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**University of Southampton**

Faculty of Environmental and Life Sciences

School of Psychology

**An Exploration of the Experiences of Families Affected by ADHD**

Volumes 1 & 2

by

**Kristina Todorova**

Thesis for the degree of Doctorate in Clinical Psychology

15<sup>th</sup> September 2023

# University of Southampton

## Abstract

Faculty of Environmental and Life Sciences

School of Psychology

Thesis for the degree of Doctorate in Clinical Psychology

An Exploration of the Experiences of Families Affected by ADHD

by

Kristina Todorova

This thesis explores the experiences of families who are affected by Attention Deficit Hyperactivity Disorder (ADHD). The first chapter contains a systematic literature review looking into the relationship between parental ADHD and parenting stress, and other possible relevant factors that may influence this relationship. Eight studies which fit the eligibility criteria were identified. The data was analysed and presented via narrative synthesis. 80% of studies indicated that when parents experienced higher levels of ADHD, they reported more parenting stress, although two studies suggested the converse relationship for fathers. Parenting stress levels were higher if their child also had neurodevelopmental difficulties. Situational factors were explored by fewer studies. However, some evidence suggests that lower parental educational status and social support were associated with higher levels of parenting stress. Future research could focus on situational factors and strength-based aspects of parental ADHD. Researchers may wish to consider developing a new model of parenting stress which better considers the complex interaction between parent, child, and situational factors (Abidin, 1983). The second chapter explores parents' experiences of their child being assessed for and receiving an ADHD diagnosis. An IPA qualitative methodology was used to interview six participants whose children were diagnosed with ADHD in England in the last 12 months. After analysis, three superordinate themes were identified: "surviving" the assessment, "every feeling under the sun" – parent emotional experiences, and "on the other side" – changes after ADHD diagnosis. Seven subthemes emerged: "battle" with services, effect on family relationships, parenting self-efficacy, stages of psychological acceptance, "I know my child best", knowing what to do next – accessing support, and hopes for the future. The study suggests two models of psychological acceptance may provide a clinically-relevant framework representing parents' emotional experiences in relation to their child receiving an ADHD diagnosis. Suggestions for future research were discussed and recommendations for clinical practice are highlighted in relation to assessment waiting times and improving communication with parents/carers.

# Table of Contents

<b>Table of Contents</b> .....	<b>iv</b>
<b>Table of Tables</b> .....	<b>vii</b>
<b>Table of Figures</b> .....	<b>viii</b>
<b>Research Thesis: Declaration of Authorship</b> .....	<b>ix</b>
<b>Acknowledgements</b> .....	<b>x</b>
<b>Chapter 1 Systematic literature review: What is the relationship between parental ADHD and parenting stress?</b> .....	<b>1</b>
1.1 Abstract .....	1
1.1.1 Key terms.....	1
1.2 Introduction.....	1
1.2.1 Parenting Stress.....	2
1.2.2 Parental ADHD.....	4
1.2.3 Review Aims .....	6
1.3 Methodology .....	7
1.3.1 Search strategy and paper selection .....	7
1.3.2 Inclusion and exclusion criteria .....	8
1.3.3 Data extraction .....	8
1.3.4 Quality appraisal of studies .....	9
1.3.5 Analysis.....	9
1.4 Results .....	10
1.4.1 Characteristics of included studies .....	11
1.4.2 Description of research studies.....	11
1.4.3 Quality assessment and risk of bias .....	12
1.4.4 Narrative synthesis.....	15
1.4.4.1 Parenting stress and parental ADHD.....	15
1.4.4.2 Mediating and moderating factors – parent, child, situational .....	15
1.5 Discussion .....	19
1.5.1 Parent Factors .....	20

1.5.2	Child factors.....	21
1.5.3	Situational factors .....	22
1.5.4	Strengths and limitations of included studies.....	23
1.5.5	Strengths and limitations of this review .....	25
1.6	Conclusion .....	26
<b>Chapter 2 Parents' Experience of their Child Receiving an ADHD Diagnosis in England</b>		
<b>27</b>		
2.1	Abstract .....	27
2.1.1	Key terms.....	27
2.2	Introduction.....	27
2.2.1	Stigmatisation of parents of children with ADHD .....	28
2.2.2	Pharmacological ADHD interventions .....	28
2.2.3	Cultural and demographic factors.....	29
2.2.4	Adults' experiences of receiving an ADHD diagnosis.....	30
2.2.5	Research aims.....	30
2.3	Method .....	31
2.3.1	Study design .....	31
2.3.2	Position Statement.....	32
2.3.3	Participants and recruitment .....	32
2.3.4	Procedure .....	35
2.3.5	Analysis.....	35
2.4	Findings .....	36
2.4.1	Superordinate theme 1: "Surviving" the assessment .....	37
2.4.1.1	The "battle" with services .....	38
2.4.1.2	Effect on family relationships.....	39
2.4.2	Superordinate theme 2: "Every feeling under the sun" – Parent emotional experiences .....	40
2.4.2.1	Parenting self-efficacy .....	40
2.4.2.2	Stages of psychological acceptance .....	41
2.4.2.3	"I know my child best" .....	42

2.4.3	Superordinate theme 3: “On the other side” – Changes with ADHD diagnosis	42
2.4.3.1	Knowing what to do next – accessing support.....	43
2.4.3.2	Hopes for the future.....	43
2.5	Discussion .....	44
2.5.1	Strengths and limitations of study .....	47
2.6	Conclusion .....	48
	<b>Appendix A Downs and Black Checklist Quality Assessment .....</b>	<b>51</b>
	<b>Appendix B Field Notes.....</b>	<b>57</b>
	<b>Appendix C Participant Information Sheet .....</b>	<b>59</b>
	<b>Appendix D Consent Form and Brief Questionnaire .....</b>	<b>63</b>
	<b>Appendix E Debriefing Form .....</b>	<b>65</b>
	<b>Appendix F Interview Topic Guide .....</b>	<b>66</b>
	<b>Appendix G Ethical Approval.....</b>	<b>69</b>
	<b>Appendix H Thematic Map Evolution .....</b>	<b>70</b>
	<b>Appendix I Journal Submission guidelines.....</b>	<b>72</b>
	<b>List of References .....</b>	<b>73</b>

# Table of Tables

**Table 1.** Characteristics of studies included in the systematic review (n=8) .....13

**Table 2.** Narrative synthesis summary of systematic review findings .....17

**Table 3.** Participant demographics and family history .....33

**Table 4.** Child demographics and ADHD assessment history .....34

**Table 5.** Superordinate themes, subthemes, and their frequency .....36

## Table of Figures

<b>Figure 1.</b> Parenting stress model, adapted from Abidin (1983).....	4
<b>Figure 2.</b> The PRISMA flow diagram detailing steps in the study selection process.....	10
<b>Figure 3.</b> Updated parenting stress model, adapted from Abidin (1983).....	25



## Research Thesis: Declaration of Authorship

Print name: KRISTINA TODOROVA

Title of thesis: An Exploration of the Experiences of Families Affected by ADHD

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signature: XXXXXXXX Date: 2<sup>nd</sup> June 2023.....

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# Chapter 1 Systematic literature review: What is the relationship between parental ADHD and parenting stress?

## 1.1 Abstract

The systematic review aims to explore the relationship between parental ADHD and parenting stress, as well as look into other possible relevant factors that may influence this relationship. Eight studies which fitted the eligibility criteria were identified. The data was analysed and presented via narrative synthesis. Overall, the findings indicated that when parents experienced higher levels of ADHD symptomology, they also reported more parenting stress (80% studies). However, the results showed differences between mothers and fathers in terms of experiencing parenting stress when they also reported elevated ADHD symptoms. The review identified that parenting stress levels were in some instances higher when parents reported more ADHD symptoms as well as having a child with neurodevelopmental difficulties. Situational factors appeared to be explored less by studies included in the review, however some evidence suggests that lower parental educational status and having less social support are associated with higher levels of parenting stress. Future directions for research may focus on exploring situational and contextual factors explicitly as well as the positive aspects of parental ADHD. Researchers may wish to consider the development of an up-to-date model of parenting stress which better considers the complex interaction between parent-child-situational factors which form part of parents' experience of stress when parenting their children, as originally proposed by Abidin in 1983.

### 1.1.1 Key terms

*Parenting stress; Parental ADHD; Systematic review*

## 1.2 Introduction

The process of raising a child is considered by many to be one of the most meaningful and rewarding experiences in one's life (Aassve et al., 2012). Nevertheless, parenting is often associated with continual challenges and varying degrees of stress as a result of many internal and

external pressures (Crnic & Greenberg, 1990; Fang et al., 2022). The literature suggests that approximately 4% of the adult population meets the criteria for an *Attention Deficit Hyperactivity Disorder (ADHD)* diagnosis (Kessler et al., 2006) and ADHD is considered to be a chronic and pervasive neurodevelopmental condition which typically manifests during childhood and is characterised within three major domains: inattention, hyperactivity and impulsivity (DSM V, American Psychological Association, 2013). ADHD symptoms can have a negative impact on aspects of daily functioning, especially in relation to tasks associated with executive function (Fauermaier et al., 2015), and emotion regulation (Christiansen et al., 2019), which have been demonstrated as playing important roles in parenting (Havighurst & Kehoe, 2017; Wilson & Gross, 2018).

The relationship between a child's neurodevelopment and their parents' *parenting stress* has received some attention within the research community (Biondic et al., 2019; Gordon & Hinshaw, 2017; Weiner et al., 2016). Previous systematic literature reviews have concluded that parents of children with neurodevelopmental difficulties, including conditions such as Autism Spectrum Disorder (ASD) and ADHD, tend to experience higher levels of parenting stress (Barroso et al., 2018; Theule et al., 2013). There has been an emphasis on exploring research perspectives which situate the issue within the individual (i.e. the child) and this will be discussed further below. To our knowledge, this is the first literature review which aims to examine the relationship between *parental ADHD* symptoms and parenting stress.

### **1.2.1 Parenting Stress**

Parenting stress is defined as a negative affective experience related to the parent's perception of parenting demands which outweigh the resources available to them (Deater-Deckard, 2004). The psychological theory behind parenting stress has a longstanding history dating back to 1974 when Abidin first started to develop the Parenting Stress Index (PSI) questionnaire (Abidin, 1983, 1990, 1995, 2012). Abidin's model (1983) suggests that parenting stress is influenced by parent factors (e.g. self-efficacy), child factors (e.g. behavioural characteristics) and situational factors (e.g. socioeconomic factors). Abidin (1983) also highlights that parenting stress is a transdiagnostic construct which can often have an impact on other life domains such as employment stress as well as the broader parenting experience and child development (Creasey & Reese, 1996; Holly et al., 2017). Notably, the dominant discourse in the literature appears to be focused on the relationship between parenting stress and child-related factors as evidenced by the vast number of studies exploring this relationship (Barroso et al.,

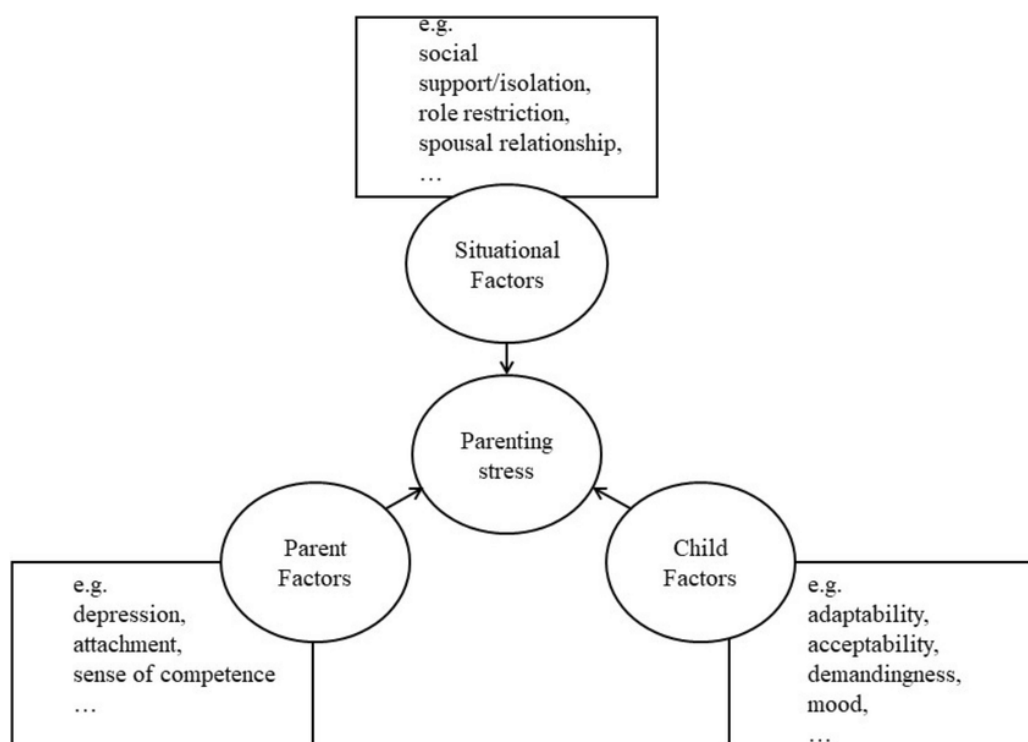
2018; Cousino & Hazen, 2013; Neece et al., 2012; Pinquart, 2018; Solem et al., 2011; Tsotsi et al., 2019). Parent-related factors also appear to have received some attention by researchers, particularly focusing on personality (Molfese et al., 2010; Rantanen et al., 2015) and mental health factors (Barroso et al., 2018; Martin et al., 2019). **Figure 1** contains Abidin's parenting stress model (1983).

Another psychological model that may provide further insight into this interaction is Lazarus and Folkman's (1984) Transactional Model of Stress and Coping. The model has also been adapted for parents of adults with learning disabilities (Hill & Rose, 2010). The model suggests that people appraise stimuli within their environment (e.g. child cries late at night) which in turn generates emotions (e.g. anxiety, frustration) if the stimuli are perceived as "stressors", resulting in distress which initiates coping strategies (e.g. wake up, feed child) to manage that feeling. The coping response also produces an outcome (e.g. child stops crying) which is once again appraised as favourable, unfavourable or unresolved, with favourable outcomes eliciting positive feelings and unresolved or unfavourable producing further feelings of distress. The feedback loop nature of the model suggests that individuals are able to reduce their levels of stress by employing coping strategies successfully (Biggs et al., 2017).

There is a vast amount of research evidence that explores the negative impact of parenting stress on children as well as parents themselves. Some research has concluded that parenting stress can have a negative impact on the relationship between child and parent (Morgan et al., 2005), for example higher parenting stress can impact parents' ability to manage their child's behaviour effectively (Smith, 2010) and in a way that fosters positive attachments (Moreira et al., 2015; Tharner et al., 2012). Furthermore, parenting stress can influence parents' own perception of being a successful parent (Crnic & Ross, 2017), and it has been shown to negatively influence parental practices (Abidin, 1992; Belsky, 1984; Kazdin, 1995). For example, Bonds and colleagues (2002) found that mothers who experienced less stress engaged with more positive parenting practices, particularly when they perceived that they had more social support around them. The effects of parenting stress on child behaviour have further been described by Deater-Deckard (1998) and a more recent systematic review (Barroso et al., 2018) identified a link between parenting stress and child behavioural difficulties with an emphasis on externalising behaviours. The review highlighted the importance of assessing parenting stress routinely when planning clinical interventions (Barroso et al., 2018). Some studies have found a direct link between higher levels of parenting stress and increased challenging behaviour in preschool (Crnic et al., 2005) and school aged children (Anthony et al., 2005). Parenting stress has also been linked to children's

difficulty in adjusting to the classroom (Anthony et al., 2005). A study by Tharner and colleagues (2012) found that parenting stress was related to aggression and inattention difficulties as well as behavioural withdrawal in children with an insecure attachment to their parental figures. These findings are in line with research suggesting that parenting stress is associated with internalising (Rodriguez, 2011) as well as externalising (Dubois-Comtois et al., 2013) behavioural presentations in children.

**Figure 1.** Parenting stress model, adapted from Abidin (1983)



### 1.2.2 Parental ADHD

Many adults are diagnosed with ADHD (Larsson et al., 2014). A systematic review undertaken by Polanczyk and colleagues (2014) estimated that the prevalence rate of ADHD is ~5% and that the rate of diagnosis of children has remained relatively stable across the last three decades. The research suggests that between 30% and 70% of adults who were diagnosed with ADHD during childhood continue to experience symptoms associated with the condition (Barkley et al., 2002) and there is some evidence of ADHD heritability and higher prevalence within some families (Faraone et al., 2005; Johnston et al., 2012; Larsson et al., 2014).

The impact of adult ADHD on many aspects of daily functioning has been an area of interest within healthcare research, as it is now recognised as a serious medical condition with long-term consequences (Guo et al., 2021; Hodgkins et al., 2012). Some research suggests a link between ADHD in adulthood and educational success and employment (Able et al., 2007; Kessler et al., 2006; Mannuzza et al., 2011), where a higher level of severity of ADHD symptoms may be associated with decreased work performance and lower educational attainment. Several studies have also highlighted that adults with ADHD are at higher risk of experiencing mental health difficulties such as depression and anxiety, as well as difficulties with addictive substances (Barkley et al., 2008; Barkley, 2015). These factors may all have indirect implications for parenting by adults with (Johnston et al., 2012). Linking these findings back to Abidin's (1983) parenting stress model, the effects of parental ADHD symptoms may fall under the parent-related and situational-related domains that influence parenting stress.

The literature suggests that ADHD can also have direct negative impact on two related aspects of parenting behaviour: effective behavioural control, and emotional responsiveness to the child (Johnston et al., 2012). Effective behavioural control relates to parents' ability to supervise their child, to give instructions and guidance, to plan and to problem-solve in accordance with consequences, and to promote independence, which requires efficient executive functioning skills (Darling & Steinberg, 1993; Rothbaum & Weisz, 1994). It is likely that parenting behaviours related to effective behavioural control would be mostly situated within the parent-related factors domain of Abidin's (1983) model. The emotional responsiveness aspect of parenting behaviour focuses on the interaction between parent and child, the ability to attend to the child's needs, be present and respond with empathy (Darling & Steinberg, 1993; Rothbaum & Weisz, 1994), skills which seem dependent of good emotion regulation skills. Once again, emotionally responsive parenting behaviours are likely to be categorised within the parent factors domain on Abidin's (1983) model. Johnston and colleagues (2012) suggest that parents with ADHD may find aspects of both dimensions of parenting behaviour challenging in light of experienced difficulties with inattention, hyperactivity and impulsivity. This dynamic appears to be influenced further by factors related to child developmental presentations, for example parents with ADHD finding it more difficult to parent children who also have ADHD (Johnston et al., 2012). This strongly suggests that the continuous interaction between parent-child-situational factors is central to the experience of parenting stress, as parents' skills in effective behavioural control and emotional responsiveness will likely depend on how the child presents as well as the availability of environmental resources to the parent.

A call from some in the research community has urged researchers and clinicians to consider the positive aspects of ADHD in adults, highlighting the non-binary continuum nature of the condition (Sedgwick et al., 2019; Lubke et al., 2009). In an editorial review, Lesch (2018) described that individuals with high-functioning ADHD may put twice as much effort, be able to hyperfocus, and have high levels of energy and enthusiasm (Mahdi et al., 2017) which can significantly mitigate and compensate for ADHD-related difficulties. Some studies have shown a link between high levels of creativity and people with ADHD (White & Shah, 2011; White & Shah, 2006). Two qualitative studies where people with ADHD were interviewed about the positive side of ADHD identified energy and drive, agreeableness and humanity, cognitive dynamism and hyperfocus, resilience and courage as some of the main themes (Mahdi et al., 2017; Sedgewick et al., 2019). However, there is little research looking at the positive aspects of parental ADHD and parenting, with most studies focusing on intervention and treatment (Sedgewick et al., 2019).

### **1.2.3 Review Aims**

The primary aim for the current systematic literature review was to explore the relationship between parental ADHD symptoms and parenting stress. To our knowledge, there has been no review to this date looking into this relationship explicitly and therefore there is a gap in the literature. Previous systematic reviews have explored the relationship between parental ADHD and parenting behaviours (Park et al., 2017), as well as parenting stress and child developmental presentations (Barroso et al., 2018), and parenting stress and children's ADHD interventions (Theule et al., 2018). Other literature reviews have focused on the relationship between parental mental health and parenting children with neurodevelopmental conditions (Robinson et al., 2022), and parenting stress, parental mental health, and child sleep (Martin et al., 2019). These reviews highlight the historic emphasis on exploring factors most commonly related to children's presentations and their effect on parenting stress.

The review's secondary aims are to explore potential mediating and moderating factors within this relationship, based on Abidin's (1983) categorisation of parent factors (e.g. mental health profile), child factors (e.g. neurodevelopmental profile), and situational factors (e.g. household status). It is hoped that the review might shed some light on how relevant Abidin's (1983) model may be today, as well as to identify the next best avenues for research. This topic is clinically relevant and could play an important role in tailored support for families affected by ADHD. It is hoped that the review results may help to identify some targets for support and



intervention as well as protective and resilience considerations when working with parents who may have ADHD.

### **1.3 Methodology**

The review was planned and executed within a systematic framework (Booth et al., 2021) and in accordance with the PRISMA guidelines (Liberati et al., 2009) which enabled the identification of appropriate data sources and synthesis of findings to address the primary and secondary aims. In the spirit of transparency and replicability, the search strategy has been detailed in the following section (Boland, Dickson & Cherry, 2017).

#### **1.3.1 Search strategy and paper selection**

Preliminary searches confirmed that there were no previous comprehensive reviews looking into the relationship between parental ADHD and parenting stress, and the review was registered with PROSPERO (CRD42023389765):

[https://www.crd.york.ac.uk/prospero/display\\_record.php?RecordID=389765](https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=389765).

Relevant research articles were searched for within literature databases PsycINFO, MEDLINE and PsycArticles via the EBSCO platform. The first 10 pages of Google Scholar and the library catalogue were reviewed for any relevant grey literature. Database searches were conducted across a period between October 2022 and December 2022. Search terms were discussed and reviewed with a librarian at the University of Southampton as well as within research supervision. The final search terms were: parent\* ADHD OR parent\* Attention Deficit Hyperactivity Disorder OR parent\* Attention Deficit-Hyperactivity Disorder OR parent\* Attention Deficit Disorder OR parent\* add OR parent\* attention-deficit OR parent\* attention deficit OR parent\* hyperkinetic disorder OR parent\* inattention OR parent\* hyperactivity OR maternal ADHD OR maternal Attention Deficit Hyperactivity Disorder OR maternal Attention Deficit-Hyperactivity Disorder OR maternal Attention Deficit Disorder OR maternal add OR maternal attention-deficit OR maternal attention deficit OR maternal hyperkinetic disorder OR maternal inattention OR maternal hyperactivity OR paternal ADHD OR paternal Attention Deficit Hyperactivity Disorder OR paternal Attention Deficit-Hyperactivity Disorder OR paternal Attention Deficit Disorder OR paternal add OR paternal attention-deficit OR paternal attention deficit OR paternal hyperkinetic disorder OR paternal inattention OR paternal hyperactivity OR mother\* ADHD OR mother\* Attention Deficit Hyperactivity Disorder OR mother\* Attention Deficit-Hyperactivity Disorder OR mother\* Attention Deficit Disorder OR mother\* add OR mother\*

attention-deficit OR mother\* attention deficit OR mother\* hyperkinetic disorder OR mother\* inattention OR mother\* hyperactivity OR father\* ADHD OR father\* Attention Deficit Hyperactivity Disorder OR father\* Attention Deficit-Hyperactivity Disorder OR father\* Attention Deficit Disorder OR father\* add OR father\* attention-deficit OR father\* attention deficit OR father\* hyperkinetic disorder OR father\* inattention OR father\* hyperactivity AND parent\* stress OR caregiver stress OR maternal stress OR paternal stress.

### 1.3.2 Inclusion and exclusion criteria

The following inclusion criteria were used to decide which articles to include in the review:

- Papers which examined associations between parenting stress, and parental ADHD
- Studies must include a researched measure of parenting stress such as the PSI (Abidin, 2012) or its derivatives
- Studies must include parents who have a formal diagnosis of ADHD or who would meet criteria for ADHD based on a validated assessment tool and/or clinical interview and observations
- Studies examining effectiveness of an intervention must present pre-intervention data on parenting stress, parental ADHD, and their association

Papers were excluded if:

- They solely presented qualitative data without any quantitative exploration on the topic
- They were reviews, book chapters, conference extracts or dissertations
- They were not written in the English language

### 1.3.3 Data extraction

The different stages of data extraction included identification of records through database searching; screening of titles, screening of abstracts, screening of whole texts, and studies included in the final selection. A second reviewer was also involved in paper selection. The second reviewer examined 10% ( $N = 26$ ) of the abstract stage of assessment for eligibility, and they engaged with this step of the process by reviewing abstracts based on the inclusion and exclusion criteria before deciding if the paper should progress to the next stage of data extraction or if it should be excluded at this stage. There was a strong level of agreement between first and second reviewer ratings,  $\kappa = .866$  (95% CI: .611- .990),  $p < .001$ . The literature suggests that a strong level of agreement between reviewers is satisfactory and adequate when undertaking systematic

reviews (Banarjee et al., 1999; McHugh, 2012). Any differences between reviewers were discussed until an agreement between reviewers was reached. The second reviewer also offered some support when data was being extracted from papers which were included in the final sample. This happened when the first reviewer experienced uncertainties in interpreting any statistical findings and the ways in which studies analysed their data.

#### **1.3.4 Quality appraisal of studies**

A hypothetical benefit of undertaking and analysing robust quantitative research is that it can yield generalisable results depending on the satisfaction of a multitude of complex research conditions. The quality of research can be assessed against a set of criteria defined within appraisal tools which were developed to suit different methodological designs (Higgins and Green, 2011). The quality of articles included in this review were assessed following data extraction. One benefit of doing so is being able to remain blind to study quality making it less likely to be biased when reporting findings (Boland, Dickson & Cherry, 2017).

The Downs and Black Checklist (Downs & Black, 1998) is a quality assessment tool developed to evaluate randomised and non-randomised studies within health care. The checklist examines studies by answering 27 questions across four different domains including reporting, external validity, internal validity or selection bias, and power. Response options for most questions include “Yes” or “No”, with a small number of questions also providing the option of “Partially” or “Unclear”. Each answer is awarded a score where: yes = 2 or 1, no = 0, partially = 1, unclear = 0. The statistical power domain is rated on a scale of 0 to 5 points. Score ranges are assigned varying levels in terms of their quality as previously reported by Hooper and colleagues (2008): excellent (26-28), good (20-25), fair (15-19), and poor ( $\leq 14$ ).

#### **1.3.5 Analysis**

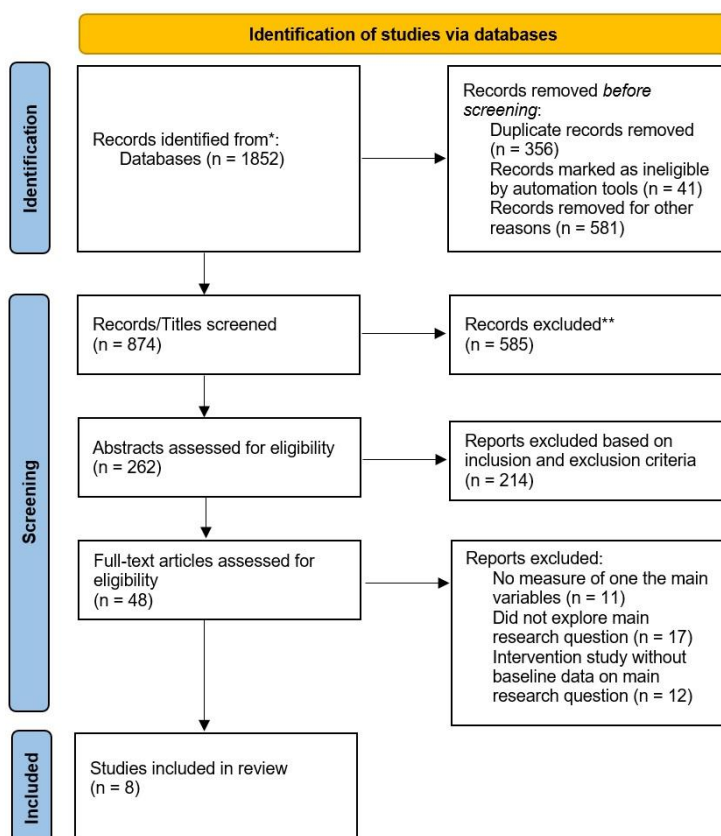
As the studies were highly heterogeneous narrative synthesis appeared to be most appropriate in terms of analysing and presenting the results of studies with varying methodological designs. The review findings were analysed and reported based on the Synthesis Without Meta-Analysis (SWiM) guideline developed by Campbell and colleagues (2020). The SWiM guidelines were established following criticism in the research community that many systematic reviews which reported narrative synthesis of quantitative data lacked in transparency, and therefore can render the validity of findings questionable (Campbell et al.,

2019). The results and presentation of findings is guided by the PRISMA guidelines (Moher et al., 2015; Page et al, 2021).

## 1.4 Results

The search yielded 1852 results from which duplicates, book extracts, conference materials and dissertation reports were removed to give 1167 records. The search engine also allowed me to exclude publications which were not written in the English language, resulting in 874 records. All titles were screened and articles from unrelated fields were removed, leaving a total of 262 records. The abstracts of all remaining publications were screened and those that did not meet the inclusion criteria were excluded. If unable to decide based on the abstract, the full article was reviewed. Through this method, 48 full articles were read, of which 8 satisfied the inclusion criteria and were therefore included in the review. The reference lists of all included articles were reviewed, however no new articles were added to the final number. **Figure 2** depicts a flowchart of the selection process.

**Figure 2.** The PRISMA flow diagram detailing steps in the study selection process.



### 1.4.1 Characteristics of included studies

Eight studies were included in the review. The countries of research included Canada ( $n=4$ ), USA ( $n=2$ ), Netherlands ( $n=1$ ), and a collaboration between the USA and the UK ( $n=1$ ). Sample sizes ranged between 78 and 667 and participants' mean age ranged from 33.88 to 50.71. Where relevant, the mean age of participants' children ranged from 2 to 20 years old. A summary of the characteristics of all included studies can be found in **Table 1**. Each study was assigned a unique reference number and will be referred to by its allocated number hereafter.

### 1.4.2 Description of research studies

All studies included in the systematic review have a quantitative methodology ( $n=8$ ) which is in line with the inclusion and exclusion criteria outlined in the previous section. The papers included correlational  $n=3$  (studies 3, 4, 7), intervention  $n=2$  (studies 5, 6), and group comparison designs  $n=3$  (studies 1, 2, 8). All studies utilised self-report questionnaires ( $n=8$ ) either cross-sectionally ( $n=6$ , studies 1, 2, 3, 4, 7, 8) or at multiple points in time ( $n=2$ , studies 5, 6), and one study included a semi-structured clinical interview (study 6).

The studies recruited participants via local clinics (3, 4, 7, 8), schools (5, 6, 7), research centres and university research groups (2, 3, 8), and online, newspaper or community centre ads (1, 3, 4, 5, 7). Two studies (1, 2) recruited mothers only, with the remainder of studies (3, 4, 5, 6, 7, 8) recruiting both mothers and fathers to their participant samples. In one of the studies (8) both parents from the same family were recruited to the sample. Most of the studies (1, 2, 3, 4, 5, 6, 7) recruited participants with varied cultural identities such as English-speaking/American, Spanish/Hispanic, African, Chinese, French, with only one study (8) recruiting participants from an entirely European Caucasian descent. Where this was explored and reported (studies 1, 2, 3, 4, 6, 7), a significant majority of parent participants appeared to be married or partnered, in employment, and educated to a high-school graduate or university bachelor's degree level. Only one study (8) explored and reported factors related to ASD in parent participants, and five studies (1, 2, 3, 6, 8) explored factors related to parental mental health status such as depression.

In terms of child characteristics, two studies (5, 6) included children of preschool age, one study (7) pre-adolescent school age children, two studies (3, 4) adolescents, and one (8) study

included children from developmental stages between toddler and young adult. Child samples across studies varied in terms of neurodevelopmental profiles. Children were suspected to have or were formally diagnosed with ADHD (studies 2, 3, 4, 5, 6, 7, 8), ASD (studies 5, 6, 8), ADHD and ASD combined (studies 5, 6, 8), or they had no diagnosis at all (studies 2, 3, 4, 7, 8).

Most of the studies included in this review focused on exploring a variety of factors related to parenting children who have ADHD, including personality (1, 2, 6), depression (1, 2, 3, 6, 8), and anxiety (1, 6). Parental neurodevelopmental profile was a variable central to the research question and hypothesis in four studies (1, 2, 5, 8), and only pre-intervention data from the intervention studies (5, 6) were relevant for the purposes of this literature review.

### **1.4.3 Quality assessment and risk of bias**

The risk of bias was assessed and reviewed prior to and during data extraction which aligns with recommendations made by Boland et al. (2017) and Drucker et al. (2016). The data extracted from studies was heterogenous which is the result of different methodologies, population samples, broad research question and study aims, as well as depending on geographical location of studies. The studies included in the review all scored within the good level of quality, with scores ranging from 20 to 25 with a mean score of 22.63. The details of the Downs and Black Checklist (Downs & Black, 1998) for all articles included can be found in Appendix A. Sample sizes across the studies were mostly satisfactory in terms of precision of estimates as well as power where these were relevant, therefore some degree of generalisability of results may be suggestive. Overall, the quality of studies included in the review were of satisfactory quality as their methodologies appeared to be adequately thought through and in line with their research aims. Studies appeared to report methodological steps with clarity and transparency, and results were mostly clearly stated. A significant methodological flaw may be related to studies exploring parent participant samples who do not have a formal diagnosis of ADHD, and I will discuss this further in the discussion section of this report.

**Table 1.** Characteristics of studies included in the systematic review ( $n=8$ )

Study number	Reference; Country of research	Research design and Statistical Analyses	Parenting Stress measures	Parental ADHD measures	Sample Size	Parent Mean age	Child age
1	Williamson & Johnston (2019); Canada	Cross-sectional study; Group comparison design; Bivariate correlations & mediation analyses	Parenting Stress Index Short Form (PSI-SF); Parental Stress Scale (PSS) items; 7 vignettes drawn from Written Analogue Questionnaire (WAQ)	Barkley Adult ADHD Rating Scale IV (BAARS-IV)	120	33.88	
2	Algorta et al. (2018); USA and UK	Cross-sectional study; Group comparison design; Hierarchical regression analyses: used data from previous RCT with multi-year follow up	Parenting Stress Index Short Form (PSI-SF); composite score of Distress and Dysfunctional Interaction scales	Conners Adult ADHD Rating Scale (CAARS)	667	Mothers of children with ADHD 39.03 Mothers of children without ADHD 36.28	
3	Biondic et al. (2019); Canada	Cross-sectional study; Correlational design; Two-tailed t-tests to compare ADHD and comparison groups; Pearson product-moment correlations calculated & four step-wise multiple regression analyses	Stress Index for Parents of Adolescents (SIPA); Adolescent-Focused Stress (AFS); Parent Domain Stress (PFS)	Conners Adult ADHD Rating Scale (CAARS)	130	ADHD group - mothers 48.34, fathers 50.03 Comparison group - mothers 48.87, fathers 50.35	13 to 18 years old
4	Wiener et al. (2015); Canada	Cross-sectional study; Correlational design; Two-way ANOVA for groups comparison; MANOVA with post hoc comparisons for parents in both groups on subscales within adolescent and parent domains (mothers and fathers separately); predictors of maternal and paternal stress examined with Pearson correlation and hierarchical regression	Stress Index for Parents of Adolescents (SIPA)	Conners Adult ADHD Self-Report Rating Scale- Short Version (CAARS-S:S)	78	ADHD group - mothers 47.62, fathers 49.6 Non-ADHD group - mothers 48.69, fathers 50.71	13 to 18 years old

5	Ros-deMarize et al. (2022); USA	Longitudinal study; Intervention design; Independent regressions controlled for pre-treatment levels of the outcome variable: bivariate correlations	Parenting Stress Index (PSI)	Adult ADHD Self Report Scale (ASRS)	233		Mean age 4.97
6	Dale et al. (2022); USA	Longitudinal study; Intervention design; Multi-informant, multi-method approach to assess parent, family, and child pre-treatment factors: Latent Profile Analysis	Parenting Stress Index- Revised (PSI-R)	Assessment of Adult Attention Deficit Hyperactivity Disorder (AAA) - clinical interview	164		Mean age 3.57
7	Theule et al. (2011); Canada	Cross-sectional study; Correlational design; Hierarchical multiple regressions to predict parenting distress	Parenting Stress Index Short Form (PSI-SF)	Conners Adult ADHD Rating Scale (CAARS)	95	41.64	8 to 12 years old Mean age 10.10
8	van Steijn et al. (2015); Netherlands	Cross-sectional study; Group comparison design; ANOVA; Structural equation modelling to estimate best fitting model	Parenting Stress Index Short Form (PSI-SF)	Conners Adult ADHD Rating Scale (CAARS)	348		2 to 20 years old

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#### **1.4.4 Narrative synthesis**

A summary of the narrative synthesis of systematic literature review findings can be found in **Table 2**.

##### **1.4.4.1 Parenting stress and parental ADHD**

Six out of eight studies (80%; studies 1, 2, 3, 4, 7, 8) suggest that parents with higher scores on ADHD measures tend to report high levels of parenting stress; although one study found a positive, but not statistically significant correlation between parental ADHD and parenting stress (6). Three studies (37.5%; 3, 4, 8) suggested a positive correlation between maternal ADHD and maternal stress, whereas paternal ADHD and paternal stress were negatively associated (4, 8). Paternal stress was also associated with maternal ADHD symptoms and maternal depression (3). One study did not find a significant relationship between parental stress and ADHD (5) in the pre-treatment phase even though following intervention they reported that parental ADHD symptoms predicted higher parenting stress for parents of children with ASD.

##### **1.4.4.2 Mediating and moderating factors – parent, child, situational**

A number of additional factors played a role in the relationship between parenting stress and parental ADHD. In terms of parent-related factors, one study (12.5 %; 1) found that parenting self-efficacy beliefs significantly mediated the relationship between parenting stress and parental ADHD symptoms. While three studies (37.5%; 1, 3, 8) showed that parental mental health symptoms (e.g. anxiety, depression) related to parenting stress in a similar way to parental ADHD symptoms, two studies (25%; 5, 7) did not find a significant correlation between parent variables and parenting stress or parental ADHD. One study (12.5 %; 2) identified that conscientiousness was negatively associated with parenting stress for mothers of children without ADHD, but not mothers of children with ADHD. Finally, one study (12.5%; 8) showed that paternal ASD and ADHD symptoms had a direct effect on parenting stress, as well as parental ADHD in both mothers and fathers had an effect on depressive symptoms and in turn on parenting stress.

In terms of child-related factors, four studies (50%; 2, 3, 4, 5) showed that having a child with ADHD was associated with higher levels of parenting stress, especially when parenting adolescents (3), or when mothers experienced high levels of parental ADHD symptoms (2). One study (12.5%; 5) showed that mothers of children with ADHD reported more parenting stress compared to fathers, however both parents experienced high stress when their child had ADHD

and ASD. There was also a strong association of stress with oppositional defiance disorder symptoms as demonstrated by one study (12.5%; 4). Nonetheless, one study (12.5%; 7) reported that child factors did not predict parenting stress over and above other contextual factors, and one study (12.5%; 5) did not find a significant association between child factors and the variables of interest.

Upon exploring contextual and environmental factors, one study (12.5%; 5) found an association between parental education level and parenting stress, where parents with lower education level reported higher parent stress. However, another study did not find a correlation between parent education and parenting stress (12.5%; 7). One of the studies (12.5%; 7) reported that parents with higher levels of ADHD symptoms and lower levels of social support tended to report more parental stress. Another study (12.5%; 2) showed no significant effect of marital status.

**Table 2.** Narrative synthesis summary of systematic review findings

Study number	Reference; Country of research	Parental ADHD and Parenting Stress – statistic	Child-related factors (mediators/moderators)	Parent-related factors (mediators/moderators)	Environment-related factors (mediators/moderators)
1	Williamson & Johnston (2019); Canada	Maternal ADHD symptoms moderately related to parenting stress at levels $\beta = .30$		Parenting self-efficacy beliefs significantly mediated relationship between parenting stress and ADHD; maternal psychological symptoms (i.e., depression, anxiety, and hostility) were related to parenting self-efficacy beliefs and parenting stress similarly to maternal ADHD symptoms	
2	Algorta et al. (2018); USA and UK	Significant interactions observed on inattention/cognitive problems $\beta = -.73$ , 95% CI = [-1.29, -.16]; and hyperactivity/restlessness $\beta = -.70$ , 95% CI = [-1.28, -.11]	Having a child with ADHD and the mother having a high level of ADHD symptomatology were associated with high levels of parenting stress	Conscientiousness was negatively associated with parenting stress for mothers of children without ADHD $\beta = -8.04$ , 95% CI [-12.68, -3.39] but not mothers of children with ADHD $\beta = 0.24$ , 95% CI [-2.78, 3.27]; maternal stress is already high by having a child with ADHD combined-type that it is not increased further by maternal ADHD symptomatology	No significant effect of marital status
3	Biondic et al. (2019); Canada	Mothers' self-reported ADHD Index scores positively correlated with maternal adolescent-focused stress $r = 0.51$ , $p < .001$ and parent-domain stress $r = 0.42$ , $p < .001$ ; paternal adolescent-focused stress $r = 0.37$ , $p < .05$ and parent-domain stress $r = 0.32$ , $p < .05$ positively correlated with maternal ADHD, paternal adolescent-focused stress correlated with and maternal depression $r = 0.36$ , $p < .05$	Mothers $d = 1.36$ and fathers $d = 0.68$ of adolescents with ADHD reported higher adolescent-focused stress than parents of adolescents without ADHD; no significant differences in parent-domain stress, mothers: $d = 0.45$ & fathers: $d = 0.00$	Mothers' $r = 0.57$ , $p < .001$ and fathers' $r = 0.42$ , $p < .01$ parent-domain stress was correlated with depression symptoms	
4	Wiener et al. (2015); Canada	Maternal ADHD symptoms and maternal stress $R^2 = 0.38$ , $F(3, 101) = 20.86$ , $p < .001$ ; paternal ADHD symptoms and	Mothers $F(4, 129) = 21.40$ , $p = 0.001$ , $\eta^2 = 0.40$ and fathers $F(4, 92) = 7.36$ , $p = 0.001$ , $\eta^2 = 0.24$ of children with		

		paternal stress were negatively associated $R^2=0.08$ , $F(2,94)=4.38$ , $p=.02$	ADHD reported significantly more stress - strong association with oppositional defiance disorder symptoms		
5	Ros-deMarize et al. (2022); USA	No significant result, not explicitly reported a statistic; post-treatment parental ADHD symptoms predicted higher parenting stress for the ASD and EBP intervention group	Child variables (e.g. age) were not significantly associated with variables of interest	Parent variables (e.g. gender) were not significantly associated with variables of interest	Associations between parental education level and parenting stress, parents with lower levels of education tended to report higher levels of parent stress at pre-treatment $r = -0.23$ , $p < 0.05$
6	Dale et al. (2022); USA	Parental ADHD and parenting stress positively correlated but not significant $r=.144$ , $p>.05$			
7	Theule et al. (2011); Canada	Parent and contextual factors explained an 25% of the variance in parental distress over and above child factors, $R^2\Delta = .25$ , $F(5, 86)$ , $p < .001$	Child factors did not predict parental distress over and above parent and contextual factors, $R^2\Delta = .03$ , $F(3, 86)$ , $p = .22$ .	No significant correlation between parent age and education and parenting stress	Parents with higher levels of ADHD symptoms and lower levels of social support tended to report more parental distress
8	van Steijn et al. (2015); Netherlands	Maternal ADHD (not paternal ADHD) symptoms appeared to have a direct effect on parenting stress	Mothers of affected children reported more parenting stress than did the fathers of children with ASD $t(45) 2.00$ , $p = .05$ or ADHD $t(63) 2.75$ , $p = .01$ ; this difference was not seen in families with children with ASD/ADHD $t(53) .40$ , $p = .69$	Paternal ASD (not maternal ASD) and ADHD symptoms appeared to have a direct effect on parenting stress. In both fathers and mothers, ADHD symptoms (not ASD symptoms) had an effect on depressive symptoms and in turn on parenting stress	

## 1.5 Discussion

The present systematic review provides an overview of the literature published to date with regards to the relationship between parenting stress and parental ADHD symptoms. The systematic review findings point towards a somewhat complex and mixed picture when attempting to understand how the two main variables interact. It is important to note that the relationship between parenting stress and parental ADHD was examined to varying degrees by all the studies included in this systematic review, and this was dependent on the papers' primary aims and methodological designs. Furthermore, the central research question explored in this review was also focal for only half of the studies included. The level of significance of this finding varied between studies, where some reported a strong or moderate correlation, while one showed a small non-significant correlation. This points us towards the notion of other factors that play an important role in the interaction between the variables of interest. As highlighted by Williamson & Johnston (2019), ADHD symptoms alone may not be sufficient in understanding the experience of parenting. Parenting stress is likely mediated and moderated by other additional processes, which could be broadly categorised as parent, child, and situational factors (Abidin, 1983). Additionally, it may be that positive aspects of adult ADHD (Lesch, 2018; Sedgwick et al., 2019; Mahdi et al., 2017) further mitigate the amount of stress that parents experience when parenting their children.

Broadly summarising, the results of this review propose that when parents score higher on ADHD-related measures, they tend to report feeling more stressed when parenting their children. This may mean that when parents are experiencing more ADHD-related symptoms, they may also experience higher levels of parenting stress. The studies included in this review also suggest the presence of other influential factors or conditions where this interaction was observed and significant. For example, some papers highlighted differences between mothers' and fathers' ADHD symptoms and their experience of parenting stress. The findings suggest that when mothers report higher scores on ADHD measures, they tend to experience higher levels of parenting stress, however the opposite is true for fathers (Wiener et al., 2015; van Steijn et al., 2015). Fathers tended to report feeling more parenting stress when their partner experienced more ADHD symptoms. Additionally, when fathers had ADHD and ASD symptoms, they reported feeling more stressed when parenting their children. In terms of similarities, ADHD symptoms for both fathers and mothers increased their depressive symptoms which in turn impacted on parenting stress (Biondic et al., 2019; van Steijn et al., 2015). These findings might indicate that

the relationship between mothers' and fathers', their broader functioning ability, and their roles within the family may influence parents' experience of parental stress.

### **1.5.1 Parent Factors**

It is not entirely clear what may be driving these gender differences, however it is possible that mothers and fathers fulfil different roles in the day-to-day functioning of their families (Bianchi & Raley, 2005; Parke, 2000). For example, mothers may be more likely to have more responsibilities that relate to planning and monitoring their children's activities (Parke, 2000, Pleck & Masciadrelli, 1997; Weiner et al., 2016). Therefore, when mothers experience more ADHD symptoms, they might become more stressed as they try to navigate parenting tasks independently or with less support from their spouse. This is in line with suggestions made by Johnston et al. (2012), pointing towards the idea that difficulties with executive functioning and emotion regulation associated with ADHD in adults can in turn impact their parenting practices. Nonetheless, Cabrera and colleagues (2018) suggest that how fathers engage with and develop their parenting is likely influenced by a complex interaction between individual, social, cultural, and ecological factors. Historically, mothers have been more likely to spend more time at home with the children while fathers took responsibility for financially supporting the family, however recent socio-economic changes, especially in Western societies, suggest an increased number of women in the labour force (ILO, 2017).

According to some researchers (Cabrera et al., 2018; Fagan et al., 2014), there has been a lack of integration of fathers into the parenting literature, and two of the studies included in the review focused specifically on mothers only. It is possible that given this historical context, researchers still engage in assumptions about fathers' role in parenting and family dynamics (Cabrera et al., 2018) which in turn can influence how research into parenting is conceptualised and methodologically approached, perpetuating a less up-to-date understanding of family functioning models (Diniz et al., 2021). Such biases in sampling may be related to assumptions around reduced paternal presence in family homes, or perhaps fathers do not take part in family studies or parenting interventions as readily as mothers. A literature review by Diniz and colleagues (2021) called for the systematic integration of broader social, cultural and ecological factors given the vast diversity of family ecosystems.

In light of some researchers' call for further exploration of the positive aspects of ADHD, it is also important for future research to consider ways in which parental ADHD may influence parenting positively. It is possible that some of the differences between mothers and father

identified by this review could be explained to some extent by compensatory strategies associated with ADHD helping parents to review levels of parenting stress. It is possible that parents' ADHD provides them with an additional source of energy and hyperfocus, as well the ability to be creative with their parenting methods, however there is no research which explores this.

The role of depressive symptoms in parents was also highlighted by the current review, with some articles concluding that, in a similar way to ADHD symptoms, when parents experienced elevated levels of depression, they tended to experience more parenting stress. Research exploring the links between maternal depression and parenting stress appears to be dominating the literature (Farmer & Lee, 2011; Mason et al., 2011; Riva Crugnola et al., 2016; Shin & Kim, 2010). It has been previously suggested that stresses associated with parenting directly link with maternal depression (Farmer & Lee, 2011), however the papers in the current review were not able to comment on the direction of the correlation between variables. One suggested explanation points towards a shift in responsibilities from mothers to fathers when mothers are particularly affected by ADHD, leading to elevated stress and depression symptoms in fathers. It is unclear whether this is actually the case, and this is something that has not received much of researchers' attention previously. One study in this review also explored the impact of maternal conscientiousness on parenting stress and found that it can have a protective influence, identifying that perhaps there are also personality factors that are important. As previously mentioned, the notion of individual factors alongside broader socio-ecological factors has not been fully and methodically explored (Diniz et al., 2021). The current review recommends further explorations in the domain of parent factors in parenting stress as it highlights a gap in our scientific understanding of the interplay between factors associated with parental roles within diverse family systems. Qualitative research methodologies may offer an in-depth exploration and analysis of this complex topic.

### **1.5.2 Child factors**

Perhaps unsurprisingly, the review results highlight the role of child-related factors in mediating the relationship between parental ADHD and parenting stress. Some of the included studies identified that having a child with ADHD and high level of parental ADHD symptoms (especially in mothers) were associated with higher levels of parenting stress. The findings also propose that other child presentations such as ASD and oppositional or externalising behaviours can also significantly influence parents' experience of stress when parental ADHD is also elevated.

One of the included studies proposed that maternal stress is already likely to be high due to having a child with ADHD, and that parental ADHD symptoms do not appear to increase stress further. This is in some ways consistent with idea that parenting children who experience difficulties related to congenital or acquired conditions is more challenging and therefore more stressful for parents (Barroso et al., 2018; Cousino & Hazen, 2013; Neece et al., 2012; Solem et al., 2011; Tsotsi et al., 2019). It is also evident that there has been a dominant focus on exploring how child presentations relate with parenting stress, with less attention being paid to parent-related factors, creating a somewhat child-pathologizing narrative in the scientific literature. This has remained the case even though there are some research findings to suggest that perhaps parent-related factors play a greater role in mediating and moderating parenting stress compared to child-related factors (Theule et al., 2011).

Furthermore, some of the current review studies reported that child-related factors did not predict parenting stress over and above parent and situational or contextual factors. As previously suggested, it is likely that the interplay between factors from the different domains (parent, child, situational) can explain the mixture of findings, specifically that challenges related to child presentation do not always result in more parenting stress when parents have elevated ADHD symptoms. There have been intervention studies focusing on both children (Evans et al., 2018; McGoey et al., 2002) and parents (Coates et al., 2015; Sonuga-Barke et al., 2002) which showcase a favourable outcome in terms of reducing parenting stress.

### **1.5.3 Situational factors**

Even though contextual factors appeared to be explored less by the included studies, the current review findings suggest that situational factors may also play an important role in the relationship between parenting stress and parental ADHD. One of the studies identified that social support was a predictor for parenting stress when parents experienced high levels of ADHD symptoms. This finding is consistent with reports in the literature about the negative association between parenting stress and parents' perceptions around social support (Riany & Ihsana, 2021; Theule et al., 2011). Previous research has also identified that when parents are more socially supported and they are experiencing less parenting stress, this seems to impact on their ability to engage with more positive parenting practices of children with and without diagnosable conditions such as ADHD and ASD (Riany & Ihsana, 2021; Taylor et al., 2015). Therefore, it is possible that environmental factors could play an even more important role in the overall experience of parenting, beyond mediating parental stress levels, and directly impacting



children's wellbeing and life outcomes. It is important to note that one of the included studies did not identify a significant effect of marital status which is contrary to previous literature findings (Taylor et al., 2015, Theule et al., 2011, Tomeny et al., 2016).

Finally, one of the included studies identified that parents with lower levels of educational attainment tended to report higher levels of parenting stress. It appears that parental educational level is somewhat less explored within the research literature, however there is some suggestion that parenting stress may be higher in lower (Hughes et al., 2015) and higher socioeconomic brackets (Parkes et al., 2015) compared to intermediate socioeconomic status. It has been reported that this might be the case due to economic hardship in the lower bracket and employment pressure in the high bracket. A study by Parkes and colleagues (2015) reported that mothers who were both least and most educated tended to report higher levels of parental stress. They also identified that migrant single-parents tended to be most affected by parenting stress which is consistent with other research findings (Sepa et al., 2004), however this effect seemed to be mediated by social support such as frequency of contact with grandparents. Once more, this points towards the importance of broader environmental and contextual factors in parenting stress.

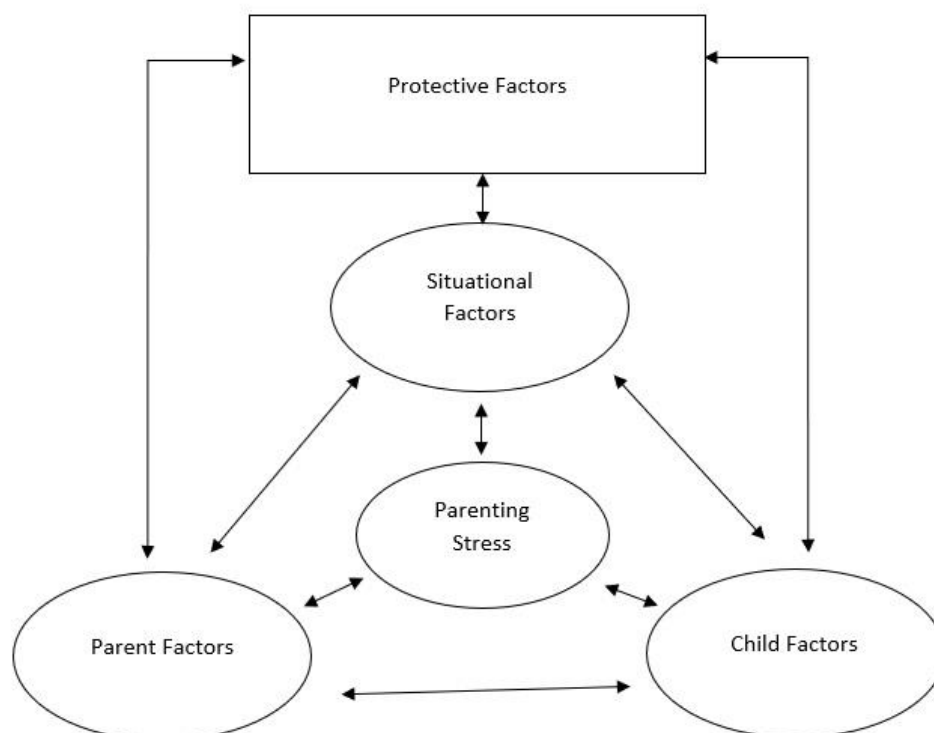
#### **1.5.4 Strengths and limitations of included studies**

Most of the studies included in this review recruited satisfactory sample sizes as well as participants which were culturally representative of local ethnic demographics which appears methodologically appropriate. There is however a potential issue in relation to studies heavily relying on participant self-report measures and the collection of cross-sectional data only. Similarly to previous findings (Diniz et al., 2021), the results of the current literature review suggest that even though studies tended to collect broad and varied data in relation to situational and demographic factors, this data was mostly used to manage biases in relation to sampling.

All of the included studies employed well-researched and validated tools to assess parental ADHD symptoms, however most of the studies did not recruit parent participants who have a formal diagnosis of ADHD, and one study reported that parents' scores on their ADHD self-report measure did not reach a clinically significant threshold. This highlights a potential issue related to generalising conclusions that are fully relevant for parents who have a formal ADHD diagnosis. Furthermore, the studies do not explore the context of parents who may be accessing an intervention for their own ADHD symptoms, for example medication, and therefore it is difficult to know how such interventions may mitigate parenting stress. Future research should focus on

exploring interventions for parental ADHD more specifically. This will allow researchers to hypothesise about the direction of the relationship between parental ADHD and parenting stress. It is important to point out once again that parental ADHD symptoms and parenting stress was a central avenue for exploration for only half of the papers included in this review. Another avenue for future research should focus on exploring the positive aspects of parental ADHD more fully, as the current literature appears to be deficit-focused and often driven by negative consequences of a condition which in reality resides on a spectrum.

It appears that Abidin's (1983) model of parenting stress is still the preferred model for conceptualisation by researchers and a query from this systematic review may be around the need for an updated model. Literature findings appear to closely align with the broad categorisation of parent, child and situational factors, however the lack of consistent findings may highlight the importance of the interaction between factors and their fluid nature. Given that so far there has been a stronger emphasis on exploring child and parent factors, it may be reasonable to suggest that future research should focus on gaining a better understanding of the environmental, socio-situational factors that have so far received significantly less attention by researchers. The current review suggests that a new biopsychosocial model of parenting stress is needed (please see **Figure 3** for a proposal on an updated parenting stress model (Abidin, 1983)). It is possible to hypothesise that an updated model of parenting stress which highlights the interaction between child-parent-environment factors will lend itself more useful in terms of how we conceptualise parenting stress. It may be important that the updated model acknowledges the importance of protective factors and their influence on child-parent-environment factors, for example positive aspects of parental ADHD or consistent access to a wide social support network. An updated model may prove useful when working with other professionals supporting families affected by ADHD. This could in terms have more favourable implications in clinical practice and the work tailored to support those families. By understanding and communicating the important role of situational factors on parents' experience of parenting stress, parents who have ADHD may feel more validated and less blamed, and therefore may be more likely to engage with interventions which emphasise the importance of multiple systemic factors.

**Figure 3.** Updated Parenting Stress Model, adapted by Abidin (1983)

### 1.5.5 Strengths and limitations of this review

To my knowledge, this is the first literature review that seeks to explore the relationship between parenting stress and parental ADHD, thus driving the focus on factors related to parental functioning rather than child psychopathology which appears to be the trend in previous research. Some of the strengths of this review are in relation to the analysing and synthesis of the studies included, in particular the studies that were driven by very different central research hypotheses. The methodological decision to only include quantitative data has its benefits and limitations, as working with large-sampled data from multiple sources tends to yield good generalisable results, however there may be rich contextualising information missed by excluding qualitative accounts on the topic. It also appeared most sensible to synthesise the data through narrative rather than undertake a meta-analysis as the studies included in the review varied in their designs and methodologies. A potential review limitation relates to the low number of

studies included (8 studies in total) therefore caution should be exercised when generalising any findings.

A potential limitation of this review relates to the different stages of study selection, and any missed out papers that may contain relevant data. I devised a robust search strategy with a lengthy list of key search terms which yielded a big number of results, thus the title and abstract selection stage was time consuming and challenging. This screening phase is the most likely stage for selection errors to have occurred. This was managed by carefully thinking about making the best use of a second rater in attempts to minimise the risk of errors and this is a relative strength of this review. As previously mentioned, the majority of research tends to focus on children who have ADHD, meaning that many of the screened articles' method sections had to be reviewed to check whether they met the criterion of including parent participants measures of ADHD. Furthermore, it may have been helpful for the second reviewer to be included in more of the screening stages in order to minimise the risk of missing out relevant research further. A further limitation related to not undertaking reliability checks of the quality appraisal ratings of each of the studies included. It may have been useful for the second rater to undertake quality appraisal of the studies in parallel, and for any difference in scores to be discussed and reviewed.

Another potential limitation may be the choice of quality assessment tool which was perhaps too broad and not always most relevant given the methodological design of some studies. There are some strengths to using the Downs and Black Checklist (1998) as it is a well-researched tool which has good construct validity and given the variety of study designs included in this review it may be that there is no "perfect tool" for the purposes of this review.

## **1.6 Conclusion**

The findings from this systematic review suggest that the relationship between parenting stress and parental ADHD is a complex one, even though there is some indication that elevated parental ADHD may be correlated with higher levels of parenting stress. The review highlights differences between mothers and fathers as well as other important child and situation-related factors. The review identifies that research is perhaps overly focused on mothers' experiences and that there may be need for a more up-to-date model of parenting stress. Finally, it may be counterproductive to try to simplify the relationship between parental ADHD and parenting stress because scientifically as well as anecdotally, the reality of parenting a child while navigating unique individual, family and societal pressures is an immensely complex one.

## Chapter 2 Parents' Experience of their Child Receiving an ADHD Diagnosis in England

### 2.1 Abstract

Parents play a central role in the ADHD assessment and diagnosis of their children. The study explored parents' experiences of their child being assessed for and receiving an ADHD diagnosis. An IPA qualitative methodology was used to interview six parent participants whose children were diagnosed with ADHD in the last 12 months. The interviews were transcribed, and the data analysed. Three superordinate themes were identified: *"surviving" the assessment*, *"every feeling under the sun" – parent emotional experiences*, and *"on the other side" – changes after ADHD diagnosis*. There were seven subthemes which included *"battle" with services*, *effect on family relationships*, *parenting self-efficacy*, *stages of psychological acceptance*, *"I know my child best"*, *knowing what to do next – accessing support*, *hopes for the future*. Participants spoke about the positive and negative aspects of going through the journey of getting their child assessed for ADHD and getting a diagnosis. The study suggests two models of psychological acceptance that may provide a clinically relevant framework representing parents' emotional experiences in relation to their child's ADHD diagnosis. Parents made recommendations to improve service communication and they called for a solution around assessment waiting times. Suggestions for future research were discussed and recommendations for clinical practice are highlighted in relation to assessment waiting times and improving communication with parents and carers.

#### 2.1.1 Key terms

*Parent experiences; Parent perspectives; ADHD assessment; ADHD diagnosis; IPA*

### 2.2 Introduction

According to NHS England (2019), around 3-5% of children in the UK are diagnosed with *Attention Deficit Hyperactivity Disorder (ADHD)*, it is more commonly found in boys than in girls (4:1), however, there is some evidence to suggest that ADHD is under-recognised in girls (Chronis-Tuscano, 2022). Currently, specialist NHS services only treat 0.5% of affected young people (NHS England, 2019). Based on the National Institute for Health and Care Excellence (NICE) guidelines, *ADHD assessments* for children and young people involve the collection of extensive information

from multiple sources, including home and school reports, and observations within a clinical context. For a *diagnosis* to be reached, a full developmental and mental health history has to be taken, typically with a parent or primary caregiver (NICE, 2019). Parents play a central role in the ADHD assessment process, however, little is known about their experiences during assessment and at the time of diagnosis. The aim of the current study is to explore *parents' experiences* of their child being assessed for and diagnosed with ADHD.

### **2.2.1 Stigmatisation of parents of children with ADHD**

A study undertaken by DosReis and colleagues (2010) explored stigmatising experiences of parents of children with a new ADHD diagnosis. The study employed Grounded Theory qualitative methodology whereby the researchers remain grounded in their knowledge of the published literature, aiming to refine or extend previous findings. The study recruited 48 participants who were interviewed a month after their child received an ADHD diagnosis and interview questions were specifically developed to examine parents' experiences of stigma in relation to their child's ADHD diagnosis and treatment. The study identified six major themes in the data: concerns with ADHD label, feelings of social isolation and rejection, perceptions of a dismissive society, influence of negative public views, exposure to negative media, and mistrust of medical assessments (DosReis et al., 2010). The paper concluded that stigma related to ADHD diagnosis is a complex issue experienced differently across families, nonetheless, the findings suggested that parents felt most judged by others in relation to their child taking ADHD medication. It is important to note that the paper conceptualised ADHD as a paediatric mental health condition, therefore some of the interpretation of findings was aligned with literature on stigmatisation of children's mental health difficulties. There is an ongoing debate regarding ADHD's aetiology (Pajo & Cohen, 2013), however, the DSM V (2013) categorises ADHD as a neurodevelopmental disorder as opposed to a mental health disorder.

### **2.2.2 Pharmacological ADHD interventions**

Other previous research has focused on exploring parents' attitudes towards psychopharmacological interventions following their child's ADHD diagnosis (Berger et al., 2008; Davis et al., 2012; Travell & Visser, 2006). One study identified that parents were suspicious and apprehensive towards methylphenidate treatment, and that this was influenced by being exposed to negative information about medication prior to treatment starting (Berger et al., 2008). The paper concluded that the most effective factor which influenced parents' attitudes towards

medication was the assessing physician's explanation about treatment. Another study examined parents and their children's perspectives on ADHD symptoms, behaviour, diagnosis, and treatment (Travell & Visser, 2006). The paper identified that individual family circumstances vary greatly and therefore perceptions of ADHD are complex, however, they also noted that parent experiences were influenced by early intervention and support, as well as by school attitudes. The study recommended that services focus on implementing early interventions and support for families affected by ADHD. Furthermore, Davis and colleagues (2012) explored families' perspectives on ADHD treatment and decision-making processes, the cause and impact of their child's symptoms, and the treatment goals and preferences. Their findings suggest that parents prefer to be primary or shared decision-makers regarding treatment (Davis et al., 2012). They also found that parents had different perspectives on their child's symptoms which often did not match the diagnostic framework (Davis et al., 2012). Attitudes towards treatments were mixed, with some indication that parents were interested in interventions outside of guideline recommendations, for example by changing their child's diet.

### **2.2.3 Cultural and demographic factors**

Some research studies have explored cultural and demographic factors that may influence parents' perceptions about ADHD (Bauermeister et al., 2010; Singh, 2003; Slobodin & Masalha, 2020; Timimi & Taylor, 2004). A qualitative study by Singh (2003) explored the difference between mothers' and fathers' attitudes about their children's ADHD. The findings suggested that fathers' views could be broadly categorised along two dimensions – "reluctant believers" and "tolerant non-believers". Singh (2003) spoke about fathers' identifying with their children's behaviours and concluding that what they observed was typical, and the paper recommended that researchers should aim to design studies that are inclusive of fathers as they seem to be under-represented in the ADHD literature. A systematic review by Slobodin & Masalha (2020) found differences in ADHD detection and quality of care for children from ethnic minority background. They concluded that the differences reflect the cultural diversity in attitudes towards mental health, as well as barriers to accessing the right support from qualified clinicians (Slobodin & Masalha, 2020). They queried whether cultural differences in terms of language and behaviour may lead to over-diagnosis of ADHD in children from ethnic minority backgrounds.

#### **2.2.4 Adults' experiences of receiving an ADHD diagnosis**

There are some qualitative studies that explore adults' experience of receiving an ADHD diagnosis (Brod et al., 2012; Hansson Halleröd et al., 2015; Schrevel et al., 2016). Previous literature findings have been mixed, with some research suggesting that adults' experiences are mostly positive as diagnosis provided an explanation for "unexplained" past experiences (Hansson Halleröd et al., 2015). Research has suggested that adults gain self-knowledge and value from an ADHD diagnosis but also a sense of concern about their identity (Hansson Halleröd et al., 2015; Brod et al., 2012). Adults also identified a wish for a diagnosis to have been reached earlier in their lives (Hansson Halleröd et al., 2015). Other findings suggest that adults perceived that their ADHD symptoms affected them socially, and there was a sense of powerlessness and poor self-image (Schrevel et al., 2016).

#### **2.2.5 Research aims**

The existing literature suggests that parents' experiences of their child receiving an ADHD diagnosis are likely affected by multiple factors related to culture and stigmatisation, as well as their attitudes towards pharmacological approaches to treatment. It is unclear how these findings relate to the current NHS context. Given the rise in demand for ADHD assessment and diagnosis (Smith et al., 2018), it may be that there are less concerns about diagnostically "labelling" children and that diagnosis is perceived to be helpful, therefore sought after by parents.

The current study aims to explore parents' experiences in relation to their children receiving an ADHD diagnosis in England, given the gap in the literature looking into this issue. No previous research has explored parents' perspectives. Having worked with parents going through the ADHD assessment and diagnosis process in an NHS service in England, I recall at times thinking that they felt blamed for their child's difficulties, and this seemed to impact on them psychologically. This made me wonder about any particular psychological acceptance or adjustment processes which may occur for parents, for example similarly to those of parents of children diagnosed with Autism (Fernández-Alcántara et al., 2016). As my interest piqued and I identified a lack of relevant literature to aid my clinical work, I felt it was appropriate to explore this topic as part of my clinical doctorate training. It is important to undertake this research as it may have significant implications for children's development, given the non-negotiable role that parents play in the process.



The study design employs a qualitative methodology which is in line with the exploratory nature of this topic, and therefore, there are no pre-determined research hypotheses prior to undertaking the study. The study aims to examine parents' psychological and family experiences in relation to ADHD assessment and diagnosis, for example what the diagnosis has meant for them and their child, the benefits and challenges associated with this. In terms of clinical utility, the project identifies information relevant to NHS services, exploring implications in terms of family support and follow-up interventions. Future directions for research are also explored.

## **2.3 Method**

### **2.3.1 Study design**

A qualitative research framework was used in order to explore the subject in a way that might challenge preconceived assumptions as well as highlight lived-experience phenomena that have not been identified by previous research (Salmon, 2013). This project employed Interpretative Phenomenological Analysis (IPA) (Smith et al., 1999; Hefferon & Gil-Rodriguez, 2011) as it considers the participants' personal perception and accounts of events while it acknowledges that the interviewing process is dynamic. IPA assumes that the interviewer is not entirely able to separate their own perceptions of the world (Smith & Osborn, 2003), hence the researcher engages in a 'double hermeneutic' as the researcher is making sense of participants' meaning making (Larkin et al., 2021). This notion also fits with my own social constructionist position and epistemological approach to undertaking this research project, as I have focused on how participants talk about their world and experiences, constructing their own realities through language which is dependent on sociocultural and historical processes (Eatough & Smith, 2008; Willig, 2012).

It felt important and most appropriate to use IPA for the purposes of this study, as I was aware that I am embarking on a potentially highly sensitive topic for parents and therefore the design of the study needed to allow for an in-depth analysis of interviews. Where more traditional Thematic Analysis (Braun & Clarke, 2006) tends to employ 12 participants or more, IPA typically recruits less participants whose data gets analysed more intimately and this felt appropriate with this topic. Given the novelty of the research area at hand, Grounded Theory qualitative methodologies were considered inappropriate as they remain rooted in previous research findings and aim to extend existing scientific knowledge. Furthermore, given my own personal experience with the topic, it also felt important to opt for design methodology which aided the

process of interpretation of findings by acknowledging and working with my personal biases advantageously.

### **2.3.2 Position Statement**

In the spirit of double hermeneutics and in attempts to acknowledge the potential contribution of my own experiences and bias, it is important to note that I am a thirty-one-year-old white Eastern European woman, who does not have children and is due to get married later this year. I have worked with families and young people affected by neurodevelopmental conditions prior to and during clinical psychology training, both in the National Health Service (NHS) and in the private sector. I also suspect that I may be to some degree neurodiverse, and Autism and ADHD can be found in my own family. By keeping a reflective log, I attempted to identify my own preconceptions when interpreting participant stories, and I discussed those reflections alongside the data with my thesis supervisors. For a more detailed summary of my own reflections during different phases of the study, please go to the field notes in Appendix B.

### **2.3.3 Participants and recruitment**

Posters advertising the study were used to recruit participants from across England. In the initial phases of recruitment, I contacted community organisations which specialise in supporting families and children with ADHD and information about my study was forwarded to members of those organisations. As the response rates were low, I also advertised my study via social media platforms and word of mouth. As prospective participants enquired about the study, an information sheet (Appendix C), consent form and brief questionnaire (Appendix D) were sent out via email for them to complete. Based on responses from the brief questionnaire which asked participants basic information about their child's ADHD assessment, age and diagnoses, a decision was made to proceed with an interview. Parents were included in the study if they were over 18 years old and the child received an ADHD diagnosis within the last 12 months. A diagnosis had to be reached within the last 12 months to allow the exploration of experiences that occurred relatively recently. There were no other exclusion criteria. Following completion of consent form and questionnaire, a meeting was set up for an online interview via the Microsoft Teams platform. After interview, participants were sent a debrief form (Appendix E) as well as a £25 Amazon voucher to thank them for taking the time to take part in the research project.

I recruited six parents of children diagnosed with ADHD in the last 12 months using a purposive sampling strategy (Palinkas et al., 2015; Etikam et al., 2016). A benefit of purposive

sampling, also known as judgement sampling, is the deliberate choice of participants based on qualities they have (Etikam et al., 2016) in order to collect the richest, most relevant and trustworthy data on the research topic (Campbell et al., 2020). For the purposes of the current study, I decided that it was important to include both mothers ( $n=3$ ) and fathers ( $n=3$ ) as I wanted the findings to be representative of both genders, and it has been suggested that historically, the parenting literature has predominantly focused on mothers (Cabrera et al., 2018). I also recruited participants with varied family constitutions and ethnicity (White British  $n=4$ ; Black African  $n=1$ ; Black British  $n=1$ ) as I was interested in whether factors related to culture, family and social support played a part in parents' experiences as their child was being assessed and consequentially diagnosed with ADHD. I did not specifically select parents based on their employment status or family diagnostic profiles, and interestingly most participants were in full-time employment ( $n=5$ ) with only one parent working part-time ( $n=1$ ). Most participants reported no diagnostic history of mental health or neurodevelopmental conditions ( $n=4$ ), and two participants shared a first degree relative other than the index child being diagnosed with ADHD ( $n=2$ ). Participant ages ranged between 29 and 40 with a mean age of  $M=33.5$ . All participants ( $n=6$ ) live in England, UK. Please see **Table 3** for more details on participant demographics and family history, the names of each participant have been changed to protect their identities.

**Table 3.** Participant demographics and family history

Participant	Age	Ethnicity	Gender	Employment	Family Diagnoses	Family status
Julia	33	White British	F	Full-time	None	Civil partnership - stepfather, three children
Ben	33	White British	M	Full-time	None	Married - one child, no siblings
Abi	40	White British	F	Full-time	None	Married (same sex couple) - one child (IVF baby), no siblings
Simone	40	White British	F	Full-time	None	Married - one child no siblings
Oumar	29	Black African (Senegal)	M	Part-time	Participant's brother (ADHD)	Married - two children
Christopher	32	Black British	M	Full-time	Participant's father (ADHD)	Single father - one child, no siblings

I also decided that it was important to recruit participants whose children were assessed and diagnosed via an NHS service ( $n=2$ ), private sector organisation ( $n=2$ ), or a mixture of both ( $n=2$ ). Two children ( $n=2$ ) who were assessed by private sector organisations were referred to these services and funded for the assessment by an NHS CAMHS service. Two children ( $n=2$ ) who were originally assessed by a private sector organisation had their assessments contested by an NHS CAMHS service, resulting in aspects of the assessment being completed and diagnosis being confirmed by the NHS CAMHS service. In terms of child characteristics, I thought it was important to interview parents whose children had ADHD only ( $n=2$ ) as well as parents whose children had other neurodevelopmental conditions such as Autism ( $n=4$ ) given the common comorbid presentation in children (Francés et al., 2022). I did not selectively recruit based on child gender, and interestingly most participants' children were boys (boys,  $n=5$ ; girls  $n=1$ ). Participants' children were mostly in mainstream school full-time ( $n=5$ ), with only one child being home schooled ( $n=1$ ), and three of the children that were in school had previously experienced periods of being out of school or being on a reduced timetable. Child ages ranged between eight and 13 with a mean age of  $M=10.5$ . Please see **Table 4** for more details on child demographics and ADHD assessment history.

**Table 4.** Child demographics and ADHD assessment history

<b>Participant</b>	<b>Child age</b>	<b>Gender</b>	<b>Other diagnoses</b>	<b>Education</b>	<b>ADHD assessment</b>
Julia	10	F	Tourette's Syndrome	Full-time mainstream	Private assessment & NHS CAMHS (mixed)
Ben	11	M	None	Full-time mainstream	NHS CAMHS
Abi	12	F	Autism	Full-time mainstream	Private assessment (referred by NHS CAMHS)
Simone	13	F	Autism, hearing impairment	Full-time mainstream	Private assessment & NHS CAMHS (mixed)
Oumar	9	M	Autism	Home schooled	Private assessment (referred by NHS CAMHS)
Christopher	8	M	None	Full-time mainstream	NHS CAMHS

### **2.3.4 Procedure**

The study had all the necessary ethical approvals (ERGO ID: 78252) from the University of Southampton Ethics and Research Governance Committee (Appendix G).

With the support of my thesis supervisors, I developed a topic guide to collect data through semi-structured interviews in line with guidance from the IPA literature (Larking & Tompson, 2012; Eatough & Smith, 2008). As part of the initial stages of planning the study, the main research questions and interview topic guide were reviewed by public and patient involvement (PPI) within an NHS service with a parent of a child with ADHD. There is evidence to show that engaging with PPI in the early stages of research design can lead to improved designs and relevance of research (Varkonyi-Sepp et al., 2017). The PPI feedback on the current study was thoughtfully considered when preparing for interviews with participants. For example, it was identified how important it is for the interviewer to present as warm and approachable and how this can be at times difficult to achieve in an online interview. This made me conscious about using facial expressions and body language consciously to connect and respond when people share their stories. A small change was made to the interview questions following PPI feedback and discussions with supervisors which was around collecting demographic information at the start of interview and thinking about what to ask first. To see the interview topic guide, please go to Appendix F.

The interview appointments started off with introductions and overview of the study aims and an explanation of what participants could expect. There was also a chance for clarification and questions. With participant consent, the interview was recorded so that it could be later transcribed, and the length of interviews ranged from 28-44 minutes ( $M=38$  minutes). At the end of the interview, participants were verbally debriefed and provided with an opportunity to ask any questions.

### **2.3.5 Analysis**

I transcribed the first interview straight after it occurred and started to analyse it immediately as it has been suggested that the first interview is very important in the IPA process (Eatough & Smith, 2008). As previously mentioned, analysis involved a two-stage 'double

hermeneutics' interpretation process (Smith & Osborn, 2003), as I attempted to make sense of how the participant made sense of their experience, while noting down field notes. I read the first interview multiple times until it felt very familiar, and I wrote some initial notes by hand on the transcript pages. I followed an idiographic approach to analysis (Smith, 2004) as I started the coding process (Saldaña, 2015; Braun & Clarke, 2006) by writing down codes on the left side of the transcript, and initial themes on the right. I used a colour-based system to connect my initial notes and codes with each broader emerging theme. According to some IPA guidelines, the first interview should be analysed over the course of one month by being repeatedly revisited, codes and themes reviewed, new ideas written down (Eatogh & Smith, 2008; Smith & Osborn, 2003). This was my approach in this instance, and even though I interviewed most participants within the month of analysing the first transcript, I did not move on to analyse consequent interviews until I felt confident that I had exhausted analytical findings of the initial interview. Consistent with the IPA literature (Eatogh & Smith, 2008), I found that later interviews required less time to analyse as I was quickly able to identify new or previously undiscovered concepts, which tended to be subthemes of broader already identified superordinate themes. Themes were considered as recurrent when they were present across four out of six participants. An initial thematic map was created, findings discussed with supervisors, before the map was reviewed and updated. Appendix H contains the evolution of the study thematic map.

An important part of the analytic process was the use of research supervision to discuss preliminary findings and formulate major themes which started to emerge. The supervision space provided an opportunity for me to discuss any personal experiences which may be influencing how I was interpreting the data, which was an important step in managing the validity of findings. The research supervisors were consistently curious about my own position and relationship with the emerging themes, challenging me to think about what seemed to be important for participants and what evidence there was for this in their body language or choice of words.

## 2.4 Findings

The IPA analysis of the interview data resulted in three superordinate themes and seven subthemes. **Table 5** provides details on the themes and their frequency distribution across participants.

**Table 5.** Superordinate themes, subthemes, and their frequency

<b>Superordinate theme</b>	<b>Subtheme</b>	<b>Frequency</b>
“Surviving” the assessment	The “battle” with services	5
	Effect on family relationships	6
“Every feeling under the sun” – Parent emotional experiences	Parenting self-efficacy	6
	Stages of psychological acceptance	5
	“I know my child best”	5
“On the other side” – Changes with ADHD diagnosis	Knowing what to do next – accessing support	6
	Hopes for the future	6

#### **2.4.1 Superordinate theme 1: “Surviving” the assessment**

One of the superordinate themes identified was related to the difficulties participants experienced when their child was going through the ADHD assessment. There was a shared view that the overall assessment time was too lengthy from the moment of referral for assessment until a diagnosis was reached. Participants spoke about various hurdles along the way, including challenges in relation to service processes and waiting times, as well as the emotionally demanding content of assessment-related appointments. Most participants reflected on the rigour of the assessment which was often described as “thorough”, and this was the case for both private assessments and NHS CAMHS assessments. Participants acknowledged another important challenge they faced during the period of assessment relating to their child’s difficulties at the time which had initiated the assessment process. There was a shared sense of helplessness amongst the interviewees as they described how difficult it was to see their child struggle at home and at school while waiting for the assessment to progress. When asked to describe how it was to

be a parent navigating through ADHD assessment processes, Abi summarised her experience as follows:

*“It was horrific, absolutely horrific... I’m educated and I found it absolutely soul-destroying because I have this small person who I’m responsible for and they were telling me that they weren’t coping. Uhm... I can’t use any more words than that. I would not wish what we’ve been through on anyone.”*

Abi used highly emotive words such as “horrific” while her tone of voice and facial expressions appeared sad, pausing between sentences as she seemed to remember the times during the lengthy assessment. She shook her head when she spoke about not wanting others to experience what her family went through.

#### **2.4.1.1 The “battle” with services**

The challenges that parents faced when engaging with services was a common theme across the interviews. Furthermore, participants who opted for a private ADHD assessment for their children explained that they had done so in attempts to access the right support for them and their child more promptly, as they were informed about the waiting times within NHS CAMHS services. Simone spoke about her decision to pursue a private ADHD assessment for her son after her was referred to an NHS CAMHS service:

*“I mean, the private (assessment) was quick and that’s cause um... I had said to CAMHS about doing an ADHD assessment and they said they would do it. But it was kind of like “how long is a piece of string” type thing. You know, “we’ll get to round to it when we get round to it” kind of thing. And I’d wanted the information to inform the local authority when choosing a school. So I couldn’t really wait for that and that’s why we went private...”*

Simone appeared calm when she explained her decision-making. She lifted her eyebrows after she shared what the NHS CAMHS team had told her about the waiting times. She presented her logic with conviction, her body language and vocal demeanour suggesting that she felt like did not have any other option.

Participants spoke about issues they experienced with communication when they had queries in relation to their child’s assessment, explaining that it often took a long time for someone to get back to them. Julia’s voice sounded frustrated as she described her experience of communicating with an NHS CAMHS service after her son’s private ADHD assessment and diagnosis letter were being contested:



*“The support was non-existent every time we tried to make a phone call or contact someone or e-mail, it took weeks to get a response... and I know that they’re massively overstretched... But we never, ever thought that we would be listened to.”*

Overall, parents expressed feeling like their child’s assessment was a journey throughout which they had to continually negotiate and challenge the service in order to achieve what they and their child needed at the time. As Ben described this process:

*“We had to look after our own best interest, so we had to keep fighting.”*

#### **2.4.1.2 Effect on family relationships**

There was a theme around the impact of ADHD assessment on the family which was shared across interviewees. Participants described experiencing tensions with their partners or with their child which seemed to be influenced by the stress their families felt under during the length of the assessment. Parents reflected that when they felt like they were “battling through” the assessment, this seemed to consume their lives, as they were busy with lengthy and stressful appointments on top of providing for their family. Participants shared that during this period, they argued with their partner often and the general atmosphere in the house felt difficult. Participants also shared that as the assessment progressed and they were asked to think about their child’s early developmental history, they started to notice their child’s difficulties even more. This often led them to feel irritated or embarrassed, as they sometimes questioned their parenting ability, and they felt resentful that their child could not do the things that other children could. Christopher spoke about the tension between him and his son when he started to learn more about ADHD through the assessment process:

*“...and especially being a single parent, I think all your efforts have to double. I felt under a lot of pressure, and he (son) wasn’t listening or doing anything he was meant to. God, it got me frustrated you know... Um... And I started seeing it (ADHD) all the time when he’s doing something so I’d try and intervene more, and then arguments and so on. It was hard for some time...”*

Christopher’s speech sped up as he was describing the difficulties he experienced with his son. His tone of voice changed as he emphasised the words “God” and “frustrated”, before taking a pause while shaking his head with what seemed like disapproval.

As Abi described the tensions in her family during the assessment, she seemed emotional when remembering conflicts and she spoke with conviction, her gaze looking away from the camera:

*“...now we're all very cohesive and XXX (daughter) is happy and XXX (wife) and our relationship is good. But when you're going through the trauma of fighting for your child, it's awful. Um, we were arguing a lot, XXX (wife) and I, to the point that we even ended up possibly separating at one point, and it would have been over this. This is what caused us all of our difficulties.”*

#### **2.4.2 Superordinate theme 2: “Every feeling under the sun” – Parent emotional experiences**

Another superordinate theme identified in the data related to the vast array of emotional experiences that participants described during the assessment, when their child was diagnosed, and following ADHD diagnosis. Parents described feelings of frustration and confusion as they were going through the assessment, but there was also a sense of motivation and determination.

##### **2.4.2.1 Parenting self-efficacy**

In the earlier stages of ADHD assessment, some parents described questioning their ability to parent their child and they described a feeling of parent-blaming. This experience was sometimes in the context of the assessment itself, however at other times parents felt judged by their child’s school or other parents in their community. Simone described her experience of feeling judged, questioning her parenting, and how this impacted on her relationship with her son:

*“I think mums are judged by their children, so if you've got children who are well turned out, you know, nice and tidy and clean and well behaved, then you're a good mum. And I think that... things like ... not wanting to share and snatching things off people and you're getting judged as well, you know. “Haven't you told your child not to do that?” And you think: Yes, I have mentioned it about 1000 times, but it's not sinking in. But yeah. And then I started to get really uptight. And say lots of “no”, lots of “you cannot do that, “no, you will not do that”. And that really impacted on our relationship and made it a lot worse.”*

Simone appeared calm as she spoke, speeding up the rate of her speech when describing what other parents said to her. She changed her tone of voice to suggest that she might have been “fed up” with others’ trite suggestions, as she was continually making efforts in her parenting.

Participants spoke about the tensions with the education system and experiencing a lot of pressure to support their child to achieve their full potential at school while often there was a sense that schools were not able to provide the right support themselves. Some parents shared having to change their child's school, and most participants described periods of time when their child was excluded from or refusing to go to school. Oumar's tone of voice and body language appeared angry as he spoke about his experience of deciding to home school his son after he felt that the school were dismissive of his concerns:

*"I decide to withdraw him from school from now, so... The plan is for me and my partner to help him. They (school) say "Oooh, there's nothing wrong with him", they don't listen to me when I say he is struggling, he cannot understand. So when he got diagnosed I said "that's it, I'm taking him out". They were wrong."*

#### **2.4.2.2 Stages of psychological acceptance**

Another theme across the interviews was around parents psychologically adapting to the idea that their child has a neurodevelopmental condition such as ADHD and what that might mean for their lives and futures. Different parents went through different stages at different times, however, there were similarities in terms of their emotional experiences. For example, parents described a sense of guilt that maybe they could have noticed earlier, or that they didn't do a good enough job. They also described feeling angry when people questioned their child's abilities, or when they were describing a difficulty that was not observed by professionals. There was sense of relief when others recognised the same signs that they themselves recognise, which was a validating experience, restoring their confidence as parents. Similarly, when their child was diagnosed with ADHD, parents described a feeling of shock, irrespective of how certain they were previously that their child has ADHD. Some degree of anxiety and perhaps confusion seemed to be present for most participants. Parents spoke about grief, however brief it may be, for the child they thought they would have, the "normal" child. However, all parents recognised that the child they have is also "normal" in so many ways, and they spoke about how thankful they are to have them. When asked what it was like for her when her daughter got the ADHD diagnosis, Abi described her experience and the psychological processes she noticed:

*"I guess a relief, really. That's probably the first thing that came to me. That kind of acceptance and realisation that XXX's (daughter) brain is not neurotypical, and a lot of the stuff that she struggles with we would be able to help her with, and then probably. Yeah, I'd say that it was hard, a little bit overwhelming. Because with any sort of diagnosis you... you know, you feel a*

*huge amount of emotions, don't you? It was a huge amount of emotions in one go. Grief in a way, because this child that I had all these hopes and dreams for might not be able to achieve those things, but I know she will. But at that time it was painful and loss again for that kid that is going to be slightly different to the one that I thought that I might have had. And again, I don't mind that at all."*

Christopher shared having limited knowledge about ADHD prior to the assessment, and he described feeling quite anxious and confused after the diagnostic appointment. He lifted his eyebrows and shoulders when he talked about now knowing how to respond to his son's struggles, emphasising his confusion at the time:

*"I was confused about the outcome (ADHD diagnosis). I was confused about what would be required of me. And then if I will, if I would be able to, you know, to do what I had to do to help him (son)? He (son) was having trouble and I didn't know how to manage it."*

#### **2.4.2.3 "I know my child best"**

Participants described a sense of renewed confidence in their abilities as parents once their child was given an ADHD diagnosis. This appeared to be the case especially for parents who strongly suspected that their child had ADHD prior to or at the beginning of the assessment. Parents described the confirmation of diagnosis as validating and reparational to some degree, as most participants shared that the diagnostic appointment was conducted thoughtfully, sensitively and with a lot of care. This was parents' experience in both NHS services and private sector organisations. When asked about the diagnostic appointment within an NHS CAMHS service, Ben shared feeling that his parenting was positively acknowledged:

*"They spoke to us (parents) first and told us he has ADHD and explained what it means and so on. They could see we were not surprised and they said that we've clearly done a good job to help him manage until now... which was nice to hear, you know."*

Ben's demeanour perhaps suggested a degree of pride as he paused and tilted his head to one side, lifting his shoulder slightly.

#### **2.4.3 Superordinate theme 3: "On the other side" – Changes with ADHD diagnosis**

The final superordinate theme was around parents' experiences in relation to changes since their child got the ADHD diagnosis. All parents spoke about positive changes once the assessment process was complete and feeling like a new chapter in their family lives was about to begin.

Participants varied in terms of how much they knew about ADHD prior to diagnosis, however, all parents recognised that their child needed additional support and the diagnosis provided them with options for such.

#### **2.4.3.1 Knowing what to do next – accessing support**

A common theme amongst all participants was around future directions and accessing support for their child. Depending on how knowledgeable the parent was about ADHD prior to the diagnosis, they reported having engaged in changes at home to varying degrees. Parents who were already quite knowledgeable or had started to acquire lots of additional knowledge from the start of assessment had already started adapting their parenting style to suit the needs of their child better. All participants acknowledged the benefits of gaining access to more support and interventions following their child's diagnosis, including medication and parenting groups. Parents also felt more confident about adjustments being made for their children at school which was considered a very important benefit of the diagnosis. Julia spoke about school support and the positive changes their family noticed since her son started ADHD medication:

*“He started the medication last August, after he was diagnosed, and this year we've only had one internal exclusion. He has full one to one support in school. He doesn't go into all of his lessons, but they do try and kind of get him into a lot of them. So we have had a number of challenges which are getting better, now that he's getting more support... You can kind of reason with him better. He's able to kind of concentrate a little bit better than what he did before. He's kind of, he's not as impulsive... So I think that for him it's just given him a better quality of life.”*

Julia's facial expressions appeared happy as she smiled when describing her son's ability to talk things through more effectively. Julia placed emphasis on the word “one” when she spoke about the number of exclusions recently, suggesting how significant a change this is from their past experiences, confident that the medication works well for her son.

#### **2.4.3.2 Hopes for the future**

Finally, there was a shared theme of parents feeling hopeful for their children's future. Participants reflected on the lengthy assessment journey, multiple challenges which they have overcome, and gratitude and love for their child and family. While there were still some apprehensions about future challenges, especially in relation to education, participants shared feeling like they know what they and their child need to do now. With a smile, Abi described her daughter's positive outlook about having ADHD:

*“She was happy for them all (daughter’s friends) to know that she had ADHD because she likes being bouncy. She likes being the clown and the centre of attention. And with that, she doesn’t need much sleep, and she’s always up early in the morning, and she’s always on the go. And her friends yawning away in the corner after a day at school, and she’s like “come on, come on, let’s go on the trampoline” and constantly wild.”*

## 2.5 Discussion

This study focused on exploring parents’ experiences of their child receiving an ADHD diagnosis in England using qualitative IPA methodology. The data analysis revealed three superordinate themes: *“surviving” the assessment*, *“every feeling under the sun” – parent emotional experiences*, and *“on the other side” – changes after ADHD diagnosis*. There were seven subthemes which included *“battle” with services*, *effect on family relationships*, *parenting self-efficacy*, *stages of psychological acceptance*, *“I know my child best”*, *knowing what to do next – accessing support*, *hopes for the future*. Participants spoke about the positive and negative aspects of going through the journey of getting their child assessed for ADHD and getting a diagnosis. It is important to note that there is some overlap between themes which is not uncommon in qualitative research (Smith, 2013).

A major difficulty identified by participants was the length of waiting times at different stages of the assessment process within NHS CAMHS contexts. A study in 2018 (Smith et al., 2018) found that waiting time for initial appointment in relation to hyperactivity/inattention difficulties in a CAMHS service was around 22 weeks or over five months, which was significantly longer than waiting times for emotional and behaviour difficulties, general mental health, eating disorders, and self-harm (12 weeks). Since COVID19, demand for CAMHS services have dramatically increased, and there have been reports of demands growing faster than service capacity after the initial months of lockdown associated with the COVID19 pandemic (Cooke et al., 2022). A study highlights that COVID19 likely accelerated this trajectory rather than created it, and there is an indication that in 2021, the average waiting time for a child to be seen for an initial appointment in CAMHS was around 52 weeks or close to a year (Cooke, et al., 2022). ADHD assessments require multiple appointments with clinicians which is in line with the NICE guidelines (NICE, 2019), resulting in waiting times at each stage of the process, meaning that an ADHD assessment from start to finish may take several years. Several years is a long time in child development, as many bio-psycho-social developmental changes occur within a short space of time (Lourenço, 2016). It is unclear what the implications of such significant delays in ADHD assessments might be

for young people and their families. Some research has suggested that there is a long-term association between late adolescent/young adult ADHD diagnosis and poorer mental health and psychosocial outcomes and difficulties with addiction (Agnew-Blais et al., 2018).

A distinction between private sector organisation and NHS service was that parents reported short waiting times for assessment by private clinics. However, if parents wanted to then access medication via an NHS CAMHS service, the private diagnosis was often contested, resulting in parts of the assessment being repeated and a new set of waiting times imposed. Under these circumstances, it is somewhat unsurprising that parents participating in this study described feeling like they were “battling” with services as they tried to “survive” the assessment. This finding is also consistent with my own previous experiences of working on assessment pathways in CAMHS clinics. Recognising some of the wider systemic challenges within the NHS context and its impact on families' access to service provision is unfortunately an ethical conundrum which I am often faced with, and I acknowledge that it has an emotional impact on me as a clinician. Anecdotally, I believe other colleagues have similar experiences given the pressure that the NHS is currently under.

The results of this study showed that stresses associated with the assessment and the child's presenting difficulties were impacting on relationships within the family. Previous research has shown that higher levels of child ADHD are linked with higher levels of distress in mothers which in turn produced more family conflict, with maternal emotional state mediating the relationship between child ADHD difficulties and family conflict (Kendall et al., 2005). In the current study sample, the effect on family relationship was identified in both mothers and fathers, and it may be that the emotional state of the parent who takes a leading role in the process of ADHD assessment acts as a mediating factor. The literature also suggests that ADHD-related difficulties at home and at school become more apparent during primary school years (Harpin, 2005) which is relevant for most of the sample in this study. It is possible that tensions in the family during the period of lengthy assessment are significantly exacerbated by the child's ongoing ADHD-related difficulties as much as parent responses to assessment pressures. Another finding in the study was that during the assessment phase, parents experienced a lot of self-doubt in relation to their parenting skills. A systematic review showed parental self-efficacy is associated with many factors amongst which were child temperament, parenting stress and perceived social support (Fang et al., 2021). Further research is necessary in order to understand the factors that influence family relationships during the time of ADHD assessment. By understanding this this

relationship, clinicians may be better equipped to support families who are going through the assessment process.

Another major theme identified in the current study was around parents' emotional experiences throughout the assessment and following diagnosis. All participants reflected on going through different stages of accepting that their child is somewhat different. Parents spoke about experiencing a sense of confusion or shock, perhaps in the early stages of assessment and immediately after the diagnosis was confirmed. Following diagnosis, parents often reported feeling a sense of relief, as they felt validated by the outcome of the assessment. They also described a sense of anger or grief for the child that they thought they would have, typically experienced at the late stages of assessment or sometime after the diagnosis. Parents also spoke about accepting the facts and adjusting their expectations for the future to align with their new vision of their child. This process was aided by having a clear sense of direction in terms of support and treatment of their child's ADHD.

There has been some exploration of parents' emotional experiences following their child being diagnosed with Autism which is relevant for the outcome of this study (Fernández-Alcántara et al., 2016; Mulligan et al., 2012; O'Brien, 2007). The "unexpected loss" model by Fernández-Alcántara and colleagues (2016) suggests that parents of children diagnosed with Autism experience the loss of hopes and expectations for the child that they had until the diagnosis. They also suggest that this loss triggers a series of emotions associated with grief, such as denial, shock, guilt, sadness, and anger (Fernández-Alcántara et al., 2016). In order to resolve these feelings, parents engage in forming a new image and relationship to their child which is based on real situations (Fernández-Alcántara et al., 2016). There are many similarities between these findings and the results of the current study, and it is therefore possible that the "unexpected loss" model fits well with parents' experiences of their child receiving an ADHD diagnosis. The shared theme of hopes for the future also aligns well with this model, as parents shared examples of adjusting their expectations and learning to love their child's differences. It may be helpful for future research to focus on exploring the model with ADHD families further as it could provide a helpful framework with clinical implications for helping parents with this psychological process.

The current study findings also align with some studies from the adult ADHD literature. A model of psychological acceptance of diagnosis was suggested by Murphy (1995) which was later used and adapted to describe the experiences of adults receiving an ADHD diagnosis (Young et al., 2008). The six-stage model of psychological acceptance of ADHD diagnosis by Young and colleagues (2008) suggests that individual go through (a) relief and elation, (b) confusion and



emotional turmoil, (c) anger, (d) sadness and grief, (e) anxiety, and (f) accommodation and acceptance. The study also proposed that ADHD diagnosis and medication treatment of adults has a big impact on the individual's view of themselves and expectations for the future (Young et al., 2008). Based on participants' accounts in the current study, it is possible that parents of children receiving an ADHD diagnosis are experiencing a process of psychological acceptance similar to the one found in adults receiving the diagnosis, given that parents are responsible for their children until they reach adulthood.

The final subordinate theme identified in the current study relates to parents' experiences following the ADHD diagnosis of their child, connecting with a strong sense of relief that the assessment has concluded, and an outcome reached. Parents described many benefits of their child getting an ADHD diagnosis such as access to individualised support at school, medication, and parenting courses and support groups, which is in line with other studies. A lot of previous research has focused on the benefits of ADHD diagnosis and intervention in children (Wolraich et al., 2019), including pharmacological (Dalsgaard et al., 2014), emotional and behavioural (Evans et al., 2018), and parent and school support (Hamed et al., 2015). And perhaps most importantly, parents also identified that the benefits of the intervention options following diagnosis outweighed the negative aspects of the assessment.

### **2.5.1 Strengths and limitations of study**

One of the strengths of the study was the sampling strategy and careful consideration to the study aims and broader methodology, specifically the balance of parent and child demographic factors. To my knowledge, this is the only study exploring parents' experiences of their child receiving an ADHD diagnosis in England, and the only study that employs an IPA approach (Smith, 2010). Another strength of the study is the exploration of assessment experiences across NHS and private organisation services, therefore the findings are clinically relevant to both contexts. The study's credibility is further strengthened by involvement from PPI at the designing stages, demonstrating efforts to faithfully reflect participants' voices and maintain relevance for parents of children with ADHD. A limitation associated with qualitative designs relates to the issue of transferability, as the study focuses on a small sample of participants. In attempts to mitigate this issue, I tried to include parents from various backgrounds and with varied family constitutions. Another strength of this project relates to the reflective efforts underpinned by the IPA design, which with I approach this study from my very

initial meeting with supervisors right until the very end. The reflective log (Appendix B. Field Notes) demonstrates this further.

A key clinical implication from the study relates to the identification of psychological acceptance and adjustment processes for parents of children who get diagnosed with ADHD, which is something that has not been explored in the scientific literature previously. Having a better understanding of the psychological processes that parents go through when their child is diagnosed with ADHD may help clinicians to support families more effectively. By having a better understanding and compassion for parents' psychological adjustment processes, clinicians are less likely to feel frustrated with demands being placed on them and their services, as they are already working in highly stressful environments with highly distressed children and parents. The findings have generated some ideas about future research, for example exploring factors of family conflict during ADHD assessment or exploring the proposed stages of psychological acceptance further.

The study also highlights issues in relation to ADHD assessment processes in NHS CAMHS services including waiting times and communication breakdown. Some suggestions made by the study participants included for better communication processes to be developed and deadlines for responding to parents to be set. The participants suggested that clinicians think carefully when gathering information during the assessment, as this can be experienced as "parent-blaming" at times. There was also a degree of recognition that there are many systemic interacting factors that perpetuate these service issues. The study also recommends that services continually review how parents' expectations are managed, particularly in the context of waiting times, consistent communication, and transparency of assessment and diagnostic processes. Clinicians should have an awareness of the emotional "rollercoaster" the assessment can be for parents and services may wish to develop self-help resources to support them through the process. The current study suggests that validating parents' experiences could be crucial in helping them to navigate the challenging psychological adjustment process as their child is assessed and diagnosed with ADHD. There may be need for clear protocols for managing ADHD assessment queries and parent support for clinicians answering duty lines.

## **2.6 Conclusion**

The current study suggests that parents experience many circumstantial and psychological challenges when their children are assessed and diagnosed with ADHD in England. Some of the challenges experienced by parents are in relation to organisational barriers such as waiting times and breakdown of communication. Parents also experience challenges associated with going

through different stages of psychological acceptance related to their child's diagnosis, and the study proposes two models which may represent this experience appropriately. The study suggests that ADHD diagnosis has positive implications for families as it offers varied options for intervention and support. Key recommendations for services include assessment communication protocols, awareness of parental psychological experiences in relation to assessment and diagnosis, and self-help resources for parent support.



## Appendix A      Downs and Black Checklist Quality Assessment

<b>REPORTING</b>	<b>Yes/No/Partially</b>	<b>Score</b> Study 1	<b>Score</b> Study 2	<b>Score</b> Study 3	<b>Score</b> Study 4	<b>Score</b> Study 5	<b>Score</b> Study 6	<b>Score</b> Study 7	<b>Score</b> Study 8
1. Is the objective of the study clear?	Yes = 1, No = 0	1	1	1	1	1	1	1	1
2. Are the main outcomes clearly described in the Introduction or Methods?	Yes = 1, No = 0	1	1	1	1	1	1	1	1
3. Are characteristics of the patients included in the study clearly described?	Yes = 1, No = 0	1	1	1	1	1	1	1	1
4. Are the interventions clearly described?	Yes = 1, No = 0	1	1	1	1	1	1	1	1
5. Are the distributions of principal confounders in each group of subjects clearly described?	Yes = 2, Partially = 1, No = 0	1	2	1	1	2	0	1	2
6. Are the main findings of the study clearly described?	Yes = 1, No = 0	1	1	1	1	1	1	1	1
7. Does the study estimate random variability in data for main outcomes?	Yes = 1, No = 0	1	1	1	1	1	1	1	1
8. Have all the important adverse events consequential	Yes = 1, No = 0	1	1	1	1	1	1	1	1

to the intervention been reported?

9. Have characteristics of patients lost to follow-up been described?

Yes = 1, No = 0

1 1 1 1 1 1 1 1

10. Have actual probability values been reported for the main outcomes except probability < 0.001?

Yes = 1, No = 0

1 1 1 1 1 1 1 1

11. Is the source of funding clearly stated?

Yes = 1, No = 0

1 1 1 1 1 1 1 1

**Score Score Score Score Score Score Score Score**

**EXTERNAL VALIDITY**

**Yes/No/Unclear**

12. Were subjects who were asked to participate in the study representative of the entire population recruited?

Yes = 1, No = 0, Unclear = 0

1 1 1 0 1 1 0 1

13. Were those subjects who were prepared to participate representative of the recruited population?

Yes = 1, No = 0, Unclear = 0

1 1 0 0 1 1 0 1

14. Were staff, places, and facilities where patients were treated representative of treatment most received?

Yes = 1, No = 0, Unclear = 0

0 0 1 1 0 1 0 1

**Score Score Score Score Score Score Score Score**

**INTERNAL**

**VALIDITY**

**Yes/No/Unclear**

Study 1

15. Was an attempt made to blind study subjects to the intervention?

Yes = 1, No = 0,  
Unclear = 0

0 0 0 0 0 0 0 0

16. Was an attempt made to blind those measuring the main outcomes?

Yes = 1, No = 0,  
Unclear = 0

0 0 0 0 0 0 0 0

17. If any of the results of the study were based on data dredging was this made clear?

Yes = 1, No = 0,  
Unclear = 0

0 0 0 0 0 0 0 0

18. Was the time period between intervention and outcome the same for intervention and control groups or adjusted for?

Yes = 1, No = 0,  
Unclear = 0

1 1 1 1 1 1 1 1

19. Were the statistical tests used to assess main outcomes appropriate?

Yes = 1, No = 0,  
Unclear = 0

1 1 1 1 1 1 1 1

20. Was compliance with the interventions reliable?

Yes = 1, No = 0,  
Unclear = 0

1 1 1 1 1 1 1 1

21. Were main outcome measures used accurate? (valid and reliable)

Yes = 1, No = 0,  
Unclear = 0

1 0

**Score Score Score Score Score Score Score Score**

**INTERNAL**

**VALIDITY-**

**CONFOUNDING**

**(SELECTION**

**BIAS)**

**Yes/No/Unclear**

Study 1

22. Were patients in different intervention groups recruited from the same population?	Yes = 1, No = 0, Unclear = 0	1	1	0	0	1	1	0	1
23. Were study subjects in different intervention groups recruited over the same period of time?	Yes = 1, No = 0, Unclear = 0	0	1	0	0	1	1	0	1
24. Were study subjects randomized to intervention groups?	Yes = 1, No = 0, Unclear = 0	1	0	0	0	0	0	0	0
25. Was the randomized intervention assignment concealed from patients and staff until recruitment was complete?	Yes = 1, No = 0, Unclear = 0	1	0	0	0	0	0	0	0
26. Was there adequate adjustment for confounding in the analyses from which main findings were drawn?	Yes = 1, No = 0, Unclear = 0	1	1	1	1	1	1	1	1
27. Were losses of patients to follow-up taken into account?	Yes = 1, No = 0, Unclear = 0	1	1	1	1	1	1	1	1
		<b>Score</b>	<b>Score</b>	<b>Score</b>	<b>Score</b>	<b>Score</b>	<b>Score</b>	<b>Score</b>	<b>Score</b>
<b>POWER</b>	<b>Size of Smallest Intervention Group Score of 0 to 5</b>	<b>Study 1</b>							
28. Was the study sufficiently powered to		3	4	2	3	3	2	4	3



detect clinically important effects where probability value for a difference due to chance is < 5%?

excellent (26-28), good (20-25), fair (15-19), and poor ( $\leq 14$ )

Total:

	<b>25</b>	<b>25</b>	<b>20</b>	<b>20</b>	<b>24</b>	<b>22</b>	<b>20</b>	<b>25</b>
	Good	Good	Good	Good	Good	Good	Good	Good

Mean score **22.625**



## Appendix B      Field Notes

Example summary of my reflections during the study:

I have been incredibly conscious about the fact that I represent the NHS and all of the parents have been telling about how much they have struggled with CAMHS service. Having worked at CAMHS prior to training and doing lots of neurodevelopmental assessments with the ND team, I remember many occasions when I've answered calls from parents, just like the ones I've interviewed for this study. And I remember at times feeling irritated for having to take these calls, how helpless I felt because I knew I would be telling them that they are still on the waitlist. How upset the parents were, and angry sometimes. Difficult experiences from the past. I also remember feeling a tension between my own values and how the service operated, thinking "it is not good enough, how can these kids wait for this long, so much changes at that age, who knows what the impact will be but it can't be all good" – a cascade of anxiety provoking thoughts that I had to battle with often when I was working in CAMHS. I am also very aware of my wish to go back to working in CAMHS once I qualify and this study has helped to ground me somewhat. I feel connected to my own mission and purpose for working with families, I hope that I do not let go of that through the stresses and pressure of the working environment. I also hope that I have done a good enough job to interpret what parents tried to share with me, and that I have not softened unjustifiably their upset with NHS services, but I am conscious that I might have a little bit. It is also possible that I have amplified their anger as I have felt angry myself. I recognise how sensitive this theme is, and I have attempted to look at each side of the story with utmost empathy.

I am getting married later this year and parents talking about arguing with their partners really got to me at times. One of the mums described how her and her wife almost broke up because of the stresses with the assessment and arguments about appointments and responsibilities. Perhaps as I am looking to start my own family and since getting engaged, I have thought a lot about what it means to start a family, how it would be different than owning a house together and the changes I have noticed in terms of our commitment to each other. I noticed feeling quite upset when this mum told me about marriage trouble, how could an assessment do this sort of thing, I was shocked and appalled! More so than when parents have previously told me about their child being excluded from school! So I was really careful when interpreting this segment of the interview.

Brief summary of notes on each interview:

Interview 1: quite angry mum, spoke very fast when she told me about troubles with NHS, some of it still ongoing; I did not need to use many of the prompts as participant seemed ready to share in detail; ideas about semi-structured

interview, perhaps could have asked a little more/again about parent feelings when diagnosis was reached, get more richer information

Interview 2: friendly and pleasant dad, a bit brief about his own experiences but a lot of details about child; mixed up thoughts and feelings often, difficult to elicit information about emotional experiences at times

Interview 3: very rich answers and information gained, not many prompts required from questions; reflective and thoughtful mum, a bit distracted at times as son came into the room to see what she is doing, said hello to him before he left

Interview 4: rich interview, great detail about feelings at diagnosis appointment, thoughtful mum and keen to share, not many prompts used, spoke a bit about autism as well, to be carefully interpreted in those sections to avoid mix up

Interview 5: friendly dad, keen to share but brief in answers, especially about feelings, used quite a few prompts, interesting information about school and taking him out, distracted by phone a couple of times

Interview 6: thoughtful dad, liked the occasional cheeky joke, loves his son, felt sad for him as partner left, seems to be well supported by other family, seemed very present throughout the interview

## Appendix C Participant Information Sheet

### Participant Information Sheet

**Study Title:** Parents' Experience of their Child Receiving an ADHD Diagnosis in England

**Researcher:** Kristina Todorova

**ERGO number:** 78252

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You will be offered a £25 voucher to thank you for your time and participation. You may like to discuss it with others, but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form. If you wish to take part, please email Kristina Todorova on [XXX](#)

#### **What is the research about?**

My name is Kristina Todorova and I am completing a Doctorate in Clinical Psychology at the University of Southampton. I am undertaking this research project due to my interest and passion in better understanding and helping families who engage with services within and outside of the NHS.

The aim of this research is to gain an understanding of what it was like for you when your child was assessed and diagnosed with ADHD. There is not much written about this topic, and previous studies have tended to focus on medications and adults going through assessment and diagnosis of ADHD.

The study will involve completing a brief questionnaire about your child which will be followed by an interview. The interview will take somewhere between 20 and 60 minutes, during which you will be asked questions relating to your experience as a parent of a child that was diagnosed with ADHD.

#### **Why have I been asked to participate?**

You may have seen my study being advertised online, or you may have been approached by someone in your support group because you are a parent of a child who has recently received an ADHD diagnosis. We understand how important parents' views are and we hope that this project will provide you with an opportunity to share your experiences in relation to your child's ADHD assessment and diagnosis. We are hoping to recruit between 6 and 12 participants to take part in this project.

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

Once you return the consent form and brief questionnaire about your child, you will be contacted about going ahead with an interview if this is appropriate. You will then take part in a single interview with me. The interview can be completed via telephone or video. You can choose if you would like the camera to be switched off during the interview if you opt for video appointment. The appointment will be recorded and the interview transcribed with all identifiable information anonymised so that you cannot be identified. The anonymised information from the study will be analysed and a report will be written and submitted to the University of Southampton. The report may be adapted and submitted for publication in order to share findings with the research community and services that undertake ADHD assessments.

### **Are there any benefits in my taking part?**

You will be offered a £25 voucher for your participation in the study. The voucher will be made available to you after the interview has taken place.

Taking part in this study may help us identify what is being done well, as well as things that could be improved, thus informing future service-development within and outside the NHS. The study hopes to guide and inform future research that could be undertaken on this topic.

### **Are there any risks involved?**

There are no direct risks to taking part in the study. However, the interview may remind you of any challenges that you and your child experienced in relation to being diagnosed with ADHD. If you feel that during the interview you become upset and do not wish to continue, you have the right to withdraw from the study at any point without explanation. I will also be able to provide you with information about helpful resources and where to seek further support should you wish to.

All information discussed during the interview will remain confidential and will not be discussed with others outside the research team, unless you shared information about someone being at risk of harm. In such cases, we will agree a plan together about how to best proceed.

### **What data will be collected?**

At the start of interview you will be asked about some personal information such as your ethnicity and family situation. This information is gathered to help us to understand the context of yours and your child's experiences.

The recording of your interview will be transcribed and then deleted as soon as possible. During transcription any identifiable information will be removed, and you will be given a different name (pseudonym). The data will be safely stored on a secure server, separately from your signed consent form and email address.

### **Will my participation be confidential?**

Your participation and the information we collect about you during the course of the research will be kept strictly confidential. At the end of the project, anonymised data will be archived alongside the study report.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

### **Do I have to take part?**

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part.

### **What happens if I change my mind?**

You have the right to change your mind and withdraw at any time without giving a reason and without your participant rights being affected.

If you choose to withdraw during the interview you can do so at any time and without giving an explanation and the recording will be immediately deleted. If you choose to withdraw following the interview, you can do so by contacting Kristina Todorova on [XXX](#) before the 20<sup>th</sup> April 2023, and all the information you have provided will be deleted. If you choose to withdraw after this time, it may not be possible to remove information included in the study report.

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

Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you or your child.

### **Where can I get more information?**

If you have additional questions about the study and wish to discuss things further, please do not hesitate to get in touch with Kristina Todorova via [kvt1n20@soton.ac.uk](mailto:kvt1n20@soton.ac.uk)

### **What happens if there is a problem?**

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions. Please email Kristina Todorova on [kvt1n20@soton.ac.uk](mailto:kvt1n20@soton.ac.uk)

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, [rgoinfo@soton.ac.uk](mailto:rgoinfo@soton.ac.uk)).

### **Data Protection Privacy Notice**

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you

agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at <http://www.southampton.ac.uk/assets/sharepoint/intranet/Is/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf>

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer ([data.protection@soton.ac.uk](mailto:data.protection@soton.ac.uk)).

**Yours sincerely,**

**Kristina Todorova (Trainee Clinical Psychologist)**



# Appendix D Consent Form and Brief Questionnaire

## CONSENT FORM

**Study title:** Parents' Experience of their Child Receiving an ADHD Diagnosis in England

**Researcher name:** Kristina Todorova

**ERGO number:** 78252

Participant Identification Number (if applicable):

**Please initial the box(es) if you agree with the statement(s):**

I have read and understood the information sheet ( <i>date: 21<sup>st</sup> December 2022/Version 7</i> ) and have had the opportunity to ask questions about the study.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	
I understand my participation is voluntary and I may withdraw (at any time) for any reason without my participation rights being affected. If I withdraw, any data collected so far will be destroyed.	
I understand that taking part in the study involves video recording which will be transcribed and then destroyed for the purposes set out in the participation information sheet.	
I understand that I may be quoted directly in reports of the research but that I will not be directly identified (e.g. that my name will not be used).	

Name of participant (print name).....

Signature of participant:.....

Date.....

Name of researcher (print name).....

Signature of researcher .....

Date.....

## STUDY QUESTIONNAIRE

**Study title:** Parents' Experience of their Child Receiving an ADHD Diagnosis in England

**Researcher name:** Kristina Todorova

**ERGO number:** 78252

Participant Identification Number (if applicable):

1. Do you have a child that has a formal diagnosis of Attention Deficit Hyperactivity Disorder (ADHD)?

Yes

No

2. Did your child receive their ADHD diagnosis in the last 12 months?

Yes

No

3. Which service diagnosed your child? Please tick the appropriate box.

NHS CAMHS

Other NHS service

Healios

Psicon

Private Assessment

Other

Can you remember the name of the service? Please specify below:

\_\_\_\_\_

4. Does your child have any other diagnoses? This may include other neurodevelopmental conditions (e.g. Autism), mental health (e.g. anxiety, depression) or congenital (e.g. epilepsy). If yes, please specify the diagnosis.

No

Yes

Please specify if yes: \_\_\_\_\_

5. How old is your child? \_\_\_\_\_

6. What is their gender? Please tick the appropriate box:

Male

Female

Other

## Appendix E Debriefing Form



# Parents' Experience of their Child Receiving an ADHD Diagnosis in England

## Debriefing Statement

(Version 7; date: 21<sup>st</sup> December 2022)

ERGO ID: **78252**

The aim of this study is to gain a better understanding of parents' lived experiences in relation to their children being assessed and diagnosed with ADHD. Taking part in this study may help us identify some of the positives as well as challenges when children and their families go through this process in England. The study hopes to guide and inform future research that could be undertaken on this topic. Your data will help our understanding of this important topic area and possibly provide us with ideas for how we may continue to positively develop services that undertake ADHD assessments in England, both within and outside the NHS.

The results of this study will not include your name or any other identifying characteristics. The research did not use deception. You will be sent a copy of this summary.

If you have any further questions please contact me on XXXX

Thank you for your participation in this research.

Researcher's Signature XXXX      Date XXX.XXX.2023

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact Kristina Todorova (XXX). Alternatively, you may contact the University of Southampton Head of Research Integrity and Governance (023 8059 5058, [rgoinfo@soton.ac.uk](mailto:rgoinfo@soton.ac.uk)).

If you feel distressed after undertaking this research, please seek support by contacting your GP and/or one of the following agencies:

For further information or support relative to Mental Health:

MIND – Info-line: 0300 123 3393 or online: [www.mind.org.uk](http://www.mind.org.uk)

RETHINK – Advice and Information Team: 0808 801 0525 or online: [www.rethink.org](http://www.rethink.org)

ITalk – Info-line: 023 8038 3920 or online: <https://www.italk.org.uk/>

For further information or support relative to your child's ADHD:

BRAAIN - <https://www.braain.co.uk/>

ADDISS - <http://www.addiss.co.uk/>

## **Appendix F      Interview Topic Guide**

**Parents' Experience of their Child Receiving an ADHD Diagnosis in England**

## Semi-Structured Interview Topic Guide

### Introduction Prompts:

- Aim to think about your experiences as a parent of a child that has received a recent ADHD diagnosis
- If you do not wish to answer any particular question, please let me know and we will think together about whether you want to continue with the next question or stop the interview altogether. Similarly, if any of the questions feel upsetting we can pause and check in.
- Information Sheet and consent form- all data anonymised, confidentiality, can stop at any time
- Debriefing sheet - details of agencies which can offer further information, and support services
- Recording the interview in order to help with transcribing it later
- Any questions?

<b>Questions for Parents</b>
<b>Firstly, I would like to ask you a few questions about the questionnaire that you completed and clarify any additional information that was not noted on there. This will help me gain a better understanding of your child and your family.</b>
<p><b>1) Clarification about diagnosis within or outside of NHS – local CAMHS service or private practice? Are they accessing CAMHS support currently?</b></p> <p>Which type of ADHD did they get diagnosed with (ADHD-combined, ADHD-inattentive, ADHD-hyperactive impulsive)?</p> <p>Clarify information regarding other diagnoses?</p> <p>Does anyone else in the family have ADHD or suspect they may have it? Or any other mental health difficulties?</p> <p>Educational status? Type of school and are they in full-time or part-time?</p> <p>Clarify family ethnicity and query age of participant? Other important information about your family that I have not asked about? If I have forgotten to ask something important could I get in touch with you after the interview?</p>
<p><b>2) Can you tell me how it was for you when your child got the ADHD diagnosis?</b></p> <p>Prompts: I'd like you to picture yourself back there in that appointment, remember where you were and who was there...</p> <p>Do you remember what went through your mind at the time?</p> <p>How did you feel when they got the diagnosis?</p> <p>Since then, have your thoughts or feelings changed? In what way?</p>

**3) To what extent did you understand the information you were given at the ADHD diagnostic appointment?**

Prompts: How would you describe the information you were given? Did it make sense?

Did it fit with your understanding of your child?

Was there anything unexpected?

**4) Did you know much about ADHD before your child got the diagnosis?**

Prompts: What did you think about ADHD back then?

**5) What did you think of the ADHD assessment process?**

Prompts: What was it like for you when you were going through the ADHD assessment?

Roughly how many appointments did you have? Were they all in person?

How well did the clinicians understand your child during the assessment?

If private diagnosis – why did you opt for a private assessment rather than NHS?

**6) How has getting the ADHD diagnosis made a difference?**

Prompts: to you? and your child?

Has anything changed?

What have been the benefits and challenges of getting the diagnosis?

Positives and negatives?

**7) Do you have any recommendations for services about how you they could improve the way they undertake ADHD assessments and communicate the outcome?**

**8) Any other thoughts/comments/questions?**

## Appendix G Ethical Approval



ERGO II – Ethics and Research Governance Online <https://www.ergo2.soton.ac.uk>

Submission ID: 78252

Submission Title: Parents' Experience of their Child Receiving an ADHD Diagnosis in England

Submitter Name: Kristina Todorova

Your submission has now been approved by the Faculty Ethics Committee. You can begin your research unless you are still awaiting any other reviews or conditions of your approval.

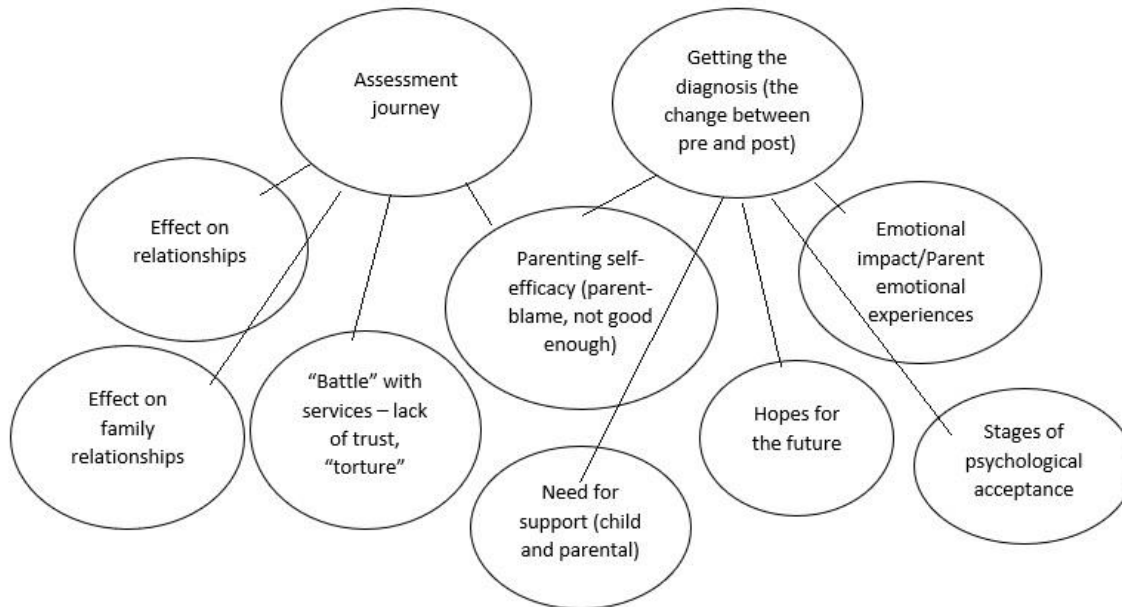
Comments:

- 
- thank you for making the requested changes. Good luck with the study

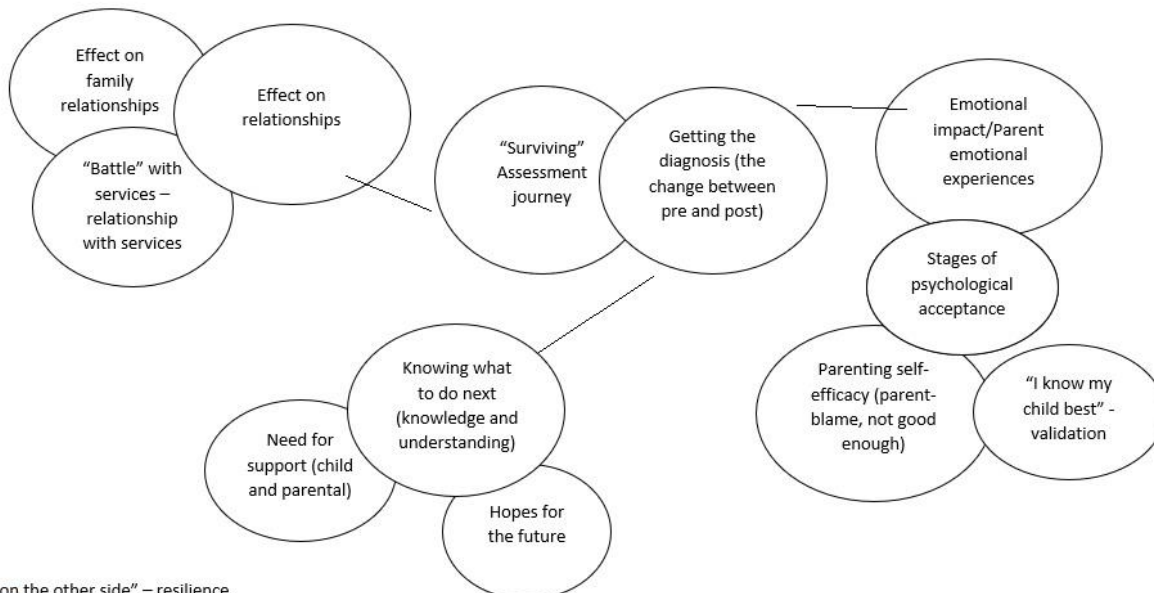
[Click here to view the submission](#)

# Appendix H Thematic Map Evolution

## Thematic map – 1<sup>st</sup> phase



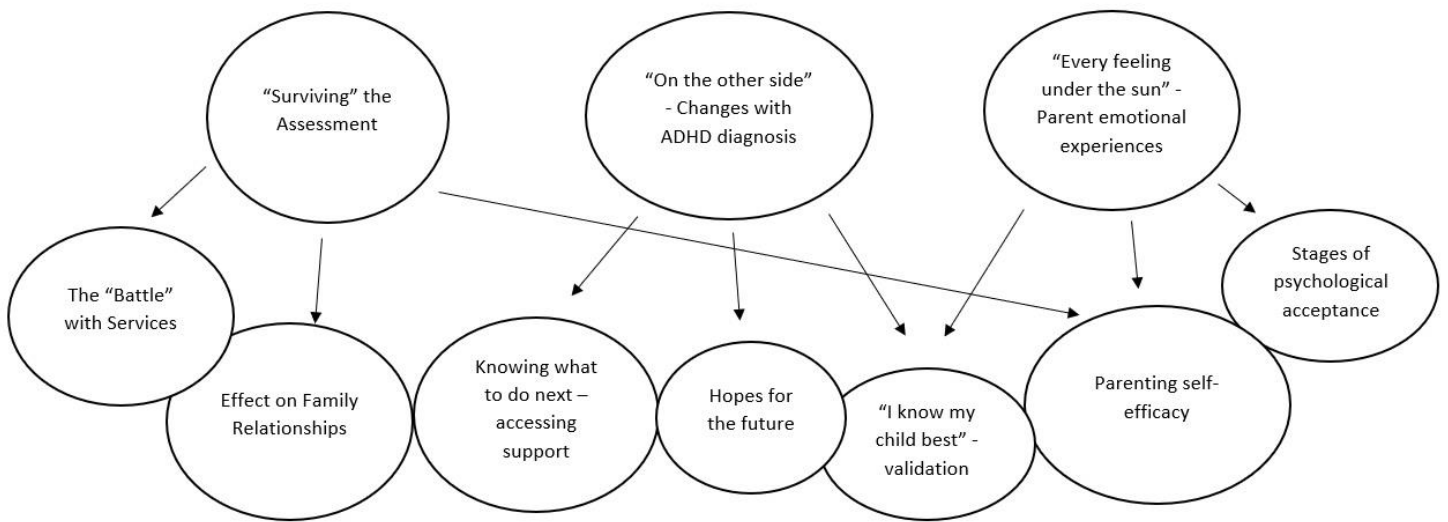
## Thematic map – 2<sup>nd</sup> phase



"on the other side" – resilience



**Thematic map – Final version**



# Appendix I      Journal Submission guidelines

Chapter 1 (Systematic review): Clinical Psychology Review

Guidelines:

<https://www.sciencedirect.com/journal/clinical-psychology-review>

Manuscripts should ordinarily not exceed 50 pages, *including* references and tabular material. Exceptions may be made with prior approval of the Editor in Chief. Manuscript length can often be managed through the judicious use of appendices. In general the References section should be limited to citations actually discussed in the text. References to articles solely included in meta-analyses should be included in an appendix, which will appear in the on line version of the paper but not in the print copy. Similarly, extensive Tables describing study characteristics, containing material published elsewhere, or presenting formulas and other technical material should also be included in an appendix. Authors can direct readers to the appendices in appropriate places in the text.

It is authors' responsibility to ensure their reviews are comprehensive and as up to date as possible (at least to 3 months within date of submission) so the data are still current at the time of publication. Authors are referred to the PRISMA Guidelines (<http://www.prisma-statement.org/>) for guidance in conducting reviews and preparing manuscripts. Adherence to the Guidelines is not required, but is recommended to enhance quality of submissions and impact of published papers on the field.

Chapter 2 (Empirical study): Journal of Child and Family Studies

Guidelines:

<https://www.springer.com/journal/10826/submission-guidelines>

## Manuscript Style

All manuscripts should follow the recommendations of the 2019 Publication Manual of the American Psychological Association (Seventh Edition). Submissions should be formatted to print out double-spaced at standard 8" x 11" paper dimensions, using a 10 pt. font size and a default typeface (recommended fonts are Times, Times New Roman, Calibri and Arial). Set all margins at one inch, and do not justify the right margin. Double-space the entire manuscript, including title page, abstract, list of references, tables, and figure captions. After the title page, number pages consecutively throughout including the reference pages, tables, and figure legends. Manuscripts should be no more than 30 pages in length, including all tables, figures, and references.

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