Autistic Adults' Experiences of Social Trauma: An Interpretative Phenomenological Analysis

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Thesis Portfolio Abstract

Background: Increasing numbers of adults are receiving a diagnosis of autism in adulthood. Following a late diagnosis, autistic adults may re-evaluate their sense of self and re-examine past events with a new framework. Limited research focuses on this population, therefore understanding the lived experience of late diagnosed adults is important.

Aims: The first aim of this thesis was to synthesis research exploring how a late diagnosis of autism may impact a person's sense of self. The second aim was to explore the experiences of social trauma in late diagnosed adults and how they make sense of these experiences before and after their diagnosis.

Methods: A systematic review of qualitative studies that explored how autistic adults made sense of their identity following a diagnosis was conducted. An empirical study was then conducted to explore the lived experiences of social trauma in late diagnosed adults. Semi-structured interviews were used, and Interpretive Phenomenological Analysis was used to analyse data.

Results: Three 'analytic' themes were identified from eleven studies in the qualitative review. These highlighted the general process autistic adults go through following a late diagnosis: renegotiating their identity through reappraising past experiences allowing them to adjust their sense of self, accepting autism as part of their identity, which then allows them to authentically connect with others with a shared identity and creates a sense of belonging that may not have existed before. In the empirical paper, four superordinate themes were identified: experiencing social trauma, making sense of socially traumatic experiences, how I manage social trauma, re-examining social trauma with a new lens.

Conclusions: Clinicians should ensure newly diagnosed adults have the opportunities to understand the impact a diagnosis can have on how they view themselves and make sense of past experiences.

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Chapter 1: Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterised by challenges in social communication and interactions along with restricted or repetitive behaviour and interests. The construction of autism has developed over time with multiple perspectives contributing to its wider understanding. The medical model has been a dominant framework, influenced by the Diagnostic and Statistical Manual of Mental Disorders (DSM), it views autism as a disorder/deficit in development (American Psychiatric Association, 2013). However, more recent perspectives construct autism as being influenced by societal norms and cultural understanding, with autistic individuals and the neurodiversity movement shaping how autism is understood as a form of diversity with its own unique strengths and challenges (Jaarsma & Welin, 2012).

ASD is a developmental condition, with behavioural markers present in early childhood. Diagnosis of ASD has been given as early as 18-24 months old (Okoye et al., 2023; Hyman et al., 2020). Early diagnosis is viewed as beneficial as it enables the opportunity for interventions to support a child’s cognition, language, and social-emotional functioning (Vivanti et al., 2014). Early diagnosis can also provide benefits for parents by enabling access to appropriate support and services for their child, which can reduce parental stress and anxiety (Grzadzinski et al., 2021).

The average age of diagnosis has remained steady at around 55 months (Brett et al., 2016), however research suggests that there is an increase in the rate of adults diagnosed in the UK (Russell et al., 2022), particularly following adult autism diagnostic services being made mandatory. In recent years, efforts have been made to improve early detection of ASD (Van’t Hof, 2021). This has been attempted by increasing awareness both for professionals and the wider public and broadening diagnostic criteria (Keyes et al., 2012). While this drive for early detection is beneficial for children and young people today, there is a ‘lost generation’ (Lai & Baron Cohen, 2015) of adults whose ASD remains undetected. Receiving an ASD diagnosis is a significant life event that can bring new understanding to the individual, but also new challenges. Taylor’s (1983) model of cognitive adaptation suggests when individuals are dealing with life altering information, a process of re-evaluating their sense of self and their possible future needs to take place. Following a diagnosis, adults would describe a process of reinterpreting past experiences, strengths, and difficulties (Hickey et al., 2018; Lewis 2016). This can lead to individuals re-examining their identity to attempt to assimilate this new diagnosis. Studies report a mixture of feelings with some adults embracing ASD as a positive part of their identity (Lewis, 2016; Tan, 2018) and others struggling to accept an autistic identity (Lilley et al., 2022), or viewing themselves and their ASD as separate (Hickey et al., 2017). Understanding how late diagnosis of ASD affects the many facets of a person’s self-identity can illuminate this unique adjustment process many experience that is affecting a growing number of adults.

Along with providing the opportunity to re-examine identity following a late ASD diagnosis, individuals may also re-examine past experiences within their new framework to make sense of what they have lived through. Before receiving their diagnosis in adulthood, autistic adults described a sense of always feeling different to others (Huang et al., 2021) and feeling the need to mask or camouflage their differences to fit in socially (Hickey et al., 2018; Lai et al., 2017), all of which can be distressing to experience. These can be considered precursors that may increase the likelihood of interpreting an experience as social trauma.

Social trauma is defined as high social threat events that involve rejection and social humiliation (Hardarson et al., 2023). Autistic individuals are at a higher risk of experiencing negative social events such as social isolation, rejection, bullying and loneliness compared to their neurotypical peers (Maïano et al., 2016). Although these social experiences are not uncommon in autistic populations, social trauma within the autistic community has been little explored. While, for some, these experiences can be characterised as distressing, autistic adults are more likely to appraise these experiences as traumatic (Haruvi-Lamdan et al., 2020). This study goes on to explore how autistic features can influence how individuals interpret adverse social events, with social communication difficulties and differences with perception and cognition impacting their understanding. This in turn may lead some to view social situations as traumatic. For autistic individuals who grew up without a diagnosis, these experiences may have a greater detrimental effect on the individual as they do not have an ASD diagnosis to contextualise what they have been through, further adding to their distress.

This thesis explores the experiences of adults who received a late diagnosis of ASD. Firstly, through a systematic review of the literature relating to late diagnosis and its impact on self-identity. This will be followed by an empirical study of the experiences of social trauma in late diagnosed adults. Limited research focuses on the population of late diagnosed autistic adults (Lupindo et al., 2023), therefore it is important to ensure research is conducted within this cohort of the ASD population to ensure that their needs are identified to aide in informing decision making around support needs following a late diagnosis. In the systematic review, a thematic synthesis was used to capture qualitative accounts of self-identity. The empirical paper also employed qualitative methods, with Interpretive Phenomenological Analysis chosen to describe participants' experiential accounts of social trauma.

Note on language use

The language used to describe neurodevelopmental conditions has been subject to much debate surrounding the use of person-first (person with autism) versus identity-first language (autistic person). Research indicates that autistic people prefer identity first language (Bury et al., 2020) as it is a way of acknowledging their autism as a part of their identity. Therefore, this thesis will adopt identity-first language except for purposes where it is using a direct quote from a participant.

Chapter Two

Impact of receiving a late diagnosis of Autism on self-identity: A qualitative systematic review

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Abstract

There are a growing number of qualitative studies exploring experiences of adults who received a late diagnosis of autism. Before receiving a late diagnosis, individuals may have developed their own understanding of themselves and their identity. A late diagnosis may impact their sense of self. This review aims to understand how self-identity may evolve in adults following a late autism diagnosis and the impact this may have on their wellbeing by identifying reoccurring themes. This review used a thematic synthesis to synthesise the qualitative data from 11 studies on the impact a late autism diagnosis has on an individuals' self-identity from PsychINFO, MEDLINE Ultimate, CINAHL Ultimate, and Scopus. The Critical Appraisal Skills Programme was used to quality assess the included papers. Three analytic themes were identified: (1) Processing the past and questioning who they are (2) Accepted by the self and others for who they are and (3) Knowing who they are helps with finding a place in the world. After receiving a late diagnosis, some autistic adults' relationship with their identity changed as they began to question their identity. This enabled them to accept their autistic self, and a new sense of a belonging was formed. However, some autistic adults also experienced internalised stigma which hindered their ability to embrace their autistic identity.

Key words: ASD, Autism, Late diagnosis, Self-identity

Background

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterised by difficulties with social communication and interactions, and repetitive and restrictive behaviours and interests (DSM-5, 2013). Rates of autism diagnosis have increased since the 1990s (Russell et al., 2022). This is likely a consequence of increased awareness of ASD, the changes and widening of diagnostic criteria, and wider access to diagnostic services (Russell et al., 2022). Nevertheless, there are still a considerable number of people who do not receive a diagnosis until adulthood. By reviewing primary care data from over hundreds of GP clinics in England, O'Nions et al. (2023) found that up to 1.1 million adults could be autistic and undiagnosed (estimated 150,000 – 500,000 aged 20 – 49, and 250,000 – 600,000 aged 50+).

Adults who received a diagnosis of ASD in adulthood (i.e. a late diagnosis) may have unique experiences throughout their development. There are a growing number of qualitative studies exploring experiences of adults who received a late diagnosis of ASD (Brugh et al., 2011; Molloy & Vasil, 2004; Hickey et al.,2018; Leedham et al., 2020; Stagg & Belcher, 2019; Wylie, 2014). Before being diagnosed in adulthood, they may have developed their own narrative and understanding of themselves and their identity, as well as their life experiences, without referencing to a universal diagnostic framework (Brugha et al., 2011). Receiving a late diagnosis may provide an individual with an explanation for their difficulties and foster re-appraisal of past experiences (Molloy & Vasil, 2004). In addition, receiving a late diagnosis may impact their sense of self (Stagg & Belcher, 2019), and promote their self-acceptance (Wylie, 2014).

There is not a universally agreed-upon age cutoff for what is considered a late diagnosis. In studies, late diagnosis has been reported as diagnoses received in late childhood and early adolescents (Davidovitch et al., 2022; Mandy et el., 2022). In other studies, late diagnosis refers to a diagnosis received in adulthood at the age of 18 (Lupindo et al., 2023; Ghanouni & Seaker, 2023). In this review late diagnosis has been defined as 18 years and above.

While there are a greater number of adults receiving an ASC diagnosis, understanding of how a late diagnosis affects a person’s self-identity has only recently been explored. Key aspects of self-identity, such as self-concept (e.g. ‘who am I’) and self-acceptance (e.g. ‘I’m ok with who I am’), are closely linked to one’s wellbeing (Sirgy, 2021; Cordaro, 2024). Individual experiences can vary when conceptualising identity. Hickey et al. (2018) described how participants may reject ASC as being a part of their identity. Whereas Kapp et al. (2013) reported that over time participants began embracing their autistic identity and viewed their differences positively. How individual’s construct and understand autism itself may influence how they reconstruct their identity following a late diagnosis. Those who view autism through the medical model may need to adjust to identifying with a disability label. Those who consider autism through a neurodiversity paradigm may view their self-identity differently following a diagnosis and not view autism as only a diagnosis, but a core part of their identity. However, there may be common themes across studies. Identifying these experiences may help to expand our understanding of how self-identity may evolve or adjust in adults following a late ASD diagnosis and the impact this may have on their wellbeing.

A systematic review (Wilson et al., 2023) was conducted to identify and review evidence in relation to autistic individuals' experiences of the diagnostic process for autism in the UK. They identified 19 relevant studies that focused on participants across lifespan. Using thematic analysis, they identified three superordinate themes, one of which relates to “negotiating self-identity", with some participants experiencing conflicting feelings towards their diagnosis, whilst others developed self-understanding and self-kindness. Their synthesis highlighted that the self-identity negotiating process is common yet non-linear.

Despite their findings, there are some limitations. First, the findings reported by Wilson et al. (2023) may not be a complete representation of their experiences of adults who received a diagnosis in adulthood, as studies for children and adults were included and their data were synthesised together. Individuals are likely to have developed a clear and stable sense of their identity by adulthood (Lodi-Smith, 2017). Receiving an autism diagnosis during adulthood may impact their self-identity differently, for example, one may feel angry and disappointed that professionals involved in their care have failed to identify this condition early in their life. Second, the review by Wilson et al. (2023) focussed on studies conducted in the UK, meaning that data collected from studies outside the UK have not been reviewed and synthesised. To address these limitations, this systematic review was conducted with an aim to develop a focussed understanding of the impact of receiving an autism diagnosis in adulthood on one’s self-identity. Therefore, the research question is ‘What do qualitative studies tell us about how receiving an autism diagnosis in adulthood affects a person’s sense of self-identity?

Methods

Pre-registration

This systematic review followed Preferred Reporting Guidelines for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Page et al., 2021) and was registered on PROSPERO on 05.09.2023 (CRD42023456503).

Search procedure

The SPIDER criteria (Sample, Phenomenon of Interest, Design, Evaluation, Research type, Cooke et al., 2012) was used to develop the review question (see Table 1). The SPIDER criteria was chosen due to its suitability in developing search terms to identify relevant literature in qualitative studies.

Table 1.

Key elements of review question using SPIDER criteria

Criteria	Description
Sample	Adults with late diagnosis of ASD
Phenomenon of Interest	Self-identity following diagnosis
Design	Interviews/surveys
Evaluation	Experiences
Research type	Qualitative or mixed methods (only qualitative data to be included in review

Multiple databases were searched in September 2023 (PsychINFO, MEDLINE Ultimate, CINAHL Ultimate, and Scopus). These databases were selected as they contain studies relevant to the review question. Search terms were developed by performing a manual search on google scholar to identify key words and articles (see Table 2). Manual searches of reference lists of selected articles were carried out to identify further studies. There were no restrictions on date limits. Only peer-reviewed articles were included.

Table 2.

Final search terms

Autism	Late diagnosis	Phenomenology
"autis*"	"diagnos* N3 (adult or late) – W/3 in scopus	"reflecti*"
"ASD"		"qualitative*"
"asperger"		"interview"
"ASC"		"oral history"
		"biograph*"
		"autobiography*"
		"phenomenolog*"

Selection criteria

Inclusion and exclusion criteria are presented in Table 3 below.

Table 3.

Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Research where at least some of the participants received an autism diagnosis in adulthood (18 years old and above), Research that reported qualitative data, Published in an English peer-reviewed journal, Relating to self-identity following a diagnosis	Studies that reported quantitative data only, No formal diagnosis of ASD was mentioned

Studies identified by searches were extracted to Zotero (Zotero, 2023). Following duplicates being removed, titles and abstracts were screened, and studies removed if they did not clearly meet inclusion criteria. The remaining articles were read in full to assess eligibility. 20% of the titles and abstracts and 20% of full-text articles were reviewed by a second reviewer independently. Disagreements were discussed at each stage to develop a consensus between the screeners. This resulted in a final number of 11 studies (see Figure 1. for PRISMA flowchart).

Critical appraisal

The Critical Appraisal Skills Programme (CASP) (2018) tool was used to critically appraise quality of the selected studies. The CASP tool was chosen as it is widely used in qualitative systematic reviews and is compatible with Thomas and Harden's (2008) approach to thematic synthesis. In line with other published reviews (Hendry et al., 2017; McCann et al., 2016), we adopted a scoring system to rate each CASP criterion (detailed response = 2, partial response = 1, no response or little information = 0). A total quality score was calculated for each study (≥ 17 = high quality, 11-16 = moderate quality, and <11 low quality), consistent with similar reviews (Hendry et al., 2017; McCann et al., 2016; Rushbrooke et al., 2014). Quality scores were used to support data synthesis by organising findings from studies of higher quality while retaining pertinent findings from studies of lower quality (Long et al., 2020).

Data Extraction

Relevant data were extracted by CG, including participant characteristics, method of data collection, analysis used, and key findings from participants quotations and researchers commentary and interpretations.

Data that was categorised as findings or results, which comprised participant quotes, author interpretations, and themes, were extracted and subjected to analysis (Thomas & Harden, 2008).

Data synthesis

Data were thematically synthesised following recommendations by Thomas and Harden (2008): inductive coding of the data, developing descriptive themes from the primary studies, and generating analytical themes from the reviewer's interpretation to develop new constructs, explanations and hypotheses. This approach was chosen due to its clear and rigorous methodology that ensures descriptive themes remain close to the primary data, and its alignment with a critical realist position. It considers the objective events and experiences that shape identity, such as an autism diagnosis, and acknowledges that our understanding of these events is subjective and socially constructed. It provides a framework for understanding the complexities of identity formation through considering how participants construct their identity following real life changing event (late-diagnosis). A modified approach was used to organise the synthesis based on quality ratings (Long et al., 2020). Specifically, initially coded were findings from higher quality studies (quality scores of 17 and above) to create the main code list. This list was then used to code findings from studies considered medium quality, with new codes created and integrated into the existing code list if relevant to the research question. Finally, the updated code list was used to find new codes in studies of considered low quality. By this stage though, no new codes were identified. Instead, these findings provided support for the existing codes. From here descriptive themes were developed from the codes. This was achieved through grouping related codes together and developing descriptive themes that capture the meaning of these initial codes. This was done independently by the first author, who then discussed the descriptive themes with the fourth author (KC). Following this, analytical themes emerged which intend to go beyond the original findings and attempt to generate new understandings

(Thomas & Harden, 2008). Strengths of the approach developed by Long et al. (2020) include not excluding any studies based on quality alone. This ensures a diverse range of perspectives and findings are included in the synthesis. Additionally, Long et al. (2020) organise the data synthesis based on the quality appraisal results by prioritising findings from studies considered higher quality. This approach strengthens the rigour of the synthesis findings.

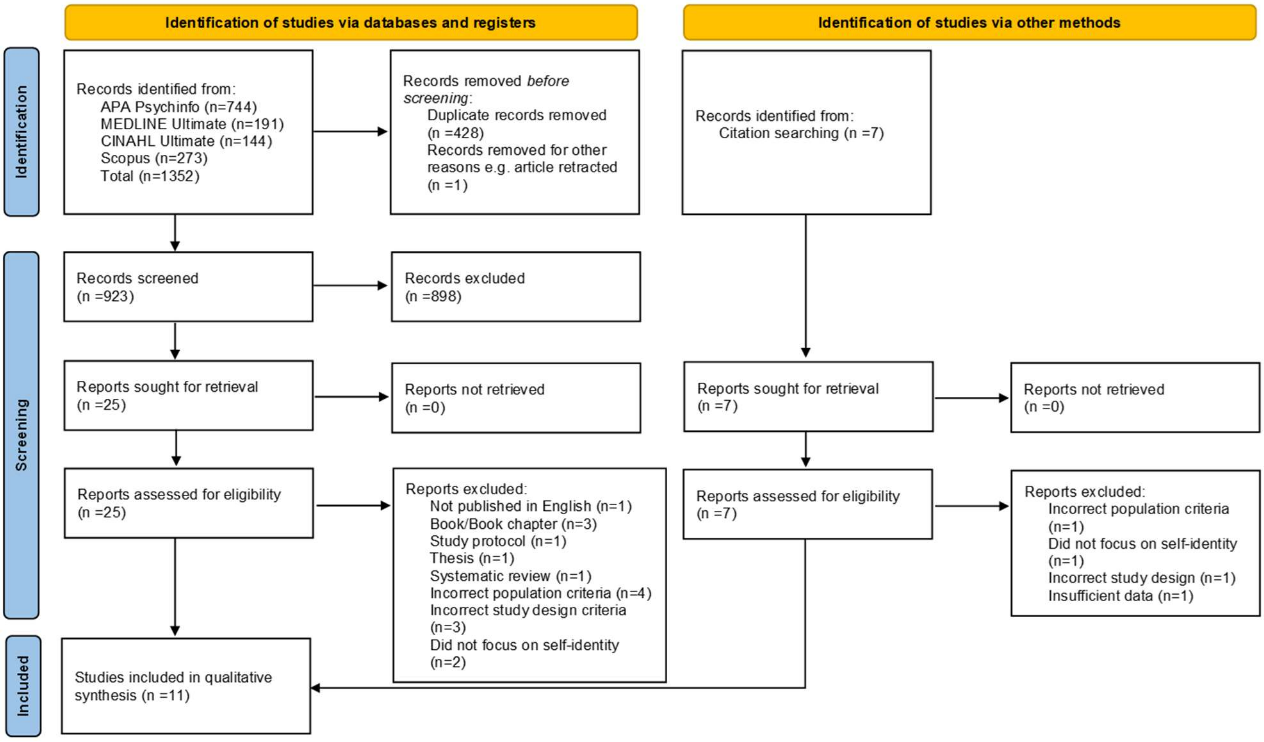
Results

Search results

A total of 1352 papers were identified by searches, with 923 remaining after duplicates and retracted articles were removed (see Figure 1 for PRISMA flow diagram). Following titles and abstracts screenings, 25 full-text articles were reviewed, which resulted in a total of 11 papers for inclusion. HF reviewed 20% of the article's title and abstracts, and 20% of the full-text articles. Of the 20% of papers that were independently checked, there was an inter-rater reliability of 90.86% between the two reviewers.

Figure 1.

PRISMA Flow Diagram



Study Characteristics

Study characteristics of included studies were presented in Table 4. Studies were conducted across five countries: UK (n=4), Australia (n=4), France (n=1), South Africa (n=1), and Canada (n=1). There was a total of 314 participants with a late diagnosis of ASD across the papers. Huang et al. (2022) had four support persons as part of their participants, Ghanouni and Seeker (2023) included five parent participants. However, data from these participants was not included in the review as it was not relevant to the research question. The majority of studies used interviews to collect qualitative data, with semi-structured (n=9) and a narrative interview (n=1) employed. There was one exception that used a survey with open and closed questions to collect qualitative and quantitative data (Huang et al., 2021). Thematic analysis was the most frequent method of analysis employed (n=8), followed by interpretive phenomenological analysis (n=2), with the remainder using content analysis (n=1).

Quality appraisal

The majority of papers were rated as moderate (n=9) with the remaining rated as high (n=2). No papers were considered low quality. Appendix B provides quality ratings. All papers had a clear statement of aims of their research and used an appropriate qualitative methodology. Of note, over half the studies did not consider the relationship between the researcher and participants (n=6), with some not explicit in how this relationship was considered (n=3). Only two studies (Huang et al., 2022; Lupindo et al., 2022) adequately addressed this issue. Finally, the majority of studies presented a clear statement of their findings (n=10) and adequately discussed their significance in relation to existing literature (n=9).

Table 4.

Study Characteristics

Author/Year of publication	Country	Overall sample size (N)	Age range (median)	Gender	Data collection method	Analytic method	Quality score (out of 20)	Main findings
Huang et al. (2022)	Australia	23 (19 autistic adults, 4 support persons)	25-65	7 males, 13 females, 3 non-binary.	Semi-structured interviews	Reflexive thematic analysis	18	Following diagnosis participants described wanting to find other people with a shared identity and connect with the autistic community. This helped them understand themselves better. It started a path of self-discover and enabled them to let go of the expectation to act neurotypical, and reduced self-blame 'It meant that things weren't all my fault… I wasn't just a problem'.

Lilley et al. (2022)	Australia	28	45-70 (52)	14 females, 10 males, 1 non-binary, 1 preferred not to say	Semi-structured interviews	Thematic analysis	16	Majority of participants found receiving a diagnosis ‘profoundly’ changed their sense of self by enabling them to understand themselves. This allowed them to reconstruct perspectives of who they are and who they want to be. There was a shift in how they conceptualised difficulties; instead of believing mental illness was the reason for their difficulties, they were now explained by ASD traits. Some participants felt uncertainty about who they are post-diagnosis and were trying to navigate how they now fit into the world.

Huang et al. (2021)	Australia	190 (All participants in study, 137 (Participants formally diagnosed with ASD)	(41)	39 males, 129 females, 18 other, 4 missing gender data	Survey with open and closed questions	Mixed-methods: qualitative data - thematic analysis used to analysis open-ended responses. Quantitative data - descriptive statistics, chi-squared test, independent samples t-test.	11	Participants re-evaluated their strengths and difficulties. For some this led to self-acceptance. Others became fixated on perceived deficits and described feeling shame and inadequate. For some, over time there was a shift from a negative to a positive view of self 'At first I felt bad about my diagnosis… Since then I have… I have started to understand how autism is a part of me and how it affects my life'. Some described an increased sense of belonging, whilst others felt alienated from mainstream society.
Leedham et al. (2020)	UK	11	43-64	11 females, received ASC diagnosis at or over the age of 40 years	Semi-structured interview	Interpretive Phenomenological Analysis	14	Participants described feeling worried about how the diagnosis would impact their identity, with it creating doubts about their abilities, and concerns it reduces their identity to just being autistic 'Am I just anything other than

								these symptoms'. For others the diagnosis provided a 'framework' for who they are and enabled a kinder view of themselves, from self-criticism to self-compassion. Some described having their difficulties validating and it gave them strength and pride. They no longer felt the need to conform to be accepted.
Lilley et al. (2023)	Australia	26	45-72	14 females, 10 males, 1 non-binary, 1 preferred not to say, received diagnosis after the age of 35	Oral history interview	Reflexive thematic analysis	16	Participants felt empowered following their diagnosis as they were finally able to be themselves and drop neurotypical behaviours. Taking on a new autistic identity allowed them to connect with others who are autistic and gave them a sense of belonging. Some also described how it was important for them to be a role model for others and felt able to support they did not receive themselves. Some did have

								difficulty letting go of their old neurotypical identity, which could lead them to questioning their diagnosis. Others endured family members doubting the diagnosis which caused them to further question their diagnosis.
Bureau & Clement (2023)	France	12	19-58	5 females, 5 males, 2 non-binary	Semi-structured interviews	Content analysis	14	Participants described needing time to adjust to identifying as autistic. There were mixed feelings with considering themselves disabled, with concerns that they did not fit this label. Others embraced it as it acknowledged past difficulties. Some participants described feeling trapped by having an ASD label and were worried how it would be perceived socially. For some receiving a diagnosis helped them feel connected and like they belonged. Others

								described how they saw themselves in relation to ASD; was it a core part of their identity or separate and something they lived with?
Punshon et al. (2009)	UK	10	22-45 (31)	7 males, 3 females.	Semi-structured interviews	Interpretive Phenomenological Analysis	16	The diagnosis helped some participants reframe critical beliefs they had held 'I know it's not just because I'm weird, it's because I have got specific impairments'. Many valued how it allowed them to fit in socially as themselves and allowed them to identify autistic traits as strengths. Some felt overwhelmed by the permanence of an ASD label 'I am stuck being like this now' and felt uncertain about how to navigate this new part of their identity.
Ghanouni & Seaker (2023)	Canada	13 (autistic participants),	27-53 (autistic participants),	9 males, 4 females	Semi-structured interviews	Thematic analysis	13	Following the diagnosis participants gained new perspectives about their

		5 (Parents/ guardians)	46-63 (parents/ guardians)	(autistic participants) 2 males, 3 females (parents/ guardians)				identity. They described no longer viewing themselves as bad for past difficulties. They described letting go of a neurotypical identity, and accepting that it was ok to be different. This was explained as being normal in a different way. Past difficulties were understood as autistic traits, having been previously attributed to mental ill health.
Hickey et al. (2017)	UK	13	51-71	10 males, 3 females	Semi-structured interviews	Thematic analysis	16	The diagnosis provided participants with an explanation for past difficulties. This helped reduce self-blame and increased self-compassion. Participants reviewed aspects of their life. For some they concluded that autism was ‘separate from their true selves’. They attributed difficulties to their autism rather than to the self, with autism being a behavioural feature and not part of their core self.

								Others described the label as enabling self-acceptance where they no longer hid their true self. There was also a process of trying to determine where on the spectrum they saw themselves, trying to make sense of their autistic identity.
Lupindo et al. (2022)	South Africa	10	28-64	10 males	Life history semi-structured interview	Thematic analysis	18	Participants described the diagnosis helped them accept who they were and feel complete. For some making sense of their new identity was an active process as they no longer had to make themselves fit in. This allowed them to feel they were being authentic. Some felt pride and embraced their autistic traits as part of them, others viewed these as seperate from the self. Others questioned how they would explain their label to others and described fears of experiencing discrimination for who they are.

Stagg & Belcher (2019)	UK	9	52-54	5 females, 4 males	Narrative interviews	Thematic analysis	16	Participants described having to work out who they were following a diagnosis. There was an increase in self-awareness that gave them a sense of control over their lives. For others the diagnosis led them to feel robbed of their old identity while they adjusted to a new one.

Thematic synthesis

Three reoccurring ‘analytic’ themes were identified from the eleven studies which were able to provide a richer understanding into the self-identity of adults who received a late diagnosis of ASD. These were (1) Processing the past and questioning who they are (2) Accepted by the self and others for who they are and (3) Knowing who they are helps with finding a place in the world.

Processing the past and questioning who they are

This theme describes participants’ process of attempting to integrate their ASD diagnosis into their current identity through examining their past with a new understanding to try and make sense of who they are, and adjusting to a new identity for themselves being formed.

Participants described how receiving a diagnosis enabled them to look back at past behaviours and experiences through a new lens. The ability it had to provide an explanation for past difficulties gave them a greater understanding of themselves and was an illuminating process, *“[It was] the missing piece of the jigsaw, it put everything into place for me and I got the bigger picture then. I knew why this had happened, this was happening and that had happened… it all just came together”* (Punshon et al., 2009, p. 277). Along with providing an explanation, the diagnosis also offered participants the opportunity to reinterpret past events, “*For Malcolm, too, ‘the light came on’ with diagnosis allowing him to ‘reconstruct my perspective of who I am and who I want to be*’”. (Lilley et al., 2022, p.1402). This enabled participants to reappraise their identity through an autism lens and gave them a clearer sense of who they are with participants noticing a “*paradigm shift in my thinking about myself*” (Ghanouni & Seaker, 2023, p.6). While for many, this reappraisal resulted in a more positive view of themselves forming, for others it could cause pain as they reflect on experiences where they feel they failed, “*it was looking back and then suddenly realising* *there was this genetic connection and great feelings of inadequacy*" (Hickey et al., 2018, p.361), and a perception of them as a failure was experienced.

For some participants, part of this reappraisal of identity involved reattributing negative behaviours which had previously been viewed as a core part of themselves to their autism instead, "*it makes you realise that all the problems you've had in the past you can put it down to one reason. And it's nothing to do with yourself*". (Hickey et al., 2018, p. 361). In this way, autism was viewed as external to themselves and separate from the self and could be evidence of self-stigmatising views. Naming these difficulties as autism was an explanation to themselves as well as to others. It was not only difficult experiences that were reattributed to autism, but also mental health labels, "*Interviewees further mentioned that they now conceptualised some of their mental health issues as 'autistic burnout' rather than depression, and that they feel 'burnout' is a destigmatising construct: 'I don't think I've got long-standing clinical depression. Long-standing autism – tricky but not sick*" (Lilley et al., 2023, p.1402). This felt very powerful for participants as it changed the perception that they were someone chronically suffering from a mental illness, to being autistic and recognising differences as part of their autism. While this was felt as a positive reframing of their symptoms, there was also the realisation that "*I have got labelled with something else*" (Punshon et al., 2009,p. 278), and coming to terms with the permanence of what an ASD diagnosis means for their identity and place in society. These experiences demonstrate the difficulties participants can have of integrating autism as a positive part of their identity.

Part of the renegotiating of their identity involved the process of letting go of their old identity and taking on another. There were some participants who found it difficult to adjust from identifying as neurotypical to viewing themselves as neurodiverse as they did not think they fit the expected autism identity which led them to question the validity of the diagnosis

"*Sarski commented, 'maybe I'm not autistic enough', lamenting 'I'm so good at trying to be neurotypical that I've forgotten how to be autistic*'" (Lilley et al., 2023, p.1153). For others the diagnosis offered the opportunity to let go of the need to make themselves fit in with an identity in a society that was confusing for them, "*It represented a parallel 'letting go' of an old life, pre-diagnosis, one where they no longer needed to assimilate to meet social norm*" (Leedham et al., 2020, p. 141). These contrasting views of the self were reflected in the participants descriptions of identifying as disabled. Some participants existing views on what being disabled looked like meant that they struggled to apply this identity to themselves too "*I wasn't quite comfortable with disability either and a lot of signs were there that I was succeeding at things that 'people like that' don't succeed at. So, could that be me?"* (Lilley et al., 2023, p. 1153). However, other participants were more open to embracing disability as part of their identity as it acknowledged the difficulties and barriers they have, and will continue to live with:

> *I'm sorry but being disabled is not the end of the world. It's the way things are. I hate people dancing around the word, using 'special needs.' Yes, they have special needs, because they're disabled. It's this word, disabled that ensures our rights are protected*. (Bureau & Clement, 2023, p. 5).

Letting go of their old identity was made more difficult by the fact that the diagnosis had come late in their life, after they had already formed a relatively stable identity for themselves. For some, their view of themself had suddenly changed and taken from them, "*I think there's always going to be an element of the why me, so it sort of robs you of that right to be like everyone else*" (Stagg & Belcher, 2019, p. 354). They were then left with trying to make sense of who they were now.

Adjusting to a new autistic identity was a dynamic process. For many, before their diagnosis participants held a negative view of themselves, but following the diagnosis this shifted to reflect a new positive view of themselves. This was also reflected in the language they directed toward themselves. Initially the tone was self-critical, but this evolved with more time following diagnosis, "*At first I felt bad about my diagnosis… Since then I have… started to understand how autism is part of me and how it affects my life. I feel a lot more positive about it because I've learnt some different strategies to cope better*" (Huang et al., 2022, p.2992). For some participants this process was not so linear and appeared more complex and involved "*alternating phases of feeling at ease with the idea (sometimes even embracing it) and feeling lost, confused or even completely rejecting it*" (Bureau & Clement, 2023, p.6).

Accepted by the self and others for who they are

This theme describes the role of acceptance following a diagnosis. This includes participants acceptance of their new autistic identity, but also how feeling accepted by others or not, can impact a person's identity.

Having the opportunity to re-evaluate their strengths and difficulties after a diagnosis promoted "*self-acceptance and a positive view of autism*" (Huang et al., 2021, p. 2992). With more time since the diagnosis, participants began to accept "*autism as a permanent and positive part of themselves that should not be erased: It's not an impediment. It's just a different way of doing things*" (Huang et al., 2022, p, 9). Some participants spoke of feeling less shame about certain behaviours that had previously made little sense to them "While we were just talking about various things, them saying, '*Oh, I have a problem with babies and noise.' And I used to be ashamed of that*." (Hickey et al., 2018). However, they were now able to view themselves with greater tolerance and compassion that helped them normalise experiences within the context of autism, "*I wasn't a bad person, I was autistic*" (Ghanouni & Seaker, 2023, p. 6).

Participants frequently spoke about how with the diagnosis and new acceptance of themselves, they felt an empowering transformation that enabled them to be their authentic self, “And what was my life before diagnosis? It was bits and pieces of disconnected things… I was a failure, right? And there was no centre. [But] there was a centre, me, the centre is I’m autistic. And that explained all of that”. (Lilley et al., 2022, p. 1402). A key part of enabling this was reduced internal pressure to appear to fit in with others and recognising that they had been masking to appear neurotypical:

> *You don’t try and copy other people and try and fit in. You’re trying to be yourself… It’s almost every time it’s like you’re wearing a mask, or you play a character around people. But I’ve kind of stopped trying to do that. (Lupindo et al., 2022, p. 24192).*

Sharing their diagnosis with others had both positive and negative consequences for participants identity. Some participants shared how grateful they felt at finally being accepted for their true self by those important to them after feeling rejected for so long, “*blessed to have such lovely people around… care enough about me not to be bothered by my weird quirks and funny ways… It makes a change after years of bullying and being penalised for being odd*”. (Leedham et al., 2020, p.140). It fostered a sense of safety for them where they no longer felt they needed to hide aspects of themselves, and in fact, the acceptance from others made it easier for themselves to accept their new identity “*because of that acceptance, it kind of made it easier for me to accept myself*”. (Lupindo et al., 2022, p. 24193). Contrastingly, other participants recalled times where they had disclosed their diagnosis and the reactions from others made them feel invalidated, which in turn made them reluctant to put themselves in situations where they were open about this part of themselves with others going forward “*Cheryl said her autism diagnosis was also met with scepticism by her GP who told her, ‘you seem perfectly fine to me’. These doubts on the part of others, including family and professionals, made her wary of disclosing: ‘So I haven’t told many people after that yet’*”. (Lilley et al., 2023, p. 1153). Similarly, there was fear and confliction about wanting to show their true selves, but also worry that they would face rejection. This led some participants to transition “from a psychological position of seeking to hide their true selves to feeling invisible and dismissed, fighting for their true needs to be recognised”. (Leedham et al., 2020, p. 141). There was also a sad and frustrating realisation that because of their identity, they could face increased stigma and discrimination, “I don’t want to be afraid of being reported to child services if I say I’m autistic”. (Bureau & Clement, 2023, p.7). Again this fed into the belief that that not sharing their autism more widely would be the safest course of action.

Knowing who they are helps with finding a place in the world

This theme describes how following identity formation, it was important for participants to find a community who shared their identity, as well as taking ownership of their identity. This helped give them meaning and a sense of belonging.

The diagnosis had a significant impact on participants sense of belonging. For participants in the majority of studies, connecting with an autistic community was beneficial, and provided participants with “*comfort in the thought that they were ‘not alone*’”. (Huang et al., 2021, p.2992). For some it was about learning and a “*deliberate effort to gather additional information about autism and how it applied to their lives*” (Hickey et al., 2018, p. 363) to develop a greater understanding of themselves and who they are. For others it was about finally finding a place where they felt they belonged and were valued, “*one of the most valued aspects of support individuals mentioned concerned meeting other people with Asperger syndrome, making friends and feeling as though they ‘fitted in’ with a group of people*” (Punshon et al., 2009, p. 277). This was meaningful for some participants as it may have been the first-time participants experienced feeling as though they had shared beliefs and an identity with others, and less alone, “*I’ve never fitted in that jigsaw puzzle… [now] I fit somewhere, I belong somewhere with other people somewhere who are like me*” (Leedham et al., 2020, p. 142). While participants in the studies viewed being able to connect with autistic communities as important, it was not always clear to them how to connect with these communities following a diagnosis as there was often little post-diagnostic support or signposting. Difficulties with accessing these communities may have inadvertent effect of delaying autistic individuals gaining that sense of belonging.

Participants within a couple of the studies mentioned the idea of finding their autistic tribe post diagnosis: "*Finding a tribe of other people who are as they are and can be proud of who they are has just made such a difference for me as a human being*" (Lilley et al., 2023, p. 1152). The use of the word tribe implies that they are part of an in-group where their behaviours and characteristics are normalised within the group norm and suggests a deeper connection with other members of the tribe compared to other groups they could be part of. However, this sense of connection with their autistic tribe also meant that they grew to feel increasingly out of place within the wider neurotypical world "*It was common for participants to depict autistic and non-autistic people as two tribes or communities with complimentary abilities and preferences, where the dominance of non-autistic norms led to autistic people's alienation from mainstream society*" (Huang et al., 2022, p. 9).

The sentiment reported in Stagg and Belcher (2019, p. 354) that a "*greater level of self-awareness that comes with a diagnosis allows individuals to have more control over their lives and manage the way they react to situations*" was shared by many participants. Before their diagnosis, participants may have found it challenging understanding their needs. Once they have the understanding and awareness of themselves and their needs, they are able to begin living a life that reflects their true choices. This then builds a belief that they are an expert in their new identity and helps them feel as though they belong in the world around them. A participant from Ghanouni and Seaker (2023, p. 6) provided an example of how they are making adaptations to their life after finding out they are autistic to help them feel more comfortable in their daily life:

> *I'm to re-vamp my entire life so that I'm making accommodations for myself knowing what I know now. Um, so I would want to know, when I'm going into a place where I hope to be working, I would want to know that it was autism friendly… I would want to know I wasn't facing barriers in communication*.

For them it not only helps them feel they belong in their environment, but also provides them with the opportunity to plan for their future.

Many participants suggested that as their autistic identity grew stronger, some participants used their knowledge to advocate for, or support others with similar experiences, "*In instances where participants had children who also had conditions on the autism spectrum, they described how the knowledge and understanding of their diagnosis helped them understand their children's difficulties and how they could best manage and support them*" (Lupindo et al., 2023, p. 140). There was recognition that while participants could not change difficulties they faced from not having a diagnosis earlier, they now had their own expertise to shape how others could be treated and supported. In fact, Bureau and Clement (2023, p. 6) reported that the majority of their participants took part in activism as way to use their knowledge and experience to have some control over the discourse of autism in wider society. Advocating for others gave participants a sense of purpose and empowerment, as well as encouraging connectedness with others who share their identity and values.

Discussion

This systematic review thematically synthesised qualitative studies exploring how receiving an autism diagnosis in adulthood affects a person's sense of self-identity. The thematic synthesis of eleven qualitative studies led to three reoccurring analytic themes being identified. The themes were: (1) Processing the past and questioning who they are (2) Accepted by the self and others for who they are and (3) Knowing who they are helps with finding a place in the world. This was the first review to focus exclusively on participants self-identity following a late diagnosis and therefore gave a deeper understanding of how receiving an ASD diagnosis impacts a person's sense of self and the dynamic process they experience. Whilst this review highlights the positive aspects to a person's identity a diagnosis later in life can provide, it also suggests the challenges individuals face when receiving a life changing diagnosis both to how they view themselves but also how their sense of self is affected in the context of wider society.

In keeping with previous findings (Wilson et al., 2023), the review highlighted that late diagnosed adults experience a dynamic adjustment process where they attempt to understand their sense of self. However, this review extended previous findings by highlighting how re-appraising identity through an autism lens was a key process for participants in making sense of their identity. This re-appraisal was essential for participants to begin to let go of their old identity and begin to adjust to a new autistic identity. This re-appraisal process is present in the receipt of other diagnoses. In a systematic review exploring the impact of psychiatric diagnoses on individual's self-concept, similar findings were reported. O'Connor et al. (2018) found that receiving a diagnosis provided greater understanding along with providing an explanation for individuals' difficulties. They also reported having the potential to negatively impact a person's identity by exposing them to stigma. This was also seen in the current review, however in addition to experiencing stigma from others receiving a diagnosis highlighted the presence of internalised stigma felt by participants. This was evidenced through participants descriptions of their autism and their self as separate of one another when reflecting on difficulties they experience, as well as reluctance with identifying with an autism or disability label (Bureau & Clement, 2023; Hickey et al., 2018; Huang et al., 2022; Lilley et al., 2023; Lupindo et al., 2023; Punshon et al., 2009).

While self-understanding has been reported to protect against internalised stigma developing (Huang et al., 2023) this appears not to mitigate it completely. Increase in self-understanding following a diagnosis was reported in all studies in the current review, yet internalised stigma was still a prominent factor in over half of the studies. The current study highlighted that the role of internalised stigma has on externalising autistic behaviour may complicate the identity formation process and hinder autistic adults' ability to fully accept and embrace their autistic identity. This may be more challenging for older late diagnosed adults to overcome, as the society in which they grew up in had a poorer understanding of autism. Further exploration is needed to understand whether the externalisation of autism in late diagnosed adults is due to exposure to stigma in society, or due to difficulties with adjusting from their pre-diagnosis identity. This would help with identifying what support would appropriately meet their needs.

Another key finding was in relation to the power the diagnosis had in enabling self-acceptance of their identity. The reduced pressure to conform to neurotypical norms was felt to be a primary consideration as the diagnosis appeared to give permission for autistic adults to be themselves and no longer mask or camouflage autistic behaviour. While it is not known how much camouflaging effects late diagnosed adults (Hull et al., 2020) a reported

94% of autistic adults having used masking techniques at some point in their lives (Sedgewick et al., 2021) and can lead to a fragmented sense of self (Atherton et al., 2022). The reviews findings that autistic adults felt more comfortable embracing their autistic traits rather than masking them following a diagnosis is supported in the literature (Kelly et al., 2024). However, this review highlights the role this plays in fostering acceptance and allowing individuals to live more authentically and expressing their true selves, with the diagnosis appearing to provide permission for an individual to let go of masking and let their true self out.

The final theme which explores how connecting with other members of the autistic community fosters a sense of belonging for autistic adults supports what is already known about the benefit connecting with an autistic community can have for an individual (Botha et al., 2022; Tan, 2018). However, this review extends this understanding by highlighting that as a connection to their autistic 'tribe' grows, individuals felt more alienated from mainstream society. As a result, a sense of kinship with other autistic people increases (Huang et al., 2022) and it can act as a springboard for autistic individuals to use their knowledge to support others and make significant societal change for the benefit of the wider autistic community.

The themes identified in this review fit with the nine degrees of autism framework proposed by Wylie et al. (2015) who posited that adults diagnosed with ASD experience a journey beginning with 'pre-identity alignment' where the individual recognises they are different but struggles to understand why. This is followed by the 'identity alignment' stage where individuals begin to identify as autistic but also question their sense of self. Eventually, they enter a 'post-identity alignment' where they view themselves with self-acceptance and have gained mastery, or a sense of expertise over their identity. While this model has yet to be validated (Lewis, 2016), this review’s themes reflect the journey Wylie et al. (2015) propose autistic adults go through after a diagnosis as well as offering further insight. While Wylie et al. (2015) suggests that generally an individual is able to integrate autism into one’s identity before moving on to acceptance, the current review suggests that this process is complex and some individuals may struggle with this integration and continue to hold autism and their self as separate and may not move forward in this process. However, it is possible that in time participants who held this view may have had success with this integration of identity.

Strengths and Limitations

Overall, the strength of the current qualitative review was that this is the first review that focuses on how an autism diagnosis impacts self-identity, and explores in depth the impact to identity with this group of people and demonstrate the pathway of this process through the thematic synthesis. The use of the adapted approach to appraising qualitative studies by Long et al. (2020) allowed the impact from lower quality studies to be mitigated, but importantly ensured that all the studies in the review contributed to the synthesis.

There are some limitations in this review. This review adopted the widely used CASP guidelines for appraising quality of the studies, however, there is debate about the use of appraisal checklists in qualitative research with concerns related to whether they do in fact assess the design of the study and methodology, or instead are limited to the researchers reporting (Goldsmith et al., 2007), and miss the interpretive context of the study which is a key component of what qualitative research offers. While a strength of using the CASP checklist in the current review facilitated a deeper engagement with the data and critical discussion between the reviewers, the conclusions and ratings given to each study was subjective and based on individual interpretation. This could lead to inconsistencies with the evaluation process.

The methodologies included in the review consisted of thematic analysis, IPA, and content analysis, the majority of which were thematic analysis. Thematic analysis focuses on identifying common patterns/themes across participants. Therefore, it is possible that unique and/or contradictory experiences that may be identified in methodologies such as IPA, grounded theory, or narrative inquiry were not equally represented in this review. This limited range of methodologies used in the current review may reflect how historically there has been a lack of focus on autistic perspectives that capture lived experiences in published research (Milton, 2012), and only recently has there been a shift toward qualitative research methods. Similarly, the majority of review studies used semi-structured interviews that are limited to capture verbal data, therefore, deeper contextual insights may not be possible to interpret.

There was considerable variation in the length of time since participants received their diagnosis from, as little as 3 months (Punshon et al., 2009) to 20 years (Hickey et al., 2018). The variation in time may impact where a person is on their adjustment journey since diagnosis, with the more recently diagnosed still assimilating ASD into their identity and may not be able to have had experiences that represent all stages in the analytic themes. Similarly, the age at which a diagnosis was received varied greatly from 18 years old (Ghanouni & Seaker, 2023) to 64 years old (Lupindo et al., 2023). It is possible that adults who received their diagnosis in early adulthood may have very different experiences of their identity compared to studies that focused on older adults. Further research focusing on diagnosis both in early and late adulthood may provide us with more information regarding the role that age may have in identity formation following a diagnosis.

Clinical implications

The review highlights clear implications for clinical practice. Receiving a diagnosis in adulthood can have both a positive and negative impact on individuals' self-identity and feelings, and the impact appears to be idiosyncratic and dynamic. It may be helpful for clinicians to be curious about how this event is being appraised, and its effect on their client's mental well-being. For some people, receiving a diagnosis may be associated with the development of acceptance, forgiveness, and a motivation to connect. There may be opportunities for health professionals to work with clients to formulate the impact of this event on them following a strength-based approach.

Further, the findings highlighted that internalised stigma could hinder self-acceptance. Healthcare professionals can play a role in reducing this by educating and providing resources to newly diagnosed individuals and their families, as well as facilitating access to support groups where autistic adults can share and normalise experiences. It is also important for healthcare professionals to use their position of power to advocate for further campaigns to tackle societal stigma.

Conclusion

The aim of this review was to thematically synthesise qualitative studies that explored how a late diagnosis of ASD impacted self-identity in adults. The synthesis of eleven studies led to the identification of three reoccurring analytic themes. Overall, the review demonstrated the general process autistic adults go through following a late diagnosis: renegotiating their identity through reappraising past experiences allowing them to adjust their sense of self, accepting autism as part of their identity, which then allows them to authentically connect with others with a shared identity and creates a sense of belonging that may not have existed before. This review suggests that a barrier that may hinder autistic adults developing an autistic identity include stigma, from both society and internalised that may prevent autistic adults from sharing with others their new identity and make letting go of a pre-diagnosis identity difficult. It is important for clinicians to ensure newly diagnosed adults have opportunities to understand the impact a diagnosis can have on them and their view of themselves.

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Chapter 3: Bridging Chapter

The qualitative systematic review explored key issues regarding self-identity for autistic adults who received a late ASD diagnosis. In particular it highlighted the identity formation process that occurs following a late diagnosis. Key to this was a reappraisal and renegotiation of their previous identity to an autistic identity through gaining a more complete understanding of themselves. For many late diagnosed adults, experiences growing up can be confusing and distressing without having an ASD framework in which to make sense of them (Leedham et al., 2020). Receiving a diagnosis allows them the opportunity to begin a re-examination process of all aspects of their life.

Despite a growing number of adults receiving an ASD diagnosis, research with this population remains limited (Russell et al., 2021). The empirical paper presented in the next chapter further seeks to understand the experiences of social trauma in late diagnosed adults. This will be achieved through a qualitative inquiry that will provide an in-depth exploration of participants' experiences. The purpose of this is to develop a foundational understanding of this phenomenon that has minimal existing research. The identified themes will be presented in the following chapter, with additional methodology reported in chapter six.

Chapter 4

Autistic adults' experiences of social trauma: An Interpretive Phenomenological Analysis

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Word Count: 6000

Abstract

Autistic adults are more likely to interpret adverse social events as socially traumatic. Currently we know very little about how a late diagnosis of autism impacts a person's interpretation of socially traumatic events. This study aims to explore the experiences of social trauma in late diagnosed adults and how they make sense of these experiences before and after their diagnosis. Six late-diagnosed autistic adults completed semi-structured interviews. Data was then analysed using Interpretive Phenomenological Analysis (IPA) and four superordinate themes were identified: (1) experiencing social trauma, (2) making sense of socially traumatic experiences, (3) how I manage social trauma, (4) re-examining social trauma with a new lens. Participants described experiences of rejection, exclusion, and social humiliation in social situations as socially traumatic. Autistic traits can play a prominent role in socially traumatic events, both in the cause of social trauma and in increasing the likelihood an event will be interpreted as traumatic. This research highlights that a diagnosis helps autistic adults to reframe past traumatic experiences through the lens of an autism diagnosis, which can reduce negative feelings attached to these memories, and instead encourage self-acceptance and self-compassion.

Key words: Autism, ASC, Social trauma, Late diagnosis

Background

In the UK approximately 700,000 people have a diagnosis of autism spectrum condition (ASC), around 1-2% of the population (British Medical Association, 2020). Historically autism was constructed as biological and understood through a deficit and medical model (Glynne-Owen, 2010). Despite the lack of evidence of identifying a single genetic marker, autism has been assumed to have an identifiable biogenetic cause. This discourse was rooted in positivist professionalised science perspective (Begon & Billignton, 2019). This understanding of autism through a medical/deficit model has over the past years been challenged in part due to its stigmatising perspective that considered autism as an impairment of social communication, as well as its inability to capture the complex and heterogeneous autistic experience. This construction of autism has evolved over time through considering autism in terms of cognitive differences seen in theories such as Theory of Mind (Baron-Cohen, 2000) and Weak Central Coherence Theory (Frith, 1989). With the growth of the neurodiversity movement, autism is increasingly being viewed as a natural variation, and the social model proposes that autism is shaped by social attitudes and barriers (Anderson-Chavarria, 2022). Challenges autistic individuals may face are not due to inherent impairments, but rather because society is formed from neurotypical norms. This can put autistic individuals at a similar or increased likelihood of experiencing ill mental health compared to a non-autistic population (Buck et al., 2014).

Within the autism population, post-traumatic stress disorder (PTSD) is reported to occur at a similar or a higher rate compared to a non-autistic population (Rumball, 2019; Rumball et al., 2020). While there is a considerable body of research exploring autism and traumatic events separately, the experiences of trauma, and presentation of trauma and PTSD in autistic individuals is limited (Peterson, et al., 2019). Within the existing research, focus is predominantly on DSM-5 trauma and Criterion A diagnosed PTSD (Rumball, 2019; Stavropoulos et al. 2018), which the DSM-5 defines as “exposure to actual or threatened death, serious injury or sexual violence" (American Psychiatric Association, 2013). However, numerous studies have shown autistic adults have an increased risk of experiencing non-DSM-5 traumatic and stressful life events, which can result in developing PTSD symptoms (Allely & Faccini, 2019; Fuld, 2018; Haruvi-Lamdan, et al., 2020; Rosen & Lilienfeld, 2008). It has also been suggested that autistic adults have heightened stress reactivity (Brewin et al., 2009) and those who have unique perceptual experiences, including autism (Brewin, Rumball & Happe, 2019), may be more susceptible to developing PTSD symptoms following lower intensity, non-DSM-5 trauma events. Due to commonly seen core features of autism, such as overstimulation by sensory sensitivities, changes in routine, including loss of availability/access to a specialist interest, and the anxiety around social confusion and miscommunication, a broader range of life events may be interpreted as traumatising compared to non-autistic individuals (Brewin, Rumball & Happe, 2019).

Autistic individuals are at risk of experiencing adverse social events, such as humiliation, rejection, bullying, verbal insult, and social exclusion (Maïano et al., 2016), with 44% of autistic students reported being bullied (Maïano et al., 2016). Autistic adults are more likely than non-autistic adults to experience negative life experiences (Griffiths et al., 2019). They are also more likely to interpret these adverse social events as 'socially traumatic', meaning that these events have an enduring negative effect on an individual (Haruvi-Lamdan et al., 2020). Experience of social trauma has been found to be associated with post-traumatic stress symptoms in autistic individuals (Allely & Faccini, 2019; Fuld, 2018; Haruvi-Lamdan, et al., 2020; Rosen & Lilienfeld, 2008) and reduced quality of life (Hong et al., 2016). However, evidence of statistical association cannot explain the possible mechanisms behind it. Therefore, it is important to understand how autistic individuals make sense of these adverse social traumatic events.

Over recent years, increasing numbers of adults have received diagnosis of ASC (Huang et al., 2020; Leedham et al., 2020). Receiving a diagnosis can have a positive impact on an individual’s sense of self by providing an explanation and retrospective understanding of their own past and insight into past challenges and experiences (Stagg & Belcher, 2019). Individuals also reported a shift towards a positive perception of difficulties and away from negative perceptions (Lilley et al., 2022). Tan (2018) described how receiving a diagnosis later in life enables individuals to develop a new ‘autistic identity’ and re-evaluate critical life events through the lens of autism. Research therefore suggests that following a diagnosis, individuals are likely to experience key phenomena including re-evaluating identity and producing a new self-narrative (Molloy & Vasil,2004; Punshon et al., 2009) along with a positive increase in social esteem (Jones et al., 2001). This can be particularly relevant for autistic adults when they re-evaluate their relationship with adverse social events.

There is a lack of in-depth qualitative research that explores the potentially unique perception of socially traumatic events of autistic adults. While there is existing research that explores experiences that are considered socially traumatic, such as bullying and social rejection (Maïano et al., 2016) in the autistic population, we do not yet understand how the impact of how a late autism diagnosis impacts a person’s interpretation of socially traumatic events. Existing research suggests that receiving a diagnosis in adulthood promotes a re-evaluation process of past events (Hickey et al., 2018; Leedham et al., 2020). Therefore, the aim of this study was to explore the experiences and perspectives of social trauma in late diagnosed autistic adults, and further understand how late diagnosed adults make sense of such events before and after receiving a diagnosis of autism in adulthood

Methods

Methodological approach

This study adopted a qualitative research approach to explore late diagnosed autistic participants experiences of social trauma. Interpretive Phenomenological Analysis (IPA) (Smith et al., 2009) was the qualitative framework used with semi-structured interviews. The focus on exploring individual lived experience allows IPA to examine topics closely that may be complex, vague, and emotionally charged in a personal context. This makes it useful in areas where little is known about the issue being examined. IPA is primarily concerned with the individual experience (Smith et al., 2009) and looks at how this is contextualised within society and culture. This can be relevant to autism research in so far as autistic symptoms are defined in a social context and viewed as impairments.

Participants

A purposive sample was used to recruit participants from an NHS adult autism diagnostic service. To participate, individuals were required to: have received a diagnosis of ASC at least 3 months before the interview took place, be fluent in English, be over the age of eighteen years, and have experienced events that are interpreted as traumatic but are non-DSM-5 traumas. Participants were not able to take part if they had an intellectual disability, or have a current diagnosis of post-traumatic stress disorder (PTSD). Six participants took part in the study. Participant characteristics, including their gender, age range, ethnicity, and length of diagnosis are shown in Table 1.

Table 1

Participant demographics

Participant pseudonym	Gender	Age range	Ethnicity	Length of time since diagnosis
Blake	Male	51-65	English/Welsh/Scottish/ Northern Irish/British	4 months
Sam	Male	35-50	Self-employed	6 months
Oliver	Male	18-34	English/Welsh/Scottish/ Northern Irish/British	8 months
Ashley	Non-binary	18-34	English/Welsh/Scottish/ Northern Irish/British	6 months
Richard	Male	35-50	English/Welsh/Scottish/ Northern Irish/British	11 months
Poppy	Female	35-50	Any other White background, please describe	13 months

Procedure

Ethics

Ethical approval for the study was obtained from the Health Research Authority and NHS ethics (ref: 23/YH/0143) and the relevant NHS Trust Research and Development (HRA approval letter, Appendix C; REC approval letter, Appendix D).

Recruitment

A clinician from the NHS autism diagnosis service identified eligible participants by screening their internal clinical record, and they were informed about the research study. Eight individuals who expressed an interest in taking part gave their consent to having their details passed on to the first author. Afterwards, the first author contacted them to discuss the purpose of the study and share an information pack. After at least 24 hours, six out of eight participants gave their consent to take part in this study by engaging in either an in-person interview (n = 3) and an online video interview (n = 3). Participants were made aware that interviews were recorded, of their right to withdraw, and that personal data would be pseudonymised.

Interviews

The first author (CG) conducted all the interviews using an interview schedule which consisted of four open-ended questions (see Table 2). Prompt questions were used to gather further information. During and after the interview, CG noted down reflections of the interview process to develop and maintain awareness of their own beliefs and experiences, and how these may affect their interpretation of the data. The interviews lasted from 54 to 90 minutes, with a mean length of 68 minutes. Participants were debriefed at the end of the interview and were given a £10 Amazon gift voucher.

Table 2.

Interview Schedule

Question Number	Main Questions
1	What are your experiences of social trauma?
2	Did receiving a diagnosis of autism have any impact on how you make sense of these experiences?
3	How has autism influenced how you make sense of these experiences?
4	How did growing up without having a diagnosis of autism impact on how you make sense of these experiences?

Data analysis

Transcripts were analysed by the first author (CG) using the IPA procedure recommended by Smith et al. (2009). CG transcribed the recorded interviews to become fully immersed in the data. The transcripts were then re-read to ensure familiarity with the text. Initial notes and comments (descriptive, linguistic and conceptual) were made through the entire first transcript. Once completed, emergent themes from the initial notes were collated. Themes were named either as they were found in the data, developed from identifying concepts, or descriptive and based on what was occurring in the data (Fade, 2004). Once the whole transcript was coded this way, themes were listed, and connections identified and clustered in a meaningful way while some emerged as superordinate themes. The themes identified in the first transcript were then set to one side and the steps repeated with the remaining interviews (Smith, 1996; Smith, 2010).

Once all transcripts were analysed CG established connections and identified differences and similarities across the interviews to recognise the consensus in participants experiences as well as conflicts (Smith and Shinebourne, 2012). Recurrent themes were cross referenced with the data with extracts from the transcript supporting each theme noted. As the analysis progressed some themes were dropped due to insufficient evidence. The analytic process was iterative, with movement between the analytic stages to ensure themes were representative of participants responses. Finally, a list of superordinate themes, subordinate themes, and supportive examples was produced to accurately reflect the findings.

Quality assurance

In line with Yardley's (2000) principles for qualitative research quality assessment, a reflective diary was used, and reflective discussions with the wider research team were held at all stages of the research process. Additionally, two of the transcripts were reviewed by co-authors to review initial codes and themes and ensure emerging themes were based on the data. Findings were discussed to support the validity of data interpretations.

Reflexivity and position of the researcher

In previous clinical roles, I have worked with recently diagnosed autistic adults and have observed how people can feel their voices and experiences are not heard or represented. I am keen to use my position as a researcher and clinician to promote underrepresented experiences to help increase our understanding. I am aware that as a non-autistic researcher conducting research on autism, I do not have the lived experience of that which I am researching, and recognise that this will influence how I interpret qualitative data from autistic participants. Conscious of this, I kept a reflexive journal throughout the interview and analysis process that helped me to maintain awareness of my perspectives and the impact they may have. I was aware that the topic of the research, social trauma, may be sensitive to discuss, especially with someone they are unfamiliar with. I tried to use my experience and skills from clinical psychology training and previous clinical roles to create an environment where participants felt safe to discuss potentially distressing experiences.

Findings

Four superordinate themes were identified in the analytic process (1) Experiencing social trauma; (2) Making sense of socially traumatic experiences; (3) How I manage social trauma; (4) Re-examining social trauma with a new lens. Table 3 illustrates participant representation across the themes. Superordinate themes and the supporting subordinate themes are discussed below.

Table 3.

Representation of participants across themes

Superordinate and subordinate themes	Total	Blake	Sam	Oliver	Ashley	Richard	Poppy
Experiencing social trauma	6	●	●	●	●	●	●
Feeling like an outsider	5	●	●	●	●	●	
The role of other people in my trauma	4	●		●		●	●
Making sense of socially traumatic experiences	6	●	●	●	●	●	●
Am I the problem?	5	●	●	●	●		●
Living in confusion	4	●	●		●	●	
The injustice of being misunderstood	2	●				●	
How I manage social trauma	5	●	●	●		●	●
I can't handle this – feeling overwhelmed	5	●	●	●		●	●
What I do to help me cope	4		●	●		●	●
Re-examining social trauma with a new lens	6	●	●	●	●	●	●
Looking back with regret	5	●		●	●	●	●
Everything makes sense now	6	●	●	●	●	●	●

Experiencing social trauma

This theme captures participants' interpersonal experiences and how participants relate to those experiences, including how they can impact what may be interpreted as socially traumatic or not. Two subordinate themes represented these experiences: *feeling like an outsider* and *the role of other people in my trauma.*

Feeling like an outsider

Most participants described from an early age having a sense they were different from others. Blake spoke about this feeling, and described an awareness he had of experiencing the world differently to others and how others did not always respond positively to him: *'I was aware very early on that I didn't… always rationalise things the same way as other people did. Because I was aware quite early on that sometimes I did things that… jarred with people'.* (Blake). Participants also described experiences of being bullied in their younger years.

> *Sometimes you thought someone was being your friend, so you try and tell them like how you felt or what you're in, what you liked or what you been up to. Next thing you know, they're, telling the people who sort of pick on you, bully you and then use [it] against you. (Richard).*

For some, it was their autistic traits that made them stand out and increased their vulnerability to being bullied. Richard frequently experienced other children making fun of the way he behaved and his interests, which impacted his view of himself, *'That I was abnormal. Well, I've been told it, you know, you're weird. So it just gets to the stage where you believe it, that you are weird'.* (Richard). Participants could then hold the belief that this lack of acceptance and understanding from others resulted in them being excluded or unwanted, leading to feelings of rejection: *'I was kind of just there and I just felt like I was just the person who was just there, but no one really would care if I was gone.'* (Ashley).

An accumulation of these experiences may have led some participants to believe that there was something wrong with them and internalise the rejection reinforcing the belief that they are outsiders and '*didn't deserve to fit in'*. For some participants this resulted in them isolating themselves more as a way to protect them from further social rejection. Ashley describes this process of pre-emptively pushing others away to stay safe in order to avoid later rejection: *'And it kind of made me feel like… I need to keep people at arm's length. You know, like 'cause, they hung out with me, like one on one, or they would just realise I was not normal'* (Ashley). However, this in turn made them feel lonelier and unwanted which led to further traumatic experiences.

Poppy described very different experiences to other participants. Overall, she felt like she had managed to avoid socially traumatic experiences amongst peers. She attributed this to feeling accepted by others.

> *If I wanted to do I'd just join them and no one would comment on it. So I think it would have been really different if I couldn't have joined them. Because then it wouldn't have been a choice not to. Now I could choose, I could be on my own, be with them, or do whatever I wanted to do. People were pretty accepting when I was little.*

For Poppy, although she felt different to others, she did not feel these differences prevented her from being part of a group. That ability to have a choice appears to be an important aspect in whether participants would go on to view themselves as an outsider or not.

The role of other people in my trauma

Participants discussed the role others played in their socially traumatic experiences. Richard described being taken advantage of by others: '*they think you're overly trusting, you're a bit of a sucker'.* For him this had a long-term impact: *'I didn't trust people for a long time'.* Blake shared similar feelings. He goes on to describe experiencing betrayal and the devastation and frustration he felt when he realised he had lost a friendship that was important to him.

> *That particular social thing has done me for a while. I'm just, at the end of that… how things were so great, so cool, so fantastic. I've found a best friend, to be very, very*

> *Disney about the whole thing. To end up like that… I was on the floor… It's five years later, it still just has that infuriating effect.*

It was not only in-person social experiences that could result in socially traumatic experiences. For Richard, negative experiences in online social spaces lead to real world changes in his behaviour, '*That's one thing I stay dead away from now because of the experience I had with social media, I wouldn't want it'.* In contrast, Poppy spoke about how support from others was a factor to reduce social trauma. When reasonable adjustments were made (such as working from home to avoid loud and crowded spaces) Poppy felt able to manage distressing situations in a way that did not lead to social trauma: '*You know, the teacher would just let me, she would let me sit, she would check that was alright. And then she'd let me sit out… and she'd let me sit there until I was ready to come in.'*

Making sense of socially traumatic experiences

This theme considers the ways in which participants attempt to make sense of their socially traumatic experiences and the understanding they eventually come to, and demonstrates the thought process of considering their own role in what they have experienced.

Am I the problem?

Many participants described feeling responsible for the socially traumatic experiences they have lived through. Ashley believed that they had behaved in a way that was wrong and that had upset others: *'I just assumed that people didn't like me and I was doing something wrong that meant that I didn't deserve to fit in'* which resulted in experiences of self-blame and '*more guilt than like is normal'.*

For some participants, having their words and actions misunderstood by others could contribute to distressing situations. In these situations, the responsibility for these misinterpretations occurring was predominantly held by the participants. Blake describes how this felt like *‘such a hammer blow’* and created a lot of self-doubt for him in social situations: *‘every time I said anything, it was always taking the worst possible light. So before I said anything, I was running it through my head double, triple checking it’.* It was evident how exhausting it had become for Blake trying to work if he had done something wrong. For Oliver, this behaviour appeared to others as controlling: *‘I'd always get that you’re controlling. That whole controlling card would come up a lot. I'm not controlling you. I'm just saying, like, I… don’t like surprises’.* This felt both hurtful and frustrating having his behaviour misinterpreted so negatively.

Following this misinterpretation stage was the thought process of ‘*what I should have done instead’* (Sam) and a general sense of feeling responsible for fixing the situation. For Blake, trying to make sense of what happened became a problem he would fixate on: ‘*And I get caught in this little obsessive loop of how can I fix this? How can I make it better?’.* Frequent use of the word ‘I’ amongst participants suggests a strong belief that interpersonal difficulties were their fault and not others . This internalising could then lead to negative beliefs being formed about themselves *‘It just kind of added up that I was a bad person’* (Ashley).

In contrast to the majority of participants, Poppy gave an account where she felt she was fortunate to avoid many socially traumatic experiences that other autistic adults have experienced. Poppy believed this was *‘possibly because I don't care what people think’*. While other participants may have had to cope with interpersonal difficulties such as bullying, social exclusion and humiliation, Poppy felt ‘*I was never the aim of anything if that* *makes sense and I don't remember anything, or at least I didn't notice'.* While other participants may have described feeling embarrassment or shame when committing social faux pas', Poppy's lack of awareness could have meant that she was not attuned to the opinions of others '*Because why would I?'.* Poppy surmised that this lack of interest in other's opinions acted as a protective factor for her, and reduced the likelihood of her interpreting situations as distressing, '*It's my brain just does not, compute the other people in the crowd. Which I think is quite lucky [laughs] because I think it's saved me from one of these traumatic experiences'.*

Living in confusion

Confusion was a cause of social trauma due to interacting in a world that may not make sense, but was also frequently experienced after a socially traumatic experience. Richard experienced confusion as feeling stuck in a cycle.

> *I don't understand something, my brain struggles to makes sense of what happened. And if we don't understand something leads to confusion which leads to more anxiety, which leads to more upset you know. Like one of those self-eating circles. Where does it end?.*

For others that confusion was more prominent following socially traumatic experiences. For Blake this confusion felt sudden,

> *It's just one of those things where the, the world as I knew it or the, the situation as I knew it and saw it was shattered for me, it was the inverse of what I was, of what I knew. And, in a very… clear and brutal fashion.* (Blake).

For Blake, the world that he knew felt broken, he felt broken, and he appeared uncertain of what to do going forward. This loss of certainty was echoed by Ashely when they spoke of a lost friendship: '*I couldn't tell what they didn't like about me. Like I couldn't tell what I'd done* *to, like, offend them or upset them. But I just felt like I was being normal'*. For Sam it was not only the initial experience that caused confusion, but also his reaction to what he went through that did not make sense to him to the point where he felt his response was unreasonable.

> *So you know, it's not something that bothers me too much anymore. But it did for several years afterwards, which seemed like a horrendous overreaction. I've no idea why it was so traumatic to me at the time that I could not stop thinking about it.*

The lack of diagnosis also plays an important role in participants experiences of confusion, and appears to almost prevent them from moving forward,

> *It's sort of like if, if, I don't know why I messed this up then… before I got a diagnosis, whenever the, the, the situation comes to mind… I'm still not good enough to know what I did wrong. I haven't reached that level of… knowing how that happened*. (Blake).

This suggests that before receiving his diagnosis Blake felt stuck and unable to process traumatic events, further contributing to his feelings of distress.

The injustice of being misunderstood

Participants often felt blamed for misunderstandings. Blake explained how '*every time I said anything, it was always taking the worst possible light'* and how he felt the need to defend his actions from '*the injustice of it'* and being interpreted negatively: *'that's not what I'm, it's not what I'm trying to do'.* Blake explained how infuriating he found it when he followed through with what he said he would do, only to have other people '*surprised that when I say I do something, I mean it'.* For Blake, it does not seem fair that others should be upset with him in this situation, but it left him feeling *'emotionally incompetent or socially incompetent'.*

Richard described having a black and white approach to right and wrong. He reflected that this could put him in a position where interpersonal conflict may be more likely to occur,

> *‘If someone does something that I know is wrong… I'm like a dog with a bone and I won't let go, and I will make them know what they are saying is wrong or what they're doing is wrong. Sometimes get me into trouble, which is one of the traumatic things.* (Richard).

Richard went on to describe an experience where he felt he was unfairly punished for the mistake of someone else *‘she had reacted in a completely unprofessional way. Yet she’s being unpunished for it and we're being told we're at fault’*.

How I manage social trauma

This theme considers the ways in which participants were emotionally impacted by social trauma and their attempts to manage their feelings following social trauma.

I can’t handle this – feeling overwhelmed

Many participants described feeling overwhelmed and unable to cope with distressing emotions: ‘*I was over stimulated just trying to manage things’* (Blake), and ‘*there was always a sort of a conflict of I'm at the pub having fun. Why do you want to go, like that whole sort of internal war of fighting, feeling tense and anxious, and having had enough of everything’* (Oliver). For others, they noticed these emotions after an experience took place: ‘*it ended with me breaking down in tears and running away’* (Poppy), *‘I don't know why, but I got so upset by it. I basically didn't eat for two weeks’* (Sam).

For some participants they found that experiencing sensory overload contributed to their traumatic experiences. Oliver describes when this happens there is a '*need to sort of escape'*. Coming to the decision that he needs to leave appeared to be an overwhelming cognitive process.

> *I don't want to be here. I've got to go. I don't why I've got to go. But I just want to get, like, almost, like, involuntarily sort of stand up and leave. Like I'm still walking away, why am I walking away.*

Along with feeling cognitively overwhelmed, Richard describes feeling physically overwhelmed: *'it's like a being plugged into the mains, not in a good way. Your whole body is vibrating on the negative thing'*. Both of these accounts demonstrate the exhausting toll of being overwhelmed. There is also the sense that both men feel as though they have very little control over their response to these situations.

What I do to help me cope

Participants spoke of various ways they dealt with past social traumas. Avoidance appeared to be a prominent method of coping with distress. Richard provided several descriptions of avoidance. From not wanting '*to draw attention to myself'* and stay in the *'background'* to fit in with others and minimise difficult social interactions, to avoiding thinking about past traumatic experiences so as to *'protect myself from things that make me feel like that'* and avoiding reliving distressing events. For him, the alternative of discussing them would only '*bring back them horrible suicidal thoughts'*. Richard felt that there was no other way to cope with these experiences. Avoidance in order to prevent social trauma was similarly seen in Oliver's account. He described avoiding arguments '*I kind of find myself pulling out of arguments'* and taking the blame unnecessarily *'I definitely find myself like apologising to things that probably aren't even my fault'* to appease others and prevent an escalation in conflict.

Poppy described feeling fortunate when she was younger as she felt she was in an environment that supported and adapted to her needs, even if her difficulties were not completely understood: *'There was no such thing as any sensory room or anything obviously back then, but I think that was probably a fairly close approximation of creating an environment, even if it was accidental'.* Having this foundation when younger appeared to reinforce the belief that she is able to make changes to ensure she leads a fulfilling life and feels comfortable making adaptations if needed: *'I've adapted my life really well to avoid those sort of uncomfortable situations. I work from home for example.'*

Re-examining social trauma with a new lens

This theme describes how an individual makes sense of their socially traumatic experiences following a diagnosis of autism, and the re-evaluative process they go through in developing a new understanding of past experiences.

Looking back with regret

Following their diagnosis, participants appeared to experience a re-examination of past social traumas. A shared experience for many participants were feelings of regret when looking back.

Blake describes the regret he feels when looking back at traumatic social interactions with this new understanding of himself and questioning if things could have turned out differently: '*if I'd known then what I know now then that well, that could have all gone a lot better and it's, it's, it's sometime, like it's a double-edged sword'.* This implies that receiving the diagnosis for Blake brought relief and understanding, but also bitterness as he is forced to look back at *'missed opportunities and missed friends'.* This sentiment was shared by Oliver who reflected on how his past actions may have unintentionally caused distress, and the regret he has at now recognising this: *‘maybe I should have been a little bit more conscientious than what I’ve done before’.* However, for Oliver regret was followed by acceptance and allowed him to *‘put a lid on things’* and move forward.

For Poppy and Ashley, the sentiment ‘if only’ appears to capture their experiences. Ashely questions if only they had received the diagnosis earlier would they *‘have got treated a lot better if I’d got diagnosed back then’.* Ashley described feelings of sadness when considering that traumatic events of their youth may have been avoided if they knew they were autistic. Poppy shared similar beliefs that having the diagnosis earlier may have helped her understand herself and enabled her to ‘*communicate properly’*, thus reducing distressing interactions.

Everything makes sense now

All participants discussed how they were able to reflect on their past social trauma with a new perspective following their autism diagnosis. For some, the diagnosis *‘has a lot of explanatory power’* (Blake) and helped them understand their responses to socially traumatic experiences. Before the diagnosis, it felt difficult trying to make sense of what they didn’t understand. Sam describes how receiving an autism diagnosis helped *‘make some of my social failures a bit easier to understand’.* Poppy described receiving the diagnosis as ‘*the missing puzzle piece that sort of makes the whole picture clearer’.*

The diagnosis also allowed participants to change beliefs about themselves, ‘*I'm not just, not just strange [laughs]. I'm not just the one in the group that disappears, there's actually a reason behind it. It's kind of that answered a lot of unknowns’* (Oliver). From Oliver’s perspective there is a sense of relief and justification for his differences and the diagnosis provides validation for why he struggled. From Blake’s perspective, it’s provided an alternative identity. Instead of viewing himself as ‘*socially incompetent’*, there was now a compassionate understanding of why he may struggle socially: ‘*I’m autistic’*.

There appeared a notable shift in blaming themselves when remembering past trauma: ‘*if I did just recall a memory and think, oh, I feel bad about that, I would realise, OK, it’s because of autism, it's not because of me’* (Ashley). This account shows how they are able to move from a critical perspective of themselves to becoming empathetic of their difficulties. This in turn appeared to help their ‘*self-esteem and confidence’* (Ashley) where they no longer felt as though they need to put themselves in situations that may be distressing.

While having the diagnosis could provide transparency for participants responses in social situations, it has led some participants to question the behaviours of others and their role in traumatic experiences: *‘You know, realising you’re autistic, maybe makes sense of the, the events that led up to being traumatized, it doesn't make sense for people's behaviour or their attitudes, though’*. (Richard).

The researcher reflected that there was a sense of clarity that came to participants when discussing their socially traumatic events following re-examination after a diagnosis. Feelings of confusion and frustration appeared to be dominant before diagnosis, but after having received that missing piece of the puzzle, some participants described these emotions being replaced by a strong sense of anger and feeling let down by the world around them. This was highlighted by Ashley’s reflection that:

> *It just makes me angry at the whole world for it just being that way. But the trauma isn't, it’s just not directed at me anymore. It's not like I'm traumatised because people*

> *are treating me badly because I deserve it. It's the other round. It's I'm traumatised because the world is horrible.*

Discussion

Overview

The study aimed to explore the experiences of social trauma in autistic adults who received their diagnosis in adulthood, and to explore how a late diagnosis affected their understanding of social trauma. Six semi-structured interviews were conducted with adult service users recruited from an NHS autism diagnostic service. Four superordinate themes were identified using IPA: (1) experiencing social trauma, (2) making sense of socially traumatic experiences, (3) how I manage social trauma, (4) re-examining social trauma with a new lens.

Participants described a variety of situations they appraised as socially traumatic, from having their actions misinterpreted, to being excluded by others. Traumatic experiences can be understood to be experiences that threaten a person's sense of self or safety (Barry & Noam, 2003; Lanius et al., 2020). The experiences described by participants can be viewed with this perspective. Experiences of exclusion, rejection, and feeling misinterpreted were considered traumatic for participants as they could be perceived as harmful to their sense of self. This was evident in participants accounts of bullying where there was a fear that others would use personal information shared in confidence against them, and in participants use of self-critical language such as 'weird' and 'abnormal'. These experiences were interpreted as emphasising a negative sense of self. This reinforced beliefs that they did not deserve to fit in and were outsiders.

This study also highlighted the unique role that autism has in socially traumatic experiences. Autistic traits can play a prominent role in socially traumatic events, both in the cause of social trauma and in increasing the likelihood an event will be interpreted as traumatic. Participants frequently described communication difficulties, in particular with verbal communication, which is supported by existing literature (Meyer et al., 2006; Volden, 2004). A key part of this for participants was how misinterpreting others and having their actions misinterpreted themselves could result in distress. This was seen in accounts from Oliver and Richard, who, following socially traumatic experiences choose to avoid future social interactions with the intention to protect themselves from further distress. However frequent instances of this may further hinder their ability to navigate future social interactions (Levi et al., 2023). It can be hypothesised that increasing avoidance may reduce their perceived ability to cope with social situations and therefore lead them to feel more anxious and distressed when faced with social experiences in future. The use of avoidance coping strategies is associated with increased levels of distress (Littleton et al., 2007). This avoidance can create a negative feedback loop where individuals become overwhelmed and continue to avoid situations which can lead to an enduring negative effect on their social self-efficacy.

An interesting finding of this study was from Poppy who reported appraising challenging social situations more positively. She discussed how difficulties in understanding or predicting what other people may be thinking have acted as a protective factor from interpreting events as traumatic. For Poppy, a lack of interest in the opinions of others meant that she felt little internal pressure to fit in with society's norms and reported fewer feelings of shame and embarrassment. Autistic individuals may struggle with social cues and nonverbal information (Baron-Cohen, 2000) which was seen in some participants accounts where they were acutely aware of the discrimination and bullying they experienced from others due to social difficulties. However, Poppy's experiences suggest that for some autistic individuals this may in fact protect them from interpreting social behaviours as negative. A different perception of social norms may make them less likely to feel the same social expectations and pressures that can lead to social trauma.

Participants described experiencing sensory overload in social situations where they became overwhelmed and felt the need to escape. These experiences felt so distressing to participants that they appraised their anxious arousal as socially traumatic. It was not clear to participants at the time why they struggled in these environments which added to their distress (Leedham et al., 2020). Following a diagnosis, anxious arousal was understood as part of their autism. They were now able to interpret their anxious arousal to mean that they were feeling more because of who they were, not because the situation was traumatic. This sentiment was summed up by Oliver when he shared '*I'm not just the one in the group that disappears, there's actually a reason behind it'.*

The re-evaluation of socially traumatic experiences following a diagnosis was another notable area of exploration for participants. The diagnosis validated experiences and acted as confirmation that challenging social experiences were not imagined. It provided an explanation that these experiences were not due to personal failings, but rather differences in neurodevelopment. This in turn helped participants to be able to process these traumatic memories and reduce negative feelings attached to these memories, such as shame. This encouraged acceptance and self-compassion when looking back on past experiences and allowed them to develop a new autistic identity. This self-compassion was evident in the change of language that was used. Previous labels or explanations participants had told themselves were now replaced with the new understanding, 'I'm autistic'. This process is echoed by Stagg and Belcher (2019) who suggested individuals were able to reframe their identity with the late diagnosis giving context to their past struggles.

Research Implications

In this study undiagnosed autistic traits played a prominent role in socially traumatic experiences. However, individuals who received a diagnosis earlier in life grew up with an autism framework to explain their social difficulties, and therefore may have very different social traumas. Further exploration would be needed to determine if these findings are representative of the experiences of others within this community, and whether an early explanation of their social difficulties affected what experiences were perceived as socially traumatic.

Clinical implications

This study has several clinical implications. The findings in this study suggest that autistic individuals who grew up without a diagnosis do so without an understanding for why they may have experienced difficulties in social situations, leading them to appraise these experiences as traumatic and develop their own beliefs regarding their social trauma. Making sense of long-held beliefs is unlikely to occur after one assessment. Therefore, clinicians working with autistic adults should consider how they can normalise this re-evaluation experience and the ensuing mixed emotions that are felt, and foster forgiveness and acceptance. It is also important for clinicians to recognise how an autism assessment can itself be a therapeutic process and how an autism diagnosis helps individuals develop an understanding of why they may have experienced social difficulties throughout their life. It is important that the implications of these findings be considered to a wider context than only the autistic population. Clinicians working in neurodevelopmental services may want to explore whether their clients have experienced social trauma and how this has affected their sense of self, social-efficacy, and resilience.

Lastly, participants descriptions suggest that without an understanding a diagnosis offers, individuals may develop negative beliefs about themselves that can be detrimental. Therefore, the findings from the current study offer support to implications drawn by Punshon et al. (2009) that early diagnosis and support should be a priority for services as it provides individuals with the knowledge of why they may struggle in social situations and how to manage this.

Strengths and limitations

This study's primary strength lay in its ability to give voice to a marginalised population and enabling us to delve into the experiences of social trauma within the autistic population. Given that there are surprisingly few research studies that enable autistic individuals to discuss how they make sense of social trauma despite its prevalence in this population, this study is valuable in building this knowledge. A further strength of this study is the depth and detail of data which was gathered due to using IPA methodology and its ability to capture unique and rich experiences of social trauma in adults who received their diagnosis in adulthood (Pietkiewicz & Smith, 2014).

Nevertheless, this study has several limitations. Only one female participant was included in this study. While the higher proportion of male participants is representative of the proportion of males with autism (Baron-Cohen et al., 2011), it does limit the voice of the non-male population. Further research is needed that accounts for gender differences. Another limitation of this study is the limited length of time since participants received a diagnosis which ranged from four months to thirteen months. Five out of six participants had received their diagnosis under a year ago. Individuals who have had longer to process their diagnosis would likely have very different experiences that were not captured in the present study.

Conclusions

The study aimed to explore the experiences of social trauma in adults who received a diagnosis of autism in adulthood. Experiences of rejection, exclusion, and social humiliation in social situations were felt as socially traumatic. Participants described how their autistic traits increased the likelihood of receiving negative treatment from others or of feeling overwhelmed in social situations. However, the study also highlighted the protective role that some autistic traits, like a lack of concern for others' opinions, can play in mitigating the perception of trauma. These findings suggest that a diagnosis helps participants to reframe past traumatic experiences and move from a place of confusion, frustration and self-blame, to one of understanding and acceptance by allowing individuals to re-examine past social traumas with a new neurodevelopmental context.

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Chapter Five: Additional Methodology and Design Chapter

This chapter provides further information into the design and methodology sections of the empirical paper, providing additional details on the qualitative research design and the Interpretative Phenomenological Analysis (IPA) method.

Ontology and Epistemology

It is important to recognise one's own ontological and epistemological orientation within the research paradigm as it can affect the course of one's approach to research (Hussey & Hussey, 1997). Ontology refers to the way in which we construct reality and concerns with 'how things really are' and 'how things work' (Denzin and Lincoln, 2011; Guba, 1990). Ontology helps researchers understand the extent to which they can be certain about the nature and existence of the objects they study (Moon & Blackman, 2014). The core ontological assumptions can be considered on a spectrum. One end of this is realism where there is an objective reality which can be measured (Clarke & Braun, 2013). The opposite end of this spectrum is relativism, where multiple realities exist and are intangible mental constructions (Levers, 2013). Typically, due to the aims of qualitative research to understand the world from subjective experiences, it is underpinned by a constructivist ontology.

Epistemology relates to the study of knowledge and how individuals make sense of the world. Epistemological inquiry explores the relationship between individuals and knowledge (Denzin and Lincoln, 2005) and seeks to understand how we know what we think we know (Crotty, 1998). Like ontology, epistemological frameworks are considered on a spectrum. This can range from positivism and constructionism. Positivism proposes that knowledge must be gained objectively through our sensory experience of the world, and which can be measured. However, constructionism’s position means that knowledge is socially constructed through engagement with the world (Moon & Blackman, 2014).

This empirical project in this thesis portfolio adopted a critical realist approach and can be regarded as both an ontological and epistemological stance (Yucel, 2018). Critical realism attempts to offer a middle ground between positivism and social constructivism by drawing from a realist ontology that an external reality exists, while also maintaining elements from a constructivist epistemology that argues that this reality is experienced through subjective interpretations (Lawani, 2021; McEvoy and Richards, 2003). A critical realist approach aligns with IPA whereby IPA is interested in the individual’s subjective interpretation of a world that exists independently (Vincent & Mahoney, 2018).

Holding a critical realist perspective can provide a balanced understanding when exploring neurodevelopmental disorders and mental health conditions. The ontological position of diagnoses and conditions can be understood through both a realist (disease and conditions exist independent of individual perception) (Lovett & Hood, 2011) and constructivist perspective (viewed as constructs defined by social and cultural norms) (Pérez-Álvarez et al., 2008). Our understanding of how diagnoses are experienced lends itself to a constructionist understanding. Considering this a critical realist position felt appropriate to explore participants individual viewpoints of their social trauma who have a shared diagnosis of autism. It is also particularly relevant to autism research in so far as symptoms of ASD are defined in a social context and viewed as impairments.

Ethical Considerations

Potential for distress

Due to the topic of the research, there was a potential that participants could experience distress and was considered during the interview process. The interview schedule (Appendix E) was designed to have open-ended questions to allow participants to navigate and discuss their experiences in a way that was comfortable for them. The participant information sheet (Appendix F) contained signposting to support available if needed. Participants also consented for their GP to be informed they were taking part in the interviews (Appendix G), in the possibility that they required further support. In order to maintain confidentiality, interviews took place in private rooms at the University of East Angia, or they were conducted remotely. At the end of the interviews, participants were offered a verbal debrief with the interviewer and reminded of the support options available to them.

Coercion

Participants were informed that participating in the interviews was completely their choice, along with making it clear that if they decided not to take part, their care would not be impacted in any way. This was communicated to them through the participant information sheet, consent form (Appendix H), and verbally before signing the consent form.

Consent

Participant consent was gained by clinicians within the NHS service agreeing to be contacted to discuss the study with the researcher. The NHS clinicians were also required to determine if participants had the capacity to consent to take part. All participants were deemed to have consent to take part in the before meeting the researcher to discuss the study and before the interviews took place. Written consent was obtained by the researcher prior to the interviews taking place.

Confidentiality

Participants were informed that information they provided during the interview process would remain confidential unless there was indication that there was risk to self or others. This was detailed in the participant information sheet and consent form. Participants were given pseudonyms and identifying information was removed. There were no confidentiality breaches in this research.

Data protection

To protect anonymity, participants were allocated a participant number and given a pseudonym which was used in the interview transcriptions and for quotations. Data was stored in line with the General Data Protection Act (2018) and the university's Research Data Management Policy (2019). Interviews were transcribed by the researcher, with all identifiable information removed. Interviews were transferred from the recording device to the secure OneDrive and password protected. Documents containing identifiable participants data were stored separately on the secure OneDrive. Audio recordings will be deleted at the end of the study date. Research data (e.g. consent forms) will be stored following UEA research data management guidance for 10 years, after which they will be destroyed.

Analysis

Given that the research question aimed to explore experience, a phenomenological approach was considered suitable with Interpretative Phenomenological Analysis (IPA) identified as the appropriate analytic method.

Theoretical foundation of IPA

IPA is informed by three key areas of philosophical knowledge: phenomenology, hermeneutics, and idiography (Smith et al., 2009). A phenomenological perspective aims to explore how individuals actively interpret their experiences and how they make sense of the world through their experiences. These subjective experiences and the meanings that are attributed to them affect how people relate to the world around them (Langdridge, 2007). IPA's focus is on the subjective, first-person perspective. To make sense of these experiences, a level of interpretation is involved. Heidegger (1962) posited that understanding is always interpretive as individuals are always situated within contexts that shape their experiences.

Within IPA the researcher takes on a dual role, and is in a sense both a researcher and participant themselves. This 'double hermeneutic' principle (Smith & Osborn, 2003) is a core facet of IPA, where the researcher attempts to make sense of the participant making sense of their own experiences. IPA attempts to take a balanced stance of being both empathic and questioning through wanting to adopt an insider's perspective (Conrad, 1987), whilst also standing alongside the participants to explore their experiences with a different perspective (Smith et al., 2009).

The idiographic approach is evident in IPA where the aim is for rich, in-depth exploration of the particular individual experience. This is not always possible in nomothetic research approaches that which aim to identify general trends to make predictions on human behaviour, and relies on aggregated data (Smith, 2004; Smith et al., 1995). These underpinnings of IPA ensure a detailed, context-rich exploration that allows for a nuanced and comprehensive understanding of an individual's experience.

Analysis process

Within the literature on analysis in IPA, there is not one single method for interacting with the data. The analytic process of IPA can be characterised as flexible and involves an iterative and inductive approach (Smith et al., 2009). Its focus lies in its attempts to make sense of participants experiences. While there is no definitive right or wrong way to conduct analysis, Smith et al. (2009) provide a six-step process to assist in interacting and making sense of the data, to recognising patterns with and across accounts. The steps of this process are presented below:

1. *Reading and re-reading*

   The first step of this process involves becoming immersed in the data to enable the participant to become the focus of the analysis. This was achieved by multiple readings of the transcripts whilst listening to audio recordings of the data. This allowed for a deeper understanding of the participants world to emerge as it captured non-verbal cues (e.g. tone of voice) that add richness to the participants experiences. During this stage, the researcher noted down their own assumptions, recollections and observations from the data. This bracketing off of the researchers own experiences and beliefs allow the focus to remain on the data to avoid misrepresenting a participant's intended meaning, but provides the ability to revisit these thoughts at a later stage of the interpretation.

2. Initial noting

During this stage of analysis, the researcher begins to free note detailed commentary of the data remaining close to its content. This encourages an increasing familiarity with the data. This commentary involved three levels: descriptive (describing the content), linguistic (exploring specific use of language), and conceptual (engaging with the data more interpretively and interrogatively). An example of this can be found in Appendix I.

3. Developing emergent themes

The focus for the researcher in this next stage is to develop emergent themes. The exploratory comments developed in the previous step are a focus in this point in the analysis allowing the researcher to focus on chunks within the transcript. However, at the same time the researcher also holds what they have learnt from the whole process of making comments. The hermeneutic circle process is evident here where the researcher is interpreting discrete chunks of data in relation to the whole, and considering interpretation of the whole in relation to discrete parts. It is at this stage where the researcher attempted to introduce their own interpretations of the participants experiences. The data is reorganised to identify connections and patterns to develop emergent themes that reflect the participants language and sense-making with the researcher's interpretation.

4. Searching for connections across emergent themes

At this stage there is an established set of themes. These now need to be re-organised in a way the researcher thinks they best fit together. This is considered in relation to the overall research question, with not all emergent themes needing to be included at this stage of analysis. To help develop the structure of the themes, the researcher followed suggestions by Smith et al. (2009) to look for connections. Print out the list of themes and cut the up so each theme is separate. Use a space to move the themes around to explore how they relate to each other until they form clusters of related themes. What is produced is a structure that represents and communicates aspects from the participants accounts that are considered the most important and interesting.

5. *Moving to the next case*

Once the first analysis of an individual account is completed, the researcher then moves on to the next participant's transcript and repeats the process described above. In keeping with the idiographic focus of IPA, it is important for the researcher to bracket ideas from previous participant accounts while working on another.

6. *Looking for patterns across cases*

This final theme involves looking for patterns across participants transcripts. At this stage a theoretical approach can be helpful in recognising concepts in themes and superordinate themes in one account can be represented in concepts within another account. This process can be creative with themes reconstructed and renamed. Eventually themes are arranged into superordinate and subordinate themes. An example of this is provided in Appendix J.

Reflexivity

Two excerpts from the reflective diary are provided below. Throughout the interview process diary entries were made before and after interviews to capture the researchers' thoughts and reflections. Below is an example of this reflective process capturing the researchers' pre- and post-interview reflections.

1. **Example reflective journal entry pre-interview for Ashley:**

I decided to revisit Smith's IPA book before the interview to re-read about the iterative process for interviewing. I felt I was too directive and guided with my questions in the last interview and wasn't trusting in the process enough to be guided by the participant. I think I was stuck in my head with worries about hoping for answers that would be 'good' for my analysis which was a barrier sometimes for being in the moment with the participant. It was more a reflection of my anxiety about doing IPA 'right' and doing justice for the participants. After reading over the process again I feel more confident with my upcoming interview to stay more present with the participant and be guided by them

2. **Example reflective journal entry post-interview for Ashley:**

Ashley's experiences left me with a sense of how hurt and confused some of their social experiences have had on them, as well as emotionally devasting impact this has had and continues to have on them. I noticed feeling angry on their behalf when they described the way they have been treated, and similarly hopeful for them when they spoke of the positive impact a diagnosis had on their sense making of past trauma. Considering the interview process, after a few questions it became clear that Ashley required longer to process the questions and their response. It made me think about adaptations to the interview process to support neurodiverse participants. While interview questions in IPA tend to be open to allow the participant to lead, for Ashley they could struggle with this so I needed to adapt my questions to be more direct initially and then follow up with more open questions. It made me think about how vulnerable they could be to miscommunication or misunderstandings in social situations if communication is not adapted and how this could lead to distressing situations.

Quality assurance

When assessing the quality and validity of qualitative research, Yardley (2000) recommended four key principles to consider: (1) sensitivity to context, (2) commitment and rigor, (3) transparency and coherence, and (4) impact and importance. An overview of how these principles were applied is presented in Table 1.

Table 1.

Quality assurance

Guideline	How principles were met
Sensitivity to context	• The research team has experience of working with this population which helped provide context and perspective to participants accounts. • The researcher kept a reflective journal to note down their thoughts and observations, and to be mindful of their own biases and beliefs. • Participants had the opportunity to discuss the study with the researcher before the interview took place, allowing for rapport to be developed and reduce the power imbalance between the researcher and participant. • Participant accounts that appeared contradictory were explored during the interview process. • Findings and analysis were discussed in supervision to gain varied perspectives. • Participants were offered options for where the interview took place (online or in-person) and with the duration of the interview (having breaks and offering the interviews over multiple sessions) to support participants with their communication needs.
Commitment and rigour	• A purposive sample was used to recruit participants. • Research supervision was used to discuss and explore understanding of the topic and participant’s accounts and develop interpretation of the data.

	• The researcher used individual supervision, peer supervision, and their own reading of the literature to continually familiarise and gain knowledge in the method of analysis.
Transparency and coherence	• Participants have all been offered a summary of the research following its completion. • To ensure transparency of analysis detailed records were kept of the data and analytic process, along with a reflective journal kept by the researcher that noted their assumptions, intentions and actions. • To ensure coherence of fit between the research question and analysis undertaken a phenomenological analysis was considered the most appropriate as it aimed to explore and give voice to the personal perspectives of autistic adults who have experienced social trauma.
Impact and importance	• The research gives a voice to a group of people who are not widely represented in research literature (late diagnosed autistic adults) • The findings have clinical importance as they provide new knowledge and understanding within an area that has not been explored before (social trauma in late diagnosed autistic adults) and paves they way for further research.

Chapter 6: Discussion and Critical Evaluation

This chapter will consider the findings of both the systematic review and the empirical paper. Initially, reflections from the researcher on the research process will be presented. Following this, the research papers findings will be discussed together. Finally, wider strengths and limitations of the research studies will be critically evaluated.

Researcher reflections

My background includes working in an adult autism diagnostic service. This experience increased my interest in conducting research with this population as I have witnessed the emotional impact receiving a diagnosis can have on individuals. This is both in terms of how a diagnosis can help them to begin to make sense of their past experiences within a new context of autism, and how they begin to consider what the diagnosis means to them. While my involvement with working with this population came to an end following the assessment outcome, it was clear that for those I worked with that the diagnosis was the beginning of a new stage in their lives. However, I was aware that following a diagnosis some autistic adults could feel let down with the amount of post-diagnostic support available and overwhelmed making sense of a life changing diagnosis alone. I felt this landscape for late-diagnosed autistic adults was exacerbated by the limited evidence-base. This research project was therefore aimed at addressing this gap by increasing our knowledge of autistic adults' experiences after receiving a diagnosis.

Considering my limited experience of IPA, it has felt like a steep learning curve. However, it enabled me to develop my skills with this approach and demonstrated to me the importance of understanding the individuals' unique experience, and the value of not generalising this understanding to a wider population level. Similarly, I had never carried out a systematic review. The process of doing this felt daunting at times, but I developed valuable review-writing and critical evaluation skills. Taking on two qualitative research projects was challenging considering the analysis process of both. I was very grateful to have a supportive supervisory team to help me navigate difficulties and challenge my thinking.

Summary of findings

The systematic review aimed to identify, collate and synthesise qualitative studies on how receiving an autism diagnosis in adulthood affects self-identity. The analysis of the eleven studies identified three recurring analytical themes: Processing the past and questioning self-identity, acceptance by self and others, and understanding self-identity helps in finding one's place in the world. These themes demonstrated key processes related to identity formation following a diagnosis in adulthood. This involved a re-evaluation of their identity through the lens of autism, which helped them make sense of their past. In turn, this re-appraisal process was crucial for letting go of an old identity and attempting to adjust to a new autistic identity. While, for some, the diagnosis led to self-acceptance and reduced the pressure to conform to neurotypical norms, it also demonstrated the challenge internalised stigma can play in complicating the acceptance of an autistic identity. To encourage a sense of belonging, it was important to have connections with the wider autistic community as it empowered individuals and gave new meaning. However, this also had the outcome of alienating some from mainstream society. Clinical implications from the analysis suggest that clinicians play a crucial role in providing understanding and support to newly diagnosed adults.

The empirical paper explored the experiences of social trauma in autistic adults diagnosed in adulthood and how a late diagnosis affected their understanding of socially traumatic experiences. Through six semi-structured interviews, four superordinate themes emerged: experiencing social trauma, making sense of socially traumatic experiences, managing social trauma, and re-examining social trauma with a new lens. Participants described traumatic experiences that included feeling misinterpreted, rejected and excluded, which could be interpreted as harmful to their sense of self. Autistic traits could play a role in both the cause and increasing the likelihood that an event will be interpreted as socially traumatic. To protect themselves from distress, avoidance strategies were adopted. However, there was a risk that this could lead to increased distress and lower self-efficacy. The study also highlighted how autistic traits could also act as a protective factor. These findings suggest that a diagnosis provides a framework for understanding and processing past traumas within a neurodevelopmental context, fostering self-compassion and acceptance.

Combined Discussion

This thesis aimed to add to the limited, but gradually growing, body of literature that focuses on late diagnosed autistic adults (Lilley et al., 2023). The significant impact a late diagnosis can have on a person's sense making, both of their view of themselves and how they understand past events was clearly documented across the qualitative systematic review and the empirical paper. Both papers demonstrate the re-evaluation process that occurs following a late diagnosis where previous beliefs and explanations were replaced with a new understanding that reframed past difficulties within the context of their autism (Stagg & Belcher, 2019). For some of the participants, this process enabled individuals to begin to accept themselves and their difficulties. In the empirical paper, this was demonstrated in the change of language used to talk about themselves. Before their diagnosis, the use of critical language such as ‘weird’ and ‘bad’ were used to describe how they viewed themselves.

However, this shifted after receiving a diagnosis where participants felt able to compassionately recognise if they were struggling socially, there was a valid explanation for this. Similarly, in the systematic review a diagnosis provided the opportunity for participants to accept their autistic traits rather than masking them and feeling pressure to conform to societal norms.

Both papers highlight the positive and negative aspects of receiving a late diagnosis. In the systematic review the impact of re-appraising a person's identity through an autistic lens was key for the individual to understand their sense of self and developing an identity that reflects their true, authentic self. Once participants were able to be their authentic self, they found it important to connect with the autistic community and build a sense of kinship with others (Huang et al., 2022). However, while the autism diagnosis brought understanding, it also demonstrated that internalised stigma could be prominent and hinder the formation of an autistic identity. Participants would view negative behaviours as separate from the self and attributed them to their autism instead. In the empirical paper this externalising appeared to be positive for participants wellbeing. The view 'it's because of autism, it's not because of me' in fact allowed participants to view these difficulties with empathy and helped their self-esteem and confidence. However, it is not certain if internalised stigma still plays a role in these views developing, despite the positive outcome it appears to have for participants. The presence of internalised stigma may be a prominent occurrence within this population, particularly in older participants who grew up in a time where individuals with neurodevelopmental conditions were more likely to experience stigma in society.

Critically evaluating strengths and limitations

Strengths and imitations of both papers have been discussed in the individual publications; therefore, the focus here will be to discuss wider strengths and limitations of the work.

For the purpose of this portfolio, late diagnosis was defined as someone who had received an autism diagnosis from the age of 18 years old and upwards. However, there is no official agreed upon age, with great variation in the existing literature with some studies defining it as early as 8-14 years old (Mandy et al., 2022), to the loosely defined 'late adolescence' (Bargiela et al., 2016), to the concept of late diagnosis as considered in adulthood over the age of 18 years old (Ghanouni & Seaker, 2023; Punshon et al., 2009). This portfolio was able to capture the experiences of autistic adults diagnosed at any point from 18 years old, which allowed for varied experiences to be discussed and represented.

However, older adults' experiences may be significantly different from those of younger adults; the oldest one participant in the empirical paper was diagnosed in their 50s. There are some unique stressful life experiences that are specific to older adults such as retirement and ill health, that may also play a role in social trauma but had not been experienced by the participant. Older adults have also lived the majority of their adult life without a diagnosis and their experiences may differ substantially than those in early to middle adulthood. Further research that focuses on older adults' experiences may be able to capture these nuances.

The inclusion and exclusion criteria for the systematic review were considered and reviewed by the authors. However, the final decisions reached by the authors will likely have ramifications to the findings and conclusions of the review. The exclusion of grey literature meant that there were possible relevant unpublished studies that were not included. Further to this, there were studies relevant to the research question that included participants who received their diagnosis before and after the age of 18 years old. Due to the strict criteria of the review, these studies were not included. These studies may have been able to provide further rich data to the synthesis. However, the result of the exclusion was that the review consisted of a more homogeneous sample.

Clinical and research implications

Receiving a diagnosis was frequently viewed as therapeutic. It normalised participants perceived differences and validated the difficulties they had experienced (Leedham et al., 2020). This portfolio suggests that the therapeutic nature of the diagnosis may begin to occur during the assessment period. For some, this could be the first time they have been able to discuss their lived experiences and struggles growing up. This view is supported by Crane et al. (2018) who reported revisiting the past as a therapeutic process for participants as it enabled them to be open with others about their differences and difficulties. This could be considered in the context of the findings of the empirical paper where participants were able to process socially traumatic memories and reduce the distressing feelings that are attached to these memories following the re-evaluation process after the receipt of a diagnosis. The reduction of negative feelings related to socially traumatic events is similar to the aims of processing traumatic memories in trauma-focused therapy (Ford, 2018). Further research that explores the therapeutic nature of the diagnosis would provide us with greater understanding of the wider impact a diagnosis can offer.

The findings in the systematic review demonstrate the identity formation process individuals experience after receiving a diagnosis. For some, adjusting to a new label and autistic identity can progress quickly, where they feel able to embrace a change in how they viewed themselves. For others, this adjustment process was challenging. Letting go of their previous identity and accepting a new one was difficult for many reasons, such as: not seeing themselves as disabled (Lilley et al., 2023), concerns with facing stigma and discrimination (Bureau & Clement, 2023), and the reluctance having a permanent label (Punshon et al., 2009). Not all late diagnosed autistic adults will struggle with adjusting to a new diagnosis, and it is important to normalise that the process of developing a new identity may be difficult at times. However, it is important for healthcare professionals to be aware of this process and be able to offer scaffolded support for individuals who could be struggling. It may be helpful to consider how support is offered for groups such as those diagnosed with chronic illness, whose self-identity may often be challenged and an adjustment to how they view themselves occurs (Oris et al., 2018).

Conclusions

The empirical paper and systematic review aimed to explore how a late diagnosis of autism impacts how adults' make sense of social trauma and their self-identity. Participants in the empirical paper reported that rejection, exclusion, and social humiliation were perceived as socially traumatic, with autistic traits often exacerbating these experiences. However, autistic traits could also protect them from interpreting negative social behaviours as negative. It also suggests that receiving a diagnosis helps individuals reframe past traumatic experiences, shifting from confusion and self-blame to understanding and acceptance by re-evaluating their social traumas through a neurodevelopmental lens. The thematic synthesis of eleven studies identified a general process of identity formation following diagnosis: renegotiating identity through reappraising past experiences, accepting autism as part of one's identity, and fostering authentic connections with others. Stigma, both societal and internalised, can hinder this identity development. Taken together, the findings of the review and empirical study highlight the importance for late diagnosed adults to have a framework of autism in which to view themselves and their experiences. It is important for clinicians to ensure newly diagnosed adults have opportunities to understand the impact a diagnosis can have on their view of themselves and how they make sense of past distress.

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Appendices

Appendix A: Autism Author Guidelines

Manuscript Submission Guidelines:
This Journal is a member of the Committee on Publication Ethics

Please read the guidelines below then visit the Journal's submission site http://mc.manuscriptcentral.com/autism to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned.

Only manuscripts of sufficient quality that meet the aims and scope of Autism will be reviewed.

There are no fees payable to submit or publish in this Journal. Open Access options are available - see section 3.3 below.

As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Autism, please ensure you have read the Aims & Scope.

There is no need to submit a pre-submission enquiry to the journal, and in fact we discourage this as our scope is clearly stated at the link above.

It is journal policy for all submitted manuscripts to be screened by an Editor who will decide whether to send the manuscript for review. In this screening process, Editors will focus on:

- fit with the journal aims and scope, and listed Article Types (see below)
- relevance to autistic people’s quality of life
- justification of the research question
- relevance and quality of the methods and analysis methods for the topic under study

- validity of the conclusions in relation to the methods and findings
- quality of the writing
- potential for practical impact

1.2 Article Types

The Journal considers the following kinds of article for publication:

Research Reports. Full papers describing new empirical findings. These papers may present quantitative and/or qualitative data. In each case, the methods should be carefully selected to address the research question being posed, with due justification being given for: needfulness of the research; relevance to autistic people's quality of life; appropriateness of the sample size and diversity; quality of the methods; robustness of the analysis methods; validity of the conclusions.

Fundamental or basic scientific discoveries can be considered for publication but need to make a convincing case for relevance to autistic people's lives, especially if future implementation of the discovery is still far off.

Research Reports are generally restricted to a maximum of 6,000 words, including all elements (title page, abstract [200 words maximum], notes, tables, text), but excluding references. Editors may ask authors to make certain cuts before sending the article out for review

Before submitting a Research Report, please make sure to review the author guidelines, and especially section 2.8 for our reporting expectations.

Review Articles. General reviews that provide a synthesis of an area of autism research. These will normally be systematic but narrative and/or focused reviews can be considered if the authors make a convincing case for their ability to address a gap in knowledge.

Review Articles are generally restricted to a maximum of 6,000 words, including all elements (title page, abstract [200 words maximum], notes, tables, text), but excluding references. Editors may ask authors to make certain cuts before sending the article out for review.

Before submitting a Review, please make sure to review the author guidelines and especially section 2.8 for our reporting expectations.

Short Reports. Brief papers restricted to a maximum of 2,000 words with no more than two tables. The title should begin with 'Short Report'. Short reports also report empirical findings from quantitative and / or qualitative data, but these may be preliminary, low-impact, or otherwise less substantial than a Research Report. Another reason to submit a Short Report is if your rationale, methods and findings are simple and neat. If your paper can be reported within the 2000 word limit we would encourage you to do so.

Letters to the Editors. Readers' letters should address issues raised by articles published in our journal, or issues in the field of autism research more generally. The issues should be contextualised within the literature to permit readers to draw general conclusions. Letters might cover: discussions of existing debates in the literature, articulations of new or controversial ideas, comments on work published in our journal, theoretical perspectives, methodological or conceptual critiques, The decision to publish is made by the Editors, in order to ensure a timely appearance in print. Letters should be no more than 1000 words, with no tables and a maximum of 5 references.

Registered Reports, Pre-Data or Post-Data:

There are two types of Registered Reports:

- Registered Reports – Pre-Data, i.e., before any data have been gathered
- Registered Reports – Post-Data, i.e., before already existing data have been examined and analysed.

These submissions are reviewed in two stages. In Stage 1, a study proposal is considered for publication prior to data collection and/or analysis. Stage 1 submissions should include a complete Introduction, Methods, and Proposed Analyses. High-quality proposals will be accepted in principle before data collection and/or data analysis commences. Once the study is completed, the author will finish the article including Results and Discussion sections (Stage 2). Publication of the Stage 2 submission is guaranteed as long as the approved Stage 1 protocol is followed and the conclusions are appropriate. Full details can be found here. The Journal's manuscript requirements should be adhered to for the stage 2 submission.

1.3 Writing your paper

The Sage Author Gateway has some general advice and on how to get published, plus links to further resources. Sage Author Services also offers authors a variety of ways to improve and enhance their article including English language editing, plagiarism detection, and video abstract and infographic preparation.

1.3.1 Make your article discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online.

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2. Editorial policies

2.1 Peer review policy

Autism operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. The reviewer may at their own discretion opt to reveal their name to the author in their review but our standard practice is for both identities to remain concealed. Each new submission is carefully read by one of the Editors to decide whether it has a reasonable chance of getting published, consulting with other Editors if and when they feel it is necessary. Our Editors strive to make this initial review within two weeks after submission, so that authors do not have to wait long for a rejection. In some cases, feedback may also be provided on how to improve the manuscript, or what other journal would be more suitable. The criteria used by the Editors when determining what to reject or send for review as described here [https://journals.sagepub.com/author-instructions/aut#Aims-Scope]. Each manuscript which passes this initial screening, is sent out for peer review by at least two referees. All manuscripts are reviewed as rapidly as possible, and an editorial decision is generally reached within (e.g.) 6-8 weeks of submission.

2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

Please note that AI chatbots, for example ChatGPT, should not be listed as authors. For more information see the policy on Use of ChatGPT and generative AI tools.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Please supply any personal acknowledgements separately to the main text to facilitate anonymous peer review.

2.3.1 Third party submissions

Where an individual who is not listed as an author submits a manuscript on behalf of the author(s), a statement must be included in the Acknowledgements section of the manuscript and in the accompanying cover letter. The statements must:

- Disclose this type of editorial assistance – including the individual's name, company and level of input
- Identify any entities that paid for this assistance
- Confirm that the listed authors have authorized the submission of their manuscript via third party and approved any statements or declarations, e.g. conflicting interests, funding, etc.

Where appropriate, Sage reserves the right to deny consideration to manuscripts submitted by a third party rather than by the authors themselves.

2.4 Funding

Autism requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the Sage Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Important note: If you have any concerns that the provision of this information may compromise your anonymity, you should withhold this information until you submit your final accepted manuscript.

2.4.1 National Institutes of Health (NIH) funded articles

If you have received NIH funding for your research, please state this in your submission and if your paper is accepted by *Autism* an electronic version of the paper will automatically be sent to be indexed with the National Library of Medicine's PubMed Central as stipulated in the NIH policy.

2.5 Declaration of conflicting interests

Autism encourages authors to include a declaration of any conflicting interests and recommends you review the good practice guidelines on the Sage Journal Author Gateway. In particular, for working reporting on the development or evaluation of interventions the ICJME Conflict of Interest form provides an excellent template for considering a range of potential sources of conflict, and this can be uploaded and submitted with your manuscript if relevant.

Where an Editor of Autism is a lead or contributing author to a paper submitted to publication, the paper is always handled through the peer review process by another member of the Editor team and three reviews are obtained in each case. A statement is also published on each article where this occurs.

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants

2.7 Clinical trials

Autism conforms to the ICMJE requirement that clinical trials are registered in a WHO-approved public trials registry at or before the time of first patient enrolment as a condition of consideration for publication. The trial registry name and URL, and registration number must be included at the end of the abstract.

2.8 Reporting guidelines

2.8.1 Transparent reporting of trials

The relevant EQUATOR Network reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed CONSORT flow chart as a cited figure and the completed CONSORT checklist should be uploaded with your submission as a supplementary file. Systematic reviews and meta-analyses should include the completed PRISMA flow chart as a cited figure and the completed PRISMA checklist should be uploaded with your submission as a supplementary file. The EQUATOR wizard can help you identify the appropriate guideline.

The What Works Clearinghouse (WWC) guidelines should be followed when submitting in single-case design (SCD) and meet the standards outlined for internal validity of the SCD.

Other resources can be found at NLM's Research Reporting Guidelines and Initiatives

2.8.2 Sample selection and demographic characteristics

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’ or ‘integrated knowledge translation’.

We therefore now require authors to include a community involvement statement at the end of the Methods section for Research Reports, outlining whether autistic people or family members, community providers, policy makers, agency leaders or other community stakeholders were involved in developing the research question, study design, measures, implementation, or 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. We recommend that authors follow the BMJ’s editorial guidelines for documenting how community stakeholders were involved in their research.

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

For more details about the reasoning behind this journal requirement, and editorial expectations of authors, please download this FAQs document.

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 and Open Access agreements, where authors can publish open access either discounted or free of charge depending on the agreement with Sage. Find out if your institution is participating by visiting Open Access Agreements at Sage. For more information on Open Access publishing options at Sage please visit Sage Open Access. For information on funding body compliance, and depositing your article in repositories, please visit Sage’s Author Archiving and Re-Use Guidelines and Publishing Policies.

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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

4.4.1 Terminology about autism and autistic people

Autism has researched and produced its own guidance on terminology and language used in autism research. Please consult the guide here: autism terminology guidelines.

4.4.2 Language used to discuss race and ethnicity

Likewise, *Autism* has also produced the following guidance to be considered when writing about race and ethnicity. Please consult the guide here: race and ethnicity language guidelines.

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 Plain Language Summaries

As part of your submission, you will be asked to provide a Plain Language Summary of your article. Plain Language Summaries 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, Plain Language Summaries should avoid both technical terminology and the reporting of statistics. Examples of Plain Language Summaries are provided in recent issues of the journal.

Authors may consider the following questions when composing their Plain Language Summaries.
a. What is already known about the topic?
b. What does this paper add?
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
- Are lay abstracts published in Autism readable enough for the general public? A short report - Lan Yi, Xiaohu Yang, 2023 (sagepub.com)

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.

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.

Appendix B: Individual Quality Rating for the Qualitative Review

Study	Clear aims?	Appropriate qualitative methodology?	Appropriate research design?	Appropriate recruitment strategy?	Appropriate data collection to address question?	Has the relationship between the researcher and participants been considered?	Have ethical issues been considered?	Was the data analysis rigorous?	Is there a clear statement of findings?	How Valuable is the research	Overall quality rating
Bureau & Clement (2023)	2	2	1	2	1	0	1	1	2	2	14
Ghanouni & Seaker (2023)	2	2	1	1	1	0	1	2	2	1	13
Hickey et al. (2017)	2	2	2	2	1	0	1	2	2	2	16
Huang et al. (2021)	2	2	1	1	1	0	0	1	1	2	11
Huang et al. (2022)	2	2	2	1	2	2	1	2	2	2	18
Leedham et al. (2020)	2	2	2	1	2	0	0	1	2	2	14
Lilley et al. (2022)	2	2	2	1	2	1	1	1	2	2	16
Lilley et al. (2023)	2	2	2	1	2	1	1	1	2	2	16

Study	Clear aims?	Appropriate qualitative methodology?	Appropriate research design?	Appropriate recruitment strategy?	Appropriate data collection to address question?	Has the relationship between the researcher and participants been considered?	Have ethical issues been considered?	Was the data analysis rigorous?	Is there a clear statement of findings?	How Valuable is the research	Overall quality rating
Lupindo et al. (2022)	2	2	1	1	2	2	2	2	2	2	18
Punshon et al. (2009)	2	2	1	2	2	0	1	2	2	2	16
Stagg & Belcher (2019)	2	2	2	1	2	1	2	1	2	1	16

Appendix C: HRA Approval Letter

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

Health Research Authority

Ms Caitlin Green
Trainee Clinical Psychologist
University of East Anglia
Department of Clinical Psychology and Psychological Therapies
University of East Anglia
NR4 7TJ

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

21 July 2023 (Re-issued 11-08-23)

Dear Ms Green

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Autistic Adults' Experience of Social Trauma: An Interpretive Phenomenological Analysis**
IRAS project ID:	**322252**
REC reference:	**23/YH/0143**
Sponsor	**University of East Anglia**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation.

The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **322252**. Please quote this on all correspondence.

Yours sincerely,

Libby Williamson

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Ms Tracy Moulton*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional Indemnity]		01 August 2022
GP/consultant information sheets or letters [GP Letter]	1	05 June 2023
Interview schedules or topic guides for participants [Interview questions]	1	16 June 2023
IRAS Application Form [IRAS_Form_09062023]		09 June 2023
Letter from sponsor [Cover Letter]		02 June 2023
Non-validated questionnaire [Participant demographic information form]	2	11 July 2023
Other [PIC form]	1	05 June 2023
Participant consent form [Consent to contact form]	2	11 July 2023
Participant consent form [Participant consent form]	3	21 July 2023
Participant information sheet (PIS) [Participant information sheet (PIS)]	3	21 July 2023
Protocol [Protocol]	2	11 July 2023
Response to Request for Further Information [REC/HRA review feedback]		
Summary CV for Chief Investigator (CI) [CV]		13 February 2023
Summary CV for student [Student CV Caitlin Green]		13 February 2023
Summary CV for supervisor (student research) [Research Supervisor CV Kenny Chiu]		20 January 2023
Summary CV for supervisor (student research) [Research Supervisor CV Louise Mullineaux]		25 January 2023
Summary CV for supervisor (student research) [Research Supervisor CV Paul Fisher]		21 April 2023

IRAS project ID	**322252**

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
Activities at NHS organisations will involve PIC activity only, including the identification of participants and mailing out consent to contact forms. A local collaborator may also be responsible for arranging room bookings for interviews, if required, but these will not take place at the NHS site itself.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study in accordance with the contracting expectations detailed. Due to the nature of the activities involved, organisations will be expected to provide that confirmation to the sponsor 1) Within 35 days of receipt of the local information pack 2) After HRA/HCRW Approval has been issued. If the organisation is not able to formally confirm capacity and capability within this timeframe, they must inform the sponsor of this and provide a justification. If the sponsor is not satisfied with the justification, then the sponsor may escalate to the National Coordinating Function where the participating NHS organisation is located.	The sponsor has provided the appropriate model non-commercial PIC agreement that it intends to use as a subcontract between participating organisations and NHS organisations acting as their Participant Identification Centres (PICs).	Sponsor is not providing funding to PICs	The Chief Investigator will be responsible for all study activities performed at PICs. However a local collaborator may be appointed for the purposes of arranging room bookings for interviews at the NHS site, if required.	Where an external individual will be conducting any of the research activities that will be undertaken at this site type then they would be expected to hold a Letter of Access. This should be issued be on the basis of a Research Passport (if university employed) or an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed).

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix D: REC Approval Letter

Health Research Authority

Yorkshire & The Humber - Sheffield Research Ethics Committee

NHS Blood and Transplant Blood Donor Centre
Holland Drive Newcastle upon Tyne Tyne and Wear
NE2 4NQ

Telephone: 0207 104 8388

Please note: This is the favourable opinion of the REC only and does not allow

you to start your study at NHS sites in England until you receive HRA Approval

07 July 2023

Ms Caitlin Green
Trainee Clinical Psychologist University
of East Anglia
Department of Clinical Psychology and Psychological Therapies
University of East Anglia
NR4 7TJ

Dear Ms Green

Study title: **Autistic Adults' Experience of Social Trauma: An Interpretive Phenomenological Analysis**
REC reference: **23/YH/0143**
IRAS project ID: **322252**

The Research Ethics Committee (REC) reviewed the above application at the meeting held on 03 July 2023. Thank you for attending to discuss the application.

Ethical opinion

The members of the Committee present 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. .

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

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

Number	**Condition**	**Response from the applicant**
1	*Please make clear in the PIS that recordings of the results would not be stored in the participants clinical records other than in a safeguarding situation*	
2	*Please ensure that the consent form is sent out to participants prior to them undertaking the interviews (in cases where the intent is to conduct the interview over the phone).*	
3	*Please update the Protocol to fall in line with the information in the PIS.*	
4	*Please add at least 1 phone number for the patient to contact a researcher for further information in the PIS*	
5	*Please add a postal address to the consent form for returning a paper CF if the participant doesn't attend face-to-face*	
6	*Please add a space to the Consent to contact form for the patients name to ensure you are talking to the correct patient when*	

	telephoning them.	
7	*In the PIS, in the sentence 'You have received an autism diagnosis at least 3 months before they take part in the study'. Please replace 'they' with 'you'*	
8	*Participant Demographic Information Form: Please add the Study title*	

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make 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.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as:

- 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.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/covid-19-research/approved-covid-19- research/

Clinical trial authorisation must be obtained from the Medicines and Healthcare products Regulatory Agency (MHRA).

The sponsor is asked to provide the Committee with a copy of the notice from the MHRA, either confirming clinical trial authorisation or giving grounds for non-acceptance, as soon as this is available.

Notice of no objection must be obtained from the Medicines and Healthcare products Regulatory Agency (MHRA).

The sponsor is asked to provide the Committee with a copy of the notice from the MHRA, either confirming no objection or giving grounds for objection, as soon as this is available.

The sponsor must ensure that all participants enrolled into the study are registered with The Over Volunteering Prevention System (TOPS).

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).

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, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland)being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional Indemnity]		01 August 2022
GP/consultant information sheets or letters [GP Letter]	1	05 June 2023
Interview schedules or topic guides for participants [Interview questions]	1	16 June 2023
IRAS Application Form [IRAS_Form_09062023]		09 June 2023
Letter from sponsor [Cover Letter]		02 June 2023
Letters of invitation to participant [Consent to Contact Form]	1	05 June 2023
Non-validated questionnaire [Participant Demographic Information Form]	1.0	26 June 2023
Participant consent form [Participant Consent Form]	1	05 June 2023
Participant information sheet (PIS) [Participant Information Sheet]	1	05 June 2023
Research protocol or project proposal [Study Protocol]	1	05 June 2023
Summary CV for Chief Investigator (CI) [CV]		13 February 2023
Summary CV for student [Student CV Caitlin Green]		13 February 2023
Summary CV for supervisor (student research) [Research Supervisor CV Kenny Chiu]		20 January 2023
Summary CV for supervisor (student research) [Research Supervisor CV Louise Mullineaux]		25 January 2023
Summary CV for supervisor (student research) [Research Supervisor CV Paul Fisher]		21 April 2023

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

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.

User Feedback

The Health Research Authority 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 HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 322252	**Please quote this number on all correspondence**

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

sincerely

On Behalf Of Dr
Tim Sprosen
Chair

E-mail: sheffield.rec@hra.nhs.uk

Yorkshire & The Humber - Sheffield Research Ethics Committee

Attendance at Committee meeting on 03 July 2023

Committee Members:

Name	*Profession*	*Present*	*Notes*
Ms Helen Barlow	Knowledge Service Manager	Yes	
Miss Katrina Budesha	Student	No	
Miss Rachel Flockton	Research Nurse	No	
Mr Raymond Harris	Chartered Statistician	No	
Dr Marie Marron	BHF Research Fellow	Yes	
Dr Jane McKeown	University Teacher	Yes	
Miss Helen Parry	Registered Nurse (semi retired)	No	
Mrs Brenda Riley	Retired IT Trainer	Yes	
Dr Shukrat Salisu-Olatunji	Registered Medical Doctor	No	
Dr Tim Sprosen	Epidemiologist	Yes	Chair
Mrs Yvonne Stephenson	Retired Lead Technician in the Department of Infection and Immunity	Yes	
Dr Robert Upshall	Chair of Trustees and Directors (Voluntary)	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Mrs Stacey Bamford	Approvals Administrator
Mr Taimoor Hassan	Approvals Administrator
Mrs Libby Williamson	Approvals Specialist

Appendix E: Interview schedule

University of East Anglia

Norfolk Community
Health and Care
NHS Trust

Interview Questions

- What are your experiences of social trauma?
- Did receiving a diagnosis of autism have any impact on how you make sense of these experiences?
- How has autism influenced how you make sense of these experiences?
- How did growing up without having a diagnosis of autism impact on how you make sense of these experiences?

Appendix F: Participant Information Sheet

Participant Information Sheet

"Autistic adults experience social trauma: An Interpretive Phenomenological Analysis."

We would like to invite you to take part in our research study. Before you decide, we would like you to understand why the research is being done and what it would involve for you.

If you have any questions, please get in touch. You can contact us by email or write to us using the contact details at the end of this sheet.

Who are the researchers?

The study is being conducted by Caitlin Green, Postgraduate Researcher on the Doctorate in Clinical Psychology Programme (ClinPsyD) at Norwich Medical School, University of East Anglia (UEA). The primary research supervisor is Dr Kenny Chiu, and the secondary supervisors are Dr Louise Mullineaux and Dr Paul Fisher.

The study is sponsored by UEA.

Approvals

The study has been checked at several stages during planning by UEA internal review panels and has full ethical approval from the Health Research Authority. This is a national organisation that ensures that all research done in health and social care is of good quality and protects the interests of the participants. This study has been reviewed and approved by this organisation. We have also been given permission by Norfolk Community Health and Care NHS Trust (NCHC) to conduct the research in their organisation.

What is the purpose of this study?

The purpose of this study is to explore how autistic adults experience socially traumatic events, and whether having received an Autism Spectrum Disorder (ASD) diagnosis in adulthood impacts how a person interprets these events. The study also aims to develop a better understanding of what and why negative social events may be considered traumatic in autistic adults, and any areas helpful in the recovery process.

Why am I being asked to participate?

You have been invited to take part as you have received a diagnosis of ASD in adulthood and meet the criteria of the study which includes:

- You are 18 years old and above.
- You have received an autism diagnosis at least 3 months before you take part in the study.
- You have experienced events that involves social trauma such as:
  - Bullying
  - Teasing
  - Anxiety provoking remarks
  - Rejection by other people/not included
  - Social mishap/ social faux pas
  - Being an outsider/ the feeling of being an outsider

What will happen in the study?

As a participant you will be individually interviewed and asked about your thoughts and feelings of your experiences. Interviews will be conducted either face-to-face on UEA premises or via a video call, this is up to you. The interview will be conducted by Caitlin Green, the lead researcher. The interview will be audio recorded and a word-for-word transcript will be written of what was said. There may be one longer interview or more shorter interviews, this is also up to you. The interview(s) will be no longer than 90 minutes, and may be shorter. We will know if further interviews are necessary if there are areas that you feel are important that we have not yet talked about.

If you have expressed interest in taking part in this study and given consent to be contacted by the research team, the lead researcher will contact you by telephone to discuss any questions you might have and give more details about the procedure of the study. If you decide to take part we will arrange a time for the interview. Your GP will also be made aware that you are taking part in the study, however, we will not share the results of the study or recordings with them. Before the interview you will be asked to sign a consent form to say that you are happy to take part and that you have had the study explained to you.

On the day of the interview, you will have time to discuss any questions or concerns beforehand and will be asked some demographic information, e.g. your age and ethnicity.

After the interview, the interviewer will check whether you are okay and will offer you a debrief of the study. You will have the opportunity to ask questions, and you will be offered a £10.00 Amazon voucher to thank you for your time.

What are the possible disadvantages of taking part?

It can be challenging talking to someone new, and some of the interview questions may bring up feelings that may cause you to feel a mixture of emotions, good and bad. If you feel upset or just need a break, please let the researcher know who will be able to offer you a break. The interview could be resumed after a break or can be stopped and re-arranged for another day to complete. If you want more support, you will be put in touch with the mental health team normally responsible for your care. Alternatively, you may prefer to talk to your GP or can contact the following services:

- Samaritans – 24/7 confidential emotional support: Tel: 116 123
- First Response– 24/7 helpline offering immediate advice and support for people with mental health difficulties. Tel: 111 option 2

The interviews will take up to 90 minutes. You can do the interview at your home, but if you choose to do the interview on UEA premises, you will need to pay for your own transport and parking costs.

What are the possible benefits of taking part?

It is the hope that the findings from the study can help to better understand the experiences of people with ASD who have experienced social trauma, as this is an area with little research. This information may be helpful in building our understanding of what a socially traumatic experience is for someone with ASD, and how it may impact that person, along with identifying what support may be beneficial. You will also receive a £10 Amazon gift voucher for your participation.

Do I have to participate?

No, you do not have to participate. Participation is completely voluntary. You can say no right from the start. If you do decide to take part but then change your mind, you are free to withdraw without giving a reason. There are no consequences if you do decide to no longer participate, and this will not affect your clinical care within NCHC. If you change your mind after the interview, you can let the research team know within 2 weeks after the interview takes place and your data will not be saved. After the 2 weeks the removal of your individual data will be difficult as the researcher will have started the data analysis. If you wish to withdraw after the period of 2 weeks, the study will not include any direct quotes from your interview.

How will my data be kept confidential?

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number or pseudonym instead. Any identifiable information will only be accessed by the research team and will be removed in the phase of the transcription of the interview. The lead researcher, Caitlin Green, will transcribe your interview. The transcript data will be anonymised, and audio recordings will be deleted at the end of the study date, September 2024.

Only non-identifiable information will be recorded. Data will be stored securely according to relevant regulations and UEA policy. Specifically, they will be saved on password-protected documents within password protected systems. Only the lead researcher and research supervisors will have access to these. The recordings and results of the study will not be uploaded to your clinical records. The only exception would be if there is a risk to yours or someone else's safety where it will be appropriate to have this on record.

Once we have finished the study, we will keep some of your data so we can check the results. A paper copy of your consent form will be held securely at UEA. Following the completion of the study, the information will be held securely by UEA for a period of 10 years.

If, during the research interview, you tell the researcher something which makes them concerned that you or someone else may be at risk of harm, it is possible that this information may have to be shared with the manager responsible for your care or with your GP. You will be told before this happens and, whenever possible, the situation will be discussed openly with you so that you understand why it was necessary to break confidentiality.

On rare occasions it is necessary to break confidentiality without letting a participant know, but this is only done if telling you first would jeopardise your safety or the safety of someone else.

How will we use information about you?

We will need to use information from you for this research project. This information will include:

- Your name and contact details to contact you throughout the study. This information will be deleted following the completion of the study and will not be shared with any person who is not a member of the research team.
- Your transcribed interview, and demographic information, such as your age, ethnicity, disability, sexuality, socio-economic status and employment status.

The results of the study will be written up for a doctoral thesis and may be published in an academic journal. Direct quotes from your interview may be used in publication. The researchers will make sure if your quotes are used every step will be taken to anonymise your information and it will be written in a way that no-one can work out that you took part in the study.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- or by sending an email to UEA's Data Protection Officer dataprotection@uea.ac.uk

Will I be told the results of the study?

You have the right to receive feedback about the results of this study after its completion. The findings of the study will be shared with you in the form of a summary. If you are interested in this, please confirm on the consent form and provide an email address. All data in the summary given to you will be anonymised.

What if I have a complaint?

If you have any questions or concerns about the study, you can contact a member of the research team. If you would like to raise concerns or complaints to someone independent from the study, you can contact:

Dr Jo Hodgekins
UEA PGR Director
Email: j.hodgekins@uea.ac.uk.

Patient Advice and Liaison Service (PALS)
Tel: 0800 088 4449
Email:pals@nchc.nhs.uk

If you would like more information, the main point of contact is:

Caitlin Green
Trainee Clinical Psychologist
Email: caitlin.green@uea.ac.uk
Phone; 07949028680

You can also contact the following members of the research team:

Dr Kenny Chiu
Research Supervisor
Email: Kenny.chiu@uea.ac.uk

Dr Louise Mullineaux
Research Supervisor
Email: louise.mullineaux@nchc.nhs.uk

Dr Paul Fisher
Research Supervisor
Email: p.fisher@uea.ac.uk

Appendix G: Letter to GP

University of East Anglia

NHS
Norfolk Community
Health and Care
NHS Trust

Dear Doctor

I am writing to inform you that your patient, (insert name), has agreed to take part in a research study exploring the experiences of autistic adults in social situation. This study, tilted “Autistic adults’ experience of social trauma: An Interpretive Phenomenological Analysis’, will form part of my thesis portfolio as I am undertaking doctoral clinical psychology training. Please find attached a participant information sheet for further details about the study.

The purpose of this study is to gain insight into the experiences of autistic adults in social situations, with the aim to improve support and resources for this population. The study will involve interviews with the patient about their thoughts and feeling of their experiences in social situations, such as relational bullying and rejection. We appreciate the willingness of the participant to share their experience and contribute to this under-researched topic.

We recognise that some of the questions may be challenging at times. A trained professional such as myself will be involved in conducting the interview, and to provide emotional support should your patient become temporarily distressed during the study. We have advised participants that if they disclose that themselves or others are at imminent risk of harm, we may notify their relevant professionals, including their GP.

If you have any further questions or concerns, please do not hesitate to contact me via email at caitlin.green@uea.ac.uk.

Kind regards,

Caitlin Green
Trainee Clinical Psychologist
Postgraduate student (ClinPsyD)
University of East Anglia

Supervised by

Dr Kenny Chiu
Clinical Lecturer in Clinical Psychology, UEA ClinPsyD Programme
Dr Louise Mullineaux

Specialist Clinical Psychologist & Supervisor UEA ClinPsyD Programme
Dr Paul Fisher
Clinical Lecturer in Clinical Psychology, UEA ClinPsyD Programme

Appendix H: Participant Consent Form

Participant Consent Form

Participant Identification Number for this trial:

Title of project: Autistic adults experience social trauma: An Interpretive Phenomenological Analysis.

Name of researchers:

Caitlin Green (Trainee Clinical Psychologist and Principal Researcher, UEA)
Dr Kenny Chiu (Clinical Psychologist and Primary Project Supervisor, UEA)
Dr Louise Mullineaux (Clinical Psychologist and Secondary Project Supervisor, NCHC)
Dr Paul Fisher (Clinical Psychologist and Secondary Project Supervisor, UEA)

Please Initial Box

1. I confirm that I have read, or had the information sheet (version 3 Date :) read aloud and understand the participant information sheet for the above study. I have had the opportunity to consider the information and ask any questions and had these explained to my satisfaction. ☐

2. I confirm that I am signing this consent form at least 24 hours after having first had the study explained to me. ☐

3. I understand that I am giving consent for the use of audio recording, with possible use of verbatim quotation. ☐

4. I understand that the research team may have access to personal data (e.g. name, contact details) and that this will not be shared with anyone outside the research team. ☐

5. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights or medical care being affected. ☐

6. I consent for my GP to be informed that I am taking part in the study, and for them to be informed if I disclose that myself or others may be at risk. ☐

7. I agree to take part in the above study. ☐

8. I am interested in being emailed a summary of the results of this study. ☐

   Email:

Name of Participant	Date	Signature
Primary Investigator	Date	Signature

If returning by post, please send to: Dr Louise Mullineaux, Autism Service Norfolk, Room 97, Norwich Community Hospital, Bowthorpe Road, Norwich, Norfolk, NR2 3TU

You will be given a copy of the consent form for your records. In addition, a copy will be stored on the UEA secure drive, and one sent to your GP informing them of your participation.

Appendix I: Initial Commentary Example

Participant	Emergent themes	Original transcript	Exploratory comments	Reflective commentary
Ashley	Strong emotional impact from social trauma Loss of confidence following trauma Confused at the cause of rejection Burden to others Taking responsibility for other people’s behaviours Lack of social connection to others View of self as separate from others	Ashley: [Pause] I guess in school, like a lot of very small things happen, but I still just remember them vividly. Like there was someone who I’d walk to school with every day and… it was the start of the new year. And she just wasn't there at the time that we usually meet. So I was, like, texting her. And I was like, you know, where are you? We’re gonna be late for the bus. And she just didn't reply and, uh… I can’t remember what happened exactly. I don't know if I spoke, I don't think I did because my confidence was just so low. I thought, like, you know, if someone doesn't have to be friends with me, that's probably a good reason. Because I'm not, I just don’t fit in. And she just kind of found someone else to walk to school with. Umm, she didn't already tell me. [Pause] And I didn’t really have many friends at school a lot of time. [Long pause] Like in primary school, I kind of just hang out by myself. And then secondary school… Like I'd hang around, like in a group, but no one was really my friend. I was kind of just there and I just felt like I was just the person who was just there, but no	Still strongly affected by past events at school *Strong visual memories with intense emotions* Abandoned Lost confidence Sees herself as different from others. What does that mean about her worth. Views this difference as a burden that others shouldn't have to put up with? *Language and tone sound very defeatist and uncertain* Let down by others. Not treated how they would treat others	From Ashley’s description of this event, you get a sense of how sad and confused they were growing up. The language and tone they used, such as the repeated use of ‘just’ gave the impression that they had learnt to accept this treatment and they didn’t understand it so there was no way they could change. I got the sense that fitting

	Low self-worth Internal blame Normalised negative experiences Struggling to fit in Struggling to understand typical social interactions	one really would care if I was gone [long pause]. Interviewer: How did that feel at the time? Ashley: Like it was really sad, but at the same time it kind of felt like I deserved it like, it because you are sad about it as well, but it was just normal for me. Like I didn't know what it was like to have friends. And I did just wonder after a while why I just didn't fit in [Pause]. In the school at that point I didn't even really speak much because it was very hard for me to talk like even in lessons or like with teachers and stuff. Umm, ‘cause I guess I felt like I would say something weird or, I just didn't understand what was weird or normal, so I just didn't say anything at all.	Spent a lot of time growing up by themselves, lack of social connection with peers *Needs more time to think about what they want to say and share. Longer time needed for processing* Needs more time to think about what they want to say and share. Longer time needed for processing On the periphery of the friendship group. Felt unwanted and still separate from the group. Didn’t see themselves as being valued and was never treated as though they had value in the group Blamed themselves, they deserved this treatment Overthinking and worrying what others may think of them.	in was important to them. I noticed myself feeling sad and angry on their behalf.

			Others may see that they are not ‘normal’. They didn't speak and this was their protective strategy as it would bring less attention to them. Struggling to understand social complexities in a neurotypical world Fear of being rejected, unwanted.	

Appendix J: Developing Themes Example

Emergent themes	Quotes	Grouping of emergent themes	Subordinate theme	Superordinate theme
Re-examining past with new understanding Diagnosis gives understanding to what led up to trauma	“But now looking back, I'm just like, I was just autistic and very uncomfortable.” (Ashley) “You know, realising you’re autistic, maybe makes sense of the, the events that led up to being traumatised, it doesn't make sense for people's behaviour or their attitudes, though.” (Richard)	Seeing my traumatic experiences through a new lens	Everything makes sense now	Re-examining social trauma with a new lens
Diagnosis as a therapeutic process Developing new identity educed self-blame	“So if I did just recall a memory and think, oh, I feel bad about that, I would realise, OK, it’s because of autism, it's not because of me. So it was quite sudden, but there's still things like that.” (Ashley “I'm not going to take it more on myself and	Developing compassion and understanding to past experiences following diagnosis		

Overwhelmed in busy environment Sensory overload in social situations Better understanding how his behaviours might be perceived by others Diagnosis provides explanation for struggles	blame me and get upset because I was that way out, I am that way.” (Oliver) “I'm fairly sure, looking back, it was probably I was overwhelmed with whole school situation.” (Poppy) “Knowing that I'm autistic, knowing that I have it, I can come across in certain ways. I can come across as blunt, without meaning to. It makes sense. It makes sense in some, some level of how, of, of how certain times people have reacted to me.” (Blake) “You know that puzzle piece that represents autism and I know a lot of people don't like it, but I really like that imagery because the diagnosis is the missing puzzle piece	The role of ASD in social trauma		

Struggles and differences put in context of autism Diagnosis gives validation for past difficulties Self as different to others Diagnosis provides an answer for why he feels different to others Differences put in a context that makes sense and helps him recognise when he struggles	that sort of makes the whole picture clearer." (Poppy) "I've got… more aware that maybe my reactions to these things are not- I was going to say not normal. They're not the sort of average response to these things. And the way that I sort of pick up on conversations and other people's motivations is maybe a little lacking. So that sort of explains why these things happen, which does make them, I think, easier to deal with." (Sam) "it's kind of become an answer to, why. I can look back now and go, Oh, right. There's not, so I'm not just, not just strange [laughs]. I'm not just the one in the group that disappears, there's actually a reason behind it." (Oliver)	Gaining a new perspective following my diagnosis Awareness of my difficulties and accepting them		

Accepting of autistic self Relief after diagnosis	“And like trying as well, just trying to be normal then and now I just realised, OK, I'm not going to be able to be that because that's not me. It feels like a relief, that I don't have to change like. Like I can just stop trying to do that.” Ashley			