Alice Childs BSc Hons PGCert

# THE LIVED EXPERIENCE OF ADOLESCENTS AND YOUTH WITH A BRAIN INJURY; NAVIGATING NEW LANDSCAPES.

## Section A:

Understanding the adolescent and youth experience of living with a brain injury; a meta-ethnography.
Word Count: 6,927 (7,198)

## Section B:

An exploration of young people's sense of self-identity following a traumatic brain injury in adolescence
Word Count: 7,988 (8,040)

Overall Word Count: 14,915 (15,238)

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

**APRIL 2024**

# Acknowledgements

First and foremost thankyou to the young people who took time to speak with me for this study, some of them discussing their experiences of TBI for the first time. Thankyou for going there and trusting me with your stories.

Thankyou to my supervisors Dr Andrea Pickering and Dr Carmel Digman for their support throughout; I always left our meetings with a strengthened passion for this project.

To my late Grandma who once told me that the hardest things are often the ones most worthwhile; I have always held on to these words throughout all my endeavours.

# Summary

## Part A

A systematic literature review exploring the experiences of adolescents and youth living with a brain injury. A meta-ethnographic synthesis of 18 qualitative studies identified six themes reflecting the lived experience of this cohort including managing brain injury sequelae, navigating new landscapes relationally and the described internal cognitive and emotional processes of adjustment to changes. The findings provide further supporting evidence for the specificity of adolescence in living with a brain injury and interactions between the inter and intra-personal experiences of this cohort.

## Part B

There is limited research considering the experience of those who have acquired a Traumatic Brain Injury (TBI) during the period of adolescence.  Seven young people were interviewed about their self-identity over time following TBI in adolescence. Through Interpretative Phenomenological Analysis (IPA), themes developed indicated that young people understand themselves in a number of ways, including relationally and with a heightened sense of an embodied self.  Participants' held narratives about their injury event within the context of adolescence, whilst trying to fill in the gaps left by memory deficits related to TBI. A number of different processes over time were described, moving from an initial discovery of post-injury traits to acceptance.

# Contents

## Tables

Section A

Section B

## Figures

Section A

Section B

# Section A

## Understanding the adolescent and youth experience of living with a brain injury; a systematic review and meta-ethnography.

**Word Count: 6,927 (7,198)**

# Abstract

The aim of this review was to consider the adolescent and youth perspective on living with a brain injury (BI) given the importance of this key developmental stage and dearth of literature for this cohort. It aimed to synthesise qualitative research that has a focus on exploring adolescent and youth understanding of and meaning-making processes around navigating living with a BI. A systematic literature search and meta-ethnographic synthesis of qualitative studies was conducted. Eighteen studies were included and appraised using the CASP tool for qualitative research (CASP, 2018). None of the studies evaluated were deemed to be of a low enough quality to be removed from this review. Six overarching themes (third-order constructs) were developed from 37 underlying researcher-interpreted themes (second-order constructs) that had been identified within the research. These are; *1) navigating the new landscape of life with a brain injury; direct consequences, 2) navigating the relational landscape of life with a brain injury; peer and support relationships, 3) an altered family landscape in life with a brain injury; relational dynamics and support, 4) cognitive processes in relation to understanding changes, 5) cognitive and emotional processes of adjustment to changes and loss 6) coping and post-traumatic growth.* The findings provide further supporting evidence for the specificity of adolescence in living with a brain injury and highlights some of the described processes related to change following brain injury.

**Keywords: brain injury, adolescence, experience**

# Introduction

Acquired Brain Injury (ABI) is best defined as a brain injury sustained after a period of normal development, i.e. after birth. It is an umbrella term encompassing the various mechanisms leading to a brain injury including trauma (Traumatic Brain Injury) and non-traumatic causes such as infection, stroke and tumours. Despite broad differences in the causal mechanisms of brain injury, the outcomes of non-traumatic and traumatic brain injury are similar, with children and young people found to have similar needs regardless of the cause. As Forsyth and Kirkham (2012) noted "what children with ABI's have in common is greater than what distinguishes them" (p.1262). As such, research is not always conducted on groups specific to etiological classification; many studies apply the umbrella term of ABI to its recruitment criteria. There are some differences however, in that some populations are overrepresented in the TBI cohort, including those with higher levels of impulsivity and from backgrounds of socioeconomic deprivation (Forsyth & Kirkham, 2012).

Traumatic Brain Injury (TBI) makes up a large percentage of all ABI's. Worldwide, 69 million people are estimated to sustain a TBI each year (Dewan et al., 2018), with adolescence a high-risk period for such traumatic injuries (Christensen et al., 2021). Some estimates indicate 30-60% of TBI's to be within the paediatric population (Mulligan et al., 2023). TBI is the leading cause of death and disability in childhood and adolescence, with ABI impacting a further portion of children and young people (McCarron et al., 2019). Figures are thought to be underestimations of the true scope of the impact of brain injury due to under-reporting, including those who may experience more milder forms of brain injury (e.g. concussions) and not access services.

Menon et al., (2010) noted that there were differing definitions in the literature around the term "traumatic brain injury" and clarified that TBI is "defined as an alteration in brain function, or other evidence of brain pathology, caused by an external force” (p.1637). They went on to further explain that the following clinical signs represent an alteration in brain function; loss of or decreased consciousness, including confusion, disorientation or similar, a loss of memory for the events either immediately before or after the injury and neurological deficits such as weakness, paralysis, loss of balance, sensory losses or aphasia.

In addition to the more immediate effects of a TBI, there are many longer term sequelae. Self-report and qualitative studies have demonstrated some of the aspects that are important to those who have experienced a TBI. Longer term sequelae include fatigue, headaches, difficulties with memory, concentration, information processing, mobility and psychosocial issues (Mulligan et al., 2023; Ylvisaker et al., 2005). It has also been observed that children with brain injuries, despite how heterogenous, have similar needs (Forsyth & Kirkham, 2012; Goldman et al., 2022).

Much of the research exploring individual experiences of the outcomes following TBI focuses on the adult population. However, a number of studies indicate that the developmental stage at the time of the injury predicts longer term outcomes; adolescents have been found to take longer to recover from mild TBI, and the age at TBI has also been found to modulate the risk of developing deficits linked to the injury (Christensen et al., 2021; Sariaslan et al., 2016). Adolescents in particular have been found to exhibit greater memory impairments (Arroyos- Jurado et al., 2006) and excessive daytime sleepiness (Osorio et al., 2013) post injury compared to younger children. Academic deficits have also been demonstrated to be influenced by the age at the time of the injury, alongside a number of other factors. Adolescence is also a critical window for brain plasticity and a period of significant brain development. It can therefore be reasonable to consider that those who experience a TBI during this period of development may have different experiences of a TBI, outcomes and recovery. Brain injuries have been shown to have an impact on the key developmental tasks of adolescence (Mulligan et al., 2023), including the move towards more independence (Ocampo et al., 1997).

Mulligan et al. (2023) interviewed adults who had sustained a TBI in the adolescence period retrospectively about their experience; themes of a broad impact on different areas of life and on developing identity were identified. They also identified the importance of both individual and social factors which impact on coping with brain injury related difficulties. Studies have demonstrated the social impact of TBI, with individuals reporting social isolation, feelings of loneliness and social conflicts (Yeates et al., 2004). As adolescence is a stage of life in which there is a strong emphasis on peer relationships and social identity (Rohrbeck, 2003), exploration of the experiences of those who acquired a TBI within adolescence in relation to their social world may highlight areas of importance to consider when providing neurorehabilitation to this cohort. Mealings, Douglas and Olver (2017) investigated adjustment in young people after a TBI through their participation in study and noted that participating in education is an important life goal for this cohort. Different developmental stages may mean an emphasis on different social roles and therefore a specific consideration of the experiences of the adolescent experience of TBI is warranted.

The period of adolescence is a unique stage of rapid biological and social development during the transition from childhood to adulthood. The World Health Organisation defines adolescence as occurring from the ages 10 through to 19 (WHO, 2023). It is also acknowledged that there is variation across cultures and time as to when some of the social transitions associated with adolescence occur, and so some have expanded the definition to include those up to the age of 24 (Sawyer et al., 2012). The United Nations also defines “youth” as those between the ages of 15 to 24 (UN, 2023). As such, in order to fully consider the question of how adolescents and youth experience living with a brain injury across countries, this review has considered research with participants between the ages of 10 and

24. The terms adolescent, youth and young people will be used throughout this review in reference to the participants and their data.

The aim of this current review is therefore to consider the adolescent and youth perspective related to living with a brain injury given the importance of this key developmental stage. It will aim to synthesise the current qualitative research to answer the question; how do adolescents and youth make sense of living with a brain injury? Qualitative research was deemed the most appropriate in order to consider the viewpoints of this specific cohort of individuals in depth.

## Method

To accurately consider the research question, a systematic review of the current qualitative literature exploring adolescent and youth experiences of living with a brain injury, was completed. Firstly, a systematic search of the literature in peer-reviewed journals was conducted, with subsequent studies retrieved and included within the review subject to a critical appraisal. Finally, a meta-ethnographic synthesis of these studies informed by Noblit and Hare (1988) is outlined.

### Systematic Review

A systematic review of the current peer-reviewed literature was conducted. Inclusion and exclusion criteria can be seen in Table 1.

**Table 1**

*Initial study inclusion and exclusion criteria*

*Inclusion Criteria:*

- A qualitative study
- Published in a peer-reviewed journal
- Qualitative data from the adolescent and youth perspective (age between 10 and 24)
- Studies specifically exploring adolescent and youth perspectives on living with a brain injury (any aspect)
- Any brain injury that comes under the umbrella term “Acquired Brain Injury” including Traumatic Brain Injury that occurred either in childhood or adolescence
- Sample primarily consists of adolescent and youth perspective
- Adolescent and youth perspectives individually identifiable in the Results

*Exclusion Criteria:*

- Mixed methodology
- Quantitative methodology
- Adult sample
- Study sample age range too broad (either including children or adult perspectives)
- Study sample is majority adult/ parent/professional or sibling data

## Search Strategy

The literature search was conducted in October 2023 and consisted of the five following databases: PsycInfo, ASSIA, Cinahl, SCOPUS and MedLine. A search of Google Scholar and the citations in identified studies was also subsequently conducted. The search terms outlined in Table 2 were searched for in both Title and Abstracts. There were no limits placed on the date range of studies.

**Table 2**

*Literature Search Terms*

| Search terms | Search of |
|---|---|
| identity or phenomenolo* or self or "biographical disruption" or impact or experience or perspective or "lived experience" or coping or adaptat* or stress or depression or anxiety or "mental health" or satisfaction or "social support" or "interpersonal relations" or family or "quality of life" or QOL or develop* AND | Title and Abstract |
| narrative or interview or "focus group" or "IPA" or grounded or qualitative AND | Title and Abstract |
| paediatric or adolesc* or student or puberty or youth or "emerging adult" or "young adult" AND | Title and Abstract |
| "traumatic brain injury" or "TBI" or "brain injury" or "ABI" or "acquired brain injury" | Title and Abstract |

* denotes Wildcard option for search

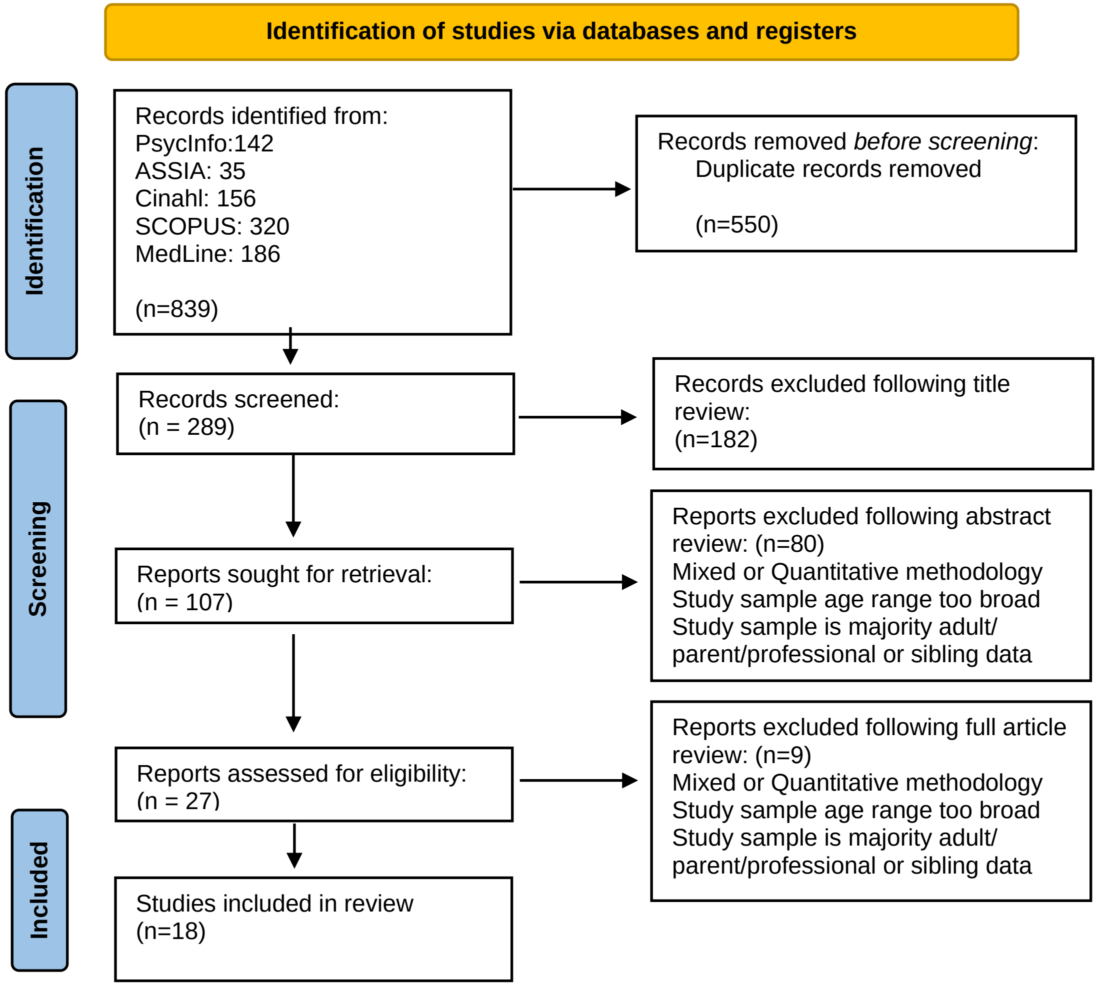
In line with the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA; Page et al., 2021), Figure 1 demonstrates the systematic review process and the outcomes, indicating the number of records considered. The literature search overall identified 839 records of which 550 were duplicates. The following 289 reports were then reviewed by title and 182 excluded upon the basis of the inclusion and exclusion criteria outlined in Table 1. The abstracts of the remaining 107 studies were then screened and an additional 80 were excluded. The full articles of the final 27 studies were read and 18 were included in the final review.

## Critical Appraisal

The 18 studies included in the review were all evaluated using the Critical Appraisal Skills Programme tool (CASP, 2018) for qualitative research. This ten question checklist is used to assess the quality of research considering different aspects including the research aims, methodology, data collection and analysis and the reported findings. In addition, the tool also considers the degree to which the researcher has considered their own positioning and relation to the participants and the data (reflexivity). Ethics and the value of the research are also taken into consideration. None of the studies evaluated were deemed to be of a low enough quality to be removed from this review and the subsequent meta-ethnography (Table 5).

**Figure 1**

*Systematic literature search process (PRISMA flow diagram)*



## Meta-ethnography

Meta-ethnography aims to synthesise qualitative research findings through its unique process of translation. Translation involves “comparing the metaphors and concepts in one account with the metaphors and concepts in others” to produce a “translation of qualitative studies *into* one another” (Noblit & Hare, 1988, p.25). It was initially developed by Noblit and Hare (1988) and further developed by Britten et al. (2002). The use of meta-ethnography for synthesising qualitative research has been demonstrated to be particularly applicable to health research (Malpass et al., 2009; Sattar et al., 2021).

Meta-ethnography is an inductive, interpretative approach where the reviewer further interprets (to develop third order constructs) the initial interpretations of the researchers (second order constructs) in each paper, also taking into account direct participant quotes and views (first order constructs). It aims to not only consider similarities, through reciprocal synthesis but also the differences between studies through refutational synthesis. This allows a new level of insight, acknowledging the reflexive positions of both the authors and the reviewer.

Table 3 outlines the steps taken for this current review.

**Table 3**

*Seven stages of meta-ethnography as outlined by Noblit and Hare (1988).*

| | |
|---|---|
| **Step One** | **Assessing the suitability of meta-ethnography to address the review question.** |
| | The area of interest was identified and the aims of meta-ethnography compared to the aims of the review. |
| **Step Two** | **Defining the scope of the review** |
| | Inclusion and exclusion criteria were developed and definitions of key terms considered. Studies were then selected for inclusion and their quality assessed. |
| **Step Three** | **Reading the studies** |

| | |
|---|---|
| | The studies were read and re-read in order to identify key concepts and note the characteristics of each study. First and second order constructs were extracted. |
| **Step Four** | **Determining how the studies are related**<br>Recurring concepts were identified across studies and (second-order) themes were created. This was an iterative process with themes being revised. |
| **Step Five** | **Translation of studies into one another**<br>Initial third order constructs were created through comparisons of each concept and theme identified from the studies where both similarities and differences were considered. |
| **Step Six** | **Synthesising translations**<br>Meta-ethnography identifies two stages of synthesising translations; reciprocal and refutational synthesis and line of argument synthesis.<br>Firstly, similarities across studies were again considered in order to refine the initial constructs identified. Next, the differences between second order constructs were synthesised to re order and rename the third order constructs. Finally, a line of argument synthesis was developed in order to offer a meaningful narrative around the third order constructs identified. |
| **Step Seven** | **Reporting of findings** |

## Results

### Description of the included studies

Following systematic review of the literature, eighteen studies were identified as suitable for inclusion (see Table 4). These studies were published between 2006 and 2023. Eight of the studies were conducted in the USA and Canada, and five in Australia. Studies from the UK, South Africa and Norway were also included.

Overall, the studies within the review included a total of 121 participants (72 male, 49 female) that were between the ages of 11 and 25 at the time of the study. Three of these participants' data was included in two studies. Two participants were aged 25, and this age range was included by Paniccia et al. (2019) due to it often being considered the "transition age” (p. 1332). Nine of the studies reported the participants’ age at the time of their brain injury with others reporting the amount of time that had passed since the injury. Some studies reported both. The time since the brain injury ranged from one week to 17 years. Four studies reported ethnicity, with participants being described as Caucasian (n=15), White British (n=6), Black (n=1), European (n=2), South Asian (n=1), East Asian (n=4), Middle Eastern (n=1), Latino (n=1) and European American and Hispanic (n=4). Four studies included participants that had had an ABI, with a mixture of ABI and TBI reported. The remaining 14 including participants who had experienced TBI, ranging from mild (multiple concussions for example) to severe.

Ten of the studies also included participants such as parents, friends, school teachers and professionals. Four studies interviewed either parents, friends, or siblings at the same time as the young person. The remaining six interviewed others separately to the young person. Due to the focus of the current review, studies were included where the individual views of adolescents and youths were clearly outlined in the reporting of the results.

Two studies (Mealings & Douglas, 2010; Mealings, Douglas & Olver, 2017) used the same data from three adolescent participants with different analyses and Quatman-Yates et al. (2021) used data that was part of a wider study.

Studies focussed on adolescent and parent or family experiences of service needs, quality of life, identity adjustment, communication, transitions around school and work related roles, coping, impact on family functioning and resilience, and factors influencing recovery and adjustment following a brain injury. They used varying qualitative methodologies for analysis of interview data including Interpretative Phenomenological Analysis (IPA), Grounded Theory, Thematic Analysis and qualitative analysis from a constructivist perspective.

**Table 4**

*Overview of studies analysed*

| Authors and Location | Study sample (adolescents and youth) | Interview type | Data analysis methodology | Study Aims | Note |
|---|---|---|---|---|---|
| Gagnon et al. (2008), Canada | Mild TBI<br>15 participants (10m, 5f), aged 12-16 years.<br>Time since injury: 3-15 months | Semi-structured individual interviews | Qualitative phenomenological | "To explore the specific service needs of adolescents (12-18 years) after a mTBI" | Sample also included separate parent interviews for each young person. |
| Di Battista et al. (2014), Australia | Mild- Severe TBI<br>10 participants (7m,3f), aged 13-19 years.<br>Time since injury: 1yr11ms to 10yr 9ms<br>Ethnicity: Caucasian Australians | Semi-structured individual interviews | Interpretative Phenomenological Analysis (IPA) | "To explore the individual, adolescent phenomenology of quality of life after brain injury" | |

| | | | | | |
|---|---|---|---|---|---|
| Glennon et al. (2022), UK | Acquired brain injury<br>6 participants (5m, 1f), aged 15-18 years.<br>Time since injury: 2-7 years<br>Injury type: 3 TBI and 3 ABI<br>Ethnicity: All White British | Semi-structured individual interviews | Novel relational qualitative grounded theory approach | “to develop an understanding of the process of identity adjustment following adolescent ABI, with sensitivity and attentiveness to the relational context of the parent-child dyad” | Sample also included separate parent interviews for each young person. |
| Buckeridge, Clarke and Sellers (2020), UK | Acquired brain injury<br>6 participants (4m,2f), 11-18.<br>Time since injury: 3-11 years<br>Injury type: 1 TBI and 5 ABI | Semi-structured individual interviews | IPA | “to explore adolescents’ everyday experiences of communication following ABI” | |

| | | | | |
|---|---|---|---|---|
| Paniccia et al. (2019), Canada | Acquired brain injury<br>14 participants (6m, 8f), aged 16-25 years.<br>Time since (most recent) injury: 0-17 years.<br>Ethnicity:<br>5 Caucasian, 2 European, 1 South Asian, 4 East Asian, 1 Middle Eastern, 1 Latino | Semi-structured individual interviews | Thematic analysis | “to provide insight on youth and young adults with ABI by examining young people’s experiences of, and transition towards work related roles” |
| Rodset (2008), Norway | Severe Traumatic Brain Injury<br>6 participants (4m, 2f)<br>Age at injury: 13-16 years.<br>Time since injury: 1.5-6.1 years. | Semi-structured individual interviews | Phenomenological-hermeneutic approach | “to examine the adolescents’ own experiences in a coping perspective, after being discharged from the rehabilitation hospital.<br>Question: How do adolescents with Traumatic Brain Injury experience and cope with their school situation?” |

| | | | | | |
|---|---|---|---|---|---|
| Sharp et al. (2006), Australia | Severe acquired brain injury<br>8 participants (5m, 3f), aged 14-19 years<br>Age at injury: 14-17 | Longitudinal design with interviews with parents present, a number of interviews over a period of up to 16 months | Grounded theory approach | “exploring longitudinally the return to school experiences of Australian adolescents with a recent severe ABI, and the experiences of their families” | Sample included parents. |
| Mealings and Douglas (2010), Australia | Severe Traumatic Brain Injury<br>3 male participants, aged 14-19<br>Age at injury: 13-17<br>Time since injury: 1 year 5 months – 3 years 4 months. | Semi-structured individual interviews | Grounded theory approach | “to hear the stories of three adolescent male students as they reflected on their own experiences of what it was like to go back to school after sustaining a severe TBI” | |
| Rennie and Goforth (2020), USA | Mild- Moderate Traumatic Brain Injury<br>4 participants (1m, 3f), aged 15-18 | Semi-structured individual interviews | Grounded theory approach | “examine the experiences of rural adolescents with TBI” | Sample included three parents interviewed separately. |

| | | | | | |
|---|---|---|---|---|---|
| | Age at injury: 8-16<br>Time since injury: 2 – 7 years.<br>Ethnicity: “European American and Hispanic” | | | | |
| Quatman-Yates et al. (2021), USA | Mild Traumatic Brain Injury<br>27 participants (13m, 14f) aged 13-17, all within one week of the injury. | Semi-structured interviews with parents | Thematic analysis | “explore adolescent and parent perceptions of the impact of the injury on family functioning and activity levels in the initial weeks following mTBI” | Parents interviewed at the same time as adolescents. Part of a bigger study. |
| Mealings, Douglas and Olver (2017), Australia | Severe Traumatic Brain Injury<br>3 male participants, aged 14-19<br>Age at injury: 13-17<br>Time since injury: 1 year 5 months – 3 years 4 months. | Semi-structured individual interviews | Grounded theory approach | “to provide a description of issues identified by students with TBI that affect educational participation beyond their academic performance” | Note use of same data from previous study. |

| | | | | | |
|---|---|---|---|---|---|
| Woods and Zachry (2023), USA | Traumatic Brain Injury (each participant – multiple concussions)<br>4 participants (3m, 1f) aged 16-17 years.<br>Time since injury: more than 2 years since initial TBI and less than a year since their most recent concussion | Semi-structured interviews with parents | Thematic cross-case analysis | “to gain an understanding of the shared perspectives of parental caregivers of parental caregivers and their adolescent children as to what factors supported and hindered recovery and adjustment after traumatic brain injury” | Sample included 5 parents |
| Gauvin-Lepage and Lefebvre (2010), Canada | Moderate Traumatic Brain Injury<br>3 participants (1m, 2f) aged 14-15 years.<br>Time since injury: 1- | Semi-structured individual interviews | Qualitative analysis from a constructivist perspective | “to explore the perceptions of adolescents, their parents and professionals as to the social inclusion of adolescents who have suffered a moderate TBI” | Sample included four parents interviewed separately and a focus group of four professionals. |

| | | | | | |
|---|---|---|---|---|---|
| | 3 years. | | | | |
| Jacobs-Nzuzi Khuabi, Swart and Soeker (2019), South Africa | Mild- Severe Traumatic Brain Injury<br>8 participants (5m, 3f), aged 15-20<br>Age at injury: 14-17<br>Time since injury: 1-5 years<br>Socioeconomic status reported as low-middle. | Semi-structured individual interviews | Qualitative analysis from a constructivist perspective | "to explore the perspectives on and experiences of high school learners and their relevant stakeholders regarding school reentry and school participation post TBI…" | Interviews were also conducted with each participants parent, teacher and school principal. |
| Drummond, Curtin and Shanahan (2014), Australia | Mild Traumatic Brain Injury<br>One female participant, aged 14 years (case study)<br>Time since injury: one year | Semi-structured interviews with both parent and friend | IPA | "to examine the impact of social communication impairment on the life of an adolescent with TBI, from the perspectives of the adolescent, one of her parents and a friend" | Two interviews were conducted, one with a parent and second with a parent and friend also. |

| | | | | | |
|---|---|---|---|---|---|
| Gauvin-Lepage (2019), Canada | Severe Traumatic Brain Injury<br>One female participant (case study)<br>Age at injury: 17 years | Semi-structured family interviews | Thematic content analysis | “to better understand the family resilience process within the context of a severe TBI during adolescence” | |
| Jacobs-Nzuzi Khuabi et al. (2022), South Africa | Traumatic Brain Injury<br>4 male participants aged 13-18 years<br>Age at injury: 8-13<br>Time since injury: 1-6 years<br>Class reported as poor and middle-class. | Semi-structured individual interviews | IPA | “…explore the lived experiences of adolescent learners with TBI from a low to middle-income context when they transition from primary to secondary school” | |
| Mayes (2018), USA | Moderate Traumatic Brain Injury | Semi-structured individual | Lens: Critical Race Theory and | “to garner an in-depth knowledge of experiences around the intersection of | Individual interviews were |

|  |  |  |  |  |  |
|---|---|---|---|---|---|
|  | One Black male participant (case study) age 16<br>Age at injury: 7th grade (12/13 years) | interviews | Disability Studies | TBI and giftedness for Black students” | also conducted with parent. |

## Assessment of Quality

All included studies clearly outlined the research aims and provided a rationale as to the value that the study would bring within the context of both previous literature and the clinical context of the country within which the research was being conducted. All of the research aims were related to exploration of participants’ views or developing understanding of participants’ experiences related to living with a brain injury, as such qualitative methodology was deemed appropriate for all studies. The research design therefore was also deemed to be appropriate for all but one study. Mealings, Douglas and Olver (2017) used the same participant data from Mealings and Douglas (2010). They reported that they had returned to the original interview transcripts with the view of broadening the focus. Both studies utilised a Grounded Theory methodology. The decision to complete a second analysis with a broader focus may have been influenced by the researchers as opposed to being data driven. However, each resultant theme was illustrated with direct participant quotations and the authors utilised several strategies to ensure credibility and trustworthiness.

Recruitment methods were detailed in all but one study and were deemed to be appropriate and ethical. Gauvin-LePage (2019) reported a case study of an adolescent following severe TBI. The method of recruitment was not discussed in the paper. It was difficult to ascertain if samples were representative due to the lack of reporting on demographic data including ethnicity and socioeconomic status. The two studies based in South Africa were the only ones to note participants’ social class status, which may reflect the importance of this within that cultural context. There were overall more males than females which is typical of studies considering brain injuries (especially TBI) as statistics demonstrate that males are more likely than females to experience a TBI (Goldman et al., 2022). Representativeness of the sample in qualitative research is deemed to be of less importance in comparison to quantitative due to the importance of exploring individual perspectives, and limited generalisability.

In relation to researcher reflexivity there was a relative weakness across eight of the studies in that this was either not discussed within the peer reviewed article (and therefore was assessed as “Can’t tell”), or it was evident that this had not been considered in terms of how the paper’s authors had reflected upon their own relationship with the participants and the data. Gagnon et al. (2008) for example, only reported that each researcher’s “interpretation and choices were questioned.” (p. 164) Overall, the studies were rated to have met the criteria on all or most of the other domains, and so were included in this study.

All studies included a clear statement of their findings; within the abstract, the results and further discussion. Some studies utilised diagrams and tables easily present the outcome of their analysis.

**Table 5**

*Assessment of study quality using CASP appraisal criteria for qualitative research (CASP, 2018)*

| Appraisal criteria for qualitative research | Gagnon et al. (2008) | Di Battista et al. (2014) | Glennon et al. (2022) | Buckeridge, Clarke & Sellers (2020) | Paniccia et al. (2019) | Rodset (2008) | Sharp et al. (2006) | Mealings & Douglas (2010) | Rennie & Goforth (2020) |
|---|---|---|---|---|---|---|---|---|---|
| Aims | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Method | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Design | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Recruitment | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Data Collection | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Reflexivity | No | Yes | Yes | Yes | Yes | No | Yes | No | Yes |
| Ethical Issues | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Data Analysis | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Findings | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Value | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |

| Appraisal criteria for qualitative research | Quatman-Yates et al. (2021) | Mealings, Douglas & Olver (2017) | Woods & Zachry (2023) | Gauvin-Lepage & Lefebvre (2010) | Jacobs-Nzuzi Khuabi, Swart & Soeker (2019) | Drummond, Curtin & Shanahan (2014) | Gauvin-Lepage (2019) | Jacobs-Nzuzi Khuabi et al. (2022) | Mayes (2018) |
|---|---|---|---|---|---|---|---|---|---|
| Aims | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Method | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Design | Yes | Can’t Tell | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Recruitment | Yes | Yes | Yes | Yes | Yes | Yes | Can’t Tell | Yes | Yes |
| Data Collection | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Reflexivity | Yes | No | Can’t Tell | No | Yes | Yes | No | Yes | Can’t Tell |
| Ethical Issues | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Data Analysis | Yes | No | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Findings | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Value | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |

## Synthesis findings

Overall, 37 second order constructs were identified and synthesised into six third order constructs (See Appendix A for full synthesis). These third order constructs are best understood under two different headings. Firstly, “Navigating new landscapes” consists of *1) navigating the new landscape of life with a brain injury; direct consequences, 2) navigating the relational landscape of life with a brain injury; peer and support relationships, 3) an altered family landscape in life with a brain injury; relational dynamics and support.* Further, “Individual cognitive and emotional processes” consists of *4) cognitive processes in relation to understanding changes, 5) cognitive and emotional processes of adjustment to changes and loss 6) coping and post-traumatic growth.*

### Navigating new landscapes

### Navigating the new landscape of life with a brain injury; direct consequences

This third-order construct describes the disruption that is caused to daily life by the direct consequences of a brain injury and how young people found themselves having to navigate this new landscape.

Twelve studies identified themes relating to the direct sequalae of brain injury experienced by young people. Nine studies identified constructs of having to manage the symptoms of the brain injury (Buckeridge, Clarke & Sellers, 2020; Drummond, Curtin & Shanahan, 2014; Gagnon et al., 2008; Gauvin-LePage & Lefebvre, 2010; Jacobs-Nzuzi Khuabi et al., 2022; Quatman-Yates et al., 2021; Rennie & Goforth, 2020; Sharp et al., 2006; Woods & Zachry, 2023), this included the broad range of consequences of a brain injury including the physical, emotional, cognitive, educational and social sequelae. These symptoms were identified to be disruptive to the young person’s life; “[the injury] threw a wrench in my normal day to day life” (Quatman-Yates et al., 2021, p.283). Another common theme identified in four studies was the importance of having information about brain injuries, particularly in order for young people and their families to be able to make decisions in relation to rest and recovery, so that they could work towards resuming participation in daily life. A lack of information or knowing who they could ask regarding brain injuries was linked to reports of anxiety and uncertainty.

Some sequelae were noted to impact the relationship adolescents had with the world, for example through spoken language but also through “changes in internal state, with a focus on anxiety, avoidance and hesitancy” (Rennie & Goforth, 2020, p.96). This demonstrates not only the impact of the brain injury itself but also the circumstances surrounding the injury and the emotional impact of this.

Six studies specifically referenced the challenges that young people faced due to the invisible and subtle nature of some of the consequences of a brain injury; for example noting that at times they felt misunderstood, or that their difficulties went unacknowledged by those around them: “just ‘cause I’m walking doesn’t mean that everything in my head’s ticking correctly” (Mealings, Douglas & Olver, 2017, p.444). This is also related to the theme of young people having to contend with poor awareness and understanding of brain injury within their communities. This compounded their feelings of being misunderstood, or that their needs were not always met.

Table 6 outlines examples of the first and second-order constructs that were synthesised to develop this third order construct.

**Table 6**

*Exemplar first and second order constructs synthesised in the development of the third-order construct; "Navigating the new landscape of life with a brain injury; direct consequences"*

| Example first-order constructs (direct participant quotations) | Example second-order constructs (direct author quotations) | Studies containing construct | Second-order theme (reviewer interpretation) | Third-order construct |
|---|---|---|---|---|
| "basically all I wanted was to get rid of the headaches, they were so bad and everything they gave me wouldn't work" (Gagnon et al., 2008, p.165) | "needs related to the impairments, activity limitations and participation restrictions secondary to the mTBI" (Gagnon et al., 2008, p.165) | -Gagnon et al. (2008)<br>-Sharp et al. (2006)<br>-Quatman-Yates et al. (2021) | | **Navigating the new landscape of life with a brain injury; direct consequences** |
| "I remember just being like so tired that I couldn't respond in the way I wanted to if at all, and thinking, oh no I've kind of ruined it with that person or this teacher doesn't think that I'm kind of bright enough or something" (Buckeridge et al., 2020, p.103) | "it exposed a disturbance in the relationship adolescents had with the world through their spoken language" (Buckeridge et al., 2020, p .106) | -Buckeridge et al. (2020)<br>-Drummond, Curtin & Shanahan (2014) | | |

| | | | |
|---|---|---|---|
| “because of the accident, I could say something to someone’s face… I wasn’t like that before” (Gauvin-Lepage & Lefebvre, 2010, p.1091) | “Consequences of TBIs are neurological, cognitive, behavioural and social” (Gauvin-Lepage & Lefebvre, 2010, p.1090) | -Rennie & Goforth (2020)<br>-Woods & Zachry (2023)<br>-Gauvin-Lepage & Lefebvre (2010)<br>-Jacobs-Nzuzi Khuabi et al. (2022) | |
| “my ABI is invisible to others, but present nonetheless” (Pannicia et al., 2019, p.1333) | “Noticeable problems”<br>“because their impairments were not physical in nature, it was difficult for others to believe that they were struggling, or in need of accommodations. For these reasons, they often felt misunderstood” (Paniccia et al., 2019, p.1336) | -Sharp et al., (2006)<br>-Gagnon et al. (2008)<br>-Buckeridge, Clarke & Sellers (2020)<br>-Paniccia et al. (2019)<br>-Sharp et al. (2006)<br>-Mealings, Douglas & Olver (2017)<br>-Gauvin-Lepage & Lefebvre (2010) | Managing poor awareness, understanding and the invisible nature of brain injury |
| “…but most of them don’t understand” (Mealings, Douglas & Olver, 2017, p.444) | “TBI is not a widely recognised or well understood concept in most communities…this reduced awareness and lack of understanding may lead to misdiagnosis of the | -Mealings, Douglas & Olver (2017)<br>-Rodset (2008)<br>-Sharp et al. (2006) | |

| | | | |
|---|---|---|---|
| | student’s needs” (Mealings, Douglas & Olver, 2017, p.444) | -Rennie & Goforth (2020)<br>-Jacobs-Nzuzi Khuabi, Swart & Soeker (2019) | |
| “my parents contacted the school” (Jacobs-Nzuzi Khuabi et al., 2019, p.10) | Educating teachers and peers | -Sharp et al. (2006)<br>-Jacobs-Nzuzi Khuabi et al. (2019) | |
| “when it first happened, all I wanted to know what how bad my head injury was. Because I have had so many concussions, I was really worried because the doctors always said don’t hit your head again, because it could be the last time. And so I was really worried about that” (Gagnon et al., 2008, p.166) | “Information was requested primarily about the circumstances of the injury (what happened), mTBI sequelae and recovery (what to expect) and about the return to activities (what can I do now?)” (Gagnon et al., 2008, p.165) | -Gagnon et al. (2008)<br>-Rennie & Goforth (2020)<br>-Woods & Zachry (2023)<br>-Jacobs-Nzuzi Khuabi, Swart & Soeker (2019) | Anxiety around needing information |

### Navigating the relational landscape of life with a brain injury; peer and support relationships

This third order construct acknowledges the impact of the brain injury and its consequences on the relationships within an adolescent's life, specifically their peer group and the wider community in terms of support systems and education.

Thirteen studies highlighted a theme related to the impact of having a brain injury on an individual's social experience and how they were perceived by others. For many young people, there was a great deal of importance placed on "fitting back in" to their peer group and friendship groups, typically following an acute period of absence. Participants reported a sense of feeling like outsiders and experiencing the prejudices of their peers, including being thought of as a "weirdo" (Glennon et al., 2022, p.1914), "mad" (Jacobs-Nzuzi Khuabi et al., 2019, p.8), or "crazy" (Woods & Zachry, 2023, p.6). Some participants also reported being teased. The challenge faced by young people with a brain injury was described by Sharp et al. (2006) as "the challenge to be 'equal', not 'alienated' and to 'prove' they were the 'same'" (p.774). One participant described this as "like trying to fit a square into a circle" (Sharp et al., 2006, p. 774) as individuals were inevitably changed by their injury.  Some participants also noted the impact of their injury on their own engagement in social situations; "I find it hard to say things, so I just don't bother, I just sit there" (Drummond, Curtin & Shanahan, 2014, p.130) and "well I didn't want to be around anybody [be]cause…I got irritated really easily…that was a side effect" (Woods & Zachry, 2023, p.7).

There was a range of responses from peers and other networks in relation to the brain injury; some participants talked of losing friends, whereas others noted that their friends were supportive and accommodating of their newfound difficulties or needs. The importance of positive responses from peers was reflected particularly by one participant who noted "that if

I hadn’t had my friends, I wouldn’t have gone back to school” (Gauvin-Lepage & Lefebvre, 2010, p. 1092).

There is great meaning and value placed by young people on returning to school, with school being seen as “a normal part of life, making it a natural step in their life participation after injury” (Mealings & Douglas, 2010, p.6). Young people saw school as important as it provided routine, opportunities to socialise and symbolised progression post- brain injury. Eleven studies referenced the importance to young people of participating in school and having their educational needs understood.

Young people highlighted the impact of their injury on participating in school, including difficulties with fatigue, concentration and processing speed (Gauvin-LePage & Lefebvre, 2010; Jacobs-Nzuzi Khuabi et al., 2022). The interventions or accommodations provided by professionals were therefore deemed to be important to adolescents in order to aid their ability to participate (Gagnon et al, 2008). How successful or helpful accommodations were thought to be related to how the young person felt they were progressing academically but also how they maintained their independence within that; “students were more likely to accept help when they felt they were contributing… when they were involved in the decision making and when the assistance supported them to do the work on their own” (Mealings & Douglas, 2010, p.9).

Much like with peers, individuals experienced a range of responses from teachers, from feeling that the teachers did not really understand to teachers making more time and being flexible (Jacobs-Nzuzi Khuabi et al., 2022). How teachers responded to young people was particularly important in that their “feelings about teachers’ behaviour toward them contributed to whether school provided positive or negative learning experiences” (Buckeridge, Clark & Sellers, 2020, p.106).

Table 7 outlines examples of the first and second-order constructs that were synthesised to develop this third-order construct.

**Table 7**

*Exemplar first and second order constructs synthesised in the development of the third-order construct; "Navigating the relational landscape of life with a brain injury; peer and support relationships"*

| Example first-order constructs (direct participant quotations) | Example second-order constructs (direct author quotations) | Studies containing construct | Second-order theme (reviewer interpretation) | Third-order construct |
|---|---|---|---|---|
| "Susan described this as 'like trying to fit a square into a circle'" (Sharp et al., 2006, p. 774)<br>"I try my best and they don't really care, and I feel left out, like always I feel left out" (Rennie & Goforth, 2020, p.96) | Fitting back in;<br>"This is the challenge to be 'equal', not 'alienated' and to 'prove' they were the 'same'. This challenge was inherently difficult as the adolescents were no longer the same as a result of their injury and experiences" (Sharp et al., 2006, p.774) | -Glennon et al. (2022)<br>-Buckeridge, Clarke & Sellers (2020)<br>-Sharp et al. (2006)<br>-Rennie & Goforth (2020)<br>-Mealings, Doulgas & Olver (2017)<br>-Jacobs-Nzuzi Khuabi, Swart & Soeker (2019) | Group and peer relationships | **Navigating the relational landscape of life with a brain injury; peer and support relationships** |
| "well I didn't want to be around anybody [be]cause… I got irritated really easily…that was a | Impact of brain injury on social experiences and friendships; | -Rodset (2008)<br>-Woods & Zachry (2023)<br>-Gauvin-Lepage & | | |

| | | |
|---|---|---|
| side effect.” (Woods & Zachry, 2023, p.7) | | Lefebvre (2010) |
| “I find it hard to say things, so I just don’t bother, I just sit there” (Drummond, Curtin & Shanahan, 2014, p.130)<br>“my friend group that I had before, stopped being my friends and I was kind of alone” (Jacobs-Nzuzi Khuabi, Swart & Soeker, 2019, p.10) | “given the impact of the TBI on the learner’s interpersonal interactions, the adjustment to the changed life circumstances often resulted in decreased social interaction and the loss of friendships” (Jacobs-Nzuzi Khuabi, Swart & Soeker, 2019, p.10) | -Jacobs-Nzuzi Khuabi, Swart & Soeker (2019)<br>-Drummond, Curtin & Shanahan (2014)<br>-Jacobs-Nzuzi Khuabi et al. (2022)<br>-Mayes (2018) |
| “they just acted like everyone else. My friends didn’t care if I was hit by a car or anything like that” (Mealings & Douglas, 2010, p.9) | “When the adolescents returned to school, responses from teachers and peers… had to be positive enough to allow the adolescents to feel well supported at school” (Sharp et al., 2006, p.775) | -Sharp et al. (2006)<br>-Mealings & Douglas (2010)<br>-Rennie & Goforth (2020)<br>-Jacobs-Nzuzi Khuabi, Swart & Soeker (2019) |

| | | | |
|---|---|---|---|
| “I believe that if I hadn’t had my friends, I wouldn’t have gone back to school” (Gauvin-Lepage & Lefebvre, 2010, p.1092)<br>“my friends have been accommodating. They look after me” (Woods & Zachry, 2023, p.7) | Support of friends;<br>“the importance of connection, empathy and social support” (Woods & Zachry, 2023, p.7) | -Gagnon et al. (2008)<br>-Woods & Zachry (2023)<br>-Gauvin-Lepage (2019)<br>-Quatman-Yates et al. (2021)<br>-Gauvin-Lepage & Lefebvre (2010)<br>-Jacobs-Nzuzi Khuabi et al. (2022) | Support |
| “I mean, a lot of people prayed. I mean we had Priests all over the world praying” (Jacobs-Nzuzi Khuabi, Swart & Soeker, 2019, p.10)<br>“teachers didn’t really see the concussion as a big thing, they didn’t really believe in it” (Mayes, 2018, p.148) | “Support from community partners” (Gagnon et al., 2008, p.167) | -Gagnon et al. (2008)<br>-Sharp et al. (2006)<br>-Jacobs-Nzuzi Khuabi et al. (2022)<br>-Mayes (2018) | |

| | | |
|---|---|---|
| “they did help me [the teachers] and kinda helped like if they knew what happened and then they told me like after school if I didn’t understand and so on I can come back and they will explain the work to me…” (Jacobs-Nzuzi Khuabi et al., 2022, p.40) | | |
| “so I was really in the dark as far as what I can do and what cant I do and it seems like the doctor that I was seeing didn’t really care” (Paniccia et al., 2019, p.1337) | Navigating support systems to transition to work (Paniccia et al., 2019) | -Paniccia et al. (2019) |
| “then they fired me. Then I was like “you let me go because I have an injury and I cant come to work?” and they never replied” (Paniccia et al., 2019, p. 1337) | | |

| | | | |
|---|---|---|---|
| “they’re just, they give you space, they, they let you do whatever but they just help you where they gotta help you”<br>“If I need help they [integration aides] just try to, not tell me but just [help me] figure it out” (Mealings & Douglas, 2010, p.9) | Quality of support;<br>“students were more likely to accept help when they felt they were contributing…when they were involved in the decision making and when the assistance supported them to do the work on their own” (Mealings & Douglas, 2010, p.9) | -Mealings & Douglas (2010) | |
| “I really wanted to go back… school’s a big part of your life for 13 years, you know it just gets routine… so I sort of needed that just for a routine” (Mealings & Douglas, 2010, p.6)<br>“It was like, that was the whole point of me wanting to go back to school, like hang out with my friends” (Mealings & Douglas, | Meaning and value in participating in school<br>“students generally saw the role of school as a normal part of life, making it a natural step in their life participation after injury” ( Mealings & Douglas, 2010, p. 6) | -Mealings & Douglas (2010)<br>-Mealings, Douglas & Olver (2017)<br>-Jacobs-Nzuzi Khuabi, Swart & Soeker (2019) | The role of school in recovery; educational and social needs |

| | | |
|---|---|---|
| 2010, p.6) | “this reflects the role of the school in the learner’s journey to recovery and adaptation post TBI. It includes views of how non-participation in school impacted on their recovery post TBI as well as how the school served as a vehicle for learners to progress post TBI.” (Jacobs-Nzuzi Khuabi, Swart & Soeker, 2019, p.4) | |
| “I’d like to go to a school where they understand me and stuff… just that really. Where they actually understand how hard things are for me” (Quatman-Yates et al., 2021, p.)<br>“I wasn’t all there… I was a bit lost because I wasn’t | Life in the classroom, understanding of individual needs<br>“participants’ feelings about teacher’s behaviour toward them contributed to whether school provided positive and negative learning experiences” (Buckeridge, | - Buckeridge, Clarke & Sellers (2020)<br>- Rodset (2008)<br>- Rennie & Goforth (2020)<br>- Quatman- Yates et al. (2021)<br>-Jacobs-Nzuzi Khuabi, Swart & Soeker (2019) |

| | | |
|---|---|---|
| thinking straight, and I was a bit tired” (Gauvin-Lepage & Lefebvre, 2010, p.1092)<br>“Also for me when I went back, because I used to be quite academic, they put me in the academic class where everyone, it was the highest class with the smartest people in it, which maybe wasn’t the best idea initially” (Jacobs-Nzuzi Khuabi, Swart & Soeker, 2019, p.7)<br>“…after the accident I was slow, and I took my time to answer the question the teacher put on the board” ( Jacobs-Nzuzi Khuabi et al., 2022, p.39) | Clarke & Sellers, 2020, p.106)<br>“the implications of participants not understanding what was being asked of them ranged from getting angry, misbehaving or being left in a state of confusion” (Buckeridge, Clarke & Sellers, 2020, p.106) | -Jacobs-Nzuzi Khuabi et al. (2022)<br>- Mayes (2018) |

| | | |
|---|---|---|
| “I had meetings or something like that… with some of my teachers, my integration aide, people from rehab…” (Mealings, Douglas & Olver, 2017, p.444)<br>“they would allow me to take breaks or leave school in the day whenever I was feeling bad or had a headache… that was probably the best thing” (Quatman-Yates et al., 2021, p.286)<br>“The people at the hospital should tell the school more about brain injury” (Jacobs-Nzuzi Khuabi, Swart & Soeker, 2019, p.6) | Back to school support and planning<br>“communication between professionals working with adolescents was described as poor overall, including communication between medical providers and the schools” (Rennie & Goforth, 2020, p. 99) | -Rodset (2008)<br>-Sharp et al. (2006)<br>- Rennie & Goforth (2020)<br>- Quatman-Yates et al. (2021)<br>- Mealings, Douglas & Olver (2017)<br>- Jacobs-Nzuzi Khuabi, Swart & Soeker (2019)<br>- Gauvin-Lepage (2019) |

## An altered family landscape in life with a brain injury; relational dynamics and support

Nine studies (Di Battista et al., 2014; Gagnon et al., 2008; Gauvin-LePage & Lefebvre, 2010; Gauvin-LePage, 2019; Jacobs-Nzuzi Khuabi, Swart & Soeker , 2019;  Jacobs-Nzuzi Khuabi et al., 2022; Rennie & Goforth, 2020; Quatman-Yates et al., 2021; Woods & Zachry, 2023) highlighted the impact of the brain injury on the wider family network and how parents were seen by young people as crucial to their recovery from brain injury.

The changes post-injury altered the family dynamics, as noted in references to differences including “Mum has to help me a lot more, she has to help me with a whole lot more in my life” (Di Battista et al., 2014, p. 980) and “it’s been hard for my brother…just trying not to be as loud” (Quatman-Yates et al., 2021, p.287). Participants also noted the strain that such changes and the circumstances surrounding the injury had on their parents, noting their levels of worry about them, stress, and with one participant recognising “it was the hardest time of her [Mothers] life” (Woods & Zachry, 2023, p.6). The value, however, of parental support can not be understated and adolescents recognised the role that this played in their outcomes and progress; “I wouldn’t be how I am today without them, without their help, I think that’s what made the difference” (Gauvin LePage, 2019, p.3). Participants viewed the support from their family as essential.

Table 8 outlines examples of the first and second-order constructs that were synthesised to develop this third-order construct.

**Table 8**

*Exemplar first and second order constructs synthesised in the development of the third-order construct; "An altered family landscape in life with a brain injury; relational dynamics and support"*

| Example first-order constructs (direct participant quotations) | Example second-order constructs (some direct author quotations) | Studies containing construct | Second-order theme (reviewer interpretation) | Third-order construct |
|---|---|---|---|---|
| …"she was very stressed out. And… I could feel the stress." (Woods & Zachry, 2023, p.6).<br>"they're still worried about me. They're still looking out for me" (Gauvin-Lepage & Lefebvre, 2010, p.1091). | Parental stress and guilt; recognition of the impact on parents. | -Woods & Zachry (2023)<br>- Gauvin-Lepage & Lefebvre (2010) | Family Impact | **An altered family landscape in life with a brain injury; relational dynamics and support** |
| "Mum has to help me a lot more, she has to help me with a whole lot more in my life" (De Battista et al., 2014, p.980)<br>"it's been hard for my brother…just trying not to | Family relationships and roles; "post injury changes resulted in altered family dynamics; e.g how the adolescent saw themselves as part of the family system, their role within the family and their | -De Battista et al. (2014)<br>-Quatman-Yates et al. (2021)<br>-Woods & Zachry (2023)<br>- Gauvin-Lepage & | | |

|  |  |  |
|---|---|---|
| be as loud” (Quatman-Yates et al., 2021, p.287) | perceived responsibility for those changes” (Di Battista et al., 2014, p.980) | Lefebvre (2010) |
| “my family played the supporting role. It’s a role that they like never gave up on me” (Jacobs-Nzuzi, Swart & Soeker, 2019, p.10)<br>“my parents were there for me… I wouldn’t be how I am today without them, without their help, I think that’s what made the difference” (Gauvin-Lepage, 2019, p.3)<br>“I didn’t understand, I really needed my Mom there, she was there…” (Gagnon et al., 2008, p.167) | Family support; “parents being present and patient in the helping process” (Rennie & Goforth, 2020, p. 97) | -Gagnon et al. (2008)<br>-Rennie & Goforth (2020)<br>-Jacobs-Nzuzi Khuabi, Swart & Soeker (2019)<br>-Gauvin-Lepage (2019)<br>-Jacobs-Nzuzi Khuabi et al. (2022) |

### Individual cognitive and emotional processes

Through synthesis of the 18 studies, the individual processes implicated in managing the impact of brain injury on life were evident. This seemed best understood in stages of progression, the following third-order constructs reflect the different individual processes in relation to change and progression following brain injury.

### Cognitive processes in relation to understanding changes

The first step identified through this review for an individual with a brain injury is recognition of the changes resulting from the injury. This mostly seemed to occur through comparisons between the perceived current self post-injury and the past self, unlived self, social self and peers. Through this comparison process, individuals perceived discrepancies which they labelled in relation to life “before” and life “after” the brain injury (Di Battista et al., 2014). Ten of the 18 studies noted themes that spoke to such processes.

Some participants noted particular skills or traits that they felt were changed post-injury, whereas others described a more global sense of change; “I was a different person when I came back” (Glennon et al., 2022, p.1913). Two studies (Di Battista et al., 2014; Glennon et al., 2022) noted that adolescents’ explanations of or understanding of changes were often tied to the social context, for example “before the incident in uh like primary school I used to be quite vocal about things… more confident…in high school… due to that incident… I became very quiet, shy”. This reflects the importance of this particular stage of development, as during adolescence, the “individual self is very much entrenched in the social arena” (Di Battista et al., 2014, p. 981).

The nature of change was also discussed in the context that there is an acute phase following injury, after which “things improved a bit” (Gauvin-LePage & Lefebvre, 2010, p. 1091) but that there are also some changes and disruptions that can still have an impact years later.

As part of the process of recognising changes and discrepancies, individuals also then tried to make sense of these changes, through attributing them. Four studies (Di Battista et al., 2014; Gauvin-LePage & Lefebvre, 2010; Mealings, Douglas & Olver, 2017; Rennie & Goforth, 2020) specifically spoke to the difficulties that some young people and those around them experienced in knowing what to attribute to the brain injury, and what to attribute to adolescence, maturational processes, or individual character. How changes were attributed was related to subsequent challenges, for example if (by self and others) changes were attributed to character, ageing or adolescence then responses were different and accommodations less likely to be made, for example with issues such as “lack of motivation…. forgetfulness and poor social regulation” (Mealings, Douglas & Olver, 2017, p.444).

Not only were the perceived changes attributed to something in the meaning making process, they were also appraised; “Not all changes were identified as positive experiences, especially where the change restricted the students’ participation in activities they had previously enjoyed” (Mealings & Douglas, 2010, p.8).

It is important to note that “those participants who had a brain injury when young did not see themselves as a changed person as they had fewer memories of their life before ABI. Their …difficulties were already embedded within their identity and so were part of their biography. In contrast, participants who had a brain injury in adolescence had a clear sense of two different periods in their lives” (Buckeridge, Clarke & Sellers, 2020, p. 105).

Table 9 outlines examples of the first and second-order constructs that were synthesised to develop this third-order construct.

**Table 9**

*Exemplar first and second order constructs synthesised in the development of the third-order construct; "Cognitive processes in relation to understanding changes"*

| Example first-order constructs (direct participant quotations) | Example second-order constructs (direct author quotations) | Studies containing construct | Second-order theme (reviewer interpretation) | Third-order construct |
|---|---|---|---|---|
| "if I wouldn't have had the accident, I would've been in the big class with everyone else" (Glennon et al., 2022, p.1913)<br>"Knowing I could do something beforehand, before my accident and then knowing I couldn't do it now… just messed with my head" (Mealings & Douglas, 2010, p.7)<br>"before the incident in uh like primary school I used to be quite vocal about things… more confident… in high school… due to that | "adolescents described to varying degrees how they experienced tensions between change and continuity across different aspects of 'self'… Those arose where the adolescent reflected on their past self, their lost future self or compared themselves to others" (Glennon et al., 2022, p.1912)<br>"personal and social discrepancy processes were identified. This process is defined as the labelling of differences and providing insights between life "before" (i.e pre-injury) | - De Battista et al. (2014)<br>- Glennon et al. (2022)<br>- Rodset (2008)<br>- Mealings & Douglas (2010)<br>- Mealings, Douglas & Olver (2017)<br>- Jacobs-Nzuzi Khuabi et al. (2022) | Recognising and appraising change through comparisons between past self/ unlived self/ social self and peers | **Cognitive processes in relation to understanding changes** |

| | | |
|---|---|---|
| incident… I became very quiet, shy" (De Battista et al., 2014, p. 980) | and life "after" (i.e post-injury)." (Di Battista et al., 2014, p.980) | |
| "It took six months before things improved a bit" (Gauvin-Lepage & Lefebvre, 2010, p.1091) | The nature of change (sudden or gradual, short-term or long-term)<br>"all participants remained affected by these [social] disruptions several years later" (Rennie & Goforth, 2020, p.100) | - Rennie & Goforth (2020)<br>- Mealings, Douglas & Olver (2017)<br>- Gauvin-Lepage & Lefebvre (2010) |
| "having the brain tumour, it was a big sort of… part of my life. Like there was my life prior to the tumor and then my life now after the tumour which is, I dunno, it just seems worlds apart" (Buckeridge, Clarke & Sellers, 2020, p. 102) | Self-concept change<br>"those participants who had a brain injury when young did not see themselves as a changed person as they had fewer memories of their life before ABI. Their communication difficulties were already embedded within their identity and so were part of their biography. In contrast, participants who had a brain injury in adolescence had a clear sense of two | - Buckeridge, Clarke & Sellers (2020)<br>- Mealings, Douglas & Olver (2017)<br>- Jacobs- Nzuzi Khuabi, Swart & Soeker (2019) |

| | | | |
|---|---|---|---|
| | different periods in their lives” (Buckeridge, Clarke & Sellers, 2020, p.105) | | |
| “I gave [piano] up…the piano was a huge part of my life and I sort of moved on to academics but I don’t know whether that’s just me growing up or me after a car accident” (De Battista et al., 2014, p.980) | Attribution of changes by self and others “attributions for changes to abilities post injury were made to either normal age related attributions or the TBI sequalae” (De Battista et al., 2014, p.980)<br>“common changes caused by TBI may present in a student that mimics other issues such as disinterest, lack of motivation, laziness, forgetfulness and poor social regulation. Without a clear understanding of why these issues are occuring, it is easy to attribute student’s presentation to their character or adolescent stage of life” (Mealings, Douglas & Olver, 2017, p. 444-445). | - De Battista et al. (2014)<br>- Rennie & Goforth (2020)<br>- Mealings, Douglas & Olver (2017)<br>- Gauvin-Lepage & Lefebvre (2010) | Attribution and appraisal of changes |

| | | |
|---|---|---|
| | Appraisal of changes<br>“participants’ attitudes changed and included positive and negative interpretations of the unfolding of injury-related sequelae” (Rennie & Goforth, 2020, p. 95) | - Mealings & Douglas (2010)<br>- Rennie & Goforth (2020)<br>- Jacobs-Nzuzi Khuabi et al. (2022) |

## Cognitive and emotional processes of adjustment to changes and loss

Once the changes and discrepancies have been recognised, depending on how they have been appraised and attributed individuals then appear to go through a process of adjustment, including the processing of any feelings of grief or loss related to change. The importance of going through the process of acknowledging difficulties or limitations was noted in that in circumstances where this did not happen, and where individuals did not make any adjustments in their life, recovery was seen to be impeded or indeed “reversed” (Paniccia et al., 2019). Glennon et al. (2022) noted that “the ways in which participants made sense of or tried to resolve or acknowledge issues of change and continuity resonated across all accounts, representing a range of complete or partial acknowledgment or rejection of the injury and changes” (p. 1914). There appeared to therefore be individual differences in this, including in rejection of any labels that come with the injury such as disabled or “not normal”. The social context of such labels is also acknowledged when considering also the relevance of adolescence; “adolescents become very sensitive to comments and opinions expressed by others and this can make it difficult for them to develop self-esteem” (Gauvin-LePage & Lefebvre, 2010, p.1091). The social implications of acknowledging or rejecting certain changes and the associated labels is relevant.

Adjusting to personal loss meant also acknowledging a loss of certainty and confidence, for example “in the way that you think your life will travel” (Sharp et al., 2006, p. 774), one individual noted “I wanted to become a scientist, and now I see science is not for me. I do not know what I want to be” (Jacobs-Nzuzi Khuabi, Swart & Soeker, 2019, p.9). Adjustments that were made, were made in relation to future goals, with alternative recreational or sports activities and goals pursued. Table 10 outlines examples of the first and second-order constructs that were synthesised to develop this third-order construct.

**Table 10**

*Exemplar first and second order constructs synthesised in the development of the third-order construct; "Cognitive and emotional processes of adjustment to changes and loss"*

| **Example first-order constructs (direct participant quotations)** | **Example second-order constructs (some direct author quotations)** | **Studies containing construct** | **Second-order theme (reviewer interpretation)** | **Third-order construct** |
|---|---|---|---|---|
| | Impact on self esteem<br>"this a fragile time in one's life and a TBI exacerbates all the attendant problems. Adolescents become very sensitive to comments and opinions expressed by others and this can make it difficult for them to develop self-esteem" (Gauvin-Lepage & Lefebvre, 2010, p. 1091) | - Gauvin-Lepage & Lefebvre (2010) | | **Cognitive and emotional processes of adjustment to changes and loss** |
| "I just want to be normal, I want to kind of see myself as a normal person" | Acknowledging and rejecting | - Glennon et al. (2022) | | |

|  |  |  |
|---|---|---|
| (Glennon et al., 2022, p.1914) | “the ways in which participants made sense of or tried to resolve or acknowledge issues of change and continuity resonated across all accounts, representing a range of complete or partial acknowledgement or rejection of the injury and changes” (Glennon et al., 2022, p.1914) |  |
| “just the fact that I had to hold back a little bit on what I’d normally like to do” (Paniccia et al., 2019, p.1335) | Realising and adapting to post ABI qualities<br>“it was important for young people to see progress in recovering from the ABI and accept their limitations because this helped them to avoid being in a situation that could potentially reverse their recovery”<br>“when youth and young adults with ABI refused to acknowledge a change in their pre and post ABI capabilities, recovery appeared to be impeded” | Paniccia et al. (2019) |

| | | |
|---|---|---|
| | (Paniccia et al., 2019, p.1339) | |
| “I know I could have been so good, but now I don’t think I can, I really don’t. I think I have lost too much” (Sharp et al., 2006, p. 774)<br>“I wanted to become a scientist, and now I see science is not for me. I do not know what I want to be” (Jacobs-Nzuzi Khuabi, Swart & Soeker, 2019, p. 9) | Adjusting to personal loss | - Sharp et al. (2006)<br>- Mealings, Douglas & Olver (2017)<br>- Jacobs-Nzuzi Khuabi, Swart & Soeker (2019) |

## Coping and Post-Traumatic Growth

Finally, the last third-order construct is related to coping experiences and post-traumatic growth that individuals identified as part of their experience of living with a brain injury. Di Battista et al. (2014) noted that "coping occurs acutely post-injury, whereas PTG [post-traumatic growth] is an incremental, enduring psychological change that develops post-injury." (p. 46).

Eleven studies reflected the various strategies and learning experiences individuals shared that lead to a perceived sense of progress and moving forward from the injury. Some strategies were practical ones that supported difficulties with communication and memory, whereas others were the adjustment of goals, and continued exploration of "gifts and future plans" (Mayes, 2018, p.150) that led to "happiness and a sense of accomplishment (Woods & Zachry, 2023, p.7). Two studies (Jacobs- Nzuzi Khuabi et al., 2022; Pannicia et al., 2019) specifically spoke of taking control of your own experience as a strategy individuals found gave a sense of purpose and enabled them to transition back to school and participate. As part of this taking control, linked to the previously discussed hidden nature of brain injuries for some, individuals had the ability to decide if and how they disclosed the information about their injury to others. Independence was also discussed previously in relation to the perceived success and acceptability of support and accommodations. Independence is also an important task of adolescence and may be particularly important to those at this life stage.

Finding meaning in the injury and its consequences enabled individuals to gain a sense of purpose. Such positive appraisals of circumstances helped individuals to progress towards different goals and the future; "[my ABI] helped me because I've like grown from those experiences. Since I stopped playing hockey it's kind of been my goal to be a sports medicine doctor. I get to make a difference and help kids that I pretty much was not too long ago. It's the ability to go back and to help, just to know that like my experience and what I do there can help other kids that have been concussed" (Paniccia et al., 2019, p. 1338). Individuals also reported a change in perspective on the meaning of things in their lives; "I would tell the younger me that, you know your health is more important than your high school football team" (Paniccia et al, 2019, p. 1335). One also spoke of realising "how fast life can be taken away" (Rennie & Goforth, 2020, p.96). Changes in perspective also related to a change in how individuals viewed the injury in their life narrative; "I'm trying to see it as more of a positive thing than as a negative thing, because seeing it as something that's always holding me back, then I'm always going to be held back for the rest of my life" (Glennon et al., 2022, p.1918) and also individuals relationship with themselves; "because if I didn't believe in myself then I didn't really have anyone who did, and if I didn't believe I could do it then I wouldn't be able to do it" (Rennie & Goforth, 2020, p.95).

Table 11 outlines examples of the first and second-order constructs that were synthesised to develop this third-order construct.

**Table 11**

*Exemplar first and second order constructs synthesised in the development of the third-order construct; "Coping and Post-traumatic growth"*

| Example first-order constructs (direct participant quotations) | Example second-order constructs (direct author quotations) | Studies containing construct | Second-order theme (reviewer interpretation) | Third-order construct |
|---|---|---|---|---|
| "I started making music. I did that all the time 'cause I didn't have anything else to do" (Woods & Zachry, 2023, p.7)<br>"so, like on my phone also I will put the alarm on and a reminder and then I would like put the heading of the reminder, like state everything that I have to do" (Mayes, 2018, p. 40)<br>"[typing is] just easier, 'cause I don't have to verbally say it, I just type it." (Drummond, Curtin & Shanahan, 2014, p. 130) | "post-injury, the adolescents with TBI were able to adjust their goals by developing other interests that led to happiness and a sense of accomplishment" (Woods & Zachry, 2023, p.7)<br>"continuation of exploration of gifts and future plans" (Mayes, 2018, p.151) | - Rennie & Goforth (2020)<br>- Woods & Zachry (2023)<br>- Jacobs-Nzuzi Khuabi, Swart & Soeker (2019)<br>- Drummond, Curtin & Shanahan (2014)<br>- Jacobs-Nzuzi Khuabi et al. (2022)<br>-Mayes (2018) | Strategies used to adapt | **Coping and Post-traumatic growth** |

| | | |
|---|---|---|
| “I just didn’t feel comfortable telling [work] that I had a disability” (Paniccia et al., 2019, p.1335) | Taking control of own experience<br>“youth and young adults with ABI also found that gaining control of their experience attributed to gaining a sense of purpose” (Paniccia et al., 2019, p.1339) | - Pannicia et al. (2019)<br>- Jacobs-Nzuzi Khuabi et al. (2022) |
| “I would tell the younger me that, you know your health is more important than your high school football team” (Paniccia et al., 2019, p.1335)<br>“I appreciate them a lot more [friends]… I realise how fast life can be taken away” (Rennie & Goforth, 2020, p. 96) | Learning through personal reflections<br>“gaining insight into their earlier ABI-related decisions helped them [participants] adjust their present and future expectations” (Paniccia et al., 2019, p.1336) | - Paniccia et al. (2019)<br>- Rennie & Goforth (2020) |
| “[my ABI] helped me because I’ve like grown from those experiences. Since I stopped playing hockey it’s kind of been my goal to be a sports medicine doctor. I get to make a difference and help kids | Gaining a sense of purpose<br>“being able to view their ABI in way that brought meaning to their lives helped participants to gain a sense of purpose, and comfort” (Paniccia et al., | Paniccia et al. (2019) |

| | | |
|---|---|---|
| that I pretty much was not too long ago. It’s the ability to give back and to help, just to know that like my experience and what I do there can help other kids that have been concussed” (Paniccia et al., 2019, p.1338) | 2019, p.1338) | |
| “it’s horrible what it does to you, ‘cause it limits you a lot… but with time things become better… if you apply yourself you can achieve great things, move mountains almost…” (Di Battista et al., 2014, p.981)<br>“I’m trying to see it as more of a positive thing than as a negative thing, because seeing it as something that’s always holding me back, then I’m always going to be held back for the rest of my life” (Glennon et al., 2022, p.1918)<br>“…what happened, | Coping and post-traumatic growth<br>“participants reported both internal and external factors for coping”<br>“coping occurs acutely post-injury, whereas post-traumatic growth is an incremental, enduring psychological change that develops post-injury”<br>“this theme reflects the positive personal attributes driving recovery and adaptation, the role of faith, the role of self-acceptance, and acceptance from others that assisted adolescents on | - De Battista et al. (2014)<br>- Glennon et al. (2022)<br>- Mealings & Douglas (2010)<br>- Rennie & Goforth (2020)<br>-Jacobs-Nzuzi Khuabi, Swart & Soeker (2019)<br>- Jacobs-Nzuzi Khuabi et al. (2022) |

happened… no matter how much anyone would wish or I wished or family wished, it couldn't be changed, what was done was done. You can't change that, so may as well move on with your life" (Mealings & Douglas, 2010, p.6)

"because if I didn't believe in myself then I didn't really have anyone who did, and if I didn't believe I could do it then I wouldn't be able to do it" (Rennie & Goforth, 2020, p.95)

"I kept my sense of humour and this helped me a lot, the fact that I always laughed… my accident, I laughed about it because it was easier. It was easier to get past it and then to joke about it… this helped me because people stopped treating me like a victim, stopped treating me like I was disabled and needed help" (Gauvin-Lepage, their journey of personal growth" (Jacobs-Nzuzi Khuabi, Swart & Soeker, 2019, p.4)

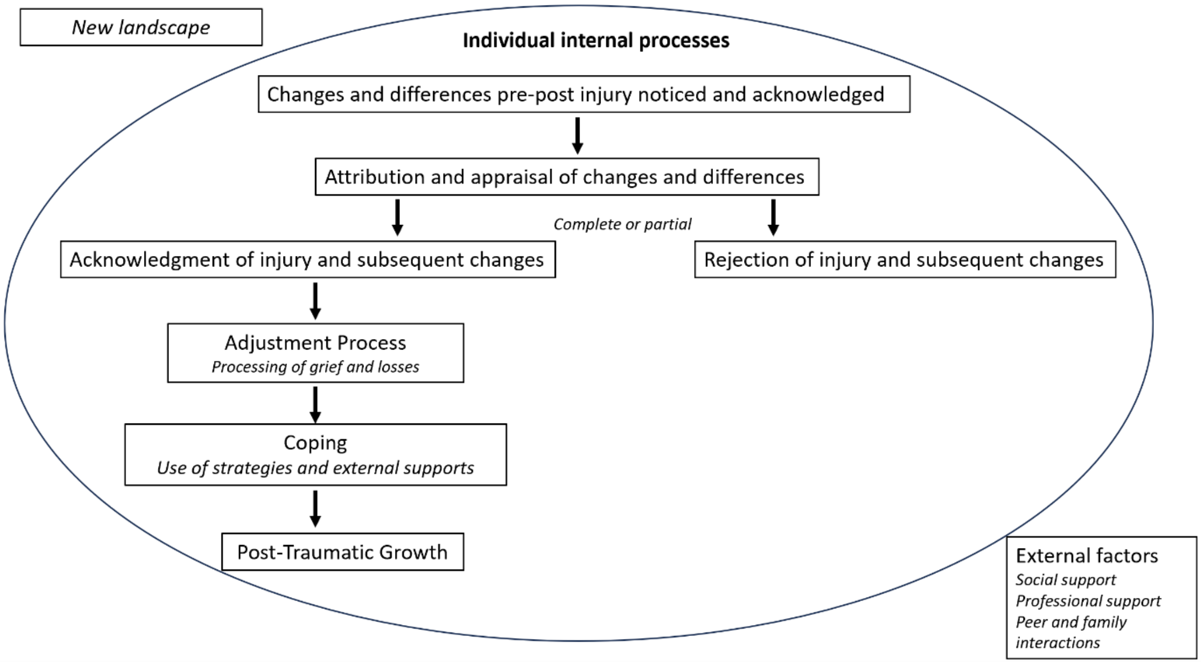
| | | |
|---|---|---|
| 2019, p. 3) | | |
| | Perspectives on the future “perspectives on their future can be summarised in two main expectations, where one is tied to the belief of recovery and the other is related to personal expectations of their ability to cope with future demands” (Rodset, 2008, p.99) | - Rodset (2008) |

### *Results Summary*

Figure 2 outlines in further detail the third-order constructs developed through meta-ethnographic synthesis in relation to how the identified internal cognitive processes occur within the context of the wider landscapes of life post-brain injury. Adolescents' reports of their experiences living with a brain injury across the literature spoke to facing an altered relational dynamic with peers, family and wider support networks. This is alongside managing the direct sequelae from the brain injury. Experiences had with one's wider networks (the interpersonal) were demonstrated to interact with the intrapersonal processes of adjustment to change following injury. As noted, where individuals and those around them did not acknowledge difficulties post-injury and therefore make the relevant adjustments to continue participation in daily life, recovery was felt to be impeded or "reversed" (Paniccia et al., 2019).

**Figure 2**

*Navigating new landscapes of living with a brain injury; the intra and inter- personal*



## Discussion

The aim of this review was to consider the adolescent and youth perspective on living with a brain injury, which has been highlighted as an understudied area despite high numbers of brain injury recorded to impact this demographic across the globe (Christensen et al., 2021). This lack of research means that the adult or child literature and its subsequent recommendations are often incorrectly applied to the unique adolescent population, overlooking the specificity of this developmental stage (Kakonge et al., 2022; Wales et al., 2013).

This review and synthesis of the current qualitative literature identified eighteen relevant and good quality studies, providing an insight into the lived experience of a brain injury in the period of adolescence. Six overarching themes (third-order constructs) were developed; *1) navigating the new landscape of life with a brain injury; direct consequences, 2) navigating the relational landscape of life with a brain injury; peer and support relationships, 3) an altered family landscape in life with a brain injury; relational dynamics and support, 4) cognitive processes in relation to understanding changes, 5) cognitive and emotional processes of adjustment to changes and loss 6) coping and post-traumatic growth.*

Included studies focussed on various aspects including service need, quality of life, communication, transitions, coping, family functioning and adjustment among others. That consistent themes were found across studies suggests there may be underlying mechanisms or ways of understanding the adolescent TBI experience. Service provision that aims to support individuals with underlying, transdiagnostic processes may indirectly impact on broader, related challenges (Gracey et al., 2016; Shields et al., 2016).

The results demonstrate how adolescents face altered interpersonal experiences and dynamics within family, peer groups and other support networks.  These experiences were described to interact with intrapersonal processes of adjustment, all within the context of management of the symptoms of TBI. This indicates that adolescents can face similar experiences following TBI as adults and that the “Y shaped process model of rehabilitation” developed by Gracey et al., (2009), primarily based on the adult literature can also be applied. The Y shaped model identifies change and discrepancies that can be targeted in rehabilitation including social and interpersonal discrepancies and personal (intrapersonal) discrepancies. Such discrepancies have been identified within the current review. Gracey et al., (2009) consider that working towards resolving some of these discrepancies enables adjustment and psychological growth. Further research into the interaction between interpersonal and intrapersonal factors would progress understanding on potential predictors of poor adjustment, which is linked to negative outcomes (Anderson et al., 2005; Johnson et al., 2009).

### Intrapersonal processes

In typical development, adolescents demonstrate an increase in self-awareness (Sandu et al., 2015). However, this self-awareness has been found to be impaired following TBI (Wales et al., 2019), presenting a challenge for those seeking to understand young people’s perspectives. In some of the included studies, the views of parents or teachers were sought in order to triangulate experiences and get a sense of this. The participants in the included studies however were able to articulate and their responses point to a number of different cognitive processes.  As noted in this review, and by Buckeridge, Clarke and Sellers (2020), the age at which the brain injury occurred is significant, in that it can mean that participants have either already embedded their “difficulties” into their sense of self and life narrative, or they have a clear sense of loss connected with memories of their life before injury. How individuals navigate feelings of loss can impact on adjustment and coping in the longer term (Buckeridge et al., 2020; Di Battista et al., 2014).

Individuals with a TBI are highly over-represented within the population of those who come into contact with the criminal justice system (Chan et al., 2023) with other research demonstrating the link between TBI, substance misuse and a negative life trajectory (Ilie et al., 2015). It is vital for young people to have access to support in order to maximise their outcomes and trajectories.

### Strengths and Limitations

Noblit and Hare (1988) outline that a meta-ethnography is an "interpretation on interpretations on interpretations" (p.35). Through the completion of this review, the wordings of both the original participants and the research authors has been maintained through the use of direct quotations both in iteration tables (whilst going through the process of conducting the synthesis) but also as presented in this final account. This aims to counter any reviewer bias through the use of original language and explanations and enables the voice of young people, oft neglected in the relevant literature to be clearly heard. It is important to note that although meta-ethnography posits a refutational synthesis, this was difficult to achieve during the current review due to the contradictions *within* research studies, reflecting the very individualised experiences of living with a brain injury. For example, this review demonstrated that some individuals felt isolated, and lost friends whereas others had supportive friends and did not feel that they experienced such a loss. Some had good experiences with teachers and accommodations, whereas others did not.

Some of the reviewed studies were case studies or had small numbers of participants, as is in line with qualitative research. It does mean that the conclusions of the current review are based on a smaller number of participants. Qualitative methods however aim to provide in-depth insight into lived experiences, and so it is felt that this review demonstrates a depth rather than a breadth of insight. Current research also reflects that there is no consistent measurement of outcomes, with some studies using quality of life measures, consideration of a return to education, or indicators of family functioning. This can make it difficult to accurately represent what is meant by recovery.

### Implications for Research and Practice

It is important to note that the majority of participants in the included studies were Caucasian, and the voices of those of a global majority are less represented. Research has demonstrated that characteristics such as race, as well as gender impact on an individual's access to care and can increase the likelihood of negative outcomes following TBI (Haarbauer-Krupa et al., 2021; Matney, Bowman & Berwick, 2022). Aspects of identity therefore can lead to differing experiences following TBI. Aspects of ourselves such as race and gender are also inherently incorporated into our self-identity as our membership of social groups (Rhodes & Baron, 2019) and are therefore key components of identity to consider and may influence how one understands themselves and navigates their TBI. Further research giving voice to those with different identities and how these aspects may intersect will therefore be important to consider.

Studies also represent a broad range of countries and so the impact of specific support structures and services that are country-specific is more difficult to ascertain. Socioeconomic status was reported in two of the included studies conducted in South Africa. Given that those of a lower socioeconomic status are over-represented in the TBI population, the specific experiences of this cohort, including how aspects of identity might impact on access to services and support would be important.

The current study has highlighted intrapersonal, cognitive processes described by young people living with a brain injury. Differences in the appraisal of changes and whether they are acknowledged or rejected were noted to impact on individual's trajectories. Kendall and Terry's model of psychosocial adjustment following brain injury (Kendall & Terry, 1996) acknowledged that in addition to the direct influence of neurological impacts of BI, inter and intrapersonal factors were mediated by appraisal and coping as outlined by Lazarus and Folkman (1984). Lazurus and Folkman's theory of stress and coping posits that how an individual appraises and makes sense of their health-related challenges is a key part of coping. This theory considers appraisal of problems as controllable or uncontrollable, in addition to this, the current review indicates an appraisal based on the perceived outcomes.

Further research considering processes over time and how young people understand themselves in relation to TBI may further understanding into relevant factors and time related processes. This in turn could inform the timing of any services or interventions to be offered. It is not known whether the identified processes occur in stages cumulatively or are iterative. However, initial noticing and acknowledgement of differences pre-post injury does appear to be one of the initial steps in how adolescents have understood life following on from a brain injury.

### *Clinical practice*

In the context of a lack of guidance for the longer-term rehabilitation needs for children and young people (NICE, 2023), it is important to note the factors that are important to the young people in the included studies. A number of studies referred to the lack of information and the anxiety surrounding not knowing what to expect, what happened or what is "typical" for brain injuries. It is important that timely information is provided to young people and their families to reduce anxiety but also to enable them to develop an ongoing narrative of their TBI experience. Participants also spoke of the importance of a wider, general public knowledge of brain injury, and described how poor wider knowledge of brain injuries and their sequelae impacted on their experiences with support, particularly in education and the wider community. Professionals working in neurorehabilitation have a duty to disseminate knowledge in an accessible way beyond directly impacted families.

The current studies also highlighted how young people understood themselves within a relational context, making comparisons to peers. Some participants spoke of the importance of going back to school and being reconnected with their friends and peer groups. Where there were negative experiences with peers and teachers, participants expressed an impact on their learning experiences and engagement with others. Important to the context of adolescence and this developmental stage in which peer socialisation is key, neurorehabilitation goals should be expanded to include wider social support networks including peers. Individualised goals enabling young people to reconnect with shared activities and hobbies consistent with their pre-injury self was also reflected in the current review to feel important to young people.

# References

**NB: Those noted with * were included in the meta-ethnography**

Anderson, V. A., Catroppa, C., Haritou, F., Morse, S., & Rosenfeld, J. V. (2005). Identifying factors contributing to child and family outcome 30 months after traumatic brain injury in children. *Journal of Neurology, Neurosurgery & Psychiatry*, *76*(3), 401-408. 10.1136/jnnp.2003.019174

Arroyos-Jurado, E., Paulsen, J. S., Ehly, S., & Max, J. E. (2006). Traumatic Brain Injury in Children and Adolescents: Academic and Intellectual Outcomes Following Injury. *Exceptionality*, *14*(3), 125–140. https://doi.org/10.1207/s15327035ex1403_2

Britten, N., Campbell, R., Pope, C., Donovan, J., Morgan, M., & Pill, R. (2002). Using meta ethnography to synthesise qualitative research: a worked example. *Journal of Health Services Research & Policy, 7*(4), 209–215. 10.1258/135581902320432732

*****Buckeridge, K., Clarke, C., & Sellers, D. (2020). Adolescents' experiences of communication following acquired brain injury. *International Journal of Language and Communication Disorders*, *55*(1), 97–109. https://doi.org/10.1111/1460-6984.12506

CASP: Critical Appraisal Skills Programme UK. (2018). CASP checklists. https://casp-uk.net/casptools-checklists/

Chan, V., Estrella, M. J., Syed, S., Lopez, A., Shah, R., Colclough, Z., & Colantonio, A. (2023). Rehabilitation among individuals with traumatic brain injury who intersect with the criminal justice system: A scoping review. *Frontiers in Neurology*, *13,* 1052294. 10.3389/fneur.2022.1052294

Christensen, J., Eyolfson, E., Salberg, S., & Mychasiuk, R. (2021). Traumatic brain injury in adolescence: A review of the neurobiological and behavioural underpinnings and outcomes. *Developmental Review, 59*. https://doi.org/10.1016/j.dr.2020.100943

Dewan, M. C., Rattani, A., Gupta, S., Baticulon, R. E., Hung, Y. C., Punchak, M., Agrawal, A., Adeleye, A. O., Shrime, M. G., Rubiano, A. M., Rosenfeld, J. V., & Park, K. B. (2018). Estimating the global incidence of traumatic brain injury. *Journal of neurosurgery,* 1–18. https://doi.org/10.3171/2017.10.JNS17352

*****Di Battista, A., Godfrey, C., Soo, C., Catroppa, C., & Anderson, V. (2014). “In my before life”: Relationships, coping and post-traumatic growth in adolescent survivors of a traumatic brain injury. *Journal of Rehabilitation Medicine, 46*(10), 975–983. https://doi.org/10.2340/16501977-1883

*****Drummond, J., Curtin, M., & Shananhan, L. (2014). “Can you speak English?”: The effects of social communication impairment on the life of an adolescent with traumatic brain injury. *Journal of Clinical Practice in Speech-Language Pathology*, *16*(3), 127–132. https://researchoutput.csu.edu.au/en/publications/can-you-speak-english-the-effects-of-social-communication-impairm

Forsyth, R., & Kirkham, F. (2012). Predicting outcome after childhood brain injury. *Canadian Medical Association journal, 184 (11),* 1257–1264. https://doi.org/10.1503/cmaj.111045

*****Gagnon, I., Swaine, B., Champagne, F., & Lefebvre, H. (2008). Perspectives of adolescents and their parents regarding service needs following a mild traumatic brain injury. *Brain Injury*, *22*(2), 161–173. https://doi.org/10.1080/02699050701867381

*Gauvin-Lepage, J. (2019). Traumatic Brain Injury in Adolescence and the Family Resilience Process: A Case Study. *SAGE Open Nursing*, *5*, 2377960819848231. 10.1177/2377960819848231

*Gauvin-Lepage, J., & Lefebvre, H. (2010). Social inclusion of persons with moderate head injuries: the points of view of adolescents with brain injuries, their parents and professionals. *Brain Injury*, *24*(9), 1087–1097. https://doi.org/10.3109/02699052.2010.494593

*Glennon, C., Watson, S., Fisher, P., & Gracey, F. (2022). The process of identity change following ABI from the perspectives of adolescents and their mothers: A relational grounded theory approach. *Neuropsychological Rehabilitation, 32*(8), 1904–1927. https://doi.org/10.1080/09602011.2022.2100796

Gracey, F., Evans, J. J., & Malley, D. (2009). Capturing process and outcome in complex rehabilitation interventions: A “Y-shaped” model. *Neuropsychological Rehabilitation*, *19*(6), 867–890. https://doi.org/10.1080/09602010903027763

Gracey, F., Longworth, C., & Psaila, K. (2016). A provisional transdiagnostic cognitive behavioural model of post brain injury emotional adjustment. *Neuro-Disability and Psychotherapy*, *3*(2), 154-185.https://www.researchgate.net/publication/303042683_A_provisional_transdiagnostic_cognitive_behavioural_model_of_post_brain_injury_emotional_adjustment

Goldman, L., Siddiqui, E. M., Khan, A., Jahan, S., Rehman, M. U., Mehan, S., Sharma, R., Budkin, S., Kumar, S. N., Sahu, A., Kumar, M., & Vaibhav, K. (2022). Understanding Acquired Brain Injury: A Review. *Biomedicines*, *10*(9), 2167. https://doi.org/10.3390/biomedicines10092167

Ilie, G., Mann, R. E., Hamilton, H., Adlaf, E. M., Boak, A., Asbridge, M., & Cusimano, M. D. (2015). Substance use and related harms among adolescents with and without traumatic brain injury. *The Journal of head trauma rehabilitation*, *30*(5), 293-301. 10.1097/HTR.0000000000000101

*****Jacobs-Nzuzi Khuabi, L. A., Swart, E., & Soeker, M. S. (2019). A Service User Perspective Informing the Role of Occupational Therapy in School Transition Practice for High School Learners with TBI: An African Perspective. *Occupational Therapy International*, *2* https://doi.org/10.1155/2019/1201689

*****Jacobs-Nzuzi Khuabi, L., Ally, K., Khan, S., Moolman, M., Mustapha, A., & Parker, S. (2022). Primary to secondary school transition of learners with traumatic brain injuries in the Cape metropolitan area: A learner perspective. *South African Journal of Occupational Therapy*, *52*(2), 36–45. https://doi.org/10.17159/2310-3833/2022/VOL52N2A5

Johnson, A. R., DeMatt, E., & Salorio, C. F. (2009). Predictors of outcome following acquired brain injury in children. *Developmental disabilities research reviews*, *15*(2), 124-132. 10.1002/ddrr.63

Kakonge, L., Charron, V. P., Vedder, J., Wormald, K., & Turkstra, L. S. (2022). A mapping review of adolescent identity after TBI: what clinicians need to know. *Neuropsychological Rehabilitation, 32* (8), 1868-1903. https://doi.org/10.1080/09602011.2022.2071299

Kendall, E., & Terry, D. J. (1996). Psychosocial adjustment following closed head injury: A model for understanding individual differences and predicting outcome. *Neuropsychological Rehabilitation*. https://doi.org/10.1080/713755502

Lazarus, R., & Folkman, S. (1984). *Stress, appraisal and coping.* Springer. New York.

Malpass, A., Shaw, A., Sharp, D., Walter, F., Feder, G., Ridd, M., & Kessler, D. (2009). “Medication career” or “Moral career”? The two sides of managing anti-depressants: A meta-ethnography of patients’ experience of anti-depressants. *Social Science & Medicine*, *68,* 154–168. https://doi.org/10.1016/j.socscimed.2008.09.068

Matney, C., Bowman, K., & Berwick, D. (Eds.). (2022). *Traumatic Brain Injury: A Roadmap for Accelerating Progress*. National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Health Care Services; Board on Health Sciences Policy; Committee on Accelerating Progress in Traumatic Brain Injury Research and Care. National Academies Press (US). https://doi.org/10.17226/25394

*Mayes, R. D. (2018). “They will leave you lost”: Experiences of a gifted Black male with a traumatic brain injury. *The Urban Review*, *50*, 140-155. https://doi.org/10.1007/s11256-017-0433-x

Mccarron, R. H., Watson, S., & Gracey, F. (2019). What do kids with Acquired Brain Injury want? Mapping neuropsychological rehabilitation goals to the International Classification of Functioning, Disability and Health Europe PMC Funders Group. *Journal of the International Neuropsychological Society*, *25*(4), 403–412. https://doi.org/10.1017/S1355617719000213

*Mealings, M., & Douglas, J. (2010). ‘School’s a big part of your life …’: Adolescent Perspectives of Their School Participation Following Traumatic Brain Injury. *Brain Impairment*, *11*(1), 1–16. https://doi.org/10.1375/BRIM.11.1.1

*Mealings, M., Douglas, J., & Olver, J. (2017). Beyond academic performance: Practice implications for working with students following traumatic brain injury. *International*

*Journal of Speech-Language Pathology, 19*(5), 441–453. https://doi.org/10.1080/17549507.2016.1221453

Menon, D. K., Schwab, K., Wright, D. W., & Maas, A. I. (2010). Position Statement: Definition of Traumatic Brain Injury. *Archives of Physical Medicine and Rehabilitation, 91*(11), 1637–1640. https://doi.org/10.1016/J.APMR.2010.05.017

Mulligan, T., Barker-Collo, S., Gibson, K., & Jones, K. (2023). You only get one brain: adult reflections on coping and recovery after traumatic brain injury in adolescence. *Brain Injury*, *37*(11), 1221–1230. https://doi.org/10.1080/02699052.2023.2243824

NICE (National Institute for Health and Care Excellence). (2023). *Head Injury: Quality Standard [QS74]* https://www.nice.org.uk/guidance/qs74/chapter/Quality-statement-8-placeholder-Postacute-phase-rehabilitation-for-children-and-young-people

Noblit, G., & Hare, R. (1988). *Meta-ethnography: Synthesizing qualitative studies*. Stage Publication.

Ocampo, S., Dawson, D., & Colantonio, A. (1997). Outcomes after head injury: level of agreement between subjects and their informants. *Occupational Therapy International, 4*(3), 163–179. https://doi.org/10.1002/OTI.54

Osorio, M. B., Kurowski, B. G., Beebe, D., Taylor, H. G., Brown, T. M., Kirkwood, M. W., & Wade, S. L. (2013). *Association of Daytime Somnolence With Executive Functioning in the First 6 Months After Adolescent Traumatic Brain Injury*. *5*(7), 554–562. https://doi.org/10.1016/j.pmrj.2012.11.006

Page, M. J., Mckenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., Mcdonald, S., McGuinness, L.A., … Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *British Medical Journal, 372,* 71 https://doi.org/10.1136/bmj.n71

*****Paniccia, A., Colquhoun, H., Kirsh, B., & Lindsay, S. (2019). Youth and young adults with acquired brain injury transition towards work-related roles: a qualitative study. *Disability and Rehabilitation*, *41*(11), 1331–1342. https://doi.org/10.1080/09638288.2018.1425743

*****Quatman-Yates, C. C., Miley, A. E., Morrison, P., Hugentobler, J., Wade, S. L., Rhine, T. D., & Kurowski, B. G. (2022). Adolescent and Parent Perceptions of the Impact of Concussion/mTBI on Family Functioning and Activity Levels in Recovery. *Journal of Head Trauma Rehabilitation*, *37*(4), E280–E291. https://doi.org/10.1097/HTR.0000000000000725

*****Rennie, B. J., & Goforth, A. N. (2020). A Qualitative Examination of Social Changes and Challenges in Rural Adolescents With Traumatic Brain Injury. *Rural Special Education Quarterly*, *39*(2), 91–103. https://doi.org/10.1177/8756870519892886

Rhodes, M., & Baron, A. (2019). The Development of Social Categorization. *Annual review of developmental psychology*, *1*, 359–386. https://doi.org/10.1146/annurev-devpsych-121318-084824

***** Rødset, M. (2008). Adolescents with Traumatic Brain Injury and their School Situation: A Qualitative Study. *Scandinavian Journal of Disability Research*, *10*(2), 90-103. https://doi.org/10.1080/15017410801927807

Rohrbeck, C. A. (2003). *Peer relationships, adolescence.* In Encyclopedia of primary prevention and health promotion (pp. 808-812). Springer, Boston, MA.

Sandu, C. M., Pânişoarã, G., & Pânişoarã, I. O. (2015). Study on the development of self-awareness in teenagers. *Procedia-Social and Behavioral Sciences, 180*, 1656-1660. https://doi.org/10.1016/j.sbspro.2015.05.060

Sariaslan, A., Sharp, D. J., D'onofrio, B. M., Larsson, H., & Fazel, S. (2016). *Long-Term Outcomes Associated with* Traumatic Brain Injury in Childhood and Adolescence: A Nationwide Swedish Cohort Study of a Wide Range of Medical and Social Outcomes. *PloS Medicine, 13* (8) https://doi.org/10.1371/journal.pmed.1002103

Sattar, R., Lawton, R., Panagioti, M., & Johnson, J. (2021). Meta-ethnography in healthcare research: a guide to using a meta-ethnographic approach for literature synthesis. *BMC Health Services Research*, *21*(1), 1–13. https://doi.org/10.1186/S12913-020-06049-W/TABLES/2

Sawyer, S. M., Afifi, R. A., Bearinger, L. H., Blakemore, S. J., Dick, B., Ezeh, A. C., & Patton, G. C. (2012). Adolescence: a foundation for future health. *The Lancet*, *379*(9826), 1630–1640. https://doi.org/10.1016/S0140-6736(12)60072-5

*****Sharp, N. L., Bye, R. A., Llewellyn, G. M., & Cusick, A. (2006). Fitting back in: Adolescents returning to school after severe acquired brain injury. *Disability and Rehabilitation*, *28*(12), 767–778. https://doi.org/10.1080/09638280500386668

Shields, C., Ownsworth, T., O'Donovan, A., & Fleming, J. (2016). A transdiagnostic investigation of emotional distress after traumatic brain injury. *Neuropsychological Rehabilitation, 26* (3), 410-445. https://doi.org/10.1080/09602011.2015.1037772

United Nations (UN). (2023). *Global Issues: Youth.* https://www.un.org/en/global-issues/youth

Wales, L., Hawley, C., & Sidebotham, P. (2013). How an occupational therapist should conceptualise self-awareness following traumatic brain injury in childhood- A literature review. *British Journal of Occupational Therapy, 76* (7), 325-332. https://psycnet.apa.org/doi/10.4276/030802213X13729279115013

Wales, L., Sidebotham, P., & Hawley, C. (2019). Self-awareness following a traumatic brain injury in childhood: a developmental perspective. *Brain Injury, 33*(5), 633–642. https://doi.org/10.1080/02699052.2019.1566838#

*****Woods, L. R., & Zachry, A. H. (2023). Factors that support and hinder recovery and adjustment after traumatic brain injury: a qualitative multiple case study. *International Journal of Therapy and Rehabilitation*, *30*(2). https://doi.org/10.12968/IJTR.2021.0190

World Health Organisation (WHO). (2023) *Adolescent Health.* https://www.who.int/health-topics/adolescent-health/#tab=tab_1

Yeates, K. O., Swift, E., Taylor, H. G., Wade, S. L., Drotar, D., Stancin, T., & Minich, N. (2004). Short-and long-term social outcomes following pediatric traumatic brain injury. *Journal of the International Neuropsychological Society, 10*(3), 412-426. DOI: 10.10170S1355617704103093

Ylvisaker, M., Adelson, P. D., Braga, L. W., Burnett, S. M., Glang, A., Feeney, T., & Todis, B. (2005). Rehabilitation and ongoing support after pediatric TBI: twenty years of progress. *The Journal of head trauma rehabilitation, 20*(1), 95-109. doi: 10.1097/00001199-200501000-00009.

# Section B

## An exploration of young people's sense of self-identity following a traumatic brain injury in adolescence

**Word Count: 7,988 (8,040)**

**For submission to: Clinical Child Psychology and Psychiatry**

## Abstract

**Background**: Previous research has demonstrated that identity reconstruction is a key component of rehabilitation in the adult Traumatic Brain Injury (TBI) population. TBI processes may disrupt the already developing sense of self-identity in adolescence, a critical period of development. This study aimed to explore individual's experiences relating to self-identity following a TBI in the period of adolescence, particularly how they perceived any changes over time since the injury. **Method**: Semi structured individual interviews were conducted with seven young people aged 15-21 years (5 male, 2 female) who acquired a TBI in the period of adolescence (12 - 19 years). Transcripts were analysed using Interpretative Phenomenological Analysis (IPA). **Results:** Five themes were identified relating to how participants experienced their sense of self-identity following on from their TBI. 1) Participants described making temporal comparisons which identified what they had gained, lost and what remained consistent following their TBI. Through 2) understanding of themselves relationally and with a 3) heightened awareness of an embodied self, young people attempt to 4) build a narrative of their TBI in their life contexts. Participants note the specificity of the life stage of adolescence as they also try to fill in the gaps in memory and information surrounding their injury. Finally, 5) participants described stages of development over time, moving from a point of discovery of their post-injury traits and abilities through to an acceptance of self. **Conclusions:** This study adds to the literature on adolescent and youth navigation of living with a TBI, further highlighting the specificity of adolescence in how TBI is experienced. Recommendations are made in relation to future research to consider potential stages of self-development over time post-TBI and for the longer-term rehabilitation needs of this cohort.

**Key words: Traumatic Brain Injury (TBI), adolescence, identity, adjustment**

# Introduction

## *Traumatic Brain Injury*

A Traumatic brain injury (TBI) is defined as “a disruption of the normal function or structure of the brain caused by a head impact or external force” (Menon et al., 2010) and is typically classified as mild, moderate to severe. An estimated 69 million people worldwide are thought to sustain a TBI each year (Dewan et al., 2018), coined as a global public health concern due to being a leading cause of death and disability (Haarbauer-Krupa et al., 2021). In the UK, there are 900,000 annual attendances at A&E departments for TBI (Menon, 2018); mild TBI accounts for 75% of all TBI presentations, moderate for 22% and severe for 3% (Foss et al., 2020). Incidences of such injuries peak three times across the lifespan; in childhood, adolescence and again in older adulthood (Gardner et al., 2018). It is thought that most estimations of the prevalence of TBI are underestimates due to the number that may go unreported and undetected (Brazinova et al., 2021; Haarbauer-Krupa et al., 2021). This could particularly be the case with mild TBI, where individuals may not access services or know they have experienced a brain injury. It is also known that there is the absence of a systematic process for reporting TBI presentations within the NHS (Menon, 2018).

## *Identity*

Research with adults with a TBI has identified several aspects of recovery that are important for individuals. In addition to difficulties related to the physical, social, emotional, and cognitive impairments following TBI, a metasynthesis of 23 studies highlighted that individuals also experience a disconnect with their pre-injury identity and face the task of reconstructing their self-identity and place in the world (Levack, Kayes & Fadyl, 2010). Self-discrepancy theory (Higgins, 1987) states that individuals have different self-representations and if there is a discrepancy between the "actual" self and other representations such as the "ideal" self, this can be linked to anxiety and depression (Mason et al, 2019; Shields et al, 2016). In individuals who have acquired a TBI, the pre-injury self may be discrepant from the perceived current or "actual" self post-injury (Cantor et al., 2005). Perceived changes in self-identity following TBI were often found to be experienced by individuals as negative which has been demonstrated to be linked with poorer emotional outcomes and greater levels of distress (Beadle et al., 2016; Cantor et al., 2005; Gracey et al., 2009). Perkins et al. (2022) concluded that the adult literature on identity changes and transition post-injury highlights the importance of subsequent tasks such as reducing this discrepancy and enhancing the felt sense of continuity of self for individuals.

### ***Adolescence***

Overall, there is a paucity of research in paediatric patients with TBI compared to adults (Kakonge et al., 2022; Nwafor et al., 2022; Rennie & Goforth, 2020; Sharp et al., 2006), despite adolescence being a high-risk period for such injuries (Christensen et al, 2021). This heightened risk is in part thought to be due to the increase observed in impulsivity and risk-taking behaviours when compared to adulthood (Steinberg, 2008). Additionally many TBI's are sports-related injuries, with adolescence being a key time for engagement in organised sports (Ilie et al., 2013; 2020; Haarbauer-Krupa et al., 2021). Research has demonstrated that the stage of development at the time of the TBI predicts the functional outcome (Christensen et al., 2021; Nacoti et al., 2021). Adolescence is a unique developmental stage and a critical period of significant brain maturation and specialisation through plasticity (National Academies of Sciences, Engineering, and Medicine, 2019). The adolescent experience is dependent on both context and culture; in Western cultures, it is a stage of life encompassing several transitions, identity exploration and novelty seeking (Sawyer et al., 2018).  It is also characterised by an expansion of an individual’s social world, with more time spent with peers than earlier on in childhood (Crone & van Duijvenvoorde, 2021). An increased importance is placed on the peer group, with peer approval and belonging being considered crucial (Tomova et al., 2021). Social Identity Theory (Tajfel & Turner, 1986) distinguishes an individual’s sense of self in relation to their group belonging as their social identity. These identities can be internalised as part of the self-concept and dependent on the appraisal of the group. If there is a loss of social identity, it can have a negative impact on wellbeing (Haslam et al., 2009). Adolescents who have experienced a TBI may not only experience a felt sense of loss of social identity but may also have to navigate being labelled post-injury as “disabled”.

The sequelae of TBI can disrupt key tasks associated with this developmental stage. For example, following on from a TBI, adolescents report being more dependent on their parents and other caregivers at a time when forging independence is a central goal (Di Battista et al., 2014; Mealings & Douglas, 2010; Ocampo et al., 1997). Studies have also demonstrated the social impact of TBI, with individuals reporting social isolation, feelings of loneliness and social conflicts (Yeates et al, 2004). This may be explained by the findings of Tousignant et al. (2018) who found that adolescents with a TBI demonstrated poorer social cognition, including mentalising and perspective taking.

Theories of identity have posited that individuals seek consistency in their sense of self across both social contexts and time, particularly in Western cultures (Branje et al., 2021; English & Chen, 2011). Some TBI symptoms may occur early in the acute phase and either improve or deteriorate over time, whereas others may appear later (Haarbauer-Krupa et al., 2021). This can in part be due to maturational processes of the brain which occur at different times as well as highlighting the injured regions which are compromised and adversely impact skill acquisition and meeting developmental milestones in line with their peers (Nacoti et al., 2021). This diverse landscape for the impact of a TBI may therefore disrupt an individual’s developing sense of self and the process of striving towards consistency. Forming a coherent sense of self and identity is noted to be one of the key developmental tasks of adolescence (Erikson, 1968), with success in this task considered to be linked to better outcomes in terms of both physical and psychological wellbeing (Meeus, 2011; Tomova et al., 2021; van Doeselaar et al., 2018). Young people post-TBI are managing adjustments to loss, including lost abilities, friendships and certainty around their future trajectory (Sharp et al., 2006). This adjustment is occurring within a time when they are exploring their identity and finding out where they fit in, in relation to their peers (Mealings & Douglas, 2010). Ylvisaker et al. (2005) noted that adolescents face the task of integrating their already evolving pre-injury sense of self with the new landscape imposed on them due to their TBI. Therefore, identity development is likely to be complicated by a TBI.

Kakonge et al (2022) conducted a mapping review of the literature on identity in adolescents with mild to severe TBI. Identity reconstruction has already been noted to be an important component of rehabilitation in adults with a TBI, with the goal of integration of pre and post injury selves, including the aspired-to-self. Few studies were identified to have explored the impact of a TBI on an adolescent’s identity development and any implications for rehabilitation. The initial results demonstrated that adolescents do experience changes in self-identity following TBI and  have unique experiences due to their life stage when facing identity reformation. This review recommended future research considers intersectional aspects of identity in the context of TBI such as race, gender and cultural background. It’s included studies also focussed on outpatient settings for neurorehabilitation following TBI and often included joint interviews with parents or professionals. The current study will use individual interviews and consider intersectionality and all settings of support; both inpatient, outpatient and any alternative experiences.

### *Aim*

This study aimed to investigate the current gaps in the literature through an in-depth exploration of individual’s experiences relating to self-identity following TBI in the period of adolescence. Specifically, through utilising Interpretative Phenomenological Analysis (IPA) it aimed to explore how some young people make sense of any perceived changes in their self-identity over time following a TBI.

### *Research questions*

1. Does a participant’s sense of self-identity change following a traumatic brain injury in adolescence?
2. How does a participant’s sense of self-identity change following a traumatic brain injury in adolescence?
3. What do participants’ experience as the key features of any identity change?
4. How do participants’ make sense of any changes over time since the TBI?

## Method

### *Design*

This was a cross sectional, qualitative study utilising IPA. IPA seeks to gain a rich understanding of the meaning an individual applies to a particular experiential phenomenon, namely TBI in adolescence. Brain injuries are known to be heterogenous in their impact

(Covington & Duff, 2021) therefore the use of IPA and its ideographic approach allowed a focus on each individual participant's experience and the nuances of this.

### *Participants*

The study sought young people up to the age of 25 who had acquired a TBI in the period of adolescence (between the ages of 10 and 19 as identified by the World Health Organisation). They were required to be living in the community and have sufficient communication skills to be able to engage in a semi-structured interview. The study excluded those with a pre-identified risk to self that may likely have been exacerbated by discussion of potentially distressing topics in the research interview. Participant demographics are detailed in Table 1.

**Table 1**

*Participant demographics*

| ID | Pseudonym | Gender | Ethnicity | Age | Age at injury | Cause of TBI | Current Circumstances |
|---|---|---|---|---|---|---|---|
| 1 | George | Male | White British | 21 | 16 | Vehicle Collision | At home with parents |
| 2 | Arabella | Female | Mixed White and Black Caribbean | 15 | 12 | Vehicle Collision | At home with parent |
| 3 | Ben | Male | Black British | 21 | 19 | Vehicle Collision | At home with parents |
| 4 | Ed | Male | Black British | 20 | 17 | Fight (impact with a wall) | At home with parents |
| 5 | Sam | Male | Black British | 19 | 14 | Sports-related injury | At home with parents |
| 6 | Keiran | Male | Black British | 18 | 13 | Fall | At home with parents |
| 7 | Sarah | Female | White British | 21 | 19 | Fall | Shared university accommodation |

### ***Procedures***

A purposive sampling strategy was adopted, with participants initially recruited through Recolo UK, a community neurorehabilitation service for children and young people with a brain injury. Clinicians working with those who met the criteria approached the young person and/ or their parent/carer with the study information. The charities Childhood Brain Injury Trust (CBIT) and Anchorpoint also shared the invitation to participate poster (Appendix B) via their Coordinators and social media. Interested individuals either contacted the researcher directly or via a clinician. The five participants recruited this way via social media were therefore self-selected. Interested individuals were contacted by the researcher to discuss the study and informed consent was gathered. For the one participant under 16, consent was given by her parent and she gave assent.

An interview schedule (Appendix C) was developed using the limited current literature. Individual semi-structured interviews utilising this schedule were completed with participants, with all but one opting for these to be conducted online via video call. One individual was interviewed in their home with their allocated neurorehabilitation clinician present to enable them to engage in the interview process. Interviews lasted for approximately one hour. Adaptations were made on an individual basis including offering frequent breaks and repeating questions as often as needed. Several participants required their answers to be repeated back to them in order to support them to continue with their train of thought. The interview protocol outlined that participants were able to pause or stop the interview at any time, and a discussion about early warning signs of distress was had. Upon completion of the interview, participants were provided with a £10 voucher for their time. Interviews were audio recorded and subsequently transcribed verbatim.

### ***Ethical Considerations***

The researcher undertook this study as part of a Clinical Doctorate degree. Ethical approval was obtained from Salomons Institute for Applied Psychology (Appendix D). The Data Protection Act and Information Governance frameworks were adhered to in relation to the collection, handling and storage of participant data which was also anonymised. Consideration was given to the participant experience of engaging in the research interviews, including acknowledgement of the impact of TBI on individual’s concentration, communication, and alertness. In addition, the potential of participants experiencing distress due to the nature of the subject matter was addressed. All participants engaged in a debrief at the end of the study, which included reorienting them to time and place and an invitation to reflect on the experience of the interview and the topic of discussion. Participants were reminded of their right to withdraw their data from the study up to one week after the interview. Participants were provided in the debrief material information of organisations they could access if required (Appendix E).

### ***Data Analysis***

The following steps of analysis as outlined by Smith, Flowers and Larkin (2021) were conducted with the interview transcripts following data collection; 1) immersing self in the data through reading each transcript multiple times, 2) exploratory noting (writing initial notes in the margin), 3) developing experiential statements, 4) searching for connections across experiential statements, 5) naming the personal experiential themes derived from statements, 6) continuing the stages of analysis across the other transcripts and 7) developing group experiential themes. This process from annotated transcript through experiential statements to personal experiential themes can be observed in Appendices F-H.

### ***Quality assurance and reflexivity***

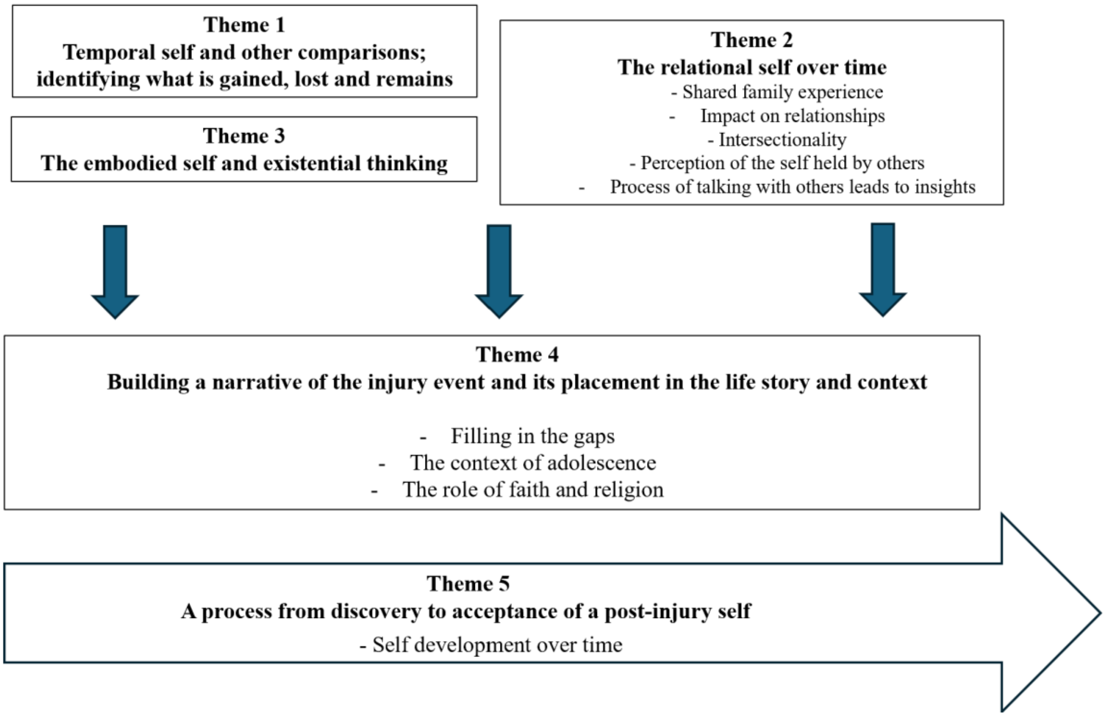
The values of sensitivity to context, commitment and rigour, coherence and transparency and impact and importance as outlined by Yardley (2024) have been used as guidance throughout the current study and are reflected in the following processes. In keeping with qualitative research and specifically the double hermeneutic aspect of IPA, in which the “role of the researcher in the construction of research knowledge” (Rolls & Relf, 2006, p.288) is considered key, the lead researcher kept a reflexive diary (Appendix I). As identified by Fischer (2009), it is important for the researcher’s influence to be acknowledged and attended to throughout the project, from the development of the research questions and procedures through to the data analysis and conclusions drawn. Bracketing interviews with a supervisor were conducted on three occasions across the research process, to bring into awareness any assumptions or values that may influence the way the researcher engaged with participants and the data. One key aspect of this was the researcher's own personal experience of a family member who experienced a traumatic brain injury in adolescence. Reflections were also made on aspects of intersectionality, including being a White British female. This process ensured that the interpretations made were grounded in the data as much as possible. A White British 19-year-old male who had experience of TBI was consulted during the final stages of data analysis alongside additional discussions with the research supervisors. One of the research supervisors also reviewed a transcript and the subsequent coding, this enabled us to ensure that the researcher's interpretation was logical and would make sense to readers. IPA cautions against other methods of validity measurement often used in qualitative research such as member-checking as it is viewed to contrast with the epistemological position of IPA; namely the double hermeneutic and the role of the researcher in interpretation (Gauntlett et al., 2017; Smith, 2021)

## Results

Seven young people (two female and five male) aged between 15-21 years who had sustained a TBI during the period of adolescence (12-19 years) participated in this study. Five inter-related themes emerged from the analysis of interview transcripts and are summarised in Figure 1. All participants spoke to the recognition of changes in themselves following TBI. They described several different processes and ways of thinking about themselves (Theme 1: Temporal self and other comparisons, Theme 2: The relational self and Theme 3: The embodied self) which were built into (Theme 4) their narrative of the event that caused the injury, and where it was placed in the context of their life story and timeline. Processes over time were highlighted which ultimately moved participants from a position of initial discovery of post-injury traits towards acceptance (Theme 5).

**Figure 1**

*Themes and Subthemes*



### *Theme 1: Temporal self and other comparisons; identifying what is gained, lost and remains*

All seven participants described their current selves in reference to how they had understood themselves before the injury, noting a sense of change post-injury. Participants often used phrases such as *“before my accident”* or *“that’s not how I was”,* anchoring the injury event as a significant point in time for comparisons to be made. Comparisons identified differing aspects of change; including gains and losses, but also features that had remained relatively consistent over time.

**Table 2**

*Gains, losses and consistencies*

| | |
|---|---|
| **Gains** | *"I'm a lot more, like appreciative of people's problems" (George)* |
| **Losses** | *"I could go watch my friends play games, and literally they're enjoying themselves and I understand what they're doing, I mean I'm talking of basketball and all I can do is just… I was once there and now I can't be there" (Ed)* |
| | *"I'm like a little bit, I don't know, slower than I used to be, like cognitively and very like, I'm very forgetful. That's one thing aswell that's changed is I have no memory whatsoever" (Sarah)* |
| **Consistencies** | *"I used to be artistic… I drew a picture of me and Mum for Mum's 40th birthday… I go to pottery now, so still slightly artistic" (Arabella)* |

Some of the changes post-injury were experienced as frustrating, particularly due to participants having the knowledge of how they managed things before. There was also a sense that individuals' experiences were not how it is "supposed to be". Sarah talked of feeling like she should not have additional challenges with processing information, whereas Ed shared that he was feeling like he should be having a different reaction to his dissatisfaction with his current *"state".* This reflects how participants may have an "ought self" in mind that they comparing to.

> *"I think it's just the fact that it's more frustrating for me because I know what it was like to not have this thing… I just have much slower, like, cognitive processing*

> *generally… and it's just really frustrating… and so I feel like they're new barriers that I feel like I shouldn't have" (Sarah)*

> *"I sometimes wonder because I look back at things and I'm like, I'm not doing all the things I am supposed to be doing. I'm supposed to be ranting, I'm supposed to be p***ed, I'm supposed to, you know, show that yes, I'm not liking the state I'm in, but instead I'm just calm." (Ed)*

There were limited comparisons made between the current self and same age peers. Many participants spoke of how they had more limited contact with friends than prior to their injury. However, when comparisons were made with peers, this was experienced as frustrating or as a loss of something that the individual was able do previously along with shared activities with friends; *"I'll get frustrated with myself...seeing other people do what I wanna do" (George).*

One participant, Ed in contrast, expressed his belief in the futility of comparing himself to others, noting the importance of individuality;

> *"One of my principles in life is that I never compare…. Everybody just wants what they want. What I want isn't what they want, even if we might have the same need – we're not gonna get it in the same way… I don't have someone who is like me. I'm just me… being in a position where you compare yourself with someone is stressful… These things are natural occurrences. There are people who might be able to do something that you are finding very difficult, but to them it's a piece of cake." (Ed)*

When participants did make comparisons, it was experienced as frustrating and difficult as they started to gain a sense of an altered self and life being lived following their TBI. They also attempted to identify where there was a consistent thread of their individuality over time, for example a continued interest in a hobby.

### ***Theme 2: The relational self over time***

When sharing their lived experience, participants located themselves relationally to others in their lives, including peers and families. They understood themselves and their post-injury challenges in relation to how they navigate roles and interactions within social circles.

#### *Shared family experience*

Six participants particularly noted how the experience of TBI was one shared by family and reflected on the importance of family to them. Four particularly conveyed how their parents have *"always been there" ... "throughout everything" ... "no matter what".* They reflected on the ripples of the impact of their injury on their family due to their part in that system, noting that it was a difficult period for all and led to changes in the family dynamics, including parental concern and care.

> *"I was really afraid if I was gonna die, you know being the only child like I was wondering how my parents were gonna think... how were they going to feel..." (Ben)*

> *"they [parents] just prefer we are always around them... I think it's made them a little more alert to their kids whereabouts and stuff like that" (Ed)*

*Impact on relationships*

In addition to family dynamics, participants thought about their roles within wider groups and contexts, noting how these had also been altered by the TBI and its sequelae. This included if and how the individual participated in social interactions.

> *"I do know that there are times when I have, yeah, times when I could go all quiet, like we can be having a conversation, I can just go all quiet" (Ed)*

> *"My friends say they miss doing things with me. [Best friend] said she really misses going to school every day with me, and I instantly agree with her" (Arabella)*

Two participants also noted how they did not have a particular interest in friends following their injury, especially initially. For these participants, friends and peer group were implicated in their injury events in some way and they also reflected on how this made them question their friendships.

> *"I don't speak to my friends, or some friends quite often, but if I'm honest, I'm not really bothered" (George)*

Keiran talked of how he experienced mood swings post-injury as *"debilitating"* socially as he was quick to anger with others. He spoke of feeling remorseful about this and worried about the impact on others when this was a dynamic that was repeated; *"but I don't really know… someone saying that they are sorry but still coming back to do the same bad character, bad thing …".* Keiran noted that he felt *"that people are always trying to be* *cautious and careful when they talk to me".* This was something he had noticed when talking with family and friends and understood to be a direct consequence to his described "mood swings".

### *Perception of the self, held by others*

Some participants spoke of an awareness of a version of themselves that others hold in mind, and how they feel this might be influenced by the knowledge that they had acquired a TBI. This was particularly relevant to the hidden nature of TBI and its sequelae. This in turn impacted on their thoughts around sharing information about their injury with others, demonstrating an understanding that they have some power in what knowledge others have about them, which may shape perceptions. Sam expressed how he now chooses to keep parts of himself hidden from others, and through talking about his hobby of playing basketball described how he considers that others may view his vulnerabilities post-TBI as a chance to *"take advantage"* on the court. Ben also noted how others may see things as a *"weakness".* Similar feelings about how others may perceive him were also described by Keiran;

> *"Like, if you didn't already know I had an incident, I try my best to keep it, you know, a bit secretive, because once they know about this, they tend to see you in a different way. They tend to perceive me differently…*
>
> *… I don't want that bias or stereotype…in my day-to-day meeting with people, I want them to just see me as that guy, like no bias or stereotype." (Keiran)*

Keiran also expressed that he did not have his own sense of changes in his personality following his TBI due to having limited memory from the injury event and before. In his case, he described incorporating his parent's perceptions into his understanding of himself.

> *"Well, it happened when I was 13, so I don't really have much, you know, memory like that at all…. I don't really have much memory of how I was or how my behaviour was before the incident…. So if they [parents] said I was a bit different after the incident, I uhhh, changed my personality in a way… I believe what they say about it" (Keiran)*

*Process of talking with others leads to insights*

Family and friends sharing their own perceptions of the young person with a TBI through conversation was identified to support participants in developing their understanding of themselves. Initially, these insights would be met with denial, but participants then described how they became integrated into their current thinking about themselves.

> *"They [friends] pointed it out to me that since then they think … I'm better at like, standing up for myself… and when they first said that I was like, mmm that doesn't sound like me. But then I just got thinking about it, and I was like, actually, yeah, you know what I think that's true!" (Sarah)*
>
> *"For ages they were saying… you've changed, you've become this. And I didn't accept it. Well, I couldn't accept it. You know, I didn't feel like I had" (George)*

Participants also spoke about the importance placed on being able to talk with others about their own experiences of living with TBI and expressed this through talking about their decision to take part in the current study, with Sam describing it as a *"milestone"*. Ben also felt that having engaged in the research interview, it may allow him to work towards sharing more with others over time.

> *"I'm OK sharing with you though… I just wanna try something new … to see if I could be like, actually do it in the future, so might as well start somewhere… it's still a little bit difficult, but I'm pretty sure in the future I'm gonna like, be strong enough, you know, to say more hopefully." (Ben)*

Reflections were made on how the process of saying some truths aloud and to another person had an impact. This led to further realisations about participants' post-injury selves including a sense of the enormity of their TBI experience;

> *"It was helpful [therapy]… but it was… bringing up my problems, you know… kind of saying it out loud… like problems I didn't really realise I had… then I said it out loud and I thought 'Jesus Christ!'" (George)*

> *"The more I speak about it to other people like, gauging their reactions and like how in shock they are and how seriously they're taking it I'm like - ohh like I guess it is pretty crazy that I'm OK and I'm actually doing well" (Sarah)*

### *Intersectionality*

Four participants were black males, two of whom spoke about their race as a critical aspect of self that impacts upon their sense of the expectations and views held by others. For these individuals, this led to a drive to want to go against expectations and the limitations they experience. This was very much perceived as independent to the brain injury, and both made a comparison to the experience of white individuals.

> *"…being who I am, you know, in the society as who we are [black], it's kind of like different… there are things that… you [the researcher] can go and you can easily get... compared to us… in this society, there are levels… They're giving us a limit to where they want us to be, like work … but I think that's not how it is for some of us you know, some of us are trying to like, not live up to that expectation that they have towards us." (Ben)*

Keiran also explained how his racial identity influenced how he viewed others and the world around him.

> *"You know, I think race is… something we don't just overlook in our society now you know… my parents also told me that this is how the world is … so race actually shaped the way I perceived the world in a way. You know, it's like walking through the streets as a black man is different from going as a white man… so you know, race actually shaped my perspective of things" (Keiran)*

Gender was another aspect incorporated into how participants viewed themselves. George expressed how he viewed being more emotional since his injury through the lens of his held gender identity. This also impacted on his relationship to this perceived change over time; feeling like this is something he must hide.

> *"I'm overly emotional half the time. That's what I am now… I just make sure no one sees that, none of my old friends… I can't be over emotional because I'm a guy… I've got to keep a shield up." (George)*

Keiran expressed how his held gender identity of being a man influenced his relationship to help from others, and how he did not want to be taken care of following his injury.

> *"I'm a man, you know, I want to experience life…I don't want people just treating me, or taking care of me like I'm a Princess or something" (Keiran)*

This theme demonstrated an understanding of self which is relative to others, not only within participants' immediate social circles but wider society. Participants demonstrated the role that others can have in shaping their own view of themselves when they share their own perceptions. Wider societal influences such as beliefs around brain injuries, race and gender were also named.

### ***Theme 3: The embodied self and existential thinking***

All seven participants described the physical, embodied experience of living with a TBI. Ed spoke of feeling more connected to his body, describing how his TBI has *"made [him] study [his] body even more".* As part of this, participants also described an enhanced awareness of their physical vulnerability as human beings and were anxious about coming to more physical harm. Many participants spoke of their awareness of not wanting to hit their head again and being hypersensitive to potential risks in the environment.

> *"I'm definitely more cautious… Like this is a silly example* but *… I was walking to the gym and I live like on top of a hill so everywhere is downwards, to get to anything is like quite a steep hill, and there were like wet leaves and water and stuff and I was like really worried or scared that I was gonna fall and hit my head or something. So I was really taking my time and holding the railings and stuff"*

> *"it's always the head thing… I'm also just worried that like that could happen and I'll hit my head. It's all like head based, right" (Sarah)*

With this enhanced awareness of the embodied self, participants also demonstrated existential thought processes, highlighting an awareness of the self as part of a broader existence as human beings.

> *"Just like a … hypersensitivity of trying to stay safe … it makes me feel vulnerable. But I also got told in church that vulnerability is actually what makes us human. We have to be vulnerable to those things that happen" (Keiran)*

> *"You just have to calm down and just let things happen the way they are meant to be. We only but small fishes in the ocean, so just tend to just go where the tide takes us." (Sam)*

### *Theme 4: Understanding of the injury event and its placement in the life story and context*

#### *Filling in the gaps*

One of the key sequelae of TBI experienced was an impact on participants' memory during the acute phase post-injury. This led participants to attempt to fill in the gaps around the injury event in their developing life stories. Often, stories were held by others and participants relied on their recollections and information imparted. This was then incorporated into their own narratives about this time in their life, although participants expressed still feeling a sense of disconnect with that period, describing how it felt indescribable, not real or feels like a *"movie"*.

> *"I heard from my parents that before the incident I was actually a free person. You know, I used to go out and play and talk and be more like an open person, but they said they noticed some behavioural changes after my incident that I became more of an introvert and an exclusive person and from what my Mum told me, she said something about frontal lobes and stuff and the rest" (Keiran)*

Participants also spoke of the importance of being given information about TBI. Sarah spoke in detail about her experience in hospital at the time of her injury, in which she was alone due to being classed as an "adult" at age 19 and the COVID-19 restrictions at the time. Not having information repeated or given at a more appropriate time felt vital to her in being able to make sense of what she was experiencing both in the short and long term.

> *"I couldn't retain anything they were telling me, I could barely listen, so it's kind of scary to think of what they might have told me that might be really important, but I just have no idea…*
>
> *… I've always been worried… about them telling me things in hospital that I just don't have any recognition of, and I don't know if like the things that were happening to me were actually normal or if like, because of something they told me previously they were expecting it and so it's fine…. Like I feel like I was missing a big load of information… I feel like a few days post brain bleed is not like the ideal situation to*

> *gain knowledge about what's actually going on because you don't know what's happening" (Sarah)*

Both Sarah and George blamed themselves for not knowing more about brain injuries, with Sarah describing herself as *"silly"* and George stating that it is his *"fault"* for not knowing more. This may reflect feelings that they "should" have this information, highlighting how essential it feels.

Arabella shared how she felt that having memory loss was *"probably a good thing"* as she tried to process very difficult feelings about her injury and its impact on her life, describing it as *"a lot to process"* and following on from doing some research into TBI, Keiran expressed that *"I think the less I know, the better for me"* reflecting how difficult contemplating the missing knowledge might be for participants.

*The context of adolescence*

Six of the participants placed the injury event and their understanding of themselves within the context of their life stage at the time of the injury, i.e., adolescence. Specific aspects of adolescence such as impulsivity and lack of concern for the potential consequences of risk-taking behaviours were tied to the injury event for some.

> *"There's an eagerness for everything. Like if an idea pops up…there's that eagerness to want to make trouble. Ha, you know, the normal teenage life thing where everything seems funny and fun at the same time…Let's just … bear the consequences later…then after my injury at first I was like… Should I actually have picked that fight?" (Ed)*

For Sarah, she felt her age impacted on the professional care she received directly following her injury event; *"when I first went to A&E, all the staff assumed that I was just drunk, like a drunk teenager and so they didn't check my head at all"*. Sarah also expressed how at the time of her injury she felt she had already been through a period of adolescent identity confusion which she felt had been resolved. The injury event had then thrown this into question and left her reconsidering her understanding of herself and her goals.

> *"My injury happened when I was 19… I feel like by that age and at that age, you've already gone through like three identity crisises [sic], like you don't know what's going on. And I feel like around the ages of 17, 18, 19, I felt like I finally had it figured out, kind of enough… I knew what I wanted to do, I knew who I was as a person… and then this happened, and it is like ohh, maybe, maybe that's not what I wanna do, maybe that's not who I am." (Sarah)*

### *The role of faith and religion*

Three participants described how their faith and religion played a crucial role in their processing of the injury event, particularly in relation to trying to understand what happened and how it fits into the bigger picture of their life story. Sam and Keiran conveyed how the injury left them questioning their relationship with God;

> *"I will say prayer and reading the word, they were major steps for me, you know? So like we have from where I was… God loves everyone. So like that period, I kinda feel like for this to happen to me, I wasn't loved." (Sam)*
>
> *"Religion is actually very powerful for me… umm at some point actually I started asking, questioning God… I fully believe in God so I fully like questioned, why did this happen to me? Why did I get into a coma? And then why am I having behavioural changes at all? Why did God let this happen to me?" (Keiran)*

However, through accessing the support of their Church communities and engaging in practices such as prayer and reading the Bible, they developed a greater sense of understanding of God but also felt more able to accept their current selves. As articulated by Sam;

> *"I understood that there is a deeper love greater than what I was expecting. So kind of like, went deeper, to get like better understanding. And I think that kind of like opened my mind to what I need to accept, you know…"*
>
> *"… like nothing happens without a reason. Like, there's always a reason something happens. So back then, I didn't understand. So I had to, you know, dig deep… something could happen to you… so you could realise yourself on time to, you know, put you on the right path."*

### ***Theme 5: A process from discovery to acceptance of a post-injury self***

With the above-named processes as a backdrop (thinking about the self relationally, the embodied experience and making comparisons), all seven participants articulated ways in which they moved through different stages over time post-injury. Participants went from the initial injury experience and the acute phase post-injury which was expressed as *"difficult"* *"dark"* and *"traumatic"* through moments of discovery and realisation about their post-injury selves to adapting to, accepting and appreciating their post-injury identities. Some participants acknowledged enhanced aspects of themselves from the TBI experience demonstrating post-traumatic growth.

Table 3 demonstrates each of these identified stages of self-development over time from the injury event in further detail, illustrated with the words of all seven participants.

**Table 3**

*A process from discovery to acceptance of a post-injury self; illustrated by participant quotes.*

| Stage | Quotes |
|---|---|
| **The initial injury experience** | *"it's very very difficult, you know … having a brain injury"* **(George)**<br>*"There was a long time where I didn't see the point. I was down… my mindset… wasn't good"* **(George)**<br>*"I had a year off, when I was just… my mindset was none"* **(George)**<br>*" I didn't really do much because it was like a dark place. You know what, that moment, you know, having the injury… it was kind of like dark, you know, it was a place where you wouldn't want to, you know, go back to or wish for anyone else"* **(Ben)**<br>*"The pain. The trauma, you know. Like like like like a shock. You know, like…. What words can I use to describe this? Like you never thought like any of this can ever happen to you like to this level… nobody imagines this you understand, so it was like unbelievable for me"* **(Ben)**<br>*"Going to school… uhh yeah it impacted them… (sigh), those were just dark moments for me though"* **(Sam)**<br>*"it was really traumatic. It wasn't easy, you know, going through that process, the vomiting, the headaches that won't go, you know, it was kind of like when is this ever gonna end"* **(Sam)** |

| | |
|---|---|
| **Discovery and realisation** | *"There have been things that have like, slowly popped up umm that weren't present during the first phone call [NHS follow up appointment] because I was only a month in recovery like that whole, I was still very like bed bound. Like I couldn't really do anything for myself, so I hadn't gone out into the world and seen first-hand what problems might have arose – so that happened later on, at least for me."* ***(Sarah)***<br>*"Throughout this I've really found out more about myself"* ***(George)***<br>*"For ages they were saying… you've changed, you've become this. And I didn't accept it. Well, I couldn't accept it. You know, I didn't feel like I had"* ***(George)***<br>*"I actually did some minor researching. I'm very much of a nerdy person and all, I just did a few research about the brain injury and the rest and actually for the cause of most of the things and the signs and symptoms that my parents mentioned…"* ***(Keiran)***<br>*"I actually even like it because it's like made me calm and I've been able to think a lot… it's made me be calm and I listen to myself a lot. It's made me study my body even more. It's made me realise a whole lot of things"* ***(Ed)*** |
| **Reappraisal and reframing** | *"yes, I might never be able to sleep again, but think of all the amazing things I can do"* ***(George)***<br>*"I've gotta keep telling myself I can still play football…and yes, it's not the same as it was, but if I carry on, you never know where I can go"* ***(George)***<br>*"now this has happened to me, I've seen life in a totally different picture and I've actually got a chance"* ***(George)***<br>*"I don't really call it an injury, in a way I try my best not to make it look that bad or portray it in a bad light, as a bad memory because most of the time it rarely comes up now"* ***(Keiran)***<br>*"I'm trying not to get, you know, in a way feel bad about myself for doing some things… I am sorry about what I* |

| | |
|---|---|
| | *said, I am sorry about how I reacted. So in a way, I feel that you know, from what I heard like it wasn't me. This is not how I used to be, so I do my best to draw on and refer to that"* ***(Keiran)***<br>*"I'm pretty sure if this was gonna hit me later on in life it would have been much harder, you know, with more responsibilities and the rest. So like I said, everything happens for a reason."* ***(Sam)***<br>*"my Mum says to me if it happened if I was younger or older I would have died, so I'm grateful. I was so close to dying"* ***(Arabella)***<br>*"I'm just waiting for that period [when symptoms subside], so since I can wait for that period, I can do every other thing that doesn't stress me. I can do every other thing that wont put me in some sort of uhh distress. So why not?"* ***(Ed)*** |
| **Adapting and Coping strategies** | *"to some sense I have a way of like controlling myself and trying to manage everything [emotions]. So in a way I have like improved my management and everything, but um I am not really where I want to be"* ***(Keiran)***<br>*"I think overtime I'm getting to understand myself better and when I notice that I'm having a conversation that would be provocative and that could cause me to react, I try to withdraw or ask to change the topic and all. That's actually helped me to adapt better"* ***(Keiran)***<br>*"I go with one or two of my friends and just run around the court, and I don't do aggressive, we just do some kind of scrimmage or just do free throws and 'who shoots best'- something that doesn't stress me"* ***(Ed)***<br>*"I think for what I see, part of the recovery was like getting over that fear of going back to the court [place of injury event]"* ***(Sam)***<br>*"Gradually… the recovery process like had to accept, you know, find a new path towards doing things"* ***(Sam)***<br>*"sometimes people tend to work hard, and some tend to work smart. So you know, like preserve the energy and not strain yourself too much."* ***(Sam)*** |

| | |
|---|---|
| | *“ Before, I played the violin… and I was talking to Mum about… having lessons and Mum said I could just get a violin stand”* ***(Arabella)*** |
| **Acceptance** | *“I used to be able to do things, now I can’t do it, I’ve got to accept it and not get frustrated and not get annoyed at myself”* ***(George)***<br>*“it’s more like I transformed into someone I normally wouldn’t want to be then, but now I’m that kind of person that’s… live with it. There’s no point pouting”* ***(Ed)***<br>*“I would say everything happens for a reason, and I know me having the injury was not by chance like, it was meant to be, to put me on the right path to become maybe who I wanna be, you know?”* ***(Sam)***<br>*“It’s mostly anger and like, overreacting most of the time, so from what I heard, I was just kind of a cool person, gentle or no, so all of a sudden that I just get angry and start lashing out, that felt like different for me in a way… Afterwards you know, I knew it was not my fault as I started managing it better… start getting support like I said from parents, umm it’s totally cool. It’s not my fault and they see this also happened after my incident”* ***(Keiran)***<br>*“every time I do have doubts about how long an essays taking me, or how annoying I’m finding it, at the end of the day like I know I can do it and I know it’s gonna be OK and it’s fine. Like if you need a little bit longer, its OK, you will do it”* ***(Sarah)*** |
| **Appreciations** | *“they obviously did their magic and umm kept me alive… I’m so grateful to be blessed… I’ve been in some sense, lucky to have you know, the people working on me”* ***(George)***<br>*“I think I kind of like this peace and quiet, I just… I don’t know why I like it, but it’s made me realise that there is a lot to being peaceful than what I’ve always been”* ***(Ed)***<br>*“it kind of like, made me be more grateful and very, very, really, really, thankful, you know, wake up in the morning, you thank God that you are alive, you are able to see the day. You know, I’m pretty sure there are* |

| | |
|---|---|
| | *others who could not see that day with you aswell”* **(Ben)**<br>*“When I say I’m disabled I feel proud because I’m alive to say that”* **(Arabella)**<br>*“it shouldn’t take a brain injury for it to happen, but I think in this case it did help me just realise, like I am very capable and…. Giving myself a little bit of slack I guess”* **(Sarah)**<br>*“there’s definitely things about myself that have changed since the brain injury and like ways that I feel and see* things, but I think like yeah, being like positive and spontaneous definitely like got enhanced since the injury, *‘cause I dunno, I guess it just puts into perspective like you could be fine and then you’re really not fine. And it’s like, I was lucky enough to be OK”* **(Sarah)** |
| **Post-traumatic growth** | *“I’ve become a lot more… a lot more accepting of myself”* **(George)**<br>*“I actually even like it because it’s like made me calm and I’ve been able to think a lot… its made me be calm* and I listen to myself a lot. *It’s made me study my body even more. It’s made me realise a whole lot of things and yeah, so it’s a good thing”* **(Ed)**<br>*“I’m really proud to say that I’m more really what I was, you know [in relation to emotional lability], So there has actually been an improvement over the couple years, so I think that’s actually a good thing in a way”* **(Keiran)**<br>*“I see myself as much stronger than I ever have before… so yeah, I think I’ve realised that I’m stronger than I thought and I can take more and do more than I thought I could… I think that is a big thing is just like a gained self-respect I guess.”* **(Sarah)**<br>*“I think that’s been most important for me is like realising myself as a strong, capable person who can get through things and like, can do things people wouldn’t even imagine having to go through. Like at the other end of it, and still maintaining like a positive, optimistic attitude… Ive been able to give myself a lot more respect for that”* **(Sarah)** |

Participants each had different and unique experiences within each stage of the process described, with not all participants reporting experience of all identified stages. For example, Ed felt that he had not experienced any emotional trauma and reflected a positive interpretation of his TBI journey.

> *"I've accepted being and I'm not even feeling pained about it. …. I still credit myself for accepting it, because deep down I know … I know how a lot of people deal with emotional trauma. But I didn't have any emotional trauma."*

## Discussion

The current study aimed to address the following research questions in relation to the lived experience of young people following a TBI in adolescence; *Do participants experience a change in their self-identity over time? If so, how? What are the key features of any identity change? How do participants make sense of any changes over time?* Some of the key aspects will be discussed here.

### *Do participants experience a change in their self-identity over time? If so, how?*

Participants shared that they experienced changes in their self-identity following TBI in adolescence and felt that change was ongoing. They expressed how they made intrapersonal comparisons between their pre and post injury selves and interpersonal comparisons with their peers. In line with self-discrepancy theory (Higgins, 1987) and the adult TBI literature (Levack, Kayes & Fadyl, 2010), comparisons were found to identify incongruities and losses, which were experienced as frustrating. It has been noted in the adult brain injury literature that narratives around change often sit alongside narratives of continuity (Ellis-Hill et al., 2019) and the current participants were also able to recognise what had remained consistent for them over time. Some participants also highlighted positive gains through this process, which has also been demonstrated in adult populations (Klinger, 2005; Shields et al., 2016). Positive appraisals of changes post-injury have also been linked to post-traumatic growth (Thomas et al., 2014). Further investigation into the factors related to this positive outcome specific to the adolescent population could identify areas for intervention to promote better outcomes.

### ***What are the key features of any identity change?***

Participants described how changes were experienced as unexpected, with some sudden and acute and others gradual. Some differences were not noticed until later on until participants were engaging in more, as articulated by Sarah: "*I hadn't gone out into the world and seen first-hand what problems might have arose – so that happened later on".*

#### *Relational self*

Di Battista et al. (2014) noted how the personal discrepancies felt by adolescents with a TBI were often understood and expressed within a social context. Participants in the current study understood themselves post-injury within a relational context, including the male participants who described themselves as introverted, with reduced peer interactions and an increased importance on family relationships. In contrast to the evidence that suggests young people are at risk of isolation, bullying and rejection (Kakonge et al., 2022) however, participants in the current study did not report a negative appraisal of reduced social interaction with peers. They may potentially be attempting to reconcile any distress associated with social isolation by adopting an 'introvert' identity. It is also important to note that where peers were implicated in the injury event, current participants re-evaluated their social circles and placed less emphasis on their peers, associating them with behaviours linked to the traumatic injury event. This and the renewed importance placed on family is not in line with typical adolescent development where peer socialisation is principal (Tomova et al., 2021). Current recommendations for clinical goals for adolescents post-TBI emphasise the importance of facilitating social participation (Mealings et al., 2020; O'Rourke et al., 2020) and this will be important to acknowledge and navigate with young people.

### ***How do participants make sense of any changes over time?***

#### *Intersectionality*

Results further highlighted the importance of understanding intersectional aspects of individual's identities and how this interacts with their TBI experience. Some male participants' held gender identities were found to have impacted on how they appraised their post-injury changes and accepted support from others. Previous research into masculine identities following TBI with adults noted how participants feared being judged as 'less of a man' and that beliefs about masculinity can be a barrier to help-seeking (MacQueen et al., 2020).

Those with religious beliefs expressed the important role that faith and religion played in their understanding and incorporation of the TBI into their life narrative. Guidance from faith leaders and engagement in reading holy texts and prayer were found to be mechanisms that supported an acceptance of the TBI and changes experienced post-injury. Research has noted how spirituality has a role in adapting and coping in neurorehabilitation (Johnstone & Yoon, 2009), faith leaders may have a role in neurorehabilitation services. Alternatively, Jones et al. (2020) surveyed current rehabilitation professionals in adult services who noted they did not feel confident to provide spiritual care and recommended training in this area.

### ***Strengths and Limitations***

The current study drew on Yardley's (2024) criteria for quality qualitative research. Sensitivity to context has been demonstrated through reflections in the researcher's diary, and with an awareness of the current study's conceptualisation of adolescence and identity through a Western lens. The use of participant quotes, presentation of subsequent themes and subthemes and the use of a reflexive diary and bracketing interviews contributes to the transparency of the presented analysis. Participants that were recruited online were self-selected, and as such they self-reported their TBI's, and further information was not sought to validate or specify the severity. However, the subsequent interviews were felt to accurately reflect and corroborate what is known about TBI as well as providing further depth. IPA's idiographic approach emphasises the lived experience, perceptions and understandings specific to the included participants, however the experiences described and subsequent themes may resonate with other individuals who themselves have acquired a TBI during adolescence. It does not aim to provide a direct evaluation of the processes described. Recruitment for the current study was not conducted via the NHS which enabled those who may not have accessed services to have a voice.

### *Reflexivity*

Due to the double hermeneutic of IPA, it is likely that there is some researcher bias; in follow-up questions in interviews and during the analysis. The presented results are reflective of the researcher's interpretations of participants' interpretations. When the concept of racial identity arose in two of the research interviews, the researcher clearly stated her awareness of her own white identity. The researcher's understanding in the moment was reflected back to participants to try to ensure that the researcher's power did not unduly influence this aspect of the research findings and that participant meaning-making was accurately represented. Power differentials were discussed in bracketing interviews alongside highlighting other assumptions the researcher had such as contact with the NHS and professionals.

### *Practice Implications*

The National Institute for Health and Care Excellence (NICE) quality standard “Post-acute phase rehabilitation for children and young people” (NICE, 2023) is currently a placeholder statement, indicating a need for evidence-based guidance for rehabilitation for children and young people in the longer term following TBI. There is currently scarce and inconsistent NHS provision overall (Barber et al., 2018; Headway, 2023). Two of the participants in the current study were accessing support funded through legal means and provided by an independent organisation. One participant also spoke of her dissatisfaction with the NHS care received. The current study suggests that participants experienced an ongoing sense of uncertainty, with different challenges and sequelae of the TBI being discovered unexpectedly at varying points over the years post-injury. Information about TBI and what to expect was noted to be important to be able to make sense of their post-injury self and incorporate this into a life narrative. The timing of the delivery of this information is also important to consider, due to memory and attention deficits in the acute phase post TBI (Choudhury et al., 2020; Kohler et al., 2020; Savage et al., 2005). Participants may need to be re-offered services at different times post-injury. The vital need for information relating to BI from professionals has been consistently expressed by young people, families and parents in the literature for many years (Savage et al., 2005), current processes within services may need to be reviewed and updated in the light of continued evidence suggesting this need is yet to be met.

### *Future Research*

Participants described the value of speaking about their TBI experience. Some participants discussed this for the first time in the current research interviews, noting it as a milestone and identifying that in the future they may feel able to share more. Future research interviewing individuals at several time points may provide further insight into the processes behind adjustment to a changed self-identity following TBI.  It could be that those participants talking about their experience of TBI in depth for the first time may be at an earlier stage of a process. Several individual factors influence outcomes following brain injury independent of the severity of the injury including pre-injury cognitive, psychosocial and behavioural functioning as well as family functioning (Gracey et al., 2015), therefore, there may likely be individual differences in the pace of working through stages towards acceptance of the post-injury self. This may also be independent to the amount of time passed since the injury event. Due to the unpredictable and ever-changing landscape of TBI sequelae over time each stage may be revisited many times by each individual. Further research to explore if these stages are cumulative, linear, or iterative is also recommended.

## **Conclusion**

The current study highlighted ways in which young people who have acquired a TBI in the period of adolescence make sense of their experienced changes in self-identity. Participants considered their relational selves, an embodied self and made inter and intrapersonal temporal comparisons to gain an understanding of their post-injury selves. Participants attempted to incorporate the understanding gained into their life stories and within the specific context of adolescence. Impairments to memory and a lack of information about TBI left participants trying to “fill in the gaps” to be able to develop a consistent sense of self through time. Stages of progress towards adjustment to a post-injury self-identity were also described. Clinical implications include the timing of delivery of resources and the inclusion of faith leaders. Future research considering the potential iterative nature of identity reconstruction processes is also recommended.

# References

Barber, S., Bate, A., Adcock, A., Harker, R., Roberts, N., Woodhouse, J., & Mackley, A. (2018). Acquired brain injury. *House of Commons*. www.parliament.uk/commons-library|intranet.parliament.uk/commons-library|papers@parliament.uk|@commonslibrary

Beadle, E. J., Ownsworth, T., Fleming, J., & Shum, D. (2016). The impact of traumatic brain injury on self-identity: A systematic review of the evidence for self-concept changes. *Journal of Head Trauma Rehabilitation*, *31*(2), E12–E25. https://doi.org/10.1097/HTR.0000000000000158

Branje, S., de Moor, E. L., Spitzer, J., & Becht, A. I. (2021). Dynamics of Identity Development in Adolescence: A Decade in Review. *Journal of Research on Adolescence*, *31*(4), 908–927. https://doi.org/10.1111/JORA.12678

Brazinova, A., Rehorcikova, V., Taylor, M. S., Buckova, V., Majdan, M., Psota, M., Peeters, W., Feigin, V., Theadom, A., Holkovic, L., & Synnot, A. (2021). Epidemiology of Traumatic Brain Injury in Europe: A Living Systematic Review. *Journal of Neurotrauma, 38* (10), 1411 – 1440. https://doi.org/10.1089/neu.2015.4126

Brenner, E. K., Grossner, E. C., Johnson, B. N., Bernier, R. A., Soto, J., & Hillary, F. G. (2020). Race and ethnicity considerations in traumatic brain injury research: Incidence, reporting, and outcome. *Brain Injury*, *34*(6), 799–808. https://doi.org/10.1080/02699052.2020.1741033

Cantor, J., Ashman, T., Schwartz, M., Gordon, W., Hibbard, M., Brown, M., Spielman, L., Charatz, H. J., & Cheng, Z. (2005). The role of self-discrepancy theory in understanding post–traumatic brain injury affective disorders: A pilot study. *Journal of Head Trauma Rehabilitation*, *20*(6), 527–543. https://doi.org/10.1097/00001199-200511000-00005

Christensen, J., Eyolfson, E., Salberg, S., & Mychasiuk, R. (2021). Traumatic brain injury in adolescence: A review of the neurobiological and behavioural underpinnings and outcomes. *Developmental Review, 59*, 100943. https://doi.org/10.1016/j.dr.2020.100943

Choudhury, R., Kolstad, A., Prajapati, V., Samuel, G., & Yeates, K. O. (2020). Loss and recovery after concussion: Adolescent patients give voice to their concussion experience. *Health Expectations, 23*(6), 1533-1542. https://doi.org/10.1111/hex.13138

Covington, N. V, & Duff, M. C. (2021). Heterogeneity Is a Hallmark of Traumatic Brain Injury, Not a Limitation: A New Perspective on Study Design in Rehabilitation Research. *American Journal of Speech - Language Pathology, 30* (2S), 974-985. https://doi.org/10.1044/2020_AJSLP-20-00081

Crone, E. A., & Van Duijvenvoorde, A. C. K. (2021). Multiple pathways of risk taking in adolescence. *Developmental Review, 62*, 100996. https://doi.org/10.1016/j.dr.2021.100996

Dewan, M. C., Rattani, A., Gupta, S., Baticulon, R. E., Hung, Y. C., Punchak, M., Agrawal, A., Adeleye, A. O., Shrime, M. G., Rubiano, A. M., Rosenfeld, J. V., & Park, K. B. (2018). Estimating the global incidence of traumatic brain injury. *Journal of Neurosurgery*, *130*(4), 1080–1097. https://doi.org/10.3171/2017.10.JNS17352

Di Battista, A., Godfrey, C., Soo, C., Catroppa, C., & Anderson, V. (2014). “In my before life”: Relationships, coping and post-traumatic growth in adolescent survivors of a traumatic brain injury. *Journal of Rehabilitation Medicine*, *46*(10), 975–983. https://doi.org/10.2340/16501977-1883

Ellis-Hill, C., Thomas, S., Gracey, F., Lamont-Robinson, C., Cant, R., Marques, E. M., Thomas, P. W., Grant, M., Nunn, S., Paling, T., Thomas, C., Werson, A., Galvin, K. T., Reynolds, F., & Jenkinson, D. (2019). HeART of Stroke: randomised controlled, parallel-arm, feasibility study of a community-based arts and health intervention plus usual care compared with usual care to increase psychological well-being in people following a stroke. *BMJ Open, 9* (3), e021098. 10.1136/bmjopen-2017-021098

English, T., & Chen, S. (2011). Self-Concept Consistency and Culture: The Differential Impact of Two Forms of Consistency. *Article Personality and Social Psychology Bulletin*, *37*(6), 838–849. https://doi.org/10.1177/0146167211400621

Erikson, E. (1968). Youth: Identity and crisis. *New York, Ny: Ww, 10*.

Fischer, C. T. (2009). Bracketing in qualitative research: Conceptual and practical matters. *Psychotherapy Research*, *19*(4–5), 583–590. https://doi.org/10.1080/10503300902798375

Foss, L.J., et al., (2020), Setting a National Consensus for Managing Mild and Blast Traumatic Brain Injury: Post-Meeting Consensus Report, https://doi.org/10.25561/81286

Gardner, R. C., Dams-O'Connor, K., Morrissey, M. R., & Manley, G. T. (2018). Geriatric traumatic brain injury: epidemiology, outcomes, knowledge gaps, and future directions. *Journal of neurotrauma*, *35*(7), 889-906. https://doi.org/10.1089/neu.2017.5371

Gauntlett, L., Bickle, E., Thomas, G., Collins, B., Heaslip, V., & Eccles, S. (2017). Interpretative Phenomenological Analysis: A means of exploring aspiration and resilience amongst Widening Participation students. *Widening participation and lifelong learning*, *19*(2), 63-86. https://doi.org/10.5456/WPLL.19.2.63

Gómez-De-Regil, L., Estrella-Castillo, D. F., & Vega-Cauich, J. (2019). Psychological Intervention in Traumatic Brain Injury Patients. *Behavioural Neurology, 2019.* https://doi.org/10.1155/2019/6937832

Gracey, F., Evans, J. J., & Malley, D. (2009). Capturing process and outcome in complex rehabilitation interventions: A “Y-shaped” model. *Neuropsychological Rehabilitation, 19*(6), 867–890. https://doi.org/10.1080/09602010903027763

Gracey, F., Olsen, G., Austin, L., Watson, S., Malley, D. (2015). *Integrating Psychological Therapy into Interdisciplinary Child Neuropsychological Rehabilitation.* In: Reed, J., Byard, K., Fine, H. (eds) Neuropsychological Rehabilitation of Childhood Brain Injury. Palgrave Macmillan, London. https://doi.org/10.1057/9781137388223_10

Haarbauer-Krupa, J., Pugh, M. J., Prager, E. M., Harmon, N., Wolfe, J., & Yaffe, K. (2021). Epidemiology of Chronic Effects of Traumatic Brain Injury. *Journal of Neurotrauma, 38* (23), 3235 – 3247. https://doi.org/10.1089/neu.2021.0062

Haslam, S. A., Jetten, J., Postmes, T., & Haslam, C. (2009). Social Identity, Health and Well-Being: An Emerging Agenda for Applied Psychology. *Applied Psychology: An International Review, 58*(1), 1–23. https://doi.org/10.1111/j.1464-0597.2008.00379.x

Headway. (2023). *The NHS long term workforce plan - what does it mean for brain injury survivors?* https://www.headway.org.uk/news-and-campaigns/news/2023/the-nhs-long-term-workforce-plan-what-does-it-mean-for-brain-injury-survivors/

Higgins, E. T. (1987). Self-discrepancy: A theory relating self and affect. *Psychological Review, 94*(3), 319–340. https://doi.org/10.1037/0033-295X.94.3.319

Humphries, T. J., Ingram, S., Sinha, S., Lecky, F., Dawson, J., & Singh, R. (2020). The effect of socioeconomic deprivation on 12 month Traumatic Brain Injury (TBI) outcome. *Brain Injury, 34*(3), 343–349. https://doi.org/10.1080/02699052.2020.1715481

Ilie, G., Boak, A., Adlaf, E.M., Asbridge, M., & Cusimano, M. D. (2013). Prevalence and correlates of traumatic brain injuries among adolescents. *JAMA: The Journal of the American Medical Association, 309* (24), 2550-2552. https://doi.org/10.1001/jama.2013.6750

Ilie, G., Trenholm, M., Boak, A., Mann, R. E., Adlaf, E. M., Asbridge, M., Hamilton, H., Rehm, J., Rutledge, R., Cusiman, M. D., & Ammann, R.A. (2020). Adolescent traumatic brain injuries: Onset, mechanism and links with current academic performance and physical injuries. *PloS one, 15* (3). https://doi.org/10.1371/journal.pone.0229489

Johnstone, B., & Yoon, D. P. (2009). Relationships Between the Brief Multidimensional Measure of Religiousness/Spirituality and Health Outcomes for a Heterogeneous Rehabilitation Population. *Rehabilitation Psychology*, *54*(4), 422–431. https://doi.org/10.1037/A0017758

Jones, K. F., Pryor, J., Care-Unger, C., & Simpson, G. K. (2020). Rehabilitation health professionals' perceptions of spirituality and spiritual care: The results of an online survey. *NeuroRehabilitation*, *46*(1), 17–30. https://doi.org/10.3233/NRE-192857

Kakonge, L., Charron, V. P., Vedder, J., Wormald, K., & Turkstra, L. S. (2022). A mapping review of adolescent identity after TBI: what clinicians need to know. *Neuropsychological Rehabilitation, 32* (8), 1868-1903. https://doi.org/10.1080/09602011.2022.2071299

Klinger, L. (2005). Occupational Adaptation: Perspectives of People with Traumatic Brain Injury. *Journal of Occupational Science*, *12*(1), 9–16. https://doi.org/10.1080/14427591.2005.9686543

Kohler, M. J., Hendrick, M. D., Powell-Jones, A., & Bryan-Hancock, C. (2020). A Systematic Review of Cognitive Functioning after Traumatic Brain Injury in Individuals Aged 10-30 Years. *Cognitive and Behavioral Neurology*, *33*(4), 233–252. https://doi.org/10.1097/WNN.0000000000000236

Levack, W. M. M., Kayes, N. M., & Fadyl, J. K. (2010). Experience of recovery and outcome following traumatic brain injury: a metasynthesis of qualitative research. *Disability and Rehabilitation*, *32*(12), 986–999. https://doi.org/10.3109/09638281003775394

MacQueen, R., Fisher, P., & Williams, D. (2020). A qualitative investigation of masculine identity after traumatic brain injury. *Neuropsychological Rehabilitation*, *30*(2), 298–314. https://doi.org/10.1080/09602011.2018.1466714

Mason, T. B., Smith, K. E., Engwall, A., Lass, A., Mead, M., Sorby, M., Bjorlie, K., Strauman, T. J., & Wonderlich, S. (2019). Self-discrepancy theory as a transdiagnostic framework: A meta-analysis of self-discrepancy and psychopathology. *Psychological Bulletin*, *145*(4), 372–389. https://doi.org/10.1037/bul0000186

Mealings, M., & Douglas, J. (2010). 'School's a big part of your life …': Adolescent Perspectives of Their School Participation Following Traumatic Brain Injury. *Brain Impairment*, *11*(1), 1–16. https://doi.org/10.1375/BRIM.11.1.1

Mealings, M., Douglas, J., & Olver, J. (2017). Beyond academic performance: Practice implications for working with students following traumatic brain injury. *International Journal of Speech-Language Pathology*, *19*(5), 441–453. https://doi.org/10.1080/17549507.2016.1221453

Meeus, W. (2011). The study of adolescent identity formation 2000-2010: A review of longitudinal research. *Journal of Research on Adolescence*, *21*(1), 75–94. https://doi.org/10.1111/J.1532-7795.2010.00716.X

Menon, D. K., Schwab, K., Wright, D. W., & Maas, A. I. (2010). Position statement: definition of traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, *91*(11), 1637–1640. https://doi.org/10.1016/J.APMR.2010.05.017

Menon, D. (2018). Acquired Brain injury and Neurorehabilitation: Time for Change. All Party Parliamentary Group on Acquired Brain Injury. www.ukabif.org.uk/campaigns/appg-report

Nacoti, M., Fazzi, F., Biroli, F., Zangari, R., Barbui, T., & Kochanek, P. M. (2021). Addressing Key Clinical Care and Clinical Research Needs in Severe Pediatric

Traumatic Brain Injury: Perspectives From a Focused International Conference. *Frontiers in Pediatrics*, *8*, 594425. https://doi.org/10.3389/FPED.2020.594425/BIBTEX

National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Division of Behavioral and Social Sciences and Education; Board on Children, Youth, and Families; Committee on the Neurobiological and Socio-behavioral Science of Adolescent Development and Its Applications, Backes, E. P., & Bonnie, R. J. (Eds.). (2019). *The Promise of Adolescence: Realizing Opportunity for All Youth*. National Academies Press (US).

NICE (National Institute for Health and Care Excellence). (2023). *Head Injury: Quality Standard [QS74]* https://www.nice.org.uk/guidance/qs74/chapter/Quality-statement-8-placeholder-Postacute-phase-rehabilitation-for-children-and-young-people

Nwafor, D. C., Brichacek, A. L., Foster, C. H., Lucke-Wold, B. P., Ali, A., Colantonio, M. A., Brown, C. M., & Qaiser, R. (2022). Pediatric Traumatic Brain Injury: An Update on Preclinical Models, Clinical Biomarkers, and the Implications of Cerebrovascular Dysfunction. *Journal of Central Nervous System Disease*, *14*, 1–19. https://doi.org/10.1177/11795735221098125

Ocampo, S., Dawson, D., & Colantonio, A. (1997). Outcomes after head injury: level of agreement between subjects and their informants. *Occupational Therapy International*, *4*(3), 163–179. https://doi.org/10.1002/OTI.54

O’Rourke, C., Linden, M., & Bedell, G. (2020). Scoping Review of Interventions to Promote Social Participation in Adolescents and Young Adults with Neurodisability. *The Open Journal of Occupational Therapy*, *8*(1), 1–22. https://doi.org/10.15453/2168-6408.1647

Perkins, A., Gracey, F., Kelly, G., & Jim, J. (2022). A new model to guide identity-focused multidisciplinary rehabilitation for children and young people following acquired brain injury: I-FoRM. *Neuropsychological Rehabilitation*, *32*(8), 1928–1969. https://doi.org/10.1080/09602011.2022.2100794

Rennie, B. J., & Goforth, A. N. (2020). A Qualitative Examination of Social Changes and Challenges in Rural Adolescents With Traumatic Brain Injury. *Rural Special Education Quarterly*, *39*(2), 91–103. https://doi.org/10.1177/8756870519892886

Rohrbeck, C. A. (2003). *Peer relationships, adolescence.* In Encyclopedia of primary prevention and health promotion (pp. 808-812). Springer, Boston, MA.

Rolls, L., & Relf, M. (2006). Bracketing interviews: addressing methodological challenges in qualitative interviewing in bereavement and palliative care. *Mortality, 11*(3), 286–305. https://doi.org/10.1080/13576270600774893

Savage, R. C., DePompei, R., Tyler, J., & Lash, M. (2005). Paediatric traumatic brain injury: A review of pertinent issues. *Pediatric Rehabilitation, 8*(2), 92–103. https://doi.org/10.1080/13638490400022394

Sawyer, S. M., Azzopardi, P. S., Wickremarathne, D., & Patton, G. C. (2018). The age of adolescence. *The Lancet Child and Adolescent Health*. *Viewpoint, 2* (3), 223-228. https://doi.org/10.1016/S2352-4642(18)30022-1

Sharp, N. L., Bye, R. A., Llewellyn, G. M., & Cusick, A. (2006). Fitting back in: Adolescents returning to school after severe acquired brain injury. *Disability and Rehabilitation*, *28*(12), 767–778. https://doi.org/10.1080/09638280500386668

Shields, C., Ownsworth, T., O’Donovan, A., & Fleming, J. (2016). A transdiagnostic investigation of emotional distress after traumatic brain injury. *Neuropsychological Rehabilitation, 26* (3), 410-445. https://doi.org/10.1080/09602011.2015.1037772

Smith, J. A., Flowers, P., & Larkin, M. (2021). *Interpretative phenomenological analysis : theory, method and research (2nd Edition)*. London.

Steinberg, L. (2008). A social neuroscience perspective on adolescent risk-taking. *Developmental Review*, *28*(1), 78–106. https://doi.org/10.1016/J.DR.2007.08.002

Tajfel, H., & Turner, J.C. (1986). The social identity theory of intergroup behavior. *Psychology of Intergroup relations, 7-24.*

Thomas, E. J., Levack, W. M. M., & Taylor, W. J. (2014). Self-reflective meaning making in troubled times: Change in self-identity after traumatic brain injury. *Qualitative Health Research*, *24*(8), 1033–1047. https://doi.org/10.1177/1049732314542809/ASSET/IMAGES/LARGE/10.1177_1049732314542809-FIG2.JPEG

Tomova, L., Andrews, J. L., & Blakemore, S.-J. (2021). The importance of belonging and the avoidance of social risk taking in adolescence. *Developmental Review, 61*, 100981. https://doi.org/10.1016/j.dr.2021.100981

Tousignant, B., Jackson, P. L., Massicotte, E., Beauchamp, M. H., Achim, A. M., Vera-Estay, E., Bedell, G., & Sirois, K. (2016). Impact of traumatic brain injury on social cognition in adolescents and contribution of other higher order cognitive functions. *Neuropsychological Rehabilitation*, *28* (3), 429-447. https://doi.org/10.1080/09602011.2016.1158114

van Doeselaar, L., Becht, A. I., Klimstra, T. A., & Meeus, W. H. J. (2018). A review and integration of three key components of identity development: Distinctiveness, coherence, and continuity. *European Psychologist*, *23*(4), 278-288. https://doi.org/10.1027/1016-9040/a000334

World Health Organisation (WHO). (2023) *Adolescent Health.* https://www.who.int/health-topics/adolescent-health/#tab=tab_1

Yardley, L. (2024). *Demonstrating validity in qualitative psychology.* In J.A. Smith (Ed.) Qualitative psychology: A practical guide to methods (4th Edition, pp.255–271). London: Sage

Yeates, K. O., Swift, E., Taylor, H. G., Wade, S. L., Drotar, D., Stancin, T., & Minich, N. (2004). Short-and long-term social outcomes following pediatric traumatic brain injury. *Journal of the International Neuropsychological Society, 10*(3), 412-426

Ylvisaker, M., Adelson, P. D., Braga, L. W., Burnett, S. M., Glang, A., Feeney, T., & Todis, B. (2005). Rehabilitation and ongoing support after pediatric TBI: twenty years of progress. *The Journal of head trauma rehabilitation, 20*(1), 95-109.

# Part C: Appendices

## Appendix A: Meta-ethnography synthesis table

| Second order Themes | First order constructs | Second order constructs | Second order descriptors |
|---|---|---|---|
| **Managing the impact of the symptoms of a TBI (individual and social level)**<br>Rest vs reintegration into physical activity<br>Disruption to daily life<br>Visible/ Hidden | “basically all I wanted was to get rid of the headaches, they were so bad and everything they gave me it wouldn’t work” (1)<br>“I was pretty good the past week, and then it hit me again like really bad headaches for the past 3-4 days. It’s kind of on and off, depending on what I do and stuff” (10)<br>“[the injury] threw a wrench in my normal day to day life” (10) | Injury management considerations (1) (10) (7) | “needs related to the impairments, activity limitations and participation restrictions secondary to the mTBI” (1)<br>“families struggled with decisions regarding increasing physical activity and activity intensity levels” (10) |
|  | “I remember just kind of being like so tired that I couldn’t respond in the way I wanted to if at all and thinking, oh no Ive kind of ruined it with that person or this teacher doesn’t think that Im kind of bright enough or | Communication competence (4) (16) | “how word finding difficulties affected the communication of four participants and how they were able to portray themselves to others”<br>“it exposed a disturbance in the |

| | | | |
|---|---|---|---|
| | something” (4)<br>“half the time they don’t even know what I’m on about” (16) | | relationship adolescents had with the world through their spoken language” (4)<br>(16) High level language comprehension difficulties |
| | “that was when I got so nervous [about everything]” (9, p,96)<br>“…I have had [depression and] suicidal thoughts, Not that I’ve ever seriously considered it… I would be happy and the next moment, I would be sad for no reason… Good things are going on, and Im trying to be thankful, but my brain is just sad” (13,p.8)<br>“because of the accident, I could say something to someone’s face… I wasn’t like that before” (14, p.1091)<br>“but short-term if you tell me an hour ago then I would forget it” (18, p.39) | Consequences of TBI (14) (9) (13) (18)<br>Noticeable problems (7) | Noticeable physical problems; mobility, physical scarring, speech difficulties (concerns re peers reactions).<br>“there were also changes in internal state, with focus on anxiety, avoidance, and hesitancy resulting from the TBI and surrounding events (e.g accident), that result in deterring the adolescent from engaging in social behaviours” (9, p.96)<br>“social needs occurred in nearly all contexts and affected nearly all individual’s interactions with his or her environment.” (9)<br>Cognitive needs, including the need for multiple explanations and repetiton to cope with changes in memory and processing. (physical, emotional. Cognitive, and educational needs) |

| | | | |
|---|---|---|---|
| | | | “consequences of TBIs are neurological, cognitive, behavioural and social” (14, p.1090) |
| **Managing poor awareness, understanding and the invisible nature of TBI and subsequent responses from others** | “My ABI is invisible to others but present nonetheless” (5)<br>“just ‘cause I’m walking doesn’t mean that everything in my head’s ticking correctly” (12, p.444) | Invisible and subtle nature of the consequences of TBI (1) (4) (5) (7) (12) (14) | “because TBI is often a ‘silent condition’, in which there may be no visible sign that they had an injury, their problems are often ignored upon return to regular activities” (1)<br>“Participants felt that because their impairments were not physical in nature, it was difficult for others to believe that they were struggling, or in need of accommodations. For these reasons, they often felt misunderstood” (5) |
| | “I think the teachers did as much as they could. Really they need more knowledge about what a head injury is like.” (6)<br>“I am supposed to be some sort of vegetable… if I just open my eyes [teachers think] I am doing | Managing poor community awareness of TBI and subsequent reactions (12) (6) (7) (9) (15) | “TBI is not a widely recognised or well understood concept in most communities… This reduced awareness and lack of understanding may lead to misdiagnosis of the student’s needs” (12, p.444) |

| | | | |
|---|---|---|---|
| | something amazing” (7, p.773)<br>“but most of them don’t understand” (12, p.444)<br>“the teachers didn’t really understand what was wrong” (15, p.8) | | |
| | “Susan said it “made her day” when one friend said her ABI “made no difference to him”.” (7, p.774)<br>“they just acted like everyone else. My friends didn’t care if I was hit by a car or anything like that” (8, p.9)<br>“they would have to explain it to me again, oh we have to explain it again to…” (9, p.97)<br>*Peer comments on challenges associated with BI*<br>“I was teased a lot” (15, p.8) | The importance of teacher and peer reactions (7) (8) (9) (15) | “When the adolescents returned to school, responses from teachers and peers … had to be positive enough to allow the adolescents to feel well supported at school” (7)<br>“peer and community responses appeared directly linked to the visibility of the accident to the community” (9, p.97)<br>Teased by peers in relation to TBI consequences (7) (9) (15) |
| | “my parents contacted the school” (15, p.10) | Educating teachers and peers (7) (15) | Parents taking a role in liaising with school.<br>Educating peers during informal |

| | | | |
|---|---|---|---|
| | | | daily interactions, or organised with school educating peers during assembly. (7) |
| **Anxiety around needing information** | “when it first happened, all I wanted to know was how bad my head injury was. Because I have had so many concussions I was really worried because the doctors always said don’t hit your head again, because it could be the last time. And so I was really worried about that” (p. 166)<br>“they should speak more about… because it’s a lot to accept going home and needing help, so like speak to patients before they go home and tell them ‘look here, when you go back home, things are going to be different and you’re going to need a lot more help than what you needed previously’” (15, p.9)<br>“I wanted to know and he only said… no he didn’t say anything.” (p.166) | Information (1) (9) (13) (15) | “Information was requested primarily about the circumstances of the injury (what happened), mTBI sequalae and recovery (what to expect) and about the return to activities (what can I do now?” (1)<br>“participants described an absence of people to whom they could ask questions about brain injury” (9)<br>“this is needed to assist learners’ acceptance of their change in functioning post TBI and to facilitate a positive adaptation” (15, p.9) |
| **Recognising change through comparisons between past** | “I was a different person when I came back [home from hospital]” | Change – experience of current self and other selves (past, unlived | “adolescents described to varying degrees, how they experienced |

| | | | |
|---|---|---|---|
| **self/unlived self/ social self** | “if I wouldn’t have had the accident, I would’ve been in the big class with everyone else” (3, p.1913)<br>“Knowing I could do something beforehand, before me accident and then knowing I couldn’t do it now…just messed with my head” (8, p.7)<br>“things have got better and better over the years, but Ive become very handicapped in different ways.” (6)<br>“it was hard for me because I was able to, oh before my accident I was able to do everything easily and now I had to have an aide which I didn’t like having” (12, p.444)<br>“before the incident in uh like primary school I used to be quite vocal about things… more confident… in high school… due to that incident… I became very quiet, shy” (2, p.980)<br>“its harder for me to concentrate | and social) (2) (3) (6) (8) (12) (18) | tensions between change and continuity across different aspects of “self”… Those arose where the adolescent reflected on their past self, their lost future self or compared themselves to others.” (3, p.1912)<br>“in all cases, adolescents’ explanations of changed identity centred around stories about connectedness and/ or rejection within social relationships” (3)<br>“the adolescents in this study all experienced changes and compound difficulties as a consequence of the traumatic brain injuries. This affected their cognitive functioning and academic learning disabilities, but several could also report social difficulties. The main impression is that academic difficulties can be easier to deal with than social difficulties” (6)<br>“Personal and social discrepancy processes were identified. This process is defined as the labelling of differences and providing insights between life “before” (e.g |

| | | | |
|---|---|---|---|
| | since the accident. I get tired more easily" (14, p.1090) | | pre-injury) and life "after" (post-injury)" (2) |
| | "I love soccer, and played good before the accident, but now I'm not good in soccer anymore" (18, p.40) | | "personal discrepancies were often described in the social context, suggesting that at this stage of development the individual self is very much entrenched in the social arena" (2) |
| | "It took six months before things improved a bit" (14, p.1091) | The nature of change; sudden, gradual, short term, long term impact (9) (12) (14) | "disruption to social processes were reported for all participants. Furthermore, all participants remain affected by these disruptions several years later" (9) |
| **Attribution and appraisal of changes** | "I gave [piano] up… the piano was a huge part of my life and I sort of moved on to academics but I don't know whether that's just me growing up or me after a car accident" (2, p.980). | Attribution of changes by self and others (9) (2) (12) (14) | "difficulty several participants expressed in knowing what difficulties to attribute to the TBI" (9, p.99)<br>"attributions for changes to abilities post injury were made to either normal age related attributions or the TBI sequalae" (2, p.980)<br>"common changes caused by TBI may present in a student as behaviour that mimics other |

| | | |
|---|---|---|
| | | issues such as disinterest, lack of motivation, laziness, forgetfulness and poor social regulation. Without a clear understanding of why these issues are occurring, it is easy to attribute student's presentation to their character or adolescent stage of life" (12, p.444-445) |
| | How changes were appraised (8) (9) (18) | "not all changes were identified as positive experiences, especially where the change restricted the students' participation in activities they had previously enjoyed" (8)<br>"participants attitudes changed and included positive and negative interpretations of the unfolding of injury-related sequelae" (9, p.95)<br>"changes in some physical abilities and skills resulted in some learners comparing themselves to their able-bodied peers (i.e upward comparisons). This impacted on the way they viewed themselves" (18, p.41) |

|  |  |  |  |
|---|---|---|---|
| **Social Implications**<br>**Navigating the social landscape following BI – the importance of fitting back in** | “I think people will think people with brain injuries are just a bit stupid. Most of the time theyre not that smart…quite a lot of the people in our school with brain injuries have some sort of disability… no one wants to be friends with them… I don’t want to be one of them” (4, p.102)<br>“Susan described this as “like trying to fit a square into a circle’”” (7, p.774)<br>“I try my best and they don’t really care, and I feel left out, like always I feel left out” (9, p,96)<br>“just thought I was some weirdo.. I just thought that something was wrong with me.. I just didn’t know what. That’s why I was thinking that they must be thinking the same thing” (3, p..1914)<br>“always singling me out in class just ‘cause I got hit by a car..” (12, p.444)<br>“The other children would say ‘she’s mad’… then they just look | Fitting back in (12) (4) (7) (9) (3) (15) | “Some participants sensed they were outside of a social group and this led to feelings of rejection”<br>“normalisation” by rejection of the term brain injury did not ease the challenges encountered by participants. They revealed that at times they felt like outsiders, which affected their sense of belonging”. (4)<br>“This is the challenge to be “equal”, not “alienated” and to “prove” they were the “same”. This challenge was inherently difficult as the adolescents were no longer the same as a result of their injury and experiences” (7)<br>“they may try to protect their self-image by further hiding their difficulties and concealing changes” (12, p.446). Desire to preserve pre-injury identity and added concern about being publicly labelled.<br>“the negative attitude of peers is also shared by some learners as a difficulty to their initial adjustment following their school |

| | | |
|---|---|---|
| at me with that intention, they do not even meet me or anything, talk to me… just, no, shes mad” (15, p. 8) | | transition post TBI” (15, p.8) |
| “well I didn’t want to be around anybody [be]cause… I got irritated really easily…that was a side effect.” (13, p.7)<br>“…they [friends] all thought I was crazy, and they tell me now they never thought they would get me back. I was a completely different person. I didn’t really hang out [socialise] with anyone a lot of the time.” (13, p.6)<br>“after the accident, I lost some friends… I lost a lot of friends who Id had for a long time” (14, p.1092)<br>“my friend group that I had before, stopped being my friends and I was kind of alone” (15, p.10)<br>“I find it hard to say things, so I just don’t bother, I just sit there” | Impact on social experiences and friendships (6) (14) (13) (15) (16) (18) (19) | “those who experienced social difficulties mentioned changes in behaviour, such as lack of impulse control, difficulties in comprehending social cues, and difficulties in forming friendships, as the greatest barrier for inclusion. This awareness came gradually. Both those who did experience social difficulties and those who did not mentioned extra efforts made to cope with social situations” (6)<br>“given the impact of the TBI on the learner’s interpersonal interactions, the adjustment to the changed life circumstances often resulted in strained relationships… and further resulted in decreased social interaction and the loss of friendships” (15, p.10)<br>“However, once he sustained a |

| | | | |
|---|---|---|---|
| | (16, p.130)<br>“I only have one friend at school now” (18, p.39)<br>“…I had to stand and watch my friends play (soccer) and then I would just walk away because for me it was sad because I always used to play and up till today I still cant. I just have to watch and look at them.” (18, p.39) | | TBI, Douglas was immediately labelled as raced and dis/abled. These labels threw Douglas into the racial hierarchies and abled/disabled binaries” (19) |
| **Process of adjustment (to loss)**<br>**Acceptance** | “just the fact that I had to hold back a little bit on what I’d normally like to do.” | Realising and adapting to my post-ABI qualities (5) | “it was important for young people to see progress in recovering from the ABI and accept their limitations because this helped them to avoid being in a situation that could potentially reverse their recovery”<br>“when youth and young adults with ABI refused to acknowledge a change in their pre and post ABI capabilities, recovery appeared to be impeded” |

| | | | |
|---|---|---|---|
| | “I know I could have been so good, but now I don’t think I can, I really don’t. I think I have lost too much” (7, p.774)<br>“I wanted to become a scientist, and now I see science is not for me. I do not know what I want to be” (15, p.9) | Adjusting to personal loss (7) (12) (15) | “the adolescents had to make many personal adjustments following their return to school to cope with personal loss; for example loss of abilities, loss of friends, loss of being “the same”, and loss of “confidence in the way that you think your life will travel” (7)<br>“the onset of the TBI meant that learners had to pursue alternative scholastic and ultimately future career goals. This adjustment for some learners and their families proved difficult, leaving them with a sense of uncertainty about [the future].” (15, p.9) |
| | “I just feel like that’s something in my head, whats make me think differently, feel differently and just do stuff differently. Like I just feel like a completely different person because of it…than I was” (3, p.1914)<br>“I just want to be normal, I want to kind of see myself as a normal person” (3, p.1914) | Acknowledging and rejecting (response to experienced continuity or change) (3)<br>Rejection of a label | “the ways in which participants made sense of or tried to resolve or acknowledge issues of change and continuity resonated across all accounts, representing a range of complete or partial acknowledgement or rejection of the injury and changes” (3) |

| | | | |
|---|---|---|---|
| | “I started making music. I did that all the time [be]cause I didn’t have anything else to do” (13, p.7)<br>“so, like on my phone also I will put the alarm on and a reminder and then I would like put the heading of the reminder, like state everything that I have to do or like why did I put the reminder on” (18, p.40)<br>“Ill do track next year because I do need to do something” (13, p.7)<br>“[typing is] just easier, cos I don’t have to verbally say it, I just type it. Im pretty quick at typing too so it’s easier, faster” (16, p.130) | Strategies used to adapt and resume participation (15) (13) (9) (16) (18) (19) | “post-injury, the adolescents with TBI were able to adjust their goals by developing other interests that led to happiness and a sense of accomplishment” (13, p.7)<br>“continuation of exploration of gifts and future plans” (19) |
| **Decision to disclose** | “I just didn’t feel comfortable telling [work] that I had a disability , so they didn’t really know” | Taking control of my experience (5) (18) | “youth and young adults with ABI also found that gaining control of their experience attributed to gaining a sense of purpose” (5)<br>“learners demonstrated a sense of agency through the use of coping |

| | | |
|---|---|---|
| | | strategies such as taking active steps, taking preventative steps and seeking assistance from others" (18, p.41)<br>"they reflected that by demonstrating a sense of agency they were able to make the transition and participate in school following the onset of the TBI" (18, p.41) |
| **Individual experiences** | Impact on self esteem in adolescents (14) | "This is a fragile time in one's life and a TBI exacerbates all the attendant problems. Adolescents become very sensitive to comments and opinions expressed by others and this can make it difficult for them to develop self-esteem" (14, p.1091)<br>"…withdrew from difficult communication situations in an effort to reduce communicative failures… She appeared not to value or feel confident about her contributions to conversations" (16, p.130) |

|  |  |  |  |
|---|---|---|---|
|  |  | Self-concept (12) (4) (15)<br>Change in former sense of self | “those participants who had a brain injury when young did not seem themselves as a changed person as they had fewer memories of their life before ABI. Their communication difficulties were already embedded within their identity and so were part of their biography. In contrast, participants who had a brain injury in adolescence had a clear sense of two different periods in their lives” (4)<br>“Many will feel and behave differently to their prior selves… At this sensitive time, students with TBI do not want to be singled out as different” (12, p.446)<br>“changes the learners’ experience in functional abilities, skills and roles… which ultimately resulted in a change in the ways they made sense of themselves” (15, p.4) |
| **Adolescent needs to be met** | “the lady kept coming back with puzzles and baby stuff… it became annoying after a while” (1, p.168) | Specificity of adolescence (1) (16) | “some needs transcend the injury and were specific to adolescents simply because they were adolescents” (p.168) |

| | | | |
|---|---|---|---|
| | “when they say a joke or something, I click to it a couple of days later” (16, p.130) | | “the understanding of increasingly sophisticated jokes and sarcasm is an important social skill to be cultivated during the adolescent years… and is commonly impaired following a TBI” |
| | “I would tell the younger me that, you know your health is more important than your high school football team” (5)<br>“I appreciate them a lot more [friends]… I realise how fast life can be taken away” (9,p.96) | Learning through my personal reflections (5) (9) | “gaining insight into their earlier ABI-related decisions helped them [participants] adjust their present and future expectations.” (5) |
| | | Perspectives on the future (6) | “perspectives on their future can be summarised in two main expectations, where one is tied to the belief of recovery and the other is related to personal expectations of their ability to cope with future demands” |
| **Accepting the brain injury as part of life narrative /** | “it’s horrible what it does to you, ‘cos it limits you a lot… but with | Coping and post-traumatic growth (2) (3) (8) (9) (15) (18) | “participants reported both internal and external factors for |

| | | | |
|---|---|---|---|
| **integrating the good and the bad** | time things become better…if you apply yourself you can achieve great things, move mountains almost…”<br>“I’m trying to see it as more of a positive thing than as a negative thing, because seeing it as something that’s always holding me back, then Im always going to be held back for the rest of my life.” (3, p.1918)<br>“….what happened, happened… no matter how much anyone would wish or I wished or family wished, it couldn’t be changed, what was done was done. You cant change that, so may as well just move on with your life” (8, p.6)<br>“because if I didn’t believe in myself then I didn’t really have anyone who did, and if I didn’t believe I could do it then I wouldn’t be able to do it” (9, p.95)<br>“I just love myself for who I am” (18, p.40) | | coping”<br>“coping occurs acutely post-injury, whereas PTG is an incremental, enduring psychological change that develops post-injury”<br>“sense of belief in herself was essential in being able to cope with TBI” (9,p.95)<br>“this theme reflects the positive personal attributes driving recovery and adaptation, the role of faith, the role of self-acceptance, and acceptance from others that assisted adolescents on their journey of personal growth” (15, p.4)<br>“self-acceptance assisted with the adaptation” (18, p.40) |

|  |  |  |  |
|---|---|---|---|
|  | “I kept my sense of humour and this helped a lot, the fact that I always laughed… my accident, I laughed about it because it was easier. It was easier to get past it and then to joke about it…. this helped me because people stopped treating me like a victim, stopped treating me like I was disabled and needed help” (17, p.3)<br>“Im happy that my pride took over because that’s what helped me persevere. Ive been given a second life. A second chance. It’s incredible” (17, p.3) |  |  |
|  | “[my ABI] helped me because Ive like grown from those experiences. Since I stopped playing hockey its kind of been my goal to be a sports medicine doctor. I get to make a difference and help kids that I pretty much was not too long ago. It’s the ability to give back and to help, just to know that like my experience and what I do there can help other kids that have been concussed” | Gaining a sense of purpose (5) | “being able to view their ABI in way that brought meaning to their lives helped participants to gain a sense of purpose, and comfort” |

| | | | |
|---|---|---|---|
| **Support (Importance of perceived support on outcomes/ moving forward/ progress)**<br>**If perceived support is aligned with individual needs- progress and independence** | "I didn't understand, I really needed my Mom there, she was there…" (1, p.167)<br>"my family played the supporting role. It's a role that they like never gave up on me" (15, p.10)<br>"my parents were there for me…I wouldn't be how I am today without them, without their help, I think that's what made the difference" (17, p.3)<br>"my brother helps me with my homework" (18, p.40)<br>"… I would ask my mommy to like to proofread it (notes for oral) and edit it for me" (18, p.40)<br>"…my mother is always there for me and wouldn't expect anything back" (18, p.40) | Family support (1) (17) (18) (9) (15) (18) | "support in the context of recovery and reintegration" (9)<br>"parents being present and patient in the helping process"<br>"learners reflected that the support they received within their homes assisted with the primary to secondary school transition and ultimately facilitated their participation in school" (18, p.40) |
| | "my friends call me and see how I'm doing. That helps a lot" (10)<br>"my friends have been | Support of friends (1) (17) (10) (13) (14) (18) | "influence the magnitude of disruption and management challenges adolescents and their families faced" (10) |

| | | |
|---|---|---|
| accommodating. They look out for me” (13, p.7)<br>“they were supportive. Yeah, they were understanding… I have some pretty good friends” (13, p.7)<br>“my friends stayed with me” (14, p.1092)<br>“I believe, that if I hadn’t had my friends, I wouldn’t have gone back to school” (14, p.1092)<br>“some of the friends help me with my work at school” (18, p.40) | | “the importance of connection, empathy and social support” (13, p.7)<br>“the authors point out that because of this, the adolescent’s development will be built out of their contact with peers… friends will therefore have a major impact when a member of their group suffers a TBI” (14, p.1092) |
| “the teachers, they could have probably, they could have understood what happened, they could have given me more time to hand in my work” (1, p.168)<br>“the teachers did not really understand what was wrong”<br>“I mean, a lot of people prayed. I mean we had Priests all over the world praying.” (15, p.10) | Support from community partners (1) (7) (18) (19) | “school personnel and teachers did not appear to know much about mTBI and its sequelae. They did not appear to be making the appropriate accommodations to facilitate a smooth return to academic activities” (1)<br>“the interventions provided by professionals were important to adolescents.” (1)<br>“Teacher responses to the |

“I wish I could be helped better at this school” (18, p.41)

“teachers didn’t really see the concussion as a big thing, they didn’t really believe in it” (19)

“they did help me (the teachers) and kinda helped like if they knew what happened and then they told me like after school if I didn’t understand or so on I can come back and they will explain the work to me…” (18, p.40)

adolescent with ABI were an important factor in whether or not the adolescent and their family thought the return to school was successful” (7)

“the accommodation of a teacher’s aide, for example, was evaluated in terms of academic progress and independence” (7)

“This acceptance from others,their reassurance and encouragement were instrumental in assisting the learners’ school transition” (15, p.10)

“for some learners, there appeared to be a decreased level of the school’s commitment to inclusion which was reflected by the negative attitudes of some teachers. Participants in this study also attributed teachers’ negative attitudes to their lack of understanding of the learners’ support needs” (18, p.42)

“minor supports making a big difference” (19)

| | | | |
|---|---|---|---|
| **Independence**<br>**Aligned with individual wants/needs** | “they were with me all the way, like agreeing with me and sort of like, if he wants to go back let him go back and all this.” (8, p.9)<br>“If I need help they [integration aides] just try to, not tell me but just [help me] figure it out” (8,p.9)<br>“They’re just, they give you space, they, they let you do whatever but they just help you where they gotta help you” (8,p.9) | Quality of support<br>-quality of personal relationships<br>-helping style of the person (8) | “students were more likely to accept help when they felt they were contributing… when they were involved in the decision making and when the assistance supported them to do the work on their own” (8, p.9) |
| | “I mean we spend every day, all day together right? And then I wasn’t there for six weeks. Just comments, they don’t even know that affects how I feel walking in the room… Just the lack of knowledge, like they have no idea. They’ve never experienced it” (5, p.1336)<br>“so I was really in the dark as far as what I can do and what can’t I do and it seems like the doctor that I was seeing didn’t really | Navigating support systems to transition to work (5) | “described as having a profound impact on the progression of their recovery and experience of transitioning towards work-related roles was having a well established positive support network. Through these experiences, they also acknowledged the hardships they encountered when such support was unavailable” (5, p 1336) |

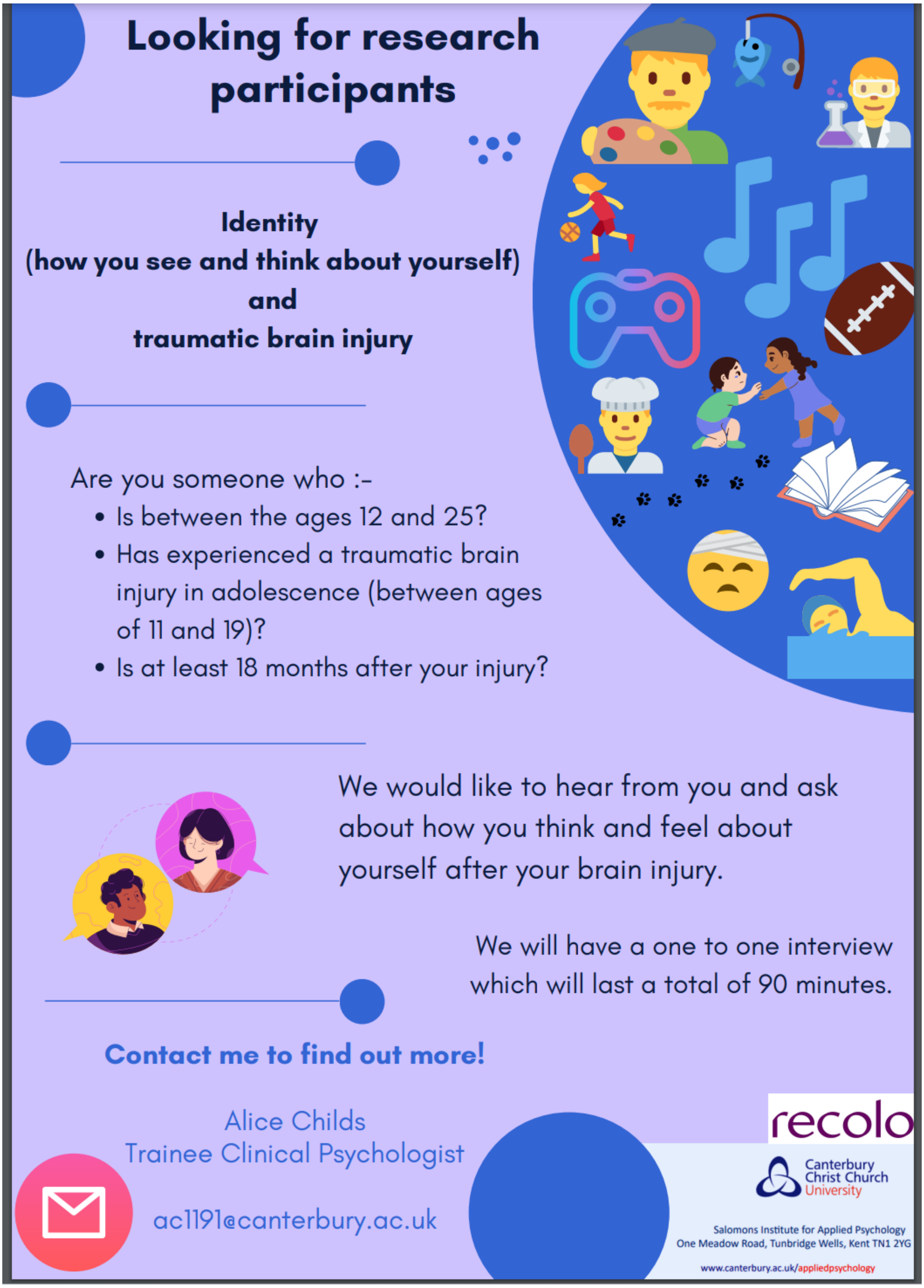
| | | | |
|---|---|---|---|
| | care” (5, p.1337)<br>“Then they fired me. Then I was like, ‘You let me go because I have an injury and I cant come to work?’ and they never replied” (5, p.1337) | | |
| **Family Impact** | “.. she was very stressed out. And… I could feel the stress” (13, p.6)<br>“it was the hardest time of her [Mothers] life” (13, p.6)<br>“they’re still worried about me. They’re still looking out for me” (14, p.1091) | Parental support, stress and guilt (13) (14) | Recognition of impact on parents. |
| | “immediately after the TBI, yes [lost independence] ‘cos I was home a lot of the time… I think I’ve become more independent because of it” (2)<br>“Mum has to help me a lot more, she has to help me with a whole lot more in my life” (2)<br>“its been hard for my brother… just trying not to be as loud” (10) | Family relationships<br>*Roles, responsibilities, independence* (2) (10) (13) (14) | “post injury changes resulted in altered family dynamics; e.g how the adolescent saw themselves as part of the family system, their role within the family and their perceived responsibility for those changes” (2)<br>Closer family relationships<br>Openness |

| | | | |
|---|---|---|---|
| **The role of school in recovery**<br>**Both educational and social needs** | “I really wanted to go back…school’s a big part of your life for 13 years you know it just gets routine…. So I sort of needed that just for a routine” (8,p.6)<br>“It was like, that was the whole point of me wanting to go back to school, like hang out with my friends” (8,p.6) | The meaning and value of participating in school (15) (8) (12) | “students generally saw the role of school as a normal part of life, making it a natural step in their life participation after injury” (8, p.6)<br>“this reflects the role of the school in the learner’s journey to recovery and adaptation post TBI. It includes views of how nonparticipation in school impacted on their recovery post TBI as well as how the school served as a vehicle for learners to progress post TBI” (15, p.4) |
| Understanding of needs- linked to positive or negative experience | “with some s not really know about it (the brain injury) but with the ones who do I find it easier to talk to”<br>“Id like to go to a school where they understand me and stuff… just that really where they actually understand how hard things are for me” (10)<br>“I wasn’t all there… I was a bit lost because I wasn’t thinking | Life in the classroom, understanding educational needs (4) (6) (10) (9) (15) (18) (19) | “participants’ feelings about teacher’s behaviour toward them contributed to whether school provided positive or negative learning experiences”<br>“The implications of participants not understanding what was being asked of them ranged from getting angry, misbehaving or being left in a state of confusion”<br>“lack of understanding by the |

| | | | |
|---|---|---|---|
| | straight, and I was a bit tired” (14, p.1092)<br>“Also for me when I went back, because I used to be quite academic, they put me in an academic class where everyone, it was the highest class with the smartest people in it, which maybe wasn’t the best idea initially” (15, p.7)<br>“…I cant concentrate in class.” (18, p.39)<br>“…after the accident I was slow, and I took my time to answer the question the teacher put on the board.” (18, p.39) | | school as a whole or a single teacher/ staff member could create a great deal of stress” (10) |
| | “I had meetings or something like that… with some of my teachers, my integration aide, people from rehab…” (12, p.444)<br>“they would allow me to take breaks or leave school in the day whenever I was feeling bad or had a headache… That was probably the best thing” (10) | Back to school support and planning (15) (17) (7) (6) (10) (9) (12) | “communication between professionals working with adolescents was described as poor overall, including communication between medical providers and the schools” (9,p.99) |

“The people at the hospital should tell the school more about brain injury” (15, p.6)

## Appendix B: Recruitment Poster



# Looking for research participants

**Identity**
**(how you see and think about yourself)**
**and**
**traumatic brain injury**

Are you someone who :-

- Is between the ages 12 and 25?
- Has experienced a traumatic brain injury in adolescence (between ages of 11 and 19)?
- Is at least 18 months after your injury?

We would like to hear from you and ask about how you think and feel about yourself after your brain injury.

We will have a one to one interview which will last a total of 90 minutes.

**Contact me to find out more!**

Alice Childs
Trainee Clinical Psychologist

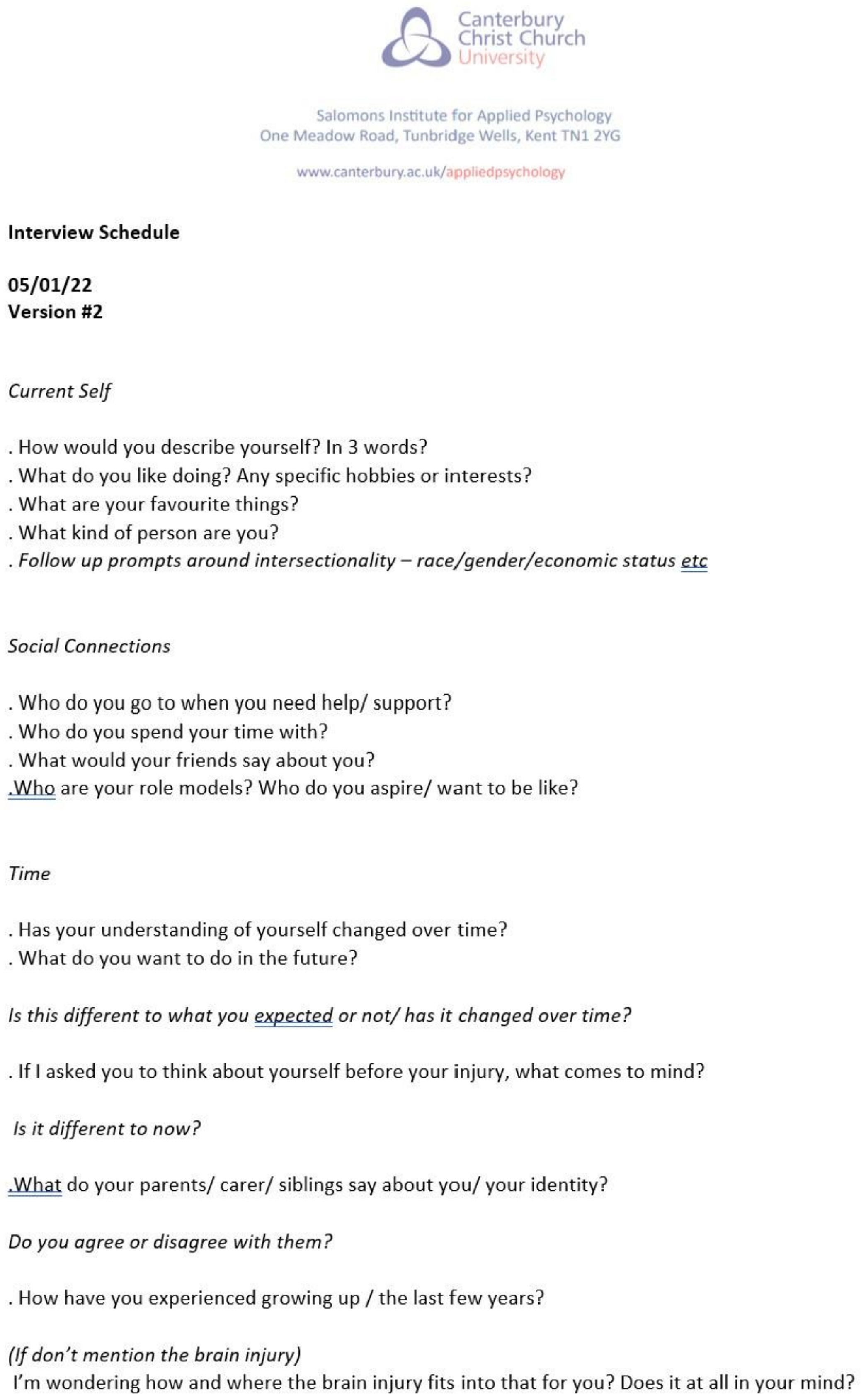
ac1191@canterbury.ac.uk

recolo

Canterbury Christ Church University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG
www.canterbury.ac.uk/appliedpsychology

# Appendix C: Interview Schedule



Canterbury
Christ Church
University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

www.canterbury.ac.uk/appliedpsychology

**Interview Schedule**

**05/01/22**
**Version #2**

*Current Self*

. How would you describe yourself? In 3 words?
. What do you like doing? Any specific hobbies or interests?
. What are your favourite things?
. What kind of person are you?
. *Follow up prompts around intersectionality – race/gender/economic status etc*

*Social Connections*

. Who do you go to when you need help/ support?
. Who do you spend your time with?
. What would your friends say about you?
.Who are your role models? Who do you aspire/ want to be like?

*Time*

. Has your understanding of yourself changed over time?
. What do you want to do in the future?

*Is this different to what you expected or not/ has it changed over time?*

. If I asked you to think about yourself before your injury, what comes to mind?

*Is it different to now?*

.What do your parents/ carer/ siblings say about you/ your identity?

*Do you agree or disagree with them?*

. How have you experienced growing up / the last few years?

*(If don't mention the brain injury)*
I'm wondering how and where the brain injury fits into that for you? Does it at all in your mind?

Canterbury
Christ Church
University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

www.canterbury.ac.uk/appliedpsychology

*Injury and its impact*

. What has happened since the injury?

. Has anyone told you that you have changed/ haven't changed?

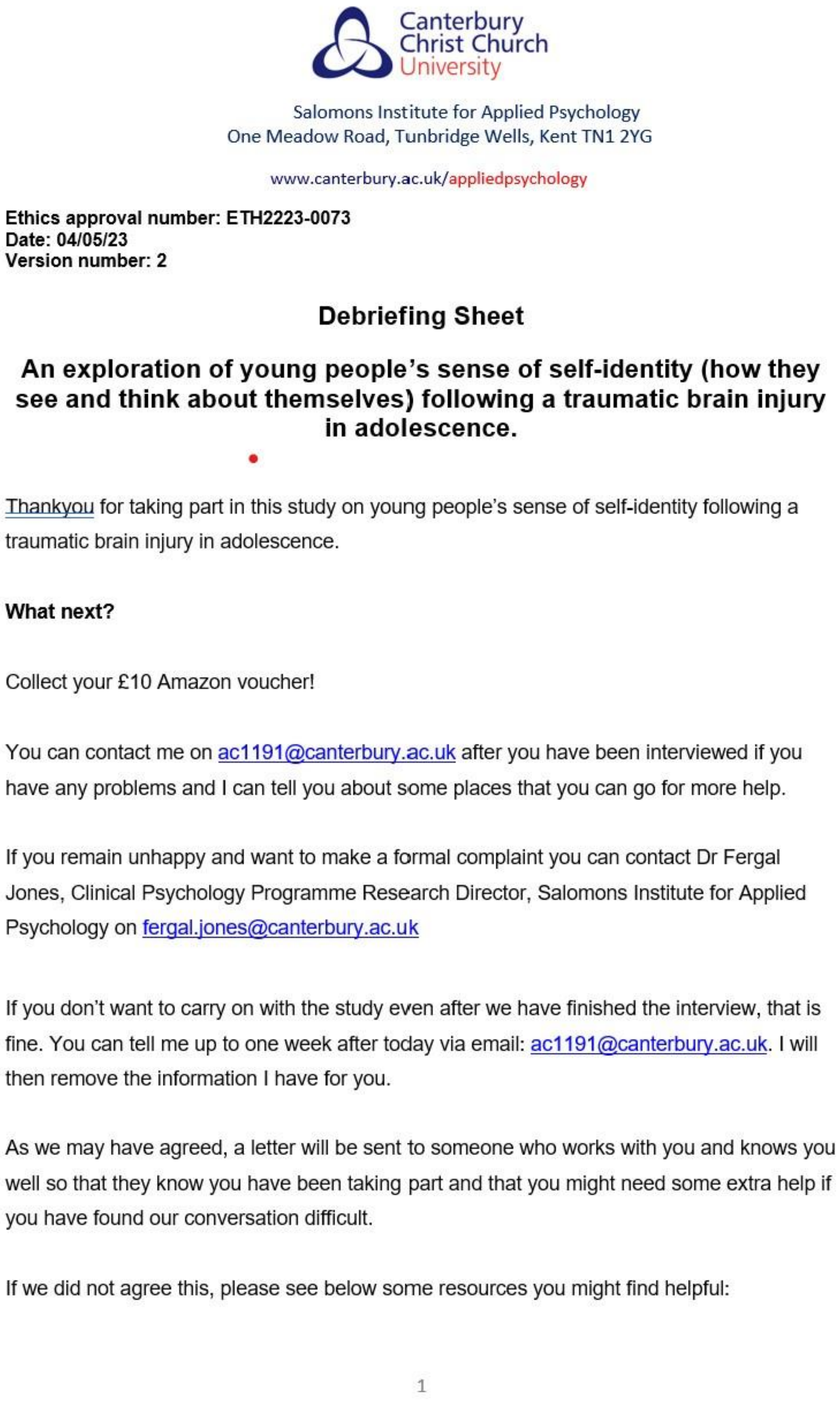
.What do you make of that/ think about that?

*. What has felt the most important change for you since your injury? (if they state they have noticed changes)*

## Appendix D: Ethical Approval Letter

***This has been removed from the electronic copy.***

# Appendix E: Debrief



Canterbury
Christ Church
University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

www.canterbury.ac.uk/appliedpsychology

**Ethics approval number: ETH2223-0073**
**Date: 04/05/23**
**Version number: 2**

## Debriefing Sheet

## An exploration of young people's sense of self-identity (how they see and think about themselves) following a traumatic brain injury in adolescence.

Thankyou for taking part in this study on young people's sense of self-identity following a traumatic brain injury in adolescence.

**What next?**

Collect your £10 Amazon voucher!

You can contact me on ac1191@canterbury.ac.uk after you have been interviewed if you have any problems and I can tell you about some places that you can go for more help.

If you remain unhappy and want to make a formal complaint you can contact Dr Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology on fergal.jones@canterbury.ac.uk

If you don't want to carry on with the study even after we have finished the interview, that is fine. You can tell me up to one week after today via email: ac1191@canterbury.ac.uk. I will then remove the information I have for you.

As we may have agreed, a letter will be sent to someone who works with you and knows you well so that they know you have been taking part and that you might need some extra help if you have found our conversation difficult.

If we did not agree this, please see below some resources you might find helpful:

**The Child Brain Injury Trust (CBIT)**

https://childbraininjurytrust.org.uk/

They also have an app you can download and access; CBIT in hand.

https://childbraininjurytrust.org.uk/how-we-help/cbit-in-hand/

**The Childrens Trust**

https://www.thechildrenstrust.org.uk/brain-injury-information/info-and-advice/approaching-adulthood

**Shout**

Text 85258 for 24/7 text support for your emotional wellbeing.

**Results**

When it is ready, I will have the results of all the interviews I have completed. If you would like to have a look at a copy of this please give me your email address now.

Thankyou!

**Alice Childs**
***Trainee Clinical Psychologist***
***Salomons Institute of Applied Psychology***
***Canterbury Christ Church University***

# Appendix F: Transcript with exploratory notes and experiential statements (Pseudonym Sarah)

***This has been removed from the electronic copy.***

## Appendix G: Personal Experiential Statements into Personal Experiential Themes (PETS) for Sarah

| Sarah Experiential Statements | |
|---|---|
| The injury causing a change in plans | P.2 |
| The injury factored into consideration of a change in plans | P.3 |
| Reliance on others for information about the events leading up to and directly after the injury due to loss of memory | P.3 |
| Others recollections become part of own story and understanding of events | P.4 |
| Reliance on friends to be the ones to seek care initially | P.4 |
| Impact of COVID on the experience of medical care | P.4 |
| Feeling there is an element of luck in relation to the injury and it's outcomes | P.4 |
| Considering alternative outcomes and viewing own as favourable | P.5 |
| Confusion and uncertainty around the injury and it's causes | P.5 |
| Experienced the NHS care received as negative | P.6 |
| Felt assumptions of NHS staff were based on being a teenager impacted on the initial response and care received | P.6 |
| Alone in the experience immediately post-injury linked to confusion | P.6 |
| Not remembering feels scary due to the fear of missing important information related to the impact of the injury | P.7 |
| Felt there was a mismatch between NHS response and the felt sense of importance and anxiety around the injury and its impact | P.7 |
| Slowly discovering problems post the acute phase of the injury and once out "into the world" | P.8 |
| Experiencing changes over time | P.8 |
| Ongoing worry experienced over the gaps in memory | P.8 |
| The missing information feels crucial and | P.8 |

| | |
|---|---|
| not knowing leads to confusion and anxiety | |
| Unsatisfactory experience of NHS Care feels worrying and disheartening. | P.9 |
| Having a TBI feels “big and real” to me but not the NHS. Discord between views | P.9 |
| Not a typical experience in the eyes of others, “odd” so a big response from them | P.10 |
| Experiencing contrast between NHS and lay response | P.10 |
| Change in others perception of self over time | P.11 |
| Acknowledging that there was a time where was not positive or optimistic (as felt post-injury) but attributing this to adolescence and typical development | P.11 |
| Experienced aspects of self as enhanced through injury | P.11 |
| Perception of and way processed the world changed | P.12 |
| Gaining of a new perspective on fragility of physical self / mortality | P.12 |
| Luck felt related to the outcome of the injury | P.12 |
| Acknowledgement of contrasting aspects of self | P.12 |
| Awareness of physical safety and worry related to this | P.12 |
| Fear of another head injury | P.13 |
| Feeling silly for not knowing more about brain injury | P.13 |
| Managing the unknown | P.14 |
| Parental fears concerning physical safety and vulnerability | P.14 |
| Parental responses to achievement felt to be different than it would have been prior to the injury | P.15 |
| Managing “new issues” | P.15 |
| Knowing what it is like to both “have” cognitive difficulties and “not have” which feels frustrating | P.15 |
| Comparisons made to own abilities and others responses both before and after injury | P.15 |
| Feeling that shouldn’t have to overcome | P.15 |

| | |
|---|---|
| these new barriers “getting down on myself” | |
| A feeling of derealisation | P.16 |
| Level of acceptance over time increasing | P.16 |
| Acclimitisation to differences over time | P.16 |
| Being perceived as “functioning” from an outward perspective | P.16 |
| Forget difficulties have unless in very specific situations | P.16 |
| Friends forget about this part of life too | P.16 |
| Geographical and time distance from the injury event | P.16 |
| Feeling grateful at being able to “forget” | P.16 |
| Difficult to discuss close to the event | P.17 |
| Gaining acceptance over time | P.17 |
| Feeling that friends who were present and knew before and after perceive injury as “big part of me now” | P.17 |
| Difference in how much injury is integrated into others sense of who I am (home vs uni friends) | P.17 |
| Contrast in perceptions of self and perceptions of others over time (polarised from pre and post injury) | P.17 |
| Friends feared that would have “a whole new personality” | P.18 |
| Feedback from others who have noticed “changes” in self | P.18 |
| Changes in self bought into awareness by friends to then consider | P.19 |
| Processing observations of others initially and feeling like they are in contrast to “the familiarity of me” | P.19 |
| Initially rejecting some observed changes from others “couldn’t imagine” and holding on to that previous understanding of self | P.19 |
| Sense of being deserving after surviving injury | P.20 |
| TBI being a situation that was out of awareness and totally unexpected occurrence in life | P.20 |
| Enhancement of belief in self following injury | P.20 |
| Injury part of life seen as a distinct period of | P.20 |

| | |
|---|---|
| time and not ongoing | |
| Experiencing a change of role in friendship groups | P.21 |
| Opposite roles and perceptions of self and from others after the injury to before | P.21 |
| No control over differences and how perceived | P.21 |
| Some challenges not perceived as important (change in perception) | P.21 |
| Reframing challenges by reducing importance placed on them – minimisation? | P.22 |
| Considering pre-injury abilities and feeling took those forgranted | P.22 |
| Recognition of new required level of effort for same tasks | P.22 |
| Awareness of not having the challenges in the past is experienced as frustrating due to being able to make comparisons | P.22 |
| Discovery of new strategies | P.22 |
| New to being eligible for and receiving institutional support- accepting this | P.23 |
| Searching for the “perfect way” of managing new challenges | P.23 |
| Discovery that old preferred strategies are no longer effective | P.23 |
| A re-learning process about self | P.23 |
| Memory difficulties one difficulty that are consistent throughout | P.23 |
| Expectation that nothing would have changed | P.24 |
| Slow process of return to activities which led to discovery of new impacts/ challenges | P.24 |
| Confusing experience- the initial discoveries of challenges where tried to manage in “old” ways- seen as an “awakening” | P.24 |
| A key point of realisation that was experienced as difficult | P.24 |
| Process of discovery is unpleasant but helpful so can make adaptions based on awareness | P.24 |
| Management of physical consequences - headaches | P.25 |
| Knowledge of the availability of | P.25 |

| | |
|---|---|
| accommodations if needed is helpful as can then choose if to access | |
| Identity crisis experienced post-injury (self, future and understanding of events) | P.26 |
| Plans and priorities changed as a result; a scary experience | P.26 |
| A re-evaluation of life goals (re education) | P.26 |
| Learning new things about self and passions | P.27 |
| Finding connection with own and family values which influences post-injury decisions | P.27 |
| A realisation and reevaluation of life goals and next steps | P.27 |
| A cross-roads, consideration of the different pathway of the “other” life | P.28 |
| Brain injury primarily viewed as negative | P.28 |
| Realisation of some positive outcomes is secondary | P.28 |
| Finding the positives from the experience has taken time | P.28 |
| Whole thing experienced as traumatic | P.28 |
| Was “bad in the moment” but a positive perspective comes after | P.28 |
| Perceived as a strengthening process | P.29 |
| Initially did not view injury and sequelae as an experience that led to development | P.29 |
| Process of talking with others and experiencing their reactions seen as part of the process of coming to a positive framing and acknowledgement of the gravity of events | P.29 |
| Adolescent experience of identity crises and feeling like they are resolved and “figured out” | P.30 |
| Injury throws sense of self into question | P.30 |
| Feeling grateful for new realisations about self | P.31 |
| Proving to self can still do things | P.31 |

| **Sarah Personal Experiential Themes (PETS)** | |
|---|---|
| **The event as a specific time-point; a crossroads in life** | |
| *Unexpected nature of having a TBI* | |
| TBI being a situation that was out of awareness and totally unexpected occurrence in life | P.20 |
| *Impact on life plans, goals and values* | |
| A cross-roads, consideration of the different pathway of the "other" life | P.28 |
| Injury throws sense of self into questions | P30 |
| The injury factored into consideration of a change in plans | P3 |
| The injury causing a change in plans | P2 |
| A realisation and reevaluation of life goals and next steps | P27 |
| A re-evaluation of life goals (re education) | P26 |
| Finding connection with own and family values which influences post-injury decisions | P.27 |
| Plans and priorities changed as a result; a scary experience | P26 |
| **Managing "new issues"** | |
| *Rejection of new difficulties* | |
| Managing "new issues" | P15 |
| Forget difficulties have unless in very specific situations | P16 |
| Feeling that shouldn't have to overcome these new barriers "getting down on myself" | P15 |
| *Accepting formal support considerations* | |
| New to being eligible for and receiving institutional support- accepting this | P23 |
| Knowledge of the availability of accommodations if needed is helpful then can choose if to access | P25 |
| *Discovery of the "new issues"* | |
| Confusing experience- the initial discoveries of challenges where tried to manage in "old" ways- seen as an "awakening" | P.24 |
| Discovery that old preferred strategies are no longer effective | P.23 |
| Recognition of new required level of effort for same tasks | P.22 |

| | |
|---|---|
| Searching for the “perfect way” of managing new challenges | P.23 |
| Discovery of new strategies | P22 |
| *Appraisal of discovered challenges* | |
| Some challenges not perceived as important; a change in perception | P21 |
| Reframing challenges by reducing importance placed on them -minimisation | P22 |
| **Development over time of understanding of self** | |
| *The role of time* | |
| Experiencing changes over time | P8 |
| Geographical and time distance from the injury event | P16 |
| Difficult to discuss close to the event | P17 |
| Expectation that nothing would have changed | P24 |
| *Discovery experience* | |
| A key point of realisation that was experienced as difficult | P24 |
| Slowly discovering problems post the acute phase of the injury and once out “into the world” | P.8 |
| Slow process of return to activities which led to discovery of new impacts/ challenges | P.24 |
| Process of discovery is unpleasant but helpful so can make adaptions based on awareness | P.24 |
| Identity crisis experienced post-injury (self, future and understanding of events) | P.26 |
| Learning new things about self and passions | P.27 |
| A re-learning process about self | P.23 |
| *Acclimatisation and acceptance* | |
| Level of acceptance over time increasing | P.16 |
| Acclimitisation to differences over time | P.16 |
| Gaining acceptance over time | P.17 |
| Experienced aspects of self as enhanced through injury | P.11 |
| *Positive appraisal of the process* | |
| Enhancement of belief in self following injury | P.20 |
| Proving to self can still do things | P20 |
| Perceived as a strengthening process | P.29 |

| | |
|---|---|
| Feeling grateful for new realisations about self | P.31 |
| Sense of being deserving after surviving injury | P.20 |
| *The role of others over time* | |
| Change in others perception of self over time | P.11 |
| Changes in self bought into awareness by friends to then consider | P.19 |
| Feedback from others who have noticed “changes” in self | P.18 |
| Processing observations of others initially and feeling like they are in contrast to “the familiarity of me” | P.19 |
| Initially rejecting some observed changes from others “couldn’t imagine” and holding on to that previous understanding of self | P.19 |
| No control over differences and how perceived | P.21 |
| Experiencing a change of role in friendship groups | P.21 |
| **Context of the time of the injury** | |
| Acknowledging that there was a time where was not positive or optimistic (as felt post-injury) but attributing this to adolescence and typical development | P.11 |
| Adolescent experience of identity crises and feeling like they are resolved and “figured out” | P.30 |
| Felt assumptions of NHS staff were based on being a teenager impacted on the initial response and care received | P.6 |
| **Embodiment of experience** | |
| Awareness of physical safety and worry related to this | P.12 |
| Fear of another head injury | P.13 |
| Gaining of a new perspective on fragility of physical self / mortality | P.12 |
| Parental fears concerning physical safety and vulnerability | P.14 |
| Management of physical consequences - headaches | P25 |
| **The unknown is confusing and scary** | |

| | |
|---|---|
| *Managing the unknown* | P14 |
| Memory difficulties one difficulty that are consistent throughout | P.23 |
| A feeling of derealisation | P16 |
| The missing information feels crucial and not knowing leads to confusion and anxiety | P.8 |
| Feeling silly for not knowing more about brain injury | P13 |
| *The injury and directly after confusion* | |
| Confusion and uncertainty around the injury and it's causes | P.5 |
| Alone in the experience immediately post-injury linked to confusion | P.6 |
| *Impact of gaps in memory* | |
| Ongoing worry experienced over the gaps in memory | P.8 |
| Not remembering feels scary due to the fear of missing important information related to the impact of the injury | P.7 |
| *Others filling in the gaps* | |
| Reliance on others for information about the events leading up to and directly after the injury due to loss of memory | P.3 |
| Others recollections become part of own story and understanding of events | P.4 |
| **Contrasting and Comparing** | |
| Acknowledgement of contrasting aspects of self | P.12 |
| Knowing what it is like to both "have" cognitive difficulties and "not have" which feels frustrating | P.15 |
| Awareness of not having the challenges in the past is experienced as frustrating due to being able to make comparisons | P.22 |
| Contrast in perceptions of self and perceptions of others over time (polarised from pre and post injury) | P.17 |
| Opposite roles and perceptions of self and from others after the injury to before | P.21 |
| Considering pre-injury abilities and feeling took those forgranted | P.22 |
| Comparisons made to own abilities and others responses both before and after injury | P.15 |

| **Differing responses of others** | |
|---|---|
| Experiencing contrast between NHS and lay response | P10 |
| Felt there was a mismatch between NHS response and the felt sense of importance and anxiety around the injury and its impact | P.7 |
| Having a TBI feels “big and real” to me but not the NHS. Discord between views | P.9 |
| Not a typical experience in the eyes of others, “odd” so a big response from them | P.10 |
| *Perception of others* | |
| Difference in how much injury is integrated into others sense of who I am (home vs uni friends) | P.17 |
| Feeling that friends who were present and knew before and after perceive injury as “big part of me now” | P.17 |
| Friends feared that would have “a whole new personality” | P.18 |
| Friends forget about this part of life too | P.16 |
| Parental responses to achievement felt to be different than it would have been prior to the injury | P.15 |
| Being perceived as “functioning” from an outward perspective | P.16 |
| **Luck** | |
| Feeling there is an element of luck in relation to the injury and it’s outcomes | P.4 |
| Luck felt related to the outcome of the injury | P.12 |
| Considering alternative outcomes and viewing own as favourable | P.5 |

## Appendix H: Group Experiential Themes (GETs) and participant quotes

| Group Experiential Themes and Sub-themes (GETS) | Codes (Personal Experiential Themes) and related participants | Quotes |
|---|---|---|
| **Temporal self and other comparisons; identifying what is gained, lost and remains** | **George:** The gains and losses of TBI<br>Making comparisons; pre-injury, comparing to others<br>**Ben**: Compare and contrast over time<br>**Ed**: Comparisons pre and post injury<br>Gains, losses and consistencies<br>**Sam**: Comparisons pre and post opposing<br>**Sarah**: Contrasting and comparing<br>**Keiran:** Change in self over time | **George**<br>“I’m a lot more, like appreciative of people’s problems”<br>“it’s opened my eyes kind of thing, and made me see it through… a different set of eyes.”<br>“I can do a lot of things that … I didn’t think … I could do before”<br>“A lot of doors have shut… A lot of doors have shut and a lot have opened equally”<br>“never forget where you know, where you’ve come from”<br>“because of this I can’t play [football] well. Well I can, you know, I can’t play normal football… so that was a massive thing for me. To try and accept that”<br>“when I first came out of hospital, it was so difficult… because all you’ve ever known is how to do it, and suddenly you cant do the things you used to”<br>“I’ll get frustrated with myself…seeing other people do what I wanna do” |

|  |  |  |
|---|---|---|
|  | **Arabella:** “Before my accident” | “all I’ve ever … you know, my whole mindset has been football so I’m hoping sooner rather than later I get back, and yeah, I’m going in with a different mindset”<br>**Ben**<br>“my thoughts have changed over time” [about self]<br>[about cycling] “ after the accident, you know, you tend to try to measure up… to see if the feeling… was the same as when you were free to peddle around without…like caring about if you could go for 15 laps”<br>“you wake up in the morning, you thank God you are alive, you’re able to see that day… I’m pretty sure there are others who could not see that day with you as well”<br>**Ed**<br>“they usually say I’m awfully too calm, because normally or before now I would, I would turn the whole house upside down. See right now, a lot of things I did before, I didn’t do that no more.”<br>“I could go watch my friends play games, and literally they’re enjoying themselves and I understand what they’re doing, I mean I’m talking of basketball and all I can do is just… I was once there and now I can’t be there”<br>“I sometimes wonder if its maturity or I don’t know, the power of the mind, I don’t know, but I sometimes wonder because I look back at things and I’m like I’m not doing all the things I am supposed to be doing. I’m supposed to be ranting, I’m supposed to be p***ed, I’m supposed to, you |

know, show that yes, I’m not liking the state I’m in, but instead I’m just calm.”

**Sam**

“yeah I would say like I was impatient. I wasn’t rational about things. You know, at that young age like I always wanted to go out there, you know, fearless. But I think right now before stuff… I tend to like, sit back, think a little bit and you know, plan ahead so that I can avoid some, you know, hurdles along the way”

“they saw how I did things smartly than before when I acted irrationally and impulsive as a younger teenager”

“ you know, being an impulsive teen and all of a sudden you’re so calm”

“like the way I was back then compared to now I will just say, like I totally love myself right now, because I’m sure there are things that I wouldn’t have understood if I was the way I was when I was a young teenager”

**Keiran**

“I’d also describe myself as a beat… I keep to myself in a way, you know, that wasn’t how I was usually but at some point I just became an introvert in a way.”

**Sarah**

“I think it’s just the fact that it’s more frustrating for me because I know what it was like to not have this thing… I just have much slower, like,

| | | |
|---|---|---|
| | | cognitive processing generally… and it's just really frustrating… and so I feel like they're new barriers that I feel like I shouldn't have and I get like down on myself"<br><br>"I'm like a little bit, I don't know, slower than I used to be, like cognitively and very like, I'm very forgetful. That's one thing aswell that's changed is I have no memory whatsoever"<br><br>I went from being so able and so intelligent and it just came easily to me, which I now realise I took massively forgranted, and now it doesn't and I really have to work twice as hard…It does get annoying and it wouldn't if I didn't know what it was like without it. But I think it's because I have that comparison, I'm like ohh this is stupid."<br><br>**Arabella**<br><br>"before my accident, I wanted to go on Britain's Got Talent!"<br><br>"I used to be artistic, and I drew a picture of me and Mum for Mum's 40th birthday… I go to pottery now, so still slightly artistic"<br><br>[re Halloween makeup looks] "Before my accident, for Halloween, I put a can on my head, and put fake blood all around! … now I try to do as good as I can"<br><br>"everyone still loves my humour!" |
| **The relational self over time** | | |
| Intersectionality | **George**: Aspects of post-injury self at odds with gender identity | **George**<br><br>"I'm overly emotional half the time. That's what I am now… I just make |

sure no one sees that, none of my old friends… I can't be over emotional because I'm a guy… I've got to keep a shield up."

**Ben:** Racial identity/ gender identity

**Keiran:** Racial and gender identity

**Ben**

"like I said, I'm black… the people think you are going to be something like that, but you are just trying to be different, you know, just trying to make a name for yourself and be able to, you know, be somebody in the future and make your parents proud".

"…being who I am, you know, in the society as who we are [black], its kind of like different… there are things that… you can go and you can easily get.. compared to us… in this society, there are levels to where they're like 'ohh'…. They're giving us a limit to where they want us to be, like work…." … but I think that's not how it is for some of us you know, some of us are trying to like, not live up to that expectation that they have towards us."

"you know, you're a man and they [parents] are definitely not gonna be in your life forever"

**Keiran**

"I'm a man, you know, I want to experience life…I don't want people just treating me, or taking care of me like I'm a Princess or something. So I want people to be honest and fair with me… I want people to treat me fairly and equally."

"you know, race plays a very critical role in it. And so I'm a young black man."

"you know, I think race is… something we don't just overlook in our

| | | |
|---|---|---|
| | | society now you know… my parents also told me that this is how the world is, this is how everything is… so race actually shaped the way I perceived the world in a way. You know, it's like walking through the streets as a black man is different from going as a white man… so you know, race actually shaped my perspective of things" |
| Shared family experience | **George:** Social support and circles<br>**Ben:** Family<br>**Ed:** Family changes<br>**Sam:** Changes in family<br>**Keiran:** Family and parental support and importance<br>**Arabella:** Family present during injury event<br>Support from a consistent Mum | **George**<br>"family's the most important thing… throughout everything, they're always there."<br>"whereas, when I speak to, you know, my loved ones, my Mum and Dad and brothers, I can let it all loose"<br>"it was such a hard period of time for me and my family"<br>**Ben**<br>"growing up as the only child, I basically had spent a lot of time with my family, you know, because they're the ones that have always been there. Basically, its been the family and not much friends."<br>"I was really afraid if I was gonna die, you know being the only child like I was wondering how my parents were gonna think… how were they going to feel…"<br>"that period of it was basically my parents doing whatever interview [with medical professionals] they were doing and all the examinations and the rest… I think they were really the ones talking to the professionals and I was just basically wanting to recover." |

**Ed**

“then the only thing was Mum and Dad holding hands together, and then my siblings by each side of the bed”
“all I can see is just fear in my parent’s eyes. Like you could tell at that point they were scared and Mum almost liked ordered for me to not have contact with people…to limit my going to school for now, so she could stay home with me”

“I guess we’ve [parents] gotten closer, maybe calmer”

“I finally started paying attention after my incident because I noticed that they all get very happy [family] while they’re conversing. I mean, even my siblings do and I’m just, I sometimes feel like the odd one.”

“[parents] they just prefer we are always around them… I think it’s made them a little more alert to their kids whereabouts and stuff like that”

“and then I look at myself in the family. I’m like, I’m now the quiet one. I’m even more quiet than everyone”

“it’s made me change and I’ve become a little closer to the family, I’ve been able to see them a lot better than what I was seeing them before, and well, probably we’ve begun to build a bond”

“my parents… there are a lot of things that they’re still like… no. I mean, it took a while before they could let me go watch my friends play basketball. It took a while before they could let me go out on casual outings with them once in a while”.

**Sam**

“I spend time with my family, I love my family so much, like I just basically always thank God, you know, for putting me in the position in the family, you know, to have them”

“I do love to spend time with my family because that’s yeah, basically the people that have your back no matter what”

“[role as the big brother], it’s basically leadership. You know, point them towards the part where you know to avoid troubles and help them discover who they are.”

“there’s definitely, you know, a period of change [in the family] when you have an injury, so they all tend to like, let’s say, pamper you, you know, until you get better… they were scared because they saw how patient and how I did things smartly than before when I acted irrationally and impulsively as a more younger teenager”

“and you also let them [younger siblings] know that, OK, things do happen for a reason. So whatever happens, you just have to just like, take it on… through my experience though”

“my parents…they are supportive”

**Keiran**

“I spend my time with family most you know, and even one thing, the pandemic taught us that family will always be there for you. And I got to like bond with my family during COVID. And so family is one of the things… that I take very very important You know, I love talking to my Dad, I love talking to my Mum about things. Then I talk to my kid sister

| | | |
|---|---|---|
| | | and stuff but she doesn’t really have an idea (laughs).”<br>“you know, my parents have been actually there for me from conception, from birth actually and then throughout my incident and after my incident. So I actually leaned to them for support. They’re the first people I run to in case for support”<br>**Arabella**<br>“I’ve had loads of surgeries to save my life when my accident happened… and I’m so glad… I’m so glad I still have the Mum I had before my accident”<br>“My family [support me], most importantly my Mumma” |
| Impact on relationships | **George:** Friendships not as important<br>**Ben:** “family not much friends”<br>**Ed:** Impact in conversations<br>**Sam:** Keeping information about his brain injury private. Seen as a vulnerability.<br>**Keiran:** Impact of mood swings and personality | **George**<br>“I don’t speak to my friends, or some friends quite often, but if I’m honest, I’m not really bothered”<br>**Ben**<br>“basically, it’s been the family and not much friends”<br>“I mean, I’m in touch with one of my friends, but most of my friends that I know have moved out…. We only really contact like once in a while, you know, to just catch up and ask each other how we’re doing”<br>“… it was kind of like hard, you know, having your friends move out from… where you guys were before”<br>“I do have friends but I don’t tend to, you know, let them in too much, you |

| | |
|---|---|
| changes on relationships<br>**Arabella:** Friendships changed<br>**Sarah:** Changed roles in groups | know, just keep it basic with everybody… they don’t basically know too much about you until I’m ready”<br>**Ed**<br>“I look at myself in the family. I’m like, I’m now the quiet one. I’m even more quiet than everyone”<br>“I do know that there are times when I have, yeah, times when I could go all quiet, like we can be having a conversation, I can just go all quiet”<br>“so sometimes I’m in front of a conversation with the family, but I’m not contributing”<br>“I didn’t want to go back to school, I didn’t want people asking me questions.”<br>**Sam**<br>“I just tend to, you know, keep things hidden, plan and move smartly, you know, to avoid any other interested parties in my plans”<br>“it become like a vulnerable spot for them, you know, to like, take advantage of you. So I just try to like cover stuff up [when playing basketball with peers]… like make things like easier… like I just play a supportive role now…”<br>“I just keep it to myself. I keep it to myself… so to them, basically it’s just like maybe I just don’t want to play [basketball] physical, because I don’t want to get into it and I think that’s just like where I’d love to leave it with them.” |

| | | |
|---|---|---|
| | | **Keiran**<br>“so I talk to my friends, talk to my family, you know, and still… feel that people are always trying to be cautious and careful when they talk to me”<br>“it was actually debilitating in a way, you know… I couldn’t really like do anything about it [mood swings, personality changes] because it wasn’t really like a physical problem, it was a psychological problem and not like medications that could actually just help, it was actually caused by the incident. So I actually felt remorse… and they told me that I also felt the remorse, but I don’t really know… someone saying that they are sorry but still coming back to do the same bad character, bad thing.. you feel like youre not actually making progress and improving at some point you know”<br>“I want my friends and family to understand and treat me with like, the love and support I need, but in my day to day meeting with people… I want them to just see me as that guy. Like no bias or stereotype”<br>**Arabella**<br>“before my accident I used to go to town [with friends]”<br>“My friends say they miss doing things with me. [Best friend] said she really misses going to school every day with me, and I instantly agree with her” |
| Perception of the self held by others | **George:**<br>**Ben:** Privacy | **George**<br>“I live in quite a small town, so you know, that’s all people really know. |

Disagree with others predictions

**Sam:**

**Keiran:** Biases and stereoypes.

Others noticing changes

**Sarah:** Contrasting and comparing

So, you know, they don’t really know who I am. Its kind of like – oh he was in a bad accident”

“I wanna kind of like, move away and identify… get another identity in a way”

“I used to go [football] training, and on my badge was “cerebral palsy”... its kind of like… the guy I’ve turned into kind of thing”

**Ben**

“how other people can like, see me… I was kind of like, mysterious, so there wasn’t basically anything they could like say about me… they just knew “OK, he had an accident”.

“they do say like he can’t be like this, you know, forever… Like I’m saying, like I’m not that kind of person, I’m not that kind of person, so they should just keep saying whatever they want to say.”

“it’s really gonna affect the way they view, like, the things going on in my life, you know… I’m sure they’re gonna tend to like, wanna be careful, you know, towards you.”

“We have to make a choice if we want to say or not… I think like it’s kind of like my power, you know? … I don’t really want, you know, people to have that, you know, too much empathy and sympathy like ‘ohh sorry I didn’t know such thing happened’. Like basically kind of see that like as a weakness you know, so just like keep it to myself”

**Keiran**

“they [parents] said they noticed some behavioural changes after my incident, that I became more of an introvert"

"in a way, they themselves [friends] also noticed my personality changes. Back then, it was a bit intense during my mood swings"

"you know, it was actually really funny…and interesting at first, but umm getting to hear that I have changed, not totally, but to some extent, you know… still gives me the creeps sometimes, you know, like I woke up and I'm changed, my personality or my behaviour"

"well it happened when I was 13, so I don't really have much, you know, memory like that at all….I don't really have much memory of how I was or how my behaviour was before the incident…. So if they [parents] said I was a bit different after the incident I uhhh, changed my personality in a way… I believe what they say about it"

"Like, if you didn't already know I had an incident, I try my best to keep it , you know, a bit secretive, because once they know about this, they tend to see you in a different way. They tend to perceive me differently"

"I don't want that bias or stereotype…in my day to day meeting with people, I want them to just see me as that guy, like no bias or stereotype."

"I think they wouldn't want to meet me before seeing you know, before hearing because it's like a small thing can trigger [me]. You know, everything's a small thing to make you upset"

**Sarah**

"this is a silly example, but I've always been quite smart throughout school, I've always got really good grades and a lot of subjects didn't phase really. Like, I was quite intelligent, and I'm not saying I'm not intelligent anymore, but I was very much known as someone who was smart back in school and college… and now here in the girl group I'm in, I'm definitely seen as one of the slightly dumber ones… like that would never ever have been my reputation before"

"I feel like there's differences that **I** can tell because my home friends and uni friends see me differently, and differences that my home friends can tell because they've seen me both ways"

"in my like group at home before the injury I was very much seen as the mum of the group, like I was the one that would like, pack a bag with everything that people needed, and like I'd make sure I had everyone's tickets for stuff and I'd have like, water and medicine and things that I knew that we would need and all of that. Like I was very much seen as the mum….
And like I'm a little bit, I don't know slower than I used to be, like, cognitively and and very like, I'm very forgetful. That is one thing as well that's changed is I have no memory whatsoever and like the amount of times I'll leave the house without keys and stuff like that, just like little things like I'm seen as like the irresponsible child kind of here, which is not something I'm striving for by any means, but I guess it's just little things that have changed since the injury have then like had knock on effects to make me slightly more irresponsible, which I didn't mean to but and yeah, so I think that's interesting because very stark differences in what sort of role I played in different groups before and after the injury."

"day to day I am very functioning like there's nothing… at least from an outward perspective, there's nothing that really appears that different"

"for them, they're never going to not think about it being like, a big part of me now and I guess they were literally there when it happened, so it's probably quite ingrained in their brain"

| | | |
|---|---|---|
| Process of talking with others leads to insights | **George:** The value in talking with others<br>**Ben:** The process of talking with others including the research<br>**Ed:** The experience of talking with others, including the research interview<br>Comparing and contrasting<br>**Sam:** Experience of talking with others and research interview<br>**Sarah:** Role of others over time<br>Talking with others<br>Comparing and contrasting | **George**<br>“it was helpful [therapy]… but it was… bringing up my problems, you know… kind of saying it out loud… like problems I didn’t really realise I had… then I said it out loud and I though Jesus Christ!”<br>“I’m saying it now… accepting that part of my life and accepting it in a good way…. I’m speaking, you know, saying it and hearing it… I’m still a little bit amazed”<br>**Ben**<br>“I’m OK sharing with you though… I just wanna try something new, so you know, to see if I could be like, actually do it in the future, so might as well start somewhere… it’s still a little bit difficult, but I’m pretty sure in the future I’m gonna like, be strong enough, you know, to say more hopefully.”<br>**Ed**<br>“aside from when talking with my friends, this is more like the first time I’m having a conversation with someone and it’s just this easy.<br>**Sam**<br>“I just feel like I need to open up, you know. You can’t hide something forever, so I just feel like letting some things out…Like I will say, theres not much people like out there doing what you do, so its kind of like an opportunity for me, you know, to just go through this”<br>[about the process of talking for the interview] “I saw you smiling, I’ve |

| | | |
|---|---|---|
| | | been laughing, so I think like it’s kind of like a milestone that I’ve crossed you know to put out like my experience and how I got to get out of that stuff”<br>**Sarah**<br>“they [friends] pointed it out to me that since then they think I take a bit less… and that I’m better at like, standing up for myself… and when they first said that I was like, mmm that doesn’t sound like me. But then I just got thinking about it, and I was like, actually, yeah, you know what I think that’s true!”<br>“the more I speak about it to other people like, gauging their reactions and like how in shock they are and how seriously they’re taking it I’m like - ohh like I guess it is pretty crazy that I’m OK and I’m actually doing well”<br>“I see myself as much stronger than I ever have before. And that’s something that like, yeah, straight away I didn’t see that, but like I think it’s the more I’ve spoken about it with other people and gauging their reactions cause while it’s like a crazy thing to happen, it’s almost like normal to me now because like it happened to me” |
| **The embodied self ( including existential thinking)** | **Ed:** Listening to body<br>**George:** Embodiment of experience<br>**Ben:** Impact of TBI – physical – psychological – vulnerability | **Ed**<br>“It’s made me to be calm and I listen to myself a lot. It’s made me study my body even more.”<br>“I was really scared because at some point, there were times when I could go by, and my head’s really heavy. I can feel this really heavy sensation like carrying something like 2,000,000 kilograms on my head or something” |

**Sam:** Physical experience of BI

Brain injury sequelae

**Sarah:** Embodiment of experience

**Keiran:** Vulnerability and hypersensitivity

**Arabella:** Benefits of therapy – comfortable in own body

“migraines, fatigue and I think I get amnesia sometimes”

**George**

“… its because my legs and my whole body took a lot of time to come back”

“ its like you’ve gotta just take your time more…”

“but not being able to sleep at all is, you know, just another problem… it just makes [my] day a lot harder”

“I do things slower now, you know, like apart from walking, I do everyday things slower”

“when you gotta learn to walk, eat, talk, everything”

**Ben**

“I was scared, was I gonna die?”

“basically, the pain, the trauma you know, like like like a shock”

“so I could actually die any moment from now, you know nothing is like you cant expect anything, it just happens so that kind of like makes me wanna be, you know, safe, you know, just pull myself out from stuff that’s gonna get me harm… basically get out of trouble. Avoid getting hit in the head… slippery floors. You know, stuff that basically could, you know, get your head”

“some of the scars, like I’m hairy. So the scars to the head, you know, kind of like covered up in hairs”

“I love to exercise, you know to bike a little bit, you know to just like build endurance towards that aspect of you know, feeling too tired.”

“It got me thinking, OK, I could actually leave anytime, so I just need to be very careful as I can… all my dreams could have just basically vanished with me”

**Sam**

“it was really traumatic. It wasn’t easy, you know, going through that process, the vomiting, the headaches that wont go, you know, it was like when is this ever gonna end?”

“the headaches. I would say they are pretty long lasting. You know when it comes to like thinking about stuff you know about what you want to do and the headaches that are meant to be mild, they tend to be more severe… it stopes me because… you can’t basically process stuff, you know, with that kind of headache”

“I do my best to avoid any contact what would lead to injuries again”

“I still play. If the opportunity comes… while still scared of the injury part though”

“all of a sudden you’re so calm and you know, try to avoid stuff happening to you again”

“you’re living through the process. I wasn’t watching it”

“inside of you telling like there's no need to rush, you just have to calm down and just let things happen the way they are meant to be. We only but small fishes in the ocean, so just tend to just go where the tide takes us.”

**Sarah**

“I’m definitely more cautious… Like this is a silly example, but it just happened yesterday because of all the storm and everything… I was walking to the gym and I live like on top of a hill. So everywhere is downwards to get to anything is like quite a steep hill, and there were like wet leaves and water and stuff and I was like really worried or scared that I was gonna fall and hit my head or something. So I was really taking my time and holding the railings and stuff”

“it’s always the head thing… I’m also just worried that like that could happen and I’ll hit my head. Its all like head based, right”

“I don’t know what it is, but I can tell the difference between like… I call it a brain headache… they come from different places and it’s not like, I don’t know, it’s not anything like any kind of headache I’ve ever experienced before”

**Keiran**

“it [the injury] plays a very big role in how I see things… I think that one of the main factors that’s gone with my introvert lifestyle and I always feel that anything could, anything could happen to you on the road, and you know, a truck come… all those kind of things”

“just like a hyper – hyper sensitivity of trying to stay safe… also means like more careful and cautious in a way… it makes me feel vulnerable. But I also got told in church that vulnerability is actually what makes us

| | | |
|---|---|---|
| | | human. We have to be vulnerable to those things that happen”<br>**Arabella**<br>“they’ve [music therapist and psychologist] made me feel more comfortable in my body… they’ve made me today” |
| **From discovery to acceptance of a post-injury self** | | |
| Self development over time from the injury event to acceptance<br>**Initial injury experience**<br>**Discovery and realisation**<br>**Reappraisal and reframing**<br>**Adapting**<br>**Acceptance**<br>**Appreciations**<br>**Post-Traumatic Growth** | **George:** Moving through time post-injury<br>Re-appraisal and re-framing of challenges<br>**Ben:** Discovering strategies for recovery<br>Appreciations<br>**Ed:** A transformative experience<br>Coping strategies – positive reframing and awareness<br>Acceptance<br>**Sam:** Coping strategies | **George**<br>“its very very difficult, you know … having a brain injury”<br>“There was a long time where I didn’t see the point. I was down… my mindset… wasn’t good”<br>“I had a year off, when I was just… my mindset was none”<br>“I know what I am and who I am now… I saw the light”<br>“Its just so difficult for your mental state of mind to accept it”<br>“And yes, its not the same as it was, but if I carry on, you never know where I can go”<br>“Throughout this I’ve really found out more about myself”<br>“it comes back to accepting the new person you’ve become and adapting to the new person you are” |

| | |
|---|---|
| Identity discovery following traumatic experience and impact on faith<br>**Keiran:** Coping strategies<br>Reframing<br>**Sarah:** managing “new” issues<br>Development over time of relationship with self post-injury<br>**Arabella:** Reframing and adapting | “I’ve become a lot more…. A lot more accepting of myself”<br>“yes, I might never be able to sleep again, but think of all the amazing things I can do”<br>“I used to be able to do things, now I can’t do it, I’ve got to accept it and not get frustrated and not get annoyed at myself”<br>“for ages they were saying… you’ve changed, you’ve become this. And I didn’t accept it. Well, I couldn’t accept it. You know, I didn’t feel like I had”<br>“if you believe you’re gonna, you know, that you’re gonna get out of it, you know, how you want to and you just keep smiling and then you will.”<br>“they obviously did their magic and umm kept me alive… I’m so grateful to be blessed… I’ve been in some sense, lucky to have you know, the people working on me”<br>*Re-appraisal and reframing*<br>“yes I cant sleep, but you know at least I can walk”<br>“I’ve gotta keep telling myself I can still play football…and yes, it’s not the same as it was, but if I carry on, you never know where I can go”<br>“now this has happened to me, I’ve seen life in a totally different picture and I’ve actually got a chance”<br>**Ben** |

“ I didn’t really do much because it was like a dark place. You know what, that moment, you know, having the injury… it was kind of like dark, you know, it was a place where you wouldn’t want to, you know, go back to or wish for anyone else”

“the pain. The trauma, you know. Like like like like a shock. You know, like…. What words can I use to describe this? Like you never thought like any of this can ever happen to you like to this level… nobody imagines this you understand, so it was like unbelievable for me”

*Appreciations*

“it kind of like, made me be more grateful and very, very, really, really, thankful, you know, wake up in the morning, you thank God that you are alive, you are able to see the da. You know, I’m pretty sure there are others who could not see that day with you aswell”

**Ed**

“I actually even like it because it’s like made me calm and I’ve been able to think a lot… its made me be calm and I listen to myself a lot. Its made me study my body even more. It’s made me realise a whole lot of things and yeah, so it’s a good thing”

“I think I kind of like this peace and quiet, I just… I don’t know why I like it, but it’s made me realise that there is a lot to being peaceful than what I’ve always been…. Its like I transformed into someone I normally wouldn’t want to be then, but now I’m that kind of person that’s…live with it. No point pouting”

“I wake up, and I’m just staring at the sky. There is tears down my eyes and … I can’t even talk, so it’s just me, my bed and the sky for a while”

“I go with one or two of my friends and just run around the court, and I don’t do aggressive, we just do some kind of scrimmage or just do free throws and ‘who shoots best’- something that doesn’t stress me”

“I’m just waiting for that period [when symptoms subside], so since I can wait for that period, I can do every other thing that doesn’t stress me. I can do every other thing that wont put me in some sort of uhh distress. So why not?”

**Keiran**

“I actually did some minor researching. I’m very much of a nerdy person and all, I just did a few research about the brain injury and the rest and actually for the cause of most of the things and the signs and symptoms that my parents mentioned… but I don’t really need to know, I think the less I know the better for me”

“I believe the biggest thing is my perception of how I see people and how people see me”

“I don’t really call it an injury, in a way I try my best not to make it look that bad or portray it in a bad light, as a bad memory because most of the time it rarely comes up now”

“to some sense I have a way of like controlling myself and trying to manage everything [emotions]. So in a way I have like improved my management and everything, but um I am not really where I want to be”

“I’m really proud to say that I’m more really what I was, you know [in relation to emotional lability], So there has actually been an improvement over the couple years, so I think that’s actually a good thing in a way”

“It’s mostly anger and like, overreacting most of the time, so from what I heard, I was just kind of a cool person, gentle or no, so all of a sudden that I just get angry and start lashing out, that felt like different for me in a way… Afterwards you know, I knew it was not my fault as I started managing it better… start getting support like I said from parents, umm it’s totally cool. It’s not my fault and they see this also happened after my incident”

“I’m trying not to get, you know, in a way feel bad about myself for doing some things… I am sorry about what I said, I am sorry about how I reacted. So in a way, I feel that you know, from what I heard like it wasn’t me. This is not how I used to be, so I do my best to draw on and refer to that”

“I think overtime I’m getting to understand myself better and when I notice that I’m having a conversation that would be provocative and that could cause me to react, I try to withdraw or ask to change the topic and all. That’s actually helped me to adapt better”

“at first I used it as an excuse [the brain injury], but growing up, I learnt to take responsibility for my actions now. So I tried to stop using that as an excuse”

**Arabella**

“ Before, I played the violin… and I was talking to Mum about… having lessons and Mum said I could just get a violin stand”

“When I say I’m disabled I feel proud because I’m alive to say that”

| | | |
|---|---|---|
| | | “since Halloween is my favourite day of the year, that makes a good story!” [about the injury event]<br>“my Mum says to me if it happened if I was younger or older I would have died, so I’m grateful. I was so close to dying”<br>“my accident makes me pissed off… all of the time”<br>**Sarah**<br>“there have been things that have like, slowly popped up umm that weren’t present during the first phone call [NHS follow up appointment] because I was only a month in recovery like that whole, I was still very like bed bound. Like I couldn’t really do anything for myself, so I hadn’t gone out into the world and seen first hand what problems might have arose – so that happened later on, at least for me.” |
| **Understanding of the injury event and its placement in the life story and context** | **Sarah:** Injury event as a specific time point<br>**Sam:** Cross-roads | **Sam**<br>“I would say everything happens for a reason and I know me having that injury was not by chance like, it was meant to be, so to put me on the right path to become maybe who I wanna be, you know?”<br>**Sarah**<br>“I think I just went through a bit of a crisis, to be honest, after my injury and I was like, I don’t know who I am, I don’t know what I’m doing, what is going on?” |
| Filling in the gaps | **George:** Importance of knowledge about BI | **Keiran**<br>“it sometimes feels like a movie, you know?” |

| | | |
|---|---|---|
| | **Keiran:** Information held by parents<br>Unreal feeling<br>**Arabella:** memory loss<br>“a stain”<br>**Sarah** | “I heard from my parents that before the incident I was actually a free person. You know, I used to go out and play and talk and be more like an open person, but they said they noticed some behavioural changes after my incident that I became more of an introvert and an exclusive person and from what my Mum told me, she said something about frontal lobes and stuff and the rest”<br>“I don’t really have much more memory because after you see I actually went into a minor coma… I don’t really have much memory of how I was or how my behaviour was before the incident”<br>“then I think they opened the door and saw me then took me to the hospital… and I was told I was in a coma…<br>**Arabella**<br>“that’s how bad my memory loss is, which is probably a good thing”<br>“it’s a lot to process, it’s a stain, it’s like a stain that’s left me disabled”<br>**Sarah**<br>“sometimes I forget what happened to me is real” |
| Context of adolescence | **George**<br>**Ben:** reflections on adolescence<br>**Sam:** understanding of self | **Sam**<br>“You know, being an impulsive teen and all of a sudden you’re so calm”<br>“I’m sure there are things that I wouldn’t have understood if I was the way I was when I was like a young teenager… compared to now... if I were to |

| | | |
|---|---|---|
| | pre-injury in context of being a teenager<br>**Keiran:** reference to self as a teenager<br>**Ed:** Reflections on adolescence<br>**Sarah:** Adolescent experience of identity | have grown, you know, with the way I was, I’m pretty sure if this was gonna hit me later on in life, it’d have been like much harder, you know, with… more responsibilities, you know, and the rest”<br>“I would say I was impatient, I wasn’t rational about things, you know at that young age, like I always wanted to go out there, you know, fearless”<br>**Keiran**<br>“I use social media a lot and I think every, every teenager will have”<br>“I’m still a teenager now, so I would still want to be in my fantasy world where I could actually um control my emotions” |
| The role of faith and religion | **Ben:** relationship with God<br>**Sam:** questioning God and faith supporting an understanding<br>**Keiran:** questioning faith and attempts to understand why | **Ben**<br>“I’m hopeful to God to keep me alive til then”<br>“you know, having faith and seeing you know, really coming out from whatever happened to you was kind of like, great. And you know that there’s an entity in this world that just keeps us alive… it kinda, it kind of like made me to be more grateful and very, very and really, really thankful, you know, wake up in the morning, you thank God that you are alive, you’re able to see the day”<br>**Sam**<br>“I will say prayer and reading the word, they were major steps for me, you know? So like we have from where I was… God loves everyone. So like that period, I kinda feel like for this to happen to me, I wasn’t loved. But |

going to read the word I understood that there is a deeper love greater than what I was expecting. So kind of like, went deeper, to get like better understanding. And I think that kind of like opened my mind to what I need to accept, you know.”

“like, nothing happens without a reason. Like, there’s always a reason something happens. So back then, I didn’t understand. So I had to, you know, dig deep. And I found out, like the Bible, that things happen for a reason. Theres something could happen to you… so you could realise yourself on time to, you know, put you on the right path. So I think that as well is how I got out of the place I was”

“I just basically kind of like, like basically like give yourself like a self rehab. Like I said, the Holy Spirit was like my guardian”

“the most important thing was just knowing God because let’s say for the fact that your parents are there, they’re not always gonna be there… like you just tend to like, think, OK, no matter what, I’m still gonna be alone at some point in life. So I kind of feel like this, this used to be like an entity that you know should be there no matter what and all and behold, it was God. So that was the single most important thing that I discovered throughout the whole process.”

**Keiran**

“Religion is actually very powerful for me… umm at some point actually I start asking, questioning God… I fully believe in God so I fully like questioned, why did this happen to me? Why did I get into a coma? And then why am I having behavioural changes at all? Why did God let this happen to me? But actually at some point in a sermon and from Church and everything, you have to go, and I actually got some of my support from Church. Yeah, so the way they were like everything actually works out for you good, means everything is going to get better and everything. So actually got that reassuring message from time to time… so I think I've got church, also played a very important role for me"

"It was him [the clergy] I went to and told him about what I feel, how I feel about God and how I felt about everything. Then he kept assuring me and giving me those confidences and support"

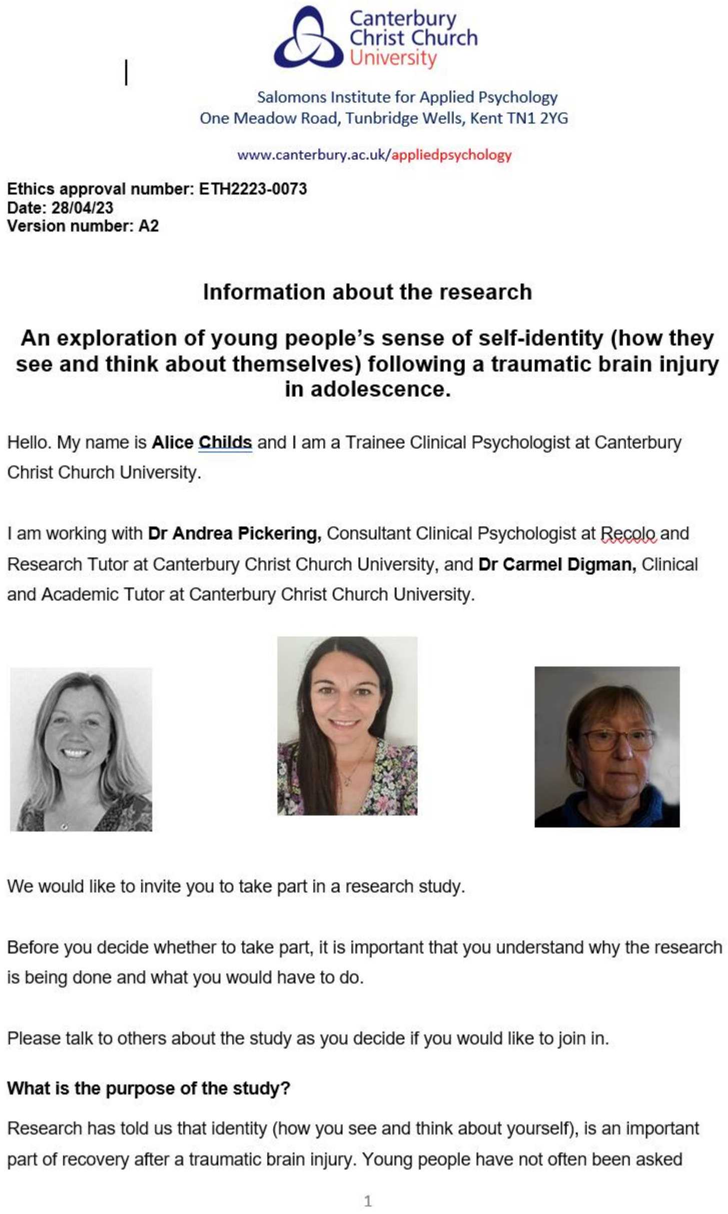
"questioning God and all those things actually affected my faith and my relationship with God and at first, but later when I got support from my clergy and I got to understand that everything in life it actually happens before in black and blue, white and red and everything. So I actually got that faith that just happen and… sometimes life takes charge. So I actually understood the goal wasn't actually this response to what happened to me, you know, I don't need to keep saying that, why this happen to me? So I got to get an understanding that things happen… and after some time actually see inside my relationship with God and how I perceive things and religion"

"so do I take a step back, and be the man my parents want me to be, my Church wants me to be. Be the man that God wants me to be. So that's the choice of always trying to do the right thing and take the right way, not the easy route has been like the biggest thing for me"

## Appendix I: Researcher’s reflexive diary extracts

***This has been removed from the electronic copy.***

# Appendix J: Information Sheet A



Canterbury Christ Church University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

www.canterbury.ac.uk/appliedpsychology

**Ethics approval number: ETH2223-0073**
**Date: 28/04/23**
**Version number: A2**

## Information about the research

## An exploration of young people's sense of self-identity (how they see and think about themselves) following a traumatic brain injury in adolescence.

Hello. My name is **Alice Childs** and I am a Trainee Clinical Psychologist at Canterbury Christ Church University.

I am working with **Dr Andrea Pickering,** Consultant Clinical Psychologist at Recolo and Research Tutor at Canterbury Christ Church University, and **Dr Carmel Digman,** Clinical and Academic Tutor at Canterbury Christ Church University.

We would like to invite you to take part in a research study.

Before you decide whether to take part, it is important that you understand why the research is being done and what you would have to do.

Please talk to others about the study as you decide if you would like to join in.

**What is the purpose of the study?**

Research has told us that identity (how you see and think about yourself), is an important part of recovery after a traumatic brain injury. Young people have not often been asked about this for research. This study hopes to ask young people about how they think about themselves after they have had a traumatic brain injury when they were a teenager.

**Why have I been invited?**

You have been invited to take part in this study because you had a traumatic brain injury during adolescence (when you were a teenager).

**Do I have to take part?**

It is up to you to decide whether to join the study. If you say yes, I will then ask you to sign a form called a consent form to show your decision.

You can change your mind at any time. Even if you have already said yes or signed a form.

**What will happen to me if I take part?**

I will ask you and/ or your parents to sign some forms.

I will then ask you some questions and record our conversation.

We can have two shorter interviews instead of one long 90 minute interview. We can talk about this together to decide.

Interviews are likely to be held online via MS Teams but can be done in person if this is better for you.

**Expenses and payments**

As a thank you for taking part in the study you will receive a £10 Amazon voucher. I will travel to you, so you won't need any money to travel for this study.

**What will I be asked to do?**

You will be asked to talk with me about who you are, your brain injury and if you feel anything is different. I have included a list of some of the interview questions with this Information Sheet so that you can see what kind of things I might ask you. This interview will last up to 90 minutes and the sound will be recorded. You can take a break or stop the interview at any time. You can ask me to come back another day if you would like.

I will have traffic light cards that you can use to tell me:

**GREEN -** I am happy with the interview
**YELLOW -** I would like to take a break
**RED -** I want the interview to stop

**What are the possible disadvantages and risks of taking part?**

It might be tiring answering lots of questions.

Thinking about your injury and how you see yourself may feel emotional and difficult.

**What are the possible benefits of taking part?**

The things that you tell us may help understanding and the treatment that people get after they have had a traumatic brain injury like you have.

**What if there is a problem?**

You can use the traffic light cards at any time.

If you need them, I can tell you about some places you can go for more help.

I will write a letter to someone who works with you and knows you well so that they know you have been taking part and that you might need some extra help if you have found our conversation difficult.

You can contact me on ac1191@canterbury.ac.uk after you have been interviewed if you have any problems and I can direct you to where you can get further help.

If you remain unhappy and want to talk to someone else you can contact Dr Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology on fergal.jones@canterbury.ac.uk

**Will information from or about me from taking part in the study be kept confidential?**

Yes. All information collected from you for this research will be kept confidential. Confidential is the word we use when we are keeping something private. So only Alice, Andrea and Carmel will know.

We will not tell your parents or staff working with you what you have said in the interview and when we write about the study we will take away your name so that no-one will know it was you. I will use a number to put on your information instead.

The only time we will share what you have told us is when we think you could be in danger. I might worry about your safety or other people's. We would talk about this during the interview.
Our interview will be recorded (just the sound). This and other information about you will be saved on a memory stick. It will then be moved onto the University computer network which is secure (private). Anything on paper I will shred. Once I have gone through the interviews I will delete them.

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

If you don't want to carry on with the study, that is fine. You can tell me when we are talking for the interview or up to one week after via email: ac1191@canterbury.ac.uk.

I will then remove the information I have for you.

**What will happen to the results of the research study?**

The results will be written up for my studies for the Doctorate in Clinical Psychology at Salomons Institute of Applied Psychology. This will be read by the examiners. I also hope to publish the results in a peer-reviewed journal.

Nobody will be able to tell it was you who told me things when I write up the research report. I will use a different name.

When it is ready, I will have the results of all the interviews I have completed. If you would like to have a look at a copy of this please give me your email address and I can send you a copy.

**Who is sponsoring and funding the research?**

Salomons Institute for Applied Psychology, Canterbury Christ Church University in partnership with Recolo UK.

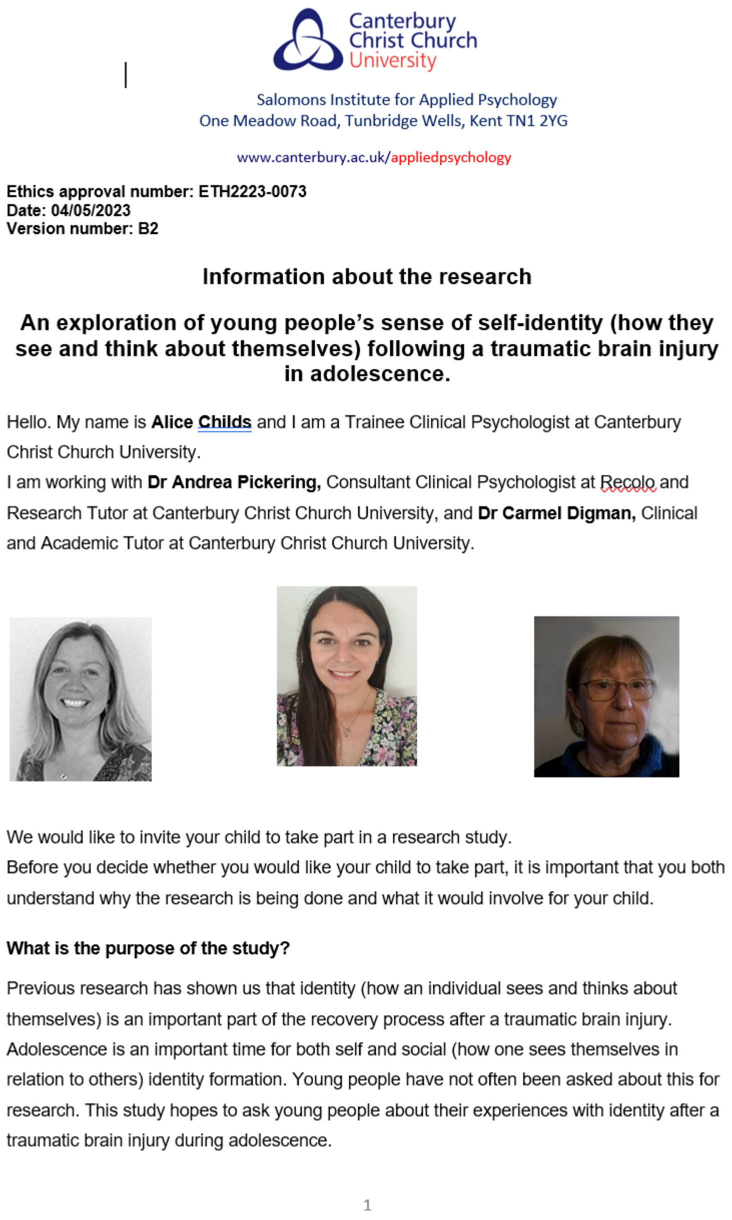
**Who has reviewed the study?**

The Salomons Ethics Panel, Salomons Institute for Applied Psychology, Canterbury Christ Church University

---

Thankyou for reading this Information Sheet. If you decide to be interviewed, you will be asked to sign a consent form. You will be given your own copy of all the forms to keep.

# Appendix K: Information Sheet B



Canterbury
Christ Church
University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

www.canterbury.ac.uk/appliedpsychology

**Ethics approval number: ETH2223-0073**
**Date: 04/05/2023**
**Version number: B2**

## Information about the research

## An exploration of young people's sense of self-identity (how they see and think about themselves) following a traumatic brain injury in adolescence.

Hello. My name is **Alice Childs** and I am a Trainee Clinical Psychologist at Canterbury Christ Church University.
I am working with **Dr Andrea Pickering,** Consultant Clinical Psychologist at Recolo and Research Tutor at Canterbury Christ Church University, and **Dr Carmel Digman,** Clinical and Academic Tutor at Canterbury Christ Church University.

We would like to invite your child to take part in a research study.
Before you decide whether you would like your child to take part, it is important that you both understand why the research is being done and what it would involve for your child.

**What is the purpose of the study?**

Previous research has shown us that identity (how an individual sees and thinks about themselves) is an important part of the recovery process after a traumatic brain injury. Adolescence is an important time for both self and social (how one sees themselves in relation to others) identity formation. Young people have not often been asked about this for research. This study hopes to ask young people about their experiences with identity after a traumatic brain injury during adolescence.

**Why has my child been invited?**

Your child has been invited to take part in this study because they had a traumatic brain injury during adolescence (whilst a teenager or going through puberty).

**Does my child have to take part?**

It is up to you and your child to decide whether they will join the study. If you agree for them to take part, I will then ask you to sign a consent form. Your child is free to withdraw up until one week after their interview, without giving a reason.

**What will happen to my child if they take part?**

This chart shows what will happen if you agree for your child to take part. Sometimes I might ask to meet with them one more time if they have told me they want a break or to stop.

What will happen?

1 Alice will speak to me and/ or my parents on the phone to answer any questions and arrange the interview.

2 I can choose where I want to have the interview. At home, school or college.

3 Alice will meet me for up to 90 minutes. I can tell her if I want to stop or have a break.

4 Alice will ask me and/ or my parents to sign some forms.

She will then ask me some questions. She will record our conversation.

5 Once we have ended our conversation I am finished! I can ask any questions.

**Expenses and payments**

As a thank you for taking part in the study your child will receive a £10 Amazon voucher. I will travel to you, so you won't need any money for travelling for this study.

### What will my child be asked to do?

Your child will be asked to have a conversation with me about who they are, their brain injury and if they feel anything has changed over time. I have included a list of some of the interview questions with this Information Sheet so that you both can see what kind of things I might ask. This interview will last up to 90 minutes and will be audio recorded. Your child can take a break or stop the interview at any time, I can also come back for a second time to finish the interview if needed.

### What are the possible disadvantages and risks of taking part?

It might be tiring for your child answering so many questions. We are also aware that thinking about the brain injury and it's potential impact on identity may be emotional and at times feel difficult.

### What are the possible benefits of taking part?

We cannot promise the study will help your child but the information we get may help understanding and improve the treatment of people after they have a traumatic brain injury in adolescence.

### What if there is a problem?

During the interview, your child will be given some traffic light cards. They can use these at any time, giving me a yellow card to tell me they want a break or a red card to tell me that they want the interview to stop.

I will also provide you and them with details of further support options if needed. I will write a letter to someone who works with your child and knows them well so that they know your child has been taking part and that they might need some extra support if they have found our conversation emotional. I will not share details of their interview with them unless they tell me something which means I am worried about their safety or others safety.

You can contact me on ac1191@canterbury.ac.uk after your child has been interviewed if you have any problems and I can direct you to where you can get further help.

If you remain unhappy and want to talk to someone else you can contact Dr Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology on fergal.jones@canterbury.ac.uk

**Will information from or about my child from taking part in the study be kept confidential?**

Yes. All information which is collected from or about your child during the course of the research will be kept strictly confidential, and any information about them will have their name and details removed so that they cannot be recognised. I will give them a participant number which will be attached to their information.

There are some rare times when I might have to share what your child has told me with someone else, this may be you or a professional involved in their care. This would be if they told me something which meant I was worried about their or others safety. I would tell them about this at the time.

I will audio record our interview and it will be saved on a secure USB memory stick before being loaded onto the secure University network. All other information will also be saved on the memory stick before being moved to the secure University network. Any paper copies will be shredded.

This study is being supervised by Dr Andrea Pickering and Dr Carmel Digman. They will have access to the information collected.

The Salomons Institute for Applied Psychology at Canterbury Christ Church University stores research data for 10 years in a locked filing cabinet in the main office. The office is in a building with 24 hour security. The custodian is Deborah Chadwick, a member of the administration staff. Only anonymised data will be stored and audio recordings will be destroyed and not kept after the data has been analysed.

**What will happen if my child doesn't want to carry on with the study?**

If your child doesn't want to carry on with the study, that is fine. You can let me know up until one week after the interview has been completed via email: ac1191@canterbury.ac.uk.

You can withdraw all of your child's information that I have collected and I will remove and destroy all of this.

**What will happen to the results of the research study?**

The results will be written up for the purpose of the academic study for the Doctorate in Clinical Psychology at Salomons Institute of Applied Psychology. This will be read by examiners. I also hope to publish the results in a peer-reviewed journal.

Your child will not be identified in any report and any quotes from your child's interview that might be used will use a different name so they will not be able to be identified.

I will also prepare a results summary for participants. If you would like to receive a copy of this at the end of the study via email please let me know.

**Who is sponsoring and funding the research?**

Salomons Institute for Applied Psychology, Canterbury Christ Church University in partnership with Recolo UK.

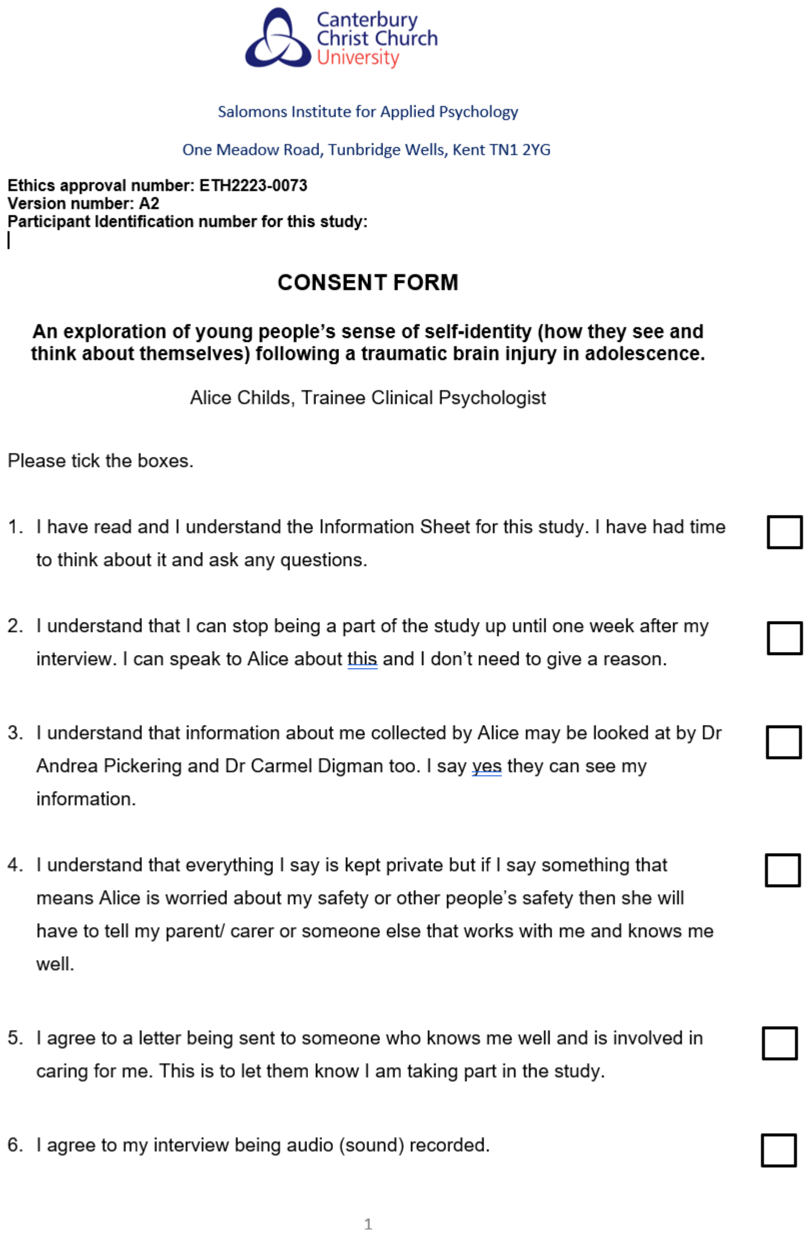
**Who has reviewed the study?**

The Salomons Ethics Panel, Salomons Institute for Applied Psychology, Canterbury Christ Church University

---

Thankyou for taking the time to read this Information Sheet. Please take the time to discuss this with your child. If you decide your child can take part, you will be asked to sign a consent form. You will be given a copy of this and the signed consent form to keep.

# Appendix L: Consent Form A



Canterbury
Christ Church
University

Salomons Institute for Applied Psychology

One Meadow Road, Tunbridge Wells, Kent TN1 2YG

**Ethics approval number: ETH2223-0073**
**Version number: A2**
**Participant Identification number for this study:**

## CONSENT FORM

**An exploration of young people's sense of self-identity (how they see and think about themselves) following a traumatic brain injury in adolescence.**

Alice Childs, Trainee Clinical Psychologist

Please tick the boxes.

1. I have read and I understand the Information Sheet for this study. I have had time to think about it and ask any questions. ☐
2. I understand that I can stop being a part of the study up until one week after my interview. I can speak to Alice about this and I don't need to give a reason. ☐
3. I understand that information about me collected by Alice may be looked at by Dr Andrea Pickering and Dr Carmel Digman too. I say yes they can see my information. ☐
4. I understand that everything I say is kept private but if I say something that means Alice is worried about my safety or other people's safety then she will have to tell my parent/ carer or someone else that works with me and knows me well. ☐
5. I agree to a letter being sent to someone who knows me well and is involved in caring for me. This is to let them know I am taking part in the study. ☐
6. I agree to my interview being audio (sound) recorded. ☐

7. I agree that things I have said in my interview might be written up exactly the same in Alice's report. Alice will not use my real name so no-one will know it was me who said it. ☐

8. I agree to take part in this study ☐

Name of Participant_____________________ Date_________________

Signature ____________________

Name of Person taking consent _______________ Date______________

Signature _____________________

# Appendix M: Consent Form B

Canterbury
Christ Church
University

Salomons Institute for Applied Psychology

One Meadow Road, Tunbridge Wells, Kent TN1 2YG

**Ethics approval number: ETH2223-0073**
**Version number: B2**
**Participant Identification number for this study:**

## CONSENT FORM – PARENT/ GUARDIAN

**An exploration of young people's sense of self-identity (how they see and think about themselves) following a traumatic brain injury in adolescence.**

Alice Childs, Trainee Clinical Psychologist

Please tick the boxes.

1. I have read and understand the Information Sheet for this study. My child and I have had the opportunity to read, think about and ask any questions about the study and have been given the answers we needed. ☐

2. I understand that my child's participation is voluntary and that they are free to withdraw at any time without giving any reason up until one week after their interview. We can speak to Alice about this. ☐

3. I understand that data collected during the study may be looked at by the lead supervisors, Dr Andrea Pickering and Dr Carmel Digman. I give permission for these individuals to have access to my child's data. ☐

4. I understand that anything my child shares in interview will be kept confidential unless Alice is concerned for their safety or the safety others. She will then share this information with either myself or a professional involved in my child's care. ☐

5. I agree to a lead professional involved in my child's care being informed of their participation in the study via letter. ☐

6. I understand that interviews will be audio recorded and agree to my child being recorded via audio only. ☐

7. I agree that anonymous quotes from my child's interview and other anonymous data may be used in published reports of the study findings. ☐

8. I agree for my child to take part in the above study. ☐

Name of Parent/ Guardian____________________ Date________________

Signature ___________________

Name of Person taking consent ______________ Date_____________

Signature ____________________

# Appendix N: Assent Form

Canterbury
Christ Church
University

Salomons Institute for Applied Psychology

One Meadow Road, Tunbridge Wells, Kent TN1 2YG

**Ethics approval number: ETH2223-0073**
**Version number: C2**
**Participant Identification number for this study:**

## ASSENT FORM

**An exploration of young people's sense of self-identity (how they see and think about themselves) following a traumatic brain injury in adolescence.**

Alice Childs, Trainee Clinical Psychologist

Please tick the boxes.

1. I have read and I understand the Information Sheet for this study. I have had time to think about it and ask any questions. ☐
2. I understand that I can stop being a part of the study up until one week after my interview. I can speak to Alice about this and I don't need to give a reason. ☐
3. I understand that information about me collected by Alice may be looked at by Dr Andrea Pickering and Dr Carmel Digman too. I say yes they can see my information. ☐
4. I understand that everything I say is kept private but if I say something that means Alice is worried about my safety or other people's safety then she will have to tell my parent/ carer or someone else that works with me and knows me well. ☐
5. I agree to a letter being sent to someone who knows me well and is involved in caring for me. This is to let them know I am taking part in the study. ☐
6. I agree to my interview being audio (sound) recorded. ☐

7. I agree that things I have said in my interview might be written up exactly the same in Alice's report. Alice will not use my real name so no-one will know it was me who said it. ☐

8. I agree to take part in this study ☐

Name of Participant giving assent

_____________________ Date_________________

Signature ____________________

Name of Person taking consent _______________ Date______________

Signature _____________________

**Please ensure this is accompanied by a parental/guardian consent form due to age of young person giving assent.**

## Appendix O: Letter to ethics panel with research summary

Dear Salomons Institute for Applied Psychology Ethics Panel,

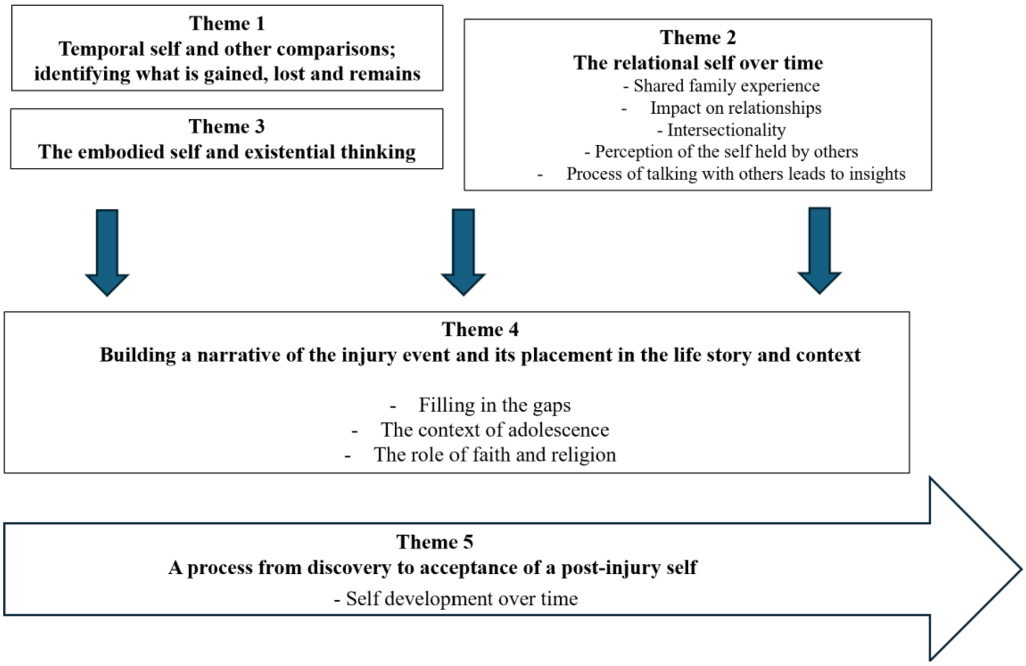
Thankyou for your approval of my research project titled: An exploration of young people's sense of self-identity following a traumatic brain injury in adolescence. I am now writing to inform you that this project has been completed and enclose a summary of the findings;

Previous research has demonstrated that identity reconstruction is a key component of rehabilitation in the adult Traumatic Brain Injury (TBI) population. There is a paucity of research investigating the adolescent experience of TBI, despite this being a high-risk period for such injuries. TBI processes may disrupt the already developing sense of self-identity in adolescence, a critical period of development.

This study aimed to provide an in-depth exploration of individual's experiences relating to self-identity following TBI in the period of adolescence. Every brain injury is known to be heterogeneous in its characteristics and impact, and as such Interpretative Phenomenological Analysis (IPA) was utilised in order to capture the nuanced meanings of the lived experience of TBI. Seven young people aged 15-21 years (5 male, 2 female) who acquired a TBI in the period of adolescence (12 - 19 years) were interviewed about their experiences relating to their self-identity following TBI.

The study hoped to answer the following questions;

*a. Does a participant's sense of self-identity change following a traumatic brain injury in adolescence?*
*b. How does a participant's sense of self-identity change following a traumatic brain injury in adolescence?*
*c. What do participants' experience as the key features of any identity change?*
*d. How do participants' make sense of any changes over time since the TBI?*
*e. Do participants' see a role for professionals?*



Five inter-related themes were identified; 1) Participants described making temporal comparisons which identified what they had gained, lost and what remained consistent following their TBI. Through 2) understanding of themselves relationally and with a 3) heightened awareness of an embodied self, young people attempt to 4) build a narrative of their TBI in their life contexts. Participants note the specificity of the life stage of adolescence as they also try to fill in the gaps in memory and information surrounding their injury. Finally, 5) participants described stages of development over time, moving from a point of discovery of their post-injury traits and abilities through to an acceptance of self.

**Conclusions:** The study highlighted ways in which young people who have acquired a TBI in the period of adolescence make sense of their experienced changes in self-identity. Participants considered their relational selves, an embodied self and made inter and intrapersonal temporal comparisons to gain an understanding of their post-injury selves. Participants attempted to incorporate the understanding gained into their life stories and within the specific context of adolescence. Impairments to memory and a lack of information about TBI left participants trying to “fill in the gaps” to be able to develop a consistent sense of self through time. Stages of progress towards adjustment to a post-injury self-identity were also described. Recommendations for future research includes further investigation of the named stages of progress and if they are cumulative, linear or iterative. Clinical implications discussed include the timing of delivery, the iterative nature of identity reconstruction processes and the inclusion of faith leaders.

Warm wishes
Alice Childs
*Trainee Clinical Psychologist*
*Salomons Institute for Applied Psychology*