Self-view and Relationships Following Prescription of ADHD Medication in Childhood

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ABSTRACT

Background: Attention Deficit Hyperactivity Disorder (ADHD) is one of the most widely diagnosed psychological presentations in childhood. Medication is commonly prescribed, however our understanding of the experiences of those who take medication in childhood is limited, especially in considering longitudinal, systemic, and contextual factors.

Aims: This study aimed to explore the experiences of young people following prescription of medication for ADHD through the eyes of their adult selves, considering longitudinal narratives and outcomes. Specifically, the aim was to investigate experiences around the developing self-view, authenticity, and social relationships, and situate these in a wider sociocultural context.

Methods: Eleven semi-structured interviews were conducted with participants from across the UK who were diagnosed and prescribed medication for ADHD in their childhood. Data was analysed using Reflexive Thematic Analysis.

Results: Findings were varied and enabled an exploration of different journeys and outcomes from childhood to adulthood. For some, medication hindered or promoted an authentic and integrated self-view based on how the ‘true’ self was perceived. Social relationships were hindered where medication caused a reduced desire and ability to socialise. Stigma, othering, and feelings of difference were universally reported, affecting individuals’ wellbeing. Many described a lack of agency in treatment-related decisions. A minority received academic support in school, and none remembered being offered psychosocial support for ADHD. Medication was seen as helpful for academic achievement by many; however, some reported no benefits, and adverse effects were also significant.

Conclusions: Findings suggest that a unidimensional medication-based treatment may not be sufficient to meet the needs of all young people diagnosed with ADHD. Young people need to be understood holistically and supported across contexts, beyond a focus on symptom reduction. Systemic changes are needed across education and healthcare, along with a shift in public perspectives through participatory action.

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1. INTRODUCTION

1.1. Chapter Overview

The first part of the introduction examines Attention Deficit Hyperactivity Disorder (ADHD) and situates this in the current global and United Kingdom (UK) contexts through a narrative review of the literature. Terminology, history, understandings and debates surrounding ADHD are explored, along with guidelines and treatments in the UK. Part two comprises of a scoping literature review and identification of gaps in research, informing the study's aims and research questions.

1.2. Reflexivity: Researcher's Position

Self-reflexivity refers to how the researcher's values, experiences and social identities have shaped the research and how, in turn, the research has influenced the researcher personally and professionally (Willig, 2001). The former will be considered in this section, whereas the latter will be addressed in the Discussion chapter.

A reflective journal was used to build awareness of my values in relation to ADHD and ADHD medication. Here I continued to add thoughts in relation to my position, new questions and dilemmas, and elements of my intersectional identity which felt relevant to the current research. I invite the reader to consider the researcher's influence on the research process by sharing a few salient points of self-reflexivity below.

The researcher is a white woman from an Eastern European background, who moved to the UK for her undergraduate studies. My interest in ADHD developed from my experiences of working with children and young people in various settings, in a special educational needs setting, a Looked After Children's home, primary and secondary schools and Child and Adolescent Mental Health Services (CAMHS). In all these different settings, I met children and young people diagnosed with ADHD of varying severity, with some children taking medication. It was not until further learning and reading as part of the Clinical Psychology Doctorate that I became more interested in psychotropic medication in childhood. As a Trainee Clinical

Psychologist at the University of East London (UEL) I have been exposed to critical social-constructionist ideas which have influenced my thinking, and I aim to adopt a curious and questioning stance in the current study. I understand ADHD as an evolving construct and I aim to view ADHD and ADHD medication in a wider context, beyond individual differences in brain and biology. My position is therefore most closely aligned with contextual understandings, as well as the wider neurodiversity movement.

I do not have a diagnosis of ADHD, and I have not taken ADHD medication. Whilst this poses a drawback through a missing layer of personal experience, it can also yield the benefits of being able to consider multiple positions, views and experiences people might hold in relation to ADHD and ADHD medication in childhood. I hold strong beliefs about the importance of amplifying marginalised and oppressed voices and attending to how ‘power’ operates in systems. I place a lot of value on lived experience, and I believe it is just as essential for research and practice as professional experience is.

In this study, I will therefore aim to present and interpret the multi-faceted lens through which ADHD can be viewed. In doing so, my aim is to engage meaningfully with the ADHD discourse and to amplify the voices of those with lived experiences. Specifically, this study will consider the impact of ADHD medication-taking on young people’s sense of self and relationships, with the aim of improving future avenues for support.

1.3. Definition and Diagnostic Criteria of ADHD

Attention Deficit Hyperactivity Disorder (ADHD) has become one of the most commonly diagnosed psychological presentations in childhood, and a common reason for referral to mental health services (Polanczyk et al., 2014; Singh, 2011). The Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM–5; American Psychiatric Association, 2013) defines ADHD as a neurodevelopmental disorder, specifying it as “a behavioural syndrome characterized by the persistent presence of six or more symptoms involving inattention and/or impulsivity and hyperactivity” (Centers for Disease Control and Prevention; CDC, 2022b).

For children and young people up to the age of sixteen to meet criteria for being diagnosed with ADHD, 6 out of 9 symptoms of either inattention, hyperactivity, or both, need to be present for at least 6 months. Inattentive symptoms include “Often fails to give close attention to details or makes careless mistakes”. Hyperactivity and impulsivity symptoms include “Often talks excessively” and “Often unable to play or take part in leisure activities quietly.” (CDC, 2022b). A notable change in the DSM-5 is the increase of the age of onset criterion from the age of 7 to 12, allowing for symptoms to be accounted for later in childhood. These symptoms need to “interfere with, or reduce the quality of, social, school, or work functioning” and children need to fit these criteria in at least two settings (CDC, 2022b). Based on the identified symptoms, three kinds of diagnoses are given – combined presentation, predominantly inattentive presentation, and predominantly hyperactive-impulsive presentation. Challenges in the changing and subjective nature of the diagnostic criteria have been highlighted, such as the word “often” being a part of each symptom’s description, and words such as “excessively” also being open to interpretation (te Meerman et al., 2022).

1.4. Outcomes Associated with ADHD

Outcomes related to ADHD have been widely studied across the lifespan. Research has shown lower academic outcomes despite many people with the diagnosis having the same level of intellectual functioning as their peers (Frazier et al., 2007; Mcgee et al., 1991; Rodriguez et al., 2007; Weyandt et al., 2017), and lower occupational attainment (Altszuler et al., 2016; Kuriyan et al., 2013). Difficulties in social contexts have also been reported (McConaughy et al., 2011), along with a negative effect of ADHD symptoms on peer relationships (Cordier et al., 2010), and higher levels of peer neglect, victimisation and relational aggression (Bacchini et al., 2008; Houck et al., 2011). Relational difficulties are said to often persist into adulthood (Bunford et al., 2018).

Rates of co-morbid diagnoses are very high for young people diagnosed with ADHD, especially diagnoses of depression and anxiety (Efron et al., 2016), and higher rates of substance use disorders in adulthood (Wilens et al., 2011). Gascon et al. (2022) report that only one in five individuals show ADHD without any co-morbid condition.

However, whilst some studies report ADHD itself causes other disorders, this is debated, considering the experiences of relational difficulties of children with ADHD (e.g. stigma and othering) are likely to lead to understandable responses which might then be diagnosed as other disorders (Konstenius et al., 2017; Brown et al., 2017). Further contextual considerations will be discussed in the sections that follow.

1.5. History of ADHD

1.5.1. Early History

A shift from religious and moral discourse in the late 18th century gave rise to the earliest identified examples of what we know as ADHD today being discussed in scientific and medical literature. Notably, medical textbooks by Weikard (1775; in Barkley & Peters, 2012) and Crichton (1798; in Lange et al., 2010) describe abnormal degrees of inattention and overactivity, with Weikard citing “biological fibres” as the root cause of the issue. These texts paved the way for 19th century medical explanations of ADHD, such as “the nervous child”, “mental instability”, “unstable nervous system” and “simple hyperexcitability” (Martinez-Badía & Martinez-Raga, 2015). Heinrich Hoffman’s stories of ‘Fidgety Phillip’ and ‘Johnny Look-in-the-Air’, written in the late 19th century, are also commonly cited as the first descriptions of a hyperactive child (Lange et al., 2010).

1.5.2. The Birth of ADHD

Sir George Frederick Still, the first Professor of Paediatrics in England, provided the first clinical description of the constellation of symptoms we would today probably label as ADHD. In 1902, Still delivered the Goulstonian lectures, where he described a group of 43 children who had what he labelled “abnormal defect of moral control” (Lange et al., 2010). The children Still described were resistant to discipline, defiant, excessively emotional, or passionate, exhibited problems with concentration and sustained attention, and could not learn from the consequences of their actions. The Goulstonian lectures are often considered to be the starting point of ADHD history (Barkley, 2006).

1.5.3. ADHD in the 20th Century

Following Still's seminal lectures, there was an exponential increase in ADHD being discussed through a medical lens (Barkley, 2015). When the encephalitis lethargica epidemic spread around the world between 1917 and 1928, further connections between brain and behaviour were established. Many of the affected children who survived showed lasting behavioural and personality changes, displaying what was termed 'postencephalitic behaviour disorder' (Rafalovich, 2004). This strengthened the assumption of a causal connection between brain damage and the symptoms of hyperactivity and distractibility. In 1932, German physicians Kramer and Pollnow reported on a "Hyperkinetic Disease of Infancy'' (Neumärker, 2005). This marked the separation of what we label as ADHD today from other similar 'diseases'.

The biological basis for hyperactivity was further promoted through the work of Strauss and Lentinen in 1947 and Strauss and Kephart in 1955 on what they termed "Minimal Brain Disorder". In the following decade, disagreements between theorists arose on whether behavioural symptoms were a result of functional disturbances or due to damage to the brain, resulting in establishing "Minimal Brain Dysfunction" as a disorder (Lange et al., 2010). Through further criticisms of the empirical evidence base, "Hyperkinetic Reaction of Childhood" became the diagnosis which for the first time entered the DSM-II (APA, 1968).

Alongside medical conceptualisations, however, there were significant environmental and psychodynamic understandings of ADHD in this same time period. Environmental perspectives posited numerous aetiologies, including: the encephalitis lethargica outbreak (Paterson & Spence, 1921), the phenomenon of premature birth (Shirley, 1939 in Chapieski & Evankovich, 1997), food additives (Feingold, 1975) and exposure to media imagery (Rutstein, 1974). Psychodynamic aetiological emphasis was focussed on the degree to which children showed healthy psycho-social reciprocity with their environment, rather than on neurological dysfunction (Klein, 1963). Behavioural symptoms were depicted as secondary to emotional states, which were "psychic manifestations of a basic phase of human development" (Rafalovich, 2004, p. 51). In the second half of the 20th century, understandings of a neurological basis and neurological treatment shifted the discourse away from social and environmental aetiologies.

ADHD continued to be reconceptualised throughout further editions of the DSM. A focus towards inattention rather than hyperactivity caused a re-labelling to ‘Attention Deficit Disorder’ in the DSM-III (APA, 1980), and further debates shifted the name again, to ‘Attention Deficit Hyperactivity Disorder’ in the DSM-IV (APA, 1994). Ongoing debates and discussions continue to broaden the criteria for ADHD diagnosis. More recently, the ADHD concept was widened to include the diagnosis of ADHD in adulthood, which has been recognised by NICE since 2008 (Matheson et al., 2013). The current study will focus on ADHD diagnosed in childhood, rather than discussing adult ADHD.

1.6. History of ADHD Pharmaceuticals

Hyperactivity was first treated with a medical intervention in 1937 by Charles Bradley, who discovered by chance that Benzedrine, a stimulant drug, caused “the most spectacular change in behaviour” (Bradley, 1937; Lange et al., 2010). Bradley was examining structural brain abnormalities in children using pneumoencephalograms, which caused his patients severe headaches. In an attempt to treat the headaches, he administered Benzedrine, “the most potent stimulant available at the time’’ (Gross, 1995). Benzedrine had a negligible effect on the headaches but had significant effects on half of the children’s behaviour and school performance (Bradley 1937, p. 582).

“[The children] were more interested in their work and performed it more quickly and accurately…[They] became emotionally subdued without, however, losing interest in their surroundings” (Bradley 1937, p. 580)

However, for the next 25 years Bradley’s findings were not influential in the field, possibly because of the prominence of psychoanalysis, and the assumption that behavioural disorders do not have a biological basis (Rafalovich, 2004). It wasn’t until 1944, when methylphenidate was first synthesized and marketed as Ritalin, that prescribing medication for hyperactivity gradually became the norm. Methylphenidate, originally used in the treatment of “chronic fatigue, lethargy, depressive states, disturbed senile behaviour and psychosis” (Leonard et al., 2004, p. 151) became the most widely prescribed psychostimulant and first-line treatment for ADHD (Lange et al., 2010).

1.7. Current Understandings of ADHD

Multiple understandings of the aetiology of ADHD exist simultaneously in contemporary discourse. Clinical psychology as a field appears to be positioned at the intersection of the understandings below (Rafalovich, 2004). It is therefore useful to consider these in turn.

1.7.1. Biological Understandings of ADHD

The way ADHD is understood and conceptualised in mental health services is underpinned by predominantly biological, developmental, and epidemiological research (Biederman, 2005; Faraone et al., 2021).

Research from the 20th century onwards has focussed on finding and treating the cause for ADHD through a focus on neurochemicals, and differences in brain function, size, and structure. One of the most widely cited theories of ADHD, The Executive Dysfunction Theory, arose from neuroimaging study results showing a slower rate of development of the frontal regions of the brain of young people with ADHD as compared to those who do not have ADHD (Barkley, 1997; Willcutt et al., 2005). The theory suggests that ADHD symptoms arise from a deficit in executive functioning, however, research is divided on whether the differences observed are due to brain abnormalities or a maturational lag. Longitudinal research has shown that the brains of those with ADHD generally follow a normal developmental pattern, although they might develop at a slower rate of approximately two to three years behind their non-ADHD peers (Shaw et al., 2007).

A range of further neurobiological studies have been suggested to explain the cause of ADHD symptoms, with a focus on deficits in various areas of functioning (Barkley, 2002). This includes the State Regulation Model (Sergeant & van der Meere, 1990), the Dynamic Developmental Theory of ADHD (Sagvolden et al., 2005) and the Delay Aversion & Dual Pathways Theories (Sonuga-Barke et al., 1992).

More recently, the Reward Deficiency Syndrome, otherwise known as the Dopamine Hypothesis, has been widely cited as the cause for ADHD (Blum et al., 2008). Dopamine is a key chemical for sustained attention, working memory and motivational processes which acts as a transmitter between brain cells by combining with specialised receptors on nerve cells. The most widely prescribed ADHD drug, Ritalin, works by increasing the levels of dopamine that bind to the receptors. Research suggested that ADHD is the result of fundamental abnormalities in dopamine transmission, and Ritalin therefore works especially well for those with ADHD (Blum et al., 2008). However, further research by Del Campo et al. (2013) challenged this hypothesis, reporting that dopamine receptors in the relevant brain areas were similar for those with and without diagnosis of ADHD, and Ritalin improved sustained attention and performance similarly in both groups.

There has also been a surge in ADHD genetic and hereditability research in the past two decades, with new studies aiming to find combinations of genes responsible for ADHD (Grimm et al., 2020; Brikell et al., 2021). An average estimate of hereditability of ADHD was shown to be 76% across 20 twin studies, and adoption studies suggest ADHD has a genetic component (Faraone et al., 2005; Thapar et al., 2013). However, no design to date has reliably separated inheritance due to shared environmental influences from purely genetic influences (G. Russell et al., 2014). Specific genetic risk factors identified tend to be rare and have small effect sizes, have been shown to be present across the whole population to a varying extent, and often increase risk not just for ADHD but a variety of other diagnoses (Faraone et al., 2021; Maher, 2008; Thapar et al., 2013).

The above biomedical discourse highlights the changing nature of the field, with hypotheses about the causes of ADHD in constant flux. The main critique of biomedical understandings is their focus on individual deficits, neglecting the role of environmental distress and wider social and political context, which can lead to a two-dimensional understanding of ADHD (Ruiz, 2014; Smith, 2014).

1.7.2. Contextual Understandings of ADHD

1.7.2.1. ADHD, Social Class, and Deprivation

Diagnosis and medication rates of ADHD are higher in areas with lower average socioeconomic status (SES) (CDC, 2024; McKechnie et al., 2023). Research indicates that “ADHD was associated with a range of indicators of social and economic disadvantage including poverty, housing tenure, maternal education, income, lone parenthood and younger motherhood" (A. E. Russell et al., 2015; G. Russell et al., 2014). It is important to note that longitudinal findings from the Millenium Cohort Study found no evidence for ADHD to be a causal effect for low SES, concluding that the aetiology of ADHD appears to be influenced by SES (G. Russell et al., 2014). Health inequality models see ADHD as an effect of socioeconomic disadvantage, as children in more deprived areas will have a higher likelihood of perinatal, prenatal or childhood exposure to risk factors (Kim et al., 2020; Najman et al., 2004). Risk factors may include tobacco smoke and alcohol exposure in utero (Han et al., 2015; Linnet et al., 2005), a less nutritious diet (McCann et al., 2007) and higher rates of family conflict and parenting difficulties growing up (Deault, 2010; Johnston & Mash, 2001)

This raises questions about power and privilege, and some children's behaviours arising as an environmental response in disadvantaged social situations. It is particularly pertinent to consider this in the current climate of austerity and growing inequalities (Lee et al., 2023; Piera Pi-Sunyer et al., 2023).

1.7.2.2. ADHD and Family Factors

Theoretical models of developmental psychopathology emphasise the dynamic bidirectional influences between children and their environment and family, highlighting that for some, a high-risk family environment may function as the primary determinant of the ADHD symptoms (Johnston & Mash, 2001). A child's family environment can influence their development of self-regulation and behaviour through multiple pathways. Maltreatment, neglect, parental separation, loss of attachment figures, and a turbulent home environment can affect the development of children's regulatory processes, attention processes and executive function skills (Humphreys & Zeanah, 2015; van der Bij et al., 2020, Auersperg et al., 2019; Pallini et al., 2019, Romano et al., 2006, Strathearn et al., 2020). Parental interactions, warmth, and exposure to media at a young age has further been hypothesized to impact on self-regulation and attention development (Beyens et al., 2018). Breaux & Harvey (2019) highlight that the role of parenting patterns and broader familial issues should not be neglected, as identifying family support needs and offering early intervention can in turn lead to a reduction in children's ADHD symptoms and increased positive outcomes.

1.7.2.3. ADHD and Trauma

Research in the past 20 years has found evidence for the relationship between trauma and ADHD (Foltz et al., 2013; Fuller-Thomson et al., 2014; Sanderud et al., 2016; Song, 2023; Szymanski et al., 2014). Children who have been through traumatic life events are more likely to exhibit behaviours corresponding to an ADHD profile (Ford et al., 1999; Szymanski et al., 2014). For example, Carroll et al. (2012) show that emotional abuse exposure was associated with an eleven times heightened risk for ADHD diagnosis, and Bücker et al. (2012) report that children who were exposed to early trauma showed significant impairments in attention relative to controls. Linares et al., (2013) found that 55% of maltreated children in foster placements received an ADHD diagnosis. A recent systematic review reports high rates of comorbidity between ADHD and trauma across the world, and evidence of longitudinal research showing that early exposure to maltreatment is a risk factor for ADHD diagnosis; although more research is required on this causal effect (Craig et al., 2020; González et al., 2019).

Considering trauma and exposure to maltreatment as a possible contextual factor of ADHD is key, as solely locating normal responses to abnormal circumstances as difficulties in the child can have lasting consequences on children's mental health and sense of self, and worse outcomes and quality of life in adulthood (Gascon et al., 2022; Rucklidge et al., 2006).

1.7.2.4. ADHD as a Social Construct

Timimi (2010) argues that ADHD behaviours might be linked to increased distress in childhood in the context of industrial capitalism, including changes in adults' working patterns and views around parenting, individualism and consumerism, technological advances and globalisation, and increasing expectations on children to be 'mini adults' and to achieve academically (Messenger et al., 2007). These factors, together with increasingly under-resourced school-, health- and support systems can result in behavioural responses from children, such as inattention and hyperactivity (Timimi & Radcliffe, 2005). When these responses are diagnosed as ADHD, they might become located as problem behaviours to be resolved within the child, rather than within the systems and society around them (Beljan et al., 2006; Timimi, 2015; Timimi et al., 2004). Consequently, Horton-Salway and Davies (2018) argue that the ADHD diagnostic category may mask wider societal issues.

In the education system, this can lead to systemic pressures to seek diagnoses for children who are harder to manage, as only through this are funding and resources made available for adequate support (Simoni & Drentea, 2016). Western education systems value and expect sitting still, watching, listening and writing, which are mentalistic ways of learning (i.e. separating the mind from the body) (Macedonia, 2019). Higher and higher standards for productivity and performance in these systems can lead to what some researchers term the ‘medicalisation of underperformance’ where children are not able to meet these demands (Gascon et al., 2022). A ‘relative age effect’ is also reported by research, meaning that younger children in a school class are more likely to be diagnosed and given medication for ADHD than their older peers, raising questions around whether some age-appropriate behaviours might be interpreted as a disorder (Holland & Sayal, 2019; Koutsoklenis et al., 2020).

Critical approaches also examine how gender biases punctuate the construction of ADHD as a diagnostic label. Societal gender expectations towards boys and girls tend to differ, with boys being socialised to be more assertive and active and less emotionally expressive than girls (Garcia, 2019). Considering ADHD as an expression of distress, contextual understandings discuss how boys’ distress might be expressed in higher rates as externalising behaviour (anger and aggression) whereas girls’ distress is often internalised (anxiety and depression), leading to these socialised expressions of distress attracting different diagnoses (Copeland & Hess, 1995; Timimi, 2015). Thus the ADHD diagnosis can be seen as one way to medicalise boys’ expressions of distress in particular (e.g. 11.6% of boys vs 5.1% of girls diagnosed in the USA; Bergey et al., 2022).

The validity and reliability of ADHD as a diagnostic category is questioned by some researchers, citing a lack of evidence-based measures for diagnosing, biased sampling in research, inconsistency through time, an over-reliance on small group differences, and no particular pattern of brain activity being necessary or sufficient for an ADHD classification (Gascon et al., 2022; Mills, 2022; Moncrieff & Timimi, 2013; te Meerman et al., 2022; Timimi, 2017; Timimi & Taylor, 2004).

Critical psychiatric and psychosocial ways of understanding ADHD therefore aim to consider explanations of the ADHD cluster of symptoms in a wider context. The main critique of understandings of ADHD as a social construct are linked to its challenges of the ADHD diagnostic category, as diagnosis is seen by many to be an affirmation and validation of the very real individual difficulties experienced, and it is currently the only way for children to access the support they require (Gascon et al., 2022; S. Jones & Hesse, 2018).

1.7.3. The Neurodiversity Perspective

Emerging from the social model of disability and the autism rights movement, the neurodiversity perspective regards ADHD as part of normal human cognitive variation in the population. This perspective argues that we as a society have ideas about how ‘typical’ brains work, and individuals with ADHD are ‘wired’ differently rather than wrongly, in the context of biodiversity. The neurodiversity movement, although highlighting ‘neuro’ differences, is aiming to position itself as a challenge to the medical model, through a move away from viewing differences as neuropathology, disordered or abnormal. There is a focus on the celebration of diversity, without forgetting the need for accessible systems and environments to support those who are neurodiverse. The neurodiversity movement builds on the social model of disability and the politics of minority groups, with advocates arguing for the recognition and support of both strengths and weaknesses that neurodiverse individuals have (Hendrickx, 2010; Jensen et al., 1997).

ADHD through a neurodiversity lens focuses on the connections between ADHD, creativity and divergent thinking as well as exploring episodes of ‘hyperfocus’ (Healey & Rucklidge, 2006; Hupfeld et al., 2019; Taylor et al., 2020). Dodson’s (2024) theory of the ‘interest-based nervous system’ posits that people with ADHD pay ‘too much attention to everything’, and ADHD is therefore a difference in inconsistent attention driven by individual interests, rather than a deficit (Bertilsdotter

Rosqvist et al., 2023; Dodson, 2024). Thomas (2024) discusses critical psychology's role in challenging the pathologisation of difference, and combatting ableism.

The neurodiversity movement has gained traction and growing popularity in the past two decades. It has generally been met with approval from those with lived experience, although some critique has been expressed amongst disability advocates around the risk of downplaying the suffering experienced by groups of neurodiverse people, and the dangers of focussing on strengths rather than support needs.

1.7.4. The Bio-Psycho-Social Model

A bio-psycho-social understanding of ADHD aims to take a holistic approach in thinking about individual biological factors in the context of young people's environment, psychological and social factors affecting them. This integrative model is commonly cited as the current 'gold standard' for understanding and treating ADHD and is endorsed by the British Psychological Society (BPS) and other organisations (Adler, 2009). However, current uses of this model might position psychological and social factors as secondary elements in whether biological predispositions are activated (Richards, 2013). For example, Overmeyer et al. (1999) found that when clinicians were told that a child has an ADHD diagnosis, they were less likely to notice psychosocial issues facing the child and less likely to ask about physical abuse. To achieve a holistic, integrative bio-psycho-social model, there is a need to consider all three elements equally.

1.8. Global and UK Context

1.8.1. Global Context of ADHD

The diagnosis of ADHD was originally devised in the United States (US), where it remains the most highly diagnosed (11.3% amongst children aged 5-17; CDC, 2024) and medicated (between 38%-81% of diagnosed children, depending on the state; CDC, 2022a) childhood mental health condition. In the past 30 years, however, increasingly attention has been drawn to the diagnosis and treatment of ADHD globally. Smith (2017) discusses how Western individualised understandings of distress are becoming more widespread globally through diagnostic tools such as the DSM and the growth of pharmaceutical companies. Large variations have been documented between how ADHD is perceived and treated globally. For example, in Iceland children are more than ten times as likely to be prescribed medication for ADHD than those in Finland, where ADHD is viewed as ‘an everyday educational challenge’ rather than a medical disorder (Jahnukainen, 2010; Smith, 2017). With medical information being more widely available than ever, there is also a degree of distortion present in information shared online and through other media domains (Horton-Salway & Davies, 2018; Ponnou et al., 2020).

Bergey (2018), and authors across 16 countries discuss ADHD’s rise globally. They argue that ADHD does not have a fixed ontology worldwide, and is made up of “…fluid, heterogeneous elements” (p. 378). ADHD diagnosis and treatment is mediated by national health systems worldwide, as well as the public presence of advocacy groups and attitudes towards parenting and children’s development, professionals’ training models and funding mechanisms (Smith, 2017). With increasing industrialisation and growing pressures on performance and achievement, ADHD diagnosis and treatment are expected to become more similar to the US picture globally (Gascon et al., 2022; Hinshaw & Scheffler, 2014).

1.8.2. UK Context of ADHD

In the United Kingdom (UK), the picture of ADHD includes a strong biomedical investment, alongside a degree of public scepticism regarding mental health conditions and treatments in general (Singh, 2018). There is a growing focus on prevention and early identification of ADHD, with researchers investigating ‘prodromal’ ADHD in baby and toddler groups (Geddes, 2015). A notable difference from the US view of ADHD is the focus on conduct problems, with ADHD being seen as an “anger problem” in children before being seen as an academic problem (Singh, 2011; Singh, 2018; Speerforck et al., 2019).

In the UK, clinical practice is guided by the National Institute for Health and Care Excellence (NICE), which uses both the DSM-5 (APA, 2013) and ICD-11 (World

Health Organization, 2019) diagnostic criteria of ADHD and categorises ADHD along a dimension of 'mild', 'moderate' and 'severe'. Using DSM-5, NICE estimate that 3-9% of UK schoolchildren meet ADHD diagnostic criteria (NICE, 2018). Diagnosis and treatment is available through the National Health Service (NHS), however multiple-year-long waiting lists drive demand for private diagnosis and treatment (Peasgood et al., 2021). Advocacy is steadily growing and happens largely through third sector charitable and non-profit organisations.

Important issues in the UK context are rooted in social class inequalities and stigma. In deprived areas of the UK, poverty and lack of school resources lead to lower rates of support for special educational needs (Hire et al., 2015). Large scale research has also found that ADHD diagnosis and medication prescription rates are approximately two times higher in the most deprived quintile compared to the least deprived quintile (McKechnie et al., 2023).

1.8.3. The Role of Pharmaceutical Companies

In the United Kingdom pharmaceutical companies sponsor a considerable amount of biological research and are a key player in the economic sphere (Singh, 2018). Collaboration between pharmaceutical companies and healthcare professionals is seen by many as boosting innovation and efficiency in healthcare, however it can also create a potential for conflicts of interest that may bias research and decisions about treatment (Mulinari & Ozieranski, 2018). An independent audit of drug company influence within the NHS showed that training events (51%) and direct talks (40%) by pharmaceutical companies were common (Harrop et al., 2019). Targeted engagements with physicians have been shown to significantly influence prescribing practices (Soumerai & Avorn, 1990).

Pharmaceutical companies in the UK need to adhere to restrictions on direct-to-consumer advertising, but there are ways in which they have established themselves in the lives of families, for example through the availability of ADHD information resources (Singh, 2018). Research by Mitchell & Read (2012) also found that drug company funded websites were significantly more likely to recommend medication over psychosocial treatment options. In the context of limited NHS resources, clinicians, educators, and parents are drawn to find financial, practical, and emotional support in pharmaceutical industry partners. Singh (2018) advises that we need to acknowledge the role of the industry in ADHD, whist taking measures to indicate where this role causes the most potential harm and minimising this harm.

1.9. Guidelines and Treatments

1.9.1. Psychosocial Interventions

NICE guidelines recommend parenting interventions as the first line of treatment before direct pharmacological treatment is indicated for children (NICE, 2018). School and educational support is also highlighted, although no specific recommendations are provided. The only other non-pharmacological intervention in the official NICE guidelines is Cognitive Behavioural Therapy (CBT) for the children who have benefitted from medication, but their symptoms are still causing difficulties.

There is a lack of evidence-based psychosocial and school interventions offered to children with ADHD and their families, despite evidence showing the efficacy of these interventions is similar to medication, with medium to large effects on ADHD symptoms and associated functional impairments (DuPaul et al., 2012; Evans et al., 2018; Fabiano et al., 2009). For example, Danielson et al. (2018) reported that only 31% of families received behavioural parent training, compared to 91% receiving medication. In contrast to prevailing models of care emphasising the reduction of symptoms, a life course model proposed by Evans et al. (2014) focusses on long-term outcomes, highlighting the need for early, evidence-based psychosocial support for young people across multiple contexts.

The foundation for psychosocial treatments for many years has been behavioural treatment, focussing on teaching parents and educators ways of supporting children and creating a helpful environment in which children with ADHD can perform at the best of their abilities (e.g. Behavioural Parent Training; Chronis et al., 2004). More recently, interventions aimed at adolescents (Evans et al., 2016; Langberg et al., 2012), motivational interviewing techniques (Sibley et al., 2016), and cognitive-behavioural approaches (Boyer et al., 2015; Sprich et al., 2016; Vidal et al., 2015), have also gained traction. Furthermore, family therapy approaches have been further studied and improved for supporting adolescents with ADHD (Fabiano et al., 2016; Sibley et al., 2016). Timimi (2017) suggests the Relational Awareness Programme (RAP) as an intervention to support children who match the ADHD profile. RAP works by shifting the focus from controlling children's behaviour to building emotional connections. Similarly, advancements in mentalisation-based approaches have been shown as effective for supporting adults around the child to understand their internal world, beyond a focus on changing behaviours (Conway et al., 2019; Midgley et al., 2017). Psychosocial approaches have overall been shown to improve functioning and wellbeing in the long-term, beyond the reduction of core symptoms of inattention and hyperactivity (DuPaul et al., 2020; Evans et al., 2018).

1.9.2. Pharmacological Interventions

Whilst psychosocial treatments have an established evidence-base and have gained some traction in the past two decades (Moore et al., 2016), pharmacological interventions are by far the most widely used treatment for ADHD. The use of medication for ADHD has expanded exponentially, by 800% between 1995 and 2015 (Renoux et al., 2016). In the UK, about 60% of the children diagnosed with ADHD take medication, 81% of whom are boys (McKechnie et al., 2023). Psychostimulants, such as methylphenidate (e.g. brand names Ritalin and Concerta) or amphetamines (e.g. Vyvanse) have immediate effects. Non-stimulants such as atomoxetine (e.g. brand name Strattera) take a few weeks to build up – these medications are mostly used when the desired effect through psychostimulants has not been achieved.

The effects of ADHD medication are described by the NHS as "helping with hyperactivity and impulsive behaviour, and allowing children to concentrate better" (NHS, 2021). Medication has been shown to be effective for managing ADHD symptoms, with efficacy studies showing that 70-85% of children report a decrease in core symptoms of ADHD (Faraone, Biederman, Spencer, et al., 2006; Findling et al., 2011). Meijer et al. (2009) caution that there is a lack of knowledge on the long-term use of medication for ADHD. The Multimodal Treatment Study of ADHD (MTA) is the largest ever long-term controlled trial of ADHD medication, involving 500 participants (Swanson & Volkow, 2009). This showed that ADHD medication ceased to have a therapeutic effect after 3 years, recommending that this is used for a time-limited period. Children can also become tolerant to stimulants' effects, and this results in gradually increasing doses being prescribed (Cortese, 2023; Timimi, 2004). Adverse effects can considerably impact on children and young people, including growth retardation, decreased appetite, insomnia, changes in blood pressure and heart rate, headaches, irritability and suicidal thoughts (NHS, 2018; Specialist Pharmacy Service, 2023).

Furthermore, research shows that despite engagement with medication treatment, many have poorer outcomes in adulthood compared to their peers (Efron et al., 2016; Kuriyan et al., 2013; Michielsen et al., 2013; Wehmeier et al., 2010) Understanding young people's experiences with ADHD medication is therefore crucial for improving overall support services and long-term outcomes (Fattore et al., 2017; Varley, 2011).

1.10. Experiences of ADHD Medication

The voices of people with ADHD have been absent or underrepresented in efficacy and outcome research, resulting in a call for qualitative studies to fill these gaps (J. Kendall et al., 2003). This has resulted in more qualitative research in the last two decades, especially around young people's experiences of the ADHD diagnosis (J. Kendall et al., 2003), school experiences (Wiener & Daniels, 2016), experience of treatment services (Cheung et al., 2015) and the transition to college (Schaefer et al., 2017).

Recently published meta-syntheses (Eccleston et al., 2019; Ringer, 2020) provide a useful starting point for considering gaps in research and understanding. Eccleston et al.'s (2019) meta-synthesis of 11 studies is the first to synthesise findings on adolescents' experiences, and they highlight the paucity of qualitative research in contrast with the abundant quantitative studies in the field of ADHD outcome research (e.g. Faraone, Biederman, & Mick, 2006; Frazier et al., 2007; Nikolas & Burt, 2010; Simon et al., 2009; Van der Oord et al., 2008). They report that many young people considered symptoms of ADHD to be a core part of their personality and character. They also found that where the environment adapts to the young person, and therefore the mismatch between expectations and abilities is reduced, young people report less difficulties (e.g. Gallichan & Curle, 2008). Young people with a diagnosis of ADHD consistently reported low self-esteem, feelings of difference and identity loss, and commonly experienced bullying, stigma and rejection (e.g. Bringewatt, 2013; Singh et al., 2010). Although Eccleston et al.'s (2019) systematic review looked at all treatment offered, it concluded that very little attention was given to psychosocial interventions, and overwhelmingly, treatment was through medication. In Ringer's (2020) meta-synthesis of 16 studies, the author discusses the possible separation between young people's sense of self and the behaviours, thoughts and emotions which they attribute to ADHD. The ambivalence of young people towards their social environment is highlighted, with others (family, teachers, and peers) being seen as both a source of support and a source of demands which perpetuate feelings of being othered and disabled.

Many of the studies included in both systematic reviews were conducted in the early 2000s. However, as discussed in the sections above, medication prescribing practices, as well as social and public views of medication have shifted considerably in the past 20 years. It is therefore useful to consider research published more recently, in the past 10 years, to inform the focus of the current study.

Furthermore, there is an interesting phenomenon of ADHD medication prescription rates increasing between the ages of 6-12, and showing a sharp decline afterwards (Molina et al., 2009; Sultan et al., 2018). This decline seems to coincide with the onset of adolescence, where young people begin to negotiate their autonomy and identity (Erikson, 1968, 1994). For example, Newlove-Delgado et al. (2019) report that the median time to stopping ADHD medication from the age of 16 was 1.51 years. Despite concerns these studies highlight regarding early discontinuation of medication, research has not sufficiently considered the link between medication discontinuation, and the increasing agency and developmental tasks of adolescence (Erikson, 1968). There is also a paucity of research taking a longitudinal view, and examining how young people's views towards the ADHD diagnosis and medication change over time, in the wider context of their lives (Brady, 2014; Titheradge et al., 2022).

1.11. Literature Review

The purpose of the literature review that follows was to map relevant literature in the area of childhood experiences following prescription of ADHD medication, and to identify gaps in the literature which have informed the conceptualisation of this research. The five stages of scoping reviews delineated by Arksey & O'Malley (2005) were followed. These stages are not linear, but rather iterative and require a reflexive approach, and, where necessary, the repetition of steps to ensure the literature is covered in a comprehensive way (Peters et al., 2015).

1.11.1. Stage 1: Identifying the Research Questions

Setting wider parameters and definitions at this stage of the process has been recommended to scope out the breadth of literature available, eventually leading to more narrow and sensitive searches of the literature to achieve depth in the relevant topic area. The initial guiding question informing the literature search was:

What are young people's experiences of taking ADHD medication?

Throughout the scoping review process, research questions became narrower, and in the final stages focussed on mapping out two specific areas related to:

1) *What are young people's experiences of ADHD medication treatment and services?*

2) What is known about the impact of medication-taking on young people's self-view and relationships?

1.11.2. Stage 2: Identifying Relevant Studies

A systematic search for relevant literature was completed in three electronic databases: PsychInfo, Academic Search Ultimate and CINAHL Complete. To ensure the author also attended to literature available to the public and 'grey literature', searches were also performed on Google Scholar and other openly available sources, for example, ResearchGate. Hand-searching of relevant reference lists was also performed to achieve a comprehensive search.

All searches were restricted to articles in English due to practical constraints. Given the importance of the changing field of ADHD, as discussed in the section above, the decision was made to only include studies published in the last 10 years, between the 1st of March 2014 and the 1st of March 2024. This timeframe was felt to best capture recent developments in the field of ADHD and public perspectives, whilst considering constraints in relation to the current research.

Arksey & O’Malley (2005) described the reflexive nature of this stage of the scoping literature review in terms of consideration of relevant databases, search terms, and piloting the search strategy to allow for refinement.

Based on increasing familiarity with the literature, inclusion and exclusion criteria were developed to narrow the focus of the literature search. These criteria were also shaped by the researcher’s own position and lens of interpretation. The decision was made to include articles which explored medication-taking experiences beyond a focus on increasing medication adherence, to enable a wider and more critical exploration of research in the field. Inclusion and exclusion criteria for the final literature search are presented in Table 1.

Table 1 – Inclusion and Exclusion Criteria for Final Literature Search

	Include	**Exclude**
Population	People of any age who were diagnosed and medicated for ADHD in their childhood (under the age of 18)	People who do not have an ADHD diagnosis and have not taken ADHD medication.
Focus	Direct focus on the views of people with ADHD who took ADHD medication in their childhood. AND Exploration of experiences in childhood (under the age of 18).	Explored experiences or views of anyone other than the person with the ADHD diagnosis. Focus of the study is on medication adherence. Focus is on exploration of experiences in adulthood (above the age of 18).
Methodology	Qualitative, Mixed	Quantitative
Publication Date	Publication between March 2014 – March 2024	Published before March 2014
Language	English	Any language other than English
Geographical location	Worldwide	None

The final literature search of articles with full-text availability yielded 115 results on PsychInfo, 82 on Academic Search Ultimate and 118 on CINAHL Complete. A further 8 studies were identified using Google Scholar Search and a ResearchGate search, with the first 5 pages of results examined due to the nature of these search websites producing less and less relevant results. A further 17 studies were identified through snowballing, a technique whereby the references of relevant articles are examined to identify further key studies. This resulted in a total of 340 studies, the titles and abstracts of which were examined to manually select relevant studies.

Following the removal of duplicates and application of the inclusion criteria outlined in Table 1, a total of 21 articles met the inclusion criteria for a full-text review.

1.11.3. Stage 3: Study Selection

The full text of the 21 articles were examined for eligibility. After consideration of the full-text articles, 12 were excluded due to the following reasons:

- No focus on medication-taking experiences (n=2)
- Interviews completed with parents only (n=1)
- Focus on experiences in adulthood (n=3)
- Quantitative methodology (n=1)
- Focus on medication adherence (n=5)

For the exact search terms and combinations, and a diagrammatic representation of the literature review process, please see Appendix A.

1.11.4. Stage 4: Charting the Data

The nine papers identified in the current literature review are presented below.

1) *Brady, 2014*: The focus of this UK-based research was on studying children's (6 boys, 1 girl; aged 6-15) experiences of ADHD treatment and considering their rights in treatment-related decisions. The methodology included a mixture of oral, written and artistic methods. Brady (2014) drew attention to the importance of considering children as beings in their own right, and granting them their legal rights to privacy, confidentiality and withdrawal of their consent to treatment. Findings indicated that children are active and capable decision-makers, making choices and accepting responsibility for their care, however they are often not considered as such. Limitations of this study are in the skewed gender distribution of the sample, and the method for analysis of the results not being described in the methodology section.

2) *Cheung et al., 2015*: The study explored patient experiences in accessing ADHD services in Hong Kong through semi-structured interviews, conducted with 40 participants (27 boys, 13 girls; aged 16-23). Using a Grounded Theory approach, authors concluded that parents and teachers were influential in treatment-related decisions, and children themselves had little input into this. Participants described that non-pharmacological treatment options were

limited, accessed for a short time or only in childhood, and had short-term effects. Medication was seen as effective despite side effects experienced. Insufficient public awareness of ADHD and limited specialist services in adulthood were highlighted. Limitations included the overrepresentation of those on a waiting list to access services, and a sample of young people who were ‘generally well’ as indicated through self-report measures.

3) *Charach et al., 2014*: Canadian adolescents’ (6 boys, 6 girls; aged 12-15) and their parents’ experiences were explored using mixed methods, with interviews analysed through an interpretive interactionist framework. Charach et al., (2014) reported that parents’ beliefs were more homogenous than adolescents’, with parents reporting more benefits of medication and more likely to see ADHD as a biological disorder requiring medication. Responsibility for treatment-related decisions was transferred from adults to young people over time. Limitations are highlighted in the small sample size selected from a specialized clinic, with some young people at the start of their medication treatment. A further limitation is in the implications being provided to clinicians only focussing on involvement of young people early on to improve their knowledge about medication, rather than to meaningfully consider treatment options.

4) *Clancy et al., (2020)*: Adolescents’ (4 girls, 1 boy; aged 16-17) interpersonal experiences were explored through three consecutive interviews, analysed through a psychodynamically-informed framework. All participants attended an Irish CAMHS for between 1 and 5 years. Adolescents described not being able to ‘get out’ of difficult emotion, feeling ‘unsoothed’, and experiences of being in and out of control. Authors suggested that the symptoms of ADHD can be understood as adolescents’ attempts to manage intolerable emotional pain in their turbulent inner atmosphere. The need for a therapeutic space for adolescents was highlighted along with placing adolescent experience at the centre of research and treatment-related decisions. Limitations arise from a lack of standardised interview approach; and no reliable separation of adolescents’ experiences arising from their developmental stage versus their experiences of living with an ADHD diagnosis.

5) *Fleishmann & Kaliski (2017)*: The authors interviewed 38 young people (18 boys, 20 girls; aged 15-19) in Israel with the aim of examining the change that young people experienced when taking stimulant medication, their experiences of controlling this change and the meaning of this in their lives. Findings indicated that participants were aware of the wide-ranging effects of ADHD medication. Participants noted methylphenidate diminished their desire to interact with others and shifted their preference towards sitting still and learning. Most reported feeling morose and not feeling like themselves when on medication. However, many reported using their personal autonomy to take medication in a way that best served their goals, for example to pass exams.

6) *Avisar & Lavie-Ajayi (2014)*: 14 adolescents (8 boys, 6 girls; aged 12-16) living in central Israel were interviewed about their experiences of stimulant medication, and data was analysed using interpretative phenomenological analysis principles. Young people were passive actors in the diagnostic process. Half described academic improvements, however most noted emotional side effects, identity loss and difficulties with interpersonal relationships, with many speaking about ‘feeling as though they are in a bubble of their own’. One young person noted medication helped their relationships by making them less aggressive. Limitations arise from participants’ developing sense of self in adolescence, and the study potentially not being able to separate the effects of medication from developmental effects.

7) *Levy (2020)*: The author interviewed 12 young adults (4 male, 8 female; aged 18-24) in the USA using semi-structured interviews, investigating the role of medication in self-representations, and the intersection of these with young adults’ minoritised ethnicities. Levy (2020) found varied results, showing that stigma was a barrier to participants accessing mental health treatment, and this effect was more pronounced in some minoritised ethnic communities. Participants appeared to have a ‘looking-glass-self orientation’, a self-view which is conditional upon others’ perceptions of them, rather than a ‘bottom-

up' representation which is more stable over time (Harter et al., 1996). The difference between the unmedicated and medicated self was highlighted, with half of the participants reporting this posed a threat to their authenticity. Participants engaged in social comparison, highlighting the differences between themselves and peers. Stigma and negative social experiences were often reported, and participants' medication-related decisions were also influenced by the impact of this on their social functioning.

8) *Carr-Fanning & Guckin, (2018)*: Stress and coping were explored amongst 15 young people (9 boys, 6 girls; aged 7-17) and their parents in Ireland, through semi-structured interviews and triangulated methods, analysed using thematic analysis. All identified difficulties in their pathways through care, with some reporting a 'wait to fail' approach due to early identification of difficulties but a long wait until diagnosis. Misdiagnosis, conflicting diagnosis, mother-blame, and professionals' general lack of knowledge was reported. Young people often reported not knowing about other treatment options apart from medication, and expressed they did not always find this helpful. Limitations include an over-reliance on parents' voices in this study, and only interpreting young people's confusions around medication as a need for education on medication effectiveness.

9) *Sikirica et al., (2015)*: The authors examined 28 adolescents' (14 boys, 14 girls; aged 13-17) and parents' unmet needs in eight European countries. Adolescents reported medication treatment reduced but did not fully eliminate difficulties, leading to strained relationships, difficulties with social interactions, emotional issues and low self-esteem, underperformance, and disciplinary issues in school. They had a self-awareness about their difficulties and the impacts of these, including impacts on family relationships. A lack of understanding by teachers and other students, and experiences of bullying were also reported. Adolescents' accounts in this study are more limited and the main discussion points are drawn from parents' reports. Furthermore, those with severe comorbidities, who are likely to have more significant unmet needs were excluded.

1.11.5. Stage 5: Collating, Summarising and Reporting the Results

The final step in the systemic scoping literature review was in presenting an overview of all material reviewed to provide an overarching ‘map’. The following section collates and summarises insights from the literature, in relation to the two research questions.

1.11.5.1. What are young people’s experiences of ADHD medication treatment and services?

The agency of children in treatment-related decisions was investigated by multiple studies (Avisar & Lavie-Ajayi, 2014; Brady, 2014; Carr-Fanning & Guckin, 2018; Cheung et al., 2015). Experiences of having to wait until things worsen, or a ‘wait to fail’ approach was reported by Carr-Fanning & Guckin (2018). Young people were often not considered equal decision-makers in their treatment (Avisar & Lavie-Ajayi, 2014), potentially due to intersecting identities they held as ‘minors’ and ‘patients’, as well as their diagnosis of ADHD. Brady (2014) argued that viewing children as human ‘becomings’ (future beings) rather than human beings (present focus) leads to little attention provided to children as social actors in healthcare.

> “I didn’t decide; it was the decision of my mother and my father because they saw it in my report, that it didn’t help me in the report” (Avisar & Lavie-Ajayi, 2014, p.45).
>
> “Doctor makes the decision. I’m not qualified” (Cheung et al., 2015, p.6)

At times this caused conflict between young people and their parents (“my mom tries to force me to take it.” Charach et al., 2014, p. 8). It should be noted that some also reported positive experiences of agency in their treatment:

> “The doctor will ask me the effect after medications and then I can make decision” (Cheung et al., 2015, p.6)

The views of adolescents and their parents regarding ADHD and ADHD medication were distinct from each other, with parents holding more uniformly positive views regarding the effects of medication (Charach et al., 2014; Sikirica et al., 2015). Most young people were ‘passive’ in decisions about their treatment, especially at the time of diagnosis and medication prescription, and some felt they were not taken seriously (Avisar & Lavie-Ajayi, 2014). Over time, many became more involved and active in treatment-related decisions (Fleishmann & Kaliski, 2017). Medication was noted by many to be effective, helping them academically, with some becoming informed decision-makers about when and how to take it to meet their goals (Fleishmann & Kaliski, 2017; Levy, 2020).

> "It's kind of freedom. Because when I'm with Ritalin it's much easier to concentrate" (Fleishmann & Kaliski, 2017, p.423)

However, medication did not address all young people's difficulties, and for some it created adverse effects physically and emotionally (Avisar & Lavie-Ajayi, 2014; Sikirica et al., 2015). Many were not aware of treatment options other than medication (Carr-Fanning & Guckin, 2018; Cheung et al., 2015).

> "It suppresses appetite and suppresses yourself. Generally, I longed for the afternoon when the pill would stop affecting me" (Avisar & Lavie-Ajayi, 2014, p.43)

1.11.5.2. What is known about the impact of medication-taking on young people's self-view and relationships?

A difference between the medicated and unmedicated self was highlighted across some studies (Avisar & Lavie-Ajayi, 2014; Charach et al., 2014; Fleishmann & Kaliski, 2017). Some people reported medication inhibited the positive parts of ADHD, and shared "I just didn't feel like me", with some describing this as "being in a bubble". Participants also described tolerating the negative effects due to the perceived benefits of medication:

> "I didn't like who I was on the meds if that makes sense. I didn't like what they did to me…but [4 sec pause] it did what it had to" (Levy, 2020, p. 149)

Others noted the positive effects of medication helping them be "a better version" of themselves.

> “For me, my ADHD self is not a good person compared to my, my medication self, because I feel like when I was my medication self in high school people got along with me pretty well” (Levy, 2020, p. 150)

When examining relationships, most of the studies found that young people struggled with social relationships. In Clancy et al.’s (2020) study, adolescents described difficulties arising as part of their attempts to manage emotional pain, and highlighted turbulence in terms of self-views and relationships with others, resulting in a feeling of being uncontained and ‘unsoothed’. Results are somewhat mixed regarding the effects of medication, with some perceiving positive effects, noting they were less angry, more attentive and compliant with social norms:

> “My parents, they’re a lot happier, and my brother’s coming to me and my grammas’s not yelling at me anymore.” (Charach et al., 2014, p. 5)
>
> “... I would get on peoples’ nerves people ... [but] when I’m on my medication I would feel different like I would actual feel quiet I’d feel like normal like other people ...” (Carr-Fanning & Guckin, 2018, p. 209)

Some studies, however reported negative effects of medication, such as a decreased ability to socialise, detachment and passivity, and feelings of apathy and anhedonia, which perpetuated feelings of exclusion from social groups:

> “I don’t talk with people as well. Because it’s less myself. It extinguishes parts of me. It makes me concentrate more, but looking at it altogether, it’s harmful”. (Fleishmann & Kaliski, 2017, p. 425)
>
> “But most of my friends recommend that I stop with this, since they see me on days that I am without and days that I am with, and say that without it I have more joy of life and all of that, and with it, I seem more depressed.” (Avisar & Lavie-Ajayi, 2014, p. 43)

Experiences of stigma, peer victimisation and peer rejection were commonly reported. Young people engaged in social comparisons, describing how they are different to others. A lack of information about ADHD was also noted both for young people themselves and for others (Cheung et al., 2015).

> "…When I get angry – this was more when I was younger; I started fights with pupils in my class. Then I got bullied, and I was not feeling well at all. No teachers cared." (Sikirica et al., 2015, p. 276)

1.12. Research Gaps

The scoping literature review identified some gaps in research that relate to the current study. Firstly, exploring experiences through a qualitative design can provide depth and nuance not captured by the large number of quantitative outcome research in the field (Efron et al., 2016; Kuriyan et al., 2013; Michielsen et al., 2013; Wehmeier et al., 2010). Secondly, there is a call for research centring the experiences of people who were diagnosed and treated for ADHD in their childhood (Clancy et al., 2020). Often, studies focus on the experiences of parents, teachers or mental health practitioners (e.g. Ibrahim et al., 2016), and whilst these views are important to explore they do not capture the lived experiences and stories of those with ADHD, which have been shown to be different to the adults' around them (Charach et al., 2014). This is also an important consideration due to ethical duties of upholding children's rights, as highlighted by Brady (2014) and others. In relation to this, it is important to note that following review of the 21 full-text articles, the most common reason for exclusion of studies (n=5) was due to the predominant focus on seeking the views of young people in relation to their medication use, with the aim of increasing medication adherence. These studies highlighted that engagement of young people in their treatment is essential, however only discussed aspects of young people's lives in relation to their treatment and appeared to position them as "someone who needs to be treated" (e.g. Druedahl & Kälvemark Sporrong, 2018). This illuminates gaps in the understanding of wider effects of ADHD diagnosis and medication.

Furthermore, research overwhelmingly appears to focus on individual factors and difficulties, and medication's effectiveness in managing these (e.g. Sikirica et al., 2015). Whilst focussing on individual differences, academic achievement, and behaviour management can bring valuable insights into young people's experiences, these need to be interpreted in the wider context of their lives. As Lloyd (2006) argues, there is a need to "redress the balance between addressing the needs of the individual child and critically examining the systems" within which ADHD gains meaning (Lloyd et al., 2006, p. 3). Additionally, Levy (2020) concludes, there is a need for further research to examine the role of poor social functioning in the lives of those taking medication. Indeed, social functioning and relationships appear to be investigated from a perspective of deficits and medication effects, rather than through a developmental (Erikson, 1968, 1994) and systemic lens. It is also key to highlight conflicting findings in previous research. For example Singh et al. (2010) and Singh (2007), highlight the benefits of medication on young people's sense of self and peer relationships, whilst Avisar & Lavie-Ajayi (2014) report finding the opposite, with young people describing the negative emotional side effects, identity loss, and the toll on interpersonal relationships related to medication-taking.

Finally, a key limitation in several studies with adolescent participants arose from not being able to separate medication-related experiences of self-concept and social relationships from developmental effects, as these were very live in adolescent's narratives (e.g. Avisar & Lavie-Ajayi, 2014; Clancy et al., 2020). Therefore, listening to stories of adults who were diagnosed and prescribed medication in their childhood can provide valuable insight into self-view and social relationships, with reflections from beyond the period of adolescence. Only one other study with adult participants reflecting on their childhood experiences was found (Levy, 2020), however this was in a US context and appeared to focus more on individual rather than systemic factors.

1.13. Research Aims

The current research aimed to address the gaps in literature discussed above. The experiences of young people following prescription of medication for ADHD were discussed through the eyes of their adult selves, exploring longitudinal narratives and outcomes. Specifically, experiences around the developing self-view and authenticity, and social relationships were investigated. The study anchored explorations at different levels of context with the aim of moving away from a purely individualistic understanding, to consider individual, relational, organisational, and wider systemic factors in interpreting the results. Theories of developmental - , ego - and self-psychology guided interpretations, along with cognitive-developmental and ecological systems theory (Bronfenbrenner, 1979; Cote & Levine, 2002; Erikson, 1968; Fischer & Bidell, 2007; Fischer & Pipp, 1984; Lerner, 1996; Piaget, 1970).

1.14. Research Questions

The following research questions were explored using semi-structured interviews:

1) How did ADHD medication affect people's sense of self and their relationships with others in childhood?
2) What was people's experience of ADHD diagnosis and medication in their childhood, and over time?

2. METHOD

2.1. Chapter Overview

The epistemological stance of the study is introduced at the beginning of this chapter. This is followed by an outline of the research procedure, ethical considerations and the analytic approach applied.

2.2. Epistemology

The present research is underpinned by a critical realist epistemology. Critical realism exhibits a realist ontology, acknowledging the existence of a real world and real processes, whilst positing that this reality is not directly available and observable in an objective way. Reality cannot be directly studied, as the only ‘reality’ accessible to us is through our own lens of interpretation (Willig, 2016). Research can be used to make better approximations to reality, even if reality will never be accessible to us directly (Pilgrim, 2019).

This stands in contrast with what is considered an attempt at objectivity through a positivist epistemology (Michell, 2003). Traditionally described by some researchers as a more ‘scientific’ approach, a positivist position assumes that there is one ‘truth’ and one reality which exist independently of the mind, and which can be discovered through research and science. Critical realism, however, posits that the objective ‘truth’ cannot be studied directly, only through the historical, cultural, and social lens through which the observer/researcher is interpreting it. Through a critical realist understanding, the experiences and behaviours associated with ADHD are real and are reported by many people around the world. However, the way these experiences are interpreted as Attention Deficit Hyperactivity Disorder is mediated by history, culture and language, and seen through the lens of the researcher and the participants in this study.

2.3. Design

The study uses a qualitative design to explore the research questions. This is consistent with the underlying epistemology. Qualitative research offers insights into the complexity of human behaviour, experiences, and social phenomena, and it has been recommended for understanding experiences and processes within their wider contexts (Barker et al., 2015). Individual, semi-structured interviews were employed to facilitate an exploratory stance, and to allow for both guidance and flexibility during participant interviews. This method of interviewing also offers opportunities to capture unexpected insights, beyond the questions originally devised for the interview schedule (Marks & Yardley, 2004).

2.4. Consultation

Significant discrepancies have been reported between what research is investigating, and what is actually important to people with lived experience (Barber et al., 2011; Shippee et al., 2015; Staley, 2012). Stakeholder consultation was especially important as the researcher does not herself have direct lived experience of ADHD, which increases the risk of missing the 'real-world connection' between what the research is focussing on and what is relevant and important to those with ADHD. The main aim of the consultation process was therefore to review the validity, or 'appropriateness' of the interview materials and procedure, and to ensure that these are suitable, inclusive and appropriately adapted in line with ethical and moral standards (Leung, 2015).

Separate consultations with three individuals were carried out in July and August 2023 over Microsoft Teams video calls which lasted between 30 minutes and 1 hour. Stakeholders were recruited through social media posts (Facebook, Instagram, Reddit; see Appendix B), and through snowball sampling. All three stakeholders have a diagnosis of ADHD, are aged over 18, live in the UK, and have experience of working with others who have a diagnosis of ADHD. This additional expertise in the field of ADHD was seen as especially beneficial for informing the interview materials and procedure.

Stakeholders reviewed the two research questions the current study is focussing on as well as the semi-structured interview schedule and interview process (Appendix C) through a discussion with the researcher. All three stakeholders were asked open-ended questions in relation to the content and language of the semi-structured interview, along with exploring their views of anything else they would change or add based on their experience and expertise. All three expressed enthusiasm towards the study and emphasised the need for research within the field of ADHD. Following consultations and discussions with the Director of Studies (DoS), key adaptations included:

- Changes to the interview process: ensuring participants know they do not need to maintain eye contact during the interview, and they can go over the 1-hour approximate time for the interview; keeping wording simple and straightforward.
- Changes to the interview questions: wording changes (e.g. clarification of the word ‘stigma’ for participants who might not be familiar with this), addition of questions (e.g. ‘What were you told about what ADHD medication does?’).

2.5. Participants

2.5.1. Recruitment Criteria

Participants recruited for the current research were:

- Currently aged 18-45.
- Diagnosed with ADHD before the age of 16 and took medication for ADHD (stimulant or non-stimulant) for at least 3 months before the age of 16.
- English speaker, living in the UK, with access to the internet and Microsoft Teams.

The participant age criterion was chosen after careful consideration of the possible effects of asking in-depth questions regarding medication and agency, to protect vulnerable participants below the age of eighteen (Aldridge, 2014). Additionally, as discussed in Chapter 1, it was felt that adult participants would be better able to reflect on childhood experiences and changes they have experienced over time (Levy, 2020).

The ADHD diagnosis and medication-taking age criterion was chosen following review of relevant research, to account for these experiences to be explored in the period of childhood and adolescence (e.g. Avisar & Lavie-Ajayi, 2014; Fleishmann & Kaliski, 2017).

2.5.2. Recruitment Process

Details of the research were posted on identified social media platforms (Instagram, Facebook, Reddit) from research accounts generated specifically for the purpose of the study. Additionally, ADHD charities and third sector organisations were approached by the researcher and the researcher's DoS via e-mail communications. Several organisations shared the research on their social media platforms and member newsletters. Finally, UK university society representatives were approached via e-mail communications, and one neurodiversity society shared the research with its members. Written permission was obtained from every organisation and society in order for the research to be shared. The research was advertised in the form of text (Appendix D), or the research poster created for the study (Appendix E).

A criterion sampling method was initially undertaken with the aim of increasing heterogeneity of the selected sample (Moser & Korstjens, 2018). This sampling method consisted of pre-selection questions relating to self-identified gender identity, ethnicity and views around medication (see Appendix H). Due to unexpected difficulties during the recruitment process, the criterion sampling approach was replaced with a convenience sampling method to reach a point at which conceptual generalisations could be drawn (Pope & Mays, 2006).

2.6. Procedure

2.6.1. Initial Contact

Participants indicated their interest by contacting the researcher either via the social media platforms created for the purpose of the research, via UEL e-mail, or through the organisations who participated in spreading the word about the research. In the initial phase of the research, demographic data for criterion sampling was gathered at this stage, using the Pre-Selection Questions (Appendix H) to support a heterogeneous sample in terms of gender, ethnicity, and views around medication. Eligible participants were e-mailed back with further information about the study, along with the Participant Information Sheet (PIS; Appendix F) and Participant Consent Form (Appendix G), and letting participants know they can ask any questions they have. Individuals who were interested in participating confirmed this via e-mail response, and a mutually convenient time was arranged to meet over Microsoft Teams video call.

2.6.2. Semi-Structured Interview

Interviews were conducted over Microsoft Teams video calls set up through the researcher's UEL account. This method of interviewing was chosen to enable recruitment of participants from a wide geographical area across the UK, which was found to be a common limitation in previous studies recruiting from a single area or clinic (Carr-Fanning & Guckin, 2018; Charach et al., 2014; Rashid et al., 2018).

Prior to commencing the interview, participants were given the opportunity to ask any questions about the PIS and about the research. Most participants had sent back the completed consent form (Appendix G) before the meeting; for participants who had not completed this, the consent form was reviewed prior to the interview. Consent was indicated for each item by participants initialling the relevant tick box. Following an introduction to the study, some time was devoted to creating an inclusive and safe space, which was felt to be especially important as the interviews were conducted online (Żadkowska et al., 2022).

Individual semi-structured interviews lasted between 60 to 90 minutes, and they were approached in a way that was focussed but flexible. The interview schedule was developed by the researcher, based on the research epistemology and previous studies in the field, with input from the Director of Studies and from the stakeholder consultation (Appendix C). This was used as a guide to ensure relevant topics were covered, however the path taken through topics was unique to each participant. This method of interviewing was intended to generate a reflective exploration of individuals' specific experiences related to their ADHD diagnosis and medication. Questions started out open-ended, and for each sub-section there were more detailed questions to act as prompts and to support a deeper understanding of participants' experiences. Breaks and adaptations were incorporated into the interview. All interviews concluded with a debrief.

2.6.3. Debrief

Time was allocated at the end of each interview for a debrief where the participant was given the opportunity to reflect on how they found the experience and raise any questions or concerns they might have (Oates et al., 2021). Consent was revisited and a debrief sheet including support services was shared with participants via e-mail (Appendix I).

2.6.4. Transcription

Transcription is an active process of transformation rather than replication (Braun & Clarke, 2013; Sandelowski, 1994). The researcher transcribed all interviews using an orthographic transcription with consistent inclusion of paralinguistic features of the data, as recommended by Braun & Clarke (2013). To improve readability and comprehensiveness of the transcript, punctuation was included, where relevant, along with indicating indecipherable and inaudible utterances. Where part of the extract is ambiguous, contextual information was provided within (brackets) and paralinguistic features were noted in ((double brackets)). Names were replaced with pseudonyms, and any identifiable details were replaced with words within [square brackets].

2.7. Ethics

Ethical Approval was granted from the UEL School of Psychology Ethics Committee. Subsequent amendments were granted in October and December of 2023 to address difficulties with recruitment through widening the participant age range criterion and the avenues for recruitment. A title change was approved in February 2024 to better reflect the study. The full ethics application and approval can be found in Appendix J and Appendix K. The study's design, implementation and data governance is aligned with the BPS's Code of Human Research Ethics (Oates et al., 2021).

2.7.1. Informed Consent

Participants were sent the Participant Information Sheet (Appendix F) and Consent Form (Appendix G), detailing the benefits and possible disadvantages of participating, what to expect from taking part, confidentiality, data protection, plans for analysis, write up and dissemination of the final thesis. All participants were encouraged to ask questions about the research before commencing the interview. Participation in the study was voluntary. Participants were informed they can withdraw at any point before or during the interview process, as well as up to 3 weeks following the date of their interview, at which point the analysis of the data will commence. Consent to participate was provided in writing, as well as verbally as part of the interview process.

2.7.2. Data Governance and Confidentiality

As outlined in the PIS and discussed with participants, the data collected as part of the research was handled in accordance with the Data Protection Act (1998, 2018). A Data Management Plan was approved by UEL to ensure all elements of data protection were suitably addressed, and participants were informed of data security as part of the PIS and in the interview. A secure, password-protected, non-networked device was used for the purpose of this research. Interviews, transcription, analysis and writeup were undertaken only by the researcher. Personal information, consent forms, interview recordings, and transcripts were all kept in separate folders on UEL OneDrive for Business, which is a secure and encrypted storage space.

Interview recordings were created in UEL's Microsoft Teams and immediately uploaded to OneDrive for Business. Confidentiality of the data was ensured at the transcription stage using guidance from the Information Commissioner's Office (2012), through pseudonymisation and changing of any identifiable information (e.g. locations, dates, job titles). Any quotations used in the thesis were carefully selected to ensure they are non-identifying. All personal information and recordings of interviews were destroyed upon completion of data analysis. All other data, including anonymised transcripts and analysis data, will be deleted within 3 years of data collection.

2.7.3. Remuneration

Participants were offered a £10 Amazon voucher as a compensation for their time and valuable contributions. Remuneration was aligned with the researcher's ethical and moral values, stemming from the view of a prima facie moral obligation towards research participants (Różyńska, 2022). Vouchers were requested through the allocated research funding for the current study. Details of remuneration were included in the PIS and discussed with participants prior to commencing the interview. Receipt of the voucher was optional and participants who wished to receive the voucher were asked to provide personal information (name, address, date of birth and national insurance number) in line with HMRC and UEL regulations. This information was handled in line with the Data Protection Act (1998, 2018) and was only shared with a UEL representative to confirm the voucher claim as lawful. Seven participants asked for the voucher, and four declined this.

2.7.4. Potential Distress

The PIS acknowledged that some participants might find it difficult to discuss their experiences in childhood and adolescence in relation to ADHD. Care was taken to minimise potential distress by ensuring participants were aware they did not have to answer questions they did not wish to and could ask for brakes and the termination of the interview without having to provide a reason for doing so. Interviews were conducted in a sensitive manner, checking in with participants following difficult topics discussed, and reassessing consent to continue at multiple time points. Participants were additionally provided with a debrief sheet including a list of support services (Appendix I).

2.7.5. Protection of Vulnerable Participants and Adaptations

Vulnerability in research is about more than just capacity for self-determination, and involves a range of complex considerations, including the researcher's disproportionate power over participants (Anderson & Corneli, 2018). Consideration was put into empowering participants to make informed decisions, as detailed in sections above. Participant resources were adapted to use straightforward and accessible language, based on stakeholder consultation and ADHD research literature. Further measures were taken during interview (check-in, brakes, use of strategies to support attention) and after the interview (debriefing, information about support services) to support participants.

2.7.6. Hurdles with Recruitment

The online recruitment and process of the current study brought unexpected hurdles in the form of mass false expressions of interest through social media and via e-mail. Over 200 false sign ups were received, with some appearing indistinguishable from real participant registrations. These registrations were potentially made using artificial intelligence software, as they were often sent closely in time and at times followed a similar structure. Interviews with 4 of these participants were arranged, who however did not appear to be aware of the study or about ADHD at the commencement of the interview. These interviews were terminated by the researcher once it became clear that the person who joined did not meet the inclusion criteria, and in all four cases this was detected within the first few minutes of interviewing. Mass false expressions of interest posed a considerable time hindrance but did not impact on the data collected for the research study.

As discussed by Teitcher et al. (2015), studies are increasingly being conducted online, and this also raises fraudulent registrations, especially when incentives are offered for participation. Fraudulent participation is harmful not just to the study, but to the whole field and to the people whose voices the research seeks to amplify. The authors propose ways of discouraging fraudulent participation (e.g. offering to have a ‘prize draw’ rather than a guaranteed incentive for participating), however they note that these same methods also reduce genuine participation.

2.8. Analytic Approach

2.8.1. Reflexive Thematic Analysis

A reflexive thematic analysis (TA) approach was chosen as the method of data analysis, in consideration of the research questions and epistemological stance. Thematic analysis is centred on exploration of participants’ subjective experience and sense-making (Braun & Clarke, 2013; Willig, 2001). Reflexive TA, in particular the approach developed by Braun & Clarke (Braun & Clarke, 2006, 2013, 2019, 2021b), is different to codebook TA and coding reliability TA approaches. The main difference is in how themes are conceptualised. In reflexive TA, themes cannot exist separately from the researcher; they are generated by the researcher through analytic and interpretative work, and mediated by the researcher’s values, skills, experience, and training (Braun & Clarke, 2021a, 2021b). As such, the coding process is organic and unstructured, and themes evolve as the researcher’s understanding of the data deepens. Inevitably, through the researcher’s engagement with the data, they delimit and shape the coding process, and therefore, self-reflexivity is an integral part of reflexive TA as an approach (Braun & Clarke, 2019; Byrne, 2022). Braun & Clarke (2023) encourage the researcher to ‘own’ their perspectives, both personal and theoretical, to be deliberative in their decision-making.

The researcher’s overall aim in interpreting the data was to gain an understanding of participants’ sense-making of their medication and diagnosis experiences, particularly in relation to how these affected their sense of self and relationships. A combination of both inductive and deductive approaches was used, with more emphasis on inductive, where codes, themes and interpretations were both bottom-up readings of the data (Braun & Clarke, 2021a). However, interpretations were also deductive in that they were guided by the interview schedule and informed by existing theory and research. Reflexive TA understands participants' experiences as contextual, influenced by the historical, cultural, and social environment, which is well-aligned with a critical realist epistemology (Braun & Clarke, 2006, 2021b). It should be noted that a critical realist approach to the research acknowledges interpretations and resulting codes and themes as tentative, recognising that there are always alternative ways of interpreting the data.

2.8.2. Phases of Analysis

Braun & Clarke's (2006) six-phase approach to thematic analysis was undertaken in the interpretation of the data. Analysis is not a linear process, but rather, a recursive one, where movement back and forth throughout the phases takes place as needed. It is a process that develops over time, with writing being an integral part of the analysis from the beginning and throughout the entire coding and analysis process. The six phases are outlined below:

1) *Familiarisation with the data*: This phase commenced with transcription of the eleven interviews completed as part of this research, followed by active reading and re-reading of the data to become familiar with the depth and breadth of the content. The researcher also started taking notes and marking ideas for coding.
2) *Generating initial codes*: The researcher organised the data into meaningful basic elements, called codes, with each code identifying a feature of interest in the data. NVivo (12) software was used to store and organise codes. A predominantly data-driven approach was adopted, however, with a focus on features related to the research questions.
3) *Searching for themes*: Codes were clustered and re-clustered into themes and sub-themes based on unifying features. Visual aids were particularly useful at this stage, including thematic mapping.
4) *Reviewing themes*: The researcher considered the validity of the themes in relation to the entire dataset.

5) *Further defining and naming themes*: This phase included further refinement of the themes and reflection on the essence of each theme to support with naming and definition. The story of the research was considered in the way themes come together (Braun & Clarke, 2022). In addition to the approach outlined by Braun & Clarke (2006), the Director of Studies (DoS) received the definition and examples of sub-themes and themes generated by the researcher. The DoS then sorted a random selection of quotes into the sub-themes in the hope that any discrepancies between researcher and DoS might produce discussion about the clarity of the definitions and the fit between the quotes and the sub-themes.
6) *Producing the report*: In the write-up phase, the aim was to tell a coherent story, going beyond just describing the data to draw conclusions in relation to the research questions. Anonymised quotes from transcripts were chosen to capture each theme, reporting each theme in an order which tells a clear and coherent narrative (Braun & Clarke, 2006).

3. RESULTS

3.1. Chapter Overview

This chapter provides the main findings of the data analysis and interpretation. A summary of the sample demographics is presented, followed by an overview of the final thematic map, and a discussion of each sub-theme illustrated through raw data excerpts.

3.2. Participant Demographics

Table 2 summarises the demographic details of the eleven participants. All names used are pseudonyms.

Table 2 – Participant Demographics

Pseudonym	Age	Gender	Ethnicity	Age at diagnosis	Age prescribed ADHD medication	Currently taking ADHD medication
Adam	32	Male	White British	6	6	No
Barbara	36	Female	White British	12	12	Yes
Freya	26	Female	White Scottish	13-14	14-15	Yes
Grace	24	Female	White British	6 and 10-11	11	Yes
James	29	Male	White British	9	9.5	No
Liam	34	Male	White British	12	12	No
Mathias	29	Male	White - Other	16	16	Yes
Max	19	Male	White British	8	9	No
Nina	22	Female	Black British	13	15	Yes
Rory	29	Male	White British	5-6	5-6	Yes
Vihaan	30	Male	Asian - Indian	15	15	No

Due to the online nature of the research, participants were recruited from areas across the United Kingdom. All eleven individuals were diagnosed with ADHD and prescribed medication before the age of 16, and 54.5% of the participants were taking ADHD medication at the time of the study.

3.3. Overview of Themes and Thematic Map

Interview data was analysed following Braun & Clarke's (2006, 2013, 2023) Reflexive Thematic Analysis guidelines. In the process of data analysis and interpretation multiple thematic maps were developed to represent the rich and diverse data captured in participant interviews.

The Director of Studies was provided with ten randomly selected quotes and attempted to code them into an original set of sub-themes. There was agreement on seven of the ten sub-themes. Discussions of the three disagreements led to a slight re-grouping of sub-themes and clearer definitions of two sub-themes. It also became apparent that some quotes required more context to fully understand their meaning. Examples of earlier versions of the thematic map can be found in Appendix P.

Following examination of the thesis, themes were further narrowed to focus on sub-themes closely relating to experiences of ADHD medication. Contextual sub-themes were therefore removed or re-grouped, including sub-themes relating to young people's experiences of navigating social contexts, their journeys in understanding ADHD as a part of them, and of navigating ADHD over time. The previous thematic map and definitions are presented in Appendix P and Appendix Q. A visual representation of the final thematic map is presented in Figure 1 and definitions are presented in Table 3 below.

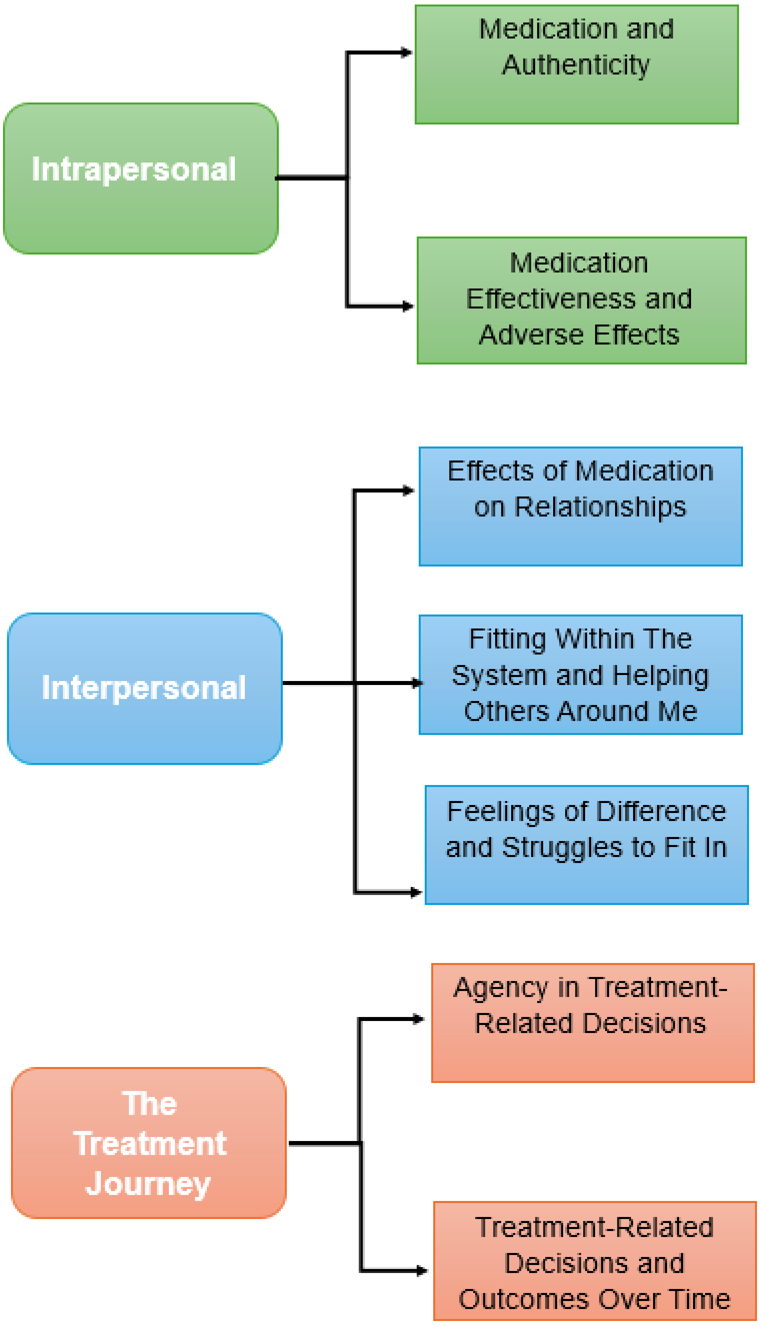

Figure 1 – Thematic Map

Table 3 – Overview of Themes and Sub-Themes

Theme	Sub-Theme	Definition
Theme 1: Intrapersonal	Medication and Authenticity	Experiences of the medicated and unmedicated self, and whether the two are the same or different.
	Medication Effectiveness and Adverse Effects	The effectiveness of medication and adverse effects experienced.
Theme 2: Interpersonal	Effects of Medication on Relationships	How taking ADHD medication affected young people's relationships.
	Fitting Within The System and Helping Others Around Me	Taking medication to help others rather than for the self, and to work better within the system.
	Feelings of Difference and Struggles to Fit In	Feeling different from others, difficulties with forming new relationships and hiding parts of the self to fit in.
Theme 3: The Treatment Journey	Agency in Treatment-Related Decisions	Involvement in decisions about treatment at the time of diagnosis.
	Treatment-Related Decisions and Outcomes Over Time	Changes in treatment-related decisions and coping over time.

3.4. Theme 1: Intrapersonal

The first overarching theme relates to intrapersonal elements of participants' stories related to medication, exploring inner personal experiences and meaning-making.

3.4.1. Sub-Theme: Medication and Authenticity

One of the main questions explored as part of the research related to how ADHD medication affected young people's sense of self. In other words, did young people who took ADHD medication experience that their inner 'self' remained the same, or did they notice that their unmedicated and medicated selves felt qualitatively different?

Participants offered varied accounts of their sense of self on and off medication. Six described feeling 'like a different person' (Nina) when medicated, with some reporting this difference as negative, whereas others describing it as more neutral or positive.

> And I I had I kind of…like it was almost like two different personalities, and I hated the side that I was when I was on my meds (Adam)
>
> [Mathias] with medication is very different to [Mathias] without medication, even, even now…(edited for brevity) I liked that version [the medicated self] of me a lot. (Mathias)

Some participants spoke of 'feeling more normal off medication' and 'not being able to be fully themselves' when on medication. Medication in this context appeared to be a barrier to being their authentic selves. Here Nina talks about her experience of a three-month break between two different types of ADHD medication:

> I felt like it's it's honestly, it felt like I had gone on vacation and I wasn't myself for the duration which I was on medication. I felt really different, like when I was off [medication], I felt like 'Ohh, I'm back now'. Like I I felt I felt like this feels normal. (Nina)

The feeling of a different sense of self was perhaps most prominent in Grace's account of medication-taking in her adolescence. Grace spoke about not seeing herself, in a way losing her sense of self when on medication:

> I, when I was taking the medication, I feel like I didn't see myself. Because I was just kind of existing to get through school. My my focus was school, trying to get my GCSEs to the grades that I wanted them to be…umm, the only time I ever saw my 'self'…was when it was pointed out to me by my family, that I'd lost weight that I looked like a bag of bones…And it, there was, when I think back, there, there isn't a time where I saw me unless it was pointed out to me…if that makes sense. (Grace)

Elements of Grace's hyper-focus on studies are reflected in other participants' accounts of how medication affected their sense of self:

> It felt like I had become like this person, like, it felt like you’re following a schedule like of lists to check once you've done stuff, yeah. (Nina)

Contrary to the experiences of a different sense of self, three participants reported feeling like ‘the same person’ (Barbara) on and off medication.

> Once again, I don't think the medication changes you. I think it changes your ability to cope with things. (Barbara)

Similarly, Max spoke about feeling the same, which he felt was due to his parents being able to explain ADHD and ADHD medication to him ‘in a positive way’.

> I didn't, I didn't see a change, so with me, I didn't see a change. I I couldn't tell if I was on medication or if I was off medication. (Max)

In Liam’s case he did not notice the medication making any difference, but he expressed this being linked more to his strong negative self-view, and medication not having an effect on his sense of self, stating ‘I felt pretty bad quite a lot of the time anyway’.

3.4.2. Sub-Theme: Medication Effectiveness and Adverse Effects

All participants spoke about the effectiveness of medication beyond effects on the sense of self and relationships. This sub-theme captures the experiences of perceived benefits of psychostimulant medication on executive functioning, or lack thereof, as well as the wide-ranging side effects reported by individuals in this study.

3.4.2.1. Medication Effectiveness

Eight participants credited ADHD medication for increasing their ability to perform academically and sustain focus and motivation (8), as well as ‘smoothing out’ the ups and downs they experienced (3). Once again, the concept of this being a trade-off was echoed by many participants, and it is therefore important to note the nuance in individuals’ perceptions of medication effectiveness.

> You know, my energy was…just wild, I was hard to settle, uh I was restless and excitable and impulsive. Uh and I, you know, again from from an outward perspective, I “misbehaved” ((gestures)). Umm, and, uh, the the medication that I was taking at the time regulated all of those things and just sort of smoothed things over. (Rory)
>
> So in school… Umm, it it very much made me a lot more…. placated, if that's the right word, umm, docile. And I didn't mind that because it was very it was very relieving that I could sit in a, in a in a class without shuffling, without having to play with something, without having to distract my peers. And I liked that version of me a lot. (Mathias)
>
> So yeah, I was horrible on it, but at least I managed to get some sort of education out of it. And I just took them, take the rough with the smooth, don’t ya? (Adam)

> [talking about getting treatment for acne and going vegetarian] …and these were things that maybe, cause I was so over-stimulated all the time before, I didn't really think about that - these things mattered, but like suddenly they did. (Freya)

However, medication wasn’t effective for all. Three participants reported not experiencing any positive effects. Liam was diagnosed and prescribed medication following a traumatic event happening in primary school and described ‘acting out’ and adults in his life deciding he ‘needs to see someone’ about this. Liam did not find any of the benefits of ADHD medication described by other participants above:

> I I felt pretty bad, quite a lot of the time anyway, just because of the things that happened in primary school. So I didn't see it [medication] helping me feel better. (Liam)

Vihaan shared similar views:

> One thing is that the medication didn't work for me and, the other thing is that apart from not working, it's causing side effect and it's causing, it's causing other complications as well. (Vihaan)

3.4.2.2. Adverse Effects

Whilst eight participants described benefits, ten described adverse effects. Some described these as ‘scary’ and ‘unexpected’. Adverse effects experienced included: insomnia (n=6), loss of appetite (n=6), significant weight loss (n=5), heightened emotions and irritability (n=4), depression and low mood (n=4), fatigue (n=4), growth stunt (n=2), high blood pressure and heart palpitations (n=2), urinary and bladder issues (n=2), suppression of spontaneity (n=2), dry mouth (n=2), suicidal thoughts (n=1), tics (n=1), nausea (n=1), dizziness (n=1) and memory problems (n=1).

> So the first, the first thing I did experience was the palpitations and…then the tic-ing. (Grace)

> I struggled, I struggled with suicidal tendencies, depression, everything, when I was on and off the Ritalin. (Adam)

> It was, my mood swings were kicking in and I was just like, I became really tired in the morning, I'd be struggling to get out of bed and stuff like that. (Max)
>
> Ehm, and cause I was like a bit overweight when I got diagnosed and then I lost five stone. But I became sort of like fixated on this idea of, like, losing that much weight. (Freya)

> I would, I'd get thinner and thinner and thinner, and I was…my ribs were like poking through, you could see my collarbones, really quite deep. (Grace)
>
> So yeah, I experience the dizziness and, uh urinary problems and, uh…I would say also concentration, there is a loss of memory loss as well. (Vihaan)

Certain adverse effects were treated by prescribing additional drugs (e.g. sleeping tablets), whereas for other adverse effects physicians initiated a change in ADHD medication. For many participants, however, it took them feeling significantly unwell for this change to be initiated, for example for Adam, ‘It took me to not sleep for three days straight as a child for them to realise maybe the dosage is too heavy?’. Two participants reported significant lasting adverse effects which did not resolve after stopping or changing ADHD medication.

3.5. Theme 2: Interpersonal

The second overarching theme encapsulates young people’s experiences of ADHD and ADHD medication in navigating social contexts and interpersonal relationships.

3.5.1. Sub-Theme: ADHD Medication and Relationships

Participants gave varying and nuanced accounts of how ADHD medication helped or hindered them in relating to others, including establishing and maintaining relationships. Three spoke of mainly positive effects, three described medication mainly hindering social relationships and three endorsed a mixture of positive and negative elements.

3.5.1.1. Helping Relationships

Participants named positive effects of taking ADHD medication on relationships, through making them ‘feel like others’, and helping them ‘understand others’ better:

> I also understand, understood situations as well that I might not have understood without medication. (Mathias)

> I get closer with friends…and I get more, uhm into friends when I am on medication, like I -, I I associate better and interact better. (Nina)

Rory, Nina and Freya spoke of medication helping them relate to others better and maintain key relationships in their lives. They described medication ‘slowing things down', which Freya illustrated through the metaphor of her brain 'feeling like a carousel'. Medication helps to slow down the carousel, putting her more in control of her responses and reactions in social situations:

> I always think that it's, in the sense of, like when I'm not on medication, I'm definitely more of like…Likely to sort of fall out with someone or like get nippy at someone almost, like for a little thing that is totally irrational. But like it's almost like I'm a bit snappy without it, because I'm not, because I'm suddenly thinking at such a high sort of speed of like, 'Oh my God, this is all the things I need to do today. Oh, my God, blah'. Like, that sort of way of being. But, like, on medication, I'm more reasonable with it. (Freya)

Barbara used 'the spoon analogy' to explain the beneficial effects of medication in helping her have the headspace and energy to spend time with others:

> I think it changes it - back to the spoon analogy, gives you a few more spoons to be able to get through your day. So that when you're at the end of the day and spending time with your people who you actually want to spend time with, you're not a [inaudible] mess because you can't - you're overwhelmed and over-stimulated. (Barbara)

Some also spoke of these positive effects of medication with a bittersweet note, noting the effects of medication in helping them feel 'normal' and 'on the same level as others':

> Umm…to think that I could feel normal, that the prospect of feeling that of, of, of knowing that what I was experiencing wasn't normal, and that there was something that could help me feel normal, like everyone else, it was kind of relieving. (Mathias)

Supportive relationships in young people's lives had the potential to partially diffuse some of the harm from negative social experiences, feelings of difference and exclusion.

3.5.1.2. Hindering Relationships

Participants also shared their experiences of medication hindering them socially. Grace shared medication helped her focus in school; however, her friends would often tell her was less funny and more serious when she was on medication:

> With friends…((laughs)) Uhm, they would often tell me, '[Grace], you're so much more funnier when you're off your medication'. And I would say like, 'Yeah, but I need it to focus, else I'm just gonna fail school if I don't do this.' And I I have I have this one friend, who I'm still friends with now, he would often moan at me to not take my medication because I was funnier.

Grace and other participants describe the double bind they were faced with: weighing the perceived benefits of ADHD medication in helping them focus in school with the perceived drawbacks of not being their more interesting or spontaneous social selves. For these young people, ADHD medication appeared to accentuate their 'academic selves' at the expense of their 'social selves', as expressed by Adam:

> It was like on the meds, all I was interested in was getting my head down, doing work and concentrating. And off the meds, all I was interested in is social aspects and like just spending time with people and like, yeah…But it was constant push and pull anyway, 'cause I think I just used to dip in and out of the moods anyway, depending on how…how strong the meds were acting on the day, I guess, or…I don't know.

This view is also shared by Max, who described that he felt that his 'fun and humorous' spontaneous side, which is an important and valued part of him, was dulled when on medication:

> I think it, this is part of the ADHD, and my mum's trait, where I don't really care if I'm in public or not. If I get a laugh out of it it makes me feel good.
>
> *Yeah. And that's part of your personality. And I wonder whether the ADHD medication was maybe helpful for that part or unhelpful.*

Hindering.

Participants reported further social disadvantages and ‘missing out’ due to side-effects of ADHD medication. Nina, for example spoke about concentrating very hard in school, but feeling too drained to be able to socialise at night as an adolescent:

> I got to a point where when people are staying up to like twelve and midnight, I was going to bed at nine, at ten. And, um, when you’re, when you’re in high school, you’re kind of, like you're missing out.

This stands in contrast with Barbara’s experience of medication helping to ‘give more spoons’ so that she had the energy to spend time with others.

Overall, participants’ varying accounts of how medication affected their relationships ties in with complexities of feelings of difference, wanting to be like others and wanting to find their place in social groups as adolescents.

3.5.2. Sub-Theme: Fitting Within The System and Helping Others Around Me

This sub-theme relates to participants’ feelings of having to take ADHD medication to help others in their environment, and to change themselves to fit within a rigid system. Seven mentioned how they were perceived in their childhood as ‘a handful and hard to handle’, often in several different contexts. Four spoke about medication helping others around them to cope with them, helping parents and teachers to ‘put up with them’ and ‘manage’ them.

> So when I was younger, my mom was very honest, she said, ‘Look, your ADHD medication is there to help you maintain a somewhat regular lifestyle through your, middle of your day. But it's also to help me when you're not at school, to help me, you know, not have to scream at you cause you won't bloody listen to me all the time.’ (James)

Some described worry about disappointing others:

> I I think about it now and I think if I hated it that much, why didn't I just not take the meds? But like, I think I was so scared of disappointing everyone and not…((pause)) and, or doing something wrong, that I just took them anyway, if you know what I mean. (Adam)

Young people also had to shoulder the ‘burden of treatment’ in the face of unchanging and rigid systems around them. Five people spoke about facing the rigid academic system and social care system, where they were not supported. For some, medication provided a way to function within the unchanging system:

> The medication helped me work with the typical environment, right, the, the normative environment. I was able to be everyone else. I was able to be what everyone else could do and that was great, but my worldview hadn't changed. Well, so if the system changed when I wasn’t on medication that'd been great, but I could work with the system when I was. (Mathias)

Participants described how public perspectives and understanding of ADHD were lacking at the time they were diagnosed. They felt strongly that the education system and other systems they inhabited were not accommodating of children with ADHD. They also expressed their desire for others around them to understand, support and include them better.

> If they change the academic system, which isn’t gonna happen overnight of, to situate people with ADHD and learning difficulty so it was more active and less, like active learning as opposed to just classroom-based stuff, it'd probably work a lot better…(Adam)

> A form of, you know, a welcoming environment and…there should be more, you know, you should not be, you should not feel secluded in…you should feel a part of society, you should feel a part of your group, your class,

> whatever. I think, uh, that it alleviates half of the pain and agony that you're dealing with (Vihaan)

However, there was also feeling that public perspectives have shifted over time, and ADHD is more widely recognised now. Participants expressed a desire for more awareness and understanding of ADHD publicly to reduce social and societal stigma.

> Ermm, when I was diagnosed, there was very little understanding about ADHD and its effects in schools, and there was very, there was very little training and sort of information for teachers and academics in school. (Rory)

> I don't think it's stigmatising anymore because of social media. I think it's become such a norm that ‘oh ten ways you might have ADHD’, right? Just trivialises it completely, which is another conversation. But I think it also has the effect of normalising ADHD as well. (Mathias)

3.5.3. Sub-Theme: Feelings of Difference and Struggles to Fit In

All eleven reported a degree of harmful social experiences, stigma from others or society, or de-validation of their experiences by others. Participants linked most of these experiences to misinformation and a lack of understanding not just from those around them, but society as a whole.

All eleven participants described qualitative feelings of difference from their peers:

> I just, I knew something…I knew, I always knew I wasn't like other kids (Max)

> I’ve always felt…different, like, in terms of how I understand situations, in terms of how I follow conversation, how my… kind of brain works and just how I perceive certain things…(Nina)

> I was seeing so many other people in high school live their lives in such a…a normal way and I was always the odd one out, I was always not quite the same. (Rory)

Whilst some participants did not feel different in their early childhood, by adolescence they were ‘acutely aware’ of the differences between them and their peers, often concluding that something is ‘wrong’ with them.

> My brain didn't work as everyone else’s did. I actually think that’s what the psychiatrist said, ‘your brain doesn't work like everyone else's’ and I I kind of understood that as ‘my brain's broken’. (Mathias)

> I began to understand that there was something wrong, compared to like other other kids that I had to be like, sort of separated and and given extra attention. (Rory)

These feelings of difference and ‘something being wrong’ with them understandably had significant effects on young people’s self-view and wellbeing. Many (8) participants described difficulties with forming new relationships, struggles in social situations and not fitting into friendship groups, with three feeling socially isolated:

> I struggle with social queues, I I struggle with, I I still speak my mind quite a lot as well, and a lot of it is…It's not always the nicest. My girlfriend says I've got no filter and I do really struggle with it. (Adam)

> I think I think it was just more about just feeling different…like just feeling like I couldn't…kinda like talk to people or make conversations, so I’d just kind of like, just avoid everyone just to stay away from trying to havin to talk. (Liam)

Adam spoke about losing friends who could not deal with his real self, whilst James and Max described being more susceptible to peer pressure. Nina and Max described finding out there were peers trying to make friends with them with the intent to ‘seem nice in the eyes of others’ or to ‘control’ them.

Young people strived to overcome feelings of difference by hiding elements of themselves, in other words, ‘masking’, which was mentioned in various different forms in participants’ accounts of striving for social connections:

> Umm at school I would naturally put on this mask, but then when I was at home and I'd get told ‘Why are you doing this, stop this, that's childish, stop

> doing that.' I then had to try and, I need to take the mask away from school and put it into home. (Grace)
>
> The fact is that I couldn't fully be myself. Because the majority of the world found it unacceptable. (James)
>
> Externally when you look from outside, no one used to be able to tell what's going on, I don't know, what it's doing and how pain and agony is feeling (Vihaan)

In the process of masking, young people tried to hide the 'unacceptable' parts of themselves with the aim of being like others, being 'normal'. Participants often expressed the great personal cost of masking and trying to fit in:

> So probably like a few years ago was actually the point when I started to realise that, a lot of my sort of feelings of depression come from masking. And actually I'm literally suppressing feeling like almost like meltdowns, and I'm like masking, and I'm making myself depressed. (Freya)

3.6. Theme 3: The Treatment Journey

The third overarching theme captures participants' experiences in relation to their treatment journeys, exploring their agency in the process and how this evolved over time.

3.6.1. Sub-Theme: Agency in Treatment-Related Decisions

Young people's ability to advocate for themselves, have their voice acknowledged, and feel empowered varied greatly. Their agency in treatment-related decisions fluctuated as a factor of their age, parental views and involvement and the approach of professionals and other adults.

3.6.1.1. Not Involved in Treatment-Related Decisions

Six participants said they did not feel involved in treatment-related decisions in the process of diagnosis and medication prescription. For some, like Max, this felt natural due to their young age, recalling feeling happy to be taken out of school for appointments. Others spoke about their voice not being sought in treatment-related decisions, or feeling unable to share their views, even when they reached adolescence:

> I would, rather than speaking about all the bad thoughts I was having, all the suicidal thoughts I was having, I just told them, kind of like what my mum wanted them to hear so I could get the ADHD diagnosis, I think. I I think my my mum did do a lot of talking as well because I, I do…struggle to talk about a lot of things. (Liam)

> They [the psychiatrist] were asking my parents quite a lot of the questions of how it was affecting <u>me</u> and it's like, I'd never really tell anyone how it was actually affecting me because obviously as long as I was doing better in school, and I wasn't getting in as much trouble then they were obviously working. (Adam)

> I wanted to give my opinions, but my opinions were not very, uh considered. So…yeah only GP's, what they felt relevant, they did their own stuff. (Vihaan)

Similarly, Mathias shared 'My parents were asked. I wasn't asked, I was just given.'. Mathias spoke about professionals involving him more in his brother's ADHD diagnosis at a younger age, than in his own diagnosis aged 16. This sense of disempowerment was present in participants' accounts of others in positions of power, often medical professionals, 'knowing what's right' for them:

> My parents didn't want to give me medication at a young age, but I was, you know, that's what the doctor told me to do, and the doctor's right, because you know, the power (Mathias)

Two participants used stronger language, to describe feeling like they had no choice but to take ADHD medication, feeling ‘forced’ by their parents who had good intentions of helping them:

> So I think they they [my parents] just seen that I was having troubles and kind of forced that [the medication] upon me…as some kind of help. (Liam)
>
> My parents convinced me, uh, I would say…forcefully, uh…Uh, not a bad intention, their intention was good…(Vihaan)

Participants also spoke about the process of frequently changing mental health professionals feeling ‘terrifying’ and ‘troublesome’, and James described a powerful visual of having frequent changes to his medication: ‘I used to think of it as like myself as a jug, like a jug of water, and basically the jug is me and the water is the medication.’ James goes on to describe that the ‘jug’ would have to be filled more and more after each growth spurt, until he reached the highest possible dose.

Five reported not receiving information about what their ADHD medication does and described poor communication from professionals. One young person developed a mistrust of professionals and the medical system:

> I I don't want to see them [professionals] and they're not helping me out or, uhmm, everyone is against me and nothing is going in my way so…distress and lack of belief, I would say. (Vihaan)

3.6.1.2. Involved in Treatment-Related Decisions

The other five participants described positive experiences of being involved in treatment-related decisions:

> We were able to have those conversations. And he [the doctor] was basically like, he managed in his own way to explain why I am the way that I am. (Rory)
>
> So my mum kept me very much involved. She felt like because it was my condition I should be involved in the process (James)

> I literally persuaded, uhm my mum so that we could, I could get the prescription prescribed like medication and just so that I I wanted to try and…I wanted to cope better and I I just wanted to, you know, fit in kind of (Nina)

> My CAMHS mental health nurse was amazing and she was really great, and I loved going to see her. (Freya)

Almost all of them spoke about having medical professionals who were attentive and understanding, taking the time to explain things to young people in a way that made sense to them. Participants also mentioned doing their own research into ADHD and ADHD medication, and the feeling of empowerment this brought them.

3.6.1.3. Feelings About Receiving an ADHD Diagnosis and Medication

Most participants felt their ADHD diagnosis was ‘affirming and useful’, and helped to explain their difficulties and struggles:

> I think the diagnosis is extremely helpful. I think we need to have diagnosis for ADHD so that we can get the support in place. (Mathias)

> I remember like, going through the questions and stuff, I mean and like ‘Oh my God, like this makes sense.’ And like this actually does make sense of why things are like this. (Freya)

However, for some, they did not feel the diagnosis and treatment was helpful or appropriate, as in Liam’s case, who was diagnosed following a traumatic childhood experience so that ‘some kind of support’ could be put in place, as he was, understandably, struggling to cope. Vihaan also described that whilst he was happy to finally get a diagnosis, over time he did not find this useful and began questioning it:

> There is no good standard for diagnosing, so one person says this, another one will say this, another one will say this. (Vihaan)

3.6.1.4. Alternatives to Medication in Childhood

Six reported not receiving any other support apart from medication:

> So I was kind of left for two years at school without any support. Uhmm, they didn't realise that I even had ADHD, even though I was taking tablets to school. (Grace)
>
> I don't remember there being any sort of…like, systemic environmental support. It was more like…you gotta…this is my biggest frustration with with the system (Mathias)

When young people were offered support in school, this was often after a long delay, and at times did not meet their needs, for example in the case of support offered to James, "…the only thing that came of the SENCo (Special Education Needs Coordinator), sort of hidden away area, was my development of the love of the game Uno'. Others, like Rory, report that school support brought a positive impact: "By the time that I'd left primary school, I was receiving so much support that I didn't feel like I was, I was being left out, which is amazing.".

None of the participants spoke about receiving psychosocial interventions or coping skills to help them with ADHD. One was referred to the school counsellor, however this support was not related to ADHD, and one participants' mother attended a parenting group. Other sources of support or attempted support for young people and their families included lifestyle and diet changes (n=3), sports (n=2), and social support group (n=1).

3.6.2. Sub-theme: Treatment-related Decisions and Outcomes Over Time

3.6.2.1. Medication-Related Decisions Over Time

Over time, all participants reported their agency in treatment-related decisions increasing. Throughout adolescence and in young adulthood, over half (6) chose to stop taking medication due to severe adverse effects, increased agency and seeking control, the medication not working for them or losing effectiveness over time. Two others did not have a choice but to stop due to the gap between CAMHS and adult services and no longer ‘qualifying’ for ADHD medication.

> By that point I realized that my tablets were basically just me putting on a mask every day so that everyone else could cope and I was unhappy. Um, that's when I made the decision [to stop taking medication]. (James)

For James, Max, and others, stopping medication led to an increase in wellbeing and sense of authenticity. On the other hand, Liam and Rory expressed regret at the decision to stop medication at the age of 16, leading to an increase in their academic difficulties and later substance misuse.

> I think it was just like, I think I just wanted to try live a life without medication. Uh, and see how it affected me and…it, I'll be honest, it was just a blur, I don't remember that much about that time. Ermm ((pause)) thinking back now, I regret making that decision [coming off medication] wholeheartedly. (Rory)

Rory, and Barbara and Grace, who stopped medication due to the gap in services, re-started medication in their adulthood, reporting more control, agency, and knowledge in their treatment-related decisions as adults.

> Yes, so I went back on it when I was [age]. And that's because effectively I got to the stage where I was so anxious, I like, was shaking one day and uhm I went to see my GP and she went ‘I think your ADHD is really the issue here. Let's get you back to see a psychiatrist and see what's happening.’ (Barbara)

Three participants expressed their views that ‘children shouldn't be prescribed it [medication] from such a young age’ (Mathias), whereas one felt the opposite, ‘if you actually treated people properly earlier, other issues wouldn't happen’ (Barbara).

3.6.2.2. Coping in Adulthood

Participants reflected on their journey and experiences of ADHD throughout the years. Over time, most individuals (8) found they moved towards self-acceptance and developed ways of coping and managing day-to-day:

> But actually like, no, it's okay like it's okay to be who you are and be the person like that, and not try and be like other people. (Freya)
>
> I do get excitable and I think my friends quite like that as well, and I think that is what makes me me now (Mathias)
>
> I do quite a lot of exercise now. I do personal training, I…um, I'm doing a stretch session with some friends and, doing, I do boxing on a [time of week]. So I do, I find it helps. (Barbara)

Some participants spoke about feeling like they have 'grown out of' parts of their ADHD, and feeling like they are in a better place now.

Others described ongoing struggles and uncertainty in recent years:

> My relationships were failing and you know obviously I had gone through a very severe three-year long addiction and recovery. (Rory)
>
> You know, ADHD, I'm still suffering from that…I'm still, so it's very long time that I'm suffering from this and still I'm not able to find answers and no relief in my symptoms (Vihaan)

In summary, these rich accounts of participants' journeys over time illustrate the complexities faced from childhood to adulthood in negotiating individuals' understandings of themselves and the world around them.

4. DISCUSSION

4.1. Chapter Overview

This final chapter considers the findings of the research in relation to the research aims and in the context of existing literature. Implications of the research findings are discussed for different domain levels, along with limitations and future directions. The chapter ends with a reflexive review and conclusion.

4.2. Discussion of Results

Results of this study explored ADHD medication-taking experiences in childhood, with the aim to expand understanding beyond the effects on behaviour management and academic achievement. Specifically, this study aimed to engender a better understanding of the effects of ADHD medication on young people's sense of self and relationships, and their evolving experience of ADHD and ADHD medication into their adulthood.

The following research questions were explored through 11 semi-structured interviews with participants across the UK:

- How did ADHD medication affect people's sense of self and their relationships with others in childhood?
- What was people's experience of ADHD diagnosis and medication in their childhood, and over time?

Three main themes were identified through thematic analysis: 'Intrapersonal', 'Interpersonal' and 'The Treatment Journey'.

4.2.1. How did ADHD medication affect people's sense of self and their relationships with others in childhood?

4.2.1.1. Self-view, Authenticity and Stimulants

When considering the effects of ADHD medication on the sense of self, the main question is *Is the 'me' on medication the same or different to the 'me' off medication?* Participants in this study evidenced mixed perspectives, with six expressing they felt qualitatively different when on medication in their childhood, whilst three reported the same essential 'self' when medicated and unmedicated.

As discussed in the literature review in chapter one, research in the area of ADHD medication and self-view is inconclusive. In Singh's Voices on Identity, Childhood, Ethics and Stimulants (VOICES; Singh, 2013b) study, for example, the research team found that only 8% of children (N=151) reported an impact on authenticity. This stands in contrast with qualitative work covering the lifespan, such as the qualitative synthesis by Eccleston et al. (2019), who identified that young people in the studies reviewed 'consistently' reported feeling 'different' when on medication and some reported 'a loss of identity'. These terms were used by some of the participants in the current study, suggesting this difference between the two 'selves' as negative – medication contributing to losing, distancing, covering up the true self. Others, however noted that the change the medicated self brought was welcomed, as it unlocked their potential and enhanced their abilities, helping them fit in and be like others.

This raises important questions around what 'the true self' and 'authenticity' might mean for individuals. Bolt & Schermer (2009) discuss the different sides of the empirical debate, with some researchers viewing psychotropic medication as removing the barriers to individuals being their 'true' selves, whereas others positing that psychotropic medication separates us from who we truly are, resulting in an inauthentic self, designed to fit society's ideas of what is 'normal' (Elliott, 2004; Kramer, 1997; Riis et al., 2008).

Importantly, for those taking psychotropic medication, this was more than an empirical debate and involved the weighing of the perceived benefits and adverse effects of medication. Individuals sharing their stories in the present research expressed varied views, aligning with both sides of this debate. Freya spoke about medication helping her access parts of herself she was not previously aware of and starting to care more about herself, and Matheas discussed how, in many ways, he preferred being on medication as it helped him feel like he was on the ‘same level playing field’ as his peers. Both of these experiences might be considered to fall into the realm of medication removing barriers to these young people’s authenticity (Riis et al., 2008). On the contrary, Nina and Grace both spoke about their medicated selves feeling disconnected in some way from their true ‘core’ selves in adolescence, and James described it felt like putting on a mask. These accounts are closer aligned with experiencing the medicated self as inauthentic (Elliott, 2004). Ultimately, individuals have varying experiences of the degree to which stimulant medication helped or hindered their authentic selves to be expressed, and theories of authenticity can provide a lens through which these different experiences can be understood.

4.2.1.2. Feelings of Difference

All participants described qualitative feelings of difference from others. Whilst some of these feelings of difference are independent of medication effects, they are closely tied in with participants’ self-view. Participants provided varied accounts of their experiences of difference, with some speaking of always knowing they were ‘the odd one out’, whilst others described only realising they were not the same as their peers in their adolescence. Feelings of difference from others have been widely reported in the literature (Gallichan & Curle, 2008; Krueger & Kendall, 2001; Travell & Visser, 2006). It is difficult to tell whether feelings of difference arose as a result of young people’s ADHD diagnosis. Rather, it appears that young people started using diagnostic and medical language to put these feelings into words, for example, stating ‘my brain works differently’. For some, this appears to have further reinforced and deepened a sense of difference, for example in Mathias’ case who took the psychiatrist’s explanation to mean that his brain was ‘broken’. It is possible that medication might then come to be perceived as a way to ‘fix’ this ‘brokenness’ or difference (Meaux et al., 2006).

Participants shared accounts of others finding their behaviour, ways of thinking or essential parts of their inner selves ‘too much’, ‘weird’ or ‘not normal’, experiences echoed in other qualitative studies (Gallichan & Curle, 2008; Walker-Noack et al., 2013; Wiener & Daniels, 2016). Understandably, these interactions with the world fuelled further internalised feelings of difference. As an attempt to resolve this, some young people attempted to hide ‘unacceptable’ parts of themselves and fit in with others through ‘masking’. Over time, however, masking often came at a great personal cost, affecting young people’s mental health (Becker et al., 2012). These findings can be seen to contextualise why individuals with ADHD demonstrate a higher level of psychiatric comorbidity (Cadman et al., 2016; Weyandt et al., 2013).

4.2.1.3. Medication and Social Relationships

The findings of this study indicate that individuals experienced both helpful and hindering effects of stimulant medication on their social interactions and relationships, and interviewees embraced these in equal numbers. Some reported medication helped them in providing them with the headspace or energy to interact with others. Helpful aspects shared by participants included feeling like they could understand others more, and feeling more similar to others, which some described as feeling more ‘normal’. Nina described her relationship with her sister improving after she received her ADHD diagnosis and medication, as this helped to explain differences between them and brought them closer. These individual experiences are consistent with literature reporting that medication supports ‘the alleviation of ADHD symptoms’ to improve social behaviours (Boland et al., 2020; Charach et al., 2014). Similar findings were also reported by Singh (2010), although it is important to note that the participants in the current study did not emphasise the reduction in behavioural difficulties in a social context, but instead spoke of medication’s benefits in slowing their racing thoughts down and helping them focus on others, which supported them with their social relationships.

Conversely, the other half of participants reported that medication had an adverse effect on their spontaneity and their fun side, with some losing the interest or energy to socialise with others and becoming ‘a social recluse’, findings also reported by Brinkman et al. (2012) and Meaux et al. (2006). Similarly to the young people in

Avisar & Lavie-Ajayi's (2014) research, participants reported feeling more social, active and lively when unmedicated. For Adam, these deficits in socialising experienced in adolescence led to missing out on key developmental experiences in connecting with peers (Erikson, 1968, 1994) . Looking back as an adult, he expressed regrets at his social self being ‘blocked’ in adolescence and reflected on these difficulties resolving when he stopped taking ADHD medication.

An interesting finding is the clear distinction five participants made between their unmedicated versus their medicated selves, describing the unmedicated self as more ‘social and fun’, and the medicated self as more ‘academic and focussed’. Whilst previous research has separately reported these effects of medication on academic performance, the adverse effects on social functioning have mostly been interpreted as constellations of side effects of the medication (Brinkman et al., 2012; Fleishmann & Kaliski, 2017; Levy, 2020). The distinction the five participants in this study made between the two selves, however, needs to be highlighted, especially as there has been a call for research to focus on social functioning (Fleishmann & Kaliski, 2017; Singh et al., 2010). The differences experienced between their medicated and unmedicated selves led young people to a double bind, as they described weighing the benefits of ADHD medication academically with the drawbacks on their social capabilities (Bolt & Schermer, 2009).

A further striking finding was in participants’ accounts of taking medication not for themselves, but for others around them. Some participants spoke of this with vivid examples of knowing they needed to take medication as a child as they were a handful and hard to handle and needed to ‘make life easier’ for others around them. James spoke about having days when he ‘wouldn’t let the tablets work’ so that he can be himself, and other days when he ‘would let them work’ to help others. There was also a feeling amongst some young people that medication helps them ‘not go off the rails’, and despite experiencing negative effects they worried about what might happen if they stopped taking medication. These findings are curiously not well-documented in ADHD literature (Avisar & Lavie-Ajayi, 2014), however appear in wider literature focussed on adolescents’ medication-taking experiences, with young people stating that their medication is not for them but for their parents and others around them (Floersch et al., 2009).

4.2.1.4. Functioning Within The System

Despite the aforementioned effects of medication in areas related to social functioning and authenticity, most participants reported, retrospectively, that they needed to take ADHD medication to succeed academically. This is consistent with findings from Eccleston et al.'s (2019) meta-synthesis, which identified academic performance as the primary criteria young people, their parents and clinicians used in determining the efficacy of stimulant medication. This raises important questions around societal values and pressures for academic success that young people are positioned to prioritise. Western society values high academic success, however some young people embody alternative strengths and might struggle to learn in the ways expected by traditional education systems (Wiener & Daniels, 2016). This has been referred to as ‘fitting square pegs into round holes’ by Gallichan & Curle (2008). Crucially, they found that where the system (the ‘hole) adapted to the child (the ‘peg’), children did not report experiencing difficulties. Young people’s understanding and experiences of ADHD therefore appeared to be influenced by their inability to meet various societal expectations (Eccleston et al., 2019).

Here it is useful to consider the wider picture in the UK: the growing pressure and expectations towards young people from the current academic system, including the underfunded education sector and teachers who are often overwhelmed, overworked, and underpaid (Burrow et al., 2020). Despite young people’s struggles, evidence of their ADHD diagnosis and medication, the systems around them often did not adapt to their needs. As one participant stated, ‘the system doesn’t want to come down to my level’, and others spoke about unchanged expectations in academic environments, and at times even judgement and negative singling out by school staff. In the face of the rigid and unchanging systems they navigated, young people were left to shoulder the burden of treatment in order to function within these systems (Avisar & Lavie-Ajayi, 2014).

This key finding is not widely present in ADHD research with young people, but has been described in research on psychotropic medication and wider systemic factors more generally (Angermeyer et al., 2016; Flore et al., 2019). As participants in the research were adults reporting on their childhood experiences, it is possible that their perceptions had an added layer of reflection, and therefore these findings are more absent from research involving adolescent participants. What is common with these findings and previous research, however, is participants' desire for the academic system and others around them to understand, support and accommodate them better (Jones & Hesse, 2018; Schaefer et al., 2017; Singh et al., 2010; Walker-Noack et al., 2013).

4.2.1.5. The Impact of Social Context

All participants spoke of the impact of navigating positive and negative social experiences. Despite general feelings of divergence and not fitting in with peers, most reported at least one supportive person in their lives, who was accommodating, compassionate, understanding or advocating for their needs. Research shows that children with ADHD generally report lower levels of social support than their neurotypical peers, and increasing levels of social support can promote self-concept and wellbeing (Mastoras et al., 2015). Indeed, most participants who reported significant ongoing struggles in their adulthood also reported lower levels of social support.

The findings of this study do not fully support previous findings reporting that young people with ADHD have fewer and more volatile friendships (Blachman & Hinshaw, 2002; Hoza, 2007; Normand et al., 2011). Although participants generally reported struggling with forming new relationships and fitting into wider social groups, most shared stories of forming meaningful and lasting friendships with like-minded peers, which helped them feel a sense of belonging (Dvorsky et al., 2018). It should be noted, however, that three participants reported feeling socially isolated, affecting their wellbeing and outcomes in adulthood (Kwan et al., 2020).

Harmful social experiences, bullying, labelling, stigma and de-validation of their experiences by others were experienced by all participants. This is a finding consistently reported in research (Levy, 2020; Mckeague et al., 2015; Walker-Noack et al., 2013; Wiener & Daniels, 2016). Many young people appeared to internalise these negative experiences, further impacting on their low self-esteem and feelings of difference, and contributing to young people's decisions to hide parts of themselves away (Fonseca et al., 2019). Negative judgement and stigma from adults, such as teachers, was also notable in participants' accounts. Similarly to young people in Kendall's (2016) study, who were regularly shouted at and singled out, these experiences led to an exacerbation of academic difficulties and negative self-image. Participants expressed a desire for more knowledge of ADHD publicly, to reduce social and societal stigma, and many spoke about the positive effect of social media and growing awareness in recent years (Bergey et al., 2018; Bisset et al., 2022)

4.2.2. What was people's experience of ADHD diagnosis and medication in their childhood, and over time?

4.2.2.1. Agency in treatment-related decisions

How much young people's voices were sought and considered in their treatment varied greatly between participants as a factor of their age, parental views and professionals' approach. Some participants described little to no involvement in decisions about their own treatment. Medical professionals engaged almost exclusively with their parents, or they attempted to voice their views, but these were not listened to. Strikingly, these experiences were reported independently of participants' age, and some described not having agency in their treatment even in late adolescence. Despite evidence and treatment guidelines on best practice, it appears that these young people were not considered as stakeholders and equal decision-makers in their care. Brady (2014) describes how this can be linked to pathologizing children's behaviour and merging the child with their ADHD diagnosis, leading to children being "regarded as incompetent, impulsive, irrational and incapable of being responsible" (p. 226). Mathias' striking account of his involvement in his brother's ADHD diagnosis in childhood, but not in his own diagnosis in late adolescence raises ethical questions around diminishing the value of young people's voices once they are "the identified patient" (H. C. Johnson, 1987). Are the voices of children with ADHD sought and valued less in treatment-related decisions than the voices of children without the diagnosis? The danger here is that these children's complex emotional, psychological and social experiences are overlooked in favour of needing to achieve a reduction in symptoms.

Those who were younger at the time of diagnosis described not really knowing or caring much for the diagnosis process and being happy to be taken out of school. In terms of cognitive development, younger children at the pre-operational and concrete operational stages are reliant on their carers and most will act in ways aligned with adults' wishes (Fischer, 1980; Piaget, 1970). As Singh (2013a) notes, "concrete reasoning and a desire to please adults may increase the risk that stimulant drug treatment 'bypasses' moral struggle" (Singh, 2013a, p. 361). Accordingly, some participants voiced concerns over children being prescribed medication from a young age, whereas others felt that early intervention using medication leads to less social and emotional difficulties further down the line.

Children and adolescents can be viewed as unreliable informants and decision-makers in their care, which is alarming when considering that they are the ones carrying the burden of treatment (Avisar & Lavie-Ajayi, 2014; Bussing et al., 2012; Ibrahim et al., 2016). Participants spoke about 'the doctor knowing best' and the power exerted over them in decision-making, with two individuals describing feeling forced to take medication despite finding this ineffective and suffering from adverse effects. These findings are consistent with literature documenting discrepancies between self- and informant-reported effects, with young people often reporting the influence of medication on their well-being as less significant and reporting more serious adverse effects compared to the adults around them (Brinkman et al., 2012; Charach et al., 2014). Looking back on their childhood experiences from an adult's eyes, participants expressed a desire for better communication and more information from professionals and adults around them, and an empowerment and value placed on their younger selves' voices. Young people with a diagnosis of ADHD are competent reporters of their own experiences, and their moral reasoning and agency should be recognised as such (Alderson, 2014; Brady, 2014).

Conversely, the other half of individuals reported positive experiences of being involved in treatment-related decisions, experiences of their voices being valued and taken seriously in decisions about their care. Common amongst these experiences was the involvement of medical professionals who took their time to get to know and understand the young person and explain things in a developmentally appropriate way (Cheung et al., 2015; Fleishmann & Kaliski, 2017). Shared decision-making is highly valued by adolescents, and prerequisites to this include building mutual trust and establishing a good therapeutic relationship (Bjønness et al., 2020; Bussing et al., 2012). Consistently highlighted both by existing research and participants' accounts is the need to look beyond the diagnosis and think about addressing the individuals' needs. This brings up questions around the current rates of ADHD diagnosis and the potential lack of capacity in CAMH services to build meaningful connections with each individual child, and consider their needs holistically (Efstathopoulou et al., 2022; McNicholas et al., 2020).

4.2.2.2. Diagnosis and Treatment Journey Over Time

Whilst those diagnosed at a young age did not fully understand it at first, diagnosis came, for many, to be seen as affirming and helpful in adolescence. Participants described how their ADHD diagnosis 'made sense' in explaining their difficulties and struggles, and for some led to more support and better recognition of these difficulties in academic settings. Most defined ADHD in biobehavioural terms, as a condition rooted in genetics and differences in brain function and neurobiology, similarly to young people in other studies (Charach et al., 2014; Gallichan & Curle, 2008; Honkasilta et al., 2016). Whilst some saw ADHD as a 'debilitating disease', others spoke about seeing it as a 'difference or dysregulation' rather than a disorder.

Importantly, ADHD was also seen as an integral part of how young people defined themselves, with ADHD bringing energy, vitality, friendliness, and new connections, drive to pursue hobbies and the ability to work in busy and fast environments, amongst other positive aspects described by participants. Whilst reported by some studies, most research on ADHD-related experiences is heavily deficit-focussed (Brinkman et al., 2012; Knipp, 2006). Furthermore, positive associations likely became more salient in participants' self-views as they moved through adolescence and young adulthood, and many came to a position of self-acceptance. For some, however, the struggles and uncertainty persisted, and they were left to continue looking for appropriate treatment and support (Fields et al., 2017).

As documented by previous research, children's agency increased over time, and they became more involved in their own treatment as they got older (Brinkman et al., 2012; Levy, 2020). As young people sought more control and independence and made sense of their experiences, some felt the balance in trade-offs between the benefits and adverse effects of medication had shifted, leading to their decision to discontinue medication. Individuals' journeys over time appeared to be mediated by perceptions of the congruence between their evolving self-view and the effects of medication. This points to a complex interaction between self-creating and self-discovery, where the role of medication is negotiated and re-negotiated over time (Fleishmann & Kaliski, 2017).

4.2.2.3. Experiences of Treatment

ADHD medication was generally described as effective in reducing inattention and impulsivity and helping young people better concentrate in academic settings, a finding reflected in the literature (Charach et al., 2014; Cheung et al., 2015). Some young people experienced less ups and downs in their thinking and emotions, as well as a slowing down of their racing thoughts. This led to a sense of empowerment and newfound focus, mainly in the academic sphere, but also at times socially and personally (Fleishmann & Kaliski, 2017). Being on medication could make it easier to fit in and to navigate social contexts, to understand others and to decide where to direct one's attention. Once again, a continuum of trade-offs was described by individuals, with some finding medication more effective than others.

However, consistent with findings by Hechtman et al. (2016) and others, who found that 20-30% of the young people considered medication to be ineffective, three participants reported not experiencing any helpful effects. Liam described his diagnosis following a traumatic event in primary school and spoke about not being believed and validated by adults around him, leading to his parents seeking the diagnosis in an attempt to resolve what was viewed as ADHD symptoms. Research has recognised that the ADHD diagnostic label may 'mask' experiences of trauma, and as such can result in a misdiagnosis and surface-level management of symptoms, without addressing the core problem (Foltz et al., 2013; Szymanski et al., 2014; Weber & Reynolds, 2004). Sari Gokten et al., (2016) report that in a sample of 104 children with ADHD and 104 with no diagnosis, ADHD children were exposed to significantly more physical (96.2%) and emotional abuse (87.5%) compared to controls (46.2% and 34.6%). The causal relationship between trauma and ADHD continues to accumulate evidence, as discussed in Chapter 1. This is an important finding for further investigation through research, especially as research also points to trauma disrupting critical development windows and milestones, resulting in shared symptoms and characteristics between PTSD and ADHD (Weber & Reynolds, 2004; Weinstein et al., 2000).

Adverse effects were reported by all but one participant. Some described these effects as scary and unexpected. Adverse effects not mentioned in official NHS guidelines included urinary problems, memory problems and fatigue. Importantly, the degree of intensity of side effects reported by several participants is classified by the NHS as ‘serious and uncommon’, meaning it should occur in less than 1 out of 100 people (NHS, 2021). These are high blood pressure and heart palpitations, suicidal thoughts, and tics, all reported by three participants (27%) in the sample. Furthermore, two participants continue to experience adverse effects (urinary problems and tics) which did not resolve, even after discontinuing or changing ADHD medication. Adverse responses such as insomnia and sleep difficulties, appetite suppression, nausea, dizziness, changes in mood and depressive states are commonly reported in the literature (Cheung et al., 2015; Gallichan & Curle, 2008; Meaux et al., 2006; Schaefer et al., 2017; Sciberras et al., 2011). Urinary adverse effects have been found in a recent meta-analysis (Trinchieri et al., 2021), whereas memory problems have not been documented as an adverse effect, and would require further research. Despite adverse effects being reported across qualitative research, these do not seem to be reflected in official NHS guidelines to the same degree of severity and prevalence. One possible explanation of this discrepancy is the lack of conclusive large-scale studies and meta-analyses on adverse effects (Pozzi et al., 2018). As described by Read & Williams (2018), asking people directly reveals higher rates of adverse responses than when relying on traditional research methodologies. Understanding the extent of adverse responses to medication is imperative to informing treatment options and decisions for those with a diagnosis of ADHD.

Apart from pharmacological treatment, no form of psychosocial treatment for ADHD was offered to young people. Only one participant was aware of their parent partaking in a parenting group and one other reported receiving counselling in school, however this did not focus on ADHD specifically. This is an important finding, considering the effectiveness of behavioural interventions for ADHD has been well-established and researched (Coates et al., 2015; Daley et al., 2014, 2018; DuPaul et al., 2020; Vacher et al., 2020). Despite research and meta-analyses indicating that psychotherapeutic interventions are not inferior to pharmacological management, the former remain scarcely considered in treatment-related decisions, or are considered only in ‘high risk and comorbid cases’ (Lambez et al., 2020; Linderkamp & Lauth, 2011; Scholle et al., 2020). This lack of treatment and support options, other than medication has been reported in other studies (Carr-Fanning & Guckin, 2018; Cheung et al., 2015; Sikirica et al., 2015). However, it is also important to note that participants in this study reported lower levels of non-pharmacological support than some studies find. For example, a U.S. large-scale parent-report study indicated that of the 77% of children aged 2-17 who received treatment following ADHD diagnosis: 30% were treated with medication alone, 15% received behaviour treatment alone, and 32% received a combination of both (Danielson, Bitsko et al., 2018).

There is a possibility that due to their young age participants were not aware of support offered directly to their parents or family more widely (such as behavioural parenting interventions), as parent support is the first line of treatment in the UK according to NICE guidelines (NICE, 2018). Many described a lack of general academic support, and when offered, this being significantly delayed and not meeting individuals’ needs. It is important to note that a few described helpful academic and learning support and reported feeling well-supported in school. Over time, participants became resourceful in learning ways to cope, such as through high-level sports activities, online CBT accessed as an adult, and lifestyle changes, alongside decisions regarding the continuation of medication.

Overall, individuals’ journeys over time took unique trajectories, and were both influencing and influenced by young people’s experiences of the world, their relationships, and self-views.

4.3. Implications

The study’s findings highlight the importance of a deeper understanding of young people’s complex experiences of ADHD medication-taking, and the need for organisational and systemic change to reduce stigma and improve support. Implications at different levels of the system are discussed.

4.3.1. Individual

Findings suggest ADHD medication has different effectiveness and adverse effects for different people, and points to the need for individual children's circumstances and wellbeing to be considered rather than treating the ADHD label uniformly. Taking a longitudinal view of adults reflecting on their childhood gives us a glimpse into experiences and learning they found helpful and that led to positive outcomes – namely, moving towards self-acceptance and learning coping skills, both of which will be considered below.

Self-acceptance and self-compassion are linked to social experiences and messages from others and the world towards acceptability of 'the ADHD child', and therefore need to be addressed in tandem. One way of achieving this may be through mentalisation-informed psychodynamic psychotherapy approaches, such as the Cultivating Compassion ADHD Project (Conway et al., 2019). This approach specifically aims to change the way children with ADHD are seen by others and by themselves, with a focus on inter/intrapersonal dynamics rather than purely behavioural modification. Through involving not only the child, but their caregivers and teachers in therapeutic treatment, the child's internal world can be explored, and compassion can be cultivated in a way that de-pathologizes ADHD-related symptoms and fosters insight and self-regulation (Conway, 2015; Lusk, 2019). Mentalisation-based approaches map on exceptionally well to what participants described has helped them move towards self-acceptance, in creating a space for them and others to understand their experiences beyond circular explanations of 'the child misbehaves because they have ADHD' and 'having ADHD means they misbehave'. A key driver for change in mentalisation-based approaches is the understanding of how the child's behaviours are inextricably linked to their internal world (Badoud et al., 2018; Midgley et al., 2017).

Equipping young people with appropriate coping skills early on can be empowering and can positively impact later outcomes and wellbeing. Learning more behavioural strategies, such as time awareness, scheduling, and time management has been shown to be an appropriate first-line approach to treatment of ADHD symptoms (LaCount et al., 2018). Organisational and time management coping skills interventions have been shown to be effective for managing difficulties stemming from inattention, yielding similar effects to stimulant medications with a lower risk of adverse effects (Hartung et al., 2013; Rabiner et al., 2009; Weyandt & DuPaul, 2008; Wilens et al., 1998). Social skills training can be helpful for supporting young people to understand their peers and nourishing peer relationships, although it is important for social skills approaches to simultaneously target peer victimisation and stigma, and therefore to involve others around the young person (Willis et al., 2019). The importance of supporting children to nourish social connections should not be overlooked, as this has the power to cultivate long-term positive outcomes (Dvorsky et al., 2018; Mastoras et al., 2015). Relationship-based interventions should underlie all other support offered, creating a web of support around the child rather than placing the burden of treatment on them as individuals (Edelman, 2004).

4.3.2. Organisational and Family

Findings of this study indicate that some young people were not involved in decisions about their own treatment, and their voices were not sought or were minimised and disregarded. The possibility of young people's voices being diminished as a result of their ADHD diagnosis is concerning, especially as ADHD is a protected disability under the Equality Act (2010). Policy and legislation assert the rights of young people to be consulted and involved in the decision-making process on matters affecting them (Human Rights Act 1998; Children Act 1989). For professionals to meaningfully involve young people in their own care, conscious effort needs to be made to elicit young people's voices, with an awareness that young people might mask difficulties or might not share concerns in relation to treatment in fear of disappointing others. Building a therapeutic relationship and sharing information with young people in an age-appropriate way is the first step towards this (Stewart & Echterling, 2013). This is a key implication for clinical psychologists, who are well-placed to provide training and consultation in CAMH services and beyond, and to initiate change at an organisational level.

These implications are increasingly crucial to consider in the current climate of the NHS, with CAMHS waiting lists spanning multiple years for children to access diagnosis and treatment. The danger is that growing service pressures come at the detriment of evidence-based, multi-disciplinary and person-centred care due to a lack of resources and significant demands on clinicians' time (Efstathopoulou et al., 2022; Gascon et al., 2022; McNicholas et al., 2020). Furthermore, only searching for the ADHD constellation of symptoms runs the risk of disregarding significant life events, trauma, major life transitions, and adverse childhood experiences (Gnaulati, 2014; Harrison et al., 2011; Overmeyer et al., 1999). This increases risks of misdiagnosis, inappropriate treatment, and the medicalisation of children's expressions of distress.

Reviews of evidence-based psychosocial treatments indicate that Behavioural Parent Training, Behavioural Classroom Management and Behavioural Peer Interventions programmes have a robust evidence base and are well-established to be first-line treatments for ADHD (DuPaul et al., 2020; Pelham & Fabiano, 2008). Despite the evidence base for psychosocial treatments, UK NICE guidelines only include offering 'additional parent support', which "can be group based and as few as 1 or 2 sessions" (NICE, 2018). This is often used more as a pre-requisite before moving on to prescription of a variety of stimulant and non-stimulant drugs for children aged 5 and over. Cognitive behavioural therapy is only recommended "for young people who benefitted from medication but whose symptoms are still causing significant impairment". Findings of this study indicate that whilst pharmacological treatment was effective for some young people, for others there were either no benefits or these were outweighed by the costs and adverse effects. Despite this, medication was the only treatment offered to most. If young people are to be supported as individuals, rather than providing a blanket treatment for ADHD, a variety of evidence-based options need to be incorporated into national guidelines, including offering psychosocial and other non-medical interventions to ensure the best possible support and outcomes (DuPaul et al., 2020; Foltz, 2012; Vacher et al., 2020).

In conjunction with previous research (Anastopoulos et al., 2009; Breaux & Harvey, 2019; Johnston & Chronis-Tuscano, 2015; Zhao et al., 2019), implications for practice further indicate the consideration of involvement of the child's family in treatment and support. Apart from affecting individuals, ADHD impacts on the whole family and various areas of family functioning including parenting, parent psychopathology, and life stress (Dupaul et al., 2001; J. H. Johnson & Reader, 2002;

Margari et al., 2013). Family functioning and coping styles can influence child behaviour (McKee et al., 2004). Beyond the effectiveness of Behavioural Parent Training, several studies have explored the benefits of targeting multiple aspects of family functioning affecting ADHD symptoms, such as addressing parent depression (Chronis-Tuscano et al., 2013), stress and anxiety (Sanders et al., 2000), and parent ADHD symptoms (Babinski et al., 2014). Given the bidirectional relationship between child ADHD and family functioning, improving family functioning can result in a positive feedback loop, which improves child ADHD symptoms and in turn has a further positive impact on the family (Breaux & Harvey, 2019).

4.3.3. Wider Systems

Changes in supporting young people with ADHD cannot occur in isolation, and wider systemic action is needed to shift public perspectives, and the environments young people navigate. Wider systems implications below are discussed in conjunction with previous research, and with the acknowledgement that the results of this study are limited in scope and would require replication on a larger scale.

Findings of this study indicate that systems around young people were often rigid and not responsive to their needs. The education system's growing expectations are challenging to navigate for all young people, not just those with ADHD (Ball, 2021). Specific guidelines on school-based and environmental support would be highly beneficial for supporting young people outside of clinical treatment, as these are currently lacking and left to individual organisations (Moore et al., 2017; NICE, 2018). Ultimately, research shows that children report significantly less ADHD-related distress and difficulties where the environment around them adapts to meet their needs.

In the UK, there is a growing interest in early intervention and treatment of ADHD and other conditions. This might lead to earlier and earlier pharmacological treatments for young children's ADHD symptoms. For example, Morkem et al. (2020) reported that there was a 2.6-fold increase in prescriptions for children under the age of 5 between 2005 and 2015. However, this contradicts research showing that before the age of 5 all children have "little ability to sustain attention on task, [and are] easily distracted by irrelevant stimuli" (Stahl, 2008, p. 883). The underlying intention of early intervention lies in the early identification of support needs, and prevention of escalation of difficulties through wider changes (Rappaport et al., 1998; Shephard et al., 2022). However, currently, children face barriers to accessing key environmental support without having a diagnosis of ADHD, and CAMHS neurodevelopmental diagnostic waiting lists span multiple years, which leads to missing out on meaningful early intervention opportunities (Dan, 2016). Systemic changes and an increase in funding is needed for children and their families to receive support when difficulties arise, rather than being left without this for years (Jones et al., 2008). Clinical psychologists as researcher-practitioners would be well-placed to drive systemic change to improve early access to support for children, young people and their families.

Wider public perspectives are in constant flux, and although there is greater acknowledgement and recognition of ADHD now than when participants in this study were growing up, discussions around ADHD remain individualising, and still carry stigma and blame towards children's behaviours. Shifts in public perspectives need to be underlined by early psychoeducation on diversity in thinking, learning, and perceiving the world, which would in turn reduce peer victimisation and exclusion. There is potential to harness the ADHD community's power, and perhaps there has been no better time to do this - online spaces, social media, and people's sharing of experiences and knowledge is at an all-time high (Dauman et al., 2019; Mertan et al., 2021; Thelwall et al., 2021). In the current study, consultation with those with lived experience was hoped to improve the inclusivity and sensitivity of the research and highlight the importance of employing consultation as a standard when conducting ADHD or other mental health research. Using community psychology principles and co-creating guidelines for support and treatment with people with a diagnosis of ADHD could be a meaningful avenue for shifting existing power dynamics in practice and research, and amplifying the voices of those who were diagnosed and treated for ADHD (Seedat et al., 2001; Suarez-Balcazar et al., 2023).

4.4. Limitations

Several limitations must be considered when interpreting the findings. As with any qualitative study, the reading of research interview data is only one possible way of making sense of results, and there are multiple other possible interpretations of coding and grouping of the raw data. Despite efforts to minimise the influence of the author’s own values and biases through reflective logs, using reflexive TA, an inductive approach to data analysis, and the involvement of the research supervisor (see Chapter 2) the researcher’s lens inevitably shapes the research (Reissman, 1993; Stratton, 1997). Similarly, the author’s choice of questions and exposure to previous theory and concepts has likely influenced the analytic process and interpretation of results.

Participation was voluntary and participants self-selected. Although efforts were made to advertise this study widely using a variety of online platforms and through key organisations, it is likely that only those who felt comfortable sharing their experiences and ADHD journeys registered their interest to participate. This might mean that participants either had largely helpful or unhelpful experiences, and more neutral or mixed journeys were not adequately captured by the study. Findings must be considered in light of their lack of generalisability to all young people in the UK, due to the qualitative and small-scale nature of the study. Criterion sampling was initially implemented, followed by convenience sampling due to hurdles in recruitment. Whilst these efforts potentially supported the recruitment of a more diverse sample demographically, findings do not generalise to specific groups’ experiences. It is important to acknowledge that generalisability is not the aim of qualitative data (Willig, 2013). Rather, these findings offer important insights into understanding the complexity of human experience, the nuance of which is likely to be missed in standardised large-scale quantitative research.

Research interviews were conducted online, which brough the benefits of being able to include people from all across the UK. However, it might have also resulted in participants feeling less comfortable to share their experiences with the absence of a shared face-to-face environment and in-person queues. Furthermore, participants were adults, who reflected on their childhood experiences. This means that their accounts could have been influenced by recall bias and were interpreted from their adult selves’ perspectives. Nevertheless, this also brought the benefits of having processed and made sense of childhood experiences, which allowed the exploration of change over time.

An attempt was made to balance gathering enough demographic information to contextualise results whilst protecting the confidentiality of participants. The researcher therefore did not ask participants for certain demographic data, such as sexual orientation and family income, which might have provided a richer understanding of intersectional factors. Due to time constraints and the small scale of the present study, formal measures of participants' ADHD symptoms, strengths and difficulties were not conducted. Incorporating a standardised measure, such as the Conners' Adult ADHD Rating Scale (Conners et al., 1999) and a measure of social relationships and wellbeing, such as the Ryff Scales of Psychological Well-Being (Ryff, 1989) might have provided additional dimension to people's experiences through mixed method approach. Finally, participants were not required to report the exact type, length, and dosage of ADHD medication they were taking, which might have obscured dose-response relationships. Similarly, effectiveness and adverse effects might not apply to all types of stimulant medication equally.

4.5. Reflexive Review

The author engaged in self-reflexivity throughout the research process, which was found to be highly beneficial in all stages of conducting the study and is a crucial factor in conducting ethical research (Attia & Edge, 2017; Willig, 2001). Whilst self-reflexivity provides opportunities to engage with one's own values and biases, it is key to go one step further and consider how these might have impacted the interpretation of the results of this research. My value of amplifying marginalised voices was potentially drawing me in the direction of focussing on participants' difficult or negative experiences. Whilst this was useful for identifying implications for treatment and future research, it is possible that positive experiences were therefore given less emphasis. Furthermore, social constructionist ideas and theories, as well as engagement with the literature has likely influenced the creation and interpretation of themes in this study, with more emphasis placed on wider systemic factors related to young people's wellbeing.

My identities as a trainee clinical psychologist and someone without an ADHD diagnosis may have impacted how participants engaged with the interview; and the study approach, response and interpretation could have been different had I held differing identities (for example, if I had positive or negative ADHD medication-taking experiences of my own). Additionally, as part of holding both positions of a clinician and a researcher, at times I experienced what has been referred to as ‘interrole conflict‘ (Yanos & Ziedonis, 2006). I was conflicted in navigating difficult conversations in interviews, not wanting to slip into providing therapy whilst wanting the space to remain therapeutically informed. Conversations in supervision were useful for negotiating this interrole conflict and reflecting on my position as a researcher.

Participants conveyed an eagerness to share their experiences to improve the outcomes for future young people who are diagnosed and medicated for ADHD. Stories and journeys were unique to individuals, with experiences of resilience, overcoming difficulties and hopefulness permeating personal narratives. As a researcher, I gained a much richer understanding of the nuances and complexities of ADHD and experiences of taking ADHD medication in childhood and beyond. It was particularly impactful to hear about stigma and feelings of difference, which were a core part of participants’ social experiences. This strengthened my commitment in driving social change, as there is so much more we, in our organisations and society, need to do to support young people with diverse identities. Another striking finding was the extent of adverse effects and trade-offs young people had to negotiate with taking ADHD medication. Whilst it is daunting to engage with these discussions in a field dominated by psychiatry, it has drawn my attention to the importance of psychological perspectives in understandings of distress, treatment, and social change.

4.6. Future Research

This study indicates the need for further research in understanding the complexities of the experiences of people diagnosed and prescribed medication for ADHD. Firstly, large scale research with a quantitative methodology would be well-placed to explore the effects of ADHD medication on social relationships and the social self, above and beyond purely looking at ADHD symptom reduction in childhood. Findings of this study and other research in the field indicate that some young people found medication helped in this area, whilst others experienced it hindered their social relationships and ‘blocked’ their social selves. Large-scale studies of this population could be especially beneficial for informing assessment and treatment guidelines, as well as our understanding of ADHD medication more broadly. A further avenue for research arises in investigating people’s experiences who have been diagnosed with ADHD following trauma and Adverse Childhood Experiences (ACEs). Childhood trauma can result in ADHD symptoms, which can then be mislabelled and treated as ADHD rather than seeing these as understandable trauma responses (Weber & Reynolds, 2004; Weinstein et al., 2000). Understanding more about the rates of childhood trauma experienced by those who received an ADHD diagnosis and medication would be crucial for furthering our understanding of the overlap and causality of the two. Additionally, given the prevalence and severity of adverse effects of ADHD medication reported by the sample in this study, large-scale research would be well-placed to quantify wider prevalence rates of adverse effects to inform prescribers’ understanding and treatment guidelines.

Further large-scale research is needed on the impact of psychosocial interventions on supporting young people with ADHD and their families. Widening the focus of the research lens beyond the individual, further studies could focus on investigating and improving family interventions, as it is understood that ADHD and family functioning affect each other bidirectionally (Breaux & Harvey, 2019). Findings from research on psychosocial and family support could inform evidence-based treatment guidelines and improve support beyond the current psychopharmacological focus.

Finally, in future qualitative studies researchers might benefit from selecting homogenous rather than heterogeneous groups to explore how minority identities (e.g., ethnicity, gender identity, sexual orientation, physical ability status) might intersect with ADHD and stimulant use. This would be an important avenue for future research, given the findings of this study and other literature demonstrate that young people with ADHD are often othered and marginalised.

4.7. Conclusions

This study explored the effects of ADHD medication on young people’s sense of self and relationships, and their medication-taking experiences from childhood to adulthood. Eleven participants shared their stories, offering a range of perspectives and insights. Overall, findings were varied and enabled an exploration and discussion of different journeys and outcomes from childhood to adulthood. Individual experiences of medication differed in hindering or promoting an authentic and integrated self-view, putting into question what the ‘true’ self might mean for different people. Feelings of difference from others and attempts at hiding parts of their true selves were universal across the sample. Social relationships were helped or hindered by medication for different individuals, through increasing or decreasing young people’s ability and desire to socialise with others. Stigma and othering were common experiences in the sample, whilst belonging to a social group appeared to ameliorate negative social outcomes. An interesting finding was some participants’ descriptions of the medicated self as ‘focussed and academic’ and the unmedicated self as ‘social and fun’.

A lack of agency in decisions about their own treatment was reported by some, despite the capacity to be involved in decision-making. Many described medication as effective and helpful in their lives, mainly for academic achievement. However, adverse effects were reported by all but one participant, with severity and prevalence that is not documented in NHS guidelines. Individuals’ journeys over time appeared to be mediated by perceptions of the congruence between their evolving self-view and the effects of medication.

These findings indicate that a unidimensional, medication-based treatment is not sufficient in meeting all young people’s needs, and for some this is ineffective or harmful. There is a need to look beyond focussing on a cluster of symptoms, to see young people holistically and in their social context. Psychosocial interventions and family support need to be available more widely and considered in light of their evidence-base as a first-line treatment option. Schools should be supported, through funding and training, to be more responsive to children’s needs early on, rather than waiting years till young people are diagnosed. Importantly, these changes cannot occur in isolation, and wider systemic action is needed to shift public perspectives through participatory action, and to create environments where young people with ADHD are understood and supported.

This study contributes to the ADHD literature by presenting novel insights into UK young people’s experiences of ADHD and ADHD medication, viewed through the eyes of their adult selves. It is unique in taking a longitudinal view of participants' experiences relating to self-view and relationships. The findings gain importance through being contextualised in the UK social, cultural, and economic setting. It is hoped that the present research signifies a step towards a broader understanding of the complexities of children's experiences of ADHD diagnosis and medication.

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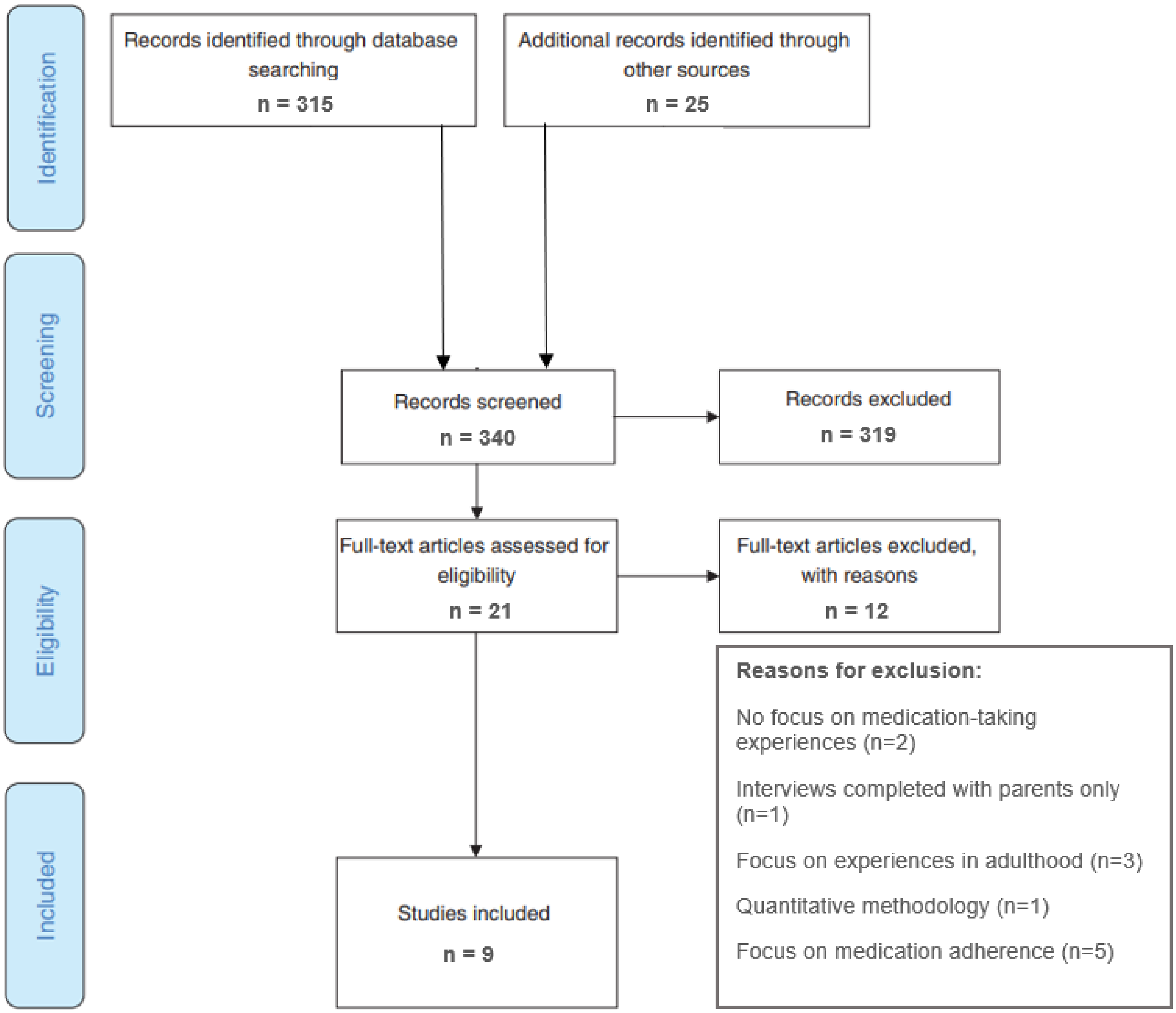
6. APPENDICES

6.1. Appendix A – Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram for the scoping review process

Search terms entered into three databases – PsychInfo, Academic Search Ultimate and CINAHL Complete

SU (adhd or attention deficit hyperactivity disorder or attention deficit-hyperactivity disorder) AND SU (medication or drugs or medicine or pharmacological therapy) AND SU (experiences or perceptions or attitudes or views or feelings or qualitative or perspective)

Limiters - Publication Date: 20140301-20240331
Expanders - Apply equivalent subjects
Narrow by Language: - english
Search modes - Boolean/Phrase



6.2. Appendix B – Stakeholder Consultation Advertisement

My name is Emma and I am doing my research study as part of my clinical psychology doctorate programme in the UK. I would like my research to be inclusive and helpful to the ADHD community, and I would love to hear from you as experts by experience!

Having your input would not only improve my research study but also set standards for the importance of consultation in the ADHD research field.

What is my research about?

I am interested in finding out about people's experiences of being diagnosed with ADHD and taking ADHD medication in their childhood.

What is a consultation?

To make sure my research is designed well, is inclusive and helpful to the ADHD community, I need your help. A consultation means seeking out advice from those who have ADHD and have taken/are taking ADHD medication to improve my doctorate research.

This would involve meeting online on Microsoft Teams to look through the research interview questions together.

You could join the consultation if you...

- Are diagnosed with ADHD and have taken/are taking ADHD medication
- Live in the UK

Please don't hesitate to reach out to me via e-mail on u2195646@uel.ac.uk for more information and any questions.

Thank you for your time and consideration and hoping to hear from some of you!

6.3. Appendix C – Semi-Structured Interview Schedule and Procedure

1) Check whether participant is in a safe and confidential space. Check the space is free from distractions.

2) Introductions and problem-free talk
    - Check participant's preferred name and pronouns.

3) Brief background to project
    - Check where the participant saw the research study advertisement.

4) Actions before interview
    - Check participant's understanding of the Participant Information Sheet, establish verbal consent and check that written consent was provided by participant. Ensure participant understands the right to withdraw and check if they are happy to continue.
    - Discuss what will happen if internet connection is lost during interview.
    - Request permission to record the interview.
    - Discuss the interview will last approximately 1 hour, but it is okay to go over this too.
    - Revisit confidentiality and establish participant's understanding of this.
    - Explain that there are no right or wrong answers, and it is important to learn about the participant's own experiences.
    - Revisit the areas and topics the interview will focus on. Share these in the Microsoft Teams chat if helpful, so that participants have a visual guide to follow. Explain to participant that they can choose not to answer questions if they do not wish to. Participants can use the 'hand up' function if overwhelmed and needing a break.
    - Let participants know the researcher will check in throughout the interview to ask if they would like to take short breaks. Explain that participants can also request a break at any time.
    - Explain participants are welcome to look away from the screen if more comfortable and do not need to maintain eye contact. Participants can also use strategies that help them cope (e.g. fidget toys, movement breaks) during the interview.
    - Check whether participant has any further questions.

5) Semi-structured interview schedule

Follow-up questions will be asked if necessary to clarify information, expand on information or gather further key information. Consequently, not all questions outlined in the interview schedule below might be asked.

I. Tell me a bit about ADHD and your diagnosis.

Optional follow-up:

- What is your understanding of what ADHD is?
- What do you think causes ADHD?
- What is your understanding of why you got your ADHD diagnosis?

II. Tell me about the time you were diagnosed with ADHD and prescribed medication.

Optional follow-up:

- What was the process like? Who did what?
- What were you told by…
    - your parents/carers?
    - your teachers/school?
    - professionals?
- What were you told about what ADHD is?
- What were you told about what ADHD medication does?
- How much were you involved in the process? How much were your views considered? How much did you feel you were part of the decisions?
- How did you feel about receiving an ADHD diagnosis? How did you feel about being prescribed medication for ADHD?

III. Tell me about the time you started/took ADHD medication, how did it affect how you felt about yourself?

Optional follow-up:

- How did you see yourself on and off medication? How did you feel about yourself? How did you think of yourself?
- Did you see yourself the same or different on medication? Why?
- Did you experience any side effects (physical, emotional, other)? If yes, what side effects did you experience?

IV. How did taking ADHD medication affect your relationships with others?

Optional follow-up:

- Did your relationships change or stay the same? Can you tell me more about this?
- What about your relationship with...
    - your family/parents/siblings?
    - school and teachers/tutors?

    - your friends/peers? (How did you feel about your friendships? Did you feel socially included?)
    - Any other relationships?
- Who did you tell about your ADHD diagnosis? How did they respond?
- How did other people see/perceive you when you started taking ADHD medication?
- Did you experience any stigma (negative experiences)? Can you tell me more about this?
- Who were the people in your life who were helpful/unhelpful? What made them helpful/unhelpful?

V. Did your view about your ADHD diagnosis and ADHD medication change over time or stay the same?

Optional follow-up:

- Did you notice your relationship to the ADHD diagnosis and medication changing over time or staying the same? Why do you think that is?
    - If your views changed, what brought this change about?
- What are your views about ADHD and ADHD medication now?
    - Are you currently taking ADHD medication?
    - If you were to rate your feelings regarding ADHD medication on a scale of 1-5, where 1 is the worst and 5 is the best, what rating would you give? Why did you give the rating you gave?
- Did the ADHD medication help you? Why/why not?
- Were you offered any other support apart from medication?
- Is there anything you wish would have been done differently that would have helped you? What else might have been helpful?
- What did you learn along the way? What do you wish your adolescent self knew at the time?

VI. Is there anything else you would like to add about any of the things we have been talking about?

6) Thank participants for their time. Debrief and check in with participants. Share list of support services. Discuss details for receiving £10 Amazon voucher if the participant would like to opt in for this. Discuss whether participant would like to receive a summary of the research findings once the study has been completed (this will be sent via e-mail).

6.4. Appendix D - Research Advertisement Text

Research Participation Opportunity - ADHD medication, Self-view and Relationships

As part of a Clinical Psychology Doctorate research study, we are interested in finding out more about people's experiences of being diagnosed with ADHD and taking ADHD medication before the age of 16.

The hope is that in hearing people's stories about their ADHD diagnosis and medication journey we can learn how medication affects different aspects of people's lives, and how support in the UK can be improved.

If you are…

- Aged 18-45 and live in the UK
- Diagnosed with ADHD before the age of 16
- Took ADHD medication for at least 3 months before the age of 16

… we would love to hear from you!

Your participation would involve an online conversation about your experiences and story. All contact will remain confidential. You will also be offered a **£10 Amazon voucher** as a thank you for your participation.

To take part of for more information contact Emma Zaharieva on **u2195646@uel.ac.uk**.

This doctorate research has been approved by the UEL School of Psychology Research Ethics Committee.

6.5. Appendix E - Research Poster

University of East London

This research has been approved by the University of East London School of Psychology Ethics Committee.

RESEARCH OPPORTUNITY

ADHD medication, Self-view and Relationships

We are hoping to find out more about people's experiences of being diagnosed with ADHD and taking ADHD medication before the age of 16.

We hope that by hearing about these experiences we can learn how medication affects different aspects of people's lives, and how support in the UK can be improved.

What does it involve?

We would meet online on Microsoft Teams for a conversation about your experiences, lasting around 1 hour.

If you are...

- **Aged 18-45, live in the UK and have access to Microsoft Teams**
- **Diagnosed with ADHD before you were 16**
- **Took ADHD medication for at least 3 months before the age of 16**

... we would love to hear from you!

£10

AMAZON VOUCHER

for your participation

Please contact Emma on

u2195646@uel.ac.uk

if you would like to take part or for more information.

6.6. Appendix F – Participant Information Sheet (PIS)

PARTICIPANT INFORMATION SHEET

Self-view and Relationships After Starting ADHD Medication

Contact person: Emma Zaharieva

Email: u2195646@uel.ac.uk

You are being invited to participate in a research study. Before you decide whether to take part or not, please carefully read through the following information which outlines what your participation would involve. Feel free to talk with others about the study (e.g., friends, family, etc.) before making your decision. If anything is unclear or you have any questions, please do not hesitate to contact me on the above email.

Who am I?

My name is Emma Zaharieva. I am a postgraduate student in the School of Psychology at the University of East London (UEL) and I am studying for a Professional Doctorate in Clinical Psychology. As part of my studies, I am conducting the research that you are being invited to participate in.

What is the purpose of the research?

I am conducting research into the experiences of people who were prescribed ADHD medication in their childhood. Particularly, I am interested in ADHD medication and how people felt about themselves, what their relationships to others were like, and how they view their diagnosis and the role of medication.

Why have I been invited to take part?

To address the study aims, I am inviting people to take part in my research who are:

- Aged 18-45 and live in the UK, speak English and have access to Microsoft Teams
- Diagnosed with ADHD before they turned 16
- Took medication for ADHD for at least 3 months between the ages of 10 and 16

If all of the above are true for you, you are eligible to take part in the study. It is entirely up to you whether you take part or not, participation is voluntary.

What will I be asked to do if I agree to take part?

If you agree to take part, we will find a suitable time to meet for an online informal chat over a Microsoft Teams video call. This will be with me and it will take up to one hour.

I will ask you about your own experiences of ADHD and ADHD medication. The questions will focus on the time you were diagnosed with ADHD and started taking medication for this, and whether taking ADHD medication affected how you viewed yourself and your relationships with others (e.g. parents/carers, friends, teachers, etc.).

I will record our video call so that I can use it for my research. The recording will be kept on a secure device and available only to me before being deleted. You can find more information about this in the sections below.

You will be offered a £10 Amazon voucher as a thank you for your participation. In order to receive your voucher, I am required to ask for your name, address, date of birth, and national insurance number. It is entirely up to you if you would like to provide this information and receive your voucher.

Can I change my mind?

Yes, you can change your mind at any time and withdraw without explanation, disadvantage or consequence. If you would like to withdraw during the interview, you can just let me know at any point and we will stop. If you withdraw, your data and interview will not be used as part of the research.

Separately, you can also request to withdraw your data from being used even after you have taken part in the study, provided that this request is made *3 weeks* of the interview meeting (after which point the data analysis will begin, and withdrawal will not be possible).

Are there any disadvantages to taking part?

Some people might find it difficult to talk about their experiences around their ADHD diagnosis, medication, their view of themselves or their relationships with others. It is important to know that you do not have to answer any questions you would not like to, and all questions are optional. I will check in with you before, during, and after the interview, and you will also receive information about support services, in case this could be helpful.

How will the information I provide be kept secure and confidential?

What you share in the interview will be kept *confidential* and details of our conversation would only be shared with my supervisor, Dr John Read, who oversees my work. If I am worried about your safety or anyone else's safety I would need to share relevant details with my supervisor and others who would be able to support.

The interview will be *transcribed*, which means it will be written up in the form of text to be used for my research. In this process all personal information will be *anonymised* (changed or removed) so that individuals are not identifiable. This anonymised data will be analysed and the main themes discussed in my research. Any personal details (e.g. e-mail addresses, names) will be stored separately from the research data. All data will be stored on a secure encrypted device and external storage space. Personal data will only be available to me as the researcher, and my supervisor, Dr John Read. Anonymised data may be shared with my supervisor and examiners, if requested.

Recordings of interviews and personal data will be deleted as soon as they are no longer needed, and by October 2024 the latest. Non-identifiable information may be kept for up to 3 years and stored securely by my UEL supervisor, Dr John Read. Data will be transferred using secure UEL e-mails internally.

For the purposes of data protection, the University of East London is the Data Controller for the personal information processed as part of this research project. The University processes this information under the 'public task' condition contained in the General Data Protection Regulation (GDPR). Where the University processes particularly sensitive data (known as 'special category data' in the GDPR), it does so because the processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. For more information about how the University processes personal data please see www.uel.ac.uk/about/about-uel/governance/information-assurance/data-protection

What will happen to the results of the research?

The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL's online Repository. Findings might also be shared with others (e.g., academics, clinicians, public, etc.) through journal articles, conference presentations or talks. In all material produced, your identity will remain anonymous, in that, it will not be possible to identify you personally. Key quotes may be included from the interview; however, these quotes will be carefully selected to make sure no one can be personally identified.

You will be given the option to receive a summary of the research findings once the study has been completed from the contact information at the top of this sheet.

Anonymised research data will be securely stored by Dr John Read (j.read2@uel.ac.uk) for a maximum of 3 years, following which all data will be deleted.

Who has reviewed the research?

My research has been approved by the School of Psychology Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

Who can I contact if I have any questions/concerns?

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Emma Zaharieva

u2195646@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor Dr John Read. School of Psychology, University of East London, Water Lane, London E15 4LZ,

Email: j.read2@uel.ac.uk

or

Chair of School Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.

(Email: t.patel@uel.ac.uk)

Thank you for taking the time to read this information sheet

6.7. Appendix G – Participant Consent Form

University of
East London

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Self-view and Relationships After Starting ADHD Medication

Contact person: Emma Zaharieva

Email: u2195646@uel.ac.uk

		Please initial
	I have read and understand the participant information sheet.	
?	I have been able to consider the information, ask questions and have them answered.	
Before During	I understand that my participation in the study is voluntary and that I can withdraw at any time before or during the interview, without explanation or disadvantage. If I withdraw during the study, my data will not be used.	
3 WEEKS	I understand that I have 3 weeks after the date of my interview to withdraw from the study.	
Microsoft Teams	I understand that the interview will be recorded using Microsoft Teams.	
🔒	I understand that my personal information and the recording of the interview will be securely stored and remain confidential. Only the research team will have access to this information, to which I give my permission.	
🔍	I understand what will happen to the data once the research has been completed.	
“	I understand that individual anonymised quotes may be used in conference presentations, reports, articles in academic journals resulting from the study and that these will not personally identify me.	
💻	I want to receive a summary of the research findings once the research is completed.	
💭	I agree to take part in the study.	

Participant’s Name (BLOCK CAPITALS)

…………………………………………………………………………………….

Participant’s Signature

…………………………………….……………………………………………

Researcher’s Name

…………………………………………………………………………………….

Researcher’s Signature

……………………………………………………………………………………

Date

……………………………………………………………………………………

6.8. Appendix H – Participant Pre-Selection Questions

Participants were asked to indicate their responses to the questions below over e-mail exchange as part of participant selection (criterion sampling) for the present qualitative study. Based on this, the researcher aimed to select a heterogenous sample, to ensure a variety of views and backgrounds are encompassed in this research.

1. What is your age?
2. What is your gender?
3. How would you describe your ethnicity? (e.g. White British, Black Caribbean)
4. How satisfied have you been with ADHD medication overall?

    1 = Highly dissatisfied

    2 = Dissatisfied

    3 = Neither satisfied nor dissatisfied

    4 = Satisfied

    5 = Highly satisfied

6.9. Appendix I – Participant Debrief Sheet

PARTICIPANT DEBRIEF SHEET

Self-view and Relationships After Starting ADHD Medication

Thank you for participating in my research study looking at ADHD, ADHD medication and how people felt about themselves and their relationships. This document offers information that may be relevant in light of you having now taken part.

How will my data be managed?

The University of East London is the Data Controller for the personal information processed as part of this research project. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. More detailed information is available in the Participant Information Sheet, which you received when you agreed to take part in the research.

What will happen to the results of the research?

The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL's online Repository. Findings might also be shared with a range of audiences (e.g., academics, clinicians, public, etc.) through journal articles, conference presentations, talks. In all material produced, your identity will remain anonymous, in that, it will not be possible to identify you personally.

You will have indicated at the end of your interview whether you would like to receive a summary of the research findings. If you said yes, a summary will be sent to your e-mail address after the study has been completed.

Anonymised research data will be securely stored by Dr John Read for a maximum of 3 years, following which all data will be deleted.

What if I been adversely affected by taking part?

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise distress or harm of any kind. Nevertheless, it is possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways, you may find the following resources/services helpful in relation to obtaining information and support.

Support services:

- Shout - https://www.giveusashout.org/ - text **85258**.
- Samaritans - https://www.samaritans.org/ - Call **116 123**.
- Search for your local urgent mental health support - https://www.nhs.uk/nhs-services/mental-health-services/where-to-get-urgent-help-for-mental-health/
- If you are in university or college, speak to your Student Wellbeing Team.
- Further support services on the Mental Health Foundation website: https://www.mentalhealth.org.uk/explore-mental-health/get-help

ADHD and mental health:

- Mind: https://www.mind.org.uk/information-support/tips-for-everyday-living/adhd-and-mental-health/
- ADHD UK: https://adhduk.co.uk/
- Young Minds (for those aged 18-25): https://www.youngminds.org.uk/young-person/mental-health-conditions/adhd-and-mental-health/ The Mix (for those aged 18-25): https://www.themix.org.uk/

Who can I contact if I have any questions/concerns?

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Emma Zaharieva

u2195646@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor, Dr John Read. School of Psychology, University of East London, Water Lane, London E15 4LZ,

Email: j.read2@uel.ac.uk

or

Chair of School Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.

(Email: t.patel@uel.ac.uk)

Thank you for taking part in my study

6.10. Appendix J – UEL Ethics Application

UNIVERSITY OF EAST LONDON

School of Psychology

APPLICATION FOR RESEARCH ETHICS APPROVAL

FOR RESEARCH INVOLVING HUMAN PARTICIPANTS

FOR BSc RESEARCH;

MSc/MA RESEARCH;

PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING & EDUCATIONAL PSYCHOLOGY

Section 1 – Guidance on Completing the Application Form (please read carefully)	
1.1	Before completing this application, please familiarise yourself with: ▪ British Psychological Society's Code of Ethics and Conduct ▪ UEL's Code of Practice for Research Ethics ▪ UEL's Research Data Management Policy ▪ UEL's Data Backup Policy
1.2	Email your supervisor the completed application and all attachments as ONE WORD DOCUMENT. Your supervisor will look over your application and provide feedback.
1.3	When your application demonstrates a sound ethical protocol, your supervisor will submit it for review.
1.4	Your supervisor will let you know the outcome of your application. Recruitment and data collection must **NOT** commence until your ethics application has been approved, along with other approvals that may be necessary (see section 7).
1.5	Research in the NHS: ▪ If your research involves patients or service users of the NHS, their relatives or carers, as well as those in receipt of services provided under contract to the NHS, you will need to apply for HRA approval/NHS permission (through IRAS). You DO NOT need to apply to the School of Psychology for ethical clearance. ▪ Useful websites: https://www.myresearchproject.org.uk/Signin.aspx https://www.hra.nhs.uk/approvals-amendments/what-approvals-do-i-need/hra-approval/

	▪ If recruitment involves NHS staff via the NHS, an application will need to be submitted to the HRA in order to obtain R&D approval. This is in addition to separate approval via the R&D department of the NHS Trust involved in the research. UEL ethical approval will also be required. ▪ HRA/R&D approval is not required for research when NHS employees are not recruited directly through NHS lines of communication (UEL ethical approval is required). This means that NHS staff can participate in research without HRA approval when a student recruits via their own social/professional networks or through a professional body such as the BPS, for example. ▪ The School strongly discourages BSc and MSc/MA students from designing research that requires HRA approval for research involving the NHS, as this can be a very demanding and lengthy process.
1.6	If you require Disclosure Barring Service (DBS) clearance (see section 6), please request a DBS clearance form from the Hub, complete it fully, and return it to applicantchecks@uel.ac.uk. Once the form has been approved, you will be registered with GBG Online Disclosures and a registration email will be sent to you. Guidance for completing the online form is provided on the GBG website: https://fadv.onlinedisclosures.co.uk/Authentication/Login You may also find the following website to be a useful resource: https://www.gov.uk/government/organisations/disclosure-and-barring-service
1.7	Checklist, the following attachments should be included if appropriate: ▪ Study advertisement ▪ Participant Information Sheet (PIS) ▪ Participant Consent Form ▪ Participant Debrief Sheet ▪ Risk Assessment Form/Country-Specific Risk Assessment Form (see section 5) ▪ Permission from an external organisation (see section 7) ▪ Original and/or pre-existing questionnaire(s) and test(s) you intend to use ▪ Interview guide for qualitative studies ▪ Visual material(s) you intend showing participants

Section 2 – Your Details		
2.1	**Your name:**	**Emma Zaharieva**
2.2	**Your supervisor's name:**	**Prof John Read**
2.3	**Name(s) of additional UEL supervisors:**	**Dr Trishna Patel**
		3rd supervisor (if applicable)
2.4	**Title of your programme:**	**Professional Doctorate in Clinical Psychology**
2.5	**UEL assignment submission date:**	**20/05/2024**
		Re-sit date (if applicable)

Section 3 – Project Details		
Please give as much detail as necessary for a reviewer to be able to fully understand the nature and purpose of your research.		
3.1	**Study title:** Please note - If your study requires registration, the title inserted here must be the same as that on PhD Manager	Young people's self-view and relationships after starting ADHD medication
3.2	**Summary of study background and aims (using lay language):**	BACKGROUND: Attention Deficit Hyperactivity Disorder (ADHD) is the most common and most widely debated mental health diagnosis in children. Stimulant and non-stimulant medication remains the most common treatment for ADHD, with prescription rates increasing by 800% between 1995 and 2015. Importantly, the rates of medication prescription for children and young people are highest between the ages of 6-12, showing a decline afterwards. This decline comes at a time when agency increases, and adolescents develop a stronger sense of identity. Additionally, as children go through adolescence an active role in relationships, especially peer relationships, becomes increasingly significant and meaningful in their lives. Young people who take ADHD medication often report changes in their sense of self, including feelings of low self-esteem, difference, stigma, and identity loss, impacting negatively on their relationships. In contrast, some studies do not find these effects and highlight the benefits of medication on young people's sense of self and peer relationships. To date, no studies have focused directly on exploring how young people's ADHD medication-taking experiences impact on all their various relationships – with others, with themselves, and ultimately, with their evolving views on their diagnosis and medication over time and into adulthood. AIMS: This study will aim to gain a deeper understanding into people's journey with their ADHD diagnosis and medication from childhood by focussing on key relationships in their lives. The stories of adults who were diagnosed and took ADHD medication in childhood will be explored through interviews, which will be transcribed and analysed by the researcher. Interpretation of the main themes, and connections

		between these will be explored and discussed in the thesis.
3.3	**Research question(s):**	1)How did young people experience the process of ADHD diagnosis and being prescribed ADHD medication?2) How did ADHD medication affect young people's sense of self and their relationships with others? 3) How did young people's relationship to their ADHD diagnosis and ADHD medication evolve?
3.4	**Research design:**	The study uses a qualitative cross-sectional design. Adults (aged 18-45) will be interviewed using a semi-structured interview method, asking about their diagnosis and medication-taking experiences in childhood. The interviews will be transcribed and analysed thematically in line with guidance on reflexive thematic analysis (Braun & Clarke, 2020).
3.5	**Participants:** Include all relevant information including inclusion and exclusion criteria	Based on relevant published research and in order to address the research questions, the following recruitment criteria will be applied: 1) Participants recruited from the 18-45 age group. This criterion was chosen after careful consideration of the possible effects of asking in-depth questions regarding medication and agency, to keep with ethical procedures and protect vulnerable participants below the age of eighteen. 2) Diagnosed with ADHD below the age of sixteen and took medication for ADHD (stimulant or non-stimulant) for at least 3 months between the ages of 10-16. 3) English speaker, living in the UK, with access to the internet and Microsoft Teams. Criterion sampling will be undertaken to aim for heterogeneity in terms of gender, ethnic background, and views around medication. This will be carried out through e-mail exchange between the researcher and potential participants who have expressed interest (see Appendix D). Determining a priori sample sizes in qualitative research has been argued to be inconsistent with a relativist epistemology and reflexive thematic analysis. For practical reasons, 15-20 participants will be recruited for an approximate 10-12 semi-structured interviews. Each interview is expected to last between 20 minutes and 1 hour, depending on the length at which participants wish to answer.
3.6	**Recruitment strategy:** Provide as much detail as possible and include a backup plan if relevant	Participants for the study will be recruited on a voluntary basis through social media, forums and ADHD charities. Participants will also be recruited through UK universities and university societies, with written confirmation and permission sought from each university and university

		society, who can then advertise the research study internally. Recruitment plan: 1) Social media (Facebook groups, Instagram posts/reels, TikTok posts, Twitter/X posts); 2) Forums (ADHD Forum - mentalhealthforum.net, Support Groups - The UK ADHD Partnership, Forum - AADD-UK - aadduk.org, Scope's online community, Attention Deficit Hyperactivity Disorder Forum - Psych forums, ADHD (reddit.com). 3) ADHD charities and mental health charities (ADHD foundation, Mind, ADHD UK, ADDISS, The National Attention Deficit Disorder Information and Support Service, Centre of ADHD and Autism support). 4) Universities and university societies, through connecting with the relevant psychology research department or person responsible for overseeing the society/research. Written permission will be sought separately from each university or university society.
3.7	**Measures, materials or equipment:** Provide detailed information, e.g., for measures, include scoring instructions, psychometric properties, if freely available, permissions required, etc.	Measures: Semi-structured interviews will be conducted using an interview schedule developed by the researcher. Materials: Participant Selection Questions (Appendix D), Participant Information Sheet (Appendix A), Participant Consent Form (Appendix B), Interview Process and Schedule (Appendix E), Debriefing and Further Support sheet (Appendix C), Amazon vouchers accessed from UEL School of Psychology, E-mail accounts and social media platforms created specifically for recruitment and communication, MS Teams access and recording enabled; Equipment: Secure and encrypted laptop for video calls and video/audio recordings
3.8	**Data collection:** Provide information on how data will be collected from the point of consent to debrief	Demographic information will be collected via secure e-mail correspondence, prior to the interviews. Following the participant reading the Participant Information sheet, and Participant Consent form, they will be requested to sign the consent form electronically if they wish to participate in the study. An interview date will be arranged with participants over e-mail (using the researcher's UEL e-mail address). Before the start of the interview, the main areas of the Participant Information Sheet will be revisited and consent will be confirmed verbally. Participation is voluntary, and it will be reiterated that participants can withdraw from the study up to 3 weeks following their interview date – this is to allow for analysis to begin following this time. Participants will then be asked a series of questions about the process of their ADHD diagnosis and

		medication prescription, whether this affected their self-view and their relationships with other people in their lives. A semi-structured interview schedule has been developed by the researcher to ensure that a standard format is followed. The interviews will be conducted over Microsoft Teams video calls with 10-12 participants, from a secure encrypted device. Recordings will be created in Microsoft Teams and stored securely in a video or audio format. The interview schedule is semi-structured, meaning that based on participants’ answers different follow-up questions will be asked to get a better understanding of all areas of their experiences. Participants can decline to answer any number of questions. Questions start with more open-ended, exploratory questions and funnel down to more closed questions (see Appendix E). Breaks and adaptations will be incorporated into the interview. Following the end of the interview participants will be debriefed and a list of support services will be sent to them electronically (Appendix C). Participant email addresses and demographic information needed for receiving the £10 Amazon voucher will be collected via the researcher’s UEL email – this will be optional and each participant can decide if they would like to receive the voucher. Transcriptions will be created by the researcher based on the audio/video material recorded during the interviews. These will be stored on a password-protected, secure device. Recordings will be stored with the following file-naming convention to ensure they are non-identifying: [ProjectCode] – [InterviewerInitials] – [ParticipantNumber] – [Date].mp4/mp3 (Video file format or Audio file format)	
3.9	**Will you be engaging in deception?**	**YES** ☐	**NO** ☒
	If yes, what will participants be told about the nature of the research, and how/when will you inform them about its real nature?	If you selected yes, please provide more information here	
3.10	**Will participants be reimbursed?**	**YES** ☒	**NO** ☐
	If yes, please detail why it is necessary.	It is in the ethos of the researcher to provide reimbursement to participants for their time. Amazon vouchers will be requested through the UEL funding available as part of the doctorate course. Due to the	

		limited funding available for this research study, the decision had to be made for participants to be offered a £10 Amazon voucher as compensation for their time. The necessary details will be collected from participants (name, date of birth, address, and national insurance number), who can choose to opt out of this if they would not like to share their details. Participants will be informed it will only be possible to receive the £10 voucher if they provide the necessary information as per UEL guidelines.
	How much will you offer? Please note - This must be in the form of vouchers, not cash.	A £10 Amazon voucher will be offered to participants who would like to opt in following completion of their interview. Receiving the voucher will be optional.
3.11	**Data analysis:**	Following Braun and Clarke (2021, 2006) a reflexive thematic analysis will be undertaken after the transcription of interviews. This will include stages of familiarization with the data, coding, generating themes, reviewing, and refining themes before writing up the findings. This process acknowledges the role of the researcher and frames thematic analysis as an inductive process (Clarke & Braun, 2013). Codes and themes will be made and stored in appropriate software (NVivo). MS Teams recordings and demographic information will be deleted once they are no longer needed for data analysis, which would be by September 2024.

Section 4 – Confidentiality, Security and Data Retention

It is vital that data are handled carefully, particularly the details about participants. For information in this area, please see the UEL guidance on data protection, and also the UK government guide to data protection regulations.

If a Research Data Management Plan (RDMP) has been completed and reviewed, information from this document can be inserted here.

4.1	**Will the participants be anonymised at source?**	**YES** ☐	**NO** ☒
	If yes, please provide details of how the data will be anonymised.	Please detail how data will be anonymised	
4.2	**Are participants' responses anonymised or are an anonymised sample?**	**YES** ☒	**NO** ☐
	If yes, please provide details of how data will be anonymised (e.g., all identifying	At the transcription stage the data will be pseudonymised by changing participant names to pseudonyms and other	

	information will be removed during transcription, pseudonyms used, etc.).	identifiable information such as geographical location, will be replaced with a meaningful descriptive which typifies the location (e.g. ‘Harrow’ to ‘North London’). Other names and specific locations will also be replaced with a generic descriptor (e.g. ‘Mr Smith’ to ‘teacher’ and ‘Greenford High School’ to ‘high school’). Any identifying information which cannot be amended in the above way will be removed during transcription.
4.3	**How will you ensure participant details will be kept confidential?**	All participants will be sent a Participant Information Sheet and asked to sign the Consent Form indicating that they have read and understood this. Participation in the study will be voluntary, and participants will be informed they can withdraw at any point before or during the interview process, as well as up to 3 weeks following the date of their interview. Participants will be informed of the data management plan, plans for analysis, write up and possible publication of the final report prior to consenting to participate in the research. Recordings of the interviews and any personal data will be created on a secure encrypted device. Recordings will then be transferred to and stored on UEL OneDrive for Business and they will be available to the researcher only. Confidentiality of the data will be ensured at the transcription stage where the data will be pseudonymised by changing names to pseudonyms and other identifiable information such as geographical location, will be replaced with a meaningful descriptive which typifies the location (e.g. ‘Harrow’ to ‘North London’). Transcription will be undertaken only by the researcher to protect confidentiality of the participant. Participants’ names and details will be anonymised in the resulting thesis and any following dissemination. Anonymisation will be completed following guidance from the Information Commissioner’s Office (2012), including changing the details in the thesis (redacting people’s names, redacting precise place names, redacting precise dates etc.). Any quotations used from interviews will be carefully selected to ensure they are non-identifying. All information and recordings will be destroyed within 3 years.
4.4	**How will data be securely stored and backed up during the research?** Please include details of how you will manage access, sharing and security	ACCESS: - Data will be accessed through a secure, non-networked laptop available to the researcher. The password to the laptop is known only to the researcher.- The researcher will use UEL OneDrive for Business to store interview files and transcripts. This is a secure and encrypted storage space. Identifiers (pseudonyms) will be stored separately, to make sure relevant files can be deleted should participants wish to

		withdraw within the 3-week timeframe. - Transcript files will be pseudonymised and stored in a separate password-protected folder.- Similarly, the coding document, completed consent forms, and participant demographic information will all be stored in separate sections on UEL OneDrive for Business and the folder will be password-protected.- A password-protected, encrypted hard drive will be used as back up storage. The password to the hard drive is known only to the researcher. SECURITY: - Encryption and password protection for additional layer of security. Password will only be known to the researcher.- Anonymised data (e.g. transcripts) will be stored separately from demographic and personal information (e.g. e-mail address).- Storage of data and meta data will be on UEL's OneDrive for Business. File names will be pseudonymised. – The researcher and primary supervisor will be the only ones who have access to the raw data (recordings of interviews) - Anonymised transcript data may be shared with the researcher's supervisor and with examiners if requested for the purpose of examination. Anonymisation would be carried out as mentioned above, based on the ICO (2012) guidelines. If any data needs to be shared, this will be done so by creating a secure link via UEL OneDrive for Business. SHARING: - The resulting thesis might be of interest to researchers and practitioners in the field of ADHD, medication, and mental health.- In the resulting thesis, any quotations used from interviews will be carefully selected to ensure they are non-identifying.- Participant demographic information used in the thesis will be minimal and non-identifying.- Extracts from the anonymised transcripts will be written up into a thesis which will be deposited and shared via the UEL's Research Repository at project end in September/October 2024.- In order to make the thesis suitable for sharing, it will be shared in a PDF file format, and it will be assigned a Digital Object Identifier (DOI) when shared.- The contents of the thesis will be submitted to UEL's Research Repository under the Creative Commons Attribution-Non Commercial-No Derivatives 4.0 International Licence (CC BY-NC-ND).- Any other data, including recordings of interviews, full transcriptions and any identifying demographic information will not be shared since the information gathered may be too sensitive even if anonymised.- A lay summary of findings made available to participants who request it will include general insights

		from the thesis submission and will not identify any individuals.	
4.5	**Who will have access to the data and in what form?** (e.g., raw data, anonymised data)	Interviews, transcription, analysis and writeup will be undertaken only by the researcher. The researcher and the primary supervisor will be the only ones who have access to the raw data (audio/video recordings of interviews) which will be stored separately from demographic information and transcriptions, in a password-protected folder on an encrypted device. The password will be known only to the researcher. Anonymised transcript data may be shared with the researcher's supervisor and with examiners if requested for the purpose of examination. Anonymisation would be carried out as mentioned above, based on the ICO (2012) guidelines. If any data needs to be shared, this will be done so by creating a secure link via UEL OneDrive for Business.	
4.6	**Which data are of long-term value and will be retained?** (e.g., anonymised interview transcripts, anonymised databases)	The resulting thesis and lay summary should be retained, shared and/or preserved, as per the UEL Research Data Management Policy. MS Teams recordings, demographic information and any identifying information will be deleted once they are no longer needed for data analysis, which would be by September 2024 when the researcher is expected to complete their doctorate course. All other data, including anonymised transcripts and analysis data will be deleted within 3 years of data collection. Until then this data will be stored by the supervisor on the UEL OneDrive.	
4.7	**What is the long-term retention plan for this data?**	The MS Teams recordings will be destroyed upon the researcher's completion of the doctorate programme in September 2024. The resulting thesis will be submitted to the University of East London Research Repository. Dissemination of a lay summary will be carried out electronically to interested participants. Any further dissemination or publication would adhere to the Data Management Plan and the UEL Research Ethics regulations. Anonymised data and metadata will be moved from the researcher's UEL OneDrive for Business by October 2024. These will be sent to the research supervisor who will store them on their UEL OneDrive for business for up to 3 years. Participants will be informed (through the Participant Information Sheet) of the length of time non-identifiable information might be kept (3 years).	
4.8	**Will anonymised data be made available for use in future research by other researchers?**	**YES** ☐	**NO** ☒

	If yes, have participants been informed of this?	**YES** ☐	**NO** ☐
4.9	**Will personal contact details be retained to contact participants in the future for other research studies?**	**YES** ☐	**NO** ☒
	If yes, have participants been informed of this?	**YES** ☐	**NO** ☐

Section 5 – Risk Assessment			
If you have serious concerns about the safety of a participant, or others, during the course of your research please speak with your supervisor as soon as possible. If there is any unexpected occurrence while you are collecting your data (e.g., a participant or the researcher injures themselves), please report this to your supervisor as soon as possible.			
5.1	**Are there any potential physical or psychological risks to participants related to taking part?** (e.g., potential adverse effects, pain, discomfort, emotional distress, intrusion, etc.)	**YES** ☒	**NO** ☐
	If yes, what are these, and how will they be minimised?	Although this is not expected, some participants might find it difficult to talk about their experiences around their ADHD diagnosis, medication, their view of themselves or their relationships with others. Risks will be minimised through careful consideration of the interview schedule and consultation with stakeholders. On the day of the interview, risks will be minimised by letting participants know before the study and as part of the PIS that they do not have to answer any questions that they would not want to, and all questions are optional. The researcher will check in with participants before, during, and after the interview, and participants will also receive information about support services as part of the debrief (verbally and in written format as part of the debrief sheet).	
5.2	**Are there any potential physical or psychological risks to you as a researcher?**	**YES** ☐	**NO** ☒
	If yes, what are these, and how will they be minimised?	Please detail the potential risks and include measures you will take to minimise these for yourself as the researcher	
5.3	**If you answered yes to either 5.1 and/or 5.2, you will need to complete and include a General Risk Assessment (GRA) form (signed by your supervisor). Please confirm that**	**YES** ☒	

	you have attached a GRA form as an appendix:			
5.4	**If necessary, have appropriate support services been identified in material provided to participants?**	**YES** ☒	**NO** ☐	**N/A** ☐
5.5	**Does the research take place outside the UEL campus?**	**YES** ☒	**NO** ☐	
	If yes, where?	The research takes place online, using Microsoft Teams video calls.		
5.6	**Does the research take place outside the UK?**	**YES** ☐	**NO** ☒	
	If yes, where?	Please state the country and other relevant details		
	If yes, in addition to the General Risk Assessment form, a Country-Specific Risk Assessment form must also be completed and included (available in the Ethics folder in the Psychology Noticeboard). Please confirm a Country-Specific Risk Assessment form has been attached as an appendix. Please note - A Country-Specific Risk Assessment form is not needed if the research is online only (e.g., Qualtrics survey), regardless of the location of the researcher or the participants.	**YES** ☐		
5.7	**Additional guidance:** ▪ For assistance in completing the risk assessment, please use the AIG Travel Guard website to ascertain risk levels. Click on 'sign in' and then 'register here' using policy # 0015865161. Please also consult the Foreign Office travel advice website for further guidance. ▪ For on campus students, once the ethics application has been approved by a reviewer, all risk assessments for research abroad must then be signed by the Director of Impact and Innovation, Professor Ian Tucker (who may escalate it up to the Vice Chancellor). ▪ For distance learning students conducting research abroad in the country where they currently reside, a risk assessment must also be carried out. To minimise risk, it is recommended that such students only conduct data collection online. If the project is deemed low risk, then it is not necessary for the risk assessment to be signed by the Director of Impact and Innovation. However, if not deemed low risk, it must be signed by the Director of Impact and Innovation (or potentially the Vice Chancellor).			

	- Undergraduate and M-level students are not explicitly prohibited from conducting research abroad. However, it is discouraged because of the inexperience of the students and the time constraints they have to complete their degree.

Section 6 – Disclosure and Barring Service (DBS) Clearance			
6.1	**Does your research involve working with children (aged 16 or under) or vulnerable adults (*see below for definition)?** If yes, you will require Disclosure Barring Service (DBS) or equivalent (for those residing in countries outside of the UK) clearance to conduct the research project	**YES** ☐	**NO** ☒
	* You are required to have DBS or equivalent clearance if your participant group involves: (1) Children and young people who are 16 years of age or under, or (2) 'Vulnerable' people aged 16 and over with particular psychiatric diagnoses, cognitive difficulties, receiving domestic care, in nursing homes, in palliative care, living in institutions or sheltered accommodation, or involved in the criminal justice system, for example. Vulnerable people are understood to be persons who are not necessarily able to freely consent to participating in your research, or who may find it difficult to withhold consent. If in doubt about the extent of the vulnerability of your intended participant group, speak with your supervisor. Methods that maximise the understanding and ability of vulnerable people to give consent should be used whenever possible.		
6.2	**Do you have DBS or equivalent (for those residing in countries outside of the UK) clearance to conduct the research project?**	**YES** ☐	**NO** ☐
6.3	**Is your DBS or equivalent (for those residing in countries outside of the UK) clearance valid for the duration of the research project?**	**YES** ☐	**NO** ☐
6.4	**If you have current DBS clearance, please provide your DBS certificate number:**	Please enter your DBS certificate number	
	If residing outside of the UK, please detail the type of clearance and/or provide certificate number.	Please provide details of the type of clearance, including any identification information such as a certificate number	
6.5	**Additional guidance:** - If participants are aged 16 or under, you will need two separate information sheets, consent forms, and debrief forms (one for the participant, and one for their parent/guardian).		

	▪ For younger participants, their information sheets, consent form, and debrief form need to be written in age-appropriate language.

Section 7 – Other Permissions			
7.1	**Does the research involve other organisations (e.g., a school, charity, workplace, local authority, care home, etc.)?**	**YES** ☐	**NO** ☒
	If yes, please provide their details.	Please provide details of organisation	
	If yes, written permission is needed from such organisations (i.e., if they are helping you with recruitment and/or data collection, if you are collecting data on their premises, or if you are using any material owned by the institution/organisation). Please confirm that you have attached written permission as an appendix.	**YES** ☐	
7.2	**Additional guidance:** ▪ Before the research commences, once your ethics application has been approved, please ensure that you provide the organisation with a copy of the final, approved ethics application or approval letter. Please then prepare a version of the consent form for the organisation themselves to sign. You can adapt it by replacing words such as 'my' or 'I' with 'our organisation' or with the title of the organisation. This organisational consent form must be signed before the research can commence. ▪ If the organisation has their own ethics committee and review process, a SREC application and approval is still required. Ethics approval from SREC can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by the School and other ethics committee/s.		

Section 8 – Declarations		
8.1	**Declaration by student. I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor:**	**YES** ☒
8.2	**Student's name:** (Typed name acts as a signature)	**Emma Zaharieva**
8.3	**Student's number:**	**u2195646**

8.4	**Date:** **Amendment date: 04/12/2023**	**26/05/2023**
Supervisor's declaration of support is given upon their electronic submission of the application		

6.11. Appendix K – UEL Ethics Approval Letter

School of Psychology Ethics Committee

NOTICE OF ETHICS REVIEW DECISION LETTER

For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

Reviewer: Please complete sections in blue | **Student:** Please complete/read sections in orange

Details

Reviewer:	**Navya Anand**
Supervisor:	**John Read**
Student:	**Emma Zaharieva**
Course:	**Prof Doc in Clinical Psychology**
Title of proposed study:	**Young people's self-view and relationships after starting ADHD medication**

Checklist

(Optional)

	YES	NO	N/A
Concerns regarding study aims (e.g., ethically/morally questionable, unsuitable topic area for level of study, etc.)	☐	☐	☐
Detailed account of participants, including inclusion and exclusion criteria	☐	☐	☐
Concerns regarding participants/target sample	☐	☐	☐
Detailed account of recruitment strategy	☐	☐	☐
Concerns regarding recruitment strategy	☐	☐	☐
All relevant study materials attached (e.g., freely available questionnaires, interview schedules, tests, etc.)	☐	☐	☐
Study materials (e.g., questionnaires, tests, etc.) are appropriate for target sample	☐	☐	☐
Clear and detailed outline of data collection	☐	☐	☐

Data collection appropriate for target sample	☐	☐	☐
If deception being used, rationale provided, and appropriate steps followed to communicate study aims at a later point	☐	☐	☐
If data collection is not anonymous, appropriate steps taken at later stages to ensure participant anonymity (e.g., data analysis, dissemination, etc.) – anonymisation, pseudonymisation	☐	☐	☐
Concerns regarding data storage (e.g., location, type of data, etc.)	☐	☐	☐
Concerns regarding data sharing (e.g., who will have access and how)	☐	☐	☐
Concerns regarding data retention (e.g., unspecified length of time, unclear why data will be retained/who will have access/where stored)	☐	☐	☐
If required, General Risk Assessment form attached	☐	☐	☐
Any physical/psychological risks/burdens to participants have been sufficiently considered and appropriate attempts will be made to minimise	☐	☐	☐
Any physical/psychological risks to the researcher have been sufficiently considered and appropriate attempts will be made to minimise	☐	☐	☐
If required, Country-Specific Risk Assessment form attached	☐	☐	☐
If required, a DBS or equivalent certificate number/information provided	☐	☐	☐
If required, permissions from recruiting organisations attached (e.g., school, charity organisation, etc.)	☐	☐	☐
All relevant information included in the participant information sheet (PIS)	☐	☐	☐
Information in the PIS is study specific	☐	☐	☐
Language used in the PIS is appropriate for the target audience	☐	☐	☐
All issues specific to the study are covered in the consent form	☐	☐	☐
Language used in the consent form is appropriate for the target audience	☐	☐	☐
All necessary information included in the participant debrief sheet	☐	☐	☐
Language used in the debrief sheet is appropriate for the target audience	☐	☐	☐
Study advertisement included	☐	☐	☐
Content of study advertisement is appropriate (e.g., researcher's personal contact details are not shared, appropriate language/visual material used, etc.)	☐	☐	☐

Decision options	
APPROVED	Ethics approval for the above-named research study has been granted from the date of approval (see end of this notice), to the date it is submitted for assessment.
APPROVED - BUT MINOR AMENDMENTS ARE REQUIRED <u>BEFORE</u> THE RESEARCH COMMENCES	In this circumstance, the student must confirm with their supervisor that all minor amendments have been made **<u>before</u>** the research commences. Students are to do this by filling in the confirmation box at the end of this form once all amendments have been attended to and emailing a copy of this decision notice to the supervisor. The supervisor will then forward the student's confirmation to the School for its records.

	Minor amendments guidance: typically involve clarifying/amending information presented to participants (e.g., in the PIS, instructions), further detailing of how data will be securely handled/stored, and/or ensuring consistency in information presented across materials.
NOT APPROVED - MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED	In this circumstance, a revised ethics application **must** be submitted and approved **before** any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application. **Major amendments guidance:** typically insufficient information has been provided, insufficient consideration given to several key aspects, there are serious concerns regarding any aspect of the project, and/or serious concerns in the candidate's ability to ethically, safely and sensitively execute the study.

Decision on the above-named proposed research study

Please indicate the decision:	**APPROVED**

Minor amendments

Please clearly detail the amendments the student is required to make

Major amendments

Please clearly detail the amendments the student is required to make

Assessment of risk to researcher

Has an adequate risk assessment been offered in the application form?	**YES** ☐	**NO** ☐
	If no, please request resubmission with an **adequate risk assessment.**	

If the proposed research could expose the researcher to any kind of emotional, physical or health and safety hazard, please rate the degree of risk:

HIGH	Please **do not approve a high-risk** application. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not be approved on this basis. If unsure, please refer to the Chair of Ethics.	☐
MEDIUM	Approve but include appropriate recommendations in the below box.	☐
LOW	Approve and if necessary, include any recommendations in the below box.	☐
Reviewer recommendations in relation to risk (if any):	Please insert any recommendations	

Reviewer's signature

Reviewer: (Typed name to act as signature)	**Navya Anand (Ethics Chair, Trishna Patel, confirms that Navya Anand reviewed this application)**
Date:	**15/06/2023**

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Ethics Committee

RESEARCHER PLEASE NOTE

For the researcher and participants involved in the above-named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UEL's Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard.

Confirmation of minor amendments

(Student to complete)

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data

Student name: (Typed name to act as signature)	Please type your full name
Student number:	Please type your student number
Date:	Click or tap to enter a date

Please submit a copy of this decision letter to your supervisor with this box completed if minor amendments to your ethics application are required

6.12. Appendix L – UEL Ethics Amendment Approvals

Ethics Amendment Approval – 12th of October 2023

School of Psychology Ethics Committee

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology

Note that approval must be given for significant change to research procedure that impact on ethical protocol. If you are not sure as to whether your proposed amendment warrants approval, consult your supervisor or contact Dr Trishna Patel (Chair of School Ethics Committee).

How to complete and submit the request

1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	When submitting this request form, ensure that all necessary documents are attached (see below).
4	Using your UEL email address, email the completed request form along with associated documents to Dr Trishna Patel: t.patel@uel.ac.uk
5	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.
6	Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

Required documents

A copy of your previously approved ethics application with proposed amendment(s) added with track changes.	**YES** ☒

Copies of updated documents that may relate to your proposed amendment(s). For example, an updated recruitment notice, updated participant information sheet, updated consent form, etc.	**YES** ☒
A copy of the approval of your initial ethics application.	**YES** ☒

Details

Name of applicant:	**Emma Zaharieva**
Programme of study:	**Professional Doctorate in Clinical Psychology**
Title of research:	**Young people's self-view and relationships after starting ADHD medication**
Name of supervisor:	**Dr John Read**

Proposed amendment(s)

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	**Rationale**
Expanding recruitment age range from 18-25 to 18-45	Due to difficulties with recruitment the participant age range was increased following consultation with Dr John Read. All other recruitment criteria was left unchanged, as the focus would remain on medication-taking experiences before the age of 16. The title of the research study may be slightly adapted accordingly, and necessary paperwork for this would be completed separately.
Additional recruitment through universities and university societies	Recruiting through universities has been added to the channels for recruitment in order to expand the reach of the research, with a view of reaching a higher number of young adults. Details of the recruitment process through universities have been specified in the ethics form. Written confirmation and permission will be sought from each university and university society.
Proposed amendment	Rationale for proposed amendment
Proposed amendment	Rationale for proposed amendment

Confirmation

Is your supervisor aware of your proposed amendment(s) and have they agreed to these changes?	**YES** ☒	**NO** ☐

Student's signature

Student: (Typed name to act as signature)	**Emma Zaharieva**
Date:	**10/10/2023**

Reviewer's decision

Amendment(s) approved:	**YES** ☒	**NO** ☐
Comments:	**Please ensure that a separate social media account is set up specifically for the research (i.e., no personal accounts should be used).**	
Reviewer: (Typed name to act as signature)	**Trishna Patel**	
Date:	**12/10/2023**	

Ethics Amendment Approval – 4th of December 2023

School of Psychology Ethics Committee

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology

Note that approval must be given for significant change to research procedure that impact on ethical protocol. If you are not sure as to whether your proposed amendment warrants approval, consult your supervisor or contact Dr Trishna Patel (Chair of School Ethics Committee).

How to complete and submit the request

1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	When submitting this request form, ensure that all necessary documents are attached (see below).
4	Using your UEL email address, email the completed request form along with associated documents to Dr Trishna Patel: t.patel@uel.ac.uk
5	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.
6	Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

Required documents

A copy of your previously approved ethics application with proposed amendment(s) added with track changes.	**YES** ☒

Copies of updated documents that may relate to your proposed amendment(s). For example, an updated recruitment notice, updated participant information sheet, updated consent form, etc.	**YES** ☒
A copy of the approval of your initial ethics application.	**YES** ☒

Details

Name of applicant:	**Emma Zaharieva**
Programme of study:	**Professional Doctorate in Clinical Psychology**
Title of research:	**Young people's self-view and relationships after starting ADHD medication**
Name of supervisor:	**Dr John Read**

Proposed amendment(s)

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	**Rationale**
Changing participant reimbursement to offer each participant who completed the interview a £10 Amazon voucher	Participants are currently offered a chance to win 2 x £50 Amazon vouchers. In the ethos of the researcher, and with an additional thought to drive recruitment, it is proposed that each participant will be offered a guaranteed £10 Amazon voucher for completing the research interview (with the aim to reach 10-12 participants in total). This change is proposed following consultation with stakeholders and discussion with DoS, Dr John Read. The two participants who have already completed the research with the previous reimbursement offer are in agreement with going ahead with this change, and will also be offered a £10 Amazon voucher.
Proposed amendment	
Proposed amendment	Rationale for proposed amendment
Proposed amendment	Rationale for proposed amendment

Confirmation

Is your supervisor aware of your proposed amendment(s) and have they agreed to these changes?	**YES** ☒	**NO** ☐

Student's signature

Student: (Typed name to act as signature)	**Emma Zaharieva**
Date:	**04/12/2023**

Reviewer's decision

Amendment(s) approved:	**YES** ☒	**NO** ☐
Comments:		
Reviewer: (Typed name to act as signature)	**Trishna Patel**	
Date:	**04/12/2023**	

6.13. Appendix M – UEL Ethics Title Change Approval

School of Psychology Ethics Committee

REQUEST FOR TITLE CHANGE TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

Please complete this form if you are requesting approval for a proposed title change to an ethics application that has been approved by the School of Psychology

By applying for a change of title request, you confirm that in doing so, the process by which you have collected your data/conducted your research has not changed or deviated from your original ethics approval. If either of these have changed, then you are required to complete an 'Ethics Application Amendment Form'.

How to complete and submit the request

1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	Using your UEL email address, email the completed request form along with associated documents to Dr Jérémy Lemoine (School Ethics Committee Member): j.lemoine@uel.ac.uk
4	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.

Required documents

A copy of the approval of your initial ethics application.	**YES** ☒

Details

Name of applicant:	**Emma Zaharieva**

Programme of study:	**Professional Doctorate in Clinical Psychology**
Title of research:	**Young people's self-view and relationships after starting ADHD medication**
Name of supervisor:	**Prof John Read**

Proposed title change

Briefly outline the nature of your proposed title change in the boxes below

Old title:	Young people's self-view and relationships after starting ADHD medication
New title:	Self-view and Relationships Following Prescription of ADHD Medication in Childhood
Rationale:	The participant age range was extended from 18-25 to 18-45 to support with recruitment from a wider pool of participants. Therefore, it was necessary to change the original title to describe the research more accurately.

Confirmation

Is your supervisor aware of your proposed change of title and in agreement with it?	**YES** ☒	**NO** ☐
Does your change of title impact the process of how you collected your data/conducted your research?	**YES** ☐	**NO** ☒

Student's signature

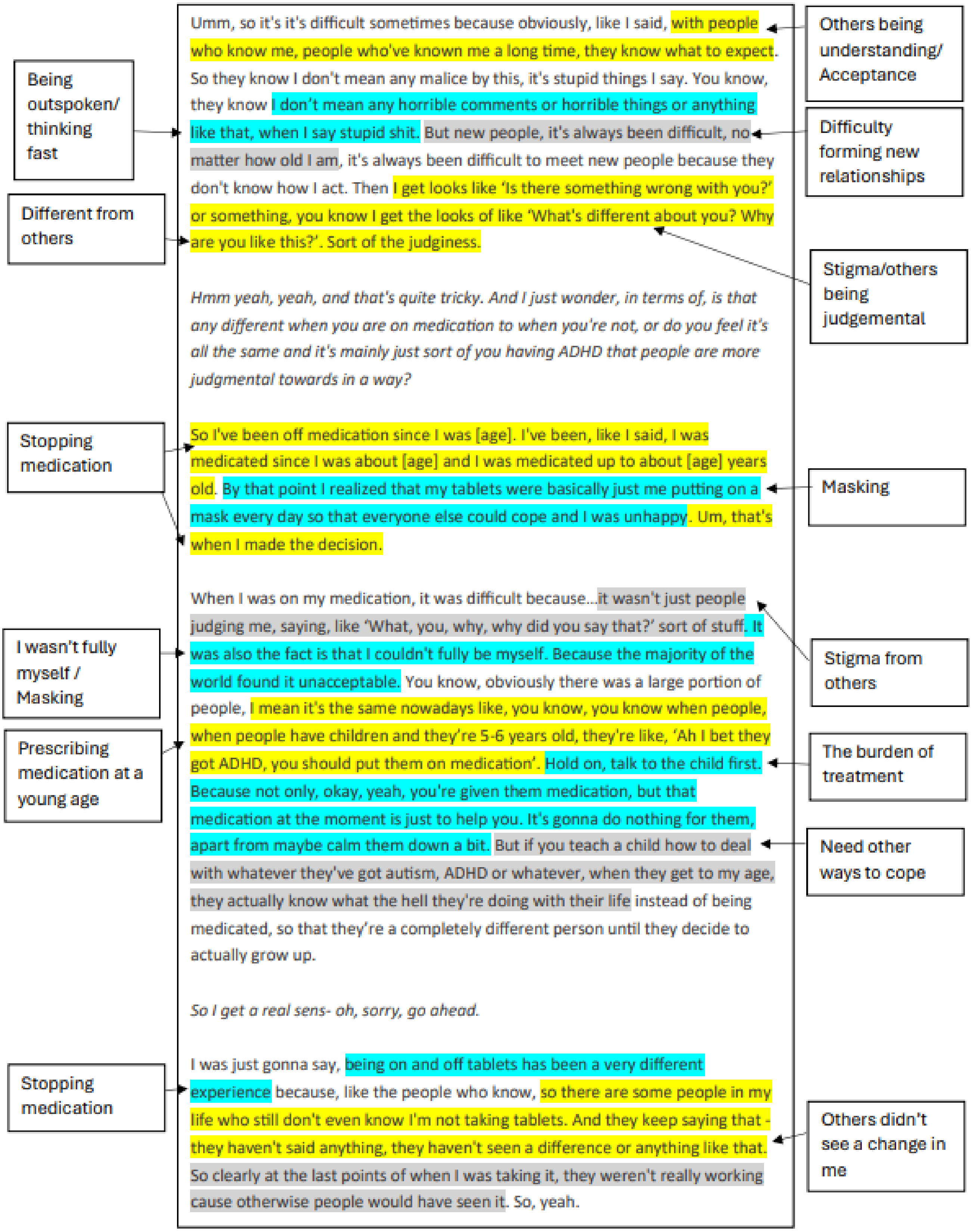
Student: (Typed name to act as signature)	**Emma Zaharieva**
Date:	**01/02/2024**

Reviewer's decision

Title change approved:	**YES** ☒	**NO** ☐
Comments:	**The new title reflects better the research study and will not impact the process of how the data are collected or how the research is conducted.**	
Reviewer: (Typed name to act as signature)	**Dr Jérémy Lemoine**	

Date:	**02/02/2024**

6.14. Appendix N – Coded Transcript



Umm, so it's it's difficult sometimes because obviously, like I said, with people who know me, people who've known me a long time, they know what to expect. So they know I don't mean any malice by this, it's stupid things I say. You know, they know I don't mean any horrible comments or horrible things or anything like that, when I say stupid shit. But new people, it's always been difficult, no matter how old I am, it's always been difficult to meet new people because they don't know how I act. Then I get looks like 'Is there something wrong with you?' or something, you know I get the looks of like 'What's different about you? Why are you like this?'. Sort of the judginess.

Hmm yeah, yeah, and that's quite tricky. And I just wonder, in terms of, is that any different when you are on medication to when you're not, or do you feel it's all the same and it's mainly just sort of you having ADHD that people are more judgmental towards in a way?

So I've been off medication since I was [age]. I've been, like I said, I was medicated since I was about [age] and I was medicated up to about [age] years old. By that point I realized that my tablets were basically just me putting on a mask every day so that everyone else could cope and I was unhappy. Um, that's when I made the decision.

When I was on my medication, it was difficult because...it wasn't just people judging me, saying, like 'What, you, why, why did you say that?' sort of stuff. It was also the fact is that I couldn't fully be myself. Because the majority of the world found it unacceptable. You know, obviously there was a large portion of people, I mean it's the same nowadays like, you know, you know when people, when people have children and they're 5-6 years old, they're like, 'Ah I bet they got ADHD, you should put them on medication'. Hold on, talk to the child first. Because not only, okay, yeah, you're given them medication, but that medication at the moment is just to help you. It's gonna do nothing for them, apart from maybe calm them down a bit. But if you teach a child how to deal with whatever they've got autism, ADHD or whatever, when they get to my age, they actually know what the hell they're doing with their life instead of being medicated, so that they're a completely different person until they decide to actually grow up.

So I get a real sens- oh, sorry, go ahead.

I was just gonna say, being on and off tablets has been a very different experience because, like the people who know, so there are some people in my life who still don't even know I'm not taking tablets. And they keep saying that - they haven't said anything, they haven't seen a difference or anything like that. So clearly at the last points of when I was taking it, they weren't really working cause otherwise people would have seen it. So, yeah.

6.15. Appendix O – Initial Codes Generated

A handful and hard to control
A lack of understanding of ADHD
Acceptance
Acceptance of self
Accommodating
ADHD - an academic disadvantage
ADHD different in women
ADHD is a part of me
Advocacy
Attracted 'bad' kids
Behind others
Brain wired differently to others
Bullying
Changing medication many times
Community activities
Compassionate and understanding
Constant change of professionals
Created more medical problems
Dependent on it
De-validation - ADHD is not real
Developing ways to cope
Diagnosis as useful
Diagnosis is affirming
Did my own research into it
Didn't help
Didn't understand it
Didn't want to be treated differently

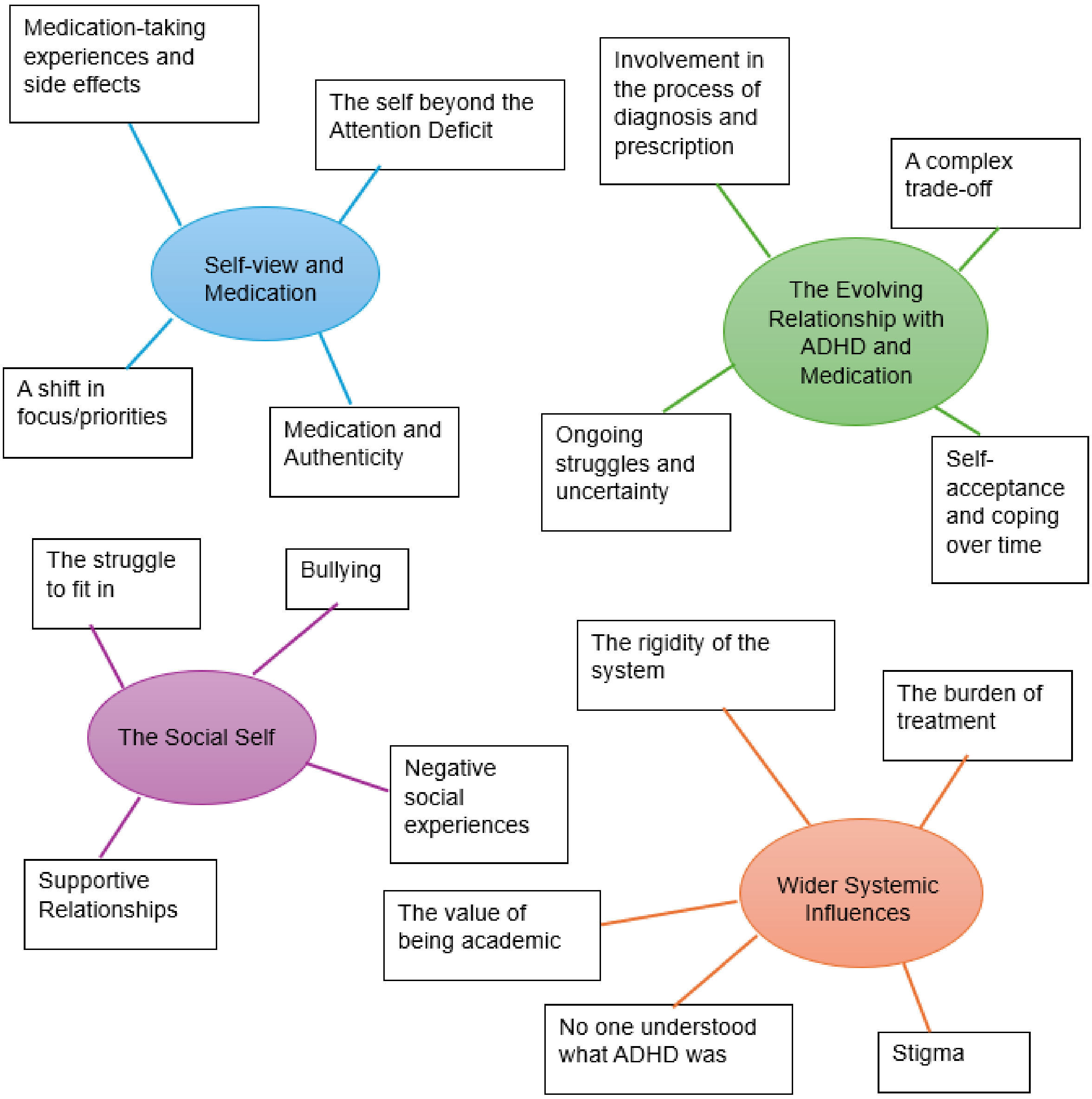
Didn't work
Difference, not disorder
Different from others
Difficulties in focussing
Difficulty forming new relationships
Distancing from parts of ADHD
Emotional regulation difficulties
Everyone could get it
Fake friends
Falling out with friends
Family didn't want me on medication
Felt more normal off medication
Finding different things difficult
Focus more on self when off medication
Focus shifted towards academic side when on medication
Friends are different, they're like me
Getting in trouble
Going back on medication
Good things about having ADHD
Growing out of it
Hated it
Helpful medical professionals
Helps with education
Hindered socially
Hurdles in accessing support
I could control it
I could understand my peers
I didn't see a change in me
I lost myself

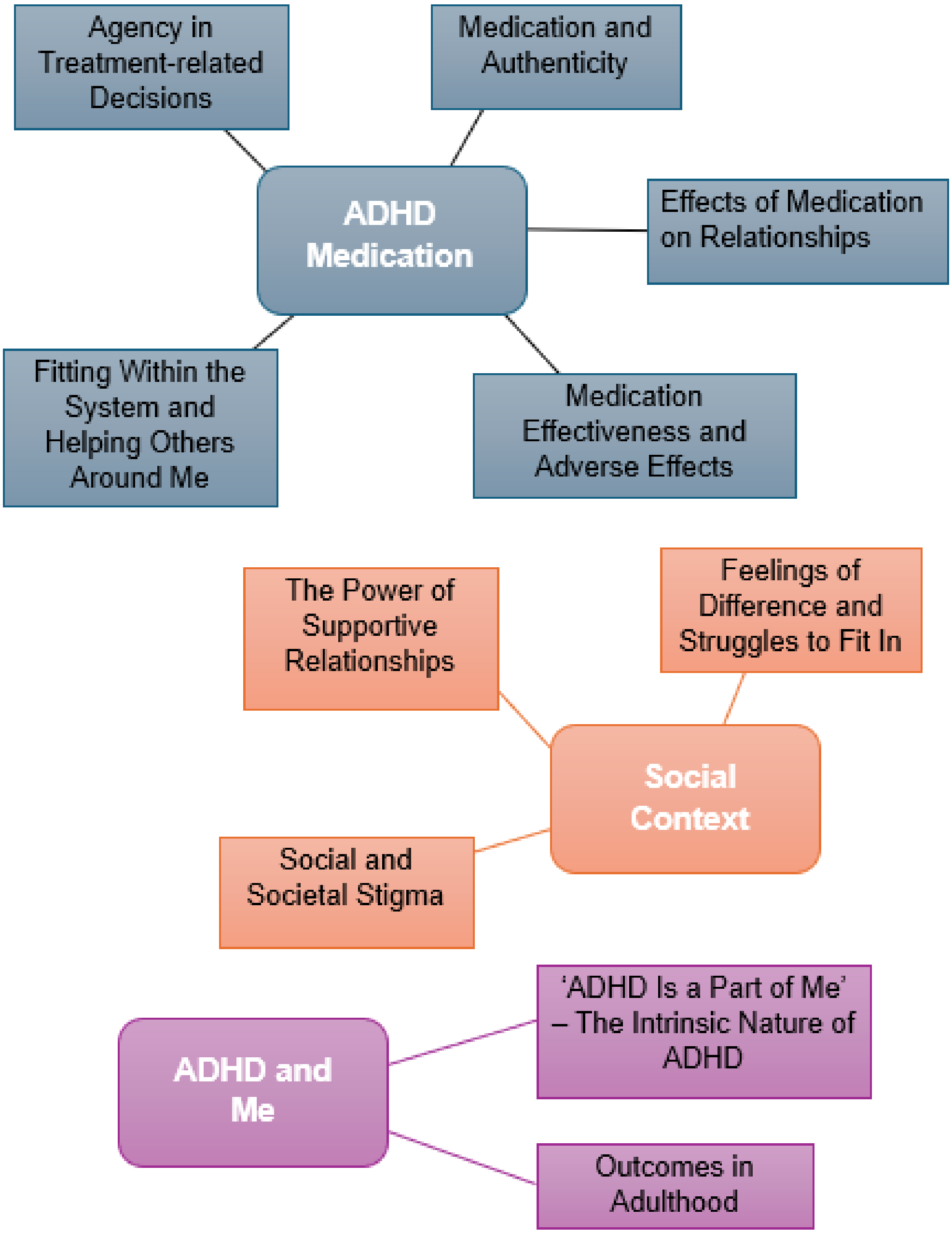
I thought of myself as stupid
I was academic
I was like a container for medication
I wasn't fully myself
Important to have diagnosis
In a better place now
Inconvenient
Interrupting others
Involved in process
It was already too late
It works
Learning support
Less support in adulthood
Less ups and downs, smoothed things over
Lifestyle changes
Losing friends
Lots of work to just be me
Masking
Medication helped me be like others
Medication helped me feel 'normal'
Medication helped me focus
Medication helped me understand others
Medication helping to fit in
Medication helps me live the way I want
Medication helps others ‘put up with me’
Medication slows things down; I can choose how I act
Medication helps maintain relationships
Missing out because of medication-taking
Mistrust of professionals

More widely recognised now
No communication from professionals
No other support apart from medication
Not being able to focus
Not fitting into friendship groups
Not involved in decisions about ADHD medication
Not telling others about meds
Only focus on academics, getting things done
Other substances
Parent support group
Positive relationships
Potential misdiagnosis
Prescribing medication at a young age
Regret going off medication
Reinventing self
Routine
Runs in the family
Saving others vs Saving myself
Self-stigma, low self-image
Side effects
Social media
Social support group
Socially included
Socially isolated
Societal value of being academic
Something's wrong with me
Sports
Stigma from others
Stopping medication

Struggle academically
Struggle in social situations
Struggling
Support needed
Supportive home environment
Supportive relationships
Susceptible to peer pressure
Taking medication was a hassle/burden
Teachers being unhelpful
The burden of treatment
The doctor said so (Power)
The pros outweigh the cons
The rigidity of the system
The unaccommodating education system
Therapy
Things mattered more
Thinking at high speed
Told them what they wanted to hear
Trauma
Two different selves on medication and off medication
Unacceptable part of self
Uncertainty about the future
Unhelpful others
Value of helping others
Wanting to take control
Worry about disappointing others
You but in another form

6.16. Appendix P – Theme Development




Agency in Treatment-related Decisions
Medication and Authenticity
ADHD Medication
Effects of Medication on Relationships
Fitting Within the System and Helping Others Around Me
Medication Effectiveness and Adverse Effects
The Power of Supportive Relationships
Feelings of Difference and Struggles to Fit In
Social Context
Social and Societal Stigma
'ADHD Is a Part of Me' – The Intrinsic Nature of ADHD
ADHD and Me
Outcomes in Adulthood

6.17. Appendix Q – Earlier Version of Themes and Definitions

Theme	Sub-Theme	Definition
Theme 1: ADHD Medication	Medication and Authenticity	Experiences of the medicated and unmedicated self, and whether the two are the same or different.
	Effects of Medication on Relationships	How taking ADHD medication affected young people's relationships.
	Medication Effectiveness and Adverse Effects	The effectiveness of medication and adverse effects experienced.
	Fitting Within The System and Helping Others Around Me	Taking medication to help others rather than for the self, and to work better within the system.
	Agency In Treatment-Related Decisions	Involvement in decisions about treatment at the time of diagnosis and over time.
Theme 2: Social Context	Feelings of Difference and Struggles to Fit In	Feeling different from others, difficulties with forming new relationships and hiding parts of the self to fit in.
	Social and Societal Stigma	Stigma and bullying, linked to others' lack of understanding and information about ADHD.
	The Power of Supportive Relationships	Helpful others and social inclusion.
Theme 3: ADHD and Me	'ADHD is a Part of Me' – The Intrinsic Nature of ADHD	ADHD beyond a profile of deficits, identifying strengths and linking the diagnosis to one's personality.
	Outcomes in Adulthood	Changes in coping and self-acceptance over time.