Lancaster University Doctoral Programme in Clinical Psychology

Submitted in partial fulfilment of the Lancaster University Doctorate in Clinical Psychology

February 2021

Doctoral Thesis

Neurodevelopmental disorders and the journey to diagnosis: an exploration of adults' experiences

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Word Count

Thesis section	Text	Tables, references and appendices	Total
Abstract	298	-	298
Literature review	7,933	4,407	12,340
Research paper	8,000	6,277	14,277
Critical review	1,605	259	1,864
Ethics section	3,103	2,446	5,549
Totals	**20,939**	**13,389**	**34,328**

Thesis Abstract

This thesis comprises of three sections including a literature review, research paper, and a critical appraisal. Initially, with the aim of exploring adults' experiences of receiving a diagnosis of ADHD in adulthood, including capturing life pre- and-post diagnosis, a meta-synthesis was conducted of seven qualitative papers. In applying a meta-ethnographic approach, three core concepts emerged: 1) Living with the 'unknown' and trying to survive; 2) Receiving a diagnosis of ADHD: a blessing and a curse; and 3) Adjusting to the diagnosis and re-evaluating life. The findings highlight the challenges adults encountered, pre- and post-diagnosis and their responses to this, before moving to a position of self-acceptance.

The research paper focused on exploring adults' prior experiences of living with undiagnosed ASD, including the process of pursuing, receiving, and adjusting to a diagnosis in adulthood. IPA was used to explore adults' lived experiences and identified four superordinate themes: 1) 'Lost in space': Feeling different and like an outsider; 2) The process of pursuing an explanation for the difference; 3) Shock, disappointment, and relief: the emotional responses to receiving a diagnosis; and 4) Adjusting to the diagnosis: rediscovering myself and learning to accept the difference. These findings captured the journey adults embarked on in attempting to make sense of themselves in a 'neurotypical' world, including the barriers they had to overcome in the process.

Both experiences of living without a diagnosis of a neurodevelopmental 'disorder' and receiving one later in life, represented a 'trauma' which stemmed from an awareness of being 'different' and not 'fitting-in' to a 'neurotypical' world. In response to this, adults defaulted to a '*fight or flight*' position, with the ultimate aim of surviving. These findings illustrate the importance of providing support to the 'neurodiverse' community and raising awareness of their unique attributes to alleviate feelings of 'difference'.

Declaration

This thesis records work undertaken for the Doctorate in Clinical Psychology at the Division of Health Research at Lancaster University from the start of the project in October 2015 to the completion of the thesis in February 2021. The work presented in this thesis is my own, except where references are made accordingly. The work has not been submitted for the award of a higher degree elsewhere.

Name: Claire Evans

Date: 26th February 2021

Acknowledgements

Firstly, I would like to thank all of the participants who took part in the research who without them, this thesis would not have been possible - thank you. I would also like to thank my research supervisor, Ian Fletcher, and my field supervisor, Frank Chapman - I am extremely grateful to both of you for your continued support, guidance, and feedback throughout this process.

On a personal note, a heartful thankyou goes to my family, especially my Dad, brother Lee, and husband, Paul – and not forgetting, my dog, Alfie! This would not have been possible without your constant words of encouragement and support, and cuddles from you Alfie when things felt tough. I would also like to say a big thankyou to my special friends, old and new – you all know who you are and how thankful I am to have you in my life.

Finally, this thesis is dedicated to my best friend, who once said “I see good things for you Claire” - this is for you Mum, I love you and miss you.

Contents

Section One: Literature Review

The journey to receiving a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) and adjusting to this in adulthood: a metasynthesis

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Word Count: 7,933

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Abstract

Objective:

Living with undiagnosed ADHD and receiving a diagnosis later in life, presents adults with challenges which impair their daily functioning and adversely affect their overall well-being. The synthesis reviewed the available qualitative research to offer an insight into adults' experiences of the diagnostic journey.

Method: A systematic literature search was conducted over three electronic databases: PsycINFO, CINAHL, and MEDLINE. A meta-ethnography approach based on Noblit and Hare's (1988) seven step process for synthesizing qualitative studies was used.

Results: Seven papers were identified for inclusion in the review. Three core concepts emerged from the synthesis: 1) Living with the 'unknown' and trying to survive, 2) Receiving a diagnosis of ADHD: a blessing and a curse, and 3) Adjusting to the diagnosis and re-evaluating life.

Conclusion: The findings illustrate the importance of providing psychological support to adults who receive a diagnosis of ADHD in adulthood.

Keywords

ADHD, Diagnosis, Adults, Experiences

Attention Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder which is characterised by pervasive and persistent features of inattention, hyperactivity, and impulsivity that adversely affect psychological, social, and educational or occupational functioning (NICE guidance, 2019; Matte et al., 2015). The term ADHD was formally introduced in the revised version of the Diagnostic and Statistical Manual of Mental Disorders, Third Edition (DSM-III-R) in 1987 and the publication of the DSM-IV in 1994 saw the introduction of three subtypes of ADHD, namely Inattentive, Hyperactive-Impulsive, and Combined (American Psychiatric Association, 1987, 1994). The most recent changes in the DSM-V are suggested to reflect the increased knowledge regarding the clinical nature and structure of ADHD (American Psychiatric Association, 2013; Epstein & Loren, 2013; Posner & Polanczyk, 2020) and include revisions in the terminology used to describe symptomology and subtypes of ADHD. Alongside this, there was a reduction in the number of symptoms required to reach a diagnosis of ADHD (from six to five) for older adolescents and adults, and an increase in the age of onset of symptoms from before 7 years of age to by 12 years of age (American Psychiatric Association, 2013). These revisions were considered pertinent in highlighting the role of ADHD across the life span, as well as improving the diagnostic process in assessing for ADHD in adulthood (Epstein & Loren, 2013; Hechtman, French, Mongia, & Cherkasova, 2011).

Historically, ADHD was considered to be a disorder of childhood which remitted before or during adolescence, and the prevalence and management of ADHD in adulthood was regarded as ‘poorly understood’ (Craig, 1996; Kieling & Rohde, 2010; Taylor & Keltner, 2002). However, the construct of adult ADHD has received increased attention in the field of research and progressively gained recognition as a valid and clinically relevant entity (Matte, Rohde, & Grevet, 2012). Alongside this, there has been an acknowledgement that symptoms associated with ADHD frequently persist into adulthood and recent research indicates the

possibility of a presentation of ADHD which may have an adult onset (Faraone & Biederman, 2016; Geffen & Forster, 2018; Moffit et al., 2015). In a longitudinal study of 110 boys with a diagnosis of ADHD, Biederman et al. (2010) found that 35% continued to meet the DSM-IV diagnostic criteria for ADHD in adolescence and early adulthood. Similarly, Caye, Sibley, Swanson, and Rohde (2017) summarised that late onset of symptoms associated with ADHD were estimated to occur in 2.5% to 6.3% of cases in birth-cohort studies.

Since ADHD was traditionally conceptualised as a childhood disorder, prevalence rates of adult ADHD are less established and more conservative in their estimates, indicating that ADHD in adulthood is underdiagnosed (Geffen & Forster, 2018). The two most comprehensive assessments of adult ADHD based on DSM-IV diagnostic criterion reported prevalence rates between 2.5% to 2.8% (Simon, Czobor, Balint, Meszaros, & Bitter, 2009; Fayyad et al., 2017). In the first comprehensive evaluation of the DSM-V criteria for ADHD in a large sample of young adults, Matte et al. (2015) identified a prevalence rate of 3.55%, compared to 2.8% for DSM-IV ADHD criteria. This represented a 27% increase in the expected prevalence of adult ADHD when applying the current DSM-V diagnostic criteria. While this might signify a more reliable process for assessing and diagnosing ADHD in adulthood, concerns have also been raised about the potential overdiagnosis and overtreatment of the disorder, as well as inflated prevalence rates (Regier et al., 2013). This is of particular importance when considering the most appropriate treatment pathway for individuals who might experience difficulties associated with ADHD.

There is a plethora of research which illustrates the overlap between ADHD symptoms and several other related disorders and as such, care and consideration are advised in the process of differential diagnosis (NICE guidance, 2019; Post & Kurlansik, 2012). Hechtman et al. (2011) suggest that difficulty sustaining concentration is a key characteristic

associated with ADHD, anxiety, and depression and advises clarifying that attention difficulties are present, exclusive of the mood and/or anxiety disorder, for a diagnosis of ADHD to be considered. Alongside this, it is recognised that these disorders frequently co-exist and issues relating to co-morbidity may present as an additional barrier in the process of diagnosing ADHD in adulthood. In a study comprising 367 adults with a diagnosis of ADHD, Piñeiro-Dieguez et al. (2014) found that 66.2% had a co-occurring condition and the most common co-morbidities included substance use disorders (39.2%), anxiety disorders (23%), and mood disorders (18.1%). The elevated rates of co-morbidities in adults with ADHD not only leads to poorer outcomes and greater levels of impairment, but also, may mask the main symptoms of ADHD (Kooij et al., 2012; Sobanski, 2006). Therefore, contributing to a delayed diagnosis, increasing the likelihood of experiencing co-morbid conditions, and adversely affecting quality of life (NICE guidance, 2019).

The process of assessing and diagnosing ADHD in adulthood may be further complicated by the presentation of symptoms, which have been observed to change with age. More specifically, inattention has been demonstrated to become more prominent in adulthood, than symptoms of hyperactivity and/or impulsivity, and been identified as the greatest predictor of impairment in adults (Hechtman et al., 2011; Matte et al., 2015). Difficulties associated with inattention include problems with engaging in tasks that require sustained focus, patterns of inconsistency in performance over time, and underachievement. These difficulties, alongside the other symptoms associated with ADHD, result in impaired functioning in psychological, social, and educational or occupational aspects of life (Holthe & Langvik, 2017; Gillig, Gentile, & Atig, 2004).

Research which has explored the impact of a delayed diagnosis of ADHD indicates that adults encounter an array of adversities which can affect all aspects of their functioning (Okie, 2006; Rucklidge & Kaplan, 1997). More specifically, in a study exploring functional

and psychosocial impairment in adults with undiagnosed ADHD, Able, Johnston, Alder, and Swindle (2007) found significantly higher rates of depression, substance use disorders, lower educational attainment, and increased emotional and interpersonal difficulties amongst 752 undiagnosed ADHD adults who participated in the study. Additionally, living with undiagnosed ADHD has been associated with lower levels of self-esteem as adults attempt to make sense of their difficulties without access to appropriate support. Therefore, resulting in experiences of failure and feelings of inadequacy which increase the risk of encountering co-morbid conditions (Holthe & Langvik, 2017; Quinn, 2005).

These difficulties have been observed to extend beyond receiving a diagnosis of ADHD in adulthood, with significantly reduced reports of quality of life found in adults with newly diagnosed ADHD and those who have received a diagnosis of ADHD in late adulthood (Ahnermark et al., 2018; Lensing, Zeiner, Sandvik, & Opjordsmoen, 2015). The burden of living with ADHD and its impact on quality of life has also been evidenced in older adults (Brod, Schmitt, Goodwin, Hodgkins, & Nieber, 2012), and found to affect adults lives similarly across different countries (Brod, Pohlman, Lasser, & Hodgkins, 2012). In a study exploring the problems and needs of adults with ADHD, Schrevel, Dedding, van Aken, and Broerse (2016) reported that in addition to being affected by the core symptoms of ADHD, adults experienced more difficulties as a result of the social consequences which arose from living with ADHD. There is a growing body of literature which illustrates the intense social stigma associated with ADHD and the consequences of this for individuals who receive a diagnosis of ADHD. These include reduced quality of life, lowered self-esteem, increased social isolation, reluctance towards pursuing an assessment of ADHD, avoidance of disclosing a diagnosis of ADHD, and disengagement with treatment interventions (Heflinger & Hinshaw, 2010; Holthe & Langvik, 2017; Mueller, Fuermaier, Koerts, & Tucha, 2012).

In account of the wealth of literature and attention the construct of ADHD has received from both a clinical and psychiatric perspective, there have been an increasing number of literature reviews conducted in the field of adult research. Noticeably, these have predominantly focused on the diagnosis and treatment of ADHD in adulthood, including factors which might influence this process (Asherson et al., 2012; Culpepper & Mattingly, 2010; Rösler, Casas, Konofal, & Buitelaar, 2010). These reviews have highlighted the substantial impact ADHD can have on adults' lives and how the process of diagnosis in adulthood can be complicated by co-morbid conditions and compensatory strategies which adults have developed to manage the symptoms associated with ADHD. In a later review, Cook, Knight, Hume, and Qureshi (2014) documented the association between ADHD and low self-esteem in adulthood and recommended the provision of psychotherapeutic work in reducing these difficulties.

While there has been extensive interest in the recognition and remediation of ADHD, the experiences of adults living with symptoms associated with ADHD remain largely unexplored in the literature base (Schrevel et al., 2016). Consequently, the number of qualitative literature reviews which have been conducted synthesising these findings are extremely limited. Of particular relevance to the present review, Bjerrum, Pederson, and Larsen (2017) undertook a systematic review of qualitative evidence focusing on how adults experience living with ADHD. In doing this, they synthesised the results of 10 qualitative studies and presented four key findings which included 'adults are aware of being different from others and strive to be integrated, accepted part of the community', 'adults with ADHD are creative and inventive', 'adults with ADHD develop coping strategies in striving for a healthy balance in life', and 'for adults with ADHD, accomplishing and organising tasks in everyday life is a challenge but it can also be rewarding'.

Although this review provided a valuable insight into the lived experiences of adults with ADHD, it did not capture the diagnostic journey which adults encountered, from living with undiagnosed ADHD to receiving a diagnosis in later in life. This seems of particular importance considering the extensive literature which highlights the numerous challenges adults experience before receiving a diagnosis of ADHD, and the subsequent impact these have on their overall well-being and quality of life. Alongside this, adults encounter a prolonged and arduous journey to diagnosis which can be complicated by differential diagnosis and co-morbid conditions, thus further exacerbating their difficulties. Research also indicates that these difficulties extend beyond the point of diagnosis, as adults adjust to receiving a diagnosis of ADHD and process the longer-term implications associated with this. Therefore, the aim of the present review is to provide further insights into adults' experiences of the entire diagnostic journey, capturing life pre- and post-diagnosis, to help inform diagnostic pathways and guide treatment interventions for adults with ADHD.

Method

The Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) guidelines were used as a framework when documenting the process of completing the metasynthesis (Tong, Flemming, McInnes, Oliver, & Craig, 2012).

Selection Criteria

The aim of the present review was to explore adults' experiences of receiving a diagnosis of ADHD in adulthood, taking into consideration life pre- and post-diagnosis and any challenges they encountered throughout the diagnostic process. Accordingly, studies were selected and included in the review if they met the following inclusion criteria:

(i) the research aim(s) or a proportion of the findings focused on exploring adults' experiences of receiving a diagnosis of ADHD (or ADD) in adulthood

(ii) employed qualitative methods of data collection and analysis

(iii) were published in a peer reviewed journal

(iv) were written and published in the English language.

Studies were excluded if they focused exclusively on adults' experiences of living with ADHD, including the impact or burden of this on their lives and their associated support needs. Studies were also excluded if they included adults' who had received a diagnosis of ADHD in childhood. These factors were not considered relevant or consistent with the main aim(s) of the review.

There were no specific parameters applied regarding adults' diagnoses of ADHD, namely the diagnostic criteria and/or manual(s) which had been employed. The rationale for this decision centred around the lack of clarity which remains around the understanding of ADHD in adulthood and the changes in the diagnostic criteria presented in the DSM-V (American Psychiatric Association, 2013) which do not appear to be fully embedded in the literature base. More generally, there is a recognition that ADHD represents an ever-evolving construct which continues to receive increased attention regarding its characteristics and composition (Posner & Polanczyk, 2020).

Search Strategy

A systematic literature search was conducted over three electronic databases, from December 2020 to January 2021, to identify peer reviewed papers considered relevant to the aim(s) of the present review: PsycINFO, CINAHL, and MEDLINE. No specific publication date limits were applied when searching for articles in order to maximise the number of papers retrieved. Free text terms were used alongside conducting subject mapped searches in the Thesaurus function within each electronic database. A faculty librarian was also consulted in reviewing the search terms and completing search strategy testing to increase the

sensitivity of the literature search. The full text search terms used in each of the three databases are detailed in Table 1.

Insert Table 1 here

The search generated a total of 914 papers (PsycINFO = 445, CINAHL = 267, and MEDLINE = 202). The titles and abstracts of these papers were reviewed to determine their relevance to the present review and duplicates were excluded accordingly. The full texts of 14 papers were obtained and reviewed, and this resulted in the identification of five papers. The reference lists of each of these papers were hand searched and an additional two papers were identified after reviewing the full texts, resulting in a total of seven papers for inclusion in the synthesis (Figure 1). The details of the seven papers included in the present review are presented in Table 2.

Insert Figure 1 here

Insert Table 2 here

Of the seven papers included in the review, two originated from the same study, however, two methods of analysis were used (Fleischmann & Fleischmann, 2012; Fleischmann & Miller, 2013). More specifically, the paper by Fleischmann and Fleischmann (2012) presents the findings from employing Grounded Theory on all of the 71 biographical narratives they sourced. The researchers then reviewed 40 of the biographical narratives and applied an additional method of analysis; Labov's method of Narrative Analysis and

summarised the findings in a separate paper (Fleishmann & Miller, 2013). Fleischmann and Fleischmann (2012) explain that two methods of qualitative analysis were employed with the aim of strengthening the validity of their findings. Research also provides support to combining qualitative methods of analysis based on the premise that researchers demonstrate sufficient knowledge of the different approaches used and provide a clear rationale for combining methods (Lal, Suto, & Ungar, 2012). After reviewing the two papers it was considered that both of these aspects were reflected in the write-up of the study. Additionally, the researchers acknowledged that while there were overarching similarities drawn from using the data set, the distinct emphases of the two methods of analysis extracted different findings (Fleischmann & Fleischmann, 2012).

Furthermore, it is of worth to note that the aforementioned study analysed biographical narratives derived from internet sources therefore, raising concerns about the validity of the findings presented. Santos and LeBaron (2006) recommend using online transcripts as a triangulated data source in validating the interpretations drawn from these. In accordance with this, Fleischmann and Fleischmann (2012) detailed how they shared the online biographical narratives with three adults who had received a diagnosis of ADHD in adulthood to verify the authenticity of the accounts. Therefore, based on the researchers attempts to increase the credibility of their findings and the level of transparency presented in documenting these processes, the decision was made to include both of the papers in the present review.

Quality Appraisal

The Critical Appraisal Skills Programme (CASP) checklist (Public Health Resource Unit, 2018) was used to assess the quality of the papers identified for inclusion in the synthesis (Table 3). This is considered to be the most commonly used tool for conducting quality appraisal in qualitative syntheses and has received endorsement from the Cochrane

Qualitative and Implementation Methods Group (Long, French, & Brooks, 2020). The CASP consists of ten questions designed to assist in evaluating the quality of qualitative research. The usefulness of quality appraisal checklists has received considerable attention in the literature base and witnessed much debate therefore, it was decided that no papers would be excluded on the outcome of the quality appraisal as asserted by Sandelowski, Docherty, and Emden (1997).

Insert Table 3 here

Analysis

A meta-ethnography approach was utilised in analysing and synthesising the studies included in the present review. Meta-ethnography was originally developed by Noblit and Hare (1988) as one of the first methods for synthesising qualitative research and has been described as the most well-established and influential models in the field (Britten et al., 2002; Tong et al., 2012). Noblit and Hare (1988) provide a seven-step process for conducting a meta-ethnography which includes i) getting started, ii) deciding what is relevant to the initial interest, iii) reading the studies, iv) determining how the studies are related, v) translating the studies into one another, vi) synthesizing translations, and vii) expressing the synthesis (Britten et al., 2002).

In conducting the meta-ethnography and starting the process of synthesising the studies, the papers were repeatedly read to enable the identification of key themes which were re-occurring across the studies and relevant to the aim(s) of the present review. The connections between these key themes were considered and the process of translating the studies into one another began, from which core concepts emerged (Appendix 1-A). These core concepts were then reviewed in relation to the original interpretations and explanations

in the studies to ensure that there was "preservation of meaning" (Britten et al., 2002, p. 210). The outcome of the synthesis was then expressed as detailed in the next section.

Results

The seven papers included in the present review originated from six studies which captured an international perspective of adults' experiences of receiving a diagnosis of ADHD in adulthood. Five of the seven papers incorporated both male and female experiences of receiving a diagnosis of ADHD in adulthood, while one paper focused solely on male perspectives, and another explored the experiences of older females who had received a diagnosis of ADHD after the age of 60. In five of the seven papers, there was a total of 60 participants, comprising of 30 males and 30 females, aged between 20 and 91 years old. The two remaining papers, which originated from the same study, used biographical narratives self-published on the internet by adults with ADHD (or ADD) as their data source. Therefore, no demographic information, with the exception of the gender of the participants, was made available to the researchers of the study.

Three core concepts emerged from the process of analysing and synthesising the selected studies, these included, 1) living with the 'unknown' and trying to survive, 2) receiving a diagnosis of ADHD: a blessing and a curse, and 3) adjusting to the diagnosis and re-evaluating life. The findings represented the journey adults embarked on from living with undiagnosed ADHD to receiving a diagnosis in adulthood, including their emotional responses to this and how they adjusted to life post-diagnosis. Each concept will now be expressed alongside key quotations to illustrate the authenticity of the findings.

1) Living with the 'unknown' and trying to survive

The initial concept captured adults' experiences of living with undiagnosed ADHD (aka the 'unknown'), including some of the challenges this presented and how they responded to these in their attempts to find 'their way in the world' (Fleischmann & Miller, 2013).

Adults initially described a life characterised by 'chaos' and 'disorder' (Toner, O'Donoghue, & Houghton, 2006), which was evident throughout their childhood and adolescence, particularly in relationships with others and disrupted all aspects of daily functioning. Many adults reported having frequently changed schools, jobs, friendships, and relationships and primarily attributed this to elevating feelings of boredom, as well as reflecting a consequence of living with undiagnosed ADHD: "in the last 12 years since finishing college I've probably had 15 different jobs. Fired from some, left others before I was fired" (Fleischmann & Miller, 2013, p. 54). This pattern of repeated transitions also represented adults desire to find some sense of stability and order amongst the 'chaos'. However, due to the difficulties associated with living with the 'unknown', this was not possible to achieve.

Alongside the 'unpredictable nature' (Fleischmann & Fleischmann, 2012) of their lives, adults reported an acute awareness of feeling "different" (Henry & Jones, 2011, p. 253) from others but not knowing why: "as a kid [child] I always knew there was something wrong about me. I could never figure it out" (Fleischmann & Fleischmann, 2012, p. 1489). This led to some adults expressing feelings of confusion and/or frustration as they were unable to make sense of the 'difference' and the difficulties which it presented. This feeling of being 'different' also impacted on adults' sense of belonging to their families: "I didn't fit in the family. It was almost like when somebody – when a child gets swapped at birth" (Young, Bramham, Gray, & Rose, 2008, p. 495). Many adults further recalled how these 'differences' were highlighted and/or emphasised by those around them as they were

'compared unfavourably' (Young et al., 2008) to their same age peers and perceived as being "always the odd one out" (Toner et al., 2006, p. 252).

In the absence of being able to understand or explain the origin of the 'difference', including the difficulties which accompanied it, this became conceptualised as reflecting personal flaws or failings on the part of the individual: "I was told more or less daily, that it was just naughtiness, being disruptive purely out of seeking attention…" (Young et al., 2008, p. 495). These persistent negative messages, which adults were exposed to from different mediums throughout their lives, subsequently became internalised: "they called me a liar, a lazy bum, a procrastinator, a crybaby. The saddest thing was that I believed them so firmly…" (Fleischmann & Fleischmann, 2012, p. 1489). Consequently, this had a detrimental impact on adults' self-esteem and feelings of self-worth, including their expectations of what they could achieve in life: "my confidence was so completely shattered. I hadn't been successful in anything" (Fleischmann & Miller, 2013, p. 54). Furthermore, as an additional consequence of feeling 'different' and repeatedly being informed that there was 'something wrong with them' (Young et al., 2008), many adults expressed feeling socially isolated and experienced associated mental health difficulties, namely anxiety and/or depression (Fleischmann & Miller, 2013; Toner et al., 2006).

In response to this, and the overwhelming feelings of failure and internalised shame which had featured throughout their lives, many adults reflected on their coping strategies and appeared to become caught in a vicious cycle which resembled a '*fight or flight*' response. More specifically, adults either took on ('*fight*') additional tasks to gain a sense of purpose and reduce associated feelings of inadequacy or avoided ('*flight*') confronting demands as a result of feeling overwhelmed and lacking confidence in one's ability. These conflicting responses seemed to represent adults united attempt at surviving living with undiagnosed ADHD. Both, however, were too difficult to sustain and subsequently led to

adults experiencing further mental health difficulties and increased the burden of living with the 'unknown': "I had gotten used to feeling tired before I even got out of bed, of dreading the new day and its various obligations, I was exhausted, struggling at work and at home with my kids" (Fleischmann & Fleischmann, 2012, p. 1490).

Subsequent to this, in their attempts to navigate life and make sense of the 'unknown', many adults reported having gained clarity about the nature of their difficulties after observing similarities in their children, or the children of close friends, all of whom had received a diagnosis of ADHD (Fleischmann & Fleischmann, 2012; Toner et al., 2006; Young et al., 2008). Some adults were encouraged to seek a formal assessment of ADHD by close family and/or friends, while others pursued a diagnosis after conducting research about the nature of their difficulties (Fleischmann & Miller, 2013; Toner et al., 2006). For all adults, these experiences marked the start of their journey to receiving a diagnosis of ADHD in adulthood.

2) Receiving a diagnosis of ADHD: a blessing and a curse

The second concept reflected adults' experiences of becoming aware of the 'unknown' and receiving a diagnosis of ADHD in adulthood, focusing on the emotional and behavioural responses to this.

The process of diagnosis was initially accompanied with an overwhelming sense of relief for all adults as they finally had an explanation for the difficulties they had encountered throughout their lives: "oh, there's an actual reason why I acted like that" (Young et al., 2008, p. 496). Alongside this, many adults gained clarity regarding the origin of their difficulties and reported reduced feelings of confusion, which had originally arisen in the absence of having an explanation: "something unknown and unidentified, which I have had for a long time, has been cleared up. I feel so much better knowing about ADHD" (Aoki, Tsuboi, Furuno, Watanabe, & Kayama, 2020, p. 4). The diagnosis also represented a form of closure

after years of feeling 'different' and wondering why: "…the puzzle piece that made the most sense in my life, was my diagnosis of ADHD" (Fleischmann & Miller, 2013, p. 55).

From this, adults were then able to reconceptualise the nature of their difficulties and locate them in an external source (i.e., a diagnosis), as opposed to believing that they reflected aspects of them as originally thought (Young et al., 2008). With this, came an increased understanding and acceptance of self (Halleröd, Anckarsäter, Råstam, & Scherman, 2015; Henry & Jones, 2011), with adults beginning to view themselves more positively and expressing more hope for the future (Fleischmann & Fleischmann, 2012; Toner et al., 2006). This also helped to reduce associated feelings of guilt, blame, and shame (Fleischmann & Miller, 2013) for the various challenges adults had encountered throughout their lives: "all my negative behaviours and nasty personality traits finally made sense to me…I intend to forgive myself for the past and hope to make the most of my 'new' future. Now that I know what 'my problem' is" (Fleischmann & Fleischmann, 2012, p. 1491).

Although the diagnosis of ADHD was evidently experienced as a 'blessing' for many adults, the descriptions used to reflect their newfound knowledge were noticeably laden with negative connotations which seemed to still position the difficulties within them: "I was relieved to find out what was wrong with me" (Fleischmann & Miller, 2013, p. 54). This led to some adults distancing themselves from the diagnosis and/or acquiring further information about ADHD and the different treatment options available (Aoki et al., 2020). With this increased knowledge, came a realisation of the long-term implications of being diagnosed with ADHD: "I knew there was no way to get better, there are no tricks to become healthy…so it's a handicap…I have to live with it" (Halleröd et al., 2015, p. 6).

Adults subsequently expressed concerns that they would be perceived as 'less' of a person (Halleröd et al., 2015) and become defined by the diagnosis: "I don't want them to judge me any different, I want them to know me just for me without a label" (Young et al.,

2008, p. 498). These concerns stemmed from an awareness of the stigma attached to ADHD (Aoki et al., 2020; Halleröd et al., 2015; Toner et al., 2006; Young et al., 2008) and potentially accounted for the description's adults used to define their difficulties. The diagnosis also represented confirmation that there was something (neurodevelopmentally) 'different' about them (Toner et al., 2006) and the original pre-conceptualisations of their difficulties were reignited: "…you do things wrong, everyone who criticised you, suddenly it feels like they were right" (Halleröd et al., 2015, p. 6). Consequently, ADHD was now perceived as a 'curse' and the initial feelings of relief were accompanied with anxiety as adults continued to adjust to the diagnosis.

3) Adjusting to the diagnosis and re-evaluating life

The third and final concept summarised adults' experiences of adjusting to receiving a diagnosis of ADHD, from disguising their difficulties to 'gaining control' of their lives (Toner et al., 2006).

Upon becoming aware of the long-term nature of their difficulties, including the stigma surrounding ADHD, some adults expressed increasing concerns that they would be perceived differently and excluded by others in account of the diagnosis, and it would be viewed as an 'excuse' as opposed to an explanation for the 'difference' (Halleröd et al., 2015; Young et al., 2008). In response to this, adults appeared to revert back to their pre-diagnosis coping styles which resembled a '*fight or flight*' response. That is, many adults avoided (*flight*) disclosing their diagnosis with others and carried on as 'normal' (*fight*), in the fear that they would be negatively judged and further ostracised: "…that's the main trick, being able to present an exterior, because otherwise what you end up showing is something pitiful. So you don't" (Toner et al., 2006, p. 258). However, again, this became too difficult to maintain and resulted in adults experiencing increased anxiety.

As they continued to adjust to the diagnosis of ADHD, adults expressed feelings of anger and sadness at not being diagnosed sooner (Halleröd et al., 2015; Young et al., 2008) as they started to grieve "the lost years" (Toner et al., 2006, p. 256). During this, adults wondered what their lives would have been like if they had received a diagnosis of ADHD earlier and a theme of injustice emerged. This centred around the persistent challenge's adults had unfairly encountered throughout their lives, and a view that these would have been prevented or avoided with a diagnosis and access to appropriate treatment: "imagine if someone had figured out ten years ago that I had ADHD, then I'd have been spared all of this…wouldn't have had to live with the life I've lived" (Halleröd et al., 2015, p. 10).

In response to feelings of injustice and unfairness, many adults sought comfort by surrounding themselves with people who had shared lived experience, through participation in support groups, both virtually and face-to-face (Fleischmann & Fleischmann, 2012; Fleischmann & Miller, 2013; Henry & Jones, 2011; Toner et al., 2006). This allowed adults to gain a sense of connectedness with others who they could identify with, reducing feelings of isolation which had arisen from living with the 'unknown' (and which continued to present a threat as adults adjusted to the diagnosis): "…for the first time in my life I felt like I'd found people who understood me" (Fleischmann & Miller, 2013, p. 54). Adults also reflected on the importance of sharing their own knowledge and experience (Henry & Jones, 2011), with the primary aim of preventing others from enduring the same 'ordeal' (Fleischmann & Fleischmann, 2012) and 'suffering' (Halleröd et al., 2015) which they had experienced prior to receiving a diagnosis of ADHD.

From this, many adults described having discovered a new purpose in their lives, which contributed to increased feelings of self-worth and empowered adults to take control, particularly in developing their own coping strategies (Aoki et al., 2020; Fleischmann & Fleischmann, 2012; Toner et al., 2006). Some adults also identified pharmacological

interventions, namely medication as being a helpful 'tool' (Aoki et al., 2020) in managing the difficulties associated with ADHD. This, alongside support groups and coping strategies allowed adults to move from a position of *being* the 'difference' to *making* the 'difference':

> So why am I making my life story available to millions of people via the WWW? I dunno. I guess it's because I hope it might make a difference for someone who felt as I did before I found out about ADD. You're not alone! (Fleischmann & Fleischmann, 2012, p. 1493).

Discussion

The purpose of the present review was to explore adults' experiences of the diagnostic journey, from living with undiagnosed ADHD to receiving a diagnosis in adulthood, including the different challenges this presented and how they responded to these as they adjusted to life post-diagnosis. In applying a meta-ethnographic approach to the synthesis, three core concepts were identified which captured adults' experiences of the entire diagnostic process. The findings from the review have similarities with some of the key themes which have been detailed in the existing literature base, while also offering insights into how adults experience being diagnosed with ADHD in adulthood. In reviewing the findings presented, it is important to reiterate that two of the papers used in the present review originated from the same study, which used biographical narratives obtained from the internet as their data source (Fleischmann & Fleischmann, 2012; Fleischmann & Miller, 2013). Therefore, it is recognised that these offer a unique perspective in comparison to the other papers used and will feature more heavily, contributing to a possible skew in the findings and reducing generalisability. Nonetheless, core concepts did emerge from the synthesis of the seven papers used in the present review.

Initially, adults' lives were characterised by 'chaos' (Toner et al., 2006) which impacted on all areas of their daily functioning and appeared to be consistent with the core

features of ADHD, namely inattention, hyperactivity, and impulsivity (NICE guidance, 2019). This finding supports previous research which highlights the adverse experiences adults encounter when living with undiagnosed ADHD (Okie, 2006; Rucklidge & Kaplan, 1997). Alongside this, adults described feeling 'different' to others and detailed the detrimental impact this had on their overall well-being, reducing feelings of self-worth as the 'difference' became conceptualised and internalised as reflecting individual failings as a person. Both Quinn (2005) and Holthe and Langvik (2017) document the lower levels of self-esteem which are reported among adults living without a diagnosis of ADHD, particularly females. These researchers also highlight the subsequent risk of experiencing co-morbid conditions, including anxiety and mood disorders; a finding which was reflected in the present review.

The awareness of feeling 'different' and subsequently social isolated from others was also evidenced in the recent systematic literature review conducted by Bjerrum et al. (2017). In their findings, Bjerrum et al. (2017) suggested that in response to feeling 'different' and lacking a sense of belonging, adults strive to be accepted by others with the aim of fitting in. This is a similar response conveyed by the adults represented in the present review. More specifically, adults reported taking on additional tasks and carrying on as 'normal' as a way of reducing feelings of inadequacy and preventing further ridicule and rejection, both pre- and post-diagnosis. Conversely, the current synthesis also captured those adults who avoided demands due to feeling consumed by feelings of failure. Further to this, many adults opted not to disclose their diagnosis of ADHD with others after acquiring further information about the long-term implications of the condition, expressing concerns that they would be further ostracised by others as a result. This decision was confounded by an increased awareness of the stigma surrounding ADHD and is consistent with previous research which identifies

"avoidance of diagnosis disclosure" and "social isolation" as some of the consequences of the stigma associated with living with ADHD (Holthe & Langvik, 2017, p. 3).

An additional similarity observed between the current synthesis and recent review completed by Bjerrum et al. (2017) is the emotional journey adults encountered as they adjusted to receiving a diagnosis of ADHD in adulthood. Relief was identified as adult's initial response to the diagnosis as it provided an explanation for the difficulties they experienced and enabled them to reconceptualise the nature of these, externalising them to the diagnosis itself. Feelings of anger or frustration at not being diagnosed earlier and an improved self-acceptance as adults adjusted to the diagnosis of ADHD, were additional emotional responses which featured in both reviews.

The present review extends beyond this and adds to the current literature base by highlighting what the diagnosis represented for adults. That is, it reignited the original conceptualisations of their difficulties and reinforced the underlying feeling of being (neurodevelopmentally) 'different'. In response to this and the emotional experiences associated with receiving and adjusting to a diagnosis of ADHD, adults recovered by seeking support and helping others. This enabled adults to take a more active role in managing the difficulties associated with ADHD and medication was identified as playing a part in supporting this process; a finding which was observed when adults were 'striving for a healthy balance in life', as detailed in the review conducted by Bjerrum et al. (2017). The combination of receiving and providing support to others, alongside the use of medication were significant factors in strengthening adults' self-worth and allowed them to reconceptualise themselves as *making* a 'difference' (as opposed to *being* the 'difference').

Limitations

While the present review offers an insight into adults' experiences of the diagnostic process, from life pre-diagnosis to receiving and adjusting to a diagnosis of ADHD in

adulthood, it is acknowledged that the search strategy used to identify papers for inclusion in the review may present as a possible limitation. Although advice and guidance were sought from a faculty librarian during this process, the omission of additional electronic databases such as, Web of Science, PubMed, and EMBASE in the search for literature will have reduced the number of papers generated for the present review. Therefore, inadvertently excluding any studies which may have been deemed appropriate for inclusion and offered further insights into adults' experiences of the diagnostic process, strengthening the accuracy of the findings presented. However, it is recognised that the reduced number of papers available for inclusion in the review may also reflect the lack of qualitative research conducted in the area therefore, highlighting the need for further recognition and understanding of ADHD in adulthood (Ahnermark et al., 2018; Schrevel et al., 2016).

Nonetheless, the relatively low number of studies included in the synthesis is identified as a potential limitation in reducing the applicability of the findings. The issue of 'self-selection' bias will have also been inadvertently introduced by adults opting to participate in the respective studies therefore, choosing to share their experiences of receiving a diagnosis of ADHD later in life. These 'self-selected' samples will not have been representative of the experiences of adults who chose not to participate thus, further reducing the generalisability of the findings presented. However, core concepts did emerge across the studies therefore, highlighting the value of the current synthesis.

Although, the papers identified for inclusion in the review reflect an international perspective of adults' experiences of receiving a diagnosis of ADHD, the studies were predominantly conducted in developed countries with established socio-economic statuses and healthcare provisions. Therefore, these factors are likely to have influenced the process of receiving and adjusting to a diagnosis of ADHD in adulthood, including access to relevant support services. The synthesised findings from these studies are also not representative of

adults' experiences in lower socio-economic countries with disparate healthcare services. Furthermore, the present review will not account for the diverse cultural narratives which exist amongst the studies and influence adults' experiences of receiving and adjusting to a diagnosis of ADHD in adulthood. However, similarities were observed across the studies therefore, highlighting the value of drawing on different perspectives to offer an insight into adults' experiences.

Moreover, the role of age and gender are likely to have influenced adults' individual experiences, from living with undiagnosed ADHD to receiving and adjusting to a diagnosis later in life. Research indicates that ADHD is predominantly associated with males and diagnosed at a ratio of 3:1 in comparison to females in childhood (Biederman et al., 1999). This potential under-representation of females with ADHD has been evidenced to decline with age (Biederman et al., 1994; Kessler et al., 2006) and understood in relation to how ADHD is expressed in males and females (Skogli, Teicher, Anderson, Hovik, & Øie, 2013). The issue of societal norms and gender role expectations are also recognised as potentially influencing the differential diagnosis rates and ultimately, adults' experiences of receiving a diagnosis of ADHD in adulthood.

A further limitation of the present review could be understood in relation to the decision to not apply specific selection criteria regarding adults' diagnoses of ADHD and what diagnostic manual(s) had been implemented in reaching these decisions. While there was a clear rationale for this decision in light of the lack of understanding of ADHD in adulthood, the review cannot account for the validity of all the diagnoses in the studies. However, taking into consideration the limited qualitative research which exists in the field and the outcome of the quality appraisal which indicated that the studies were valuable to the current literature base, it was deemed appropriate to proceed with the synthesis and offer an insight into what has been a largely neglected issue.

Lastly, while the quality appraisal indicated that most of the papers identified for inclusion in the synthesis met the criteria outlined in the CASP checklist, the researchers in only two of the seven papers adequately considered their relationship with the participants and the possible implications of this for their recruitment strategy. Although this presented an ambiguous issue for the two papers which used biographical narratives sourced from the Internet, it raised some concerns about the level of reflexivity demonstrated by the researchers in the remaining studies. Therefore, this had implications when assessing the reliability of the papers and the integrity of the findings which are incorporated in the synthesis.

Implications and recommendations

The present review initially highlights the multitude of challenges adults encounter as they navigate life without a diagnosis of ADHD, including the impact this has on their social, emotional, psychological, and educational or occupational functioning. Consequently, it is imperative that this is taken into consideration when adults reach the point of assessment and used to identify the most appropriate treatment pathway. Specifically, the risk of experiencing co-morbid conditions is well documented in the literature base (Pineiro-Dieguez et al., 2014) and was evidenced in the present review. Therefore, in accordance with the National Institute for Health and Care Excellence (NICE, 2019) guidance regarding the diagnosis and management of ADHD, clinicians are advised to liaise with relevant healthcare colleagues during the process of assessment and diagnosis to inform the development of the treatment plan, ensuring they obtain consent and actively involve adults in this process.

Alongside this, it is recommended that clinicians adopt a curious position in assisting adults to make sense of the nature of their difficulties. This may involve practitioners who are responsible for assessing children for symptoms associated with ADHD to consider the presence of similar difficulties in their parents (Ginsberg, Quintero, Anand, Casillas, &

Upadhyaya, 2014). This represented the point at which many adults in the present review gained clarity regarding the nature of their own difficulties and research indicates that parents of children with a diagnosis of ADHD are four times more likely to meet the diagnostic criteria for ADHD themselves (Faraone & Doyle, 2000). It is expected that this will help to mitigate the factors identified as complicating the diagnostic process, such as misdiagnosis and differential diagnosis and provide further clarity to individuals who have been living with undiagnosed ADHD. Further research exploring the reasons why individuals seek a diagnosis of ADHD in adulthood will also help to improve diagnostic pathways and inform the interventions offered to adults with ADHD.

The emotional journey which adults embark upon after receiving a diagnosis of ADHD illustrates the importance of providing psychoeducation and post-diagnostic support. These interventions should initially focus on educating adults about ADHD, with the aim of normalising their experiences and reducing associated stigma. Adults should also be informed about additional forums where they can seek further advice and guidance, such as self-help websites and voluntary organisations (NICE guidance, 2019). Furthermore, the provision of longer-term support should be considered as adults continue to adjust to the diagnosis, including the challenges which may accompany this as evidenced in the present review. This is currently recommended as a minimum intervention in the NICE guidance (2019), particularly for adults where non-pharmacological treatments are indicated. It is advised that adults with ADHD are offered a structured psychological intervention and regular follow-up appointments, either remotely or face-to-face. Longitudinal research exploring how adults experience adjusting to receiving a diagnosis of ADHD over an extended period of time, with and without pharmacological treatments may indicate that this is a provision which all adults would benefit from receiving post-diagnosis. Existing research also advocates the involvement of significant others in post-diagnostic interventions to

promote the collaborative management of ADHD and alleviate burden, thus improving quality of life (Dixon et al., 2001; Hirvikoski et al., 2017).

Alongside this, services should consider the implementation of group-based interventions, including individual post-diagnostic support where indicated. This would enable adults to share their lived experiences and seek social support; something which may have been confounded by the impact of stigma. The benefits associated with engagement in groups were evidenced in the present review and have received increased recognition in the literature base, offered as an adjunct or alternative to pharmacological-based treatment (Fullen, Jones, Emerson, & Adamou, 2020). While there are positive outcomes associated with participation in group interventions, it is recognised that these reflect the experiences of adults who are willing and able to seek support in these types of forums. Therefore, it is the responsibility of clinicians who are involved in supporting adults with ADHD to work creatively in engaging those individuals who will continue to 'suffer in silence'; community outreach work may be one possible solution.

More generally, it is acknowledged that while the construct of ADHD has received extensive attention, the understanding regarding its presentation in adulthood and the perspectives of adults with ADHD are in their infancy. In addition, societal knowledge of ADHD is considered poor (Hirvikoski et al., 2017), despite it representing one of the most prevalent neurodevelopmental conditions worldwide (Fullen, et al., 2020). While these disparities exist they are likely to continue to present barriers in the process of pursing, receiving, and adjusting to a diagnosis of ADHD in adulthood. Therefore, these should be considered as representing opportunities in clinical practice, specifically in terms of providing teaching and training, as well as indicating avenues for future research.

Conclusion

This synthesis adopted a meta-ethnographic approach to uncover the experiences of adults who had received a diagnosis of ADHD in adulthood. Three core concepts captured the journey adults endured as they transitioned from living with undiagnosed ADHD to receiving a diagnosis and adjusting to this in adulthood. This process presented adults with numerous challenges which adversely affected their daily functioning and emotional and psychological well-being. In response to this, adults initially appeared to default to a survival mode of coping before gradually gaining a sense of control over their lives and the ADHD. The findings illustrate the importance of the provision of psychological support to individuals diagnosed with ADHD in adulthood and highlight the need for further qualitative research in the area.

References

*Indicates papers included in the synthesis

Able, S. L., Johnston, J.A., Alder, L.A., & Swindle, R.W. (2007). Functional and psychosocial impairment in adults with undiagnosed ADHD. *Psychological Medicine*, *37*, 97-107. doi:10.1017/S0033291706008713

Ahnermark, E., Schiena, M, Di., Fredman, A.C., Medin. E., Söderling, J.K., & Ginsberg, Y. (2018). Health-related quality of life and burden of illness in adults with newly diagnosed attention-deficit/hyperactivity disorder in Sweden. *BMC Psychiatry*, *18*(223), 1-11. doi: 10.1186/s12888-018-1803-y

American Psychiatric Association. (1968). *Diagnostic and Statistical Manual for Mental Disorders*. 4. Washington, DC: American Psychiatric Press.

American Psychiatric Association. (1994). *Diagnostic and Statistical Manual for Mental Disorders*. 4. Washington, DC: American Psychiatric Press.

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual for Mental Disorders*. 5. Washington, DC: American Psychiatric Press.

*Aoki, Y., Tsuboi, T., Furuno, T., Watanabe, K., & Kayama, M. (2020). The experiences of receiving a diagnosis of attention deficit hyperactivity disorder during adulthood in Japan: a qualitative study. *BMC Psychiatry*, *20*(373), 1-8. doi: 10.1186/s12888-020-02774-y

Asherson, P., Akehurst, R., Kooji, S., Huss, M., Beusterien, K., Sasane, R…Hodgkins, P. (2012). Under Diagnosis of Adult ADHD: Cultural Influences and Societal Burden. *Journal of Attention Disorders*, *16*(5), 205-385. doi: 10.1177/1087054711435360

Biederman, J., Faraone, S.V., Mick, E., Williamson, S., Wilen, T.E., Spencer, T.J….Zallen, B. (1999). Clinical correlates of ADHD in females: findings from a large group of girls ascertained from pediatric and psychiatric referral sources. *Journal of the American Academy of Child and Adolescent Psychiatry*, *38*(8), 966-975. doi:10.1097/00004583-199908000-00012

Biederman, J., Petty, C.R., Evans, M., Small, J., & Faraone, S.V. (2010). How persistent is ADHD? A controlled 10-year follow-up study of boys with ADHD. *Psychiatry Research*, *177*, 299-304. doi: 10.1016/j.psychres.2009.12.010

Bjerrum, M., B., Pederson, P.U., & Larsen, P. (2017). Living with symptoms of attention deficit hyperactivity disorder in adulthood: a systematic review of qualitative evidence. *JBI Database of Systematic Reviews and Implementation Reports*, *15*(4), 1080-1153. doi: 10.11124/JBISRIR-2017-003357

Britten, N., Campbell, R., Pope, C., Donovan, J., & Morgan, M. (2002). Using metaethnography to synthesise qualitative research: a worked example. *Journal of Health Services Research and Policy*, *7*(4), 209-215. doi: 10.1258/135581902320432732

Brod, M., Pohlman, B., Lasser, R., & Hodgkins, P. (2012). Comparison of the burden of illness for adults with ADHD across seven countries: a qualitative study. *Health and Quality of Life Outcomes*, *10*(1), 47. doi: 10.1186/1477-7525-10-47

Brod, M., Schmitt, E., Goodwin, M., Hodgkins, P., & Nieber, G. (2012). ADHD burden of illness in older adults: a life course perspective. *Quality of Life Research*, *21*, 795-799. doi: 10.1007/s11136-011-9981-9

Caye, A., Sibley, M.H., Swanson, J.M., & Rohde, L.A. (2017). Late-Onset ADHD: Understanding the Evidence and Building Theoretical Frameworks. *Current Psychiatry Reports*, *19*(12). doi: 10.1007/s11920-017-0858-7

Cook, J., Knight, E., Hume, I., & Qureshi, A. (2014). The self-esteem of adults diagnosed with attention-deficit/hyperactivity disorder (ADHD): a systematic review of the literature. *Attention Deficit and Hyperactivity Disorders*, *6*, 249-268. doi: 10.1007/s12402-014-0133-2

Craig, C. (1996). Clinical recognition and management of adult attention deficit hyperactivity disorder. *Nurse Practitioner*, *21*(11), 101-106. Retrieved from: https://pubmed.ncbi.nlm.nih.gov/8933539/

Culpepper, L., & Mattingly, G. (2010). Challenges in identifying and managing attention-deficit/hyperactivity disorder in adults in the primary care setting: a review of the literature. *Primary care companion to the Journal of clinical psychiatry*, *12*(6). doi:10.4088/PCC.10r00951pur

Dixon, L., McFarlane, W.R., Lefley, H., Lucksted, A., Cohen, M., Falloon, I.…Sondheimer, D. (2001). Evidence-based practices for services to families of people with psychiatric disabilities. *Psychiatric Services*, *52*(7), 903-910. doi: 10.1176/appi.ps.52.7.903

Epstein, J.N., & Loren, R.E.A. (2013). Changes in the Definition of ADHD in DSM-5: Subtle but Important. *Neuropsychiatry (London)*, *3*(5), 455-458. doi: 10.2217/npy.13.59

Faraone, S.V., & Biederman, J. (2016). Can Attention-Defict/Hyperactivity Disorder Onset Occur in Adulthood? *JAMA Psychiatry*, *73*(7), 655-656. doi:10.1001/jamapsychiatry.2016.0400

Faraone, S.V., & Doyle, A.E. (2000). Genetic influences on attention deficit hyperactivity disorder. *Current Psychiatry Reports, 2*, 143-146. doi: 10.1007/s11920-000-0059-6

Fayyad, J., Sampson, N.A., Hwang, I., Adamowski, T., Aguilar-Gaxiola, S., Al-Hamzawi…Kessler, R.C. (2017). The descriptive epidemiology of DSM-V Adult ADHD in the World Health Organization World Mental Health Surveys. *Attention Deficit Hyperactivity Disorders*, *9*(1), 47-65. doi: 10.1007/s12402-016-0208-3

*Fleischmann, A., & Fleischmann, R.H. (2012). Advantages of an ADHD Diagnosis in Adulthood: Evidence From Online Narratives. *Qualitative Health Research*, *22*(11), 1486-1496. doi: 10.1177/1049732312457468

*Fleischmann, A., & Miller, E.C. (2013). Online Narratives by Adults with ADHD Who Were Diagnosed in Adulthood. *Learning Disability Quarterly*, *36*(1), 47-60. doi:10.1177/0731948712461448

Fullen, T., Jones, S.L., Emerson, L.M., & Adamou, M (2020). Psychological Treatments in Adult ADHD: A Systematic Review. *Journal of Psychopathology and Behavioral Assessment*, *42*, 500-518. doi:10.1007/s10862-020-09794-8

Geffen, J., & Forster, K. (2018). Treatment of adult ADHD: a clinical perspective. *Therapeutic Advances in Psychopharmacology*, *8*(1), 25-32. doi: 10.1177/2045125317734977

Gillig, P.M., Gentile, J.P., & Atig, R. (2004). Attention-defict/hyperactivity disorder in adults. *Journal of Clinical Outcomes Management*, *11*(1), 51-60. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2957278/

Ginsberg, Y., Quintero, J., Anand, E., Casillas, M., & Upadhyaya, H.P. (2014). Underdiagnosis of Attention-Deficit/Hyperactivity Disorder in Adult Patients: A Review of the Literature. *Prim Care Companion CNS Disord*, *16*(3). doi: 10.4088/PCC.13r01600

*Halleröd, S.L.H., Anckarsäter, H., Råstam, M., & Scherman, M.H. (2015). Experienced consequences of being diagnosed with ADHD as an adult – a qualitative study. *BMC Psychiatry*, *15*(31). doi: 10.1186/s12888-015-0410-4

Hechtman, L., French, L.R., Mongia, M., & Cherkasova, M.V. (2011). Diagnosing ADHD in adults: limitations to DSM-IV and DSM-V proposals and challenges ahead. Neuropsychiatry, 1(6), 579-590. Retrieved from: https://www.jneuropsychiatry.org/peer-review/diagnosing-adhd-in-adults-limitations-to-dsmiv-and-dsmv-proposals-and-challenges-ahead-neuropsychiatry.pdf

Heflinger, C.A., & Hinshaw, S.P. (2010). Stigma in child and adolescent mental health services research: Understanding professional and institutional stigmatization of youth with mental health problems and their families. *Administration and Policy in Mental Health and Mental Health Services Research*, *37*(1-2), 61-70. doi:10.1007/s10488-010-0294-z

*Henry, E., & Jones, S.H. (2011). Experiences of older adult women diagnosed with attention deficit hyperactivity disorder. *Journal of Women & Aging*, *23*(3), 246-262. doi:10.1080/08952841.2011.589285

Hirvikoski, T., Lindström, T., Carlsson, J., Waaler, E., Jokinen, J., & Bölte, S. (2017). Psychoeducational groups for adults with ADHD and their signficaint others

(PEGASUS): A pragmatic multicenter and randomized controlled trial. *European Psychiatry*, *44*, 141-152. doi: 10.1016/j.eurpsy.2017.04.005

Holthe, M., & Langvik, E. (2017). The Strives, Struggles, and Successes of Women Diagnosed with ADHD as Adults. *SAGE Open*, 1-12. doi: 10.1177/2158244017701799

Kessler, R.C., Alder. L., Barkley, R., Biederman, J., Conners, K.C., Demler, O…Zazlavsky, A.M. (2006). The prevalence and correlates of adult ADHD in the United States: results from the National Comorbidity Survey Replication. *The American Journal of Psychiatry*, *163*(4), 716-723. doi: 10.1176/ajp.2006.163.4.716

Kieling, R., & Rohde, L.A. (2010). ADHD in Children and Adults: Diagnosis and Prognosis. *Current Topics in Behavioral Neurosciences*, *9*, 1-16. doi: 10.1007/7854_2010_115

Kooij, S.J.J., Huss, M., Asherson, P., Akehurst, R., Beusterien, K., French, A…Hodgkins, P. (2012). Distinguishing Comorbidity and Successful Management of Adult ADHD. *Journal of Attention Disorders*, *16*(5), 3-19. doi:10.1177/1087054711435361

Lal, S., Suto, M., & Ungar, M. (2012). Examining the Potential of Combining the Methods of Grounded Theory and Narrative Inquiry: A Comparative Analysis. *The Qualitative Report*, *17*(41), 1-22. Retrieved from: https://core.ac.uk/download/pdf/51087607.pdf

Lensing, M.B., Zeiner, P., Sandvik, L., & Opjordsmoen, S. (2015). Quality of life in adults aged 50+ with ADHD. *Journal of Attention Disorders*, *19*(5), 405-413. doi: 10.1177/1087054713480035

Long, H.A., French, D. P., & Brooks, J.M. (2020). Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence

synthesis. *Research Methods in Medicine & Health Services*, *1*(1), 31-42. doi:10.1177/2632084320947559

Matte, B., Anselmi, L., Salum, G.A., Kieling, C., Gonçalves, H., Menezes, A…Rohde, L.A. (2015). ADHD in DSM-5: a field trail in a large, representative sample of 18- to 19-year-old adults. *Psychological Medicine, 45*, 361-373. doi: 10.1017/S0033291714001470

Matte, B., Rohde, L.A., & Grevet, E.H. (2012). ADHD in adults: a concept in evolution. *Attention Deficit Hyperactivity Disorders, 4*, 53-62. doi: 10.1007/s12402-012-0077-3

Moffit, T.E., Houts, R., Asherson, P., Belsky, D.W., Corcoran, D.L., Hammerie, M…Caspi, A. (2015). Is Adult ADHD a Childhood-Onset Neurodevelopmental Disorder? Evidence From a Four-Decade Longitudinal Cohort Study. *The American Journal of Psychiatry*, *172*(10), 967-977. doi: 10.1176/appi.ajp.2015.14101266

Mueller, A.K., Fuermaier, A.B., Koerts, J., & Tucha, L. (2012). Stigma in attention deficit hyperactivity disorder. *Attention Deficit Hyperactivity Disorders*, *4*(3), 101-114. doi: 10.1007/s12402-012-0085-3

National Institute for Health and Care Excellence. (2019). Attention deficit hyperactivity disorder: diagnosis and management. Retrieved from: https://www.nice.org.uk/guidance/ng87

Noblit, G. W., & Hare, R, D. (1988) *Meta-ethnography: synthesizing qualitative studies*. Newbury Park: Sage.

Okie, S (2006). ADHD in adults. *New England Journal of Medicine*, *354*(25), 2637-2641. doi:10.1056/NEJMp068113

Piñeiro-Dieguez, B., Balanzá-Martínez, V., García-García, P., Soler-López, B., & the CAT Study Group. (2014). Psychiatric Comorbodity at the Time of Diagnosis in Adults with ADHD: The CAT study. *Journal of Attention Disorders*, 1-10. doi:10.1177/1087054713518240

Posner, J., & Polanczyk, G.V. (2020). Attention-deficit hyperactivity disorder. *The Lancet*, *395*(10222), 450-462. doi: 10.1016/S0140-6736(19)33004-1

Post, R.E., & Kurlansik, S.L. (2012). Diagnosis and Management of Attention-Deficit/Hyperactivity Disorder in Adults. *American Academy of Family Physicians*, *85*(9), 890-896. Retrieved from: https://www.aafp.org/afp/2012/0501/p890.html

Public Health Resource Unit. Critical Appraisal Skills Programme (CASP, 2018): Making Sense of evidence. England: Public Health Resource Unit. Retrieved from: https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist-2018.pdf. Accessed 18th December 2020.

Quinn, P. (2005). Treating adolescent girls and women with ADHD: Gender-specific issues. *Journal of Clinical Psychology, 61*, 579-587. doi:10.1002/jclp.20121

Regier, D.A., Narrow, W.E., Clarke, D.E., Kraemer, H.C., Kuramoto, S.J., Kuhl, E.A., & Kupfer, D.J. (2013). DSM-5 field trials in the United States and Canada, Part 11: test-retest reliability of selected categorical diagnoses. *American Journal of Psychiatry*, *170*(1), 59-70. doi: 10.1176/appi.ajp.2012.12070999

Rösler, M., Casas, M., Konofal, E., & Buitelaar, J. (2010). Attention deficit hyperactivity disorder in adults. *The World Journal of Biological Psychiatry*, *11*(5), 684-698. doi: 10.3109/15622975.2010.483249

Rucklidge, J., & Kaplan, B.J. (1997). Psychological functioning of women identified in adulthood with AD/HD. *Journal of Attention Disorders, 2*(3), 167-176. doi:10.1177/108705479700200303

Sandelowski, M., Docherty, S., & Emden, C. (1997). Focus on Qualitative methods. Qualitative Metasynthesis: Issues and Techniques. *Research in Nursing & Health, 20*(4), 365-371. doi:10.1002/(sici)1098-240x(199708)20:4<365::aid-nur9>3.0.co;2-e. PMID: 9256882

Santos, I., & LeBaron, J. (2006). Ethical constraints in the valid interpretation of transcribed communication in online study. *Internet and Higher Education, 9,* 191-199. doi:10.1016/j.iheduc.2006.06.004

Schrevel, S.J., Dedding, C., van Aken, J.A., & Broerse, J.E. (2016). 'Do I need to become someone else? A qualitative exploratory study into the experiences and needs of adults with ADHD. *Health Expectations, 19*(1), 39-48. doi:10.1111/hex.12328

Simon, V., Czobor, P., Bálint, S., Mészáros, A., & Bitter, I (2009). Prevalence and correlates of adult attention-deficit hyperactivity disorder: meta-analysis. *The British Journal of Psychiatry, 194*, 204-211. doi:10.1192/bjp.bp.107.048827

Skogli, E.W., Teicher, M.H., Anderson, P.N., Hovik, K.T., & Øie, M. (2013). ADHD in girls and boys – gender differences in co-existing symptoms and executive function measures. *BMC Psychiatry, 13*(298). doi: 10.1186/1471-244X-13-298

Sobanski, E. (2006). Psychiatric comorbidity in adults with attention-deficit/hyperactivity disorder (ADHD). *European archives of psychiatry and clinical neuroscience, 256*, 26-31. doi: 10.1007/s00406-006-1004-4

Taylor, E.W., & Keltner, N.L. (2002). Messy Purse Girls: Adults Females and ADHD. *Biological Perspectives*, *38*(2), 69-72. doi:10.1111/j.1744-6163.2002.tb00659.x

*Toner, M., O'Donoghue, T., & Houghton, S. (2006). Living in Chaos and Striving for Control: How adults with Attention Deficit Hyperactivity Disorder deal with their disorder. *International Journal of Disability, Development and Education*, 53(2), 247-261. doi: 10.1080/10349120600716190

Tong, A., Flemming, K., McInnes, E., Oliver, S., & Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Medical Research Methodology*, *12*(181), 1-8. doi:10.1186/1471-2288-12-181

*Young, S., Bramham, J., Gray, K., & Rose, E. (2008). The Experiences of Receiving a Diagnosis and Treatment of ADHD in Adulthood: a qualitative study of clinically referred patients using Interpretative Phenomenological Analysis. *Journal of Attention Disorders*, *11*(4), 493-503. doi: 10.1177/1087054707305172

Table 1

Full text terms used in each of three electronic databases

	PsycINFO	**CINAHL**	**MEDLINE**
Subject areas			
ADHD	DE "Attention Deficit Disorder" OR "ADD" OR DE "Attention Deficit Disorder with Hyperactivity" OR "Hyperkinesis" OR DE "Attention Span" OR "Attention Deficit Hyperactivity Disorder" OR "ADHD" OR "Hyperactivity" OR "Inappropriate Attention" OR "Impulsive" OR "Distractibility"	((MH "Attention Deficit Hyperactivity Disorder") OR (MH "Hyperkinesis")) OR TI ("Attention Deficit Disorder" OR "ADD" OR "Attention Deficit Disorder with Hyperactivity" OR "Attention Span" OR "ADHD" OR "Hyperactivity" OR "Inappropriate Attention" OR "Impulsive" OR "Distractibility") OR AB ("Attention Deficit Disorder" OR "ADD" OR "Attention Deficit Disorder with Hyperactivity" OR "Attention Span" OR "ADHD" OR "Hyperactivity" OR "Inappropriate Attention" OR "Impulsive" OR "Distractibility")	((MH "Attention Deficit Disorder with Hyperactivity") OR (MH "Attention Deficit and Disruptive Behavior Disorders") OR (MH "Neurodevelopmental Disorders") OR (MH "Hyperkinesis")) OR TI ("Attention Deficit Disorder" OR "ADD" OR "Attention Deficit Hyperactivity Disorder" OR "Attention Span" OR "ADHD" OR "Hyperactivity" OR "Inappropriate Attention" OR "Impulsive" OR "Distractibility") OR AB ("Attention Deficit Disorder" OR "ADD" OR "Attention Deficit Hyperactivity Disorder" OR "Attention Span" OR "ADHD" OR "Hyperactivity" OR "Inappropriate Attention" OR "Impulsive" OR "Distractibility")
Diagnosis	DE "Diagnosis" OR DE "Computer Assisted Diagnosis" OR DE "Diagnosis Related Groups" OR DE "Differential Diagnosis" OR DE "Dual Diagnosis" OR DE "Educational Diagnosis" OR DE "Galvanic Skin Response" OR DE "Medical Diagnosis" OR DE	((MH "Diagnosis") OR (MH "Clinical Assessment Tools") OR (MH "Diagnosis, Computer Assisted") OR (MH "Diagnosis, Developmental") OR (MH "Diagnosis, Neurologic") OR (MH "Diagnosis, Psychosocial") OR (MH "Early Diagnosis") OR (MH "Health Screening")	((MH "Diagnosis") OR (MH "Early Diagnosis") OR (MH "Diagnosis, Computer-Assisted") OR (MH "Missed Diagnosis") OR (MH "Delayed Diagnosis")) OR TI ("Diagnosis Related Groups" OR "Differential Diagnosis" OR "Dual Diagnosis" OR "Educational

	"Misdiagnosis" OR DE "Neuroimaging" OR DE "Psychodiagnosis"	OR (MH "Patient Assessment") OR (MH "Self Diagnosis")) OR TI ("Diagnosis Related Groups" OR "Differential Diagnosis" OR "Dual Diagnosis" OR "Educational Diagnosis" OR "Galvanic Skin Response" OR "Medical Diagnosis" OR "Misdiagnosis" OR "Neuroimaging" OR "Psychodiagnosis" OR ((medical OR self OR clinical) N5 diagnosis)) OR AB ("Diagnosis Related Groups" OR "Differential Diagnosis" OR "Dual Diagnosis" OR "Educational Diagnosis" OR "Galvanic Skin Response" OR "Medical Diagnosis" OR "Misdiagnosis" OR "Neuroimaging" OR "Psychodiagnosis" OR ((medical OR self OR clinical) N5 diagnosis))	Diagnosis" OR "Galvanic Skin Response" OR "Medical Diagnosis" OR "Misdiagnosis" OR "Neuroimaging" OR "Psychodiagnosis" OR ((medical OR self OR clinical) N5 diagnosis)) OR AB ("Diagnosis Related Groups" OR "Differential Diagnosis" OR "Dual Diagnosis" OR "Educational Diagnosis" OR "Galvanic Skin Response" OR "Medical Diagnosis" OR "Misdiagnosis" OR "Neuroimaging" OR "Psychodiagnosis" OR ((medical OR self OR clinical) N5 diagnosis))
Qualitative	(DE "Qualitative Methods" OR "Qualitative Measures" OR "Qualitative Research" OR DE "Focus Group" OR DE "Grounded Theory" OR DE "Interpretative Phenomenological Analysis" OR DE "Narrative Analysis" OR DE "Semi-Structured Interview" OR DE "Thematic Analysis" or "Qualitative" OR "Lived Experiences" OR "Experiences" OR "Perceptions" OR "Perspectives") OR ((patient* OR stakeholder* OR client* OR "service user*" OR individual* OR adult*) N5 (experience* OR perspective* OR stor* OR narrati* OR view*))	(MH "Qualitative Studies+") OR TI ("Qualitative" OR "Lived Experiences" OR "Experiences" OR "Perceptions" OR "Perspectives") OR ((patient* OR stakeholder* OR client* OR "service user*" OR individual* OR adult*) N5 (experience* OR perspective* OR stor* OR narrati* OR view*)) OR AB ("Qualitative" OR "Lived Experiences" OR "Experiences" OR "Perceptions" OR "Perspectives") OR ((patient* OR stakeholder* OR client* OR "service user*" OR individual* OR adult*) N5 (experience* OR perspective* OR stor* OR narrati* OR view*))	(MH "Qualitative Research+") OR TI ("Qualitative" OR "Lived Experiences" OR "Experiences" OR "Perceptions" OR "Perspectives" OR ((patient* OR stakeholder* OR client* OR "service user*" OR individual* OR adult*) N5 (experience* OR perspective* OR stor* OR narrati* OR view*)) OR AB ("Qualitative" OR "Lived Experiences" OR "Experiences" OR "Perceptions" OR "Perspectives" OR ((patient* OR stakeholder* OR client* OR "service user*" OR individual* OR adult*) N5 (experience* OR perspective* OR stor* OR narrati* OR view*))

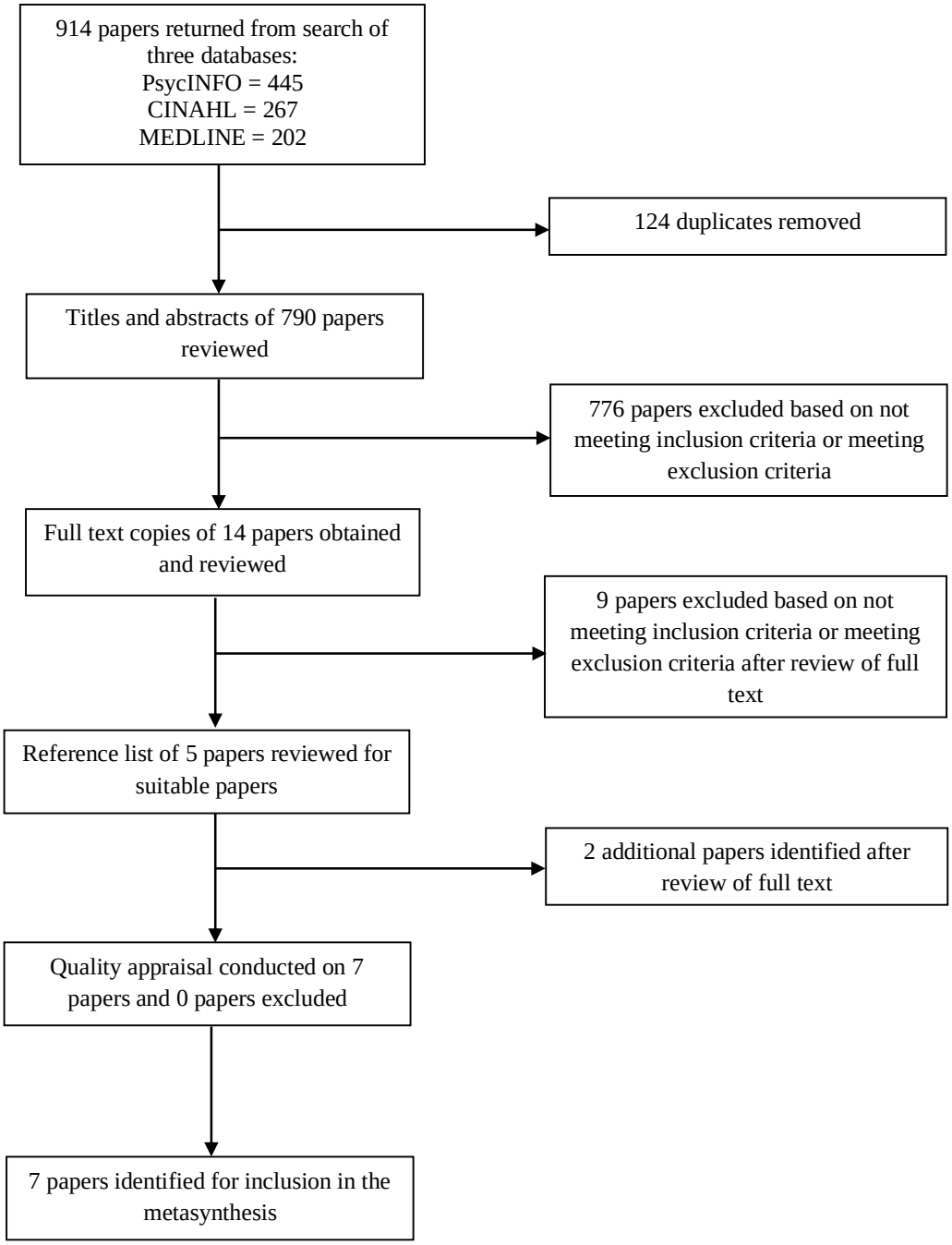

Figure 1. Flowchart illustrating the identification of papers for inclusion in the metasynthesis

Table 2

Summary of each paper selected for inclusion in the present metasynthesis

Author & year	**Title of papers**	**Research aim(s)**	**Participants (Sample)**	**Origin of sample**	**Methodology**
Fleischmann and Fleischmann (2012)	Advantages of an ADHD Diagnosis in Adulthood: Evidence From Online Narrative.	To explore the impact of a diagnosis of adult ADHD on coping among diagnosed adults.	71 biographical narratives/personal life stories, self-published on the Internet by adults with ADHD (or ADD).	Two internet sources: personal websites of individuals with ADHD who posted their biographies and websites dedicated to coping with ADHD.	Grounded Theory
Halleröd, Anckarsäter, Råstam and Scherman (2015)	Experienced consequences of being diagnosed with ADHD as an adult – a qualitative study.	To explore and describe qualitatively different ways in which adults perceive and experience being diagnosed with ADHD.	21 adults (11 women and 10 men), approximately aged between 20 and 57 years old, diagnosed with ADHD.	Sweden.	Qualitative phenomenographical approach/analysis
Fleischmann and Miller (2013)	Online Narratives by Adults With ADHD Who Were Diagnosed in Adulthood.	To examine the self-perceptions of life experiences and the management processes of individuals diagnosed with ADHD.	40 biographical narratives/personal life stories, self-published on the Internet by adults with ADHD (or ADD).	Two internet sources: personal websites of individuals with ADHD who posted their biographies and websites dedicated to coping with ADHD.	Labov's model of Narrative Analysis (& Grounded Theory)
Young, Bramham, Gray and Rose (2008)	The Experiences of Receiving a Diagnosis and Treatment of ADHD in Adulthood: A Qualitative Study of Clinically Referred Patients Using Interpretative	To evaluate the psychological impact of receiving diagnosis of ADHD in adulthood and treatment with medication. To examine how diagnosis and treatment with	8 adults (4 women and 4 men), aged between 21 and 50 years old, diagnosed with ADHD.	United Kingdom.	Interpretative Phenomenological Analysis

	Phenomenological Analysis.	medication changes an individual's self-perception and view of the future.			
Aoki, Tsuboi, Furuno, Watanabe and Kayama (2020)	The experiences of receiving a diagnosis of attention deficit hyperactivity disorder during adulthood in Japan: a qualitative study.	To explore and better understand the diagnosis-related experiences and needs of adults with adult-diagnosed ADHD.	12 adults (6 women and 6 men), aged between 23 and 55 years old, diagnosed with ADHD during adulthood.	Japan.	Thematic Analysis
Toner, O`Donoghue and Houghton (2006)	Living in Chaos and Striving for Control: How adults with Attention Deficit Hyperactivity Disorder deal with their disorder.	How adults with ADHD (who were undiagnosed during childhood) deal with their disorder.	10 adult males, aged between 30 and 57 years old, diagnosed with ADHD.	Australia.	Grounded Theory
Henry and Jones (2011)	Experiences of Older Adult Women Diagnosed with Attention Deficit Hyperactivity Disorder.	To explore the experiences of older adult women diagnosed with ADHD in late adulthood.	9 adult females, aged between 62 and 91 years old, diagnosed with ADHD after the age of 60.	United States of America (USA).	Qualitative research technique guided by the ecological systems model

Table 3

Critical appraisal of each study using the CASP qualitative assessment tool

	Fleischmann and Fleischmann (2012)	Halleröd, Anckarsäter, Råstam and Scherman (2015)	Fleischmann and Miller (2013)	Young, Bramham, Gray and Rose (2008)	Aoki, Tsuboi, Furuno, Watanabe and Kayama (2020)	Toner, O`Donoghue and Houghton (2006)	Henry and Jones (2011)
1. Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2. Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
3. Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
4. Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
5. Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
6. Has the relationship between researcher and participants been adequately considered?	Can’t tell	Yes	Can’t tell	No	Yes	No	No
7. Have ethical issues been taken into consideration?	Yes	Yes	Yes	No	Yes	No	Can’t tell
8. Was the data analysis sufficiently rigorous?	Yes	Yes	Yes	Yes	Yes	No	No
9. Is there a clear statement of findings?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
10. How valuable is the research?	Fairly valuable	Fairly valuable	Fairly valuable	Fairly valuable	Fairly valuable	Fairly valuable	Extremely valuable

Appendix 1-A

Key themes within the core concepts

	Core concepts		
	Living with the 'unknown' and trying to survive	**Receiving a diagnosis of ADHD: a blessing and a curse**	**Adjusting to the diagnosis and re-evaluating life**
Key themes	• Lives are chaotic • Feeling different • Strive for order and control • Overcompensate or avoid • Unable to make sense of difficulties • Others noticing the difference • Blaming themselves • Impact of feeling different	• Recognising difficulties • Relief+++ • Have an explanation • Able to make sense of difficulties • Accepting self • Seeking more information • 'I am different' • Awareness/impact of stigma	• Feeling different (again) • Avoid sharing diagnosis • Grieving for pre-diagnosis life • Connecting with others • Helping others • Gaining control • Acquiring additional coping strategies

Author Guidelines: Journal of Attention Disorders

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Journal of Attention Disorders (*JAD*) focuses on basic and applied science concerning attention and related functions in children, adolescents, and adults. *JAD* publishes articles including, but not limited to, diagnosis, comorbidity, neuropsychological functioning, psychopharmacology, and psychosocial issues. The journal welcomes manuscripts addressing timely, notable topics in practice, policy, and theory, as well as review articles, commentaries, in-depth analyses, empirical research articles, and case presentations or program evaluations that illustrate theoretical issues or new phenomena.

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Style for all submissions must follow that of the *Publication Manual of the American Psychological Association*. Submission to the journal implies that the manuscript has not been published elsewhere and is not in consideration by any other journal. Submission to the Applied Research section should be no more than 30 double-spaced pages, including an abstract of 150 words or less using a sectional guideline (Objective, Method, Results, and Conclusion), a brief biographical statement for each contributing author, endnotes, references, tables, and figures, all on separate pages. Author names and affiliations should appear on a separate cover page and the manuscript should be formatted for anonymous review. Authors are also asked to provide to submit names, academic affiliations, and contact information for six colleagues in the field familiar with the topic of their paper when submitting they're manuscript.

Journal of Attention Disorders only accepts submissions electronically. Electronic submissions should be sent to http://mc.manuscriptcentral.com/jad. Submissions must be in Microsoft Word. Please ensure that tables are editable files in Word or Excel, not images. Artwork should have a resolution of 300 dpi or higher. Images are best submitted separately from the text document. Please do not embed images into your file, as embedding raster image files (photographs) in Word or similar programs automatically reduces the resolution below what is needed for quality print publication.

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and agree not to publish a more comprehensive version of the article in another source. Finally, the journal is interested in publishing literature reviews. These reviews should be no more than 50 double-spaced pages. Authors considering writing a literature review should consider contacting the editor before submission. JAD will also publish relevant letters describing interesting cases of developments in the field relative to clinical practice.

The journal also welcomes Letters to the Editor of no more than 300 words. Letters will be published at the editor's discretion. Opinion essays on relevant topics in ADHD are published by invitation only.

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Section Two: Research Paper

Autistic adults' experiences of life pre-diagnosis, their journey to diagnosis, and adjusting to life post-diagnosis

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Word Count: 8,000

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Prepared for: Autism

Abstract

It is common practice for autistic people to be misdiagnosed or go undiagnosed until adulthood due to a multitude of factors complicating the diagnostic process. This study aimed to extend the existing literature by exploring autistic adults' experiences of the diagnostic process, including what led them to pursue a diagnosis of ASD and how they adjusted to this. A total of nine autistic adults, five males and four females, aged between 23 and 47 years old participated in the study and engaged with semi-structured interviews. Interpretative Phenomenological Analysis was used to analyse adults accounts and identified four superordinate themes: 'Lost in space': Feeling different and like an outsider; The process of pursuing an explanation for the difference; Shock, disappointment, and relief: the emotional responses to receiving a diagnosis; and Adjusting to the diagnosis: rediscovering myself and learning to accept the difference. The findings illustrated the journey autistic adults experienced from living with undiagnosed ASD to receiving a diagnosis later in life, including how they adjusted to this. Autistic adults expressed 'shock', 'disappointment', and 'relief' in response to the diagnosis and this was underpinned by a sense of feeling 'different' from others. As adults adjusted to the diagnosis, they reported an increased sense of self and reflected on the challenges which lay ahead, illustrating the importance of post-diagnostic support.

Keywords

Autism, ASD, Diagnosis, Adults, Experiences

The term ‘autism’ was introduced in the literature base in 1943 by psychiatrist, Leo Kanner. The concept ‘infantile autism’ was used to describe a cohort of children who had impaired social interaction, restricted and repetitive interests, a desire for sameness, and were resistant to change. Concurrently, during the Second World War, paediatrician Dr Hans Asperger wrote an article detailing a group of children he observed in his clinic who shared similar features and referred to this as ‘autistic psychopathology’. This work was later developed in 1981 by English psychiatrist, Dr Lorna Wing to define a subgroup of children based on Asperger’s description. The term ‘Asperger syndrome’ was coined to refer to children who had good cognitive skills, were verbally fluent, and demonstrated typical development in the early years of life (Barahona-Corrêa & Filipe, 2016; Baron-Cohen, 2015; Glazzard & Overall, 2012; Klin, 2003).

Kanner’s description of ‘autism’ appeared in the Diagnostic and Statistical Manual of Mental Disorders, Third Edition (DSM-III) in 1980, followed by Asperger’s Disorder which was introduced as a separate diagnostic term in the fourth edition of the DSM (American Psychiatric Association, 1980, 1994). Due to difficulties in the application of the diagnostic criteria and distinguishing Asperger’s Disorder from autism, the concepts were merged and replaced with the umbrella term, Autism Spectrum Disorder (ASD) in the DSM-V (American Psychiatric Association, 2013; Barahona-Corrêa & Filipe, 2016). Additionally, in light of evidence supporting a dyadic conceptualisation of symptomology, the traditional triad of impairment in autism was reduced to a combination of impaired social communication and restricted, repetitive patterns of behaviour (Loomes, Hull, & Mandy, 2017; Skuse, Mandy, & Tang, 2020). It has been suggested that the changes in the DSM-V criteria improve both diagnostic sensitivity and specificity however, there remains ongoing debate surrounding this (Maenner et al., 2014; Tsai, 2015; Wiggins et al., 2019).

There is also variability in the terms used to describe autism and a survey exploring the perspectives of the autism community in the United Kingdom (UK), indicated that there is "no universally accepted way to describe autism" (Kenny et al., 2016, p. 453). However, there is a recognition of the negative connotations associated with the term 'disorder' and the potential this has to pathologize autistic people[1]. Therefore, there is a call for the term to be replaced with 'condition' (Baron-Cohen, 2000). This will be used herein, with the exception of when referring to the recognised diagnostic terminology for autism.

The modifications to the definition of Autism Spectrum Condition (ASC) and the diagnostic criteria have had implications for prevalence rates, which have increased as the construct of autism has evolved and received more attention. It is estimated that 1 in 160 children have been identified as having autism, which represents an exponential increase compared to earlier prevalence rates of 4 to 5 children per 10,000 (Fombonne, 2020; World Health Organisation, 2019). The rise in the occurrence of ASC has been attributed to the changes in diagnostic criteria and an increased understanding of the diversity of the condition (Skuse, 2020). However, there is limited evidence regarding estimates of ASC in adulthood (Howlin & Moss, 2012). In an epidemiological study of autism in adults in England, Brugha et al. (2016) reported a prevalence of 1.1%. This has been suggested to increase to between 2.4% and 9.9% for adults residing in inpatient psychiatric settings (Tromans, Chester, Kiani, Alexander, & Brugha, 2018).

Literature demonstrates the disproportionate risk of autistic individuals experiencing co-occurring mental health difficulties, namely anxiety and depression (Hollocks, Lerh, Magiati, Meiser-Stedman, & Brugha, 2019). It is suggested that approximately 70% of autistic people will experience at least one mental health condition, with the risk of co-morbidity increasing with age. The presence of a co-occurring condition(s) has been

[1] The use of 'identity-first' language is preferred by autistic adults and will be used herein (Kenny et al., 2016).

associated with poorer long-term outcomes, impaired functioning, and reduced quality of life (Gillberg, Helles, Billstedt, & Gillberg, 2016; Joshi et al., 2013; Lai, Lombardo, & Baron-Cohen, 2013). Additionally, the occurrence of co-morbidities has implications for differential diagnoses and can contribute to a late diagnosis due to an overlap in symptoms (Lai et al., 2019; Lai & Baron-Cohen, 2015; Lehnhardt et al., 2013). There is a recent recognition that some individuals, particularly females develop coping strategies aimed at 'masking' or 'camouflaging' the difficulties associated with ASC therefore, delaying the diagnostic process (Hull et al., 2017; Skuse, 2020).

Autistic people encounter difficulties in all aspects of their daily functioning and are considered to be socially, economically, and educationally or occupationally disadvantaged (Howlin & Magiati, 2017). Consequently, there is an emphasis on early identification and intervention to mitigate the challenges ASC can present (Lai et al., 2013; Wiggins et al., 2019). Despite this, it is common practice for individuals to be diagnosed with ASD in adulthood, as a result of misdiagnosis or no diagnosis in childhood (Geurts & Jansen, 2011; Pellicano et al., 2020). Glazzard and Overall (2012) indicate that many autistic children were misdiagnosed as having an 'intellectual disability' which resulted in them being segregated from their peers, excluded from classrooms, and in some cases, institutionalised. The absence of a diagnosis for autistic adults is recognised as exacerbating their experience of co-occurring difficulties, having a detrimental effect on quality of life (Lewis, 2016a).

The pathway to diagnosis will have been further confounded by the lack of adult diagnostic services which existed across England in 2009 (National Autistic Society, 2018). In response to this, and concerns regarding the poorer outcomes for inadequately supported autistic adults, the Autism Act (2009) and Autism Strategy (2010, 2014) were introduced. These documents were supported by the introduction of a statutory guidance, published by the Government (Department of Health, 2015). This placed a legal responsibility on National

Health Service (NHS) organisations and Local Authorities (LAs) to improve support to autistic adults, ensuring that diagnostic services were available and accessible.

There was also a recommendation that each locality should have a specialist, multi-agency team which is responsible for developing, implementing, and reviewing the delivery of services for autistic adults, including providing support to other professionals. These were referred to as Specialist Autism Teams (SATs) in the National Institute for Health and Care Excellence (NICE, 2012) guidance regarding the diagnosis and management of ASD in adults. In the first study evaluating the provision of SATs across England, Beresford et al. (2020) reported positive outcomes for this model of care, particularly for adults who received extended post-diagnostic support. However, relatively few SATs were found to exist suggesting that autistic adults will continue to encounter difficulties in navigating the diagnostic process.

Research exploring experiences of the diagnostic process has focused on parents, siblings, and health care professionals' perspectives however, there is a recognition of the importance of obtaining first-hand accounts from the individuals involved (DePape & Lindsay, 2016). This is of significance for autistic adults whose diagnostic journey has been found to be complicated and arduous, with an average delay of five years from the point of first recognising they might be autistic to being diagnosed (Crane et al., 2018). In a survey of 128 autistic adults in the UK, Jones, Goddard, Hill, Henry, and Crane (2014) found that while 47% of adults reported feeling 'very' or 'quite' satisfied with the diagnostic process, 40% of adults were 'very' or 'quite' dissatisfied and described feeling misunderstood and dismissed by health care professionals. The challenges the diagnostic process presents suggests that further research is required to capture individuals' perspectives, with the aim of improving the identification of ASC and informing diagnostic practices (Pellicano et al., 2020).

The experience of receiving a diagnosis is well-documented as being a complex and unique phenomenon which presents an emotional turmoil (Gallagher, Arber, Chaplin, & Quirk, 2010; Lewis, 2016b; Powell & Acker, 2016). There has been an increased interest in exploring autistic adults' accounts of receiving a diagnosis, including their experiences of adjusting to this (Leedham, Thompson, Smith, & Freeth, 2019; Hickey, Crabtree, & Stott, 2018). Research indicates that there is a myriad of emotions associated with the diagnostic process, with autistic adults initially reflecting on the positive aspects of receiving a diagnosis (Calzada, Pistrang, & Mandy, 2012; Punshon, Skirrow, & Murphy, 2009). In a study exploring the experience of an Asperger Syndrome diagnosis in adulthood, Powell and Acker (2016) described how adults expressed 'relief' in response to being diagnosed, which they attributed to developing an increased understanding of themselves. However, relief was replaced or combined with sadness and anger as adults reflected on past experiences and wondered what life would have been like if they had been diagnosed sooner. It is during this process of '*biographical disruption'* (Bury, 1982) that autistic adults are at an increased risk of experiencing co-occurring mental health difficulties, including anxiety, depression, and suicidal ideation (Cassidy et al., 2014; Lewis, 2016b). Therefore, receiving a diagnosis of ASD is considered to represent a milestone and life-changing experience (Crane et al., 2018; Woodbury-Smith, Robinson, Wheelwright, & Baron-Cohen, 2005).

In response to the growing literature capturing the views of autistic individuals, DePape and Lindsay (2016) conducted a systematic literature review in which they synthesised 33 qualitative studies exploring the lived experiences of autistic children, adolescents, and adults. In their findings, DePape and Lindsay (2016) identified that individuals reported changes in their perceptions of self and expressed relief at receiving a diagnosis as it provided answers to their questions. Some individuals reported feeling different from others and experienced helplessness, as they focused on the long-term

implications associated with ASC. Changes were also observed in interactions with others and some individuals sought comfort from family and friends about their diagnosis, while others reflected on the impact it had on their relationships. Finally, living with ASC had implications for education and occupation, specifically in terms of the challenges they encountered and what support they required.

These synthesised findings were echoed in a qualitative study conducted by Stagg and Belcher (2019) who explored adults experiences of receiving a diagnosis of autism in middle and over middle age. They identified five superordinate themes including 'early signs of ASC', 'awareness of being different', 'receiving a diagnosis', 'the usefulness of a diagnosis', and 'support and coping'. This study, alongside the systematic literature review, offer valuable insights into the lived experiences of autistic adults, including the process of receiving a diagnosis in adulthood and the effect this has an individual's life. However, in account of the sustained challenges autistic adults encounter before embarking on the diagnostic journey, including the factors which complicate this process and the detrimental impact this has, the present study aims to offer insights into adults' prior experiences of living with undiagnosed ASD. Alongside this, the study will build upon the existing literature base by exploring adults' experiences of pursing and receiving a diagnosis of autism, including how they adjust to life post-diagnosis. It is proposed that any attempts to capture autistic adults' perspectives of the diagnostic process, including life pre- and post-diagnosis will have implications for future research and clinical practice.

Method

The Consolidated criteria for reporting qualitative research (COREQ) checklist was used as a guide when reporting the completion of the present study (Tong, Sainsbury, & Craig, 2007).

Design

A qualitative research design was used to explore autistic individuals' experiences of the diagnostic process. Interpretative Phenomenological Analysis (IPA) was identified as the most appropriate qualitative methodology as it involves an in-depth analysis which would enable a detailed exploration into the lived experiences of autistic adults and their journey to diagnosis. IPA has gained momentum as a methodological approach in the field of autism research and is considered an effective tool in illuminating the lived experiences of autistic people (Howard, Katsos, & Gibson, 2019). IPA is an integrative hermeneutic phenomenology which is committed to examining how people make sense of their life experiences and what meanings these events hold (Smith, Flowers, & Larkin, 2009; Smith & Osborn, 2008).

Ethical approval

Ethical approval was gained from a NHS research ethics committee (REC reference 15/NS/0110) and R&D approval was obtained from three NHS trusts within which the study took place.

Participants

Inclusion and exclusion criteria.

Participants were included in the study if they met the following criteria:

1. Aged 16 years old or older as this was the minimum age at which each of the services accepted referrals for assessment of ASC.
2. Received a diagnosis of ASD within the last 12 months to ensure that a fairly homogenous sample of participants were recruited to the study.

Participants were excluded from the current study based on the following criteria:

1. Had a diagnosis of a Learning Disability (LD) and received a diagnosis of ASD in adulthood. While these two entities can co-exist and share commonalities, there

are distinct differences between the two conditions which means they can also be exclusive from one another. The main area of difference relates to the level of academic ability, which represents a global difficulty for individuals with LD. This can include difficulties with understanding complex information, developing new skills, and a reduced ability to live independently, all of which may require some level of support (Bailey, 2020; Baldry, 2016). Therefore, taking this into consideration, the aforementioned criterion was identified to account for the difficulties individuals with LD may encounter by participating in a study of this nature.

2. Received a diagnosis of ASD in childhood as this would not be in keeping with the main aims of the research.
3. Were not fluent in English due to monetary and time restraints.

A total of nine autistic individuals participated in the study, consisting of five males and four females, aged between 23 and 47 years old. All of the participants had received a diagnosis of ASD within the last 12 months. The time since diagnosis ranged from two weeks to ten months, with the average period of time post diagnosis falling between five-and six-months. The participants were recruited from sites across three NHS trusts, each of which offered post-diagnostic support, including group-based interventions and individual clinical input.

More specifically, one trust delivered an 8-week post-diagnostic workshop or 1:1 sessions supporting individuals to understand their diagnosis and develop coping strategies for situations they were experiencing difficulty with. One out of the two participants recruited from this site were attending the workshop, whereas the other had recently engaged with individual therapy. Another trust initially offered 1:1 support to individuals in managing current difficulties, before inviting them to attend a 10-week post diagnostic support group focusing on adjusting to the diagnosis. A total of five of the six participants recruited from

this trust were attending the post-diagnostic support group, and the remaining participant was seeking support from self-help groups. The third and final trust provided 1:1 clinical input and/or a 12-week post-diagnostic group programme designed to develop awareness and acceptance of the diagnosis. The participant recruited from this site had been provided with psychoeducation material and was involved in self-help groups, as well as having previously engaged with individual therapy.

Materials.

The interview schedule (Appendix 2-1), alongside the materials used to advertise the research, were informed by a discussion with an autistic individual who had accessed mental health services and received a diagnosis of ASD in adulthood. This occurred in the planning stages of the research and was influential in guiding the design and content of the interview schedule and advertisement material. This was considered an essential part of the research given that many autistic individuals are not involved in the development stages of a study (Pellicano, Dinsmore, & Charman, 2014).

Procedure

Materials advertising the study, including information packs were distributed to each of the sites and participants were able to opt-in to the research, either by contacting the author or via the clinician responsible for their care. All of the participants opted-in to the study via their assigned clinician and requested to be contacted by the author, providing verbal consent for their contact details to be shared. Participants who expressed an interest in taking part in the study were invited to take part in semi-structured interviews and informed that these could take place at a convenient location for them. Four participants requested to be interviewed at their home and five participants chose to be interviewed at one of the different sites across the three NHS trusts.

Semi-structured interviews were conducted as these are the chosen method for qualitative data collection and adopt a flexible approach which allows individuals to tell their story from their position as experts on the subject (Reid, Flowers, & Larkin, 2005; Smith & Osborn, 2008). This is of importance in providing a "much-needed voice to autistic individuals" (Howard et al., 2019, p. 7). The interviews followed a semi-structured format, and an interview schedule was used to explore autistic individuals' experiences of the diagnostic process. Interviews were audio recorded on a portable digital device and transcribed verbatim by the author. The interviews lasted between 30 minutes and 142 minutes. At the end of interviews, participants assigned themselves a pseudonym of their choice to ensure their anonymity.

Analysis

In applying IPA, an idiographic approach to data analysis was adopted and individual transcripts were examined case by case (Smith, Harre, & Van Langenhove, 1995; Smith & Osborn, 2008). This process involved an in-depth, sustained, and interpretative engagement with the individual transcripts, during which a 'double hermeneutic' emerges. That is, the author attempts to make sense of the experiences of the participants, who are trying to make sense of their own personal and social world (Smith et al., 2009; Smith & Osborn, 2008). During this, each transcript was read a number of times and initial notes were made to capture the significance of what participants had said. These initial notes were then transformed into succinct phrases which reflected what had been found in the text and were documented as emerging theme titles. Connections between these themes were then explored, specifically in terms of convergence and divergence, and subsequently grouped under broader themes known as 'superordinate themes' (Appendix 2-2). As this process commenced, the themes were checked against the individual transcripts to ensure the connections represented the original words of the participants (Smith & Osborn, 2008).

Reflexivity.

The author kept a reflexive log to capture their observations from the initial interview to the analysis of the individual transcripts. The ability to 'own one's perspective' (Elliott, Fischer, & Rennie, 1999) is regarded as evidence of good practice within the field of qualitative research. Advice regarding the credibility of the findings was also sought from the research supervisor during the analysis of the individual transcripts. This provided clarification regarding the initial interpretations and facilitated a higher level of interpretation, thus maintaining the validity and reliability.

Results

The process of analysis identified four superordinate themes: 1) 'Lost in space': Feeling different and like an outsider; 2) The process of pursuing an explanation for the difference; 3) Shock, disappointment, and relief: emotional responses to a diagnosis; and 4) Adjusting to the diagnosis: rediscovering myself and learning to accept the difference. Each theme will be discussed individually, alongside extracts from the participants accounts to illustrate the authenticity of the results.

1) 'Lost in space': Feeling different and wanting to understand why

Prior to embarking on their diagnostic journey, participants reflected on their experiences of living with undiagnosed ASD and the challenges this presented as they navigated through life. Primarily, each of the participants referred to having felt 'different' from others, or on the periphery of society throughout their lives:

I'd always felt like I was different to everybody else. (Keyser Soze)

Ever since I was young, I've always been that bit of an outsider. (Antony)

For some participants, the awareness of feeling ‘different’ stemmed from making comparison to others or was highlighted by those closest to them, namely family who sometimes offered an explanation for the ‘difference’:

I felt different from my brothers because they were very outgoing. (Keyser Soze)

My father, my sister saw something different in me to other people. (Danielson)

My sister’s, kind of, always known and my brother-in-law you know, has always been pretty damn sure I was on the spectrum. (Ewan)

Other participants described how they became more aware of the ‘difference’ when they entered higher education and/or started employment; it was these situations where the sense of feeling ‘different’ became most pronounced and presented the greatest source of difficulty, when the environment exceeded the individual’s capabilities:

I just couldn't cope with college. I couldn’t cope with anything socializing and planning and doing things independently. (Lucy)

I think when I went into a working environment where [pause], where communication is quite important and you’re forced to it almost and then that’s when it became apparent. (James Bond)

Many participants detailed the difficulties they encountered as a result of the ‘difference’, including experiencing bullying in school, and struggling to navigate social situations. This had an adverse impact on participants well-being and led to some feeling disconnected from others:

I was ridiculed for being different…that was quite difficult. (Grace)

I didn't feel like I connected with the people much…it felt like I couldn't connect to anyone. (Fernando)

I've always struggled with friendships and in social situations…how I find it uncomfortable and how I've had to change myself to do a lot. (Eve)

Eve's description alludes to the coping strategies she implemented to compensate for the relational challenges she experienced and conveys a sense of personal responsibility in doing this. Other participants appeared to respond differently to the difficulties they experienced, and a theme of social isolation emerged. This stemmed from participants feeling disconnected from others and represented a choice which some made, almost as a form of self-preservation:

I kind of locked myself in and I didn't go anywhere…I didn't do anything…engage with people at all, because I felt very inhibited by it. (Ewan)

But there's the other side where you start to feel isolated…I didn't want to get involved. (Keyser Soze)

The sense of feeling 'different' from others presented participants with a number of challenges, and as it persisted throughout their lives, it became laden with negative connotations. In the absence of being able to explain the existence of the 'difference', participants internalised it as representing a deficit and something inherently 'wrong' with them:

I felt abit different … it got abit tough like why do I feel like this, why can't you be different. (Fernando)

I was self-aware enough to know that there was something wrong, definitely wrong with the way I thought. (Lucy)

2) The process of pursing an explanation for the difference

In response to feeling 'different' throughout their lives and this becoming more prominent (and problematic) as they became older, participants reflected on what prompted them to pursue an explanation for the 'difference'. For many, it was other people who had noticed the 'difference' and encouraged and/or supported participants to seek an assessment for autism:

There was an occupational therapist who picked up on it and she mentioned to my care co-ordinator that she wondered if I might have autism. (Fernando)

My wife's sister has a daughter who's got autism, and she recognised some of the same things in me…she was probably one of the first people who mentioned maybe being autistic. (Keyser Soze)

Similar to the experience of Keyser Soze, some participants sought clarification for the difficulties they were experiencing after observing similarities in their own children and undertook research to confirm their suspicions:

I started my own research and I just got more and more convinced that that's what was going on for him…I had the same difficulties, but for him it was different. (Eve)

I've looked at autism…because when my son was developing, I thought he may have Asperger's, so I researched it then and thought, oh well, I'm abit like that. (Lucy)

The process of completing research enabled participants to feel more prepared as they embarked on the next stage of their diagnostic journey, and the GP was the first port of call.

So I wrote all that down and so I was then able to give clear instructions to that GP what they needed to do to make that happen. (Eve)

Upon reaching this point, a couple of the participants expressed hesitation at pursing things further and attributed this to receiving additional diagnoses or 'labels', potentially reflecting their previous experiences of accessing healthcare services:

All people end up, kind of, pursuing some kind of help but end up getting diagnosed or labelled with something else. (Grace)

I'm sick of getting labels because I've got too many already. (Danielson)

Conversely, other participants focused on what they hoped to achieve from the process, and this centred around finding an explanation for the 'difference':

I used to wonder like if I had things like OCD or other stuff, so I was kind of keen to have something like that to explain things. (Fernando)

Known for a long time that, you know…I felt very differently to most people, and it was like there must be a reason behind it, there must be some sort of explanation. (Antony)

Some participants were more specific in detailing what they wanted to gain from pursuing an assessment of autism, including their desired outcome:

I was just lost, and I just wanted stability and I believe stability would allow me to grow as a person. (Lucy)

I went to my GP anyway…with the hope that I could have the assessment…and then they might realise what is wrong with me and that it would be fixable. (James Bond)

The expectation expressed by James Bond reflects the negative narrative surrounding the 'difference', and how this had become internalised as representing a personal flaw. Therefore, the desire to find a 'fix' to what is 'wrong' may help to alleviate feelings of self-blame and represent a need to 'fit in', after spending their life on the periphery of society.

Upon approaching the first port of call on their diagnostic journey, many participants described encountering a 'battle', in which they felt like they had to prove themselves after initially being dismissed and/or not feeling believed:

Erm, well my GP, I wasn't happy with her. She [pause], I felt erm, I felt a little bit like I was being dismissed…I was kind of feeling like well, it's taken me 30 years to sit in your office and tell you that I feel different to people and now you're dismissing me. (James Bond)

I've been trying to get somewhere with my doctor…for 8 years. It was like batting my head against a brick wall. (Antony)

These experiences are likely to have exacerbated the participants existing difficulties, including reinforcing the feeling of being 'different' and prolonging the process of finding an explanation for this; ultimately delaying the diagnostic journey.

3) Shock, disappointment, and relief: the emotional responses to receiving a diagnosis

After enduring a 'battle' in pursuing an explanation for the 'difference' and subsequently receiving a diagnosis of ASD in adulthood, many of the participants identified 'shock' as their initial response despite already having their own 'suspicions':

My own sort of confirmation, you know, about my own suspicions over the last 8 years…and they said, well, when I first heard it, I was actually, I was abit in shock thinking about it. (Antony)

I was shocked…it took me 7 years to find out that I have got this thing. (Danielson)

For Antony and Danielson, this feeling of 'shock' appeared to primarily relate to the length of time they had had to wait until they received the diagnosis and obtained confirmation of their suspicions. Other participants discussed their initial response of 'shock' in the context of their pre-conceptions of autism and how they could not relate to these:

I didn't know what autism really was other than the extremities of it that was sort of in films. Erm, so I, I didn't really relate to it. (James Bond)

Erm, I suppose partly where I'd met autistic people and things and its like that 'oh there's them and then there's me' and its kinda like being one of those people kinda was abit unusual. (Fernando)

These descriptions indicate the negative connotations associated with autism and the impact these had on participants willingness to initially accept the diagnosis. Subsequent to this, the feeling of 'shock' was accompanied by disappointment as participants started to adjust to the diagnosis and process the possible implications associated with it:

I was shocked by it and I was, that I was disappointed…because it was then explained to me that its not something that is like you can take a tablet and it goes away, erm, so right away I realised there was limitations on what I could do. (James Bond)

I went into a really, really bad shut down…where I suddenly became confronted with all the limitations and this is never going to get better, I'm always going to be like this. (Lucy)

It is evident from these accounts that with the diagnosis came a realisation that there was no immediate 'fix' for what was 'wrong' and a sense of permanency and feeling 'stuck' emerged. Additionally, it is recognised that the diagnosis potentially provided confirmation that the participants were (neurodevelopmentally) 'different' and reinforced the notion that

there was something 'wrong' with them. Therefore, increasing feelings of self-blame and resulting in some participants initially wanting to distance themselves from the diagnosis.

Overarching the emotional responses associated with receiving a diagnosis was an overwhelming sense of 'relief', which was reported by all of the participants. This was primarily attributed to having an explanation and/or confirmation for why they had felt 'different' throughout their lives, and seemed to signify the point where participants started to welcome this as they adjusted to the diagnosis:

When he said that was it, it was this complete relief really…it made sense. (Eve)

It's kind of like a big relief…there was something different about me. (Ewan)

4) Adjusting to the diagnosis: rediscovering myself and learning to accept the difference

After processing the immediate emotional responses associated with receiving a diagnosis of ASD in adulthood, many of the participants relocated the source of their difficulties in their diagnosis which helped to reduce feelings of self-blame:

There's a reason why and it's not just me. (James Bond)

It wasn't just all in my head, making excuses for not being able to do it. (Grace)

In doing this, participants started to reflect on their past experiences and re-evaluate these in the context of their new diagnosis. This enabled participants to make sense of themselves and provided a '*legitimate reason*' (Fernando) as to why they had encountered difficulties throughout their lives:

I can sort of look back on the things that I've been through in my life…and make sense of it all now. (Antony)

When I made all those mistakes and hiccups in my life, it's because of autism. (Lucy)

During this process, some participants acknowledged the pressure they had put on themselves to 'fit-in' to mainstream society, and the impact this had their well-being:

I was trying to pass as normal…get by sort of thing and you know…I started to struggle. (Ewan)

I've always pushed myself to carry on with like, get up and carry on doing what's expected of me and then it just spirals into me feeling more tired and more agitated and having further meltdowns. (James Bond)

As a further consequence, a couple of participants described how the mental health difficulties they experienced in response to living with undiagnosed ASD led to this being overlooked as a possible explanation for the 'difference', resulting in a delayed diagnostic journey:

So that sort of seemed to mask the autism underneath. (Grace)

…there's a lot more going on than what you can say, and this is a hidden disability for a reason. (Eve)

While adjusting to the diagnosis, some participants reported having developed an increased understanding of self, which enabled them to be more compassionate towards themselves and had a positive effect on their well-being:

It's made me more confident…I know if I'm going to struggle or if I feel like I'm struggling, and I understand why now. (Keyser Soze)

Its cemented things for me, who I am, what my limitations are and that's fine…it's made me feel so much more comfortable with who I am. (Lucy)

Other participants detailed what had helped them to reach this position and this predominantly revolved around the support they received from attending a post-diagnostic group. This allowed participants to connect with others through shared experiences, offering a sense of acceptance and belonging, while mitigating the difficulties associated with the 'difference' and facilitating the adjustment process:

I've been coming to group sessions…and I feel like I fit in a box again like know where I belong now…makes me feel a little less lost in space. (James Bond)

It's helped me adjust abit…having people who understand it…that makes things easier for me than it did before. (Fernando)

Conversely, Fernando expressed less confidence in communicating the diagnosis to family members due to concerns that he would not be believed. This was echoed by Danielson who reflected on the importance of obtaining further information prior to disclosing the diagnosis to others:

Well, I haven't told many members of my family because like my sister can be…I assumed that she wouldn't think I had it, so I've never really been sure how to break it to her and other family members. (Fernando)

I'm kind of [pause] too scared to say that I've got it, erm, because I don't know people's reactions. Erm, so I'll just take it easy until I find out everything. (Danielson)

These accounts reflect the difficulties which participants encountered when initially pursuing a diagnosis, in that they had to prove themselves after feeling dismissed. It is acknowledged that the prospect of disclosing the diagnosis reignited these same concerns and represented another source of rejection for participants, inadvertently reinforcing the feeling of being 'different' and disconnected from others.

The process of adjusting to the diagnosis represented an ongoing process for participants, with them experiencing different emotional states and shifting between positions in response to the diagnosis. Therefore, reflecting the complexities associated with pursuing and receiving a diagnosis of ASD in adulthood.

Discussion

The present study aimed to explore adults' experiences of living with undiagnosed ASD, including the process of them pursuing, receiving, and adjusting to a diagnosis in adulthood. In applying IPA, four superordinate themes emerged which captured the diagnostic journey. The findings echo what is detailed in the existing literature and offer further insights into autistic adults lived experiences prior to, during, and after the diagnostic process.

Initially, participants described feeling 'different' from others which persisted throughout their lives and was laden with negative connotations. This awareness of feeling 'different' is consistent with findings presented by DePape and Lindsay (2016) and Stagg and Belcher (2019), who both documented this as a theme for autistic individuals. Stagg and Belcher (2019) also highlighted the negative expressions which were used to describe the 'difference' and how this was attributed to them as being 'bad' people. The impact this had on participants' overall well-being, as detailed in the present study, provides further evidence of the increased risk autistic individuals are at of experiencing co-morbid difficulties (Hollocks et al., 2019).

In response to feeling 'different', participants sought an explanation for this which echoes the findings presented by Stagg and Belcher (2019) who detailed "knowledge of being different brings with it a search for explanations" (p. 353). For most of the participants, the rationale for pursuing an explanation was prompted by other people who noticed the

'difference' however, for two female participants, the decision to seek a diagnosis came after observing similarities in their children. This finding is perhaps unsurprising in account of the literature which indicates that autistic females are at an increased risk of going unnoticed and having their needs misunderstood, resulting in a late diagnosis in comparison to males (Bargiela, Steward, & Mandy, 2016; Lai et al., 2011). It was also female participants who identified their co-occurring mental health difficulties as 'masking' the autism, illustrating the impact differential diagnoses can have on the diagnostic process (Lai & Baron-Cohen, 2015; Lehnhardt et al., 2013).

When reflecting on their responses to the difficulties associated with living with undiagnosed ASD, a female participant described having to '*change*' (Eve) herself in order to navigate social situations. This appears to be reflective of the recent phenomenon of 'masking' or 'camouflaging', which is associated with autistic women and girls (Baldwin & Costley, 2016; Hull et al., 2017). The challenges which participants described encountering on their pursuit of finding an explanation for the 'difference', specifically in terms of feeling dismissed by health care professionals, also represents a shared experience amongst autistic adults (Jones et al., 2014).

The emotional journey participants embarked upon receiving the diagnosis is well documented, with 'relief' appearing the most prominent response reported by autistic adults (DePape & Lindsay, 2016; Leedham et al., 2019; Stagg & Belcher, 2019). As detailed in the present study, the sense of 'relief' arose from having an explanation for the 'difference' which enabled participants to relocate the source of their difficulties in the diagnosis, alleviating feelings of self-blame. Prior to this, the present study draws attention to the 'shock' participants experienced in response to the diagnosis after it did not fit with their pre-conceptions of autism or fulfil their original hopes of wanting a 'fix'. There was also a recognition that the diagnosis reinforced the feeling of being 'different' and led to some

participants expressing disappointment as they processed the long-term implications associated with autism. This echoes previous findings which documented that autistic individuals experienced feelings of helplessness, sadness, and anger as they adjusted to the diagnosis and re-evaluated their past experiences (DePape & Lindsay, 2016; Powell & Acker, 2016).

As participants adjusted to the diagnosis, they expressed an increased sense of self which was informed by reflecting on their lives pre-diagnosis, as evidenced in previous research (DePape & Lindsay, 2016; Stagg & Belcher, 2019). Participants spoke positively about attending a post-diagnostic support group in helping the adjustment process and recent research reported improved outcomes for autistic adults who receive extended post-diagnostic input (Beresford et al., 2020). Previous research has also identified family and friends as being a source of comfort (DePape & Lindsay, 2016) however, some participants in the present study expressed reluctance at informing others due to concerns that they would not be believed. This is consistent with existing literature which identified discrimination and stigmatisation as barriers to autistic adults disclosing their diagnoses (DePape & Lindsay, 2016; Stagg & Belcher, 2019). This issue represented an ongoing predicament for the participants as they adjusted to the diagnosis and rediscovered themselves.

Methodological limitations

While this present study offers a valuable insight into autistic adults' experiences of the diagnostic journey, there are methodological issues which need to be considered. Primarily, the issue of bias may have been introduced into the research by the recruitment strategy adopted. That is, the study may have been of more interest to individuals who were accepting of their diagnosis and in a position to share their thoughts and feelings around this. This may have extended to the process of analysis, with those more able to express themselves being over-represented in the development of the themes.

While a primary aim of qualitative research is to not make generalisations from the findings (Smith et al., 1995), the present study focuses on adults' diagnostic experiences within the past 12 months therefore, presenting limitations in applying the research to those who received a diagnosis beyond this point. Additionally, although the sample of participants within this study were considered to fulfil a key prerequisite of IPA research and represented a fairly homogenous sample of autistic individuals, disparities will have existed which will have influenced their experiences of the diagnostic journey.

Most notably, the issue of gender, which features throughout the field of autism research is a key consideration, with females being under-recognised in the prevalence rates (Gould, 2017). In the present study, there were some observable differences in participants experiences and gender was identified as a potential influencing factor, indicating that this needs to be considered when reviewing the findings presented. Additionally, age is another influential issue with research indicating that prior to there being a clear definition of ASD, autistic individuals born before 1980 are likely to have been misdiagnosed or not diagnosed at all (American Psychiatric Association, 1980; Brugha et al., 2011; Guerts, Stek, & Comijs, 2015).

Furthermore, although studies implementing IPA have received increased recognition within autism research, caution has been advised around using qualitative research with this population. This originates in the 'double-empathy problem' which suggests that the disjuncture in reciprocity between autistic individuals and non-autistic individuals, can have implications for the interpretations made and undermine the authenticity of the research (Howard et al., 2019; Milton, 2012). However, based on the in-depth and reflexive engagement with participants accounts and its positioning of participants as experts in their experiences, IPA is an approach which might mitigate these difficulties (Howard et al., 2019; MacLeod, Allan, Lewis, & Robertson, 2017).

As a result of the time lapsed from data collection to the point of analysis, it was not possible to involve participants in reviewing the results. This would have strengthened the authenticity of the findings and assisted in alleviating the 'double-empathy problem' (Milton, 2012). Also, the limited methodological expertise held by the author may have reduced the richness in participants' accounts and allowed more in-depth interpretations to be drawn from the transcripts. Nevertheless, the author took steps to mitigate this, including keeping a reflexive log and seeking supervisory support.

Implications and recommendations

This study illustrates the numerous challenges participants encountered on their diagnostic journey and the impact these had on their well-being as they adjusted to receiving a diagnosis of ASD in adulthood. In account of this, and the increased risk autistic adults are at of experiencing co-occurring mental health conditions (Hollocks et al., 2019), healthcare professionals need to take this into consideration and screen for co-morbidities in their initial assessment (Lewis, 2016a). This will help inform what support is offered to autistic adults and is fundamental in promoting positive outcomes in other areas (Beresford et al., 2020; Lai et al., 2019).

The difficulties which participants encountered on their pursuit for a diagnosis, in terms of feeling dismissed by healthcare professionals suggests that further intervention is required with practitioners to increase their knowledge of autism, including factors which complicate the diagnostic process. This echoes recommendations in existing research (Crane et al., 2018; Jones et al., 2014; Stagg & Belcher, 2019), as well as being documented in the Autism Strategy (2010, 2014) and NICE (2012) guidance regarding the diagnosis and management of ASD in adults. Training would need to incorporate the different presentations of autism, with a focus on the role of gender and issues, such as 'masking' or 'camouflaging' which are receiving increased attention in autism research (Hull et al., 2017;

Hull, Petrides, & Mandy, 2020). Further exploration of gender differences in autistic adults, with a focus on capturing female perspectives using a narrative analysis approach are identified as avenues for future research.

The emotional journey which ensued upon participants receiving a diagnosis is a complex process, with responses changing over time. Research indicates that autistic adults are vulnerable to experiencing increased mental health difficulties during this time (Cassidy et al., 2014) therefore, highlighting the importance of post-diagnostic support. This was identified as being helpful in facilitating the adjustment process for participants and has been associated with improved quality of life and reduced experience of co-occurring mental health difficulties (National Autistic Society, 2008; Renty & Roeyers, 2006). The provision of extended psychoeducation has recently been demonstrated to be fundamental in supporting the immediate and longer-term adjustment to a diagnosis of ASD in adulthood (Beresford et al., 2020), and is of relevance to participants in the present study, who ranged from two weeks to ten months in terms of time passed since diagnosis. Follow-up research with the same participants would be helpful in offering further insights into the adjustment process, including the provision of support during this time.

The Autism Strategy (2010, 2014) and statutory government guidance (Department of Health, 2015) also stipulate that a diagnosis of autism should be accompanied by a needs assessment to ensure that adults have access to the appropriate support. However, only 16% of autistic adults were found to have been offered an assessment (National Autistic Society, 2001). Similarly, recent research evaluating the provision of specialist autism services across England, an additional recommendation in the government guidance, identified that the majority of localities do not offer this model of care (Beresford et al., 2020). The existing specialist services have also observed increases in their rates of referrals, with no additional funding to support these. These issues alone, notwithstanding the challenges which autistic

adults encounter on their pursuit for a diagnosis, will continue to present barriers to accessing diagnostic services.

Recommendations which are identified as helping to overcome these barriers and improve outcomes for autistic adults primarily involve increased investment, specifically to strengthen the development of SATs. This would allow these services to continue to provide high-quality care, while also broadening their role in offering consultation and supervision to other mainstream services supporting autistic adults. This was identified as a recommendation from the study conducted by Beresford et al. (2020) and would contribute to clearer diagnostic pathways due to the increased availability of services equipped to meet the needs of autistic adults. Clinical psychologists are also encouraged to apply the 'scientist-practitioner-advocate' model (Mallinckrodt, Miles, & Levy, 2014) in working with NHS organisations and LAs to improve access to diagnostic services and support, referring back to legislation and statutory guidance as part of this. For these recommendations to be successful practitioners need to work in collaboration with autistic individuals, ensuring they are involved in decisions relating to their care and services are tailored to their needs, with the aim of improving diagnostic processes and enhancing quality of life (Coleman-Fountain, Buckley, & Beresford, 2019; Department of Health, 2014; NICE guidance 2012).

Conclusion

The findings reaffirm what is captured in the existing literature, while offering additional insights into autistic adults' experiences of the diagnostic process. Alongside an awareness of feeling 'different' from others which became internalised and had a detrimental impact on well-being, participants endured a battle in trying to make sense of this. While the diagnosis provided 'relief', it was also met with 'disappointment' and 'shock' as participants adjusted to the diagnosis and what it represented. During this, participants reflected on their lives pre-diagnosis and began to rediscover themselves, while acknowledging the barriers

which lay ahead. The provision of support to autistic individuals is paramount in alleviating distress and training to frontline professionals will help reduce the difficulties associated with the diagnostic journey.

References

American Psychiatric Association. (1980). *Diagnostic and Statistical Manual for Mental Disorders*. 4. Washington, DC: American Psychiatric Press.

American Psychiatric Association. (1994). *Diagnostic and Statistical Manual for Mental Disorders*. 4. Washington, DC: American Psychiatric Press.

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual for Mental Disorders*. 5. Washington, DC: American Psychiatric Press.

Bailey, E. (2020, January 12). How to differentiate Autism from a Learning Disability. Retrieved from: https://www.additudemag.com/autism-learning-disability-symptoms/

Baldwin, S., & Costley, D. (2016). The experiences and needs of female adults with high-functioning autism spectrum disorder. *Autism*, *20*(4), 483-495. doi: 10.1177/1362361315590805

Baldry, K. (2016, July 12). Autism and Learning Disabilities: What's the Difference? Retrieved from: https://welldoing.org/article/autism-and-learning-difficulties-difference

Barahona-Corrêa, J.B., & Filipe, C.N. (2016). A Concise History of Asperger Syndrome: The Short Reign of a Troublesome Diagnosis. *Frontiers in Psychology*, *6*(2024), 1-7. doi:10.3389/fpsyg.2015.02024

Bargiela, S., Steward, R., & Mandy, W. (2016). The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype. *Journal of Autism and Developmental Disorders, 46,* 3281-3294. doi: 10.1007/s10803-016-2871-8

Baron-Cohen, S. (2000). Is Asperger syndrome/high functioning autism necessarily a disability? *Developmental and Psychopathology, 12,* 489-500. doi:10.1017/S0954579400003126

Baron-Cohen, S. (2015). Leo Kanner, Hans Asperger and the discovery of autism. *Lancet Psychiatry, 386*(3), 1329-1330. Retrieved from https://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(15)00337-2.pdf

Beresford, B., Mukherjee, S., Mayhew, E., Heavy, E., Park, A-L., Stuttard, L, et al. (2020). Evaluating specialist autism teams' provision of care and support for autistic adults without learning disabilities: the SHAPE mixed-methods study. *Health Services and Delivery Research, 8*(48), 1-236. doi: 10.3310/hsdr08480

Brugha, T.S., McManus, S., Bankart, J., Scott, F., Purdon, S., Smith, J…Meltzer, H. (2011). Epidemiology of Autism Spectrum Disorders in Adults in the Community in England. *Archives of General Psychiatry, 68*(5), 459-65. doi: 10.1001/archgenpsychiatry.2011.38

Brugha, T.S., Spiers, N., Bankart, J., Cooper, S-A., McManus, S., Scott, F.J…Tyrer, F. (2016). Epidemiology of autism in adults across age groups and ability levels. *British Journal of Psychiatry, 209*(6), 498-503. doi: 10.1192/bjp.bp.115.174649

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness, 4*(2), 167-182. doi: 10.1111/1467-9566.ep11339939

Calzada, L.R., Pistrang, N., & Mandy, W.P.L. (2012). High-functioning autism and Asperger's disorder: utility and meaning for families. *Journal of Autism and Developmental Disorders, 42*(2), 230-243. doi: 10.1007/s10803-011-1238-5

Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M., & Baron-Cohen, S. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study. *Lancet Psychiatry*, *1*(2), 142-147. doi: 10.1016/S2215-0366(14)70248-2

Coleman-Fountain, E., Buckley, C., & Beresford, B. (2019). Improving mental health in autistic young adults: a qualitative study exploring help-seeking barriers in UK primary care. *British Journal of General Practice*, *70*(694), 356-363. doi: 10.3399/bjgp20X709421

Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L.A., & Hill, E.L. (2018). Autism diagnosis in the United Kingdom: Perspectives of autistics adults, parents and professionals. *Journal of Autism and Developmental Disorders, 48,* 3761-3772. doi:10.1007/s10803-018-3639-1

DePape, A-M., & Lindsay, S. (2016). Lived Experiences From the Perspective of Individuals with Autism Spectrum Disorder: A Qualitative Meta-Synthesis. *Focus on Autism and Other Developmental Disabilities*, *31*(1), 60-71. doi: 10.1177/1088357615587504

Department of Health (2010, 2014). *Think Autism Strategy*. Accessed 19 July 2020 from: https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy

Department of Health (2015). Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy. Accessed 02 July 2021 from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf

Elliott, R., Fischer, C.T., & Rennie, D.L. (1999). Elolving guidelines for publication of qualitative research studies in psychology and related fields. *The British Journal of Clinical Psychology*, *38*(3), 215-229. doi: 10.1348/014466599162782

Fombonne, E. (2020). Epidemiological controversies in autism. *Swiss Archives of Neurology, Psychiatry and Psychotherapy*, *171*, 1-3. doi:10.4414/sanp.2020.03084

Gallagher, A., Arber, A., Chaplin, R., & Quirk, A. (2010). Service users' experience of receiving bad news about their mental health. *Journal of Mental Health*, *19*(1), 34-42. doi: 10.3109/09638230903469137

Geurts, H.M., & Jansen, M.D. (2011). A retrospective chart study: The pathway to a diagnosis for adults referred for ASD assessment. *Autism*, *16*(3), 299-305. Doi: 10.1177/1362361311421775

Geurts, H.M., Stek, M., & Comijs, H. (2015). Autism characteristics in older adults with depressive disorder. *American Journal of Geriatric Psychiatry*, *38*(6), 1011-1018. doi:10.1016/j.jap.2015.08.003

Gillberg, I.C., Helles, A., Billstedt, E., & Gillberg, C. (2016). Boys with Asperger Syndrome Grow Up: Psychiatric and Neurodevelopmental Disorders 20 Years After Initial Diagnosis. *Journal of Autism and Developmental Disorders*, *46*(1), 74-82. doi:10.1007/s10803-015-2544-0

Glazzard, J., & Overall, K. (2012). Living with autistic spectrum disorder: Parental experiences of raising a child with autistic spectrum disorder (ASD). *Support For Learning*, *27*(1), 37-45. doi:10.1111/j.1467-9604.2011.01505.x

Gould, J. (2017). Towards understanding the under-recognition of girls and women on the autism spectrum. *Autism*, *21*, 703-705. doi:10.1177/1362361317706174

Hickey, A., Crabtree, J., & Stott, J. (2018). 'Suddenly the first fifty years of my life made sense': Experiences of older people with autism. *Autism*, *22*(3), 357-367. doi: 10.1177/1362361316680914

Hollocks, M.J., Lerh, J.W., Magiati, I., Meiser-Stedman, R., & Brugha, T.S. (2019). Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis. *Psychological Medicine*, *49*(4), 559-572. doi:10.1017/S0033291718002283

Howard, K., Katsos, N., & Gibson, J. (2019). Short Report: Using Interpretative Phenomenological Analysis in Autism Research. *Autism: the international journal of research and practice, 23*(7), 1871-1876. doi:10.1177/1362361318823902

Howlin, P., & Magiati, I. (2017). Autism spectrum disorder: outcomes in adulthood. *Current Opinion in Psychiatry*, *30*(2), 69-76. doi:10.1097/YCO.0000000000000308

Howlin, P., & Moss, P. (2012). Adults with Autism Spectrum Disorders. *Canadian Journal of Psychiatry*, *57*(5), 275-283. doi:10.1177/070674371205700502

Hull, L., Petrides, K.V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M.C., & Mandy, W. (2017). "Putting on My Best Normal": Social Camouflaging in Adults with Autism Spectrum Conditions. *Journal of Autism and Developmental Disorders, 47*, 2519-2534. doi:10.1007/s10803-017-3166-5

Hull, L., Petrides, K.V., & Mandy, W. (2020). The Female Autism Phenotype and Camouflaging: a Narrative Review. *Journal of Autism and Developmental Disorders, 7,* 306-317. doi:10.1007/s40489-020-00197-9

Jones, L., Goddard, L., Hill, E. L., Henry, L.A., & Crane, L (2014). Experiences of Receiving a Diagnosis of Autism Spectrum Disorder: A Survey of Adults in the United Kingdom. *Journal of Autism and Developmental Disorders*, *44,* 3033-3044. doi:10.1007/s10803-014-2161-3

Joshi, G., Wozniak, J., Petty, C., Martlelon, M.K., Fried, R., Bolfek, A…Biederman, J. (2013). Psychiatric comorbidity and functioning in a clinically referred population of adults with autism spectrum disorders: a comparative study. *Journal of Autism and Developmental Disorders, 43*(6), 1314-1325. doi:10.1007/s10803-012-1679-5

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism, 20*(4), 442-462. doi:10.1177/1362361315588200

Klin, A. (2003). Asperger Syndrome: an update. *Brazialian Journal of Psychiatry*, *25*(2), 103-109. doi:10.1590/s1516-44462003000200011

Lai, M-C., Lombardo, M.V., Pasco, G., Ruigrok, A.N.V., Wheelwright, S.J., Sadek, S.A…Baron-Cohen, S. (2011). A Behavioural Comparison of Male and Female Adults with High Functioning Autism Spectrum Conditions. *PLoS ONE, 6*(6) :e20835. doi: 10.1371/journal.pone.0020835

Lai, M-C., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. *Lancet Psychiatry*, *2*(11), 1013-1027. doi:10.1016/S2215-0366(15)00277-1

Lai, M-C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W…Ameis, S.H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *Lancet Psychiatry*, *6*, 819-829. doi:10.1016/S2215-0366(19)30289-5

Lai, M-C., Lombardo, M.V., & Baron-Cohen, S. (2013). Autism. *Lancet Psychiatry*, *383*(9920). doi:10.1016/S0140-67369(13)61539-1

Leedham, A., Thompson, A.R., Smith, R., & Freeth, M. (2019). 'I was exhausted trying to figure it out': The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism*, *24*(1), 135-146. doi:10.1177/1362361319853442

Lehnhardt, F.G., Gawronski, A., Pfeiffer, K., Kockler, H., Schilbach, L., & Vogeley, K. (2013). The investigation and differential diagnosis of Asperger Syndrome in Adults. *Deutsches Arzteblatt international*, *110*(45), 755–763. doi:10.3238/arztebl.2013.0755

Lewis, L.F. (2016a). Exploring the Experience of Self-Diagnosis of Autism Spectrum Disorder in Adults. *Archives of Psychiatric Nursing*, *30*, 575-580. doi:10.1016/j.apnu.2016.03.009

Lewis, L.F. (2016b). Realising a diagnosis of autism spectrum disorder as an adult. *International Journal of Mental Health Nursing*, *25*, 346-354. doi: 10.111/inm.12200

Loomes, R., Hull, L., & Mandy, W.P.L. (2017). What is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis. *Journal of the*

American Academy of Child and Adolescent Psychiatry, *56*(6), 466-474. doi:10.1016/j.jaac.2017.03.013

MacLeod, A., Allan, J., Lewis, A., & Robertson, C. (2017). 'Here I come again': the cost of success for higher education students diagnosed with autism. *International Journal of Inclusive Education, Online*, 1-15. doi:10.1080/13603116.2017.1396502

Maenner, M.J., Rice, C.E., Arneson, C.L., Cunniff, C., Schieve, L.A., Carpenter, L.A…Durkin, M.S. (2014). Potential impact of DSM-5 criteria on autism spectrum disorder prevalence estimates. *JAMA Psychiatry*, *71*(3), 292-300. doi:10.1001/jamapsychiatry.2013.3893

Mallinckrodt, B., Miles, J.R., & Levy. J.L. (2014). The Scientist-Practitioner-Advocate Model: Addressing Contemporary Training Needs for Social Justice Advocacy. *Training and Education in Professional Psychology*, *8*(4), 303-311. doi: 10.1037/tep0000045

Milton, D. (2012). On the ontological status of autism: the 'double empathy problem'. *Disability & Society, 27*(6), 883-887. doi:10.1080/09687599.2012.710008

National Autistic Society. (2001). *Ignored or Ineligible? The reality for adults with autism spectrum disorders*. London: The National Autistic Society.

National Autistic Society. (2008). *I Exist: The message from adults with autism in England*. London: The National Autistic Society.

National Autistic Society. (2018). *Autism Strategy Overview*. London: The National Autistic Society.

National Institute for Health and Care Excellence (2012). Autism Spectrum Disorder in adults: diagnosis and management. Retrieved from https://www.nice.org.uk/guidance/cg142

Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*, *18*(7), 756-770. doi:10.1177/1362361314529627

Pellicano, E., Lawson, W., Hall, G., Mahony, J., Lilley, R., Davis, C…Yudell, M. (2020). Documenting the untold histories of late-diagnosed autistic adults: a qualitative study protocol using oral history methodology. *BMJ Open*, *10*. doi:10.1136/bmjopen-2020-037968

Powell, T., & Acker, L. (2016). Adult's experience of an Asperger Syndrome Diagnosis: Analysis of its emotional meaning and effect on participants lives. *Focus on Autism and Other Developmental Disabilities*, *31*(1), 72-80. doi: 10.1177/1088357615588516

Punshon, C., Skirrow, P., & Murphy, G. (2009). The 'not guilty' verdict: Psychological reactions to a diagnosis of Asperger syndrome in adulthood. *Autism*, *13*(3), 265-283. doi:10.1177/1362361309103795

Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, *18*(1) 20-23. Retrieved from https://thepsychologist.bps.org.uk/getfile/2452

Renty, J., & Roeyers, H. (2006). Quality of life in high-functioning adults with autism spectrum disorder. *Autism*, *10*, 511-524. doi:10.1177/1362361306066604

Skuse, D. (2020). Autism – 25 years on: A lot had changed!. *Clinical Child Psychology and Psychiatry*, *0*(0), 1-5. doi:10.1177/1359104520929729

Skuse, D., Mandy, W., & Tang, J. (2020). Validating the bidimensional reconceptualization of the autism phenotype. *Human Behaviour*, *1*(1), 1-7. doi:10.37716/HAB.2020010101

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage.

Smith, J. A., Harre, R., & Van Langenhove, L. (1995). Idiography and the case study. In Smith, J. A., Harre, R., & Van Langenhove, L. (Eds), *Rethinking Psychology*. London: Sage.

Smith, J. A., & Osborn, M. (2008). Interpretative Phenomenological Analysis. In Smith, J. A. (Eds), *Qualitative Psychology: A Practical Guide to Research Methods* (pp. 53-80). London: Sage.

Stagg, S.D., & Belcher, H. (2019). Living with autism without knowing: receiving a diagnosis in later life. *Health Psychology and Behavioural Medicine*, *7*(1), 348-361. doi:10.1080/21642850.2019.1684920

The Autism Act 2009. Available at https://www.legislation.gov.uk/ukpga/2009/15/contents (Accessed: 19 July 2020).

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, *19*(6), 349-357. doi:10.1093/intqhc/mzm042

Tromans, S., Chester, V., Kiani, R., Alexander, R., & Brugha, T. (2018). The Prevalence of Autism Spectrum Disorders in Adult Psychiatric Inpatients: A Systematic Review.

Clinical Practice & Epidemiology in Mental Health, *14*, 177-187. doi:10.2174/1745017901814010177

Tsai, L.Y. (2015). The Impact of DSM-5 on Autism Spectrum Disorder. *Journal of Experimental Psychopathology*, *2*(1), 3-16. doi:10.5127/pr.035414

Wiggins, L.D., Rice, C.E., Barger, B., Soke, G.N., Lee, L-C., Moody, E…Levy, S.E. (2019). DSM-5 criteria for autism spectrum disorder maximizes diagnostic sensitivity and specificity in preschool children. *Social psychiatry and psychiatric epidemiology*, *54*(6), 693–701. doi:10.1007/s00127-019-01674-1

Woodbury-Smith, M.R., Robinson, J., Wheelwright, S., & Baron-Cohen, S. (2005). Screening adults for Asperger syndrome using the AQ: A preliminary study of its diagnostic validity in clinical practice. *Journal of Autism and Developmental Disorders*, *35*, 331-335. doi: 10.1007/s10803-005-3300-7

World Health Organisation (2019). Autism Spectrum Disorders. Retrieved from https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders

Appendix 2-1: Interview schedule

Experiences of living with undiagnosed Autism Spectrum Disorder (ASD)

What was your life like before you received a diagnosis of ASD? Was it easy or difficult living with undiagnosed ASD?

Did you or your family ever try to pursue a diagnosis of ASD when you were growing up? If so, what happened? What was this like? Was it a good or bad experience? How did it make you feel?

Have you received any other diagnoses before? If so, was that a good or bad experience for you? Why? How did it make you feel?

Have you previously been misdiagnosed with any other condition? If so, is there anything you would like to tell me about this? What it a good or bad experience for you? Why? How did it make you feel? What did you think?

Experiences of receiving a diagnosis of ASD in adulthood

When did you receive your diagnosis of ASD?

Who gave you the diagnosis?

How old were you when you received your diagnosis?

How long did it take for you to receive your diagnosis, from the decision to pursue a diagnosis to actually receiving the diagnosis?

Whose decision was it to go for an assessment? Why?

What was it like for you receiving a diagnosis of ASD? How did you feel?

What does it mean to you receiving the diagnosis of ASD?

How has your life changed since receiving the diagnosis?

Appendix 2-2

Emerging themes within the superordinate themes

	Superordinate themes			
	'Lost in space': Feeling different and like an outsider	**The process of pursuing an explanation for the difference**	**Shock, disappointment, and relief: the emotional responses to receiving a diagnosis**	**Adjusting to the diagnosis: rediscovering myself and learning to accept the difference**
Emerging themes	• Feeling different and not 'fitting in' • Noticing the difference • Not being able to make sense of the difference • Questioning themselves • Problems associated with the difference • Impact of living with undiagnosed autism	• Others noticing the difference • Recognising similarities in others • Wanting to understand what's 'wrong' • Battling to get a diagnosis (& having to go armed) • Doubting themselves • Hopes and fears for the diagnosis	• Shock (came as a surprise) • (Mis)understanding around autism • Disappointment at reality of diagnosis • 'There is something different about me' • Relief – 'it makes sense' • Have a reason/confirmation for feeling different	• Externalising the difference • Reflecting on life pre-diagnosis • Making sense of things (gradually) • Understanding and accepting self • Sense of belonging • Deciding who to tell

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Autism now requires authors to report the following information for all Research Reports (including systematic reviews):

i. procedures for sample selection and recruitment; and
ii. major demographic characteristics, including age, gender, race/ethnicity and socioeconomic status.

Including this information will provide greater clarity regarding sample characteristics and generalisability of the findings, even when such characteristics are not used in the analysis (although we encourage investigation of subgroup differences, where possible). It should also encourage researchers to consider the way in which context and culture contribute to their findings.

If authors are unable to report some or all of this information, its absence must be acknowledged with a clear statement of explanation (e.g., "specific data on socioeconomic status and educational attainment levels were not recorded"). Manuscripts that contain neither the required information nor an appropriate statement will be returned prior to consideration by the editors.

2.8.3 Community involvement

Autism encourages research that is actively carried out 'with' or 'by' members of the Autistic and autism communities (rather than 'to', 'about', or 'for' them), often referred to as 'co-production', 'participatory research', 'patient and public involvement (PPI)' or 'integrated knowledge translation (iKT)'.

We therefore recommend that authors follow the BMJ's editorial guidelines in which authors clearly document how community stakeholders were involved in their research. We suggest that authors include a community involvement statement at the end of the Methods section for Research Reports, outlining whether autistic people and/or family members, community providers, policy makers, agency leaders or other community stakeholders were involved in the development of the research question and outcome measures, the design of the study, its implementation, and/or the interpretation and dissemination of the findings. Community members should be duly acknowledged – as authors or in the acknowledgements section – depending on the extent and nature of their contribution.

If community members were not involved in the study, authors should state this.

2.9 Data Policy Statement

Autism supports open research practices and FAIR principles. As such encourages authors to share their data wherever possible and submit their data (or a link to it) and where applicable, their syntax/command files for the analyses presented in the contribution. Authors can make

data available through a third party data repository or on the journal website as a supplementary data file.

If cited data is restricted (e.g. classified, require confidentiality protections, were obtained under a non-disclosure agreement, or have inherent logistical constraints), authors should notify the editor at the time of submission. The editor shall have full discretion to follow their journal's policy on restricted data, including declining to review the manuscript or granting an exemption with or without conditions. The editor shall inform the author of this decision prior to review.

Where data is sensitive and cannot be shared in an open forum, authors are encouraged to share metadata and provide a contact for requesting access if the raw data itself cannot be made available.

Data can be submitted with your article and hosted on the SAGE *Autism* website where we work with Figshare to host data content. Authors can use a recognised third party data repository service to host their data such as Open Science framework. Authors may use their institution's data sharing repository.

Autism also encourages authors to delineate clearly the analytic procedures upon which their published claims rely, and where possible provide access to all relevant analytic materials. If such materials are not published with the article, we encourage authors to share to the greatest extent possible through a digital repository (above).

Autism encourages authors to use data citation practices that identify a dataset's author(s), title, date, version, and a persistent identifier. In sum, data should be referenced and cited, where possible, as an intellectual product of value.

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3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway.

3.1.1 Plagiarism

Autism and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

3.1.2 Prior publication

If material has been previously published it is not generally acceptable for publication in a SAGE journal. However, there are certain circumstances where previously published material can be considered for publication. Please refer to the guidance on the SAGE Author Gateway or if in doubt, contact the Editor at the address given below.

3.2 Contributor's publishing agreement

Before publication, SAGE requires the author as the rights holder to sign a Journal Contributor’s Publishing Agreement. SAGE’s Journal Contributor’s Publishing Agreement is an exclusive licence agreement which means that the author retains copyright in the work but grants SAGE the sole and exclusive right and licence to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright in the work will be assigned from the author to the society. For more information please visit the SAGE Author Gateway.

3.3 Open access and author archiving

Autism offers optional open access publishing via the SAGE Choice programme. For more information please visit the SAGE Choice website. For information on funding body

compliance, and depositing your article in repositories, please visit SAGE Publishing Policies on our Journal Author Gateway.

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4. Preparing your manuscript for submission

4.1 Formatting

Autism asks that authors use the APA style for formatting. The APA Guide for New Authors can be found on the APA website, as can more general advice for authors.

4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

4.4 Terminology

Autism has researched and compiled their own Terminology Guidelineswhich all authors should follow.

4.5 Reference style

Autism adheres to the APA reference style. View the APA guidelines to ensure your manuscript conforms to this reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

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5. Submitting your manuscript

Autism is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit http://mc.manuscriptcentral.com/autism to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

5.1 ORCID

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a unique and persistent digital identifier that distinguishes researchers from every other researcher, even those who share the same name, and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities, ensuring that their work is recognized.

The collection of ORCID iDs from corresponding authors is now part of the submission process of this journal. If you already have an ORCID iD you will be asked to associate that to your submission during the online submission process. We also strongly encourage all co-authors to link their ORCID ID to their accounts in our online peer review platforms. It takes seconds to do: click the link when prompted, sign into your ORCID account and our systems are automatically updated. Your ORCID iD will become part of your accepted publication's metadata, making your work

attributable to you and only you. Your ORCID iD is published with your article so that fellow researchers reading your work can link to your ORCID profile and from there link to your other publications.

If you do not already have an ORCID iD please follow this link to create one or visit our ORCID homepage to learn more.

5.2 Information required for completing your submission

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

5.3 Lay Abstracts

As part of your submission you will be asked to provide a lay abstract of your article. Lay abstracts are a brief (max 250 words) description of the paper that is easily understandable. These abstracts will be made widely available (to the general public, and particularly to autistic people and their families). As such, lay abstracts should avoid both technical terminology and the reporting of statistics. Examples of lay abstracts are provided in recent issues of the journal.

Authors may consider the following questions when composing their lay abstract.

a. What is already known about the topic?
b. What this paper adds?
c. Implications for practice, research or policy

Authors may also find the following resources helpful on this topic:

- How to write a summary paragraph
- Self Advocacy Resource and Technical Assistance Center (SARTAC): Plain Language
- Center for Plain Langauage: Five steps to Plain Language

5.4 Permissions

Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the SAGE Author Gateway

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6. On acceptance and publication

6.1 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be sent by PDF to the corresponding author and should be returned promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate. Please note that if there are any changes to the author list at this stage all authors will be required to complete and sign a form authorising the change.

6.2 Online First publication

Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the SAGE Journals help page for more details, including how to cite Online First articles.

6.3 Access to your published article

SAGE provides authors with online access to their final article.

6.4 Promoting your article

Publication is not the end of the process! You can help disseminate your paper and ensure it is as widely read and cited as possible. The SAGE Author Gateway has numerous resources to help you promote your work. Visit the Promote Your Article page on the Gateway for tips and advice.

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7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the Autism editorial office as follows:

Katie Maras
Department of Psychology
University of Bath, UK
Email: katiemaras.autism@gmail.com

Section Three: Critical Appraisal

Claire Evans

Trainee Clinical Psychologist

Lancaster University

Word Count: 1,605

Correspondence to be addressed to:

Ms Claire Evans

Doctorate in Clinical Psychology

Division of Health Research

Lancaster University

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This critical appraisal will focus on providing an overview of the key findings from the thesis, including some of my reflections which emerged during the completion of the research and the context of these within my own lived experiences. As part of this, areas for future research will be considered, alongside ongoing issues which will have implications for clinical practice and importantly, the lives of 'neurodiverse' people.

Summary of findings

The findings from the literature review and research paper evidently indicate that there are key similarities for adults who receive a diagnosis of ADHD or ASD later in life. Primarily, adults described an acute awareness of feeling 'different' from others and reflected on the numerous challenges this presented as they attempted to navigate their way in a 'neurotypical' world. In doing this, adults detailed the adverse impact this had on their level of functioning in all aspects of their lives and how this was further confounded by the absence of an explanation for the 'difference'. This subsequently became conceptualised and internalised as representing a personal failing or flaw which appeared to activate a '*fight or flight*' response in adults as a means of surviving. These factors contributed to a delayed diagnostic journey for adults which commenced after observing similarities in those closest to them (i.e. their own children) or was prompted by others who had noticed the 'difference'.

Upon embarking on the journey to receiving a diagnosis of a neurodevelopmental condition, adults experienced a myriad of emotional responses which appeared to change over time as they adjusted to the diagnosis. While 'relief' was identified as being the overarching emotion associated with receiving the diagnosis, of particular significance was the discovery that the diagnosis also provided confirmation that adults were (neurodevelopmentally) 'different'. Subsequently, there was a shift in adults' responses and relief was accompanied by feelings of anger, sadness, and disappointment as adults adjusted to the diagnosis, illustrating the unique complexities associated with this process. The

provision of support during this time, specifically in terms of connecting with others with shared lived experiences was significant in strengthening adults' self-worth and mitigating the difficulties associated with being 'neurodiverse' in a 'neurotypical' world.

The power of language

Throughout the completion of the thesis, I became increasingly aware of the language I used to describe and define the difficulties adults experienced living without a diagnosis and/or receiving a diagnosis of a neurodevelopmental condition in adulthood. As Kenny et al. (2016) suggest "whatever the cause, the language that we use has the power both to reflect and to shape people's perceptions of autism" (p. 442). Alongside this, there is an increased recognition and preference amongst the autistic community to move away from *person-first language* ('person with autism') to *identity-first language* ('autistic person') and this has been discussed in relation to the debate between the medical vs. social model of disability which exists in the field of autism research (Kenny et al., 2016; Milton, 2012). More specifically, it is argued that people are not 'disabled' in account of the 'disorder' (condition) they have been diagnosed with, but this is shaped and influenced by the way in which society responds to individuals who fall outside of the 'neurotypical' norm (Baker, 2011; Oliver, 1990).

Having spent quality time with autistic people during the completion of the research project, and in both my personal and professional life, I felt a sense of responsibility to embed this preferred narrative and conceptualisation of autism in my writing. In doing this, I became aware that this initially felt incongruent with my usual approach of wanting to externalise any perceived or actual difficulties away from a person, as opposed to seeming to position the 'problem' within them. However, I also came to appreciate that this could be reflective of my own interpretations and experiences of living in a 'neurotypical' world.

To be (different) or not to be, that is the question

During the completion of both the literature review and research paper, I was struck by the core similarities which were observed between the two areas of interest, namely ADHD and ASC. Both are conceptualised as neurodevelopmental conditions which typically appear in childhood and persist into adolescence and adulthood and are considered to be significantly increasing in prevalence. There is also an acknowledgement of the substantial overlap between the two conditions, with them both presenting impairments in social performance and executive functioning and sharing genetic heritability. Subsequently, they have been found to commonly co-occur with one another (Antshel & Russo, 2019).

The overarching similarity which emerged from the thesis paradoxically related to an awareness of 'difference' which was reported by all adults. This 'difference' appeared to stem from not 'fitting-in' to and feeling disconnected from a social world which was attuned to neurotypical normality. In the absence of being able to explain the 'difference', this became pathologized as representing a 'deficit' and was subsequently internalised by adults. Milton (2012) describes this process as a "form of internalised oppression" and highlights the risk of this becoming a self-fulling prophecy which results in a "psycho-emotional disablement" (p. 885). In line with this, it became apparent from adults' accounts in the thesis that living without a diagnosis of a neurodevelopmental condition represented a 'trauma' which initiated a '*fight or flight'* response with the ultimate aim of surviving. Consequently, increased importance was assigned to finding an explanation for the 'difference'.

This response resonated with my own experience of undergoing an assessment of a specific learning need during clinical training and the subsequent difficulties this presented in reaching this point. Upon failing two of my academic assignments, it was advised that my university work would be 'paused' while a cognitive assessment was completed to explore if there were any underlying support needs. On completion of the assessment, I was informed

that while I had a ‘strange and spikey’ cognitive profile, this did not fulfil the criteria for a diagnosis of dyslexia. This resulted in me questioning the explanation for my ‘difference’ and led me to re-evaluate my position on the importance of diagnoses; something which was highlighted by adults in this thesis.

The role of gender

An additional similarity which was noted across both the literature review and research paper was the under-representation of females in prevalence rates of ADHD and ASC. While the disparity in gender ratios of diagnoses declines with age, females remain at risk of being overlooked, resulting in them further internalising the feeling of ‘difference’ and increasing the likelihood of them experiencing co-occurring mental health difficulties which complicate the diagnostic process. Theories around why this gender discrepancy exists appear to predominantly draw on a medical model of disability focusing on symptomology and how ADHD and ASC are expressed ‘differently’ in males and females (Head, McGillivray, & Stokes, 2014; Sedgewick, Hill, Yates, Pickering, & Pellicano, 2016).

More recently, the concept of ‘masking’ or ‘camouflaging’ was introduced in the field of autism research to reflect the coping strategies autistic females develop to ‘fit in’ to social situations and was identified as a contributing factor to delayed diagnoses (Hull et al., 2017). From a social model of disability perspective, this strategy is considered to be an adaptive response to the challenges which the ‘neurotypical’ world presents to ‘neurodiverse’ people. Additionally, the historical context surrounding the construct of ASC indicates that the stereotypical autism presentation was associated with “male and intellectually disabled” and has only started to evolve in recent years (Skuse, 2020, p. 2). This is reflected in the knowledge base which is primarily derived from male samples and used to inform the diagnostic tools for assessing ASC. Therefore, contributing to the underdiagnosis of autistic females.

Areas for future research

In account of the key issues which arose during the completion of this thesis as detailed above, there are specific avenues for future research which are identified for consideration.

Primarily, as the field of autism research continues to receive increased attention, it is of paramount importance that the voices of autistic individuals are captured by involving them as active collaborators in the research process. This echoes the words of Pellicano et al. (2018) who identified autism research as a "shared endeavour" which is directed at meeting the individual needs of "autistic people living in the here and now" (p. 82). This collaborative process would ensure that services are designed to meet the needs of the individuals who require it, with the aim of having a direct positive impact on quality of life.

Additionally, further research exploring the gender differences which exist among the constructs of ADHD and ASC is identified as an area of priority, especially in light of the ongoing under-representation of females in the prevalence rates. While the concept of 'masking' or 'camouflaging' offers a valuable insight into the experiences of autistic females, as it is a relatively new phenomenon it is not yet fully embedded in the literature base, or clinical practice, and would therefore benefit from further research. Alongside this, consideration should be given to the potential influence of social norms and gender role stereotypes on the presentations of both ADHD and ASC, as well as further developing understanding and awareness of these constructs across the lifespan.

ADHD and ASC are considered to represent a "public health concern" and therefore, warrant increased attention from a clinical and research perspective (Antshel & Russo, 2019, p. 1). However, I cannot help but wonder if the 'neurotypical' world has contributed to this 'epidemic':

"Extremes of any combination come to be seen as 'psychiatric deviance'. In the argument presented here, where disorder begins is entirely down to social convention, and where one decides to draw the link across the spectrum." (Milton, 1999)

References

Antshel, K.M., & Russo, N. (2019). Autism Spectrum Disorders and ADHD: Overlapping Phenomenology, Diagnostic Issues, and Treatment Considerations. *Current Psychiatry Reports*, 21-34. doi:10.1007/s11920-019-1020-5

Baker, D.L. (2011). *The Politics of Neurodiversity: Why Public Policy Matters*. Boulder, CO: Lynne Reinner.

Head, A.M., McGillivray, J.A., & Stokes, M.A. (2014). Gender differences in emotionality and sociability in children with autism spectrum disorders. *Molecular Autism, 5*(19). doi:10.1186/2040-2392-5-19

Hull, L., Petrides, K.V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M.C., & Mandy, W. (2017). "Putting on My Best Normal": Social Camouflaging in Adults with Autism Spectrum Conditions. *Journal of Autism and Developmental Disorders*, *47*, 2519-2534. doi:10.1007/s10803-017-3166-5

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, *20*(4), 442-462. doi:10.1177/1362361315588200

Milton, D. (1999). Impaired compared to what? Embodiment and diversity. Retrieved from https://madstudies2014.files.wordpress.com/2015/06/damian-milton-impaird-compared-to-what.pdf

Milton, D. (2012). On the ontological status of autism: the 'double empathy problem'. *Disability & Society*, *27*(6), 883-887. doi:10.1080/09687599.2012.710008

Oliver, M. (1990). *The Politics of Disablement*. London: Macmillan Publishers.

Pellicano, L., Mandy, W., Bölte, S., Stahmer, A., Lounds Taylor, J., & Mandell, D.S. (2018). A new era for autism research, and for our journal. *Autism*, *22*(2), 82-83. doi:10.1177/1362361317748556

Sedgewick, F., Hill, V., Yates, R., Pickering, L., & Pellicano, E. (2016). Gender Differences in the Social Motivation and Friendship Experiences of Autistic and Non-autistic Adolescents. *Journal of autism and developmental disorders*, *46*(4), 1297–1306. doi:10.1007/s10803-015-2669-1

Skuse, D. (2020). Autism – 25 years on: A lot had changed!. *Clinical Child Psychology and Psychiatry*, *0*(0), 1-5. doi:10.1177/1359104520929729

Section Four: Ethics Section

Ethics Application for Research Paper: Adults prior experiences of living with undiagnosed Autism Spectrum Disorder (ASD)

Claire Evans
Trainee Clinical Psychologist
Lancaster University

Correspondence to be addressed to:

Ms Claire Evans
Doctorate in Clinical Psychology
Division of Health Research
Lancaster University
Lancaster
LA1 4YG

Favourable opinion with conditions: NHS ethics committee

[redacted]

Telephone: [redacted]
Facsimile: [redacted]
Email: [redacted]

15 October 2015

[redacted]

Dear [redacted]

Study title: **Adults' prior experiences of living with undiagnosed Autism Spectrum Disorder.**

REC reference: [redacted]
IRAS project ID: [redacted]

The Proportionate Review Sub-Committee of the [redacted] (1) reviewed the above application by correspondence.

We plan to publish your research summary wording for the above study on the [redacted] website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the [redacted]. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

On behalf of the Committee, the Proportionate Review Sub-Committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study:

1. Please change the Poster and Handy Card to reflect that the clinician will be the first point of contact, and forward revised copies of the Poster and Handy Card to the Committee.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at [redacted].

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact [redacted]. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the [redacted]. Guidance on where to register is provided on the [redacted] website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the [redacted] office prior to the start of the study (see "Conditions of the favourable opinion").

Summary of clarification by researcher

Informed consent process and the adequacy and completeness of participant information

The PR Sub-Committee contacted the researcher regarding the issue that informed consent had not been addressed. The approach to potential patients should come from the clinician in charge of the participant's care who would be in a position to judge whether the patient was capable of fully informed consent. The patients could then apply to the researcher.

The researcher replied that the posters and handy cards advertising the research would be distributed directly to clinicians at each of the different sites across the [redacted] as opposed to placing them in the reception areas and/or waiting rooms. That way, clinicians would be able to provide the necessary information about the research to individuals who they considered eligible to take part in the study and provide informed consent.

Approved documents

The documents reviewed and approved were:

Document	Version	Date
Copies of advertisement materials for research participants: Poster	1	13 August 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only): Employers certificate of liability insurance	1	01 August 2015
Interview schedules or topic guides for participants	1	13 August 2015
IRAS Checklist XML: Checklist 06102015		06 October 2015
Letter from sponsor	1	01 October 2015
Handy card advertising the research	1	13 August 2015
Employers certificate of liability insurance 2	1	13 August 2015
Employers certificate of liability insurance 3	1	20 July 2015
Programme team reviewer comments	1	02 February 2015
Research supervisor reviewer comments	1	06 October 2015
Research support office reviewer comments	1	06 October 2015
Participant consent form	1	13 August 2015
Participant information sheet (PIS)	1	13 August 2015
REC Application Form: REC Form 05102015	187204855 9781565	05 October 2015
Research protocol or project proposal: Research protocol and materials	1	13 August 2015
Summary CV for Chief Investigator (CI)	1	21 August 2015
Summary CV for supervisor (student research)	1	02 October 2015

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The [redacted] website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The [redacted] is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the [redacted]A website:
[redacted]

[redacted] **Training**

We are pleased to welcome researchers and R&D staff at our training days – see details at [redacted]

With the Committee's best wishes for the success of this project.

[redacted] **Please quote this number on all correspondence**

Yours sincerely

[redacted]

Enclosures: List of names and professions of members who took part in the review

"After ethical review – guidance for researchers" SL-AR2

Copy to: [redacted]

[redacted]

Attendance at PRS Sub-Committee of the REC meeting by correspondece

Committee Members:

Name	Profession	Present	Notes
[redacted]			
[redacted]			
[redacted]			

Also in attendance:

Name	Position (or reason for attending)
[redacted]	[redacted]

Approval letter conditions met: NHS ethics committee

[redacted]

Telephone: [redacted]
Facsimile: [redacted]
Email: [redacted]

20 October 2015

[redacted]

Dear [redacted]

Study title: **Adults' prior experiences of living with undiagnosed Autism Spectrum Disorder.**

REC reference: [redacted]
IRAS project ID: [redacted]

Thank you for e-submitting the revised documents and your e-mail of 19 October 2015. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 15 October 2015

Documents received

The documents received were as follows:

Document	Version	Date
Copies of advertisement materials for research participants: Poster advertising the research	2	19 October 2015
IRAS Checklist XML: Checklist 19102015		19 October 2015
Handy card advertising the research	2	19 October 2015

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Copies of advertisement materials for research participants: Poster advertising the research		

Employers certificate of liability insurance	1	01 August 2015
Interview schedule	1	13 August 2015
IRAS Checklist XML: Checklist 19102015		19 October 2015
Letter of confirmation of sponsorship	1	01 October 2015
Employers certificate of liability insurance 2	1	13 August 2015
Employers certificate of liability insurance 3	1	20 July 2015
Programme team reviewer comments	1	02 February 2015
Research supervisor reviewer comments	1	06 October 2015
Research support office reviewer comments	1	06 October 2015
Handy card advertising the research	2	19 October 2015
Consent form	1	13 August 2015
Participant Information Sheet	1	13 August 2015
REC Application Form: REC Form 05102015	187204855 9781565	05 October 2015
Research protocol or project proposal: Research protocol and materials	1	13 August 2015
Summary CV for Chief Investigator (CI): CV for CI	1	21 August 2015
Summary CV for supervisor (student research): CV for research supervisor	1	02 October 2015

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

[redacted] **Please quote this number on all correspondence**

Yours sincerely

[redacted]

Copy to: [redacted]

R&D approval letter from NHS trust 1

[redacted]

[redacted]

Date: 4th November 2015

Tel: [redacted]
Fax: [redacted]
Email: [redacted]

[redacted]

Dear [redacted],

Re: NHS Trust Permission to Proceed

Project Reference: [redacted]

Project Title: Adults' prior experiences of living with undiagnosed Autism Spectrum Disorder

I am pleased to inform you that the above project has received research governance permission.

Please take the time to read through this letter carefully and contact me if you would like any further information. You will need this letter as proof of your permission.

Trust R&D permission covers all locations within the Trust; however you will only be allowed to recruit from the sites/services you have indicated in section 3 of the SSI application form. If you would like to expand recruitment into other services in the Trust that are not on the original SSI then you must contact the R&D department immediately to discuss this before doing so.

You also must ensure you have liaised with and obtained the agreement of individual service/ward managers before commencing recruitment in that service and you must contact the relevant service/ward managers prior to accessing the service to make an appointment to visit before you can commence your study in the Trust.

Please make sure that you take your Trust permission letter with you when accessing Trust premises and please include the Trust reference number on any correspondence/emails so that the services are assured permission has been granted.

Recruitment
Researchers must recruit the first participant to [redacted] within 30 days of being granted Trust permission and ensure that studies recruit to time and target.

National guidelines expect Trusts to report the date when the first participant is recruited to the study, therefore please can you provide this information at that point to the R&D department at [redacted]

If you have any concerns with recruitment please contact the R&D team immediately for assistance.

Monitoring
If your study duration is less than one year, you will be required to complete an end of study feedback report on completion. However if your study duration is more than one year, you will be required to complete a short electronic progress report quarterly and an end of study report on completion. As part of this requirement, please ensure that you are able to supply an accurate breakdown of research participant numbers for this Trust (recruitment target, actual numbers recruited). To reduce bureaucracy, progress reporting is kept to a minimum; however, if you fail to supply the information requested, the Trust may withdraw permission.

Honorary Research contracts (HRC)
All researchers with no contractual relationship with any NHS body, who are to interact with individuals in a way that directly affects the quality of their care, should hold Honorary Research NHS contracts. Researchers have a contractual relationship with an NHS body either when they are employees or when they are contracted to provide NHS services, for example as independent practitioners or when they are employed by an independent practitioner (*Research Governance Framework for Health and Social Care,* 2005). If a researcher does not require an HRC, they would require a Letter of Access (LoA). For more information on whether you or any of your research team will require an HRC or LoA please liaise with this office. It is your responsibility to inform us if any of your team do not hold Honorary Research NHS contracts/Letters of Access.

Staff involved in research in NHS organisations may frequently change during the course of a research project. Any changes to the research team or any changes in the circumstances of researchers that may have an impact on their suitability to conduct research MUST be notified to the Trust immediately by the Principal Investigator (or nominated person) so that the necessary arrangements can be put in place

Research Governance
The Research Governance Sponsor for this study is [redacted]. Whilst conducting this study you must fully comply with the Research Governance Framework. This can be accessed at:
http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4108962&chk=Wde1Tv
For further information or guidance concerning your responsibilities, please contact your research governance sponsor or your local R&D office.

Risk and Incident Reporting
Much effort goes into designing and planning high quality research which reduces risk; however untoward incidents or unexpected events (i.e. not noted in the protocol) may occur in any research project. Where these events take place on Trust premises, or involve

Trust service users, carers or staff, you must report the incident within 48 hours via the incident reporting system. If you are in any doubt whatsoever whether an incident should be reported, please contact us for support and guidance.

Regardless of who your employer is when undertaking the research within [redacted] you must adhere to Trust policies and procedures at all times.

Confidentiality and Information Governance
All personnel working on this project are bound by a duty of confidentiality. All material accessed in the Trust must be treated in accordance with the Data Protection Act (1998). For good practice guidance on information governance contact us.

Protocol / Substantial Amendments
You must ensure that the approved protocol is followed at all times. Should you need to amend the protocol, please follow the Research Ethics Committee procedures and inform all NHS organisations participating in your research.

Final Reports
At the end of your research study, we will request a final summary report so that your findings are made available to local NHS staff. The details from this report may be published on the NHS Trust internet site to ensure findings are disseminated as widely as possible to stakeholders.

On behalf of this Trust, may I wish you every success with your research. Please do not hesitate to contact us for further information or guidance.

Yours sincerely,

[redacted]

Cc: [redacted]
Trust

R&D approval letter from NHS trust 2

Standardised Process for Electronic Approval of Research

[redacted]

[redacted]

Tel: [redacted]

Email: [redacted]

WE ARE SOCIAL

Dear [redacted]

Information for ID Badge if required:
Research Project Ref No: [redacted]
Expiry Date: 29/08/16
You must take this letter with you.

Re: NHS Permission for Research

Project Reference: [redacted]
REC Reference Number: [redacted]
IRAS Reference Number: [redacted]
Sponsor: [redacted]

Project Title: Adults' prior experiences of living with undiagnosed Autism Spectrum Disorder
Date of Permission: 21 October 2015

Further to your request for permission to conduct the above research study at this Trust, we are pleased to inform you that this Trust has given NHS permission for the research. **Your NHS permission to conduct research at this site is only valid upon receipt of a signed 'Conditions for NHS Permission Reply Slip' which is enclosed**.

Please take the time to read the attached conditions for NHS permission. Please contact the R&D Office should you require any further information. You will need this letter as proof of NHS permission. Please note when contacting the R&D office about your study you must always provide the project reference numbers provided above.

NHS permission for the above research has been granted on the basis described in the IRAS application form, Protocol and supporting documentation.

The documents reviewed were:

Document	Version	Date
Protocol	1.0	13/08/15
Participant Information Sheet	1.0	13/08/15
Participant Consent Form	1.0	13/08/15
IRAS R&D Form	5.0	02/10/15
IRAS SSI Form	5.0	18/09/15

The Trust is committed to safeguarding children, young people and vulnerable adults and requires all staff and volunteers to share this commitment.

[redacted]

Chair: [redacted] **Chief Executive:** [redacted]

REC letter giving favourable ethical opinion		20/10/15
Poster and handy card	2.0	19/10/15

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework, ICH GCP (if applicable), and NHS Trust policies and procedures. Permission is only granted for the activities for which a favourable opinion has been given by the Ethics Committee.

Permission covers all locations within the Trust, however, you should ensure you have liaised with and obtained the agreement of individual service/ward managers before commencing your research.

We would like to point out that hosting research studies incurs costs for the Trust such as: staff time, usage of rooms, arrangements for governance of research. We can confirm that in this instance we will not charge for these. However, we would like to remind you that Trust costs should be considered and costed at the earliest stage in the development of any future proposals.

May I wish you every success with your research.

Yours sincerely

[redacted]

cc : Sponsor: [redacted]

Enc: Approval Conditions Leaflet
Induction & ID Badge Information

Study Ref Number: [redacted]
Study Title: Adults' prior experiences of living with undiagnosed ASD

Conditions for NHS Permission Reply Slip

In order for your NHS permission to be valid, please return this form to the address below to confirm that you have read and understood the conditions of NHS permission to conduct research.

1. I confirm that I have read and understand my duties and responsibilities as part of the conditions for permission to conduct research at this site.

2. I understand that I must submit the following information to the Trust's R&D department:

- Recruitment figures on a monthly basis
- New researcher details prior to them commencing on the research project
- Any amendments submitted to the Ethics Committee
- Changes to the status of the research project
- Any urgent safety measure incorporated
- Untoward Incidents and Unexpected Events within 24 hours of their occurrence
- A final summary report
- A copy of the Ethics letter confirming receipt of the End of Study Declaration

3. I understand I must complete and return in a timely manner any audit forms sent to me by the Trust.

4. I understand that I must gain permission from the trust in order to publish or place information of the current research into the public domain.

Signed…….

PRINT NAME……..

Date…….....

Estimated Start date to commence research at this Trust …….

Which site will you approach first? …….

Expected recruitment target at this Trust? …….

Please return to: [redacted]

R&D approval letter from NHS trust 3

[redacted]

[redacted]

[redacted]

5th November, 2015

[redacted]

NHS to NHS Letter of Access for Research

2015/32: Adults' prior experiences of living with undiagnosed Autism Spectrum Disorder.

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this NHS organisation that the necessary pre-engagement check are in place in accordance with the role you plan to carry out in this organisation. This letter confirms your right of access to conduct research through [redacted] for the purpose and on the terms and conditions set out below. This right of access commences on the 5th November, 2015 and ends on the nd October 2013 and ends on the 31st August, 2016*unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to [redacted] premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through [redacted], you will remain accountable to your employer Lancashire Care NHS Foundation Trust but you are required to follow the reasonable instructions of [redacted] who is the link for the study.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with [redacted] policies and procedures, which are on the Trust website or available to you upon request, and the Research Governance Framework.

You are required to co-operate with [redacted] in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while [redacted]. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and the Trust's R&D department prior to commencing your research role at the Trust.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice [redacted] and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

[redacted] will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or suitability to work with adults or children, or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the NHS organisation that employs you through its normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

[redacted]

* end date of substantive contract

cc: [redacted]

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
Adults' prior experiences of living with undiagnosed ASD

1. Is your project research?

(●) Yes ( ) No

2. Select one category from the list below:

( ) Clinical trial of an investigational medicinal product

( ) Clinical investigation or other study of a medical device

( ) Combined trial of an investigational medicinal product and an investigational medical device

( ) Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice

( ) Basic science study involving procedures with human participants

( ) Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology

(●) Study involving qualitative methods only

( ) Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)

( ) Study limited to working with data (specific project only)

( ) Research tissue bank

( ) Research database

If your work does not fit any of these categories, select the option below:

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation? ( ) Yes (●) No

b) Will you be taking new human tissue samples (or other human biological samples)? ( ) Yes (●) No

c) Will you be using existing human tissue samples (or other human biological samples)? ( ) Yes (●) No

3. In which countries of the UK will the research sites be located?*(Tick all that apply)*

- [x] England
- [ ] Scotland
- [ ] Wales
- [ ] Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- (●) England
- ( ) Scotland
- ( ) Wales
- ( ) Northern Ireland
- ( ) This study does not involve the NHS

4. Which review bodies are you applying to?

- [ ] HRA Approval
- [x] NHS/HSC Research and Development offices
- [ ] Social Care Research Ethics Committee
- [x] Research Ethics Committee
- [ ] Confidentiality Advisory Group (CAG)
- [ ] National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

(●) Yes ( ) No

5a. Are all the research costs and infrastructure costs for this study provided by an NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC) or NIHR Research Centre for Patient Safety & Service Quality in all study sites?

( ) Yes (●) No

If yes and you have selected HRA Approval in question 4 above, your study will be processed through HRA Approval.

If yes, and you have not selected HRA Approval in question 4 above, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP).

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) support and inclusion in the NIHR Clinical Research Network (CRN) Portfolio? Please see information button for further details.

( ) Yes (●) No

If yes, you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form immediately after completing this project filter and before submitting other applications. If you have selected HRA Approval in question 4 above your study will be processed through HRA Approval. If not, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP).

6. Do you plan to include any participants who are children?

( ) Yes (●) No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

( ) Yes (●) No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory

Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes ◉ No

9. Is the study or any part of it being undertaken as an educational project?

◉ Yes ○ No

Please describe briefly the involvement of the student(s):
The project is being undertaken as part of the Chief Investigator's Doctorate in Clinical Psychology.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

◉ Yes ○ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

○ Yes ◉ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

○ Yes ◉ No

Integrated Research Application System
Application Form for Research involving qualitative methods only

NHS
Health Research Authority

Application to NHS/HSC Research Ethics Committee

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Adults' prior experiences of living with undiagnosed ASD

Please complete these details after you have booked the REC application for review.

REC Name:

REC Reference Number: **Submission date:**

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

Adults' prior experiences of living with undiagnosed Autism Spectrum Disorder.

A2-1. Educational projects

Name and contact details of student(s):

Student 1

Title Forename/Initials Surname [redacted]
Address [redacted]
Post Code [redacted]
E-mail [redacted]
Telephone
Fax

Give details of the educational course or degree for which this research is being undertaken:
Name and level of course/ degree:

[redacted]

Name of educational establishment:
[redacted].

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title Forename/Initials Surname
	[redacted]
Address	[redacted]
	[redacted]
	[redacted]
Post Code	[redacted]
E-mail	[redacted]
Telephone	[redacted]
Fax	

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	**Academic supervisor(s)**
Student 1 [redacted]	☐ [redacted]

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- (●) Student
- ( ) Academic supervisor
- ( ) Other

A3-1. Chief Investigator:

	Title Forename/Initials Surname
	[redacted]
Post	[redacted]
Qualifications	[redacted]
	[redacted]
Employer	[redacted]
Work Address	[redacted]
	[redacted]
	[redacted]
Post Code	[redacted]
Work E-mail	[redacted]
* Personal E-mail	

Work Telephone
* Personal Telephone/Mobile
Fax

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.

Title Forename/Initials Surname
[redacted]
Address [redacted]
[redacted]
[redacted]
Post Code [redacted]
E-mail [redacted]
Telephone [redacted]
Fax

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):
Sponsor's/protocol number:
Protocol Version:
Protocol Date:
Funder's reference number:
Project website:

Additional reference number(s):

Ref.Number Description	Reference Number

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

○ Yes ◉ No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language*

easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.

The definition of Autism Spectrum Disorder (ASD) has recently been revised in the publication of the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) in May 2013 (American Psychiatric Association, 2013). ASD is now used as a single umbrella term to represent a continuum on which individuals' will fall (American Psychiatric Association, 2013).

In terms of the occurrence of ASD, research suggests that the number of children diagnosed with ASD has gradually increased over the past 20 years, with one in a hundred children now being diagnosed with ASD (Glazzard & Overall, 2012). This is compared to earlier estimates of 4 to 6 cases per 10,000 people in 1980 (Fombonne, 2001). It was during this time when children, who met the diagnostic criteria for ASD, were found to be often misdiagnosed as having an 'intellectual development disorder'. This resulted in children being segregated from their peers, excluded from classrooms and in some cases, institutionalised (Glazzard & Overall, 2012).

A search of the literature base indicates that qualitative research in the area of ASD has neglected to consider individuals' prior experiences of living with undiagnosed ASD. Existing research indicates that living with undiagnosed ASD can result in individuals experiencing secondary difficulties including anxiety and depression (Spicer, 1998).
Therefore, the present study aims to build on the existing literature base and gain insight into what has been an overlooked area by exploring individuals' prior experiences of living with undiagnosed ASD.

A qualitative research design involving semi-structured interviews will be used to explore individuals' experiences of living with undiagnosed ASD. Participants will be recruited from three sites across [redacted]; [redacted] invited to take part in an interview which will last up to one hour.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Ethical approval for the study will initially be sought from [redacted], after which R&D approval will be sought from the [redacted]. The main ethical issues identified include informed consent, confidentiality and risk of distress to participants.

Participants who express an interest to take part in the study will initially be required to provide their informed consent and provided with an information sheet (Appendix A) and asked to sign a consent form (Appendix B) confirming their wish to participate in the research. Participants will be informed that their participation in the study is voluntary and as such, they have the right to withdraw from the research at any point during the interview and up to two weeks after the interview, at which point data analysis will have begun. Participants will be informed that any information collected during this period will be deleted and/or destroyed if they do choose to withdraw from the study.

In addition to the above, a number of steps will be taken throughout the research process to ensure that participants' information remains confidential. Initially, the Chief Investigator will not have access to the names and contact details of potential participants. Participants will be required to 'opt-in' to the research; contacting the Chief Investigator directly to express an interest in taking part in the study, at which point they will provide their contact details. The only exception to this is if participants 'opt-in' to the research via the clinician responsible for their care and request to be contacted by the Chief Investigator directly. In these circumstances, the clinician would seek verbal consent from the participant for their contact details to be shared with the Chief Investigator.

Participants will be informed that their participation in the study will remain confidential. That is, any identifying information e.g. participants' names will only be known to the Chief Investigator after they have expressed an interest to, or decided to take part in the study, and that these will be anonymised when the interviews are transcribed by assigning each participant with a pseudonym of their choice. Furthermore, participants will be advised that all identifiable information disclosed during the interview will be anonymised during transcription. Participants will be informed that the only exception to this is if the Chief Investigator thought that what the participant said in the interview indicates that they or someone else is at significant risk of harm. At which point, the Chief Investigator would have to break confidentiality and inform another person, primarily the field supervisor, a clinical psychologist and/or the clinician involved in the participants care if applicable. This is outlined in both the participant information sheet

(Appendix A) and consent form (Appendix B) and participants will be reminded about the limits of confidentiality prior to the commencement of the interviews.

Furthermore, in the event that a participant becomes distressed during the interview, they will be offered the opportunity to take a break and asked if they would like to continue, or to terminate the interview. If the participant expresses that they would like to continue with the interview, they will be advised that they can terminate it at any point. If a participant becomes distressed as a result of taking part in the interview they will initially be directed to the list of support services available in the participant information sheet (Appendix A). However, if a participant becomes distressed and presents as a risk to themselves or others, then it is the responsibility of the Chief Investigator to inform another person or persons. This would primarily be the field supervisor, a clinical psychologist and/or the clinician involved in the participants care if applicable. For participants who choose to be interviewed at their home, the local mental health assessment team would be contacted should the participant present as a risk to themselves or others.

In addition, if participants wish to make a complaint or raise any concerns regarding the study itself, then they will be directed to the contact details contained within the participant information sheet (Appendix A). Alternatively, if participants wish to make a complaint or raise concerns about the service itself, then participants will be provided with a leaflet which includes information about the relevant trust's complaints procedure.

At the end of each interview, participants will initially be thanked for their time and participation and informed of the proposed dissemination process for the research. Participants will have the option of receiving a shortened report outlining the results of the study or alternatively, they will be able to attend a presentation where the results of the research will be summarised and presented accordingly.

In addition the above, it is noted that as participants are offered the opportunity to be interviewed in their homes, this may place the Chief Investigator at some risk. As an employee of [redacted], the Chief Investigator is responsible for adhering to the [redacted] Lone Worker Policy.

In terms of data management, the audio recordings of the interviews will be kept for a maximum of six months following the interview itself in order to allow time for the interview to be transcribed and checked, after which point they will be destroyed. The electronic transcripts of the interviews will be transferred electronically using a secure method that is supported by the university to the research co-ordinator and stored in a secure location by the university in a password protected file for a maximum of 10 years, in accordance with the [redacted] guidelines regarding the ethical storage of data. At the end of this period, they will be destroyed by a staff member responsible in the [redacted]

In line with the above, any paper files (e.g. consent forms) used by the Chief Investigator during the study will initially be stored securely in a locked cabinet. These will then be scanned and stored securely by the university in a password protected file for a maximum of 10 years. After this point, they will be destroyed by a staff member responsible in the [redacted]. Audio recordings and electronic transcripts used by the Chief Investigator will be uploaded and stored onto the Chief Investigator's personal file space on the [redacted].

A6-3. Proportionate review of REC application *The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6-2, you consider there are ethical issues that require consideration at a full REC meeting.*

(●) Yes - proportionate review ( ) No - review by full REC meeting

Further comments (optional):

Note: This question only applies to the REC application.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply*:

- [ ] Case series/ case note review Case
- [ ] control
- [ ] Cohort observation

- [ ] Controlled trial without randomisation
- [ ] Cross-sectional study
- [ ] Database analysis
- [ ] Epidemiology Feasibility/
- [ ] pilot study Laboratory
- [ ] study Metanalysis
- [ ] Qualitative research
- [x] Questionnaire, interview or observation study
- [ ] Randomised controlled trial
- [ ] Other (please specify)
- [ ]

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

The present study aims to explore adults' prior experiences of living with undiagnosied ASD.

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

To explore adults' experiences of receiving a diagnosis of ASD in adulthood, including what has led them to pursue and receive a diagnosis.

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

Autism Spectrum Disorder (ASD) has traditionally been used an umbrella term to refer to five developmental disorders including autism, Aspergers syndrome, pervasive developmental disorder, Rett's syndrome and childhood disintegrative disorder (American Psychiatric Association, 2000; Hebert & Koulouglioti, 2010; Gabovitch & Curtin, 2009; Smith & Elder, 2010). The definition of ASD, including the diagnostic criterion which accompanies it, has since been revised in the publication of the DSM-V in May 2013 (American Psychiatric Association, 2013). Within the DSM-V, Aspergers syndrome, pervasive developmental disorder, Rett's syndrome and childhood disintegrative disorder have been collapsed and incorporated under the single umbrella term, ASD. This term is used to represent a continuum on which individuals' will fall and accounts for the variability in symptoms and presentation, thus potentially providing a more accurate framework for diagnosing individuals (American Psychiatric Association, 2013).

In terms of the occurrence of ASD, research suggests that the number of children diagnosed with ASD has gradually increased over the past 20 years, with one in a hundred children now being diagnosed with ASD (Glazzard & Overall, 2012). This represents a significant increase in the occurrence of ASD when compared to earlier estimates of 4 to 6 cases per 10,000 people in 1980 (Fombonne, 2001 cited in Gabovitch & Curtin, 2009). It was during this time when children, who met the diagnostic criteria for ASD, were found to be often misdiagnosed as having an 'intellectual development disorder'. This resulted in children being segregated from their peers, excluded from classrooms and in some cases, institutionalised (Glazzard & Overall, 2012). Due to the marked increase in the occurrence of ASD and uncertainty with regards the cause of ASD and the effectiveness of treatment, the construct of ASD received a considerable amount of attention in recent years (Zhou & Chun Li, 2014).

A preliminary search of the literature base indicates that qualitative research in the area of ASD has predominantly focused on exploring parents and/or siblings experiences of caring for, and/or living with, an individual with a diagnosis of ASD (Bromley, Hare, Davison & Emerson, 2004; Glazzard & Overall, 2012; Mascha & Boucher, 2006). Research has so far neglected to consider individuals' prior experiences of living with undiagnosed ASD, despite this being highlighted by Glazzard and Overall (2012) as a potentially challenging experience for those involved. This is in line with existing research which indicates that living with undiagnosed ASD can result in individuals experiencing secondary difficulties including anxiety and depression (Nylander, Holmqvist, Jönsson, Gustafson & Gillberg, 2010; Spicer, 1998).

Therefore, it is proposed that any attempts to better understand individuals' prior experiences of living with undiagnosed ASD is likely to have implications for future research and clinical practice. That is, it will inform clinicians' regarding the potential psychological support needs of individuals who have had experience of living with undiagnosed ASD. In addition, it is hoped that exploring what has led individuals to pursue and receive a diagnosis of ASD in adulthood will not only inform clinicians' understanding of the process of seeking a diagnosis of ASD, but also help in

the review and development of appropriate service pathways. Therefore, the present study aims to build on the existing literature base and gain insight into what has been an overlooked area by exploring individuals' prior experiences of living with ASD, including what has led them to pursue and receive a diagnosis of ASD in adulthood.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

A qualitative research design is identified as being the most appropriate method of inquiry for this present study as it will allow the Chief Investigator to explore the experiences of individuals who have received a diagnosis of ASD in adulthood. Semi-structured interviews will be conducted as these provide a flexible source of data collection to develop insights into the individuals' lived experiences. Participants who express an interest to take part in the study will be invited to take part in an interview which will last up to one hour and informed that they can be interviewed in a location which is most convenient for them, whether that be at their home or in the clinic at a time and date which is most suitable for them.

The information collected from the participants interviews will be analysed using Interpretative Phenomenological Analysis (IPA). This model of analysis is favoured as it offers a flexible approach to exploring and analysing qualitative data and will allow the Chief Investigator to examine the lived experiences of individuals who have received a diagnosis of ASD in adulthood, specifically in terms of how they make sense of these experiences and what meanings these hold for the individuals concerned (Smith & Osborn, 2008).

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- [x] Design of the research
- [ ] Management of the research
- [ ] Undertaking the research
- [x] Analysis of results
- [x] Dissemination of findings
- [ ] None of the above

Give details of involvement, or if none please justify the absence of involvement.
In the early stages of planning the research, I, the Chief Investigator consulted with a (past) service user who had previously accessed mental health services and received a diagnosis of ASD in adulthood. She was able to provide very helpful advice, specifically in terms of the design and content of the interview schedule, and poster and handy 'pocket' card which advertise the research.

In addition to the above, at the end of the interviews, participants will be informed of the proposed dissemination process for the research. That is, participants will have the option of receiving a shortened report outlining the results of the study or alternatively, they will be able to attend a presentation where the results of the research will be summarised and presented accordingly. In addition, it is envisaged that I, the Chief Investigator will return the final results (superordinate themes) of the analysis to participants for their feedback.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

Participants will be individuals who have received a diagnosis of ASD in adulthood. In order to be eligible for the study, participants must be aged 16 years old or older as this is the minimum age at which each of the services accepts referrals for assessments of ASD. Participants must also have received a diagnosis of ASD within the last 12 months.

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

Individuals with a diagnosis of a Learning Disability (LD) who have received a diagnosis of ASD in adulthood will not

be eligible to take part in the study due to the different experiences they may have encountered, particularly in terms of schooling. In addition, individuals who have received a diagnosis of ASD in childhood will not be included in the present study. Due to monetary and time restraints of the present study, individuals who are not fluent in English will also be excluded from the study.

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Seeking informed consent	1	0	10-15 minutes	It is the responsibility of the Chief Investigator to gain informed consent. This will take place prior to the commencement of the interviews, which will be conducted at a location most convenient for the participants.
Interviews	1	0	Up to 60 minutes	The Chief Investigator will conduct the interviews and these will take place at a location most convenient for the participants.

A21. How long do you expect each participant to be in the study in total?

This predominantly depends on what point participants decide that they would like to take part in the study. However, the maximum duration of participation is calculated at approximately 10 months. This is calculated from when participants give informed consent prior to the commencement of the interview, until their last contact with the research team at the proposed dissemination process of the project.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

It is recognised that the present study may have the potential to cause participants to experience distress as a result of their participation, specifically in terms of exploring their experiences of living with undiagnosed ASD and the challenges this may have presented.

In the event that a participant becomes distressed during the interview, they will be offered the opportunity to take a break and asked if they would like to continue, or to terminate the interview. If the participant expresses that they would like to continue with the interview, they will be advised that they can terminate it at any point.

If a participant becomes distressed as a result of taking part in the interview they will initially be directed to the list of support services available in the participant information sheet (Appendix A). However, if a participant becomes distressed and presents as a risk to themselves or others, then it is the responsibility of the Chief Investigator to inform another person or persons. This would primarily be the field supervisor ([redacted]) and/or the clinician involved in the participants care if applicable. For participants who choose to be interviewed at their home, the local mental health assessment team would be contacted should the participant present as a risk to themselves or others. This is outlined in both the participant information sheet (Appendix A) and consent form (Appendix B) and participants will be reminded of the limits of confidentiality prior to the commencement of the interviews.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

◉ Yes ○ No

If Yes, please give details of procedures in place to deal with these issues:

As noted previously, in the event that a participant becomes distressed during the interview, they will initially be offered the opportunity to take a break and asked if they would like to continue, or to terminate the interview. If the participant expresses that they would like to continue with the interview, they will be advised that they can terminate it at any point.

If a participant becomes distressed as a result of taking part in the interview they will initially be directed to the list of support services available in the participant information sheet (Appendix A). However, if a participant becomes distressed and presents as a risk to themselves or others, then it is the responsibility of the Chief Investigator to inform another person, primarily the field supervisor ([redacted]) and/or the clinician involved in the participants care if applicable. For participants who choose to be interviewed at their home, the local mental health assessment team would be contacted should the participant present as a risk to themselves or others. This is outlined in both the participant information sheet (Appendix A) and consent form (Appendix B) and participants will be reminded about the limits of confidentiality prior to the commencement of the interviews.

A24. What is the potential for benefit to research participants?

There are no direct benefits to participants in taking part in the study.

A26. What are the potential risks for the researchers themselves? *(if any)*

As participants are offered the opportunity to be interviewed in their homes, it is recognised that this may place the Chief Investigator at some risk. As an employee of [redacted], the Chief Investigator is responsible for adhering to the [redacted] Lone Worker Policy and informing another 'buddy' colleague of when and where the interviews will take place. It is also the responsibility of the Chief Investigator to contact the 'buddy' upon arriving and after leaving the participant's home and to agree a time by which the 'buddy' should try to make contact with the Chief Investigator if they have not heard from them. If this proves unsuccessful, the 'buddy' will then inform the police of the Chief Investigator's whereabouts.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used?*For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

The Chief Investigator will not have access to the names and contact details of potential participants. Participants will be required to 'opt-in' to the research; contacting the Chief Investigator directly to express an interest in taking part in the study, at which point they will provide their contact details. The only exception to this is if participants 'opt-in' to the research via the clinician responsible for their care and request to be contacted by the Chief Investigator directly. In these circumstances, the clinician would seek verbal consent from the participant for their contact details to be shared with the Chief Investigator.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

○ Yes ◉ No

Please give details below:

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

◉ Yes ○ No

If Yes, please give details of how and where publicity will be conducted, and enclose copy of all advertising material

(with version numbers and dates).

A poster (Appendix D) advertising the research and providing information about the study, including the contact details of the Chief Investigator, will be placed in the waiting rooms in each of the different sites across the three NHS trusts; [redacted] Handy 'pocket' cards (Appendix E) including information about the study and the contact details of the Chief Investigator will also be distributed to each of the different sites and placed at the reception areas and in the waiting rooms.

In addition to the above, information packs including a copy of the participant information sheet (Appendix A) and a copy of the consent form (Appendix B) for the study will be distributed to the different sites across the [redacted] which participants will be able to request from the reception staff or the clinician who is responsible for their care. Clinicians at each of the different sites will also distribute information packs to individuals who fall within the inclusion criteria for the study and who express an interest to take part in the research.

A29. How and by whom will potential participants first be approached?

As noted previously, participants will be required to 'opt-in' to the research; contacting the Chief Investigator directly to express an interest in taking part in the study. The only exception to this is if participants 'opt-in' to the research via the clinician responsible for their care and request to be contacted by the Chief Investigator directly. In these circumstances, the clinician would seek verbal consent from the participant for their contact details to be shared with the Chief Investigator.

In addition to the above, participants who express an interest to take part in the study after being made aware of the research at the ASD post-diagnostic support groups, will be given an additional 5-7 days to consider their participation in the study prior to arranging an interview.

All participants who decide that they would like to take part in the study will be informed, prior to the commencement of the interviews, that their participation is voluntary and reminded that they have the right to withdraw from the research at any point during the interview and up to two weeks after the interview, at which point data analysis will begin. Participants will be informed that any information collected during this period will be deleted and/or destroyed if they do choose to withdraw from the study. This is outlined in the consent form (Appendix B).

A30-1. Will you obtain informed consent from or on behalf of research participants?

(●) Yes ( ) No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

Prior to the commencement of the interviews, participants will initially be provided with a participant information sheet (Appendix A) and given the opportunity to ask any questions they may have. If participants express that they would like to take part in the study, they will be required to provide their informed consent and asked to sign a consent form (Appendix B) confirming their wish to participate in the research.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

(●) Yes ( ) No

A31. How long will you allow potential participants to decide whether or not to take part?

As noted previously, participants will be required to 'opt-in' to the research should they wish to take part; contacting the Chief Investigator directly to express an interest. The only exception to this is if participants 'opt-in' to the research via the clinician responsible for their care and request to be contacted by the Chief Investigator directly. In these

circumstances, the clinician will seek verbal consent from the participant for their contact details to be shared with the Chief Investigator. They will then be informed of the purpose of the study via telephone contact and advised that they can be interviewed in a location which is most convenient for them, whether that be at their home or in the clinic at a time and date most suitable for them.

Participants who express an interest to take part in the study from the second phase of recruitment, in which the Chief Investigator attends ASD post-diagnostic support groups which are ran at each of the three sites, will be given an additional 5-7 days to consider their participation in the study prior to arranging an interview.

Once participants have decided that they would like to take part in the study, the Chief Investigator will then travel to the participants chosen location to conduct the interview. Prior to the commencement of the interviews, participants will be provided with a copy of the participant information sheet (Appendix A) and given the opportunity to ask any questions they may have.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? *(e.g. translation, use of interpreters)*

Due to monetary and time restraints of the present study, individuals who are not fluent in English will be excluded from the study.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

- ○ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- ◉ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- ○ The participant would continue to be included in the study.
- ○ Not applicable – informed consent will not be sought from any participants in this research.
- ○ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

The participant would initially be withdrawn from the study and no additional information would be collected. However, as outlined in the participant information sheet (Appendix A) and consent form (Appendix B), participants are assigned with a pseudonym of their choice when their interviews are transcribed and the information from the interviews is pooled together and incorporated into themes. Therefore, it may not be possible for the participant's information to be withdrawn however, every attempt will be made to extract the participant's data up to the point of publication.

If you plan to retain and make further use of identifiable data/tissue following loss of capacity, you should inform participants about this when seeking their consent initially.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? *(Tick as appropriate)*

- ☐ Access to medical records by those outside the direct healthcare team
- ☐ Electronic transfer by magnetic or optical media, email or computer networks
- ☐ Sharing of personal data with other organisations

☐ Export of personal data outside the EEA

☑ Use of personal addresses, postcodes, faxes, emails or telephone numbers Publication of direct quotations from respondents

☑ Publication of data that might allow identification of individuals Use of audio/visual recording devices

☐ Storage of personal data on any of the following:

☑ Manual files including X−rays NHS computers

☑ Home or other personal computers University computers

☑ Private company computers Laptop computers

☐

☐

☑

☐

☐

Further details:
The use of personal telephone numbers will be required for those participants who express a wish to take part in the study via the clinician responsible for their care and who request to be contacted by the Chief Investigator directly.
Personal addresses will also be required for those participants who choose to be interviewed at their home.

In addition to the above, as outlined in both the participant information sheet (Appendix A) and consent form (Appendix B), participants interviews will be audio recorded on a digital audio recording device and anonymised direct quotations from participants may be used in the reports or publications from the study. As the digital audio recording device cannot be encrypted, the audio recordings of the interviews will be uploaded from the device onto the Chief Investigator's personal file space on the [redacted], after which point they will be immediately deleted from the recording device. In the meantime, the audio recording device will be stored securely with the Chief Investigator. The audio recordings will be kept for a maximum of six months following the interview itself in order to allow time for the interview to be transcribed and checked, after which point they will be destroyed.

Audio recordings and transcripts used by the Chief Investigator will be stored on the Chief Investigator's personal file space on the [redacted]. Any paper files (e.g. consent forms) used by the Chief Investigator during the study will be scanned and stored securely by the university in a password protected file for a maximum of 10 years.
After this point, they will be destroyed by a staff member responsible in the [redacted]

The above information is outlined in the participant information sheet (Appendix A) and/or consent form (Appendix B).

A38. How will you ensure the confidentiality of personal data? *Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

In order to ensure that participants' information remains confidential, a number of steps will be taken throughout the research process. Initially, participants will be informed that their participation in the study will remain confidential. That is, any identifying information e.g. participants' names will only be known to the Chief Investigator after they have expressed an interest to, or decided to, take part in the study, and that these will be anonymised when the interviews are transcribed by assigning each participant with a pseudonym of their choice.

Participants will be informed that the only exception to ensuring confidentiality is if I, the Chief Investigator thought that what the participants said in the interview indicates that they or someone else is at significant risk of harm. At this point, confidentiality would be breached and another person or persons would be informed, primarily the field supervisor (a clinical psychologist) and/or the clinician involved in the participants care if applicable. For participants who choose to be interviewed at their home, the local mental health assessment team would be contacted should the participant present as a risk to themselves or others. This is outlined to participants in both the participant information sheet (Appendix A) and consent form (Appendix B) and participants will be reminded of the limits of confidentiality prior to the commencement of the interviews.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

As noted previously, participants will be informed that their participation in the study will remain confidential in that

personal information will only be known to the Chief Investigator.

The research supervisor and field supervisor involved in the project will be given access to anonymised transcripts for supervisory support.

Storage and use of data after the end of the study

A43. How long will personal data be stored or accessed after the study has ended?

- (●) Less than 3 months
- ( ) 3 – 6 months
- ( ) 6 – 12 months
- ( ) 12 months – 3 years
- ( ) Over 3 years

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

(●) Yes ( ) No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.
Participants will be informed that they will be reimbursed for travel expenses up to the value of £20 should they wish to travel to meet the Chief Investigator for the interview.

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

( ) Yes (●) No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

( ) Yes (●) No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

( ) Yes (●) No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

( ) Yes (●) No

Please give details, or justify if not registering the research.
No suitable register exists for research conducted as part of the [redacted]

Registration of research studies is encouraged wherever possible.
You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

- [x] Peer reviewed scientific journals
- [x] Internal report
- [x] Conference presentation
- [ ] Publication on website
- [ ] Other publication
- [ ] Submission to regulatory authorities
- [ ] Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- [ ] No plans to report or disseminate the results
- [ ] Other (please specify)

A53. Will you inform participants of the results?

(•) Yes ( ) No

Please give details of how you will inform participants or justify if not doing so.
At the end of each interview, participants will be informed of the proposed dissemination process for the research. That is, participants will have the option of receiving a shortened report outlining the results of the study or alternatively, they will be able to attend a presentation where the results of the research will be summarised and presented accordingly.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? *Tick as appropriate:*

- [ ] Independent external review
- [ ] Review within a company
- [ ] Review within a multi−centre research group
- [x] Review within the Chief Investigator's institution or host organisation
- [ ] Review within the research team
- [x] Review by educational supervisor
- [ ] Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:
The scientific quality of the proposed research has been reviewed within the [redacted], by the research supervisor and research support office at [redacted].

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size: 12
Total international sample size (including UK): 0
Total in European Economic Area: 0

Further details:
A total of up to 12 participants will be recruited from different sites across three NHS trusts [redacted].
Participants will be individuals who have received a diagnosis of ASD in adulthood. In order to be eligible for the study, participants must be aged 16 years old or older as this is the minimum age at which each of the services accepts referrals for assessments of ASD. Participants must also have received a diagnosis of ASD within the last 12 months.

Purposive sampling will be used in order to recruit a more closely defined and homogenous group of participants which is in line with the proposed method of analysis, Interpretative Phenomenological Analysis (IPA).

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

A sample size of up to 12 was considered sufficient in order to offer a detailed insight into the experiences of individuals who have received a diagnosis of ASD in adulthood. However, it is acknowledged that the proposed method of analysis, IPA can be conducted on smaller sample sizes (Smith & Osborn, 2008).

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

IPA will be used to analyse the data collected from the participants' interviews. This model of analysis is favoured as it offers a flexible approach to exploring and analysing qualitative data and can potentially produce a richer account of the data set (Smith & Osborn, 2008).

As the research is concerned with exploring the experiences of individuals who have received a diagnosis of ASD in adulthood, a critical realist stance will be adopted to the collection and analysis of the data. This will allow the Chief Investigator to examine the individual lived experiences of the participants, specifically in terms of how they make sense of these experiences and what meanings these hold for the individuals concerned (Smith & Osborn, 2008). This will involve an in-depth engagement with, and detailed analysis of, the individual transcripts from which themes will emerge and be explored in relation to the topic areas identified in the interview schedule (Appendix C). The connections between the themes will be explored in terms of similarity and difference, convergence and divergence (Smith & Osborn, 2008) and then eventually grouped under broader themes known as 'superordinate themes'.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co−applicants, protocol co−authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title Forename/Initials Surname
	[redacted]
Post	[redacted]
Qualifications	
Employer	[redacted]
Work Address	[redacted]
	[redacted]
	[redacted]
Post Code	[redacted]

Telephone [redacted]
Fax
Mobile
Work Email [redacted]

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status:
- ○ NHS or HSC care organisation
- ◉ Academic
- ○ Pharmaceutical industry
- ○ Medical device industry
- ○ Local Authority
- ○ Other social care provider (including voluntary sector or private organisation)
- ○ Other

Commercial status:

If Other, please specify:

Contact person

Name of organisation [redacted]
Given name [redacted]
Family name [redacted]
Address [redacted]
Town/city [redacted]
Post code [redacted]
Country [redacted]
Telephone [redacted]
Fax
E-mail [redacted]

Is the sponsor based outside the UK?
○ Yes ◉ No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

- ☐ Funding secured from one or more funders
- ☐ External funding application to one or more funders in progress
- ☑ No application for external funding will be made

What type of research project is this?

◉ Standalone project

- ○ Project that is part of a programme grant
- ○ Project that is part of a Centre grant
- ○ Project that is part of a fellowship/ personal award/ research training award
- ○ Other

Other – please state:

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

○ Yes ◉ No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

Title Forename/Initials Surname

Organisation [redacted]
Address [redacted]
[redacted]
[redacted]
Post Code [redacted]
Work Email
Telephone [redacted]
Fax
Mobile

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

A69-1. How long do you expect the study to last in the UK?

Planned start date: 19/10/2015
Planned end date: 29/08/2016
Total duration:
Years: 0 Months: 10 Days: 11

A71-2. Where will the research take place? *(Tick as appropriate)*

- ☑ England
- ☐ Scotland
- ☐ Wales
- ☐ Northern Ireland
- ☐ Other countries in European Economic Area

Total UK sites in study 3

Does this trial involve countries outside the EU?

○ Yes ◉ No

A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? *Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:*

- [x] NHS organisations in England 3
- [ ] NHS organisations in Wales
- [ ] NHS organisations in Scotland
- [ ] HSC organisations in Northern Ireland
- [ ] GP practices in England
- [ ] GP practices in Wales
- [ ] GP practices in Scotland
- [ ] GP practices in Northern Ireland
- [ ] Social care organisations
- [ ] Phase 1 trial units
- [ ] Prison establishments
- [ ] Probation areas
- [ ] Independent hospitals
- [ ] Educational establishments
- [ ] Independent research units
- [ ] Other (give details)

Total UK sites in study: 3

A76. Insurance/ indemnity to meet potential legal liabilities

***Note:* in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland**

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? *Please tick box(es) as applicable.*

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

- [ ] NHS indemnity scheme will apply (NHS sponsors only)
- [x] Other insurance or indemnity arrangements will apply (give details below)

[redacted] legal liability cover will apply.

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? *Please tick box(es) as applicable.*

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

- [ ] NHS indemnity scheme will apply (protocol authors with NHS contracts only)
- [x] Other insurance or indemnity arrangements will apply (give details below)

[redacted] legal liability cover will apply.

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the <u>conduct</u> of the research?

<u>Note</u>: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

- [x] NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
- [ ] Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Please enclose a copy of relevant documents.

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.*

Research site		Investigator/ Collaborator/ Contact	
Institution name	[redacted]	Title	[redacted]
Department name	[redacted]	First name/ Initials	[redacted]
Street address	[redacted]	Surname	[redacted]
Town/city	[redacted]		
Post Code	[redacted]		
Institution name	[redacted]	Title	[redacted]
Department name		First name/ Initials	[redacted]
Street address	[redacted]	Surname	[redacted]
Town/city	[redacted]		
Post Code	[redacted]		
Institution name	[redacted]	Title	[redacted]
Department name		First name/ Initials	[redacted]
Street address	[redacted]	Surname	[redacted]
Town/city	[redacted]		
Post Code	[redacted]		

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.

3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.

4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.

5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.

6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.

7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.

8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.

9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:

    - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
    - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
    - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
    - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
    - May be sent by email to REC members.

10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.

11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication*(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

Chief Investigator Sponsor

- ○ Study co-ordinator
- ○ Student
- ○ Other – please give details
- ○ None

Access to application for training purposes *(Not applicable for R&D Forms)*

Optional – please tick as appropriate:

☐ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

Signature: .....

Print Name:

Date: *(dd/mm/yyyy)*

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.

2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.

3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.

4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.

5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.

6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

   Please note: *The declarations below do not form part of the application for approval above. They will not be considered by the Research Ethics Committee.*

7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

Signature: .....

Print Name:

Post:

Organisation:

Date: *(dd/mm/yyyy)*

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

Signature: .....

Print Name:

Post:

Organisation:

Date: *(dd/mm/yyyy)*

:

Lancaster University

Research Protocol

Adults' prior experiences of living with undiagnosed Autism Spectrum Disorder.

Introduction

Autism Spectrum Disorder (ASD) has traditionally been used an umbrella term to refer to five developmental disorders including autism, Aspergers syndrome, pervasive developmental disorder, Rett's syndrome and childhood disintegrative disorder (American Psychiatric Association, 2000; Hebert & Koulouglioti, 2010; Gabovitch & Curtin, 2009; Smith & Elder, 2010). According to the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), ASD is defined by three core features including delayed and disordered communication, impaired social interaction and restricted and/or repetitive behaviour (American Psychiatric Association, 2000). This definition of ASD, including the diagnostic criterion which accompanies it, has since been revised in the publication of the DSM-V in May 2013 (American Psychiatric Association, 2013).

Within the DSM-V, Aspergers syndrome, pervasive developmental disorder, Rett's syndrome and childhood disintegrative disorder have been collapsed and incorporated under the single umbrella term, ASD. This term is used to represent a continuum and accounts for the variability in symptoms and presentation within ASD. Thus, it has been proposed that this will potentially provide a more accurate diagnostic framework (American Psychiatric Association, 2013). In addition, the three 'core features' of ASD have now been reduced into two main areas: social communication and interaction and restricted, repetitive patterns of behaviour, interests or activities. As a result of these revisions, individuals who are assessed using the DSM-V diagnostic criterion will now receive a diagnosis of ASD as opposed to

being given a diagnosis of one of the other developmental disorders (The National Autistic Society, 2015).

In line with the above, it is expected that these same revisions will be made in the publication of the 11th edition of the International Classification of Diseases (ICD-11) later this year. However, it is important to note that as it stands, individuals diagnosed using the existing criterion within the ICD-10, will be given a diagnosis more reflective of the DSM-IV diagnostic criterion for ASD (World Health Organisation, 1992).

In terms of the occurrence of ASD, research suggests that the number of children diagnosed with ASD has gradually increased over the past 20 years, with one in a hundred children now being diagnosed with ASD in the United Kingdom (UK) (Glazzard & Overall, 2012). This represents a significant increase in the occurrence of ASD when compared to earlier estimates of 4 to 6 children per 10,000 in 1980 (Fombonne, 2001 cited in Gabovitch & Curtin, 2009). It was during this time when children, who met the diagnostic criteria for ASD, were found to be frequently misdiagnosed as having an 'intellectual development disorder'. This resulted in children being segregated from their peers, excluded from classrooms and in some cases, institutionalised (Glazzard & Overall, 2012). The marked increase in the occurrence of ASD and uncertainty with regards to the cause and effectiveness of treatment for ASD, contributed to the construct of ASD receiving such considerable amount of attention in recent years (Zhou & Chun Li, 2014).

A preliminary search of the literature base indicates that qualitative research in the area of ASD has predominantly focused on exploring parents and/or siblings experiences of caring for, and/or living with, an individual with a diagnosis of ASD (Bromley, Hare, Davison & Emerson, 2004; Glazzard & Overall, 2012; Mascha & Boucher, 2006). Research has so far neglected to consider individuals' prior experiences of living with undiagnosed

ASD, despite this being highlighted by Glazzard and Overall (2012) as a potentially challenging experience for those involved. This is in line with existing research which indicates that living with undiagnosed ASD can result in individuals experiencing secondary difficulties including anxiety and depression (Nylander, Holmqvist, Jönsson, Gustafson & Gillberg, 2010; Spicer, 1998).

It is proposed that any attempts to better understand individuals' prior experiences of living with undiagnosed ASD is likely to have implications for future research and clinical practice. That is, it will inform clinicians' regarding the potential psychological support needs of individuals who have had experience of living with undiagnosed ASD. In addition, it is hoped that exploring what has led individuals to pursue and receive a diagnosis of ASD in adulthood will not only inform clinicians' understanding of the process of seeking a diagnosis of ASD, but also help in the review and development of appropriate service pathways. Therefore, the present study aims to build on the existing literature base and gain insight into what has been an overlooked area in the literature by exploring individuals' prior experiences of living with ASD, including what has led them to pursue and receive a diagnosis of ASD in adulthood.

Method

Inclusion criteria

Participants will be individuals who have received a diagnosis of ASD in adulthood. In order to be eligible for the study, participants must be aged 16 years old or older as this is the minimum age at which each of the services accepts referrals for assessments of ASD. Participants must also have received a diagnosis of ASD within the last 12 months.

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A total of up to 12 participants will be recruited from different sites across three NHS trusts; [redacted].

Exclusion criteria

Individuals with a diagnosis of a Learning Disability (LD) who have received a diagnosis of ASD in adulthood will not be eligible to take part in the study due to the different experiences they may have encountered, particularly in terms of schooling. In addition, individuals who have received a diagnosis of ASD in childhood will not be included in the present study. Due to monetary and time restraints of the present study, individuals who are not fluent in English will also be excluded from the study.

Ethical considerations

Ethical approval for the study will initially be sought from a [redacted] Ethics Committee, after which R&D approval will be sought from the [redacted]. The following ethical concerns have also been considered in the development of this research.

Confidentiality/Anonymity

In order to ensure that participants' information remains confidential, a number of steps will be taken throughout the research process. Initially, the Chief Investigator will not have access to the names and contact details of potential participants. Participants will be required to 'opt-in' to the research; contacting the Chief Investigator directly to express an interest in taking part in the study, at which point they will provide their contact details. The only exception to this is if participants 'opt-in' to the research via the clinician responsible for their

care and request to be contacted by the Chief Investigator directly. In these circumstances, the clinician would seek verbal consent from the participant for their contact details to be shared with the Chief Investigator.

In addition to the above, participants will be informed that their participation in the study will remain confidential. That is, any identifying information e.g. participants' names will only be known to the Chief Investigator after they have expressed an interest to, or decided to take part in the study, and that these will be anonymised when the interviews are transcribed by assigning each participant with a pseudonym of their choice. Furthermore, participants will be advised that all identifiable information disclosed during the interview will be anonymised during transcription.

Informed consent

Participants will be required to provide informed consent to take part in the study and will initially be provided with an information sheet (Appendix A) and then asked to sign a consent form (Appendix B) confirming their wish to participate in the research. Participants will be informed that their participation is voluntary and reminded that they have the right to withdraw from the research at any point during the interview and up to two weeks after the interview, at which point data analysis will begin. Participants will be informed that any information collected during this period will be deleted and/or destroyed if they do choose to withdraw from the study.

Distress

In the event that a participant becomes distressed during the interview, they will be offered the opportunity to take a break and asked if they would like to continue, or to terminate the interview. If the participant expresses that they would like to continue with the interview, they will be advised that they can terminate it at any point.

If a participant becomes distressed as a result of taking part in the interview they will initially be directed to the list of support services available in the participant information sheet (Appendix A). However, if a participant becomes distressed and presents as a risk to themselves or others, then it is the responsibility of the Chief Investigator to inform another person or persons and seek advice with regards to the appropriate course of action. This would primarily be the field supervisor ([redacted]) and/or the clinician involved in the participants care if applicable. For participants who choose to be interviewed at their home, the local mental health assessment team would be contacted should the participant present as a risk to themselves or others.

Lone working

As participants are offered the opportunity to be interviewed in their homes, it is recognised that this may place the Chief Investigator at potential risk. As an employee of Lancashire Care NHS Foundation Trust (LCFT), the Chief Investigator is responsible for adhering to the LCFT's Lone Worker Policy and informing another 'buddy' colleague of when and where the interviews will take place. It is also the responsibility of the Chief Investigator to contact the 'buddy' upon arriving and after leaving the participant's home and to agree a time by which the 'buddy' should try to make contact with the Chief Investigator if they have not heard from them. If this proves unsuccessful, the 'buddy' will then inform the police of the Chief Investigator's whereabouts.

Design

A qualitative research design will be employed to explore the experiences of individuals who have received a diagnosis of ASD in adulthood. Semi-structured interviews

will be conducted as these provide a flexible source of data collection to develop insights into the individuals' lived experiences. In addition, semi-structured interviews will offer individuals the opportunity to tell their own story from their position as experts on the subject (Smith & Osborn, 2008).

Materials

An interview schedule (Appendix C) has been developed which focuses on exploring two main topic areas: individuals' experiences of living with undiagnosed ASD (e.g. What was your life like before you received a diagnosis of ASD? Was it easy or difficult living with undiagnosed ASD?) and individuals' experiences of receiving a diagnosis of ASD in adulthood (e.g. What was it like for you receiving a diagnosis of ASD? How did you feel?). The topic areas were primarily informed by the existing literature base on the construct of ASD.

Procedure

Recruitment

The following two-phased recruitment strategy will be employed:

- A poster (Appendix D) advertising the research and providing information about the study, including the contact details of the Chief Investigator, will be placed in the waiting rooms in each of the different sites across the three NHS trusts; [redacted]. Handy 'pocket' cards (Appendix E) including information about the study and the contact details of the Chief Investigator will also be distributed to the different sites and placed at the reception areas and in the waiting rooms. As such, participants will have to 'opt-in' to the research should they wish to take part.

In addition to the above, information packs including a copy of the participant information sheet (Appendix A) and a copy of the consent form (Appendix B) for the study will be distributed to the different sites across the three NHS trusts which participants will be able to request from the reception staff or the clinician who is responsible for their care. Clinicians at each of the different sites will also distribute information packs to individuals who fall within the inclusion criteria for the study and who express an interest to take part in the research. The participants will then be able to contact the Chief Investigator directly should they wish to take part in the study. On contacting the Chief Investigator, participants will be informed that they can be interviewed in a location which is most convenient for them, whether that be at their home or in the clinic at a time and date most suitable for them.

Alternatively, those participants who 'opt-in' to the research via the clinician responsible for their care will be informed that they can request to be contacted directly by the Chief Investigator. They will then be informed of the purpose of the study via telephone contact.

- If this initial strategy does not result in enough participants being recruited to the study after a time period of approximately four weeks, the Chief Investigator will attend ASD post-diagnostic support groups at each of the different sites across the three NHS trusts to provide information about the study. Participants will be provided with an information pack and advised to contact the Chief Investigator directly or speak to the clinician responsible for their care if applicable should they decide to take part in the study. Participants will be given an additional 5-7 days to consider their participation in the study prior to arranging an interview.

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Interviews

Prior to the interview commencing, participants will be provided with a copy of the participant information sheet (Appendix A) and given the opportunity to ask any questions. At this point, the Chief Investigator will also remind participants of the limits of confidentiality as outlined in the participant information sheet. That is, if what is said in the interview makes the Chief Investigator think that the participant, or somebody else, is at significant risk of harm, then confidentiality would be breached and another person or persons would be informed. If participants express that they would like to take part in the study, then they will be asked to read through and sign a consent form (Appendix B).

The interview will then commence and last up to one hour and follow the format of a semi-structured interview. Interviews will be audio recorded on a digital audio recording device and transcribed verbatim by the Chief Investigator. Upon completion of the interview, participants will be thanked for their time and participation and informed of the proposed dissemination process for the research. Participants will have the option of receiving a shortened report outlining the results of the study or alternatively, they will be able to attend a presentation where the results of the research will be summarised and presented accordingly.

Proposed Analysis

Interpretative Phenomenological Analysis (IPA) will be used to analyse the data collected from the participants' interviews. This model of analysis is favoured as it offers a flexible approach to exploring and analysing qualitative data and can potentially produce a richer account of the data set (Smith & Osborn, 2008).

As the research is concerned with exploring the experiences of individuals who have received a diagnosis of ASD in adulthood, a critical realist stance will be adopted to the

collection and analysis of the data. This will allow the Chief Investigator to examine the individual lived experiences of the participants, specifically in terms of how they make sense of these experiences and what meanings these hold for the individuals concerned (Smith & Osborn, 2008). This will involve an in-depth engagement with, and detailed analysis of, the individual transcripts from which themes will emerge and be explored in relation to the topic areas identified in the interview schedule (Appendix C). The connections between the themes will be explored in terms of similarity and difference, convergence and divergence (Smith & Osborn, 2008) and then eventually grouped under broader themes known as 'superordinate themes'.

Practical issues

Initially, the audio recordings of the interviews will be uploaded from the digital audio recording device onto the Chief Investigator's personal file space on the University's secure server, after which point they will be immediately deleted from the recording device. The audio recordings will be kept for a maximum of six months following the interview itself in order to allow time for the interview to be transcribed and checked, after which point they will be destroyed.

The electronic transcripts of the interviews will also be stored on the University's secure server during the analysis of the data. These will then be transferred electronically using a secure method that is supported by the University to the research co-ordinator and stored in a secure location by the university in a password protected file for a maximum of 10 years, in accordance with the Lancaster DClinPsy Programme guidelines regarding the ethical storage of data. At the end of this period, they will be destroyed by a staff member responsible in the Lancaster Doctorate in Clinical Psychology (DClinPsy) Programme.

In line with the above, any paper files (e.g. consent forms) used by the Chief Investigator during the study will initially be stored securely in a locked cabinet. These will then be scanned and stored securely by the university in a password protected file for a maximum of 10 years. After this point, they will be destroyed by a staff member responsible in the Lancaster Doctorate in Clinical Psychology (DClinPsy) Programme. The above information will be outlined to participants in the participant information sheet (Appendix A) and consent form (Appendix B).

In addition to the above, as participants are offered the opportunity to be interviewed at the clinic at a time and date most convenient for them, it is the responsibility of the Chief Investigator to liaise with each of the different sites across the three NHS trusts [redacted] to identify an appropriate venue in which the interviews can be conducted.

With regards to the potential monetary costs of the research, participants will be informed that they will be reimbursed for travel expenses up to the value of £20 should they wish to travel to meet the Chief Investigator for the interview. Any additional costs relating to printing and/or photocopying of material for the purposes of the study will be accommodated by the university.

Complaints

If participants wish to make a complaint or raise any concerns regarding the study itself, then they will be directed to the contact details contained within the participant information sheet (Appendix A). Alternatively, if participants wish to make a complaint or raise concerns

about the service itself, then participants will be provided with a leaflet which includes information about the relevant trust's complaints procedure.

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Appendices

Appendix A: Participant Information Sheet

Participant Information Sheet

Adults' prior experiences of living with undiagnosed Autism Spectrum Disorder.

My name is [redacted] and I am conducting this research as a trainee on the Doctorate in Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?
The purpose of this study is to explore what life was like for people before they were diagnosed with Autism Spectrum Disorder (ASD). The study also aims to look at people's experiences of receiving a diagnosis of ASD in adulthood.

Why have I been approached?
You have been approached because you are an adult (aged 16 years or older) who has received a diagnosis of ASD within the last 12 months. Adults with a diagnosis of both a Learning Disability (LD) and ASD will not be able to take part in the study.

Do I have to take part?
No. It's completely up to you to decide whether or not you take part in the study. If you decide you do not want to take part, this will not affect the service you and/or your family receive.

What will I be asked to do if I take part?
If you decide to take part, I will ring you to invite you to take part in an interview which will last up to 1 hour. I will talk to you about what your life was like before you received the diagnosis of ASD and what your experience has been of receiving the diagnosis of ASD. I will record the interviews to help me remember what you have said.

Interviews can take place at your home or in the clinic, at a date and time which is most suitable for you. Any travel expenses (e.g. bus fare, etc) you have to pay to take part in the study will be paid back to you up to the value of £20. You will have to provide receipts and/or tickets of any travel expenses you have had to pay.

Will my data be kept confidential?
All of the information you provide will be kept confidential. The information collected will be stored securely and only the researchers involved in the study will have access to it:

- The recordings of the interviews will be kept for a maximum of six months following the interview in order to allow time for the interview to be transcribed, after which point they will be destroyed.

- The transcripts of the interviews will be stored securely on a computer. This means that no-one other than the researchers involved in the study will be able to access them.
- The transcripts of the interviews will be made anonymous by removing any identifiable information, e.g. your name. Once the transcript has been anonymised it will not be possible to withdraw the information you have provided. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.
- At the end of the study, the transcripts of the interviews will be stored in a secure location by Lancaster University for a maximum of 10 years. At the end of this time, they will be destroyed by a staff member in the Lancaster Doctorate in Clinical Psychology (DClinPsy) Programme.

There are some limits to confidentiality: if what you say in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this and/or the local mental health assessment team. If possible, I will tell you first if I have to do this.

What will happen to the results?
The results from the study will initially be put together and summarised in a research project as part of my training on the Doctorate in Clinical Psychology programme. The results will also be submitted for publication in an academic or professional journal. In addition, the results from the study will be fed back to the ASD services in [redacted], so that they can learn from your experiences.

Are there any risks?
It is expected that there will be no risks from taking part in this study. However, if you do experience any distress from taking part in the study, you are encouraged to inform the main researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?
Although you might find participating interesting, there are no direct benefits in taking part in the study. The study will help us to understand more about people's experiences of living with undiagnosed ASD and what it is like receiving a diagnosis of ASD in adulthood. As such, it is hoped that it will help us to understand what kinds of support are most useful for people who receive a diagnosis of ASD in adulthood, and in what ways we can make services better meet the needs of people with ASD.

Who has reviewed the project?
This study has been reviewed and approved by a [redacted] NHS Research Ethics Committee and by the Research and Development departments in [redacted].

Where can I get more information about the study if I need it?
If you have any questions about the study, please contact the main researcher:
[redacted]
Email: [redacted]
Mobile [redacted]

Research supervisor:
[redacted]
Email: [redacted]
Phone: [redacted]

Field supervisor:
[redacted]
Phone: [redacted]

Complaints
If you want to make a complaint or raise any concerns about the study and do not want to talk to the main researcher, you can contact:

Name: [redacted]
Email: [redacted]
Tel: [redacted]
Doctorate in Clinical Psychology
Division of Health Research
Furness Building
Lancaster University
Bailrigg
Lancaster
LA1 4YG
United Kingdom

If you want to speak to someone outside of the Clinical Psychology Doctorate Programme, you can also contact:

[redacted]
Email: [redacted]
Tel: [redacted]
Faculty of Health and Medicine Division of Biomedical and Life Sciences
Lancaster University
Bailrigg
Lancaster
LA1 4YG
United Kingdom

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

Support services in the event of distress
Should you feel distressed either as a result of taking part in the study, or in the future, the following support services may be of help to you.

Autism Helpline
www.autism.org.uk/helpline
0808 800 4104

The Sanctuary
[redacted]

Mind
www.mind.org.uk/help/advice_lines
0300 123 3393

Samaritans
www.samaritans.org
08457 909090

Appendix B: Consent form

Consent Form

Adults' prior experiences of living with Autism Spectrum Disorder.

	Please initial box after each statement
1. I confirm that I have read the information sheet (Version 1, Date: 10/07/2015) and fully understand what is expected of me within this study.	
2. I confirm that I have had the opportunity to ask any questions and to have them answered.	
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript.	
4. I understand that audio recordings will be kept for a maximum of six months following the interview in order to allow time for the interview to be transcribed and checked, after which point they will be destroyed.	
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
6. I understand that relevant sections of data collected during the study may be looked at by individuals from Lancaster University, from regulatory authorities or from the NHS trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to the data.	

7. I understand that relevant sections of data collected during the study may be looked at by individuals from Lancaster University, from regulatory authorities or from the NHS trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to the data. ☐

8. I understand that once my data have been anonymised and incorporated into themes it will not be possible for it to be withdrawn. ☐

9. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published. ☐

10. I consent to information and quotations from my interview being used in reports, conferences and training events. ☐

11. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the chief investigator will need to share this information with other healthcare professionals, including the local mental health assessment team if applicable. ☐

12. I consent to Lancaster University keeping electronic transcriptions of the interview for 10 years after the study has finished. ☐

13. I consent to take part in the above study. ☐

Name of Participant_____ **Signature**_____ **Date** _____

Name of Researcher _____ **Signature** _____ **Date** _____

Appendix C: Interview Schedule

Experiences of living with undiagnosed Autism Spectrum Disorder (ASD)

What was your life like before you received a diagnosis of ASD? Was it easy or difficult living with undiagnosed ASD?

Did you or your family ever try to pursue a diagnosis of ASD when you were growing up? If so, what happened? What was this like? Was it a good or bad experience? How did it make you feel?

Have you received any other diagnoses before? If so, was that a good or bad experience for you? Why? How did it make you feel?

Have you previously been misdiagnosed with any other condition? If so, is there anything you would like to tell me about this? What it a good or bad experience for you? Why? How did it make you feel? What did you think?

Experiences of receiving a diagnosis of ASD in adulthood

When did you receive your diagnosis of ASD?

Who gave you the diagnosis?

How old were you when you received your diagnosis?

How long did it take for you to receive your diagnosis, from the decision to pursue a diagnosis to actually receiving the diagnosis?

Whose decision was it to go for an assessment? Why?

What was it like for you receiving a diagnosis of ASD? How did you feel?

What does it mean to you receiving the diagnosis of ASD?

How has your life changed since receiving the diagnosis?

Version 1 Date: 13/08/2015

Appendix D: Poster

Lancaster University

Adults' prior experiences of living with undiagnosed Autism Spectrum Disorder (ASD)

The study aims to explore what life was like for people before they were diagnosed with ASD. The study also aims to look at people's experiences of receiving a diagnosis of ASD in adulthood.

INTERESTED IN TAKING PART?

- ✓ **Are you aged 16 years or older?**
- ✓ **Have you received a diagnosis of ASD in the last 12 months?**
- ✓ **You do NOT have a diagnosis of a Learning Disability (LD)**
- ✓ **You did NOT receive a diagnosis of ASD in childhood**

YES, BUT WHAT DO I DO IF I WANT TO TAKE PART?

You can contact me, [redacted] directly on [redacted] OR e-mail me at [redacted]

OR

You can speak to a member of the **reception staff** OR **your clinician** who can provide you with an information pack about the study.

Appendix E: Handy 'pocket' card

Lancaster University

Adults' prior experiences of living with undiagnosed Autism Spectrum Disorder (ASD)

- ✓ **Are you aged 16 years or older?**
- ✓ **Have you received a diagnosis of ASD in the last 12 months?**
- ✓ **You do NOT have a diagnosis of a Learning Disability (LD)**
- ✓ **You did NOT receive a diagnosis of ASD in childhood**

If yes, then you can contact me, [redacted], the main researcher directly on [redacted] OR e-mail me at [redacted] for more information. You can also speak to a member of the **reception staff** OR **your clinician** who can provide you with an information pack about the study.

ETHICS SECTION

Version 1 Date: 13/08/2015

References

American Psychiatric Association. (2000). Diagnostic and statistical manual for mental disorders. 4. Washington, DC: American Psychiatric Press.

American Psychiatric Association. (2013). Diagnostic and statistical manual for mental disorders. 5. Washington, DC: American Psychiatric Press.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. doi: 10.1191/1478088706qp063oa

Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism*, *8*(4), 409-423. doi:10.1177/1362361304047224

Gabovitch, E. M., & Curtin, C. (2009). Family-centered care for children with autism spectrum disorders: A review. *Marriage & Family Review*, *45*(5), 469-498. doi:10.1080/01494920903050755.

Glazzard, J., & Overall, K. (2012). Living with autistic spectrum disorder: Parental experiences of raising a child with autistic spectrum disorder (ASD). *Support For Learning*, *27*(1), 37-45. doi:10.1111/j.1467-9604.2011.01505.x

Hebert, E., & Koulouglioti, C. (2010). Parental beliefs about cause and course of their child's autism and outcomes of their beliefs: A review of the literature. *Issues In Comprehensive Paediatric Nursing*, *33*(3), 149-163. doi:10.3109/01460862.2010.498331.

Mascha, K., & Boucher, J. (2006). Preliminary investigation of a qualitative method of examining siblings' experiences of living with a child with ASD. *British Journal Of Developmental Disabilities*, *52*(102), 19-28. doi:10.1179/096979506799103659

Nylander, L., Holmqvist, M., Jönsson, S., Gustafson, L., & Gillberg, C. (2010). Is it possible to measure the impact of a developmental disorder diagnosis received in adulthood? An attempt at follow-up and discussion of difficulties encountered in the process. *Clinical Audit*, 127-136. doi:10.2147/ca.s13941.

Smith, L. O., & Elder, J. H. (2010). Siblings and family environments of persons with autism spectrum disorder: A review of the literature. *Journal Of Child And Adolescent Psychiatric Nursing*, *23*(3), 189-195. doi:10.1111/j.1744-6171.2010.00240.x.

Smith, J. A., & Osborn, M. (2008). Interpretative Phenomenological Analysis. In Smith, J. A. (Eds), *Qualitative Psychology: A Practical Guide to Research Methods* (pp. 53-80). London: Sage.

Spicer, D. (1998). Autistic and Undiagnosed. Asperger Syndrome or High-Functioning Autism?. *Current Issues in Autism*, 377–382. doi:10.1007/978-1-4615-5369-4_19.

Taylor, G. W., & Ussher, J. M. (2001), Making sense of S&M: A discourse analytic account. *Sexualities*, *4*(3), 293-314. doi: 10.1177/136346001004003002

The National Autistic Society (2015). Q&A: DSM-5. Retrieved from http://www.autism.org.uk/about-autism/all-about-diagnosis/changes-to-autism-and-as-diagnostic-criteria/qanda-dsm-5.aspx

ETHICS SECTION

Version 1 Date: 13/08/2015

World Health Organization. (1992). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. Geneva: World Health Organization.

Zhou, T., & Chun Li, Y. (2014). Parenting Styles and Parent's Perspectives on How Their Own Emotions Affect the Functioning of Children with Autism Spectrum Disorders. *Family Process*, *53* (1), 67-79. doi: 10.1111/famp.12058.