WHAT ARE THE LIVED EXPERIENCES OF SIBLINGS OF CHILDREN AND YOUNG PEOPLE WITH ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD)? AN INTERPRETIVE PHENOMENOLOGICAL ANALYSIS

By

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ABSTRACT

Attention Deficit Hyperactivity Disorder (ADHD) is a prevalent diagnosis affecting many children and young people (CYP) in the UK. Despite this, there is little previous research relating directly to CYP's experiences of having a sibling with ADHD. Having a sibling with a disability or a mental health need can influence familial relationships and emotional well-being. In particular, sibling relationships can be affected and characterised by increased conflict. The purpose of the current research was to explore the lived experience of CYP with a sibling with a confirmed diagnosis of ADHD, seeking to understand positive experiences and challenges. Listening to and valuing participants' views was at the core of this research. Six participants aged eleven to 18 took part in semi-structured interviews. Interpretative Phenomenological Analysis (IPA) was used to interpret participants' experiences looking at individual experience and shared meaning across the data. Findings suggest CYP with a sibling with ADHD have positive experiences but there are several challenges and threats to their sibling relationship and their own emotional well-being. The findings are presented and used to inform ideas for future research and suggestions are made for professional practice.

DEDICATION

To my brother, Jarrod.

You've been my inspiration for the pursuit of my career and this thesis.

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I would like to express my thanks and gratitude to all those who have supported me through this journey both professionally and personally.

Special thanks to Dr Anita Soni, my University Supervisor. Your patience, encouragement and support to ‘keep going’ over the last three years has been invaluable. Thank you so much for all your help.

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CHAPTER ONE: INTRODUCTION

1 Introduction

The research presented here is the first of two volumes of literature completed as part of the three-year Doctorate in Applied Educational and Child Psychology at the University of Birmingham. This qualitative research study explores the significance of having a sibling with ADHD on six young people in the West Midlands. This research was conducted during the second and third year of the Doctorate course whilst completing my placement in my role as a Trainee Educational Psychologist (EP).

1.1 Research context

Over the past decade there has been an increase in diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) which is considered the most researched childhood condition worldwide (Barkley, 2014), with prevalence rates believed to be between 5-7% worldwide in the child and adolescent population (ADHD Institute, 2018). Research indicates having a diagnosis of ADHD has implications for academic attainment (Birchwood and Daley, 2010) the development of social relationships (Wehmeier, Schacht and Barkley, 2010), family relationships (Harpin, 2005) and long term outcomes such as job prospects (Hamed, Kauer and Stevens, 2015). A literature review conducted in 2001 concluded that having a child with ADHD in the family had the potential to disrupt parent-child relationships, increase parental stress, reduce parenting efficacy and influence

family and marital conflict (Johnston and Mash, 2001). Further research in 2013 found that as the severity of externalising behaviours of the child or young person (CYP) with ADHD increased, so did the levels of parenting stress (Theule *et al.*, 2012). Whilst there is research investigating the influence of a CYP with ADHD on parents and family systems, there is little focus on the effects of ADHD on sibling relationships.

A sibling relationship is unique and is likely to be the longest relationship an individual will experience within their lifetime. However, sibling relationships have not received the same research attention as other family relationships such as parent-child (McHale, Updegraff and Whiteman, 2012). Sibling relationships can be characterised by conflict, closeness and contact, communication, sharing of interests and caregiving and may provide a number of benefits during development through childhood and adolescence (Hodge, 2014). Having a sibling with an additional need such as a chronic physical or mental health condition can influence the sibling relationship and put siblings at greater risk of poor psychological functioning than their peers (Mckenzie *et al.*, 2018). Having a child in the family with an additional need can also place financial, emotional, practical and educational pressures on the family and therefore may have further implications for siblings as part of the wider family system. Relatively little research has considered the specific impact on siblings of CYP with ADHD in comparison to research with siblings of CYP with physical or chronic illnesses.

CYP with ADHD have a propensity to demonstrate externalising behaviours and may find it difficult to regulate and inhibit behaviours, emotions and thoughts (Smith, Barkley and Shapiro, 2007). Individuals may react to disruptions from their sibling by accommodating or reciprocating relational and physical aggression (Kendall, 1999). For example, having a child with ADHD is associated with increased sibling rivalry and family conflict (Mikami and Pfiffner, 2008). Some research suggests this has a negative impact on siblings, leaving them feeling victimised as a result of being targeted by acts of aggression (Kendall, 1999). The nature of a sibling relationship may be dependent on factors such as home environment, degree of externalising behaviour from sibling, parental stress and subtype of ADHD diagnosis (Smith *et al.*, 2002; Mikami and Pfiffner, 2008; Steiner, 2014). However, the literature review in this study only identified two published studies exploring the experiences of siblings of CYP with ADHD with a focus on their individual views.

Throughout this thesis, I refer to terms used by authors when presenting their research. For example, in some of the American literature ADHD is referred to as a disability, special need or mental illness. I use the term 'additional need' to encompass ADHD and a variety of other learning or social and emotional needs which a CYP can present with, as this is the term I now use professionally and personally.

1.2 Research rationale

Having grown up with a younger sibling diagnosed with ADHD at age 6, when I was 8, I have always had a natural curiosity about the diagnosis. I observed my brother experience the education system, friendships and more recently working life, in a different way to myself. Over the last few years, I have reflected on the influence my relationship with my brother has had on my own life thus far and whether his diagnosis has played a role.

In addition, during my placements I encountered two young people with siblings with ADHD referred to me for their own difficulties with regulating their emotions and behaviours. I began to explore this with them and realised neither young person had a clear understanding of their sibling's needs and how this may be influencing their own thoughts, feelings and behaviours. I then explored the literature on the theory of sibling relationships and their complexities. Having additional needs has the potential to influence the development and maintenance of a sibling relationship in a variety of ways. I was surprised to find such a paucity of research exploring the views of CYP with a sibling with ADHD, given the findings of studies looking at other mental health and developmental disorders suggest there may be a significant impact.

One of the key principles of work as an EP is that views of all CYP are considered, highlighted in the Special Educational Needs and Disabilities (SEND) Code of Practice (CoP) (Department for Education (DfE) and Department of Health (DoH), 2015). This research seeks to gain insight into the experiences of siblings therefore giving them a voice. Additionally, it is recognised within the field of

educational psychology that family experiences help to shape a child's emotional development and well-being as well as attainment. It is anticipated in my role as a Trainee EP and future EP, I can use the findings from this research to help raise awareness of the importance of listening to the voice of siblings of CYP with a diagnosis of ADHD.

1.3 Methodological orientation

This research has a specific focus on exploring the experiences of CYP who have siblings with a diagnosis of ADHD. The methodological approach for this study is Interpretive Phenomenological Analysis (IPA), adopted to examine how individuals make sense of their life experiences. Each participant's views are considered on an individual basis, before any shared meanings are explored. As part of the interpretive process I recognise the significance of my own experience as an individual with a brother with ADHD and this is discussed in greater depth in Chapter Five. Through deeper understanding of the effects and characteristics of ADHD as described by their siblings, I suggest EPs will be better equipped to meet their needs and suggest appropriate interventions if necessary.

1.4 Overview of structure

The focus of this research is to understand the experiences of siblings who have a brother or sister with a diagnosis of ADHD. The structure of the study is presented as follows:

- A critical review of literature relating to the diagnosis of ADHD, sibling relationships, siblings of children with additional needs and siblings of children with ADHD
- An explanation of the rationale for chosen methodology
- Details of the procedure for conducting the research
- A critical discussion of the findings in relation to the study research questions, situated in relation to previous literature
- Conclusions of the research, implications for the work of EPs, critical evaluation of the present research and recommendations for future research and practice

CHAPTER TWO: LITERATURE REVIEW

2 Literature Review

2.1 Introduction

This chapter presents a summary of literature relevant to the context of this research study. The first section provides an overview of the criteria for an ADHD diagnosis, its prevalence and debate surrounding the aetiology. Section 2.3 explains the nature of sibling relationships before moving on to consider the influence of having a sibling with additional needs in section 2.4. In section 2.5, a critical review of literature is presented to determine the impact of having a sibling with ADHD. Finally, a summary of the chapter is provided, concluding with the research aims for this study.

2.2 Attention Deficit Hyperactivity Disorder

ADHD is considered a developmental disorder and is currently the most common mental health diagnosis given to children in the UK (Timimi and Leo, 2009). With a reported rise in the number of CYP receiving a diagnosis in the UK, there has been an increase in published literature. The predominant focus of this literature is an exploration of the characteristics of the ADHD and its impact on learning, social and familial relationships. ADHD is characterised by a pattern of behaviours which include inattention, hyperactivity and impulsivity (Hill and Turner, 2016). It has

been proposed behaviours associated with ADHD can have a negative impact on children, their families and the community (Hamed, Kauer and Stevens, 2015). In particular, the relationship between siblings may be affected (King, Alexander and Seabi, 2016) although researchers are in the early stages of exploring this.

2.2.1 ADHD diagnosis

The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM V) states that ADHD is characterised by '*a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development*.' (APA, 2013). To meet the diagnostic criteria the behaviours must:

- Be uncharacteristic of the developmental age of the child
- Be seen across a variety of situations and settings, for example home and school
- Have started before the age of 12
- Cause difficulties with social and academic performance
- Be present for at least 6 months

The DSM V identifies three different presentations of ADHD; predominantly inattentive, predominantly hyperactive and combined presentation based on observed behaviours. Where a child presents as both inattentive and hyperactive, a diagnosis may be made of combined presentation. By offering a categorical description of behaviours, a clear distinction is made between a typically developing child and one who presents with ADHD.

ADHD is listed as a disability in the SEND CoP and is categorised as a social, emotional and mental health need (SEND DfE/DoH, 2015, p.98). However, it should be recognised there are also implications for cognition and learning. Where necessary, CYP should be offered SEND support in school to help mediate their needs in their learning environment.

National Institute for Health and Care Excellent (NICE) guidelines recommend that appropriately qualified healthcare professionals make the diagnosis of ADHD (NICE, 2015). EPs are rarely involved in the ADHD assessment process (Hill and Turner, 2016) despite advice suggesting a comprehensive assessment should be completed drawing on evidence from a variety of professionals and parent reports. This may have serious implications for CYP as it has been evidenced there are cases of diagnosis without rigorous assessment in the UK, with CYP consequently taking unnecessary medication (The Scotsman, 2004).

Timimi (2017) points out there is no biological test for ADHD and diagnosis is made purely on accounts of observable behaviours, complicating the diagnosis process. Diller (2006) suggests diagnosis can be controversial as no scientific data for ADHD can be provided, therefore a label of ADHD is often based on expert '*opinion*' (p.8). This has significance for CYP who are treated using prescription medications to manage their ADHD.

ADHD is associated with a number of characteristics including hyperactive, impulsive and inattentive behaviours such as fidgeting, interrupting others, disorganisation, forgetfulness, being easily distracted and finding it difficult to maintain concentration on tasks and activities including those which the child enjoys (Burston, 2005). The developmental profile of a child with ADHD can change over time and outcomes for CYP with ADHD depend on a variety of factors such as family socio-economic status and comorbidity with other disorders (Peasgood *et al.*, 2016).

2.2.2 Prevalence

Worldwide, it is estimated prevalence rates of ADHD are between 5-7% of the child and adolescent population (ADHD Institute, 2018). However, it is believed this figure may be affected by differing diagnostic criteria between studies, environmental and cultural influences. In recent years, there has been an increase in diagnosis in the United States with latest figures suggesting 8.4% of children currently hold a diagnosis (Danielson, 2018). The UK appears to have followed this trend with a wide belief the prevalence has risen markedly over the past 20 years (Holden *et al.,* 2013). It is thought 3-9% of school-aged children in the UK are affected by ADHD (NICE, 2015), with diagnosis most commonly made between the ages of 8-9 (DeNisco, Tiago & Kravitz, 2005). Boys are more likely to receive a diagnosis than girls; it is possible this is due to boys typically presenting with more disruptive behaviours, prompting faster referrals. Girls typically present with the inattentive subtype of ADHD, accounting for 20-30% of cases (NICE,

2015). Parallel to the rise in identification of ADHD, there has been a rise in the prescription of psychostimulant medications as a form of treatment (Graham, 2008) despite NICE guidelines (NICE, 2018) recommending psychological approaches are trialled first.

Prevalence of ADHD can be affected by age, gender and presentation and is often co-morbid with other diagnosis such as oppositional defiant disorder, conduct disorder, anxiety and depression (Hill and Turner, 2016). It is now believed ADHD persists into adulthood with current rates estimated at 5-9% of the adult population (Simon *et al*., 2009). This figure may include adults who were not diagnosed as children.

2.2.3 Aetiology

ADHD has a complex aetiology and there is currently no single identified cause. It is hypothesised a combination of environmental and genetic factors may contribute to the probability of ADHD developing. Some researchers suggest social influence and family factors play a role (Lange *et al.,* 2005). Kinderman *et al.*, (2013) conclude despite predominant biological explanations of ADHD, there are complex interactions at play between biological, social and psychological factors. It could therfore be argued the aetiology of ADHD is continuing to evolve.

The most prominent theories have been developed due to the greatest proportion of research focussing on brain and neurochemical studies. It is possible this is due

to research being favoured because of funds being provided by medical and pharmaceutical companies (Traxson, 2010). Thus, a narrative of ADHD as a neurodevelopmental disorder has been created with other descriptions and explanations minimised (Brady, 2004).

2.2.4 A biomedical perspective

It is posited by some that ADHD is an expression of brain dysfunction (Barkley, 2014; Barkley and Murphy, 2006; Fonagy *et al.,* 2002) and has origins rooted in genetics (Williams *et al.,* 2010). Some research suggests ADHD behaviours may be observed because of an imbalance of neurochemicals in the brain, required for adequate control of attention and behaviour (Spencer *et al.*, 2005). Furthermore, research has investigated structural brain abnormalities, identified through brain imaging scans, to determine differences between those with and without ADHD (Castellanos *et al.,* 2002; Nakao *et al.,* 2011). However, there are multiple confounding variables which may influence these brain imaging results (Furman, 2009). ADHD has also been linked to several biological risk factors such as being exposed to maternal smoke and alcohol during pregnancy (Langley *et al.,* 2005) and low birthweight (Johnson *et al.,* 2010).

ADHD is considered a heritable psychiatric condition (Faraone *et al.,* 2005; Nikolas and Burt, 2010). If a family has a child with ADHD, there is a 30-40% chance a sibling will also receive a diagnosis, increased to 90% in identical twins (Green and Chee, 1997). Despite this, Thapar and colleagues (2013) found no

single risk factor contributes to ADHD; both inherited and non-inherited factors are involved. Thus, a purely biological perspective is reductionist, does not account for alternative influences which may affect a child's development and therefore does not offer a comprehensive explanation of the cause of ADHD.

2.2.5 Alternative conceptualisations of ADHD

ADHD is a complex diagnosis, resulting in a variety of both personal and professional perspectives by its definition, causality and proposed treatments. There has been significant debate within literature regarding the differing ways in which ADHD can be conceptualised. It is beyond the scope of this research to debate the existence of ADHD and I do not intend to promote one theory over another. Yet, it is important to present differing positions and conceptualisations of ADHD to consider how they may influence the siblings' views within my research study and how this may influence their experiences.

As discussed above, at present the more dominant conceptualisation within both the literature and in my experiences within professional practice, is a medicalised perspective of ADHD. Researchers Timimi and Taylor, (2004) highlight the dangers of overreliance on a biological explanation as it removes the responsibility of parents and professionals to address the variety of contextual and environmental factors which may have a significant influence on behaviours. The authors argue for a shift in perspective to consider ADHD as a result of social and cultural constructs (Timimi and Redcliffe, 2005). Timimi (2010) suggests the

increase in diagnosis of ADHD stems from a socio-political stance resulting from how society perceives children and their emotions and behaviour, rather than an increase in professionals' understanding of the condition.

Cooper (2008) offers an alternative suggestion, arguing for a bio-psychosocial model of ADHD. Using a holistic approach rather than a single lens, ADHD is conceptualised as the result of an interaction between a biological predisposition, subsequently influenced by psychological and social factors. The British Psychological Society (BPS, 2018) advocate a more integrated model, adopting a biopsychosocial approach towards understanding ADHD. Consideration is then made of biological factors, psychological factors including emotional processes and social factors, particularly parenting practices and classroom management. In a recent amendment, the BPS consulted with NICE to amend guidelines for diagnosis, adding the importance of considering environmental influences on behaviour:

> "*Environmental factors must be fully accounted for and appropriately adapted prior to a diagnosis of ADHD being made*."
> (BPS, 2018, p.1)

2.2.6 Alternative intervention approaches for ADHD

With the growing recognition that environmental and contextual factors may influence the presentation and severity of ADHD 'symptoms' and that a biomedical perspective may be too reductionist, it is important to consider alternative

interventions to medication for managing ADHD. Recent NICE recommendations suggest before any treatment for ADHD is commenced, discussions should be offered about the benefits and harms of non-pharmacological and pharmacological treatments for ADHD (NICE, 2018). For example, a comparison of the efficacy of medication compared with non-pharmacological treatments. This discussion should include an exploration of non-pharmacological options for managing ADHD such as improving lifestyle through diet changes and increased exercise. Furthermore, it is recommended that psychological interventions such as Cognitive Behavioural Therapy (CBT) are considered alongside or prior to the commencement of medication.

One approach to managing ADHD is using behaviour therapy to address specific behaviours through offering more structure in the home or school environment, establishing predictability and routine, reinforcement of positive behaviour and being consistent with approaches used (Moore *et al.,* 2015). A cost analysis in the USA concluded initiating treatment with low-intensity behaviour modification had superior outcomes to the initial commencement of medication and this option is more cost effective for CYP with ADHD (Page *et al*., 2016), although the details about what the behaviour modification inventions entailed are unclear. School-based interventions are one alternative to medication and their efficacy has been explored in several systematic reviews (Moore *et al.,* 2015). However, it is recognised that contextual issues such as relationships between CYP with ADHD and their teachers and peers and attributions about the aetiology of ADHD may have some influence on the effectiveness of these interventions.

Timimi (2017) suggests developing and improving relationships should form part of intervention for CYP with ADHD. He recognises the significance of relationships between families as playing an important role in the development of ADHD behaviours and suggests intervention should target these. The Relational Awareness Programme (RAP) utilises systemic and family therapy techniques, delivered through parent workshops, to prioritise building relationships. The rationale for this is that placing too much emphasis on behaviour control can cause further damage to relationships by focusing on wrongs. By building strong foundations for relationships with a focus on positives, different emotions can be valued and the scripts of a CYP being a challenging 'troublemaker' can be challenged. The programme offers follow up support to parents and carers online and whilst there has been no study yet conducted with a comparative control group, those who have adopted this approach have spoken favourably of it reporting a positive shift in attitude towards their child.

Whilst a systemic, family therapeutic approach offers one alternative to a pharmacological approach to intervention for ADHD, Timimi (2017) highlights the importance of drawing from a variety of approaches to intervention rather than adopting one specific approach for all. It could be suggested that a holistic assessment of the CYP's needs should first be undertaken to develop a clear rationale for adopting one approach over another.

2.2.7 My position

For the purpose of this research, ADHD is understood to be a social label applied to describe a set of behaviours an individual may present with which includes inattention, hyperactivity and impulsivity. I am interested in exploring the perceptions of ADHD as described by the CYP who took part in the present research and what the meaning of the label held for them.

My conceptualisation of ADHD has been shaped by both personal and professional experience linked to my interest in researching this topic. Growing up with a younger brother with ADHD, I understood the medical definition (APA, 2013) and believed there to be something different with the chemicals and structure of my brother's brain when compared with mine. This was reinforced as he was prescribed medication to 'control' his behaviours. Through my experience as a teacher, when CYP with ADHD took medication, I witnessed the difference in their behaviour and therefore their ability to concentrate and learn.

When I began my professional training my perspective began to shift. I became more aware of the need to evaluate each individual's unique set of circumstances and see behaviours as a result of a combination of biopsychosocial influences, particularly in the learning environment of school. I have become more aware of the complex interactions between 'systems' of development (Bronfenbrenner, 2001) and therefore how a unilateral approach to supporting a CYP with ADHD, such as medication, is unlikely to be affective. Throughout my training I have also

actively engaged with the debate about the validity of an ADHD diagnosis. Albeit, I have witnessed both positive and negative effects of being ascribed a label. In my personal experience, the label provided my parents with an explanation for the difference in behaviours between my brother and myself and helped them to access support for him in school.

Throughout the research for this thesis and once I had adopted my chosen methodology, my assumptions about ADHD were further challenged. In line with my epistemological beliefs, I came to understand ADHD as a social construct whereby the diagnosis is given to describe behaviours that do not meet prescribed social norms (Timimi and Redcliffe, 2005). However, that is not to say that ADHD is not real to individuals and their families, but more that each individual will come to make their own sense of the diagnosis. For this research, I attempted to bracket my own journey of understanding and experiences (see Section 3.4.4 for further explanation of 'bracketing' in IPA) and simply represent in my findings each participant's own sense making of the diagnosis and what this holds for them.

2.2.8 The consequences of ADHD

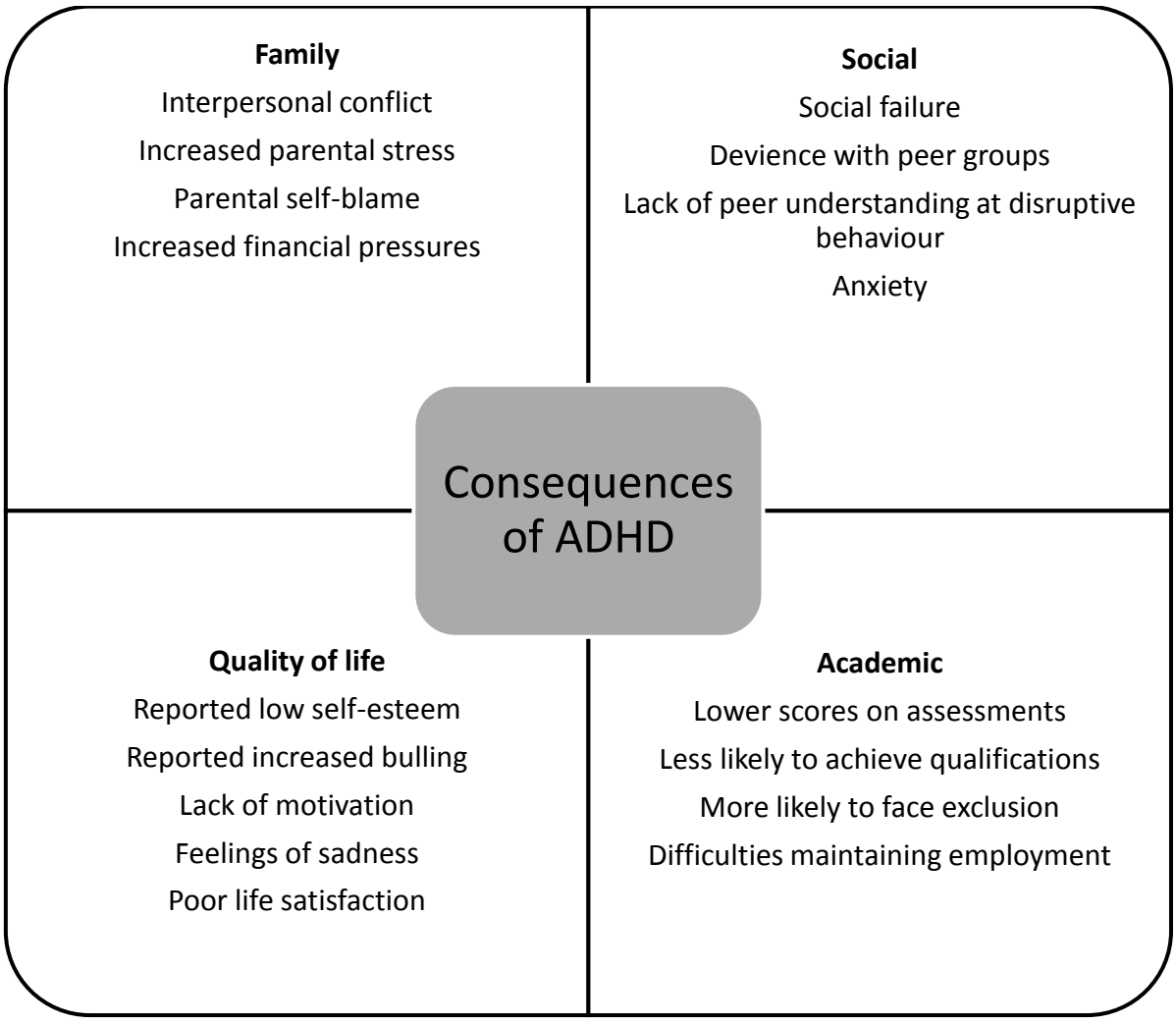
The consequences of behaviours associated with ADHD for children, their families and society can be serious; they can influence multiple aspects of a child's life including family relationships, academic performance, social skills and self-esteem (Salmeron, 2009), see Figure 1. It has been found a diagnosis of ADHD is correlated with a reduction in quality of life including lower health, subjective well-

being, less sleep and increased bullying when compared to control participants (Peasgood *et al.*, 2016). When comorbid with externalising behaviours such as aggression and defiance, additional stress may be placed on family members (Podolski and Nigg, 2001). Parents may feel further stress due to stigmatising beliefs that ADHD behaviours are purely a result of poor parenting (Burston, 2005).

There is some debate as to whether CYP outgrow ADHD. It is believed that up to 60% of CYP with ADHD continue to have significant needs into adulthood (Weiss, Hechtman and Weiss, 1999). Common issues which affect those with ADHD into adolescence and adulthood include failure to complete academic studies, risk of developing substance disorder, social isolation and involvement with deviant peer groups (Marshal, Molina and Pehlam, 2003).

To summarise, despite an absence of a clear and accepted definition of ADHD there are several behaviours which are associated with the diagnosis which influence a CYP's experience of the education system, social and familial relationships and experiences within the community. The impacts of ADHD behaviours have been reported from perspectives of parents, teachers and CYP themselves but little is known about the perceptions of siblings.

Figure 1: An overview of the consequences of ADHD for a child or young person. This figure was comprised from several research studies (Johnston and Mash, 2001; Salmeron, 2009; Birchwood and Daley, 2010; Hamed, Kauer and Stevens, 2015)



2.3 Sibling relationships

Sibling relationships hold great significance as they are likely the longest lasting relationship many individuals will experience. A growing body of research highlights the developmental significance of sibling relationships over a lifespan (Feinberg, Solmeyer and McHale, 2012) and how sibling relationships can vary significantly. In 1985, CYP's perceptions of their sibling relationships were recorded using interviews and questionnaire data. It was concluded, due to the mixture of both positive and negative aspects of sibling relationships, there are a multitude of dimensions by which a sibling relationship can vary (Furman and Buhrmester, 1985). Broadly speaking, sibling relationships may be defined as being close or distant, harmonious or conflicted, competitive or co-operative.

Siblings serve a variety of roles to each other i.e: teachers, competitors, confidantes, role models, emotional support (Furman and Buhrmester, 1985; Branje *et al.,* 2004). Through interacting with siblings, individuals learn positive and negative ways of relating to others, thus influencing their socialisation over the course of their lifetime (Cicirelli, 1995). Sibling relationships are thought to make a significant contribution to the development of social competence, understanding and empathy, identity development, conflict resolution and psychological adjustment (Pike, Coldwell and Dunn, 2005; Kramer, 2010; Feinberg, Solmeyer and McHale 2012). For example, daily contact coupled with emotional intensity helps young children to develop their social understanding (Dunn, 1998). Sibling relationships are likely to span multiple generations and the nature and dynamic of the relationship may fluctuate over time (Dunn, 1998).

2.3.1 Features of sibling relationships

There are several contextual factors thought to affect the nature of a sibling relationship related to family composition. Birth order and age difference, gender, parent relationship status, family stressors, family size and having a sibling with an additional need all have the potential to play a role in influencing sibling relationships (Mehok, 2017). A natural hierarchy may be created whereby older siblings are likely to provide advice, act as role models and provide care for their younger siblings (Tucker, McHale and Crouter, 2001). However, factors such as birth order, gender and number of siblings within the family confound research in the field of sibling relationships and to obtain rich, detailed data on siblings, longitudinal studies are needed which are time consuming and challenging to recruit to (Howe and Recchia, 2014).

Sibling conflict is a natural feature of sibling relationships. Research suggests sibling conflict can occur as frequently as eight times an hour (Dunn and Munn, 1985) and aggression between siblings is common (Button and Gealt, 2009). It is, however, thought this conflict can help support children's development of social and emotional competencies and opportunities to develop skills to aid conflict management (Kramer, 2010). Perceived differential treatment from parents is thought to trigger conflict between siblings. Parents' behaviour towards their children is interpreted in a way which lets them know how much they are valued

by their parents (Brody, 2004). If children believe they are being treated differently, this can lead to negativity in the sibling relationship and may lead to increased sibling rivalry. Other factors such as reduced family cohesion, parental conflict and siblings' temperament may also contribute to sibling conflict (Brody, Stoneman and McCoy, 1994). Overall though, it is not thought that moderate quantities of sibling conflict are damaging to a sibling relationship, particularly when there is a good balance with sibling warmth and closeness. This interaction between warmth and conflict may contribute to overall sibling relationship quality and individual's psychological well-being.

Close sibling relationships provide an opportunity for developing skills required for making and maintaining peer and romantic relationships. A well-researched positive dimension of sibling relationships is warmth and closeness. This is characterised by affection, acceptance, support and intimacy, particularly when there are shared qualities across siblings (Stocker, Lanthier and Furman, 1997). When there is reported warmth in a relationship, siblings show increased levels of psychological well-being, high social competency and lower levels of psychopathology (Kim *et al.,* 2007). Individuals will experience their sibling relationships differently over their development but a warm sibling relationship can be an important source of support (Van Volkom, Machiz and Reich, 2011) and is often associated with more prosocial behaviours (Pike, Coldwell and Dunn, 2005). There are thought to be processes of social learning that take place such as modelling and reinforcement which may link sibling relationship quality with peer competence (Kim *et al.,* 2007). For example, CYP may develop positive

expectations about relationships through warm relationships with their siblings which in turn may lead them to approach their peers more positively. The nature of this mechanism could be bidirectional and it is hypothesised that social competence could underpin a good sibling relationship (Steiner, 2014). Overall, researchers have agreed there is potential for sibling relationships to impact on our personality, identity and influence our future relationships (Edwards *et al.,* 2006; Siegal and Silverstein, 1994).

2.4 Siblings with additional needs

Based on existing research, psychological effects of having a sister or brother with a disability fall on a continuum of both positive and negative outcomes (Powell and Gallagher, 1993). Many studies report the influence of having a sibling with additional needs according to an individual's psychological functioning. This can be defined as their ability to achieve their goals, within themselves and their environment, including their emotional regulation, behaviour, social skills and mental health. In the literature summarised below, psychological functioning is typically measured using self-report questionnaire tools for participants to rate their emotional symptoms and behaviour adjustments. Relatively little research has adopted a qualitative approach to ask siblings to explain their experiences in their own words (Kendall, 1999; Petalas *et al.*, 2009; Day, 2016; Mehok, 2017).

A meta-analysis conducted in 2002, reviewed 51 studies looking at the psychological impact of having a sibling with a chronic illness. Overall, there was a

significant negative impact particularly on psychological functioning, peer activities and cognitive development (Sharpe and Rossiter, 2002). In 2012, these findings were repeated with a small but significant effect on psychological functioning (Vermaes, van Susante and van Bakel, 2012). Participants reported more internalising difficulties, appeared less resilient and had less positive self-attributes than controls. However, mixed findings were reported, some studies indicated that growing up with a sibling with a chronic illness could also have beneficial effects (Houtzager *et al.,* 2004).

Research literature suggests having a sibling with a disability can place a CYP at greater risk of developing depression or anxiety (Barker, 2011). For example, in comparison with peers who have typically developing siblings, higher rates of depression and generalised anxiety are reported (McHale and Gamble, 1989; Rodrigue, Geffken and Morgan, 1993) and often reach clinical levels (Fisman *et al.,* 2000). Studies also report siblings can be vulnerable to guilt, aggression, confusion and isolation (Hartling *et al*., 2010).

Some research has attempted to identify specific factors which may make a sibling more vulnerable or protected against negative effects. A child's position within their family system may influence how significantly their sibling's additional needs impacts them (Barker, 2011). For example, being the eldest female sibling in a family where a younger sibling has additional needs can place a sister at higher risk of being adversely affected (Stoneman *et al*., 1998). In contrast, Cuskelly and Gunn (2003) found that caretaking for a sibling with Down Syndrome

(DS) occurred regardless of birth order but may be more significantly affected by gender, with girls more likely to take a caretaking role into later adulthood (Seltzer *et al.,* 2005). Levels of increased responsibility and caretaking have been found to be positively correlated with increased stress, greater sibling conflict and fewer positive interactions than control peers (Stoneman *et al.,* 1998). Family size is thought to be positively associated with the psychological functioning of siblings. Larger families provide more frequent opportunities for skill development as well as affording additional siblings without additional needs to practice interpersonal skills and share responsibilities with (Downey and Condron, 2004).

A CYP's response to having a sibling with any form of additional need is likely influenced by their parents' reactions to dealing with the needs. Variation in this response may be dependent upon the age of diagnosis, severity of need and the amount of support received from family and friends. Parents should try to consider the needs of other children by providing enough information for them to understand their sibling's needs, helping them to understand the diagnosis and what it means for them and their sibling.

In some areas of functioning, no differences have been found between siblings of CYP who have a disability and those without (Kaminsky and Dewey, 2002). Moreover, studies have identified positive effects of having a sibling with needs such as DS and cancer, for example increased maturity, empathy for others and their needs (Cuskelly and Gunn, 1993; Sloper, 2000), greater satisfaction with their sibling relationship (Rivers and Stoneman, 2003) and greater co-operative

behaviour (Mandleco *et al.*, 2003). In a three-year longitudinal study, Fisman and colleagues found that participants had increased warmth and understanding towards their sibling with DS (Fisman *et al.,* 2000). When CYP were asked about their experiences of having a sibling with Autism Spectrum Disorder (ASD), most spoke of a number of positive aspects of their experience including having fun with their sibling, feeling proud of them and being impressed by their sibling's achievements (Petalas *et al.*, 2009).

A key difference between research conducted with children who have a physical disability or chronic illness and those with mental health needs is the visibility of the condition. Moyson and Roeyers (2011) found the invisibility of ASD caused siblings and peers to struggle to understand the diagnosis and even doubt the presence of any differences. They concluded learning and developmental disabilities which did not require a physical aid such as a wheelchair, were treated with more prejudice and ignorance. This can leave siblings with feelings of internal conflict regarding their interactions with their own peers, leading to hesitation at explaining their sibling's diagnosis for fear of rejection (Petalas *et al.*, 2012).

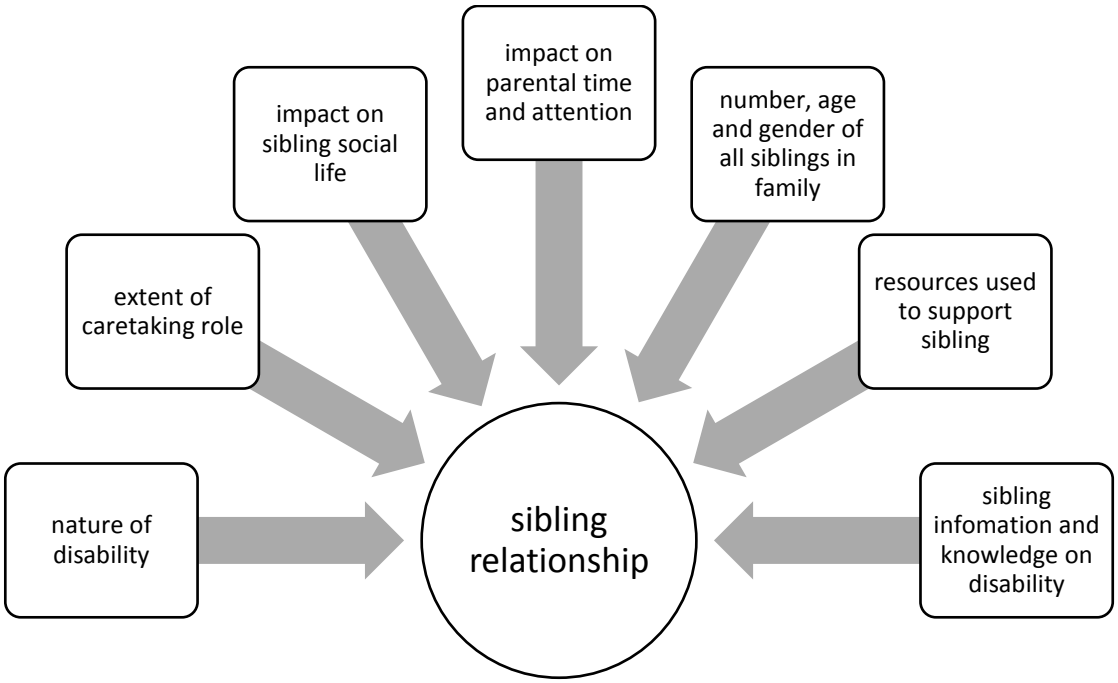
The extent to which a sibling can provide cognitive and affective empathy in a sibling relationship can determine the degree of conflict and closeness of the relationship (Shortt and Gottman, 1997). Empathy enables people to feel supported, cared for and listened to and if an individual can provide this for their sibling with an additional need; this may act as a protective factor against a variety of negative feedback they may experience in other contexts

2.4.1 Relationships

Factors which influence typically developing sibling relationship can also affect those with additional needs. For example, as previously mentioned: birth order, sibling age, gender and family socio-economic status (Tomeny, Barry and Bader, 2014). In addition, the nature and severity and visibility of the need, coupled with the individual's understanding of it, can influence the likelihood of the sibling's relationship being affected (Steiner, 2014).

Siblings of CYP with ASD describe their sibling relationships with more adversity than success. Negative relationships were predominantly associated with the disruption to their daily lives, differences in parental expectations, worries for the future and feelings of loss at a 'typical' sibling relationship (Petalas *et al*., 2012). Participants reported aggressive behaviours from their sibling and unpredictable outbursts affected the time they spent as a family together and had a negative impact on enjoyment of recreational activities (Petalas *et al.,* 2009). Fractious and resentful relationships have also been reported in siblings of CYP with a diagnosis of DS (Nielsen *et al.,* 2010). It should be noted there appear to be fewer empirical research studies investigating the positive factors associated with having a sibling with a chronical illness, disability or additional need. Figure 2 illustrates a range of factors which may influence a sibling relationship in the presence of an additional need, assimilated from the literature cited above.

Figure 2: Figure depicting factors which can influence a sibling relationship where a sibling has a disability or additional needs



2.4.2 Influence on identity

Forming self-identity is crucial for all individuals and is considered a lifelong process. Erikson proposed identity development occurs during adolescence (Erikson, 1968) when young people explore the roles they play to discover who they are. This in turn helps them to form an identity. Although research literature does not tend to focus on this area, the importance of having a sibling with additional needs on identity formation is mentioned. However, the term identity tends to be used diffusely and it is not the focus of the research, typically mentioned alongside exploration of the caretaking role. Findings from an unpublished thesis conducted with siblings of CYP with ASD in America suggest

an individual's identity may be largely shaped and defined by their experiences with their diagnosed sibling (Dumke, 2015). Through further understanding experiences of CYP with a sibling with ADHD, it may be possible to ascertain whether their identity may be affected.

2.5 Siblings of children and young people with ADHD

My own experience of having a brother with ADHD has undoubtedly shaped my development, in particular my interest in supporting others with additional needs. My relationship with my brother was characterised with both conflict and warmth and I have always had enormous empathy and respect for the way in which he faced challenges, particularly at school. I was very interested to read literature around this area to understand whether other siblings had the same experience as myself, as on reflection, I do not feel I was afforded many opportunities to share my experiences with others as a child.

Family members of CYP with ADHD experience life differently to those with family members who do not have ADHD. Having a brother or sister with ADHD is reported to impact on siblings' psychological well-being and quality of life. However, each experience is individual depending on a variety of family and environmental factors. It has been suggested children's relationships with their siblings who have ADHD can be characterised by disruption and conflict (Barkley, 2014). One study has shown the most significantly negative and high in conflict

relationships occur between siblings who are highly active, a temperament often found in CYP with ADHD (Stoneman and Brody, 1993).

This section reviews seven studies, qualitative (n=2) and quantitative (n=5) exploring the impact of living with a sibling with ADHD. First, scoping searches were performed to identify literature on the impact of having a sibling with additional needs including physical and mental health needs. At this point, there were numerous articles available, therefore the focus of the review was narrowed to siblings of CYP with ADHD.

Studies were identified during a systematic search of databases; EBSCO, Scopus, and Google Scholar in 2017 and 2018. Reference lists of retrieved articles were also examined although they failed to yield any additional papers. The search terms ‘sibling$’, ‘ADHD’ and ‘attention deficit hyperactivity disorder’ were used. Seven articles met the following parameters:

- Peer reviewed journal articles
- Studies conducted between 1995-2018
- A focus on lived experiences or quality of life
- Participants with a diagnosis of ADHD
- Written in English

The review of literature was limited to CYP’s experiences during early and middle childhood although one paper focused on adults' recollections of their experiences

during this period of their life. Studies were excluded if they focused purely on sibling research to explore the genetic links and risk factors for other disorders/conditions or comorbidities. The majority of the studies were conducted in the USA. Studies were also completed in the UK, Switzerland and South Africa. The research design and methodological approach varied (questionnaire data, grounded theory, thematic analysis) but several shared experiences can be summarised from the data.

Following identification and reading of the papers, the aim was to identify any natural groupings in the data which could be used to form conclusions about participants' experiences. This synthesis procedure was conducted using a top-down approach. Key findings from each paper can be found in Table 1. After completing familiarisation with the data, key findings were noted and keywords were then identified across all papers to group the findings. Two key areas were grouped across both the qualitative and quantitative research: emotional needs and conflict and disruption. Due to the limitations of using questionnaire data to evaluate life experiences in the home, two additional areas were identified from the two qualitative papers (Kendall, 1999; King, Alexander and Seabi, 2016): caretaking and coping strategies. Each of these themes is explored in turn in the next section.

Table 1: Table of papers included in review of literature

Study design	Authors	Country	Methods/measures	Participants	Findings
Qualitative	Kendall (1999)	USA	Grounded Theory Three-year study Constant comparison method	13 sibs Younger (n=8) Older (n=5) Boys (n=7) Girls (n=6)	Core categories: • Victimisation – subject to aggressive acts of violence, verbal aggression, manipulation and control, parents minimisation of these acts • Caretaking role – befriending, playing with and supervising, not a role with pride, induced worry • Sorrow and loss – yearning for peace and quiet, feeling overlooked and ignored (invisible), wanting family to be 'normal' Coping strategies: retaliation, accommodation, avoidance
	King, Alexander and Seabi (2016)	South Africa	Thematic analysis Semi structured interviews	8 sibs Female (n=8) Mean age 20	Themes: • Differential parental treatment – attention and inconsistent discipline at home • Rejection – from parents • Discipline discrepancy – ADHD diagnosis allowed excuse for behaviour

Study design	Authors	Country	Methods/measures	Participants	Findings
					• Parentified child – expectations of caretaking role; giving medication, helping with homework
Quantitative	Jones, Welsh, Glassmire and Tavegia (2006)	USA	Children's Depression Inventory Paediatric Anger Scale (Trait scale: frequency of emotion, State scale: intensity of emotion at that time) Paediatric Anxiety Scale (as above) Children self-report on the above measures	45 sibs 46 control Aged 9-13	• Children with siblings with ADHD had higher levels of Trait Anger compared with controls • No significant differences on Stage anger, anxiety, curiosity, depression or Trait anxiety, curiosity or depression Limitations: • Children completed questionnaires at home • No parent ratings included • Non-independence in data where multiple siblings from one family used • No severity rating of ADHD

Study design	Authors	Country	Methods/measures	Participants	Findings
	Listug-Lunde, Zevenbergen and Petros (2008)	USA	Children's Depression Inventory (child self-report) Multidimensional Anxiety Scale for Children (child self-report) Child Behaviour Checklist (parent report) Disruptive Behaviour Rating Scale (parent report)	41 sibs 30 control Aged 9-14	Siblings of CYP with *high levels of* ADHD *symptomology (*representing 56% of pps) reported: • Poorer internalising • Hyperactivity and inattention difficulties • No significant difference in externalising problems • No significant difference in anxiety or depression Limitations • Parent reports of both sibling with ADHD and participant – may have over or reduced externalising difficulties during comparison between children
	Mikami and Pfiffner (2008)	USA	Sibling Relationship Quality-Brief Version (mother, sibling and participant reports)	77 sibs 14 control Aged 5-11	Siblings of CYP with ADHD show: • Greater sibling relationship problems • Inhibition and self-regulation problems when interacting with peers • High conflict between siblings

Study design	Authors	Country	Methods/measures	Participants	Findings
			Child Symptom Inventory (for externalising problems – mother reports) Child Depression Inventory (child self-report)		• Age of sibling, birth order and gender match can affect sibling relationship quality Limitations: • Relied on self-report data, did not use observational reports • Small control sample
	Steinhausen *et al.,* (2012)	Switzerland	Connors Parent Rating Scale Connors Teacher Rating Scale Strengths and Difficulties Questionnaire (parent and teacher report) Child Behaviour	32 sibs 35 sibs (without ADHD) 36 control Aged 5-17	Siblings of CYP with ADHD show: • Higher anxious/shy behaviour • Increased perfectionism • Increased emotional lability • More emotional problems Limitations: • Overrepresentation of girls in ADHD population (predominantly inattentive rather than hyperactive subtype) – therefore could have affected results • Overrepresentation of girls as siblings, does this account for more emotional

Study design	Authors	Country	Methods/measures	Participants	Findings
			Checklist		problems?
	Peasgood *et al.,* (2016)	United Kingdom	Large cross-section, observational study Child health utility-9D (child self-report) Euro-Quality of Life-5D-Youth (child self-report) Life Satisfaction Bullying Sleep (parent report) SDQ (parent report)	392 sibs 136 control Aged 6-18	Siblings of CYP with ADHD show: • No differences on health related quality of life including physical and emotional health • Lower overall happiness with life • Greater dissatisfaction with family • Increased risk of bullying, name calling and taking of belongings by their siblings • Unmet needs in overall happiness and wellbeing Limitations: • Cannot be sure of causality • Did not include those being treated for ADHD • Self-selected sample

2.5.1 Emotional needs

The literature reviewed suggests overall; CYP who have a sibling with ADHD experience emotions which affect their overall happiness and satisfaction with life (Peasgood *et al.*, 2016). In this study, it was found siblings were as unhappy with their lives as their sibling with ADHD, suggesting they both had unmet needs in terms of their well-being. Compared with control participants, CYP with a sibling with ADHD showed higher rates of anxious and shy behaviour (Steinhausen *et al.*, 2012) and increased frequency of anger (Jones *et al.*, 2006). There are several possible explanations for these findings. Kendall (1999) found siblings described feeling anxious, worried and sad and described their family life as chaotic and exhausting. Siblings expressed that these feelings arose from a desire to have what they couldn't – a '*normal*' family life (p.9). There were numerous examples where participants described how they felt worried about their sibling's potential to 'ruin' their day or cause a change to plans (Kendall, 1999). They also described feeling invisible, being overlook and ignored within their family, as their sibling with ADHD drew focus the majority of the time. Parents were reported to frequently minimise their worry and emotions, due the insignificance of their needs in relation to their sibling's. It is possible CYP with a sibling with ADHD experience higher anxiety and more sadness due to the feelings of rejection from their parents (King, Alexander and Seabi, 2016). Feelings of worry could also be triggered by concern for their sibling.

In contrast to the above findings, with the exception of trait anger, no significant differences were found between other emotional needs, anxiety or depression from control participants (Jones *et al.*, 2006; Listug-Lunde, Zevenbergen and Petros, 2008). Of note, the sibling's parents reported more differences with internalising symptoms with their children than control parents (Listug-Lunde, Zevenbergen and Petros, 2008) and teachers reported fewer behavioural differences than parents (Steinhausen *et al.*, 2012). This finding was inconsistent with the siblings' own self-report, highlighting the dangers of using parent report data to draw conclusions about their children's psychological functioning. It is possible CYP's feelings of frustration, worry and sadness did not translate into self-reported symptoms as measured by the indexes used in the above studies. Furthermore, parents in these studies were asked to rate both their children's scores, therefore they may have deflated the sibling's needs when making comparisons to their child with ADHD.

2.5.2 Conflict and disruption

The research suggests CYP who have a sibling with ADHD experience high conflict within their sibling relationships (Kendall, 1999; Mikami and Pfiffner, 2008). The risk of conflict is increased if the CYP with ADHD has a high level of externalising difficulties (Mikami and Pfiffner, 2008). The finding is replicated in studies which report increased conflict between peers and parents for CYP who have ADHD (Firmin and Phillips, 2009). This may be due to the child's difficulties with social understanding and impulsive tendencies (Carpenter Rich *et al.*, 2009)

or limited understanding of CYP's needs from their peers and siblings who may find it difficult to understand the differences between themselves and the affected CYP.

Conflict between a CYP and their sibling with ADHD may present through both physical and verbal acts of aggression (Kendall, 1999). In this study, physical aggression was more likely to occur between two boys and the age of child or birth order did not affect aggression levels (Kendall, 1999). It was further reported CYP with ADHD and their siblings experienced increased levels of bullying from their peers when compared with control participants (Mikami and Pfiffner, 2008). CYP with a sibling with ADHD experienced further bulling from their sibling, being exposed to name calling and having their possessions destroyed or taken from them. Sibling bullying has been reported to be predictive of depression and anxiety (Bowes *et al.,* 2014). Some participants engaged in retaliatory aggression towards their sibling in order to defend themselves (Kendall, 1999). It is possible this is linked to the higher levels of anger which siblings hold as a result of their experiences (Jones *et al.*, 2006). If a family is experiencing a high level of conflict, this would likely increase the wide range of heightened emotions family members may be likely to feel.

Another finding from the research was the differential parental treatment participants felt they experienced (Kendall, 1999; Mikami and Pfiffner, 2008; King, Alexander and Seabi, 2016). This could manifest as parents minimising acts of aggression and violence from their sibling with ADHD (Kendall, 1999). In addition,

a key concern expressed by siblings was their sibling with ADHD would receive fewer consequences for bad behaviour (King, Alexander and Seabi, 2016). Parents would make excuses for the behaviour and this would in turn cause the participant to feel angry or frustrated. A consequence of differential parental attention and treatment can be poorer sibling adjustment and relationships (Jensen *et al.*, 2013) and the child's perception of differential treatment may have a significant effect itself (Coldwell, Pike and Dunn, 2008).

2.5.3 Caretaking

Participants in both qualitative studies spoke of the daily expectation they would take on a role of responsibility or care within their family system (Kendall, 1999; King, Alexander and Seabi, 2016). Amongst these caretaking activities, participants were expected to play with and supervise their siblings at home. This included giving their siblings medication and helping them with their homework (King, Alexander and Seabi, 2016). The CYP's role could also be extended to school where they may be expected to organise lunch money, befriend and supervise their sibling on the playground, talk with their sibling's teachers, cover up from their sibling's misbehaviour and preventing them from acting on impulse (Kendall, 1999). Participants spoke across both studies how this proxy parenting role was expected of them by their parents and in some cases this would lead to resentment towards their sibling. This expectation did not differ according to position of the child within the family, however the participants who were younger than their siblings with ADHD appeared to view this role more positively, as it gave

them a specific role within their family (Kendall, 1999). This reflects research with CYP with siblings with DS, where individuals are expected to provide care for their brother or sister regardless of their age or position in the family (Cuskelly and Gunn, 2003).

2.5.4 Coping strategies

Only one study reported the ways in which siblings manage their relationships with their siblings, in light of the difficulties they experience. It is likely this did not arise in the other studies as there is no valid assessment to measure coping strategies and King and colleagues study had a more specific focus on the role of parents. Kendall (1999) recruited 11 families which included thirteen siblings of CYP with ADHD and twelve boys with ADHD. Eleven biological mothers, five biological fathers and two step-fathers took part. Participants were interviewed and wrote in a diary a least once a week for eight weeks. Kendall (1999) concluded siblings managed the reported disruption associated with having a sibling with ADHD in three ways: retaliation, accommodation and avoidance. Ten siblings declared they had become resigned to their situation and therefore developed strategies to avoid or accommodate their brother. For example one sibling stated,

> *"I just stay out of his way..." (Kendall, 1999, p.10).*

Another explained,

> *"I only talk to him about what he wants to talk about and that way he won't get mad at me." (Kendall, 1999, p.10).*

This helps to build a picture that overall, CYP can be significantly affected by their sibling's needs and appear to lack strategies to support them which do not make further impact on their life. CYP with siblings with ASD also discuss coping strategies they employ to cope with their frustration at their sibling's challenging behaviours and highlight the importance of having a key person to speak to at times of high emotion (Mehok, 2017).

2.5.5 Limitations of previous research

As with much of the research with siblings, conclusions have been drawn about sibling relationships and the impact of having a sibling with additional needs from self-report, quantitative measures. There are fewer research studies which account for individuals' experiences. Methodological concerns can be noted in the sibling research using a quantitative methodology. First, in many research designs parent reports dominate the findings and siblings are rarely asked about their own experiences. Parents can over/under estimate their child's distress therefore it can be unwise to rely solely on parental reports (De Los Reyes *et al.*, 2013). When siblings are asked about their experiences, they are frequently asked to complete quantitative self-report measures. Alderfer and colleagues (2009) highlighted a discrepancy in the findings of qualitative and quantitative studies looking at psychosocial adjustment in siblings of children with cancer. Whilst quantitative studies indicate healthy functioning for siblings of CYP with cancer, the qualitative studies point to psychological adjustment different from peers who do not have a sibling with cancer. Therefore, quantitative studies may not assess the relevant

constructs to siblings' experiences. De Los Reyes and Kazdin (2005) warn there is no 'gold standard' for the accurate reporting of emotions which are internalised such as anxiety however, due to the subjective nature of these emotions, the child is in the best position to provide this information. Quantitative studies suggest mixed findings for psychological functioning for CYP with siblings with ADHD and this may be due to methodological limitations(Jones *et al.*, 2006; Listug-Lunde, Zevenbergen and Petros, 2008; Mikami and Pfiffner, 2008; Peasgood *et al.*, 2016). These studies also fail to provide opportunity for participants to share positive experiences of their lives and sibling relationship. Petalas *et al.,* (2009) found siblings of CYP with ASD were keen to share positives when interviewed about their sibling experience.

The findings from this review of literature on siblings of CYP with ADHD indicate there is a paucity of research on this topic, particularly in the UK. Five studies relied on objective, self-report questionnaire measures to describe a set of behaviours and emotions, with limited explanations for the findings. Data were collected at one point in time and therefore are unlikely to represent the fluctuations over time in family relationships. Within the quantitative studies, with the exception of Peasgood and colleagues, sample sizes were small therefore conclusions about psychological functioning in siblings of CYP with ADHD should be drawn with caution. Only two studies offered an in-depth analysis of CYP's experiences using a qualitative methodology. King, Alexander and Seabi, (2016) interviewed adults and therefore formed conclusions about their participant's experiences from their recollections of their early experiences, their memories

may have become subject to bias over time. Furthermore, they only interviewed female participants who may have viewed their role in the family system differently to male counterparts. Kendall (1999) recruited siblings of male CYP with ADHD. These CYP's experiences with their brothers may have been different to that of sisters. Kendall (1999) used grounded theory and collected data over a three-year period. Whilst there is strength in collating views over time, grounded theory fails to recognise the researcher as embedded in the research process and does not account for their agency in managing and interpreting the data.

2.6 Chapter summary

ADHD is a label frequently applied to CYP displaying behaviours characterised by inattention, hyperactivity and impulsivity. This set of behaviours can have negative consequences for the individual and their families, including their sibling. Sibling relationships are individual and can be influenced by a multitude of factors such as birth order, gender, family stressors and having a sibling with an additional need. Siblings of children with additional needs such as a chronic illness, developmental disorder or mental health condition are at risk of having a negative experience with the sibling relationship and may be characterised by high conflict. This can impact on their own psychological functioning and identity development although research findings are currently mixed in this area.

Research indicates CYP are at risk of experiencing several negative consequences from having a sibling in the family with ADHD. However, there is a

paucity of research exploring this area. Overall, accounts from siblings suggest they can feel victimised, experience conflict within the family system, undertake caring roles and may be at increased risk of emotional problems such as anxiety. It is therefore suggested it is important for more research to take place to further explore these negative consequences and establish whether there are any positive experiences for CYP.

To date, no published research has examined siblings' perspectives of living with a brother or sister with ADHD in the UK. There may be cultural differences in terms of parenting style, family systems and expectations and school experiences between the UK, America and South Africa therefore the findings from previous research may not apply to CYP in the UK. For example, King and colleagues (2016) point out parental roles are more frequently assigned to siblings with South Africa due to a loss of parent to AIDS.

Following consideration of the methodological limitations of previous research and synthesis of the findings, it was determined this study should adopt a methodological approach which would allow participants to share both positive and negative experience, explain what ADHD means to them and provide a description of their sibling relationship. Due to my own personal experience of having a brother with ADHD, it was important that the approach adopted allowed for my experience to be accounted for in the data collection and analysis process. Thus, an IPA methodology was selected as most appropriate to support this research meet the aims.

The aim of this study is to understand more about siblings' experiences by addressing the following research questions:

- 'How do participants describe the characteristics associated with their siblings' ADHD?'
- 'What is it like growing up with a sibling with ADHD?'
- 'How do children and young people with a sibling with ADHD experience their sibling relationship?'
- 'How do participants describe the positive characteristics of their sibling?'

CHAPTER THREE: METHODOLOGY

3 Method and methodology

3.1 Chapter overview

It is important to distinguish between method and methodology; Silverman (1993) identifies the difference as the former referring to a specific research technique such as interview or focus group and the latter concerned with the overall approach to studying a research topic. A methodological approach encompasses a researcher's philosophical approach which will be discussed in this chapter. The approach I have chosen for this research is Interpretative Phenomenological Analysis.

This chapter will provide a rationale for my choice and position of: ontology, epistemology, methodology and methods as well as addressing the aims and research questions.

3.2 Research questions

It is my aim throughout this research to develop a clear understanding of experiences of CYP who have a sibling with ADHD. As part of this, I aim to build a picture of how CYP conceptualise their sibling's ADHD and what they believe the key associated behaviours are. In addition, I aim to understand how participants

experience their sibling relationship. Overall, I look to see if any of the participants have a shared meaning across their experiences. To do this, a case study design frame was adopted. *"A case study involves in-depth research into one case or a small set of cases"* (Thomas, 2009, p. 115). By using a small number of participants, the purpose was to obtain a rich and detailed understanding through examining the data in depth.

To meet the aims, the following research questions are addressed:

- 'How do participants describe the characteristics associated with their siblings' ADHD?'
- 'What is it like growing up with a sibling with ADHD?'
- 'How do children and young people with a sibling with ADHD experience their sibling relationship?'
- 'How do participants describe the positive characteristics of their sibling?'

3.3 Methodology

It is generally accepted researchers conduct their work within a research paradigm which reflects their ontological and epistemological viewpoint (Denzin and Lincoln, 2008). Primarily, a researcher must decide if their work is going to be qualitative or quantitative. Qualitative research provides naturalistic descriptions or interpretations of phenomena and the meanings held by participants (Langdridge, 2007). In contrast to this, quantitative research is concerned with measuring some aspect of a phenomenon to make generalisations about the data (Cohen, Manion

and Morrison, 2011). A qualitative approach was selected for this study as it is concerned with how CYP with a sibling with ADHD make sense of their experiences, a phenomenon which cannot be measured. The CYP's subjective experiences were of primary interest therefore the focus was to obtain a rich description from participants.

In all research, inquiry is approached from two key philosophical positions. They are the researcher's ontological and epistemological positions which are closely related and underpin the design and strategy they implement (Willig, 2013).

3.3.1 Ontology

Ontology is concerned with being, what exists, what we think exists and refers to the study of reality (Cohen, Manion and Morrison, 2011). Ontological positions can range from relativist to realist (Willig, 2013). In realism, it is understood reality exists separately from our representations of it and would continue to exist regardless of our consideration of it. In contrast, relativism asserts there are many interpretations of reality in existence and therefore they cannot exist independently of language and thought (Cohen, Manion and Morrison, 2011). Therefore, multiple realities can be constructed differently by individuals.

It is posited ontological beliefs cannot be separated from epistemological beliefs (Crotty, 1998), these are discussed below.

3.3.2 Epistemology

Epistemology asks what knowledge is, how we know what we know and how we can be sure of it. It is considered knowledge is subjective and we can only know about the world based on our own perspectives (Carson *et al.* ,2001). Epistemology can be broadly defined as subjectivism, linked to a relativist ontology, with the belief we cannot know about the world independent of our own perspectives (Gray, 2004). Conversely, objectivism which is linked to a realist ontology suggests a stable and observable world exists and we can gain knowledge about the outside world objectively (Gray, 2004).

Ontological and epistemological positions tend to be associated with wider theoretical paradigms (Crotty, 1998). At one end of the spectrum lies interpretivism (or relativism) with positivism at the other end. Positivists assert understanding behaviour may be achieved through observations whereas interpretivists reject the notion of observable social laws which govern the social world (Willig, 2013). Therefore, the experience of human beings is subjective.

Through reflexivity, I have determined my own position on how the social world may be understood. Therefore, I have approached this research with a relativist ontology and subjective epistemology in line with social constructionism. For example, I am undertaking the research with the belief there is no objective knowledge independent of people to be studied. It is my understanding the creation of knowledge is an ongoing process (Bryman, 2008). However, it is my

understanding there is a spectrum at which relativism lies at one end and positivism at the other. I am adopting a 'softer' relativist approach as although I am prioritising individual experience above generalisable claims, I will seek to explore if there are any shared experiences across participants. In line with a social constructionist perspective, the experience of having a sibling with ADHD is individual and does not have an objective reality. However, there may be commonalities across experiences which are of interest to me. The aim of this study is to explore participants' subjective experience through their individual discourses by interviewing six CYP with a sibling with ADHD. I accept that each individual's experience is their reality and through listening to their experiences I bring my own reality, interpreted as the researcher.

3.3.3 Phenomenological approach

The aim of phenomenological research is to generate knowledge about the subjective experience of research participants. The key premise is that a phenomenological researcher may be able to understand this experience without being preoccupied or distracted by what is 'really' going on (Willig, 2013). For example, I am interested in finding out how my participants *experience* having a sibling with ADHD, not what is actually happening to them in their sibling relationship. It is recognised that there is more than one world to be explored and from a phenomenological perspective, the phenomena of having a sibling with ADHD can be experienced in many different ways. Therefore, in this research each participant's viewpoint will be considered as individual. However, while the

focus is idiographic I will also be interested in looking for shared experiences to form themes and patterns from the data collected by all participants.

3.4 Interpretive Phenomenological Analysis

There has been recent interest in using IPA in social science research to examine how individuals make sense of life experiences (Pietkiewicz and Smith, 2012). Rather than adopting an experimental approach, searching for 'truth' about a phenomenon, IPA allows for a reflective approach where individuals are afforded space to think and feel as they work through what their experiences mean (Smith, Flowers and Larkin, 2009). Therefore, there is no objective truth about these experiences.

IPA is a qualitative approach to research, concerned with the way in which people make sense of important experiences in their lives (Smith, Flowers and Larkin, 2009). The approach differs from descriptive phenomenology as accounts are not taken at face value but the *meaning* of an account is prioritised (Willig, 2013). The experience explored using IPA should have great significance on a person's life. These experiences may encourage a person to reflect on the significance of the event, the aim for the IPA researcher is to engage with these reflections. IPA holds the view that as humans try to make sense of their experiences in life, through engaging in research, the researcher may begin to understand this sense making.

IPA is a dynamic approach involving an active role from the researcher who attempts to access their participants' experiences through interpretation, in order to make sense of their personal world.

3.4.1 Phenomenology

Considered the father of phenomenology, Husserl (1859-1938) was concerned with the way individuals experience and make sense of their lives and understand experiences of the world. Phenomenology can be considered the study of how people perceive and talk about events in their lives rather than focusing on describing it. Therefore, phenomenological researchers aim to understand and describe their participants' experiences of the everyday world, in the way in which they see it (Daly, 2007). Crucially, researchers must allow these experiences to be expressed in their own words rather than matching them to the experiences of others. An important concept raised by Husserl is that of intentionality. This refers to the nature of consciousness, whenever one is conscious they are always conscious of something (Langdridge, 2007). Therefore, phenomenological research attends to people's experiences as they appear to them, rather than their cognitions.

Phenomenology was further developed by Heidegger (1962) who himself was concerned with what it means to exist or 'be human'. This notion was further developed by Satre and Merleau-Ponty who dominated the phenomenological movement during the middle part of the twentieth century. These

phenomenologists were more concerned with the interpretive nature of phenomenology; understanding that relationships, culture and language will have an effect on people's experiences (Smith, Flowers and Larkin, 2009).

3.4.2 Hermeneutics

The word hermeneutics is derived from the Greek 'to interpret' or 'to make clear' and can be defined as the theory of interpretation (Smith, Flowers and Larkin, 2009). For an IPA researcher to interpret and draw conclusions about an individual's experiences, they must attempt to stand in the shoes of their participants. They can first do this through gaining an overall view of their participants' experiences but then must perform a detailed analysis, considering psychological theories (Schleiermacher, 1998).

In IPA, a double hermeneutic is experienced where participants first make sense of their worlds, then the researcher tries to interpret this meaning, making sense of their participants' meaning making (Smith and Osborn, 2008). Therefore, the researcher is attempting to understand what an experience is like from their participant's perspective. In the case of the present research, I am aiming to understand what it is like to have a sibling with ADHD from the perspective of my participants.

Smith and colleagues highlight the importance of the dualism of phenomenology and hermeneutics when using IPA explaining, "*without the phenomenology, there*

would be nothing to interpret; without the hermeneutics, the phenomenon would not be seen." (Smith, Flowers and Larkin, 2009, p. 37).

3.4.3 Idiography

IPA relies upon idiography which is the in-depth analysis of single cases. The individual perspectives of participants are considered critical and these are explored prior to any general statements being made about the phenomena studied (Pietkiewicz and Smith, 2012). This is due to the assumption about the uniqueness of humans, who may be affected by a particular set of circumstances and factors. In contrast to quantitative methodologies, which seek to generalise universal truths, ideography is concerned with the particular, not the universal (Smith, Flowers and Larkin, 2009). That is not to say the researcher cannot generate themes across participants but the examination of the individual cases in depth is the primary priority. Individual cases can be compared and contrasted but each case must be explored with equal depth. IPA is considered idiographic as the priority is to understand how specific phenomena are understood from the perspective of particular people, in a specific context (Smith, Flowers and Larkin, 2009). For example, the present research seeks to examine specific and unique cases of growing up with a sibling with ADHD. This offers unique value as previous research studies have been concerned with making generalisations about the way in which CYP are affected by having a sibling with ADHD. The meanings attached to CYP's experiences in this study may shed light on

relationships previously found between having a sibling with ADHD and increased family conflict and feelings of injustice for example.

3.4.4 Bracketing

Bracketing, sometimes called epoche, refers to the process in which researchers should try to refrain from allowing their beliefs and assumptions to influence the way in which they see their participants' experiences. It is widely debated how possible it is to 'bracket' preconceptions of experience (Langdridge, 2007). For example, Heidegger argued people are not able to put aside the way they see and identify a phenomenon and the way in which experiences are understood should be situated within its historical and cultural context, thus giving rise to interpretation rather than just description. Philosopher, Gadamer (1960) agreed with Heidegger, adding that one's awareness of preconceptions may only begin once interpretation has begun. Therefore, there is discourse between the words of the participant and the preconceptions of the researcher. This cycle is referred to as the hermeneutic circle (Langdridge, 2007). Interpretation in IPA is described by this process; in order to understand the part, the whole must be considered, in order to understand the whole, consideration must be given to the parts (Smith, Flowers and Larkin, 2009). In this research, I used a reflective diary throughout data collection and analysis to remain aware of the above process (see Appendix 1 for example).

3.4.5 Reflexivity

A qualitative researcher requires reflexivity to reflect on their relationship with their research and their experiences of it. It is argued there are two types of reflexivity a researcher must consider: personal reflexivity and epistemological reflexivity (Willig, 2013). Personal reflexivity refers to the way in which a researcher's own values, experiences, beliefs and interests have shaped their research. Furthermore, a researcher must consider how conducting the research may have affected them in both their personal life and as a researcher. Epistemological reflexivity is concerned with a researcher's reflection on the assumptions they have made about the world and knowledge throughout the research process (Willig, 2013). In this study, reflexivity is of particular importance due my pre-existing relationship with the subject matter, having a brother with ADHD.

In summary, IPA combines phenomenology and hermeneutics to provide a methodology which is multi levelled. First, the process is descriptive, allowing for participants to describe events or objects as they appear. Second, the process is interpretive as it is recognised these events or objects are unavoidably interpreted with influence from personal experience and theory.

3.5 Justification for the use of IPA

IPA focuses on the detailed exploration and interpretation of the lived experiences of participants. A key aim is to allow these experiences to be understood in their

own terms, without being assigned to a predefined category (Smith, Flowers and Larkin., 2009). After consideration of a range of qualitative methodologies (eg, narrative psychology, grounded theory) I selected IPA as an approach as I was keen to gain an understanding of individuals' accounts of their own experiences of having a sibling with ADHD. IPA appears the most valid way of accessing, understanding and interpreting these experiences and meeting the research aims. I eliminated thematic analysis as a method of analysing my data as I recognise due to both my personal and professional experiences, I am part of the research and this would not be reflected in thematic analysis or grounded theory. The strengths and limitations of using IPA are discussed in Chapter Five (5.3).

3.6 Method

This section denotes a discussion of the methods and procedure used to carry out the research so the process is transparent, offering quality assurance.

3.6.1 Data Collection

Data were collected using face-to-face, semi-structured interviews (SSIs). SSIs were selected as an appropriate tool as they allow flexibility where necessary and it was my intention to elicit *detailed* views about living with a sibling with ADHD. SSIs provide the researcher with an interview guide which can be modified to meet the flow of the interview (Robson, 2011). For example, the wording and sequence of the questions may be altered and vary between each interview.

Conducting SSIs allowed me to treat the participants as the ‘experts’ in their experiences, following their lead and direction where appropriate. This aspect is central to the principles of IPA (Reid, Flowers and Larkin, 2005).

The interview schedule was constructed following guidance from Kvale (1996) who advocates a phenomenological and hermeneutical mode of understanding a qualitative research interview. The interviews started with an opening question followed by questions to determine fact, emotion, perspectives, reflection and follow up before closing with a general question. The philosophical principles of IPA therefore permeate this conception of carrying out interviews for data collection in research (Kvale, 1996). Questions were formulated by looking at previous research studies which utilised an IPA approach with CYP to ensure they were pitched at the correct level. All questions were designed to help me elicit answers to gain a deeper understanding of my participants’ experiences, in line with an IPA methodology.

The process of conducting and refining the interviews was iterative, for example each interview was informed by the previous one. The initial schedule was trialled with a ‘pilot’ participant. Through reflection and supervision, I modified the wording of two questions and added an additional two questions to the original interview schedule (see 0, changes made are highlighted in red). I also decided to start the interview with the Kinetic Family Drawing (KFD) (Burns and Kaufman, 1970) discussed below.

Given the lower age of some of my participants and my limited knowledge of participants' language abilities in advance of meeting them, I used a visual and drawing tool to initiate discussion about sibling relationships. Drawings can be used to understand more about CYP's interactions with their family and attitudes towards them. The KFD is a method used to support CYP to depict each member of their family engaged in an activity. Typically, analysis of KFDs looks at the interaction between the child and family members to gain an understanding of the CYPs sense of self within the family (Fan, 2012). However, in this study the purpose of using the KFD was not analyse the drawings but to use it as a tool to initiate discussion and verbal reflection on the members of the participant's family. For this reason, participant's drawings are not presented as part of this research.

3.6.2 Inclusion and Exclusion Criteria

For participants to take part in the research, they had to fulfil several inclusion criteria. This was to aid homogeneity of the sample, to ensure participants could meet the demands of the study and to allow a degree of confidence issues discussed were related to ADHD and not other additional needs.

Table 2: Inclusion criteria for participation

Inclusion Criteria	**Exclusion Criteria**
Has at least one sibling with a confirmed diagnosis of ADHD and no other diagnosis or condition	A participant diagnosis of ADHD
Age 8-18 years old	Children subject to a Child in Need Plan or child protection concerns
Cohabits with sibling for 7 days a week	Any current involvement with the Child and Adolescent Mental Health Service
Willing to attend at least two out of three activity sessions (at time of consent)	
Sufficient competence in English to verbally share their views	

3.6.3 Sampling

A purposive sample was used as suggested by IPA researchers (Smith, Flowers and Larkin, 2009). Potential participants were sought on the basis they had experience of living with a sibling with ADHD and they would be able to share information on this research topic. I considered this to be a research topic which has relevance and significance to participants. Smith and colleagues (2009) recommend a relatively homogenous sample to sustain a focus on the individual as well as allowing identification of convergence and divergence between participants. In this study, the sample was homogenous in that all participants had a sibling with a diagnosis of ADHD however, due to the wide range and variety of family constructions and differing parental opinions on medication for ADHD, there

is a level of diversity between the participants for example total number of siblings in the family.

A key concern in IPA is to allow full appreciation of each individual case in depth. For this reason, IPA samples are typically small, to allow for detailed and time consuming case-by-case analysis (Pietkiewicz and Smith, 2012). For this reason, a sample size of six was considered appropriate for this study.

3.6.4 Ethics

3.6.4.1 Ethical Approval

Ethical approval was sought and granted from the University of Birmingham's Ethical Review Process (Appendix 3). To guide ethics of the research process, the BPS ethical research guidelines were observed and adhered to (The British Psychological Society (BPS), 2014).

3.6.4.2 Informed Consent

Consent was sought from a member of senior leadership from all schools where the research took place (Appendix 4). Secondly, consent was sought from parents of participants, as the participants and/or their siblings were under 16 at the time of interview (Appendix 5). Consent was also received from the participant and their sibling with ADHD (Appendix 6 and 7). The sibling with ADHD was

consenting to them being the topic of conversation during the interviews although they did not provide data for the research. Written and verbal consent was received and this was discussed at each session with the participants. Participants were reminded they need not take part in the research, informed of their right to withdraw at any time without consequence and were given a clear description of the purpose of the research. All participants and their parents were given the contact details of the researcher to ask any questions at any point for the duration of the study.

3.6.4.3 Confidentiality

Confidentially is an important concern in human research, this includes the anonymity of any participants their siblings taking part in the research. To achieve anonymity, participants selected a pseudonym to be used in all written documentation and all audio files were stored securely under this pseudonym according to the University of Birmingham's Data Protection procedures.

It was recognised due to the recruitment procedure, a limited number of school staff (SENCo and class teachers) were aware of participants taking part in the research. To ensure privacy during the interviews, a quiet room in school was used. Participants were reminded of my need to break confidentiality should I be concerned about anything discussed which may lead me to think about their safety or the safety of others. In two of my interviews, safeguarding concerns were raised and information was shared with a member of school staff (designated

safeguarding lead). Further discussion of how these safeguarding disclosures affected the interviews and findings can be found in Chapter Five, section 5.3.

3.6.4.4 Avoidance of harm and addressing the power differential

BPS guidelines are clear in that all researchers must prevent any participants coming to any harm during participation in a research study (BPS, 2014). During the research interviews I remained mindful that in talking about their relationship with their sibling, participants may become uncomfortable or upset. Participants were reminded they could stop at any time and they did not have to answer questions if they did not want to. I also reassured participants there were no right or wrong answers to the questions and I was purely interested in learning about their experiences. My training as a TEP allowed me to build a rapport with participants and I could draw upon therapeutic skills where necessary to ensure I was responding empathetically to concerns raised. I also shared with participants that I have a brother with ADHD, although I was careful not to talk about my own experiences during the interview. It appeared as though this self-disclosure helped the participants feel comfortable talking about their own experiences.

3.6.5 Recruitment

The stages of recruiting participants to the study are detailed in Table 3 below. All parent/carers who were approached by the SENCo, gave permission for their children to take part and all participant's siblings gave written consent.

Recruitment was slower and more challenging than anticipated as several potential participants had siblings who did not meet the inclusion criteria (for example, they were too young or had additional needs themselves) and because several children had co-morbid diagnoses with ADHD.

Table 3: Stages of recruitment procedure

Stage 1	The school's Special Educational Needs Co-ordinator (SENCo) was first approached to obtain permission to recruit participants via the school. A member of the Senior Leadership Team was provided with an information sheet and asked to sign a consent form for interviews to take place on school premises.
Stage 2	The SENCo identified any pupil in their school for whom they had received a letter from a medical professional, confirming a diagnosis of ADHD and who was known to have a sibling who would meet the eligibility criteria. The SENCo shared the parental and participant information sheet with parents/carers. Once the parent/carers had read the information sheet, the SENCo clarified whether the parent/carers were willing to be contacted by the researcher to proceed with participation.
Stage 3	Once parent/carers had confirmed they were happy to be contacted, the researcher arranged a phone call to confirm eligibility, answer any questions and arrange the first session with the participant in a mutually convenient setting (either school, home or researcher's office). The parent/carers were also asked to share the participant and sibling information sheets with their children.
Stage 4	The researcher met with the participant (and in some cases their sibling) to read through the information sheet and obtain written consent.

3.6.6 Procedure

Session one

Participants were invited to meet with the researcher for an introductory session lasting approximately 20 minutes. The purpose of this session was to build rapport and introduce the participants to the nature of the research prior to the interview. First, the researcher read through the information and consent form. If the participant agreed, consent was received in written form and counter signed by the researcher. Following this, a few games and activities were offered for the researcher and participant to engage in together. These included playing Connect 4, colouring in, reading a book together and sharing of personal stories.

Session two

Participants were offered the opportunity to meet with the researcher at their home, school or the researcher's office. All participants chose to meet at school. The researcher re-read through the information sheet with participants, reminding them they could stop the session at any time should they wish. After the audio recording devices were switched on, the researcher conducted the drawing activity and SSI. All interviews were audio recorded with permission from the participants.

Session three

This session was an additional extra and was only taken up by one participant. Prior to this session, I prepared a page of quotes from the participant which were positive in nature, to be shared with their sibling (see Appendix 8 for an example). This session was to celebrate the positives within their relationships and to provide positive feedback for the sibling with ADHD. All participants were given a 'thank you' letter for taking part (Appendix 9).

3.6.7 Participants

Six participants were sought to allow for the intensive and idiographic analysis which IPA requires. Participants were recruited across five mainstream primary and secondary schools within the Local Authority in which I was working. The final sample of participants consisted of one boy and five girls aged between 11 and 18. Table 4 provides details for each participant. The siblings with ADHD comprised two girls and two boys aged eight and 14 (see Figure 3 below). All participants were older than their sibling with ADHD with the exception of Ben whose twin has ADHD. All participants were from white, working class families. Two families experienced overcrowding in the home resulting in multiple siblings sharing bedrooms. In three out of the four families, the parents were separated.

Figure 3: Participants and siblings by gender

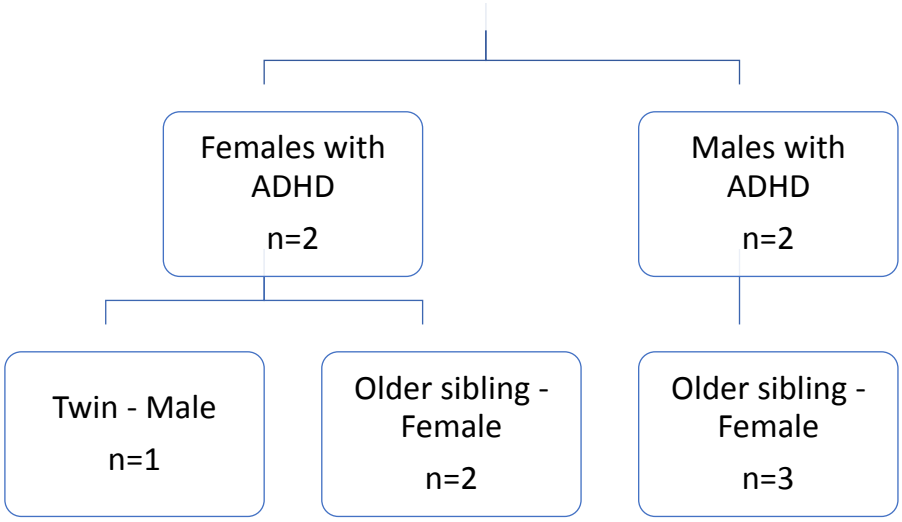


Table 4: Participant and sibling information

Name (pseudonym), age and gender	**Sibling with ADHD (pseudonym)**	**Ethnic origin**	**Additional Siblings (pseudonyms and age)**	**Total number of people living in home**
Katy (11) Female	Georgie (8) Female	White British	Taylor (14) Grace (6) Sarah (4 months)	6
Taylor (14) Female		White British	Katy (11) Grace (6) Sarah (4 months)	6
Chloe (11) Female	Joshua (8) Male	White British	Lily (9 months) Siblings who do not live at home but are visited at weekends: half-sister, Rose (3)	5

			Step sister, Charlotte (unknown) Step brother, Callum (unknown) –	
Ben (14) Male	Rachel (14) Female	White British	Robert (28) Siblings who do not live at home: Jennie (22) Kylie (29)	4
Jess (18) Female	Tom (14) Male	White British	Lauren (16) Son: Kaiden (10 months) Siblings who do not live at home: Daisy (unknown) – visits regularly during the evenings	7
Lauren (16) Female		White British	Jess (18) Nephew lives at home: Kaiden (10 months) Siblings who do not live at home: Daisy (unknown) – visits regularly during the evenings	7

3.7 Data analysis

The researcher moves between *emic* and *etic* perspectives. Etic requires the researcher to look at the data through a psychological lens, using psychological concepts and theories to help understand the research problem (Pietkiewicz and

Smith, 2012). Emic perspectives protect the researcher from psychological reductionism. For IPA analysis, the researcher is required to make sense of the participant's attempts at making sense of their own experiences referred to as the double hermeneutic process (Smith, Flowers and Larkin, 2009). The whole process should be reflective so the results reflect the process by which the researcher thinks about how the participant thinks.

Smith and colleagues (2009) do not prescribe one specific way for analysis to be conducted. However, as a novice to IPA I closely followed the step-by-step process. See Table 5 below.

Table 5: Stages of IPA analysis (adapted from Smith, Flowers and Larkin, 2009)

Stage 1	Verbatim transcription	In order to feel fully immersed within the data, I completed verbatim transcription of each participant's audio recording
Stage 2	Reading and re-reading	Overall impressions of each interview were first noted in my research journal (see Appendix 10 for example). I added notes here on my own responses The first reading was accompanied by listening to the audio recording. This enabled me to become familiar with the interview as a whole and make notes on intonation and hesitations. The participant remained the focus of the analysis.
Stage 3	Initial noting	Each transcript was examined five times. Initial thoughts and notes were handwritten onto the right hand margin of the transcripts at this stage, using different colours for descriptive, linguistic and conceptual content. Comments were noted during each

		read of the transcript to allow for a 'fine grained' analysis. (Appendix 11)
Stage 4	Developing emergent themes	Using the notes made during Stage 3, the data was reduced to produce precise, brief statements deemed to be of significance reflecting an understanding of the participant's words. Coloured post-it notes were used for comments which were directly relevant to each of the research questions (Appendix 12). A fifth colour was used for notes which did not appear to fit with a specific research question. Some themes had already begun to emerge in the initial noting stage, these were further analysed during this stage.
Stage 5	Searching for connections across emergent themes	This stage involved mapping how the emergent themes fit together to develop themes. Some notes made during the emergent themes phase were discarded at this phase. I organised the post-it notes with emergent themes into clusters and then by research question to develop themes. Themes were determined through a number of processes: Abstraction (placing similar themes together to produce superordinate themes) Subsumption (emergent themes become superordinate as they bring together themes) Polarisation (identifying opposing themes) Contextualisation (relating themes to life events) Numeration (considering the number of times a theme is discussed) A mind map was then created to produce a graphic representation of the themes created (Appendix 13)
Stage 6	Moving onto the next	At this stage I would move from one participant's transcript to the next to repeat stages 2-5, making sure

	case	I did my best to bracket (set aside) ideas which had emerged from the previous participant's interview.
Stage 7	Looking for patterns across cases	At this final stage, I searched for connections between and across each of the interviews looking for both individual and shared meaning. This involved looking across all the participants' mind maps.

3.7.1 Reflexivity during analysis

As discussed above, IPA analysis includes the researcher's own subjective position thus interpretations are unique to the researcher. I sought opportunities to discuss each stage of my analysis procedure with my supervisors and through peer supervision. The purpose of this discussion was to demonstrate my process and thinking and to offer justifications for my ideas and the way in which I felt they were related to the data. I also kept notes in my research diary in order to understand my own position through the analysis.

3.7.2 Quality assurance in qualitative research

There has been much debate within the field of qualitative research as to whether validity can be assessed or not (Bryman, 2008). As there is no objective truth to be studied within qualitative research, it is not possible to determine whether the research has achieved the goal of measuring that which it intended. Therefore, Meyrick (2006) suggests researchers should convey enough about the research process that readers are able to make a judgement about rigour and quality. Therefore, I have made a determined effort to be transparent about the decisions

made throughout the research process. Furthermore, Yardley (2008) indicates that valid qualitative research maintains a focus on a topic which is useful for others or explores something interesting and important. An original contribution was sought with this study, adding new perspectives to an under researched topic, placing significance on the views of siblings. The implication of this study can be found in Chapter 5 (5.5).

3.8 Chapter summary

This chapter has presented the methodology of IPA and how I used the approach to plan, conduct and analyse my research data. I have presented the details of the recruitment of participants and the collection of data. The research findings and discussion are presented in the next chapter.

CHAPTER FOUR: FINDINGS AND DISCUSSION

4 Findings and Discussion

This chapter provides an account of the six participants who shared their experiences of having a sibling with ADHD. The first component of the chapter, which reflects the process by which analysis was carried out, is a summary of the participants' individual experience (see Table 8). This provides an overview of each participant's story as they described it to me. My interpretation of their stories is saved for presentation with the themes. Second, shared meaning across the participants are addressed and presented by research question. Quotations from participants are used to highlight the themes. Superordinate and subordinate themes are presented to address three of the four research questions (see Table 7 for overview). Table 6 summarises how each research question is addressed:

Table 6: Summary of how research questions are addressed

How do participants describe the	Individual experience examined	Focus on shared experiences using

characteristics associated with their siblings' ADHD?		themes
What is it like growing up with a sibling with ADHD?	Individual experience examined (Table 8)	Focus on shared experiences using themes
How do children and young people with a sibling with ADHD experience their sibling relationship?	Individual experience examined (Table 8)	Focus on shared experiences using themes
How do participants describe the positive characteristics of their sibling?	Focus on individual experience, findings presented by individual participant (Table 9)	

The findings are discussed in relation to research findings from previous literature and my interpretation of the implications for participants. A thematic map is presented to provide an overview of the themes which were generated after careful analysis of each individual experience. This was to gain a comprehensive understanding of participant's experience, before shared meanings were explored across their accounts. Where relevant, unique perspectives are presented in contrast with the overall theme. This is to reflect the experiences of the majority of participants whilst maintaining the subjective nature of their experience.

Table 7: Overview of superordinate and subordinate themes relating to research questions two, three and four

Research Question	Superordinate themes	Subordinate themes
How do participants describe the characteristics associated with their siblings' ADHD?	❖ Siblings' understanding of ADHD	
	❖ Anger	
	❖ Externalising behaviours	❖ Moods ❖ Hyperactivity
	❖ Influence on siblings' identity	
What is it like growing up with a sibling with ADHD?	❖ Feelings of powerlessness	
	❖ Strategies for coping	❖ Understanding ❖ Avoidance
	❖ External support	
How do children and young people with a sibling with ADHD experience their sibling relationship?	❖ Challenges and threats to sibling relationship	
	❖ Role of responsibility within the family system	

4.1 Overview of individual experience

The table below (Table 8) summarises the individual experience by participant to provide an overview of their story as told to me. During the interviews, I was mindful to regularly check with the participant that I was understanding their meaning. This table summarises their experiences as told to me prior to my interpretation.

After interpretation, I clustered themes by participant before searching for shared experiences. Each participant's mind map demonstrating the clustering of themes can be found in Appendix 13. Chloe's is presented as an example in Figure 4 below.

Figure 4: Mind map showing clustering of themes for Chloe

Table 8: Pen portraits of each participant with an overview of their experiences

Participant	Unique experience
Taylor (14)	Taylor is the eldest of five girls and sister to participant, Katy. Her middle sister Georgie has a diagnosis of ADHD and takes medication daily. She does not attend the same school as Georgie. Taylor is from a white, working class family. She does not describe her relationship with her father as close and she lives with her step father. Taylor described her relationship with Georgie as warm and close and she felt a special bond with her sister. She enjoyed her responsibilities as eldest sister but acknowledged how this was at times stressful for her. Taylor expressed empathy for Georgie and wanted to support her in any way she could. She would also take the blame for her at times when things had gone wrong, in order to keep Georgie out of trouble. Taylor had strong views about Georgie taking medication as she felt as though it altered her sister in some way. Taylor recognised she experienced anxiety and felt comfortable talking to a friend and her mum about this. Taylor's anxiety was expressed during the interview and this led me to share my concerns about her well-being with her mother and school staff.
Katy (11)	Katy is the second eldest of five girls and sister to participant, Taylor. Her middle sister Georgie has a diagnosis of ADHD and takes medication daily. She does not attend the same school as Georgie, having recently moved to Year 7. Katy is from a white, working class family and lives with her step father. She did not tell me how often she sees her father. Katy likes to be helpful at home and support her mum with looking after her younger sisters. She felt her sister Georgie could be annoying sometimes but described having a close relationship with her overall. Katy felt protective of Georgie, sticking up for her at school when peers were picking on Georgie. Katy described having friends in common with Georgie and they would all play together.
Jess (18)	Jess is the second eldest of four siblings and sister to participant, Lauren. She is from a white, working class family. Her brother Tom, the youngest in the family has a diagnosis of ADHD and takes medication daily. She

	has a son of 10 months and her boyfriend spends a lot of time at the house. Jess does not work and has not attended the same school as Tom. Jess described her relationship with Tom as unstable and dependant on Tom's moods. She described some conflict with him but recognised this was to a lesser extent than the conflict between Tom and sister Lauren. Jess was reflective about her responses to arguments with Tom and is now able to limit arguments in the home. She described feeling defensive of Tom and would stick up for him if she felt it necessary.
Lauren (16)	Lauren is the second youngest of four siblings and sister to participant, Jess. She is from a white, working class family. Her younger brother Tom has a diagnosis of ADHD and takes medication daily. Lauren recently left school which she attended with Tom for one year. She works in a bar and is studying hairdressing at college. Lauren described having a good relationship with her parents and older sisters but a difficult relationship with Tom, with daily conflict. She recognised this conflict was induced and heightened due to sharing a room with Tom, putting a strain on their relationship. This is as a result of overcrowding in her family home. She reflected on a period of time when she was not sharing a room with him and the conflict reduced. Lauren recognised this conflict caused her stress. Lauren also felt protective of Tom and wanted to improve her relationship with him. Lauren admitted being reluctant to ask for help and support with managing her own stress.
Chloe (11)	Chloe is older sister to her brother Josh who has a diagnosis of ADHD and was not taking medication at the time of the interview. She has step and half siblings who she sees regularly at weekends when she visits her father. She is from a white, working class family. Chloe longed for a better relationship with Josh, describing regular conflict with him – sometimes physical. She stated Josh would be in a mood with her every day. She felt she saw a different side to Josh depending on whether she was at her mum's or dad's house. Chloe felt protective of Josh and wanted to spend more quality time with him at home. She felt conflicted about him potentially attending the same school as her in the coming year. Chloe expressed some concerns about her family's financial situation during the interview. She also raised some concerns about physical behaviour in the house and a safeguarding referral was made through school.
Ben (14)	Ben is a twin to sister Rachel who has a diagnosis of ADHD and takes medication daily. He has three older siblings, only one of whom still lives at home. He remains in close contact with his siblings who do not live with him. Ben attends the same school as Rachel. Ben is from a white, working class family.

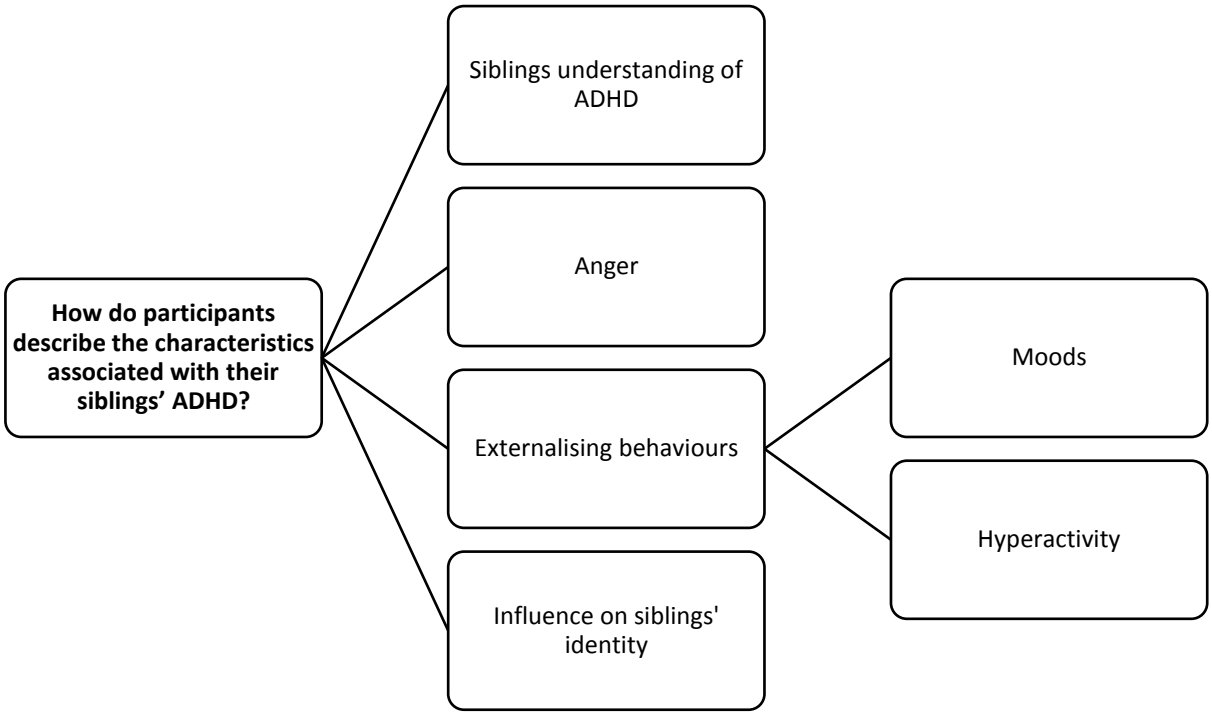
	Ben's relationship with Rachel is characterised by daily verbal and sometimes physical conflict. Ben felt as though Rachel's actions were personal towards him and this left him feeling hurt. He described being able to see a clear difference between his relationship with Rachel and his older siblings. He felt Rachel was protective of him and that he would stand up for her if he had to but recognised a difference between their approaches to conflict. Ben tried to avoid Rachel both in school and at home to reduce the conflict. Ben became emotionally distressed during his interview when talking about his relationship with his sister. I shared my concerns about Ben's well-being with school staff after terminating the interview early.

4.2 How do participants describe the characteristics associated with their siblings' ADHD?

All participants understood and verbalised challenges associated with having a sibling with ADHD. Some participants made specific, spontaneous reference to the challenges being directly related to their siblings' diagnosis whereas other participants described challenges which they felt could be typical of any sibling relationship. Participants expressed some confusion surrounding their understanding of the term ADHD and how this influenced their siblings' behaviours and identity.

I interpreted three themes in relation to behaviours which participants attributed to their siblings' diagnosis: siblings' understanding of ADHD, externalising behaviours and the influence of ADHD on their siblings' identity. This is represented in Figure 5 below.

Figure 5: Thematic map illustrating superordinate and subordinate themes relating to how participants describe the characteristics associated with their siblings' ADHD



4.2.1 Siblings' understanding of ADHD

This theme refers specifically to the participant's factual knowledge of the medical diagnosis of ADHD and the way in which they conceptualised the diagnosis. It was evident throughout each interview that participants had not been asked about the diagnosis of ADHD before. When asked what the letters in ADHD stood for, none of the participants could correctly identify what any of the letters represented. One participant guessed at 'A' representing active. Two of the participants believed the first 'A' was for anger, perhaps as a result of seeing angry behaviours in the home which they may have attributed to their siblings' diagnosis. For example when asked what ADHD meant to her, Katy responded with:

"Anger issues, erm sensitive, hits people erm she has to have medication and erm and she struggles a bit." (Katy, p.7)

Neither King and colleagues (2016) or Kendall (1999) reported any findings related to participants' understanding of their siblings' diagnosis of ADHD. The findings from Day's (2016) thesis established participants with a sibling with ASD felt their lack of understanding of the diagnosis affected their ability to bond and communicate effectively with their siblings. As they grew older they developed an increased awareness through attending sibling support groups and questioning their parents. However, as with the present research, participants all understood there was a diagnosis and this meant their sibling was different from other children.

There was also some uncertainty and confusion around what they understood about their siblings' diagnosis. Ben and Chloe both referred to their sibling as having *'issues'* but were not able to further explicate what they meant by this. This lack of understanding had implications for some participants; Taylor expressed a desire to find out more to be able to support her sister and Chloe stated when she found out her brother had ADHD she began to treat him '*better*'. Research suggests CYP develop more sophisticated understanding and levels of reasoning about the definition and their conceptualisations of a diagnosis of ASD as they get older (Glasberg, 2000). In Glasberg's unique study, siblings of CYP with ASD were interviewed about their understanding of their sibling's diagnosis. Not all participants knew what ASD stood for and the interviewer used terminology which

was familiar to the CYP as used in their home or asked them why their sibling attended a special school. The author suggests understanding developmental disabilities or mental health needs is more abstract and less common than with a physical illness or disability therefore the concepts may be harder to grasp. They conclude in the age group eleven to 17, CYP can reason logically about events which have happened and could also predict the child's difficulties associated with ASD on future situations. This may suggest as Taylor and Chloe learned more about their siblings' diagnosis, they began to reason about its impact and therefore altered their approach towards their sibling or sought further information.

Despite an overall lack of awareness and understanding of the diagnosis of ADHD, I have interpreted the data as evidencing that participants demonstrated an ability to empathise with their sibling, showing an awareness of their difficulties based on the circumstances. This demonstrated participants may be feeling sorry for their sibling, having an ability to put aside their own feelings and understand what their sibling may be feeling, particularly during times of anger and frustration. For example, Taylor expressed empathy for her sister:

> *"…but I feel like that if she didn't have ADHD people would be like you know, wouldn't be shouting at her all the time or wouldn't be saying you can control it because say if someone told me to stop talking too much, (laughs), I wouldn't be able to because that's me at the end of the day…" (Taylor, p.10)*

This contrasts with previous research suggesting adequate knowledge of ADHD improves an individual's ability to empathise with their sibling through accurate understanding of the internal processes and their intentions (Steiner, 2014). As ADHD contrasts with physical difficulties, in that it manifests through responses and behaviours, family members may find it difficult to know what to expect from the CYP and how best to respond to them. However, despite having little knowledge about the diagnosis itself, participants in this study showed understanding and empathy for their sibling's needs.

Participants were aware of the differences between themselves and their sibling. Two participants were keen to normalise their siblings' diagnosis in both how they treated their sibling and how they explained their siblings' needs to their friends.

> *"Sometimes they [friends] say, 'oh how come, what's wrong with him?' like if he's moody, I wouldn't, I wouldn't say to em 'oh, he's got ADHD,' I say like, 'he's just in a mood,' or 'it's just one of em days,' that's what I'd say. But I don't, I'm not like, 'Oh he's got ADHD.' Like I don't make it a big, a thing if you know what I mean?" (Jess, p.10)*

The findings suggest CYP's sense making of their siblings' diagnosis was characterised by uncertainty and they did not have a clear understanding of the label. This lack of knowledge led them to construct the diagnosis through labelling behaviours they witnessed in their siblings, discussed below in section 4.3.2, in line with the clinical picture of ADHD. In the case of Taylor, it left her wanting to

find out more to offer further support to her sister similar to a previous finding by Burston, (2005), although she was unsure of the best way to approach this. Research with children who have a sibling with a mental health difficulty suggests by offering more information about the diagnosis to further understand their siblings' behaviours, would benefit their ability to cope and experience less intense emotions (Pitman and Matthey, 2004).

4.2.2 Anger

Although the term ADHD did not appear to be widely and spontaneously used in participants' vocabularies, they were able to offer behavioural and emotional descriptors of their siblings' needs. These descriptors represented the conflict they experienced as part of their sibling relationship and their perceptions of the meaning of these were based primarily on their relationship experiences. Of note, nearly all participants referred to anger in their descriptions of both their sibling and their behaviours, believing anger was directly related to the diagnosis of ADHD. Participants discussed times where their siblings would behave with either physical or verbal aggression towards them. When describing these events, they talked about emotions they believed would lead to their sibling to externalising their behaviour through anger. Although it is not unique for incidents of aggression to occur between siblings, the intensity and frequency of aggressive interactions is thought to be greater when one sibling has ADHD (Burston, 2005).

Anger was identified as a theme as all participants discussed accounts of their sibling being angry or alluded to anger through descriptions of their behaviours. There were no clear triggers for angry behaviour; however some participants believed they could sometimes be responsible for their siblings' outbursts by asking them for help or saying the 'wrong' thing in front of them. Taylor identified her sister would become angry as a direct response to others' reactions to her behaviour. For example:

> *"They're not angry like all the time but when they do things wrong I think what triggers it is like how people respond to it, so say if she just knocks down like a glass of water like I said and people shout at her I think that's when she gets angry cos I think she knows herself that she's done that wrong but when people shout at her it gets stressful for her and thinks that's when she gets angry so…" (Taylor, p.6)*

Taylor's use of the word 'they' suggests she views all CYP with ADHD as having a common set of characteristics, including expressing anger. She finds a way of justifying this anger by looking for triggers for example, other people's responses to accidents.

Siblings' anger could be expressed in a variety of ways from '*screaming*' and *'shouting*' (Ben, p.5) to physical behaviours such as '*thrashing*' and *'hitting'* (Chloe, p6; Jess, p.4; Katy, p.4). Lauren identified anger as being the key feature that would be different in her brother if he did not have ADHD.

Ben explained how he would often be on the receiving end of his sister's anger which left him feeling victimised. I interpreted for Ben, this influenced his self-esteem and negative feelings towards himself as his sister targeted her anger towards him. However, later in the interview he clarified his sister would become angry towards her friends as well:

> *"Cos it isn't just, she don't take her anger out on just me, it will sometimes be other people like her friends, she'll either get angry at them and stuff like that." (Ben, p.13)*

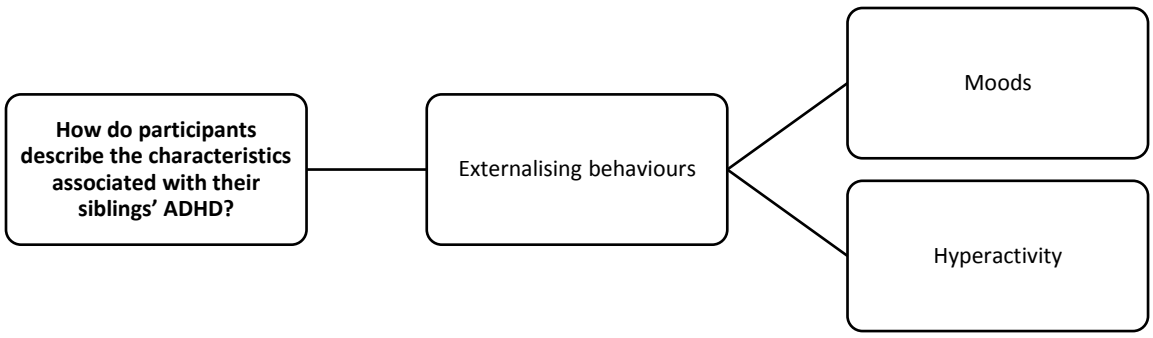
It is unsurprising participants frequently discussed their siblings' anger. This finding supports previous research which suggests CYP with a sibling with ADHD experience victimisation through aggressive acts such as physical violence or verbal aggression and this leaves feelings of powerlessness about being the focus of this anger (Kendall, 1999). This in turn led CYP to express their own anger in retaliation towards their siblings. Although all sibling relationships can be defined by some level of conflict, including angry outbursts, the impact on an individual can become more significant when it is perceived as aggressive (Dirks *et al.,* 2015).

The use of the term 'anger' is also reflected in research looking at CYP's conceptualisations of their own ADHD diagnosis. When asked to describe the problems and difficulties participants associated with their own ADHD, responses indicated participants viewed several 'symptoms' such as arguing, shouting and

aggressive behaviour (Travell and Visser, 2006) and their anger left them feeling out of control (Kenny, 2016). Feelings of anger have been identified by this population as something that distinguishes them from their peers (Kildea, Wright and Davies, 2011). In addition, children with ADHD, their parents and teachers have been shown to self-report more anger compared with their peers (Kitchens, Rosen and Braaten, 1999).

4.2.3 Externalising behaviours

Figure 6: Thematic map illustrating subthemes associated with 'externalising behaviours' superordinate theme



In addition to discussing anger, participants talked about their siblings externalising their behaviour through either a low mood which would at times be directed towards them. Furthermore, they referred to witnessing an element of hyperactivity in their siblings' behaviour.

4.2.3.1 Moods

This sub-theme explains the finding that participants' siblings appeared to experience frequent negative moods or could change mood very quickly. Some participants made spontaneous, specific reference to their siblings' negative moods, a surprising finding not mentioned in any previous research. I interpreted being exposed to their siblings' negative moods could have an impact on the participants' own mood, particularly if the perceived negative mood had preceded an argument between the siblings. Lauren found this the most frustrating aspect of her brother's behaviour; she also discussed the fragility of her brother's and her own mood and how unexpectedly it could change:

> *"Like, we can be like when we're both in a good mood we can get along but then if one little thing annoys one of us that's just it, that's ruined the whole thing." (Lauren, p.4)*

I interpreted Jess felt ADHD was directly responsible for affecting her brother's mood, making his moods '*extreme*'. This implies she saw a variation between her own moods in comparison to her brother's. As part of these negative moods, participants experienced a frustration at their siblings being unable to '*let things*

go' and had a perception that once their sibling was in a bad mood there would be no restoration for the remainder of the day. For example:

> *"… if he wakes up in a bad mood he's in a bad mood for the whole day." (Jess, p.2)*

There is some evidence CYP with ADHD find it difficult to self-regulate their emotions (Wehmeier, Schacht and Barkley, 2010). This is particularly noticeable with anger, coping with frustration and empathy. ADHD is also linked to poor self-esteem which can affect an individual's attitude towards themselves. This can lead to anxiety and depression, which are commonly comorbid with ADHD (Escobar *et al.,* 2005). As siblings spend a lot of time together, it is understandable that they may be the first to experience this variation and intensity in mood. Furthermore, the DSM-V states CYP with ADHD may appear as though they are not listening when spoken to directly (APA, 2013). Participants spoke of their frustration at their siblings not listening to them and it is possible that they perceived their siblings to be in a negative mood at these times.

4.2.3.2 Hyperactivity

With the exception of one, participants made specific, spontaneous reference to their siblings' hyperactive behaviours at home. This was the behaviour most commonly identified as making their sibling stand out as '*different*' from other siblings. When asked to explain what hyper looks like and provide examples of

these behaviours, participants talked about their siblings becoming '*over excited*', an inability to '*sit still'*, poor attention and listening, '*jumping and running around'* and impulsive behaviours such as shouting out. This is unsurprising, when compared with their siblings without ADHD, CYP with ADHD scored more highly on rated measures of hyperactive behaviour and boys show more hyperactive behaviours than girls (Steinhausen *et al.*, 2012).

Participants viewed hyperactivity as part of their sibling and something they are unable to control. Whilst some participants found this element of their siblings' behaviour annoying, they demonstrated empathy and understanding of this element of their siblings' difficulty. When Jess' younger brother opened up to her about feeling upset about his diagnosis and feeling different from others, she minimised his diagnosis to explain:

> *"Oh, Tom, it's not a bad thing" it's just you're a bit hyperer than all of us. (Jess, p.5)*

From the comments made about their siblings' hyperactivity, I have interpreted this caused some disruption to their daily lives. At times, the hyperactive behaviours would lead to family conflicts. However, the participants appeared to make sense of this hyperactive behaviour by ascribing it to the ADHD and not their sibling, explaining that they can't help it or control themselves.

4.2.4 Influence of ADHD on siblings' identity

Participants discussed the externalising behaviours of their sibling which they felt held most significance and during these conversations it emerged participants believed their sibling's ADHD formed part of their identity and therefore defined them. In these cases, the ADHD was viewed as part of them which they were unable to control indicating they may attribute a biological cause of ADHD, a suggestion proposed by Gallichan and Curle (2008). Dunn and Burcaw (2013) suggest a disability identity helps individuals feel connected to a community or group. Although Dunn and Burcaw's research is conducted with individuals with the disability themselves, participants in the current study appeared to identify the diagnosis of ADHD as part of their siblings' identity, so the sibling in turn was part of a wider community of people who have a diagnosis of ADHD. This may have also permitted participants to feel part of a group who have siblings with ADHD. Furthermore, it allows participants to have attributions for their siblings' behaviours and to blame the diagnosis rather than their sibling. Katy held this perspective, when asked about her sister's ADHD she responded:

> *"Erm, I don't really mind. Because she can't help it… and it's not her fault." (Katy, p.9)*

Katy's older sister, Taylor held a stronger view her sibling's behaviour was a direct result of her diagnosis of ADHD and was fixed:

> *"And I know sometimes she can control it but like sometimes it's not her fault generally because she's got this ADHD and that's like something you're born with so... I understand..." (Taylor, p.7)*

This view was also held by Chloe who expressed sadness at people's responses to her brother's behaviours at times because:

> *"… it just makes me feel sad cos he can't like help it being that and then he gets punished for it. And it's sad." (Chloe, p.3)*

Jess believed her brother's ADHD made his behaviours worse explaining his diagnosis meant he was '*extra moody*' but it is a '*part of him'* and she would find it '*a bit weird'* if he no longer had it. (Jess, p.10).

All participants explained they understood their sibling was different in some way and used the diagnosis of ADHD to explain these differences. Despite finding the behaviours associated with ADHD frustrating, when asked if she would change anything about her brother, in a touching moment during the interview Jess replied:

> *"No! Tom is Tom I wouldn't want him to be different now." (Jess, p.10)*

Ben held an opposing view and perceived his sister was in control of her behaviours despite her diagnosis of ADHD. Whilst he understood she had a diagnosis of ADHD, I interpreted he struggled to understand the implications of this for her behaviour towards him and felt she was choosing to deliberately target him with anger and '*nasty'* comments. In this case, it appears Ben viewed ADHD

as less influential on his sister's identity, seeing it as a separate entity to her. In this way, he viewed her as able to control her behaviours. This had apparent implications for his own self-esteem as he felt she was targeting him personally without a valid cause or reason.

Evidence suggests self-identity in individuals can be shaped by the contribution of how others view them (Leary and Tangney, 2012). Therefore, CYP with ADHD may perceive themselves as having differences in part because of their sibling ascribing them a disability identity. It has been found generally, CYP with ADHD feel negatively about themselves and their self-identity, despite it providing them with an explanation of their differences (Kildea, Wright and Davies, 2011)

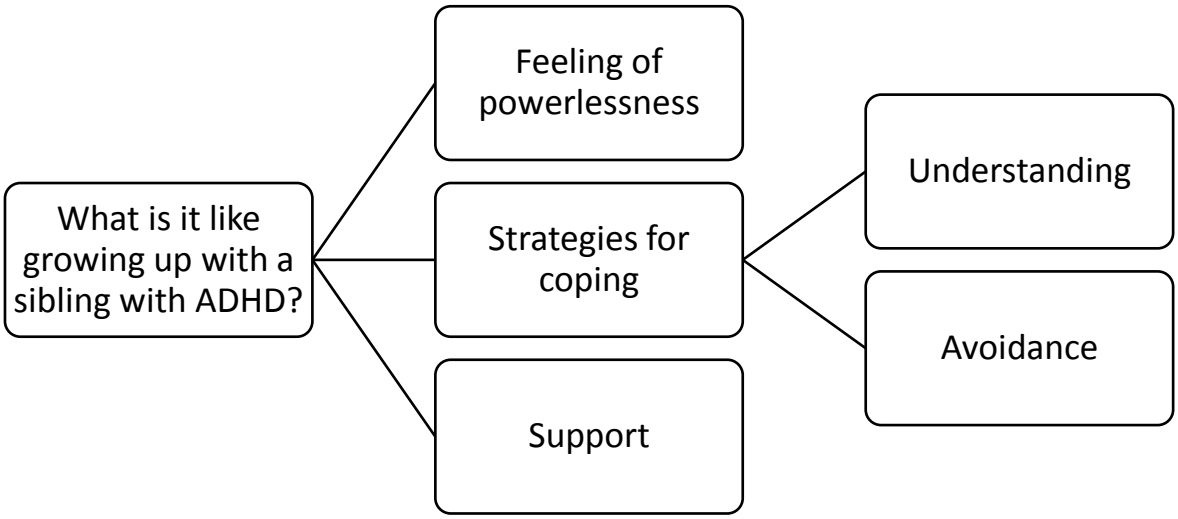
4.2.5 Summary

Overall, characteristics associated with participant's siblings' ADHD are anger, moods and hyperactivity. Participants could describe these behaviours despite being unable to provide the correct terminology for ADHD. With the exception of Ben, participants believed ADHD was a part of their sibling, forming part of their identity. I have suggested this means participants believed their siblings were unable to control the behaviours associated with ADHD. This may explain the empathy participants showed towards their sibling despite being used as an outlet for their siblings' anger.

4.3 What is it like growing up with a sibling with ADHD?

Growing up with a sibling with ADHD is a unique experience for. For example, two pairs of participants were interviewed about the same sibling and presented different and unique accounts of their experiences based on their own interpretations of their siblings' diagnosis and differences in relationship. Furthermore, ADHD can present differently from one individual to the next which may influence the relationship and dynamics. Accounts of the perceived impact of living with a sibling with ADHD varied as did their strategies for managing the difficulties. However, there were some shared experiences.

Figure 7: Thematic map illustrating superordinate and subordinate themes for participants' views on what it is like growing up with a sibling with ADHD



4.3.1 Emotional experiences

Participants experience a range of complex emotions related to themselves and their siblings. The interviews revealed positive and negative feelings and reactions to all aspects of their experiences and interactions with their siblings, in line with findings from Kendall (1999) and King, Alexander and Seabi, (2016). This includes their own anger, frustration, stress, guilt, sadness and empathy. I interpreted some of these emotional experiences were triggered by feelings of powerlessness at their situation. This suggests services for siblings needs to be increased, with a focus on offering mental health support.

4.3.1.1 Feeling of powerlessness

Participants expressed most of their frustration and anxiety at their lack of control and ability to change their situation with their sibling. This left them feeling powerless in their family system and their own lives. At times, they felt they had to resign to a certain way of responding to their sibling, making accommodations in their own lives. I interpreted for the participants this was due to several failed attempts at resolving matters in a variety of ways. Their lack of success at changing their interactions or situation with their sibling led them to believe there was no longer a point in trying, as there was nothing left they could do. This left participants feeling sad, angry or stressed at their situation.

> *"You will get stressed, you'll get stressed with him or them but you just have to take it in because there's nothing you can really do."*
>
> *(Jess, p.10)*

Jess' use of the word '*them'* suggests she feels other CYP with siblings with ADHD may experience a similar feeling of stress due to the lack of control at being able to change the situation. Ben identified there was no purpose in asking for help with managing difficult interactions with his sister suggesting he had reached a stage of hopelessness. I interpreted for Ben, this left him feeling vulnerable and exposed to experiencing intense emotions at times of high conflict. I asked him if he ever talked to his other siblings, parents or teachers about the conflict which upset him, to which he responded:

> *"…no point. It's not like they're gonna do anything about it." (Ben, p.17)*

Participants also discussed a desire for feeling calm and wanting peace but felt they were unable to achieve this due to their siblings' behaviours. Jess and Lauren explained how their brother's behaviour caused stress as Tom denied them access to peace and quiet:

> *"Alright, but me and Tom argue like every single day and like more than 20 times." "***In a day***?" "Yer" "***And what's that like for you?***" "Stressful with work and like college as well, I can't have peace." (Lauren, p.2)*

Katy also expressed frustration at having a lack of power. This was due to her perception she was not able to support her sister in the way she felt she should

because of constraints placed on her by her school teachers. She had been '*told off'* on more than one occasion for trying to defend her sister when she was being '*picked on'.* Katy's perception she was therefore no longer able to support her sister in the way she wanted, left her feeling sad and worried.

Alongside feelings of hopelessness about situations participants found themselves in, was frustration at a power imbalance within their sibling relationship, contributing further to feelings of hopelessness. It is possible because all participants in my study (except Ben) were older siblings, they had expectations of being able to assert power over their brother or sister. Raven (1993) defines power in social relationships as relating to the availability of resources which each partner has, to influence the behaviour of their partner. Volling (2003) suggests an older sibling should assert more power due to age, experience and knowledge allowing older siblings greater chance at controlling the interactions. I interpreted participants viewed their interactions with their siblings as power struggles. Reference was made to siblings not listening to them, giving them 'attitude', dominating play and recreational activities and using their personal resources without asking. This led to feelings of anger, confusion and sadness and may have contributed to their hopelessness.

Given both King, Alexander and Seabi, (2016) and Kendall (1999) found siblings of CYP with ADHD experienced differences in parental treatment which contributed to their feelings of hopelessness, I was surprised this was not mentioned by my participants. However, Chloe did refer to challenges her mother

faced with managing her brother's behaviour and how she witnessed a power imbalance in the parent-child relationships in her family, alongside a difference in power between her mother and step-father when dealing with her brother's outbursts. She described how her mother would be powerless until her step-father was present to help resolve the conflict or outburst. She commented on how on rare occasions, witnessing her step-father use physical behaviour towards her brother made her feel angry as she could not help her brother and felt how he was treated was unjust. I interpreted not only did this contribute to Chloe's own feeling of hopelessness but she witnessed similar feelings of hopelessness in her mother as well.

Research has found adolescent siblings of children with ADHD report increased levels of anger, emotional reactivity and depression compared with peers who have typically developing siblings (Barker, 2011) and participants in this research reported these feelings. These findings could be explained in part by participant's frustration at feeling powerless to control aspects of their own lives and sibling relationships.

Notably, I was surprised to find participants had views on their siblings' use of medication for their ADHD. Three out of four siblings were being medicated and there was discussion around Chloe's brother being started on medication imminently although this was cause for strong debate between her parents. Taylor discussed how it made her upset that her sister required medication for her ADHD as she felt it changed her. I interpreted she felt as though her sister was being

altered in some way by the medication and this posed a threat to their relationship. She also felt uncomfortable as she viewed ADHD as part of her sister so by taking medication, her sister was in some way being altered:

> *"I don't really like the medication that she's been getting cos it changes her diet so when she has the medication she doesn't eat properly, like after the medication kicks in you, you see immediate change like she's always quiet… but like when I see her with the medication I just don't like it because that isn't Georgie." (Taylor, p.9)*

Both Taylor and Chloe appeared frustrated their parents did not listen to their views about medication. Although these views were not reflected across all participants, I felt it important to include given the controversy surrounding the medication of CYP with ADHD (Traxson, 2010). It could be suggested CYP should be involved in discussions about supporting their sibling, being informed on all interventions including medication.

4.3.2 Strategies for coping

The most common response for managing conflict at home was for participants to avoid their sibling. I interpreted this was effective for participants as they could remove themselves from being the target of their siblings' behaviours. Participants discussed using this as a precautionary method or as a reaction to avoid being drawn into conflict at times their sibling was feeling angry. It was most common for

participants to retreat to their bedroom while they waited for a situation to diffuse. Ben discussed avoiding talking to his sister when he felt she may have a negative reaction to his attempts to engage with her. This supports the finding in Kendall's (1999) research where CYP discussed the impact of their siblings on their daily lives, retreating or avoiding their sibling.

As in Kendall's (1999) study, participants learned to make accommodations for their sibling, influencing their own behaviour and lives. This was reiterated when their sibling was not around as they felt more calm and able to relax:

> *"It's quite tough cos then I have to feel like I have to like tiptoe around what I'm saying around her or stuff like that so I have to be a bit more careful if I say something that she don't like then I know I won't hear the end of it." (Ben, p.5)*

Accommodation for siblings' needs is a common finding with CYP with a sibling with ASD (Petalas *et al.,* 2009). Despite wanting change, participants found their own ways to come to terms with their situation, finding strategies for managing the disruption caused by their sibling. One implication of this is that feelings of ambivalence and tension could be created, particularly when CYP reflected upon the ways in which their lives are different to their peers due to the accommodations they made for their sibling.

In contrast with previous research (Kendall, 1999; Burston, 2005) participants in the present research did not discuss using retaliatory aggression as a strategy for

managing conflict. This may be explained by the level of empathy and understanding participants showed towards their siblings and their parents and by their desire for peace and harmony in the house. Alternatively, as it is less socially acceptable to be aggressive, participants may have avoided retaliation for social desirability factors. This increased introspection indicated that participants were willing to put their siblings' needs before their own.

4.3.3 Support

All participants had someone who they felt they could communicate with at times of conflict, typically their mother or a close peer. Participants described talking to their parents to help resolve arguments and conflict with their sibling. This was usually managed through calm discussion but ranged to parents engaging in their own physical or verbal struggles. In the case of all but one participant, mothers most frequently engaged in conflict resolution in the home, offering support when required. However, in contrast to findings from Burston (2005), none of the participants viewed either family members, professionals or peers as a source of emotional support. I got the sense participants felt their own emotions were something they should manage alone, so as not to cause their parents any more concern. Two participants discussed times where their mother was stressed or upset at home and therefore may not have felt confident to approach them for support with their own needs.

> *"…cos me and Joshua fight over the laptop and like I really wanna play on it for homework and I need to do a homework but Joshua just plays on the laptop and like my mum just,*

sometimes my mum just like starts crying because erm she can't like deal with it anymore like Joshua." (Chloe, p.10)

In a role reversal, Chloe later expressed how she offered her mother reassurance during times she was upset and her brother was being challenging. It is possible therefore, siblings may have felt their families needed more support feeling conflict was not always effectively managed by parents. The value of providing formal support for siblings of CYP with ADHD has not yet been examined, but Singer (1997) found children who attended family therapy camps for children with siblings with special needs helpful. However, overall there are inconsistent findings across studies and programmes of support for siblings of CYP with chronic illness or disability (Hartling *et al.*, 2014). The authors suggest interventions should be tailored to the differences in stages of sibling experience. For example, more input should be provided at the time of diagnosis. It has also been suggested siblings should have a role in the treatment of their siblings for those who have mental health problems (Ma *et al.*, 2017).

I became concerned about Taylor during her interview as she expressed high levels of anxiety, particularly towards the end of the interview. When I asked her to tell me where she could seek support for this she replied:

"Erm, sometimes from you as well so, you help me with like you know understanding as well, sometimes my mum." (Taylor, p.14)

The interview was my second encounter with Taylor and she was aware she was only likely to see me once more. This led me to believe Taylor did not have adequate support systems in place to help her manage her anxiety and with her permission I shared my concern with her mother and school staff who agreed to offer her a keyworker in school to provide emotional support and guidance. Whilst I do not claim Taylor's anxiety was caused by having a sibling with ADHD, this incident highlighted the importance of listening to CYP with siblings with additional needs to offer emotional support if required.

Taylor, Ben and Chloe referred to speaking with their friends about their sibling but appeared to keep the nature of their discussions with them superficial. For example, Ben would tell his friends:

> *"Yer, sometimes like I do tell them [friends] that "Oh Rachel's annoying me" and stuff like that." (Ben, p.14)*

Chloe wanted to share her experiences with someone but felt restrained by the fact her friends were not in the same position as her:

> *"I wish some of my friends, like their brothers had ADHD so I can compare it to mine, like I'm not the only one cos I feel like I'm the only like one, cos it's just really annoying." (Chloe, p.10)*

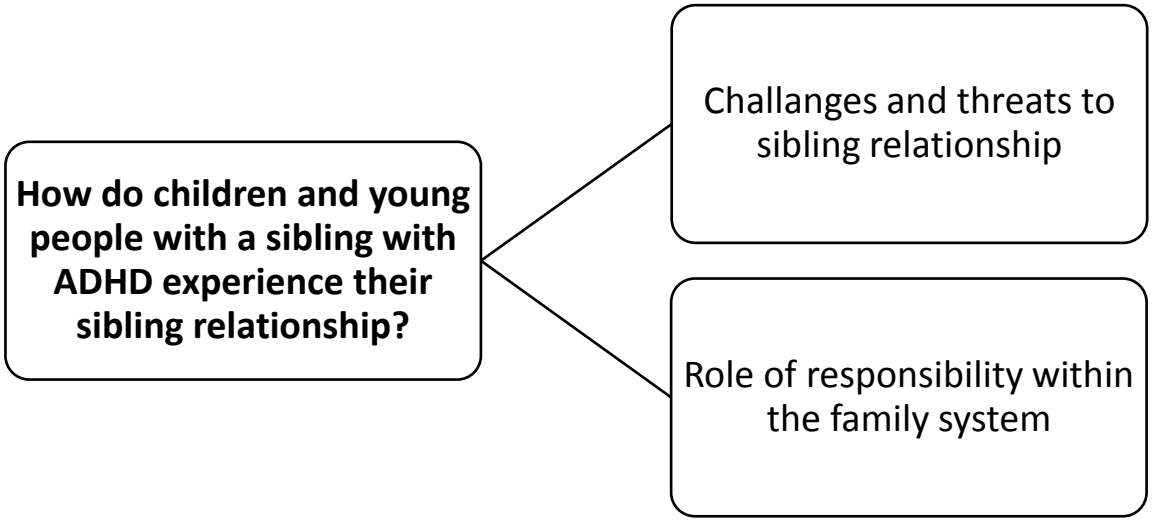
This suggests that Chloe may benefit from attending a support group for siblings of CYP with ADHD to share her experiences and feel less alone.

4.3.4 Summary

Overall, participants experience a range of complex emotions as part of their experience of growing up with a sibling with ADHD. All participants explained their own circumstances and the ways in which their lives were affected by having a sibling with ADHD. Participants appeared to be left with a feeling of internal conflict from wanting to be supportive of their sibling but not being able to manage their own emotions at times of high stress in their relationship. This could result in feelings of hopelessness at their situation, through having little control over how best to manage conflict and stress. Participants described how avoiding their sibling was an effective strategy for managing conflict but they acknowledged the impact this had on their own life satisfaction. Participants sought support from family members and friends to vent frustration with their sibling or manage conflict but did not see value in seeking support to manage their own emotions to maintain positive emotional well-being. As a result, participants felt isolated at times.

4.4 How do children and young people with a sibling with ADHD experience their sibling relationship?

Figure 8: Thematic map illustrating how children and young people experience their sibling relationship



All participants discussed important elements of their relationship with their sibling and how they felt this may or may not be affected by their sibling's ADHD as referred to in previous quotes. This theme comprises how the nature of the sibling relationship is shaped by interactions between participants and their siblings and the role they felt they played in supporting their sibling. Each participant relationship with their sibling was unique and broadly defined as either close and reciprocal or difficult.

4.4.1 Challenges and threats to sibling relationship

Nearly all participants described how there was some form of sibling conflict, which at times made their relationship difficult; varying from daily arguments to physical confrontations but this differed between individuals. This is not unique to

sibling relationships where there is a sibling with additional needs. There are a multitude of dimensions by which typical sibling relationships can vary, comprising positive and negative factors (Furman and Buhrmester, 1985). However, due to increased conflict within relationships where a CYP has ADHD (Burston, 2005) relationships have the potential to be more difficult to negotiate.

Four out of the six participants reported daily conflict with their siblings which they believed affected the nature of their relationship with their sibling. This conflict ranged from arguments to physical behaviours such as objects being thrown in anger. In one case, verbal conflict left Ben feeling victimised within his relationship and he felt afraid at times for his safety, due to the nature of the threats made by his sister. Ben's body language and voice intonation conveyed his distress, relating how profoundly these threats affected him. During the interview Ben began to cry as he retold me several examples of this:

> *"Sad sometimes, to know that my own sister is saying to me (starts crying) 'I'm gonna kill ya.'" (Ben, p.15)*

This affected his relationship with his sister so much that he recalled he had told his sister that he wished he wasn't a twin with her.

Chloe reflected this view pausing before telling me:

> *"Sometimes I wish I didn't have a brother but like, that's sad. I wish I had a brother without ADHD or like something and I just can't." (Chloe, p.9)*

For both these participants, the conflict experienced within their sibling relationship had such a negative effect on their own well-being they experienced moments where they wished they did not have a sibling or that their relationship was different in some way.

Three participants discussed ways in which they wished their relationship with their sibling was different, indicating their discontent with their current relationship. Chloe desired to be able to talk to her brother more and '*draw pictures'* with him. She explained how she tries to engage in activities with him but he gets frustrated, ending the activity with destruction. Lauren also explained how she wanted a '*nice*' relationship with her brother but described how '*one little thing'* could annoy him and that would ruin their day, putting a strain on their relationship. These examples highlight the fragility of relationships the siblings experienced.

Ben expressed sadness at how he didn't have the relationship he wanted with his sister. He made comparisons between the relationship he had with his older siblings (without ADHD) and with his twin, making specific reference to his inability to have a joke with his twin for fear of making her angry. He reflected on how his twin may have perceived seeing him having a different relationship with his older sisters, concluding it would make her feel excluded demonstrating his empathy for

her. Sibling conflict has been a significant theme in the limited research in this area (Singer, 1997; Kendall, 1999; Burston, 2005) however, the severity and intensity of aggressive behaviours from siblings did not appear to be as severe in the present research.

In contrast to these views, Taylor and Katy appeared to experience less conflict with their sister and discussed their understanding of Georgie's needs. They both described times when they supported their sister and both spoke positively about her throughout their interviews than other participants. Taylor and Katy were the two eldest siblings of five girls who spoke of warm relationships between the rest of their siblings. This may explain the differences in their experience when compared with the other participants. In addition, Taylor described the close bond she felt within her sibling relationship:

> *"that's how close we are so like, me and Georgie, I think we're like, I don't know it's hard to explain but I have more of a bond to Georgie than all of my other sisters cos I understand her." (Taylor, p.5)*

This bond within a sibling relationship is reported in the literature exploring experiences of siblings of CYP with ASD (Petalas *et al.*, 2009; McHale, Updegraff and Feinberg, 2016; Mehok, 2017). The bond is thought to be strengthened through engaging in bonding activities, sharing positive experiences and through CYP demonstrating empathy for their siblings.

Jess and Lauren described having a close relationship with each other but had different relationships with their brother, Tom. Lauren's experience of her relationship was significantly affected by sharing a bedroom with her younger brother. As a 17 year old female, she found this particularly restrictive on her social life and held her brother responsible for this. Her negative feelings towards him and their relationship appeared to stem from her frustration at having to share her personal space. She felt this made their relationship fragile and this frustrated her. When asked what it was like having a difficult relationship with Tom she replied:

> *"Annoying, because I would want a nice relationship with my little brother…but I don't think it will happen…" (Lauren, p.4)*

She later agreed if she were no longer sharing a room with him she could imagine her relationship with Tom would improve. Her older sister Jess described differences between her relationship with her brother and Lauren's. She described her own relationship with him as one where "*we get along more than we argue*." (Jess, p.11)

One of the factors which appeared to play a role in creating conflict within the sibling relationship were issues around intentionality of behaviour. Despite making earlier claims about understanding their siblings could not help or control their behaviour, some participants felt they were targeted by their siblings' behaviour and their sibling was causing conflict deliberately. Participants who reported more

conflict between themselves and their sibling were more likely to hold this view. For example, Lauren stated that despite her trying to support her brother:

> *"… he doesn't see that. He just takes it all out on me."* *(Lauren, p.3)*

4.4.2 Role of responsibility within the family system

As part of their relationship with their sibling, all participants discussed the variety of ways in which they felt they supported their sibling in either a parental or caregiving role, regardless of whether they felt they had a close or difficult relationship. Some participants reported their parents expected them to play a role in supporting their siblings whereas others appeared to take it upon themselves to assume a caring role. This is a strong theme from the literature where CYP have a sibling with ASD (McHale, Updegraff and Feinberg, 2016), chronic illness or disability (Alderfer *et al.*, 2009; Hartling *et al.*, 2014) and ADHD (Kendall, 1999; Burston, 2005; Steiner, 2014; King, Alexander and Seabi, 2016; Peasgood *et al.*, 2016)

Participants discussed the ways in which they would supervise and support their sibling, particularly when their sibling was in some form of trouble. For example:

> *"Or like, I'd stick up for Tom, like he's broke his phone or something and mum and dad would go mad at him if he's broke his phone and he'd be like, "oh no I've broke my phone." So I'd go downstairs and be like "Oh, I've just dropped Tom's phone." You know like I'd stick*

up for Tom so he wouldn't get into trouble cos I don't like that…"(Jess, p.5)

For some participants, this role was extended when they were in school, supporting their sibling on the playground at times they felt they were being bullied or picked on. Of those participants who were asked how or why they assumed this role, they viewed it as their duty and because their parents were not present at certain times. I interpreted this finding could explain some of the emotional experiences participants described as previous research has reported siblings with a heavy caretaking role and role of responsibility are more likely to experience difficulties with regulating their emotions and behaviours than their peers (McHale and Gamble, 1989).

Most participants appeared to take pride in providing a supervisory and supportive role for their siblings, speaking positively about all they did to support them. However, for Chloe this role seemed unreasonable as she did not feel her brother reciprocated the care she provided for him at times she wanted or needed:

"Yer. But he don't protect me. Well, he shares things with me but like he doesn't like protect me as well as I protect him." (Chloe, p.5)

This role of responsibility led some participants to feel ambivalent. At times, they disliked this role as it had potential to lead them into conflict with their siblings. For example, when parents asked them to wake their sibling up for school, support

them with homework or help make dinner for them, this would often end in conflict. Participants also worried about their siblings in school, in the community and at home. They described instances of sticking up for their siblings in front of peers, protecting their feelings when peers made nasty comments, minimising their diagnosis and worrying about the times when their sibling may get into conflict with their peers.

> *"… she always used to come crying to me saying that people are picking on her and everything and I had to go sort it out and then I got into trouble for it." (Katy, p.9)*

Although only one participant referred to age-related factors, the participants' ordinal position in the family may have played a role in them assuming a caretaking role for their younger sibling. It is possible this was a strong theme from the data as all the participants were older siblings. For example, Stoneman *et al.,* (1998) found that typically the eldest female sibling adopts more caretaking roles within the family and tend to be most adversely affected by this. The exception was for Ben who was a twin. Ben's twin offered a parental role reversal, trying to act as a parent towards him.

I interpreted both participants' ordinal position in their family, assuming a caretaking role and experiences of having a sibling with ADHD influenced their identity formation. Experiences in life help you to determine how you see yourself. These become accommodated into a sense of self so it is reasonable to assume participants' experiences of caretaking and their sibling relationship may become

assimilated into their identity. At this stage, this assumption is my interpretation from my findings and there is no previous literature concerned with the identity of siblings of CYP with ADHD. This is something future research should consider.

4.4.3 Summary

Each participant experienced their sibling relationship differently but all experienced conflict at times. Sibling relationships are reported to be punctuated with conflict and tension which can manifest from arguments to physical behaviour and the findings confirm what has been reported in previous literature (Kendall, 1999; Burston, 2005; King, Alexander and Seabi, 2016). This has implications for the emotional well-being of individuals with a sibling with ADHD. However, not all participants perceived their relationships as negative with their siblings. Having multiple siblings and being of the same gender (female) appears to offer some protective factors and help a warmer, more reciprocal relationship form. Participants who did not view their relationship with their sibling as warm, showed a desire to improve this. It has been suggested including siblings in the treatment of mental health problems can help improve family relationships (Ma *et al.*, 2017). Future research could explore whether such an approach could be effective for CYP with a sibling with ADHD.

All participants adopted a form of caregiving role to their younger siblings, offering them emotional and practical support through their individual challenges. I suggest that could influence their identity development. It has been found siblings of

children with mental health problems are more likely to go on to work in caring professions (Ma *et al.*, 2017). Therefore, it could be implied by taking on a caring role for a sibling with additional needs, their future aspirations are influenced. Not all siblings view this caring role with pride. Professionals should have an increased awareness of the demands which may be placed on siblings to care for their brother or sister and the implications this may have for their own well-being.

4.5 How do participants describe the positive characteristics of their sibling?

As part of the semi-structured interview, each participant was explicitly asked to describe the best thing about their sibling and provide an example of a time they had done something well together. Although all participants acknowledged they experienced challenges at times with their siblings, they were all able to identify at least two positive aspects of their relationship and their siblings' characteristics. The table below (*Table 9*) presents a summary of the positive characteristics by participant, as these perspectives were personal and unique. I did not look for superordinate themes and subordinate themes for this research question as it did not relate explicitly to the presence of ADHD in the participant's siblings' lives.

Table 9: Positive characteristics of sibling with ADHD as described by participants

Sibling	Participant	Characteristic	Quote/Examples
Georgie	Taylor	Happy Generous Creative Active	*"I think she's more creative as well cos some of the things that she makes with like the toilet paper and everything, I wouldn't be able to do that…but she's really creative" (p.6)* *"I know she's a really happy girl and she can be like really nice when she wants to be" (p.7)*
	Katy	Happy Funny Honest Playful	*"We'll play like tag, hide and seek erm we would play with our toys and we'll play dodgeball" (p.3)* *"She's funny…she erm, she makes funny faces, she tickles people" (p.4)* *"…she likes making people laugh" (p.6)*
Tom	Lauren	Funny Active Nice	*"…when he's in a good mood he's actually really nice so and like if he's in like, even on his game he'll try and like get me involved with it" (p.5)* *"…he'll get like a song but without words and he'll just rap randomly like, he'll just rap random words and he just rhymes this, it's funny what he says" (p.5)*
	Jess	Funny Active Sensitive Honest Kind	"*I dunno but he can just be so funny"(p.6)* *"…he can be really sensitive sometimes like say if me or like Lauren was crying he's come up, "oh are you ok?" (p.7)* *"…if my mum's upset or she's just feeling down or something or whatever, he'd just*

Sibling	Participant	Characteristic	Quote/Examples
			go up to her give her a hug and a kiss" (p.7) *"He loves going on his, like going out on his mountain bike and stuff like with his friends. He'll come back like really proper dirty like last night because he was going down all these track and stuff with all of his friends." (p.5)*
Rachel	Ben	Nice Generous Imaginative Happy Active Protective	*"She can be quite a happy person sometimes if she's not in a mood" (p.5)* *"…actually I do remember one time we used our imaginations and we erm built like a time machine type thing and then we spent time together and we were fine." (p.8)* *"Yer, she's quite protective of me" (p.9)*
Joshua	Chloe	Kind Generous Playful	*"…he chooses his moments like sometimes he can be really kind and like cos he always does things to me, if I do something he copies me and like if I like wanted an ice cream and there's only one left he'll give it to me like" (p.10)*

4.5.1 Summary

All participants expressed some positive views of their sibling, although to varying extents. This included positive descriptions of their sibling's behaviour and positive interactions and time spent together. The majority of participants described their siblings as being 'active' and could easily recall times they had enjoyed engaging in play and recreational activities together, typically outdoors. This offers insight into the type of activities participants enjoyed taking part in with their siblings. It is interesting to note that being 'active' was an important characteristic as it could be argued this is linked to their conceptualisation of their sibling's diagnosis. A similar finding was reported in a study designed to elicit the perceptions of twelve adolescents with a brother with ASD (Petalas *et al.*, 2012). In one of few studies to report positive perceptions and experiences of having a sibling with ASD, participants described moments of fun and pleasure they had together. They also commented on the positive aspects of their brother's character and temperament. Participants in the present study were also keen to share their siblings were happy, funny and generous. This finding indicates they have a good knowledge of their sibling's overall character and although they present a bias towards reporting negative attributes, they can acknowledge alternative attributes.

Participants reporting positives about their sibling was a unique finding when compared to previous literature exploring experiences of CYP with a sibling with ADHD. None of the papers reviewed for the purposes of the literature review in this research made reference to any positive features of the sibling relationship, or

sibling characteristics. This may be explained by the research design and methodology used in five of the studies, which did not intend to explore this phenomenon (Jones *et al.*, 2006; Listug-Lunde, Zevenbergen and Petros, 2008; Mikami and Pfiffner, 2008; Steinhausen *et al.*, 2012; Peasgood *et al.*, 2016). When designing my interview schedule, I intended to explore participants' thoughts taking a positive approach, but it is possible they would have not identified any positives without this prompt. This influenced the participants' thinking and the interview, as only a minority of the positive comments were made spontaneously. From early in development, humans demonstrate a negativity bias when processing social information (Vaish, Grossmann and Woodward, 2008). This suggests individuals attend more frequently to information which is negative and are more likely to recall this (Fivush *et al*., 2003). To overcome this bias and to address the lack of positive sibling relationship reports in previous literature, I was deliberately direct in my questioning to elicit positive attributes. This provided me with an understanding of the participants' relationships and experience as a whole.

CHAPTER FIVE: CONCLUSION

5 Conclusion

5.1 Introduction to chapter

The purpose of this research was to explore the experiences of CYP with a sibling with ADHD to address a gap in the literature and promote a person-centred approach to the findings. Specifically, this study aimed to shed light on how participants understand their siblings' ADHD including the positive aspects, how they experienced their sibling relationship and growing up with their sibling. This chapter provides a summary of the findings, critical evaluation of the research, suggestions for future research and implications for EPs in the UK.

5.2 Summary of research findings and original contribution to research area

This study was the first to take an in depth look at the experiences of CYP with a sibling with ADHD in the UK using a qualitative approach. Previous studies have looked at quality of life and psychological functioning in siblings, generalising the findings across participants rather than seeking their individual views. This research, aligned with my theoretical positioning, prioritised individual experience above making generalisable claims about a population of CYP who may share some similar experiences. Two previous studies have explored this but in two different countries where ideas about family systems, the conceptualisation of ADHD and the context of the education system may differ. In addition, one of

these studies relied on adult participants reflecting on their experiences as children. Their current views on their relationship with their sibling may have affected these reflections.

Sibling relationships and the presentation of ADHD in a CYP may be affected by several factors which contribute to creating an individual set of circumstances for CYP's experiences. It was my intention to explore these experiences through immersion in the data to interpret how participants made sense of their experiences. This helped me to understand more about factors which may influence their sibling relationship and their lives. Although IPA has been used to explore experiences of siblings with other disabilities and illnesses (Teuma, 2013; Dervishaliaj and Murati, 2014; Petalas *et al.*, 2015), this is the first to my knowledge which has used this methodology with siblings of CYP with ADHD. I have therefore been transparent with the design frame and analysis procedure.

When comparing my findings to previous research in the area, I found there are some shared experiences such as conflict within the sibling relationship but some unique to my participants for example, the lack of understanding of ADHD and the influence of adopting a caretaking role on identity development. This may suggest despite cultural differences between the UK, USA and South Africa, behaviours associated with ADHD present in similar ways and may have a comparable impact on sibling relationships. Furthermore, despite quantitative studies suggesting there are differences in psychological functioning in siblings of CYP with ADHD when compared with control siblings, little has changed in terms of identification and

awareness of the needs of this population and support is not yet sufficient for this group of CYP. This study highlights participants' need to accommodate their siblings' behaviours including avoiding their sibling. This may contribute to the emotions described by participants which they appeared to fail to have effective strategies for managing.

The present research demonstrates that despite challenges faced within the sibling relationship, CYP with a sibling with ADHD can make positive attributions about their sibling. Participants talked fondly about enjoyable moments they shared together and where there were difficulties, participants wanted to improve their relationship. Few studies have explored positives associated with having a sibling with disabilities and research tends to draw attention to deficits in siblings' lives. To maintain a balance in the literature, future research should ensure to identification of positives, where possible.

5.3 Critical evaluation of the research

A strength of this study is it adds to the limited research base on the experiences of CYP who have a sibling with ADHD and the possible influence this may have on their lives and identity. However, it is important to recognise it is not possible to assume causality and claim the presence of ADHD in the sibling is the reason for the findings. The present research places significant value and importance on the voice of CYP themselves, whereas previous research may have been biased by parental reports and questionnaire tools not sensitive enough to detect the ways in

which siblings feel they are affected. Furthermore, this research provides new perspectives for professionals who may work with individuals who have a sibling diagnosed with ADHD.

I approached this research using a social constructionist paradigm and as discussed in Chapter 3, reliability and validity cannot be used to determine whether research maintains rigour (Burr, 2003). It was not my intention to identify objective facts or make claims about truth from my findings. For my findings to be considered acceptable I included a thorough explanation of the data analysis procedure in section 3.7 and examples of this can be found in the appendix. In addition, a peer and supervisor assisted me with clarifying my themes due to my limited experience with using IPA and to reduce bias where possible. It was important for me to document my reflexivity during the interview and analysis procedure and research diaries were kept to aid this (Appendix 1).

A limitation of this study in relation to data analysis is the lack of engagement from participants with stage 3 of the study. This stage would have allowed me to share my analysis of the data with participants for them to check I had represented their experiences with accuracy which Pring (2004) suggests would add to validity of the findings. Three participants did not want to take part in this stage without offering a reason, two were willing to take part but due to logistical complications after four attempts at arranging this session it was agreed the session would not be carried out. One participant wanted to engage in the third session but to date a suitable time/place has not been agreed on. However, for the research to remain

participatory and for findings to be shared with participants and their siblings, a summary sheet of the positive descriptions of their sibling was sent to them in the post with a thank you letter (Appendix 8 and 9).

To counter further potential threat to the quality assurance of the research findings using IPA, the limitations of the inductive nature of the process need to be acknowledged. I was aware from conception of this research idea that my own experience of having a younger brother with ADHD may influence my aims, the questions in the SSI, data analysis procedure and reporting of the findings. The issue of qualitative researchers being members of the population which they are studying has been discussed with differing views on the benefits and limitations of being an 'insider researcher' (Cho and Trent, 2006; Dwyer, 2009). On reflection, I feel being an insider researcher makes me a different type of researcher and I acknowledge the strength and limitations of this. It can be argued being an insider researcher can enhance the depth and breadth of understanding within a population which may not be accessible to outsider researchers (Dwyer, 2009). It also allows quick acceptance by participants; I disclosed my justification for selecting this population to participants and their parents. Participants may have therefore been more open and honest with their answers to me. Two participants told me outside the interview they had never spoken openly or at length about their feelings towards their sibling before and while there may have been other reasons for this, perhaps feeling I would understand influenced their honesty. However, it is possible my perceptions may have been affected by my personal experience and the SSIs and analysis may have been guided by core aspects of

my own experience and not my participants'. For example, I may have placed emphasis on shared factors between myself and the participant and not noticed factors which were discrepant from my experience. However, I attempted to alleviate this through seeking supervision through the analysis procedure.

Another factor which may have influenced two of the SSIs was safeguarding disclosures which were made. For one participant, I became concerned about her ability to manage her anxiety towards the end of the interview therefore it did not affect what was discussed prior to this. However, the direction of the interview was altered towards the end as I asked more questions related to the participant's anxiety and support mechanisms. This may have had an effect during the analysis of her data as I may have interpreted some of her experiences differently after having conversations with her mother and school pastoral lead as they shared more information about her anxiety at home and in school. For the second participant, concerns were raised around the way physical restraint and management of her brother were used by her step-father. This required a referral to 'Early Help' with the permission of the parent. My concerns and the words used by the participant were shared with the safeguarding leads at both my participant's school and her sibling's, who made the referral and liaised with the parent. The parent was offered the chance to withdraw data from the study but did not feel this was necessary. This disclosure also affected the direction of the interview as the participant appeared to be nervous about being honest for some of the following questions. I also shared my concerns about a third participant become emotional during his interview with the pastoral lead at school although this was not

considered a safeguarding concern. As half of the participants in this study raised concerns significant enough for me to share, this highlights the importance of listening to this population of CYP.

Finally, the research findings presented in this study present only a snapshot in time which may have been affected by the conditions of the day and time the interview took place. For example, outside of the interview one participant reported he had had an argument with his sister that morning. Given that sibling relationships can fluctuate over time (Kramer, 2010) it may have been useful to collect data over a several time points as part of the research process, using a participant diary. Or, if a narrative approach was adopted participants could be encouraged to story their relationships to date over time and imagine their future relationship. Therefore, this research could be improved if participants were encouraged to offer thoughts on their experiences over time.

5.4 Future research

Drawing on the findings and the critical evaluation of the present research, there are several directions for future research to consider. The present study included six CYP who were all older (or the same age) as their sibling with ADHD. Previous research has identified older siblings are more likely to adopt a caretaking role in their relationship. Therefore, it may be interesting for future research to explore whether siblings who are younger than their sibling with ADHD have the same experiences and adopt the same role. However, through my experience of using

IPA with CYP as young as eleven I would suggest if it were used in future research with participants a similar age or younger, it would require adaptation to aid CYP sharing their ideas through games or activities.

The sample of participants in past research and the present study lacks cultural diversity. The participants in this study were all white, British. As there are cultural differences in attitudes towards levels of inattention and activity (Sonuga-Barke *et al.*, 1993) it may be that a diagnosis of ADHD is not sought from members of different ethnic groups. It is reported diagnosis of ADHD is distributed unequally by social class and ethnicity (Timimi, 2006). Different environmental circumstances for these differing groups may mediate the experiences of siblings of CYP with ADHD which may warrant further exploration in future research. Furthermore, sibling relationships differ across cultures (Weisner, 1989) and experiences of CYP with a sibling with ADHD may present differently.

It was of interest in the present research there was some indication having a sibling with ADHD may influence identity development. While there is research which supports the finding that CYP with ADHD may themselves adopt a disability identity (Kenny, 2016), little has been done previously to explore how having a sibling with ADHD may interact with identity development. This study suggests adopting a caretaking role within a sibling relationship may be assimilated into the individual's identity but this warrants further exploration from future research.

5.5 Implications for Educational Psychologists

As advocates for all CYP, EPs should be aware and well-informed of the unique concerns and challenges which siblings face. Having a sibling with ADHD may put CYP at risk of greater emotional reactivity and exposure to conflict and there is not yet an established intervention for supporting this population. By recognising the risk factors which may play a role in CYP's psychological functioning and identity development, EPs can attempt to address these areas to mediate the impact of their sibling's needs on them. If EPs are aware of a CYP with a diagnosis of ADHD, they may be well positioned to raise awareness of the potential additional needs for a sibling to parents and school staff.

Reflections from my own experience and this research have lead me to conclude specific intervention may not be necessary. Having an identified key adult to provide pastoral support and listen to the CYP may be sufficient and it is likely this is more achievable in a short timeframe than more intensive psychological intervention at a time when access to support services is challenging. The interviews in this study appeared to have a therapeutic effect with some participants, allowing them to share their thoughts and feelings on a topic which they may not have previously been asked about. One participant told me she'd never talked to anyone about herself so openly before and appeared to value the opportunity to share her thoughts and feelings about her brother. This has an important implication for EPs who may find themselves uniquely placed to offer

time and space for a CYP to share their views, or recommend that they are offered a key person in school to the same effect. Research has reported there are benefits to siblings sharing their experiences with those who are in a similar situation as this can help them to feel positive towards their sibling (Johnson and Sandall, 2005). However, with the recent shift to a traded model of service delivery in the majority of UK LA EP services, it may be that siblings of CYP with ADHD do not meet the criteria for referral to the EP service and therefore would be unable to access direct support without this prioritisation.

A study which examined siblings of children who had a chronic illness or developmental disability found where siblings had an increased knowledge of their siblings' condition, they had improved well-being (Williams et al., 2002). It has also been reported siblings found information sessions and support groups useful for learning more about their sibling's additional needs (Sharpe and Rossiter, 2002). Considering the finding that none of the participants in this study could define what ADHD is, it could be recommended EPs help to raise awareness of the importance of sharing information with siblings and signposting to support groups for this population or support schools to offer joint sessions for the CYP and their sibling to encourage positive experiences together. Furthermore, emotional support from family and friends should be promoted as this appears to have a protective role in siblings of children with a chronic illness (Barrera, Fleming and Khan, 2004). It may be also beneficial at the point of diagnosis, to offer alternative views to the medical conceptualisation so siblings understanding there are different approaches to supporting their sibling available. Although my participants

did to varying degrees demonstrate empathy for their siblings with ADHD without fully understanding their diagnosis it could be suggested with further understanding, some of the frustration and anger could be reduced. Brodzinsky *et al.,* (1986) in Glasberg (2000, p.152) suggest there is a clear distinction between 'telling' on the part of the adult (parent) and 'understanding' on the part of the child. As there is evidence to suggest the developmental level of the child may influence their understanding of the implications of a diagnosis, EPs may be able to support parents and school staff in ensuring CYP with a sibling with ADHD understand the implications of their sibling's diagnosis.

There is indication in the findings from this research that a purely medical approach to the definition and intervention for ADHD is too reductionist. Therefore, it does not allow for a full understanding of the complexities of other factors which may influence the development and maintenance of ADHD behaviours in a CYP. This may have had an influence on the participants' feelings of powerlessness to change their situation and therefore contributed to the maintenance of a high-conflict, emotional home environment. As BPS (2018) and NICE guidelines (2018) recommend, ADHD should be understood using a biopsychosocial model. Adopting this approach considers biological, psychological and social factors which may influence development and functioning in CYP with ADHD. Furthermore, there is an emphasis on assessment at a systemic level which can then inform intervention to be targeted at the most appropriate levels (Pham, 2015). EPs should be encouraged to consider cognitive, academic, behavioural, socio-emotional and physical factors to determine overall functioning, tailoring

intervention appropriately to meet the needs of the CYP. As part of this assessment, consideration should be given to how the CYP interacts with their different environments within their ecological systems (Bronfenbrenner, 1979). This may include determining what relationships are like between siblings and within family systems.

Familial factors have been explored in relation to severity of ADHD behaviours and aggression and defiance have been demonstrated to be linked to the context of negative and harsh parenting or difficult parenting environments (Campbell *et al.,* 1996). One way of measuring family context and emotional tone within the family environment is through parental expressed emotion (Musser *et al.,* 2016). This can be understood as an index of emotional intensity in the home comprised of criticism and emotional over-involvement from parents (Musser *et al.,* 2016). Expressed emotion is typically assessed during semi-structured interviews and high expressed emotion has been linked with ADHD behaviour severity. In the present study, the focus was not to determine parental expressed emotion but comments made by participants indicate this may be something that warrants future exploration and may be useful to determine prior to the implementation of intervention at a family system level.

Bronfenbrenner's ecological systems theory may help EPs to determine the most appropriate course of intervention for CYP with ADHD and their families, whilst keeping in the mind the challenges of delivering these interventions at a time when austerity and resulting cuts to support services is having an impact on the

ability for schools and services to deliver the required intervention (Rhodes, 2017). For example, interactions within the microsystem of Bronfenbrenner's model include familial relationships. Intervention such as the Relational Awareness Programme (Timimi, 2017) targets these relationships to support the development of more positive relationships within a household. As siblings are part of this system, they could be included in this type of intervention and this may improve their overall experiences of having a sibling with ADHD.

Finally, the present and previous research suggest a comprehensive approach to working with and supporting families manage conflict in the home may be beneficial. EPs could offer training and support with conflict resolution and restorative practice in attempt to create more harmonious relationships between siblings. These types of intervention move away from a 'within-child' understanding of ADHD and therefore place less emphasis on the need for medication as a sole form of intervention for a CYP with ADHD.

5.6 Concluding comments

To summarise, this small-scale research study has added to the paucity of research exploring the lived experiences of CYP who have a sibling with ADHD. The significance and meaning of this experience was explored using IPA to offer insight into the worlds of six participants. It was found that despite individuals having a different experience with their sibling, there were several common themes amongst participants' views. This study has original contribution to this

area and several practical implications for supporting siblings of CYP with ADHD and ideas for future research have been recommended.

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APPENDIX 1 : EXAMPLE REFLECTIVE DIARY ENTRY – (BEN)

Student interview – Ben

- Able to develop rapport with Ben, referred to some discussion from Session One
- Felt more fluent with questioning technique as last interview conducted – did not need to look at interview schedule as much.
- Still too many 'yeahs' which interrupted some of the flow
- Found it tricky not to be influenced by the content of the previous interview – in future would not conduct more than one interview on one day so as not to have any bias based on what was noted from previous interview
- Did I check back my understanding of his words enough during the interview?
- How well has this interview helped him tell his story? Has it had a therapeutic affect being able to share his experiences for the first time?
- Felt as though Ben could articulate himself fluently
- Considered if Ben's argument with his sister in the morning influenced the direction of the interview making him more biased towards his negative experiences with Rachel.
- Overall sense that Ben has not talked like this with anyone about his feelings before – why not? Linked to his feelings of hopelessness?
- Ben found it difficult to talk about positives with his sister
- Shared concerns with school about the victimisation Ben talked about in his interview
- Turned audio recording off when interview had finished but had further discussion but changed topic of conversation to help Ben calm down before he went back to class
- Ben misunderstood my questions about how Rachel is different from other sisters, comparing Rachel to his other sisters rather than sisters in general

Transcribing

- It is noticeable that when Ben is talking about something emotional, he stutters and trips over some of his words
- Becoming more aware of how significantly the conflict with Rachel is affecting him - has this affected his self-esteem?
- Noticed how he really accommodates Rachel's behaviour towards him

APPENDIX 2 : INTERVIEW SCHEDULE

Prior to interview:

Remind the participant of the purpose of the research using the information sheet
Read aloud the consent form and ask the participant to sign
Remind the participant about using a voice recorder (session 2 only)
Remind the participant they can stop the session at any point without reason
Remind the participant that their information will be confidential unless they share anything which causes the researcher to worry
Choose pseudonym with the participant
Ask the participant if they have any questions before the session starts

Recording on tape: this is Tamzin talking to (Pseudonym)

Interview questions: (prompts, probes in brackets)

Kinetic family drawing

Can you tell me a bit about your picture?

Can you tell me about who is in your family? (what do they do, what are they like?)

Can you tell me a bit about yourself? (how would you describe yourself, how would your friend, teacher describe you?)

Tell me what it is like to be X's brother/sister? (what is it like growing up with them?)

Can you tell me about your brother/sister? (how would you describe them to your friends? What do they like/dislike? What is the best/worst thing about them?)

How do you spend your time with your brother/sister? (what do you enjoy doing? What is your favourite activity/game you play with your brother/sister?)

Can you tell me a time when you and your brother/sister have done something really well together?

How is your brother/sister similar or different to others?

How would things be different if your brother/sister did not have ADHD?

What does ADHD mean to you? (How would you describe ADHD to someone who doesn't know about it?)

What advice would you give to other people who have a brother/sister with ADHD?

Do you think it affects you at school? (how)?

Do you think it affects you at home? (how)? Do you think it affects your friendships? (how)? Is there anything that school/family/friends do that helps you? What is it like growing up with your brother/sister? Is there anything else you would like to tell me?
End of session: End audio recording Thank the child for their participation and remind them of the importance of their views.

APPENDIX 3 : APPLICATION FOR ETHICAL REVIEW

☆ **Samantha Waldron** 13 June 2017 at 10:37 Details SW

Application for Ethical Review ERN_17-0263

To: Anita Soni, Cc: Tamzin Messeter

Dear Dr Soni,

Re: "What are the lived experiences of siblings of children and young people with attention deficit hyperactivity disorder (ADHD): An Interpretive Phenomenological Analysis."
Application for Ethical Review ERN_17-0263

Thank you for your application for ethical review for the above project, which was reviewed by the Humanities and Social Sciences Ethical Review Committee.

On behalf of the Committee, I confirm that this study now has full ethical approval.

I would like to remind you that any substantive changes to the nature of the study as described in the Application for Ethical Review, and/or any adverse events occurring during the study should be promptly bought to the Committee's attention by the Principal Investigator and may necessitate further ethical review.

Please also ensure that the relevant requirements within the University's Code of Practice for Research and the information and guidance provided on the University's ethics webpages (available at https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Links-and-Resources.aspx) are adhered to and referred to in any future applications for ethical review. It is now a requirement on the revised application form (https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Ethical-Review-Forms.aspx) to confirm that this guidance has been consulted and is understood, and that it has been taken into account when completing your application for ethical review.

Please be aware that whilst Health and Safety (H&S) issues may be considered during the ethical review process, you are still required to follow the University's guidance on H&S and to ensure that H&S risk assessments have been carried out as appropriate. For further information about this, please contact your School H&S representative or the University's H&S Unit at healthandsafety@contacts.bham.ac.uk.

Kind regards,

Miss Sam Waldron
Deputy Research Ethics Officer
Research Support Group

[redacted]

Web: https://intranet.birmingham.ac.uk/finance/accounting/research-support-group/Research-Ethics

Please remember to submit a new Self-Assessment Form for each new project.

Click Ethical Review Process for further details regarding the University's Ethical Review process, or email ethics-queries@contacts.bham.ac.uk with any queries.

Click Research Governance for further details regarding the University's Research Governance and Clinical Trials Insurance processes, or email researchgovernance@contacts.bham.ac.uk with any queries

UNIVERSITY OF BIRMINGHAM APPLICATION FOR ETHICAL REVIEW	*OFFICE USE ONLY:* Application No: **ERN_17-0263** Date Received:

1. TITLE OF PROJECT

What are the lived experiences of siblings of children and young people with attention deficit hyperactivity disorder (ADHD): An Interpretive Phenomenological Analysis.

1. **THIS PROJECT IS:**

University of Birmingham Staff Research project ☐
University of Birmingham Postgraduate Research (PGR) Student project ☒
Other ☐ (Please specify):

2. **INVESTIGATORS**

a) PLEASE GIVE DETAILS OF THE PRINCIPAL INVESTIGATORS OR SUPERVISORS (FOR PGR STUDENT PROJECTS)

Name: Title / first name / family name	Dr Anita Soni
Highest qualification & position held:	Educational Psychology Doctorate, Academic Supervisor
School/Department	School of Education
Telephone: Email address:	

Name: Title / first name / family name	
Highest qualification & position held:	
School/Department	
Telephone:	
Email address:	

b) PLEASE GIVE DETAILS OF ANY CO-INVESTIGATORS OR CO-SUPERVISORS (FOR PGR STUDENT PROJECTS)

Name: Title / first name / family name	
Highest qualification & position held:	
School/Department	
Telephone:	
Email address:	

c) In the case of PGR student projects, please give details of the student

Name of student:	Tamzin Messeter	Student No:	
Course of study:	Applied Educational and Child Psychology Doctorate	Email address:	
Principal supervisor:	Dr Anita Soni		

3. **ESTIMATED START OF PROJECT** Date: 22/05/2017

ESTIMATED END OF PROJECT Date: 04/06/2018

4. **FUNDING**

List the funding sources (including internal sources) and give the status of each source.

Funding Body	*Approved/Pending/To be submitted*
N/A	

If you are requesting a quick turnaround on your application, please explain the reasons below (including funding-related deadlines). You should be aware that whilst effort will be made in cases of genuine urgency, it will not always be possible for the Ethics Committees to meet such requests.

To allow adequate time to identify participants and request their involvement before the summer holidays begin, it is hoped the project will commence by the beginning of June at the latest.

5. **SUMMARY OF PROJECT**

Describe the purpose, background rationale for the proposed project, as well as the hypotheses/research questions to be examined and expected outcomes. This description should be in everyday language that is free from jargon. Please explain any technical terms or discipline-specific phrases.

Purpose:

The purpose of this research is to explore the lived experiences of children and young people (CYP) who have a sibling with a confirmed diagnosis of ADHD. The individual, lived experiences of each sibling are of primary interest and listening to and valuing their views is at the core of this research. The rationale is to understand experiences of siblings which are unique to them but may share some commonalities.

Background information:

There is very little research relating directly to CYPs experiences of having a sibling with ADHD. Research that has been conducted has relied on historical accounts of growing up with a sibling with ADHD or has reported clinical data such as statistical differences in health and wellbeing. Much research involving siblings concerns CYP who have a sibling with Autism Spectrum Condition or life limiting physical/medical conditions. This research highlighted several positives to having a sibling with a difference but also sheds light on the difficulties such as competing for parent attention or the requirement to fulfil caring roles.

As having a sibling with additional needs can impact familial relationships and mental wellbeing, I consider it important to explore how they experience growing up with a sibling with ADHD. I am keen to explore the view that better understanding of these experiences can be used to highlight positives of the sibling relationship rather than focus on the difficulties.

Research questions:

The aim of the study is to explore the experiences of CYP who have a sibling with ADHD. The overall question that the research hopes to answer is:

"What is it like growing up with a sibling with ADHD?"

Secondary research questions which will be answered during the interpretation stage are:
"What are the positive factors associated with having a sibling with ADHD?"
"Does a CYP with a sibling with ADHD feel they require extra support?"
"How do CYP with a sibling with ADHD experience their sibling relationship?"

Expected outcomes:

The research will illustrate a small number of participants' experiences of living with a sibling who has ADHD. The outcomes will be to identify if there are any similarities or differences in these experiences and to use the findings to inform future professional practice. For example, offering parental support in managing sibling conflict, a better understanding of how siblings feel they could be supported and improve understanding of how relationships may be experienced within families of CYP with ADHD.
It is expected the research will highlight the positives and challenges to living with a CYP with ADHD.

6. CONDUCT OF PROJECT

Please give a description of the research methodology that will be used

The research methodology for this study will be Interpretative Phenomenological Analysis (IPA). This is a qualitative research approach that allows flexibility and creativity with data collection methods. A case study approach will be used.

Qualitative data will be collected through audio recorded semi-structured interviews (see Appendix 1) and visual techniques (see Appendix 2). The participants may also be asked to take part in drawing activities such as drawing a picture of their family members. I will adapt the language used to instruct the participants to suit their age and language ability.

The plan is to have 3 'activity sessions' with the participant (sibling of CYP with ADHD) as follows (data will only be collected for analyses at Session 2):

Session 1 → Meet for 30-45 mins to develop rapport – *Explain nature/purpose of study, go through consent form together, complete 2-3 activities e.g. reading a book, completing some colouring, play a board game.*
Session 2 → Data collection – *Semi-structured interview, drawing/visual activities*
Session 3 → Debrief session with participant and their sibling with ADHD – *Debrief the participant and their sibling(s), answer any questions, share positive experiences and stories with permission of the participant.*

It is hoped there will be approximately one week between sessions 1 and 2 and four weeks between sessions 2 and 3 although this will be flexible to be convenient for the participants and their families.

Quantitative information:
See Appendix 3 for brief demographic information which will be collected at time of consent. This information will be gathered purely to determine homogeneity of the sample.

7. DOES THE PROJECT INVOLVE PARTICIPATION OF PEOPLE OTHER THAN THE RESEARCHERS AND SUPERVISORS?

Yes ☒ No ☐

Note: 'Participation' includes both active participation (such as when participants take part in an interview) and cases where participants take part in the study without their knowledge and consent at the time (for example, in crowd behaviour research).

If you have answered NO please go to Section 18. If you have answered YES to this question please complete all the following sections.

8. PARTICIPANTS AS THE SUBJECTS OF THE RESEARCH

Describe the number of participants and important characteristics (such as age, gender, location, affiliation, level of fitness, intellectual ability etc.). Specify any inclusion/exclusion criteria to be used.

Participants will be recruited from mainstream primary and secondary schools within the local authority that the researcher is undertaking a professional practice placement as a trainee educational psychologist (TEP).

It is hoped that 5 siblings of CYP with ADHD will be recruited to be participants for the study (1 participant will be used for the pilot study):

Inclusion:
Has a least one sibling with a confirmed diagnosis of ADHD and no other diagnosis or condition
Aged 8-16 years old
Lives with the sibling for 7 days a week
Male or female
Willing to attend three activity sessions with researcher (at time of consent)
Sufficient competence in English to verbally share their views

Exclusion:
A confirmed diagnosis of any diagnosis or condition
A sibling who does not live with the participant for 7 days a week
Insufficient competence in English to verbally share their views

If there is more than one sibling of the CYP with ADHD, all siblings will be invited to take part provided they meet the inclusion criteria.

School staff (Head teacher and SENCo), parents and the CYP with ADHD will not be 'active' participants in the research as no data will be collected from them. However, they will be asked for their consent at the start of the process. The SENCo will agree to assist the researcher identify suitable participants, parents will be asked to support their child to find a picture of them with their sibling and the CYP with ADHD will be invited to join the third activity session with the participant.

9. RECRUITMENT

Please state clearly how the participants will be identified, approached and recruited. Include any relationship between the investigator(s) and participant(s) (e.g. instructor-student).

Note: Attach a copy of any poster(s), advertisement(s) or letter(s) to be used for recruitment.

The researcher (TEP) and placement supervisor (EP) are commissioned to work in primary and secondary schools in a large local authority and already have relationships with the schools in which they work. Initially, one secondary and three primary schools within which relationships are established, will be approached to help with recruitment. This will be extended to further primary schools should the recruitment target not be reached. However, a staged approach to recruitment will be used to avoid disappointing participants who would like to take part. For example, no more than five participants will be approached to begin with. If for any reason more participants are approached than are needed, I will have a conversation with them about their experiences, thank them for their interest and signpost to support groups if required.

The recruitment strategy is detailed below:

1. The school's head teacher and Special Educational Needs Co-ordinator (SENCo) will first be approached to obtain permission to recruit via the school. The head teacher will be provided with an information sheet (Appendix 4a) and asked to consent to the school's involvement in the study (Appendix 4b).
2. The SENCo will identify any pupil in their school for whom they have had a letter confirming a diagnosis of ADHD from a paediatrician or a child development clinic and who is known to have a sibling. The SENCo will approach the parents to pass on the parent information sheet (Appendix 5a) and confirm if they are happy to be contacted by the researcher (TEP). The SENCo will not share parent contact details with the researcher until they have received verbal consent from the parents to do so.
3. Once parents have confirmed to they are happy to be contacted, the researcher will give a phone call to the parents to answer any questions and determine if they are willing to provide written consent (Appendix 5b) for their child(ren) to take part, provided they meet the eligibility criteria.
4. Parent/carers will ask their children if they would like to be included in the study. They will be provided with an information sheet for both the participant (Appendix 6a) and the CYP with ADHD (Appendix 7a).
5. The CYP with ADHD will read the information sheet at home with parent/carers and sign a consent form to confirm they are happy for their sibling to participate and talk about matters concerning them (Appendix 7b).
6. If the participant has agreed to take part in the study a mutually convenient place (home or school) and time will be arranged via the parent for the first activity session.

10. CONSENT

a) Describe the process that the investigator(s) will be using to obtain valid consent. If consent is not to be obtained explain why. If the participants are minors or for other reasons are not competent to consent, describe the proposed alternate source of consent, including any permission / information letter to be provided to the person(s) providing the consent.

First, the school will consent to allowing recruitment and interviews to take place on their premises (Appendix 4b).

Parents/carers will have received the information sheets for themselves and their children (Appendices 5a, 6a & 7a) and will first provide consent for their child(ren) to take part (Appendix 5b). They will have been given the opportunity to ask the researcher any questions over the telephone or in person should they wish.

The CYP with ADHD will consent to their siblings participating after reading the information sheet (Appendix 7a) given to them by their parent/carers. They can contact the researcher for more information about the study should they wish. If the CYP with ADHD does not consent their sibling to participate, their sibling will not be approached for consent.

Participants will be given an information sheet about the study by their parents (Appendix 6a). If they agree to take part, the researcher will go through the consent form (Appendix 6b) with them at Session 1 to allow for any questions to be asked. This consent form will be re visited and re dated at the beginning of Session 2 and 3.

Note: Attach a copy of the Participant Information Sheet (if applicable), the Consent Form (if applicable), the content of any telephone script (if applicable) and any other material that will be used in the consent process.

b) Will the participants be deceived in any way about the purpose of the study? **Yes** ☐ **No** ☒

11. PARTICIPANT FEEDBACK

Explain what feedback/ information will be provided to the participants after participation in the research. (For example, a more complete description of the purpose of the research, or access to the results of the research).

A debrief meeting will be scheduled at the end of the study – session 3. The CYP with ADHD and their participant sibling(s) will be invited to attend this 'sharing' session where all the positive aspects of being a sibling will be discussed once agreed with the participant. This will also allow the CYP with ADHD to feel as though they have been included in the process. Participants will be provided with a letter of thanks for taking part (Appendix 8)

A summary of the key themes will be shared with parents and the SENCo via a brief information sheet written in plain English (max 1000 words). Participant schools and families will be informed they can gain access to the final write up of the research project should they wish, once the thesis has been finalised.

12. PARTICIPANT WITHDRAWAL

a) Describe how the participants will be informed of their right to withdraw from the project.

Participants will have the right to withdraw and this will be explained in the participant information sheets, consent forms and through discussion with the researcher. It should be clear that the participants can withdraw themselves and their data up until the point of analysis – one month after Session 2. After this time, I will not be able to remove data from the write-up. Participants may contact the researcher directly or indirectly to withdraw their data.

b) Explain any consequences for the participant of withdrawing from the study and indicate what will be done with the participant's data if they withdraw.

Should the participant withdraw within the specified time limit, they will be assured there will be no further data or analysis of their data and there will be no consequences for the withdrawal. Any initial data collected will be destroyed from records.

13. COMPENSATION

Will participants receive compensation for participation?

i) Financial **Yes** ☐ **No** ☒

ii) Non-financial **Yes** ☐ **No** ☒

If **Yes** to **either** i) or ii) above, please provide details.

If participants choose to withdraw, how will you deal with compensation?

14. CONFIDENTIALITY

a) Will all participants be anonymous? **Yes** ☐ **No** ☒

b) Will all data be treated as confidential? **Yes** ☒ **No** ☐

Note: Participants' identity/data will be confidential if an assigned ID code or number is used, but it will not be anonymous. Anonymous data cannot be traced back to an individual participant.

Describe the procedures to be used to ensure anonymity of participants and/or confidentiality of data both during the conduct of the research and in the release of its findings.

As the participants will be meeting with the researcher face to face, it is not possible for them to be anonymous in this study. Due to the small sample size of participants (n=5), the researcher will be able to identify participants by their initials. The CYP and their siblings' names will not be written during the analysis or write-up of the study. Each of the participants will be invited to choose an alias name by which they will be represented. The researcher will have access to the alias name and the corresponding initials of the participants so their data can be withdrawn if required. Therefore, the data will be treated as confidential but not anonymous.

Session 2 will be audio taped for transcription. The participant will be asked to state their alias name and refer to their sibling as 'brother or sister' during the interview. Should they mention their siblings' real name, this will be changed during transcription. The audio file will be labelled under the participants' alias name.

Names of people and places including the local authority or schools in which the research is taking place will not be included as part of the findings.

Participants will be informed that if they share any concerns which may lead them or someone they know to be in harm's way, this information will be shared with an appropriate adult (the Designated Safeguarding Lead) in the school.

If participant anonymity or confidentiality is not appropriate to this research project, explain, providing details of how all participants will be advised of the fact that data will not be anonymous or confidential.

Participants and their parents will be informed via the information sheets (Appendices 5a and 7a) and through discussion that their data will be treated as confidential. They will be made away that the researcher will have access to their data and that some members of school staff may know their child is taking part but will not be able to access the data.

The participants will be reassured that their data will not be shared with their peers and other family members. However, participants will be asked if they are happy to share some positive experiences with their sibling during Session 3 and this will be agreed and predetermined between the researcher and participant during Session 2.

Participants will be informed their name will not appear on the final report to limit the chance of identification.

15. **STORAGE, ACCESS AND DISPOSAL OF DATA**

Describe what research data will be stored, where, for what period of time, the measures that will be put in place to ensure security of the data, who will have access to the data, and the method and timing of disposal of the data.

Written data such as consent forms will be stored in a locked cabinet when not in use.
Documents which identify participant initials with alias names will be stored on an encrypted and secure laptop or memory stick which only the researcher has access to.
Voice recordings of interviews will be recorded on a Dictaphone then transferred to an encrypted and password-protected laptop which is stored in locked cabinet when not in use. The recordings will be saved by date and alias name.
Original transcripts from interviews will be stored securely on a password protected laptop and any paper transcripts will be stored in a locked cabinet then shredded once the thesis has been deposited in the University library.
Data will be stored for ten years, in accordance with the University of Birmingham research code of practice.

16. OTHER APPROVALS REQUIRED? e.g. Criminal Records Bureau (CRB) checks or NHS R&D approvals.

☐ YES ☒ NO ☐ NOT APPLICABLE

If yes, please specify.

The researcher holds a valid, current DBS certificate.

17. **SIGNIFICANCE/BENEFITS**
Outline the potential significance and/or benefits of the research

There are benefits from furthering the understanding of this subject area as there is little research on this topic despite growing prevalence of ADHD. Several charities and support groups operate in the area where the research will be conducted, families can be signposted for support with ADHD and sibling support at these groups. It is possible the sibling relationship may benefit from the focus on strengths and positives in the relationship and sharing this with each other and parents. The participant may benefit from having their voice heard which may lead to increased self-esteem. This underrepresented group may benefit from having their experiences shared with professionals and academics.

18. RISKS

a) Outline any potential risks to **INDIVIDUALS**, including research staff, research participants, other individuals not involved in the research and the measures that will be taken to minimise any risks and the procedures to be adopted in the event of mishap

Research staff:

There is minimal risk to the researcher. It is possible the researcher may conduct activity sessions at the participants' home if that is where the participant would feel most comfortable. If this were to occur the sessions would take place during the working day so the researcher can contact a member of staff from the local authority or peer to inform the meeting is over. A locked Outlook Calendar invite will be sent to the researcher's supervisor to inform of the date and time of the home visit.

The researcher has a responsibility to the CYP they are working with. If the researcher had any concerns about the social, emotional and mental health of the participants these would be shared with the parent/carer.

It is *possible* that as the researcher is a sibling of a person with ADHD that some of the issues raised by participants may cause unexpected emotional responses. To minimise this risk, the researcher will discuss this in supervision prior to conducting the research and will terminate any interview which arouses strong emotions. If this is to occur it will be reflected upon in supervision.

Participants:

There is minimal risk to the participants. It is possible that meeting with myself may be unsettling for the participants. To minimise this risk the participants will be offered the choice of having the sessions conducted at home or school and will be reminded they can stop at any point should they wish.

It is possible the participants may become emotional during the interview if they have particularly challenging relationships with their siblings. To minimise this risk, the questioning has been designed to focus on strengths and positives of their relationship. If a participant were to become distressed during a session the researcher would ensure the session did not end on this distress. The participant would be encouraged to discuss any troubling issues with their parents/carers. Participants will be informed information will be shared with other adults if the researcher were to become concerned or a risk of harm to the participant or their sibling.

It is possible that by asking parents to consent for their children, participants may feel pressured to take part by their parents or sibling. To minimise this risk at the first activity session the researcher will ensure the participant is willing to take part and will remind them there is no harm done by not participating.

It is possible the participants may experience feelings of abandonment as the research will take place over 3 sessions. As a trainee educational psychologist, the researcher will reduce this risk using skills to provide boundaries during the sessions and by providing the participant with a letter of thanks (Appendix 8) at the end of the research.

It is possible that parents may feel concerned about their children when first approached about the research. The information sheet states clearly the research is designed to explore experiences and this should reduce any feelings of alarm. The researcher's contact details are on the information sheet should parents wish to discuss any aspect of the research. The researcher can also provide details of support groups and charities should the parents wish.

It is possible participants may feel inhibited from sharing information if they are unclear about the procedure for Session 3. Participants will be informed that only information which they are willing to share will be discussed in Session 3. They will be reminded the focus of the session will be to share something positive with their sibling. The researcher will ensure they are clear on the wishes of the participant with regards to the sharing of information.

It is possible that family discord could arise in relation to Session 3 should the participant and their sibling not have a good relationship. If the researcher is concerned that this may be the case after Session 2 (for example they cannot think of anything positive or have discussed a negative relationship), they will check with parent(s)/guardian(s) as to whether it is appropriate for the sibling to attend Session 3 with the participant. If discord should arise *during* the session, the researcher will first draw upon their experience and skills in working with children and young people to diffuse any tension. They will then cease the session if required and inform parent(s)/guardian(s) of the issue. If the session has taken place in school, the SENCo will be informed.

b) Outline any potential risks to **THE ENVIRONMENT and/or SOCIETY** and the measures that will be taken to minimise any risks and the procedures to be adopted in the event of mishap.

There are no anticipated risks to the environment or society associated with this research project.

19. ARE THERE ANY OTHER ETHICAL ISSUES RAISED BY THE RESEARCH?

Yes ☐ **No** ☒

If yes, please specify

20. EXPERT REVIEWER/OPINION

You may be asked to nominate an expert reviewer for certain types of project, including those of an interventional nature or those involving significant risks. If you anticipate that this may apply to your work and you would like to nominate an expert reviewer at this stage, please provide details below.

Name
Contact details (including email address)
Brief explanation of reasons for nominating and/or nominee's suitability

21. CHECKLIST

Please mark if the study involves any of the following:

- Vulnerable groups, such as children and young people aged under 18 years, those with learning disability, or cognitive impairments ☒
- Research that induces or results in or causes anxiety, stress, pain or physical discomfort, or poses a risk of harm to participants (which is more than is expected from everyday life) ☐
- Risk to the personal safety of the researcher ☐
- Deception or research that is conducted without full and informed consent of the participants at time study is carried out ☐
- Administration of a chemical agent or vaccines or other substances (including vitamins or food substances) to human participants. ☐
- Production and/or use of genetically modified plants or microbes ☐
- Results that may have an adverse impact on the environment or food safety ☐
- Results that may be used to develop chemical or biological weapons ☐

22. DECLARATION BY APPLICANTS

I submit this application on the basis that the information it contains is confidential and will be used by the University of Birmingham for the purposes of ethical review and monitoring of the research project described herein, and to satisfy reporting requirements to regulatory bodies. The information will not be used for any other purpose without my prior consent.

I declare that:

- The information in this form together with any accompanying information is complete and correct to the best of my knowledge and belief and I take full responsibility for it.
- I undertake to abide by University Code of Practice for Research (http://www.as.bham.ac.uk/legislation/docs/COP_Research.pdf) alongside any other relevant professional bodies' codes of conduct and/or ethical guidelines.
- I will report any changes affecting the ethical aspects of the project to the University of Birmingham Research Ethics Officer.
- I will report any adverse or unforeseen events which occur to the relevant Ethics Committee via the University of Birmingham Research Ethics Officer.

Name of principal investigator/project supervisor:	Dr Anita Soni
Date:	20.3.17

Please now save your completed form, print a copy for your records, and then email a copy to the Research Ethics Officer, at aer-ethics@contacts.bham.ac.uk. As noted above, please do not submit a paper copy.

APPENDIX 4 : INFORMATION AND CONSENT FORM FOR SCHOOLS

Research Information Sheet

What are the experiences of children who have a sibling with ADHD?

UNIVERSITY OF BIRMINGHAM

Background Information

My name is Tamzin Messeter and I am completing my doctorate in Educational Psychology at the University of Birmingham. I am also working with the Birmingham Educational Psychology Service therefore I hold a DBS certificate. As part of my training I am conducting a research study to explore the experiences of children who have a sibling with Attention Deficit Hyperactivity Disorder (ADHD). This research has received ethical approval from the Ethical Review Committee at The University of Birmingham.

I am writing to you as you may have pupils attending your school who are eligible to take part. It is important that you read the information below before providing consent for pupils at your school to be included in the study. If you require any further information, my contact details can be found at the end of this letter.

Purpose of the research

The purpose of this research is to explore the experiences of children and young people who have a sibling with ADHD. There is currently very little research in this area but I believe it is important to hear the views of children who *may* be impacted by their sibling's additional needs. The project hopes to offer an original contribution to research in this area which in turn may aid the understanding of support that be offered. Children's participation will be valuable in understanding more about the positives, as well as the challenges of having a sibling with ADHD.

Who will be involved?

I would like to invite the SENCo at your school to assist me in identifying pupils who have a confirmed diagnosis of ADHD and at least one brother or sister aged 8-16 and good fluency in English. They will then pass on the information sheet to parents and ask permission for their contact details to be shared with me to proceed with the research. The child/young person with ADHD will be invited join the final part of the research.

What will the research involve?

The research will involve carrying out three 'activity sessions' with the participant and they will last between 30 mins and one hour.

Where will the research take place?

The participants will be offered to the opportunity to take part in the activity sessions at school or in their homes. If the sessions happen at school, this will be co-ordinated with the pupil's class teacher to ensure they are only borrowed from lessons at a convenient time.

What happens next?

I will be in contact shortly to discuss if you are happy for the research to take place in your school and answer any questions you may have. There is a consent form attached at the end of this letter which will need to be signed before parents are approached about the research.

I thank you for taking the time to read this information and consider taking part.

Tamzin Messeter
Trainee Educational Psychologist

Email: [redacted]
Phone: [redacted]

Supervising Tutor at University of Birmingham: Anita Soni ([redacted])
Supervising Educational Psychologist: Amy Ostrowski [redacted]

UNIVERSITY OF BIRMINGHAM

Dear Head Teacher

Thank you for reading the information about my research project designed to understand the experiences of children and young people who have a sibling with ADHD.

The research has received ethical approval from the University of Birmingham and is supervised by an Educational Psychologist and University Tutor.

I am writing to ask for your permission to include pupils attending your school in the study. Further consent will be sought from parents/carers of the young person and their sibling (with ADHD).

Further details about what the study entails can be found on the enclosed information sheet.

Consent

Please tick the boxes below if you agree with the statement and sign at the bottom.

☐ I agree school may assist the Trainee Educational Psychologist in identifying suitable participants to take part in the research.

☐ I agree that identified students can take part in the activity sessions at school pending further consent from parent/carers and the young person.

School name	
Signed	
Print	
Date	

APPENDIX 5 : PARENT INFORMATION AND CONSENT FORM

UNIVERSITY OF BIRMINGHAM

Research Information Sheet

What are the experiences of children who have a sibling with ADHD?

Dear parent/carer

This letter is to let you know about a research project which your child may be eligible to take part in. *I would be extremely grateful if you could read the information below.*

My name is Tamzin Messeter and I am completing my doctorate in Educational Psychology at the University of Birmingham. I am also working with the Birmingham Educational Psychology Service therefore I hold a DBS certificate. As part of my training I am conducting a research study to explore the experiences of children who have a sibling with Attention Deficit Hyperactivity Disorder (ADHD). This research has received ethical approval from the Ethical Review Committee at The University of Birmingham.

Purpose of the research

The purpose of this research is to explore the experiences of children and young people who have a sibling with ADHD. There is currently very little research in this area but I believe it is important to hear the views of children who *may* be impacted by their sibling's additional needs. The project hopes to offer an original contribution to research in this area which in turn may aid the understanding of support that be offered. Your child's participation will be valuable in understanding more about the positives, as well as the challenges of having a sibling with ADHD.

✶ Who can take part?

I am inviting children and young people aged between 8 and 16 years old to take part in this research. They must have at least one sibling who has a diagnosis of ADHD with no other educational or medical needs. They must have no additional needs themselves and have good fluency in English language. The siblings must live together for 7 days a week and be willing to meet with me up to three times. If your child has more than one sibling, they will both/all be invited to take part.

Your child does not have to participate in this research study if you do not want them to. If you *do* give permission, I will then seek consent from your child with ADHD to ensure they are happy for their sibling to take part. Please share the relevant information sheets with them.

✶ What will the research involve?

After written consent has been received, the study will begin. I would particularly like to speak to your child to explore their experiences. I hope to meet with them three times at a location of their choice (your child's school or your home) and at a convenient time. These meetings will be called 'activity sessions'. They will be held one-to-one with your child and are detailed below:

Session 1:

An introductory session. This will allow your child to get to know me, ask any questions about the research and sign the consent form. We will then complete 2-3 activities together such as reading a book, playing a board game or doing some artwork. This session will last between 30-45 minutes.

Session2:

The activity session. This is the session I will be collecting the data for the research. I will have a discussion with your child about their experiences of growing up with their brother or sister who has ADHD. I may also ask them to draw me some pictures of their family. This session ONLY will be tape-recorded and will last between 30-60 minutes.

Session3:

The debrief session. I will invite your child with ADHD to attend this session with their sibling although their attendance will be optional. This will be a chance for them to talk about and share all the fun and happy memories they have together. This session will last between 30-45 minutes

At the end of the first session I will be asking your child to bring a photograph of themselves with their sibling to session 2. I would be grateful if you could help them with this. I am happy to print the photograph if you are able to provide me with an electronic copy.

✶ **Are there any risks or benefits to taking part?**

It is hoped that your child will enjoy taking part in the research, sharing their stories about their time spent with their sibling. They will receive a letter of thanks

for their contribution. Their views are very important as little is known about these experiences. It is hoped that this research will help adults understand if siblings need a little more support or if they are not affected at all by their brother/sister's diagnosis. There is minimal risk to your child taking part. Your child will be reassured they can stop the sessions without any reason at any time if they want to.

✶ What will happen to my child's information?

All data collected as part of this study will comply with the Data Protection Act (1998). Discussions with your child will be treated as confidential therefore information will be not shared unless you child tells me something which worries me. At the beginning of the research, your child will choose an alias name to be known by in the write up of the study so no participant will be personally identifiable. All written information such as consent forms will be stored securely in a locked cabinet at the Birmingham Educational Psychology Service. Any data such as voice recordings, which will be stored electronically, will be saved on a password protected and encrypted laptop. Data will be destroyed 10 years after the research is completed.

If any point you or your child wish to withdraw from the study you can do so without reason by writing to the researcher. You child's data can be withdrawn from the study up to one month after completing Session 2.

✶ How can I get more information about this research?

This research is being organised by the University of Birmingham and Birmingham Educational Psychology Service. If you have any further questions about the study or would like more information about support groups you can contact any of the people at the bottom of this letter.

A summary of the findings from this research will be shared with you in an information sheet once the data has been explored and the study is finished. In addition, the results of the study will be written up as part of the researcher's thesis and may be shared as an academic journal article or at conferences. You child's name and school will be kept anonymous at all times.

✶ Who can I contact for more information?

Tamzin Messeter	[redacted]
Anita Soni (University Tutor/Supervisor)	[redacted]
Amy Ostrowski (Supervising Educational Psychologist)	[redacted]

Thank you for reading this information sheet. If you are happy for your child to participate, please complete the consent form.

What are the experiences of children who have a sibling with ADHD?

Dear parent/carer

Before signing this consent form, please make sure you have read the information sheet and discussed the researcher with your children.

Please read each statement carefully and put a tick in each box if you agree. Then sign and date at the bottom. Please contact the researcher if there is anything you do not understand or if you need any assistance completing this form

- ☐ I have read and understood the information sheet.
- ☐ I have discussed the research project with my children.
- ☐ I agree my children can take part in the research.
- ☐ I agree that my child's voice will be recorded as part of the research and that this will be treated as confidential.
- ☐ I understand that participation is voluntary and that either myself or my children can withdraw at any point without giving a reason. Any information collected can be withdrawn up to a month after Session 2.
- ☐ I agree the results of this study will be written up as part of the researcher's thesis but that my child's name and school will not be included in this report.

Child's name	
Parent/carer name	
Signature	
Date	
Researcher signature	
Date	

Thank you for completing this form. If you have any questions, please get in touch.

Yours sincerely,
Tamzin Messeter

APPENDIX 6 : PARTICIPANT INFORMATION AND CONSENT FORM

My name is Tamzin Messeter and I am a Trainee Educational Psychologist at the University of Birmingham. I am doing a research project and would like to invite you to take part.

In this project, I would like to find out what it is like to have a brother or sister with ADHD. You are being invited to take part because you have a brother or sister with ADHD and your views are very important.

I would like to find out:

- About you
- How you would describe your brother or sister
- What things you enjoy doing together
- What might make things even better

What would I have to do?

I would like to meet with you so we could have three activity sessions together. We could meet at school or at home, wherever you would feel most comfortable.

1. **Session1** - I would explain everything about the project and you can ask me any questions. Then you would sign a consent form by writing your name on the page. We would get to know each other and do some activities and play some games. **30-45 mins**
2. **Session 2** - I would like to ask you some questions about you and your brother/sister. We

What else do I need to know?

- There are no right or wrong answers, I just want to listen to anything you have to say
- In **Session 2,** I will use a voice recorder so I can remember everything we have talked about
- You will get to choose a code name which I will use when I write about what we've talked about, so no one will know it was you!
- If you meet with me and decide you want to stop. You can just tell me. You will not get into any trouble.
- I will keep all your data (what we talk about in the sessions) safe.
- If you tell me anything that makes me feel worried, I will share this with another adult.

Do I have to take part?

No. If you don't want to meet with me or you change your mind that is fine! You can just tell your parent/carer.

What happens next?

If you have read this information sheet with your parent/carer they will let me know if you are happy to take part. We will then arrange a time and a place to meet for **Session 1.**

Thank you for reading this leaflet.

Please listen carefully to the sentences I am going to read aloud. If you understand each sentence and agree with it, I'd like you to put a tick in the box next to the sentence. If you do not understand, please ask me to explain it again.

- ☐ I have had this information leaflet read to me.
- ☐ I am happy to take part in the project and meet with the researcher (Tamzin) at home or at school.
- ☐ I am happy for Tamzin to ask me questions about myself and my brother/sister.
- ☐ I am happy for Tamzin to record what I say so she can listen to it later.
- ☐ I know I can leave at any point if I change my mind and I don't need to give a reason.
- ☐ I know if I say anything that Tamzin is worried about, she would need to speak to another adult.

I understand what to do and I am happy to take part in this study.

Name	
Signature	
Date	
Researcher signature	
Date	

APPENDIX 7 : SIBLING WITH ADHD INFORMATION AND CONSENT FORM

My name is Tamzin Messeter and I am a Trainee Educational Psychologist at the University of Birmingham.

You have been given this letter to read because your brother / sister might like to take part in a research project with me. You might like to join us at the end of the project to hear about what we've talked about.

I would like to meet with your brother/sister to find out:

- What it is like to grow up in your family
- What does your brother / sister really enjoy doing with you
- Do they need any extra help with anything

What will happen?

I would like to meet with your brother or sister up to three times to do some activities and talk with them. All the information will be kept private so no one will know what we have talked about. I will only share things with your parents if your brother / sister tells me something which makes me feel worried. Your brother / sister will choose a code name for to help keep the information private.

The last time I meet with your brother / sister I would like to meet with you too. It would be nice to talk about some of the really nice and positive things you and your brother / sister do together. You can tell me a little bit about yourself then too!

Do I have to take part?

No, you do not have to agree for your brother / sister to meet with me and that is fine. You may be happy for them to meet me but you may not want to join us for the last session. Just tell your parent / carer and they will let me know.

Please read the sentences below and if you understand please put a tick in the box. If there is something you are not sure about, please ask a grown up for help.

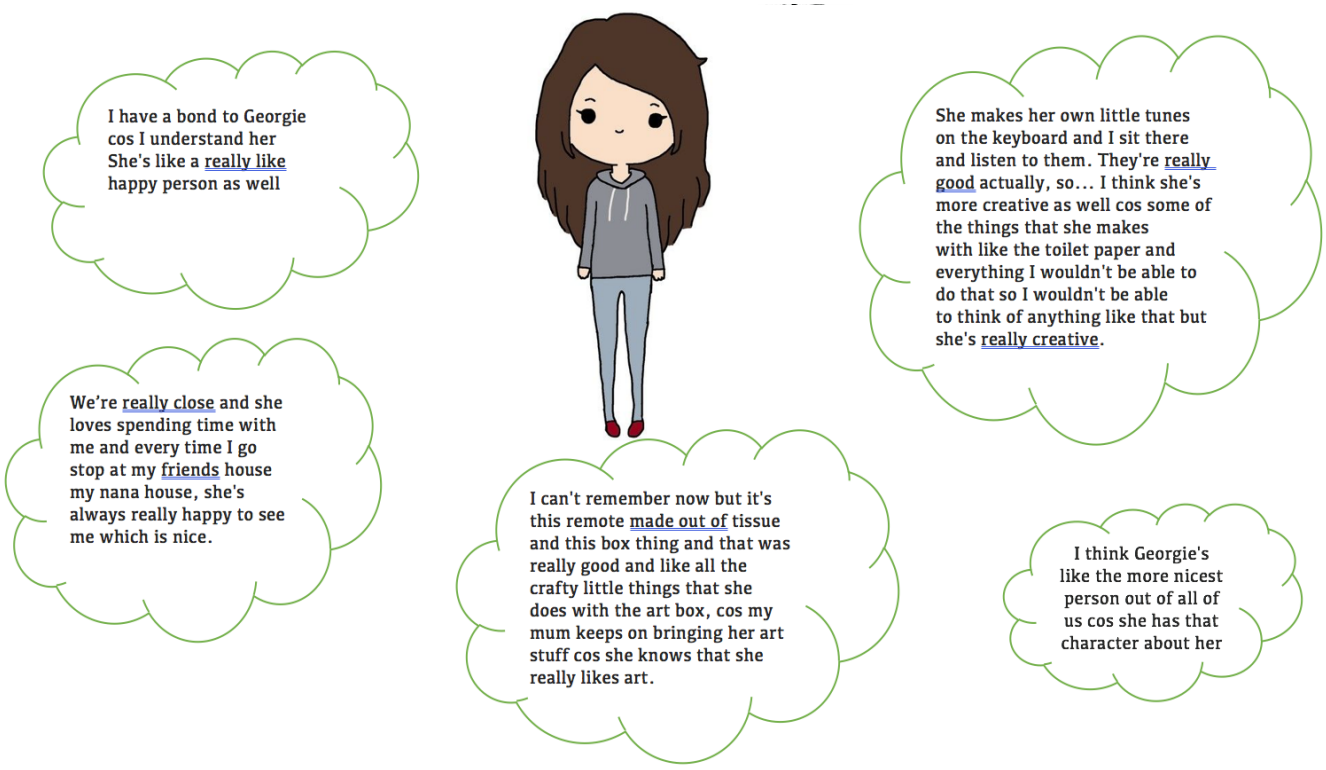
I am happy for my brother or sister to take part in the research.
I understand you will not share any information they tell you unless you are worried.
I understand my name will not be used in any write up of the research.

I would like to meet with you and my brother / sister for the last session **Yes / No**

Name	
Signature	
Date	

APPENDIX 8 : POSITIVE QUOTES SHARED WITH SIBLINGS (TAYLOR)

APPENDIX 9 : THANK YOU LETTER FOR PARTICIPANTS



Your views on having a brother or sister with ADHD are very important. The things you have shared with me will be used to help adults understand a bit more about what it is like for you. Remember you can ask for help if you feel like you need it.

If you have any questions now our sessions have finished you can speak to your parents or your teacher.

I will send you a letter when I have written up all the results from the study.

I hope you have enjoyed taking part.

Thank you,

Tamzin

APPENDIX 10 : OVERALL IMPRESSIONS FROM INTERVIEW (KATY)

Powerful recollections:

Katy found it difficult to fully articulate her views fully. Required prompting and encouragement to expand her views.
Katy was easily distracted during the interview, was this from nerves?
Consideration of 'ideal self' has come from work and experience of being a TEP – trying to identify what characteristics make ideal self
Have I picked up on her repetition of the word play and focused on this through my line of questioning? (7:45)
On first read of transcript, picked up on the word angry straight away as it is a term I got a sense of noticing as recurring throughout the interviews. Also links to my own experiences of having an 'angry' brother.

I am developing an understanding of her sense of self – being playful is important to her.
Am I cued in to noticing 'hitting' and physical behaviour due to my own experiences?
No real impact on life but perhaps on sense of self/identity?

APPENDIX 11 : TRANSCRIPT EXAMPLE (TAYLOR)

① ② ③ ④

- descriptive comments
- linguistic comments
- conceptual comment.

Participant – Taylor Normal text: Researcher *Italics:* Participant

Ok, all I want you to do on that piece of paper, is draw everybody in your family. Including yourself, doing something.	
Doing something, ok. Does it mean I can do stick people?	
You can do stick people	
(laughs) ok	
but it's just everybody doing something, and it will help me if you label them at the top, who everybody is as well and then we'll have a chat about it afterwards	
ok, ermm. Pause. My hand is killing me from art so it won't be that good... DRAWING	Lacks confidence?
What have you been doing in art?	Rapport building
erm, I could show you, it's in my bag, I'll show you after	
Ok	
errr, its supposed to be a table, it's not that good... DRAWING... erm that's gonna be the TV there, do I have to label the stuff as well?	
Just the people when you put the people on	
Ok, erm, I'm just gonna put Hollyoaks on there cos my sister watches Hollyoaks all the time (laughs)	
Do you like Hollyoaks?	
Yer, it's alright I guess. When I get bored I just watch it erm... this isn't really good, I'm so sorry	More lacking confidence
Do not apologise, I am the worst drawer in the world	
The only (inaudible) thing about this, I'm like the worst	
What sort of things do you enjoy drawing?	
Erm, mostly cartoon people and characters so things like this I'm not really good at...so	Rapport building
Oh yer, is it like the Japanese *yer..* stuff that you do?	
Yer, I like that. It's kinda weird but I like doing that.	
hmm	
they've really got big heads DRAWING Do I put our real names on there?	
Erm, yer cos I'll change all the erm names afterwards	
Ok, erm... DRAWING Georgie has her hair all like up and all spikey, so...DRAWING Does that include like my step-dad as well?	
Mmhmm	
Ok, I'm gonna do the back of his head (laughs)	

1

So he's watching TV?	
Yer, this is my mum's back of the head as well....this is terrible, shall I put my mum's real name?	lack of confidence
You can just write mum	
Ok, erm I don't call him step-dad all the time but informally I put step-dad but I'll put Will	
Is that what you call him at home?	
Yer, Will. But my mum wants me to call him my step dad cos my mum and dad broke up	
Hmm	
Erm, I'm just gonna put Sarah and the baby bed here.....She's so tiny (laughs). DRAWING. She (inaudible) fish. There you go, I don't know.... but I tried	
Awesome, no - most people just draw like each individual person so I like how you've set it up as like the family altogether, it looks really good.	
Honestly, that's like the worst drawing ever	worried about perfection of drawing?
So you've got... you and Katy are sat round the table with Grace, are you waiting for dinner or...	
Erm, yer we're waiting for dinner	
You're waiting for dinner, ok... and Georgie, what's Georgie up to?	
Ooh, she's watching TV because when Will tells her to sit at the table she doesn't do it first time and she doesn't like sit at the table properly, she used to like sit with her legs crossed on the actual chair and like her nighty or the dress that she's wearing is over her knees and mum and Will tells us to never do that but she doesn't listen sometimes	Sister doesn't follow instructions first time. She doesn't listen - awareness of non-conformity to house rules
Oh, ok.	
Yer	
So she's sitting on the floor	
Yer	
Sarah's in her little baby basket..?	
Yer (laughs)	
And so Will and mum are watching TV	
Mmhmm	
Perfect, ok. So I'm just gonna go through everybody that's in your family and just ask you to just sort of describe them to me sort of what they're like, erm, maybe things that they enjoy doing and things that they don't. So we'll start with Katy...what's she like? Can you describe her for me?	
Well, as being a little sister she can be sometimes be annoying so, that's probably ironic for everyone to say that but she has her days like when she's really nice to me and we get like when we	Ironic - what does she mean by this? Reflecting on nature of relationship in the past 'close'

were little we used to be like really close, and I think its because I've gotten older and I don't play with toys anymore we don't really like play with dolls anymore, so like I wouldn't say we've gone apart but we don't play with each other anymore so like, yer, thats (Katy (inaudible)). We can have a laugh sometimes and when mum tells her off I go and see if she's ok and ask her what did she do and tell her not to do that because as her older sister I have to be responsible sometimes for like telling her not to do that or this when my mums not like, you know, when she's busy. So, that's what Katy's like.	Awareness that she has moved on to new stage in her life – this has influenced nature of the sibling relationship. Play – was reoccuring theme in sisters (Katy) account – Play has become less important to Taylor sense of responsibility towards siblings → does she percieve herself as having a parental role?
Mmm, so it sounds like you've got quite an important job being the older sister...	
Yer, sometimes it can be stressful but at the same time I enjoy it because I get more responsibilities so like I get to go out with my friends and I think Katy gets a little bit jealous of that because she gets like "awww she gets to go out and not me" and I go to her "if you start growing up and you know being more mature you get to come out with me and my friends" so..	finds stress in the role of responsibility but also enjoys being the eldest for additional allowances made eg, spending time out w/friends If you grow up → language modelled by her mother? Then used in mothering role. Caretaking role (with all siblings?)
Yer, that makes sense. What about Grace, what's she like?	
Erm, Grace, well when I'm in the morning, you know how it is sometimes, you wake up and you're in one of those moods like "oh, I've gotta go school" and everything I'm like that, and I know I shouldn't be but that's just how I am in the morning and she asks me to do her some food and I say in 5 minutes, I never end up doing it, I ask my mum to do it when she gets up so I do it anyway for her, and then she saws Katy and me "can I have this, can I have that" and when I have my phone she asks me to play on it so XXXX (inaudible) and like when she's crying I go see if she's ok and when we go to places like the Whacky Warehouse I go and play with her.	I know I shouldn't be – dissonance between self + ideal self. makes food for younger siblings – role of responsibility. when shes crying – I see if shes ok – important to feel like shes providing support for younger sibs. More evidence of caretaking role
Ok. How old is Grace at the moment?	
Erm, she's 6	
She's 6, so there's a big age gap between you and Grace as well isn't there?	
yer	
And, we'll leave Georgie to the end. What about mum, what's she like?	
Erm, mum she's really like, like really caring and what she likes doing. She likes drawing like me, I think that's where I got my drawing skills from because she's a really good artist.	like me – sense of similarities between her + her mother – is this where she gets her role of responsibility from? compares art skills to that of mothers – sees this as close link between them.
Mmhmm	
And me and mum we're like really, like before we go out we always take like selfies and I would say I'm a mum's girl more than a daddy's girl.	'mum's girl' close to mom
Mmhmm	

So like, when I'm talking about my problems at school she's always there, and when I'm upset she comes to see if I'm ok and when I don't like the food that my sisters like, I always like help with making Sunday dinner and like curries and stuff so me and mum are like really close	Always there - sees mother as dependable + reliable - is this a way in which she wishes to be viewed by her younger sibs? help - offers support to mother with practical tasks. Really close
Good, that's really nice..	
We've actually got, when we went to hospital cos I cut my chin, the receptionist said that, well she thought that I was her sister (laughs), well because I'm like more mature than, well my mum said I'm more mature for my age, so like when I..I go to places like hospital I always get called my mum's sister	more mature - sees self as older than her years? Confirmed by mothers statement always - has this happened more than once? Enjoys people noticing the similarity between herself + her mother?
Yer	
Because she thinks I'm her sister	
Yer, do you look quite similar as well then?	
Yer, kinda (Laughs)	
Aww that must be nice though	
She's really short though so..	
Is she? (laughs)	
Yer, so that's why.	
Erm and what about Will, what's Will like?	
Erm, exactly like Katy, he has the childish moments so like err he can wind me up sometimes saying that "oh the internet's gone, you gonna be moaning now?" I was like "no" and everything and he keeps on calling himself a Don	Childlike relationship with stepfather - does not see him as having role of responsibility?
A Don?	
A Don, cos his names called Will he calls himself Donial and... he can be really childish sometimes but at the same time when he shouts at us for doing the wrong things I go "oh you're not my dad" when I shouldn't do that but I think he's trying to stick up for mum which is understandable so.. yer. Me and Will aren't close close, but when I'm upset he's always like saying if I'm alright.	Repetition of word 'childish'. shouldn't do that - cog dissonance - conflicting thoughts about her Elvis understands why Will is on Mums side. Close close - these are some aspects of being close for example him checking on how she's feeling.
Yer	
He helps me with homework which is good	Practical support offered.
Oh, that's good. Excellent. And then what's Sarah like, as a baby?	
Well... she's a really happy baby. She goes to sleep a lot which is good so and well before when she was born I thought she was gonna be like you know, one of those babies that keeps up all night, but she doesn't because she's lazy and me and like I feed Sarah nearly all the time and change her when my mum's busy with the housework on the weekends. And like I look after her so.. and I love her a lot as well.	Further evidence of parental role - performing tasks for the baby to support her mother

Yer, so you like that. You like having that job to do for her?	
Yer, is it weird like, I like the smell of babies as well?	
Babies do smell nice, there....	
Yer, like I told my friend as well and she's like you're a weirdo, I was like "no I'm not, I just love the smell of babies"	
Yer, they do have quite a nice smell, babies.	
I think it's the erm brands that they use	
Yer. Erm, and then ok so let's finish up with Georgie. What's she like then?	
Well, Georgie. Erm, well when she has her like anger problems erm, I tell her "oh you need to stop doing that Georgie" and sh she usually just goes in he her off, I get like guilty afte sometimes, but sometime of water you know, I'll be when she's upset and I sh tell her I'm sorry and I jus like, I don't know it's hard cos I understand her. An know how it feels and I th Warehouse, she was bulli there. And in McDonald's people were just laughing at her and I told them to stop because it's not her own fault and I'm getting emotional now, but erm with Georgie we're just close in that way. And when she went to the hospital I woke up with her so yer. We're really close there in that way	- first mention is of anger problems → something that is detrimental to Georgies functioning. Immediately takes parental role to try + take control of the behaviour Identifies when sister is feeling different emotions: guilt → feels responsible for causing negative emotions in her sister - feels that she's done something wrong with her parental role? Repetition of problems - guilt comes from understanding of sister's ADHD being something that she can't control. She can't help it - does she perceive the ADHD as something external, controlling her sister → 'give a hug' - important to repair relationship Stupidest things - accidental things? Tell her off - parental role - doesn't feel the guilt for these things - is this because something practical/physical has happened? shout at her - parental role - apology - does this come from the guilt? didn't mean to' - taking responsibility away from Georgie - perception of ADHD externally controlling close - sees positive relationship w/Georgie - talks of bond more so than with other sisters due to understanding her - in what way does she do this? Empathises with bullying. Bond due to understanding of her needs? Significant event in Whacky Warehouse - defending sibling EMOTIONAL NOW. Recognises feelings associated with defending her sister Reference to significant events.
Mmm.	
It's kind of hard to explain how close I am with her because I don't see her all the time because I'm at school, but like over the weekends we always like you know, really close and she loves spending time with me and every time I go stop at my friend's house my nana house, she's always really happy to see me so which is nice.	close repetition Belief that relationship is reciprocal - experiences close relationship, what does this look like? Honest/open? Enjoyment of time spent together. Enjoys reunion when they have been ~~sp~~ seperated.
So it sounds like it's really important to you to be a good sister to her?	
Yer, I mean like erm because my erm my other sisters, they're like, all my little sisters are really close cos we're all like playing with toys and I'm like "I don't play with them I'm sorry" but when any of them are upset I'm always there for them so like I think it's important to like you know be there for them as	Important to be good sister. Second reference to moving on in terms of play. Important to 'be there' for her younger sibs Is this as a result of birth order or personality characteristics.

don't feel guilty in same way when its stupid thing - is this because it's an accident/unintentional?
bond → this indicates a strong relationship - She attributes this to being able to empathise with her sister's predicament.
stuck up for her - defending sister - is this because she's the older sister OR because of her needs?
It's not her own fault → ey feels sorry for her being bullied for something she's not in control of.
repetition of close → ~~emp~~ feels like its important to emphasise the nature of their relationship.

well as like, cos sometimes I don't play with them but like if they get upset I'm always there with them so..	Example of providing comfort in a situation where sibs are upset. Recognises that relationship dynamic is more than just play + being emotionally available is important.
Mmm, yer. What sort of things does Georgie like to do to sort of play with, to relax?	
Erm, well she goes on my my mum's phone a lot because she likes playing this erm cars game because she's more of a tomboy than an actual girl (???) erm she likes watching TV like the Lego thing, so she likes watching that and I sometimes put films on for her on the TV and she likes drawing and I kinda got angry for her for using all my paints but at the same time I was like, ok it's not your fault so I let her use my art equipment and she likes drawing, I think I said that but...	sister likes playing on phone/watching TV, drawing. draws attention to support she gives sister - eg putting films on TV repetition - it's not your fault for using paints? Tolerant of her actions due to belief that the blurs are uncontrollable. Shares resources with sister. tomboy - is this because shes a 'more active' child?
Mmm	
and she likes playing with a lot of like boys car toys so like and the piano, she likes playing the piano as well like the little keyboard and she keeps on telling me to like teach her which I do, but I don't know anything so I'm like oh I can't help you with that because I'm not that good on piano. But she makes her own little tunes on there and I sit there and listen to them. They're really good actually, so... I think she's more creative as well cos some of the things that she makes with like the toilet paper and everything I wouldn't be able to do that so I wouldn't be able to think of anything like that but she's really creative.	can't support sister with piano playing due to her own limitations. I sit + listen to them - spending time with her is important - to show her love/respect/care? Positive language used about sisters performance sees sister as creative - positive attribute - compares sister to self - admiration for sisters' talents? Emphasis on really creative - keen to share this w/me?
Hmm. So you can learn a little bit from her as well as..	Reciprocal relationship.
Yeah	
..teaching her, yeah.	
She's like a really like happy person as well, like most of the time and despite having the medication she's actually really good. So, some people like think when people have ADHD they're angry all the time but they're actually not cos that's what people don't understand. They're not angry like all the time but when they do things wrong I think what triggers it is like how people respond to it, so say if she just knocks down like a glass of water like I said and people shout at her I think that's when she gets angry cos I think she knows herself that she's done that wrong but when people shout at her it gets stressful for her and thinks that's when she gets angry so... so generally she's really like nice person and if you ask her for like anything she'll give it to you straight away, with no like fuss or anything but if someone's like really close to her like I dunno if they had to have ..she'd be like no that's mine	sees sister as happy despite - what does she see the medications purpose? sees medication as negative? good - what does she mean by this? Not angry, can be happy at times. upset by some people's perceptions of ADHD? Has she had negative experiences to inform this thinking? Feels people (other) don't understand the diagnosis - does she experience her own confusion about this? They're not.. Sees all ppl with ADHD as having similar characteristics? looking for triggers for sisters blurt. Sees other people as responsible for her anger/behaviour. Identifies others shouting @ sister as a triggers for behaviour (stress). Does this mean she experiences an element of 'walking on eggshells' at home in order to avoid these triggers? generous sister Georgie is generous at sharing.
Yeah	
So..	
So she's got some things that she's a bit possessive over?	

	Yer, some things like she's had this teddy since she was like I think it was 3 months now and she's kept it till now and she's really close with that. And I know that's really close to her so every time I go touch she like snatches it from me like no, that's mine.	sister has special toy
	Laughs. So you know that winds her up a bit yeah?	
	Yeah	
	So what's it, I guess really I would like to understand what it's like being her sister. So what it's like sort of growing up with her?	
(1)	*Erm, well because I have my own room I think she wants to be like me, like being more in like my place in like the family because being the older sister you get more like opportunities than the others so like you have your own room, you have your own space when you need it, and*	Sees self as role model for younger sibs? Feels being oldest in family has advantages Recognises Georgie does not get the space she necessarily requires in the family home.
(4)	*with Georgie because she's got all the sisters around her and she wants to be like left alone when she's angry she sometimes goes in my room or my mum puts her in my room and I'm like "oh can you not put her in my room because I think that she's gonna like mess everything in there." when she gets angry the room just gets a mess and like I've got so much stuff in there that can't be ruined and...*	Repitition of angry Experiences physical destruction of property during times of Georgie's anger. room/space - seen as being valuable assets. Identified 'needing space' as a trigger for some behaviour Valuable possessions which are under threat from sister's behaviour.
(1)	*when that does happen I'm like "can you just put her in her room" and I know, I understand now that they can't because my sisters go in there and play and my mum can't stop them from playing when they want to, so I go in to talk to her and being her sister's like, well being an older sister to her is actually like, I wouldn't say fun but like... I dunno, you get like, it's really hard to explain, but like when she gets upset you just immediately feel guilty because you know she can't help it sometimes and I think sometimes you have to be in her shoes and know how she feels so when she's like*	Has to be tolerant "I understand now" → developed greater awareness of sisters' needs? Mum doesn't want to disrupt other siblings play? older - birth order is important for her - feels guilty when sis is upset - tries to empathise with her Repetition - she can't help it. Trying to empathise with sister's experience - is this why she feels close? because she is willing to put herself in Georgie's shoes?
(4)	*crying, saying she's sorry I don't mean it, I only do get upset and I'm like oh you don't mean it Georgie. It's not your fault, but sometimes you just have to like, like you know keep control of it because I know she's got these tablets now but I know she's a really happy girl and she can be like*	Advising sister to try + 'keep control' of it (behaviour) happy - to describe Georgie
(1)	*really nice when she wants to be. But like sometimes she can be like angry so...*	conflicting view? Suggests element of choice over behaviour at times 'confusion for Taylor'
16:54	So for you it sounds like sometimes you have to carry a bit of guilt, and you feel a little bit guilty sometimes that she ends up in situations where she's upset or angry.	
(4)	*Yer, my mum shouts at her and I and I'm like, mum don't shout at her it's not her fault and she goes, well she can control it Taylor, and I'm like no she can't. And I know sometimes she can control it but like sometimes it's not her fault generally because she's got this ADHD and that's like something you're born with so... I understand...so when people shout at her I'm like it's not her fault and I think*	ADHD as external - can't control her bhvr. Argues w/mother over this you're born with - external control belief he sister's behaviour is controlled by the ADHD and there's nothing she can do about it. Confusion? not her fault feeling defensive of sister + excusing the behaviour conflict - sometimes she controls it - other times she can't.
(1)	*I'm more, like I'm more you know, respectful to her than the other people in the family like Will erm, when Will shouts at her I'm get really angry at Will, that's why me and Will aren't close because I go to Will, don't shout at her Will, you're not her like dad," you don't understand what she's been through and like 'yes I do, I know this' and you know you're not the older one, but I'm old enough to like*	perceives self to be more respectful to sister than other family members protective of her sister - takes defensive/parental role in arguments with step dad.

understand what she's been going through. So that's how were close, like why me and Georgie are close because I understand her, I wouldn't say fully understand her but like, I understand why she gets upset so because people always shout at her and she's like oh it's always me you know, being like why are you always picking on me and I'm like, Georgie they're picking on you because you're different, that's why. And that's why people don't see, she is different but like you know.. cos like, I think she feels like she gets treated differently than the others because these like, when she gets like opportunities like play and toys and gadgets, I think that's, I think that's like good for her but at the same time you shouldn't like treat her differently but you should treat her like as the same as us but give her more respect than any of us because she's got this problem that we need to like understand and like, you know when she gets upset you need to like say, 'oh no, it's not your fault.' But they don't do that, they're like, 'oh stop crying you're being pathetic.' That's what they say but like they need to be more like understandable.	highlighting differences between her sister + her friends. she's got a problem → sees herself as different from her sister → Recognises the allowances the rest of the family need to make. disagrees/feels conflict? with how other people are treating Georgie. wants peers/family to understand/empathise more with Georgies needs.
Mmm, so you feel like you're more, the most understanding in your family of her situation?	
Yer, I keep saying like, I keep saying like now, sorry	
That's ok.	
I'm not very good at vocabulary	
I think you're speaking really well.	
(Laughs) thank you.	
Erm, let's have a think about... is there anything that you and Georgie have done really well together?	
Really well together. erm, well personally I think the most, well, when she used to have the PlayStation GTA, I used to do all the challenges for her so... that's good. And when she does something really creative, I help her so...	works well together at computer games + creative activities.
Mmm	
I think the most, well the one that's really, I can't remember now but it's this remote made out of tissue and this box thing and that was really good and like all the crafty little things that she does with the art box, cos my mum keeps on bringing her art stuff cos she knows that she really likes art. I think it like relieves stress as well, doing all this art stuff so.	creative/crafty activities - attributes art activities to relieving stress during difficult times.
Yer. So before you were talking about erm, you've said a couple of times "oh it's not her fault like she can't help it. Does Georgie ever say things like that? Does she say things and say she can't help it?	
Erm, well I don't think she wants to say that because she doesn't want like, I think in her head she wants to be treated the same, but at the same time when she does things like you that she doesn't mean, she gets upset because I think people, I think because, somethings I feel like people are	Belief that Georgie wants to be seen as same as others - understands that in her sister.

always on my back, I think that's what she feels like all the time cos people like shout at her for doing things wrong and I don't think...I think she wants to get round to people's heads saying that it isn't my fault but she doesn't wanna say it in general because she wants to be treated the same but at the same time she wants to have like more stress off her shoulders if you understand what I'm trying to say?	Trying to make sense of her sister's feelings
Yer, I do. I do, and so do you feel like sometimes you take some of that stress for her?	
Yer, so when, well when Georgie does something wrong I'm like "oh no, I've done that" cos I don't want her getting in trouble because in like, I know she's done that wrong but like at the same time, I don't want her shouted at because you know, it's not always her fault, it's like, cos I think with ADHD (2) *don't think. Sometimes I do things and I don't think but she can't like, she doesn't know how to control it. and when she does things like you know she does things like mess up things or break toys, I like you know, I take the blame for her. Sometimes, not all the time cos I know she needs to understand what she did wrong but like sometimes I get shouted at as well for like keeping an eye on* (1) *her, but I'll go to my mum "I can't always keep an eye on her, she isn't an animal, she's a human being" and when she nearly broke the TV the other day I got shouted at for not keeping an eye, which is understandable but at the end of the day she didn't mean to so she didn't break it hopefully or thankfully, so...*	role? Takes responsibility for Georgie's actions to avoid her sister getting unduly stressed out. and due to belief that she 'can't help it' sense about ADHD - impulsive 'don't think' - lack of control of this impulsivity. Takes blame to help sister out. Mum is putting same responsibility on Taylor for care of Georgie's behaviours when she is supposed to be keeping an eye on her. She has essentially resigned herself to certain duties as an older sibling ↳ justifies parent getting frustrated at her - feels like she should have this responsibility?
Oh that's good news (laughs)	
She spilt water on the box so we had to get a new box but that's all sorted now	is this the same event of spilling water as referred to earlier?
Oh good...	
And the good thing is she like, when she does something wrong she says sorry like she really knows what she's done and I think that's good and like I don't really like the medication that she's been getting cos it changes her diet so when she has the medication she doesn't eat properly, like after the medication kicks in you, you see immediate change like she's always quiet and she does word search a lot which like helps her and I think she likes things being more occupied that anything, I think she gets bored really easily because she can't sit down still and when she's on these medication, erm, it you know calms her down and when she does like word search I ask her do you want anything to eat because I do my sister's lunch and she's like no, I don't want anything, you sure, (1) *so that's what I don't like about it because it's knocking down all her nutrients which isn't good.*	Belief that Georgie should take responsibility for her actions + apologise. Finds positives where possible. Strong views about medication - is she expressing concern for sister's wellbeing? concern about sister's diet - taken on worries that she's not responsible for.
Ok. So you see a real change in her when she takes the medication?	
Yer because I feel like it sounds a bit bad, but I feel like ADHD is part of Georgie and that's (2) *what Georgie is, so I'm used to seeing Georgie more hyper than anything, than being calmed down, because Georgie is like, I think the ADHD that she has is like more hyper than anything so she doesn't get angry really easily, like she doesn't go mad. When someone like winds her up she*	ADHD is part of Georgie + that's what she is prefers her sister as she is rather than as she is modified by medication sense that she might lose a part of her (Georgie's) identity / sense of self therefore the relationship they have as result of meds. Expressing concern about 'change'

23:33

takes it like, she's like ah that's a joke but most people like, I've got a friend in the school call Morgan, she's got ADHD and when someone like gets her angry she really gets angry but Georgie she gets really hyper, she can't sit still and she likes playing with like everyone that she sees which is good but like when I see her with the medication I just don't like it because that isn't Georgie and the birthmark was part of her and when that went I got upset cos that was part of Georgie as well. And I don't want her to change cos she's my sister but you know, I think you know.. when I see her with this medication it just changes her which I don't like that..	Reference to someone else known with ADHD. Anger+hyper → sees more of hyper in her sister than anger. Seeking more positives Sees the medication as altering her sister + doesn't like this - unsure of how it changes her? ↳ makes her upset to see change in sister due to medication -
Yer, you sound like you understand quite a lot about ADHD, how, where have you learnt about it from?	
Erm, well when she got diagnosed with it I can't remember when it was, I actually searched it up cos I wanted to help her as well cos the Doctor said you can help her and stuff like you know you can be more committed to the thing that she had. But like I searched it up and its, I don't think its more anger issues I think it's like being hyper and then like when you get told you're like, you're just immediately (inaudible) in it like oh this isn't me so most people when they get told they take it on board but like with ADHD, when you get told you just say that isn't me and you just get angry from that but like being more hyper I think that's like the main thing cos like most people think that ADHD is more like anger issues but that's like totally different. I think it's being more hyper and not taking things on board and you don't think. That's what I think ADHD is. I'm not an expert but that's what I think it is.	used internet to research diagnosis when sister received diagnosis. - keen to help her sister - is this because she's the oldest or due to an attitude/personality characteristics. Doctor indicated she could help. ↳ towards ADHD committed? What does she mean by this? Belives the ADHD is more due to hyperactivity rather than anger? Does she believe that people with ADHD can tell there is a difference in their behaviour that feels like its not really them acting? Repetition that ADHD is about being hyper rather than angry → does she feel these are more negative connotations with anger + want to protect her sister? You don't think (impulsive) if you have ~~ADHD~~. Not expert - not confident in own knowledge
Yer, no it's interesting that you've looked that up yourself. Have you spoken to your mum about it as well?	
Erm, I've tried to speak to my mum but she keeps on bringing up the thing saying well she should know how to control it, but being hyper you can't control that cos that's your personality and you're born with that and that's what you live with so like you can't change who you are no matter how hard you try. even though, I know the medication changes her for like an hour or like longer, but at the end of the day that is Georgie and seeing her like that upsets me because that isn't her,	Dissonance with Mothers view as she believes her sister is not in control of her actions. Fixed with personality - unable to change what you're born with You can't change who you are... acceptance of sister how she is Repetition that medication has changed her sister + seeing that upsets her - why? does she feel it affects their relationship when Georgie takes the medication?
Yer, so do you think things would be different for her if she didn't have ADHD?	
Well, because I've known her since she was born and how hyper she is I wouldn't really know what she'd be like but I feel like that if she didn't have ADHD people would be like you know, wouldn't be shouting at her all the time or wouldn't be saying you can control it because say if someone told me to stop talking too much, (laughs), I wouldn't be able to because that's me at the end of the day and like I wouldn't be able to like stop that so if she didn't have the ADHD I think people would be more off her back with all like you should control it scenario and...	Other people would react differently to Georgie if she didn't have ADHD. Has concerns about how others view/treat her sister. Able to reflect on similarities between herself + sister. Does she feel that its unfair how Georgie is treated by others? Acceptance that everyone is unique but 'fixed mindset' that if someone has certain characteristics, they will remain that way?

So it sounds like its more like other people's problems than her problem in that case so you're saying if she didn't have the ADHD it would make things different for other people because they wouldn't have to get on her back rather than it being something that would...	
I think people would be like more with their own, you know, because in our family people are like everyone in the house has like their own person so like I'm always in my room, my mum's always in the kitchen cooking, Will's always watching TV erm watching football, Grace is either upstairs with Georgie and Katy's just, I dunno where Katy is she's all over the place but erm yer like in the morning like Georgie comes downstairs and she's really like you know chilled and everything cos she's had a nice long sleep and she like, when it gets further into the day I think she's more hyper and after school when I see her on Wednesdays she like you know, rushes out of school and she like rushes out because at school people are pretty mean to her, because of her ADHD and like at school she's got these teachers saying like she's always naughty and everything but I don't believe anything that they say because Georgie isn't naughty she just... its hard to explain but I think she's just more hyper than anything, I think she can't sit still and like when people talk to her she doesn't listen to it and she can't control it	Each member of the family has their own role within the household. Reflecting on Georgies moods throughout the day. Believes people are mean to Georgie because of her ADHD - has she experienced something to support this? Disagrees with teacher's views that Georgie is naughty she 'can't control' her hypeactivity and inability to listen. Sticking up for/defending Georgie + her behaviour - believes her sister is misunderstood? She can't control it.
Another good word to describe that would be impulsive, so that's so you've got the hyperactivity bit but also with ADHD sometimes you get this impulsivity and that's that doing things without thinking and then you sort of realise afterwards, oh I've done the wrong thing, but erm, being impulsive is a big part of it and doing actions without thinking first and it's almost like automatic like so she won't be able to like kind of help it she'll do it and then think afterwards oh, whereas you or I might have a little bit more time to think about what we're gonna do first and weigh up the pros and cons or options.	
To be honest I think, Georgie's actually, well I think Georgie's like the more nicest person out of all of us cos she has that character about her I think Georgie's like the more nicest person out of all of us cos she has that character about her and like not very many people you know say that so like when people hear the word ADHD I think they just mean like aww they can't like get angry so do you know those erm, what is it, the nanny thing on TV	Responds to my ~~addition~~ suggestion of impulsivity with positive comment about Georgie - been to share positives about her sister as she believes she can't help her this? Doesn't feel many other people are positive about her sister Worried people will stereotype as according to TV show?
Oh yer	
I don't think like that, like that's not ADHD cos you know they're just angry, they've got anger problems. I don't know what that is but they've got something that you know they're just angry for a reason but I think with ADHD I think it's more like impulsive things like impulsive character and Georgie, some things she does take on board and she doesn't do it again so like more serious things but like when it's like oh don't do this again she will do it after so...	Real sense that she does not believe her sister has anger issues - is ADHD a more socially acceptable way of explaining Georgies differences that she wants to assert as there is more stigma attached to anger probs? Or others have been reinforcing message that Georgie does have ability to learn from mistakes if they're serious.
Mmm	They're - they're - assumption that everyone with ADHD presents in the same ways?

But I think Georgie's like I think she's the golden one out of all of us which sounds weird but she actually is.	Why does she assume Georgie being the golden one is weird?
yer	
She does do things like that mum tells her to do but some things she doesn't like when I tell her to do things like oh can you vacuum your room for me she's like no you do it. I end up doing it anyway but things like that she doesn't but with behaviour she's really good. so...	Georgie doesn't listen to Taylors requests - this is significant for her formation - takes on roles to do things for her sister in these situations. Georgie is better behaved than she is at fulfilling requests.
Do you know what the letters in ADHD stand for?	
Errr no.	Doesn't know what letters in ADHD stand for
So its attention deficit hyperactivity disorder. So you know, you've talked about the hyperactivity. The attention deficit is that not being able to concentrate on things for very long	
Oh yer she can't control, like some movies she gets bored straight away so... the movies that she likes she'll watch the whole thing throughout like the same ones all the time, when I show her something new like, oh what's that film, Moana, she just like she just gets bored and plays with toys, which is fine cos some things I watch that she watches I get bored so...	Can't control - lack of ability to control her behavior in situations where she's not highly motivated Movies don't always provide enough stimulation for Georgie
Yer. But Moana's a good one, I like Moana.	
I like Moana too, I don't know why she doesn't like that. I think its the songs that she likes and she gets scared really easily with some films like, have you watched Corraline?	
No, or if I have it was a long time ago	
It's just this girl she's got like two families well the same family but one's got buttons with the eyes and one's got like no buttons. it's a really weird film but it's really good at the same time, my mum showed it me, it's really good.	
I'm just wondering cos you seem like you've got a really good understanding so I'm just wondering what advice you might give to other people who've got either a brother or a sister who's got ADHD?	
Erm, well if you've got like a brother or a sister with ADHD and you're like, I wouldn't say victim but like you're living with them, I would say like try at least talk to them and like don't blame them for like all the things that they do because sometimes you can't help it and like as a human you do things that you can't help sometimes and that's part of nature like our nature but like when people shout at them and like, like release some weight off their shoulders, and just talk to them about it. And like, when they get upset just talk to them again so it's more like more talking and more comforting than anything. So just let them know that you're not diff..well you are different but like at the same time you're still, you know a human and like we do understand you but sometimes you might feel like, no-one is on, everyone's on your back but they're actually not they just don't understand like the rest of us. So like, just let them know that you're there for them that's the main thing so...	Victim - interesting use of word - has she felt like a victim in the past? Be respectful towards s/b with ADHD - don't blame them Should just talk to them - is this beyond what you'd do for a sibling w/o ADHD -> Should provide a comforting role Empathetic with how Georgie might feel Should be supportive to the sibling + be there for them.

31-4	That sounds like very good advice. Erm, I'm just wondering then from all the things that you've said, do you think having a sister with ADHD affects you at all when you're in school?	
	Erm, well with a sister with ADHD it doesn't really affect anyone..like me in school, it does affect homework cos when she's on the laptop I don't really have time to like do my homework, that's one of the things that...it doesn't like get me mad I just like, ah wish I could have more time and I don't really mind cos I understand why she uses it erm it doesn't really affect me in school	sharing of resources at home is difficult Key aspect of conflict is sharing laptop for homework wish - for more time on laptop. However is understanding of sisters need to use it as well.
	No?	
	Because I'm in school and I just focus on my education	Able to prioritise + focus on education
	Yep. Erm, do you think it affects your friendships at all?	
	My friendships? With like my friends in school?	
	Yer, or it could be friends that you've got at home maybe that erm Georgie knows as well that you spend time with at the weekends or it could be your friendships in school	
	Erm, well yer. Well I've had this friend and I know is called Sophie and that's Katy's friend and I think she's more spoilt and everything and I think she's a little bit spoilt and I don't wanna pick on her or anything because Katy can choose her own friends at the end of the day, I don't really care. But like, she sometimes picks on Georgie and sometimes one of those days she's like she actually like talks to Georgie and sometimes she like rejects her and that's like really horrible because that's not how friends should be but when she picks, like be's mean to Georgie I get a little bit mad so I sometimes shout at her which I shouldn't cos she's younger than me but I'm like, "oh you shouldn't be picking on her you should like be there for her" and that affects some friendships for me because like, you should control your sister and when I was in primary school people say "oh your sister was doing this, can you see what she's been doing?" I'm like "yer I know". I have to sometimes like agree with them because I know my friends have to agree with her which is horrible but sometimes we agree with them then I go talk to her saying "oh my friend said this about you, are you ok?" because I wanna know if anyone's like picking, like being mean to her so in primary school she got bullied for that because my friends were being mean to her and like that upset me and that's what like to me means Georgie's getting bullied because I've got a sister, they immediately think that you know when people say they've got like four, five more sisters they feel like they've got a rough living life but they actually don't, and like when they heard about my sister's ADHD, they said oh that your sister needs help and I'm like "no she doesn't" she's just Georgie's character. And this medication, I really don't like it as well, so that upsets me.	Friend of Katy picks on Georgie + this bothers her as she feels protective of sister → defensive of how a friend has rejected Georgie and she (Taylor) stands up for Georgie + tries to resolve the situation through intervening. Fixed idea of how friends should be? → Gets protective + tries to resolve situation for Georgie with friend who has picked on her. → Feels like she should control her sister - element of responsibility conflict between maintaining friendship + defending sister - does she sometimes feel in the middle? Checks in on Georgie - demonstrating empathy lots of negative words describing treatment of Georgie by others. → causes emotional upset to see her sister treated this way. - has experienced people making assumptions about her life? Doesn't like people telling her her sister needs help. Repetition of acceptance for how her sister is negative repetition of feelings about medication.
	Hmm so it can be quite erm, conflicting for you to balance your friendships with looking out for your sister? So you've got like two roles there?	

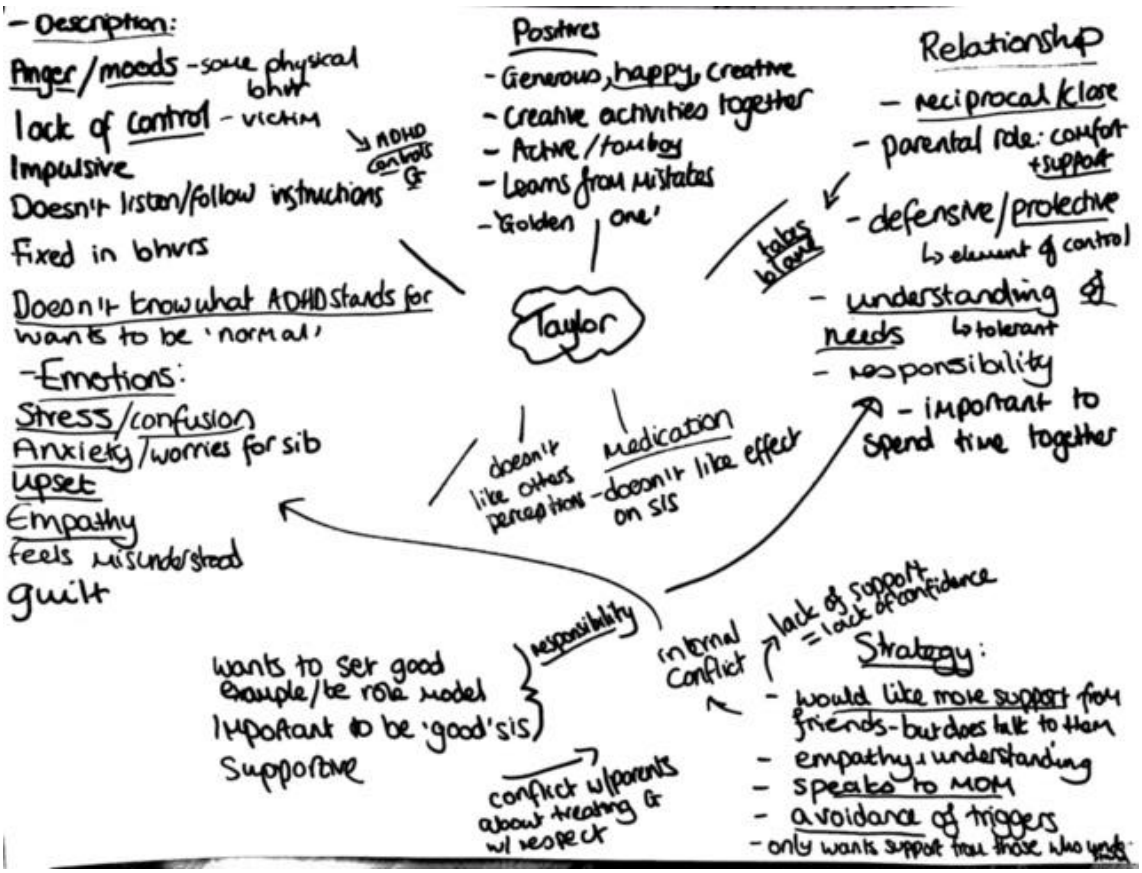
Yer so like I don't want friends that judge her and I don't want friends that you know, always blame her, I want friends that understand and like help me more with Georgie as well, so I want friends that comfort Georgie and you know, tell what's, don't tell her what's right and wrong, but tell her like not to do this next time in the future and explain to her what that could, you know, like how that affects some people.	Is she worried about what her friends think or about how this would make Georgie feel? Feels like she'd like more support from friends? would like her friends to take same role as she has? wants friends to explain how Georgie should behave
Yer, how do you see the future for Georgie?	
Erm, well my mum keeps saying she'll end up robbing a bank (laughs) which I don't believe but I think that when she gets older, I think like that because she isn't naughty, because I think she's like more like good than any of us but I think when she gets older I don't think she'll listen that much, you know when she goes secondary school erm, I think she'll get really bored really easily and like when she gets a job, I dunno, she chooses what path she wants to go down to but I will also be there to support her so, I dunno where she'll go with that though.	Her view contradicts her mothers. does not conceptualise Georgies behaviours as naughty predetermined future for George? Focus on positive more good than any of us Had thoughts about Georgie's future supportive + understanding of whatever her sister decides
Yer, erm is there anything that school or your family or friends do that support you? Cos it sounds like you do a lot of supporting for her, where do you kind of get your support and help from?	
Erm, sometimes from you as well so, you help me with like you know understanding as well, sometimes my mum. When she's on Georgie's case she does talk to me saying "you've done so well looking after Georgie" and like sometimes when Georgie gets mad I go to the shop for my mum, I'm like "do you wanna come with me Georgie?" and we have a talk. And yer so. And her friends as well, she's got friends at school and they all support her and they're like asking me like " you're such a good sister, which I had a sister like you" and I'm like "stop" (Laughs) so I have, I do be moody cos I'm a teenager that's what happens but my mum and my dad are really supportive as well. I don't see my dad that much but he supports me as much as he needs to so...	Mentioned me first as support - does this indicate a lack of support from professionals/family? likes to support + help mum, Recognition + praise from mother at adopting parental role Recognition from sisters' peers that she is a 'good sister' dad does not live with them - does feel she receives some support from him
Mmhm, and do you feel like there's anything else that anyone could do to support you and to support Georgie?	
Erm well I think my mum well, I think we should do, I know there's like struggles with money and everything but I think people, well my mum and Georgie should go out together like to the park or something and you know, just let Georgie be, have less stress on her back and I actually have anxiety so sometimes it gets stressful for me and my mum has anxiety too so that's like you know it can be hard for her sometimes but you know Georgie and mum needs to do something with Will, because Will is constantly on her back and I feel like Will needs to be like more active, like doing more things with her so he actually understands what she's like so..	trying to take some of the responsibility / understands responsibility that Mum has to provide for all chdn. own emotional needs - anxiety. Feeling that Step-father is not involved enough in supporting the family?
Yer, do you get any support in school with erm, any of this like feeling anxious or just about you know helping everybody else out or do you have like a mentor in school or anybody that you speak to?	

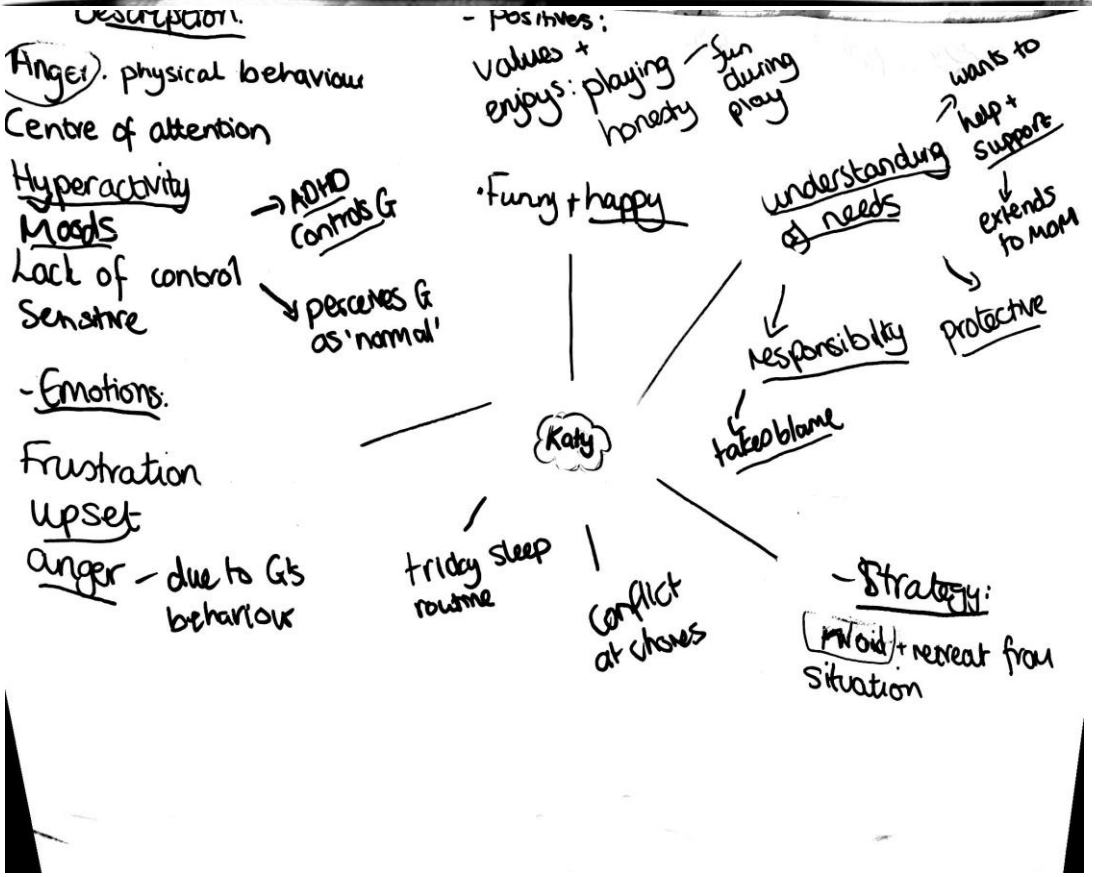
About what?	
Just about anything?	
Erm, well we had assembly about mental health issues	
Mmhm	
But I don't like going there because sometimes I don't really understand like, sometimes I don't understand as much but I know that they help but like I think my mum understands more because she's been like living with me and when they say you should go and visit these people, because they haven't been living with me they don't like really know what your life has been like, I just talk to my mum mostly.	Reluctant to accept support from those who don't understand her... more willing to confide in mum as she feels like she understands her more as she's been living w/her. Feels others won't understand as they have not experienced her life.
Yer	
And in school I talk to my friend Clemmie and she's like a sister to me, I've known her since primary school so I talk to her all the time.	Has one close friend in school. Uses talking to friends + mum at times to manage her own emotions.
So you don't feel like it would be helpful to have someone else to speak to in school?	
No, so like when I tell Clemmie something I go "don't tell anyone else" ok, which I know I should open myself up more to people but like some people I can't trust like I've got this girl and she, I talk to her about everything but she just goes off and tells everyone, I don't talk to her anymore so. I don't talk to her anymore. And with Miss Adyne, because I've had like a bad Year 7 you know, experience because I used to be one of those girls that used to like get in trouble all the time and like I didn't listen at all, so like I used to have like a bad first impression so I can't talk to her cos she doesn't believe me sometimes and I don't, I can't talk to the head teacher cos she's busy so I just talk to my friends or my mum.	Feels she should be more open/honest with people. Feels there are people she can't trust to talk to + share things with but appreciates these may be value to doing this Believes staff have a fixed view of her due to past things. Feels some teaching staff are too busy to hear her concerns.
Mmhm, ok. Erm right I think that's probably just about it, is there anything else that you think it would be useful for me to know about you, or about Georgie or things that you do?	
Erm, about well other than Georgie having this fetish for chasing birds I don't know. Cos she chases birds all the time, I think she likes, she likes running as well so, she likes doing football so I think she likes to be more active than sitting down, that's the thing so. She likes, she wants to be doing something, so than just like being bored, so on the weekend she's like oh "can we do this, can we do that?" and sometimes we don't have the money but like, (coughs) sorry my throat hurts. Like when we go out she just like, she's really hyper.	Georgie gets bored easily + enjoys being active. → keen to try many activities (Georgie)
Yer, it is quite common for erm children who've got ADHD to be more active and do outdoor, outdoorsy things cos	
(coughs) Oh my throat is killing me	

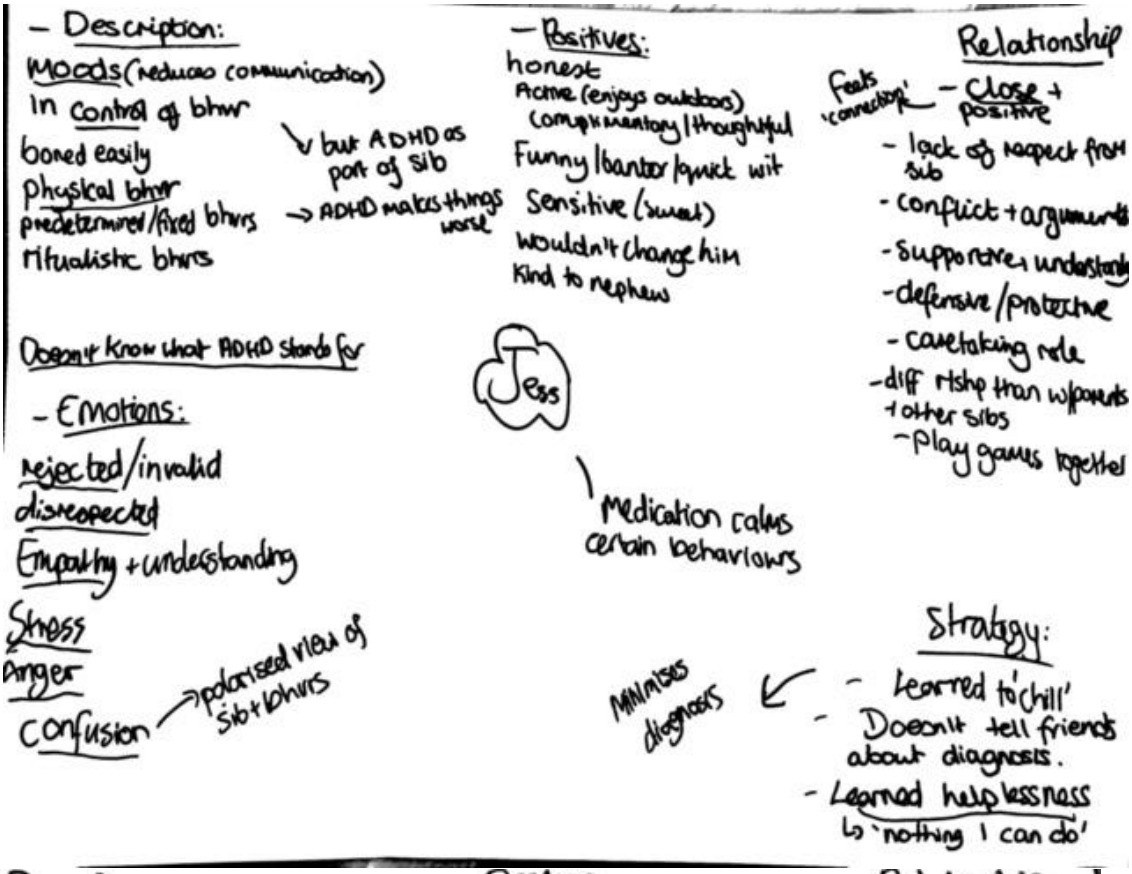
Yer, ok we'll finish up now anyway and then you can go and grab a drink. Alright I'll just turn these off. Obviously I'm going to say a big thank you.	

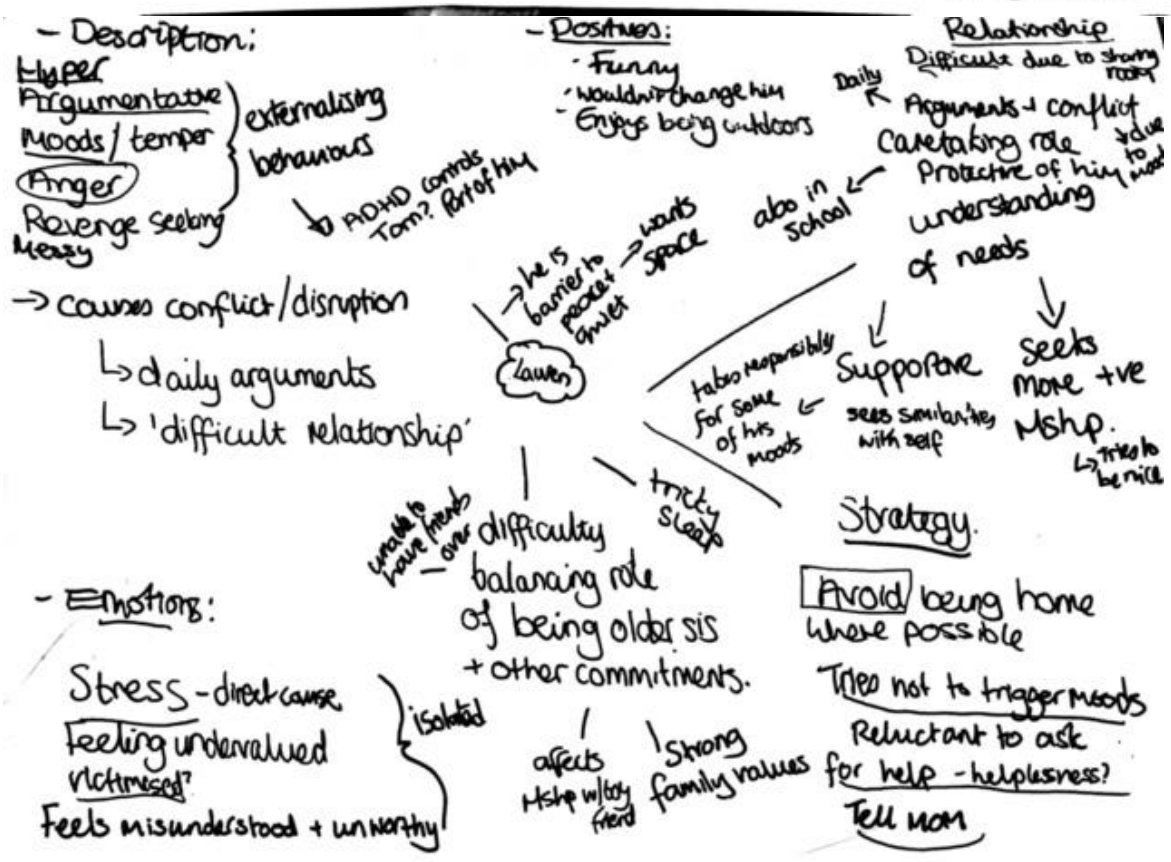
APPENDIX 12 : POST IT NOTES FOR THEMES (TAYLOR)

APPENDIX 13 : MIND MAPS FOR EACH PARTICIPANT






- Description:
Moods (reduced communication)
In control of bhvr
bored easily
physical bhvr
predetermined/fixed bhvrs
ritualistic bhvrs
↘ but ADHD as part of sib
→ ADHD makes things worse
Doesn't know what ADHD stands for
- Emotions:
Rejected/invalid
disrespected
Empathy + understanding
Stress
Anger
Confusion
→ polarised view of sib + bhvrs
- Positives:
honest
Active (enjoys outdoors)
Complimentary/thoughtful
Funny/banter/quick wit
Sensitive (sweet)
Wouldn't change him
Kind to nephew
Jess
Medication calms certain behaviours
Relationship
Feels 'connected'
- Close + positive
- lack of respect from sib
- conflict + arguments
- supportive, understanding
- defensive/protective
- caretaking role
- diff rtshp than w/parents + other sibs
- Play games together
Strategy:
MINIMISES diagnosis
- Learned to 'chill'
- Doesn't tell friends about diagnosis.
- Learned helplessness
↳ 'nothing I can do'


- Description:
Hyper
Argumentative
Moods / temper
Anger
Revenge seeking
Messy
externalising behaviours
↳ ADHD controls Tom? Part of him
→ causes conflict/disruption
↳ daily arguments
↳ 'difficult relationship'
- Positives:
- Funny
- Wouldn't change him
- Enjoys being outdoors
Relationship
Difficult due to sharing room
Daily
Arguments + conflict
Caretaking role
Protective of him
understanding of needs
also in school
→ he is barrier to peaceful quiet → wants space
Lewis
takes responsibility for some of his moods
Supportive
sees similarities with self
Seeks more +ve Rtshp.
↳ Tries to be nice
unable to have friends over
difficulty balancing role of being older sis + other commitments.
tricky sleep
affects Rtshp w/boy friend
Strong family values
- Emotions:
Stress - direct cause.
Feeling undervalued
victimised?
Feels misunderstood + unworthy
isolated
Strategy.
Avoid being home where possible
Tries not to trigger moods
Reluctant to ask for help - helplessness?
Tell mom


Description:
Attention seeking
Threatening
Misleads people
Horrible/nasty/bossy
Angry (screaming/shouting)
Negative - can't take a joke
Make choices about bhvr (control)
Doesn't know what ADHD stands for
Attitude
- Emotions:
Anxiety
Confusion → lack of understanding of bhvr
Hurt/upset
rejection / unfair
Fear (of triggering negative interaction)
Doesn't want to show emotions in front of her
↳ vulnerable
disrespected
victimised
positives:
- Nice + generous
- Enjoys being outdoors
- Defensive of him/protects him
- Imaginative
- Happy + fun
Ben
- She is barrier to peace + quiet
Medication would be 'nightmare' without it
Significant impact on life
not impacted rlshp.
can behave differently when she's not around
sometimes wishes wasn't a twin
internal conflict
Relationship:
- Change in rlshp due to ADHD diagnosis - deterioration
↳ rivalry
- Daily conflict (takes some responsibility)
- Expectation of negative interactions
- Feels powerless / she controls
- considerate + understanding
- Fair parental treatment
- Seeks more +ve rlshp
- Different rlshp w/other sibs
- No apologies
- Interactions on her terms
Unpredictable
Strategy:
- Tries to turn negatives into positives
- Avoid where possible
- Apologises to 'keep peace'
- Monitors own bhvr daily
- Hopeless | learned helpless
- Support from friends
- Seeks support from mum
Description:
physical bhvrs - destruction of property
Moods
Impulsive
screaming / tantrums
↳ swearing
Angry
ADHD controls J - is not separate to him
Doesn't know what letters stand for
Naughty / different from others
Hyper
↳ wishes he didn't have ADHD
Positives
- Enjoys playing together
- prefers him calm
- kind
- generous
- joke together
Ashamed of his bhvr
Chloe
→ would like him to be calm + change
medication would be better for him
Other family rlshps 'chaotic'
Significant impact on life
he IS barrier to quiet + time w/friends
doesn't like others perceptions
injustice - parenting
Emotions:
Confusion over diagnosis
Misunderstood (by brother)
Empathy
rejected - hurt
Anger
upset / sad
frustrated (ignored)
Some emotions due to brother
isolated / powerless
Relationship
- Treated him differently after diagnosis
- Supportive (enjoys this)
- protective
- role of responsibility
- seeks comfort from him
- puts his needs first
- moods affect rlshp
- daily arguments
- conflict
real sense of confusion about diagnosis + how she feels about their relationship
from family?
Strategy:
- seeks support from m
- Learned helplessness
- Would like more support