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# "I felt like a broken person": The Experiences of Women Navigating A Late Neurodiversity Diagnosis.

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Portfolio submitted in fulfilment of the requirements for the Professional Doctorate in Counselling Psychology (DPsych)

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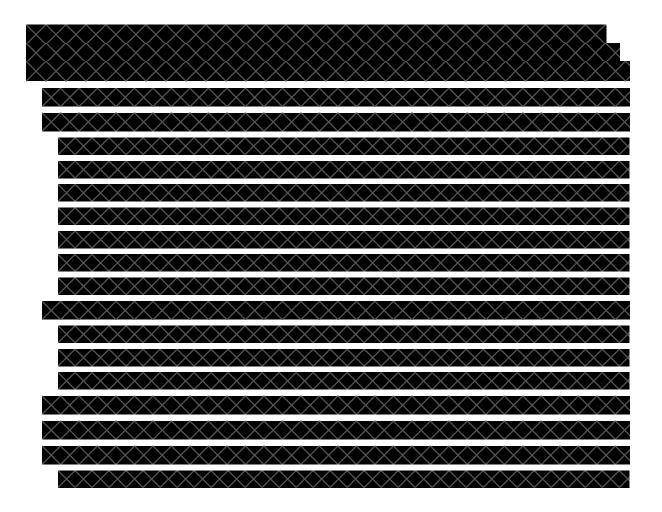
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## **List of Abbreviations**

ADHD = Attention Deficit Hyperactivity Disorder

NHS = National Health Services

BIPOC = Black, Indigenous, and People of Colour

POC = People of Colour

APA = American Psychological Association

NICE = National Institute for Health and Care Excellence

DSM = The Diagnostic and Statistical Manual of Mental Disorders

WHO = World Health Organisation

ICD = International Classification of Diseases

PTSD = Post Traumatic Stress Disorder

CBT = Cognitive Behavioural Therapy

GT = Grounded Theory

TA = Thematic Analysis

GP = General Practitioner

CAMHS = Child and Adolescent Mental Health Services

RTA = Reflexive Thematic Analysis

RSD = Rejection Sensitive Dysphoria

CPN = Community Psychiatric Nurse

BPS = British Psychological Society

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## **Declaration of Powers of Discretion**

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#### **Preface**

#### **Introduction to the Preface**

From my earliest experiences learning about human behaviour, I have been taught about what behaviour we as a collective label as 'normal', thus allowing us to classify behaviour that is deemed 'abnormal' as 'disordered'. The presence of diagnostic manuals and guidelines stood as proof that normal and abnormal are fixed, universal concepts, thus influencing the way I interacted with the world. However, the more I engaged with these systems and institutions, the more I questioned if these norms were the 'absolute truth' and whether they were social constructs instead, dictated and shaped by those in power.

This awareness came with an understanding of the systematic marginalisation and injustice experienced by those who we other by labelling them as 'abnormal' or 'disordered'. Sitting and witnessing this injustice was painful but truly fostered a spirit of social justice within me, prompting my own journey of deconstructing 'normalcy'. Here, engagement with the counselling psychology training, working with clients, and conducting this research project in tandem furthered my ability to critically interact with the world around me. It encouraged the idea of multiplicity of truth, allowing me to move away from this idea of 'one' truth. The intersectionality theory was key in facilitating an understanding of how our experiences are shaped by the multiple identities we hold, thereby guiding our 'truth'. In parallel with the process of deconstructing, I began integrating the novel insights generated from my journey, enabling the development of a new worldview that was updated, nuanced, and considered.

Therefore, as I began reflecting on different themes that linked my journey on the doctoral programme, the research project, publishable paper, and case study, the theme of integration felt apt. Here, integration could be defined as the act of 'bringing together' different elements or parts creating a cohesive whole.

#### Overview of the Portfolio

In the following three sections, I will provide a summary of the components that make up this portfolio, namely (A) The Doctorial Research Thesis; (B) The Publishable Paper; (C) The Combined Case Study and Process Report. Following this, the theme of integration is explored in the context of each of these components, before concluding with a reflection on my personal ties to the theme.

#### Part A: Doctoral Research Thesis

In Part A, I present my doctoral research thesis, a study exploring the experiences of women navigating a late ADHD diagnosis in the UK. Data was gathered through semi-structured interviews with eight women who have grappled with this reality. The methodology of a reflexive thematic analysis was adopted to systematically understand the data collected, which allowed the production of a convincing and coherent story for the reader. A critical realist stance was assumed, and both a social constructionist and experiential epistemological stance were taken towards the analysis. Moreover, the reflexive nature of this methodology facilitated a deep and thorough reflection on the ways in which my multiple identities shaped the study. The finding illuminated the multi-layered impact that a late diagnosis had on an individual, from their sense of self to their interpersonal relationships. The various novel findings of this study were examined against existing literature. Clinical and wider implications as well as future directions for research are also reported.

## Part B: Publishable Paper

The second component of this portfolio is a manuscript written for submission to the SAGE Publications Journal of Attention Disorders (JAD). It includes a summary of the research presented in part A.

JAD was specifically chosen due to its focus on attention disorders which would enable this research to be received by a multidisciplinary audience, while simultaneously allowing for high visibility, enabling both short-term and long-term change. It is hoped that this study amplifies the voices of those calling for systematic change in how we understand and diagnose ADHD. The publishable paper is written in accordance with the guidelines provided by the JAD, which have been appended to the publishable paper.

# Part C: Combined Case Study and Process Report

The last component of this portfolio includes my clinical work conducted during my final year placement at a disability charity, titled "Being With Versus Doing To: Integrating Person-Centred Approaches and Psychodynamic Approaches to Formulate Avoidance". The piece explores my experience of working with a 27-year-old, White British, Cis-Gendered woman, Charlotte (pseudonym), who was diagnosed with Dyslexia in young adulthood. Due to being diagnosed in adulthood, Charlotte grew up internalising her Dyslexia symptom as being representations of personality flaws (e.g., being a 'slow' learner). Moreover, she adopted a range of coping/masking strategies as a way of survival, which often came at the detriment of her health and well-being.

In my work with Charlotte, I aimed to adopt a non-judgemental, safe, neuro-affirmative approach that embodied the values of the humanistic underpinnings of counselling psychology. We initially began working together using a person-centred approach which revealed Charlotte's introjected belief that showing emotion is a sign of weakness. Charlotte's avoidance of emotions also began showing up in our therapeutic space as I noticed that she would avoid going near content that would elicit a strong emotional reaction, leading to a feeling of stuck-ness. I found it difficult to address this within the frame of the person-centred approach, leading me to draw on assimilative integration, integrating elements of psychodynamic approaches within the host model of person-centred therapy.

While integrating these two models enabled therapeutic movement, it also led to feelings of stuckness, between the "being with" encouraged stance of person-centred therapy and the "doing to" stance encouraged psychodynamic approaches. I reflect on this tension and the impact that my own avoidance had on the therapeutic process, exploring how this awareness enabled movement away from the stuck-ness. In turn, this allowed Charlotte to reconnect with her emotions and begin the process of attuning to her actualising tendency, facilitating growth and change. The ability to attune to my felt sense and therapeutic voice have been core and formative skills I have gained during the doctoral programme.

## 'Integration' as Core Theme

The theme of integration relates to the three pieces detailed above in several ways. First and foremost, the journey of receiving a neurodiversity diagnosis in adulthood was defined as being life-changing by both, the participants of the research project and my client, Charlotte. The diagnosis evoked a blend of emotions from feeling validated to relieved to angry and bitter, with each emotion stemming from a different part. For example, participants often felt relief as they knew something was 'wrong' but struggled to put a finger on it. On the other hand, participants also felt angry for how long it had taken them to receive the diagnosis. The ability to notice and sit with these different emotions and parts enabled participants to move towards acceptance and integration.

Alongside this, participants also reflected on the process of integrating their diagnosis or neurodiversity with the way they viewed themselves and with the other identities they held. Here, it appeared the diagnosis provided participants with a new lens or perspective to view themselves and their experiences. The framework provided by the diagnosis prompted participants to re-engage in the process of meaning-making, whereby they reflected on past versions of themselves that struggled as a consequence of their undiagnosed ADHD. Instead of meeting these parts with judgment or criticism, the understanding provided by the diagnosis enabled them to meet these parts with compassion and understanding. The ability to accept all their different parts and experiences facilitated movement towards an integrated, whole. However, this journey was not straightforward and linear but instead was characterised by oscillation between stages. Intriguingly, I felt as though this movement is what truly enabled integration.

The aforementioned theme of integration also felt deeply relevant to the client case study presented, which explores Charlotte's journey towards integration. Similarly to the participants presented in Part A and Part B, Charlotte was also faced with the lived experience of navigating a late neurodiversity diagnosis in adulthood. While there were many differences within the nuances of these experiences, Charlotte's case study highlights her own journey of acceptance of her identity as being neurodivergent and the integration of this identity with her other identities.

Simultaneously, the study case also explores Charlotte's internal conflict between being vulnerable by showing her emotions and staying psychologically safe. It seemed that this conflict arose from two parts of her with opposing desires—one seeking connection and the other seeking safety. By unpacking this conflict and events that influenced Charlotte's belief of emotions being a sign of weakness, Charlotte was able to gradually begin re-gaining contact with her emotions and expressing them. This was perhaps a sign of her integrating these two parts and moving towards resolution.

Alongside Emms's journey towards integration, this case study also follows my own journey towards integration. By recognising the conflict between the part of me that wanted to "be with" the material versus the part that wanted to "do to", I was able to notice the origins of this tension and reflect on its impact on the therapeutic space. This understanding furthered my ability to synthesise these two modes, leading to me embracing a "doing with" approach.

#### **Personal Ties to The Theme**

I have engaged with the themes detailed above on a personal level as a trainee counselling psychologist and as a client. As someone who has a long-stance history of chasing perfection, I held the belief that to be perfectly integrated one must eliminate all inner conflict and be in perfect alignment. Unsurprisingly, this led to the denial of many parts of myself that I deemed as being unworthy fostering deep feelings of shame and guilt. However, it was the journey of this doctoral programme that highlighted that integration is not about being in perfect alignment, but instead is about allowing different aspects of myself to coexist and accepting these parts for what they are.

This course has been far from easy and has occasionally led to moments of internal disharmony. During these moments, it was my village, my collective, that gave me the courage to re-engage in the journey of integration. For this reason, it feels like the theme of a collective runs deep with this portfolio being a product of co-creation between the participants who engaged in this research, my client(s), supervisors, peers, colleagues, and all those whom I encountered on this journey.

The portfolio detailed below, therefore, stands as somewhat of an example of human beings engaging in the act of integrating. As I come to the end of this course, I recognise that this is not the end of this process, yet I believe that the learning and growth from three years of this training programme (and the many years that led to this moment), will sustain me on the journey ahead.

PART A: Doctoral Research Thesis: "I felt like a broken person": The Experiences Of Women Navigating A Late ADHD Diagnosis In The UK

#### Abstract

**Aim:** To explore the experiences of women diagnosed with ADHD in adulthood, in the UK.

**Background**: Women are more likely to be diagnosed with ADHD later in life, than men. Yet, there is limited research that has explored women's experiences of navigating a late diagnosis, specifically in the UK.

**Methods**: Eight women who were diagnosed with ADHD in adulthood were interviewed. Women were aged between 28 - 53 years and were diagnosed via the National Health Services in the UK. Interviews were transcribed verbatim, and the resulting data was analysed using a reflexive thematic analysis. Four themes were developed as a result.

Findings: 'A childhood of undiagnosed ADHD' revealed that participants experienced distress from a young age and reported low self-esteem. The shared narrative of being misunderstood and dismissed by professionals was uncovered, with some reporting that the ADHD diagnosis was overshadowed by another diagnosis. 'ADHD as a possibility and seeking out a diagnosis' captured the series of events that led to participants seeking out a diagnosis, with a running theme of self-advocacy being present. 'Receiving an ADHD diagnosis' highlights the mixed emotions felt by participants following the diagnosis, the process of re-framing past experiences through the lens of ADHD, and the support (or lack thereof) after receiving the diagnosis. 'Life with an ADHD diagnosis' highlights the impact that the diagnosis had on participants' sense of self and identity and the interplay between the diagnosis and their other identities. Participants' accounts also brought to light the role that stigma and social discourses had on their experience of ADHD.

**Conclusion**: The finding illuminated the multi-layered impact that a late diagnosis had on an individual, from their sense of self to their interpersonal relationships. Targets for future research, service and policy development, as well as clinical practice, are identified and explored.

# **Chapter 1: Introduction**

#### 1.1. Introduction

This research project seeks to explore the experience of women who have received a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) in adulthood. This comes following the recent surge in demand for ADHD assessments over recent years (Lang et al., 2024). This chapter will explore and review the literature on what research is available on gender disparities in ADHD. To synthesise information on this topic, the chapter has been broken down into different sections. First, the topic of ADHD is introduced, exploring its history and origins, symptomology, prevalence rates, and trends. Discourses around ADHD are then discussed, situating the current project within the wider social landscape at this time. Next, the presence of gender disparities in rates of diagnosis is explored using a bio-psycho-social lens, highlighting a plausible pipeline for these disparities. The impact of a late diagnosis and the current state of ADHD services in the UK is then discussed. An important aspect of this chapter is that it aims to identify limitations and gaps in the literature. This enables the development of a clear rationale for the research, and details around its aims and objectives are then mentioned before discussing its relevance to the field of counselling psychology. The chapter concluded with a reflexivity section.

## 1.2. Statement On Language Used

It is to be noted that this thesis refers to the concept of gender and sex as the same construct for the sake of the argument. However, the author recognised that while the two may be deeply interwoven, they are separate constructs. Gender refers to the characteristics of women, men, girls, and boys that are socially constructed, while sex refers to the biological aspects of a human determined by their anatomy, chromosomes, and hormones (Stroller, 1964; De Beauvoir, 1949). Present literature has failed to acknowledge this difference; therefore, the terms males/females and men/women have been used interchangeably.

Alongside this, there are long-standing differences in opinions around the language of ADHD, with some individuals with lived experience expressing a preference for person-first language (e.g., individual with ADHD), whilst others prefer identity-first

language (e.g., ADHDer or neurodivergent). Individuals who prefer using person-first language often report that identity-first language reduces them to a specific disorder. While this has been a well-researched topic in Autism research (e.g., Kenny et al., 2016), there is a lack of research that has explored language preference in ADHD. In an attempt to reconcile this tension, I have tried to stay with the language used by the author, and by my participants; therefore, I have switched between person-first language and identity-first language.

The language of race and ethnicity is complex and nuanced (Atkin et al. 2022; Fernando, 1991). As the author, I have decided to use the term Black, and Indigenous People of Colour (BIPOC) instead of People of Colour (POC). This decision has been made as I feel as though the title of PoC reinforced the binary of White and "the Other", therefore perpetuating White-centeredness.

# 1.3. Terminology & Definitions

This section is intended to offer the definitions of some of the key terms, explaining how they are understood within the context of the present study.

**Attention Deficit Hyperactivity Disorder (ADHD)**: A neurodevelopmental disorder characterised by executive dysfunction leading to symptoms of hyperactivity, impulsivity, and emotional dysregulation (APA, 2013).

**Neurodiversity**: Refers to the natural variations in human brain functioning and cognitive processes. It suggests that conditions such as autism, ADHD, dyslexia, and others are part of normal human diversity rather than disorders to be cured (Singer, 1998; Chapman, 2020).

**Neurotypical**: Refers to an individual or a group of individuals whose brain function and cognitive processes are considered the norm within the general population (Singer, 1998; Chapman, 2020).

**Neurodivergent (singular), Neurodiverse (plural)**: An alternative to deficit-based language such as disorder. Refers to an individual or a group of individuals whose

brain processes information in a way that is not considered to be the norm within the general population (Singer, 1998; Chapman, 2020).

**Neurodiversity-affirmative (commonly referred to as neuro-affirming)**: Refers to an approach that recognises, validates, and values neurodiversity (Hartman et al., 2023).

**National Health Services (NHS)**: The NHS is the publicly funded healthcare system of the UK comprising NHS England, NHS Scotland, and NHS Wales.

**Right to Choose**: Refers to a right provided under the NHS Choice Framework published in the NHS Constitution for England in 2018. It outlines that any individual registered with a GP surgery in England has the legal right to choose the location of their first out-patient appointment with any provider that holds an NHS-commissioned contract (includes both NHS services and privately-run services) (NHS, 2023).

**Ableism**: Refers to the discrimination of individuals with disabilities (both visible and invisible), in favour of individuals without disabilities. It can be both conscious/explicit, or unconscious/implicit in nature (Hartman et al., 2023).

**Camouflaging:** Refers to a strategy used by neurodivergent individuals, consciously or unconsciously, to blend in or camouflage to appear more 'neurotypical' and thus be more accepted by society (Bradley et al., 2021; Van Der Putten et al., 2024). Such strategies can often involve **masking** symptoms and/or employing the use of **compensatory** strategies to overcome social difficulties (Livingston, Shah, & Happé, 2019; Van Der Putten et al., 2024)

**Co-occurring**: Refers to the presence of two or more conditions are present at the same time, in the same individual, without implying a specific relationship between them (Tyrer, 2017). An encouraged alternative to the term "comorbid" as it avoids pathologising the individual and shifts the focus from the clinical diagnosis to the holistic experience.

# 1.4. "Brain Damage Syndrome": The History of ADHD

ADHD first made its appearance in the official diagnostic nomenclature in 1968 within the second Diagnostic and Statistical Manual of Mental Disorders (DSM-II) under the name of "hyperkinetic impulse disorder" (APA, 1968). This diagnosis was re-named in the third edition of the DSM (APA, 1980), to Attention Deficit Disorder (ADD), defined with two main subtypes — with hyperactivity and without hyperactivity. However, disagreements between professionals regarding the subtypes of ADD prompted APA to remove these in the revised version of the DSM-III, DSM-III-R, and instead creating a new category of ADD without hyperactivity, referring to it as undifferentiated ADHD, giving rise to the familiar title that is now commonly used. Published in 1987, this revised manual also had two major changes. Firstly, the DSM-III-R now formally recognised that ADHD symptoms persist into adulthood, however, diagnoses made in adulthood were required to illustrate that symptom onset began in childhood (Adler & Chua, 2002). Alongside this, the DSM-III-R is also where the three subtypes of ADHD first emerged under the names of predominantly inattentive type, predominantly hyperactive type, and a combined type of ADHD.

In 2013, the latest version of the DSM, DSM-V was published where ADHD is defined as a "neurodevelopmental disorder" which is characterised by a group of shared core symptoms, namely, hyperactivity, impulsivity, and/or inattention (APA, 2013). The subtypes of ADHD are now referred to as "presentations", which can be experienced in varying intensities from mild, to moderate, to severe. The movement between names and descriptions illuminates how our understanding of ADHD has evolved over the years.

It is often this history that makes people think ADHD is a "modern disorder". However, the core symptoms of hyperactivity, impulsivity, and inattention have been recognised in a cluster for much longer than their first appearance in the DSM. Whilst the exact origin of ADHD is unclear, some have dated its first reference back to Hippocrates (400 BC), who described a patient who had "...quickened responses to sensory experience, but also less tenaciousness because the soul moves on quickly to the next impression" (Hippocrates, 1849, taken from Martinez-Badía & Martinez-Raga, 2015, p.382). For decades following, these core symptoms were reported in case

studies and books under the names of attention deficit (Melchior Adam Weikard, 1775; Barkley & Peters, 2012), disease of attention (Alexander Crichton, 1798; Berrios, 2006), and brain damage syndrome (George Still, 1902). Therefore, ADHD is by no means a "modern" disorder and has been observed for centuries. However, it appears that more recently, the diagnosis has been 'medicalised' as witnessed by its introduction into the DSM. Medicalisation, which literally means "to make medical", happens when an everyday occurrence is conceptualised using a medical framework and medical terminology to describe it (Conrad & Schneider, 1992, p. 210). Reflecting on the socio-political context around the time when ADHD was first recognised by the DSM, provides clues as to why this phenomenon may have occurred. For instance, in 1870, the Education Act was passed in the UK that mandated education for children (Martinez-Badía & Martinez-Raga, 2015). The movement into school-based settings may have accentuated ADHD symptoms in children, that would have otherwise remained unnamed. Subsequently, educators and parents may have turned to professionals (e.g., paediatricians) in order to understand this behaviour. In the longterm, this may have spurred the process of medicalisation of ADHD.

Currently, to be diagnosed with ADHD, an individual should meet clear diagnostic criteria outlined in the DSM-5 (APA, 2013) or the International Classification of Diseases (ICD-11; World Health Organisation, 2019) (See Appendix A for more information). Interestingly, the ICD-11, which has recently come into effect, is the first edition of this manual that uses the term "ADHD". Prior to this, ADHD was referred to as 'hyperkinetic disorder' (WHO, 2016). According to the newer manual, ADHD symptoms are categorised into two domains – inattention and hyperactive and impulsivity.

Although diagnostic manuals outline the symptoms and characteristics of ADHD, doubts persist about the possibility of achieving an objective diagnosis for the condition (Gualtieri & Johnson, 2005). Presently, the "gold-standard" for ADHD diagnosis includes comprehensive clinical history and examination (usually involving parents/caregivers), rating scales, behavioural observations, and neuropsychological testing (see Appendix A for a list of diagnostic measures). However, the subjective nature of these assessments, coupled with the financial burden, has fostered

disagreements around the objectivity of ADHD diagnoses between professionals (Gualtieri & Johnson, 2005).

Here, is it important to note that the DSM criteria for ADHD has been heavily criticised for its construction of ADHD through a 'deficit' lens, consequently ignoring internal experiences of ADHD (Jane Wise, 2024). For instance, Sonny Jane Wise, a lived experience educator, has advocated for the reframing of the criteria for ADHD moving away from a deficit lens to a difference lens. Therefore, rather than the criteria for a diagnosis being "[the individual] often has difficulty sustaining attention in tasks or play activities", Wise suggests that it could be rephrased to say, "experiences a non-linear attention span where one's attention is determined by personal interest, values, urgency, novelty, and capacity". Alternatively, researchers have also suggested employing the use of the biopsychosocial model as a way of holistically understanding, assessing, and this managing ADHD (Salamanca, 2013).

# 1.5. Prevalence, Trends, & ADHD

In terms of trends and prevalence, ADHD is a common disorder. Worldwide prevalence falls between 5 and 7% in children and adolescents (Thomas et al., 2015; Polanczyk et al., 2014), and 2 and 4% in adults (Willcutt, 2012; Simon et al., 2009). The heterogeneity in diagnosis stems from the use of different diagnostic tools used to measure symptoms of ADHD (Döpfner et al., 2008). In the last two decades, there has been a significant increase in rates of diagnosis of ADHD in the UK (Renoux, 2016; Young et al., 2021). Furthermore, data spanned across two decades suggests an upward trend in the prescription of medication, highlighting the rise in diagnosis rates (NICE, 2013).

Another common misconception is that ADHD symptoms disappear after childhood. In reality, ADHD is a chronic condition, impacting individuals across the lifespan. In other words, individuals present symptoms beginning in childhood and persist into adulthood (Faraone, Biederman & Mick, 2006; Uchida et al., 2018; Lieshout et al., 2016). However, ADHD symptoms do tend to decline with an increase in age. A greater decline has been noted for hyperactivity-impulsive symptoms, in comparison to inattention symptoms (Döpfner et al., 2015). For this reason, adults with ADHD tend

to have subtler presentations characterised by more inattention-internalised symptoms rather than overt externalised behaviour (Young et al., 2020)

# 1.6. Discourses around ADHD: The Myth of 'Normal'?

The current research has been conducted at a time of great debate within the field, which is characterised by the multiple discourses around ADHD, with each of these being subject to a wide debate. These tensions are attributable, in part to the very different ways in which people experience and understand ADHD. Therefore, in order to introduce ADHD, it is necessary to explore some of the discourses that surround it.

#### 1.6.1. The Medical Model of ADHD

Perhaps the most dominant discourse is that of the medical model, which posits that ADHD is a 'neurodevelopmental impairment' and results in individuals developing deficits and functional limitations. According to this model, the appropriate response to ADHD is to strive to 'fix' or 'treat' the individual with the implied goal of getting them to fit into society (Dwyer, 2022). Therefore, medication is a cornerstone of treatment in the medical model. Central nervous system stimulants (e.g., Methylphenidate and Lisdexamphetamine) are frequently prescribed to help individuals manage ADHD symptoms. These medications are believed to operate by blocking the reuptake or reabsorption of Dopamine and Norepinephrine – two key neurotransmitters indicated in pre-frontal lobe functioning (Idress et al., 2023; Del Campo et al., 2011). The prefrontal context has previously been implicated in the regulation of attention, behaviour, and emotion, with deficits in prefrontal context functioning being linked to ADHD symptoms, such as poor impulse control and difficulties with sustaining attention (Salavert et al., 2015). This model is supported by research that has highlighted high medication efficacy, with studies finding that stimulant treatment leads to measurable improvement in daily function for individuals with ADHD (Surman et al., 2013). The dominance of this model is emphasised by the use of the terms "deficit" and "disorder" within the diagnostic label and the widescale use of medications by individuals diagnosed with ADHD (McKechnie et al., 2023).

# 1.6.2. Social Disability Theory & The Neurodiversity Movement

The social disability theory, linked to the social model of disability, refutes that ADHD is a "disorder", shifting the focus from individual impairments to societal barriers and attitudes that disable people with ADHD (Thacher, 2024). Therefore, rather than the "disorder" or "disability" being inside an individual, the social disability theory suggests that an individual experiences disability as a result of the interaction between the individual and society (Shaw, 2021).

An offspring of the social disability theory is the neurodiversity movement, with the term "neurodiversity" being coined by Harvey Blume (1997) and made popular by Judy Singer (1998) (Botha et al., 2024). Here, the term 'neuro' alludes to neuroscience and differences in brain structure, and 'diversity' is a political term referencing differences with its origins in the Black American civil rights movement (Harris, 2023). The term also draws influence from the principle of 'Biodiversity' which advocates for the conservation of all species as being essential for a flourishing ecosystem (Doyle, 2020). As suggested by its name, this movement views neurological differences as being variation of human diversity. Like the social disability theory, it challenges the medical model's implication of individuals with ADHD (and other neurodevelopmental conditions), as being "disordered" or somehow "less than", "neurotypicals". It also moves away from the binary categories of diagnosis and instead suggests that the spectrum of traits associated with ADHD exists in all human beings but is experienced at a greater intensity by those individuals who are labelled as having ADHD. Both these models also question the intention of ADHD medication, querying if its purpose is to "fix" individuals by transforming their 'undesirable' ADHD behaviour (Druedahl & Sporrong, 2020).

Table 1 summaries the main differences between the medical model, the social disability theory, and the neurodiversity paradigm in relation to ADHD.

# 1.6.3. "Is ADHD Real?": Trauma & ADHD

In the context of these discourses, some of queried the validity of ADHD, connecting its symptomology and presentation to other diagnoses, such as trauma.

Van Der Kolk (2000) defined a traumatic event as one that confronts an individual "with such horror and threat that it may temporarily or permanently alter their capacity to cope, their biological threat perception, and their concepts of themselves" (p. 8). As a consequence of experiencing trauma, an individual may begin exhibiting symptoms such as inattention, emotional dysregulation, and/or sleep disturbances. These symptoms overlap substantially with the symptomatic profile of ADHD, leading many to speculate if ADHD and trauma are related or if ADHD is a manifestation of trauma (Szymanski, Sapanski, & Conway, 2011).

This discourse has been prevalent for a long time, with some practitioners questioning the "realness" of ADHD. For instance, Seitler (2015) asks the question, "Is ADHD a real neurological disorder or collection of psychosocial symptomatic behaviours?", with Honkasilta and Koutsoklenis (2022) reflecting on "The (Un)real Existence of ADHD". Whilst questioning the legitimacy of ADHD, both authors spotlight research that has failed to identify a unique aetiology for ADHD. For instance, whilst ADHD is considered to be in part genetic, no genetic markers for ADHD have consistently been reported with high effect sizes (Buitelaar et al., 2022; Gallo and Posner, 2016). This discourse has significant implications with some practitioners asserting the view that by "treating" the symptoms of ADHD through psychological treatment, we can "cure" individuals from their ADHD (Seitler, 2015; Rafalovich, 2002).

The relationship between ADHD and trauma is complex. This complexity in part may be attributable to lack of the consensus surrounding the definition of trauma. For instance, the DSM-5 (APA, 2013) only makes mention of Post-Traumatic Stress Disorder (PSTD), which is caused by a single traumatic event or a series of discrete traumatic events (e.g., war, natural disasters). However, alongside this, practitioners have long debated the presence of "complex PSTD", often referred to as c-PSTD, which is caused by prolonged, repeated exposure to trauma, particularly during early developmental periods or in situations where an individual cannot escape (e.g., domestic violence, child abuse; Franco, 2021; Herman, 1992). c-PTSD is recognised in ICD-11, but not within the DSM-5 questioning the clinical utility of the diagnosis (Rød & Schmidt, 2021). This difference in opinion has further complicated research, with researchers resolving this by measuring PSTD.

Early research studying the link between the two suggested that ADHD was not a risk factor for the development of PSTD, however, more recent research has painted a different picture. For instance, Spencer and Colleagues (2016) reported a bi-directional link between ADHD and PTSD, suggesting that the relative risk for PTSD in individuals with ADHD is four times that of individuals without ADHD. Research investigating this area has also emphasised that living in a world constructed and designed for 'neurotypical' individuals results in chronic stress for individuals who are neurodivergent (Grove et al., 2023). This chronic stress can exacerbate the risk of developing PTSD. The bi-directional nature of this relationship raises the question of well, what came first?

**Table 1**Key differences between the Medical Model of Disability, the Social Model of Disability, and the Neurodiversity Paradigm in relation to ADHD

	The Medical Model	The Social	The
	of ADHD	Disability Theory	Neurodiversity
	OI ADIID	of ADHD	Paradigm
View on ADHD	ADHD is a neurodevelopmental condition which to deficits and impairments.	ADHD is experienced as disabling as result of societal barriers and ableistic beliefs.	ADHD is a natural variation in human function rather than a disorder.
Aim/Objective	To diagnose and treat individuals with ADHD, with the aim of fixing them so that they may fit into society.	To address and remove structural barriers, to increase accessibility.	To promote understanding and acceptance of neurodivergence.
Perception of the Individual	Viewed as a disordered or someone to be fixed.	Viewed as a person who is disabled by	Viewed as a person with unique strengths and challenges.

		societal structures.	
Responsibility of ADHD	Lies with medical professionals to fix the individual and the individual to 'comply' with professionals.	Lies with society to adapt and be more inclusive.	Lies with society to value and support neurodiversity.
Intervention(s)	Medication and psycho-social treatment aimed at 'fixing' the deficit.	Social, structural and attitudinal changes to increase accessibility and reduce stigma.	Educational and structural changes to promote inclusion and reduce stigma.

# 1.7. ADHD & Gender Disparities

The following section will explore the gender disparities prevalent in the rates of ADHD diagnoses, particularly focusing on the experiences of women and girls. The academic literature presented is based on a comprehensive literature search on gender disparities in ADHD. Literature was sourced using Psychlnfo. The search began with the topic of 'ADHD', which produced too many search items therefore the Boolean operator of 'AND' was used in conjunction with terms such as "women" and "female". This yielded 1,631 results. A Google Scholar search was also conducted to ensure all relevant literature was included.

ADHD was once thought of as a predominantly male disorder. While this myth has been debunked, statistics suggest that ADHD is diagnosed more often in boys than girls. The most frequent reported statistic is a 3:1 difference, however, the exact statistic has differed based on diagnostic tools and populations (Döpfner et al., 2015). Intriguingly, by adulthood, the male to female gender ratio of ADHD is closer to 1:1 (Biederman et al., 1994; Kessler et al., 2006). This phenomenon has raised two plausible hypotheses: (1) ADHD is less common in girls than boys or (2) ADHD is being underdiagnosed and therefore undertreated in girls.

Empirical evidence has suggested that the latter may be true, such that these gender disparities primarily exist as ADHD symptoms manifest differently in males and females. Rucklidge (2010) summarised the gender differences such that females present with higher inattention symptoms, meanwhile males present with high impulsivity symptoms. Females also tend to report lower self-esteem and higher symptoms of depression and anxiety. Moreover, while males with ADHD are more likely to experience delinquent behaviour, women are more likely to report drug use or become pregnant younger.

In addition to this, women with ADHD are more likely to experience inattention, hyperactivity, and impairments in comparison to men with ADHD. A cross-sectional study by Fedele et al., (2012) sampled 164 US college students with ADHD and 710 US college students without ADHD. They asked participants to complete online measures of symptoms and 'impairments' caused by ADHD. Impairments were assessed using Barkley's Current and Childhood Symptoms Scale and measured the extent to which participants' ADHD symptoms impacted multiple life domains (e.g., family, work, social, education, relationships, money, driving, recreation, and daily responsibilities), in the past six months. The study found that women with ADHD endorsed higher levels of impairment (M = 15.20, SD = 6.65) than men (M = 12.08, SD = 5.31). These impairments had implications on their home and social life, education, and finances. However, the cross-sectional nature of data collection makes it difficult to assess the directionality of this association. The reliance on self-reported data also threatens the validity and reliability of the conclusions reached.

The study sample also limits the findings for various reasons. For instance, the sample consisted of students and was based in the US, with 85% of participants being White Americans. Furthermore, research has also found ADHD symptoms may be context-dependent, with certain environments being more conducive to ADHD symptoms than others (Lasky et al., 2016). This threatens the validity and generatability of these findings to a wider population (e.g., individuals who are not currently at university or have never been to university).

# 1.8. Gender Disparities: But Why?

Several hypotheses have been postulated to account for factors that may be driving the gender gap that exists in the rates of ADHD diagnosis. A bio-psycho-social lens has been adopted to provide a holistic and comprehensive understanding of potential causes.

# 1.8.1. Biological Factors: Hormonal Fluctuations

Research has indicated that ADHD symptoms tend to get more salient for females following puberty due to the unique interplay with brain maturation, hormonal influence and/or pre-existing vulnerabilities (Quinn, 2005; Waite, 2010; Martin, 2024). However, there is a paucity of evidence that has explored the mechanism of interaction between these factors.

A few studies have attempted to take on a lifespan approach by exploring ADHD during different life stages for females (Antoniou et al., 2021). Emerging evidence has suggested that neuroendocrine factors (e.g., hormones) impact the expression of ADHD symptoms. Monitoring of ADHD symptoms during different phases of the menstrual cycle suggests that the first two weeks of the menstrual cycle (which typically lasts about 28 days or 4-weeks) are linked to better control over symptoms, than the latter two weeks (Antoniou et al., 2021). It is hypothesised that this is driven by a rise in progesterone levels. During the luteal phase, consisting of weeks three and four of the menstrual cycle, progesterone decreases further exacerbating the symptoms of ADHD. The unique interaction has also been indicated to impact the effectiveness of medication in females. Quinn & Madhoo (2014) suggest that medication dosage may need to be titrated for females throughout their menstrual cycle for optimal symptom control. There is, however, a lack of literature testing these findings in larger, representative samples, with systematic reviews highlighting that the literature on the relationship between sex hormones and ADHD is not only limited, but also contradictory (Camara, Padoin, & Bolea, 2022; Martin, 2024). Furthermore, there appeared to be a vast body of findings published in women's health magazines, as opposed to peer-reviewed journals, impacting the creditability of findings.

# 1.8.2. Social Factors: Gender Theory & Social Norms

The common saying 'women internalise, and men externalise' rings true with ADHD, whereby girls/women present with inattentive symptoms and men/boys present with hyperactive-impulsive symptoms (Rucklidge, 2010). A plausible explanation for this perhaps comes from Gender Theory which examines how societal norms, expectations, and roles related to gender impact individuals (De Beauvoir, 1949). Applying this theory to the gender disparities in ADHD suggests that the phenomenon of women presenting with more inattention-based symptoms and men presenting with more hyperactive-based symptoms is due to what is deemed socially and culturally acceptable for each gender. For instance, hyperactive behaviour is commonly judged as less socially acceptable in women and girls. Moreover, women and girls face the burden of societal consequences (e.g., marginalisation) if their behaviour falls out of line with what is expected of them (Mellström, 2023). Researchers have also found both boys and girls may exhibit hyperactivity behaviour however, this behaviour may manifest in different ways. For instance, while boys may exhibit anger or aggression, girls may exhibit symptoms such as hyper-talkativeness, flight of thoughts, internal restlessness, and emotional reactivity (Hinshaw, 2002; Nussbaum, 2012). These social norms and gender biases do not just impact how women experience symptoms, but also informs the diagnostic criteria used to diagnose ADHD. Hartung and Widiger (1998) looked at research published in the Journal of Abnormal Child Psychology over the 6 years between the publication of the DSM-III-R (APA, 1987) and the publication of the DSM-IV (APA, 1994). 70 of those studies concerned ADHD, with 81% of participants being male and only 19% female. This research is further supported by the fact that until 1979, there was no systematic research conducted on women with ADHD (Kashani et al., 1979).

Notably, there appears to be an overreliance on quantitative findings to investigate the impact of gender norms on ADHD in women. While quantitative studies have allowed researchers to recognise a link between social norms and ADHD symptoms in girls/women, they arguably fail to capture the depth of this experience. Holthe & Langvik (2017) were one of the first researchers in the field to document the strives and successes of women diagnosed with ADHD as adults. They conducted semi-structured interviews with five women aged 32-to-50 years old. While talking about

their experiences with ADHD, participants spoke about the conflict that occurs between ADHD symptoms and gender norms. For instance, one woman said, "I think women are expected to be able to do all the clean-up and routine work also, in addition to their 'main task'" (p.7) Participants also spoke about how their experience of taking on the role as a mother has exacerbated this frustration, "when I drop my daughter off at the day care, I'm always late, and I can see what the teachers are thinking. People think you're a bad mother, right?" (p.7). This research brings to light that gender norms play a salient role shaping the experience of ADHD. However, it is important to note that all participants in this study were recruited from the US, and vital demographic data such as the ethnicity of the participants is missing. This along with the small sample size questions the transferability and generalisability of findings.

Morgan (2023) conducted a similar study exploring the experiences of women diagnosed with ADHD in adulthood in the UK. Narrative interviews were conducted with 52 women aged 19-to-52 years old with 23 participants identifying as White, seven as Black British, and six as British Asian. When reflecting on their late diagnosis of ADHD, participants reflected on the role that gendered stereotypes had on their experience of ADHD. For some women, being a "good girl" or "being helpful" led them to being 'invisible' and 'slipping through the cracks.' Out of the fear of drawing negative attention or being reprimanded for their symptoms, women adopted strategies that they used to "fit in" or "mask" (e.g., tapping their foot, changing positions, asking to go to the toilet). Whilst these symptoms allowed them to fit in, it also kept them away from being diagnosed with ADHD in a timely manner. When participants attempted to receive support for their symptoms, they were misdiagnosed due to gender-based assumptions made by practitioners. This research extends the findings of Holthe & Langvik (2017) by investigating this phenomenon and its lived experience in the UK, with a larger, more representative sample size. However, this study is not without limitations. For instance, the majority of participants were university students which questions the generalisability of findings to women who did not attend university or are not currently at university. Moreover, research has highlighted that the manifestation of the core symptoms of ADHD may change in different settings (e.g., education setting versus work-based setting) (Lasky et al., 2016; Black, 2023). This jeopardises the transferability of these findings.

The impact of gender biases and gender-based assumptions does not only occur in clinical settings but also in the perceptions of parents and teachers, which may impact the rate at which males and females are referred for an assessment and thus treatment. For instance, Ohan and Visser (2009) recruited 96 parents and 140 teachers in Australia and asked them to read a vignette describing a child displaying symptoms of ADHD. Half of the participants read the vignette with a male name, and the other half read the same vignette with a female name. At the end, participants were asked if they would seek out additional support (e.g., a diagnosis) for the child. Participants, both parents and teachers, were less likely to seek out support for the girls than the boys. A similar study was conducted in England by Groenewald, Emond, and Sayal (2009), whereby 212 teachers from 40 primary schools were asked to read a case vignette (based on DSM-IV criteria) describing a girl with either combined or predominantly inattentive ADHD. Teachers were then asked their view of the girl's difficulties and whether a specialist referral was required. Whilst almost all (98%) of teachers recognised a problem, they were less likely to correctly detect a girl with inattentive ADHD, than combined subtype, or endorse a clinical referral for her. While both these studies have low ecological validity as they involved vignettes rather than real children/cases, they highlight how gender biases impact the likelihood of being referred for an ADHD assessment or further support.

These findings were conceptualised by Lynch and Davison (2024), who suggested an inequitable gendered cycle of ADHD, which begins with ADHD being conceptualised by largely affecting males. As males are more likely to experience hyperactivity-based symptoms, our understanding of ADHD has become one that has privileged this narrative, leading to the belief that ADHD is hyperactive/externalised behaviour. As a result, inattention is often not associated with ADHD and is to some degree, normalised. When situated within an education context, because internalised symptoms of ADHD are not disruptive, females with primarily inattentive ADHD may go un-recognised as they do not display the condition as teachers have come to expect. In turn, fewer girls are referred for clinical assessment for ADHD – and when they are, clinicians will often utilise other diagnoses to explain their symptoms. This leads to the under-diagnosis of ADHD in females, which in turn, further reinforces the belief that ADHD is a 'male' condition. And thus, the cycle continues.

Another social factor that may impact diagnosis rates is stigma. Goffman (1968) defines stigmatisation as being characterised by a person or group that deviates or is devalued from society and social contexts. A growing body of research has highlighted that ADHD carried a strong social stigma within society (Godfrey et al., 2021; Mueller et al., 2012; Holthe & Langvick, 2017). This stigma consequently accentuates the symptoms of ADHD whilst also making it harder for women and girls to be diagnosed and received support for ADHD. For instance, Holthe and Langvick (2017)'s participants reported widespread stigma towards ADHD with some questioning the validity of the diagnosis (e.g., "I think that people think ADHD is sort of a made-up excuse for being unfocused and undisciplined, that it just takes self-control or something." (p. 8)). Furthermore, querying the 'realness' of ADHD does not only minimise and trivialise an individual experience, but also stuns the cultivation of feelings such as empathy and compassion for these individuals. In order to lessen this stigma, some women have made the choice to concealing their diagnosis from some, employing the use of selective disclosure (Holthe & Langvick, 2017; Young et al., 2019).

When understanding stigma and its impact on individuals with ADHD, research has failed to account for intersectional stigma. The term intersectionality was developed by Kimberlé Crenshaw to describe how multiple forms of discrimination, power, and privilege intersect therefore highlighting that everyone has their own unique experiences of discrimination and privilege (Crenshaw, 1991, 2013). Applying this concept to stigma, Turan and Colleagues (2019) refer to intersectional stigma as a "concept that has emerged to characterise the convergence of multiple stigmatised identities within a person or group, and to address their joint effects on health and wellbeing." (p.1). Applying this to the concept to ADHD, the stigma associated with this diagnosis does not exist in a vacuum but instead, stigma from the intersections of identities such as race and gender interact with one another to produce a cumulative effect. Women with ADHD are already faced with the reality of how this marginalised identity impacts and shapes their experience of ADHD. When adding other layers of oppression or multiple marginalised identities, they are faced with stigma that is greater than the sum of its parts. This is especially important as racial disparities have long been reported in the rates of ADHD diagnoses such as individuals from BAME

communities are less likely to receive this diagnosis than their White counterparts in the US (Shi et al., 2021).

The only study to my knowledge that has looked at the lived experience of ADHD in BAME women comes from Waite and Tran (2009). They sampled 16 women recruited from university settings in the US. The sample composed of five African American participants (31%), three Hispanic participants (19%), and two Asian participants (13%). The narratives shared by these women highlighted that increased stigma led to denial of their experiences aligning with that of ADHD, with some noting decreased social support due to this perceived stigma. For instance, one participant shared "Even though some family know about my diagnoses, it's really not open for discussion. Some family members believe doctors made up ADHD just to medicate us [referring to Blacks]. They'd prefer I didn't take the medicine, but without it I sometimes feel like I want to jump out of my skin." (p.81). Taken together, the findings of this study provide key insights into how the intersection between race, gender, and ADHD may interact to further drive the gender disparities prevalent in the rates of diagnosis. However, these findings cannot be transferred to the UK as while there might be similarities within the experience, racial identity is experienced differently in the US and the UK due to distinct historical, social, and cultural factors.

The concepts of intersectional stigma and intersectional privilege are also essential when understanding and deconstructing some of the narratives surrounding ADHD. For instance, more recently, some women have actively attempted to move away from a deficit-focused way of constructing their ADHD, instead regarding their symptoms as being their "superpower". In other words, their ADHD is not something to be fixed but instead provides them with unique strengths and abilities (ADDitude Editors, 2022). However, while this narrative has received some support due to its empowering stance, it has also garnered criticism from others who reflect on how this narrative can be harmful as it glosses over the debilitating nature of ADHD (Seven, 2023).

This is particularly salient for women who experience compounding challenges due to their intersecting identities (such as gender, race, class, or sexuality), as women who hold intersectional privilege based on their other intersecting identities are afforded the ability to reframe ADHD more positively. This may be because they may

experience fewer barriers and systemic inequities. For example, when thinking about Black women with ADHD, the superpower narrative also intersects with other narratives, such as the "strong Black woman" narrative. Together, the intersection of these narratives leads to many Black women with ADHD being under pressure to overemphasise their strengths and be "strong" or "resilient" while downplaying their struggles or challenges (Lackey, 2022). Furthermore, this may also act as a barrier for Black women to seek out support, as the act of help-seeking may riddled with shame and guilt, as it may be a representation that they have failed. Taken together, the concept of intersectionality sheds light on the role that intersectional privilege and stigma have on the narratives that surround ADHD and women.

## 1.8.3. Psychological Factors: Co-occurrences

The socio-cultural norms laid out in front of women at an early age undoubtedly impacts the way girls view themselves, others, and the world. This emotional distress experienced increases the risk of developing co-occurrent conditions, and women who are diagnosed with ADHD in adulthood are more likely to suffer from depressive symptoms, anxiety disorders, eating disorders, substance use, and low self-esteem (Hinshaw et al., 2006; Rucklidge & Kaplan, 1997; Waite, 2010). A late or missed diagnosis is also linked to parenting struggles and problems in maintaining jobs, resulting in a reduced quality of life (Lensing, Zeiner, Sandvik, & Opjordsmoen, 2015; Nadeau & Quinn, 2002). While some researchers believe that these co-occurring disorders are independent of ADHD, others believe they develop as a consequence of undiagnosed ADHD. Regardless, their presence may decrease the likelihood of receiving an ADHD diagnosis in women (Nadeau & Quinn, 2002).

The phenomenon of one diagnosis overshadowing or preventing the accurate diagnosis and treatment of another condition is commonly referred to as diagnostic overshadowing (Agnew-Blais, 2024; Skoglund et al., 2024). Given that women with ADHD are at a greater risk of experiencing co-occurring conditions, practitioners may be more likely to formulate and understand their presentation through the lens of mental health difficulties, thus eclipsing the underlying ADHD (Agnew-Blais, 2024; Morgan, 2023). This is especially important given that practitioners may not associate

women's presentations with ADHD due to the immense focus placed on hyperactive symptoms.

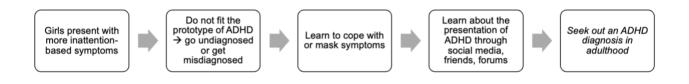
This phenomenon was further supported by qualitative research by Morgan (2023), who found that when participants sought out support, they were often diagnosed with "an emotional condition" such as anxiety and depression, with little effort placed into understanding the cause of the symptoms. In instances where participants sought out support, practitioners were more likely to attribute their symptoms to their childhood rather than querying ADHD. Participants experiencing co-occurring conditions found that this decreased the likelihood of receiving an ADHD diagnosis as the focus turned to management and treatment of the condition.

## 1.9. Plausible Pipeline: From Underdiagnosed to Diagnosis

Based on the research presented above, a plausible pipeline has been proposed for the gender gap (see Figure 1 for diagrammatic representation). Firstly, girls present with more inattention-based symptoms or have learned to internalise their symptoms, than boys. As a result, rather than disrupting the classroom, they may suffer in silence (Morgan, 2023; Lynch & Davison, 2024). Parents, educators, and professionals may either not notice this behaviour or attribute their behaviour to other factors or diagnoses (Holthe & Langvik, 2017). Consequently, girls may adopt self-management as a way of coping with ADHD symptoms (Antoniou et al., 2021; Canela et al., 2017). While these skills may enable them to mask symptoms, they may further exacerbate symptoms in the longer term and lead to secondary conditions such as anxiety, depression, and/or substance use (Boland et al., 2020; Antoniou et al., 2021). Later, women learn about a more comprehensive presentation of ADHD and the manifestation of symptoms in women and girls through social media, friends, and forums, leading them to seeking out a diagnosis in adulthood.

### Figure 1

A Plausible Pipeline For Why Women Are More Often Diagnosed with ADHD in Adulthood



## 1.10. Impact of Late Diagnosis

The implications of undiagnosed ADHD have been known to be grave for several decades (Rucklidge & Kaplan, 1997). While numerous quantitative studies have captured the psychological (e.g., increased anxiety) and functional (e.g., organisational, time management, etc.) implications of undiagnosed ADHD, qualitative studies have allowed for a better understanding of these experiences in-depth. For instance, Attoe and Climie (2023) conducted a narrative systematic literature review of qualitative research on adult women diagnosed with ADHD in adulthood. In total, they reviewed eight papers which were analysed using a thematic analysis, revealing four main themes: (1) impact on social-emotional wellbeing: (2) difficulties in interpersonal relationships; (3) lack of control; and (4) self-acceptance after diagnosis. All eight papers in the review highlighted negative impacts on social-emotional well-being with women with undiagnosed ADHD reporting "notably low self-esteem". Without a better explanation, symptoms were often understood as perceived personality flaws, fostering self-blame (Stenner et al., 2019; Attoe & Climie, 2023). This is evidenced by negative automatic thoughts and core beliefs such as "You are a failure" and "What is wrong with you?" (Lynn, 2019; Attoe & Climie, 2023).

In their systematic review, Attoe and Climie (2023) also noted that participants across these eight studies shared the common experience of feeling 'different' and alienated in childhood, with a sense of disconnection from their peers (Bartlett et al., 2005; Burgess, 2000; Henry & Jones, 2011; Holthe & Langvik, 2017; Lynn, 2019; Stenner et al., 2019). As a result, many women experienced early childhood experiences of being bullied and isolated from others. Difficulties in forming and maintaining relationships was reported by participants, not just in childhood but also in adulthood. Seven of the eight papers reporting that women with a late diagnosis had a harder time getting into and maintaining romantic relationships and family relationships. Upon receiving the diagnosis, participants reported experiencing acceptance, relief, and validation. They also added that the diagnosis permitted them to reduce self-blame and gain back

control of the impact that their symptoms have on their lives. This review adds to the growing body of research that has highlighted the negative impact of a late diagnosis of ADHD on women. Nevertheless, this review is limited by the fact that of the eight studies included, only one study (Stenner et al., 2019) was conducted in the UK. Furthermore, Stenner and Colleagues fail to disclose any information on contextual factors such as age, ethnicity, time since diagnosis, etc. The lack of context provided by the authors on the participants therefore greatly limits the findings of this study.

Another aspect of a late diagnosis of ADHD is that women are unable to access treatment. Research suggests that access to psychological, pharmaceutical and skills-based treatment may allow individuals with ADHD to better manage symptoms and comorbidities, consequently reducing the distress experienced. For instance, Quinn et al., (2017) found that medication usage reduced the likelihood of women experiencing substance abuse, when compared with women who were unmedicated (Quinn et al., 2017). Systematic reviews and meta-analyses have further validated these findings by extending the protective effects of medication to academic outcomes, reduction in suicidality, and mood disorders (Boland et al., 2020). However, the discussion around medication is complex, nuanced and deeply personal with strong feelings on both sides of the argument. For instance, Druedahl and Sporrong (2018) found that young adults (aged 18-29 years) reported individual differences in medication experiences and impact.

A single-participant clinical case study by Ramsay & Rostain (2005) further validates these findings. The case study documents the lived experience of a 19-year-old college student, Amanda, who presents to a clinic in the US after being put on academic suspension with moderate levels of depression and anxiety. In her words, she was wondering how "life got so out of hand" and was struggling in different facets of life (i.e., education, sleep, finances). Following a comprehensive psychiatric evaluation, Amada was diagnosed with ADHD, with the family interview suggesting that her symptoms commenced in childhood, however, these symptoms were disregarded as personality characteristics such as shyness or irritability. Gaining an ADHD diagnosis provided Amanda with assess to treatment – both psychological (CBT) and pharmacological (medication). Over time, Amanda was able to develop and implement skills to manage her symptoms, consequently boosting her overall well-

being. While this case study captures a single woman's experience of being diagnosed with ADHD in adolescents in the US based in an educational context and may not be representative of the general population, it captures the depth and impact that a misdiagnosis may have on a woman's functioning.

### 1.11. State of Services in the UK

The socio-political context also impacts the lived experience of ADHD. For instance, in 2008, The National Institute for Clinical Excellence (NICE) published its first guidelines for ADHD in adults. This coupled with factors such as increased awareness of ADHD in women has perhaps led to an increase in the demand for adult ADHD assessments in the UK (McKechnie et al., 2023). Currently, adult ADHD services have been reported to be in "crisis" (Smith et al., 2023). NHS wait time for an ADHD assessment is between 12 weeks and 550 weeks (10 years), with the demand for assessment outstripping the capacity of services. Smith et al., (2023) highlight two factors that have exacerbated this - the onset of the COVID-19 pandemic and underfunding of NHS adult ADHD services. As a response to this unprecedented demand, independent and private services have stepped up by offering ADHD assessments with waitlists being significantly shorter (a matter of days or weeks). Moreover, exercising the right to choose, many individuals have access to ADHD assessment through private services (e.g., Psychiatry UK). Whilst this has been a welcome option used by many, it has furthered the problem of a fragmented system with some individuals reporting that they have been left behind without medication, following their assessment, due to their GP having a lack of confidence in the diagnosis (Smith et al., 2023). Questions around the confidence and validity of private diagnoses have also been fore fronted following a BBC Panorama documentary titled "ADHD: Private clinics exposed by BBC undercover investigation" (BBC Panorama Team, 2023).

In March 2024, NHS England joined forces with the government and launched a cross-sector ADHD taskforce in England, attending to the concerns that have been raised for decades. The task force aims to include a wide range of professionals including service users, service providers, teachers, local authorities, and many more. The

findings of the task force are due to the published at the end of 2024, with the recommendations of this review guiding the way forward for the nation (NHS, 2024).

## 1.12. Gaps in Research

Review of current literature suggested the prevalence of gender disparities in the rate of ADHD, with clear evidence of decreased recognition, referral, and diagnosis of ADHD in females. The reason behind these disparities is multi-facilitated with biological, psychological, and social factors being at play. Whilst the topic of ADHD in women has gained momentum is the last decade, there still exists a large gap in research. First and foremost, there has been little qualitative research documenting the in-depth experiences of individuals who seek an ADHD diagnosis in adulthood. As mentioned by Chronis-Tuscano (2022), qualitative methods will illuminate the lived experience of women with ADHD, while simultaneously allowing for systematic data collection. Furthermore, much of the present literature on the field comes from the US and/or has predominantly sampled university students. As mentioned by Young et. al., (2021), the ADHD public healthcare system (i.e., the NHS) in the UK is incomparable to the private healthcare system in the US. One study exploring the experience of women diagnosed with ADHD in adulthood was set in the UK (Morgan, 2023). However, more than half the participants recruited were diagnosed via the right-tochoose pathway rather than the NHS and were sampled from a university context. This calls for research to explore the experience of women diagnosed with ADHD as adults in the UK via the NHS.

## 1.13. Rationale, Aims & Research Question(s)

This study aims to bridge this gap in research by qualitatively exploring the experiences of women diagnosed with ADHD as adults in the UK. Two main questions that will be explored are:

- 1. How do women diagnosed with ADHD in adulthood describe their experience of being diagnosed in the UK?
- 2. How has their ADHD diagnosis impacted their identity and daily life functioning?

## 1.14. Relevance to Counselling Psychology

The values of the profession of counselling psychology are rooted in humanism, pluralism, and social justice (Boshoff, 2020). These models promote the uniqueness of each individual and embrace the view that everyone deserves equal opportunity. For this reason, counselling psychology lends itself to a phenomenological investigation and qualitative research methods. Moreover, exploring the unique lived experiences of individuals diagnosed with ADHD in adulthood facilitates the voices of these women to be heard. By amplifying these voices, this research tackles the rampant issue of epistemic injustice in this area, therefore also aligning with the social justice nature of this field (Craddock, 2024).

This research is also important as women who have a late diagnosis may seek counselling or therapy to make meaning of their past experiences (Carlander et al., 2022). Research by Young et al., (2008) has highlighted that psychological therapy can have a positive impact on coping with an ADHD diagnosis in adulthood, thereby boosting well-being. In such cases, it may be important for psychologists and other professionals to be aware of this experience, prior to their presentation to services. This is especially important in light of the research detailed above that highlights the elevated risk of co-occurring conditions (e.g., anxiety and depression) experienced by this population. Such research may also bring to light targets for future research – both qualitative and quantitative.

Lastly, as highlighted by Waite (2010), primary care practitioners play a central role in the recognition and treatment of women with ADHD. Therefore, a better insight into the lived experience of these women may facilitate better understanding within professionals whilst also highlights key areas for practice and policy change. In the long term, this will boost timely recognise of ADHD, in the hopes that no woman is faced with the reality of a late ADHD diagnosis.

## 1.15. Reflexivity – My View on The Discourses Surrounding ADHD

The first time I heard about ADHD was during my early education at school. My understanding of ADHD was heavily shaped by the systems in which I existed, wherein ADHD was repeatedly referred to as a "disorder" that needed to be "managed" through

medication. This view was further reinforced in my undergraduate programme, where ADHD was commonly referred to as a "disorder", with no mention of the other discourses surrounding it. Therefore, for many years, I held the view that ADHD was a 'disorder' and consequently believed that individuals with ADHD had deficits or impairments. These views promoted the development of implicit ableist assumptions towards neurodivergent individuals (e.g., my understanding of adjustments was through a deficit lens rather than an equal opportunity lens).

Flash forward to the time of commencing this project; I felt surrounded by ADHD – from close friends being diagnosed in adulthood to my social media algorithm pushing the trending topic of ADHD onto my 'explore' page (Instagram) and 'for you page' (TikTok). I soon noticed that ADHD was far from the medicalised condition I once believed it to be, with different people and creators experiencing ADHD in different and divergent ways. This prompted me to turn to research as a way of better understanding ADHD.

Much to my surprise, a vast majority of the research published followed the notions of the medical model, which is often evidenced by the language used by these studies and the failure to account for other ways of constructing ADHD. Furthermore, the voices of individuals with lived experience felt far removed from these pieces of research. I wondered if this was an instance of epistemic injustice whereby research aligning with the medical model was privileged over other research. Alongside this, the focus on qualitative research made me wonder if individuals with lived experience were being excluded from the process of meaning-making as a way of further marginating them (Crichton, Carcel, & Kidd, 2017; Okoroji et al., 2023; Chapman & Carel, 2022; Craddock, 2024).

On the hunt to hear these voices more clearly, I found myself on magazine websites (e.g., ADDitude) or websites such as Reddit, which provided me with an unfiltered account of the lived experience of ADHD. Reading these narratives allowed me to recognise and appreciate how each discourse has its own merits and provided me with an appreciation for the nuances. For instance, I initially found myself critical of the medical model, rejecting it for this over-medicalisation of ADHD, and instead embraced the neurodiversity movement for its de-medicalised view of ADHD.

However, by engaging with these voices I was able to appreciate the validation that the medical model has provided individuals with ADHD, with the 'realness' of ADHD permitting individuals to feel their difference. On the other hand, the neurodiversity movement allowed some to feel less alone and connect with a community of others. Buried within these were also the voices of women who felt torn between these different discourses with some questioning if taking ADHD medication made them less neuro affirmative. I also witnessed these accounts in my third-year placement in a charity that provides psychotherapy for individuals with neurodiversity. Hearing my clients' accounts of neurodivergence helped me further understand how disability is not something that resides within an individual but instead is felt during interaction between the individual and their environment. It also helped me recognise the complexity of the relationship between ADHD and trauma.

As a woman who does not hold an ADHD diagnosis, hearing the voices of those with lived experience helped me navigate my outsider position with this research. At the point of writing this thesis, I see merit in moving away from a reductionist approach, favouring one main discourse but instead think a more holistic approach aligns with my view of ADHD better. This was especially important when engaging in this research as by understanding and recognising my own biases and assumptions, I could have a greater awareness of how this shaped my engagement with this research (Braun & Clarke, 2021).

## **Chapter 2: Methodology**

## 2.1. Overview of Chapter

This chapter includes a description of the methodology used to answer the questions detailed in the introductory chapter. It begins with an exploration into the underlying assumptions that underpin the present study. The consideration of other methodologies and the decision to employ the use of a Reflexive Thematic Analysis (RTA) is discussed. Following this, the methods used to conduct the study are detailed, including the ethical considerations, the recruitment process, and participant demographics. Subsequently, the chapter details the analytic process with an exploration into the steps taken to ensure good quality and rigour. The chapter concludes with a reflexivity section, acknowledging the role that I, the researcher, played in the research process.

## 2.2. Ontology and Epistemological Considerations

Ontology is concerned with what is out there to be known and relates to the assumptions one holds as to the nature of reality (Willig, 2013). Epistemology is concerned with how we gain knowledge of what exists. The way we perceive reality determines how we obtain knowledge about it, which in turn guides our methodological procedure and analysis (Guba & Lincoln, 1994; Willig, 2013; Braun & Clarke, 2022). Therefore, after deciding on the research aims and questions, I needed to investigate the ontology and epistemological assumptions embedded within this research, as well as my own stance. This section delves into the ontological, epistemological and methodological assumptions underpinning the present study, demonstrating how this sits in relation to existing paradigms and literature.

# 2.2.1. Ontological Stance: "What is there to know?" (Willing, 2013)

Ontology is often understood as comprising of three main paradigms – realism, relativism, and critical realism. A realist ontology assumes "a knowable reality, which can be uncovered in an accurate and objective way" (Braun and Clarke, 2022, p. 168). On the other hand, a relativist ontology steps away from the notion of a singular reality and instead suggests that all reality is subjective. In between these two positions, lies

critical realism that suggests that an objective reality exists it that this reality can only be known indirectly. Therefore, according to this paradigm our knowledge of reality is always partial and imperfect (Braun and Clarke, 2022; Willig, 2013).

The ontological stance of ADHD has been a subject of debate. This debate is partly attributable to the different ways groups construct and experience ADHD, evidenced by the presence of different perspectives on ADHD. These perspectives or models have been explored in greater depth in the introduction chapter of this thesis (see section 1.6). On one hand, ADHD has been conceptualised from a medical perspective, which situations ADHD as a neurodevelopmental disorder, attributing its aetiology to risk factors (e.g., genetic, neurological, environmental factors). Moreover, it posits that individuals with ADHD have a 'real neurological difference' when compared with those who do not have ADHD, and as a result allows practitioners to objectively diagnose ADHD (Qui et al., 2011). Therefore, the medical view of ADHD as a neurological deficit lies within a realist world view – that is, that there is an objective reality that can be known directly.

Conversely, some reject the medical model for its lack of acknowledgement of constructionism and the subsequent impact it has on the presentation of ADHD (Timimi and Taylor, 2004). The social constructionism theory of ADHD believes instead of being a disorder, the category was developed to explain behaviours that do not fit within prescribed social norms, aligning with the social disability model of ADHD and the neurodiversity paradigm (Moncrieff, Rapley, Timimi, 2015). Here, these two models are arguably situation more within the post-positivist or critical realist ontology, which holds that an objective reality exists (there is a real neurological difference), but that this reality can only be known indirectly, i.e., through our social constructions.

Following a comprehensive reflection on the multiple ways the ontology of ADHD is viewed, it felt clear to me that my ontological stance is that there is an objective and independent reality but that we make sense of these realities via our subjective experiences and perspectives (Middleton and Shaw 2007). I, therefore, reject naïve realism, or this belief that there is a singular 'truth' out there, and instead embrace the stance of critical realism which believes that there are multiple versions of reality (Willig, 2013). In the context of my research, I assume that there is a 'real' neurological

difference in participants with ADHD, but that the lived experience of this difference is mediated by different socially constructed discourses – ADHD 'diagnosis' being one such construction; the 'neurodiversity paradigm', often espoused by the online community, being another.

## 2.2.2. Epistemological Stance: "How can we know?" (Willig, 2013)

Epistemology or the approach to knowledge production is classified into three categories – positivism, experiential, and social constructionist. Whilst these are commonly viewed as distinct categories as they take different approaches to how we generate knowledge; they are not mutually exclusive and may be combined (Willig, 2013). This is referred to as epistemological pluralism (Miller et al., 2008). A secondary advantage of epistemological pluralism is that it promotes the researcher to extract multiple layers of meaning from a text (Frost, 2009). My research incorporates two stances – social constructionist and experiential, thereby adopting epistemological pluralism.

A social constructionist perspective is founded on the principle that we subjectively construct our own realities and knowledge. This relates to the aforementioned discourses around ADHD being a 'medical disorder' versus a 'neurological difference' (Qui et al., 2011; Moncrieff, Rapley, Timimi, 2015). These different discourses undoubtedly mediate the participants' meaning making and thereby colour the lived experience of the phenomenon. The lived experience of the phenomenon is intimately tied to the participants' identity or sense of self. For instance, an individual who views ADHD as a medical disorder may believe "I have a disorder" versus "I am different to others", thereby shaping their subjective experiences of ADHD. This aligns more with an experiential approach to gaining knowledge where the aim is to produce knowledge about the subjective experience of individuals, focusing on quality, rather than to discover the causes of the phenomenon (Willig, 2013). Neither of these perspectives in isolation aligns with my view on the process of how we gain knowledge. Instead, I recognise that both assumptions give us access to knowledge of the phenomenon.

## 2.2.3. Epistemological Reflexivity: Clarifying my Epistemological Stance.

When adopting an epistemological pluralistic stance, one cannot turn a blind eye to the philosophical tensions between these different categories. Consequently, this may result in favouring one model, over another and is particularly salient whilst interpreting data (Braun & Clarke, 2022). As I began my analysis, I recognised that there were two layers of analysis – a social constructionist layer and an experiential layer. During the coding and developing themes stage, I recognised that the experiential approach aligned more with the aims of the study than the social constructionist. Whilst I recognise that social discourses around ADHD mediate one's lived experience of ADHD, I am more concerned with the lived experience of this phenomenon and the process of meaning making. In terms of my analysis, I have attempted to pay attention to both the social constructionist layer and the experiential layer, however, I have paid greater attention to the experiential layer.

# 2.3. Changes in Methodology: Finding the 'Right Fit'

After agreeing on my research aims, I initially developed three questions to answer my research aims. The three questions were: (1) How do women diagnosed with ADHD in adulthood describe their experience of being diagnosed in the UK? (2) How has their ADHD diagnosis impacted their identity and daily life functioning? (3) How has social media, if at all, informed their experience of being diagnosed with ADHD as adults? Following this, I began reflecting on the different methodologies that were available.

Interpretive Phenomenological Analysis (IPA) was initially considered for this study (Smith, Flowers, & Larkin, 2009). The rationale for this choice was due to the critical realist position and experiential focus that is inherent in the methodology itself. Adopting this methodology would facilitate a deep enquiry into participants' lived experiences allowing me to make sense of or interpret the meaning people assign to the experience of being diagnosed. Alongside this, a researcher doing IPA is also called to engage in 'double hermeneutics', in that the researcher is making sense of the participants' sense making. This therefore highlights the central and subjective role that the researcher plays in the analysis and interpretation of the participants' experience (Smith, Flowers, & Larkin, 2021; Willig, 2008).

However, after engaging in further conversation with my supervisor, it became apparent that there was tension between my first two questions, which focused on subjective experiences of being diagnosed, aligning with phenomenology, and the last question that attended to the role that social media played in this process, suiting a social constructionist positioning. It was evident that an IPA methodology was not the best fit for this project. During this time, a Foucauldian Discourse Analysis (FDA) was considered due to its alignment with the social constructionist epistemological stance. FAD focuses on how language is used to construct meaning, shape social realities, and maintain or challenge power dynamics within society, drawing from Michel Foucault's theories (1972). This would enable an exploration into the discourses that surround ADHD and how these discourses impact individuals with ADHD. However, this method of analysis would hinder the ability to investigate the lived experience of what ADHD was like for women. It was therefore decided that this did not fit with the aims of this study.

A Thematic Analysis (TA) appeared to be a better fit for this project, than IPA due to its lack of allegiance to a singular theory, allowing for flexibility and freedom for the researcher. This would enable the adoption of two epistemological stances rather than a singular one. However, around this time, it was brought to my attention that of the three questions set at the start, two of them appeared to fit well with the chosen methodology, but the third question investigating the role of social media did not fit with an inductive, qualitative approach and appeared to be more in alignment with hypothesis testing. This would jeopardise the validity and the coherent conceptualisation of the overall research project and the findings produced. There appeared to be two options available to me to resolve this dilemma. Firstly, I could remove this third question and continue with the analysis focusing on the first two questions. The second option was that I could change methodologies and focus solely on the relationship between social media and adult diagnosis of ADHD. It was here that a Grounded Theory (GT) was considered, enabling me to look at the way in which social media shapes the experience of late ADHD diagnosis in women. The GT methodology would facilitate an exploration in the process facilitating the development of a theory (Glaser & Strauss, 2017). However, following additional consultation, conversations with peers, and discussions with my supervisor, it was agreed that it felt best to drop the last question looking at the role of social media. This decision was underpinned by the fact that as a researcher, I was more interested in understanding and exploring the experiences of women navigating a late ADHD diagnosis in the UK, than the role of social media in this process.

## 2.4. Reflexive Thematic Analysis (RTA)

Following the abandonment of the final research question, I returned to the TA methodology. This decision was driven as I was convinced that TA was well-suited for this project as it aligned well with not just my research aims and questions, but also my values and worldviews.

TA is a methodology for analysing qualitative data that entails searching across a data set to identify, analyse, and report repeated patterns (Braun & Clarke, 2022). The end goal is to produce a convincing story for the audience or reader. However, in a paper published by Braun and Clarke (2021), they acknowledged that TA has "expanded and diversified" since its initial proposition in 2006. This expansion has been reflected in the development of many versions of TA with differences in underlying assumptions which drastically impact their applicability (Braun & Clarke, 2006). Over time, this growth led to "problematic practices" and assumptions that arguably did not align with the ideology or premise of the originally developed TA. The main source of disagreement stemmed from the development of rules and procedures that governed TA, succumbing to "proceduralism" (King & Brooks, 2021). Instead, they encourage researchers to view their 2006 paper as a starting point that may be adapted and adjusted based on the ontological and epistemological positioning of the study.

Therefore, broadly speaking, there are two main approaches to TA: those developed within a positivism framework, which emphasises 'code reliability' (Joffee, 2012), and those that align with interpretivism and embrace the subjective skills that the research brings to the analytical process. I have chosen the latter version by employing the use of a reflexive TA. The main reason why I have chosen a reflexive TA, over other methodologies and versions of TA is due to the fact that it aligns with the critical realist claims as well as fitting within a social constructionist and experiential paradigm. This flexibility granted me access to rich and complex accounts of the experiences of a late

diagnosis of ADHD, whilst also provided me with a systematic procedure to develop and generate codes from the data (Braun & Clarke, 2006; Braun & Clarke, 2021).

Byrne (2022) reviewed Braun and Clarke's publications (2006, 2012, 2021) and noted four main assumptions that should be addressed prior to conducting an RTA. The four continua are: essentialist versus constructionist epistemologies; experiential versus critical orientation to data; inductive versus deductive analyses; and semantic versus latent coding of data. The first two assumptions were addressed in the ontology and epistemology section of this chapter.

In terms of inductive versus detective approaches, this study has elements of both. We cannot ignore the fact that this research is driven by research questions which were built on theoretical frameworks, in other words, 'theory-driven'. On the other hand, whilst there is a framework for understanding participants' experiences, the questions were open-ended to ensure that the lived experience of participants is captured. Moreover, the questions posed were driven by participants' responses. In instances where the approach tends to fall 'somewhere in between', Braun & Clarke (2012) point out that one approach does tend to be predominant over the other, and the dominant approach should be identified and stated.

I believe this study aligns more with an inductive approach or data-driven approach, as opposed to a deductive or theory-driven approach. This further fits with the social constructionist and experiential stance adopted by this study. Lastly, both semantic and latent coding were used. Semantic codes were produced when meaningful semantic information was present and latent codes were produced when meaningful latent information was interpreted (Byrne, 2022).

# 2.4.1. Interpretation: "doing what human beings do" (Braun & Clake, 2022, p.196 taken from Smith, 2019, p.171).

Braun and Clarke (2022) highlight that all forms of TA require the research to interpret and is embedded into the analytical process. Interpretation in lay man terms is simply the act of making sense of something (Braun & Clake, 2022). By making sense of participants' experiences, the researcher is able to tell a story, giving the reader a

"clear take home message", highlighting why those interpretations are important and valid (p. 197). However, as indicated by the authors, the story told is always contextualised, and depends on both the researcher, and the wider context of the data. Braun and Clarke (2022) echo the words of Willig and Rogers (2008) by suggesting that interpretation goes beyond the data, facilitating the emergence of a new dimension, that may not be available at face value. However, interpretation leads the researcher having to embrace the challenge of finding the right balance in knowing how far to go with the interpretation, whilst still staying close to the data and participants sense-making. Willig and Rogers (2008) propose that the researcher can find the right balance if they refrain from imposing meaning on the phenomenon or attempt to fit it to a particular theoretical formulation. Moreover, Braun and Clarke (2022) suggest that all interpretation made must be defensible, highlighted the need for transparency on why interpretations are made.

As mentioned earlier, an inductive approach or data-driven approach was taken towards the analysis. This was so that I could stay close to the data and to participants' sense making, rather than getting 'carried away' with interpretating. This is positioned more towards an experiential TA and was embraced by me due to the aware of my outsider status and the subsequent impact that this may have on the interpretations made. For instance, as mentioned above, a researcher subjectivity shapes the interpretations made and thus the data generated. Here, I feared that the interpretations made by me might be 'problematic', leading to this research becoming yet another case of epistemological violence (Smith, 2013; Teo, 2010, 2011; Braun & Clarke, 2022). As conceptualised by Braun and Clarke (2022), "The concept of epistemological violence has been developed to capture the way interpretation of data from or relation to, and subsequent representation of, the Other, can-do harm." (p.217).

However, after my initial engagement with the data, I found that my dual roles of being a counselling psychologist and a researcher, alongside my pre-existing knowledge on the matter of ADHD in women, led to my interpretations veering towards a more 'critical interpretative' mode (Braun and Clarke, 2022, pp.204-207). This was evidenced by me feeling that while my experiential interpretation revealed an important element of my participants experiences navigating a late ADHD diagnosis,

I felt that there was a deeper level of understanding that needed to be extracted. Here, a more "interpretative, contextualised, and theoretically informed suspicious analysis" (Braun and Clarke, 2022, p. 207) allowed me to make better sense of the data collected. Rather than choosing between these two modes, I made use of both as it enabled the extract the experiential layer and the social constructionist layer (Willig, 2017). This was therefore not only in line with my epistemology, but also my critical realist ontology whereby my *critical* interpretations captured a part of the reality even if it is out of participants' awareness but is observable to me.

### 2.4.2. Limitations of RTA

While debating on the best fit of methodology for this study, the limitations of RTA were also taken into consideration. While RTA is often endorsed for its flexibility, it is this trait that can lead to what Braun and Clake (2022) refer to as 'analytic paralysis' whereby the researcher may struggle to make decisions, due to the wide range of adaptable variables. It is for this reason that the authors recommend that the researcher(s) must deliberate the theoretical assumptions that underpin the research before commencing data analysis. If not done in this order, the lack of reflexivity may seep into the analysis, hindering the quality of the findings generated. Furthermore, the authors also warn researchers about the notions of methodological incoherence. This captures research where the different elements of the methodology, such as the research question, theoretical assumptions, and data analysis methodologies, aren't in conceptual alignment. This lack of coherence may further constrain the analysis, and the findings generated. These three limitations stood out as being important in the context of my limited experience of engaging with qualitative research and methodologies.

The interpretative nature of TA is also a limitation for several reasons. Firstly, the interpretative nature of the identification of themes relies heavily on the researcher's perspectives. While the subjectivity of a researcher is endorsed heavily by the authors of RTA, an unclear and non-transparent methodology may lead to the findings generated being threatened by subjectivity biases. Furthermore, the broad nature of RTA alongside the lack of standardisation may lead to a 'superficial analysis', whereby the depth and nuance of the experience being investigated are neglected.

### 2.5. Method

## 2.5.1. Sampling

The minimum sample size required for an RTA has been widely debated by researchers and statisticians. Here, the point of data saturation or the point at which no new themes emerge from the data is usually embraced (Braun & Clarke, 2019; Guba & Lincoln, 1994). The ambiguity surrounding the point of data saturation resulted in the operationalisation of this concept (Guest, Bunce, and Johnson, 2006); Constantinou, Georgiou, and Perdikogianni, 2017). However, publications that have attempted to operationalisation data saturation have reported different estimates for the sample size needed. For instance, Francis et al. (2010) suggested ten-plus-three interviews, with the plus three referring to the number of interviews with no new data, while Constantinou, Georgiou, and Perdikogianni (2017) claimed that this point was achieved at seven interviews. The heterogeneity of the sample reported accentuates the ambiguity that surrounds this topic, with most of these numbers being based on arbitrary principles.

Moreover, as highlighted by Braun & Clarke (2021), setting out a pre-determined sample number suggests that "themes as entities that pre-exist analysis (to some extent), that reside in data" (p. 205). This clashes with the fundamental value of an RTA that suggests that "meaning is not inherent or self-evident in data, instead meaning resides at the intersection of the data and the researcher's context and interpretations" (p. 210). Therefore, attempting to predict the point of data saturation may be futile.

However, given that this study had a practical need to determine a sample size due to the time-constrains, following the guidance proposed by Braun & Clarke (2019), I estimated a provisional sample size of eight participants, with the anticipated lower range being six participants and the upper range being ten participants. This estimate was built based on similar research in the field that has investigated this phenomenon (Holthe & Langvik, 2017).

Non-probability purposive sampling was used to select participants for this study, as participants were recruited based on predetermined requirements (Creswell & Clark,

2017; Palinkas et al., 2015). This technique appeared to be a helpful strategy as it facilitated the recruitment of a fairly homogeneous sample in terms of participants' characteristics and experience, which allowed the research to generate more depth on the phenomenon being studied (Palinkas et al., 2015). Snowball sampling was also used whereby participants who engaged in this study were asked to make individuals who also met the inclusion criteria aware of the study. However, this did not appear to be as helpful as most participants shared that their close friends and family who had an ADHD diagnosis had received this via the Right-to-Choose pathway.

The inclusion and exclusion criteria were set to ensure some homogeneity between participants, which consequently boosted the quality of the data collected.

Inclusion Criteria: To be eligible for inclusion in the study, potential participants must be assigned female at birth, aged 23 or older, and hold an ADHD diagnosis that was given in the UK via the NHS. The age range was set to participants aged 23 or older as participants who would be younger than 23 would have received this diagnosis via Child and Adolescent Mental Health Services (CAMHS) or education institutions (e.g., university) which would impact the experience of being diagnosed. Moreover, to ensure some homogeneity among participants, I decided to only include participants diagnosed in the NHS. This decision was driven by the understanding that participants diagnosed privately or through the Right to Choose pathways may have had different experiences of being diagnosed (e.g., smaller wait-times). Therefore, sampling participant diagnosed from both routes would add heterogeneity, whilst simultaneously detract from the ability to capture and understand the impact that the current state of adult ADHD services in UK are having on service users.

While no explicit inclusion criteria were set regarding the time elapsed since participants received their ADHD diagnosis, time from diagnosis varied from six months to eight years and six months at the time of the study. Given that participants were at least six months post-diagnosis, participants had some time to reflect and process the diagnosis, thus ensuring their psychological safety. However, given the variations in time since diagnosis, participants' experiences differed based on how much time had passed since their diagnosis. For instance, participants who were

diagnosed longer ago would have had more time to reflect, process, and navigate their diagnosis, than participants diagnosed more recently.

**Exclusion Criteria:** Participants who were currently experiencing distress or who were at active risk (e.g., if they were experiencing a psychiatric episode), were excluded from this study, as participating in this study may have been further destabilising and cause additional distress. However, potential participants who had co-morbid conditions (e.g., bipolar personality disorder) were deemed fit to participate as long as their participation does not pose an active risk (see section 2.7.3 for more information). The decision to include these participants was made to increase inclusivity and representation as ADHD is a highly co-occurring condition, therefore, eliminating individuals with other mental or physical health problems would limit the findings of the study (Christiansen et al., 2019; Philipsen, 2006).

Following the first round of recruitment, I had a conversation with my supervisor regarding the inclusion of participants diagnosed via the Right to Choose pathway. This conversation came about as I wondered if broadening the inclusion criteria would allow the sampling of more participants within the limited timescale of this project. Following our agreement, I put forward an amendment within my ethics application to include participants who were diagnosed via the Right to Choose pathway which was accepted (see Appendix D). However, a few weeks later, I had managed to recruit enough participants who had been diagnosed by the NHS. After discussing this further with my supervisor, we agreed it would be best to retain the inclusion criteria of the study to only participants who had been diagnosed through the NHS. Therefore, no individuals diagnosed through Right to Choose were interviewed or called to participate in this study.

#### 2.5.2. Recruitment Process

Recruitment was done using social media and involved two rounds: one round in May 2023 and one round in September 2023. The flyer, in Appendix E, was shared with the administrators of various Facebook pages for women with ADHD. Rather than posting the advert myself, I asked the administrators to post the advertisement on my behalf. The rationale behind this was two-fold. Firstly, it protected my safety. Secondly,

I was aware that many of these groups are safe spaces for women to interact with each other, without the fear of judgement from others. Therefore, I wanted to ensure that I did not encroach on these spaces. Effort was made to contact local charities and groups specifically for BIPOC women; however, no response was received.

A total of 29 women contacted me. Six participants did not meet the inclusion criteria as they had been diagnosed via the Right to Choose pathway and were therefore turned away. 23 participants were sent the information sheet and invited to the screening call. Nine participants returned the consent forms; one participant did not attend the interview. Therefore, eight participants were interviewed. I was initially surprised by the number of women who got in touch expressing a desire to participate. Many of these women shared their own experiences within these emails and highlighted a need for systemic change to ensure that women are being diagnosed in a timely manner. Upon reflecting on it further, I believe that this response may have also been a consequence of the wide attention that ADHD was receiving at the time in both mass media and social media. I felt disheartened to turn away participants who were diagnosed via the right to choose pathway as I worried if this made some individuals question the validity of their diagnosis. Given that this has been a subject of wide scale debate, this may have been a real possibility.

### 2.5.3. Procedure

As per the flyer, individuals interested in participating in this study were asked to contact me via email. Individuals who got in touch and met the inclusion criteria were emailed the participant information sheet (see Appendix F for information sheet) and were invited to a pre-screening interview call. The purpose of the screening call was to confirm that all potential participants met the inclusion criteria and that the risk of participation was low. Participants were asked questions such as: How has your mood been lately? Do you feel this is a good time for you to be participating in this study? Do you have any concerns about participating? Do you feel safe to explore your experience of being diagnosed? When did you receive your diagnosis, was this via the NHS or a private company? My clinical judgment was used here to make this decision.

If all criteria were met, participants were asked for availability and their personal preference on modality (face-to-face or online). The option of face-to-face meetings was provided as emerging evidence suggests that neurodivergent individuals may find it hard to engage in virtual meetings in the same manner. For instance, in an article published by a woman diagnosed with ADHD in adulthood, Ungar (2022), it was reported that factors such as hype-focusing, a trait of ADHD, makes it harder for some to engage in virtual meetings. However, all participants expressed a desire to participate online due to other commitments such as looking after children or working. One participant initially asked to meet face-to-face for the interview, however, she later asked to move the interview online as this was more convenient for her. Following this, participants who met the criteria were also sent the consent form and demographic information sheet (see Appendix G and I respectfully). They were asked to complete and return these to me via email prior to participation.

Semi-structured interviews were conducted. Following completion of the interview, all participants were debriefed, and a check-in was conducted on their wellbeing. Most participants reflected on finding the interview experience interesting and felt as though it gave them the space to reflect on their journey. While no participants reported distress from the interview process, the support organisations detailed in the debrief were highlighted regardless.

Participants were asked if they would like to receive a summary of the final results following the completion of the research project, to which all participants said yes. At this stage, participants were also made aware that they had 30 days from the date of the interview to react to their interview highlighting that they did not have to give me a rationale for doing this. As no participants contacted me to redact their transcript, I commenced the analysis. No compensation was provided for participation.

#### 2.5.4. Data Collection

Data collection took place in two stages: (1) the demographic information sheet and (2) the semi-structured interviews.

The Demographic Information Sheet. All participants were asked to fill in a demographic information sheet before participating in this study (see Appendix G). Basic demographic information such as ethnicity, gender, and whether the participant is currently prescribed and taking ADHD medication was collected. This information was collected as I believe that it is important to contextualise the participants within their frame of reference when reading their experiences. For instance, an individual who is not currently taking ADHD medication may have a different experience of ADHD symptoms, in comparison to an individual who is taking ADHD medication. Given that robust ethnic disparities are prevalent in ADHD diagnosis such that black and ethnic minority (BAME) individuals are more likely to receive this diagnosis than their white counterparts (Shi et al., 2021), data on ethnicity is needed. Furthermore, emerging systematic reviews have highlighted the importance of including data on ethnicity as this impacts the interpretation and reliability of the findings (Ginapp et al., 2022).

**Semi-structured Interviews.** Semi-structured interviews were conducted on a one-to-one basis. An interview guide was used (see Appendix H), which included open-ended questions. These questions were influenced by existing literature exploring the impact of a late ADHD diagnosis in women. Participants were briefed at the beginning that they could ask me to repeat questions at any point and that prompts would be used in the instance that they went off track from the posed question. All participants reported finding this helpful. Follow-up questions were used to generate more depth on the experience; however, given the emotional and deeply personal nature of this study, caution was expressed when asking these questions to ensure the wellbeing of the participants. More often, participants covered several topics when asked one question, therefore the interview guide was used flexibility. This also allowed me to focus on the participant's experience and immerse myself into their frame of reference rather than imposing predefined ideas or assumptions (Britten, 1995).

The average interview length was 60 minutes, with one interview being shorter (50 minutes) due to childcare commitments and one interview being longer (1 hour and 20 minutes) as the participant explored a range of topics.

# 2.5.5. Participants

Table 2 summarises participant demographic information. The information below is not a character summary but instead aims to contextualise the participants within their frame of experience. As a researcher, I understand and recognise that the socio-cultural backdrop of an individual undoubtedly impacts their lived experience of ADHD.

**Table 2**Participant demographic information

Name	Age	Ethnicity	Years since	Prescribed medication as a
	Bracket		diagnosis	form of symptoms
				management?
Ava	40 – 45 years	White British	2 years and 2 months	Yes
Daphne	35 – 40 years	White British	5 years	Yes
Lauren	50 – 55 years	White British	8 years	Yes
Sophia	40 – 45 years	White British	6 months	Yes
Ayesha	40 – 45 years	Asian or Asian British – South Asian	8 years and 6 months	Yes
Zara	35 – 40 years	Asian or Asian British – South Asian	11 months	Yes
Ella	40 – 45 years	White British	1 year and 10 months	Yes
Emma	25 – 30 years	White British	1 year	Yes

Here, it is important to note that all participants who engaged in this study were prescribed with medication as a form of symptom management and were therefore currently engaging with NHS treatment pathways. As mentioned in section 2.5.4., this would have undoubtedly shaped their experience of ADHD.

### 2.6. Ethical Considerations

This research project was granted ethical approval by the Ethics Committee of the Department of Psychology at City, University of London (see Appendix B for proof of ethical approval). Two ethics amendments, one to remove the final question regarding the role of social media and one to widen the inclusion criteria, were made and both were accepted (see Appendix C and D respectfully). To ensure that the research met ethical standards, the study complied with the British Psychological Society (BPS) ethical guidelines (BPS, 2018) and the Health and Care Professions Council (HCPC) ethical guidance for students (HCPC, 2016). Furthermore, ethical considerations were monitored throughout the study.

### 2.6.1. Informed Consent

As set out by the BPS (2018), "consent is not valid unless it is given from an informed perspective" (p.12). In alignment with this, all participants who expressed a desire to participate in this study were sent the participant information sheet which detailed the aims of the study, what participation would entail, what would happen with their data and so on (see Appendix F for participant information Sheet). Participants were given as much time as required to read the information sheet and will be asked to re-contact me if they would like to engage in the study/have any further questions. All potential participants were then contacted via telephone for a screening call during which I asked them if they had any questions or concerns about participating in this study. All participants were asked to email the electronically signed and completed consent sheets before the interview date. Participants were made aware of their right to withdraw from the study during or up to one month after the interview. After completing the interview, participants were debriefed, which involved reiteration of the aims of the research project, gaining insight into participants' experience of the interview, and signposting to appropriate psychological support if it was deemed appropriate.

Participants were also sent a debriefing sheet (see appendix J) which outlined the aims of the study, their rights, my contact details, and avenues for counselling support and services.

### 2.6.2. Interview Distress Protocol

To ensure the safety and well-being of both the participants and me, a distress protocol was created (Appendix K). The protocol was adapted from Haigh and Witham's (2005) distress protocol for qualitative data collection and details a step-by-step procedure that would be followed in the event that the participant exhibits verbal and/or non-verbal signs of distress (e.g., crying uncontrollably, starring in the distance). None of the participants exhibited or expressed signs of distress and therefore this was not used.

GP details were also collected in the demographic form to ensure that the participants were safeguarded. This decision was made in the context of research that has highlighted that ADHD may be associated with emotional dysregulation (Retz et al., 2014). Furthermore, research has suggested a link between ADHD and impulsivity and other co-occurring conditions such as bipolar disorder, suggests that these individuals may be at higher risk of experiencing distress (Christiansen et al., 2019; Klassen, Katzman, & Chokka, 2010). Therefore, to ensure that participants are safeguarded, participant GP details were collected. None of the participant's GPs were contacted.

### 2.6.3. Confidentiality and Anonymity

Confidentiality was protected by anonymising any identifying or personal information and using pseudonyms instead. All participants were informed of the limits of confidentiality, and that confidentiality would only be broken if I felt that there was a risk of serious harm to the participant or otherwise, where I am legally obliged to do so. All personal data was processed in accordance with the Data Protection Act 2018 and the General Data Protection Regulations (GDPR). I only kept the email addresses of the participants who gave their consent to receive the research findings; their personal data will be deleted once the study is completed and the findings are

disseminated. All the digital documents (e.g., electronically signed consent sheet, demographic information sheet) were stored on the university's OneDrive.

## 2.7. Analysis

Although Braun and Clarke (2022) describe a six-stage process, they caution the researcher by suggesting that these stages are guidelines and endorse a recursive rather than a step-by-step, linear approach. Therefore, while I engaged with each phase of the stages detailed below, I also kept room for movement between stages.

Phase 1: Familiarisation with The Data Set. This phrase included three key stages and began by familiarising myself with the data set. I did so by listening to the interview recordings and transcribing them. Following this, I re-listed to the audio whilst reading the transcript line-by-line which allowed me to recognise any missed elements in the transcripts and enabled me to immerse myself within data. However, while deeply immersed, I also attempted to critically engage with the data.

During these two stages, I often closed my eyes trying to paint a picture of what my participant was saying. I also asked myself questions such as: "How did my participant make sense of what they are discussing? What was it like for them?". Alongside this, I took preliminary notes writing down any initial ideas or thoughts that were coming to me. I paid special attention to any reactions or feelings that cultivated inside me.

Phase 2: Coding. Doing coding was often an evolving process and began with a line-by-line reading of the transcript, stopping every time something relevant to my research questions was spotted. Here, I found it helpful to have a copy of my research questions with me, which I went back to every time I felt stuck or unsure. If something felt relevant, I developed an analytically meaningful description, also referred to as a code. If a code already existed, I added it to the pre-existing code and reflected on whether its name needed to be tweaked. The coding was refined multiple times until I was satisfied with the amount and depth of the codes.

Following my first round of coding, I shared my transcript with my supervisor. During our discussion, it was brought to my awareness that my coding focused more on the

social constructivist layer, at times ignoring the experiential layer (as previously mentioned in section 2.2.3). Here, my supervisor encouraged me to return to the transcripts paying closer attention to the experiential layer. I was also encouraged to dig more deeply into the latent aspect of the experiential layer, interrogating what the participant's language or non-linguist features, such as repetition or pauses might reveal about the quality of their experience. Re-doing the coding at this stage enabled the development of codes that may have been otherwise neglected. An example section of a coded transcript is included in Appendix L.

Phase 3: Generating Initial Themes. The analysis then shifted from codes to themes, where the aim was to develop a shared pattern of meaning organised around a central concept across the dataset. Codes that shared a core idea or concept that were relevant to my research question were clustered together giving rise to candidate themes (see Appendix M for an illustrative example). As expected, this yielded a large number of themes, which I remain cautious of given Braun and Clarke's (2022) suggestion that "a large number of themes can produce an incoherent analysis" (p.91). This brought me to the next stage of the analysis.

Phase 4: Developing and Reviewing Themes. This phase aimed to continue assessing if the candidate themes fit the data. Here, I found it helpful to develop a theme map as it helped me visually map how the data sits together. Themes that did not fit with the data set or were not addressing the research question were discarded. This was often a recursive process whereby I went back and forth and attempted not to get too attached to the story I was developing. Please see Appendix N for an example of an initial theme map generated.

Phase 5: Refining, Defining, and Naming Themes. After having a set of themes and codes that told a story, I began fine-tuning the analysis. Following the guidance of Braun and Clake (2022) I wrote a theme definition for each of the themes generated which was essentially an abstract or description of each theme (See Appendix O). These themes were then shared with my supervisor, with whose guidance the names of the themes were revised. For instance, the first theme was initially called "Childhood of Undiagnosed ADHD", however, after further reflection on the transcripts I realised

that this theme covered participants experiences of childhood and early adolescents. Therefore, the theme name was revised to "Growing Up with ADHD Undiagnosed".

Phase 6: Writing Up. This phase calls on the researcher to build an analytical narrative that tells a coherent and persuasive story to the reader. Therefore, following my initial write-up and discussions with my supervisor, I revisited Phase 4 and Phase 5, which facilitated the development of a more robust and coherent story. For instance, in the initial analysis, five themes were developed with the last theme titled "Intersectionality, Stigma, and ADHD". However, after reviewing this it felt as though rather than being an isolated theme in itself, both intersectionality and stigma were part of the four theme "Life with An ADHD Diagnosis", therefore, the fifth theme was removed and merged with the fourth theme, creating a more coherent story.

# 2.8. Quality and Rigour

Historically speaking, qualitative research has been criticised for its innate level of research influence, which questions the validity and reliability of the findings reached (Labuschagne, 2003). Moreover, as noted in section 2.6 of this chapter, this has also been named as a limitation of the RTA methodology, threatening the quality of rigour of the analysis (Braun & Clarke, 2022; Finlay, 2021). To evaluate and monitor the quality of this research, the 15-point checklist for good RTA developed by Braun and Clarke (2022) was completed. A summarised response to each item on the checklist has been included below.

Table 3

My Response To The 15-point Checklist For Good RTA

No.	Process	Criteria Methodo	logical Response
1	Transcription	The data have been All transo	cripts were re-read
		transcribed to an appropriate and che	cked against the
		level of detail; all transcripts recording	s. Details such as
		have been checked against non-lingu	istic features were
		the original recordings for noted.	
		'accuracy'.	

2	Coding and	Each data item has been given	Transcripts were reviewed
	theme	thorough and repeated	multiple times to generate
	development	attention in the coding	codes. Codes were refined
		process.	and renamed multiple times.
3		The coding process has been	The coding process was
		thorough, inclusive, and	thorough, inclusive, and
		comprehensive; themes have	comprehensive, as the entire
		not been developed from a few	dataset was used to
		vivid examples (an anecdotal	generate codes and develop
		approach).	themes. Each theme was
			derived from a multitude of
			codes collated from the
			accounts of all participants.
4		All relevant extracts for each	All extracts for each theme
		theme have been collated.	were collated together in a
			coding manual, which was
			then used to develop theme
			description (see Appendix
			N).
5		Candidate themes have been	Candidate themes were
		checked against coded data	checked against the coded
		and back to the original	data and led me back to the
		dataset.	transcript. As detailed
			above, themes generated
			were discussed with my
			supervisor and were revised
			accordingly.
6		Themes are internally	Themes developed were
		coherent, consistent, and	discussed with my
		distinctive; each theme	supervisor and peers. This
		contains a well-defined central	feedback allowed me to
		organising concept; any	
		subthemes share the central	more coherent and

		organising concept of the	distinctive. Sub-themes were
		theme.	moved around to ensure that
			they all shared the central
			organising concept of the
			theme.
7	Analysis and	Data has been analysed-	As evidenced in the analysis
	interpretation	interpreted, made sense of	chapter, data was thoroughly
		rather than just summarised,	analysed. This is illustrated
		described, or paraphrased.	by the depth and meaning of
			the findings, highlighting
			moving beyond mere
			summarisation.
8		Analysis and data match each	As evident in the results and
		other- the extracts evidence	discussion chapter, the
		the analytic claims.	analytic claims stay with the
			participants experiences and
			closely match the
			transcripts.
9		Analysis tells a convincing and	The analytical process
		well-organised story about the	detailed above provides
		data and topic; analysis	transparency into the
			analytic process highlighting
		question.	the various steps that were
			taken to ensure that the
			analysis tells a well-
			organised story about the
			data collected whilst
			simultaneously answering
10		An appropriate helence	the research question.
10		An appropriate balance	A combination of analytic
		between analytical narrative	narrative and data extracts
		and data extracts is provided.	have been used in the
			analysis chapter.

11	Overall	Enough time has been	Although this project had
		allocated to complete all	time limitations, plenty of
		phases of the analysis	time was allocated to the
		adequately, without rushing a	various phrases of the
		phase or giving it a once- over-	project. Previous phases
		lightly (including returning to	were revisited if needed.
		earlier phases or redoing the	
		analysis if need be).	
12	Written	The specific approach to	The theoretical positions and
	report	thematic analysis, and the	assumptions have been
		particulars of the approach,	detailed above.
		including theoretical positions	
		and assumptions, are clearly	
		explicated.	
13		There is good fit between what	As evidenced in the
		was claimed, and what was	methodology, analysis, and
		done - i.e., the described	findings chapter.
		method and reported analysis	
		are consistent.	
14		The language and concepts	As evidenced in this chapter
		used in the report are	above, the ontological and
		consistent with the ontological	epistemological positions
		and epistemological positions	were reflected on prior to the
		of the analysis.	analysis and thus shaped
			the findings that were
			generated and the thus the
			analytic story told.
15		The researcher is positioned	Reflexivity sections detailing
		as active in the research	my positioning and impact
		process; themes do not just	on the research process has
		'emerge'.	been detailed in the
			introduction, methodology,
			and discussion chapters.
			and discussion chapters.

The conscious decision to
use first-person language
was also made to evidence
ownership of interpretations
and findings. The use of the
term 'emerge' was avoided
and instead was replaced by
developed which highlights
the active and subjective role
I played in the research
process.

*Note:* The 15-point checklist has been taken from Braun and Clarke (2022, p.269)

# 2.9. Reflexivity – "The Fuel That Drives the Engine" (Braun & Clarke, 2022, p.12)

While some researchers highlight that the subjective nature of qualitative research as a limitation, Braun & Clarke (2022) embrace this as a strength of the analysis. This is signified by the use of the word *reflexive* within the name of the methodology, which places subjectivity at the heart of the methodology. On this note, the authors say, "viewing subjectivity as something valuable, rather than problematic, is a key aspect of qualitative sensibility" (p.12). However, rather than simply acknowledging the role we play in shaping the research we conduct, the authors call on researchers to turn their lens back inwards allowing them to take responsibility for their own situatedness within the research and the impact that this has on the entire research process – from the questions being asked, the data that has been conducted, and the interpretations made (Berger, 2015; Finlay & Gough, 2008). Therefore, in order to protect the integrity of research, I regularly engaged in different practices of reflexivity from documenting my thoughts in journals to engaging in dialogue with peers, colleagues, and my supervisor. To illuminate my reflexivity process, this section will detail the different aspects of me that were most likely interact with the research process.

Qualitative researchers often make use of the dichotomous terms "insider" and "outsider" when reflecting on the implications of being a member of the studied population. This binary way of categorising a researcher's positionality has been

heavily criticised and frowned upon by some, who instead advocate for a more fluid, context-dependent continuum (Katyal & King, 2014; Yip, 2024). Dhillon and Thomas (2019) further suggest that a researcher's positionalities are multiple and influenced by the power relations between the researcher and participants. My outsider position of not holding an ADHD diagnosis has already been mentioned within the first half of this paper. However, as illuminated by Dhillon and Thomas (2019), I held multiple positionalities with one of these being a woman. It was this identity that initially fostered my interest in researching this topic. As a woman, I have witnessed the different ways in which women have been historically systematically excluded from knowledge production and how this serves the future and marginalises them as being "the second sex". Therefore, when I first learned about ADHD in women, particularly the phenomena of late diagnosis, I recognised that this was yet another consequence of this marginalisation and exclusion.

Along with acknowledging my insider status, my outsider status of being a "neurotypical" has also shaped this research in numerous ways. I acknowledge that I do not have first-hand experiences in either having an ADHD diagnosis or seeking out an ADHD diagnosis in adulthood. As a result, I knew that I could not fully comprehend the lived experiences of navigating this experience, consequently hindering my ability to fully portray the meaning and experiences of women with ADHD. Here, I also occupy a position of social privilege than participants as we continue to exist within an ableist world. This privilege subsequently grants me a great degree of power in how I portray this lived experience from the questions I ask my participants, the quotes I chose, to the story that is told. Moreover, as a psychologist and a researcher, I held "role power" too, which may be highly significant to those whose diagnosis had been granted at the hands of allied health professionals. From the moment I commenced this research journey, I felt acutely aware of my differences and feared that this would hinder participants from engaging in this study due to fears of how they would be portrayed. Alternatively, I wondered if my participants would conceal parts of themselves or their experiences due to fears around judgements from me. While there was no way to minimise this difference, bringing it into my conscious awareness allowed me to better understand how this interacted with this study. Furthermore, reflecting on this allowed me to better engage with my participant's stories as they were, rather than imposing my own process onto theirs.

Furthermore, my dual role of being a counselling psychologist and a researcher interreacted with one another as my third-year placement focused on providing psychotherapy for individuals with disabilities, including neurodiversity. This placement provided me with rich insights into the lives of those who have lived experience of a late diagnosis from a therapeutic perspective. Engaging in this experience, alongside conducting this research, helped me identify my biases whilst also making me an advocate for destigmatising neurodiversity, instead recognising the ways in which we, as a society, hinder neurodivergent individuals from thriving. As a researcher, many of these insights also came through conversations with my supervisor, who has lived experience of navigating a late diagnosis in adulthood. Here, her provision of safe and non-judgemental space allowed me to recognise my ableist assumptions and the ways in which this showed up in the ways I interacted with this research. For instance, as mentioned before, when I first approached this research subject, my understanding of ADHD was heavily shaped by the medical model which further influenced the language I used. This was evident in me constructing ADHD as a disorder which led to "impairments". It was through the conversations with my supervisor, and engagement with grey literature, which introduced me to alternative ways of constructing ADHD (e.g., the neurodiversity paradigm and the social disability model of ADHD). These conversations shaped the study as a whole, from the language used (e.g., the use of the world co-morbidities versus the use of the term cooccurrences), to the questions asked in the interview schedule (e.g., asking participants in their opinion what they think needs to be changed or improved on). Moreover, when engaging with the data, I attempted to adopt this same open and nonjudgemental attitude, staying with my participant's experience, focusing on the research aims and questions, rather than seeing what I wanted to see within the data. As encouraged by Braun and Clake (2022), a researcher needs to avoid getting too attached to the data and instead go where the data takes them.

During the research course, I also engaged in multiple dialogues with others from the field which was truly an asset in building my understanding and sensitivity in interacting with this research. I presented my research in the form of a poster, a presentation, and later a symposium, with the latter project being one where I collaborated with another trainee counselling psychologist whose research also explored the lived experience of

women with ADHD, with a focus on motherhood. Alongside presenting my research, I also attended talks and seminars about neurodiversity which illuminated 'blind spots', whilst also allowing me to learn more, thus furthering my ability to meaningfully engage with this research as a whole.

Lastly, my social-cultural context of being a South-Asian counselling psychologist who grew up in a Middle Eastern country and later moved to the UK, also interacted with my engagement with this research. Given my intersectional identity, the experience of being minoritised and marginalised by society was not new to me and, in some ways, truly connected me with this topic. While the ways in which this marginalisation occurs is different, the core experience has similarities. The presence of ethnic disparities within the rates of ADHD diagnoses and how individuals who are neurodivergent are repeatedly stigmatised within these cultural contexts is one that I have had first-hand accounts of both professionally and personally. This felt particularly salient when engaging with the accounts of the two South-Asian women who engaged with this study, as I felt a degree of understanding towards their experiences. The interaction between my identity and this research made me question the ethics of superimposing participants' experiences with concepts of normality shaped by Eurocentric, ableist theories, rooted in positivist frameworks, which often overlooking the nuanced realities of ADHD. These theories also play a large role in continuing the stigmatise and marginalise individuals with ADHD and made me question the ways in which this research may further contribute to the stigmatisation and oppression of participants who engaged with this study.

**Chapter 3: Analysis** 

3. Overview of Chapter

The following chapter will present the findings generated by the RTA, guided by the

research questions (1) How do women diagnosed with ADHD in adulthood describe

their experience of being diagnosed in the UK? (2) How has their ADHD diagnosis

impacted their identity and daily life functioning?

Consistent with the research aims and objects, the findings presented reflect both

experiential and social constructionist themes, to capture the complex interplay of

social discourse and lived experience.

This chapter includes direct quotes from participants taken directly from the transcripts

of the interviews. Text in brackets has been used to provide missing words when

deemed essential to aid the reader or when information has had to be retracted to

preserve the confidentiality and anonymity of the participant. At times, I have used

ellipsis points (a series of three dots) when I have left some words out of the

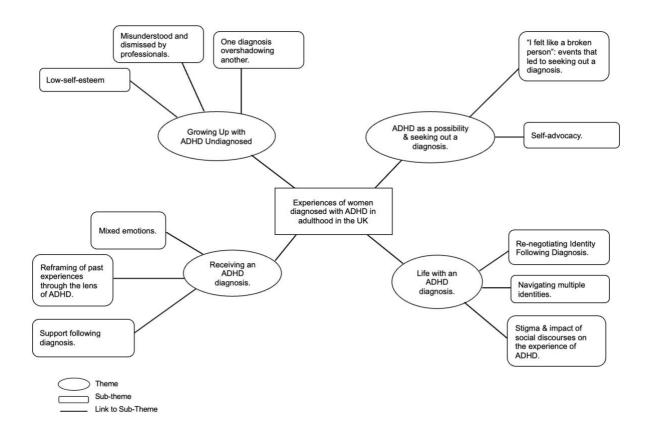
participant's original quote. Here, special care has been taken to ensure that do not

alter the quotation in a way that inaccurately represents the participant's experiences.

Figure 2

Thematic Map of Main Themes and Sub-Themes

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As represented above, four themes were developed from the analysis, and within these 11 further sub-themes. These theses are (1) Growing up with ADHD undiagnosed, (2) ADHD as a possibility and seeking out a diagnosis; (3) Receiving an ADHD diagnosis; (4) Life with an ADHD diagnosis.

### 3.1. Theme 1: Growing Up With ADHD Undiagnosed

In this theme, women reflected on the impact that undiagnosed ADHD had on their childhood. Participants recall feeling 'different' than the people around them and without knowledge of ADHD, participants did not have a framework to understand themselves and their experience. This led to women regarding this difference as a characterological flaw, hindering their sense of self/self-worth (3.1.1. Low-Self Esteem). Additionally, when these women sought out support from professionals (e.g., GPs, teachers), they frequently felt misunderstood or dismissed (3.1.2. Misunderstood and Dismissed by Professionals). Consequently, they were often misdiagnosed with other psychological or neurodevelopmental conditions which ultimately led to the overshadowing of one diagnosis, over the ADHD diagnosis (3.1.3. One Diagnosis Overshadowing Another).

#### 3.1.1. Sub-theme: Low-Self-Esteem

When exploring their childhood, all participants reported feeling "different" than the people around them. This feeling was often encountered at a very young age. Without a framework to understand this different, participants often associated their difference as being representative of personality flaws (e.g., being a failure, or lazy), which consequently hindered their sense of self and their self-worth. For instance, Zara stated:

"I've always known, like throughout my childhood that there was something [brief pause] something not right" (p.2, L38-39).

However, Zara could not "put her finger on it". This narrative was reinforced by her friends/peers, who regarded Zara as being a "weirdo", "quirky", and "eccentric". Furthermore, Zara was regarded as "lazy" by her parents from a young age due to her inability to complete household chores which was exacerbated by her ADHD symptoms. These comments reinforced her sense of difference and led to her believing that this difference was representative of something being innately "wrong" with her. Over time, Zara internalised these comments, which hindered her sense of self making her feel like a failure.

This feeling of failure was further reinforced by academic pressures that surrounded Zara. When recalling her early years of school, she regarded them as "tormenting her" highlighting the distress and lasting impact that they had on her.

"I think early years of school even now sort of torments me sometimes because I was this loser. I was, you know, this stupid, idiot who didn't know anything." (Zara, p.9, L184-185).

Zara grew up in South Asian where she experienced a great deal of pressure to perform well in mathematics and science-based subjects. However, she felt disinterested in these subjects, and found that her mind was "not geared" towards these topics. Consequently, Zara did not perform well on these subjects. Her failure to

perform in line with expectations was attributed to her "not putting in enough effort", which positioned her as the "problem". She was also compared to siblings who would do better in these subjects, ultimately reinforcing her feelings of difference, making her feel like a "failure". Overall, these thoughts and beliefs, hindered her sense of self.

A similar experience was shared by Emma reflected on always feeling like there was a "missing piece", which she could "never get". On this note, she shared:

"I've always had this back thought of there's something different with you, and there's something wrong with you, but what is it?" (Emma, p.26, L437-438).

Whilst Emma felt different than the people around her, she wondered if this difference was representative of something be "wrong" with her. As time progressed, Emma felt drawn to human behaviour as a means to better understand other people, and pinpoint what was "wrong with her". This ultimately suggests that the "difference" or "wrongness" was located inside Emma, indicative of an innate flaw.

"It just fascinates me how much I didn't understand people and how different I was, and I was so cautious of how different I was that I wanted to understand it more, and also understand what was wrong with me." (Emma, p.17, L278-279).

Ella echoed Zara and Emma's experience and shared:

"I've always had issues through my my whole life from being very, very young, um and always knew that I was different and even like locally I live in a very, very small place. So, if you're different, you really standout." (Ella, p.3, L52-54).

In the extract above, Ella's use of the words 'very, very young' highlights how early on she became aware of this difference. When exploring the impact of this difference, Ella shared that as a consequence of "standing out", she was "bullied relentlessly throughout school for her difference". She also reflected on feeling unable to understand these differences saying, "I didn't know why I was thinking or feeling anything". Without a template to understand her thinking or feelings, Ella felt isolated

from the people around her, and learned to take herself out of social situations and way of protecting and preserving herself.

"I preferred to just, you know, take myself away because I knew I was, you know, odd and different. And in order to stop me being picked on or getting into trouble I would just take myself away." (Ella, p.5, L105-107).

Ella's experience of social isolation or bullying is not an isolated experience, but was shared by Sophia who shared that she experienced bullying not just by other peers but also by teachers.

"It was very much, well, you can do maths, so there's nothing wrong with you. You're just lazy. They'd [the teachers] would tear my work up in front of me in class and they'd use it as an example of what not to do and I-I-I got really quite bullied by the teachers." (Sophia, p.3, L70-72).

As highlighted my Daphne, the experience of being bullying or being attributed with negative traits had a grave impact for her sense of self. Growing up, Daphne was regarded to as "lazy", "messy", or someone who "doesn't listen". These messages led to her "beating herself up":

"I would always beat myself up in the past about um, oh, I can't, you know, like procrastinating and stuff like that, and I'd be like "just get on with it", "just do it", "just do it". And I couldn't. My brain would stop me, and I would beat myself up about it." (Daphne, p.8., L163-165).

Here, Daphne's extract highlights the turmoil or the conflict that she experienced internally when she needed to complete a task. On one hand, she had a drive to "get on with it", whilst on the other than she faced the reality where she "couldn't" because her "brain would stop her". Here, the repeated use of the metaphor "beat myself up about it" highlights the blame and shame she experienced for not being able to complete the tasks. This phrase also implies a sense of harshness or aggressiveness in the way Daphne would speak to herself in these moments.

Ava echoed Daphne's experience further added that when she would tell teachers she "couldn't" do it, she was "not believed".

"Having like employers and teachers and all these people tell me that I, you know, I should be able to do this, and me saying, "I can't", and nobody believing me, and thinking it was a personal failing [...] I've spent so much time in my life being like oh, I'm such a failure" (Ava, p.3. L93-95).

The experience of not being believed had a significant impact on Ava as she internalised the failure as being a "personal failing". This led to her spending a significant time in her life situating herself as the "problem", believing that she is a "failure", a belief that she since carried with her.

# 3.1.2. Sub-theme: Misunderstood and Dismissed by Professionals

Perhaps a consequence of the low-self-esteem, participants reported experiencing mental health distress, which began at a young age. All participants reported at least one event of seeking out professional support for the distress they were experiencing. For many of them, this began by their parents reaching out to their GPs with the aim of getting more answers.

In Ava's experience, she began experiencing distress when she was only six years old.

"My first period of sever anxiety when I was six – was when I was six years old [brief pause], I don't know how anybody could look at a six-year-old and just think, "oh well, that's just anxiety" (Ava, p.12. L222-224).

In the extract above, Ava highlights the way her experience of distress was understood as anxiety. Moreover, Ava's use of the phrase "just anxiety", suggests that the framework of anxiety did not adequately capture what she was experiencing at that time, leading to her feeling misunderstood. Ava goes onto say that she was often told, "she'll grow out of it" and "she's just got the nerves" which further highlights the dismissal she experienced. When reflecting these memories, Ava recalled the

experience as being "atrocious" and "awful", suggesting that the process of being misunderstood and dismissed had a lasting psychological impact on her.

Whilst most participants experienced their distress on a psychological level, some participants also experienced their distress on a psycho-somatic level. For instance, Emma shared:

"I was first seen by kind of somebody for mental health or worry when I was seven, and I've still got the letter, and it's so interesting now because it's basically ADHD. I was getting a lot of tension headaches, which I know is from really trying to do better in the classroom but not being able to take in information." (Emma, p.11, L175-178)

The manifestations of Emma's ADHD symptoms hindered her ability to pay attention in the classroom, which she was not afforded the space to understand due to the fear of being reprimanded or getting "negative feedback". This then led her masking or compensating, giving rise to tension headaches. Emma then adds:

"So, I went to the doctor and she literally – I've still got the letter – she wrote "Emma will likely suffer with psychosomatic symptoms for the rest of her life" [...] Yeah so, they recognised that it was my neurology like but nothing else was kind of looked into." (Emma, p.11, L183-189).

Emma's extract above highlights that her doctor recognises the psychosomatic symptoms that she is experiencing but makes no meaningful attempt to understand the basis of these symptoms. A similar experience occurred when Emma was 12 years old where her mother tried to get her to see the school counsellors and her GP, however they were "all so dismissive and uninterested" (p.12, 197-198). When recalling these events, Emma reflected on feeling a profound sense of disappointment and anger for the lack of understanding provided by professionals.

### 3.1.3. Sub-theme: One Diagnosis Overshadowing Another

After experiencing persistent and enduring mental health distress, most women were given a clinical diagnosis by GPs, clinicians, or professionals. In Emma's experience, her "struggles have always been framed as mental health" (p.16, L253-254). Consequently, Emma was offered Cognitive Behavioural Therapy (CBT) as a means of reducing the distress she was experiencing. However, Emma felt like this did not capture the full picture.

"I could do CBT till I'm blue in the face. I know why I behave in certain ways. I like to think I know my emotions well, but I still figuring that out, but like, I can name them, if that makes sense? But there is still something missed, and I do not know what it is." (Emma, p.28, L476-478).

Emma's use of the metaphor "blue in the face" gives us a deeper understanding of how commonly CBT was pushed on her as way of addressing her distress. Ava experiences aligned with that of Emma's:

"I'd always thought that I'd had anxiety, and people kept diagnosing me with anxiety [brief pause], but it was treatment resistant anxiety, and any therapy I went to was usually cognitive behavioural therapy, and that involves homework, and I never did it" (Ava, p.10, L184-186).

As with Emma, Ava's distress was framed as mental health problems, leading to her being prescribed with CBT. Whilst Emma found CBT helpful in some respects, Ava found it hard to engage and complete the homework. Her symptoms were then regarded to as "treatment resistant anxiety", which is a term used to describe clinical cases where an individual does not respond to "first-line" treatments for anxiety. In both these women's experience, practitioners and clinicians aimed to address the presenting anxiety or distress, without investigating the deeper causes. This led to the underlying ADHD being overshadowed by diagnosis of anxiety or depression.

In Daphne's case, she was first given the diagnosis of depression, however, when she was seventeen, she was also given a diagnosis of borderline personality disorder

(BPD). Later, her diagnosis was changed to bipolar disorder, and she was told that she does not have BPD. The constant movement between diagnoses left Daphne's feeling unheard, as she did not believe they were "correct". More recently, she was diagnosed with ADHD and Autism.

"Now, I've been diagnosed with ADHD and-and Autism, and they make far more sense than the diagnoses I had in the past. I very bitter about it. I can't deny it. I am so angry" (Daphne, p.14, L330-331).

As highlighted by Daphne's experience, the diagnosis ascribed to her, did not align with her view of what was going on. Overtime, these diagnoses overshadowed her underlying ADHD, which she regards as making "far more sense" than her previous diagnoses. In this extract, Daphne reflects on her feeling of anger and bitterness for not feeling heard or being assess in a timely manner.

In Sophie's case, rather than a mental health condition, it was a neurodevelopmental condition that overshadowed her ADHD. Sophie was first diagnosed with Dyslexia whilst at school.

"Dyslexia was kind of because of school, and my spelling, and my reading, and my writing erm, and getting frustrated in class." (Sophie, p.3, L54-55).

However, Sophie was not supported by her school to be assessed for dyslexia, but instead shared that her mother had to seek out a private assessor in order to "have her diagnosis done". Moreover, Sophie also added:

"One of the schools that I had gone to erm early on did not believe that – in dyslexia." (Sophie, p.3, L65-66).

The experience of not being believed for having a neurodevelopmental condition left Sophie feeling dismissed and unheard. She later moved to another school, one that recognised dyslexia. As Sophie grew older, she recalled that ADHD "was never really put up". Instead, "it was put down as depression or social anxiety". Moreover, the things that has had put in place to manage her Dyslexia were no longer working. This

led to Sophie feeling frustrated as "all the things were the same things that I've been saying for years", illuminating that she had not been heard or listed to "for years".

This theme summarises participants early life experiences of growing up with ADHD. Participants' experiences highlighted that they experienced feeling 'different' than the people around them from a young age. However, without a framework or space to understand this their difficulties, women regarded this difference as a negative connotation, questioning what was "wrong" with them. These negative connotations were also reinforced by teachers, parents, and other peers who without the understanding of ADHD, ascribed negative labels to their behaviours. Being surrounded by negative comments, women internalised these labels viewing them as characterological flaws. Overtime, this led to low self-esteem which was undoubtably distressing. Participants also reported experiencing psychological distress starting at a young age. This led to them to seek out support from their GPs, however, they reported feeling either misunderstood or dismissed by professionals. Often, their distress was conceptualised through the framework of mental health, and they were provided with a diagnosis accordingly. However, these diagnoses then overshadowed the ADHD diagnosis.

### 3.2. Theme 2: ADHD As a Possibility & Seeking Out a Diagnosis

After a childhood of undiagnosed ADHD, women often continued experiencing mental health distress persisting into adulthood. This theme aims to capture the journey that occurs after women learn and query the possibility of their symptoms being manifestations of ADHD, and the subsequent process of seeking out a diagnosis (3.2.1. "I felt like a broken person": Events That Led to a Diagnosis). It also delves into a common experience where women had to advocate for themselves to obtain an ADHD assessment (3.2.2. Self-advocacy).

**3.2.1. Sub-Theme:** "I felt like a broken person": Events That Led To A Diagnosis
This sub-theme relates to the events that led to participants seeking out an ADHD diagnosis. Women often learned about the gender specific presentation of ADHD through articles written by other women who had been diagnosed with ADHD in

adulthood. In Ava's case, she first came across ADHD after reading an article written by an acquaintance documenting her lived experience of being diagnosed. When reflecting on her first impression of reading the article, she reported that she found it "interesting", but she didn't "think anything more of it".

"I read it and then I didn't think about it again for quite a while. For about six months. And it was like, yeah, well, that's fine for that person because they've got something wrong with them, but I'm just useless, you know?" (Ava, p.13, L253-255).

Ava initially dismissed the possibility of ADHD as she held the belief that her symptoms were representative of characterological flaws (i.e., being "useless"). As explored above, this was a narrative that was reinforced by the people around her. When looking back at this time, Ava recall that she was in distress but felt as though the NHS did not know how to "deal" with her, as she was not "mad enough" to require inpatient care and was "too much" for just CBT. As time passed, the article "tickled something in the back" of Ava's mind, prompting her to re-read the article.

"I went back and read it, and I was like Oh My God [laughs], this is me, like this is my entire life. Like this is everything. And like there were things she'd set out that were like – I've been through every single one of these things." (Ava, p.9., L160-162).

Ava's use of the phrase "Oh My God" captures the unique blend of emotions she was feeling at the time that was ignited by her sense of identification with the author experience. The statements "this is me" and "this is my entire life" suggests that she felt seen and understood by the article, perhaps in a way she has never been seen prior. This prompted her to share the article with her mother asking her, "what do you think?". Her mother replied saying, "Oh My Goodness. Yeah, that does sound like you". Here, her mother's comments were validating of her experience, in the process making her feel more seen and understood.

However, following this Ava "didn't have the courage to go for the diagnosis". The use of the word courage by her suggests that the act of seeking out a diagnosis frighted

her and required bravery. However, following the onset of the COVID-19 pandemic, Ava's mental health further declined, saying her "mental health is in the toilet", illuminating the profound distress she was experience. Additionally, the metaphor also highlights that her mental health was not serving a function was perhaps ready to be 'flushed away'. She then reached a point where she thought, "something needs to happen now", leading her to seek out a diagnosis.

Sophia's experience overlapped with that of Ava's. Sophia first learned about ADHD through the media. However, echoing Ava's experience, she "didn't really think anything of it". Following that, Sophia found herself looking into ADHD as she recently starting dating somebody whose son's behaviour aligned with what she understood of ADHD.

"I started dating somebody, and his son [brief pause], OMG withing 10-minutes of meeting his kid, I was like pfft there's no doubt in my mind that you've got ADHD. Typical – what you'd expect from what the media portrays for boys." (Sophia, p.1, L24-26).

Her partner's son's experience felt "typical" perhaps aligning with a more stereotypical presentation of ADHD which overemphasises the hyperactive symptoms of ADHD. Sophia highlights that the hyperactive presentation has formed the dominate way we understand ADHD and its presentation. After struggling with his behaviour, Sophia turned to researching to better understand how she could deal with them.

"I was struggling with this [with her partner's children], so I started researching how to deal with them better and then through researching it, I was like [exhales] hold on, this makes more sense of me [...] but because I wasn't what you would perceive it to be in the media, you know, I wasn't the naught kid at school. I wasn't getting into trouble. I wasn't running around. I could sit still." (Sophia, p.2, L28-32).

Sophia's research led her to identify with the diagnosis herself, with her exhale perhaps being representative of the relief she may have experienced after feeling seen. There appears to be a dissonance between Sophia's experience of ADHD and

the media's portrayal of ADHD. Furthermore, this dissonance may have led to feelings of shock and confusion which was highlighted by her saying, "I wasn't the naughty kid at school". She may have also experienced some internal shame or judgement for being associated with a diagnosis for "naughty kids". Therefore, the stereotypes that surrounded ADHD allowed her to connect the diagnosis with her partner's son's behaviour much more swiftly than she could with herself. She then added:

"It wasn't something that I thought of for me, but the more I read into it, it made a lot of sense" (Sophia, p.2., L33-34).

Sophia's statement "it made a lot of sense", further highlights that she felt seen and understood by these articles. The timing of this felt crucial as Sophia was struggling with her everyday life and mental health.

"The things that I kind of put in place for my Dyslexia weren't necessarily working as well and other things were getting in the way" (Sophia, p.1, L20-21).

During this process, Sophia worried that she was "completely losing it" and "going mental", highlighting the distress she was experiencing at the time. This prompted Sophia to ask her GP for an onward referral and during the appointment she said:

"I've been for counselling, I've been for help, and it kind of worked for a bit but didn't, and then I got to a point where I was just like, I need some help with something, and nobody seems to be able to point me in the right direction for the assistance I was needing and it was a case of well, this actually fits more of everything, than anything ever has." (Sophia).

This then led to an onward referral for an ADHD assessment. Whilst Ella's experience aligns with Ava and Sophia's, her journey to learning about ADHD started differently. Ella recalled that in the summer of 2021, she was doing a redecoration project which she later forgot about, abandoning it prior to completion. This prompted her daughter to say, "Mum, you must have ADHD or something because you never finish anything" (p.9, L184-185). However, Ella "totally dismissed it" (p.9, L185-186), not thinking much

into it, However, Ella had been struggling with her short-term memory and not remembering things. She recalled:

"I'm totally zoned into what I'm doing, and you could be talking to me, you could be standing right beside me right her [signals right next to her], but I'm not hearing what you're saying because I'm so busy doing what I'm doing [...] and my partner turned around to me, and he called me ignorant, which, you know, I'm not an ignorant person, and I was really upset about that. And I was like I don't know what is wrong with me." (Ella, p.9, L190-195).

This event caused a great deal of distress for Ella which is highlighted by saying, "I don't know what is wrong with me". Without having a framework to understand this behaviour, Ella began worrying that her symptoms may be representative of an underlying neurological condition that may have not been picked up on, such as early onset dementia or as a consequence of a head injury. Therefore, after this interaction, Ella turned to researching.

"I thought after that interaction with my partner when he called be ignorant, I just sat, and I must — I obviously used the correct search terms, and I used hyperfocus and I used short-term memory problems. [...] It was just ADHD that came up and I just kind of like scoffed because my daughter had said that you know a month or two before." (Ella, p.10, L225-229).

However, Ella's laughter soon turned into tears as she began reading articles:

"I started reading it and the tears just started falling, like they just fell [...] because I was like oh my God, that's me. That is – that is me. How was I so unaware?" (Ella, p.11, 233-238).

As highlighted by Ella, this article led her to have a "eureka" moment, which is often a word used to celebrate a discovery. Perhaps the discovery made by Ella was about herself, finally having a framework to understand herself, whilst also validating her doubts she had earlier of "something not being right" and knowing she wasn't "normal". Whilst watching her cry, Ella's partner advised her to "stop reading that you're just

getting really upset", to which she replied, "I wasn't upset, I wasn't angry", instead "I am relieved". This relief may be connected to her finally being able to understand herself. Following these events, Ella spoke with her GP asking to be referred for an assessment.

Unlike in the experiences above, in Ayesha and Daphne's experience, the ADHD diagnosis was brought to their awareness after it was recommended by a clinician. Ayesha had experienced a series of difficult events, following the ending of her marriage and her return to university as a mature student, where her "inability to grasp one assignment within a philosophy module" was "catastrophised to me failing the module, failing the course, being kicked out of university, not being able to provide for my children, and my children being taken away from me" (p3, L78-79). Ayesha also adds that her background of being a South Asian British woman, further exasperated these experiences:

"There was so much linked to me going back to studies [brief pause] culturally, within the family, for myself." (Ayesha, p.3, L67-68).

Faced with these distressing thoughts, Ayesha felt as though she "can't cope with this", resulting in her attempting to end her life. Reflecting on this time, Ayesha says:

"I obviously believe it was a cry for help. I don't believe I genuinely wanted to die" (Ayesha, p4, L80-81).

Ayesha's attempt to end her life highlights the immense distress she was experiencing prior to the diagnosis. Her regarding this experience as a "cry for help" suggests that her distress perhaps was not being seen at this time, leading to her not being supported. Moreover, without the diagnosis of ADHD, she did not have a label of understanding the distress she was experiencing. On this note, she says:

"At that point, if you had spoken to me back then, it would be a very, very different case. I felt like a broken person. [...] Like there is something wrong with me." (p. 2-3, L.54-61).

Following this, she was taken to a psychiatric outpatient unit where a mental health social worker queried ADHD.

"I was really lucky, the mental health social worker I had was really in tune and within minutes of speaking to me [...] asked if I'd ever been spoken to or suggested or assessed for ADHD, and I said no, and he said – he said I'd like to, and I said that's fine." (Ayesha, p.4, L83-85).

Reflecting on this experience, Ayesha uses the phrase "really lucky", which suggests that the process of her being referred for a diagnosis felt like a positive, unexpected outcome that came without her having to seek out the diagnosis herself. It perhaps also suggests that an alternative of not having the diagnosis would have meant that she would have to continue living her life experiencing debilitating distress; without a framework to understand both the distress and herself.

In Daphne's experience, the possibility of ADHD arose when she was eight months pregnant with twins by her psychiatrist with whom she had regular appointments due to her comorbid diagnoses.

"It never occurred to me when it was first mentioned in 2011. I straight away said, "oh no, I don't have that. Like not even a possibility." (Daphne, p.3, L. 47-48).

Daphne's response to her psychiatrist querying ADHD was denial and dismissal. Later, the psychiatrist who had initially queried ADHD left the service, leading to this never getting followed up. However, five years later, the possibility of ADHD was questioned again. This time, Daphne said:

"Oh well, you can put me on the waiting list, if you want, I don't really think I have it." (Daphne, p.3, L.49-50).

Although Daphne still did not think that her symptoms aligned with ADHD, the experience of it being mentioned twice led to her being open to an assessment. When reflecting on why Daphne responded with an immediate "no", she says:

"I don't have that because obviously, I mean, more recently it's ADHD in adults has been I suppose more talked about, but in 2011, no one – it was naughty boys in classrooms. So, I thought, you know, I'm a grown woman, I've got three children, I don't have ADHD. [...] I wasn't insulted but I just thought, you know, I don't have that. I am not naughty. And it wasn't until 2018 that I looked into it and actual adult, rather than the stereotypical naughty boy and I thought oh, I didn't even know these symptoms existed especially in women." (Daphne, p.4, L.73-79).

As shared by other participants, Daphne's denial of the ADHD diagnosis stemmed from the incongruence that existed between her own lived experience of ADHD and her understanding of ADHD, which was heavily influenced by stereotypes. This incongruence was heightened within her context of being an adult and a mother at the time, both of which contrasted the 'naughty boy' stereotype associated with ADHD.

This experience was shared by Emma who noticed that her understanding of ADHD was impacted by the narratives that she grew up around, whereby she observed a link between class or socio-economic status and being "disruptive".

"So, I grew up in [a town in west England], which is predominantly kind of white middle-class town. [...] sometimes I think it's like a class problem, or maybe I did when I was younger. Like the people who lived on council estates would be more disruptive in class and it's like the "naughty boy syndrome". So, it was my understanding of ADHD, you know?" (Emma, p.14, L222-232).

Emma later added that during her childhood ADHD was spoken about as an "insult":

"One of the mothers once was really annoyed at my mum because he'd [her younger brother] been disruptive in a party, and she was like [...], "he looks like he as ADHD", and it was an insult. So, I always thought of ADHD as a negative thing, and you wouldn't want to have that, and my mum was really upset, and I was like oh, this is bad." (Emma, p.14-15, L235-238).

Emma's use of the terms, "insult" and "negative thing" highlights the shame and stigma that was associated with ADHD. Out of fear of being seen in a negative light, she never considered the possibility of having ADHD. Later, Emma found herself working in a clinic, under the ADHD pathway, during which, she would administer the Quantitative Behavioural (QB) test to children and young people. The QB test is a diagnostic screening tool used (in conjunction with other ADHD assessment tools), to aid the assessment of ADHD. As a way of familiarising herself with the test, Emma conducted the test on herself, with the results indicating ADHD. Emma's first reaction was "Oh, it says I have ADHD, but it must just be because I'm tired" (p.24, L418). This prompted Emma to re-do the test again "in the morning" and after she'd had her morning cup of tea. This test yielded similar results, which she found "funny", highlighting how unexpected and perhaps uncomfortable these results were for her.

She kept these results and did not seek out a diagnosis immediately. Instead, she sought out a diagnosis following the onset of the COVID-19 pandemic which had significantly compounded her mental health.

In Zara's experience, the possibility of ADHD arose after her peers brought it to her attention.

"I'm training to be a counsellor, and we have to triads as part of the assessment and within the triad, I noticed myself kind of going, if you will, and like they could see it in my eyes like, you're there, but you're not there, and a few people picked up on it." (Zara, p.2, L27-30).

Whilst Zara knew about ADHD, she just never put herself "in the category of ADHD" attributing this to both denial and lack of awareness. However, the comments made by Zara's peers were the "icing on the cake" as they helped her find words for an experience she has "never been able to articulate". Following this, she reached out to a few friends who had been diagnosed with ADHD, with them saying, "we can see it in you", prompting her to contact her GP for an assessment.

# 3.2.2. Sub-Theme: Self-Advocacy

Following ADHD becoming a possibility, women would then begin the process of seeking out a diagnosis. A commonality between the experiences of some women was the process of advocating for oneself in order to receive access to an assessment. On this note, Ava said:

"The more I read up on it, more I was like, "Oh God, yeah, this is definitely something I need" because I felt like [brief pause], I needed to have enough evidence to go to the doctor with, you know, that was the thing, like how can I prove this? Like how can I go in there [...] to get my best outcome because, you know, a lot of us are used to battling medical professionals and kind of asking for respect and to be asked, you know, spoken to, and to have our problems taken seriously." (Ava, p.13, L259-264).

Ava's account suggests that upon seeking out a diagnosis she was anticipating that she would need to "battle" the medical professionals. Ava also talks about needing "courage" to ask for the assessment, which took her some time to gather, suggesting that she perhaps felt frightened that she would be dismissed or rejected. Here, her past experiences of being dismissed and misunderstood by professionals have contributed towards this anticipation and led to her going into her appointment with "evidence" to "prove" that her experience aligns with the symptoms of ADHD.

However, during the GP appointment, she noted that her practitioner "wasn't very gatekeeping" with the assessment. Ava did add that she "stretched the truth a little", by saying "I've got a friend who is a psychologist, and she's suggested to me that I think maybe I should go for this". When exploring why Ava found herself needing to stretch the truth, she shared it "landed me a bit more validity" and "that really seemed to grease the wheels". This perhaps highlights that Ava felt as though her own research and opinions would not give her as much validity or cogency.

Following the referral to an NHS clinic, she was told:

"When they first referred, they said [...] we want you – we need you to think in years and not months." (Ava, p3., L47-48).

Ava was dishearten and surprised but agreed. However, later, Ava's distress intensified leading to her re-contacting the service. During her research, Ava was made aware of the right to choose pathway which would allow her to choose an alternative provider to receive her NHS diagnosis. Upon asking for a referral to use this pathway, she was given an appointment "quite quickly after".

In Ella's experiences, her GP put her forward for as assessment after she shared a few examples of how her symptoms may align with ADHD, instead of the "depression and anxiety thing". However, after being referred on, Ella found herself being stuck on a waiting list for an assessment.

"I was waiting for this one single appointment letter to come through the post. [...] I just feel like I'm sitting in this big waiting room. That waiting room was my head. It was my-my home, you know?" (Ella, p.14, L309-312)

When exploring what this waiting room would give Ella access to, she shared it would give access to "her inner monologue", which suggests that at this point she could connect with her inner voice. This is perhaps further indicative of the disconnection she experienced with herself. Ella then championed for herself which led to her appointment getting moved forward. Reflecting on this experience, Ella says:

"It felt like forever, but to be honest, I didn't have to wait as long as so many others, and I'm very fortunate for that but I'm also very good at advocating for myself sometimes. Sometimes, not all the time. But it was also important enough for me to get this diagnosis could that I could move on with my life." (Ella, p.15, L325-328).

Ella's comment conveys a sense of impossibility of moving "on with life" without the diagnosis, which further highlights the pivotal role of a diagnosis. Emma's experience aligns with both Ava and Ella's, whereby she took the results of her QB test with her to her GP appointment.

"It would have been [...] about mid-2020 that I went through and at that point I didn't really know what to say. I was just like I used to work on the ADHD pathway, and I did the QB test and it kind of showed up. I've done all this therapy, and nothing quite cuts it." (Emma, p.28, L469-472).

Alongside the QB test, Ella also references her own experience and expertise of working within the ADHD pathway, earning her credibility and validity. When reflecting on the need to prove herself, Emma recognises that her past experiences of help-seeking have shaped her current relationship with help-seeking.

"I've had that rejection so many times throughout my life. You know, I couldn't obviously as a teen and stuff, remember specific things or perhaps appreciate the different points that my mum had taken me for support, but it had always been faced with kind of "you just need to sort things out" or [...] "things will sort out when your hormones regulate" [...] and you know there was always something like oh it's likely situational anxiety, depression, it's like hang on a minute, [brief pause], what if the situation is my life and my brain like?" (Emma, p.29, L493-503).

Unlike Emma's past experiences of help-seeking, she was heard and listened to which was reflected by an onward referral for an ADHD assessment. In Zara's experience, she had to advocate for herself to be referred for the assessment, which is highlighted by her use of the term "convince".

"Then I rang my GP, and it was a bit of a process, to be honest, and I was trying to convince my GP to put me through with the assessment" (Zara, p.2, L31-32).

On the other hand, upon asking her GP to put her forward for an assessment, Lauren was told, "oh no, it might affect your mortgage" and "it might affect your insurance" (p. 3, L49; p. 30, L670). Whilst she now recognises the lack of validity that these statements held; they led to some initial concerns. However, this did not deter her from being assessed and she was then referred to a psychiatric hospital for an assessment.

This theme touches on the journey that occurs following women learning about ADHD and later seeking out a diagnosis. All women reflected on growing up surrounded by the understanding that ADHD was a 'naughty boy syndrome' with its traits being disruptive boys in the classroom and impulsive behaviours. The focus on hyperactive behaviour therefore led to women not recognising their symptoms as being manifestations of ADHD. This awareness often came after women did their independent research by reading articles. In the experience of two women, ADHD was queried by professionals. With the prior experience of being dismissed, misunderstood, and rejected by professionals, women who learned about ADHD through research found it daunting to raise this with their GP, fearing that they would be rejected once again. However, they advocated for themselves, giving them access to an ADHD assessment.

# 3.3. Theme 3. Receiving an ADHD Diagnosis

This theme relates to the experience of receiving an ADHD diagnosis. It begins with an exploration into the emotions felt by participants upon being told that they had ADHD (3.3.1. Mixed Emotions). The diagnosis often prompted them to reflect on prior experience where they had been labelled as the 'problem', instead reframing these experiences through the lens of ADHD (3.3.2. Re-framing Past Experiences through the lens of ADHD). By re-framing these experiences, participants were able to extend compassion, not just to themselves, but also others, including caregivers. Lastly, participants' experience of Support Following Diagnosis is discussed (3.3.3).

## 3.3.1. Sub-Theme: Mixed Emotions

When asked how they felt after receiving the diagnosis, participants often reflected on feeling mixed emotions. For instance, on one hand, the provision of the diagnosis gave rise to feelings of validation and relief.

"Validating because it was like I'd suspected by the time I got a seat; I'd been suspecting it for a few years and it was like, yeah, this is who you are. This is what you need. This is you know – and it was somebody telling me that you will find it difficult and there's a reason for it." (Ava, p.7, L. 118-120).

Here, Ava's experience highlights that her feelings of validation stem from the fact the diagnosis provided her with both confirmation and a rationale for her difficulties. Moreover, after years of being dismissed by professionals, this was a reparative experience where Ava was both heard and validated. Zara felt similarly to Ava, recalling that she felt "relief".

"In a way I felt complete. So, I'd say relief, complete, and the final word coming to mind like oh finally. So, kind of like it's been a long-time coming." (Zara, p.4, L76-77).

When exploring what Zara picked these words to describe how she was feeling, Zara said:

"The reason why I picked finally, because finally I've got some answers" (Zara, p.4, L86).

"Relief again very similar to finally like you know, just getting that um [brief pause] not validation as such but getting that sort of stamp almost like actually you weren't wrong all this time, you were right in having those [brief pause] not concerns even, doubts about there is something there but just not knowing what it is." (Zara, p.5, L94-96).

Emma echoed Zara's word of feeling complete saying:

"There was always a piece missing and I could never get that without the clarity of how your brain works in this way." (Emma, p.7, L106-107).

The clarity provided by the diagnosis made Emma feel "validation" and "relief". However, alongside these emotions, participants also felt emotions such as anger.

"I think I remember for the first say two weeks or so, I didn't tell anybody because I just felt really, really angry, like the angriest I've ever felt, and I just felt frustrated and [...] it was almost like I had processed it being a relief in the

waiting period so then at that point you know the different stages of grief? I was literally grieving for my little Emma [gets teary]." (Emma, p.7, L111-115).

"For the first time, I allowed myself to be angry at other people, and not just myself" (Emma, p.10, L150-151).

When sharing this Emma gets teary perhaps conveying the depth of the anger, grief, and sadness she felt for her younger self, who had been repeatedly been dismissed or rejected. This was also the first time where her feeling of being dismissed were validated giving her the permission "to be angry at other people", and not just herself.

## Emma expands on this further saying:

"But thinking about little me and how much I struggled and how quickly it was then decided that you know, she [the assessor] did listen. [...] I just felt angry at the world for like failing me [...] and that did make a lot of kind of resentment because there were missed opportunities [...] I did struggle, and I've been in different environments where it should have been picked up, especially when I was a child. So, I was just angry and always like I didn't care that I got it anymore because I was just like angry at the world, I guess. So, it was really strange because I thought I would feel a lot happier." (Emma, p8, 123-132).

In this extract, Emma first begins by reflecting on her experience of being heard and listened to by the assessor. This felt like a contrast to her prior experiences which is perhaps why it may have stood out to Emma. This is further conveyed in her profound sense of anger which appears to stem from "missed opportunities" where she wasn't listened to and therefore suffered immense distress. The intensity of her anger is further highlighted by the statement "I didn't care that I got it anymore, because I was just like angry the world". These emotions appeared to have been surprising for Emma herself who regarded these emotions as being "strange" and she thought she would have "felt a lot happier".

This experience as shared by Ava who shared feeling "bitter-sweet", capturing the blend of emotions she felt upon receiving a diagnosis.

"The bitter-sweet thing is like, yes, I have these answers, but I didn't have those answers for 40 years. I thought it was me." (Ava, p. 8, L152-153).

Like Emma, for years prior to the diagnosis, Ava did not have access to "answers" leading to her living a life of immense suffering and distress. Therefore, whilst she feels relief for having the diagnosis, she also feels "bitter" for receiving it so late, reflecting on a life that could have been. This was echoed by Daphne, who said:

"After the first, you know, after the initial assessment when I came home, validation and um, I was little annoyed, I think. Not at the diagnosis but at the fact that I'd been in the mental health system since 2000, so this was 18-years later, and I've been diagnosed with all sorts [...]. I could have been, you know, I could have been medicated in 2001, and perhaps my life would have been different." (Daphne, p,5, L.104-109).

Whilst Daphne felt validated, she also felt "annoyed" at how long it took for her to be diagnosed with ADHD. This feels especially important given how long Daphne had been in the mental health system, which also highlights how long she had been experiencing distress. In this extract, she looks back at her life questioning how different her life could have been, had she been diagnosed and supported in a timely manner. This perhaps highlights a sense of loss or grief for a life that Daphne could have lived. Later, Daphne reflects on this experience adding:

"I do feel a bit robbed and in turn that robbed me of my kids' childhood, and stuff because when they were born, I wasn't right, and I wasn't being treated properly for the right diagnosis." (Daphne, p.18., L.428-430).

The repeated use of the word "robbed" conveys that the late diagnosis stole or took something away from Daphne, and these stolen moments can unfortunately never be returned or given back to her.

### 3.3.2. Sub-theme: Reframing of Past Experiences Through the Lens Of ADHD

Following the ADHD diagnosis, women went through a journey of reflecting on past experiences and reframing them through the lens of ADHD. As articulated by Ava, the diagnosis allowed her to "understand herself a lot more" and describes the process of diagnosis as giving her the "right manual" to operate from.

"I always kind of describe it as you've been trying to operate your brain with one manual and it's the wrong manual and now somebody's given you the right manual." (Ava, p.7. L136-138).

### She adds:

"I always say it's like you have an iPhone and you've always had an iPhone, and somebody hands you an Android phone, and you try to work it like an iPhone, you're not going to get anywhere. But if somebody tells you how to work an Android phone, then you'll be alright [...] it's about applying neurotypical rules to a neurodivergent situation [brief pause], you're never going to be happy, and you're never going to get that right, and you're never going to feel like a whole person. And then somebody says, well actually no, you're an iPhone [laughs] alright, okay, well that makes a lot more sense" (Ava, p. 8, L.142-148).

In this extract, Ava uses the metaphor of phone operating systems to highlight that prior to the diagnosis, Ava did not have a template to understand herself. Instead, she attempted to live her life by "neurotypical rules" which led to an immense amount of distress. This distress is illuminated by her saying "you're never going to be happy and you're never going to get that right". Furthermore, the intensity of this distress led to her not feeling like a "whole person", perhaps suggesting that she felt incomplete or broken. Ava also hints at a feeling of stuck-ness in her life prior to the diagnosis which is articulated by her saying "you're not going to get anywhere". Here, the diagnosis provided her with the "right" operating system allowing her to make sense of herself. It also highlights the importance of her diagnosis, without which she would not be able to understand herself and move forward in life.

In Daphne's experience, the diagnosis allowed herself to look at her earlier life experiences through a different lens.

"I'd done really well at school in my GCSE's and then when it got to a-levels, my life just fell apart, and it all went horribly wrong from then and people said "I didn't pay enough effort in" and I felt bad about myself, and then when I got the diagnosis, [...] it wasn't like an excuse, but it was a reason that these things might have happened, and [...] it wasn't that I was a failure in everything, it was just that I hadn't properly received treatment for um neurodiversity, I suppose." (Daphne, p.6, L.120-125).

In this extract, Daphne looks back at a moment in her life when things began going "horribly wrong" for her, with the term horribly detailing the profound distress she experienced at this time. Without a framework to understand herself and for people to understand her, she was told she was not putting "enough effort in". This judgement was internalised by her leading to her feeling "bad about herself", perhaps also highlighting the shame she experienced during this time for not being "good enough". The narrative of her "not putting enough effort in" also became a lens through which she made sense of herself and her experiences. Here, the diagnosis played a key role in allowing her to modify this narrative to recognise that she wasn't a "failure", but instead, because she did not have a timely diagnosis, and thus treatment for ADHD/neurodiversity.

Equipped with the knowledge and awareness provided by the diagnosis, participants had a template to understand themselves. This understanding fostered feelings of self-compassion and acceptance as participants could recognise that the label ascribed to them at an early age was not representative of personality flaws or something being innately 'wrong' with them, but instead the manifestation of ADHD symptoms. This is also evidenced by a shift in language from questioning "wrongness" to talking about "difference".

"You know, they've called me lazy for this, and-and there's a reason. It's not that I'm just lazy, my brain's not wired in the normal way." (Daphne, p.6., L131-132).

"No, I'm not lazy. It's just the way that my brain processes things, you know? If you're asking me something, I will stand there for 30 seconds [brief pause], it's not just me looking at you, but it's my brain actually processing it [brief pause], so it's just a difference." (Zara, p.4, L86-89).

"It [the ADHD diagnosis] kind of helped because [...] it shows that I'm not lazy [...]. Knowing I've got ADHD kind of helps realise and pace myself and not beat myself up too much." (Lauren, p.29, L628-633).

Emma echoes the words of Daphne, Zara, and Lauren, highlighting the pivotal role that the diagnosis played in provoking her with a language to understand herself. This language fostered compassion towards herself.

"But that kind of compassion, I guess. I could never have got to the place I am with that without it [the ADHD diagnosis] because it would always be a barrier because people would say to me, why have you done this or nobody else would act like that? And why have you? and I didn't have the answers. I couldn't explain it. I didn't have the language. I literally didn't have the words or the language to explain it because I didn't know [brief pause] and one of the most difficult things is when you feel something and you don't know how to explain it and other people are, you know, rightfully so, probably upset by your actions." (Emma, p.35, L587-596).

Before the ADHD diagnosis, Emma felt disabled in certain situations as she "didn't have the language" to understand and make sense of her experiences, and then communicate this to others. This experience was distressing and upsetting both for her and the people around her. Gaining her diagnosis has provided Emma with the language to understand and communicate her experiences, cultivating empathy and understanding. When reflecting on her experience, Emma also articulates a sense of impossibility of moving on or "getting to the place she is at now" without the diagnosis. Taken together, this highlights the pivotal role of the diagnosis.

This experience was shared by Ava who said:

"I would never be nice to myself because I always thought I was a failure. You know that I was a broken person, and I'm not at all. I'm just a very, very typical inattentive ADHD women, and there are thousands like me. [...] I'm not broken, not like wrong, just different" (Ava, p.31, L645-656).

In Ava's account, we can see the transition that occurs from her being labelled as a "failure" or a "broken person", to being a "very, very typical inattentive ADHD woman", who isn't broken "at all". The repeated use of the term very accentuates the contrast between these two statements – from being a failure/broken person to being a very typical.

For some women, the diagnosis also enabled them to find a language for experiences that they previously understood as being representative of personality flaws. A such example that was shared across participants was regarding Rejection Sensitive Dysphoria (RSD). RSD is a condition commonly associated with ADHD that manifests as extreme distress due to perceived or actual rejection or criticism.

"My rejection sensitivity is through her [signals that her rejection sensitivity has increased], but I didn't even know about rejection sensitivity six months ago." (Ayesha, p.11, L264-265).

"Reflecting over the past year is a lot of the kind of things that are like rejection sensitivity." (Emma, p.6, L98-99).

For some, the knowledge of RSD has allowed them to regulate their emotional state.

"So, I'll constantly keep going over that negative comment or that thing that they've said, and they probably don't think all the time. [...] and now I'm able to kind of – not disregard other people's feelings and thoughts, but be able to listen and go yeah, I don't really agree." (Sophia, p.20, L503-506).

The movement from a narrative filled with judgement and shame, to one encompassing understanding and compassion also allowed women to find new ways of managing their distress.

"Not that it's an excuse, [...] but it stopped me kicking myself as much, and helped me find new ways to regulate because I could then look at what might set me off and get things online." (Sophia, p.2, L44-46).

"Once I got diagnosed, there became less negative talk because, you know, I could say, okay or that I had more resources and techniques that I could put in place to help complete tasks" (Daphne, p. 8, L165-167).

As highlighted by Emma, this has significantly alleviated her distress, allowing her to "be herself".

"I genuinely haven't felt anxious. Apart from like a few times, when I drink too much caffeine like, but it's almost like it will stop even when I wasn't taking the ADHD medication. So, like I know it's not the medication, it's genuinely just my thought process and understanding of what anxiety is. And so, I think that helped a lot because I was able to then be myself." (Emma, p.40, L670-674).

Alongside compassion for themselves, participants also reported that receiving the diagnosis also facilitated feelings of compassion towards others, including caregivers. In Ella's experience, she felt "a lot of anger" towards her family, perhaps for not getting her the diagnosis sooner. However, this anger shifted follow the diagnosis:

"I did feel a lot of anger towards my family, but then I've kind of look back now and I feel really sorry for my mum because she did really try at different points. She was always the catalyst." (Emma, p.12, L194-196).

She later adds:

"I do look back on different times where she [her mother] tried to get me the professional support and it, but nobody helped her. So that's kind of brought my compassion, I guess to my mum." (Emma, p.13, L205-206).

Therefore, the diagnosis changed the relationship between Emma and her mother, moving from anger to a feeling of compassion and understanding. Ella echoed a similar sentiment:

"I've got more acceptance of-of everything and when I say everything, I mean, I accept the fact that, you know, my parents couldn't meet my needs because they weren't equipped themselves knowing what I know now [...] I've been able to cut them some slack. I've been able to cut myself some slack." (Ella, p.27, L.610-614).

The knowledge and understanding provided by the ADHD diagnosis has given Ella a new lens to view herself, her life experience, and her parents through, fostering a sense of understanding and compassion towards them. Both Emma and Ella acknowledge that their parents did try to get them support but ultimately, they were led down by other professionals and other systemic factors that rendered their efforts futile.

# 3.3.3. Sub-Theme: Support Following Diagnosis

One of the many motivating factors for women to seek out the diagnosis was access to support and help. However, upon receiving the diagnosis, most women were only offered medication as a form of support and management.

"But in the actual moment of being diagnosed, I was like angry, and then it was yeah, yeah, do you want a medication appointment or not? I'll send you a report and see you later." (Emma, p.9, L136-138).

In Emma's experience, she felt anger but had no space to experience or feel this anger as the attention of appointment swiftly shifted from "You have ADHD" to "Do you want

a medication appointment?" No further support was signposted to her. This experience was shared by Ella who says:

"The only conversation I had with him [the assessor] the day [of the diagnosis] - he phoned me and was "Hello, is this [participant's name]?" and "Yes, you have ADD". And I went, "Okay [brief pause] what does that mean? And he said, you will get medication. We will book you in for an ECG [Electrocardiogram], and then you'll get medication, and he was like okay, and that was that." (Ella, p.19, L410-413).

When reflecting on her experience of being given the ADHD diagnosis, Ella she did not know what would happen after receiving the diagnosis. Upon asking for more information from the assessor, she was told that she would receive medication. Unlike in Emma's experience, she was not consulted as to if medication is something she was like, but instead was told she would get booked in for an ECG and get medication. Her use of the phrase "that was that" highlights the resistance she experienced from her assessor when asking for additional information. Ella reflected on finding this experience "very abrupt".

However, on the phone, Ella asked him for additional support based on the research that she had conducted prior to receiving the diagnosis.

"In fact, I'd asked him on the phone, I said, because I knew about titration, all that kind of stuff, because I had researched it before." (Ella, p.20, L433-434).

"I'd asked him, do I get support with, you know, do I get a CPN [community psychiatric nurse]? And he went no, your GP will see to that. So anyway, I was left on my own. I had support from my GP now and again, but she wasn't experienced in any of this, you know ADHD stuff and it's not for her to changing my meds [medication] either. It's more psychiatry and it's for my CPN." (Ella, p.20, L442-445).

As highlighted by these extracts, following the diagnosis, Ella wanted access to further support and a referral to a community psychiatric nurse (CPN). However, Ella was

turned away from the assessor who handed the responsibility of further support back to Ella's GP, who wasn't equipped with the knowledge of ADHD to provide her with further support. This left Ella on her own with limited support. After a few months, Ella knew that her dosage of the medication should change, however, no one had contacted her regarding this change.

"January, I had started on the meds [medication] [...] By March I was kind of like I should have gone up in my dosage by now [...] and I spoke to the GP, [...] and she said, "I don't really know about it" and she said, "I'll refer to back to the CPN, Community Psychiatric Nurse". So, I ended up with the same nurse that helped me fill out the DIVA [Diagnostic Interview for ADHD] [...] and she got in touch with me, absolutely fizzing mad, fizzing mad, that the psychiatrist hadn't been in touch with them. [...] She's been absolutely wonderful and she's at the end of the phone should I ever need help and support, but she's disgusted with how my whole diagnosis went because it should have never happened like that." (Ella, p.20, L446-465).

In Ella's experience, her assessor delegated the responsibility of further support and management to her GP. This appears to be a replication of past experiences of help seeking where Ella had been dismissed and left to her own devises with no guidance or support. However, later it was revealed that the psychiatrist who conducted her assessment was in fact the gatekeeper for her gaining access to support. The anger and disgust expressed by the CPN highlights the systemic failures that occurred in Ella's care which led to her only gaining access to care after she had advocated for herself.

The process of needing to advocate for themselves to receive access to support is unfortunately not an isolated one. In Sophia's experience, upon receiving an ADHD diagnosis, she was offered counselling delivered in a group format.

"When I did have my diagnosis, the guy said to me that they would put me in touch with some kind of counselling or something, and would I be interested? And I was like, yes, and they did put me on drugs for a while, and said they'd have it reviewed quicker than it was [...] and then they kind of sent me a thing

saying they were discharging me to my GP, and I was like, kind of like well, hold on what about this counselling and everything you offered me?" (Sophia, p.6-7, L154-159).

Akin to Ella's experience, medication was the only support given to Sophia, and whilst her medication was monitored and titrated (albeit later than it should have been), she was not signposted to further support. Sophia had to call the clinic who apologised and referred her for further support, which in this case was a group.

"It was a group. It was, as I say, organised by the ADHD clinic [...] it was ran by I think it was a nurse who also had ADHD [...] and she'd do like a presentation, some slides and she shared some experiences that were hypothetical or whatever and then she'd ask us if we could relate, if we tried anything erm could we give an example of something that had gone like that? And then she'd give us some tips on maybe how to deal with it. [...] It was only four sessions, and it was for an hour, and it was literally every week for four weeks." (Sophia, p.7, L175-182).

When reflecting on her experience of participating in a group, Sophia reported that she found it helpful as she found some strategies that she could implement into her life that she had not heard of before. She also reported that she found the community aspect of the group particularly helpful.

"Well, it was nice to know that other people were struggling." (Sophia, p.8, L187-188).

## She later adds:

"You feel like a bad person. You feel like you're taking too much on. You feel like you're a crap mum [...] and it's nice to know that it's normal even if it's just normal for this group, if that makes sense?" (Sophia, p.9, L210-212).

As a consequence of living a life with undiagnosed ADHD, Sophia had spent much of her life struggling and suffering in silence. This did not change following the diagnosis as whilst she had a framework for understanding herself, she still struggled. The lack of support offered to her perhaps perpetuated her feelings of isolation with her experiences. Here, the group was a place that fostered connection and community, helping her feel less isolated within her experiences, and feel more "normal".

However, Sophia's case of receiving support in the form of a group was not a shared experience. Instead, some women were only offered medication-based support and nothing further. Ella reflects on this experience and says:

"On one hand it's like [...] woo, I've solved the problem. You know, like eureka, I know what it is, you know the problem I've been trying to figure out for 40 years, I figured it out, but then it's - you're kind of left with that, I guess emptiness because there is no support when you turn – when you're in adulthood." (Ella, p.21, L477-480).

On one hand, Ella feels ecstatic to have "solved the problem" and "figured it out", but after that feeling of elation subsides, Ella is filled with a feeling of emptiness. Without any support to turn to, Ella is left alone to navigate this feeling. She recognises that had she been diagnosed in childhood or in adolescence, she would have been given access to more support than she is being given now. The dearth of support feels especially important given that not all women had a positive experience with medication.

"So initially, in 2018, I was prescribed atomoxetine which is the non-stimulant, and I went on it, and it was just horrible. I became very, very depressed and I-I just remember sitting on the sofa and sort of not getting up for a week." (Daphne, p.9, L.180-192).

Some participants did not want to begin taking medication due to side effects and past experiences of being medicated:

"My impression and understanding of the medication that were available at the time was that a lot of them did come with the side effects of anxiety, depression, and suicidal thoughts and I was already in that, and I was like I can't really –

can't really risk it. I mean I tried one antidepressant, and it zonked me out so much that I couldn't even drive my children to school. So, there are so many layers to consider and so I decided – I took the choice not to." (Ayesha, p.7, L163-167).

Without adequate support to turn to, participants shared that they began engaging in Facebook groups as a way of building connections with other women who were also going through the same thing.

"Being diagnosed right now and having that label is quiet empowering for me because I do [brief pause] I've recently, in the last year or so, done things like join Facebook groups, um, Instagram, followed particular people [...] and it's been really nice to see that I'm not the only crazy one out there [laughs]." (Ayesha, p. 8, L194-198).

Ayesha shares that the diagnosis has made her feel empowered because she can now access online groups and follow people who also have ADHD. This has made her feel less isolated with her distress and make her feel like she is not the only "crazy" one out there. Her laugh when sharing this perhaps conveys some relief for not being to only one struggling and suffering. However, connecting with a community of others was not always a positive experience:

"I feel quite guilty about this thought but I-I think it's a really core experience for a lot of people. It's the flip side of feeling like you're special and that you're different and you're unknowable, and you know nobody can understand you [...], and then you find thousands of people who are exactly like you, and you're probably never had a unique experience in your life [laughs]." (Ava).

Ava expanded on this experience further by connecting it to her early childhood experiences of being bullied and being told by her mother "you think differently, you're special". Upon joining these communities, she no longer felt different or special, and whilst this experience of validating, it also "stung" a little.

Based on these women's experience, the support offered post-diagnosis appears to vary based on the borough that they reside in. Furthermore, women who were given access to further support (e.g., a CPN or groups) reported that most of these initiatives were started by individuals who had lived experience of being diagnosed with ADHD and started groups by "taking it upon themselves", without access to additional funding. Instead, they have attempted to find money "within the existing budget to create a new service". Therefore, support that goes beyond just medication appears to be a postcode lottery. This often leaves participants needing to access traditional mainstream support (e.g., talking therapies), which may not be catered to their diagnosis. For instance, in Lauren's experience, she accessed a group for low self-esteem and struggled to engage due to the group set-up.

"So, when I went for my erm – when I went for my confidence and low self-esteem therapy, it was group sessions, but I went there [brief pause], bright yellow walls and the lights are on, and I straight away, I was like – and I felt bad because obviously [...] on one else there had ADHD, they all had different things. So, I was like, I said, you know, I felt really bad, I was like, "can you turn the lights down?" (Lauren, p.33, L738-742).

Lauren's repeated use of the word "bad" highlights how guilty she felt for asking for accommodations to ensure that she could engage in the group. Lauren later reflects on the lack of support saying:

"There needs to be more support groups out therefore, support groups for adults definitely, because there's hardly anything around." (Lauren, p. 34, L777-778).

Ayesha further adds to this by reflecting to the financial barriers to access adequate support:

"You know what, there's lots of great community groups and there's loads of groups, if you've got the money, there's loads of help out there" (Ayesha, p.11, L275-276).

This theme captures women's lived experiences of being diagnosed with ADHD. Most women recalled experiencing a unique blend of emotions from feeling validated and relieved, to feeling angry and bitter. The diagnosis also gave women a framework to understand themselves, allowing them to recognise that the personality flaws or characteristics ascribed to them at an early age were not due to something being innately wrong with them, but instead because they are different. This awareness also reduced distress and allowed them to be compassionate towards their selves. This compassion and understanding also extended towards others, including family members as they were able to recognise the wider systemic factors that impacted their inability to get them a diagnosis in a timely manner. Alongside this, participants also reflected on the support offered post-diagnosis. For most, medication was the only treatment option available to them. However, some participants were offered groups and a CPN. Most women reflected on a positive experience of connecting with a community of others.

### 3.4. Theme 4: Life With an ADHD Diagnosis

This theme captures the experiences of women reflecting on their lives post-diagnosis. It begins with women reflecting on their journey of renegotiating their identity following their diagnosis (3.4.1.). Alongside the process of re-negotiating their relationship with themselves, participants also reflected on navigating multiple such as motherhood, being a woman, and their cultural identity, in the context of their ADHD diagnosis (3.4.2. navigating multiple identities). The final theme highlights the impact of social discourses and stigma on participants' lived experience of ADHD (3.4.3.).

#### 3.4.1. Sub-theme: Re-negotiating Identity Following ADHD Diagnosis

As previously mentioned by Ella, after the diagnosis she felt as though she had "solved the problem". Other women, such as Ayesha, had a similar experience:

"You feel like you're going to get better. Oh, I'm going to get better or oh, I'm going to be 'fixed' and it's not until you get further down the line that you realise that ADHD is a chronic illness. It's like heart disease. [...] You don't get better; you don't have ADHD anymore. You learn how to be more self-aware. You

learn how to regulate your emotions because they're very different." (Ayesha, p.12, L288-291).

This segment illuminates that some women believed that upon receiving a diagnosis they would be "cured" or "fixed" in some way. However, as articulated by Ayesha, ADHD is a "chronic illness", with symptoms persisting into adulthood. Moreover, whilst gaining the diagnosis doesn't 'cure her', it allows her to develop self-awareness and regulate her emotions by understanding her "difference".

# Ayesha later adds:

"I sometimes don't want to spoil the bubble for people or, or especially women who are on the cusp of being diagnosed because they're like yeah, I'm going to be – I'm getting my diagnosis and everything's going to be alright, and inside I'm going, now the real work starts. Because I spent a very long time trying to fit my neurodiversity into what everyone says is normal and do that, and as the more I did that the more my mental health struggled, and the more challenges I had and the more my life, excuse my language, fucking sucked for me" (Ayesha, p.10, L236-241).

Upon receiving her diagnosis, Ayesha was perhaps unaware or isolated of the external reality of gaining her diagnosis. This is evidenced in her reflection of women who are on the cusp of diagnosis being in a "bubble", with the "real work" starting post-diagnosis. In her experience, the "real work" began after she stopped fitting her 'neurodiversity' into what people said was normal as this led to her living a life of profound suffering and distress, prior to the diagnosis. Here, the diagnosis permitted her to stop fitting in her neurodiversity with "what everyone says is normal". It appears that this has alleviated some of the distress Ayesha was previously feeling.

In Ella's experience, the diagnosis made her question who is truly is. This process often began with her losing her identity and sense of self.

"I lost my identity. I lost it. Completely gone." (Ella, p.21, L476).

#### She later adds:

"A lot of people don't, you know, they just go oh, it's ADHD and they don't actually learn what that actually means for you as a person [...] I'm not ADHD. ADHD is not me, you know, but there are elements of me and I'm like "Oh My God, you're so ADHD" and that gives me like — I can forgive myself for some of that shit, you know? [laughs]. But as far as identity, I really struggled for while like who am I? What am I? Like is is anything that I have felt like a real thing or is it just [brief pause] I felt all of these things because I have ADHD, you know, has any of my human existence been genuine and authentic? [...] have I just covered myself up for so long or you know, like there's all these existential questions." (Ella, p.22, L482-489).

The two extracts presented above highlight the impact of the diagnosis on Ella's identity and sense of self. It appears that following the diagnosis, Ella began renegotiating her identity in the light of ADHD. This is evidenced by questioning "What is ADHD and what is me?" – a question that did not have a straightforward answer. As explored above, the diagnosis provided Ella with a lens through which she could view experiences, allowing her to extend forgiveness to herself, however, at the same time, it made Ella question who she truly is. The diagnosis also leads to questions around authenticity for Ella which is highlighted by her enquiry into the realness and genuineness of her life experiences.

These questions appear to have stemmed from Ella "covering" herself up from a young age, leading to her living a life disconnected from herself. Here, the act of her "covering" herself or masking may have been a compensatory strategy developed at a young age as a means of protecting herself from rejection. However, a secondary consequence was that she gradually lost touch with the parts of herself that she concealed.

The process of questioning "Who I am?" is one that was shared by many participants, including Ayesha. She says:

"It's really quiet conflicting actually, because at the same time you look over your behaviours and actions throughout your life and situations and circumstances, and you think – how much of that is ADHD and how much of that is me? When you're diagnosed quite later in life, it's really difficult to-to-to categorically go "well that's because I've got ADHD", because I've-I've lived 30 plus years of my life." (Ayesha, p.10, L247-251).

Ayesha refers to this process of questioning as "quiet conflicting", perhaps highlighting that this is an aspect that she is still making sense of years after the initial diagnosis. Her use of the word "difficult" gives us an insight into the effort and hardship this journey or process has been.

Emma's experience aligns with Ella and Ayesha. She adds the ADHD "completely" changed her identity and sense of self.

"To be honest it has completely, completely changed the whole kind of guess identity." (Emma, p.35, L579-580).

#### She later adds:

"I feel like I didn't know who I was anymore. Um, I feel like I didn't have a clue who I'd ever been because I'd always been trying to be somebody else or do what people told me I should be doing, or the things that we know are 'good'". (Emma, p.37, L622-624).

"So, I guess I'm kind of questioning some of these things. I'm questioning some of these things. I'm thinking are these actually my goals or are the stereotypical goals?" (Emma, p.41, L687-688).

"I guess my understanding of what I'm allowed to like value different things or I'm allowed to want to be on my own most of the time that doesn't mean I'm depressed." (Emma, p.38, L633-634).

In Emma's experience, she spent much of her life before the diagnosis, conforming with norms and doing the things "that we know are good". Without the diagnosis to understand her difference, perhaps Emma used social norms and expectations as a way of 'fitting in' with the people around her, allowing her to be socially accepted. Consequently, she lost touch with what she truly wanted, highlighting a disconnection from her authentic self. Here, the diagnosis has given her the permission to question what she values and live a life that is more in alignment with her values. The diagnosis also gives her permission to step away from the labels ascribed to her by people, including professionals.

Emma elaborates on this further sharing that the diagnosis has also given her the permission to "unmask" and be who she is.

"It also quite a vulnerable place to be because [...] you've probably heard of the term unmasking. So, trying to be who I am. I realised recently there's a lot of vulnerability in that because when you unmask, it's not choosing [...] what you will unmask, you just start being yourself' (Emma, p.40, L662-665).

Emma's experience suggests that without the diagnosis, she would not be able to give herself permission to 'unmask'. However, the process of unmasking has been one that has required a great deal of vulnerability as it exposes her to the potential of being judged and shamed for others. When viewing this in the light of Emma's past experiences, this seems especially significant as she would previous fear judgement and shame from other for being "different". However, for this reason, some participants were cautious against unmasking all the time, as a way of self-preservation.

"So, I mean they kind of call it masking at the moment, doesn't they? You know, putting on a face and fitting in and I don't necessarily think that's a great thing all the time, but you know, sometimes you just got to with certain situations, you know?" (Sophia, p.24, L623-625).

Both Emma and Ella recognised that renegotiating their identity is an on-going journey:

"I think I'm - I think I will still be figuring out who I am for a while" (Emma, p.38, L642).

"It's every day. It's still – it's still discovery, you know, like every day is a school day" (Ella, p.25, L568).

#### 3.4.2. Sub-Theme: Navigating Multiple Identities

Alongside re-negotiating their relationship with themselves, participants also spoke about how their experience of navigating their multiple identities in the context of the ADHD diagnosis. In the following sub-theme, the interaction between having ADHD and being a woman, is explored in the context of being a mother, being a female, and holding a cultural identity.

Of the eight participants recruited, six participants reflected on the interplay between their ADHD diagnosis, being a woman, and their experience of motherhood. For some participants, such as Ella, the manifestation of ADHD symptoms compounded the pressures of motherhood, therefore impacting their experience of motherhood. However, prior to the diagnosis, Ella did not have a framework to understand her experiences.

"When there's the pressure of work – you're working full time, you've got a child, you're a lone parent, you've got to keep the house to keep – you can't, you can't do it all." (Ella, p.29, L650-651).

Ella inability to "do it all" led to her being shamed people, specifically her mother.

"I've been shamed by people, especially my mother. [...] My mother would come in and there would be piled of washing on the table or dishes, you know, left drying on the sink, and she'd be like oh, you just can't, you know, this is an absolute disgrace." (Ella, p.29-30, L650-680).

This shame was internalised by Ella who questioned her parenting. Without a framework to understand the conflict between ADHD symptoms and the pressures of motherhood, Ella took to risky behaviours as a way of coping.

"That's where you end up with the risky behaviour. So, I was drinking more. I was taking cocaine. I was, you know, all these kind of things that were out of character for me, but you know, it was the pressures of everything just getting bigger and bigger, and bigger and bigger until poof, you know?" (Ella, p.29, L657-659).

These behaviours felt "out of character" for Ella, suggesting that she may have lost touch with herself during this process. Moreover, Ella's repeated use of the word bigger highlights the intensity of the pressure that was experienced by her. This pressure was immensely distressing, with her using alcohol and drugs as a way of potentially self-medicating her ADHD symptoms.

In Zara's experience, she found that her ADHD symptoms hindered her ability to engage in parenting-related tasks. This had a significant impact on her sense of self.

"I mean my time keeping is awful. It's awful. [...] Before, the school [her child's school] was about ten minutes away and I'm not even joking, every single day, I was late, and it got to the point where one day, I said no [brief pause] and this was before my diagnosis I'm going to wake up at six in the morning [brief pause] there's no way that I can be late, and I'm still late. Can you believe it? [...] So, it's just really frustrating". (Zara, p.8, L167-172).

Zara's use of the phrase "Can you believe it?" highlights the shock that she felt for being late. This circumstance may have also given rise to feelings of shame and guilt for being late. When reflecting on the feelings that these events stirred, Zara added:

"I'm so useless like Oh My God, I woke up at six, and I'm still late, and it's only a ten-minute walk away like how does that make sense? I've only got one child to get ready and I'm still late. It's kind of a reinforcement. Also, you know, you're lazy, you can't do anything right" (Zara, p.8, L176-178).

Without with the diagnosis, Zara internalised the manifestation of her ADHD symptoms as being a reinforcement that there is something wrong with her (e.g., being useless, lazy, can't do anything right). This experience was profoundly debilitating and distressing for her. Following the diagnosis, the negative self-talk reduced.

"In terms of housework and things like that, I'm trying to be little bit easier on myself in that I'm not calling myself names like you're so stupid and lazy, you can't even do this." (Zara, p.13, L299-300).

When speaking on the interaction between ADHD and her experience of motherhood, Sophia reflected on experiencing different challenges during the different stages of motherhood.

"When they [her children] were younger, I'd put things in place and routines, so I didn't necessarily get so stressed out. So, we do things in a certain way to make it easier, to make it organised. I was actually quite good. We never missed a school function. You know, if there were a thing coming up at school, I always knew about it. So, the typical ADHD of missing things and appointments and everything being last minute wasn't because I was fighting so hard to keep up with other parents, that I kind of put things in a place to deal with it." (Sophia, p. 12, L299-304).

Sophia shares that when her children were younger, she found ways of coping that allowed her to compensate for her ADHD symptoms. She refers to this process as "fighting so hard to keep up with other parents" which perhaps suggests that this process was a constant battle for her.

"But the older the kids get, the more I fight against it. Their teenagers, you're told to relax, let them do it more but then when I don't, I then forget stuff, and I don't remember the meetings or something and they'll come up and they'll say, I told you about that and it's like I didn't take it in, and because the coping strategies that had I weren't using anymore, it all became very apparent. I would get frustrated erm, I would deal with maybe big issues, and maybe snap a little.

But eventually, you'd get to that boiling point. That boiling point would be over nothing." (Sophia, p.12, L304-309).

However, these compensatory techniques lost their effectiveness as her children grew older. This has led to Sophia "fighting against it more" indicating the negative toll that this has taken on her mental health. Consequently, she has been feeling frustrated leading to her reaching her "boiling point" leading to her "snapping". When exploring the impact that this has had on her, Sophia shared:

"I do suffer from the rejection side and feeling like I'm being criticised or I'm not good enough." (Sophia, p.13, L323).

Whilst Sophia has her diagnosis, she still feels judgment for her ADHD symptoms and the impact that they have on her experience of parenting and motherhood. These have led to her feeling "not good enough" as a parent.

Like Ella, Sophia also faced judgement and shame, not just internally, but also from the people around her.

"And I went for a meeting and-and they asked me what I was going to do to be a better parent [laughs], and I reamed off all the things that I had been doing over the years, all the different techniques I've tried with them [her children], and all the parenting books that I had read and all the things I had done." (Sophia, p.13, 333-335).

Sophia's laughter whilst talking about this meeting accentuates her distress and discomfort of being judged as not being "good enough", with questions about what she would be doing to be a "better parent". Later, Sophia expands on how her rejection sensitivity further exacerbated the distress experienced by this situation, compounding her mental health.

In Ayesha's experience, prior to the diagnosis, she has put her symptoms "down to depression". This has an impact on her experience of motherhood.

"There were times before my diagnosis, which I just put down to depression, where I would be in bed for a week and my mum would have to come in and help with the children." (Ayesha, p.15, L352-354).

She now frames these experiences as being consequences of "masking" and "pushing it down" or "suppressing everything" to be present for her children. However, after a while, she would "crash and burn". This cycle was something that she did not have a framework to understand prior to the diagnosis, with the diagnosis giving her the ability to "understand and manage it". Ayesha still experiences episodes where it "all gets too much", but the diagnosis has given her a way to communicate her differences with her children. Alongside her ADHD diagnosis, Ayesha was also diagnosed with cyclothymia – a mood disorder which causes mood changes from feeling low to emotional highs.

"The way I explain it is like my bed is my safe space, almost like when it all gets all too much and I cannot cope and [...] I'm so exhausted I can't even talk. I can't even put a sentence together. I'm pointing at the glass, and I can't tell you what it is. But I try to keep an open dialogue with my children about it, because I don't want them to assume things. I'd rather they be more aware of the factual basis of it and how it actually – there's nothing wrong with mummy, my brain is just wired differently" (Ayesha, p.17, L405-410).

Ayesha's experience of ADHD is that it can sometimes be debilitating with times when she is extremely exhausted, impacting her ability to connect and communicate with the world. This has undoubtedly had an impact on her children. Here, the diagnosis has allowed her to communicate "the factual basis" of the diagnosis, allowing her to highlight her difference, and that there isn't anything "wrong with mummy".

This was an experience shared by Daphne who found that her diagnosis made her a better parent.

"So, um I'm very open with them [her children] about it. My younger son actually had ADHD as well. He's been diagnosed and we're very open and we found a lot of similarities. So, it's made me able to – whereas before I'd say oh, why

can't you do this? You know or why can't you do that? Now I'm like oh no, I know why because it's not your fault. So, I actually think it has made me a better parent that I'm more aware of difficulties." (Daphne, p. 10, L. 221-225).

"Yeah, so as a parent I would say [...] I'm so much more present, whereas before I would say "oh yeah" you know, "in a minute", now I'm like no let's do it now. I'm much more um yeah, much more available and you know, willing to like play games or whatever. So, parenting wise, yeah, I'd say, it's improved my parenting" (Daphne).

The diagnosis has given Daphne a way of understanding her son's experience with ADHD, providing them a way to connect. This has allowed her to offer him compassion and understanding, both of which she did not receive in childhood. Additionally, the diagnosis has also facilitated her being more present and "available" for her children, improving her parenting.

However, for Zara, whilst her diagnosis journey has given her awareness and compassion for her daughter, who she believes may have ADHD as well, it has also led to difficult moments.

"So, it's difficult, you know, being a parent um when you can pick up the sort of things that your child is doing. So, I suppose if anything, it has given me a lot of awareness um which can sometimes be like [...] I was to switch it off and just be really um aloof to what's going on around me. But you can't." (Zara, p.12, L303-306).

In Zara's experience, ADHD has been a confronting experience where she has noticed her daughter "basically doing exactly what I used to do". Armed with the knowledge and awareness of ADHD, Zara is careful to not meet her with the same judgement she was met with. However, this has been "difficult" at times.

Participants also reflected on the interplay between ADHD, being a female, and the impact of hormonal influences and menopause, on their experience of ADHD. Both

Ayesha and Ella reported worsening of ADHD symptoms, following the onset of perimenopause/menopause.

"Especially now, in the menopause bit, because everything is exasperated. As I said, even more so. I feel even more bonkers now. I'm more clumsy" (Ayesha, p.8, L198-199).

"Everything in the last two years has just become way worst for me and when I say worse, I just mean exasperated in terms of where I am within my cycle." (Ayesha, p.8, L185-187).

"Yeah, especially because I'm going through puberty again, the hormones are going wild [laughs]." (Ella, p.22, L.494).

Moreover, in Ayesha's experience, she has only grown aware of this interaction as she is "going out there and finding information herself" (p.8, L187-188)

Interestingly, both women reflected on being able to see a connection between hormonal changes and worsening of ADHD symptoms, at different stages of their life. For instance, Ella shared that she has experienced "issues with hormonal birth control".

"I have issues with hormonal birth control like they send me scatty but apparently it's quite common with people with neurodivergence that they cannot tolerate hormonal birth control" (Ella, p.23, L506-508).

Ella expressed her anger for the fact that this interplay is "not something that's spoken about or discussed".

"And even when I went to my gynaecologist and I explained to my gynaecologist, [...] I had a Mirena coil inserted and within, like, a couple of weeks of having that Mirena coil inserted [brief pause] I went dark. I went into a very, very dark, dark place. [...] And I behaved in a manner that I have never

believed in before in my life. And and yeah, the pure anger that I had - and I smashed my head into the wall in my living room." (Ella, p.22, L514-518).

In the above extract, Ella highlights the immense distress she experienced upon fitting the Mirena coil, a hormonal coil often used as a form of birth control. This led to her going into a "dark place" where things were "pretty grim", suggesting that they exacerbated her mood. The act of her smashing her head into the wall communicates the profound sense of anger and distress she was experiencing. Ella then reached a point where she could not cope leading to her reaching out to her gynaecologist. However, upon saying, "the Mirena coil has caused me some severe psychiatric problems", she was met with judgement, with the gynaecologist looking at her like she was "crazy".

"He [the gynaecologist] looked at me like I was absolutely bad-shit crazy and how dare I say that the Mirena coil would cause such side effects, and that it was nonsense. And I went onto say, do you realise that women with ADHD tend to have problems with synthetic hormones because I had read studies on it." (Ella, p.24, L538-541).

The judgement Ella was met with may have been fostered by the lack of information that is available on the interplay between ADHD symptoms and hormonal influences. Instead, she was "pipped as being anxious", leading to her having to draw on scientific evidence as a way of gaining validity and being taken seriously. The lack of information available on this topic was also commented on by Ayesha who stated, "women's health always comes second" (p.9, L219-220).

In Ayesha experience, looking back at her life allowed her to recognise that her ADHD symptoms had also worsening when she had started got her first period and had children.

"So, when I look back at some of the, I joke, the stunts I pulled or some of the scraps I got myself into, I see a massive connection to when I started my period and the connection to it subsequently when I had my – when I look back as well – everything was exasperated when I had children [...], following having them I

struggled heavily with my mental health, and I do believe now that, that would have been exasperated by ADHD." (Ayesha, p.18, L434-437).

On this note, Ayesha advocates for more "research, research, research".

"I think there needs to be more work done, not just on girls because we owe it to them, but we've got a whole generation of women in their like 30s and 40s who are [brief pause] the symptoms of menopause and ADHD are very, very, almost identical." (Ayesha, p.18, L446-448).

"Menopause is a joke out there. It is serious, serious, big thing, and it needs – it interacts with everything for us in this day and age." (Ayesha, p.21, L502-504).

"I think women of a certain age are well – we are put on a scrap heap. I've got a whole lot of life left in me. I feel like I'm getting into my second coming if you'd like [laughs]." (Ayesha, p.19, L469-470).

In Ayesha's experience, women who reach menopause, marking the end of their reproductive years, are placed on a "scrap heap". Her use of humour and laughter when talking about this is potentially a marker of her discomfort about this. Therefore, whilst she recognises that we must ensure that research should be done on girls and young women, she also highlights the importance of women in their 30s and 40s not being forgotten or neglected by research.

Another aspect that was highlighted by Ayesha was how her identity of being a woman and her cultural identity, have impacted her experience of ADHD. On this note, she says:

"I suppose my experience will be very different from a middle-aged white woman, um, who was born and brought up here, uh, to a man, to a gay person, [...] there are running commonality themes and commonalities. I mean, again, with the diagnosis and knowing where to look and listening to podcasts and reading books, the common thing that I feel it's the same but different. So, I'm

listening to other people's stories and experiences and resonating and understanding so much, but intricacies of them are obviously different. The characters are different, the stories are different." (Ayesha, p.11, L256-262).

Ayesha then goes onto share that she was born in a diverse community in London surrounded by a "nice [South Asian] community". However, a couple of years later, her family relocated to another area, not too far from where she was born. She recalled:

"It was lovely, like real nice [brief pause], but we were different. We were different." (Ayesha, p.13, L323).

The backdrop of her upbringing subsequently impacted her experience growing up.

"I have to also include I'm a first generation born here so I had very traditional Muslim, Asian parents and I grew up in a very White, middle-class area and I just wanted to access and do things that normal teenagers in my area did and back then it was very difficult for me. So, I understand now that I was already masking from a young age [brief pause], elements that didn't have anything to do with ADHD, if that makes sense?" (Ayesha, p.5, L122-126).

The term 'masking' is often used when referring to individuals with ADHD concealing or compensating for their traits as a way of fitting in or not being rejected by others. However, Ayesha highlights that her experience of growing up in an area where was a minority, led to her masking at a young age, independent of ADHD. This perhaps mediated her experience of ADHD, as she may have been "double masking".

In Zara's experience, the stigma of ADHD in South Asian communities has led to her facing increased stigma and shame.

"I do think there's still a lot of ignorance and quiet a lot of almost stigma and embarrassment attached to it and for example, you know, most members of my family, if I say I've got ADHD, they'll look the other way and start talking about something else." (Zara, p.15, L331-333).

The experience of her family members "looking the other way" and "talking about something else", highlights the discomfort that these topics stir in these individuals, with their behaviours further perpetuating the shame and stigma surrounding ADHD. Zara recognises "I just think it is very much ignorant on their part and it is not my issue" (p.15, L334-335), however, she goes on to add that her family members continue to question the validity of her diagnosis.

"My mum still, you know, very much, it's not, you know – you're just lazy and you've always been lazy." (Zara, p.15, L340-341).

"I mean I've had my diagnosis and still my mum is like, you know, there was no ADHD in my day and age, and it's all these mobile phones and you know blah, blah." (Zara, p.7, L146-147).

Zara's use of the phrase "blah, blah, blah" perhaps illustrates her feelings of annoyance towards her mother and other members of her family who have dismissed her experience and continue to attribute the manifestation of symptoms as being personality flaws. Therefore, in Zara's experience, the intersection of her marginalised identities has led to her facing increased stigma, consequently dismissing and invaliding her lived experience of ADHD.

# 3.4.3. Sub-theme: Impact of Social Discourses & Stigma on the Experience of ADHD

As discussed in the introduction, ADHD has been understood and constructed through various paradigms underpinned by different discourses (e.g., the medical model of disability or the social model of disability). Intriguingly, it appeared that the way in which participants understood ADHD, influenced the way they experienced ADHD. For instance, for some participants, ADHD was viewed as a "black-and-white scientific thing":

"It's like being given kind of a black-and-white scientific thing nobody can argue with because I think, you know, I work in mental health and I think people argue

with depression and anxiety, whereas with ADHD, it's much more neurological and you know it's just something that you were born with, that's your brain." (Emma, p.10, L155-158).

For Emma, ADHD being something you were "born with", provided comfort and validation for her as it mediated a sense of shame that she held throughout childhood which was perpetuated by other professionals who told her to "do better" or "you need to change", allowing her to feel emotions such as anger, towards them. This scientific validation removed any ownership she had felt for perceived 'deficits' she internalised as characterological flaws.

This experience was shared by Ava:

"They've called me lazy for this, and there's a reason it's not that I'm lazy, you know, my brain's not wired the normal way." (Ava).

Ava's belief of her brain not being wired the "normal" way, provided her with both the validation and the permission to "step-away" from the labels ascribed to her at an early age ("lazy"). Ava reflected on aligning herself with the neurodiversity paradigm, with the label of 'neurodivergent' fostering a sense of pride in her.

"I'm very, you know, I'm very proud of who I am. I think I'm very proud of being neurodivergent. [...] I can really see what I bring to situations now where maybe other people might not or haven't in the past, you know?" (Ava, p. 18, L367-369).

Viewing her experiences from the neurodiversity paradigm allowed Ava to detach herself from a deficit-based model, moving towards an approach that prides her uniqueness. This provides her with a sense of empowerment, allowing her to step away from a shame-filled narrative.

"Especially at work, it's really important for me at work [...] and it's not to say that people don't still get frustrated, I mean, I get frustrated at people and there's misunderstandings, but I think I'm able to say now, actually coming from my

position as a disabled person, or as a neurodivergent person [...] and that's that's unique." (Ava, p.18-19, L370-373).

Whilst Ava recognises that there are still moments of frustration, re-framing her experience through the lens of neurodiversity, has allowed her to speak from a "position of authority" or "position of lived experience" at work.

However, some participants had different associations with the term 'neurotypical' and 'neurodiversity. For instance, on this note, Ayesha says:

"They're very different to neurotypical – I really hate those terms. I think more people are divergent that neurotypical, but the language as well I hate. It's not very friendly, warm. [brief pause] Neurodiversity, oh I hate that! [laughs]." (Ayesha, p.12, L291-293).

For Ayesha, the term neurotypical feels deprived of warmth and friendliness, leading to her disliking the term. She later adds:

"Well, I suppose hate is a strong word. [...] I think it sounds really clinical and you know, we say mental illness, and you know, it-it connotates that something is wrong with you, and I-I-I believe we're in a space now – when I was younger at school something was wrong with you. They thought something was wrong with you, and now, you know, we're looking at it as okay, there's not something wrong with you. You're just different, and this is how we're going to try and support you being different." (Ayesha, p.12, 297-308).

Her feelings of dislike for these terms stem from a feeling of it sounding "clinical", suggesting that there is a sense of pathologisation of neurodiverse experiences. Ayesha compares these labels to that of "mental illness" and its connotations of something being "wrong with you". This label perhaps also accompanies shame and stigma for having something "wrong" with you, which does not align with Ayesha's experience of ADHD as being a "difference".

In some experiences, the rise in awareness of ADHD has negatively impacted the lived experience of ADHD, leading to increased stigma. As articulated by Zara, ADHD has become a "trendy" or "hip" diagnosis, which has undermined the disabling and debilitating nature of ADHD.

"I understand that it's a very new thing, you know? And I think people see it as a very "hip" thing to have – it's the most "in" thing, you know? "I have ADHD" or "everyone has ADHD" [brief pause], but for someone like me, it's a real struggle." (Zara, p.3, L.63-65).

For Zara, her experience of ADHD has been minimised by the increased awareness of ADHD which has led to some people voicing harmful sentiments such as "everyone has ADHD". Later in the interview, Zara shared that this stigma has led to her worrying about the legitimacy of her diagnosis.

"The imposter syndrome kicks in like do you really have ADHD or is this an excuse? To the point where I'm doubting myself and thinking maybe I don't have ADHD [...] I suppose there is a bit of stigma attached to it because everyone I mentioned it to was like [clicks tongue], I wish I had ADHD because, I've got DSL like um like a plan for basically for – so I get like a laptop to do my exams for example. "Oh, I wish I had ADHD so I could have a laptop", and I'm thinking, you have no idea" (Zara, p.12, L261-276).

The use of the phrase "you have no idea" conveys a sense of distance between other people's perceptions of ADHD and Zara's lived experience. The dissonance between these two has often left Zara feeling "dismissed" with her disapproval of these statements being accentuated by her clicking her tongue. Furthermore, Zara reflected on a fear of being seen as getting "special treatment" by her colleagues and peers, perhaps highlighting the shame that is experienced by Zara when receiving support for her ADHD.

For some, the invisible nature of ADHD fostered discrimination. This was heightened during the COVID-19 pandemic where Lauren was refused an appointment to get her eyes tested as she could not wear a mask, although she was exempt from wearing a

mask. This led her to have a panic attack, highlighting the profound distress she experienced as a result.

"Because I wasn't in a wheelchair or because I didn't only have one arm, or because I didn't have two heads, or because I didn't have scars showing, I was penalised [...] I was discriminated against." (Lauren, p.23, L518-520).

"I mean, I was using a walking stick for 18-months because I had severe sciatica and people noticed that, but because, you know, it's [ADHD] not noticed so we're discriminated - discriminated again, which is not fair." (Lauren, p.24, L528-530).

Lauren then added that she has always had to "fight" to be treated in a fair manner that accounts for her ADHD.

On the other hand, in Daphne's experience, having the ADHD diagnosis has reduced the stigma perpetuated towards her, specifically from professionals. She was initially diagnosed with BPD, prior to being diagnosed with ADHD.

"I also feel that since being diagnosed, there's been a lot more understanding towards me in terms of professionals' um so, when it was [...] the BPD diagnosis, I'd go to hospital and I was very stigmatised, and I was just placed in a box and that was it. Whereas now that I-I don't know if it's a more acceptable diagnosis." (Daphne, p.16, 382-385).

Daphne's experience of being "placed in a box" suggest that she was judged unfairly and not see for who she truly is, but instead was seen through the BPD label. Additionally, whilst her BPD diagnosis has since been refuted, it has continued to "haunt her", inhibiting her from gaining access to assessments and treatments specifically for neurodivergence.

"I only got diagnosed with Autism this year and what happened was I was contacted by the assessor, and he said, "oh, I can't put you through the assessment because you've got BPD, and I said oh no, I don't - haven't had it

for over 10 years and they said – he said, oh the GP said you've got it in here but that's what they've passed forward and because we haven't got any aftercare, I'm worried about if you're diagnosed with Autism, what the effects will have on you, how you'll react to it – if it'll make you suicidal, if it will make you self-harm. And I said, no I haven't - I haven't self-harmed in a decade like that. It doesn't exist anymore, but it's being – it's on my file and I just feel like it's this thing that's [brief pause] haunting me." (Daphne, p.17, L.398-404).

This theme captures participants' lives post-diagnosis. A shared experience between participants was that of re-negotiating their identity and their relationship with themselves, post-diagnosis. This was often illuminated by participants pondering over questions such as, "Who am I?" and "What is me and what is ADHD". These questions did not have straightforward answers, with this process being regarded as an ongoing journey.

A parallel process alongside this was participants navigating all their ADHD in the context of their other identities (being a mother, a woman, and holding a cultural identity). On the note of motherhood, participants reflected on the conflict between ADHD symptoms and the demands of motherhood, with some reflecting on the shame that is associated with not being able to meet these demands. The interplay between ADHD, hormonal changes, and menopause was also unpacked with participants reporting a worsening of ADHD symptoms during periods of hormonal changes such as following the onset of puberty, after giving birth, and menopause. The interaction between ADHD and cultural identity was also examined, with participants reflecting on how their cultural background has shaped their experience of ADHD. The final subtheme explored the impact of social discourses and stigma on the experience of ADHD, with participants sharing experiences of both increased stigma and decreased stigma following the diagnosis.

## **Chapter Four: Discussion**

# 4.1. Overview of Chapter

In this chapter, the findings of this research project will be examined and considered within the context of the research aims and questions. The chapter will begin by contextualising the findings of this study within the existing literature. A theme-by-theme approach has been taken to this section. Next, methodological considerations will be explained to highlight the study's strengths and limitations. Following this, clinical implications for professionals will be discussed. Finally, there will be suggestions for future research, and ending with a reflexivity section discussing my personal reflections of the research process.

# 4.2. Discussion of Findings

The aim of this study was to explore the experiences of women diagnosed with ADHD in adulthood in the UK. It aimed to do so by answering two main research questions:

- 1. How do women diagnosed with ADHD in adulthood describe their experience of being diagnosed in the UK?
- 2. How has their ADHD diagnosis impacted their identity and daily life functioning?

The study used an RTA to generate themes around women's experiences of navigating a late ADHD diagnosis in the UK. Four main themes were identified from the thematic analysis. These were: (1) Growing up with ADHD undiagnosed; (2) ADHD as a possibility and seeking out a diagnosis; (3) Receiving an ADHD diagnosis; (4) Life with an ADHD diagnosis.

#### 4.2.1. Theme 1: Growing Up with ADHD Undiagnosed

All participants reported experiencing ADHD symptoms in childhood. These symptoms led to a feeling of "difference" within these participants, in comparison to their peers. Without the diagnosis, participants did not have a framework to understand this difference, often leading to the internalisation of symptoms as innate personality flaws. This finding aligns with previous research that has found that individuals diagnosed with ADHD in adulthood tend to experience a sense of difference from others (Young, Bramham, Gray, & Rose, 2008; Schrevel, Dedding, Aken, Broerse, 2016). Similarly to

Attoe and Climie (2023), this study found that this feeling of difference was experienced by women diagnosed with ADHD in adulthood as well. The process of internalisation was further fostered by family, teachers, and peers who labelled participants with negative traits such as being lazy or stupid. The repeated nature of this negative feedback hindered the participant's sense of self, leading to low self-esteem. It appears that the deterioration of self-esteem was not a consequence of the ADHD symptoms themselves, but instead was a byproduct of the environment that participants were surrounded with whereby, participants were reprimanded for their differences or not afforded the space to understand their differences. This finding echoes Schrevel et al., (2016), who suggest that ADHD appears to become "most problematic in the social environment" (p.47), aligning with the social model of disability. Low self-esteem in individuals with ADHD compared to individuals without ADHD has been well-established in women (Quinn & Madhoo, 2014).

For some participants, the negative feedback snowballed into being bullied, not just by peers, but also by teachers. As a means of self-preservation, participants reported that they would often resort to taking themselves out of social situations. Consequently, this magnified the feelings of difference among participants. This finding adds to the current body of evidence that has suggested that adults with ADHD are at an increased risk of experiencing loneliness and extends these findings by suggesting a plausible reason for this association (Stickley et al., 2017; Webster, 2018). Jastrowski and Colleagues (2014) also found that the bullying, rejection and subsequent distress experienced by individuals with ADHD may be minimised following disclosure of the diagnosis. This finding came after the researchers gave 306 young adults (between 18-26 years) vignettes of individuals with ADHD randomising them into two groups, preventative disclosure and non-disclosure. The results generated by the study suggested that preventative disclosure may "greatly reduce socially rejecting attitudes" (p.274). While this study holds low ecological validity due to its use of vignettes, it highlights the impact that the late ADHD diagnosis can have on psychosocial and interpersonal functioning.

Participants also reported experienced distress from an early age. For some participants, distress was experienced not just psychologically, but also psychosomatically (e.g., tension headaches). All participants had at least one

experience of help-seeking during childhood; however, they often left these meetings feeling misunderstood or dismissed by professionals, who made no meaningful attempt to understand the basis of their symptoms. This finding aligns with current research that has highlighted the shared experience of women being missed and dismissed by professionals (Craddock, 2024; Webster, 2018; Matheson et al., 2013). Co-occurring mood and anxiety disorders were a common experience shared amongst participants. This finding is echoed by Goodman and Thase (2015) who suggested that mood and anxiety disorders are highly co-occurring with ADHD, attributing this to overlapping symptom profiles. However, misdiagnosis was also common with some participants feeling that these diagnoses were given to them as a consequence of being misunderstood and dismissed by professionals. When exploring this further, participants reflected on how their distress was repeatedly framed through the lens of mental health, leading to them being provided with a diagnosis accordingly. These labels then overshadowed the underlying ADHD.

This finding also aligns with emerging research that has highlighted the common experience of women diagnosed with ADHD in adulthood being dismissed and missed by professionals and the phenomenon of one diagnosis overshadowing another (Webster, 2018; Craddock, 2024). This finding relates to the phenomenon of diagnostic overshadowing which often results in delayed or missed diagnosis of ADHD as practitioners will often attribute symptoms to other conditions such as depression or anxiety, thus overlooking ADHD as the underlying issue (Agnew-Blais, 2024; Skoglund et al., 2024). The role that diagnostic overshadowing plays in women's experiences of being diagnosed in adulthood was also noted by Morgan (2023), who found that when participants attempted to seek out for support, their distress was often framed through the lens of mental health. In the long-term, this diagnosis overshadowed the underlying ADHD. This finding was further echoed by this research. Alarmingly, research from over a decade ago has called for mandatory screening of ADHD by GPs and other professionals, but this has yet to be routinely actioned (Goodman & Thase, 2009; Webster, 2018).

Moreover, the findings of this study also suggest that alongside mental health diagnoses, neurodevelopmental diagnoses also overshadowed the ADHD diagnosis. This finding is not surprising as research has indicated that around 20-65% of

neurodivergent individuals are both Autistic and ADHD (commonly referred to as AuADHD; Chellappa, 2024; Leitner, 2014; Panagiotidi, Overton, & Stafford, 2017). It is these statistics that have led to researchers calling for a 'transdiagnostic revolution' whereby diagnoses are made along dimensional spectrums rather than as distinct categories (Astle et al., 2022; Sakiris & Berle, 2019). Therefore, rather than understanding ADHD as a discrete and isolated diagnosis, it is viewed as a condition that shares common features or symptoms with other psychological or neurodevelopmental disorders. The findings of this study suggest that transdiagnostic mapping may be a helpful tool to tackle the common issue of diagnostic overshadowing. Additionally, assessments conducted using this technique may be more holistic and person-centred as the diagnosis is based on the individuals' presentations rather than a diagnostic criterion.

A secondary consequence of this was that participants were prescribed with psychological treatments such as CBT, which they did not report as finding helpful. In some experiences, ADHD symptoms hindered their ability to engage with CBT meaningfully. Consequently, they were labelled as being 'treatment resistant' by professionals, giving rise to feelings of shame and blame, while also reinforcing narratives of something being innately 'wrong' with them. Building further on this, William et al., (2024) found that non-adapted, generic CBT in the UK (delivered by both NHS and private providers) was experienced by adults with ADHD as being "unhelpful, overwhelming, and at times harmful to their mental well-being" (p.1), and had the potential of further deploring their self-esteem.

# 4.2.2. Theme 2: ADHD As A Possibility & Seeking Out A Diagnosis

The distress experienced by participants at a young age persisted into adolescence and adulthood, leading to many women 'cobbing' through life. One participant felt like services did not know what to 'do' with her as she was not 'mad enough' to require inpatient care, and 'too much for just CBT and medication'. Other participants faced multiple psychiatric in-patient admissions, highlighting the distress they were experiencing. This study therefore adds to the body of evidence that has highlighted the trauma and suffering associated with a delayed diagnosis of ADHD (Bargiela et al., 2016; Craddock, 2024; Long & Coats, 2022). The distress could have been

reduced with an earlier diagnosis, emphasising the importance of a timely diagnosis (Long & Coats, 2022). This finding also aligns with and extends Lines and Sadek's (2018) research, which reported a significantly higher prevalence rate for ADHD among individuals admitted to acute psychiatric inpatients, than in a community setting. However, the majority of these cases were individuals with undiagnosed ADHD who had not been screened previously, advocating for routine screening of ADHD in this setting.

Looking back at this time, participants recognised that their understanding of ADHD was based on outdated and flawed stereotypes, such as ADHD being a 'naughty boys' syndrome'. These portrayals not only hindered their ability to connect this diagnosis to their experiences but also added a layer of shame and stigma to ADHD. This mirrors the findings of previous research that has suggested that the incongruence between stereotypical portrayals of ADHD and symptom manifestation in women, hinders their ability to get diagnosed in a timely manner (Holthe & Langvik, 2017; Morgan, 2023, Craddock, 2024). The awareness of a more updated and holistic understanding of ADHD often came after women engaged in articles written by individuals with lived experience or professionals who have experience of working with women with ADHD. For a quarter of the participants (two of the eight participants), the diagnosis was queried by professionals. However, irrespective of how they learned about ADHD, a common narrative was that participants initially dismissed the diagnosis as being relevant to them. The connection between themselves and the diagnosis often came later, which made participants feel seen and understood, in a way that some had never felt before.

However, in spite of making this connection, participants held off from approaching their GP to query a diagnosis, citing that this act required 'courage'. When exploring this further, it appeared that participants believed that approaching their GP would lead to them re-engaging in a familiar 'battle' with professionals, with fears around losing this battle and being dismissed once again, being eminent. This resulted in participants only seeking help from their GP after reaching a point of crisis which was characterised by a decline in mental health. When considering these findings along with participants early childhood experiences of help-seeking, it becomes apparent that prior experiences contributed to their current perceptions of professionals and

services, creating a reluctancy to seek help. This coupled with participants' accounts of chronic and recurring patterns of rejection from others, may have amplified the fear of rejection from professionals.

Participants accounts also reflected that they often had to advocate for themselves to gain access to support and care. This was a theme that ran through their narratives during various stages of their journey, from pre-diagnosis (advocating for an assessment) to post-diagnosis (advocating for support). For instance, during the GP appointment, participants armoured themselves with 'proof' as a way of gaining validity and cogency from professionals. This is perhaps yet another consequence of the epistemic injustice that excluded women from knowledge production of ADHD, thereby further marginalising them (Craddock, 2024). This translated into participants having to fight to be seen and heard, as although some participants had a positive and straightforward experience of an onward referral from their GP, this was not a shared experience. The inconsistency within this experience suggests that despite noticeable improvements this is yet to be seen and experienced across the board.

The journey between learning about ADHD and seeking out a diagnosis is one that has received minimal attention in research. Most qualitative studies spotlight childhood or adolescent experiences of distress and adult experiences of receiving a diagnosis. For instance, in a narrative systematic review of the psycho-social impact of a late ADHD diagnosis, Long and Coats (2022) say, "Delayed diagnosis affected how participants viewed their past and future, and how it had contributed to their struggles in childhood and adolescence." (p.1154). Moreover, the experience of seeking a referral for an ADHD assessment and diagnosis has also been neglected by research, which may be due to the belief that seeking a referral is a straightforward process. Taken together, this study sheds light on the distress experienced between these two stages, and that seeking an ADHD diagnosis is not a straightforward process in the UK.

#### 4.2.3. Theme 3: Receiving an ADHD Diagnosis

This theme captures the experience of participants being told that they had ADHD. The emotional and psychological impact of the diagnosis was mixed and varied with

some participants reflecting on feelings of relief and validation, with others experienced feelings of anger and grief. More specifically, participants felt as though the diagnosis had validated their feelings of difference and the lifelong quest for finding an explanation for their difficulties had *finally* come to an end. Feelings of anger, sadness, and grief were also common experiences, with some participants expressing anger for the multiple systemic failures that hindered their chances of getting a timely ADHD diagnosis, and the distress they endured as a result. Young et al., (2008, p. 499) proposed a six-stage process of adjustments after receiving an ADHD diagnosis, similar to that proposed by Murphy (1995), which were: (1) relief and elation; (2) confusion and emotional turmoil; (3) anger; (4) sadness and grief; (5) anxiety; (6) accommodation and acceptance. A similar account of emotions was shared by the participants of this study.

The diagnosis also provided participants with a framework to understand and re-frame their experiences. Armed with this knowledge, participants were able to re-locate some of the blame they had internalised for their previous difficulties and failures, alleviating some of the distress they were experiencing. These findings align with the body of evidence that has highlighted that women with undiagnosed ADHD are more likely to have an external locus of control, resulting in feelings of powerlessness, self-blame, and anger (Attoe & Climie, 2023; Lynn, 2019). The present study extends these findings by adding that the diagnosis facilitated the movement towards a more balanced locus of control, empowering women as a result. Contentiously, some researchers have suggested that an ADHD diagnosis diminishes self-control and therefore responsibility due to increased focus on deficits (Koi, 2020). However, the accounts shared by participants in this study suggested a contrary finding whereby the diagnosis empowered women to take back control and responsibility.

The feelings of compassion and acceptance were frequently reflected on by participants, following the diagnosis. These feelings extended not just to the self but also to others, including parents and caregivers. The reduction in blame and shame appeared to alleviate the distress participants were feeling before the diagnosis. This experience was in alignment with the findings reported by Stenner et al., (2019), Waite (2010), and Morgan (2024), who found that an ADHD diagnosis can often lead to a reduction in self-blame and increased self-acceptance. Alongside this, research

exploring the link between self-compassion and mental health in individuals with ADHD has gained momentum recently, with empirical evidence highlighting a link between the two. For instance, Beaton, Sirois, and Milne (2022) reported that low self-compassion contributes to poorer mental health in adults with ADHD compared to adults without ADHD. Given the correlational nature of the study, it is hard to draw conclusions however when linking this with the present study suggest that boosting self-compassion at this stage (e.g., through compassion-focused therapy), may improve mental health and well-being outcomes.

In terms of support following diagnosis, experiences were varied, with some participants being offered CPNs and access to support groups, while others were only offered medication. These findings are consistent with that of Morgan (2023) and taken together suggest that support following an ADHD diagnosis is a 'postcode lottery' with participants in certain regions of the country being given access to more support, than others. This appears to be another byproduct of a fragmented and inconsistent system, with the NHS falling short of meeting its aim to ensure individuals across the UK have equal access to care (Smith et al., 2023). The lack of psychological support offered was also concerning as participants in this study reflected on having mixed experiences with ADHD medications, with some finding this more helpful in managing symptoms, than others. Recently, it has emerged that the postcode lottery that impacts access to support, also impacts access to medication, particularly in the light of ongoing medication shortages (Royal College of Psychiatrists, 2023). Taken together, these experiences indicate that some individuals are being left with little-to-no support following their diagnosis.

Understanding these findings in the context of emotional dysregulation, which is commonly associated with ADHD (see Retz et al., 2012), highlights the importance of support for individuals' post-diagnosis. Here, emotional dysregulation refers to the inability to respond and manage emotional states resulting in intense and prolonged emotional reactions (Retz et al., 2012; Hirsch et al., 2018; Mitchell et al., 2012). The experiences shared by the participants of the present study suggest that receiving a diagnosis may be an emotionally intense period where an individual may experience a range of emotions. Moreover, this may be a period of increased reflection where participants look back at different moments in their lives that may be distressing in

nature. Taken together, the lack of support offered to individuals following a diagnosis is concerning as individuals may be in significant distress at this time. This study therefore echoes the recommendation of Retz et al., (2012) who suggested that individuals with ADHD must have access to *both* psychological and pharmacological interventions.

The theme of connection and community was also shared across participants, with a particular focus on online communities. In many respects, commencing with others created understanding and normalised participants experience, however, some participants demonstrated a degree of ambivalence towards this. For example, one participant felt that connecting with others made her feel like she was less unique or special than she had grown up to be. Here, it appeared that being 'special' became a self-protective strategy adopted at a young age to protect participants from the psychological consequence of being different (i.e., I am misunderstood because I am special or different).

This finding feels important given research that has suggested that increased severity of ADHD symptoms in adults is associated with 'functional impairments' in interpersonal relationships (Bruner et al., 2015; Safren et al., 2010). While the cause of these impairments has not been clearly understood by research, factors such as emotional dysregulation in adults with ADHD (Bruner et al., 2015) and stigma and discrimination (Masuch et al., 2019) have been suggested to mediate this relationship. The accounts shared by the participants of this study may further indicate that the 'functional impairments' reported in studies may not reside in the individual but instead were a product of the interaction between the individuals and their environment, consistent with the social model of disability. Therefore, when the environment is conducive to their needs, individuals with ADHD are more able to navigate interpersonal relationships. Alongside this, a recent study by Ginapp et al., (2023) found that online communities such as Facebook were experienced as helpful by adults with ADHD as they increased understanding of symptoms and helped them develop coping skills. However, drawbacks such as misinformation and difficulty managing online communication were also reported. The findings of this study, taken with the current body of research, suggest that the diagnosis facilitates the ability of individuals to connect with a community of others which may reduce some of the distress experienced.

## 4.2.4. Theme 4: Life With An ADHD Diagnosis

Participants experiences further revealed that following the diagnosis, they went through a journey of re-adjusting to life with this new identity or assimilating a new identity. For many, the diagnosis impacted their sense of self leading to questions such as "Who am I?" and "Who have I ever been?". The process of renegotiating their identity was prompted as the diagnosis gave women the permission to un-mask and re-connect with their authentic selves, which previously had been concealed due to shame and judgement or as a form of self-preservation. The theme of identity has been more extensively researched in children and adolescents than for adults, however this research has produced mixed findings. On one hand, ADHD provided individuals with validation and understand, while on the other hand it led to an identity conflict characterised by questions such as, "What is ADHD?" and "What is me?" For instance, Krueger and Kendall (2011) conducted a qualitative study exploring how adolescents experience ADHD and found that "An ADHD adolescent's sense of self is distorted, due to integrating one's identity with the disorder" (p.61) and "They were their ADHD, and their ADHD was them" (p. 64). Alternatively, Brady (2014) suggested that children neither embrace nor completely dismiss the medical view of ADHD but instead chose to actively re-define what ADHD means for them. This enabled them to maintain a sense of control and agency over their lives. When viewed together, these mixed findings are perhaps an indication that there are individual differences between participants renegotiating their sense of self.

As mentioned above, research in adults in sparse. However, the experiences described by participants in this study aligned with that of Nieslsen (2017), who conducted a two-year anthropological fieldwork study in Denmark and found that individuals diagnosed with ADHD experience a battle between seeing ADHD as an identity versus as a disorder. This finding was conceptualised by her participants expressing a tension between the views of "I am ADHD" and "I have ADHD", with many sharing that they find themselves identifying with and distancing from ADHD at

different stages of their journey following diagnosis. A similar narrative was shared by the participants of this study, who regarded this as an ongoing journey.

Alongside their relationship with themselves, participants also spoke about how they navigated their multiple identities in the context of the ADHD diagnosis. Firstly, participants who had children recognised the additional challenges they faced during motherhood, a gendered-experience, due to their ADHD. Without the diagnosis, participants experienced increased shame and stigma which was internalised as being a failure and led to increased distress. The challenges faced by participants also changed during different stages of motherhood leading to a battle to "keep up" with other parents. Most mothers shared that the diagnosis had a positive impact on their experience of parenting as it gave them a language to communicate with their children. While the research on the experience of motherhood in women diagnosed with ADHD is young, the conflict between gender norms and ADHD symptoms was also reflected in the findings of Holthe and Langvik (2017), who found that motherhood led to additional challenges faced by women. This finding adds to the limited body of evidence that has studied this experience and highlights the need for further research in this field.

This research also exposed the interplay between ADHD, being a female and the impact of hormonal influences on the experience of ADHD. This is an area of research that has been heavily neglected which may be due to the fact that women's health has been systemically underfunded (Galea & Parekh, 2023). Participants in this study reported worsening of ADHD symptoms during menopause, voicing that they had a limited evidence-base to turn to as a way of better understanding this interaction. Like women's health, menopause is an area that has also experienced neglect which has translated to limited evidence-based research, leaving much room for misinformation (The Lancet, 2022). The participants of this study also noticed that they experienced a worsening of symptoms during periods of hormonal fluctuations such as following childbirth and the onset of mensuration. These experiences are supported by research that has highlighted that women with ADHD are at a higher risk for hormone-related mood disorders, specifically premenstrual dysphoric disorder (PMDD) and postpartum depression symptoms (PPD) (Dorani et al., 2021). The present study therefore

advocates for further research to investigate the relationship between hormonal changes and ADHD symptoms.

Women in this study suggested that the intersection between ADHD, gender, and ethnicity led to increased stigmatisation, which was a byproduct of multiple factors. First and foremost, participants reflected on ethnicity-specific stigmas whereby ADHD was portrayed as a moral failing, with some family members and members of the wider community sharing sentiments such as "I will pray for you" upon participants disclosing their diagnosis. Secondly, the conflict between gender norms and ADHD symptoms was amplified in the light of cultural norms of being a woman. These norms often overemphasised gender roles such as caretaking and characteristics such as being "good". Moreover, the experience of being from a BIPOC background, in the UK led to some participants masking aspects of themselves "that had nothing to do with the ADHD". This experience links to the concept of cultural masking which refers to the practice of concealing or suppressing aspects of one's identity or culture to conform to societal norms or avoid negative stereotypes, discrimination, or prejudice, and may manifest in behaviours such as code-switching (Glenn & Johnson, 2012). Research investigating the impact of masking on mental health in individuals with ADHD has already found that behaviours such as masking can negatively impact mental health leading to increased symptoms such as social anxiety (e.g., Mylett, 2022). The finding of this study suggests that when reflecting on the impact of masking on an individual, an intersectional lens must be adopted as it can illuminate nuances to this experience that may be otherwise neglected.

The intersectionality theory, along with the concept of intersectional stigma, is therefore highly relevant to the findings of this study. As explored in the introduction, the intersectionality framework, describes how different aspects of an individual's identity (e.g., class, gender, race, and other individual characteristics) 'intersect' with one another creating different and unique points of discrimination and privilege (Crenshaw, 1991). Thus far, the intersection between gender and neurodiversity has been the focus of this research project, highlighting the impact that being a woman has on an individual's experience of ADHD. However, this intersection cannot be viewed in isolation, as participants experiences illuminated ways in which other intersecting identities came together to create their own, unique experiences of ADHD.

For example, as highlighted above, participants' experiences of being a woman and having ADHD was further shaped by their ethnicity and culture.

While research on this topic is young, recent figures published by NHS Digital highlighted that black women represented the highest percentage of people aged over 16 screened positive for ADHD in the UK (NHS Digital, 2017). The second highest ethnic group in women who screened positive for ADHD was Asian women (to note: the website does not provide much further information on the breakdown of these statistics based on ethnic group). Therefore, these populations are at a higher risk of being underdiagnosed in childhood. Given these statistics, it is alarming to see that there has been no qualitative research on documenting the lived experience and voices of BIPOC individuals based in a UK setting. These voices have begun emerging in mass media (e.g., Tedx Talks) whereby women have shared how their intersectionality identity contributed to their late diagnosis and has impacted their experience of ADHD (Agyei, 2022).

Understanding the findings of the study detailed above in the context of this intersectionality framework therefore highlights that this unique intersection created multiple points of oppression for these participants resulting in them battling multiple systems of oppression (e.g., sexism, ableism, and systematic racism; Anderson-Elahi, 2022). This intersectional stigma shaped the participant's lived experience of ADHD.

The power of social discourses was another salient theme that was developed. Discourses played a significant role in shaping how participants experience ADHD, influencing not only their understanding but also how they perceive themselves. The medical model approaches to ADHD have garnered wide-scale criticism in research due to its pathologisation of deficits (Bertilsdotter Rosqvist et al., 2020). Intriguingly, participant accounts suggested that for some, aligning with the medical model provided comfort and validation, in a way that the social model of disability could not. The scientific validation provided by the medical model removed ownership for perceived 'deficits' attributed to participants from a young age. However, rather than aligning themselves with one paradigm, participants' accounts suggested that they found themselves aligning with multiple paradigms. For instance, along with the medical model, some participants felt that the neurodiversity movement and the label

of being 'neurodivergent' evoked a strong sense of pride and belonging. However, this was not a shared experience as some participants did not like the terms 'neurodiverse' and 'neurotypical' as they felt 'clinical', suggesting that there has been a pathologisation of neurodiverse experience. The diversity within these experiences suggests that this is an aspect that may be deeply subjective and personal. Therefore, a degree of caution is needed before making generalisations about the neurodivergent community as a whole.

# 4.3. Key Take Home Points & Theoretical Contributions

This study addresses a significant gap in ADHD research by exploring women's experiences of navigating a late diagnosis in the UK. The present study has produced multiple novel findings, thus producing significant theoretical contributions to research.

Firstly, participants' experiences revealed the different ways in which biological (e.g., hormonal changes), psychological (e.g., co-occurrences and overshadowing), and social factors (e.g., stigma) contributed to their late diagnosis. While previous research has uncovered the role that some of these factors play in the phenomenon of a late diagnosis, this research added a layer of nuance to these findings while simultaneously adding to this body of research. For instance, Holthe and Langvik (2017) and Morgan (2023) both found that participants often reported experiencing psychological co-occurrences alongside their ADHD (e.g., mood or anxiety disorders) and that this overshadowed the ADHD diagnosis, thus resulting in women being diagnosed later in life. This study echoed those findings whilst also highlighting that neurodevelopmental co-occurrences may also overshadow ADHD. Furthermore, this study also illuminated the various ways in which biological factors such as hormonal influences may shape the lived experience of ADHD. This has been an area that has been neglected by much of the present body of research.

Participants' experiences also illuminated the psychological, social, and psychosomatic impact of a late diagnosis, with research suggesting that these impacts may have been diminished by a timely diagnosis. For instance, feelings of isolation and disconnection from others a shared experience among participants. However, participants added that they would often take themselves out of social situations as a

form of self-preservation from behaviours such as bullying. This could have been different had participants had a framework to understand themselves and for others to understand them.

When describing their experience of being diagnosed, it became apparent that seeking out a diagnosis was not a straightforward experience and was instead complicated by factors such as participants' prior experiences of help-seeking, and the state of current ADHD services which has led to discontinuity in care. This is a novel finding produced by this study, as much of the research conducted on women's experiences of being diagnosed with ADHD in adulthood has recruited participants diagnosed through private pathways, thus detracting from the ability to conceptualise the role that adult ADHD services have on individuals and service users.

Following the diagnosis, participants experience a complex landscape of emotions, from being relieved and elated to feeling angry. While this finding has been articulated by previous research (e.g., Holthe and Langvik, 2017), this study adds depth and nuance to this conversation as it highlights some of the reasons behind this emotional landscape. For instance, participants' anger was often driven by the systemic failures that led to their diagnoses. This research also exposed the current post-code lottery that is at play when it comes to support following a diagnosis, with some participants across the country having access to more support, than others. While previous studies have highlighted the lack of support following a diagnosis (Morgan, 2023), the difference in support based on an individual's post-code was a novel finding generated.

In relation to the second question posed - how has the ADHD diagnosis impacted identity and daily life functioning, this study both echoed previous findings and reported original findings. There is currently a void in the research that has explored the impact that ADHD has on an individual's identity. This research filled this gap in research by illuminating the journey of identity reconstruction and the process of assimilating their diagnosis with their ADHD, following the diagnosis. Participants' experiences also revealed that they were navigating their ADHD diagnosis in the context of their other identities (e.g., being a woman, being a mother, holding a cultural identity). Holthe and Langvik (2017) previously highlighted the conflict between ADHD, motherhood, and

gender-specific issues, however, the present study extended these findings to the UK sample, while adding more depth to this finding. For instance, participants in this study reported that the challenges they experienced during motherhood changed during the various stages of motherhood.

Moreover, the interplay between ADHD and holding a cultural identity has been neglected by research, specifically in the UK. This study was able to attend to this gap in research. By foregrounding participants' experiences, this research was able to highlight that the experience of being diagnosed with ADHD are not monolithic. Instead, participants' experiences were shaped by the unique intersection of their identities, which created a unique model of privilege and discrimination. This finding was particularly relevant when thinking about stigma as it felt apparent that the stigma of ADHD did not exist in a vacuum. Instead, participants experienced the cumulative stigma of their multiple identities.

### 4.4. Implications & Applications

The findings generated in this study have important implications for clinical practice, research, and policy development. The implications detailed below also include implications and improvements detailed by my participants when they were asked the question, "in your opinion, what needs to be changed and/or improved on" during the interview. To provide a comprehensive view of the implications of this study, a themeby-theme approach has been taken towards this section.

The first theme, growing up with ADHD undiagnosed, advocates for increased training for multiple professionals across different settings including teachers, GPs, and mental health professionals, on the ways in which ADHD symptoms may manifest in girls and women. Echoing the words of Mogan (2023), this training should focus on how ADHD may manifest in women and girls differently, in comparison to men and/or the stereotypical perception of ADHD which conflates hyperactivity with ADHD. Here, practitioners may also benefit from further training on diagnostic overshadowing and how this phenomenon may lead to practitioners diagnosing a mental health condition and missing the underlying ADHD. This would foster the timely identification, detection, and diagnosis of ADHD. It further advises the use of an intersectional lens

within these trainings, shedding light on how aspects such as multiple points of oppression in one's identity may shape their experience of ADHD. It is hoped that increased training will facilitate compassion and empathy, battling the feelings of being misunderstood and dismissed by professionals. Furthermore, understanding the presentation of ADHD in a more holistic yet comprehensive manner will allow practitioners from being able to distinguish between diagnoses, and consequently reduce the number of women and girls getting "missed". Given the high rates of distress experienced by participants, it is hoped that this would also ensure that diagnoses are made promptly and in a timely manner, allowing for access to support and treatment. The findings of this theme also suggest that when diagnosed in childhood, parents and caregivers may benefit from advice and guidance on navigating neurodiversity and supporting their child.

The second theme, ADHD as a possibility and seeking out a diagnosis, highlights the important role that GPs play in gatekeeping ADHD assessments. This finding further stresses the importance of increased training for professionals to better understanding, recognise, and diagnose ADHD in women and girls. It also chimes in on the concern of the current state of ADHD adult services advocating for the need for increased funding across the board. Services and practitioners should be aware that individuals who have had the lived experience of a late diagnosis, may also have prior experiences of being rejected and dismissed by professionals. This rejection may impact current help-seeking and may foster feelings of mistrust or fear of re-rejection. A compassionate, person-centred, non-judgmental approach towards individuals may facilitate re-gaining trust, giving room for feelings of connection and empathy to develop.

The final two themes highlight the need for neuro-affirmation ADHD assessments. The reshaping of these assessments should involve consultation from women and adults who have had lived experience of receiving an ADHD diagnosis in adulthood. If screened positive for ADHD, participants must receive access to specially tailored support (both psycho-social and medication-based) promptly. Having a safe and non-judgemental space may facilitate the processing of these emotions, reducing the distress experienced by individuals at this time. Here, practitioners may benefit from further training to help them provide therapy that is neuro affirmative (e.g., ensuring

that therapy is delivered in sensory-friendly environments, homework tasks are adapted to meet client needs). Support groups may also be particularly helpful as they foster a sense of connection with a community of others. Adapted, neuro-affirmative compassion-focused therapy may also be useful in the context of increased self-criticism experienced by this population. Support provided following diagnosis must be equal to all diagnosed, with the need for seamless care as participants transition through various stages (i.e., pre-diagnosis, diagnosis, post-diagnosis).

Clinically speaking, the findings of this study also highlight that while there may be similarities within the experiences of these women, adopting an intersectional lens when understanding their experiences may facilitate a richer understanding. It is hoped that the increased understanding informed by evidence-based research that represents the voice of those with lived experience will help tackle the rampant issue of misinformation and thus stigma experienced by individuals with ADHD.

**Table 4**Summary of the interventions and training programmes identified by this research and the individual it is aimed at.

Individual Aimed At	Training/Intervention
GPs	<ul> <li>Training on how ADHD may manifest in women and girls, and how this may differ to the stereotypical understanding of ADHD.</li> <li>The topics of diagnostic overshadowing and co-occurrences as well as the ways in which intersecting identities shape the lived experience of ADHD should be addressed.</li> <li>Incorporating ADHD and neurodiversity training into GP and medical school trainings.</li> </ul>
Teachers/Educators	<ul> <li>Training on how ADHD may manifest in school-based contexts.</li> <li>Similar to GPs, the intersectionality framework may aid teachers in understanding how the intersection of</li> </ul>

		various identities may shape the lived experience of
		ADHD and symptom manifestation.
Parents/Caregivers	•	Training aimed at raising awareness, reducing
		stigma, and providing parents with the opportunity to
		better understand how they can support their children
		following an ADHD diagnosis.
Therapists, mental	•	Training aimed at equipping practitioner with the
health practitioners,		necessary insights for them to be able to recognise
healthcare services		and query an ADHD diagnosis in clients.
	•	Practitioners may further benefit from learning about
		ADHD through an intersectional lens, highlighting that
		experiences are not monolithic.
	•	Therapists may also benefit from learning about ways
		in which they could adapt their therapeutic approach
		for neurodivergent clients.
ADHD assessors	•	Training aimed at highlighting the impact that past
		experiences of help seeking may have on women
		who seek out a diagnosis in adulthood.
	•	Further training to ensure that assessments are
		neuro-affirmative, and enquiry is compassionate.

# 4.5. Evaluation of the study

## 4.5.1. Strengths

A major strength of this study is that it attends to an important gap in research that has documented the lived experience of women navigating a late ADHD diagnosis in the UK. Existing literature in this area has not only predominantly been conducted in the US but has also over-relied on a university sample. Moreover, the studies conducted in the UK often include both participants diagnosed via the NHS and through private services (including right-to-choose), which adds heterogeneity in experiences, and hinders the ability to highlight the impact that the current state of UK adult ADHD services are having on individuals, particularly women. Additionally, research that has explored gender disparities within ADHD diagnosis has predominantly done so using

quantitative methods. Here, the use of qualitative methodology added depth and richness to the insight on the lived experience, in a way that quantitative studies have not. The use of RTA has also facilitated the process of telling a story about patterns of meaning and why they matter. Taken together, it is hoped that this research adds to the current body of evidence with the many novel findings discussed above.

The varied and representative sample was also a further strength of this study. Being based in London, I assumed that most of my participants would be from here, however, the use of online data collection allowed for women from across the UK to engage in this research. The representative sample aided the development of themes such as the postcode lottery that is currently at play regarding support following diagnosis, which may not have been as apparent otherwise. The participants of this study were also from a range of age groups which allowed the collection of data from different perspectives and experiences. The study also includes two participants from an Asian/Asian British background, an ethnicity that is currently underrepresented in research that has explored late diagnosis in women, thereby attending to some of this gap.

#### 4.5.2. Limitations

Despite the aforementioned strengths of this study, it is not without limitations, which should be considered when interpreting the findings. Firstly, recruitment was primarily conducted on social media, whereby the advert for the study was posted on Facebook groups for women with ADHD. As a result, individuals who may not use this platform may have been missed, losing an additional layer to the findings in the process. In addition to this, the purpose of these groups is often to provide a safe space for women with ADHD to interact and connect without the fear of being judged by outsiders. I therefore wonder if the posting my advert in these spaces created a sense of being 'targeted' by researchers and professionals. This is accentuated in the light of some women's past experiences of help-seeking whereby they were repeatedly dismissed by professionals, which may have led to these feelings being re-activated following the posting of my study advertisement.

Furthermore, the sample recruited for this study comprised only participants diagnosed through the NHS; with all participants being prescribed medication as a form of symptom management. Therefore, the findings produced by this research do not capture the reality of those who have been diagnosed through private pathways or individuals who are not prescribed medication as a form of symptom management.

Time elapsed since diagnosis also varied greatly with one participant being diagnosed six months prior to the interview and another participant being diagnosed eight years and six months prior to the interview. While this enabled this study to capture a range of experiences, it could have also impacted the finding generated by this study, as participants have been at different stages of their journey following diagnosis. For instance, when asked about the impact of their diagnosis on identity and daily life, participants diagnosed later may have had more space and time to reflect and think about this, than participants diagnosed recently.

In addition to the above, off the eight participants, the majority (six participants) were White British. Therefore, the findings generated above largely stem from these viewpoints, with the nuances of other ethnicities being absent. Given that only two participants were Asian/Asian British, I attempted where possible to include their perspectives in the findings chapter. This is a finding that is especially important in light of racial disparities that are prevalent in the rates of ADHD diagnosis (Shi et al., 2021). This limitation may have been avoided with a more diversified recruitment strategies (e.g., building a relationship with local charities and communities, advertising my research through other means such as posters and podcasts).

Lastly, the sample size of this study is also smaller than other RTA studies which have typically reported a sample of 10-12 participants. This was primarily due to the fact that some women who emailed me expressing a desire to participate in this study were diagnosed via the right to choose pathway (n = 6) and therefore did not meet the inclusion criteria of this study. Others who initially expressed a desire to participate either dropped out or did not show up to the screening call or the interview (n = 15). Moreover, given the time-limited nature of this study, there were also practical constraints around prolonged recruitment.

Another limitation of this study pertains to recall bias which may have been at play as participants were diagnosed, on average, three years and six months prior to the interview. This is longer than the studies that have previously researched this topic (e.g., Morgan (2023) where participants had been interviewed within two years of the research interview). While this allowed a longer-term exploration of participants' experience, this systematic error may have led to participants not remembering previous events accurately or led to them omitting certain details which may have been relevant to their experiences of being diagnosed. Core ADHD traits such as inattentiveness and emerging research suggesting working memory deficits may further increase the risk of recall bias. This is particularly relevant for events such as receiving a diagnosis which in the context of emotional dysregulation, may alter the ability to recall events accurately. Pre-existing research has highlighted that late adolescents and young adults with ADHD have a high rate of inaccuracy when recalling childhood symptoms (Breda et al., 2020). Therefore, is it quite possible that recall bias impacted the data collected and therefore the finding of this present study. Alongside this, ADHD services may have changed since participants were interviewed.

Despite my best efforts to minimise power imbalances in this study, I acknowledge that the lack of consultation of individuals with lived experience through the various stages of this study, alongside my identity of being a 'neurotypical' led to the power differentials still being at play. When designing this study, I had set out to gain expert by experience consultation, however time constraints prevented my implementation of this step. Including the perspectives of participants through the research process would have aided in ensuring that the study was more neuro-affirmative and inclusive. This additional level of participant involvement may have strengthened the findings generated whilst increasing its credibility.

## 4.6. Future Directions: "Research, Research, Research"

The discussion of the findings of this study along with its limitations highlights directions for future research. First and foremost, this study echoes the recommendation of Morgan (2023) who highlighted the need for further research to better understand the intersection of ethnicity and an ADHD diagnosis. This

specifically extends to marginalised communities as research from the US has suggested the underdiagnosis of African American and Latino children in comparison to their white counterparts (Coker et al., 2016; Rowland et al., 2002). However, racial identity might be experienced differently in the UK versus the US due to distinct historical, cultural, and social contexts, leading to different experiences and perceptions of race and ethnicity. As a result, further research is needed exploring this experience in a UK setting. This phenomenon also needs to be studied not just in women, but also in men from these communities, as they may also face the reality of being under-diagnosed with ADHD. This recommendation is based on evidence that has highlighted the lower likelihood of children from minoritised communities being diagnosed with ADHD (Farkas and Morgan 2018; Morgan et al. 2013), and the greater tendency for institutions to label youth from BIPOC communities, as violent and/or criminal (Ferguson 2001; Rios 2011). In other words, their behaviour is viewed and framed through a lens that reflects self-determined poor behaviour, rather than framing their behaviour through the lens of ADHD. This consequently leads to youth from BIPOC communities not having access to treatment, instead exposing them to overpunishment, leading to the materialisation of the so-called 'school-to-prison' pipeline (Moody, 2016). Additionally, the social stigma surrounding ADHD within these communities may cause individuals to "mask" or hide their behaviour due to fear of reprimand or ostracization (Olaniyan et al., 2007). When conducting this research, caution should be expressed in not inappropriately aggregating all minorities into a large group of 'people of colour'. This is a common phenomenon in research and often creates a binary way of viewing ethnicity and race as being 'White' or 'non-White' and may overshadow some of the nuances within participants' experiences. Documenting these experiences will help tackle current epistemic injustice in this area by allowing individuals from these ethnicities to be representative in research, which in the long term may improve more accurate and timely detection of ADHD (Asherson et al., 2012).

Further research is also needed on the intersection between ADHD and other identities. For instance, this study sampled cis-gendered women who were assigned female at birth, therefore excluding transgender and gender-diverse individuals. As recently highlighted by Goetz and Adams (2024), there is a noticeable gap in research that has studied, both qualitatively and quantitatively, the experiences of ADHD among

transgender and gender-diverse, with initial research suggesting an increased prevalence of ADHD within this population. This research may have significant implications for the way we understand ADHD and may allow for more inclusive assessments and evaluations.

Menopause is a chronically underfunded and understudied phenomenon which impacts up to 50% of women worldwide (The Lancet, 2022). As a consequence, much of the available literature exploring the interplay between ADHD and hormonal changes appears to come from women's health magazines, as opposed to peer-reviewed journals. In the context of participants' experiences of worsening ADHD symptoms, further empirical research is needed to explore the interplay between hormonal changes and ADHD. This knowledge may facilitate the development of interventions, whilst also informing practitioners on ways in which medication may need to be titrated to help women manage worsening symptoms. Furthermore, this clarification may illuminate the biological factors which, alongside the psychological and social factors, may lead to the underdiagnosis of women and girls, allowing us to better tackle this issue.

There currently exists a rampant issue of misinformation around ADHD, with some citing social media to blame. Yeung et al., (2022) found that of 100 videos uploaded on the social media site TikTok, more than half (52%) were classified as misleading. This widespread dissemination of misinformation is perhaps a consequence of the lack of empirical evidence available on ADHD, particularly in women. This showed up in the present study as well with topics such as rejection sensitivity or RSD being a recurring theme in participants narratives. However, limited academic research exists on RSD in individuals with ADHD, despite this being commonly referenced online. A qualitative study exploring symptomology of ADHD in young adults (18–35-year-olds) found that RSD was a common symptom experienced by participants, however, was more frequently reported in females, than in males (Ginapp et al., 2023). This study was conducted in the US with a largely White sample; therefore, further research is needed to better clarify our understanding RSD. Consequently, this research would also enhance our current understanding of ADHD and help develop psychosocial interventions for its emotional idiosyncrasies.

Research on the topic of ADHD in women is rapidly growing. However, emerging studies have continued to employ quantitative methods. There is therefore a need for research that has looked at this phenomenon through a range of methodologies and methods which may facilitate a deeper and holistic understanding of ADHD. For instance, given concerns around recall bias in individuals with ADHD, photo elicitation may be used as a way of allowing participants to connect to memories, consequently facilitating deeper reflections during the interview (Kyololo et al., 2023).

#### 4.7. Reflections Of The Research Process

My research experience before this project was predominantly quantitative. The shift to qualitative methodology required me to step away from what I knew and embark on a new journey of sitting with the discomfort of not knowing. The act of stepping away and re-learning has comprised moments of finding, losing, and then finding my way again. This journey albeit challenging and non-linear, has been highly rewarding and transformed me in ways more than one. During moments when I felt utterly lost, the advice and guidance of my peers, colleagues, other fellow researchers, and my supervisor provided me with direction, and the encouragement to keep going.

My positionality has been at the forefront of my mind when conducting this research, as I was aware that I was not a neutral or distant observer, and that I played an active role in shaping the analysis and thus the knowledge generated by this study. My insider-outside position has been an aspect I have attempted to be transparent about throughout this thesis, noting my insider position of being a cis-gendered woman, and my outsider position of not holding an ADHD diagnosis myself. In the context of the epistemic injustice and persistent marginalisation experienced by individuals with ADHD, particularly women with ADHD, I was aware of the harm that researchers have done in perpetuating stigma and maintaining this marginalisation. For instance, a vast majority of the research that I interacted with while engaging in this research made overt use of the medical model and some openly placed the blame and burden of ADHD on the individual. Therefore, I knew coming into this that a sensitive and considered approach would be needed to ensure that I do not follow suit with the actions of the previous research. This was not an easy task but was made possible by immersing myself in the work of those with lived experience. This involved reading

books, articles, talks, and accounts written by authors with experience of being diagnosed with ADHD. Social media was also a great resource as it allowed me to peer into the lives of women with ADHD and listen to their stories, facilitating positive movement with this project. This combined with the many conversations I had with peers, friends, family members, other researchers, and even clients with ADHD, illuminated aspects of these experiences that I may have otherwise neglected, bringing them into my frame of reference.

My dual identity of being a counselling psychologist and researcher was another aspect that I was also mindful of whilst conducting this study. This was especially relevant when participants shared their accounts of being rejected and dismissed by professionals, as I was aware that this involved the profession that I was actively training in. Hearing these accounts evoked feelings of anger and injustice within me as they illuminated the ways in which structural inequalities operate to marginalise neurodivergent individuals. In these moments, I turned to my reflexive journal, which often afforded me the space to document my feelings and observe them from a broader perspective. This allowed me to make sense of them, permitting me to continue engaging with this research in a meaningful manner. I hope that the findings of this study helped tackle and add to the dismantling of the structural inequalities at play.

I also want to acknowledge how privileged I feel to have had the opportunity to conduct this research. I am honoured by the participants of this study who willingly and courageously let me into their worlds, sharing with me intimate details of their experiences. Given the account shared by my participants, I can imagine that participating in this research was, to some extent, emotional and challenging. However, in exchange, I hope that participating in this research provided women with a space to reflect on their experiences and feel empowered by them. I hope that the findings of this thesis find those women who are hesitantly waiting to seek out a diagnosis, those at the cusp of diagnosis, and those who were also faced with this reality, allowing them to feel seen and validated.

#### 4.8. Conclusion

Gender disparities in the rates of ADHD diagnosis have been well-established and suggest that women are more likely to be diagnosed with ADHD later in life, than men. However, there is limited research that has explored the experiences of women diagnosed with ADHD in adulthood, specifically in the UK. This study sought to bridge this gap in research by exploring the experiences of women navigating a late diagnosis in the UK and generated multiple significant findings. Firstly, it added to the body of research that has highlighted the negative impact that a late diagnosis can have on both an individual's sense of self and on psycho-social outcomes. It also reveals the transformative nature of a diagnosis and the impact that a diagnosis can have on identity and everyday life. Moreover, this study also calls for the adoption of an intersectional lens as it highlights that the experiences of individuals with ADHD are not monolithic. Finally, this study generated findings on the impact that stigma and social discourse have on the lived experience of individuals with ADHD. It is hoped that consistent with the British Psychological Society (2017) guidelines, this research will encourage therapists, researchers, and other professionals to hold compassion towards the experiences of this group. Altogether, the findings of this research offer a comprehensive insight into the lived experience of women who are faced with the reality of a late diagnosis in the UK.

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# **Appendices**

Appendix A: Tools and Measures Used Clinically to Diagnose ADHD in adults

Tool/Measure	Description
Diagnostic and	The criteria provided by the DSM-5 are widely used my clinicians
Statistical	to assess and diagnose ADHD in adults. The DSM-5 lists two
Manual of	main category of symptoms – inattention and hyperactive
Mental	impulsive. Off the nine symptoms detailed under each criterion,
Disorders, 5th	at least five much be present.
Edition (DSM-5)	
	In the instance that sufficient inattentive symptoms are present
	but not enough hyperactive-impulsive symptoms, the individual
	would be diagnosed with predominantly inattentive ADHD. In the
	instance that sufficient hyperactive-impulsive symptoms are
	present but not enough inattentive symptoms, the individual
	would be diagnosed with predominantly hyperactive-impulsive
	ADHD. If enough symptoms for both categories are present,
	participants will be diagnosed with a combined presentation of
	ADHD.
International	Symptoms are categorised into two main categories – inattention
Classification of	and hyperactivity and impulsivity. In order to be diagnosed with
Diseases, 10th	ADHD, adults must present with at least five symptoms from each
Revision (ICD-	category with evidence that symptoms must be present before
11)	the age of 12.
Diagnostic	A structured assessment tool specifically designed to assess
Interview for	ADHD in adults which was developed based of the DSM-5 criteria
ADHD in Adults,	for ADHD. It is widely used during the semi-structured
Version 5	assessment interviews as it enabled clinicians to gather
(DIVA-5).	information and determine if the individual meets the criteria for
	ADHD.
Qb-Test	The Qb-Test is a computerised, standardized tool that aims to
	measure specific aspects of attention, impulsivity, and
	hyperactivity. Data collected is often used alongside other

	diagnostic tools (such as the DIVA-5) in order to clinically	
	diagnose ADHD.	
The Adult	ASRS is a widely used self-report tool that is often used as a	
ADHD Self-	way of screening for the presence and assessing the severity of	
Report Scale	ADHD symptoms in adults. It consists of 18 items assessing	
Screener,	both inattention and impulsivity-hyperactivity based symptoms.	
Version 1.1	It is commonly used as a screening tool.	
(ASRS-v1.1)		

### **Appendix B: Proof of Ethics Approval**

## City, University of London

Dear Sara

Reference: ETH2223-0250

Project title: Exploring the experiences of women diagnosed with ADHD as adults

in the UK

Start date: 3 Jan 2023

End date: 2 Sep 2024

I am writing to you to confirm that the research proposal detailed above has been granted formal approval from the Psychology committee: medium risk. The Committee's response is based on the protocol described in the application form and supporting documentation. Approval has been given for the submitted application only and the research must be conducted accordingly. You are now free to start recruitment.

### The approval was given with the following conditions:

 the recruitment flyer states that participants should be older than 18 which does not match the exclusion criteria (<23 years)</li>

Please ensure that you are familiar with <u>City's Framework for Good Practice in Research</u> and any appropriate Departmental/School guidelines, as well as applicable external relevant policies.

Please note the following:

### Project amendments/extension

You will need to submit an amendment or request an extension if you wish to make any of the following changes to your research project:

- · Change or add a new category of participants;
- · Change or add researchers involved in the project, including PI and supervisor;

- Change to the sponsorship/collaboration;
- · Add a new or change a territory for international projects;
- Change the procedures undertaken by participants, including any change relating
  to the safety or physical or mental integrity of research participants, or to the
  risk/benefit assessment for the project or collecting additional types of data from
  research participants;
- Change the design and/or methodology of the study, including changing or adding a new research method and/or research instrument;
- Change project documentation such as protocol, participant information sheets, consent forms, questionnaires, letters of invitation, information sheets for relatives or carers;
- · Change to the insurance or indemnity arrangements for the project;
- · Change the end date of the project.

### Adverse events or untoward incidents

You will need to submit an Adverse Events or Untoward Incidents report in the event of any of the following:

- a) Adverse events
- b) Breaches of confidentiality
- c) Safeguarding issues relating to children or vulnerable adults
- d) Incidents that affect the personal safety of a participant or researcher

Issues a) and b) should be reported as soon as possible and no later than five days after the event. Issues c) and d) should be reported immediately. Where appropriate, the researcher should also report adverse events to other relevant institutions, such as the police or social services.

Should you have any further queries relating to this matter, please do not hesitate to contact me. On behalf of the Psychology committee: medium risk, I do hope that the project meets with success.

Kind regards

Tina Forster

Psychology committee: medium risk

City, University of London

Ethics ETH2223-0250: Miss Sara Baig (Medium risk)

### **Appendix C: First Ethics Amendment**

### Ethics ETH2223-1674: Miss Sara Baig (Medium risk)

 Date Created
 09 Mar 2023

 Date Submitted
 09 Mar 2023

 Date forwarded to
 09 Mar 2023

committee

Academic Staff Miss Sara Baig Student ID 210028124

Category Doctoral Researcher
Supervisor Dr Holly Kahya

Project "I felt like a broken person": The experiences of women navigating a

late ADHD diagnosis in the UK.

School School of Health & Psychological Sciences

Department Psychology Current status Approved

### Ethics application

### Amendments

### SA1) Types of modification/s

Change project documentation such as protocol, information sheets, consent forms, questionnaires, recruitment materials (please upload the relevant files with highlighted changes)

### SA2) Details of modification

In the initial ethics application, I proposed three sub-questions to expiore the experiences of women diagnosed with ADHD as adults in the UK. The three questions were:

- How do women diagnosed with ADHD in adulthood describe their experience of being diagnosed in the UK?
- 2. How has their ADHD diagnosis impacted their identity and daily life functioning?
- 3. How has social media, if at all, informed their experience of being diagnosed with ADHD as adults?

I have now decided to omit the final question that explores the role that social media plays in the process of seeking an ADHD diagnosis in adulthood. This change has been reflected in my debrief form and interview agenda. The information sheet, advertisement poster, and consent form were not amended as they did not mention the final question on social media. The main question and title will remain the same

### SA3) Justify why the amendment is needed

I have decided to remove the question "How has social media, if at all, informed their experience of being diagnosed with ADHD as adults?" as it does not fit with the inductive qualitative approach adopted in this study and instead is looking to test a hypothesis. This in turn risks the overall validity of the study. To address this, I have decided to make the aforementioned amendments.

### SA4) Other information

### SA5) Please upload all relevant documentation with highlighted changes Project amendments

### P1) Project title

Exploring the experiences of women diagnosed with ADHD as adults in the UK.

### P2) Principal Applicant

### Name

Miss Sara Baig

Provide a summary of the researcher's training and experience that is relevant to this research project.

The researcher is currently enrolled in the doctorate of counselling psychology.

- P3) Co-Applicant(s) at City
- P4) External Co-Applicant(s)
- P5) Supervisor(s)

Dr Holly Kahya

### **Appendix D: Second Ethics Amendment**

### Ethics ETH2223-2011: Miss Sara Baig (Medium risk)

Date Created 17 Apr 2023

Date Submitted 17 Apr 2023

Date forwarded to 24 Apr 2023

committee

Academic Staff Miss Sara Baig Student ID 210028124

Category Doctoral Researcher
Supervisor Dr Holly Kahya

Project "I felt like a broken person": The experiences of women navigating a

late ADHD diagnosis in the UK.

School School of Health & Psychological Sciences

Department Psychology
Current status Approved

### **Ethics application**

### **Amendments**

### SA1) Types of modification/s

Change or add a new category of participants

### SA2) Details of modification

The research project has broaden its inclusion criteria to include participants that were diagnosed with ADHD via the right to choose pathway. This amendment has been reflected in the demographic information sheet, participant information sheet, and the poster advertisement. The demographic information sheet now includes an added box asking participants if they were diagnosed via the NHS or right to choose pathway. The interview agenda remains unchanged.

### SA3) Justify why the amendment is needed

The primary researcher decided to make this amendment as participants who are diagnosed via the NHS pathway have been noted to have older diagnosis and/or tend to have received this diagnosis due to comorbid mental health problems. These factors impact the validity of the study as most individuals at the moment are having to wait years for an ADHD assessment via the NHS. To ensure that the study is grounded in the real-life experience of being diagnosed with ADHD in adulthood, the inclusion criteria has been opened up to include individuals diagnosed via the right to choose pathway.

### SA4) Other information

### SA5) Please upload all relevant documentation with highlighted changes **Project amendments**

### P1) Project title

**Doctoral Research Project** 

### P2) Principal Applicant

Name

Miss Sara Baig

Provide a summary of the researcher's training and experience that is relevant to this research project.

The researcher is currently enrolled in the doctorate of counselling psychology.

- P3) Co-Applicant(s) at City
- P4) External Co-Applicant(s)
- P5) Supervisor(s)

Dr Holly Kahya

### Appendix E: Research Recruitment Study Flyer



# HAVE YOU BEEN DIAGNOSED WITH ADHD IN ADULTHOOD?

### **ARE YOU ELIGIBLE?**

- 23 years or older,
- Assigned female at birth and identify as female,
- Hold an ADHD diganosis given via the NHS.

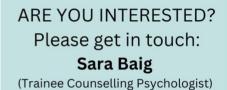
### AIMS OF THIS STUDY: derstanding of the expe

- Better understanding of the experience of being diganosed with ADHD in adulthood.
- Inform both therapists and researchers understanding of ADHD in women.

STUDY EXPLORING EXPERIENCES OF BEING DIGANOSED WITH ADHD Participants will be invited to take part in an interview of approx. 60 minutes to speak about their experiences of being ADHD in adulthood.

Participation is voluntary and confidential. All data will be anonymised and personal data we be protected.

60-90 minute interview via online or face to face (based on your preference)





This study has been reviewed by, and received ethics clearance through the School of Health and Social Sciences, City, University of London. If you would like to complain about any aspect of the study, please contact the Secretary to the Senate Research Ethics Committee on 020 7040 3040 or via email: Annah.Whyton@citv.ac.uk

City, University of London is the data controller for the personal data collected for this research project. If you have any data protection concerns about this research project, please contact City's Information Compliance Team at dataprotection@city.ac.uk

**Appendix F: Participant Information Sheet** 

Title of the study: Exploring the experiences of women diagnosed with ADHD as

adults in the UK.

**REC reference number**: ETH2223-1674

Date: 12/02/2023

Name of principal investigator/researcher: Sara Baig

We would like to invite you to take part in a research study. Before you decide whether

you would like to take part it is important that you understand why the research is being

done and what it would involve for you. Please take time to read the following

information carefully and discuss it with others if you wish. Ask us if there is anything

that is not clear or if you would like more information. You will be given a copy of this

information sheet to keep.

What is the purpose of the study?

In the last few decades, we have seen an increase in the number of women diagnosed

with ADHD in adulthood. This study aims to qualitatively (non-numerically) explore the

experience of women diagnosed with ADHD in adulthood in the UK. This study forms

part of a thesis for the Professional Doctorate in Counselling Psychology at City

University London and is intended to run until September 2024.

Why have I been invited to take part?

You have been invited to participate in this study as you have told the researcher you

are over the age of 23, assigned female at birth, and hold a diagnosis of ADHD that

was given to you via the National Health Service (NHS) or via the right to choose

pathway in the UK. Please inform the researcher if any of these details are incorrect.

Do I have to take part?

Participation in the project is voluntary, and you can choose not to participate in part

or all of the project. You can withdraw at any stage of the project without being

penalised or disadvantaged in any way. It is up to you to decide whether or not to take

part. If you do decide to take part, you will be asked to sign a consent form. If you

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decide to take part, you are still free to withdraw at any time and without giving a reason. All collected data will be destroyed upon withdrawal.

You can withdraw your data a month after the interview was conducted. Following this stage, transcription and analysis would have begun.

### What will happen if I take part?

If you wish to take part, you will be invited to attend a one-to-one interview expected to last 60-90 minutes. The interview can be helped face to face or online based on your personal preference. Online interviews will be held via zoom and face to face interviews will be held at City, University of London.

The interview will be semi-structured, so there will be five open-ended questions which are expected to lead onto further topics. You will be encouraged to take the lead in sharing your experiences. The interview will be audio recorded (and video recorded if conducted via zoom), all recordings will be made on an encrypted recording device and transferred to a password protected computer for storage. Recordings will be accessible only to the researcher. After the interview recordings will be transcribed, replacing any identifying or personal information with pseudonyms to ensure your identity remains anonymous. The information, including quotations will then be looked at using a thematic approach and broader themes with be extracted. If you wish, there will be an opportunity to review the analysis of your transcript and the themes extracted from it.

The study is expected to last until September 2024 and recordings will be destroyed at the end of the study.

### What are the possible disadvantages and risks of taking part?

Due to the nature of this topic, it is possible that talking about your experience of being diagnosed with ADHD may involve some emotional upset. If this was to occur, we would be able to take a break from the interview. Also please remember your participation is voluntary and you are able to withdraw at any stage.

### What are the possible benefits of taking part?

This is an opportunity to share your views and experiences of being diagnosed with ADHD in adulthood and may provide a space to be listened to and reflect on what this journey has been like for you. You will also be contributing to research on an important topic that may shape future policy development and enlighten avenues for future research. The researcher aims to publish the findings of this study in a peer reviewed journey to ensure that the findings are widely accessible to other researchers and practitioners.

### **Expenses and Payments**

Whilst there are no direct, immediate benefits for those participating in the project, it is hoped that this work will provide much-needed knowledge and clarification on the experiences of women who have been diagnosed with ADHD in adulthood.

If the interview is being conducted face-to-face, the researcher will refund you any incurred travel costs.

### How is the project being funded?

The author has not received any funding support for this research.

### **Conflicts of interests**

No conflicts of interest.

### What should I do if I want to take part?

If you are interested in taking part, please do contact the researcher at to express your interest.

### **Data privacy statement**

City, University of London is the sponsor and the data controller of this study based in the United Kingdom. This means that we are responsible for looking after your information and using it properly. The legal basis under which your data will be processed is City's public task.

Your right to access, change or move your information are limited, as we need to manage your information in a specific way in order for the research to be reliable and

accurate. To safeguard your rights, we will use the minimum personal-identifiable information possible (for further information please see <a href="https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/public-task/">https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/public-task/</a>).

City will use your name and contact details to contact you about the research study as necessary. If you wish to receive the results of the study, your contact details will also be kept for this purpose. The only people at City will have access to your identifiable information will be the primary research, Sara Baig. City will keep identifiable information about you from this study for 10 years after the study has finished.

You can find out more about how City handles data by visiting <a href="https://www.city.ac.uk/about/governance/legal">https://www.city.ac.uk/about/governance/legal</a>. If you are concerned about how we have processed your personal data, you can contact the Information Commissioner's Office (IOC) <a href="https://ico.org.uk/">https://ico.org.uk/</a>.

### Will my taking part in the study be kept confidential?

All the information that we collect about you during the research will be kept strictly confidential. All recordings will be accessible only to the researcher and stored securely on a password protected computer on OneDrive for 10 years. Confidentiality will only be broken if the researcher feels there is risk of serious harm either to yourself or others, or where the researcher is legally obliged to do so. Names will be pseudonymised in the report, meaning your name will be changed such that it will not be possible to identify you in any publications. Your contact details will not be shared with any third parties and future use of personal contact information will be used only if you express interest in being informed of the results of the study once completed.

### What will happen to the results?

The findings of this study will be written up as part of a thesis for a Professional Doctorate in Counselling Psychology. The findings may also be included in various future academic publications. All details, including direct quotations from interviews will be listed under a pseudonym to maintain anonymity. There will be no identifiable or personal information in the final thesis or any other publications, so there will be no way for readers to identify you. If you would like to be sent the results of the study,

please inform the researcher and consent to your contact details being kept for this

purpose on the 'participant consent form'. The results of the study will include key

findings and themes extracted from all transcripts.

Who has reviewed the study?

This study has been approved by City, University of London School of Health &

Psychological Sciences Research Ethics Committee.

What if there is a problem?

If you have any problems, concerns, or questions about this study, you should ask to

speak to a member of the research team. If you remain unhappy and wish to complain

formally, you can do this through City's complaints procedure. To complain about the

study, you need to phone 020 7040 3040. You can then ask to speak to the

Secretary to Senate Research Ethics Committee and inform them that the name of the

project is "exploring the experience of women diagnosed with ADHD in adulthood in

the UK".

You can also write to the Secretary at:

Annah Whyton

Research & Enterprise Office

City, University of London

Northampton Square

London, EC1V 0HB

Email: Annah.Whyton@city.ac.uk

Insurance

City holds insurance policies which apply to this study. If you feel you have been

harmed or injured by taking part in this study, you may be eligible to claim

compensation. This does not affect your legal rights to seek compensation. If you are

harmed due to someone's negligence, then you may have grounds for legal action.

Further information and contact details:

Primary Researcher: Sara Baig

Supervisor: Dr. Holly Kahya

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Thank you for taking the time to read this information sheet.

### **Appendix G: Participant Demographic Information Sheet**

Thank you for volunteering to take part in this study exploring the experiences of women diagnosed with ADHD in adulthood in the UK (REC reference number: ETH2223-1674). In order to better analyse the information collected in these interviews, the researcher requires some additional information. If you have any questions, please feel free to ask the researcher or contact them via email sara.baig@city.ac.uk.

How old are you?	
YEARS	
Which group best describes your ethnicity?	
Asian or Asian British	
Indian	
Pakistani	
Bangladeshi	
Chinese	
Any other Asian background	
Black, Black British, Caribbean, or African	
Caribbean	
African	
Any other Black, Black British, or Caribbean background	
Notice of an arrange of the state of the sta	
Mixed or multiple ethnic groups	
White and Black Caribbean	
White and Black African	
White and Asian	
Any other Mixed or multiple ethnic background	
White	
English, Welsh, Scottish, Northern Irish or British	
	1

Irish					
Gypsy or Irish Traveller Roma					
Any other White background					
Other ethnic group					
Arab					
Any other ethnic group					
How long ago did you receive your ADHD diagnosis?					
YEARS	MONTHS				
Have you been prescribed any medication to manage the symptoms of ADHD?					
YES	NO				
Please provide your GP information below (Note: these details will only be used if					

the researcher notes a serious risk to self or others).

### **Appendix H: Interview Topic Guide**

# Exploring the experiences of women diagnosed with ADHD as adults in the UK.

Hi. Thank you so much for joining in and for your time. As you know this study is exploring the experiences of women diagnosed with ADHD in adulthood in the UK. It should last about 60 minutes, so we have until 0:00 pm and during the interview I'll be asking you questions about your personal experience of being diagnosed with ADHD. I might ask you a few further questions to either get back on track or to explore your response further. If anything in the interview makes you feel distressed, then please do tell me. We can stop the interview or finish on a later day.

### **Questions of Interest:**

- 1. How do women diagnosed with ADHD in adulthood describe their experience of being diagnosed in the UK?
- 2. How has their ADHD diagnosis impacted their identity and daily life functioning?

### **Interview Questions:**

- Can you tell me about your experience of being diagnosed with ADHD?
- 2. What drove you to seek an ADHD diagnosis?
- 3. How did the ADHD diagnosed in adulthood impact how you view yourself/your identity?
- 4. How did the ADHD diagnosis impact your daily life functioning?
- 5. In your opinion, what needs to be changed or improved on?

# Appendix I: Consent Form

Name	value of principal investigator/researcher. Sala baig					
REC r	eference number: E	TH2223-1674				
Explor	ing the experiences	of women diagnosed with ADHD a	s adults in the UK.			
·		· ·	Please tick			
			(√) or put			
			your			
			initial in the			
			box			
1.	I confirm that I have r	ead and understood the participant ir	formation			
	dated 10/03/2023 for	the above study. I have had the opport	ortunity to			
	consider the informat	ion and ask questions which have be	en answered			
	satisfactorily.					
2.	I understand that my	participation is voluntary and that I ar	n free to			
	withdraw without givin	ng a reason without being penalised o	or			
	disadvantaged.					
3.	I understand that I wi	ll be able to withdraw my data up to o	ne-month			
	post interview.					
4.	I agree to the intervie	w being audio recorded.				
I agree to City recording and processing this information about me. I						
	understand that this information will be used only for the purpose(s)					
	explained in the parti	cipant information and my consent is	conditional on			
	City complying with its duties and obligations under the General Data					
	Protection Regulation	n (GDPR).				
7. I would like to be informed of the results of this study once it has been						
	completed and under	stand that my contact details will be r	etained for			
	this purpose (after wh	nich they will be destroyed).				
9.	I agree to take part in	the above study.				
Name	of Participant	Signature	Date			
			_			
Name	of Researcher	Signature	Date			
		<b>3</b>	<del></del>			

**Appendix J: Debriefing Form** 

Thank you for taking part in this study. Now that it's finished, we'd like to tell you a bit

more about it.

This study aimed to explore the experiences of women diagnosed with ADHD as

adults in the UK. In order to understand the experience of being diagnosed, the

research looked at two main questions:

3. How do women diagnosed with ADHD in adulthood describe their experience

of being diagnosed in the UK?

4. How has their ADHD diagnosis impacted their identity and daily life functioning?

If participating in this research has raised any issues, please do not hesitate to contact

the researcher on the contact details provided below. Additionally, please find a list of

support lines and websites that might be helpful in cases of psychological distress:

• The Samaritans: Someone to talk to who won't judge. Call 116 123 (24/7)

• UK Adult ADHD Network: Professional body aims to support individuals

diagnosed with ADHD in adulthood and has establish clinical services for adults

in the UK.

Contact your GP and let them know.

We hope you found the study interesting. If you have any other questions, please do

not hesitate to contact us at the following:

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Ethics approval code: ETH2223-1674.

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# Appendix K: Distress Protocol

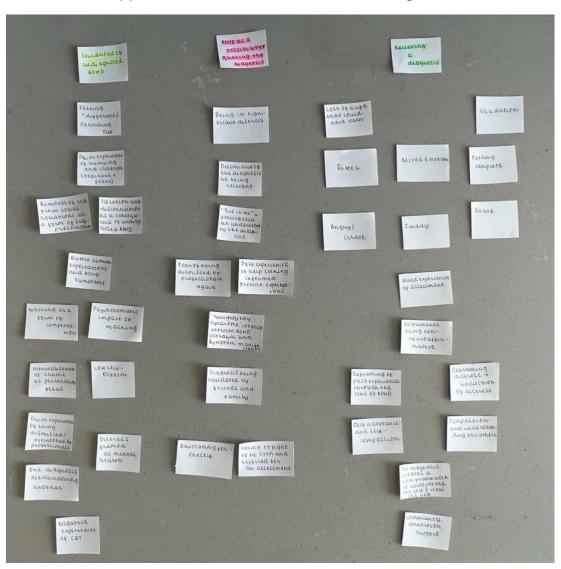
# Adapted from Haigh & Witham (2015)

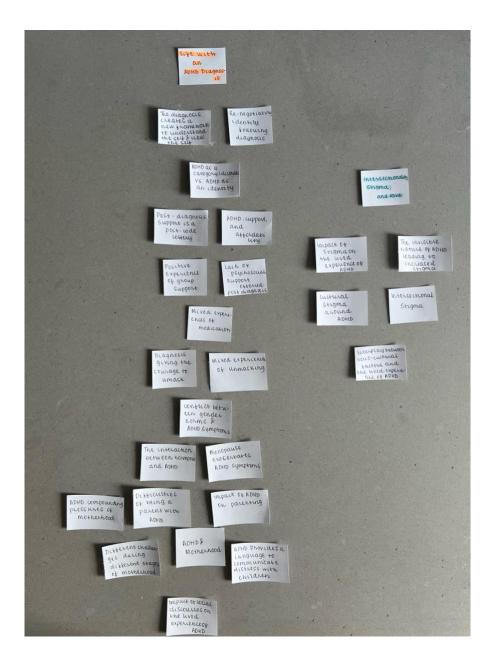
Distress	A participant indicates that they are experiencing a high level of emotional distress OR     Exhibiting behaviours suggestive that the interview discussion is too stressful such as uncontrolled crying, shaking, etc.
Stage 1: Response	<ul> <li>Pause the interview.</li> <li>Offer immediate support.</li> <li>Assess mental state:</li> <li>Tell me what thoughts you are having?</li> <li>Tell me what you are feeling right now?</li> <li>Do you feel that you can go about your day?</li> <li>Do you feel safe?</li> </ul>
Review	<ul> <li>If the participant feels able to carry on → resume interview/discussion.</li> <li>If the participant is unable to carry on → go to stage 2.</li> </ul>
Stage 2: Response	Stop the interview.  Encourage the participant to contact their GP OR  Offer, with participant consent, for the researcher to do so OR  With participant consent, contact their GP for further advice/support
Follow-Up	Follow participant up with courtesy call (if participant consents) OR     Encourage the participant to call either if he/she experiences increased distress in the hours/days following the interview.

### **Appendix L: Coded Transcript**

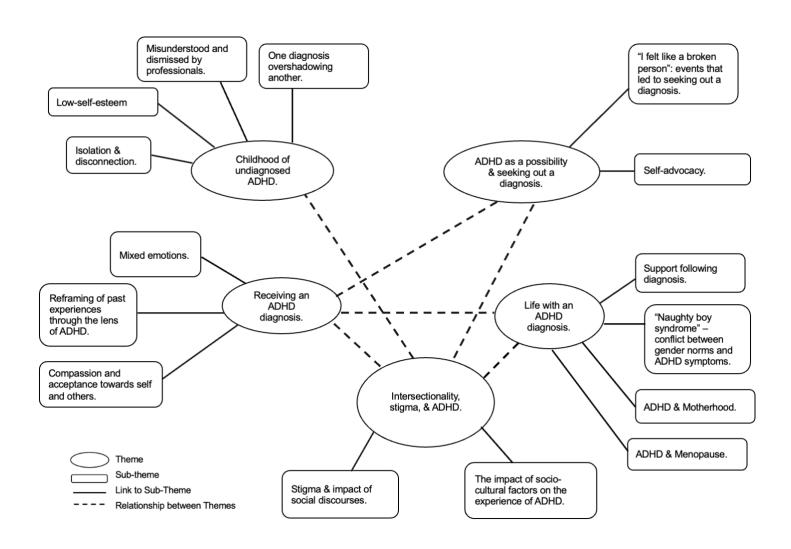
"Drawn to ADHD" and Interview 8 (Emma) "familar" - feeling seen and understood by ADHD? A connection. INTERVIEWER 167 Experiencing distress And I guess there's kind of leads me well into my next question, which is almost what drove you to seek 168 from a young age psychosomatic the diagnosis? Because from what I'm hearing, it wasn't that ADHD appeared one day, but it sounds like 169 manifestation of distress there was a process that led you to ADHD. 170 - body is communicating distress. "A lot" of tension headaches = in PARTICIPANT 8 Growing up with 171 significant distress **ADHD** undiagnosed -172 Yeah, it's actually and really, really interesting. And because I kind of stumbled on ADHD through my Worry/anxiety - one distress diagnosis experienced as career and reflecting back now, I wonder how much of it was drawn to because of how my brain worked 173 overshadowing another a consequence and how it interests me in how familiar it was. And so, the first kind of first thing as a child, I was extremely, of not having a diagnosis. Feeling unsupported, let extremely shy. I was first seen by kind of somebody for mental health or worry when I was seven and I've 175 down, and dismissed by still got the letter and it's so interesting now because it's basically ADHD. I was getting a lot of tension 176 GPs and doctors. Growing up with 177 headaches which of course, which I know is from really trying to do better in the classroom but not being ADHD Lived experience being undiagnosed able to take in information. And I was academically really clever as a child and it dropped off a bit as I got 178 mediated by social norms misunderstood for women and girls (e.g., and dismissed older but as a child, I was academically clever, and I think I had this real real need to please people and 179 people pleasing and doing by professionals 180 do well. And so that kind of manifested in me being a very anxious at school and I'd go really red, and I Being reprimanded/getting 181 could be like really high, proactive, and impulsive but that would always lead me to being more kind of red 'negative feedback' for Growing up with 182 and I'd get negative feedback. So, I was like oh this is a bad thing, and you need to not. But then I would manifestations of ADHD **ADHD** symptoms be anxious about absolutely everything, so I went to the doctor and she literally - I've still got the letter 183 undiagnosed one diagnosis "Oh, this is a bad thing" she wrote on it "[participants name] will likely suffer with psychosomatic symptoms for the rest of her life". over shadowing and "you need to not" another insight into her internal INTERVIEWER 185 monologue. Self-criticism. Meaning making of past experience through the 11 lens of ADHD - "it's basically ADHD"

### **Appendix M: Initial Codes Clustered Together**





### **Appendix N: Initial Theme Map Generated**



### **Appendix O: Sample of Theme Description**

### Theme 1: Growing up with ADHD undiagnosed

Description: this theme captures participants early childhood and adolescent experiences of growing up with undiagnosed ADHD. The codes capture participants' experience of low self-esteem, being misunderstood and dismissed by professionals, and the process of one diagnosis overshadowing the underlying ADHD diagnosis.

	p.2	L38-39
Zara	p.2	L184-185
Emma	p.26	L437-438
	p.17	L278-279
	p.11	L175-178
	p.11	L183-189
	p.28	L476-478
	p.10	L184-186
Ella	p.3	L52-54
	p.5	L105-107
Sophia	p.3	L70-72
	p.3	L54-55
	p.3	L65-66
Daphne	p.8	L163-165
	p.14	L330-331
Ava	p.3	L93-95
	p.12	L222-224

PART B: Publishable Paper: "I felt like a broken person": The Experiences Of Women Navigating A Late ADHD Diagnosis In The UK.

This article was prepared with the intention of submission for publication in the *Journal* of *Attention Disorders*. The submission guidelines are presented in the Appendix.

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# PART C: Combined Process Report & Case Study:

Being With Versus Doing To: Integrating Person-Centred Approaches & Psychodynamic Approaches to Formulate Avoidance. This content has been removed for copyright protection/confidentiality reasons