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**A phenomenological study to explore the social and emotional impact of having a sibling with Attention-Deficit Hyperactivity Disorder (ADHD).**

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**Report Title: A phenomenological study to explore the social and emotional impact of having a sibling with Attention-Deficit Hyperactivity Disorder (ADHD).**

## **ABSTRACT**

Attention-Deficit Hyperactivity Disorder (ADHD) is a common childhood disorder, affecting 2-4% of the school-age population in the UK. Various studies have explored the impact of ADHD on the family environment and dynamic. Research to date has examined the parental experience of having a child with ADHD, with parents experiencing great amounts of stress and often focusing their efforts primarily on the child with ADHD more than their other children. Therefore, it is relevant to investigate how the disorder affects other family members, specifically siblings. The main purpose of the current study is to explore the experiences surrounding having a sibling with ADHD using Interpretative Phenomenological Analysis (IPA) and to add to the marginal amount of literature exploring siblings' accounts. Semi-structured interviewing was used to generate data from 3 female students ( $n=3$ ) from Manchester Metropolitan University who have a sibling with ADHD. Analysis of interviews with participants gave rise to three emergent themes: the retrospective view of the diagnosis of ADHD, alongside understanding changes in feelings, intersubjectivity and protecting the vulnerable sibling, and spatiality and living with ADHD. Overall positive experiences were presented by the siblings of children with ADHD, and despite feeling that they were difficult to live with, participants felt an innate response to protect their vulnerable sibling.

<b>KEY WORDS:</b>	ATTENTION-DEFICIT HYPERACTIVITY DISORDER	SIBLINGS	RELATIONSHIPS	IPA	EXPERIENCES
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## **Introduction**

Attention-Deficit Hyperactivity Disorder (ADHD) is one of the most common disorders within children, affecting 2-4% of the school-age population in the United Kingdom (NICE, 2013). The core symptoms of the condition include inattention and hyperactivity or impulsivity, which make interacting and being sociable with others difficult. Children and adolescents with ADHD, tend to be more impulsive, have a lower frustration tolerance and great difficulty in monitoring their own behaviours (Kendall, 1999).

The term ADHD was first presented in the DSM III in 1980; it had previously been called hyperkinetic reaction of childhood in the DSM II (1968). The term and diagnosis of ADHD is still in its infancy, and although extensive research has been carried out into the condition, when compared with other disorders it has not received as much attention. However, over the past decade, there have been several important developments in treatment of ADHD and various psychological therapies have been developed to help with both treatment and management. These include behavioural therapy, interpersonal psychotherapy, family therapy and parent management training (Soguna-Barke et al., 2013). These therapeutic interventions aim to encourage the development of coping strategies for children and families in managing the behavioural disturbances that occur with ADHD (Taylor et al., 2004; cited in NCCMH, 2009).

The condition affects everyone in the family, from the individual themselves to parents, siblings, and grandparents; therefore family therapy is of vital importance when a child has ADHD (Everett & Everett, 2001). Several studies have examined the impact of this chronic behavioural disorder on the family environment and dynamic. The body of research to date has largely investigated the parental experience of having a child with ADHD (Ahmed et al., 2014). Due to the unpredictable symptoms of the condition, parenting can prove extremely difficult, with parents experiencing great amounts of stress and often dedicating more time and energy to the child with ADHD than their other children. Although these parents may not have deficits in their parenting skills as a whole, they may experience pressure to maintain what they perceive as a 'normal' family environment (Moen et al., 2014). Kendall et al. (2005) reported that parents suffered from increased rates of depression, social isolation, and marital discord, indicating that it can often be difficult to achieve a 'typical' family life. This leads to higher rates of divorce, with divorce being up to three times more likely to occur within families where ADHD is present in children, and such families are reported to have fewer positive experiences when compared with families with neurotypical children (Salmeron, 2008).

Furthermore, as ADHD often does not occur in isolation, comorbidities can exacerbate the severity of the condition, and the impact on families can be profound. Families of children and adolescents who have ADHD may require increased social support, which can include help within the home and family support workers. In light of this, it is important to explore further how the rest of the family is affected by the disorder in general. The inattentive nature of ADHD limits the extent to which children can learn interactions in a social environment, reduces the opportunity to acquire social skills and to attend to the social cues which are necessary for social interaction (DeBoo & Prins, 2007). Therefore, social difficulties are extremely typical

within ADHD. Although the impacts of these ADHD behaviours have largely been reported from the perspective of children and adolescents with the diagnosis, not much is known about the perceptions of siblings of the diagnosed children. Sibling relationships are one of the most intensive and lifelong interpersonal relationships in one's lifetime and play an integral part in the lives of families (Hackenberg, 2008; Howe & Recchia, 2009). Additionally, according to ecological systems theory (Bronfenbrenner, 1992) siblings are apparent in the microsystem, which has the most immediate and direct impact to a child's development and are also viewed as a central component of family systems and serve as an important context for learning and development (Brody, 1998), thus affirming the importance of studying from this perspective. Prior studies have focused on siblings of children with a variety of chronic conditions, and report that they are more likely to struggle with feelings of neglect, loneliness, anxiety, and depression (Knecht et al., 2015). However, these studies reported that siblings are also likely to experience positive effects such as greater compassion over the long-term. Therefore it is imperative that healthcare professionals be aware of the effect of living with childhood illness has on siblings (O'Brien et al., 2009).

Despite this need, a dearth of research has focused on sibling relationships and experiences in families with children with ADHD through a qualitative approach. Kendall (1999) piloted the exploration into this field and summarised qualitative accounts of thirteen siblings of children with ADHD. Kendall reported that a major theme with siblings was disruption, which ultimately caused them to feel victimised and experience sorrow and loss. Additionally, siblings reported feeling victimised by acts of aggression from their sibling with ADHD, which included physical violence, verbal aggression, and manipulation; resulting in the siblings utilising managing strategies such as retaliation and avoidance. Overall, siblings reported to have felt that their life was dependent on the child with ADHD. Even though this study was conducted in 1999 and can be perceived as outdated in comparison with current psychological research, it serves as a foundation for subsequent investigations. Kendall (1999) stated that additional research should be carried out in order to provide a better understanding of the interaction between the behavioural manifestations of the disorder and the subsequent impact on relational and family dynamics. The accounts in this study focused on the negative aspects of the sibling relationship and everyday family life and further included perspectives of the rest of the family rather than focusing directly on sibling accounts. While this research contributed greatly to the field surrounding sibling experiences of ADHD, it would be beneficial to carry out a contemporary study to explore experiences as a whole, including positive narratives rather than solely negative.

Adding to this area of research, Mikami & Pfiffner (2008) reported that sibling relationships of children with ADHD appear to be categorised with higher conflict than those without a clinical disorder. They also state that impairments within sibling relationships appear to be similar to those documented in parent-child relationships and peer relationships, in that children with ADHD tend to be more argumentative and generally engage in more conflicts. This research supports Whalen & Henker (1992) as they suggest that ADHD is a catalyst for negative social interactions. The main findings in this study are consistent with the reports in past literature of many of the negative aspects of the experience of living with a sibling who has ADHD.

Specific focus on the child with ADHD and their overriding needs can result in siblings feeling isolated, left out and often unappreciated.

Likewise, Peasgood et al. (2016) quantified the impact of ADHD with patients and their siblings through measuring their health-related quality of life and happiness levels. It was found that although siblings did not report lessened health-related quality of life, they do report lower overall happiness levels, regarding their life and family environment, when compared to a control group of siblings of neurotypical children. This leads to suggest that a reduced quality of life is caused by ADHD, both in the child themselves and their siblings. However, as stated previously, the participants may only have a memory of living with a sibling with ADHD and potentially be unaware that they report lower levels of happiness when compared to control siblings. Such research advocates the need for further exploration into how the siblings of children with ADHD are affected and what can be done to support them.

Supplementary research recently conducted by King et al. (2016) featured a qualitative study that explored siblings' perceptions of the impact a sibling diagnosed with ADHD has within the family system in South Africa. They synthesized that the research in this area reveals high levels of dysfunction among families. Main themes emerging from the analysis showed that participants experienced differential parental treatment, which resulted in feelings of rejection, facing varying degrees of discipline, and their sibling with ADHD often facing lesser consequences for actions than they did. Furthermore, siblings felt that their role within the family system involved a caretaking role, identified in the theme 'the parentified child'. This theme supports the work of Kendall (1999) where siblings reported that their parents expected them to care for and protect their siblings with ADHD because of the social and emotional immaturity associated with the disorder. This study is current and proves insightful when studying and exploring the experiences surrounding having a sibling with ADHD, however as it was conducted in South Africa, due to cultural differences across family life and experience it cannot possess ecological validity within the UK. Additionally, participants interviewed were solely female, and therefore the research does not account for gender differences. Buhrmester and Furman (1990) reported that gender composition between siblings affects the quality of relationships between brothers and sisters throughout childhood and adolescence. While this research provides an in-depth analysis of how the relationships and roles changed within the family system following the diagnosis, this research does not explore the emotional impact these factors had on the siblings themselves.

In light of the aforementioned research, this study aims to contribute to the existing body of research by exploring the experiences surrounding having a sibling with ADHD. The majority of research focuses on how to help the child with ADHD but there is a lack of emphasis on how to help the siblings within the family. Therefore, this study hopes to offer a platform for neurotypical siblings who have first-hand experience as to what it is like living with a sibling with ADHD to express their feelings, and to understand what it is like living within a family where this disorder is present. Furthermore, the intended aim of this research is to raise particular attention to the neurotypical sibling, in the hope of promoting positive outcomes for the development and strengthening of relationships, for both individuals and families.

## **Research Questions**

The main research question of this study is 'What are the experiences surrounding having a sibling with a diagnosis of Attention-Deficit Hyperactivity Disorder (ADHD)?'

Following this single main research question, providing a multi-faceted approach to the project:

1. 'How do people experience relationships with their sibling with ADHD?'
2. 'How do people experience relationships with their parents when a sibling has ADHD?'
3. 'How does the diagnosis of ADHD on a sibling affect the other siblings in the family both socially and emotionally?'

## **Methodology**

### *Design*

This study employed an explorative design using a phenomenological epistemological approach, which involved face-to-face semi-structured interviews as a method of data collection and Interpretative Phenomenological Analysis as the analytic strategy. A phenomenological epistemological approach was adopted throughout the study, which assumes that individuals have the consciousness to explore and express their experiences allowing the researcher to embrace an insider perspective (Willig, 2008)

### *Participants*

The sample consisted of three female students ( $n=3$ ) (aged 18-21) recruited for this study from Manchester Metropolitan University through purposive opportunity sampling, who all have a sibling with a formal diagnosis of ADHD. The sample was considered homogenous, as all participants were first-born with younger brothers with ADHD.

Purposive sampling is largely used in qualitative research, as it allows for the identification and selection of specific participants most relevant to the study, maximising the effectiveness of limited time (Patton, 2002). In this case, purposive opportunity sampling allowed the recruitment of the target population, students at Manchester Metropolitan University who have a sibling with a formal diagnosis of ADHD who were available at the time of the study. Participants were recruited through the university research 'participation pool' portal. This portal allows for students to sign up to studies to help fellow students with research and in return, as an incentive, the participants receive points for their time. This contained a descriptive invitation containing important information featuring the inclusion and exclusion criteria (seen in Appendix 1) necessary for taking part. In order to qualify for this study, students had to have a sibling who has a diagnosis of ADHD. Information regarding this was clearly stated on the website to ensure participants met this inclusion criteria. Participants expressed their interest by responding to this invitation and a time slot was arranged to schedule an interview.

This sample size coincided with the prospective time frame for the study and proposed method of analysis. Smith et al., (2009) suggest that when conducting analysis through IPA, between 3 and 6 participants are necessary for undergraduate and masters level of study. Eatough & Smith (2006) advocate this notion by stating

that small sample sizes are paramount in phenomenological research to be able to encapsulate experience through analysis.

### *Data collection*

The data collection method used for this explorative research project was qualitative semi-structured interviewing, involving a one-on-one face-to-face interview with each participant. This method was used as it allows rich and substantial data to be collected, in an attempt to explore the participants' experiences. The chosen methodology of interviewing is the most common format of data collection within qualitative research. Smith et al., (2009:p?) state that 'A qualitative research interview is often described as a conversation with a purpose'; allowing for an in-depth, first-person account to be created.

Upon expressing interest in the study, participants liaised with the researcher in order to schedule an interview time suitable for both parties. Interviews took place on the first floor of the Manchester Metropolitan University Brooks Building in a pre-arranged location. The participants were given an information sheet to read prior to the interview and given the opportunity to ask any questions relating to the study (Appendix 2), then required to sign a consent form (Appendix 3).

Following completion of this necessary paperwork, the interviews lasted around 20 minutes in duration guided by the interview guide (Appendix 4), and the audio was recorded using a digital voice recorder. After the interview, the researcher presented the participant with the debrief sheet and the participant was fully debriefed (Appendix 5), and their right to withdraw was made explicit. Upon collection of the data, and after the withdrawal deadline passed, data was transcribed verbatim by the researcher on to a Microsoft Word document on a password-protected computer.

The vast majority of data from qualitative research designs using IPA has been obtained using semi-structured interviews. Within semi-structured interviews, the researcher will have a set of questions on an interview schedule, aimed to guide the interview rather than dictate it. Interview guides prove useful as they achieve optimum use of the interview time (Jamshed, 2014). This type of interviewing is beneficial as it allows the researcher to instantly begin establishing a rapport with the participant, which in turn may help the participants feel more comfortable when opening up about experiences within their life. The semi-structured interview guide contained four broad core questions based on previous literature. Subsequently, many small prompts, which relate to the central questions, were included in order to add more depth to the topic and allow for flexibility; if the participant was initially reluctant to go into detail.

### *Data Analysis*

Qualitative analysis is a way of developing rich explanations from an individual's reported experience (Willig, 2009). The data analysis method chosen for this research was Interpretative Phenomenological Analysis (IPA). The overall aim of IPA is to explore in detail individual, personal and lived experience and to examine how participants are making sense of their personal and social world through a phenomenological lens (Lyons & Coyle, 2016).

IPA is not a prescriptive or dictatorial analysis approach, it provides a set of flexible guidelines, which can be adapted by individual researchers in regards to their research aims. IPA is especially valuable when examining complex topics, which can be multifaceted and laden with emotion (Smith & Osborn, 2015). Smith & Osborn (2015), further highlight that using IPA gives 'painstaking' attention to enable the participant to give as much and as a rich recount of their experiences as possible and that a good IPA study can illuminate the issues surrounding a sensitive subject.

Data was analysed through various in-depth steps. According to Lyons & Coyle (2016), the initial step included reading and re-reading the transcripts multiple times in order to ensure the participant becomes the focus of the analysis. Step 2 consisted of making initial notes and identifying and labelling themes within the transcription (Appendix 6); which Smith et al., (2009) say is the most detailed and time-consuming part of the analysis process. This process required the researcher to be incredibly familiar with the transcript and examine the transcript on an exploratory level. These initial notes were made into a table that highlight parts of the transcript used and exploratory comments made. Stage 3 and 4 included linking such themes and identifying clusters and thus producing a summary table of superordinate themes and important quotes (Appendix 7). These tables allowed the researcher to easily search for connections across the emergent themes, in order to fit themes together and how experiences of participants converged.

### *Ethical Considerations*

Prior to conducting any research or recruiting any participants, ethical approval was required. These ethics adhered to the British Psychological Society (BPS) code of Ethics and Conduct (2009), moderated by the faculty at Manchester Metropolitan University. These guidelines are outlined within the ethical documentation (Appendix 8). Four main domains outlined by the BPS (2009) for ethics are; respect, competence, responsibility, and integrity.

To ensure the safety of both the participant and the researcher during the study, a lone-worker policy was in place. This was designed to manage and reduce the risks involved when conducting individual face-to-face interviews. Although interviews took place at the Manchester Metropolitan University Brooks building, a safe and public place, it was still important to have this policy in place prior to the interviews to ensure good ethical practice.

Participants were asked to carefully read and complete the consent form prior to participating in any research and their right to withdraw was made explicit, and by generating a unique participant number, they were given until 17/03/18 to withdraw their data, after which time the analysis of the data would commence. Following the interview taking place, participants were fully debriefed and provided a debrief sheet containing relevant information. No participant chose to withdraw data.

The interviews were recorded, however, the information provided by the participants were anonymised through the creation of pseudonyms, and so although some parts of the interview will be quoted verbatim, the information is unidentifiable. The data collected for this study was stored securely and only the researcher and supervisor conducting this study had access to this data. The researcher was the sole person conducting and transcribing the interviews; therefore held full responsibility for

destroying any information following transcription. After transcription of the audio recordings, they were destroyed. Data was stored on a password-protected and encrypted computer, and signed consent forms were stored in a locked cabinet.

### *Quality Criteria*

Although the quality of qualitative research cannot be encapsulated within a rigid set of rules, quality is central throughout all levels of qualitative research (Bergman & Loxon, 2005). IPA holds credibility due to its core focus being on themes and interpretations which are clearly evident within the transcript and the participants meaning-making of their individual experience (Lawthom & Tindall, 2011). Pre-interview questions helped establish a strong rapport with participants allowing them to open up, enhancing authenticity of accounts. Such experiential accounts would be difficult to access by using quantitative methods as it is less flexible and less personal (Long & Godfrey, 2004). In order to eliminate the process of researcher bias and enhance credibility, interpretations and themes were member checked (Birt et al., 2016).

### **Analysis & Discussion**

This research contributes to the under-researched area of how siblings experience ADHD (Listug-Lunde et al., 2008). Three main aspects of shared experience were constructed following analysis of the dataset and are documented among participants present in this research. Initially, the analysis focused on the first theme of 'The retrospective view of the diagnosis of ADHD & being able to understand more as time went on' which links to the common life-world feature of temporality (Lawthom & Tindall, 2011). The second theme referred to 'protecting the vulnerable sibling', which relates to the common life-world feature of intersubjectivity (Grunwald & Thiersch, 2009), and the third and final theme focused on 'living with ADHD', and living in the same space as the sibling suffering with the disorder, linking to the life-world feature of spatiality.

#### **1. The retrospective view of the diagnosis of ADHD & being able to understand change of feelings and more about the diagnosis as time went on.**

This theme appeared across all participants, with each participant describing the experience of how they felt as though when they were younger they knew very little about their siblings' diagnosis, partly due to the fact that they were also young and naïve themselves. In particular, Natalie focuses on the experience of her younger brother being more difficult to deal with when he was younger, and that he would try and cause problems within the family dynamic, supporting the research of Whalen & Henker (1992) who suggest that ADHD is a catalyst for negative social interactions.

*'.. so.. it's slightly better now but when I was younger he's very... hard to deal with a lot of the time.. so when we were growing up he would always like cause like a tantrum or something'*

(Natalie - Lines 16-18)

Furthermore, Natalie also highlights how prior to his diagnosis people were trying to help her brother, however it was not until he received the formal diagnosis that there was an explanation for his behaviour which ultimately helped the family, and sometimes cannot be noticed until in hindsight. This statement loosely supports the research of Ahmed et al. (2014), who reported that parents of children with ADHD

made conscious efforts to improve knowledge after their child's diagnosis, and it can be inferred that because parents are teachers to children (Becker, 1971), the children have learned through this constructionist view of experience (Harter, 1999).

*'they were trying to help them and before he was diagnosed with ADHD, it was kind of, it felt like you were just talking to a blank wall, you could not get through to him erm and now that, now they've suddenly got [an explanation for his behaviour]'*

(Natalie - Lines 111-115)

Retrospectively, the experience for Natalie proved to be a positive one, and she now realises that the diagnosis was beneficial for her family, and she can understand that if they had not received said diagnosis they may be in a worse position today. Within this statement, Natalie also supports the use of psychiatric diagnostic tools and from this it can be inferred that diagnosis can be relevant and appropriate for certain psychiatric disorders and can explain the child's behaviour. Moreover, Natalie's account of her experience is mirrored by Caroline, who states that the relationship between her and her siblings has strengthened over time, further supports this theme.

*'Well we fought a lot when we were little, like bickering and picking on each other and stuff, but we've gotten a lot closer as we've gotten older.'*

(Caroline - Lines 16-17)

This is made evident throughout the transcript, with Caroline reiterating several times that she recognises that when her brother was diagnosed, she was too young to comprehend the situation and now understands more about ADHD, and his behaviour. However, this increased understanding was not due to education provided by clinical professionals, it was independently sourced by participants. This questions whether clinicians are adequately supporting families following diagnosis of ADHD (Ghanizadeh & Zarei, 2010). Furthermore, it can be inferred from this quote that the relationship between Caroline and her siblings has improved with age, supported in the research of Buhrmester & Fuhrman (1990) who report that as children get older their sibling relationships become less conflictual.

*'it was hard to see him like that and not be able to help, and since we were young, I was too young to understand it.'*

(Caroline - Lines 25-27)

*'Oliver's behaviour used to put a strain on mine and Jack's relationship with my parents because we just didn't understand why they treated him differently or punished him differently'*

(Caroline - Lines 41-43)

Caroline concludes that although she was unaware of why she felt she was treated differently as she has gotten older, she now understands why she felt this and comprehends the reasons for him being treated differently. Research from Johnston et al. (2012), indicates that the siblings often experience and perceive an absence of parental attention and feelings of different treatment in families where ADHD is present. Additionally, Zara's perspective reasserts this theme, explaining that she feels somewhat guilty in relation to her past feelings of slight resentment towards her brother, but that now she understands the diagnosis and the condition, and wants to give her brother more support.

*'it was difficult for all of us, and for my dad and step-mum to share their time between us all, he definitely got the most of it, I did resent him, and even though I loved him as a brother, [inaudible] ... but it was more of a resentment towards him, whereas now I understand, and I do want to be there for him'*

(Zara - Lines 26-29)

Zara also reflects on the fact that she now understands that when she was younger was slightly selfish and self-centered, which was mainly where her feelings of resentment stemmed from, and now comprehends that her brother was the focus of the family due to his condition.

*'he was in the spotlight, and now I understand but when you're younger you do just think of yourself.'*

(Zara - Lines 49-50)

Overall, participants report that as they have aged, they understand more about their siblings' disorder. The notion of greater understanding with age refers to Kolb's experiential learning theory (Kolb, 1984) that defines experiential learning as the process whereby knowledge is created through the transformation of experience which can be seen to be evident throughout the transcripts, with participants explaining their current and retrospective views. To further explore these views around the experience of understanding, a longitudinal phenomenological study could be carried out within families to examine current and retrospective views of having a sibling with ADHD and how this changes over time. It could be noted that participant's memories of experiences of ADHD could be skewed due to cognitive bias and selective processing of emotion-relevant information (MacLeod & Rutherford, 1992), so a longitudinal study would help improve the quality and veracity of the study.

## 2. Intersubjectivity and protecting the vulnerable sibling.

Apparent within participants' accounts was also the maternal instinct of protecting the younger, more vulnerable sibling who has ADHD. This was present in transcripts following the question surrounding the social impact of the diagnosis. Especially in Caroline's transcript, where she explicitly states,

*'I'm really protective of them [her brothers], to a fierce extent, I always have been like that. I do my best to never let people hurt them'*

(Caroline - Lines 17-20)

However, it is unclear as to whether this theme is solely related to siblings of ADHD, or whether neurotypical older siblings feel the same need to protect their younger siblings, as all participants featured in this sample are the eldest, first-born child within their family. This theme supports the research of Barr et al. (2008), who stated that siblings could take on the role of the protector for their sibling with a disability to ultimately protect them against the outside world. Natalie amplifies this notion of protecting her younger sibling stating that she was always trying to help him.

*'..I was like in Lower sixth form when he came to [my] secondary school so I was very much like trying to help him... if he was getting picked on, I would go and talk to a teacher about it... or if he was getting upset I would [help]...'*

(Natalie - Line 70-76)

And focuses on the notion of maternal instinct.

*'it was almost like I was trying to like mother him..'*

(Natalie - Line 77)

Furthermore, she states that following his diagnosis, people were able to help a little more, which meant that she had to take a step back and let other people look after him, and although she admitted she found overwhelming at first, it proved to be beneficial for them both. This experience supports the research of Kendall (1999) and her theme of the 'caretaking role' among siblings of children with ADHD.

*'It was a bit scary actually, cause there were bits where I was like.. I wanna help you, my little baby brother'*

(Natalie - Lines 86-88)

Moreover, Zara states that she feels that her brother does not get enough support for his ADHD, therefore she feels compelled to support him more, and wants to help him.

*'he often comes to me for advice with school, cause he's really struggling in school and getting kicked out all the time, I don't really think he received enough help and I do want to help him'*

(Zara - Lines 10-12)

From this quote, Zara describes how she thinks her brother experiences having ADHD, and because she feels he does not receive enough support, she believes that she should intervene and try to help him; and as she is at university, can provide good advice for someone struggling in school. Although this extract supports the notion that children with ADHD have a higher risk of academic expulsion (Faraone et al., 2001), this experience also relates back to the idea of being the protective older sibling (Whiteman et al., 2011). Although this research does support King et al. (2016), as this theme is similar to the 'parentified child' affect (Earley & Cushway, 2002), none of the participants in the present study describe their role as a protector being placed upon them, here it is something which they have very much engaged with themselves, as a compassionate older sibling.

In contrast to prior research, where many siblings reported negative interactions with their sibling with ADHD, each participant in this study reflects on the relationship with their sibling as generally positive. A positive sibling relationship can strongly contribute to high resilience among children with ADHD and can contribute to improved therapeutic outcomes (Mikami & Pfiffner, 2008). Additionally, the positivity of these relationships supports research of Knecht et al. (2015) who report that siblings are highly likely to experience positive effects such as greater compassion over the long-term.

### **3. Spatiality and living with ADHD.**

This theme illustrates the difficulties around living in the same house as someone with a behaviour disorder. This is initially highlighted in the interview with Zara, where she explains how she did not live with her brother who has ADHD full-time, and that she only lived with him on the weekends, when she would stay with her dad. Zara explains that it was incredibly difficult to live with him on the weekend, and it can be interpreted that she resented him for overshadowing the quality time that she did spend with her dad, supporting research of Kendall (1999) with the concept of 'loss', here relating to the loss of normality.

*'It was really difficult to live with him on the weekends, I mean we couldn't even sit down and watch TV because he would be running about the house'*

(Zara - Lines 37 – 39)

This interpretation is evidenced further into the interview, and Zara describing the strain that her brother's ADHD put on her bond with her dad, and virtually damaging the relationship.

*'I did get fed up of him and it did make me not want to go to my dad's at the weekend because if his behaviour had been really bad that past weekend wouldn't wanna go the next ...'*

(Zara - Lines 73-76)

This proves important as it showed that there was a large social impact on Zara throughout her childhood, further highlighting the experience that life was dependent on her brother with ADHD, which supports prior research of Kendall (1999), and states that the day-to-day experience of living with ADHD and its effects has the potential to influence siblings in a negative way.

*'I never lived in the same house as him so I don't know what that would have been like, it was just on the weekend.'*

(Zara - Lines 51-53)

On the contrary, Natalie highlights that since moving away to university, she believes that the dynamics within her family have improved, partly due to the fact that because she is no longer there her brothers are somewhat forced to get on with each other. This further highlights the importance of spatiality, and the possibility of spending too much time with a loved one, especially one who has ADHD can be draining, and time away can improve relationships.

*'I get on with them both great, actually since coming to university, and I think because I'm no longer in the picture, I think they're actually getting on better'*

(Natalie - Lines 60-62)

It can be further interpreted from this quote that since Natalie is no longer living in the same space as her brothers, that even without the presence of ADHD, relationships were bound to improve.

The data subjects featured within this study align with the general statistics that males are more likely to be diagnosed with ADHD than females (Willcutt, 2012), as all participants in this study have younger brothers who suffer with ADHD. Further research could be conducted to explore the differences in experience of having a brother with ADHD compared to a sister, this would prove particularly interesting considering ADHD tends to manifest itself differently dependent on biological sex, with males more likely to meet the criteria for all three ADHD sub-types outlined in the DSM-V (APA, 2013).

The current research does not account for gender differences due to the sampling and recruitment issues, however still proves insightful into the experience of having a sibling with ADHD. Buhrmester and Furman (1990) reported that gender composition between siblings affects the quality of relationships between brothers and sisters throughout childhood and adolescence. The demographics of each participant were very similar, which means that this experience cannot be generalised across cultures, and further research is needed to explore the affect of ADHD on families and siblings in ethnic minorities.

## Summary

This research summarises three main themes that were made apparent across transcripts. Overall, ADHD has a profound effect on siblings and the family dynamic, however, as documented within this research, such relationships and dynamic improve as support increases for the child with ADHD and clarity the diagnosis provides. Additional research is needed to explore further demographics within ADHD, such as how girls with ADHD affect the family dynamic, and younger sibling experiences. Siblings are an important reciprocal relationship of long duration. They play an important role in development during adolescence and early adulthood. These relationships may be an underutilised protective factor due to their inherent benefits and social support (Macks & Reeve, 2006). It is clear that growing up with a

behaviourally challenged child presents distinct psychological challenges as well as caring opportunities for siblings, therefore it is important that further inquiry is performed into this area. Longitudinal studies using IPA would prove useful in order to record experience with ADHD over time, or focus group interventions for participants to share experiences.

Schuntermann (2009) proposed a model for engaging siblings in time-limited focused conversations about living with developmentally and behaviourally challenged brothers or sisters. It is designed to proactively and preventatively contribute to siblings overall understanding and relatedness to their affected sibling, and enable the siblings to overcome difficulties of being 'entrenched' in negative interactions in mutually helpful ways, by enhancing sibling capacities to mentalize their experiences. This could prove useful to enhance the positive experiences in siblings of children with ADHD documented throughout this research.

### **Reflexive Analysis**

Due to adopting qualitative approach to research, researchers must recognise how their subjectivity influences data collection and analysis (Finlay, 2002). It is imperative to be reflexive in qualitative research, especially in terms of personal reflexivity, as prior beliefs and assumptions can inherently shape the data analysis and subject being studied (Watt, 2007).

From using Willig's (2013) model of reflexivity throughout this research project, I must consider my personal and epistemological reflexivity both as a person and theorist respectively. My personal reflexivity standpoint refers to the initial reason for wanting to study this topic area, which rose from working on a behavioural treatment programme, in Summer 2017. The treatment programme was structured as a day camp, for children with predominantly ADHD and other conduct and behaviour disorders, and took place in New York, USA. This evidence-based programme provides social, academic and recreational enrichment that helps to treat children with ADHD and try to suitably prepare them for returning to mainstream school and society. This camp offered parent training, however I noticed that little attention was paid to the siblings of the children with ADHD. However, other than working on this treatment programme, I have no personal experience of living with a sibling with ADHD, so I believe I was an active yet impartial researcher.

In reference to my epistemological reflexivity, my own views align with Smith & Osborn (2003), who believe participants are the experts in their own experiences. Prior to conducting interviews, I had the assumption that many of the experiences discussed were going to be negative, especially following the prior research. However, my view has now changed, due to the participants in this study expressing mainly positive experiences. Nevertheless, I am a novice researcher and due to the epistemology being a phenomenological approach, findings cannot be generalisable and are only true of participants present in this research, and my interpretations of their meaning-making of experiences.

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