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Exploring autism: a systematic review of parental coping and qualitative exploration of adolescent experiences of cyberbullying.

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Table of Contents

Tables

Figures

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Chapter 1

Coping strategies of parents of autistic children: an updated systematic review.

Prepared in accordance with the author requirements for the Journal of Autism & Developmental Disorders; Author submission guidelines

Abstract

Purpose: Parents of autistic children utilise coping strategies to manage challenges of parenting. This review aimed to explore tools measuring coping strategies of parents of autistic children, factors which influence coping strategies and examine how stress and quality of life interact with coping strategies.

Methods: This study replicated and updated a review by Vernhet et al. (2019). A systematic search was conducted on Medline, PsychINFO and Eric databases**.** Inclusion criteria were peer-reviewed, quantitative studies with samples of parents of autistic children under 18 years old, which used standardised coping questionnaires. Intervention studies were excluded. A quality appraisal tool was used to assess risk of bias. The study was registered on PROSPERO (CRD42025624033). No funding was granted for this review.

Results: Twelve studies were included in the review with a total sample size of 2040 parents. Descriptive synthesis of results indicated a range of self-report questionnaires were used to measure parental coping. Findings indicated avoidant coping is associated with poorer mental health outcomes whilst positive reframing and problem-focused coping are adaptive coping strategies for psychological wellbeing and quality of life.

Conclusion: The Brief COPE is the most frequently used and reliable measure of coping across studies of parents of autistic children. Coping styles are important risk and protective factors for parents' psychological wellbeing and quality of life. This has implications for clinical practice.

Keywords: Coping, Parents, Children, Autism, Systematic Review

Introduction

Autism is a neurodevelopmental condition affecting communication and interaction with others, alongside the presence of restricted interests and repetitive behaviours (American Psychiatric Association (APA), 2013). Global prevalence rates of autism are increasing and currently estimated at 1 in 100 children (Zeidan et al., 2022). Prevalence rates vary substantially across studies, with some well-controlled studies reporting substantially higher figures (Zeidan et al., 2022). The prevalence of autism in many low and middle-income countries is unknown (Zeidan et al., 2022). Diagnostic terminology refers to Autism Spectrum Disorder (ASD) (APA, 2013) but within the autistic community (autistic people, parents and their broader support network) there is disagreement about the way autism is and should be described (Kenny et al., 2016). ‘Autistic person’ is a common preference and will be used throughout this study (Kenny et al., 2016).

Raising an autistic child involves long term challenges for parents, which can include managing challenging behaviour, increased caregiving demands, stigma and isolation, managing impacts on relationships within the family and navigating complex service systems (Ludlow, 2012; Pepperell et al., 2018). Research consistently indicates that parents of autistic children report higher levels of stress when compared to parents of typically developing children and children with other psychological or physical conditions (Hayes & Watson, 2013; Kuusikko-Gauffin et al., 2013; Mazefsky et al., 2008; Padden & James, 2017). Though there may be stress associated with raising autistic children, parents can also report positive experiences in which having autistic children can enrich their family life (King et al., 2012).

Parents employ coping strategies to manage challenges that arise in parenting autistic children. Lazarus and Folkman's (1984) transactional theory of stress and coping underpins much of the current research about coping. They conceptualise coping as a process, rather than a personal trait, in which a person uses "cognitive and behavioral efforts" to manage stress. These efforts are categorised into two types of coping; emotion focused, or problem focused (Lazarus & Folkman, 1984). Emotion focused coping refers to managing emotional distress caused by a situation (Lazarus & Folkman, 1984) and can include a broad range of strategies such as denial, focusing on and venting of emotions, positive reinterpretation of events, and seeking out social support (Lazarus & Folkman, 1984). Problem focused coping involves attempts to resolve the difficulty by generating options for problem solving, evaluating pros and cons of these options and taking action (Lazarus & Folkman, 1984). The predominant view within the literature around coping is that emotion focused coping can be a maladaptive strategy. Avoidant coping (a form of emotion focused coping) has been found to be a predictor of increased depression and anxiety in parents of autistic children (Hastings et al., 2005) and in another study of parents of autistic children emotion focused coping was found to increase stress and decrease quality of life, whilst the opposite effect occurred with problem-focused coping (Cappe et al., 2011). However, a systematic review of 11 studies, which included 1388 parents of autistic children, indicated that overall, the effectiveness of emotion-focused coping varies depending upon which strategy was used and how it was applied. Seeking social support was found to be beneficial to parents, whereas avoidance was less helpful (Vernhet et al., 2019).

Though coping strategies have been well defined throughout the research they have been measured using a wide range of self-report questionnaires and there has been limited evaluation of these measures across the literature (Vernhet et al., 2019). Understanding the measures used to assess coping strategies in parents of autistic children is essential for advancing both research and clinical practice. As parents in this population often experience unique, chronic stressors in comparison to parents of neurotypical children, it is crucial that tools accurately reflect and measure parents' experiences (Padden & James, 2017). Validity and reliability of measures directly affect the strength of the evidence linking parental coping to outcomes, including mental health, family functioning, and child wellbeing. Accurate assessment tools enable researchers and clinicians to identify effective coping styles, tailor interventions, and monitor changes over time (Padden & James, 2017; Vernet et al., 2019). In addition, measures that are culturally adaptable and psychometrically sound across diverse populations ensure that findings and support systems are equitable and inclusive (Beaton et al., 2000). Therefore, reviewing and appraising the quality of coping measures used in studies involving parents of autistic children is a critical step in improving research quality, clinical interventions, and ultimately, family outcomes (Kazdin, 2021).

There is increasing interest in parental coping across research, which is important as studies indicate parental coping styles directly impact stress and wellbeing of parents and can impact the child (Hayes & Watson, 2013). Research has indicated that tailored support can reduce burnout and improve outcomes for families (Weiss et al., 2012). Research has also shown that coping strategies are not isolated; rather, they interact dynamically with parental stress, quality of life, and various environmental and individual factors in parents of autistic children (Derguy et al., 2016; Lai & Oei, 2014; Suen et al., 2021). Several reviews have sought to understand stress, quality of life and specific coping strategies (such as positive reappraisal) in parents of autistic children

(Lai & Oei, 2014; Suen et al., 2021). For example, studies have found that adaptive coping strategies are related to a higher quality of life, whereas maladaptive coping techniques are related to a worse quality of life (Suen et al., 2021). Negative correlations have been found between parenting stress, positive reappraisal coping and quality of life of parents of autistic children (Suen et al., 2021).

Despite the research interest in this area, a review by Vernhet el al. (2019) remains unique in synthesising the range of measures assessing parental coping in addition to links between coping and antecedents, stress and quality of life. The review indicated that more parents of autistic children used more avoidance than social support seeking strategies, with emotion focused coping identified as a risk factor (Vernhet et al., 2019). Problem focused coping was found to be a protective factor against parental stress and quality of life (Vernhet et al., 2019).

Although the systematic review by Vernhet et al. (2019) provided valuable insights into the coping strategies used by parents of autistic children, an updated review allows for a re-evaluation of methodological quality across more recent studies. Given the rapid pace of research in both autism and caregiver wellbeing (Enea & Rusu, 2020), synthesising the most recent literature is critical for evidence-informed decision-making and development of psychoeducational interventions aimed at parents of autistic children.

This review intended to replicate and update the previous work by Vernhet et al. (2019) and in doing so sought to answer the same four research questions regarding coping strategies used by parents of autistic children.

1. What tools are used to measure coping strategies used by parents of autistic children and what are their strengths and weaknesses?

2. What environmental and individual factors are likely to influence parental coping strategies?
3. What are the interactions between parental coping strategies and perceived stress?
4. What is the impact of parental coping strategies on their quality of life?

Method

Search strategy

As this was study sought to replicate the previous study with more recent papers, the methodology from Vernhet et al. (2019) review was replicated and is described below.

The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines were used for this review (Page et al., 2021). Reporting checklists are included in Appendix 1A, page 82. A systematic search was conducted on Medline, PsycINFO and Embase databases on 27th January 2025. The review was prospectively registered with PROSPERO (registration no. CRD42025624033). As this review updated a systematic review the current search was limited to the date the last search was run, therefore this review was limited to studies from August 2017 to present (January 2025). Search terms included were “Autistic Disorder” OR “Autis*” OR “ASD” OR “ASC” OR “Asperger*” OR “PDD-NOS” OR "Autism Spectrum Disorder" AND “Parents” OR “Caregivers” OR “Famil” OR “Mother” OR “Father* OR "Birth Parent* AND “(psychological adjustment OR stress management OR resilience OR problem-solving OR emotional regulation)” OR “(emotion-focused coping OR problem-focused coping)”

A line-by-line search strategy is included in Appendix 1B, pg. 84. Search terms and strategies were chosen through review of previous literature and via consultation with a specialist university librarian.

Eligibility criteria and study selection

Inclusion and exclusion criteria were established by the previous review by Vernhet et al. (2019) and were replicated for the current review.

Inclusion criteria were:

- quantitative studies
- original research articles published in peer reviewed journals
- samples including parents having an autistic child diagnosed according to ICD-10, DSM-IV-TR, DSM-5 criteria or ADI-R
- children aged under 18 years
- standardised and validated questionnaires of parental coping strategies.

The exclusion criteria were:

- studies focused on parental training programs or validation tools
- samples included parents of children with a condition other than autism
- intervention and pharmacological studies.

Title and abstracts of results were screened before full articles were then screened by the first reviewer (CH). A second reviewer (EK) independently screened 10% of titles and abstracts (n=80) and 9.5 % of full text studies (n =4). Disagreements were settled through discussion based around inclusion/exclusion criteria.

Data extraction

Data was extracted from full texts by first reviewer (CH), in replication of the extraction method of Vernhet et al. (2019) and details recorded included: (1) participant characteristics: number of participants, number of fathers, mothers, or other caregivers, age, gender, marital status and employment status; (2) child characteristics: age, diagnosis, and diagnostic tool; (3) coping measure and (4) statistical analysis and main results. The second reviewer (EK) checked data extracted from 17% of studies (n=2).

Due to diversity in the measurement tools, statistical analysis and methodological designs of included studies, it was not possible to conduct a meta-analysis. Instead, a descriptive synthesis was used to report results. This is a textual approach which offers a descriptive summary of the outcomes related to the research questions and highlights the relationships between findings across different studies (Popay et al., 2006). A preliminary synthesis was developed organising findings together. Studies were grouped by outcomes and textual descriptions then developed. Patterns across studies were identified and similarities and differences reported. The robustness of synthesis was then considered in the context of the strength and quality of the evidence (Popay et al., 2006).

Quality appraisal

To ensure consistency across systematic reviews, this study utilised the quality appraisal tool devised and used within the systematic review by Vernhet et al. (2019). This tool consists of a combination of 12 criteria from the "The STROBE Reporting Guidelines for writing and reading observational studies in epidemiology (Von Elm et al., 2014), two criteria from "Critical review form – quantitative studies" (Law & MacDermid, 2008) in addition to 4 items developed by Vernet et al. (2019).

In total 18 items within the quality appraisal tool were used to assess the quality of individual studies. For each criterion a score was given of 2= complete, 1= partially complete, 0=imprecise. Scores were then totalled to indicate overall quality. Studies rated as poor scored less than 12 points. Studies rated as fair quality scored between 13 and 24. Good studies were rated between 25 and 30 points, with excellent studies scoring between 30 and 36 points (Vernhet et al., 2019). Vernet et al. (2019) do not explicitly justify the derivation of the cut-off thresholds applied in their quality assessment framework.

First reviewer (CH) critically appraised included studies and second reviewer (EK) duplicated appraisal on a random selection 42% (n=5) of included studies. Results were independently recorded on an Excel spreadsheet, with reviewers blinded to each other's decisions until comparisons had been made. Discrepancies between scores were resolved through discussion.

Inter-rater reliability

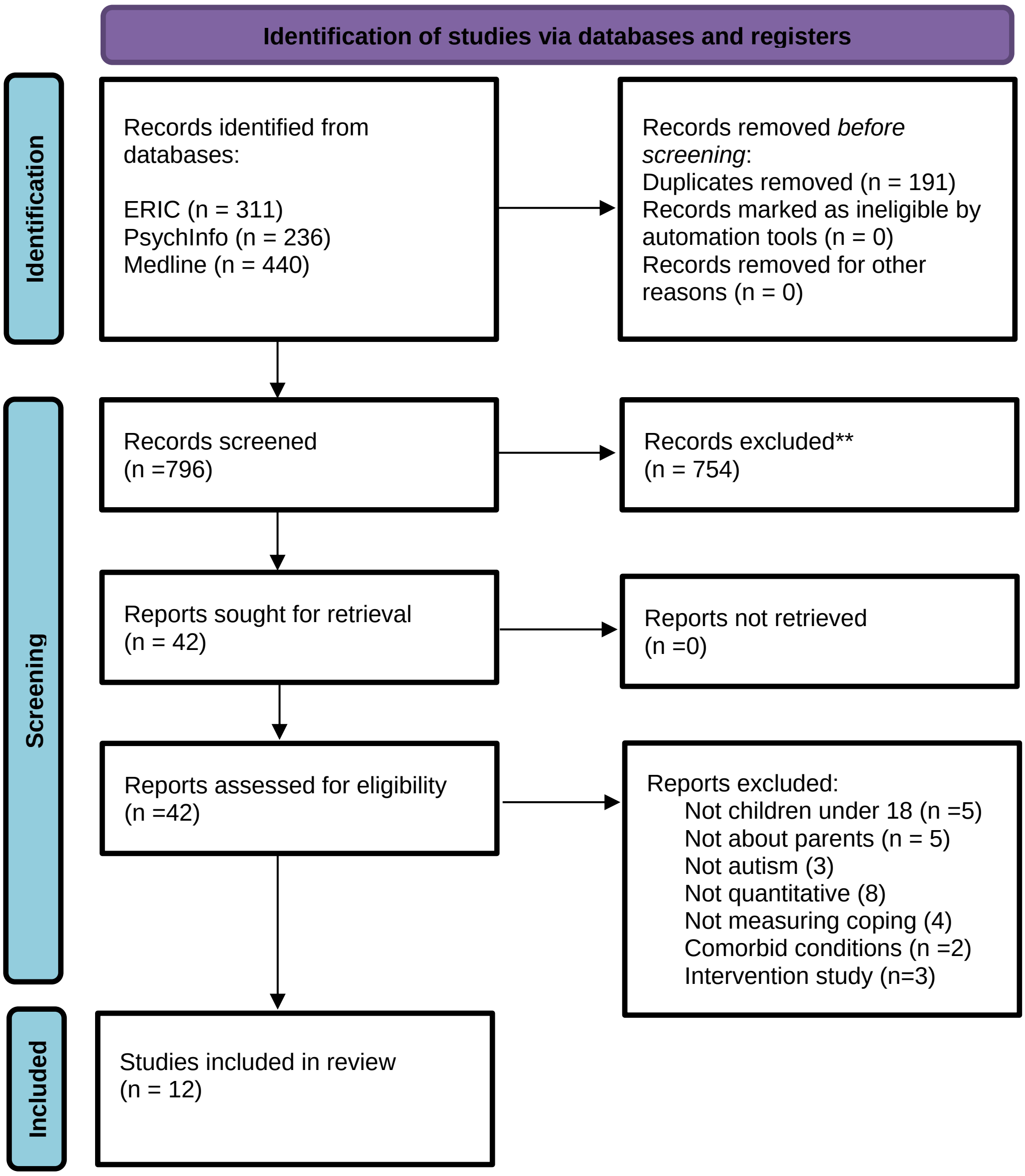
Inter-rater reliability was assessed at data extraction and quality appraisal stages. Cohen's Kappa coefficients were calculated using an online calculator to assess inter-rater agreement. Inter-rater checks were completed for 10% of titles and abstracts screened (n=80) with 94% agreement (κ =0.48). 9.5 % of full text studies (n=4) were checked with 100% agreement (κ=1.0). Data extraction were completed for 17% of studies (n=2) with 100% agreement (κ=1.0), 42% of critical appraisal scores were checked by the second reviewer, with moderate agreement achieved between raters (κ =0.47).

Results

Study search summary

The search returned 987 results. After removal of duplicate results (n=191), 796 results remained. Following title/abstract screening, 754 studies were excluded. Full texts of the remaining 42 studies were screened, leaving 12 studies for inclusion; details are highlighted in Figure 1.

Figure 1



PRISMA Flowchart of Search Results

Study Quality

The quality rating was “fair” for one study (Cai et al., 2020), “good” for six studies (Al Busaidi et al., 2022; Alostaz et al., 2022; Gagat-Matu tuła; 2022; Mohammad et al., 2022; Miranda et al., 2019; Tsioka et al., 2024) and “excellent” for the remaining five (Ang & Loh, 2019; Liu et al., 2023; Papadopoulos et al.,2024; Picardi et al.,2018; Rattaz et al., 2023.) Full ratings are indicated in Appendix 1C pg. 87.

This distribution suggests that the overall quality of the evidence base is predominantly good to excellent. Although one study received a “fair” rating (as the protocol and inclusion, exclusion criteria were not fully detailed), it was not considered methodologically poor, still met minimum inclusion criteria and contributed relevant data to the synthesis. Therefore, the quality of the studies did not influence the main synthesis of results.

Study characteristics

Most of the studies employed a cross-sectional design (Al Busaidi et al., 2022; Alostaz et al., 2022; Ang & Loh, 2019; Cai et al., 2020; Gagat-Matula, 2022; Liu et al., 2023; Miranda et al., 2019; Mohammad et al., 2022; Picardi et al., 2018; Tsioka et al., 2024). Two studies used a longitudinal design: Papadopoulos et al. (2024) included a one-year follow-up, while Rattaz et al. (2023) conducted a three-year follow-up.

The studies were conducted across a diverse range of countries. Two were from Greece (Papadopoulos et al., 2024; Tsioka et al., 2024), whilst the others originated from Oman (Al Busaidi et al., 2022), the United States (Alostaz et al., 2022), Singapore (Ang & Loh, 2019), the United Kingdom (Cai et al., 2020), Poland (Gagat-Matula, 2022), China (Liu et al., 2023), Spain (Miranda et al., 2019), Iran (Mohammad et al., 2022), Italy (Picardi et al., 2018), and France (Rattaz et al., 2023).

Participant characteristics

Overall, the sample size of the 12 selected studies was 2040. Of the 11 studies which reported the number of mothers and fathers participating, most were mothers (n= 1589, 83.2% versus 842, 16.8% fathers). The mean parental age in the 12 studies was 38.13 years old. Marital status was reported in 8 studies and the percentage of parents married ranged from 78.84% - 100%. Employment status was reported across 7 studies and ranged from 32% - 94%. The mean age of children across the 11 studies which reported this information was 8. 38 years old. Full participant characteristics are shown in Table 1.1.

Table 1.1

Participant Characteristics

Study	**n (cases/control/ other diagnosis)**	**Mothers/fathers**	**Mean age of parents (standard deviation)**	**Marital status (% married)**	**Employment status (% employed)**	**Country of study**	**Mean age of children (standard deviation)**	**Diagnosis of child**	**Diagnosis establishment**	**Coping Questionnaires**
Al Busaidi et al., 2022	304 (304/0/0)	181/123	Mothers: 39.1(6.5) Fathers: 42.1 (7.3) Total: 40.4 (6.9)	95.4%	Mothers: 44.1 Fathers: 79.8	Oman	8.4 (2.3)	ASD	DSM-IV	WCC-R
Alostaz et al., 2022	63 (63/0/0)	63/0	7.89 (1.47)	-	-	USA	7.89 (1.47)	ASD	ADOS-2	Brief COPE CCNES
Ang & Loh, 2019	203 (203/0/0)	106/97	Mothers:40.44 (4.57) Fathers:43.94 (5.25) Total: 42.11 (5.20)	97	Mothers: 66 Fathers: 94 Total: 79.2	Singapore	8.78 (1.59)	ASD (80.8%) Autistic Disorder (6.9%) AS (3.9%) PDD (4.4%)	DSM-IV DSM-V	Brief COPE
Cai et al., 2020	50 (50/0/0)	50/0	44.28 (6.58)	-	-	UK	10.58 (3.83)	ASD	DSM-IV-TR ICD-10	WCQ
Gagat-Matuła, 2022	100 (100/0/0)	50/50	44	100	-	Poland	-	ASD	DSM-V	CISS
Liu et al., 2023	193 (193/0/0)	157/36	33.58 (5.04)	-	69.4	China	3.16 (0.97)	ASD	DSM-V ICD-10	SCSQ
Miranda et al., 2019	52 (52/0/0)	52/0	40.17 (4.82)	78.84	33	Spain	8.59 (1.38)	AS(n=31) ASD (n = 11) PDD (n = 10)	DSM-V ADI-R	Brief COPE
Mohammad et al., 2022	110 (110/0/0)	110/0	34.74 (3.16)	88.18	50	Iran	9.7 (2.25)	Autism	DSM-V	CSQ

Table 1.1 (continued)

Study	**n (cases/control/ other diagnosis)**	**Mothers/fathers**	**Mean age of parents (standard deviation)**	**Marital status (% married)**	**Employment status (% employed)**	**Country of study**	**Mean age of children (standard deviation)**	**Diagnosis of child**	**Diagnosis establishment**	**Coping Questionnaires**
Papadopoulos et al., 2024	53(53/0/0)	53/0	39.08 (4.43)	79.2	32	Greece	4.49 (1.57)	ASD	DSM-V	Brief-Cope
Picardi et al., 2018	659(359/145/155)	ASD: 351/288 Down Syndrome: 140/115 Type 1 Diabetes: 153/133	Mothers 42.5 (6.0) Fathers: 45.8 (6.8)	Mothers 88.4 Fathers 90.3	Mothers 59.2 Fathers 91.8	Italy	ASD 9.9 (3.7) DS 10.3 (3.9) T1DM 11.0 (3.5)	ASD Autism AS PDD-NOS	DSM-IV-TR ADOS	Brief-Cope
Rattaz et al., 2023	130 (130/0/0)	-	Mothers: 37.3 (5.3) Fathers: 40.9 (6.3)	-	-	France	5.7 (2.7)	ASD	DSM-V ADOS-II ADI-R	WCC-R
Tsioka et al., 2024	123 (123/0/0)	123/0	41.12 (5.17)	82.1	-	Greece	9.04 (4.35)	ASD	DSM-V ICD-10	Brief-COPE

AS Asperger's syndrome, *ASD* Autism spectrum disorder, *PDD-NOS* Pervasive Developmental Disorder – not otherwise specified, *ADI-R* Autism diagnostic interview-revised, *ADOS-2* Autism Diagnostic Observation Schedule – 2, *DSM-IV-TR* Diagnostic and Statistical Manual of Mental Disorders Fourth Edition Text Revision, *ICD-10* International Classification of Diseases and Related Health Problems Tenth Edition, *COPE* Coping Orientations to Problems Experienced, *WCQ* Ways of Coping Questionnaire, *WCC-R* Ways of Coping Checklist, *CISS* Coping Inventory for Stressful Situations, *CCNES* Coping with Children's Negative Emotions Scale**,** SCSQ Simplified Coping Style Questionnaire

Research Question 1: What tools are used to measure coping strategies used by parents of autistic children and what are their strengths and weaknesses?

The authors used questionnaires to assess parents’ coping in the 12 selected studies. The questionnaires are described according to their use, below.

Ways of Coping Questionnaire (WCQ) or Ways of Coping Checklist (WCC-R)

Three of the 12 selected studies used the WCQ (Cai et al., 2020) and the WCC-R (Al Busaidi et al., 2022; Rattaz et al., 2023). Both scales are based on Lazarus and Folkman’s (1984) transaction model of stress using a four-point Likert scale. Items are grouped into eight subscales representing different coping strategies: confronting coping, distancing, self-controlling, seeking social support, accepting responsibility, escape avoidance, planful problem-solving and positive reappraisal. Cai et al. (2020) used the WCQ and focused on subscales of escape avoidance and planful problem solving subscales, but did not report any information on reliability or validity.

Al Busaidi et al. (2022) used a translated Arabic version of WCC-R. The original 66 item checklist was used to determine how individuals respond and behave during specific stressful events. Rattaz et al. (2023) used an adapted and abridged version of the translated and validated WCC-R in French. This version is comprised of 27 items with scores analysed through dimensions of problem-focused coping, emotion-focused coping and social support seeking. The internal consistency for this version was satisfactory (α = .71–.82), and test–retest reliability over one week was strong (r = .90, .84, and .75, respectively; Rattaz et al., 2023).

Brief Coping Orientations to Problems Experienced (Brief COPE)

Six of the 12 selected studies used the Brief COPE (Alostaz et al., 2022; Ang & Loh, 2019; Miranda et al., 2019; Papadopoulos et al., 2024; Picardi et al., 2018; Tsioka et al., 2024)

The Brief COPE is a self-report 28 item version of the longer COPE and measures adaptive and maladaptive coping strategies, with items rated on a four-point scale. Pairs of items are summed to generate 14 subscales (Carver, 1997). Picardi et al. (2018) and Miranda et al. (2019) grouped the subscales into dimensions of engagement, disengagement, distraction and cognitive reframing (Benson, 2010).

Picardi et al. (2018) reported similar reliability scores for both parents, with Cronbach's alpha values for mothers reported as $\alpha = .80$, .62, .71, and .63 across different subscales. Miranda et al. (2019) used the Spanish adaptation (Morán et al.,2010) and reported internal consistency ranging from $\alpha = .71$ (disengagement) to $\alpha = .77$ (engagement). Alostaz et al. (2022) found an overall internal consistency of $\alpha = .84$. Tsioka et al. (2022) reported acceptable reliability with $\alpha = .74$. Papadopoulos et al. (2024) used the validated Greek-language version of the scale and reported Cronbach's alpha of $\alpha = .736$.

Coping Inventory for Stressful Situations (CISS)

Gagat-Matuła (2022) was the only study to use the Coping Inventory for Stressful Situations (CISS), which used the Polish adaptation developed by Strelau, Jaworska, Wrześniewski, and Szczepaniak (Strelau et al., 2009). The CISS consists of 48 items which assess parental reactions to stressful situations on a five-point Likert scale, measuring three dimensions: task-oriented coping, emotion-oriented coping, and avoidance-oriented coping (via social diversion and distraction). Reported internal consistency values for the individual scales range from $\alpha = .72$ to .92 (Gagat-Matuła, 2022; Strelau et al., 2009).

Coping Style Questionnaire (CSQ) and Simplified Coping Style Questionnaire (SCSQ)

Two studies used the CSQ and SCSQ. Mohammad et al., (2022) utilised the CSQ which is a questionnaire of 66 questions with 8 dimensions of direct coping, avoidance, self-control, seeking social support, responsibility, escape and avoidance, managerial problem-solving and positive re-evaluation. Questions are scored on a 4-point Likert scale, with reported internal consistency values ranging from $\alpha = .61$ to .79 (Attaran, 2013; Mohammad et al., 2022).

Liu et al., (2023) used the SCSQ which was developed based on Folkman and Lazarus' Ways of Coping Questionnaire (WCQ) (Folkman & Lazarus, 1988; Xie, 1998). This is a 20-item self-report questionnaire consisting of two domains of positive and negative coping strategies with each item rated on a 4-point Likert Scale. The SCSQ demonstrates good internal consistency, with Cronbach's alpha reported at $\alpha = .90$ among Chinese populations (Xie, 1998). Liu et al. (2023) reported an internal consistency of $\alpha = .76$ for the SCSQ.

Coping with Children's Negative Emotions Scale (CCNES)

One of the selected studies used the CCNES (Alostaz et al., 2022). This scale is comprised of six subscales that are considered supportive (expressive encouragement, emotion-focused reactions and problem-focused reactions) and unsupportive (distress reactions, punitive reactions and minimisation reactions) of social-emotional development of children. The scale demonstrates adequate internal consistency, test–retest reliability, and construct validity (Fabes et al., 2002) and has been used in studies involving families of autistic children (Bougher-Muckian et al., 2016). Alostaz et al. (2022) reported acceptable internal consistency, with Cronbach's alpha values of $\alpha = .87$ for supportive coping and $\alpha = .86$ for unsupportive coping.

Research Question 2: What environmental and individual factors are likely to influence parental coping strategies?

Studies explored several environmental and individual factors including parent's gender, parent's mental health and length of time since their child's diagnosis of autism.

Link between coping and parents' gender.

Several studies reported no statistically significant gender differences in overall coping patterns of parents of autistic children (Al Busaidi et al., 2022; Gagat-Matuła, 2022; Rattaz et al., 2023). Al Busaidi et al., (2022) found that seeking social support was the most common coping strategy used by parents and that escape avoidance was least common with no differences observed between Omani mothers and fathers. Similarly, Gagat-Matuła (2022) found that mothers and fathers of autistic children exhibited similar levels of resilience and coping, with no statistically significant gender differences overall. However, some differences emerged in specific avoidance coping subtypes. Mothers reported greater use of social contact-seeking strategies than fathers ($M = 17.01$ vs. $M = 15.05$), although this difference did not reach statistical significance ($p = .077$). Fathers showed slightly higher engagement in substitute activities ($M = 18.80$ vs. $M = 17.99$), but this difference was also not statistically significant ($p = .499$).

Rattaz et al. (2023) identified that problem-focused coping was the most frequently used strategy for coping in mothers and fathers of autistic children. No significant difference in emotion focused or problem-solving coping strategies in either mothers or fathers was indicated (Rattaz et al., 2023). However, at the time of their child's autism diagnosis, mothers reported significantly greater use of social support-seeking strategies than fathers ($M = 21.3$ vs. $M = 19.9$, $p < .001$). In contrast a study of parents of autistic children in Singapore, Ang and Loh (2019) found that active avoidance coping significantly moderated the relationship between stress and depression in both fathers and mothers. Among fathers, higher levels of avoidance coping were linked to a stronger association between stress and depression ($\beta = .48$, $p < .05$) (Ang & Loh, 2019). This moderating effect was even stronger for mothers ($\beta = .93$, p

$< .01$; Ang & Loh, 2019). Fathers were found to be more likely to use emotional coping strategies, such as suppressing emotions or distracting themselves with work. In contrast, mothers were more likely to adopt problem-focused coping and were significantly more likely to seek social support than fathers (Ang & Loh, 2019).

Link between coping and mental health.

Two studies examined the relationship between coping strategies and mental health outcomes in parents of autistic children (Ang & Loh, 2019; Cai et al., 2020). Findings from both studies consistently indicated that avoidant coping strategies were associated with poorer mental health, including higher levels of anxiety and depression.

Cai et al. (2020) found that greater intolerance of uncertainty ($\beta = 0.41$, $p = .002$) and more frequent use of avoidant coping strategies ($\beta = 0.34$, $p = .01$) were significantly associated with higher anxiety in mothers of autistic children. Similarly, higher levels of uncertainty ($\beta = 0.39$, $p = .002$), more avoidant coping ($\beta = 0.38$, $p = .002$), and less problem-focused coping ($\beta = –0.33$, $p = .005$) were associated with greater depression. In contrast, mothers who used more problem-focused coping strategies reported better psychological well-being, with the model explaining 17.4% of the variance ($F = 7.77$, $p = .008$).

Similarly, Ang and Loh (2019) found that in a study of parents of autistic children in Singapore, active avoidance coping (including self-blame and behavioural disengagement) was a significant predictor of depression in mothers ($\beta = .26$, $p < .01$) and fathers ($\beta = .25$, $p < .01$). Active avoidance coping strengthened the relationship between stress and depression for both parents, indicating its role as a maladaptive coping mechanism (Ang & Loh, 2019). Taken together, these findings suggest that avoidant coping may serve as a maladaptive strategy for parents and is associated with an increase psychological distress. In contrast, problem-focused coping may act as a protective factor, particularly in mothers, and is associated with better psychological outcomes.

Link between coping strategies and time after child's diagnosis.

One study examined the link between parental coping in relation to when their child was diagnosed with autism (Rattaz et al., 2023). A significant decrease in emotion-focused strategies in mothers was evidenced during the three years following diagnosis of autism ($p < .001$, Cohen's $d = 0.50$; Rattaz et al., 2023). As only one study of twelve selected for review examined relationships between coping strategies and time after child's diagnosis, limited conclusions can be drawn from these results.

Research question 3: What are the interactions between parental coping strategies and perceived stress?

Of the 12 studies selected, two focused on the link between coping and stress. Rattaz et al. (2023) found that mother's stress levels significantly reduced three years after the diagnosis of their child ($p < .001$) along with a significant decrease in their use of emotion focused coping ($p < .001$). Miranda et al. (2019) identified in a study of 52 mothers of autistic children that parenting stress was negatively correlated with engagement coping ($r = -.28$, $p < .05$) and confidant social support ($r = -.28$, $p < .05$). Engagement coping and behavioural difficulties were significant mediators in the relationship between a child's socio-communicative impairments, repetitive behaviours and restricted interests (referred to within the study as autistic symptoms) and parenting stress (Miranda et al., 2019). However, as only two of twelve studies examined the links between parental coping and stress limited conclusions can be drawn in relation to this research question.

Research Question 4: What is the impact of parental coping strategies on their quality of life?

Among the selected studies, only Papadopoulous et al. (2024) examined the link between coping strategies and family quality of life (FQoL), which focused on mothers of autistic children immediately after diagnosis and a year later. Though Al Busaidi et al. (2022) considered quality of life and coping strategies used by parents, the relationship and impact of each variable on each other was not considered, so findings are omitted here.

Findings from Papadopoulos et al. (2024) indicated that parental coping strategies significantly influence FQoL following a child's autism diagnosis. Positive reframing was a strong positive predictor of FQoL at both Time 1 ($\beta = 0.166$, $p < .001$) and Time 2 ($\beta = 0.107$, $p = .028$). In contrast, self-blame was a significant negative predictor at Time 1 ($\beta = -0.133$, $p = .004$), and denial was negatively correlated with FQoL at both time points (T1: $r = -0.308$, $p < .05$; T2: $r = -0.439$, $p < .01$). By Time 2, additional adaptive strategies including acceptance ($r = .402$, $p < .01$), planning ($r = .333$, $p < .05$), active coping ($r = .323$, $p < .05$), and informational support ($r = .286$, $p < .05$) were positively associated with improved FQoL. The variance explained by the model was higher at Time 1 ($R^2 = .65$) than at Time 2 ($R^2 = .31$), suggesting early coping responses may be particularly influential (Papadopoulos et al., 2024). However, as only one of twelve studies selected for review examined the link between coping and FQoL limited conclusions can be drawn from the results.

Discussion

This systematic review examined coping strategies amongst parents of autistic children. Reviewed papers underwent quality appraisal and fulfilled most of the required criteria, indicating there was an overall good quality of papers with a low risk of bias of results. The first research question of the review aimed to identify the tools used to assess parental coping strategies. A total of 5 self-reported questionnaires were identified, with differences across scales making it difficult to compare studies. Similar coping measures were used within the earlier review by Vernhet et al. (2019), though the current review did not include any studies using the Cognitive Emotion Regulation Questionnaire (CERQ) or the Coping Strategy Inventory (CSI). Instead, the current review included an additional measure of Coping with Children's Negative Emotions Scale (CCNES) (Alostaz et al., 2022). The WCC-R and Brief Cope (used most frequently in studies) examine coping strategies relating to specific situations associated with parenting an autistic child. The CCNES, CSQ and CISS use generic situations.

Reliability of the tools varied. The CCNES and Brief COPE showed good reliability across studies which was consistent with findings reported by Vernhet et al. (2019). CISS also demonstrated acceptable to excellent reliability across scales within the measure, whereas review by Vernhet et al. (2019) found the CISS demonstrated insufficient internal consistency. Though the CISS was used with Polish samples within studies across both reviews, the difference of internal consistency may be explained by how reliability was reported (individual subscales vs. overall range) and differences of sample characteristics (Dabrowska & Pisula, 2010; Gagat-Matuła, 2022). Several tools were validated for use cross culturally (all with acceptable or above reliability). CISS was adapted in Polish, WCC-R in French and Arabic and Brief COPE in Spanish. This highlights the cross-cultural nature of the studies and the validity of their use across countries. SCSQ (20 items), WCC-R (27 items) and Brief COPE (28 items) had the smallest number of items, making them more accessible for parents, whereas other tools items ranged from 48-72 items, which was consistent with findings from Vernhet et al. (2019) review. Therefore, the Brief COPE is the most suited questionnaire in terms of reliability, validity, specificity and length for measuring coping in parents of autistic children, which is consistent with earlier findings (Vernhet et al., 2019). However, the earlier review also indicated that in addition to the Brief COPE the WCC-R was adequate (Vernhet et al., 2019) whilst within the current literature the Brief COPE was found to be more reliable, valid and accessible across domains above all other tools.

Secondly, the review aimed to capture the impact of individual differences on coping. Four of the 12 studies examined the differences between mothers and fathers and coping. No differences were found across most subsets of coping. However, mothers were found to be more likely to utilise social support seeking strategies than fathers after their child's diagnosis (Rattaz et al., 2023) and mothers were significantly more likely than fathers to use problem focused and social support coping (Ang & Loh, 2019). These mixed findings are consistent with broader literature and the review by Vernhet et al. (2019), in which differences between coping by gender were small. Similarly to studies within the review by Vernhet et al. (2019), the proportion of fathers in the total review sample size is low and therefore further research would require more fathers to be recruited as participants (Vernhet et al., 2019).

Two studies analysed the impact of coping on mental health. Both cross-sectional studies highlighted an association between avoidant coping strategies and parental mental health (Ang & Loh, 2019; Cai et al., 2020). There was an association found between mothers who engaged more frequently in avoidant coping and exhibited higher intolerance of uncertainty with greater symptoms of anxiety and depression (Cai et al., 2020). Active avoidance coping (self-blame and behavioural disengagement) was significantly associated with higher levels of depression (Ang & Loh, 2019). This has been highlighted by earlier studies in which avoidant strategies are maladaptive overtime, leading to emotional exhaustion and burnout (Hastings et al., 2005). Despite only two studies examining the relationship between parental coping and mental health, there were no studies within the Vernhet et al. (2019) review which examined these relationships.

The third aim of the review was to examine relationships between stress and coping; only two studies examined this relationship and therefore limited conclusions and interpretations can be made (Miranda et al., 2019; Rattaz et al., 2023). In comparison, the earlier review examined these relationships within five studies (Vernhet et al., 2019). Rattaz et al. (2023)

found that maternal stress significantly decreased over the three years following a child's autism diagnosis, accompanied by a notable reduction in emotion-focused coping. This suggests that parental coping strategies may evolve over time, potentially becoming more adaptive as families adjust to the diagnosis and establish support systems (Rattaz et al., 2023). Further research in this area is required, as there is limited longitudinal research on stress and coping in parents of autistic children (Benson, 2014; Gray, 2006). Miranda et al., (2019) identified through multiple mediation analysis that engagement coping and behavioural difficulties were significant mediators in the relationship between symptoms associated with autism and parenting stress. Together, these findings point to the importance of the context and timing in which coping strategies are used and the need to promote engagement coping in order to buffer the impact of stress in parents (Miranda et al., 2019). This replicates similar results in the earlier review and therefore builds on existing literature.

Only one study explored the relationship between coping and family quality of life (FQoL) amongst parents of autistic children, and therefore conclusions and interpretations of results are limited. Within Vernhet et al. (2019) only two studies selected within the review examined these relationships, suggesting research in this area remains limited. Positive reframing emerged as a positive predictor of quality of life across time points, suggesting that the ability to cognitively reinterpret challenges may play a protective role over time (Papadopoulos et al., 2024). Positive reframing is an emotion focused coping strategy and therefore this contradicts earlier research identified within the Vernhet et al. (2019) review, in which emotion focused coping was identified as a risk factor for stress and quality of life (Cappe et al., 2011). As findings from Papadopoulous et al. (2024) highlight, different types of coping within the wider framework of 'emotion focused coping' require individual scrutiny. Self-blame significantly predicted lower FQoL at baseline, indicating that maladaptive internalising responses may undermine wellbeing, particularly in the earlier stages of adjustment (Papadopoulos et al., 2024). These findings highlight the protective role of adaptive coping, particularly positive reframing, and the detrimental impact of avoidant or self-critical strategies on parental well-being, and suggest early coping responses are influential, which is consistent with earlier literature (Benson, 2010; Hastings et al., 2005).

Overall, this updated review builds upon and confirms similar findings from the earlier review by Vernhet et al. 2019, particularly around adaptive and maladaptive coping, gender trends, and importance of problem-focused coping strategies. Overall, both reviews reported use of similar questionnaires to measure coping and little difference in coping styles between genders were reported (Vernhet et al., 2019). Both reviews identified problem-focused coping was associated with reduced stress and better psychological outcomes. The original review found that problem-focused coping was associated with lower parental stress and improved quality of life (Vernhet et al., 2019) whilst the updated review reports that problem-focused coping in mothers was associated with better well-being, particularly shortly after diagnosis (Cai et al., 2020; Papadopoulos et al., 2024). Additionally, both reviews identified an association with avoidant coping and poorer mental health. Vernhet et al. (2019) described avoidant and emotion-focused coping as being associated with increased stress and lower quality of life reducing quality of life. This updated review highlighted avoidant coping was associated with higher levels of depression and anxiety (Ang & Loh, 2019; Cai et al., 2020).

Strengths and Limitations.

This systematic review captures a range of good quality studies using a replicable methodology to examine measures of coping in parents of autistic children and interactions of a range of variables that interact with coping. To ensure the review was methodologically robust, PRISMA guidelines were followed, the review was prospectively registered on PROSPERO and a quality appraisal tool was used to evaluate risk of bias. A second reviewer independently reviewed a percentage of studies for screening, data extraction and quality appraisal to reduce bias and increase accuracy and rigour of results.

Although stress and quality of life, along with their interactions with coping, were included in the research questions, they were not used as inclusion criteria for the review, in line with the methodology of Vernhet et al. (2019). Therefore, returned studies relating to stress and quality of life and their interactions with coping were limited. Future reviews may wish to specify inclusion of quality of life and stress measures to ensure their interactions within parental coping can be addressed more fully.

The quality appraisal tool used was a replication of the customised tool used within the earlier review by Vernhet et al. (2019) to allow for comparison between quality of papers in the earlier and current review. However, as this tool has not been validated and indicated moderate inter-rater reliability (Vernhet et al., 2019) the appraisal findings should be interpreted with caution, and conclusions regarding study quality may be subject to bias or variability.

Several of the included studies showed methodological limitations, including a reliance on cross-sectional designs and limited reporting of psychometric properties. Variation in the cultural adaptation and validation of coping measures, such as the CISS (Gagat-Matuła, 2022) may account for inconsistent reliability findings across studies within Vernhet et al. (2019) and the current review. Similarly to studies within Vernet et al. (2019), severity of autism and age of children were not routinely considered across all studies and therefore understanding how these variables interact with coping in parents of autistic children would be helpful for future studies.

Implications.

Results from this review have several implications for clinical practice. Embedding brief, validated coping questionnaires such as the Brief COPE into routine assessments used in autism support services could help practitioners better understand family resilience and tailor support accordingly. Research has shown psychoeducational interventions can improve parent coping (Singer et al., 2007). As coping strategies like positive reframing and problem focused coping were linked to better quality of life and mental health outcomes (Miranda et al., 2019; Papadopoulous et al. 2024) these skills could be specifically targeted in psychoeducation for parents, whilst screening for avoidant or emotion-focused coping styles which have been associated with higher stress and depression (Ang & Loh, 2019; Cai et al., 2020). Evidence has suggested the importance of addressing parental mental health within children's autism pathways (Yorke et al., 2018). As findings in this review highlight links between mental health and avoidant coping (Ang & Loh, 2019; Cai et al., 2020), integration of coping assessments of parents within autism diagnostic pathways could be crucial (Vernhet et al., 2019).

Conclusion

This systematic review examined coping strategies used by parents of autistic children, focusing on the tools used to measure coping, the influence of individual differences and the relationship between coping, stress and quality of life. Across the 12 included studies, five self-report measures were identified, with the Brief COPE emerging as the most widely used and psychometrically robust tool. Findings also confirmed that avoidant coping is associated with poorer mental health outcomes (Ang & Loh, 2019; Cai et al., 2020), whilst adaptive strategies such as positive reframing and problem-focused coping are linked to better psychological well-being and family quality of life (Miranda et al., 2019; Papadopoulous et al. 2024). The findings highlight the importance of integrating brief, validated coping assessments into services and tailoring support for parents of autistic children based on their individual coping profiles.

Statements and Declarations.

This review did not receive funding. The author(s) have no competing interests to declare. Data can be shared with other researchers upon request.

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Chapter 2

Major Research Project: Exploring the experiences and impact of cyberbullying on autistic adolescents.

Prepared in accordance with the author requirements for the Journal of Autism & Developmental Disorders; Author submission guidelines

Plain Language Summary

Title: Exploring the experiences and impact of cyberbullying on autistic adolescents.

Background: Studies show that autistic adolescents are more likely to be bullied than non-autistic adolescents (Humphrey & Hebron, 2015). Cyberbullying (bullying which takes place online), has been found to have negative impacts on adolescents. The experiences and effects of cyberbullying on autistic adolescents is currently a growing area of research (Holfield et al., 2019).

Aims and Questions: To explore the experiences and impact of cyberbullying on autistic adolescents.

Methods: Six autistic adolescents with experience of cyberbullying were recruited through social media and through organisations which provide support to autistic young people. To be included in the study participants had to: (1) be an adolescent with a diagnosis of autism via NHS, (2) have experienced cyberbullying within the last two years, (3) be aged between 14 and 19, (4) speak fluent English, (5) live in the UK. Adolescents who were currently having an autism assessment, or who had an intellectual disability were unable to take part. Semi-structured interviews with adolescents were studied using Interpretative Phenomenological Analysis (Smith et al., 2022), which involves looking for and making sense of important patterns and meanings (themes) in what adolescents said.

Main findings and conclusions: Three main themes were found: 1) No safe space, 2) Am I enough? 3) Responses to cyberbullying. This study adds to the evidence base about autistic adolescent’s experiences of cyberbullying bullying. This information can be used by parents and those working with autistic adolescents to provide improved support to those who experience cyberbullying.

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Abstract

Purpose: Autistic adolescents are more likely to experience bullying victimisation than their neuro-typical peers. Cyberbullying refers to online bullying and is associated with poor mental health outcomes including anxiety, depression, self-harm and suicidality. There is limited research within the field of cyberbullying which explores the experiences of adolescents with an autism diagnosis. This study aimed to explore the experiences and impact of cyberbullying in autistic adolescents.

Methods: Semi-structured interviews were conducted with six autistic adolescents living in the UK, aged between 17 – 18 years old, who self-reported cyberbullying within the last two years. Interpretative Phenomenological Analysis (IPA) was used to explore themes.

Results: Analysis elicited three group experiential themes. 1) No safe space, 2) Am I enough? 3) Responses to cyberbullying.

Conclusion: Participants shared a range of insights into their experiences and challenges of cyberbullying. Cyberbullying was pervasive and lead to participants responding with both adaptive and maladaptive strategies. This has implications for parents and professionals supporting autistic adolescents.

Keywords: Autism, Cyberbullying, Adolescents.

Introduction

Cyberbullying amongst adolescents in the general population is a well-researched area (Zhu et al., 2021). Far less is known about the experiences of cyberbullying and the impact on autistic adolescents, although this is an emerging area of research interest (Beckman et al., 2020; Holfield et al., 2019). Autism is a neurodevelopmental condition which results in impairments in communication and social interaction, in addition to repetitive and restricted interests (American Psychiatric Association (APA), 2013; Scottish Intercollegiate Guidelines Network (SIGN), 2016). Autism is heterogeneous with impairments occurring along a continuum from mild to severe (Christensen et al., 2018). Prevalence rates of autism in the United Kingdom are estimated to be between 1 % and 1.7 % with a rising rate of diagnosis amongst school children (Baron-Cohen et al., 2009; Christensen et al., 2018; McConkey, 2020). Research suggests this is due to changes to diagnostic criteria and an increasing awareness and recognition of autism amongst both parents and professionals (McConkey, 2020; Wing & Potter, 2002). Diagnostic terminology refers to Autism Spectrum Disorder (ASD) (APA, 2013), but within the autistic community (autistic people, parents and their broader support network) there is disagreement about the way autism is, and should be, described (Kenny et al., 2016). ‘Autistic person’ is a common preference and will be used throughout this study (Kenny et al., 2016). Difficulties with communication and social interactions associated with autism can impact negatively on peer relationships and understanding of non-verbal communication, which are risk factors for bullying (Cappadocia et al., 2012; Hebron et al., 2015) and poorer mental health outcomes (Abregú-Crespo, et al., 2024; Zablotsky et al., 2013).

Cyberbullying refers to online bullying, though conceptualisations and definitions vary across the literature. Bullying can be defined as repeated, unwanted, negative or aggressive behaviour within an interpersonal relationship which most frequently is characterised by a power imbalance (Olweus et al., 1999). There is disagreement amongst researchers as to whether cyberbullying should be defined as its own concept or viewed as a sub-category of bullying (Olweus & Limber, 2018; Smith, 2012). Emerging evidence indicates that cyberbullying can consist of similar behaviours to generalised bullying but additionally includes publicity and possible anonymity of the perpetrator (Thomas et al., 2015). Therefore, the above criteria are used to define cyberbullying for the purposes of this study.

Early research into cyberbullying was predominately quantitative; but more recently there has been a shift towards using more diverse methodologies (Dennehy et al., 2020). Qualitative studies offer an opportunity to analyse in-depth, rich data to fully understand adolescent's experiences of cyberbullying. In a meta-synthesis of 13 studies which investigated a total sample of 753 neuro-typical adolescent's conceptualisations of cyberbullying; disempowerment of victims was identified across five key concepts of intent, repetition, accessibility, anonymity and barriers to disclosure (Dennehy et al., 2020). The study indicated that in conceptualising cyberbullying, young people focussed on victim impact and the immediacy of sharing content and wide dissemination; in contrast to the repetitive nature characterised by generalised bullying (Dennehy et al., 2020). This was supported by Macaulay et al. (2022), in which 1438 teenagers from secondary schools and a college in England rated severity of bullying in vignettes. Severity ratings were higher in public settings when bullies were anonymous (Macaulay et al., 2022).

Cyberbullying is associated with poor mental health outcomes amongst adolescents within the general population, including increased risk of suicidal and self-harm behaviours (Dorol & Mishara, 2021), higher levels of depression and anxiety when compared to generalised bullying (Campbell et al., 2012; Kowalski & Limber, 2013; Yang & Salmivalli, 2013) and problems with adjustment in school (Kowalski & Limber, 2013). Therefore, understanding experiences and impacts of cyberbullying may be helpful in providing support to individuals, parents, carers and schools. A systematic review of meta-analyses by Zych et al. (2019) identified key protective factors against bullying and cyberbullying in adolescents, including parental monitoring and supervision of technology use, as well as strong social-emotional skills and empathy.

Cyberbullying within autistic populations is less well researched than in the general population; but evidence indicates that prevalence of bullying experienced by autistic adolescents is higher than typically developing teenagers (Humphrey & Hebron, 2015; Rowley et al., 2012; Schroeder at al., 2014; Symes & Humphrey, 2010). Studies have indicated that autistic individuals spend more time online than neurotypical counterparts which increases the possibility of experiencing cyberbullying (MacMullin et al., 2016; Must et al., 2014).

A recent meta-analysis of cyberbullying in adolescents with a range of neurodevelopmental conditions, including autism, indicated issues with the research design of studies in this field, including small sample sizes and lack of control groups (Beckman et al., 2020). There is heterogeneity across cyberbullying research studies, with different recall periods and thresholds for definitions of cyberbullying (Smith, 2012). Prevalence rates of cyberbullying vary, as research studies have employed different measures (Olweus & Limber, 2018). Additionally, prevalence rates in bullying research are thought to be impacted by informant type (Beckman et al., 2020; Branson

& Cornell, 2009). Whilst most research on typically developing adolescents has relied on self-report measures, studies involving autistic populations have more frequently utilised reports from parents and teachers (Beckman et al., 2020). Because cyberbullying is often concealed from adults, studies that rely on methods other than self-report may underestimate its prevalence (Beckman et al., 2020). For example, a study on general bullying among school pupils found that 41% of students self-reported being frequently bullied, whereas 71.4% of staff estimated that less than 15% of students experienced frequent bullying (Bradshaw at al., 2007). This highlights the difference in perceptions of self-report compared with reporting by others.

The prevalence of cyberbullying and its association with a range of mental health conditions in autistic adolescents warrants further research (Hu et al., 2019). There is also limited qualitative research exploring the experiences of young autistic people and cyberbullying (Hwang et al., 2018; Holfield et al. 2019), which this research project aimed to address. Understanding how young autistic adolescents interpret their experiences from their own perspective is crucial. Qualitative research provides the opportunity for in-depth exploration and greater insight into the experiences and effects of cyberbullying. Therefore, this study sought to explore the lived experiences of cyberbullying among autistic adolescents through interviews and examined the impact these experiences had upon them.

Methods

Design

The focus of this study was to gain meaningful insights into autistic adolescent's experiences of cyberbullying and the impact of these experiences upon them. A qualitative research design was considered the most appropriate method to gather detailed data to explore individual experiences. Semi-structured, one-to-one interviews were used to ensure a flexible format to explore participants' experiences. This flexibility allowed for the interviewer to respond individually to participant's unique interpretations of their experiences (Merriam & Tisdell, 2025).

Interpretative Phenomenological Analysis (IPA) was selected as the appropriate analytic methodology, as it seeks to examine the reflections and sense-making of an individual's specific experiences (Smith et al., 2022). Central theoretical underpinnings of IPA include focusing on the individual's lived experience (phenomenology), interpretation of these experiences (hermeneutics) and thorough, detailed examination of experiences (idiography) (Smith et al., 2022). A double hermeneutic approach is adopted within IPA in which the researcher attempts to understand the participants' sense making of their own experiences to gain meaningful insights into a group's lived experience (Smith et al., 2022).

Participants

As the research question related to a specific group (autistic adolescents who have experienced cyberbullying), purposive sampling, in which a specific group of individuals are targeted for analysis, was used to select participants. Six autistic older adolescents were recruited in total. Though it has been suggested that there is no optimal sample size within IPA due to the idiographic nature of this type of analysis, smaller samples are common (Smith et al., 2022). Clarke (2010) has suggested that for doctoral level studies sample sizes between 4 – 10 participants is sufficient to gain meaningful insight into data. Participants' ages ranged from 17 to 18 years old (M = 17.7). The age range was defined based on the World Health Organization's (WHO, 2018) classification of older adolescents as individuals between 14 and 19 years old.

The older adolescent age was selected as this age group were more likely to be engaged independently in online forums and communities than younger adolescents (Reid Chassiakos et al., 2016). Additionally, this was to ensure some homogeneity of the sample group, as small age differentials would allow for better understanding of the adolescent experience (Smith et al., 2022). Full participant demographics are shown in Appendix 2A, pg. 92.

Inclusion criteria for participating in the study were: (1) adolescent with a diagnosis of autism via NHS, (2) adolescent self-identified as having experienced cyberbullying within the last two years, (3) adolescent was aged between 14 and 19, (4) adolescent spoke fluent English, (5) adolescent resided in the UK. Exclusion criteria were as follows: (1) adolescent was currently undergoing an autism assessment, (2) adolescent had an intellectual disability.

Non-participation.

Twelve potential participants contacted the researcher expressing initial interest in the study. Two were not eligible to take part as they were based internationally. Four potential participants who stated their eligibility did not result in interviews, either due to no further correspondence when contacted by the researcher, or non-attendance at interview.

Ethical Approval.

Ethical approval was granted by University of Glasgow‘s College of Medicine, Veterinary & Life Sciences (MLVS) Ethics Committee (Appendix 2B pg. 93)

Procedure.

Following ethical approval, the study was advertised online via social media (e.g. Reddit, Facebook, X) and through third sector organisations supporting autistic adolescents (e.g. Autistica, Carers Together, Hope for Autism) who advertised via social media accounts and mailing lists. See Appendix 2C pg. 95 for recruitment poster. After individuals contacted the researcher via email, an online meeting was arranged on Teams. Participants, all of whom were aged 16 and over, completed a consent form (Appendix 2D pg. 96). Participants completed a short demographic form prior to the interview commencing which requested their age, gender, location and ethnicity.

Data was collected through semi-structured interviews and the interview schedule consisted of seven questions (full interview schedule listed in Appendix 2E pg. 97) and was emailed to participants in advance. The interview schedule was developed with research supervisors and a young autistic adult (age 20), recruited through the lead researcher's network, consulted on the questions to ensure their appropriateness for capturing individual's experiences. Participants were interviewed by the lead researcher (CH). The duration of interviews was between 32 and 58 minutes (M = 46.3 minutes). Participants were aware they could have someone with them during the interview, but all participants chose to be interviewed alone. Interviews were recorded on Teams via a secure password protected system. Following each interview the participant was given a verbal debrief and then emailed a debrief document for their reference (Appendix 2F pg. 98). Reflective notes were completed by the researcher after each interview.

Analysis Plan.

Smith et al.’s (2022) IPA process was used to guide analysis and is described below. Firstly, interviews were transcribed verbatim and read and re-read. To maintain an idiographic focus transcripts were analysed separately and within descriptive, linguistic and conceptual frameworks (Smith et al., 2022). The analysis involved initial exploratory notes which were used to construct experiential statements. Next, connections across experiential statements were searched for to organise clusters of statements. These were consolidated into groups of personal experiential themes (PETs) for each transcript. The themes were then checked against transcripts to ensure fit with the source material. Similarities and differences of PETS across transcripts were identified with similar PETS clustered into Group Experiential Themes (GETS) to highlight the shared and unique features of participants experiences (Smith et al., 2022). To strengthen accuracy and credibility of the analysis, the researcher recorded reflections after each interview to monitor potential bias, which were discussed within research supervision. To ensure analysis was conducted with multiple perspectives and to reduce bias, one full transcript along with corresponding exploratory notes, experiential statements and PETS along with GETS were read and checked by the research supervisor. Analysis was also discussed in academic supervision. The study adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007), see Appendix 2F, pg. 100. Quotations have been reported along with the associated participant pseudonym to illustrate findings and aid transparency of analysis.

Researcher Reflexivity.

Key within IPA is the acknowledgement that a researcher's own viewpoint may impact how they contextualise and make sense of a participant's experiences.

Some of the researcher's (CH) attributes that may have influenced the research process include being a white neurotypical female, having her own perceptions about, and usage of, social media and not having any personal experience of cyberbullying. The researcher held an MSc Applied Psychology (Healthcare) for Children and Young People and at the time of the study was employed by the NHS as part of the Doctorate in Clinical Psychology. The researcher's background is in working with autistic adolescents in clinical settings in which experiences of bullying were often discussed. The researcher acknowledges these differences in position and the effect this may have on both the interaction between researcher and participants and the interpretation of the data collected. Discussion of interview protocols and theme development within supervision helped to maintain awareness of these differences and to limit the influence on analysis (Appendix 2F, pg. 98). Participants were unknown to the researcher prior to the study and were made aware of the researcher's reasons behind pursuing the research at the beginning of each interview.

Results

The analysis elicited three Group Experiential Themes (GETs), which included several Personal Experiential Themes (PETS) within each (see Table 2.1).

Table 2.1

Group Experiential Themes and Personal Experiential Themes

Group Experiential Themes	Personal Experiential Themes
No safe space	1. Online and offline 2. Anonymity
Am I enough?	1. Betrayal by friends 2. Autistic identity
Responses to cyberbullying	1. Shame and withdrawal 2. Mental health difficulties 3. Setting boundaries 4. Disclosing cyberbullying

No Safe Space

Each participant described feeling as though they were under threat wherever they were, with cyberbullying permeating their home and school lives. This was underpinned by their experiences of cyberbullying moving between online to offline environments. Peer-initiated bullying within the school environment frequently extended into participants' online experiences, whilst in other cases, instances of cyberbullying were recognised and reinforced by peers in their offline, ‘real-world’ interactions. Participants' feelings of insecurity were heightened by their lack of anonymity, which was in direct contrast to the power held by their bullies, who could choose to remain nameless.

Online and offline

Each of the participants described their experiences of cyberbullying transitioning between online and into their everyday life, offline. All six participants reported that cyberbullying spanned across multiple online platforms, leading to repeated exposure and constant reminders anytime they were online, or using their phone, which increased their emotional distress. Gemma, who was 18, had shared photos and videos of herself online, resulting in hurtful comments about her appearance and edited pictures began circulating about her. She indicated:

"It spread like wildfire and I felt so bad. It started on TikTok but but before I knew it, it was like the same stuff was being shared on Instagram and then WhatsApp…then I was getting DMs [direct messages]" (Gemma).

Bullying described by participants was cross-contextual with cyberbullying either leading to, or being an extended form of, in-person bulling. Each participant described experiences of being targeted both online and in public spaces, with every participant finding cyberbullying permeated into their school experience. Nadia, an 18-year-old girl, shared a video of a musician on her social media, as his music was a shared passion for both her and her mother. This led to her being mocked online by peers, with derogatory comments and unfounded allegations made about her on her post:

"the next day at school it was like all hell broke loose…I'd already seen the messages online and told my mum I wasn't going to go back. She she sort of made me after a few days and and I was kind of, of begging her to not make me go back but I did go and there was like people saying stuff and playing his music when I walked in a room and just like like just laughing. Just you know like kind of people people talking behind my back" (Nadia).

The ubiquitous nature of cyberbullying meant that in their private spaces, such as whilst in their bedrooms at home on their own, or with family, participants continued to receive notifications and hurtful messages via their phones and laptops, giving them a sense that danger was ever-present and that there was no escape from being targeted:

"And then you can't switch off you know. It's like in school it's there, you go home, it's there. You can't get away from it" (Gemma).

Anonymity.

Peers and strangers had access to participants' personal information, which undermined any sense of anonymity they felt in their online worlds. In contrast, perpetrators of cyberbullying, and those viewing unkind content about participants, could choose to remain anonymous. Three of the participants spoke about being 'doxxed', in which their personal details were shared publicly online without consent. Jane is a 17-year-old, who was targeted by people she had perceived as friends for several years:

"they posted my name, address and number on TikToks, so I would get random phone calls from unknown numbers and they'd tell me to go and kill myself" (Jane).

The participants' lack of anonymity highlighted the power imbalance between them and the often-nameless perpetrators of cyberbullying. Not knowing who was targeting them contributed to a diminished sense of safety. The anonymity afforded to online bullies by digital spaces further reinforced participants' feelings of vulnerability and powerlessness. David, aged 18, had fake accounts set up using his photographs and these accounts shared fake information and offensive statements about him, which in turn others would send to his personal accounts.

"It was really scary, it just felt like everyone knew who I was and like they wouldn't stop messaging me really nasty stuff, but I didn't have a clue who they were cos they were like from anonymous accounts so there wasn't much I could do" (David).

Perpetrators of cyberbullying were in control of whether they revealed to their victim who they were. This power was not shared by the participants who had feelings of helplessness and circumstances being out of their control as Gemma noted:

"*It was like everything I'd put up in the past was being used against me. Everyone knew my personal information and personal stuff about me you know… it was out there being shared, and I couldn't even see who was looking at it anymore 'cos they'd screenshot it and share it with other people, who weren't even people who follow me"* (Gemma).

The pervasiveness of cyberbullying moving offline along with the anonymity of perpetrators led to a sense of paranoia for two participants. Craig, aged 17, whose personal messages with a friend were widely disseminated online without his knowledge or permission found the uncertainty of who had viewed and shared his information difficult to cope with and stated, "*you see people at school, and you do wonder was it you or you or you?"*. Similarly, David had a sense of his peers being against him, exacerbating his sense of loneliness and difference: *"It felt like everyone was out to get me".*

Therefore, participants were experiencing a pervasive sense of threat and lacked power, in direct contrast to their bullies. This in turn began to undermine how participants self-identify, which is explored within the next group experiential theme.

Am I enough?

Participants discussed how being cyberbullied led them to question their understanding of themselves and the world around them. They described a sense of betrayal by people they had thought of as friends and the impact their autism had on their own sense of self as well as other's perceptions of them.

Betrayal by friends.

Four of the six participants reported that people they had thought of as close friends had been the initial perpetrators of their experience of being cyberbullied. Craig's friend who he had known since primary school and felt he had a strong connection with, shared his personal messages to her on TikTok:

"I would have liked to know why, but that was why it was so confusing because I had thought we were friends you know. But she turned on me" (Craig).

This sense of shock and confusion about how someone they had perceived to be close to them could instigate cyberbullying against them was echoed by others. Hayley, whose close friend had made derogatory comments about some of her posts about Hayley being autistic and her personal identity around this, shared her disbelief: *"Surely this person I've just called my best friend, surely like, she wouldn't do that"*.

For Craig, adding to the sense of betrayal was the private information he had shared with his friend was disseminated:

"She wasn't my friend, I just hadn't realised that…they were private messages I was telling her about my thoughts. She'd uploaded loads of my chats with her" (Craig).

Betrayal by friends led to feelings of confusion and uncertainty and questioning of their own role in the cyberbullying. Three participants indicated they had internalised what had happened and shared cognitions of self-blame about being the cause of their cyberbullying experiences. Craig appeared to shoulder the blame, but also remained unclear about what he had done:

"*And then it made me think I must have done something wrong, but I don't really know what it was"* (Craig).

Hayley's best friend had made cruel comments on a post she had shared online celebrating her autism and sharing pictures of her autism assistance dog. This had escalated to others sharing this content and her best friend's network also making judgements and unkind comments. Hayley was struggling to understand if she had caused this to happen and was blaming herself, whilst also wondering if she had misunderstood the communication from her friend:

"I feel like…because I take things like a lot of times, I will take things out of context or take things too literally, because you know I always have never wanted anyone to speak to the person that was doing something, because what if I just took it the wrong way?... I felt a bit foolish for doing that and then also embarrassed because for a second I thought maybe she was right" (Hayley).

David noticed the impact of his experience upon his ability to trust and make friends. He had withdrawn from connecting with others to protect himself following cyberbullying:

"I'm kind of an open person, but after that I thought I should probably be more careful about who I called a friend and don't just tell even your closest friends stuff" (David).

Autistic Identity.

Two participants explicitly described viewing their autism as a disability, which they felt set them apart from their peers. For both, a key trigger for cyberbullying was that their differences weren't outwardly visible to friends, leading to misunderstandings and a lack of empathy and understanding from others. Jane experienced cyberbullying instigated by a group of longstanding friends, some of whom she had known since primary school:

"They said I was faking my disabilities. Being my friend was too hard because of my difficulties…I don't understand jokes, I get confused easily, I get frustrated, but my friends didn't understand that I had a disability because I wasn't in a wheelchair". (Jane)

Hayley took pride in her identity as an autistic young woman, but this triggered conflict with her friends who preferred her to keep this side of herself hidden. Hayley's friends did not want to be seen with her in public spaces when she was with her autism assistance dog:

"She told me 'you're not disabled you are just different' and she didn't want to be seen with someone who was disabled…I explained, and you know it should be something that's celebrated, not something I have to hide". But she had a sense from others that she should not view herself as unique or needing additional support "*I had this teacher…he said you're not the only one in class like you".*

Craig had been diagnosed as autistic in the last year and though he seemed to still be grappling with this new identity and any possible impact this had on his cyberbullying experiences, he did recognise a sense of being 'different' from his peers:

"*I don't think she picked on me because I was autistic. It didn't have anything to do with that I don't think… I'm just a bit different you know. I think part of it is having an autistic mind...I have friends who are autistic, but they say I'm not as autistic as them and my mum didn't think I was autistic until the counsellor said I probably was".* (Craig)

There was a sense from several participants they were concerned that being autistic should not be seen as an excuse for their victimisation by others. Jane said, "C*yberbullying doesn't always start just from autism with autistic people, it starts with other disabilities or jealousy*". David had been diagnosed as autistic at primary school and recognised there was not a single cause of his cyberbullying, "*I'm not sure how much being autistic had to do with it, who knows. It might have been part of it, but it wasn't all of it".*

Therefore, some participants appeared to be internalising their experiences of cyberbullying; leaving them questioning their friendships, their roles within friendships and how their autism impacted upon these experiences. For others, autism was not viewed as a key part of their identity and they felt their diagnosis was a simplification of explaining their experiences. How they made sense of their experiences impacted some of their responses.

Responses to cyberbullying.

The participants shared a range of responses to their experiences of cyberbullying. These included feelings of shame which led to withdrawal, mental health difficulties, setting up boundaries and whether to tell an adult, or to choose not to disclose cyberbullying.

Shame and withdrawal.

A common theme that emerged across all the participants was a sense of shame. Gemma was taunted about being overweight and hurtful comments about her appearance were shared with peers and strangers online.

"It was like this horrible feeling in my stomach, a deep pit. I would cringe to myself and like blink and just hope and hope I'd well sort of imagined it and it wasn't happening" (Gemma).

She repeatedly came back to crippling shame again and said, *"it was just everyone knew and I wanted to curl up in a ball"*. Her shame was hidden from others but also made her want to hide. She internalised these feelings when she said, "*I just felt there is something wrong with me, obviously*" and then doubted her own feelings about the experience were valid, "*I did have thoughts of just maybe I was making too much of it*".

Similarly, Hayley described feelings of shame making her want to be invisible:

"*It makes you quite upset and like nervous to I guess, exist. It pushes you into a corner ...it had really sort of shut me down. Like I felt pushed into a corner and was like, you know, you stay there and keep your head down*" (Hayley).

Along with these feelings of shame participants recognised the extent of the impact of cyberbullying; for some, they simply withdrew themselves from day-to-day life:

"*I didn't really speak to anyone on my phone, I wasn't really contacting any people from where I lived…I very much isolated myself in the real world as well as online*" (Hayley).

Most of the participants reduced or stopped their attendance of school and described keeping to themselves if they were able to attend. Nadia had struggled with attending school prior to her experiences of cyberbullying, describing it as an overwhelming environment. She had friends but described difficulties connecting with a lot of her peers. She commented that after being derided online and taunted by peers she could not return: "*that was it for school for me. I mean it was bad before and there was no way I could face it anymore*".

Hayley was able to continue with school, though she reported *"I often had a sore tummy after that and wouldn't go in"* but she noted even when she made it in *"you know, I was very nervous in class and daily life. Yeah, I think I lost a lot of confidence during that time"* (Hayley).

Mental health difficulties.

All six participants had experienced mental health difficulties during adolescence. Five of the participants reported they had received support from mental health services during their teenage years, prior to, during and post their experiences of cyberbullying. All six participants reported their mental health difficulties were exacerbated by cyberbullying. Gemma reported, *"yeah my anxiety went through the roof after that".* Nadia said, *"I had been in CAMHS before for like depression and anxiety and after that it just sort of spiralled".* The severity of the consequences of cyberbullying on mental health were laid bare by Jane as she stated, *"I tried to kill myself because of it. I attempted suicide by an overdose and ended up in A & E."*

Setting boundaries.

Across several of the participants there was a sense of feeling out of control when they experienced cyberbullying. As Gemma said when she was being tagged and her image shared on multiple platforms without her consent, *'it was like whoa, hold on a second'* and later she repeated this to say, *'it was just like I didn't have a say in my own life'.* In response to this, most of the participants appeared to have used strategies to try and regain control of their online lives. All six participants indicated they changed their social media settings:

"*on all platforms my accounts are private, and I have to approve messages or followers"* (Jane).

"*If anyone talks to me like, 'oh, I'm getting picked on online' or something, something that I'll always say to them is block them, delete everything they said and don't give it like a second of your time*" (Hayley).

Though there were boundaries that could be upheld whilst using social media platforms, psychological boundaries were more difficult to maintain which was indicated by Hayley as she stated, *"it sort of just gets into your mind and takes over".*

Disclosing cyberbullying.

Participants battled with the decision about whether to disclose to adults they were being cyberbullied.

"It was a big debate in my head, would they have my back or was I better just to leave it" (David).

Parents also fought to get schools to understand the implications of cyberbullying and to take action to protect adolescents. Language from participants indicated a struggle: "*my parents fought with school over it as they weren't doing anything"* (Jane).

Though Hayley reported it was helpful having a teacher who listened to her when she shared her most recent experience of cyberbullying, she summarised that '*there was nothing that could really be done about it'*. This highlights the sense of helplessness and hopelessness that surrounded her experience of cyberbullying even when this was reported to adults.

Some had positive experiences telling an adult. David said it gave him a sense of relief to share his experiences with an adult:

'eventually I told mum, and she was immediately like "nah this isn't happening I'm gonna get this sorted" and I felt like sort of a bit of weight had been sort of lifted'.

Craig's approach to his cyberbullying experience was more passive and he chose not to share with his parents until he had left school a year later. His mum's response appeared to help him better understand that what had happened to him was not acceptable *"she told me that it wasn't ok and I shouldn't have to put up with stuff like that".*

There were concerns from four of the participants that telling either a parent or teacher would make things worse. Hayley had experienced cyberbullying multiple times and had shared this with teachers at times, but at other times chosen not to disclose anything. She noticed that she already felt different from her peers and worried that sharing what was happening to her would exacerbate this feeling of being different. After one experience of cyberbullying Haley said: *"telling anyone would have just made me stand out"*. She also remained protective of the perpetrator she had perceived to be her best friend, stating: *"I didn't want to get people into trouble".*

Overall, there were mixed responses as to whether to disclose their cyberbullying; for those that did it could be helpful, but there was a sense of lack of tangible action that could be taken to support them.

Discussion

This study explored the lived experiences of autistic teenagers who had been targets of cyberbullying. It aimed to better understand these experiences and their impact. Three overarching themes emerged: the lack of a safe space, challenges to self-identity and a range of coping strategies and psychological consequences. Findings underscored how cyberbullying permeates all aspects of participants' lives.

Consistent with other research, this study highlights the pervasiveness and inescapable nature of cyberbullying and highlights the frequency of bullying moving between digital and physical 'real-world' settings (Kowalski et al., 2014). For autistic participants, this sense of "no safe space" was acute, which may reflect a heightened sensitivity to social threats and the need for predictable, secure environments associated with autism (APA, 2013). The repeated exposure across platforms created increasing distress, which aligns with research on the cumulative impact of digital victimisation (Evans et al., 2014).

Perpetrators of cyberbullying were often peers, some remained anonymous, though this was not always the case. However, a sense of lost anonymity due to their personal information being widely shared was felt keenly by participants. This reflects the imbalance of power between perpetrator and victim and adds a further layer to the helplessness experienced by participants. This has been found in other research in the wider population, in which cyberbullying perpetrators are often known to the victim and many bystanders viewing content are peers (Moretti & Herkovits, 2021).

Several participants experienced cyberbullying by peers they had viewed to be their friends, leading to confusion and questioning about their own role within the friendship and self-blame for cyberbullying. Though studies have evidenced autistic adolescents are more likely than their neurotypical peers to be bullied (Humphrey & Hebron, 2015), there is very little existing literature evidence around autistic people's experiences of being bullied by people they perceive to be their friends. Betrayal by friends may be understood in the context of social communication impairments associated with autism, in which autistic individuals experience difficulties in social communication as well as differences in social-cognitive processing. These skills are required for successful interpretation of social cues and utilisation of non-verbal communication during social interactions (Livingston & Happé, 2021). Deficits in these can be associated with difficulties in establishing and maintaining friendships (Bennett et al., 2018). A systematic review highlighted studies indicated autistic young peoples' social-communicative difficulties were a barrier to developing friendships, as mutual misunderstandings could make bonding difficult (Cresswell et al., 2019). There is also emerging evidence about 'mate crimes' in which vulnerable groups, most commonly those with disabilities, are exposed to humiliation and cruelty by people they have considered to be friends (Thomas, 2011). Despite additional vulnerabilities within autistic populations, cyberbullying by friends is not unique to autistic adolescents, with some research indicating this can also occur within neurotypical adolescent populations (Brandau & Evanson, 2018; Nilan et al., 2015; Ševčíková et al., 2013).

Participants grappled with internalised stigma, questioning whether their autism made them a target. Whilst not all participants linked their diagnosis directly to bullying, many perceived being "different" as a contributing factor. These narratives support the idea that autistic identity can be a source of both pride and vulnerability (Botha et al., 2022). These insights also echo findings by Humphrey & Hebron (2015), who emphasised how autistic students often feel socially marginalised in mainstream school settings.

Participants responded to their experiences in several ways. Practical solutions involved creating online boundaries, using technical solutions of changing privacy settings and blocking and deleting comments and contacts. These have been found to be effective coping strategies within cyberbullying literature (Machackova et al., 2013). There were also psychological consequences in which participants reported feelings of shame, leading to their withdrawal from social interactions and avoidance of school; responses which align with existing literature on adolescents' reactions to cyberbullying (Randa & Reyns, 2014). Shame can underpin a variety of mental health difficulties, with avoidance behaviours commonly observed in conditions such as anxiety and depression (Yakeley, 2018). All participants indicated that their mental health struggles were exacerbated by cyberbullying, with some reports of this leading to suicidal ideation or attempts. The findings within this study are consistent with broader research suggesting that cyberbullying can have severe psychological effects (Arif et al., 2024; Cassidy et al., 2014). These results underscore the urgent need for early intervention and trauma-informed support services for autistic adolescents who are particularly susceptible to cyberbullying.

Contemporary research suggests that adolescents are ambivalent about disclosing cyberbullying experiences to adults, in part due to fear of the consequences, such as losing access to technology (Dennehy et al., 2020) or doubts about the possibility of effective intervention by adults (Aliyu et al., 2024). This aligns with research showing that autistic students may be reluctant to seek help due to prior negative experiences or perceived futility of attempts to support them (Hebron & Humphrey, 2014). However, despite these doubts and in contrast to existing research, each participant did disclose their experiences to adults. Results of this varied; some found relief, whilst others feared retaliation or further alienation which added to their sense of hopelessness when no further action was taken.

Strengths and limitations.

Findings are based on the reflections of six autistic adolescents who agreed to be interviewed. The use of a small homogeneous sample size is in line with the principles of IPA. This facilitated an in-depth exploration of autistic adolescent's experiences and the impact of cyberbullying upon them. A detailed analysis across a range of key areas revealed themes consistent with the wider literature on experiences of cyberbullying. In choosing to highlight and elaborate upon certain recurrent themes in the pursuit of synthesising the experiences across the whole sample of autistic adolescents, it is acknowledged that some nuances may have been lost through the process of the analysis. Due to resource constraints of the study, checking with members their agreement with the researcher's understanding of their experiences was not possible. This study represents these six individuals' experiences but the generalisability of this is limited, especially as there was little diversity within the sample. Five of six participants identified as white and all participants were UK-based, making it difficult to explore the representation of experiences from a wider population. Future research could seek to better understand how experiences of cyberbullying vary across genders, races, or socioeconomic backgrounds within the autistic community.

Several variables including length of time since diagnosis and other co-occurring diagnoses (such as ADHD or anxiety) were not routinely collected in this study. These factors may have impacted upon how adolescents made sense of their experiences.

Future research could consider the role of these variables and how they impact autistic adolescent experiences of cyberbullying.

Inclusion criteria for the study were that cyberbullying had occurred within the last two years, to ensure experiences were within the adolescent phase and could be easily recalled. However, it was possible participants were still processing their feelings about very recent incidents at the time of interviews, which may have impacted their evaluation of their experiences.

Given that the study sought to recruit participants who experience social communication difficulties, an interview with an unknown researcher may have precluded some autistic adolescents from wishing to participate in this study. This specific group may have benefited from an alternative approach, such as emailing interview questions, which has been a successful approach for other exploratory studies (Park-Cardoso & Silva, 2023).

Research in traditional bullying has indicated that there may be differences in how adolescents may interpret their experiences as victimisation which may be different to non-autistic peers (Schroeder et al., 2014; van Roekel et al., 2010). However, there is a paucity of research on whether this also translates to cyberbullying, in which social cues and dynamics may be further obscured due to the nature of being online and was beyond the scope of this research (Holfield et al., 2019). Future research should seek to examine the aspects of the scenarios that autistic adolescents pay attention to and how they interpret the situations. (Holfield et al., 2019)

Implications.

It is crucial to have a robust evidence base to understand how autistic adolescents experience and are impacted by cyberbullying, to allow schools and support networks to provide preventative strategies and to respond appropriately. In England and Wales, the Children and Families Act 2014 creates a framework for Education, Health and Care Plans (EHCPs) to ensure issues which are affecting a child's development, education or wellbeing are addressed, all of which may be impacted by cyberbullying (Department for Education, & Department of Health, 2015). Similarly, policies are in place within Scotland to direct support young people being bullied, including via cyberbullying (Scottish Government, 2017). An increased evidence base may strengthen support for the implementation of strategies to protect young people, such as promoting safe internet use, peer support schemes and digital citizenship (John et al., 2018). Research in this area may also improve understanding of clinicians in Child and Adolescent Mental Health settings working with autistic adolescents who have experienced cyberbullying (John et al., 2018). More evidence is required in this field, as wider concerns about the negative consequences of social media on adolescents is currently being debated with countries such as Australia taking steps to ban adolescent access (Blake et al., 2025).

Conclusion.

The findings of this study provide insight and understanding of the unique experiences and challenges of autistic adolescents who have been cyberbullied. Within this study cyberbullying was found to be pervasive and impacted upon the participants' sense of self, leading to adaptive and maladaptive strategies in response. The current study enriches our knowledge about autistic adolescents and cyberbullying. This has implications for clinical practice and future research, to provide increased understanding and support to this group, their parents and professionals.

Statements and Declarations:

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Appendices

Appendix 1A: PRISMA reporting checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Pg 11
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Pg 12
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Pg 13 - 16
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Pg 16 &17
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Pg 18
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.	Pg 17
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Pg 84 - 86
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.	Pg 18
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.	Pg 18
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.	Pg 19
	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.	Pg 19
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.	Pg 19 - 20
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.	Pg 25 - 31
Synthesis	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and	Pg 23

Section and Topic	Item #	Checklist item	Location where item is reported
methods		comparing against the planned groups for each synthesis (item #5)).	
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	N/a
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Pg 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.	N/a
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/a
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/a
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/a
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/a
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.	Pg 20 - 21
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	N/a
Study characteristics	17	Cite each included study and present its characteristics.	Pg 23
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Pg 86 - 89
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.	N/a
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Pg 25 - 31
	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.	Pg 25 - 31
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	Pg 25 - 31
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/a
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/a
Certainty of	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/a

Section and Topic	Item #	Checklist item	Location where item is reported
evidence			
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Pgs 31 - 34
	23b	Discuss any limitations of the evidence included in the review.	Pg 34 & 35
	23c	Discuss any limitations of the review processes used.	Pg 34 & 35
	23d	Discuss implications of the results for practice, policy, and future research.	Pg 35
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.	Pg 17
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Pg 17
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/a
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Pg 36
Competing interests	26	Declare any competing interests of review authors.	Pg 36
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.	Pg 36

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.

Appendix 1B: Search Strategies

ERIC, EBSCO Host Search Strategy

S1 DE "Autism" OR DE "Pervasive Developmental Disorders"

S2 TI (Autis*) OR AB (Autis*) OR TX (Autis*)

S3 TI (ASD) OR AB (ASD) OR TX (ASD)

S4 TI (ASC) OR AB (ASC) OR TX (ASC)

S5 TI (Asperger*) OR AB (Asperger*) OR TX (Asperger*)

S7 TI (PDD-NOS) OR AB (PDD-NOS) OR TX (PDD-NOS)

S8 TI ("Autism Spectrum Disorder") OR AB ("Autism Spectrum Disorder") OR TX ("Autism Spectrum Disorder")

S9 (S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8)

S10 TI (Parent* OR Caregiver* OR "Care giver*" OR Famil* OR Mother* OR Father* OR "Birth Parent*") OR AB (Parent* OR Caregiver* OR "Care giver*" OR Famil* OR Mother* OR Father* OR "Birth Parent*") OR TX (Parent* OR Caregiver* OR "Care giver*" OR Famil* OR Mother* OR Father* OR "Birth Parent*")

S11 DE "Coping" OR DE "Stress Management" OR DE "Resilience (Psychology)"

S12 TI (psychological adjustment OR stress management OR resilience OR problem-solving OR emotional regulation) OR AB (psychological adjustment OR stress management OR resilience OR problem-solving OR emotional regulation) OR TX (psychological adjustment OR stress management OR resilience OR problem-solving OR emotional regulation)

S13 TI (emotion-focused coping OR problem-focused coping) OR AB (emotion-focused coping OR problem-focused coping) OR TX (emotion-focused coping OR problem-focused coping)

S14 (S11 OR S12 OR S13)

S15 (S10 AND S13 AND S18)

OVID Medline Search Strategy

1. exp Autistic Disorder/

2. Autis*.ti,ab,kw

3. ASD.ti,ab,kw

4. ASC.ti,ab,kw.

5. Asperger*.ti,ab,kw

6. PDD-NOS.ti,ab,kw.

7. "Autism Spectrum Disorder".ti,ab,kw.

8. 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7

9. exp Parents/

10. exp Caregivers/

11. (Parent* OR Caregiver* OR "Care giver*" OR Famil* OR Mother* OR Father* OR "Birth Parent*").ti,ab,kw.

12. 9 OR 10 OR 11

13. (coping adj3 (strategy OR strategies OR mechanism* OR skill* OR behavio?r* OR process* OR response* OR style*)).ti,ab,kw.

14. (psychological adjustment OR stress management OR resilience OR problem-solving OR emotional regulation).ti,ab,kw.

15. (emotion-focused coping OR problem-focused coping).ti,ab,kw.

16. 13 OR 14 OR 15

20. 8 AND 12 AND 16

PsychINFO EBSCO Host Search Strategy

S1 DE "Autistic Disorder"

S2 TI (Autis*) OR AB (Autis*) OR KW (Autis*)

S3 TI (ASD) OR AB (ASD) OR KW (ASD)

S4 TI (ASC) OR AB (ASC) OR KW (ASC)

S5 TI (Asperger*) OR AB (Asperger*) OR KW (Asperger*)

S6 TI (PDD-NOS) OR AB (PDD-NOS) OR KW (PDD-NOS)

S7 TI ("Autism Spectrum Disorder") OR AB ("Autism Spectrum Disorder") OR KW ("Autism Spectrum Disorder")

S8 (S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7)

S9 DE "Parents"

S10 DE "Caregivers"

S11 TI (Parent* OR Caregiver* OR "Care giver*" OR Famil* OR Mother* OR Father* OR "Birth Parent*") OR AB (Parent* OR Caregiver* OR "Care giver*" OR Famil* OR Mother* OR Father* OR "Birth Parent*") OR KW (Parent* OR Caregiver* OR "Care giver*" OR Famil* OR Mother* OR Father* OR "Birth Parent*")

S12 (S9 OR S10 OR S11)

S13 TI (coping N3 (strategy OR strategies OR mechanism* OR skill* OR behavio?r* OR process* OR response* OR style*)) OR AB (coping N3 (strategy OR strategies OR mechanism* OR skill* OR behavio?r* OR process* OR response* OR style*)) OR KW (coping N3 (strategy OR strategies OR mechanism* OR skill* OR behavio?r* OR process* OR response* OR style*))

S14 TI (emotion-focused coping OR problem-focused coping) OR AB (emotion-focused coping OR problem-focused coping) OR KW (emotion-focused coping OR problem-focused coping)

S15 (S13 OR S14)

S16 (S8 AND S12 AND S15)

Appendix 1C: Quality Appraisal

Table 2

Quality Appraisal Scoring

Scoring: Complete = 2, Partially Complete = 1, Imprecise = 0

	Al Busaidi et al., 2022	Alostazer al., 2022	Ang & Loh, 2019	Cai et al., 2020	Gagat-Matuła, 2022	Liu et al., 2023	Miranda et al., 2019	Mohammad et al., 2022	Papadopoulos et al., 2024	Picardi et al., 2018	Rattaz et al., 2023	Tsioka et al., 2024
Introduction												
Justification of the study in the actual context	2	2	2	2	2	2	2	2	2	2	2	2
Clear and well described aims	2	1	2	2	2	2	2	2	2	2	2	2
Accurate Hypothesis	2	2	2	1	0	0	2	2	0	1	0	0

Table 2 (continued)

	Al Busaidi et al., 2022	Alostazer al., 2022	Ang & Loh, 2019	Cai et al., 2020	Gagat-Matutuła, 2022	Liu et al., 2023	Miranda et al., 2019	Mohammad et al., 2022	Papadopoulos et al., 2024	Picardi et al., 2018	Rattaz et al., 2023	Tsioka et al., 2024
Method												
Replicable protocol	2	2	2	1	1	1	2	1	2	2	2	2
Population												
Inclusion-exclusion criteria shown	1	1	2	1	1	2	1	2	1	1	2	1
Participants number in each group shown	2	2	2	2	2	2	2	2	2	2	2	2
Non-participation reason shown	0	1	2	0	1	1	1	2	2	1	1	0
Accurate population characteristics	2	1	2	1	1	1	2	2	2	2	2	1

Table 2 (continued)

	Al Busaidi et al., 2022	Alostazer al., 2022	Ang & Loh, 2019	Cai et al., 2020	Gagat-Matutuła, 2022	Liu et al., 2023	Miranda et al., 2019	Mohammad et al., 2022	Papadopoulos et al., 2024	Picardi et al., 2018	Rattaz et al., 2023	Tsioka et al., 2024
Variables												
Tools presentation	1	2	2	1	1	2	2	2	2	2	2	2
Tools relevance	2	2	2	2	2	2	2	2	2	2	2	2
Data analysis												
Justification of sample size	0	0	0	0	0	2	0	0	1	0	1	0
Results												
Appropriate analysis plan	2	2	2	2	2	2	2	1	2	2	2	2

Table 2 (continued)

	Al Busaidi et al., 2022	Alostazer al., 2022	Ang & Loh, 2019	Cai et al., 2020	Gagat-Matutuła, 2022	Liu et al., 2023	Miranda et al., 2019	Mohammad et al., 2022	Papadopoulos et al., 2024	Picardi et al., 2018	Rattaz et al., 2023	Tsioka et al., 2024
Clear result presentation	2	2	2	2	2	2	2	1	2	2	2	2
Discussion												
Most results shown and relevant interpretation	1	2	2	1	2	2	2	1	2	2	2	2
Results discussed according to the literature	2	2	2	2	2	2	2	2	2	2	2	2
Limitations shown	2	2	2	2	2	2	2	2	2	2	2	2
Relevant conclusion	2	2	2	2	2	2	2	2	2	2	2	2
Other information												
Conflict of interest	2	0	0	0	2	2	0	2	2	2	2	2

Table 2 (continued)

	Al Busaidi et al., 2022	Alostazer al., 2022	Ang & Loh, 2019	Cai et al., 2020	Gagat-Matutuła, 2022	Liu et al., 2023	Miranda et al., 2019	Mohammad et al., 2022	Papadopoulos et al., 2024	Picardi et al., 2018	Rattaz et al., 2023	Tsioka et al., 2024
Total score	29	28	32	24	27	31	30	31	32	31	32	28

Appendix 2A: Participant Demographics

Participant Demographics

Participant*	**Age**	**Gender**	**Ethnicity**	**Location**	**Diagnosis**	**Length of Interview (minutes)**
Craig	17	Male	Scottish-Pakistani	Scotland	ASD	53
Jane	17	Female	White - British	England	ASD	32
Hayley	18	Female	White-British	Scotland	ASD	58
Nadia	18	Female	White - Scottish	Scotland	ASD	46
Gemma	18	Female	White-Scottish	Scotland	ASD	49
David	18	Male	White - British	England	ASD	40

ASD Autism Spectrum Disorder

*Pseudonyms for participants to protect anonymity

Appendix 2B: Ethical Approval

Professor Deborah Cairns

MVLS College Ethics Committee

Exploring the Experiences and Impact of Cyberbullying in Adolescents with Autism Spectrum Condition. 200230317

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study.

We are happy therefore to approve the project, subject to the following conditions

- Project end date as stipulated in original application.
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research: (http://www.gla.ac.uk/media/media_227599_en.pdf)
- The research should be carried out only on the sites, and/or groups or datasets as defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- For projects requiring the use of an online questionnaire, the University has an Online Surveys account for research. To request access, see the University's application procedure at https://www.gla.ac.uk/research/strategy/ourpolicies/useofonlinesurveystoolforresearch/.
- You should submit a short end of study report within 3 months of completion.

Yours sincerely

Terry Quinn
FWSO, FESO, MD, FRCP, BSc (hons), MBChB (hons)

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The University of Glasgow, charity number SC004401

Dr Terry Quinn

Appendix 2C: Recruitment Poster

https://osf.io/q2jus/?view_only=639c9d0cc3ea4d8f98994eb268e5c9a9

Appendix 2D: Consent Form

https://osf.io/mdgq7/?view_only=260d726e646d4fe686eb79c4bbeb220f

Appendix 2E: Interview Schedule

Question Number	**Question**
Question 1	How do you use social media and what do you like to do online? *Follow-up:* Which platforms do you use the most?
Question 2	Can you tell me about your experience of cyberbullying? *Follow-up:* Which platform were you using? *Follow-up:* Did you know the person bullying you? *Follow-up:* Why do you think they bullied you?
Question 3	What happened after being cyberbullied? *Follow-up:* How did you feel? *Follow-up:* Did you talk to anyone about it?
Question 4	How do you think being autistic affected your experience of being bullied? *Follow-up:* Can you share any experiences where your autism was used as a reason to bully you online?
Question 5	How has cyberbullying affected you? *Follow-up:* Has it changed what you do online or offline?
Question 6	Do you have ways to avoid cyberbullying? *Follow-up:* Do you or your friends do anything to avoid online conflicts?
Question 7	Is there anything else you would like to share with me, or think it would be helpful for me to know?

Appendix 2F: Debrief Document

https://osf.io/8q3g5/?view_only=04fc81cc82044f4992fafdb66a8821d0

Appendix 2G: COREQ (Consolidated criteria for Reporting Qualitative research) Checklist

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	55
Credentials	2	What were the researcher’s credentials? E.g. PhD, MD	55
Occupation	3	What was their occupation at the time of the study?	55
Gender	4	Was the researcher male or female?	53
Experience and training	5	What experience or training did the researcher have?	55
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	55
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	55
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	55
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	51
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	51
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	53
Sample size	12	How many participants were in the study?	51-52
Non-participation	13	How many people refused to participate or dropped out? Reasons?	52
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	53
Presence of nonparticipants	15	Was anyone else present besides the participants and researchers?	53
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	92
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	53

Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	n/a
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	53
Field notes	20	Were field notes made during and/or after the inter view or focus group?	53
Duration	21	What was the duration of the inter views or focus group?	53
Data saturation	22	Was data saturation discussed?	n/a
Transcripts returned	23	Were transcripts returned to participants for comment and/or	70-71
Topic	**Item No.**	**Guide Questions/Description**	**Reported on Page No.**
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	54
Description of the coding tree	25	Did authors provide a description of the coding tree?	55-56
Derivation of themes	26	Were themes identified in advance or derived from the data?	54
Software	27	What software, if applicable, was used to manage the data?	n/a
Participant checking	28	Did participants provide feedback on the findings?	70-71
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	56-67
Data and findings consistent	30	Was there consistency between the data presented and the findings?	56-67
Clarity of major themes	31	Were major themes clearly presented in the findings?	56-67
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	56-67

Appendix 2H: Sample of reflective journal notes.

Sample 1

Personal reflections following interview with participant 1, first interview on 18/12/2024.

I felt nervous before the interview. Although I had the questions ready there was still a feeling of uncertainty about what to expect. It also felt strange I had some brief email contact with the participant beforehand, but had no real sense of what they might be like. In the clinical context I always have a lot of background information, so this felt much more like going into the unknown. As I was waiting for the participant to come on the call, I noticed I was feeling quite anxious. This made me think about how anxiety-provoking this situation could be for participants, given they are adolescents. I also thought about some of the differences in my knowledge from them as I realised I was not even sure if adolescents would be familiar with using TEAMS or if they would be used to different meeting platforms through school. Overall, this gave me a sense that even attending an interview could potentially be a big challenge. For any individuals who lacked confidence this could be a real barrier for participation.

At the beginning of the interview, it felt a little hard to get going, but we had some general chat which helped to build a bit of rapport. I was feeling more confident towards the end of the interview. Some of the questions did feel repetitive as the participant had already mentioned some areas I was later planning to ask about. But checking in with the participant was helpful as he said he was happy to go into more detail. I was mindful of using some of my clinical skills, such as summarising what he had said and active listening. However, I was also trying to get the balance right of not going into ‘therapy mode’. When he told me about some challenging experiences of being bullied, I did notice I had to stop myself from engaging with the client as I perhaps would in CAMHS. I did have to remind myself this was research, and the point was to listen and understand someone’s experience.

Sample 2.

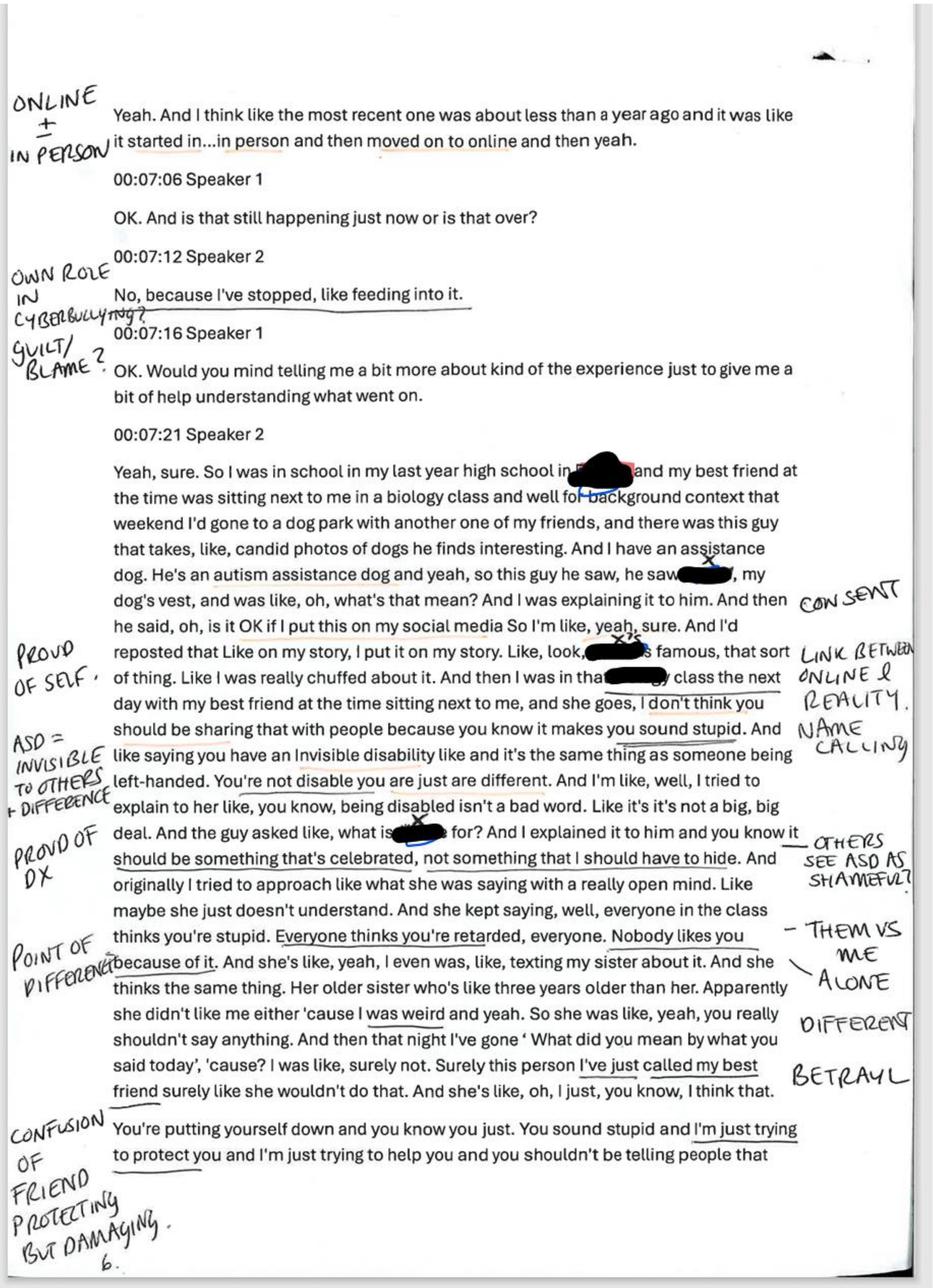
Reflections on discussion with academic supervisor discussing experiential themes following final interview. 17/02/25.

We reflected on how differences in age and understanding of social media/internet use for younger people and myself can lead to a sense of difference within interviews. We spoke about how remaining curious had been helpful with an effort not to patronise participants, but to show interest and acknowledge when I did not know something (such as them talking about an online game I was unaware of). Reflected with supervisor on the nature of some of the content from participants and the severe consequences for some participants of cyberbullying, such as suicidal ideation. I reflected that as someone who grew up without social media during adolescence this makes it harder to share in participant’s experiences. Despite their experiences most remained on social media and I discussed with my supervisor how not being online did not seem to be an option for adolescents.

Discussed with my supervisor my previous role in CAMHS and reflected on how clinical experience can enrich and influence research. Discussed how I feel that I might be viewed by participants and whether this has impacted my questions and knowledge of the area.

Appendix 2I: Example of exploratory notes

Participant 2.



ONLINE
+
IN PERSON

Yeah. And I think like the most recent one was about less than a year ago and it was like it started in...in person and then moved on to online and then yeah.

00:07:06 Speaker 1

OK. And is that still happening just now or is that over?

00:07:12 Speaker 2

No, because I've stopped, like feeding into it.

OWN ROLE IN CYBERBULLYING?
GUILT/ BLAME?

00:07:16 Speaker 1

OK. Would you mind telling me a bit more about kind of the experience just to give me a bit of help understanding what went on.

00:07:21 Speaker 2

Yeah, sure. So I was in school in my last year high school in [redacted] and my best friend at the time was sitting next to me in a biology class and well for background context that weekend I'd gone to a dog park with another one of my friends, and there was this guy that takes, like, candid photos of dogs he finds interesting. And I have an assistance dog. He's an autism assistance dog and yeah, so this guy he saw, he saw [redacted], my dog's vest, and was like, oh, what's that mean? And I was explaining it to him. And then he said, oh, is it OK if I put this on my social media So I'm like, yeah, sure. And I'd reposted that Like on my story, I put it on my story. Like, look, [redacted] famous, that sort of thing. Like I was really chuffed about it. And then I was in that [redacted] class the next day with my best friend at the time sitting next to me, and she goes, I don't think you should be sharing that with people because you know it makes you sound stupid. And like saying you have an Invisible disability like and it's the same thing as someone being left-handed. You're not disable you are just are different. And I'm like, well, I tried to explain to her like, you know, being disabled isn't a bad word. Like it's it's not a big, big deal. And the guy asked like, what is [redacted] for? And I explained it to him and you know it should be something that's celebrated, not something that I should have to hide. And originally I tried to approach like what she was saying with a really open mind. Like maybe she just doesn't understand. And she kept saying, well, everyone in the class thinks you're stupid. Everyone thinks you're retarded, everyone. Nobody likes you because of it. And she's like, yeah, I even was, like, texting my sister about it. And she thinks the same thing. Her older sister who's like three years older than her. Apparently she didn't like me either 'cause I was weird and yeah. So she was like, yeah, you really shouldn't say anything. And then that night I've gone ' What did you mean by what you said today', 'cause? I was like, surely not. Surely this person I've just called my best friend surely like she wouldn't do that. And she's like, oh, I just, you know, I think that.

CONSENT

PROUD OF SELF.

LINK BETWEEN ONLINE & REALITY.

NAME CALLING

ASD = INVISIBLE TO OTHERS + DIFFERENCE

PROUD OF DX

OTHERS SEE ASD AS SHAMEFUL?

- THEM VS ME ALONE

POINT OF DIFFERENCE

DIFFERENT

BETRAYL

You're putting yourself down and you know you just. You sound stupid and I'm just trying to protect you and I'm just trying to help you and you shouldn't be telling people that

CONFUSION OF FRIEND PROTECTING BUT DAMAGING.

6.

Appendix 2J: Example of personal experiential themes derived from exploratory notes (Participant 2)

Personal experiential statements	**Original Transcript**
Friendship difficulties	"Surely this person I've just called my best friend surely like she wouldn't do that" pg 6
Questioning own role in being cyberbullied	"I've stopped feeding into it" pg 6 "I will take things out of context or take things too literally" pg 12 "what if I took it the wrong way" pg 12 "I felt a bit foolish for doing that and then also embarrassed because for a second I thought maybe she was right" pg 13 "she's like you sound stupid and I'm just trying to protect you" pg 6
Bullying at school too	"It started in…in person and then moved online" Pg 6 "I was in class the next day with my best friend at the time sitting next to me, and she goes, I don't think you should be sharing that with people because you know it makes you sound stupid…everyone thinks you are retarded, everyone. Nobody likes you because of it" Pg 6
Autism makes me different – but others think I should try to hide this	"you're not disabled you are just different" "I explained to him and you know it should be something that's celebrated, not something I have to hide" pg 6 "And if I was with the dog and he had his vest or anything I don't know, she like, she wouldn't like that. .she would only want to go places where you know if I was bringing the dog he wouldn't need his vest of anything, so she didn't have to be seen with someone who was disabled" pg 8 "You know, she's right. You know you shouldn't be telling other people." Pg 11
Impacts of cyber bullying: On school - avoidance	"it made me very avoidant towards going to school…I'd wake up in the morning and I'd go my stomach hurts,

	can't go to school…I'd skip quite a few classes" pg 19
- relationships with teachers	"I had this French teacher…he said you're not the only one in class like you" pg 19
- Relationships with peers and friends	"I felt like I'd lost a part of me…I was really, really was so close to her" pg 13
On mental health – depression, loss of confidence	"it makes you quite upset and like nervous to I guess, exist. It pushes you into a corner and makes you feel quite ashamed of yourself". "It had really sort of shut me down. Like I felt pushed into a corner and was like, you know, you stay there and keep your head down" pg 14 "I became quite like socially isolated and very anxious. Like I just didn't want to speak to anybody. And you know, I was very nervous in class and daily life. Yeah I think I lost a lot of confidence during that time…I just sort of wanted to be as small as I could and like, nobody could see me, that sort of this. I didn't really speak to anyone on my phone, I wasn't really contacting any people from where I lived…I very much isolated myself in the real world as well as online" Pg 14

Appendix K: MRP Proposal

https://osf.io/f384w/?view_only=7a2ddc8c3db94955b9d99550bffad75e

Appendix 2L: Participant Information Sheet

https://osf.io/9kh8q/?view_only=7ba582fb728e49f591ff754a2c43157c

Appendix 2M: Detailed Analysis Plan

https://osf.io/zcnb4/?view_only=f84b00058c764b0eb340f1bf6fb26890

Appendix 2N: Data Availability Statement

Due to the sensitive nature of data and to protect participants anonymity, data will not be shared on an open repository. It can be shared with other researchers upon reasonable request.