Restricted and Repetitive Behaviours in Autistic Women: A Mixed Methods Approach

Lucy Mitchell

MA (Hons), MSc

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School of Health and Wellbeing

College of Medical, Veterinary and Life Sciences

University of Glasgow

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Chapter 1: Systematic Review

Effectiveness of Cognitive Behavioural Therapy for the Treatment of Depression in Autistic Adolescents and Adults: A Systematic Review and Meta-Analysis

Prepared in accordance with the author requirements for Research in Autism Spectrum Disorder

https://www.sciencedirect.com/journal/research-in-autism/publish/guide-for-authors

Abstract

Autistic adolescents and adults experience elevated rates of depression compared to their neurotypical counterparts. Although adapted Cognitive Behavioural Therapy (CBT) is recommended for the treatment of depression there is limited evidence regarding its effectiveness in symptom reduction. Previous systematic reviews and meta-analyses have suggested CBT is effective, however these findings are limited by methodological weaknesses including uncontrolled studies or interventions that did not primarily target depressive symptoms. This systematic review and meta-analysis aimed to examine the effectiveness of CBT for the treatment of depression among autistic adolescents and adults. Following a systematic search of four electronic databases (CINAHL, PsycINFO, EMBASE, and MEDLINE) four studies (number of participants = 164) met the inclusion criteria. Studies were evaluated as having a low to moderate risk of bias using the Cochrane ROBINS-I V2 tool. The meta-analysis indicated a small statistically significant treatment effect favouring CBT relative to control conditions (g = -0.35, 95% CI = [-0.67, -0.04]). However, this finding must be interpreted with consideration of the methodological limitations of the studies.

Introduction

Depression is a mental health condition characterised by persistent sadness and low mood together with a range of accompanying physical, emotional and behavioural features (APA, 2013). Autistic adolescents and adults[1] experience elevated rates of depression with an estimated combined point and lifetime prevalence of 18% (95% Confidence Intervals [CI] = 15-21%; Micai et al., 2023). The onset of symptoms typically begins in adolescence, peaking in early adulthood, before gradually decreasing into older adulthood (Ghaziuddin et al., 2002; Mayes et al., 2011; Uljarevic et al., 2020).

Although the pathway to developing depression may be similar in neurotypical and autistic individuals, certain factors may increase the risk for autistic individuals. For example, autistic individuals are more likely to experience traumatic events such as physical of sexual assault (Andrzejewski et al., 2024). They also report greater stress in response to everyday tasks, such as shopping or using public transport (Gillot & Stranden, 2007). This heightened stress response may be party explained by sensory and cognitive differences which lower threshold for arousal and impact the processing of environmental demands (e.g., not feeling in control of life and stressors; van Heijst et al., 2020; Oakley et al., 2021). Additionally, 40-65% of autistic individuals have difficulties identifying and describing emotions (i.e., 'alexithymia') compared to 10% the neurotypical population (Bird & Cook, 2013; Kinnard et al., 2019). Alexithymia can impede emotion regulation and has been reported to mediate the relationship with depressive symptoms (Morie et al., 2019). Additionally, rigid thinking patterns and perseverative tendencies related to RRBs may also manifest as perseverative attention and rumination on, negative thoughts or events (Cooper & Russell, 2025) which may precede the onset of depression (Oakley et al., 2021).

Depression can have profound negative consequences including reduced quality of life (Oakley et al., 2021), increased mortality through suicide (Cassidy et al., 2022), loneliness and unemployment (Hedley et al., 2018). Developing interventions to address co-occurring mental health conditions is a high research priority for stakeholders in the autistic community (Frazier et al., 2018; Pellicano et al., 2014). Cognitive Behavioural Therapy (CBT) is well-supported by evidence within neurotypical populations compared to control conditions (e.g., treatment as usual or waitlist control; g = 0.79, 95% CI [0.70, 0.89]; Cuijpers et al., 2023). CBT is a relatively

[1] Identify-first language will used throughout as this was surveyed to be the preference of most autistic people (Kenny et al., 2016).

short-term psychotherapy of between 5 and 20 weekly sessions delivered in an individual or group format. Through CBT individuals learn to recognise and restructure unhelpful beliefs and negative thoughts and implement problem-solving skills to cope with their emotions (Beck, 1976; Leahy, 1997).

Many features of CBT suggest its suitability for the autistic population. For instance, sessions are structured and predictable and there is an emphasis on applying strategies across different contexts (e.g., graded exposure) to support the generalisation of skills (Spain & Happé, 2020). However, difficulties related to alexithymia. perspective-taking and cognitive inflexibility may make it more difficult to engage with some aspects of CBT (Spain et al., 2020). For example, fundamental aspects of CBT include labelling and connecting thoughts with emotions and behaviours and cognitive restructuring. Additionally, sensory sensitivities (Koenig and Rudney 2010) and executive functioning impairments (Tsatsanis 2014) may also impact information processing during sessions (Spain et al., 2020). Considering this, the National Institute for Health and Care Excellence (NICE, 2012) recommends tailoring CBT to accommodate the needs of autistic individuals. Several adaptions have been proposed to support engagement with CBT including using written and pictorial methods; incorporating idiosyncratic descriptions of emotions; individualised outcome measures, emphasising behavioural change and supporting emotional literacy (Anderson & Morris, 2006; Attwood, 2004; Gaus, 2011; Spain et al., 2015).

While CBT has been reported to reduce anxiety in autistic children (for a review see Perihan et al., 2020) less is known about its applicability for depression and suitability for autistic adults. To the author's knowledge, the last systematic review evaluating the treatment of depression for autistic adolescents and adults was carried out by Menezes and colleagues (2020). Of the 7 studies that included a CBT intervention, 5 reported a significant reduction in depression symptoms while 2 reported non-significant results. Consequently, the reviewers concluded there was limited evidence to support the effectiveness of CBT. More recently, within a broader meta-analysis of randomised control trials (RCTs) it was reported that CBT improved depression symptoms in autistic adults (k = 3, g = –0.39, 95% CI [–0.73, –0.05]; Wichers et al., 2022). However, this finding may be limited as it included studies where depression was not the primary focus on the intervention. For instance, primary outcome measures included quality of life, sense of coherence, and self-esteem (Hesselmark et al., 2014) or anxiety symptoms (Langdon et al., 2016). As improvements in depression symptoms were secondary rather than the intended effect of the intervention it may reduce their clinical relevance. Although the content of CBT interventions will overlap, they are often tailored to the presenting mental health condition. As such techniques included in these interventions

may not reflect CBT interventions intended to treat depression symptoms (e.g., behavioural activation, cognitive restructuring for negative thoughts).

Although adapted CBT interventions are recommended for the treatment of depression in autistic adolescents and adults (NICE, 2012), the evidence base regarding the effectiveness of these interventions for this population remains limited. The current review aimed to systematically review the effectiveness of CBT for symptoms of depression in this population and if possible, conduct a meta-analysis to estimate the overall effect from evidence pooled from randomised and non-randomised controlled trials. While previous reviews have examined the effectiveness of CBT for depression symptoms, they were limited by the inclusion of studies where this was not the primary focus of the intervention. To address this the current review will exclude studies that did not include depression as a primary outcome measure. It is proposed this this will limit studies to those that specifically focused on targeting depression symptoms.

Methods

Search Strategy

This systematic review was conducted following the updated 2020 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Page et al., 2021; see Appendix 1). The protocol for this review was registered on Prospero (ID=CRD42024579725).

The search strategy was developed in consultation with a research librarian (see Appendix 2 for an example). Electronic databases (CINAHL, PsycINFO, EMBASE, and MEDLINE) were systematically searched in August 2024 (repeated in February 2025) for relevant studies.

Eligibility Criteria

Studies were be included if they met the following criteria:

- Randomised (or non-randomised) control trial design
- Participants were autistic adolescents and adults (age 13 and over). While it is recognised the onset of adolescence is shaped by cultural and contextual factors (Sawyer et al., 2018), the current review considered 13-years-old to be the onset of adolescence as this has been reported as a critical period for depression onset (Hankin et al., 2015).
- Implemented a cognitive behavioural-based intervention

- Included a measure of depression symptoms as a primary outcome measure
- Provided sufficient quantitative data to calculate effect sizes (e.g., means, SD). If this is not included, authors will be contacted to see if this is available.
- Published in English
- Published in a peer-reviewed journal

Study Selection

Studies generated from the searches were collated on Covidence, an online systematic review management tool (Covidence systematic review software, n.d.). After excluding duplicate studies, 2 reviewers (LM and RG) independently screened the titles and abstracts using the eligibility criteria. Then, the same 2 reviewers independently read the full text of the remaining articles to determine the final selection. Cohen's Kappa was 0.42 for titles and abstracts and 0.48 for full text representing moderate agreement (Landis & Koch, 1977). Consensus was reached through discussion with a third reviewer (CM).

Data Extraction and Synthesis

Data from the included studies were extracted by 1 reviewer (LM) and then analysed using a narrative synthesis approach (Popay et al., 2006). The preliminary synthesis involved tabulating the extracted data (study design, participant characteristics and recruitment, type of CBT intervention, outcome measures, and main findings). Following this, the relationships between the articles were explored considering factors that may have influenced the study outcomes.

Since there was sufficient data (at least 3 trials), a pairwise meta-analysis was conducted using Review Manager (RevMan, version 5.4; 2020). As trials included different outcome measures, the standardised mean difference (SMD) with 95% CI was estimated, and a random effects model was applied. Heterogeneity was evaluated by observing the overlap of CI on the forest plots, the I^2 value with 95% CI to assess statistical variation (25%, 50% and 75% indicating low, medium and high heterogeneity) and the Q-statistic to identify if the heterogeneity is significant (Borenstein et al., 2011).

Risk of Bias

The methodology quality of the included studies was assessed using Cochrane's Risk of Bias in Non-Randomised Studies of Interventions, Version 2 (ROBINS-I V2; Sterne et al., 2024). The risk of bias is evaluated across seven

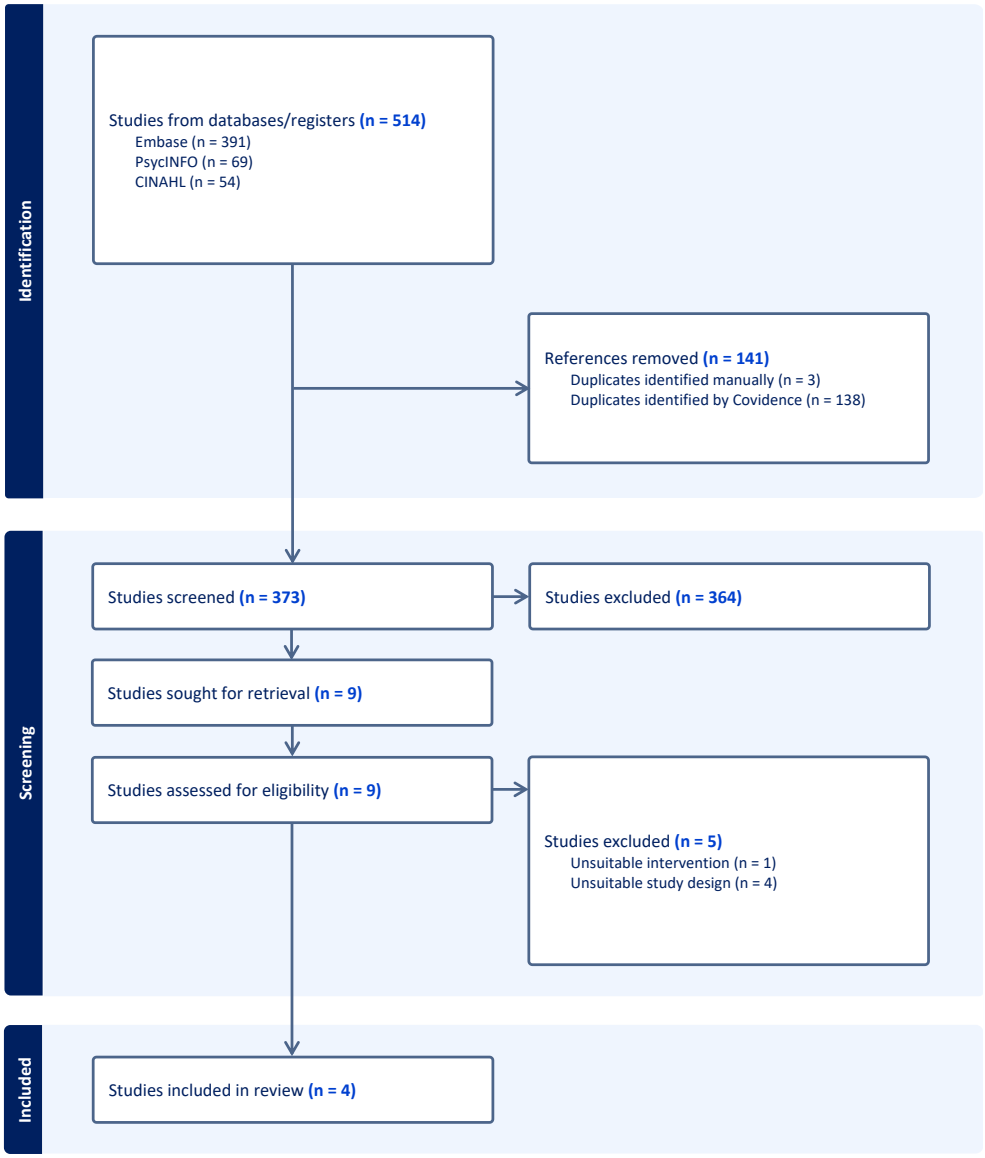
domains covering pre-intervention, at-intervention and post-intervention phases. Each domain is rated as ‘low risk’, ‘moderate risk’, ‘serious risk’, ‘critical risk’ or ‘no information’. The overall risk of bias is determined based on the lowest rating across domains (Sterne et al., 2024). Each paper was appraised by two independent researchers (LM and CM) and discrepancies were resolved through discussion until consensus was reached.

Results

Study Selection

Database searches produced 514 records. After importing these to Covidence, 141 duplicates were removed. The titles and abstracts of the remaining records were screened against the eligibility criteria, and 364 were excluded. The researchers read the full texts of the 9 remaining articles, and 5 were excluded (Hesselmark et al., 2014; Mackay et al., 2017; Russell et al., 2017; Selvapandiyan, 2019; Swartzman et al., 2024). Different factors led to their exclusion, including unsuitable study design (n = 4) and unsuitable intervention (n = 1). Four studies were included in the final synthesis. Figure 1 illustrates a PRISMA flowchart of the study selection.

Figure 1.1: PRISMA Flowchart



Study Characteristics

Study characteristics and main findings from studies are reported in Table 1. In terms of their study design, one study was an RCT (Capriola-Hall et al., 2021), two studies were pilot RCTs (Russell et al., 2020; Santomauro et al., 2016) and one study had a quasi-experimental study design (McGillivray et al., 2014). Two of the studies were conducted in Australia (McGillivray et al., 2014; Santomauro et al., 2016), one was conducted in the United Kingdom (UK; Russell et al., 2020) and one was conducted in the United States of America (USA; Capriola-Hall et al., 2021).

Participant Characteristics

The combined sample from the 4 studies included 164 participants (CBT = 87; control group [CG] = 77). Sample sizes ranged from 23 (Santomauro et al., 2016) to 70 (Russell et al., 2020). Males made up 73% (N = 119) of the sample. Age ranges were not reported by each study (see Table 1 for the mean age of participants in each study). Participants were recruited from adult autism services (Russell et al., 2020), and community samples (Capriola-Hall et al., 2021; McGillivray et al., 2014; Santomauro et al., 2016).

All studies required participants to be of average intelligence. Two studies required participants to have a Full-Scale IQ ≥ 80 (Capriola-Hall et al., 2021) or a Verbal Intelligence Quotient (VIQ) ≥ 85 (Santomauro et al., 2016) on the Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler,1999). Although an IQ score was not stipulated in the inclusion criteria, Russell et al.'s (2020) exclusion criteria included an item related to literacy and language skills and McGillivray et al.'s, (2014) inclusion criteria required a diagnosis of Aspergers Syndrome or 'High-Functioning Autism.'

All the studies required participants to have an autism diagnosis, and two studies independently confirmed this before the intervention (Capriola-Hall et al., 2021; McGillivray et al., 2014).

Studies differed in baseline symptoms of depression. Two studies required participants to score above a threshold on a validated measure of depression. Russell et al. (2020) required participants to have a PHQ-9 score ≥ 10 and Santomauro et al. (2016) a BDI score ≥ 15. Additionally, Russell et al., (2020) reported that 65% (n = 23) of participants had a primary diagnosis of mild (14%, n = 5), moderate (37%, n = 13) or severe (14%, n = 5) depression. By contrast, the remaining studies may have included participants without clinically meaningful self-reported symptoms of depression. Capriola et al., (2020) reported 22% of participants (n = 7) had baseline scores falling within the clinically elevated range on the ASR depression subscale, while an additional 22% (n = 7) were in the borderline range. McGilvray et al., (2014) reported 83% of participants (n = 35) scored above the normal range on the DASS depression, anxiety and stress subscales.

Intervention Characteristics

All studies included CBT interventions that were delivered weekly for between 9 and 16 weeks in either an individual (Capriola-Hall et al., 2021; Russell et al., 2020) or group format (McGillivray et al., 2014; Santomauro et al., 2016).

The content of the CBT interventions delivered by the studies was heterogeneous. Three of the studies included interventions primarily focused on improving symptoms of depression (McGillivray et al., 2014; Russell et al., 2020; Santomauro et al., 2016). Capriola-Hall et al. (2021) reported incorporating cognitive behavioural techniques to support skills development for participants transitioning to college. Three of the studies reported the intervention included a cognitive element (e.g., thought-challenging, cognitive structuring; Capriola-Hall et al. 2021; McGillivray et al., 2014; Santomauro et al., 2016). By contrast, Russell et al. (2020) intervention was based on Behavioural Activation (BA) and focused on the relationship between situations, emotions and behaviours, and used this information to schedule activities that elicit pleasant emotions.

Russell et al., (2020) explicitly described autism-specific adaptations to the intervention including materials having a consistent structure and format and supplementing written materials with visual images. They also reported that emotional literacy and executive functioning differences were supported throughout the intervention, and an initial session was held so the therapist could enquire about additional autism-specific adaptions (Russell et al., 2020). The remaining studies did not outline any autism-specific adaptations, but McGillivray et al. (2014) reported that the intervention was developed with consideration of the social difficulties experienced by autistic young people and the subsequent impact this can have on their self-perception.

Control conditions were treatment as usual (TAU; Russell et al., 2020) or a waitlist (Capriola-Hall et al., 2021; McGillivray et al., 2014; Santomauro et al., 2020). Russell et al., (2020) outlined that there were no constraints to the TAU condition and of the participants who completed the follow-up 63% were prescribed antidepressant medication (n = 15) compared to 51% (n = 18) at baseline. Additionally, 38% (n = 9) were offered primary care mental health support and 1 participant received input from secondary care mental health services.

Depression Outcome Measures

All studies used self-report measures to assess depressive symptoms. Two studies (McGillivray et al., 2014; Santomauro et al., 2016) administered the Depression Anxiety Stress Scales (DASS; Lovibond & Lovibond, 1995). Santomauro et al., (2016) reported that the depression subscale of the DASS had very good internal reliability in their sample ($\alpha = .85$). Similarly, McGillivray et al., (2014) reported $\alpha = .97$. Two studies (Russell et al., 2020; Santomauro et al., 2016) used the Beck Depression Inventory-II (BDI-II; Beck et al., 1996). Santomauro et al., (2016) reported that the BDI-II had excellent internal reliability ($\alpha = .94$). Russell et al., (2020) reported that the BDI-II had been validated by a previous study and demonstrated good internal consistency ($\alpha =$

0.90; Gotham et al., 2015). Russell et al., (2020) also administered the Patient Health Questionnaire-9 (PHQ-9; Kroenke & Spitzer, 2002). They reported that it had very good to excellent internal reliability (α = 0.83–0.94) but its psychometric properties had not been investigated among the autistic population. Finally, Capriola et al., (2020) reported that the Adult Self Report (ASR; Achenbach et al., 2003) had acceptable internal consistency across time points for depression (α = 0.84 at pre-treatment; 0.88 at post-treatment).

One study (Russell et al., 2020) also used an observer-rated measure, the GRID-Hamilton Rating Scale for Depression (GRID-HAM-D-17; Hamilton, 1960; Williams et al., 2008) and reported high (> 90%) inter-rater reliability on the total score but lower inter-rater reliability for some items (e.g., 37.5% on depressed mood and 87.5% for insomnia).

Secondary Outcomes Measures

Both Capriola-Hall et al., (2021) and McGillivray et al., (2014) reported non-significant differences on measures of anxiety following the CBT intervention by comparison to the control condition (Capriola-Hall et al., 2021; $F(1,22) = 0.57$, $p = 0.457$, $\eta 2 = 0.03$; McGillivray et al., 2014; $F(1,40) = 0.05$, $p > 0.05$, g2=0.00). Similarly, Capriola et al., (2021) reported a non-significant finding for loneliness ($F(1,26) = 2.69$, $p = 0.113$, $\eta 2 = 0.09$). McGillivray et al., (2014) reported a statistically significant difference on the DASS Stress Subscale when only when including participants who scored below the normal range at baseline ($F(1,26) = 5.10$ $p < 0.05$, g2=0.16).

Santomauro et al., (2016) explored changes in emotion regulation (Emotion Regulation Questionnaire [ERQ]; Gross & John, 2003) and reported statistically significant increase in the use of cognitive reappraisal from pre-intervention to post-intervention for both the intervention and control group. However, there was no significant difference between the groups over time ($F(1, 18) = .14$, $p = .713$, $\eta 2 = .01$).

Russell et al., (2020) included several secondary outcome measures including the General Anxiety Disorder-7 (GAD-7; Spitzer et al., 2006); Obsessive Compulsive Inventory-Revised (OCI-R; Foa et al., 2002); Positive and Negative Affect Schedule (PANAS; Crawford & Henry, 2004); Work and Social Adjustment Scale (WSAS; Mundt et al., 2002); EuroQol 5-Dimensions 5-Level questionnaire (EQ-5D-5L; Herdman et al., 2011) and 12-Item Short Form Health Survey (Ware et al., 1996). As this study did not carry out a statistical analysis, it is not possible to report the impact of the CBT intervention on these outcomes.

Attrition Rates

Across the included studies, few participants dropped out of the CBT intervention. One study reported 86% (n = 30/35) of participants received the minimum 'dose' of the intervention (Russell et al., 2020), while two studies reported no dropouts (McGillivray et al., 2014; Santomauro et al., 2016). Another study noted missing outcome data but provided no further details (Capriola-Hall et al., 2021). Reasons for participants dropping out were not reported (Capriola-Hall et al., 2021; Russell et al., 2020).

Table 1.1: Description of Studies

Study Details	Sample Characteristics and Recruitment	Intervention and Control	Outcome Measures	Relevant Findings
Capriola-Hall et. al. (2021) USA RCT	N = 32 (CBT = 16, CG = 16) 8 females and 24 males Age range = 16-25 years old. Mean age (SD) = 19.74 (2.07) Participants were required to have an autism diagnosis confirmed by ADOS and a Full-Scale IQ ≥ 80 confirmed by WASI-II. Participants were excluded if they were experiencing significant mental health problems (e.g., clear suicidal intent or psychosis), and/or if they or their family were in therapy or receiving services considered redundant with the study intervention. No requirements regarding baseline depression severity.	12 to 16 individual weekly sessions, lasting 1 hour with a counsellor (doctoral students under the supervision of a licensed psychologist) 4–6 counsellor-accompanied outings in the community and weekly check-ins either by telephone or email to ensure between-session practices were done and to check in on goals. CG = waitlist	Depression outcome measures: ASR Additional measures: UCLAS, DERS, AIR-SD Assessment timepoints: Pre-intervention and post-intervention	Repeated measures ANOVA indicated a statistically significant effect for time, $F(1,22) = 6.60$, $p = 0.017$, $\eta 2 = 0.23$ suggesting an improvement across both groups. There was also a significant Group x Time interaction $F(1,22) = 7.13$, $p = 0.014$, $\eta 2 = 0.25$, indicating that participants in the intervention group experienced greater reductions in depressive symptoms than those in the control group.

McGillvray et al. (2014) Australia Quasi-experimental design	N = 42 (CBT = 26, CG = 16) 10 females and 32 males Age range = 15-25 years old. Mean age (SD) = 20.6 (4.1) Participants were required to have an autism diagnosis confirmed by face-to-face interview undertaken by an experienced psychologist and to score above the normal range in the DASS depression, anxiety, stress, and/or ATQ and/or ASSQ and/or SSS. Participants were excluded if there were obvious signs of cognitive impairment	9 weekly group sessions, lasting 2 hours with the same facilitator (second author) Facilitator received supervision from an experienced clinician to ensure treatment fidelity. CG = waitlist	Depression outcome measures: DASS Additional measures: ATQ, ASSQ Assessment timepoints: Pre-intervention, post-intervention, 3-month FU, 9-month FU	Repeated measures ANOVA indicated a statistically significant effect for time, where participants in both the intervention and CG had a reduction in depression scores ($F(1,40) = 4.46$, $p > 0.05$, $\eta^2=0.1$). There was no significant effect for Group x Time interaction ($F(1,40) = 2.76$, $p < 0.05$, $\eta^2 = 0.06$). In the ATQ there was also a significant effect for time ($F(1,40) = 7.94$, $p < 0.01$, $\eta^2 = 0.17$) where both groups indicated a reduction in scores. There was no significant effect for Group x Time interaction ($F(1,40) = 0.38$, $p > 0.05$, $\eta^2 = 0.01$). Participants who scored above the normal range for depression, indicated a significant effect for time, $F(1,23) = 7.77$ $p < 0.01$ $\eta^2=0.25$ with both groups indicating a reduction in scores, and a significant effect for Group x Time interaction ($F(1,23)=4.25$ $p < 0.05$ $\eta^2=0.15$
Russell et al. (2020) UK Pilot RCT	N = 70 (CBT = 35, CG = 35) 19 females and 51 males	9 weekly sessions completed with the support of a coach (graduate level psychologist). Coaches received weekly supervision (1 h in duration) from the research	Depression outcome measures: PHQ-9, BDI, GRID-HAM-D-17 Additional measures: GAD-7, OCI-R, PANAS, WSAS, EQ-5D-5L and SF-12	As this is a feasibility study, a statistical analysis comparing intervention and CG was not carried out.

	Mean age (SD), CBT = 35.3 (13.6), CG = 40.2 (12.6) Participants were required to have an autism diagnosis and current depression (PHQ-9 score ≥ 10) Participants were excluded if there were assessed to have a risk of suicide that would exceed a low-intensity intervention, current alcohol or substance-use dependence, untreated epilepsy, history of psychosis, and received ≥ 6 sessions of individual CBT in the last 6 months	clinical psychologists who designed the intervention. CG = TAU (non-standardised)	Assessment timepoints: Pre-intervention, post-intervention, 16 week FU, 24 week FU	
Santomauro et al. (2016) Australia Pilot RCT	N = 23 (CBT = 11, CG = 12) 11 females and 12 males Mean Age (SD), CBT Group = 16 (1.33), CG = 15.50 (1.43) Participants were required to have an autism diagnosis from a medical practitioner, paediatrician, psychiatrist, psychologist, or multi-disciplinary team, score ≥ 85 on the VIQ of the WASI and score ≥ 14 on the BDI.	10 weekly group sessions, lasting 1 hour, delivered by clinical psychologists. A booster session delivered 4 weeks after the final session. CG = waitlist	Depression outcome measures: BDI, DASS Additional measures: ERQ Assessment timepoints: Pre-intervention, week 5 (only intervention group), post-intervention, 4-week FU (only intervention group), 8-week FU (only intervention group)	Repeated measures ANOVA indicated a no significant effect for time, $F(1,18)=0.54$, $p=.474$, $\eta2=.03$ or Group x Time interaction for the BDI, $F(1,18) = 0.02$, $p = 0.893$, $\eta2< 0.01$. Similarly, there was no significant effect for time, $F(1,18)=0.28$, $p=.602$, $\eta2=.02$, or Group x Time interaction, $F(1,18) = 3.86$, $p = 0.065$, $\eta2 = 0.17$, for the DASS depression subscale.

	Participants were excluded if they were at high-risk of suicide.			

Abbreviations: SD = standard deviation; CBT = cognitive behavioural therapy; RCT = randomised control trial, CG = control group; TAU = treatment as usual; IQ = intelligence quotient; VIQ = verbal intelligence quotient; FU = follow-up; ADOS = Autism Diagnostic Observation Schedule; WASI-II = Wechsler Abbreviated Scale of Intelligence; ASR = Adult Self Report; DERS = Difficulties in Emotion Regulation Scale; AIR-SD = American Institutes for Research Self Determination Scale; DASS = Depression Anxiety Stress Scales; ATQ = Automatic Thoughts Questionnaire; PHQ-9 = Patient Health Questionnaire; BDI-II = Beck Depression Inventory; GRID-HAM-D-= GRID-Hamilton Depression Rating Scale; ERQ = Emotion Regulation Questionnaire; UCLAS = UCLA Loneliness Scale; ASSQ = Anxious Self-Statements Questionnaire; GAD-7 = Generalised Anxiety Disorder; OCI-R = Obsessive Compulsive Inventory-Revised; PANAS = Positive and Negative Affect Schedule; WSAS = Work and Social Adjustment Scale; EQ-5D-5L = EuroQol 5 Dimensions 5 Level Version; SF-12 = 12-Item Short Form Health Survey

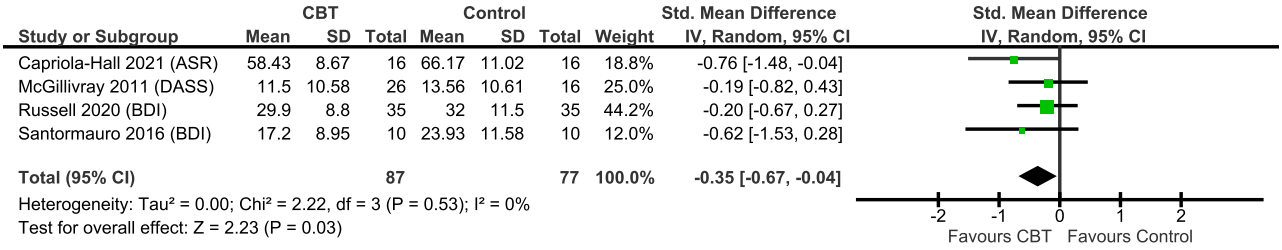
Risk of Bias Within Studies

A summary of the ROBINS-I Vol. 2 (Sterne et al., 2024) is reported in Appendix 3. One study was evaluated as having a moderate risk of bias in the 'missing data' domain, as there was an unspecified amount of missing outcome data. It was unclear whether any corrective procedures were used or if analyses were conducted to assess potential bias (Capriola-Hall et al., 2021). One study was evaluated as having a moderate risk of bias in the 'bias due to deviations from intended intervention' domain. During the study period, a proportion of participants in both conditions received additional treatments for depression and anxiety, which was not accounted for in the statistical analysis. While no statistically significant differences were reported at baseline (treatment, n = 15, 57.7%; waitlist, n = 7, 43.7%), similar proportions of participants began receiving (treatment, n =2, 6.3%; waitlist, n = 3, 9.4%) or discontinued (treatment, n = 5, 15.6%; waitlist, n = 4, 12.5%) additional treatment this was not accounted for in the statistical analysis (McGillivray et al., 2014).

Meta-Analysis Results

The meta-analysis (4 studies, 164 participants) indicated that CBT was effective in reducing symptoms of depression relative to controls (g = -0.35, 95% CI = [-0.67, -0.04]) with low heterogeneity (I^2 = 0%; Figure 1).

Figure 1.2: Forest Plot of Included Studies



Abbreviations: ASR = Adult Self-Report, DASS = Depression Anxiety Stress Scales, BDI = Beck Depression Inventory.

Follow-Up

A meta-analysis exploring the long-term impact of CBT on depression outcomes could not be completed due to limited data. One study did not readminister outcome measures after the post-intervention point (Capriola-Hall et al., 2021). One study readministered measures of depression to both the intervention and control groups at follow-up but did not complete a statistical analysis so the findings cannot be reported (Russell et al., 2020).

Two studies completed a within-group analysis to explore the effect of the intervention over time. Santomauro et al (2016) combined participants in the intervention and waitlist group (who received the intervention after week 10 measures were completed, total n = 19) and reported a significant drop in the DASS score 4 weeks post-intervention compared to pre-intervention ($t(51) = 3.51$, $p = .003$) but this was not maintained at 3 months ($t(51) = 0.83$, $p = .422$). A similar pattern was reported for the BDI ($t(68) = 3.59$, $p = .002$ and $t(68) = .11$, $p = .893$, respectively). By contrast, McGillivray et al., (2014) explored DASS scores over time in participants who were initially symptomatic (n = 15) and reported a statistically significant effect that was maintained at the 9-month follow-up ($F = 19.39$ (3,12) $p < 0.01$, $g2 = 0.83$).

Discussion

This systematic review and meta-analysis evaluated the effectiveness of CBT in reducing depressive symptoms in autistic adolescents and adults. From the systematic search, four studies were identified, highlighting that this remains an under-researched area. The meta-analysis revealed a small treatment effect (g = -0.35, 95% CI = [-0.67, -0.04]), suggesting that while CBT may be beneficial, its impact may be more modest than in neurotypical populations (g = 0.79, 95% CI = [0.70-0.89]; Cuijpers et al., 2023).

The finding in the current review is consistent with a previous meta-analysis of the effectiveness of CBT for depression in autistic adults (*k = 3,* g = -0.39; 95% CI [-0.73 to -0.05]; Wichers et al., 2022). This is interesting considering the methodological differences between Wichers et al., (2022) and the current review. For instance, within the meta-analysis Wichers et al., (2022) included both self-report and clinician-rated measures while the current review only included self-report measures. This is of significance for Russell et al.'s (2020) study, which was included by both reviews, as the clinician-rated, GRID-HAM-17 indicated a statistically significant improvement (-0.59, 95% CI [-1.183, -0.002]) that was not observed for the self-reported BDI-II (-0.20, 95% CI [-0.67, 0.27]). This is supported by previous research that has reported discrepancies between clinician-rated and self-report measures (Park et al., 2020). However, this may also be influenced by there being poor inter-rater reliability for the GRID-HAM-D-17 (Russell et al., 2020).

Although promising, it is difficult to ascertain whether this reduction in symptom score reflects a clinically meaningful improvement for autistic individuals. For instance, previous research has indicated that the threshold for a clinically meaningful improvement on the BDI-II varies depending on initial symptom severity, with those with higher baseline scores requiring a larger reduction in scores to feel better. Consequently, it was recommended

that research and clinical practice report the percentage change from the starting score rather than a point improvement (Button et al., 2015).

Additionally, while self-report measures are commonly administered, there is a paucity of research exploring their reliability and validity for this population (Cassidy et al., 2018; Wigham & McConachie, 2014). This may be important as autistic individuals can find it challenging to identify and describe their emotions (Hill et al., 2004, Bird et al., 2010), which may lead to difficulties responding to items that inquire about "feeling depressed or hopeless.'' Difficulties understanding non-literal and ambiguous language (APA, 2013) may make it challenging to interpret figures of speech (e.g., feeling 'blue'; Morsanyi et al., 2020). Finally, depression measures have been developed from the presentation of the neurotypical population so they may not adequately capture depressive symptoms as they manifest in autistic individuals (Angel et al., 2023; Hinze et al., 2024).

All studies reported no or relatively low attrition rates, which may indicate CBT is acceptable to autistic adolescents and adults. Russell et al., (2020) reported that participants who received CBT found it beneficial to receive an autism-tailored intervention. In a subsequent qualitative study, it was reported that participants had found previous CBT interventions were unhelpful due to difficulties they had describing their experiences and a lack of helpful practical tasks (Horwood et al., 2021). This may suggest that the GSH intervention without a cognitive element offered by Russell et al., (2020) may be more suitable for autistic individuals. However, some participants also reported positive impacts (Horwood et al., 2021), aligning with research indicating autistic adults perceived that cognitive strategies helped reduce rumination and redirect negative thoughts (Mazurek et al., 2023).

Low attrition rates may have also been driven by the therapists' expertise in working with autistic individuals (Mazurek et al., 2023). As this may not occur in routine clinical practice, it may account for some of the negative experiences (Horwood et al., 2021). However, this may also be influenced by sample bias. Participants in the included studies may not be representative of the wider population of autistic adolescents and adults experiencing depression. For example, participants in two studies reported low levels of depressive symptoms so these findings may not reflect the experience of individuals with a more severe presentation (Capriola-Hall et al., 2021; McGillivray et al., 2014). Furthermore, Santomauro et al., (2016) reported difficulties recruiting autistic adolescents with more significant depression symptoms ($\geq$ 14 on the BDI) due to prior negative experiences of programmes or research projects, anxiety about being in a group setting, and perceived lack of need for help. This highlights additional barriers to engaging with CBT interventions autistic individuals with depression may encounter.

Strengths and Limitations

A strength of this review was that it highlighted that despite CBT being recommended for the treatment of depression few randomised (or non-randomised) control trials have been completed.

Results must be interpreted with consideration of the methodological limitations of the included studies. All the studies were limited by small sample sizes, which may have impacted statistical power. Between studies, there was variability in baseline levels of depression severity. Two studies included participants with subthreshold depression symptoms, this may have reduced the potential for symptom improvement and underestimated the treatment effects. This was supported by one study reporting a statistically significant treatment effect after excluding asymptomatic participants from the analysis (McGillivray et al., 2014).

Additionally, it is difficult to ascertain the unique impact of CBT as participants in two studies received additional interventions during the study period (McGillivray et al., 2011; Russell et al., 2020). There was limited evidence regarding the underlying mechanisms that contribute to the improvement of depression symptoms. For instance, cognitive change has been identified as mediating reductions in depression symptoms in neurotypical populations (Lorenzo-Luaces et al., 2015). While one study reported an increase in self-reported cognitive reappraisal following the CBT intervention, this was also reported by the control group, suggesting it may be unrelated to the CBT intervention (Santomauro et al., 2016). Finally, it is unclear whether treatment effects are maintained, highlighting the need for future research to explore strategies that support autistic individuals in applying learned techniques to daily life. This is particularly important given previous findings that autistic adults have reported difficulties transferring these strategies beyond the therapy setting (Mazurek et al., 2022).

This review also has several limitations that need to be considered. Although it was anticipated that requiring the inclusion of a measure of depression as a primary outcome measure would exclude studies where the CBT intervention did not specifically focus on depression symptoms, one study reported that the CBT intervention aimed to improve college adjustment (Capriola-Hall et al., 2021). This may reduce the clinical relevance of these findings as the content of the intervention could differ from routine clinical practice. However, it was reported that a significant part of the intervention was related to emotion and stress management, which are important change mechanisms in improving depression in the neurotypical population (Fehlinger et al., 2013).

Due to the small number of included studies, it was not possible to conduct further analysis to account for differences in the therapeutic format (i.e., delivered in a group versus individual format). While there are several

benefits from including self-report measures within the meta-analysis, it may have been improved by incorporating other measures of depression including clinician-rated measures to obtain a fuller picture of symptoms change. The unpublished literature was not searched, which may have led to publication bias. Finally, ss the included studies did not include participants with an intellectual disability, 32% of the autistic population was excluded (Lyall et al., 2017). While the CBT interventions delivered by the included studies may have been unsuitable for individuals with an intellectual disability, it is important for future research to explore effective interventions for this population.

Future Research

This review has highlighted the need for further RCTs to be conducted. These studies should prioritise the inclusion of participants who meet the clinical threshold for depression to better determine if CBT can lead to long-lasting clinically meaningful improvement. This could also be supported by qualitative research focusing on participants experiences of receiving CBT to better understand the underlying mechanisms facilitating change. Finally, it is important that research focuses on examining the reliability and validity of self-report and clinician-rated outcome measures for this population.

Conclusion

Overall, this review highlighted there is limited research regarding the effectiveness of CBT for depression among autistic adolescents and adults. While a small treatment effect was found favouring CBT, due to the small number of relevant studies and their methodological limitations it cannot be concluded that CBT is effective for treating depression in autistic adolescents and adults. To address this future research should prioritise the inclusion of participants who meet the clinical threshold for depression which will help increase the clinical relevance of findings. It is also important to consider the validity and reliability of depression outcomes which may involve developing specific measures for autistic individuals. Finally, it is important to examine the mechanisms facilitating positive treatment outcomes so these can be incorporated in clinical practice.

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Chapter 2: Major Research Project

Restricted and Repetitive Behaviours in Autistic Women: A Mixed Methods Approach

Prepared in accordance with the author requirements for Research in Autism Spectrum Disorder

https://www.sciencedirect.com/journal/research-in-autism-spectrum-disorders/publish/guide-for-authors

Explanation of Terminology

Gender identity refers to an internal sense of self which may align with masculinity, femininity or outside of this binary (e.g., gender fluid, non-binary; Lindqvist et al., 2020). Participants were recruited to this study if they identified as a 'woman' so this terminology will be used. The wider literature often conflates sex and gender with the terminology 'female' being more commonly used. For continuity 'female' will be used when referring to other studies unless they state otherwise.

Plain Language Summary

Title: Restricted and Repetitive Behaviours in Autistic Women: A Mixed Methods Approach

Background: Autism is more commonly diagnosed in males, with 4 males diagnosed for every female (Loomes et al., 2017). One reason for this may be that autism is under-recognised because their autistic features look different from how it presents in males. For example, autistic females are often reported to have fewer restricted and repetitive behaviours (RRBs). However, they may be overlooked as they manifest differently from stereotypical male behaviours (Hull et al., 2020). Many autistic females also camouflage or hide their autistic features in social situations, which may lead to them being overlooked or misdiagnosed. RRBs have previously been perceived as problematic and there has been considerable effort to reduce or change them which has been perceived as harmful by autistic individuals. There is increasing evidence that RRBs are important in helping autistic individuals manage stressful environments and overwhelming sensory input. This suggests a close relationship with mental health and well-being. There is limited evidence regarding the relationship between RRBs and mental health well-being among autistic females, especially considering the potential impact of camouflaging. It is important to understand this relationship is important to be able to develop effective supports and interventions.

Aims: The study aimed to increase understanding of the presentation of RRBs in autistic women including whether they are camouflaged. Specifically, it will explore the RRBIs reported considering their frequency and severity of behaviour and their relationship with mental health and well-being. It will also seek to understand autistic women's perception of the function of RRBs, if they camouflage them and the impact of this on their mental health and well-being.

Methods: Participants in the study were adult women with a clinical or self-diagnosis of autism. Participants were recruited through advertising in online groups. Participants provided their written consent before partaking in the study. The study had a two-phase mixed-methods study design. In Phase 1 participants completed self-report questionnaires related to RRBs and mental health and well-being, In Phase 2 participants engaged in an individual semi-structured interview about their RRBs.

Results: Autistic women reported a range of RRBs, with ISB reported more than RSMB. Both RSMB and ISB were positively associated with depression and anxiety symptoms. Participants who rated themselves as having

poorer QoL had more RRBs. Five themes were identified from the qualitative data: self-regulation; enjoyment, more than one thing at once, negative impact and camouflaging.

Conclusion: Autistic women self-reported a range of RRBs, which could help them manage difficult situations. However, RRBs could also negatively impact their mental health and well-being. Autistic women reported being self-conscious of their RRBs so would camouflage behaviours which could have a negative impact on their mental health. Additionally, as this may make RRBs less visible to others it could reduce the likelihood of diagnosis.

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Hull, L., Petrides, K. V., & Mandy, W. (2020). The female autism phenotype and camouflaging: A narrative review. Review Journal of Autism and Developmental Disorders, 7, 306-317.

Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. Journal of the American Academy of Child & Adolescent Psychiatry, 56(6), 466-474.

Abstract

Background: Autism is proposed to be under-recognised in females, partly because the diagnostic criteria have been developed from male samples. As a result, these criteria may not adequately capture the Female Autism Phenotype. Although females are reported to present with fewer Restricted and Repetitive Behaviours (RRBs), these behaviours may manifest differently making them less observable to others. Previous research has prioritised observer-rated reports, limiting understanding of autistic individuals lived experiences.

Method: The current study used an explanatory sequential mixed methods study design aimed to improve understanding of autistic women's experience of RRBs. In the quantitative phase, 51 participants completed self-report measures assessing RRBs, mental health and wellbeing. Subsequently, 6 participants completed semi-structured interviews to further explore their experience of RRBs.

Results: Statistical analyses revealed significant positive correlations between RRBs and both anxiety ($r = .44$, $p < .01$, 95% CI [.19, .64]) and depression ($r_s = .43$, $p < .01$, 95% CI [.17, .63]) and a non-significant negative correlation with quality of life ($r_s = –.16$, $p = .26$, 95% CI [–.42, .13]). Reflexive thematic analysis of the interview data identified five themes: *"self-regulation"; "enjoyment", "more than one thing at once", "negative impact"* and *"camouflaging"*.

Conclusions: Autistic women self-reported a range of RRBs which they tended to camouflage from others which may impact diagnostic outcomes. RRBs has a complex and multifaceted relationship with mental health and wellbeing, highlighting the importance of considering both RRBs and the impact of camouflaging in clinical practice.

Introduction

Autism is characterised by social and communication differences together with a pattern of Restricted and Repetitive Behaviours (RRB; APA, 2013). RRBs encompass a wide-ranging number of behaviours, which have been broadly categorised as Repetitive Sensory and Motor Behaviours (RSMB, e.g., simple motor stereotypies and excessive smelling or touching of objects) and Insistence on Sameness Behaviours (ISB, e.g., routines, rigid behaviours and restricted interests; APA, 2013). Autism is more frequently diagnosed in males, with a meta-analysis of 54 studies estimating a male-to-female ratio of 4:1. However, significant variation was reported depending on the study methodology. Studies that actively screened for autism within the general population rather than relying on existing clinical diagnosis had a lower ratio of 3:1. This indicates that some females who meet the clinical threshold remain undiagnosed (Loomes et al., 2017). This may be because male populations have predominately shaped the diagnostic criteria, neglecting the experiences of females (Kirkovski et al. 2013; Kopp & Gillberg 2011). As a result, current referral and diagnostic processes may not adequately capture the Female Autism Phenotype (FAP; Hull et al., 2020).

RRBs are less predictive of diagnosis among females (Duvekot et al., 2016). Research has commonly reported that autistic females[2] present with fewer RRBs than males (see Lai et al., 2015; van Wijngaarden-Cremers et al., 2014 for reviews). However, exploration of RRBs at the narrow construct level has indicated that while autistic males present with higher levels of stereotyped behaviours and restricted interests compared to autistic females there are no differences in sensory experiences and ISBs (Edwards et al, 2024). Additionally, some differences may be overestimated because current conceptualisation of autism do not capture the female presentation of RRBs. For instance, autistic females restricted interests often include conventional topics (e.g., animals or fictional characters) which may not be as easily recognised as part of autism despite the intensity of interest (Grove et al., 2018).

Diagnosis may be further complicated by reports that autistic females consciously or unconsciously engage in strategies to camouflage the appearance of their autistic features in social settings (e.g., hiding intense interests that may appear unusual to peers; Hull et al., 2020). Camouflaging is motivated by conventional (e.g., success at work) and relational factors (e.g., fitting in with friends; Cage & Troxell-Whitman, 2019; Hull et al., 2017) and

[2] Identify-first language (e.g., autistic female/woman) will used throughout as this was surveyed to be the preference of most autistic people (Kenny et al., 2016).

may be more prevalent among females as they show higher levels of social motivation (Sedgewick et al., 2016) and experience different sociocultural influences (e.g., cultural, school and community norms). For instance, it has been proposed that females are more likely to experience negative consequences from disruptive or non-conforming behaviour (e.g., being socially insensitive) as this contradicts expected gender roles (e.g., being interpersonally sensitive, empathic and emotionally attuned). As a result, they may be more inclined to mimic gender-normative behaviour and mask behaviours that could result in social disapproval (Kreiser et al., 2014). Although camouflaging may serve an adaptive function in social contexts, it can have negative impacts on mental health as it has been associated with increased anxiety, depression (Hull et al., 2021) and suicidality (Cassidy et al., 2018). Camouflaging research has primarily focused on social communication and interaction rather than specifically RRBs (see Cook et al., 2021 for review). Although research has indicated that autistic adults suppress RSMBs less is understood about the impact of this on mental health and well-being (Hull et al., 2017, Collis et al., 2024).

RRBs have historically been interpreted through the lens of parents, teachers and clinicians (Jaswal & Akhtar, 2018). As they can present challenges to caregivers, they are often perceived as problematic, and significant effort has been made to develop behavioural intervention to reduce or modify behaviours (Lecavalier et al., 2006; Ludlow et al., 2012). Previously there has been less consideration on the potential function of RRBs and costs of these interventions. Autistic adults who received Applied Behaviour Analysis (ABA, Baer, Wolf & Risley, 1968) during childhood have reported that it had harmful consequences, often describing the experience as traumatic and dehumanising (Anderson, 2023; McGill & Robinson, 2021). It has been suggested that RRBs are related to mental health and well-being. Studies have reported positive associations between RRBs and internalising behaviours (anxiety, depression, withdrawal, somatic symptoms) in autistic children (Jasim & Perry, 2023). Although less studies have included autistic adults, one study reported that higher- and lower-order RRBs were predictive of anxiety (Kuzminskaite et al., 2020). Moreover, it has been reported that autistic adults perceive RRBs as self-regulatory mechanisms (Collis et al., 2022; Kapp et al., 2019; Manor-Binyamini & Schreiber-Divon., 2019). These findings suggest that RRBs may contribute to the emergence of mental health problems and/or be used as coping strategies (Spiker et al., 2012).

Autism research has primarily focused on the experience of men, which may have contributed to the underdiagnosis of women. There is evidence to suggest that RRBs present differently among women and currently referral and diagnostic processes do not adequately recognise these differences (Hull et al., 2020). This exploratory

study aims to improve understanding of autistic women of RRBs using an explanatory sequential mixed-methods design. Firstly, the quantitative phase will examine the frequency and intensity of self-reported RRBs and explore any associations with anxiety, depression and quality of life (QoL). Following this, the qualitative phase will offer further context to the quantitative phase (McBride et al., 2019) by exploring autistic women's perception of the function of their RRBs, relationship with mental health and well-being and whether they are camouflaged/masked. The findings from both phases will then be compared, with consideration of existing research.

Research Questions

Phase One:

- What types of RRBs do autistic women experience?
- What are the intensity and frequency of the RRBs experienced by autistic women?
- Are there differences in the intensity and frequency of RRBs experiences by autistic women with and without a clinical diagnosis of autism?
- Is there a relationship between the intensity and frequency of RRBs and measures of anxiety, depression and quality of life?

Phase Two

- What are autistic women's perceptions of the function of their RRBs?
- What are autistic women's views on how RRBs relate to mental health and wellbeing?
- Do autistic women camouflage/mask RRBs, and what are their motivations for this decision?

Methods

Study Design

An explanatory sequential mixed methods study design (Creswell & Creswell, 2018) was chosen as it complimented the exploratory nature of the study. The emergent approach offers flexibility as the qualitative phase could be shaped by the quantitative findings allowing them to be explored in more depth. It also provides an opportunity to select participants for the qualitative phase based on their responses at the quantitative stage, facilitating the recruitment of a diverse range of participants. For ease of analysis and synthesis, the research is divided into two phases. After a description of the participants and ethical considerations, each phase is outlined separately, followed by the corresponding results.

Participants

Inclusion Criteria

Participants were included if they were aged 18 years or older and self-identified as autistic. A clinical diagnosis of autism was not required, as this allows for the exploration of potential differences between clinically diagnosed and self-diagnosed females.

Participants were included based on gender identity, which refers to an internal sense of self which may align with masculinity, femininity or outside of this binary (e.g., gender fluid, non-binary; Lindqvist et al., 2020). This differs from sex which is defined by biological characteristics including chromosomes, hormonal variations, and reproductive anatomy, which differentiate males, females and intersex individuals (Bhargava et al., 2021). By contrast, gender is a multifaceted concept influenced by societal and cultural values, roles and expectations associated with being male or female (Schiebinger & Stefanick, 2016). Research has typically conflated sex and gender the contribution of sex-specific factors or social gender expectations to the presentation of RRBs remains unclear.

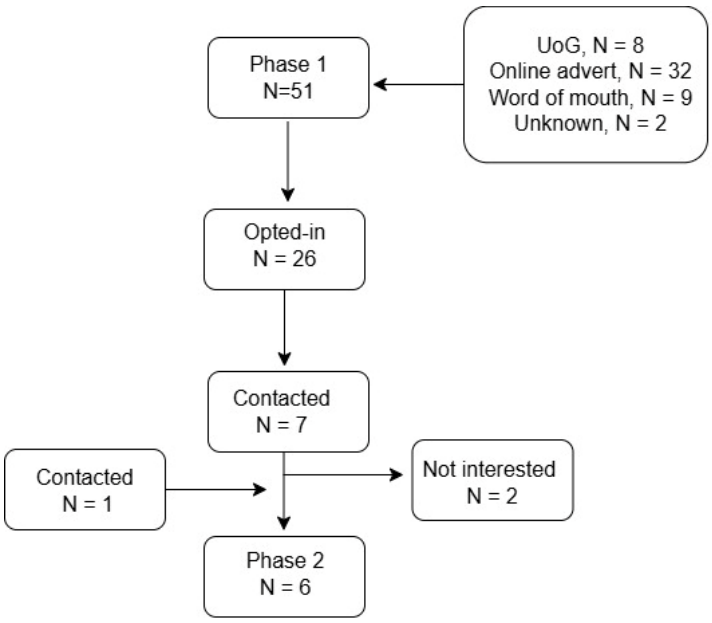
Exclusion Criteria

Participants were excluded if they were unable to complete questionnaires and/or interview in English

Recruitment Procedure

Participants were recruited from several sources including staff and students at the University of Glasgow, online groups and non-profit organisations (Appendix 9: Recruitment Advert). Organisations were informed about the study by email and asked if they would circulate the study advert to potential participants. During Phase 1 participants had the option to consent to be contacted to participate in Phase 2. Participants were selected for Phase 2 based on their demographic information (e.g., age, autism diagnosis) and responses to the questionnaires, so a range of perspectives were represented. See Figure 2.1 for a summary of the recruitment procedure.

Figure 2.1: Recruitment Procedure



Abbreviations: UoG = University of Glasgow

Ethical Considerations

Ethical approval was received from the University of Glasgow College of Medical, Veterinary and Life Sciences (Application no: 200230323) (Appendix 7: Ethical Approval Letter).

Participants were provided with the Participant Information Sheet and Privacy Notice (see Appendices 10 and 11) that was approved by the University of Glasgow and was GDPR compliant. Participants provided their written consent prior to taking part in the study (Appendix 12: Participant Consent Forms). Participation was voluntary and participants did not receive any incentives or compensation for participation. Study data was fully anonymised and stored on a secure University of Glasgow OneDrive account.

Participants were provided with information about relevant organisations they could contact for mental health or autism specific support (Appendix 13: Debrief Sheet). Participants were also made aware of the limits of confidentiality and that if they or someone else was thought to be at significant risk the interviewer may report this to the relevant organisation.

To improve the accessibility and inclusivity of the study alternative forms of participation and additional support were offered. Participants had the option to complete the interview in person or over video call. Participants also received advance information about the planned structure of the interview.

Phase One

Participants completed the following self-report measures via Microsoft Forms: Social Responsiveness Scale-Second Edition: Adult Self-Report (SRS-2; Constantino & Gruber, 2012), Adult Repetitive Behaviour Questionnaire-2 (RBQ-2A; Barrett et al., 2015), World Health Organisation Quality of Life-Brief Version (WHOQOL-BREF; Williams & Gotham, 2021; The WHOQOL Group, 1998; Patient Health Questionnaire (PHQ-9; Kroenke et al., 1999) and Generalised Anxiety Disorder-7 (GAD-7; Spitzer et al., 2006). See Appendix 14 for further information about the self-report measures.

Data Analysis

Statistical analysis was conducted using IBM SPSS 29 (International Business Machines (IBM) Corp., 2022).

Sample characteristics were explored descriptively and presented as mean (M) values with standard deviations (SD) for continuous variables, or numbers and percentages for categorical variables. The normality of the data was assessed using the Shapiro-Wilk test. If this was not met, non-parametric equivalent tests were performed.

Comparisons of sample characteristics were calculated for participants with and without a clinical diagnosis of autism using an independent-sample t-test or Mann-Whitney U test. A Wilcoxon Signed-Rank Test was calculated to compare participant scores on the RSMB and ISB.

Pearson's correlations (Spearman's correlations for non-normal data) were used to explore the association of RRBs with the PHQ-9, GAD-7 and WHOQOL-4. Before this, the RBQ-2A was rescored so the fourth option was not collapsed into three (max score = 73). $P < 0.05$ was considered statistically significant.

A categorical analysis of the WHOQOL-4 was also calculated for the 'Global QoL' item as this directly assessed participant perspective on their QoL. Participants' responses on this item were categorised as 'Good' (Very Good and Good), 'Neither Good nor Poor' or 'Poor' (Poor and Very Poor). A one-way analysis of variance (ANOVA) or Kruskal-Wallis H test was performed to identify any differences in RBQ-2A scores (total score, RSMB and ISB) between groups.

Results

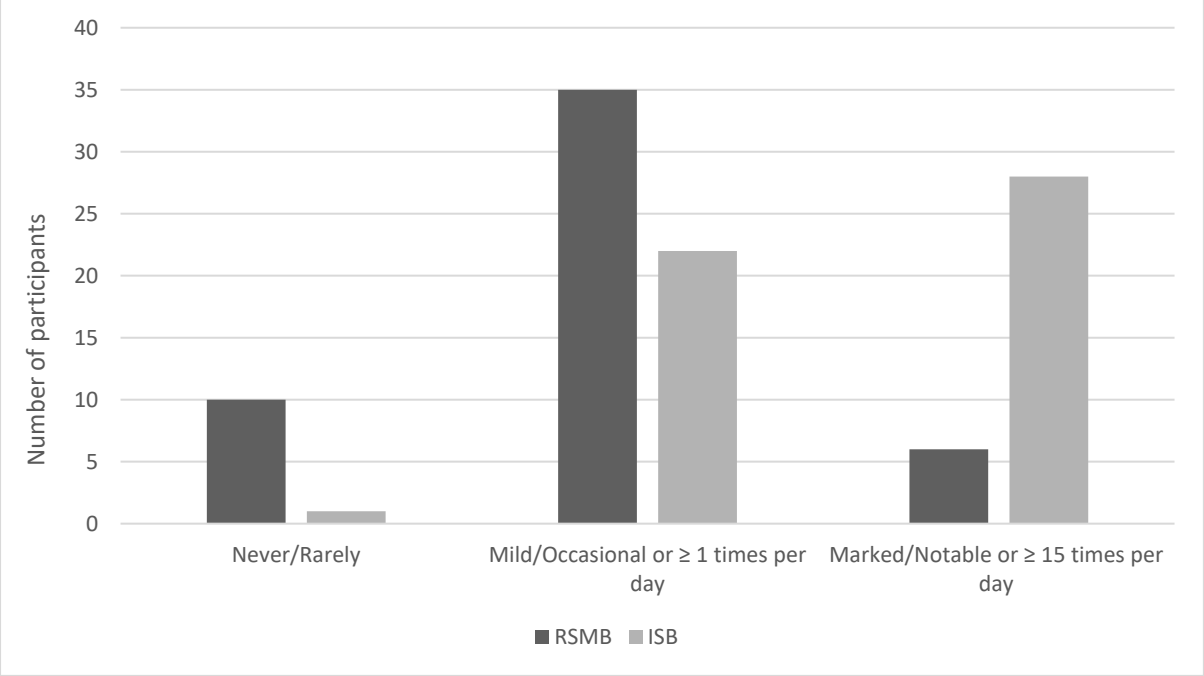
Participants and Demographics

Fifty-one participants aged 18-65 were recruited (M = 34.08, SD = 11.25). The majority reported having a diagnosis of autism (N = 33, 64.7%), received when they were 6-55 years old (M = 30.1, SD = 14.97). Further demographic information is presented in Appendix 16.

In the SRS-2, participants scores ranged from 59-86T (M = 71.49, SD = 6.32) which represented scoring within normal limits to the severe range. One participant scored 59T or below (within normal limits), 8 scored between 60T to 65T (mild range), 28 scored between 66T to 75T (moderate range), and 14 scored 76T or higher (severe range). See Table 1 for the SRS-2 subscale scores.

In the RBQ-2A, participants had a total score between 27-60 (M = 43.69, SD = 7.94). Participants had a higher mean score for ISB (M = 2.38, SD = 0.45) compared to RSMB (M = 1.98, SD = 0.46). As the data was not normally distributed, a Wilcoxon Signed-Rank Test indicated this difference reached statistical significance (W=1194.50, Z=5.38, p<.001, n = 51).). See Figure 4 for an illustration of the distribution of mean scores for the RSMB and ISB subscales. Appendix 17 illustrates the responses to the RBQ-2A in more detail.

Figure 2.2: Distribution of Mean Scores for RSMB and ISB



From the WHOQOL-BREF, almost half of the participants reported having a 'good' overall quality of life (N = 45, 49%). In the PHQ-9, participants scores ranged from 2 to 27 (M = 13.3, SD = 7.7), indicating none/minimal to severe presentations of depression. Scores in the GAD-7 ranged from 0 to 21 (M = 11.3, SD = 5.8), indicating none/minimal to severe presentations of generalised anxiety disorder.

No statistically significant differences were found between participants with and without an autism diagnosis on all measures (Appendix 18).

Spearman rank correlations indicated that age was not significantly related to any of the variables of analysis (p = 0.10 – 0.43) so therefore it was not included as a covariate. A Shapiro-Wilk test indicated that ISB on the RBQ-2A (W = .93, p <0.05, skewness = -.48), PHQ-9 (W = .95, p <0.05, skewness = .21) and WHOQOL-4 (W = .84, p <0.01, skewness = .11) were not normally distributed. Therefore, nonparametric statistics were used in analyses that involved these variables.

The RBQ-2A total score has a statistically significant positive association of a medium effect size with PHQ-9 (Spearman's correlation coefficient [rs] = .43, p <0.01, 95% CI [.17 ; .63]) and GAD-7 (Pearson correlation coefficient [r] = .44, p<0.01, 95% CI [.19; .64]) There was a negative association between the RBQ-2A and WHOQOL-4 but this did not reach statistical significance (rs = -.16, p = 0.26, 95% CI [-.42; .13]). A one-way ANOVA revealed a statistically significant difference in the RBQ-2A scores between participants who reported having 'good' (N = 26), 'neither good nor poor' (N = 12) and 'poor' (N = 13) QoL, F (2, 48) = 4.35, p < 0.05. Post-hoc comparisons using Turkey's HSD test revealed that the 'poor' QoL group (M = 50.85, SD = 10.40) has a significantly higher RBQ-2A score than the 'good' QoL group (M = 42.23, SD = 8.25).

Scores on the RBQ-2A RSMB subscale had a statistically significant positive association of a medium effect size with the PHQ-9 (rs = .35, p = 0.01, 95% CI [.08 - .58]) and the GAD-7 (r = .40, p<0.01, 95% CI [.14 - .61]). There was a negative association with the WHOQOL-4, but this did not reach statistical significance (rs = -.13, p = .37, 95% CI [-.40 - .16]). Similarly, a one-way ANOVA revealed no statistically significant difference between RSMB scores between participants who reported having 'good', 'neither good nor poor' and 'poor' QoL, F (2, 48) = 2.69, p = 0.8.

Scores on the RBQ-2A IS subscale had a statistically significant positive association of a medium effect size with the PHQ-9 (rs = .39, p = <0.01, 95% CI [.13 - .61]) and the GAD-7 (r = .39, p<0.01, 95% CI [.13 - .60]). There was a negative association with the WHOQOL-4, but this did not reach statistical significance (rs = -.09, p = .52,

95% CI [-.37 - .20]). A Kruskal-Wallis H test was conducted to identify if there were differences in ISB scores across the QoL groups. The results indicated a statistically significant difference between groups, H (2) = 6.73, p = 0.03. Post hoc comparisons revealed a statistically significant difference between the 'good' (mean rank = 20.83) and the 'poor' groups (mean rank = 32.81), adjusted p-value = 0.05.

Table 2.1: Results from Correlational Analysis

	PHQ-9	**GAD-7**	**WHOQOL-4**	**WHOQOL ('Good' vs 'Neither Good nor Poor' vs 'Poor' QoL)**
RBQ-2A	rs = .43, p <0.01, 95% CI [.17; .63]	r = .44, p<0.01, 95% CI [.19; .64]	rs = -.16, p = 0.26, 95% CI [-.42; .13]	F (2, 48) = 4.35, p < 0.05 Significant difference between 'Poor' and 'Good' QoL, with 'Poor' having higher RBQ-2A scores
RBQ-2A RSMB subscale	rs = .35, p = 0.01, 95% CI [.08 - .58]	r = .40, p<0.01, 95% CI [.14 - .61]	rs = -.13, p = .37, 95% CI [-.40 - .16]	F (2, 48) = 2.69, p = 0.8
RBQ-2A ISB subscale	rs = .39, p = <0.01, 95% CI [.13 - .61]	(r = .39, p<0.01, 95% CI [.13 - .60]	rs = -.09, p = .52, 95% CI [-.37 - .20]	H (2) = 6.73, p = 0.03. Significant difference between 'Poor' and 'Good' QoL, with 'Poor' having higher RBQ-2A scores

Phase Two

Six participants completed an interview in-person or via Microsoft Teams with the researcher. The interviews were audio recorded and lasted between 46 and 72 minutes.

Adapted from the study protocol outlined by Collis et al., (2022), before their interview participant's responses from the RBQ-2A were reviewed and categorised into 4 lists depending on their severity/frequency and whether they were a higher- or lower-order behaviour. RRBs were categorised as low frequency when they were rated as occurring never/rarely, one or more times daily, mild/occasional severity. RRBs were categorised as high frequency when rated as 15 or more times daily, 30 or more times daily, marked/notable, or serious/severe severity. In line with the two-factor scale of the RBQ-2A insistence on sameness is a higher-order RRB while repetitive sensory-motor behaviours are a lower-order RRB.

At the beginning of the interview, participants were asked to reflect on their answer to the final question on the RBQ-2A ('If you are left to occupy yourself, will you choose from a restricted range of repetitive activities?). After this, they were presented with their personalised lists of RRBs and were asked to select a list and then a specific RRB that they would be willing to talk about. Guided by the interviewer, they outlined their experience of this RRB considering its possible functions. Further questions were posed to encourage reflection on the relationship between RRBs and their mental health and well-being and whether they camouflaged/masked RRBs and their motivations for this decision. This process was repeated using each list, with the intention that participants would describe their experience of four RRBs. See Appendix 19 for an example of the interview schedule.

Interviews were transcribed verbatim by the researcher. Participants who opted-in were contacted by email to review a summary of their interview and initial themes developed by the researcher so they could provide further reflection and commentary.

Data Analysis

Data were analysed using reflexive thematic analysis (Braun & Clarke, 2006). This approach was selected because of its suitability for research examining how a specific group conceptualises a topic (Joffe, 2011). Following the six-phase model (Braun & Clark, 2006), the primary researcher re-listened and re-read the audio recordings and transcripts multiple times. During this process, initial reflections and potential areas of analytic interest were noted. Each transcript was carefully read and annotated with code labels relevant to the research question (see Appendix 21). This was an iterative and dynamic process, where earlier codes were revisited as new insights emerged. Similar codes were clustered and re-clustered to identify potential patterns of shared meaning to develop initial themes (see Appendix 22). Themes were reviewed and checked with the coded extracts. Finally, themes were refined and reported on. This inductive approach allowed the analysis to centre on the participants' narrative while acknowledging the influence of the researcher's experiences, beliefs, culture and language in its interpretation (Braun & Clark, 2021).

Reflexivity Statement

The author is a female trainee clinical psychologist with experience working with autistic individuals in a clinical setting. As she does not identify as autistic, her outsider perspective may have led to unintentionally misinterpreting or overlooking subtleties in the data. Additionally, her clinical training may have influenced how

she engaged with and interpreted the experiences of autistic women. A reflexive log was kept throughout the project to explore these potential influences on interpretation.

Results

Participants and Demographics

Six participants were interviewed in Phase 2. Braun and Clarke (2006) recommend recruitment of between 6 and 12 participants for thematic analysis. Following 6 interviews, there was a strong sense of recurring experiences across participants. These narratives were concluded to be substantial enough to thoroughly explore and address the research questions.

Participants were selected for Phase 2 with consideration their demographics and questionnaire responses with the aim of including a diverse range of perspectives. Participants were aged between 24 and 65 (M = 42.77, SD = 16.79), and 3 (50%) participants reported having a diagnosis of autism, diagnosed between 24 and 55 (M = 42.33, SD = 16.26). See Appendix 20 for further demographic information.

Using reflexive thematic analysis, five main themes were constructed from the interviews: *"self-regulation", "enjoyment", "more than one thing at once", "negative impact"* and *"camouflaging"*. These themes will be outlined in further detail below before being considered within the context of the study's aims in the discussion.

Theme 1: Self-regulation

Self-regulation was reported as an important function of RRBs. Participants reported engaging in RSMB, such as skin-picking or fiddling with items, because it redirected their attention:

> *"I get quite anxious. . . tapping the pen or feeling the pen or feeling something kind of makes me come back to like reality in almost like in a way. . . to be able to like not think in my mind and just because I'm sat there doing paperwork or whatever, I kind of go off in my head. So you know, doing something with my hands or whatever kind of helps me, you know calm down or stop thinking so much."* (Participant 2)

> *"I'd say the fiddling [with items], especially in the meetings. It allows me to like communicate more clearly 'cause if not, then I'm just really caught up"* (Participant 6)

As illustrated above, participants reported that RSMB helped improve their focus and performance by reducing distraction from overwhelming thoughts or sensory inputs. Although the descriptions above suggested these were consciously chosen strategies, repetitive movements could also occur automatically:

> *"I had to take him to A&E, which is literally my idea of hell because it was so full and so many people. . . and then and then noticed at one point I was on my phone and like the waiting room was full I noticed I was absolutely swaying side to side."* (Participant 1).

This suggests that repetitive physical movements are self-soothing. Participants consistently reported that RSMB provided a sense of comfort and reassurance because the provided sensory feedback through smell or touch:

> *"There's a lot of anxiety about where I'm going and will I be able to go in and all of that. And so that's like an, yeah, it's almost like a just a reassurance thing because this is your familiar scarf it's the familiar material and it feels really nice."* (Participant 1)

This suggests that objects can be used as grounding tools, perhaps by narrowing their focus of attention and introducing familiarity into the environment, to reduce feelings of anxiety. It also suggests that ISBs, which may initially appear unrelated to self-regulation, may have a self-regulatory function through their connection to RSMB. While the above experience reflects sensory-seeking behaviour, other participants described sensory-avoiding behaviours, such as insistence on wearing the same clothes to avoid uncomfortable sensory input.

ISBs could function as self-regulation strategies because they attempted to reduce unpredictability and uncertainty, which is perceived as overwhelming:

> *"When I'm feeling anxious maybe there's something going on in life that's not normal day-to-day routine as I'll I'll go to the same foods because then and I didn't understand ever why I did that. But I now do is because it provides me with certainty."* (Participant 1)

> *"Especially after a long day or if I'm tired or I don't have the mental energy. I find it easier to read something that I already know or I know what it's gonna be like, rather than something like something new."* (Participant 2)

This suggests that during stressful periods, individuals may automatically turn to familiar routines, such as eating the same food or watching the same content, to reduce additional sources of change. This may help by reducing

sensory unpredictability and lowering emotional and cognitive demand, which prevents or supports recovery from overstimulation.

Theme 2: Enjoyment

RRBs were also associated with enjoyment and comfort because of the pleasurable sensory experiences they elicited through physical movement, touch or smell:

> *"The smell thing is like a lot of the time it's an enjoyable thing because I like to smell things and like one of my favourite smells is cinnamon." (*Participant 1)

> *"I'd say listen to music for both, but that's more an enjoyment if I'm listening to music and spinning compared to pacing, that's more to get the anxiety out."* (Participant 6)

Theme 3: More than One Thing at Once

Participants' descriptions suggest the multi-layered nature of their RRB experiences. Although behaviours were conceptualised within the RRB framework, it was also recognised that other factors could underpin them:

> *"It's like a lot of things about body image as well and eating and food, it's all tied up together/"* (Participant 1)

This highlights that the lived experience of these behaviours may not be explained by one singular cause or label. Consequently, this suggests the potential challenges of differentiating autism-specific RRBs from indicators of mental health problems. Another participant reported being diagnosed with anorexia as a teenager, but perceived it did not capture her difficulties related to food:

> *"'It's just the easy thing to do [eating the same foods] and it's feels safe for me, I went through a really difficult time as as a teenager I was diagnosed with anorexia and I don't believe I had anorexia because it wasn't that sort of thing it was more that I was just really overwhelmed with food choices and I I find it really difficult to decide what I'm going to have."* (Participant 5)

There is a sense that this participant's perception of her lived experience was not reflected in this diagnostic label. While RRBs resemble features of mental health problems, they may be driven by different factors.

There were also differences between participants in their lived experience of self-harm behaviours. One participant reported self-harming since childhood but had begun to use RSMB instead:

> *"I'd struggled with self-harm from the age of 11 and done it like consistently all throughout school. And it's only now with having like fidget toys and that that I've gone 317 days, so like almost a full year, and that's the longest I've gone since I was 11."* (Participant 6)

Self-harm behaviour and RRBs may both function as self-regulatory mechanisms. Although this participant suggested these behaviours could be interchangeable, another (Participant 4) did not categorise her self-harm behaviours within the RRB framework, suggesting they may also have different functions.

Theme 4: Negative Impact

While RRBs could have a positive impact as self-regulation mechanisms, participants also spoke about the negative impact RRBs could have on their mental health and well-being:

> *"'It (RRBs) does have a massive impact on me, just in a negative way, just like very draining, overwhelming. I think just the feeling of just not being like everyone else can make you feel really ashamed."'* (Participant 5)

> *'And at one point I noticed that beneath the table I was just clawing at my fingernails at clawing at the skin around my fingernails and they were they were they were fucked by the end of the day'* (Participant 4)

This illustrates both the emotional and physical impact of RRBs. Additionally, Participant 5 conveys a strong sense of isolation and self-blame associated with these experiences. This may be influenced by other people's reactions to RRBs:

> *'He used to say 'oh [participant's name] why is it that nobody else can do anything as good as you' and that is a fair question, because that is how I feel, don't attempt it 'cause you won't do it my way and then it's and then makes me really upset and angry and there's times like I've cried because someone's made a mess in my kitchen, and it's made me so frustrated. . . You carry around the thing that you're a burden . . . because you feel that you're putting this impact on everybody'* (Participant 1)

This suggests that family members and friends may have a limited understanding of the function of RRBs, which can lead to frustration and conflict within relationships. Additionally, it highlights worries and guilt about the impact of these behaviours on other people. Interestingly, the same participant reported the benefits of receiving the diagnosis had on her relationships:

> *'We get on great now and it's all fine because he now understands the diagnosis and wish we'd known earlier, and because he just seen it as me being just really, really difficult'* (Participant 1)

The above description suggests that receiving an autism diagnosis provided a framework through which others could better understand her ISBs. This seemed to facilitate a shift away from personalisation and blame, toward recognising these behaviours as part of a neurodevelopmental condition.

Theme 5: Camouflaging

Participants consistently reported being self-conscious about their RRBs because of perceptions that their behaviours *'look wrong to others,'* were not *'normal'* and that they would be *'classified as a weirdo'* as a result. These perceptions appeared to be influenced by other people's reactions to their RRBs throughout their lives:

> *'I remember swinging on my chair. I used to love doing that when I was in school, but I would always get told off and yeah. So, it that sort of things does affect you and you know it stays with you. But yeah, so I'll try not to because I know that I shouldn't I'm more aware.'* (Participant 5)

This indicates that negative reactions had a significant impact on the perception of RRBs and motivated camouflaging behaviours in adulthood. Participants described camouflaging their RRBs by adjusting their behaviours with consideration of social norms:

> *'It was always just being more socially acceptable. And if I was outside and needing to pace, if I'd lit up a cigarette, then people are just going to think it's not as not as much or just I'm stressed and smoking.'* (Participant 6)

> *'So I try to do it kind of like more sort of like say a pen because a lot of people, you know, would play with the pen for example. Instead of bringing things out that I would use at home, or in the car, kind of like fidget toys or things like that.'* (Participant 2)

Participants reported trying to be more flexible about their need for sameness, with one describing concern about the negative impact her ISBs may have on others:

> *'They [her children] are like so important that that it's almost like I can make a little exception for them and even though it's still really hard.'* (Participant 1)

Although camouflaging RRBs could be helpful in reducing the risk of negative reactions from others, it was reported to negatively impact mental health and well-being:

> *'I tend to mask most of the time but if I try not to do it too much, it does make me a lot more anxious' (*Participant 2)

> *'It is burn out, I guess because em you can only if you don't get to do the things that are the things that you feel will help you em then it just it builds and builds and builds and then to a point when for me it's like burn out is a kind of exhaustion type thing but then it does it it's and then always like reverts round to a sort of depression.'* (Participant 1)

As illustrated above, suppressing RRBs can impact mental health and well-being because of their functions as self-regulation mechanisms. In the short term, this could increase feelings of anxiety, which makes situations more difficult to manage. The removal of coping strategies in the long term can lead to exhaustion and burnout.

Discussion

The current study used a mixed-methods approach to improve understanding of RRBs among autistic women. Autistic women self-reported a range of RRBs, with ISB being more commonly endorsed than RSMB. While Phase 1 indicated positive associations between RRBs and mental health and well-being, Phase 2 suggested a nuanced relationship where RRBs were coping strategies but could also have a negative impact. Autistic women reported camouflaging their RRBs which negatively impacted their mental health by increasing anxiety. In the longer-term camouflaging was perceived to contribute to the development of burnout and depression. The following will synthesis the findings from Phases 1 and 2 with consideration of the research aims.

Autistic women self-reported engaging in a range of RRBs, with ISBs reported at higher frequencies and intensities than RSMBs. In the absence of a comparator group, it is not possible to identify gender differences. A meta-analysis of 22 studies reported significantly higher rates of stereotyped behaviours in autistic males but no

gender differences in ISBs (Edwards, 2024). This difference in RRB presentation could contribute to lower rates of diagnosis in autistic women. As ISBs are often internalised behaviours with few behavioural exemplars they may not be recognised. Moreover, if they are not accompanied by overt RSMBs they may not be conceptualised within the autism framework and instead be attributed to mental health conditions. This is supported by previous research which has reported that more autistic females than males perceive they were misdiagnosed with a mental health condition before receiving an autism diagnosis (Kentrou et al., 2024).

RSMBs may have also been underestimated as the RBQ-2A did not include self-injurious behaviours (SIB, e.g., skin picking) which was consistently reported in Phase 2. Prior research has reported that SIB (e.g., 'pulls hair/skin', 'rubs/scratches self') are more common among autistic females (aged between 3-18 years old) than males (Antezana et al., 2018). While this may be indicative of gender-based differences in the presentation of RRBs, some forms of SIB have been reported as a possible epiphenomenon of mental health problems (Maddox et al., 2017; Moseley et al., 2020). In support of previous research, results from the current study indicated that SIB were perceived to be underpinned by autistic-specific or non-autism-related factors (Marsden et al., 2025).

RRBs were interlinked with mental health and well-being. Self-regulation was identified as an important function of RRBs. Autistic women reported engaging in RSMBs to manage unpleasant emotions including anxiety because they narrowed sensory input and refocused attention away from overwhelming thoughts and physical sensations. This is consistent with previous studies (see Lung et al., 2024 for a review) and suggests RSMBs may function to regain homeostasis in response to overwhelming environments, thoughts, emotions or sensory overload by regulating arousal levels (Kapp et al., 2019). ISB also supported self-regulation by introducing predictability into the environment (Lung et al., 2024). Autistic women reported that ISBs were comforting because they were predictable, and that novelty was experienced as overwhelming. This experience may also be related to sensory hypersensitivity, which has been reported to be positively associated with ISB, with this relationship mediated by intolerance of uncertainty (the perception of uncertain or ambiguous events as stressful, upsetting, and/or dangerous, Wigham et al., 2015).

Although this elucidates the relationship with anxiety, it does not account for depression. Previous research also reported positive associations between repetitive behaviours and depressive symptoms, loneliness or suicidality in autistic individuals (South et al., 2020; Stratis et al., 2013). The current study indicated that RRBs may contribute to depression indirectly through the negative responses they elicit from others. When RRBs are

misunderstood or lead to social rejection this may experience increase social isolation, low self-esteem or internalised stigma and lead to the emergence of depressive symptoms. By contrast, research has indicated that greater acceptance of autism identity, along with the perception of societal acceptance, is negatively associated with depression scores (Cage et al., 2018).

Compared to previous research, participants reported a comparatively higher quality of life, despite experiencing high levels of internalising symptoms (Johansson & Sandin, 2023). Consistent with a previous study, those with 'poor' QoL had significantly more ISB but not RSMB (Johansson et al., 2023). While ISB can be a self-regulatory mechanism, it may negatively impact well-being through associations with emotional distress, self-harming behaviour and physical health problems (Deserno et al., 2018). This was reflected by the participants in the current study who reported significant distress in response to change (e.g., in routine, in the environment). Moreover, as ISB could be misunderstood by others, this may lead to reduced social contact, which is another factor linked with lower life satisfaction (Deserno et al., 2018).

Results from the current study support earlier research (Collis et al., 2024; Hull et al., 2017) extending the concept of camouflaging beyond social communication and interaction differences (see Cook et al., 2021 for a review). Camouflaging has been proposed to be integral to the FAP (Hull et al., 2020). However, research has reported inconsistent findings with some studies reporting no differences in self-reported camouflaging (Cage & Toxell-Whitman, 2019) and others reporting that it is more common among autistic females than male (Cassidy et al., 2018; Hull et al., 2019).

Autistic women reported that camouflaging was a form of impression management. They described histories of being scolded or teased for engaging in RRBs with some expressing feelings of shame, having internalised the belief that these behaviours were inappropriate. This supports previous research which has reported that autistic individuals are up to four times more likely to experience bullying than their neurotypical peers (Sterzing et al., 2012). In this context, camouflaging RRBs may function as a protective strategy; by enabling autistic women to 'pass' as neurotypical, camouflaging may help reduce the risk of stigma and social exclusion (Perry et al., 2022). Some participants in the current study also suppressed ISB because they were concerned about the potential negative impact on others. This may reflect heightened social awareness and motivation, consistent with findings that autistic girls demonstrate levels of social motivation comparable to their neurotypical peers (Sedgewick et

al., 2015). However, it has also been reported that camouflaging behaviours motivated by relational factors were similar between autistic males and females, suggesting this this may not be gender specific (Cage et al., 2019).

Although camouflaging may be perceived as being necessary for social acceptance and protection from harm, it was also reported to negatively impact mental health and well-being. Autistic women reported that suppressing their RRBs increased anxiety because they lost their self-regulatory benefits. Moreover, the accumulated effect of this was exhausting and could lead to burnout and depression in the long term. This may have contributed to elevated levels of depression and anxiety which is consistent with previous research reporting camouflaging could be a risk factor for mental health problems in autistic adults (Hull et al., 2017, 2021).

Strengths, Limitations and Future Research

A strength of this study was the inclusion of self-diagnosed autistic women as it enabled the exploration of differences that may have been overlooked in research only including clinically diagnosed samples. Although limited by small sample sizes, the finding of comparable levels of autistic traits and RRB scores between diagnosed and self-diagnosed autistic women may suggest that other factors influence whether autistic women receive a clinical diagnosis. However, it is also possible that there were nuanced differences between these groups that were not captured by the measures included in these studies. Future research would benefit from examining for potential differences between self- and clinically diagnosed autistic women.

Although the broad inclusion criteria were suited to the exploratory nature of the study, it also has limitations. There was significant heterogeneity among the participants renders it more challenging to identify whether RRBs or other factors contribute to non-diagnosis among autistic women. This could be addressed by future research with enough participants to be able to conduct subgroup analyses based on factors including age and severity of autism presentation.

Although this study added to understanding of RRBs in autistic women, without the inclusion of a comparator group of autistic men it is not possible to conclude whether this presentation is consistent with a FAP. Future research should be conducted to examine differences in RRBs between autistic women and men. It is important that this examines differences at the narrow constructs of RRBs reflected within the DSM-5 (e.g., stereotyped behaviours, insistence on sameness, passionate interests and sensory experiences). Furthermore, as existing

measures of autistic characteristics may be biased towards the male gender, it may be important to include self-report measures that are not constrained to specific items.

The findings of this study must be interpreted with consideration of methodological limitations. The small sample size will have limited statistical power. Although the PHQ-9 and WHOQOL-4 had been validated for use in autistic adults (Arnold et al., 2020; Williams et al., 2021), the GAD-7 has not been fully validated in this population despite being used (Hull et al., 2018). This is important considering anxiety may present differently among autistic individuals (Kerns et al., 2014). Although there were strengths in the variety of participants included in the study, for example recruiting autistic females across the lifespan, these findings will likely not represent all autistic females. While the study did not exclude participants based on intelligence quotient (IQ) it is likely that the methods of recruitment and use of self-report measures may have presented barriers to participation for some autistic females. It is important for future research to improve accessibility of research so it can include a wider range of participants. This is particularly important for this research, as it has been suggested that IQ may moderate differences in RRBs between males and females (Jiujias et al., 2017; Stratis et al., 2013; Wood-Downie et al., 2021). Of the participants who completed Phase 1 of the study, a significant proportion of participants opted not to volunteer for Phase 2 (49%). This may suggest the method for collecting further information was not accessible. One participant from Phase 1 provided feedback that they would prefer to provide information in written format. This has been utilised by prior research (Park-Cardoso & Silva, 2023) and may be effective in recruiting a wider range of autistic participants. Finally, the qualitative data was interpreted by a single researcher, which may have restricted opportunities for richer, more nuanced interpretations that can emerge through collaborative analysis (Braun & Clarke, 2013).

Implications

These findings highlight some of potential diagnostic challenges for autistic women. As ISB and RSMBs are commonly camouflaged this may reduce their visibility to external observers. As such, it may be beneficial to include comprehensive self-report measures, including those that capture camouflaging. Due to the considerable overlap in presentation between RRBs and mental health conditions it is important for clinicians working in mental health settings to be aware of the nuanced presentations of autistic traits, particularly how camouflaging strategies may impact the presentation of autism.

This study further highlighted the important role of RRBs in self-regulation (Lung et al., 2024). However, it also identified that the potential for emotional distress and self-injury. Clinicians working therapeutically with autistic

women in mental health settings should ensure that interventions are sensitive to the functional significance of RRBs. It is important to work collaboratively with individuals to preserve the self-regulatory benefits while minimising potential harms. Importantly, difficulties may not occur inherently from the behaviours themselves, but from how others perceive and respond to them. As outlined by the 'double empathy problem' (Milton, 2012), autistic and non-autistic individuals may struggle to understand each other's perspectives, potentially straining relationships. As a result, autistic females may camouflage their RRBs to conform to neurotypical expectations and reduce the risk of social rejection; however, this can negatively impact their mental health. Clinical and research contexts can play an important role in shifting this narrative by adopting a strengths-based approach that recognises RRBs as potentially adaptive strategies that support self-regulation and well-being, rather than perceiving them solely as problematic behaviours that need to be changed.

Conclusions:

Autistic women reported a range of RRBs which were camouflaged from others. Although they may not be visible to others RRBs had a complex and multifaceted relationship with mental health and well-being. Although RSMBs and ISBs were positively associated with anxiety and depression, their lived experience was more nuanced as RRBs were important for self-regulation but could also be distressing. RRBs could also negatively impact autistic women indirectly through the negative responses they elicited from others. This study has highlighted the presentation and impact of RRBs among autistic women. However, it remains unclear if RRBs are differ from autistic men or whether other factors contribute to the gender differences in diagnosis rates. To address this future research should continue to compare the presentation of RRBs among autistic women and men with the inclusion of self-identified individuals without a clinical diagnosis.

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Appendices

Appendix 1: PRISMA Reporting Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	7
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	8
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	9
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	11
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	11
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.	11
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	64
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.	12
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.	12
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.	12
	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.	11
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.	12
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.	12
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	12

Section and Topic	Item #	Checklist item	Location where item is reported
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	12
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	12
	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.	12
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	24
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	24
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	24
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	24
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.	13
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	13
Study characteristics	17	Cite each included study and present its characteristics.	18
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	21 + 67
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.	21
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	14
	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.	21
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	21
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	NA
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	24
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	24
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	22

Section and Topic	Item #	Checklist item	Location where item is reported
	23b	Discuss any limitations of the evidence included in the review.	24
	23c	Discuss any limitations of the review processes used.	24
	23d	Discuss implications of the results for practice, policy, and future research.	24
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.	11
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	11
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	NA
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	11
Competing interests	26	Declare any competing interests of review authors.	11
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.	76

Appendix 2: Example Search Strategy

Search Strategy

CINAHL and PsycINFO Search Strategy

S1	(MH "Autism Spectrum Disorder") OR (MH "Asperger Syndrome") OR (MH "Pervasive Developmental Disorder Not Otherwise Specified")
S2	TI autis* OR AB autis*
S3	TI ASD OR AB ASD
S4	TI asperger* OR AB asperger*
S5	TI "pervasive n1 disorder" OR AB "pervasive n1 disorder"
S6	S1 OR S2 OR S3 OR S4 OR S5
S7	(MH "Cognitive Therapy")
S8	TI "cognitive behav* therap*" OR AB "cognitive behav* therap*"
S9	TI CBT OR AB CBT
S10	TI "cognitive therap*" OR AB "cognitive therap*"
S11	S7 OR S8 OR S9 OR S10
S12	TI depress* OR AB depress*
S13	TI MDD OR AB MDD
S14	(MH "Depression+")
S15	(MH "Adjustment Disorders")
S16	TI melanchol* OR AB melanchol*
S17	TI (((adjustment or reactive or dysthymic) adj5 disorder*))) OR AB (((adjustment or reactive or dysthymic) adj5 disorder*)))
S18	S12 OR S13 OR S14 OR S15 OR S16 OR S17
S19	(MH "Adult")
S20	(MH "Adolescence")
S21	TI adult* OR AB adult*

S22	TI adolescent* OR AB adolescent*

S23	TI "young adult*" OR AB "young adult*"
S24	TI teen* OR AB teen*
S25	TI "young person" OR AB "young person"
S26	S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25
S27	S6 AND S11 AND S18 AND S26

EMBASE and MEDLINE Search Strategy

1	exp autism/
2	autis*.tw.
3	ASD.tw.
4	asperger*.tw.
5	(Pervasive adj2 Development).tw.
6	1 or 2 or 3 or 4 or 5
7	exp cognitive behavioral therapy/
8	""cognitive behav* therap*".tw.
9	CBT.tw.
10	"cognitive therap*".tw.
11	7 or 8 or 9 or 10
12	exp depression/
13	Depression.tw.
14	"Depressive Disorder".tw.
15	Depressive.tw.
16	""Major Depressive Disorder".tw.
17	MDD.tw.
18	12 or 13 or 14 or 15 or 16 or 17
19	exp adult/
20	exp adolescence/

21	adult.tw.
22	adolescen*.tw.
23	“young adult”.tw.
24	teen*.tw.
25	“young person”.tw.
26	19 or 20 or 21 or 22 or 23 or 24 or 25
27	6 and 11 and 18 and 26

Appendix 3: Risk of Bias Assessment

	Bias due to confounding factors	Bias in classification of interventions	Bias in selection of participants into the study	Bias due to deviations from intended interventions	Bias due to missing data	Bias in the measurement of the outcome	Bias in selection of the reported result	Overall risk of bias
Capriola-Hall, Brewe, Golt & White (2021)	Low	Low	Low	Low	Moderate	Low	Low	Moderate
McGillvray & Evert, 2014	Low	Low	Low	Moderate	Low	Low	Low	Moderate
Russell et al., 2020	Low	Low	Low	Low	Low	Low	Low	Low
Santomauro, Sheffield & Sofronoff (2016)	Low	Low	Low	Low	Low	Low	Low	Low

Appendix 4: JARS - Mixed Methods Article Reporting Standards (MMARS)

Guidance sourced from https://psycnet.apa.org/fulltext/2018-00750-003.html

Table adapted from Hughes, M. C., Vernon, E., Kowalczyk, M., & Zhou, H. (2022). Experiences of caregivers and hospice leaders with telehealth for palliative care: a mixed methods study. *Annals of Palliative Medicine*, *11*(7), 2302313-2302313.

Section/Topic	Item No	Checklist Item	Reported on Page Number	Reported on Section/Paragraph
Title				
	1a	Quant – Identify the populations	32	Title
	1b	Mixed - Refrain from using words that are either qualitative (e.g., "explore," "understand") or quantitative (e.g., "determinants," "correlates"), because mixed methods stand in the middle between qualitative and quantitative research.	32	Title
	1c	Mixed - Reference the mixed methods, qualitative methods, and quantitative methods used.	32	Title
Abstract				
	2a	Mixed - Indicate the mixed methods design, including types of participants or data sources, analytic strategy, main results/findings, and major implications/significance.	35	Abstract
Introduction				
	3a	Quant - State the importance of the problem, including theoretical or practical implications.	36	Introduction
	3b	Qual - Review, critique, and synthesize the applicable literature to identify key issues/debates/theoretical frameworks in the relevant literature to clarify barriers, knowledge gaps, or practical needs.	36	Introduction
	3c	Mixed - State three types of research objectives/aims/goals:	37	Introduction Paragraph 6

		qualitative, quantitative, and mixed methods. Order these goals to reflect the type of mixed methods design used.		
Method				
	4a	Mixed -Explain why mixed methods research is appropriate as a methodology given the paper's goals.	38	Methods Paragraph 1 'Study Design'
	4b	Mixed - Indicate the qualitative approach to inquiry and the quantitative design used within the mixed methods design type.	40 44	'Phase One' Paragraph 1 'Phase Two' Paragraph 1
	4c	Quant - Report inclusion and exclusion criteria, including any restrictions based on demographic characteristics.	38	'Participants'
	4d	Qual - Describe the participants/data source selection process and inclusion/exclusion criteria.	39	'Recruitment Procedure'
	4e	Quant - Describe settings and locations where data were collected as well as dates of data collection.	40	'Phase One' Paragraph 1
	4f	Qual - Provide the general context for the study (when data were collected, sites of data collection).	44	'Phase Two' Paragraph 1
	4g	Quant - Define all primary and secondary measures and covariates.	40	'Phase One' Paragraph 1
	4h	Quant - Report major demographic characteristics and important topic-specific characteristics.	41	'Results' 'Participants and Demographics' Appendix 16
	4i	Quant - Describe procedures for selecting participants.	39	'Recruitment Procedures'
	4j	Quant - Describe agreements and payments made to participants.	39	'Ethical Considerations' Paragraph 2
	4k	Qual - State the form of data collected (e.g., interviews, questionnaires, media, observation).	44	'Phase Two' Paragraph 1
	4l	Qual - Describe questions asked in data collection: content of central questions, form of	92	'Appendix 19'

		questions (e.g., open vs. closed).		
	4m	Qual - For interview and written studies, indicate the mean and range of the time duration in the data-collection process.	44	'Phase Two' Paragraph 1
	4n	Qual - Describe any incentives or compensation, and provide assurance of relevant ethical processes of data collection and consent process as relevant.	39	'Ethical Considerations'
	4o	Describe institutional review board agreements, ethical standards met, and safety monitoring.	39	'Ethical Considerations'
Results				
	5a	Quant - Provide information detailing the statistical and data analytic methods used.	41 82	'Results' 'Appendix 8: Data Analysis Plan'
	5b	Qual - Describe research findings (e.g., themes, categories, narratives) and the meaning and understandings that the researcher has derived from the data analysis.	45	'Results'
	5c	Qual - Demonstrate the analytic process of reaching findings (e.g., quotes, excerpts of data).	44	'Results'
	5d	Mixed - Indicate how the qualitative and quantitative results were mixed.	49	'Discussion'
Discussion				
	6a	Describe the central contributions and their significance in advancing disciplinary understandings.	49	'Discussion'
	6b	Discuss similarities and differences between reported results and work of others.	49	'Discussion'
	6c	Identify the study's strengths and limitations.	52	'Strengths and Limitations'

Appendix 5: MRP Proposal

https://osf.io/ar96j

Appendix 6: MVLS Ethics Approval Letter

Professor Craig Melville

MVLS College Ethics Committee

An exploration of restricted and repetitive behaviours and interests in autistic females *200230323*

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 the original application.
- Head of School approvals.
- 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

Dr Terry Quinn

Terry Quinn

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

The University of Glasgow, charity number SC004401

College of Medicine, Veterinary & Life Sciences

School of Cardiovascular and Metabolic Health

New Lister Building, Glasgow Royal Infirmary

Glasgow G31 2ER

terry.quinn@glasgow.gla.ac.uk

Tel – 0141 201 8519

Appendix 7: 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.

Appendix 8: Data Analysis Plan

https://osf.io/q3g2j

Appendix 9: Recruitment Advert

https://osf.io/h8y9p

Appendix 10: Participant Information Sheet

https://osf.io/a4hrk

Appendix 11: Participant Privacy Notice

https://osf.io/zym3r

Appendix 12: Participant Consent Forms

https://osf.io/72xft

Appendix 13: Participant Debrief Sheet

https://osf.io/mqdkb

Appendix 14: Self-Report Measures

Social Responsiveness Scale-Second Edition: Adult Self-Report (SRS-2)

The SRS-2 (Constantino & Gruber, 2012) is a self-report measure that assesses symptoms associated with ASD. There are 65 items over five sub-scales: social awareness (e.g., item 7, "I am usually aware of how others are feeling"), social cognition (e.g., item 48, "I have a good sense of humour and can understand jokes"), social communication (e.g., item 16, "I avoid eye contact or am told that I have unusual eye contact"), social motivation (e.g., item 6, "I would rather be alone than with others"), and restrictive interests and repetitive behaviour (e.g., item 24, "I have more difficulty than others with changes in my routine"). Respondents rate their behaviour over the previous 6 months on a 4-point Likert-type scale from 1 (not true) to 4 (almost always true). The sum of all the items is calculated to provide a total score (max 195). T-scores below 59 are within the normal range, 60-65 in the mild range, 66-75 in the moderate range and over 76 in the severe range. Following recommended practice for research, raw scores were used for all analyses.

Adult Repetitive Behaviour Questionnaire-2 (RBQ-2A)

The RBQ-2A (Barrett et al., 2018) is a self-report measure to identify the presence and severity of repetitive behaviours. There are 20 items over two sub-scales: repetitive sensory-motor behaviours and insistence on sameness. Respondents rate their behaviour on a 3 or 4-point Likert-type scale from 1 (never or rarely) to 3 (15 or more times daily; marked or notable) or 4 (30 or more times daily; serious or severe). The RBQ-2A was scored in line with previous research on the RBQ-2A and RBQ-2 (Barrett et al., 2015; Barrett, Uljarević, Jones, & Leekam, 2018; Leekam et al., 2007; Lidstone et al., 2014). The fourth option was collapsed into option three while scoring (Barret et al., 2015). The sum of all the items was calculated to provide a total score (max 60). There is no clinical threshold cut-off. The RBQ-2A has good internal consistency (Cronbach's alpha: Total, α=0.83). While some measures of RRB identify sex differences (see McFayden et al., 2020), the RBQ2A does not (Barrett et al., 2015; 2018).

World Health Organisation Quality of Life-Brief Version (WHOQOL-BREF)

Adapted from Williams and Gotham (2021) to reduce participant burden, a subset of 5 items will be presented from the WHOQOL-BREF (The WHOQOL Group, 1998). These include items 1 (How would you rate your quality of life?), 5 (How much do you enjoy life?), 6 (To what extent do you feel your life to be meaningful?), 17 (How satisfied are you with your ability to perform your daily living activities?) and 19 (How satisfied are

you with yourself?). Respondents will rate their level of agreement with the statements over the previous 2 weeks on a 5-point Likert-type scale from 1 (very poor/very dissatisfied/not at all) to 5 (very good/very satisfied/an extreme amount). These items have previously been reported to be strong indicators of the 'general QoL' factor (Perera et al., 2018).

Patient Health Questionnaire (PHQ-9; Kroenke, Spitzer & Williams, 1999)

The PHQ-9 (Kroenke, Spitzer & Williams, 1999) is a brief self-report measure to screen for the presence of Major Depressive Disorder (MDD). Respondents rate their level of agreement with each of the 9 statements over the previous 2 weeks on a 4-point Likert-type scale from 0 (not at all) to 3 (nearly every day). The sum of all items is calculated to provide a total score (max 27). Scores can be classified to indicate minimal (0-4), mild (5-9), moderate (10-14), moderately severe (15-19) and severe depression (20-27).

Generalised Anxiety Disorder-7 (GAD-7; Spitzer et al., 2006)

The GAD-7 (Spitzer et al., 2006) is a brief self-report measure to screen for the presence of Generalised Anxiety Disorder (GAD). Respondents rate their level of agreement with each of the 7 statements over the previous 2 weeks on a 4-point Likert-type scale from 0 (not at all) to 3 (nearly every day). The sum of all items is calculated to provide a total score (max 21). Scores can be classified to indicate minimal (0-4), mild (5-9), moderate (10-14) and severe anxiety (15-21).

Appendix 15: SPSS Syntax File

https://osf.io/mknug

Appendix 16: Phase 1 Participant Demographics

White, N (%)	48 (94)
Occupational Status, N (%)	Student (Full-Time), 11 (21.57)
	Employment (Full and Part-Time), 26 (50.98)
	Unemployed, 12 (23.53)
	Other (retired, unpaid carer), 2 (3.92)
Highest Level of Education, N (%)	Postgraduate Degree, 15 (29)
	Undergraduate Degree, 20 (39)
	SQA Advanced Highers or Equivalent, 1 (2)
	SQA Highers or Equivalent, 6 (12)
	SQA National 5 or Equivalent, 4 (8)
	None, 1 (2)
	Other, 4 (8)
SRS-2 raw scores, M (SD)	Total score, 100.96 (18.03)
	Social Awareness, 9.84 (2.36)
	Social Cognition, 21.06 (4.33)
	Social Communication, 35.59 (7.17)
	Social Motivation, 13.39 (3.02)
	Restricted Repetitive Behaviours, 21.07 (5.62)
WHOQOL-4, Mean Score (1-5)	2.23 (1.1)

Global Quality of Life, N (%)	Very Good, 1 (2)
	Good, 25 (49)
	Neither Poor nor Good, 12 (23.5)
	Poor, 11 (21.5)
	Very Poor, 2 (4)

Appendix 17: RBQ-2A Scores

RBQ-2A Item	Frequency			
	Never or Rarely N (%)	**≥ 1 per day N (%)**	**≥ 15 times per day N (%)**	**≥30 times per day N (%)**
Like to arrange items in rows or patterns?*	8 (15.7)	36 (70.6)	5 (9.8)	2 (3.9)
Repetitively fiddle with items? (e.g., spin, twiddle, bang, twist or flick anything repeatedly?)*	5 (9.6)	9 (17.7)	19 (37.3)	18 (35.3)
Spin yourself around and around?*	33 (64.7)	15 (29.4)	2 (3.9)	1 (2.0)
Rock backwards and forwards or side to side, either when sitting or when standing?*	17 (33.3)	16 (31.4)	12 (23.5)	6 (11.8)

Pace or move around repetitively (e.g., walk to and fro across a room, or around the same path in the garden?)*	18 (35.3)	19 (37.3)	8 (15.7)	6 (11.8)
Make repetitive hand and/or finger movements? (e.g., flap, wave or flick your hands or fingers repetitively?)*	12 (23.5)	13 (25.5)	15 (29.4)	11 (21.6)
	Severity/Intensity			
	Never/Rarely N (%)	**Mild/Occasionally N (%)**	**Marked/Notably N (%)**	**Serious/Severely N (%)**
Have a fascination with specific objects? (e.g trains, road signs, or other things?)*	12 (23.5)	27 (52.9)	12 (23.5)	0 (0.0)
Like to look at objects from particular or unusual angles?*	21 (41.2)	19 (37.3)	11 (21.6)	0 (0.0)

Have a special interest in the feel of different surfaces?*	23 (45.1)	21 (41.2)	7 (13.7)	0 (0.0)
Have a special interest in the smell of people or objects?**	12 (23.5)	21 (41.2)	18 (35.3)	0 (0.0)
Have any special objects you like to carry round?**	21 (41.2)	19 (37.2)	11 (21.6)	0 (0.0)
Collect or hoard items of any sort?**	8 (15.7)	21 (41.2)	22 (43.1)	0 (0.0)
Insist on things at home remaining the same? (e.g furniture staying in the same place, things being kept in certain places, or arranged in certain ways?)**	2 (3.9)	12 (23.5)	24 (47.1)	13 (25.5)
Get upset about minor changes to objects? (e.g flecks of dirt on your clothes, minor scratched on objects?)**	3 (5.9)	21 (41.2)	18 (35.3)	9 (17.6)

Insist that aspects of daily routine must remain the same?**	4 (8)	18 (35.3)	16 (31.4)	13 (25.5)
Insist on doing things a certain way or re-doing things until they are 'just right'?**	3 (5.9)	19 (37)	16 (31)	13 (26)
Play the same music, game or video, or read the same book repeatedly?**	4 (7.8)	14 (27.5)	24 (47.1)	9 (17.7)
Insist on wearing the same clothes or refuse to wear new clothes**	9 (17.7)	19 (37.3)	18 (35.3)	5 (9.8)
Insist on eating the same foods, or a very small range of foods, at every meal?**	10 (19.6)	17 (33.3)	17 (33.3)	7 (13.7)
	A range of different and flexible self-chosen activities	**Some varied and flexible interests but commonly choose the same activities**	**Almost always choose from a restricted range of repetitive activities**	

Occupy yourself with a restricted range of repetitive activities?	1 (2.0)	24 (47.0)	26 (51.0)	

Appendix 18: Clinical vs Self-Diagnosed Participants

	ASD diagnosis (N = 33)	**No ASD diagnosis (N = 18)**	**Statistic**
SRS Raw Total Score, Mean (SD)	102.88 (16.18)	97.44 (21.05)	t(49) = -.68, p = .50
Social Awareness, Mean (SD)	9.94 (2.02)	9.67 (2.95)	t(49) = -1.03, p = .31
Social Cognition, Mean Rank	27.33	23.56	U = 253.00, Z = -.870, p = .38
Social Communication, Mean (SD)	36.45 (6.40)	34.00 (8.37)	t(49) = -1.17, p = .25
Social Motivation, Mean Rank	27.73	22.83	U = 240.00, Z = -1.131, p = .26
RRB, Mean (SD)	21.33 (5.59)	20.61 (5.81)	t(49) = -.43, p = .67
RBQ-2A, Mean (SD)	45.03 (7.11)	41.22 (8.97)	t(49) = -.1.67, p = .10
Repetitive Sensory Motor Behaviour, Mean (SD)	2.03 (0.43)	1.90 (0.51)	t(49) = -1.00, p = .32
Insistence on Sameness, Mean Rank	28.65	21.14	U = 209.50, Z = -1.73, p = .08
WHOQOL-4, Mean Rank	26.76	24.61	U = 272.00, Z = -.510, p =.610

PHQ-9, Mean Rank	26.41	25.25	U = 283.50, Z = -.27, p = .61
GAD-7, Mean (SD)	11.61 (5.54)	10.61 (6.25)	t(49) = -.59, p =.56

Appendix 19: Example of Interview Schedule

https://osf.io/qtvux

Appendix 20: Phase 2 Participant Demographics

White, N (%)	4 (80%)
Occupational Status, N (%)	Employed (Full and Part Time), 3 (50%)
	Unemployed, 2 (33)
	Other (retired), 1 (17)
Highest Level of Education, N (%)	Post-graduate degree, 1 (16.67)
	Undergraduate, 1 (16.67)
	Highers or equivalent, 1 (16.67)
	Nat 5s or equivalent, 1 (16.67)
	Other, 2 (33)
SRS-2, M (SD)	Total Score, 105 (26.35)
	Social Awareness, 10 (2.28)
	Social Cognition, 22.33 (5.54)
	Social Communication, 36 (11.71)
	Social Motivation, 12.83 (2.48)
	Restricted Repetitive Behaviours, 21.5 (6.28)

RBQ-2A, M (SD)	41.5 (9.85)
PHQ-9, M (SD)	16.33 (9.99)
GAD-7, M (SD)	12.83 (8.03)
WHOQOL-4, Mean Score (1-5)	2.21 (1.22)
Global Quality of Life, N (%)	Good, 4 (80%)
	Poor, 2 (20%)

Appendix 21: Sample of Analysed Transcript

https://osf.io/dk6h4

Appendix 22: Example of Development of Themes from Clustered Codes

https://osf.io/8g3du