

# ADHD in adulthood: A qualitative study of lived experience, self-esteem, diagnosis and service provision in the UK

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## Abstract

**Introduction:** ADHD is a neurodevelopmental condition that significantly impairs many domains of functioning and has been associated with low self-esteem. It is frequently stigmatised and stereotyped, with misunderstanding of ADHD noted in medical professionals, teachers and public alike. Although frequently diagnosed in childhood, ADHD may go unrecognised until adulthood; especially with presentation of the inattentive subtype. Living with untreated ADHD has serious consequences in terms of psychological wellbeing; this study aims to explore lived experiences of individuals diagnosed with ADHD in adulthood, with a focus on diagnosis, treatment and self-esteem.

**Method:** 23 adults were interviewed about their lives before, during and after ADHD diagnosis. Data was analysed using an inductive approach to thematic analysis.

**Results:** Four themes were identified; (1) A whole life impact, (2) The rollercoaster of diagnosis, (3) Stigma and stereotyping – A need for understanding, (4) The ADHD community.

**Conclusion:** ADHD is a condition with a whole life impact that has grave consequences when left undiagnosed and untreated. Most participants reported inadequate service provision and experiences of low self-esteem. Online support groups were reported as being beneficial for self-esteem and a source of helpful support and community. There is an urgent need to develop high quality adult ADHD services consistently across the UK. Dissemination of accurate information on adult ADHD is needed to improve knowledge in healthcare and education, and to reduce public stigmatisation of the condition.

## 1. Introduction

Attention deficit hyperactivity disorder (ADHD) is usually recognised as a childhood neurodevelopmental condition; however, it frequently persists into adulthood and is estimated to be present in 2 - 5% of the adult population (Asherson, 2016). Additionally, some individuals are newly diagnosed in adulthood; this is particularly common for those who meet diagnostic criteria for the inattentive subtype of ADHD where externalising behaviours are less prevalent (Asherson et al., 2012). Such a presentation is often noted in females and although adulthood ADHD generally manifests with less hyperactive symptoms, it may still encompass feelings of restlessness, inability to relax, procrastination, inattention and emotional instability (Jain, Jain & Montano, 2017). The emotional dysregulation aspect of ADHD has been identified as one of the most common reasons that medical consultation is sought (Shaw, Stringaris, Nigg, & Leibenluft, 2015), but impairments in cognitive function and information processing also significantly affect organisational skills, interpersonal relationships, and day-to-day living (Schrevel, Dedding, Aken & Broerse, 2015).

Adults with ADHD frequently experience difficulties in education and employment (Adamou et al., 2013; Bjerrum et al., 2013; Bolic Baric, Hellberg, Kjellberg, & Hemmingsson, 2016). Such difficulties are often perceived as failures and can result in negative self-evaluation, stigmatisation and poor self-esteem (Newark, Elsässer, & Stieglitz, 2012). A substantial body of literature has investigated ADHD and self-esteem, including a recent systematic review (Cook, Knight, Hume & Qureshi, 2014). Edbom, Granlund, Lichtenstein & Larsson (2008) used a longitudinal twin study to investigate the relationship between self-esteem and ADHD symptoms, finding that low self-esteem was related to low scores in psychological wellbeing. However, the authors noted there are conceptual issues in self-esteem research and that it is a complex, multidimensional construct. Different psychometric tools of measurement are frequently used across studies, and findings may not be comparable due to this. Newark et al. (2016) found that adults with ADHD show lower levels of self-esteem, however, this used a small sample (n=43) and replication is required to make confident conclusions about the findings of this study. Generally, research into self-esteem in ADHD is more prevalent within child and adolescent populations; the systematic review published on self-esteem in adults only retrieved 13 articles dating from 1997-2011 (Cook et al. 2014). The included studies suffered from low sample sizes, no reported power calculations and no adjustment for Type I error. Research into this area needs updating with attention given to analytical rigour so that meaningful conclusions can be drawn from results.

Poor self-esteem is linked to adverse outcomes such as depression, anxiety and impaired social functioning (Dvorsky, Langberg, Becker & Evans, 2018; Harpin et al., 2016; Hodgkins et al., 2012). The psychosocial impact of ADHD can also contribute to feelings of powerlessness (Schrevel et al., 2015) and loneliness (Stickley et al., 2017). However, Fleischmann and Miller (2013) have identified that the internet offers a means of support and community for those with ADHD. Recent research has emphasised the positive effects of social groups on health (Haslam, 2018) and ADHD groups could be utilised to great effect in service provision. To date, there is limited evidence on internet support for adults with ADHD. Recent research with participants aged 15-32 years demonstrates that online interventions offer interpersonal support for those with ADHD, where none currently exists (Sehlin, Hedman Ahlström, Andersson, & Wentz, 2018). Wentz, Nydén & Krevers (2012), also found that online coaching improved self-esteem and quality of life in a sample of participants aged 15-26 years. These are promising findings, as there is a need to develop non-pharmacological interventions based on the psychosocial needs of adults with ADHD (Bolic Baric et al., 2015). As this study will recruit by online means, the role of online groups and their effect on self-esteem will be examined.

Diagnosis in adulthood can be challenging, and studies into experiences of diagnosis and treatment of adult ADHD are rare (Hansson Halleröd, Anckarsäter, Råstam & Hansson Scherman, 2015). Comorbid psychiatric diagnosis such as anxiety and mood disorders often complicate assessment and result in ADHD remaining undiagnosed (Fischer et al., 2007; Goodman & Thase, 2009; Katzman, Bilkey, Chokka, Fallu, & Klassen, 2017; Klassen, Katzman & Chokka, 2010). Symptoms of adult ADHD can also present as a confusing paradox; restlessness together with fatigue (Rogers, Dittner, Rimes & Chalder, 2016), inattention contrasted with an ability to hyperfocus (Ozel-Kizil et al., 2016), hypersensitivity alongside a capacity to be impulsively blunt with others (Adamou et al., 2013). Additionally, when ADHD is combined with high-intelligence, symptoms are often masked as individuals are able keep up with peers in education, often achieving high grades (Hua, Schore & Makarova, 2014). Diagnosis of adult ADHD, therefore, requires a clinician with a high level of skill to differentiate between such confounding complexities. Unfortunately, recent evidence (Matheson et al., 2013; Pitts, Mangle & Asherson, 2015) has noted a lack of training on ADHD in nursing and primary care, resulting in individuals being denied access to diagnosis and treatment.

Early diagnosis is beneficial for many reasons. Diagnosis offers access to medication and non-pharmacological support. Although medication can have side-effects, it frequently enables those with ADHD to achieve a higher quality of life, increased concentration and improved relationships (Avisar & Lavie-Ajayi, 2014). However, research investigating experiences of medication in adult ADHD populations is rare and further studies are needed; the present study aims to contribute to this deficit in the evidence base. Additionally, Fleischmann & Miller (2013) found that diagnosis results in a re-evaluation of the self as individuals understand the cause of life's struggles is not due to a personality defect. This results in increased confidence, improved functioning and a belief that the future can be different. Young, Bramham, Gray, & Rose (2008) also noted that the relief and self-understanding that diagnosis provides can be a gateway to newfound optimism and self-belief. Conversely, delayed diagnosis has serious consequences for those who continue to struggle without medication or support. ADHD has been identified as a risk factor in suicide (Balazs & Keresztesy, 2017) and it is therefore imperative that a greater understanding of ADHD is reached alongside an awareness of the consequences of late diagnosis.

Upon diagnosis, a multimodal treatment package comprised of medication, psycho-education and/or cognitive behaviour therapy (CBT) is recommended in the UK (Asherson, 2016; NICE, 2018); with an emphasis that patients can make an informed decision about medication and offered alternatives if there are issues around tolerability and safety. However, Matheson et al. (2013) highlighted a significant mismatch between policy and practice, with

services being described as inadequate and patients left struggling to access treatment. In the past 10 years, this is the only academic study to have investigated experiences of service provision for adults with ADHD in the UK. The present study then, aims to further contribute to research in this area and ascertain if any improvements have been made to service provision since this study was published.

ADHD is frequently labelled as a condition linked to antisocial youth, substance misuse, and poor parenting, with such stereotyping being prevalent in mainstream media (Adamou et al., 2013; Mueller, Fuermaier, Koerts & Tucha, 2012). Prejudice of ADHD persists in perceptions of professionals and public alike (Lebowitz, 2016; Ohan, Visser, Moss & Allen, 2013; Pitts et al., 2015) and may be further reinforced by research which focuses only on the deficits and symptoms of ADHD. Such preconceptions in research can become further magnified when ADHD is viewed only through the socially constructed lens of a 'burden' (Brod, Pohlman, Lasser & Hodgkins, 2012; Michielsen et al., 2015). However, in online ADHD communities and self-help publications, individuals frequently champion the unique characteristics and strengths of the condition (Green, 2018; Kruger, 2016). These include strategic thinking, creativity, high energy levels, hyperfocus, and an ability to thrive in busy and fast-paced environments (Hansson Halleröd et al., 2015; White & Shah, 2011). Recent studies have also found that symptoms of ADHD can become strengths as opposed to weaknesses (Lasky et al., 2016). This study aims to investigate potential strengths of ADHD alongside its challenges. In doing so, it is hoped that a broader perspective of ADHD is presented, one which examines lived experience, diagnosis and service provision alongside an exploration of self-esteem.

## **2. Methodology**

### *2.1 Study design*

Semi-structured interviews were carried out via telephone and written word to gain information about participants' experiences. An interview schedule was developed to use as basis for both telephone (appendix A) and written (appendix B) interviews. The semi-structured approach enabled the researcher to explore areas of interest based on previous study findings whilst allowing flexibility for participants to contribute their own thoughts and suggestions. A contextualist epistemological stance was used as a theoretical framework; situated midpoint between realist-essentialist and social constructionist epistemologies. Contextualism acknowledges that although an aim to capture 'real' participant experience may seem ideal (known as naïve realism or essentialism), the reporting of such information will be biased both by the researcher and via socially constructed meanings which have been ascribed to experiences (Braun & Clarke, 2006; Madill, Jordan & Shirley, 2000).

The study applied an inductive thematic analysis approach (Braun & Clark, 2006) to identifying, analysing and interpreting the data by looking for themes, commonalities and differences. This method utilises a six-step approach to move from the generation of many initial codes through to the categorisation of larger themes by an iterative process of re-reading transcripts and refining thematic ideas. A codebook was developed to document this process (see appendix C). The rationale behind choosing this form of analysis was to offer a data-driven approach, and to minimise researcher bias on participants' lived experiences. It is also a pragmatic approach; an accessible form of data analysis suited to a variety of theoretical frameworks and epistemological positions.

## *2.2 Participants*

Purposive sampling was used to recruit participants from an online adulthood ADHD forum (AADD-UK) and Facebook support group (ADHD Wise UK). Participants completed an online consent form via Qualtrics survey software. During recruitment, 36 completed the consent form, however, 13 individuals did not continue to be interviewed, despite efforts to contact them via email. Unfortunately, reasons for attrition were not given. In total, 23 individuals were recruited to the study, (20 female, 3 male) with a mean age of 38.4 years (range 21-56 years). Age of adulthood diagnosis ranged from 21 to 51 years with a mean diagnosis age of 35.7 years. Participants were diagnosed between 2011-2017; a period spanning 6 years. 43% were diagnosed in 2017 (n=10), 39% were diagnosed between 2014-2016 (n=9), and 18% between 2011-2013 (n=4).

Participants were resident in 16 different areas of the UK, representing experiences in 16 distinct health authorities. Participants were over 21 with ADHD diagnosis occurring after this age. At this age it was anticipated that participants would have experienced employment or higher education; pertinent as the study aimed to explore the impact of ADHD across these settings. Participants were residents of the United Kingdom, with ADHD as their primary psychiatric diagnosis.

## *2.3 Materials*

A password protected PC was used to communicate with participants via online forums and groups. Qualtrics software was used to distribute participant information sheets and to complete the consent process. The PC was used to store consent forms and interview data. Excel software was used to create a participant database and to record demographic information. ACR Recording software was used to record telephone interviews with Transcribe software being used to aid the transcription process. NVivo software was used as a data management tool, to code transcripts and develop a codebook for the thematic analysis.

## *2.4 Procedure*

To obtain consent for participation, individuals were sent a participant information sheet (appendix D) via email or Qualtrics software. If interested in taking part in the study, a consent form (appendix E) was completed and returned to the researcher via Qualtrics. An interview schedule was developed to structure the interviews; this was based on issues previously identified in the literature but also offered opportunity for participants to contribute their own ideas.

Participants were offered the choice of taking part in a telephone or written interview. The written interview was developed on feedback from contributors to the AADD-UK forum, some of whom reported that communicating via phone was problematic due to difficulties in information processing. The use of different interview formats for participants with additional communication needs has been encouraged (Neville, Adams & Cook, 2016). A recent study into online ADHD coaching also noted a preference for communicating via written word, with participants reporting this format increased feelings of safety and reduced stress as one could consider their thoughts, taking time to respond in the comfort of their own home (Sehlin et al., 2018). Telephone interviews were carried out between 16<sup>th</sup> February – 6<sup>th</sup> March 2018 and lasted between 28 - 79 minutes in duration. They were recorded for transcription purposes with the permission of the participant. Written interviews were completed via Qualtrics software or via a word document returned by email between 12<sup>th</sup> February – 1<sup>st</sup> July 2018. Telephone recordings were transcribed verbatim by the researcher and, along with the written interviews, were coded and analysed with the aid of NVivo software. After the interview was concluded, a debrief sheet (appendix F) was sent to each via participant via email.

## *2.5 Data analysis*

Phase 1 of the thematic analysis involved initial reading of interview transcripts to search for meanings and patterns in the data. During phase 2, initial codes based on semantic meaning of the data were generated. A total of 1169 meaningful references from 23 sources were extracted and coded. Phase 3 of the thematic analysis involved searching for themes. It was decided that subthemes would be essential to give structure to the larger themes, as it became apparent that this was a complex research topic. During phase 3, initial codes were linked to 8 candidate themes and 36 subthemes. These were reviewed at phase 4, with collated extracts being re-examined to assess if they were appropriate for inclusion in their thematic category. In total, 5 themes and 16 subthemes were extracted. Phase 5 involved a final review and refinement of themes and an appraisal of how they related to the research question. Phase 6 of the thematic analysis involved producing the report, with a thematic map being produced to illustrate the main themes in visual format (figure 1).

## 2.5 Thematic map

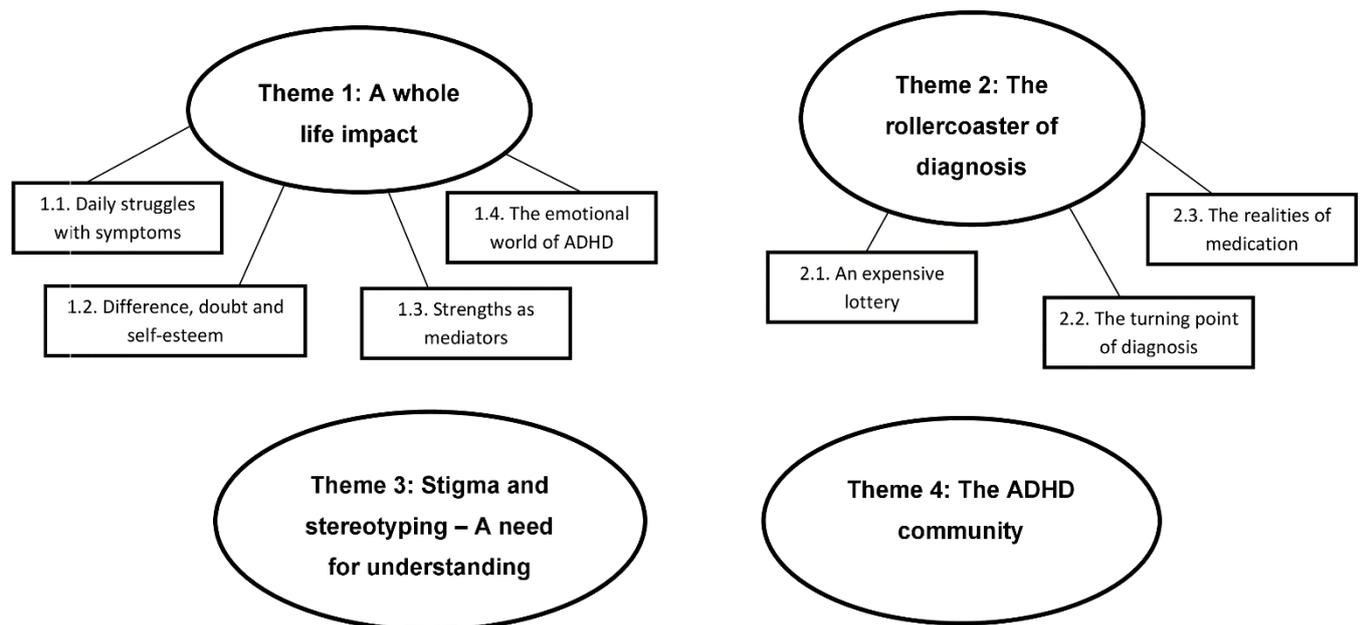


Figure 1. Final thematic map, showing four main themes and seven subthemes

## 2.6 Ethics

Ethical clearance for the study was approved via University of Derby in January 2018. With reference to the British Psychological Society Guidelines, it was decided this was a vulnerable population and that interviews should be undertaken either via phone or written interview. A full risk assessment was also carried out as part of this process. The researcher's professional occupation as a National Health Service (NHS) research assistant was considered during ethical approval and her Disclosure and Barring Service (DBS) certificate forwarded to the project supervisor.

## 3. Findings

This analysis details accounts of lived experiences of adulthood ADHD with a focus on diagnosis, service provision and self-esteem. Four themes were identified: (1) A whole life impact, (2) The rollercoaster of ADHD, (3) Stigma and stereotyping – A need for understanding, (4) The ADHD community.

### Theme 1: A whole life impact

Every participant described how ADHD impacted their life across various domains of functioning and in different contexts. As this was such a large and complex theme, it was necessary to structure it by the identification of four subthemes. The complexities of ADHD became apparent:

### 1.1. *Daily struggles with symptoms*

First descriptions of struggling with symptoms were often linked to experiences in the education system. This reflects previous findings by Bjerrum et al. (2013), who outlined the impact that ADHD can have on academic achievement and functioning at school. ADHD symptoms of inattentiveness, procrastination, and organisational difficulties were often interpreted as laziness by teachers and family members. Such experiences have been shown to impact on self-esteem and self-efficacy (Newark et al., 2016). Socially constructed concepts such as 'laziness' were internalised, and the individual came to believe that they were intrinsically faulty. This psychological process is apparent in the following extract:

"I was completely disorganised and always left things to the last minute. I couldn't take care of myself, couldn't function. My grades at school got worse and worse as independent study became more of a necessity and was written off as lazy as I had been a top student. I believed what I was told and decided I didn't care about school." [Participant 12]

Messages that teachers give to students have potential to impact on adult functioning and identity. Despite being labelled 'lazy', individuals were often working harder, in a bid to manage the organisational tasks of day-to-day living, this leading to disappointment and frustration:

"Nothing about my life worked without twice the effort of everyone else and, more often than not, I did all that work for less reward." [P35]

Gifted students with ADHD are often able to develop strategies to accommodate struggles with symptoms at school (Hua et al., 2014). However, even those who were academically successful acknowledged they were often hiding their struggles to the outside world. Such talented students were unable to reach their full potential. Earlier identification and diagnosis could result in education being less stressful and challenging for all with ADHD:

"I did well and went to University and of course everyone just assumes that it was a doddle cos you did really well in your A-levels. And I look back and go, 'it wasn't a doddle at all, it was horrible'". [P11]

Additionally, the rule-bound rigidity of educational and employment was often incongruent with many characteristics of ADHD. Previous research has investigated how school and work environments can exacerbate ADHD symptoms (Lasky et al. 2016), noting they are often context-dependent. This emphasises the importance of making adjustments for those with ADHD in employment and education. By doing so, symptoms can become less impeding and outcomes improved. The account below reflects this assertion, noting that school need not be an experience that individuals have to recover from:

"I just think kids who are different, whatever their differences are, there needs to be some, some way of giving them space in school not to be so regimented ... not try and make everyone fit into this same box, until they leave school, and then you hope that- they find a way-- to sort of get over it really." [P11]

Unfortunately, participants remained unaware of the fact they had ADHD into adulthood and school was experienced as difficult for many. At work too, symptoms frequently affected the ability to carry out duties effectively, increasing stress and reducing self-efficacy. This relates to Adamou et al. (2013) who found that procrastination, organisation and poor time management often impair performance at work – especially in administrative tasks. For one participant, the difficulty of managing such tasks in a newly appointed high-profile role resulted in him losing his dream job. The ramifications of this were grave, as he became suicidal. ADHD has been noted as a risk factor for suicide and can be exacerbated by symptoms of impulsivity (Balazs, & Keresztesy, 2017). The findings of the current study illustrate how suicide in ADHD is a serious issue; two other participants also spoke of suicidal ideation and how the whole life impact of struggling with symptoms eventually led to them reaching crisis point:

“Now imagine this now, right ... you get your dream job, and you really do well at interview and you get the dream job-- [long pause]. You can't do it ... It was awful. Awful, awful ... I had an introduction to mental health services, let's put it that way.” [P25]

Fatigue was highlighted as another symptom of ADHD with potentially fatal implications. This is a paradoxical symptom - one not associated with the classification of ADHD as a hyperactive disorder. However, it is a common feature in adulthood ADHD (Rogers et al., 2016). One participant described narrowly avoiding a serious accident on the motorway; unaware her fatigue was due to ADHD after misdiagnosis of depression. Although a substantial body of research exists on the comorbidities of ADHD (Katzman et al., 2017), there is a lack of research into the implications of undiagnosed ADHD whilst driving:

“I nodded off driving to Uni on the motorway and the cat's eyes on the hard shoulder kind of woke me up ... So, I went back to the GP again and I started with 'you know, I *know* that it has lots of the same stuff as depression', and he just said, 'right, stop', he said, 'depression doesn't make you fall asleep while you're driving on the motorway'.” [P7]

When ADHD remains undiagnosed and untreated, struggles with symptoms can jeopardise personal safety and contribute to individuals reaching crisis point. Mandatory screening has been called for in previous research to reduce these risk factors (Goodman & Thase, 2009), unfortunately this recommendation has so far remained unheeded.

### *1.2. Difference, doubt and self-esteem*

Every participant described experiences that related to difference, doubt and self-esteem, with narratives outlining how individuals often felt misunderstood in their social environment. Issues of difference and self-esteem were linked to impaired functioning at school and work and highlighted how ADHD can also affect interpersonal relationships. This relates to Schrevel et al. (2015), who found that difficulties in socialising could result in feelings of failure and a negative self-image. This process has been defined as self-stigma in previous ADHD research

(McKeague, Hennessy, O'Driscoll & Heary, 2015); summarised as a negative evaluation of the self, based on experiences of feeling different to others. The socially constructed concepts of being a 'non-person' and 'self-as-defective' are apparent in the following narratives:

"Like I still felt... *strange*. I felt kind of *off* my whole life. Like when I go to my ADHD group, we chat a lot about- we feel like there was a day in school where everyone learnt the social rules ... this is how you go about, you know, communicating with people. And we all kind of missed that day like, everyone just gets it and we just didn't get the rules. We just missed that day, where they just told everyone how to be a person." [P4]

"I felt like a fraud, blagging my way through life, and trying to keep up with everyone else. I reasoned that I just wasn't trying hard enough, and that I was defective." [P9].

Interpersonal relationships were often difficult, with some participants describing experiences of isolation. This reflects the findings of Stickley et al., (2017) who discovered a correlation between ADHD symptoms and loneliness. Research into this area is scarce and the findings of the current study also identify participant experiences of loneliness, linked to feelings of being different to others. This sometimes led to further socially withdrawal:

"I did feel *horribly* different to people. Cos I was, I was. But I didn't know why. I just thought I was a bit shit and weird ... And then I sort of grew into my weirdness a bit, sort of embraced it a bit and just you know, fucked off from school and never spoke about- hardly spoke to anybody for about twenty years." [P25]

Some participants also reported experiences of being bullied during school or college, also contributing to mental health difficulties and low self-worth:

"I'd talk quite candidly with some of the girls at college about my experiences, which made the bullying worse, but I couldn't really understand why. Things were just really, really odd and confusing, and I knew that something was up, but couldn't seem to find the right place or person to go to for help. By the end of the first year of my degree I felt so defunct I started to wish I was dead and had strong urges to harm myself." [P34]

It is important that the psychosocial aspects of ADHD are explored and addressed, as they exert a considerable effect on self-esteem and self-image. This is especially vital during developmental years when identity is formed.

### 1.3. *Strengths as mediators*

This subtheme was an area which explored aspects of ADHD that offered a mediating buffer to the struggles of living with symptoms and influenced the lives of participants in positive ways. Imagination and innovative thinking combined with passion and drive were identified as strengths which enabled participants to reach their full potential and appreciate their own unique perspective on life. This reflects the work of White & Shah (2011) who found that adults with ADHD demonstrate higher creativity and idea generation than the general

population. Lasky et al., (2016) also note how individuals can thrive in certain work environments, where autonomy is encouraged, and individuals given freedom to contribute to organisational change:

“I was constantly very, very driven - I was very successful, very young. I set up my own business when I was 25 and by the time I was in my 30s, I was earning a lot of money ... ADHD can give you this 'superpower' as I call it - this incredible drive, that other people just don't have.” [P6]

The above description of ADHD as a superpower illustrates the use of language to socially reconstruct ADHD as a positive difference (Mather, 2012); defying the negative narratives of 'self-as-defective' and 'non-person' present in the previous subtheme. This reframe has potential to alter the self-concept and esteem of the individual; a means of appreciating the uniqueness of neurodiversity. This also relates to the work of Bjerrum et al. (2013) who emphasise the need to nurture protective factors to improve self-worth for those with ADHD. Hyperfocus – the ability to sustain attention and engage intensely with an activity for an extended length of time – was also discussed by some participants as a unique strength. This reflects the findings of Ozel-Kizil et al., (2016) who identify hyperfocus as a highly under researched area. This aspect of ADHD seems another paradoxical contradiction to the concept of ADHD as a deficit of attention. Hyperfocus was found to be especially potent when combined with a passionate interest:

“I call it 'the fire'- other people with ADHD will call it 'the zone' or 'hyperfocusing' or whatever. But with me it's 'the fire' ... anything to do with the fire, I will then absorb. So, legislation, I could tell you like it all backwards, because I had to, because it was part of the fire.” [P25]

Yet again, the use of socially constructed language as a means of empowerment can be noted in the above extract. Fire is a potent cultural symbol, a dynamic force to be reckoned with; a word with associations of passion, power and energy. Participants recommended that one way to improve outcomes for adults with ADHD was to focus on harnessing such personal passions and abilities. Academic research into ADHD remains highly deficit centred; this is limiting and may shift focus away from the strengths and potential of an individual (Hua et al., 2014). When abilities are nurtured and engagement in an activity is high, benefits can be significant:

“Finding that thing to be passionate about and if you can find that thing, you can do really, really well. So, I try and see some of my good points - some of my ADHD good points as a gift really.” [P8]

“I was lucky enough to be offered the chance to do a PhD and I flourished even more during that time ... I produced my thesis and some research papers on time.” [P36]

However, it is vital to acknowledge the significant impairment of ADHD on daily functioning; research should always offer a critical approach to exploring this complex condition. Some

participants did not feel there were any positive aspects to ADHD, whilst others felt that strengths should be balanced in the light of the whole life impact:

“You don't realise how hard it is - they're so busy sharing pictures of Richard Branson but they don't have to live with it ... A lot of professionals will like, really pedal the positives, and there are positives and I agree with that, but then it does sometimes feel like that's like- undermining the lived experience.” [P29]

“A lot of people refer to their ADHD as a superpower, but I do not think this at all. I only believe hyperfocus to be a truly positive feature of my ADHD, and even that is a double-edged sword. I would rather not have ADHD.” [P26]

#### 1.4. *The emotional world of ADHD*

Many participants described how the emotional world of ADHD had a significant impact on everyday life. Emotional dysregulation was described, alongside increased empathy and a sensitivity to perceived criticism; referred to as rejection sensitivity dysphoria (RSD). No academic literature has been published on RSD, but this is a topic prevalent in online grey literature about ADHD (Dodson, 2018; Rivera, 2018). One participant described RSD in the following manner:

“They don't talk about rejection sensitive dysphoria, they don't talk about that we're overly empathic, they don't talk about how things affect us more ... It's the *emotional element* that has the biggest impact. It really does ... we can see rejection in pretty much anything and it can really hurt.” [P6]

Exploratory research into RSD would be beneficial and potentially lead to a greater understanding of ADHD; therapeutic interventions could be developed to support people with this issue. A lifetime of being criticised at school, feeling markedly different to peers, alongside frequent experiences of actual social rejection may result in individuals becoming more sensitive to perceptions of such experiences in later life. With this formulation, the presence of RSD in ADHD appears understandable. Heightened empathy was also often understood by some participants in terms of their own historic struggles, resulting in them being more compassionate:

“If I find someone struggling who feels like a bit of an outsider, I will make them feel well ... Because I've been that outsider and I don't want anyone else to feel like that.” [P4]

Other participants discussed difficulty regulating powerful emotions. This relates to Shaw et al. (2015) who identify emotional dysregulation as a defining feature of ADHD:

“Our emotions are *instant* ... my instant reaction is like, 'oh, shit!' And I go up with a big bang and then 10 minutes later when I've thought it through, it's like, 'well, actually, it's not that bad'. But I have no control over that instant 'up' that comes, you know. Our emotions are quite- *heightened* I would say.” [P7]

Anxiety and depression were also apparent in the narratives of many participants. For some, these were legitimate secondary diagnoses, but for others, these were misdiagnoses based on emotional symptoms of ADHD. This reflects the findings of Klassen et al. (2010), who highlighted that ADHD symptoms are often mistakenly assumed to be part of a differential diagnosis. Some participants lived with a misdiagnosis for years, with reduced quality of life and continued functional impairment due to untreated and undiagnosed ADHD:

“Initially I thought I had depression, but something about the cause of my issues didn’t feel like how my friends described their depression.” [P35]

“I kept going to my GP and I would say over a period of five years, going to my GP with this sleep stuff. And I kept being given different antidepressants and things. And I kept going back and saying, “these are not working.” [P7]

When the presence of comorbid mood or anxiety disorders were formulated within the context of the whole life impact of ADHD, participants were able to make sense of their experiences:

“Why wouldn’t you suffer from anxiety if you’ve had ADHD all your life? You know, it’s almost like, well, of *course* you’re gonna have something that goes along with it if you’ve had this undiagnosed condition that makes you feel useless and disorganised - why would you not?” [P8]

The subtheme of the emotional world of ADHD emphasised how vital it is to consider this aspect of experiencing and the effects it has on self-image and esteem. It also highlights how co-morbid mood disorders may be hard to differentiate from ADHD symptoms but that this distinction can be a gateway to earlier identification and diagnosis. As mentioned previously, mandatory screening and training in ADHD assessment could help prevent unnecessary suffering; either from ADHD misdiagnosed as a mood or anxiety disorder, or as untreated ADHD alongside a co-existing psychiatric diagnosis. This is vital to consider as previous research has found 80% of ADHD patients will have a co-morbid psychiatric condition (Fischer et al., 2007).

## **Theme 2: The rollercoaster of diagnosis**

The process of diagnosis was noted as a journey comprised of many ups and downs, often marking a turning point in the lives of participants. This reflects previous findings from Fleischmann & Miller (2013) who also noted the turbulence of this time and resultant changes to self-image. Three subthemes were identified, outlined below:

### *2.1. An expensive lottery*

Access to quality services and treatment appeared to be a lottery with high personal costs for those struggling to access services. This relates to Matheson et al. (2013) who similarly discovered that diagnosis was an uphill struggle for many adults with ADHD. However, the

present study also found that, in contrast, life-changing benefits were available for those living in areas with good provision. Some participants were fortunate to have a GP who was informed or open to understanding about adult ADHD. For these participants, this first part of the diagnostic process was straightforward, with them reporting the benefits of a good doctor-patient relationship:

“I don't think it was more than 3 months actually from the point I darkened her door until the sort of diagnosis ... I think it makes a big difference whether the person you see gets you or not ... She was brilliant, and so the first thing that was really helpful to me was that she was learning a lot about ADHD at the time.” [P8]

In accordance with Matheson et al (2013), some participants described issues with GP services, mostly a lack of understanding and an unwillingness to consider ADHD as a possible explanation for symptoms. Such issues in services delayed diagnosis further, acting as barriers to accessing care and medication:

“I distinctly remember that a lot of emphasis was placed on the hyperactive elements of the disorder and the fact that I had no drug/alcohol/sex addiction - and have had and loved animals my entire life without abusing them was made out to be a very important factor against a diagnosis. Due to this, I was told I did not have ADHD ... I then went to a private specialist who performed a full, thorough assessment which involved me carrying out varying tasks and tests. He concluded that I definitely did have ADHD, but inattentive presenting and high functioning.” [P12]

“Part of the problem is the lack of understanding from GPs and healthcare professionals not specialising in ADHD. Often people are turned away, because people don't know much about ADHD and how it affects adults.” [P36]

Such barriers to treatment often resulted in feelings of frustration and powerlessness whilst participants struggled to manage the impact of untreated ADHD. Many participants waited between 6 months to 2 years to see a specialist:

“The waiting list is just *huge* ... I was pushing 2 years ... it affects your life so much ... ADHD impacts on every single thing that you do.” [P7]

Approximately half the participants described problems in service provision and treatment. Due to barriers accessing assessment and treatment, nearly a quarter of participants opted for private healthcare. This was often their only option, due to the gravity of their situation, or after being informed there were no adult ADHD services available to them:

“It was a really, really choppy time and we went privately, which was against my own particular view, but it was either that or wait 6 months. And bearing in mind, I'd just tried to do myself in like-- they were just like, 'right, get him in- pronto'.” [P25]

“His actual words were 'there's no money in the NHS for adult ADHD' ... So, I went and saw another doctor, he said, 'no, I'm sorry, there's nothing I can do for you because they will not pay for you to be seen for ADHD in mental health services.' So, then I thought 'right, sod it I'll go private.'” [P6]

Unfortunately, private healthcare also demonstrated shortcomings in terms of patient care and understanding of ADHD. Diagnosis of adult ADHD often involves a retrospective reflection on the client's life to assess functioning during childhood and school, but it is emphasised that current functioning should equally be considered during assessment (Lovett & Davis, 2017). A distressing consultation with a private ADHD specialist was highlighted by one participant, where only a retrospective approach to assessment was taken:

"It was a horrible experience and they were completely useless. They tried to tell me that I didn't have it because some of my primary school reports said that I couldn't pay attention, but others didn't mention it - so therefore they couldn't tick me off .... I just turned around and just started crying." [P13]

After finally navigating the diagnostic process, there was great variation in treatments offered to participants across the UK. Some services incorporated medication alongside non-pharmacological interventions, with individuals highlighting the benefits of such an approach. This relates to Matheson et al. (2013) who also emphasised the importance of non-pharmacological treatments for adult ADHD in previous research:

"I was referred to a specialist who has been a huge help over the years ... I was also prescribed medication which has helped greatly. I have received counselling and CBT as well, both of which have been helpful to managing negative thoughts." [P12]

One participant was aware that non-pharmacological services were available, and felt frustrated at only being offered medication, a common finding from the study:

"It has been pretty frustrating at times knowing that there is something out there that may help, but I can't access it. I imagine it would be different if it was something you can't change, as you just have to accept it, but I will not do it until I have tried everything." [P31]

A novel finding from the present study, was that some participants did not find CBT to be beneficial, reporting that it negatively impacted their self-esteem. CBT often involves completing exercises at home; relying on memory and organisation skills which could be affected by ADHD symptoms:

"The treatment was very unsuccessful and actually made my mental state worse, resulting in a complete breakdown ... The methods used required a lot of filling out paperwork and doing homework which I never found time to do and just brought back those disappointing feelings and self-criticism." [P22]

These are important findings that can be used to improve treatments for those with ADHD; it is a heterogenous condition where individual treatment needs will differ greatly. Previous studies have highlighted that strengths-based coaching is often preferable for adults with ADHD (Schrevel, Dedding and Broerse, 2016) and this was also mentioned by some of the participants in the present study, who felt their needs were not currently being met within healthcare:

“More specialist services should be developed. We should be able to access therapy, CBT, ADHD counselling. Life coaching would also be brilliant, but I don't know how realistic this is.” [P31]

## 2.2. *The turning point of diagnosis*

Diagnosis signalled a turning point in the lives of all participants. This subtheme frequently identified narratives of relief, revelation, alongside a change in self-perception and self-esteem as participants made sense of their life histories in the context of ADHD. This relates to Young et al. (2008), who also described diagnosis in adulthood as a revelatory moment, and an opportunity to relocate blame for previous perceived failures in life:

“I felt massively relieved and it made things make sense. Yes, it's effected my self-esteem, positively. Because now I know and understand where all my anxiety and self-doubt come from.” [P16]

Alongside relief, it was common for participants to report conflicting emotions after diagnosis; anger, sadness, and grief for a life lost. Participants often wondered what their lives may have been like, if a diagnosis had been given sooner. Intense emotions after diagnosis could be hard to make sense of. Quite often, it took time to process such a mixture of powerful feelings relating to self-identity, change and loss. Young et al., (2008) have also noted this complex emotional response to ADHD diagnosis, as illustrated below:

“After diagnosis although it sounds like a cliché, it was an emotional roller coaster. Initially it was a relief and helped things make sense. Then I felt sad by the opportunities I had missed because no one had recognised it and I thought of how things might be different if they had. Eventually I feel that diagnosis was a life changing event for the better.” [P28]

The turning point of diagnosis frequently signalled a quest for knowledge about ADHD. Participants described an intense period of researching about the condition and being able to better understand themselves and their life experiences as a result. This process often led to greater self-acceptance and confidence, as reflected in previous research (Fleischmann & Miller, 2013) and also gave individuals confidence to talk about their diagnosis to others, some of whom could be misinformed or sceptical.

“And I think the real turning point was, doing the research ... finding out *why* is my brain like this? To have to ammunition to fight back against people and be like, ‘No! I'm very sure this is a condition that I have. This deeply affects my life.’” [P4]

In accordance with previous studies (Hansson Halleröd et al., 2015; Young et al, 2008), participants mostly described diagnosis as a positive experience. Changes to self-perception and improvement to self-esteem were described as they finally understood past struggles were due to ADHD and not because of an intrinsic personality flaw (Fleischmann & Fleischmann, 2012).

### 2.3. *The realities of medication*

Experiences of medication were extremely varied. Some participants were extremely positive about medication whilst others chose not to take medication at all; again, highlighting the heterogeneity of the condition and the need to consider personal preferences in treatment. However, it is important to note that medication could be life-changing and potentially life-saving, often accompanied by a feeling that the future could now be different; reminiscent of the findings of Young et al. (2008), who also identified how medication helped not only with symptoms, but also offered a new perspective on the future:

“The medication absolutely transforms lives. It really does with ADHD.” [P6]

“I now feel amazing ... My medication is a life saver.” [P26]

For most participants, medication was helpful but not a panacea. The most prominent narrative was that medication enabled participants to focus and concentrate, especially important for college and work. This relates to Singh et al. (2010) who noted similar findings. Tasks which had seemed painfully tedious, were now identified as being significantly easier:

“Although I feel much calmer and able to do stuff, it isn't like there's a sudden switch ... It's more that if I sit down and try and mark a set of books, I don't feel like an almost physical and mental pain ... So, it's more an absence of the discomfort of it rather than, you know, feeling great.” [P8]

The benefits of medication became noticeable when participants had a break from taking it to prevent tolerance building. This enabled one participant to appreciate how severe the impact of untreated ADHD was:

“I know when I haven't taken it, there's a massive difference ... without the meds, the weeks in between when I had to come off the tablets because I'd become dependent on them, were horrific.” [P7]

Ambivalence towards medication was illustrated in the following account, which clearly describes benefits weighed against costs. Mixed feelings about ADHD medication are common (Avisar & Lavie-Ajayi, 2014). Quite often, despite an improvement in cognitive function, participants felt that medication affected coping strategies they had previously used, and that their personality was somewhat changed:

“I found it helped regulate my focus through the day and maintain focus on a task. It helped keep my energy levels more levelled through the day but only if I got the timing right. My thoughts and mind would be slower and more organised also ... I lost some of my creativity and ability to think outside the box on medication. Others said I was quieter and more serious. I felt that I was not as much myself or as much fun.” [P22]

Some participants were still trialling different medications, persisting through unpleasant side effects, and waiting for a positive outcome. The side-effects of stimulant medication have

been noted as unpleasant and even intolerable in previous studies (Avisar & Lavie-Ajayi, 2014). Studies exploring experiences of stimulant medication in adults are still relatively rare, and the findings of the present study emphasise the importance of offering non-pharmacological support to everyone diagnosed with ADHD. Medication alone is often not sufficient to target the array of cognitive, emotional and psychosocial symptoms, and side-effects can mean that medication is not a feasible option for some:

“So far, have not seen any positive effects, just a lot of negative effects on mood, motivation and even memory. I also had problems with anxiety, insomnia, stomach acid and loss of appetite.” [P31]

A minority of participants reported that they did not take medication due to side effects. Sometimes this choice was reinforced due to an inability to access regular medication reviews. Yet again, this finding emphasises how barriers to accessing services can negatively impact the wellbeing of patients. Finding the right ADHD medication is often a process of trial and error, taking time to find the optimum formulation and dosage for the individual. Certain participants also feared that once they informed the doctor they wanted to discontinue medication, they would be discharged from the specialist service, and denied access to any further support:

“I was not offered anything other than medication, which I took for about 14 months but as the appointments were erratic, the balance was never made comfortable. The medication gave me initially great focus once I was up to a mid-range dose but with it straight away came physical feelings of anxiety ... Once I decided that meds were not for me they took me off the 'books', despite the fact that coming off them made me feel very unwell.” [P28]

“I'd probably still be on medication if I could be reviewed more regularly ... because you have to then wait 6 months to discuss that with someone- and then if you tell them you're not on medication, they go, 'oh well I'll discharge you then.’” [P29]

After experiencing advantages and disadvantages to medication, several participants described using it on an 'as needed' basis. This was often to manage specific tasks or when symptoms became challenging. It is crucial for healthcare professionals to understand that medication for ADHD need not be an all-or-nothing approach where patients are discharged from important support services if they do not wish to take medication on a regular basis:

“I prefer not to take medication, but when I spiral into my ADHD vortex and become sufficiently aware that I'm spiralling, I'll take it for a few days to get me back on an even keel ... If I have a heavy teaching load I tend not to need it. The buzz of teaching keeps me alive. When I don't have that structure and I have to prioritise other tasks, I sometimes take it to keep me on an even keel and to keep focused on the task.” [P36]

### Theme 3: Stigma and stereotyping – A need for understanding

Stigma and stereotyping were described by most participants, reflecting previous findings associating stigma with ADHD (Mueller et al., 2012). Participants reported ADHD was frequently misunderstood as a condition affecting only antisocial boys, those with addiction issues, or people involved in the criminal justice system. Such stigmatising tropes of ADHD are socially constructed phenomena; realities based on the discourses and interactions of others (Mather, 2012). As a result, some participants remained private about their diagnosis after experiencing negative or sceptical reactions from colleagues, friends and family:

“There is no way I would disclose my diagnosis to my colleagues. I hear the comments they make about students with it – I’d be a sitting duck.” [P36]

“My parents, oh my god. I think I told them once on the phone, that I was going to be assessed. And there was just kind of like, silence ... and they didn't ask anything else, nothing at all ... My Mum said absolutely nothing.” [P11]

Some participants described having to repeatedly explain ADHD to family and friends due to their lack of understanding. This became burdensome and further discouraged participants from being open about their diagnosis:

“I don't think I was sad, until I started telling people because people's reactions were so crappy ... I was so relieved, but people were so quick to say like, ‘are you *sure* though? I wouldn't say you're hyperactive’ ... I had to re-explain ADHD about 50 times.” [P4]

The dissemination of accurate information about ADHD was noted as one way to address stigma and stereotyping. This is important as stigma can result in social rejection and poor self-esteem (Lebowitz, 2016). A greater need for understanding was emphasised as crucial for education and healthcare. This finding relates to Pitts et al., (2015) who reported a lack of training in adult ADHD in nursing and primary care. Such lack of expertise and knowledge is problematic and acts as a barrier to assessment and treatment:

“My first GP wouldn't refer me, her words where ‘I don't feel it’ - because I work for the police and don't get into trouble, she didn't think I fit the criteria. Worrying I know, but I didn't have the head strength to fight.” [P16]

Some participants utilised their lived experience and expert knowledge to actively contribute to a deepened understanding of ADHD, noting that they could actively improve policy and practice. This demonstrates examples of good practice within education that could be implemented in schools around the country to improve outcomes for children with ADHD:

“I declared my ADHD at interview with my current employer and they embrace it and see the positives of it. I lead in the implementation of the whole school ADHD policy and deliver teacher training. I also deliver teacher training to schools as an independent provider and run an online support network.” [P2]

#### Theme 4: The ADHD community

Positive experiences were described by participants in relation to meeting others with ADHD, either face to face or online. ADHD support groups were described as beneficial for most, often improving self-esteem. This reflects previous findings on how the internet can be a supportive environment those with ADHD (Fleischmann & Miller, 2013).

“I feel a part of something, a bit like meeting a family member ... I would say there is a kinship of minds; finding people who make the same mistakes as you and have had the same struggles is quite grounding and you no longer feel like no one understands ... It is so empowering meeting someone else with ADHD.” [P28]

These socially constructed ‘families’ offered a valuable method of self-sought service provision; a place where participants accessed practical advice alongside emotional support:

“It is great to have a safe space where we can talk about a huge array of private issues and not be judged. This advice is all very helpful. I have no negative experiences of the group and find everyone very supportive.” [P26]

However, interactions in online groups could have negative consequences. One participant highlighted how the heterogenous nature of ADHD can often accentuate differences between individuals, leading to conflict not community. There was also an acknowledgment that the online disinhibition effect (Suler, 2004) could result in unpleasant experiences in internet support groups. This could be exacerbated by the impulsivity of ADHD and is an important consideration when offering support via online means:

“You see people putting comments on and they get absolutely roasted by somebody for like a really innocuous comment and even in friendly groups I've seen that happen ... You know, people's lives are so different. It's not like you've got this issue, you know, it's not like saying you've got autism therefore all autistic people are the same, they're all gonna have the same issues. It's the same with ADHD, everyone has different aspects that they struggle with.” [P11]

One participant initiated a support group network in her local area – demonstrating how the innovative thinking, passion and drive of ADHD could be used to improve services. Such face-to-face support was recommended as something that would be helpful for those with no current access to it:

“The vast bulk don't know another person with ADHD, they've got no-one to ask... And every single person that contacts me goes, ‘I wish this had been around years ago. I'm so pleased it's happening.’ They're all so grateful to get some sort of support cos it's just not there.” [P6]

“I would like a face to face support group where I could meet other adults with ADHD.” [P26]

These findings provide further evidence that a social perspective to healthcare can be highly beneficial (Haslam. 2018). They also demonstrate the efficacy and benefits of online

groups for those with ADHD who often experience a lack of such interpersonal support (Sehlin et al., 2018; Wentz et al, 2012).

### **Reflexivity**

The author has lived experience of feeling 'different' and stigmatised due to her own mental health difficulties from adolescence to mid-twenties. Certain thematic content described by participants may have resonated with her experiences, potentially affecting the process of data analysis and discussion of findings. This is an inescapable part of conducting qualitative research – the researcher exerts a constant, if at times, indiscernible influence on every aspect of the study.

The author is currently employed in an NHS trust as a Band 5 research assistant and has trained to postgraduate certificate level in integrative psychotherapy. Her training will have affected the way she communicated with participants and perhaps influenced responses in the telephone interview, although some of these researcher effects may have been mediated by the written format. The author's therapeutic theoretical model is rooted in the humanistic tradition; this acknowledges that both therapist and client contribute to the therapeutic relationship. In the same manner, the author recognises that qualitative research is a co-constructive process, influenced by both researcher and participant. Participants will have also made assumptions about the researcher based on race, class and gender, and additionally her student status; these would have been visible on her online profile, used during the recruitment phase. These individual characteristics all have potential to exert influence on how participants respond during interview.

### **4. Discussion**

This study aimed to explore lived experiences, diagnosis, service provision and self-esteem of people diagnosed with ADHD in adulthood. 23 participants were interviewed, with four themes being identified in the thematic analysis.

The first theme was "A whole life impact". Many participants struggled with symptoms throughout childhood with poor self-esteem developing due to negative formative experiences with peers and teachers. This reflects Schrevel et al. (2015), who identified that social difficulties are often more problematic than cognitive symptoms. The present study also identified that feeling different often resulted in experiences of social isolation and withdrawal, reflecting early research into ADHD and loneliness (Sticklely et al, 2017). This emphasises a need for early intervention in ADHD, as it is a condition that can deeply affect developmental socialisation processes and self-esteem when peer group experiences are negative. Self-perception was also affected by teaching staff at school, with nearly all participants labelled

as lazy during childhood. The social construct of laziness has damaging effects when attributed to children with ADHD, leading to internalisation of the beliefs of others and resulting in self-stigma (McKeague et al., 2015). Such stigmatisation also contributes to poor self-esteem (Newark et al. 2016) and there is a need for teachers to receive more training on the complexities of ADHD, especially on the inattentive subtype which can be harder to identify. This need has been highlighted in previous work (Matheson et al., 2013).

Co-morbid anxiety and depression were common narratives, supporting findings that adult ADHD is prevalent in those with mood disorders (Goodman & Thase, 2009). However, misdiagnoses of mood and anxiety disorders were also reported; based on the emotional symptoms of ADHD masquerading as depression or anxiety. Consequences of misdiagnoses can be disastrous, especially when considering risks of driving combined with inattention and fatigue. More studies into ADHD and fatigue are needed to improve understanding of this area, reduce risk and misdiagnosis. This finding is supported by recent recommendations of Rogers et al., (2016). Additionally, ADHD screening could be undertaken as part of every psychiatric assessment, to avoid missing diagnosis where individuals present with symptoms of anxiety or depression. Mandatory screening of ADHD has previously been called for (Goodman & Thase, 2009), but perhaps a lack of specialist skill and training on ADHD within healthcare has prevented this from being actioned.

The emotional world of ADHD was highlighted as challenging for all participants, with many experiencing hypersensitivity and emotional dysregulation. Several participants described emotional issues as being the most challenging aspect of ADHD, supporting findings from previous research (Shaw et al., 2015). No academic literature exists on the construct of rejection sensitivity dysphoria (RSD), despite this being commonly referenced in grey literature online (Dodson, 2018; Rivera, 2018). Research into RSD would be a valuable undertaking, helping to improve understanding of ADHD and develop more targeted psychosocial interventions for its emotional idiosyncrasies. Powerful emotions could however, be channelled to beneficial purposes – some participants using empathy as a strength to help others whilst working in supportive roles. Individuals also used other strengths as resources; creativity, strategic thinking, passion and drive - reflecting previous research into ADHD and creativity (White & Shah, 2011). When interested in a task, participants described being able to sustain attention and hyperfocus. There is a dearth of research into hyperfocus in ADHD and it is recommended that further studies are undertaken in this interesting area. This was also a recommendation put forth by Ozel-Kizil et al. (2016) who provided one of the few academic studies available on this phenomenon to date. Such abilities and 'superpowers' facilitated an improvement in self-esteem and self-concept for many, demonstrating the beneficial effects of socially reconstructing ADHD as a positive difference (Mather, 2012). It

is, however, important to recognise that research examining positive aspects to ADHD does so in a critical manner, to avoid minimising the serious whole life impact of the condition. Equally, limitations exist when adhering to a deficit-based formulation of ADHD, as this does not encourage individuals to identify and nurture their abilities (Hua et al., 2014).

The second theme “The rollercoaster of diagnosis”, captured the turbulent highs and lows of the diagnostic process. Diagnosis was noted as an important turning point in one’s life – a time of realisation and relief with a marked improvement to self-esteem as participants came to make sense of their lives and past struggles (Hansson Halleröd et al., 2015). Self-perception changed as participants realised their problems were not due to any personal flaw or defect, reflecting previous research (Young et al., 2008). Unfortunately, service provision was often reported as inconsistent or inadequate – reflecting findings of the only previous qualitative study into service for adult ADHD in the UK in the past decade (Matheson et al., 2013). Due to barriers to accessing services, nearly a quarter of participants opted to use private healthcare. Those without financial means were left on waiting lists from 3 months to over 2 years. This disparity needs to be addressed as a matter of urgency. Inadequate service provision has significant consequences; the most serious of which is suicide (Balazs & Keresztesy, 2017). Several participants in this study reported suicidal ideation or attempting to take their own lives. This is a grave concern and attention should be given to developing research in this area, with the objective of informing and improving policy and practice.

Benefits to ADHD medication were frequently identified, but participants were realistic about the extent to which medication could remedy all aspects of ADHD. Research into adult experiences of medication for ADHD is limited, but these findings reflect previous studies involving children and adolescents (Avisar & Lavie-Ajayi, 2014; Singh et al., 2010). Adverse side effects of medication also resulted in some participants discontinuing use and subsequently being discharged from services. Greater emphasis needs to be placed on regular medication reviews and developing non-pharmacological support. It is unrealistic to expect patients to wait 6 months for a medication review when side effects are unpleasant. It should be understood also, that some patients are able to obtain symptomatic relief by taking medication on an ‘as needed’ basis. Finding the correct medication and dosage for each patient often takes time; discharging patients from services further contributes to the significant issues that people endure when living with untreated ADHD. Additionally, many participants did not have access to non-pharmacological treatments despite having unmet psychosocial needs that could be supported in this way; again, supporting the findings of Matheson et al. (2013). Non-pharmacological treatments also need to be tailored to the personal preferences of the individual; some participants reported CBT as beneficial whereas others described it as unhelpful. This contradictory finding should be heeded; highly structured CBT with homework

and exercises may not suit everyone, especially where organisation and memory affect the ability to complete such tasks.

A minority of participants were able to access high-quality, efficient services. This finding may illustrate that improvements have been made in ADHD service provision in the UK, albeit inconsistently. Such quality services should serve as benchmarks for ADHD treatment and valuable lessons can be learnt from them. Minimal waiting times for assessment, regular medication review and a package of care that includes non-pharmacological support should be made available to all adults diagnosed with ADHD. Participants also recommended that practical support should be offered as a means of improving services for adults with ADHD; help with housing, employment, alongside life-coaching and mentoring. Such pragmatic, strength-based approaches have also been noted as beneficial in recent research (Schrevel et al., 2016), as they enable individuals to develop skills and feel positive about themselves.

“Stigma and stereotyping – A need for understanding” was identified as the third theme. Stigma and stereotyping are prevalent around ADHD, but a lack of psychometric tools exist to research this issue (Bussing & Mehta, 2013; Fuermeier et al., 2012). Recent studies have proposed that one way of reducing stigma around ADHD is via the dissemination of accurate information (Bussing & Mehta, 2013; Pitts, et al., 2015). Misinformation abounds about ADHD and there is a need for education on the complexities of the condition to be delivered in schools, healthcare, criminal justice, social work and amongst the public (Matheson et al., 2013; Pitts, et al., 2015). This was also a recommendation put forth by every participant. Some doctors considered that patients should present with either addiction issues or behavioural deviancy to meet diagnostic criteria for ADHD. This is a worrying finding from the present study. It is especially crucial that doctors and nurses are educated on the different subtypes and conflicting paradoxes of ADHD to avoid delayed diagnosis and unnecessary suffering. Several participants were refused a diagnosis due to an assessment based on historic school reports. Individuals with ADHD are often able to engage intensely with tasks they enjoy and school reports which do not demonstrate inattention should be interpreted cautiously and not used as standalone diagnostic tools. Worryingly, recent research is still perpetuating the false notion that academic success provides evidence against the presence of ADHD (Lovett & Davis, 2017). This is simply not true; several participants highlighted that they worked twice as hard to get to the same place as their peers. Such persistence has been noted as a factor in academic success for students with ADHD, especially where giftedness is present (Hua et al., 2014). Flexibility in the diagnostic process needs to be achieved, with assessment addressing the many domains of function that ADHD impacts.

In employment also, it is vital that knowledge and understanding of ADHD is improved. Despite previous recommendations calling for workforce changes for adults with ADHD (Adamou et al., 2013), the findings of this study demonstrate that even with advanced skillsets, some participants faced great challenges. Others working in high-profile roles were reluctant to disclose their ADHD to an employer, fearful of stigmatisation. Greater acceptance of adult ADHD in the workplace could lead to adults with ADHD thriving and being able to access support when necessary. In this way, individuals could find stimulating work, utilising the skills of employees to their maximum potential and reducing costs associated with absence and sickness. Such an approach could also improve confidence and combat self-stigma (McKeague et al., 2015). If individuals in positions of leadership and responsibility could be open about their diagnosis of ADHD this would offer a powerful means of addressing stigma and stereotyping; emphasising that a diagnosis of ADHD need not impede success.

The fourth theme of “The ADHD community” explored how identity was strengthened, isolation reduced, and self-esteem improved by connecting with others in ADHD support groups. This reflects previous work into online coaching for ADHD which found that such support offered reassurance, the provision of a safe space to receive help alongside improved self-esteem and quality of life (Sehlin et al. 2018; Wentz et al., 2012). Such groups could be incorporated into a package of care which would be accessible and low cost, offering psychosocial support for the aspects of ADHD that medication cannot address. At present, no research exists on formalised support groups for adult ADHD and this would be a valuable undertaking. It would be important to moderate such groups regularly to uphold the safety of all who contribute and minimise any potential negative effects of interacting online – including increased disinhibition (Suler, 2004) which could be exacerbated by symptoms of impulsivity. As medication often involves the experiencing of unwanted side-effects, it is imperative that non-pharmacological support is further researched and developed in collaboration with those who are experts by lived experience.

## **5. Limitations of the current study**

### *Methodology*

Thematic analysis has been criticised for several reasons, including that it does not have a specific theoretical or epistemological background (Nowell, Norris, White & Moules, 2017). This study chose to adopt a contextualist approach to provide a theoretical framework for the study – acknowledging that although a researcher reports lived experiences of participants, these will be situated in context, with socially constructed meanings attached to ideas of difference, mental health, school, work and interpersonal relationships (Braun & Clarke, 2006; Madill et al., 2000). Another limitation is that only one person coded the interview data;

increasing potential for researcher bias. To counter this limitation, an inductive approach to thematic analysis was used, utilising a data driven approach to develop codes and themes. Future directions could incorporate content analysis alongside thematic analysis in an intramethod approach. Content analysis would improve analytical rigour as it is a methodology which systematically codes interview data using quantitative counts of words and speech patterns (Renz, Carrington & Badger, 2018). By using thematic content analysis, the qualitative study design would become strengthened.

Participants were diagnosed between 2011-2017, a time span of 6 years; services may have already improved since participants were assessed. During this time, diagnostic criteria were also refined as DSM-V was introduced (American Psychiatric Association, 2013); resulting in a 27% increase in diagnoses compared to DSM-IV (Magnin & Maurs, 2017). However, participants described a wide range of diagnostic tools being used during the assessment process, not always DSM-V. Again, this underlines inconsistency in services and in the assessment process itself; an issue emphasised by Ozel-Kizil et al. (2016). Retrospective accounts are also prone to distortion due to the unreliability of memory; it is important to bear this limitation in mind when interviewing participants about events which occurred many years ago.

### *Sampling*

This study recruited participants via online groups for adult ADHD and may have used a biased sample. There may be qualitative differences in responses between phone and written interviews. However, the written interview may have encouraged less extroverted personalities to participate, alongside those who have difficulties communicating via phone. It is also possible that the written interview offered a means to be more open and candid as interpersonal effects were minimised; this has been noted as one of the benefits of the online disinhibition effect (Suler, 2004). Indeed, the written interviews often presented as extremely open and uninhibited, detailing life events that may have been uncomfortable to discuss verbally with a stranger. Further investigation would be recommended in this area, involving feedback from potential participants to make research into ADHD a comfortable and accessible process for all those involved. Individuals also may have been encouraged to participate due to their experiences of poor services; those with positive experiences may not have been as motivated to join the study. People may have been precluded from participation due to symptoms of ADHD such as procrastination, difficulty concentrating and low motivation.

The study used a small sample of 23 participants who were mainly female (n=20) and mostly diagnosed with the inattentive subtype of ADHD. Therefore, it does not represent as diverse a range of experiences that a larger sample might. However, it is often the inattentive

presentation that goes undiagnosed until adulthood, and this could be a recurring limitation of research involving those diagnosed with ADHD in adulthood. This study was UK based and the findings reflect western perspectives on adulthood ADHD. It would be valuable to further investigate cultural differences and attitudes to the condition to identify commonalities and differences in experiences of adults with ADHD worldwide.

## **6. Conclusion**

This study aimed to explore lived experiences of people diagnosed with ADHD in adulthood, with a focus on diagnosis, service provision and self-esteem. The findings of this research recommend that the disparity in service provision is addressed as a matter of urgency. ADHD is a condition that affects many domains of functioning; long waiting times and inaccurate diagnoses having serious consequences for the individual. Without adequate support, some individuals may experience significant, avoidable psychological distress. ADHD is a complex condition, and the dissemination of up to date and accurate information is important not only to dismantle stigmatising stereotypes but also to improve professional practice in education and healthcare.

When the personal strengths of ADHD are harnessed, individuals can become productive and successful. Developing self-esteem for those with ADHD is an area which deserves significant attention as low self-esteem can severely limit the individual and affect psychological wellbeing. Further research should be undertaken on support groups for adults with ADHD. Such groups were reported to be beneficial; reducing isolation, boosting self-esteem and offering an accessible and affordable means of receiving advice and emotional support. It is imperative that services are consistently developed, understanding increased, and stigma reduced; not only to offer high-quality treatment and support to adults currently living with ADHD, but also for those who will become adults of the future.

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## Appendix

### Appendix A: Interview schedule

**Introduction:** Obtain permission to record and revisit consent to participate.

**Orientation:** Thanks for agreeing to take part in this interview. As I mentioned to you before, this is part of a study I am doing as part of my University course. I would like to find out more about what life is like for people who are diagnosed with ADHD as adults. I hope this information can be used to improve services and also understanding of what ADHD in adulthood is like. Everything we talk about will be kept confidential and will be anonymised in the transcription. You may ask me to stop at any time and can withdraw from the interview without having to give any reason. The interview will take between 45 minutes to 1 hour.

Would you like to ask me anything before we start?

#### **Section 1 – Life before diagnosis**

- I was firstly wondering; what life was like for you before diagnosis?
- Relationships with family & managing work and/or education
- How did you feel about yourself during this time? (Self-esteem)
- What was it that made you seek advice?

#### **Section 2 - Diagnosis with ADHD as an adult**

- When were you diagnosed as an adult?
- What was the process of being diagnosed like for you?
- How did you feel about yourself after being diagnosed with ADHD? (Self-esteem)

#### **Section 3 - Treatment and support following diagnosis**

- After being diagnosed, what treatment/s were you offered?
- Can you describe your experiences of these treatments and/or services?
- What were your experiences of taking medication?
- Would other services would you like to see developed for adults with ADHD?

#### **Section 4 – Life after diagnosis**

- What is life like now for you now?
- Relationships with family & managing work and/or education
- How do you feel about yourself now in comparison to before diagnosis? (Self-esteem)
- Could you think of ways in which self-esteem can be improved for those living with ADHD?
- What are some positive things about ADHD?

#### **Section 5 – Online support groups**

- What attracted you to joining an online support group?
- What positive things do you like about these groups? Are there any negative aspects?
- I was wondering if online support groups have an effect on self-esteem?

**Conclusion:** Is there anything else you would like to talk about that you feel is important? Are you still happy for me to use the interview as part of the study?

Thank you for taking time to take part in this project.

#### **Debrief**

## Appendix B: Written interview

### WRITTEN INTERVIEW - ADHD IN ADULTHOOD

I would like to find out more about what life is like for people who are diagnosed with ADHD as adults. I hope your contributions can be used to improve services and understanding of what ADHD in adulthood is like. Everything you write will be kept confidential and will be anonymised.

The more information you can provide about your experiences, the better. Please take as much time as you need to respond fully. All written interviews need to be returned by **4<sup>th</sup> June 2018**. Please return them as an email attachment to [N.Webster4@unimail.derby.ac.uk](mailto:N.Webster4@unimail.derby.ac.uk).

Please enter your 5-character participant ID number in the box below that was created by you on the consent form. It is **last two letters of your surname** combined with the **last 3 digits of your phone**

**number** e.g. ER210

#### **Section 1 – Life before diagnosis**

I was firstly wondering; what life was like for you before diagnosis?

You could talk about relationships with others and what work or education was like.

How did you feel about yourself? What was it that made you seek advice?

#### **Section 2 - Diagnosis with ADHD as an adult**

When were you diagnosed as an adult and what was the process like?

How did you feel about yourself after diagnosis?

Did diagnosis affect your self-esteem in any way?

#### **Section 3 - Treatment and support following diagnosis**

After being diagnosed, what treatments and services were you offered?

Can you describe your experiences of these?

If you used medication, what were your experiences of this?

What other services would you like to see developed for adults with ADHD?

#### **Section 4 – Life after diagnosis**

What is life like now for you now? You could talk about:

- Personal and family relationships,
- Work / benefits system
- Education

How do you feel about yourself now in comparison to before diagnosis?

How can self-esteem can be improved for those living with ADHD?

What are some positive things about ADHD?

#### **Section 5 – Online support groups**

What attracted you to joining an online support group?

What positive things do you like about these groups?

Have you had any negative experiences?

I was wondering if online support groups have an effect on self-esteem?

#### **Conclusion**

Is there anything else you would like to talk about that you feel is important?

Many thanks for your interest in this study and consenting to take part; it is very much appreciated.

Please contact me at [N.Webster4@unimail.derby.ac.uk](mailto:N.Webster4@unimail.derby.ac.uk) if you have any questions or concerns you would like answered.

**Appendix C: Thematic analysis codebook****Phase 2 - Generating initial codes****1. Attitudes towards self**

1.1. Feeling different

1.2. Feeling like a fraud

1.3. Lazy

1.4. Low self-esteem and doubt

1.5. Positive attitudes towards self

1.6. Proud to be ADHD

**2. Diagnosis**

2.1. Difficulties with diagnosis

2.2. Feeling sad or conflicted

2.3. Incorrect diagnoses

2.4. Other people's responses to diagnosis

2.5. Positive experiences

2.6. Realising it could be ADHD

2.7. Relief and revelation

2.8. Waiting for diagnosis

**3. Education and Learning**

3.1. Difficult experiences

3.2. Intelligence

3.3. Positive experiences

**4. Employment**

4.1. Challenging experiences

4.2. Positive experiences

**5. Improving outcomes**

5.1. Considerations for work and school

5.2. Counselling &amp; Life Coaching

5.3. Educating others and reducing stigma

5.4. Focus on strengths and interests

5.5. Improving services and access to treatments

5.6. Prison service

5.7. Support groups

**6. Managing symptoms**

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6.1. Co-morbidities

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6.2. Coping and prioritising

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6.3. Daydreaming and inattention

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6.4. Disorganisation, money and time-keeping

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6.5. Emotional world of ADHD

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6.6. Hormonal issues

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6.7. Impulsivity and thrill seeking

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6.8. Memory

---

6.9. Motivation & procrastination

---

6.10. Restlessness, impatience and drive

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6.11. Sleep and fatigue

---

6.12. Working harder to get to the same place

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## **7. Medication and Treatment**

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7.1. Being realistic about medication

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7.2. Counselling, CBT and coaching

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7.3. Deciding not to medicate

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7.4. Good experiences of services

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7.5. Issues with medication

---

7.6. Medication as beneficial

---

7.7. Poor services

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## **8. Positive aspects of ADHD**

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8.1. Creativity and innovative thinking

---

8.2. Critical of positive reframing

---

8.3. Empathy and perception

---

8.4. Energy, humour and drive

---

8.5. Hyperfocus and interests

---

## **9. Relationships**

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9.1. Authority, society and rules

---

9.2. Difficulties in relationships

---

9.3. Family members with ADHD

---

9.4. Positive relationships

---

9.5. Worrying about what other people think

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## **10. The ADHD community**

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10.1. Group support as positive

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10.2. Helping others with ADHD

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10.3. Imposter experiences

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10.4. Negative experiences

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10.5. Self-help

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10.6. You're not alone

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**11. Understanding of ADHD**

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11.1. ADHD as a condition

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11.2. ADHD as a difference

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11.3. ADHD as a disability

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11.4. ADHD as a mental health issue

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11.5. Stigma and misconceptions

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[11 categories - 69 open codes]

## Phase 3 - Searching for themes

### 1. Education and employment

1.1. Difficult experiences

1.2. Positive experiences

1.3. The masking mediator of intelligence

### 2. Improving outcomes

2.1. Considerations for work and school

2.2. Educating others and reducing stigma

2.3. Focus on strengths and interests

2.4. Improving services and access to treatments

### 3. Life with ADHD

3.1. A whole life impact

3.2. Critical of positive reframing

3.3. Daydreaming, fatigue and sleep

3.4. Emotions and sensitivity

3.5. Positive aspects of ADHD

3.6. Creativity and innovative thinking

3.7. Empathy and perception

3.8. Energy, humour and drive

3.9. Hyperfocus

3.10. Stimulation and impulsivity

3.11. Working harder to get to the same place

### 4. Navigating services and access to treatment

4.1. Good experiences of services

4.2. Medication as beneficial

4.3. Other people's responses to diagnosis

4.4. Realising it could be ADHD

4.5. Struggles with services

4.6. The reality of medication

4.7. The turning point of diagnosis

### 5. Relationships

5.1. Authority, society and rules

5.2. Difficulties in relationships

5.3. Family members with ADHD

5.4. Positive relationships

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**6. Self-esteem**

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6.1. Feeling different

---

6.2. Low self-esteem and doubt

---

**7. The ADHD community**

---

7.1. Challenging experiences

---

7.2. Sharing knowledge - Finding understanding

---

7.3. You're not alone

---

**8. Understanding of ADHD**

---

8.1. Defining ADHD

---

8.2. Stigma and misconceptions

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**[8 themes - 36 subthemes]**

## Phase 4 - Reviewing themes

### 1. A need for understanding

1.1. ADHD in the balance - Symptoms and strength

1.2. But you can't have ADHD - Stereotyping and stigma

1.3. Difference, doubt and self-esteem

1.4. Emotions, empathy and sensitivity

1.5. Hyperfocus, creativity, passion – “The Fire”

### 2. The whole life impact of adult ADHD

2.1. Coping strategies - Working harder just to get by

2.2. I probably would get rid of it

### 3. Diagnosis and treatment - A National Lottery

3.1. An expensive waiting game

3.2. Realities of medication

3.3. The turning point of diagnosis

### 4. Education and employment

4.1. Challenging experiences

4.2. Positive experiences

4.3. The masking mediator of intelligence

### 5. The ADHD Family

5.1. Challenging experiences

5.2. Relatives with ADHD

5.3. You're not alone

[5 themes - 16 subthemes]

## Phase 5 - Defining and naming themes

### 1. A whole life impact

1.1. Daily struggles with symptoms

1.2. Difference, doubt and self-esteem

1.3. Strengths as mediators

1.4. The emotional world of ADHD

### 2. The rollercoaster of diagnosis

2.1. An expensive lottery

2.2. The turning point of diagnosis

2.3. The realities of medication

### 3. Stigma and stereotyping – A need for understanding

### 4. The ADHD community

[4 themes – 7 subthemes]

**Appendix D: Participant information sheet and consent form****Participant Information Sheet**

**1) Study title:** ADHD in adulthood: A qualitative study of lived experiences, self-image, diagnosis and service provision in the UK

**2) Invitation paragraph.**

You are invited to take part in a research study that I am conducting as part of my MSc Psychology final year project at the University of Derby. The study looks at:

- Personal experiences of living with adulthood ADHD including the diagnosis process.
- Experiences of service provision and treatment after diagnosis.
- What is working in service provision and how this can be improved
- ADHD online support groups and communities; positive and negative aspects.
- How adulthood ADHD impacts self-image; does self-image change as a result of diagnosis.

As part of the research, you will be asked to complete an interview which will ask questions based on these areas of interest. You will also be asked if there are any other aspects of living with adulthood ADHD that you think are important for further research and study.

**3) Do I have to take part?**

It is entirely your decision if you would like to take part in this study. Even if you choose to take part, you may later withdraw your participation without giving any reason for up to 14 days after the interview has been recorded. My details are given at the end of this document. Once the study has been written up and handed in for assessment on August 8<sup>th</sup>, 2018, it will be too late to withdraw your data from the project.

**4) What happens to me if I take part?**

An interview will be arranged which will be carried out by myself, Natalie Webster. It will be recorded so that it may be transcribed, and I will ask for your consent for this before we start the interview. The interview will last between 45-60 minutes and will take place over the phone. There will be no face to face meeting. Several questions will be asked that aim to explore the topics listed above. Your own thoughts and experiences about living with adulthood ADHD are also very much invited. If phone conversation is difficult there is the option to participate by completing a written interview via Qualtrics online survey software. You may have up to a month to complete the written interview and it will be automatically saved as you go along.

**5) Will my participation in this study be kept confidential?**

All interview data will be held in complete confidentiality. You will never be referred to by name; neither will any other personally identifiable data be recorded in the transcribed interview. Personal details will be anonymised by using a 5-character code consisting of the last two letters of your surname and the last 3 digits of your phone number. This code will not appear on the consent form. At no time will the recorded transcripts be able to be associated with your individual identity. All data will be stored on a password protected computer in a password protected filing system. The voice recording equipment will also be physically locked in a secure safety box. Recordings will be deleted immediately after assessment has taken place. Only myself and the university assessor will have access to this data.

**6) What will happen to the results of the research study?**

The study is part of a postgraduate MSc Psychology research project. Confidentiality will be ensured at all times. This is of paramount importance and in accordance with the British Psychological Society Code of Ethics and Conduct and those of University of Derby.

**7) Contact for further information**

Further information can be obtained from: **Natalie Webster** – [N.Webster4@unimail.derby.ac.uk](mailto:N.Webster4@unimail.derby.ac.uk)

Supervisor – **Dominic Petronzi** - [D.Petronzi@derby.ac.uk](mailto:D.Petronzi@derby.ac.uk) - 01332 597990

Thank you for taking the time to read this sheet. I hope that you feel able to take part in the study. If you have any further questions about the study, please let me know. If you are happy to take part in the study, please sign the attached consent form.

**Appendix E: Consent form****Consent Form**

**Title of project:** ADHD in adulthood: A qualitative study of lived experiences, self-image, diagnosis and service provision in the UK

- 1) I confirm that I have read and understood the participant information sheet for the above study and have had the opportunity to ask any questions I have.

Please mark box with an **X**

- 2) I confirm that I am over 21 and live in the UK

Please mark box with an **X**

- 3) I have a primary diagnosis of ADHD which was diagnosed during adulthood.

Please mark box with an **X**

- 4) I understand that my participation is voluntary and I am free to withdraw up to two weeks after participating without giving any reason.

Please mark box with an **X**

- 5) I agree to take part in the study.

Please mark box with an **X**

**Name:**

**Date:**

**Signature:**

Recruitment for this study will take place online and consent will be taken via email and Qualtrics software provided by University of Derby. Your participation is much appreciated but if you decide that you would like to withdraw your data from the study, you can do so without giving any reason. This withdrawal can only take place up to 14 days following the interview; after this time, it will be too late. You can withdraw your data by contacting me with a 5-character ID code via email at [N.Webster4@unimail.derby.ac.uk](mailto:N.Webster4@unimail.derby.ac.uk).

Please create a 5-character participation ID code in the space below. Use the last two letters of your **surname** and the last 3 numbers of your phone number e.g **ER210**

**5 character participation ID code:** .....

You are free to contact my supervisor, Dominic Petronzi, with any queries or concerns you may have about this study. He can be contacted by email at [D.Petronzi@derby.ac.uk](mailto:D.Petronzi@derby.ac.uk) and via telephone on 01332 597990

## Appendix F: Debrief sheet

# Debrief Sheet

Thank you very much for taking the time to participate in this study that investigates ADHD in adulthood: A qualitative study of lived experiences, self-image, diagnosis and service provision in the UK. The purpose of this study was to explore:

- Personal experiences of living with adulthood ADHD including the diagnosis process.
- Experiences of service provision and treatment after diagnosis.
- What is working in service provision and how this can be improved
- ADHD online support groups and communities; positive and negative aspects.
- How adulthood ADHD impacts self-image; does self-image change as a result of diagnosis.

All interview data will be held in complete confidentiality. You will never be referred to by name; neither will any other personally identifiable data be recorded in the transcribed interview. At no time will the recorded transcripts be able to be associated with your individual identity. All data will be stored on a password protected computer. Recordings will be deleted immediately after university assessment has taken place. Only myself, my university supervisor and examiners will have access to the anonymised data. Your participation is very much appreciated but if you decide that you would like to withdraw your data from the study, you can do so **without giving any reason**. This withdrawal should ideally place up to **14 days** following the interview but can be requested up until July 31<sup>st</sup>, 2018. After this time, it will be too late.

You can withdraw your data by contacting me with your 5-character participation ID code via email at [N.Webster4@unimail.derby.ac.uk](mailto:N.Webster4@unimail.derby.ac.uk). This ID code was created by you on your consent form and consists of the last two letters of your surname and the last 3 numbers of your phone number e.g **ER210**. You are also free to contact my supervisor, Dominic Petronzi, with any concerns or queries you may have about this study. He can be contacted by email at [D.Petronzi@derby.ac.uk](mailto:D.Petronzi@derby.ac.uk) and via telephone on 01332 597990. If your participation in this study has raised any issues that you would like to discuss further, there are a list of services below that you are encouraged to contact:

**ADHD Action:** <http://adhdaction.org/>

**ADHDWise:** <http://www.adhdwise.uk/>

**UK Adult ADHD Network:** <https://www.ukaan.org/contact-us.htm>

**AADD-UK – the site for and by adults with ADHD:** <https://aadduk.org/faq/>

**A list of specialist services as provided by AADD-UK is available here:**

<https://aadduk.org/help-support/specialists-support-and-coaches/>

Please also contact your GP if you have been made aware of any additional support that you require as a result of your participation in this study.

**Thank you again for your participation in this study; it is very much appreciated.**