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AN EXPLORATION OF EXPERIENCES OF SELF-COMPASSION IN AUTISTIC WOMEN

Section A: A Systematic Review of the Impact of Bullying on Autistic Children and Young People

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To Jack, for the endless encouragement and laughter, and always celebrating even the smallest of victories.

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To Tommy, for just being here.

Summary of Major Research Project

Section A: This systematic literature review synthesizes and critically evaluates quantitative

research into how autistic children and young people are impacted by their experiences of

bullying. The quality of thirteen papers is assessed and findings are considered, highlighting

generalisability and limitations. The findings are discussed in relation to existing

psychological theory, and the implications for clinical practice and the autistic community are

stated. Suggestions for future research are made.

Section B: There is little literature exploring the experiences of self-compassion in autistic

women. Such research is essential to understanding how autistic women relate to the world,

providing insights into how they may develop mental health difficulties, and the importance

of self-compassion in self-esteem building and perception of identity. The aim of this study

was to explore the experiences of autistic women with self-compassion using interpretative

phenomenological analysis. Three Group Experiential Themes emerged: 'Connection with

identity', 'I deserve it, right?', and 'Sense of growth'. Research and clinical implications are

discussed.

Section C: Appendices

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Section A: A Systematic Review of the Impact of Bullying on

Autistic Children and Young People

Nancy da Silva

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Abstract

Background and aims: Childhood bullying is a global phenomenon that has negative

psychological consequences and disproportionately affects autistic children and youth. This

review aimed to identify, evaluate, and synthesize the recent literature on the impacts of

childhood bullying on autistic children and young people.

Method: Four databases were systematically searched for relevant studies. Thirteen studies

met inclusion criteria.

Results: The identified studies differed in terms of sample, design, methodology and

outcomes measured. Results suggested that many autistic children and young people who are

bullied experience school refusal and internalized and externalized mental health concerns.

Conclusion: The quality, heterogeneity, and cross-sectional nature of the studies makes it

difficult to draw definite conclusions. The findings from this review highlight the impact that

bullying has on the mental health of autistic children who are bullied. Further research with

this group could increase our understanding of the experiences and investigate the long-term

impact of bullying on autistic children and young people and suggest interventions that could

target their difficulties.

Keywords: bullying, peer-victimization, autism, mental health

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Note: Identity-first language will be used throughout this paper to respect the preferences of the majority of autistic people (Kenny et al., 2016). The terms 'learning disability' and 'intellectual disability' will be used interchangeably throughout as most studies included are from outside the United Kingdom (UK; Gates & Mufuba, 2016).

A Systematic Review of the Impact of Bullying on

Autistic Children and Young People

Peer relationships across childhood are critical in the development of social and communication skills, academic achievement and learning engagement, and sense of belonging (Gross-Manos, 2014; Shao & Kang, 2022; Uslu & Gizir, 2017; Yu et al., 2023). Despite this, bullying is a common problem worldwide, with one in three children experiencing bullying in childhood (UNESCO, 2019). It has been identified by WHO as a major public health issue due to its causal role in the development of depression and anxiety, social withdrawal, school difficulties and substance misuse (World Health Organization, 2010). There is also evidence to suggest that in addition to its impact on physical and mental health, bullying also impacts social and financial outcomes (Takizawa et al. 2014).

Definition of bullying and types of victims

Bullying, or peer-victimization (these terms will be used interchangeably throughout), is defined as "aggressive behaviour including intentions to be hurtful or harmful, that is repetitive and systematic, where some sort of power imbalance between those involved exists" (Gladden et al., p.7). Bullying can be direct (completed in the presence of the victim) or indirect (not obviously communicated but targeted) and may be seen through verbal (e.g., name calling, threats), physical (e.g., hitting, damaging victim's property) and relational actions (e.g., rumours, ostracizing). Peer rejection or exclusion is not always considered

bullying or aggressive (Mulvey et al., 2010), but may cause psychological harm and have negative emotional and behavioural health outcomes (Killen & Ruttland, 2011; Mulvey et al., 2017). The increase of internet and social media use for interpersonal communication has also brought a new space and method for victimization, known as cyberbullying.

Cyberbullying's main differences are the perpetrator's ability to remain anonymous, the ability to reach broader audiences and that it can occur relentlessly at any time of day.

Bullying generally consists of three categories of participants: bullies, victims, and bully-victims (Shetgiri, 2013). Bullies are often characterized as being confident, having high self-esteem, and popular, despite being disliked and struggling with social perspective taking and empathy (Garandeau et al., 2014; Guy et al., 2019; Reijntjes at al., 2016). Victims of bullying tend to be physically weaker, more withdrawn, and with lower levels of perceived relational skills (Cocoran et al., 2012; D'urso et al., 2022; Veenstra et al., 2005). Bully-victims, those who bully others and are also bullied by their peers (Marengo et al., 2018), are identified as being more ostracised and rejected by peers than bullies (Copeland et al., 2013; Juvonen et al., 2003).

Prevalence and risk factors

There is significant variation in the prevalence of bullying across age and culture (Menesini & Salmivalli, 2017). Some research suggests prevalence in childhood as high as 45% in Eastern Mediterranean Region, 43% in Africa, 22% in the United States of America and 9% in Europe (Biswas et al., 2020; Modecki et al., 2014; National Center for Educational Statistics, 2019). Evidence indicated that bullying may start as early as age 4 (Vlachou et al., 2013) and peaks between ages 11-14 (Nylund et al., 2007). Children are less likely to be victims of traditional bullying as they get older (Bowen & Holton, 2010); this may be because older children are generally the perpetrators (Tiiri et al., 2020). During mid

childhood and adolescence children attach great significance to their friendships and peer groups (Poulin & Chan, 2010), aligning with Erikson's fourth stage of psychosocial development, 'industry vs inferiority' (Erikson, 1993). During this stage of development, peer groups become a main source of a child's self-esteem, and they seek reinforcement from these peers. Mid childhood and adolescence is also the time in which children develop autonomy from their parents (Karabanova et al., 2013), although parent support has emerged as a protective factor for young people lacking peer friendships (Schacter & Margolin, 2019). According to Kohlberg's stages of moral development (1976), mid childhood is characterized by an acceptance of social rules concerning right and wrong, and reasoning is based on the norms of the group to which the person belongs. This may encourage young people to bully to assert dominance to prevent social isolation through bullying (Evans & Mokowski, 2016). There is also evidence that boys are more likely to be victims of bullying than girls, but these differences are less marked once physical aggression and relational aspects are compared (Silva-Rocha et al., 2020).

Much of the research has indicated that bullying victims often display social difficulties in relation to peer relationships. Lack of social understanding such as taking the perspectives of others and interpreting context in social situations, is more likely to make a child a victim of bullying (Guy et al., 2017). Poor quality friendships and lack of belonging to a friendship group may isolate victims, making them easy targets. (Charamlampous et al.; 2018; Griffin & Gross, 2004). Perceived differences from the peer group such as physical appearance (Hammar et al. 2020; Pinquart, 2019), behaviour problems (de Sousa et al., 2021), and interests (Kaufman et al., 2022) can leave children isolated and excluded from groups (Guy et al., 2019). This is supported by the person-group dissimilarity model (Wright at al., 1986) which describes how deviating from the average group behaviours and characteristics can make individuals social outcasts and lead to rejection.

Relationship between autistic characteristics and bullying

Amongst school aged children and young people in England, 15.5% have been identified as having a special educational need and disability (SEND; Department of Education, 2022). Learning disabled and autistic children are at higher risk of being bullied compared to their peers (Maiano et al., 2016; Zeedyk et al., 2014). Children with autism spectrum condition (ASC) specifically are bullied with more frequency than their typically developing peers (Forest et al., 2020; Hwang et al. 2018). Furthermore, research suggests that autistic children are bullied more frequently than children with other disabilities (Bear et al., 2015; Hebron & Humphrey, 2014).

Autism spectrum condition (ASC) is characterised by combinations of difficulties in social communication and repetitive behaviours, restricted interests, and sensory behaviours (American Psychiatric Association, 2013). The concept of autism has continued to evolve over time. The heterogeneity in how autism presents in the community has encouraged the expansion of the diagnostic criteria and encouraged the use of the term 'spectrum'. Due to the spectrum being so wide, it becomes challenging to compare the experiences of autistic individuals. Therefore, individuals with similar clinical presentations can present with very different profiles (Sonuga-Barke & Thapar, 2021). When looking at the predisposing risk factors for peer victimization, it becomes clear why the inherent traits that characterize autism would make these children vulnerable to bullying.

Social communication and speech are at the core of developing peer relationships. Many autistic children develop language later or atypically compared to their peer group (Mody & Bellibeau, 2013). There is evidence suggesting that children with a history of speech and language difficulties are more vulnerable to bullying (Lindsay et al., 2008) potentially due to the inability to understand and communicate effectively with peers

relationally. Some autistic children also have challenges with social motivation and integration, spending more time engaged in solitary behaviours, and less time engaged in cooperative interactions with peers (Humphrey & Symes, 2011). As they spend more time independently, this may limit their opportunities to foster meaningful relationships with others. Autistic children's encounters with social expectations and biased attitudes face may influence their sense of belonging (Pesonen et al. 2020). Perspective taking, or theory of mind, has been researched extensively within the autistic community (Burnside et al., 2017; Livingston et al., 2019; Pedreno et al., 2017). Research suggests that theory of mind mitigates the relationship between autism and social functioning (Berenguer et al., 2018). The difficulties that autistic children may have in understanding how others feel, different beliefs, interests and experiences can create conflicts with peer groups.

There are estimates that approximately 70% of autistic children are taught in mainstream schools across the United Kingdom (National Autistic Society, 2021). There has been a push for their inclusion in mainstream education as this has been reported to improve educational performance (Myklebust, 2006), yet research suggests that they are more likely to be bullied in these environments (Zablotsky et al., 2014). When autistic children enter school settings they are often less emotionally prepared than typically developing peers, which can lead them to have more externalizing behaviours and challenges with self-regulation (Marsh et al., 2017). These challenges are heightened by impaired executive function associated with autism (Frazier et al., 2022; Maddox et al., 2018). The bright lights and loud noise, to name a few of the sensory challenges in a school environment, can be aversive for children with sensory sensitivities. The differences that these children have can be amplified by the unpredictability of the school environment. Because of these, children often require additional support from teachers or an allocated aid. This help-seeking may highlight that the child is different from peers and provide another reason for 'othering' (Nabuzoka, 2003).

The most common cause for non-attendance in school by autistic children is due to school refusal. Children with chronic illness have also been seen to school refuse, but also due to hospital appointments and bullying (Craven et al., 2023). This draws parallels with research in typically developing populations, whereby school absenteeism is related to increased bullying (Delgado et al., 2019). These increases in bullying may be related to being seen as part of the 'outgroup' and disruptions to forming positive relationships.

Autism is a hidden condition that cannot be characterized by any physical markers; this 'invisibility' makes it difficult for others to recognize the challenges this group experiences and therefore they may be misunderstood (Matsuka & Gallagher, 2020). These experiences have been seen in the research by others with invisible disabilities such as auto immune diseases, brain injuries, and mental health conditions (de Beer et al., 2022). Previous research indicates that teachers are more likely to have positive attitudes towards the inclusion of students with physical or mild disabilities compared to those with emotional, cognitive impairments or behavioural issues (De Boer et al., 2011), with less favourable attitudes specifically towards autistic pupils (Jury et al., 2021). This discrimination may cement feelings by autistic youth of loneliness and isolation at school, as well as feelings of being unsupported and misunderstood by teachers within a social and sensory environment that does not meet their needs (Goodall, 2018). Evidence suggests that the warmth and conflict that a teacher displays towards a child affects the liking and disliking towards them by their peers (Hughes & Im, 2016). In addition, autistic children who are victimized by teachers are more likely to display more severe depression and anxiety (Lin et al., 2020). If teachers are displaying unfavourable views towards autistic children, this may encourage students to also discriminate against this group. Teachers may thus be less likely to tackle the bullying of autistic children due to these biases.

Consequences of bullying

There is a robust body of literature looking at the consequences of bullying victimization in typically developing children through childhood and adolescence. Armitage (2021) suggested that the consequences of childhood bullying can be categorised as either educational or health consequences in childhood, and that these extend into adulthood. There is a relationship between the frequency and intensity of the bullying experienced and the negative consequences reported. Moore et al. (2017) conducted a meta-analysis that indicated causal associations between bullying victimization and mental health problems such as depression, anxiety, poor general health, and suicidal ideation and behaviours in childhood. Adults bullied in childhood are less likely to be employed in mid-life (Brimblecombe et al., 2018), lack social relationships (Takizawa et al., 2014), have comorbid mental health problems (Sigurdson et al., 2015), and poorer physical health (Matthews et al., 2017). Chronic bullying has been associated with emotion dysregulation and altered physiological arousal (Comodeca & Nava, 2020), and atypical production of cortisol (Knack et al., 2011). Type II traumas involve the repeated exposure to a traumatic situation, which would include being bullied. Strong associations between bullying and characteristics of post-traumatic stress disorder (PTSD) have also been found (Idsoe et al., 2012; Ossa et al., 2019). This supports research indicating that victims of bullying tend to remain in a hypervigilant state which may interfere with emotion regulation (Bonilla-Santos et al., 2022). As emotion dysregulation is substantially elevated in the autistic population compared to the general population (Conner et al., 2020), autistic children may be doubly at risk of trauma from bullying as they are more likely to be targets, and less likely to have emotion regulation as a protective factor. Alexithymia, characterized by a difficulty in identifying and communicating feelings and in differentiating between feelings and somatic sensations of emotional arousal (Nemiah et al., 1976), is highly prevalent amongst autistic children (Kinnaird et al., 2019), and can worsen due to negative experiences across developmental

stages (Moore et al. 2008). Research has suggested that alexithymia plays a crucial role in the association of bullying experiences and PTSD (Guzzo et al., 2013), and thus may put autistic children at greater risk of negative long term consequences. Research from the last decade has not only made clear the detrimental effects of childhood bullying on typically developing children, but has demonstrated that autistic children are at even greater risk for these adverse effects.

Existing Literature Reviews

There are a small number of literature reviews which have researched bullying within autistic children. Schroeder et al. (2014) reviewed literature on the prevalence of bullying involvement in the ASC population and associated factors. They confirmed that children and youth with ASC experience increased rates of perceived bullying compared to the general population and compared to peers with other mental or physical care needs. They also indicated that autistic students exhibit risk factors and lack of protective factors associated with autistic traits putting them at a higher risk of victimization. Maiano et al.'s (2016) metaanalysis found that youth with ASC were at greater risk of school victimization than their typically developing peers. They found that autistic young people from Europe or North America were significantly less vulnerable to school bullying than those in the Western Pacific region, and that school-aged autistic children were more likely to be bullied in mainstream settings than in special education settings. Park et al. (2020) examined the prevalence, risks, and factors associated with bullying involvement among students with ASD. In line with the two previous reviews, they found that these children were at significantly higher risk of bullying than typically developing children or other disabilities. Deficits in social interaction and communication, externalizing and internalizing symptoms, and integrated inclusive school settings were related to higher victimization. Hoover (2015) provided a review of the effects of trauma on autistic children, focusing on the types of

exposure, symptoms, and tools used to assess these experiences. Within this there was a particular focus on peer victimization. Humphrey and Hebron's (2014) review highlighted the increased prevalence of bullying of autistic children. They also noted that interventions at a multi-level approach focussing on autistic young people, peers, and teachers, might be effective. Since these reviews were published there has been a significant increase in literature on bullying of autistic children and young people.

Whilst the above literature provides a breadth of information on prevalence and associated risk factors for bullied autistic children, there is a gap in understanding as to how this bullying impacts them. With the autism mental health crisis being described as a paradox where "autistic people have a high chance of developing mental health problems, but a low chance of receiving effective help" (Mandy, 2022, p1), it is essential that research highlights the short and long-term effects on autistic children.

Aims for the Review

Given that previous reviews emphasis on prevalence and risk factors with little focus on how bullying affects autistic children, this review aims to summarize the published literature investigating the experiences of bullying on autistic people. It will aim to address the following question:

 What impact does the experience of bullying have on autistic people? Impacts may refer to emotional, behavioural, or practical outcomes on people's lives.

Method

Study design

This review has adopted a narrative approach, using a systematic search to review quantitative literature in the area. The aim is to create a narrative of the research available that addresses the question above.

Inclusion and exclusion criteria

Broad eligibility criteria for studies in the review were set due to the limited literature of research in this area. The review included quantitative or mixed-method studies examining the impact of childhood bullying on children or young people who identify as autistic (formal diagnosis, or self-reported), or have a diagnosis of Aspergers Syndrome or Pervasive Developmental Disorder (PDD). To ensure the data set was explored in detail, qualitative studies were excluded. To ensure that the experiences of non-verbal people were included in the review, parent views of the impact of bullying were included. Studies which included bullying as part of interpersonal trauma but did not differentiate the effects of bullying specifically in the results were excluded. Studies were included if they used a mixed group of participants (e.g with diagnoses of ADHD and ASC) if results between groups were differentiated. Studies were included if they used comparators who were either autistic and had not experienced bullying or who identified as having other neurodevelopmental or mental health diagnoses and had experienced bullying.

Table 1Summary of inclusion and exclusion criteria for the research papers.

Criteria	Include	Exclude	
Study methodology	Empirical work, quantitative	Work that is not empirical	
	in methodology	(abstracts, editorials,	

		reviews, books, and grey
		literature), qualitative
		methodology
Dates	July 2015- October 2022	<july 2015<="" th=""></july>
Language	English	Non-English
Location/Country	Any	None
Population characteristics	Children and young people	Children and young people
	who meet criteria for	with other neurological or
	diagnosis of ASC, Aspergers	developmental disabilities
	or PDD; parents of children	
	who meet criteria for	
	diagnosis of ASC, Aspergers	
	or PDD	
Outcomes	Any outcomes related to	Outcomes not related to
	potential impacts of	potential impacts of
	bullying, or trauma as the	bullying, or trauma as the
	primary outcome	primary outcome

Literature search

The researcher conducted an electronic literature search using PsychINFO, Web of Science, Pubmed and ASSIA databases. The date range included literature published between July 2015- October 2022, which prevented repetition with previous reviews (e.g., Hoover, 2015; Humphrey & Hebron, 2014). Only peer-reviewed papers were included. A review of the relevant literature informed the search terms. Key terms were combined with the Boolean operators 'AND' and 'OR'. The search terms included the following:

(autis* OR ASD OR ASC OR asperger OR pervasive developmental disorder OR PDD)

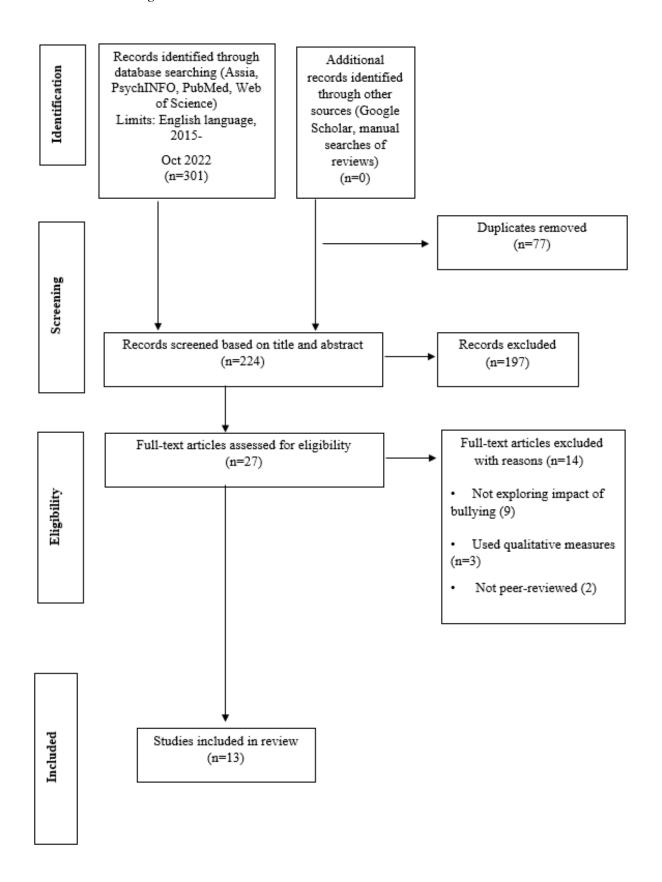
AND

(bullying OR peer victimization OR peer victimisation)

The researcher initially screened the retrieved literature titles for relevance to the topic, then the article abstracts and full texts to determine whether they met inclusion criteria. The reference lists of the studies were also searched for studies that met the inclusion criteria. Following this screening process, this literature review included twelve papers. Figure 1 depicts the number of papers retrieved at each stage of the literature search process, presented following the guidance from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Figure 1).

Figure 1

PRISMA Flow Diagram



Literature review

The identified papers are summarised in Table 2. Findings are then synthesized and critiqued. Corresponding critical appraisal of the papers can be found in Appendix A.

Table 2
Summary of studies

Study (year) Location	Research Aims	Sample	Study designs/analysis	Measure	Findings
Adams et al. (2016) USA	Examine relationship between types of peer victimization and educational outcomes in autistic youth	Study 1: N= 463 parents of children 10-18 M=12.9 years 85.2 % male 91.2 % white, 93.1% non- Hispanic 94% attended public school Study 2: N= 54 10-17 M=14.62 100% male 2.6 % Caucasian, 3.7 % Black, 1.9 % Asian, 1.9 % Bi-racial Verbal, English- speaking	Study 1: Cross-sectional survey Multiple regressions, logistic regressions	Study 1: Open ended questions, ratings on educational scale 1-4 Study 2: Shwartz Peer Victimization Scale (SPVS), Child Behavior Checklist (CBCL)	 Parents reported children experienced victimization: verbal (43.1%), physical (17.4%), ignore (30.6%), provoke (63.5%) All four types of peer victimization associated with one another Each type of victimization significantly associated with enjoying school, belonging in school, and feeling safe; verbal victimization and being ignored had the strongest association No association with parent-reported academic performance Verbal victimization, being ignored, and being provoked associated with likelihood parents told about academic problems and social problems. Study 2: Over the past month 35% reported bullying in the past month, 50% at least once a week, 61% at least once a month. All four types of peer victimization correlated with each other. Verbal, relational and ASD-related victimization, but not physical, significantly associated with disobedience at school. Verbal victimization significantly associated with fear of going to school Verbal and AS-related victimization were significantly associated with poor school work.

Ashburner et al. (2018) Australia	Examine emotional effects of bullying in autistic youth	N=89 (parents and youth) 11-16 M=12.7 86% male 51% public school	Exaplanatory sequential mixed method; Mann-Whitney U- test, Wilcox and Signed-ranks tests, Spearman's Rho correlation coefficient, McNemar's test, chi-square analysis; qualitative content analysis	Semi-structured interviews, survey	 No significant differences between parent and student reports of face-to-face victimization Parents more worried than students about face-to-face bullying Students significantly more worried about face-to-face bullying than cyberbullying Students who report face-to-face bullying are also more worried about bullying Students with anxiety disorders more likely to report face-to-face victimization Students with anxiety are more worried about face to face bullying and cyberbullying Students with depression more likely to report cyberbullying
Bitsika & Sharpley (2021) Australia	Aimed to explore the role of bullying in emerging school refusal among autistic youth.	N=67, 7-18 M=11.7 100% male IQ>70	Cross sectional; Correlational analysis (Pearson and Spearman), logistic regression	Questionnaire, Child and Adolescent Symptom Inventory, 4 th Revision (CASI- 4R)	 85.1% of boys reported being bullied at school 56.1% of boys who reported being bullied also reported asking parents to stay home as a result of bullying Boys who asked to stay home due to bullying reported significantly higher levels of feeling tense and unable to relax compared to boys who did not avoid Boys who asked to stay home from school reported sleeping difficulties and big changes to sleeping habits 83.3% of boys with school refusal reported that they were bullied "nearly every school day" compared to 16.7% of boys who did not have school refusal Being bullied 'almost every school day' was significantly and meaningfully associated with asking parents if they could avoid school due to bullying

Bitsika et al. (2022) Australia	Investigate association between emerging school refusal, social phobia and separation anxiety in autistic youth	N=71, 6-18 M=10.3 years 100% male IQ >70	Cross-sectional; Correlational analysis, logistic regression	Semi-structured interview, Child and Adolescent Symptom Inventory – Revision 4 (CASI-4)	 82% of boys reported being bullied at school 55% of boys who were bullied in school asked to stay home from school Boys who asked to stay home from school have significantly higher level of separation anxiety than boys who did not ask to stay home 2/4 social phobia symptoms were significantly correlated with the request to stay home from school 7/8 symptoms of separation anxiety were significantly correlated with the request to stay home from school
Chou et al. (2020) Taiwan	Examine differences in levels of depression, suicidality, and selfesteem in adolescents with ASD who experienced bullying	N=219 11-18 M=13.7 M FSIQ= 95.4	Cross-sectional study, logistic regression	Chinese version of the School Bullying Experience Questionnaire (C-SBEQ) Taiwanese version of the Center for Epidemiological Studies Depression Scale (T-CES-D) Taiwanese version of the Multidimensional Anxiety Scale for Children (MASC-T) Suicidality module of the epidemiological version of the Kiddie Schedule for Affective Disorders and Schizophrenia Rosenberg Self-Esteem Scale (RSES)	 Pure victims had more severe depression and anxiety No difference in depression, suicidality, anxiety, and self-esteem was found across groups of various parent-reported bullying experiences

				Chinese Social Responsiveness Scale (SRS) Short form of the Swanson, Nolan, and	
				Pelham Version IV Scale (SNAP-IV)- Chinese version	
Holden et al., 2020 United Kingdom	Investigate longitudinal association between experiencing bullying and suicidality in adolescents with ASD	N=680 <18 M=15.2 75% male 55% white 24% black 5% Asian	Cohort study, univariate analyses, chi-square test, regression analyses	NLP Application	 19% of adolescents had positive mentions of suicidality over the follow-up period, with 44% demonstrating bullying at the time of first clinical contact/assessment 31% of bullied sample was female Bullying was associated with significantly higher risk of suicidality over the course of follow-up Female gender, psychosis, affective disorder diagnoses, and higher intellectual ability were associated with suicidality in follow-up
Liu et al. (2021) Taiwan	Examine role of social anxiety in victimization and perpetration of cyberbullying and traditional bullying with children with ASD and ADHD.	N=219 11-18 M= 13.7 87.7% male	Cross-sectional, logistic regression analysis	Cyberbullying experiences questionnaire (CEQ) Chinese version of the School Bullying Experience Questionnaire (C- SBEQ) Social Anxiety subscale of the Taiwanese version of the Multidimensional Anxiety Scale for Children (MASC-T) Social Responsiveness	 Social anxiety increased the risk of being a victim of cyberbullying, traditional bullying, and a perpetrator in adolescents with ASD Social anxiety increased the risk of being a victim of traditional bullying in adolescents with ADHD
				Scale (SRS)	

Liu et al.	Examine	N=219	Cross-sectional,	Chinese version of the	• 20.54% of participants were victims of multiple types
(2022)	prevalence of	11-18	multivariate linear	School Bullying	of harassment
m :	multiple types	M=14.72	regression and	Experience	 Hyperactivity or impulsivity and ODD symptoms
Taiwan	of harassment	87.67% male	logistic regression	Questionnaire (C-	were positively associated with multiple types of
	victimizations and the	FSIQ>80 verbal		SBEQ)	harassment victimization
	relationship	verbai		Cyberbullying	Adolescents with ASD who experienced multiple
	with			Experiences	types of harassment victimization had higher severities of depression and anxiety and were more
	depression,			Questionnaire (CEQ)	likely to have suicidality than nonvictims and those
	anxiety, self-			Que stionnum (02 Q)	who experiences only one type of harassment
	esteem and			Chinese Social	victimization.
	risk of			Responsiveness Scale	120000000000000000000000000000000000000
	suicidality.				
				SNAP-IV	
				Taiwanese version of	
				the Center for	
				Epidemiological	
				Studies Depression	
				Scale (T-CES-D)	
				Multidimensional	
				Anxiety Scale for Children (MASC-T)	
				Cilidren (MASC-1)	
				Rosenberg Self-	
				Esteem Scale (RSES)	
				Kiddie Schedule for	
				Affective Disorders	
				and	
				Schizophrenia (Kiddie-	
				SADS-E)	
				Close-Ended	
				Questionnaire of the	
				Occupational Survey	
				(CEQ-OS)	

Ochi et al. (2020) Japan	Compare school refusal between children with ASD and non- ASD.	N=237 94 with ASD, 143 without ASD 6-18 71% male Retrospective chart review of psychiatric patients at hospital over 4 year period	Cross-sectional, Ch squared tests, Mann-Whitney tests, univariate and multivariate logistic regression analyses	Children's Global Assessment Scale (CGAS)	 Bullying significantly associated with school refusal in boys with ASD Maladjustment during school entry or promotions were significantly associated with school refusal in girls with ASD School refusal significantly occurred earlier in children with ASD than in those without
Paul et al. (2018) France	Determine prevalence of victimization in ASD youth compared to non-ASD and the relationship with deficits in social skills	N=92, 7-18 M=13.23 84.6% male (ASD) 84.9% male (control group)	Case-control; Pearson correlation test, t-test, Wilcoxon-Mann- Whitney test, chi square test	Juvenile Victimization Questionnaire— Screener Sum Version (JVQ) Post-traumatic stress disorder Check List- Scale (PCL-S) Social responsiveness scale (SRS)	 72% of the subjects with ASD had been victimised during the previous year 94.9% of the subjects with ASD had been victimized in their lifetime Of the subjects who has been victimized at least once, 75% had been victimized at school Peer victimization score was significantly higher than in the typically developing group and was correlated with clinical factor such as a deficit in social skills and severity of post-traumatic symptoms Symptoms of anxiety, depression, eating disorder, addictive behaviours, and self-aggressive or suicidal behaviours were identified by 79.5% of parents with ASD compared to 69.8% of parents in control group (not significant)
Rodriguez et al. (2021) USA	Identify factors associated with increased risk of bullying and associations with mental health	T1 N=187 families T2 N=161 5-12 M=7.9 86% male 34.6%= ID 84% white, non-Hispanic	Cohort study; descriptive statistics, chi-square, Cramer's V, ANOVA	Parent report, SRS-2, ADI-R, CBCL	 39% of youth with ASD reported having been a victim in the past month, increase by 41% the following year ASD youth with higher severity of autism symptoms, internalizing and externalizing mental health symptoms at study onset, experienced higher frequency of bullying

	problems 12 months later in ASD youth	Recruited through community mailings/fliers at autism clinics			 Bullying victimization at Time 1 was related to higher level of internalizing mental health problems one year later Bullying victimization was not found to be associated with externalizing mental health problems
Ung et al. (2016) USA	Examine frequency of peer victimization with ASD youth and relationship with psychological characteristics	N= 81 parents, N=78 children 9-17 M=11.91 76.5% male 77.8% white IQ>70	Cross-sectional, descriptive analysis, intraclass correlation coefficients, Pearson correlation analyses, hierarchical linear and regression analyses, linear multiple regression	The Childhood Autism Rating Scale- Second Edition High Functioning (CARS2- HF) Wechsler Abbreviated Scale of Intelligence- Second Edition (WASI-II) Revised Child Anxiety and Depression Scale (RCADS) Asher Loneliness Scale (ALS) Revised Peer Experiences Questionnaire (PEQ- R) Social Support Scale for Children/Adolescents (SSSC/A) Social Anxiety Scale for Children-Revised (SASC-R)	 Parent and child reported the frequency of peer victimization to occur a few times in the past year Peer victimization was significantly related to loneliness, anxiety/depressive symptoms, and social skills The relationship between peer victimization and anxiety and depressive symptoms and loneliness did not vary significantly as a function of the level of social support received Fear of negative evaluation did not mediate the relationship between peer victimization and social avoidance Parents and youth reported victimization was significantly associated with social avoidance and child's report of peer victimization was significantly associated with fear of negative evaluation

				Autism Social Skills Profile scale (ASSP)		
Wright & Wachs (2019)	Investigate moderating effect of peer rejection	N= 128 11-16 M=13.76 89% male	Quantitative; multiple hierarchical regression analyses	Questionnaires Center for	•	Cyber-bullying victimization related positively to traditional face-to-face bullying victimization, peer rejection, depression and anxiety Peer rejection positively related to traditional face-to-
USA	between cyberbullying, victimization, depression, and anxiety.	86% White 10% Asian 3% Black		Epidemiological Studies Depression Scale The Multidimensional Anxiety Scale for Children	•	Peer rejection positively related to traditional face-to- face bullying victimization, depression, and anxiety Face-to-face bullying victimization related positively to depression and anxiety Gender was unrelated to depression or anxiety

Overview of studies

Population/sample characteristics

Three studies involved child self-reporting (Holden et al., 2020; Ochi et al., 2020; Wright & Wachs, 2019), two involved parent reports (Paul et al., 2018; Rodriguez et al., 2021), and eight used combined parent and child reports (Adam et al., 2016; Ashburner et al., 2018; Bitsika & Sharpley, 2021; Bitsika et al., 2022; Chou et al., 2020; Liu et al., 2021; Liu et al., 2022; Ung et al., 2016). Only Paul et al. (2018) included a direct comparison sample (typically developing). The studies were conducted in several different countries; Australia (Ashburner et al., 2018; Bitsika & Sharpley, 2021; Bitsika et al., 2022), France (Paul et al., 2018), Japan (Ochi et al., 2020), Taiwan (Chou et al., 2020; Liu et al., 2021; Liu et al., 2022) the United Kingdom (Holden et al., 2020), and the USA (Adams et al., 2016; Rodriguez et al., 2021; Ung et al., 2016; Wright & Wachs 2019).

Most studies recruited participants from autism-specific community settings, outpatient clinics, e-mails to schools and e-mail to participants of previous studies. Sample sizes varied, ranging from 54-680 for children, and 54-219 for parents.

The majority of studies did not specify inclusion/exclusion criteria in detail. All studies required a formal diagnosis of ASD to be eligible. Some of the studies used the ADOS-2 (Lord et al., 2012) or ADI-R (Lord et al., 1994) to confirm diagnoses of autism, although many accepted a previous diagnosis from qualified clinicians. Bitsika and Sharpley (2021) and Bitsika et al. (2022) only included male participants. Ochi et al. (2020) and Paul et al. (2018) required all children to be participating in inclusive mainstream classrooms. Approximately half the studies excluded children who had an IQ below 80 (Ashburner et al., 2018; Bitsika et al., 2022; Chou et al., 2020; Liu et al., 2021; Liu et al., 2022; Paul et al., 2018).

Ages of child participants ranged from 5-18. The ages of parent/carers reporting were not available in most of the studies. The studies were all comprised of majority male autistic participants ranging from 71-100%. Of the studies that disclosed ethnicities, the majority of participants were white ranging from 77-91.2%.

Design/method and analysis

The majority of studies were cross-sectional studies, which involved participants completing questionnaires at one time-point. The data was mainly quantitative and analysed using correlational/regression analyses. Ashburner et al. (2018) and Bitsika et al. (2022) also included semi-structured interviews to collect further data. Holden et al. (2020) and Rodriguez et al. (2021) used a longitudinal design which involved collecting data at two time-points.

Outcomes

There were a range of outcomes identified across the studies. Some of the impacts noted were school refusal, anxiety, depression, PTSD, changes in sleep habits, and suicidality.

Four different measures were used to measure peer victimization, the Schwartz Peer Victimization Scale (SPCS), the School Bullying Experience Questionnaire [SBEQ (Chinese Version)], the Cyberbullying Experiences Questionnaire (CEQ), and the Juvenile Victimization Questionnaire (JVQ). A child's general functioning and behaviours were measured using the Child and Adolescent Symptom Inventory 4th Revision (CASI-4R), Children's Global Assessment Scale (CGAS) and the Child Behaviour Checklist (CBCL). Several different questionnaire-based measures were used to measure internalized and externalized symptoms of mental health difficulties.

Additional factors/variables

Five of the studies used questionnaires and semi-structured interview schedules created by the researchers instead of standardized measures to report on prevalence, type, and impact of bullying. These were used both with autistic young people and parents.

Quality Appraisal

Quality Appraisal Tool

Prior to synthesizing, it is accepted that critical appraisals of chosen studies should be completed to provide analytical evaluations of their quality and to minimize biases in the research (Glasziou et al., 2000). Despite cross-sectional and longitudinal study designs having different aims, the included research all reported on correlations. Therefore, the 'Quality Appraisal Checklist for Quantitative Studies reporting Correlations and Associations' (NICE, 2021a), which has been developed to assess the validity of studies reporting correlations, specifically those factors associated with positive or negative health behaviours or outcomes, was used to assess the studies. See Appendix A for a detailed table of appraisal ratings.

The quality appraisal ratings across the studies varied, with some of the studies receiving low ratings in some areas. Although some studies did receive low ratings in some areas, none were rejected due to excessively low scores, and due to the limited research on peer-victimization specifically within the autistic community. In the discussion of the outcomes of this body of research and in the conclusions, the weight placed on the studies varied depending on the appraisal ratings.

Population/Sample

Several of the studies were conducted in the UK (1) or other countries that were primarily English speaking(USA=4, Australia=3), with Western cultures, which may help the generalisability of the findings to a UK setting (location of the author). There was limited information on how participants identified ethnically, but in those that provided demographics, participants were majority white. Evidence suggests that in the United Kingdom, Black children are more likely to receive a diagnosis of autism (Roman-Urrestarazu et al., 2022), therefore participants may not have been representative of the population. All of the studies had over 70% male participants, which reflects the 4:1 male to female ratio in diagnosis (Fombonne, 2009); the requirement for formal diagnosis may lead to the under representation of female children and their families who self-identify as autistic but are less likely to be clinically diagnosed. (Loomes et al., 2017). Most of the studies did not provide detailed demographic information making it difficult to ascertain whether they were representative of their source population, thus leading to low ratings on external validity.

The inclusion/exclusion criteria differed slightly across the studies. Half of the studies excluded children meeting criteria for a learning disability, one of the main comorbidities associated with autism (Matson & Shoemaker, 2009; Mpaka et al., 2016). Many of the studies also only included children who were verbal and enrolled in a mainstream classroom. As 25-35% of children are minimally verbal and would require a specialist provision (Rose et al., 2016), their experiences would not be represented in the data. Paul et al. (2018) used exclusively parent-reports to collect data but also excluded children with learning disabilities, whereas Rodriguez et al. (2021) which also only used parent-reports allowed parents of learning-disabled children to be represented. Lastly, some studies recruited their participants from autism specific centres of community settings. Research has suggested that autistic

families from racial and ethnic minority groups and low-income families have less access to community and specialized services compared to white peers (Smith et al., 2020) leading to further under-representation of these groups in research.

Design/method and analysis

As the majority of the studies were cross-sectional, causal relationships could not be established between the variables. Two studies used a longitudinal design. Holden et al. (2020) screened electronic health care records of referrals for mentions of bullying and suicidality-related text between January 2008- December 2013 and followed up in 2016. Although there are strengths to having such a large sample size, natural language processing (NLP) is not always accurate and the bullying and suicidality data would have contained false positives and false negatives. Furthermore, diagnosis of ASC may have overshadowed comorbid mental health conditions such as anxiety disorders as they appeared at lower rates in this dataset than in the general ASC population. This may have contributed to under-reported experiences of suicidality. Rodriguez et al. (2021) collected data at two time points over one year looking at factors associated with increased risk of bullying and associations between bullying victimization and mental health problems. This study relied wholly on parent reporting, but did not account for parents being unaware of their child's experiences. Also, as the association between bullying victimization and mental health problems were assessed across 12 months, it is possible that the negative effects took shorter or longer than 12 months to develop.

Across the studies, many were rated as having low internal validity due to unidentified confounding variables. The methods used to recruit participants in the study may have influenced the families who chose to enrol in the research, and resulted in selection bias. In Adams et al. (2016), which incorporated two studies with the same participants, one study was on the topic of 'peer experiences' whilst the second was described as being related to

bullying. Thus, children who participated may have been more likely to have had difficult peer experiences. However, there is evidence that those children higher in autistic traits are more likely to have experienced bullying (Zablotsky et al., 2013), but may have been removed due to inability to access the measures because of co-occurring learning disabilities or being non-verbal. Across the study there was no information on non-responders. The smaller sample sizes in some of the studies may have led to the possibility of a Type II error, whereby researchers may not have rejected a hypothesis that is false in the population.

Ashburner et al. (2018) and Bitsika et al. (2022) used semi-structured interviews to gather additional qualitative data. The researchers provided a detailed description of how the data was analysed, and integrated this with the quantitative findings, providing a more indepth understanding of the participants' experiences.

Outcomes

Different tools were used to measure the impact of bullying on children across the studies depending on the aims of the research. Many of the measures were reliable and valid, reporting high internal consistency. However, across all the studies there was no mention of adapting standardized measures to ensure autistic participants could confidently respond. Research has indicated that autistic people feel some tools use language which is too vague or complex, do not fully capture the construct of autism, or provoke too much anxiety around answering accurately (Nicolaidis, 2020). Only three of the measure used (RCADS, CGAS, and WASI-II) had evidence of preliminary support for validity within the autistic population (Minshew et al., 2005; Sterling et al., 2014; Wagner et al., 2007;)

Ten studies used parent-report questionnaires to interpret the impact of the child's bullying experience. The use of parental reports, specifically in the two that exclusively used this method, may have led to measurement bias. As best practice guidelines recommend

families receive psycho-education post diagnosis (NICE, 2013), parents may have been aware of the risk of victimization, leading to overestimation of children's experiences. However, this may have also led to underestimation of bullying experiences as children may not always share this information with their parents.

All the studies relied on questionnaires, some of which had low reliability, and others where their own non-standardized measures were created (Ashburner et al., 2018; Bitsika & Sharpley, 2021; Wright & Wachs, 2019). This may limit the internal validity of the findings.

Key findings

The key findings can be placed within two broad categories: how bullying impacted participants through school refusal and academic performance, and through impacts on their mental health. There was significant overlap across the research, with some discussing impact on both schooling and mental health.

Impact on School Attendance and Performance

Four studies reported on rates of bullying, school refusal and academic performance and their associations to bullying (Adams et al., 2016; Bitsika & Sharpley 2021; Bitsika et al., 2022; Ochi et al. 2020). Three found that school bullying was associated with school avoidance or refusal (Bitsika & Sharpley 2021; Bitsika et al., 2022; Ochi et al. 2020).

Rates of bullying raged from 20%-95% amongst participants, with several studies indicating that this was occurring whilst at school (Adams et al., 2016; Ashburner et al., 2018; Bitsika & Sharpley 2021; Bitsika et al., 2022; Ochi et al. 2020; Paul et al., 2018). There was a significant association between school refusal and the presence and frequency of bullying (Bitsika & Sharpley 2021; Bitsika et al., 2022; Ochi et al. 2020). As seen in previous

literature (Kurita, 1991; Sreckovic et al., 2014), Ochi et al. (2020) showed that school refusal occurred earlier in autistic children compared to those without ASC, which contrasted with other findings where no significant correlation between age and school refusal was found (Bitsika & Sharpley 2021; Bitsika et al., 2022). Holden et al. (2020) found that in a sample of autistic children and young people, those who were bullied were significantly younger at baseline. Contrary to the previous studies, there was evidence that older autistic adolescents were bullied more frequently than autistic younger children (Rodriguez., 2021), making secondary school a potentially more vulnerable time.

Two papers looked at the relationships between bullying and academic performance (Adam et al., 2016; Ashburner et al., 2018). Ashburner et al. (2018) found that parents felt their child's bullying affected their academic performance, although Adams et al.'s (2016) study found no relationship between the two. Autistic bullied children reported feelings of reduced safety and being fearful when at school, as well having lower feelings of enjoyment and belonging. Behaviour and social problems, and disobedience, were also attributed to bullying. In Ashburner et al. (2018) parents expressed worry that when reporting behavioural issues with their autistic children, their experiences of bullying were not being considered by teachers.

Impact on Mental Health

Paul et al. (2018) found a significant difference in frequency of bullying between autistic and typically developing children and it was discovered that autistic children were more severely victimized by their peers. Two studies found no differences and significantly lower levels of bullying in autistic young people with an intellectual disability (Holden et al., 2020; Rodriguez et al. 2021). Rodriguez et al. (2021) found that children with more severe autistic traits as well as higher internalizing (e.g. anxiety and withdrawn behaviours) and

externalizing (e.g., aggressiveness, impulsivity, hyperactivity, and self-injury) mental health symptoms were reported to experience a higher frequency of bullying. Interestingly, bullying was associated with changes in internalized symptoms but not externalized mental health symptoms.

Bullying was significantly related to anxiety and depressive symptoms in several studies (Ashburner et al. 2018; Bitsika & Sharpley, 2021; Chou et al., 2020; Liu et al., 2021; Paul et al., 2018; Rodriguez et al., 2021; Ung et al., 2016; Wright & Wachs, 2019). One study found that that victims and bully-victims had more severe depression and anxiety than those who identified as "neutrals" (Chou et al., 2020). This study also found that autistic victims and autistic bully-victims, but not 'pure' bullies, had poorer mental health compared to autistic children who had never been involved in bullying.

Studies highlighted that children were more bullied if they had poorer social interaction skills (Paul et al., 2018; Ung et al., 2016). In contrast, Bitsika and Sharpley (2021) found that difficulties with socialising and communication were not significantly associated with the frequency of being bullied in this study. Although children who had poorer social skills were more likely to be bullied, parents also felt that this impacted the development of their skills (Ashburner et al., 2018). Autistic adolescents' sense of belonging and loneliness was affected by experiences of bullying (Adam et al., 2016; Ung et al., 2016). Peer victimization was significantly associated with social avoidance and fear of negative evaluation from peers (Ung et al., 2016).

Parents outlined concerns regarding their child's self-esteem due to bullying (Ashburner et al., 2018). Liu et al. (2022) found that autistic victims of cyberbullying, teacher harassment and those who had experienced multiple forms of bullying had significantly lower

self-esteem than those who had not been bullied. No significant differences were found in self-esteem between 'pure victims', bully-victims, bullies, and 'neutrals' (Choe et al., 2020).

Three of the studies looked at how autistic adolescents were impacted by cyberbullying experiences. In Ashburner et al. (2018) parents were significantly more worried about face-to-face bullying and cyberbullying than their children. Cyberbullying was found to be positively associated with peer rejection, anxiety, and depression amongst autistic adolescents (Wright & Wachs, 2019). A significant association between social anxiety and cyberbullying victimization amongst autistic adolescents was found (Liu et al., 2021).

Holden et al. (2020) found that autistic adolescents who experienced bullying were two times as likely to later develop suicidal thoughts. Those adolescents who experienced multiple forms of bullying were also at a higher risk of suicidality than non-bullied adolescents (Liu et al., 2022). When comparing victims, bully-victims, bullies, and 'neutrals' no significant differences were found in rates of suicidality (Chou et al., 2020).

Discussion

This paper presented a synthesis of studies exploring the impact of peer victimization on autistic children and adolescents. Several key findings emerged from the literature.

Despite the variation and aims of the studies, findings across them align with previous research indicating that autistic youth experience elevated rates of bullying compared to typically developing peers and those with other neurodevelopmental conditions (Campbell et al., 2017; Lung et al., 2019; Zweers et al., 2017). Typically developing children report a peak in bullying victimization during transition from primary to secondary school (Cross et al., 2018). This is concerning as children who are bullied at primary school are more likely to be bullied as teenagers, and it increases the risk of victimization as an adult (Takizawa et al.,

2014). In addition, children who were bullied in middle school (ages 11-13) had more severe mental health problems than those bullied during high school (ages 14-18; Yen et al., 2014). One study highlighted that autistic young people may be bullied at older ages than neurotypical children (Rodriguez et al., 2021). More recent research indicated that older autistic children were more likely to be bullied than younger autistic children (Käld et al., 2022), making this a particularly vulnerable period but also an opportunity for intervention. It is difficult to ascertain whether this is due to increased prevalence in peer victimization with age, or the increased understanding of bullying situations and confidence required to report bullying.

As these studies were comprised of both parent-reports and self-reports, conclusions should be made cautiously. There is mixed literature on whether parent reports of bullying are accurate, with some literature indicating that parents under report (Shemesh et al., 2013; Dehue et al., 2008; Larranaga et al., 2018), and others suggesting that there was high parental concordance of child's bullying experience when the child was autistic (Chen & Shwartz, 2012; Kloosterman et al., 2013). There is also conflicting research on whether autistic children understand bullying scenarios in the same ways as typically developing children. Hodgins et al. (2020) revealed that autistic adolescents may have significantly lower understanding of bullying, whereas Hwang et al. (2018) found that autistic young people were better at recognizing bullying situations than typically developing students. When reflecting on the female experience, mounting evidence suggests social behaviours and challenges of autistic girls are unique compared to boys (Dean et al. 2017). Much of the research tends to overrepresent overt and physical bullying (Sawyer et al., 2008) which may lead to under-reporting in girls and women, where bullying is more often indirect and relational (Scheithauer et al., 2006).

Some of the studies highlighted how bullied autistic children were engaging in school avoidance earlier and with more frequency than their peers. One study demonstrated a limited association in social phobia and emerging school refusal in bullied boys which contrasted with results from previous research (Randa & Wilcox, 2010; Vidourek et al., 2016). Findings also noted increased separation anxiety in school refusal mirroring findings seen in typically developing children who were not bullied (Heyne et al., 2004; Kearney & Bates, 2005), and those who were (Camargo et al., 2022).

A review by Spain et al. (2018) stated that amongst autistic children with social phobia, there was also a decreased social motivation. This could be explained by negative experiences of bullying acting as a deterrent to engaging socially. Briot et al. (2020) found associations between social motivation and social phobia which may suggest that children who were less socially motivated were more likely to have social phobia. In addition, if a child is absent from school, they are more likely to feel like an 'outsider', making integration more difficult and feeding into a vicious cycle of social exclusion.

Anderson (2020) found that autistic girls have higher rates of absenteeism than boys, yet they have little representation in the literature. Sproston, Sedgewick, and Crane (2017) found that school environments, tensions with peers and staff, and lack of understanding of their needs were key factors in influencing school exclusion in autistic girls, with rates of school exclusion two to three times higher for autistic children compared to children without SEN (Hatton, 2018). In addition, autistic girls report that having reciprocal friendships is important in creating a sense of belonging in school (Miles et al., 2019); this would be put at risk by bullying experiences and school refusal. It is essential that interventions are targeted towards these groups, who are at risk of permanent exclusion or school displacement due to absenteeism.

One study indicated that parents felt that school bullying was affecting academic performance. There is limited literature looking at academic performance in SEN or autistic young people, but within typically developing youth, self-reported peer victimization was associated with lower academic functioning (Mundy et al., 2017; Nakamoto & Shwartz, 2010). The cycle of non-attendance for extended periods of time has been found to lead to subsequent problems in school, such as poor academic outcomes and poor achievement in adult life (Pellegrini, 2007).

Co-occurring mental health conditions are significantly more prevalent in the autistic population compared to the general population (Lai et al. 2019). Across the identified studies, all referenced mental health concerns to some degree. Specifically, presentations of internalizing problems, such as depression and anxiety were highlighted, consistent with literature that autistic individuals experience these at high incidences (Briot et al., 2020; Hollocks et al., 2019; Mayes et al., 2011). The relationship between bullying and internalizing problems may be influenced by the effort these young people must apply to meet the expectations of their peers, creating and engaging in friendships and managing group social situations (Cook et al., 2018; Halsall et al., 2021). This has been supported by autistic accounts of experiencing insecurity in friendships and making efforts to conform to neurotypical social norms leading to anxiety (Black et al., 2022).

Adolescents with learning disability and autism who have been bullied perceive lower levels of happiness (Lung et al., 2019). These reports are unsurprising considering how bullying is linked to depression in typically developing populations (Kaltiala-Heino & Frojd, 2011; Winding et al., 2020). Pouw et al., (2013) found that being bullied or having low-quality friendships contributed to depression in autistic children. The relationship between depression and bullying may become a vicious cycle with worsens over time. Strong

associations exist between social isolation, anxiety, and depression (Achterbergh et al., 2020). A child who is being bullied through ignoring, or has chosen to remove themselves to avoid bullying, may continue to feed into a cycle detrimental to their mental health. Inversely, if young people who are experiencing depression isolate themselves this may make them a greater target for victimization.

Suicidality in autistic people has been deemed a major public health issue, yet unsurprisingly much of the existing literature has focused on samples of autistic adults (Hedley & Uljarevic, 2018; Zahid & Upthegrove, 2017). In accordance with the findings of this research, O'Hallaran et al.'s (2022) review found that adverse childhood experiences, such as bullying, were risk factors for suicidality. Suicide risk is three times as great in autistic girls compared to typically developing girls (Kirby et al., 2019). As adolescent girls often go undiagnosed or misdiagnosed (Lockwood et al., 2021), their experiences of bullying may not be captured in the literature. Camouflaging autistic traits is a common occurrence amongst autistic youth (Wood-Downie et al., 2020), and has been associated with experiencing "thwarted belongingness and lifetime suicidality" (Cassidy et al., 2019). There is little research on the possible associations between experiences of bullying as a motivating factor for camouflaging.

Implications

This review provides some evidence regarding the impact of bullying on autistic children. Although findings are consistent with existing literature on typically developing children, research on autistic children and adults, the small number of studies and the methodological critiques limit the conclusions that can be drawn. The following clinical and research implications should be considered.

Clinical Implications

Based on the results across the studies, it became clear that bullying victimization, depression and anxiety within autistic children and young people should be routinely screened by education and mental health care professionals. There is a lack of standardized tools to assess suicide risk in autistic youth (Howe et al., 2020), therefore these should be developed in a clinical setting to manage risk. As parents and children report peer victimization at different rates, mental health and educational professionals should not rely solely on one source of information but should also use the supports around the child to better understand their experience, and inform risk assessments.

Given the rates of school refusal amongst autistic children and young people, it would be important to expand interventions aimed at re-integrating youth into schools after periods of refusal, as there is evidence that students can be successfully supported (Preece & Howley, 2018). Adapting the learning environment, being flexible and creating individual goals in curriculum, applying a consistent approach between staff, and collaborating with parents, may lead to more positive outcomes.

As autistic young people experience and are impacted by bullying in different ways from their typically developing peers, it should be a priority to assess which types of interventions are most effective. These may include mental health interventions (Wang et al., 2021), as well as school re-integration interventions (Brouwer-Borghuis et al., 2019), antibullying interventions (Fraguas et al., 2021), social skills interventions (Dean & Chang, 2021), and anti-camouflaging interventions.

With the high risk for internalizing problems in autistic children, bullying programs may need to be adapted to target specific subgroups of autistic children who have been identified as being significantly more at risk. There is initial research suggesting that learning

effective emotional and cognitive regulation in peer relationships in school settings can prevent bullying and victimization (Yang et al., 2020).

Autistic girls face challenges with conforming to typical friendship behaviours (Kreiser & White, 2014) making them an easier target for conflict (Sedgewick et al., 2016). Clinicians should screen for autism in girls who are bullied and presenting with mental health conditions. Additionally, interventions should be adapted to meet their specific presentations.

Research Implications

Only one of the studies in this review was conducted within the United Kingdom. Although bullying is a widespread worldwide phenomenon, cross-national and ethnic cultural research is interpreted in different ways due to linguistics, what constitutes bullying, and socioeconomics, to name a few (Samara et al., 2019). Future research should aim to further understand the impact of bullying on children living within the cultural context in the UK, enhancing external validity and generalisability. More quality longitudinal research will be essential to understanding this phenomenon. In addition, research should look at how school and classroom ethos affects prevalence and types of victimization occurring, as schools exist within the greater context of communities and group dynamics.

Many of the studies recruited participants from a clinical sample therefore it would be useful to include participants from non-clinical samples and compare whether they respond to experiences of bullying in the same ways. Future studies should seek to specify the duration of the bullying experience as well as the severity, and how this may be associated with the level of impact on young people.

There was limited data on the demographics of the participants, but as children from the lowest income households are 40% more likely to be bullied compared to the wealthiest (Tippett & Wolke, 2014), it is important to shed light on how autistic children from different

socio-economic groups and ethnically minoritized groups experience bullying and how it relates to their identity.

Autism research has been grounded in male-dominated samples for decades (Geelhand et al., 2019). As autistic girls are diagnosed later and present differently socially from autistic boys it is essential that a spotlight is placed on their development through childhood into adolescence. A priority should be given to understanding what specifically puts autistic women at risk of bullying and how they understand this experience.

Teacher training on working with autistic children in the classroom, as well as managing bullying situations at school should be researched to discover what methods may be helpful in supporting the needs of autistic children as well as integrating them in a classroom environment.

Limitations of this review

The author reviewed thirteen relevant studies from the last seven years that met inclusion criteria. Only peer-reviewed literature in English from 2015 was included, therefore important research may have been excluded. Limitations of the systematic review were differences in study designs, methodology, and participant characteristics. These differences made it difficult to synthesise the data meaning comparisons between groups, such as type of impact and victimization, had to be made. The majority of the studies analysed in this review were cross-sectional, making it difficult to determine the links between peer victimization and the type of impact. Across all studies, most participants were male, with some studies excluding women completely. This is no longer representative of the entire population or data, as it is now estimated that every three males receive a diagnosis to every female (Hull et al., 2020; the ratio was previously 4:1, Zhang et al., 2020).

The primary limitation of the review was that most of the studies relied heavily measures of parent-reporting. Although in some cases this made the research more inclusive

of non-verbal participants, it made it difficult to capture the unique first-person perspective of autistic people and their thoughts and feelings. To ensure the data was manageable, the author did not include qualitative research which often captures detailed perspectives from individuals. Due to the limited research available looking at the impact of bullying on the autistic population exclusively, the author looked at studies across both childhood and adolescence. As mental health conditions are experienced differently at different points in development, this may have skewed the conclusions.

Lastly, this research was informed by the author's bias based on its relevance to her area of research interest.

Conclusion

This review set out to collate research examining the impact of bullying on autistic children. Substantial limitations to existing studied were encountered, including reliance on cross-sectional research and heterogeneity in conceptual frameworks, samples, and measures. Despite this, the results suggest that autistic children are significantly and negatively impacted by experiences of bullying, specifically regarding their internalized mental health and academic engagement. The results suggest that autistic children are more vulnerable to being bullied than their peers, and that this is partly due to their autistic traits and presentation. The long-term impacts of bullying on autistic children remain unclear. Findings extend our understanding of the impacts of peer victimization on autistic children and outline several implications for clinical practice and future research.

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Section B

An Interpretative Phenomenological	Analysis	of the l	Exploration	of Autistic	Women's
Experienc	es of Self-	- Comp	assion		

Word Count: 8000 (211)

Abstract

Background: There is limited research exploring the development, experiences, and barriers

to self-compassion in autistic women. Autistic women are likely to experience mental health

problems across their lives. Self-compassion has been linked to positive psychological well-

being in the non-autistic population. The questions explored autistic women's experiences

relating to receiving a diagnosis of autism, their understanding of self-compassion, and how

these have impacted their mental health. The present study aimed to explore the experiences

of self-compassion in a sample of autistic women.

Methods: Semi-structured interviews were held with eleven autistic women. Data was

analysed using Interpretative Phenomenological Analysis (IPA).

Analysis: Three Group Experiential Themes were developed: 'Connection with identity', 'I

deserve it, right?', and 'Sense of growth'.

Discussion: Autistic women's experiences result in negative impacts on mental health and

self-identity. Autistic women described feeling they were to blame for negative events that

occurred in their lives, and that they found it very difficult to show themselves kindness.

Psychological input could support autistic women to develop and implement self-

compassion, which may serve as a protective factor for their mental health.

Keywords: autism, women, self-compassion, mental health

An Interpretative Phenomenological Analysis of the Exploration of Autistic Women's **Experiences of Self- Compassion**

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Research has shown that autistic people are at an increased risk of developing mental health difficulties compared to the non-autistic population (Lai et al., 2019). Approximately 70%-80% of autistic children and adults experience mental health problems at some point in their lives (Bishop-Fitzpatrick & Rubenstein, 2019; Lever & Geurts, 2016). Characteristics inherent to autism may make people more susceptible to developing mental health problems. Research indicates that fears and phobias are significantly more prevalent among autistic individuals (Leyfer et al., 2006). Intolerance of uncertainty has been reported to lead to distress and anxiety for autistic individuals (Bogdashima & Casanova, 2016; Jenkison et al., 2020). Sensory processing differences may lower autistic people's abilities to tolerate uncertainty (South & Rodgers, 2017) and this may act as a mediator between sensory sensitivity and anxiety (Hwang et al., 2020). The need for predictability can lead to social anxiety and withdrawal (Boelen & Reujntjes, 2009). Indeed, autistic people face more social isolation (Orsmond et al., 2013) and loneliness (Umagami et al., 2022) than peers, which has been associated with anxiety and depression in this population (Hymas et al., 2022). Social camouflaging, or masking, is a concept used to describe the strategies that autistic people use to minimize the visibility of their autism in social situations (Hull et al., 2019). There is emerging evidence that autistic camouflaging is associated with both anxiety and depression (Bradley et al., 2021; Hull et al., 2021; Tubi-Fungueirino, M. 2020). Autistic people are also at an increased risk of experiencing potentially traumatic events, and then subsequently significantly affected (Haruvi-Lamdan et al., 2018) or developing post-traumatic stress disorder (PTSD; Stewart et al., 2021).

However, research indicates stark differences in quality of health care between autistic and non-autistic adults, including poorer access to healthcare and poorer communication (Weir et al., 2022) Crane et al. (2019) highlighted the high levels of stigma and other obstacles faced

by young autistic people when trying to access mental health support. Some traits associated with autism share common features with depression and anxiety, such as social withdrawal, poor sleep patterns, and restrictive behaviours (Kerns et al., 2015), which may make it difficult to identify mental health problems in autistic people, even when they are able to access services.

The NHS Long-Term Plan (2019) has prioritized the well-being of autistic people's physical and mental health. There have been significant efforts to understand and adapt mental health interventions for the autistic population in recent years (Dickson et al., 2021; Gilmore et al., 2022). However autistic people continue to report limited availability of adjustments and support in the current healthcare provision, specifically the sensory environment, clinical service and context, and clinician knowledge and understanding. (Brice et al., 2021). Benevides et al. (2020) worked alongside autistic people to outline mental health research priorities which included, trauma-informed care approaches, societal approaches for inclusion and acceptance of autistic individuals, community-available approaches for self-management of mental health, evaluation of adverse mental health outcomes of existing interventions, and improvements of measurements of quality of life. It is clearly important that future psychological approaches for autistic people consider their experiences and the inherent difficulties that may contribute to mental health difficulties, offer practical ways forward, and represent their voices.

There is increasingly more literature linking self-compassion to positive psychological well-being (Bluth & Blanton, 2015; Inwood & Ferrari, 2018; Min et al., 2022; Neff, 2007; Tran et al., 2022), with evidence found that it acts as a buffer for negative life experiences in the general population (Jativa & Cerezo, 2014; Wong, 2016). Neff (2003) defined self-compassion as being comprised of three elements: 'self-kindness versus self-judgment', 'common humanity versus isolation', and 'mindfulness versus over-

identification'. Self-kindness involves showing understanding to oneself when suffering or failing, opposed to ignoring these feelings or being self-critical. Common humanity is acknowledging that everyone fails and that being imperfect is part of the shared human experience. Lastly, self-compassion in relation to mindfulness involves taking a balanced approach to negative emotions, and in doing so placing suffering in a larger perspective. There is research suggesting that individuals with anxiety and depression felt that selfcompassion was meaningful in reflecting on their experiences and useful in supporting their recovery (Pauley & McPherson, 2010). There is a growing body of research indicating the effectiveness of compassion-based therapies with individuals experiencing anxiety, depression and trauma (Boersma et al., 2014; Craig et al., 2020; Gharraee et al., 2018; Irons & Lad, 2017; Takahashi et al., 2019). The research highlights how these therapies can support decreasing self-criticism and shame, mental health symptomology, whilst increasing kindness towards the self. A recent study of group-based Compassion-Focussed Therapy (CFT) with neurotypical adolescent girls with lived experience of mental health problems found that the girls were able to feel empowered to accept themselves through meeting peers who had experienced similar difficulties (Bratt et al., 2020).

To date, there is limited research examining self-compassion in autistic individuals. Cai et al. (2023) found that autistic people reported significantly lower self-compassion than non-autistic adults. Howes et al. (2020) demonstrated that autistic traits and self-compassion were negatively correlated within the general population. Galvin et al., (2021) found that self-compassion mediated the relationship between autistic traits and indicators of anxiety and depression. Another recent study suggested that self-compassion might facilitate mental health and psychological well-being through reducing the risk of developing psychological conditions in autistic adults (Cai & Brown, 2021).

Self-compassion within autistics may be expected to be lower than the neurotypical population because of inherent autistic traits, and because of societal and social factors that come from the autistic experience. The development of self-compassion emerges from early attachment and emotion attachment relationships and emotion identification (Gilbert, 2005; Neff & McGehee, 2010). Research suggests there are differences in the attachment relationships of autistic children, compared to non-autistic children (Kahane & El-Tahir, 2015), which could explain a developmentally different experience of self-compassion in this population. These differences in self-protective attachment strategies may reflect the differences in self-compassion in this group. It could be hypothesized that the soothing system in self-compassion is deactivated when and individual experiences shame or selfblame. Inversely, this system may be hyperactivated which may lead to over evaluation of the self and placing external blame. Approximately half of the autistic population identifies with traits of alexithymia (Poquerusse et al., 2018), an experience characterized by an impaired ability to be aware of, identify and describe one's feelings (Nemiah et al., 1976). This could create a barrier to identifying one's emotions and being mindful of distress. Autistic people often find it difficult to connect with others due to social impairments which could make it difficult to see distress or stress as part of "common humanity". This group is far more likely to have experienced adverse life experiences and traumas such as sexual abuse, bullying, unemployment and discrimination (Griffiths et al., 2019) leading to poorer self-esteem (Tetzner et al., 2016), and a stronger inner critic (Kopala-Sibley et al., 2014). Low levels of self-compassion in autistics may relate to the high prevalence of mental health problems.

Amongst neurotypicals, men tend to have higher levels of self-compassion than women (Yarnell et al., 2015). Recent studies indicated that receiving their autism diagnosis in adulthood facilitated autistic women's transition from being self-critical to self-

compassionate, and generated an increased sense of agency (Leedham et al., 2020). This is particularly important due to women being at a significantly higher risk of underdiagnosis and misdiagnosis (Lai & Baron-Cohen, 2015), and experiencing mental health problems at higher rates than autistic men (Sedgewick et al., 2020). In addition, autistic women in particular continue to feel like they have unmet service needs in regards to their mental health and that many of the supports available are not the right fit (Griffiths et al., 2012; Moseley et al., 2021). The female autistic experience continues to be under represented in the literature despite more evidence suggesting that the truer male to female ratio of diagnosis is 3:1 (Loomes et al., 2017). Research within the autistic community has indicated a need for more gender specific research (Pelicano et al., 2014).

Rationale for the study

The exploration of autistic women's experiences of self-compassion is essential in understanding how they relate to themselves and the world. Such work can also generate insight into how they may develop mental health difficulties, and the importance of self-compassion in fostering positive self-esteem and perception of identity. Understanding more about the role of self-compassion for autistic women may offer an opportunity to develop effective, autism-specific mental health interventions.

The present study aimed to gain an in-depth understanding of how autistic women relate their experience of self-compassion to their mental health. This includes how they conceptualize the developmental of self-compassion in relation to their autism, and how it has impacted them at different stages in their lives.

Aim and Research questions

The following questions will be explored:

- 1. What are the experiences of self-compassion in a sample of autistic women and what meaning do they make of these experiences?
- 2. How might their experiences fit into how they make sense of their autism?
- 3. How might their experiences with self-compassion and autism relate to how they view their mental health?

This project has been developed around the NHS Values of 'Commitment to Quality of Care' and 'Working Together for Patients'. This research may help non-autistic clinicians to gain a greater understanding of how to work with autistic women. In addition, it may support the case for additional funding and development of psychological input that is more neuro affirmative and individualized towards meeting this client group's needs.

Method

Design

This study design used an interpretative phenomenological analysis (IPA; Smith et al., 2009) of individual semi-structured interviews. IPA is concerned with making sense of people's lived experiences of major life events (Smith et al., 2009), and how those events may have led to changes in identity (Smith et al., 2022). This study aims to explore the experiences and meaning making of a homogenous sample of autistic women. It uses an interpretative approach and takes a double hermeneutic position, where the researcher seeks to understand and interpret how the participant is making sense of their experience, and the perspective of the researcher in considered in the research (Smith et al., 2009).

Due to the limited research looking at the experiences of autistic women with self-compassion, a qualitative approach was chosen as the most appropriate form of data collection and analysis as it allowed for the gathering of rich information from participants. Previous research has suggested that features of IPA, specifically its commitment to equality of voice and research reflexivity, helped to shine a light on the experiences of autistic people (Howard et al., 2019). Furthermore, there is research indicating that it is a useful approach to use when co-producing, which will support opportunities for autistic people to represent themselves within autism research (Macleod, 2019).

Experts by Experience Involvement

Two panels of experts by experience (EBE) were consulted in this project. These EBEs were recruited from Autistica, the UK's leading autism research and campaigning charity. These EBEs were all autistic women, which represented the recruited sample in this research. The EBE panels were made up of two groups of three women. They were involved in reviewing the information and debrief materials, as well as giving feedback on the semi-structured interview schedule. The EBEs supported the researcher in adapting questions to be less abstract and more accurately reflect language preferred by autistic people. The suggestions made by EBE were discussed in the research team before implementing the changes.

Recruitment

The participants were recruited using purposive sampling strategy as proposed by Smith et al. (2009), in order to explore perspectives of an experience, rather than the whole population. Participants were recruited via Twitter, Facebook, and Linkedin social media platforms, as well as on the Autistica research e-mail list. The advertisement poster (Appendix B) was created with supervision from research supervisors. Candidates who were

interested were asked to contact the researcher and were sent an electronic copy of the information sheet (Appendix C) and consent form (Appendix D). Those who returned a signed consent form were contacted with options of dates and how they wanted to complete the interview (e.g., over the phone, video call; one longer meeting or multiple shorter meetings, etc.). As per the recommendations of the EBEs, participants were sent the interview questions in advance.

Inclusion Criteria

The autistic women met the following inclusion criteria:

- Cisgender women
- Aged 18+
- Living in the United Kingdom
- Able to communicate verbally or through writing
- Identify with a diagnosis of autism spectrum condition

Only cis-gendered women were included in this study as previous research shows that transwomen have different experiences from those of cisgendered women (Goldsen et al., 2022). Women who self-identified as autistic were included in the criteria due to the barriers which exist to obtaining a diagnosis (Estrin et al., 2021). Research suggests that self-identified autistic women's experiences are 'remarkably similar' in reported self-esteem, stigma, and quality of life to those with a formal diagnosis (McDonald, 2020).

Participants

IPA recommends sample sizes of 8-10 participants at a professional doctoral level in order to yield a homogenous sample (Smith et al., 2009), and thereby facilitating the understanding through common themes. Initially, the intention was to interview 8 autistic

women, but due to the overwhelming response of potential candidates (over 50), the first eleven to submit consent forms were selected. The researcher also attempted to recruit participants from racially minoritized backgrounds by contacting groups and charities serving these people. Only one candidate identified as being from a minoritized group.

Table 1 displays a summary of the participant demographic data.

Table 1

Participant demographic data

Pseudonym	Age of diagnosis	Diagnosis	Ethnicity	
Olivia	28	ASC	White British	
Emma	34	ASC	White British	
Eleanor	30	ASC	White British	
Amelia	56	ASC	White British	
Ava	24	ASC	North East	
			Asian	
Sophie	46	ASC	White British	
Avery	21	ASC Other White		
			Background	
Mia	25 & 38	ASC	White British	
Harper	41	ASC	White British	
Luna	-	Self-identified	White British	
Camila	16	ASC	White British	

Ethical Considerations

Ethical approval was granted by Salomons Ethics Committee (Appendix E). Informed consent was obtained from each participant prior to the interviews. At the beginning of each

interview, participants were reminded that their interview would be recorded and saved on an encrypted memory stick, transcribed, and anonymised. Participants were advised that they could withdraw from the research within two weeks of completing the interview and were encouraged to contact the researcher if they had any questions following the interview. The researcher informed participants that they might experience distress when speaking about difficult experiences. To reduce the risk of distress, participants were offered the opportunity to complete the interviews across multiple days, or take breaks throughout the interview. The information and debrief sheets provided contact details for additional support (Appendix F). Participants were informed that if the researcher felt there was an immediate risk of harm to self or others, then they would need to break confidentiality to ensure the safety of those involved.

Interviews

A semi-structured interview schedule (Appendix G) was used to guide the topics, allowing freedom for participants to emphasize what they found most important. By using a semi-structured interview, the researcher was able to be flexible and follow the lead of the participant, consistent with IPA methodology.

Interviews were completed using Microsoft Teams, an online video conferencing software. Interviews lasted between 34-54 minutes, depending on the length of answers and the speed of the interviewing. Interviews were carried out from December 2021 to May 2022.

The interview started by asking participants about their diagnosis of autism and which characteristics and experiences they most related to. These questions were used to explore their relationship to their diagnosis and how the journey to a diagnosis impacted them.

Following this, the researcher asked about participants' understanding of self-compassion, how they process thoughts or events, and how their experience unpleasant emotions. Lastly,

they were asked about how the way they respond to themselves is affected by their autism and mental health. Throughout the interview clients were reminded that they did not have to respond to all the questions to be included in the research.

Data Analysis

The analysis of the interviews was guided by Smith et al.'s (2022) recommendations. Interviews were transcribed by the lead researcher immediately after completion. The researcher immersed themselves into the audio recording by listening once without and once with the transcripts. When reading through the transcripts a third time, exploratory notes were written, including descriptive, linguistic, and conceptual comments (Appendix H). The next step was to analyse the exploratory comments, group them together and create experiential statements. These Experiential Statements were then clustered to form psychological constructs, which point to the most interesting parts of the participant's accounts, as well as those that best answered the research question (2022). The Experiential Statements were then used to create Personal Experiential Themes (PETs) across each participant (Appendix I). When the Personal Experiential Themes were completed for all participants, similarities across all transcripts were grouped to develop Group Experiential Themes (GETs; Appendix J). The researcher identified the Group Experiential themes that best fit the aims of the study and experiences of the women. Some Personal Experiential Themes were left out to ensure the analysis captured a range of experiences.

Quality Assurance

Prior to interviewing, the researcher completed a bracketing interview with a trainee clinical psychologist (Appendix K). This allowed the researcher the space to reflect on their own biases, beliefs, and expectations from the study. In doing this, the researcher became

more aware of what perceptions they were bringing to the interviews. The researcher did not identify as autistic but assumed that participants would have had positive reactions to a diagnosis of autism and that they would have experienced some form of traumatic event(s) in their lives. A reflective diary was kept throughout the research process to capture emotional responses following the interviews, as well as the more general aspects of writing (Appendix L; Pietkiewicz & Smith, 2014). Validity was assessed using guidance from Yardley's (2000) four principles, which included sensitivity to context, commitment to rigour, transparency and coherence, and impact and importance to ensure quality in qualitative research.

Throughout the process of analysis, draft themes were discussed with the research supervisor, allowing space to explore different interpretations of the data.

Results

Analysis of the data produced three superordinate themes, and eleven subthemes (Table 2).

Table 2

Overview of Group Experiential Themes (GETS) and Sub-Themes

Sub-Themes Always feeling different	
Masking	
Processing events	
Internalizing the words of others	
Self-criticism	
•	

Sense of growth

Missing out on opportunities

Power in community

Understanding how I've changed

Connection with Identity

This Group Experiential Theme incorporated how the participants experienced autism and the journey to diagnosis in relation to their identity. Participants described an innate feeling of difference, and how this led them to seek a diagnosis of autism. The autistic women had various reactions to and interpretations of their diagnosis experience. When thinking about how they experience life as autistic women, most women described feeling the need to camouflage or mask to get through everyday situations.

Always feeling different

All participants spoke about being aware of differences from others around them from a young age.

'I've always known I was a bit different but never really understood what it could be.'
(Olivia)

There seemed to be a sense that these feelings of difference made them outsiders, looking into what appeared to be normality.

'I've always felt a bit on the periphery.' (Harper)

Experiencing the world 'on the periphery' made some women feel that this difference was attributed to negative qualities in themselves.

'I had a real sense of there being something wrong with me...I didn't think in the same ways

and rather than it just being different, it was more of something being bad or wrong.'
(Emma)

For many women these realizations came from comparing themselves to how others were developing and seemingly experiencing the world.

'I had a sense of growing up and all the way through my adult life like, everybody else had life sussed out and I haven't...one day I'll wake up and it will all fall into place and it didn't.'

(Amelia)

Some women reported that they suspected early on that they might have autism and were able to share these thoughts with their family. There were mixed responses, with some receiving acknowledgment of their differences and others feeling they were shut down.

'I kind of kept thinking like, this [autism] is me, and my parents would just say no, it's not, you know you're fine.' (Luna)

It seemed that Luna wanted the challenges she was experiencing to be noticed by others but that they were going unnoticed by those around her.

Validation and doubt through diagnosis

The majority of participants sought out their own diagnoses in adulthood and found this an empowering experience which positively impacted their well-being stating, 'it changed my life' (Mia). The word 'relief' was used repeatedly across the women.

'It was a relief when I got that diagnosis...That validation really and coming away feeling like, it's okay, it's explains a lot.' (Eleanor)

Sophie described feeling 'euphoric' and how a diagnosis brought her a greater sense of understanding.

'This explains everything. Like why I've never fit in, why everything has been such a struggle, why my mental health is being so all over the place, why everything has been so difficult...it was like fireworks and I was really, really excited.' (Sophie)

A few of the women did not embrace being identified as autistic and challenged both the assessment and the diagnosis.

'I actually didn't believe that diagnosis when I got it...so I went got re-diagnosed.' (Mia)

Understanding their diagnosis was more challenging for those who received it during difficult periods with their mental health which led to inpatient stays.

'I got really upset...I didn't want them to assess me...I had a bit of a meltdown.' (Avery)

Avery also described feeling that some of what made the diagnosis upsetting was that it was not changeable.

'I just wasn't really comfortable with the idea of it being kind of permanent.' (Avery)

For most of the women, discovering they were autistic brought some insight in regard to their thinking patterns and why they had encountered so many challenges. Having a diagnosis was identified as helpful in showing more compassion to themselves, and avoid comparing themselves to non-autistic women around them.

'Since I've been diagnosed...I have a greater understanding of why I struggle with certain things, so I think before I was comparing apples with apple, but actually I'm comparing pears with apples. I think not having a diagnosis was a barrier to being compassionate.'

(Harper)

Masking

The women recounted how they had to change themselves to 'fit in' to societal expectations. Many reasons were described for disguising their 'true self', but mostly this was to blend into environment with non-autistic peers.

'You just put on this persona that you love it and you're having fun and everything is great.'
(Luna)

A few of the women explained that they feel the need to mask, especially at work to be seen as professional.

'I don't think anyone at work would ever think there's a different me outside.' (Luna)

Camila explained that 'if something happened there, I'd just mask until I got home...I'd just keep it to myself.'

There was a feeling for Camila that there might not be an understanding if she were to speak up about how she was feeling at work, and it was safer to just deal with it on her own.

It seemed that Harper lost a part of an understanding of who she was in trying to conform to the expectations of others.

'I've always camouflaged or masked or been what I think people want me to be. I don't really have a sense of who I am very well.' (Harper)

When thinking about why they felt they needed to camouflage after discovering they were autistic, Mia explained that this mask has helped her to attain some of her goals.

'I portray that person because it's got me somewhere and it's not necessarily my true self...sometimes I drop the mask...I'm not good at being my consistent self' (Mia)

Mia also described the pressure she felt to camouflage because she held those differences.

'I'm the one that should know better because I'm the minority and I'm trying to fit in all the time.' (Mia)

This seemed to be indicative of feelings of guilt or being burdensome to others that several women described as the function of camouflaging. One woman described masking as a survival instinct that she needed to develop to get through life safely.

'There is an element of living in a sort of fight or flight a lot.' (Avery)

'I deserve it, right?'

Participants often referred to experiencing traumatic events and challenges in their lives. Whilst describing this, they often identified how they found it difficult to process and deal with these situations and the effects in the moment. Some women described the power the words of others had and how easy it was to internalize these into meaningful beliefs about themselves. Internalizing the words of others brought feelings of self-blame and criticism for most women. Most women expressed that the self-criticism they felt led to varying expressions of distress and pain.

Processing events

Participants described ruminating or needing time to fully understand situations they found upsetting to identify what effect it has had on them, as well as know how they should manage it.

For some women there was a sense that processing experiences did not come naturally and was effortful.

'I find processing of things quite difficult...it often takes me like quite a long time, even years to process some things.' (Harper)

Nearly all women felt that they spoke to themselves when processing events, some referring to it as an '*inner voice*'. They described this voice as judgemental and sometimes anxiety provoking.

'It's the ruminating, the anxiety, some sleepless nights from being self-critical and thinking about things a lot' (Mia)

Several participants agreed with Harper stating that there was a slower response to situations and that reflecting on this at a later date could be a healthier way of gaining insight, rather than reacting 'in the moment'.

'I think it [inner voice] says, 'why have you done that?', and I am able to get an answer and try and be better and maybe change next time. I think it's a delayed reflection.' (Mia)

One participant described a single event that led to the development of PTSD. Olivia reflected that she was on section at the time and feeling vulnerable, and how this added to complexity of processing the event.

'You just deal with these things and there was no real...I think the medication that I was on was affecting me a bit as well, but there was no real internal thought. There was no processing at all.' (Olivia)

It seemed that in this case, the 'inner voice' may have been quiet as it was too painful to engage with what had occurred.

Internalizing the words of others

In this sub-theme participants explained how across their lives they would take in the negative words and actions of others, which in some cases led to being victimized in abusive relationships, and severe negative self-talk.

Several participants commented on experiences of being bullied and how this impacted their beliefs about themselves.

'I was a bit bullied in school. And I think that affected my self-esteem because I didn't fit in with anybody. I was just always a little bit strange. So maybe I just listened to that feedback and just started believing it.' (Olivia)

This bullying led one participant to feel that she was to blame for how others treated her growing up, and in some ways that it was the norm.

'I just thought being bullied by your friends, it's just the way it is because you suck and you'll never have normal friends like everyone else.' (Ava)

'I was only feeling bad and I think that instils that I'm bad because they're the feelings I have...bad things happen to bad people...I deserve bad things to happen because something is wrong. I don't deserve any niceness.' (Emma)

Common phrases such as 'practice makes perfect' (Luna) were understood literally for Luna which made it difficult for her to move past things without feeling she was letting herself and others down. Another participant commented how it can become difficult to differentiate her own beliefs about herself from the judgements of others.

'I kind of let those beliefs become my beliefs and I don't stop and say, hang on a second, who told me that or where did I get that idea from.' (Avery)

Avery's statement gave the sense that internalizing the perceived judgements of others can become automatic and takes an active effort to pull apart.

Self-criticism

Participants described having an inner voice that was negative and critical. They reflected on how the critical inner voice felt quite powerful and contributed to self-blaming during adverse experiences.

'My initial thing is just to be quite negative about myself, and be like, "For God's sake, you have done it again, you idiot.' (Sophie)

Eleanor described that the self-criticism might be higher if she could attribute it to things made difficult by her autistic traits.

'I get really annoyed and frustrated at myself particularly if I think it's related to being autistic...I think, oh, my brain hasn't worked in the way that I wanted it to again.' (Eleanor)

Some participants stated that they had high expectations for themselves which fuelled the self-blame when expectations were not met.

'I expect more from myself. It frustrates me that I can't change that part about me.' (Mia)

Other participants expressed feelings of guilt and shame that they attributed to events they may not have foreseen or were out of their control. Avery felt that negative events could become all-consuming and magnified, therefore difficult to manage.

'It completely is just like the worst thing in the world and I just want to jump up and down until I fall into the Earth's core.' (Avery)

Harper described that the experiences autistic people have with criticism may be perceived differently from other.

'Autistic experiences of criticism just means that it always falls back on you...these little traumas, or not so little, like very big, you know there's always a way that is comes back to be intrinsically your fault.' (Harper)

When describing barriers to speaking to herself with kindness, Luna said 'it doesn't come naturally'. She explained how she can at times have compassion burnout from always looking out for others, leaving herself without resources to be kind to herself.

'I could be over compassionate where I just let everything slide and I just look after everybody constantly...if I have a bad emotion or if things go wrong and I can't control it, it's always my own fault.' (Luna)

Olivia described using self-criticism to avoid having to hold others accountable for their actions.

'It's so hard to be empathetic towards yourself. It's just easier to blame myself a lot of the time. It avoids confrontation with other people.' (Olivia)

Speaking about barriers to self-soothing, some participants labelled it as 'self-indulgent' and that it led them to feel guilty.

'I just don't feel I deserve that...I feel selfish or it's a waste of time and I should be doing things for other people...it comes down to not deserving nice things or kindness' (Emma)

Expressions of distress

All participants in the study spoke of being highly distressed at different points in their lives, which negatively impacted their mental health. Some women reported inpatient hospital admissions, self-harm, disordered eating, suicide attempts, depression and anxiety.

Participants explained that they experienced such strong emotions but not having the skills to cope with them.

'I would break things or punch things and it would just be like a filling up of unprocessed emotions and the I would erupt.' (Harper)

'I would just have sat and it would get worse...just tumbleweed into not being able to cope at all and it could go into full blown crying and can't cope. It's just misery.' (Luna)

One participant described how she felt that suicide would be the best option to relieve feelings of guilt she had internalized.

'I've spent a lot of my life thinking a lot about suicide, and at -I tried to kill myself...I really thought that I was doing people a favour.' (Sophie)

Several participants described using self-harm as a way to soothe themselves and that in some ways this felt like self-compassion.

'I started self-harming when I was about 11 or 12...it was like a peaceful experience. It just made everything calm up...in a weird way that was my self-compassion.' (Emma)

'Cutting myself seems like healthy coping, if I just keep letting it out in a steady stream, I avoid a big build up.' (Ava)

Avery described how using unhealthy coping mechanisms could lead to further feelings of guilt and distress and become a vicious cycle of blame and distress.

'It's not great for my self-esteem 'cause I think I don't feel like someone who copes with things well...I make the same mistake over and over again and that doesn't feel great.'

(Avery)

Sense of growth

Most participants described that their journey to this point came with a lot of learning about themselves and the world around them. Participants reflected on how their lack of self-

compassion had been a barrier to taking opportunities when they arose. All the participants described how over time they have been able to identify how they deal with difficult emotions and well as become motivated to learn new and healthier strategies.

Missing out on opportunities

Participants reflected on how lack of self-compassion led to missing out on opportunities to succeed as they avoided taking risks and achieving their goals.

'[Self-compassion] pushes you forwards to achieve different things...I might be more successful career wise because I'd take opportunities that I wouldn't normally take.' (Olivia)

Fear of making mistakes, which would lead to the vicious cycle of self-blame was also noted as a deterrent to taking chances.

'I'd probably spend more time in situations that I want to be in without fear of making a mistake...just get involved in more opportunities because I'm a bit more confident.' (Mia)

Camila felt that with increased self-compassion she would have had less difficult experiences, which would have prevented as much apprehension.

'I might have had less bad experiences doing things, so there wouldn't be so much anxiety surrounding those situations.' (Camila)

Power in community

Participants reported how important it was to have a support system and be part of a community. One participant described how it has been difficult to build connections with people and create friendships.

'I haven't really had any friends for the last few years, so I've kind of used talking out loud in its place, to talk to somebody that's not my family.' (Camila)

Several women explained how identifying as autistic allowed them opportunities to learn and connect with others having similar experiences.

'Following different autistic people on twitter and things like that had really helped because you find common ground with people.' (Olivia)

Both Amelia and Avery described how working with autistic people helped them to understand their own diagnosis as well as reduce the stigma.

'I worked with autistic people and I really understood them and I could get them.' (Amelia)

'I had to start thinking more positively...it would be really sad if my stigma impacted a young person.' (Avery)

Avery reported the value of having a close autistic friend to relate to.

'It's a helpful release. I can get through and feel quite supported and we both talk together about our roads...' (Avery)

Mia initially had doubts about being autistic and found that connecting with the autistic community helped to form a better understanding of her identity.

'I constantly questioned it and I still do that now. I had to remind myself by listening to podcasts of women or reading articles online. Yes, this is my diagnosis. I'm not a fake.' (Mia)

Understanding how I've changed

Participants reflected on how they have changed the way in which they think about themselves and the challenges they've faced in their lives. Sophie commented on how this can still be difficult.

'I definitely used to hate myself. I've worked really hard to change that, and I don't hate myself anymore. Sometimes I even love myself, but that comes and goes.' (Sophie)

Ava and Avery explained that in relying on her diagnosis she has been able to give herself space to make mistakes.

'I'm telling myself, I didn't choose this. I can do my best to be kind and try to work out things the best I can for me, but it's confusing. That's my compassion.' (Ava)

'I'm not always going to do the right things, but I still have that sense that I'm worthy of respecting myself.' (Avery)

Harper described feeling more comfortable being introspective and taking time to understand what she is experiencing.

'Spending time just sitting with myself helps me to feel a connection to me, and then I trust myself more, so I think I'm more compassionate.' (Harper)

Discussion

The aim of this study was to explore the experiences of autistic women with self-compassion using interpretative phenomenological analysis. In line with the existing research, analysis revealed that autistic women experience high self-criticism and find it challenging to engage in self-compassion. The way in which self-compassion was experienced for this group will be discussed in this section through three superordinate themes: Connection with identity, 'I deserve it, right?', and Sense of growth. The themes are discussed below to consider how the current study relates to and extends the literature.

Consistent with previous literature, many participants linked receiving a diagnosis of autism to the evolution and acceptance of their identities (Seers & Hogg., 2021). A recent review outlined how autistic people who received a diagnosis in adulthood after years of questioning felt mixed feelings of being relieved and overwhelmed (Gellini & Marczak,

2023). This was shared by participants of this study, whereby some felt that earlier diagnosis would have allowed them to show more kindness and self-compassion in times of adversity. Wilson et al. (2022) looked at self-compassion in women and found that participants developed a greater sense of self-understanding from discovering they were autistic, which facilitated self-compassion.

This study only recruited women who identified with the diagnosis of autism. This may mean that the negative impacts of a diagnosis were not voiced in the findings.

Specifically, autism, trauma, and attachment difficulties all have overlapping symptoms, but also commonly co-occur (McKenzie & Dallos, 2017). Although in this study receiving a diagnosis was seen as helpful, others may feel the diagnosis is a blanket over the challenges they experienced across their lives. That is to say, that difficulties these women experienced are attributed to their autistic characteristics, when formulating them through a different lens may have been more accurate and helpful.

This study suggested that some autistic women experience being different, or feeling like an outsider, from a young age, something that has also been found in mixed gender autistic populations (Stagg & Belcher, 2019). This supports the importance of belonging throughout life transitions (Personen et al., 2015). The 'common humanity' element of self-compassion (Neff, 2003) suggests that feeling different makes it more challenging for autistic women to develop self-compassion as they may not feel they have shared experiences with those around them. Participants in this study described idealizing peers and constantly striving to do things in ways they did not feel they could achieve.

Self-judgment and increased feelings of inadequacy linked to lack of self-compassion, led the women to 'mask'. Feeling the need to 'mask' or 'camouflage' was discussed by the participants as required to survive and adapt in social situations. This aligns with research

stating that autistic people feel they need to change to meet the expectations of others resulting in negative feelings about the self (Bernardin et al., 2021). It has been suggested that masking can create confusion for autistic women surrounding their identity both pre- and post- diagnoses (Bargiela et al., 2016). Myles et al. (2019) found that autistic girls in mainstream schools feel pressure to adapt their behaviour and minimise their differences to gain acceptance. Camouflaging exists as a response to being 'othered' and feeling the need to conform to expectations set by the non-autistic population to avoid stigma (Pearson & Rose, 2021). In this study women described needing to camouflage at work specifically in order to seem capable, which may be related to Cage and Troxell-Whitman's (2019) findings that autistic women are more likely to mask for 'conventional' and 'relational' reasons, as well as to manage others' impressions of them. The relationship between masking and negative impacts on mental health have been noted extensively in the literature (Chapman et al., 2022; Cook et al. 2021; Hull et al., 2021; Tierney et al., 2016; Wiley, 2014). Alternatively, there is some evidence that autistic people also feel that camouflaging can help with positive mental health (Bradley et al., 2021).

Participants described how they processed events differently from others and how this sometimes meant they avoided, delayed, or ruminated on a thought, which often led to feelings of increased criticism. Jackyra et al. (2022) found that life transitions, interpersonal conflicts, and active rumination about suicidal thoughts and behaviours were distressing and fatiguing for autistic adults. The impact of challenging life experiences on mental health was emphasized throughout this study, with many participants feeling that earlier identification would have reduced the severity of their mental health problems. Self-harm, suicidal ideation and eating disorders were reported in this sample. These findings are consistent with the literature that autistic girls and women are at greater risk of self-harming (Frazier et al., 2014), death by suicide (South et al., 2021), and eating disorders (Babb et al., 2021). In the

UK waitlists for autism diagnoses through the National Health Service (NHS) have become overwhelming and led to long wait times and limited funding for post-diagnostic support (Jones et al., 2014; NHS, 2019). The findings suggest that health professionals working with women need additional training to facilitate earlier identification and adequate support once receiving diagnosis.

All participants described blaming themselves for unexpected, and sometimes traumatic events that were out of their control, usually in the form of negative self-talk and criticism. This is especially concerning as autistic children and adults are at an increased vulnerability for victimization and abuse (Brown-Levoie et al., 2014; Cazalis et al., 2022; Gibbs et al., 2021; Mandell et al., 2005), and may therefore internalize these experiences. In the general population self-blame has been associated with poor coping methods and the development of PTSD (Boeschen et al., 2001; Ullman et al., 2007). According to Neff (2003) the self-judgment and criticism experienced by participants would be a barrier to showing themselves kindness. Leary et al. (2007) suggested that self-compassion may buffer people against negative self-directed feelings during distressing events, as well evaluate challenges without being overwhelmed by negative emotions.

The importance of community and support systems as both a coping mechanism and a way to foster a sense of belonging and self-compassion was reported in this study. This relates to the elements of 'common humanity versus isolation' and 'mindfulness versus overidentification' in the definition of self-compassion (Neff, 2003). By having people to rely on during times of adversity, autistic women may understand that some parts of their distressing experiences are shared by those around her. In connecting with other women from the autistic community they may connect with others who share the unique elements of what living as an autistic woman means, allowing them to put their own situation into a larger

perspective. Post-diagnostic peer support has been seen to be a useful and unique way to support autistic people (Crompton et al., 2020; Crompton et al., 2023, Shea, 2022).

Limitations

This study had several limitations. The recruitment strategy required interested women to contact the researcher; the self-selection bias may have attracted autistic women with a greater understanding or interest in self-compassion. All recruitment was completed online through social media and e-mailing which may have left out individuals without access to broadband and who do not access online social platforms. All participants were verbal without a learning disability, excluding a significant group of autistic individuals, who are often excluded from ASD research already (McKinney et al., 2021), and may have significantly different experiences from verbal individuals. Another limitation is that the study only recruited cis-gender women, although a recent review reported increased diversity and dysphoria in gender identity in autistic people (Sala, et al., 2020). Nearly all the participants were educated and white living in the UK where ethnic minority children have lower levels of diagnosis (Kelly et al., 2019). In addition, Black women seem to be invisible in autism research altogether (Diemer et al., 2022; Malone et al., 2022), which is particularly important because Black autistic youth have been seen both to mask (Pearson & Rose, 2021) and code-switch, the act of modifying one's behaviour interactions to accommodate different cultural norms and to assimilate to white, majority society (Molinsky, 2007), leading to increased risk of mental health problems Although the researcher sought a homogenous sample as per IPA guidelines (Smith et al., 2009), the homogeneity of participants should be kept in mind when reading the results of the study.

As stated above, this research only recruited women who identified with the autism diagnosis. Although autism is a lived and shared experience, there may be women who feel

that this is reductionist concept and that it lacks construct validity (Waterhouse et al., 2016).

A final limitation of this research was that although EBEs provided consultancy on the project in the early stages with resource development, they were unavailable to provide feedback on the results. IPA means that the researcher was making sense of an individual making sense of their experience, which may be a different interpretation from some who identifies as autistic.

Clinical Implications

Autistic women's accounts of their experiences highlight the importance of the autism diagnosis in allowing oneself to be self-compassionate, and how self-compassion may be more difficult in this group. This supports Bargiela et al. (2016) findings that autistic women and those high in autistic traits may be more likely to internalise challenging experiences, thus leading to reduced self-compassion. Clinicians working in mental health services should receive training on indicators of autism in girls and women, to promote earlier recognition, and minimize misdiagnosis, which can have detrimental effect (Fusar-Poli et al., 2022; Gesi et al., 2021) This recognition could bring greater sense of self-identity and relief, as seen in the literature (Pushon et al., 2009).

Autistic people have frequently reported negative experiences of primary care because of lack of expertise and systems which are not designed to meet their specific needs (Nicolaidis et al., 2012). Cooper et al. (2018) also found that therapist confidence in adapting therapy for autistic people was associated with the degree of training they received. Training programs should therefore seek to make adaptation and inclusion part of core training.

Compassion-focussed interventions may be especially useful with this population and may require additional training and supervision. There are promising results with compassion-based interventions for autistic populations for anxiety and depression. These are

likely to promote the positive mental health autistic people because they focus on reducing self-criticism and self-blame (Lunsky et al., 2022; Riebel et al., 2022).

When introducing therapeutic techniques targeting self-compassion, clinicians should be mindful that autistic women often have experiences of trauma in their past. These experiences may trigger negative emotions without having the skills to manage them, therefore these should be introduced tentatively. There is mounting evidence that compassion-focussed therapy is an effective treatment for trauma (Au et al., 2017; Naismith et al., 2021; Winders et al.2020). Interventions may focus on common humanity, where autistic women are given opportunities to share experiences with others in the autistic community. There is some research in the non-autistic population that even a short-intervention targeting self-compassion may reduce self-judgement, anxiety, and depression, and increase self-compassion, with changes remaining at a 6-month follow-up (Dundas et al., 2017). Our findings consolidate the existing literature that autistic women find it validating to connect with the autistic community, and that talking to others improved their well-being (Harmens et al., 2022).

Implications for Future Research

The findings of this study offer several potential directions for future research. As most women included in the research were identified as autistic in adulthood, it would be important to learn about the experiences of those women who were identified in childhood. Reflecting on the experiences of the sample of autistic women, women who are from Black and/or minoritized ethnic groups may have different perspectives on the influence of the autistic identity and self-criticism, as seen in the literature (Golson et al., 2021). Autistic transgender people experience additional challenges that cisgender people may not (Cooper

et al., 2021), therefore research highlighting their experiences would be important to better understand their service needs as well as their sense of belonging and connectedness.

As self-compassion has been liked to positive mental health and well-being, research on the effectiveness of psychological interventions targeting self-compassion in the autistic population are recommended. In addition, adaptations to existing self-compassion therapies should be evaluated to ensure quality and effectiveness are maintained.

Conclusion

This study suggested that autistic women are able to show more self-compassion to others than themselves. The findings were consistent with previous literature, illustrating that the development of self-compassion and experiences of this are different in this population. The way in which autistic women came to identify as autistic, such as noticing differences from peers, receiving a diagnosis, and masking to navigate social situations may have led to reduced self-compassion. Placing the blame on themselves for challenging life events led to delayed processing. By internalizing the judgments of others, participants became more self-critical, resulted in severe expressions of distress. Participants reflected on how the lack of self-compassion has meant they missed out on opportunities but how along the journey they have learned to identify unhealthy coping styles and learn new skills. Much of this learning came from connecting with others, specifically those within the autistic community. This study suggests that psychological support aimed to increase self-compassion in autistic women might help them to foster a positive self-identity and coping mechanisms.

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Part C: Appendices

Appendix A. Quality Appraisal Checklist for Quantitative Studies reporting Correlations and Associations (NICE, 2012)

	Adams et al. (2016; CS)	Ashburner et al. (2018; CS)	Bitsika & Sharpley (2021; CS)	Bitsika et al. (2022; CS)	Chou et al. (2020; CS)	Holden et al., (2020; LG)	Liu et al. (2021;CS)	Liu et al. (2022;CS)	Ochi et al. (2020; CS)	Paul et al. (2018; CS)	Rodriguez et al. (2021; LG)	Ung et al. (2016; CS)	Wright & Wachs (2019;CS)
Section 1. Population 1.1. Is the source population or source area well described?	+	++	+	+	+	++	+	+	++	+	-	+	++
1.2. Is the eligible population or area representative of the source population or area?	+	+	+	+	+	++	+	+	+	+	+	+	+
1.3. Do the selected participants or areas represent the eligible population area?	-	-	-	-	-	+	-	-	-	+	-	-	-
Section 2: Method of selection of exposure (or comparison) group 2.1. Selection of exposure (and comparison) group.	-	-	-	-	-	-	-	-	-	-	-	-	-
How was selection bias minimised?	+	+	+	+	+	+	+	+	+	+	+	+	+

2.2. Was the selection of explanatory variables based on a sound theoretical basis?	N/A												
2.3. Was the contamination acceptably low?	-	-	-	-	-	++	-	-	-	+	-	-	-
2.4. How well were likely confounding factors													
identified and controlled?	+	+	+	+	-	++	-	-	-	+	+	+	+
2.5. Is the setting applicable to the UK?													
3. Outcomes 3.1. Were outcome measures and procedures reliable?	+	-	+	+	+	+	+	+	+	+	+	+	+
3.2. Were the outcome measurements complete?	+	+	+	+	+	+	+	+	+	+	+	+	+
3.3. Were all the important outcomes assessed?	+	+	+	+	+	+	+	+	+	+	+	+	+
3.4. Was there a similar follow-up time in exposure and comparison groups?	N/A												
3.5. Was follow-up time meaningful?	N/A	N/A	N/A	N/A	N/A	++	N/A	N/A	N/A	N/A	++	N/A	N/A

4. Analyses 4.1. Was the study sufficiently powered to detect an intervention effect (if one exists)?	++	++	+	-	+	++	++	++	++	++	++	+	-
4.2. Were multiple explanatory variables considered in the analyses?	+	+	+	+	+	+	+	+	+	+	+	+	+
4.3. Were the analytical methods appropriate?	+	+	+	+	+	+	+	+	+	+	+	+	+
4.4. Was the precision of association given or calculable? Is association meaningful?	+	+	+	+	+	+	+	+	+	+	+	+	+
5. Summary 5.1. Are the study results internally valid													
(i.e.unbiased)?	2	3	2	2	2	5	2	2	3	3	1	2	3
Total + (external validity; section 1)	1	1	1	1	1	0	1	1	1	0	2	1	1
Total - (external validity; section 1)	-	+	-	-	-	++	-	-	+	+	-	-	+
5.2. Are the finding generalisable to the source													
population (i.e. externally valid)? Total + (internal validity; section 2-4)	10	9	9	8	8	15	9	11	9	11	12	9	7
Total - (internal validity; section 2-4)	3	3	1	4	3	1	3	2	3	1	2	2	3
(+	-	+	-	-	++	+	+	-	+	+	+	-

Key for completed NICE (2012) checklist:

Individual ratings:

⁺⁺ Indicates that for that particular aspect of study design, the study has been designed or conducted in such a way as to minimise the risk of bias.

- + Indicates that either the answer to the checklist question is not clear from the way the study is reported, or that the study may not have addressed all potential sources of bias for that particular aspect of study design.
- -Should be reserved for those aspects of the study design in which significant sources of bias may persist.

NR Should be reserved for those aspects in which the study under review fails to report how they (or might have) been considered.

Overall rating for internal validity (IV) and external validity (EV):

- ++All or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter.
- + Some of the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter.
- -Few or no checklist criteria have been fulfilled and the conclusions are likely or very likely to alter.

NA Should be reserved for those study design aspects that are not applicable given the study design under review (for example, allocation concealment would not be applicable for case-control studies.

Appendix B. Recruitment Poster

Salomons Institute, Canterbury Christ Church University

Are you an autistic woman? Would you like to contribute to new research exploring self-compassion?

This study will explore how autistic women experience self-compassion, relate their experience of self-compassion to their mental health, and how they conceptualize the development of self-compassion.

We would like to speak to women who identify as autistic over the age of 18 living in the UK. For more information or to take part please contact Nancy da Silva (Trainee Clinical Psychologist) at n.dasilva243@canterbury.ac.uk



We are asking for an hour of your time for an interview. This could be via video call ar telephane at a time that works for you. Interview arrangements will be flexible around individuals' needs. Topics and questions will be sent prior to our conversation. Your name will be put into a draw for one of two £25 vouchers.

Appendix C. Participant Information Sheet

Faculty of Science, Engineering and Social Sciences

Canterbury Christ Church University



Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG
www.canterbury.ac.uk/appliedpsychology

Information about the research

An Exploration of Autistic Women's Experiences of Self-Compassion

Hello. My name is Nancy da Silva and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve for you. This study has been approved by the Salomons Ethics Panel (ID: ETH2122-0067).

Talk to others about the study if you wish. (Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study).

What is the purpose of the study?

This study is aiming to explore the experience of self-compassion, or being kind to oneself, in autistic women. Within this, the study will explore how autistic women relate their experience of self-compassion to their mental health, and how they conceptualize the development (or lack) of self-compassion. This is a new area of research. We hope this may benefit services for autistic people in the future.

Why have I been invited?

I am asking any woman who is 18+ and identifies as autistic to take part. I will be looking for 8 women to take part in this research.

Do I have to take part?

No- It is up to you to decide to join the study. If you agree to help with this research, I will then ask you to give your consent to take part. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

If you decide to take part in this study, you will be given this information sheet and a copy of a signed consent form. I will contact you to arrange a convenient time to have the interview. During this interview I will ask you a range of exploratory questions around your understanding of self-compassion, your mental health and autism. There are no right or wrong answers. I am interested to hear your story, experiences and perspectives on this subject. The interview will last 60 minutes. This will be digitally recorded and typed up to

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Canterbury Christ Church University

ensure the anonymity of the participant.

Expenses and payments

All participants will be placed into a prize draw for a chance to win one of two £25 Amazon Gift Vouchers.

What will I be asked to do?

If you decide to take part, we will discuss a time to have an interview that would suit you best. You will need to find a quiet space where you have some privacy. You will need to have access to a device that is able to join a virtual meeting.

What are the possible disadvantages and risks of taking part?

I will be asking you to think about your experience of self-compassion, autism and mental health challenges, which you may find distressing. If this occurs you are able to withdraw from the study at any time by telling me you would like to end the interview. If you become distressed and would like to take a break from the interview you can inform me and the interview can be resumed at a later time or date.

A 'Participant Support Sheet' will be distributed to all participants of the study. Before the interview, we will also discuss together any support, strategy or plan that you use to manage distress. The sheet will also signpost you to where you can access any additional supports. This will encourage you to manage any difficult thoughts or feelings that you may have after engaging in this interview.

What are the possible benefits of taking part?

This study may not provide any direct benefits for you but you may enjoy and be interested by the process of sharing your thoughts and experiences on this subject. The information we get from this study could help to improve services and therapy offered to autistic women.

What if there is a problem?

Any complaint about the way you have been treated/your experiences with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2. If you have any further questions about the study, you may contact me (Trainee Clinical Psychologist, Nancy da Silva), at nd243@canterbury.ac.uk.

Will information from or about me from taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. There are some rare situations in which information would have to be shared with others. The details are included in Part 2.

This completes part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2 of the information sheet

What will happen if I don't want to carry on with the study?

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You have the right to withdraw from the study at any time before or during the interview. As the interview will be recorded, you will have the choice to have this deleted and not used as part of the data collected for analysis up until 2 weeks after the interview.

What if there is a problem?

Should you experience a problem at any stage in the research study, you are entitled to discuss this with me, or alternatively you may submit a complaint to the funding university as detailed below.

Concerns and Complaints

If you have a concern about any aspect of this study, you should ask to speak to me initially (nd243@canterbury.ac.uk) and I will do my best to address your concerns. Alternatively you can contact me, Nancy da Silva, by leaving a message on the 24-hour voicemail phone number 01227 927070. Please leave a contact number and say that the message is for me [Nancy] and I will get back to you as soon as possible.

Where to Complain

If you remain dissatisfied and wish to complain formally, you can do this by contacting Dr Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology fergal.jones@canterbury.ac.uk.

Will information from or about me from taking part in the study be kept confidential?

All information which is collected from or about you during the course of the research will be kept strictly confidential, and any information about you will have your name and address removed so that you cannot be recognized.

The only time when I would be obliged to pass on information from you to a third party would be if, as a result of something you told me, I were to become seriously concerned about your safety, or the safety of someone else.

The digital recording of the interview will be electronically stored securely on an encrypted USB disk. The digital recording will be anonymized and transcribed. You will be given a false name to maintain confidentiality. The audio-recordings will be erased as soon as they have been turned into anonymous written transcripts.

Canterbury Christ Church University is the sponsor for this study and is based in the United Kingdom. We will be using information that you have provided in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Canterbury Christ Church University will keep anonymized information about you for 10 years after the study has finished as recommended by the General Data Protection Regulation (GDPR) and then it will be disposed of securely. Only authorized persons such as myself and my research supervisors will have the access to view the anonymized transcripts.

What will happen to the results of the research study?

The results of the research will be written up with the intention to publish results in an academic journal, and potentially elsewhere (e.g. websites related to autism and self-compassion). Anonymised quotes from your interview may be used in published reports but

Faculty of Science, Engineering and Social Sciences

Canterbury Christ Church University

you will not be identified in any report/publication. Any quotes that contain information that could potentially identify you will be amended to anonymise the information before publication. The findings will be shared with you if you give consent to be contacted by email or telephone.

Who is sponsoring and funding the research?

Canterbury Christ Church University.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by The Salomons Ethics Panel, Salomons Institute for Applied Psychology, Canterbury Christ Church University.

Further information and contact details

Participants may want further information. This could be subdivided:

1. General information about research.

If you would like to speak to me and find out more about the study of have questions about it answered, you can leave a message for me on a 24-hour voicemail phone line at 01227 927070. Please say that the message is for me, Nancy da Silva, and leave a contact number so that I can get back to you.

- 2. Specific information about this research project.
 You can contact me or my project supervisor Dr Joanne Mueller, Clinical Psychologist, at drioannemueller@qmail.com.
- 3. Advice as to whether they should participate.

 If you would like some advice on whether you should participate, you can also speak to Dr Joanne Mueller (drjoannemueller@amail.com) or my academic supervisor Dr Simon Powell (simon.powell@canterbury.ac.uk).



Salomons Institute for Applied Psychology One Meadow Road, Tunbridge Wells, Kent TN1 2YG

Ethics approval number: ETH2122-0067 Version number: 1 Participant Identification number for this study:

CONSENT FORM

Title of Project: An Exploration of Autistic Women's Experiences of Self-Compassion

Name of Researcher: Nancy da Silva (Trainee Clinical Psychologist)

Please initial each box:	
1. I confirm that I have read and understand the information sheet dated November 2021 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	
3. I understand that relevant sections of data collected during the study may be looked at by the lead supervisor Dr Joanne Mueller and Dr Simon Powell. I give permission for these individuals to have access to my data.	
 I agree that anonymous quotes from my interview and other anonymous data may be used in published reports of the study findings. 	
I agree that interviews will be digitally recorded and stored by researcher on an encrypted device.	
6. I understand that I have 14 days from my interview to have the recording deleted. If my recording is deleted the data collected from my interview will not be included in the research project.	



I agree for my anonymous data to be used [OPTIONAL]	in further research studies.	
8. I agree to take part in the above study.		
Name of Participant	Date	-
Signature		
Name of Person taking consent	Date	
Signature		

Appendix E. Salomons Ethical Approval

This has been removed from the electronic copy.

Appendix F. Debrief Sheet

Dear [PARTICIPANT],

Thank you for participating in the research study, and for sharing your experiences in the interview. We understand that sometimes these experiences may be difficult to talk about, and some people can feel distress after talking about such experiences. This is not unusual, and you may find that the upset feelings fade after a while. However, if you find that these feelings stay with you for a prolonged period of time, or if you feel you would like further support, you can contact:

Samaritans

Confidential support for people experiencing feelings of distress or despair.

Phone: 116 123 (free 24-hour helpline) Website: www.samaritans.org.uk

SANE

Emotional support, information and guidance for people affected by mental illness, their families and

Phone: 0300 304 7000 (daily, 4.30 to 10.30pm)

Peer support forum: www.sane.org.uk/supportforum

Website: www.sane.org.uk/support

SHOUT Crisis Text Line text "SHOUT" to 85258

The above are not emergency services. If you do not feel you are able to keep yourself safe call 999 immediately.

If you would like any additional information, or a confidential discussion, please contact me on n.dasilva243@canterbury.ac.uk, or leave me message on 01227 927070. Please specify that the message is for Nancy da Silva and it will be forwarded to me promptly.

Thank you again for your participation in this study.

Yours Sincerely

Nancy da Silva Trainee Clinical Psychologist Canterbury Christ Church University

Supervised by

Dr Simon Powell

Salomons Centre for Applied Psychology, Canterbury Christ Church University, Tunbridge Wells, Kent TN3 0TF

and

Dr Joanne Mueller Clinical Psychologist

Appendix G. Interview Schedule

Interview Schedules

These questions will be used as prompts depending on the direction of the interview.

1. Autism Screening

- -Do you have a diagnosis of autism? If so, at what age were you diagnosed? If not, are you seeking a diagnosis? Why or why not?
- -What characteristics or experiences have you had that led you to identify as autistic?

2. Self-compassion

- -What is your understanding of self-compassion?
- -How do you feel about yourself when things don't go to plan?
- -Do you ever talk to yourself? This could be out loud, in your mind, through writing. This could also be the way in which you process events or thoughts. If so, how do you talk to yourself when things don't go as expected? If not, how do you respond to yourself in these situations?
- -When you notice you are feeling a strong or unpleasant emotion, how do you talk/react/write/think to yourself?
- -Why do you think things go wrong?
- -Who do you blame when things don't go to plan?
- -If/when you find it difficult to talk/write/think/process to yourself in gentle way, what do you think stops you from being more self-compassionate?
- -What do you think would happen if you were kinder to yourself?

3. Autism

- -How do you remember speaking to yourself throughout childhood when you felt unpleasant emotions or things went wrong?
- -How do you think you came to learn to talk/respond/think/process to yourself in that way?
- -How do you feel the way you react or speak to yourself when things don't go to plan is influenced by your autism, if at all?

4. Mental health

- -How do you think the way you talk/respond to yourself affects your mental health?
- -How do you think your mental health affects, or has affected the way you talk or respond yourself?

Appendix H: Example of coded transcript with exploratory notes and experiential statements

This has been approved from the electronic copy.

Appendix I: Example of organisation of experiential statements into personal experiential themes

Personal Experiential Statement	Experiential Statements
Always feeling different	Difference marked by comparisons to others
Validation and doubt through diagnosis	Stereotypes as the norm
	Label as affirming of identity
	Delays leading to challenges
	There is danger of going undiagnosed
Masking	Hiding self to fit the mould
Understanding of compassion	Compassion as a reciprocal action
	Barriers to seeing kindness as a tool
Processing events	Ruminating on events lead to self-blame
	Delayed processing of emotions
Internalizing views of others	Reflections from others important
	Reflections from others provide insight
	Actions of others can become ingrained
Self-criticism	Mistakes need to be criticised
	Inner voice reflects criticism
	Intrinsic feelings of being wrong
Expressions of distress	Awareness of unhealthy coping mechanisms
	Kindness as an undeserved privilege
Missed opportunities	Goals being unattained lead to worthlessness
Importance of community	Seeing herself within a new community
	Others' awareness important for safety
Sense of change	Process of learning
	Awareness of change

Appendix J: Example of organization of personal experiential themes into group experiential themes

Group Experiential Themes	Personal Experiential Themes
Connection with identity	Always feeling different
	Validation and doubt through diagnosis
	Masking
	Falling into the back drop
	Understanding of compassion
	'Frustration with what makes me, me'
'I deserve it, right?'	Processing events
	Avoidance of emotions
	Delayed reflections
	Self-compassion as self-indulgent
	Self-harm as a kindness
	Internalising the words of others
	Self-criticism
	Avoidance to cope
	Holding myself accountable
	Dealing with the trauma
Sense of growth	Missing out on opportunities
	Underachieving
	Power in community
	It's better when I talk
	Understanding how I've changed
	Knowing my worth
	Reparations

Appendix K: Abridged Bracketing Interview — Pre- Analysis Questions

This has been removed from the electronic copy.

Appendix L. Abridged Research Diary

This has been removed from the electronic copy.

Appendix M: Summary report for ethics panel

Dear ethics panel members,

Re: An Interpretative Phenomenological Analysis of the Exploration of Autistic

Women's Experiences of Self- Compassion

I am writing to inform you that this research study has been completed and submitted in partial fulfilment of the requirements of Canterbury Christ Church University Doctorate in Clinical Psychology. Enclosed is a summary of this project.

Background: Self-compassion has been linked to positive psychological well-being in the non-autistic population. There is limited research exploring the development, experiences, and barriers to self-compassion in autistic women. Autistic women are likely to experience mental health problems across their lives. The present study aimed to explore the experiences of self-compassion in a sample of autistic women. The interview questions explored autistic women's experiences relating to receiving a diagnosis of autism, their understanding of self-compassion, and how these have impacted their mental health.

Method: Eleven autistic adult women living in the UK took part in interviews, which were transcribed and analysed using Interpretative Phenomenological Analysis. The research complied with ethical codes of conduct from the British Psychological Society and Health and Care Professionals Council.

Findings: The research suggested that autistic women have reduced self-compassion and that the development of self-compassion may be different in this population. The way in which autistic women came to identify as autistic, such as noticing differences from peers, receiving a diagnosis, and masking to navigate social situations may have led to reduced self-compassion. Placing the blame on themselves for challenging life events led to delayed processing. By internalizing the judgments of others, participants became more self-critical, resulted in severe expressions of distress. Participants reflected on how the lack of self-compassion has meant they missed out on opportunities but how along the journey they have

learned to identify unhealthy coping styles and learn knew skills. Much of this learning came from connecting with others, specifically those within the autistic community.

The findings contribute towards a greater understanding of the development and barriers to self-compassion in autistic women. It suggests that psychological support aimed to increase self-compassion in autistic women might help them to foster a positive self-identity and coping mechanisms. Limitations include lack of ethnic diversity within the sample, lack of diversity in autism presentation (only verbal, non-learning disabled participants), and possible selection bias.

Implications: Clinical implications were suggested relating to supporting and training mental health professionals, particularly in identifying and promoting earlier recognition of autism in girls, and adapting compassion focused therapies to meet the needs of these women. In line with NHS values of 'improving lives' and 'commitment to quality of care', improving services for autistic women may lead them to developing greater psychological wellbeing and health. Future research should involve a more diverse sample of participants in terms of ethnicity and gender, as well as looking at the effectiveness of interventions targeting self-compassion in this population.

Feedback on the findings of the study will be disseminated to all participants and relevant stake holders.

Appendix N: Summary report for participants and stakeholders

Summary Report

An Interpretative Phenomenological Analysis of the Exploration of Autistic Women's Experiences of Self- Compassion

Dear Participant,

I am writing to you because you took part in my research study exploring autistic women's experiences of self-compassion. Thank you again for your participation and the openness and thoughtfulness you brought to the research. Below I have attached the details and findings of the study.

Background: Self-compassion has been linked to positive psychological well-being in the non-autistic population. There is limited research exploring the development, experiences, and barriers to self-compassion in autistic women. Autistic women are likely to experience mental health problems across their lives. The present study aimed to explore the experiences of self-compassion in a sample of autistic women. The interview questions explored autistic women's experiences relating to receiving a diagnosis of autism, their understanding of self-compassion, and how these have impacted their mental health.

Method: Eleven autistic adult women living in the UK took part in interviews, which were transcribed and analysed using Interpretative Phenomenological Analysis. The research complied with ethical codes of conduct from the British Psychological Society and Health and Care Professionals Council.

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Findings: The research suggested that autistic women have reduced self-compassion and that the development of self-compassion may be different in this population. The way in which autistic women came to identify as autistic, such as noticing differences from peers, receiving a diagnosis, and masking to navigate social situations may have led to reduced self-compassion. Placing the blame on themselves for challenging life events led to delayed processing. By internalizing the judgments of others, participants became more self-critical, resulted in severe expressions of distress. Participants reflected on how the lack of self-compassion has meant they missed out on opportunities but how along the journey they have learned to identify unhealthy coping styles and learn knew skills. Much of this learning came from connecting with others, specifically those within the autistic community.

The findings contribute towards a greater understanding of the development and barriers to self-compassion in autistic women. It suggests that psychological support aimed to increase self-compassion in autistic women might help them to foster a positive self-identity and coping mechanisms. Limitations include lack of ethnic diversity within the sample, lack of diversity in autism presentation (only verbal, non-learning disabled participants), and possible selection bias.

Implications:

- Offering training to clinicians in mental health services to promote earlier recognition of autism in girls.
- Offering training to clinicians on the adaptation of therapeutic techniques and inclusion. This will be most important in compassion-focussed interventions which may be especially helpful with autistic women.
- Further research should include a more ethnically and gender diverse sample.

•	Further research should look at the effectiveness of psychological interventions
	targeting self-compassion in the autistic population.

I hope that some of these results fit with the experiences you shared with me. Thank you once again for kindly taking part in this research. I wish you all the best in the future.

Yours sincerely,

Nancy da Silva

Appendix O: Manuscript Submission Guidelines to Autism: Sage Journals

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.

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
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- 5.4 Permissions
- 6. On acceptance and publication
 - **6.1 SAGE Production**
 - 6.2 Online First publication
 - 6.3 Access to your published article
 - 6.4 Promoting your article
- 7. Further information

1. What do we publish?

1.1 Aims & Scope

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

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 and 15 references. 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.

1.3 Writing your paper

The SAGE Author Gateway has some general advice and on <u>how to get published</u>, plus links to further resources.

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: <u>How to Help</u> 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

2.2 Authorship

within (e.g.) 6-8 weeks of submission.

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.

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 <u>Funding Acknowledgements</u> 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 <u>NIH policy</u>.

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 <u>ICMJE Recommendations for the Conduct</u>, <u>Reporting</u>, <u>Editing</u>, and <u>Publication of Scholarly Work in Medical Journals</u>, 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 <u>ICMJE requirement</u> 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 <u>EQUATOR Network</u> reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed <u>CONSORT</u> flow chart as a cited figure and the completed <u>CONSORT</u> checklist should be uploaded with your submission as a supplementary file. Systematic reviews and meta-analyses should include the completed <u>PRISMA</u> flow chart as a cited figure and the completed <u>PRISMA</u> checklist should be uploaded with your submission as a supplementary file. The <u>EQUATOR</u> wizard can help you identify the appropriate guideline.

The <u>What Works Clearinghouse (WWC) guidelines</u> 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 <u>BMJ's editorial guidelines</u> 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 <u>FAQs document</u>.

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2.9 Data Policy Statement

Autism supports open research practices and <u>FAIR principles</u>. 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 <u>supplementary data file</u>.

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 <u>Open Science framework</u>. 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' <u>International Standards for Authors</u> and view the Publication Ethics page on the SAGE Author Gateway.

3.1.1 Plagiarism

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4.4.1 Terminology about autism and autistic people

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

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

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

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

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