ability:	17	41	Attention:	18
			Adjustment:	14	39	Memory:	21
			Participation:	16	41	Fluency:	13
						Language:	25
						Visuospatial:	14
			Total:	*41*	*52*	*Total:*	*91*
Dean	3 (NONE)	4 (NONE)	Ability:	10	36	Attention:	18
			Adjustment:	16	41	Memory:	24
			Participation:	10	36	Fluency:	10
						Language:	25
						Visuospatial:	14
			Total:	*34*	*49*	*Total:*	91
Robert	8 (MILD)	1 (NONE)	Ability:	31	48	Attention:	18
			Adjustment:	28	47	Memory:	19
			Participation:	14	39	Fluency:	11
						Language:	25
						Visuospatial:	15
			Total:	66	59	*Total:*	85

APPENDIX 5. Severity Data

ID	Injury	Structural change	GCS	Time Unconscious	Source	Severity
Derek	Fall	Subdural haematoma.	Unknown	6 weeks in coma.	Information taken from Headway service user records.	Severe
Bruce	Assault	Severe subarachnoid haemorrhage throughout all basal cisterns, early hydrocephalus and left parietal infarct due to haemorrhage.	GCS: 5/15	6 days in coma.	Information taken from Headway service user records.	Severe
Lance	Stroke	CVA.	Unknown	None.	Directly from participant.	Mild to Severe
Percy	Road Traffic Collision	Diffused axional injury	GCS:4/15	2 weeks	Information taken from hospital outpatient clinic, supplied by participant, Further information also given by participant's partner based on discussions with intensive care unit consultant.	Severe
Dean	Fall	Skull fracture with bilateral acute subdural haematoma and right sided midline shift. Pulmonary contusion; required decompressive craniectomy and intracraniel pressure bolt.	GCS: 6/15	Unconscious for 4-5 days, plus 2 weeks induced coma.	Information taken from letter from a hospital critical care unit (as part of a research study), supplied by participant.	Severe
Robert	**Heart Attack (MI)**	**Hypoxic brain injury but no structural changes.**	**Unknown**	**Unknown**	**Directly from participant.**	**Mild to Severe**

APPENDIX 6. Ethical approval notifications



UNIVERSITY OF HERTFORDSHIRE
HEALTH & HUMAN SCIENCES

ETHICS APPROVAL NOTIFICATION

TO Jasbir Kaur Dhillon

CC David Winter

FROM Prof Barry Hunt (central) Ethics Committee Chairman on behalf of the Health and Human Sciences ECDA Chairman.

DATE 30/09/2015

Protocol number: **LMS/PGR/UH/02016**

Title of study: Cross-Cultural Constructions of Acquired Brain Injury (ABI)

Your application for ethics approval has been accepted and approved by the ECDA for your School.

This approval is valid:

From: 30/09/2015

To: 30/07/2016

Please note:

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1. Should you amend any aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit form EC2. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.

APPENDIX 6. Ethical approval notifications (Amendment 1)

UNIVERSITY OF HERTFORDSHIRE
HEALTH AND HUMAN SCIENCES

ETHICS APPROVAL NOTIFICATION

TO	Jasbir Dhillon
CC	David Winter
FROM	Dr Richard Southern, Health and Human Sciences ECDA Chairman
DATE	15/12/2015

Protocol number: aLMS/PGR/UH/02016(1)

Title of study: Cross-Cultural Constructions of Acquired Brain Injury (ABI)

Your application to modify the existing protocol as detailed below has been accepted and approved by the ECDA for your School.

Modification:

Researcher may approach potential participants at services to invite them to take part in the study.

Researcher may collect data in participant's home.

(Further detail provided on the EC2)

This approval is valid:

From: 15/12/2015

To: 30/07/2016

Please note:

Any conditions relating to the original protocol approval remain and must be complied with.

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1 or as detailed in the EC2 request. Should you amend any further aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit a further EC2 request. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

APPENDIX 6. Ethical approval notifications (Amendment 2)

UNIVERSITY OF HERTFORDSHIRE
HEALTH AND HUMAN SCIENCES

ETHICS APPROVAL NOTIFICATION

TO Jasbir Dhillon

CC Professor David Winter

FROM Dr Richard Southern, Health and Human Sciences ECDA Chairman

DATE 29/1/16

Protocol number: aLMS/PGR/UH/02016 (2)

Title of study: Constructions of Acquired Brain Injury (ABI)

Your application to modify the existing protocol LMS/PGR/UH/02016 (1) as detailed below has been accepted and approved by the ECDA for your School.

Modification:

To modify the title from Cross-Cultural Constructions of Acquired Brain Injury (ABI) to Constructions of Acquired Brain Injury (ABI);

To extend participant recruitment to include participants with mild to severe brain injury;

To recruit male participants across cultures to form one group.

This approval is valid:

From: 29/1/16

To: 30/7/16

Please note:

Any conditions relating to the original protocol approval remain and must be complied with.

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1 or as detailed in the EC2 request. Should you amend any further aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit a further EC2 request. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

APPENDIX 7. Information sheet for potential participants

Information Sheet

We are asking you to take part in our study about what people with a brain injury think about their life and their injury. This sheet will give you information about why we are doing this research, and what it will include. Please read this sheet before you decide if you want to take part in this study.

Who is doing this research:

The main researcher for this study is Jasbir Dhillon, a doctoral student at the University of Hertfordshire. This research is part of her doctoral thesis. The research is being supervised by Dr Scott Ferguson, Clinical Psychologist, and Anna Green, Neuropsychologist, and Professor David Winter who works at the University of Hertfordshire.

Who has reviewed this study:

This research has been reviewed by the University of Hertfordshire, Health and Human Sciences Ethics Committee with Delegated Authority (protocol number: aLMS/PGR/UH/02016 (2).

Why are we doing this research?

We are doing this research to learn about what people with a brain injury think about their brain injury and their life. We are asking you to take part so that we can learn how to help different people who have had a brain injury.

Why have I been invited to take part in this study?

You are being asked to take part as you have had a brain injury. We would like to speak to people who have had a brain injury like yours to learn more about your views and experience.

Do I have to take part?

No. It is your choice to take part in this study, and you will not be forced to take part if you don't want to. If you do take part in the study, you can stop at any time without giving us a reason.

What will happen if I take part?

We would ask you to:

complete some short tasks to explore the nature of your difficulties

- fill in some forms about your brain injury and your feelings

After this, there will be an interview where you will be asked about:

- your views on your life before your injury, life after your injury and what you and other people think about it
- your experience of your life before and after your brain injury

It is ok if you want someone to be with you when you take part. Taking part will take about 1.5 to 2 hours, and we will audio record the interview, so that we can listen to your answers again to analyse them further.

What are the benefits of taking part?

We hope the research will help us to understand how to help people, like you, that have had a brain injury. This might result in helping staff understand people with brain injury better, so they can give better support and help to different types of people.

What if I feel upset after the questionnaires?

If you feel upset whilst taking part, you can take a break or talk to us or someone else about how you feel. If you feel upset after taking part in the study, you have one month during which you can contact us and we can talk about how you feel.

Who will know about me taking part?

We will keep your information private- this means we will not share any of your information that you give with anyone outside the research team. We will also keep your information in a private locked place. All recordings will also be destroyed after they have been used for the research.

The only time we would share the information you give is if you told us that you or someone else was at serious risk of danger. If you told us this, we would talk to you before speaking to somebody, such as your GP.

The results of the study may be published in a journal, to help staff in healthcare to understand and help other people that have had a brain injury. We would not publish any details that might identify you, such as your name.

How can I contact you to ask questions about the study?

If you want to talk to someone about the study you can contact me, Jasbir Dhillon, by phone or email:
Phone number: XXXXXXXXXXX
Email: XXXXXXXXXX

If you have any questions then please let us know. Thank you very much for reading this information sheet. We hope you decide to take part in

APPENDIX 7. Consent form

Consent Form

Research study title: Constructions of Acquired Brain Injury

Researcher name: Ms Jasbir Dhillon

Supervisor's names: Dr Scott Ferguson, Anna Green and Professor David Winter

Please put a X in the boxes if you agree

I have read the information sheet for this study.	
I understand what this study is about.	
I have had the chance to ask questions about this study.	
My questions have been answered in a way I can understand.	
I understand that taking part in this study is my choice.	
I understand that I can choose to not take part at any time without giving a reason.	
I understand that if I choose to not take part, this will not affect my care in anyway.	
I understand that the information I give will be kept safely in a locked place, and only people running this study can look at it.	

Please write your name, date and sign on the red lines below <u>if you agree</u>:

I agree to take part in the above study:

Participant name: ______________________________________

Date: ____

Signature: ____

Researcher name: ____________________________________

Date: ____

Signature: ____

APPENDIX 8. Repertory grid used for current study

Constructs		Me before my brain injury	Me now with brain injury	Me as I'd like to be	Me as I expect I will be in the future	Me seen by others	Me as a patient	A typical person with brain injury	A typical person without a brain injury	Partner	Child
1											
2											
3											
4											
5											
6											
7											
8											
9											
10											
11											
12											
13											
14											
15											

APPENDIX 9. Interview schedule

SEMI-STRUCTURED INTERVIEW QUESTIONS

After reviewing repertory grid results:

Self:

-Thinking about how you construe/see yourself now, what do you think has led to this view of yourself? Why has that led to the way you (or use example given verbatim) view yourself now?

Life:

-Thinking about how you construe/see your life now, what has led to this view of your life? Why had that led to the way you (or use example given verbatim) view yourself? What does this mean about the things you can and can't do in your life now?

-Thinking about how you construe your life will be in the future, and what you would like it to be, what are the main differences? What does this mean about the things you can and can't do in the future?

  -Is this different or the same as how you expect someone's future will be if they have a brain injury? How?

  -Is this different or the same as how you expect someone's future will be if they don't have a brain injury?

Others*:*

-Looking at how others construe/see you, who would you say views you this way mainly? Why do you think they view you this way? Are there any people who view you differently to this?

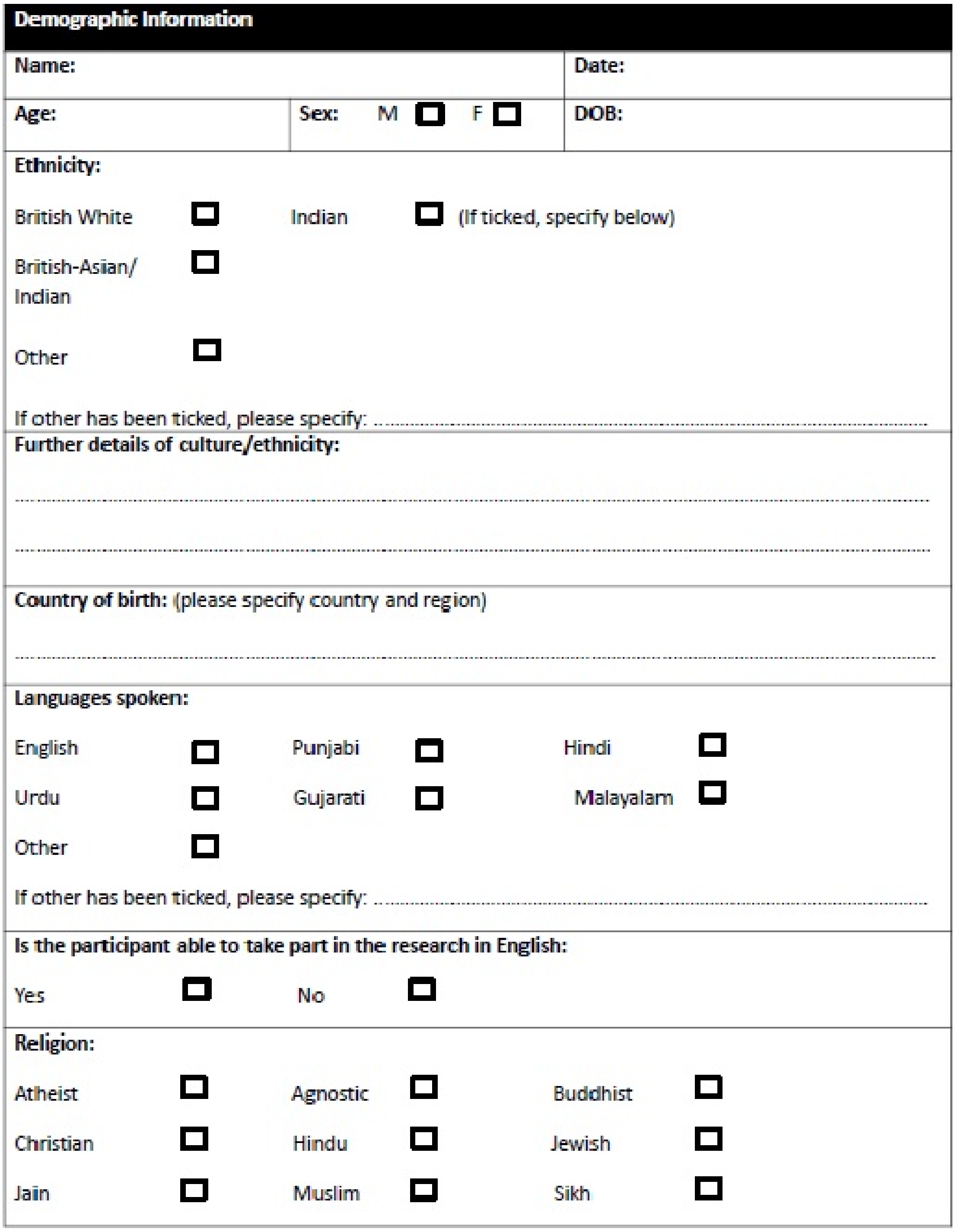
Community and culture:

-Thinking about people from your culture, how do you think they construe/view you? Why do you think they view you this way? Does this help or hinder you in any way?

Health services:

-Thinking about how you construe/see yourself as a patient, what has led to this? Why is that? What does this mean about the way you use health services now? Does this help you or hinder you in any way?

APPENDIX 10. Proforma sheet



Demographic Information

Name:		**Date:**
Age:	**Sex:** M ☐ F ☐	**DOB:**

Ethnicity:

British White ☐ Indian ☐ (If ticked, specify below)

British-Asian/ Indian ☐

Other ☐

If other has been ticked, please specify: ……………………………………………………………………

Further details of culture/ethnicity:

……………………………………………………………………………………………………

……………………………………………………………………………………………………

Country of birth: (please specify country and region)

……………………………………………………………………………………………………

Languages spoken:

English ☐ Punjabi ☐ Hindi ☐

Urdu ☐ Gujarati ☐ Malayalam ☐

Other ☐

If other has been ticked, please specify: ……………………………………………………………………

Is the participant able to take part in the research in English:

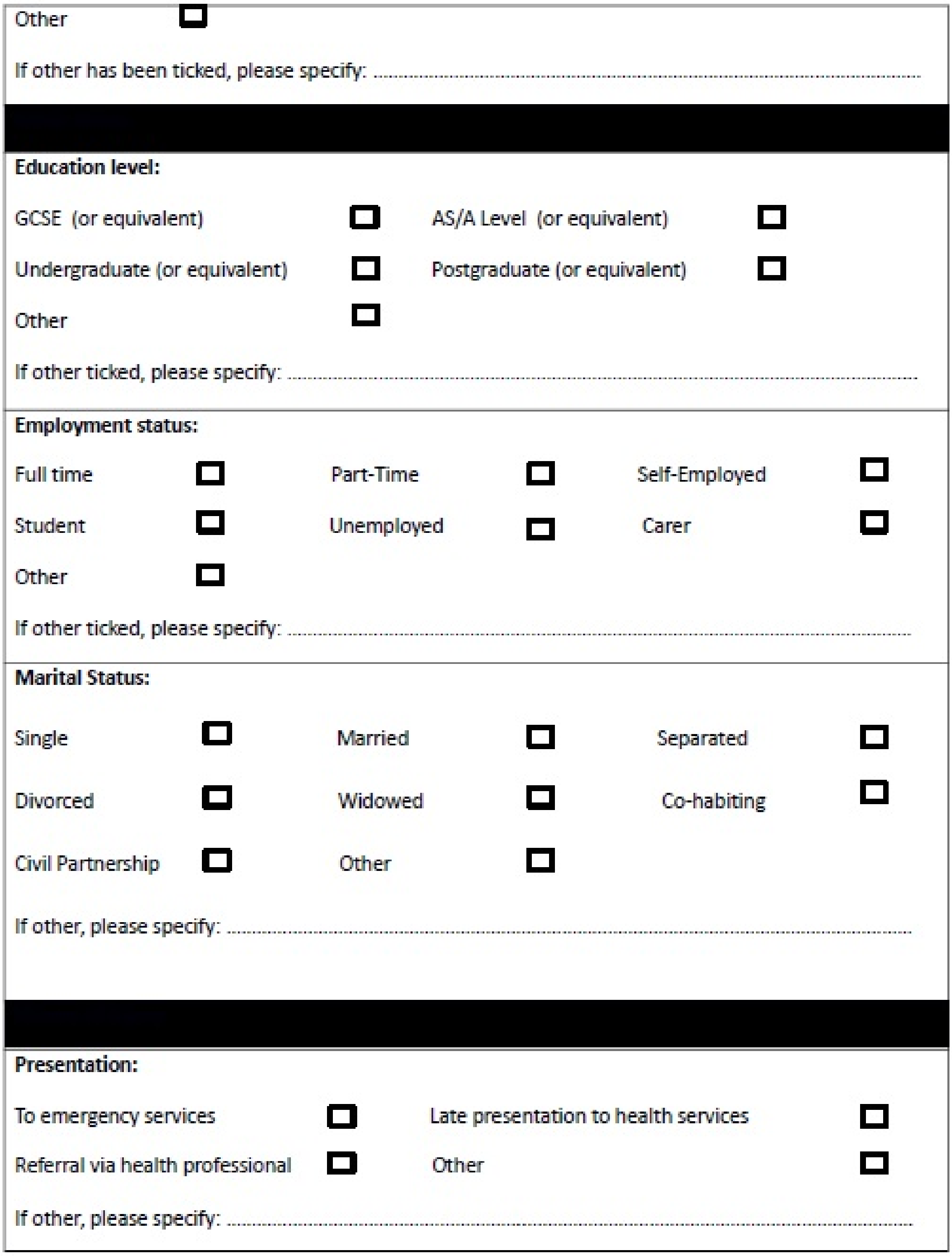
Yes ☐ No ☐

Religion:

Atheist ☐ Agnostic ☐ Buddhist ☐

Christian ☐ Hindu ☐ Jewish ☐

Jain ☐ Muslim ☐ Sikh ☐



Other ☐

If other has been ticked, please specify: ....

Education level:

GCSE (or equivalent) ☐ AS/A Level (or equivalent) ☐

Undergraduate (or equivalent) ☐ Postgraduate (or equivalent) ☐

Other ☐

If other ticked, please specify: ....

Employment status:

Full time ☐ Part-Time ☐ Self-Employed ☐

Student ☐ Unemployed ☐ Carer ☐

Other ☐

If other ticked, please specify: ....

Marital Status:

Single ☐ Married ☐ Separated ☐

Divorced ☐ Widowed ☐ Co-habiting ☐

Civil Partnership ☐ Other ☐

If other, please specify: ....

Presentation:

To emergency services ☐ Late presentation to health services ☐

Referral via health professional ☐ Other ☐

If other, please specify: ....

Primary injury:

Closed ☐ Open ☐ Crush ☐

Secondary injury:

Hypoxia ☐ Hypotension ☐ Hypothermia ☐

Extracranial ☐ Intracranial ☐ Other ☐

If other ticked, please specify: ....

Classification of injury:

Mild ☐ Moderate ☐ Severe ☐

Cause of injury:

Road Traffic Incident ☐ Blast ☐ Violence ☐

Military ☐ Other ☐

If other ticked, please specify: ....

Place:

Home ☐ Work ☐ Public place ☐

Other ☐ ☐

If other ticked, please specify: ....

[redacted]

Emergency care:

....

....

....

In-hospital:

....

....

....

Post-discharge/ outpatient care:					
Rehabilitation	☐	Surgery	☐	Medication	☐

Inclusion Criteria*		**Yes**	**No**
1	Aged between 18-65		
2	Have experienced a mild to moderate brain injury		
3	Between 1 and 10 years post injury		
4	British-White, British-Indian or Indian origin		
5	Sufficient ability to communicate in English		
Exclusion Criteria* *		**Yes**	**No**
1	Ongoing unresolved physical health issues		
2	Significant untreated mental health or substance misuse issues		

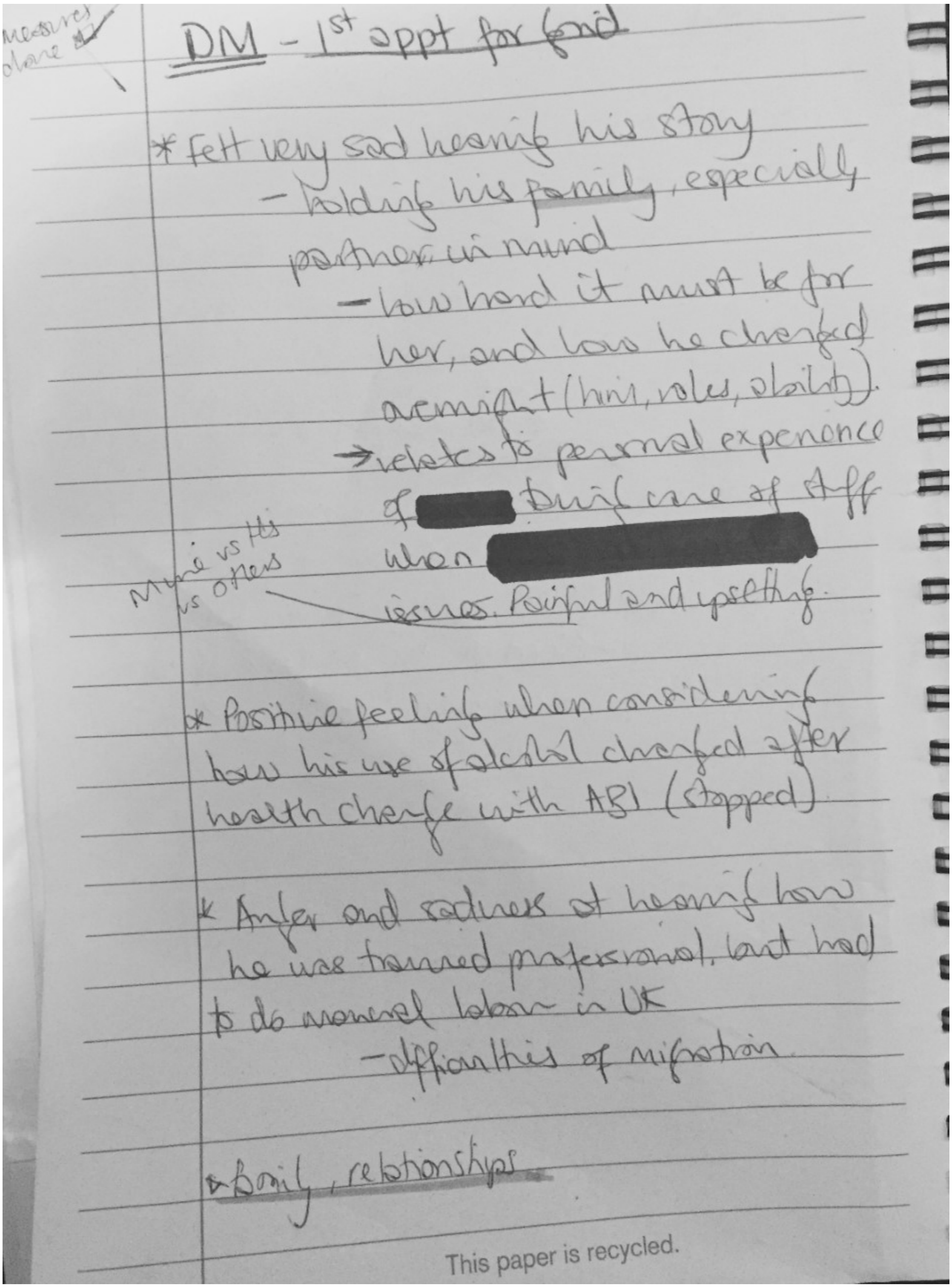
*All inclusion criteria must be answered yes

**All exclusion criteria must be answered no

Test Used	**Score**	
ACE-III		
MPAI		
HADS	**Mood**	
	Anxiety	

Did the participant meet eligibility requirements for this study: (PLEASE CIRCLE)	**YES**	**NO**

APPENDIX 11. Excerpt from reflective diary



measures done ✓

DM – 1st appt for grid

* Felt very sad hearing his story
– holding his family, especially partner in mind
– how hard it must be for her, and how he changed overnight (him, roles, ability).
→ relates to personal experience of [redacted] during care of staff when [redacted] issues. Painful and upsetting.

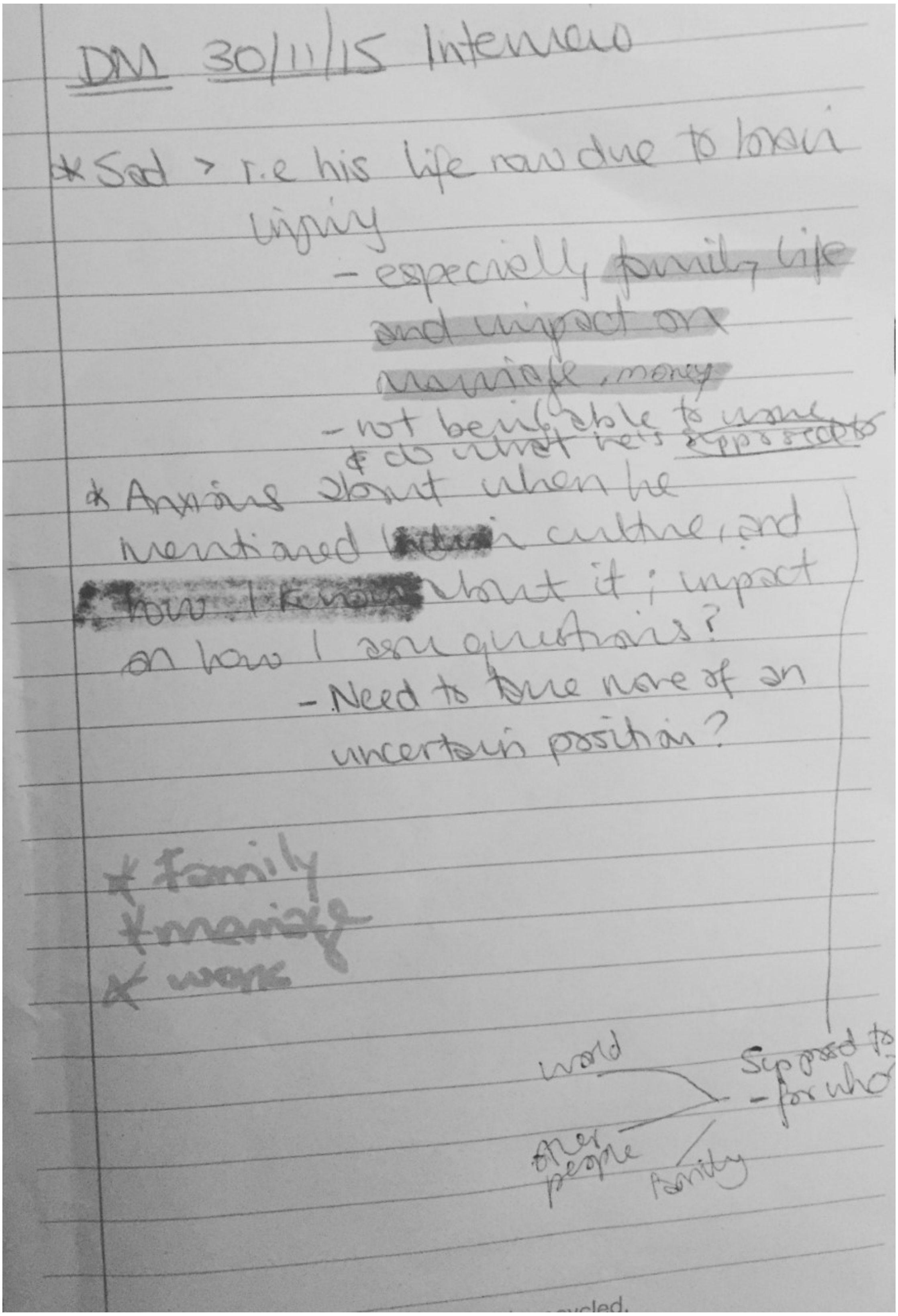
Mine vs His vs others

* Positive feeling when considering how his use of alcohol changed after health change with ABI (stopped).

* Anger and sadness at hearing how he was trained professional, but had to do manual labour in UK
– difficulties of migration.

* family, relationships

This paper is recycled.



DM 30/11/15 Interview

* Sad > i.e his life now due to brain injury
  - especially family life and impact on marriage, money
  - not being able to work & do what he's supposed to

* Anxious about when he mentioned [redacted] culture, and [redacted] about it; impact on how I ask questions?
  - Need to take more of an uncertain position?

* family
* marriage
* work

APPENDIX 12. Signed agreement from transcription service

University of Hertfordshire

Appendix 8: Transcription Agreement

University of Hertfordshire

Doctorate in Clinical Psychology
University of Hertfordshire

Transcription confidentiality/ non-disclosure agreement

This non-disclosure agreement is in reference to the following parties:
Jasbir Kaur Dhillon ('the discloser')
And
ANITA EMERY ***Transcription service*** **('the recipient')**

The recipient agrees to not divulge any information to a third party with regards to the transcription of audio recordings, as recorded by the discloser. The information shared will therefore remain confidential.

The recipient also agrees to destroy the transcripts as soon as they have been provided to the discloser.

The recipient agrees to return and or destroy any copies of the recordings they were able to access provided by the discloser.

Signed: AEmery
Name: A. EMERY
Date: 08.03.16

INVESTOR IN PEOPLE

Major Research Proposal Student No:
1.

APPENDIX 13. Audit trail for analysis: Theming and coding Percy's transcript

	1		**Interview with Participant 5**	
	2 3 4 5 6	I	Ok if we start the interview. I'd be quite curious to hear more about the way you think about yourself at the moment, (name), and in particular the things that stood out on the grid we looked at was how at the moment, with your brain injury, you see yourself as being more honest, more realistic, and I guess I was wondering about those things and why that might be?	
Remainder of former identity	7 8 9	P	(pause) I'm not really sure to be quite honest. I think that the, realism comes with the territory of my previous role as a lecturer where you set targets and, oh no I've lost the thread now, I can't remember what the question was.	Uncertainty. Realism from former occupational role. Losing the thread, loss of concentration?
Loss of concentration	10	I	I'll ask you it again, that's fine. So I was thinking about the graph we looked at	
	11	P	Yes	
	12	I	And how it showed that you now with a brain injury	
	13	P	Yes	
	14 15	I	Is close to being more honest and more realistic and I was wondering why it is that you might see yourself in that way now and what's led to that?	
Educator identity	16 17 18 19 20	P	Right, yes, as I said, my previous, one of my previous roles was in education and you set targets so the SMART acronym included realism as you know when setting the targets so anything that I set myself to do has to be realistic so that's where the more realistic bit comes into it and I've forgotten what the other part of the question was (laughs)	Past role as educator /mentor to others, became educator to self? SMART. Importance of being realistic. Working memory loss. Loss of memory
	21	I	It was about also being honest	
Loss of working memory Loss of memory	22 23 24 25 26 27 28	P	Oh yes honesty, yes, and I think we touched on this earlier when giving some feedback that you have to, you have to have all your marbles I think to be dishonest because you have to, because the dishonesty is not normally something tangible, something you've experienced that you have fabricated in your mind, it's something then which is harder to remember so you would be digging yourself a bigger hole if you were dishonest and someone questioned you later about that part you were dishonest because you wouldn't necessarily remember everything	Unable to be dishonest due to loss in memory skills. Purification through his injury? Unable to be dishonest.

		that you had said to that person and then the hole gets bigger as it were	Hole/gaps causing him social difficulty.
	I	And I know you mentioned that we were talking about this earlier and you were saying that for somebody with a brain injury it's quite difficult to continue a façade or a lie	
Avoidance of social complexities	P	Yes, yes	
	I	So I just wanted to check was it related to that conversation?	
	P	Yes	
	I	Ok and I guess it makes me wonder, so it sounds like your reasoning for why you're more honest, or why you're more realistic is very much to do with your previous experience of being a lecturer as well as being aware of your abilities now as well and I guess I was wondering why is it that you found yourself being more honest and more realistic in light of that experience. Why couldn't it have been you being not honest or not realistic?	
Loss of a relational tool	P	I think that everyone tries to steer away from tension and in some ways sometimes you can do that by being dishonest, not in a malicious way but in a way that you think is helpful but even so it is still being dishonest, telling a white lie, and these are, when I refer to telling a white lie or being dishonest before my brain injury, that was it, it would be telling a white lie and trying to avert what I considered would be a crisis	Dishonesty as helpful relational skill? Loss of this relational skill? White lies. Dishonesty a crisis resolution tool
	I	But now in terms of how you are, you see yourself as being honest but would you still have those white lies or not?	
	P	No, no, don't think so, might be telling one now (laughs)	
	I	(laughs)	
	P	No, no, honestly (laughs)	
	I	(laughs) And would that be only because of how you mentioned that it's quite difficult to maintain that lie or would there be anything else that would contribute?	
Gaining	P	Well there's no reason why I should anymore, well I don't think so, I suppose having a brain injury gives you an excuse for upsetting people so if you know one way to look at it is, it's probably been an advantage having a brain injury as an	Change of some kind. ABI excuse to behave in socially

relational advantage Changes in relational strategies		asset of being manipulative in that you, in that people would give you a little bit of leeway for what you say. Even if it's, even when you're honest and before as I said, when you were dishonest it was for a reason of what you thought would be good for them if you were dishonest and not to upset them and cause tension and friction or upset, now (laughs) because I have a brain injury, I don't expect any upset (laughs)	inappropriate way? ABI a relational tool. ABI an advantage, helps take advantage of others? One relational tool swapped for another: a purer more honest one?
Loss of responsibility for others feeling (not a bad loss)	I	And I'm interested in how you said that it's almost an advantage and I was wondering if you could tell me a bit, just tell me more about that or tell me any, I guess any examples of how it's been an advantage for you?	
	P	I think that people, when they know that you have a brain injury and they're not sure how to treat you, whether to treat you normally or treat you with kid gloves, you know tenderly, and my experience is that most people have always given me the benefit of the doubt and put anything that I said which they don't agree with down to my brain injury themselves so it works out as an advantage in that respect	Loss of responsibility/ expectation to care for others feelings?
Becoming different to others	I	And I'm looking at your graph where I can see that you put yourself now with a brain injury slightly closer to people treating you abnormally than normally and I was wondering if that was connected?	Public perception of ABI making people abnormal, vulnerable
	P	Probably	Expect the best from him, and the worst gets put down to the ABI? ABI bad object, he is good?
	I	And how do you, what do you think about that?	
	P	(laughs) Well as I say, I could use it to my advantage but I don't. I think it's the nature of things but again it's not all the case. People who know that I have a brain injury, they don't know how to treat me because it's been referred to as a hidden injury (mechanical noise in background), they don't know whether to hold back on the reins rather than jump in with both feet and upset you, cause upset, they don't know what the impact is in upsetting me so they try not to upset, you know cos I have a brain injury but it's only those people that know that I have a brain injury. Something else that we touched on a little bit earlier is that the neurological damage has an impact on my physical functions, you know I have a clonus and some feign nerve responses and I need a stick to support me walking. Now you	Doesn't take advantage of possible advantage. People don't know

Hidden injury		would expect that the walking stick would be as a badge, like a badge or an indicator, a good indicator to others that I was unsteady but I’ve been pushed and shoved more times holding the walking stick than being mistreated once people know that I have a brain injury and yet that’s a hidden injury so I don’t see where the logic is in that	how to treat him after ABI. Hidden injury. Decision: treat him cautiously or recklessly. Worry
Physically damaged Feeling physically invisible	I	I guess that made me think that on your, again I’m thinking about the graph we just looked at, you put yourself as closer to being treated differently than being treated the same now with your brain injury, and I was wondering if what you just told me there that kind of story about being in a supermarkets and having people go into you, is that an example of being treated differently in some way?	that upset will affect his brain injury, uncertainty about nature of ABI. Physical damage, physical functioning
	P	Not with a brain injury no, seeing me as someone with a walking stick, why would they assume that I had a brain injury, further from the truth, you know but people who know that I have a brain injury treat me different.	damaged. Visible aspects of difficulties, of being vulnerable?
	I	So that’s, being treated differently is more in relation to your brain injury	Uncertain/cautiousness due to
	P	Where people know that I have a brain injury yes	
	I	But when people don’t, you’ve kind of told me about what that’s like in a supermarket as an example, why do you think that is then, why do you think that’s different?	unknown/not a norm? Can't understand what you
Retention of social normality physically	P	Probably because there’s a number of people that have got walking sticks and so the tolerance level has dropped, so people are not as tolerant with people, they can’t react, this attitude, what are you doing walking around in a supermarket where there’s trolleys with a walking stick, how dare you (laughs) so there seems to be a quiet protest about people getting on with their normal day’s work with a walking stick. I just fail to see the logic or mentality of some people but that’s the way it is	can't see? Stick more normal publicly? Blend in? Physical difficulty normalising. More difficult to manage than cognitive side? Less sympathy? Treated differently
	I	You also, when I mentioned about being treated differently and how you put yourself closer to that now with your brain injury, you said that that was very much related to your brain injury, that experience that you were treated differently and was wondering if you could tell me more about that or give me some	by people who know. Normal to see everyday

		examples of when you've been treated differently?	People intolerant to physical limitations, inconvenience. Socially inappropriate to voice, quiet protest. Becoming a source of inconvenience unhappiness? Unacceptability.
	P	What with the brain injury?	
	I	Mm	
Feeling socially unacceptable	P	(pause) Well people know that one of the impacts of the, effects of my brain injury has been that fatigue, I suffer with fatigue, so the people that I play or used to play golf with know that I cannot walk 18 holes so I walk around with them a few holes but a slower pace, they are aware of that. My daughters and wife know that I suffer with fatigue so they plan, when they plan a dinner or a meeting it is very quick, nothing go out towards the end of the day or later in the day because they know that I won't stand the pace so in that sense they, there's, they make allowances for my condition	
	I	So people that know you have a brain injury make allowances or adapt?	
	P	Yes	
	I	Whereas the people who don't know you have a brain injury	
	P	Wouldn't	
	I	Don't do that	
	P	No	
	I	And it sounds like perhaps you're treated the same as others or kind of behaviour towards you is the same as it would be for somebody else?	
Fatigue	P	If they didn't know	Fatigue. Suffering. Physically limited by fatigue. Needing to go at own pace. Others planning in line with his pace. Allowances for ABI made. ABI invisible On the ball Wouldn't know unless you knew what to look for.
	I	They didn't know yeah?	
Loss of social norm	P	That I had a brain injury yes, probably because if I'm quite alert and most people at XXXXXX, when we attend XXXXX, you wouldn't know that they had brain injuries, none of them because they are quite on the ball as it were, you would only know that they had a brain injury if you knew the common denominators related to brain injury which are concentration and memory and working memory as well, working memory in particular because that's what we all suffer with and what we are familiar with. So we are aware of when people struggle as a consequence of the brain injury but we know that they're suffering during, call it the class or	

		meeting or whatever at xxxxx.	Shared experience of cognitive difficulties.
	I	And I guess I'm struck, I'm just looking at your graph that I can see again, it seems you see yourself at the moment as being more able to think about everyone as opposed to being insular, and I guess I'm struck by that cos I can hear you bringing in perspectives of how other people might think or how they might see you. Why do you think you see yourself as being able to think about everyone?	Experts on brain injury, more than general public.
Invisibility of ABI	P	I think again that is from my past you know profession, in education I've always wanted to be a teacher and as a teacher you're helping people. When you have a brain injury you don't, your personality and ideals don't change, especially from pole to pole, so they don't reverse polarity, so because I thought of people before my brain injury doesn't meant to say that I would be selfish after my brain injury, quite the opposite, it amplifies that initial, is it construct?	Former profession: as educator. Wanted identity as educator. Wanting to help people. Way you construe doesn't change poles after ABI- stable aspect of person
	I	Mmm.	ABI amplifies what was already there
Loss of working memory	P	Yeah that initial construct, so whereas I liked to and wanted to help people before my brain injury, that's what I do and enjoy doing now, is helping people.	Formerly liked helping others. Has maintained some aspects of identity.
	I	And you mentioned that it gets amplified, so does that mean that you enjoy it even more?	
Educator identity	P	I get more pleasure from it yes	Helping identity still.
	I	You also put yourself as closer now with a brain injury to having insight as opposed to having a lack of knowledge, and I think this was about the brain injury in particular, I was wondering if you could tell me more about that?	Pleasure.
Stability of self	P	Well again it's thanks to xxxxxx that the main emphasis at xxxxxx is to educate people as to what a brain injury is, how the brain functions, what parts of the brain affect what parts of the body and so on, you know about the memory, about the concentration, the management of the brain and so on, so all the parts, lobes of the brain, all those things that I've learnt since being at xxxxx, I'm more knowledgeable about brain and brain injury since my, since the accident than I was before.	Significance of educating people about ABI, brain. Physical and cognitive relationship. From educator to learner. Learnt about ABI, not own ABI (no ownership)
	I	I can hear that your kind of thinking a lot about xxxx when giving examples and I	

	4		guess it was thinking, it was making me think about your life more widely and	Importance of improving, learning, growth. Retraining??
Amplification of self	5		about how you see your life now, I guess I was wondering if you could tell me	
	6		more about that as well as if xxxxxx plays a part or not in that?	To work effectively again?
	7	P	xxxxxx does play a part in that but one of the aims of xxxxxx is to allow you to	
	8		promote the way in which you think of bettering yourself, promoting yourself, you	Life goes on.
Remainders of former identity	9		know retraining or redevelopment or something to, that you can build upon. So ok	Needing to keep going with the world. Taking control.
	10		you've had a brain injury, not so much so what but life goes on, that was then this	
	11		is now, tomorrow is the future, what are you going to do tomorrow and the next	
	12		day and so on, you know so you start to take store of your situation, knowing that.	Loss of professional role.
	13		I know now that I cannot act as an electrician or in the field of electrical work	
Redeveloping self	14		because of the difficulties that I have, however I can use my knowledge of	Remainder of past role as educator.
	15		education and theory of education and also finding other interests that you know to	
	16		focus on and to aim for/strive for. xxxxx is one part where I'm a volunteer but then	New part of identity too.
	17		I have got other interests which are wood work (laughs), and working with wood	Needing something to strive for, live for, a passion? New goals.
	18		is something that I've just grown an interest in and reading and writing you know	
	19		and I have two books that are in the process of being written	
	20	I	So you said that at xxxxx, it xxxx kind of almost kind of gives you a way of	
Adapting to difficulties	21		thinking about how life can go on and how life does go on and that for your life	
	22		you can see all these different things you can still do although you are aware there	
	23		are still things that you possibly can't do, so things like work as an electrician but	Life is same but different.
	24		you still have that knowledge, I guess I was wondering what does that mean about	
Living like a machine	25		your wider view then about life, so there are things you can still do and things you	Challenges.
	26		can't but if you had to kind of describe what your view of life now is then what is	Changes.
	27		that?	Ungodly, fight-aspects of life before struggle
	28	P	(laughs)(pause) Well it's the same but has different challenges and the routine has	
Relational benefits of ABI	29		changed. You know my routine used to be get up at ungodly hours of the day, fight	Life focus previously on work, repetitive, like a machine.
	30		my way through traffic, you know through London every day, go to work, do	
	31		work, fight my way through traffic again to get home, got home at an ungodly	
	32		hour, go into the office, do paperwork, prepare for the next job and the next day,	Didn't have a life

Adapting		and you know manage the men so I didn't really have a life for myself, it was work and at weekends play golf if the weather was good, that was it so my, I don't, I didn't benefit from seeing my grandchildren as I do now, there's so many positives that have happened as a result of my brain injury, as a result of me having to stay at home because I cannot drive anymore so that's the main one or the biggest problem that has resulted from my brain injury is the fact that I can't drive. Never tried to but there again I take the opinion that I'd be putting other people at risk because my reactions are slow and that would just cause problems so I've taken the position not to even think about driving. That has had an impact on our financial position but you make your, cut your suit according to the cloth so now we have smaller cloth, the suit is smaller (laughs) that we're looking to cut	before Benefits of life with ABI: relational. Human roles (grandad, husband). Loss of independence? Driving...problem. Social responsibility to keep others safe. Loss of processing speed (cognitive). Loss of financial position.
	I	What does that, so when you say that phrase, what does that phrase then mean in terms of what life is like now so what is your suit and how big is it?	
Becoming present to the world A more valuable life Finding spiritual benefit Improved	P	It's just different, in terms of the financial impact that it has it means that certain things that we can't no longer think about purchasing or going on holidays because we just haven't got the disposable income anymore but the I suppose the, my value of my life in terms of what I gain from it by seeing my you know grandchildren and just experiencing life and noticing what's out there a little bit more, you know going with (wife) on what we call our walks (laughs) which are more of a haul around the village and further afield if the weather's good to the sculpture park and then find a bench, sit down and watch the world go by and that's got more value than what I could ever earn working all the hours under the sun so would I go back to working all the hours under the sun and experiencing hassle every day of the week or my existence at the moment which is not a lot of financial benefit but is it spiritual benefit, far outweighs that and 64,000 dollar question is would I want to go back, turn the clocks back five years to before my accident and then have that kind of life to what I have now. My spiritual life is much better, my relationship with my children and grandchildren is much better, so the answer is that I am richer after my accident than I was before	Went from one positive to many negatives- needing to find positives otherwise it's hopeless? Loss of financial freedom to buy anything or go anywhere. Gain, relationally, more experiences, having time to be mindful and present. Being in the moment. A non-financial gain, more valuable From financial to spiritual benefit.

spiritual life Finding richness through loss	I	That’s really interesting to hear about that richness and how it’s brought out and enhanced the spiritual side of your life	Most important/valuable thing he has learnt. Spiritual life now. Better relationships. Found a richer life through his ABI. Lack of free time previously. Had to earn a living before, role he had no choice over? Previous identity as worker took away from identity as friend, relative Lack of life enjoyment previously. Own interpretation of experience, not put on him. Reached limit to concentration?
	P	Yeah	
	I	And I guess that made me wonder, why do you think what happened to you led to you being able to find that richness and being able to experience that spirituality, why was it not something more negative?	
	P	Time, time	
	I	Ok tell me more about time	
	P	Well it’s free, free time isn’t it, time to do these things because I was working and had to earn a living as it were. Unfortunately the reward was not great, as a self-employed person there are so many hidden costs which are involved in running a company and they eat away at the profit margin and if they outweigh the profit margin then you have to work more hours to make up so that takes away the time, the free time that you have in order to visit friends, visit relatives, enjoy life, you know at a slower pace.	
Hidden costs of former life	I	And I guess it’s that, I think I’m struck by how you were telling me about how know you feel you have the time to enjoy life but I was wondering about was what led to that view that it’s now possible to enjoy life, why was it that your view is that life is not enjoyable as an example, what led to that outlook on your life?	
	P	I don’t think it’s led to that outlook, it’s the conclusion you come to I suppose. Can I…	
	I	Do you want to take a break?	
	P	Yes, please	
	I	Ok, I’ll switch this off **(end of file one).** So you were telling me about why you, what led to you making that choice of enjoying life rather than life becoming not enjoyable?	Living beings, life outside
	P	Right, looking out the window?	Peace
	I	Yeah I’m looking out the window	
	P	Right, now out the window there is an orchard, in that orchard there are animals in	Almost unreal made up beauty in life

Becoming present to nature		the garden, there are animals, there are birds, bird boxes, all sorts of things going on, there’s also peace and sometimes when you get up the spiders have been out and cast a web which has got dew on the web and it looks like a spider’s web that you would see in a Walt Disney film you know in all its glory and it typifies (phone rings) oh we’ll let that go	now, glorious Others can’t trust his judgement/ ability to pass on messages?
	I	Ok	
	P	Yeah	
	I	You sure?	
	P	Yeah no it’s, it is June’s friend that said that she would phone back later which is her now but I don’t want to put her off again and so she’s not in otherwise she might think that I’m spinning around (laughs)	
	I	Ok	Beauty out there. Time to appreciate it. Mindfulness
	P	So I’d rather (phone stops ringing) ignore it	
	I	Sure so you were telling me about how you were telling me to look out the window and about spiders and spider’s web and	
	P	Yeah, yeah so much beauty out there and you just don’t have time to appreciate what is out there and what is on your doorstep, if you open your eyes and notice it and this, xxxx xxxxxx that works at xxxxxx runs what’s called a mindfulness course, I don’t know if you’ve ever heard of that term before?	Eyes have become open now, can see more. Gain in insight since ABI. Can see a different side to life now, he couldn't before. Finding purpose in the once 'mundane'.
	I	I have yeah	
Gaining time to appreciate life	P	And mindfulness is about noticing and my eyes have been opened to the world by just noticing. I have become a bit of a twitcher in watching the birds that fly around and I know that this sounds a bit like anoraky but I just love it you know (laughs). I now see what people see in it so you do see different perspectives so what you thought was you know mundane and had no purpose, now has a purpose and I can now see why people get excited about steam trains and plane watching and train spotting and all that sort of thing	Legacy, giving his insight to others: the educator identity. Second chance at life to do things differently
	I	So then if we think about your future a bit more, what would you like that to be like?	Social comparison to

Becoming present to the world	P	I have as said interests in writing, I’d like to complete what I started so that I have some legacy to hand down, something which is quite insightful, so that’s how I see the future and now. Before my accident I could never see myself in a position to do that so this is now that it’s given me a second chance.	other's experience of ABI: negative mostly.
	I	So is that one of the main differences about what your future looks like now from what it might have	
Second chance	P	Oh blimey yeah definitely. Some people say that their world has been turned upside down but I think that they use that term as a negative statement, that to be upright is to be positive, to be turned upside down has a negative impact whereas really it’s a polarisation of two worlds. My life before my brain injury was at a hundred miles an hour, now it is at a snail’s pace and I’ve become very fond of the tortoise and the hare, not a fable but it’s a oh what do they call it, I can’t remember what it is, when they say about the tortoise and the hare but I view life very much through the eyes of the tortoise. It’s at a very slow pace but at a pace where you can notice things	Polarisation of two worlds: going from one end to the other via ABI. 100mph to snail’s pace. From hare to tortoise. Noticing things in life
at life	I	And I guess I was thinking about your graph (name) and about how where you put yourself in terms of how you’d like to be in the future and you put it close to having freedom of choice, of being normal, having insight and I was wondering how do you see those things in your future, what would they look like?	More general view.
Social comparison to others with ABI A 'polarised' life Hare to tortoise	P	I think freedom of choice I was thinking more of everyone rather than personally, that everyone should have freedom of choice, how that has affected me as an individual, then my choice is being restricted in certain avenues. I can no longer work because of difficulties that I have to be able to hold a full time job down. I work three hours a week at xxxx on a Wednesday, Thursday I’m wiped out and Friday’s a better day so I would work three hours Friday then I’m wiped out for the weekend, three hours on Monday, wiped out Tuesday, three hours Wednesday, wiped out Thursday, three hours Friday, so nine hours a week I’d be able to work. Is that of a benefit to anyone?	Freedom of choice for all Own choices restricted Loss of ability to work full time. Loss of energy needed to work full time. Awareness that it wouldn't benefit Challenging how it's usually seen? Not wanting to live that life. Taking control
	I	It sounds quite different to the life you describe in terms of how you used to work	

		before your brain injury.	over how he wants to see life. Striving to hold onto the things he likes, removing what he doesn't about new life.
	P	Absolutely that's why it's now, that's where the polarisation comes in from, you know to being turned upside down but is it being all bad because as I say you know you look at being turned upside down as being more bad, well it's not all bad because it's different. It's changed. And then it's that change. You strive to hang on to those things that you like and dismiss those things, or try to dismiss those things that you don't like.	Loss of memory?
	I	It sounds like what you're saying is that life is sometimes restrictive in terms of the choices you can and can't make but it sounds like from the graph that in the future you'd like to have more freedom of choice, and I was wondering what that would look like, so what kind of choices you'd want to be able to make?	
Limited by body	P	Well the comment I can make on that is says that, from the graph shows that, but in terms of my perception, and this is where again I've lost the thread so...	
	I	Shall I repeat?	
	P	Yes	Loss of driving Own choice to not drive, agency in his decision Restriction in his movements
	I	So when we did the repertory grid and got the graph, the graph seems to show that you're quite wanting the future to have more freedom of choice	
	P	Right...	
	I	Whereas it seems at the moment and perhaps in the past since your brain injury it's felt like your freedom of choice has been restricted	
Managing the new self	P	Well only in so far as what I can do or what is, what I can do is, I can't drive anymore, well that's debatable but I choose not to drive anymore so that's restricted my choice in where I go, when I go and how I go.	Making realistic and achievable choices SMART process: how he lives his life impacted a lot by his learning since ABI
	I	And if we were thinking about the future then, in terms of the choices that you'd like to be able to make, whether it's doing something or not doing something, what would those be?	
	P	Well the choices I'd make would be within our means to do them or to achieve them, so again going back to the realistic, it's what is realistic for us to achieve which would influence the choice	

Loss of working memory	I	And I know that being realistic is something that’s quite important to you. On the graph you’ve put yourself now as being quite close to being realistic and it seems like, I’m wondering if in the future that’s something that would again play a part that you need to be realistic about what you can and can’t do	Hoping for physical progress. Choices reliant on body, something he doesn't have agency over: restriction of choices by body
	P	Big part yeah	
	I	Thinking about the things you think you could do in the future and things you couldn’t do in the future, what would they be, would they be the same as now or different?	Cognitive, energy is the ABI; change from before.
	P	Well hopefully my physical progress would continue and so that would then influence what I would choose to do so it all depends really upon whether I can get better physically you know and then do more	Unrealistic to work
	I	So whether you’re able to do some things and not is dependent on your physical ability?	Keeps saying this: is it because he wouldn't employ this version of him?
	P	Mostly yes, the brain injury which is the concentration and the fatigue. As I’ve said, to realistically work for a living is not on. There’s no-one is going to employ me under the circumstances that I would like for a reasonable wage. As I say, I realistically can work nine hours a week maximum. Is that really good for an employer? No. There’s too many, what is it, not barriers or obstacles but it’s not commercially viable.	Doesn't feel he can do it. Unable to benefit an employer
	I	And thinking about that in particular, so thinking about the example of not being sure if you’d be able to have employment because of the way in which it might impact the employer, I know you said previously when we were doing the grid that you don’t like to see people as typical, people are different but being different is still normal, but if we were to get you to think about people as typical, the future you describe in terms of your employment is it different or the same as how you expect somebody’s life would be if they had a brain injury?	Needing insight into ABI to understand their lives Awkward laughter. Shame to admit this. Previous perception of ABI as disabled, vegetative. Learned the opposite: intelligent, smart etc.
	P	Well I think to answer that question you have to first have some insight into what a person with a brain injury would be like.	
	I	Tell me more about that?	

	P	Well...	Easier to see it this way, as he has an ABI? Wanting to make it less painful to belong. Self-protection.
	I	It sounds quite important.	
Restricted by cognition	P	Well (laughs) what I might, my perception of someone with a brain injury, not proud of what I say was someone maybe slumped over at dinner table with dribble you know from the mouth and unable to do anything for themselves, you know like in a vegetative state more so, it never really occurred to me that someone with a brain injury, and as I said to you, people that I meet at xxxxxx are all very intelligent. They have attributes that they're either academically (pause) gifted or clever or smart	Perception of vegetative
	I	So it sounds like your view of what somebody with a brain injury might be like is very different to what you previously thought before your brain injury.	
	P	Yeah as I say before my brain injury, I considered people, or perceived people with a brain injury to be in a vegetative state.	Witnessing others' lives Hidden injury Fatigue Can't see it till extreme Becoming slow
	I	But from what you know now what would you imagine somebody's future would be like if they had a brain injury based on what you've seen?	
Change in perceptions about ABI Self protection	P	Well what I've seen and what I've witnessed is that it's further from the truth, that as people with a brain injury it is a hidden injury, that some difficulties they have as mine which is fatigue, doesn't show itself up automatically nor would you notice it until such time as it took a dramatic turn for the worse. My thought processes would slow down, my speech would slow down and to the point where I would have to keep repeating what did you say you know, what did you say, cos I keep losing the thread. My working memory would suffer first you know before everything and then you know as the fatigue is kicking in so you wouldn't really notice that I had a brain injury and even then you wouldn't attribute my behaviour as having a brain injury, you'd attribute it to being rude	Forgetfulness. Working memory not working Perceived as rude, drunk *either way perceived in a negative way, different to what is socially preferred or expected
	I	But thinking…	
	P	Or drunk. or both.	
	I	(laughs) But thinking about what you described, those kind of difficulties that somebody might encounter, what does that then mean about what somebody else's	

	32		future with a brain injury might be like? Would it be the same as yours in same	
	33		way or would it be different?	
	34	P	No, everyone’s different	Everyone's different
	1	I	Why’s that? I guess I’m curious	Brain injuries all different
	2	P	Because all brain injuries are different, none are the same, so you would have, you	
ABI a hidden injury	3		would demonstrate common difficulties such as concentration, fatigue, memory,	Commonalities in cognition problems.
	4		but others for instance problems with drinking, smoking, habits, would kick in and	Same but different.
	5		play a detrimental part on their futures	Moderating factors to injury. Not wanting to be lumped.
	6	I	So it’s not just having to think about someone’s cognitive abilities	
	7	P	No	
	8	I	But it’s also other factors to do with their physical health or what they might be	
	9		doing to cope, so all of those things would determine what someone’s future might	Challenges due to ABI
	10		be like? Is that accurate?	Moderators
	11	P	Well they must do	
	12	I	Oh ok, so for you in order to know what somebody’s future might be like is based	
	13		on all those things. It’s quite hard to say that somebody will have the same life as a	
	14		brain injury	
	15	P	Except that you know that it would have challenges and the degree of those	
	16		challenges would vary from individual to individual	NON-ABI same but different too
	17	I	What about if you were thinking about again I use this word, I know you don’t	
	18		like it but a typical person without a brain injury, do you think their future would	
	19		be similar to yours, or similar in some sense as somebody with a brain injury or	Cognitive skills
	20		would it be different?	
	21	P	Well it would, they would all have, as I say common elements in them but then it	
	22		would be down to the individual	Normal person (without ABI) vs (him) abnormal?
	23	I	And what do you think the common elements might be?	
	24	P	Concentration, fatigue, memory	Positioned as abnormal in relation to non-ABI
	25	I	So what a person without a brain injury, what would it look like for them in terms	
	26		of those things you’ve described – concentration…?	Loss of normality,

	P	Well one of the things that you touched upon was lying. A normal person would be able to lie and carry it off; I wouldn't. A normal person would be able to work 40 hours a week; I can't. A normal person would be able to drive; I can't. There are people at xxxx that have got brain injuries that can drive. There are people at xxxxxx with brain injuries that can't drive. There are people at xxxx with brain injuries that have problems with fatigue and others that can't sleep at all. Their sleep patterns are certainly affected but one is with too much sleep and one some with no sleep at all. Very few are not affected you know, they're sleep patterns are not affected, they're concentration is again affected, a lot of them can't read or have given up on trying to read because they can't retain the information and follow the plot so I've gone on to reading what are called quick reads which are very short stories of various levels but generally with one or two characters so the mind doesn't have to work too much in trying to keep up with the play as it were	can't do what he used to that normal people can Differing nature of ABI ABI as dominantly affecting people's lives Given up Adapting to changes in cognitive skills
	I	I guess, I'm looking at your graph and I'm seeing that one of your expectations for the future is to hopefully be treated with more individuality and I was just wondering about the importance of individuality and if that's important to you or to people with a brain injury more globally	Individual, unique
	P	I think that everyone should be treated as an individual but they should be given the same rights, so in a sense there's a bit of contradiction there isn't there so it depends how you interpret that	Same rights Contradictions
	I	How would you interpret that?	
	P	What individuality?	
Being abnormal in comparison	I	Mmm	Individuality
	P	Treated as everyone as an individual I would say	
	I	Cos I'm aware that on the graph it's quite close to being treated differently but I guess I was curious about that, about being an individual being treated differently but then you say that you also must be treated the same as well	Same rights, equality
	P	Yes, be given the same rights	
	I	The same rights but being treated differently and as an individual within that	

Adapting to new self	P	Yes	
	I	Thinking about that, are there examples of being treated that way since having had your brain injury?	
	P	Are there any…I can’t think of any (pause) no, no I would struggle to think of any	
	I	But I can see on the graph that it’s something that you hope for or you expect to do be in your future	
	P	What’s that?	
	I	To be treated more as an individual than treated differently at the same time as that? Is that something that you hope for in your future?	
Same but different	P	Well again it would depend upon my frame of mind as to how I interpreted the word individual	A fluid term, changes with his mood?
	I	Yeah but basically now you’re interpreting it now, is that what you hope for in the future?	
	P	I really don’t, don’t know, I can’t answer	Uncertainty
Invisibility of ABI	I	Ok. I guess we’ve spoke a bit about this, at the beginning of the interview where you touched on how others treat you or how others see you but I wanted to ask you a bit more about that and I was wondering what are the main ways in which you think people see you?	
	P	The people that knew me before try not to treat me any differently. They do give me leeway because they know my circumstances but I suppose for the average Joe Bloggs they treat me like any other person, you know other than the fact that I have a walking stick, they wouldn’t know that I had a brain injury	Attempts to treat him same but different Treated same by average person Brain injury invisible (cognitive side)
	I	And I know when we looked at the scores with the graph, we saw that your partner, June, and your children treat you in a similar way to each other, also quite in a similar way to what you were like before your brain injury but you said that you would make allowances	
	P	Sure	
	I	Do you agree with what I’ve just said?	
Fatigue	P	Yeah	

	I	Could you tell me a bit more about that cos I guess it makes me wonder what that is like that they see you and treat you	
Adapting to limitations Limited amount of concentration	P	Well they are aware that fatigue has a great impact on my life and how I manage to get through the day so basically I run out of steam later on in the day, I'm much better in the mornings you know in terms of concentration than I am later on in the day so they plan visits and doing anything as a group together as early in the day or as close to the end of the afternoon as possible, anything before seven o'clock because after seven o'clock I'm wiped out so that's how they make differences so there are certain things that they compensate for but they still treat me as they treated me before, same insults…	Fatigue impact on life Run out of steam: unable to keep going Self-awareness of limitations Others made adaptions
	I	So do they still see you as the same (name) as before but needing allowances	
	P	Oh yeah, yeah, yeah, yeah	
	I	Ok how about in terms of a person, so you've described a lot about the practical things that they might make allowances with, but as a person, how do they view you now and is that different to before?	Treated the same -a level of self-protection, wants to be seen as treated the same?
'Breakable'	P	I think to a certain degree they treat me with kid gloves (pause). I think they are careful that they don't break me (laughs)	
	I	Why do you think that?	
	P	Huh	
	I	Is there a particular way that they see you now which makes them worry about breaking you?	Treated with kid gloves Vulnerable to be broken?
	P	I think it's because they saw me immediately after my accident and the condition that I was in when I was admitted to hospital and I think that that has impacted or influenced how they treat me now because they saw me as this frail broken bird that had fallen from the nest I suppose for want of a better word, broken wings and all sorts.	
	I	And is that how they see you now?	
	P	Not so much but I think the, it must still be in the back of their mind because there are certain things…for instance the grandchildren you know when they jump up at	Seen as frail, broken initially

Reversal of parent-child role		me you know my daughter (laughs) nearly falls and says look don't and I say I'm ok, you know, past all that, things have improved dramatically but she says oh even so and I don't want them to hit your head	Fell from his role within their home, lost freedom he had? No longer strong working male?
	I	So because your family saw you immediately after it sounds like they see you how you describe as this bird that's fallen from its nest and you kind of said a frail bird, has fallen from its nest, do you think they still see you like that now as that frail bird or as something else?	Worries about hurting him Wants it in the past now? Daughter as protector, where as he used to protect her. Becoming his parent and protecting him?
	P	No I think at times, at times when there is a threat	
	I	How about now then? How do they see you now? So not just in terms of threat, more generally?	
Glimpses of former self Daily loss Rejection of disabled identity	P	Well, if I'm on the telephone it's same old dad especially if I'm alert, again June, depending on what time of day it is, if it's in the morning when I'm really sharp, then they will remark and the last thing that Cally said, you're so on the ball these days but (laughs) and I say well that's cos I've just got up so I would be but as time progresses then it becomes more difficult to focus on the conversation because that is using the working memory. My working memory is down there where I would like it up there but now it's down there	Threat
A hidden injury	I	And you mention that the people who don't know you have a brain injury, they might see you differently to how people who do know you see you, so thinking about people who don't know you or don't know you have a brain injury, how do you think they see you?	Same old dad on the phone, aspects of old identity remain
	P	Another individual	
	I	What does that mean?	Daily loss experienced from morning to am Decreased, wants it different
	P	(laughs) Exactly what it says on the tin	
	I	Ok so	
	P	Because I don't see myself as having a disability although as I say registered disabled, the brain injury is a hidden injury, they're not going to see me anything other than normal, and normal is the word that I don't like to use because I think they're used out of context that's why I say as another individual.	

	I	So those people who don’t know you, thinking more widely let’s say about your community, how do you think people in your community see you?	
	P	As a person with a brain injury, only because they’ve been informed and because we live in sheltered accommodation and everyone is in the same boat so next door are disabled, the woman on the end is disabled, and the people opposite are	Another, average
Rejection of disabled identity	I	Does that help or hinder you in any way that those people know and so they see you in a certain way?	Unwanted disabled identity: 'registered', not how he sees himself Hidden injury Seen as normal due to hidden-ness Normal-individual: self-protection? ABI invisible Sheltered; protected Same boat, belong together: grouped as disabled.
	P	No there’s an understanding you don’t have to explain or feel as if you have to explain yourself, you know your actions so in that respect it makes it easier but then I don’t see any of them as being disabled, I see them as being normal, you know with change	
	I	And is that how you think they see you?	
	P	Well as I hope that they see me as someone having difficulties	
	I	Do you know how they see you? Has anyone ever mentioned how they…	
	P	I think they say same old (name) (laughs) so.	
	I	Thinking a bit more widely though, so I’m thinking more in terms of widely to the point of what culture you’re from, when we were doing the forms you said you were British white?	
	P	Yeah	Quiet understanding shared Rejection of disability: normal change. Self-protection, wants others to seem him this way?
	I	If we were thinking at that level, how do you think a British white person would see you? So I know obviously you can’t know every single British white person in the UK but if you had to imagine or guess, how do you think they would view you with your brain injury?	
	P	What after I’ve talked to them for five minutes or just bumped into them on the street and said sorry (laughs)	
Dislike of former self	I	Both	
	P	Well, my view of the typical person on the street is one which is decline, again only by observation and I see that they are less tolerant, more stressed and living their lives at 90 miles an hour and getting nowhere **(end of file 2)**	Same old **** Average on the outside, until he speaks?

	I	So you were just telling me about how your view of people on the street has declined and how they're less tolerant, they're living at 90 miles per hour, and I guess I was going to ask you, what does that then mean about how they might see you once they've spoken to you or not spoken to you?	Public declining in tolerance, increasing in stress and speed.
Feeling invisible	P	I don't think that they would notice the fact that, well I know that they don't know cos a lot of people don't notice and I have a walking stick, now that is a visible, a clear visible disability so how they are going to notice one which is invisible so they're not going to pay any attention to it whatsoever	That was his former identity. Has ABI done the opposite to put him in decline?
	I	And does that help or hinder you in any way?	
	P	Well I suppose helps in so far as I know where I stand but hinders in the fact that as a normal person that doesn't get out the way when I'm walking but barges past that hinders but they're not doing anything more than well no, no, no that's it. I don't think there's any more to comment on, I'm just not very positive about you know people in general to be honest	Mindlessness Visible ignored Lack of attention with and without ABI?
	I	We'll move on from that then	Gives no reason- all bad
	P	There's the odd student that comes (laughs)	
Wanting to be treated as an individual	I	(laughs) and they're just so wonderful aren't they! (laughs) We'll move on to the last bit which is just thinking about, thinking about you as a patient	Vulnerable due to others' being an obstacle
	P	Yeah	
	I	So when we did you, we looked at the graph together, I could see that you put being a patient as close to being a clone of being cloned or treated the same as everyone else, as someone who's struggling or out of control or insular or having a lack of knowledge, and I was wondering if you could tell me more about that view that you have	Difficult to talk about. Negative attitude towards 'general people'.
	P	Well I think that all patients need personal care on an individual basis but treated the same in so far as given the same amount of care as the next person who has the same problems or the same injury so again that's kind of like a statement that is contradictory in terms of a) they have care on a personal basis but it should be the same care as someone who has the same injury if that makes sense	Needing to be cared for case by case Equal treatment wanted Contradiction

Loss of independence	I	Yeah I think so, I think it sounds like what should be underpinning choices people make is that everyone has to be treated the same with the same rights but within that treating people differently in terms of who they are as a person	
	P	Yes	
	I	You also kind of mentioned that as a patient you know there's that feeling of being out of control or struggling	
Hidden victims of ABI	P	Well yeah because there you are in the bed (laughs) you've lost your, you've completely lost your independence and you're dependent on others for your welfare so you will be or would feel out of control, that's how I see it	Loss of independence Dependence on others to be safe Out of control
	I	You also mentioned about that feeling of things becoming insular of not being able to think about everyone else anymore as a patient	
	P	I'm not sure whether that's how I thought or how that became that (pause) the notice or the attention came to me because it was noticeable that I needed attention because I'd been in an accident and had suffered as a consequence and so all the attention seemed to be on me in order to see how I was, what my welfare was, am I being looked after so and so forth. None was given to those that were supporting me that were the hidden people that were injured and that the bombshell dropped on them. My wife who was now very happy at home with a couple of dogs and taking them out and doing her bit and had her individual life, to have the rug pulled from under her feet that she's now thrust into a positon where she's looking after my welfare and there seemed to be so much attention on me. That's where the insular bit comes, the attention was on me and none was given to those that were supporting.	Needed attention Justifying attention. Suffered. Welfare, being looked after. Supporting people not looked after. Hidden people. Family injured. Wife previously happy Family's individual life
	I	Based on that experience	Unexpected changes
	P	The impact it had on their lives	Cared for to carer?
Becoming the priority	I	And thinking about that experience and the impact that you noticed, what does that mean then about what health services should be offering if it means anything?	Became supporting actors in his life?
	P	Well I think that they are there but the training is poor, you hear, not so much the training it's the time, it's the time aspect because in order for you to deal with on a	Poorly trained? Little time for patients

Protecting vulnerable self		pastoral basis, a welfare basis takes time, takes time to support somebody or to show them, point them in the right direction and the National Health Service is stretched to the limit anyway and can, that would go down fall down by the wayside you know that pastoral care and support which is required to others, that have just had their lives thrown, well turned upside down, one of your turns of phrase, so that's where the insular bit comes in, is that the focus is on me and not so much on those that support me but there are so many constraints on the services that they have to be prioritised and I supposed the prioritise is the person that's injured.	Pastoral care taking time Guidance NHS stretched Pastoral care become unimportant, costly Big life change Individual the priority, supporters ignored. As and when use
	I	What does that mean then about the way you use health services now, cos it sounds like you're very aware of constraints?	Increased vulnerability
	P	Oh no, no, well how I would use them or other people using them?	
	I	Both	Loss of immunity, tolerance to illness
	P	Well I do use them for aftercare but again I only use them as and when I feel that I need them, for sniffles and colds no, although I should do because unfortunately as a, I say unfortunately, as I am aware it's one of the unfortunate things about having a brain injury is the tolerance to other illnesses, it's decreases, goes down	Suffering due to NHS: avoids doctors to protect?
Being protected	I	So you're more likely to…	Similar relationship to health seeking as other males, stability in this phenomena?
	P	I'm more likely to pick up things and suffer as a consequence as the National Health, and the doctor has advised me to don't be afraid of bothering them to even if I get a sniffle, go around there because it could be quite serious. At one stage it was. One of things I had was serious but I don't like to burden them if I don't feel as if I have to.	Healthy for him, can't be vulnerable. Reversal of traditional gender role, she has become the protector.
	I	So it sounds as if your experience of health services hasn't hindered you, you still use them when you need them but perhaps not as much as you should but is that the same for important other people in your life like your, like you mentioned June	
	P	Mmm	
	I	What about June and how she uses health services?	Doesn't think about psychologists/therapists
	P	Well again she has to, she has a flu jab but only has a flu jab because she knows	

		that the risk of me or the impact of me catching flu or influenza has greater consequences.	Not what he needed? needed day to day support?
	I	But how about health services, so that sounds like again it's related to your needs as well as June's but how about in relation to things you mentioned about the impact it had on her and how it changed the way her life was. Has she been able to use health services in regards to that?	Experienced MH probs Understands services
	P	No, I think that you have the health service which people would call the National Health Service, you know you have the doctors and nurses but then you have all other supporting services likes Social Services, and so on. My opinion is that they are too top heavy in their structure, there's too many chiefs and not enough Indians.	Abandoned by diagnosers Gone missing/ignored as a result Not caught by those who are supposed to hold you
	I	Can you elaborate on that cos it sounds like something quite big	
	P	Well when you, you look at my mother-in-law has not been well, she has mental health problems, some that I can relate to and have a great understanding of difficulties that she has with her mental health and support teams, the people that are supposed to diagnose her from the outset have not been there, fallen by the wayside and she's fallen by the wayside and I wouldn't necessarily say that she's one of a minority that fall through the cracks, she is one of a vast number of flower granules that fall through the sieve	Taking responsibility for others by speaking out? Protecting others? Criticising Shouting Political knowledge
	I	You mentioned that you can relate to some of her difficulties, and I was wondering those difficulties that you're referring to, are they also in relation to your brain injury or are they separate	
	P	No the brain injury yeah, related to my brain injury	
	I	Again thinking about you used health services in relation to those, did you feel that you were able to or that the way health services are set up either helped or hindered you?	Anger at this? Unable to express it due to ahi has been done for him, so expressing through
	P	The health service certainly helped me tremendously. I won't have a bad word said about the health service or the National Health but I would certainly be one to criticise the health which is given to, or the attention that is paid to mental health.	

Filling the gaps		If you listen to the health secretary, can't think what his name is, oh god, yeah he's been on the television shouting from the treetops that he's doing everything in his power to improve the mental health and mental health is his top priority, well my mother-in-law has suffered from mental health problems for 50 years, there's been no improvement, in fact her condition has never been diagnosed, in 50 years, how can that be a top priority you know even now, and she's not in the minority, she's one of, one of a number of people.	someone else? Going missing Protecting vulnerable others? Significance of stat services support Knowledge of ABI from others significant to progresses. Role reversal, becoming the educator
Significance of statutory help in recovery	I	What about mental health services for people who've had a brain injury, cos like you mentioned that it's quite common that somebody with a brain injury might have other aspects of their life like their emotions impacted, what about those services?	
Significance of expert advice on daily life	P	Well again they fall by the wayside. If it wasn't for xxxxxx picking up, which is a charitable organisation, then god knows, I would never have made unless well I say would never have made, I would probably have made some progress because of (wife)'s knowledge on that side because she's worked with severely she calls them children with severe learning difficulties, brain injuries and so on, so she, her field specialises in that or should I say her knowledge, she has a vast amount of knowledge which would, what's the word, would be used to assist me so the impact on me would not be so bad but it wouldn't be as quick or as far reaching as it is now with the help of xxxx.	Awareness. Funds. Leadership. His past management skills speaking?
	I	What does that mean about what's missing then in terms of services and what they need to provide?	Half full attitude Examination, studying ABI, fits with his educator identity and value for education Filling the gaps, making whole again
	P	Awareness and funds, they are aware, it's funds and really leadership in putting the money where it's needed	
	I	And if they had those things, if they had funds and awareness and they had somebody to take that forward, what is it they would be providing to people with brain injury or people with brain injury as well as related mood or emotional difficulties?	
Loss of cognitive	P	Rehabilitation	

skills/ functioning Acceptance	I Such as? Cos it sounds like you got some of that from xxxxxx and I’m wondering what that was? P It’s looking at life where the glass is half full rather than half empty and it is to examine as we, not examine I suppose want for a better word is examine, examine brain injury and what it is, how it can impact so there’s education there, a knowledge there and so you can learn to deal with the brain injury by finding strategies that fill in the gaps. For instance, (psychologists name) gap filler was the phone and using the app on the phone or the calendar to remind you of when to take tablets and when to go down the shops and when the next doctor’s visit is and when the next haircut is and so on and we do that in conjunction with the calendar, two side by side and that works because my, keep going on about the working memory because that is what it is, it’s gone, my working memory is non-existent and I think that the exercise which you did on the first day that you were here was to tell a story and I cannot remember the names and the dates or as much as I can says it all, the feedback, the information that you get from that will tell you how good or how bad my working memory is I So it sounds like there would be that practical support that people would be providing in terms of how to overcome things like working memory difficulties or are there areas that people might need support with. Would there be any support in any terms of emotional wellbeing or not that would be needed? P Again that depends very much on the individual. Some people are more mentally strong than others, some people have got more, what’s the word, sort of realistic approach to things, it doesn’t mean to say that you resign yourself to the fact that this is it, there is a realisation that this is where we’re at but ok this is where we’re at but what’s the best I can do with it, so that’s it. I By the way I’ve asked you many questions and all of the ones I wanted to ask you but is there anything that you were hoping to mention or that you thought was important that we haven’t mentioned in the interview? P Well only briefly cos I touched on it, we did that test originally, did you mark it	To work properly Loss of working memory Mental resilience as individual skill Realistic approach Realisation Making the most of the situation, accepting

		I Yeah I can show you that outside of the interview P Well whatever I Yeah ok	

APPENDIX 13- Audit trail for analysis: Superordinate and subordinate themes for Percy

Themes	S, P	Extracts
1. Unrewarding former life		
Living like a machine	(29, 6)	' You know my routine used to be get up at ungodly hours of the day'
Hidden costs of former life	(3, 8)	'Unfortunately the reward was not great, as a self-employed person…'
Second chance at life	(20, 9)	' Before my accident I could never see myself in a position to do that so this is now that it's given me a second chance'
2. A richer life		
Richer relationships		
-Finding richness through loss	(26, 7)	'my relationship with my children and grandchildren is much better, so the answer is that I am richer after my accident than I was before'
-Relational benefits	(1, 7)	' I didn't benefit from seeing my grandchildren as I do now...'
-A more valuable life	(14, 9)	'that's got more value than what I could ever earn working all the hours'
Richer inner world		
-Finding spiritual benefit	(22, 7)	'my existence at the moment which is not a lot of financial benefit but is spiritual benefit'
-Improved spiritual life	(25, 7)	' My spiritual life is much better'
Richer outer world		
-Becoming present to nature	(22, 8)	'Right, now out the window there is an orchard, in that orchard there....'
-Gaining time to appreciate life	(4, 9)	'Yeah, yeah so much beauty out there and you just don't have time to appreciate.'
-Becoming present to the world	(18, 7)	' my eyes have been opened to the world by just noticing'
-Hare to tortoise	(9,9)	'It's at a very slow pace but at a pace where you can notice things'
3. Remainders from former life		
Remainders of former self		
-Stability of self	(16, 5)	' When you have a brain injury you don't, your personality and ideals don't change, especially from pole to pole, so they don't reverse…'
-Amplification of self	(19, 5)	'my brain injury doesn't mean to say that I would be selfish after my brain injury, quite the opposite, it amplifies that initial, is it construct?'
-Glimpses of former self	(22,16)	
Remainders of former identity		
-Remainders of former lecturer identity	(7, 1)	'Well, if I'm on the telephone it's same old dad' -25
-Remainder of former helping identity	(22, 5)	'the, realism comes with the territory of my previous role as a lecturer'
-Remainder of educator identity	(7, 5)	'whereas I liked to and wanted to help people before my brain injury, that's what I do and enjoy doing now' 'So we are aware of when people struggle as a consequence of the brain' 7-9
4. Invisibility		
Invisibility of ABI		
-Invisibility of ABI	(2,5)	' you wouldn't know that they had brain injuries, none of them'
-ABI a hidden injury	(19, 12)	' it is a hidden injury, that some difficulties they have as

		mine...'
-A hidden injury	(4, 17)	'brain injury is a hidden injury; they’re not going to see me anything...'
-Hidden injury	(11, 3)	' how to treat me because it’s been referred to as a hidden…’
-Invisibility of ABI	(7, 15)	' I suppose for the average Joe Bloggs they treat me like any other person'
Feeling invisible		
-Feeling physically invisible	(19, 3)	'would expect that the walking stick would be as a badge, like a badge...'
-Feeling invisible	(7, 18)	' a lot of people don’t notice and I have a walking stick, now that is a visible'
Invisible people		
-Hidden victims of ABI	(12, 19)	' None was given to those that were supporting me that were the hidden."
5. Loss of cognitive skills		
Loss of memory	(23, 1)	'you have to have all your marbles....'
Loss of cognitive skills	(22, 22)	' my working memory is non-existent'
Commonalities in cognitive losses	(6, 5)	'working memory in particular because that’s what we all suffer with'
Daily loss	(25, 16)	'as time progresses then it becomes more difficult to focus on...'
Loss of working memory	(4, 5)	'common denominators related to brain injury which...'
Limited amount of concentration	(19, 1)	'and I’ve forgotten what the other part of the question was (laughs)'
Loss of concentration	(25, 10)	'and this is where again I’ve lost the thread so...'
	(20, 15)	'I'm much better in the mornings you know in terms of concentration than'
	(8, 1)	' oh no I’ve lost the thread now, I can’t remember what the question was'.
6. Feeling different in comparison		
Different in comparison to public		
-Being abnormal in comparison	(27, 13)	' A normal person would be able to lie and carry it off; I wouldn’t.'
-Becoming different to others	(33, 2)	' when they know that you have a brain injury and they’re not sure...’
-Feeling socially unacceptable	(5, 4)	' what are you doing walking around in a supermarket where there’s trolleys with a walking stick, how dare you'
Different in comparison to past		
-Loss of family norm	(20, 4)	' so they plan, when they plan a dinner or a meeting it is very quick'
Different in comparison to people with ABI		
-Social comparison to others with ABI	(24, 9)	'some people say that their world has been turned upside down...'
7. Being protected		
Protected by self		
-Self protection	(8, 11)	' it never really occurred to me that someone with a brain injury'
-Protecting vulnerable self	(10, 20)	'I’m more likely to pick up things and suffer as a consequence...'
-Avoidance of social complexities	(25, 1)	' you have to have all your marbles...'
Protected by others		
-Reversal of parent-child role	(10, 16)	' for instance the grandchildren you know when they jump up at me'
-Being protected	(20, 20)	' she has a flu jab but only has a flu jab because she

		knows that the…’
-Seen as 'breakable'	(33, 15)	'I think they are careful that they don’t break me (laughs)'
8. Adapting to difficulties		
Filling the gaps	(16, 22)	' learn to deal with the brain injury by finding strategies that fill in the gaps'
Adapting to limitations	(20, 15)	' I’m much better in the mornings you know in terms of concentration.'
Adapting to new self	(2, 14)	'can’t retain the information and follow the plot so I’ve gone on to reading.'
Changes in relational strategies	(25, 2)	' Even if it’s, even when you’re honest and before as I said' 25-29'
Adapting	(8, 7)	' but you make your, cut your suit according to the cloth so now we have smaller cloth, the suit is smaller'
Adapting to difficulties	(13, 6)	'I cannot act as an electrician or in the field of electrical work because...' -16

APPENDIX 13. Audit train for analysis: Superordinate themes for all six interviews

Derek: 1. Loss of body and mind 2. Focus on getting better 3. Loss of masculinity 4. Disconnection from others 5. Hopes for agency 6. Grieving for former life 7. Taking a painful place in other's eyes	Percy: 1. Unrewarding former life (contrast to others?) 2. A richer life 3. Remainders from former life 4. Invisibility 5. Loss of cognitive skills 6. Feeling different in comparison 7. Being protected 8. Adapting to difficulties
Bruce: 1. Importance of others for recovery 2. Taking control 3. Loss of normality in comparison 4. Spiritual sense-making of recovery 5. Determination 6. Developing again 7. Body not working right 8. Striving to meet expectations of masculinity	Dean: 1. Journey of discovery 2. Acceptance 3. Confusion 4. Educating others 5. Remainders of former self 6. Social worries 7. Public lacking knowledge of ABI 8. Significance of time 9. Importance of others in recovery 10. Protecting self
Lance: 1. The vulnerable self 2. A limiting body 3. Invisibility 4. Striving for normality 5. Lack of agency over life 6. Perceived as damaged 7.The upgraded self 8. Maintaining independence	Robert 1. Confusion 2. Cognitive difficulties 3. Understanding self again 4. Observing life 5. Regaining the former self 6. Daily struggle to live 7. Being less in comparison to former self 8. Avoidance of painful feelings

APPENDIX 13. Audit trail of analysis: Group level master, subordinate and emergent themes

	Master themes	**Subordinate themes**	**Excerpts**
1	Invisibility	*Hidden injury*	P2: 'Everyone else don’t actually know what’s happened to me. For example, the football club. Walk in there, no-one knows me, well people know me but not from my accident, they don't know I had an accident or anything. So they look at me a lot differently. And if I can’t do something they like why can’t you do that, Why can’t you talk, why can’t you do things’. P3: "wouldn’t be able to see that I’ve had that or understand that I’ve had an ABI' P4: 'that as people with a brain injury it is a hidden injury, that some difficulties they have as mine which is fatigue, doesn’t show itself up automatically nor would you notice, until such time as it took a dramatic turn for the worse' P5: 'I’m walking here and there whatever but I’m, you wouldn’t necessarily know straight away there was something wrong with me'
		Social invisibility	P1: 'but after injury nobody comes, to say hello even (pause), it’s painful, painful for me' P3: 'You lose sight of the fact that your people around you go through that as well. Ok they’re not going through the illness but they’re getting all the bad stuff and no good whatsoever'. P4: 'None was given to those that were supporting me that were the hidden people that were injured and that the bombshell dropped on them'

			P5: ''you know what, needs to happen', 'what's that', I said 'social awareness' P6: 'say somebody says to me… you know… "how are you?" … [pause] …I suppose… [pause] …the easy…answer is – and the one that Everybody wants to hear is – "I'm absolutely fine!". Yeah, and… big smile and, and they, and they're- they're happy'
2	Painful relationship with society	*Feeling unable to meet perceived expectations*	P1: 'She doing hard work, I'm not able to do anything' P2: 'I still can' play football (laughs). But everything else I am getting better. So I reckon I will play football' P3: (I: In what way do you think it would hinder you or that it does hinder you?) 'every day being accepted with that, within normal life I would say' P4: A normal person would be able to work 40 hours a week; I can't. A normal person would be able to drive; I can't. P5: 'That's a really good question, it's a hard question to answer, oh dear, dear, dear, how do I put this. We've had this discussion; we feel the problem is with this one, this is what I'm trying to say about this acceptance thing, cos something major has happened, it will be, we could have children ok, it could be the case that wife will have to Look after the baby and I would as well, but and I'm thinking, that could set my recovery right back (laughs)'
		Unwanted labels and perceptions from society	P1: 'they think oh he's not working he's 'bichara'. P3: 'in this country they pay people just to be disabled, they write them off'

			P4: Because I don’t see myself as having a disability, although as I say I'm registered disabled P5: 'Example... presume you’re drunk, presume you’re this, presume you’re that'
3	Post injury growth	*Relational gains*	P2: 'Well, I must admit, my family’s changed completely now. Because now they're not coming cos they have to, they’re coming cos they want to, so three or four of them will come down every three/four months just make sure I’m ok. But my mum, even mum’s family I’ll see them Every week, two/three days'. P3: 'I seem to get along with a lot of people easier than I did before possibly' P4: 'my relationship with my children and grandchildren is much better, so the answer is that I am richer after my accident than I was before' P5: 'Right ok, ok yeah, right and this takes a bit of getting your head around really, I can, how do I put it. Start being respectful to others' P6: 'what I, what love about my life now… is… having more time… for people. You know… down at xxxxxxx, there are lots of groups of people with learning disabilities…and… it’s a challenge to get to know them. You know, because… they don’t behave… as you’d expect a person to behave. [Laughs] You’re probably thinking: “ahh… just like xxxxx!” [laughs]. Erm… erm… but, but I, I really do enjoy… trying to… get to know them...and… and, but also seeing… the pleasure they get… out of knowing me. [Pause] You know, it’s just… it’s so rewarding'.

		Personal growth	P2: 'I don’t know; I didn’t actually know I’d be happy though. I just (pause)...I just turned out to be happy and content'. P3: ' I feel I can be more understanding now than I was before and more tolerant' P4: 'which is not a lot of financial benefit but is it spiritual benefit, far outweighs that and 64,000 dollar question is would I want to go back, turn the clocks back five years to before my accident and then have that kind of life to what I have now. My spiritual life is much better' P6: 'it’s just so nice to… put a little seed in the ground…and… [Pause] to see it grow…and then… you know… it grows into a vegetable. [Pause] That, that’s really good, I enjoy that. I get a lot of… a lot of pleasure from that. [Pause] Which is… it’s a new side of me I guess. I don’t, I mean I don’t remember ever being like that… and… [pause] people who… knew me… when I… in my previous life… said that, you know… I’d be boring them to tears, talking to them about computer programs [laughs]'.
4	A vulnerable mind	*Cognitive difficulties*	P1: 'My brain doesn’t understand what to do now' P3: 'I couldn’t run a business now, I don’t think I have the acumen or the intellect to do that and be able to make the right decisions to do that Anymore' P4: 'working memory in particular because that’s what we all suffer with' P5: ' Because with brain injuries I would say, which I found, was the way I found it, how do I put it, I think with, if you like, I’ll put it simply,

			with your computer being all messed about (laughs) which it has been. Ok, it makes it a lot, lot, lot, lot harder to think about things straight' P6: ' you need quite a bit of memory and brain power to do it. Because, is very much a… a… concentration of memory and focus, because you're [pauses and laughs]. Sorry, I've forgotten my words'.
		Emotional and psychological fragility	P1: 'I can't walk around to the town on my own because I am scared' P2: 'No, no, no, nah, nah, nah, nah. So what I can't play football. But again, I reckon I will play football again. If for example my, I'm partially blind, I can see to the Left, right I can't see anything'. But I tell my doctors, they've both said my nerves have been damaged. I can't see again. But I reckon I will see again'. P4: my perception of someone with a brain injury, not proud of what I say was someone maybe slumped over at dinner table with dribble you know from the mouth and unable to do anything for themselves, you know like in a vegetative state more so, it never really occurred to me that someone with a brain injury, and as I said to you, people that I meet at xxxxxx are all very intelligent. They have attributes that they're either academically (pause) gifted or clever or smart'. P5: 'I'm not really spending too much time (laughs) dwelling on this one because of nothing, I don't want things to screw my head up as well (laughs)'. P6: 'because… they don't behave… as you'd expect a person to behave. [Laughs]

			You’re probably thinking: “ahh… just like xxxxx!” [laughs]'.
5	Importance of others in recovery	*Learning and rehabilitation*	P1: 'I walk properly, she teach me, '(own name) don’t do this, don’t do this, like that yeah', she teach me, do that, don’t do that, like that, it’s useful' P2: for example, two of my best friends, they sorted the xxxxxx for six weeks and then once a week used to come to xxxxxxxxxxx and every time used to come then teach me something else.' P4: 'she has a vast amount of knowledge which would, what’s the word, could be used to assist me so the impact on me would not be so bad' P5: ' for help, erm as regards, how do I put this, taking on board and listening to what others have got to say, I’m talking for example xxxxx for example, What I’ve learned from xxxxx, which has been absolutely brilliant'. P6: 'by getting out and… getting involved in other people’s ways of being… you… I, I feel that that, that helps, as much as… doing other, erm, Things like cog metal (COGMED) or something like that'
		Psychological encouragement through others	P1: 'other patients, they bad from me yeah, bad condition from me, I’m thinking about them, then I think '(own name) you are better than that, better than Them, you should be alright, go through it' P2: 'I think when I see people a month afterwards and they say you said that, that and that, that makes me realise that, that means next month I'll pick up some more words and I'll be able to read a lot more'

			P3: 'they very often will be discussing something and will say well 'no, look at this way (own name), you've had a brain injury, you haven't done this on purpose', whereas I come at it as if I wanted to have a stroke and wanted to have this brain injury, you know. They paint a different picture which I can understand, so I accept things a bit better and keep going'. P5: 'wanting success for me, but not just me, other people; wife, family, friends…'

APPENDIX 14. Slater analysis of repertory grid for Percy

Slater Analyses for Blank Grid

REPERTORY GRID

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                                       Me before my brain injury
                                       .       Me now with brain injury
                                       .       .       Me as I'd like to be
                                       .       .       .       Me as I expect I will be in future
                                       .       .       .       .       Me seen by others
                                       .       .       .       .       .       Me as a patient
                                       .       .       .       .       .       .       A typical person with brain injury
                                       .       .       .       .       .       .       .       A typical person without a brain injury
                                       .       .       .       .       .       .       .       .       Partner
                                       .       .       .       .       .       .       .       .       .       Child
                           Insular    3.00    3.00    1.00    3.00    3.00    5.00    4.00    4.00    2.00    3.00   About everyone
                           Insight    5.00    4.00    7.00    5.00    5.00    3.00    4.00    4.00    6.00    6.00   Lack of knowledge
                            Normal    7.00    7.00    7.00    7.00    7.00    7.00    3.00    7.00    7.00    6.00   Abnormal
Passing off as typical (dishonest)    2.00    1.00    2.00    1.00    1.00    1.00    1.00    4.00    2.00    2.00   Being honest
                          Managing    7.00    5.00    6.00    6.00    4.00    2.00    4.00    5.00    7.00    7.00   Struggling
                        In control    6.00    5.00    5.00    5.00    5.00    4.00    5.00    5.00    6.00    6.00   Out of control
                     Individuality    6.00    7.00    7.00    7.00    7.00    4.00    7.00    6.00    7.00    6.00   Cloning
                 Freedom of choice    4.00    4.00    7.00    4.00    6.00    3.00    4.00    7.00    5.00    5.00   Autocracy
                        Idealistic    3.00    2.00    7.00    3.00    4.00    4.00    2.00    4.00    4.00    4.00   Realistic
                  Treated the same    6.00    2.00    7.00    2.00    4.00    7.00    5.00    6.00    6.00    6.00   Treated differently
```

Descriptive Statistics for Elements [Blank Grid]

```
                                             Means
                                             |        Sum of Squares
                                             |        |        Percent Total Sum of Squares
                                             |        |        |
              Me before my brain injury     0.22     6.16     4.15
               Me now with brain injury    -0.68    15.36    10.35
                   Me as I'd like to be     0.92    28.96    19.51
     Me as I expect I will be in future    -0.38    12.56     8.46
                      Me seen by others    -0.08     5.36     3.61
                        Me as a patient    -0.68    33.36    22.48
     A typical person with brain injury    -0.78    20.16    13.58
A typical person without a brain injury     0.52    12.76     8.60
                                Partner     0.52     7.56     5.09
                                  Child     0.42     6.16     4.15
```

Note. Values are based upon deviation matrix in which construct means were removed from the original grid scores.

Total SS: 148.40

Element Euclidean Distances (standardized)

```
                                             Me before my brain injury
                                             |        Me now with brain injury
                                             |        |        Me as I'd like to be
                                             |        |        |        Me as I expect I will be in future
                                             |        |        |        |        Me seen by others
                                             |        |        |        |        |        Me as a patient
                                             |        |        |        |        |        |        A typical person with brain injury
                                             |        |        |        |        |        |        |        A typical person without a brain injury
                                             |        |        |        |        |        |        |        |        Partner
                                             |        |        |        |        |        |        |        |        |        Child
                                             |        |        |        |        |        |        |        |        |        |
              Me before my brain injury     0.00
               Me now with brain injury     0.87     0.00
                   Me as I'd like to be     1.06     1.50     0.00
     Me as I expect I will be in future     0.78     0.30     1.34     0.00
                      Me seen by others     0.80     0.65     0.99     0.63     0.00
                        Me as a patient     1.17     1.28     1.60     1.36     1.10     0.00
     A typical person with brain injury     0.99     0.90     1.53     0.99     0.90     1.12     0.00
A typical person without a brain injury     0.80     1.10     1.02     1.09     0.74     1.13     1.12     0.00
                                Partner     0.39     0.99     0.74     0.84     0.74     1.37     1.12     0.82     0.00
                                  Child     0.35     1.00     0.84     0.85     0.76     1.27     0.99     0.76     0.30     0.00
```

Note. Values are standardized around the expected distance between random pairings of elements. For this grid: 5.74.

Descriptive Statistics for Constructs [(Blank Grid)]

```
                                        Means
                                        |        Sum of Squares
                                        |        |        Percent Total Sum of Squares
                                        |        |        |
                           Insular     3.10    10.90     7.35
                           Insight     4.90    12.90     8.69
                            Normal     6.50    14.50     9.77
Passing off as typical (dishonest)     1.70     8.10     5.46
                          Managing     5.30    24.10    16.24
                        In control     5.20     3.60     2.43
                     Individuality     6.40     8.40     5.66
                 Freedom of choice     4.90    16.90    11.39
                        Idealistic     3.70    18.10    12.20
                  Treated the same     5.10    30.90    20.82

Total SS:    148.40
Bias:  0.52
Variability:  0.43
```

Eigenvalue Decomposition

```
       Eigenvalue      % Variance      Cumulative %      Scree
PC_ 1     61.87           41.69           41.69        |*********
PC_ 2     41.20           27.76           69.45        |*******
PC_ 3     18.02           12.15           81.60        |***
PC_ 4     13.88            9.35           90.95        |***
PC_ 5     11.07            7.46           98.40        |**
PC_ 6      1.40            0.95           99.35        |*
PC_ 7      0.83            0.56           99.91        |*
PC_ 8      0.11            0.07           99.98        |*
PC_ 9      0.02            0.02          100.00        |*
```

Element Loadings

```
                                             PC_1
                                             |        PC_2
                                             |        |
              Me before my brain injury     0.64    -0.33
               Me now with brain injury    -2.65    -2.62
                   Me as I'd like to be     4.92     0.90
     Me as I expect I will be in future    -1.40    -2.99
                      Me seen by others    -0.31    -0.38
                        Me as a patient    -3.16     4.54
     A typical person with brain injury    -3.02     0.18
A typical person without a brain injury     0.96     1.73
                                Partner     2.30    -0.82
                                  Child     1.70    -0.20
```

Note. Values for plotting elements in the component space.

Construct Loadings

```
                                        PC_1
                                        |        PC_2
                                        |        |
                           Insular    -2.61     1.56
                           Insight     3.16    -1.18
                            Normal     1.32    -0.08
Passing off as typical (dishonest)     1.58     0.74
                          Managing     3.25    -2.84
                        In control     0.99    -0.92
                     Individuality     0.78    -2.31
                 Freedom of choice     3.08     0.24
                        Idealistic     3.41     1.70
                  Treated the same     2.74     4.43
```