Experiences of Adversity and Self-Compassion in the Autistic Population

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Declaration Form

I, the author, declare that the thesis is my own work. This work has not been previously presented for an award at the University of Sheffield, or any other university. I am aware of the University of Sheffield's Guidance on the Use of Unfair Means (www.sheffield.ac.uk/ssid/unfair-means).

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Lay Summary

Traumatic events, such as experiencing violence or neglect, can cause poorer physical and mental health. There is some evidence that autistic people experience traumatic events in childhood more often non-autistic people. Autistic individuals also often face negative attitudes and unfair treatment throughout their lives. Experiences of abuse, bullying, and a lack of kindness can cause people to feel bad about themselves and be critical of themselves. Being kind to yourself and recognising everyone makes mistakes has been found to reduce distress during difficult situations.

The first aim of this project was to bring together the research on the likelihood of autistic people facing traumatic events during childhood. The author found 39 studies looking at traumatic events during childhood for autistic people compared to non-autistic people. The outcomes were combined and found that autistic people were more than two times more likely than non-autistic people to experience a traumatic event during childhood. The studies measured different types of traumatic events, with different groups of people, which meant there were differences between the outcomes of each study. When autistic people were compared to people with other disabilities, no difference between the likelihood of experiencing a traumatic event during childhood was found. Overall, the findings suggest autistic individuals are at greater risk of experiencing traumatic events during childhood than non-autistic people. The results highlight the importance of autistic children and their families getting appropriate support to prevent traumatic events and the need for interventions to support autistic individuals recover from any traumatic events they have experienced.

The second aim of this project was to find out what helps and hinders autistic adults to be kind, caring, and understanding of themselves. Fifteen autistic adults were interviewed and shared their experiences with the researcher. The researcher read through the data several times and looked for patterns across the group of participants. The researcher created three themes and checked these with independent autistic adults, the participants, and colleagues. The themes were: How others treat me (Non-acceptance from others; Acceptance from others), Attributing responsibility (Blame myself; Relieve myself of blame) and How I treat myself (Compromising my own needs; Meeting my own needs). Criticism and disapproval from others made it hard for participants to show themselves kindness. Participants often blamed and criticised themselves for their difficulties and failings. Participants tried to hide aspects of themselves to fit in with others which made them feel like a failure. Participants also avoided social events for fear of making mistakes. Being in a place where people accepted their differences and mistakes made it easier for participants to be kind to themselves. Having an Autism diagnosis helped participants to accept their quirks and forgive their mistakes. Allowing oneself time to recover from social events and expectations was an important part of showing oneself kindness. Promoting Autism acceptance in society and supporting autistic adults to ease feelings of blame and put their own needs first, are key to improving the lives of autistic people.

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Section One: Literature Review

A Systematic Review and Meta-Analysis of the Association Between Autism and Adverse Childhood Experiences

Abstract

Objectives

This systematic review and meta-analysis (PROSPERO: CRD42022262635) aimed to determine the association between autistic individuals and adverse childhood experiences (ACEs), compared to non-autistic individuals. Several moderator analyses were also conducted.

Methods

Studies that reported dichotomous outcomes regarding the associations between ACEs and individuals with an Autism diagnosis were included, excluding studies without a comparison group of non-autistic individuals. MEDLINE, PsychINFO, CINAHL, Scopus, Web of Science, ProQuest Dissertations & Theses Global were searched up to 9th April 2022; Social Care Online and E-Theses Online Service were searched up to 3rd January 2022; Google scholar was searched up to 22nd March 2022. Risk of bias was assessed using items from the Appraisal Tool for Cross Sectional Studies and Joanne Briggs Checklists. A random-effects model was used to calculate the average Odds Ratio (OR) of the relationship between a diagnosis of Autism and ACEs.

Results

39 studies with 5,619,342 participants were included, generating an overall effect of OR 2.07 (CI 1.57-2.73). Significant differences in the magnitude of effect sizes were found across studies with regards to the type of ACEs studied, comparison groups and population types.

Conclusions

Moderate certainty evidence (downgraded for bias) indicates that autistic individuals are at greater risk of experiencing ACEs, compared to non-autistic individuals. Appropriate support for autistic individuals and their families are required to prevent ACEs and treat the impact of ACEs. The review was funded by the University of Sheffield.

Practitioner Points

- Education, health, and social care professionals should be aware of autistic people being at greater risk of experiencing ACEs compared to non-autistic people.
- Preventative measures, such as adequate support for families of autistic children and anti-bullying strategies in schools, are vital for reducing the likelihood of autistic children experiencing ACEs.
- Assessment and identification of ACEs in people diagnosed with Autism should be embedded into practice to ensure the individuals and families receive the appropriate support, such as trauma-focused therapy.
- Organisations must employ a trauma and ACE informed culture, so they are sensitive to the impacts of trauma and the potential of re-traumatisation of service users.

Introduction

Adverse childhood experiences (ACEs) refer to potentially traumatic events that occur in childhood (CDC, 2022). More than half of children and adults report experiencing at least one ACE (Felitti et al. 1998; Finkelhor et al., 2015; Porche et al., 2016). There is considerable evidence of the long-term negative impact of ACEs on health and mental health outcomes (Chapman et al., 2004; Horwitz et al., 2001; Hughes, 2017; Kessler et al., 1997; Monnat, & Chandler, 2015). Literature exploring ACEs among the autistic population suggests that autistic children experience more ACEs than their peers (Berg et al., 2016; Dodds, 2021; Hoover & Kaufman, 2018; Kerns et al., 2017; Rigles, 2017). Therefore, the aim of this meta-analysis was to examine the relationship between being autistic and experiencing an ACE, compared to a non-autistic population.

The term ACE was coined by Felitti et al. (1998) in a seminal paper on seven categories of childhood adversity: psychological abuse, physical abuse, sexual abuse, violence against the child's mother, and living with household members who are substance abusers, mentally ill or suicidal, or imprisoned. This narrow concept of ACEs has since been expanded to encompass a broader range of adverse experiences, including bereavement and bullying (Education Scotland, 2021). What constitutes an ACE is still a subject of debate. Definitions of adversity can change according to an individuals' own needs or experiences and unique characteristics of Autism may determine which events are experienced as particularly traumatic. In this study, ACEs is defined by the ACE International Questionnaire (ACE-IQ; WHO, 2018).

There is strong link between economic hardship and the likelihood of childhood abuse and neglect (Bywaters et al., 2016). There is also a clear relationship between socioeconomic position in childhood and ACEs (Walsh et al., 2019). However, poverty is often overlooked in discourse around childhood adversity (Gupta, 2017). There is an argument that childhood economic adversity should be considered an ACE (Braveman et al., 2018). Therefore, in addition to ACEs outlined in the ACE-IQ, poverty is also included in this study as an ACE.

Felitti et al. (1998) found that in the general US population, almost two-thirds of adults reported at least one ACE and more than one in five reported three or more ACEs. Findings in England reported almost half of individuals had experienced at least one ACE and 9% experienced four or more ACEs (Bellis, 2014). A systematic review by Carlson et al. (2020) found that prevalence rates varied widely by study, 41% (Boney-McCoy & Finkelhor, 1995; Zinzow et al., 2009) to 97% (Kilpatrick et al., 2000). In the child population, studies have found more than half of the school-aged population reported one or more ACE (Finkelhor et al., 2015; Porche et al., 2016). International studies of school-aged children indicate that almost two thirds of children and adolescents experience significant adversity no matter where they live in the world (Carlson, 2020).

Autism can be understood as a naturally occurring way of being that differs from society's definition of 'normal', rather than being perceived as deficient (Robertson, 2009). Autism is diagnosed by meeting a criterion of social communication and interaction differences, and restricted and repetitive behaviours (American Psychiatric Association, 2013). The prevalence rate of Autism is estimated at 1.035% across the world and 1.1% in England (Brugha et al., 2012;

MacKay et al., 2018). Autistic children have been found to have a higher probability of experiencing ACEs compared to their non-autistic peers (Berg et al., 2016; Dodds, 2021; Hoover & Kaufman, 2018; Kerns et al., 2017; Rigles, 2017). Moreover, due to the difficulties adopting socially normative behaviours, autistic children and adults may be more vulnerable to victimisation (Kerns et al, 2015).

Experiencing ACEs has been associated with poorer physical and mental health outcomes compared to individuals who do not experience ACEs (Anda et al., 2006; Bellis et al., 2015; Hughes et al., 2017). Mental health conditions are more prevalent in the autistic population that the general population (Lai, 2019; Simonoff et al., 2008). Mandell et al. (2005) found almost one in five autistic children in community mental health settings had experienced physical abuse and one in six had experienced sexual abuse. Cardiovascular risk factors, comorbid health condition and mortality risk are reported to be higher than for non-autistic people (Cashin et al., 2018; Woolfenden et al., 2012). Yet, autistic individuals often struggle to face more barriers to treatment than non-autistic people and do not receive the support they need (Adams & Young, 2021; Babb et al., 2021; Camm-Crosbie et al., 2019; Cashin et al., 2018; Jones et al., 2014; Mandy, 2022).

The aim of the present meta-analysis was to synthesize evidence across studies to estimate the overall association of ACEs and autistic individuals compared with non-autistic individuals, and to evaluate the influence of potential moderators. Having a clearer picture of autistic people’s likelihood of experiencing an ACE is key to protecting them from harm and providing appropriate restorative support. Moreover, establishing the odds of autistic people experiencing ACEs may contribute to an explanation for poorer mental health and physical health.

To the researcher’s knowledge no meta-analysis has been conducted reviewing the association of ACEs and Autism. The main objective of the study was to determine the odds of ACEs in autistic individuals compared to non-autistic individuals. An additional goal was to assess possible moderating effects of six variables. Differences may exist between rates of ACEs depending on the type of adversity. Mehtar and Mukaddes (2011) found that among autistic individuals witnessing or being a victim of accidents/disasters or violence was the most prevalent type of trauma while sexual and physical abuse was not common. Whereas population-based studies with typically developing children have reported high prevalence rates of physical and sexual abuse (Zoroglu et al., 2003). Therefore, investigating if differences exist between autistic and non-autistic samples due to the type of ACE was deemed important.

Previous findings suggest differences in rates of abuse among different genders exist in the non-autistic population, for example males have been found more likely to experience physical abuse and females have been found more likely to experience sexual abuse (Afifi et al., 2014; Conroy et al, 2009; Dube et al., 2005; Meng & D’Arcy, 2016; Thompson et al., 2004; Walker et al., 2004). Moreover, gender differences in presentations of Autism and differences in gender expectations, lead to variations in how people treat autistic males and females and contribute to disparities in diagnosis rates (Kanfiszer et al., 2017; Lai et al., 2015; Sutherland et al., 2017; Webster & Garvis, 2017). Therefore, sample gender was included as a moderator to assess how it impacted the findings.

There are arguments for and against the use of prospective and retrospective methods of data collection, based on doubts of reliability and validity (Kendall-

Tackett & Becker-Blease, 2004; London et al., 2008; Shaffer et al., 2008; Tajima et al., 2004). Therefore, the author included studies using both methods and used moderator analysis to see if they impacted the magnitude of effect. Rates of psychiatric diagnosis have been found to be lower when collected by a professional, for example by diagnostic interview, than when self-reported (Osborn et al., 2016; Spaans et al., 2017; Yirmiya & Shaked, 2005). This finding may also apply to Autism diagnoses and thus methods for diagnosis of Autism was included as a moderating variable.

Lower childhood socioeconomic position is associated with a greater risk of ACEs (Walsh, 2019). Interestingly, several studies have found higher socioeconomic status is associated with increased prevalence of Autism (Durkin et al., 2010; Fountain et al., 2011; Thomas, 2011). Therefore, socioeconomic status was identified as a planned moderator.

Finally, sample age was selected as a moderating effect. Evidence suggests that age patterns of child maltreatment vary across disabilities and compared to non-disabled children. Children with communication disabilities tend to experience first incidents of maltreatment from birth to five years in contrast to non-disabled children who tend to be maltreated between five and nine years (Sullivan & Knutson, 2000).

Language and Terminology

Value-laden terms such as ‘deficit’ and ‘disorder’, which suggest that difficulties experienced by autistic people are due to an innate problem, will be avoided unless referring to a diagnostic label (Bottema-Beutel et al., 2021; Kenny et al., 2016; Ryan & Runswick-Cole, 2009). Person-first language, such as “people with autism”, separates autism from personhood and suggests that autism is something bad (Sinclair, 2013). Therefore identity-first language, such as “autistic people”, will be used according to views from many autistic people (Bury et al., 2020; Kenny et al., 2016; Lei et al., 2021; Sinclair, 2013). Where comparison groups are not specified in papers as typically developing, they will be referred to as non-autistic, as they may be otherwise neurodivergent or have a health condition (Boucher & Bowler, 2008).

Methods

The protocol for this meta-analysis was registered on PROSPERO (https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=262635; registration number: CRD42022262635). The review was funded by the University of Sheffield. The researcher declares no conflict of interests. The researcher followed the reporting guidance from the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) 2020 statement (Page et al., 2021a, 2021b). A 27-item checklist can be found in Appendix A.

Search Strategy

On 3rd January 2022, eight online databases were searched: MEDLINE, PsychINFO, CINAHL, Scopus, Web of Science, ProQuest Dissertations & Theses Global, Social Care Online and E-Theses Online Service. Alerts for the searches were set up to notify the author of any studies recently added to the databases up to 9th April 2022, excluding EThOS and Social Care Online which did not provide this function. Searches in the reference lists of studies included in the systematic review and searches of publications citing studies included in the systematic review were conducted between 7th March 2022 and 9th April using Web of Science, and when not indexed on Web of Science, Google Scholar was used as an alternative. On 22nd March 2022, the first 100 studies appearing on Google Scholar (https://scholar.google.com) were also searched for additional studies. The date coverage for each database is provided in Appendix B.

Search terms included autis* OR asperger* OR “pervasive developmental disorder*” AND “adverse childhood experience*” OR “adverse childhood event*” OR "child* trauma" OR “child* adversit*” OR “early adversit*” OR “early-life adversit*” OR “early life adversit*” OR "child* maltreatment” OR “forced marriage” OR “parental death” OR “community violence” OR “collective violence” OR war OR “peer violence” OR bullying OR bullied OR “domestic abuse” OR “domestic violence” OR poverty.

Candidate search terms were identified by looking at search strategies used in similar reviews and trialling several draft search strategies. Search terms naming each ACE in the chosen definition generated an unworkable number of studies and so it was decided to use synonyms for ‘adverse childhood experience’ and name only the ACEs which fell outside of the traditional, well-known ACEs identified by Felitti et al., (1998). The final strategy was reviewed by a librarian and the research supervisor. The full line by line search strategy as run in each database with a sophisticated interface, or the sequence of terms that were used to search simpler interfaces, can be found in Appendix C. As per the eligibility criteria below, the strategy was limited to English language studies and there were no date restrictions.

Eligibility Criteria

Inclusion Criteria

Studies that reported data regarding the associations between ACEs and individuals with an Autism diagnosis were included. Any diagnoses under the umbrella of ‘Autism Spectrum Disorder’ were included. The measures used in each study would preferably have strong psychometric properties for the assessment of ACEs or Autism, but studies were not excluded on this basis, and this is included in the risk of bias assessment.

To be included, studies had to investigate ACEs defined by the ACE-IQ (WHO, 2018) and poverty. Eligible outcomes were broadly categorised as follows:

- ACE

    - Verbal, physical, or sexual abuse
    - Neglect
    - Witnessing domestic abuse
    - Household member substance misuse
    - Household member mental illness or suicidal
    - Household member incarceration
    - Parental separation or divorce
    - Parent/ guardian death
    - Forced marriage
    - Being bullied/ peer violence
    - Witnessing/ experiencing community and collective violence
    - Poverty
- Autism Spectrum Disorder (ASD)
    - Autistic disorder
    - Asperger’s syndrome
    - Pervasive developmental disorder not otherwise specified

Measures of ACEs at any point during childhood or retrospectively as adults were eligible for inclusion. Studies were included if they looked at dichotomous outcomes of the presence of an ACE. As poverty can be defined differently depending on the country and context, only studies which provided clear measures of poverty were included, for example using the Federal poverty level. Studies were required to use an individual or household measure of poverty. Self, parental and peer reports of ACEs and ACEs found in official records and databases were included.

For studies looking at accounts during childhood, samples with an average age below 18 years or majority (>75%) below 18 years were included. In studies that included children where the authors did not specify the age range, the researcher assumed that the oldest participants were 18 years. Studies with participants from general and clinical populations were eligible.

Only articles published in English language were included. Empirical and quantitative studies using a range of study designs such as cohort, case-control and cross-sectional studies were eligible for inclusion. All years of dissemination were included up to the date of the searches. Grey literature, including unpublished theses, were included, to reduce publication bias and increase inclusiveness. Only articles with access to full texts were included. In cases where the same cohort was reported in different publications and the same ACE was analysed, the earliest publication where relevant data could be extracted was used. If the same cohort was reported in different publications and different ACEs were analysed, the most comprehensive paper in terms of number of ACEs and sample size was included.

Exclusion Criteria

As the review included a broad definition of ACEs, thus introducing potential heterogeneity between studies, the researcher employed a strict exclusion criterion in an attempt to reduce heterogeneity between studies. Studies without a comparison group of non-autistic individuals were excluded. Studies investigating autistic traits in individuals and polygenic scores, without a confirmed Autism diagnosis were also excluded. Studies looking at continuous data, for example on frequency of an ACE or symptom severity, were excluded due to the scope of the project. ACEs reported by other parties, such as teachers, were excluded as the nature of their relationship with the individual suggested the information provided may be less comprehensive.

Studies were excluded if they investigated ACEs which occurred prior to birth, such as during pregnancy or familial history. Although the researcher recognises intergenerational transmission of trauma and prenatal adverse experiences exist, this study is limited to direct individual-level ACEs due to the scope of the project. Studies which include childhood experiences which do not fit the outlined ACE definition or additional variables mixed in were excluded. Papers which looked at household member mental illness symptoms or stress without a diagnosis were excluded, as these outcomes were deemed less robust. Studies looking at area-based measures, such as poverty area, were excluded, as these were regarded as less reliable. Qualitative studies, case studies, books chapters, conference publications, reviews or commentaries were excluded.

Study Selection

3756 articles were identified in database searching and were imported to EndNote reference manager. After duplicates removal, 2126 articles were screened and 1987 were excluded because they did not fit the inclusion criteria. 142 full text articles were reviewed for eligibility. Excluding a further 112 studies left 30 studies for inclusion. Searching documents that cited any of the initially included studies as well as the references of the initially included studies identified 76 studies for full text screening, seven studies were identified from google scholar and four studies were identified from the researcher’s preliminary scoping search. Of these 87 studies, 78 studies were excluded leaving an additional 9 for inclusion in the meta-analysis. Therefore, a total of 39 studies were included in the review (See Figure 1 for PRISMA diagram).

Data Collection Process

Titles and abstracts of studies retrieved through initial searches were screened by one author against the inclusion and exclusion criteria. Full texts of retrieved articles were screened by one author and checked via forward and backward search strategies for any additional papers to include. The research assistant independently screened a random 10% sample (n=23) of full texts identified from the databases and other methods. Inter-rater reliability was calculated using the Kappa statistic (Cohen, 1992), finding a substantial level of agreement (k = 0.617 95% CI: 0.278-0.955; Landis & Koch, 1977). Disagreements between screeners were resolved through discussion until consensus was obtained. A list of studies that appear to meet inclusion criteria and reasons for exclusion can be found in Appendix D.

A data extraction table recorded study characteristics, key information for the meta-analyses and planned moderator analysis for eligible studies. The author extracted data on the author, year, sample type and size, sample age, study design, country, whether published or not, and effect size. When data from different years were reported, the data from the latest year was included, so that it was more current. Moderator information recorded for each study included type of ACE, method for determining ACE, child or retrospective account, method for determining Autism, comparison group, population type, region, and sample gender. The second reviewer checked 20% of the data extraction (n=8) and there was 100% agreement.

Where multiple ACEs or composites of ACEs were reported, the results were extracted and pooled together using a meta-analysis software, Comprehensive Meta-Analysis (CMA; Borenstein et al., 2014). Odds Ratios were chosen to analyse the dichotomous main outcome because this measure was commonly used in eligible studies and is a useful measure of the likelihood of the occurrence of a health event among one group compared to another group. The Odds Ratio and 95% confidence intervals were extracted from the articles and when not reported, data that would enable this to be calculated was extracted. The following guideline was used to interpret the effect size: if the confidence interval includes an Odds Ratio of one, the result is not significant (Sandercock, 1989). Where relevant data was not reported, corresponding authors were contacted via email to request additional information, including primary data requests and unadjusted effect size requests. The author obtained the requested information for two out of fourteen requests. When these requests were not successful, the studies were excluded if unadjusted effect sizes could not be calculated, due to the difficulties comparing effect sizes adjusted for different covariates.

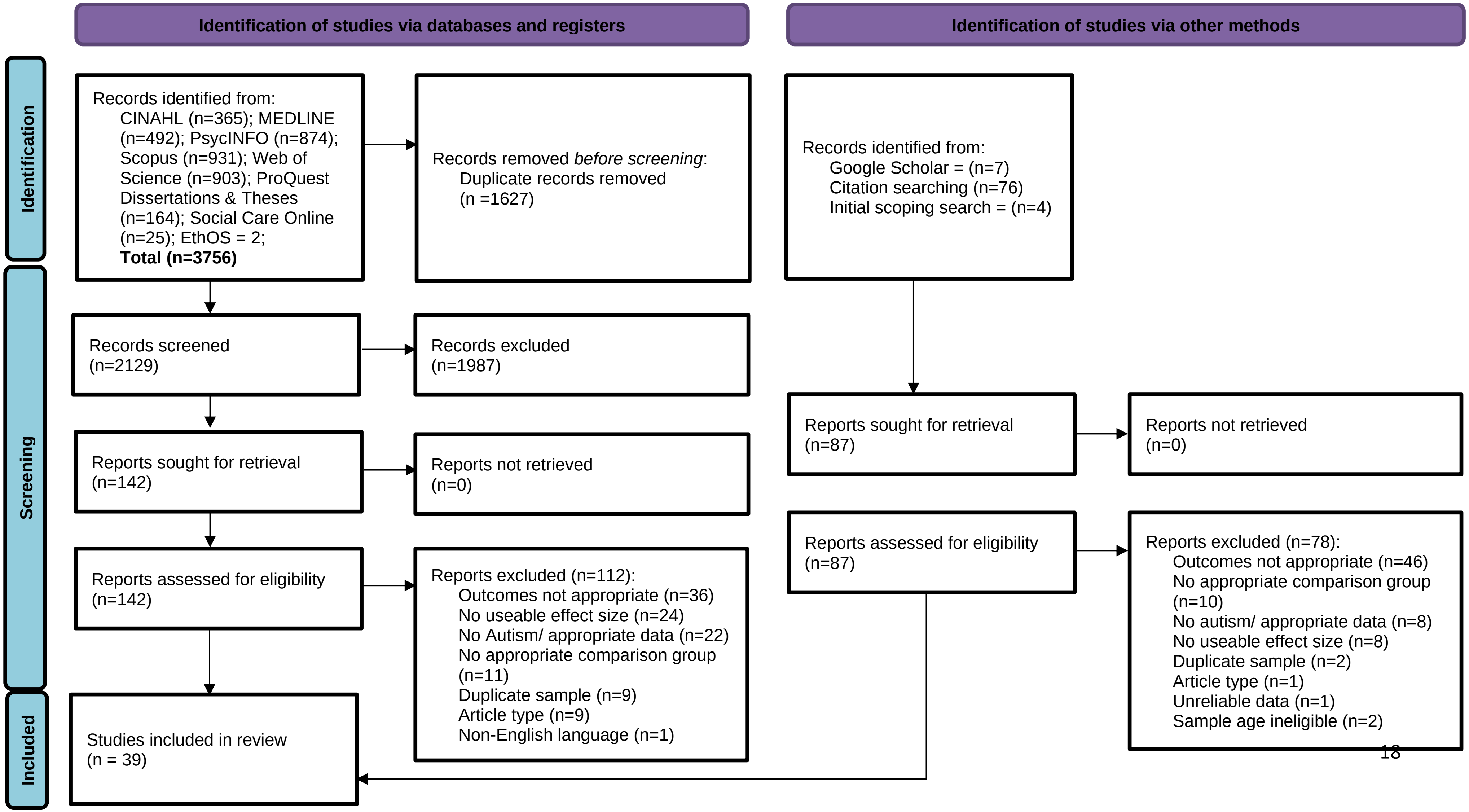
Study Risk of Bias Assessment

The Cochrane handbook and PRISMA 2020 guidelines suggest that in systematic reviews, the focus should be on risk of bias, rather than methodological quality (Higgins et al., 2022; Page et al., 2021b). Many tools have been criticised because of their content extending beyond study limitations that have the potential to bias findings (Page et al., 2021b). As suggested by Quintana (2015), a bespoke tool was developed integrating criteria suited to the meta-analysis. Items were selected from the Appraisal tool for Cross Sectional Studies (AXIS; Downes et al., 2016) and Joanne Briggs Checklists (for prevalence and cohort studies) that focused on risks of bias (Joanne Briggs Institute, 2020). Migliavacaa et al.’s (2020) summary of items applicable for the quality of prevalence studies was consulted to check that key risks of bias were included. The tool, assessing selection bias, bias in the measurement of outcomes, selective reporting bias, design flaws, and inappropriate influence of funders, can be found in Appendix E. The researcher used a sample of 85 people as a minimum threshold in response to the question about an adequate sample size, as recommended by Cohen (1992) to detect a medium effect size with an alpha of 0.05, an approach also used by Baird et al. (2021). The Cochrane handbook notes that it is impossible to know the extent of bias in a given study, therefore the ability to validate any proposed tool is limited (Higgins et al., 2022).

Studies were assessed by the researcher and a research assistant independently and discrepancies in judgement were resolved through discussion to reach a consensus. The use of scales and overall summary scores are discouraged (Higgins et al., 2022, Page et al., 2021b); therefore, overall judgements were determined using a criterion based on the Cochrane handbook and each item is presented to enable the reader to understand each component that are at risk of bias in each study (Higgins et al., 2022, Page et al., 2021b). Inter-rater agreement was calculated and assessed using Cohen’s Kappa coefficient (Cohen, 1992).

Figure 1.

PRISMA Flow Diagram for the Search Strategy (Page et al., 2021a)



Data Synthesis

An online calculator was used to calculate the Odds Ratios for studies that did not report Odds Ratios (MedCalc Software Ltd, 2022). The Odds Ratio and 95% confidence interval were calculated according to Altman (1991) where OR=(a/b)/(c/d) and 95%CI=exp(1n(OR)-1.96*SE{1n(OR}) to exp(1n(OR)+1.96*SE{1n(OR)}). A random effects model was selected to calculate the average effect size of the relationship between diagnosis of Autism and ACEs. All analyses were run using the CMA software by the main researcher (Borenstein et al., 2014). A forest plot was created to provide a graphical overview of the effect sizes and confidence intervals. The extent and impact of between-study heterogeneity in effect sizes were assessed using two statistical tests to determine whether moderator analyses were necessary. The Q-test was used to assess the degree of variability among the pool of effects sizes, with moderator analysis warranted if this was significant (Card, 2012). The I^2 test was used to estimate the proportion of variability present that was not due to sampling error within studies. The I^2 threshold of 25% variance reflected low variance, 50% reflected moderate variance and 75% reflected high variance (Higgins et al., 2003).

Moderator analyses assessed the potential causes of statistical heterogeneity. Planned subgroup analysis compared the type of ACE, method for determining Autism, and child or retrospective accounts. Socioeconomic status was unable to be included as a moderator as planned due to insufficient data reported by the studies included. Moderators which were not pre-specified included method for determining ACEs, comparison group type, and population type as these were unforeseen variations. Moderator analysis was only run if there was minimum of three studies per subgroup (Card, 2012). Moderator analyses were conducted using a mixed effects approach where subgroups were analysed with a random effects model to assess heterogeneity within each subgroup and analysed using a fixed effects model to assess heterogeneity between subgroups. Sample gender, expressed as percentage female, was assessed via random-effects meta-regression analysis. A meta-regression analysis was unable to assess sample age as planned due to less than 10 studies reporting overall sample age.

Post-hoc sensitivity meta-analyses were conducted which excluded studies participants over 18 years, and deviations from ACE type, for example the inclusion of discrimination.

Publication Bias

Although grey literature was included in this meta-analysis, there was still potential for bias due to missing results, therefore publication bias was assessed for using a funnel plot, trim-and-fill, Egger's regression test and the fail-safe *N* (Duval & Tweedie, 2000; Egger et al., 1997; Rosenthal, 1979). An asymmetrical funnel plot demonstrated the possibility of publication bias (Card, 2012). Duval and Tweedie's (2000) 'trim and fill' approach and Egger et al.'s (1997) regression test was used to test the potential presence of publication bias. The fail-safe *N* statistic provided an estimate of the number of studies with non-significant results ($p > .05$) required to threaten the conclusion of a significant association (Rosenthal, 1979). Rosenthal (1979) suggests an adequately high fail-safe *N* should be greater than 5k + 10, where k = the number of studies included. Using multiple tests reduces the risk of a Type 1 error (Card, 2012; Ferguson & Brannick, 2012).

Certainty Assessment

To determine confidence in the body of evidence that contributed to the meta-analyses, the researcher and research assistant jointly applied the Grading of Recommendations Assessment, Development and Evaluation approach (GRADE; Schünemann et al., 2013; Higgins et al., 2022). Disagreements between assessors were resolved through discussion. The GRADE approach specifies four levels of the certainty for a body of evidence for a given outcome: high, moderate, low, and very low. The five GRADE factors (study limitations, consistency of effect, indirectness, imprecision, and publication bias) were used to make an overall judgement of the level of certainty for the estimate of the effect across the studies. This involved rating the group of studies, rather than each study as a single unit. Decisions to down- or up- grade the certainty of studies and justifications are provided. Guidance for these decision rules were taken from the GRADE handbook and working group (Harder et al., 2015; Iorio et al., 2015; Schünemann et al., 2013).

Results

Study Characteristics

Key characteristics of each study can be found in Table 1. Of the 39 included studies identified for inclusion, 14 were conducted in North America, eight in Europe, seven in the United Kingdom, five in Australia and five in Asia. 29 studies were of current accounts of children, and ten studies were retrospective accounts from adults. 36 studies were published, and three studies were unpublished theses. 25 studies employed a cross-sectional design, five were case-control studies, three were longitudinal, two were cohort studies, two were record linkage studies and two were retrospective chart reviews. The publications years for the studies ranged from 2002 to 2021. The studies captured all ACEs described in the inclusion criteria apart from forced marriage.

Risk of Bias

A summary of the risk of bias for each of the included studies is presented in Table 2. In terms of overall risk of bias, there were concerns about risk of bias for the majority of studies (31), with five of these assessed as at high risk of bias. Two studies were assessed as low risk of bias and six were assessed as unclear risk of bias due to missing information being reported. Inter-rater agreement was substantial at 91.17% agreement (k = 0.765, 95% CI 0.691-0.839) (Cohen, 1992; Landis & Koch, 1977). Justifications for items which required discussion following a disagreement can be found in Appendix F.

Table 1

Study Characteristics

Authors and Year	Analysed *n*, Autistic Group *n*, and Comparison Group *n*	Sample Type	Study Design	Country	Sample Age	Sample Gender (%)	Method for Determining Autism	Type of ACE	Method for Determining ACEs
1. Bethell et al. (2014)	Analysed *n*=84448, Autistic *n*=1609, Comparison *n*=82839	National sample of noninstitutionalised children	Cross-sectional	US	0-17 years	Not reported	Reported by parent/ guardian	Poverty, divorce/ separation, parent/guardian death, domestic violence, victim/ witness violence, family member mental illness/ suicidal, family member substance misuse, discrimination (bullying)	Parent/ guardian report
2. Blake et al. (2012)	Analysed *n*=8860, Autistic *n*=968, Comparison *n*=7892	National sample of children in special education	Longitudinal	US	6-12 years	Not reported	Reported by school district	Being bullied	Parent/ guardian report
3. Campbell et al. (2017)	Analysed *n*=208, Autistic *n*=104, Comparison *n*=104	Typically developing students matched with autistic students	Case-control	Australia	12.69 years ± 1.42	12.50% female 87.50% male	Provided by a registered clinician	Being bullied: face to face and cyberbullying	Self-report questionnaire
4. Carr (2002)	Analysed *n*=3950708, Autistic *n*=7374, Comparison *n*=3943334	Special school student population	Cross-sectional	US	Not reported	Not reported	Identified by database from education agency	Poverty	Qualify for free/ reduced lunch
5. Christoffersen (2019)	Analysed *n*=678520, Autistic *n*=62419, Comparison *n*=616101	National birth cohorts of children (includes typically developing children and children with other disabilities)	Cohort	Denmark	7-18 years	Not reported	Diagnosed in psychiatric wards and provided by a register	Experiencing violence	Police records
6. Cohrs & Leslie (2017)	Analysed *n*=85,298, Autistic *n*=42,649, Comparison *n*=42,649	Data of reimbursed health care claims for employees, retirees, and their dependents. Autistic children	Cross-sectional	US	9.3 years ± 4.2	18.19% female 81.81% male	Identified by research database	Parental mental illness	Identified by research database

		matched to non-autistic children							
7. Eroglu & Kilic (2020)	Analysed *n*=91, Autistic *n*=45, Comparison *n*=46	Children referred to Child and Adolescent Psychiatry Department and general paediatrics outpatient clinics	Cross-sectional	Turkey	Autistic group 10.16 ± 2.82 years Comparison group 9.48 ± 2.18 years	21.98% female 78.02% male	Turkish Childhood Autism Rating Scale (Sucuoglu et al., 1996) applied by researcher	Being bullied	Olweus Peer Bullying Questionnaire for Students (Tipirdamaz Sipahi et al. 2008)
8. Fairthorne et al. (2016)	Analysed *n*=272947 Autistic *n*=1698 Comparison *n*=271249	Cohort of mothers in Western Australia. Autistic children with and without an intellectual disability compared to non-autistic children without an intellectual disability	Record linkage	Australia	Not reported	Not reported	Identified by a population-based database	Maternal mental illness, substance misuse	State-based registries
9. Fisher et al. (2019)	Analysed *n*=24,306 Autistic *n*=387 Comparison *n*=23,919	Children from the Tennessee Autism and Developmental Disability Monitoring surveillance area	Cross-sectional	US	All 10 years	48.79% female 51.21% male	Identified by Autism and Developmental Disability Monitoring network records	Physical violence, abuse, or neglect	Child protection system records
10. Gibbs et al. (2021)	Analysed *n*=294 Autistic *n*=245 Comparison *n*=49	Autistic adults from the Australian Longitudinal Study of Autism in Adulthood	Cross-sectional	Australia	Autistic group 43.85 ± 12.05 Comparison group 43.90 ± 12.42	62.59% female 30.27% male 7.14% other	Mixture of professional diagnosis and self-identified, all meeting the cut-off on the Autism Spectrum Quotient self-administered questionnaire	Sexual and physical violence	Childhood Traumatic Events Scale (Pennebaker & Susman, 1988)
11. Gotby et al. (2018)	Analysed *n*=4500 Autistic *n*= Not reported Comparison *n*= Not reported	Population-based study of all twins in Sweden	Longitudinal	Sweden	All 18 years	57.73% female 42.27% male	Autism –Tics, AD/HD and other Comorbidities inventory (Larson et al, 2010)	Sexual abuse	Self-reported via questionnaire
12. Greger et al. (2015)	Analysed *n*= 323 Autistic *n*= 75 Comparison *n*= 248	Adolescents from residential care units	Cross-sectional	Norway	Maltreatment group 17.0 ± 1.31 Non maltreatment group 16.5 ± 1.30	33.45% female 66.45% male	Identified via clinical interview	Physical violence, sexual abuse or/and witnessing violence	Interview with child with questions about ACEs

13. Griffiths et al. (2019)	Analysed *n*=694 Autistic *n*=426 Comparison *n*=268	Autistic population and general population interested in research	Cross sectional	UK	Autistic group 44 ± 14.37 Comparison group 51 ± 15.33	57.21% female 7.86% other 34.93% male	Provided by registered clinician	Being bullied, physical abuse, peer violence, sexual abuse, verbal abuse	Self-report Vulnerability Experiences Quotient – childhood victimization section (Griffiths et al., 2019)
14. Hebron (2012)	Analysed *n*=2164 Autistic *n*=134 Comparison *n*=2030	Children in mainstream schools, special schools and pupil referral units on the Special Educational Needs register	Cross-sectional	UK	Not reported	Not reported	Not reported	Being bullied	Parent reported via survey
15. Holmes et al. (2021)	Analysed *n*=267 Autistic *n*=75 Comparison *n*=192	Children who attended a community paediatric clinic	Retrospective chart review	Australia	0-15 years	30% female 70% male	Identified by medical notes and letters	Parental separation, domestic abuse, parental substance misuse, parental mental illness, parental incarceration	Identified by medical notes and letters
16. Hwang et al. (2017)	Analysed *n*=12480 Autistic *n*=160 Comparison *n*=12320	Children attending regular education elementary schools	Cross-sectional	South Korea	Autistic group 9.0 ± 1.6 Comparison group 9.3 ± 1.7	50.88% female 48.12% male	Korean Autism Diagnostic Observation Schedule and Autism Diagnostic Interview-Revised by registered clinicians (Kim et al. 2016; Kim et al. 2011)	Being bullied	Self-report item about being teased
17. Iglesias et al. (2019)	Analysed *n*=136 Autistic *n*=31 Comparison *n*=105	People with Asperger syndrome and a control group of young people with neurotypical development	Cross-sectional	Spain	Autistic group 15 ± 3.9 Comparison group 15 ± 3.1	49.26% female 50.74% male	Not reported	Being bullied	Cyber-victimisation Questionnaire for Adolescents (Álvarez-García et al., 2017)
18. Jahan et al. (2020)	Analysed *n*=351 Autistic *n*=139 Comparison *n*=212	Children attending ASD-specialised schools and typical schools	Cross-sectional	Bangladesh	4-15 years	39.32% female 60.68% male	ASD-specialised schools	Parent suicidal	Mothers answered questions on suicidal behaviours
19. Jokiranta et al. (2013)	Analysed *n*=23562 Autistic *n*=4713 Comparison *n*=18,849	Population-based study of autistic children matched to non-autistic children	Case-control	Finland	Not reported	Not reported	Identified from a hospital register	Parental mental illness	Hospital Register

20. Kloosterman et al. (2013)	Analysed *n*=48 Autistic *n*=24 Comparison *n*=24	Adolescent boys recruited through three secondary schools and various community organizations	Cross-sectional	Canada	14.76 ± 1.90	100% male	Autism diagnostic observation schedule-generic	Being bullied	Self-report via bullying/ victimization questionnaire
21. Kumagami & Matsuura (2009)	Analysed *n*=317 Autistic *n*=28 Comparison *n*=289	Family court juvenile cases	Cross-sectional	Japan	14-19 years (Mode 17 years)	Not reported	Provided by a child psychiatrist, except for cases previously diagnosed	Physical abuse, verbal abuse, neglect, parental substance misuse, witnessing domestic violence, household member mental illness or suicidal, parental separation/ no biological parents, household member incarceration	Adverse childhood experiences questionnaire (Felitti et al., 1998)
22. Mallory (2014)	Analysed *n*=111 Autistic *n*=47 Comparison *n*=64	Autistic children, other disabilities, and without a disability attending public, private and charter schools	Cross-sectional	US	12.17 ± 1.81	Not reported	Reported by parents and checked with Autism Spectrum Quotient-Adolescent Version (Baron-Cohen et al., 2006)	Peer violence and being bullied	Reported by caregivers via survey
23. Matthias et al. (2021)	Analysed *n*=7740 Autistic *n*=820 Comparison *n*=6920* *reported to nearest 10	Nationally representative students receiving special education services	Longitudinal	US	11–22 years (Autism 93.7% <18, comparison 97.7% <18)	32.29% female 67.71% male	Documented in school district records	Poverty	Qualify for Free School Meal
24. Montes & Halterman (2007)	Analysed *n*= 61772 Autistic *n*= 364 Comparison *n*= 61408	School-aged children from a nationwide, population based, survey	Cross-sectional	US	4-17 years	48.86% female 51.14% male	Reported by parent	Witness domestic violence, poverty	Self-report item and household income
25. Morgan et al. (2012)	Analysed *n*=6303 Autistic *n*=9 Comparison *n*=6294	Children born to mothers with and without psychiatric illness. Autism group with co-occurring intellectual disability	Record linkage	Australia	Not reported	47.44% female 52.56% male	Identified using the intellectual disability register	Maternal mental illness	Psychiatric case register

26. Morton (2021)	Analysed *n*=335 Autistic *n*=218 Comparison *n*=117	Autistic young people with and without ADHD compared with non-autistic young people.	Cross-sectional	US	11.62 ± 3.42	28.17% female 71.83% male	Reported by parent	Being bullied	Parent reported by Assessment of Bullying Experiences (Morton, 2021)
27. Mukherjee et al. (2019)	Analysed *n*=91 Autistic *n*=62 Comparison *n*=29	Patients with Fetal Alcohol Spectrum Disorder (FASD) diagnoses	Retrospective chart review	UK	6 - 26 years (78% aged 14 years or younger)	40% female 60% male	Clinical observation, interview and assessment and standardised questionnaires	Neglect	Self-report, adoption paperwork, and wider medical and social work records
28. Nowell et al. (2014)	Analysed *n*=142 Autistic *n*=74 Comparison *n*=68	Families with only one autistic child and typically developing siblings	Cross-sectional	US	Autistic group 9.6 ± 2.7 years Comparison group 9.7 ± 4.2 years	30.99% female 69.01% male	ADI-R and ADOS (Lord et al., 2000; Rutter et al., 2009)	Being bullied	Parent-reported via item on questionnaire
29. Paul et al. (2018)	Analysed *n*=92 Autistic *n*=39 Comparison *n*=53	Patients diagnosed at an Autism expert centre and control participants from private regular school institution	Cross-sectional	France	13.23 years ± 2.96 Comparison group 12.82 ± 2.49	15.22% female 84.78% male	ADI-R and ADOS-G (Lord et al., 1989, 1994)	Physical abuse, verbal abuse, neglect, family abduction, peer or sibling violence, being bullied, sexual abuse, witness domestic violence, conventional crime including violence, experiencing community and collective violence, murder of family member/ friend	Juvenile Victimization Questionnaire (Hamby et al., 2004)
30. Rowley et al. (2012)	Analysed *n*=4193 Autistic *n*=95 Comparison *n*=4113	Autistic children compared to IQ-matched group of non-autistic children with special educational needs	Cross-sectional	UK	11.43 ± 0.69	Not reported	Diagnostic assessment including ADOS-G and ADI-R (Lord et al., 1994, 2000).	Being bullied	Parent reported via item on questionnaire
31. Schrooten et al. (2018)	Analysed *n*=1003 Autistic *n*=260 Comparison *n*=7430	Autistic adolescents and typically developing adolescents	Cross-sectional	The Netherlands	Autistic group 13.75 ± 1.42 Comparison group 13.41 ± 1.24	39.78% female 60.22% male	Diagnoses by registered clinicians	Being bullied	Peer reported via item on questionnaire

32. Spencer et al. (2005)	Analysed *n*=119729 Autistic *n*= Not reported Comparison *n*= Not reported	Whole-population birth cohort	Cohort	UK	All 19 years	Not reported	Records using information from health care and education professionals	Physical abuse	Child-protection register
33. Sullivan et al. (2012)	Analysed *n*=54826 Autistic *n*=4982 Comparison *n*=49 844	Autistic children with and without intellectual disability, compared with matched non-autistic children	Case-control	Sweden	0-17 years	27.1% female 72.9% male	Health services registers	Parental mental health	Health services registers
34. Takara & Kondo (2014)	Analysed *n*=430 Autistic *n*=70 Comparison *n*=360	Depressed adult outpatients	Case-control	Japan	40.4 ± 14.7	39.07% female 60.93% male	Japanese version of Autism Spectrum Quotient (Kurita et al., 2005) and an expert interview	Being bullied	Self-reported via item on questionnaire
35. Totsika et al. (2011)	Analysed *n*=14526 Autistic *n*=82 Comparison *n*=14444	Population-representative Sample of 5-year-old autistic and non-autistic children	Cross-sectional	UK	All 5 years	19.13% female 80.87% male	Reported by caregiver	Poverty, maternal mental illness	Household income and General Health Questionnaire (GHQ-12; Goldberg & Williams, 1988)
36. Twyman et al. (2010)	Analysed *n*=105 Autistic *n*=32 Comparison *n*=73	Patients at a primary care or subspecialty paediatric clinic	Cross-sectional	US	Autistic group 11.0 Comparison group 13.1	46.67% female 53.33% male	Extracted from medical records	Being bullied	Reynolds' Bully-Victimization Scale (Reynolds, 2003)
37. Wainscot et al (2008)	Analysed *n*=57 Autistic *n*=30 Comparison *n*=27	Mainstream secondary school pupils with Asperger's syndrome and matched controls	Case-control	UK	11-18 years	3.51% female 96.49% male	Reported by SENCOs	Being bullied	Self-reported via item on questionnaire
38. Weiss & Fardella (2018)	Analysed *n*=87 Autistic *n*=45 Comparison *n*=42	Autistic adults compared to a non-autistic matched sample	Cross-sectional	Canada	Autistic group 30.00 ± 1.48 Comparison group 32.12 ± 8.62	54.02% female 45.98% male	Self-report and met the clinical cut-off on the ADOS-2 Module 4 (Lord et al., 2012)	Physical abuse, verbal abuse, neglect, family abduction, peer or sibling violence, being bullied, sexual abuse, witness domestic violence, witnessing and experiencing	Juvenile Victimization Questionnaire (Hamby et al., 2004)

								community and collective violence	
39. Zarei et al. (2021)	Analysed *n*=129309 Autistic *n*=3515 Comparison *n*=125794	A nationwide, population based, survey	Cross-sectional	US	0–17 years	Not reported	Reported by parent/ carer	Parental incarceration, family violence, household mental illness, household substance misuse, parental divorce/ separation, parental death, poverty	Reported by parents/ guardians or an adult in the household via questionnaire

Note. Where available, mean age and standard deviation have been reported.

Table 2

Risk of bias

Authors (Date)	Population	Selection	Sample Size	Autism Measure	ACEs Measure	Statistical Analysis	Results Reported	Funding Sources	Limitations	Risk-of-Bias Judgement
1. Bethell et al. (2014)	1	1	1	0	1	1	1	1	1	Some concerns
2. Blake et al. (2012)	1	1	1	?	0	1	1	1	1	Some concerns
3. Campbell et al. (2017)	1	0.5	1	1	1	1	1	1	1	Some concerns
4. Carr (2002)	1	1	1	?	1	1	1	1	1	Unclear risk of bias
5. Christoffersen (2019)	1	1	1	1	1	1	0	1	1	Some concerns
6. Cohrs & Leslie (2017)	0	0	1	0.5	0.5	1	1	1	1	Some concerns
7. Eroglu & Kilic (2020)	?	?	1	1	1	1	1	1	1	Unclear risk of bias
8. Fairthorne et al. (2016)	1	1	1	?	0.5	1	1	1	1	Some concerns
9. Fisher et al. (2019)	1	1	1	1	1	1	1	1	1	Low risk of bias
10. Gibbs et al. (2021)	?	?	1	1	1	1	1	1	1	Unclear risk of bias
11. Gotby et al. (2018)	1	1	1	0.5	0	1	1	1	1	Some concerns
12. Greger et al. (2015)	1	0	1	1	1	1	1	1	1	Some concerns
13. Griffiths et al. (2019)	0	0	1	1	0.5	1	1	1	1	Some concerns
14. Hebron (2012)	1	0	1	?	1	1	1	1	1	Some concerns
15. Holmes et al. (2021)	1	1	1	?	1	1	1	1	1	Unclear risk of bias
16. Hwang et al. (2017)	1	0	1	1	0	1	1	0	1	Some concerns
17. Iglesias et al. (2019)	0	0	1	?	1	1	0	1	1	High risk of bias
18. Jahan et al. (2020)	0	?	1	?	1	1	1	1	1	Some concerns

19. Jokiranta et al. (2013)	1	1	1	1	0.5	1	1	1	1	Some concerns
20. Kloosterman et al. (2013)	0	?	0	1	0	1	1	1	1	High risk of bias
21. Kumagami & Matsuura (2009)	?	?	1	1	?	1	1	1	1	Unclear risk of bias
22. Mallory (2014)	0	0	0	1	0	1	1	1	1	High risk of bias
23. Matthias et al. (2021)	1	1	1	?	0	1	1	1	1	Some concerns
24. Montes & Halterman (2007)	?	?	1	0	0	1	0	1	1	High risk of bias
25. Morgan et al. (2012)	1	1	1	0	1	1	1	1	1	Some concerns
26. Morton (2021)	1	0	1	0.5	1	1	0	1	1	Some concerns
27. Mukherjee et al. (2019)	0	0	1	1	1	1	1	1	1	Some concerns
28. Nowell et al. (2014)	0	0	1	1	0	1	1	1	1	Some concerns
29. Paul et al. (2018)	0	1	1	1	1	1	0	1	1	Some concerns
30. Rowley et al. (2012)	1	?	1	1	0	1	1	1	1	Some concerns
31. Schrooten et al. (2018)	1	?	1	1	1	1	1	1	1	Unclear risk of bias
32. Spencer et al. (2005)	1	1	1	1	1	1	1	1	1	Low risk of bias
33. Sullivan et al. (2012)	1	1	1	0.5	1	1	1	1	1	Some concerns
34. Takara & Kondo (2014)	1	1	1	1	0	1	1	1	1	Some concerns
35. Totsika et al. (2011)	1	1	1	1	1	1	1	1	0	Some concerns
36. Twyman et al. (2010)	1	0	1	1	1	1	0	1	1	Some concerns
37. Wainscot et al (2008)	1	0	0	?	0	1	1	1	1	High risk of bias
38. Weiss & Fardella (2018)	0	0	1	1	0	1	1	1	1	Some concerns
39. Zarei et al. (2021)	1	1	1	0	0	1	1	1	1	Some concerns

Meta-Analysis Results

Table 3 presents the results for the meta-analyses for Autism and ACEs. The data analysed from the 39 studies included a pooled total sample of 5,619,342 participants. 15 studies reported unadjusted ORs, 22 studies provided sufficient raw data to calculate ORs, one author provided unadjusted ORs via email and one author provided sufficient raw data via email. A total of 92 effect sizes were extracted or calculated and condensed to 39 (one per study). A table of individual extracted effect sizes which were pooled can be found in Appendix G. The meta-analysis of the unadjusted effects revealed a significant ($p < .001$) association between being autistic and experiencing at least one ACE, OR 2.07 (CI 1.57-2.73); moderate certainty evidence. Figure 2 displays a forest plot to visually display the results of each study and a summary estimate. The test of heterogeneity of the effects sizes was significant Q(38) = 2821.064, $p < .001$, $I^2 = 98.653$. The I^2 value was above the 75% threshold, suggesting high between-study heterogeneity. Therefore, moderator analyses were conducted to probe the source of heterogeneity.

Table 3

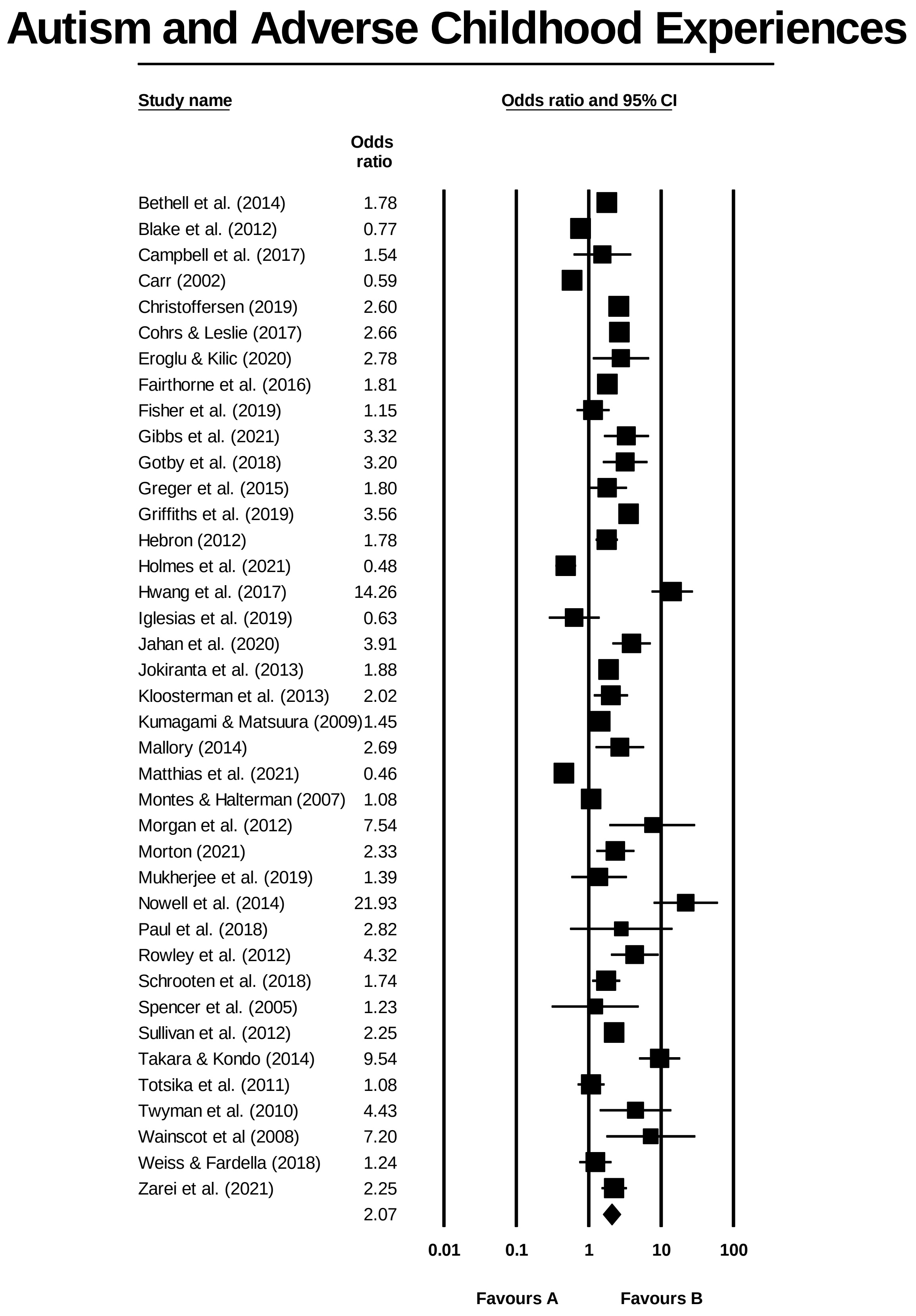
Meta-Analysed Effect Sizes

Study	Analysed *N*	ACEs measured (n)	Final/ pooled OR	95% CI
1. Bethell et al. (2014)	84448	≥1	1.78	1.61-1.97
2. Blake et al. (2012)	8860	1	0.77	0.70-0.85
3. Campbell et al. (2017)	208	1	1.54	0.62-3.86
4. Carr (2002)	3950708	1	0.59	0.56-0.62
5. Christoffersen (2019)	678520	1	2.60	2.50-2.70
6. Cohrs & Leslie (2017)	153262	1	2.66	2.19-3.23
7. Eroglu & Kilic (2020)	91	1	2.78	1.14-6.82

8. Fairthorne et al. (2016)	272947	1	1.81	1.42-2.31
9. Fisher et al. (2019)	24306	>1	1.15	0.68–1.95
10. Gibbs et al. (2021)	294	>1	3.32	1.62-6.79
11. Gotby et al. (2018)	323	≥1	3.20	1.57-6.51
12. Greger et al. (2015)	694	>1	1.80	0.96-3.37
13. Griffiths et al. (2019)	2164	1	3.56	2.72-4.66
14. Hebron (2012)	267	>1	1.78	1.25 - 2.53
15. Holmes et al. (2021)	12480	1	0.48	0.35-0.67
16. Hwang et al. (2017)	136	1	14.26	7.36-27.63
17. Iglesias et al. (2019)	351	1	0.63	0.28-1.41
18. Jahan et al. (2020)	23562	1	3.91	2.12-7.21
19. Jokiranta et al. (2013)	48	1	1.88	1.49-2.37
20. Kloosterman et al. (2013)	317	>1	2.02	1.17-3.49
21. Kumagami & Matsuura (2009)	111	1	1.45	1.07-1.95
22. Mallory (2014)	7740	1	2.69	1.24-5.83
23. Matthias et al. (2021)	61772	>1	0.46	0.39-0.53
24. Montes & Halterman (2007)	6303	1	1.08	0.89-1.32
25. Morgan et al. (2012)	335	1	7.54	1.92-29.58
26. Morton (2021)	91	1	2.33	1.27- 4.27
27. Mukherjee et al. (2019)	142	1	1.39	0.57 to 3.36
28. Nowell et al. (2014)	4500	1	21.93	7.86-61.20
29. Paul et al. (2018)	92	>1	2.82	0.55-14.37
30. Rowley et al. (2012)	4198	1	4.32	2.02-9.23
31. Schrooten et al. (2018)	1003	1	1.74	1.11-2.73
32. Spencer et al. (2005)	119729	1	1.23	0.31-4.96
33. Sullivan et al. (2012)	54826	1	2.25	1.68-3.00
34. Takara & Kondo (2014)	430	1	9.54	4.95-18.37
35. Totsika et al. (2011)	14526	>1	1.08	0.70-1.66
36. Twyman et al. (2010)	105	1	4.43	1.42–13.86
37. Wainscot et al (2008)	57	1	7.20	1.75-29.61
38. Weiss & Fardella (2018)	87	>1	1.24	0.74-2.07
39. Zarei et al. (2021)	129309	≥1	2.25	1.50-3.37

Figure 1

Forest Plot of *Meta-Analysed Effect Size*



Moderator Analysis

Table 4 shows the results of the planned moderator analysis. Subgroup analysis found that the effects obtained from studies that looked at different types of ACEs were significantly different in magnitude. Subgroup analysis revealed the effects garnered from studies gathering data from a child sample and adults reporting on ACEs retrospectively were not significantly different. In addition, subgroup analyses revealed there was no significant difference between effect sizes depending on the method for determining Autism. A list of studies contributing to each subgroup can be found in Appendix H.

12 studies did not report on the sample gender and therefore could not be included in the meta-regression. For the remaining 27 studies, the meta-regression for gender was non-significant, indicating the association between being having Autism and experiencing one or more ACE does not vary as a function of gender (b=0.36 [-2.02 - 2.75], Q_{model} (1) = 0.09, p=0.76, $Q_{residual}$ (25) = 521.67, $p < .001$). A scatterplot with the study effect estimates plotted against sample gender is presented in Figure 2.

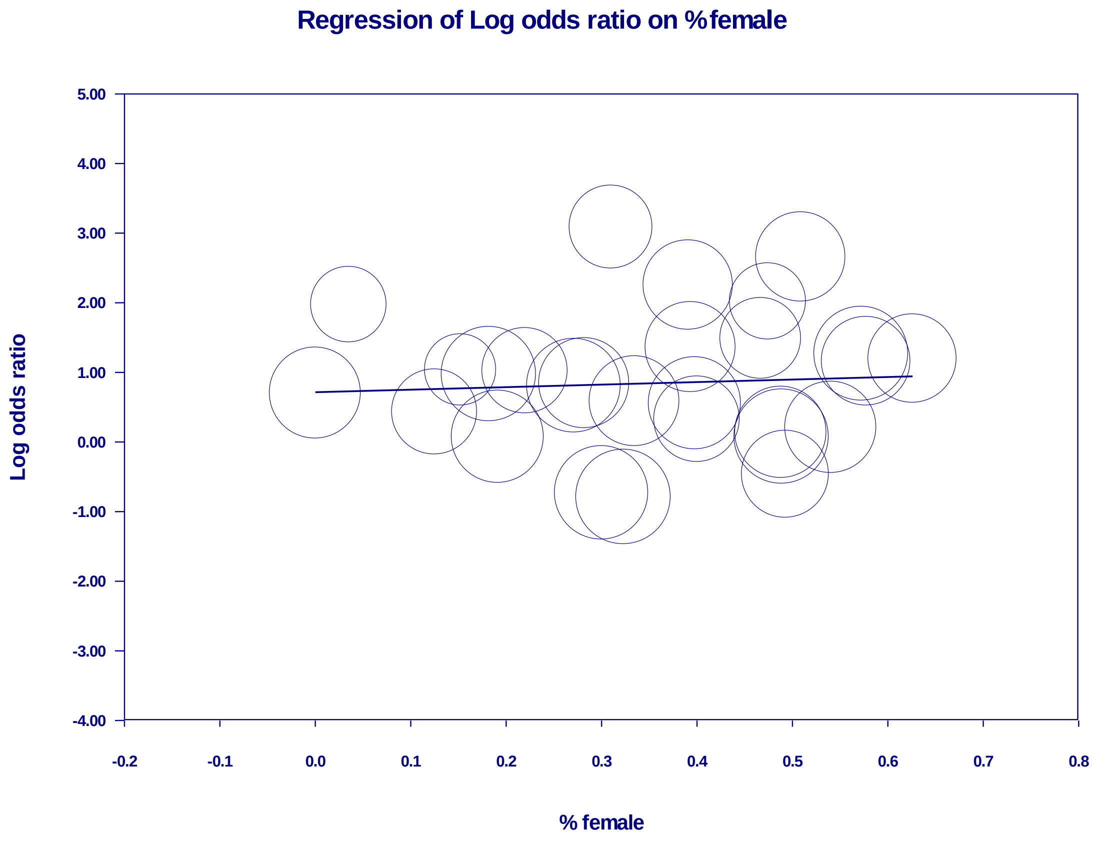
Table 4

Planned Moderator Analyses

Moderator	Subgroups	k	OR	95% CI	Cochrane's Q
Type of ACE	Bullying/ peer violence	15	3.04	1.76-5.27	Q(3) 10.332, *p* = .016
	Abuse, violence, or neglect	7	2.07	1.49-2.87	
	Parental mental health	5	2.49	1.94-3.20	
	Other/ mixed	12	1.22	0.82-1.84	
Child or retrospective adult account	Child	29	1.98	1.51-2.60	Q(1) 0.109, *p* = .741
	Retrospective	10	2.14	1.49-3.07	
Method for determining Autism	Assessment tool	13	3.56	2.18-5.78	Q(5) 9.320, *p* = 0.970
	Clinician	4	2.00	1.17-3.41	
	Documents	12	1.59	0.93-2.71	
	School	3	2.17	0.35-13.58	
	Self/parent	5	1.56	1.14-2.14	

Figure 2

Scatterplot of Meta-Regression for Gender



Supplemental Analysis

To further understand the sources of heterogeneity across the samples, additional unplanned moderator analyses were conducted (see Table 5). Subgroup analysis for method for determining ACE was non-significant. Subgroup analysis found that the effects obtained from studies that had different types of comparison groups were significantly different in magnitude. Studies that looked at the general population differed significantly in effect sizes from studies that looked at special populations, including special education needs, Fetal Alcohol Syndrome, paediatric clinics, residential care, court cases and depressed adults. Subgroups of the location of the studies found no significant difference in effect sizes.

Table 5

Unplanned moderator analyses

Moderator	Subgroups	k	OR	95% CI	Q
Method for determining ACE	Self	17	2.50	1.71-3.68	Q(2) 2.607, *p* = 0.272
	Parent/peer	11	2.24	1.52-3.31	
	Documents	11	1.41	0.78-2.54	
Comparison group	General population	18	2.16	1.78-2.62	Q(4) 25.425, *p* <.001
	Typical developing	6	2.63	1.21-5.72	
	Disabilities	6	0.91	0.68-1.23	
	Mixed	6	2.19	0.92-5.22	
	Other	3	2.85	0.96-8.45	
Special population	Yes	14	1.53	1.13-2.06	Q(1) 4.168, *p* = 0.041
	No	25	2.20	1.84-2.63	
Region	North America	14	1.60	1.12-2.26	Q(4) 4.675, *p* = 0.322
	Europe	8	2.04	1.62-2.56	
	UK	7	2.22	1.35-3.63	
	Asia	5	4.84	1.75-12.03	
	Australia	5	1.81	0.78-4.19	

Sensitivity Analysis

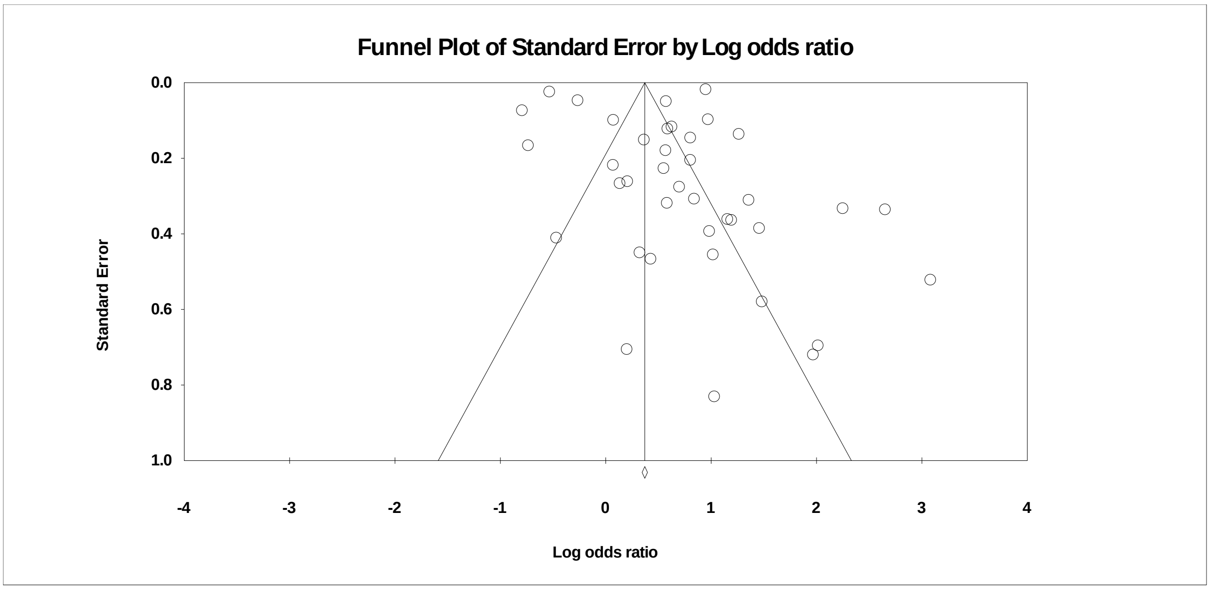
Studies that included participants over 18 years old were removed for analysis (Kumagami & Matsuura, 2009; Matthias et al., 2021; Mukherjee et al., 2019). After removing these studies, the average effect size was similar (OR 2.22 [1.67-2.95). There was still considerable heterogeneity across studies (1^2=98.64; Q(35)=2576.94, *p* <.001). Three studies included in the overall analyses measured some ACEs that covered a wider range of ACEs, namely discrimination, family abduction and convention crime (Bethell et al., 2014; Paul et al., 2018; Weiss & Fardella, 2018). After removal of these studies, there was only a minimal difference in the effect size found (OR 2.11 [1.56-2.86], $1^{2=}$ 98.75; Q(35)=2802.27, *p* <.001). Finally, due to the debate about poverty being an ACE, it was decided to run the analyses excluding studies which included poverty as a measure (Bethell et al., 2014; Carr, 2002; Matthias et al., 2021, Montes & Halterman, 2007; Totsika et al., 2011; Zarei et al., 2021). After removing these studies the OR was 2.36 [1.83-3.03], 1^2 95.74, Q(32) = 751.56, *p* <.001. Overall, these results indicate the findings from the main meta-analyses were robust to slight variations to sample age and ACE types.

Publication Bias Tests

The funnel plot was somewhat asymmetrical (Figure 3). There was a lack of studies in both the bottom left and right quadrants, with most studies on both sides having higher precision. The distribution of the studies to the far right of the mean effect, representing large effect sizes, suggests there may be some studies with large negative effect sizes that have not been included in this analysis. The trim and fill test resulted in 9 studies being trimmed and a smaller value for the imputed effects, yet still significant (OR 1.52 [1.18-1.96]). One possible explanation for this set of results is publication bias, although other possible sources are poor methodological quality leading to spuriously inflated effects in smaller studies and heterogeneity (Egger 1997; Sterne, 2011). In contrast, Egger's test of the intercept was non-significant, *b*0 = 0.86 [-2.63-4.36], t(37)=0.50, *p*=0.62, suggesting no evidence of publication bias. Moreover, the fail-safe *N* analysis found that an additional 4085 studies would need to be included in the meta-analysis to increase the *p* value above 0.05. This was well above the threshold value of 205, using methods described by Rosenthal (1979). It must be noted that there are statistical problems using standard-error-based funnel plots and tests for funnel plot asymmetry when effects are expressed as Odds Ratios, which can result in false-positive results (Deeks, 1998).

Figure 3

Funnel plot of the distribution of studies



Certainty of Evidence Assessment

The overall level of certainty in the body of evidence was rated as moderate. Explanations for each judgement are provided in Table 6.

Table 6

GRADE Assessment

Factor	Decision	Reasons
Study design	Start at high quality	The GRADE working group suggest community based or population based observational studies with evidence from active and passive surveillance would enter as high quality (Harder et al., 2015; Iorio et al., 2015).
Limitations in study design or execution (risk of bias)	↓ 1 level Moderate	There was some risk of bias across most studies regarding sampling bias, bias in measures or selective reporting bias.
Inconsistency of results	Remain at moderate	A large I^2 statistic suggested high levels of between-study heterogeneity. However, moderator analyses provided clinical differences and methodological differences between studies as plausible explanations.
Indirectness of evidence	Remain at moderate	The findings were applicable as the study populations were similar to the target population and the outcomes of interest were measured directly.
Imprecision	Remain at moderate	Total number of patients in the review is very large and the 95% CI excludes no effect.
Publication bias	Remain at moderate	Three unpublished studies were included in the analysis. The results from publication bias tests were mixed and should be interpreted with caution due to false-positives when used with Odds Ratios.

Discussion

The aim of this meta-analysis was to examine the relationship between being autistic and experiencing an ACE, compared to a non-autistic population. This study is the first meta-analysis to summarise the association between having an Autism diagnosis and experiencing an ACE. The findings supported the hypothesis that autistic people would be more likely to experience an ACE than non-autistic people. The strong association between Autism and ACEs indicated the odds of an autistic person experiencing at least one ACE is more than twice as likely than a non-autistic person. There was significant heterogeneity across studies, which was expected as the context, outcomes and methodology varied. Significant differences in the magnitude of effect sizes were found across studies with regards to the types of ACE studied, comparison groups, and population types. A meta-regression indicated that the association does not vary according to sample gender.

The overall finding that an autistic person is at greater risk of experiencing an ACE than a non-autistic person extends existing research that disabled children are more likely to experience maltreatment and abuse (Fisher et al. 2008; Horner-Johnson & Drum 2006; Jaudes & Mackey-Bilaver 2008; Jones et al., 2012; Kelly, 1992; Paul & Cawson, 2002; Stalker et al., 2012; Sullivan & Knutson, 2000; Svensson et al., 2013; Turner et al. 2011; Westcott & Jones 1999). Potential factors suggested to increase disabled children’s vulnerability to abuse are problems in communication, the greater use of residential care, and amplified unequal power relationships (Westcott, 1993). Being perceived as “different” and social isolation has been noted as vulnerabilities to being bullied in autistic children (Humphrey & Hebron, 2015). Moreover, child behaviour problems and parenting stress have also been identified as contributing to increased risk of abuse (Mash & Johnston 1990; Whipple 1991; Rodriguez & Green 1997). Research has found that parents of autistic children experience challenging behaviour, judgements from others, high levels of stress and receive a lack of support for parental needs (Ludlow et al., 2012; Plumb, 2011; Selimoglu et al. 2013). Furthermore, low levels of support are strong predictors of depression and anxiety in mothers of autistic children (Boyd, 2002). An alternative explanation is that autistic children are more likely to be seen by professionals and have more opportunity to be identified as experiencing ACEs or children experiencing ACEs are more likely to be seen by services and referred for an Autism assessment when it otherwise is missed.

An important finding from the subgroup analyses was the strong associations found among studies investigating bullying and parental mental health. This is consistent with previous meta-analyses by Maiano et al. (2016), Park (2020) and Schnabel (2020), which found autistic individuals are at significantly higher risk of bullying and parents with mental health difficulties than typically developing children and the general population. The Odds Ratio for the abuse, violence and neglect category also suggested autistic individuals were at a significantly greater risk than non-autistic individuals. The mixed category showed a smaller effect size with a confidence interval including one, therefore was not significant. One possible explanation for this is the inclusion of poverty in the mixed category. The effect sizes for studies investigating poverty or poverty with one other variable were all negative effect sizes or close to one, suggesting that autistic children are not more likely to be in poverty than non-autistic children. This may be explained by research that has found either Autism rates are lower for children of lower socioeconomic status or found no relationship (Baird et al., 2006; Bakian et al., 2015; Durkin et al., 2010;

Fountain et al., 2011; Larsson et al., 2005; Sun et al., 2014; Thomas et al., 2011). Moreover, children from poorer households have been found to receive Autism diagnoses later than their peers (Daniels & Mandell, 2014; Fountain et al., 2011; Kerns et al., 2017). However, Rai et al. (2012) found lower socioeconomic status was associated with an increased risk of autism.

Subgroup analysis found that studies that compared an autistic sample to samples from special populations, such as special education needs, paediatric clinics, residential care, court cases and adults with depression found a smaller difference than when compared to the general population. Moreover, when studies used comparison groups of children with other disabilities, the effect size was not significant, suggesting they are equally likely to experience ACEs.

Limitations and Strengths

There are several potential limitations and strengths to consider when interpreting the findings of this meta-analysis. In terms of the studies included many of the studies had large sample sizes and several studies were population-based samples. The variety of populations included in the analyses increases the confidence in generalising to other samples. The forest plot suggested high levels of precision among the studies and the overall effect had a confidence interval which excludes no effect. The risk of bias and certainty of evidence assessments were conducted with two people, therefore increasing the confidence in these ratings.

However, the breadth of the definition of ACEs meant that each ACE could not be specified in the search terms. Although a range of search terms were used, it is possible some studies may have not been identified. The search was restricted to English language, therefore publications in other languages might have been missed. Only 10% of full texts were dually screened, 20% of data extraction was checked by another person and one researcher calculated the Odds Ratios from reported data which may have introduced risk of errors.

Difficulties in gathering information on ACEs, for example issues around disclosure, could mean that the association is inaccurate. Studies have found that there may be more reluctance to disclose the abuse of disabled children compared to non-disabled children, therefore the effect size could be underestimated (Tharinger et al., 1990; Kvam, 2000).

Implications for Practice, Policy and Research

These results have some implications for clinical practice and policy. Preventative measures, such as adequate support for parents and carers and anti-bullying strategies, are vital for reducing the likelihood of autistic children experiencing ACEs. Education, health, and social care professionals should be aware of autistic individuals' greater risk of experiencing ACEs. It is important that assessment and identification of ACEs in autistic children is embedded into practice to ensure the individuals and families receive the appropriate support. One such way would be through Autism diagnostic services. Previous research has identified that a lack of training, specialised assessment tools, and time are all barriers to implementing comprehensive trauma assessment practices in Autism diagnostic services (Ahlers, 2019).

Moreover, it can be difficult to differentiate between Autism and trauma symptoms, and NICE guidelines (2012) note that attachment disorders may be differential diagnoses. Morgan (2012) introduced a detailed criteria to help clinicians identify between the two groups and assist in differential diagnosis, to avoid inappropriate diagnosis. Morgan (2012) notes that a very small number of children will have both autism and attachment problems. The current study brings to light the likelihood of having both. Therefore, clinicians should be cautious of excluding the potential of a child having both an Autism diagnosis and ACEs.

Specialised, reliable, and validated tools are essential for improving the identification of ACEs in autistic children. An assessment tool designed to assess self-reported trauma exposure and symptoms in autistic children has been developed (Hoover, 2019). Tools like this may provide an alternative way of gathering data.

Trauma-informed practice, which recognises the wide impact of trauma and aims to prevent the re-traumatisation of service users, will be important to consider when working with both autistic children and adults. Tools such as the Trauma-Informed Care and Practice Organisational Toolkit (TICPOT) and Trauma and ACE (TrACE) Informed Organisations Toolkit may be useful tools to assess current practice and guide changes (ACE Aware Wales, 2021; Mental Health Coordinating Council., et al. 2018). Furthermore, an evidence-based therapy to support autistic individuals who have experienced ACEs and trauma is much needed.

There are some areas identified from this meta-analysis that would benefit from further research. Continued investigation into the prevalence of different types of ACEs in autistic children is needed across different populations and regions. A greater number of studies on individual ACEs would enable more specific estimates to be generated. A review of existing literature on the association between socioeconomic status and Autism would be useful to clarify the strength and direction of association. Finally, evidence suggests a graded dose-response relationship between ACEs and negative health and well-being outcomes (Felitti et al., 1998). This meta-analysis explored the risk of experiencing one or more ACEs, therefore does not measure multiple ACEs. Further research into the number of ACEs experienced by autistic children would be valuable.

Conclusions

To conclude, the current meta-analysis of 39 studies, with 5,619,342 participants in total, found the odds of an autistic person experiencing at least one ACE is more than twice as likely than a non-autistic person. Significant differences in the magnitude of effect sizes were found across studies with regards to the types of ACE studied, comparison groups and population types. There was some risk of bias across the studies, however overall level of certainty in the body of evidence was rated as moderate using the GRADE approach. Recognition among professionals of the increased likelihood of autistic individuals experiencing an ACE is essential for ensuring autistic individuals are better protected and receive appropriate support.

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Appendices

Appendix A

PRISMA 2020 for Abstracts Checklist and PRISMA 2020 Checklist

PRISMA 2020 Abstract Checklist

Section and Topic	Item	Checklist item	Reported
TITLE			
Title	1	Identify the report as a systematic review.	Yes
BACKGROUND			
Objectives	2	Provide an explicit statement of the main objective(s) or question(s) the review addresses.	Yes
METHODS			
Eligibility criteria	3	Specify the inclusion and exclusion criteria for the review.	Yes
Information sources	4	Specify the information sources (e.g. databases, registers) used to identify studies and the date when each was last searched.	Yes
Risk of bias	5	Specify the methods used to assess risk of bias in the included studies.	Yes
Synthesis of results	6	Specify the methods used to present and synthesise results.	Yes
RESULTS			
Included studies	7	Give the total number of included studies and participants and summarise relevant characteristics of studies.	Yes
Synthesis of results	8	Present results for main outcomes, preferably indicating the number of included studies and participants for each. If meta-analysis was done, report the summary estimate and confidence/credible interval. If comparing groups, indicate the direction of the effect (i.e. which group is favoured).	Yes
DISCUSSION			
Limitations of evidence	9	Provide a brief summary of the limitations of the evidence included in the review (e.g. study risk of bias, inconsistency and imprecision).	Yes
Interpretation	10	Provide a general interpretation of the results and important implications.	Yes
OTHER			
Funding	11	Specify the primary source of funding for the review.	Yes
Registration	12	Provide the register name and registration number.	Yes

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Page 1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Page 2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Page 6
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 6-8
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Page 11-14
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Page 10
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Appendix C
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Page 14
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Page 15
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Page 15-16
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Page 15

Section and Topic	Item #	Checklist item	Location where item is reported
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Page 16-17
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	Page 15
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	N/A
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Page 19
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Page 19
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Page 19
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	Page 19-20
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	Page 20
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	Page 20
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	Page 21
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Page 14 & 18
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Appendix D
Study characteristics	17	Cite each included study and present its characteristics.	Page 23-29
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Page 30-31

Section and Topic	Item #	Checklist item	Location where item is reported
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Page 33 & 34
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Page 22
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	Page 32
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	Page 35-37
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	Page 38
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	Page 38-39
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Page 39-40
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Page 41-44
	23b	Discuss any limitations of the evidence included in the review.	Page 44-45
	23c	Discuss any limitations of the review processes used.	Page 44-45
	23d	Discuss implications of the results for practice, policy, and future research.	Page 45-46
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Page 10
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Page 10
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Page 19-20

Section and Topic	Item #	Checklist item	Location where item is reported
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Page 10
Competing interests	26	Declare any competing interests of review authors.	Page 10
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

Appendix B

Database Dates of Coverage

Database	Coverage
Ovid	
MEDLINE	1946 to present
PsychINFO	1806 to present
EBSCO	
CINAHL	1937 to present
Scopus	1788 to present
Web of Science	1900 to present
ProQuest Dissertations & Theses Global	1637 to present
Social Care Online	1980s to present
E-Theses Online Service (EThOS)	1787 to present

Appendix C

Full Search Strategy

Database	**Search Strategy**
CINAHL via EBSCO (no field selected)	autis* OR asperger* OR “pervasive developmental disorder*” AND “adverse childhood experience*” OR “adverse childhood event*” OR "child* trauma" OR “child* adversit*” OR “early adversit*” OR “early-life adversit*” OR “early life adversit*” OR "child* maltreatment” OR “forced marriage” OR “parental death” OR “community violence” OR “collective violence” OR war OR “peer violence” OR bullying OR bullied OR “domestic abuse” OR “domestic violence” OR poverty
MEDLINE via OVID - Title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word	exp Autism Spectrum Disorders/ or autis* OR asperger* OR “pervasive developmental disorder*” AND exp Childhood Adversity/ or exp Child Abuse/ or “adverse childhood experience*” OR “adverse childhood event*” OR "child* trauma" OR “child* adversit*” OR “early adversit*” OR “early-life adversit*” OR “early life adversit*” OR exp Child Neglect/ or “child* maltreatment” OR “forced marriage” OR “parental death” or exp Parental Death/ OR exp Exposure to Violence/ or “community violence” OR “collective violence” OR war or exp War/ OR “peer violence” OR bullying OR bullied or exp Bullying/ OR

	“domestic abuse” OR “domestic violence” OR Domestic Violence/ OR poverty or exp Poverty/
PscyINFO via OVID - Title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word	exp Autism Spectrum Disorders/ or autis* OR asperger* OR “pervasive developmental disorder*” AND exp Childhood Adversity/ or exp Child Abuse/ or “adverse childhood experience*” OR “adverse childhood event*” OR "child* trauma" OR “child* adversit*” OR “early adversit*” OR “early-life adversit*” OR “early life adversit*” OR exp Child Neglect/ or “child* maltreatment” OR “forced marriage” OR “parental death” or exp Parental Death/ OR exp Exposure to Violence/ or “community violence” OR “collective violence” OR war or exp War/ OR “peer violence” OR bullying OR bullied or exp Bullying/ OR “domestic abuse” OR “domestic violence” OR Domestic Violence/ OR poverty or exp Poverty/
Scopus - Article title, abstract, keywords	autis* OR asperger* OR “pervasive developmental disorder*” AND “adverse childhood experience*” OR “adverse childhood event*” OR "child* trauma" OR “child* adversit*” OR “early adversit*” OR “early-life adversit*” OR “early life adversit*” OR "child* maltreatment” OR “forced marriage” OR “parental death” OR “community violence” OR “collective violence” OR war OR “peer violence” OR bullying OR bullied OR “domestic abuse” OR “domestic violence” OR poverty

Web of Science - (Web of Science Core Collection Databse) Searched for within Topic which covers Title, Abstract, and Keywords and Keywords Plus	autis* OR asperger* OR “pervasive developmental disorder*” AND “adverse childhood experience*” OR “adverse childhood event*” OR "child* trauma" OR “child* adversit*” OR “early adversit*” OR “early-life adversit*” OR “early life adversit*” OR "child* maltreatment” OR “forced marriage” OR “parental death” OR “community violence” OR “collective violence” OR war OR “peer violence” OR bullying OR bullied OR “domestic abuse” OR “domestic violence” OR poverty
ProQuest Dissertations & Theses Global (Anywhere except full text)	noft((autis* OR asperger* OR "pervasive developmental disorder*")) AND noft(("adverse childhood experience*" OR "adverse childhood event*" OR "child* trauma" OR "child* adversit*" OR "early adversit*" OR "early-life adversit*" OR "early life adversit*" OR "child* maltreatment" OR "forced marriage" OR "parental death" OR "community violence" OR "collective violence" OR war OR "peer violence" OR bullying OR bullied OR "domestic abuse" OR "domestic violence" OR poverty))
Social Care Online - all fields	(autis* OR asperger* OR “pervasive developmental disorder*”) AND (“adverse childhood experience*” OR “adverse childhood event*” OR "child* trauma" OR “child* adversit*” OR “early adversit*” OR “early-life adversit*” OR “early life adversit*” OR "child* maltreatment” OR “forced marriage” OR “parental death” OR

	“community violence” OR “collective violence” OR war OR “peer violence” OR bullying OR bullied OR “domestic abuse” OR “domestic violence” OR poverty)
EthOS (any word)	Autism AND adverse childhood experience OR adverse childhood event OR childhood trauma OR bullying OR poverty
Google Scholar (first 10 pages)	autis* AND "adverse childhood experience*"

Appendix D

Reasons for Exclusion for Studies that Appear to Meet Inclusion Criteria

Identification of studies via databases	
Study	**Reason for exclusion**
Blake, J. J., Zhou, Q., Kwok, O. M., & Benz, M. R. (2016). Predictors of bullying behavior, victimization, and bully-victim risk among high school students with disabilities. *Remedial and Special Education*, *37*(5), 285-295. https://doi.org/10.1177/0741932516638860	No usable effect size
Dillenburger, K., Jordan, J. A., McKerr, L., & Keenan, M. (2015). The Millennium child with autism: Early childhood trajectories for health, education and economic wellbeing. *Developmental Neurorehabilitation*, *18*(1), 37-46. https://doi.org/10.3109/17518423.2014.964378	No usable effect size
Drohan, M. A. (2011). *Chronic child sexual abuse, psychiatric, and medical conditions among adolescents in residential care*. (Publication No. AAI3450793). [Doctoral Dissertation, University of Rhode Island] ProQuest Dissertations Publishing.	No usable effect size
Durkin, M. S., Maenner, M. J., Baio, J., Christensen, D., Daniels, J., Fitzgerald, R., Imm, P., Lee, L., Schieve, L.A., Van Naarden Braun, K., Wingate, M, S. & Yeargin-Allsopp, M. (2017). Autism spectrum disorder among US children (2002–2010): Socioeconomic, racial, and ethnic disparities. *American journal of public health*, *107*(11), 1818-1826. https://doi.org/10.2105/ajph.2017.304032	No usable effect size

Green, H., McGinnity, Á., Meltzer, H., Ford, T., & Goodman, R. (2005). *Mental health of children and young people in Great Britain, 2004.* Palgrave macmillan. https://doi.org/10.1037/e557702010-001	No usable effect size
Lebrun-Harris, L. A., Sherman, L. J., Limber, S. P., Miller, B. D., & Edgerton, E. A. (2019). Bullying victimization and perpetration among US children and adolescents: 2016 National Survey of Children’s Health. *Journal of Child and Family Studies, 28*(9), 2543-2557. https://doi.org/10.1007/s10826-018-1170-9	No usable effect size
Liptak, G. S., Benzoni, L. B., Mruzek, D. W., Nolan, K. W., Thingvoll, M. A., Wade, C. M., & Fryer, G. E. (2008). Disparities in diagnosis and access to health services for children with autism: data from the National Survey of Children's Health. *Journal of Developmental & Behavioral Pediatrics*, *29*(3), 152-160. https://doi.org/10.1097/dbp.0b013e318165c7a0	No usable effect size
Lung, F. W., Shu, B. C., Chiang, T. L., & Lin, S. J. (2019). Prevalence of bullying and perceived happiness in adolescents with learning disability, intellectual disability, ADHD, and autism spectrum disorder: In the Taiwan Birth Cohort Pilot Study. *Medicine*, *98*(6), e14483-e14483. https://doi.org/10.1097/md.0000000000014483	No usable effect size
Maclean, M. J., Sims, S., Bower, C., Leonard, H., Stanley, F. J., & O’Donnell, M. (2017). Maltreatment risk among children with disabilities. *Pediatrics*, *139*(4), 1-10. https://doi.org/10.1542/peds.2016-1817	No usable effect size
Mayes, S. D., Calhoun, S. L., Baweja, R., & Mahr, F. (2015). Maternal ratings of bullying and victimization: Differences in frequencies between psychiatric diagnoses in a large	No usable effect size

sample of children. *Psychological Reports, 116*(3), 710-722. https://doi.org/10.2466/16.pr0.116k30w8	
Mullick, M. S. I., & R. Goodman. (2005). The prevalence of psychiatric disorders among 5-10 year olds in rural, urban and slum areas in Bangladesh: An exploratory study. *Social psychiatry and psychiatric epidemiology, 40*(8), 663-671. https://doi.org/10.1007/s00127-005-0939-5	No usable effect size
NHS Digital. (2018). *Mental Health of Children and Young People in England, 2017.* https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-of-children-and-young-people-in-england/2017/2017	No usable effect size
Pulcini, C. D., Perrin, J. M., Houtrow, A. J., Sargent, J., Shui, A., & Kuhlthau, K. (2015). Examining trends and coexisting conditions among children qualifying for SSI under ADHD, ASD, and ID. *Acedmic Pediatrics, 15*(4), 439-443. https://doi.org/10.1016/j.acap.2015.05.002	No usable effect size
Ronis, S. D., Lee, E., Cuffman, C., & Burkhart, K. (2021). Impact of social and relational adversities on access to services among US children with autism spectrum disorder 2016-2019. *Children, 8*(12), 1099. https://doi.org/10.3390/children8121099	No usable effect size
Sivasundaram, L., Trivedi, N. N., Gatta, J., Ning, A. Y., Kim, C., Mistovich, J. (2019). Demographics and risk factors for non-accidental orthopedic trauma. *Clinical Pediatrics, 58*(6), 618-626. https://doi.org/10.1177/0009922819829045	No usable effect size

Spencer, K. M. (1996). *Factors relating to the prevalence of autism.* (Publication Number: 9716593). [Doctorate Thesis, Ann Arbor, Texas Woman's University]. ProQuest Dissertations Publishing.	No usable effect size
Sterzing, P. R., Shattuck, P. T., Narendorf, S. C., Wagner, M., & Cooper, B. P. (2012). Bullying involvement and autism spectrum disorders: Prevalence and correlates of bullying involvement among adolescents with an autism spectrum disorder. *Archives of Pediatrics & Adolescent Medicine, 166*(11), 1058-1064. https://doi.org/10.1001/archpediatrics.2012.790	No usable effect size
Berg, K. L., Shiu, C., Acharya, K., Stolbach, B. C., & Msall, M. E. (2016). Disparities in adversity among children with autism spectrum disorder: a population-based study. *Developmental medicine and child neurology, 58*(11), 1124-1131. https://doi.org/10.1111/dmcn.13161	Duplicate sample
Christoffersen, M. N. (2020). Sexual Crime Against Schoolchildren With Disabilities: A Nationwide Prospective Birth Cohort Study. *Journal of interpersonal violence, 37*(3-4), NP2177-NP2205. https://doi.org/10.1177/0886260520934442	Duplicate sample
Iyanda, A. E. (2022) Bullying Victimization of Children with Mental, Emotional, and Developmental or Behavioral (MEDB) Disorders in the United States. *Journal of Child & Adolescent Trauma, 15*(2), 221-223. https://doi.org/10.1007/s40653-021-00368-8	Duplicate sample
Kerns, C. M., Newschaffer, C. J., Berkowitz, S., & Lee, B. K. (2017). Brief Report: Examining the Association of Autism and Adverse Childhood Experiences in the National Survey of Children's Health: The Important Role of Income and Co-occurring Mental Health	Duplicate sample

Conditions. *Journal of autism and developmental disorders, 47*(7), 2275-2281 https://doi.org/10.1007/s10803-017-3111-7	
Kloosterman, P. H. (2017). Behavioral profiles of bullying and victimization in adolescents with special needs. (Publication Number: 10155164). [Queen's University Canada] ProQuest Dissertations Publishing.	Duplicate sample
Morton, H. E. (2021). *Development and validation of the assessment of bullying experiences questionnaire: A data-driven measure for bullying assessment in youth with autism spectrum disorder.* (Publication Number 2454351393) [State University of New York at Binghamton] ProQuest Dissertations Publishing.	Duplicate sample
Rowley, E. (2008). *The experience of friendship and bullying in children with an autism spectrum disorder. (*Publication Number: U593151) [University of London, University College London] ProQuest Dissertations Publishing.	Duplicate sample
Toseeb, U., McChesney, G., Oldfield, J., & Wolke, D. (2020). Sibling Bullying in Middle Childhood is Associated with Psychosocial Difficulties in Early Adolescence: The Case of Individuals with Autism Spectrum Disorder. *Journal of Autism & Developmental Disorders, 50*(5), 1457-1469. https://doi.org/10.1007/s10803-019-04116-8	Duplicate sample
Toseeb, U., McChesney, G., & Wolke, D. (2018). The Prevalence and Psychopathological Correlates of Sibling Bullying in Children with and without Autism Spectrum Disorder. *Journal of Autism & Developmental Disorders, 48*(7), 2308-2318. https://doi.org/10.1007/s10803-018-3484-2	Duplicate sample

Chan, K. L., Lo, C. K. M., & Ip, P. (2018). Associating disabilities, school environments, and child victimization. *Child Abuse & Neglect, 83,* 21-30. https://doi.org/10.1016/j.chiabu.2018.07.001	Unable to obtain unadjusted data
Emerson, E. (2012). Deprivation, ethnicity and the prevalence of intellectual and developmental disabilities. *Journal of Epidemiology and Community Health, 66*(3), 218-224. https://doi.org/10.1136/jech.2010.111773	Unable to obtain unadjusted data
Jackson, D. B., Vaughn, M. G., & Kremer, K. P. (2019). Bully victimization and child and adolescent health: New evidence from the 2016 NSCH. *Annals of Epidemiology, 29,* 60-66. https://doi.org/10.1016/j.annepidem.2018.09.004	Unable to obtain unadjusted data
Kelly, M. M., & K. Li. (2019). Poverty, toxic stress, and education in children born preterm. *Nursing Research, 68*(4), 275-284. https://doi.org/10.1097/nnr.0000000000000360	Unable to obtain unadjusted data
Larson, K., & N. Halfon. (2010). Family Income Gradients in the Health and Health Care Access of US Children. *Maternal and Child Health Journal, 14*(3), 332-342. https://doi.org/10.1007/s10995-009-0477-y	Unable to obtain unadjusted data
McDonnell, C. G., Boan, A. D., Bradley, C. C., Seay, K. D., Charles, J. M., Carpenter, L. A. (2019). Child maltreatment in autism spectrum disorder and intellectual disability: results from a population-based sample. *Journal of Child Psychology & Psychiatry, 60*(5), 576-584. https://doi.org/10.1111/jcpp.12993	Unable to obtain unadjusted data

Rigles, B. (2017). The relationship between adverse childhood events, resiliency and health among children with autism. *Journal of Autism & Developmental Disorders, 47*(1), 187-202. https://doi.org/10.1007/s10803-016-2905-3	Unable to obtain unadjusted data
Identification of studies via other methods	
Study	**Reason for exclusion**
Hodge, D., Hoffman, C. D., & Sweeney, D. P. (2011). Increased psychopathology in parents of children with autism: Genetic liability or burden of caregiving? *Journal of Developmental and Physical Disabilities, 23*(3), 227-239. https://doi.org/10.1007/s10882-010-9218-9	No useable effect size
Sullivan, P. M., & Knutson, J. F. (2000). Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse & Neglect, 24*(1), 1257-1273. https://doi.org/10.1016/s0145-2134(00)00190-3	No useable effect size
Blake, J. J., Kim, E. S., Lund, E. M., Zhou, Q., Kwok, O., Benz, M. R. (2016). Predictors of bully victimization in students with disabilities. *Journal of Disability Policy Studies, 26*(4), 199-208. https://doi.org/10.1177/1044207314539012	No useable effect size
Samadi, S. A., McConkey, R., & Bunting, B. (2014). Parent wellbeing of Iranian families with children who have developmental disabilities. *Research in Developmental Disabilities, 35*(7), 1639-1647. https://doi.org/10.1016/j.ridd.2014.04.001	No useable effect size
Chen, L., Chen, M., Hsu, J., Huang, K., Bai, Y., Chen, T., Wang, P., Pan, T., & Su, T. (2020). Association of parental depression with offspring attention deficit hyperactivity	No useable effect size

disorder and autism spectrum disorder: A nationwide birth cohort study. *Journal of Affective Disorders, 277*(1), 109-114. https://doi.org/10.1016/j.jad.2020.07.059	
Bright, M. A., & Thompson, L. A. (2018). Association of adverse childhood experiences with co-occuring health conditions in early childhood. *Journal of Developmental & Behavioural Pediatrics, 39*(1), 37-45. https://doi.org/10.1097/dbp.0000000000000514	No useable effect size
Li, N., Chen, G., Song, X., Du, W., & Zheng, X. (2011). Prevalence of autism-caused disability among Chinese: A national population-based survey. *Epilepsy & Behavior, 22*(4), 786-789. https://doi.org/10.1016/j.yebeh.2011.10.002	No confidence intervals reported
Altourah, A. J., Ansari, A. M. A., & Jahrami, H. (2020). Depression, anxiety and stress among mothers of children with autism spectrum disorder. *Bahrain Medical Bulletin, 42*(2), 125-128.	Duplicate sample
Daniels, J. L., Forssen, U., Hultman, C. M., Cnattingius, S., Savitz, D. A., Feychting, M., & Sparen, P. (2008). Parental psychiatric disorders associated with autism spectrum disorders in the offspring. *Pediatrics, 121*(5), e1357-e1362. https://doi.org/10.1542/peds.2007-2296	Unable to obtain unadjusted data
Bae, S., Jackson, B., Banini, S., Loa, K., Lykens, K., & Singh, K. (2011). Financial stress and income disparities in parents of children with special health care needs. In: F. Chan, D. Marinova, & R. S. Anderssen (Eds.), *MODSIM2011 19th International Congress on Modelling and Simulation* *https://doi.org/10.36334/modsim.2011.a1.bae*	Unable to obtain unadjusted data

Piven, J., & Palmer, P. (1999). Psychiatric disorder and the broad autism phenotype: Evidence from a family study of multiple-incidence autism families. *The American Journal of Psychiatry. 156*(4), 557-563. https://doi.org/10.1176/ajp.156.4.557	Data recorded past childhood
Fairthorne, J., Hammond, G., Bourke, J., Jacoby, P., & Leonard, H. (2014). Early mortality and primary causes of death in mothers of children with intellectual disability or autism spectrum disorder: A retrospective cohort study. *PLoS ONE, 9*(12), e113430. https://doi.org/10.1371/journal.pone.0113430	Data recorded past childhood
Khan, I., Rehman, Z. U., Khan, A., Samin, K. A., & Khan, M. M. (2021). A comparative study on depressive disorders among the mothers of children with and without autism spectrum disorder. *Pakistan Journal of Medical and Health Sciences, 15*(12), 594-597. https://doi.org/10.3329/bjpsy.v31i2.45372	Unreliable data (differences reported in abstract and main text)

Appendix E

Risk of bias

Questions:

1. Was the sample taken from an appropriate population base so that it closely represented the target/reference population under investigation?
2. Was the selection process likely to select participants that were representative of the target/reference population under investigation?
3. Was the sample size for analysed *N* >85?
4. Was Autism measured in a valid and reliable way?
5. Were ACEs measured in a valid and reliable way?
6. Was appropriate statistical analysis used for the association?
7. Were the results provided for all analyses described in the methods?
8. Were there any funding sources or conflicts of interest that may affect authors interpretations of results?
9. Did the study describe any limitations?

Scores and Risk of Bias Judgement:

Rates as Yes (1) = green; No (0) = red, Partially (0.5) = orange; Can't determine (?) = yellow. Question 8 reverse scored.

Low risk of bias: The study received '1' for all items

Unclear risk of bias: The study received '?' for one or more items, but no '0'

Some concerns: At least 1 item received a '0' or '0.5'

High risk of bias: At least 4 items received '0' or '?'

Appendix F

Reasons for Risk of Bias Scores Where Disagreements Occurred

Study	Item	Final Score	Reason
Campbell et al. (2017)	2	0.5	Comparison group randomly selected. Autistic group selection not reported
Cohrs & Leslie (2017)	1	0	Database of reimbursed health care claims not representative
	4	0.5	ICD-9 codes used but no information on assessment process
	5	0.5	ICD-9 codes used but no information on assessment process
Fairthorne et al. (2016)	4	X	Database used to acquire Autism diagnosis but no information provided on assessment process or diagnostic manual used
Gibbs et al. (2021)	4	1	Self-reported a professional diagnosis or self-identified autistic with scores above cut off on Autism Quotient Short Form
Gotby et al. (2018)	4	0.5	Screening interview for Autism used but not full assessment
	5	0	No standardised questionnaire used
Greger et al. (2015)	5	1	Child and Adolescent Psychiatric Assessment used
Griffiths et al. (2019)	1	0	Research databases of people interested in research therefore not representative
	5	0.5	Measure reported good reliability, but not reported on validity
Hwang et al. (2017)	2	0	Not all schools agreed to participate

	5	0	Measure used not designed for assessing bullying and only one item used for victimisation
	8	1	Funded by Autism Speaks, may be influenced to find significant results and no comments that report is independent of funding sources
Jahan et al. (2020)	5	1	Agreed that questions on past-year suicidal behaviours were sufficient.
Kloosterman et al. (2013)	1	0	Recruited only boys
	2	X	Authors did not report on recruitment strategy
	5	0	No information reported on bully/victim inventory (Olweus, 1997) and unable to find in literature
Kumagami & Matsuura (2009)	5	X	Reference provided for ACE measure but not enough information reported to determine
Matthias et al. (2021)	4	X	Obtained from school registers but not enough information provided about diagnostic procedure
Montes & Halterman (2007)	1	X	Large survey but no information provided about sample
	2	X	No information reported about sampling
	7	0	Chi square figure not reported in results
Morgan et al. (2012)	4	0	Obtained from intellectual disability register but no information on assessment process or diagnostic manual used reported
Morton (2021)	1	1	Used different methods for recruitment and should closely represent target/ reference population

	4	0.5	Social Responsiveness Scale used in addition to parent reports, however some participants were still included when didn't meet clinical cut off
Paul et al. (2018)	1	0	From an Autism clinic, not general autism population
Sullivan et al. (2012)	4	0.5	Participants had DSM-IV, ICD-9 or ICD-10 diagnosis or treatment from Autism centre. Diagnostic process not reported
	5	1	Decided National Patient Register and outpatient treatment registers were reliable, valid sources
Twyman et al. (2010)	4	1	Autism diagnosis provided by professionals via clinic
Weiss & Fardella (2018)	5	0	Measure for ACE does not have psychometric properties established

Appendix G

Individual and Pooled Effect Sizes

Study (year)	ACE Type	OR	95% CI	Pooled OR	Pooled CI
Blake et al. (2012)	Bullied (elementary school)	0.80	0.74-0.87	0.78	0.70-0.85
	Bullied (middle school)	0.73	0.64-0.82		
Campbell et al. (2017)	Face to face bullying	2.36	1.36-4.13	1.54	0.62-3.86
	Cyber bullying	0.923	0.42-2.02		
Cohrs & Leslie (2017)	Mothers with depression	2.93	2.79-3.08	2.66	2.19-3.23
	Fathers with depression	2.40	2.25-2.57		
Fairthorne et al. (2016)	Onset of at least one psychiatric disorder in mothers (Autism and ID)	1.62	1.37-1.90	1.81	1.42-2.31
	Onset of at least one psychiatric disorder in mothers (Autism without ID)	2.07	1.66-2.58		
Gotby et al. (2018)	Sexual abuse males	4.06	0.93 - 17.73	3.20	1.57-6.51
	Sexual abuse females	2.97	1.32 - 6.71		
Griffiths et al. (2019)	As a child, other children bullied me	5.78	3.99–8.36	3.56	2.72-4.66
	As a child, an adult hurt me badly enough that it left marks on my body	2.11	1.44-3.11		

	As a child, other children left me out of activities	6.43	4.51-9.18		
	As a child, children spread rumours about me or talked about me behind my back	4.21	3.02-5.86		
	As a child, another child hurt me badly enough that it left marks on my body (e.g. bruises or scratches)	3.12	2.23-4.37		
	As a child, children called me names or insulted me	4.41	3.08-6.33		
	As a child, an adult humiliated, embarrassed or scared me	3.41	2.44-4.75		
	As a child, an adult touched me in a sexual way, or tried to make me touch them in a sexual way	1.71	1.19-2.46		
	As a child, an adult swore at me or called me names like stupid, ugly or lazy	3.41	2.47-4.70		
Holmes et al. (2021)	Parental separation	0.35	0.19-0.64	0.48	0.35-0.67
	Mother treated violently	0.59	0.28-1.17		
	Parental substance abuse	0.47	0.18-1.06		
	Parental mental illness	0.6	0.34-1.05		
	Parental incarceration	0.19	0.01-1.00		
Hwang et al. (2017)	Bullying (DSM IV diagnosis)	16.3	6.8-39.6	14.26	7.36-27.63

	Bullying (DSM 5 diagnosis)	12.0	4.4-32.6		
Jokiranta et al. (2013)	Psychiatric diagnosis in mother	2.12	1.90-2.37	1.88	1.49-2.37
	Psychiatric diagnosis in father	1.67	1.5105-1.8530		
Kloosterman et al. (2013)	Bullying – physical	2.06	0.51-8.25	2.02	1.17-3.49
	Called mean names, made fun of, or teased in a hurtful way	1.00	0.32-3.15		
	Bullied with mean names and comments about race or colour	1.57	0.24-10.37		
	Bullied with mean names and comments about religion	10.76	0.55-211.70		
	Bullied with sexual jokes, comments, or gestures	9.47	1.06-84.38		
	Excluded from a group of friends or was completely ignored	3.22	0.90-11.46		
	Told lies or spread false rumours	1.90	0.52-6.97		
	Bullied using a computer or e-mail messages or pictures	3.29	0.32-34.08		
	Bullied using a mobile phone	0.18	0.01-4.04		
Kumagami & Matsuura (2009)	Physical abuse	2.58	1.15–5.78	1.45	1.07-1.95
	Emotional abuse	2.33	1.33–4.80		

	Substance misuse	1.94	0.60–6.24		
	Mother being treated violently	1.11	0.36–3.41		
	Living with someone who is chronically depressed, suicidal, institutionalised or mentally ill	1.03	0.34–3.17		
	One or no biological parents	1.13	0.76–1.69		
	An incarcerated household member	0.94	0.23–3.78		
	Neglected by parents	2.06	0.86–4.97		
Montes & Halterman (2007)	Domestic violence	1.24	0.90-1.71	1.08	0.89-1.32
	Poverty	1.01	0.80-1.26		
Morgan et al. (2012)	Mother with Schizophrenia	5.1	0.3-81.2	7.54	1.92-29.58
	Mother with Bipolar disorder	9.6	1.1-86.4		
	Mother with Unipolar depression	7.5	0.8-72.1		
Rowley et al. (2012)	Bullied compared to UK norm	6.02	3.85-9.40	4.32	2.02-9.23
	Bullied compared to SEN without ASD	2.75	1.30-5.82		
Sullivan et al. (2012)	Schizophrenia Sweden national outpatient + inpatient	2.9	2.5-3.4	2.25	1.68-3.00
	Bipolar Disorder Sweden national outpatient + inpatient	1.9	1.7-2.1		
	Schizophrenia Stockholm County	2.9	2.0-4.1		

	outpatient + inpatient				
	Bipolar Disorder Stockholm County Outpatient + inpatient	1.6	1.1-2.1		
Totsika et al. (2011)	Poverty	0.99	0.62-1.60	1.08	0.70-1.66
	Maternal mental illness	1.56	0.57-4.29		
Weiss & Fardella (2018)	Physical assault	2.91	0.53-15.87	1.24	0.74-2.07
	Child maltreatment	4	1.55-10.33		
	Peer/sibling victimisation	7.33	0.84-63.74		
	Witness domestic violence	0.79	0.27-2.29		
	Witness physical abuse	1.21	0.43-3.44		
	Witness assault with a weapon	0.81	0.34-1.91		
	Witness assault without a weapon	0.93	0.40-2.19		
	Someone close murdered	0.09	0.01-1.80		
	Exposure to shooting, bombs, riots	0.31	0.09-1.09		
	Sexual victimization	1.25	0.54-2.91		
Zarei et al. (2021)	1 [a]	1.57	1.29–1.91	2.25	1.50-3.37
	2 [a]	2.46	1.88–3.23		
	>3 [a]	2.98	2.35–3.77		

Note. Figures have been rounded to 2 decimal places for reporting. When 2 decimal places were not reported, they have remained 1 decimal place.

[a] Parental incarceration, family violence, household mental illness, household alcohol/drug problems, parental divorce/separation, parental death, household poverty

Appendix H

Studies Assigned to Each Subgroup

Moderator	Subgroups	k	Study authors
Type of ACE	Bullying/ peer violence	15	Blake et al. (2012); Campbell et al. (2017); Ergolu & Kilic (2020); Hebron (2012), Hwang et al. (2017); Iglesias et al. (2019); Kloosterman et al. (2013); Mallory (2014); Morton (2021); Nowell et al. (2014); Rowley et al. (2012); Schrooten et al. (2018); Takara & Kondo (2014); Twyman et al. (2010); Wainscott et al. (2008)
	Abuse, violence, or neglect	7	Christoffersen (2019); Fisher et al. (2019); Gibbs et al. (2021); Gotby et al. (2018); Greger et al. (2015); Mukherjee et al. (2019); Spencer et al. (2005)
	Parental mental health	5	Cohrs & Leslie (2017); Jahan et al. (2020), Jokiranta et al. (2013); Morgan et al. (2012); Sullivan et al. (2012)
	Other/ mixed	12	Bethell et al (2014); Carr (2002); Fairthorne et al. (2016); Griffiths et al. (2019); Holmes et al. (2021); Kumagami & Matsuura (2009); Matthias et al. (2021); Montes & Halterman (2007); Paul et al. (2018); Totsika et al. (2011); Weiss & Fardella (2018) Zarei et al. (2021)
Child or retrospective adult account	Child	29	Bethell et al. (2014); Blake et al. (2012); Campbell et al. (2017); Carr (2002); Cohrs & Leslie (2017); Ergolu & Kilic (2020); Fisher et al. (2019); Greger et al. (2015); Hebron (2012), Hwang et al. (2017); Iglesias et al. (2019); Jahan et al. (2020), Kloosterman et al. (2013); Kumagami & Matsuura (2009); Mallory (2014); Matthias et al. (2021); Montes & Halterman (2007); Morgan et al. (2012); Morton

			(2021); Mukherjee et al. (2019); Nowell et al. (2014); Paul et al. (2018); Rowley et al. (2012); Schrooten et al. (2018); Sullivan et al. (2012); Totsika et al. (2011); Twyman et al. (2010); Wainscott et al. (2008); Zarei et al. (2021)
	Retrospective	10	Christoffersen (2019); Fairthorne et al. (2016); Gibbs et al. (2021); Gotby et al. (2018); Griffiths et al. (2019); Holmes et al. (2021); Jokiranta et al. (2013); Spencer et al. (2005); Takara & Kondo (2014); Weiss & Fardella (2018)
Method for determining Autism	Assessment tool	13	Ergolu & Kilic (2020); Gibbs et al. (2021); Gotby et al. (2018); Greger et al. (2015); Hwang et al. (2017); Kloosterman et al. (2013); Mallory (2014); Mukherjee et al. (2019); Nowell et al. (2014); Paul et al. (2018); Rowley et al. (2012); Takara & Kondo (2014); Weiss & Fardella (2018)
	Clinician	4	Campbell et al. (2017); Griffiths et al. (2019); Kumagami & Matsuura (2009); Schrooten et al. (2018)
	Documents	12	Blake et al. (2012); Carr (2002); Christoffersen (2019); Cohrs & Leslie (2017); Fairthorne et al. (2016); Fisher et al. (2019); Holmes et al. (2021); Jokiranta et al. (2013); Morgan et al. (2012); Spencer et al. (2005); Sullivan et al. (2012); Twyman et al. (2010)
	School	3	Jahan et al. (2020), Matthias et al. (2021); Wainscott et al. (2008); Schrooten et al. (2018)
	Self/parent	5	Bethell et al. (2014); Montes & Halterman (2007); Morton (2021); Totsika et al. (2011); Zarei et al. (2021)

Method for determining ACE	Self	17	Campbell et al. (2017); Eroglu & Kilic (2020); Gibbs et al. (2021); Gotby et al. (2018); Greger et al. (2015); Griffiths et al. (2019); Hwang et al. (2017); Iglesias et al. (2019); Kloosterman et al. (2013); Kumagami & Matsuura (2009); Montes & Halterman (2007); Mukherjee et al. (2019); Paul et al. (2018); Takara & Kondo (2014); Twyman et al. (2010); Wainscot et al (2008); Weiss & Fardella (2018)
	Parent/peer	11	Bethell et al. (2014); Blake et al. (2012); Hebron (2012); Jahan et al. (2020); Mallory (2014); Morton (2021); Nowell et al. (2014); Rowley et al. (2012); Schrooten et al. (2018); Totsika et al. (2011); Zarei et al. (2021)
	Documents	11	Carr (2002); Christoffersen (2019); Cohrs & Leslie (2017); Fairthorne et al. (2016); Fisher et al. (2019); Holmes et al. (2021); Jokiranta et al. (2013); Matthias et al. (2021); Morgan et al. (2012); Spencer et al. (2005); Sullivan et al. (2012)
Comparison group	General population	18	Bethell et al. (2014); Christoffersen (2019); Cohrs & Leslie (2017); Fairthorne et al. (2016); Fisher et al. (2019); Gibbs et al. (2021); Gotby et al. (2018); Griffiths et al. (2019); Hwang et al. (2017); Jokiranta et al. (2013); Montes & Halterman (2007); Morgan et al. (2012); Paul et al. (2018); Spencer et al. (2005); Sullivan et al. (2012); Totsika et al. (2011); Weiss & Fardella (2018); Zarei et al. (2021)
	Typical developing	6	Campbell et al. (2017); Eroglu & Kilic (2020); Iglesias et al. (2019); Jahan et al. (2020); Nowell et al. (2014); Schrooten et al. (2018)
	Disabilities	6	Blake et al. (2012); Carr (2002); Hebron (2012); Matthias et al. (2021); Mukherjee et al. (2019); Rowley et al. (2012);

	Mixed	6	Holmes et al. (2021); Kloosterman et al. (2013); Mallory (2014); Morton (2021); Twyman et al. (2010); Wainscot et al (2008)
	Other	3	Greger et al. (2015); Kumagami & Matsuura (2009); Totsika et al. (2011)
Special population	Yes	14	Blake et al. (2012); Carr (2002); Eroglu & Kilic (2020); Fairthorne et al. (2016); Greger et al. (2015); Holmes et al. (2021); Jahan et al. (2020); Kumagami & Matsuura (2009); Matthias et al. (2021); Morton (2021); Mukherjee et al. (2019); Rowley et al. (2012); Takara & Kondo (2014); Twyman et al. (2010)
	No	25	Bethell et al. (2014); Campbell et al. (2017); Christoffersen (2019); Cohrs & Leslie (2017); Fisher et al. (2019); Gibbs et al. (2021); Gotby et al. (2018); Griffiths et al. (2019); Hebron (2012); Hwang et al. (2017); Iglesias et al. (2019); Jokiranta et al. (2013); Kloosterman et al. (2013); Mallory (2014); Montes & Halterman (2007); Morgan et al. (2012); Nowell et al. (2014); Paul et al. (2018); Schrooten et al. (2018); Spencer et al. (2005); Sullivan et al. (2012); Totsika et al. (2011); Wainscot et al (2008); Weiss & Fardella (2018); Zarei et al. (2021)
Region	North America	14	Bethell et al. (2014); Blake et al. (2012); Carr (2002); Cohrs & Leslie (2017); Fisher et al. (2019); Kloosterman et al. (2013); Mallory (2014); Matthias et al. (2021); Montes & Halterman (2007); Morgan et al. (2012); Nowell et al. (2014); Twyman et al. (2010); Weiss & Fardella (2018); Zarei et al. (2021)
	Europe	8	Christoffersen (2019); Gotby et al. (2018); Greger et al. (2015); Iglesias et al. (2019); Jokiranta et al. (2013); Paul et al. (2018); Schrooten et al. (2018); Sullivan et al. (2012)

UK	7	Griffiths et al. (2019); Hebron (2012); Mukherjee et al. (2019); Rowley et al. (2012); Spencer et al. (2005); Totsika et al. (2011); Wainscot et al (2008)
Asia	5	Eroglu & Kilic (2020); Hwang et al. (2017); Jahan et al. (2020); Kumagami & Matsuura (2009); Takara & Kondo (2014)
Australia	5	Campbell et al. (2017); Fairthorne et al. (2016); Gibbs et al. (2021); Holmes et al. (2021); Morgan et al. (2012)

Section Two: Empirical Study

Autistic Adults’ Experiences of Self-Compassion: A Thematic Analysis

Abstract

Objectives

This study aimed to investigate autistic adults' experiences of self-compassion and what they perceive as helping or hindering their ability to demonstrate self-compassion.

Design and methods

This study used a qualitative research design and a phenomenological approach. A critical realist position was taken with a contextualist epistemology. Random sampling recruited fifteen autistic adults and semi-structured one-to-one interviews were conducted. Reflexive Thematic Analysis was used to interpret the data. Rigor and trustworthiness were established through consultations with experts by experiences, member checking, sense checking with colleagues, a reflexive journal, a peer audit of each stage of analysis, and use of The Standards for Reporting Qualitative Research.

Results

Three themes were generated with six subthemes: How others treat me (Non-acceptance from others; Acceptance from others), Attributing responsibility (Blame myself; Relieve myself of blame) and How I treat myself (Compromising my own needs; Meeting my own needs). Participants' abilities to show self-kindness was largely hindered by criticism and disapproval from others. Participants often blamed themselves for difficulties they encountered and engaged in self-criticism. To avoid negative attention, participants camouflaged or withdrew from social events. Acceptance from others enabled participants to engage in the world in a way that made them feel comfortable. Finding an explanation for their difficulties, in the form

of an Autism diagnosis, relieved participants of blame and facilitated forgiveness of mistakes. Finally, awareness of one’s own needs and making necessary adaptations was an example of self-compassion.

Conclusion

Promoting an acceptance of difference in society and providing autistic adults with interventions that relieve self-blame and strengthen self-compassion are essential for improving the lives of autistic adults.

Practitioner Points

- Raising awareness and understanding of Autism in schools, workplaces, and the community is crucial for fostering Autism acceptance.
- Putting resources into identifying and diagnosing Autism earlier in life more facilitate self-compassion in autistic people.
- Services should support family members and significant others to celebrate differences and acknowledge the harmful effects of unobtainable standards.
- Autistic adults should be offered therapy which aims nurture self-compassion and reduce blame, shame and self-criticism.

Introduction

Autistic individuals often face discrimination and stigma from people who lack an understanding of Autism or acceptance of traits that deviate from an assumed norm (Cage, 2019; Goffman, 1990; Griffith et al., 2012; Heasman & Kinnear et al., 2016; Sasson et al., 2017; Schroeder et al., 2014; Sterzing et al., 2012). Inaccurate representations of Autism have persisted in the media generating negative discourses and affecting how autistic people view themselves (Bagatell, 2007; Parsloe, 2015; Sarrett, 2011). Unhelpful and stereotypical attitudes can be internalised by applying negative attitudes to oneself, known as self-stigma (Corrigan & Watson, 2002). To avoid discrimination and negative attitudes of others, some autistic individuals hide their autistic traits to fit in with social groups, known as camouflaging (Dean et al., 2017; Hull et al., 2017). However, camouflaging can be exhausting, lead individuals to feel they are not being their authentic self and result in negative emotions and attitudes towards oneself (Bargiela et al., 2016; Hull et al., 2017).

Self-compassion is a particular way of relating to oneself that involves being warm and understanding and can impact on how we make sense of our experiences and how we respond to challenging situations (Neff & Dahm, 2015). Because research suggests self-compassion can be beneficial for individuals experiencing stigma (Chan et al., 2020; Health et al, 2018; Skinta et al., 2019; Wong et al., 2016; Wong et al., 2019; Yang et al., 2017), gaining an understanding of autistic adults' experiences of self-compassion can provide insight into how autistic adults deal with their unique challenges. Accordingly, this study aimed to explore the experiences of self-compassion in autistic adults.

The Impact of a Deficit Model

The stigma attached to Autism comes from a deficit model, focused on perceived individual deficits and as a disorder with behaviours to be cured or corrected (Akhtar & Jaswal, 2013; Dinishak, 2016; Lewin & Akhtar., 2020; Ne'eam, 2010). The Diagnostic and Statistical Manual of Mental Disorders fifth edition (DSM-V: American Psychiatric Association, 2013) outlines persistent deficits in social communication and social interaction and restricted, repetitive patterns of behaviour in the criteria for Autism Spectrum Disorder. The prevalence rate of Autism is estimated at 1.035% across the world and 1.1% in England (Brugha et al., 2012; MacKay et al., 2018). Autistic individuals can internalise views that are consistent with the deficit model, for example that there is 'something wrong' with them, they are 'weird and strange,' or they are a 'freak' (Humphrey & Lewis, 2008; Punshon et al., 2009).

Increasingly Autism is being regarded as a naturally occurring way of being that differs from society's definition of 'normal' (Robertson, 2009). The neurodiversity movement promotes the view that society's response, such as negative attitudes or systemic barriers, causes the challenges faced by autistic people (Lewin & Akhtar, 2020).

Self-Compassion as a Buffer Against the Impact of Stigma

Self-compassion helps people deal with life struggles by showing warmth and understanding to themselves during hardship or perceived inadequacy. Neff (2003a) proposed three components of self-compassion as treating self with kindness, seeing negative experiences as part of human experience and acknowledging pain without exaggerating it. Self-compassion can protect against self-stigma and buffer against negative self-feelings in response to negative events (Hilbert et al., 2015;

Leary et al, 2007; Yang, 2017; Zhao, 2018). Moreover, self-compassion is negatively associated with self-criticism, rumination, and neurotic perfectionism, which may be triggered by stigma (Neff, 2003b). However, findings from Vigna (2018) suggest that lower self-compassion levels are associated with stigmatised identities.

Self-compassion can be viewed as a trait and as a psychological process that can be taught and strengthened through different treatments and appears to be a mechanism of change in different forms of therapy (Baer, 2010; Barnard & Curry, 2012; Neff & Germer, 2013). Experiencing negative attitudes and stigma from society can lead to self-criticism and self-stigma (Corrigan & Watson, 2002; Gilbert & Irons, 2008). Due to the challenges that autistic individuals face, self-compassion may be a helpful quality that can be cultivated to promote a healthy attitude and relationship to oneself and facilitate resilience against the negative effects of stigma on well-being.

Existing Research on Autism and Self-Compassion

To date, there has been little research exploring self-compassion among autistic adults. Research examining Autism and self-compassion has focused on the wellbeing of parents of autistic children (Bohadana et al., 2019; Bohadana et al., 2020; Darvishi & Khayatan, 2017; Neff & Faso, 2015; Torbet et al., 2019; Wong et al., 2016). Findings suggest that adults with low self-compassion who are parents of autistic children engage in negative self-evaluation and self-judgement which amplifies the impact of any affiliated stigma; whereas self-compassion has been identified as a protective factor against psychological distress caused by affiliated stigma (Torbet, 2019; Wong, 2016). Applying these findings to autistic adults facing stigma would suggest that self-compassion is an important quality to explore.

Research within the general population has found several barriers to being self-compassionate which may apply to autistic individuals. Barriers to self-compassion include perfectionist tendencies, long-standing negative attitudes towards self, critical others, and negative misperceptions of self-compassion (Bayir & Lomas, 2016; Biskas et al., 2021; Pauley & McPherson, 2010; Robinson et al., 2016). In addition, messages from Western culture regarding stoicism, capitalism and individualism were identified as factors making self-compassion difficult (Campion & Glover, 2017).

Aims

This study aimed to help gain insight into the attitudes autistic adults hold of themselves, their responses to challenges, and the factors deemed to influence these. Furthermore, this study aimed to gain an insight into what autistic adults perceive as helping or hindering their ability to demonstrate self-compassion. Researching autistic adults' perspectives on self-compassion may help assess its usefulness in clinical practice and inform its application to interventions promoting healthy attitudes to oneself and resilience to stigma.

Research Questions

- How do autistic adults view and experience self-compassion in their day to day lives?
  - How do autistic adults think they experience self-compassion?
  - How do autistic adults think they experience a lack of self-compassion?
  - What do autistic adults perceive to be the facilitators and barriers to their ability to be self-compassionate?

Language and Terminology

Based on the preferences of the majority of participants involved in this study, identity-first language, such as “autistic people”, will be used (Gillespie-Lynch, et al., 2017), which is also in line with many other autistic people (Bury et al., 2020; Kenny et al., 2016; Lei et al., 2021; Sinclair, 2013).

Method

Design, Ontology and Epistemology

This study used a qualitative research design with semi structured one-to-one interviews and a phenomenological approach. A critical realist position was taken with a contextualist epistemology (Bhaskar, 1975; Harper & Thompson, 2012; Willig & Stainton-Rogers, 2008). Therefore, this study takes the stance that some ‘authentic’ reality exists, a truth can be accessed through language and knowledge can be valid in certain contexts; However, also believes that knowledge is socially influenced and emerging from contexts, therefore can only partially be accessed (Braun & Clark, 2013).

Participants

Fifteen participants were recruited via random sampling. The concept of information power guided the decisions regarding adequate sample size (Malterud et al., 2015). The concept of saturation, when additional data fails to generate new information, are not consistent with the values and assumptions of reflexive thematic analysis (Braun & Clarke 2021; Morse, 1995; Sandelowski, 1995). Information power of the interview sample was determined by study aim, sample specificity, use of established theory, quality of dialogue, and analysis strategy (Malterud et al., 2015). The study focused on identifying patterns across participants and cross-case analysis, therefore required more participants to offer sufficient information power. The participants had an Autism diagnosis which was highly specific for the study aim and relatively homogeneous, however other characteristics such as age and gender, were more diverse, therefore required more participants due to heterogeneity of the sample. As the researcher holds more than average background knowledge about the topic and engaged in strong and clear communication with the participants, fewer participants were required to offer sufficient information power. In addition, the study was supported by theoretical perspectives and the study's aim was fairly narrow, therefore fewer participants were necessary to provide information power.

The inclusion criteria were:

- All gender identities
- Aged 18 years and older
- Had a diagnosis of Autism Spectrum Disorder

Participants were excluded if they lacked capacity to consent to participate, were 17 years and younger and were unable to speak fluent English. Table 1 provides demographic information for all participants. Pseudonyms have been used to protect confidentiality. Self-Compassion Scale scores mostly fell within the low to moderate range for self-compassion, with two participants suggesting high levels of self-compassion. Generally, participants' scores on the Self-Compassion Scale matched the researcher's impression of levels of self-compassion demonstrated during the interview.

Procedure

Ethical approval for the study was obtained from the University of Sheffield Research Ethics Committee (see Appendix A). Participants were provided with information about the research via an information sheet (Appendix B). Informed consent was obtained by participants via a consent form (Appendix C).

Participants were recruited from the Sheffield Autism Research Lab (ShARL), a database of autistic adults who have shown an interest in taking part in research and have consented to being contacted to be invited to take part in research. Individuals on the database were randomly selected by a random number generator and invited to take part in the project by email (see Appendix D). Participants who expressed an interest were sent a participant information sheet and a link to the online consent form and survey via Qualtrics (see Appendix E). Once participants completed the consent form and survey, they were then contacted to arrange an interview. Participants were sent an overview of topics covered in the interview and an information sheet about self-compassion (see Appendices F and G). Participants were asked for their preferred terminology to use during the interview.

Semi-structured, one-to-one interviews were chosen for eliciting stories, thoughts, and feelings from the participants. The semi-structured interview guide was developed by the researcher and feedback was gathered from experts by experience (Appendix H). Topics raised by participants were followed up if they were relevant to the research question even if they were not on the interview schedule. An overview of the main questions can be found in Table 2. The interview was piloted with three experts by experience independent to the research.

Interviews were conducted remotely via Googlemeet or telephone. Interviews were audio-recorded using an encrypted digital recorder. Interviews lasted between 58 minutes and 122 minutes and the mean length of interviews was 81 minutes. Participants were given an electronic £5 amazon voucher or Love2shop as compensation for their time to participate in the study. The researcher transcribed six interviews and employed a transcriber to transcribe nine interviews.

Table 1

Participant Demographics

Name[a]	Age (years)[b]	Diagnosis	Age (years) at diagnosis[b]	Preferred terminology	Gender	Ethnicity	Country of Residence	Education level	Mean score on SCS
Lois	20-29	ASD[c]	10-19	Female with Autism	Female	White British	UK	Bachelor's degree level	3.23 (moderate)
Daniel	50-59	Asperger's Syndrome	30-39	None	Male	White British	UK	Secondary school with formal qualification	3.77 (high)
Iris	70-79	High Functioning Autism	60-69	Autistic	Female	White British	UK	Bachelor's degree level	1.81 (low)
Abigail	30-39	Asperger's Syndrome/ ASD	30-39	Autism	Female	White British	UK	Bachelor's degree level	2.81 (moderate)
Helen	60-69	ASD	50-59	Autistic, rather than have Autism	Female	White British	UK	Bachelor's degree level	1.62 (low)
Mary	50-59	Asperger's Syndrome plus ADHD	50-59	Aspie	Female in life (neutral to me)	White Other	UK	Bachelor's degree level	1.81 (low)

Gwen	50-59	High Functioning Autism	50-59	Autistic	Female	White British	UK	Further education	2.23 (low)
Molly	30-39	High Functioning ASD	20-29	Neurodiverse	Female	White British	UK	Postgraduate level qualification	3.85 (high)
Nora	60-69	Asperger’s Syndrome	50-59	On the Autism Spectrum	Female	White British	UK	Bachelor’s degree level	2.96 (moderate)
Frances	50-59	Asperger’s Syndrome	30-39	Autistic person	Female	White British	UK	Postgraduate level qualification	2.00 (low)
Rachel	40-49	ASD Level 1	40-49	Autistic	Female	White Other	Canada	Postgraduate level qualification	1.50 (low)
Arthur	20-29	Asperger's Syndrome	0-9	Autism	Male	White British	UK	Further education	1.23 (low)
Randall	30-39	Asperger's Syndrome	20-29	Autistic	Male	White British	UK	Postgraduate level qualification	1.96 (low)
Oliver	20-29	High Functioning ASD	20-29	No preference	Male	White British	UK	Postgraduate level qualification	2.62 (moderate)
Peter	60-69	Asperger’s Syndrome	50-59	Asperger or Autism	Male	White British	UK	Postgraduate level qualification	1.46 (low)

[a]Pseudonyms [b]Exact ages are not reported to protect confidentiality. [c]ASD = Autism Spectrum Disorder

Table 2

Interview Topic Guide

Statement	**Main Questions**
1. One aspect of self-compassion involves being kind, caring and understanding of ourselves when things are difficult. This could be with big or small events and things that are under or out of your control.	a) When things are difficult, are there times when you are show kindness, care, or understanding to yourself, for example being accepting of who you are, saying kind words to yourself, or forgiving yourself for mistakes?
	b) Most of us have times when we might instead be critical or judgemental towards ourselves, for example being judgemental about our flaws, having a negative voice in our head telling us we're not good enough, or focusing on things we don't like about ourselves. Are there are times when you are tough on yourself like this or in a different way?
2. Self-compassion involves recognising that everyone faces challenges and being imperfect is part of being human.	a) When things feel difficult, are there times when you can see your difficulties and/ or imperfections as part of life and that everyone has their own struggles?
	b) When life gets difficult or we feel down, we can feel alone and believe we are to blame for our difficulties or imperfections. When things go wrong, are there times when you feel like you are the only one facing problems, or making mistakes?
3) Another aspect of self-compassion is acknowledging our negative thoughts and feelings with openness and curiosity.	a) When something bad happens, are there times when you can take a moment to notice and validate your thoughts and feelings rather than thinking "I shouldn't be feeling like this" or feeling overwhelmed by them?
	b) When something bad happens, are there times when you get consumed by or dwell on your thoughts and feelings?

	c) Sometimes we can find ourselves either supressing our thoughts and feelings rather than be open to them. When something bad happens, are there times when you get try to supress your thoughts and feelings, for example distract yourself from them?
4) Is there anything else you would like to tell me in relation to your experience of self-compassion?	

Materials

The survey included a demographic questionnaire and a questionnaire which measured Self-Compassion. Self-compassion was assessed with the Self-Compassion Scale (Neff, 2016), a 26-item measure. Items are rated from ‘almost always’ to ‘almost never’ with scores ranging from one to five. The Self-Compassion Scale has good internal consistency ranging from .75 to .81 for the subscales. Good re-test reliability was demonstrated ranging from .80 to .93 for the subscales (Neff, 2003b). Convergent validity was demonstrated through comparison with measures of self-criticism, social connectedness and experience of mood states (Neff, 2003b). As a rough guide, an overall score of 1-2.5 indicates low self-compassion, 2.5-3.5 indicates moderate self-compassion and 3.5-5.0 indicates high self-compassion (Neff, 2022).

The demographic questionnaire asked about age, gender, ethnicity, country of residence, and education. This provides contextual information for the analysis which may be useful for understanding the participants’ narratives.

Expert by Experience Involvement

Two autistic service users, one woman and one man, from Sheffield Adult Autism and Neurodevelopmental Service were consulted throughout the research project, informed the research process and materials, provided feedback on the analysis, and made suggestions for dissemination. The interview schedule was also piloted with three autistic experts by experience. Table 3 shows details of the changes made from experts by experience involvement.

Table 3

Expert by Experience Feedback

Element of Research	**Feedback Given and Changes Made**
All	Changed terminology – “accepting towards myself” replaced with “accepting of myself”.
Initial Invite	Added more information about why the research topic is valuable and the difference the research aimed to make. Added information about how many other people would be interviewed.
Self-Compassion Definition Sheet	Abstract concept is difficult to understand. Added in a picture, a concrete example and used plain English to explain the concept.
Topic Information Sheet	Agreed to it would be a good idea to give information about interview questions in advance. Developed information sheet with experts by experience to give participants broad themes of questions asked.
Questionnaire	Changed education questions from more American terminology to more English terminology.
Interview schedule	Edited grammar. Added information to how findings will be communicated at the end of interview. *From pilot interviews:* Added some extra prompts. Highlighted barrier and facilitator prompts so they are not overlooked. Questions during interview tended to flow and did not need changing. Ask participants if they would like a break halfway.

Analysis and Findings	Edited presentation and punctuation of quotes. Feedback that themes make sense and many aspects they can resonate with. Very accurate and insightful in reflecting their experiences.

Reflexivity

Researcher subjectivity is noted as a key tool for reflexive thematic analysis, rather than something to get rid of (Braun & Clarke, 2021; Elliot et al, 1999; Gough & Madill, 2012). Researchers must recognise and take responsibility for their own perspective and influence on the study process and interpretation of the participants' experiences (Berger, 2015; Elliot et al., 1999; Harper, 2011). The researcher engaged in personal reflexivity, interpersonal reflexivity, methodological reflexivity and contextual by keeping a diary of values, preconceptions, and reflections (Braun & Clarke, 2021; Finlay & Gough 2003; Shaw, 2010; Walsh, 2003). Elements from the diary were discussed with members of the research team and the impact they had on the research process and analysis. See Appendix I for excerpts.

Analysis

Interpretative Phenomenological Analysis (IPA) was considered for the analysis of this study as it is concerned with the detailed examination of personal lived experience (Smith et al., 2009). The use of an 'a priori' theoretical construct, namely Neff's self-compassion model which informed the interview schedule, raised questions about the appropriateness of IPA. In addition, due to the inclusion of all genders and ages over 18 years old and a focus on group level claims, IPA was deemed not appropriate.

Reflexive thematic analysis suits questions related to people's experiences and can be used within different theoretic frameworks (Braun & Clark, 2013). An inductive, primarily semantic, and contextualist approach will be taken, where coding and theme development are directed by the content of the data, reflect the explicit context of the data, and focuses on the ways individuals make meaning of their experience and the ways the broader social context impinges on those meanings (Boyatzis, 1998; Patton, 1990; Willig, 1999).

The researcher followed the six-phase process outlined by Braun and Clarke (2021) to analyse the transcripts. The researcher listened to audio recordings and read and reread the electronic copies of the transcripts to become familiar with the data. The researcher then identified relevant segments and applied code labels via NVivo software. Single coding is regarded as normal and good practice in reflexive thematic analysis (Braun & Clarke, 2021). Coding produced 443 codes, most of which clustered easily into six broad patterns (See Appendix J). The researcher then compiled clusters of codes that seem to share core ideas or concepts to construct themes. The researcher drew several thematic maps to make sense of the data and understand potential themes in relation to each other (See Appendix K). The researcher reviewed and revised the themes continuously until the write up was complete.

Quality Appraisal

Several credibility checks were taken to ensure quality control as recommended by O'Brien et al. (2014), Tong et al. (2007), Nowell et al. (2017) and Tracy (2010). The researcher discussed initial themes and codes with members of the research team to sense-check and gather alternative insights into the meaning of the themes (Braun & Clarke, 2019). Experts by experience were also consulted during the analysis process. Participants were sent copies of transcripts and findings and invited to provide feedback on whether they recognised that as accurate and meaningful (See Appendix L). A member of the research team conducted an audit of each stage of analysis to check the validity of the approach used based on a 15-Point Checklist of Criteria for Good Thematic Analysis Process (Braun & Clarke, 2006; See Appendix M). Finally, the Standards for Reporting Qualitative Research was used to ensure high quality of the report (See Appendix N).

Results

Themes

Three themes and six subthemes were generated from the data and presented in Figure 1. The first theme, ‘how others treat me’ encapsulates the experiences participants had of receiving acceptance or a lack of acceptance from others, particularly during childhood. These experiences shaped how participants viewed themselves and how they attributed blame for perceived failings or flaws, which is the second theme ‘attributing responsibility’. Finally, how participants met their own needs, described in theme number three ‘how I treat myself’ was influenced by the first two themes.

A typical journey through these themes described by participants was to receive disapproval and criticism from parents, teachers and peers, leading participants to blame themselves and put pressure on themselves to change and try to fit in thereby compromising their own needs. Participants much less frequently described elements of the self-compassionate journey with acceptance from others, more balanced attribution of responsibility and meeting their own needs. These two journeys are not exclusive, and participants often spoke of experiencing both sides.

The blue arrows (Figure 1) identify common routes described by participants to gaining more self-compassion. An Autism diagnosis was a key facilitator for self-compassion and most participants received their diagnosis in adulthood, therefore time has been included as an element in the diagram to demonstrate the journey through childhood and adulthood, including further time taken to understand one’s own needs. However, all three themes appeared applicable in both childhood and adulthood.

Frances: “You know, you're on a journey of self-discovery even from the year dot in a way, and I’d always been trying to work out why I felt so out of place, and it definitely was a feeling out of place.”

Participants contribution to each theme are displayed in Table 4. Irrelevant data has been replaced by the use of ‘…’ and additional information is provided within ‘[ ]’. Pseudonyms are used to protect participant’s anonymity.

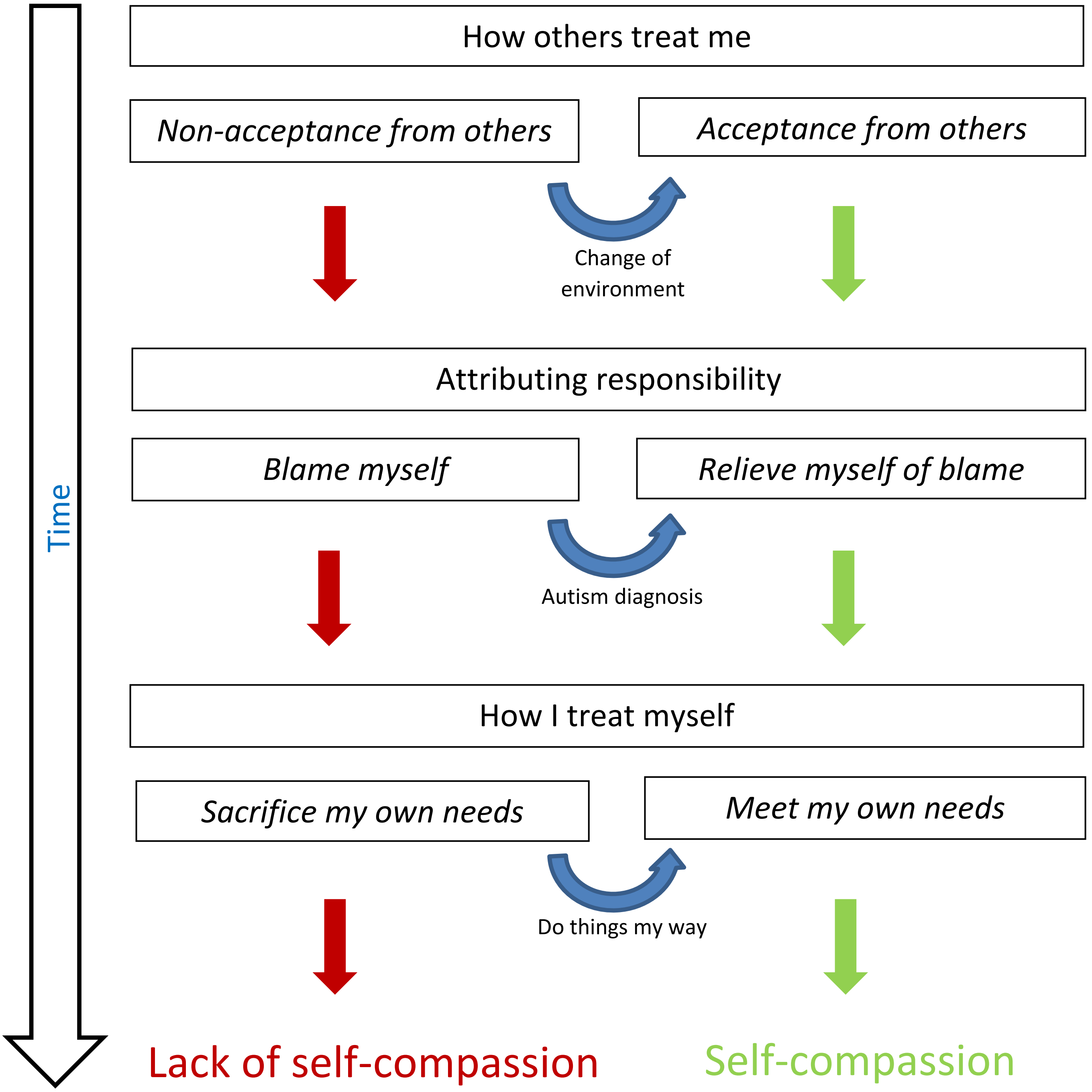
Table 4

Summary of Participant Contributions to Each Theme

Name	**How others treat me**		**Attributing responsibility**		**How I treat myself**	
	Non-acceptance from others	Acceptance from others	Blame myself	Relieve myself of blame	Compromising my own needs	Meeting my own needs
Lois	√	√		√	√	√
Daniel	√		√		√	
Iris	√		√	√	√	√
Abigail	√		√	√	√	√
Helen	√	√	√	√	√	√
Mary	√		√		√	√
Gwen	√		√	√		√
Molly	√	√	√	√	√	√
Nora		√	√	√	√	√
Frances	√		√	√	√	
Rachel	√	√	√	√	√	√
Arthur	√		√		√	
Randall	√		√	√	√	
Oliver	√	√	√	√		√
Peter	√	√	√		√	√

Figure 1

Thematic Map



Theme 1: How Others Treat Me

Non-Acceptance from Others

Most participants spoke about how a lack of self-compassion from others impacted their ability to be self-compassionate. Many participants spoke about how their parents' attitude towards them left them feeling not good enough in some way. Participants experienced abuse, criticism, disapproval, blame, and a lack of praise.

Iris: "I think part of it comes from, erm, when I was a child, because my mum was extremely critical of me and frequently angry and, err, so, (SIGH) I think it's more that I'm not really that accustomed to other people showing compassion to me, so it sort of didn't occur to me to show it to myself."

Participants spoke of expectations or standards set by parents and society in general which they found difficult to reach, which left them to repeatedly make mistakes, behave in unexpected ways and feel they had failed. Parents overtly and covertly communicated feelings of disappointment and embarrassment regarding their children's behaviour and characteristic, giving the impression they were not valued or undesirable. Some specific expectations described were around social communication and relationships, body movements, clothing, interests, and executive functioning, but it was also perceived as an ambiguous standard set by neurotypical people that was difficult to understand.

Peter: "[My parents] were extremely critical of me for being such a failure in life, because they were both straightforward sort of people, who had a very simple view of what people should do with their lives (LAUGH), and I wasn't able to do that, and they were not very kind to me."

Some participants also described receiving a lack of empathy to expressing their emotions, causing them to supress their emotions which was deemed more acceptable, or not share their emotions as people’s responses made them feel worse. Several participants also reported how they were treated differently at school, including being bullied, teased, and singled out by both peers and teachers.

Frances: “I think one of the things that happens to you, when you’re a child, is you have that inner compassionate streak absolutely knocked out of you. You’re bullied to heck at school, often by the teachers, as well as the children, so you have no safe place to go.”

Having a lack of a supportive social network to care for you when you make a mistake was mentioned as a barrier to being forgiving of your mistakes. Overall, a lack of experiencing kindness from others, less tolerance for difference, harsh judgments, and unobtainable standards meant that participants formed negative perceptions of self in childhood which fostered a default position of self-criticism.

Molly: “If you're in an environment where people are being quite toxic and hostile, it sinks into your psyche a bit easier if you are neurodiverse, as you may have received messages from being a child that “oh you're rude” or something like that, you know.”

The experience of people being unkind, and getting things ‘wrong’, also continued into adulthood, with participants reporting difficulties in relationships in their personal life, at work and in the community, therefore contributing to the negative view of themselves.

Acceptance from Others

Being in an environment where people were accepting and kind appeared to facilitate self-compassion, however this was reported much less frequently. Participants shared that feeling comfortable to be themselves and being around people who appreciated their strengths helped them to feel more positive about themselves and more accepting of their differences. One participant described how she changed from being very quiet to very confident and loud once the people who bullied her had left school:

Lois: “It’s like when I was like in the sixth form, I was like more myself, so, like, in the lower school, you could see maybe I camouflaged and masked quite a bit, like hiding my true self, and then in the sixth form I was like, you know what, I’m going to be kinder and I feel more comfortable in this environment, I’m going to be myself more, I enjoyed it more.”

In addition, other significant people displaying compassion taught participants compassion skills they could apply to themselves and others. Being able to be open about mistakes, difficulties, or misunderstandings enabled participants to be more forgiving towards themselves.

Nora: “It helps [at work] because people are kind…so it’s easier to say “sorry I just completely messed up or something”. If you can be open about things, it’s a lot easier to deal with, like, when you’ve got to hide things, that gets really bad, then it eats into you.”

Theme 2: Attributing Responsibility

Blame Myself

Participants often spoke about what they viewed as their faults or flaws and placed the responsibility with themselves for difficulties they had. One participant felt that because his failings were truths, he was unable to be kind to himself.

Randall: “I’m aware of my short comings, to say that I’ve got a, to say that I’m not in any relationship, that’s not blowing things out of proportion, actually that’s true… If I say I don’t know how to get things done, that’s not subjective opinion, I see everyone else getting things done and moving on with their life, I don’t see me doing that, so that’s just not me being hard on myself. That is objective facts, so no I don’t feel, I don’t feel the need to soften my analysis, I’d say it’s pretty accurate.”

Participants often felt to blame for things they had done wrong or were not very good at, particularly communication misunderstandings, relationship difficulties and feeling out of place. It was felt that the judgemental attitudes of people who aren’t autistic added to the belief that it must be something they were doing wrong.

Mary: “Being mystified to as to why everything has gone wrong, well not everything, things have gone wrong, and then I would always analyse “oh shit what went wrong there” because I didn’t understand it was Asperger’s and it was PDA [Pathological Demand Avoidance]… I wasn’t able to take that as a factor, so it was very much like ground hog day. You inevitably blame yourself… The problem for me is that I know intellectually that doesn’t help, but emotionally and kind of instinctively you do give yourself a good whipping over stuff.”

Participants also judged their behaviours in a binary manner, namely as right or wrong. Therefore, participants regarded anything slightly less than perfect or one small mistake as a failure, dismissing the grey area in between and focusing on the mistakes.

Helen: “If I hadn’t done something as good as I had done the day before, my automatic mind set was, and I’ll be honest still is ‘fail’, I find it very hard to get out of that fail… It’s probably black and white, I couldn’t see the middle ground and… I’d just pick on the things I did wrong rather than the things I did right.”

Locating the problem in themselves led to participants labelling themselves with negative terms such as “stupid”, “mad” and “inarticulate”. Participants spoke of this blame mindset being deeply entrenched, an automatic reaction and a habit. It was noted that accumulating evidence throughout their lifetime for their failings made it difficult to challenge the negative view of themselves and apply a more compassionate approach.

Participants shared that when they had performed well, they did not give themselves the credit and attributed the success to other people. Participants identified feeling arrogant as a barrier to acknowledging one’s own strengths and achievements.

Feeling they were responsible for the challenges they faced was exacerbated by comparing themselves unfavourably to others, particularly neurotypical people. Participants compared themselves for a range of abilities, such as being able to cope day to day, maintaining romantic relationships and excelling at specific skills.

Frances: “You're thinking to yourself, other people can cope with this, why can't I. You know, you're a rubbish human being sort of thing, yeah this is a huge ableist streak to it all because, you know, it takes time to work out that actually, maybe some of this is down to your sensory profile and actually the things that, you know, that walking into a really brightly, fluorescent lit space and getting a migraine is not because you're weak or inferior in anyway, it's because your sensory profile is such that you can't cope with that kind of lighting."

Relieve Myself of Blame

A common theme across participants was the influence of receiving an Autism diagnosis on their ability to being accepting of themselves. Participants shared how the diagnosis provided them with an explanation for the challenges they had encountered, relieving them of blame and helping them to understand why they were unable to meet the expectations placed on them. Having this framework enabled participants to be more accepting of their quirks and achievements, more forgiving of past experiences and more confident to be themselves.

Gwen: "To discover that the problems you've had all your life, are down to something that you could not, you didn't know about, and you didn't understand, and it would've meant that life would have been a lot easier if I'd known then, than finding out now, but it's still given me the ability to be able to look back and start to forgive myself for some of the things I've done and said."

In addition to attributing their difficulties to an Autism diagnosis, participants relieved blame of themselves by acknowledging the role other people play in their experience, for example that social interactions and communication are two-way process with shared responsibility or that people who treat you with unkindness are to blame.

Abigail: "I always used to consider myself to be the person, okay well this is my communication difference, therefore I am responsible for it, therefore if I don't understand, or they don't understand me, it's my fault, erm, and that's really difficult

(LAUGH). That’s a really difficult way to, erm, get through life I think, taking all that responsibility and, you know, yeah, and just, you know, my therapist is sort of reiterating I suppose that communication has to be 50/50.”

Locating difficulties in the diagnosis was not always regarded as helpful to how participants viewed themselves. Negative perceptions of Autism by others, including Autism as an illness or cognitive impairment and unhelpful stereotypes like “rain man”, were noted as reasons to not share their diagnoses with others. Participants reported being treated differently following a disclosure of their diagnosis or relationships ending, therefore reinforcing a negative self-image.

Arthur: “The few people that I've told, every single one of those, immediately after, the air felt different, and they drifted away… so it just, again, it negatively reinforces that self-image… It’s like I said, it's like they’re seeing an alien, that's why I tend to cover it up, because it's, like, I want to just be a human being like everyone else.”

Some participants shared they did not wish to be associated with Autism and that being with autistic people reminded them of their own flaws. Moreover, participants had encountered other people not believing the Autism diagnosis and regarding it as an excuse, rather than a valid reason. One participant found that they blamed all weaknesses on the Autism diagnosis, like a scapegoat, which was not helpful. In addition, one participant felt that despite absolving themselves of responsibility for many of their difficulties by placing the blame with genetics, this was irrelevant as it did not change the situation they were in. Thus, having an Autism diagnosis had a complicated relationship with participants’ ability to be self-compassionate.

Arthur: “Because of my very complicated and negative view of myself, I always feel ashamed to say it but, I hate autistic people, because they remind me of myself. I see all of these things about myself, that I am super critical of, that I hate about myself, that I really wish weren't true.”

Theme 3: How I Treat Myself

Sacrificing My Needs

Many participants spoke about hiding their true self through camouflaging or keeping a low profile to avoid negative attention, such as bullying. Participants shared that trying to fit in involved pushing oneself to do things that were uncomfortable and painful, for example large group events and parties or going to the supermarket at busy, lively periods, with consequences of exhaustion, stress and reduced confidence.

Abigail: “You know, ten years ago, or as a teenager, it would have been a case of, well, nobody else has to wear noise cancelling headphones in Tesco, therefore I shouldn’t either, if they can do it, I can do it, erm but then of course, you know, that led to a very miserable number of years for me (LAUGH)”.

Participants also spoke of trying to hide tic and self-stimulatory behaviour, such as hand flapping. Trying to be something you are not was recognised as a route to failure and frustration.

Rachel: “You kind of get the whole, like, well, how to speak, well you should smile and make eye contact, and make sure you ask lots of questions, all of that crap over and over again, the whole, sort of, generic stuff, and it's like, but I can't do that, so then you fail again, because, and it's like, you’re just setting myself up for failure again, it's like, but knowing that no I can't do that.”

Participants also altered what clothes they wore and kept quiet, which was at odds with their true personality. Moreover, trying to fit in involved analysing situations to prevent problems occurring in the future or to perform ‘better’. Participants also rehearsed conversations and tried to plan ahead so that situations would go differently next time. These strategies are both time-consuming and tiring.

Iris: “I’ll be replaying a lot of conversations that I’ve had with other people, “okay how did I do this right?”, “how did I do this wrong?”, like, “what did they mean when they said this?”, “how can I do this better in the future?”, “what did they think of me now?”, “is this something that I need to bring up with them again?”. There will be a lot of working out the day, which leads to not sleeping at night (LAUGH), erm, and it can be really difficult to stop those thoughts.”

In addition to sacrificing one’s own needs, external threats to basic needs were regarded as a challenge to self-compassion as it generated strong self-critical thoughts.

Peter: “Until the problems go away, no matter how nice I try to be to myself, if the problems are still huge, like the accommodation problem that I’m going through at the moment, then they will always have a louder voice, and they’ll be able to shut down the voice that tries to be nicer.”

Meet My Own Needs

One participant shared she felt much happier in herself when she acted naturally according to her character, even if it meant she received some negative attention from others. In addition, participants described being kind to themselves by understanding their own needs and socialising and engaging in activities in a way that suited them. Participants reported being kind to themselves involved being more selective about events they attended and saying no to events that would cause discomfort or anxiety. Participants also reported the need to leave situations if they felt too overwhelmed or uncomfortable due to sensory sensitivities or social anxiety.

Oliver: “Yeah it really just got me, sort of, kind of, an explanation. It’s kind of, for myself, it’s like, it’s okay, you don’t need to do this, like your autistic, and there’s a reason for it, and it, kind of, made me feel like I have my peace of mind, and sort of say no to things, and give myself more time to recover.”

However, participants noted the importance of finding a balance so that they did not avoid socialising completely causing feelings of loneliness or a lack of contribution to society, both of which led to more self-criticism. Participants shared that they had learned ways of engaging with others that made them feel more comfortable, such as meeting with friends one-to-one, being in a small class size and doing a physical activity alongside talking.

Lois: “Being able to form a few friendships, you know, something basic as that, you know, has made me feel a lot more accepting and happier of myself, and, like, I can still do it, I just have to do it in my own way, so it’s not like a neurotypical way of maybe making friends, or a neurotypical expectation, my expectations are just different, and my way of doing it is also different, it doesn’t make me any more or less of a person.”

Another aspect of self-compassion recognised by participants was giving themselves time to do what they want without judgment and being in control of their own routine. Having less energy due to the demands of everyday life and socialising meant that giving oneself time to recover was an important part of self-care. When reflecting on their experience of school, the library was regarded as a safe place to escape. However, participants also reported withdrawing from activities and relationships for fear of getting hurt and making mistakes. It was noted that doing less meant participants had less opportunity to get things right and their world got smaller. Therefore, taking time for oneself appeared to have different functions which could be both self-compassionate and self-sabotaging.

Daniel: “Perhaps being in trouble, or I’ve done something wrong, or I’ve been told off, it’s just something like that, and I think “oh my gosh”, you know “what have I done now, what haven’t I done right” and I thought, you know, it just puts me off, and it shouldn’t do, but it does, and that’s why I kind of be a bit reluctant to get involved… I just don’t want to get hurt again or shouted at.”

Several participants mentioned that therapy helped them to develop their understanding of themselves and to raise awareness of their needs. Therapy helped to identify needs that were being neglected and support participants to put their own needs as a priority.

Molly: “I suppose I've worked a lot, in the past couple of years, of putting my needs first, which I suppose comes under self-compassion and self-care… I always used to do things like “right you can have something to eat when you finish writing this or finished doing this” when actually, that's going to make it a lot harder for yourself, because you’re going to be tired and hungry. So I was always like a strict parent to myself, but in a very bad way.”

Making adaptions for sensory needs was one way that helped participants engage in the world while preventing unnecessary discomfort. One participant identified that messages from her upbringing that putting yourself first was vain and selfish was a barrier to putting her own needs first. In addition, several participants described being unaware of their emotions. One way of making sense of this it that having difficulty interpreting their emotions would impact on their ability to be compassionate toward their emotions.

Nora: “I’m not very sure about feelings, er, sometimes I have to notice what song’s come into my head… because that would give me a clue if there was a feeling going on. Then I would perhaps think “mmm interesting, what about that song” and then I might realise that maybe I was feeling a bit low or something… I mean it’s easy to know what thoughts are because you know they come in words. I suppose it’s more difficult to identify feelings.”

Discussion

This study aimed to investigate autistic adults' experiences of self-compassion. Three themes were established: *How others treat me*, *Attributing responsibility* and *How I treat myself.* In terms of the three elements of Neff's model (2003a), the experiences of the participants suggest that their ability to show self-kindness was largely hindered by negative interactions with others. Participants often felt isolated in their experiences and perceived failings, contributing to self-blame and isolation. Finally, participants described analysing and ruminating on past events and often struggled to recognise their feelings in the present moment which appeared to hinder the third component, mindfulness.

The first theme suggests that participants' ability to treat themselves with kindness is greatly influenced by how others treat them, particularly in childhood and teenage years. This finding is consistent with Gilbert's (2005, 2010) proposal that capacities for compassion are based on the attachment system. Others treating you with affection and care are central to feeling safe and experiencing positive feelings about the self (Bowlby, 1969; Mikulincer & Shaver, 2007). Whereas experiencing a lack of affection, bullying and abuse often result in a fear of self-compassion, and problems of shame and self-criticism (Andrews, 1998; Gilbert, 2007; Kaufman 1989; Schore 1998).

Participants described how other people modelling criticism and disapproval instead of compassion and acceptance meant they were not taught how to show themselves self-compassion. The negative treatment they received shaped how they saw themselves, and their internal monologues, which influenced how they made sense of personal differences and perceived mistakes. These experiences can be understood through the long-standing concepts of individuals learning to behave by modelling significant others, striving to meet conditions to receive approval from others, evaluating others based on similarities and differences, and developing self-concepts through interactions with significant others in childhood (Bandura, 1977; Baumrind, 1977; Coopersmith, 1967; Rogers, 1959; Tajfel & Turner, 1979).

Most participants felt their inability to meet a desired standard was to blame for the difficulties they encountered. It appears that many social norms and neurotypical standards are at odds with the differences held by autistic individuals, therefore making it difficult to meet the expectations of others. Participants reported a lack of acceptance and unfair treatment which contributed to self-criticism and became a default mindset. Gilbert (2009) explains how individuals with early experiences of hostility can become sensitive to threats of rejection and criticism and cope by attacking oneself. The extent to which autistic individuals face oppression has been well documented, for example high levels of discrimination in the community (Jones et al., 2022), stigma and social rejection from peers at university (Underhill et al., 2019) and greater risk of school victimization and verbal bullying than typically developing peers (Maïano et al., 2016).

According to the attribution of responsibility literature, evading personal responsibility for behaviour that has negative outcomes and having an external locus of control, known as self-serving bias, can protect one's self-image and alleviate some of the unpleasant consequences (Mezulis et al., 2004; Phares, 1979; Schlenker et al., 1990; Snyder et al., 1983, Weiner et al., 1986). Participants often attributed perceived failures to their own characteristics, yet attributed successes to external factors. The conventional understanding of Autism, which stems from the medical model, also attributes autistics people's difficulties to personal deficits, disregarding interpersonal and societal contributions to autistic people's challenges

(American Psychiatric Association, 2013; Camus et al., 2022). Furthermore, Autism research has historically presented autistic characteristics as impairments and placed the responsibility of interaction difficulties on autistic people (Camus et al., 2022).

Feeling responsible for mistakes and flaws caused participants to analyse past events, hide parts of their character, and push themselves to engage in actions they found uncomfortable or unbearable. A desire to feel socially accepted, and a fear of rejection, fed into rumination and a pressure to sacrifice one's own needs to fit in, which was a significant barrier to practicing self-compassion. Participants reported consequences of exhaustion, stress, and a lack of confidence. Similarly, Hull (2017) found that pressures of the typical social world prevented autistic individuals from showing their 'true' or natural behaviours and many found camouflaging mentally, physically, and emotionally draining.

Feeling isolated is a threat to one's sense of belonging and connectedness (Neff, 2003). Participants often reported feeling their own difficulties were unique or more severe. In addition, participants reported that other people hiding their struggles or not being obvious about their struggles made it difficult to recognise they are not alone in having struggles. Some participants also shared that recognising other people have struggles meant they felt high levels of empathy and ended up feeling worse. This may be explained by evidence that autistic individuals experience overwhelming emotional empathy compared to typically developed individuals (Markram et al. 2007; Smith, 2009).

Participants described difficulties recognising their feelings in the present moment. Research suggests alexithymia, difficulties in recognising and expressing emotions and bodily sensations, is heightened in the autistic population (Kinnaird, 2019), and may impact ability to feel compassion for one's feelings.

A problem that participants encountered was avoiding socialising and withdrawing to the point of feeling lonely. Dreisoerner et al. (2021) describes how self-criticism leads to shame, which leads to less socially oriented behaviour, ultimately leading to social exclusion. Participants attempted to protect themselves against social difficulties by withdrawing which led to further isolation. Autistic adults and adolescents have reported higher levels of loneliness than non-autistic adults (Deckers et al., 2017).

Participants described a more self-compassionate approach was to be themselves and engage in the world a way that made them feel comfortable. This was partly influenced by how people in the environment acted towards them, for example being accepting of and kind in response to misunderstandings and mistakes. Leary et al. (2007) found that self-compassion can be an effective buffer against stress caused by failure, rejection, or embarrassment. This study has found that one's environment is a key factor to facilitating this self-compassion.

This study also found that having an explanation for being different facilitated self-compassion. This is supported by Leedham et al.'s (2020) research which found that a diagnosis facilitated letting go of blame, acceptance of themselves and kindness towards themselves. Bullus and Sesterka (2020) also assert that a diagnosis of Autism helped traits to feel understandable and acceptable.

Adopting the philosophy of the neurodiversity movement, which celebrates and respects neurological differences, would help both autistic individuals and society as a whole appreciate their traits (Den Houting, 2019; Nicolaidis, 2012). In addition, acknowledging the wider systemic issues, such as how neutral and positive differences are pathologised, would be a useful step towards relieving some blame and facilitating self-compassion. Difficulties with social communication and interaction are often placed in autistic individuals, when it is a two-sided process (Milton, 2012). Research has found that non-autistic people also have difficulty interpreting autistic people's behaviour, and misunderstandings are a joint experience (Edey et al., 2016; Heasman & Gillespie, 2018). Milton (2012) has proposed the double empathy problem which recognises difficulties in communication are due to lack of a *shared* understanding between autistic and non-autistic individuals. Sharing responsibility for communication issues is important for limiting damage to one's self-concept.

Strengths and Limitations

The findings of this study add an original contribution to the limited research conducted in self-compassion and Autism. Moreover, a substantial amount of rich data was gathered from the participants. Among the sample, most participants were White British, received a diagnosis in adulthood and engaged in higher education. Although the eligibility criteria included all genders, the sample was predominantly women. Therefore, this may limit the transferability of findings to other contexts. Previous research suggests that neurotypical women tend to have lower levels of self-compassion than men (Yarnell et al., 2015), which may have been a pattern within the sample in this study. There may be differences in the experiences of autistic people from minority groups who face additional discrimination, prejudice, or non-acceptance. This study did not gather information on many social and personal identity areas, such as sexual orientation or disability, which can impact an individuals' experience. Gathering this information would have provided additional context to the findings. Another possible limitation of the research is that the lead researcher is non-autistic. Although the lead researcher involved experts by experience via consultation throughout the process, the research has not been truly co-produced with autistic people.

Implications for Research and Practice

Further research focused on the experiences of autistic individuals diagnosed during childhood would be valuable, to see if their experiences of self-compassion are similar to the sample used in this study. Having an explanation during childhood for difficulties encountered may provide a route to self-compassion earlier in life. Currently Autism diagnostic services are failing to meet the level of demand and there are long waiting times for assessments (BMA, 2020). The current study suggests that earlier diagnosis may be beneficial for facilitating self-compassion and preventing a self-critical attitude becoming ingrained. Thus, highlighting the importance of reducing waiting times and timely referrals.

A key finding of this study is the influence of significant others and peers on self-compassion. Incorporating education on Autism into the National Curriculum is crucial for promoting Autism acceptance in schools. Campaigns to raise public awareness of Autism have been successful (Dillenburger et al., 2015), however more needs to be done to create a more inclusive society. Policies to support employers to welcome diversity and to embed inclusive practice in the workplace are fundamental. It is key that family members and carers of autistic individuals are supported by services to demonstrate kindness, care and understanding, particularly in relation to behaviours which may not meet an expected standard. Professionals modelling and encouraging a celebration of neurodiversity, using strength-based approaches, will facilitate a compassionate environment.

Interventions focused on reducing feelings of blame and isolation may be useful for autistic individuals. Compassion-focused therapy is designed to address shame and self-criticism (Gilbert, 2009b). Feelings of inadequacy and shame are linked to self-blame and self-criticism. Interventions targeting these areas can help facilitate self-compassion, which in turn can improve well-being and reduce psychological distress (Sommers-Spijkerman et al., 2018). Additionally, supporting autistic individuals to engage socially in the world in a way that successfully meets their social, emotional, and sensory needs successfully will be a key element to any intervention.

Conclusions

Evidence suggests that autistic adults unfairly face stigma and a lack of acceptance in the community. Self-compassion is a quality that has been found to improve mental wellbeing and act as a buffer for stigma. This study found that a lack of acceptance from parents and peers fed into self-blame and self-criticism. To protect themselves from social rejection, participants described hiding their true self or withdrawing from social events. Being in an accepting and forgiving environment, and having an explanation for their difficulties, facilitated self-kindness. Participants reported that having a diagnosis enabled them to understand their own needs better and socialise on their own terms. Recognising the role of society in the difficulties faced by autistic individuals and promoting an acceptance of difference may help to relieve some self-blame and strengthen self-compassion among autistic individuals.

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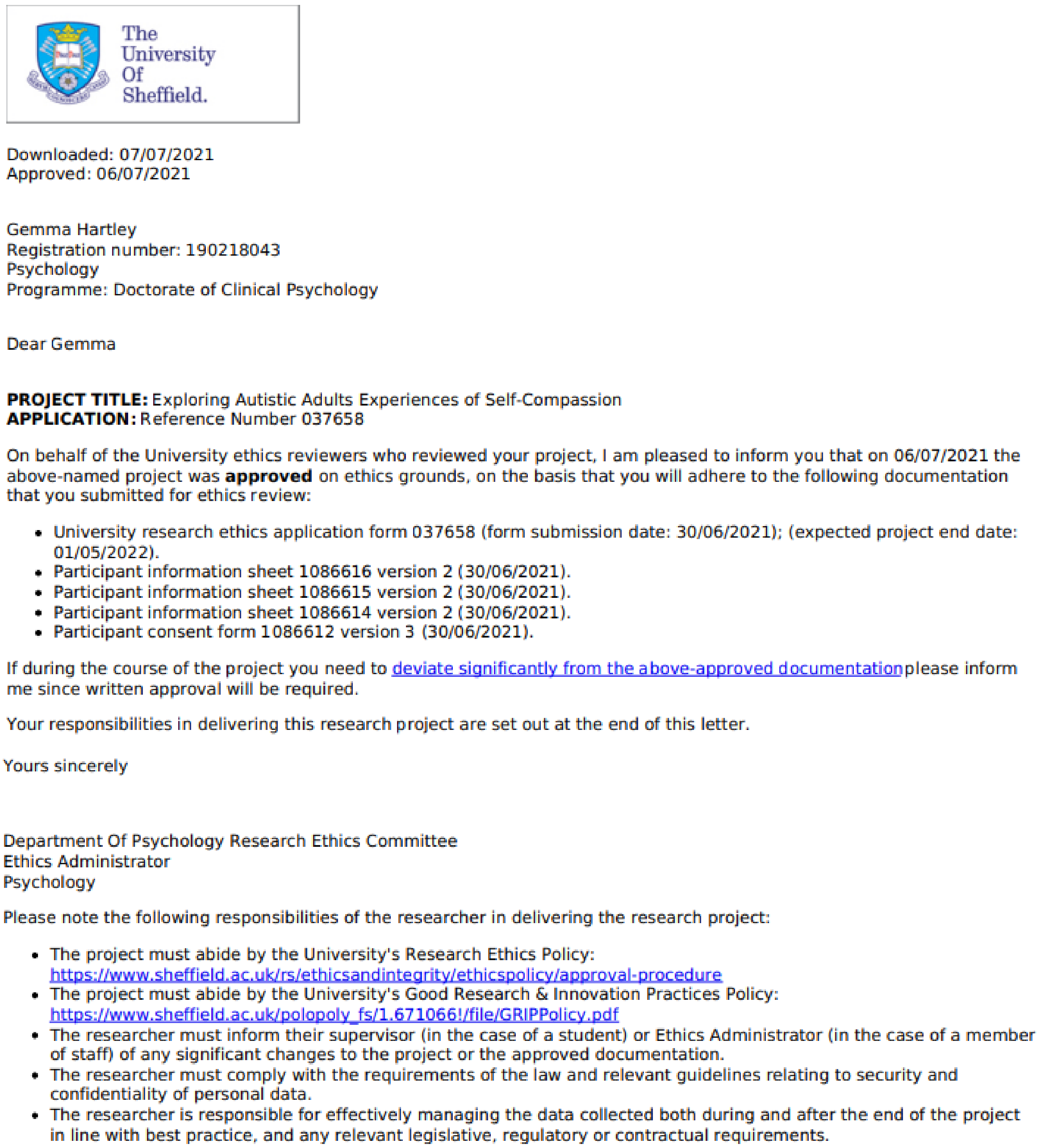
Appendices

Appendix A

Ethical Approval Letter



Downloaded: 07/07/2021
Approved: 06/07/2021

Gemma Hartley
Registration number: 190218043
Psychology
Programme: Doctorate of Clinical Psychology

Dear Gemma

PROJECT TITLE: Exploring Autistic Adults Experiences of Self-Compassion
APPLICATION: Reference Number 037658

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 06/07/2021 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 037658 (form submission date: 30/06/2021); (expected project end date: 01/05/2022).
- Participant information sheet 1086616 version 2 (30/06/2021).
- Participant information sheet 1086615 version 2 (30/06/2021).
- Participant information sheet 1086614 version 2 (30/06/2021).
- Participant consent form 1086612 version 3 (30/06/2021).

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

Department Of Psychology Research Ethics Committee
Ethics Administrator
Psychology

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy: https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/approval-procedure
- The project must abide by the University's Good Research & Innovation Practices Policy: https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf
- The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member of staff) of any significant changes to the project or the approved documentation.
- The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

Appendix B

Participant Information Sheet

The
University
Of
Sheffield.

Department Of Psychology.

Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme

You are invited to take part in the following research project: ‘Having Autism and Being Kind, Understanding and Accepting Of Myself: What Helps and What Makes it Difficult?’

You are being invited to take part in a research project. Before you decide whether or not to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the research?

The purpose of the research is to find out more about autistic adults’ experiences of being kind, understanding and accepting of oneself. This involves thinking about how you view and treat yourself, how you make sense of difficult experiences and how you respond to negative thoughts and feelings. The research aims to hear from autistic adults’ perspectives what factors make it easier and more difficult to be kind, understanding and accepting of oneself.

The research is being conducted by Gemma Hartley, a Trainee Clinical Psychologist at the University of Sheffield as part of her Doctorate in Clinical Psychology. The project will run till May 2022.

Why have I been invited to take part?

You have previously agreed to being contacted to be invited to take part in research projects. Gemma would like to interview approximately fourteen autistic adults for the research project.

What will happen to me if I take part and what do I have to do?

You will be asked to complete a consent form. You will then be asked to provide demographic information about your age, gender, place of residence, ethnicity, education, and details of autism diagnosis. You will also be asked to complete a questionnaire which indicates your level of self-compassion. You will take part in one interview which will take between 60-90 minutes. The interview will be conducted remotely, either via a telephone call or video call depending on your preference. You will be asked questions about how you view yourself and how you deal with difficult experiences. Questions will be open to enable you to discuss this topic in-depth. Hearing about your experiences will provide insight into what factors make it easier and more difficult to be kind, understanding and accepting of oneself.

Will I be recorded and how will the recording be used?

Gemma will ask for your permission to digitally audio record the interview so she can listen back to it and so they can be transcribed. Interviews over the phone will be placed on loud speak to allow the audio to be recorded. The audio recordings of your interview made during this research will be used only for analysis and for illustration in conference presentations and lectures. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.

The recorder is encrypted, meaning only a person with a password can access this. Recordings from the interview will be moved to a password-protected data repository, then deleted from the recorder. Only Gemma, her supervisors and a transcriber will have access to this information. Once they have been transcribed, they will be disposed of appropriately.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you then change your mind you can withdraw at any time during data collection and up to one month after the interview. If you chose to withdraw you will remain on the database for invitations future research and there will be no negative consequences. You do not have to give a reason. If you wish to withdraw from the research, please contact Gemma Hartley via email (ghartley3@sheffield.ac.uk) or phone (01142226650). You also have the right to not answer any questions during the interview or stop the interview.

What are the possible disadvantages and risks of taking part?

In the interview, you may talk about difficult experiences that have impacted your ability to be kind, understanding and accepting of yourself or led you to be critical of yourself. If you do feel uncomfortable or upset during the interview, the interview can be ended or paused. During the interview, please tell Gemma if you wish to take a break or end the interview. If Gemma is concerned about your wellbeing or the wellbeing of someone else based on something you say, she will talk to you about this. If needed, she will talk to you about services that can support you, such as your GP or the Samaritans.

What are the possible benefits of taking part?

You will receive a £5 amazon voucher as a thank you for your time. In addition, whilst there are no other immediate benefits for those people participating in the project, they can find it helpful to talk about their experiences and feel they are contributing to the wider society. It is hoped that this work will help to create an understanding of autistic adults' experiences, which will be useful for thinking about ways to improve wellbeing.

Will my taking part in this project be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential and will only be accessible to members of the research team. You will not be able to be identified in any reports or publications unless you have given your explicit consent for this. If you agree to us sharing the information you provide with other researchers, then your personal details will not be included unless you explicitly request this.

In the unlikely event that Gemma has immediate and serious concerns about your wellbeing or another person's wellbeing, she has a duty to ensure your safety and that of other people. In an emergency, if Gemma believes you or someone else are at risk of serious harm, she may need to arrange a police welfare check to prevent serious harm.

What will happen to the data collected, and the results of the research project?

The interview will be transcribed by Gemma or a transcriber. The transcriber will be bound by confidentiality guidelines. The transcriptions will be reviewed and themes will be identified linking the interviews together.

Gemma plans to publish the findings from the research in the Journal of Autism and Developmental Disorders. The findings will be shared at conferences, lectures, online, such as the Sheffield Autism Research Lab webpage and paper resources, such as Your Autism magazine.

To ensure anonymity (keeping your identity unknown), the researcher will remove any details that will potentially identify you as a participant, such as your name or address, from any documents, websites, presentations, or publications. A pseudonym (fictional name) will be assigned to your data to further maintain anonymity. Sensitive information, such as your age, gender, place of residence, ethnicity, education, and details of autism diagnosis, will be combined with the information of the other participants to describe the group and will not be connected to your data.

The data will be stored securely until the research project is completed, which aims to be within 18 months of the interview, but no longer than six years and then destroyed confidentially. Identifiable personal data will be destroyed one month after the interview.

You will be asked to electronically sign a form confirming that you have received the amazon voucher. This form will be saved securely in a password-protected data repository for seven years after the end of the project, accessible by the University finance and administrative staff for reference in the event of a financial audit.

Who is organising and funding the research?

This research project is funded by the University of Sheffield.

What is the legal basis for processing my personal data?

In order to collect and use your personal information as part of this research project, we must have a basis in law to do so. The basis that we are using is that the research is ‘a task in the public interest’. Further information can be found in the University’s Privacy Notice:

https://www.sheffield.ac.uk/govern/data-protection/privacy/general

As we will be collecting some data that is defined in the legislation as more sensitive (information about your ethnicity) we also need to let you know that we are applying the following condition in law: that the use of your data is ‘necessary for scientific or historical research purposes’.

For more guidance on legal bases, including the additional conditions that apply to ‘Special Category’ personal data, refer to the University’s Research Ethics Policy Note, and Specialist Research Ethics Guidance paper, on ‘Anonymity, Confidentiality and Data Protection’:

https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/further-guidance/homepage

Who is the Data Controller?

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

Who has ethically reviewed the project?

This project has received ethical approval from the Department of Psychology Ethics Committee.

What if something goes wrong and I wish to complain about the research?

If you are concerned about anything about the project, please contact Gemma and she will do her best to address this.

If you wish to raise a complaint contact, please contact:

The research supervisor: Fuschia Sirois (f.sirois@sheffield.ac.uk)

If you feel your complaint has not been handled to your satisfaction, you can contact Head of Department, who will then escalate the complaint through the appropriate channels.

Head of department: Liz Milne (e.milne@sheffield.sheffield.ac.uk)

If the complaint relates to your treatment by researchers, please contact Fuschia Sirois (f.sirois@sheffield.ac.uk).

If the complaint relates to a serious event occurring during or following their participation in the project please contact Liz Milne (e.milne@sheffield.sheffield.ac.uk).

If the complaint relates to how your personal data has been handled, information about how to raise a complaint can be found in the University's Privacy Notice: https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

Contact for further information

For further information about the project please contact:

Lead researcher: Gemma Hartley

Email address: ghartley3@sheffield.ac.uk

Phone number: 01142226650 (leave a message with the Research Support Officer Amrit Sinha 01142226650 and Gemma will call you back)

Supervisor: Fuschia Sirois

Email address: f.sirois@sheffield.ac.uk

Thank you for taking part in the project.

Appendix C

Consent Form

Please Select the appropriate response.

	Yes	No
Taking Part in the Project		
I am the above-named person.	☐	☐
I have read and understood the project information sheet or the project has been fully explained to me. (If you will answer No to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.)	☐	☐
I have been given the opportunity to ask questions about the project.	☐	☐
I agree to take part in the project. I understand that taking part in the project will include providing demographic information (age, gender, place of residence, ethnicity, education, and details of autism diagnosis), completing one questionnaire and being audio recorded during an interview which will take approximately 60- 90 minutes and be conducted over the telephone or via videocall.	☐	☐
I understand that my taking part is voluntary and that I can withdraw from the study up to one month following the interview;I do not have to give any reasons for why I no longer want to take part and there will be no adverse consequences if I choose to withdraw.	☐	☐
If I do not want to answer any question or questions, I understand that I am free to decline.	☐	☐
How my information will be used during and after the project		
I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project, unless deemed necessary for my safety or the safety of someone else.	☐	☐
I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs unless I specifically request this.	☐	☐
I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	☐	☐
I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	☐	☐
If, during my interview, I were to tell the researcher that I or someone else was at risk of harm, I understand that confidentiality may be broken to ensure my safety and that of other people (as outlined in the participant information sheet).		
I give permission for the anonymous data that I provide to be deposited in the Dept. of Psychology at the University of Sheffield so it can be used for future research and learning.		

So that the information you provide can be used legally by the researchers		
I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.	☐	☐

Do you wish to continue?

To acknowledge that you have read and understood this information and would like to continue with the research study, please click on “I agree”.

☐ I agree

☐ No thank you

Appendix D

Participant Invitation Email

The
University
Of
Sheffield.

Department Of Psychology.

Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme

Invitation to take part in research

Dear [participant name],

I hope my email finds you well. My name is Gemma Hartley and I am a Trainee Clinical Psychologist at the University of Sheffield.

You have previously agreed to being contacted to be invited to take part in research projects. I am emailing to ask if you would be interested in taking part in my research study: ‘Having Autism and Being Kind, Understanding and Accepting of Myself: What Helps and What Makes it Difficult?’.

Why This Research Topic?

Research has shown that treating yourself with kindness and care has several benefits, including greater life satisfaction and less anxiety. Although research into this area has been growing, there is very little research looking at how autistic individuals experience being kind, understanding and accepting of themselves, which is why I would like to hear about your experience. You might feel that you are more critical of yourself and I am interested in hearing about this too.

It is known that autistic individuals can be treated unfairly by others, which can lead individuals to have negative views of themselves. Treating yourself with kindness and care can reduce negative views of yourself and help you to cope with difficulties. This way of treating yourself is a skill that can be taught and strengthened, but things can get in the way. Therefore, I would like to hear about what factors you think impact your ability to be kind and caring towards yourself.

Research has shown that therapy and training focused on being kind and caring to yourself can result in improvements in wellbeing and reduced self-criticism. The research I am inviting you to take part in will help to create an understanding of autistic adults’ experiences, which will be useful for thinking about ways to improve wellbeing.

How Will It Be Conducted?

I will be interviewing about fourteen participants one at a time to find out about their perspectives. Each participant will be invited to one interview which will be conducted remotely, either via a telephone call or videocall depending on your preference. During the interview I would be asking about how you view and treat yourself, how you make sense of difficult experiences and how you respond to negative thoughts and feelings.

Who Is Eligible?

To be included in the project you need to meet the following criteria:

- Aged 18 years and older
- Have a diagnosis of Autism or Asperger's
- Any gender identity
- Be able to consent to participate
- Speak English fluently

What Should I Do If I'm Interested?

If you are interested in taking part in this study, please contact me by my email: ghartley3@sheffield.ac.uk stating your interest. I will then email you a copy of the information sheet and a weblink to a consent form and survey, and if you would like to take part, we can arrange a remote interview at a convenient date and time.

If you have any questions, please contact me on ghartley3@sheffield.ac.uk.

The project has ethical approval from University of Sheffield. This study is voluntary. If you do not wish to take part, please ignore this email.

Thank you for your time.

Kind regards,

Gemma Hartley

Appendix E

Survey

Demographics Questionnaire

What is your current age (in years)?

____

How would you describe your gender identity?

____

In what country/ continent do you currently live?

United Kingdom

Australia

USA

Canada

Europe

Other (please specify)

____

What ethnic/cultural background do you most identify with? (For example: White British, White and Black Caribbean, Indian, Black African, Arab, etc.)

____

What is your highest level of education/ qualification? (Choose one only)

☐ Primary school

☐ Secondary school with no formal qualification

☐ Secondary school with formal qualification (GCSE or equivalent)

☐ Further education (A Level or equivalent)

☐ Higher education below Bachelor’s degree level (Diploma of Higher Education, Foundation Degree or equivalent)

☐ Bachelor’s degree level (Bachelor’s degree or equivalent)

☐ Postgraduate level qualification (Master’s level and above)

What diagnostic term did you receive in relation to Autism?

____

What age were you when you received this diagnosis (in years)?

____

How many years has it been since you received this diagnosis?

____

What is your preferred term to use in relation to Autism?

____

<u>Self-Compassion Scale</u>

How I Typically Act Towards Myself In Difficult Times

Please read each statement carefully before answering. To the left of each item, indicate how often you behave in the stated manner, using the following scale:

Almost never				Almost always
1	2	3	4	5

____ 1. I'm disapproving and judgmental about my own flaws and inadequacies.

____ 2. When I'm feeling down, I tend to obsess and fixate on everything that's wrong.

____ 3. When things are going badly for me, I see the difficulties as part of life that everyone goes through.

____ 4. When I think about my inadequacies, it tends to make me feel more separate and cut off from the rest of the world.

____ 5. I try to be loving towards myself when I'm feeling emotional pain.

____ 6. When I fail at something important to me, I become consumed by feelings of inadequacy.

____ 7. When I'm down and out, I remind myself that there are lots of other people in the world feeling like I am.

____ 8. When times are really difficult, I tend to be tough on myself.

____ 9. When something upsets me, I try to keep my emotions in balance.

____ 10. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.

____ 11. I’m intolerant and impatient towards those aspects of my personality I don't like.

____ 12. When I’m going through a very hard time, I give myself the caring and tenderness I need.

____ 13. When I’m feeling down, I tend to feel like most other people are probably happier than I am.

____ 14. When something painful happens, I try to take a balanced view of the situation.

____ 15. I try to see my failings as part of the human condition.

____ 16. When I see aspects of myself that I don’t like, I get down on myself.

____ 17. When I fail at something important to me, I try to keep things in perspective.

____ 18. When I’m really struggling, I tend to feel like other people must be having an easier time of it.

____ 19. I’m kind to myself when I’m experiencing suffering.

____ 20. When something upsets me, I get carried away with my feelings.

____ 21. I can be a bit cold-hearted towards myself when I'm experiencing suffering.

____ 22. When I'm feeling down, I try to approach my feelings with curiosity and openness.

____ 23. I’m tolerant of my own flaws and inadequacies.

____ 24. When something painful happens, I tend to blow the incident out of proportion.

____ 25. When I fail at something that's important to me, I tend to feel alone in my failure.

____ 26. I try to be understanding and patient towards those aspects of my personality I don't like.

Thank you for your time. It is greatly appreciated. Please click the arrow below to send your responses. Gemma will be in touch shortly to offer interview dates and times.

Appendix F

Definition of Self-Compassion

What is Self-Compassion?

As defined by Dr. Kristin Neff.

Image taken from https://goalive.eu/self-compassion/

When we feel compassion for another person, we notice they are suffering. If we ignore the suffering, we cannot feel compassion for how difficult that person’s experience is. We feel warmth and caring towards their suffering and offer understanding and kindness in response to failures or mistakes, rather than judging them harshly. Rather than feeling pity, we realise that suffering, failure and imperfection is something that all humans experience.

These three elements also apply when we have self-compassion. For example, if you experience something upsetting, instead of ignoring your feelings and pretending everything is ok, you stop to acknowledge your feelings and how difficult the situation is. You think about how you can comfort and care for yourself. Self-compassion means remembering that you are not alone and we ALL experience challenging times.

Having self-compassion means you accept things will not always go the way you want them to and we all have flaws and make mistakes. Rather than getting angry when your expectations are not met or criticising yourself, self-compassion means you are kind and understanding to yourself.

Appendix G

Interview Topics

What Topics Will I Be Asked About in The Interview?

I thought it would be useful to give you an idea of the sort of things you will be asked in the interview, to give you time to think beforehand about your experiences and prevent you from feeling 'put on the spot'. These questions are not the exact version of the interview questions, but a rough guide. The interview will be guided by what you say and will change accordingly to allow you to share what you think is important.

Feel free to jot down notes if you feel they would be helpful, but this is not an expectation. Please do not discuss these questions with anyone before the interview as I am interested in *your* thoughts and experiences and do not want these to be influenced by someone else.

During the interview, I will ask you to talk about:

- Times when you have shown yourself kindness e.g. saying nice words to yourself or forgiving your mistakes
- Times when you've been tough on self e.g. feeling not good enough or focusing on your flaws
- Times you have recognised that everyone has difficulties and imperfections as it is part of being human
- Times when you feel like you are the only one facing problems or making mistakes
- Times you have acknowledged and accepted your thoughts and feelings without judgement or feeling overwhelmed
- Times you have tried to supress/ ignore your thoughts and feelings
- Times you get consumed by/ overwhelmed by your thoughts and feelings

For each of these areas, I will ask you about what you think has influenced the way you view yourself and your experiences e.g. your past experiences, society, relationships with others, autism or anything else.

I will also ask for your thoughts about what helps you to be self-compassionate and what makes it difficult.

Appendix H

Interview Schedule

1. One aspect of self-compassion involves being kind, caring and understanding of ourselves when things are difficult. This could be with big or small events and things that are under or out of your control.

   a) When things are difficult, are there times when you are show kindness, care or understanding to yourself, for example being accepting of who you are, saying kind words to yourself or forgiving yourself for mistakes?

   Prompts:

- Could you tell me more about how you show kindness, care or understanding to yourself?
- Are there times when you take time for yourself or to do things you enjoy?
- Can you tell me about a time in your life where you were kind, caring or understanding to yourself and describe this to me in as much detail as possible?
- Do you think having Autism has influenced this?
- Has there been anything that has helped you to be accepting of yourself during difficult times?
- How has your past experiences such as childhood, society's influence, relationships with others impacted how you treat yourself positively?

   b) Most of us have times when we might instead be critical or judgemental towards ourselves, for example being judgemental about our flaws, having a negative voice in our head telling us we're not good enough or focusing on things we don't like about ourselves. Are there are times when you are tough on yourself like this or in a different way?

   Prompts:

- Could you tell me more about what you do or say to yourself when you're being tough on yourself?
- Have you noticed any triggers for this?
- Do you think having Autism has influenced this?
- Can you tell me about a time in your life where you were tough on yourself and describe this to me in as much detail as possible?

- What do you think feeds the behaviour of being tough on yourself? (For example, childhood, past experiences, society's influence, relationships with others or anything you've learned). Do you think having Autism has influenced this?
- What makes it harder for you to be kind towards yourself? Do you think having Autism has influenced this?
- Is there anything you think would help you to be more accepting of yourself or less critical of yourself?

[Check if participant needs a break]

2. Self-compassion involves recognising that everyone faces challenges and being imperfect is part of being human.

    a) When things feel difficult, are there times when you can see your difficulties and/ or imperfections as part of life and that everyone has their own struggles?

    Prompts:

- Can you tell me more about this?
- What thoughts do you have?
- Do you think having Autism has influenced this?
- Can you tell me about a time in your life when you saw your difficulties as normal or natural?
- Can you tell me about a time in your life when you saw your imperfections or mistakes as normal or natural?
- What kind of things have helped you see your difficulties or imperfections as normal or natural? (For example your past experiences, society's influence, relationships with others or anything you've learned).
- Is there anything that helps you to remember that difficulties are part of life and you are not the only one having difficulties and/ or imperfections? Do you think having Autism has influenced this?
- Do you have any connections with other people with Autism?

    b) When life gets difficult or we feel down, we can feel alone and believe we are to blame for our difficulties or imperfections. When things go wrong, are there times when you feel like you are the only one facing problems or making mistakes?

Prompts:

- Can you tell me more about this? Do you think having Autism has influenced this?
- What kind of things make you feel more alone or separate from everyone else? Do you think having Autism has influenced this?
- Can you tell me about a time in your life when you felt you were the only person suffering with difficult feelings or making mistakes?
- What makes it harder for you to see your difficulties as a normal part of life? What has influenced this? (For example past experiences, society's influence, relationships with others or anything you've learned). Do you think having Autism has influenced this?
- Is there anything you think would help you to recognise that failings and difficulties are a shared human experience and you are not alone in having struggles?

[Check if participant needs a break]

3) Another aspect of self-compassion is acknowledging our negative thoughts and feelings with openness and curiosity.

a) When something bad happens, are there times when you can take a moment to notice and validate your thoughts and feelings rather than thinking "I shouldn't be feeling like this" or feeling overwhelmed by them?
   - Do you find you are able to keep your feelings in balance and keep things in perspective?
   - What impact does this have on you and your life?
   - Can you tell me more about this?
   - Do you think having Autism has influenced this?
   - Can you tell me about a time in your life when you have been open to having difficult thoughts and feelings? How was this for you?
   - What helps you to notice and validate your thoughts and feelings? What has influenced this? (For example past experiences, society's influence, relationships with others or anything you've learned). Do you think having Autism has influenced this?
   - What helps you to keep your feelings in balance and keep things in perspective? Do you think having Autism has influenced this?

b) When something bad happens, are there times when you get consumed by or dwell on your thoughts and feelings?

- What happens?

- Do you find that you fixate on what is wrong or what went wrong?
- Can you tell me more about this?
- Do you think having Autism has influenced this?
- What makes you more likely to get caught up with your thoughts and feelings? Do you think having Autism has influenced this?
- What makes it difficult to keep your feelings in balance? Do you think having Autism has influenced this?
- What has influenced this? (For example past experiences, society's influence, relationships with others or anything you've learned).
- Is there anything you think would help you to keep your feelings in balance and keep things in perspective?

c) Sometimes we can find ourselves either supressing our thoughts and feelings rather than be open to them. When something bad happens, are there times when you get try to supress your thoughts and feelings e.g. distract yourself from them?

    - Can you tell me more about what you do and what happens?

  - Do you think having Autism has influenced this?
  - What makes you more likely to supress your thoughts and feelings? Do you think having Autism has influenced this?
  - What has influenced this? (For example past experiences, society's influence, relationships with others or anything you've learned).
  - Is there anything you think would help you to be more open to your thoughts and feelings?

4) Is there anything else you would like to tell me in relation to your experience of self-compassion?

Appendix I

Excerpts from Reflexivity Log

Personal Reflexivity

Initial Thoughts

I am a non-autistic researcher, therefore recognise my own limitations interpreting the experiences of autistic people. I have strong values around social justice and celebrating diversity. I am a heterosexual, middle class, white British, cis-gender, non-disabled, younger, non-migrant living in Britain and acknowledge the privileged position this brings. I am female which brings with it some challenges and marginality in society, however within my society I mostly feel empowered and independent. I have left-wing, liberal political views, supporting equality and internationalism. I am a trainee clinical psychologist, which I am aware can place me in a position of power. My experience working in a paediatric Autism diagnostic service has shown me the improvements needed to support autistic people, which drives my interest in this research area. Colleagues in the field have anecdotally commented on the self-critical tendencies of autistic clients they have seen, so it will be interesting to hear about how the autistic participants experience self-compassion. I believe people generally say what they think and how they feel and will not be interrogating meaning behind the words spoken. I hope to get the research published and influence services.

Reflecting During Writing

Although I feel there is some distance between my personal experiences and the experiences of the group of participants, there are elements that I can resonate with. I used to be very self-critical myself and have been on a journey to being more self-compassionate, so it is interesting to see the similarities and differences between my own experiences and those of the participants. The level of disapproval the group experienced is so much more extreme than anything I experienced, so I can really appreciate the impact this would have on their ability to be self-compassionate. A negative internal monologue is something I can identify with, but the context of mistakes in social situations is separate to my own experience. The final theme about putting one’s own needs first is something I have been able to achieve as I have aged, which appears to be similar to some of the participants.

Interpersonal Reflexivity

Interviews

1) Just did another interview. I found it really hard to get a clear, coherent answer from the person, so it didn’t go like I’d hoped. I was trying to make sense of what they were saying and clarify by summarising back. I managed to build a good rapport so if felt ok that I kept repeating things back. REDACTED. I felt a lot of admiration for this person as they spoke about facing challenges and pushing themselves.
   Notes to self: Make sure to use their words in analysis stage.

2) REDACTED. Overall, it felt quite messy and I feel exhausted. I think it will take a lot of time to code that one!
   Notes to self: Be aware of any feelings of irritation that might come up during coding process.

3) REDACTED. I had to be careful not to turn into therapist mode and remind myself it was a research interview.

Methodological reflexivity

Theoretical presuppositions

I thought I’d start off with some reflections about my own theoretical assumptions. I studied disability studies at undergraduate level, so I have the social model of disability ingrained in me. For this project, this means that rather than focusing on individual impairments, like social or sensory difficulties, I believe autistic people’s difficulties in day to day life often lies with society, such as people's attitudes to difference. I think this will have a big influence on the way I ask questions in the interviews and how I interpret what the participants say. I would like to promote this view; however, I will still be guided by what the participants say. I recognise that not all participants will have the same views as me and they may understand things from a medical model (more individual level), especially as the diagnosis comes from this framework.

Reflections with Expert by experience

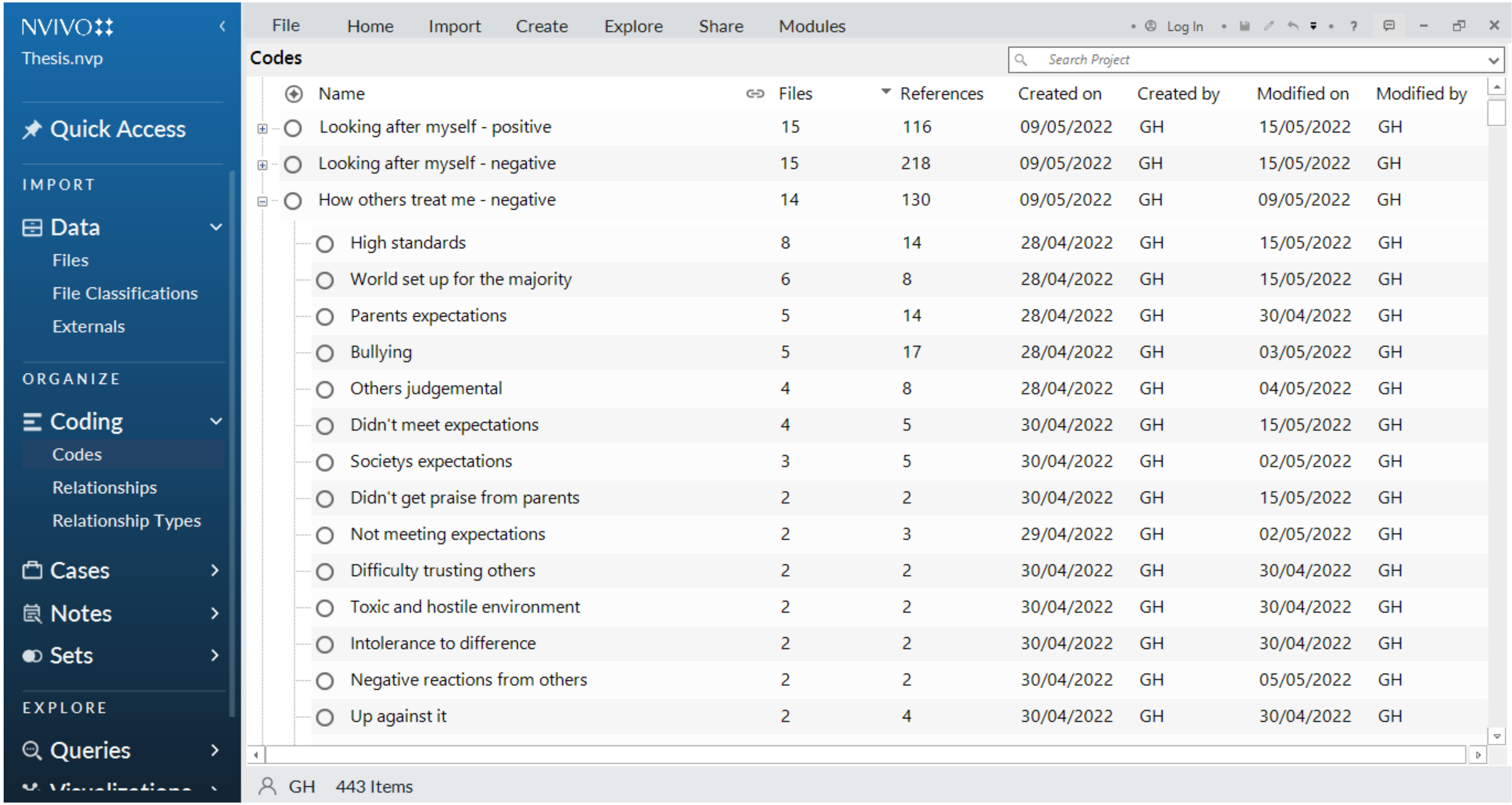
I spoke to one of the experts by experience today. We had a really interesting discussion about autistic people generally not being clear communicators. She spoke about her experience of verbally getting stuck even though all the knowledge is in her head. She reflected on how the quotes I had put in the results section showed the hesitant and long-winded nature of the participants' speech patterns. We discussed the possibility of editing the quotes so they were more concise, but we both felt if was important to keep them as authentic as possible. This conversation made me think about how these communication differences have impacted the data collection and analytic process. I think it makes it even more important that I check my findings out with the participants to hear if they represent their experience.

Contextual reflexivity

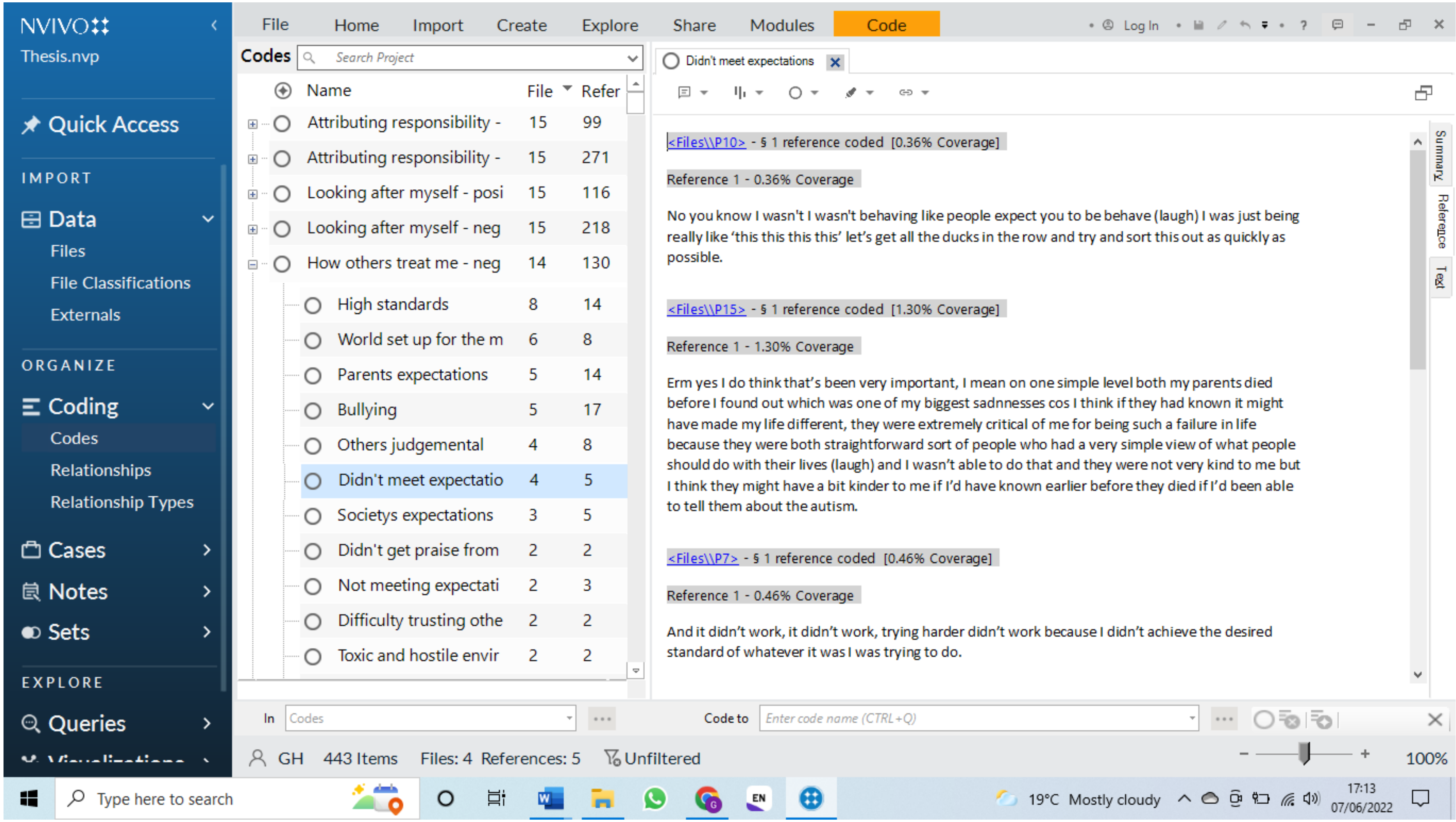
In my community, Autism is quite well-known, although there are still misunderstandings about what it is, and stereotypes exist. Working in an Autism diagnostic service, I see that there are long waiting lists for Autism assessments, demonstrating the awareness of Autism has increased. Among the literature, recent research has focused on experiences of autistic people and stigma, in addition to biology and genetics research. There is an advancement in research looking at autistic women as this has previously been neglected, particularly around camouflaging. However, I would like to include all genders in my research, so that no group is excluded. Most of the research is done by non-autistic people, but it is being recognised more and more that autistic people should be included in Autism research. I'm a bit worried about being criticised for doing the research as a non-autistic person on behalf of the autistic population. I will be including autistic experts by experience in the process, so hopefully we can work together to ensure the project is relevant and meaningful.

Appendix J

Themes and Codes Examples



Name	Files	References	Created on	Created by	Modified on	Modified by
Looking after myself - positive	15	116	09/05/2022	GH	15/05/2022	GH
Looking after myself - negative	15	218	09/05/2022	GH	15/05/2022	GH
How others treat me - negative	14	130	09/05/2022	GH	09/05/2022	GH
High standards	8	14	28/04/2022	GH	15/05/2022	GH
World set up for the majority	6	8	28/04/2022	GH	15/05/2022	GH
Parents expectations	5	14	28/04/2022	GH	30/04/2022	GH
Bullying	5	17	28/04/2022	GH	03/05/2022	GH
Others judgemental	4	8	28/04/2022	GH	04/05/2022	GH
Didn't meet expectations	4	5	30/04/2022	GH	15/05/2022	GH
Societys expectations	3	5	30/04/2022	GH	02/05/2022	GH
Didn't get praise from parents	2	2	30/04/2022	GH	15/05/2022	GH
Not meeting expectations	2	3	29/04/2022	GH	02/05/2022	GH
Difficulty trusting others	2	2	30/04/2022	GH	30/04/2022	GH
Toxic and hostile environment	2	2	30/04/2022	GH	30/04/2022	GH
Intolerance to difference	2	2	30/04/2022	GH	30/04/2022	GH
Negative reactions from others	2	2	30/04/2022	GH	05/05/2022	GH
Up against it	2	4	30/04/2022	GH	30/04/2022	GH



Name	File	Refer
Attributing responsibility -	15	99
Attributing responsibility -	15	271
Looking after myself - posi	15	116
Looking after myself - neg	15	218
How others treat me - neg	14	130
High standards	8	14
World set up for the m	6	8
Parents expectations	5	14
Bullying	5	17
Others judgemental	4	8
Didn't meet expectatio	4	5
Societys expectations	3	5
Didn't get praise from	2	2
Not meeting expectati	2	3
Difficulty trusting othe	2	2
Toxic and hostile envir	2	2

<Files\\P10> - § 1 reference coded [0.36% Coverage]

Reference 1 - 0.36% Coverage

No you know I wasn't I wasn't behaving like people expect you to be behave (laugh) I was just being really like 'this this this this' let's get all the ducks in the row and try and sort this out as quickly as possible.

<Files\\P15> - § 1 reference coded [1.30% Coverage]

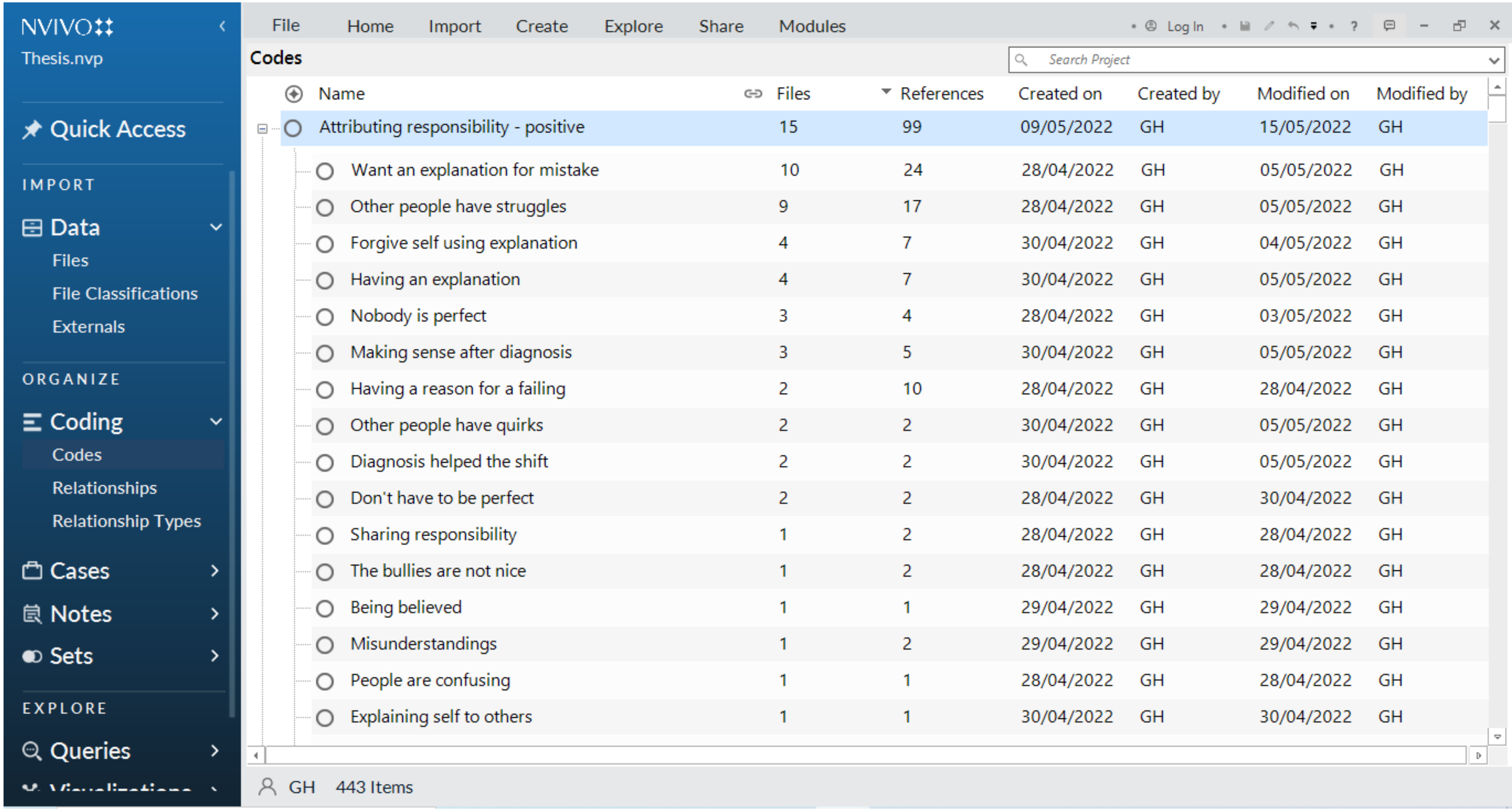
Reference 1 - 1.30% Coverage

Erm yes I do think that's been very important, I mean on one simple level both my parents died before I found out which was one of my biggest sadnnesses cos I think if they had known it might have made my life different, they were extremely critical of me for being such a failure in life because they were both straightforward sort of people who had a very simple view of what people should do with their lives (laugh) and I wasn't able to do that and they were not very kind to me but I think they might have a bit kinder to me if I'd have known earlier before they died if I'd been able to tell them about the autism.

<Files\\P7> - § 1 reference coded [0.46% Coverage]

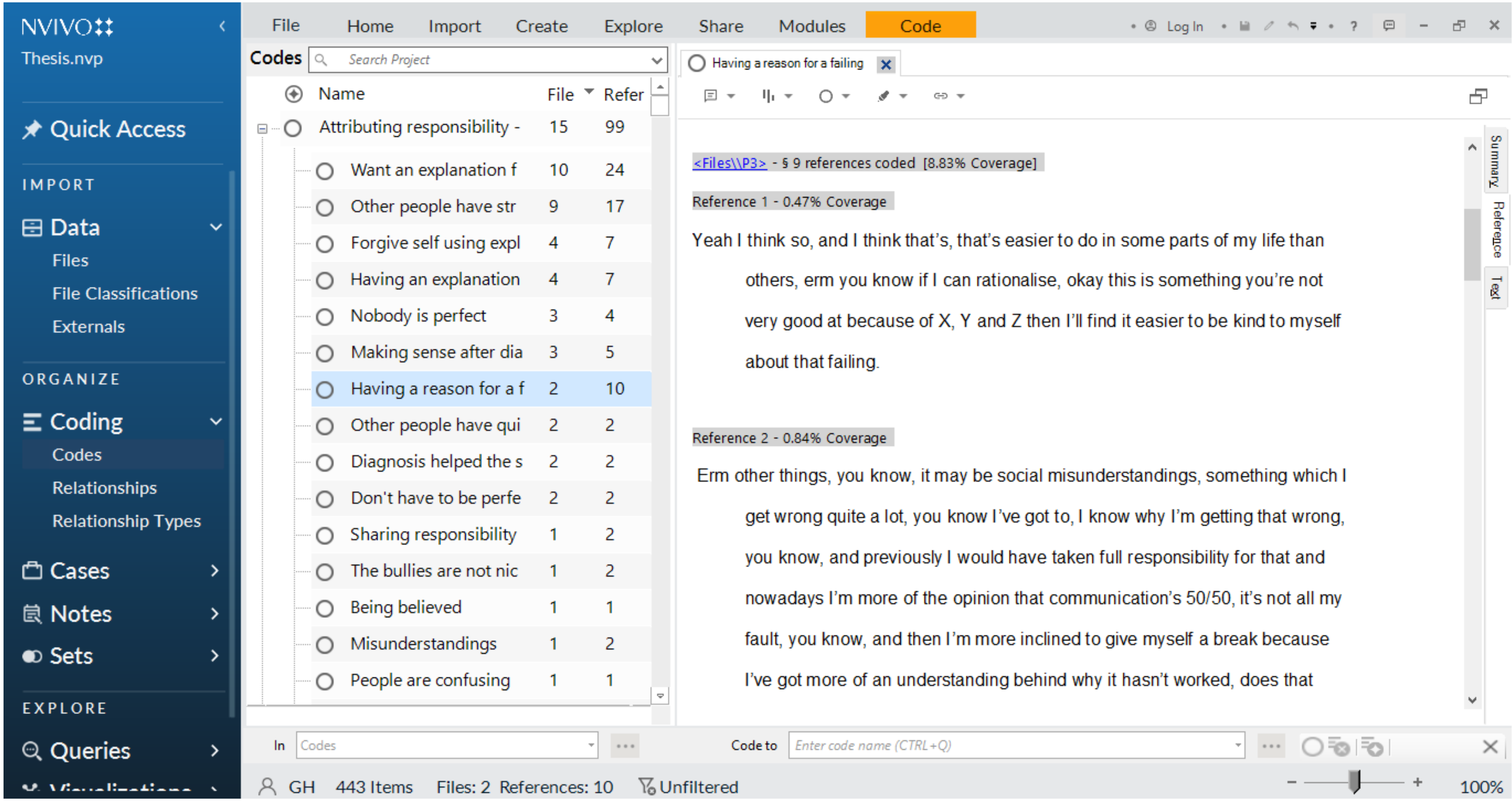
Reference 1 - 0.46% Coverage

And it didn't work, it didn't work, trying harder didn't work because I didn't achieve the desired standard of whatever it was I was trying to do.



Codes

Name	Files	References	Created on	Created by	Modified on	Modified by
Attributing responsibility - positive	15	99	09/05/2022	GH	15/05/2022	GH
Want an explanation for mistake	10	24	28/04/2022	GH	05/05/2022	GH
Other people have struggles	9	17	28/04/2022	GH	05/05/2022	GH
Forgive self using explanation	4	7	30/04/2022	GH	04/05/2022	GH
Having an explanation	4	7	30/04/2022	GH	05/05/2022	GH
Nobody is perfect	3	4	28/04/2022	GH	03/05/2022	GH
Making sense after diagnosis	3	5	30/04/2022	GH	05/05/2022	GH
Having a reason for a failing	2	10	28/04/2022	GH	28/04/2022	GH
Other people have quirks	2	2	30/04/2022	GH	05/05/2022	GH
Diagnosis helped the shift	2	2	30/04/2022	GH	05/05/2022	GH
Don't have to be perfect	2	2	28/04/2022	GH	30/04/2022	GH
Sharing responsibility	1	2	28/04/2022	GH	28/04/2022	GH
The bullies are not nice	1	2	28/04/2022	GH	28/04/2022	GH
Being believed	1	1	29/04/2022	GH	29/04/2022	GH
Misunderstandings	1	2	29/04/2022	GH	29/04/2022	GH
People are confusing	1	1	28/04/2022	GH	28/04/2022	GH
Explaining self to others	1	1	30/04/2022	GH	30/04/2022	GH



Name	File	Refer
Attributing responsibility -	15	99
Want an explanation f	10	24
Other people have str	9	17
Forgive self using expl	4	7
Having an explanation	4	7
Nobody is perfect	3	4
Making sense after dia	3	5
Having a reason for a f	2	10
Other people have qui	2	2
Diagnosis helped the s	2	2
Don't have to be perfe	2	2
Sharing responsibility	1	2
The bullies are not nic	1	2
Being believed	1	1
Misunderstandings	1	2
People are confusing	1	1

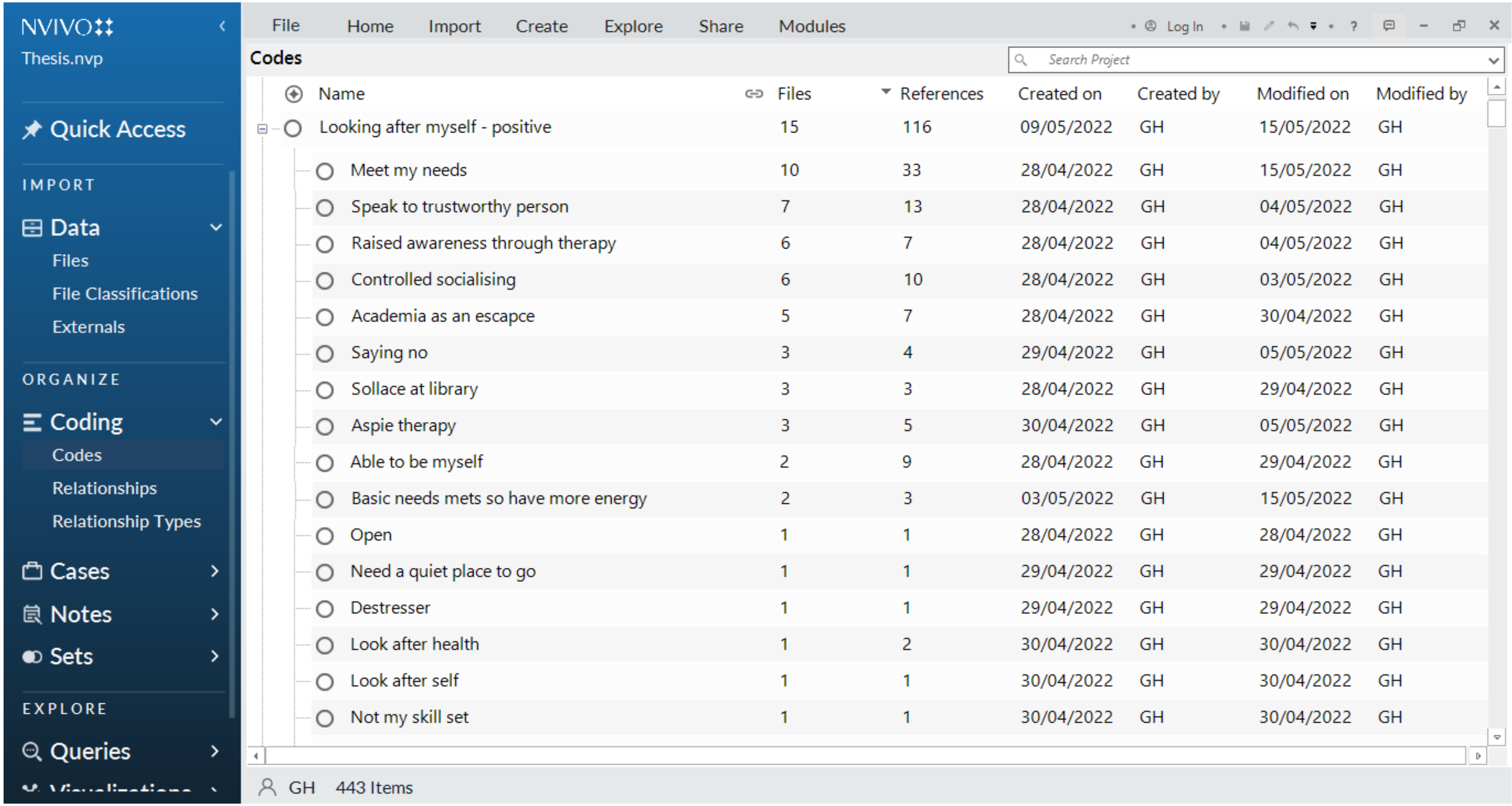
<Files\\P3> - § 9 references coded [8.83% Coverage]

Reference 1 - 0.47% Coverage

Yeah I think so, and I think that's, that's easier to do in some parts of my life than others, erm you know if I can rationalise, okay this is something you're not very good at because of X, Y and Z then I'll find it easier to be kind to myself about that failing.

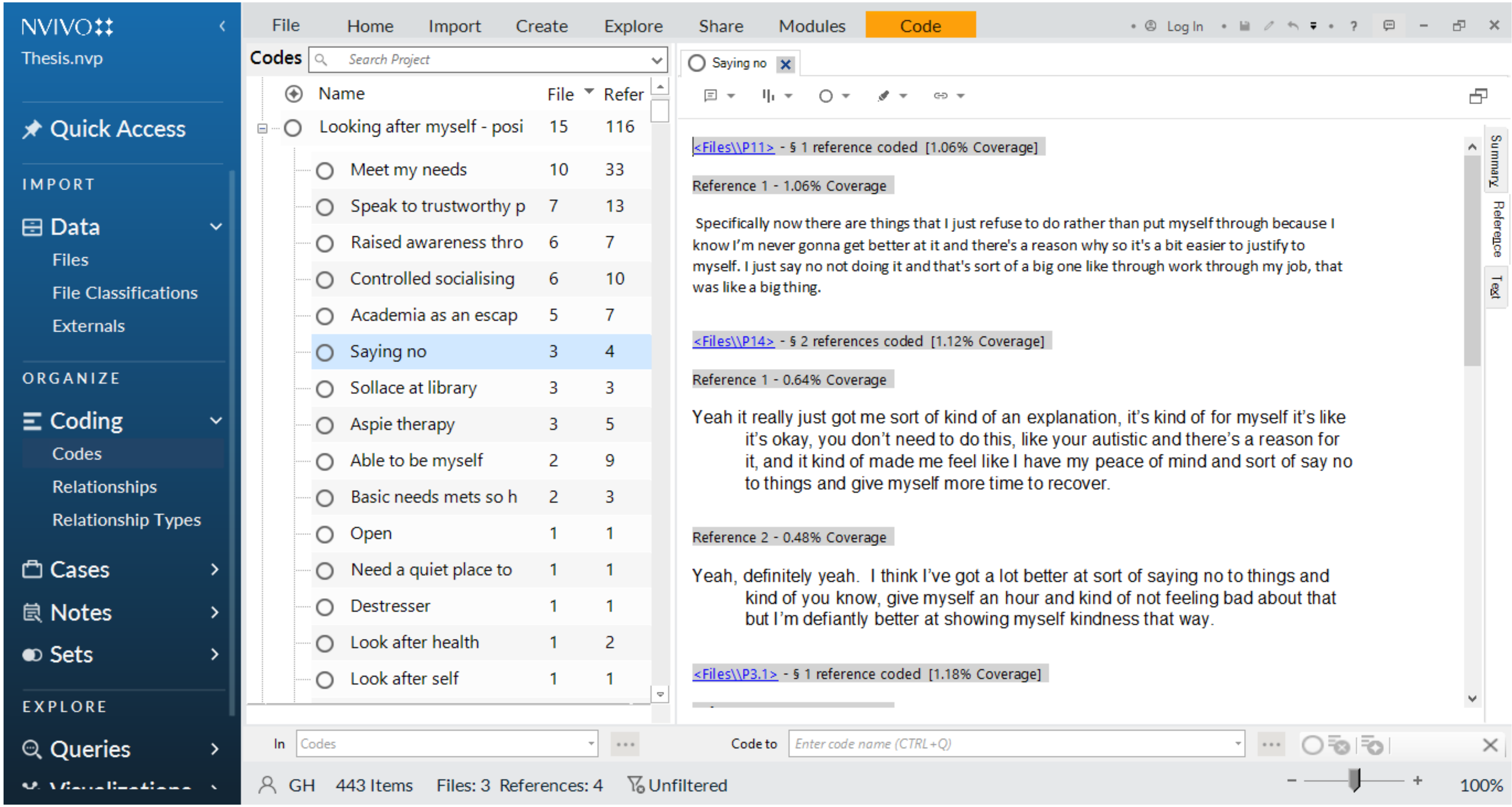
Reference 2 - 0.84% Coverage

Erm other things, you know, it may be social misunderstandings, something which I get wrong quite a lot, you know I've got to, I know why I'm getting that wrong, you know, and previously I would have taken full responsibility for that and nowadays I'm more of the opinion that communication's 50/50, it's not all my fault, you know, and then I'm more inclined to give myself a break because I've got more of an understanding behind why it hasn't worked, does that



Codes

Name	Files	References	Created on	Created by	Modified on	Modified by
Looking after myself - positive	15	116	09/05/2022	GH	15/05/2022	GH
Meet my needs	10	33	28/04/2022	GH	15/05/2022	GH
Speak to trustworthy person	7	13	28/04/2022	GH	04/05/2022	GH
Raised awareness through therapy	6	7	28/04/2022	GH	04/05/2022	GH
Controlled socialising	6	10	28/04/2022	GH	03/05/2022	GH
Academia as an escapce	5	7	28/04/2022	GH	30/04/2022	GH
Saying no	3	4	29/04/2022	GH	05/05/2022	GH
Sollace at library	3	3	28/04/2022	GH	29/04/2022	GH
Aspie therapy	3	5	30/04/2022	GH	05/05/2022	GH
Able to be myself	2	9	28/04/2022	GH	29/04/2022	GH
Basic needs mets so have more energy	2	3	03/05/2022	GH	15/05/2022	GH
Open	1	1	28/04/2022	GH	28/04/2022	GH
Need a quiet place to go	1	1	29/04/2022	GH	29/04/2022	GH
Destresser	1	1	29/04/2022	GH	29/04/2022	GH
Look after health	1	2	30/04/2022	GH	30/04/2022	GH
Look after self	1	1	30/04/2022	GH	30/04/2022	GH
Not my skill set	1	1	30/04/2022	GH	30/04/2022	GH



Name	File	Refer
Looking after myself - posi	15	116
Meet my needs	10	33
Speak to trustworthy p	7	13
Raised awareness thro	6	7
Controlled socialising	6	10
Academia as an escap	5	7
Saying no	3	4
Sollace at library	3	3
Aspie therapy	3	5
Able to be myself	2	9
Basic needs mets so h	2	3
Open	1	1
Need a quiet place to	1	1
Destresser	1	1
Look after health	1	2
Look after self	1	1

<Files\\P11> - § 1 reference coded [1.06% Coverage]

Reference 1 - 1.06% Coverage

Specifically now there are things that I just refuse to do rather than put myself through because I know I'm never gonna get better at it and there's a reason why so it's a bit easier to justify to myself. I just say no not doing it and that's sort of a big one like through work through my job, that was like a big thing.

<Files\\P14> - § 2 references coded [1.12% Coverage]

Reference 1 - 0.64% Coverage

Yeah it really just got me sort of kind of an explanation, it's kind of for myself it's like it's okay, you don't need to do this, like your autistic and there's a reason for it, and it kind of made me feel like I have my peace of mind and sort of say no to things and give myself more time to recover.

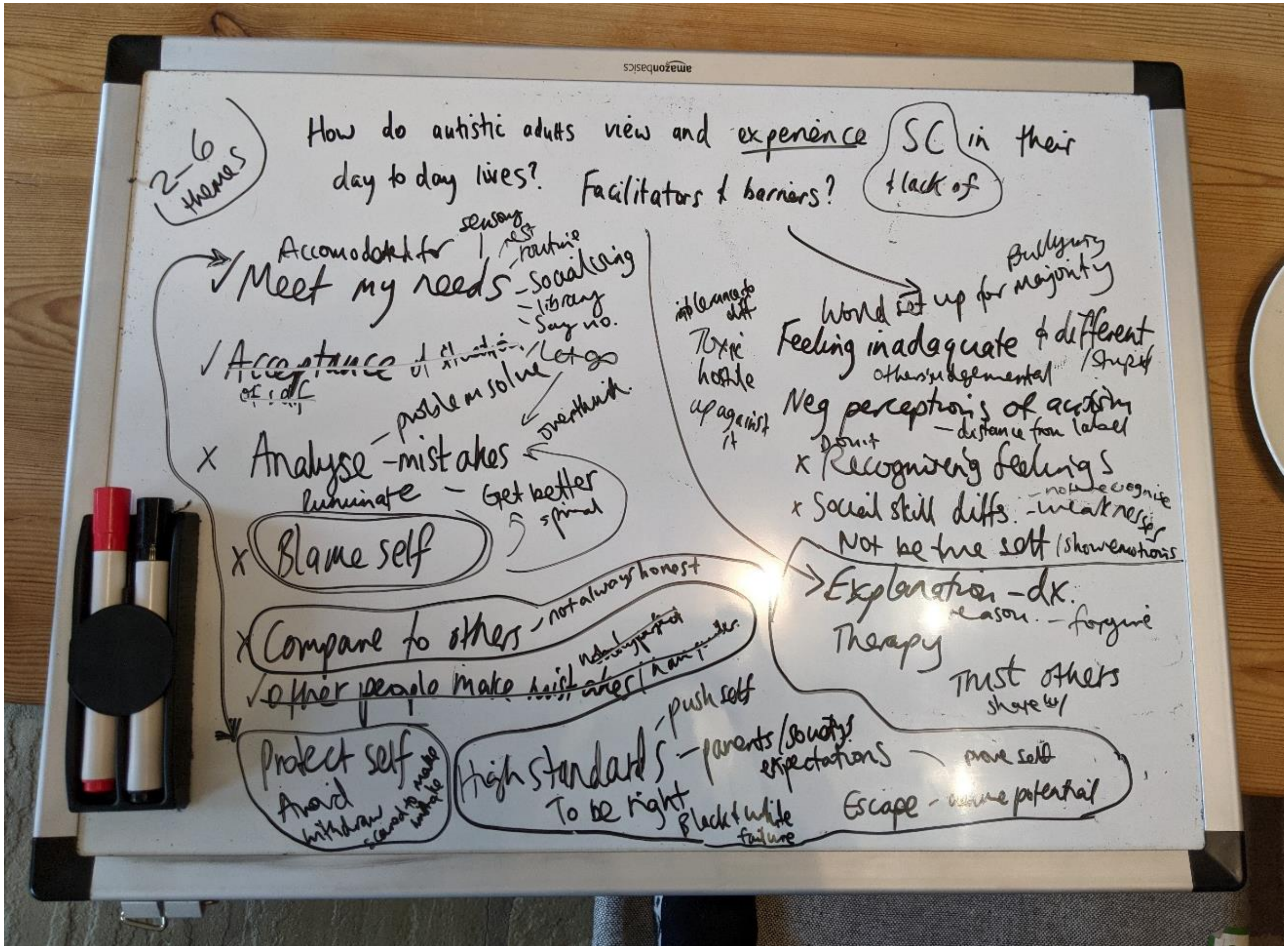
Reference 2 - 0.48% Coverage

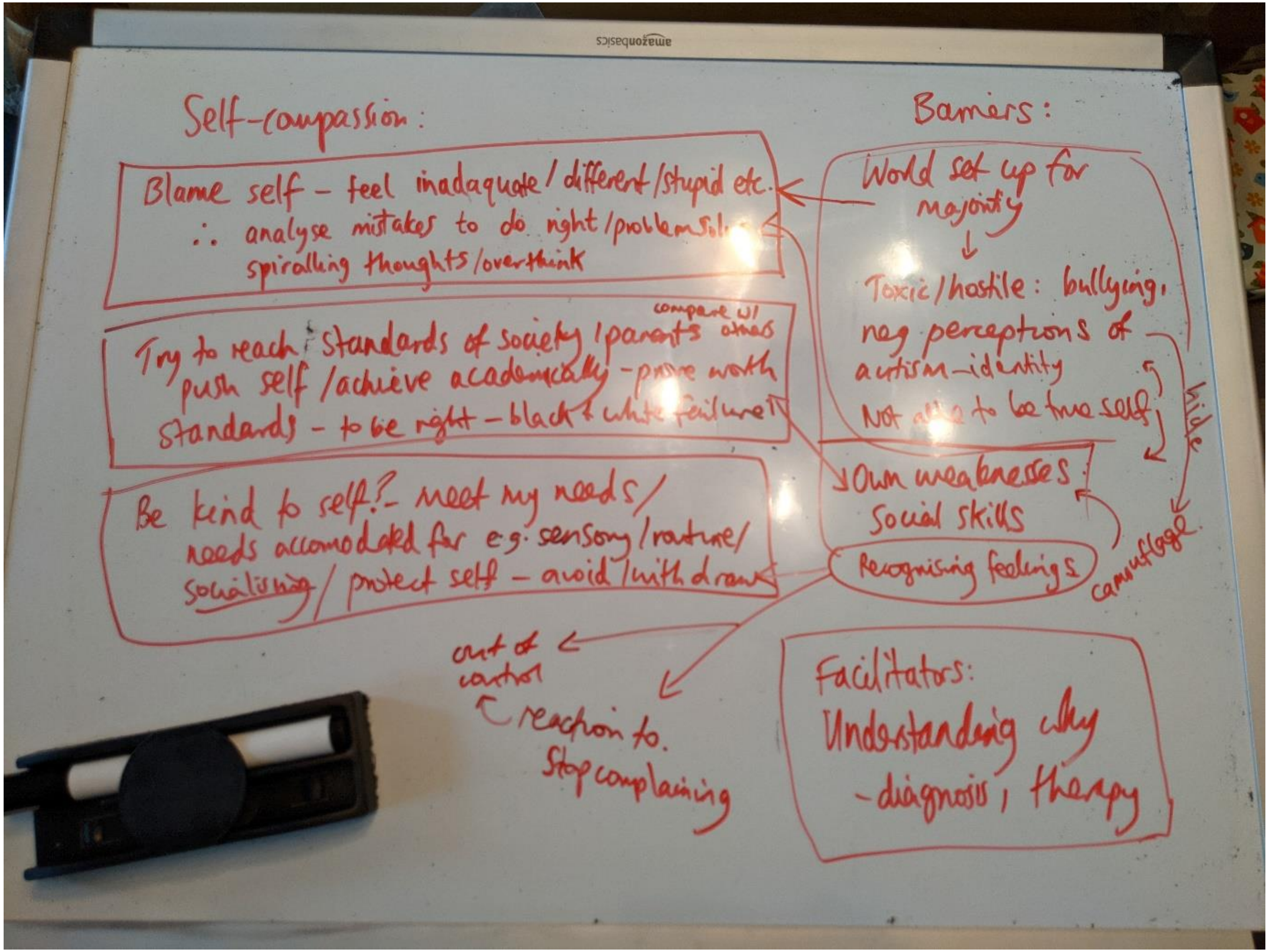
Yeah, definitely yeah. I think I've got a lot better at sort of saying no to things and kind of you know, give myself an hour and kind of not feeling bad about that but I'm defiantly better at showing myself kindness that way.

<Files\\P3.1> - § 1 reference coded [1.18% Coverage]

Appendix K

Theme Development/ Code Clustering





Self-compassion:

Blame self – feel inadaquate / different / stupid etc.
∴ analyse mistakes to do right / problem solving
spiralling thoughts / overthink

Try to reach standards of society / parents / compare w/ others
push self / achieve academically – prove worth
standards – to be right – black & white failure ?!

Be kind to self? – meet my needs /
needs accomodated for e.g. sensory / routine /
socialising / protect self – avoid / withdraw

out of control

reaction to. Stop complaining

Barriers:

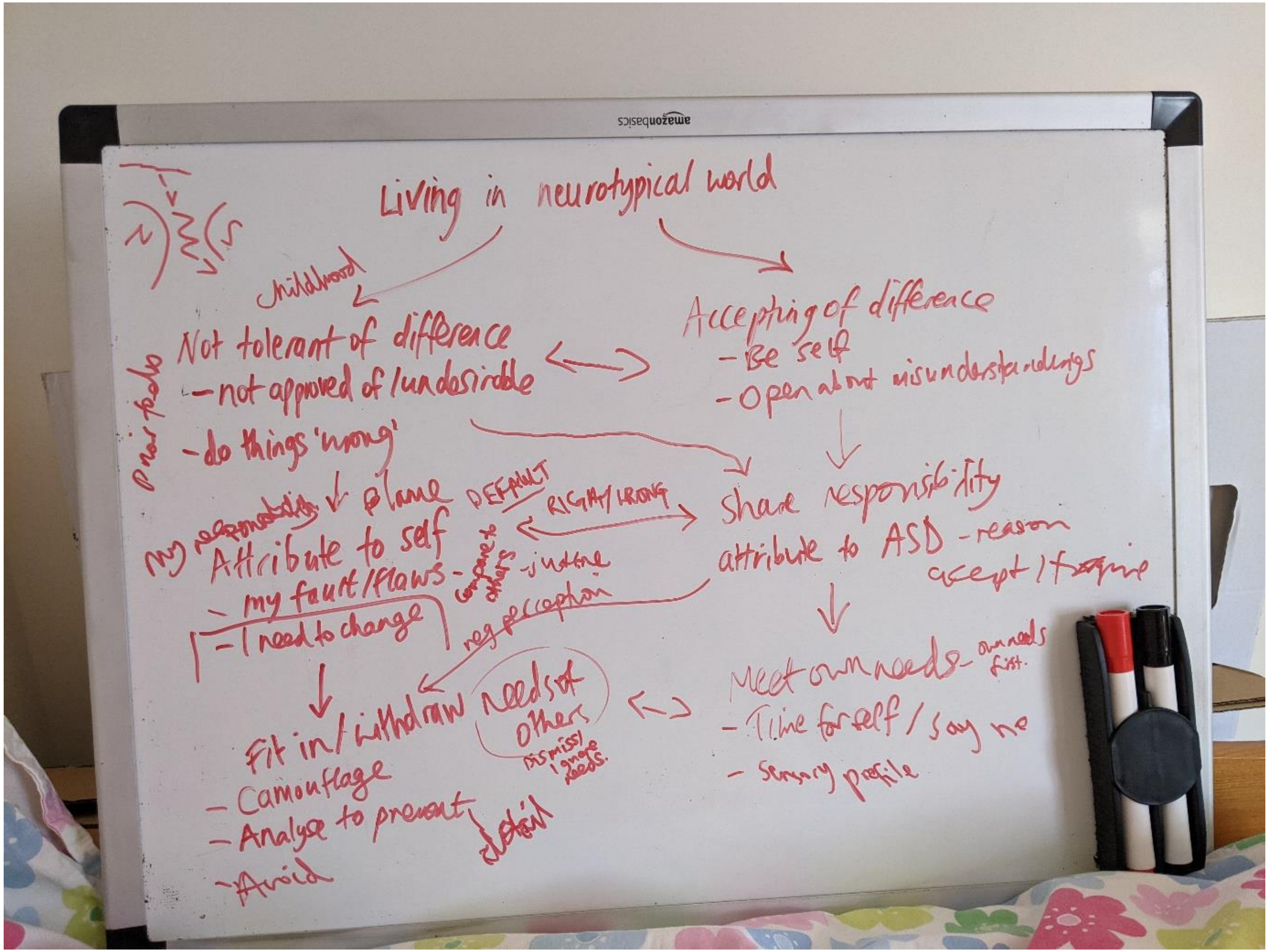
World set up for majority
↓
Toxic / hostile: bullying,
neg perceptions of
autism – identity
Not able to be true self

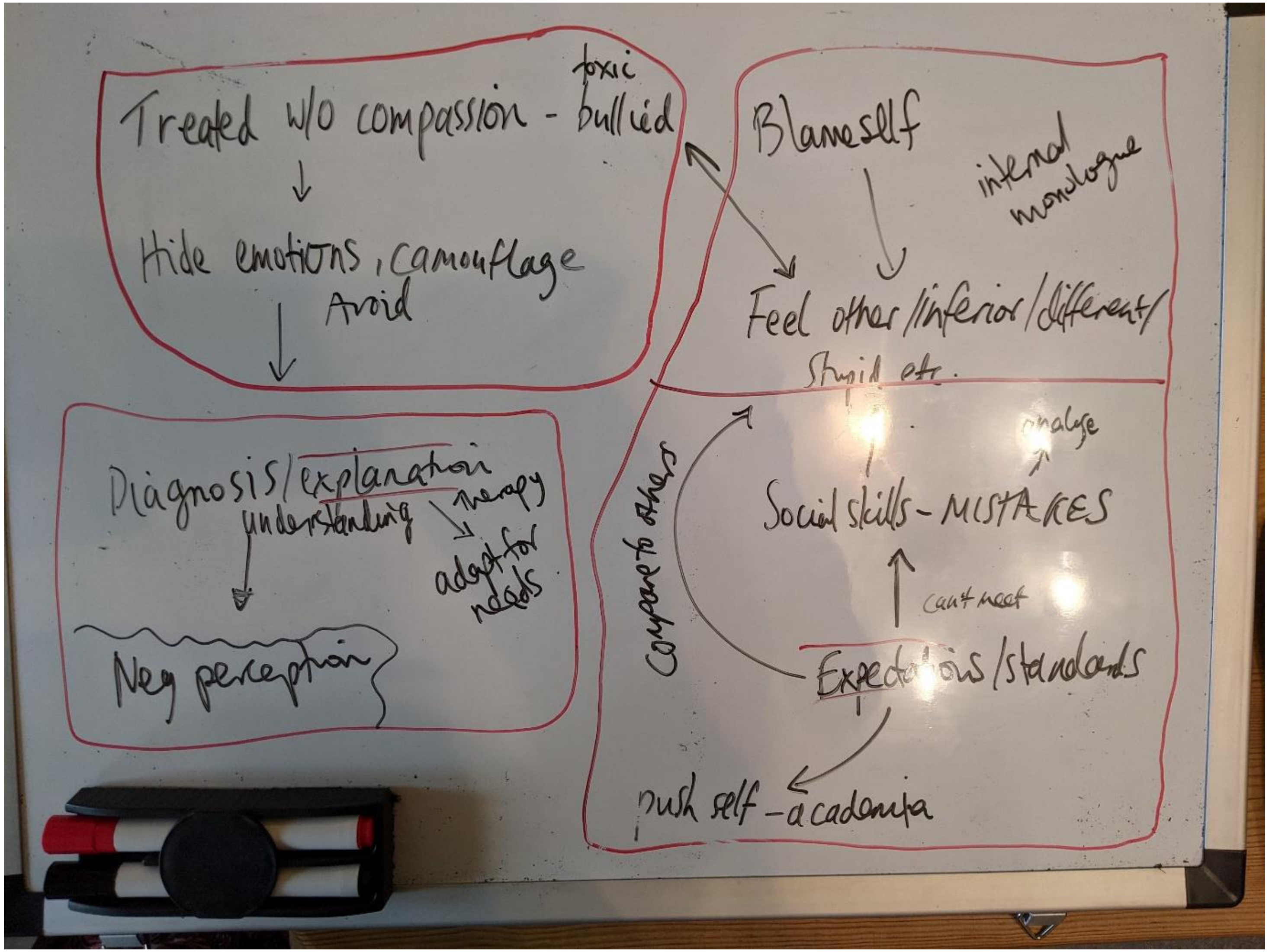
Own weaknesses:
Social skills
Recognising feelings

hide

camouflage.

Facilitators:
Understanding why
– diagnosis, therapy


amazonbasics
Living in neurotypical world
childhood
Not tolerant of difference
- not approved of / undesirable
- do things 'wrong'
Prior to dx
blame
my responsibility
Attribute to self
- my fault / flaws
- I need to change
compare to others
- internal
DEFAULT
RIGHT / WRONG
neg perception
Fit in / withdraw
- Camouflage
- Analyse to prevent
detail
- Avoid
Needs of Others
Dismiss / Ignore needs.
Accepting of difference
- Be self
- Open about misunderstandings
Share responsibility
attribute to ASD - reason
accept / forgive
Meet own needs - own needs first.
- Time for self / say no
- Sensory profile


toxic
Treated w/o compassion - bullied
Hide emotions, camouflage
Avoid
Blame self
internal monologue
Feel other/inferior/different/
Stupid etc.
Diagnosis/explanation
understanding
therapy
adapt for needs
Neg perception
Compare to others
analyse
Social skills - MISTAKES
can't meet
Expectations/standards
push self - academia

Appendix L

Member Checking

Status	**Comments**
Expert by experience	In short, I think it's great! It's absolutely 'spot on'. It could be all about me: it's so accurate and insightful in reflecting my life!
Expert by experience	I think your themes make sense and like your revised version. In figure 1 you mention the autism diagnosis being a factor in changing from people blaming themselves. I think that's accurate, and there can be so many other factors. It perhaps takes a big change like a diagnosis to 'jolt' people into thinking differently. There are many items in your report I can resonate with.
Participant	The results are really interesting, they definitely resonate strongly with me. It's quite nice to read other people's experiences and know that I'm not the only one who's struggled in the way I have. Autism can feel quite lonely at times and this definitely makes me feel less alone.
Participant	I found the results section fascinating! Even though we've had different experiences there is just so much of what's being described that I relate to. I think you've really managed to pull out those common themes.
Participant	I have read the summary of findings which was interesting. Some of it resonated with me e.g. finding it hard to put emotions into words, and how that affects our ability to practice self-compassion.

Appendix M

Audit

Phase	No.	Question	Comments
Transcription	1.	Has the data been transcribed to an appropriate level of detail?	Yes, audio files transcribed verbatim.
Coding	2.	Has each data item been given equal attention in the coding process?	Yes, high number of codes and references in each data file in NVivo.
	3.	Has the coding process been thorough, inclusive and comprehensive?	Yes, all aspects of the transcripts relevant to the question have been coded.
	4.	Have all relevant extracts for each theme been collated?	Yes, NVivo software has supported this.
	5.	Check themes against each other and back to the original data set – are they consistent?	Yes, NVivo software has supported this.
	6.	Are themes internally coherent, consistent, and distinctive?	Yes.
Analysis	7.	Have data been analysed rather than just paraphrased or described?	Yes, extensive theme generation during analysis.
	8.	Does the analysis and data match each other? Do the extracts illustrate the analytic claims?	Yes, quotes within the raw data represent the themes which pertain them.
	9.	Does the analysis tell a convincing and well-organised story about the data and topic?	Yes.
	10.	Is there a good balance between analytic narrative and illustrative extracts is provided?	Yes, there is an appropriate balance.
Overall	11.	Is there evidence that enough time has been allocated to complete all phases of the analysis	Yes, appropriate timeline.

		adequately, without rushing a phase or giving it a once-over-lightly?	
Written report	12.	Are the assumptions about TA clearly explicated?	Yes, present in the methods.
	13.	Is there a good fit between what they claim to do, and what they show to have done – i.e., described method and reported analysis are consistent?	Yes, analysis approach in methods and reported analysis are consistent.
	14.	Are the language and concepts used in the report consistent with the epistemological position of the analysis?	Yes.
	15.	Is the researcher positioned as *active* in the research process; themes do not just 'emerge'?	Yes, the researcher acknowledges that themes are generated.

Signature of researcher

GHartley

Gemma Hartley

Signature of auditor

Jack Purrington

Appendix N

Quality Checklist

No.	Topic	Item	Evidenced
	Title and Abstract		
S1	Title	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interviews, focus group) is recommended	Page 113
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Page 114
	Introduction		
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Page 116-119
S4	Purpose or research question	Purpose of the study and specific objectives or questions	Page 119
	Methods		
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale[b]	Page 121
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Page 130
S7	Context	Setting/site and salient contextual factors; rationale[b]	Page 124
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale[b]	Page 121-122
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Page 122-123 Appendix A
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale[b]	Page 122-131
S11	Data collection, instruments, and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Page 123 & 128 Appendix H
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 124-125, Page 128
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and	Page 130

		security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale[b]	Page 130-132
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale[b]	Page 131-132
	Results/Findings		
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Page 133-147
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Page 133-147
	Discussion		
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/ generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Page 148-154
S19	Limitations	Trustworthiness and limitations of findings	Page 152-153 Appendix L, M
	Other		
S20	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	N/A
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Page 178