An exploration of parent-child and family relationships following a childhood diagnosis of ADHD

Lauren Atherton

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Supervised by:

Dr Jim Williams

Dr Laura Eccleston

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Thesis overview

Attention deficit hyperactivity disorder (ADHD) is a neurodevelopmental condition which is frequently diagnosed in children and young people, estimated at 5.3% based on systematic review of global prevalence rates (Polanczyk et al. 2014). Research suggests that many parents of children with an ADHD diagnosis experience high levels of parental stress (Weiner et al. 2016), with disruptions to home life and challenging family relationships frequently cited by parents as contributors to their emotional distress (Corcoran et al. 2017). This thesis both synthesises and extends existing qualitative research exploring relationships in families of children with an ADHD diagnosis, with a particular focus on the parent-child relationship. It is comprised of a systematic literature review and an original piece of empirical research, both of which were prepared for submission to "Emotional and Behavioural Difficulties".

Chapter two of this thesis features a systematic literature review of the qualitative literature exploring family life and family relationships for children and young people diagnosed with ADHD and their relatives. Fourteen studies were eligible for inclusion and a thematic synthesis of their findings was conducted. The review identified six analytical themes: Relationships: conflict and strain; Relationships: strengths and supports; Family challenges; Family responses; Family identity and Family growth and coping. Findings highlight the different ways in which families respond to the challenges they face and emphasise the importance of recognising the strengths and needs of the whole family system.

Chapter three presents an empirical research study which explored parents' experiences of the parent-child relationship and the impact that their child's ADHD diagnosis had upon this. Ten parents of children (aged 8-16 years old) who had received a diagnosis of ADHD between eighteen months and five years prior to the interview participated in the study. Grounded theory methodology was utilised to develop a theoretical model of

development in the parent-child relationship, which depicted that their child's ADHD diagnosis had impacted positively on the parent-child relationship. In particular, parents reported increased understanding and empathy for their child post-diagnosis. However, the extent to which the diagnosis was viewed as positively impactful varied amongst participants and was mediated by a range of factors. The importance of effective and timely access to support for parents of children with an ADHD diagnosis is discussed.

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Chapter One

The experiences of family life and family relationships for children and young people with a diagnosis of ADHD and their relatives: A systematic review and thematic synthesis

Lauren Atherton

Correspondence to be addressed to:

Lauren Atherton

Department of Clinical Psychology

Whelan Building

Quadrangle

Brown Hill

Liverpool

L69 3GB

Telephone: 0151 794 5534

Email: lauren.atherton@liverpool.ac.uk

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1 The author guidelines for this journal can be found in Appendix 1. Chicago Manual of Style 16th Edition (author – date) referencing is used. The word count for this journal is 8000 words, however as permitted by current thesis guidelines for the purpose of thesis submission the word count of this paper is 9,592.

The experiences of family life and family relationships for children and young people with a diagnosis of ADHD and their relatives: A systematic review and thematic synthesis

Abstract

Families of children diagnosed with ADHD are often left without appropriate support, despite experiencing significant challenges within family relationships and the home context. This review synthesised qualitative research exploring experiences of family life and family relationships for both children with a diagnosis of ADHD and their relatives. Five electronic databases were systematically searched between November 2019 – July 2020 for English language, qualitative peer-reviewed studies. Fourteen studies met the inclusion criteria and were subject to quality appraisal and thematic synthesis. Six analytical themes were generated: 1) Relationships: conflict and strain, 2) Relationships: strengths and supports, 3) Family challenges, 4) Family responses, 5) Family identity, and 6) Family growth and coping. Findings indicate that families experience both stress and positive growth in response to the challenges they experience, highlighting the need for families to receive personalised support which builds on their existing strengths.

Keywords: ADHD, child, family, systematic review, qualitative synthesis

Introduction

Attention deficit hyperactivity disorder (ADHD) is one of the most frequently made diagnoses in children, with a global prevalence rate of approximately 5% (Tarver, Daley and Sayal 2014). The most widely used diagnostic criteria for identifying ADHD in children and adults is presented in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, APA 2013). In order for a diagnosis of ADHD to be made there must be a pattern of persistent inattention and/or hyperactivity over at least six months, which significantly impacts an individual's functioning or development across at least two contexts (APA 2013). However it is also important to acknowledge the wider systemic contexts in which difficulties with inattention, hyperactivity and impulsivity are conceptualised, for example the incongruence between the behavioural expectations placed on children within specific social contexts and their ability to comply (Carr 2016).

Whilst ADHD is most commonly understood within the dominant biomedical framework upon which the DSM-5 is based (Barkley 2015), the lack of evidence for specific biological markers for ADHD means that this is a complex theoretical area that has attracted criticism regarding the validity of ADHD as a diagnostic concept, particularly from a social-constructionist perspective (Timimi and Taylor 2004). Rather than becoming entrenched in 'either/or' arguments this paper adopts a position which acknowledges both the problematic conceptualisation of ADHD within the prevailing biomedical model, whilst recognising the extensive range of evidence which supports the validity of ADHD as a discrete diagnostic concept (NICE 2018).

Children who receive a diagnosis of ADHD may experience a range of difficulties across different social contexts. Difficulties attending to teachers, sitting still in a classroom and inhibiting impulses can present barriers to academic engagement for some children with an ADHD diagnosis (Wiener and Daniels 2016). Impulsivity and behavioural expressions of

frustration may lead to difficulties initiating and maintaining friendships with peers (Hoza 2007).

Children diagnosed with ADHD and their relatives may also experience difficulties within the context of the family system. Such families experience significant relational stress, with parents indicating heightened stress levels (Babinski et al. 2020; Wiener et al. 2016) and lower levels of marital satisfaction (Zarei, Rostami and Ghapanchi 2010), in addition to relational stress within both parent-child and sibling relationships (Hulsbosch, Boyer and Van der Oord 2020; Peasgood et al. 2016). Family life more broadly may also be impacted, with families reporting disruption to daily domestic routines and family activities (Harpin 2005).

Understanding family contexts and experiences

Family systems are children's earliest social context, occupying a uniquely important position in their emotional, social and psychological development (Carr 2016). Research has long established the importance of understanding children's family contexts and experiences due to their link to a wide range of health and wellbeing outcomes, with children who grow up in families which feature disorganisation and problems in marital and sibling relationships at greater risk of developing psychological difficulties (Davies and Cummings 2006; Defoe et al. 2013). Patterns of interaction between children and their relatives may also unintentionally maintain difficulties for the child, for example through inadvertent reinforcement and confused patterns of communication (Carr 2016). Conversely, a range of factors within the family system including structure, organisation and clear patterns of communication can serve as powerful protective factors for children who may otherwise be at increased risk of experiencing psychological distress (Carr 2016; Goldstein and Brooks 2013).

Theories of family functioning which apply a systemic lens (Bowen 1978) and Bronfenbrenner's ecological systems theory (1979) posit a bi-directional and reciprocal

relationship of influence between children and their family system. This reciprocity is captured within models which have been developed to better understand families of children diagnosed with ADHD, such as the developmental-transactional model, in which the experiences and behaviours of individual family members have a mutually reciprocal influence upon one another (Johnston and Chronis-Tuscano 2015). Within this model, the parent-child relationship is seen as central for a range of more or less adaptive outcomes for children and is in constant interaction with other family sub-systems (e.g. inter-parental relationships and sibling relationships) and contexts (e.g. social and cultural experiences of support or stigma) (Johnston and Chronis-Tuscano 2015).

The highly complex and nuanced interactions between the experiences of children with an ADHD diagnosis, the experiences of their family members and their relation to a range of health outcomes highlights the need to better understand experiences of family relationships and family life for this population. Although quantitative research is important in indicating the type, prevalence and interaction of difficulties experienced by children diagnosed with ADHD and their relatives, qualitative research is uniquely positioned to provide a rich understanding of the lived experiences of families and how they make personal sense of the challenges they face. Despite the relative lack of qualitative research compared to quantitative research, there have been an increasing number of qualitative studies exploring the experiences of family life and family relationships for children with ADHD and their relatives (Firmin and Phillips 2009; Moen, Hall-Lord and Hedelin 2014; Wong and Goh 2014).

One previous narrative review of research concerning families of children diagnosed with ADHD has been conducted, however this focused exclusively on quantitative research and concluded that the interaction of family factors and childhood ADHD are extremely complex, with significant gaps in the existing knowledge base (Johnston and Mash 2001). A

more recent systematic review of the qualitative literature was presented by Corcoran et al. in 2017, which synthesised research exploring parental experiences of raising a child with ADHD. This focussed largely on experiences of parental stress and views of medicating their child for ADHD, with little or no focus on the experiences of the wider family system

The increased utilisation of healthcare services by families of children with an ADHD diagnosis (Holden et al. 2013) and recent updates to clinical guidance on the treatment and management of childhood ADHD which highlights the importance of support for the whole family (NICE 2018), emphasises the importance of considering the experiences and needs of the family system in providing support for children with a diagnosis of ADHD. As such, a systematic review of the qualitative research exploring the experiences of family life and family relationships would be valuable for professionals working with children in receipt of an ADHD diagnosis in order to better understand both their needs within a family environment and the support needs of their family system.

Review aims

The present review aims to synthesise the existing qualitative research base which explores both daily life for families of children with an ADHD diagnosis and family relationships between children and their parents, siblings and other family members. This review will address the question: what are the experiences of family relationships and family life for children and young people with ADHD and their relatives?

Methods

The present systematic review was conducted and reported in line with the Preferred Reporting Items for Systematic reviews and Meta-analyses (PRISMA) guidance (Moher et al.

2009). The protocol for this review was registered on the PROSPERO database for systematic reviews (https://www.crd.york.ac.uk/prospero/, protocol ID: CRD42020178115).

Search strategy

The following electronic databases were searched systematically: Embase, CINAHL, PsychINFO, Medline and Web of Science. The PROSPERO database and the Cochrane Library were also searched to identify existing or anticipated reviews of relevance. Additionally the following journals were individually searched: Emotional and Behavioural Difficulties; Journal of Child and Family Studies, ADHD Attention Deficit and Hyperactivity Disorders and Journal of Child Psychology and Psychiatry. Hand searching of cited articles from eligible studies also took place. Searches were carried out in November 2019 and replicated again in July 2020 in order to identify any further papers that had been published since the initial search. Reference management software assisted in the storage and organisation of references yielded through the search process (EndNote X9).

Search terms were generated using the SPIDER framework (Cooke, Smith and Booth 2012). Relevant search terms were also identified for each individual database using the available thesaurus tools in the advanced search settings (for example Medical Subject Headings tool). Search terms were entered into the database search engine using Boolean operators (such as “OR”, “AND”) in order to build and combine search sets appropriately.

Table 1: Identification of search terms using the SPIDER framework

Domain		Search terms
S	Sample	young pe*, child*, adolescen*, girl*, boy*, brother*, sister*, parent*, sibling*, mother*, father*, famil*, relative*, relation*, system*, mum*, mom*, dad*, parent-child relation*, sibling relation*, family relation*, family conflict, family functioning, family life, nuclear family, extended family, mother-child relation*, father-child relation*
Pi	Phenomenon of interest	ADHD, "attention deficit hyperactivity disorder", "attention deficit disorder with hyperactivity", "attention deficit disorder", hyperactiv*
D	Design	qualitative, "qualitative research", "grounded theory", "interpretative phenomenological analysis", "thematic analysis", "content analysis", "narrative analysis", interview*, "focus group*", "discourse analysis", phenomenolog*
E	Evaluation	experience*, expectation*, opinion*, stor*3, narrative*, perspective*, perception*, reflection*, "lived experience*"

Inclusion and exclusion criteria

The below inclusion criteria were applied to the search results:

- Participants who were children or adolescents (aged 18 years old or younger) with a formal diagnosis of ADHD and/or their family relatives (this included but was not limited to parents and siblings of children with an ADHD diagnosis)
- studies which focussed on the experiences of family relationships or family life
- original, primary research published in a peer-reviewed journal
- published or available in English

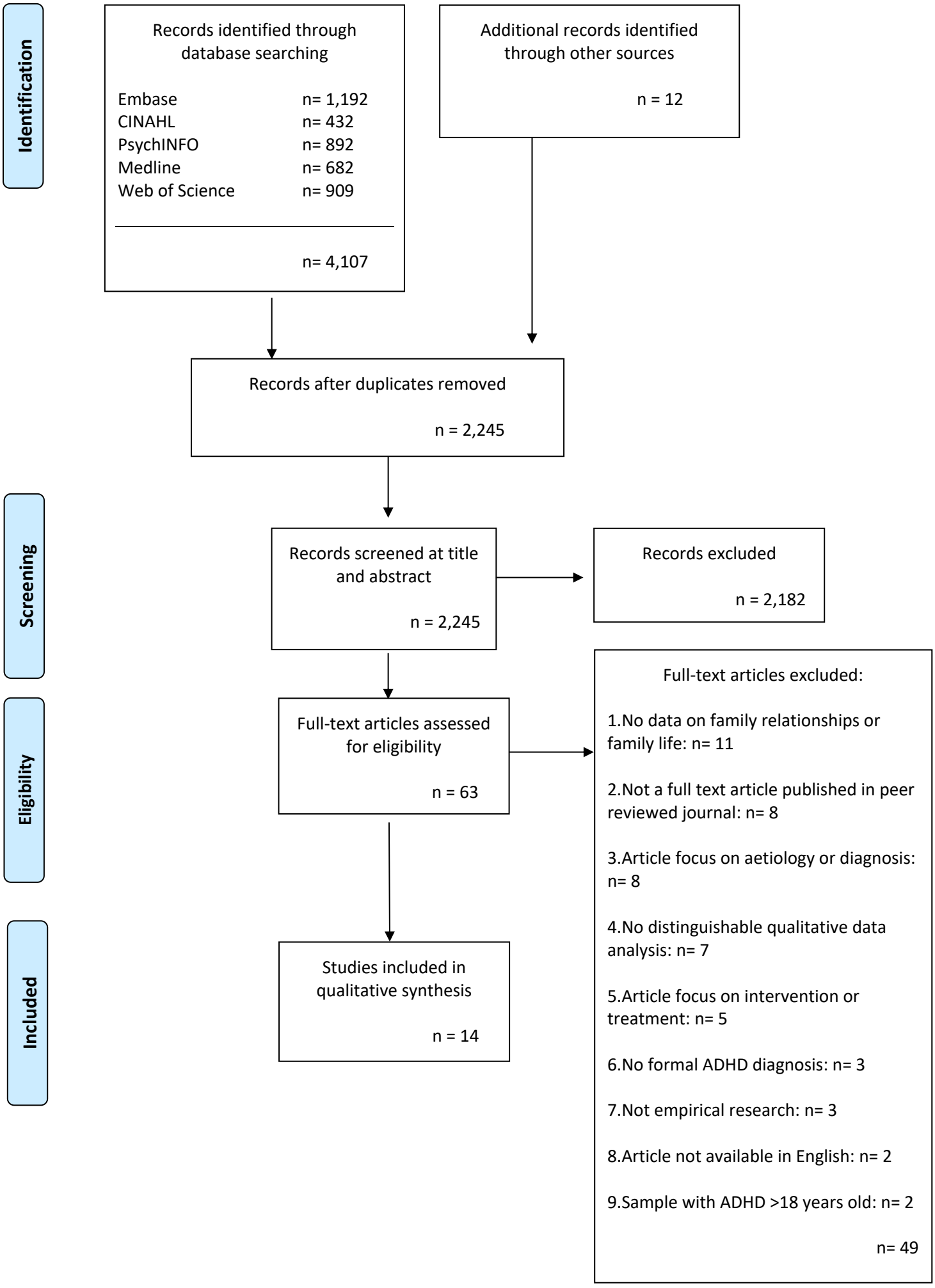
Papers were excluded if family narratives could not be separated from professional narratives or if narratives from child or adolescent participants with ADHD could not be distinguished from either those over 18 years of age or those who had an alternative neurodevelopmental diagnosis (such as Intellectual Disability or Autism Spectrum Condition). Papers were excluded if the study focussed exclusively on treatment interventions (such as medication). Papers which focussed solely on the diagnosis or aetiology of ADHD were also excluded

after being identified at full text screen. Such papers presented the different biomedical, cultural and social-environmental theories that parents of children with an ADHD diagnosis draw upon when broadly discussing ADHD as a diagnostic concept. However as these papers did not feature participant accounts of their family relationships or family life, or report on how participants' engagement with these different theories impacted this, these papers did not meet the inclusion criteria for the current review and were therefore excluded as appropriate. Additionally, studies which did not apply any qualitative data analysis were excluded. Date parameters were not applied to the search strategy as no previous systematic review of the experiences of family life and family relationships with this participant sample has been conducted.

Study selection

The search yielded a total of 4,107 articles (Figure 1). A further 12 articles were identified by hand searching. Reference management software assisted in the identification and removal of duplicate articles. The inclusion and exclusion criteria were applied to the remaining articles and fourteen studies were identified as suitable for the review. 10% of the articles were selected for screening at both title/abstract and full text by a colleague of LA (MO), in addition to applying the inclusion and exclusion criteria to each of the final fourteen studies to confirm their eligibility. No disagreements arose in the decision making process.

Figure 1: Flow chart of systematic search process (Moher et al. 2010)



Quality assessment

The Critical Appraisal Skills Programme (CASP 2015) framework was used to assess the quality of included studies. Although the CASP favours a checklist approach, formal numerical scoring systems have been developed and implemented (Butler, Hall and Copnell 2016,) which the current review utilised in the scoring of the studies (item not met=1, item partially met/unsure=2, item fully met=3). LA and a colleague (MO) independently assessed the studies using the CASP. Any disagreements were discussed and an agreed score was reached for each paper, the maximum of which could be 30 (Appendix 2). The quality assessment applied to the studies was used to contextualise the subsequent data synthesis, rather than being used as a tool of exclusion.

Data extraction and synthesis

Descriptive data from the studies was extracted using the Joanna Briggs Institute Quality Assessment and Review Instrument (The Joanna Briggs Institute 2014). Thematic synthesis (Thomas and Harden 2008) was undertaken as the chosen method of data synthesis, due to the clearly defined methodology and rich level of data abstraction that it provides, producing robust interpretations which 'go beyond' the original data to produce novel meanings and hypotheses. Thematic synthesis considers all text within the 'results' or 'findings' sections of studies to be data, and as such these were entered into QSR NVivo-12 (qualitative data analysis software). Data synthesis followed the three step approach outlined by Thomas and Harden (2008) and started by closely coding each sentence in order to capture its content and meaning, with the majority of sentences having more than one code applied to it. The application of existing codes and the generation of new ones where necessary facilitated the 'translation' of concepts across the full range of studies. In the second stage of synthesis LA inspected the codes for any similarities and differences, organising these

hierarchically where possible, which aided the identification of descriptive themes. The final stage of synthesis, the generation of analytical themes, involved grouping and further refining themes with the review question in mind. LA conducted the data synthesis and discussed the process and outcomes with JW and LE.

Results

Study characteristics

The key study characteristics of the fourteen papers included in this review are presented in Table 2. Of these, nine studies explored the experiences of family caregivers of children diagnosed with ADHD; the majority of which featured the voices of mothers but also included narratives from fathers and grandparents. The remaining five studies focussed on the experiences of children and young people with an ADHD diagnosis alongside their parents, three of which also included siblings' narratives. No eligible studies were identified that had children and young people with an ADHD diagnosis as their sole participant sample, reflecting the paucity of research which gives voice to their experiences.

The majority of studies scored highly on the quality assessment, with most studies clearly reporting their research design, methodology and data analysis. Only three of the studies scored less than 25 out of 30, with failure to name a specific qualitative approach or provide sufficient detail about data analysis the most common reasons for receiving a lower score. Although receipt of a lower quality appraisal score did not result in the exclusion of these studies, the queries this generated about their rigour resulted in a more tentative treatment of their findings in the subsequent data synthesis. Therefore, the descriptive themes developed from data which included these studies also had to be present across a broad range of other studies in the data set with high quality appraisal scores, in order to support the finding. The distribution of themes across the whole data set can be found in Table 3.

Table 2: Data extraction table for included studies

Author(s) Year	Method[2]	Phenomena	Setting	Geography	Culture	Participants & sampling method	Analysis	Conclusions	CASP Score /30
Firmin and Phillips, 2009	Interviews (30-40 minutes)	Daily family experiences and routines	Not stated	USA	15 dual parent families; 2 single-parent families. Developed country	17 families, parents only Purposive sampling	Strauss and Corbin (1990) protocol	Families attune to child's needs; make adaptations; strategies. Mornings and doing homework stressful times of the day.	27
Hallberg et al., 2008	Interviews (60-90 minutes)	Raising a teenage daughter with ADHD	Interviewer's workplace	Sweden	Developed country Single and married parents	12 parents (one father). Purposive sampling	Grounded theory	Mothers experience long term stress; struggle without support. Role in supporting daughters and resolving family conflicts.	25
Kendall, 1998	Individual and family interviews (30-90 minutes)	Family experiences and how they cope with child's ADHD	Participants home	USA	Developed country. Dual parent, single parent and step-parent families.	15 mothers, 10 fathers, 20 children with ADHD;14 non-ADHD siblings. Purposive.	Grounded theory	Parents experience significant distress. Develop processes that facilitate acceptance. Need for increased clinical support for all family.	28
Kendall, 1999	Individual and family interviews (30-60 minutes) Diary entries.	Experiences of siblings of children with ADHD	School-based	USA	Developed country. Caucasian. Mixture of dual parent and single parent families	12 children with ADHD, 13 non-ADHD siblings, 11 mothers, 5 fathers. P	Grounded theory	Difficult family relationships; report aggression and violence from their sibling with ADHD; require own support. Positive aspects of care-giving to their sibling with ADHD.	27

[2] All interviews are open ended and semi structured unless stated otherwise

Leitch et al., 2019	2 focus groups; 2 meetings per group; each 2 hours	Experiences of parental stress	University	Australia	Developed country.	13 parents from 11 families;. 11 mothers; 2 fathers.	Thematic analysis	Home life described as "warzone"; long-term parental stress; family level impact of ADHD.	28
Lin, Huang and Hung, 2009	Interviews (60-120 minutes)	Caregivers' experiences	Not stated	Taiwan	Countries of origin: Indonesia; Vietnam; China; Taiwan.	10 mothers; one step-mother; one grandmother. Purposive sampling.	Descriptive phenomenology	Mothers experience frustration due to emotional burdens and family conflicts. Lack of support for families.	28
Moen, Hall-Lord and Hedelin 2011	Interviews (30-60 minutes)	Experiences of everyday family life	Family home	Norway	Developed country. Single and dual parent families.	6 mothers, 3 fathers, 4 siblings and 4 children with ADHD.	Phenomenographic approach.	Family conflicts. Families develop skills and strategies. Parents require early support. Striving strengthened companionship and growth within the family.	25
Paidipati et al. 2020	Interviews (14-52 minutes)	Parent and family management of childhood ADHD	Health care clinics	USA	Developed country. Single and dual parent families.	50 caregivers (98% female)	Directed content analysis; qualitative descriptive methods	Physical, emotional, psychological demand on parents. Importance of consistent parenting. Optimistic about family's future.	28
Ringer et al. 2019	Interviews (40-80 minutes)	Parents' meaning-making of child's ADHD	Participants' home or workplace. Researchers office.	Sweden	Developed country.	4 fathers; 8 mothers. Theoretical sampling.	Charmaz (2006) inductive approach	Diagnosis enables parents to adapt; cope; integrate ADHD into family life. Seeking 'normalcy' in relationship with child.	28

Segal and Frank 1998	1-4 interviews with families (90 minutes to 5 hours)	Adaptation of families' afternoon schedules	Not stated	USA	Developed country. Single and dual parent families.	17 mothers and 3 fathers. Purposive sampling	Naturalistic inductive approach	Importance of scheduling family activities; adapting to the needs the child; family values and cultural norms.	18
Segal 1998	2 interviews with each family totalling 2-3 hours.	Family experiences; adaption of daily routines	Not stated	USA	Developed country. European. Single and dual parent families.	17 mothers and 3 fathers. Purposive sampling	Grounded theory	Morning routines and homework difficult times of the day. Parents develop strategies; impact on daily routines of whole family	22
Sikirica et al. 2015	Interviews (30-90 minutes)	Unmet needs of children and adolescents with ADHD and their caregivers	Telephone	France, Germany, Italy, Norway, Spain, Sweden and UK	Developed countries. Single and dual parent families. employed and	38 caregivers; 28 adolescents with ADHD. Purposive sampling.	Content and thematic analysis	Multiple unmet needs of caregivers impact on relationships; adolescents experience social impact. ADHD affected family relationships.	28
Wallace 2005	Interviews (60-90 minutes)	The experiences of mothers of boys with ADHD	Not stated	Australia	Developed country.	10 mothers. Convenience sampling.	Grounded theory	Mothers' responsibility for their child; increased tensions between siblings; difficult relationships with extended family	23
Wong and Goh 2014	Interviews (30-45 minutes)	The dynamics between parents and their children with ADHD	Participants' own home	Singapore	Developing country.	8 parents and 5 children. Purposive sampling.	Qualitative coding	Stressful moments re: child behaviour and homework. Bilateral process of parent-child interaction. Parent-child relationships generally considered good.	26

Thematic synthesis

Six analytical themes capturing how family relationships and family life are experienced for children with a diagnosis of ADHD and their family relatives were developed, derived from a range of descriptive themes (given in brackets): 1) Relationships: conflict and strain (parent-child relationships, sibling relationships, parental/partner relationships, extended family); 2) Relationships: strengths and supports (parent-child relationships, family closeness); 3) Family challenges (impact of ADHD on everyday family life, stigma of ADHD, familial ADHD, parental distress, negotiating sorrow and loss), 4) Family responses (routine and organisation, accommodating and prioritising ADHD, parental involvement and vigilance), 5) Family identity (different to other families, hard work and perseverance, experts) and 6) Family growth and coping (sharing responsibility, accepting child, opportunities for healing). Examples of supporting quotations can be found in Table 4.

Table 3: Distribution of themes across papers

Analytical and Descriptive Themes	Firmin and Phillips, 2009	Hallberg et al., 2008	Kendall, 1998	Kendall, 1999	Leitch et al., 2019	Lin, Huang and Hung, 2009	Moen et al, 2011	Paidipati et al. 2020	Ringer et al 2019	Segal and Frank 1998	Segal 1998	Sikirica et al 2015	Wallace 2005	Wong et al 2014
Relationships: conflict and strain														
Parent-child relationships	X	X	X		X	X	X			X	X	X	X	X
Sibling relationships			X	X	X	X	X					X	X	
Parental/partner relationships		X	X		X	X						X	X	
Extended family and friends			X	X	X	X	X					X	X	
Relationships: strengths and supports														
Parent-child relationships	X		X			X	X	X	X		X		X	X
Family closeness	X		X			X	X			X	X			
Family challenges														
Impact of ADHD on everyday family life	X		X	X	X	X	X			X	X	X		
Stigma of ADHD			X	X	X	X	X		X			X	X	
Familial ADHD	X		X				X					X		
Parental distress	X	X	X	X	X	X	X	X	X			X	X	X
Negotiating sorrow and loss			X	X	X				X				X	
Family responses														
Routine and organisation	X		X		X		X	X		X	X	X		
Accommodating and prioritising ADHD	X	X	X	X	X		X	X	X	X	X	X		
Parental involvement	X	X	X		X	X		X		X		X	X	
Family identity														
Different to other families	X	X	X	X						X	X			
Hard work and perseverance	X	X	X		X			X						
Experts	X		X			X	X		X					
Family growth and coping														
Sharing responsibility and load	X		X				X	X			X			X
Accepting child	X		X		X	X	X	X	X					X
Opportunities for healing			X		X	X	X	X		X	X			

Table 4: Quotations illustrating analytical and descriptive themes

Analytical and descriptive themes	***Participants' quotations* and/or authors' explanations**
Relationships: conflict and strain	
Parent-child relationships	It was common…that the teenage daughters had assaulted the parents, especially the mothers… *"We have to have a tutor just because I felt like I was a policeman. It wasn't any fun! It's like, your child; but this isn't a fun relationship, to be the policeman!"*
Sibling relationships	*"If I don't do what he wants right when he says it I know he will be awful to me all night. I dread coming home sometimes."* *"…my siblings like to tease me, say that I'm not worth as much as they are, get on my nerves and things like that. Then I have my outbursts and just scream."*
Parental/partner relationships	*"And there's a lot of single parent families too because the stress of having a child like that on your relationship is massive and unfortunately a lot of relationships don't survive it."* One couple discussed how the "nervous tension" in the house sometimes lead to a "spat" between them…
Extended family	*"My in-laws don't believe there is such a thing as ADHD. They think he's just a naughty boy. They certainly don't think he should be on medication. My sister and my mother have joined together on this and I don't see or hear from them anymore".*
Relationships: strengths and supports.	
Parent-child relationships	However, despite the moments of stress, parent–child relationships in these families are reported to be generally positive. Parents and children also share pleasant moments, such as playing games and sports together.
Family closeness	Some family members stated that they think they have closer bonds than other families have and give much support to each other.
Family challenges	
Impact of ADHD on everyday family life	Siblings described their family life as chaotic, conflictual, and exhausting. Caregivers avoided taking the child shopping, to social events, or public places where the child's behavior might cause disruptions.
Stigma of ADHD	Parents expressed that they felt "isolated" and "ostracized" because the public did not understand ADHD, its consequences, and the value of medication

Familial ADHD	*"If we go…to a restaurant, it almost always leads to arguments…Dad and both my little brothers are ADHD patients…they cannot cope with having to wait for anything so arguments are bound to happen."*
Parental distress	The mothers in the present study had largely developed stress related diseases themselves, including chronic pain and different physical and/or psychosomatic symptoms Additionally, parents reported that their stress negatively impacted all children in the family, including children with ADHD and siblings alike.
Negotiating sorrow and loss	*"It's like a death. Nothing is like I expected, nothing is ever the same."* Siblings shared their sorrow about what they could not have because of the ADHD; a normal family, normal childhood, quiet times, happy family outings, privacy, and an identity not associated with being the sibling of an ADHD child.
Family responses	
Routine and organisation	Other parents reported similar experiences, highlighting the demands placed on them to be organized and prepared, anticipating every aspect of the family's needs with an almost military precision.
Accommodating and prioritising ADHD	The result was that disruption became a way of life for families with ADHD children, and family life often was centered around the ADHD children. Caregivers also had to make other sacrifices, including giving up on personal pursuits, personal time, and/or time alone with their partner.
Parental involvement and vigilance	Information from the mothers during interviews reflects the unrelenting vigilance demanded of them. One parent described her parenting experience as "being constantly mentally engaged" in order to remain one step ahead of her child.
Family identity	
Different to other families	*"We don't fall into routines. whereas stuff like that in everybody else's household just happens because it's a habit! We don't have habits."*
Hard work and perseverance	"*I don't care what it takes. We're gonna learn this condition that he has, and I'm willing to give whatever I got to help him."*
Experts	Acquiring Knowledge and Becoming an Expert: Many parents described an ongoing process of actively searching for knowledge about the diagnosis.

Family growth	
Sharing responsibility and load	Parents…came to the conclusion that they could not help their children succeed if it did not come from within the children…they had to step back and let the children take responsibility for their actions… To reduce the frustration and chaos, it is important to share the responsibility with professionals.
Accepting child	Another mentioned a recent period of growth, where she had cultivated states of compassion and acceptance to deal with her child's difficult behaviours. *"But here I understand it's not his fault, if you can put it that way. It's not just that he's not concentrating; he just isn't able to take in more than one thing at a time."*
Opportunities for healing	Having a respite is seen as being absolutely essential for both siblings and parents to help maintain themselves as individuals, as well as having enough energy for family activities.

The key elements of each analytical and descriptive theme are summarised below.

Theme 1. Relationships: conflict and strain

Many participants described difficult family relationships between parents and children, siblings, parents/partners and with extended family members and friends. These relationships were characterised by persistent conflict and some such relationships had broken down.

Parent-child relationships

Many participants described difficult parent-child relationships. Both parents and children diagnosed with ADHD described verbal arguments with one another, which commonly occurred in the context of difficult times of the day (e.g. completing homework). Parents reported feelings of frustration towards their child when they had difficulty following their instructions or feeling as if they needed to walk on 'eggshells', which parents reported placed strain on their relationship. Other parents expressed that their constant need to be

authoritative and vigilant over their child to ensure their completion of tasks took the 'fun' out of the relationship. Less commonly, conflicts between parents and children (particularly mothers and teenage daughters) escalated physically with parents describing 'smacking' their child, or parental reports of their child assaulting them. Siblings described feeling overlooked by their parents, with parents expressing regret that their focus on their child often came at the expense of maintaining an attentive relationship with their other children.

Sibling relationships

Sibling relationships also experienced conflict and challenge. Children diagnosed with ADHD described their hurt at being teased over their difficulties or of being excluded from games by their siblings without a diagnosis of ADHD. Some siblings of children diagnosed with ADHD described feeling embarrassed by their sibling's behaviour and avoided bringing school friends home. Verbal and physical aggression between siblings was a common feature across participant experiences, with some describing being physically assaulted and being frightened of them. Other siblings responded to the aggression they received by retaliating physically.

Parental/partner relationships

Parents of children diagnosed with ADHD expressed difficulties in their relationship with one another, commonly reporting that their caring responsibilities towards their child resulted in little time to invest in their marital relationship or describing increased arguments with one another as result of the general stress in the household. It was not unusual in the studies for parental relationships to have broken down completely resulting in separation or divorce, with parents often disagreeing on how best to respond to their child's behaviour. Mothers commonly expressed feeling unsupported by their child's father or doubtful of his ability to parent their child effectively.

Extended family

Seven papers included data on relationships with extended family relations, most commonly grandparents of children with ADHD. Parents frequently described difficult relationships with their own parents and in-laws, which commonly featured arguments regarding their parenting choices or their decision to medicate their child for ADHD. Grandparents were also often reported as dismissive of ADHD as a diagnosis and labelled their grandchild as 'naughty'. In some cases such disagreements resulted in the nuclear family of a child diagnosed with ADHD being ostracised and excluded by the wider family.

Theme 2. Relationships: strengths and supports

This analytical theme reflects the positive aspects of family relationships and the quality time enjoyed by families. Despite the challenges experienced within family relationships, it was evident that family members cared for and supported one another.

Parent-child relationships

Despite at times feeling frustrated with their child, parents of children diagnosed with ADHD also described feelings of love and a sense of a strong bond with their child. Parents described feeling attuned to their child's distress, with one paper highlighting that mothers appeared to be particularly sensitive to their son's emotional wellbeing (Kendall 1998). Parents reported containing their child's emotions and supporting their child to regulate difficult feelings when they felt overwhelmed. Several parents described enjoying quality time with their child, for example playing games, which appeared to be the times parents felt their relationship with their child was at its most 'normal'. Children also described appreciating this time and felt that in some ways they were closer to their parents because of the increased amount of time they spent with them.

Family closeness

Several papers described how parents of children diagnosed with ADHD spent a great deal of time and energy organising family schedules in a way which prioritised quality time together as a family; for example eating dinner together at the table every day. Other participants expressed that the challenges they faced as a family brought them closer together and valued the support they provided one another. Parents expressed that when their relationship with their child improved and they felt more skilled in supporting their child, that this had a positive impact on family relationships more broadly.

Theme 3. Family challenges

This analytical theme reflects the range of family challenges experienced by children diagnosed with ADHD and their relatives.

Impact of ADHD on everyday family life

Participants described family life as chaotic, unpredictable and exhausting, with daily family activities regularly disrupted as a result of the difficulties experienced by the child diagnosed with ADHD. Such activities commonly included morning routines involving getting ready for school and after-school activities including homework completion, which were difficult for children with an ADHD diagnosis to attend to and regularly resulted in their frustration and distress being expressed behaviourally, which had a 'knock on' impact on siblings. Family routines were often significantly adapted around the child diagnosed with ADHD and some family activities (e.g. visits or meals out) were avoided altogether, possibly due to the difficulties they experienced.

Stigma of ADHD

Children with a diagnosis of ADHD, their parents and their siblings all reported experiences of stigma, suggesting that the stigma associated with the challenges of living

with a diagnosis of ADHD can be experienced at a family, as well as an individual level. Parents reported being criticised and perceived by others in society as 'bad parents' who are incapable of managing their child's behaviour. Likewise, some children who had received a formal diagnosis of ADHD were still nevertheless labelled as 'naughty' by their peers' parents and by extended family members. Across a variety of geographies, families of children diagnosed with ADHD felt that there was little understanding of the diagnosis amongst both the general public and within the educational profession, which led to anxiety about disclosing the diagnosis to others and how well this would be understood.

Familial ADHD

A number of studies featured participants living in a family where more than one member had received a diagnosis of ADHD, most commonly a parent or a sibling. Families with parents or siblings who had also received a diagnosis of ADHD described increased levels of stress, largely due to difficulties imposing the high levels of structure and organisation which were perceived to be particularly necessary for these families. However, some participants reported that having a parental diagnosis of ADHD could provide a unique understanding of their child's difficulties due to an ability to take their perspective, with sibling accounts also describing relational strengths such as the ability to provide mutual support in navigating some of the challenges they experienced.

Parental distress

A theme which featured across almost every paper were the significant levels of distress experienced by parents of children diagnosed with ADHD. Parents reported feelings of fatigue and exhaustion in relation to their care-giving responsibilities and experienced feelings of helplessness and guilt. Many parents reported receiving diagnoses of anxiety and depression or developing chronic illness perceived to be related to stress. Parents expressed that their levels of stress had a negative impact on all members of the family and increased

levels of family conflict. Sibling accounts described an avoidance of approaching their parents with their own needs for fear of further burdening them. Many participants reported that support for children with an ADHD diagnosis and their families was inadequate and further exacerbated levels of parental stress.

Negotiating sorrow and loss

Several parents of children with an ADHD diagnosis reported feelings of sorrow and loss, describing grief over the loss of a 'normal' child and 'normal' family life. This appeared to be triggered in response to their child's distress or when they felt unable to parent in alignment with their values, such as a belief they should be able to attend to all of their children equally and fairly. Parents described the need to find ways to navigate this grief both for their own wellbeing and that of their children. Sibling accounts also featured experiences of sorrow in relation to the loss of a 'normal' childhood, for example days out as a family.

Theme 4. Family responses

Families developed a range of strategies in response to some of the immediate challenges they experienced, in order to minimise the impact they had on everyday family life.

Routine and organisation

Parents of children with an ADHD diagnosis developed a range of strategies focussed on providing a consistent and structured routine for all members of the family. Parents utilised techniques such as preparing meals in advance and using visual planning aids (such as whiteboards or large calendars) in order to facilitate smoother transitions between home and school and to minimise the stress of difficult times of the day for the family. Parents reported that in doing so they were able to promote a degree of security and control for the

family. Mothers in particular appeared to largely take responsibility for this domestic planning and labour.

Accommodating and prioritising ADHD

Relatives living with children diagnosed with ADHD made a number of accommodations to their own routines, tasks and preferences in order to prioritise their child's needs and wellbeing. This ranged from everyday tasks such as parents and siblings delaying their own personal care needs to facilitate the child completing their morning routine, to more significant personal sacrifices made by parents in order to focus on supporting their child such as stepping away from leisure time, relationships and job opportunities. Siblings of children with an ADHD diagnosis described learning to interpret their brother or sister's needs and moods and modifying their interactions accordingly. Subsequently, families were able to some extent to reduce the conflict and stress they experienced. However, this was at times to the cost of their wellbeing and had the unintentional effect of family life revolving around the needs and difficulties of the child diagnosed with ADHD.

Parental involvement and vigilance

Parents described being unable to "switch off" within the family home due to the need to be constantly engaged with their child, either constantly monitoring and supervising their child in their daily activities or anticipating what they may need next. These parents expressed being in a state of near constant vigilance, fearing that their child may lose focus and abandon tasks or behave in a way that was dangerous to either themselves or their siblings. This response from parents was intended to both support their child and minimise the impact that the child's difficulties had on everyday family life, however this was often described by parents as stressful and exhausting.

Theme 5. Family identity

This analytical theme reflects the commonly reported ways in which families described themselves and expressed their identity as a family unit.

Different to other families

Families described themselves as qualitatively different to 'normal' families who did not have a child with a diagnosis of ADHD. Central to this 'otherness' was the need for highly structured family routines and organisation to combat the 'chaos'. This was framed in stark contrast to 'laid back' families who could enjoy the freedoms of spontaneity without stressful consequences. However this lack of flexibility was not necessarily perceived as a negative feature of family life. For one family, the highly structured nature of their family routine was seen as an expression of love, with routine providing a sense of safety and predictability (Kendall, 1998). However, siblings expressed sadness about their family's differences to others, in the context of being unable to do 'normal' things as a family .

Hard work and perseverance

Parents of children with an ADHD diagnosis described the importance of working hard towards their goal of learning more about ADHD, supporting their child with their difficulties and having a harmonious family life. Parents spoke of their determination to persevere with a range of different parenting strategies in order to achieve this. Perhaps in acknowledgement of the high levels of stress they experienced in their care-giving role and the need for continuous changes to parenting strategy, parents defined their identities as those of 'hard workers' who were willing to give their all and persevere in the face of considerable difficulty.

Experts

Families of children with an ADHD diagnosis acquired an expert level of knowledge of ADHD, both from their lived experiences and from other sources of knowledge which

included researching, reading, attending courses and talking to other families. Parents of children with an ADHD diagnosis moved from a position of being a lay person to one who holds special knowledge and skills about ADHD, whilst at the same time acknowledging this as an ongoing process and desiring further information. In identifying as experts, parents were able to communicate their understanding to other people in order to facilitate better interactions with their children.

Theme 6. Family growth

The final analytical theme refers to the ways in which families experienced positive growth through the challenges they had experienced and developed in ways which allowed them to thrive as a family rather than simply survive.

Sharing responsibility and load

One way in which families appeared better able to cope in the longer term with some of the challenges they experienced was to share the responsibility and workload of caring with others. This included active engagement with healthcare professionals and close liaison with educational professionals. Parents discussed the relief they felt in being able to share the caring responsibility with professionals. Furthermore, parents moved towards a position of encouraging their children to take more responsibility for themselves, for example by 'stepping back' from being so actively involved in their child's homework completion. In doing so, parents not only reduced some of their fatigue as carers but also gave their children the opportunity to experience more independence.

Accepting child

Many parents of children with ADHD reported that as time progressed they moved towards a position of accepting their child, which was seen as important both for the parent-child relationship and for family harmony more broadly. For several parents, accepting and

understanding their child's difficulties removed feelings of blame and invited feelings of empathy towards their child, as well as an appreciation of their individuality. Other parents spoke of the relief that came from letting go of preconceived societal standards of how their child and family life 'should' be and focussing instead on the positive things their child brought to the family and the bright futures they imagined for their child.

Opportunities for healing

Families of children diagnosed with ADHD discussed the importance of family members engaging in opportunities for self-care and respite. Parents in particular reported that making time for themselves to re-engage with previously enjoyed activities and hobbies was an important stress management technique. Parents also engaged in their own personal therapy, found solace from peer support groups, or friendships that might otherwise have been neglected. Siblings of children diagnosed with ADHD also appreciated 'time out' to focus on their own interests and activities.

Discussion

This review presents the experiences of family life and family relationships for children and young people with a diagnosis of ADHD and their relatives. Data from a total of fourteen studies with participants from a range of geographies was synthesised. Narratives from participants included those from children with an ADHD diagnosis, their parents and their siblings. A total of six analytical themes were developed: 1) Relationships: conflict and strain; 2) Relationships: strengths and supports; 3) Family challenges; 4) Family responses; 5) Family identity and 6) Family growth and coping. The review synthesises findings on both the challenges and strengths of relationships in families of children with an ADHD diagnosis, providing new insights into how family relationships function across several different family sub-systems. Additional themes include the everyday challenges that families of children with ADHD experience and the ways in which families have responded to these difficulties,

suggesting that families develop strategies which over time become an important part of family life. Families expressed strong identities which although marked them as "different" were largely positive in nature. There was a sense that despite facing challenges, families experienced opportunities for positive growth.

Participants described conflictual relationships across the family system. Parents described several challenges within the parent-child relationship, as is already well documented in the literature (Johnston and Mash 2001). This included the need to adopt a vigilant and somewhat authoritative position in order to manage their child's behaviour, whilst conversely feeling tentative and 'on eggshells'. Parents of adolescent girls in particular reported fearing for their child's safety as they engaged in risky behaviours and several described being assaulted by their teenage daughters (Hallberg et al., 2008). With parent-adolescent conflict a risk factor for experiences of psychological distress in young people (Hollenstein and Lougheed 2013) and parent-adolescent conflict more likely to occur in dyads where the young person has a diagnosis of ADHD (Hulsbosch, Boyer and Van der Oord 2020), it is important to understand the functioning of these relationships and the impact they have on the rest of the family, such as siblings who may feel overlooked (Kendall 1999).

All seven of the papers which included data on sibling relationships reported conflict between children diagnosed with ADHD and their siblings. Congruent with these findings is evidence that suggests that children with an ADHD diagnosis and their siblings report similar levels of dissatisfaction with family life and that inter-sibling bullying is a key factor, with siblings and children diagnosed with ADHD both identifying as perpetrators and victims of bullying (Peasgood et al. 2016). This is important to note as sibling conflict can negatively impact the wellbeing of both individuals (Bowes et al. 2014) and the family system as a whole (Feinberg, Solmeyer and McHale 2012). Furthermore, positive sibling relationships

can support children to cope with some of the difficulties commonly experienced in families of children with an ADHD diagnosis, such as increased parental psychological distress and inter-parental conflict (Davies et al. 2019; Keeton et al. 2015).

Many participants also reported strained relationships with their extended family network, resulting in experiences of isolation for many parents and reduced access to informal support. This is concerning as parents of children with an ADHD diagnosis are more likely to experience significant levels of stress and challenges in their parenting role (Corcoran et al. 2017) yet receiving social support from family members has been evidenced in decreasing the distress of caregivers and positively impacting on parenting behaviours (McConnell, Breitkreuz and Savage 2011).

Despite the difficulties experienced by families, many participants also described supportive family relationships and moments of closeness within the parent-child relationship, with both parents and children valuing quality time together engaging in 'normal' activities such as play. The importance of play for parent-child relationships has been well documented in the literature on child development, providing opportunities for children to express themselves and feel that their parents are paying attention to them (Glascott Burriss and Tsao 2002). Opportunities for play in families of children with an ADHD diagnosis may therefore be of particular importance given the increased risk of parent-child conflict in this population (Johnston and Mash 2001). Participants also expressed that improvements in the parent-child relationship had a positive impact on family relationships more broadly across the system, as suggested by family systems theory which describes the impact that the quality of the relationship in one family sub-system can have on the other sub-systems within the family whole (Carr 2016).

The particular challenges experienced by families of children with an ADHD diagnosis included the impact that ADHD had on everyday family life, with participants

describing disruption to their daily schedules and 'chaos' within the family home. Home chaos has been defined as significant levels of noise, unpredictability and distraction in the home context (Matheny et al. 1995) and is associated with a range of negative outcomes for children's development (Dush, Schmeer and Taylor 2013). It is also associated with increased parenting stress (Valiente, Lemery-Chalfant and Reiser 2007), experiences of which featured consistently in participant narratives. High levels of parenting stress in families of children with an ADHD diagnosis has been widely reported in the qualitative literature (see review by Corcoran et al. 2017), with participants within this review stating that their distress was exacerbated by a lack of family support from clinical and educational services. As significant and chronic parental distress may predispose children to psychological difficulty later in their life (Carr 2016), the importance of providing accessible support for parents of children diagnosed with ADHD is paramount.

Several participants in this review also described a sense of increased stress within families where more than one family member had received a diagnosis of ADHD. Kessler et al. (2006) found that diagnoses of ADHD in both children and parents is not uncommon and that over half of adults diagnosed with ADHD have children who also receive the diagnosis. Although this has been associated with increased parenting difficulties (Johnston et al. 2012), some parents in this review reported that their personal experiences of the difficulties associated with ADHD helped them to better understand their child. This is congruent with findings from Psychogiou et al. (2007) that reported increased parental empathy for children diagnosed with ADHD and more positive parenting practices in those parents who had received a diagnosis of ADHD themselves.

Families responded to challenges they experienced in a range of ways, including family members accommodating the needs of the child with ADHD as a priority (often sacrificing their own daily self-care needs) and increased levels of vigilance from parents

(which although maintained a sense of "control" appeared to contribute to their feelings of fatigue and burn-out). Both strategies may be contextualised by systemic family theories and potentially serve as examples of problem-maintaining factors; understandable ways of responding to challenges in the family system that unintentionally contribute to problematic patterns of functioning (Dallos and Draper 2015).

One of the most universally reported family responses appeared to be high levels of organisation, structure and routine within the family home. This may be an especially effective coping strategy for families of children diagnosed with ADHD in the face of increased levels of home chaos (Wirth et al. 2019). Whilst many family routines had largely pragmatic purposes (for example organising children in the morning or at bedtime), such routines can also be conceptualised as symbolic rituals which unite families in a shared set of values and facilitate closeness (Fiese et al. 2002; Prime, Wade and Browne 2020). Research also suggests that strong family rituals can predict secure family attachments and cohesion (Spagnola and Fiese 2007). This fits with participant reports that family routines were not only practical but also facilitated a sense of security and safety for family members, becoming an important part of family identity that made them positively 'different' from 'normal' families.

Other aspects of family identity expressed by participants were that of being 'hard workers' and becoming 'experts', which appeared to be important ways that families made sense of and resolved the challenges they faced. Developing a shared belief system as a family (such as strong identity about 'who we are'), is one way in which families' develop resilience in the face of challenge and enhance a sense of family cohesion (Walsh 2015). Becoming experts involved parents gaining in-depth knowledge about ADHD via their own research, attending courses and learning from peers. Recognising parental expertise and the

valuable insights parents can provide is important (NICE 2018), whilst balancing this with not over-burdening parents in the management of their child's care (Vanderlee et al. 2020).

Finally, families of children with an ADHD diagnosis appeared to move to a position of positive growth whereby parents developed greater acceptance of their child. This appeared to enable parents to reframe their child's difficulties by focusing on their positive contributions to family life and contextualising them as individuals in their own right. Although there is no current evidence on the importance of psychological acceptance for parents of children with an ADHD diagnosis, emerging evidence with parents of children with an autism spectrum condition (ASC) diagnosis suggest that psychological acceptance significantly reduces parental psychological distress when experiencing child behaviours which challenge them (Jones et al. 2014; Weiss et al. 2012). Further evidence also suggests that parents of children with an intellectual disability benefit from acceptance and commitment therapy (ACT) based approaches (Reid et al. 2016). Such findings suggest that developing acceptance may be of similar benefit to parents of children with other neurodevelopmental diagnoses such as ADHD.

Other ways in which families appeared to experience positive growth were by reinvestment in their own self-care activities and sharing the caring load with others. Participants' accounts of sharing the responsibility of care with professionals and re-engaging with their other important social relationships may be seen as examples of accessing social resources, collaborative problem-solving and emotional sharing which are outlined in Walsh's family resilience framework (2015) as important processes through which families move to a position of resilience after a period of challenge.

Clinical implications

Relationships in families of children diagnosed with ADHD are particularly vulnerable to strain and conflict. Practitioners working with these families should consider family relationships in their assessments and if appropriate consider family level interventions aimed at increasing support and building relationships. Particular support may be required for adolescents and their parents given the increased risk of parent-child conflict in this population. Practitioners should also be aware of the strengths in relationships that exist in parent-child dyads and across the broader family system, giving voice to these experiences in what can often become a problem-saturated narrative which overlooks the strengths and resources of family systems.

Professionals working with families of children with an ADHD diagnosis should be mindful of the challenges they experience. These include experiences of stigma with children with an ADHD diagnosis being labelled as 'naughty' and parents feeling they are perceived as 'bad parents'. Therefore, professionals should be mindful of adopting a curious and non-blaming approach when working with families. Given the importance cited by families in having structure, organisation and routine and the evidence base which highlights its importance in mitigating the impact of home chaos and improving family cohesion (Wirth et al. 2019) practitioners should ask families about their family organisation and offer support in creating routines and structure if this is required. Congruent with current national guidance (NICE 2018), families with a parent and/or siblings who also have an ADHD diagnosis may benefit in particular from such support due the likelihood of increased difficulties implementing routines (Johnston and Chronis-Tuscano 2015).

Significant levels of psychological distress is well documented in parents of children with an ADHD diagnosis and unsurprisingly emerged as finding in this review. Due to the impact that long-term parental distress can have on child development (Carr 2016) clinicians

working with children with an ADHD diagnosis should include parental wellbeing in their assessment and explore with parents whether they would benefit from any individual support, facilitating timely referrals where clinically indicated. Clinical approaches that draw on ACT when working therapeutically with parents of children with an ADHD diagnosis may be of particular benefit given the importance that participants placed on moving to a position of acceptance. Practitioners could also support conversations with parents and adolescents about their longer term coping strategies which may include prioritising self-care and re-engaging with previously enjoyed activities that have been neglected.

Strengths and limitations

Despite the importance of understanding family experiences when working with children and young people (Carr 2016) and well-established systemic theories highlighting the complex and reciprocal relationship between the individual and their family system (Bowen 1978; Dallos and Draper 2015), to the authors' knowledge this is the first systematic review that has attempted to synthesise the qualitative literature base concerning the experiences of family relationships and family life for children and young people with an ADHD diagnosis and their relatives. The review utilised an appropriate quality assessment tool and followed a rigorous protocol for search strategy and study inclusion, in line with PRISMA guidelines for the reporting of systematic reviews (Moher et al. 2009). The studies included in this review were largely of a high methodological quality, with the use of the CASP highlighting which studies were less rigorous and therefore interpreted more tentatively during the data synthesis. The decision not to apply date parameters within the search strategy ensured that the full range of eligible studies were included in the review, maximising the number of participants contributing to the review's data set. However, family formations, family routines (including the division of household labour and the working

patterns of parents) and family life more broadly has changed over the past two decades reflecting wider cultural, political and socio-economic developments (Hantrais, Brannen and Bennett 2020). Therefore, data from older studies within this review may reflect some experiences that are not representative of current family life for all families of children with an ADHD diagnosis. Furthermore, although the decision to exclude papers which focussed solely on the aetiology and diagnosis of ADHD ensured that the aims of the review were adhered to, this also resulted in the exclusion of participant narratives which focussed on the cultural and social contexts in which parents' make sense of ADHD as a diagnostic concept.

The review would have been strengthened by a greater inclusion of children and young people's voices, with parent participants currently providing the dominant narrative. This directly reflects the limited amount of empirical research with children and young people which explores their experiences of family life and family relationships. The paucity of qualitative research as opposed to quantitative research inevitably limited the number of studies for inclusion in the review and focusing on qualitative literature by nature reduced the number of participants contributing to the review's data set. Whilst a relaxation of the inclusion criteria to include grey literature may have resulted in a greater range of eligible studies, these would not have been subject to peer-review and therefore may have undermined the quality of the review's findings. Furthermore, the rich detail of participant experiences inherent in qualitative approaches provides a level of depth and insight into family experiences not possible in quantitative meta-analyses with broader participant samples.

Future research

As noted above, a fruitful area for future research is to expand the limited research base exploring family relationships and family life with children and young people who have

ADHD as its primary participants. Further research should also focus on how families of children with an ADHD diagnosis develop resilience and coping strategies, in line with a move towards producing more evidence on positive coping rather than problem focussed coping (Weiss et al. 2012). Research that can further inform the evidence base for family interventions would also be of great value, for example exploring the efficacy and acceptability of ACT informed interventions for parents of children with an ADHD diagnosis given that its utility in supporting parents of children with other neurodevelopmental diagnoses has started to emerge (Reid et al. 2016). The findings highlight that although many parent-child relationships experience conflict, there are others that enjoy strengths and are a valuable resource within the system, although little is known about why these differences may develop. Further qualitative research which can provide insight into the developmental trajectory of these parent-child relationships, in order to better understand the factors which facilitate closeness or present challenges within the parent-child relationship, would be of value.

Conclusion

ADHD is an increasingly common neurodevelopmental diagnosis in children and young people, which has a range of implications for how children and their relatives experience the family system. This review synthesised the qualitative literature base exploring family relationships and family life for children and young people with a diagnosis of ADHD and their relatives. Six analytical themes were generated which capture the functioning of family relationships across the system, the challenges families experience and the ways in which families respond, develop identities and experience growth. Practitioners working with children diagnosed with ADHD have an important role to play in considering the needs of the whole family system. Supporting families to build on the strengths in their

relationships and to develop long-term coping strategies which focus on structure, self-care and acceptance can help families to cope with the challenges to daily life that they experience.

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Chapter Two

Understanding parents' perspectives of the impact of their child's ADHD diagnosis on the parent child relationship: A grounded theory approach

Lauren Atherton

Correspondence to be addressed to:

Lauren Atherton

Department of Clinical Psychology

Whelan Building

Quadrangle

Brown Hill

Liverpool

L69 3GB

Telephone: 0151 794 5534

Email: lauren.atherton@liverpool.ac.uk

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Understanding parents' perspectives of the impact of their child's ADHD diagnosis on the parent child relationship: A grounded theory approach

Abstract

Parental experiences of raising a child with an ADHD diagnosis have been characterised in the qualitative literature by high levels of parental stress and challenging parent-child relationships. However, little is known about the development of the parent-child relationship in the context of this diagnosis or how a diagnosis of ADHD may impact this, which this grounded theory study explores. Semi-structured interviews regarding parents' experiences of the parent-child relationship were conducted with 10 parents of children with an ADHD diagnosis. Participants universally identified that their child's diagnosis had a positive impact on the parent-child relationship, leading to increased understanding of and empathy for their child. However, the degree of impact that this had varied amongst participants and was mediated by a range of factors. A range of clinical implications are discussed which highlight the importance of supporting parents throughout the assessment journey.

Keywords: ADHD, parental experiences, parent-child relationship, qualitative

Introduction

Background

Attention deficit hyperactivity disorder (ADHD) is a neurodevelopmental condition frequently diagnosed in children and young people, approximated at between 5.9% and 7.1% for diagnoses of ADHD made using the Diagnostic and Statistical Manual of Mental Disorders (DSM) (Willcutt 2012). Common difficulties required for a diagnosis of ADHD include inattention, hyperactivity and impulsivity (DSM-5, American Psychiatric Association [APA] 2013). These difficulties can present a range of challenging experiences for children and young people including problematic family and peer relationships, elevated risk-taking behaviours, difficulties with school attainment and low self-esteem (Carr 2016).

Whilst the aetiology of ADHD remains unclear and is likely to be multi-factorial in nature (Johnston and Mash 2001; Thapar and Cooper 2016), research has largely focussed on establishing strong support for biological and neuropsychological hypotheses (Barkley 2015; Faraone et al. 2005; Thapar et al. 2013). Other findings indicate that difficulties in family functioning and family relationships are associated to varying degrees with the developmental trajectory of ADHD and its treatment outcomes (Johnston and Mash 2001).

However, controversy surrounding the diagnosis has been fuelled by concerns regarding the increasing rate of diagnosis in children and young people (Kazda et al. 2021; Timimi and Radcliffe 2005), high rates of pharmacological intervention (Miller and Leger 2003) and schools of thought which have questioned the scientific validity of ADHD, arguing that it is a largely social construct (Timini and Taylor 2004). This paper acknowledges these arguments and the problems inherent within biomedical models of ADHD, with no biological markers having yet been identified for ADHD, despite extensive research (Timimi 2005). However, comprehensive systematic reviews of the evidence base suggests that whilst ADHD remains a complex and poorly understood clinical area, data consistently supports the

conceptualisation of ADHD as a valid diagnostic category which is discrete from other diagnoses (National Collaborating Centre for Mental Health 2009; NICE 2018). The current paper adopts a position congruent with this perspective.

Parental experiences of raising a child with ADHD

It is important to acknowledge these competing discourses, in part because of the specific challenges they can present for parents of children with an ADHD diagnosis. Conceptualisations of ADHD as a solely social construct may unintentionally locate blame within the child's immediate social system (Goodwillie 2014), with parents frequently reporting experiences of being assigned blame for their child's difficulties (DosReis et al. 2010; McIntyre and Hennessey 2012; Singh 2004). Parents describe significant levels of stress as a result of negative interactions with professionals who they believe do not recognise the legitimacy of ADHD as a diagnosis (Cronin 2004; Klasen and Goodman 2000; Wallace 2005; Wilder, Koro-Ljungberg and Bussing 2009), particularly when they perceive that professionals believe their child's ADHD symptoms to be largely the result of social and parenting factors (Harbone, Wolpert and Clare 2004).

Understandably, parents of children with an ADHD diagnosis also appear to have great difficulty making sense of the competing explanations that surround ADHD (Brunton et al. 2014) and do not feel they are provided with adequate definitive information regarding their child's diagnosis (Ahmed, McCaffery and Aslani, 2013). Decision making processes regarding the use of pharmacological intervention for the management of their child's ADHD is a further challenge for parents. A meta synthesis of the many qualitive research studies which explore parental perspectives of medicating their child for ADHD found that parents had difficulty coming to terms with the diagnosis, difficulty making sense of the competing

arguments regarding the validity of ADHD and experienced concerns about the side effects and long-term consequences of medication use (Ahmed, McCaffery and Aslani 2013).

A recent systematic review of the plethora of qualitative research exploring parental experiences of raising a child with ADHD also identified high levels of parenting stress as a theme across participants' narratives, with parents reporting daily stress and exhaustion related to managing their child's difficulties and behaviours (for example running off, impulsive risk taking behaviours and difficulties listening) (Corcoran et al. 2017). Managing family routines such as the school run and homework completion are also identified as significant sources of stress for parents of children diagnosed with ADHD (Firmin and Phillips 2009; Segal 1998; Segal and Frank 1998), compounded by parents' experiences that typical parenting strategies such as rewarding or punishing behaviours are not particularly effective for their child (Bussing et al. 2006; Kendall 1998). Furthermore, parents describe experiencing acute levels of personal distress which impact on both their psychological and physical wellbeing (Hallberg et al. 2008; Peters and Jackson 2009), also reporting that the stress of managing their child's difficulties has negative impacts on other aspects of their social world including their jobs, friendships and marital relationships (Lin, Huang and Hung 2009; McIntyre and Hennessy 2012; Moen, Hall Lord and Hedelin 2011).

The importance of parent-child relationships

An established literature base has developed which identifies the parent-child relationship as a highly significant factor in children's emotional, psychological and social development (Cassidy and Shaver 2008). Much of the research has examined the quality of the parent-child attachment relationship; the ways in which children's primary caregivers are attuned to and consistently meet their child's needs for care and safety, forming an important template for children's relationships to both their self and others throughout their life

(Bowlby, 1988). The extent to which children develop a secure attachment relationship with their caregivers has been identified as an important factor in children's psychological development, with insecure attachments identified as a predisposing factor for later psychological difficulties (Bradley, Caldwell and Corwyn 2003; Carr 2016; Cassidy and Shaver 2008; Waters and Cummings 2000;).

The way in which different parenting styles impact the quality of the parent-child relationship and produce different developmental outcomes for children has also historically received great attention (Baumrind 1966), with research identifying that an authoritative parenting style which combines both warmth and controlled boundaries is most conducive to children developing into confident adults (Larzelere, Morris and Harrist 2013). Conversely, authoritarian parenting styles (characterised by more controlled and rigid parenting) can be problematic for child development (Carr 2016) and are positively correlated with high levels of parental stress over time (Deater-Deckard and Scarr 1996; Crnic and Low 2002).

Parent-child relationships in families of children with an ADHD diagnosis

Given the significance of the parent-child relationship and the detrimental impact of long-term parental stress, it is unsurprising that the parent-child relationship in families of children with an ADHD diagnosis has received great attention. Reviews of the literature consistently describe conflictual parent-child interactions and more authoritarian parenting styles (Deault 2010; Johnston and Mash 2001), with difficulties in the parent-child relationship identified across a broad range of childhood developmental stages (Johnston and Lee-Flynn 2011).

Although there have been few attempts to develop a theoretical model of the parent-child relationship in relation to this population, Johnston and Chronis-Tuscano (2015) posit a transactional developmental model which outlines a bi-directional pattern of influence

between parents and children. Longitudinal studies examining the nature of this bidirectional influence suggest that child difficulties associated with ADHD are a key driver for a range of parenting difficulties (Burke, Pardinin and Loeber 2008) and that difficulties in parent-child relationships are predictive of increases of disruptive behaviour over time in children with this diagnosis (Lifford, Harold and Thapar 2008). Research broadly agrees that whilst family environments do not appear critical to the origin of ADHD, they are a predictive factor in its trajectory and various outcomes, with the need for a better understanding of family contexts and parent-child relationships (Johnston and Chronis-Tuscano 2015).

There has been a surprising paucity of qualitative research exploring the development of the parent-child relationship in families of children with a diagnosis of ADHD, despite a considerable amount of quantitative research highlighting its importance. However, a select number of studies which explore parental experiences more broadly have examined the parent-child relationship in the sub-themes of their findings. Ringer et al. (2020) found that receiving an ADHD diagnosis for their child was key to Norwegian parents' developing a better understanding of their child's difficulties, after which they both pro-actively and reactively modified their parenting behaviours in order to better support their child. Consequently, parents described being better able to regulate their negative emotions towards their child (e.g. using the diagnosis to reduce feelings of frustration towards their child and increase empathy) and feeling less shamed and criticised by others (using the diagnosis to explain their child's behaviours and validate their difficult experiences as parents). Therefore, the ADHD diagnosis appeared to serve several important functions for parents in reducing both their experiences of shame and promoting positive parent-child interactions.

Examining the relational dynamics between parents and children diagnosed with ADHD in Singapore, Wong and Goh (2014) found that parents were more likely to 'back away' from disagreements following their child's ADHD diagnosis which promoted recovery

from more negative parent-child interactions. Furthermore, examination of the grey literature highlights that parents experience an increased understanding of their child following an ADHD diagnosis, facilitating more positive parent-child interactions and better management of their child's behaviours which challenge (DuCharme 1996; Egbert 1996; Kilcarr 1996; Seawell 2010).

Whilst receiving a diagnosis of ADHD for their child appears to have an important impact for parents and their experience of the parent-child relationship, to the best of the authors' knowledge no qualitative study to date has examined the impact of an ADHD diagnosis on the parent-child relationship as its primary focus. The current study therefore addresses a significant gap in the current research landscape, which seems particularly important to better understand in the context of our existing knowledge regarding parent-child relationships and increased parental stress within this population. The use of grounded theory (GT) methodology to produce a theoretical model of relationship change over time is particularly useful in indicating the various mechanisms that may be important in the development of the parent-child relationship. In particular, it is important to ascertain the role that parental experiences of support may play in these processes, given the key position that clinical and educational professionals have in supporting parents of children with an ADHD diagnosis (Corcoran et al. 2017; NICE 2018) yet the varying levels of support historically available to parents within the United Kingdom (Dennis et al. 2008).

Aims and Research Questions

The study aimed to explore parents' retrospective experiences of the parent-child relationship prior to and following their child's ADHD diagnosis, in order to produce a theoretical model of any developments and changes in the parent-child relationship over this time. The primary research question asked;

- What are parents' experiences of the impact of their child's ADHD diagnosis on the parent-child relationship?

The secondary aims of the research included:

- To identify factors which facilitate closeness in the parent-child relationship and those which present challenges
- To explore how an ADHD diagnosis impacts parental understanding of their child's behaviour
- To identify how parental experiences of support and services have promoted or impeded these processes

Methods

Design

Grounded theory methodology was used to develop a theoretical model of the parent-child relationship, identifying factors which had inhibited or facilitated relationship development following the child's ADHD diagnosis. Strauss and Corbin's (2015) structured analytical GT framework was utilised, however during data collection and analysis the researcher also acknowledged the role of researcher subjectivity in co-constructing the data (Charmaz, 2000).

Input from experts by experience

Members of the Liverpool Expert by Experience (LExE) group and a parent expert by experience were consulted during the initial stages of the research design, which informed the development of the recruitment strategy and interview materials. Informal feedback was sought from participants at the end of every interview and helped to shape the procedure for subsequent interviews, in particular considering participants' preferences for adaptations made to conduct the later interviews remotely due to the COVID-19 pandemic.

Participants and sampling

In accordance with the study's inclusion criteria, all participants had children aged between 8-16 years who had received their diagnosis within eighteen months to five years prior to the interview. This time period was chosen to allow sufficient time for any changes in the parent-child relationship to have developed following their child's ADHD diagnosis whilst still enabling participants to be able to effectively recall their retrospective experiences. Participants were excluded if their child had an additional diagnosis of autism spectrum condition or learning disability, or if they identified as step or adoptive parents, as the unique parenting experiences of this population of participants may have confounded the data gathered. The final sample consisted of ten White British mothers of children who had been formally diagnosed with ADHD. Six of the participants had sons and four had daughters.

Sampling strategy

Participant demographics were gathered prior to interviews (Table 1) and were used to inform the sampling strategy. The first four participants were a convenience sample which aimed for a wide range of participant demographics, in order to maximise the variation in participants' experiences as much as possible. The next four participants represented a theoretical sample, further exploring emerging hypotheses in the context of the gender of the child, the age the child received their diagnosis, the role of siblings and the use of medication. The final two participant samples informed the selective coding of the data and facilitated the refinement of the theoretical model.

Table 1: Participant demographics

Pseudonym	Age (Years)	Relationship status	Employment status	Age of child (Years)	Gender of child	Age diagnosed (Years)	Current use of medication (Yes/No)	Siblings (Yes/No)
Michelle	40-45	Co-habiting	Employed part time	12	Female	10	Yes	Yes
Louise	30-35	Single	Carer	9	Male	7	Yes	Yes
Helen	40-45	Single	Employed full time	8	Male	6	Yes	Yes
Rachel	40-45	Married	Employed full time	14	Male	12	Yes	Yes
Fiona	30-35	Single	Unemployed	13	Female	8	Yes	Yes
Trish	50-55	Married	Employed full time	16	Female	14	No	No
Becky	35-40	Married	Employed full time	9	Male	7	Yes	Yes
Naomi	40-45	Co-habiting	Home-maker	9	Female	7	No	Yes
Robyn	30-35	Married	Employed full time	9	Male	6	Yes	Yes
Harriet	45-50	Single	Employed full time	15	Male	14	Yes	No

Procedure

Ethics

Ethical approval was granted by the relevant NHS Research Ethics Committee (Appendix 3). All participants provided informed written consent prior to participation and were made aware of their right to withdraw from the study. Any personally identifiable data was removed from data at the point of transcription in order to preserve participant anonymity. All names are pseudonyms.

Recruitment

Participants were recruited from both NHS and non-NHS sites across the north west of England. Within NHS sites, clinicians provided participants with a study information sheet

(Appendix 4), with those who were interested in finding out more giving consent for the researcher to make contact with them. Across non-NHS sites (parent support groups and third sector organisations) parents were given an information sheet by group leaders or viewed the study advert via the organisation's social media page and contacted the researcher directly. All participants provided informed written consent prior to participation (Appendix 5) and were thanked for their time with a £10 high street voucher. As a result of the COVID-19 pandemic recruitment was temporarily suspended in March 2020, recommencing in August 2020 with the relevant measures in place.

Research interviews

The first three interviews took place face to face at a location of the participants' choosing, largely children's centres. Due to the COVID-19 pandemic, the subsequent seven interviews took place remotely and changes to the study protocol were approved by the relevant bodies (Appendix 6). Participants were given the choice of doing the interview either via video call or telephone call, with the majority opting for video call. Interviews were approximately an hour long and were semi-structured, guided by an initial interview schedule (Appendix 7). Reflective memos were written immediately following each interview capturing a summary of the interview, emerging hypotheses and reflections from the researcher (Appendix 8). This supported the development of a subsequent interview schedule (Appendix 9) and the emerging theoretical model.

Analysis

Data analysis followed Strauss and Corbin's GT methodology (2015) with three distinct phases guiding the analysis; open coding, axial coding and selective coding. Interviews one to four were subject to open coding, during which a line-by-line micro-analysis of the data was

conducted and a number of initial codes were generated (Appendix 10). Supervision, reflection on interview memos and the development of a narrative storyline facilitated the clustering of these initial codes into larger categories and sub-categories. Axial coding during interviews four to eight explored the emerging relationships that existed between categories and identified hypotheses, leading to the development of a comprehensive theoretical model. Coding categories were well defined by interview eight, with no new data emerging and theoretical saturation approaching. The final two interviews were therefore subject to selective coding, which further refined the model and considered its ability to successfully predict key mediating factors and outcomes within participant narratives. The final coding structure against which all interviews were coded and re-coded can be found in Appendix 11.

Each interview was coded prior to the subsequent interview taking place, with data collection and analysis undertaken simultaneously (Glaser, 1992; Strauss & Corbin 2015). As is key to GT methodology, data analysis was iterative with new data constantly compared to existing data in order to identify emerging hypotheses and conceptual categories (Glaser, 1992). The use of qualitative data software was used to support analysis and store codes (NVivo 12, QSR International 2020).

Reflexivity

Prior to undertaking the first interview, the researcher wrote a reflexive statement presenting her reflections on her motivations and expectations for the research study (Appendix 12). This was subsequently reflected on during supervision and data analysis to ensure these did not impact on data collection or analysis.

Results

Narrative Summary of the Model

The diagrammatic model (Figure 1) presents the developmental journey of the parent-child relationship over time as perceived by participants, with earlier experiences at the top of the model and most recent experiences at the bottom. Narratives often featured reflections by participants on their early relationship with their child, which was largely described as positive and a time of great closeness.

As participants' children grew older and their difficulties became more noticeable, parents began a process of noticing differences in their child, which appeared to be increased for those with older children with whom to compare. This often marked the beginning of a period of uncertainty for participants, which increased as their child entered the school system. Two clear 'trigger points' were identified from data analysis as periods of time which participants described as particularly difficult for their child, due to increased demands placed on them within the school environment and a decreased ability to 'mask' their difficulties. These were the transition from infant to junior school at the age of 7-8 and the transition from primary to secondary school at the age of 11-12, with girls appearing to find the latter more challenging and boys the former.

Participants described an escalation in their child's difficulties and distress at these times, often precipitating a referral to the ADHD assessment pathway and increased efforts by parents to seek answers and support for their child. Participants described this period as a time when their own personal stress levels increased and the parent-child relationship was experienced as particularly vulnerable, with those parents reporting a higher degree of stress also reporting the most difficulties in their relationships. Similarly, participants who reported less parental stress during this time also reported less challenge in the parent-child relationship. A range of factors which appeared to be a risk to parental wellbeing and the parent-child

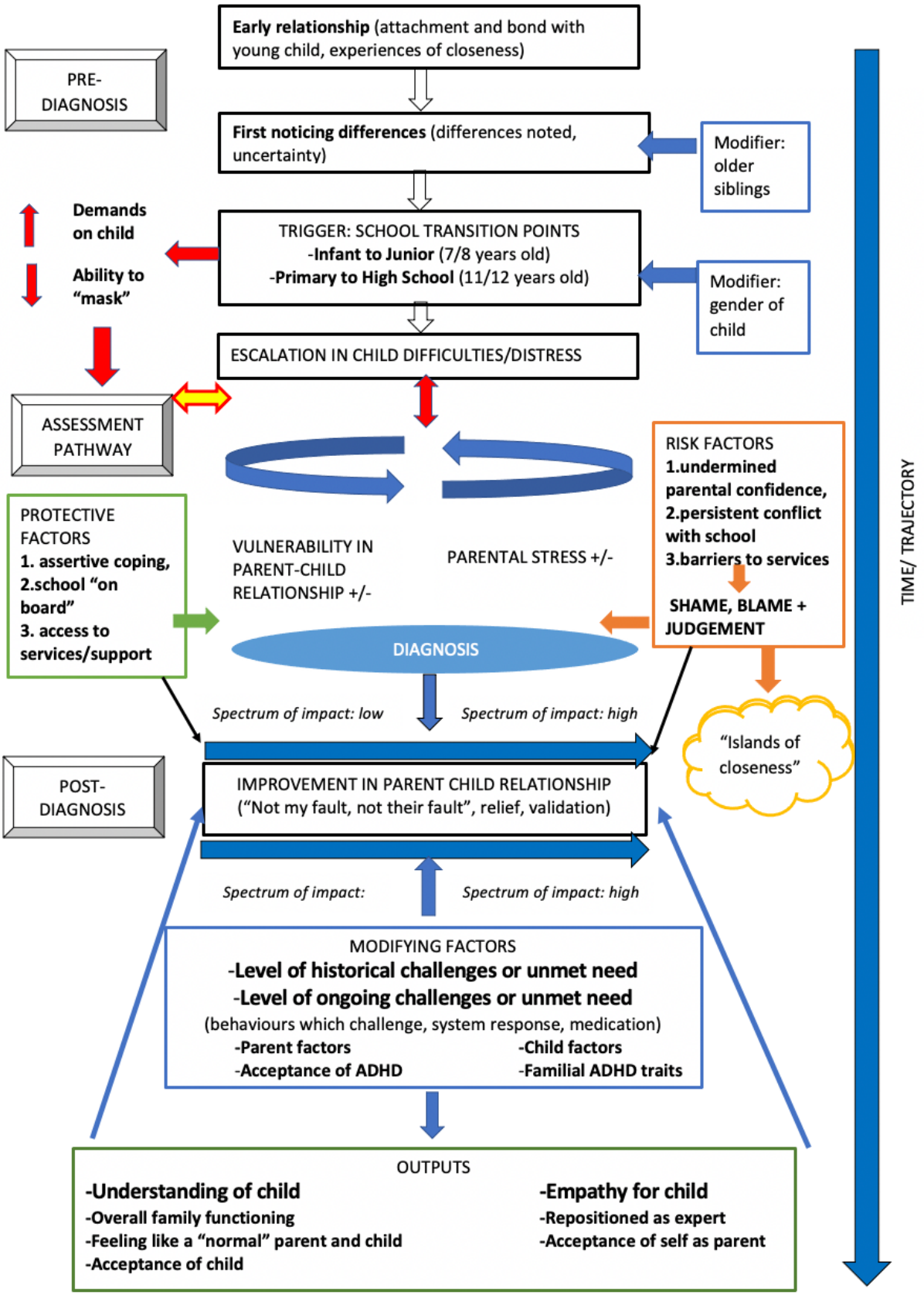
relationship were identified: undermined parental confidence, persistent conflict with their child's school and barriers to services. For many participants these factors culminated in experiences of shame, blame and judgement in their parental role. However, there also appeared to be opportunities for 'islands of closeness' with their child during this adverse time. A range of protective factors were also identified: assertive coping, the child's school being 'on board' and access to services and support.

Participants described the moment their child received their ADHD diagnosis as a meaningful experience which brought feelings of relief and validation for them as parents. All participants reported that their child's ADHD diagnosis had a positive impact on the parent-child relationship. However, the extent of this impact varied amongst the participant sample and ranged from the diagnosis significantly improving the parent-child relationship to having only a very minor positive impact.

Data analysis identified a range of factors which had a modifying effect on the impact of an ADHD diagnosis on the parent-child relationship, the most important being the level of both historical and current challenges and unmet needs experienced by parents and their children. Participants who reported greater historical challenges and unmet needs which had subsequently reduced significantly following their child's ADHD diagnosis described the diagnosis as more positively impactful than participants with a relatively low level of historical challenge, or participants who continued to experience significant ongoing challenges. In other words, the greater the reported reduction in challenges, the greater the reported positive impact on the parent-child relationship.

A range of outputs in the model were identified which capture the various mechanisms underlying an improvement in the parent-child relationship following the child's ADHD diagnosis, the two most commonly reported by participants being an improved understanding of their child and increased empathy for their child.

Figure 1: Diagrammatic Representation of the Theoretical Model



Major Conceptual Categories and Sub-Categories

Early Relationship and First Noticing Differences

Several participants described enhanced closeness in their early parent-child relationship, when their child was noted to be 'very loving and affectionate' (Trish). Parents described enjoying 'being like an attachment type parent… carrying him in the sling' (Helen). This period of time was also characterised by participants first noticing differences between their child and other children, with concerns predominately around their child's sleep, heightened activity, poor motor control and difficulties with attention. This period of time introduced uncertainty for participants of 'something not [being] right…we're missing something' (Rachel). Participants who also had older children described noticing differences earlier via a process of comparison between their children, with participants who did not have older children appearing to note differences at a later age; '…we didn't really pick up on her issues. And I think that's because she was the first child, so you've got nothing to compare to' (Michelle).

School Transition Points

After their child entered the school system, participants identified two key 'trigger' points as precipitators to both an escalation in their child's difficulties and increased challenges in the parent-child relationship. Several participants reported a notable escalation in their child's difficulties towards the end of their infant school journey: 'it was the end of year two where like his little mask started to slip…. children with ADHD- I think year three is massive for them' (Louise). For other participants, their child transitioning to high school was identified as a key trigger point in the sudden intensification in their child's difficulties: '…in year seven after a few months at school in high school she just changed' (Fiona).

Participants identified that these trigger points were related to increased demands placed on their child by the school system, resulting in their child finding it harder to cope with and 'mask' their difficulties; 'obviously the curriculum changes, school is a lot more structured. In many primary schools you lose a play-time as well….' (Louise). In addition to increased academic expectations, participants also commented upon their child's difficulty navigating their increasingly complex social world as they transitioned to high school. The transition year which participants identified as most salient for their child appeared to be largely influenced by the gender of the child, with parents of girls reporting that the transition to high school was harder for their child. Participants explained this by referring to gendered differences in the presentation of ADHD in children, expressing that girls are better able to suppress their difficulties for longer in order to 'keep up with peers' (Michelle).

Escalation in Child Difficulties and Distress

Following on from these noted 'trigger points' participants reported an escalation in their child's distress, describing that their child isolated themselves from their peers and became distressed about attending school '…we had the attendance officer here…he was 8 and they'd be saying "you've got to go to school" and he would be cowering under a bed' (Rachel). Participants also reported an increase in their child's distress at home during this period of time, often presenting as behaviours which challenged parents: '…hitting, kicking, breaking things erm yes kind of real lashings out' (Robyn). This escalation commonly resulted in parents either beginning to formally pursue an ADHD diagnosis for the first time or increasing their efforts to facilitate appointments for those already on the assessment pathway.

Participants described the period of time in which they were awaiting an ADHD diagnosis for their increasingly distressed child as a particularly challenging time for both the parent-child relationship and their own levels of parental stress. There appeared to be a close

relationship between the two sub-categories of challenges in the parent-child relationship and parental stress, and a suggestion of a reciprocal relationship.

Challenge in the Parent-Child Relationship

Participants described their child's behavioural expressions of distress and increased levels of aggression toward both them and other family members as a significant challenge to closeness in the parent-child relationship during this time; '[it's] difficult to have a close relationship with someone that causes so much stress… some days you just absolutely wanted to hide away from her' (Trish). Difficulties managing their child's behaviours resulted in several participants not feeling like a 'proper mum' within the parent-child relationship, lacking the 'parental authority' (Louise) to manage their child's sometimes risky behaviours (such as running away) and feeling 'scared of the questions that she was going to ask [about ADHD]…because I never knew the answers' (Fiona).

Parental Stress

Understandably, many participants reported a significant increase in their own levels of stress during this period of time. Participants described feeling emotionally exhausted by their attempts to support their child in school and at home, which often impacted on other areas of their life such as their personal relationships or work. Many participants talked about the significant impact of this period of challenge on their own mental health, with several participants reporting that they sought professional help for experiences of depression and 'profound anxiety coming home because I knew what it would be like…the meltdowns would happen' (Louise).

Protective Factors

The extent to which parents experienced personal stress and identified increased challenges in the parent-child relationship during this period of time varied amongst participants. The presence of the following protective factors appeared to mitigate some of the impacts of this challenging time.

Assertive coping. All participants' narratives featured the need to 'fight and battle' for support for themselves and their child. Participants described having to 'grow in confidence' as part of this process 'because it's your child and if you don't fight for them then nobody will' (Rachel) and that increasing their knowledge about ADHD and service pathways was integral to this; 'the more research I did the more empowered I became' (Harriet). Participants also described directly challenging professionals when they did not feel heard and re-establishing their 'expertise as a parent' (Rachel).

School 'on board'. Participants who described their child's school as 'on board and quite quick to start building up evidence' (Helen) in support of their child's ADHD assessment reported that this significantly reduced the barriers parents faced in accessing the assessment pathway. Furthermore, some schools took a pro-active approach to supporting children by introducing bespoke coping strategies, which participants expressed as particularly helpful.

Access to services and support. Participants who had been able to access support during this difficult period from either their informal support network or parent support groups described this as protective to their parental wellbeing. Parent support groups were particularly valued by participants as they could be accessed without a formal ADHD diagnosis and reduced participants sense of isolation; 'you know you're not alone as a parent…' (Robyn).

Risk Factors

Just as the presence of the above factors appeared protective against parental stress and increased challenge in the parent-child relationship, the following risk factors were identified which were reported by parents who described higher levels of parent-child distress during this time.

Undermined parental confidence. Participants described that their parental confidence was undermined during this time, reporting that their difficulties managing their child's behaviours in addition to negative interactions with professionals reduced their sense of parental efficacy. Participants described feeling like a 'bad parent' and 'so guilty' (Louise) when the parenting strategies they were advised to try by professionals were not effective. Several participants also described feeling undermined by professionals who informed parents that that their child could not possibly have ADHD because they were 'fine in school….[and] "school know her better than you"'(Michelle)

Persistent conflict with school. Several participants described persistent and highly stressful interactions with their child's school during this period of time, with a common stressor for parents reported as 'constant' phone calls about their child's 'disruptive behaviour' (Naomi). A highly stressful experience for several participants was the sense that their child was viewed as 'a naughty child in educational settings' (Louise), resulting in the fear of their child's expulsion for many parents; 'and they threatened to expel him…he was going to lose his place in school and I was drained' (Harriet), including three occasions where expulsion from school did in fact occur.

Barriers to services. The vast majority of participants described the process of obtaining an ADHD diagnosis for their child as a 'very long, convoluted, frustrating process' (Harriet) with reported waiting times from referral to diagnosis for the majority of participants varying between two and five years. A particular difficulty for many participants was feeling

uncontained by services and unsure of the assessment process: 'there's no management of expectations. I would rather they've had said from the beginning "right, this is going to take two years" than have literally no idea' (Michelle).

Shame, blame and judgement. The cumulative impacts of these risk factors are captured in the category 'shame, blame and judgement', which appeared to be a commonly experienced phenomena for parents and one that was particularly toxic to parental wellbeing. Participants perceived some professionals as 'very judgemental…casting aspersions and doubt on my [parenting] ability' (Harriet), with many participants interpreting their referral to a parenting course as further evidence that they were 'bad parents'. Several participants also experienced extended family members and other parents as critical of their parenting, which led many participants to isolate themselves. The impact of these experiences were reported by participants to have had a detrimental impact on psychological wellbeing: 'if people are constantly judging you or criticising…you can get…desperately low" (Helen)

Islands of Closeness

Despite the challenges to the parent-child relationship during this time, for many participants moments of closeness with their child existed alongside the adversity they faced. Participants reported a strong desire to care for their distressed child and to 'protect' him or her from being misunderstood or judged harshly by others. In doing so, participants often found themselves more aligned with their child as they took their perspective and advocated for them. Other participants talked about using soothing physical touch to regulate their child's distress and establish moments of closeness: 'because I'd done that and he felt calm and he felt cuddled and stuff…it wasn't a negative when he was…really angry" (Becky).

Receiving the diagnosis

This stage of the journey was described by the majority of participants as a meaningful and emotional moment, which marked the end of several years of uncertainty and difficulty pursuing an ADHD diagnosis. Several participants recollected crying with relief, feeling 'over the moon' (Michelle) that their child's difficulties had been formally recognised and that support would now be available. Receiving an ADHD diagnosis 'meant the world' (Louise) to participants after spending many years 'constantly between GP and school looking for an answer, looking for help….because nobody wants to see their baby struggle' (Rachel).

Improvement in the Parent-Child Relationship

All participants reported that their child receiving an ADHD diagnosis improved the parent-child relationship, with one of the most commonly reported immediate impacts being parents reframing their sense of self from 'bad parent' to 'it's a condition which he's got and…it's not nothing that I've done wrong' (Robyn). Participants also described their sense of validation that their child's difficulties had been formally recognised by a professional and 'it wasn't me like going out my mind' (Trish). The longer term impacts of the diagnosis on the parent-child relationship are discussed in more detail in the 'outputs' section of the findings.

However, the spectrum of impact that the ADHD diagnosis had on the parent-child relationship varied amongst participants. At the 'high' impact end of the spectrum, participants described that the diagnosis had been 'a game changer' for their relationship with their child and 'it's just brilliant now…I've got my son back' (Louise). Other participants reported that the diagnosis had reduced stress in the relationship but that otherwise 'we have got a really lovely relationship and we always have' (Helen). A range of modifying factors were identified which were associated with this variation in impact and are elaborated further below.

Modifying Factors

Level of historical challenges or unmet need. Participants who had experienced a greater level of historical challenge and exposure to the identified risk factors reported that the diagnosis had a greater positive impact on the parent-child relationship than those participants with protective factors who had experienced less pre-diagnostic parent-child distress. For example, participants who had experienced persistent conflict with their child's school and prolonged difficulties securing clinical and educational support for their child; 'so long fighting for him, so long saying "it's not him", so long being ridiculed by professionals…' (Louise), experienced the diagnosis to be highly significant, resulting in support being secured for their child, a reduction in their child's distress and improvement in the parent-child relationship. The category is labelled in larger font in the model in order to signify that this was a consistent finding.

Level of ongoing challenges or unmet need. Similarly, participants who reported a significant reduction in the level of ongoing challenges they experienced following their child's ADHD diagnosis described it as more impactful than participants who reported only a marginal reduction in the challenges they faced. The following sub-categories were identified as salient aspects in participants' experiences of this.

Behaviours which challenge. Participants largely reported that their child's behaviours which they found most challenging to manage (physical and verbal aggression, their child engaging in risky behaviours and emotional 'meltdowns') were significantly reduced in frequency following their child receiving their diagnosis, as a result of intervention and support from a variety of sources. These participants identified this reduction as facilitative to more quality time and closeness with their child; 'I mean we've always been very close but I think it's that…he hasn't been violent for such a long time…' (Robyn).

System response. Participants' experiences highlighted that the wider systems' response to their child (school, services and extended family) as a result of the ADHD diagnosis was important in reducing challenges to the parent-child relationship and parental stress. The most common narrative reported by participants was their child's school reframing their view of their child from 'naughty' to a child requiring additional support, with strategies put in place. Subsequently, parents reported reduced conflict with their child's school; 'from that moment on they never once pulled me up about anything she was doing' (Fiona). For some participants, their child's diagnosis had meant they were now able to access specialist educational provision and clinical services for their child, greatly improving their child's wellbeing.

However, a small number of participants expressed that despite their child's ADHD diagnosis they were still having to 'fight and battle' school in order to secure support for their child. Other participants also described a breakdown in relationships with family members who did not acknowledge ADHD as a 'real diagnosis'. For these participants, the ADHD diagnosis was viewed as less impactful than for those parents where the system response had been tangible and significant.

Medication. The majority of the participant sample reported that their child took medication following their ADHD diagnosis, with parents reporting that this had been facilitative to improved quality time with their child; 'it's been life changing for Reuben, but it's been life changing for us as a family. We can do so much more' (Louise). Participants whose child did take ADHD medication generally reported high levels of satisfaction, describing a reduction in conflict and negativity in their relationship with their child; 'obviously now he's on the medication he is a lot more settled you know he's not aggressive anymore'(Becky).

Secondary modifying factors. Participants' narratives highlighted a range of additional modifying factors, however these were not reported as universally by participants and have

therefore been identified within the model as secondary to the above. These included parent factors, such as participants' experiences of developing effective parenting strategies and their level of engagement with self-care and coping strategies; 'it's hugely important that you look after yourself because without you the whole thing falls down!' (Helen). Whilst a small number of participants reported little difference between the genders in parenting style or relationship with their child, many described fathers as more 'authoritative' (Rachel) and less likely to adapt their parenting as a result of their child's ADHD diagnosis.

Child modifying factors included the age of the child at diagnosis, with participants whose child had received their diagnosis at a later age describing their journey to diagnosis as highly stressful, largely as a result of prolonged periods of conflict with their child's school (commonly resulting in their child's expulsion) and frustrating delays along the assessment pathway. As such, this sub-group of participants described experiencing a longer period of parental distress and challenges in the parent-child relationship than parents of children who received their diagnosis earlier.

Acceptance of the ADHD diagnosis was noted as important for several participants, who felt that learning 'to embrace it and feel proud of it' (Helen) facilitated new opportunities for moments of closeness with their child in being able to talk about what ADHD means and frame this in a positive way; 'I always say to Reuben "you can do whatever you want to do. It's a superpower" (Louise).

Over half of the participant sample reported that either they or a close family member had a formal or suspected ADHD diagnosis. Participants who could identify personally with some of the difficulties their child presented with viewed this as a positive factor in their relationship with their child, enhancing understanding and empathy; 'me and Billy just sort of get each other on a certain level' (Helen). Participants also reported that extended family members with an ADHD diagnosis were better able to 'spot' their child's difficulties, thereby

enabling earlier support seeking. However, other participants described additional stressors of having both a close family member and a child with an ADHD diagnosis within the same family household; 'they just sometimes clash' (Michelle).

Outputs

Understanding of child

All participants in the sample identified that increased understanding of their child following the ADHD diagnosis was one of the most important longer term impacts on the parent-child relationship, and as such it is depicted in larger font in the diagrammatic theoretical model. Participants described the importance of better understanding their child's behaviour and adjusting their expectations accordingly in reducing feelings of frustration in the parent-child relationship; 'there's a rationale behind it. Whereas before I just thought "he's pressing my buttons"' (Rachel). For many participants, increased understanding of their child helped to reduce the frequency and intensity of their child's emotional distress by anticipating what might be a 'trigger situation' for their child: 'very early on in the diagnosis I could erm you know envisage a situation coming up…and I could talk to him very quickly about some of the strategies that he could use so…the diagnosis itself was so powerful' (Robyn).

Participants also described greater capacity for reflection during moments of distress for their child; 'after the ADHD [diagnosis] I would say automatically without even thinking about it, my reflection upon how I go about dealing with the ADHD increased' (Harriet), which participants described as facilitative to more responsive parenting that de-escalated moments of potential conflict and 'meltdowns'; 'like when she's having a meltdown and kicking off instead of going "don't be stupid blah blah blah" shouting and making things worse you think like "how am I going to calm this situation down"' (Trish).

Empathy for child. This outcome was also identified as universally important within the participant sample and is therefore depicted in larger font in the diagrammatic model. Participants described an ability to take their child's perspective following the ADHD diagnosis, enhancing feelings of empathy towards their child as participants 'got alongside' their difficulties; '…his life must be nothing but people trying to get his attention to do things. You know, it must be hard' (Helen). Contextualising their child's difficulties within an established medical framework which absolved their child of blame also increased participants' feelings of empathy towards their child, reframing 'naughty' behaviours as part of their child's condition; 'it wasn't just her being bad, there was a reason' (Trish). For several participants, having a diagnosis allowed for some separation of their child from 'the ADHD' and provided a platform for feelings of frustration to be directed towards; 'I'm really angry at the condition…that it makes Nathan struggle, but I'm not angry at Nathan. I'm angry at the condition that's part of Nathan' (Rachel). Reframing their child's behaviours which challenge as an unmet need allowed other participants to also reframe their position as a parent, from someone who 'bears the brunt' of their child's behaviours to someone 'safe' for their child to experience difficult feelings around 'because he knows…that he can release that stress of the day with me' (Becky).

Secondary outputs. A range of additional impacts of their child's ADHD diagnosis on the parent-child and family relationships were described by many participants. These were identified as secondary to the above outputs as they were identified in many, though not all participant narratives. These included an improvement in overall family functioning, with participants describing that improvements in their child's mood had a positive impact on the rest of the family; 'if Alfie's calm then the whole family's just a little bit calmer' (Robyn). Many participants also described increased opportunities for quality time together following their child's ADHD diagnosis, which participants experienced as feeling like a 'normal' parent

and child; ‘we had a lovely time, erm and it felt- it felt a bit more like when I see my friends with [their] girls…it felt a bit more normal’ (Michelle).

Following their child’s ADHD diagnosis many participants described repositioning themselves as the expert in their child, increasing parental confidence by confirming what they had long suspected; ‘you have the confidence in the fact that a professional has turned around and gone “you’re right”’ (Rachel). Several participants also described engaging with courses and learning following their child’s diagnosis, repositioning them as the experts in their own child and equipping them with ‘power’ to navigate the complex system of health and social care.

Acceptance of their child ‘for who [he] is’ (Rachel) following their ADHD diagnosis led to reflection for many participants on their pride in the hurdles their child had overcome and in their skills; ‘I see that Harvey is a very gifted and talented young man who has learnt to develop very good strategies (Harriet)’. Many participants also moved towards greater acceptance of themselves as a parent, with their child’s ADHD diagnosis appearing important in giving participants permission to learn by trial and error and to cultivate self-compassion during moments of parental challenge; ‘I try to think to myself “well I’m only human”. You know? That’s life isn’t it’ (Michelle).

Discussion

The research study met its primary aim of exploring parents’ perspectives of the impact that their child’s ADHD diagnosis had on the parent-child relationship, with the production of a theoretical model of relationship development. All participants viewed their child’s ADHD diagnosis as positively impactful on the parent-child relationship, with the most commonly reported outcomes being an improved understanding of their child and increased empathy for their child post-diagnosis.

Congruent with previous findings in the qualitative literature base, participants' increased understanding of their child following their diagnosis helped parents to begin to better anticipate difficult situations for their child and reflect on how best to support them; decreasing their child's distress and increasing opportunities for closeness within the parent-child relationship (Ringer et al. 2019). One way in which the diagnosis is likely to have increased parental understanding of their child is by reducing the multiple explanations parents previously held and providing an explanatory framework for their child's behaviour (Ringer 2019). The clarity provided by having a diagnosis also appeared to facilitate parents learning more about ADHD, with many participants in the sample describing an increased focus on research, reading and engagement with parent courses following their child's diagnosis, further increasing parental understanding.

In line with existing research (Corcoran et al. 2017; Roosa 2003; Villegas 2007) participants also described increased empathy for their child following their ADHD diagnosis, as they re-evaluated their child's behaviour as something they could not control rather than would not control. Negative parental evaluation of child behaviour is predictive of increases in behaviour which challenges, even when the child's initial ADHD symptoms and family factors have been accounted for (Johnston, Hommerson and Seipp 2009). This suggests that parental re-evaluation of their child's behaviour from a position of increased empathy following their child's ADHD diagnosis may result in decreased incidences of behaviour which challenges parents. Furthermore, several participants described that their child's diagnosis increased empathy for their child by helping them to externalise their child's difficulties associated with ADHD, directing feelings of frustration at 'The ADHD' rather than at their child. Drawing on theory from narrative therapy (White 2007), it is possible that the ADHD diagnosis supported parents to separate their child from 'The ADHD' and to see problems in a new way, creating opportunities for narratives that focussed

on strength-based aspects of both their own parenting and their child's achievements. This is reflected in some of the other outputs identified in the model which included participants' increased acceptance of their child and themselves as a parent.

All participants reported that their child's ADHD diagnosis had a positive impact on the parent-child relationship, however the extent of this impact was determined by a number of modifying factors. The most salient of these appeared to be the level of historical challenge to parental wellbeing and the parent-child relationship and the extent to which participants perceived that these challenges had been alleviated following their child's ADHD diagnosis. Critical to this alleviation for many participants was the wider system (e.g. the child's school and extended family) responding in a positive way to their child's diagnosis. Support and understanding often came in the form of access to specialist educational provision and additional support offered by schools. However, other participants described the system as sceptical of the diagnosis and felt that their child's behaviour continued to be framed largely within the context of parenting difficulties (Cronin 2004; Klasen and Goodman 2000; Wallace 2005; Wilder, Koro-Ljungberg and Bussing, 2009). This may offer insight into why some parents of children with an established ADHD diagnosis continue to experience parental shame and judgement, whilst others do not (Dos Reis et al. 2013; Mikami et al. 2013).

The study's secondary aims were also met, with increased parental understanding of their child identified as one of the key outcomes of improvement in the parent-child relationship following the child's ADHD diagnosis. The study also achieved its aim of exploring parental experiences of accessing services, with significant barriers to support reported widely within the participant sample. This replicates findings in previous studies (McIntyre and Hennessey 2012; Moen, Hall-Lord and Hedelin 2011; Ringer et al. 2019), suggesting there continues to be barriers to support following diagnosis, despite its importance for parental wellbeing and

their relationship with their child. The final secondary aim was also met, with the model identifying a range of risk and protective factors pertinent to the parent-child relationship and parental wellbeing, which included the ease or difficulty with which parents were able to access support.

Additional risk factors included a loss of parental confidence for many participants, stemming from negative interactions with professionals and feeling ineffective as a parent. Parental efficacy has been defined as parents' beliefs about their competence and their confidence in their parental role (Heath et al. 2015). Parents of children with ADHD have lower levels of parental efficacy and experience more feelings of helplessness than parents of children without ADHD (Primack et al. 2012). This has important clinical implications for parental wellbeing and child outcomes, with low parental efficacy a predictor both of parental stress (Crnic and Ross 2017) and reduced reluctance to attempt new parenting techniques learnt in ADHD parent workshops (Heath et al. 2015; Primack et al. 2012).

The cumulative impact of the risk factors experienced by many participants resulted in experiences of parental shame, blame and judgement, congruent with much of the existing research base (Singh 2004; Dos Reis et al 2010; McIntyre and Hennessey 2012). The experience of shame within the parenting role has in part been attributed to Western society's focus on 'competitive parenting' and comparison of the self to other parents, which can be particularly difficult for parents of children who may not conform to prevailing social or academic expectations (Gopnik 2014). As such, parents of children with an ADHD diagnosis may be at particular risk of parental shame, the presence of which has been correlated with problematic parenting approaches and increased levels of parental distress (Kirby et al. 2019).

Finally, participants identified significant difficulties for their child within school environments, which appeared to be exacerbated at specific school transition points as their

child progressed through the academic system. The gradual increase in academic and behavioural expectations as children progress through the educational system is likely to be particularly difficult for children who have difficulties with executive and self-regulatory function (Barkley 2015; Boyer, Geurts and Van der Oord 2018). The current research highlights that these increasing expectations at school transition points may precipitate increases in the distress experienced both for children with suspected or confirmed ADHD and their parents.

Clinical Implications

The present study developed a comprehensive theoretical model of the development of the parent-child relationship in families of children with an ADHD diagnosis, which has several practical applications for practitioners working with children and families. Parental narratives highlighted significant barriers to accessing support whilst awaiting an ADHD diagnosis for their child, describing the detrimental impact this had both on their child and on the parent-child relationship. The move within child and adolescent services to models of provision which focus on providing support that is not contingent upon diagnosis, acuity or service pathways but instead are led by the needs expressed by children and their parents (Wolpert et al. 2019) are therefore likely to be of particular benefit to children who have difficulties with attention and hyperactivity, reducing reliance on diagnosis being the only mechanism through which children and their families are able to access appropriate support.

The model also identifies key transition points within the context of children's progression through the educational system, which were characterised by significant increases in the distress that children experienced within the school environment as they found it increasingly difficult to 'mask' their difficulties. Consideration of these factors by clinicians working with this population of children may increase understanding of their

individual support needs at these key times and provide insights into how educational professionals can facilitate this support, for example the allocation of a mentor in the year above and creating opportunities for children to engage in soothing and regulatory activity. This may include more frequent break times, access to sensory based activities and increased opportunities for play and social connection. Clinicians may also have a role in supporting schools to promote movement based physical activity, in the recognition that this is beneficial for the mood regulation of all children (Siegel and Bryson 2012) but is particularly helpful for children with difficulties with inattention, hyperactivity and impulsivity (Gawrilo et al. 2013).

The model further highlighted parents' difficult experiences of parental stress, feeling unsupported and feeling criticised. The promotion of compassionate systems and the recognition of parents' lived experiences and expertise, in addition to strength-based approaches which highlight parents' existing skills and capabilities is important. There is a need for professionals working with children and families to consider the potential support needs of parents, either providing this directly or signposting to where such support can be accessed. Working with parents to increase their understanding of the impact of parental stress and the importance of appropriate self-care may help parents to invest in coping strategies that benefit both them and the wider family. Post-diagnostic support which recognises parents' desire for accurate information about ADHD, the provision of containing reflective spaces for parents and access to skills-based workshops are likely to be facilitative to increasing parental understanding and empathy in the parent-child relationship. Finally, clear explanations to parents about service pathways and candour about potential waiting times for ADHD assessments may help to manage parental expectations and stress for those who have children awaiting diagnosis.

Strengths and Limitations

To the best of the authors' knowledge this is the first study of its kind to produce a theoretical framework of the development of the parent-child relationship following a childhood diagnosis of ADHD, therefore novel findings have been presented which have a range of practical and clinical applications. The study is strengthened by the use of GT methodology in identifying a range of modifying factors linked to improvement in the parent-child relationship and provides some insight into why some parent-child relationships appear to experience greater challenges than others. Strauss and Corbin's (2015) approach was followed closely in the design and analysis of the study.

However, as is the case with all qualitative methodology, the ability to generalise these findings more widely are limited. As such the findings in this study should be interpreted as hypotheses that require further exploration and research (Sullivan and Sargeant 2011). Furthermore, the role of social desirability in participants' responses to questions about their relationship with their child must be considered. However, the candour of participants when talking about a range of difficult experiences suggests that participants were not 'holding back' or filtering their responses.

Another factor that must be considered in all qualitative research is the importance of researcher reflexivity in acknowledging the different subjective experiences and positions that the researcher may hold. This is perhaps of particular salience when exploring a complex clinical area such as ADHD, which presents several different theoretical approaches in how this diagnosis is conceptualised. Whilst the current paper adopted a position that conceptualised ADHD as a valid and discrete diagnostic construct, other positions include social-constructionist perspectives which position ADHD as a largely social construct (Timimi and Taylor 2004). Research which adopted this perspective may have asked different questions, analysed the data in different ways or even used different methodologies

more aligned with its theoretical approach (such as Critical Discourse Analysis, Potter and Wetherell 1987). Therefore, the current findings present only one interpretation of the data. The development of a reflexive statement, the recording of reflections post-interviews in detailed research memos and the use of research supervision are all tools the present study utilised to good effect.

The study is limited by a self-selecting participant sample of White British participants, a limitation which has been identified in many other research studies concerning parents of children with an ADHD diagnosis (Corcoran et al. 2017). The lack of male participants also means that the voices of fathers are not captured within this study and it is important to acknowledge that the participant sample in this current study (mothers whose children were predominately medicated for ADHD) represents only one version of the experiences had by families of children with an ADHD diagnosis. It is possible to hypothesise that mothers were more likely to view and respond to the research advertisement due to many mothers of children with ADHD giving up their employment in order to support their child and accompany them to appointments (Johnston and Chronis-Tuscano 2015), or that mothers perhaps felt more confident in communicating their parental experiences.

The finding that every participant engaged to some extent in 'assertive coping' techniques may be reflective of the personal characteristics of participants who choose to volunteer in research and therefore led to the self-selection of those individuals who feel confident sharing their experiences and advocating on behalf of other parents. Similarly, the finding that all participants experienced their child's ADHD diagnosis as helpful to some extent may be due to participants with less positive experiences feeling unable or unwilling to share their experiences. Continued consultation with experts by experience during the later stages of the research would have been beneficial, for example during data analysis in order to provide respondent validation of the emerging theoretical model. Unfortunately, practical

difficulties relating to the challenges of conducting research during the Covid-19 pandemic prevented the facilitation of this.

Future Research

As the aims and focus of this research study were novel, future replication studies are justified both to add strength to findings of this study and importantly to explore how parents of children with an ADHD diagnosis who are not represented in the current study (for example fathers and parents who do not identify as White British) perceive their child's ADHD diagnosis to have impacted on the parent-child relationship. It would also be of interest to explore the parental experiences of those parents whose child was referred for assessment but did not receive an ADHD diagnosis, in order to ascertain whether they received any other explanations for their child's difficulties and whether or not this was helpful.

Furthermore, there is a dearth of research which features the voices of children and young people with a diagnosis of ADHD. Future research which explores their experiences of the parent-child relationship prior to and following their ADHD diagnosis would provide valuable insight into whether children also felt that their diagnosis impacted positively on their relationship with their parents, or whether their experiences are in fact quite different.

Finally, consideration of longitudinal designs regarding the impact of a child's ADHD diagnosis on the parent-child relationship could be considered. For example, measures of parental stress and the quality of the parent-child relationship taken with parents at various stages of their child's assessment journey from pre-diagnosis to post-diagnosis would provide quantitative data which may strengthen the findings from this study or provide avenues for further consideration.

Conclusion

This study provides novel insight into how parents of children with an ADHD diagnosis experience the parent-child relationship prior to and following their child's ADHD diagnosis, with participants universally identifying that their child's ADHD diagnosis impacted positively on the parent-child relationship. The study expands existing knowledge about how an ADHD diagnosis increases parents' understanding of and empathy for their child and highlights the important role that educational and clinical professionals play in supporting parental wellbeing and parent-child relationships.

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Appendix 2

CASP scoring table for included studies

Study	Aims	Methodology	Research Design	Sampling/ recruitment	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Value of Research	Overall
Firmin and Phillips (2009)	3	3	3	3	3	1	2	3	3	3	27
Hallberg et al. (2008)	3	3	3	3	3	1	1	3	3	2	25
Kendall (1998)	2	3	3	3	3	2	3	3	3	3	28
Kendall (1999)	2	3	3	3	3	2	2	3	3	3	27
Leitch 2019	3	3	3	3	3	2	2	3	3	3	28
Lin, Huang and Hung (2009)	3	3	3	3	3	1	3	3	3	3	28
Moen, Hall-Lord and Hedelin (2014)	3	3	2	1	3	1	3	3	3	3	25
Paidipati et al. 2020	3	3	3	3	3	1	3	3	3	3	28
Ringer et al 2019	2	3	3	3	3	3	3	3	3	2	28
Segal and Frank 1998	2	3	1	2	3	1	1	1	2	2	18
Segal 1998	3	3	2	2	3	1	1	1	3	3	22
Sikirica et al 2015	3	3	3	3	3	1	3	3	3	3	28
Wallace 2005	3	3	3	2	1	1	3	1	3	3	23
Wong et al 2014	3	3	3	3	3	1	3	1	3	3	26

1=little or no justification or explanation for a particular area
2=moderate justification or explanation but not fully elaborated
3=strong justification or explanation and explained relevant issue at hand

Appendix 7

Example questions from first interview schedule

If we could start by you telling me a little bit about your son/daughter. What is his/her name?
How would you describe him/her?? How would you describe their personality?
What is life like at home with X? At school?
What is it like being a parent to X?
What do you like doing with X (hobbies/activities/time spent together etc)? Are there any hobbies/activities etc you would like to do with X but can't?
How would you describe your relationship with X?
Is there anything that helps you and X to feel close? Is there anything that can make this hard?

If we could talk a little bit about what things were like before X got their diagnosis of ADHD.
What were things like?/ What was it like being a parent to X before their diagnosis?
What was life like at home/school before X got their diagnosis?
Did you/others suspect that X might have difficulties with their attention/hyperactivity? Who first suggested this? What did they notice?
What was your understanding of X during this time? What sense did you make of what was happening with/for X?
What was it like being a parent to X during this time?
What was your relationship with X like during this time?
Did you have any help/ access any support/ services before X got their diagnosis?

If we could talk now about what it was like when X got their ADHD diagnosis. How did you go about getting this?
Were there any hard things about trying to get a diagnosis for X? Was there anything straightforward about it?
What did you think when you found out that X had ADHD?
What did you know about ADHD when X got the diagnosis? What do you know now?
How did you find out this information about ADHD?
Did anything change after X got their diagnosis of ADHD?
Did your relationship with X change? How did it change? What is different about your relationship now?

Did you, X or your family access any kind of support from services/groups after X got their diagnosis of ADHD?
If yes
What was this support like?
What was good/helpful about it? What was not so good/helpful about it?
Did this support have any impact on your relationship with X?
What could services do differently to improve the support they offer/ what should they keep the same?
If no
Did you want support but could not access it?
Did you not want/ need support?
Did you have other ways of coping/ sources of support?
Did this have any impact on your relationship with X?

Is there anything we've not touched on today that you would like to share/ think it is helpful for me to know in relation to exploring your experiences of parenting X?

Appendix 8

Shortened example of reflective memo

Summary of narrative and overview of key themes

Participant 4 talked about how important it was for her to be able to continue to 'see' her son and not 'just see the ADHD'. Things that helped with this was encouraging her sons' hobbies and interests and spending quality time with him talking about things. 'Seeing' her son in this way one was thing that participant 4 identified as helping her to cultivate closeness in their relationship. Participant 4 identified that it was harder to 'see' her son when it felt like the ADHD was 'taking over'. She gave examples of this as times when her son might have a 'meltdowns' or be physically destructive in the house (e.g. kicking doors off their hinges). Her son describes these aspects of his ADHD as 'the hulk ADHD'. Participant 4 felt like these times and other difficult aspects of her son's behaviour were the times it impacted on their relationship and it was harder to feel close. Participant 4 described that receiving a diagnosis for her son had helped to navigate these more difficult aspects of their relationship and lessen the impact it had on their mother-son relationship. This was in part about an improved understanding of her son and what he is/isn't capable of. She also talked about how the diagnosis helped to externalise his behaviours as part of the ADHD and not part of him. Participant 4 gave an example of how these behaviours can make her feel angry, but this anger is projected on to the ADHD and not her son.

What is still not known/ future questions

-Exploring how feelings of being undermined and losing parental confidence as a result of blame/judgement impacts parent-child relationship – do parents feel more uncertain of how to manage difficult behaviours/situations? Does this lead to more conflict in the relationship?

Emerging hypotheses

- Parents of children with ADHD are more likely to experience guilt, criticism and judgement than other parents. This comes in part from being labelled a 'bad parent' and being shamed by others.
- Children with ADHD are also more likely to experience criticism and judgement from others than children without ADHD. Their needs and difficulties are labelled as 'naughty' and 'behaviours'.
- As children are labelled 'naughty children', parents are labelled 'bad parents'

Reflections

This interview confirmed some of the previous findings from earlier interviews particularly around closeness. It was also interesting to hear new ideas and information, and I was particularly interested in the concept of parents being able to 'see' their children for who they are, and the role this plays in maintaining closeness in the relationship. The diagnosis itself seems pivotal in this – almost a vessel for the difficult behaviour to be channelled into and subsequent parental feelings like anger to be safely projected and contained in, in a way that is kept separate from the child and therefore protects the integrity of the relationship. I also wonder what else helps with 'seeing' children, as it seems it is harder to 'see' them when behaviours are difficult.

Appendix 9

Example questions from second interview schedule

- Do you think mum/son, mum-daughter relationships are different when raising a child with ADHD?
- Do you think father-child relationships are different to mother-child relationships when raising a child with ADHD?
- How did you and X manage their difficulties before the diagnosis?
- Have you noticed a change in yours and X's relationship over time?
  -When were the harder/easier times?
  -What do you think contributed to that?
- If participant talks about a ''trigger point' for increase in child difficulties or increase in challenges in parent-child relationship
  -What do you think led up to/ contributed to that?
  -What helped to cope/manage during this time?
- Some parents have talked about feeling blamed or judged by others. Is this something you have felt?
  - Do you think it had any impact on you and X? Did it change the way you parented?
  -If had impact on parental confidence: what helped you to rebuild that?
  -What helped/helps you cope with/overcome blame and judgement?
- Some parents have talked about having to fight their child's battles and stick up for them against others.
  -Is that something you have experienced?
  -How did it affect you and X?

Appendix 11

Final coding hierarchy

Appendix 12

Reflexive statement

As a parent myself, I come from a position of recognising that parenthood can be a time filled with unimagined joy but can also at times be a challenging and stressful experience that provokes self-doubt and uncertainty. This made me curious to better understand the experiences of parents who report high levels of parental stress, such as those who are caring for children with a diagnosis of ADHD. This curiosity was further sparked during my training as a Clinical Psychologist, a substantial part of which has involved thinking and practicing using a Systemic Family Therapy approach. This developed my thinking around the importance of family relationships and the resources within them when trying to understand difficult experiences.

Whilst the experiences of parents who have a child with an ADHD diagnosis is an area of academic interest for me, my clinical experience prior to conducting this research has largely been within adult mental health contexts. As such, ADHD is a new area for me as a researcher that I have little prior knowledge about. Being able to adopt a 'naïve' position may have some advantages in being able to consider participants' narratives without prior professional experiences or knowledge impacting the direction of analysis. However, my professional background in adult mental health may impact the direction of analysis in alternative ways, for example empathising with the difficult experiences of parents and having a strong awareness of the impact of poor parental mental health. Furthermore, ADHD is a complex clinical area with a range of competing views regarding its aetiology and validity. My professional experiences and empathy for parents may impact on how the diagnostic concept of ADHD is conceptualised within the study and the extent to which this aligns with parental conceptualisations.

I am curious how, or if, the parent-child relationship changes as a result of parents finally having a diagnosis or 'explanation' for their child's behaviour. As a trainee clinical psychologist, I favour a formulation based approach to understanding an individual's difficulties, but I recognise that for many people obtaining a diagnosis for them or a loved one is an important milestone in their journey. I am particularly interested in how an ADHD diagnosis has been helpful or unhelpful for parents, as I recognise that this is a diagnosis that both parents and children may experience as stigmatising.

My expectations about the research findings are that for many parents, obtaining a diagnosis of ADHD for their child will have had a positive impact on the parent-child relationship. I would expect that for these parents obtaining a diagnosis for child will have increased understanding and opened pathways to support that were previously unavailable. I am also expecting that for other parents, the diagnosis will have been less helpful. These parents may have already felt they had a good understanding of their child's behaviour before the diagnosis or may not have felt well supported after obtaining the diagnosis for their child.