

An exploration of the experiences of young adults who acquired a brain injury

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Abstract

In the United Kingdom at least 15,600 young adults are admitted to hospital following an acquired brain injury each year. For those who survive, the brain injury-related consequences to their psychological well-being (e.g. feelings of anxiety and low mood, low self-esteem) and social environment (e.g. very limited social support, loss of relationships and friendships) are understood to be the ones that have the most effect on a young person's life in the long term. The social environment, such as family and friends, is important for the development of a young person's identity, independence and self-esteem. Most young people with an acquired brain injury rely on their families to help them to manage the long-term psychosocial consequences. It is understood that society tends to denigrate the unproductiveness and dependence of those young people who do not have a visible sign of the injury.

The aim of this study was to explore the experiences of young people aged 18 to 31 living with a brain injury who do not have visible impairments and who sustained their injury more than two years ago. Six men and two women who attended the young people's group at Headway House in East London were interviewed. Thematic analysis within a critical-realist epistemology was undertaken to analyse the interviews for shared and distinct themes.

Four main themes and four subthemes were identified, representing the participants' experiences of how their brain injury had led to a range of inabilities, for example cognitive, physical, behavioural, communicative and personality, which changed their sense of self, their social relationships and their return to work or school. These changes consequently led to feelings of lost purpose and meaning in life and ultimately to feelings of low mood, frustration and exclusion. The participants felt supported by family and professional services and they described that acknowledgement of inabilities was necessary to make effective use of provided support. Yet, the participants felt that they were excluded by our society and left to their own devices to find themselves a meaningful place in society. Therefore, it is recommended that the general public and professionals would benefit from general education about the challenges young brain injury survivors face and the support they need.

1. Introduction

In this section I review the literature on traumatic brain injury and its consequences including psychosocial consequences, pathways of rehabilitation and research related to young adults and adolescents. The section closes with the research aims of my study.

For the literature review of this study, papers were obtained following a literature search of PsycINFO, EBSCOhost and MEDLINE databases using the terms: young adults, adolescents, brain injury, long-term consequences, psychosocial consequences and adjustment. The articles found were read and searched for any other relevant references for this study, which were obtained through the library or internet.

1.1. Traumatic brain injury

In the United Kingdom (UK) at least 15,600 young adults are admitted to hospital following an Acquired Brain Injury (ABI) each year (Beecham et al., 2009). An ABI is defined as a non-degenerative injury to the brain including both open and closed head injuries. ABI includes a range of diagnoses or causes including strokes or tumours. A head injury through trauma is a common cause of ABI among young adults (Beecham et al., 2009). Wongwatunyu and Porter (2005) reported that a trauma is the leading cause of death and disability among adolescents and young adults in Western industrialised countries.

A head injury caused by a trauma such as a road traffic accident, assault or fall, is often called a traumatic brain injury (TBI) although the literature does not draw a clear distinction between ABI, TBI and brain injury, and the terms are often used interchangeably (McKinney, 2012). In this study the definition of ABI cited by Beecham et al. (2009)¹ will be used to define TBI, as this definition is commonly used in the UK literature.

¹ An Acquired Brain Injury (ABI) is defined as a non-degenerative injury to the brain including both open and closed head injuries (Beecham et al., 2009).

In the UK, 20% of young people who are admitted to hospital following a TBI have been involved in a road traffic accident. The majority of TBIs in young people are caused by falls and assaults that are often alcohol related (Greenwood, 2002). The majority of young people who sustain a TBI are male aged 15 to 35 (Moreno-Lopez et al., 2011). Males are twice as likely to be injured as females, perhaps reflecting their risk-taking behaviour at this stage of life (Mealings & Douglas, 2010).

1.2. Severity of traumatic brain injury

A TBI can be classified as 'Mild', 'Moderate' and 'Severe'. The Glasgow Coma Scale (GCS; see Appendix I), introduced by Teasdale and Jennett in 1974, provides the best initial measure of severity of head injury according to Greenwood (2002). The GCS score is the sum of the scale's three measures of eye opening and best motor and verbal responses. This ranges from a score of 3 for a patient with no motor or verbal response or eye opening to painful stimuli, to 15 for a patient who is orientated, follows commands and has spontaneous eye opening. TBI is defined as mild by a GCS score of 13 to 15, moderate by a score of 9 to 12 and severe by a score of 3 to 8 (Greenwood, 2002).

Another measure used to identify the severity of the TBI is the duration of Post-Traumatic Amnesia (PTA; see Appendix I). PTA is the period following TBI when continuous memory fails. Patients are confused and disorientated and lack the capacity to store and retrieve new information. They have a wide range of cognitive problems consistent with a state of confusion and are often agitated (Greenwood, 2002).

Both the GCS and the duration of PTA are used by professionals as measures of severity and are also useful as predictors of consequences and outcome (Greenwood, 2002). This means that an increased severity of the injury is associated with an intensification of consequences and with a less complete recovery for the individual with brain injury (Thornhill et al., 2000; Mealings & Douglas, 2010).

1.3. Consequences of traumatic brain injury

In a qualitative study from Leith et al. (2004), 21 people with a TBI and their families were asked to describe their experiences throughout the recovery and rehabilitation process in semi-structured group interviews. The participants were from the United States of America (USA), aged 15 and older and their brain injury had occurred less than five years ago. The severity of the participants' brain injury was unknown. The participants in this study described that their brain injury continued to permeate their lives to the very core and remained the single most significant characteristic of their existence, in relation to which they defined all future life experiences. This is because TBI has a broad impact on a person's cognitive, physical, psychological, emotional, behavioural and social realms of life. All of the participants experienced memory and concentration problems and many of them had speech difficulties. Most participants struggled with tiredness and emotional ability. They also described feelings of isolation and helplessness (Leith et al., 2004).

Several studies focusing on the outcomes for adolescents with TBI and uninjured controls have consistently demonstrated that those who sustained brain injury experienced difficulties spanning emotional, cognitive, behavioural, social and physical consequences (Ylvisaker & Feeney, 2007; Anderson et al., 2005). However, not all young people will be constantly affected and their outcome or level of disability is influenced by a combined effect of pre-morbid, injury-related and post-injury factors (McMillan, 2003; Mealings & Douglas, 2010).

1.3.1. Disability

For young adults who survived one year after the trauma, a disability has been found in 78% of those who had a severe injury, in 54% of those who had a moderate injury and in 51% of those who had a mild injury (Beecham et al., 2009). The most common areas of disability were in behaviour, intellectual functioning and locomotion. The young people reported that these disabilities affected their daily life, causing problems at work or looking after the home (Evans et al., 2003). Although biological factors of the initial severity of the head injury are associated with a slower recovery, they are not necessarily related to disability. A study from Whitnall et al. (2006) indicated that only a modest proportion of the variation of disability is

accounted for by the initial severity of the brain injury and that this relationship may weaken over time.

Pre- and post-injury factors, and particularly psychosocial factors, have been more associated with individual variability in degree of disability than severity of brain injury. Young people with high levels of education pre-injury and high levels of social support post-injury functioned better compared with those who had low levels of education and support (Whitnall et al., 2006; Webb et al., 1995). Post-injury higher alcohol intake was associated with increased levels of disability. Low self-ratings for depression, anxiety and stress and a high self-rating for self-esteem were associated with lower levels of disability (Whitnall et al., 2006).

A variety of models have been proposed to understand and explain disability and functioning and one of these models is The International Classification of Functioning, Disability and Health (ICF; see Figure 1). This model uses a biopsychosocial approach to capture the integration of the various perspectives of a person's functioning (World Health Organization, 2001). The ICF has been accepted by 191 countries worldwide and is becoming the world standard for describing health and disabilities (Tate & Perdices, 2008).

The ICF conceives a person's functioning and disability as a dynamic interaction between health conditions (traumas, injuries) and contextual factors, including personal and environmental factors. It aims to measure the effect of a health condition/impairment on body function and structure, on activity (activity limitation) and participation (participation restriction). Environmental factors (e.g. physical, social and attitudinal environments) and personal factors (e.g. gender, race, age, fitness, lifestyle and coping styles) are also considered to have an impact on these variables and, consequently, on the person's functioning in day-to-day life (World Health Organization, 2001).

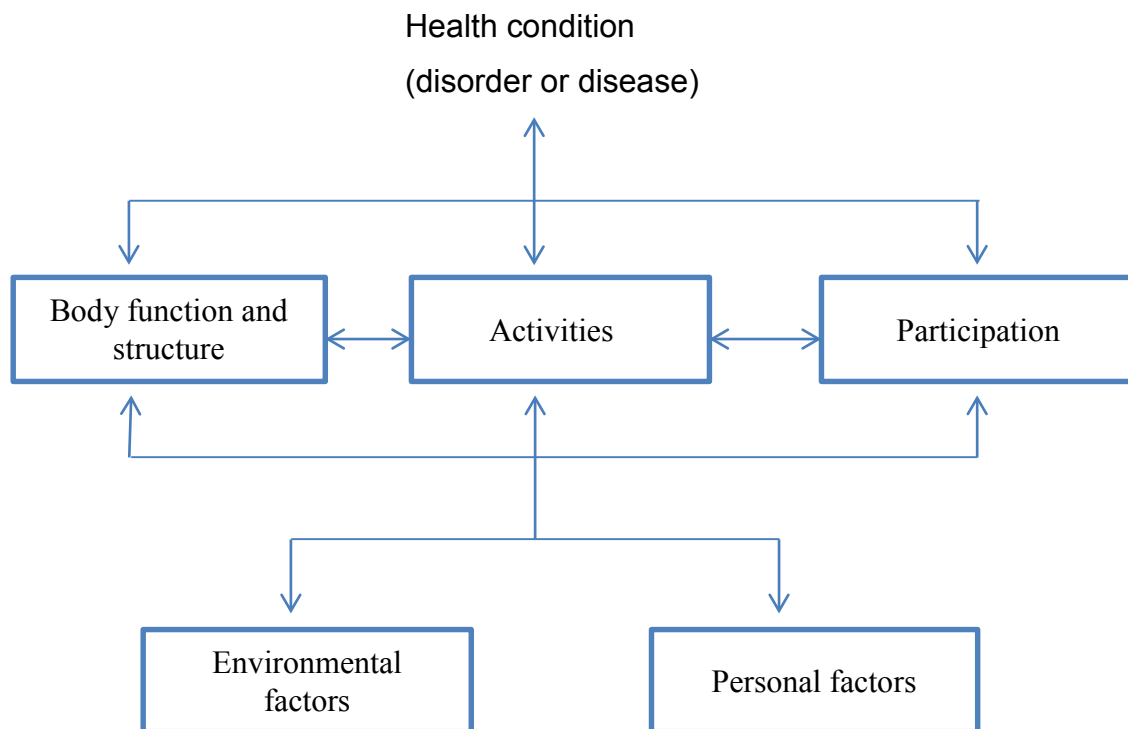


Figure 1: Overview of the International Classification of Functioning, Disability and Health (World Health Organization, 2001)

A few studies have looked at the extent of disability in young people with TBI and young people's experiences of living with a disability (Evans et al., 2003; Whitnall et al., 2006; Thornhill et al., 2000). The results of these studies revealed that there was a significant level of disability among young people one, five and seven years post-injury, and that the young people reported continuing problems with activities of daily life (Evans et al., 2003; Whitnall et al., 2006; Thornhill et al., 2000). Although both adolescence and young adulthood are usually considered a time of health and well-being, these results suggest that disability among young people with TBI might be expected to be particularly long-lasting. Due to the nature of this stage of development it might be that the consequences of a TBI can represent a break in an already complex transition from childhood to adulthood and in a process of auto-determination and independence (Gagnon et al., 2008).

The incidence of disability among young people cannot be neglected because it limits their ability to fulfil their full economic potential, which poses a significant loss to the nation and places a considerable long-term burden on the young people and their immediate family and friends. Despite the high incidence of TBI faced by young

people, little is known about the long-term consequences of traumatic injury for young survivors (Evans et al., 2003). Therefore, adolescent and young adult survivors are of special interest and are the focus of this study.

1.4. Long-term consequences

There are only a few studies that describe the long-term impact of TBIs on the lives of young people. A study by Evans et al. (2003) found that young people reported ongoing problems in daily life, such as finding work and leading an active social life, five years after their accident. In this study, 109 participants aged 11 to 24 who were resident in the UK were interviewed five years post-injury.

In 1978, Oddy et al. followed up 50 people aged 16 to 39 with a brain injury and living in the UK. Six and twelve months post-injury the people completed cognitive tests and questionnaires to assess personality changes and somatic, sensory, cognitive, and psychiatric symptoms. To assess their level of social adjustment they were also interviewed. In 1985 Oddy et al. followed up 44 persons aged 16 to 39 who had attended a rehabilitation programme in one of London's rehabilitation units. Seven years post-injury these people were interviewed about the behavioural, cognitive and social changes after their accident and they completed intellectual tests. Both studies stated that one-third of the participants reported memory and attention and concentration difficulties. These cognitive difficulties together with personality changes, such as increased irritability, impatience and a loss of interests, appeared to dominate their lives. The participants also reported feelings of anxiety, depression and tiredness.

A study by Beecham et al. (2008) indicated that many people injured as young adults continued to need help five years after the injury, as they faced long-term difficulties with living independently, driving or using public transport, returning to work or education, participating in leisure and social activities and fulfilling family roles or maintaining personal, sexual and family relationships.

According to Evans et al. (2003), 81% of young people reported that trauma-related long-term consequences affected their quality of life significantly. In particular, psychosocial consequences such as social isolation, low self-esteem and depression

remained a problem for the majority of them two years post-injury (Morton & Wehman, 1995). It is around this time that any recovery from physical, cognitive and behavioural TBI-related changes would have happened, as physical recovery from a TBI occurs within six months, cognitive recovery within 12 months and behavioural recovery within two years post-injury (Frosch et al., 1997). So at two years post-injury a young person would realise that they need to learn to cope with their remaining difficulties instead of hope that there might be an improvement or even disappearance of their disabilities (Frosch et al., 1997).

1.4.1. Coping and adjusting to the long-term consequences

Lazarus and Folkman's theory of stress and coping has been used extensively in health psychology to understand adjustment to health conditions. The theory suggests that appraising a situation as controllable elicits problem-focused coping and that appraising the event as uncontrollable elicits emotion-focused coping (Folkman & Lazarus, 1980; Lazarus, 1993; Godfrey et al., 1996). Although originally both types of coping were considered adaptive, recent research has suggested that emotion-focused coping results in poor adjustment and that problem-focused coping promotes adjustment (Bombardier et al., 1990; Felton & Revenson, 1984; McNett, 1997).

To understand the psychosocial adjustment of a person post-brain injury, several models have incorporated Lazarus and Folkman's theory of stress and adjustment (Kendall & Terry, 1996; Godfrey et al., 1996). One model is the Stress, Appraisal and Coping model proposed by Godfrey et al. (1996; see Figure 2). This model was developed in New Zealand and suggests that responses to TBI-related stressors are mediated by appraisal, coping and social support, and consequently influence the adjustment of the person to the long-term consequences (Godfrey et al., 1996).

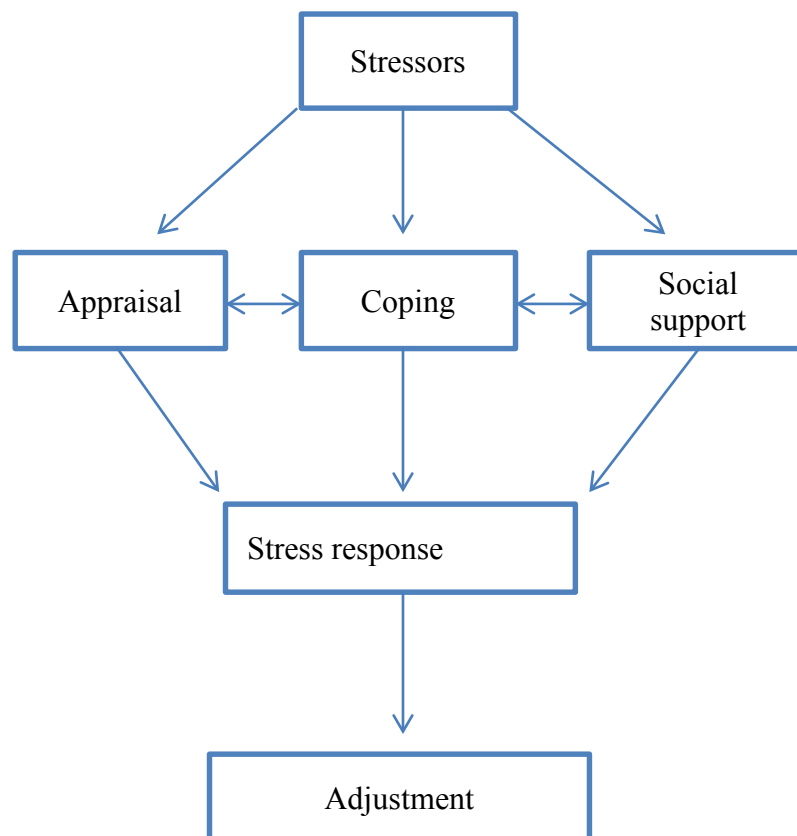


Figure 2: Stress-Appraisal-Coping model of emotional adjustment to TBI (Godfrey et al., 1996).

With this model it is hypothesised that the rate and degree of adjustment following a TBI will depend on the individual's appraisal of the significance of neuropsychological symptoms, their ability to cope effectively with these symptoms and their perception of the adequacy and availability of social support.

Social support is associated with better adjustment following TBI; it is essential for an individual to develop a sense of belonging which is known to buffer the individual from the psychological effects of adverse life events. Unfortunately, inadequate social support is common following TBI and may contribute to patients with TBI having an increased risk of poor adjustment (Godfrey et al., 1996).

The model also suggests that people with TBI experience emotional distress when they appraise the environmental demands as exceeding their personal and socially available coping resources. Responses include depression, anxiety, low self-esteem and distress about neurological symptoms (Godfrey et al., 1996).

Stressors are seen as demands placed on individuals in their everyday lives. Following a TBI, individuals may be unable to perform daily activities and tasks as competently as they could before the injury. The demands of work, family and social relationships may now exceed their level of competence, which has been reduced by neuropsychological symptoms, such as cognitive and behavioural difficulties (Godfrey et al., 1996).

Shotton et al. (2007), in a study with nine people (seven men and two women) aged 18 years and older who were at least two years post-injury, explored experiences of coping and adjusting to the psychosocial consequences following the injury. They found that these participants experienced adjustment as a process. The participants felt that they continuously had to adjust to the changes in their perceptions about the injury and their limitations (Shotton et al., 2007).

The participants who used many problem-solving strategies, such as following professional advice and information gathering, showed adaptive psychosocial adjustment and were male. These participants also learned to compensate for impairments such as memory difficulties by making use of problem-focused coping strategies. The participants in this study also mentioned that support from their family and talking to friends was invaluable in helping them to cope with the long-term consequences (Shotton et al., 2007). However, other studies of people with TBI reported that their social network generally disappeared and that the resulting isolation made it more difficult to adjust to the long-term consequences of TBI (Lefebvre et al., 2005).

Kay et al. (1992) developed an interactive model that focuses on the complex feedback loops that can develop following the process of adjusting to the consequences of TBI. This model reports that the resultant cognitive and physical impairments have a direct impact on functional outcome and that psychosocial factors are likely to influence adjustment indirectly through the impact they have on the severity of the situation as subjectively determined by the individual with TBI. Those individuals with higher levels of self-esteem and social support are less likely to perceive their circumstances as severe and consequently have a more successful adjustment process than those individuals with low levels of self-esteem and social

support. Consequently, adjustment is more likely to be successful for these individuals.

Simpson (1996) developed a model of counselling adjustment to provide guidance for clinicians who worked within the context of adjustment to TBI. The model involves four components:

- 1) Understanding: refers to acquiring an awareness of impairments and associated disabilities.
- 2) Re-integrating identity: refers to the integration of old and new aspects (pre- and post-injury) of the person into a valued sense of self.
- 3) Acceptance: involves processing the emotional impact of the injury and the ongoing process of recovery.
- 4) Restructuring: involves modifying and adapting pre-injury skills and acquiring new skills in areas of relationships, employment and independent living.

The second component is re-integrating of identity but this process is far from easy (Ylvisaker & Feeney, 2000). People with TBI described that they struggled to understand their present selves in the context of cognitive, physical and psychosocial changes and that they identified strongly with their pre-injury self and held on to the hope of returning to this positively rated self, to the potential detriment of their adjustment (Dewar & Gracey, 2006; Tyerman & Humphrey, 1984).

Nochi (1998) identified a set of three themes that emerged around a loss of self in the narratives of people with TBI. 1) The first theme included a loss of a sense of clear self-knowledge which has two components: one component is a result of memory blanks or knowledge gaps, such as the inability to remember events before and after the injury. Such gaps can make it difficult for the individual to construct a narrative that integrated the past self with the present self, causing confusion and distress. The other component has to do with functional changes in cognitive, emotional or physical capabilities that are unfamiliar, unpredictable, confusing and disturbing and that are not well understood by the individual or by others around him or her. 2) The second theme was a discontinuity between who they were before and who they are at present. Previous narratives about the self may no longer fit as well,

or at all, and the process of re-authoring those narratives involves not only discovering a new self or selves but also mourning for the lost self or selves. 3) The third theme was the loss of self in the eyes of others. Changes in physical, cognitive and emotional functions can affect the status of an individual in a variety of ways. Changes in appearance may affect both one's self-image and the way one is perceived by society.

Nochi (2000) examined the self-narratives of ten reasonably well-adjusted adults with TBI to identify patterns of successful identity reconstruction and five categories were identified: 1) the self as better than others, 2) the grown self, 3) the recovering self, 4) the self-living here and now and 5) the protesting self.

Although Nochi (1998, 2000) described the reconstruction of identity for adults in the process of adjustment, it is likely that this reconstruction or forming of identity is likely to differ considerably between adults and children with an acquired disorder such as TBI. A disorder with childhood onset typically disrupts skills that are developing or those yet to be developed whereas a disorder during adulthood leads to a loss of function (Ownsworth & Gracey, 2010).

Erikson's (1959) model of psychosocial development might indicate that people who acquired their brain injury as a child do not have to reconstruct their identity as no fixed identity was formed at the time of the injury and that people who were in the adolescent stage when they sustained their TBI and who were starting to develop a sense of identity might need to reconstruct their identity post-injury.

The literature review revealed no studies in the UK that look at how young people cope and adjust to the long-term consequences of TBI.

1.5. Psychosocial consequences for young people with TBI

Despite the use of adaptive coping strategies, receiving social support and showing adjustment to the long-term consequences of a TBI, it is suggested by researchers that adjusting to the psychosocial consequences continues to be a major challenge for the person with a TBI (Morton & Wehman, 1995; Shotton et al., 2007). Chronic psychosocial problems after a TBI can include family disruptions, problems with

independent living, decreased social contact, social isolation, depression, loneliness, decreased leisure activity, unemployment or drop-out from education (Morton & Wehman, 1995).

A literature review by Morton and Wehman (1995) concluded that psychosocial problems remain a persistent long-term problem for the majority of individuals with a TBI and in particular for young people, as they are in the early stages of establishing independence (including friendships, leisure activities, intimate relationships, residence and employment). Despite the importance of understanding the impact of the psychosocial consequences for young people, there have been only a few studies that specifically focused on this age group. However, these studies were either based on small samples, did not provide longer term follow-up data or the young adults were grouped together with children and adults (Ben-Yishay, 1996). There is, therefore, a need for studies to take young adults and adolescents into special consideration (Colantonio et al., 1998).

1.5.1. Adolescence and young adulthood

1.5.1.1. Psychodynamic approach

The age group most often affected by TBI is called by Erikson (1959) 'Adolescence' and 'Young adulthood'. According to Erikson's model of psychosocial development each person's ultimate goal in life is the quest for identity, which is accumulated across eight stages and at each stage the person faces a personal dilemma. Adolescence is the fifth stage and the dilemma is identity versus role confusion. Young adulthood is the sixth stage and the dilemma is intimacy versus isolation.

Erikson noted that the period between 18 and 40 years of age is the time when the adolescent's core psychological task is the acquisition of an ego-identity through friendships and the young adult's core task is to develop a mature capacity for intimacy through friendships and romantic relationships (Erikson, 1959).

Adolescence is described by Erikson as the period during which the individual must establish a sense of personal identity and avoid the dangers of identity confusion. The adolescent makes an assessment of his or her assets and liabilities and how

they want to use them. They also answer questions for themselves about where they came from, who they are and what they will become. Identity, or a sense of sameness and continuity, must be searched for by the person and is acquired through the person's individual effort. In addition, the adolescent must receive consistent and meaningful recognition of his or her achievements from others in order to acquire a strong and healthy identity (Erikson, 1959). Erikson (1959) stated that a final identity is fixed at the end of adolescence.

Young adulthood emerges from the adolescent search for a sense of identity and the young adult can be eager and willing to fuse his or her identity in mutual intimacy and to share it with individuals who, in work, sexuality and friendship are complementary. The person can be in love or engage in intimacy and is able to commit to concrete affiliations which may call for significant sacrifices and compromises. The psychosocial antithesis to intimacy, however, is isolation and a fear of remaining separate and unrecognised by others (Erikson, 1959).

1.5.1.2. Cognitive approach

In addition to Erikson's psychodynamic theory of identity development other major theories are cognitive, systemic and narrative. Based on a cognitive approach, Berzonsky (2004) represents a social-cognitive process model of identity, which highlights the role social-cognitive strategies and processes play as adolescents engage in or manage to avoid the process of constructing and revising a sense of identity.

According to this model identity is seen as a structure as well as a process. Identity as a cognitive structure serves as a personal frame of reference for interpreting experience and self-relevant information and answering questions about the meaning, significance and purpose of life. Identity as a process directs and governs the resources adolescents use to cope and adapt in everyday life (Berzonsky, 2004). Berzonsky (2004) stated that adolescents use three social-cognitive strategies to deal with or to avoid identity information and to construct a sense of identity. These strategies are called: informational, normative and diffuse-avoidant.

Adolescents who use an informational processing orientation are self-reflective and they actively seek out and evaluate self-relevant information. They will have an achieved identity status. Adolescents who make use of normative strategies conform to expectations and values that are important to significant others in order to preserve existing self-constructs. The diffuse-avoidant strategy is characterised by procrastination and a reluctance to confront and face up to decisional situations, personal problems and identity conflicts. Adolescents who use this strategy are at risk for personal and behavioural problems such as drug and alcohol problems, depressive reactions and conduct disorders. Both informational and normative styles are positively associated with a sense of direction and purpose in life and are associated with identity achievement (Berzonsky, 2004).

The social-cognitive model that Berzonsky (2004) presents follows the ideas of Erikson, who proposed that adolescents are at a developmental phase (e.g. the formal operational thinking phase) in which they experience that their cognitive abilities are ready to alter and transform their current beliefs and perspectives (McLean & Pratt, 2006).

Berzonsky's model (2004) is also strongly related to Marcia's identity status model (1966) which is viewed as an important elaboration of Erikson's views on identity formation. In the identity status model four identity statuses are described: 1) achievement – the adolescent has finished a period of active exploration and has subsequently made a commitment, 2) moratorium – the adolescent is in a state of exploration but has not made significant commitments, 3) foreclosure – the adolescent has made a commitment without much prior exploration, and 4) diffusion – the adolescent has not yet made a commitment regarding a specific developmental task (Meeus, 2011). Marcia (1987) stated that a person's identity is achieved when a commitment is made regarding who they are as a person.

Associations between Berzonsky's social-cognitive strategies and Marcia's identity statuses have been consistently replicated in the identity literature and it is found that the informational style is positively associated to identity achievement and moratorium, the normative style is strongly related to foreclosure, and the diffuse-avoidant style is positively related to diffusion-status (Crocetti et al., 2012). Although

Berzonsky (2004) proposes a social-cognitive model of identity development, based on the assumption that people actively play a role in constructing both who they think they are and the reality within which they live, according to the literature this model and approach also has a lot in common with Erikson's psychodynamic approach.

1.5.1.3. Systemic approach

Carter and McGoldrick (2004) present a model of identity development, called the life cycle, which is based on systemic ideas. The identity status paradigm of both Erikson and Berzonsky has been criticised for focusing primarily on individual differences in the outcome of the identity formation process (Cote & Levine, 1988; Van Hoof, 1999) but the life cycle emphasises that identity development can only be realised in individuals who are helped by their families and society (Carter & McGoldrick, 2004). This model also proposes that identity development is a continuous process of interaction between individuals and the sociocultural environment they encounter (Meyers et al., 1991) in contrast to the models of Erikson (1968) and Berzonsky (2004) in which a final identity is fixed at the end of adolescence (Erikson, 1968).

Carter and McGoldrick (2004) state that identity development takes place in the context of family relationships and that therefore individuals and families must be seen in their cultural and historical context of past and present in order to be understood and changed. Each system (individual or family) can be presented schematically (see Figure 3). For the individual person the vertical axes include the biological heritage and the person's behaviour. The horizontal axes relates to the individual's emotional, cognitive, interpersonal and physical development over the life span within a specific historical context (Carter & McGoldrick, 2004). Over time a person's identity development can either be crystallised into rigid behaviours or elaborated into broader and more flexible repertoires (Carter & McGoldrick, 2004).

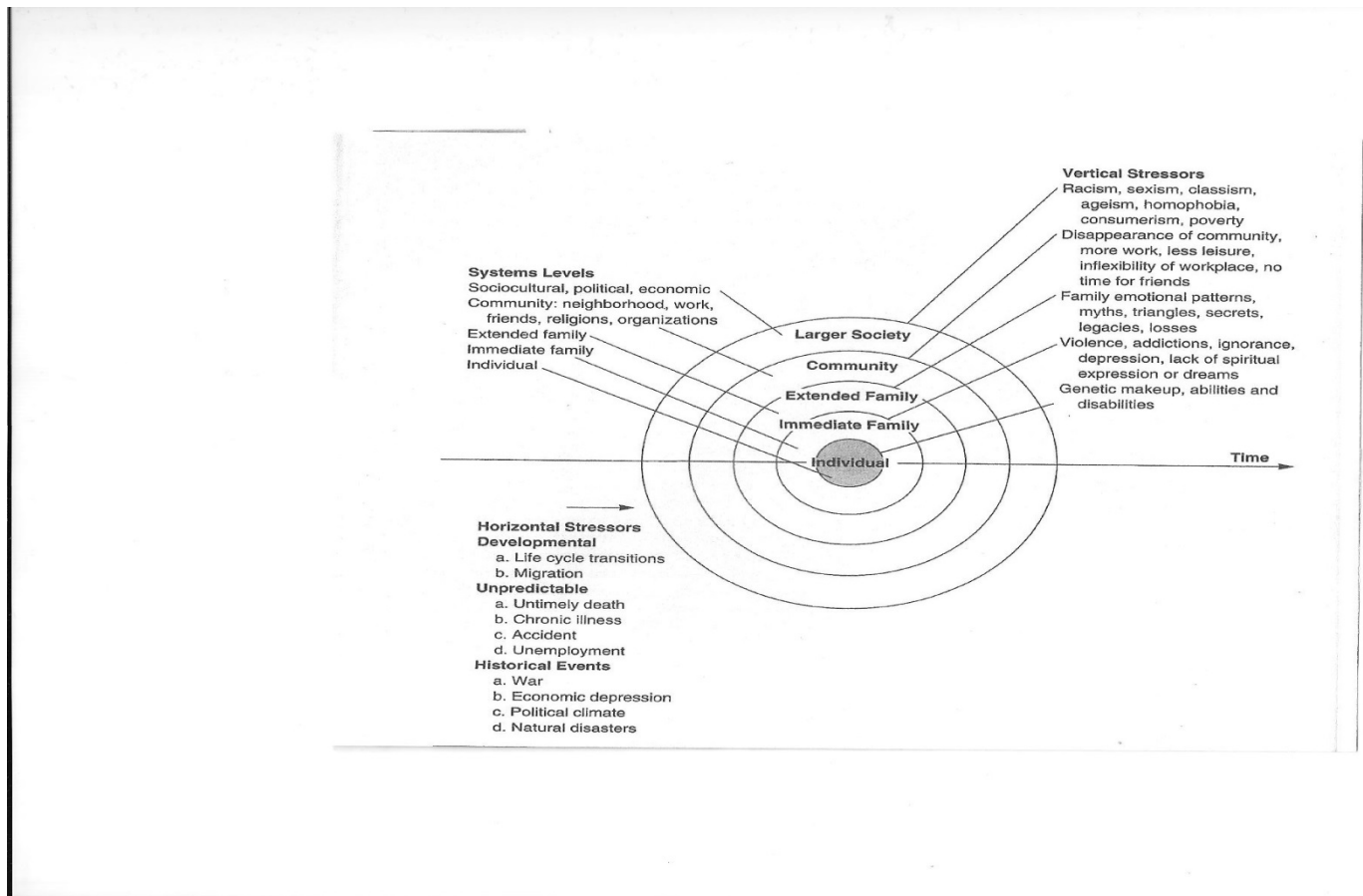


Figure 3: Flow of stress through the family (Carter & McGoldrick, 2004).

Although the family life cycle model has been built on Erikson's ideas of psychosocial development it also emphasises that human identity is bound up with one's relationship to others, as human beings cannot exist in isolation. Carter and McGoldrick (2004) are of the opinion that Erikson's eight stages emphasise individual characteristics (mostly traits of autonomy) in response to the demands of social interaction but they think it is wrong to assume that autonomy and the formulation of identity are separate from family and societal relationships.

Carter and McGoldrick (2004) also state that Erikson's eight stages have clearly been equated with male development and that he tended to ignore female development or subsume it under male development, which was taken as the standard for human functioning. Separation and autonomy have been considered the primary values for male development, and the values of caring and attachment, interdependence, relationship and attention to context being primary in female development (Carter & McGoldrick, 2004). Therefore their model/theory of individual

development integrate race, class, gender and culture, which form a basis structure within which individuals learn and establish a solid sense of their unique selves in the context of others (Carter & McGoldrick, 2004).

1.5.1.4. Narrative approach

McAdams (1993) described a narrative approach to identity development. The narrative life story approach (McAdams, 1993) emerged from Erikson's (1968) early theorising; however while the identity status approach grew out of Erikson's idea of the management of crisis and investigates identity achievement by measuring the extent of the adolescent's life choices and actions, the narrative approach grew out of Erikson's emphasis on life span development and psychobiography and defines identity as a personal life story that helps people to understand and to give continuity and meaning to their life experiences (Dumas et al., 2009; McLean & Pratt, 2006).

McAdams (1993, 2001) proposed that narrative identity follows a sequences of eras in which a person first experiences life without forming a self-story, then creates a self-story from life experiences and finally reviews the created self-story for a sense of meaning and completeness. According to the narrative approach, a person achieves a healthy identity as they develop a coherent life story that integrates their various self-stories into a meaningful whole and reflects a clear understanding of events and the self across time and situations. Research has shown that during adolescence the continuity of identity and coherence of a person's life story develops (Meeus, 2011). Coherence refers to the structure, form or content of the story (McAdams, 2006).

McAdams (2006) argued that one of the problems with narrative coherence is that the coherence of a story relies largely on the person's ability in relation to reconstruction, imagination and synthesis and that people differ substantially with respect to their abilities to tell life stories exhibiting causal and thematic coherence. Another problem with narrative coherence is the ability of being understood in a social context (McAdams, 2006). In all cultures, storytellers are constrained by people's expectations about human nature and social relationships, and different societies hold different expectations about life course (McAdams, 2006). This might mean that people in one culture feel that a person's life story reflecting another

culture is not coherent, and that therefore this person is not able to develop a healthy identity.

1.5.1.5. Erikson's stage model

Based on the literature review of the different approaches of identity development it is evident that approaches, such as cognitive, systemic and narrative and their proposed identity developmental models, have all incorporated parts of Erikson's ideas and views of identity development. Although Erikson's model is widely used it has also been critiqued from various standpoints, of which some are described under paragraph 1.5.1.4. Narrative approach.

In addition, from a multicultural perspective, Erikson's model fails to take into account factors such as race, ethnicity, environment, history, sexual orientation, age, education, religious orientation and socioeconomic status. From a postmodern perspective, there is scepticism about truth claims of Erikson's psychosocial life cycle work and development sequence of human beings. Postmodern theorists, such as Bingaman (2006) have argued that these claims might be true for some individuals but that this is no longer the case for most people. Bingaman states that childhood, particularly for girls, is becoming shorter and shorter, to such an extent that we may want to consider an in-between stage of pre-adolescence. Bingaman (2006) also notes that in this time and age, young adults take longer to settle into a career and family life and that therefore we might want to extend adolescence through a person's twenties and thirties. However, adolescence is getting shorter for working class youth who do not have the time or the financial resources to have an extended adolescence.

Although Erikson's model of identity can be critiqued from different perspectives, it was felt that Erikson's stage model was most appropriate for this piece of research, as it gives a clear definition about what is considered to be an adolescent or young adult and clearly defines the age range for both adolescence (13 to 19) and young adults (20 to 40), which guided the recruitment of participants. In addition, it was noticed that identity development models from different theoretical perspectives all built on the foundations of Erikson and often lack a clear definition and description of adolescence and young adulthood.

Erikson (1959) stated that it is important for both adolescents and young adults to participate and engage in meaningful social situations when they search for their sense of identity and that both rely upon their peer groups for the development of social norms and intimate relationships. For young people who sustained a brain injury their social support system is often abruptly disrupted and they are often left with significantly decreased social support, which leaves them in the midst of their identity search (Morton & Wehman, 1995).

If social isolation results, then there may be further negative effects on the social development of young people as social interactions serve a variety of important functions. At this age group, social interaction serves not only as a medium for the development and maintenance of identity and intimate relationships but also as a vehicle for exchanging social knowledge and practising social skills, such as the ability to empathise with the mental state of others (Turkstra et al., 2008). When the person's social support has decreased, this might influence his or her social development and can lead to poor social performance, which can lead to rejection by peers, a reduction in the frequency of dating and making friends, reduced participation in social activities, difficulty with maintaining employment and fewer opportunities to experience positive social interactions (Turkstra et al., 2008).

There is very limited research available on the psychosocial development of adolescents and young people who have sustained a TBI. In research the adolescent is often grouped with children, and young adults are often grouped with adults (Colantonio et al., 1998).

As adolescence and young adulthood are considered to be significant developmental periods, it can be argued that both groups need special consideration. It is for this reason that this research project focuses on the age group 18 to 40 years old, capturing both the adolescent and young adult life stages, but treating them as one group. Because of the age range of the young people in this study, there might be a lot of variability in their life situations. Some will be at school, some will have finished school, some will be working and some might even be married.

By treating both adolescents and young adults as one group the variability between the young people socio-economic status and the influence this might have on the young people's perception of living with a TBI, might be difficult to detect. It is, however, hoped that combining both developmental stages will facilitate the recruitment of enough participants for this study.

1.5.2. Friendships and self-identification

The development and maintenance of friendships is a significant stage in the development of young people's identity and they rely heavily upon their peer group for social norms and their sense of self-identification. Weddell et al. (1980) stated that two years post-injury most close friendships have been found to be diminished and substituted by casual acquaintances. Oddy et al. (1985) and Lefebvre et al. (2005) reported that young people with TBI had difficulty with maintaining friendships built over many years due to enforced withdrawal from their social networks because of disabilities, such as chronic fatigue, headaches and confusion, and changes in personality, such as impulsiveness and irritability. Opportunities to meet people through engaging in leisure activities were also restricted, as they had lost some social skills and often lacked the initiative and interest to do so (Oddy et al., 1985). However, when they were supported to engage in leisure activities and to establish good relationships with others, this positively affected their social competence and improved their well-being (Mealings & Douglas, 2010).

1.5.3. Dependency and interdependency

The problems of social isolation create a renewed dependency of the young adult on his or her family for social interaction, activities and community recreation activities (Morton & Wehman, 1995). A study by Thornhill et al. (2000) reported that an increased dependency was reported in 45% of survivors with a severe injury, 30% with a moderate injury and 28% with a mild injury. Young people may, however, resent the strong presence of their family at a time when they are trying to assert their independence and autonomy (Colantonio et al., 1998). Mothers of young people indicated that they strived for a balance between the safety of their child and promotion of the young adult's independence in daily activities (Wongvatunyu & Porter, 2005).

Autonomy is strongly connected with a person's self-esteem (Cooper-Evans et al., 2008). Self-esteem is viewed as an emotional and subjective evaluation of the self, giving an indication of how individuals experience themselves (Cooper-Evans et al., 2008). Self-esteem is associated with functional behaviour, life-satisfaction and physical and mental well-being. In general, high self-esteem is linked with occupational success, healthy social relationships and subjective well-being, whereas low self-esteem is linked to depression, health problems and anti-social behaviour (Cooper-Evans et al., 2008). Self-esteem is relatively stable during adulthood but is in the process of development during adolescence and young adulthood.

The nature and extent of the impact of a TBI on self-esteem is relatively unexplored. A study by Oddy et al. (1985) indicated that the loss of social support contributes to feelings of low self-esteem in young people. In a study by Cooper-Evans et al. (2008), participants reported that their current self-esteem was lower than their retrospective perceptions of self-esteem prior to injury. Most studies of people with TBI found that self-esteem develops in the context of meaningful community involvement (e.g. attending school, being employed or being involved in voluntary and leisure activities), as it allows the person to feel useful and contribute something to society (Lefebvre et al., 2005).

1.5.4. Return to school

During adolescence school participation is an everyday role that helps to shape the adolescent's direction in life and contributes to the importance of social expectations. School is also a place where students develop a sense of who they are and what they may want to do with their future (Mealings & Douglas, 2010).

Given that school participation is an important issue for adolescents, it is not surprising that there is a substantial body of literature that describes the difficulties students with a TBI face when they return to school. It is suggested that difficulties which have the greatest impact within the academic environment include cognitive changes (such as reduced concentration, distractibility, slowed processing, less effective memory and learning), communication changes and behavioural changes (such as reduced frustration tolerance, impulsivity, reduced energy and motivation),

emotional changes (such as anxiety and depression) and reduced confidence (Ylvisaker et al., 2001). In Australia, educators and rehabilitation staff have developed processes and supports to assist students with returning to their studies (Mealings & Douglas, 2010). To the researcher's knowledge no such interventions are available for adolescents and young people who return to school in the UK.

There have been only a few studies where students were asked to describe their experience of returning to school following a TBI. In one Australian study, three adolescents were asked to reflect on their experiences of what it was like going back to school after the TBI. The participants stated that they saw school as a normal part of life after the injury. They described socialisation as a core function of school life and an important component to their personal identity. The importance of friends, having a good relationship with a range of people at school, and enjoying activities, made going back to school a success for these young people, which highlights the importance of social competence. The participants also reported that educational and vocational goals gave them direction and purpose towards a career and goals for the future (Mealings & Douglas, 2010).

1.5.5. Return to work

Return to work is often one of the main goals for people with a TBI, as it provides a sense of purpose, independence and social inclusion and reduces emotional distress (McCrimmon & Oddy, 2006). Kersel et al. (2001) suggest that unemployment decreases the opportunity to develop social contacts and leisure activities, thereby leading to increased isolation and higher levels of depression.

In a five-year follow-up study, Evans et al. (2003) found that 50 out of 101 young people reported that they were no longer in full-time education and were without a job. Half of those unemployed said that their disability following the TBI made it impossible for them to work, although the other half said that greater availability of sheltered and part-time work would assist their return to employment.

Having a significant physical disability, a psychosocial impairment and/or a cognitive impairment have been suggested to affect a person's return to work (McCrimmon & Oddy, 2006). Psychosocial problems such as decreased social contact, depression,

anxiety and loneliness negatively influenced the process of return to work and maintenance of employment following TBI (McCrimmon & Oddy, 2006).

Supported employment schemes have been advocated in the USA to help facilitate a successful return to work (Yasuda et al., 2001). As people with TBI are often faced with loss of friendships, loss of social support and isolation, it is not unusual for them to look for a workplace that supports the development of a social network and an increase of leisure activities (Yasuda et al., 2001).

The people who returned back to employment successfully found the support groups that focused on adjustment and addressed coping strategies for cognitive difficulties, role-playing for social situations, people skills, assertiveness and organisation extremely effective (Parente et al., 1991).

Both the literature on return to school and return to work emphasise that educational and vocational environments facilitate social support, friendships and leisure activities, which are so important for young people's process of self-development and adjustment to their limitations. As there are only a few studies that ask about the adolescents' and young peoples' experiences of going back to school or work, this will be addressed in the current study.

1.5.6. Psychological distress

Research has shown that people with TBI experience psychological distress, such as feelings of low mood and anxiety, and that these feelings become more prominent as time goes on after the injury (William & Evans, 2003). A study from Williams and Evans (2003) reported that brain injury survivors showed feelings of low mood when they became more aware of their losses and the implications of the injuries for their life goals and social roles. In this study it was also found that anxious feelings were associated with the adjustment process to the brain injury and may, for example, be focused on feeling out of control and insecure over the future and social roles.

There is extensive literature on the prevalence of feelings of low mood and anxiety in adolescents and young adults but there are only a few studies that address feelings

of low mood and anxiety in adolescents and young adults with a TBI, although it is known that depressive tendencies are common in this group (Viguier et al., 2001).

When a TBI occurs in adolescents and young adults it disturbs their normal development and often increases the risk of social isolation (Viguier et al., 2001). It is known that the loss of social support not only makes it difficult for a young person to adapt to their limitations but also contributes to feelings of loneliness, low mood and anxiety (Lefebvre et al., 2005). Lezak (1988) stated that anxiety and low mood are definite results of a decrease in friendships, while Ranseen (1990) links anxiety and low mood to a natural course of recovery following disruptions in interpersonal relationships.

Although several studies have assessed anxiety and low mood from the survivor's perspective there are only a few studies that looked specifically at adolescents and young adults. A study from Viguier et al. (2001) used self-reports from adolescent and young adult inpatients with and without TBI to compare the frequency of psychological difficulties such as low mood and anxiety between the two groups. The conclusion of this study was that depressive tendencies were common for adolescents and young adults who sustained a TBI. They scored higher for items related to depressive mood, such as feeling depressed, feeling despair about the future, feeling down, not in fine spirits, compared to the group without the TBI. However, the group with TBI did not score higher for items related to anxiety, such as having anxiety attacks and feeling nervous (Viguier et al., 2001).

A study by Oddy et al. (1985), in which a group of 44 young people were followed up seven years after their brain injury, found that 25% of the group had reported symptoms of anxiety and low mood. In line with the idea that social isolation and loneliness might contribute to emotional difficulties, none of these young people were in employment (Oddy et al., 1985).

Given the predominance of psychological distress, such as feelings of low mood and anxiety following TBI, it is surprising that emotional adjustment has been the focus of so little intervention outcome research (Godfrey et al., 1996). This will therefore be addressed in this study.

1.6 Pathways of rehabilitation

1.6.1. Severity of brain injury and visible impairments

As discussed in Sections 1.3 and 1.4, the consequences of a TBI during adolescence and young adulthood intensify with increasing injury severity (Sherwin & O'Shanick, 2000). However, even a mild TBI sustained during this period can represent a break in an already complex developmental period (Gagnon et al., 2008). There is evidence that people with a mild brain injury and no physical disabilities experience more difficulties compared with those with severe brain injury and physical disabilities (Lefebvre et al., 2005). This may be because the brain injury-related disabilities of the person with intact physical appearances are not immediately apparent to others, who then form expectations that the person cannot live up to. This can lead to people with TBI becoming 'walking wounded' because others are unaware of their invisible problems and interact with them as if they were 'normal' and attribute any behavioural or cognitive deficits to other conditions (Lefebvre et al., 2005). Many people, even health professionals, simply underestimate the broad impact of TBI-related injuries on the physical, psychological, emotional, behavioural, social and economic realms of a person's life (Swift & Wilson, 2001; Hooper & Callahan, 2001). This can lead to psychological suffering which might manifest itself in attitudes of anger and discontent of the adolescent and young adult (Lefebvre et al., 2005).

In addition, our social environment supported by Western society's values about autonomy and independence, tends to denigrate and stigmatise people with less visible disabilities by disapproving of their unproductiveness (Lefebvre et al., 2005). Such responses by society could also lead to psychological and social suffering of the young adults, as the social environment plays such an important part in this developmental period (Lefebvre et al., 2005).

Young adults reported that their problems were often ignored when they returned to activities (school, work and leisure) because there was no visible sign that they had an injury (Gagnon et al., 2008). Dropping out of regular work or school can put young adults at risk for social isolation at a time when association with peers is critical for self-esteem and development of independence (Colantonio, 1998). This study will

look at the impact of TBI on a young person's life when no visible difficulties are present.

1.6.2. Rehabilitation

Following the acute phase of a TBI, most young people without physical disabilities are likely to be discharged from hospital to their home and family, with often little understanding of the possible impact of TBI on daily life (McMillan, 2003). Young people and their families are not routinely offered follow-up, support, education or rehabilitation if needed. It is estimated that in the UK only 5% of the 15,600 young adults who are admitted to hospital each year following TBI receive rehabilitation (Beecham et al., 2009).

The term rehabilitation is used for a range of interventions and programmes, including vocational and recreational activities. The overall aim of rehabilitation is to improve a person's quality of life and to maximise their participation in social settings (Wade & de Jong, 2000). Rehabilitation is likely to be delivered by at least two professional disciplines and can take place in 24-hour care settings, such as a hospital or specialist rehabilitation unit, as a day treatment or in the person's home (Turner-Stokes et al., 2005).

In the UK efforts are made to develop appropriate inpatient and outpatient services for brain injury survivors. However, the effects of rehabilitation for individuals in the long term rest on adequate development of community-based resources. The work that is undertaken in rehabilitative units may not materialise unless there is community support (William & Evans, 2003).

Although much has been written about how community-based services should be provided for people with brain injury, it is well known that there is an absence of comprehensive and well-organised rehabilitation services for people with brain injury in the UK (McMillan, 2003). A study by Beecham et al. (2009) reported that under-provision of rehabilitation services in the community for young adults is the norm in the UK and that the services which are available are felt to be inadequate by 39% of service users; who reported that their needs were not met.

There is, however, a need for young people and their families to be supported and guided by professional services on how to cope with and adjust to the consequences of TBI (Leith et al., 2003). Several studies have indicated that young people and their families need support and guidance after the individual with TBI returned home and that they also continued to need this several years post-injury (Oddy et al., 1985, Leith et al., 2003, Gagnon et al., 2008). Some even say that a young adult continues to need support five years after the injury (Evans et al., 2003).

Without appropriate rehabilitation, individuals with a TBI and their families may find themselves in a situation of social isolation and seclusion, partly resulting from the disabilities that the trauma may have caused, partly because of the shortage of organised support services for reintegrating into the community (Lefebvre et al., 2005) and partly because many become lost to health and social care services (Wade et al., 1998).

Therefore, in this study participants will be asked what their experiences are of receiving input from services, as they may have particular social, emotional and clinical needs that may not be adequately met by routine service provision (Evans et al., 2003). It is felt important to get this understanding, as this might inform health care services and professionals about the difficulties these young people face in life and the support they need; especially as health care professionals often hold a central role in making treatment decisions for people with brain injury and referring them to appropriate statutory and voluntary organisations (Leith et al., 2004).

1.7. Research related to young adults and adolescents

Despite the high incidence of TBI faced by young people, little is known about the long-term consequences of TBI for young survivors. Most studies have looked into the psychosocial consequences for adults with a TBI, but there are only a few and dated studies in the UK that look at how young people manage and adjust to the TBI-related psychosocial consequences long term.

Both adolescence and young adulthood are usually considered a time of health and well-being and as a time of transitions, of finding out who you are and where you fit in. It is also a time of transition from childhood to independent adulthood, when

dreams for the future, aspirations for life and career start to take place (Mealings & Douglas, 2010). Therefore, a TBI sustained in this period of life can alter the ongoing process of normal development and may have a major impact on the life of young TBI survivors (Gagnon et al., 2008).

1.7.1. Young adults and adolescents

To get an understanding of young people's experiences, qualitative studies are recommended, as they are able to reflect an individual's views and opinions (Willig, 2001). It is also acknowledged that there is a need for studies in which the impact of the brain injury from the injured person's perspective is considered (Shotton et al., 2003). In the UK, three qualitative studies were identified which looked at the psychosocial experiences of young adults and adolescents who suffered a TBI (Oddy et al., 1975; Oddy et al., 1985; Shotton et al., 2007). In the 1980s, Oddy et al. (1985, 1975) interviewed young people and assessed their social integration and adjustment seven and ten years post-injury; they found that individuals with TBI experienced a more restricted social life.

One can, however, question whether results from the 1980s will be representative for our current society. Since then, the information technology in our society has developed at a very quick pace. Access through social media networks to establish and maintain social relationships and as a way of communication is prevalent. All sorts of technical gadgets such as an iPhone are a 'must have' among adolescents and young adults. This might mean that adolescents and young adults growing up in the 21st century have different experiences than those who grew up at the end of the 20th century.

A recent study by Shotton et al. (2007) looked specifically at the coping and adaptive psychosocial adjustment of adults with TBI. They found that understanding and accepting the TBI-related consequences positively influenced a person's way of coping with their psychosocial disabilities. Although their study does interview young adults, the focus is on adults and it is unknown if the participants had any visible impairments.

1.8. Research project

Based on the literature review, it is felt that there is a gap in the UK literature with regards to the long-term psychosocial experiences of adolescents and young adults who have suffered a TBI and who do not have visible impairments. Understanding young people's psychosocial experiences is very important, as they are in a developmental period in which one's social environment significantly influences the development of personal identity and psychological well-being (Morton & Wehman, 1995). The mental health of individuals with TBI is of greatest concern but little is known about this regarding young people (Colantonio et al., 1998). Understanding the psychological and social consequences for young people living with a TBI might help health care services and professionals to be responsive to the needs of adolescents and young adults (Leith et al., 2004).

The specific research aims for this study are:

- To explore young people's perceptions of how their brain injury affected their psychosocial functioning when they do not have visible difficulties.
- To explore the strategies young people use to manage the psychosocial consequences which are directly or indirectly caused by the brain injury.
- To explore young people's perceptions of the support systems in place and how they make use of them.

2. Methodology

2.1. Qualitative research

Qualitative researchers are interested in how people make sense of the world and how they experience events. They aim to understand what it is like to experience particular conditions, such as TBI, and how people manage in daily life (Willig, 2008). Qualitative research facilitates the generation of new insights and understanding and pays attention to exceptional cases, unlike quantitative research which tends to discard 'outliers' (Willig, 2008).

As qualitative researchers are concerned with experience, it was felt that qualitative research was needed to get an understanding of the psychosocial consequences experienced by young adults with TBI. There is a need for this understanding, as these experiences are not well understood and might significantly affect a young person's mental well-being. In the absence of extensive knowledge about young people's experiences of living with the consequences of a TBI, an exploratory qualitative approach is indicated to get an understanding of the difficulties these young people face in day-to-day life.

2.2. Epistemological position

The model of Carter and Little (2007; see Figure 4) provided the researcher with a framework to think, plan and implement the three fundamental facets (e.g. epistemology, methodology and method) to ensure the quality of this qualitative study.

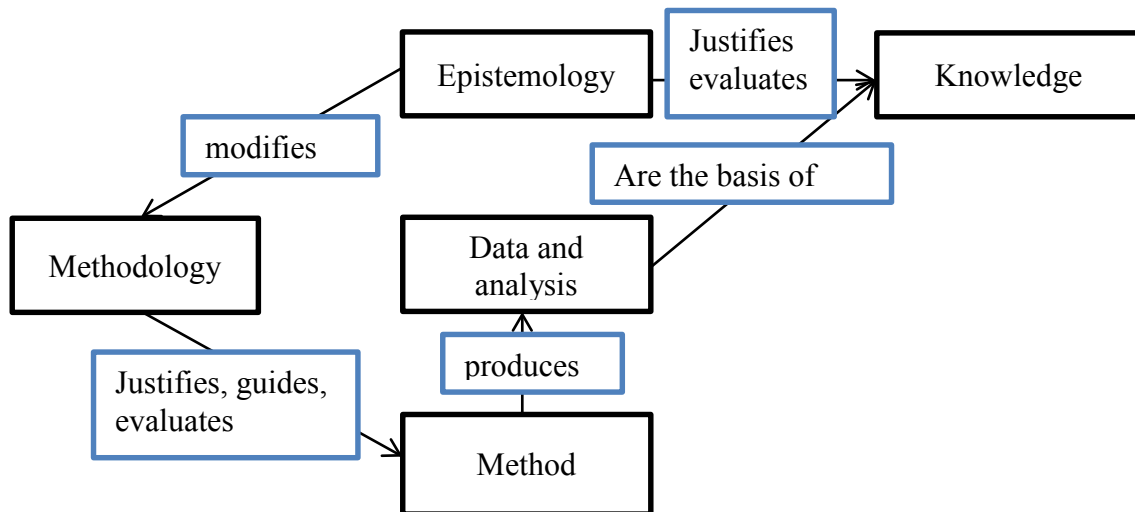


Figure 4: The simple relationship between epistemology, methodology and method (Carter & Little, 2007).

This model describes that the starting point in qualitative research is to choose an epistemological position to answer the research question of the study (Carter & Little, 2007). Epistemology is defined as “the study of nature of knowledge and justification” (Schwandt, 2001 p 71). As a researcher it is necessary to adopt an epistemological position as it addresses questions about how we can know what we know and whether this knowledge is reliable (Harper, 2012; Willig, 2008). To choose an epistemological position is important as it influences choice of methodology and method, which clarifies how the findings of the study will make sense in relation to the research question (Harper, 2012; Carter & Little, 2007).

To answer the research questions of this study it was felt that a critical realist position would be the most appropriate epistemological position for the researcher. This position is between a realist and relativist position and combines the realist ambition to gain a better understanding of what is going on in the world, with the relativist view that the data the researcher gathers may not provide direct access to this reality. This position views personal experiences as the product of interpretation and that they are constructed (flexible) instead of being determined (fixed). Nevertheless, it acknowledges that these experiences are ‘real’ to the person who is having the experience (Willig, 2008).

Taking this position as a researcher might give me the possibility of obtaining/developing an understanding of the psychosocial consequences young people face in day-to-day life by asking them about their experiences of living with a TBI.

2.3. Methodology and method

Although it is important to label the epistemological position the researcher takes to answer the research question, Willig (2008) also notes that it is important that the researcher identifies clearly and correctly what type of knowledge is aimed for and that a research method is selected that is designed to generate that type of knowledge.

In the literature, the term methodology is often used loosely and different definitions are used (Carter & Little, 2007). One definition is from Kaplan (1964), who defined methodology as “the study, the description, the explanation, and the justification of methods and not the methods themselves” (p. 18). Following this definition, the methodology that is chosen to answer the research questions of this study is determined partly by the critical realist position of the researcher and partly by the profession of psychology, as the researcher is a clinical psychologist in training (Carter & Little, 2007).

Psychologists are trained to collect data and make sense of people’s complex and rich personal histories and experiences, which fits well with the critical realist assumption that people can tell us about their experiences (their reality) but that they may not be fully aware of all the factors that influence their experiences (Thompson & Harper, 2012).

Guided by the researcher’s epistemological and professional position, it was felt that research methods such as Interpretative Phenomenological Analysis (IPA), Narrative analysis, the realist form of Grounded theory or Thematic analysis (TA) might be appropriate ways of approaching the research questions (Harper, 2012).

IPA is an approach to qualitative analysis that has a particular interest in how people make sense of their experiences. It also tries to understand how people relate to the world through the meaning they make and therefore requires a verbatim transcript of a first person's account in the form of a semi-structured one-to-one interview. During the interview, the researcher has to collect detailed, reflective and first person accounts from the research participant. An IPA interview is not about collecting facts, it is about exploring meanings. The focus in an IPA interview is on how things are understood rather than on what happened (Larkin & Thompson, 2012).

Narrative analysis is derived from hermeneutic phenomenology which is concerned with how we interpret the world around us. Narrative psychology is interested in the stories people tell themselves and others about their everyday experiences. For example: the stories that people tell about their experiences of having particular health problems, such as a TBI. The aim of the researcher is to explore the character of these different types of narratives and how they connect with everyday social life. Researchers who use narrative analysis are interested in the character of the stories, the language people use, how the stories connect with the person's experiences, how stories can change and how they are shared with others (Murray & Sargeant, 2012).

The Grounded theory method aims to produce an inductively driven theory of social or psychological processes grounded in the material from which it was derived. This method makes use of a broad range of open-ended research questions to understand patterns and meaning of a person's experience and views (Tweed & Charmaz, 2012). In a realist version of Grounded theory it is assumed that during the research process categories are identified from the data, which capture the person's experiences. This method enables the researcher to identify categories, to make links between categories and to establish relationships between them (Willig, 2008). Grounded theory can be employed where existing theories or areas of research are under-defined or patchy and it has the flexibility and sensitivity to be responsive to changing contexts and conditions (Henwood & Pidgeon, 2003). Grounded theorists also use a series of analytical and reflective strategies to aid the process of developing theory. These strategies are: comparative method, memo-writing and theoretical sampling (Tweed & Charmaz, 2012).

TA is a method for identifying and analysing patterns of meaning in a data set (Braun & Clarke, 2006). It illustrates which themes are important in the description of the phenomenon under study (Joffe, 2012). The end result of a TA should highlight the most salient constellations of meanings present in the data set. TA is not tied to a particular theoretical outlook and so can be applied when using a range of theories and epistemological approaches. This method is best suited to get to know the specific nature of a specific group's ideas and views of the phenomenon under study (Joffe, 2012).

As the current study is an exploratory study, it was deemed important to get an understanding of the psychosocial experiences young people with TBI face. As the emphasis in this piece of research is more on hearing the facts about what happened to the person with TBI rather than obtaining a detailed account of the person's reflections about the impact of TBI on their daily life, it was felt that IPA was not the most suitable method for this piece of research. Although, this piece of research is very much interested in the stories of people with TBI, it is not necessarily interested in the character of the stories and the language that is used by the person with TBI. In addition, a TBI might cause language and cognitive difficulties, which would potentially make it very hard for people with TBI to give a detailed and chronological account of their experiences. This could make it difficult for the researcher to analyse the stories that are told by people with TBI and to understand how these stories connect with everyday life. This means that Narrative analysis is not the most appropriate method for this piece of research. Although Grounded theory tries to understand patterns and meaning of a person's experience and views, this method is also about developing a theory inductively. As this study is about getting an understanding of a person's ideas and views of living with TBI without being tied to a particular theory or developing one, TA was chosen as the most appropriate method to analyse the data set.

2.3.1. Thematic analysis

Although TA has been widely used within psychology, it has been recognised as a method in its own right only recently. Braun and Clarke (2006) stated that TA is a foundational method for any qualitative analysis and that it provides the researcher with core skills that will be useful for conducting many other forms of qualitative

analysis, as many of them are essentially thematic. TA is not wedded to any pre-existing theoretical framework but this method can provide the necessary groundwork for establishing valid models of a person's thinking, feeling and behaviour (Braun & Clarke, 2006; Joffe, 2012). TA is described as the most systematic and transparent form of qualitative analysis, because it holds the prevalence of themes to be important without sacrificing the depth of analysis (Joffe, 2012).

Because TA refers to themes, the description of a theme will be discussed in more detail. A theme captures something important about the data in relation to the research question and refers to a specific pattern of meaning found in the data (Joffe, 2012; Braun & Clarke, 2006). It can contain manifest content or a latent content. Manifest content indicates something that is directly identifiable, such as mentions of stigma across a series of interview transcripts. Latent content is described as references in transcripts to which reference is implicit. For example stigma, when participants talk about maintaining a social distance from a particular group (Joffe, 2012). The researcher drew on both types of content during the analysis of the data set in this study.

Although three studies in the UK have aimed to explore the psychosocial consequences experienced by young adults with TBI, there are key differences between those studies and this current study. The study by Shotton et al. (2007) drew on a stress-coping framework in order to explore appraisal, coping and adjustment of young adults with TBI. They made use of IPA to analyse the data set. In the two studies by Oddy et al. (1978, 1985), participants were asked to fill in questionnaires measuring subjective impairment, social recovery and social adjustment. In the 1978 study relatives of the participants were also interviewed. In both the 1978 and 1985 studies it is unclear if a quantitative or qualitative methodology was used because this was not described.

2.3.1.1. Interviews

As the aim of this study is to understand the psychosocial consequences experienced by young people with TBI, the challenge for the researcher was to find a data collection method that encouraged young people to express themselves as

freely and openly as possible so that the researcher would get an understanding of their feelings and experiences. Verbal interviews, focus groups or email interviews would all fit within the epistemological position of the researcher and the methodology of this study.

Verbal interview data are widely used in thematic research and usually collected via semi-structured interviews containing five to seven topics that the respondent is prompted to talk about (Wilkinson et al., 2004). The topics then prompt participants to think about the meaning of the topic to them and to share this with the researcher who then might be able to understand the participants' experience. This method allows for each participant to share their experiences in a one-to-one conversation (Wilkinson et al., 2004).

Focus groups are often praised as providing an opportunity for participants to share their experiences and difficulties within a potentially supportive environment of others. Finding a time and place to meet everyone's needs can be challenging and it can be difficult for participants to share minority views and experiences (Frith, 2000; Kreuger, 2008).

As young people are very familiar with communication through social media, such as email, Facebook and Twitter, and often find it difficult to articulate their experiences in face-to-face meetings, they may prefer to participate in an online interview (Fox et al., 2007). However, during an online interview it is difficult to build a rapport with the person and to ensure confidentiality. The process can also be full of time delays, which can lead to the participant forgetting about the interview topics.

Comparing the advantages and disadvantages of the three data collection methods, the researcher felt that semi-structured interviews would be the most suitable method. This was because the participants all attended the young people's group, which is an open group so their attendance is not consistent. As adolescents and young adults are more prone to peer pressure, this might make it more difficult for a person to express a minority view or experience in a group setting. As all participants in this study have a TBI, it was very probable that they would have cognitive

difficulties which could have an impact on their understanding of the interview topics, their ability to express their views and my understanding of their experiences.

To enhance both the researcher's and participants' understanding, the interviews were held in a quiet room with minimum distractions and in each interview both verbal and non-verbal communication skills were used. As the interview topics were about personal experiences, which could be distressing for the young person, it was also felt that individual meetings would ensure confidentiality, would give the researcher the opportunity to identify distress immediately and the ability to offer any needed support to the young person. Previous studies have also indicated that individuals with TBI successfully participate in interviews (Patterson & Scott-Findlay, 2002).

2.4. Reflexivity

Unlike many other qualitative methods, studies utilising TA tend not to reflect on the impact of the researcher's preconceived ideas and presence on the data that emerge (Joffe, 2012). However, the researcher anticipated that her ideas and presence might influence and inform the research and felt that reflexivity was also part of conducting good qualitative research (Harper, 2012). Willig (2008) also states that reflexivity requires acknowledgement from the researcher that it is impossible to remain outside of one's subject matter while conducting the research, and that it also requires an awareness of the researcher that she contributes to the construction of meanings throughout the research process. When the researcher reflected upon her own values, experiences, interests and beliefs the following were identified:

As a nurse and, subsequently, a clinical psychologist in training, the researcher has worked in different settings for young people with TBI. This allowed her to experience the distress young people and their families face from the acute phase in hospital until the recovery phase when young people are at home. These experiences have shaped the researcher's ideas about the professional input that is needed for young people to be supported in order to maximise their quality of life. However, it might be that the views of young people differ from the ideas that health professionals have about the level and type of support they need, in order to have what they view as a good and meaningful life. The researcher, therefore, felt that

throughout the study she might need to step outside her role as a health professional in order to value and hear from participants what it is they need to live a good life. The researcher did this by being reflective and trying to set aside her professional assumptions and models and to write this down in a few sentences. As the researcher wanted to see things as a non-professional might see them, she looked at this verbal account throughout the research process in order to be reminded about not looking through the lenses of a nurse or psychologist during the interviews or when analysing the data.

2.5. Selection and recruitment of participants

2.5.1. Sample

Inclusion criteria: men and women aged between 18 and 40 years who acquired their brain injury more than two years ago. The age range covers the developmental period of late adolescence and young adulthood. These men and women also needed to attend or be part of the weekly young people's group at Headway East London. They may represent different ethnic and cultural backgrounds.

The men and women who attended the young people's group were between 18-31 years old and it is, therefore, that the youngest participant in this study was 18 years old and that the eldest participant was 31 years old. Erikson (1968) described that the search for identity that adolescents experience is indispensable to young adulthood, and specifically from about age 19 to 30. This means, that although only participants aged between 18-31 were recruited for this study, the sample still captures both the developmental stages of adolescent and young adulthood. It, however, might be more appropriate to talk about young adults/people instead of adolescents and young adults in this study.

Exclusion criteria: the presence of visible physical disabilities, meaning that people could see that a person has a physical disability (e.g. use of a walking aid, hemiplegia, use of a wheelchair).

In this study only participants who had their TBI more than two years ago were included, as the literature suggests that people with a TBI make the fastest and most

significant recovery within the first two years and that, consequently, two years post-injury is an appropriate time to investigate long-term outcomes (Ownsworth et al., 2007). A study by Frosch (1997) indicated that physical recovery from a TBI occurs within the first six months, cognitive recovery within 12 months and behavioural recovery within two years post-injury (Frosch, 1997; Morton & Wehman, 1995; Oddy et al., 1985). A study from Musack et al. (2006) showed that there is a fast recovery within the first year post-injury and that the rate of recovery depends on factors such as pre-injury functioning capacities, age, level of unconsciousness and extent of neurological damage within the first year after sustaining a TBI. After this period a person's recovery slows considerably and neither age nor initial severity of injury shows an association with the recovery rate thereafter (Whitnall et al., 2006).

Several studies have also demonstrated that within the first two years post-injury (also called the acute stage of recovery) the social support network of survivors significantly decreases and pre-injury friendships dissolve (Oddy et al., 1978; Oddy et al., 1985; Klonoff et al., 1986; Ownsworth et al., 2007).

Brooks et al. (1987) suggested that the psychosocial problems one to five years following injury were not exclusively due to brain damage per se. They suggested that people with TBI may become more aware of and consequently more frustrated by their disabilities as time post-injury increases (Brooks et al., 1987). This consequently indicates that psychosocial problems of anxiety, depression and social isolation are long-term effects of TBI and ideally are to be measured two years post-injury when recovery has considerably slowed down and the person with TBI needs to adjust to the remaining difficulties.

Ownsworth et al. (2007) stated that people with TBI, who are in the more acute stage of recovery, experience a different process of adjustment to individuals with more long-term injuries. It is for this reason that this study only includes participants whose brain injury was more than two years ago. Adjusting to the psychosocial consequences of TBI is considered to be the greatest challenge for a person as their difficulties can be extremely stressful as they are forced to confront a life that is significantly changed. (Shotton et al, 2007).

2.5.2. Recruitment method and process

As young people with TBI are rarely involved with statutory services, particularly two years post-injury, the researcher made links with the national organisation Headway that provides support for individuals with a brain injury. Headway East London runs a weekly group for young people aged 16 to 30 with TBI and covers 14 London boroughs. This specialist service was established for young people in recognition of their needs and interests. The group meets weekly at Headway house and provides a supportive environment for young people who may feel isolated and misunderstood by their peers. The group members are encouraged to use the group as a platform to explore their interests, to engage in creative and practical activities and to socialise and support one another.

As the researcher had been a volunteer at Headway House before studying for a Doctorate in Clinical Psychology, she contacted the occupational lead of Headway East London to discuss with him the research proposal of this study and the possibility of recruiting participants from the young people's group. The occupational lead agreed to be the clinical supervisor of this study and also brought the researcher in contact with the coordinator of the young person's service. The researcher explained the purpose and aims of this study in a meeting with the coordinator, who showed an interest in the study and stated that the researcher was welcome to attend the weekly young people's group meetings and to speak to its members. As both the occupational lead and the coordinator had either studied psychology or had an interest in psychology, the researcher was aware that their enthusiasm and interest for this research project would not necessarily reflect those of the young people.

From November 2012 to February 2013, the researcher visited the weekly young people's group. In the first meeting, the coordinator of the young person's service had organised a meeting for all the young people and the researcher. This meeting was facilitated by the coordinator and in this meeting the young people and the researcher were introduced to one another. The researcher was also given the opportunity to explain the rationale of the study and the aim of her presence in the group for the coming three months. Following the meeting, the researcher approached the group members to ask for their participation in the study but found

that the young people were either hesitant or even declined to take part when they were approached while they were among their peers. Reflecting on this, the researcher felt that there was group pressure and that the group members needed some time to get to know the researcher and/or to assess if she could be trusted.

2.5.3. Building trust and establishing familiarity and confidence

To establish familiarity between the group members and the researcher, the latter took time to build a relationship and rapport with the young people by attending the weekly group meetings and sharing lunches with the group. However, the researcher was aware that when these activities are coupled with the in-depth sharing of feelings and beliefs that are characteristic of an interview, the young person may misconstrue the research experience as an opportunity to develop a friendship (Dickson-Swift et al., 2006).

To clearly identify the researcher's role, the young people could approach the researcher in the communal area of Headway House to discuss the purpose of the study or any other related questions and queries. It was also hoped that the clear identification of the researcher's role would facilitate trust between the researcher and young people and minimise any mistrust and false expectations the young people might have of the researcher's role throughout the study.

Being aware of peer pressure and respecting the young people's level of autonomy, the researcher had also put an information pack of the study on a noticeboard in the hallway of the house. The package contained a flyer with the researcher's contact details, an information sheet of the study and a consent form, so that young people could familiarise themselves with the study at their own pace and contact the researcher anonymously.

The researcher also reflected on the level of power there was between her and the young adults. As these were young people who were depending on Headway for their social and practical support, it was felt that the researcher by no means should influence the young person's decision to take part in the study. In negotiation with the young person's coordinator, the interviews were held either before or after the group members had participated in their activities so that the research did not affect

their programme. In addition, the researcher did not take part in the young person's programme of scheduled activities so that the young people did not feel pressured by the researcher's presence to participate in the study.

During the three months of the researcher's presence at the young people's group, eight from the 12 people agreed to take part in the study. Although the researcher's position was to be highly inclusive, by including as many people's perspectives as possible in this study, two people were excluded from taking part: both had visible physical difficulties (e.g., one person sat in a wheelchair and one person walked with a walking stick). In addition, one person declined to take part in the study and one person left the group all together. Table 1 shows the details of the eight participants who took part in this study and pseudonyms were used to name the participants.

Table 1: Demographic details of participants

| Participant | Gender | Ethnicity/Cultural Background | Age | Year of brain injury |
|-------------|--------|-------------------------------|-----|----------------------|
| Beth | Woman | British-Irish | 21 | 2008/2009 |
| Chris | Man | Latin-American | 23 | 2006 |
| Jacob | Man | Jamaican | 31 | 2007/2008 |
| William | Man | White-British | 25 | 2010 |
| Wesley | Man | White-British | 19 | 2010 |
| Ben | Man | Bengali | >20 | 2006/2007 |
| Wendy | Woman | White-British | 28 | 2006 |
| Asa | Man | Asian | 18 | 2002 |

2.6. Ethical issues

As the researcher and participants are people with emotions, both are vulnerable in certain situations and contexts to physical or psychological harm. It is, therefore, for the researcher to reflect on the ways in which the study might create vulnerability and to be guided by ethical guidelines throughout the different phases of the study (Thompson & Chambers, 2012). The researcher used the ethical guidelines from the British Psychological Society (BPS) as her guidance to consider ethical aspects and dilemmas of the study (BPS, 2010).

2.6.1. Ethical approval

Ethical approval for this study was sought and obtained from the University of East London's Ethics committee (Appendix II).

2.6.2. Informed consent

Informed consent was sought from the young people when they had approached the researcher and showed an interest to take part in the study. In a one-to-one meeting the participant was given the information leaflet, which contained information about the overall purpose of the research project, voluntary participation of the participant, confidentiality and who will have access to the interview and any distress that the participant might experience following the interview (see Appendix III). As the choice of a qualitative design and one-to-one conversations are in line with the ethos of the young people's group, it was anticipated that the participants would not be distressed after sharing with the researcher their experiences, ideas and views of living with a brain injury. As a trainee clinical psychologist it was felt that if participants showed signs of distress, the researcher would be able to deal with these and be able to stay with participants at the conclusion of an interview, to contain their reactions and to recommend further support (Thompson & Chambers, 2012).

After the participant had read the information letter, he/she was given the space to ask questions and to think about whether or not they still wanted to participate in the study. If so, then the participant was given the consent form (Appendix IV), which outlined that he/she had read the information letter, had understood confidentiality and had the right to withdraw from the study at any time. It was felt that this

knowledge would also empower the participant to have control in relation to terminating the interview (Thompson & Chambers, 2012).

Being aware that the participants in this study probably would have cognitive difficulties caused by their brain injury, both the information and consent form were written in a clear and concrete manner. After the participant had read one of the forms, the researcher summarised the information it contained. The researcher also asked if the participant had understood the information and if they had any questions. Throughout this process, the researcher made a brief assessment as to whether the participant had the capacity to make the decision to participate in this study, through assessing whether the person understood the information, could hold the information, could weight up the pros and cons of the information and could make a decision (DoH, 2005). To inform this assessment, the researcher also worked closely with the young people's coordinator and facilitator of the group, who knew all the young people well.

2.6.3. Confidentiality

After signing the consent form, the concept of confidentiality and anonymity of the study were explained to the participants. Each participant was also informed about the procedures that would follow when he/she disclosed information during our interview which could indicate a risk to the participant's safety or those who have a close relationship with the participant. It was discussed that in this case minimal information would be passed on to the necessary people and organisations to ensure safety for those who are at risk.

2.7. Interview process

After participants had agreed to take part in the study, signed the consent form and confidentiality was discussed, the interview would start. All eight interviews were held in one of the interview rooms at Headway house, which were booked by the young people's coordinator. The interview setting gave the researcher and the participants privacy to talk about the participants' experiences of living with the consequences of a brain injury and to minimise any outside distraction. It also helped participants to feel relatively at ease and empowered during the interview, as they were familiar with the setting, the staff and other group members.

2.7.1. Materials and interview schedule

The researcher used an Olympus digital voice recorder (VN 7600) to audio tape the interviews with all eight participants. With full consent of the participant, the voice recorder was placed between the researcher and participant and switched on.

Guided by the literature review, an interview schedule with the main questions was developed around the aims of the research project (Appendix V). The schedule was used as a guide as the interview was semi-structured and the questions were used to encourage participants to share with the researcher their experiences of living with the long-term consequences of a brain injury (Floersch et al., 2010).

As the researcher was interested in the views and ideas of young people with TBI, it was felt important that the researcher was open to and reflective of unfamiliar ideas and views. In order to facilitate hearing these ideas and views, the researcher made use of narrative ideas so that participants could tell their story about how the brain injury affected their lives. This approach gave participants space to share their story, which was shaped by their worldview and experiences. It also empowered them to share with the researcher only those ideas, views and feelings that they wanted to disclose. With this approach it was hoped that the researcher would also encounter new ideas, views and perspectives about young people's experiences of living with a TBI.

2.7.2. Anonymity and confidentiality of the data

Confidentiality of the data was ensured throughout the study, in writing up the thesis and in any feedback to services by removing any information which could be used to identify participants. To ensure anonymity, each participant was assigned a personal code so that only the researcher could identify the participant. Details of the codes that correspond to each participant and signed consent forms were kept in a separate locked cabinet to the digital recordings and transcriptions. The researcher transcribed all the interviews. Only the researcher and internal supervisor had access to the transcribed material. All the data were kept securely in a locked cabinet.

2.8. Thematic analysis

2.8.1. Process of analysis

Braun and Clarke (2006) state that both a deductive (theory-led) and inductive (data-driven) approach can be used for TA. A deductive approach is bounded by pre-existing theories, which risks that the researcher focuses on certain aspects of the data set at the expense of other potentially important aspects. Yet, other researchers argue that this approach would enhance the analysis by sensitising the researcher to more subtle features of the data set (Tuckett, 2005). An inductive approach is not bounded by pre-existing theories and aims for the generation of data codes, subthemes and themes from the raw data itself.

The researcher used both approaches in the analysis of the data set. This meant that the researcher analysed the data making use of certain preconceived categories mainly derived from the psychodynamic identity theory of Erikson (1959), for example the concept of independence, but also remained open to new concepts that emerged (Joffe, 2012). Joffe (2012) stated that it is important for the researcher to approach each data set with knowledge of previous findings in the area to prevent reinventing the wheel and to take seriously any findings that do not match with previous theoretical ideas and have the potential to generate new knowledge about the topic under investigation.

The researcher made use of the six-phase framework (Braun & Clarke, 2006) as a guide for the process of data analysis. The different phases are summarised in Table 2.

Table 2: Phases of Thematic analysis (Braun & Clarke, 2006)

| Phase | Description of the process |
|---|--|
| 1. Familiarising yourself with your data. | Transcribing data, reading and re-reading the data, noting down initial ideas. |
| 2. Generating initial codes. | Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code. |
| 3. Searching for themes. | Collating codes into potential themes, gathering all data relevant to each potential theme. |
| 4. Reviewing themes. | Checking if the themes work in relation to the coded extracts and the entire data set, generating a thematic 'map' of the analysis. |
| 5. Defining and naming themes. | Ongoing analysis to refine the specifics of each theme and the overall story the analysis tells, generating clear definitions and names for each theme. |
| 6. Producing the report. | The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back to the research question and literature, producing a scholarly report of the analysis. |

Although in the following paragraphs the process of data analysis is described as a linear process of moving from one phase to the next, it is important to note that the analysis of the data was a recursive process, where there was a back and forth movement throughout all six phases (Braun & Clarke, 2006). It was also a process that developed over time and was not rushed (Ely et al., 1997).

Phase 1: Familiarising yourself with your data

The researcher familiarised herself with the data through the process of transcription, repeated reading and re-reading of the data in an active way, which meant searching for an initial list of ideas for possible meanings and patterns and what was interesting about this.

Phase 2: Generating initial codes

This list formed the basis for the production of initial codes from the data set.

Boyatzis (1999) describes a code as “the most basic segment, or element, of the raw data or information that can be accessed in a meaningful way regarding the phenomenon” (p. 63). The researcher worked systematically through the entire data set, giving full and equal attention to each data item and identifying interesting aspects in the data set that may form the basis of repeated patterns (themes). The researcher coded the data set manually by using coloured pens to indicate potential patterns and ensured that all actual data extracts were coded. While coding the data extracts the researcher also included some of the surrounding data so that the context of the data was kept. Certain data extracts were coded many times as they seemed to fit into many different ‘themes’. After the researcher had coded the entire data set and had identified a long list of different codes, the analysis was taken to the next phase.

Phase 3: Searching for themes

This phase involved sorting the different codes into potential themes and collating all the relevant coded data extracts within the identified themes. During this phase the researcher made use of a thematic map to help sort the different codes into themes. At this point the researcher started to think about the relationship between codes and themes and depicted this onto the initial thematic map (see Appendix VI).

This initial map was revised through analysing how different codes and themes could be combined to form overarching themes. The revision of the initial thematic map led to the presence of 14 overarching themes, and a collection of subthemes and candidate themes; see Appendix VII for the revised thematic map. Although there were a lot of themes identified, the researcher felt that at this stage none of the identified themes could be combined, refined, separated or discarded without looking at all the extracts in detail again.

Phase 4: Reviewing themes

This phase involved two levels of reviewing and refining the themes. Level one involved reviewing the coded data extracts, which meant that the researcher re-read all the extracts for each theme and considered if they appeared to form a coherent

pattern. The dual criteria of internal homogeneity and external heterogeneity were considered during this phase as the researcher was mindful that the data within themes should cohere together meaningfully, while there should be clear and identifiable distinctions between themes (Patton, 1990). Following the first level, the researcher was able to make a first candidate 'thematic map' in which six overarching themes were identified (see Appendix VIII).

Once the first 'thematic map' was established, the researcher moved to the second level of this phase. At this level the researcher considered the validity of the individual themes in relation to the data and if the candidate thematic map accurately reflected the meaning of the whole data set. The researcher, therefore, re-read the entire data set to ascertain if the identified themes worked in relation to the data. This resulted in the second candidate thematic map (see Appendix IX). At the end of this phase the researcher felt that this thematic map reflected how the different themes fitted together and told a story about the data.

Phase 5: Defining and naming themes

In this phase the researcher continued to identify the essences of what each theme was about and determined what aspects of the data each theme captured. The researcher did this by going back to the data extracts for each theme and organised these into a coherent story. In addition, the researcher considered how each story would fit into the broader story of the entire data set, in relation to the three formulated research questions. This resulted in the final thematic map, which consists of four themes and four subthemes (Appendix X).

2.8.2. Presentation of data extracts

As this study looked at an under-researched area, a rich thematic description of the entire data set was chosen and is presented in the Results section of this thesis. In this section, data extracts from different participants are presented and their names are pseudonyms, such as William. In addition an indication of the number of participants who reported the same issue is provided by including numbers (e.g. two participants) and broader categories such as 'some', 'most' and 'all the participants'.

3. Results

Following the interviews with the eight participants, the content of each conversation was transcribed and followed by an analysis of the data. From the analysis, four themes and four subthemes emerged; they are displayed in Table 3. These themes capture the range of difficulties experienced by the participants, which consequently affected their sense of identity and their relationships. The analysis also showed that participants felt that the consequences of the brain injury affected their possibility of returning to their jobs or to continue or commence any form of education. The participants indicated that they could deal with the brain injury-related consequences with support from professionals and family, once they were aware and had accepted their difficulties:

Wendy: "So I look at it now, you know what I have got is a brain injury and I know I have got issues and I can deal with them the best way I can. It does not always happen, if I go to new places now, I apologise beforehand, like I have got a brain injury, I can be very rude, I can be very loud, and I try not to be, sometimes I do not know that I am acting that way, please do not be offended and that is usually."

Throughout the eight interviews and during the transcription of the data it was noticed that most participants had expressive and receptive communication difficulties. These difficulties are reflected in the written quotes of the participants as the quotes are often short, not fluent and have grammatical errors.

Table 3: Themes and subthemes of final thematic map

| Themes | Subthemes |
|--|---|
| <p><u>1. Impact of the brain injury</u></p> <p>The participants reported that the brain injury had led to changes in their cognition, communication, physical health, behaviour and personality, which affected their sense of identity and their relationships (social, intimate and family).</p> | <p>1.1. Sense of identity</p> <p>1.2. Relationships</p> |
| <p><u>2. Inclusion and exclusion</u></p> <p>Due to their disabilities, participants were unable to return to their jobs or educational programmes, which led to feelings of lost purpose and meaning in life and ultimately to feelings of low mood, frustration and exclusion from society.</p> | |
| <p><u>3. Dealing with the impact of the consequences of the brain injury</u></p> <p>Participants stated that they first had to be aware and to accept their limitations in order to make use of behavioural and cognitive strategies to manage their limitations and to live a life as 'normal' as possible.</p> | |
| <p><u>4. Support</u></p> <p>Participants were offered and accepted support from a range of services and close relationships to help them manage and deal with their limitations to gain maximum independence in daily life.</p> | <p>4.1. Inpatient rehabilitation</p> <p>4.2. Community services</p> |

3.1. Theme one: Impact of the brain injury

All participants felt that the brain injury had changed their lives and some of them even felt that it had 'ruined' everything, as they experienced significant changes in their cognitive abilities, communication skills, physical abilities, behaviour and personality. These findings are consistent with those of Ylvisaker and Feeney (2007) and Anderson et al. (2005). In both studies adolescents described that they experienced emotional, cognitive, behavioural, social and physical consequences following TBI.

The participants reported that they had changed significantly as a person due to the complexity and pervasiveness of changes in their abilities, their behaviour and personal traits as a result of their injury. They also indicated that it was hard to comprehend what had happened to them and that they looked at the brain injury as an entity that controls their lives:

I: "So what has changed for you after the brain injury?"

William: "Everything, it's like everything has changed. It is like hm (silence)."

I: "Where do you start?"

William: "Yeah, exactly where do you start. The brain injury controls everything. Can't even think about the same stuff without given its permission, it, it is like (silence). I was paralysed on this side, on the left side and it is still much weaker than the right side 'cause I can close this eye, but this eye is hard to keep closed. And there is few little things that someone will notice. I have a drink of water and then water goes down the wrong hole 'cause of this trachea I had. Water goes down the wrong hole and I start choking. Then people said to me do you want some water and start, water did make this happen. It is just unimaginable the things that change. Everything."

I: "Do you think that your personality has been the same or that it has been changed?"

William: "Hm my personality, like I said, everything changes after a brain injury 'cause it ruins everything."

All participants reported that they experienced physical health changes after their brain injury and that these changes included: epilepsy, headaches, tiredness, sleeping difficulties, pain and mobility issues.

Most participants stated that they experienced significant changes to their memory and that they found it very difficult to remember information from before and after the brain injury. The participants indicated that the communication difficulties and the physical and cognitive changes resulted in their living with profound disabilities, which gave rise to intense feelings of despair, hopelessness and low mood:

I: "So you mentioned that your memory has really changed?"

Beth: "It is shattered, try to repeat and hold it all together is just so very difficult.

Sometimes when I talk to old friends, I do not exactly remember things from them, 'cause they say, yeah, right or one thing or the other and then I think, yeah right.

Which one is that, oh ye that is the one that is the one! Oh in my secondary school it is year eight, year nine, year ten, year 11 that is how they talk, that is how they explain the years. But for some reason I remember it as first, second and third year as some of the other secondary schools do."

I: "So your memory has changed a bit and you mentioned school. Did you go back to school?"

Beth: "No that is the saddest bit. Afterwards, I never thought that I would say that.

Because after the brain injury I suffered, they basically said".... (Beth whispered)

I: "Sorry."

Beth: "You do not have got any depth of memory to go back".

I: "So you could not go back to school because of the memory problems?"

Beth: "They said, it is none of your fault, remember, but it is just, it is just so very difficult and they were very nice about it. But it is just really difficult because I never got to take my A levels and I remember studying psychology and I was loving it and about the human brains, it was so great and so interesting but it did not work for my side, did it?"

Five of the eight participants were involved in a road traffic accident and they reported that their memories about the cause of their brain injury were very vivid and gave rise to intense feelings of anxiety, which consequently affected their daily life. These symptoms do suggest that participants were suffering from post-traumatic stress (Keane & Barlow, 2004):

Asa: "My brain injury was caused by, 2002 when I was seven. I cannot remember what day but it was a lunch break and then after that I went home, came back and then when I was coming back I was hit by an ambulance. I did understand about the traffic lights, but it was flashing green, so I thought I could go, but what happened, an ambulance hit me and then I was damaged for long."

I: "You seemed to remember it very clear?"

Asa: "I remember bits and bobs. The good bits not the bad bits, but every time when I used to see an ambulance I would freak out. With freak out, I mean have flashbacks. When I would see an ambulance, I see in my eyes me as a little kid walking on the white stripes. Now when I see an ambulance it freaks me out still."

During the interviews it was observed that five interviewees had communication difficulties and three of them reported that these difficulties affected their day-to-day life. These findings are consistent with those in a study of Leith et al. (2004), in which all participants experienced memory problems and many of the participants also had speech difficulties.

With the exception of Asa, all other participants in this study also indicated that they had noticed a change in their personality or behaviour. The changes in personality varied between participants, but being quieter, withdrawn and more relaxed were mentioned several times:

I: "Have you noticed any changes in yourself after the brain injury?"

Jacob: "I am quieter than normal."

I: "Quieter than normal."

Jacob: "Before I was always upbeat and active and be calm and collective."

I: "Can you describe how your life was before the brain injury."

Jacob: "Before I was upbeat, seen those guys who like to rave, I was that guy."

I: "You liked the raving?"

Jacob: "Yeah, but now that is lost. Sit down, relax most of the day, that is me."

As Asa's injury happened ten years ago, when he was a child, it was very hard for him to reflect if the brain injury had caused any changes in his personality or behaviour. Asa, however, did mention that his behaviour at school and at home got him into serious trouble and that these behaviours are often triggered by things in the environment such as noise or bright lights, which give him a serious headache. The literature states that following a TBI, environmental factors could cause people with a TBI to behave in such a way that it jeopardises their safety and that of others and Asa's account of his behaviour is consistent with this finding (Alderman, 2003). Asa also described that he had learned to manage his behaviour over time:

I: "How do you mean getting into trouble?"

Asa: "I can get tempers with things like, when really and truly this happens at home, even when I am right and then I have got a headache, just say shut up. I thought it will get me into trouble because (stopped his sentence). You feel nausea, you feel sweaty. I used to hit people, smash people but I am not doing that shit anymore."

Most participants indicated that they had encountered prejudices from society as there was not an obvious cause or visible cue that provided an explanation for their difficulties, which resulted in people drawing incorrect conclusions, for example to think that the person was drunk or drugged. The participants also stated that people in society used negative labels such as being mentally ill or learning disabled to explain the difficulties they displayed during social interactions:

I: "Sometimes when people have a brain injury they notice changes in their memory as you say but sometimes people also notice a change in their concentration and attention. Do you notice any of that?"

Ben: "No not really. Sometimes when I had to answer a question someone said can you write it down but sometimes it is not clear what he meant. Sometimes I am like what do you mean. I'll give you an example: I'll try this stuff you know but I have not been good at understanding. So people are like this guy is stupid and I can't blame,

it is not something that happened to them. Thinking about it I am not impressed you live, and they will look at me like I am sort of idiot.”

All participants stated that changes in cognition, communication, physical health, behaviour and personality led to inabilities in different areas of their lives such as recognising people, responding to events and being understandable to others. These inabilities affected the participants' self-confidence and influenced their ability to relate to the world. The participants described that their confidence in their skills and abilities was undermined and that, therefore, the world had become unpredictable as they were not sure if they could handle events and situations. This resulted in feelings of nervousness, low mood, anxiety, anger and frustration:

Beth: “I was sent home and then I found it so difficult there because forgetting exactly what just happened to me. Mum would make me a cup of tea and I would drink it and then I put the cup right in front of me and then I forget I put the cup right in front of me and then I would ask mum: ‘Can I have a cup of tea?’. Then I saw her face and realised I just had one and I got quite angry about that ‘cause, so I got so pissed off with why and on my first day I asked: ‘Oh where is Jean?’ who was my first cat when I was a child. Jean she died years ago and no you do not remember do you, I am sorry Jean is not around anymore.”

I: “So your mum had to explain that Jean was not around anymore?”

Beth: “Yeah and then I sort of thought oh yeh and then I sat down and thought oh my goodness, I can’t remember (participant shouted grandma W, grandma W) ‘cause I can remember grandma W and she is dead for years. It was terrible to say that ‘cause I loved her.”

Two participants described that these feelings were so intense that professional support was needed to help them manage the situations when the feelings took over:

Wendy: “For instance on Wednesday I had a panic attack, and this is the first one I have had I had to call an ambulance out. Usually I can control them.”

I: “How do you do that?”

Wendy: "I went so see my psychologist and she sort of said to accept that they are going to pass, take deep breaths and take yourself for a brisk walk. If you feel nausea do not eat or drink cause that can make it worse."

3.1.1. Subtheme: Sense of identity

Most participants reported that the changes also altered the way they viewed themselves. They explained that the way they viewed themselves was related to the views and beliefs they had about people with difficulties, which were developed throughout their lives and influenced by their cultural background. The male White-British participants expressed ideas that males had to be strong and that having difficulties, which might be associated with having a learning disability or mental illness, is something of which to be ashamed:

I: "Do you think that your personality in general has been the same or that it has been changed?"

William: "Hm my personality. Like I said, everything changes after a brain injury 'cause it ruins everything. It is like, hm, pf, I, I have changed in every way. I have changed in the way I think about it, it is pretty shameful to admit but unless I was...I was, I am, I knew there were disabled persons before my accident but would not really make the effort to get to know anyone you know. Hm, but since the accident I realised like, got to have really...I have now...I have met interesting people. I meant when I went to the rehab centre and thought about all of that and getting to know a bit. I made some good friends there."

William: " But from the age of about 20, I thought it was not really manly to cry so I just tried not to cry and I keep on that for a long time before my accident. I do not think it has to do why I can't cry now."

One of the Asian male participants expressed that having the brain injury-related difficulties meant that back in his country of origin he would not be seen as a male role model as he is not able to take care of himself or future family:

Ben: "Get married, have children.... You can't have that in my country...and that is cultural."

I: "So how does that work when you get married? Do you find yourself a wife or do you need to, or do other people do that for you in a sense?"

Ben: "I do not know... in my...should be...different. But that is a different story but it depends how I feel for her...I would need to be able to look after my wife."

The participants also explained that their view about themselves was also influenced by how they thought other people might view them and by the experiences they had when they met and socially interacted with others. They described that they were laughed at or excluded from social groups since the brain injury. They reported that their own views about themselves, the anticipated views from others, and their experiences influenced their self-esteem and confidence. The participants also explained that they started to feel stupid and incompetent and that they became less confident in their social interactions with others. This affected the participants' ability to maintain and establish social and intimate relationships:

Chris: "Lots of times I do not feel like talking 'cause, I think that, hm people do not understand me. Hm, yeh and you know. Yeh people like, oh what is wrong with him? Without talking to me. Yeh."

I: "Have you noticed that people say that to you or to other people?"

Chris: "Hm, yeh, I kind of noticed it. Yeh."

I: "And how does that make you feel?"

Chris: "Hm well, it really makes me feel very frustrated, but not anymore. Because there was once, I met two friends who I know from before my accident on the bus and I started talking with them and one of them said: 'Oh what is he saying' to his other friend and his other friend said: 'I do not know'. Yeh, so."

With the exception of Asa, all other participants reported that they reflected upon their lives and felt that so much of themselves and their lives were lost due to the experienced changes (e.g. memory, mobility). They described that the changes had contributed to an altered sense of identity such as seeing oneself as disabled and mentally ill, without any prospect of change, instead of seeing oneself as a young

physically active and bright person with a life full of potential. These reflections led the participants to grieve for what has been lost and resulted in feelings of low mood:

Ben: "I was run over by a car."

I: "Do you remember what happened afterwards?"

Ben: "If I could remember that, I would be fine. I wish (silence). No I think about it 24 hours a day at least once, so what I know is, every day I think about it honestly, because I do think about it more rather than less because... (stopped the sentence). I remember that day, I remember it has been a long way I have come. The reason is not so the injury but the pain in my back, that is the significant effect and the injury to my back, there are no words to describe it. It's one of the worst things that can happen."

I: "Can you tell me more about your mood. How has that changed?"

Ben: "One time I felt confident but now I feel like shit, not shit but feel like shit. Thinking why am I here and think why am I here just (stopped) think why is it like this. Why am I having these feelings, it is not nice. But now I am just feeling so lonely and it is not only the injury, it is just something in general has affected me a lot. It takes time, maybe it is more of a long thing. And my back pain how that has been destroyed the future when I think about."

Compared to the male participants, it was noticed that the two female participants also reflected upon how the brain injury not only changed their lives but also that of their families and partners. They explained that due to the level of care they needed, their families or partner had lost important parts of their own lives such as a job and friends. These thoughts gave both women feelings of guilt and low mood as they felt responsible for these losses and felt that they had no control in changing the situation. The reflections also affected the women's sense of identity as they identified themselves as people who were depending on others instead of being independent people. These findings are in line with the idea of Carter and McGoldrick (2004) that identity development takes place in the context of family relationships and that therefore individuals must be seen in their cultural and historical context of past and present in order to be understood and changed:

I: "How is that for you that your mum has given up her full-time job?"

Beth: "I feel so sorry for her 'cause in the kitchen the other ladies there were her best friends and it feels like I have robbed her of her best friends. She says, 'It is none of your fault. Do not worry', she always says that to me but then I say, 'But it does not stop you feel bad about it.'"

I: "Because you feel that your mum has given something up for you?"

Beth: "And I would like to give it back to her but I can't. Because I think sort of, 'Oh give her Esther and the rest of them back please.'"

Beth: "I feel bad 'cause I sort of think, oh, what should make it better for it. I do not know why/how to make it all better. 'Cause you sort of think, how could it have been different and how could I have made any of it better. But because I am not in charge in any of it, it is so difficult, you feel bad."

Interestingly, only the two women talked about a change in self-identity without being prompted during the interview and both of them explained that they thought less of themselves after the brain injury as they were depending on others to live daily life. Although Erikson (1959) described that autonomy was one of the primary values of male identity, the quotes of the females in this study also seemed to indicate that independence was very important to them:

Wendy: "Even now, that I am a stressful being for the one to look after and for me trying to ensure that I am doing the things I should do on a daily basis."

Wendy: "I am very short now. I used to be very patient person before and with the people here I am so patient, hm, but if it is for myself, if I am waiting in a line or if I am at the doctor's surgery or I am at the hospital and I do not get seen specifically on time, I was supposed to be seen, people will know that, 'cause I sort of will start raising my voice and I did not realise that I acted in this way."

The researcher noticed that the male participants disclosed indirectly how they saw themselves by talking about their physical appearance and how important it was for them to look 'normal', meaning hiding those physical appearances that could tell that something might be wrong:

William: "Like the doctors just told me that I may not walk again and I pfff like then that was about it really, 'cause that was really the only thing that bothered me a lot because I have always been a physical sort of person, not really academic."

I: "How did you manage?"

William: "I think 'cause I never really made any progress until I reached the rehabilitation centre. And the rehabilitation centre and that really gave me... 'cause when I was in hospital, I saw, like I had forgotten a bit... Before my accident if someone told me I could not do so then I stayed there for ages until I could do it."

Asa: "They are looking at me and they start moaning and bitching at me. I feel like I am different. People do not accept me for who I am, that is why I socialise on Facebook, making friends."

3.1.2. Subtheme: Relationships

With the exception of Asa, the other seven participants described that they had lost contact with their friends because friends were moving on with their lives or had excluded them when the brain injury-related difficulties were visible and noticeable during social interaction with others. This loss of contact resulted in feelings of isolation and loneliness:

I: "Are there any friends that support you?"

Beth: "Well most of them have gone off to uni and then other friends have sort of gone from meeting up with their boyfriends and that sort of things and then go out and it is not no fault of their own, it is they need to grow up as well but they do not know and I do not regret that but because it is sad because you miss your mates."

Although Asa had his injury at an age when he did not have an established group of peers (one you have when you are an adolescent or young adult) he did indicate that he felt isolated and lonely as he found it hard to establish new friendships:

Asa: "I feel like I am different. People do not accept me for who I am, that is why I socialise on Facebook. Making friends. My case manager thinks it is a bad thing to do but... I would like to socialise more, meet people face to face. Being able to stag for a concert. I would like to see Jean-Paul."

Most participants indicated that they felt more confident and at ease to establish social relationships with peers they met at a brain injury rehabilitation centre or brain injury daycentre such as Headway. The participants explained that meeting other young people who are in a similar situation helped them to feel understood and accepted. In addition, the participants felt that their contributions to relationships was seen as meaningful and valued by their peers, which positively affected their self-esteem. These findings are consistent with the idea that self-esteem develops in the context of meaningful community involvement, such as voluntary work, as it allows the person to feel useful and to contribute something to society (Lefebvre et al., 2005):

I: "So how do you find it being at Headway?"

Chris: "Well it is good because I see lots of people who have got acquired brain injury as well. And you know 'cause there is nothing to see what happened to them and you know, to know that I am not the only one."

I: "What sort of things do help you here at Headway?"

Chris: "Yeh, because there is a lot of people that come here that have got problems and you know I talk with them. Like for example I talk with them, with T and S who do not have a got a brain injury and they look normal."

I: "So coming to this place helps you to meet people with a brain injury and without a brain injury. And in what way does it help you to talk to all these people?"

Chris: "Well it makes me good a little bit more. I can tell them so they understand like where I am coming from, yeh."

However, the male participants who were in their mid-twenties and thirties continued to worry about where to meet partners with whom to establish an intimate relationship, as they encountered prejudices and stigmatisation of having a disability when they approached people in everyday society. Consequently, they felt less confident in meeting and approaching potential partners:

Jacob: "I am single, I would like to have a girlfriend. Someone who can do stuff for you, you can go to."

I: "Have you tried to find a girlfriend?"

Jacob: "Yeah, I tried. No one likes to go out with me. They do not wanna know."

I: "Have you experienced that?"

Jacob: "Well at college, I met this girl, nice girl and she was always laughing at me and she said, I do not wanna know you, I do not wanna know you because you have got a brain injury."

William: "I find it difficult to meet girls now, 'cause I like hm, well before I just would go up to them and talk to them. Now I have got, well I have got balance issues so people often look at me like I am drunk."

I: "Do you feel that people judge you in a particular way when you are out and about?"

William: "Hm yeah, they probably do but like, I think, how can they judge me without knowing me? That is why I think it would be easier to meet up with an ex-girlfriend and them friends because they know how I was like before my accident and know that I am not drunk."

Yet, for the male participants from an Asian or Bengali background finding a partner was not a worry for them. They described that due to their cultural background their families would arrange a partner for them and that they felt confident about having a relationship and family in the future.

One female participant (Wendy) was in a long-term relationship with the same partner before and after her accident. The other female participant (Beth) was in her twenties and she was more worried about losing friendships and establishing new ones than in finding a partner:

I: "Are you able to make some new friends? Do you feel up for that?"

Beth: "Well new friends are only the people I meet from here, or from the disability club, or art club I go to on Mondays, with other disabilities but because they have got disabilities it means that they have got a few holdbacks on their life and be able to go out and go to places."

I: "And are there friends around which you feel you can relate to or with whom you have something in common with?"

Beth: "Not as much as it was really".

Beth: "I took a computer course and I got quite irritated by it 'cause it was just me and a lot of boys, on that course lots of boys were doing it, and all they did was porn, porn, porn, for goodness' sake. It was just so irritating so I did not find out the internet or how to work the computer, because I thought that would be quite interesting, 'cause that was how I felt, the world is moving on these days."

Nearly all participants reported that their difficulties had strengthened their relationship with their families such as parents, brothers and sisters. They explained that after the brain injury they felt unconditionally accepted and valued by their families for the person they are. This positively affected their self-esteem and self-confidence:

I: "What about your family?"

Chris: "They are really supportive with me. As such and they are like because most, all of my family and the family I have got in my town understand what has happened to me. And my mum, she is now my support worker, Yeh, because she says, 'write stuff down' and she always helps me a lot."

I: "So she has been really supportive?"

Chris: "Yeah."

I: "Any other members in your family that are supportive?"

Chris: "Well my brothers, my sisters. I have got a sister, that she is really helpful as well. Yeh, they are all supportive. Really supportive."

However, they also reported that their inabilities influenced the intensity of the family relationships, which meant that family members and parents in particular, expressed more worries about the participants' well-being and that these worrying thoughts affected the participants' independence. These findings are consistent with those of Thornhill et al. (2000) and Colantonio et al. (1998) who stated that brain injury survivors reported an increased dependency on their families at a time when they are trying to assert their independence and autonomy:

Beth: "They worry more if I am going anywhere."

I: "Why is that you think? Why do they worry more?"

Beth: "Cause they just think she will have a fit. They think that when I am on the bus on my own that I will have a fit and that people around me not necessarily know that this is an epileptic fit, so what I do is this or the other, being overactive and things like that. They will just think, what is that lady doing there? Oh my god is she dead?"

I: "So your parents worry quite a bit, so how is that for you when you want to go out and about?"

Beth: "Well the most interesting place I get to get out now is to walk up to the shop up the road. Go to the bakers to buy a sandwich, which is why I think my life is kind of enclosed and really crap because nothing happens."

In addition, some of the participants explained that parenthood itself and cultural background also contributed to the level of independence the participant had in day-to-day life. Although two White-British participants had to move back to their family homes because of the inabilities they experienced after the brain injury, they moved out and started to live on their own as soon as this was possible. It was also noticed that the participants living on their own were 25-years old and older, which in our culture is seen as an age in which people are independent from their parents and start their own families. These findings are consistent with Erikson's idea that people who are in their mid-twenties strive for autonomy and independence (Erikson, 1959):

I: "How do you think your parents will respond when you tell them that you would like to live on your own?"

Ben: "They will be worried. I think worried definitely. They, especially around this time, I think I need to be a bit more, I do not know."

I: "Why do you think they would be worried?"

Ben: "Just being part of a family. Are you a parent?"

I: "No."

Ben: "I think that is what parents do and it is also an Asian cultural thing. Is not it?"

The participants with an Asian or Latin-American background indicated that they might want to live on their own but that their cultural values and norms would make it very difficult for them to move out of their parental home, as living independently on their own would look ungrateful and disrespectful to their families. They, however, also indicated that they were aware of their difficulties and the support they needed:

Ben: "No, I have enough support, 'cause I want to move out yeah. Some time I want to move out."

I: "Move out from your parents' house?"

Ben: "Something like that. It is a cultural thing so it might be a bit difficult, so I have been silent about it. But that is in time. I need to do a bit more before I do that. I just want to try. I need a job and I need help. Yeah, I need help to be independent."

Interestingly only two participants mentioned social media, such as Facebook, as a way to establish and maintain social relationships. One participant mentioned that Facebook was not helpful to maintain social relationships as friends did not respond to any of her messages because of her brain injury-related disabilities:

Wendy: "It must be difficult you know, knowing that your friend is not your friend and is another person and sometimes it is hard for people. I do not know, I can only think how hard, it must be hard seeing your friend totally different to what they are, not being able to cope. I do not know. But now I am very much happy about it, cause now when I see all of their Facebook updates everything is just drama, you know and life is about enjoyment, not fighting, getting drunk, taking drugs, falling over, hurting yourself. You are supposed to enjoy life the way it is."

I: "So do you have contact with them through Facebook?"

Wendy: "I do not speak to them. I try to speak to them on Facebook but I do not get responses, so I just speak to them in the street when I see them."

However, another participant reported that Facebook was the way to socialise and meet new people, as others could not see or were not aware of the participant's disabilities.

3.2. Theme two: Inclusion and exclusion

All participants described that one of their main goals or purposes in life was related to education or employment, which is consistent with findings in the study of Mealings and Douglas (2010). However, they reported that it was difficult for them to fulfil these aims due to the difficulties they experienced. The participants also reported that their memory difficulties, physical health problems, communication

difficulties and changes in behaviour and personality influenced their ability to go back to school or work. These findings are consistent with those in a study by Ylvisaker et al. (2001) in which they stated that cognitive, communication and behavioural changes have the greatest impact on a person's functioning in an academic environment.

The participants described that they stopped their education or work after others had said to them that they could not continue their studies or work due to the difficulties they experienced. In addition, they also explained that they received either very limited or no support at all to continue with their education or work. They described that these experiences triggered feelings of having very limited control to change the situation they were in and that this was making them feel frustrated and low in mood. The participants also described that with the loss of education or employment, a significant part of their meaning and purpose in life was taken away, which consequently led to feelings of low mood. This is consistent with findings in a study carried out by Mealings and Douglas (2010) in which participants described how school participation helped to shape their everyday role and direction in life. School is seen as a place where one develops a sense of who one is and what one may want to do in the future.

The participants explained that their inability to go back to work or to continue their education also made them feel excluded from society. They described that this influenced their self-esteem as they felt they were not good enough to participate in education and to contribute their skills and abilities to the workplace. It also affected their self-confidence as they were not sure what had remained of their skills and abilities after the brain injury and they wondered what sort of job they could do or to which level of education they could return. Research from Mealings and Douglas (2010) has shown that adolescents experience emotional changes such as anxiety, depression and reduced confidence on their return or while attempting to return to formal education following a TBI.

The participants described that they felt frustrated, low and lost when they thought about the situation they were in and the limited support they received with finding a

suitable job or course. They indicated that their family relationships and their love for their families gave them meaning in life and a sense of belonging:

Beth: "I just feel like a broken leaf, there is not much left of me. And it is quite depressing really, cause you sort of, when you think of, how much you have got left, you know yeah, I have not got much chance of getting a job in this economy. And my head is gonna be, constantly from now on shattered and the most interesting thing on the tele today is this funny thing that happened on Jeremy Kyle this morning, and stuff like that and you sit and think about how depressing the world is at the moment."

I: "Do you feel a bit empty?"

Beth: "Yeah, so you think what is so great in you and then you think hmmm am I supposed to have any, it is really horrible but then you sort of think, but I love my parents and I love my brother."

All participants reported that they were very eager to be in paid employment and four of them had started voluntary work. Those who had commenced voluntary work had organised it themselves and stated that it gave them a plan and purpose for the future. The participants also described that it positively affected their self-esteem and self-confidence as they were valued for their skills and abilities and started to understand of what they were capable.

In addition, these participants reported that doing the voluntary work helped them to think about paid work possibilities in the near future and to feel more included in society, which helped them to alleviate some of the feelings of low mood. These findings are consistent with the idea that return to work is one of the goals identified by people with a TBI as it provides them with a sense of purpose, an identity, independence and social inclusion (McCrimmon & Oddy, 2006). The participants also described that doing voluntary work might help them to gain the skills and, if needed, the qualifications to find a paid job in the future.

Wesley: "I have done my GCSEs but I was in college studying to be an electrician. I passed my level one and while I was doing my level two I had my accident."

I: "Alright and how many levels are there?"

Wesley: *"Three."*

I: *"There are three levels. So you were already half way. So did you try to go back to college?"*

Wesley: *"No because of, obviously my left hand now, and the job, being an electrician you constantly need to have two hands. And I can't really do that. I am thinking what other things I could do. So I have been thinking about youth work or something."*

I: *"Alright and is somebody supporting you with looking for alternatives."*

Wesley: *"Yeh, I have done it. I have started my voluntary work in my youth club."*

I: *"You have already started that?"*

Wesley: *"Yeh, I have started, I have done, I have been there once. But I am going there again on Wednesday."*

I: *"Ok and how is that?"*

Wesley: *"That is, when I went there first it was alright."*

I: *"So youth work in a youth club. What sort of things do you do?"*

Wesley: *"I support the staff and stay with the child..., kids, children like that. Like table tennis and pool and it's working with computers, help cooking. Stuff like that."*

The young people who were not in education or in voluntary employment reported that their leisure activities were very important to them, as this gave them a routine and purpose for the day and hopes for the future, which positively affected their mood:

Asa: *"I mean my friends from school, I see them now and again. After the brain injury they got a job, I could not get one. My girl and my mates work. Now I am busy, busy with my music. I am making this label, singing, going to concerts and stuff like that. I hope to start recording my own music."*

I: *"Do you make the music on your own or do you play in a band?"*

Asa: *"I am on my own, I make my own music. I am doing it from the age of 12/13. I have met some of the people of HMG and people such as JCK."*

3.3. Theme three: Dealing with the impact of the consequences of the brain injury

With the exception of Asa, all of the participants indicated that they made use of behavioural and cognitive strategies to manage their psychological well-being, to deal with their social, physical and cognitive changes and to make plans for the future. However, most participants stated that they first needed to be aware of these changes, before they could accept support and make effective use of any proposed strategies to manage daily life and to live it as independently as possible. However, it was noticed that two participants, who not only were aware of the changes following the brain injury but who also experienced severe levels of low mood, really struggled to come up with strategies that were helpful to them.

More than half of the participants reported that doing activities, ideally in a structured manner or as part of a routine, helped them to develop a sense of self-reliance, to manage feelings of low mood, distracted them from physical pain and discomfort and gave them a purpose for the day. Although they indicated that at times it was hard to carry out these activities, especially when they did not feel up to it, most participants emphasised that motivation and determination were needed to change and make the best of the situation:

Chris: "On Mondays I am going to football with some of my friends and I go to college as well. On Tuesday I have got college as well."

I: "You go to college?"

Chris: "Yeh, yeh, On Tuesday I have got college as well. On Wednesday I have got college as well, on Thursday I have got gym and on Friday I come here. On Saturday I'll do football again and on Sunday I do not do anything. Yeh, that is my day off."

I: "So you have got a bit of a routine?"

Chris: "Yeh, Yeh"

I: "How do you find that?"

Chris: "I find that, like good."

I: "If there is somebody with a brain injury and you had to give them one or two tips, what would you say to them to pull themselves through the day?"

Chris: "Hm I would say the things you thought were difficult, you just have to go through it. Hm yeh, you have to go through it, pull through it and make sure you do it."

And you know do not always rely on other people to do stuff for you, make sure you do it."

Those participants whose physical mobility was severely impaired after the brain injury showed lots of motivation and determination to walk again. It was noticed that the young people associated their physical mobility with regaining their independence to go out and about, to look 'normal' and to live a life as normal as possible. At the time of this study all participants walked without an aid:

I: "You are not in a wheelchair at the moment so how did you manage to get out of that wheelchair?"

Wendy: "It took me nine months. When I moved into that flat I thought that is it. I do not want the wheelchair. Hm, it was all on one level. I could walk to the shops by myself but that then also caused problems with hh, having my independence back. Cause I did not feel safe walking around on the street unless I was talking to someone and unless someone was physically with me. I was on the phone all the time."

I: "Ok, so did you need a bit of a distraction?"

Wendy: "Yeah, I did not feel confident with going out. I am not like that now. I am not on the phone now, but it has been a long struggle through the recovery."

Both women participants described that they binged on food to manage their emotions, particularly sadness and anger:

Beth: "I try my best to keep it levelled but sometimes when my mum makes a massive pudding, I think, oh I am in a bad mood and I just destroy that."

I: "Is it a bit like comfort eating?"

Beth: "It is comfort eating to quite a level but the rest of it is just I got to work on that I will not comfort eat, as it will not solve the trouble. If I eat, I will still have the problems, the epilepsy."

I: "So is the eating, does it come when you feel low, when you feel like I am not sure about today?"

Beth: "Cause I try to stick to my diet really high, really behaving if I am in a good mood. Because I sort of think, yeah I do not need that cause that does not solve the

trouble. So what I am actually going to do and then do something else. But if I am feeling rough, then it is sod it, Ben & Jerry's."

Four participants, both women and two men, indicated that they made use of a range of cognitive strategies such as thought challenging, negative thought replacement, normalisation, generating positive thoughts about the future and making use of the knowledge that you are not the only one who suffered a brain injury, to help them manage their psychological well-being and live day-to-day life:

Wendy: "You always gonna have a bad day, everyone always has a bad day. Hm you might be forgetful one day but you might not be the next. You know, just take every day as it comes. Just try to wake up and be positive when you get up in the morning. 'Cause sometimes just getting up in the morning and feeling positive that gets you through. 'Cause otherwise it is one long odd day, and that is just one day."

Both women and two male participants who sustained their brain injury at least four years ago, talked about accepting the consequences of the brain injury in order to move on with their lives. These findings confirm those in the literature which suggest that brain injury survivors need to learn to cope with their remaining difficulties two years post-injury instead of hoping that there might be an improvement or disappearance of brain injury-related consequences (Frosch et al., 1997). Each of these four participants was in the process of accepting some consequences of the brain injury but struggling with other consequences. Some participants indicated that they just needed to get on with life and did not want to think too much about the impact of the brain injury on their lives as it could negatively influence their motivation to live daily life, their mood, self-esteem and self-confidence:

I: "As you said things have changed so much after the brain injury, so how do you cope, how do you manage?"

William: "Well it is like, like I have said at the start and like I have said to my family, there is no pause or restart button in life. You just have to keep going and hm, it is not like I am the only one that this is happened to and I, I just think, like to be honest, I do not really know but it is just got to be done I think."

3.4. Theme four: Support

Although the participants reported that it was mainly their families who were very supportive towards them, they also stated that they were offered, and accepted, support from a range of services (e.g. statutory and voluntary sector) to help them manage the physical, psychological and social changes they experienced and to gain maximum independence. The participants described that the level of support of their families influenced their self-esteem and emotional well-being, as it made them realise how much they were depending on their families to help them manage their inabilities:

I: "Who is supporting you through all of this?"

Ben: "Family, without my family I would be dead. I can't imagine how much my family has done it is unbelievable. It is not something I expected in life. When I think about it sometimes I would like to cry. Thinking about it, I do not wish it upon anyone. Anyone should be treated nicely. I do not think it is a nice feeling and I try not to be sad about. I have lost a lot of power, not power as in power, but more power like control. Individual like your own person."

Both women and the male participants who were in their mid-twenties supported other people who had a brain injury or members of their close family. This gave them a sense of purpose and meaningfulness and positively affected their self-esteem and self-confidence:

William: "I have been talking to my brother and sister and I have been giving them advice and so. And I said to my sister I am just telling you because I do not want you to feel the way I am feeling when you are two years older. I am seeing the same thing happening to my brother and I just...and I realised that it is me who has to do things to help him out you know. So I took him out clothing shopping last weekend and we are going to see the new James Bond film."

3.4.1. Subtheme: Inpatient rehabilitation

Seven of the eight participants received rehabilitation after they were discharged from hospital, which differs from findings in the literature that suggest that only 5% of young people with TBI receive rehabilitation (Beecham et al., 2009). Wendy was not offered any inpatient rehabilitation following her discharge from hospital as her brain injury was diagnosed two years post-injury.

Of the seven participants in this study, six went to an inpatient rehabilitation centre and Asa had rehabilitation at home. All seven participants described that the treatment in the rehabilitation centre and at home focused on symptoms and deficits to maximise their level of independence and was facilitated by qualified health professionals, which is consistent with findings of Chamberlain (2006). They also indicated that the rehabilitation improved their quality of life and facilitated their participation in social settings, which is in line with the overall aim of specialist rehabilitation units in the UK (Beecham et al., 2009).

Participants who had significant physical difficulties indicated that the rehabilitation had given them back their independence as they had relearned to carry out daily living skills, to walk again and to go out and about in the community. Those participants who suffered more from cognitive difficulties, such as forgetting information, mentioned that the rehabilitation focused on learning strategies to manage memory difficulties. Two participants also mentioned that rehabilitation provided them with some sort of psychological support (e.g. counselling and relaxation techniques).

With the exception of Asa, all other six participants indicated that staff at the rehabilitation centre used a client-centred approach, as they felt supported that their needs were met. Participants described that they had gained confidence in their own skills and abilities, were able to make effective use of cognitive strategies and had reached a maximum level of independence before being discharged home:

Wesley: "I could not do shopping on my own. But now it is just normal. If it was not for the rehabilitation centre. Yeh I could show my mum that I could go out, go to the shop, buy stuff, go home, all of that. Go from the rehabilitation centre on the week,

hm Friday get how. Obviously stay at home for the weekend and go back to the rehabilitation centre in the evening on Sunday. If it were not for all of that, I might have been at home, chucked up like a prisoner. My mum would not trust me to be able to go out on my own and do stuff."

3.4.2. Subtheme: Community services

With the exception of Beth, who was cared for by her mother, all other participants were supported by a support worker. This finding is consistent with those of Parish and Oddy (2007) who state that several years post-injury, care of the client has often passed to the family or to low intensity, low cost services primarily involving support staff with no professional qualifications (Parish & Oddy, 2007).

The participants indicated that the support worker was an important part of their social relationships as the support worker supported the participants to undertake social activities in the community and to maintain and improve their physical well-being. The participants mentioned that this support positively influenced their self-confidence to go out and about in the community independently or with a peer and to come across as someone who leads a 'normal' life. The participants stated that improving their physical well-being would help them to hide any physical and mobility inabilities so that they might encounter less exclusion from social groups and society when they were out and about:

Wesley: "This guy called Maverick came and I really liked him, because you know, he was really talkative, making jokes hm and he was telling me oh let's go out, let's go to the National Gallery and do something you know. Stuff like that and I like that."

I: "What about doing activities with him has that changed things for you?"

Wesley: "Yeh, I think so. I feel I have become more talkative. But you know on the way here, when he comes with me, I talk more and after he goes I still talk more."

After being diagnosed with having a brain injury, Wendy was offered mainly psychological support from a community disabilities team, as it was identified that she needed support to deal with the impact of the brain injury and to maintain her general well-being. This support was provided by an allied health professional who applied substantial knowledge on psychological aspects of impairment and functioning following TBI to the environment in which Wendy lived and participated.

Parish and Oddy (2007) stated that such professional support might lead to an improvement of the brain injury survivor's mood, to an increase in their social support networks and to an improvement in their social relationships and meaningful vocational choices. Wendy stated that the psychological support helped her to manage her mood and in particular her intense feelings of anxiety:

I: "What is happening when you have these panic attacks?"

Wendy: "I feel fluttering in my chest but then my head does not tell me right, it is just adrenaline. You do not know what is happening. It is just adrenaline pumping into your heart. Yes, your hands are gonna go now, you will be short of breath. One my brain does not tell me that I should breathe and that is gonna pass. My head tell me to hold my breath so that I can feel my heart and it is just a vicious cycle. Usually I can control them."

Four participants, who were in their mid-twenties or older, indicated that they had changed from support worker to another one recently, as they felt that the quality of support was not good enough. These findings are consistent with those from Beecham et al. (2009) in which 39% of brain injury survivors mentioned that their needs were not met in the community. Three of these four participants lived on their own or with a partner, and their support worker also had to support them to complete daily living tasks to maintain their level of independence.

It was noticed that these four participants were very much aware of their inabilities and the support they needed. They showed confidence and assertiveness by asking for appropriate support and they mentioned that they had learned to stick up for themselves after the brain injury. These participants indicated that living independently positively affected their self-esteem and self-confidence because they could identify themselves as someone who manages to deal with their inabilities, makes effective use of support and comes across as someone who lives a life that most of their peers would do. The participants reported that there are positives as well as negatives associated with receiving professional support. They explained that the right support was important to them as this would maintain and potentially extend their independence by relying less on family support and being supported to find a meaningful aim and purpose in life such as a job or course. They however also

explained that receiving support which did not fit their needs was very frustrating and distressing as they felt that it affected their independence negatively.

I: "We were talking about your support worker, like the one from Suborbiton."

Wendy: "They are more a hinderage than a help. It's like, every week them's were late and I am very much like a child eh and I just stared and looking out of the bedroom window waiting for someone to come like a little sad puppy. Or like a child for their mummy to come home. It is very frustrating as I call my mum, 'mum they are not here.' You know and then it turns out, they just leave me like: 'You can go home from town on your own, can you?' Hm, so and I was too nice to say it to people then, but now I have realised you know what, I am paying for your support. You should be supporting me. I was very easy going then and I still am to an extent but it did not work with them. So in November I have finished working with Suborbiton. I then sort of trailed the support from Hans and it took off."

All participants indicated that coming to Headway served different purposes for them. Having an aim for the day, being engaged in meaningful and enjoyable activities, socialising and receiving and giving peer support were the most important ones:

I: "Does it help you to come to Headway?"

Jacob: "Yeah, I am always glad that it is Friday."

I: "Glad that it is Friday. So when you wake up on a Friday you think?"

Jacob: "I woke up this morning and say yes it is Friday and jump in the shower and then go to Headway."

I: "What do you like about coming to Headway?"

Jacob: "Cooking, the music, there are lots of activities for me to do. Built the shed. Can you see? Over there, must be that blue one. The shed."

I: "Yes, did you make it?"

Jacob: "Yes together with Tim. The blue thing."

4. Discussion

4.1. Summary

In this study, all the young people indicated that the brain injury itself had led to a variety of changes in cognition, communication and physical health. Many of the participants experienced memory problems and speech difficulties and these findings are consistent with those of several studies (Leith et al., 2004; Ylvisaker & Feeney, 2007; Anderson et al., 2005). With the exception Asa, who sustained his injury when he was a child, all other participants indicated that they had noticed behavioural and personality changes after their injury and these findings are consistent with those of Leith et al. (2004).

The participants indicated that the brain injury-related changes had led to a range of disabilities in different areas of their daily life, which affected their sense of self, their relationships with family and friends and their educational and occupational opportunities. The time since the participants had their injury ranged from two to ten years and it is known that young people experience a significant level of disability and continuing problems with activities in daily life, one, five and seven years post-injury (Evans et al., 2003; Whitnall et al., 2006; Thornhill et al., 2000). All the young people in this study also indicated that they had encountered prejudices from society and were treated very negatively within educational, vocational and social contexts as there was not an obvious cause or visible cue that provided an explanation for their difficulties. The two female participants even described how they were denied support to reintegrate back into educational programmes and vocational programmes, which is consistent with the findings of Harder (2009).

The young people reported that their difficulties had contributed to an altered sense of identity, such as seeing themselves as disabled and mentally ill. They stated that the way they viewed themselves was related to the views and beliefs they had about people with difficulties, which were influenced by their cultural background and gender roles. White-British male participants indicated that they had to be 'strong' and that having a disability is something to be ashamed of while the Asian men stated that having a disability means that you cannot take care of your family, which

is one of the most important male responsibilities. The female participants located their sense of identity more in the context of family relationships and they described themselves as a dependent person instead of an independent person; independence is important in Western culture. When the participants reflected upon their altered sense of identity, feelings of grief for what has been lost and feelings of low mood, anger and frustration were prominent. To the researcher's knowledge there are no other studies with similar findings.

The participants described how their family relationships had become more intense as family members, and parents in particular, supported them in managing their disabilities at home and in the community, which affected their independence. Those participants from a White-British background who were in their mid-twenties and thirties strived for and had gained more independence from their family, such as living on their own, compared to those who were younger and from an Asian or Latin-American background. Being dependent on their family to live their daily life negatively affected the participants' self-esteem and led to feelings of low mood. In addition the two female participants also reported that they experienced feelings of guilt when they reflected on how the brain injury affected their family and partner's autonomy and independence. To the researcher's knowledge there are no other studies with similar findings.

Although the participants' relationship with family members got closer, this was in contrast to the relationships with their friends. The participants felt that the stigma and prejudices that come with having a disability had led to a loss of their friendships and negatively affected their self-esteem, their self-confidence to meet people and to interact socially. These findings are consistent with those of Weddell et al. (1980) who reported that two years post-injury most close friendships were found to be diminished. The White-British male participants also expressed concerns about finding a partner in contrast to the Asian male participants who felt confident about having an intimate relationship in the near future as their families will arrange a marriage for them. The increased dependence of the participants on family and the loss of peers contributed substantially to feelings of loneliness and isolation.

These feelings were more prominent when participants were not able to continue their job or education because of their disabilities. They described that with the loss of employment or education a significant part of their identity, meaning and purpose in life was taken away. It also negatively affected the participants' self-esteem and self-confidence as they felt not good enough to participate and contribute to society, which consequently made them feel excluded by society. These findings are in line with the idea that self-esteem develops in the context of meaningful activities such as voluntary work and employment (Lefebvre et al., 2005).

The way that the participants perceived their difficulties appeared to be related to their adjustment, and the stress-appraisal-coping model of Godfrey et al. (1996) seemed to be a helpful way of understanding the relationship between difficulties and adjustment. According to this model, the degree of the participants' adjustment following the TBI depended on their appraisal of the significance of their disability, their ability to manage their difficulties and their perception of the adequacy and availability of social support (Godfrey et al., 1996). The young people in this study all showed different rates and degree of adjustment which is consistent with the idea that adaptation to the effects of TBI is dynamic, complex and highly specific to the individual's circumstances (Godfrey et al., 1996).

With the exception of Asa, all participants indicated that they first needed to be aware that the demands of work, education and social relationships may now exceed their level of competence due to their difficulties following their brain injury, which consequently would mean that they are unable to perform their daily activities and tasks as competently as they could before the injury. Only the participants who sustained their brain injury at least four years ago indicated that they had to be aware and accept their disabilities in order to move on with their lives. This finding confirms those in the literature which suggest that brain injury survivors need to learn to cope with their difficulties two years post-injury as around this time any recovery from TBI-related changes would have happened (Frosch et al., 1997). It also suggests that awareness, acceptance and realism are important factors in the process of adjustment, which is in line with the idea of the stress-appraisal-coping model of adjustment to TBI and consistent with findings of Morris et al. (2005) and Godfrey (1996).

With the exception of Asa, the participants made use of a range of behavioural and cognitive strategies to manage their difficulties and the psychosocial consequences of these, although those participants who experienced severe levels of low mood struggled to make effective use of any strategies. This finding is in line with the idea that people who experience emotional distress feel that they do not have the skills and abilities to manage daily life (Godfrey et al., 1996). It was noticed that the female participants made use of binge eating to manage feelings of low mood and frustration and to deal with any negative feelings about themselves. However, the binge eating negatively affected the participants' self-image and feelings of self-worth.

Attending Headway enabled the young people to meet new people and peers who were in a similar situation, which contributed to higher levels of self-esteem and self-confidence. It also contributed to building a new sense of self as the participants felt part of a social group, which positively influenced their identity because they felt they were valued and accepted as people. This sense of belonging is an important part in the process of adjustment and for the development of identity according to Erikson (Erikson, 1959; Godfrey et al., 1996). Four of the eight participants had started voluntary work and they hoped that this would assist their return to paid employment. They indicated that work provided them with a sense of purpose, an identity, independence and social inclusion, which is consistent with the findings in a study by McCrimmon and Oddy (2006).

Social support is also associated with better adjustment following TBI and all participants stated that their families had been and continued to be a great source of support to them, psychologically and practically (Godfrey et al., 1996). They reported that the support of family members helped them to manage their emotional well-being, to socialise and to have access to the community, although some participants also felt that their family support restricted them in having community access, which consequently affected their level of independence and their emotional well-being.

All participants attended Headway regularly and they explained that the support from this service was invaluable to them as it gave them a purpose for the day, and

opportunity to establish and maintain social relationships with other young brain injury survivors, which alleviated their feelings of loneliness and isolation. Those participants who were in their mid-twenties and older supported other brain injury survivors which contributed to a more positive sense of self and higher self-esteem, as they felt that their skills and abilities were valued. These findings are consistent with those from Lefebvre et al. (2005), who stated that self-esteem develops in the context of meaningful activities. These findings are also in line with the idea that meaningful recognition of a person's achievement from others at this age would contribute to a strong and healthy identity (Erikson, 1959).

The participants in this study indicated that they needed support to manage daily life but they also reported that the support they had was sufficient. Six of the eight participants had received inpatient rehabilitation within the first two years post-injury and they reported that the rehabilitation mainly focused on their physical health and their cognition, which contributed to an increased level of independence and self-esteem. Two years post-injury, seven of the eight young people received community support, mainly from a support worker who supported them in maintaining their level of independence, in engaging in leisure activities and helped them access the community. These findings are in line with the idea that the work that is undertaken in rehabilitative units may only materialise when there is appropriate community support (William & Evans, 2003). The participants, in particular those who were in their mid-twenties, stated that the quality of community support varied and indicated that good support positively influenced their well-being, their social competence and their independence while inappropriate support led to dependence and feelings of distress and low mood. These findings are consistent with those in a study by Mealings and Douglas (2010) and are also in line with the idea that independence for this age group is very important (Erikson, 1959).

During the interview and analysis, it was noted that Asa was consistently different from the others. Asa sustained his brain injury ten years ago when he was a seven-year-old child while the other participants sustained their injury when they were adolescents or young adults. Asa seemed to find it difficult to reflect on any brain injury-related personality, behavioural and social changes and it might be that the time since the injury occurred and the fact that Asa still was a child when he

sustained his brain injury contributed to this. He, however, described very clearly the memory and attention and concentration difficulties he currently experienced and this finding is consistent with that of Klonoff et al., (1993) in which young adults reported impairments of memory and concentration, 23 years post-injury.

4.2. Contributions to the existing literature

Health professionals have long advocated the need to gain the perspective of people living with a brain injury, so that the brain injury survivor's experience and expertise can be shared with other survivors and professionals (Prigatano, 2000).

However, health care institutions and professionals have often ignored the perspectives of individuals on their health and health care (Lorenz, 2010). People whose health status places them in the most vulnerable or deprived sectors of our society, may find it difficult to engage in research and policy making as service users' contributions often have been undermined and have not been taken seriously by service providers (Rose, 2001). In order to engage brain injury survivors in reflecting on and advocating for their perspectives on health, illness and health care, Lorenz (2010) made use of a visual approach called PhotoVoice (Lorenz, 2010). PhotoVoice is a research process that is carried out as a group activity in which participants: 1) take photographs and discuss them in order to understand positive and negative aspects of a situation, community, problem or illness; and 2) carry out outreach activities for education or advocacy purposes for example holding public exhibits, posting participant photographs and narratives on the internet and presenting at conferences. With this method researchers and participants co-create knowledge and build alliances in the planning, implementation and dissemination of the research process (Lorenz, 2010).

PhotoVoice generates visual metaphors of lived experience which may be particularly appropriate for use by brain injury survivors, given the cognitive, communication and self-esteem challenges they face post-injury. This visual approach provides brain injury survivors with the opportunity to see themselves and for them to be seen as the expert regarding their experiences of living with a brain injury. This might give health professionals such as clinical psychologists a greater awareness of and empathy with survivors' struggles, which might in turn facilitate more person-centred care. This visual method also contributes to a dialogue, as it

creates a bridge between a life world of the brain-injured person and the larger society and fosters new knowledge, which is particularly successful in giving brain injury survivors an experience of having a say in research and policy contexts (Lorenz, 2010). PhotoVoice also makes visible the survivors' brain injury and their efforts to deal with its daily difficulties, which can contribute to discovering a new purpose in life (Lorenz, 2010).

In the UK only three qualitative studies have explored the experiences of young people who sustained a brain injury more than two years ago. Two of these studies were conducted in the 1980s and emphasised social adjustment (Oddy et al., 1985, 1975) and the third study looked specifically at psychosocial adjustment (Shotton et al., 2007). The present exploratory study looked at the experiences of young people who acquired their TBI more than two years ago and contributes to the existing literature in several ways.

The young people in this study indicated that two years after sustaining their brain injury they continued to experience significant difficulties in their physical health, communication skills, cognition, behaviour and personality. They described how these difficulties led to a range of disabilities and consequently had an impact on their level of independence, self-esteem, self-confidence, self-identity, emotional well-being, and their ability to go to work or school, to participate in society and to maintain and establish social relationships. These findings are consistent with studies which look at the long-term consequences for adults who sustained a brain injury and suggest that the difficulties young people experience will persist into adulthood (Mealings & Douglas, 2010; Lorenz, 2010).

In this study the participants clearly indicated that their disabilities contributed to a changed sense of their identity and negatively influenced their self-esteem and self-confidence. They described how they believe that their disabilities are associated with stigmatised conditions, such as having a mental illness or being learning disabled.

It is not uncommon for people to associate the diversity of personality and behavioural and cognitive difficulties resulting from the brain injury with a mental

illness or a learning disability, as the brain injured, mentally ill or learning disabled person differs from other members of the community. These people might act irrationally, do not engage with others, respond slowly, have a reduced ability to understand, or show rapid changes in temper (Linden & Boylan, 2010; Linden & Crothers, 2006).

One of the misconceptions about mental illness in the UK and the USA is that people who are mentally unwell should be feared and therefore kept out of most communities (Corrigan & Watson, 2002). The behavioural impact that results from this misconception is social avoidance and exclusion as society strives not to interact with people with mental difficulties (Corrigan & Watson, 2002).

People with difficulties resulting from a brain injury might internalise these misconceptions and believe that they are less valued because of their difficulties, which consequently affects their self-esteem and self-confidence in their future (Corrigan & Watson, 2002). They may also withdraw from social situations which could lead to feelings of isolation (Linden & Crothers, 2006). Although the participants in this study were from different ethnic backgrounds, they all had grown up in the UK and their statements seemed to indicate that they had internalised these Western misconceptions about having a mental illness or the characteristics of those with learning difficulties. The participants stated that because of how they communicated and interacted socially it was understandable that they were seen by their peers and society as mentally ill or learning disabled and consequently were excluded.

Exclusion, however, has a great impact on the development of social interactions and the reintegration of survivors of brain injury into their communities, which are so important for adolescents and young adults (Linden & Boylan, 2010). Exclusion refers to the process of actively rejecting a member of a group and can refer to exclusion from a peer group to the wider social world (Bunning & Horton, 2007).

The participants in this study clearly described how their peers, teachers, employers and members of the public responded to their disabilities, which made them feel excluded and negatively influenced their self-esteem and self-confidence. It also

affected their social development, such as establishing and maintaining relationships, as they felt less confident in approaching other people in social situations. These findings are consistent with those from a study by Sharp et al. (2006) in which students with a brain injury were singled out due to a lack of understanding from their peers regarding their disabilities and the support they needed.

Linden and Boylan (2010) state that when individuals are denied the right to inclusion this will damage the social bonds that tie together our society; therefore, it is important to strive for an inclusive society. According to Linden and Boylan (2010) being included refers to having relationships with others, both on a personal and societal level.

Linden and Boylan (2010) felt that it was important to look into public understanding and misconceptions about brain injury survivors in order to understand why members of the public exclude these survivors. Therefore, 16 members of the general public in Ireland were asked to describe someone with a brain injury. The responses of these participants contained mainly negative language such as: 'can't think for themselves', 'can't function properly', 'not normal', 'simple' and 'mentally disabled'. The majority of the participants mentioned that following a brain injury there would be some form of physical impairment that would identify a brain injury survivor and they hardly mentioned any emotional, behavioural and cognitive problems. The participants stated that they got their ideas and views about brain injury survivors mainly from the media and a little bit through education and from brain injury survivors' stories (Linden & Boylan, 2010).

Media campaigns in which survivors of road traffic accidents are portrayed as wheelchair bound, in need of constant care and a burden to family members, provide unrealistic ideas and views about the lives of brain injury survivors, especially those without visible physical difficulties (Linden & Boylan, 2010). They may also lead to a lack of knowledge in relation to behavioural, cognitive and emotional difficulties following a brain injury and any issues around the recovery from these difficulties (Linden & Boylan, 2010). Swift and Wilson (2001) described how this lack of

knowledge of the general public could have a significant impact on how brain injury survivors are treated by society.

The visibility of physical problems following a brain injury may lead members of the public to distance themselves from someone they perceive as disabled. Yet, it is also possible that those brain injury survivors who are physically disabled may be given greater consideration than those whose difficulties are not physical and apparent (Linden & Boylan, 2010). The participants in the current study did not have visible physical difficulties but experienced speech difficulties and problems with balance, which often resulted in being treated very negatively by members of the public. They described that they continued to experience social exclusion and a lack of understanding about their difficulties, which is consistent with findings in studies by Morris et al. (2005) and Harder (2009).

The participants in this study also noted that a lack of understanding of their difficulties such as memory problems, communication difficulties, tiredness, behavioural and personality changes, which all became apparent during social interactions with others, negatively affected their integration at school, in the workplace and in society. The few studies that have addressed work and school re-entry suggest that these difficulties have the greatest impact within the academic and work environment and appear to be predictors of success at school or at work (Isaki & Turkstra, 2000; Mealings & Douglas, 2010). Success meant that students had identified achievable educational goals, had good relationships with a range of people at school and enjoyed academic and social activities (Mealings & Douglas, 2010).

The participants mentioned that their difficulties negatively affected their skills and abilities to continue their job or participation in school, and contributed to losing either their education or employment. This self-awareness of their deficits is an important aspect in the process of seeking and accepting support and becoming productive in the community again through either taking up education, voluntary work or paid work (Yasuda et al., 2001).

The participants clearly indicated that they had lost an important part of their meaning and purpose in life when they could not return to their previous school or job, which led to feelings of grief and low mood. They indicated that they saw the role of school and employment as a normal part of life after the injury, as a part of developing their identity of who they are and what they want to do with their future and as a place to socialise with their peers, which is consistent with findings in a study from Mealings and Douglas (2010).

The two participants who were both in full-time employment before the brain injury were unable to return post-injury, partly because of the demands of the job, partly because of their disabilities and partly because of the lack of support. Although the importance of workplace accommodation and modification in order for a person to return to work are well acknowledged, the attitude and willingness to provide this varies among employers (Yasuda et al., 2001). One of the participants in the present study was offered medical retirement at the age of 23 by her employer instead of supporting her to maintain a job within the organisation.

The participants in this study mentioned that they felt lonely and isolated and it is known that with the loss of education and employment social isolation results (Turkstra et al., 2008). When this happens there may be negative effects on social development of young people as they need their peer relationships to practice and develop their social skills. When their social performance is poor they are more likely to be rejected by their peers, less likely to make new friends and to participate in social activities (Turkstra et al., 2008). This might lead to substantial feelings of low mood and anxiety for prolonged periods, which negatively influences any form of community integration (Yasuda et al., 2001).

The participants in this study stated that both inpatient rehabilitation and community support had been and were essential for them to manage daily life and to participate in society. They stated that in the inpatient rehabilitation centre the main focus was on improving their physical health and cognition, which had been very important to them. Being physically mobile was associated with an increased level of independence for the young person and a higher level of self-esteem and confidence to participate in society, as they would look 'normal'. This is in line with the idea that

health has become associated with all that is most valued in our society: youth, strength, independence and optimism. If such cultural and moral values regarding health are embedded in various institutional and cultural forms as well as in medical ideology and practice, it is not surprising that the brain-injured person wants to get back to their level of functioning from before the brain injury (Chamberlain, 2005).

Some research has shown that there is very little evidence for the effectiveness of rehabilitation for people more than five years post-injury as natural recovery from a brain injury is often considered to taper off after two years (Frosch et al., 1997). However, it was apparent that the young people in this study reported that their physical mobility continued to improve with the support of their family or support worker.

A UK study in which four participants were given low intensity rehabilitation from a trained support worker under the supervision of an occupational therapist, showed that people with a brain injury can acquire new skills many years after the injury (Parish & Oddy, 2007). The results of this study also suggested that the people who had acquired their brain injuries in childhood were not only regaining lost skills but sometimes developing entirely new ones. It was reported that the acquisition of functional skills not only increased the person's independence but also their self-esteem and self-confidence, which contributed to more interactions with other members in the community (Parish & Oddy, 2007).

The results from the Parish and Oddy's (2007) study suggest that quality rehabilitation would be very beneficial for the participants of this study who lived either independently or with their parents to maintain and acquire skills to live a life as independently as possible. This would not only increase their independence but also their self-esteem, self-confidence and social interactions, which the participants indicated as being important to them but is also important for all young people who are in the developmental phase of adolescence and young adulthood.

However, the participants whose brain injury happened four or more years ago indicated that in order to get the most out of their rehabilitation they first needed to be aware of their difficulties before they could make use of any strategies to manage

daily life, which is consistent with findings from Tant et al. (2002). This finding is also in line with the idea that over time people become more aware of the implications of their injuries for their life goals and social roles (Williams, 2003). Anosognosia or lack of awareness of injury-related difficulties has been documented in people with TBI and it can persist for weeks, months or even years post injury (Oddy et al., 1985; Prigatano & Schacter, 1991). Impaired awareness may have serious consequences for rehabilitation, including decreased participation in treatment (Borgaro et al., 2003). In this study one of the participants mentioned that after being discharged from rehabilitation back home, she slowly became more and more aware of the difficulties she encountered in daily life and that it was essential for her to make use of strategies to live her life as independently as possible. Other participants mentioned that they had learned to make use of strategies while they were in the inpatient rehabilitation service. Specialised brain injury rehabilitation centres have programmes in which the focus is on therapy activities, which aim to increase the brain-injured person's awareness of injury-related impairments. As most participants in this study went to a specialist brain injury rehabilitation centre it might well be that they followed such programmes (Ben-Yishay, 1996).

The participants in this study also mentioned that it was very important to them to make effective use of strategies to maintain their relearned skills and abilities and it is known that the effects of rehabilitation for individuals in the long term rests on adequate development of community-based services (Williams & Evans, 2003).

Several studies have indicated the patchy and uncoordinated nature of service provision for people with a brain injury in the UK and that the community services that are available are felt to be inadequate by most service users (Kneafsey & Gawthorpe, 2003; McMillan, 2003). The findings in this study seem to confirm that the community support that is provided by support workers is not adequate as more than half of the participants changed support worker because they felt that their needs were not met. As nearly all participants had had intensive rehabilitation before being discharged home, it is felt crucial by health care professionals that they are supported to generalise and maintain their skills and abilities back in the community. This support not only gives young brain injury survivors a greater independence but

also positively influences their psychosocial well-being such as reintegration back to work or school and feeling less low, angry and frustrated.

Although the participants indicated that they would like to be supported with returning back to either employment or education, they also stated that they feared that more support might negatively influence their independence. They indicated that they valued the support that was provided to them but felt that more support would make them too dependent on others to live daily life. A few participants described that the support was perceived as helpful when they had a good relationship with the person providing the support, when they had a sense of ownership of the support that was provided and were involved in developing strategies. These findings are consistent with those in a study from Mealings and Douglas (2010) and suggest that young people's perspective and input is needed to provide successful support.

However, for young people to have input into the support they get from their family can be very difficult. The participants in this study stated that their families, and their mothers in particular, had been and continued to be a great source of support to them, but some participants also felt that family support restricted them going out and about, which consequently affected their level of independence. In a study by Wongvatunyu and Porter (2005), mothers of brain injury survivors reported that considering their child's safety by preventing re-injury to the brain was their main concern. The mothers described that they prohibited their brain-injured son or daughter from undertaking any risky activities and that they first would check out places before they would allow the young adult to go there on her or his own. These findings are consistent with the experiences of the participants in this study who lived at home. They described that their mother would accompany them to social gatherings and would check out their friends before they were allowed to go out with them. Although this kind of support is understandable from a mother's point of view it does restrict the young person in establishing their independence and opportunities to socialise.

4.3. Reflection

Due to the brain injury, all participants in this study had cognitive impairments which affected their ability to focus and understand the interview questions. During the

interviews it also became evident that more than half of the participants had communication difficulties. People who have speech difficulties are often not selected as research participants because often researchers believe that the effort required in obtaining interview data will be overwhelming (Paterson & Scott-Findlay, 2002). However, as these people are often excluded from research and there is a need to investigate the experiences of people living with the consequences of a brain injury, it was felt important that all young people with TBI attending Headway and who were willing to share their experiences, were included in this study. Consequently, this meant that during the study several challenges had to be faced.

The first challenge was that the participants' ability to recall events was affected by the nature and extent of their injuries. Because of the memory deficits caused by TBI most participants did not recall events immediately after their injury and their recall of events immediately after discharge from the hospital was often limited. Their statements were derived primarily from what had been told to them by others or from vague memories. This meant that participants could not remember how long they had been in a coma for, which made it difficult for the researcher to get an understanding if participants suffered a brain injury which could be classified as mild, moderate or severe according to the GCS. Although severity of the injury is associated with an intensification of consequences, it is understood that only a modest proportion of a person's disability is accounted for by the initial severity of the brain injury and that this relationship weakens over time (Thornhill et al., 2000; Mealings & Douglas, 2010; Whitnall et al., 2006). It therefore was felt by the researcher that not having this information would not significantly change the outcome of this study. However, the researcher did notice that during the interviews participants focused on present and future events due to their memory difficulties, which gave the researcher a good understanding of how the participants continued to live with the consequences of a brain injury.

Memory is at the heart of the way most people think about personal identity. Klein and Nichols (2012) state that the view of memory is based on the widely held position that long-term memory consists of multiple systems and that it is the episodic component of declarative memory that historically has been the focus of interest for psychologists in studying the relation between self and memory. Episodic

memory has been thought to involve re-experiencing events from one's past, thus providing the person with a content by which he or she is able to construct a personal narrative that is his or her life story.

Possible selves are constructed, maintained and transformed by the stories that we tell and repeat to ourselves, as well as the stories about ourselves that we share with others. Narratives are created by individuals to tell a story about their lives and the nature of their social and personal identities (Heller et al., 2006). Memory difficulties due to TBI can lead to memory blanks or knowledge gaps, such as the inability to remember events before or after the brain injury. Such gaps can make it difficult for an individual to construct a narrative that integrates the past self with the present self, causing confusion and distress (Nochi, 1998).

According to linear theories of identity development such as those of Erikson (1959) and Berzonsky (2004), personal identity is the belief that a person's present self is the same self as the one that he or she experienced in the past and the one he or she will experience in the future and that there is a psychological relation between these selves (Klein & Gangi, 2010; Klein & Nichols, 2012). This might mean for the young people in this study that, due to their memory difficulties, they are missing narratives which are part of the self and that they cannot make a relation between these selves across time.

As in this study verbal interviews were used to gather data, the researcher relied on the participants' ability to tell a story about their lives before and after the brain injury. It, however, was very difficult for the participants to give a detailed and chronological account of their experiences because of their memory difficulties. This made it difficult for the researcher to analyse the stories they told and to understand how the stories connected with everyday life.

Another challenge that was faced in this study, were the expressive and receptive communication difficulties most participants experienced. For the participants this meant that they lacked the words to describe their experiences and to make appropriate use of the nouns and verbs in their responses. In addition, participants showed difficulty with understanding the questions, which then had to be repeated or

rephrased. This meant that it was hard for the researcher to hear and understand the words and sentences the participants pronounced and to get an in-depth response. It was felt that communication techniques such as making use of pictures, drawings or essays during the interview would have facilitated better communication and understanding between researcher and participants. Lorenz (2010) stated that making use of photographs is particularly appropriate for brain injury survivors to communicate to others their lived experiences.

During the interviews it was observed that most participants became tired and distracted. They were either slumping in their chairs or they needed a walk around the interview room. As the interview progressed and particularly after 30 minutes of interviewing, their responses became less focused and more concrete. These observations are consistent with findings from Hibbard et al. (1998) and Patterson and Scott-Findlay (2002). Although the researcher discussed and negotiated with the participants concerning the length and timing of the interview and the breaks, with hindsight it is possible that a follow-up interview would have been helpful to give participants the space to think and expand further on the topics and the time to re-energise themselves.

In qualitative research, broad open-ended questions are recommended to prompt free recall in interviews but in this study it was observed that the participants frequently struggled with such questions (Patterson & Scott-Findlay, 2002). In order for the participants to tell their stories, they needed guidance by asking specific and direct questions to help them initiate an answer as they did not know where to start and what to say. In addition, some participants needed a verbal prompt to stay on topic or to elaborate on their one word answers. So although this study was set up as an explorative piece of research without a theoretical framework, by making use of guiding questions a theoretical framework has indirectly been incorporated.

Joffe (2012) developed a naturalistic method to elicit material which followed the pathway of the respondents' thoughts and feelings rather than imposing questions and topics. At the beginning of the meeting, each participant was presented with a grid containing four empty boxes in order to elicit their first thoughts. The participants were then prompted to write or draw in each box any word, image or feeling that

came to mind concerning the research issue. It might be worth making use of this method in future research with brain injury survivors so that one gets a better understanding of their thoughts and feelings about living with a brain injury

Despite the challenges and limitations of this study, it is believed that during the interviews the participants provided data that were relevant to the research questions and contributed significantly to research concerning young people who have sustained a brain injury.

4.4. Limitations of the study

4.4.1. Quality of research

To ensure the quality of qualitative research several criteria can be applied to both data collection and analyses. Spencer and Ritchie (2012) state that contribution, credibility and rigour are the main quality criteria to be used across different qualitative methods while Yardley (2000) proposed four key dimensions on which studies using qualitative methods can be assessed (see Table 4). In keeping with the philosophy of qualitative research, the suggested criteria from both Spencer and Ritchie (2012) and Yardley (2000) are not in the form of rigid rules or prescriptions but are themselves open to flexible interpretation and application (Yardley, 2000). This means that both sets of criteria can be applied to different types of qualitative research such as the thematic form of analysis which was used in this study. As the criteria from Yardley (2000) are described more extensively, the researcher felt that applying these criteria to evaluate the quality of this study would be more transparent and beneficial to the reader and contribute to the value of this study.

Table 4: Characteristics of good (qualitative) research (Yardley, 2000)

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|--|
| <p>Sensitivity to context</p> <p><i>Theoretical: relevant literature, empirical data, sociocultural setting, participants' perspective, ethical issues.</i></p> |
| <p>Commitment and rigour</p> <p><i>In-depth engagement with topic, methodological competence/skill, thorough data collection, depth/breadth of analysis.</i></p> |
| <p>Transparency and coherence</p> <p><i>Clarity and power of description/argument, transparent methods and data presentation, fit between theory and method, reflexivity.</i></p> |
| <p>Impact and importance</p> <p><i>Theoretical (enriching understanding), sociocultural, practical (for community), policy makers, health workers.</i></p> |

Throughout this study several criteria from Yardley (2000) such as commitment, rigour and transparency are discussed in the Method section. However, there are several criteria that need more explanation and these will be discussed in the following paragraphs.

Sensitivity to context

Throughout the study the researcher took into consideration how her gender and her status as a health professional could influence the balance of power in the process of investigations. As described earlier, from the eight participants only two were female and two were White-British. As the researcher is White and female she identified more with the gender and cultural difficulties that were described by both female participants than those of the male participants and those from different ethnic backgrounds.

At times these participants challenged the researcher's position as they indicated that the researcher was mostly seen as a woman with whom one could start an intimate relationship. This made the researcher reflect even more upon her own

values and ideas about gender and the role of researcher and consequently to ensure that she remained sensitive to the different perspectives of all participants at every stage of the analysis and writing up of this study while keeping a professional distance.

Although the researcher remained open to the perspectives of all participants in this study, it was difficult to overcome the inevitable imbalance in power relations between those participants who were selected for involvement in the study and the researcher who initiated and controlled the process of research. Throughout the study the researcher was aware of this power imbalance and therefore tried to increase the power for the participants by given them the opportunity to guide the interview about what they wanted to share of their story, how long the interview would last and how many meetings they would like to have to tell their story. In addition, participants could withdraw their data at any time during the research process, which is also part of good practice.

Transparency and coherence: Reflexivity

Researchers believe that their experiences of the world are mainly influenced by their assumptions, intentions and actions and that these factors might affect the research process. It is therefore important for researchers to reflect on their experiences and motivations that led them to undertake a particular investigation (Yardley, 2000). The researcher in this study had worked with people with a brain injury in different settings (e.g. hospital, rehabilitation centre, community) and in different professional roles (nurse, volunteer and trainee clinical psychologist). These experiences led the researcher to understand that adults and, in particular, young adults, experienced a range of difficulties, for example cognitive, physical, psychological and social, in the first two years after sustaining their brain injury. Through clinical sessions and conversations with the people with TBI and their families, the researcher gained an understanding that these people and their families found it very difficult to manage the changes and that there were lots of uncertainties about future support and their ability to manage daily life. This information led the researcher to set up this research project.

As the researcher had supported adults with TBI and their families in her role as a clinician, she was very much of the opinion that young adults needed continuous support. In addition, the researcher felt that young people have their whole life ahead and that therefore young people with TBI need support to make the best of their lives. These assumptions were reflected in research questions such as: Do you get support? Who or what is supporting you? Do you feel this is enough and what sort of support do you need? When several participants in this study mentioned that they received enough support and felt that more support could influence their independence negatively, these views were new to the researcher. This led the researcher to be much more aware of and open to different views and ideas about support and needs for young people with a TBI.

4.4.2. Thematic analysis

TA is described as a method for identifying and analysing patterns of meaning in a data set so that it illustrates which themes are important in answering the research questions (Braun & Clarke, 2006).

As TA is a form of qualitative analysis there is no firm rule of what proportion of the data set needs to display evidence of a theme for it to be considered to be a theme (Braun & Clarke, 2006). In this study the researcher counted the number of different speakers who articulated the themes across the entire data set in order to determine what a theme was. In addition, the researcher felt the four main themes and four subthemes captured important and useful information in relation to the overall research questions. During the analysis of the data set the researcher was aware that her judgement was necessary to determine what a theme was but that her judgement was also subjective and consequently influenced the reliability of the results. Therefore the researcher discussed and reviewed with her supervisor the analysis of the data set to increase the quality of the study. However, credibility checks as described by Elliot et al. (1999) would have been a better method to ensure the quality of this piece of work.

In this study the researcher chose a rich thematic description of the data set so that the reader got a sense of the important themes. This meant that during the analysis, some depth and complexity of the data was lost but that a rich overall description of

the content of the entire data set was maintained (Braun & Clarke, 2006). As this study investigated an under-researched area with participants whose views were hardly known, this method was particularly useful as it would give the reader a sense of how it must be to live with the consequences of a TBI and the support that is needed.

4.5. Implications of the study for clinical practice, social policy and research

The participants in this study stated that they had lost an important part of their meaning and purpose in life when they could not return to their previous school or job because of no or very limited support to help them manage the brain injury-related consequences. They described that the lack of support negatively affected their emotional well-being and their self-identity, as school was a place to socialise and to develop their identity, which is consistent with findings in a study from Mealings and Douglas (2010).

In Mealings and Douglas's (2010) qualitative study conducted in Australia, three male adolescents were interviewed to hear their stories about what it was like to go back to school. From these interviews three key themes emerged: the adolescent student's sense of self, the experienced brain injury-related changes and the received support. A tentative model describing the relationships between these three areas in which the young person is the central component was developed. Although this model is based on a single case study with a very small number of participants, it is suggested that this model can be applied at all times, from transition to and from school to ongoing participation at school, by educators and clinicians (Mealings & Douglas, 2010). As there are no specific interventions and support in place for young brain injury survivors in the UK who want to go back to some form of education, it would be useful for clinicians and educators to trial this model to support young people with reintegration to school.

However, before such a model can be implemented, students with TBI have to be identified in school and at the moment they are not despite major efforts by brain injury advocacy groups in the UK (Turkstra et al., 2008). This suggests that the first stage in intervention to support these students in returning to school is to have in place the mechanisms to identify who these students are and to provide basic advice

for teachers about the consequences of TBI and the implications for educational development (Turkstra et al., 2008).

Those participants who were employed before the brain injury stated that they could not go back to their previous job without appropriate support for the skills and abilities lost after the TBI and to find strategies to optimise preserved skills and abilities. Studies in the USA have indicated that supported employment programmes can be successful in helping people with TBI return to work when they have access to the necessary services and when staff are well trained to provide this assistance (Yasuda et al., 2001). The participants in this study indicated that such programmes were not available to them.

As unemployment is associated with long-term mental health problems, it is felt essential that professionals or well-trained support workers need to start supporting young people to reintegrate back to employment or school (Evans et al., 2003). In addition our society loses valuable resources of economic earning power when young brain injury survivors are unemployed (Evans et al., 2003). The profession of psychology could start with making links with employers and voluntary organisations to give psycho-education about TBI and support the young people with TBI to find a suitable and meaningful purpose in life.

In this study a few participants had independently arranged voluntary work to give themselves a purpose in life, in spite of the fact that some of them had profound communication difficulties. There are a few studies that have addressed communication ability and work re-entry and it is suggested that communication difficulties negatively affect finding work (Isaki & Turkstra, 2000). It therefore is an unexpected outcome of this study that those participants with communication difficulties found voluntary employment and did this independently. Further research into this topic is therefore needed.

One of the ways to support young brain injury survivors with their reintegration back into the community and to find themselves a meaningful purpose in life is to have adequate community-based services, which are available to them however much time has passed since their injury (Parish & Oddy, 2007). These services could

support young people to generalise and maintain those relearned skills and abilities back in the community, such as reintegration back to work or school, which not only influence their independence but also their psychosocial well-being and feelings of low mood, anger and frustration. Although the National Institute for Health and Care Excellence (NICE, 2007) amended the guidelines on the early management of with a brain injury in 2007, there are no specific guidelines which address the provision of services for people with a brain injury in the community.

However, the young people in this study showed ambivalence about seeking support as they feel that this might negatively influence their independence. In order to avoid young people finding themselves in a situation of social isolation and seclusion and getting lost to health and social care services, partly resulting from their view about seeking support and partly from the shortage of organised community services, health professionals might need to be more proactive to reach these young people and to link with voluntary organisations such as Headway (Wade et al., 1988; Lefebvre et al., 2005).

Brain injury survivors have indicated that it is not only the provision of support but also public awareness about brain injury that will help them to find a meaningful place in society. They stated that raising awareness might change some of the public's misconceptions about brain injury and the way brain injury survivors are treated by society, resulting in them being included instead of excluded. A range of charitable organisations such as Headway exist in the UK and they attempt to raise awareness of brain injury and at the same time provide support (Linden & Boylan, 2010). Unfortunately, at a governmental level little effort has been made to educate members of the public and it might be helpful if they start with educating and informing professionals and the general public about the consequences of a brain injury (Linden & Boylan, 2010).

Although brain injury survivors have indicated that support and public awareness will help them dealing with brain injury-related consequences, exploratory research has reported that there are gender differences in what is perceived as helpful. Women valued support, being assertive, professional input and spiritual strength whereas men managed through inclusion, family decision, fulfilling a family role, being

productive and being realistic about their limitations (Willer et al., 1991). These findings are somewhat consistent with those of the current study in which the female participants mentioned that professional input helped them to manage their emotional well-being while the male participants indicated that being productive, either through voluntary work or leisure activities, was beneficial to them.

In this study two of the eight participants were female and this ratio of brain injury survivors 3:1 (6 men and 2 women) is representative of the ratio of brain injury survivors in the general population (Shotton et al., 2007). Because more men than women sustain a TBI, brain injury-related studies mainly reflect the ideas and views of the male population as there is more information available on how male survivors manage brain injury-related consequences (Alston et al., 2012).

There has also been criticism that research questions and approaches are framed for the male experience (Hobfoll et al., 1994). In addition it is felt by the researcher that in brain injury-related studies the ideas and views of female survivors on how they manage the brain injury-related consequences are relatively unknown and consequently undervalued, which is in line with research findings from Alston et al. (2012) who indicated that there is very limited research, qualitative or quantitative, on the impact of gender difference on outcome following TBI. Not only the perceptions and experiences of TBI among women but also among people from different cultural groups remain poorly understood (Saltapidas & Ponsford, 2008).

This study contributes to the literature as it identified that both gender and cultural background influenced the way male and female brain injury survivors constructed their sense of identity. While the male participants constructed their identity from an egocentric perspective the female participants' construction of identity was more in relation with their social environment. The participants with an Asian background described that 'taking care of' was important for their sense of self while the White-British male participants reported that 'being strong' was important for their identity.

In this study both gender differences and cultural background also contributed to how participants experienced the changes in social relationships following their brain injury. The White male participants strived for independence, which is in line with the

Western idea that young people need to be independent, but the participants from an Asian and Latin American background struggled more to get this independence as their families felt that they had to be taken care of. The female participants also strived for independence but were also very aware of the fact that the brain injury also had a significant impact on the lives of their partner and/or parents.

The above showed that both gender and cultural background are important factors in how young adults experience the psychosocial consequences following their brain injury and that there is a diversity of experiences between brain injury survivors in their process of rehabilitation. As there has been little research directly examining the experiences of the psychosocial consequences among female brain injury survivors and among individuals from culturally diverse backgrounds and minority groups, a greater understanding of these issues is important, as it could potentially guide the formulation of rehabilitation strategies and interventions that are more culturally meaningful and gender specific in an effort to adequately meet the needs of brain injury survivors (Saltapidas & Ponsford, 2008). Colantonio et al. (2010) state more specifically that rehabilitation services should offer programmes that include cognitive, physical and psychosocial components in order to facilitate a successful integration of brain injury survivors back in the community.

4.6. Conclusions

In this study young people aged 18 to 31 both male and female indicated that a brain injury changed their lives and that the changes in their physical health, cognition, communication skills, personality and behaviour affected their ability to participate in society, their ability to establish and maintain social relationships, their sense of self and their emotional well-being. The participants mentioned that because of their disabilities they felt excluded by society, which consequently affected their opportunities to commence any occupation or education and to establish and maintain social relationships. Nearly all participants indicated that the inpatient rehabilitation they had had and the community support they continued to have contributed to their living their life as independently as possible. Although they felt that more support would negatively influence their independence they wanted to feel included by society by being supported in returning to some form of education or employment.

The outcome of this study indicated that young people with a brain injury are somewhat left to their own devices to find themselves a meaningful place in society two years post-injury as they felt excluded because of their difficulties. It is felt, therefore, that the general public and health professionals would benefit from general education about the disabilities following a brain injury so that there is an understanding about the challenges brain injury survivors face and the support from which they would benefit. With this understanding it is hoped that brain injury survivors are supported to commence either employment or education, to encounter less prejudices and consequently to feel included by our society. This not only would positively influence a person's mental health but also his or her economic earning power. In addition, it is felt that as a society in which we support those people who are socioeconomically deprived, we are also obliged to support young brain injury survivors to fulfil their potential as they have a whole life ahead.

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6. Appendices

6.1. Appendix I

| Consequences of traumatic brain injury: basic measures of injury severity and outcome | |
|--|---|
| Glasgow Coma Scale (GCS) Eye opening (E) 4. spontaneous 3. to speech 2. to pain 1. nil Motor response (M) 6. obeys 5. localises 4. withdraws 3. abnormal flexion 2. extends 1. nil Verbal response (V) 5. orientated 4. confused conversation 3. inappropriate words 2. incomprehensible sounds 1. nil Score (E+M+V)= 3-15 | Post-traumatic amnesia (PTA) < 5 mins: minimal 5-60 min: mild 1-24 hours: moderate 1-7 days: severe 1-4 weeks: very severe 4-12 weeks: extremely severe 12-24 weeks: exceptionally severe >24 weeks: devastating |

Greenwood 2012, adapted from Jennett and Teasdale and other sources

6.2. Appendix II: Ethical approval

SCHOOL OF PSYCHOLOGY

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



Isabella Schrover
45 St James's Avenue
Beckenham
Kent BR3 4HF

19 May 2011

Student Number: u0831983

Dear Isabella,

Registration as a Candidate for the University's Research Degree

I am pleased to inform you that the Research Degrees Subcommittee on behalf of the University Quality and Standards Committee, has registered you for the degree of Professional Doctorate.

Title of Professional Doctorate: Professional Doctorate in Clinical Psychology

Director of Studies: Dr Kenneth Gannon

Supervisor/s: Dr Matthew Jones Chesters

Expected completion: According to your actual date of registration, which is **1 October 2010**, the registration period is as follows:

Minimum 18 months, maximum 48 months (4 years), according to a full time mode of study.

Your thesis is therefore due to be submitted between:

1 April 2012 and 1 October 2014

I wish you all the best with your intended research degree programme. Please contact me if you have any further queries regarding to this matter.

Yours sincerely,

Dr James J Walsh
School Research Degrees Leader
Direct line: 020 8223 4471
Email: j.j.walsh@uel.ac.uk

Cc: Dr Kenneth Gannon

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6.3. Appendix III: Information letter and leaflet

Information letter

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in this study.

Study: An exploration of the experiences of young adults who have acquired a brain injury.

Invitation to the study

You are invited to take part in a research study. Before you decide to take part, it is important for you to understand why this study is carried out and what it will involve. Please read the following information carefully and approach the researcher (Isabella) at Headway if you have any questions.

Background to the study

It is understood that in the UK at least 15 000 young suffer from a traumatic brain injury each year. Those who survived felt that the consequences of the brain injury remained the single most significant characteristic of their lives. However, little is known about the long-term impact on young people's lives and it is acknowledged that there is a need for studies in which the brain injury related consequences from the injured person's perspective is considered.

The aim of this study is to ask young adults who attend the young people's group at Headway what their experiences are of living with the consequences of a brain injury. If you decide to take part then please contact the researcher (Isabella) by email or telephone or let Thomas and/ or Ben at Headway know.

Taking part

When you decide to take part in this study, you will be asked to read and sign a consent form. You will then take part in an interview with the researcher (Isabella). The interview will last approximately one hour and will take place on a date and time that is convenient for you. The interview will be recorded and transcribed (typed into text). All names and other personal information will be omitted for confidentiality purposes. You are free to withdraw at any time of this study and you will not be asked to give a reason.

Advantages and disadvantages of taking part

It is not anticipated that there will be any disadvantages associated with taking part in this study. The advantages of taking part are that you will provide information that could help to increase the understanding of young people's experiences of living with the consequences of a brain injury. This could have an impact on the way services are offered in your community.

Confidentiality

Your participation will be kept confidential. All material from the interviews will be stored in a locked cabinet. Any information identifying you (such as names) will be stored separately from the typed copy of your interview. Comments that you make in the interview will be used in the write up of the research. However, all identifying information will be removed. The recording of the interviews will be destroyed at the end of this study and the transcripts will be destroyed after five years. Only the researcher, supervisor of this study and examiners will have access to the tapes and transcripts. Your participation will remain anonymous and only the research will know the identity of those involved.

Ethical approval

This study has obtained ethical approval from the University of East London's Ethics Committee.

If you have any queries regarding the conduct of the programme in which you are being asked to participate, please contact the Secretary of the University Research Ethics Committee, Ms Debbie Dada, Admissions and Ethics Officer, Graduate School, University of East London, Docklands Campus, London E16 2RD (Tel 020 8223 2976, Email: d.dada@uel.ac.uk)

Contact for further information

If you would like to take part or have any questions please contact Isabella Schrover on: Telephone: 020 8223 4174/ 4567 (University of East London, Doctorate in Clinical Psychology Office)

Email: I.Schrover@uel.ac.uk

You also could speak to Thomas and Ben and let them know that you would like to take part in this study. Thank you for taking the time to read this information sheet.

Isabella Schrover



What is the long-term impact of a brain injury on the lives of young people?

If you are between 18 and 40 years old then you are invited to take part in this study.

DID YOU KNOW THAT IN THE UK AT LEAST 15 600 YOUNG PEOPLE SUFFER FROM A BRAIN INJURY EACH YEAR?

Very little is known about the long-term impact of a brain injury on the lives of young people.

This study is set up to interview young people how the brain injury affects their lives.

See the information leaflet for more information about this study.

If you would like to take part in this study then contact Thomas or Ben at Headway or email me at: l.schrover@uel.ac.uk

I look forward to meeting you.

Isabella

6.4. Appendix IV: Consent form

Consent form

An exploration of the experiences of young adults who have acquired a brain injury.

I have read the information leaflet relating to the above programme of research in which I have been asked to participate and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed. The procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researchers involved in the study will have access to the data. It has been explained to me what will happen once the experimental programme has been completed.

I thereby freely and fully consent to participate in the study which has been fully explained to me.

Having given this consent I understand that I have the right to withdraw from the programme at any time without disadvantage to myself and without being obliged to give any reason.

Participant's Name (Block Capitals)

Participant's Signature

Researcher's Name (Block Capitals).....

Researcher's Signature

Date:

6.5. Appendix V: Interview schedule

I would like to thank you for participating in this study. The interview will last approximately one hour. If you need a break during the interview just let me know. I will tape the session and I will also make some notes.

Male/ Female:

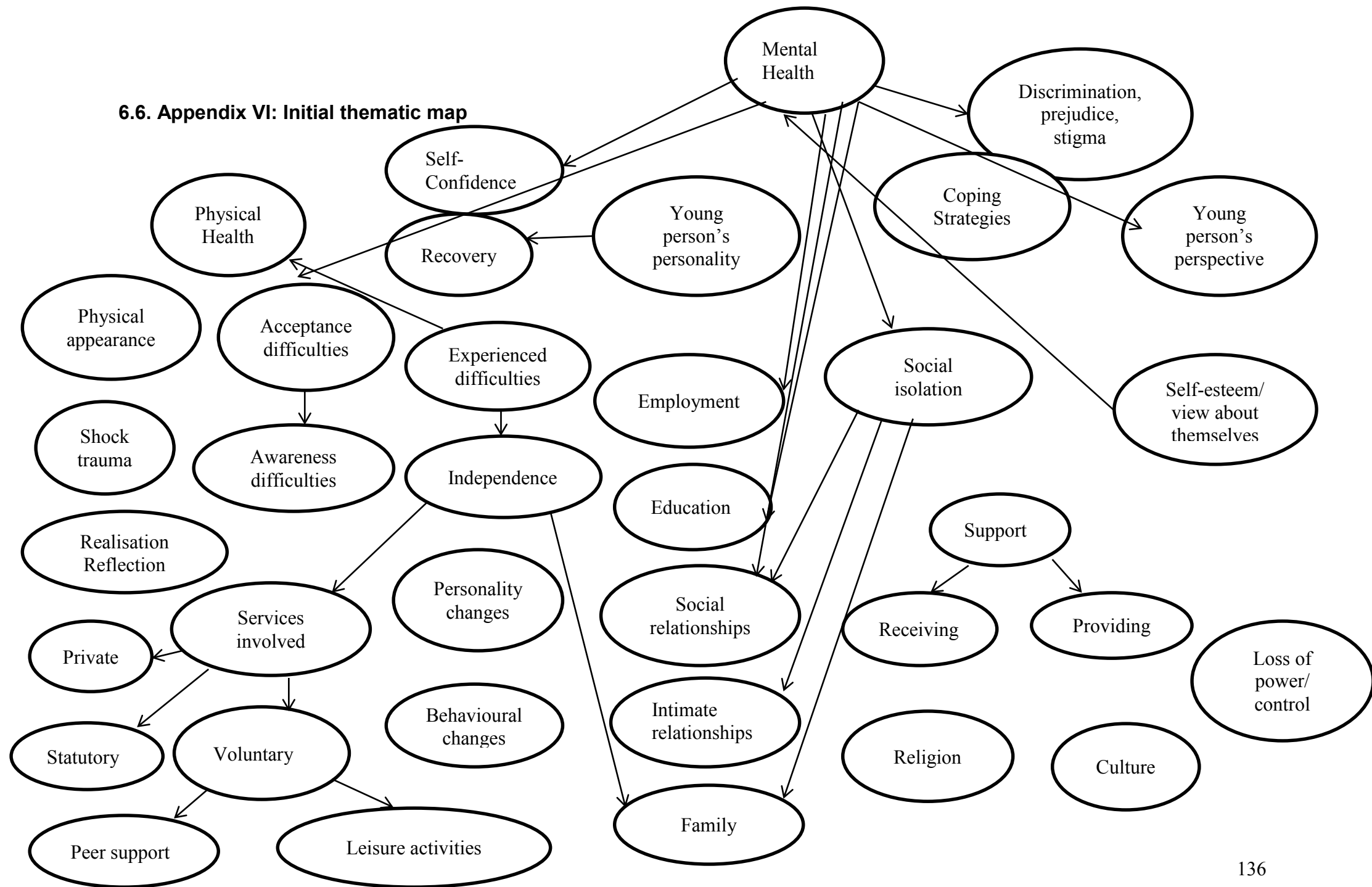
Age:

Ethnicity:

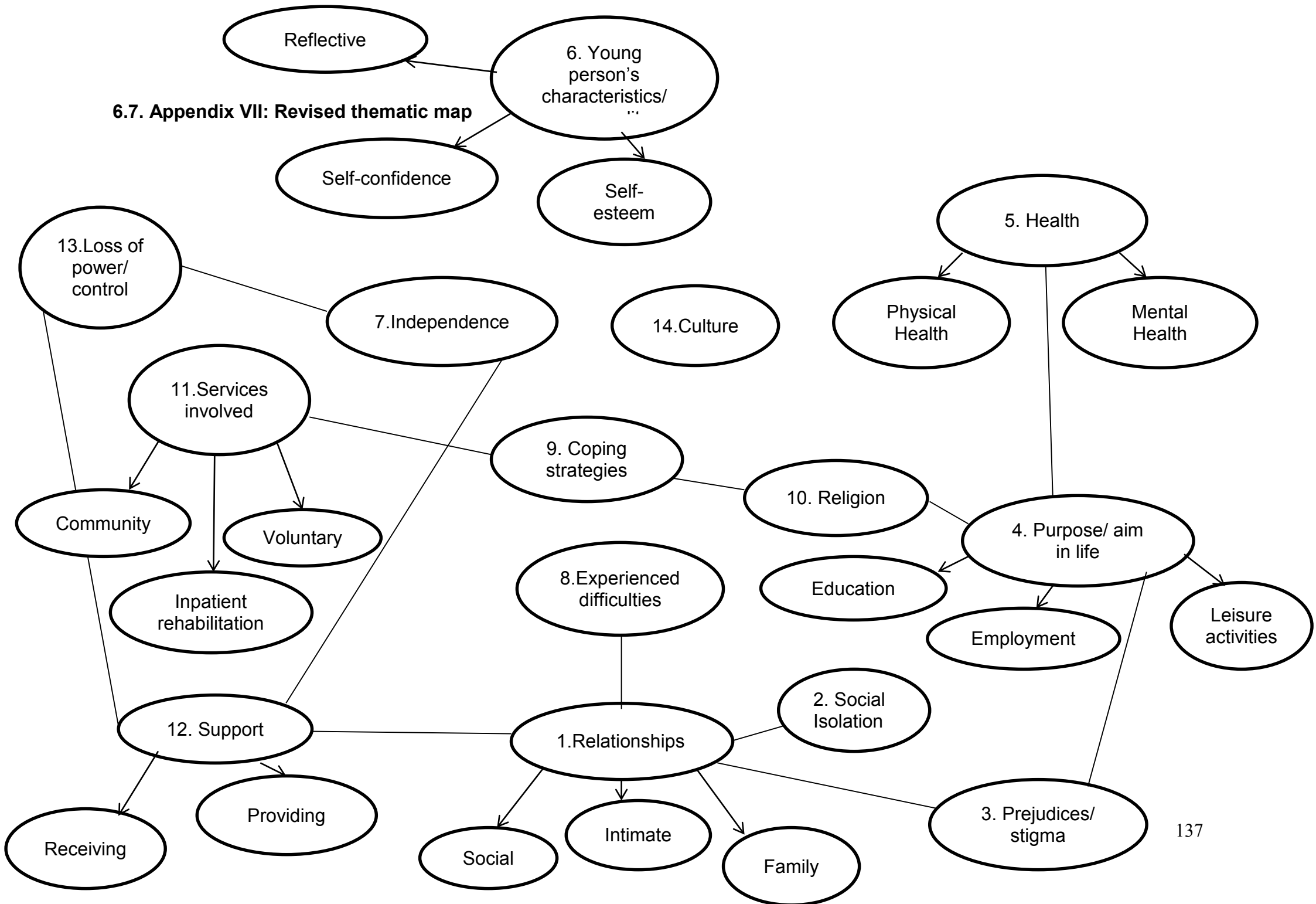
- A) What has caused your brain injury?
When was this?
Do you remember how long you were in coma/ unconscious?
Do you remember if the doctors explained to you about the severity of the brain injury? Mild/Moderate/Severe
- B) Following the brain injury were you admitted to hospital? Were you involved with any other services after discharge, if so which services, professionals and with which aims.
- C) How did you get involved with Headway?
- D) In what way has the brain injury changed your life?
(Think about physical, cognitive (memory, attention, concentration), emotional, behavioural (impulsivity), personality, social (family, friends, leisure, school, employment) and psychological consequences (depression, anxiety, self-esteem).
How do you know/ notice?
What are your experiences of living with these changes in daily life. How is it to live with these difficulties?
- E) Thinking about psychosocial consequences. Social consequences: What sort of social activities did you undertake before and after the brain injury. What about school and/ or employment? What about your friendships, relationships with important others and family. Any changes before and after the brain injury? How do you cope/ manage these changes?
- F) Who have supported you through difficult times since the brain injury? In what way have family and friends been supportive? Has your relationship with family and friends changed and if so in what way?
- G) Thinking about psychological consequences. How did you see yourself before the brain injury and how do you see yourself now. Has this any effect on your daily life e.g. self-confidence? Do you experience any feelings of anxiety or nervousness which you did not experience before brain injury? The same for low mood. How do you cope/ manage these feelings. Have you seen a psychologist / psychiatrist in the past/ before brain injury regarding your mental health.
- H) How do you manage in day to day life? What would you like to change in your current situation (recovery of affected skills/ abilities, rehabilitation, service input, participation in community, work, education, social and leisure activities).

- I) Is there anything that you feel is important for me to know to get a full understanding about your experiences of living with the consequences of a brain injury but which I have not asked you.
- J) Thank you very much for your participation. It is planned that the Thesis is submitted. Do you want me to notify you and send you a short summary? If yes, then I'll send it to Headway and then to the attention of

6.6. Appendix VI: Initial thematic map



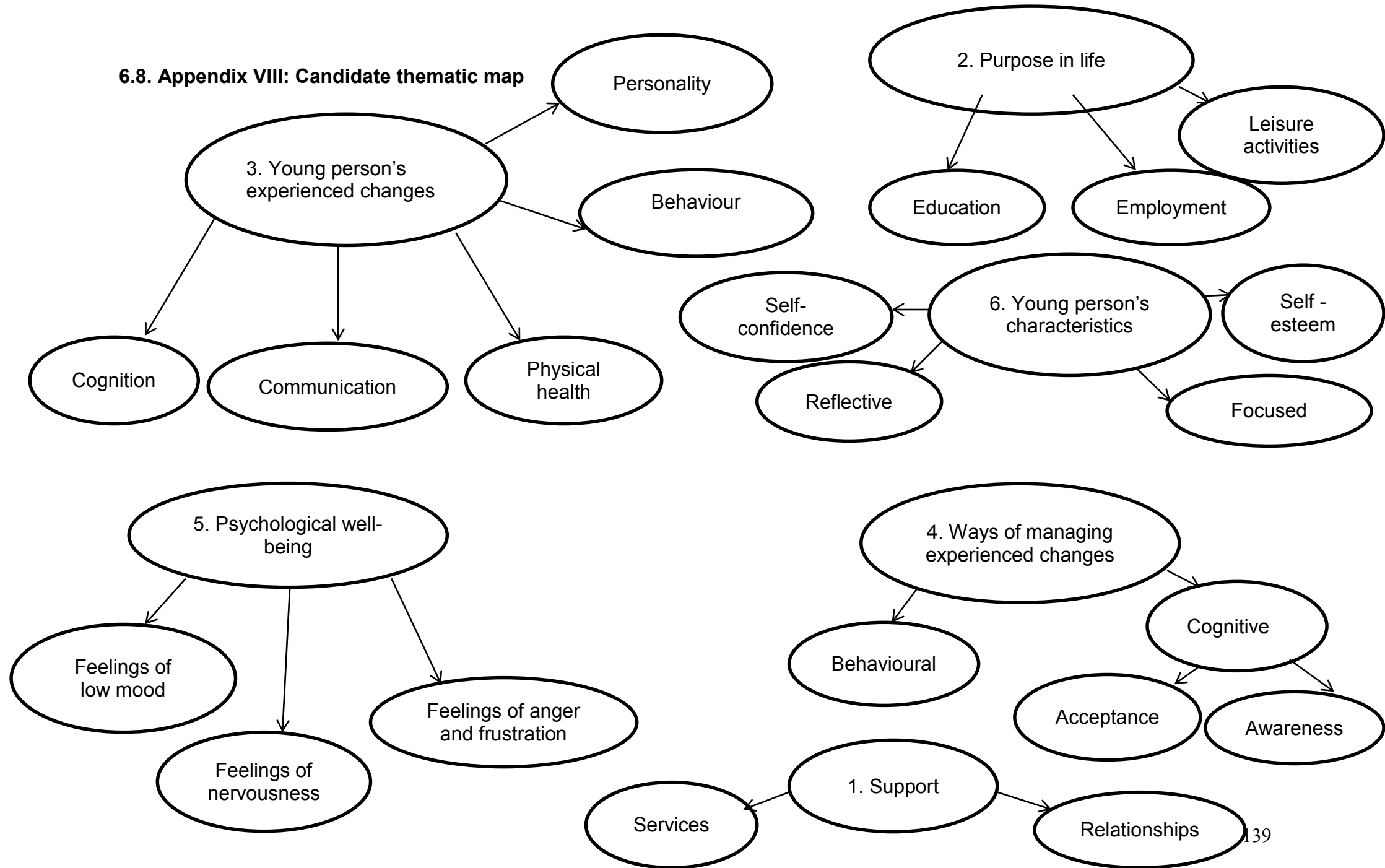
6.7. Appendix VII: Revised thematic map



6.7. Appendix VII: Revised thematic map

The revision of the initial thematic map led to the presence of 14 overarching themes, and a collection of sub-themes and candidate themes. The overarching theses were: Purpose/aim in life, Intimate relationships, Social relationships, and Leisure activities formed Relationships. Mental Health and Physical health formed Health. Self-Confidence, Self-Esteem and Reflectivity were included in the theme: Young person's personality/ characteristics. It was also analysed that the themes Awareness and Acceptance of difficulties would be better to fit under the theme Coping strategies.

6.8. Appendix VIII: Candidate thematic map

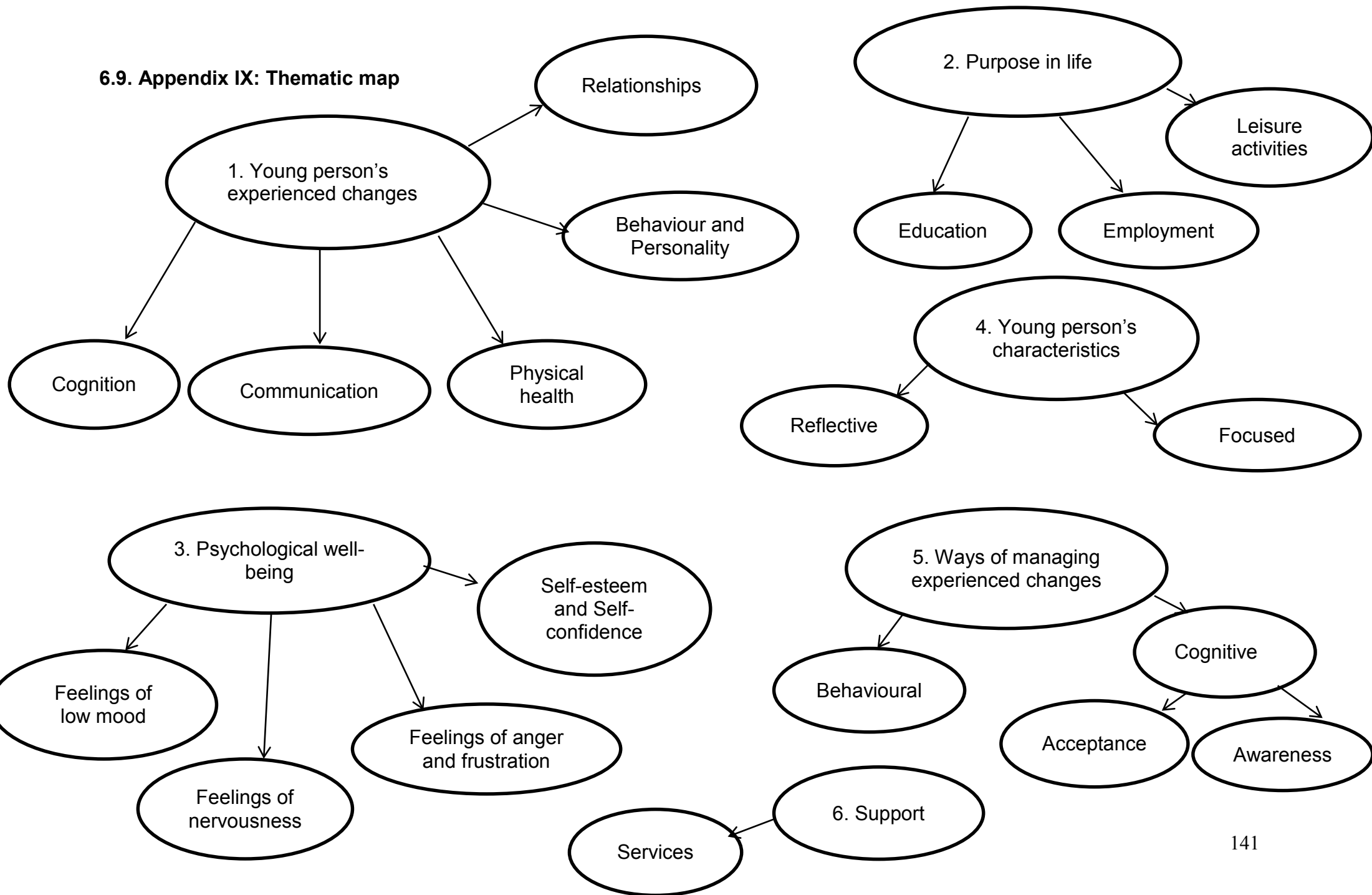


6.8. Appendix VIII: Candidate thematic map

In thematic map VII the first theme was: Support and had as sub-themes: Services and Relationship. As there was minimal external heterogeneity between the themes Relationship and Social isolation, both were collated and called Relationships. The second theme was the existing theme Purpose and aim in life, with Education, employment, and Leisure activities as subthemes. Theme three: Young person's experienced changes, continued to be a separate theme and included several subthemes. Theme four: Ways of dealing with the experienced changes included the previous themes: Coping strategies, Awareness and Acceptance. The candidate theme of Discrimination/ Stigma/ Prejudice and subtheme Physical health, were discarded as they did not have enough data to support them as separate themes or sub-themes. They were included within theme one, two and four as they formed an important part of the contexts of these three themes. The fifth theme was identified as: Psychological well-being. This theme was part of the previous called Health theme and included Mental health. The researcher felt that the name Psychological well-being reflected more accurate what the theme was about. Theme six: Young person's characteristics/ personality continued to be a separate theme.

As there was not enough data to support the candidate themes Power and Religion, both themes were included in respectively theme five, four and two as they strengthened the homogeneity of each theme. The candidate theme Culture was incorporated within the theme of Support as the participant's culture was mentioned in the context of support. The researcher also concluded that Independence should be part of the overarching theme Support instead of being a separate theme. This as Independence was strongly correlated with Services and Relationship.

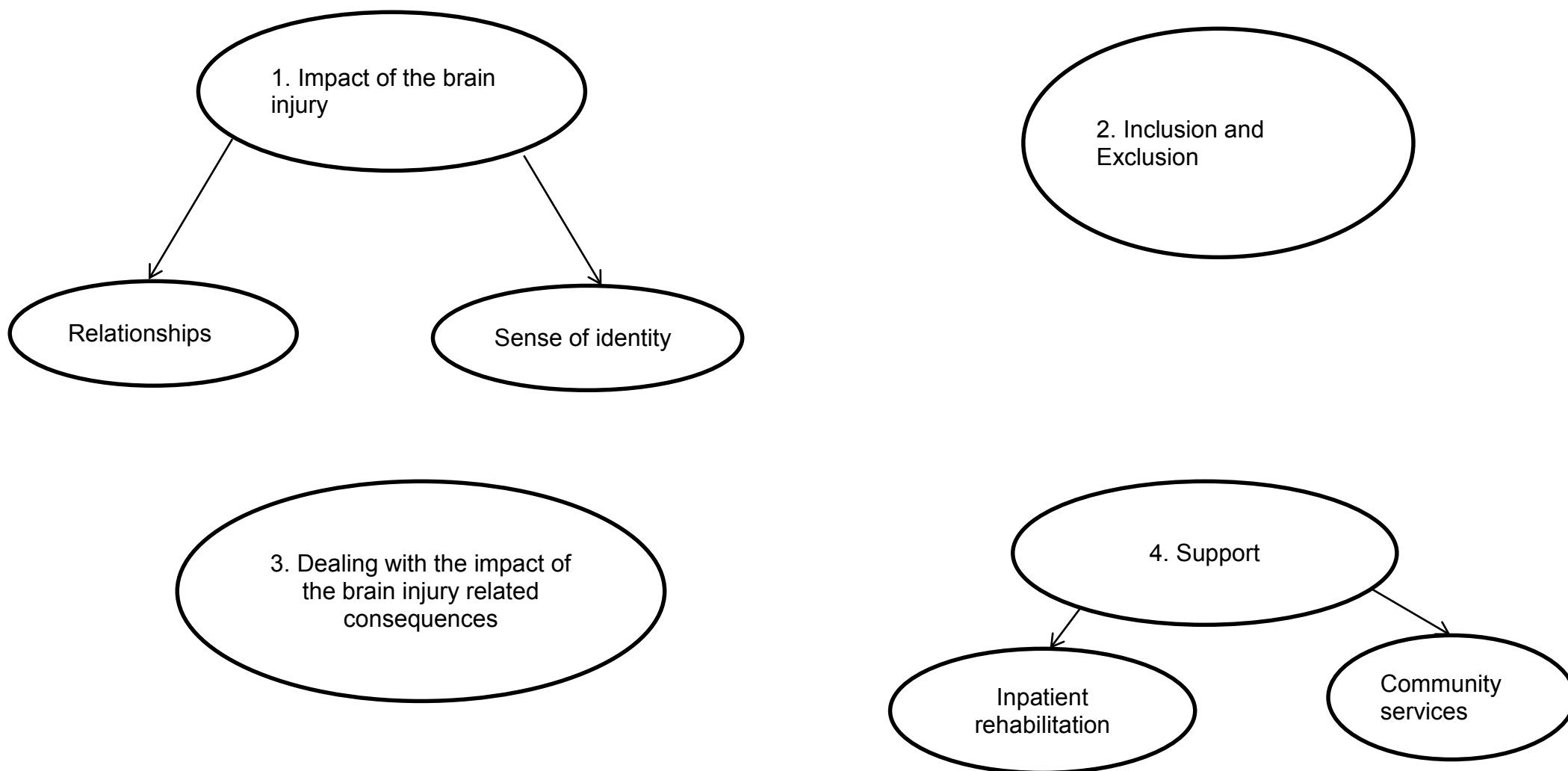
6.9. Appendix IX: Thematic map



6.9. Appendix: Thematic map

With the exception of theme two: Purpose in life, all other themes were renumbered. In addition, the sub-themes: Self-confidence and Self-esteem were relocated to theme three: Psychological well-being. Subtheme: Relationships was relocated from theme six: Support to theme one: Young person's experienced changes. This as the participants mentioned that changed relationships was one of the key difficulties since the brain injury and therefore would better fit under the first theme. The two separate subthemes Behaviour and Personality were taken together as there was a strong homogeneity within both data.

6.10. Appendix X: Final thematic map



Appendix X: Final thematic map

To strengthen the internal homogeneity of theme one: Young person's experienced changes, the sub-themes: Cognition, Communication, Physical Health, Behaviour and Personality were included. Theme one was renamed as: The impact of the Brain Injury, as this would reflect better the stories of the participants. Relationships continued to be a sub-theme. Sub-theme Self-esteem and Self-Confidence were relocated from theme three to theme one and renamed as Sense of Identity.

Theme two was renamed as: Inclusion and Exclusion, because the participants had indicated that they either felt being included or excluded by our society when they were or were not in employment or education. Theme three: Psychological well-being with the sub-themes, feelings of low mood, nervousness, anger and frustration were incorporated in theme two as the participants had indicated in their stories that inclusion/ exclusion was strongly linked with their psychological well-being.

Theme four: Young person's characteristics, was incorporated in theme five: Ways of managing experienced changes. This as the researcher felt that there was a strong relationship between the participants' characteristics and ways of dealing with the brain injury related consequences. In addition theme five was renumbered as theme three and renamed as: Dealing with the impact of the brain injury related consequences.

Theme six: Support continued to be a separate theme but was renumbered as theme four. Subtheme: Services was replaced by the two subthemes: Inpatient Rehabilitation and Community Services. This as the participants made a clear distinction about the usefulness of both services.