Living with a moderate head injury:

An interpretative phenomenological analysis of young people's and their mothers' lived experiences

Thesis submitted in partial fulfilment of the degree of

Doctor of Nursing

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Abstract

Background: Childhood head injuries can be mild, moderate or severe. This severity relates to the degree of injury to the brain, which can have a direct effect on their lived experiences. Moderate head injuries in children and young people (CYP) is an area that is rarely researched, particularly from the CYP's perspective. The motivation for this study stems from my clinical practice as a paediatric neurosurgical nurse specialist, a wish to further understanding of the long-term effects a moderate head injury can have on a CYP and the mother together with a desire to increase the evidence base care for CYP's.

Aims: To explore how the lifeworlds of CYP (aged 6 to 13 years) and the mothers are affected by a moderate head injury.

To better understand, in a manner consistent with interpretative phenomenological analysis utilising the concept of lifeworld, how the CYP and their mothers are affected by moderate head injuries.

Methods: An interpretative phenomenological analysis (IPA) approach was adopted, using longitudinal semi-structured interviews over nine months. Following the granting of research ethics and governance approvals, three young people who had experienced a moderate head injury and two mothers were recruited from a tertiary NHS Health Board in Wales. CYP's involvement was used in the initial stages (a Children's Advisory Group was used from a primary school) to aid in the research design. The data were analysed using the IPA method, explored longitudinally and discussed by using a combination of the adapted Corbin and Strauss Chronic Illness Trajectory (Halcomb and Davidson 2005) and the lifeworld (Galvin and Todres 2013).

Main Findings: Three main superordinate themes were developed from the findings for each of the participant groups; for the CYP these were 'Impact of Restrictions', 'Relational Impact of Restrictions' and 'Resilience and Post-Traumatic Changes'; for the mothers these were 'Parental Psychological Trauma', 'Family and Friends' and 'Recovery Journey'. The main

findings for the CYP showed that even though the restrictions were important in protecting them from further harm, but they had a large impact on all aspects of their lifeworlds including altered friendships. There was also evidence for defiant behaviour as a coping mechanism and when the restrictions were removed, the CYP did not immediately return to their 'normality'. For the mothers, the findings pointed to their recovery being embedded in psychological trauma, emotion and anxiety and they had to contend with a duality of roles; one a restriction enforcer and as a mother. At the end of the study period, they had not completed their recovery journey.

Discussion: The review of literature shows that a longitudinal analysis of CYP's lived experiences using a lifeworld concept during the recovery from a moderate head injury has not previously been undertaken. The benefits of adopting a longitudinal approach are clearly demonstrated in the study's findings. Utilising an IPA approach generated rich data and provided valuable insights into how CYP and the mothers viewed their experiences. For example, the way in which CYP experience their lifeworld and the process of recovery fluctuates over time. It is not linear and the restrictions that were placed on the CYP to keep them safe had lasting implications, even when the restrictions were removed. This has implications for service delivery and longer-term care of CYP following moderate head injuries. The findings suggest that the CYP's and mothers' non-linear recovery trajectories and experiences are at odds with the linear care pathways and service planning that dominate current service delivery.

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Contents

List of Figures

List of Tables

1 Introduction to the Study

1.1   Introduction

Head injury is the leading cause of acquired disability and mortality amongst children and young people (CYP) worldwide (Lloyd et al. 2015). Following a head injury, a CYP might experience emotional and behavioural changes, have ongoing health needs and cognitive sequelae (Braine 2013), all of which can affect their quality of life and lived experiences. This thesis is fundamentally important as it will consider CYP's recovery over a nine-month period following a moderate head injury and the effects of both on the mothers. The perspectives of three CYP and the mothers, all living in Wales, will be explored with the intention of improving care for families by improving clinical practice. This chapter will first explore my professional experience and how this influenced my study, the role of quality of life, the study question, aims and objectives, and finishing with the thesis structure.

1.2   Professional Experience and Influence on the Study

The following sections will briefly explore my clinical work, the origins of my study, the influences that led to the study's generation, quality of life and its role in the study, followed by the study's question, aim and objectives.

1.2.1   Clinical Background

Having worked as a paediatric neurosurgical nurse specialist for over thirteen years, and within the field of paediatric neurosciences for over two decades, the question of how CYP recover from a head injury or cerebral trauma is of particular interest to me. This was

triggered by countless clinical experiences of some CYP recovering exceptionally well from moderate head injuries – and also sometimes in ways that seemed surprising – but others making poor recoveries from similar injuries. These questions continue to be of direct relevance as I continue to support these CYP and their families in my current clinical position, particularly as parents often ask how their CYP is going to recover.

1.2.2   Influences on Designing the Study

The emergence of my research topic resulted from my clinical work as a paediatric neurosurgical nurse specialist. It soon became clear that whilst substantial work had been carried out into mild and severe head injuries, there were few studies concerning the experiences of CYP's recovery from moderate head injuries. Reviewing the CYP literature around moderate head injuries revealed that no single study was conducted into this type of head injury. However, in the adult population, moderate head injuries have been described as a "unique subset" of head injuries, without the clarity in standards of care that both mild and severe head injuries have (mild head injury patients might get referred to an outpatient rehabilitation service and severe head injuries have inpatient rehabilitation) (Bergman et al. 2010, p. 102). My study was designed to explore this gap in a way that would add to the partial theoretical knowledge base of post head injury recovery for CYP and would, in due course, improve clinical practice. Undertaking the Professional Doctorate course provided the opportunity to do this, offering a framework for neophyte researchers which aided the development of a suitable research question. The evolution and crystallisation of this research question followed the carrying out of a comprehensive literature review (which will be discussed in Chapter 3).

1.2.3   Quality of Life and its Role in the Study

During the early stages of planning this study, I realised that Quality of Life (QoL) was a prominent concept in the literature for exploring the recovery process of CYP. This literature influenced my decision making, for example underpinning the formation of the adapted interview schedule (which will be discussed in Chapter 5 of this thesis). At that stage in my research planning the following definitions were influential as they addressed some of the questions around post head injury recovery; however, they continued to leave key questions about the recovery journey unanswered. Taylor (2000) defined QoL as a broad subject which encompasses happiness and satisfaction, something that can be seen as being unique to the individual. Wilson (2015) gave an interpretation of it as a multidimensional concept, encompassing health, longevity and how a person may feel in different time frames. It has also been described as an "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO 2012, p. 2).

In addressing the clinical questions that I often face as a clinician, which are concerned with recovery, basing answers mainly on statistics from quantitative studies is not holistic enough and fails to address the key questions of how CYP and the mothers experience their recovery. This highlights the need for qualitative studies which explore the prominent position of the lived experiences of CYP and the mothers. In understanding these experiences, the concept of the lifeworld (which will be discussed briefly in the next chapter) within an interpretative phenomenological analysis (IPA), proved to be a more effective approach in the interpretation of the qualitative data. However, the concept of the lifeworld can be seen as an integral part of the broader definition of QoL, hence understanding the lifeworld gives an

insight into the participants' QoL. As such, the lifeworld is an integral part of the multidimensional QoL. Therefore, this thesis will focus on the lifeworld.

1.2.4   Study Question, Aim and Objectives

The overarching research question for my study is:

> "How do CYP and their mothers view their lived experiences during the
>
> nine-month recovery period following a post moderate head injury?"

In answering this clinically relevant question, the following aims and objectives were developed.

The aims of this study were:

- To explore how the experiences of CYP (aged 6 to 13 years) and their mothers are affected by a moderate head injury.

- To better understand, in a manner consistent with interpretative phenomenological analysis utilising the concept of lifeworld, how the CYP and their mothers are affected by moderate head injuries.

The objectives for this study were:

- To undertake a longitudinal analysis of qualitative semi-structured interviews with CYP who have suffered a moderate head injury aged between 6 and 13 years, at 2 weeks and 3, 6- and 9-months post discharge from hospital.

- To determine, in a manner consistent with interpretative phenomenological analysis, to determine how the mothers' lifeworlds are affected and how they view the CYP's lifeworlds following the moderate head injury, at 6- and 9-months post-discharge.

- To identify clear recommendations for clinical practice based on CYP's and mothers' longitudinal perceptions of their lifeworlds following head injury.

1.3 Thesis Structure

In order to orientate the reader to this thesis, this section will provide a brief summary of the content and structure of each of the chapters, starting with Chapter 2.

Chapter 2

The next chapter will form the background chapter where it will define key terms used within this thesis including that of the CYP, the importance of including the mothers within the study and how head injuries in CYP are classified. Lifeworld will also be discussed together with the significance of this thesis. Government frameworks (including national guidance) will be explored and the significance of this thesis.

Chapter 3

Chapter 3 will set the scene by placing this study within the published literature, show the design of the search strategy, highlight the acute shortage of qualitative data compared to the multitude of quantitative data and further highlight the rationale for this study. Two literature searches were carried out and will be presented as one comprehensive search, with the results being presented thematically with each theme containing a summary.

Chapter 4

The fourth chapter will discuss a focussed view of the study methodology, its theoretical underpinnings together with a rationale for it. IPA will be explored alongside social constructivism as an effective approach. The role of the Children's Advisory Group (CAG) will be explored, it's ethical considerations and how using public involvement improved the study design.

Chapter 5

Chapter 5 will explore the research methods and the process used for this study. Data collection methods will be discussed for both the CYP and the mothers, including the analysis strategies of the semi-structured interviews. Research ethics will be explored including consent and assent, power and the insider/outsider considerations.

Chapter 6

The sixth chapter will present the idiographic findings for the three CYP together with two of the mothers. A deep analysis of each of each case will be carried out with respect to their lived experiences within their lifeworlds. This analysis will show a longitudinal interpretation of the data with emergent themes being discussed with supporting extracts. Tables will be used to present and support the idiographic discussions for each participant and the formation of the subordinate themes from the emergent themes.

Chapter 7

Chapter 7 will carry out a group level analysis and show the formation of the superordinate themes from the subordinate themes. For the CYP, three superordinate themes will be

created: "Relational Impact of Head Injury", "Impact of Restrictions and Resilience" and "Post-Traumatic Changes". For the mothers, three superordinate themes will be identified also: "Parental Psychological Trauma", "Family and Friends" and "Recovery Journey". Both sets will be presented in Master Tables together with Figures to demonstrate how the themes are interlinked and discussed in a Cross-Group Analysis section.

Chapter 8

The eighth chapter will discuss the findings in relation to the wider literature and identify gaps. The findings are discussed by combining Halcomb and Davidson's (2005) adaptation of Corbin and Strauss Chronic Illness Trajectory with Galvin and Todres's (2013) lifeworld concept which will offer a unique insight into the lived experiences of the participants. A section, "Germination of a Little Gem", will also be included that will discuss how gender might influence defiance.

Chapter 9

The concluding chapter will provide a brief summary of the thesis, highlight its key findings and contribution to knowledge together with the limitations of the study. Recommendations will also be made which relate to clinical and research practice, and how the findings from this study can lead to improved care for the patient. The role of reflexivity will also be discussed and supported by evidence from the thesis.

2 Background

2.1 Introduction

This chapter will expand on the term CYP, including its definition together with how they are viewed in society and in the family. The justification for including mothers into the study will also be touched upon together with Government frameworks including national guidance will be explored together with head injury classification and the recovery model together. An introduction to the lifeworld concept will be discussed together with the significance of the thesis.

2.2 Children and Young People (CYP)

2.2.1 Definition

For clarity within this thesis, this section will explore which term best describes the (CYP) participants. According to Timim (2004), since World War II the meaning of childhood has changed, which has also been associated with changes in parenting techniques, a deterioration in the extended family and changes in the economic status of families, in that they have become more pleasure driven. However, the key point made by Timim (2004), one pertinent to this thesis as it relates to the term used for the participants, was that is it difficult to determine when childhood ends and adulthood starts: "children" are exposed to the adult world earlier than they used to be, and consequently the transition between childhood and adulthood should be viewed as being fluid rather than occurring at a permanent or fixed point or age.

This lack of clarity in when childhood ends continues as exampled by these contrasting thoughts: the "UN Convention on the Rights of the Child" (UN 1989) stated that childhood lasts until the age of 18; Bronstein and Montgomery (2011, p. 46) viewed childhood as a period lasting until up to 25 years old and used the term "young people" to describe children; and Manning (2015) simplified things by proposing that childhood stops at 12 years old and adolescence runs from this age up to 25 years old. This complexity in identifying when childhood ends was acknowledged by Hyde et al. (2010) who viewed it as requiring a multidisciplinary perspective that, for example, needs to consider biological, psychological, physiological and social factors. They went on to say that contemporary thinking considers the concept of agency (the ability of children to understand their own world and to act upon it) as a measure of childhood but they did not identify an age when his happens, rather they alluded to it being fluid.

For the purpose of this thesis, as the participants in my study were aged between 11 and 13 years old, the term "children and young people"/"child and young person" (CYP) will be used when describing the group as it can be seen as being all embracing and terms daughter, son and child will be used on a personal level. Several recent publications have chosen this term (CYP), for example "Getting it Right for Children and Young People" (RCN 2017), an earlier publication by the Department of Health DH (2004), and some doctoral theses: Hughes (2012), Hemming (2017), Lamb (2017) and Harvest (2018). However, on occasions other terms like "children" may be used when citing authors who have these terms.

2.2.2   Role of CYP in Society

Biologically, CYP are important for the continuing existence of the human race and for the passing on of genetic information (Volk and Atkinson 2008), but the role of CYP is more than this. Importantly Hill and Tisdall (2014, p. 1) highlighted that "children are not simply passive recipients of adults' models, knowledge and values, but contribute actively to the creation of the social worlds in which they live, both individually and collectively". They also added that the proportion of CYP compared to the total population has fallen, and that CYP should be viewed as human beings not "human becomings" (Hill and Tisdall 2014, p. 20). The authors have here drawn attention to the status that CYP should have in society and how they should be viewed as equal human beings.

Brocklehurst (2006, p. 20) discussed that CYP have their own agency, where there is a need to "to reappraise our understanding of childhood as a rehearsal for adult life" and reinforced that CYP should have their rights respected. It is beyond the scope of this section to address all the factors that would examine the role of CYP in society. Both Hill and Tisdall (2014) and Brocklehurst (2006) outlined that CYP should be regarded as having agency. The essence of this is catered for in my study: I ask the CYP participants directly about their lived experiences with the intention of improving care for future CYP, whilst acknowledging that the CYP is also part of a larger family. Seeing the CYP as part of a larger family will be touched upon in the following section.

2.2.3   CYP and their Families

This study follows an IPA approach, further details of which will be discussed in Chapter 4. Of note at this point in the thesis is that IPA has a strong idiographic focus; it is concerned

about the "particular" (Smith et al. 2009). Smith et al. (2009) went on to describe IPA as a commitment to the particular or detail, which in turn results in a depth of analysis. This then leads to generating an understanding of how the particular is then understood "from the perspective of particular people in a particular context" (Smith et al. 2009, p. 29). In my study, the "particular" was the participants' views of their recoveries.

In wanting to understand the "particular" lived experience of recovering from a head injury, I made the decision to include mothers in the six- and nine-month interviews. The decision to include mothers in this study originated from the observation of the complex interactions that existed between them and their CYP during the first interview (and the out-of-interview discussions that were included in the field notes). I also gained further insights into the complexity of the recovery process by doing this. The time required to make a major amendment with the Research Ethics Committee (REC) resulted in the mothers' inclusion within the study being at the six-month interview.

Other studies have investigated shared experiences in order to understand the "particular". A study by Dancyger et al. (2010) explored the motivations of patients and their families with respect to genetic testing for hereditary breast and ovarian cancer. The authors looked at "the influence of family communication and relationships upon their motivations" (p. 1289), which resonated with my study as I was interested in these dynamics between the mothers and the CYP. In a more recent paper, Larkin et al. (2018, p. 183) focussed on multiperspectival designs and processes within IPA; the authors discussed how two or more focal perspectives can aid data collections and analysis (including intersubjectivity, relational aspects), can extend the impact and reach of "experiential research in the real world". Even

though Larkin et al. (2018) alluded to this generally being used in larger IPA studies, the longitudinal dyad approach that was used in my study proved to be beneficial and generated fifteen interviews.

Larkin et al. (2018), speaking of the justification made by Dancyger et al. (2010) for their approach, described the women and their family members as being "tangled in the same web" and introduced the term "caseness", which they defined as a multi-layered concept with which the shared experience within multiple-perspective studies can be looked at in order to understand the event/particular. In my study, the shared experience is the journey that the participants undertake in their recoveries, journeys that the CYP do not make alone as they are supported by their mothers and are part of more complex family structures. Understanding the mothers' perspectives on the recovery journeys and, to a lesser extent, the influence of the wider families will aid in considering the experiences of the CYP involved in my study.

Having discussed the rationale for the inclusion of the mothers in my study the next section will discuss the current national Government Frameworks.

2.2.4   Government Frameworks

There are four main sources of documents that influence healthcare within the UK: the National Institute for Health and Care Excellence (NICE), which forms the "bedrock" of decision making; the Scottish Intercollegiate Guidelines Network (SIGN); the Welsh Health Specialised Services Committee (WHSSC); and the Neurological Conditions Implementation

Group (NCIG 2017). I am aware that other national guidance does exist within the developed world but, for the purpose of this thesis, these organisations will be the focus in this section due to their significance to moderate head injury management within the UK.

In 2014, NICE released its clinical guideline "Head injury: assessment and early Management (CG 176)" in order to provide best practice guidance (NICE 2014b). In reviewing this guidance, a surveillance report was carried out three years later (NICE 2017). The following section will focus on the 2014 guidance, as this continues to be the full guideline used for clinical reference. (The 2017 surveillance report did not make any clinically relevant changes.)

The 2014 NICE guideline was multi-collaborative and was developed by representatives from organisations such as the Child Brain Injury Trust (patient representative), Association of British Neurologists, Society of British Neurological Surgeons, Headway (patient representative), and the British Society of Rehabilitation Medicine (NICE 2014b). The guideline highlighted that patient support was important, and that there was a need for "reassurance and support for coping; support from family and friends; support from professionals; and support from community partners" (p.186). However, disappointingly, whilst the guideline did state that information should be given together with a discharge letter for the GP, it did not give details about what this would involve – especially in key topics such as returning to school, work, sports and everyday activities. In my experience, there is a large variance in the type and quality of information given to CYP and their families, demonstrating the lack of a clear standard of information. Like the 2014 guideline, the 2017 surveillance report focussed predominantly on acute management, and whilst it added the

possibility of using text messaging as a tool to follow up and offer advice, it went no further in exploring clinical recommendations on follow-up and advice giving (NICE 2017).

As with the 2014 NICE guideline, the Scottish guideline "Early Management of Patients With a Head Injury, A National Clinical Guideline" (SIGN 2009), used evidence from a range of studies to form its guidance which focussed largely on early management. However, it did suggest that there was a need for a discharge plan, that there was a need for written information on discharge, that a discharge letter should be sent to the GP and that a telephone consultation should be carried out by an experienced healthcare professional (such as a clinical nurse specialist, CNS). The evidence in the Scottish guidelines largely points to adult patients; however, they advised that CYP with moderate/severe head injuries should be followed up by a specialist multidisciplinary team; their parents should be given information and advice on short/long term difficulties that the CYP might suffer from; and the teachers, school health team and primary healthcare team should be notified.

The 2009 SIGN guideline, like its NICE counterpart, did not go any further in highlighting what information should be given post discharge, However, it did include a section on "Key Messages From Patients", including a section outlining "Discharge and Follow Up". Here, SIGN (2009) mentioned that patients expressed a need for written and verbal information, a concern about not knowing what happens next, a need for follow-up and an opinion on how often this should happen. Even though this section looked at adult patients, it highlighted the need for individualised care planning throughout the recovery process.

Within Wales there has been a history of strategic governmental movements to improve patient care and service provision. In 2002, the "Tertiary Children's Services For Wales: A Review" was published (SHSCW 2002). Here, the strategy was to improve sustainability of services, including paediatric neurosurgery, incorporating safe staffing (appropriate staffing – including staff training and numbers) and patient safety; this publication was influenced by the feedback of the "Bristol Royal Infirmary Inquiry" (SHSCW 2002). This review led to the movement of paediatric neurosurgical services on to a single Welsh site (except for provision in North Wales, which utilised Alder Hey Hospital in Liverpool). The importance of the CYP in planning and prioritising care was also highlighted by a Welsh Assembly Government (WAG) document: "All Wales Neurosciences Standards for Children and Young People's Specialised Healthcare Services" (WAG 2009a). This highlighted the value that CNSs bring to care delivery. It clearly differentiated between the types of neurosurgical intervention and again reiterated the need for a lead neurosurgical centre. It also highlighted the need for discharge planning but did not go beyond this.

The role of safe, fast and effective care for CYP who need neurosurgical intervention was also highlighted by the Neurological Conditions Implementation Group (NCIG 2017), which put the emphasis on health boards to ensure that this is possible. This document also highlighted the need for neurosurgical centres within Wales to be undertaking national clinical audits, thereby reiterating the need for safe care for CYP. This ethos is also incorporated by the Public Health Wales initiative entitled "1000 Lives Improvement" (PHW 2018), which aims to save 1000 lives per annum by improving patient safety, improving capacity and capability within the NHS, and by ensuring that care is seamless, person centred and sustainable. Even though this latter document is not just about CYP, it laid the foundation for care to be person centred and quality driven whilst having the ability to explore new ideas

and practice. This fundamentally is what my doctoral study is about – the recognition of a gap in service care, providing research evidence and instigating a plan to improve service provision.

In 2018, the Welsh Health Specialised Services Committee (WHSSC) released its commissioning policy CP160, entitled "Specialised Paediatric Neurological Rehabilitation" (WHSSC 2018). This document is important as it recognised that specialist rehabilitation services should work alongside CYP neurosurgery; it also emphasised the need for acute rehabilitation during the initial recovery phase, followed by rehabilitation by the tertiary specialist neuro-rehabilitation team once the acute phase has ended. The policy also stated that long-term rehabilitation should be carried out by a community team and that follow-up should be by the neuro-rehabilitation Consultant for up to one year. For the CYP cohort who suffer from severe head injuries, this recent development is effective. However, my study's research participants would not have met the criteria for admission into the neuro-rehabilitation service as their head injuries were classed as moderate. But as my study indicates, they did suffer from adverse outcomes, hence providing evidence of the need for further recognition surrounding the complexities of moderate head injury recovery.

In summarising these policies, it is possible to see a move to improved patient care for the CYP cohort. However, even though follow-up discharge advice is clinically recommended, these documents do not go far enough in informing clinicians what advice and follow-up should be given; this is instead left to the individual professional and the assessment that they have carried out. Even the recent "Specialised Paediatric Neurological Rehabilitation" document by WHSSC (2018) leaves the referral process open to interpretation. This can be

examped by practice that I have witnessed: CYP being discharged by Consultants assessing patients using the medical model (as opposed to a more biopsychosocial model) and failing to detect ongoing issues for the CYP. My study raises awareness of these ongoing issues and recommendations will be discussed in the Conclusion and Recommendations chapter.

2.2.5   CYP Nursing

The latest version of the UK nursing code clearly outlines its expectations from registered (including CYP) nurses (NMC 2018). Key phrases used within the code refer to treating patients as individuals, treating them with respect, ensuring high standards of practice, improving and maintaining health, and keeping knowledge and skills up to date (NMC 2018). These phrases are resonated in my study.

An earlier document "Standards for competence for registered nurses" published by the NMC (2010) – and its CYP component – reinforced the later publication by the NMC (2018). Across those publications, the authors stated that CYP should be involved in any decision making together with family members (where appropriate); be aware of emotional, physical and intellectual needs; and (in this case, together with the parent) be empowered to influence best care.

The roles of individuality, family-centred care and decision making are key concepts that will be evidenced within my study as I look at the lived experiences of the CYP and the mothers. Throughout this study, which has a strong idiographic focus, the participants will be

recognised as individuals and will know that their lived experiences are important for
improving evidenced based healthcare.

2.3   Head Injury in CYP

This section will describe what a head injury is and how it is classified by its GCS (Glasgow
Coma Scale) score, followed by its prevalence and aetiology. A head injury's acute
management together with the impact of acquiring such an injury will also be touched upon.

2.3.1   Classification

Head injuries can be classified as traumatic when there is evidence of some alteration in
cerebral function, such as altered consciousness, neurological deficits and/or altered cerebral
pathology, caused by some external force (Braine and Smith 2013). The head being struck, or
itself striking an object, can result in an open or closed injury. It is possible to divide the
severity of head injuries into three main categories: mild, moderate (the focus of this study)
and severe (Hessen et al. 2008). The GCS, which will be discussed in the next paragraph, is a
way of classifying the type of head injury by its effect on consciousness.

The Glasgow Coma Scale (GCS) (see Appendix 1) is the "gold standard" when carrying out
an assessment of consciousness (Woodward and Mestecky 2011) and is a key diagnostic tool
used by both nurses and doctors when treating CYP with head injuries. The GCS is used to
assess three components by means of allocating a numerical value for responsiveness of eye
opening, motor responses and verbal responses – with each having different possible
responses to stimuli (Hickey 2003). The diagnostic scale's score ranges from 3 to 15, with 3

demonstrating coma/death and 15 representing a fully alert, orientated person. The maximum

scores are 4 for eye opening, 5 for verbal responses and 6 for motor responses (Hickey 2003).

These are then added together to give a total score out of 15.

The focus of this study is the experiences of CYP recovering from moderate head injuries and

how this also impacts the mothers. The importance of the GCS to this study lies with the

inclusion criteria: the GCS score was one determining factor for whether a participant could

be recruited or was excluded.

In closer examination of what an altered GCS means for the CYP, the paediatric GCS scale

published by NICE (2014a) – see Table 2.1 – provided some useful examples.

Table 2.1: Paediatric GCS Scoring – adapted from NICE (2014).

Record No:	Date & Name:		Time			
Eye Opening	4	Opens spontaneously				
	3	Opening to verbal command				
	2	Opening to pain				
	1	No opening				
Verbal Responses	5	Alert, usual ability				
	4	Less than usual ability				
	3	Cries inappropriately				
	2	Occasionally whimpers/moans				
	1	No vocal responses				
Motor Responses	6	Normal movement				
	5	Localises to pain / withdraws to touch				
	4	Withdraws to painful stimuli				
	3	Abnormal flexion to pain				
	2	Abnormal extension to pain				
	1	No motor responses to pain				
		GCS Score (out of 15)				

From this Table we can see that the maximum score for a fully orientated person is 15. For the moderate head injury CYP, this score would drop to between 9 and 12. From Table 2.1, each response is given a score, for example "Eye Opening" (from column 1) has an option of "Opens spontaneously" (column 2), which if present in the CYP would score 4, sliding incrementally to a score of 1 if there was no response, indicating possibility of a serious head injury. This is repeated for "Verbal Responses" and "Motor Responses", with each relating to criteria (which have a numerical score) in column 2. These scores are then added to give the GCS. An example of a GCS of 12, a moderate head injury, would indicate a CYP whose eyes are "Opening to verbal command" (score 3), whose verbal response shows "Less than usual ability" (score 4) and who "Localises to pain / withdraws to touch" (score 5) – total score 12. For a score of 9, an example would be eyes "Opening to pain" (score 2), "Cries inappropriately" (score 3) and "Withdraws to painful stimuli" (score 4).

A moderate head injury, in lay terms, alters a person's awareness of sensations such as pain and may make them more lethargic than usual. Headaches, difficulty remembering information and tiredness may also be experienced and this may range from several days to something that can affect them for a long time. In the short term, these facts can improve as the bleeding and bruising within the brain subside. The time taken and overall experience of recovery from moderate injury is very variable and dependent on factors that are often unique to the CYP and their families. Subsequently, the emotional adjustments required during recovery can result in a difficult time for all family members.

2.3.2 Prevalence

Hessen et al. (2008) in their paper stated that 81–86% of cases of head injury are mild, approximately 8% are moderate and 6% are severe, with 5% of the latter being fatal. In a systematic review carried out by Lloyd et al. (2015), it was discovered that annually approximately 865 per 100,000 CYP under the age of 18 sustain some form of a head injury. Data by Braine and Smith (2013) differed to this and suggested that between 100 and 300 per 100,000 CYP per year experience a head injury, but the authors also stated that numbers as high as 1000–3000 per 100,000 per year have been recorded. (Additionally, CYP who have experienced a head injury are deemed to be at greater risk of sustaining another head injury.) In the United States, this equates to approximately 500,000 CYP visiting an emergency department each year (Lloyd et al. 2015). In the UK, approximately 700,000 patients (both CYP and adults) per year experience a head injury, with people aged between 15 and 24 years old and those over 75 years old being the most at risk of sustaining a head injury (Woodward and Mestecky 2011). Furthermore, it has been reported that 20% of CYP who suffer a head injury will require some form of hospitalisation, with 70–88% of those CYP being male (Woodward and Mestecky 2011).

2.3.3 Aetiology

An interesting point raised by Braine and Smith (2013), and one which is relevant to this study, is the concept of primary and secondary damage. "Primary" refers to the damage done at the time of the injury/impact, whilst "secondary" refers to harm done by the consequences of the primary injury, such as cerebral oedema, raised intracranial pressure and seizures. When not controlled homoeostatically by the body or by medical interventions, this secondary damage can lead to cerebral hypoxia and eventually to life-threatening conditions.

There is some variability not only in the causation of the primary head injury but also in the forms of secondary damage, which can be influenced by cerebral plasticity, compliance, etc. Thus, patients' experiences and outcomes of head injury are also individual. My thesis will explore these unique individual experiences in order to improve patient follow up.

2.3.4   Acute Management

The acute management of any head injury is covered by the guidance provided by both NICE (2014b) and SIGN (2009). In brief, the role of acute management is to prevent or limit the extent of raised intracranial pressure caused by secondary damage. This is assessed by the GCS, which can be used as a measurement of illness progression (Kay and Teasdale 2001). Kay and Teasdale (2001) also mentioned that prehospital support by paramedics is vital in providing a smooth transfer for patients from the site of the injury to the hospital. They furthermore recommended that the paramedic should attend "Prehospital Trauma Life Support (PHTLS) course and the Prehospital Paediatric Life Support (PHPLS) course" (Kay and Teasdale 2001, p. 1211).

In some cases a CT scan will be used to identify any lesions; the criteria for this might be vomiting, severe persistent headache and an alteration to consciousness (Kay and Teasdale 2001). Kay and Teasdale (2001) went on to say that around one third of patients, both adults and CYP, who suffer a severe head injury will need intracranial surgery which will be done via a burr hole or craniotomy. They also mentioned that improvements with head injury outcome appear to be the result in part of development and reviews of guidelines.

2.3.5 Impact

As it can directly affect the CYP's and mothers lifeworlds (and so all the participants' lived experiences), the issue of co-morbidity, and how it is associated with a moderate head injury, is important for the study. It has been suggested by Holcomb et al. (2012) that medical co-morbidities can be used as predictors of patient outcomes. Interestingly, Valderas et al. (2009) proposed more than one theory of what co-morbidity actually is, thereby highlighting the confusion around defining this term. They described it as a multi-morbidity that can be caused by different diseases and ailments.

Feinstein, in Valderas et al. (2009, p. 358), described co-morbidity thus: "Any distinct additional entity that has existed or may occur during the clinical course of a patient who has the index disease under study". Here, the index disease refers to the head injury, and the additional entity to any neurocognitive sequelae that were produced as a result of the head injury. Examples of these neurocognitive sequelae include problems with cerebral processing, poor memory, attention issues, fatigue, headaches and poor sleep hygiene (Braine 2013). Awareness of these co-morbidities for this study is important as they can directly affect the lived experiences of the participants, who could also have one or more of these problems.

The impact of a head injury also has a financial cost for the NHS. In the United States over $1 billion is spent every year on CYP's head injury management (Lloyd et al. 2015). It has also been estimated that the actual annual cost in the UK, including rehabilitation, is more than £1 billion (Hayward 2011). However, it has been suggested that adopting cost-saving exercises recommended by NICE may save £19,700 per 500,000 of the adult and paediatric population (NICE 2014c). Such figures draw attention to the need for a system that is more

prudent and patient focussed, especially in the modern NHS in which the careful allocation of resources is needed. A consideration of the financial issues around head injuries is beyond the scope of this thesis; however, these insights help to place the study within a broader context.

2.4 Recovery

2.4.1 Definition

Jensen et al. (2019) have viewed recovery from two perspectives. Firstly, from a clinical perspective they described it as reduction in the signs and symptoms of the illness together with a restoration of social, cognitive and occupational functioning. Secondly, they viewed it as "the process of constructing a personally meaningful life" (Jensen et al. 2019, p. 2). They supported the definition of Mueser et al. (2006, p. S32), who described recovery as the "remission of symptoms and return to prior functioning". Both these papers focussed on mental health as opposed to head injuries, but a clear cross over can be seen between the two: the return to a preinjury state can be seen as the goal and when this is not possible, it becomes helping the CYP and the mother adapt to life changes.

2.4.2 Medical Model and its Limitations

According to Haegele and Hodge (2016), the medical model originated in the time when religious leaders were replaced by doctors and scientists. Within this model, illness and disability are viewed from a biological perspective; they are "considered to be a result of impairment of body functions and structures, including the mind, and can be caused by disease, injury, or health conditions" (Haegele and Hodge 2016, p. 195). Haegele and Hodge also discussed how treatment is seen as fixing the problem, and Wade and Halligan (2017, p.

996) added that the biomedical model sees the disease or illness as an "entity independent of social behaviour, [and that] it also requires that behavioural aberrations be explained on the basis of disordered somatic (biochemical or neurophysiological) processes".

Both Haegele and Hodge (2016) and Wade and Halligan (2017) critiqued the medical model, claiming that it fails to consider the social aspects, a person's individuality and humanity. Both papers made reference to alternative models: Haegele and Hodge (2016) look at a social model and Wade and Halligan (2017) introduced the biopsychosocial model. The latter is echoed in this thesis and forms a more holistic model; it provides a comprehensive view of healthcare and illness and builds on the medical model by incorporating psychological and social factors.

2.5   Lifeworld

This section will introduce the concept of the lifeworld, which is central to this thesis, particularly with respect to the data analysis. Each of the participants saw an abrupt change in their lifeworlds, caused by the moderate head injury.

Van Manen (1990, p. 182) defined the lifeworld as "the world of lived experience… the world of immediate experience" and continued to say that it is the pregiven world – the world of "already there". This was added to by Brooks (2015, p. 642), who said that the lifeworld is pre-reflective (the focus is on what is perceived rather than how we perceive) and is inhabited by "us as conscious beings, and incorporates the way in which phenomena (events, objects, emotions) appear to us". Van Manen (1990) highlighted the words of Husserl by saying that

each individual lifeworld is comprised of its own structures; this will be explored in this thesis by the in-depth analysis of each of the participant's idiographic lived experiences.

The concept of the lifeworld was theorised by Husserl and further developed by Heidegger (Brooks 2015). Of importance to this thesis are Heidegger's theory that our relationship with the world is both relational and interpretational, and his claim that to understand an individual's reality we need to understand their detailed lived experiences in relation to the bigger picture. Brooks (2015) related this to the hermeneutic circle (which will be discussed in Chapter 4). The lifeworld approach that will be used in this thesis consists of six components (temporality, intersubjectivity, spatiality, identity, mood and embodiment) which are taken Galvin and Todres's (2013) model. Each of these components will be explored in Chapter 8, which will further explore the lifeworld concept in relation to this thesis, describe it in more detail and highlight its importance in understanding the lived experiences of the participants.

2.6   Significance of the Thesis

In reviewing the significance of this thesis and what it will add to the knowledge base of CYP moderate head injury management, one needs to be aware of the current state of knowledge. The NICE (2014c) guidance for head injury management highlighted the need for research into long-term sequelae following head injury, which may be present even in mild head injuries. They argued that a head injury classification is a clinical decision that can be imprecise, and that further research is needed to aid patient management. NICE (2014c) were alluding to the shortage of evidence that is concerned with how someone recovers from a head injury. The present study will address this directly by performing semi-structured

interviews that have been analysed in depth, and could ultimately lead to improved patient care by improving service delivery to better fit the needs of the individual.

Battista et al. (2014) highlighted the need for future research into traumatic head injuries, emphasising the need for in-depth research using semi-structured qualitative interviews; this supports the approach that my study uses. D'Cruz et al. (2016) accepted that there is a gap in the research knowledge base in this area of adult moderate-to-severe head injuries. Furthermore, they used a constructivist grounded theory approach, which is similar to the qualitative approach that my study uses: a social constructivist approach together with IPA. In addition, D'Cruz et al. sought to improve patient-centred care by gaining the perspectives of the participants, which is one of the primary aims of my study.

This study will aim to understand how CYP aged 6–13 years recover from moderate head injuries and how the mothers were affected, by exploring their lived experiences within their lifeworlds. I believe that by understanding these experiences, it is possible to improve patient care into the future. To achieve this, participants were interviewed from early on in their recovery and up to nine months following their initial injury. This longitudinal analysis is a significant addition to the knowledge base, with no similar studies having been identified following exhaustive searches of the literature.

2.7 Summary

This chapter has set out the term CYP will be used to describe all the participant in the 6 to 13-year category except when discussing at a more personal level, when daughter, son or

child will be used. The inclusion and justification of the mothers into the study was also

discussed with the extra perspective that they would bring to the study analysis. Government

frameworks and CYP nursing were also briefly explored together with an overview of head

injury in CYP. Recovery was also looked at and discussed along with its definition, and the

problems that could be associated with the medical model of assessment. Concluding this

chapter, lifeworld and its components were introduced together with the significance of this

thesis and how this study will add to knowledge base.

3 Literature Review

3.1 Introduction

This chapter will set the scene by locating this thesis within the current body of knowledge. Smith et al. (2009) mentioned that a literature review can expose gaps in the literature and help with development of the research question but they cautioned over preconceptions – a topic that will be discussed in Chapter 9 ("Conclusion and Recommendations"; section 9.5). A comprehensive systematic search with inclusion and exclusion criteria together with search strategy will be explored with the intention to fully explore the literature, inform the research question and to explore any pre-existing beliefs.

In the spirit the "openness", as mentioned by Smith et al. (2009), to the research process, a preliminary search was carried out in order to inform the research question and theoretical framework, the results of which also supported my observations about the lack of research exploring the experiences of CYP following a moderate head injury. Once the data were analysed, a further, more comprehensive literature search was carried out with the findings being presented thematically, an approach similar to Flynn (2018) and Bennett (2015). Search alerts were also setup with the major search engines/platforms as a method to stay up to date with new research. A difficulty that was encountered during the literature search revolved around how moderate head injury was discussed: a common theme that resonated through the results was that the moderate head injury group was with combined with either the mild or the severe head injury groups. This brought difficulties to analysing the findings but through careful working, four themes were identified from the literature searches including "Memory,

Learning and Problem Solving", "Social Competence, Cognition and Theory of Mind",

"Psychosocial Effects of a Head Injury", and "Parents' Views".

3.2 Setting the Scene

The background chapter to this thesis briefly described the occurrence of head injuries in

CYP together with an introduction to the effects of sustaining a head injury and some of the

terminology used. Here, I will explore the current literature with respect to what is known

about how a CYP's and the mothers lived experiences are affected by a moderate head injury.

What becomes apparent is the lack of research that could be classed as standalone moderate

CYP head injury studies. For example, CYP who experience moderate head injuries are

incorporated into larger head injury groups, the most common example of which is "moderate

to severe". As mentioned in the introduction chapter, a severe head injury involves a general

worsening of symptoms/consciousness, so there is potential for different outcomes for those

patients to those with moderate a head injury. I will draw out the relevant sections from the

studies/papers in the following sections as an aid to setting the scene for this thesis, beginning

with the aims of the study.

3.2.1 Aims of the Study

The task of the literature review for this thesis is to evaluate the current published literature in

response to the research aims:

- To explore how the experiences of CYP (aged 6 to 13 years) and their mothers are

  affected by a moderate head injury.

- To better understand, in a manner consistent with interpretative phenomenological analysis utilising the concept of lifeworld, how the CYP and their mothers are affected by moderate head injuries.

The next section will discuss the search strategy used for this study.

3.3 Designing the Search Strategy

The role of the literature review is to help give an answer to a problem though highlighting in a single document the key findings and salient point information from multiple papers through the combination of common themes and conclusions (Harden and Thomas 2005). In carrying out a thorough search of the literature, what became apparent (and was evidenced by the search findings) was that the majority of the papers were found from quantitative studies, with fewer from qualitative studies. This chapter will use a thematic approach in order to provide a comprehensive appraisal of all the academic papers and manage the complexity of the CYP moderate head injury topic with the associated factors (such as family, friendships) that need to be considered.

Harden and Thomas (2005) also stated that a systematic review search helps to avoid wrong or misleading conclusions, reduce bias (which can give an incorrect presentation of the research papers present in the literature), and ensure the correct interpretation of the research findings. It is also stated by Methley et al. (2014) that a systematic review search is important in the formation of evidence-based practice and it, by its comprehensive nature, reduces the risk of bias, where bias can be seen to not providing a true portrayal of the current research.

Concerning the formulation of a search strategy, Methley et al. (2014) discussed the use of

search processes/frameworks. Two of these are shown in Figure 3-1: PICO and SPIDER –

the ones chosen for this literature review. Figure 3-1 shows the meanings and qual-

/quantitative usage for each of the mnemonic formats (PICO was applied to quantitative

research and SPIDER to qualitative). Both of these search processes/frameworks fed into the

mixed method synthesis. By employing this type of approach, a more comprehensive view of

a phenomenon can be created, "with the intention of leading to a theoretical

'triangulation'"(Harden and Thomas 2005).

The following section will discuss the inclusion and exclusion criteria.

Awareness of Issue

Focussed Review Questions:

How do CYP and their mothers view their lived experiences during the nine-month recovery period following a post moderate head injury?

Quantitative Studies:

P – population

I – intervention

C – comparison

O – outcome

Qualitative Studies:

S – sample

P – phenomena of **I**nterest

D – design

E – evaluation

R – research

Quantitative and Qualitative Synthesis:

Thematic presentation of results

Figure 3-1: Adaptation of Harden and Thomas (2007). Mixed Different Study Type – Systematic Search of the Literature.

3.3.1   Inclusion and exclusion criteria

The following table, Table 3.1 demonstrates the inclusion and exclusion criteria used in the search strategy. This table is designed to show each of the criteria for the PICO and SPIDER processes/frameworks in a transparent manner. Studies were included if they overlapped the

age of the CYP population but did not fit the 6–13-year-old criteria exactly, and if their findings were deemed relevant. Studies were also considered, when suggested by the search engine (results page), were deemed relevant by myself, and these were entered into the screening process. Also, in a process of secondary/supplementary searching Holly et al. (2017), when the papers' reference lists were reviewed, relevant studies were included. Table 3.1 also shows the exclusion criteria; this involved removing studies that looked at the adult population and were not written in English.

Table 3.1: Inclusion and Exclusion Criteria.

PICO – Inclusion	SPIDER – Inclusion	Exclusion Criteria
Population (quantitative) / **S**ample (qualitative) CYP aged 6 to 13 years old and mothers.		CYP who are less than 6 years and older than 13 years old – other CYP studies considered if findings deemed relevant.
Intervention Any study which contained moderate head injury; exampled by those combining mild or severe head injuries with those of moderate head injuries.	**P**henomena of **I**nterest CYP aged up to 18 years of age Mothers Moderate head injury Quality of life.	Studies that did not contain moderate head injuries.

Comparison	Design	Studies not written in the English Language
Papers were included if they showed a comparison between the moderate head injury group and those having no head injury, a severe head injury or a mild head injury.	Any design or theoretical framework including those of mixed methods – no restrictions.	
Outcomes	Evaluation	
Outcomes were considered if they showed an adverse outcome or no adverse outcome within the moderate head injury group compared to any of the three other groups: no head injury, severe head injury and mild head injury. As my study was looking at in-depth experiences in which either change or no change post moderate head injury was possible, a "no change" was considered equally important as a change.	Evaluative criteria were considered which looked at subjective terms which included but were not limited to attitudes, experiences and views of research participants and the researchers.	
	Research	
	Two main research types: mixed methods and qualitative.	

3.3.2   Search Strategy/Technique:

According to Holly et al. (2017), many authors have discussed the formulation of an efficient

search strategy that reduces bias and maximises search yield whilst avoiding flaws and

missteps. Examples cited by Holly et al. (2017) include "Author Searching", "Citation

Chasing" and "Hand Searching", together with examples from database reference searching.

These will be discussed in the following sections with the intention of maximising the yield of literature pertaining to CYP who have sustained a moderate head injury.

3.3.2.1   Search Terms, Boolean Connectors and Full Electronic Scoping.

In order to undertake a full comprehensive search strategy, search terms were generated which would generate a maximum yield and were then linked together by the use of the Boolean connectors shown in Table 3.2.

Table 3.2: Search Terms with Boolean Connectors.

Child* **OR** p#ediatric* **OR** adolescent* **OR** Young person*
And
Moderate*
And
Head inj* **OR** head trauma* **OR** Cerebral impact* **OR** cerebral trauma* **OR** acquired brain inj* **OR** Brain inj* **OR** Brain trauma*
And
Quality of Life* **OR** QoL **OR** physical* **OR** Mental* **OR** Social*

To help place this thesis in context and to obtain a more focussed perspective, additional variables were considered for each database. These variables are shown in Table 3.3.

Table 3.3: Additional Variables.

Interview*
And
IPA **OR** Interpretative Phenomenological Analys*

The electronic databases and the search yields are summarised in Table 3.4. Six search engines were used for the literature review. Three of these were "platforms" and consequently used multiple databases to aid their search: "ProQuest", "SCOPUS" and "Web

of Science". In using these platforms, and large databases like "PsycINFO", additional limiters, such as excluding papers more than 10 years old or written in another language, were used to manage the large search yields. Duplicate papers were also removed using EndNote X7.

3.3.2.2   Non-Electronic Searches

Alongside the electronic searches, non-electronic searching and "hand searching" (Holly et al. 2017) were also carried out, including within grey literature, book publications and, as previously mentioned, manual searches of reference lists used in academic papers (which were used to support findings), which Holly et al. (2017, p. 164) described as "pearling" (citation searching). Alongside this strategy, I also drew upon my personal collection of papers which have been gathering since my interest in this field began. By using this comprehensive strategy, publication bias (where papers are published earlier or have a higher chance of publication if they demonstrated positive results) was reduced (Dubben and Beck-Bornholdt 2005). This strategy was proven to be effective by the discovery in my personal collection of an Australian IPA study of adolescents post head injury (Battista et al. 2014) that did not appear in the online searches.

3.3.2.3   Screening Process

The screening process continued with each paper having its abstract examined. If the abstract met only the inclusion criteria, the whole paper was scrutinised with regard to both the inclusion and exclusion criteria. These selected papers were then analysed using the appropriate JBI (2014) checklists such as the "JBI Critical Appraisal Checklist for Qualitative Research" and "JBI Critical Appraisal Checklist for Systematic Reviews (Figure 3-2 shows

an image of a completed form) and Research Syntheses". By adopting this approach, a robust

critical analysis was carried out.

Figure 3-2 Completed JBI Systematic Review Checklist; JBI (2014)

JBI Critical Appraisal Checklist for Systematic Reviews and Research Syntheses

Reviewer _____ Date _____
Author Lloyd et al _____ Year 2015 Record Number 25

		Yes	No	Unclear	Not applicable
1.	Is the review question clearly and explicitly stated?	☑	☐	☐	☐
2.	Were the inclusion criteria appropriate for the review question?	☑	☐	☐	☐
3.	Was the search strategy appropriate?	☑	☐	☐	☐
4.	Were the sources and resources used to search for studies adequate?	☑	☐	☐	☐
5.	Were the criteria for appraising studies appropriate?	☑	☐	☐	☐
6.	Was critical appraisal conducted by two or more reviewers independently?	☑	☐	☐	☐
7.	Were there methods to minimize errors in data extraction?	☑	☐	☐	☐
8.	Were the methods used to combine studies appropriate?	☑	☐	☐	☐
9.	Was the likelihood of publication bias assessed?	☑	☐	☐	☐
10.	Were recommendations for policy and/or practice supported by the reported data?	☐	☐	☐	☑
11.	Were the specific directives for new research appropriate?	☑	☐	☐	☐

Overall appraisal: Include ⟨☑⟩   Exclude ☐   Seek further info ☐

Comprehensive study - looked @ 8553 children and adolescent aged 0-18 years - Mild & Moderate TBI

Table 3.4 highlights the databases and platforms used for the searches, together with their

search yield.

Table 3.4: Summary of Database Searches.

Database	Limiters Applied	Initial Numbers after Limiters Applied		Number of Papers Selected for Abstract Review	Additional Papers Included as Recommended by Search Engine		Number of Papers Selected	Number of Papers including both "Interviews" and IPA
ProQuest (incl. ASSIA, BRITISH NURSING INDEX, IBSS)	Peer reviewed; 2008–2018; English Language; America, UK, Canada and Australia;	150		3	6		9	0
PsycINFO	Peer reviewed; 2008–2018; English Language; age limited to 0–17-year-olds; longitudinal	316		41	0		41	0
PUBMED including MEDLINE	2008–2018; Up to 18 years of age; English Language; Longitudinal	66		10	0		10	0
SCOPUS Including EMBASE and MEDLINE	English Language; Europe, United States, Canada, Australia; journals; exclude adult; in result search variable "longitudinal" due to large number of 654.	351		54	8		19	0
CINAHL	Peer reviewed; English Language; all child; Europe, USA, UK and Australia	163		32	0		32	0
Web of Science	English Language; 2008–2018; papers; Europe, USA, UK and Australia	288		64	0		49	0
				Total After Considered for Review and Duplicates Removed:			73	0

(adapted from Bennett (2015)

3.4 Thematic Discussion

The following section will explore the selected papers, both qualitative and quantitative, and will present them via a thematic approach. Themes were identified from the papers by their topic of focus and their findings. These themes were then compiled to form a series of overarching themes, four of which were identified:

- Theme One – Memory, Learning and Problem Solving

- Theme Two – Social Competence, Cognition and Theory of Mind,

- Theme Three – Psychosocial Effects of a Head Injury,

- Theme Four – Parents' Views

Even though a comprehensive search was done, the literature search also identified an apparent dominance of Australian and American/Canadian papers, which is evidenced by the occurrence of Dr Vicki Anderson as a researcher in a number of the included papers.

Papers for this review were selected for relevance and their impact (including journal impact). Quantitative studies were only included in the literature review if they showed significance in their analysis. Papers were also discussed if they included CYP (aged between 0 and 18 years old) as some of the relevant studies included age ranges which overlapped with the age inclusion criterion for my thesis (6–13-year-olds).

3.4.1 Theme One – Memory, Learning and Problem Solving

Understanding the neuropsychological effects on cognition following a moderate head injury is highly relevant as they include elements such as memory, learning and executive functioning, the latter of which can be seen as "problem solving, planning, inhibition, and

cognitive flexibility" (Tousignant et al. 2018, p. 432). For a CYP, these elements can influence schooling and behaviours, and – broadly put – can directly affect their lifeworld and lived experience, where an abrupt change can be noted from the time before the head injury to the time following the head injury.

Lloyd et al. (2015) conducted a systematic review (published in the journal *Brain Injury*) of literature between 2008 and 2013; they focussed on both mild and moderate head injuries, and on neuropsychosocial, academic and psychosocial outcomes. In total, 55 studies met their inclusion criteria, including 8,553 CYP, aged up to 18 years of age, but only 22 studies focussed on moderate head injuries. The authors summarised that it is important, clinically, to monitor recovery over time –emphasising the need for a longitudinal approach. Lloyd et al. (2015) used clear and appropriate inclusion and exclusion criteria in order to gauge the strength of the papers' findings. The clear methodology approach used by Lloyd et al. (2015) and the transparency in their findings highlight the significance of their study. Limitations were briefly identified by the authors as some of the included studies had methodological shortcomings, including low recruitment numbers, absence of a control group (twenty-one of the included studies), biases caused by only including intervention studies and the lack of blinding in some studies; the authors did not discuss this any further than just mentioning it.

Lloyd et al. (2015) included both mild and moderate head injury groups, and 40% of these papers demonstrated adverse neuropsychological outcomes. Of benefit to my study is that a clear distinction was made by Lloyd et al. (2015) between the head injury severity groups and they are discussed separately. In the moderate head injury group, 45% demonstrated adverse neuropsychological outcomes (in children and adolescents) including those of reduced

executive functioning; the authors highlighted that aspects of memory and learning were not affected equally, hence variability in findings were shown. Lloyd et al. (2015) also concluded that the majority of the CYP did not demonstrate academic deficits and that the effect on academia was proportional to the classification of head injury: mild head injuries had the least effect and severe head injuries saw the largest impact.

This significant review by Lloyd et al. (2015) concluded that in both the mild and moderate head injury groups conflicting results were also shown in how CYP recover over time. The educational findings by Lloyd et al. (2015) were also supported by Prasad et al. (2017) American study, who carried out a cross-sectional analysis of four groups: CYP with a severe head injury; complicated mild and moderate; orthopaedic injury; and a healthy control group. They looked at educational difficulties, including cognitive function, and concurred that complicated mild to moderate head injuries resulted in increased academic challenges and that educational support was more likely if their head injury was viewed as being complicated (described by Prasad et al. (2017) as being those with parenchymal (brain tissue) injury and the lowest post resuscitation score). Useful to my study was that Prasad et al. (2017) used a control group in order to compare their findings, and in total 99 CYP head injury participants engaged in the long-term outcome components, out of which four were lost to follow-up, one withdrew and one was unable to participate due to severe adverse cognitive functions. For their research, two studies were carried out with the first being a longitudinal study between 1994 and 1998 (with an age range of two months to six years), and the second a prospective longitudinal study carried out between 2004 and 2007 (with an age range of 8 to 15 years). Importantly, the inclusion criteria remained the same for both cohorts, and the head injury groups and healthy control were recruited across both cohorts – the orthopaedic group was

only recruited in the second cohort. Prasad et al. (2017) used, as part of their measures, school records and parental ratings of school competency and functional academic skill.

Unfortunately, Prasad et al. (2017) did not differentiate between moderate and complicated mild head injury groups, but they did highlight the disparity between the educational provision of different participant's educational settings. They also pointed to the matter of educational issues becoming increasingly evident as the CYP aged and more educational demands were placed on them. Prasad et al. (2017) did discuss the limitations of their study, which included the research design (including the inability to assess CYP who were too young for school), difficulties with locating school records, and the subjectiveness of parent and teacher reporting. By including this paper in this literature review, I am hoping that the reader obtains an insight into some of the educational difficulties that CYP who suffer from head injuries experience. Furthermore, School is not only a place of learning but a place where CYP socialise.

An Australian longitudinal study carried out by Anderson et al. (2012) utilised parental questionnaires to appraise changes in QoL, executive functioning, behaviour and adaptive functioning amongst 6–14-year-olds (n=205) at the start of their study and at six months post injury. The parent or primary carer also took part in a demographic-medical interview at the first interview, which looked at the social/educational history, developmental history and preinjury medical – together with questions concerning parental occupation, family setup and parental educational level – in order to see if these factors influenced head injury recovery. An IQ assessment of the CYP was carried out at three months. This was part of a larger study

with the data being collected and analysed for each classification of head injury (mild, moderate and severe).

The results from the study of Anderson et al. (2012) were then quantitatively analysed using SPSS. Anderson et al. (2012) showed CYP with moderate head injuries had difficulties with their working memory, planning and problem solving. Interestingly, they also showed that a poorer outcome was associated with both an earlier age at the time of injury and low family cohesion; the latter was discussed and explored by Battista et al. (2014). Anderson et al. (2012) also showed that the families' socio-economic status did not significantly affect recovery at six months.

The effect on education, social activities and social groupings was also highlighted by the qualitative study by Roscigno et al. (2011) (explored in the next theme) which supports the findings of Anderson et al. (2012) concerning functional impairment; however, Roscigno et al. (2011) indicated that these educational and social effects are more negative than Anderson et al. (2012) suggested in their paper.

3.4.1.1 **Summary**

The findings from this theme clearly highlight that CYP who have suffered a moderate head injury are at risk of developing adverse neuropsychological outcomes, including poor working memory, poor planning and poor problem solving (executive functioning). This is highly relevant but does not identify how these outcomes can influence the lifeworld of the CYP, their recovery or effect the mothers. It is not apparent what the meaning of these adverse neuropsychological problems are for the to the moderate head injury sufferer (from a

neuropsychological perspective). Furthermore, no qualitative studies were found which explored the lifeworld perspective of the CYP, indicating a need for further research, focussing on the lived experiences in order to see the impact of these adverse neuropsychological problems and the effect they have on the mothers. It was also discussed by Lloyd et al. (2015) that variability also exists in recovery. This lends itself to the need for an individualised assessment process that caters for this variance and ultimately addresses the needs of the moderate head injury sufferer.

This theme has also shown that the socioeconomic status of families does not significantly hamper recovery at six months but suffering an injury at a younger age can negatively influence head injury outcome.

The next section will explore the literature surrounding social competence, cognition and theory of mind (TOM) in the CYP cohort following a moderate head injury.

3.4.2   Theme Two – Social Competence, Cognition and Theory of Mind

Introducing this theme here provides an opportunity to review the literature around the psychological concepts of social competence, cognition and theory of mind (TOM) as they can have a direct effect on the next theme, "Psychosocial Effects of a Head Injury". These psychological concepts can influence behaviours and social relationships and, as such, exploring the research around these concepts helps to provide a "window" of understanding for the reader and researcher in the interpretation of the CYP's lived experiences. The first explanation to be briefly explored is social competence.

Moran et al. (2015) in their American and Canadian paper, described social competence as being comprised of social information processing, which can affect social behaviour; it can be seen as an important and critical behaviour that can be negatively influenced by a head injury. This can lead to problems with maintaining friendships and developing of personal relationships; affect functional and academic outcomes (including problems with academic and long-term occupational success); and, particularly in CYP, lead to anti-social behaviour, drug abuse, mood problems and possibly suicide (Tlustos et al. 2016). CYP who suffer from these problems are more likely to ask for adult intervention (Moran et al. 2015). With respect to mental disorders and maladaptive behaviours (including CYP with co-existing offending behaviour), Ryan et al. (2016b) in their Australian and Canadian paper, mentioned that there is a fourfold increase following a head injury compared to the general CYP population but they stated that the full mechanism underpinning this is unclear.

Social cognition was also explored in a recent, small American Canadian study by Tousignant et al. (2018), which included 23 adolescents (mean age at injury: 14.77) who had suffered a moderate-to-severe head injury. They were compared to a control group of 23 peers with the aim of examining mentalising, social knowledge, empathy and emotion recognition. In a comprehensive approach, Tousignant et al. (2018) used questionnaires as well as tests (for example, a social knowledge test, combined stories test and emotion recognition test), which were carried out at least six months post injury. Their findings showed that adolescents who had suffered a moderate-to-severe head injury had greater difficulty in understanding other people's perspectives, and that reductions in higher-order

cognitive functioning (which Tousignant et al. (2018) described as working memory, executive functioning, and attention) might be a partial cause for social cognition deficits.

In an Australian quantitative study, Muscara et al. (2009) grouped moderate and severe head injuries (placing mild injuries in a separate group) and analysed social outcomes post head injury. This study, which formed part of a larger study, looked at 36 CYP aged between 8 and 12 years old at the time of the head injury and recruitment, with the study being carried out 7–10 years later. This study predominantly used questionnaires, which were statistically analysed. Muscara et al. (2009) admitted that sample size was an issue, together with the study's recruitment being 7–10 years earlier, but they argued that their results can contribute to the literature.

Of interest was that Muscara et al. (2009) found that CYP who suffered moderate-to-severe head injuries had greater difficulties in social functioning and reintegration together with communication issues and a reduction in their quality of daily living. Muscara et al. (2009) also stated that social functioning is a difficult area to assess, although they added that adaptive behaviour functioning may worsen over time. A study in the same year (Levin et al. 2009) showed an association between cognitive ability and social functioning, and that these are controlled by social information processing, which is related to frontal lobe integrity (and functioning), although this goes beyond the scope of this review. Interestingly, they added that cognitive recovery varies over time. This is pertinent to my study, which is longitudinal, as this cognition can influence factors such as friendships and school. Levin et al. (2009) had carried out an American cross-sectional study which analysed 52 CYP aged 7–17 years old (at the time of injury) at 12 months post injury. Cognitive measures, including memory tests,

reaction times and adaptive behaviour scales, were used; these were then analysed with t tests and by Chi-square tests. The study did not discuss the limitations of its research, but the authors felt that their study extended the literature on long-term social functioning and stressed the importance of rehabilitation and clinical follow-up.

TOM is described as a "multi-dimensional construct that allows individuals to ascribe a variety of psychological states, such as intentions or emotions, to others and thereby understand and subsequently predict behaviors" Ryan et al. (2016a, p. 684). Yeates et al. (2014) in their American Canadian cross-sectional study discussed TOM and social competence, contributing an interesting point: they highlighted that, for social competence and TOM to function properly, involvement of the various lobes of the brain is required, and in cases of head injuries in which multiple lobes are affected, a significantly greater effect would be observed, possibly resulting in the CYP suffering a head injury having a larger adverse effect. For this study, 8–13-year-olds were recruited (82 with a traumatic brain injury (TBI) and 61 with orthopaedic injuries) and the authors completed a series of tests (including an MRI, classroom observations and parent rating questionnaires) at approximately 2.5 years post injury. The study had clear aims and the results were statistically analysed; this included brain volume measurements and Voxel-based partial correlation (VBM) analysis (measurement of brain activity) together with three TOM measures. All participants showed significant correlation between brain volume and TOM (all $p < 0.05$). Sample size was seen as a limitation, as were comparability across scanners in the VBM analysis. Yeates et al. (2014) summarised in their findings that CYP who suffered traumatic head injuries were at risk of poor social outcomes (including social adjustment, social interaction and social cognition). They also showed that where there were reductions in brain volume, this also positively correlated with TOM. Yeates et al. (2014, p. 103) explained these findings by adding that for

the "social brain" to be competently operational, it involves spatially remote regions to be interacting, arears that can be associated with maturation. Problems with TOM were also associated with social rejection and victimisation in their study (Yeates et al. 2014).

3.4.2.1   **Summary**

This theme briefly touched upon social competence, cognition and TOM. Both Yeates et al. (2014) and Tousignant et al. (2018) highlighted a direct connection between these factors (social competence, cognition and TOM) in relation to head injuries, especially where there were reductions in brain volume (brain atrophy). These studies were largely quantitative in nature and, similar to the last theme, identified effects of a head injury such as social competence, cognition and TOM but did not expand on how the CYP or the mother is affected. For both the CYP and the mothers, these are important aspects of recovery and need to be understood. Understanding how a moderate head injury can effect social competence, cognition and TOM is important, as these can directly affect not only recovery but reintegration back into normality. Understanding the lived experiences of both the CYP and the mother would be able to provide information on how social competence, cognition and TOM affects the moderate head injury patient. By understanding this, discharge planning from the ward can be improved together with ongoing support.

3.4.3   Theme Three – Psychosocial Effects of a Head Injury

This theme will review the literature regarding how a moderate head injury can impact the psychosocial aspects of a CYP's life. Lloyd et al. (2015) was discussed above in relation to the neuropsychological effects of a head injury. They also stated that out of the 51% of the

papers reviewed demonstrated adverse effects, 50% of these papers discussed psychosocial effects. In the moderate head injury group, 31.8% demonstrated adverse psychosocial outcomes, including problems with post-injury adjustment, lower QoL, behaviour changes, altered routine, reduced concentration, post-traumatic stress disorder (PTSD) and acquired attention deficit hyperactive disorder. They also highlighted the need for more longitudinal studies and that a CYP's recovery may be positively influenced by being home with their family.

An American study by Roscigno et al. (2011) carried out a descriptive phenomenological investigation of CYP who had sustained a moderate-to-severe head injury. The authors described the study as the "first published investigation providing an in-depth first person account of children's appraisals of experiences and life quality after TBI" (Roscigno et al. 2011, p. 889). Roscigno et al. (2011) interviewed 39 CYP aged between 6 and 18 years – each participant was interviewed twice, at least one year apart. They demonstrated a comprehensive recruitment process and described the study limitations including that the CYP had to self-select to be involved, and that the sample was largely Caucasian, non-Hispanic and English speaking. Like IPA, descriptive phenomenology is not intended for generalisation (Roscigno et al. 2011).

Roscigno et al. (2011, p. 882) identified six themes: (1) It is like waking up in a bad dream; (2) I thought going home would get me back to my old life, but it did not; (3) Everything is such hard work; (4) You feel like you will never be like the person you were before; (5) It is not all bad; and (6) Some people get it, but many people do not. Roscigno et al. (2011) stated that their study both helped change the way CYP's QoL are perceived by others and showed

that social support was important for the CYP in order for them to adapt to change and loss (following their head injury).

The conclusions from Roscigno et al. (2011) mainly concerned severe head injuries, with some of the moderate head injury CYP also showing similar reactions. There were five main points: (1) CYP with these types of injuries can have significant changes in their family, school, social activities, self and social groupings; (2) the CYP were not always ready for the negative views or misunderstandings of others; (3) all the CYP experienced loss and grieved changes, which was affected by social support – the more support, the less time this lasted; (4) by the second interview, most of the CYP had adjusted to their changes but a couple continued to experience problems; and (5) CYP can alter and change their current thinking about how they are viewed by participating in qualitative research, with respect to life quality post head injury.

In an IPA Australian study carried out by Battista et al. (2014), the authors interviewed ten CYP with a mean age of approximately 17 years who were recruited by a purposive sampling technique, following a recognition of the lack of exploration of adolescents' perspectives in the literature. All the participants had a head injury at least twelve months previously (which included some moderate head injuries) and had no preinjury record of neurological, developmental or mental health disorder. Positively, this created a small homogeneous group which was then analysed via IPA; the development of this size of homogeneous group is supported by Smith et al. (2009). Data analysis was carried out by a team who co-analysed the data, increasing the trustworthiness of the findings. Limitations to the study were discussed openly, including that it contained a largely male sample and therefore did not

explore gender differences. Battista et al. (2014), in their in-depth study, explored the participants' phenomenology of life post head injury using a HRQoL (Health Related QoL) model together with an mDNA (multi-threaded DNA) approach to aid their thematic analysis.

In the study by Battista et al. (2014), the authors undertook semi-structured interviews between two and ten years after the time of the injury. The authors identified the following themes from their findings which were affected by the head injury: "personal and social discrepancies", "family relationships", "coping and post-traumatic growth" and "happiness". They found that sustaining a head injury did not always impact on how their participants viewed their QoL and that any impact can vary depending on the life domains (as exampled by relationships, school performance, happiness - Battista et al. (2014)) that are important to the CYP. Secondly, they found that any effect on life domains was influenced by the head injury and by the participants' normal maturation processes.

Interestingly, as in some of the previously mentioned papers which looked at psychosocial outcomes post head injury, Anderson et al. (2011), in their Australian quantitative study, examined long-term outcomes with respect to intellectual ability, QoL and personality in adult survivors of paediatric head injury. In their study they recruited 50 adolescents and young adults (31 were male) and grouped the participants' head injuries into severity groups (mild n=20, moderate n=12 and severe n=18). They found that the intellectual outcomes of those with moderate head injuries mirrored those of CYP who suffered mild head injuries: they did not require additional help in school but were less likely to achieve higher educational grades.

Anderson et al. (2011, p. 178) also demonstrated that the QoL of the moderate head injury group, which included "Work and Leisure, Relationships and Living Skills", was similar to that of the mild head injury group, in which they found no problems noted with QoL. The participants' personality (measure by NEO – a standardised measure of personality function including openness, agreeability, neuroticism, extraversion and conscientiousness – Anderson et al. (2011)) and intellect were also similar between the two groups. Of note, however, was that the mean injury age was 9.5 years old and the follow-up assessments were done when the participants were 26.9 years old (mean). As part of their assessment they used questionnaires and an intelligence evaluation. This study, in looking at the long-term outcomes from a moderate head injury, demonstrated that around 13.3 years after the injury the participants had no reported problems with QoL, personality and intellect. Data that were collected in this study (including an evaluation and questionnaires), as in the previous quantitative studies, were appropriately statistically analysed.

A later Swedish study by Aaro Jonsson et al. (2014) does not fully support the findings of Anderson et al. (2011). Aaro Jonsson et al. (2014), in a quantitative study, carried out telephone interviews at 13 years post head injury. In their review of QoL, they found variance in the moderate-to-severe group which ranged between "relatively good" to "moderate/severe limitations". The areas which they found to be of concern were around fatigue, irritability and transportation (for example, driving). They also added that CYP who required neurosurgical intervention had reduced QoL. The authors highlighted the need to analyse data on an individual level or at a particular head injury group level. The reasoning behind this lay with the large amount of variance that exists within head injury severity groups, which is often lost when data means (averaging) are used to review data.

3.4.3.1 **Summary**

This theme illustrated some key findings. Lloyd et al. (2015) identified in their systematic review that 51% of papers that demonstrated adverse effects, and 31.8% demonstrated adverse psychosocial outcomes in the moderate head injury group. Battista et al. (2014) found that QoL was not always affected; however, in those life domains that were affected, the participant's normal maturation process had to be considered. Roscigno et al. (2011) also showed altered psychosocial outcomes, which is supported by Battista et al. (2014) and Lloyd et al. (2015), but furthermore considered the element of loss and grief. Roscigno et al. (2011) highlighted that not all the adverse psychosocial outcomes had returned to a preinjury state by their second interview, pointing to the long term nature of the recovery process. Adding to this, Aaro Jonsson et al. (2014) in agreement with the later findings of Lloyd et al. (2015) noted additional problems: fatigue, irritability and transportation. They also interestingly added that CYP who required neurosurgical intervention had more problems with their QoL. Conversely, Anderson et al. (2011) looked at follow-up assessments and stated that around 13.3 years after the injury the participants had no reported problems with QoL, personality or intellect.

A key point in reviewing these papers lies with the duration of time that has elapsed since the head injury taking place to the collection of data: Battista et al. (2014) had a mean time of 4.62 years and Roscigno et al. (2011) in their qualitative research carried out their initial interviews with a mean time of 15 months post injury, with a follow up telephone or by a face to face interview approximately a year later; Aaro Jonsson et al. (2014) and Anderson et al. (2011) in their quantitative papers 13 years and 13.3 (mean) years later respectively.

This highlights the need for studies that consider the months immediately following the head injury, when the CYP and the mother has to adjust to a post injury lifeworld. Also the studies by Roscigno et al. (2011) and Battista et al. (2014) clearly demonstrated the value of understanding lived experiences and the rich data that semi-structured interviews can create for analysis. From a study perspective, by combining the benefits seen by Roscigno et al. (2011) and Battista et al. (2014) explorations of lived experiences; with the need to understand how these are affected in real time during in the recovery process, will ultimately lead to an improved support process in follow up care for the head injury sufferer.

3.4.4 Theme Four – Parents' Views

Chapter 2 of this thesis explored the connection between CYP and their families (section 2.2.3). A CYP's moderate head injury, and the following recovery, can affect the family; to explore this, this fourth theme will review the relevant literature starting with an IPA study of ten mothers by Clark et al. (2008).

Clark et al. (2008) in a UK based study, interviewed ten mothers using a semi-structured approach between two and ten years following their child's head injury. The mothers' were comprised of whose child (aged 0–16 years old) had suffered a moderate-to-severe head injury through which they had lost consciousness for between 20 minutes and 36 hours. According to Smith et al. (2009), the interviewing of ten individuals is adequate for an IPA study. Validity was discussed: an independent audit was carried out of the analysis and homogeneity (which is an important aspect of IPA - Smith et al. (2009)), CYP were selected by the causation of the injury and a purposive sampling strategy was used.

Clark et al. (2008) generated six themes: (1) "physical, psychological and social effect on mother"; (2) "mother's process of coping and support"; (3) "effects on whole family"; (4) "changes to and loss of the past child"; (5) "contact with services"; and (6) "changed roles". Their study concluded that the CYP's head injury can have large effects on the family, which should be taken into account in rehabilitation. Furthermore, Clark et al. also suggested further research is required to explore PTSD in parents, the grieving process of parents, and attachment and protection-seeking behaviour. Of clinical interest is that they also showed the need for professional intervention, through which the parents can be helped to understand and normalise their experience. This intervention would need to understand the non-linear grieving process experienced by the mothers as outlined by Clark et al. (2008).

Wongvatunyu and Porter (2008) in an American study used descriptive phenomenology to explore the lifeworlds of seven mothers who had a young adult son or daughter that had suffered a moderate-to-severe head injury at least six months earlier. The mothers were recruited by posting notices in local clinics and in specialised clinics for TBI survivors. The ages of the young adults ranged from 20 to 36 years old with a mean age of 25 years. This age range would normally have excluded this paper from the literature search; however, some parallels can be drawn as six of the seven young adult lived at home with their mothers.

Wongvatunyu and Porter (2008) used open-ended questions and neutral language in three in-depth interviews over a two-month period. From their interviews and subsequent analysis, they discerned five lifeworld features: (1) "perceiving that the world has really changed"; (2) "believing that my child is still able"; (3) "having a child who survived a TBI as a young

adult"; (4) "having sufficient support/feeling bereft of any help"; and (5) "believing I can help my child". Wongvatunyu and Porter (2008) supported the recommendations of Clark et al. (2008), highlighting the need for professional support for the mothers, but they also added that each mother's lifeworld varied from that of the others. Wongvatunyu and Porter (2008) supported the need for individualised approaches to support for the mothers. An interesting point was made in the paper: they referenced an extract, "[it] never, ever ends", which indicates that the recovery post head injury appears to take a long time for the mothers – it feels like a slowing down of time.

An Australian longitudinal quantitative study by Brown et al. (2016), which formed part of a larger study, explored how parents reported their CYP's QoL. They used a sample of 182 CYP aged between 6 and 14 years old. Their study focussed on mild and moderate-to-severe head injuries, and used questionnaires to collect data at three, six, twelve and eighteen months. These data were then analysed using SPSS (version 22) together with multilevel modelling (which included covariance structure and diagonal covariance). The limitations of the study were discussed by Brown et al. (2016) and included limited generalisability of their findings (as did previous studies discussed in this chapter); the participants being predominantly Caucasian and English speaking; that CYP with post-trauma amnesia of more than 28 days were excluded; and, importantly for my thesis, the possibility that combining the moderate head injury group with the severe one could have masked findings.

The results from the study by Brown et al. (2016) showed that different dimensions of HRQoL reacted differently to the head injury, which supports the previous studies. This effect is greater than that seen in CYP who have only suffered a mild head injury. However,

these differences disappeared by eighteen months. Brown et al. (2016) combined the moderate and severe head injuries together and found that at three months this group had more physical-functioning limitations than the mild head injury group, and that from six months these physical components continually improved.

Brown et al. (2016) also added that parents reported that their son and daughters had significant behavioural problems at three and six months, which they considered had returned to normal by twelve months. Brown et al. also noted that the parents' activities were dependent upon the functional ability of their CYP. The authors recognised that using a parent's view on their sons' and daughters' HRQoL can be seen as a weakness in the study, but this is justified by their inclusion of 6-year-olds and the difficulties in getting a CYP of this age to talk and reflect on their HRQoL.

3.4.4.1 Summary

This theme has shown a connection between the CYP who has suffered a head injury and their parent's perceptions. Both Clark et al. (2008) and Wongvatunyu and Porter (2008) demonstrated in their studies that parents also are affected by the CYP's head injury. Clark et al. (2008) proposed the need for further research into how parents are affected and for further understanding of PTSD, grieving, attachment and protection seeking behaviour – all of which can be non-linear. These findings are supported by Wongvatunyu and Porter (2008) who highlighted the need for professional support for the mothers, especially because each mother's lifeworld could show variance from one another. Brown et al. (2016) also added that parents' activities were also dependent upon the functional ability of their CYP, which shows a synergistical relationship between CYP and their families.

The papers in this summary provide a useful insight into the current literature database and clearly indicate the need for further research into how families are affected by a CYP who has suffered a moderate head injury. Again, as seen in the previous theme, there is a gap in time between when the head injury takes place and when the research as evidenced by Clark et al. (2008) and Wongvatunyu and Porter (2008) studies, thereby indicating the need for research in real time to explore how families are affected. Brown et al. (2016) did carry out research from three months, but did not directly explore how families were affected with respect to their lifeworlds. They did, however, demonstrate a functional link between parenting behaviour and their CYP's functional ability. Carrying out research in real time and looking at the lifeworlds of both the CYP and their mothers would address the comments of Clark et al. (2008) about the need for further research, and would explore parenting behaviour (including PTSD, grieving, attachment and protection seeking) and how this can influence the recovery of the CYP.

3.5   Summary

Through a comprehensive systematic literature search, this chapter has presented the main findings thematically. By undertaking this review, gaps in the literature have been noted and the need for future research highlighted. This literature review has also identified a lack of UK-based studies into moderate head injury recovery together with a bias towards quantitative studies. Clinically understanding how a CYP recovers from moderate head injury in real time is vitally important for planning appropriate healthcare that will benefit the sufferer. Very few studies explored the lived experiences of the CYP or their families during the first year of recovery and none during the first couple of months. Gender has not been

discussed in the literature in relation to the recovery process. Post moderate head injury restrictions have also not been discussed and how these might affect the CYP or the mother has not been explored. From a lifeworld perspective, only the mothers have been explored and this was carried out by Wongvatunyu and Porter (2008) and where no studies have explored the lifeworld of the CYP.

The literature review has demonstrated a void in studies that explore qualitatively, the lived experiences of CYP and the mothers from the period of time of being discharged from the hospital ward to nine months. No studies have explored how restrictions placed on the CYP and enforced by the mothers, have been conducted and how gender might influence this together with elements of defiancy. The inclusion age for my study has also not been thoroughly explored in the literature and as such adds to the void in not fully understanding the full impact the recovery process has on the lived experiences of the CYP and the mothers; something which my study will attempt to address.

The following chapter will discuss and explore the methodology for my study.

4 Study Methodology

4.1   Introduction

Despite a plethora of research being carried out into head injuries, there is a gap in the literature: the CYP's and their mothers' voices are not heard, and their perspectives on head injury recovery are not comprehensively explored. In response, this study aimed to listen to their voices and ultimately improve their experiences during the recovery process. This chapter will therefore explore the theoretical underpinnings for my study, the rationale for the study methodology and why an interpretative phenomenological analysis (IPA) approach was appropriate together with a critique. This chapter will discuss how public involvement in the form of the CAG (Children's Advisory Group) and its ethical considerations informed the study design.

The following section will present the study aims and objectives.

4.2   Study Aims and Objectives

The aims of this study were:

- To explore how the experiences of CYP (aged 6 to 13 years) and their mothers are affected by a moderate head injury.
- To better understand, in a manner consistent with interpretative phenomenological analysis utilising the concept of lifeworld, how the CYP and their mothers are affected by moderate head injuries.

The objectives for this study were:

- To undertake a longitudinal analysis of qualitative semi-structured interviews with CYP who have suffered a moderate head injury aged between 6 and 13 years, at 2 weeks and 3, 6- and 9-months post discharge from hospital.

- To determine, in a manner consistent with interpretative phenomenological analysis, how the mothers' lifeworlds are affected and how they view the CYP's lifeworlds following the moderate head injury, at 6- and 9-months post discharge.

- To identify clear recommendations for clinical practice based on CYP's and mothers' longitudinal perceptions of their lifeworlds following head injury.

4.3   Theoretical Underpinnings

The following sections will explore the theoretical underpinnings of the research process. They will explore my theoretical paradigm together with the ontological, epistemological and axiological stances taken within this study. Part of my epistemological stance is the theoretical lens used (social constructivism); this will also be discussed to help inform the reader how the data was viewed, interpreted and analysed. The following section will explore what is meant by a paradigm and will provide examples.

4.3.1   My Paradigm

The term "research paradigm" is used to describe a philosophical way of thinking and originates from the Greek word meaning "*pattern*" (Kivunja and Kuyini 2017). Kivunja and Kuyini (2017) added that a paradigm reflects the researcher's belief and forms a conceptual lens that informs the meaning and interpretation of the research data. Robinson and McCartan

(2016) furthered this by saying that is it a shared belief within a group of people. Creswell and Creswell (2018) used the term "Philosophical Worldviews" as an alternative for "paradigms" and gave four examples: postpositivist, constructivist, transformative and pragmatic. This was added to by Flynn (2018) who included feminism, critical theory, interpretivism, postmodernism and positivism, amongst others. It was also mentioned by Creswell and Creswell (2018) that constructivism can be combined with interpretivism (a combination used in my study), whereby an interpretation can be used to understand the lifeworlds of the CYP and their mothers whilst appreciating that this knowledge can be socially constructed. Denzin and Lincoln (2018, pp. 810-811) also discussed that an interpretative approach can enable insight into "living with" any given experience; this correlates well with my study, in which the participants, the CYP and mothers, are "living with" their recovery post moderate head injury.

An area of interest to me, as a clinical nurse specialist, is how the CYP group recover and, in particular, how they and the mothers view recovery. This study will utilise a lifeworld approach (Galvin and Todres 2013); it will also consider each of the CYP as individuals – each person will have unique interpretation of their own experiences. Individuality and subjectivity are seen as hallmarks of postmodernism, which sees knowledge as a social construct (Cohen et al. 2011).

Flynn (2018) mentioned that a paradigm is comprised of a philosophical trinity – ontology, epistemology and axiology. These will be discussed in the following sections.

4.3.2   Ontology

The term "ontology" was first used in the seventeenth century by Rudolf Gockel and Jacob

Lorhand and can be translated as the "study of existence" (Guizzardi 2005). It was also

mentioned by Howell (2013) that access to reality is only through perceptual capabilities –

the process of the mind understanding the phenomena. From an ontological position, I

believe that differing and multiple realities exist between myself, the mothers and the CYP

involved in my study (Bennett 2015, Ivanoff and Hultberg 2006). This concept is very

important to this study, as it reinforces the idea of individuality. Denzin and Lincoln (2018, p.

706) said that ontology is "a matter of continuous becoming(s) rather than extant forms of

being". My interpretation of Denzin and Lincoln (2018) is founded on my further belief that

reality is continually changing, is not stagnant, hence viewpoints also change. Over the

course of my longitudinal study, in which time does not stand still, the perspectives of the

participants might have changed.

In bringing these concepts together, it is possible to show that reality is personal to the

individual, and this needs to be considered in this thesis. For example, in this study, each of

the CYP and the mothers had separate realities that I, as the researcher, had to interpret whilst

staying true to the meaning of their experiences.

4.3.3   Epistemology

The term "epistemology" originates from the Greek "*episteme*" (knowledge) and "*logos*"

(theory), hence it is the theory of knowledge (Delanty and Strydom 2003). From a social

constructivist perspective, knowledge is created by social interactions (Flick 2018) including

components of linguistics (Miller 2016) which is an important component of IPA analysis.

This thesis will take a social constructivist approach to understanding the meaning within the findings. A shared meaning was created with the CYP and the mothers – a social constructivist construction of knowledge – and it was enhanced through the longitudinal nature of the study, although it should be acknowledged that this can be subjective (Howell 2013). One of the key benefits of the longitudinal approach used in this study was found in the exploration of the themes – each interview improved the clarity of meaning/knowledge – and this was particularly evident when themes were discussed in depth.

4.3.3.1 **Epistemological Perspective – Social Constructivism**

In contemplating my epistemological stance within this study, I needed to select the optimal lens, the one best positioned to interpret the lived experiences of the CYP and their mothers. To understand the complexities of their experiences, social constructivism was selected. This stance, which can be associated with Heidegger's view on interpretation, believes that the individual's reality is partly constructed from culture and language (Smith et al. 2015). Delanty and Strydom (2003, p. 373) added to this by saying that the "social world is socially constructed" and the individual's world is constructed with "cognitive structures". It was also outlined by Flick (2018) that social dialogue/interchange (social phenomenon) is the creation of knowledge, which is influenced by linguistics. Flick (2018) went on to say that research is also a form of social construction of what can be seen in the social world.

In further exploration of social constructivism and in the construction of knowledge from social interactions, Flick (2018) discussed the use of first- and second-degree constructions between text and reality, through which explanations of social phenomenon can lead to the

development of scientific explanations/concepts (second-degree construction). As Flick (2018) considered, this can be problematic due to the subjectivity of the taking the lived experience from a text, and can lead to potential problems with validity, reliability and generalisation. With social constructivism, it is believed that the participants will understand their own reality through meaning/interpretation of experiences and that social research needs to accept this when dealing with social realities. In this study, my constructions of knowledge were based on the answers given during the interviews. First degree constructions can be seen as the participants' views of their illness/recovery, which for my study is their recovery post moderate head injury. From these first-degree constructions, second-degree constructions (which can be seen as scientific knowledge) are formed which are based on my understanding and interpretation (Flick 2018). Delanty and Strydom (2003) highlighted that second-degree constructions can be termed double hermeneutics, where the researcher is attempting to understand the participants' lived experiences, as the participants themselves are trying to understand these experiences. In my study this is incorporated into IPA but also forms part of the hermeneutic circle. The hermeneutic circle is a key theme that is present in hermeneutic research and it presents a non-linear process that is dynamic and explores the connection between the whole and the part (Smith et al. 2009). This cyclic-thought pathway relies on the concept that to understand the whole you need to understand the part and vice versa. These two components are inter-reliant and inter-twined. In this study, the hermeneutic circle provided a way to analyse the transcripts whilst relating the data to the cultural and biopsychosocial elements that contribute to the holistic picture.

The connection between the hermeneutic circle and first- and second-degree constructions are demonstrated in Figure 4-1, together with mimesis (which will be explored in the next paragraph). Figure 4-1 also demonstrates the cyclic nature that exits between the creation of constructions, interpretations and experiences: the constructions are being continually influenced by interpretations and experiences, and vice versa.
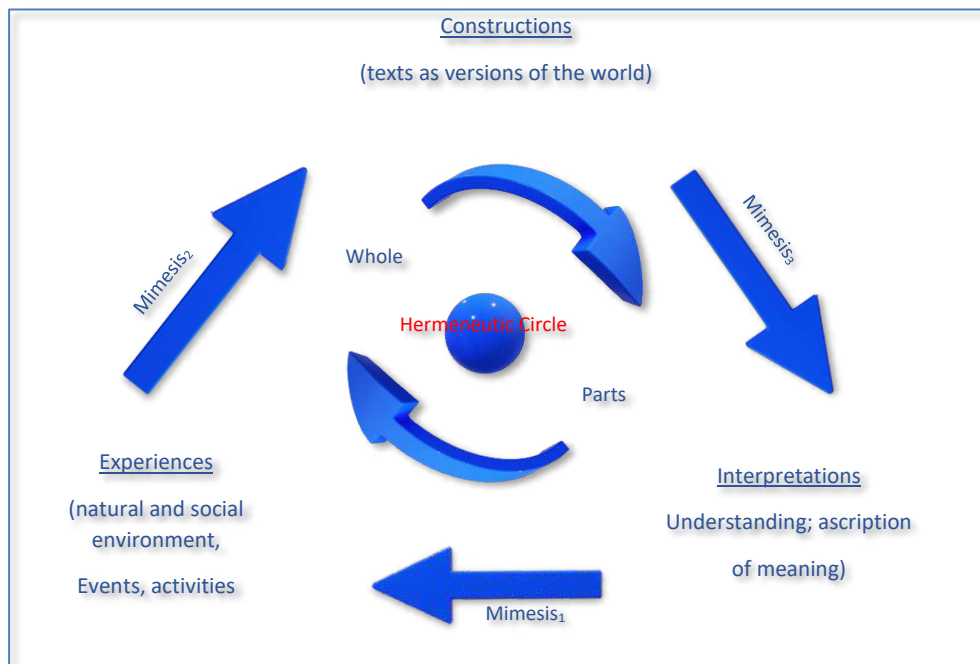
Figure 4-1: Link between Construction, Interpretation, Mimesis and the Hermeneutic Circle. Adapted from Flick (2018)

Mimesis was also discussed by Flick (2018, pp. 71-72); he highlighted the formation of "the natural worlds into symbolic worlds", the formation of narrative/text from experiences and during interpretation, the conversion of this narrative/text into an everyday context. The term "mimesis" was also explained by Gadamer (2013, p. 119): it is not simply a process of imitation, but a cognitive understanding of the essence, a "bringing forth" of knowledge. Whilst cognition will be explored further on in this chapter, Smith et al. (2009) highlighted that cognition is essential for interpretation, sense-making and analysis. This will be demonstrated in this thesis by the interpretation of the interviews, the formation and

understanding of the findings and how these can be best utilised to improve the recovery journey for future moderate head injury sufferers.

This section has explained my epistemological position within this study. By adopting a social constructivist approach, it is possible to add to the scientific literature by the process of first- and second-degree constructions and by understanding that differing social realities exist. Through the co-construction of the participants' realities, it is possible to gain an insight into their lived experiences. By adopting a longitudinal approach to the study, I believe that the co-construction of knowledge will become more effective (as time will add more meaning) whilst exploring the CYP's and mothers lived experiences during their recovery.

4.3.4   Axiology

Axiology was defined by Bourne et al. (2017, p. 1) as a branch of philosophy that considers the question "what is of value?", and it relates to what society views as being good. This study has an important ethical value to future CYP who would have sustained a moderate head injury by improving post head injury support/follow up. The focus of this study was simply to explore the lived experiences of the three participants and the mothers from their perspectives. The axiological stance of this study (which is intertwined with the ontological and epistemological stances) is: to accurately present these lived experiences with the purpose of improving care post-head injury locally and nationally.

4.3.5   Lived Experiences and the Lifeworld

Van Manen (1990) described the term "lived experience" within phenomenological research as referring to an instantaneous pre-reflective awareness – an awareness we have before reflecting on experience. The lived experience is the start and end of any phenomenological research and, to fully understand the participants' phenomena (experiences), a sense of immersion should exist (Van Manen 1990). This immersion is achieved by reading and re-reading the transcripts, listening to the audio recordings of the interviews and finally by analysing the transcripts whilst looking for emergent themes. Van Manen (1990) also mentioned that lived experiences are hermeneutically important: words and phrases allow the researcher an insight into the patient's journey.

Galvin and Todres (2013, pp. 27-28) stated that the lifeworld concept was discussed by Husserl, with it including basic components of "embodiment, temporality and spatiality". They adapted this concept to a healthcare model, adding "mood" (which is internal, interactive and has an interpretive awareness) and "intersubjectivity" to the existing components. They also added that the lifeworld is a world of lived relationships that are meaningful to the individual. From these perspectives, lived experiences form part of the lifeworld. Understanding these concepts was an important step during my early reading and thinking about the study's design, and they became an integral part of this research. I found them crucially important in understanding how CYP and mothers are affected by a moderate head injury – how their lifeworlds were changed by their lived experiences.

4.3.6   Summary of Theoretical Underpinnings

The above section discussed the theoretical underpinnings used in this study, and social constructivism was introduced as the lens used to interpret the findings from the lived experiences and the lifeworld of this study's CYP and the mothers. The following section will explore the methodology used and how, by choosing IPA, the lived experiences were analysed in depth.

4.4   Rationale for Study Methodology

This section will provide an overview of IPA, its components and why was it selected for my study.   A critique of IPA will also be discussed followed by a summary of this section.

4.4.1   Interpretative Phenomenological Analysis

Biggerstaff and Thompson (2008) stated that IPA was developed by Jonathan Smith as a method to understand the idiographic subjectiveness of a person's experiences. IPA comprises three main components: phenomenology, hermeneutics and idiography (Smith et al. 2009). Fade (2007) added that IPA originated partly in health psychology and has its foundations in the social cognition paradigm, in which "social" relates to relationships and "cognition", to the way we think (Bennett 2015). The social-cognition-paradigm concept reflects these three aspects and is also influenced by human behaviour and speech (Fade 2007). The following sections will explore the three main components of IPA.

4.4.1.1 **Phenomenology**

Smith et al. (2009, p. 13) described phenomenology as a "philosophical approach to the study of experience" and stated its main contributory philosophers to be Husserl, Heidegger, Merleau-Ponty, Sartre and Gadamer.

Husserl, a German philosopher, asserted that experiences should be carefully examined. Van Manen (2016) described Husserl as the philosophical founder of phenomenology. Smith et al. (2009, p. 12) portrayed Husserl's description of phenomenology as an "experiential content of consciousness" by which the observer removes themselves from everyday experience and adopts a reflexive approach. For this to happen, Husserl developed the phenomenological method, which involves separating oneself from the world we take for granted and then concentrating on the perception of that world (Smith et al. 2009). Husserl also developed the concept of time-consciousness, which Vessey (2007, p. 1) described as a "fundamental level of consciousness, in that any consciousness is consciousness of a temporal object or event" and which Mölder (2014, p. 48) described as "temporal experience". Vessey (2007, p. 1) also added that "fundamental level of consciousness" is one of the central concepts in phenomenology and points to how a person interprets meaning at a single point in time, though taking into account previous experiences, the present and the possible future – in practice this points to the continuing change in sense-making as time is constant, which influences how we interpret experiences. For my study it emphasises the value of collecting data in real time as this captures the participants' experiences at that point and which have not been influenced by the movement of time.

Heidegger, who was a student of Husserl, commenced work that moved away from Husserl's transcendental approach (the consciousness content) and leant more towards hermeneutics. Hermeneutics can be seen as reflecting on a lived experience (Van Manen 2016), and Smith et al. (2015) added that it is a theory of interpretation. Heidegger was more concerned with the "ontological question of existence", which can be simply viewed as what is "possible and meaningful" with respect to human relationships and activities (Smith et al. 2009, pp. 16-17). Central to Heidegger's thinking is phenomenological intersubjectivity and the "person in context" theme: understanding how someone fits in the world is multifactorial and draws on self-reflection, social engagement, and temporal and social understanding. Heidegger moved away from Husserl's narrative phenomenology towards an interpretative one. These, together with language, relationships and sense-making activities, are central to IPA.

Merleau-Ponty hypothesised that as humans we see ourselves as observers in the world and are holistic beings (Smith and Osborn 2015). Merleau-Ponty went on to say that one's perspective of someone else's experiences is ultimately influenced by one's own experiences. He discussed the role of the perception that a person uses to understand the world rather than simply engage with it.

Smith et al. (2009) discussed Sartre, who said that human beings seek meaning that is often action-orientated. Humans are self-conscious, which is how we engage with the world that we inhabit. Sartre was not just concerned with things that are visible but also the things that are absent – "nothingness"– and viewed the latter as equally important (Smith et al. 2009). With respect to IPA, Sartre can be seen to extend the concepts introduced by Heidegger,

discussing the social and personal experiences of one's self and how this connects or not with other people.

Gadamer is also an influential philosopher within phenomenology who, according to Smith et al. (2009), concerned himself with the importance of tradition and history in the interpretative process. Gadamer recognised the complexities that exist between the interpreter and interpreted (Smith et al. 2009), which is supported Heidegger's approach. And, like Heidegger, he was a follower of the "time-consciousness" concept, which Vessey (2007) stated is intrinsically linked to experience. Importantly for my study, Vessey (2007) also discussed the concepts of temporality and how "time-consciousness" can change over different time frames and discussed the concepts of "varied horizons" and "a horizon of understanding". "Horizon", in this context, refers to the "totality of all that can be realised or thought about by a person at a given time in history" (Clark et al. 2008, p. 58). Gadamer also introduced the concept "fusion of horizons", in which the new horizon is influenced by the previous one. Gadamer's concepts of "horizons" are visible throughout my study as the exploration of the lived experiences of the CYP and the mothers at different time frames reveal different perspectives.

My study explored the experiences of CYP who had suffered a head injury and were trying to make sense of what had happened to them being influenced by *Dasein* which Inwood (1997) describes as coming from the verb "to exist or to be there, to be here" and it can be seen as the "existence of an entity". Bennett (2015) referred to *Dasein* as the relationship between the world and the self ("self" refers to animate and inanimate entities within the world), with neither being able to exist in isolation. My study explored the experiences of the mothers

together with their sons and daughter and the way in which these experiences were interrelated, or not. This is evident throughout the interviews and the discussion of their analyses. This is a reiteration that people do not exist in social isolation as separate entities but live in a shared world with other people. Temporality is another concept that is significant for this study and is discussed by Heidegger (Inwood 1997). All the interviews were undertaken in real time and reviewed longitudinally as memories can be influenced over time by external factors. By carrying out the interviews in real time, it was hoped to achieve "authentic temporality" (Inwood 1997): the CYP's and their mothers' perceptions are influenced by their past and the present, and will influence their future. If these interviews were carried out retrospectively then, according to Heidegger's theory, their perceptions of their quality of life would be altered or imprecise.

Understanding the CYP's and their mothers' perspectives of their recovery post head injury is vitally important in planning family-based care and in delivering care where it is most needed. As will be shown later, IPA as a methodology allowed an understanding to emerge of how the CYP's perceptions of their "self" changed and how their mothers perceived and experienced their CYP's head injury. Phenomenology, the study of phenomena, is best suited to explore this concept.

4.4.1.2 Hermeneutics

Hermeneutics, a major component of IPA, can be seen as the "art and science of interpretation" (Tuffour 2017, p. 3) and concerns the analysis of the research data. Ricoeur discussed a link between language and experience (Tuffour 2017): language can be seen as an expression of the lived experience as well as being descriptive. Thus Tuffour (2017, p. 4)

explained that meanings are reconstructed through "textual interpretation" which are viewed by a subjective approach.

IPA uses the concept of double hermeneutics (Smith and Osborn 2015), which considers how the researcher tries to understand the life experiences of the participant, who, in turn, is trying to understand the events that have happened to them. In my study, I tried to ascertain the lived experiences of the CYP who was still trying to understand both the moderate head injury that they suffered and the consequences of that head injury. Smith et al. (2009) also mentioned that the researcher has two personas: firstly, the researcher can be seen as a person with their own lived experiences and as a participant within the research; secondly, the researcher is allowed access to the participant's lived experiences via the interview/information given by the participant. This information is then interpreted by the researcher through their "lens", which can be seen as an interpretation derived from the researcher's own perspective, understanding and lived experience.

My study explores the concept of double hermeneutics from two different perspectives. Within my study, I became curious about each mother's interpretation of their son's or daughter's head injury as well as the CYP's own interpretation of that injury. This fits in well with the lifeworld approach as individuals are not single entities, existing in isolation, but are part of a complex social system, often with their own social discourse. Interpreting the interview transcripts of both the CYP and their mothers added to the "part and the whole" (hermeneutic circle), which for this study provided rich valuable data.

4.4.1.3 **Idiography**

According to Smith (2004), IPA has a strong idiographic component to it. Pietkiewicz and Smith (2014) described idiography as an in-depth analysis of each individual case that should be undertaken before any generalised comments are made by the researcher. It is a focus on the particular as opposed to a more generalised viewpoint. This is reinforced by Smith et al. (2009) who also added that there are two levels: the first highlights the need for detail and the second explores how the participant understands their lived experience (the phenomena). Smith et al. (2009) further explained that as IPA is idiographic which is best suited to smaller studies.

Idiography is well suited to this study's longitudinal approach, because it is possible to compare and contrast themes using the interview/transcript narrative. This approach has been supported by Shaw et al. (2016) who also added that idiography is appropriate for phenomenological studies. Whilst Shaw et al. (2016) focussed on social housing, and interviewed participants up to 18 months after they started to live in social housing, they agreed that idiography also correlates well with the lifeworld concept. Zeiders et al. (2015) also used a longitudinal idiographic approach in their study, analysing socio-cultural stressors across a five-year period. These academic papers highlight the appropriateness of using an idiographic approach in longitudinal studies that wish to explore themes across time and the way themes are shared between participants.

4.4.2 IPA and Social Constructivism

Quality of Life (QoL) was initially selected as a way to explore the impact of the head injury on CYP and it became an umbrella term for what was more important: the lived experience.

To understand the full extent of this experience and to examine it comprehensively, IPA appeared the most appropriate approach to analyse a homogeneous group's experiences of a common phenomenon: recovery from a moderate head injury. Smith et al. (2009) described their guidance on IPA as a template empowering the researcher to adapt this approach. Understanding that the IPA has flexibility, allowed me to address the research question, by using a Children's Advisory Group (CAG) in the research design phase and to collect the data longitudinally. It is this longitudinal approach that tells the story of how the CYP's recovery progressed as time passed.

4.4.3   Choosing IPA

When choosing the appropriate methodological approach, several non-phenomenological approaches were considered. Grounded Theory was rejected as a methodology due to the need for a saturation point (when nothing else is learnt) in constructing a theory and because Bryant and Charmaz (2007) suggested a need for 20–30 interviews, which was not possible with the potential recruitment numbers for my study. Ethnography, which is useful in exploring culture and is similar to Grounded Theory, was also turned down due to the potential issues with theoretical saturation (Bryman 2016). Also, both grounded theory and ethnography were not suitable candidates for addressing the research question which looked at the lived experiences of CYP and the mothers post moderate head injury.

An in-depth enquiry into the lived experiences of each of the participant's experiences was sought and therefore a phenomenological approach was adopted for my study. This will be discussed in this section.

As discussed by Smith et al. (2009), IPA is not the only phenomenological approach in qualitative research. Phenomenology can be split into two main forms: transcendental/ descriptive and hermeneutic/interpretive (Neubauer et al. 2019). The key differences between descriptive and interpretive phenomenology are summarised in Table 3.1.

Table 4.1: Differences Between Descriptive and Interpretive Phenomenology – adapted from Wojnar and Swanson (2007), and Neubauer et al. (2019).

Descriptive Phenomenology	Interpretive Phenomenology
Philosophical origin: Husserl	Philosophical origin: Heidegger and Gadamer
Emphasis is on describing universal essences.	Emphasis is on understanding the phenomena in context.
Viewing a person as one representative of the world in which he/she lives.	Viewing a person as a self-interpretive being.
Reality is internal to the knower	Understanding lived experiences is an interpretative process positioned within the lifeworld
A belief that the consciousness is what humans share.	A belief that the contexts of culture, practice and language are what humans share.
Self-reflection and conscious "stripping" of previous knowledge help to enable an investigator-free description of the phenomenon.	As pre-reflexive beings, researchers actively co-create interpretations of phenomenon.
Adherence to established scientific rigor ensures description of universal essences or eidetic structures.	One needs to establish contextual criteria for trustworthiness of co-created interpretations.
Bracketing ensures that interpretation is free of bias.	Understanding and co-creation by the researcher and the participants are what makes interpretation meaningful.

In keeping with the aims of my study, an interpretive stance was taken and, as such, this study moved beyond the descriptive level of enquiry to one where knowledge is co-constructed. Furthermore, I was interested in (1) exploring the "patient journey" and the experiences of their mothers idiographically (including their lived experiences), and examining the phenomenon in context (recovery post head injury and parental views), and (2) understanding that the CYP and their mothers are self-interpretative and will have their own thoughts that reflect their view of social reality, and whilst recognising the co-creation of knowledge by myself, the CYP and their mothers. These four things support the interpretative

stance. In shaping and improving care, the voices of the CYP together with their mothers is pivotal because care needs to be centred around what they feel is needed. This is essential for an efficient and holistic healthcare service that is patient focussed – which I see as the main aim of undertaking a Professional Doctorate, a viewpoint supported by Griffiths et al. (2010). IPA is an approach that looks at human experience and can shape healthcare (including policy and practice).

4.4.3.1 IPA as a Methodology – a Critique

It is possible to critique, in some form, most methodologies. IPA is not an exception to this. However, IPA does offer a "good fit" in that the lived experiences of the participants are the focus of the research, the sample size is small and I was interested in forming new knowledge that was co-constructed with CYP and mothers – moving away from a descriptive approach. As a novice researcher, IPA also offered a structured way of examining/exploring the participants lived experiences and finding meaning within these.

Table 4.2 gives a brief overview of how Tuffour (2017) viewed IPA as being criticised. Each criticism will be further explored after the table.

Table 4.2: Criticism of IPA as Outlined by Tuffour (2017).

Criticism 1	Language is not integrally recognised
Criticism 2	Can IPA precisely capture the meaning of experience?
Criticism 3	IPA focusses on perception – views can be problematic and limited by understanding.
Criticism 4	Focus on cognition is not compatible with phenomenology

In discussing the first criticism from Table 4.2, that the use of language is not integrally recognised, both Tuffour (2017) and Smith et al. (2009) highlight that meaning is intertwined with language through discourse and narrative. Smith et al. (2009, p. 194) referenced

Heidegger, saying that "language as the 'house of being'" and that "interpretations of experience are always shaped, limited and enabled by language". IPA can be seen in part as a cultural enquiry of "the person", where language is viewed as being hermeneutic, contextual and idiographic – "an interpretation of the meaning for a particular person in a particular context" (Smith et al. 2009, p. 195).

With the second criticism, Tuffour (2017) highlighted the issue of whether IPA can fully encapsulate the participant's experience or only present mere opinions. This can be seen as an elitist viewpoint as it questions whether the researcher and participant have the "requisite communication skills to successfully communicate the nuances of experiences" (Tuffour 2017, p. 4).   Tuffour (2017) does not address this criticism but raises it awareness to the reader.

The third criticism is that IPA uses idiography together with hermeneutics in order to comprehend the cultural position of the participant's experiences (Smith et al. 2009). Tuffour (2017) answers the criticism, that phenomenology only explores the lived experience and not the cause, by saying that IPA looks at the reasons behind the lived experience, which are positioned in histories, past events and in the social-cultural domain.

The fourth and final criticism mentioned by Tuffour (2017) outlined that some aspects of phenomenology are not compatible with cognition (and are poorly understood). Comments by Smith et al. (2009) have rebuffed this, saying that IPA, through its role of sense- and meaning-making together with reflection, is similar to cognitive psychology. Smith et al. (2009) also mentioned that cognition is involved in the pre-reflective, reflective and

hermeneutic aspects of IPA – examples of this include analysis, sense-making and interpretation, formalising a link with theory (process of undertaking IPA), more reflection, awareness, intuitive reflection, "hot cognition", rumination, and meaning-making. Smith et al. (2009) described cognition as a dynamic process, one that is emotional and embodied. Hot cognition refers to emotion-based reasoning whilst cold (cool) cognition indicates the cognitive processing of information that is independent of emotion (Anstey 2012).

Tuffour (2017) makes several valuable points contributing to ongoing discussions within IPA, which have been discussed in the previous paragraphs. However, the findings and subsequent discussion chapters in this thesis will show that there is a real value to identifying and analysing for example, emotions, narrative and discourse, as these allow the researcher to fully appreciate and communicate the meaning of the participants' lived experiences. Examples of this would be in the interpretation of metaphors, their meaning and where hot or cold cognition can be used to interpret the lived experience of the participants. The alternative would be a rather more sanitised and superficial version of the participants' lifeworld and how it is affected by a moderate head injury.

4.4.4   Summary of Methodology Rationale

This section has discussed IPA as the methodology of choice for my study. IPA offers a strong idiographic focus as well as the ability to explore the lived experiences of each participant. By developing an in-depth focus, by understanding the experiences of the CYP and their mothers during the recovery process, and by credibly analysing the data from the interviews, it is possible to shape and improve healthcare provision for future head injury sufferers.

The following section will discuss the development of the Children's Advisory Group and the role that they played in the research design.

4.5 The Development and Important Role of the Children's Advisory Group (CAG)

This study established a Children's Advisory Group (CAG), who were instrumental in developing tools to help facilitate data collection with CYP. This section will therefore outline the important role that they played together with ethical considerations which needed to be considered.

Benefits of public involvement throughout all stages of the research process have been suggested (Grant and Ramcharan (2010), Coyne and Carter (2018)) – these include identifying research priorities and the development of appropriate outcomes; empowerment; and better assessment of outcomes. Bailey et al. (2015) asserted that CYP have the right to be involved in research, a position which was also supported by INVOLVE (2012) (especially when that research includes CYP within its focus), and that they have the capacity to offer unique perspectives. Grant and Ramcharan (2010) described three types of research – traditional, participatory and emancipatory. In traditional research approaches, public involvement has not always held an important place whereas in participatory research methods there is a strong partnership between the researcher and the public. With emancipatory research, the research is owned by service users and is often focussed on changing people's lives and social circumstances. Most public involvement is participatory but not all participatory research is evenly weighted between the researcher and the public (Grant and Ramcharan 2010). The role of public involvement in research has also been endorsed in UK government policy, as utilisation of the user voice in research is now

fundamental to the work of the NIHR (National Institute for Health Research) and the HRA (Health Research Authority) (Grant and Ramcharan 2010; Snodin et al. 2016). Robertson et al. (2014) highlighted that co-design, the inclusion of CYP into improvements into patient care, should be seen as the gold standard. As this study is fundamentally about improving patient follow-up care, this further emphasises the need for public involvement and the involvement of CYP.

Involving CYP in research needs to be undertaken in an ethical way even though there is no formal requirements for ethical approval (Mitchell et al. 2019). INVOLVE (2019, p. 13) has identified four main benefits of the inclusion of CYP in research:

- "ensuring that the research is relevant"

- "helping develop materials that were appropriate"

- "improving tools and data analysis"

- "increasing the self-esteem of those involved".

To best incorporate CYP into this study in a way that is consistent with adopting an IPA approach, I decided to establish a Children's Advisory Group (CAG). The CAG played an important role in influencing how the semi-structured interviews were undertaken by helping with language, nuances (for example, age appropriate meaning) which helped in gaining rich data and for myself to understand this data in a small homogeneous group. CYP can be seen as "an independent social group with their own culture, characteristics and meaning" (Brady 2006, p. 2). According to Shaw et al. (2011), involving CYP in an advisory capacity within a study can keep the researcher mindful of a CYP's perspective. This has been supported by Coad et al. (2015) and Snodin et al. (2016), who both added that this can help with

recruitment, ensuring the study is communicated in the right way and is appropriate for the target audience. For example, acting on feedback from the CAG, this study's semi-structured questions were adjusted to make them more age/developmentally appropriate. The creation of the happiness scale (which was used as an ice breaker) was also formed because of feedback from the CAG, together with the flash cards (used for prompts to help the participants decide what aspects of QoL were important to them). Undertaking interview role play (which helped me pitch my questions correctly), followed by a general discussion around the interview structure, helped with improved engagement with the interview participants, but also formed a sharing environment within the advisory group that was informative to both parties.

Table 4.3 gives an example of an ethical approach to Patient and Public Involvement (PPI) (Mitchell et al. 2019). This step-by-step guide will be discussed in relation to my study, even though my involvement with the CAG/PPI predates this guidance, the following sections will demonstrate that my PPI involvement with the CAG was ethical and, as a researcher, I adhered to these ethical principles.

Table 4.3: Ethical Approach to PPI; Adapted from Mitchell et al. (2019).

Step	Ethical Approach
1	Prioritise PPI with CYP
2	Agree language and work towards a shared understanding of tasks
3	Gain consent for PPI
4	Maximise the benefits for PPI members
5	Minimise the risk of harm
6	Ensure equity of access to PPI
7	Provide training for the researcher
8	Offer training for the PPI group
9	Provide funding and recognition

Step 1: Prioritise PPI with CYP

Step 1 from Table 4.3 covers the fact that CYP need to be prioritised within research. Elements of this have been briefly discussed but, adding to this, Mitchell et al. (2019) said that CYP want their involvement to have an impact and that this can be difficult as the viewpoint of the CYP might be different to that of the researcher. Mitchell et al. (2019, p. 196) also referenced Article 12 of the UN Convention on the Rights of the Child, emphasising that CYP are capable of forming their own views and that these views should be listened to – according to age and maturity.

Considering the target age of those CYP recruited to this study, approaching a local primary school seemed to be the best approach for the formation of the CAG. To create the CAG, I made an appointment with a local primary school to discuss the research project, what the role of the CAG would be and the benefits it would bring to the CYP involved in the research group, thereby evidencing how to effectively use the CAG (Bate et al. 2016). Following this productive meeting, an agreement was arranged for access and the CAG was formed with a Year 5 class, with an age range of 9–10 years. This reflected the approximate mean of the recruitment age. The closeness of age was important as I needed to consider both the neuro-cognitive and psychological variances that occur between age groups. I also wanted the CAG to provide an accurate representation of the participants.

Step 2: Agree language and work towards a shared understanding of tasks

Step 2 points to a number of things: a shared understanding for each allocated task for the CAG; the use of focussed questions; and the need for each task to be given to the CAG in an understandable way, with regular discussions to ensure that these tasks are fully understood

(Mitchell et al. 2019). The first session with the CAG was designed to be interactive: the pupils were encouraged to express their viewpoints and feelings regarding the research methods. A PowerPoint presentation, with discussion, was used to explain the role and aims of the group together with outlining the purpose of the research. Following an active discussion about the aims of the study and the reasons for the research, the group was divided into subgroups and these were given the task of developing a happiness scale, which would be used during data collection as an ice breaker and a way of developing rapport.

The development of the scale was paramount to the research, as this would help in data collection as it created an ice breaker and a way to discuss things that were important to the participants. As a result, I placed an emphasis on how the scale was going to be used (see "Data Collection", section 5.2). To help in creating a useable tool, examples of other tools were shown on PowerPoint slides. The overall aims were: guide the group, let their imaginations "run" and evaluate the end product. The larger group then separated into smaller groups, with the pupils deciding who they worked with. To help the groups, templates were drawn on to pieces of paper outlining a circular smiley face, which they then filled in (see Appendix 2). This helped to create some uniformity and comparability between the groups and also helped with getting an end product within the time allowed for each session.

During the group work, I noted that some of the groups were creating pain scales as opposed to happiness scales. At this point, the groups were called back, and further instructions were given as to the purpose of the scale (Appendix 3 shows the scale). Near the end of this session, each group's work was collected with the aim of merging the scales into one that could be universally agreed upon by the pupils during feedback at the next session. The last

piece of work that each group completed was a list of activities (and/or things) that were important to them as individuals or, alternatively, as a collective – in essence, the pupils identified things which were important for their QoL. A PowerPoint slide showed examples, which included activities such as family, football and chocolate. The object was to create a list of QoL factors that could be used as flash cards during the interviews if participants could not think of any or had difficulty in finding five. These flashcards (Appendix 4) proved to be useful in the interviews and were used as prompts.

Between this first session and the second, a month later, the CAG's work was examined, with each happiness scale contributing to the draft final version and the draft flash cards were created from the CAG's feedback. During the second meeting, these were shown to the group as a whole and discussed. The final happiness scale and flash cards were then collectively agreed by the group (Appendices 3 and 4). Once this was settled, the next aim for that session was to discuss the interview questions and sequencing, a process that was informed by an existing QoL scale called SEIQoL (O'Boyle et al. 1993), which was adjusted for interviewing CYP and for the differences in the research methodology. This was undertaken in a large group with all the participating pupils; the interview sequence was discussed together with the wording and interpretation of the questions. Role plays were also undertaken with a few of the pupils to see if the questions were fully understood, and their responses were gauged in preparation for the research participants' interviews. This exercise clearly demonstrated that the questions had to be simplified. An example of this is:

First look at this box (indicate). As you can see, there are spaces at the bottom in which I can write five important life areas of my life (indicate), and there is a scale along the left hand side (indicate). The scale ranges from "worst possible" on the bottom to "best possible" on the top, and passes through

levels such as "very bad" – "bad" – "neither good nor bad" – "good" – and "very good" between the two extremes (O'Boyle et al. 1993).

Was adapted to:

First look at this scale (indicate). As you can see, there is space at the bottom in which I can write five important life areas of my life (indicate). The scale ranges from "Very Happy" on the left to "Very Sad" on the right and passes through levels such as "Happy" – "Okay" (neither happy or sad) – and "Sad".

At the end of this session, the Participant Information Sheet (Appendix 7) was shown to the group and discussed. Selective questioning was used to test understanding and suitability, and, where appropriate, words and phrases were changed to make it more readable.

At this point the steering role of the CAG was completed as their role was to assist in the study's design. Further involvement of the CAG, for example to discuss early findings from the interviews, did not occur due a potential conflict with using the IPA approach. If the peer group reviewed the findings, each pupil would form their own interpretation of the participants' narratives. This could have led to eighteen different interpretations, which, whilst being interesting, would have gone beyond the scope of this research. Instead, my analysis and findings were fed back to the group, followed by a question and answer session, which had the positive aspect of giving them closure for their hard work.

Step 3: Gain consent for PPI

Gaining consent for PPI/CAG involvement is the subject of Step 3 (Table 4.3). Mitchell et al. (2019) and McDonagh and Bateman (2012) highlighted that informed consent should be

carefully considered especially with topics that are sensitive and when participants are under the age of 16 years old. Mitchell et al. (2019) also highlighted that verbal consent (assent) should be considered and that each individual within the PPI/CAG can make the choice to opt out, which was also supported by Bate et al. (2016). Before the CAG's work was possible, consent was sought from parents (see Appendix 5) for their CYP to be involved.

Parents were provided with an overview of the research, together with the consent form, which were written in conjunction with the school and which adhered to the school's educational guidelines for participatory research. These consent forms were distributed by the school to a class of 31 pupils, with the aim of recruiting a minimum of 12 because I proposed that the pupils would work in small groups and in class discussions. However, a total of 18 pupils were given parental consent to participate and all were included. The completed consent forms were then kept at the school for information security and confidentiality purposes.

In partnership with the school, it was agreed that all the sessions would be carried out during the school day as part of their usual lessons and vary between 1 and 1.5 hours in duration. As a result, the pupils did not lose any of their recreational time. In addition, the school viewed this as an educational opportunity for the pupils. The sessions were carried out in the year group's classroom. The pupils whose parents did not provide written consent were taken by the teacher into another classroom to undertake separate activities. Chaperoning was provided at regular intervals throughout the session, as the teacher came to check on the pupils and myself. A letter of access (Appendix 6) was supplied by the school to evidence the school's acceptance of being involved in the research.

Step 4: Maximise the benefits for PPI members

With Step 4 of Table 4.3, Mitchell et al. (2019) highlighted the gain that members of the PPI/CAG should obtain from their involvement. In my study, the CAG involvement was during the design phase but nevertheless they did gain from the experience. From the early stages of my involvement with the PPI/CAG, a dual process of learning and teaching was utilised. I, in managing the CAG, provided education on what research was (as supported by (Bate et al. 2016)), together with brief overview of head injuries (in an age-and-development-appropriate way). Appropriate guidance was provided so the group could create the happiness scale (Appendix 3) and the flash cards (which were used in identifying what was important to each of the CYP and how they rated it – see Appendix 4), and take part in the re-wording of the interview schedule and interview role play. During the last session with the CAG, the class teacher was present throughout and verbal feedback from the school indicated that they saw this as an educational experience for the pupils who were involved. In this final session, the CAG and teacher were provided with a recap of the work the group had done together with a thematic overview of the findings, in an attempt to illustrate to the CAG how CYP are affected by moderate head injuries. Emphasis was placed on the positive contribution that the CAG brought to the study and the potential benefits that this will bring to future CYP who suffer from moderate head injuries, by improving care and follow-up. Providing feedback to the CAG is supported by Bate et al. (2016).

Step 5: Minimise the risk of harm

The next step in the process, "Minimise the risk of harm", is crucial. Mitchell et al. (2019) highlighted that discussing sensitive topics has the potential to harm members of the CAG.

They carried out a risk assessment of the potential issues and discussed the need to support members of the PPI group (Mitchell et al. 2019, p. 198). From the first meeting with the school, which was initially with the headmistress and later with the class teacher, the issue of the sensitivity of the topic was discussed. My sessions with the CAG were intermittently chaperoned (the class teacher would come in for part of the session to ensure that the CYP were okay) and in the final session the class teacher was present throughout. The class teacher also gained verbal feedback from the group after I had left, so they could talk freely; this feedback was always positive and no problems were identified. I utilised my professional and personal experience – I am a paediatric nurse, have taught in a school and am a father (with a CYP of the same age as the CAG's members) – to continually monitor for signs of distress, but throughout the sessions I did not detect any. Instead, I received positive feedback from the group, who enjoyed their involvement.

Step 6: Ensure equity of access to PPI

With this step, the entirety of the class was invited to partake in the formation of the CAG. I acknowledge that a larger group might have provided more unique insights; however, the group size was manageable and worked cohesively together. Positively, working with a community such as a school as part of PPI is supported by Robertson et al. (2014).

Step 7: Training for the Researcher

Concerning Step 7, my training as the researcher, I drew upon my previous teaching experience (I hold a postgraduate teaching qualification), together with my experience as a clinical nurse specialist and father; this enabled me to facilitate the group.

Step 8: Training for the CAG

Mitchell et al. (2019) mentioned the need for training but also spoke of allowing the group to develop and design their own research. As previously discussed, members of the CAG generated, with minimal guidance, the happiness scale and flash cards, and assisted with the interview schedule. This allowed them the opportunity to provide valuable insights.

Step 9: Funding and Recognition

Recognition was first supplied by acknowledgment in the Participant Information Sheet and will be continued by the publication of this thesis and by the possible presentation of findings at local and national events.

4.5.1 Reflexivity – CAG

The CAG had the main function of aiding the research design, and providing a voice for CYP, but my role in facilitating the group was also important. Being a qualified paediatric nurse with 25 years of experience of talking to CYP professionally, together with my experience of spending a year in secondary school teaching, helped me to feel comfortable working with working with the CAG, letting them work freely with their thoughts and ideas. This consequently had a positive effect on the input generated from the CAG and their influence on the research design.

4.6 Summary

This chapter has covered my study aims and objectives followed by the study's theoretical underpinnings. Social constructivism was discussed, as well as how it fits in with IPA and, in

particular, with Heidegger and Gadamer. Although it is mentioned throughout, the longitudinal approach of my study was touched upon and can be associated with Gadamer's concept of the "fusion of horizons": seeing subsequent interviews as being part of a journey, being influenced by previous events/horizons.

This chapter has also explored the concept of the lifeworld and the lived experience, and how these can be used to understand the devastating impact that a moderate head injury can have on the CYP and their mothers. This chapter has explored the three components of IPA (phenomenology, hermeneutics and idiography) and discussed them in relation to this study. With social constructivism, this chapter has touched upon the cognitive processes involved in the translation of the interviews into the findings, the cyclic relationship between first- and second-degree constructions. I have also drawn a comparison between this and the hermeneutic circle (Figure 4-1), which is an important component of IPA. Importantly the role of the CAG and how it was developed and facilitated in an ethical way was also explored, along with the positive input this group had on the research design. An example was given of one direct result of role play and interview discussions: the simplification of an interview question. The next chapter will explore this study's research methods, including data collection and analysis.

5 Research Methods

This chapter will explore how CYP and their mothers were recruited to the study, and how data were generated through semi-structured interviews and then analysed using an IPA approach. Research ethics will be discussed with principles such as consent and assent will being explored along with how power was dealt with during the interview process. The duality of the researcher as "insider" and "outsider" was also considered together with confidentiality. But first, this chapter will explore participant recruitment and sampling.

5.1   Recruitment and Sampling

In IPA studies, the number of participants recruited becomes secondary to the richness of the data collected (Smith et al. 2009). In addition, Smith et al. (2009) stated that in research for a Professional Doctorate no more than ten interviews should take place. They justified this by adding that if too many interviews are carried out, problems can arise and the researcher is at risk of being overwhelmed with the amount of data generated. Smith et al. (2009) stated that an effective analysis requires time and reflection, which can be restricted by larger datasets. The following paragraph discusses the recruitment process but, needless to say, the eventual sample size with a total of fifteen interviews, aided an in-depth analysis to be carried out in this thesis.

This longitudinal study was originally designed to recruit between six and ten CYP, allowing for the potential that some CYP may have wished to withdraw from the research study. (Both Teague et al. (2018) and Abshire et al. (2017) highlighted the issue of participant retention and point to some loss even when studies have a high retention number.) I planned to

interview participants four times over nine months: at two weeks and three, six and nine months post discharge. However, it was only possible to recruit three CYP, due to a low number of referrals to the neurosurgical unit and therefore few patients being eligible for the study. As a result, I decided to recruit a parent for each of the participants, which added depth and richness to the data collected and provided a useful perspective on the CYP's lived experiences (this is discussed further below). Two mothers were therefore recruited to the study: Gwen (Betsi's mother) and Ffion (Afan's mother) – Cai's mother chose not to participate. Table 5.1 outlines the 15 interviews undertaken with the participants: Betsi and Afan were interviewed four times, Cai three times (he then chose to withdraw from the study) and each of the mothers two times. This exceeded the recommendations by Smith et al. (2009).

Table 5.1: Number of Participants and their Interviews.

			Time of Interview				**Total Number of Interviews per Participant**	**Total Number of Interviews per Group**
			2 weeks	3 months	6 months	9 months		
Participants	CYP (names)	Cai	Yes	Yes	Yes	No	3	11
		Betsi	Yes	Yes	Yes	Yes	4	
		Afan	Yes	Yes	Yes	Yes	4	
	Mothers (names)	Ffion	No	No	Yes	Yes	2	4
		Gwen	No	No	Yes	Yes	2	
						Total Number of Interviews:		15

Participants were recruited at the local NHS tertiary centre for paediatric neurosurgery and had a neurosurgical and neurological medical evaluation performed. As these evaluations were carried out in a single paediatric tertiary centre, there was some standardisation in the

CYP's clinical assessment (as the CYP would be only admitted under one of three paediatric neurosurgeons). To avoid any sense of coercion being experienced by parents, all recruitment was undertaken by a member of the clinical team – who acted as a "gatekeeper" – rather than by the researcher. Participants were initially identified by either a Paediatric Clinical Nurse Specialist or by a Paediatric Consultant in Neurology or Neurosurgery (the gatekeepers), all of whom had been briefed on the purpose of the research.

By involving gatekeepers in the research design, I was demonstrating awareness of the possible influence of my professional role within the recruitment site. For example, as a Paediatric Clinical Nurse Specialist working within the neurosurgical unit where recruitment was arranged, albeit in an outreach position with limited contact with the ward, I wanted to ensure that the initial recruitment was independent of my involvement. This is similar to Bennett (2015), in which the use of gatekeepers prevented coercion. A gatekeeper can be seen simply as an individual who controls access (Singh and Wassenaar 2016), which in this case was to the CYP and their family. Collings et al. (2016) took this further, describing "the gatekeeper" as a phenomenon whereby the adult (gatekeeper) controls access to the CYP and can be seen as a proxy for consent, provide protection of the CYP and allows them their voice. Collings et al. (2016) also highlighted in their study that gatekeepers can also prevent the recruitment of CYP, and thereby not allowing the voice of the CYP to be heard. Singh and Wassenaar (2016) described the gatekeeper as an undervalued role in the development of research data, also adding that they have a role in ethical behaviour and that the researcher should listen to any concerns generated by them. The following steps were taken when preparing the gatekeepers:

- fully discussed my research study with them

- carried out a PowerPoint presentation covering the main points

- gave a comprehensive "run through" of all the paperwork

- allowed ample time to answer any questions

- reduced the risk of organisational breakdown

- promoted ethical behaviour with the gatekeepers.

To listen to any concerns raised by the gatekeepers, I arranged weekly meetings to answer any questions and to discuss updates.

When a CYP was admitted who met the inclusion criteria (see next section), the healthcare professional asked the families if their contact details could be sent to the researcher. If the family agreed, they were contacted, and I provided more information and eventually arranging the initial interview. Participant information sheets were given to the CYP and their families; these were approved by an NHS Research Ethics Committee and by the Research and Development department at the tertiary centre, and clearly outlined the purpose of the research together with additional information (see Appendices 7 (Participant Information Sheet) and 8 (Parent Information Sheet)). Written consent was obtained from the parent/guardian whilst the CYP was still an in-patient or at the first interview. Copies of the consent forms were kept in the medical notes and the research file, and another copy was also given to the parent/guardian – see section 5.4.1.

Purposive homogeneous sampling was used for the recruitment process: all the participants met the study's inclusion criteria. This is an approach supported by Smith et al. (2009) in IPA studies as it allows for the detailed psychological variability within a given group. I decided

on this approach in order to explore the lived experiences of CYP who had suffered a moderate head injury – a defined homogeneous group (see Table 5.2). I wanted to explore how each participant recovered over time, and what similarities and differences existed between the members of the group. Constructing a robust research design that includes appropriate sampling and recruitment, according to Smith et al. (2009), means that theoretical transferability can take place. Generalisation, however, is difficult with homogeneous groupings. The aim for my study was to ensure that my findings are considered transferable to other clinical settings by the reader.

Table 5.2: Overview of the Participating CYP.

	Sex	Age	Cause of heady injury
Cai	Male	13 years old	Came off bike and hit head on road/pavement
Betsi	Female	11 years old	Road Traffic Collision – hit by car
Afan	Male	11 years old	Road Traffic Collision – hit by car

During the data collection stage of my study, I decided to incorporate the mothers into the study. Part of the reasoning behind was that one of the mothers wanted to be included in the study (Ffion) as she saw this as an important piece of research; another part was my interest in how the mothers saw their son's/daughter's lived experiences during their recovery, in order to add richness top the data; and lastly, it increased the number of participants. This necessitated a revised consent form (Appendix 9) together with a major amendment to my ethics form. Previous studies by Dancyger et al. (2010) and Larkin et al. (2018) highlighted that it is possible within IPA to look at multiple perspectives in order to further understand the shared experience. As a result, purposive sampling was used to recruit the mothers (Ffion and Gwen – see Table 5.3) and they were interviewed at six and nine months.

Table 5.3: Overview of the Participating Mothers.

	Mother to	Age (years)
Ffion	Afan	Approximate early 40s
Gwen	Betsi	Approximate late 30s

5.1.1 Participant Inclusion and Exclusion Criteria

The inclusion criteria for recruitment into my study were CYP aged between 6 and 13 years inclusively at the time of the head injury. This range links with Piaget's Concrete operational stage of development (6 years to about 12 years), one of four stages of development and the one in which CYP start to think During this stage, CYP begin to think logically about concrete events, thinking becomes more organised and logical, and they start to use inductive logic (Feldman 2004). This area of development also forms an area that is poorly researched in head injury recovery. The inclusion criteria also included a GCS score of between 9 and 12 inclusively, thereby indicating a moderate head injury. This decision regarding recruitment was taken in conjunction with the neurology and neurosurgical teams as I saw this as way to reduce any recruitment error associated with the GCS score. As a translation service could not be supplied, the CYP's first language had to be either English or Welsh (or their English/Welsh needed to be understood without the aid of an interpreter), which reflected the languages that I could speak and am familiar with. CYP were only included in the study if the parent(s)/guardian(s) could provide written consent. Mothers were included in the study providing that they were willing and signed the consent form.

Exclusion criteria included any ongoing litigation cases as a result of the head injury; this was for legal reasons, making recruitment inadvisable as it could potentially lead to data biases which could have affected the results. The legal complexities in "looked after children" meant that they were also excluded due to the potential problems with obtaining consent (for

example, a fostered CYP's "parental consent" remains with social services, as they are the legal guardians, but the social worker may not be present during the consent process for the CYP, who may still live with a foster family) and the possibility of the CYP having to change home address because of potential changes to foster homes. These issues could have created difficulties in achieving longitudinal interviews.

5.2   Data Collection

In IPA studies, which as previously explained have a phenomenological foundation, data are collected via interviews. For my data collection, I chose to use semi-structured interviews to enable this data collection. Appendix 10 shows the interview schedule for the first interview, with an amended version for all subsequent interviews.

Harrell and Bradley (2009) discussed the advantages of semi-structured interviews and highlighted that even though the questions remain the same for all participants (which can help with standardisation) their order can be adjusted by the interviewer with the benefit that a conversational approach can be used if necessary. Semi-structured interviews also enable the interviewer to explore points of interest in more depth (Harrell and Bradley 2009) whilst allowing the participants to talk about topics that are important to them. This flexibility was evident in the study by Maltby et al. (2010), enabling a "tunnelling down" approach whereby emergent issues of interest during the interview could be further explored. Harrell and Bradley (2009) also suggested that a conversational approach during interviews can be effective when interviewing CYP, as the direct approach is not always the best way of obtaining engagement. Tappen (2016) added that semi-structured interviews allow the

interviewer an opportunity both to explore the answers received from the interviewee and to take notes (context and interaction) for future analysis.

The first interview of my study was carried out within two weeks of the CYP's discharge, with subsequent interviews at three, six and nine months – and at six and nine months for the mothers. The semi-structured interviews for the CYP followed a topic guide (see Appendix 10), which was initially loosely based on the SEIQoL instrument (O'Boyle et al. 1993) before being amended in conjunction with the Children's Advisory Group (CAG) to fit the research design and the target population. As a result, the questions were mostly open, with appropriate adjustments made for the CYP's understanding and cognitive capability during the interview.

Analogue scales, in the form of a happiness scale, were used to guide the discussion. Each happiness scale had three options and the CYP, depending on their preference, used either the "smiley" faces, the chosen words (such as sad or happy) or a numerical scale of even numbers from two to ten (see Figure 5-1). The role of the happiness scale was multi-faceted: it was used to help the participant identify and apply a score to their QoL (which was not collected as research data) in addition to being used as an ice breaker and to encourage conversation. This helped to build rapport, which is a complicated process that started before the interview and is integral to a trustful, respectful relationship (Maltby et al. 2010). If the CYP was unable to select or think of a QoL factor, flash cards that were generated as prompts by the CAG were used (see Appendix 4).

As previously stated, the "score" generated by the happiness scale was used solely as a discussion point rather than a formal quantitative measure. One scale was used for each QoL factor selected by the CYP. Five scales were used per interview, and the QoL domains picked were then discussed during the first interview. For subsequent interviews, comparisons were made to the previous interview(s) and differences that were identified were discussed within this interview. Using this method resulted in each interview becoming bespoke for that time frame.

Happiness Scale

2	4	6	8	10
Very Happy	Happy	Okay	Sad	Very Sad
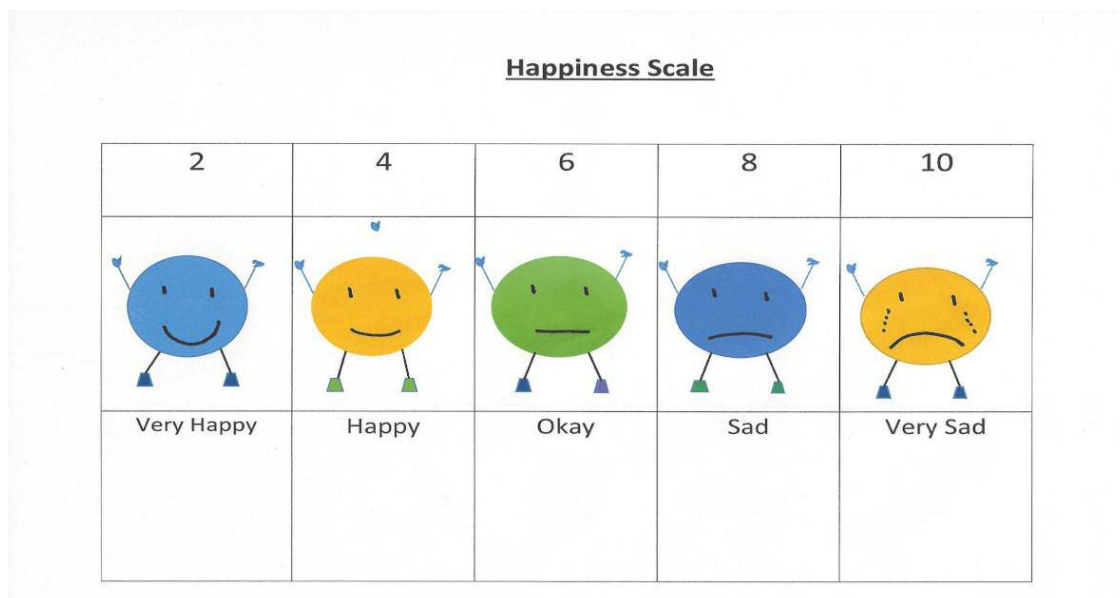
Figure 5-1: Happiness Scale.

Each interview's audio was digitally recorded with the participant's consent. Two devices were used to record the interviews, the second recording being used as a backup. Both devices were placed slightly out of view of the CYP and the mothers, usually on a table. In order to prevent the recorders being a distraction and thus hampering the interview, the focus of the CYP and their mothers was gained and drawn away from the recorders. Following the interview, the digital recordings together with the verbatim transcribed documents, once

completed, were uploaded to the Cardiff University secure server. This formed part of data protection and participant confidentiality.

The process of verbatim transcription, which according to Tappen (2016) is the best system for beginning analysis, was completed by me after initially listening to the audio recordings. Other noises like laughter and speech were included. This process proved to be a lengthy one but had the distinct advantage that the audio recordings were listened to repeatedly before the transcript was completed. This proved to be beneficial as it helped with the initial immersion into the data.

5.2.1   The Interview Process

5.2.1.1   **Interviewing the CYP**

Carrying out an interview with a CYP can offer unique information and insight into their thoughts and feelings (Coyne and Carter 2018). Docherty and Sandelowski (1999) expressed a view that is still relevant today, outlining that research involving CYP is changing from gaining information about them to gaining knowledge from them. Coyne and Carter (2018) highlighted that, in nursing, the CYP's experiences have been poorly explored and not until the 1990s did this start to change. McCrum and Hughes (1998) emphasised that CYP have different perspectives from adults, that they have a right to be heard and that the researcher will learn something from the CYP's perspective, a view that is also supported by Manning (2015). McCrum and Hughes (1998) also added that the CYP and their culture should be treated with respect, which ultimately helps with the researcher–participant relationship.

Coyne and Carter (2018) suggested that boundaries should be set, so each party of the researcher–participant relationship understands the rules, helping both to understand what is expected. These authors also mentioned that interviews with CYP give them a voice – which was also previously mentioned by Kortesluoma et al. (2003) – especially concerning their life events, experiences and feelings. Manning (2015) added that CYP can be seen as a vulnerable group compared to adults. Kortesluoma et al. (2003) raised key points for the interview process, including that the researcher should get to know the CYP beforehand – which takes time – and allow extra time at the end of the interview for the CYP to talk and to finish the interview positively. They highlighted a number of important points: it is best practice to accept the participants' answers without any criticism; the CYP's feelings can usually be approached through their actual lived experiences, which can lead to a discussion-based approach to the interview; long interviews should be avoided due to CYP's limited concentrations times; and the interview process should be viewed as a mutually beneficial partnership.

Coad et al. (2015) also added that finishing the interview and leaving the CYP's home can be difficult but they included that the researcher should aim for emotional stability and balance with the CYP. In my study, I was very aware of this comment and it was incorporated into the interview planning in two ways. Firstly, the CYP was asked if they had anything that they wanted to talk about, which helped with the researcher–participant relationship by showing that it was not all focussed on what the researcher's needs were. Secondly, I spent some time with the families after the interviews in order to ensure that there were no problems or unanswered questions following the interview, thus promoting emotional stability.

I chose a semi-structured format to interview both the CYP and their mothers. The interviews were piloted with the CAG in the form of role play, as previously discussed in Chapter 4. Coad et al. (2015) supported the flexible semi-structured approach in interviewing CYP and this worked very well for my interviews. For example, it provided the ability to adapt to the CYP's needs when on occasions they wanted to discuss other matters that were not always directly relevant to the study. These asides were useful as they often provided insights into the CYP's overall experiences. An example of this was provided by Cai who, when asked if there were any other things that he wanted to discuss, talked about the communication breakdown that he and his mother had had with one of the agency nurses. Listening to his concerns and anxieties, and providing feedback, helped strengthen the researcher–participant relationship; Cai knew that his lived experiences had been listened to and that they mattered.

The interview schedule proved to be effective in creating some structure in the interviews at two weeks and three months. However, during the interviews at six and nine months, the schedule was occasionally a bit of a hindrance and a risk to the participants' engagement. As a result, during the final phase of interviews, the schedule was used less, and a more relaxed conversational approach was taken instead, taking advantage of the rapport built during previous interviews. This relaxed, participant-focussed approach enabled me to maintain engagement but still collect data within a mostly semi-structured format. An example of how the interview schedule was a hindrance was seen in Afan's interviews: he was a quiet young man during the first interviews at two weeks and three months and to overcome this, the interview schedule was adapted in response to his lack of response. This improved the interview dynamics and Afan became slightly more talkative.

The work by the CAG that contributed to the happiness scale proved to be very helpful and the scale served well as an ice breaker. The use of an ice breaker during interviewing is supported by Coad et al. (2015) and Coyne and Carter (2018), and helped form the initial discussion around the participants' experiences. The happiness scale also proved useful in the longitudinal interviews as it formed a constant from which the different interviews' discussions could arise. By carefully integrating the happiness scale together with a conversational semi-structured interview approach, I was able to maintain a good flow to the interviews and obtain rich data. This flexible approach worked very well with all the CYP, and with their mothers, in establishing a relationship in which they knew that they were being listened to.

In preparing the interview schedule, I hoped that the interviews would last for at least 40 minutes in order to fully explore the questions. However, I was also aware that I was interviewing CYP who were recovering from head injuries, and who might have problems with concentration and headaches, so I did not want to tire them out needlessly as I believed this would be unethical. During the interview, six questions were asked that centred on exploring things that were important to the CYP. The majority of interviews took 35–40 minutes to complete, with two lasting over an hour.

All of the CYP interviews were conducted in the presence of their parent(s) because this was previously outlined in the REC form discussed in the REC panel meeting; this was a way of reducing risk for the CYP. Theoretically, having the parent(s) present during the interview could have had an impact on the data gathered (potentially reducing or increasing the amount of data being collected); however, having the parent(s) present largely aided in the data

gathering, especially with Afan and Betsi. However, Cai's openness did lead to frank discussions with his mother, giving evidence of some previous disagreements or that he did not always agree with the things his mother occasionally said during his interviews.

The majority of the interviews were carried out in the family home, whilst one participant chose a family friend's home. I provided each of the families a choice of venues, which included the school, a hospital/clinic and their home. Overall, interviewing in the home proved to be successful. Baillie (2019) commented that carrying out interviews within the patient's home promotes the comfort of the participant, their control and convenience. Anderson et al. (2010) added that it can also reduce power relations and viewed the home as a social space. Even though these papers look at adult participants, their points are also relevant to CYP.

One of the difficulties that I faced as a novice researcher arose with interviewing CYP for this study. I have been working professionally with CYP for over 25 years but carrying out an interview created new challenges. The first of which was encouraging the participants to talk and expand on what they were saying. Interviewing for this study presented different problems to those seen in a clinical consultation. In some ways, a clinical consultation is like a semi-structured interview but is more directed around set aims and outcomes. These can be limited by time and in them clinical experience is drawn upon to guide decision making. Interviewing for my IPA study required a different approach: initially I was the novice required to build my skills in investigative interviewing, allowing the participating CYP to convey their journey. This often involved gentle probing and prompting when time allowed, in order to learn about the CYP's experiences. This at times led to the second problem for me

– namely, in trying to encourage the participant to expand on their lived experiences, I inadvertently fell into the position of occasionally asking leading questions; this might have led to a loss of opportunity for the CYP to fully discuss their experiences or to potential bias but, working reflectively, I minimised this as the interviews progressed and as my own personal confidence with interviewing grew, resulting in less leading, closed or multiple-choice questions.

Carrying out a longitudinal study not only provided an insight into the recovery process of the CYP and the lived experiences of them and their mothers, it also added to the richness and value of the data. Due to the ongoing contact with the participants, a relationship of trust and understanding was formed, which supports the views of Kortesluoma et al. (2003) about the need to get to know the research participants; each subsequent interview became easier as researcher–participant relationship was built, which in turn resulted in better questioning from me and answers from the participants. Also, as the researcher, I was interested in knowing how the CYP viewed their lived experiences and how these experiences were changing as the journey of injury and recovery progressed. This was achieved by the use of the happiness scale at the start of each interview, with the scores generated being discussed in relation to the previous interviews scores – the interview at two weeks discussed these scores in relation to their preinjury experience. Philosophically, this supports Gadamer's "fusion of horizons", where each time frame is influenced by previous time frames (see section 4.4.1.1). In brief, each interview carried out with the CYP and mothers informed the next interview, with previous findings used as a starting point for discussions.

5.2.1.2   **Interviewing the Mothers**

In interviewing the mothers, a semi-structured approach (based on six main questions – see Appendix 10) was selected. Each mother's interview followed that of their daughter's or son's – this is because I wanted to explore each mother's view on the answers that their CYP gave as well as using each mother's second interview to expand on their first. This approach, which supports the social constructivist stance by attempting to understand the mother's reality, is advocated by Wildemuth (2017). As the mothers' interviews were carried out at six and nine months post injury (of their son/daughter), a detailed insight into the CYP's lived experience had already been substantially developed; therefore, the semi-structured interview was used because the phenomenon in question, the head injury, was understood (Wildemuth 2017). By undertaking the unstructured interview, I wanted the mothers to feel comfortable whilst I explored the narrative that emerged from their answers, with a focus on understanding the lived experiences of the mother as a parent of a CYP who had suffered a head injury.

The interviews with the mothers generally lasted for around 40–45 minutes and, like the interviews of the CYP, were digitally recorded and verbatim transcribed. In carrying out the mothers' interviews, I left it up to the mothers if they wanted their daughter/son present; however, in the majority of the interviews the CYP opted not to stay during the interview, especially Afan. However, Betsi did sit in on Gwen's interviews for short periods of time – she would say a few things and then leave. From my observations, these interactions did not affect the quality of the interviews; it also fitted my aim to have an open, relaxed and comfortable atmosphere to aid in data collection.

Field Data

Field data were written immediately after each interview whilst the information was vivid in my mind in order to add to the rich data and contextualise the interview (Phillippi and Lauderdale 2018). (They were not written during the interviews as I was reluctant to distract from the interview and gave the participants my full attention). Anstey (2012) supports the use of field data as it helps with the inductive processes of IPA and can help in uncovering embedded information and understanding the idiographic experience. My field data included key points and observations, such as how the participants acted in response to questions, who was present during the interviews, any relevant non-verbal behaviours, location (with description) of the interviews, and a critical reflection of the interview (Phillippi and Lauderdale 2018). Table 5.4 shows a simplified extract from my field notes based on the reflexive working of Darawsheh and Stanley (2014).

Table 5.4: Simplified Example of Field Data with Reflexivity – adapted from Darawsheh and Stanley (2014).

Field Data with Reflexivity and Future Planning			
Context of reflection	**Trigger for reflexivity**	**Thinking about my own thinking**	**Outcome of reflexivity**
Interview 2 – Afan. Conducted at mother's house. Dad not present at this interview.	Completed interview schedule.	Subsequent interview schedule worked well. All questions asked and understood.	To keep with interview schedule as this worked. To allow more freedom for the participant to pursue areas they want to discuss.
Appeared well and asymptomatic.	Communication gap still remained.	Afan remained quiet in the interview and was eager to get away when the interview finished.	To re-examine power issues during the interview process – to try and improve communication.
	Became upset during the interview when asked how he felt.	Questions can be upsetting and emotionally based when asked to discuss thoughts and feelings.	To understand what led to Afan becoming upset – potential problems with articulating feelings. To consider other strategies for future questioning.

5.3 Data Analysis

Smith et al. (2009) stated researchers can find the method that is best for them; however, they also suggested a six-step process to carry out the analysis. As a novice researcher, I was aware of the importance of good data analysis and therefore followed the six-step analytical process (Smith et al. 2009, pp. 79-80). This will be discussed in the following sections:

Reading and Re-reading

Reading and re-reading was undertaken once the transcripts were transcribed verbatim, a process that allowed me to gain an immersion into the participants' lived experiences as I listened to the voices of the participants, noting their responses, nuances and characteristics. As my study was longitudinal, in preparation for the following interview the audio recordings were re-listened to and the transcripts were re-read, often with listening to the audio recordings, which helped submerge myself further into the data.

Initial Noting

With initial noting, I had to consider the longitudinal nature of the study. Following this, each transcript was analysed line by line, which is demonstrated in Appendix 12 with extracts from Ffion's first interview. Smith et al. (2009) described this stage of the process as being the most time consuming as well as being a way to look at language and semantic content on an exploratory level. Notes were made which looked at descriptive, conceptual and linguistic comments. These were recorded on a template, identical for all the participants: the left column contained the emergent themes, the second contained the line numbers, third was the transcript body and, lastly, the exploratory/conceptual/descriptive comments were in the fourth column.

Development of Emergent Themes

To develop the emergent themes, I partly moved away from the transcripts and focussed on the notes made during the previous stage, and I considered the hermeneutic circle for my study which was carried out longitudinally. I chose to use mind maps for each of the participants to help this stage. The mind maps were used to draw out key words/points across the study period and provided an oversight to the participants' experiences. Appendix 11 (showing one timeline over three images) provides an example of Cai's mind map. Completing these also helped with the hermeneutic circle, in which the part and the whole are intrinsically intertwined.

As this covered all the interviews, this stage was done once all the interviews had been completed. Chapter 6 of my thesis will demonstrate the creation of the emergent themes from the notes together with interview extract quotes – see Appendix 13. The emergent themes used the participants' language and identity alongside my interpretation. Forming these themes was carried out by the use of white boards, note taking and computer usage (using Microsoft office to bring ideas together) which formed a comprehensive approach.

Searching for Connections across Emergent Themes

In the creation of the of the superordinate themes from the emergent themes, the following approach were considered outlined by Smith et al. (2009, pp. 96-99) and will be demonstrated in Chapter 6:

- Abstraction – identifying patterns which have a "like with like" structure.

- Subsumption – in this example the emergent theme requires a superordinate theme in order to bring "together a series of related themes".

- Polarization – looks at emergent themes that are oppositional (difference compared to similarity).

- Contextualization – the connection between themes that have narrative, temporal and contextual elements in common.

- Numeration – examines the frequency with which themes are present.

- Function – where themes have specific functions; these can be positive and negative representations.

Moving to the Next Case

Smith et al. (2009) cautioned over the inability to allow new themes to emerge between cases. This was addressed in my study, where each case was analysed separately, following the above steps, and the idiographic focus was maintained: each participant's lived experiences were valued and formed an image of how CYP recover from a moderate head injury.

Looking for Patterns Across Cases

Looking for patterns across cases brings them together to look for convergence and divergence. Chapter 7 of my thesis explores this at group level and uses master tables to display these findings. A challenge I encountered in generating these tables (one for the CYP and one for the mothers) was in the limited number of participants involved. Another challenge was in displaying the data which reflects the longitudinal study design. These challenges bring a positive contribution to the study as they not only demonstrate the non-

linear relationship of recovery with time, but this is demonstrated for each participant. The tables also provide transferability of findings.

5.4   Research ethics

Manning (2015) highlighted that there appear to be anxieties around, and some resistance to, undertaking research with CYP, as they can be described as a vulnerable population. This vulnerability can be enhanced by the nature of a head injury and the effect this can have on CYP's cognition and life skills. The following sections will cover how this study dealt sensitively with the ethical issues of conducting research with CYP with head injuries.

Research approval for this study was gained initially from the Postgraduate Research Students Review and Ethics Screening Committee of Cardiff University in 2015 (see Appendix 14). Following this, sponsorship was obtained from Cardiff University. Permission was then granted by the NHS Research Ethics Committee (REC) as this study involved patients. Finally, permission was granted by the Research and Development (R & D) department at the participating Health Board.

During the research process, because of the logistical problems of recruitment and the modification of the study, two amendments were made to NHS REC and R & D. The first of these changes was a minor amendment that involved increasing the upper age limit from 11 years to 13 years; the second, a major amendment, involved the recruitment of the parents (mothers) – see Appendix 15.

Participant and family autonomy was respected throughout the research and the CYP and their families all had the opportunity to withdraw from the study at any time if they wished. Cai withdrew from the study after the six-month interview with no reason given.

5.4.1   Consent and Assent of the Participants

Lambert and Glacken (2011) described consent as a legal process that involves the parent/guardian. They referenced the Children's Act (1989) in which it is stated that the parent/guardian can provide written consent on behalf of CYP under 16 years of age. Lambert and Glacken (2011) also stated that, whilst CYP cannot legally give *consent*, they can give *assent* – which is described as a sign of their willingness to engage with the research. This provides the CYP with a sense of autonomy and control. They mentioned that, for true assent, a three-way pathway exists between CYP, parent and researcher. Welsh Assembly Government WAG (2009b), in their Research Governance Framework, stated that care should be taken when seeking consent from CYP, that their rights should be protected and that information should be appropriately written and in pictorial form, where appropriate (this is demonstrated in Appendix 7 which shows an adapted information sheet).

In further exploring consent with CYP, two main guidelines exist: Gillick competence and Fraser guidelines (Cornock 2007). Gillick competence was originally designed to assess consent in girls under the age of 16 years regarding contraceptive advice without their parent's awareness. This later was adapted to assess whether consent could be obtained for other medical treatments/interventions where the CYP has the understanding/intelligence to understand aspects such as risk and success rates, and that other options may exist. These are assessed by the Gillick test; if it is not passed, the parent must give consent.

Fraser guidelines relate only to advice concerning sexual health (sexually transmitted diseases), contraception and pregnancy termination in CYP under the age of 16 years without parental awareness (Wheeler 2006; Cornock 2007). Like Gillick competence, they are based on intelligence and maturity, and are in the CYP's best interest – but they differ in that in this instance they are concerned that the CYP are very likely to have sexual intercourse with or without contraception. To be Fraser competent can be a determinant of Gillick competence (Cornock 2007).

From my perspective as a researcher, and keeping in line with Wendler (2006), the concept of understanding and comprehending the research question is a key point: a CYP cannot provide informed consent unless they fully understand what they are consenting to. As the CYP were under the age of 16 years and I had no formal way of assessing competence, the parent(s) gave consent and the CYP provided assent. Parent(s)/guardian(s) can be seen as gatekeepers for their CYP (Shaw et al. 2011) and can provide consent for participation in research on behalf of their CYP. However, unless the CYP had assented to their involvement within my study, thereby providing an indication of their willingness to participate, the interviews would not have taken place, even if the parent(s)/guardian(s) provided consent. Wendler (2006) suggested that true assent can only be obtained when the CYP understands the research question, which they stated can happen when the CYP reaches 14 years of age. However, contrary to this, Lambert and Glacken (2011) highlighted that assent for non-therapeutic interventions can take place between the ages of 12 and 14 years.

Gaining consent and assent was, therefore, an essential component of this study that I had to consider. Once the CYP and their family members were offered the opportunity to take part in the study (which was done via the gatekeeper supplying the initial information about the study), I reiterated the key information for this study, ensuring that the family understood not just the requirements of the study but also what the aims of the study were. I was fully aware of the difference in power between myself as a researcher/healthcare professional and the CYP and their family. The CAG also helped in ensuring that the information for the study was communicated in an age-appropriate manner, thereby ensuring informed assent from the CYP.

Being able to carry out role play interviews with the CAG helped to ensure that the interview questions were presented at an appropriate level of language and meaning that would help to engage with the potential participant. Wendler (2006) discussed dissent and how this might be presented by participants during interviews – verbal and non-verbal discomfort are given as examples. As a paediatric nurse, I was fully aware of this and considered it throughout the interviews and interactions. During the study, this only happened once: one of the participants became visibly distressed near the end of the interview. At this point I gave the CYP the option to stop the interview and to reconvene at a more appropriate time; however, the CYP gave assent to continue and the mother, who was present, was happy for the interview to continue. Therefore, consent and assent were reiterated; they were likewise considered throughout the interview process.

An example both of how I put the CYP first and of their confirmed assent can be in seen in the extract below. In Betsi's third interview (six months post discharge), she faced personal

loss through the death of her grandfather, who she was very close to. I gave the option to postpone the interview if Betsi wanted to, but she decided to continue (transcript 3; lines 1040–1044):

Interviewer: *Okay. You put family as very sad. I think we know why, 'cause your grampy passed didn't he?* **Okay. So, if you want to stop at any point that's fine, okay.**

Another example of respecting the assent of the participant and consent of the parent took place with Cai. He decided to withdraw from the study at six months with no reasons given, although he and his mother were happy for his data collected up until that point to be used. This decision was respected and no further interviews took place.

During the consent process, I gained confirmation from the parent(s) in the form of written consent indicating that they had asked whether the CYP gave assent to the interview process. The families were given the option to sign the consent form whilst on the hospital ward, or to take it home and for me to collect it at the start of the first interview. To ensure that this was informed consent/assent, written information was given to every family (see Appendices 7 and 8) which had been approved by the NHS REC. During the consent process with each parent(s), I talked them through the information sheets, answering questions as they were asked, in a language that was appropriate for both the parent(s) and their daughter/son. I requested that the CYP be present throughout this process and discussed what consent meant. I also reinforced that they could withdraw their consent at any time. Two of the three families signed the consent forms on the ward and one in their family home; but due to the major amendment concerning the invitation for the parents to participate, the revised consent forms for the mothers were signed in the family homes.

5.4.2   Power

This section will discuss the differences in power both between the CYP and me as the researcher, and between the parent and me. It will also consider how power differences were reduced. A robust research methodology needs to consider the issue of power, especially when the research involves CYP who have sustained a head injury. CYP are classified as a vulnerable group, but CYP who have sustained a head injury can be more vulnerable. For example, Blakeborough (2016) highlighted that CYP who have acquired brain injuries can develop mental health problems and developmental disorders, which together can have an effect on their cognition and cerebral processing. In trying to understand the CYP's experience of recovering from a head injury, any forms of power play must be minimised. Docherty and Sandelowski (1999) highlighted that CYP are in the best position to recall their experiences, and Kirk (2007) mentioned that inequalities of power between the adult population and the CYP's population can be transferred into the research process. This can lead to problems in information gathering. This study aimed to minimise the power gap through multiple methods, some of which have been covered elsewhere in this section (and which were also discussed by Thomas and O'Kane (1998); Docherty and Sandelowski (1999) and Kirk (2007)). These methods included asking the CYP if they were happy to engage with the study, utilising a CAG, involving the CYP within the interview process and allowing them time to discuss experiences that were important to them – this was highlighted by the last question of the interview schedule, asking the CYP if there was anything else that they wanted to discuss or say.

An example of how I tried to remove any researcher power bias took place in an interview with Betsi. Working reflexively in the first interview, I noticed that she was quite anxious about the interview. To overcome this, I simply sat on the floor as a trial, so I was lower than Betsi as she was sat on the sofa. This simple move appeared to make Betsi relax and helped with the interview process. In subsequent interviews, I adopted the same position, which was successful and improved the researcher–participant relationship.

With the mothers, power was reduced by the use of unstructured interviews and allowing these interviews to follow a more conversational route whilst listening to and engaging with the mothers. At the point the mothers engaged with the interviews (at six months), a rapport had already been established; this was different from the situation at the CYP's first interviews, which were only the second time that the CYP had met me (the first time being on the ward). Similar strategies were used with the mothers as with their son or daughter: ensuring that they were happy to engage and knew they could withdraw from the study at any point (which gave them control), treating the mothers with respect, and demonstrating that all experiences were valued. At the end of the interview, the mothers were also asked if they had anything else that they wanted to add, allowing them to guide the interview with experiences that were important to them.

To conclude, power was managed by giving choice and autonomy to the participants and to their families; an example of this was allowing the families to choose where the interview was to take place. Other examples included sitting either at the same height as the participant or below so as to appear less imposing, giving the participants the time to finish their narrative, and giving them a voice during the interview process. I also put a great emphasis

on neutralising any power play which could have negatively impacted on the semi-structured interview schedule, such as when the CYP might have answered questions with the answers that they thought I wanted to hear, rather than with what they really thought.

5.4.3 Reflexivity

Within this study, reflexivity is considered an important and integral element and the criteria set out by Yardley (2017) will be used to discuss its role. To avoid any duplication, this will be explored in Chapter 9 (Conclusion and Recommendations"; section 9.5).

5.4.4 Insider/Outsider role of the researcher

As is common with other research approaches, it is imperative that the dual role of the researcher as outsider and insider be considered within the IPA approach. Bennett (2015) described this dual role as an oscillation and blur (a movement between the insider and outsider roles, which will be explored below). In this study, I was an outsider to the family with no insight into the CYP's or mother's lifeworld. I was not a CYP of between 6 and 13 years old (but have a vague memory of being one), nor had I suffered a head injury. Gregory et al. (2011) added that being an outsider has the potential to see things from a different perspective. Reid et al. (2005) stated that this different/outsider perspective is an integral part of the interpretative component of IPA.

However, I also had some insider status from being a healthcare professional and someone who had for over two decades looked after CYP and families following moderate head injuries. I also had an understanding of some of the nuances that exist within this group, as

well as being a father of an 11/12-year-old at the time. This insider status helped in the creation of a purposeful research question.

Working reflexively can be seen as utilising the cognitive ability of people to see themselves in relation to their social contexts (Watts 2018); doing so within this study helped throughout with the balance between my insider-outsider relationship in that I tried very hard to neutralise any power inequalities, which is a topic that has and will be explored a number of times throughout this thesis. Adding to this, Dwyer and Buckle (2009) described the insider–outsider relationship as a paradoxical one in which the researcher is aware of their biases and preconceptions, whilst understanding the experiences of the participants. Reid et al. (2005) mentioned that IPA methodology helps the researcher take the insider perspective, which is an integral part of the analytical process. This insider knowledge brought major benefits to the study, the main one being evident during communication: As both a parent and a paediatric nurse, I have worked and communicated with CYP of varying cognitive or linguistic levels, and this was a strength I brought to the interviews. In CYP who have suffered a head injury, both cognition and linguistic capabilities could be affected. Being able to communicate whist being aware of these difficulties helped me to prepare for an interview, and understanding age-appropriate nuances helped me to form a rapport with the participants, which is vitally important in the interview relationship (Kortesluoma et al. 2003).

It can be argued that understanding the insider status can add to authentic data interpretations due to a developed experiential knowledge base (Bennett 2015). However, my deep concern was that this familiarity with the research topic could influence my findings and interpretations. I was fully aware of the biases that could exist within the interview process

and I carefully considered these factors throughout the interviews and analysis. Several steps were used to minimise these influences: Firstly, by ensuring the CYP's and mother's voices were clearly represented in the data (which were then analysed using the hermeneutic circle and by interpreting the mothers' views). Secondly, using a CAG helped steer the research design and, to a point, the aims; public involvement, via the CAG, also helped in the grounding of the research in the CYP's perspective. Thirdly, carrying out semi-structured interviews allowed for the CYP and the mother to contribute to the direction of the interview; this helped shift the power balance to the CYP and mother. Fourthly, the familiarity problem was also tackled by adding in at the end of the interview an opportunity for the participant to add anything else that was important to them, which in turn shows warmth and interest by the researcher (Kirk 2007).

5.4.5   Confidentiality

Kirk (2007) highlighted that confidentiality can be a potential problem that needs addressing within the research process. To counter some of the potential issues related to confidentiality, the research was carried out (the participants had choice of venue) in the family or in a friend's home. Whilst boundaries and the ability to talk freely might be compromised in some ways (for example, parents overhearing CYP's answers), there is potentially less risk to confidentiality than in a public place or on a hospital ward.

Other considerations have been highlighted by the Nursing and Midwifery Council (NMC 2015): everyone has a right to privacy, they should be informed about how the information collected is going to be used, and information should be only shared if needed, such as in cases of public protection (an example of which would be a safeguarding concern). In this

study, the research interviews took place in the presence of a parent(s) – the reasoning for this has been discussed previously. Kirk (2007) discussed the issue of disclosure and how any sensitive information revealed by the CYP is dealt with. In my study this was a potential issue, but if the CYP had disclosed concerning information, or was "at risk", then the appropriate professional bodies would have been informed, as is a requirement of my registration with the NMC.

The parents' and CYP's information sheets reinforced the value of confidentiality to the families. The confidentiality principles for this research adhered to the Caldicott (2013) principles: (1) have justification for using confidential information; (2) do not use confidential data unless necessary; (3) keep the usage of personal data to a minimum; (4) ensure access to personal information is on a need-to-know basis; (5) be aware of own responsibilities; and (6) comply with the law. By following these principles, I ensured that confidentiality was maintained for the CYP and their families. Crook (2003) and NMC (2015) stated that holding participant information should be justified, that it should use only minimal recognisable information and that everyone should be aware of their responsibilities. My study adhered to this, along with the RCN (2009) guidance on research ethics and data protection: pseudonyms were used to protect participants' identities and data were stored on Cardiff University's secure server. The only personal identifiable information that was used during the research data collection process included the addresses of the participants and their names. These were only used for getting to the family homes and then were destroyed. These steps to protect the CYP's and families' identities and ensure confidentiality adhered to the Research Governance Framework (WAG 2009b).

Data Usage

This study also considered short- and long-term plans for the data. Short term, the data from the CYP and mothers was used to inform the idiographic analysis and the comparative chapters. Long term, as discussed during the consent process (and included on the consent form), the data from the interviews (and this thesis) will be used for relevant publications; this will involve transferring the relevant data from Cardiff University's secure server to the NHS Trust's secure server where I work.

5.5 Summary

This chapter has explored the recruitment and sampling process for the study, which was in line with Smith et al. (2009) and how the number of participants in my study strengthened the depth of the analysis of the data. I discussed inclusion/exclusion criteria, and I have at length discussed the interview process and outlined the importance of interviewing CYP and the mother directly in order to understand their lived experiences, and the value that this can bring to the literature. These findings, I have described the analyse process for the interview transcripts which will be explored line by line via a hermeneutic circle approach where the "parts and whole" were comprehensively explored, explored via a mind map and where emergent themes are generated from the extracts which then form the subordinate and superordinate themes.

The role of the mothers was also explored in this chapter, highlighting some of the differences that exist in the interview process and how power can be seen differently between

the CYP, their mother and the researcher. Interviews with the mothers were semi-structured as I wanted to explore their lived experiences and their thoughts on the interviews carried out with their daughter/son. The mothers were present in each interview carried out with their son/daughter, which formed part of research ethics (this was discussed and agreed with the NHS REC), and therefore each CYP was aware that whatever they said to me was also heard by their mother; and where the mother interviews might have been heard by their child - as it was the mother's choice to have their child present or not. Consent and assent were explored together with the importance of each to this study. Confidentiality was also discussed alongside data usage, both short and long term.

The next chapter will explore the idiographic findings.

6 Idiographic Findings

6.1 Introduction

In this chapter, I will be presenting the three CYP's idiographic cases, together with two of the mothers'. In each of the idiographic cases, the emergent themes will be discussed across each of the interview time frames – at the end of each individual's section, the emergent themes will be grouped together to form the subordinate themes. The idiographic findings for each of the participants will be briefly interpreted with respect to the literature, and three unique idiographic elements will be identified for each case.

In interviewing CYP as a researcher, was a very privileged position to be in. All of the CYP were still in the very early stages of recovery, were very vulnerable and were going through a horrendous experience. Few researchers, if any, have interviewed at this point in the recovery process and doing so offers an opportunity to explore the participants lived experiences in the early stages.

The following sections will explore the idiographic findings for each of the participants, beginning with Cai.

6.2 Idiographic – Cai

At the time of Cai's recruitment into the study he was 13 years old, lived in a coastal town, attended the local comprehensive school and came across as being highly sociable. Cai was an only child and, as his father had died when Cai was only a toddler, he lived at home with his mother. Cai was diagnosed with a moderate head injury after falling from his BMX bike

whilst travelling downhill at speed without wearing a helmet. This accident resulted in a loss of consciousness, a skull fracture and some retrograde amnesia. The fracture was initially conservatively managed, and Cai did not require surgery prior to the first interview. Between the first and second interviews, however, he suffered a secondary bleed from the head injury and required re-admission for a surgical evacuation of a haematoma; his presenting symptoms included headaches, nausea and tiredness. In conversations with Cai outside of the first and second interviews, he commented that he had experienced episodes of disinhibited behaviour and speech. He also had outbursts of verbal aggression. The surgical intervention was successful in treating his headaches and his nausea, and over the six-month interview schedule his disinhibition gradually disappeared. However, Cai was left with possible hearing loss in one ear as a result of the head injury and had to contend with his surgical scars. On discharge from the ward on both occasions, he had restrictions placed on him by the medical team. He was advised to stop doing sports that could result in him reinjuring his head like rugby and football, to stop using his motorbike, to avoid the busyness of the school corridors, to leave lessons slightly earlier and to avoid the school playground which was deemed a risk due to other CYP playing ball games together with other activities where there was a chance he might knock his head.

At the family's request, all the interviews were carried out in the home of a family friend and were digitally recorded with his mother being present. Following his head injury, Cai had to cope with the loss of both rugby and the use of his motorbike; these were central to him for his socialisation and identity.

This section will further explore other components of Cai's lifeworld and how his lived experiences presented over the six months that he was involved in the study.

The three subordinate themes for Cai are:

- Not Being Allowed

- Relationships Do Change

- Coping and Maturity.

6.2.1 Descriptive Analysis of Emergent Themes

Once Cai had overcome his initial nervousness about the interview, which was dealt with by using a relaxed approach, he appeared to start enjoying it: he wanted each interview to last longer than the previous one. He verbally monitored the time sporadically, as exampled by him jokingly saying "*29 minutes*" (Transcript 2, line 1527) during the second interview, which also indicated agency. He took a personal interest in the process which was also exampled by him saying in the second interview, "*Interview terminated at, hold on, 18:12*" (lines 3189–91), showing that he wanted to stop the interview. This also demonstrated control and the ability to have agency in decision making during the interview process (when to stop) which also points to a good balance of power between myself and Cai. During each of the interviews, Cai presented himself as the "perfect host" by offering drinks before the start of (and in some cases during) the interviews and appeared to only have headaches during the first one. Interpretatively, this could be seen as ensuring that I, the researcher, was welcome and comfortable whilst also reinforcing that I was a guest within the home. This could be seen as another instance of Cai demonstrating control over the situation.

The brief examples above highlighted some of the benefits of undertaking a longitudinal research approach: over time the relationship formed and power biases were negotiated. The longitudinal approach to the study also shows the journey that Cai travelled from the time of the moderate head injury through to six months post injury. But even at the six-month interview, Cai still was negotiating his way through recovery. In keeping to the longitudinal nature of this study, each of the different time frames (two weeks, three months and six months) will explored in turn.

The following sections will explore the emergent themes that were derived from the interviews, with each one being explored longitudinally.

6.2.1.1   *"I used to get angry"* **but I understood why**

This emergent theme focusses on Cai's motorbike and his loss of being able to use it due to the restrictions. Cai appeared to see things in a concrete way and used a mixture of cold and hot cognition (hot cognition indicates emotional based responses and cold cognition implies logic and critical analysis) to demonstrate this. At two weeks post injury, Cai indicated that he knew the risk of further injury during his recovery in this matter-of-fact, unemotional response:

"I know I can hurt myself if I fall off it" (Transcript 1; lines 206–7).

In further discussing his motorbike, Cai accepted the fact that he was not allowed to ride it and knew that he could fall off. The motorbike shows a connection with the accident he

suffered, occurring when he came off his BMX bike. The above comment was quickly followed by the following extract which shows a resolute, simple response encased in a strong emotion:

"I wouldn't do it!" [reference to using his motorbike for motocross] (Transcript 1; line 225).

Cai's interview at three months showed some marked changes in his lived experiences. In regard to his motorbike, which he had previously accepted not being able to go on, his speech demonstrated marked negative emotions about how he was feeling: his choice of terminology (*"Oh God"*) emphasised the negativity and magnitude of his emotions, and the frustration he felt as a result of restrictions over his use of the motorbike.

"Oh God. Very sad! I can't go on it to after Christmas. Next year." (Transcript 2; lines 350–1).
"Very, very, very sad!" (Transcript 2; line 356).

In the second extract he uses the word "very" three times, which highlights a high degree of sadness. Interpretatively, these extracts point to Cai struggling with loss (not being able to go on his motorbike) and sadness (because of this loss and the length of time that he had to wait until he could use his motorbike, which would signify a return to his preinjury self).

At six months, in his third and final interview, Cai's view had changed; however, it is possible to see the consequences of the moderate head injury his motorbiking – something that was important to him. Specifically, by this point in time Cai had sold his motorbike, hence removing the temptation of using it. This could be seen as a mature response in terms

of risk avoidance, but one which simultaneously resulted in a feeling of sadness. For example, Cai's use of "*sad*" twice in his response to my question resonates with negativity about the restrictions placed on him.

"Sad 'cause I haven't got a motorbike. I was sad because I couldn't ride one"
    (Transcript 3; lines 901–3)

How Cai used the word is interesting, pointing to an overarching sadness which had a variety of causes and magnitudes at different times: I was sad (as a result of not being allowed to go on the motorbike) but am still sad (because of selling the motorbike). Ultimately, the head injury and its consequences had a negative impact on Cai's motorbike use, which he had identified as a very important activity.

6.2.1.2   "*Rugby is important*" and loss of identity

Rugby, like motorbiking, was identified by Cai as being important to him, as is strongly emphasised in the extract below.

"Oh god, Rugby is important" (Transcript 1; line 24).

When exploring how the restrictions imposed because of his head injury denied Cai opportunities to play rugby, there was (like with his motorbike) an acceptance that he could not play it and felt "*okay*" about it. However, when collating extracts from different time points in the interview, it became clear that he missed aspects of the game – seen in both the physical aspects of the game ("*I miss tackling*") and the relational aspects of playing sport ("*people*" – alluding to the social element of the game, which was important to Cai). A

dichotomy of thoughts was evident in Cai's acceptance of restrictions on playing rugby – he both accepted it but also missed it as it was part of his identity:

"I'm okay" (Transcript 1; line 188).

"I miss tackling people" (Transcript 1; line 366).

At three months, there was a change in his thoughts and in his lived experiences. The following extracts clearly identify a greater amount of hot cognition compared to the first interview. Here Cai used terms like "*sad*", "*hitting*", *hurting*", "*angry*" and "*fuming*" to display his thoughts, thereby highlighting both the negative impact that restrictions had when placed on him and Cai's realisation of their impact:

"Well I'm sad. I can't do none really" (Transcript 2; line 338–9).

"Hitting people… Hurting people. Not hurting them but yeah…Yeah training"
     (Transcript 2; lines 435–44).

"Angry. Fuming!" (Transcript 2; line 534).

Cai also described not being able to meet and have a chat with his friends, to socialise, at rugby training. He was denied his sense of normality as a consequence of the restrictions placed on him. Cai used the terms "*club*" and "*nice coffee*" to demonstrate his lost enjoyment of socialising at the rugby club with his friends.

"Well, we all go into the club. We all sit down and have a nice coffee" (Transcript
     2; lines 500–1).

Interestingly, at six months – the point at which he is allowed to resume playing rugby – Cai displayed a transition in his thoughts: the anger has been replaced with uncertainty ("*I am*

debating") and being "*paranoid*". Over the duration of his recovery, therefore, initial anger caused by his restrictions had now been displaced by concern that he might reinjure his head and the potential consequences of this. Cai's interview responses presented insights into his recovery and how he was having an internal "battle" with risk and had an unwillingness to suffer another head injury, and the return of restrictions that would occur:

"Ah, I am debating" (Transcript 3; line 289).

"There's like, if you're playing rugby you are paranoid!" (Transcript 3; lines 342–
   3).

6.2.1.3   **Being a "*Rebel*"**

The "rebel" theme is an interesting one as it arose during the third interview when Cai was thinking about the time since the accident. As his recovery was progressing well (and possibly as an indication of the development of rapport during the interview), Cai openly admitted that he did not stay in during breaktimes at school when he was asked to (as part of the restrictions placed on him by the clinical team). He clearly understood that his actions were contrary to advice when he referred himself as a "*rebel*". Cai took this risk due to his need to socialise with his friends, thereby indicating that socialising and friendship were more important than the risk of another potential head injury. Interpretatively this can also be seen as a strategy by which Cai coped with the loss of things that were important to him (like rugby and his motorbike). However, he was unwilling to sacrifice his friendships, which metaphorically could be seen as an anchor for him and a link to his preinjury self.

"Yeah, I had to stay in at breaktimes!" (Transcript 3; line 1034).

"I didn't stay in at break!" (Transcript 3; line 1045).

"Rebel" (Transcript 3; line 1050).

6.2.1.4 "*My head would be fine*" – a battle for normality

Cai portrayed himself as trying to be positive about his future, his recovery. During the first interview, Cai did not discuss any thoughts about his recovery, indicating that he did not think about it at this stage. However, at three months, Cai started to contemplate his recovery: he thought positively about it and hoped that he could resume riding his motorbike by his "*birthday*" – or on his "*birthday*", suggesting some fluidity in his hopes and a willingness to change his expectation slightly. This also indicates an uncertainty about when he would return to normal. However, in the second extract he felt that his head would be "*fine*", demonstrating some positive thinking:

"I hope I can go on it by my birthday or on my birthday. I'm going on it on my birthday!" (Transcript 2; lines 1074–6).

"Yeah, but my head would be fine though!" (Transcript 2; lines 2908–9).

At six months, Cai used interesting terminology to describe his journey up to that point. He referred to his scars metaphorically as "*war wounds*", which raised images of how he saw his recovery: a battle. His use of the metaphor can be explained as a cognitive linguistic explanation of his thoughts which is contextual and describes his thoughts. He had also moved away from a positive position to one where he emphasised his anxiety over reinjuring his head whilst understanding that it could have been worse: he could have been "*paralysed*".

"I am very concerned about my head, if I hit it by there" [indicating an area on his head] (Transcript 3; line 1253).

This change from the previous interview highlights the non-linear way in which Cai perceived his recovery and what could have been. Interpretatively (but beyond my scope as a novice researcher) this suggests that possibly Cai had been traumatised by his lived

135

experiences. The removal of his restrictions made Cai think about what had happened and what could have happened:

"Well, I have not been left paralysed or something like that!" (Transcript 3; lines 1321–2).

"War wounds!" (Transcript 3; line 1338).

6.2.1.5   "*Family is important*" but dynamics change

Family was identified by Cai as being "*important*", which he stated quite matter-of-factly; it is a given. He also recognised his mother's stress and, in doing so, laughed. In looking at this in the wider context of the interview, this laugh indicated that he was enjoying the extra attention/focus he was receiving from his mother. In the third extract below, Cai saw his mother as being more concerned:

"Family is important" (Transcript 1; line 83).

"Well my mum is more stressed" [laughs jokingly] (Transcript 1; line 310).

"Because she is more concerned about me" [referring to his mother] (Transcript 1; line 329–330.

The enjoyment Cai took from the extra attention changed drastically by three months. Cai's choice of language ("*Oh God!*") when asked how he felt about his family highlighted the magnitude of change. When explored further, these thoughts/feelings seemed to stem from his mother being overprotective and an increase in arguments within the home setting. Cai possibly saw his mother's overprotectiveness as negatively influencing his identity, his loss of freedom, which he struggled with; this highlights a change from what he was used to before the head injury:

"Oh God!" [in reference to thoughts about family] (Transcript 2; line 291).

"Yes, angry 'cause there's always arguments" (Transcript 2; lines 619–20).

"Yeah. She's overprotective" (Transcript 2; line 695).

However, in the third interview, at six months, Cai described his relationship with his mother as being more settled – a return to its preinjury status. He admitted to the "*odd argument*", which he explained was a normal occurrence – "*everyone does*" – within a parent–CYP relationship, and indicated that he had accepted the normality of his relationship with his mother – a clear shift from the second interview:

"We have the odd argument… That's normal…Everyone does" (Transcript 3; lines
        564–73).

6.2.1.6   "*I've lost contact*" but it's okay now

Cai's experiences of friendships, which were embedded in his "love" for rugby, were directly impacted on by the restrictions placed on him, which aimed to protect him from head injuries during the critical recovery period. During the first interview Cai emphasised the magnitude of this impact: he missed "*playing*" with his "*mates*" and as a consequence displayed negative language to encapsulate his thoughts – "*sad, left out*". This also negatively influenced Cai's personal identity. He was seen as a sociable person but his head injury and subsequent restrictions led to Cai being socially isolated from his usual group of friends:

"Yeah, I miss playing with my mates!" (Transcript 1; lines 417–18).

"Yeah, very… sad, left out" (Transcript 1; line 427).

This loss of identity and how he interacted with his friends started to show a change in the second interview. At this point his friendships, which were grounded in rugby, were still

affected and he admitted to losing "*contact*" with his friends; this had a direct impact on him due to the continuing social isolation his friends. However, friendships that were not sports based were seen to return to normal as Cai met with them outside of school:

"Oh yeah. No, I've lost contact!" (Transcript 2; line 1425).

"Yeah" [confirmed socialising with friends outside school] (Transcript 2; line 1469).

In the third interview, when given the opportunity to discuss friendships and the negative aspects of his recovery, Cai made no mention of issues with friends. This indicated that friendships were not an issue for him.

6.2.1.7 *"I wouldn't say"* it before – a change in perception

This is a subtle theme which only started to develop through the analysis of the data using the hermeneutic circle. The first indication that Cai's general perception might have changed as a result of his head injury (although one cannot exclude normal psychosocial development) appeared in the second interview. He admitted that his perception had changed and that he said things that before he would not have previously said – thereby indicating some potential change in his maturity:

"Yes, I do because before I wouldn't say nothing. But yeah, I do" (Transcript 2; lines 647–8).

Evidence of Cai's perceptional changes also appeared in his third interview when he started to think about playing rugby ("*debating*"). This was interesting as rugby was a major component of his preinjury identity, but post injury he is considering the issues around going back to it. In the earlier interviews, Cai alluded to not wanting to wear a protective skull cap,

but in the third interview he wanted to wear one in order to "*protect*" his head, indicating a change in his perception, a maturing.

"Ah, I am debating" [about playing rugby] (Transcript 3; line 289).

"Protect me" [in relation to wearing a skull cap – did not previously wear one] (Transcript 3; line 379).

6.2.2   Interpretation

The longitudinal data that were collected from Cai show clear evidence of a non-linear journey of recovery, with a clear demarcation between the first and second interviews where significant changes were seen in his tolerance of the restrictions placed on him. Even at six months, Cai was still demonstrating difficulty with returning to his preinjury self. Unfortunately, at this point Cai withdrew from the study and no further information could be obtained in order to explore this unfinished recovery journey. The emergent themes that were derived from the data (as shown in Figure 6-1) formed the subordinate themes: "Not Being Allowed", "Relationships Do Change" and "Coping and Maturity". These show the macroscopic picture of Cai's moderate head injury recovery.

The interviews at two weeks and three months provided a unique insight. They showed Cai initially demonstrating general acceptance of the restrictions and head injury at two weeks before becoming aware by the three-month interview of the impact of the restrictions and head injury on all aspects of his lifeworld, leading to a drastic change in his perception. Roscigno et al. (2011, p. 888) discussed "Longing for Everydayness", which they described as their participants adjustment process from their old self (preinjury) which was at times in conflict with their new self (life after a head injury). This phrase is useful for further

understanding Cai's lived experiences. For example, Cal longed for normality with respect to friendship, family and sporting interests, but when these were affected or unattainable, anger and frustration were evident in his responses during interviews. Even when some semblance of returning to normality was attainable (when the restrictions were removed), a new Cai emerged who was more cautious, a risk assessor rather than risk taker – somebody who had become very aware that accidents happened and that the decisions he made could severely affect his lifeworld.

Further interpretation of the findings showed additional similarities between Cai's recovery processes and those of others who have recovered from head injuries. Battista et al. (2014) highlighted the link between head injuries and changes with identity, family dynamics and independence, and post-traumatic growth. Identity, in particular, featured quite prominently in Battista et al.'s (2014) findings, which my study's findings reinforce. In contrast, participants in Battista et al.'s (2014) study reported that they were happy with their perceived quality of life (at over four and a half years post injury), which is different to Cai's experiences – he was still coming to terms with elements of his post injury self. Cai's relationships had appeared to return to normal, but he struggled with returning to rugby and motorbiking.

In conceptualising why Cai did not fully adhere to his restrictions (placed on him by the health professionals and enforced by his mother), it would not be right to view this as blatant defiant behaviour. Rather it was a way for Cai to gain back some control over his life and a way by which he improved his own resilience to what had happened to him (head injury) and what was happening (recovery). This also directly leads into his coping with the loss of things

that were dear to him. Cai valued friendships and even though his friendships were altered by the restrictions placed on him, he adjusted the dynamics of these friendships in order for him to fit in with what was expected of him and to cope with the loss he experienced.

Emergent Themes		Subordinate Themes
"I used to get angry" but I understood why	}	Not Being Allowed
"Rugby is Important" and loss of identity		
"Family is important" but dynamics change	}	Relationships Do Change
"I've lost contact" but it's okay now		
"My head would be fine" – a battle for normality	}	Coping and Maturity
"I wouldn't say it before" – a change in perception		
Being a "Rebel"		
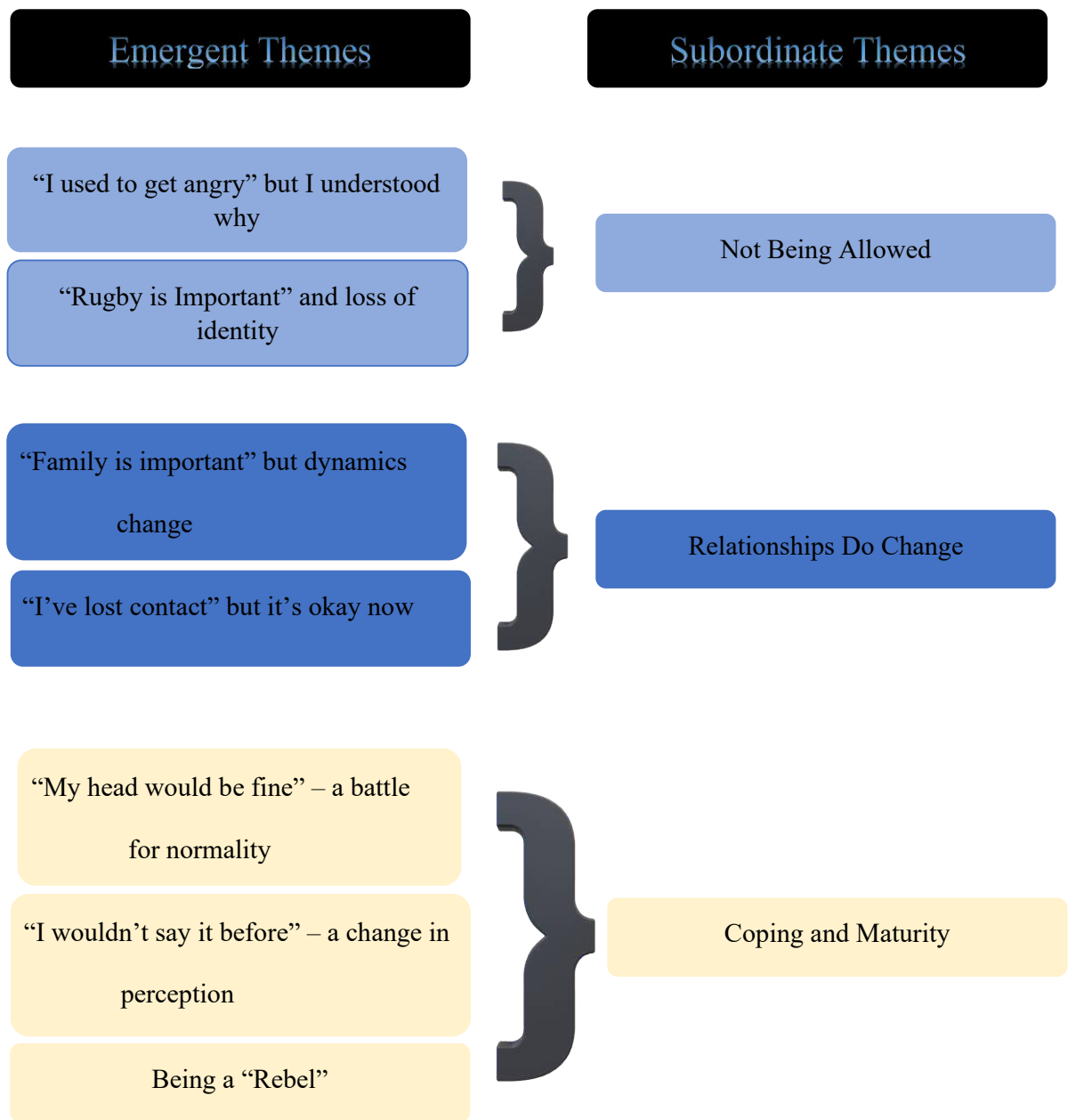
Figure 6-1: Formulation of Subordinate Themes from Emergent Themes.

6.2.3 Cai's Three Unique Idiographic Elements:

- Significant differences are noted between two weeks and three months in relation to Cai's lived experiences

- Identity was drastically affected by head injury and subsequent restrictions

- Even when the restrictions were removed, normality was not attainable immediately.

The next idiographic case will present a longitudinal view of Betsi's recovery and will explore a nine-month period.

6.3 Idiographic – Betsi

The second idiographic case is that of Betsi, an 11-year-old girl who sustained a frontal head injury following a collision with a car whilst crossing a busy road near to her home. At the time she suffered retrograde amnesia, experienced a soft tissue injury to her leg and received a scar on her forehead that continued to cause her some distress, both physically and psychologically. Betsi spent seven days in hospital, including in the critical care and neurosurgical wards. From a neurosurgical perspective, she required a frontal burr hole to drain an extradural haematoma; no other surgical intervention was required.

Like Cai, Betsi lived with her mother but, unlike Cai, her father was still alive and became a topic of discussion within the interviews. Betsi was interviewed at two weeks and three, six and nine months after her head injury, with her mother (Gwen) being interviewed at six and

nine months. Gwen's interviews will be explored in a separate idiographic analysis (section 6.5).

As is routinely the case with a CYP's head injury (and as seen with the other CYP interviewed), to keep Betsi safe and to reduce the risk of any further head injury she had restrictions placed on her; these included avoiding any sporting activities and leaving her school lessons early to avoid the busyness of school corridors. However, these restrictions and the injuries from the accident had a noticeable effect on her lifeworld.

This section will further explore how these restrictions, recovery from her head injury affected components of her lifeworld and how her lived experiences presented over the nine months, that she was involved in the study.

The three subordinate themes derived from Betsi's emergent themes and data are:

- Imposed Restrictions
- Alteration in Relationships
- Resilience and Maturity.

6.3.1 Descriptive Analysis of Emergent Themes

Betsi, like Cai, appeared to enjoy the interviews and having the opportunity to discuss matters (like friendships) that were important to her. Using SEIQoL contributed to this: Betsi liked the focus of each interview and appeared to like the process, once she had overcome some

initial nerves. In the interviews with her mother (Gwen), Betsi would often make an appearance and add to the interview. She appeared close to her mother, which became apparent not only during the interviews but also in the dialogue surrounding them. For the purpose of an IPA approach, both Gwen and Betsi need to be separated idiographically in order to answer the research question and to understand how Gwen and Betsi are individually affected by Betsi's head injury. However, their lifeworlds are closely intertwined, which will be demonstrated here and in Gwen's idiographic analysis.

The following sections will discuss the emergent themes that arose from Betsi's interviews, which eventually form the subordinate themes that will be presented diagrammatically at the end of Betsi's idiographic discussion (Figure 6-2, section 6.3.2).

6.3.1.1 *"You can't do anything"* – but I remain worried

This emergent theme focusses on how Betsi dealt with the restrictions placed on her. In the first interview, at two weeks, Betsi clearly stated her feelings and the frustration that she felt. Her choice of the words "*bad*", "*Every day*" and "*bored*" accentuated her negative feelings about not being able to do the activities that she had undertaken before the accident. She felt that she could not do anything, pointing to an emptiness, a void in her lived experiences.

"No, it makes me feel bad. Every day I'm bored" (Transcript 1; lines 729–30).

"'Cause you can't do anything" (Transcript 1; line 735).

Betsi's feeling of boredom also resonated in the second interview. Here she talked about getting a dog, something that she had longed for. She wanted to play with the dog which she saw as a way to help with her feeling of boredom she encountered with the restrictions and

her physical ailments; looking forward to getting a dog was also a coping strategy for Betsi. Her mother had said to Betsi that they would look at buying one, which is something that Betsi looked forward to, which kept her positive.

"At least I can sit down here and do something with the dog" (Transcript 2; lines 258-60).

Further along in the second interview, Betsi portrayed herself as someone who appeared to have accepted the restrictions placed on her, which is partly evidenced in the following extract. In response to a question about cycling and how she felt about not being able to, she replies "*Well I know I can't*" indicating that she accepted the restrictions. In this extract she acknowledged the risk that a further head injury would pose to her and clearly stated that she needed a helmet in order to cycle. The second part of the extract also shows that even if she had a helmet, it would not fit on her head. This could be related to her forehead scar and how a helmet may not fit as a result of the head injury.

"Well I know I can't, well I need a helmet to start with and if I do have a helmet, I can barely get it on my head" (Transcript 2; lines 650–2).

In the third interview, Betsi continued to demonstrate an acceptance of the restrictions and of her not being able to cycle as her physical injuries were still present, even though they were improving. Betsi demonstrated a largely positive approach towards her feelings (which will be explored in the "'*It's going to take five months*' – but it will take longer" theme), which is shown in the first extract. When asked about how she felt about cycling, she changed from being positive to displaying feelings of being disheartened and dispirited, which is demonstrated in the second extract. She used the term "*slumped*", which is a powerful descriptive word to emphasise her feelings and was related to an earlier conversation where

she had sat on the saddle of her bike (in her garden). An example of how the restrictions imposed on Betsi denied her the opportunity to partake in activities she enjoyed.

"I felt like, um, I felt like I'm almost there, I'm going to be outside soon"
    (Transcript 3; lines 397–9).

"I just slumped back in the saddle" [in response to question enquiring about how
    she felt about not being able to cycle] (Transcript 3; line 404).

The following extracts from Betsi's final interview, when all her restrictions had been removed and she was able to resume all of her preinjury activities, show her concern and her worry: "*I can't… I'm scared*" and "*could hit*". These powerful emotions/words highlight the magnitude of her concern over the risk of reinjuring her head – the residual anxiety she was being forced to contend with at the end of the study period.

"In case my leg goes, and I can't ride and I'm scared I'm going to fall" (Transcript
    4; lines 256–8).

"I could hit my head" (Transcript 4; line 261).

6.3.1.2   "*Over, overprotective*" – an impact on identity

Betsi identified friendships as being very important to her both socially and in terms of her self-identity. The following extracts give an insight into Betsi's happy relationship with her friends before the accident; here she talked about going out with her friends to the shops, park or café – her view of normality. She described her family as being "*like family*" that you can "*have forever*", pointing to her view of a permanence to friendship.

"Happy because they are like family… you can have forever" (Transcript 1; lines
    292–3).

*"If we were both happy then we'd have something to eat there or and then we'd go
to the park, park next to it, and if the café wasn't open we'd go, and if we
had money, we'd just go to Aldi's"* (Transcript 1; lines 697–702).

However, Betsi's preinjury friendship dynamics were dramatically altered by her head injury. Interestingly, whilst earlier she had compared her friends to being "like family", her later answers demonstrated some tension with her friendship group as Betsi perceived them as being overprotective. This overprotectiveness emerged from her friends' concern and from Betsi's mother asking some of them to keep a watchful eye on her. In the following extracts she used negative, emotive language to describe her feelings – "*no*", "*sit down*" and "*not letting*", pointing to how her emotions are embedded in her friends being protective of her. She felt that her friends were being protective of her because they cared for her – a dichotomy of feelings where she liked them enough to consider them as family, but they also annoyed her, which Betsi did not like.

"I was going, 'oh I'll go out' and they were going, 'no you sit down'" (Transcript 1;
lines 716–18).
"They're not letting me do anything fun" (Transcript 1; lines 834–5).

Furthermore, Betsi seemed to struggle with her lack of autonomy in terms of decision making – her identity was directly affected in that she could not make her own decisions. Betsi used the term "*should*" to highlight some uncertainty over this though, hence showing some confusion between what she can do and what she would like to do.

"Over, overprotective, like my dad now" (Transcript 1; lines 815–16).
"I think I should be able to make my own decisions" (Transcript 1; lines 881).

In the second interview, there was a deterioration in how Betsi spoke about her friends. Betsi perceived her friends as a continued negative influence on her sense of self and personal identity. This can be seen in the extract "*you just sit there*" – a well-meaning attempt by her friends to limit any involvement in physical education and therefore reduce risk, which Betsi perceived as breaching her autonomy.

"It's like I know they're trying to like help me and like take care of me and make sure I don't hurt myself but they're like saying, 'ah no thank you, you just sit there'" (Transcript 2; lines 420–4).

In the following extract, she felt that her closest friends did not trust her; they wanted to look after her, and when asked how she felt about this, she replied "*Bored and upset*" (Transcript 2; line 435); the term "*upset*" in this context indicates a negative emotion that is embedded in altered friendships. Betsi was more exasperated with her friend's overprotectiveness, more than during the first interview, causing her to feel annoyed. Betsi's views were also conflicted here: she wanted to sit on a bench with another one of her friends who had a physical injury, but her mother had specifically identified which of Betsi's friends could look after her. This highlighted Gwen's anxiety and the continuing impact on Betsi's autonomous self-identity of her mother asking her friends to enforce and/or oversee some of the restrictions. Betsi used the term "*specifically*" to highlight her mother's direct wishes and Betsi's reluctance to disobey them.

"Because they don't trust me enough, and today [names friend A], or my friend [names friend B], she irritated me in school. She [names friend A] and there was [names friend B,] when she popped last time, so she's on crutches but in PE couldn't me and [names friend B] just share a bench…? 'How are you going to look after Betsi?' and ''cause I'm supposed to look after Betsi' but my mum's specifically said [names friend C]" (Transcript 2; lines 439–453).

At six months, Betsi continued to feel that her friends were overprotective, which continued to affect her identity. In the extract below, Betsi used negative, emotional-based responses to highlight her feelings towards a friend: "*get back in here now… moan, moan, moan and… shut up!*" The way that Betsi repeated the term "*moan*" three times highlighted the extent to which she found her friends "*annoying*". The term "*get back in here*" points to Betsi's loss of freedom and autonomy, where her friends are not behaving typically as friends would, as they have taken up a proxy parenting role as requested by Gwen – leading to a reduction in friends that she can relate to. These emotions are encapsulated by Betsi saying "*shut up*".

"I know she's trying to protect me but it's like basically she, she's being a bit too
    overprotective and if I do want, if I go outside for like five seconds she's like,
    'get back in here now' and moan, moan, moan. It's like, shut up!"
    (Transcript 3; lines 596–602).

The following extract further demonstrates Betsi's changed social standing with her peers; she gets called "*lazy*" but also "*lucky*" for not doing PE. Betsi also implied that the name-calling and her annoyance at this had increased over time. These comments highlight the issues with restrictions that were put in place to keep her safe but were also having a negative effect on Betsi's identity. She did not see herself as being lucky, far from it.

"People call me like lazy and they say like, 'ah you're lucky' but I'm not lucky"
    (Transcript 3; lines 708–710).

In her final interview, at nine months, Betsi reported that she was gradually returning to participating in sports and PE, the name-calling had stopped and her friends had returned to how they were before the accident, facilitated by the removal the responsibility put on her

friends to keep an eye on her. By her friends treating her as they did before, Betsi regained, or was working towards regaining, her "normal" social identity within the school setting. This was demonstrated in the quote below – in answer to the question, "Do you think your relationships with your friends have gone back to how they were before (the accident)?", she simply said:

"Yeah" (Transcript 4; line 796).

When asked about why Betis was not engaging with the full PE lesson, she replied "*my legs*", pointing to her other physical injuries (as she was having spasms in her knees). Betsi's legs were also a source of anxiety for her; she was worried that her legs would fail her – "*in case my leg goes… and I'm scared I'm going to fall*". Betsi had to contend with ongoing physical injuries and psychological worries, even though she had been discharged from neurosurgical services. These worries did not impact her enough to stop her doing a full PE lesson, as shown in the first extract, and as such she maintained her identity in that respect. However, Betsi seemed to be continually aware of her ongoing physical injuries (extract 2).

"Kind of" [in relation to being back to PE and games] (Transcript 4; line 813).
"'Cause I keep having spasms in my knees." (Transcript 4; lines 874–5).

6.3.1.3 **"They never did it before" – a changing family**

In Betsi's first interview, she demonstrated complex emotions. In the first extract, she described a strong bond with her family ("*they've always got my back*") and that she felt supported and loved. However, the following extracts show a change in how she viewed her family, particularly her father and aunty. Prior to the head injury, Betsi did not normally see them because her parents were separated, and she lived with her mother. Since Betsi's head

injury, her father had started to visit her and offer support. This was a change in the family's dynamics and not one that Betsi was completely at ease with (exampled in the second extract), nor was she completely happy with the level of attention shown. The fourth extract also shows she wasn't quite at ease with the generosity being shown, where more biscuits were purchased than required. However, she did not voice her feelings to her father (exampled below when she ate more cookies than she wanted). Betsi showed a dichotomy of emotions: she used "*nice of him*" followed by "*annoyed*" to describe how she felt.

"Well I think, well I know they've always got my back and um, I love them" (Transcript 1; line 313–14).

"My dad and my aunty. No, I don't, I know, I know they love but they're just touching. Rub my back or my knee. Like I got scabs on my knees, my head's hurting" (Transcript 1; lines 342–6).

"Well they never did it before" (Transcript 1; line 360).

"Well, if I don't ask, or if I ask for like cookies then he brought me two plates of cookies and I didn't want them but I ate them though. They were really nice so it was nice of him but I only wanted one" (Transcript 1; lines 383–8).

"Annoyed" (Transcript 1; line 399).

At three months, a similar profile is seen. Betsi felt that her dad was "*nice*", and their relationship was improved, largely because Betsi's father was not over-compensating as before. However, the extracts below also reveal that Betsi's relationship with her father, within the context of her recovery, was not altogether without tension. Here she expressed sadness about her father's lack of understanding about her vulnerability to sustaining a further head injury, and about the language he used when speaking to her – the use of the word "*tart*" points to a lack of respect and discourtesy, together with being an unusual term to refer to a daughter.

"It's okay. Well my dad's being really like nice to me but he, he kicked my bum and
    I could have gone, I could have hit my head on the table or the tray"
    (Transcript 2; lines 765–9).

"'Ah don't be such a little tart.' He always calls me that" (Transcript 2; lines 779–
    81).

"Yeah, he's not bad" [reference to overprotection] (Transcript 2; line 804).

In terms of her mother, Betsi accepted her overprotectiveness, stating "*Yeah but it's only*

because she loves me" (Transcript 2; lines 830–1). This is an example of a hot cognition,

which implies warmth and affection. In addition, the acceptance of the restrictions from her

mother suggests a mature insight into relationships which contain a mutual respect.

At six months, Betsi's narrative indicated a further deterioration in her relationship with her

father. The extracts below are laced with negative emotions and perceptions, including

"*attitude*", "*don't deserve*" and "*prat*", which describe how Betsi viewed her relationship.

 "Dad says he wants to like, ah, you are, if I come around then my dad's been giving
    me attitude what I don't deserve" (Transcript 3; lines 1059–61).

"He's a prat!" (Transcript 3; line 1109).

At this point in her recovery, Betsi did not mention anything positive about her father.

However, she did reveal some mixed emotions, stating "*I just want him to be here*"

(Transcript 3; line 1089–90), indicating that her father is around less and, even though she

found that his presence was sometimes a negative factor during her recovery, she would have

liked him around. This highlighted the fact that she missed him.

In Betsi's final interview, she talked briefly about the duality of the parental role of her mother, who functioned as both mother and father. She felt that her mother was always there for her and was a constant in her life. However, her view of her father had further deteriorated – she used the terms "*waster*", "*buy love*" and "*horrible*" to describe him, which are negatively infused terms. Betsi did say that he was previously a "*nice father*" suggests that this was the state of affairs before the injury.

"She's always been my mum and dad" (Transcript 4; lines 709–10).

"He was a nice father, again to me he's just a horrible person" (Transcript 4; lines 601–2).

"'Cause he's just a waster. He, he, he tries to buy love" (Transcript 4; lines 607–8).

6.3.1.4   **"It's going to take five months" – but it will take longer**

In the first interview, Betsi contemplated her recovery taking five months; however, she measured her recovery not only as the time taken for her head injury to heal but also in terms of the time taken for the recovery of her injured legs, which caused her the most discomfort. She used the term "*going on and off*" which forms images of a switch or a machine that in this context she disliked as she had little control over it. As demonstrated elsewhere in this thesis, Betsi's recovery (and the recovery process more generally) is better seen as multi-factorial, and that those exploring recovery from head injury should also take into account other physical or behavioural issues.

"I think it's going to take five months to get me better" (Transcript 1; lines 986–7).

"I don't know really because my legs just keep going on and off. I just don't like it" (Transcript 1; lines 998–1000).

153

At three months, Betsi's views of her recovery were very different: she suggested that it would take "*1,000 years*", which indicated the frustration she was feeling about the length of time her physical recovery was taking. This reflected a feeling of helplessness at not knowing when it would end, where a 1,000 years alludes to a time without end. Interestingly, in talking about her recovery, she used the word "*even my head*", which gives the impression that the injuries to her knee and elbow and her general discomfort had at least as much, if not more, of an impact on her lived experiences as did her head pain.

"In 1,000 years" (Transcript 2; line 923).

"I recovered quite well (unclear) but then I got better and then ever since like I've gone to school it's not like every day but like a couple, well most days, um I've come home and with like my knee hurting, um, my elbow. It's just like, like every, like most days I'm like hurting all around, even my head" (Transcript 2; lines 934–41).

In the third interview, at six months, Betsi continued to feel that her physical recovery was going "*slow*" and that her lack of activity (caused by her physical pain) was hampering the recovery of the leg injuries. Betsi wanted to do more exercise to strengthen her legs and for her legs to heal. She also voiced some concern, interestingly, over not understanding what was wrong with her head and whether it was healing; this was highlighted by her repetition of the words "*I don't*". These extracts also show a change in focus: previously her general discomfort was the problem, at this point her head recovery took priority.

"Slow" (Transcript 3; line 948).

"Well, I had. Well really, I've just been staying inside 'cause I, I have been trying to keep it, it's mainly because of my head but I need to do more exercise to get my legs working. I haven't had much. I just want this to heal. I don't, I don't even know whether it's healing" (Transcript 3; lines 953–60).

154

"I don't even know what's wrong with it" (Transcript 3; lines 965–6).

At this time, Betsi also remained resilient during her recovery and her outlook on life changed, as seen in the following extracts. She felt that she was not positive in the past and acknowledged she has "*got to try to be positive*". In both extracts below she gave examples of this: "*I will be able to ride my bike*" and "*I'm almost there, I'm going to be outside soon*". Here, she focussed on things that were important to her, which anchored her positive thoughts.

"I know, I know it's not going to be for a while yet but at one point I will be able to ride my bike, so I've just got to be positive. I'm, I'm never positive before and I've just got to try to be positive" (Transcript 3; lines 379–84).

"I felt like, um, I felt like I'm almost there, I'm going to be outside soon" (Transcript 3; lines 397–9).

In Betsi's final interview, she appeared more optimistic about her future recovery. She felt that her recovery would take a year. Also of interest is that she commented that she would never make a full recovery, just "*85*" per cent. This appears as a resignation to never achieving her preinjury health. The fourth extract below shows some of the causation for this negativity: she used the term "*chop them off*" to accentuate the magnitude of her frustration with her legs and the discomfort that they were giving her.

"In a year" (Transcript 4; line 896).

"Yeah, not 100" (Transcript 4; line 902).

"85" (Transcript 4; line 910).

"Yeah… Can't I just chop them off?" [in relation to legs] (Transcript 4; line 937).

6.3.1.5 "I've got to try to do stuff by myself" – a view into maturation

This theme offers an insight into how over the course of nine months of data collection Betsi had matured; this maturation was not actively looked for but nevertheless became evident as the transcripts were analysed. In the first transcript, Betsi identified her "teddy bears" as an important element in her life. She showed signs of embarrassment when selecting them which highlighted an awareness of what she thought was inappropriate for her age. The following extract shows a concrete statement, a statement of fact:

"My teddy bear is important to me…" (Transcript 1; line 70).

At three months, Betsi demonstrated a sense of self-awareness when she described her mother crying, hence showing consideration for her mother's feelings and a willingness to understand. Betsi also enforced her description by using a strong emotive term, "*hate*", to describe her feelings about the subject of the second extract: she wanted her mother to come to her, to turn to her for support. But, as seen in the third extract, her mother did not and Betsi felt that her mother still regarded her as a child, a view of how Betsi saw her mother's perception of her.

"No. I hate her crying" (Transcript 2; line 1027).
"I don't feel like she comes to me when she's like upset" (Transcript 2; 1031–2).
"'Cause I'm a kid. She feels like I'm not responsible like I'm just a child"
    (Transcript 2; line 1038–9).

Betsi's six-month interview was influenced by the recent death of her grandfather. In the first extract below, Betsi showed an increase in her awareness of the fragility of life – of ageing and mortality – when she mentioned that her mother might not be there in the future. She was quite matter-of-fact in her views, which were influenced by her recent life experiences. Betsi

acknowledged she had matured, which was evidenced by the quote in the first extract, "*I've grown up*", and which also alludes to how she viewed maturity as a dynamic process. Her awareness of her teddy bear not being there also points to this maturing. The second extract shows a willingness by Betsi "*to do stuff by myself*", which points to a need to self-manage, to look after herself – and her use of the term "*I've got*" shows determination.

"I hate to say that but at one point none of them will be here. I've grown up, my teddy bears might have gone, and my mum might have gone by then" (Transcript 3, lines 274–80).

"So, I've got to try to do stuff by myself" (Transcript 3; line 284).

The following extract, from the nine-month interview, shows a mature response to her recovery when discussing her cycling. Betsi was aware of her own ongoing physical restrictions; therefore, she remained cautious but optimistic and used a mature, articulate idiom to convey her thoughts: "*one step at a time*".

"Because it's like one step at a time. Like when you walk, you don't want to run and you don't want to gallop, you just want to walk" (Transcript 4; lines 333–6).

6.3.2   Interpretation

Betsi's recovery shows a complicated trajectory which was physically multifactorial (head and leg injuries) and deeply embedded in her relationships with family and friends. Her family life was complicated by the re-emergence of her father, which occurred as a direct consequence of the accident, and by the death of her grandfather, which triggered Betsi to reflect on life and death during her recovery. This highlighted that during the recovery process life events continue to happen and that these events influence the recovery trajectory and lived experience of the CYP. As with Cai at the end of his participation in the study,

157

Betsi was still on her recovery journey. Betsi's experience will be interpreted here in relation to key literature, focussing on three subordinate themes (see Figure 6-2): "Imposed Restrictions", "Alteration in Relationships" and "Resilience and Maturity".

A key insight into how Betsi viewed her friendships post head injury was touched upon in this idiographic discussion. Betsi often described how her recovery process and the imposition/enforcement of restrictions altered friendships and influenced her sense of autonomy and self-identity. Roscigno et al. (2011) highlighted similar findings when describing how CYP can be exposed to a lack of empathy from other people which can lead to social isolation. Betsi's experiences of alienation during PE is reminiscent of these findings. Roscigno et al. (2011, p. 890) used a term "longing for their old self" which can be utilised to describe Betsi's feelings of her friendships, especially with their perceived overprotectiveness and her loss of identity – here she longs for her "old self" and her need to be treated normally.

In understanding the alterations in the family relationships that Betsi experienced, Clark et al's (2008) exploration of attachment theory proves useful. For example, Clark et al. (2008) described this theory as keeping one's children from danger and protecting them. In Betsi's case, her father's reappearance in her life was well meaning but disruptive – before the accident, he did not see Betsi routinely. This change to seeing her regularly in the initial stages of her recovery returned to a preinjury level of engagement shortly afterwards – causing significant changes in her family dynamics. The father's behaviour could be seen as a way of protecting her but also alludes to a sense of guilt. In a study by Brown et al. (2019) that researched paediatric burn injuries, the authors looked at parental guilt as a factor. Here

we could hypothesise that the showering of Betsi with gifts by her father and his increased presence in her life was a form of excessive reassurance, which Brown et al. (2019) described as a distress promoting behaviour. These findings by Brown et al. (2019) correlate well with Betsi's view of this overindulgence: she found it annoying. Her father's presence in her life triggered Betsi to reflect that she simply wanted him to be present, but as her recovery progressed, he returned to his preinjury involvement, having little contact with Betsi, which understandably resulted in negative and emotive outbursts about him being expressed. However, whilst her father's behaviour was viewed largely negatively by Betsi, the overprotectiveness of Gwen was tolerated, as this was seen as her role as Betsi's mother.

Betsi adopted strategies during the nine months of the study to aid her resilience and showed changes in her maturity. At times she showed frustration and anger, but analysing the interviews longitudinally using the hermeneutic circle reveals that she considered her actions and attempted to remain positive about her recovery. This behaviour resonates with the findings by Battista et al. (2014, p. 980) who describe positivity and maturation as components of "post-traumatic growth" and coping. Their participants saw their experiences as ways to raise achievement levels and focus the mind. Roscigno et al. (2011, p. 887) also touched upon similar findings and named them "It is not all bad", thereby indicating that Betsi's ability to cope, her resilience, had a similarity with other CYP who were recovering from a head injury.
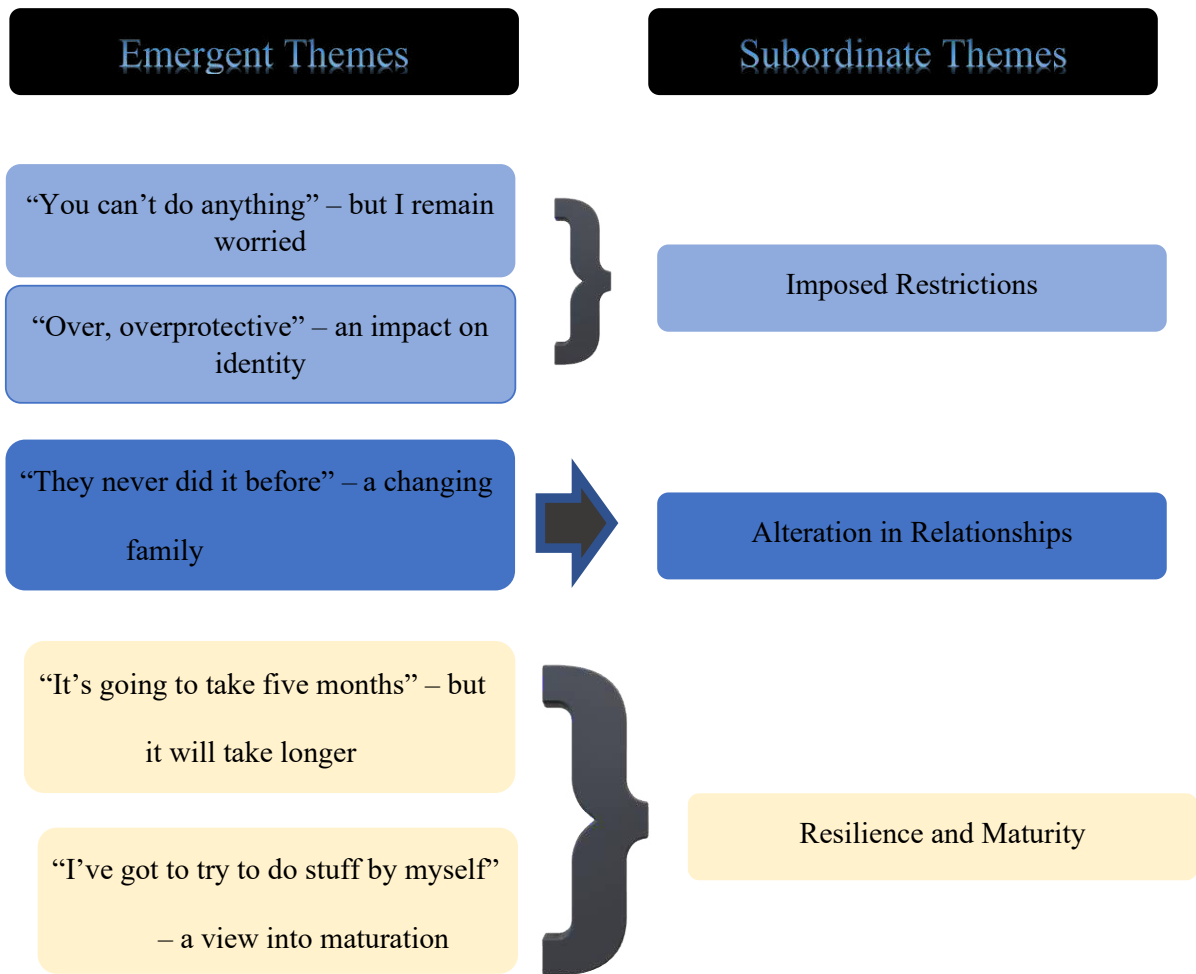
Figure 6-2: Formulation of Subordinate Themes from Emergent Themes.

6.3.3   Three areas of learning

- Recovery from a head injury needs to be synergistically monitored alongside other physical ailments

- Parental changes as a result of the CYP's head injury can be transient as well as having longer-term implications

- Betsi's lifeworld was directly affected by significant life events – including the death of her grandfather.

The next idiographic case will present a longitudinal view of Afan's recovery and will explore a nine-month period.

6.4   Idiographic – Afan

At the time of his accident, Afan was 11 years and 10 months old. He lived at home with his mother and two brothers (16 and 6 years old) in a rural coastal town and attended the local mainstream comprehensive school. His parents had recently separated. He lived with his mother, but he continued to have some contact with his father every fortnight. I interviewed Afan at two weeks and three, six and nine months post head injury. His mother Ffion was also interviewed at six and nine months which will be explored in a separate idiographic analysis (section 6.6).

Afan was hit by a car whilst crossing the road. He suffered an extradural and subdural haematoma and had some retrograde amnesia. To maintain Afan's safety for the journey to the local paediatric neurosurgical centre, he was intubated for retrieval (transport). He spent nine days within the centre where he was also diagnosed with lung contusions. He did not require an operative procedure in the treatment of his cerebral bleeds as these self-resolved. His main problems noted at the first interview were unsteadiness on his feet and short-term memory loss. Afan's reintegration into school started approximately two weeks after discharge, but he had restrictions placed on him by the medical team and enforced by his parents for six months. These restrictions were comprised of avoiding activities that might involve him injuring his head such as PE, games (including rugby and football); leaving lessons slightly early as to avoid the busyness of the school corridors; and avoiding parts of the school playground where ball games were played.

Afan's assent was always checked at the start of each interview and he was happy to participate. Afan was a quiet person who did not fully expand on his thoughts and feelings. His choices of QoL factors were centred around his physical interests (such as football and rugby), his friendships and playing on the PlayStation. As a strategy to get maximum engagement from Afan, the conversations were focussed on these interests and the results were then analysed, using a double hermeneutic approach, and organised into the themes discussed throughout this chapter.

The three subordinate themes (see Figure 6-3) that emerged from Afan emergent themes are:

- Cost of Restrictions
- Family and Friends do Worry
- Coping and Being Positive.

6.4.1   Descriptive Analysis of Emergent Themes

6.4.1.1   "*Just miss it!*" – a transient sense of loss

At two weeks post head injury, Afan described football as being important to him; this was clearly illustrated by being the first QoL factor he selected. He showed pride in being a striker. He had accepted the restrictions placed on him by the clinical team by confirming that he was not playing football and felt "*fine*". He did not elaborate any further on these feelings and appeared definite in his answer regarding football. However, in response to rugby he appeared to hesitate slightly with an "*um*", thereby indicating some doubt about being "*fine*" about not playing.

"Fine". [In relation to not playing football] (Transcript 1; line 361).

"Um, fine". [In relation to not playing rugby] (Transcript 1; line 430).

During the second interview, Afan presented himself very differently compared to the first interview. Here he expanded on his thinking by saying that he missed football, before becoming upset and crying. This is highly significant as his crying is an intense display of negative emotions, likely to be a consequence of the restrictions placed on him and the sense of loss they created. The three extracts below show the difficulty that Afan had in articulating his feelings; the first two are his responses to whether he missed football and the third is his answer to how he felt about it. The difficulty he had in articulating his thoughts may have provoked frustration which, in turn, possibly led to the episode of crying. Therefore, his crying can be viewed as a way of him demonstrating his sadness/frustration/loss – an instance of non-verbal communication. In the first interview, Afan appeared relaxed, content and happy; however, in the second interview he appeared more anxious, unsettled and less content with the way he perceived saw his lifeworld with the imposed restrictions.

"Just miss it!" [Became upset and cried] (Transcript 2; line 443).

"A bit". (Transcript 2; line 470).

"I don't know". (Transcript 2; line 475).

In the next interview at six months post head injury, Afan appeared more expressive at describing his emotions. For example, his choice of words, which he used to describe his feelings of being unable to play football, was loaded with negative connotations: "*frustrated*", "*can't*" and "*annoyed*". These words echo some of Afan's emotions demonstrated in interview two, but his expression of loss had increased. He used short "concrete" statements

to describe his feelings and did not expand any further why he felt like that but, nevertheless, he adequately communicated his thoughts:

"Yeah, Frustrated" (Transcript 3; line 266).

"Because I can't play!" (Transcript 3; line 271).

"Annoyed!" (Transcript 3; line 279).

At nine months Afan's feelings were in contrast to his interview at six months. Here, Afan used positive language to describe his feelings. As usual, he did not expand on his feelings and merely stated that he was "*happy*" and "*good*". These feelings were embedded in the removal of the restrictions placed on him and the permission to return to playing football and rugby. These can clearly be viewed as important aspects of his preinjury lifeworld, and a return to the activities that he enjoyed triggered positive emotional descriptors such as "*happy*" and "*good*".

"Happy" [in relation to his view on football] (Transcript 4; line 54).

"Good" [view of football] (Transcript 4; line 119).

For Afan, the imposed restrictions resulted in a significant change to his lifeworld which he was not immediately aware of. At two weeks he appeared fine with the restrictions but at three months, the full realisation of them became obvious; where he became upset and cried. It was not until we saw the removal of his imposed restrictions that we saw Afan's feelings improve towards football and rugby. However, even at nine months, he did show some reluctance to engage fully with rugby, alluding to some residual psychological concern over reinjuring his head. Preinjury, he played full contact rugby; at nine months, he was only playing touch rugby – minimal-contact.

6.4.1.2   **"*Because I can't go out!*" – a struggle for identity**

This theme will explore how Afan's identity was changed by the restrictions placed on him and how he regained his independence; it will also explore his increased usage of the PlayStation (a gaming console). The PlayStation will be viewed in this theme as a social enabler which enabled Afan to communicate with his friends; Afan also used it as a compensatory strategy, helping him accept the loss of his sports. Viewing the PlayStation as a social enabler makes it possible to visualise how Afan's identity was affected.

The PlayStation proved important for Afan during his recovery, and he rated himself as happy *("I'm happy*": Transcript 1; line 303) with it during the first interview. Interestingly, he seemed to replace the time he would have spent playing outside (as he was unable) with playing on the PlayStation, particularly the game FIFA 16 (football game). He also found a different way to socialise, not during football/rugby games but by using the PlayStation's social network, PlayStation Plus. This formed an adapted way of expressing his identity and it is possible to infer that he used PlayStation Plus prior to the head injury but with a lesser degree of usage. Prior to the head injury he played outside frequently (from field notes) but since the accident, he communicated/socialised with friends with the PlayStation. The following extract confirms this with a simple "*Yeah*"; a matter-of-fact term which he did not expand on, implying that he had no negative feelings about it.

Interviewer: "Do your mates go on there as well?" (Transcript 1: line 477–8).

Afan: "Yeah" [response to playing with friends on PlayStation Plus] (Transcript 1; line 480).

At three months, he was not very forthcoming about how many hours he played the PlayStation, but he eventually said that it was more than before his head injury. The first two extracts offer very brief answers to enquiring questions. Firstly he answers "Yeah" in response to being asked if he saw the PlayStation replacing his football and rugby, and secondly "No" to being asked if he saw it giving him the same satisfaction; these replies highlighted that the PlayStation, even though it replaced his football and rugby, did not give him the same enjoyment. This suggested that he was okay with continuing to use the PlayStation as a way of expressing his identity – a way to socialise via gaming – but it did not give him the same satisfaction and could be seen a temporary coping measure. The third extract clearly states why his use of the PlayStation had increased: "*I can't go out*". In a conversation in which Afan mainly gave brief answers, this longer extract is significant as it is a negatively based statement. This implies that he felt confined or restricted to the house, which suggests some of the reasons his usage of the PlayStation increased.

"Yeah" [felt the PlayStation was replacing physical football and rugby] (Transcript 2; line 820).

"No" [Do you think FIFA 16 gives you what you're missing in the football?] (Transcript 2; line 865).

"Because I can't go out!" (Transcript 2; line 791).

At six months, a further change in his usage of the PlayStation was noted. Here, he commented that he did not get the same satisfaction from it as before; he used the term "*A little bit*" in a non-committal way to communicate this. In the second extract, he added that the PlayStation was also a source of frustration for him; this mirrored the frustration he felt about not being able to play football or rugby (frustration seen in the interview and in discussions outside the interview).

"A little bit" [do you get the same sort of satisfaction playing PlayStation 4 games?]
(Transcript 3; line 502).

"Yeah" [response to feeling frustrated] (Transcript 3; line 508).

In his final interview, he felt that he played a similar amount of time on the PlayStation as before the accident. His reduction in time spent playing on the PlayStation was confirmed by a simple non-descriptive "*Yeah*", which indicated that he was content with this reduced usage and that the amount of time spent on the PlayStation resembled the amount before the accident, indicating a return to his preinjury state.

"Yeah" [But do you think you play less because you're playing outside more?]
(Transcript 4; line 694).

The previous theme "'*Only by the garage!*' – defiance but a way of coping" has showed that Afan had decided to play some football regardless of his restrictions, but that this did not help him regain his preinjury identity. It was only when he could enjoy playing with his friends (including football) with no restrictions in place that his sense of satisfaction and identity had returned to a preinjury state, thereby suggesting an importance of friendship in maintaining and re-establishing a sense of identity. The fluctuating and fluid sense of identity was also evidenced in this theme through his increased or decreased PlayStation usage.

6.4.1.3   *"Because I banged my head!"* **– I knew that my family were worried**

During the first six months, Afan did not make any reference to family and did not form a topic of discussion. This indicated that Afan saw no change in his family dynamics. However, at nine months, in Afan's final interview, two important facts emerged. First, Afan

felt that his parents treated him the same at this point as before the accident and parented him the same, but he understood that they were more worried – he saw no change here which was represented by simple replies "*Yeah*" and "*No*" to convey this (and, as usual for Afan, he did not expand any further).

Secondly, Afan admitted that his parents had increased their concern/anxiety for him, which is evidenced in the third extract "*Yeah*"; he acknowledged in the final extract below that this was due to his head injury. His use of the term "*banged*" was a simplistic description of his head injury which indicated that he was not too worried about it whilst possibly being unaware of the seriousness of the injury.

"Yeah" [... Do they still treat you the same? Your mum and dad?] (Transcript 4; line 863).

"No" [Yeah? No different?] (Transcript 4; line 867).

"Yeah" [Do you think your parents are more worried over you?] (Transcript 4; line 881).

"Because I banged my head!" (Transcript 4; line 885).

6.4.1.4 *"No. I'm alright"* – but my friends were worried about me

In the first interview, Afan was asked if he saw any differences between his preinjury and current friendships. He replied on two occasions: firstly, in response to how he felt about his friends, he replied "*I'm happy*" (Transcript 1; line 320); and secondly (seen in the first extract below), when asked if he was still happy with his friendships, he simply replied "*Yeah*". This implied that he was happy with his friendships, and he acknowledged that they visited him more at home – his response "*Uh yeah*" (second extract below) confirmed this, although a slight hesitation in his answer also implied that he had to think about it. The final two extracts

below showed that his view of socialising outside of the house was more negative. He used the terms: "*No. I'm alright*" and "*A bit*". The first of these point to a hidden meaning in what he is saying, a contradiction, implying that he is not really okay. For Afan, the restrictions imposed on him stopped him from socialising fully with his friends – he could socialise inside the house and via the PlayStation but could not socialise outside of the house.

"Yeah" [happy with friends] (Transcript 1; line 602).

"Uh yeah" [Do they come around more?] (Transcript 1; line 607).

"No. I'm alright" [Do you feel sad for not going out?] (Transcript 1; line 623).

"A bit" [in relation to not socialising] (Transcript 1; line 627).

At three months, a dichotomy of thoughts was evident. Initially Afan reported feeling happy with his friendships but when pursued and encouraged by his mother to be open, he offered the contradictory term "*Fed up*" – a negatively loaded term. Here it is possible to see how Afan was negatively affected by his head injury and the restrictions placed on him; this forms an image of discontentment that was embedded in these restrictions as he was unable to play football and rugby, activities at which he would have socialised with his friends.

"Yes" [Do you think things are the same in terms of your relationship?] (Transcript 2; line 186).

"Fed up!" (Transcript 2; line 237).

During the third interview, at six months, Afan seemed more upbeat with his views on friendships. He started with the usual "*Happy*" and confirmed that he was back in full-time school. He also socialised with his friends, but not to the same degree as in his preinjury state. In response to the question "*Do you go out?*" he replied "*Um no, sometimes*", indicating some hesitation alongside an instigation of a change in his answer: initially he thought no, but

169

quickly changed to the more positive, but vague, "*sometimes*". Importantly, Afan felt that his friendships had improved compared to earlier interviews and they treated him the same way as before the accident, which seems to directly correlate with his happiness. He used the brief term "*Yeah*" to confirm this.

"Happy" [with friends] (Transcript 3; line 139).

"Good" [in relation to full time school] (Transcript 3; line 157).

"Um no, sometimes" [Do you go out?] (Transcript 3; line 170).

"Yeah" [Do they treat you the same now as before your accident?] (Transcript 3;
    line 186).

In his last interview (at nine months, now three months after the restrictions were lifted), Afan indicated that his friendships had changed: he recognised that his friends were less worried than they were at six months. He confirmed that his friendships had returned back to normal and he was happy with that. Afan was asked when he felt that his friendships had returned back to normal – he stated, "*three months*". This correlated well with Afan being back in full-time school, where he socialised with his friends, suggesting that returning to school is an intrinsic part of his recovery and rebuilding normal friendships.

"Yeah" [in relation to friends being less worried] (Transcript 4; line 414).

"Yeah" [felt that friends were worried before] (Transcript 4; line 424).

"Good" [in relation to friendships returning to normal] (Transcript 4; line 435).

"Three months" [a view of when friendships returned to normal] (Transcript 4; line
    460).

6.4.1.5   *"Only by the garage!"* – defiance but a way of coping

This theme, though short, is important as offers an insight into how Afan dealt with the restrictions placed on him. His defiance only became noticeable at three months during the second interview, when he admitted to playing football against the garage. By doing this he went against the advice recommended by the medical team and increased his risk of further harm. However, this should not be viewed as a binary opposite of acceptance, but more as a complication of Afan trying to come to terms with his restrictions.

One interpretation of his defiance may be that at two weeks Afan was largely confined to the sofa/house due to his unsteadiness on his feet (as a result of his accident), whereas by three months Afan was fully mobile. His defiance was discovered unintentionally during the discussion that was taking place concerning his favourite position in football and where he was asked if he missed playing it. At this point, Afan was not supposed to be playing football due to the restrictions placed on him by the medical team.

"Only by the garage" (Transcript 2; line 433).

His choice of language shows an element of meekness or restraint ("*only by*"), suggesting that he knew that he was not allowed to play football, but he pushed this boundary slightly by playing against the garage, which he deemed acceptable. This defiance appeared to be measured. (He did not discuss this again in the interviews, although outside of the nine-month interview he said that he did not headbutt the ball and kept it below waist height as he considered headbutting the ball to be a riskier activity.) In the second interview, when he admitted to playing football against the garage, I asked him if he understood what would happen if he reinjured his head, he replied:

"I'll be back in hospital" (Transcript 2; line 497).

This suggests that Afan understood the risk, and that reinjuring his head might involve him being readmitted to hospital. This defiance can be viewed as Afan's struggle for an element of control, which also helped with his coping and resilience.

6.4.1.6   **"*Good*" – a positive view of recovery**

In Afan's first interview he made no reference to thoughts about his future recovery, but at three months Afan felt he would recover sufficiently to restart playing rugby and would retain his speed; he used the brief matter-of-fact terms "*Yeah*" and "*Yes*" to confirm this. Throughout all the interviews, he demonstrated pride in his speed and the positions he played in football (striker) and rugby (wing). Overall, Afan appeared positive about going back to playing football and rugby.

"Yeah" [intention to play ruby when better] (Transcript 2; line 569).
"Yes" [aims still to be fast after recovery] (Transcript 2; line 580).

In the third interview, Afan felt that his recovery was going well, using the term "*Good*" to describe this. When Afan was asked if he was happy with the speed of his recovery, he appeared to be positive and happy. For example, when he was asked if he had expected his recovery to go faster, he simply replied "*No*", indicating a level of satisfaction.

"Good" [view of recovery] (Transcript 3; line 582).
"No" [would you have expected your recovery to go faster?] (Transcript 3; line 596).

In Afan's last interview, at nine months, he appeared to remain positive about his recovery. However, the following extracts highlight a mix of emotions and uncertainty. In the first two extracts, he saw an improvement in his fitness and was playing touch (minimal contact) rugby. However, the third extract "*I don't know*" alludes to an uncertainty about returning to full contact rugby, a possible hesitation, unfortunately one which he did not expand on.

"Touch" [type of rugby] (Transcript 4; line 267).

"Yeah" [Do you find your fitness is getting better now?] (Transcript 4; line 273).

"I don't know" [in relation to playing contact rugby] (Transcript 4; line 283).

6.4.2   Interpretation

Afan was a quiet person who did not fully articulate his feelings and as a novice researcher this was a serious test of my abilities, and at times I struggled with it. The emergent themes that were derived from the data (as shown in Figure 6-3) formed the subordinate themes: "Cost of Restrictions", "Family and Friends do Worry" and "Coping and Being Positive". These show the macroscopic picture of Afan's recovery from his head injury.

Friendships for Afan were highly important and this aspect is embedded in most of the emergent themes that came from the transcripts. His friends, in the initial stages, came to his house to visit him but Afan seemed to miss other elements of his preinjury socialising. The importance of friendships to recovery is well documented. Yeates et al. (2013) highlighted that CYP post head injury who struggle with friendships can have poorer longer-term outcomes. This is further developed by Heverly-Fitt et al. (2014) who added that friendships that are both positive and supportive play a pivotal role in recovery: they can improve self-esteem and psychosocial adjustment whilst giving emotional and social support. These

elements together with the findings of Battista et al. (2014) – who described how friends had a powerful effect on recovery and helped with adjusting to life after a head injury – make it possible to understand that both Afan's need for his friendships and his negative comments were associated with changes that existed between the preinjury and post injury friendship dynamics.

Defiance was a coping strategy adopted by Afan in order to cope with the restrictions placed on him. Van Petegem et al. (2015) (in their analysis of four studies looking at adolescent defiance) and Pettegrew (2017) (an ethnographic study looking at defiance in cancer care settings) showed similar findings that were relevant in understanding Afan's behaviour; even though they did not look at head injury recovery, they show relevance. Both Van Petegem et al. (2015) and Pettegrew (2017) discussed defiance as a coping strategy: Van Petegem et al. (2015) saw it as a way to deal with frustration and Pettegrew (2017) added that defiance as a coping strategy is personal and individual. Afan's behaviour, was a strategy that he used to cope with the restrictions. For him, this type of behaviour was successful in helping him cope with the frustrations that he felt – even though he appeared to understand the risk of playing football against the garage.
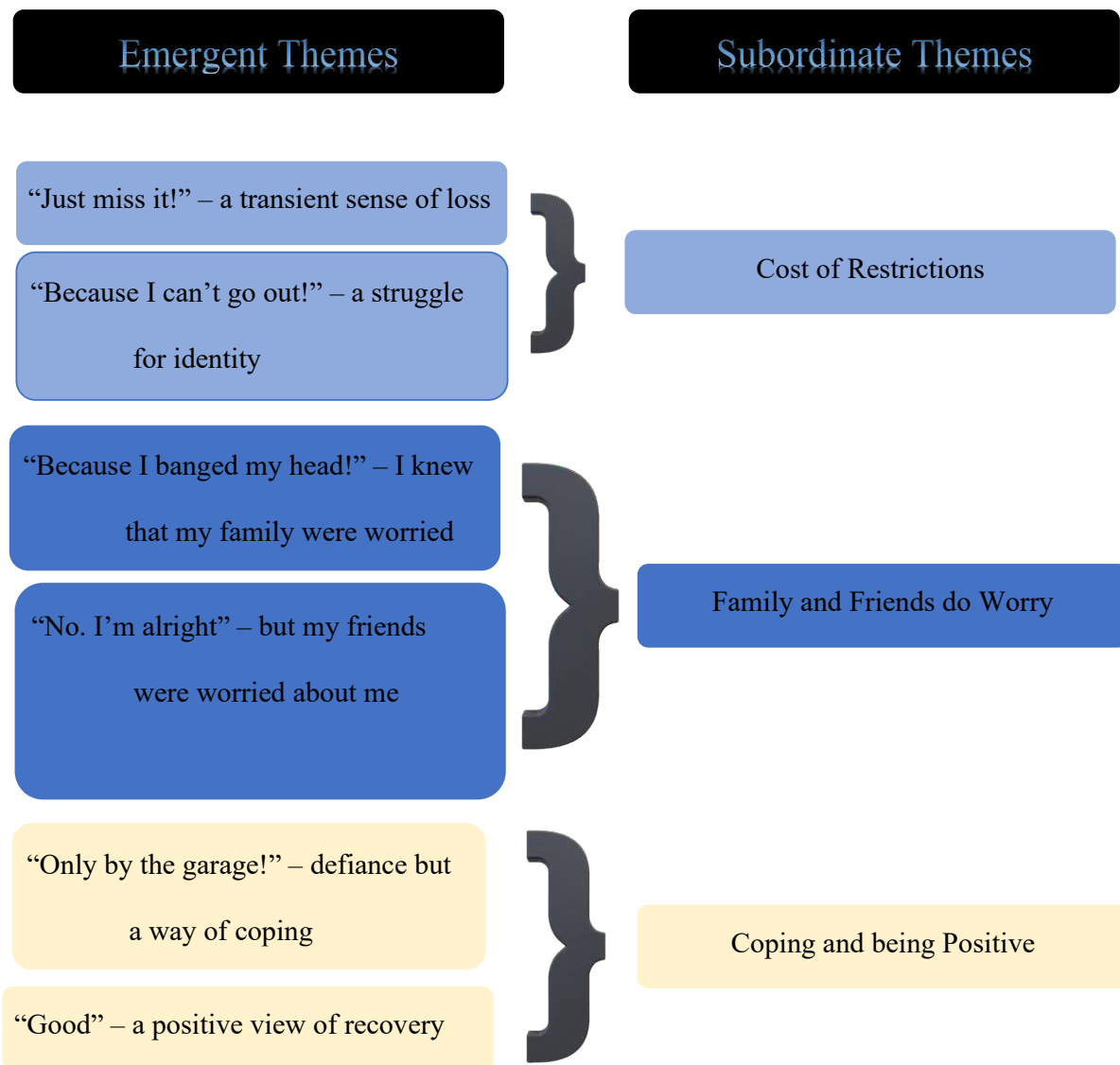
Figure 6-3: Formulation of Subordinate Themes from Emergent Themes – Afan.

6.4.3 Afan's Three Unique Idiographic Elements

- Friendships were very important to Afan's recovery and were closely linked to his identity

- His defiance was seen as a way of coping with the restrictions placed on him

- Parents can be seen as a constant – always there – but sometimes dismissed.

The next idiographic case will explore the lifeworld of Gwen, the mother of Betsi, at the six- and nine-month points.

6.5   Idiographic – Gwen

At the time of her involvement in the interviews, Betsi's mother Gwen was in her late thirties and worked as a legal secretary in a local solicitors' office. She had been separated from Betsi's father since Betsi was very young. At the time of Betsi's accident Gwen was at her house, getting ready for work. She was alerted to the accident by a knock on the front door by a neighbour's daughter/son and went immediately to the scene. It was Betsi's first time walking on her own to high school and she was hit by a car as she ran across the road. Gwen stayed with Betsi for the journey to hospital and throughout Betsi's entire hospitalisation, only going back home to collect essentials.

On discharge, Gwen was the main carer for Betsi and enforced the restrictions placed on Betsi by the medical team. During the nine-month study period, Gwen had to endure the passing of her father and the temporary re-emergence of Betsi's father into family life. This section will explore her lived experiences during the time of Betsi's recovery from her injuries, drawing on two interviews, at six- and nine-months post-accident. These experiences will form the emergent and subsequent subordinate themes. Both Gwen's transcripts have been analysed using the hermeneutic circle and will later be synthesised to form a holistic perspective.

The three subordinate themes (see Figure 6-4) derived from the emergent themes and data for Gwen are:

- Impact of Trauma

- The Role of Family and Friends

- Ongoing Issues – Recovery of the CYP.

6.5.1 Descriptive Analysis of Emergent Themes

In undertaking Gwen's interviews, I felt that I was in a very privileged position. She openly discussed her lived experiences which, as the following themes will demonstrate, were highly emotive. Betsi did appear a few times during her mother's interviews and would listen to her answers, at times adding to the discussion. During the interviews, I asked (sensitively) Gwen to think back to the time of Betsi's accident and asked questions about her own lived experiences since then. The following sections will discuss the emergent themes that arose from these interviews.

6.5.1.1 **"She was laying there on the floor… whimpering" – a never-ending nightmare**

This theme will offer an insight into Gwen's lived experiences as she thought back to the time of the accident. The following extract demonstrates her "*disbelief*", an initial sense of denial that this could have happened to Betsi. The use of terms like "*whimpering*", "*surrounded*", "*blood*" and "*worst*" clearly highlighted the magnitude and the extent of the negativity of the situation, encapsulating an image of Betsi's vulnerability and mortality. Gwen also talked about what she thought Betsi wanted – "*to pick her up and take her home*" – which interpretively can be seen as Gwen's parental need to take Betsi out of the situation

and to a place of safety. In this devastating event, Gwen also mentioned grasping on to a moment to take positive control of the situation: "*I could either sit here and cry or you keep it together and you just deal.*" Here, she appeared to "just deal" with her emotions in order to do what she perceived was right for Betsi.

> "*I knew something had happened to her and I've never run so fast in my life, walked around and I couldn't believe she was laying there on the floor and she was whimpering, she was trying to get up and she was just surrounded by blood and it was like one of those moments where I could either sit here and cry or you keep it together and you just deal with the fact that she's laying on the floor and it was the worst time of my life… I think she just wanted me to pick her up and take her home… it was just disbelief*" (Transcript 1; lines 24–53).

In Gwen's second interview, at nine months, it was possible to observe the psychological trauma that she still experienced. The following extract clearly shows that she still thought about Betsi's accident and this continued to affect her decision making. Gwen used the term "*I can still*" three times to communicate this, together with "*when I think about it*", pointing to an ongoing, personal, deep-set trauma caused by the accident. The second extract further reinforces the impression of anxiety. Gwen's use of the term "*fear*" accentuates this anxiety and drives home the ongoing worry that she was contending with.

> "*I can still, I can still, I can still see her on the floor, you know when I think about it, which I try not to, um, I can still see her on the floor*" (Transcript 2; lines 36–40).

> "*it's the fear that it happens, it would happen again*" (Transcript 2; lines 54–5).

6.5.1.2 "*I've never felt so lost*" – an attempt to rebalance control

The following extract represent Gwen's feelings during the initial stages following the accident. In this extract, Gwen used strongly emotive words with negative connotations to describe her feelings: "*scared*", "*didn't know*" and "*lose*". These words imply that Gwen was worried that she might lose Betsi and did not know what to do to prevent this; demonstrating feelings of potential loss and with no control.

> *"I've never been so scared in my life because I just didn't know how it was going to turn out with, am I going to lose her" (Transcript 1; lines 77–81).*

A similar loss of control is also present in the following extract during her stay on the ward. Gwen could not fulfil what she saw as a mother's role in looking after Betsi. Here, Gwen demonstrates a feeling of loss of her mothering role as the nurses undertook the duties which Gwen would normally have done. She also felt a sense of isolation from what she perceived she should be doing – compounding the loss of her role as a mother.

> *"I've never felt so lost. I couldn't go to her, I couldn't, I couldn't do what a mother is supposed to do. I just had a stand there while everybody else looked after her when she's my girl and I should be looking after her" (Transcript 1; lines 191–4).*

The next extract concerns Gwen's behaviour when Betsi was discharged. Prior to this extract she had commented "*I just wanted to get her home. I'm not saying I wasn't nervous*" (Transcript 1; line 302–3), hence pointing to a perceived need and desire for Gwen and Betsi to return to their normality whilst simultaneously indicating that she was nervous about the transition from the hospital ward to the home, where home can be seen as place of safety and significant step forward in Betsi recovery. The extract below highlights the lengths to which

Gwen went to safeguard her daughter from harm, including sleeping in the same bedroom. Here, Gwen was reasserting her need to regain control, which is also supported by the following quote "*it was normal, getting back to normality*" (Transcript 1; lines 323–4).

"Because I still had to give her medicines and, I slept, I brought a mattress in her room for about four or five nights because she was, if she needed the bathroom… so she could have been a bit wobbly, so if I slept in front of the bed" (Transcript 1; line 307–314).

Further along in the same interview with Gwen, the focus of control seemed to change. In this theme so far, Gwen had initially felt a loss of control and a challenge to her identity as a mother, which made her feel isolated. When Betsi was discharged from the ward, Gwen regained control and the following extracts provide an insight into Gwen's trying to balance being overprotective and not protective enough. The first extract shows Gwen acknowledging that she was "*overprotective*"; this irritated Betsi and got on her "*nerves*". Gwen justified her actions by adding that she was not going to "*lose her*". Interestingly, Gwen used the term "*had lost*" to describe her thoughts just after the accident, indicating a sense of loss, suggesting a fleeting sense of bereavement. Gwen did not want to lose her daughter again and was ensuring this by being "*overprotective*".

"I think that was the point where I probably got on my daughter's nerves because I wouldn't let her go up and down the stairs without me… to the bathroom without me…Oh, I know I was overprotective, but I had lost her, and I wasn't losing her" (Transcript 1; 370–88).

Gwen's view at six months into Betsi's recovery is encapsulated in the following extract. Here, Gwen's awareness that Betsi was finding her mother and father too overprotective prompts her to act by "*taking a step back*". Gwen's choice of words seemed synonymous

with a proud parent when their toddler starts to walk: "*she goes up and down stairs, she's started walking back from school*". It seemed as though Gwen's brave decision to be less overprotective was rewarded by Betsi achieving her own independence.

"She was going 'oh Mum and Dad are too protective'. I have taken a step back and been, she goes up and down stairs, she's started walking back from school now" (Transcript 1; 421–5).

The following extract, from nine months post injury, is highly relevant as it signifies a direct link between Gwen's lived experiences and Betsi's: Gwen need had needed to have control over Betsi actions outside of the home, which she partly achieved by utilising Betsi's friends as enforcers of the restrictions. This in turn had a negative impact on Betsi's identity. Here, Gwen justified her use of Betsi's friends as restriction enforcers but also accepted that some friends were "probably over-supportive"; pointing to the complexity and potential problems of using Betsi's friends which also resulted in tension between Betsi and Gwen. As the extract continues, Gwen used the phrase "*she's just trying*" to justify Betsi's friend's overprotectiveness.

"L (name of friend) probably was overly supportive because she knew I had put down restrictions… Betsi was like, 'she's telling me what to do'. Well no, she's not telling you what to do, she's just trying to do what I've said that I don't want you to do" (Transcript 2; lines 335–43).

6.5.1.3   "*Guilt I think*" – complex mother–father dynamics

This theme will explore the changing relationship that existed between Betsi's father, Betsi and Gwen. The following extract sees Gwen confirm that Betsi considered family to be "*very important*". Gwen's view of this was very definite and she used "*I know*" three times in the

same extract to confirm this; one instance was to outline Betsi's confused feelings about her father. Gwen felt self-assured that Betsi loved her a lot, exampled by her term "*to bits*", implying that Betsi loved every part of her.

"Family, well I know her family are very important to her. I know she does get confused about how she feels about her dad. I know she loves me to bits" (Transcript 1; lines 775–80).

The following extract touches upon how Betsi's father was late to find out about her accident, and why he was suddenly around more. Here, Gwen felt that "*guilt*" was one of the reasons, which appears to be embedded in the fact that he was not in Betsi's life enough to know what had happened. Gwen also indicated that the father loved Betsi, to the extent that "*he fell apart*" on entering Gwen's home. Within this extract, Gwen rationalised not telling him on the day of the accident because she had to get "*through it*" herself and deal with the initial shock first, then once Gwen felt ready, she informed Betsi's father.

"Guilt I think was part of it. I, he, he, he loves her, but I think part of it was guilt because A (father's name) didn't know until the following day. He didn't know the day of the accident because I had to just get through it… He literally walked in and he fell apart" (Transcript 1, lines 574–85).

Gwen outlined her thoughts about how the father appeared to be overindulging Betsi with gifts, as opposed to helping her with "*her homework*" (Transcript 1; 640). Gwen mimicked and repeated the father's use of "*I'll buy*" to indicate the magnitude of what she saw as being the problem: his attempts to purchase Betsi's affection. She also mentioned that when he did purchase the items (or over-purchase according to Betsi's data), he would then "*moan that it*

hasn't been eaten" (Transcript 1; 651–2), indicating that the father did not really know Betsi that well: if he did, he would just have purchased what was needed.

"I'll take her to the shop, and I'll buy her a bag of popcorn, I'll buy her a bag of sweets, I'll buy her a bag of donuts" (Transcript 1; lines 646–9).

Earlier in the same conversation, Gwen had talked about how the closeness of the relationship between Betsi and her father had changed. Previously he was in Betsi's life but had been more distant – he had not been aware that they had gone on a holiday for two weeks or that Betsi had gone away for a weekend, and he had missed her birthday. Gwen repeated used negative phrases to highlight the strength of her feelings: "*hadn't*" and "*didn't know*". The multiple uses of these terms in a short paragraph clearly outline her negative thoughts about the father's lack of involvement in Betsi's life.

"Well we hadn't see him, the accident happened in September, we hadn't see him since the May, he didn't know we had gone on holiday on a cruise for two weeks, he didn't know she'd gone to Llangrannog for the weekend, um, she didn't see him on his, her birthday" (Transcript 1; lines 541–9).

In the following extract, Gwen talked about her interpretation of what Betsi wanted. Here, she used the term "*rather*" twice to outline what she felt was needed. Instead of purchasing affection, Gwen felt that all Betsi wanted was for her father to play with her – she used "*playing*" three times to demonstrate these thoughts. Gwen felt that Betsi wanted personal interactions (play) as opposed to materialistic interactions (presents).

"She'd rather more time. She'd rather be happy with him playing out the back with her, playing, playing netball or, you know, chuck, kicking a ball around with her" (Transcript 1; lines 671–5).

183

In the final extract for this emergent theme, from the second interview, Gwen talked about the dilemma that Betsi was struggling with; how she viewed her father. The extract shows Gwen's interpretation of the complexity of Betsi's feelings about her father. In the first line Gwen acknowledged that Betsi would get upset over her father, which was usually masked: "*it doesn't bother me*". However, there were times when Betsi's mask failed; Gwen gave an example of when other CYP talked positively about their fathers, highlighting how delicate Betsi's feelings were about her father.

"The thing with her dad, she, she gets upset about that. She says (unclear) don't bother me, it doesn't bother me. I don't want anything to do with him but yesterday, because everybody was putting oh my dad's fabulous, oh I love you so much dad" (Transcript 2; lines 657–66).

6.5.1.4   *"She's happiest with her friends"* – the importance of friendship

At six months, Gwen felt that Betsi's friendships were back to normal, "*Yeah, back to normality*". The extract below highlights the importance of friendships to Betsi ("*she's happiest*"). Interestingly Gwen also highlights that Betsi could be herself with her friends, which suggested that Betsi sometimes needed to act differently, that in certain situations she was not being herself, not being Betsi.

"She's happiest, I think, when she's with her friends and she can be Betsi" (Transcript 1; lines 790–2).

In the following extract, Gwen used an interesting word, "*true*", which in this context implies that Betsi might have lost friendships following the accident and that only her "*true*" friends remained. Here, Gwen talked about one of Betsi's friends who made the effort to sit with

Betsi, often straight after school, in order to keep an eye on her and ensure that she was "*okay*", thereby offering a supportive network for Betsi.

"It's um, her true friends have been round… literally was coming twice a week, two or three times a week, he'd (friend) come on a Tuesday and a Thursday from, from school, to sit with her… just to sit with her to make sure she was okay" (Transcript 1; lines 955–70).

During the second interview (at nine months), Gwen continued to reinforce the importance of Betsi's friendships: "*she likes to be with her friends*". At this time, Betsi's restrictions had been removed and she had started to make "*new friends*". Gwen felt these showed normal friendship dynamics: they will "*bicker*" and then they are "*fine again*", speaking of these things positively not negatively and as a return to normality.

"She likes to be with her friends and as she said when she was talking to you, she's starting to meet new friends" (Transcript 2; lines 285–8).

"Yeah, she's, they're just getting back to, they have uh five minutes where they're fine, they bicker for two minutes then they're fine again" (Transcript 2; lines 359–61).

6.5.1.5   *"Taken a nosedive"* – a change in confidence

This theme will explore Gwen's interpretation of Betsi's confidence since the head injury. The two interviews highlighted how the accident had significantly dented Betsi's confidence and ability, using the negative term "*nosedive*" (see first extract) to describe the sudden change, a loss/drop in confidence. The second extract initially outlined Betsi's fear of crossing roads ("*got a fear of it*"), a fear embedded in the accident. As this extract continued, Gwen admitted to trying to control and lessen Betsi's fear ("*I won't let it rule*") by not letting the fear, control what they did or not do, which she did by only letting Betsi go out with

"*certain friends*". By this strategy, Gwen felt that this controlled action would build Betsi's confidence up, highlighting the lengths to which Gwen would go to. However, this also gave Gwen control over this which also build up her own confidence; pointing to a co-creation of confidence between Betsi (see Betsi idiographic section 6.3) and her mother.

"Her confidence and ability seem to have taken a bit of a nosedive" (Transcript 1; lines 1141–2).

"She's still got a fear of it, but it was an accident that happened, and I won't let it rule what she does. I mean, I only let her go with certain friends" (Transcript 2; lines 93–6).

Gwen's interpretation of Betsi's loss of confidence was echoed in the extract that shows a conflict of emotions for Betsi, an internal battle.

"She can't wait to go on the bike... she had a new bike for her birthday last year, she hasn't ridden it yet" (Transcript 2; lines 236–42).

Gwen saying that "*she can't wait*", quickly followed by "*hasn't ridden it yet*", pointed to a worry that Betsi had to contend with – Gwen felt that Betsi wanted to cycle but appeared reluctant to do so. And when this is placed in the context that she had the bike "*last year*", it shows the magnitude of Betsi's anxiety about using the bike. This resonates with Betsi's idiographic case (see section 6.3.1.1), in which she worried about her legs failing her, falling off her bike and reinjuring her head. Gwen appeared to understand Betsi's worry about the concern that she might hurt herself. From the field notes Gwen did also discuss her own anxieties which highlighted her concern that bikes are synonymous with roads, which reinforced Gwen's worry about the risk of Betsi being on a road.

6.5.1.6   **"She's never going to leave the bedroom" – the recovery journey**

In discussing Betsi's recovery, Gwen seemed to hesitate at first ("*um*") during recall, but overall felt that her recovery was slow – although she found it difficult to quantify time. Gwen also added "*oh I don't know*", which further showed the difficulty she had in accurately recalling the recovery period. This alludes possibly to a time that she might have wanted to forget, or one in which she felt that time seemed slower. However, in further thought, she quickly anchored her decision to when Betsi had double vision as a consequence of phenytoin (anticonvulsant medication) toxicity.

"Um, the, the recovery was a bit slow at the beginning because the first or actually until she was discharged for the first, oh I don't know, couple of months 'cause we were back, um a couple of weeks, no it was longer than that, because she was doing, obviously before, I'd say before the end of, well, yes, it must have been weeks, 'cause she was having the double vision"
(Transcript 1; lines 1013–23).

The following extract offers an explanation for the above: Gwen talked about Betsi not leaving the house or her bedroom as a consequence of her double vision. The image graphically described here is like that of having little freedom, or being imprisoned in their own home as a result of the head injury and the phenytoin toxicity side-effects (double vision).

"so that seemed to, at one point it was like, well is she never going to be able to like leave the bedroom and leave the house because we didn't really go anywhere" (Transcript 1; lines 1036–47).

In the same interview, Gwen also talked about the relief associated with Betsi being discharged; she used positive words like "*lovely*" and "*great news*" to illustrate that Betsi was

making progress. In the same extract Gwen also highlighted how "*distressing*" it was having to re-visit the place where Betsi was hospitalised, an act which led to a reminder of the accident and the fact that Betsi was still recovering from her injuries.

"Yeah, um I mean it was lovely when she was discharged from the Eye Clinic and the Max Fax clinic, you know, um, that, that was great news because she was getting so distressed going to these places" (Transcript 1; lines 1060–5).

In the final extract within this theme (from the second interview, at nine months), Gwen voiced some ongoing concerns: she felt that Betsi's legs were getting worse: "*complaining more*".

"Um the only concern I suppose I have now is in some ways the leg seems to be getting worse and not better as in she seems to be complaining more of the legs, because she, what she does, she does that with her toes, she points her toe and they've told her she's got to stop doing that now" (Transcript 1; lines 1081–9).

At this point Betsi was being reviewed by the physiotherapist and was given exercises in order for her to stop pointing her toes, where toe pointing can be sign of muscle or nerve damage. At nine months, Gwen added that they were still trying to find out what the problem was with Betsi's legs and this uncertainty is demonstrated in the quote: "*Like a ligament or something that's attached to the leg, hence it's going out, this is why she, the knee goes in and then pops out*" (Transcript 2; lines 210–13) – the use of words "*like*" and "*something*" accentuate this. This highlights that even though nine months had passed since the accident, and even though the head injury had recovered, the recovery journey still continued for Betsi and Gwen. This is important for clinical practice: when reviewing a patient's recovery post

head injury, other factors (including additional injuries from the accident) need to be considered due to their impact on the person's view of their recovery.

6.5.2   Interpretation

The emergent themes that were derived from Gwen's the data (as shown in Figure 6-4) formed the subordinate themes: "Impact of Trauma", "The Role of Family and Friends" and "Ongoing Issues – Recovery of CYP". These show the complex macroscopic picture of Gwen's lived experiences as the mother of Betsi, and the journey she had to make alongside her daughter.

The six- and nine-month interviews with Gwen showed how a parent is often on a parallel journey of recovery, which even at nine months had not been completed. This is similar to the findings of the descriptive phenomenological study Wongvatunyu and Porter (2008) where they looked at the lifeworld of mothers of adult children who had suffered a head injury, and who had conducted three interviews more than six months into the recovery period. Two of their study's themes are of relevance to my study: they showed that mothers also have to live with life changes and mothers believe that they can help their child.

Similar to Wongvatunyu and Porter (2008) is that Gwen can be seen as a victim of the accident and has to live with changes to her lifeworld. Different to the findings in Wongvatunyu and Porter (2008), Gwen's journey and decision making seemed to be embedded in the psychological and emotional trauma that she experienced during the early stages of Betsi's accident and her ongoing needs.

The first two themes of Gwen's idiographic case above examined the trauma of her finding Betsi, followed by her loss of control and how she regained this; her first response was to be overprotective. This psychological and emotional trauma also mirrored the findings of Clark et al. (2008), who described Gwen's behaviours as post-traumatic symptoms. Such symptoms included a "loss of the belief that family members would continue to be safe in the world" and increased anxiety (which relates to Gwen's need to be overprotective) (Clark et al. 2008, p. 579). Gwen utilised Betsi's friends as an extension of her control/overprotectiveness as a way to keep Betsi safe in the wider environment, where Gwen had limited influence. This formed an extension of her emotional need. Wongvatunyu and Porter (2008, p. 1068) in their study found that mothers wanted their children's lives to be as "normal as possible". This is also evidenced by Gwen: Betsi informing her that the overprotectiveness was having a negative impact on Betsi's identity provided a "wake up" call for Gwen. From this point Gwen consciously tried to normalise Betsi's lifeworld (back to a preinjury state) in an attempt to help her.

In her interviews, Gwen talked about the happiness she felt when Betsi was discharged from the Max Fax Clinic and the Eye Clinic – these were reminders of the accident and acted as triggers, with the appointments that both Betsi and Gwen attended causing emotional distress. This resembles the findings by Clark et al. (2008). Being discharged also positively reinforced the signs of recovery. This helped with Gwen's anxiety and control as they indicated that Betsi was improving and the risk of further injury/complications was reducing. This led to Gwen being less overprotective/controlling which promoted Betsi's normality.
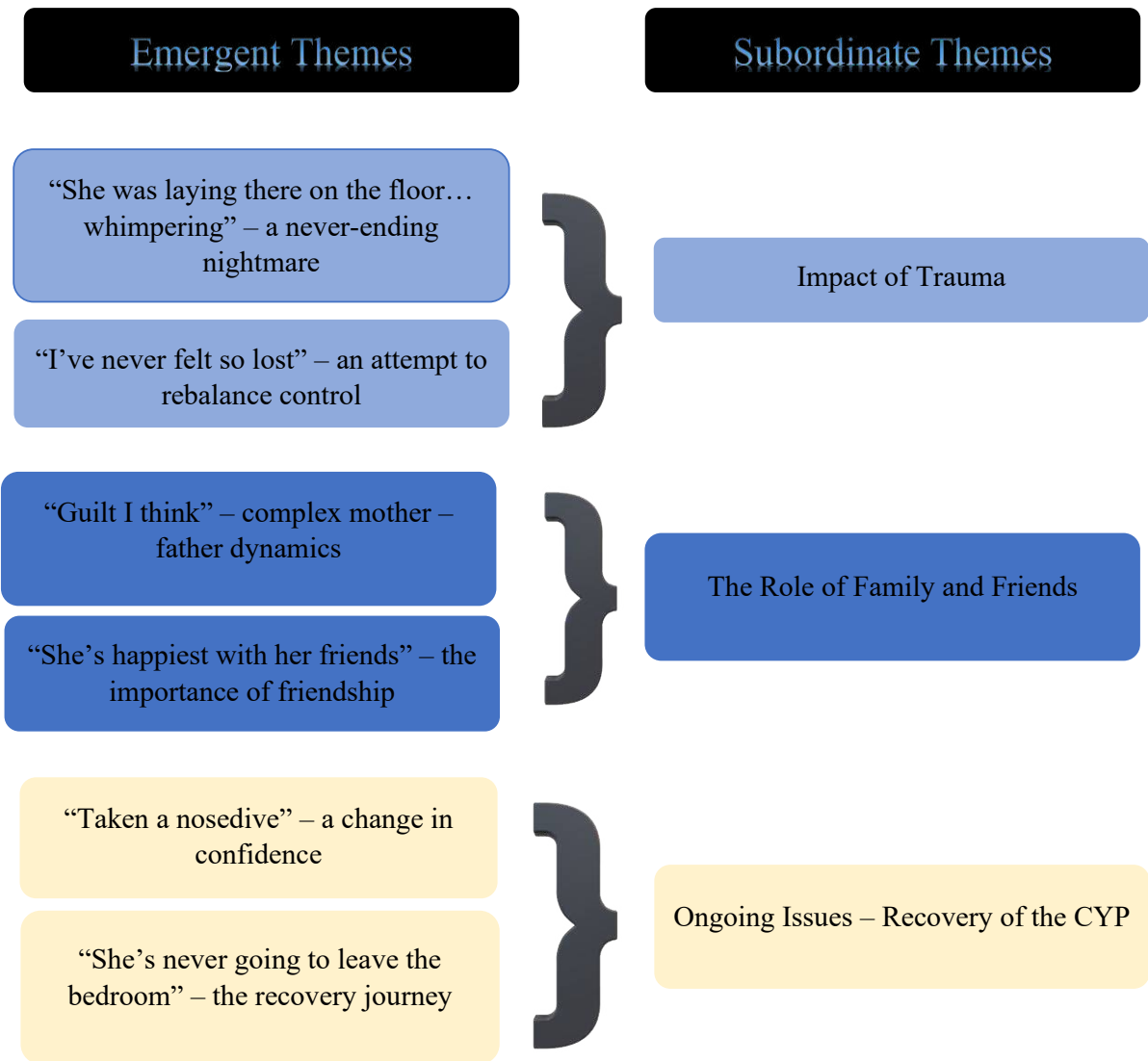
Figure 6-4: Formulation of Subordinate Themes from Emergent Themes – Gwen.

6.5.3   Gwen's Three Unique Idiographic Elements:

- Gwen travelled along her own recovery path which at nine months was not concluded

- Gwen utilised Betsi's friends as a way to try and enforce the restrictions, therefore trying to reduce her own anxiety

- Gwen's return to normality was helped by having reduced clinical input including discharge from medical follow-ups.

The next idiographic case will present a longitudinal view of Ffion's recovery and, as with Gwen's case, will explore Ffion's lived experiences at six and nine months.

6.6   Idiographic – Ffion

Ffion was, like Gwen, a single parent and was in her early forties. She was the main carer for Afan but, unlike Gwen, Ffion had only recently separated from Afan's father, and their relationship appeared disharmonious. Ffion worked as a cashier in the local bank office. She was alerted to Afan's accident – he was hit by a car whilst crossing a road – by a neighbour and witnessed him being prepared for transit to the local neurosurgical centre by air ambulance (helicopter). For this he was intubated and doing this made it a safer referral.

When Afan was discharged, Ffion was the main carer and therefore the enforcer of the restrictions placed on Afan by the medical team, which included avoiding physical sports that might reinjure his head (including football and rugby), leaving lessons slightly earlier to avoid the busyness of the corridors and avoiding aspects of the school playground where sports were being played. In the early stages of his recovery, Afan was still was unstable on his feet. Ffion was interviewed at six and nine months with the aim of understanding her lived experiences together with her views of Afan's recovery.

In an attempt to improve clarity for the reader, I will present here the three subordinate themes which are derived from the emergent themes and consequently from the data – the process being shown in Figure 6-5 (section 6.6.2). These are:

- Consequences of Trauma

- The Importance of Family and Friends

- The Pathway of Recovery.

6.6.1 Descriptive Analysis of Emergent Themes

Undertaking Ffion's interviews provided a valuable insight into her lived experience, and her view of not only Afan's recovery journey but also her own. As with Gwen, I sensitively asked Ffion to relay her experiences from the time of Afan's accident to the present, using the two interviews to form a comprehensive view of her experiences and the changes in her thoughts over time.

The following sections will discuss the emergent themes that arose during the interviews, which ultimately led to the formation of the subordinate themes.

6.6.1.1 *"I thought he was dead"* – an ongoing battle with worry

The following extracts demonstrate the extent to which Ffion continued to reflect on Afan's accident at six months post head injury and how Ffion was psychologically impacted. Thinking back to how she felt at the time of the accident, she used highly poignant, emotive words to emphasise her feelings: she was "Absolutely horrified" when she saw Afan on the floor at the site of the accident and she "thought he was dead". The second extract below points to a sense of time moving differently for her, during the time Afan spent on the road and his journey to hospital. This alteration in time lends itself to a sense of disbelief and detachment from reality, as she grasped the significance of the situation. The element of

shock she felt is shown in the third extract: she had found out about the accident (from a neighbour) and struggled with the reality of what had happened.

"Absolutely horrified, yeah" (Transcript 1; line 11).

"I suppose it went into a blur really, I suppose about the accident" (Transcript 1; lines 24–6).

"It didn't comprehend really I suppose and then when I got to the accident um, but I thought he was dead" (Transcript 1; lines 86–9).

In the first extract below, Ffion described how in the early part of Afan's recovery she had a single thought that she used as a way of coping: she wanted Afan to survive. The word "*praying*" emphasises her despair and her need for Afan to survive. The second extract shows the emotional state that Ffion was in – "*a bit of a wreck*" at the time of the accident – and the devastating impact she felt. In the same extract she also saw herself as having improved since the accident but accepted that she still struggled emotionally and would "*panic*" when Afan was not with her; this pointed to an ongoing battle with worry that this could happen again.

"I was just praying that he would stay alive. That's all I was thinking about" (Transcript 1; lines 136–7).

"I am, I am, yeah, a bit of wreck now, um, but I am improving all the time so um, I just panic when he's not with me" (Transcript 1; lines 619–22).

At nine months, in the second interview, Ffion continued to recollect her feelings from the time of the Afan's accident where she stilled expressed her horror as thinking that *"he was dead*" (Transcript 2; line 17). By saying this she demonstrated the significance of her lived experiences at the time of the accident, her ongoing anxiety which emphasised the point that this was a traumatic time in her life when she could have lost her son – a significant impact on her lifeworld that she had not fully recovered from. Ffion continued to see herself as being

"*traumatised*" (Transcript 2; line 148*)* – indicating that she saw her recovery as ongoing and had not changed since the six-month interview. Her use of impactful descriptors such as "*screaming*", "*hitting*", "*punching*" (taken from Transcript 2; lines 41–5) also provided an insight into her feelings and that her lived experience at the time of the accident still had a strong impact on her current feelings. This showed that her recovery journey was ongoing and far from complete.

6.6.1.2 **"I would have thought he would have hated me" – an acceptance of control**

Ffion appeared to show a mixture of feelings about enforcing the restrictions placed on Afan by the medical team. She felt that Afan "*would have hated*" her for this, but she said that instead he had "*accepted*" them. Ffion demonstrated elements of relief with this, which was reinforced by her ability to laugh when thinking back and by the praise she used to describe Afan's acceptance: "*He has done really well*". In the wider context, Ffion's initial concerns stemmed from the need to stop Afan doing activities like rugby and football, which were important to him, and in doing so, protect him from further harm – she was concerned over the backlash of emotions that this might have caused but Afan showed his appreciation of Ffion's enforcement by his acceptance of the restrictions.

"I think he's done really, really well. I would have thought he would have hated me, (laughter) because it is me that has stopped him" (Transcript 1; lines 278–81).

"But he hasn't and he has just accepted that he can't. He has done really well. He has just accepted that he can't" (Transcript 1; lines 285–8).

However, after pursuing Ffion's views later during the interview, a slightly different image was portrayed in relation to football. Even though Ffion saw Afan as having accepted the

restrictions, she acknowledged that he became "*frustrated*" by them, a term Ffion used twice to accentuate this point.

"Um, (pause) It's, I'd say frustrated. I would say frustrated, he's just accepted it, yeah, he has" (Transcript 1; lines 382–5).

In the following extract from the same interview, after acknowledging the frustration Afan experienced, Ffion talked about her ability to allow Afan some "controlled" freedom: she had taken him to his friends in order to play and socialise but used his older brother as a restriction enforcer, who stayed on the periphery. This pointed to an inherent need to control what Afan did with respect to his socialisation and to protect him from harm, whilst allowing him some independence. This also showed sensitivity by Ffion in understanding Afan's needs in a social setting where having your mother attend is less acceptable than your brother.

"Like a couple of times he's gone out with them but I've taken them, taken him, sort of stayed there, not with him but with his brother in the background so he's got a bit of independence" (Transcript 1; lines 685–90).

In the following extract taken from Ffion's interview at nine months, she viewed Afan as being frustrated by the restrictions placed on him and which she had to enforce. She accepted that he probably did play football when she was not aware. Ffion did not show annoyance with this defiancy/rule breaking behaviour. Rather she clearly justified his actions which she believed to be caused by his restrictions, his need to play football and his own coping strategies.

"He got very frustrated, upset by it and I think he probably did play football when I didn't know that he was playing football at school" (Transcript 2; lines 615–18).

196

However, the following extract contradicts this: Ffion viewed Afan as accepting the restrictions which she had to enforce. Here, she was happy that he had accepted the restrictions, emphasised by the "*he took it better than I thought*", which also showed elements of relief about this acceptance. In the same extract, Ffion is quite concrete in her wording ("*he just knew he had to*"); she felt that Afan followed the rules because he had to.

> *"Yeah, he did, I thought he took it better than I thought he would to be honest. He just knew he had to" (Transcript 2; lines 638–40).*

The two above extracts provide an interesting insight by Ffion into Afan's acceptance of the restrictions. In the first Ffion described Afan showing defiance and in the second she saw Afan as adhering to the restrictions. This points to a dichotomy of views at this stage in the recovery process and it is difficult to know whether Ffion had the same feelings earlier on. With the restrictions removed, and with Afan having come to no harm, she accepted this defiance. Clinically this is important as it alludes to parental variance on what is accepted by the parent with respect to their son's or daughter's activities/behaviour whilst the restrictions are still recommended by the medical team.

6.6.1.3 "*He's matured*" – a view of post head injury maturation

In the discussion with Ffion (first interview, at six months) as to whether she felt that Afan's behaviour had changed since sustaining a head injury, she thought that he had "*matured*". Ffion's perception of his maturation seemed embedded in Afan's ability to comply with the restrictions placed on him in order to protect him and not to take it out on her, which Ffion felt would not have been the case before the accident. In the extract below, Ffion started with a sigh in response to the question of whether Afan's behaviour had changed since the

accident, pointing an acknowledgement that some change had taken place, followed simply by an acknowledgment of his acceptance.

"(Sigh) probably yes because, yeah, he's matured, and he's accepted that he can't do that" (Transcript 1; lines 292–4).

Further examples of Ffion's perception of Afan's maturation came from the way that she saw his behaviour change. In the extract below, Ffion gave an example of when she believed that Afan would have become "*angry*":

"He got angry then" (laughter) (Transcript 1; line 335).

But her use of the past tense alluded to this being previous behaviour that was different from the then present. Ffion felt that Afan was "*more chilled than he was*" (Transcript 1; lines 343–4), again indicating that his behaviour had changed and she saw him as being more relaxed.

In the second interview, Ffion expanded on her view of how Afan had matured. In this extract she felt that Afan was "*more mature*" and admitted that he was not aware of it. Ffion, after a long pause to consider the rest of her answer, added a profound explanation for her thoughts. She felt that Afan was "*more aware*" of how life can change, often suddenly, and for Afan, this could have been a forced glimpse of his own mortality.

"More mature I'd say. Um, he's probably not aware of it, well, (long pause) I suppose more, more aware of how things can change I suppose" (Transcript 2; lines 312–16).

6.6.1.4   **"He just expects me to be here" – a view of family**

Ffion's view of Afan's perception of family was interesting. She believed that Afan took family for granted, which is echoed in the following extracts from the first interview. Ffion believed that Afan saw family as a constant, a non-changing factor in his life. The use of the term "*list*" (reference to SEIQoL used in Afan's first interview) pointed to a pecking order that she interpreted Afan to have for seeing what was important to him – family was not high on this list.

"He just expects me to be here" (Transcript 1; line 204).

"We wouldn't come high on his list, I knew that" (Transcript 1; lines 209–10).

Further along in the same interview, Ffion felt that the family dynamics had changed since the head injury; a change that affected the whole family lifeworlds. At six months, Afan was "*not fighting anymore*" (Transcript 1; line 821) with his brothers (and had not since the accident), which showed the importance that recovery from the head injury had for the family, the significance it was given and how Afan was viewed. The following extract showed that Ffion felt that Afan was closer to her as a consequence of the accident. However, the use of the utterance "*um*" and term "*probably*" (twice) point to some possible hesitancy and uncertainty over her thoughts. Ffion interpreted this uncertainty as being embedded in Afan's independence together with his reluctance to articulate his feelings.

"Um, he's probably, he's probably closer to me now I would say, because he was
    always quite independent, not that he wouldn't have a few moments but yeah,
    he's closer to me now" (Transcript 1; lines 774–9).

Ffion felt that the family were returning to normality at nine months, in that Afan had started mock fighting with his brothers – which is something which he did before the accident – even

though the family members understood the risks. The awareness of risk was emphasised by Ffion's use of the term "*aware*" four times in the extract together which points to the seriousness the risk posed but this was counteracted by her need to have normal family dynamics; to have her family back to how it was before the accident. The terms "*banged*" and "*accident*" highlights the tension between regaining normality and the risks this posed.

"They do fight now. I think all of us were aware that he'd banged his head. We were all still aware of it, obviously more aware of it and I think, I think we were all aware that things could happen, like accidents could happen" (Transcript 2; lines 1084–91).

6.6.1.5   "*Very lucky, very lucky*" – friendships that persevere

Ffion perceived Afan's friends as a supportive presence throughout his recovery – they even changed their friendship dynamics by coming around the family home more, in order to cater for Afan's restrictions. Ffion described them as "*a good bunch of boys*". She also added that his friends had accepted most of the restrictions that were put in place, with "*sort of*" also pointing to some reluctance to change – a willingness to go only so far. Before the head injury, Afan would play outside with his friends more, but due to the restrictions this changed; suddenly he could no longer play outside and therefore used PlayStation plus as a social enabler.

"He's still included but they sort of accept that he doesn't go with them" (Transcript 1; lines 258–9).

"Um, I think he's very lucky, very lucky, because they are a good bunch of boys. They have changed because he doesn't see them outside school anymore, but he does socialise with them on the PlayStation plus" (Transcript 1; lines 242–7).

Ffion's portrayal of Afan slightly alters later in the interview: she acknowledged that Afan became "*sad*", using this term twice in a brief portrayal of his social adjustment.

"Friends and PlayStation 4, that's his life, yeah but um, yeah. I think he gets sad
       that he can't go out with his friends, but he's accepted that he can't do
       football and rugby but he's sad that he can't go out with his friends"
       (Transcript 1; lines 418–23).

Ffion firmly acknowledged that friends and using the PlayStation were highly important, the two most important things, to Afan: "*that's his life*". The extract below portrays Afan as being sad about his inability to go out and participate in sports (further discussed in the emergent theme 6.6.1.6: "*For him it is football, rugby*" – coping with loss"). It also confirms Ffion's perception of the value of friendship to Afan: she mentions that the only time he gets upset is when he cannot "*go out with his friends*"*,* further highlighting the negative aspect of the restrictions placed on him and the frustration he felt about not going out to play.

"Um, yeah, the only time he does get upset is if he can't go out with his friends"
       (Transcript 1; lines 595–7).

In Ffion's final interview, she felt that Afan's friends treated him "*differently*" as a result of his head injury, but the extent to which they did so varied depending on how close his friends were to him, with his closest friends changing the most. Interestingly, this did not seem to negatively affect the friendship dynamics. Ffion felt that Afan would "*talk*" to his friends about his concerns and worries, which alludes to a relationship of trust and support, which is supported in:

*"Um, I suppose yes, they did treat him differently because, because he had a bad
head, so they do, some of them perhaps not as much but his closest ones,
yeah, treat him differently"* (Transcript 2; lines 502–7).

"Yeah, he did talk, yeah" (Transcript 2; line 825).

The following extract below points to Ffion's view of Afan returning to his normality, in that he was playing on the PlayStation less and was out playing more. Ffion spoke of the PlayStation as a positive tool in keeping Afan entertained but it eventually became a slight concern; her laugh in the second extract appears to point to an element of relief that usage of the PlayStation had changed and Afan was returning to his preinjury friendship dynamics.

*"A way of socialising with his friends, um, but now it seems to be less because he is
seeing them in person (laugh)"* (Transcript 2; lines 997–1000).

6.6.1.6 **"For him it is football, rugby" – coping with loss**

Ffion had clearly identified the importance of football and rugby to Afan (this is touched upon in section 6.6.1.2 – Ffion saw Afan accepting the restrictions but becoming frustrated by them). Ffion viewed the PlayStation as a strategy that Afan used to cope with the restrictions placed on him and frustration they caused. Ffion pointed to the fact that she saw the PlayStation as a "*socialiser*" for Afan that empowered him to still play with his friends (online) and talk with them – elements which were important for Afan. She also highlighted the fact that the use of the PlayStation was a way he "*compensated*" in coping with the restrictions and his inability to play the sports that he cherished.

*"PlayStation, he has compensated for football and rugby with PS4 and he's used it,
that as a socialiser"* (Transcript 1; lines 431–3).

In further discussion with Ffion about her views about Afan's use of the PlayStation, the following extract highlights how grateful she was that he used it. Here, Ffion saw the PlayStation as an alternative to Afan playing outside and playing sports. Her reference to that some children misuse the PlayStation and "*are on it all the time*", showed her awareness of correct usage. Outside of the interview (from my fieldnotes), Ffion did mention that she was grateful for the PlayStation because without it, she would have struggled to keep Afan entertained, thereby seeing the PlayStation as a strategy not only for Afan but also for herself.

> *"But I am very thankful for it because, yeah, like. I never worried about him before,*
> *some children are on it all the time but he wasn't into that but he was always*
> *quite engrossed but he'd rather be out, so he can't but now he can't he*
> *couldn't go out so I was just glad that he's got something that he enjoys"*
> *[reference to PlayStation](Transcript 1; lines 451–61).*

At nine months, a clear change was noted in Ffion's thoughts about Afan playing sports. The extract below points to Afan's loss of confidence in playing. Here, Ffion indicated that Afan was allowed to play and made reference to "*scrum cap*" four times, which highlights her need to minimise risk and for Afan to play safely. Ffion also mentioned that wearing a scrum cap was not a new thing for Afan as he wore it before the accident. Her uncertainty about why Afan was not playing was present in her use of "*I don't know*" twice in the same sentence; she was unsure but believed that this not playing was embedded in his self-confidence. This uncertainty formed an interesting indicator of change in how Ffion, from her lived experience, viewed Afan; where she pointed to not knowing Afan as well compared to before the accident.

> *"The fact that it is not because they have said that he can do rugby and wear a*
> *scrum hat. His team always wears a scrum cap and he's always worn a*
> *scrum cap, he used to go training with the scrum cap on and just never took*

it off, um, I don't know, I don't know whether he's unconfident or unsure in
himself" (Transcript 2; lines 353–62).

Ffion also discussed Afan's father and highlighted the father's confused thoughts. Here, she felt that Afan's father was reluctant for Afan to play rugby when the restrictions were initially removed, although further along in the same interview Ffion added the comment "*he probably gets it more*" (Transcript 2; lines 1171), thereby indicating the fathers willingness for Afan to return to normality, a willingness that strengthened as time elapsed.

"Um, I don't know, well he, he didn't like want him to go back to rugby. He thought
it was too soon. So, in some ways he's like, oh he's fine, and then in other
ways he shouldn't be doing that" (Transcript 2; lines 229–34).

Concerning Afan's loss of confidence and delayed return to sport, Ffion appeared more aware of why Afan's attitude to his sports had changed. Ffion used strong emotive words to describe how she perceived Afan had felt ("*angry and tearful*"). As the extract continued, her use of the past tense pointed to his loss of ability when he initially had restarted participating in sports – his loss of confidence was associated with a drop in his ability/skill. Ffion also added that he had regained this ability and confidence – "*he's playing like he was before*" – indicating a return to his preinjury self.

"When he first went back like, when he played his first game, he came off and he
was very angry and tearful, um, but now he's not, now he's playing like he
was before" (Transcript 2; lines 868–73).

6.6.1.7 *"I didn't think ahead"* – the recovery journey

Ffion's view of Afan's recovery was one of gratitude, pragmatism and hope. The first extract below shows that she felt that his recovery was good. However, in the second extract her positivity was also tinged with some uncertainty, seen in her use of "*I think, well I hope*", which give the impression that Ffion had an insight into her tendency to worry; the laugh lightened this tendency and increased the sense that she realised her worries may sometimes have undermined some of her positivity. The two parts of the think/hope statement expressed different meanings: "*I think*" implied that, based on how Afan had recovered so far, he should continue to make a good recovery; "*I hope*" then implied some doubt but general hope for a positive recovery. The use of "*I hope*" also resonates with the third extract below in which Ffion twice used it to describe her feelings of desire for Afan to continue with his good recovery. She used the term "*carry on*" and "*normal*" to describe how she hoped Afan would achieve a return to his normality.

"Um, I'm just thankful that he's made such a good recovery, yeah" (Transcript 1; lines 487–8).

"I think, well I hope that everything is going to be fine. I'm a worrier so I worry (laugh)" (Transcript 1; lines 522–4).

"I hope's he going to carry on and be back to normal, I hope" (Transcript 1; lines 663–4).

At nine months Ffion viewed Afan's recovery as going "*really well*" – which is emphasised by her using this phrase twice in the same sentence, along with a third "*really*" – conveying happiness and relief with his recovery journey. However, Ffion continued to have anxiety over his safety (fully discussed in 6.6.1.1). For Ffion, her lived experience as a parent during this recovery period appears to have been embedded in her continual worry for Afan's safety.

"Um, I suppose it's gone really, really well and has gone really well, I still think, I still worry that, you know" (Transcript 2; lines 166–9).

The following extract also shows elements of Ffion's anxiety which is conveyed in her use of "*I'm watching him*" and "*all the time thinking*". This clearly shows that Ffion's psychological worry was ongoing at nine-months, pointing to significance impact she suffered to her lifeworld when Afan sustained his head injury. Ffion felt that Afan had returned to participating in activities that he "loved", indicating a return to normality for him. This clearly highlights that even though Afan's recovery journey was positive at this point, Ffion's journey was continuing.

"Yeah that was a big change 'cause he was doing whatever he loved, being normal and um, so yeah, for me I suppose that was a big change um, but even now I'm watching him all the time, thinking is it going" (Transcript 2; lines 135–41).

6.6.2   Interpretation

The emergent themes that were derived from Ffion's data (as shown in Figure 6-5) formed the subordinate themes: "Consequences of Trauma", "The Importance of Family and Friends" and "The Pathway of Recovery". Though similar to Gwen, highlights the complex lived experiences a mother has when looking after a child who has sustained a moderate head injury.

This idiographic analysis of Ffion's lived experiences showed two clear but interrelated journeys: one for herself and one for Afan (which was presented previously). Over the two interviews it is clear that Ffion's experiences are embedded in the psychological trauma and

anxiety experienced as a result of the accident which continue to manifest as a greater worry than that which is usually associated with parenting. These experiences and feelings are, in turn, inter-twined with feelings of hope, gratitude and occasionally humour. What was very clear at the end of the nine-month interview was that whilst she saw Afan as nearly completing his recovery journey, Ffion's journey appeared to be far from over and Afan's ongoing risk of re-injury continued to govern her thoughts, feelings and behaviours.

Similarities can be seen between this study and an IPA study of the experiences of mothers whose CYP had suffered a head injury by Clark et al. (2008), hence demonstrating rigour from the results of the study. They highlighted the psychological and social trauma experienced by the mothers, with ongoing post-traumatic behaviours and a worry that their daughter/son could die – findings that resonate strongly with Ffion's concerns. During the analysis, it was also apparent that Ffion viewed her lifeworld (in relation to the family dynamics) to have changed as a direct response to Afan's head injury – for example, Afan's brothers were no longer play fighting, although this only recommenced once Afan had his restrictions removed. This alteration in family dynamics demonstrated the devastating impact that the restrictions had on Ffion's lived experiences as well as Afan's. Similarly, Clark et al. (2008) pointed out changes in family dynamics, highlighting a similarity between these studies whilst confirming that when one member of the family suffers a head injury, the family circle in its entirety is affected.

Ffion also talked about how Afan's behaviour had changed: he seemed more accepting, more patient (largely) and acknowledged the positive role that his friends had on his recovery. These findings resonate with the IPA study of Battista et al. (2014), who described these

behavioural changes as post-traumatic growth and highlighted their significance in the recovery process post head injury. Ffion viewed friendships as being important for Afan as their dynamics appeared to mould around what Afan needed. When Afan was confined to the house, Ffion did not discourage his friends from coming to their house but rather saw it as being important.

Another important experience for Ffion was her role as an enforcer of the restrictions placed on Afan by the medical team. This was a role which she took seriously but her ability to delegate it was important. In this role she was strategic and sensitive in her approach to restrictions, showing her parenting skills. As exampled when she recognised Afan's need for boundaries and from Goffman's perspective of social identity, she found ways of saving his social identify/face (Smith 2011b) by enrolling his brother as a proxy enforcer of restrictions, when she allowed Afan to go to the park to see his friends.

Wade and Halligan (2017) recognised the integral importance of social interaction and participation, and whilst this paper does not consider head injury, the findings are pertinent for this study. In their paper, a direct influence is noted between social participation, adaptability and behaviour, which mirrors Ffion's thoughts.

Emergent Themes	Subordinate Themes
"I thought he was dead" – an ongoing battle with worry	
"I would have thought he would have hated me" – an acceptance of control	Consequences of Trauma
"He's matured" – a view of post head injury maturation	
"He just expects me to be here" – a view of family	The Importance of Family and Friends
"Very lucky, very lucky" – friendships that persevere	
"For him it is football, rugby" – coping with loss	The Pathway of Recovery
"I didn't think ahead" – the recovery journey	

Figure 6-5: Formulation of Subordinate Themes from Emergent Themes – Ffion.

6.6.3   Ffion's Three Unique Idiographic Elements:

- Ffion had issues with her psychological recovery after the end of the study – this needs to be considered in future care planning

- Ffion's ability to share her enforcer role helped in Afan's return to normality

- She remained pragmatic in thinking about Afan's recovery.

This completion of Ffion's idiographic case analysis concludes the individual idiographic cases for the participants. The next chapter ("Group Level Analysis") will review the findings across participants, exploring convergent and divergent themes.

7 Group Level Analysis

7.1   Introduction

In the previous chapter, I explored the findings from the individual idiographic cases for the CYP and the mothers, and showed from the data the formation of the emergent themes, which ultimately formed the subordinate themes. This chapter will discuss these themes at a group level, looking for convergence and divergence across them. However, it would be amiss to think of these two groups (CYP and mothers) as separate entities. As evident in the previous chapter, the CYP's and their mothers' lifeworlds are synergistically linked, intertwined in a complex interactional dynamic which I will further explore in this chapter below (section 7.4: "Cross-Group Analysis and Summary").

As a result of undertaking this analysis I believe it is possible to improve care for CYP who have suffered a moderate head injury by adding to the literature (by filling a void). For example, by working on the basis that the lifeworld and its constituent parts (intersubjectivity, embodiment, identity, temporality, mood and spatiality) should form part of a holistic care approach used in CYP nursing, the findings from this chapter will feed directly into Chapter 8 ("Discussion") and this study's recommendations (Chapter 9).

At the end of each group level analysis section (7.2 and 7.3), a master table and figure are shown. The master tables present the formation of the superordinate themes from the subordinate themes and demonstrate where there is convergence or divergence in their lived experiences. The figures summarise the lifeworlds and show how each of the superordinate and subordinate themes are interrelated to each other. I faced two difficulties in constructing

the tables: the small number of participants and looking for convergence across different time points. My study provides an in-depth analysis of vulnerable groups at various times of recovery from head injury and the ongoing challenges and distress associated with recovery. To aid in in the interpretation sections of this chapter, additional literature searches were carried out in order to discuss the study findings, as recommended by Smith et al. (2009). The longitudinal contribution of this study, conducted in real time, is seldom seen in head injury research studies and forms a strength of this study. The first participant group to be presented will be the CYP.

7.2   Group Level Analysis – CYP

Analysis at group level showed a significant number of similarities across the CYP group. These are presented in Table 7.1 and discussed in section 7.2.1; they show the groupings of the subordinate themes (derived from the emergent themes) which in turn form the superordinate themes. This table is the master table for the CYP and shows the convergence and divergence between the participants' subordinate themes, a process that was discussed in section 5.3 – step 6 'Looking for Patterns Across Cases'(Smith et al. 2009). To fully capitalise on the temporality of my longitudinal data, the discussion of each subordinate theme will be separated into the interview time frames (two weeks, three months, etc.). Conceptually this process is important, as recovery for the CYP was not linear and was indeed multifactorial – as represented in Figure 7-1 (p. 236). This will be explored in the following sections, and in Chapter 9 in terms of its relevance for clinical practice. The superordinate themes for the CYP are:

- Impact of Restrictions
- Relational Impact of Head Injury

- Resilience and Post-traumatic Changes.

7.2.1   Overview of CYP Master Table and Figure of Complex Recovery Trajectories

In providing an overview the CYP group level analysis findings, Figure 7-1 diagrammatically demonstrates how the subordinate and superordinate themes are interrelated, which affects the lifeworld. This figure shows how the superordinate themes are in conjunction with each other, with arrows showing how the subordinate themes relate to each other. In the centre of the overlapping superordinate themes, an overarching theme "Complex Recovery Trajectories" is shown which encapsulates the non-linear recovery that each of the CYP make. Within the figure, two larger bidirectional arrows are also shown which symbolise how, as a result of the head injury, the lifeworld is affected which in turn affects the CYP and their relationships.

The master table (Smith et al. 2009) for the superordinate and subordinate themes (Table 7.1) shows how the superordinate themes are formed from the subordinate ones. The table demonstrates the longitudinal nature of the study and looks at each time frame in relation to the subordinate/superordinate themes. A simple yes/no is then written in the CYP column to indicate whether the theme is present. The number of "yes"s or "no"s are then added together to see if a group commonality is seen in relation to that theme – the cross-group analysis discussion.

7.2.2   Impact of Restrictions

Each of the participants had restrictions placed on them by the medical teams, and these can be viewed as clinical recommendations which on discharge from hospital become the responsibility of parents (in this case the mothers) to enforce or monitor. The purpose of these restrictions was to lessen the risk of further harm that could aggravate their head injuries. Examples of these restrictions include (but are not limited to) not playing sports or engaging in other activities in which the head could be injured, leaving lessons early to avoid the busyness of the corridors, and avoiding the playground when appropriate (especially when ball games were being played). In the current academic literature, the role of such restrictions is an area that is under-explored and under-researched, which is notable given that these restrictions formed a significant change to the CYP's lifeworlds. One of the important contributions made by this study is its longitudinal element, which enabled the collection and analysis of data relating to participants' lived experiences during the time when the restrictions were in place, as well as for a short time afterwards. Analysing these lived experiences provided a brief, yet rare and valuable, insight into the challenges faced and how the CYP and their mothers viewed their lived experiences of clinical restrictions in real time.

The subordinate themes (derived from the emergent themes) which form this superordinate theme focussing on the impact of restrictions are:

- Not Being Allowed

- Imposed Restrictions

- Cost of Restrictions.

These subordinate themes are interwoven within the discussions at each time frame.

7.2.2.1 **Two Weeks**

Little (if any) real time research has been carried out on participants at such an early and acute stage of their moderate head injury recovery. By carrying out data collection at this early stage into the recovery period, I was hoping to generate a better understanding of the CYP's lived experiences at this important time. Both Cai and Afan, whilst acknowledging the importance of sports to them, accepted the restrictions placed on them and, overtly at least, showed little or no emotional response – pointing to a limitation of interview data collection in the CYP group. In contrast to these findings, Betsi clearly discussed feelings of loss, an emptiness and a void, compared to what she could do before her accident, all of which were a consequence of the restrictions. In interpreting these findings, consideration has to be given to the small sample size, but the findings allude to a divergence in the group where both Cai and Afan showed little emotion in their acceptance of the restrictions whilst Betsi appeared more willing to articulate her feelings of boredom, as illustrated in the following extracts:

"I wouldn't do it!" [reference to using his BMX bike] (Cai; Transcript 1; line 225).

"Um, fine" [In relation to not playing rugby] (Afan; Transcript 1; line 430).

"No, it makes me feel bad. Every day I'm bored" (Betsi; Transcript 1; lines 729–
30).

Identity is an important aspect to consider when analysing head injury recovery, as all the participants demonstrated a significant, sudden change in their lifeworlds as a result of their accident – a commonality within the CYP group. However, within this commonality, variability was noted as all the participants reacted differently to the restrictions placed on them. Cai recognised the importance he placed on rugby, and even though rugby was a social conduit for him, he largely accepted his change in identity, which resulted in reduced social contact with his friends. Afan increased his usage of the PlayStation as a means to interact

with his peers, thus compensating for reduced social contact resulting from restrictions.

Betsi's experiences differed from both Afan's and Cai's. She experienced elements of

overprotectiveness from her friends which she found she did not like. However, she

compared her friends to family which indicated closeness – showing a complexity of

emotions. This alteration to their identities, compared to their preinjury identities, is

demonstrated in the following extracts from their idiographic analyses:

"I miss tackling people" (Cai; Transcript 1; line 366).

"Yeah" [response to increased playing with friends on PlayStation Plus] (Afan;
     Transcript 1; line 480).

"I think I should be able to make my own decisions" (Betsi; Transcript 1; lines 881).

7.2.2.2   **Three Months**

In the second interview, although the participants were continuing to engage with the

restrictions, the consequences of these restrictions were more apparent and there was an

interesting shift in how these affected them personally. Betsi, who had previously portrayed

herself as feeling negative about the restrictions, now appeared to accept them, displayed

little or no emotion around them, and appeared more pragmatic about the restrictions – in her

interview she simply said "*yeah*" (Betsi; Transcript 2; line 682) to illustrate her acceptance.

In contrast, both Cai and Afan were highly negative about the restrictions. Cai felt very sad

about them (a clear shift in his perception of the effects of restrictions), whilst Afan had a

greater change: he became very emotional during the interview, highlighting the degree of

sadness and frustration that he felt. This showed the significant effect of the restrictions. The

following extracts summarise these findings:

"Oh God. Very sad! I can't go on it to after Christmas. Next year" (Cai; Transcript 2; lines 350–1).

"Just miss it!" [Became upset and cried – reference to football] (Afan; Transcript 2; line 443).

"Well I need a helmet to start with and if I do have a helmet, I can barely get it on my head" (Betsi; Transcript 2; lines 650–2).

Analysing the impact of the restrictions offered an interesting insight into the effect on each of the participants' identities. This effect on identity is also more evident here than at two weeks. Interpretatively, it is possible to hypothesise that at two weeks the participants may not have grasped the full impact of the restrictions placed on them, because at that point they were not back in school and had increased attention from friends and family, which minimised the impact of the restrictions. At three months, however, all the participants were back in full-time school where the restrictions clearly impacted on their activities and ultimately their sense of self. For example, they were not allowed to take part in sports and had to leave lessons early; they were therefore starting to fully become aware of the impact of the restrictions on their daily school life.

Cai demonstrated a significant response to the restrictions. His identity was significantly affected as it was embedded in his rugby, which itself was a means of socialisation with his peers (in addition to motocross). His use of phrases demonstrated the degree of hot emotion he felt: "*sad*", "*hitting*", *hurting*", "*angry*" and "*fuming*" (Cai; Transcript 2; lines 338–534). An indication of Afan's identity change was seen in him simply saying "*I can't go out*" (Afan; Transcript 2; line 791) which outlines how frustrated he felt about the restrictions. This phrase in itself is not highly potent, but combining it with his display of crying and

217

generally being upset clearly demonstrated the impact of the restrictions on his identity; he was not able to go out or play rugby/football, which were things that he had enjoyed and which represented significant components of his preinjury identity – they had been taken from him. The following extract from Betsi's transcript can be utilised to represent how the three CYP saw changes in their lifeworld (identities). Betsi felt that she was not trusted; her friends acted as restriction-enforcers on behalf of her mother, which directly affected her identity. This will be also explored in the superordinate theme "Relational Impact of Head Injury", but the overarching point lies in the fact that the CYP were not allowed to do activities that they had enjoyed before the accident, which negatively impacted their identities. The following extract captures this well:

"It's like I know they're trying to like help me and like take care of me and make sure I don't hurt myself but…" (Betsi; Transcript 2; lines 420–2).

7.2.2.3   Six Months

At the time of the third interview (which was also Cai's last interview) there was a divergence in the participants' lived experiences that was embedded in whether the restrictions were still in place. Cai's restrictions had been removed but both Afan and Betsi had them still in place. Earlier in the study Cai admitted that he became angry because of the restrictions. He had also sold his motorbike, which had removed the temptation to use it, but at six months, when he would have been allowed to motorcycle again, he felt sad as he no longer owned one; the decisions now stopped him reengaging with his preinjury lifeworld – which led him to feeling saddened. His emotional reaction reflected the impact that the restrictions had on his lifeworld but also indicated that, in Cai's case, the removal of the restrictions did not mean an instantaneous return to a preinjury lifeworld.

"Sad 'cause I haven't got a motorbike. I was sad because I couldn't ride one" (Cai;
Transcript 3; lines 901–3).

Cai at this time was living in a world without the restrictions, whilst both Afan and Betsi coped with the restrictions differently. Afan continued to feel frustrated about them and the following extract encapsulates his feelings, resonating strongly with his responses at three months:

"Yeah, Frustrated" (Afan; Transcript 3; line 266).

Betsi continued to engage with the restrictions and was trying to remain positive. In terms of her mood, this signified an important change: at two weeks she felt bored, at three months she accepted them and at six months she was positive – pointing to a journey and development of her resilience. However, her resilience was also a complicated component of her lifeworld: she portrayed an image of someone who could be disheartened and dispirited, showing a fine line, a complexity caused by the restrictions placed on her, that she felt between being positive or negative about her experiences at that time. This is illustrated in the following extract where she felt happy to sit on the bike saddle but once she realised she could not ride it because of the restrictions, she felt deflated:

"I just slumped back in the saddle" (Betsi; Transcript 3; line 404).

In reviewing the impact that the restrictions had on the participants' identities at six months, a further divergence is noted within the group, which can also be associated with Cai's restrictions being removed whilst both Afan and Betsi had theirs still in place. Concerning Cai's identity, which was partly grounded in his love of sports, a hesitation or a concern is

noted in that he is worried about knocking his head. He used the term "*paranoid*" to describe the way he viewed his decision making. For Cai this indicated that, with regard to rugby, his journey to regaining his preinjury identity was not complete, which he saw as a risk. This amplifies the point that the removal of restrictions does not always result in a quick return to someone's former identity.

"If you're playing rugby you are paranoid…about knocking your head" (Cai Transcript 3; line 342–7).

For Afan and Betsi, at six months similarities are seen to that which was demonstrated at three months. The following extract from Betsi encapsulates her feelings but also reflects Afan's feelings of frustration and continual loss of identity.

"I know she's trying to protect me but it's like basically she, she's being a bit too overprotective and if I do want, if I go outside for like five seconds she's like, 'get back in here now' and moan, moan, moan. It's like, shut up!" (Betsi; Transcript 3; lines 596–602).

As previously mentioned in Afan's idiographic section, his strategy of using the PlayStation as a way of coping with the restrictions was proving to be less effective, which led him to share similar frustrations to those experienced by Betsi. In the above extract, Betsi also felt that her mother was being overprotective, which perpetuated Betsi's frustration. A clear convergence was seen at six months with Betsi and Afan with respect to both feeling frustrated.

7.2.2.4   **Nine Months**

By the nine-month interviews, both Betsi and Afan had their restrictions lifted and were able to return to their preinjury activities. Interestingly, a convergence was seen between Betsi at nine months and Cai at six months, with Betsi reporting residual anxiety about reinjuring her head; although a natural reaction, Betsi's response also emphasised the enduring impact of the injury and of the protective restrictions deployed by the clinical team. At the end of the study, Betsi was still expressing concern that she might reinjure her head ("*I could hit my head*" Betsi; Transcript 4; line 261). In contrast to this, Afan demonstrated a different reaction, showing no residual problems and being happy to be back participating in his preinjury activities.

At this point in time Afan's identity appears to have returned to its preinjury state. His friendships dynamics had returned to normal, his usage of his PlayStation had subsided as he increased the time spent playing football. Similarly, Betsi had also slowly returned to her preinjury state: the name calling (which happened as some of her peers called her "*lazy*" because of the restrictions) had stopped and her relationships with friends were back to their previous state. However, this return was hampered by her other physical injury (pelvis) and her return to sports was slowed by her anxiety that another injury could happen.

7.2.2.5   **Interpretation**

I have shown that the restrictions imposed on the CYP had a negative impact on their lived experiences. From a lifeworld perspective, this was reflected in their mood and identity. At a group level, the participants' lived experiences seemed to be affected more at three months compared to at two weeks, with the exception of Betsi who demonstrated evidence of

frustration and boredom. At three months, all the participants were in full-time school, where the enormity of the restrictions became more evident. At this point, both Afan and Cai felt annoyed, frustrated by the restrictions; this has been highlighted in similar studies such as Tlustos et al. (2016) and Ryan et al. (2016a). Afan became emotional during the interview and similar findings were noted by Roscigno et al. (2011), who described these behaviours as the adjustment process of living life after a head injury. In contrast, Betsi seemed to accept the restrictions.

The restrictions also impacted their identities, which was also shown in a study by Battista et al. (2014), who showed that identity was connected to dependency on the family; in my study the impact on identity was more evident at three months compared to two weeks. The findings of a study by Tjaden et al. (2012), who looked at CYP's experiences of dialysis, support my participants' loss of identity when restrictions are enforced. Cai had his restrictions removed at six months, yet even then he did not fully return to his preinjury identity and remained worried about reinjuring his head, showing that a recovery does not end when the restrictions are removed. At this time point, both Betsi and Afan continued to have their restrictions in place, with Betsi remaining optimistic (which Lingam et al. (2014) saw as an important aspect of identity for overcoming low self-esteem) but Afan feeling frustrated by them. When the restrictions were removed, the interview at nine months showed Betsi's lifeworld reflecting that of Cai at six months, in that she remained worried about reinjuring her head; Afan had returned to his sports but was playing touch rugby, not full contact, which showed some worry.

Restrictions were placed on the CYP as an essential protective measure and for these three, they successfully prevented reinjury. However, the effect or the experiences of living with the restrictions is of interest as it is rarely discussed or reviewed in the academic and clinical literature. Each of the CYP had to endure temporarily losing activities that they enjoyed and a sense of freedom, which affected their identities. As a result, they had to adjust their lives to fit in with the restrictions and consequently experienced feelings akin to grief and longing for their preinjury lifeworld. Of interest is that when the restrictions were removed, at a group level, they struggled to regain their preinjury lifeworlds, showing that the impact of the restrictions are felt even when they are removed.

7.2.3 Relational Impact of Head Injury

This section will examine, at group level, a comprehensive view into the relational aspect of the participants' lifeworlds and how these were affected by a moderate head injury, exploring how the relationships with family and friends were affected. At the end of this superordinate theme, the various time frames will be discussed together. As in the previous superordinate theme, the following subordinate themes will be interwoven into the discussions.

- Relationships Do Change
- Alteration in Relationships
- Family and Friends Do Worry.

7.2.3.1 **Two Weeks**

In the first interview, only Cai and Betsi discussed family in their interviews and both showed changes within these dynamics. Cai highlighted that his mother was more stressed; he also added that his mother was more concerned about him and he jokingly commented that he

enjoyed the extra attention he was receiving. With Betsi's relational changes, we saw that her estranged father had returned into her life and showed her affection, the latter of which she was less sure about. This was a clear change and development in the life of the family that was directly linked to the head injury. Therefore, it is possible to conclude that a convergence was seen: each of the CYP gained increased focus/concern from their parent(s) and acknowledged that family was important, as demonstrated in the following extracts.

"Family is important" (Cai; Transcript 1; line 83).

*"I know they've always got my back and [pause], I love them" (Betsi; Transcript 1;
line 313–14).*

Another aspect of the CYP's relational experiences was their relationships with school friends. All the participants were seen to show changes in their friendship dynamics as a direct result of the head injuries. However, even though each participant experienced altered friendships, the way that they were affected varied. For example, Betsi described her friends as being overprotective: "*They're* [friends] *not letting me do anything fun*" (Betsi; Transcript 1; lines 834–5). Cai also showed a significant change in his friendships and clearly stated that he missed playing with his friends. Due to the restrictions placed on him, Cai was not allowed to play rugby, which was where he also socialised with his friends: "*Yeah, I miss playing with my mates!*" (Cai; Transcript 1; lines 417–18). Afan initially said that he saw no change in his friendships but also mentioned that his friends came to his house more than before the head injury, which may have led to some changes to his friendship dynamics and his identity. Two weeks post injury was a significant period of adjustment for each of the participants as they came to terms with the restrictions placed on them and to the realisation that suffering a head injury may have longer-term consequences on both a physical and social level.

7.2.3.2 Three Months

At three months, altered family relationships are highly evident, especially for Cai and Betsi. Again, Afan did not mention his family during this interview. However, Cai's and Betsi's methods of coping with these changes are very individual. Cai pointed to an increased tension which led to him feeling angry and highlighted an increase in arguments with his mother within the home setting: "*Yes, angry 'cause there's always arguments*" (Cai; Transcript 2; lines 619–20). Betsi accepted and rationalised the extra concern: "*Yeah but it's only because she loves me*" (Betsi; Transcript 2; lines 830–1). This convergence of experiences can be summarised in the following extract from Cai, in which parental overprotectiveness is the key theme, although each participant, as highlighted, dealt with this altered parental behaviour differently.

"Yeah. She's overprotective" (Cai; Transcript 2; line 695).

A further convergence within the CYP group was evident at three months: each participant continued to experience altered friendship dynamics. Cai's altered relationships appeared to be highly significant for he had lost contact with some of his friends and missed socialising, although he had some contact with friends outside of school time. Afan mentioned that he felt "*fed up*" with his relationships and stated that he did not go out with his friends like he used to, which led to him feeling frustrated. Betsi's relationships remained largely unchanged from the two-week point, in that her friends continued to be overprotective of her. However, her reaction to her friends had deepened where she felt that her friends did not trust her, which affected her personal identity, even though she understood the reasoning behind this. The following extract from Betsi's interview at three months, even though brief, summarises the participants' lived experiences at that time, and how the continual restrictions placed on them continued to negatively affect their friendship dynamics:

"Bored and upset" (Betsi; Transcript 2; line 435).

7.2.3.3   Six Months

At six months a significant divergence of family dynamics was seen within the group. When Cai's restrictions had been removed, his relationship with his mother returned to "*normal*" with his mother being less overprotective, but he admitted to the occasional argument: "*We have the odd argument… That's normal…Everyone does*" (Cai; Transcript 3; lines 564–73). Afan did not discuss in any depth his family during this interview. Betsi's experiences at this point resembled some of the experiences expressed by Cai at three months; there was a deterioration in her relationship with her father and a need for him to be in her life, even though he annoyed her and with Cai, he argued more with his mother. Betsi and Afan showed some convergence with their altered family dynamics which occurred as a result of the head injury recovery process and restrictions.

Concerning friendships, Cai did not discuss his thoughts at this point, alluding to the fact that he saw no issues here and that he had returned to his preinjury friendship dynamics: he was allowed to play rugby, which had facilitated his re-engagement with his friends. In a potential convergence with Cai, Afan indicated that he was happy with his friendships because he was playing with his friends and was in full-time school, a change from the previous interview. Afan supports this with a simple "*Yeah*" (Afan; Transcript 3; line 186) in response to the question about whether his friends treated him the same then compared to the time before the accident – a return to normality. Betsi, in a divergence from Afan and Cai, continued to experience frustration resulting from the continuing overprotective friendships, which led to her feeling annoyed: "*my handshakes and then I feel like punching somebody*" (Betsi;

226

Transcript 3; line 636–7). Betsi friendships, unlike those of Cai and Afan, would not allow her to return to her preinjury dynamics and consequently were having a negative impact upon her wellbeing, which may have been influenced by her injury to her leg – unlike Cai and Afan who had no other physical injuries to contend with.

7.2.3.4   **Nine Months**

In the final interview, Betsi noted a further deterioration in her relationship with her father and described how her mother was both mother and father to her, thereby indicating some return to her preinjury relationships, in which her mother was her only carer. Afan felt that his parents treated him the same but was aware of the concern his parents had for him. Both Betsi's and Afan's experiences at nine months show a similarity: a return to a preinjury family dynamic that was influenced by the removal of the restrictions. This convergence was also mirrored by Cai at six months, hence emphasising how restrictions influence family dynamics.

At nine months, Afan's and Betsi's friendships saw a return to a preinjury state, which was a significant change for Betsi compared to her six-month interview. Afan indicated that he had noticed that his friendships had changed: he felt that his friends were more relaxed with him now than they had been since the head injury, which was supported by his mother's comment: "*they did treat him differently*" (Ffion; Transcript 2; lines 502–3). Betsi simply implied that her friendships were back to how they were before the injury. This convergence of experiences, which mirrors that of Cai at six months, shows the positive impact of the removal of the restrictions. Also, by their friendships returning to their preinjury state, each of the CYP started to regain a sense of their preinjury identities, hence highlighting the need

for a multi-dimensional view of recovery. Important factors in this recovery process are dependent upon other influences – this inter-dependency will be further explored in the discussion chapter.

7.2.3.5 **Interpretation**

Family and friends are well recognised in the literature as important aspects in a CYP's recovery following a head injury, as exampled by Heverly-Fitt et al. (2014) and Clark et al. (2008). However, I have been able to demonstrate the complexities and inter-dependencies that exist, the finer workings that take place within these dynamics. It is not merely a linear model in which supportive friendships support better outcomes. Heverly-Fitt et al. (2014) discussed the role of friendships: they can support or hinder recovery with respect to psychosocial adjustment. Battista et al. (2014) also found that friendships can have a powerful effect on recovery. The case of Betsi, who suffered some name calling and social alienation (Roscigno et al. 2011), also showed that friendships can be too supportive or overprotective; Betsi did not like this and it influenced her perceptions of relational and individual wellbeing. Cai, who lost friendships due to his enforced restrictions, also reacted negatively to his mother's overprotectiveness, whilst Afan in an example of divergence seemed to accept it.

Even though friendships can change as a result of a head injury and the restrictions it brings, friendships are highly important, but the *normality* of these friendships is the important link; when this is regained or restored, happiness appears to follow. This superordinate theme has demonstrated that at a group level the application of restrictions, even though temporary, can significantly destabilise existing family and friendship dynamics, even when strategies are

put in place to help (as exampled by Afan's increased usage of the PlayStation), these strategies are only temporarily. The CYP within this group were only fully content with their relational dynamics when they returned to their preinjury state.

From a healthcare perspective, these findings are highly relevant for their highlighting of when support and care needs to be prioritised. In this study, I have demonstrated times when the CYP appeared to have low mood associated with friendships and family. Mood, which is a component of the lifeworld (Galvin and Todres 2013), was affected in all the CYP as a consequence of the restrictions; this is something that is not largely recognised clinically. It is touched upon by Heverly-Fitt et al. (2014) in emphasising the importance of friendships in helping with mood, but they do not discuss this in relation to restrictions, but nevertheless they highlight the value of friendship. This component of the lifeworld will be discussed in the following chapter but the full impact that the restrictions have on mood together with how family and friends influence this is not fully realised or understood.

7.2.4   Resilience and Post-traumatic Changes

This superordinate theme will demonstrate the extent to which the CYP went in order to deal with the restrictions placed on them. This superordinate theme will also discuss how the CYP changed as a result of their head injury, often in subtle ways.

The three subordinate themes (which are interwoven in the following discussions) that formed the superordinate theme are:

- Coping and Maturity

- Resilience and Maturity

- Coping and Being Positive.

7.2.4.1   Two Weeks

At two weeks, only Betsi discussed how she saw her recovery going. Betsi's view of her recovery was largely optimistic: she felt that a full recovery would take five months. Her ability to visualise her recovery progression was important as it formed part of her coping strategy and helped her to stay positive. Betsi's findings appeared to diverge from Cai's and Afan's, who did not demonstrate any reference to coping, positivity or views of recovery. The lack of discussion by Cai and Afan alludes to their lack of need to visualise their recovery – as they did not see it as a problem.

"I think it's going to take five months to get me better" (Betsi; Transcript 1; lines 986–7).

7.2.4.2   Three Months

There were notable differences between Betsi, Cai and Afan at three months. Betsi, on being asked when she expected to make a full recovery, attempted to quantify her recovery in terms of time but her perception of when she would make a full recovery changed from five months (her answer at two weeks) to a "*in 1000 years*" (Betsi; Transcript 2; line 923) – representing a clear change in her earlier positive thoughts: here, Betsi saw recovery as being no longer a feasible prospect – she would have to endure the repercussions of the accident – and she struggled to maintain her resilience. In the same interview there were elements of maturation, with her commenting that she did not like being treated like a "*child*" anymore, pointing to a

self-awareness of her maturing and how restrictions were reinforcing the parent–child relationship:

"She feels like I'm not responsible like I'm just a child" (Betsi; Transcript 2; line 1038–9).

Afan and Cai, in their individual ways of cope with the restrictions, formed similar strategies. Afan openly admitted to playing football ("*Only by the garage*" Afan; Transcript 2; line 433), and when this was explored he commented that he kept the ball below head height and did not headbutt it – which shows a mature insight into what could have happened if he had knocked his head. This defiance also aided Afan's personal resilience and coping. In being defiant, this gave him freedom to play football which enabled him to cope with the ongoing restrictions. In the extract "*only*" refers to this limited freedom, (that he used in order to cope) which appeared to be enough for him, to be compliant with the restrictions at other times.

In his third interview (at six months, but relevant here), Cai retrospectively described the process of talking to his friends on the school playground (parts of which were boisterous and busy) and he described himself as a "*Rebel*" (Cai; Transcript 3; line 1050). Defiant behaviour seemed to be a method that Cai and Afan both used as a coping and resilience strategy, which is a stark divergence from the experiences of Betsi, who did not show defiance. Both Cai and Afan did not overdo the defiance in such a way as to put themselves at risk – showing a calculation to their thoughts.

Both Cai's and Afan's views of their recoveries also showed divergence from Betsi's: Betsi was struggling with staying positive, but Cai and Afan shared being positive about their

recoveries; which potentially is linked to them not being fully compliant with the restrictions. Afan was hopeful about regaining his skill and speed in rugby, and Cai (whilst discussing his motorbike) used the following extract that encapsulates both Afan's and Cai's thoughts:

"I hope I can go on it by my birthday or on my birthday. I'm going on it on my birthday!" (Cai; Transcript 2; lines 1074–6).

This time frame provided an insight into the variance that existed within this group. From these lived experiences and the CYP's articulation about how they coped, both Cai and Afan, who showed defiance, appeared to be more positive about their recoveries. Betsi in divergence, who did not show defiance, struggled with her view of her recovery and the amount of time it would take.

7.2.4.3 Six Months

Cai at six months, when the restrictions had been removed, presented himself as facing a dilemma as a result of his head injury. As previously highlighted, Cai enjoyed sport, which was also a conduit for socialising with his peers. In this superordinate theme, it is possible to see elements of maturity/self-awareness in that he is "*debating*" (Cai; Transcript 3; line 289) about playing rugby, and he mentioned wearing a skull cap to reduce any potential injury. He is also aware that his head injury could have been worse ("*Well, I have not been left paralysed or something like that!*" Cai; Transcript 3; lines 1321–2) and described his scars with the metaphor "*War wounds!*" (Cai; Transcript 3; line 1338), evidence that he was thinking about what had happened to him and, to a certain extent, considering his future.

Afan continued to view his recovery as being positive and was happy with his progress. Following the interview, Afan mentioned that he did still play with a football and, like before, kept it below head height. In contrast to Afan's feeling that his recovery was going as he expected, Betsi felt that hers was going "*Slow*" (Betsi; Transcript 3; line 948). The following extract from Betsi's third interview encapsulates Betsi's views and alludes to Afan's: they understood that it would take a while for a full recovery and that being positive helps. For Betsi, this extract also demonstrated her personal resilience in getting through the recovery process and that her view had changed from 1,000 years to "*one point*", which can be seen as a more realistic view of recovery time – 1,000 years indicated a time with no end point:

"I know, I know it's not going to be for a while yet but at one point I will be able to ride my bike, so I've just got to be positive. I'm, I'm never positive before and I've just got to try to be positive" (Betsi; Transcript 3; lines 379–84).

7.2.4.4 Nine Months

With the removal of Afan's restrictions, it is possible to see a convergence with Cai at six months, when Cai had the opportunity to return to full-contact rugby. At nine months Afan was positive about his recovery and was playing touch rugby, which he deemed to be a lower risk than full contact. The extract below from Betsi's final interview encompasses the main findings for both Afan and Betsi at nine months, and Cai at six months. Unlike Cai (at six months) and Afan, Betsi was still dealing with physical injuries caused by the accident: she now saw her recovery taking "*Probably about 4 years*" (Betsi; Transcript 4; line 919). Her continuing experiences of her physical injuries and the discomfort they caused here influenced her views that recovery would take a long time; however, she remained both cautious and positive. I have underlined the key message from this extract, which I feel showed maturity and common sense in dealing with the recovery process:

*"Because it's like **one step at a time**. Like when you walk, you don't want to run and you don't want to gallop, you just want to walk"* (Betsi; Transcript 4; lines 333–6).

7.2.4.5   **Interpretation**

Bringing together the components from each of the participant's interviews offers a valuable insight into aspects of their recoveries. A difficulty which I faced as a novice researcher when interviewing CYP regarding conceptual topics like resilience, coping and maturation, was gauging their understanding of these concepts (especially as the original recruitment age started at 6 years of age). However, these are important topics which were drawn out of the analysed interviews as their essence provided valuable insights in the recovery journey of each participant. All the participants showed post-traumatic changes, which connects with the study of Battista et al. (2014) who stated that but this area needs further research My study highlights such changes as Betsi's maturity and coping improving and Cai thinking he was more mature.

In interpreting this theme, key differences were noted in the way each of the participants demonstrated their resilience or changed as a result of their head injury. Betsi, who seemed to accept the restrictions, later became frustrated until finally becoming more accepting of the restrictions. Cai and Afan used facets of defiance to aid their coping and resilience, and for them this proved to be beneficial. Both Van Petegem et al. (2015) and Pettegrew (2017) discussed defiance and saw it as a coping strategy for dealing with frustration. For Cai and Afan, being defiant gave them some limited freedom which helped them cope with the restrictions at other times.

As with the other superordinate themes, it would be wrong to see this as a standalone theme; rather, it is one that is linked synergistically with the other themes – as diagrammatically represented in Figure 7-1 and explained further in section 7.4. A convergence was noted between all the participants: when the restrictions were removed they all faced an inner battle or questioning around undertaking activities that before the accident they may not have thought twice about – but here, especially with rugby (for Cai and Afan), they were debating if they should restart these activities. This was a clear indication that they had changed as a direct consequence of their head injury and the direct impact on their lifeworlds.

Table 7.1: Master Table for CYP.

Superordinate Themes		Subordinate Themes	Time of interview												
			2 weeks			Total 'Yes'	3 Months			Total 'Yes'	6 Months			Total 'Yes'	9 Months		Total 'Yes'
			Cai	Betsi	Afan		Cai	Betsi	Afan		Cai	Betsi	Afan		Betsi	Afan	
	Impact of Restrictions	Not Being Allowed	Yes	Yes	Yes	3	Yes	Yes	Yes	3	No	Yes	Yes	2	No	No	0
		Imposed Restrictions	Yes	Yes	Yes	3	Yes	Yes	Yes	3	No	Yes	Yes	2	No	No	0
		Cost of Restrictions	No	Yes	No	1	Yes	Yes	Yes	3	Yes	Yes	Yes	3	Yes	Yes	2
	Relational Impact of Head Injury	Relationships Do Change	Yes	Yes	Yes	3	Yes	Yes	Yes	3	No	Yes	Yes	2	No	No	0
		Alteration in Relationships	Yes	Yes	Yes	3	Yes	Yes	Yes	3	No	Yes	Yes	2	No	No	0
		Family and Friends do Worry	Yes	Yes	Yes	3	Yes	Yes	Yes	3	No	Yes	Yes	2	Yes	Yes	2
	Resilience and Post-Traumatic Changes	Coping and Maturity	No	Yes	No	1	Yes	No	Yes	2	Yes	Yes	Yes	3	Yes	Yes	2
		Resilience and Maturity	No	Yes	No	1	Yes	No	Yes	2	Yes	Yes	Yes	3	Yes	Yes	2
		Coping and Being Positive	No	Yes	No	1	Yes	No	Yes	2	Yes	Yes	Yes	3	Yes	Yes	2
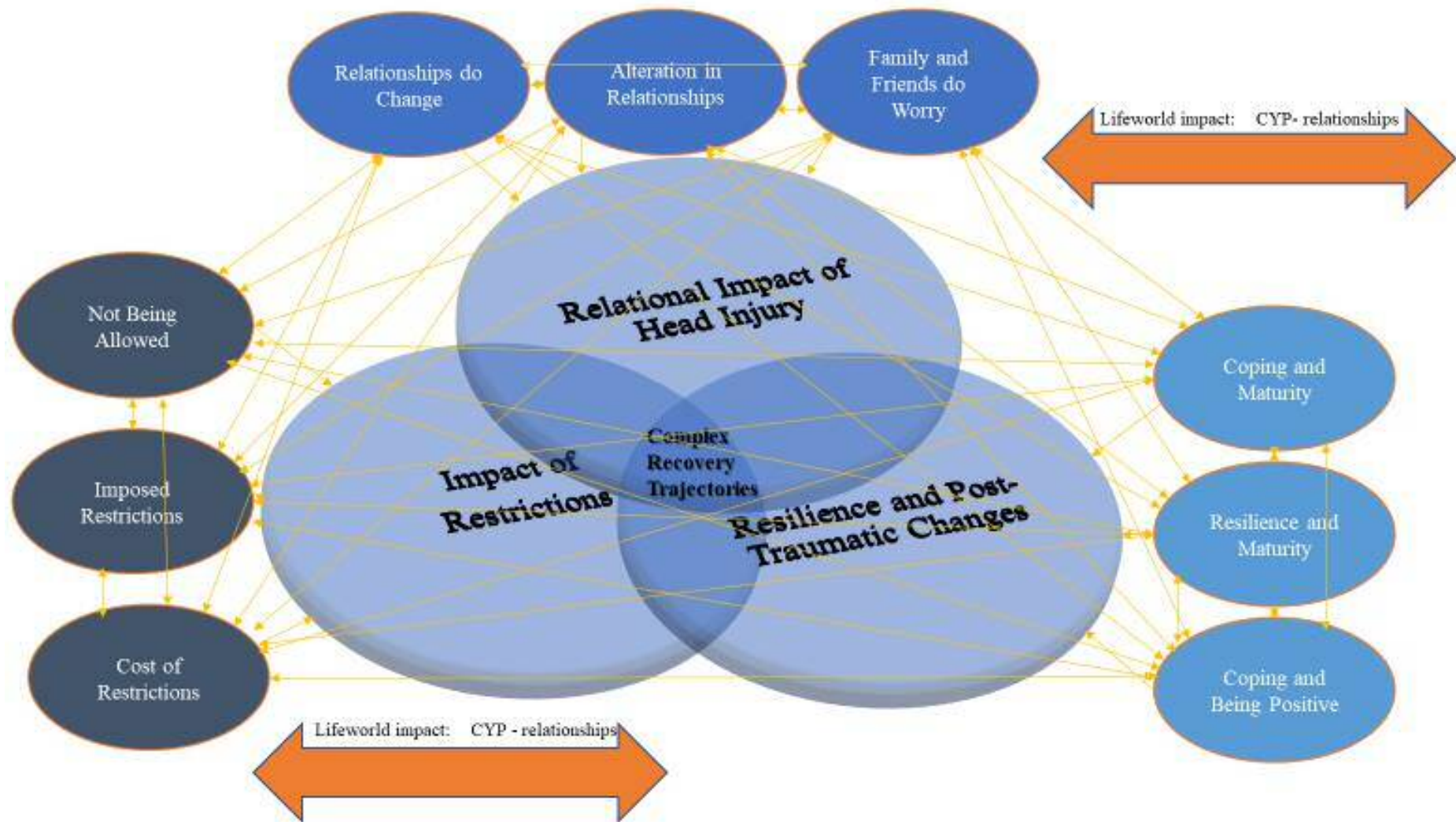
Figure 7-1: Overview of CYP's Complex Recovery Trajectories.

7.3   Group Level Analysis – Mothers

This section will present the findings from a group analysis of the mothers who were involved in the study: Gwen (mother of Betsi) and Ffion (mother of Afan). Table 7.2 (p. 250) shows the master table of how the superordinate themes were formed from the subordinate themes. In variance to the CYP, the mothers were interviewed at two time points: six and nine months. As a researcher, I was interested both in the mothers' lived experiences and in their views on their daughter's/son's experiences; Figure 7-2 (p. 251) demonstrates the complexity of these findings.

I am aware of a potential limitation within this section: the inclusion of only two mothers (although this did produce four in-depth interviews) for a group level analysis has the potential to result in the drawing of incorrect conclusions. However, it is the generation of in-depth information – which is a key characteristic of IPA (Anstey 2012) – that is important, and as such adds strength to the findings. Furthermore, only undertaking interviews with the CYP felt like telling only one part of the story given the mothers' important role in the recovery process. For completeness, therefore, I included the mothers at six and nine months. The superordinate themes that will be discussed in this section are:

- Parental Psychological Trauma

- Family and Friends

- Recovery Journey.

7.3.1 Overview of Mothers Master Table and Figure of Complex Recovery Trajectories

In keeping with the CYP analysis, this section will first introduce Figure 7-2 and Table 7.2, which represent the findings. Figure 7-2, a diagram showing the influence on the lifeworld, demonstrates the relationship between the subordinate and superordinate themes. In the centre of the overlapping superordinate themes, as with Figure 7-1 (CYP), an overarching theme "Complex Recovery Trajectories" is shown, which represents the non-linear recovery that each of the mothers makes.

Table 7.2 shows the master table (Smith et al. 2009) for the superordinate and subordinate themes. This functions similarly to the CYP master table, showing how the superordinate themes are formed from the subordinate ones –the cross-group analysis discussion.

7.3.2 Parental Psychological Trauma

It was evident in the early stages that the mothers were affected by their daughter's/son's accident and were undertaking their own, often harrowing, recovery journey; this is presented in this theme as signs of psychological trauma and control. An association could be seen between parental decision making and the effect this has on their son's/daughter's experiences: the mother often had to enforce the restrictions and make decisions about their daughter/son, whilst simultaneously dealing with their own psychological trauma. Speaking as a researcher and clinician, this is interesting as it provides an insight into the complicated dynamics that take place. The following subordinate themes will be interwoven within the theme's discussions:

- Impact of Trauma

- Consequences of Trauma.

7.3.2.1 **Six Months**

At this point during the CYP's recoveries, convergence is noted between Gwen and Ffion both in the way that they recalled the accidents and in their experiences at six months. Each mother talked about entering a state of shock, an incomprehension, a state of unreality that this had happened, but also a resilience that helped them to care for their daughter/son. The following extract from Gwen highlights the key points that both mothers had felt at the time of the accident:

"I could either sit here and cry or you keep it together and you just deal with the fact that she's laying on the floor and it was the worst time of my life… I think she just wanted me to pick her up and take her home… it was just disbelief" (Gwen; Transcript 1; lines 31–53).

The following extract from Ffion also encapsulates the mothers' worries at the time after the accident, when both just wanted their son/daughter to survive. This convergence of thought highlighted their worries but also displayed their horror at what had happened and how their need for their daughter/son to survive was the only thing that they thought about:

"I was just praying that he would stay alive. That's all I was thinking about" (Ffion; Transcript 1; lines 136–7).

A similarity was also noted in further exploration of how the mothers' experiences might have influenced their parenting roles, which would have included the need to enforce the restrictions. Both mothers understood that their daughter/son might have disliked the

239

restrictions placed on them, but both also acknowledged that their child accepted the restrictions. The following extract from Ffion summarises this key point which was evident in both Gwen's and Ffion's interviews at six months:

"I would have thought he would have hated me, (laughter) because it is me that has stopped him" (Ffion; Transcript 1; lines 279–81).

Interestingly, at six months both mothers acknowledged that the restrictions placed on their son/daughter were having a negative influence on their son's/daughter's wellbeing. This also highlighted a convergence of parental overprotectiveness: Gwen came to think that she had been overprotective, once Betsi had informed her of it, and Gwen seemed to be aware of it through noticing how Afan was reacting to her. Both mothers started to relax the restrictions over their son/daughter somewhat by allowing them to experience elements of their preinjury normality; the mothers also simultaneously were allowing themselves to adjust to these renewed elements of life. This convergence is encapsulated in an extract from Ffion, which resonated with Gwen's interview data; Ffion showed the willingness of the mothers to do what was right for the wellbeing of their daughter/son. As noted in the mothers' idiographic cases, control was a response to the fear of losing their son/daughter, so relinquishing control was a significant psychological endeavour which they undertook in a measured way.

"Like a couple of times he's gone out with them but I've taken them, taken him, sort of stayed there, not with him but with his brother in the background so he's got a bit of independence" (Ffion; Transcript 1; lines 685–90).

7.3.2.2   Nine Months

At nine months, both mothers continued to contend with the horrors that they witnessed, echoed in the following extracts, which both highlight the mothers' worries. This sustained

concern, which they continued to cope with at this time, outlined the ongoing battle and recovery from the accident that they themselves were facing. Both mothers gave voice to this ongoing struggle:

"It's the fear that it happens, it would happen again" (Gwen; Transcript 2; lines 54–5).

"I'm very traumatised" (Ffion; Transcript 2; line 148).

At nine months, the restrictions had been removed and, as previously discussed, each of the CYP was engaging with their post restriction lifeworlds with regained freedom. However, both mothers reflected on the restrictions and the effect that they had had on their son/daughter. Ffion felt that Afan "*got very frustrated, upset*" (Ffion; Transcript 2; lines 615–16) by the restrictions, indicating his feelings. Gwen felt that Betsi also became frustrated, which is alluded to in this extract: "*she's not telling you what to do, she's just trying to do what I've said that I don't want you to do*" (Gwen; Transcript 2; lines 335–43). Gwen felt that this frustration also affected Betsi's identity with her friends.

7.3.2.3   **Interpretation**

This theme has offered an insight into some of the elements of the psychological trauma that the mothers experienced at the time of the accidents; how this potentially influenced their decision making, as mentioned in the study by Clark et al. (2008); and the effect it still had at nine months into the study period. Both mothers in their interviews talked about the horrific experiences they endured when faced with their daughter/son at the scene of the accident. The findings for both Gwen and Ffion are also shown in other studies, such as that of Wongvatunyu and Porter (2008) and it is possible to visualise the mothers as having to make

their own psychological recovery journey. Without question, the mothers' traumatic lived experiences affected their decision making, which presented itself as control (a finding that resonates with Li and Liu (2013) – a head injury systematic review which showed that parenting was affected), where the mothers having to enforce the restrictions passed on by the medical team; the mothers used control to help with their own anxiety.

Little differentiation was noted between six and nine months; both the mothers continued to struggle with the trauma that they had experienced, which mirrored some of the worries that the CYP had at this time. As a clinician, this is important as it clearly highlights the need for ongoing support for both the CYP and their mothers even after any restrictions have been removed.

7.3.3 Family and Friends

This superordinate theme will analyse the mother's perceptions of changes within family and friends, which happened as a result of their daughter's/son's moderate head injury, together with any benefits or disadvantages that these changes brought to the recovery process. Examples of these are their roles as restriction enforcers and the re-emergence of two of the CYP's fathers. The subordinate themes that this superordinate theme comprises are:

- The Role of Family and Friends
- The Importance of Family and Friends.

7.3.3.1 **Six Months**

The role of family, as perceived by the mothers at six months, was a complex factor which appears unique to each family. A commonality that existed between Gwen and Ffion was that they were both single parents and were the main carers. Gwen's view was that the dynamics between Betsi and her father changed with his re-emergence into her life (which Gwen felt was guilt based). This resulted in Betsi being overindulged by her father with gifts, which Gwen saw as an attempt to buy affection. However, at six months Betsi's father had reduced his closeness and contact with Betsi to the point that he was not aware of Betsi and her mother of going on a cruise whilst in the recovery period. Gwen highlighted her daughter's need for her father to be present:

"She'd rather more time. She'd rather be happy with him playing out the back"
    (Gwen; Transcript 1; lines 671–3).

This summary described how Betsi had to deal with her father being back in her life, from the initial happiness this brought her to the gradual return to their preinjury dynamics, when the dad was not actively on the scene – a rollercoaster ride of emotions. Ffion's perception was that Afan viewed family as something that he took for granted, but she added that since the accident the normal family dynamics had changed: he was no longer fighting with his brothers and she felt that Afan was closer to her now.

With regards to family dynamics, convergence is seen as both mothers portrayed an image of altered family dynamics as a result of the head injuries, but the way the families responded highlights that families' responses are unique. This uniqueness appeared to be influenced by their pre-exiting dynamics and the recovery process.

Both mothers' perceptions of the continuing friendships which their daughter/son had were how important they were to their child's recovery as they formed some normality for them. Gwen described the importance of friendships to Betsi, which allowed her to be happy and to be herself whilst offering a supportive network. Ffion's view offered a convergence of thought with Gwen: she saw Afan's friends as being supportive, adaptable (to a point) and accepting. At six months, both mothers were aware that these relationships, even though strong, were tested: Afan became sad as he could not openly play football with his friends and Betsi had frustration over some loss of her identity through overprotective friendships.

7.3.3.2   Nine Months

At nine months, when discussing families, Gwen mentioned that Betsi continued to miss her father but that Betsi was not open to her mother about this and the feeling only manifested when friends of Betsi talked about their fathers. It is worth mentioning that Gwen reported that she and Betsi were close and could discuss most matters. Ffion mentioned that there was a return to normality for her family, in that Afan would mock fight with his brothers, something they did together before the accident. Afan's father also accepted the reduction of his restrictions (as he was the restriction enforcer when Afan stayed at his house), which he was reluctant to do at six months. The following extract from Ffion's second interview encapsulates the mothers' thoughts, a convergence of a return to a preinjury state whilst remaining slightly cautious.

"I think all of us were aware that he'd banged his head. We were all still aware of it, obviously more aware of it and I think, I think we were all aware that things could happen, like accidents could happen" (Ffion; Transcript 2; lines 1084–91).

Both mothers viewed friendships as being an important component for their daughter's/son's lifeworld; hence showing that both mothers understood the need for friendship. Gwen felt that Betsi had normal friendship dynamics and had made new friends, which is illustrated in the extract below. Ffion mentioned that Afan's friends did treat him differently as a result of the head injury but at nine months his friendships had returned to normal and he was playing on the PlayStation less as a result. The following extract shows this convergence of thought: at nine months, friendship dynamics had normalised and Betsi was making new friends alongside her existing friendships.

"She likes to be with her friends and as she said when she was talking to you, she's starting to meet new friends" (Gwen; Transcript 2; lines 285–8).

7.3.3.3   **Interpretation**

This superordinate theme has provided the mothers' views of Betsi's and Afan's family and friendship dynamics. In the case of family, both Gwen's and Ffion's families appeared to have changed significantly as a result of the head injury. The way Gwen used Betsi's friendships was informative and an interesting way to exercise control: she used Betsi's friends as proxy restriction enforcers, which influenced the dynamics between Betsi and her friends. This resonated with the increased parental anxiety seen in Clark et al. (2008) and with the study of Wongvatunyu and Porter (2008), in which the mother wanted their child to have as normal a life as possible. In combining these findings and interpreting Gwen's actions, it is possible to visualise her as creating a "protected normality" – she encouraged friendships, but the friends ensured the restriction were enforced. Ffion's approach resembled Gwen's action, albeit in a lesser form, when she utilised her other son to act as a proxy

enforcer by asking him to accompany Afan to the park, so Afan could socialise with his friends.

At the end of the study period and with the removal of the restrictions, both mothers appeared to let their daughter/son to return to what they perceived as normal friendship and family dynamics, even though the mothers continued to have their own anxieties and concerns.

7.3.4   Recovery Journey

This superordinate theme will examine the mothers' perceptions of both Betsi's and Afan's recoveries at six and nine months. Within this theme, I will examine some of the CYP's emotions perceived by the mothers to occur along their recovery journeys, together with how the mothers perceived the progression of their daughter's/son's recovery. This superordinate theme will be comprised of the following subordinate themes, with their discussions interwoven in the sections:

- Ongoing Issues – Recovery of the CYP
- The Pathway of Recovery.

7.3.4.1   **Six Months**

At six months Gwen described Betsi as suffering from a loss of confidence when crossing roads, which was how her accident happened. Gwen developed strategies, involving herself and selected friends, to encourage Betsi to overcome this fear. Afan's mother, Ffion, did not mention crossing roads being an issue for him, which is relevant as Afan was hit by a car whilst crossing a road, indicating a divergence of experiences; however, Afan did go out with

his brothers (to the park) in an attempt to build his and his mother's confidence. Re-normalising daily behaviours and attempting to progress recovery can be seen as a commonality in both mothers. The following extract from Gwen's first interview highlights the drop in confidence and the need to encourage normality as this can improve recovery:

"Her confidence and ability seem to have taken a bit of a nosedive" (Gwen; Transcript 1; lines 1141–2).

In looking at the mothers' perceptions of Afan's and Betsi's physical recoveries, a clear divergence of experiences is noted. Ffion appeared happy with and thankful for Afan's recovery up to this point ("*I'm just thankful that he's made such a good recovery*" (Ffion; Transcript 1; lines 487–8)) but she also is wary that the positive trajectory of his recovery could change: "*I hope's he going to carry on and be back to normal, I hope*" (Ffion; Transcript 1; lines 663–4*).* In contrast, Gwen highlighted that Betsi suffered from phenytoin toxicity and as a consequence had double vision (in the early stages), and was struggling with increased discomfort in her legs – though Gwen felt that Betsi was making good progress in other areas as exampled by being discharged from both ophthalmology and maxillofacial clinics – both of which Betsi found upsetting and distressing as they reminded her of her hospitalisation. Both mothers saw recovery for their child as progressing but this journey was one which was not straight forward, with obstacles to overcome; this demonstrates the non-linear recovery journey for both the CYP and their mothers – different elements of their lifeworlds recover at different rates. This is a concept which will be explored in the next chapter.

7.3.4.2 Nine Months

At nine months, Gwen viewed Betsi as being positive about her recovery. This was a contrast to her experience at six months, when she felt that whilst her daughter wanted to ride her bike, thinking about this resulted in Betsi having additional anxieties associated to the accident, as riding her bike meant she would have to negotiate roads and traffic. Gwen commented that Betsi "*doesn't like crossing this road, still*" (Gwen; Transcript 2; lines 89–90), pointing to Gwen's interpretation of Betsi's ongoing concerns and worries.

In the following extract, Ffion provided an interesting insight that Afan's anger and being tearful (speaking of events at six months) could be linked to a drop in confidence, which mirrors Betsi at six months, hence showing some convergence between their experiences. And like Betsi, Afan had regained his confidence and was playing in the same way as before the accident. Ffion viewed Afan's display of tears and anger he displayed was associated with his loss of ability in sports which became obvious when the restrictions removed and were demonstration of his frustrations and anxiety, they had caused him. Ffion saw that these emotions were no longer an issue for him and had returned to how they were before the accident – a normalisation.

"When he first went back like, when he played his first game, he came off and he was very angry and tearful, um, but now he's not, now he's playing like he was before" (Ffion; Transcript 2; lines 868–73).

It is possible to see a convergence between the findings at six months and the mothers' perceptions of Betsi's and Afan's physical recoveries in this time frame. At nine months, Ffion admitted that she was still worried about Afan but felt that his physical recovery was

going well – whilst Betsi continued to have ongoing issues with her legs, and the clinicians were still trying to find out the cause of these issues.

7.3.4.3   **Interpretation**

Analysing Gwen and Ffion's interviews at six and nine months revealed their journeys to recovery. Both Gwen and Ffion saw their daughter/son lose confidence at some point in their recovery journey, which mirrors the findings of the CYP group level analysis – both parents identified this and attempted to help: Ffion allowed Afan to socialise (with his brother providing supervision) and Gwen reduced her overprotectiveness of Betsi. However, this similarity stopped being similar as Ffion's perception was that Afan's recovery was going well whilst Gwen viewed Betsi as continuing to have difficulty at both six and nine months. Acknowledgement must be given to the difference in the extent of the injuries each of the CYP suffered, as Betsi had ongoing issues with her leg.

Key bits of information were obtained from analysing Gwen's interviews in the way she perceived Betsi's reaction during the recovery period: firstly, attending clinical appointments were upsetting, stressful and reminded both Gwen and Betsi of the time they spent on the ward recovering and when Betsi was discharged from services, Gwen viewed this as offering reassuring signs of recovery – a finding which resonates with the study of Clark et al. (2008). Secondly, recovering from a moderate head injury does not automatically mean that the CYP has recovered from any other injuries acquired during the accident and in Betsi's case, had ongoing issues.

This section has explored the mothers' views of their child's recovery. However, it is worth mentioning that both mothers were continuing along their own journey of recovery, which continued after the nine-month study period. Wongvatunyu and Porter (2008) highlighted that the mother's recovery is embedded in emotion and psychological trauma. As such, this theme for the mothers is heavily intertwined with the above theme "Parental Psychological Trauma" (section 7.3.2).

Table 7.2: Master Table for Mothers.

Superordinate Themes		Subordinate Themes	Time of interview					
			6 Months		Total 'Yes'	9 Months		Total 'Yes'
			Gwen	Ffion		Gwen	Ffion	
	Parental Psychological Trauma	Impact of Trauma	Yes	Yes	2	Yes	Yes	2
		Consequences of Trauma	Yes	Yes	2	Yes	Yes	2
	Family and Friends	The Role of Family and Friends	Yes	Yes	2	Yes	Yes	2
		The Importance of Family and Friends	Yes	Yes	2	Yes	Yes	2
	Recovery Journey	Ongoing Issues – Recovery of the CYP	Yes	Yes	2	Yes	Yes	2
		The Pathway of Recovery	Yes	Yes	2	Yes	Yes	2
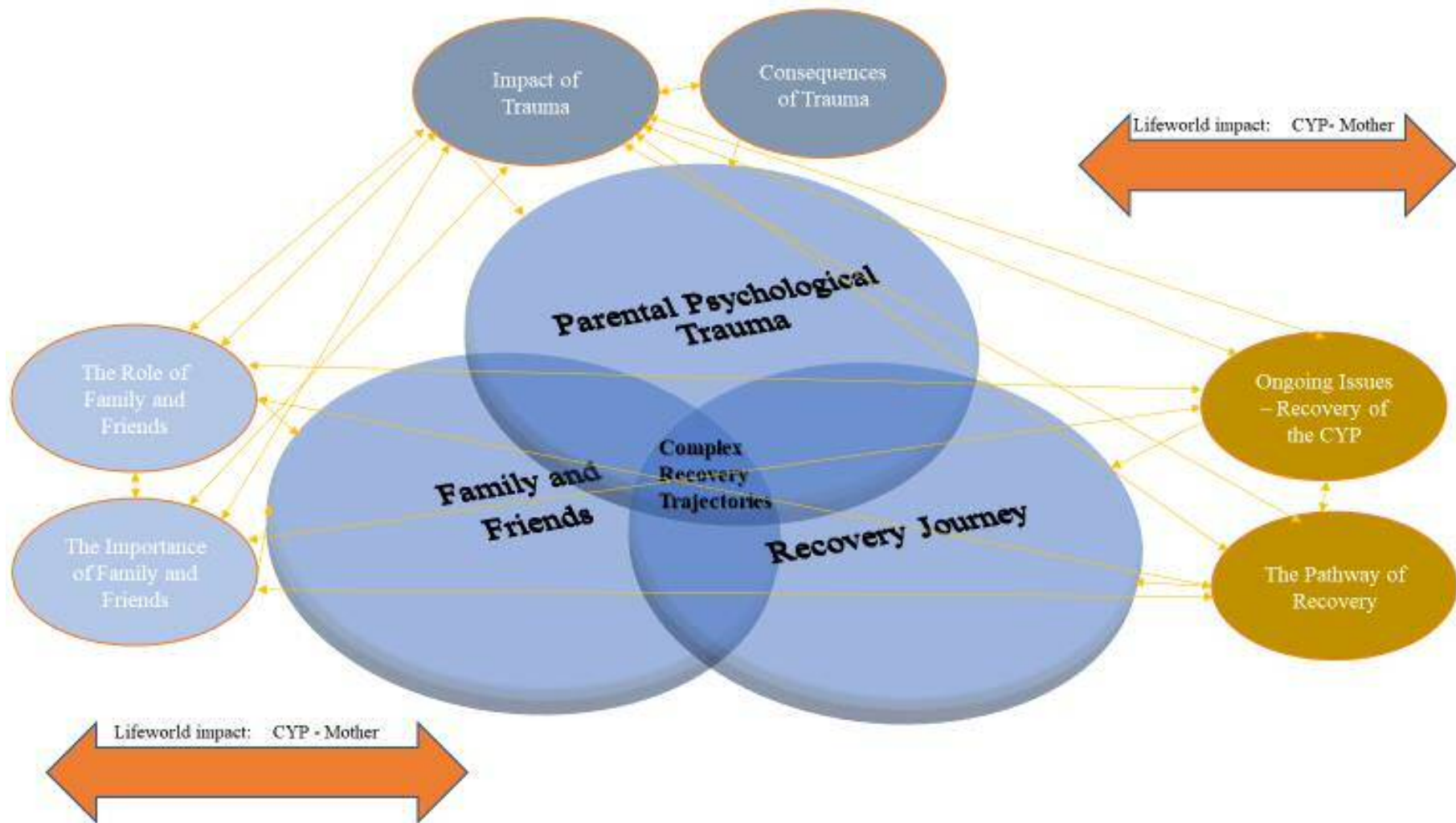
Figure 7-2: Overview of Mothers' Complex Recovery Trajectories.

7.4   Cross-Group Analysis and Summary

In this chapter, I have provided a comprehensive group level analysis of the interviews of the CYP and their mothers. Two master tables were generated (Table 7.1, p. 235, and Table 7.2, p. 250) to show the formation of the superordinate themes from the subordinates themes. Alongside these, I have created two Venn diagrams (Figure 7-1, p. 236, and Figure 7-2, p. 251) to show diagrammatically the interrelatedness of the themes. Purposely, the main overarching theme "Complex Recovery Trajectories" is kept constant in both of the Venn diagrams as this points to the shared journey that the CYP and mothers make. This chapter has shown the complexity of recovery from a moderate head injury.

A key finding that resonates throughout the themes of both the CYP and the mothers was the need to enforce but also to monitor the restrictions placed on the CYP by the medical team. These fairly standard words of guidance from the medical team had a profound effect on the lifeworlds of both the mothers and the CYP; this will be further expanded upon in Chapter 8 ("Discussion"). Comparatively, these restrictions affected the CYP's friendships, families, identities and confidence, and resulted in post-traumatic changes. The mothers, because of these restrictions, saw themselves in a duality of roles: firstly, the enforcer of restrictions and secondly, a parent. This duality casued anxiety, friction, tension and dissonance but also led to the mothers controlling their own anxiety, using the restrictions as a way to reduce their fear of losing their daughter/son.

Along their recovery journeys over the nine months, the CYP appeared to largely accept the restrictions during the early stages; however, once the CYP realised the extent to which the restrictions affected their lifeworlds, the CYP started to demonstrate elements of anger,

frustration and low mood. During these stages, the mothers had to deal with the psychological trauma caused by the accident, contending with not only their own anxieties but also their CYP's problems. Gwen used the restrictions to help control her own anxiety, a strategy she lessened once she understood the impact, they had on Betsi (the overprotectiveness which frustrated Betsi). The mothers' concerns/fears that further harm could fall upon their child appeared to influence their decision but they just wanted their daughter/son to be safe. Further understanding of this complexity will be sought in the next chapter, in which the lifeworlds of the CYP and their mothers will be explored from a shared lifeworld perspective. This intersubjectivity of behaviours justifies the rationale for including the mothers in this study. This inclusion revealed further complexities that need to be understood which currently they are not fully comprehended by the healthcare team: consideration needs to be given to future research that looks at the effect on the family, friends and other associates of CYP who have sustained a moderate head injury.

This chapter also clearly showed that once the restrictions were removed, the CYP's friendships moved from an altered state to a normal one, which showed a relationship between restrictions and altered friendship dynamics. Concerning sport, this transition was not so clear: the CYP worried about further injury, concerns spoken of by the mothers as well. An invisible boundary between safety and risk seemed to be present amongst the CYP and mothers: at one point they were happy to do certain activities but when this line was crossed, anxiety and concern rose – which influenced their decision making. As obvious as it should be, this points to a reluctance to sustain another head injury and have further restrictions placed on them.

Finally, this chapter and the previous chapter have highlighted clear findings of post-traumatic changes and maturation amongst the CYP. This is an area of head injury research that has not been directly researched. In these chapters, maturation was recognised, exampled by Cai showing maturity in the second interview and being protective of his mother, by Betsi wanting her mother to come to her for support and by Afan's mother feeling that he was more accepting and had matured. These findings resonate with those of Roscigno et al. (2011) and Battista et al. (2014), and will be further explored in the next chapter.

The following chapter will discuss these findings within the concept of the lifeworld, with a focus on the impact of the restrictions on both the CYP and their mothers.

8 Discussion

8.1   Introduction

The aim of this chapter is to discuss key findings from this study (as outlined in Table 8.1) in relation to the wider moderate head injury literature. The literature review demonstrated a dearth of research exploring the impact of restrictions (to reduce the risk of a subsequent head injury) placed on CYP following a moderate head injury. Therefore, additional literature searches were undertaken (as exampled by key words: spatiality, lifeworld, identity) in order to discuss the study findings, as recommended by Smith et al. (2009). At the end of this chapter, the "Germination of a Little Gem" will also be discussed, which offers an insight into some of the lived experiences that were observed in the findings chapters.

Table 8.1: Superordinate Themes for CYP and Mothers.

CYP Superordinate Themes	**Mothers' Superordinate Themes**
Impact of Restrictions	Parental Psychological Trauma
Relational Impact of Head Injury	Family and Friends
Resilience and Post-traumatic Changes	Recovery Journey

Consistent with an interpretative phenomenological focus, a lifeworld approach will be used throughout this discussion, as discussed in the methods chapter. The term "lifeworld" was considered an essential part of epistemological enquiry by (Husserl 1970). Husserl viewed the lifeworld as a pre-reflective reality that is based in knowable and concrete experience, but Brooks (2015, p. 642) suggested that it goes beyond this and involves the world of lived experiences, which includes the phenomena that "appear to our conscious experience". Brooks (2015) highlighted the roles of Heidegger and Merleau-Ponty, amongst others, in

developing the lifeworld concept as a lens to view lived experiences by incorporating an interpretative perspective – which has context and uses the hermeneutic circle.

Different approaches can be used to interpret and discuss data generated through studying the lifeworld, including that of Ashworth (2006) and Ashworth et al. (2006), who presented lifeworld as consisting of distinct categories such as selfhood, sociality, embodiment, spatiality, project, discourse and mood. However, I have chosen to adapt the later model by Galvin and Todres (2013), which at its core has a humanistic healthcare focus and who acknowledge that philosophers do not always agree on lifeworld domains. Galvin and Todres (2013) in their model base their approach on both Heidegger and Boss but draw upon the concepts of Merleau-Ponty and Ashworth for the notion of selfhood, which in this model, is termed identity. As such it seemed directly relevant to my study because I wanted to explore the lived experiences of the participants, especially exploring the recovery following a moderate head injury (and where the impact of restrictions influenced components of recovery). In the model of Galvin and Todres (2013), the lifeworld is comprised of six components (see Table 8.2), excluding discourse as a distinct component. However, discourse can be seen as integral within these six components. Discourse is clearly evidenced within the idiographic and comparative chapters of my thesis, highlighting the importance of language within an IPA study.

Galvin and Todres (2013) model was selected as it is directly relevant to nursing and healthcare. For my study, this model is adapted in order to understand how recovery is influenced by the lifeworld. This adapted version of the model of Galvin and Todres (2013) is illustrated in Figure 8-1, where the arrows represent recovery revolving around Galvin and

Todres's model of the lifeworld, demonstrating recovery as a non-linear continuum which continually evolves and changes.
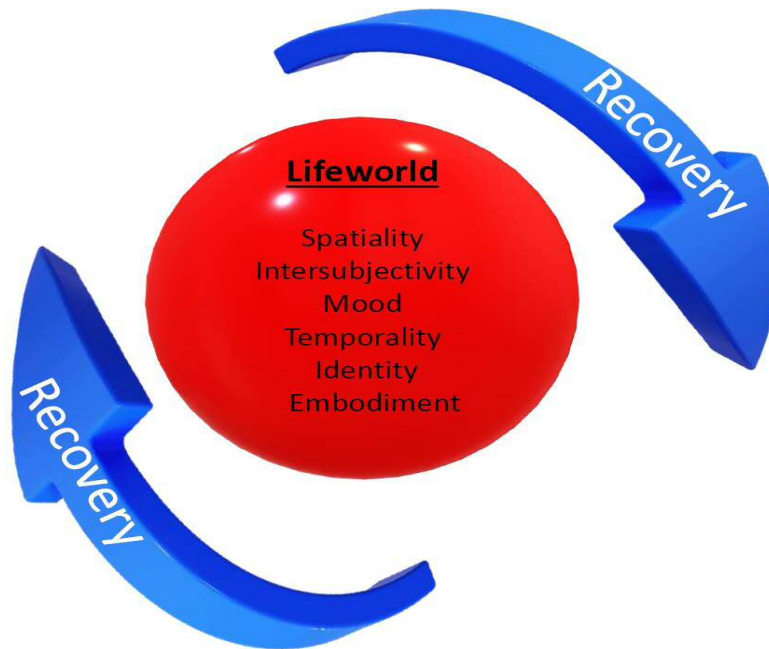
Figure 8-1: Conceptualised Model of Lifeworld (adapted from (Galvin and Todres 2013)) with Recovery.

Galvin and Todres (2013) saw that healthcare should be viewed from a lifeworld perspective and be humanistic – focussing on the human elements of health – which they see as an improvement over the biomedical model and which can provide a valuable insight into describing health and illness. As Figure 8-1 shows, their lifeworld model is comprised of six components, which will be shown in Table 8.2 with a brief description.

Table 8.2: Components of the Lifeworld – adapted from Galvin and Todres (2013).

Lifeworld Component	Brief Description
Spatiality	Refers to the world of places and things that have meaning – the environing world.
Intersubjectivity	How we are in the world with others.
Mood	How the lived experience is coloured; it's intimate in how we find ourselves; has atmosphere – is complex and goes beyond words.
Temporality	Refers to the continuities and discontinuities of time as experienced.
Identity	The self – the being as an individual – who we are.
Embodiment	The concrete here of ourselves – how the body is visualised in the lifeworld.

The following sections will discuss the data with respect to the primary aims of this thesis:

- *To explore how the lifeworlds of CYP (aged 6 to 13 years) and their mothers are affected by a moderate head injury.*

- *To better understand, in a manner consistent with interpretative phenomenological analysis utilising the concept of lifeworld, how the CYP and their mothers are affected by moderate head injuries.*

In order to assist with the discussion of the findings, and to demonstrate the lifeworld's relevance to the aims and objectives of this study, the lifeworld concept is combined with the Corbin and Strauss Chronic Illness Trajectory Model (Corbin and Strauss 1991; Halcomb and Davidson 2005). In carrying out this unique approach, it will be possible to explore the complexities involved when the lifeworlds of the CYP and their mothers are affected by a moderate head injury – this will be explored in section 8.2.1

8.2 Corbin and Strauss Chronic Illness Trajectory within the Lifeworld

8.2.1 Conceptualisation of Corbin and Strauss Chronic Illness Trajectory and Lifeworld

Analysis of the data has generated a complex, multi-dimensional insight into the lived experiences of CYP and their mothers. The linear view of recovery that can visualised by the use of the medical model does not comprehensively explain my findings. With the Corbin and Strauss Chronic Illness Trajectory, originally the end of the trajectory was often associated with death as it was used to explain the experiences of the chronically ill patient, where dying signified the end of the trajectory (Halcomb and Davidson 2005). This was adapted by Halcomb and Davidson (2005) who used it for patients who had a traumatic injury with recovery as a possibility. For them, recovery forms a potential end of the trajectory and as such this adapted model is appropriate to be used in discussing the lived experiences of my participants. In interpreting the data I have drawn upon two concepts to explain the findings, the Corbin and Strauss Chronic Illness Trajectory (Halcomb and Davidson 2005) and the lifeworld (Galvin and Todres 2013), the combination of which is shown diagrammatically in Figure 8-2.
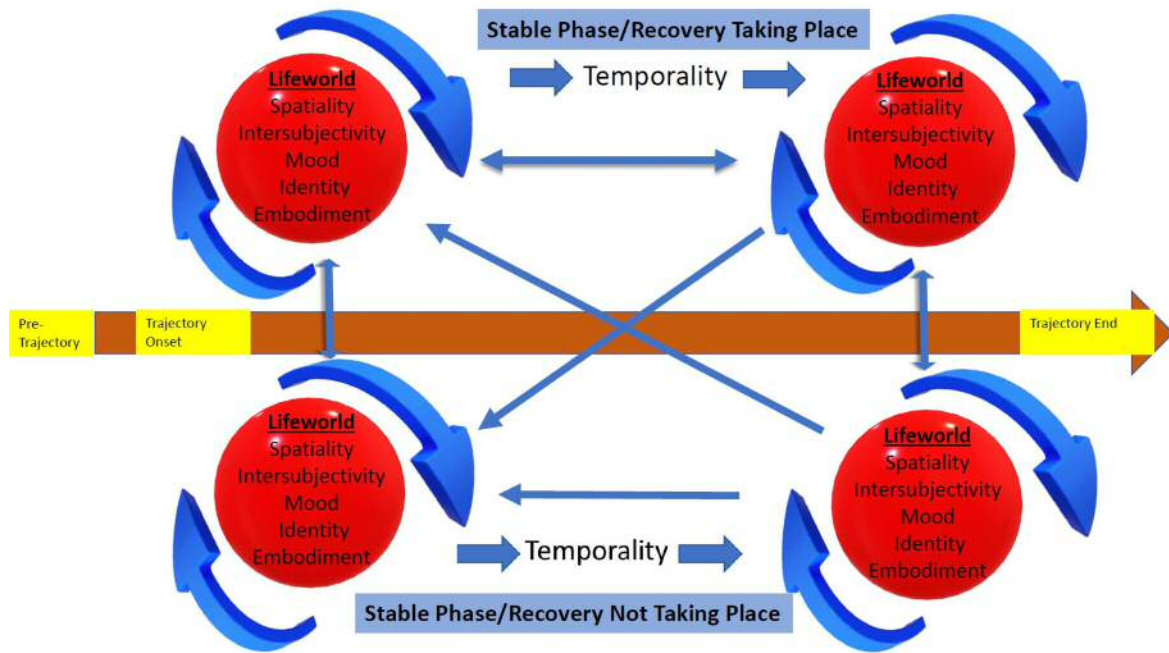
Figure 8-2: Conceptualisation of the Combination Corbin and Strauss Chronic Illness Trajectory with the Lifeworld Concept.

The lifeworlds in Figure 8-2 symbolise the potential movement of a participant's lifeworld as they move along the recovery trajectory. Temporality has been removed from the lifeworlds and used within the larger image to demonstrate the movement of time along the trajectory – a continuum where time cannot go backwards. Above the trajectory line it is possible to see recovery taking place and below the line, a worsening in the recovery process – all of which can take place in the stable phase of recovery as described in the Corbin and Strauss Chronic Illness Trajectory Model and adapted by Halcomb and Davidson (2005). The movement along the trajectory could be influenced by changes to a participant's lifeworld, such as altered friendships. Importantly, it is vital to grasp the notion that different aspects of the lifeworld, in theory, could move along the trajectory at different rates – for example, identity could move differently to intersubjectivity. It is also possible to visualise that a sudden upset in recovery could move the participant farther back along the trajectory, resulting in a

negative recovery – for example, an increase in the imposed restrictions could result in reduced spatiality, mood, identity, etc.

Viewing lived experiences using this combination may lead to a better understanding of why the participants reacted differently throughout their recovery, especially between the two-week and three-month time frames (which will be discussed in the following sections). Halcomb and Davidson (2005) suggest that the chronic illness trajectory can be seen as "crashing through space", its speed and direction being influenced by external forces, such as psychosocial ones. My study has shown that all the participants lost things that were important to them; this negatively affected them.

The following section will discuss care pathways in relation to head injury management.

8.2.2   Highlighting Current Issues – care pathways

This study's background chapter and literature review (Chapters 2 and 3) discussed the current thinking around CYP head injury care pathways. Figure 8-3 demonstrates the NICE (2014c) pathway for head injury management, with issues of main relevance for this study being in the lower three boxes. Here NICE (2014c) mentioned that follow-up, if the opportunity is presented, should be with a professional trained in the management of sequelae of brain injury. As previously discussed, my professional experience shows that follow-up post moderate head injury takes place a minimum of three months after discharge, usually longer. It is notable that during interviews undertaken with the CYP and the mothers, they reported experiencing difficulties, such as low mood, loss of identity and increased anxiety,

before they were followed up by the medical team. Practically this delay in follow-up can slow down appropriate interventions and lead to the worsening of comorbidities as a result of the head injury, e.g., anxiety and depression.
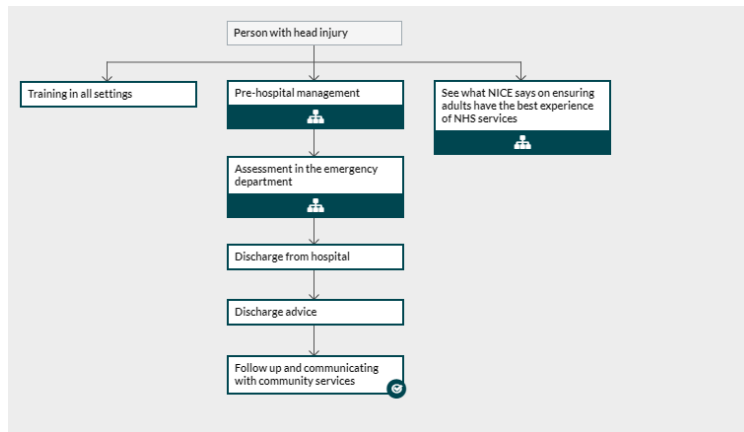
Figure 8-3: NICE Pathway (NICE 2014c).

A study published in the journal *Brain Injury* by Jourdan et al. (2019) looked at practitioners' experiences of care pathways in Finland and France. In their data collection they conducted interviews which were aimed at obtaining information at each stage of care, referrals and decision criteria, and opinions on quality care issues. They conducted a thematic analysis of their findings and concluded that the number of pathways in use varied and that there were problems with the availability of services, financial issues, variations in expertise and difficulties with follow-up, amongst other difficulties. Jourdan et al. (2019) concluded that further work was needed to improve care pathways, which also reinforces the need for more directive guidance from professional institutions like NICE and SIGN that also need to be more holistic, centred around the CYP and their family. The analysis of my findings, which are based on participants' experiences, concludes that services were mostly designed and deployed according to the biomedical model. This, as shown in my previous chapter, resulted in some needs going unmet.

Saini et al. (2017) discussed the use of the biomedical model in clinical practice and warned that focussing only on this model can lead to poor care (amongst other factors which go beyond this thesis). In touching upon these issues here, I am raising two significant issues within the current system: (1) insufficient discharge follow-up guidance and the need for "non-linear" care pathway development; and (2) follow-up assessment needs to incorporate a biopsychosocial model for a holistic approach, and as such will look at the social aspects of recovery. As previously discussed in section 8.2.1, by combining the Corbin and Strauss Chronic Illness Trajectory with the Galvin and Todres (2013) version of the lifeworld, an alternative way to conceptualise recovery can be made which is more person centred than the biomedical model.

8.2.3   Commencement of Recovery and Trajectory Onset

In placing the lifeworld concept within the recovery model for the participants, it would be amiss to think that recovery would only start when CYP return home from the hospital ward. In fact, analysis of the interviews pointed to the participants experiencing an anxiety associated with their time on the hospital ward, which was exemplified by the way the mothers recalled the time on the ward, Betsi's relief at not having to go back to the hospital for ongoing tests and by Cai's recall of his experiences.

Spatiality is a concept that has not been considered in the head injury literature; as such, comparisons will be drawn from other areas to enable this chapter to add to the body of literature. The topic of spatiality, which is important as it is associated with restrictions, will start in this section and will continue throughout this chapter. Spatiality, alongside

temporality, can be seen as one of the key aspects of Heidegger's *Dasein* (from the German "being there" or "presence") concept as it relates to being in the world and the concept of being (Horrigan-Kelly et al. 2016). Therefore, if you are in the world, you occupy a physical space and have access to a world of places that have meaning.

The term "crashing through space" (Halcomb and Davidson 2005, p. 234) can be used to describe the changes to the lifeworlds of the participants. From a spatiality perspective, the CYP and the mothers experienced a period of time in the hospital wards. This can be seen as a contracted horizon (Galvin and Todres 2013): for example, the CYP in my study were restricted to the wards (including the "games room" when a member of staff was present), with limited freedom of movement as a result of their head injuries, and the health services centred needs and priorities for clinical monitoring, meal times and medical ward rounds – the latter of which was exampled by Cai when he talked about the doctors discussing him, "*they were doing a ward round*" (Cai; Transcript 2; lines 20149–50). This reduction in spatial horizons can also be visualised as a type of incarceration; Quinney (2006, p. 269) described imprisonment as the "world of the prison and the world outside the prison". Here "imprisonment" can be utilised as a metaphor to represent the world of restrictions and the world without restrictions. Spatiality was also affected in the CYP participants' concept of their embodiment, where due to their injuries caused by the head injury – including aspects such as pain, suffering or tiredness (Galvin and Todres 2013) – they were restricted in where they could go and what they could do. Furthermore, the mothers, as exampled by Gwen, felt unable to leave the presence of their daughter/son due to their embodied maternal role, and when they did leave the immediate bedside space for short periods of time, it caused worry and stress.

Dyck (1995) described spatiality as a type of geography and formed a key link between spatiality and health. Her paper discussed adult women with multiple sclerosis and suggested a connection existed between participants' subjective experience, their disease progression, spatiality and wellbeing: spatiality decreased as illness worsened. Dyck (1995, p. 308) used the term "remap" to describe alterations in spatiality as a consequence of illness. Whilst Dyck (1995) discussed a progressive illness, her findings can be used to describe the changes that the participants in the current study would have experienced when they had to "remap" their versions of spatiality based on their physical environment, how unwell they were and what they were allowed to do by the hospital staff and by their mothers.

Both Cai and Betsi talked briefly about their time on the hospital ward, with Cai doing so more. He talked about a nurse who threatened to prosecute him for something he had said due to his disinhibited speech and slightly confused state where he later said "*Yeah but it weren't my fault though. I wasn't completely with it*" (Cai; Transcript 2; lines 2537–2538) – pointing to an altered identity and role embodiment. Both mothers also indicated that they themselves had a sense of a loss of identity associated with a loss of role embodiment (which had a large enough effect that at six months, in their first interview, they reported it), had restricted spatial horizons and had experience of the psychological trauma associated with their son's/daughter's injuries. This alteration in role identity was also discussed by Sanjari et al. (2009) who highlighted changing parental roles, the boundary changes between the CYP and their mother, and coping with uncertainty, all of which were encountered when a CYP was hospitalised.

8.2.4   Movement Along the Trajectory

This section will explore the period of time when the participants left the hospital ward and were discharged home. For readability, this section will be split into focus areas, starting with spatiality, and should be viewed as a continuation from the previous section, an ongoing recovery journey. Temporality is not discussed as a separate focus but needs to be viewed as a continuum – starting with the onset of the trajectory, movement along it and finally to its end. Therefore, temporality is viewed as an active component of each other lifeworld component.

8.2.4.1   **Spatiality Focus**

This section will explore the period of time from when the CYP were discharged from the ward and were allowed home, to the time when the restrictions were removed. For the participants, this resulted in a period of change in their living space (their spatiality) but not the restrictions: moving from the ward (where there were restrictions) to the family home (where restrictions continued). From an interpretative perspective, using a paper by Quinney (2006) on life in prison and life outside, it could be seen that the participants were moving from one type of metaphorical imprisonment, characterised by restrictions, to another. Galvin and Todres (2013, pp. 71-72) also described going home as an "homecoming" in my study, the participants were returning to a familiar environment with familiar objects together with their family. Forming an interpretative connection between Quinney (2006) and Galvin and Todres (2013), describing the discharge of the participants from hospital to home, where the participants welcome the their familiarity with their home, whilst at the same time they still having the restrictions placed on them – restricted/contracted horizons. These spatial restrictions would not have been in place before the accident and as a consequence would have been noticeable to them.

Within the current head injuries literature, little advice is given regarding the length of time for which restrictions need to be in place. Nationally, NICE (2014c) has promoted the giving of written and verbal advice, which should be age and severity appropriate, to families on discharge. Similarly, SIGN (2009) also recommend that discharge advice should be given concerning the CYP's everyday activities: sports, driving, school and work. However, both national guidelines fall short of providing further recommendations to the clinician that inform them of how long CYP should avoid these activities; rather, the decision is left to the clinician to make that choice as guidance does not consider the impact of the restrictions. An earlier Canadian paper by Swaine and Friedman (2001) also highlighted a lack of consistency with discharge advice but stated that there was agreement that most patients are advised not to do contact sports until cerebral symptoms have reduced. Swaine and Friedman (2001) added that these restrictions are put in place in order to reduce the risk of secondary injury, which can worsen symptoms. In their study, restrictions for a moderate head injury were only put in place for four weeks before being reviewed by a neurosurgeon and then possibly extended. The method of follow-up described by Swaine and Friedman (2001) differs from the follow-up policy which the participants in the current study received; for them it was planned that a review would take place after three months and a clinical decision would be made then whether or not to remove the restrictions. However, for the participants in my study this was inconsistent, and follow-up occurred between four and six months after discharge. This possibly resulted in the restrictions being in place longer, thereby negatively affecting their spatiality and their lived experiences, which would also have affected their identities and intersubjectivity.

However, guidance from NICE and SIGN, and the paper by Swaine and Friedman (2001), do contain a commonality in their recommendations that can have a significant effect on the lifeworld of the CYP: the need for restrictions post head injury. For the CYP group, their daily lives are often focussed on activities such as schooling, sports and socialising, and often involve them moving from one environment to another to engage in different activities and should be seen as being different to the adult population. Freedom to do what they want within the CYP group is also more restricted – for example, they have to go to school, as it is a legal requirement. Both SIGN (2009) and Swaine and Friedman (2001) were cautious about sports, with the former also mentioning school; in essence, these authors alluded to the need to avoid activities that could lead to a secondary head injury. The final decision regarding restrictions is grounded in the individual experience and judgement of the neurosurgeon and, as a result, can vary from professional to professional. However, this lack of detailed guidance gives the neurosurgeon freedom to tailor advice around the CYP's injuries. This is fundamentally positive, but as shown in a study by Longmuir and McCrindle (2009) with cardiology patients, this individualisation of advice can lead to parental uncertainty and stress as individual practitioners will give guidance, which may be different to other guidance – a situation worsened by the lack of published guidance. This can be linked to the restrictions placed on the CYP in my study, with no clear national guidance and where the advice is at the discretion of the neurosurgeon. However, it is important to note that appropriate restrictions play a very important role and should not be abandoned; rather, they need to be individualised to meet the needs of the patient. In the cases of the CYP, they all had head injury sequalae to contend with, at different times: Afan was initially unsteady on his feet, which quickly passed over a couple of weeks; Cai suffered headaches and required readmission; and Betsi had ongoing problems with her leg injury.

A clear distinction was noted between the group at three months and the two-week interviews (at two weeks they were not in full time school but at three months, they were), a distinction that continued until the restrictions were removed. Once their reintegration back into full-time school had commenced, the CYP experienced changes with their spatiality. Being back in school expanded their spatial horizons (together with other components of their lifeworlds) whilst simultaneously reinforcing the restriction of their spatial horizons. This was a direct consequence of the restrictions, a form of painful exile (Galvin and Todres 2013) in which access to their preinjury sports/activities was missing from their lifeworld. Each of the CYP appeared to cope differently with this but these restrictions had a significant effect on their mood and identity, which will be discussed in the following sections.

This change in spatial horizons experienced by the CYP also affected the mothers, leading to elements of loss of control, altered identity and anxiety; this experience of spatiality changed over time, which was similarly identified by Clark et al. (2008). In my study, the mothers were the main carers, which meant that they had to enforce the restrictions recommended by the medical team, thus pointing to a change in their role. This had a direct consequence on the mothers' spatiality: like the CYP, they had restricted horizons placed on them – as the main carer, they had to ensure that their CYP was not coming to further harm. Both Gwen and Ffion highlighted that they needed to take time off work in order to look after their CYP, a finding that was mirrored by Wongvatunyu and Porter (2008) who looked at the lifeworld of mothers whose CYP had a traumatic head injury. In my study their lifeworlds were embedded both in their role as a parent and in the need to provide support and care, but following the head injury, the mothers had to go above and beyond what is normally expected. Over the study period, the mothers' sense of spatiality seemed to change at key points in time – for example, their daughter/son starting their back-to-school reintegration

plans, achieving full-time school or having their restrictions lifted. As the CYP's sense of spatiality returned to normal, so did the mothers' – showing a how recovery is a shared or co-related phenomenon.

8.2.4.2   **Intersubjectivity Focus**

Alongside the effects on spatiality, changes to intersubjectivity were also noted as a result of the restrictions and head injuries. Intersubjectivity also acknowledges Heidegger's concept of *Dasein* where being in the world involves interaction with people and the thought that we are never really alone (Inwood 1997). Larkin et al. (2018) views intersubjectivity as being viewed as related and relatedness of *Being* and states that its analytically concerned with what happen between one person and another (in between); concerning itself with persons, objects and culture. Stroh (2015) sees intersubjectivity as being/living in a community and as such people are not isolated but interact with each other and will have individual and collective perspectives.

The relational dynamics of the mother with their child changed as a direct consequence of the head injury where it was possible to see a commonality in that all the CYP had connections with their mothers, shared but individual experiences. Their relationships had changed where the CYP gained extra attention, the mothers had to enforce the restrictions whilst dealing with their own psychological trauma – an overlapping of experiences.   This was clearly evident at the two-week interview and was largely accepted by the CYP. Also, at this point we saw the re-emergence of the fathers into some of the CYP's lives. The findings from the participants' families can also be compared to responses of those living with other medical conditions. In a study exploring family interactions, Barke et al. (2013) similarly showed that medical

conditions (such as neurofibromatosis) impact the family and relationships are affected – in their case, family was a source of comfort and understanding. This was also shown by Clark et al. (2008) who, like Barke et al. (2013), confirmed that the whole family is affected by a head injury and highlighted that there is initially an increase in family bonding, including increased closeness and protectiveness. Clark et al. (2008), as previously mentioned in Chapter 6 (section 6.3.2), utilised attachment theory to explain the change in family dynamics of families becoming closer in order to protect and reduce the risk of loss; this resonates with the findings from my study.

The fathers in this study also re-emerged in the CYP lifeworld; this was highly evident with Betsi and noticeable with Afan, whose father was only present during the first interview (Cai's father had died prior to his head injury). Whilst accepting that the mothers were the main carers, differences were noted between the intersubjective relationships of the mothers and fathers with their CYP: Betsi's was less tolerant of her father than of Gwen. My findings are in contrast to Wade et al. (2010), who mentioned that mothers and fathers react differently: fathers used denial whereas mothers used emotion and acceptance as coping strategies; however, Betsi's father did increase his presence in her life. An earlier study by Zinner et al. (1997) discussed guilt as a component of maternal grief, where the findings of Gwen and Ffion showed elements of this, both were dealing with issues such as anxiety, heightened emotions, and control which were present throughout the study period; these issues influenced the way they parented, enforced the restrictions and viewed their relationships with their child.

The intersubjective dynamics of friendships were also affected by the restrictions, and analysis of the data suggested that temporality was a major determinant. The findings show that whilst the restrictions were in place, the CYP experienced altered friendship dynamics and once the restrictions were removed, these friendships then normalised. A study by Heverly-Fitt et al. (2014), which explored friendship quality longitudinally post traumatic head injury, demonstrated that positive and supportive friendships yielded better psychosocial outcomes and reduced the risk of any maladaptive behaviour. In their study, positive friendship appeared to be correlated with protectiveness and satisfaction. Interestingly, Heverly-Fitt et al. (2014) also added that the benefit of positive, close friends can overcome difficulties with peer groups and buffer against any negative psychosocial outcomes, including victimisation. In my study, friendship remained a complex aspect of the participants' identities. All of the CYP experienced alterations at two weeks: Cai experienced elements of intersubjective isolation (Galvin and Todres 2013) due his restrictions and not being allowed to do sports, Betsi found her friends to be overprotective (and possibly overpowering) and Afan experienced increased attention from his friends at home. The findings at two weeks resonated with the findings at three months. And once the CYP's restrictions were removed, friendships normalised.

All three CYP retained friendships, with only Cai losing contact with some friends as a result of being unable to play rugby (although he continued to socialise with some of his friends in school). However, Cai quickly regained his friendships once he was able to play sport again (sport was an important part of Cai's relationships with his friends). Both Betsi and Afan found that their friendships adapted how they socialised in response to the restrictions, which in a sense is a sign of strong friendships: Betsi saw her friends protecting her, which in turn did annoy her but she understood the reasoning behind it; and Afan played with his friends on

a games console as opposed to playing physical football. All three CYP participants retained their social competence (which can be seen as a measure of social interaction, and is a multi-dimensional construct including social information processing and cognitive-executive functioning); whilst this is a small study, this retention of social competence conflicts both with the findings of a longitudinal quantitative study by Ryan et al. (2016c), who found a fourfold increase with social difficulties in CYP head injury cases, and with those of a quantitative study with a similar cohort, by Muscara et al. (2009), who highlighted that social competence is a difficult area to assess competently. Both these studies highlight the difficulty in exploring friendships quantitatively, the value of qualitative studies can be seen– as the rich data yielded by the current study evidences.

The findings of Heverly-Fitt et al. (2014) in relation to friendships support a slightly earlier quantitative study by Yeates et al. (2013), who highlighted that a more severe injury was associated with a greater chance of victimisation, rejection and poorer QoL, resulting in problematic peer relationships. Yeates et al. (2013) identified a direct correlation between these factors and clearly outlined the importance of mutual friendships. In my study and at a group level analysis, all the participants experienced similar positive experiences of friendship and no problematic friendships were mentioned in the interviews, with the exception of Betsi. Yeates et al. (2013) presented a link between altered friendships and the CYP demonstrating withdrawn behaviour, being shyer and less sociable, and being less popular. In contrast, none of my participants appeared to demonstrate these characteristics. Whilst Afan was a quiet individual, he did not report changes to his social groupings/social behaviour – his peer group was largely unchanged, even though the way they interacted was influenced by the restrictions placed on him (using a games console rather than meeting in person). Of the CYP participants, Afan maintained his friendship group, Cai lost some

273

friendships but by being defiant in school maintained some friendships, and Betsi, even though annoyed with her friends, maintained her friends and made new friends once the restrictions were removed. The CYP's adaptation post moderate head injury was positively influenced by their friendships, which also helped them cope with the recovery process. Roscigno et al. (2011) discussed friendships in their descriptive phenomenological study, identifying that participants distinguished between superficial friendships and more meaningful ones. To link this idea with those of Yeates et al. (2013) and Heverly-Fitt et al. (2014), the participants from my study demonstrated favourable friendships, which would have helped with their positive recoveries post moderate head injury. Betsi discussed some fluidity with some of her friendships, but she demonstrated a good core group of friends. As my findings show trustworthiness, then transferability is possible (Rolfe 2006) and as such shows credibility.

The mothers in the study showed an increased concern for their child which often resulted in overprotective behaviours; this was more prominent during the earlier stages of recovery but appeared to gradually subside as time passed, with a near return to normality noted once the restrictions were removed. These altered relationships also seemed to be affected by the parental psychological trauma and the mothers' recovery journeys, which was also seen in the study by Clark et al. (2008). The restrictions themselves appeared to be negatively associated with the participants' own personal recoveries and possibly acted as a reminder of the head injury. This study's findings also highlighted that mothers found it difficult to negotiate the transition from having restrictions to normality (life without restrictions), which resonates with the study by Clark et al. (2008). The mothers' insights into their relationships with their daughter/son's at six and nine months post injury indicated that these dynamics were still influenced by the head injury: the mothers demonstrated anxiety over the risk that a further

head injury could happen. A systematic review by de Kloet et al. (2015) identified that family functioning was impacted for at least two years post head injury which included the roles of support, nurture and parenting style. This indicates that the family dynamics are affected for longer than the restrictions on the CYP are in place (when the CYP is at greatest risk). Clinically this is relevant in planning family-based holistic care, as these findings highlight the need for longer intervention and monitoring to ensure that patients are able to regain normative relationships.

8.2.4.3 Mood Focus

During the period that the CYP participants were advised to adhere to the restrictions recommended by the clinical team, they each displayed negative emotions concerning the restrictions (for example sadness, anger, annoyance, crying, frustration), which have been highlighted by Tlustos et al. (2016) and Ryan et al. (2016a) as possible consequences of a head injury. Similar emotional changes were highlighted by Brown et al. (2016), who assessed participants at three, six, twelve and eighteen months post head injury, utilising structured questionnaires. They found that all emotions were more greatly affected in the first six months and had disappeared by twelve months, after which time behavioural problems became more evident; however, in my study no behavioural problems were reported by participants. In another study, Iadevaia et al. (2015) explored adolescents' QoL one year post concussion through semi-structured interviews. They identified that "frustration" impacting on participants' relationships was a common theme. Furthermore, feelings of "anger" and being "upset" were also common amongst the adolescents. Whilst the study by Iadevaia et al. (2015) included 12–16-year-olds with a milder form of head injury, restrictions were imposed on the participants, and their findings resonated with the lived experiences of Cai, Betsi and Afan. With this study's CYP group, it was possible to see elements of low mood and

agitation mainly from the three-month stage, when the impact of the restrictions was fully realised. These feelings appeared to stay with the CYP whilst the restrictions were still in place, and feelings of apprehension and concern were experienced even after the restrictions were removed. Each of the CYP participants had internal resilience and strategies which enabled them to cope with the restrictions.

Swaine and Friedman (2001), in discussing activity restrictions as part of discharge management for CYP who had suffered a traumatic head injury, said that anxiety can worsen when restrictions are put in place, which might place an extra burden on parents, some of whom might not be able to enforce the restrictions. However, the study only discussed the extra burden on parents briefly. Swaine and Friedman (2001) also mentioned that the monitoring of the effects of the restrictions, as well as the consequences of not adhering to the restrictions, is an area that needs further exploration – this area is one which this study addresses. The mothers' experiences of mood appeared different to that of the CYP: they struggled with the psychological trauma they had experienced but regained control over this by focussing on the wellbeing of their daughter/son. They recognised their son/daughter's mood changes, such as getting frustrated, and adopted strategies to improve things, as exampled by Ffion allowing her son to go to the park with his older brother, and by Gwen becoming less overprotective. Once the restrictions were removed, an improvement in the mothers' mood was noted, a 'deep breath', that the worst and riskier time had passed by successfully. However, even after this time, the mothers continued to experience elements of concern and anxiety, albeit less than before.

8.2.4.4   **Identity Focus**

Loss of identity was noted across all the participants, which was directly influenced by the restrictions. The mothers' loss of identity was also noted during the hospitalisation, where they were unable to offer full care to their child due to the head injury, but this reversed as their son's/daughter's condition improved. Individuality was noted in how each of the CYP experienced changes to their identity that were directly caused by the restrictions, as highlighted by Cai accepting the restrictions and stopping rugby, and by Betsi's loss of personal identity as a result of overprotective friends. The group's loss of their personal identities, caused by the restrictions, resulted in a fragmentation of their identities – fragmentation was a term used by Galvin and Todres (2013) to describe how an identity is an umbrella term which encompasses different types of identity (personal, social as examples). In my study, this was evident with the participants where their different identities affected differently at different times, which were more pronounced during the three- and six-month interviews. Once the restrictions were removed, they had to change from an identity with restrictions to one without restrictions, possibly one that resembled their preinjury states.

Some of the findings evidenced are supported by Battista et al. (2014); their IPA cross-sectional study with CYP was undertaken at least one year (mean 4.62 years) after a traumatic brain injury. Battista et al. (2014) found that participants' perceived independence was affected when there was a reliance on family members post injury. In my study, all the participants had some increased degree of reliance on their families compared to before the accident because of post-surgical care, the restrictions being in place or the need to reduce their day-to-day activities. The findings by Battista et al. (2014) support the initial loss of independence experienced by my participants but the authors found in addition that independence also improved later on in the recovery process. Roscigno (2016) found in her

study that CYP had difficulty both accepting the chronic changes to their lives (caused by an acute change as a result of their head injuries) and enduring the recovery process; it effectively forced the individual to face new realities in their life. This was evident in my study and has been discussed in previous chapters. This difficulty in accepting changes might have contributed to the defiance shown by Cai and Afan and points to the emotional and behavioural changes noted as consequences of the restrictions, which were evident between the first interview and the second.

Further evidence can be seen for the changes of identity in the current study's CYP by looking at a study by Tjaden et al. (2012) who reviewed the experiences of CYP who received dialysis and where their CYP had restrictions imposed on them. Even though Tjaden et al. (2012) included a different patient group to my study, similarities between the CYP's experiences are evident. Both groups had restrictions placed on them and both experienced a pervasive loss of identity. However, one of the key differences was that the restrictions were lifted from my study's cohort, after which their identities started to resemble their preinjury one. The removal of restrictions is not discussed by Tjaden et al. (2012) as the CYP in their study continued to have restrictions in place.

Both Betsi and Afan appeared to use coping strategies in order to deal with the impact of the restrictions placed on them and the use of strategies was also observed in the study by Tjaden et al. (2012). Afan increased his use of his games console to compensate for the loss of playing physical football and Betsi looked forward to getting a dog – possibly this was a way to cope with the restrictions placed on her at that time and a sign of post-traumatic changes. Additionally, Betsi was positive about her recovery and the future, which reflected her

personal identity – a change in her thinking process which became apparent between her third and fourth interview from seeing a poor recovery to being more optimistic. These findings from Betsi's and Afan's interviews showed that they regained their identities through measures that are expected activities for a CYP (Betsi wanting a dog and Afan with his games console), indicating they had a positive view of their (identity) recoveries. Lingam et al. (2014) outlined that remaining positive is an important component of identity and also associated it with self-esteem. Similar findings were seen by Roscigno et al. (2011) and they also added that remaining positive was seen in their participant group, who had minor cognitive impairments.

Identity change within the mothers' group was experienced differently to the CYP. Following discharge from the ward, their role as the primary care giver was affirmed. This was affirmed: they were responsible for enforcing the restrictions but also they supplied additional care to their daughter/son because of their medical and emotional needs. This reaffirmation and strengthening of the maternal identity was recognised by Gwen and Ffion, who both felt closer to their son/daughter. During the CYP's recovery period, the mothers' identities shifted from one of being the provider of all the care their CYP needed to resemble, as recovery progressed, one that was closer to the preinjury dynamics. An IPA study by Clark et al. (2008) offered an insight into some of the reasoning behind the behavioural impact of the head injuries. The authors discussed how the mothers of CYP with head injuries perceived a change in their maternal roles, having to adapt to offer more practical support and also needing to cope with educational and healthcare needs. Clark et al. (2008) explained that the whole family is systemically affected, leading to an increased "closeness and protectiveness" – which was discussed previously. This was also supported by Cummings (2018, p. 122), who added that parents "aim to place their child in a protective and safe place". Cummings

(2018) included CYP who had undergone interpersonal trauma but there are similarities with my thesis, for whilst the parents in my study were caring for a CYP who had undergone physical trauma, they later experienced, as my data have demonstrated, interpersonal turbulence with friends and family members.

8.2.4.5   **Embodiment Focus**

Moya (2014, p. 1) described embodiment as the way that "our body develops with regard to the world" which relates to the space that is inhabited. Merleau-Ponty (1978, p. 82) described it as a "vehicle for being in the world" . Finlay (2006, p. 20) described "an embodied consciousness that engages the world…in the world of my projects, daily activities, and relationships" and as such embodiment is relevant to the participants of my study. Embodiment can be used to examine areas such as intersubjectivity (Finlay 2006) and can help to understanding the perception of the participant in relation to the restrictions placed on them – their embodied perception. This embodied perception can be understood as the extent to which the participants in my study are able to interact with physical objects within the environment (Gray 2014).

In analysing the findings in relation to embodied perception, the CYP and mothers were affected differently. For the CYP group, who viewed their embodiment through their restrictions, the CYP's perceptions varied; their "vehicle for being in the world" (Merleau-Ponty 1978, p. 82) was affected by complications associated with the head injury. For example, Afan felt unsteady on his feet at two weeks, though became fully mobile by the three-month interview whilst still restricted in what he was allowed to do. Cai had to be readmitted for a drainage and evacuation of a haematoma following the two-week interview;

the resulting scar was metaphorically referred to as his "*war wounds*" – but once he had his operation he soon returned to be fully active within the restrictions. Betsi's experiences were slightly different: she suffered from phenytoin toxicity, which resulted in double vision, together with ongoing issues with her pelvis that were still present at the end of the study. Due to her double vision, Betsi was spatiality restricted to her room/house, and her leg injury resulted in her in physically doing less and, from a mood perspective, feeling frustrated – showing that the way she experienced the world was restricted by her physical difficulties and the further restrictions being placed on her.

Throughout the recovery period the restrictions reminded the CYP of the head injury and reinforced what had happened – their vehicle Merleau-Ponty (1978), for being in or seeing the world was limited by the restrictions. When the restrictions were removed, each of the CYP responded differently; their embodied perception differed as evidenced by Afan feeling frustrated and upset by the loss of his speed and strength, and by Betsi struggling to do sports because of the ongoing discomfort she was feeling – both experienced a loss of function due to their head injury. When the restrictions were removed, how the CYP saw their embodied self also changed but was impacted by the perception that there is always a risk of further injury (a message reinforced by the restrictions) and that their return to a preinjury self would be difficult – the way that they saw their embodied self-had changed. They were aware that their body as a "vehicle for being in the world" (Merleau-Ponty 1978, p. 82) was permanently altered due to the head injury.

The mothers' embodied perception was centred around enforcing the restrictions and still being a mother. Whilst the CYP viewed the world through the restrictions, the mothers'

experiences related to enforcing the restrictions and in ensuring that their son/daughter were safe. As discussed in the Chapter 6, this was a source of anxiety for the mothers and annoyance for the CYP, but carrying out their embodied role as a restriction enforcer was also a method of control: the mothers could reduce their own anxiety that another accident could happen. Clark et al. (2008) recognised this behaviour as being part of coping, thus supporting and giving trustworthiness to my findings.

8.2.5   The End is Not the End

In the Corbin and Strauss (1991) Chronic Illness Trajectory, the trajectory is said to end with dying and death, but the approach used in this thesis is that of Halcomb and Davidson (2005), who also saw the end of the trajectory as the completion of recovery. My longitudinal study over nine months ended before the participants had completed their recovery, but all the participants had been discharged from neurosurgical services and received no medical or psychological follow-up (Betsi did continue to see a physiotherapist for the injury to her leg). Ryan et al. (2016c) recognised the long-term implications of a head injury and promoted long-term follow-up of this clinical population. My study has added to this and reinforced that problems associated with a moderate head injury need a more encompassing and holistic assessment than they currently receive. This need is evidenced by the following paragraphs.

In a cross sectional study that examined follow-up at 23 years post mild head injury, Hessen et al. (2007) and Hessen et al. (2008) in their concluded remarks stated that some of participants still experienced issues such as fatigue, worry and neuropsychological problems, but in general they found that the majority of their participants made good recoveries but did not mention the statistics. In the introduction, Hessen et al. (2007) and Hessen et al. (2008)

mentioned that these neuropsychological problems can range from 7-15% in the mild-moderate head injury group. Even though these studies looked at follow-up 23 years after a mild head injury (potentially having less of an impact in comparison to a moderate head injury), a comparison can be drawn with my participants in that problems still remained following discharge from the neurosurgical service at around six months.

The lifting of the restrictions from the participants in my study created another change to the lifeworlds for them to contend with. Both Cai and Betsi appeared to have more concern/anxiety about returning to preinjury activities than Afan. However, interestingly, both Cai and Betsi had complications post discharge. In a recent study by Plourde et al. (2018), focussing on mild head injuries, the authors highlighted that psychological anxiety can worsen when recovery is delayed or seen as being poor. Whilst Lloyd et al. (2015) reported a similar finding, they also cautioned that this was an inconsistent finding and one that needs further research. However, in a systematic review of 0–18-year-olds, Li and Liu (2013) highlighted that approximately 10% of patients who had suffered a moderate or severe head injury were at risk of developing post-traumatic stress disorder (PTSD), with repeat avoidance being one of the symptoms ("avoidance" meaning not engaging with the activity that led to the head injury). The two other symptoms were re-experiencing and hyperarousal. In this thesis, I do not suggest that any of the participants suffered with clinical levels of anxiety or PTSD, but it needs to be noted that all three CYP participants showed some reservations about reinjuring their heads, which points to at least some level of caution/trepidation – this could be seen as a normal reaction as they would not have wanted to repeat the experience. Also, Gwen highlighted Betsi's anxiety about returning to the hospital for appointments and the relief Betsi felt when she was discharged from some of the services, which supports the findings by Li and Liu (2013). With the mothers, clear evidence of

anxiety was shown in the interviews: they talked about the head injury, their experiences and future worries – all of which were also found in Clark et al.'s (2008) study.

Behavioural changes were noted in all the participants when the restrictions were removed. However, how they viewed their embodiment and intersubjectivity in relation to their lifeworlds differed. Cai still saw himself differently at six months (with the restrictions removed) to how he was preinjury. Leamy et al. (2011) carried out a systematic review of recovery and generated three superordinate themes: "characteristics of the recovery journey, recovery processes and recovery stages" (p. 448). Cai appeared to be continuing his "recovery journey" (Leamy et al. 2011) and metaphorically speaking had not 'completed the journey': he experienced reservations about re-engaging with his preinjury sports, which influenced his identity. Afan and Betsi, again metaphorically speaking, at nine months had "completed the journey" and seemed to be experiencing little or no problems with regaining their independence. The above observations point to a link between identity, independence and restrictions in this group.

The analysis of the findings pointed to a gradual, carefully considered return to their preinjury spatiality which was influenced by preinjury lifeworld and their lived experiences during the recovery period. The CYP returned to activities, such as sports, that involved them experiencing new or previously experienced (stopped due the restrictions) spatial environments, a movement that was complex and multidimensional. Alongside this, the CYP also experienced a return to their preinjury freedom that the majority of CYP enjoy in that they could socialise with friends; here, the analysis of the findings pointed to a divergence within the group – Betsi found roads stressful as they reminded her of the accident but Cai

and Afan coped well. This highlights the individuality of reengagement with preinjury spatiality and the incorrect assumption that clinicians may have that once the restrictions are removed, life will return to normal. Restrictions are an important part of clinical intervention and support should be available in these transitional times, when restrictions are put in place, during and afterwards.

8.3   Germination of a Little Gem

Brooks (2015) described the gem as a "small extract that offers powerful illumination", which supports the view of Smith (2011a) that the gem is a way of offering useful insights into the data interpretation. The recognition of a little gem is cautiously made due to the small number of participants involved in my study and the recognition that this might need further research; as such, this section makes its appearance in this chapter as opposed to being in the group level analysis chapter. However, in understanding how gender influences the impact of the restrictions, some clarity can be offered in analysing the behaviours seen within the CYP group.

In a search of the literature, no papers were found that corresponded directly with defiance to restrictions and the role that gender plays within recovery post moderate head injury. An observation that was noted concerning the restrictions placed on the CYP was the way they reacted to them. Similarities were observed, but of interest was that both Cai and Afan demonstrated defiant behaviours whilst Betsi did not. The following paragraphs will discuss some of the theory which may relate to this.

Sex, which has been a highly debated topic over the last few decades, is often viewed socially as a binary – male or female – and can be seen as a social classification (Sweeting et al. 2017). Sweeting et al. (2017) also mentioned that sex and gender can be different – gender can be seen as being cultural (masculine and feminine) and sex is considered to be determined by genitalia – whilst also adding that this is not universally true. For the purposes of this section, even though the participants were not directly asked what gender they wished to identify with, the way they identified themselves as was used.

In reviewing evidence from other areas, such as education, a longitudinal qualitative study by Geven et al. (2017) looked at school defiance in male and female CYP, aged between 14 and 15 years, and noted that boys were more likely to be defiant, a difference which increased over time but was not highly correlated with peer influence. The findings in my study allude to the same conclusion: both Cai and Afan showed defiance by pushing the boundaries in a controlled way, whilst Betsi showed no defiance. Geven et al. (2017) asserted that defiance is best measured longitudinally as it can vary over time; this also resonates with the findings of my study in that the defiance demonstrated by Cai (socialising on the school yard) and Afan (playing football) did not materialise immediately, but first appeared in the second interviews. Van Petegem et al. (2015) examined adolescent defiance in relation to self-determination theory and the perspective reactance theory, and found that controlling parenting styles often have a counterproductive effect, which leads to increased defiance. The participants in my study experienced heightened parental control due to the imposition of restrictions, but it was their need to return to activities that they enjoyed (football for Afan and socialising for Cai) which influenced their behaviour. This behaviour was controlled, and appeared risk-assessed, hence showing consideration for what could happen where they could

reinjure their head, but in essence, this display of pushing the boundaries helped them cope with the restrictions whilst reinforcing their identities.

In summary, gender seemed to play a role in whether the CYP was defiant or not: both Cai and Afan demonstrated elements of defiance – risk taking which was also controlled and allowed them elements of freedom. This defiance also helped them cope and accept the restrictions at other times. The term "germination" in the title points to this finding being one that, whilst recognisably needing further research, nevertheless provides an insight into understanding the observed behaviours.

8.4   Summary

This chapter has explored the lived experiences of the CYP and their mothers during the nine-month study period in relation to the wider literature. Halcomb and Davidson's (2005) adaptation of Corbin and Strauss Chronic Illness Trajectory combined with Galvin and Todres's (2013) lifeworld model provided both a firm conceptual foundation to frame the discussion and a novel approach to the study of CYP recovering from head injury. In so doing I have addressed the aim and objectives of this thesis.

A key finding of the study, which forms an original contribution to the body of literature, is the effects that the restrictions had on all the participants – mothers and CYP. These restrictions not only affected the spatiality of the participants but also other components of their lifeworlds, as exampled by intersubjectivity and identity. Within this chapter, the findings have also illuminated limitations of both NICE (2014c) and SIGN (2009) guidelines,

whose focus is predominantly on the acute management of a head injury, with little attempt to provide guidance to the clinician about the recovery stage. Here, if the biomedical model is used then the social elements of recovery may not be examined and, consequently, not managed appropriately, with potential damaging effects on CYP and family members. My study highlighted that at nine months, the participants had been discharged from neurosurgical follow-up as they were deemed to have recovered physically from their head injury; but as the findings highlight, they had not completed their full recovery and experienced residual problems such as anxiety and physical ailments, pointing to the need for a more holistic assessment model.

This chapter adds to the literature by focussing on the impact that the restrictions had on both the CYP and their mothers. Whilst behaviours and social issues resulting from head injuries have been explored by others, focussing on the impact of restrictions on CYP and their mothers is a novel approach. By using undertaking a detailed analysis of the data, which was closely informed by key IPA principles, it has been possible to see the causes for some of the behaviours/thoughts/feelings (which are seen in clinical practice) of families when a CYP has suffered a moderate head injury. By conducting a longitudinal study, an approach seldom used by other researchers in this field, it has been possible to view important but until now hidden aspects of recovery following a moderate head injury. Of note is the demarcation noted at three months when, compared to two weeks, lived experiences had worsened and notable differences with identity, spatiality, mood, intersubjectivity and embodiment were seen – at three months all the CYP participants had re-engaged with full-time school and seemed to fully comprehend the impact of the restrictions as they entered a world that resembled their preinjury state but had to endure the restrictions placed on them.

The next chapter will focus on researcher reflexivity and the contribution of this thesis to the existing healthcare literature, acknowledge the limitations of my study, and provide recommendations for future research opportunities.

9 Conclusion and Recommendations

9.1   Introduction

This chapter summarises and outlines the main conclusions stemming from the study findings. Brief examples of how reflexivity was used throughout the study are provided – processes aided by the hermeneutic circle. Limitations will also be considered, as will the relevance and importance of this study to service users and clinicians, which are further captured in the study's recommendations for future research and clinical practice.

9.2   Summary of the Study

This unique study has provided an opportunity to analyse, in real time, the lived experiences of five participants: three CYP, during the first nine months of each's recovery from a moderate head injury, and two mothers, interviewed at six and nine months. All interviews were carried out in the participant's own homes or another place of their choosing, digitally recorded, transcribed verbatim, and analysed within the IPA framework via a cognitive process (Smith et al. 2009). The IPA approach, used in conjunction with the longitudinal data, offered a valuable and rarely seen view of how the participants experienced their recovery journeys; this allowed the voice of the participants to be heard together with the emergence of new understandings.

9.2.1　　Answering the Research Question

I believe that my study has answered the research question by exploring the lived experiences of the CYP and the mothers during the nine-month recovery period. The overarching research question for my study is:

"How do CYP and their mothers view their lived experiences during the nine-month recovery period following a post moderate head injury?"

The data from the findings formed the superordinate themes for the CYP and the mothers as shown in Table 9.1:

Table 9.1: Superordinate Themes for CYP and Mothers.

CYP Superordinate Themes	Mothers' Superordinate Themes
Impact of Restrictions	Parental Psychological Trauma
Relational Impact of Head Injury	Family and Friends
Resilience and Post-traumatic Changes	Recovery Journey

Some of the findings from the current study supported previous research. However, this thesis also enabled new insights into the lived experiences (see section 9.3) of CYP recovering from head injury and their mothers, and how they dealt with the restrictions placed on CYP. I identified a complex intertwining of themes (see Figure 7-1 and Figure 7-2), which gave an insight into participants' lifeworlds and how a significant life event in the form of a moderate head injury reverberated through all aspects of their lives. Even when the participants were given the medical all-clear and the restrictions removed, residual effects of the injury were still experienced in their lifeworlds. This showed that even when the participants were discharged from the care of the neurosurgeons, ongoing issues were noted.

Furthermore, using the social constructivist lens to consider how the participants viewed their realities resulted in an interesting insight into how they perceived what was important to them. The study identified that the participants were aware of tensions and changes in both family and peer dynamics and had strong emotional reactions to the well-meaning restrictions placed on them. There was also evidence of post-traumatic changes, which included maturational changes, for all the CYP participants; this evidence added to the growing field of knowledge in this area.

This thesis has, therefore, clearly addressed the aims and objectives of the study by exploring, from a lifeworld perspective, how the lived experiences of the CYP and the mothers were affected by the moderate head injury (a study carried out utilising IPA and a social constructivist lens). Section 9.7 will discuss future recommendations from varying perspectives.

9.3   Findings and Contribution to Knowledge

The literature review clearly demonstrated that few studies had used IPA to explore individuals' experiences of moderate head injuries, and none had combined the following features: public involvement (CAG), a longitudinal approach starting from two weeks post head jury, and an exploration of the lived experiences of CYP and their mothers following a moderate head injury. By answering the research question and achieving its aims and objectives, my study has helped to address this, adding to the literature database and the wider body of knowledge. The section 9.7 ("Recommendations") will discuss how this knowledge can improve care for patients and their families.

The main findings from this thesis can be summarised as:

- Post head injury restrictions are necessary in protecting from further harm, but these restrictions can lead to other potential problems

- From the interpretation of the findings, it was the restrictions that had the largest impact on the participants lived experiences, affecting all components of their lifeworlds, which included alterations to friendship and family dynamics

- The mothers had to face a duality of role as both a restriction enforcer and a mother

- The mothers also had their own recovery journey to make that was often embedded in psychological trauma, emotion and anxiety

- Within the CYP group, defiance was seen with Cai and Afan but this was risk-assessed, acted as a coping mechanism and allowed controlled freedom

- When the restrictions were removed, the CYP did not immediately return to their preinjury lifeworlds. They still had to make a psychological recovery and had ongoing issues

- By combining the adapted Corbin and Strauss Chronic Illness Trajectory (Halcomb and Davidson 2005) and the lifeworld (Galvin and Todres 2013), it was possible to comprehensively explain the findings.

These findings were derived from the lived experiences of the participants in recovering from a moderate head injury; such findings have not been discussed in the literature before within this context and only provide one interpretation. However, they offer a unique insight and show the value of using IPA to add to the knowledge database.

9.4 Conceptualisation of the Combination of the Corbin and Strauss Chronic Illness Trajectory with the Lifeworld Concept

In bringing together Corbin and Strauss's Chronic Illness Trajectory with the lifeworld concept, I have created a novel way to visualise the recovery journey of the participants. This approach, to the best of my knowledge, has not been used before and has enabled the voices of the participants to be heard and uncovered new understandings and areas for future research and practice. Burton (2000) highlighted that Corbin and Strauss's Chronic Illness Trajectory was developed in grounded theory as part of a nursing theory/framework. In combining this with the humanistic lifeworld approach of Galvin and Todres (2013) (which has healthcare at its core), I have brought together two conceptual approaches to bring a depth of understanding to the participants' experiences. This multi-perspective approach was endorsed by Larkin et al. (2018) as a way of exploring socially nuanced research questions.

The non-linear recovery journey experienced by all the participants was complex: the components of their lifeworlds were moving at different rates along the trajectory of recovery. Although progress towards recovery was consistently made, at times there were periods within the overall recovery trajectory that resulted in different components of the lifeworld moving backwards. Overall, my thesis pointed to a generally positive recovery journey; however, there were hurdles that had to be overcome.

9.5 Reflexivity – Overview of its Role within this Study

This study encompassed reflexivity as part of the core study design; in this section I will discuss reflexivity in relation to Yardley's four dimensions of validity: "sensitivity to context; commitment and rigor; transparency and coherence; and impact and importance" (Yardley 2017). Reflexivity forms an integral part of research and is an approach through which the researcher becomes critically self-aware of their research process from its embryonic stages to its completion (Finlay et al. 2003). Engward and Goldspink (2020) described reflexivity as an endurance task; however, it is not a task, rather it should be viewed as a way of being and a process that takes time. Bonner (2001, p. 267), stated that:

Reflexivity raises the most fundamental issue that can be raised for modern social enquiry.

Using the six-step analysis by Smith et al. (2009), which was adapted by Engward and Goldspink (2020) and is shown in Table 9.2, it is possible to visualise the analytical process that aided my reflexivity. This six-step process promotes rigour, trustworthiness and transparency – important elements within reflexivity that will be discussed in the following sections. An addition by Engward and Goldspink (2020) is shown in Step 3, referring to "reflexive echoes" (Table 9.2, 3b). Goldspink and Engward (2018) described these echoes as a combination of the researcher's and participants' words – attending to these echoes shows an increased sensitivity by researcher to their role in the analytical process, together with an increased awareness of their own presumptions. Goldspink and Engward (2018) commented that recognising these echoes adds to the phenomenological sensibility of the research subject and is a way of identifying the presence of the researcher within the analytical steps. In my case, recognising my presence helped me (by self-appraisal) to remain faithful to the

participants' data, and to accentuate their voices, not mine. As a novice researcher but experienced clinician, this journey of reflexivity has been long and challenging, but the findings presented in this thesis demonstrate that the journey has ultimately been a fruitful one.

Table 9.2: IPA Six-step Process; (adapted by Engward and Goldspink (2020)).

Step	Process
1	Read and re-read transcript to get to know the data
2	Make initial notes to systematically capture observations
3	Develop emerging (prototype) themes for each case (3b) Attend to reflexive echoes
4	Search for connections across emergent themes for each case
5	Move to the next case
6	Look for patterns across cases

As the quote by Bonner (2001) highlights, reflexivity is an important fundamental component of qualitative research and, as such, is an integral part of this study. To consider my place in this process and how I inevitably influenced the study, I will carry out a brief overview using Yardley's (2017) criteria. I will also discuss how reflexivity was combined with the hermeneutic circle.

9.5.1   Sensitivity to the Data

Sensitivity to the data was demonstrated throughout this study from the conception of the idea, one which grew out of my awareness developed through two decades of paediatric neuroscience nursing. Part of my clinical work focussed on helping CYP recover and I realised that few, if any, studies were available that explored the CYP's recovery experiences either over time or qualitatively. Being aware that my own thoughts and ideas might lead to

biases, a CAG was recruited in the initial planning stages and was intrinsically involved with the research design of this study, including the happiness scale, the creation of the flash cards and the interview questions. IPA required that I analyse the data within the hermeneutic circle and as a consequence, the CAG were not involved in this process. However, my analysis was outlined to the CAG, with the group's feedback further ensuring that my "lens" was appropriate in understanding the perspectives of the CYP. The social constructivist approach was paramount as I wanted to explore the constructed realities of the participants to gain a view of their lived experiences and to understand the nuances of their experiences.

As demonstrated above, with deep submergence into the idiographic data, appropriate sensitivity to the data was maintained whilst simultaneously questioning and exploring the data and discussing the findings with my doctoral supervisors.

9.5.1.1 **Sensitivity to Context**

An unintentional part of the purposive recruitment process, something that I was not aware of until the interviews had started, was the degree of homogeneity within the participant group. As discussed in the previous chapters, each of the CYP participants were from single-parent families; one father had died, and the other families had separated prior to the interviews. As a researcher, I had to be highly aware of this and how this might have influenced the findings with both the CYP and mothers. In showing my awareness of this, I have demonstrated reflexivity resulting in a question: would the lived experiences of the participants which I have given a voice to have been the same if a father/partner was present in the family home? This cannot be answered in this thesis but raises a question for future research.

9.5.2   Commitment and Rigour

I was very aware of being a novice researcher undertaking the doctoral journey; to assist this journey, the work of Smith et al. (2009) informed my attempts to ensure the study was rigorous. I attended IPA workshops, partook in group discussions and joined a Yahoo IPA social group in attempt to improve my knowledge and practical skills. I am aware that my study was potentially a novel approach (for example, using a longitudinal study and incorporating public involvement) that had not been used in existing research on CYP recovering from head injuries. However, rigour (which can be seen as the thoroughness of the study, and includes interview quality and the comprehensibility of the interview analysis (Smith et al. 2009)) was maintained through active discussions with my supervisors. During the interview process's initial stages, I struggled slightly with asking non-leading questions but, through reflection and discussions with my supervisors, I became more competent with this (although Afan continued to be mostly reluctant to expand on his answers). My reflexive approach and in-depth data analysis also promoted rigour in this study. Rigour was further demonstrated throughout this thesis by incorporating a transparent conceptual analysis (see Table 9.2), which according to Anstey (2012) helps to show both methodological and practical competence.

My commitment was exercised throughout by encouraging the participants to voice their feelings/thoughts/experiences by using loosely structured questions and, at the end of each interview, giving each participant the opportunity to add any other information that they felt was relevant. Commitment was also shown in the ethical recruitment of participants, giving sufficient recruitment time, the participants' treatment throughout the study and the storage of data. The fact that this study was carried out over a number of years showed commitment and the willingness to re-question findings and conclusions. Furthermore, the commitment to

relay the story/experiences of the participants has been central to this thesis. I ensured that I worked within the ethical and professional standards outlined by the NMC (2018) and the RCN (2009).

9.5.3 Transparency and Coherence

This study maintained transparency and coherence throughout. I have demonstrated this by the development of the subordinate and superordinate themes within each of the idiographic cases and across the groups, which can be seen in Chapters 6 and 7. Importantly, these themes were constructed inductively from the data and thus directly from the lived experiences of the participants by a clear audit process. These findings were discussed in a way that is consistent with using an IPA framework with a social constructivist lens, which was presented within the discussion chapter and discussed with reference to the literature. Consistency was maintained with respect to the methodology throughout the interviews and the methods and analysis chapters.

9.5.4 Impact and Importance

Employing the above three criteria (9.5.1–9.5.3) ensured the quality of the findings. This thesis is well placed to change and improve the perception of how CYP recover from a moderate head injury, provide a deeper understanding of the impact on mothers and, ultimately, direct appropriate care to the patients who need it, hence improving patient care. This study has also suggested that further research (see section 9.7.4) is needed into how CYP change following a head injury, which would include looking into resilience, coping and post-traumatic changes in the recovery period. When published, these findings will

potentially improve follow-up patient care not only locally but nationally. Informing and improving professional practice is fundamentally the role of the Professional Doctorate.

9.5.5   Reflexivity and the Hermeneutic Circle

IPA promotes the relationship between the researcher and the participants as being more important than the concept of "bracketing", a concept Tufford and Newman (2010) described as a removal of any previous preconceptions. However, as one focusses on the participants' responses and experiences during the interview process, in which a sense of immersion takes place with the lived experiences of the participant, some form of bracketing becomes automatic (Smith et al. 2009). The participants become the focus and the questioning tries to elicit their lived experiences, and I, as the researcher, become secondary to the participant. In working with CYP and their mothers, the participants of this study, the relationship between us was fundamentally important. Trust in and understanding of me and the research process were key elements of participants' engagement and, therefore, the generation of rich data. An awareness of reflexive working was included in every aspect of the study and the following paragraph will describe the reflexive analysis during the "germination of the little gem" and how the hermeneutic circle helped with its interpretation.

Mauthner and Doucet (2003) discussed and demonstrated the role of reflexivity in data analysis. They described how ontology, epistemology and research practice are intertwined and emphasised the importance of including reflexivity into the interpretational/analytical process. The "germination of a little gem" within my study was the multifactorial nature of how gender influenced defiance and the participants' acceptance of their restrictions. The approach behind this was discussed and explored in the discussion chapter (section 8.3).

Reaching such conclusions, however, was achieved by completing a series of rotations around the hermeneutic circle, reviewing the part with the whole and comparing idiographic cases. These rotations involved a deep analysis of the data within each of the subordinate themes. What seemed like a simple acceptance of the restrictions placed on them by the medical team turned out to be a complicated relationship between increased parental/peer involvement and a lack of realisation (or denial) of the impact of the restrictions on their lifeworlds. Then, at three months, in each of the participants there were significant changes in their emotions because of the restrictions: the participants started to understand the magnitude of the restrictions and a clear demarcation was noted between the reality of the restrictions and the act of just thinking about them – this demarcation would have been experienced by the participants as they re-engaged with elements of their preinjury lifeworld, for example school.

Reflexivity in this analysis involved frequent revisiting of the data, active discussions with my supervisors and looking at appropriate models in order to try to understand the findings. This iteration and toing and froing between the data and their meaning for participants highlight the influence of reflexivity in this important part of the study.

9.5.6   Separation of Clinical Role and Researcher

In creating this section, I intend to demonstrate the commitment with which I separated my two roles of clinical nurse specialist in neurosurgery and novice researcher. This was an issue which I considered from the very beginning, from the conceptualisation of my research idea to the present. I was aware of the ethical considerations that I faced, the need to consider my position within the lives of the participants: to be a researcher, or a nurse specialist or both.

I used a simple and effective strategy to separate my roles. Once the gatekeeper had identified a potential participant, I greeted the family as a researcher and followed this with an explanation of my clinical role. I often felt at this point that my clinical role enabled me as a researcher to gain access into their lives at the two-week period, a very vulnerable time for the family. All the interviews were carried out at the venue of their choice, often the family home where they felt most comfortable and empowered. As a clinician I always feel grateful and a sense of humility to be allowed into the family home – a place of safety for the family. As a researcher, I felt very honoured in being allowed to carry out research in this way. I also recognised that the duality of my role may have caused confusion for the participants. In order to minimise this, I arranged my home visits (researcher and clinic visits) to be synchronised; the families coped well because I carefully explained to them the order of events at each visit and used the same order each time. Firstly, I undertook my role as researcher; secondly, once data collection was complete, there followed a debriefing conversation with the family; and thirdly, my clinical role commenced. I clearly demarcated the transition into my clinical role with the removal of my digital recorders and happiness scales (which were anonymised) and the replacing of them with my clinical notes. The foci of conversations and questioning were also clearly different and further demarcated the transition from research to clinical work.

9.6   Limitations

One of the known generic difficulties associated with doctoral studies is the transition from novice researcher to a more competent one. In this study I was no different, starting from a novice stance, learning about and immersing myself in the IPA approach and then, at the end

of the study, feeling competent about the research process. This progression was ongoing throughout the research journey and will continue once the formal thesis assessment process has finished. Undertaking a longitudinal study helped with this journey, and my confidence and competence increased as I undertook and analysed more and more interviews. An interesting parallel was that my development of "self" also resembled the journey of the participants, who undertook their own journey of self-discovery along their recoveries. As part of my own development, a reflexive journal was kept, which formed an important component of my analysis.

Study recruitment and the final sample size could be perceived as limitations. In the initial planning stages, I had planned to recruit ten participants to the study, but recruitment was limited by the number of CYP with moderate head injuries who presented within the neurosurgical unit. Smith et al. (2009) stated that for Professional Doctorates only four to ten interviews are needed; the number of interviews as opposed to the number of participants is the important variable. This study included fifteen interviews of five participants (by including the mothers at six and nine months) which, even though was more than the ten suggested by Smith et al. (2009), allowed for deep analysis due to the longitudinal nature of the study. The inclusion of the mothers added further depth to the data.

Another limitation of this study is that whilst IPA benefits by utilising in small sample sizes (Smith et al. 2009), due to the richness of the data it generates, it can be difficult to generalise findings to larger groups. However, because of the richness of the data and by illuminating the participants' lived experiences, transferability of findings is possible (Smith et al. 2009). As the researcher, I am unable to gauge how transferable my findings are; it is the role of the

reader to determine this. However, elements of my study and thesis can encourage transferability: the carrying out of an in-depth idiographic analysis (Smith and Osborn 2015) into how CYP changed as a result of a moderate head injury, the impact on the mothers, the discovery of new findings, the utilisation of a reflexive stance throughout the whole process, and the use of CYP in the research design stage.

Time also presented a limiting factor on two fronts: firstly, the recruitment window was limited due to the format of the Professional Doctorate and, secondly, the study only collected data for nine months. As this thesis has shown, the participants were left with residual problems at the nine-month point and exploring these further would have provided a greater insight into their lived experiences through the recovery process. However, this study has offered a better insight than a cross sectional study would have done.

A further limitation was also noted when I encountered reluctance by some of the CYP participants to talk, often using brief sentences (and some responses consisted of merely one word), which in turn made linguistic interpretation difficult. This is a known problem and some of the strategies to compensate for this have been discussed by Coyne and Carter (2018), who looked at participatory research – for example, those that included play or photo-based interviews. However, by the use of the "Happiness Scale" and flash cards as ice breakers, some of these problems were overcome. In future research with CYP, as a more accomplished researcher I would include more creative tools such as drawings, photos (as also evidenced by Manning (2015)) and apps.

9.7　Recommendations

Drawing on my findings and interpretation obtained from applying the combination of the Corbin and Strauss Chronic Illness Trajectory with the lifeworld concept, recommendations will be made at three levels – macro, meso and micro – which according to Smith et al. (2019) relate to national and regulatory policy, local health service policy and day-to-day practice, respectively. In looking at these aspects separately, it is important to be continually aware that the findings from my study, due to its limited number of participants, are recommendations based on the transferability of the findings; they will need further research but do reflect patient experiences. Therefore, I will include a separate section for research recommendations. The following sections will deal with the "so what?" of my study and the ways it can improve care for the patient and their families, which in essence was the purpose of the study.

9.7.1　Macro

The lived experiences of the CYP and the mothers showed ongoing issues which extended both past the point of them being discharged from the neurosurgical service and past the end of the study period. Currently paediatric neurosurgical services follow NICE guidance during the acute stages of head injury management and follow-up management. However, NICE (2014) (and its updates: NICE (2017) and NICE (2019)) and SIGN (2009), fail to fully advise on follow-up guidance and instead leave it up to the individual healthcare professional. Both these guidelines are mainly based on quantitative studies, but acknowledgement has to be given to the increasing number of qualitative studies used. Qualitative studies are vital because exploring the lived experience informs us what it is really like to recover from a moderate head injury, growing understanding of the patient's journey and their recovery. As

such, the current national guidance from NICE (2014) and SIGN (2009) is out of step with the participants' lived experiences, as evidenced by my study.

A recent guideline by WHSSC (2018), which looked at neurorehabilitation, offered hope for sufferers of head injuries but focussed on the more severe type of head injury. However, referral into the neurorehabilitation service would need to happen whilst still an in-patient. For the follow-up patient, who has been discharged from the ward, the patient would require a referral from a neurosurgeon or community paediatrician (amongst a few other options). As evidenced in my findings, all the participants had delayed follow-up and continued to experience problems post discharge from neurosurgery, and as a consequence would not have been referred.

Recommendations at the macro level include publishing my study and adding to the current literature; this would increase the presence of important qualitative data in this field which could be accessed by the guideline review committees. From a post-doctoral perspective, as an independent researcher I would carry out further research looking at the lived experience of head injury sufferers (including mild and severe head injuries) and their families with the intention of further improving the literature concerning this topic.

Another recommendation is to increase access to the neuroscience forums (exampled by RCN) in order to increase the awareness of my research findings. Currently the neurosurgical service by which I am employed is a member of the Paediatric Neuroscience Benchmarking Group, which is a national group looking at service delivery. I have presented my findings to this group and raised the profile of my research which has raised an interest. By accessing

forums like these, it is possible to have an impact at the strategic level because members of the forums input into policy documents, and on occasion members of the government seek advice from the forums and attend meetings.

9.7.2 Meso

At an organisational level, recommendations include raising the profile of the patients' journey following a head injury and the need for further resources to improve the follow-up period. The findings in my study highlighted that the whole family is affected by a head injury and the ongoing need to enforce the restrictions. In the current NHS system within Wales, service policy is often governed by national policy. A recommendation embedded in the research is to raise the profile of the complex recovery journey that CYP travel through. Currently, I have presented my findings to members of the clinical board, who valued the findings, but to get organisational-level movement, further evidence is needed including further publications (which was discussed in the Macro section) and business cases for increased staffing.

I have demonstrated that both CYP and their mothers continued to experience problems following discharge from the neurosurgical service. This points to a current limitation in the service to protect the wellbeing of the patient and their family, a limitation that encompasses staffing and finance. This presents a risk not only for patient safety but for litigation and liability, which could be associated with a restricted service. Organisationally, being aware of this is important due to governance (organisational) and by raising awareness at this level would improve services for CYP and their families.

9.7.3   Micro

At the micro level, where the operational level and service delivery needs to be considered, this study has already informed clinical practice. The findings demonstrated that each of the participants had problems, such as anxiety and low mood; therefore, a more comprehensive holistic assessment than that currently offered by the biomedical model should be considered. The combination of the Corbin and Strauss Chronic Illness Trajectory with the lifeworld concept provides a way to view complicated lived experiences in a holistic manner.

The findings from my research have been presented to my colleagues within the paediatric neurosurgical (including the paediatric neurosurgical nurse specialists) and neurology team, this has led to a more patient-centred approach and the recognition of the complexities that can exist. A key message from the study was with the effect of restrictions and the role of the parent in enforcing them. For the service and operational levels, a recommendation would be to ensure these restrictions are appropriate, only in place for as long as they are needed and that the mother is considered in follow up appointments to see if she is coping with enforcing the restrictions. Generating a better understanding of the impact of restrictions can lead to improved care by a better understanding of the importance of individualised moderate head injury healthcare assessments and discharge planning, with the right support at the right time to enable the CYP to manage their altered self.

Another recommendation at the operational level would be to ensure that follow-up appointments are timely, form part of "prudent healthcare" (WG 2016) and, as evidenced by the current study, are continued for longer in an attempt to address the issues with psychological recovery – with appropriate referrals being made to other services if needed.

The final recommendation in this section would be for further ward-level teaching including student nurse education. This is something that already occurs, but the emphasise would be on raising awareness of the complicated trajectory moderate head injury patients have, and the ways in which advice and support is needed.

9.7.4   Research Recommendations

This thesis has highlighted the need for future research into how CYP and their mothers change following a moderate head injury. This is an area that continues to be poorly understood. Even though Battista et al. (2014) and Roscigno et al. (2011) recommended further work in this area, little else exists outside their studies in the head injury literature.

A recommendation for future research would be to explore, in the head injury patient, factors such as patient resilience and the coping strategies that they use during the recovery period. Also, further research on post-traumatic changes, and the influence of gender in the recovery period. A recommendation would be that the findings of such studies are published in journals with a high impact rating, such as "Brain Injury", in an effort to educate not only nurses but other healthcare professionals such as medical practitioners.

9.8   Conclusion

In undertaking this longitudinal IPA study, I have explored the lived experiences of three CYP and two mothers as they recover from their daughter's/son's moderate head injury. This has added to knowledge and future recommendations have been made. To interpret the

findings a lifeworld model of recovery was produced – see Figure 8-2. Figure 7-1 and Figure 7-2 diagrammatically show the complexity of the lived experiences and, importantly, show the interconnectivity of the subordinate themes with the superordinate themes and the interplay between them. This complexity reinforces the need for individualised moderate head injury healthcare assessments that should be carried out at appropriate times. As this study highlighted, these should be done for at least six months in order to detect any problems. A compiled list of future recommendations is discussed in section 9.7; these are aimed at improving the care for the recovering head injury patient and their family.

9.9   Epilogue

In bringing this thesis to a close, I feel compelled to reflect on the journey that I have undertaken during this Professional Doctorate. As a clinical nurse specialist working with CYP who had sustained a head injury, and their families, I was aware of the clear lack of qualitative research in this area, with most of the studies being medical studies utilising quantitative approaches. The taught part of the Professional Doctorate introduced me to different qualitative methodologies with their associated benefits and limitations, and I decided to use IPA – then my learning began.

In undertaking the course and the research, I initially felt that it would be a very linear journey, but I was quick to discover that this was far from the truth. The complexities of the data analysis and the findings presented their own challenges that were compounded by needing to judge how to show the participants' lived experiences in a "real way" – in a sense being honest and transparent with the data. By adjusting my mindset and following guidance from my supervisors, I felt that this was achieved – but there was always a thought that one

could be working at a higher level, which of course comes with experience and competence. And as I progress with future research, I expect to improve. The doctorate, after all, is a training course for future independent researchers.

My lens on how I view the world has changed, which has been a direct consequence of the Professional Doctorate. This has permanently altered my horizons so that I can no longer see things in simple ways or think there is a single truth. My thinking is more critical, going beyond the obvious, seeking out the hidden truths. This is evident both in the thesis with the uncovering of the "germination of the little gem" and in the fact that I would like to further explore how suffering a moderate head injury influences a CYP's lived experiences (together with their mother's) – for example, carrying out research over a longer period, working with varying ages, understanding the implications of gender and exploring the post-traumatic changes that are experienced by the CYP. Currently, my research has improved clinical practice within Wales by improving the neurosurgical nurse follow up after discharge; I have also presented it nationally and interest has been shown in incorporating my work into wider areas of practice. However, I am aware that further research is needed and see my study as the start of a rewarding journey of improving the care of patients.

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Appendices

Appendix 1: Glasgow Coma Scale

			Date:													
			Time:													
COMA SCALE		**Best Eye Response (4)**														
		Eyes open spontaneously	4													
		Eyes opening to verbal command	3													
		Eye opening to pain	2													
		No eye opening	1													
		Best Verbal Response (5)														
		Alert, babbles, coos, words or sentences to usual ability	5													
		Less than usual ability and/or spontaneous irritable cry	4													
		Cries inappropriately	3													
		Occasionally whimpers and/or moans	2													
		No vocal response	1													
		Best Motor Response (6)														
		Obeys commands/normal spontaneous movements	6													
		Localises to painful stimuli or withdraws to touch	5													
		Withdrawal to painful stimuli	4													
		Abnormal flexion to pain (decorticate)	3													
		Abnormal extension to pain (decerebrate)	2													
		No motor response to pain	1													
Coma score (out of 15)																
Significant event																

Pupil Scale (mm)

- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8

Temp.
40
39.5
39
38.5
38
37.5
37
36.5
36
35.5
35

BP
200
190
180
170
160
150
140
130
120
110
100
90
80
70
60
50
40

Pulse

Resp.

Resps
O₂ conc / FiO₂
Pain Score
O₂ sats

PUPILS	Right	Size														
		Reaction														
	Left	Size														
		Reaction														
LIMB MOVEMENT	Arms	Normal power														
		Mild weakness														
		Severe weakness														
		No response														
	Legs	Normal power														
		Mild weakness														
		Severe weakness														
		No response														

Appendix 2: Development of the Happiness Scale by the CAG
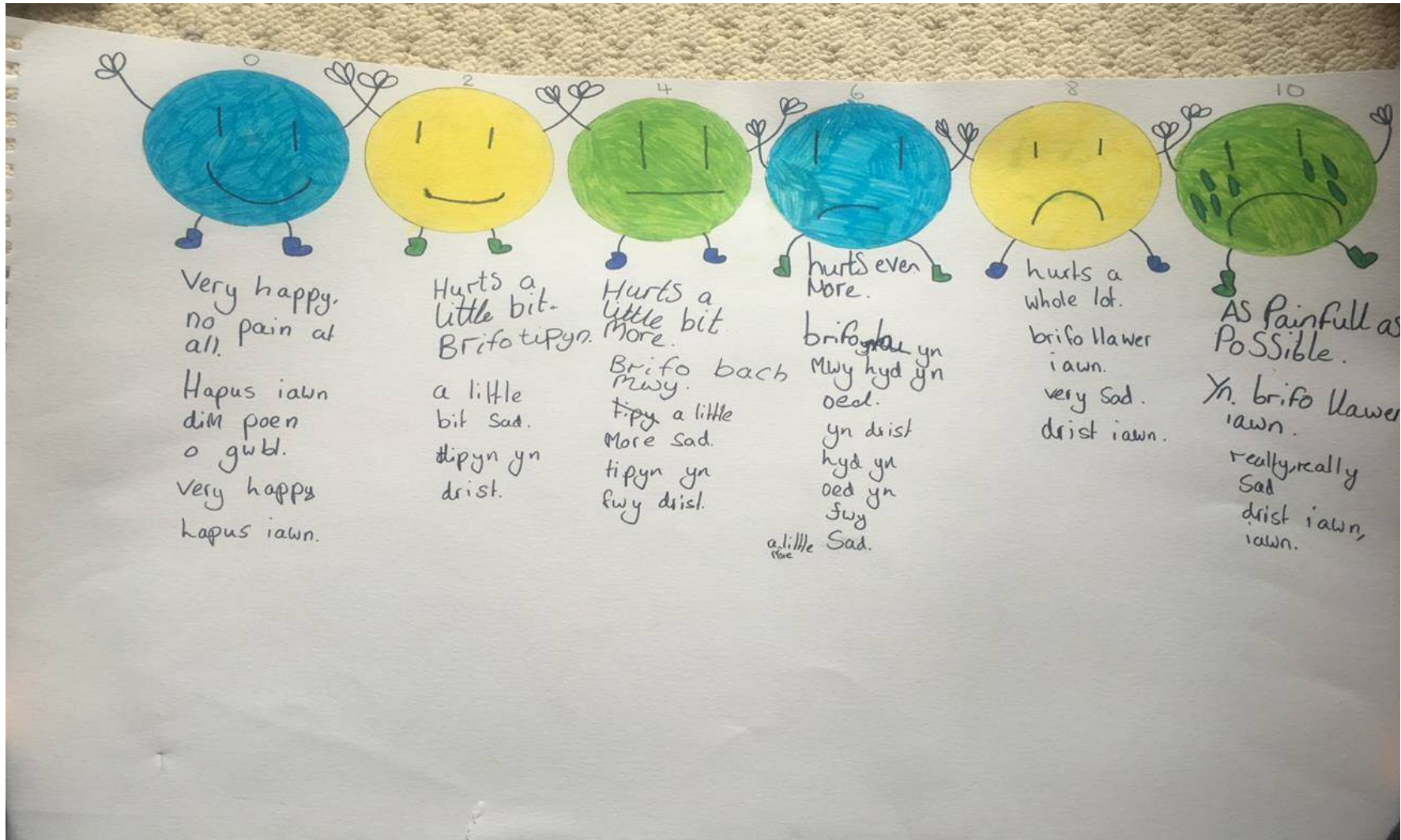
0 — Very Happy
. as cold as a iceburg
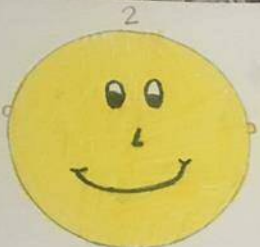
2 — Happy
- Green as a grape
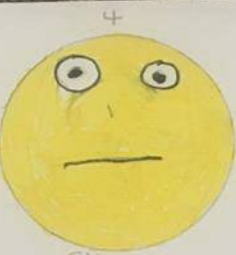
4 — Okay
. im okay
. im not grate
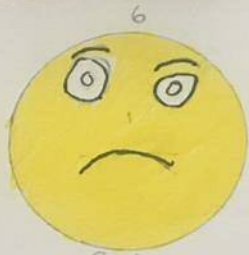
6 — Sad
im upset.

8 — Very Sad

10 — Extremely sad

0
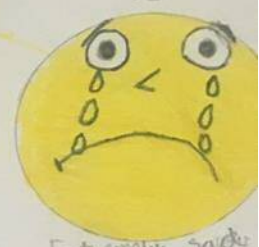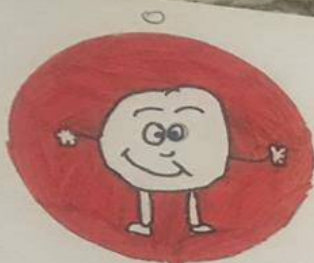
Cool as a
Cucumber

As bright
as a light

2
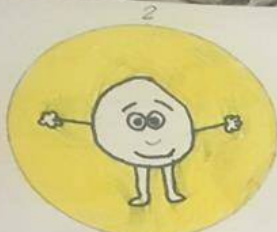
I am fine
Just a little hurt.

4

6

8

8

10

0
verry verry Hapu
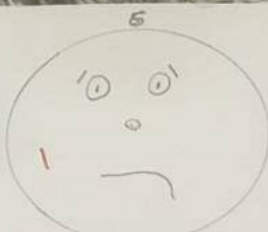
2
Hello
I am
cheese
cake
I am
OK :)
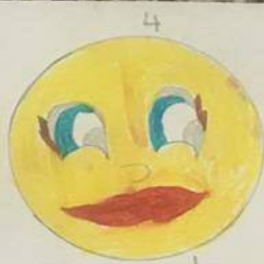
4
Ouch! it
hurts quite
alot now

6
Queit sad :(
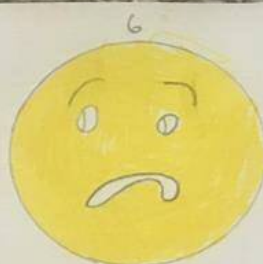
8
I am
Milk
choclate

I am
worried

I do not
now
What
to do.
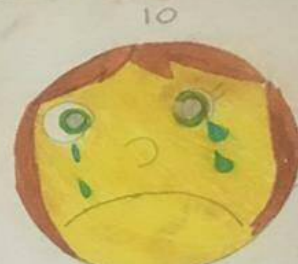
10
Heart broken,
it hurts alot

0

1-2

3-4

5-6
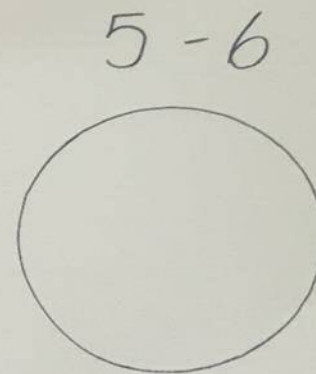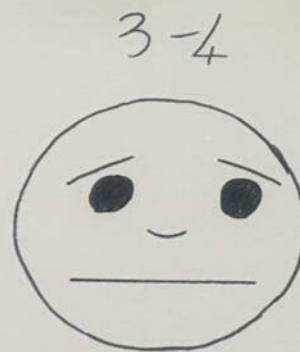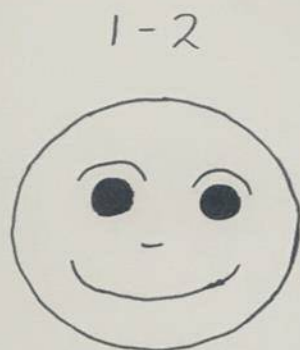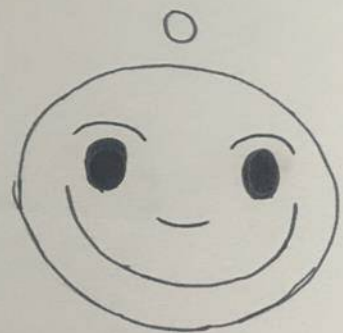
Very very happy.
No pain
No problems at all.

Hapus iawn ddim yn brifo.

7-8
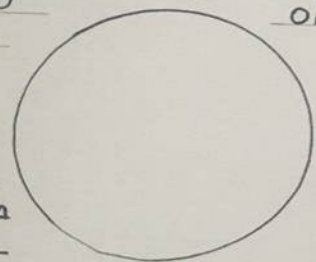
Happy little bit of pain.
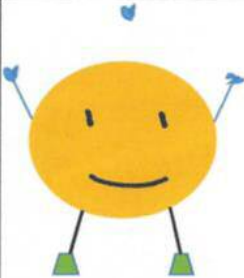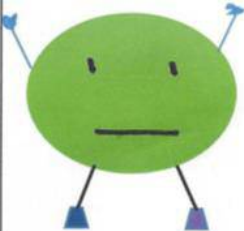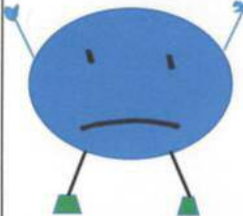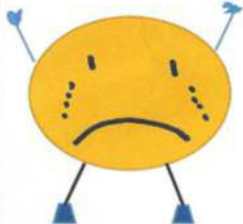
Doesn't hurt less hurts more.

9-10

0

2

4

6

8

10

9 to 10
Just
Happy

in
the
middle
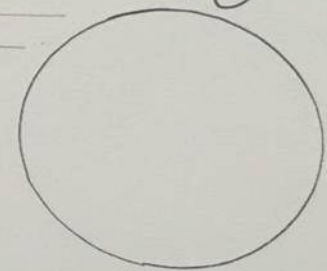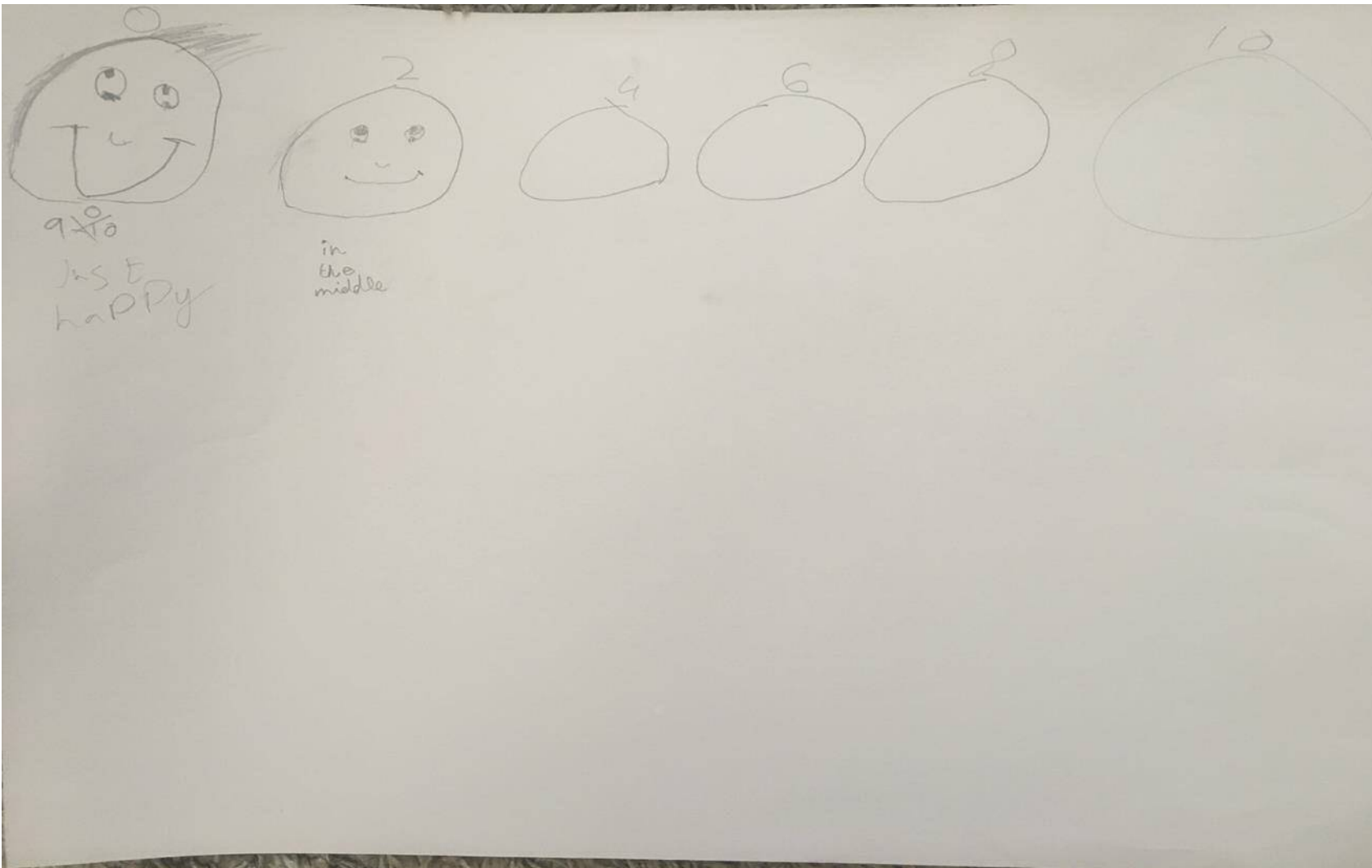
Appendix 3: Happiness Scale

2	4	6	8	10
Very Happy	Happy	Okay	Sad	Very Sad

Appendix 4: Flash Cards

Football

Wrestling

Rugby

Gymnastics

Family

Board Games

Fun Games

Athletics

Friends

Swimming   Tennis   Cricket

Computer Games   Instruments   Sleep

School

Baseball

Holidays

Cubs / Scouts

Exercise

Eating / Drinking

Sports

Chocolate

Sweets

Appendix 5: School Consent Form

Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

12th June 2015

Dear Parents / Guardians,

I am looking for children to help form an advisory group as part of a research project. Here is a brief overview of myself and the reasoning behind the research.

I currently work at the University Hospital of Wales as a Paediatric Neurosurgical Nurse Specialist and part of my role involves helping children who have suffered from head injuries. I am looking to improve outcomes for these children and in particular their quality of life. As part of this research I will be setting up an advisory group, with whom I will meet with before the end of this term and then throughout next academic year in order to do the following:

- To help develop an assessment tool /scale and interview questions.
- To help identify key words / images which will describe 'Quality of Life' to the child.
- To help in the interpretation / meanings of key phrases, expressions that will come from the research.

Yours child's involvement will be anonymous and he / she will may pull out at any time. The study itself is being overseen by Cardiff University and by NHS Ethics. Your child's involvement will provide valuable insight and will provide some learning opportunities for them to. Could you complete the enclosed form by Monday 29th June 2015 and return it to the school, please.

Many Thanks

Ian Williams

I give / do not give consent for my child to be involved in the formation of the advisory group and form part of the study.

Name of child _____   Date:_____

Name of Parent / Guardian _____ Signature of Parent / Guardian_____

346

Appendix 6: Anonymised Letter of Access
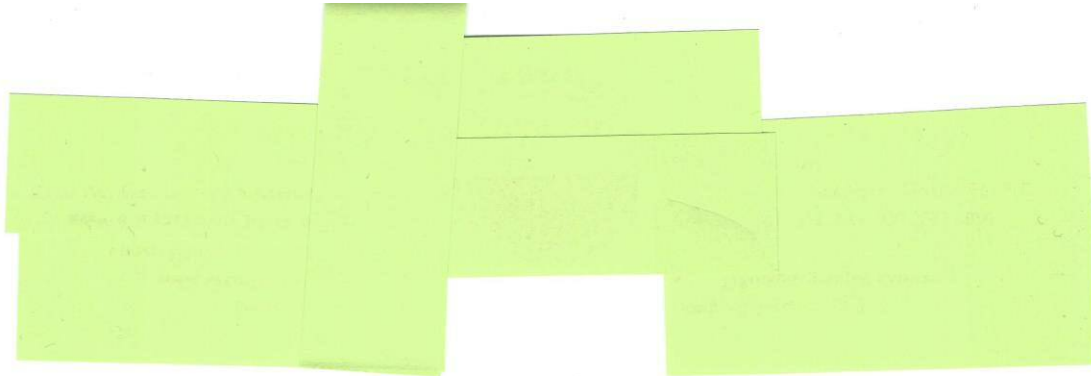
03/07/15

Dear Ian,

As we have most of the consent forms returned form the Year 4 parents I am happy for you to come in to the school to create your advisory group. I understand that this will be during school hours and will be over 3 sessions, each lasting between 60 and 90 minutes.

I understand that you have a current DBS check , however there will be a member of staff nearby at all times.

Yours sincerely
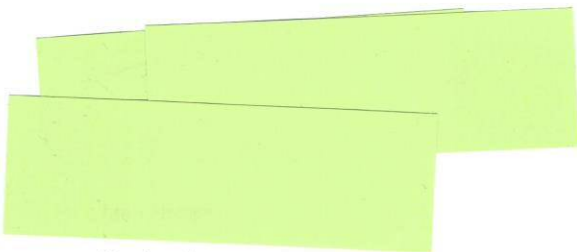
Headteacher

Appendix 7: Participant Information Sheet

Participant Information For Children
(Aged 6 to 11 years)
(To be shown to and read with parents if required)

Study Title:

How do children living in Wales experience their quality of life following a moderate head injury?

What is research? Why is this project being done?

Research is a way we try to find out the answers to questions. We want to see how you were after you knocked your head. Your help might improve care for other children who knock their heads.

Version 1.1
30th January 2016

Why have I been asked to take part?

You have been asked to take part because you knocked your head.

Did anyone else check the study is OK to do?

Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. Your project has also been checked by the NHS –hospital where you were looked after and also by a group of children the same age as you.

Do I have to take part?

You do not have to take part in the research if you do not want to.

What will happen to me if I take part in the research?

If you take part, a researcher will come to your house and will ask you about how you are since you knocked your head. The researcher will see you soon after leaving hospital, then at 3 months, 6 months and finally at one year. They will talk with you for around half an hour. In this time you will look at pictures to see how you feel, talk about things that matter to you and how they might have changed since you knocked your head.

Will joining in with the research help me?

We cannot promise the study will help you, but the information we get might help children who have knocked their heads in the future.

What happens when the research stops?

The chats and the information that you have given will be used to make care better for other children. If needed, you will still see the nurse who will help with any problems that you may still have.

What if I do not want to do the research anymore?

If at any time you do not want to do the research anymore, tell your parents, doctor or nurse. They will not be cross with you.

You will be asked if you want the collected information to be used for the research or if you want if removed and destroyed.

What else might happen?

There are no risks to you taking part in this study. Sometimes parents do not like to talk about their children's illness, but often this can be very helpful

If we find out something that we think is important about how you are recovering, the researcher will talk to your mum, dad or carer and ask them if they want to come back and have you looked at in hospital.

What happens to what the researchers find out?

When we collect your information we will make sure it is stored in a safe place and only the people doing the research study can look at it.

We will use the information to teach doctors about how to treat other children by putting it in medical magazines and on websites that doctors read.

A short summary will also be on the hospital's research website. No-one will know you were in the study but we will let you know what we find out.

Appendix 8: Parent Information Sheets

Information Sheet for Parents

Part 1 of the Information Sheet

Study title: How do children living in Wales experience their quality of life following a moderate head injury?

We are asking if you would let your child join in with a research project about their quality of life following their recent moderate head injury. My name is Ian Williams, I am a qualified nurse, and I am undertaking a Professional Doctorate at Cardiff University.

Before you decide if you want your child to join in, it is important to understand why the research is being done and what it will involve for your child. Please consider this leaflet carefully and talk to your family, friends, doctor or nurse if you want to.

Why is this research being undertaken?

We are doing this research to see how your child's quality of life is affected by their moderate head injury and to see what care they need. We hope that the results of this study will be used to improve care for future children who may have a similar injury.

Why has my child been invited to take part?

Your child has been chosen because they have experienced a moderate head injury and they live in Wales.

Do I have to let my child take part?

You do not have to let your child take part. You are free to stop your child taking part at any time during the research without giving a reason. If you decide not to take part or stop the research at any time, this will not affect the care your child will receives.

If you want the research stopped, you will be asked if you want the existing data collected, used or removed completely from the study and destroyed.

What will happen to me if I let my child take part?

If you decide to take part, the research will last for one year. I will ask you to sign a consent form. I will give you a copy of this information sheet and your signed consent form to keep.

Parent Information Sheet
Version Number 1.3
Date 3rd March, 2016

I will meet you and your child at your home or at a venue of your choice in order to talk to your child about their quality of life following their head injury.

This will take place within two weeks of going home, and then at three, six, and twelve months. The conversations with your child will each last around 30 minutes and will be recorded.

All the information that you and your child give will be anonymised and securely stored on a University computer. After the research is finished, this information will be archived by Cardiff University for 15 years.

What will I be asked to do?

If you decide to take part, you will need to let your child talk to the researcher after a couple of weeks after going home, and then at three, six, and twelve months. During these conversations, your child will be asked questions about their quality of life since their head injury and will be asked to choose a 'smiley' face to express how they are feeling

Is there any risk of harm from taking part in the research?

We do not anticipate that any harm will result from your child taking part in the research. If your child is upset talking about their experiences, the researcher will refer the child to the appropriate support involved in their care, if consent is given by yourselves as the parent / guardian.

What are the possible benefits of taking part?

This research may not directly benefit you and your child, but the information we get might help future care and recovery for children who suffer from head injuries in the future.

What do I need to do now?

If you are happy for your child to take part in the study, please inform a member of the nursing or medical team so the researcher can arrange a meeting to discuss things further and take written consent. You are free to stop your child taking part in the study at any point.

Contact details

Ian Williams: Tel 02920748268;

                     E-mail: williamsIE2@cardiff.ac.uk

Clinical Link: Claire Thirsk Paediatric Neurosurgical Nurse Specialist

                     Tel 02920748268

Thank you for reading so far – if you are still interested, please go to Part 2

Part 2 of the Information Sheet

This information sheet contains more information you need to know if you are happy for your child to take part in the research.

What happens when the research project stops?

When the project stops, you will continue to be followed up as normal by your clinical team.

Will anyone else know I'm doing this?

We will keep your child's information in confidence. This means we will only tell people who have a need or right to know.

What about confidentiality?

Confidentiality will be maintained at all times not only during the study but afterwards as well. The information (including the recording in digital format and the transcribed notes) obtained will be placed on a secure server belonging to Cardiff University. This information will be retained for 15 years before being destroyed. Only the researcher, or appropriate individuals from Cardiff University, regulatory authorities or from the NHS Trust where it is relevant, will have access to the information (recordings and transcribed notes). The recordings will be transcribed by the researcher. The researcher, as a registered children's nurse, is bound by a professional code of conduct where confidentiality is mandatory.

What will happen with the results of the study?

When the study is finished, it is hoped that the findings will lead to future research in this field. The findings may be published in professional journals and presented at professional conferences. It is believed this will lead to improvements in care for children who have suffered a moderate head injury.

Who is organising and funding the research?

The research has been organised as part of a Professional Doctorate programme undertaken at Cardiff University. This study has received no external funding.

Who has reviewed the study?

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. This project has been checked by the Wales Research Ethics Committee 6 and discussed with an advisory group consisting of children who are similar in age to your child.

What if something goes wrong?

We are not anticipating that anything will go wrong during the study and your child's happiness and wellbeing are paramount to us. However if you feel that you are not happy with the conduct of the study, you are entitled to voice your concern by contacting:

Dr Aled Jones (Research Supervisor)
Eastgate House
Cardiff University
35 – 43 Newport Road
Cardiff.
CF23 0AB

Or

Dr Jane Harden (independent)
Eastgate House
Cardiff University
35 – 43 Newport Road
Cardiff
CF23 0AB

Thank you for reading this – please feel free ask any questions.

Appendix 9: Consent Form

CONSENT FORM

Title of Project: 'How do children aged six to thirteen years old living in Wales experience their quality of life following a moderate head injury?'

Name of Researcher: Ian Williams

Please initial box

1. I confirm that I have read the information sheet dated 14th October 2016 (Version 1.4) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my child's participation is voluntary and that I am free to withdraw at any time without giving any reason, without my child's medical care or legal rights being affected. At this point it will be discussed whether the information obtained will continue to be used or removed from the study and destroyed. ☐

3. I understand that the data collected during the study, may be looked at by individuals from Cardiff University, regulatory authorities or from the NHS Trust, where it is relevant to my child taking part in this research. I give permission for these individuals to have access to my child's records. ☐

4. I understand that the information collected from this research might be used to support other research in the future. ☐

5. I agree for my child to take part in the above study and for the interviews to be audio recorded. ☐

6. I agree for my child to take part in the above study and for anonymous quotes to be used in publications. ☐

7. My child gives his/her verbal permission (assent) to be involved in this study. ☐

3. As the parent / guardian I am happy to be interviewed as part of the study and I understand that this will form part of the research; where anonymous quotes might be used in publications and for future research. I understand that the information obtained may be looked at by individuals from Cardiff University, regulatory authorities or from the NHS Trust, where it is relevant to my child taking part in this research.

Name of Child: _____

_____   _____   _____
Name of Parent / Guardian   Date   Signature

_____   _____   _____
Name of Person   Date   Signature
Taking Consent

Appendix 10: Interview Questions

CYP

Interview Questions For Happiness Scale
[adapted from SEIQoL, Boyle et al. (1993)]

- "For each of us, happiness and satisfaction in life depends on those parts or areas of life which are important to us. When these important areas are present or are going well, we are generally happy but when they are absent or are going badly we feel worried or unhappy. In other words, these important areas of life determine the quality of our lives. What is considered important varies from person to person. That which is most important to you may not be so important to me or to your husband/wife/children/parents/friends (mention one or two of these groups as appropriate)...and vice versa"

- "I am interested in knowing what the most important areas of your life are at the moment. Most of us don't usually spend a lot of time thinking about these things. Indeed, we often only notice that certain things are important when something happens to change them. Sometimes it is easier to identify what is important by thinking about the areas of life that would (or do) cause us most concern when they are missing or are going badly."

- "What are the five most important areas of your life at present - the things which make your life a relatively happy or sad one at the moment......the things that you feel determine the quality of your life?"

- "What parts of your life are most important?../ What things are most important?../ 'The most important things in my life are...'."

- "Now that you have named the five most important areas in your life, I am going to ask you to rate how each of these areas are for you at the moment. First I will show you an example of how the rating is done".

- "First look at this scale (indicate). As you can see, there is space at the bottom in which I can write five important life areas of my life (indicate. The scale ranges from 'Very Happy' on the left to 'Very Sad' on the right, and passes through levels such as 'happy' - 'okay' (neither happy or sad)- 'and sad'.

- The first important area of my life is X (use a cue not already nominated by the respondent and write it in the space below the scale) and if this is going very well at the moment, I can show this by drawing an X on the scale (indicate). The nearer I put the X to the right, the poorer my rating of that area of my life and the nearer I draw it to the left, the better my rating of that area of my life. A mark in the middle range would indicate that I am rating life as neither good nor bad, but somewhere in between."

- "This provides a picture of life as I might think of it at the moment. Thinking of my life in this way, I can now make a decision about the overall quality of my life by marking on this line" (indicate the horizontal visual analogue scale (VAS). "This line ranges from 'being Very Happy' on the extreme left to being Very Sad' on the extreme right, passing through 'Happy, okay, and Sad.

- "This provides a picture of life as I might think of it at the moment. Thinking of my life in this way, I can now make a decision about the overall quality of my life by marking on this line" (indicate the horizontal visual analogue scale (VAS)). "This line ranges from 'being Very Happy ' on the extreme left to being Very Sad' on the extreme right, passing through 'Happy, okay, and Sad'.

- "Now I want you to rate the five most important areas of your life, as you see presented here (indicate). Firstly, draw an X which represents how you would rate yourself on each of these areas at the moment. As in the example I've just shown you, the nearer put the X to the left, the happier you are rating that area of your life and the nearer you draw it to the right, the worst you're rating of that area of your life".

- "Now, thinking about these five areas of your life and how you have rated them, please indicate on this scale (indicate the horizontal visual analogue) the point that best represents your overall quality of life at the moment".

CYP

Interview Questions For Happiness Scale - Subsequent
[adapted from SEIQoL, Boyle et al. (1993)]

- I am just going to recap what quality of life is from the last interview.

- "For each of us, happiness and satisfaction in life depends on those parts or areas of life which are important to us. When these important areas are present or are going well, we are generally happy but when they are absent or are going badly we feel worried or unhappy. In other words, these important areas of life determine the quality of our lives. What is considered important varies from person to person. That which is most important to you may not be so important to me or to your family/parents/friends and vice versa"

- "I am interested in knowing what the most important areas of your life are at the moment. Most of us don't usually spend a lot of time thinking about these things. Indeed, we often only notice that certain things are important when something happens to change them. Sometimes it is easier to identify what is important by thinking about the areas of life that would (or do) cause us most concern when they are missing or are going badly."

- At the first interview you mentioned five areas of your life at present - the things which make your life a relatively happy or sad one at the moment......the things that you feel determine the quality of your life?"

- "I am going to ask you to rescore each of those quality of life areas in your life.

- "First look at this scale (indicate). As you can see, there is space at the bottom in which I can write five important life areas of my life (indicate. The scale ranges from 'Very Happy' on the left to 'Very Sad' on the right, and passes through levels such as 'happy' - 'okay' (neither happy or sad)- 'and sad'.

Interview Schedule – Mothers

1. Taking you back to the time of the incident or the accident, what were your thoughts

   at the time?

2. Thinking about the quality of life choices that were selected, were you surprised?

3. What are you views about.. ? (choose each QoL separately and discuss).

4. Do you think then that the accident has changed his/her outlook on life?

5. Can you were to think of words that would describe him/her

   (behaviour/emotions/thoughts/etc) ?

6. How do you see their recovery going / future?

Appendix 11: Example of Mind Map (Cai)

Interview 3 months

Respect
Trust
Dignity
Violation
Impact on future involvement
Betrayal

Frightened
The way he was treated in hospital
Abandonment by mum - Bereait
Wanted support and company
Treatment
Psychological Scarring

Psychological
Not listening to friends
Feels lucky
Guilt
What it would be like?
Curiosity
Fear of death
Telling event
Fear of normality
Recalling
Scarring
Recognises anecdote
Treated Differently
To cover feelings
Humour

Rugby
Very Angry - never talk
Feels to Playing
Strong Emotions - sad
Misses Training
Misses Social Aspect
Frustration
Realisation
Can't Play
Sad

Physical
Dislikes PE in school
Happy - doesn't want to do
Long Distance Running
Athletics
Tennis
Exercise
Tiredness
Means doing play / day / behaviour
Means avoid regret
Means doing it
Future Hope to do
Unable to do

Restrictions
School
Solitary
Health
Rehabilitation
Motorbike
Very very sad
Wishes he was older
Identity

Family
Maturity
Increased Anxiety / Stress
Protection Over Mum
Increased Stress
Concern over Cai
Can be OverProtective
More Compassionate
Arguments
Relationships
Mum
Anger
Power Play - Askent

School
Morality
Agression
View of teachers
Friendship
Misses
Phone
Lost contact
Guilt by friend who knocked his head
Anger - over being treated differently
Feels singled out
Very interested
Phenomenas
Mixed emotions on return to school
Feels like a strange like at school
Happy on return to friends
Doesn't Want to Return

362

Interview 6 months

Psychological

guilt
Shouldn't need to
Used coping mechanisms for future special problems
Feels remorse over his behaviour
Toothache
Comparison to battle
Lucky he survived
Will never be back to normal
War wounds
Physical scars

still feels impact of
and pain / discomfort
Had it so needed
Balance hope for not absorbing secondary blood
Did not want operation
Anxiety / fear
Mixed feelings over trust

Uncertain if he wants or will be allowed to go back on bike
Concern over future injury
Slow reintegration back to rugby
Internal struggle with doing rugby
Transitional note over feelings
Competitive spirit
Positive thoughts with rugby
Anxiety
Maturity
Uses humour to mask feelings

Outlook has changed
Okay
Important

Important to him
Back to ride, like

Not allowed by mum
Misses social aspect
Sad
Motorbike

Can play now
Just training
Wears a skull cap
Will go back to playing games
Has suffered due to Hi
Rugby
Exercise
Rehabilitation

Thoughts back to normal
Buggy

Positive aspects of..
Keeping
Hearing loss

Uncertain if life will return to normal
Previously saw himself as rule breaker / a rebel
Identity

Relationship
Family

Very Happy
Argument
Differences over freedom at mum
Mum & Dad spend less time differently..
Mum treats him differently / normal
Seat relationship - differently
Feels & normal

School
Treated the same
Bully treat differently
More likely differently
Back to normal
Very Happy
Happy
Some changes as PE
Adjusted

363

Appendix 12: Transcript Analysis Example (Ffion)

(Page numbers on document had to be changed to enable conversion of larger document to smaller document, which was converted to pdf).

Emergent Themes	Line Number	Transcript Body	Exploratory / Conceptual Comments
	1	I: There we go. He spoke this time.	
	2	(laugh). Ok. First question. Taking you	Asked to recollect thoughts
	3	back to the time of the incident or the	
	4	accident, what were your thoughts at	
	5	the time? How did you feel?	
	6		
	7	Ffion: Horrified.	Showing extent of concern of emotions –
Anxiety/psychological scarring	8		powerful emotion – 'Horrified' - hot emotion,
	9	I: Horrified.	powerful
	10		
	11	Ffion: Absolutely horrified, yeah.	Expanding with absolutely – showing extent
	12		of emotion – demonstrating magnitude of
	13	I: What was your…	emotion.
psychological scarring - worry	14		
	15	Ffion: Worried	Pre-empting my question – needs to express
	16		concern, experience
	17	I: Worried, what was your, so at	
	18	the time, over that period of time	
	19	between when you found out about the	Also showing worry
	20	accident and when he was admitted into	
	21	hospital did your thoughts change at all.	
	22	Did you think there was…	
	23		
Time seemed to change – significance of event	24	Ffion: I suppose it went into a blur	Talking about temporal changes, changes to
	25	really, I suppose about the accident but	view of time – significant life event, extent of
	26	just …	trauma to distort view time
Impact	27		
	28	I: What did you think happened?	Indicating that time changed, became a blur
	29		or how she dealt with it at that time
Shock	30		

Page 1 of 4

364

Psychological Impact	31 32 33 34	Ffion: Um, really, really worried but <mark>not quite comprehending</mark> what was happening to him, yeah.	Shock, horror, disbelief that it could happen to her son. Inability to comprehend. Shock, this is not really happening – different reality
	35 36 37	I: So what sort of information did you get from the ambulance crew.	
Local services	38 39	Ffion: Oh everyone was amazing.	
Information / communication	40 41	I: Ok	
	42 43 44 45 46 47 48 49 50	Ffion: Absolutely amazing. Um, yeah he was taken from the accident in the ambulance to W (hosp) and then everybody was amazing at W (hosp) <mark>they didn't even have a paediatrician um</mark>, and he was taken in an <mark>air ambulance</mark> then by air, yeah and then basically	Felt happy with care at the local DGH Mum was really happy with the treatment / information she received. Helped her understand the process and understand what is going to happen. Lack of local services. Air ambulance indicates the concern they had over him
	51 52	I: Did you go in the ambulance	
Anxiety	53 54 55	Ffion: Well I was <mark>not allowed</mark> in the air ambulance	Not allowed in air ambulance – appeared to accept this.
	56 57	I: How did that make you feel?	
Parenting / protection	58 59 60 61 62 63	Ffion: <mark>Um, it was fine because I was just worried about him and they came and explained that I couldn't go in there, but as long as they looked after him, I was fine with that.</mark>	Anxiety was lowered by advice given. Mum was worried but this was lowered by their professionalism and careful explanations. Mum wanted to do what was best for Afan. Relinquishing of control but in best interest.

	64	I: Yeah, ok.	
	65		
	66	Ffion: Yeah	Simple of acknowledgement that she viewed
	67		thinks to be fine.
	68	I: So, when you first saw him then	
	69	after uh the accident and you said about	
	70	the car and everything	
	71		
	72	Ffion: Yeah	
	73		
	74	I: What were your thoughts about	
	75	where are we going with this or did you	
	76	just think at the time sort of, minute to	
	77	minute, hour to hour, did you think that	
	78	there could be consequence from the	
	79	sort of head injury?	
	80		
Realisation	81	Ffion: Um, that's it, at the accident	Happy to query the question.
	82	we're talking?	
	83		
	84	I: Yes, about that sort of time yeah.	
	85		Bringing back to the accident - thought her
Thoughts of death	86	Ffion: Yeah, I didn't, it didn't quite	child was dead, then he became conscious –
	87	comp, yeah it didn't comprehend really I	therefore a confusing picture.
	88	suppose and then when I got to the	
Anxiety / worry	89	accident um but I thought he was dead -	Mum did not fully comprehend the extent of
	90	unconscious, you know, but then he	the injury – later realised impact and then
Methodological way of coping – potential	91	became conscious then but I didn't quite	became worried as he was unable to do
loss/mothers instinct.	92	comprehend, I think obviously what	things.
	93	happened and obviously I knew	Motherly instinct??
	94	something was not right, you were really	Taking things slowly, step by step, moment by
	95	worried but, you know, step by step,	moment – methodological approach to view
		and	things out of your control

Appendix 13: Development of Emergent Themes from Interview Quotes

<u>Cai</u>

Emergent themes	Quotes	Transcript, Page and line number	Emergent themes	Quotes	Transcript, Page and line number
'I used to get angry' [reference to motorbike] but I understood why.	"I know I can hurt myself if I fall off it".	1.7.206-7	"Rugby" and loss of identity.	"Oh god, Rugby is important".	1.3.24
	"I wouldn't do it!"	1.7.225		"I'm okay"	1.6.188
	"Oh God. Very sad! I can't go on it to after Christmas. Next year."	2.11.350-1		"I miss tackling people".	1.12.366
	"Very, very, very sad!"	2.11.356		"Well I'm sad. I can't do none really".	2.11.338-9
	"I hope I can go on it by my birthday or on my birthday. I'm going on it on my birthday".	2.33.1074-6		"Hitting people ..Hurting people. Not hurting them but yeah…Yeah training".	2.14.435-44
	"Sad coz I haven't got a motorbike. I was sad of because I can't ride one"	3.28.901-3		"Angry. Fuming!"	2.17.534
	"Yeah… I used to get angry that I couldn't have a go on it".	3.29.937-8		"Ah, I am debating" [about playing rugby].	3.9.289
				"There's like, if you're playing rugby you are paranoid!".	3.11.342-3

Being a *"Rebel"*.	*"Yeah, I __had__ to stay in at breaktimes!"*.	3.32.1034	*"My head would be fine", a Battle for Normality.*	*"I hope I can go on it by my birthday or on my birthday. I'm going on it on my birthday!"*	2.33.1074-6
	"Actually yeah, when I had to stay in at break…"	3.32.1040-1		*"Yeah, but my head would be fine though!"*.	2.89.2908-9
	"I didn't stay in at break!"	3.32.1045		*"I am very concerned about my head, if I hit it by there" [indicating an area on his head].*	3.39.1253
	"Rebel"	3.32.1050		*"Well, I have not been left paralysed or something like that!"*	3.41.1321-2
				"War wounds!"	3.41.1338
"Family is important" but its dynamics change	*"Family is important"*.	1.3.83	*"I've lost contact"* but it's okay now.	*"Yeah, I miss playing with my mates!"*	1.13.417-8
	"Well my mum is more stressed" [laughs but aware of mothers concern].	1.10.310		*"Yeah, very – sad, left out"*.	1.14.427
	"Oh God!"	2.9.291		*"Oh yeah. No, I've lost contact!"*	2.44.1425
	"Yes, angry 'cause there's always arguments".	2.19.619-20		*"Yeah".*[confirmed to socialising with friends outside school].	2.45.1469
	"Yeah. She's overprotective".	2.22.695			
	"We have the odd argue…That's normal…Everyone does"	3.18.564-73			

"I wouldn't say" it before – a change in perception.	*"Yes, I do because before I wouldn't say nothing. But yeah, I do"*.	2.20.647-8			
	"Ah, I am debating" [about playing rugby].	3.9.289			
	"Protect me" [in relation to wearing a skull cap – did not previously wear one].	3.12.379			

Betsi

Emergent themes	Quotes	Transcript, and line number	Emergent themes	Quotes	Transcript, and line number
"You can't do anything" - but I remain worried	No, it makes me feel bad. Every day I'm bored.	1.729-30	*"Over, overprotective"*- an impact on identity	Happy because they are like family... you can have forever.	1.292-3
	'Cause you can't do anything.	1.735		Over, overprotective, like my dad now	1.815-6
	Well I know I can't, well I need a helmet to start with and if I do have a helmet, I can barely get it on my head.	2.650-2		Don't know. I think I should be able to make my own decisions. Whether I want to get up or whether I went to get outside, sit down on a chair or bounce the ball in front of me.	1.881-85
	I just slumped back in the saddle.	3.404		Why? Her. My mother.	1.890
	In case my leg goes, and I can't ride and I'm scared I'm going to fall.	4.256-8		When I'm in school I try to like in PE, I said to my friend "ah do you want to meet up?" It's like I know they're trying to like help me and like take care of me and make sure I don't hurt myself but they're like saying, "ah no thank you, you just sit there". It's like I'm really bored and like.	2.418-25
	I could hit my head.	4.261		Bored and upset.	2.435
				Because they don't trust me enough and today [names friend A], or my friend [names friend B], she irritated me in school. She [names friend A] and there was [names friend B] when she popped last time so she's on crutches but in PE couldn't me and [names friend B] just	2.439-54

370

				share a bench and (unclear) I couldn't do it. She, well she said, ah could (unclear) we're going to go early, and they were just like "ah well how are you going to look after Betsi" and "what are you going", she said, "how are you going to look after Betsi" and 'cause I'm supposed to look after Betsi but my mum's specifically said [names friend C], [names friend D] or [names friend E] can look after me.	
				Because it's basically [names friend]. I know she's trying to protect me but it's like basically she, she's being a bit too overprotective and if I do want, if I go outside for like five seconds she's like, "get back in here now" and moan, moan, moan. It's like, shut up.	3.596-602
				Well I think it's mainly my fault because well before I was happy because I had all my friends, but then when I started High School, there was like change. I don't know many people. Like my best friend is not here. My other friends not here, I've only got this one best friend there.	3.656-63
				Well like some people call me like lazy and they say like, "ah you're lucky" but I'm not lucky. [names friend], [names friend] today she was like, "ah you're lucky, you don't have to do PE". I would rather be doing PE than sitting on the	3.708-28

				bench doing nothing. I am injured, that's why I can't do PE. Get in detention if you don't want to do PE. It's simple! Everybody says, "ah you're lucky, you're lucky" but I'm not!	
				Yeah, it annoys me really much 'cause I've got it a lot recently. [names friend] hasn't got it, no it's always me.	3.731-4
				Yeah.	4.796
				Kind of [in relation to being back to PE and games].	4.813
"It's going to take five months" but it will take longer.	I think it's going to take five months to get me better.	1.986-7	*"They never did it before"* – a changing family.	Well I think, well I know they've always got my back and um, I love them	1.313-4
	I don't know really because my legs just keep going on and off. I just don't like it.	1.998-1000		I feel (mumbling, unclear) because I can't really do things that I did before because I normally help nanny in the garden (mumbling, unclear). I don't have the strength to do anything and I can't go there as quick because of my legs and I can't help Grampy.	1.322-8
	In 1,000 years.	2.923			
	I recovered quite well (unclear) but then I got better and then ever since like I've gone to school it's not like every day but like a couple, well most days, um I've come home and with like my knee hurting, um, my elbow. It's just like, like every, like most days I'm like hurting all around, even my head.	2.934-41		My dad and my aunty. No, I don't, I know, I know they love but they're just touching. Rub my back or my knee. Like I got scabs on my knees, my head's hurting.	1.342-6
	Slow.			Well they never did it before.	

372

Well, I had. Well really, I've just been staying inside 'cause I, I have been trying to keep it, it's mainly because of my head but I need to do more exercise to get my legs working. I haven't had much. I just want this to heal. I don't, I don't even know whether it's healing. I don't even know what's wrong with it. In a year. Yeah, not 100. 85 Yeah.... Can't I just chop them off? [in relation to legs].	3.948 3.953-60 3.965-6 4.896 4.902 4.910 4.937		Well, if I don't ask, or if I ask for like cookies then he brought me two plates of cookies and I didn't want them but I ate them though. They were really nice so it was nice of him but I only wanted one. Annoyed Well my grampy's changed because he never really lies down but (unclear) he, I can't even say this without getting upset. He's, he's um (unclear) so he can't really swallow. It's okay. Well my dad's being really like nice to me but he, he kicked my bum and I could have gone, I could have hit my head on the table or the tray. Well he said. He called me, "ah don't be such a little tart". He always calls me that. Yeah, he's not bad. [reference to overprotection] Yeah but it's only because she loves me [reference to overprotection] Yes and I've, since my grampy died I've been like a bit snappy. I haven't been myself. Neither has mum. She's been	1.360. 1.383-8 1.399 2.705-9 2.765-9 2.779-81 2.804 2.830-1 3.615-25

373

				like a bit narky with me and like, oh, like friends sometimes and like sometimes with nan, but it's like with me I normally just let it go but like, things like me, I've just been (unclear) all day and it's like just be quiet. I just want to think. Just leave me alone.	
				A bit 'cause like, mum, dad says he wants to like, ah, you are, if I come around then my dad's been giving me attitude what I don't deserve.	3.1058-61
				Well, it's like, ah, ah, every time he comes around he says, ah, do you want to go out babes and I say no. Maybe I don't want to go out. Maybe I'm ill. He doesn't know that. He's hardly here to help me; it's always mum. Mum's been looking after me from the day I've been born and it's always mum. My dad don't do poo.	3.1066-74
				Well he doesn't buy me stuff anymore which I don't mind. I don't care if he. I don't care if he like didn't buy me anything I just want him to be here. My mum deserves a nice man.	3.1086-92
				He's a prat!	3.1109

				She's always been my mum and dad.	4.709-10
				He was a nice father, again to me he's just a horrible person.	4.601-2
				'Cause he's just a waster. He, he, he tries to buy love.	607-8
				He doesn't give love he buys it.	4.611
"It's going to take five months" – but it will take longer (additional info)	I know, I know it's not going to be for a while yet but at one point I will be able to ride my bike, so I've just got to be positive. I'm, I'm never positive before and I've just got to try to be positive. I felt like, um, I felt like I'm almost there, I'm going to be outside soon.	3.379-84 3.397-9	*"Over, overprotective"* – an impact on identity. (additional info)	Go in the hub for a bit. If we were both happy then we'd have something to eat there or and then we'd go to the park, park next to it, and if the café wasn't open we'd go, and if we had money, we'd just go to Aldi's [reference to before the accident]. Yeah. Mostly to Frozen Foods 'cause it's got sweets. Well when my best friend [names friend] came over with his sister we were playing piggy in the middle but I, I was going, "oh I'll go out" and they were going, "no you sit down" and so it was like, okay, and then we just [trailed off] ... It's just you can't do anything. You can't, you can't run (unclear) go on the trampoline 'cause you couldn't play catch... Over, overprotective, like my dad now [reference to friends].	1.697-702 1.706-7 1.714-22 1.815-6

				They're not letting me do anything fun.	1.834-5
				Yeah, they care about me.	1.843
				When I'm in school I try to like in PE, I said, ah, to my friend [names friend], "ah do you want to meet up?" It's like I know they're trying to like help me and like take care of me and make sure I don't hurt myself but they're like saying, "ah no thank you, you just sit there". It's like I'm really bored and like.	2.418-25
				Yeah, it's just I wish, they would just like help.	2.430-1
				Bored and upset.	2.435
				Because they don't trust me enough…	2.439
				It's like, shut up	3.602
				Well like some people call me like lazy and they say like, ah you're lucky but I'm not lucky.	3.708-10
				Yeah [reference to friendships returning back to preinjury state].	4.796

"I've got to try to do stuff by myself" – a view into maturation	My teddy bear is important to me…	1.70		
	I know I'm still a young girl, but I just want them to feel like, I not like a one-year-old anymore.	2.743-5		
	No. I hate her crying.	2.1027		
	Cause I do. 'Cause you, I don't feel like she comes to me when she's like upset. 'Cause, yeah it doesn't matter.	2.1031-3		
	Cause I'm a kid. She feels like I'm not responsible like I'm just a child.	2.1038-9		
	Kinda like my brothers and sisters [reference to the support the teddy bears were giving her].	3.157-8		
	Well I haven't really bothered with them much. I've been like trying to do stuff on my own and not like combined with my teddy bears so much.	3.259-63		
	Like, I was, when I was with mum I always, I always combined her like nothing, I wouldn't do nothing unless my mum was there but when I got, like in primary school I didn't want to do nothing and my teddies were there but now I just like, you can't do that no more, you've got to do it yourself, 'cause I, I hate to say that but at one point none of	3.266-80		

	them will be here. I've grown up, my teddy bears might have gone, and my mum might have gone by then. So, I've got to try to do stuff by myself. No [reference to how she saw changes in her teddy bears over the last nine months]. More important! [reference to the importance she placed on her teddies]. Because it's like one step at a time. Like when you walk you don't want to run and you don't want to gallop, you just want to walk.	3.284 4.149 4.153 4.333-6		

Afan

Emergent themes	Quotes	Transcript, and line number	Emergent themes	Quotes	Transcript, and line number
"Just miss it!" - a transient sense of loss.	Fine. [In relation to not playing football].	1.361	*"Only by the garage!"* – a way of coping.	Only by the garage!	2.433
	Um, fine. [In relation to not playing rugby].	1.430.			
	Just miss it! [Became upset and cried]	2.443			
	A bit.	2.470			
	I don't know.	2.475			
	Yeah, Frustrated.	3.266			
	Because I can't play!	3.271			
	Annoyed!	3.279			
	Happy. [in relation to his view on football].	4.54			
	Good. [view of football].	4.119			
"Because I can't go out!" – a struggle for identity.	Football. [PS4 favourite game].	1.447	*"Good"* - a positive view of recovery.	Yeah. [intention to play ruby when better].	2.569.
	Yeah. [response to friends playing on PS4 game].	1.480		Yes. [aims still to be fast after recovery].	2.580
	Because I can't go out!	2.791		Good. [view of recovery].	3.582

379

	Yeah. [felt PS4 was replacing physical football and rugby].	2.820		No. [Or would you have expected your recovery would go faster?].	3.596
	No. [Do you think FIFA 16 gives you what you're missing in the football?]	2.865-6		Touch. [type of rugby].	4.267
	A little bit. [do you get the same sort of satisfaction playing PlayStation 4 games?].	3.502		Yeah. [Do you find your fitness is getting better now?].	4.273
	Yeah. [do you get any, frustrated at all?].	3.508		I don't know. [in relation to playing contact rugby].	4.283
	About the same. [Do you play with your PS4 less now? Or about the same?].	4.540		Yeah. [When you're allowed is it?].	4.286
	Yeah. [But do you think you play less because you're playing outside more?].	4.694			
"Because I banged my head!" – I knew that my family were worried.	Yeah [... Do they still treat you the same? Your mum and dad?].	4.863	*"No. I'm alright"* but my friends were worried about me.	No. [In relation to any changes to friendships].	1.587
	No. [Yeah? No different?].	4.867		Yeah. [happy with friends].	1.602
	Yeah. [Do you think your parents are more worried over you?].	4.881		Uh yeah. [Do they come around more?].	1.607
	Because I banged my head!	4.885		No. I'm alright. [Do you feel sad for not going out?].	1.623
				A bit. [in relation to not socialising].	1.627
				Yes. [Do you think things are the same	

					in terms of your relationship?].	2.186
					Happy. [with friends].	3.139
					Good. [in relation to full time school].	3.157
					Um no, sometimes. [What else do you do with your mates? Do you go out?].	3.170
					Yeah. [They treat you the same now as before your accident?].	3.186
					Yeah. [in relation to friends being less worried].	4.414
					Yeah. [felt that friends were worried before].	4.424
					Good. [in relation to friendships returning to normal].	4.435
					Three months. [a view of when friendships returned to normal].	4.460

381

Gwen

Emergent themes	Quotes	Transcript, line number	Emergent themes	Quotes	Transcript, line number
"I've never felt so lost" – an attempt to rebalance control -part 1	I've never been so scared in my life because I just didn't know how it was going to turn out with, am I going to lose her. I'd waited so long to have her and I'm obviously getting too old to have another child…	1.77-83	"she was laying there on the floor… whimpering" – a never-ending nightmare	Well I had a knock at the door from the little boy that she was with and I, for some reason I'd got my keys and my shoes coz I was sorting out stuff in the kitchen… I knew something had happened to her and I've never run so fast in my life, walked around and I couldn't believe she was laying there on the floor and she was whimpering, she was trying to get up and she was just surrounded by blood and it was like one of those moments where I could either sit here and cry or you keep it together and you just deal with the fact that she's laying on the floor and it was the worst time of my life.. I think she just wanted me to pick her up and take her home.. it was just disbelief.	1.16-56
	I've never felt so lost. I couldn't go to her, I couldn't, I couldn't do what a mother is supposed to do. I just had a stand there while everybody else looked after her when she's my girl and I should be looking after her.	1.191-4			
	You know, all I wanted to do was pick her up and put her in my arms but I couldn't	1.212-216			
	And then it was sort of me and Betsi and I was giving her the medicines and stuff that I could do, um…that, that's when I felt like I was back in control so it took probably about 2 or 3 days	1.277-85			1.170-6
				…I can still, I can still, I can still see her on the floor, you know when I think about it, which I try not to, um, I can still see her on the floor, I can see her trying to get up, I can see her in the ambulance, I can see her on well in Accident &	2.36-45
	I just wanted to get her home. I'm not saying I wasn't nervous.	1.302-3			

Because I still had to give her medicines and, I slept, I brought a mattress in her room for about 4 or 5 nights because she was, if she needed the bathroom when she comes out of her room you've got the stairs so she could have been a bit wobbly so if I slept in front of the bed she would have had to.	1.307-14		Emergency, I can see her, you know, everything I can still picture, with a tube in her head and black eyes and, you know.	
Um, but I just was glad to get her home because it was um I suppose it was normal, getting back to normality. I had her home because at one point I didn't know whether I would get her home.	1.322-7		It's the, it's the fear that it happens, it would happen again when we went, we went to see my mother on Friday night, we were going to stay over but we were both shattered so we came home and we, and we crossed over together and she was just slightly in front of me crossing and (unclear) and a car came around and I was like, oh my God…	2.54-69
Yeah [being nice to be home)	1.366		Yeah well it's just a flat tire, it's just a hassle of getting the bikes out and, we've, we've got to do it but there's always something else to do for me. I've been cruel mum in a way as, you know, well her friends can cycle so I might even just say, take her over to Lilly coz Lilly likes cycling and just let say well you go over there and I know your safe and I'll just go back and get her then so	2.189-198
Yeah, coz she was, that was, that was heart breaking. She was trying to talk and you could see the panic in her trying to	1.212-6			
Oh my God when I heard this, your worst nightmare. You know, she never went out. The first time I let her out on her own and that happened it was like, why?	2.10-14		To me she's changed.	2.467
			But not in a, a huge way, as I was saying to you earlier	2.470-1
No coz she's, she's not like that and she (unclear) so she was (unclear)safety	2.19-23		I don't know whether it's the accident, she's coming up to her teenage, you	2.474-83

383

officer in the school so she did that and I got told that she literally ran,			know, she's 12, she's a teenager and her hormones are coming in, you know, the way she speaks sometimes, she doesn't mean it but the way they speak in school to each other, you know, it, it's like sometimes it's like everything. She's always been a bit, not sensitive but you know, we all get days where like, you know, what's wrong with me...Yeah (referring to low mood) ...it was bad enough him seeing her the following day when she had the black eyes and everything and he literally broke his heart. Coz my brother, obviously my brother (unclear) and my brother's a nurse and my brother literally had to keep going to see her, my dad, my dad, like my dad was very loving and caring Um, I suppose they relaxed a bit more. My mum is still concerned about her because the way her moods are.	2.532-6 2.575-585 2.611-613

"I've never felt so lost" – an attempt to rebalance control – part 2	And that, that's all I felt at the time, was it was my fault. I mean that, I think that was the point where I probably got on my daughter's nerves because I wouldn't let her go up and down the stairs without me. She couldn't go to the bathroom without me...Oh, I know I was overprotective but I had lost her and I wasn't losing her, coz if she slipped down the stairs or she did something she shouldn't have. she was going oh mum and dad are too protective, I have taken a step back and been, she goes up and down stairs, she's started walking back from school now. I still take her in the morning..she's gone over the park with her friend, there is still a part in me that, you know, you think, but, I, you can't smother kids, .. she knows she's my world.. I'd do anything to keep her safe but, you, you've got to let her stand on her own two feet. At the moment she's still nervous when crossing roads. L (name of friend) probably was overly supportive because she knew I had put down restrictions what Betsi could do and then she wasn't allowed to go on the	1.60-1 1.370-6 1.387-90 1.421-38 2.335-47	"*Guilt I think*" – t the changing dynamics of the father – part 1	Well we hadn't see him, the accident happened in September, we hadn't see him since the May, he didn't know we had gone on holiday on a cruise for two weeks, he didn't know she'd gone to Llangrannog for the weekend, um, she didn't see him on his, her birthday. Guilt I think part of it. I, he he, he loves her but I think part of it was guilt because A (father's name) didn't know until the following day. He didn't know the day of the accident because I had to just get through it...He literally walked in and he fell apart ... ...when I say oh you can do her homework with her, oh no , no I haven't got time I've got to go and do this, well that's fine but I'll take her to the shop and I'll buy her a back of popcorn, I'll buy her a bag of sweets, I'll buy her a bag of donuts...Yeah, with his other children he would chuck some money at them kind of thing. You know, he, he's very much the, (unclear) um yeah coz I never buy you anything, um, he, he's very much, I'm not saying he buys his	1.541-9 1.574-85 1.640-666

	playground, she had to stay in, so L(name of friend), by trying to abide by my rules, Betsi was like, she's telling me what to do. Well no, she's not telling you what to do she's just trying to do what I've said that I don't want you to do. You know, she's just trying to be, you know, your mum			children although it has felt like that sometimes with Betsi um	
				She'd rather more time. She'd rather be happy with him playing out the back with her, playing, playing netball or, you know, chuck, kicking a ball around with her	1.671-5
				Um, not really, well her family is very important to her, friends are important to her, her teddies because, because she hasn't got a brother or a..	2.139-143
			"*Guilt I think*" – the changing dynamics of the father – part 2	Family, well I know her family are very important to her. I know she does get confused about how she feels about her dad. I know she loves me to bits.	1.775-80
				But she was even getting a bit, um, the same with dad though coz she'd be doing that, touching him and, you know, Oh it's getting on my nerves and it's like and I said to her, it's spooky, I said to her you can't think like that because you don't know how long you've got him for.	1.1437-45

"She's happiest, I think, with her friends" – the importance of friendship	Yeah, back to normality..., I'm not saying her friends can't be a pain coz I know some of her friends and they are a pain, um, I think she takes things to heart a bit where she's feeling so many emotions at once, you know, she's frustrated, she gets angry, part of her still gets tired, um, you know, when you get frustrated somebody can say something to you one day and you go, yeah fine, say to you another day and you're not in the mood, she's like, really, why are you doing that, are you picking on, you know, it's like you just react differently.	1.759-75	*"Taken a nosedive"* – a change in confidence	if she's had a sleepover she comes back, I'm glad I'm home.	1.803-5
				It's like when I'm coming home from work I tell her what time I'm coming home. How long now before you're coming home. My mum says she just, how long's mum going to be, how long's mum going to be.	1.842-848
	You do, um, she's happiest, I think, when she's with her friends and she can be Betsi.	1.790-2		It's more, it's more since the accident.	1.853-4
	It's um, her true friends have been round, L to be fair to her um, J, out of everyone, her boyfriend, l, I know, literally was coming twice a week , two or three times a week, he'd come on a Tuesday and a Thursday from, from school, to sit with her, and he would literally, I mean he'd be sat in her bedroom and he'd sit and watch whatever, yeah I know, um, they'd sit and watch the tele and he, he'd come about 2 o'clock to about 6 o'clock on a Saturday just to sit with her to make sure	1.955-70		her confidence and ability seem to have taken a bit of a nose dive, like from that point of view where before, I don't think she was every over confident in her ability, but she seems to..	1.1141-1147
				Yeah, her confidence seems to have been taken a step back.	1.1152-3
				She's still got a fear of it but it was an accident that happened and I won't let it rule what she does. I mean, I only let her go with certain friends who, her one friend only lives over by Farm Foods so I drive her over I'll walk back and get her (unclear) um, they walk, if some of them are here, they'll all walk over or, you know, so she has a bit of freedom.	2.93-102

	she was okay so that			She can't wait to go on the bike	2.236
	Um, he comes down every now and then, obviously not the bedroom but you know, he comes down but now the weather is getting a bit better he goes out with his friends.	1.974-8		Oh yeah, she, she's pretty, she had a new bike for her birthday last year, she hasn't ridden it yet.	2.240-2
	She likes to be with her friends and as she said when she was talking to you, she's starting to meet new friends so they may be aware of the accident because they were in school at the same time	2.285-290		She doesn't go on it as much. I think she, If she goes on there she quite enjoys it, she likes going on there when her friends are over but, she plays with the basketball net out there now or she'll have a kick around or	2.249-254
	Yeah, she's, they're just getting back to, they have uh 5 minutes where they're fine, they bicker for 2 minutes then they're fine again. She's getting on my nerves, she's getting on my nerves, she's done this, she's done that, back to normal	2.359-365			
"She never going to leave the bedroom" – the recovery journey	Um, the, the recovery was a bit slow at the beginning because the first or actually until she was discharged for the first, oh I don't know, couple of months coz we were back, um a couple of weeks, no it was longer than that, because she was doing, obviously before, I'd say before the end of, well, yes, it must have been weeks, coz she was having the double vision	1.1013-23			

	Yeah, um, so that seemed to, at one point it was like, well is she never going to be able to like leave the bedroom and leave the house because we didn't really go anywhere but if I needed to go to the shop mum would come here and sit here, sit with her or I'd take her over to my mum's because, just because I didn't know how she was going to be.	1.1036-47		
	Yeah, um I mean it was lovely when she was discharged from the Eye Clinic and the Max Fax clinic, you know, um, that, that was great news because she was getting so distressed going to these places and coz her double vision just seemed to take forever to go, it, obviously, when you actually think how many weeks, coz she was back in school at the beginning of November, it just felt like it was a long time, um,	1.1060-71		
	Um the only concern I suppose I have now is in some ways the leg seems to be getting worse and not better as in she seems to be complaining more of the legs, because she, what she does, she does that with her toes, she points her toe and they've told her she's got to stop doing that now	1081-9		

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Emergent themes	Quotes	Transcript, line number	Emergent themes	Quotes	Transcript, line number
"I thought he was dead" – an ongoing battle with worry	Absolutely horrified, yeah.	1.11	*"He just expects me to be here"* – a view of family	He just expects me to be here, he expects, yeah	1.204-5
	I suppose it went into a blur really, I suppose about the accident but just...	1.24-26		We wouldn't come high on his list, I knew that. I was surprised at chocolate.	1.209-11
	Um, really, really worried but not quite comprehending what was happening to him, yeah.	1.31-33		I wouldn't know to be honest. I knew he wouldn't say family, um (laughter), I knew it wouldn't be family but...	1.407-10
	Um, it was fine because I was just worried about him and they came and explained that I couldn't go in there, but as long as they looked after him, I was fine with that. [– reference to air ambulance].	1.58-62		Um, he's probably, he's probably closer to me now I would say, because he was always quite independent, not that he wouldn't have a few moments but yeah, he's closer to me now.	1.774-9
	Yeah, I didn't, it didn't quite comp, yeah it didn't comprehend really I suppose and then when I got to the accident um but I thought he was dead - unconscious, you know, but then he became conscious then but I didn't quite comprehend, I think obviously what happened and obviously I knew something was not right, you were really worried but, you know, step by step, and when he was in Intensive Care then in C (Hosp name) and they kept asking him,	1.86-103		laugh. Um, I don't know, may be in his head he could see how much I love, not that, I don't know whether, yeah, maybe he could see how much he was cared for because, you know, it's always be all about him. Yeah. Yeah. So maybe he did feel, I don't know, special, I don't know, maybe, I don't know.	1.794-801

they woke him up and were asking him to do things, then I thought, oh my God, he can't. They were asking him to move stuff that he couldn't, and I thought, oh my God, he might not be able, yeah, it was a bit frightening		Well, not fighting anymore, um, (pause) I don't think so [brotherly mock fighting].	1.821-2
I was just praying that he would stay alive. That's all I was thinking about.	1.136-7	Um. I suppose, well, I suppose, well his dad's not here now and he was there at the first interview but then me and him don't get on so	2.210-4
So yeah, I couldn't, I couldn't, I couldn't think that this was brilliant that he was doing it in case he went backwards.	1.152-5	He thinks he's fine.	2.218
I don' know. Um, I don't know. I am, I am, yeah, a bit of wreck now, um, but I am improving all the time so um, I just panic when he's not with me.	1.619-22	Um, I don't know, well he, he didn't like want him to go back to rugby. He thought it was too soon. So, in some ways he's like, oh he's fine, and then in other ways he shouldn't be doing that. You know? So, um...	2.229-35
Yeah, I mean I think, um, he's doing really really well but I always worry now when he goes to play football. I'll be thinking watch your head. One day at a time!	1.640-4	They do fight now. I think all of us were aware that he'd banged his head. We were all still aware of it, obviously more aware of it and I think, I think we were all aware that things could happen, like accidents could happen [reference to brothers mock fighting].	2.1084-91
I was horrified and worried because and mad [reference to finding out that he was kicked in the head and didn't mention it – came from another mother].	1.740-1	He probably gets it more (laugh) [reference to dad understanding recovery].	2.1171
I thought he was dead.	2.17		

	Because he was unconscious and just on the floor.	2.21-22			
	Well he was conscious then and um, he was screaming, and he was hitting, punching his head. It was the pressure in his head. Umm	2.41-45			
	No, very concerned, very, very, very anxious. Probably not until days and days and days later. Even though he was [reference to thoughts at the time].	2.86-9			
	Yeah, um very, very very thankful and I just think of what could have gone wrong and um, I suppose perhaps when he had his um, when he was discharged from hospital, that was a main worry .	2.123-31			
	I'm very traumatised	2.148			
"Very lucky, very lucky" – friendships that persevere	Um, I think he's very lucky, very lucky, because they are a good bunch of boys. They have changed because he doesn't see them outside school anymore, but he does socialise with them on the PS4 live so.	1.242-7	"I would have thought he would have hated me" – an acceptance of control	I think he's done really, really well. I would have thought he would have hated me, (laughter) because it is me that has stopped him – [reference to restrictions].	1.278-81
	In that respect things don't seem, he continues to socialise in that way, but like they are a nice bunch of boys and they – [reference to PlayStation plus].	1.251-4		um, But he hasn't and he has just accepted that he can't. He has done really well. He has just accepted that he can't.	1.285-8

He's still included but they sort of accept that he doesn't go with them.	1.258-9	But I am very thankful for it because, yeah, like. I never worried about him before because he had, he was, he, he, some children are on it all the time but he wasn't into that but he was always quite engrossed but he'd rather be out, so he can't but now he can't he couldn't go out so I was just glad that he's got something that he enjoys. [PlayStation makes gatekeeping easier].	1.451-61
Friends and PS4, that's his life, yeah but um, yeah. I think he gets sad that he can't go out with his friends, but he's accepted that he can't do football and rugby but he's sad that he can't go out with his friends.	1.418-23		
Yeah. I do. I don't know what he would do if he didn't have the PS4. Because he is still so sociable	1.470-2	Like a couple of times he's gone out with them but I've taken them, taken him, sort of stayed there, not with him but with his brother in the background so he's got a bit of independence.	1.685-90
Um, yeah, the only time he does get upset is if he can't go out with his friends.	1.595-7		
Um, I suppose yes, they did treat him differently because, because he had a bad head, so they do, some of them perhaps not as much but his closest ones, yeah, treat him differently.	2.502-7	He got very frustrated, upset by it and I think he probably did play football when I didn't know that he was playing football at school.	2.615-8
So, he goes to meet them, he goes, we take him rather than him going there with his friends. [change in dynamics caused by moving to a new house alongside head injury] - **gatekeeper**	2.528-30	Yeah, he did, I thought he took it better than I thought he would to be honest. He just knew he had to.	2.638-40
I think they still look after him naturally, less so than they were doing obviously, but yeah, I suppose, he's little and he's the littlest as well so I think they always.	2.584-9		

	Yeah, he did talk, yeah [used to talk to friends about worries].	2.825			
	A way of socialising with his friends, um, but now it seems to be less because he is seeing them in person (laugh).	2.997-1000			
"he's matured" – a view of post head injury maturation	(sigh) probably yes because, yeah, he's matured, and he's accepted that he can't do that.	1.292-4	"For him it is football, rugby" – coping with loss	He's accepted that he knows how worried I am and he knows what he has done to his head and he's just accepted that he can't do it. Um, he has done really, he's taken to it really well, the fact that he can't, to be honest.	1.363-8
	Um, more accepting of things perhaps. It's the way it's got to be.	1.303-4			
	Yeah, he's, yeah, he has changed. He's not. He used to, um, he used to lose his temper a lot before the accident	1.321-4		Um, (pause) It's, I'd say frustrated (banging). I would say frustrated, he's just accepted it, yeah, he has. [reference to not playing].	1.382-5
	Yeah and um, like doing his homework he loses his temper and he still gets a bit mad now but he doesn't lose his temper.	1.328-31		For him it is football, rugby,	1.414
				PlayStation, he has compensated for football and rugby with PS4 and he's used it, that as a socialiser.	1.431-3
	He got angry then. (laughter)	1.335			
	Yeah, he's more chilled than he was. Yeah.	1.343-4		Yeah, yeah. The fact that it is not because they have said that he can do rugby and wear a scrum hat. His team always wears a scrum cap and he's always worn a scrum cap, he used to	2.353-62
	More mature I'd say. Um, he's probably not aware of it, well, (long pause) I	2.312-6			

				go training with the scrum cap on and just never took it off, um, I don't know, I don't know whether he's unconfident or unsure in himself.	
				Yeah, definitely. [wants to get back into sports].	2.385
				And he does some whether it's because he hasn't done sports he does worry more than he used to, whether it's coz he hasn't got the muscle to be tackled so, yeah.	2.437-42
suppose more, more aware of how things can change I suppose.				Um. He's a funny mixture, he was before, he was very confident with his peers, I suppose because of sport, in football and rugby, he was very confident with that, um, but he isn't as much now so no, he isn't as confident as he was.	2.706-13
				When he first went back like, when he played his first game, he came off and he was very angry and tearful, um, but now he's not, now he's playing like he was before. [loss of ability].	2.868-73

"I didn't think ahead" – the recovery journey	Um, I'm just thankful that he's made such a good recovery, yeah.	1.487-8			
	I didn't think ahead. I didn't think. I just prayed that he would.	1.501-2			
	I think, well I hope that everything is going to be fine. I'm a worrier so I worry (laugh).	1.522-4			
	Him or me? (laughter) I think it will be ... [response to length of time to recover].	1.548-9			
	No, he doesn't. He doesn't. But I know, know, he's never says anything.	1.560-1			
	Sad, sad, yeah, yeah [response to internalisation of Afan's worries].	1.577			
	Well that's him. Yeah, he was like that before. He wouldn't say but he would get, things would come out because he was frustrated. Because he wasn't voicing how he felt.	1.587-91			
	I hope's he going to carry on and be back to normal, I hope, um,	1.663-4			
	Yeah that was a big change coz he was doing whatever he loved, being normal and um, so yeah, for me I suppose that was a big change um, but even now I'm watching him all the time thinking is it going…, he went to the fair the other	2.135-43			

396

	day and I'm like will he be himself so that's still a bit			
	Um, I suppose it's gone really, really well and has gone really well, I still think, I still worry that, you know.	2.166-69		
	Yeah. Hate. Yeah, he'd get angry and he'd cry yeah.	2.673-4		
	He would have outbursts.	2.678		