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Coping Styles and Resilience in Autistic Adults: A Systematic Review and Psychological Wellbeing of Autistic Adults in the UK During the COVID-19 Pandemic

Thesis submitted in partial fulfilment of the requirement for the degree of:

Doctorate of Clinical Psychology (DClinPsy)

South Wales Doctoral Programme in Clinical Psychology

Cardiff University

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30th July 2021

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Acknowledgements

I would like to thank Dr John Fox, Dr Rona Aldridge and Dr Jack Underwood for all the guidance, support and compassion they have shown me during this project. I would also like to thank Dr Jacob Oleson and Logan Harris for sharing their expertise and time.

Special thanks go to all of the participants who gave up so much of their time to support this study.

I would like to thank my appraisal tutor Dr Louise Waddington for her support and kindness over the last three years.

Finally I would like to thank my wife, Caighli Taylor, for everything.

Preface

This DClinPsy thesis has been written in the format of two papers: a systematic review and an empirical study. These papers will be submitted for publication in the *Journal of Autism and Developmental Disorders*.

Both papers explore mental health in autistic adults. Autism is a lifelong developmental condition that affects how people interact with others, understand the world around them and experience their senses. Past research suggests that autistic people are at higher risk of mental health difficulties than non-autistic people, but there are also positive aspects of being autistic. Understanding more about the strengths and difficulties of being autistic can help services support autistic people better in future.

Paper 1 presents a systematic review of coping styles and resilience in autistic adults. Lots of existing autism research tries to explain why autistic people are more at risk of poor outcomes. Coping and resilience research takes a different approach, focusing instead on how and why some people achieve positive outcomes despite challenges. Coping refers to the strategies people use to manage demanding or stressful situations. Researchers have measured the concept of coping in different ways and tried to identify which coping styles are the most effective. Supporting people to develop more effective coping strategies can help to promote better mental health.

Resilience refers to the aspects of an individual's personality and environment which enable them to achieve positive outcomes despite adversity. Some researchers think of resilience as a collection of personality traits; others focus on the interaction of individual and environmental factors. Previous studies have tried to understand how people build resilience, as this can help them to avoid psychological problems.

Coping and resilience in autistic adults is less well understood, despite the fact that autistic people experience more stressful life events. This paper reviews all of the existing published research looking at both coping and resilience in autistic adults. Findings from this evidence base are reported, and the quality of these studies is assessed. It is hoped that this review will support services caring for autistic adults and give some direction for future research in the area.

Paper 2 presents an empirical study exploring the mental health of autistic adults during the COVID-19 pandemic. Social restrictions have been imposed during the pandemic have been imposed to reduce transmission of COVID-19, but this has had a negative impact on mental health for many people. Rates of depression and anxiety have increased in the UK population increased following the start of the pandemic, and some groups of people may be at higher risk of developing psychological problems. Although lots of studies have explored mental health during COVID-19, very few have focused on autistic adults specifically.

This study recruited a large sample of 124 autistic adults and asked them to complete online mental health questionnaires every two weeks between June and September 2020. 51 non-autistic adults were also recruited and completed the same questionnaires. Scores from these questionnaires were used to build statistical models showing how the psychological wellbeing of participants changed over this time. These models were used to compare the mental health trajectories of autistic and non-autistic adults. These models were also analysed to explore any individual factors that might predict greater changes in psychological wellbeing over time.

Results showed that autistic participants experienced higher rates of depression and anxiety, and lower levels of wellbeing during this time. The average scores on mental health questionnaires did not change significantly over the three-month data collection period, which might be because lockdown restrictions were starting to lift during this time. However, in the autism group, being older and having higher educational qualifications were associated with increasing psychological distress over time. The opposite trend was shown for educational status in the non-autistic group, and no relationship between age and mental health trajectory was found.

These results suggest that older autistic people, and those with higher educational qualifications, may be particularly at risk of developing mental health difficulties during COVID-19 social restrictions. These findings are discussed in relation to existing research, and recommendations are made for clinical practice and future research.

Coping Styles and Resilience in Autistic Adults: A Systematic Review

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(word count = 7518)

Prepared according to instructions for *Journal of Autism and Developmental Disorders* (see Appendix A)

Abstract

Autistic people are at increased risk of developing mental health difficulties. Interventions targeting coping styles and resilience may improve outcomes, but these concepts are not well understood in the autistic adult population. A systematic review was conducted to identify and evaluate existing research on coping and resilience in autistic adults. Narrative synthesis was used to consider findings in relation to methodological quality and measurement validity. Seven quantitative studies were included, and findings suggest a negative impact of maladaptive coping styles on resilience and psychological wellbeing. Results suggest a promising but underdeveloped evidence base currently limited by a lack of consistency in measurement and small, unrepresentative, cross-sectional samples. Interventions should target maladaptive coping styles, and future research should explore autism-specific strategies.

Keywords

autism; adult; resilience; coping; mental health

Coping Styles and Resilience in Autistic Adults: A Systematic Review

Much of the autism research literature is concerned with the core difficulties, risk factors and adverse outcomes in the lives of autistic people. Recurrent findings indicate that autistic people are at greater risk of developing a range of mental health difficulties (Eaves & Ho, 2008; Hollocks et al., 2019; Joshi et al., 2013), as well as achieving poor outcomes relative to their peers across social, educational and occupational domains. (Griffiths et al., 2019; Howlin & Magiati, 2017; Shattuck et al., 2012). These disparities in outcome may be partly attributable to pervasive difficulties in social communication and interaction (Gillott & Standen, 2007) and challenges around managing heightened sensory sensitivity in unaccommodating 'neurotypical' spaces (Baron, 2006). However, autistic people are also likely to encounter higher numbers of stressful life events, and experience higher self-perceived stress in response to these events (Bishop-Fitzpatrick et al., 2017).

Some researchers approach the issue of outcome in autism from a different perspective, focusing on factors that enable some individuals to adapt and achieve positive outcomes despite significant adversity (McCrimmon & Montgomery, 2014). The construct of resilience, or the ability to 'bounce back' following adverse experiences, offers a framework to explore such protective factors (Masten, 2001). Definitions of resilience in research literature have changed over time (Fletcher & Sarkar, 2013). Early studies focused mainly on intra-individual 'trait' or personality characteristics believed to predispose certain individuals towards an adaptive outlook (Connor & Davidson, 2003). Alternative conceptualisations of resilience have considered systemic and inter-individual factors, defining resilience as a dynamic, relational process (Fergus & Zimmerman, 2004). This view of resilience emphasizes the interaction of individual characteristics with contextual and ecological factors like availability of social support and familial relationships (Fletcher & Sarkar, 2013; Stewart & Yuen, 2011).

A range of psychometric measures have been designed to assess resilience, tapping various aspects of the construct depending on how it is operationalised (Windle et al., 2011). These measures have subsequently been used to demonstrate associations between resilience factors and a range of outcomes (Ungar & Theron, 2020). Trait resilience has been found to be a protective factor for the development of mental health difficulties such as depression and anxiety in the general population (Hu et al., 2015) and various health populations (Färber & Rosendahl, 2018; Macía et al., 2021). Interventions focused on enhancing resilience have demonstrated efficacy in reducing distress and improving quality of life in community samples (Joyce et al., 2018).

Given the increased vulnerability to stressful experiences in autistic adults (Bishop-Fitzpatrick et al., 2017; Gillott & Standen, 2007), it may be even more important to bring a resilience framework to research in this group. There may be reason to believe that unique factors contribute to resilience in autistic adults, including special interests and support from "atypical" friends (Dachez & Ndobo, 2018). Living in the current context of the COVID-19 pandemic may involve particular challenges for autistic adults (Ameis et al., 2020), and greater understanding of resilience may help autistic people and those supporting them to mitigate current and future psychological strain.

The separate but related construct of 'coping' refers to the specific processes that enable an individual to manage stressful or challenging experiences. Previous studies have shown that the way in which an individual responds to life stressors are strongly correlated with measures of wellbeing and functioning (Cheng et al., 2014). Early researchers defined coping as a range of cognitive and behavioural strategies available to meet internal and external demands perceived as taxing (Lazarus, 1993). Responses to stress can take many forms depending on the individual and their context, and might include problem solving, cognitive reappraisal, denial, rumination, or seeking help, amongst others (Skinner et al., 2003). Individual coping styles are not generally considered to be inherently adaptive or maladaptive but vary in effectiveness depending on context (Fletcher & Sarkar, 2013; Folkman & Lazarus, 1988).

A challenge for researchers exploring coping is that there is little consensus in the literature on how to define, assess and categorise coping styles (Skinner et al., 2003). Attempts at taxonomy have often focused on establishing broad domains of coping style, such as ‘problem-focused’ (active engagement to modify challenging situations), ‘emotion-focused’ (mitigating the emotional impact of a stressor), or ‘cognitive-focused’ (re-appraisal of a problematic situation) (Hawken et al., 2018; Lazarus, 1993). Individual strategies are often dichotomised as ‘engagement’ coping (active attempts to resolve problems or associated distress) or ‘disengagement’ coping (efforts to distance oneself from stressors through avoidance, denial, or withdrawal) (Muniandy et al., 2021b; Sharkansky et al., 2000). These dimensions are often retained in the numerous psychometric measures that have been developed to assess coping styles (Chesney et al., 2006; Kato, 2015). Some authors have criticised these higher-order categories as being too simplistic and disregarding the contextual nature of coping (Schwarzer & Schwarzer, 1996). Alternative systems incorporate more idiosyncratic and context-specific strategies, such as religious coping, humour, substance-abuse, and acceptance (Carver, 1997). Coping has also been examined from the perspective of self-efficacy; or the individual’s subjective perception of their own ability cope with specific situations (Chesney et al., 2006).

Despite the complications inherent to coping research, many studies have sought to establish associations between coping style and mental health outcomes. Correlations have been found between the use of disengagement coping styles and increased symptoms of depression and anxiety in studies focusing on specific health populations (Friedman-Wheeler et al., 2008), including younger autistic individuals (Khor et al., 2014). Conversely, psychological distress may be reduced in individuals who tend to use more 'engagement' coping styles (Rieffe et al., 2014). Other studies have suggested that while disengagement strategies may be adaptive as an initial response to a stressor, they may be less effective over time when faced with a chronic stressor (Pakenham et al., 2005).

Researchers exploring resilience and coping in autism have given relatively little attention to the autistic adult population (Szatmari, 2018). Parents, carers, and families have been prioritised in existing studies, which have identified effective strategies for managing the increased demands of caring for autistic individuals (Lai et al., 2015). Studies exploring coping in autistic children have found that they may display fewer 'engagement' coping styles than their non-autistic peers (Rieffe et al., 2014). A recent systematic review synthesised available research on resilience in children with autism and/or intellectual disability, highlighting a lack of consistency in the measurement and definition of the construct in this population (Clark & Adams, 2021).

At the time of writing, no systematic review of research evidence relating to resilience or coping in the autistic adult population has been conducted. Interventions that target resilience, adaptive coping skills and coping self-efficacy may promote a range of positive outcomes for autistic adults. The present study will systemically review existing studies which investigate the role of resilience and coping in the lives of autistic adults, and explore factors associated with these constructs. The following research questions will be addressed:

1. What is the quality of available research exploring resilience and coping in autistic adults?

2. How have the constructs of resilience and coping been defined, measured, and explored in existing research involving autistic adults?
3. What can existing studies tell us about factors associated with resilience and coping in autistic adults?

Methodology

Search strategies

A systematic review was carried out on 29th March 2021, following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Page et al., 2021). Five electronic databases (PsycINFO, ASSIA, MEDLINE, Scopus and Web of Knowledge) were searched for relevant published studies from their inception until March 2021. To avoid the exclusion of relevant papers due to search term specificity, a broad and inclusive approach to searching was taken, including keywords related to the topics of interest. The final search was run using the following search terms: (autis* OR asperger* OR "Pervasive developmental disorder*" OR asd) AND (resilien* OR coping OR hardiness OR "protective factor*" OR adversity OR adaptiv* OR adaptability). Search syntaxes used for each database are shown in Appendix B. Reference lists of relevant journals, existing systematic reviews and included full-text studies were manually searched for any additional relevant studies. Database searches were re-run on 19 June 2021 to identify more recently published articles.

Screening process

Following removal of duplicate records, each remaining study title was screened by the lead researcher using criteria to assess topic relevance. Abstracts of relevant titles were screened at the next stage, and remaining full texts were assessed against full eligibility criteria (shown in Table 1) to confirm suitability for inclusion. It was decided that studies including participants who had a co-occurring diagnosis of intellectual disability would be excluded from the review. Whilst intellectual disability is prevalent in the autistic population – it is estimated that at least one third of autistic people also have an ID diagnosis (Baio et al., 2018) – it was predicted that this characteristic may represent a confounding variable in synthesized findings. Exclusion criteria pertaining to this issue were determined in the interest of maintaining consistency and clarity in diagnostic procedure, and of maximising interpretability of findings. Nonetheless, this is acknowledged as a potential limitation of the current study, and it is recommended that future systematic reviews conducted around resilience and coping might incorporate discrete samples of participants with intellectual disabilities, and with co-occurring diagnoses.

it has been suggested in previous research that the constructs of resilience and coping suffer from inconsistent definition and imprecise operationalisation in the literature (Clark & Adams, 2021). Whilst some reviewers have taken a focused and proscriptive approach when selecting search terms (Clark & Adams, 2021), others have chosen to include associated concepts such as ‘hardiness’, ‘thriving’ and ‘protective factors’. It was decided that a broad and inclusive approach to database searching would be taken, including keywords related to the topics of interest. Using this approach allowed for high sensitivity at the search stage, mitigating the impact of heterogeneous construct terminology and decreasing the risk of excluding relevant papers. This was however followed by a more stringent approach to the eligibility screening process, in which inclusion and exclusion criteria were more strictly applied. It was hoped that this would ensure that while all relevant studies were identified, decisions regarding inclusion in the final review would remain systematic and rigorous, maximising both conceptual specificity and scope for synthesis and comparison of findings.

A second member of the research team independently reviewed papers against eligibility criteria, including 10% of titles, 10% of abstracts, and 25% of full-texts. Kappa statistics were calculated to assess level of agreement at each stage, with adequate agreement reached at both the title (K = 0.62) and abstract (K = 0.64) stage. Any disagreements arising were resolved through discussion until consensus was reached. Full agreement (K = 1.0) was reached on papers to be included in the final review.

Table 1 *Inclusion and exclusion criteria for screening of papers*

Inclusion Criteria	**Exclusion Criteria**
primary, peer-reviewed, published research studies	not published in peer-reviewed journals
outcomes relating to resilience, coping or related constructs in a discrete sample of adult (16+) autistic individuals were measured or explored	data relating specifically to psychological resilience, coping or factors protective of mental health not captured
autism diagnoses delivered by a trained clinician as self-reported, reassessed by research team, or supported through the use of a standardised screening measure	no evidence in support of autism diagnoses presented
study participants did not have a diagnosis of intellectual disability or IQ < 70	participants with intellectual disability included in the sample of autistic adults
resilience or coping related to broad experience of autism rather than specific contexts (e.g., natural disasters, transition between services)	study focused on resilience or coping in others (e.g., family members, carers or health professionals)
English language papers or translations available	

Data extraction and quality assessment

Table 2 lists the data items that were extracted into an Excel database by the lead author, for each included paper. The Quality Assessment Tool for Studies with Diverse Designs (QATSDD) was used to assess the quality and risk of bias in each included paper (Sirriyeh et al., 2012). The QATSDD allows for studies with heterogenous methodologies to be assessed comparatively and was considered appropriate as the review protocol allowed for inclusion of quantitative and qualitative studies. However, as no qualitative papers were eligible for inclusion in the final review, only the items relating to quantitative studies were used, yielding a total raw score out of 42. Raw scores were converted to percentages, and descriptive ranges were determined for high quality (75 – 100%), moderate quality (50 – 74%) and low quality (0 – 49%) papers. The second rater additionally performed quality assessment on 25% (n = 2) of the papers included in the final review. Agreement on QATSDD ratings was very high, with both raters scoring within a range of 1% on both papers.

Table 2 *Data items extracted from each included study*

Study characteristics	location of research setting
	research design
	study aims
Sample characteristics	sample size
	recruitment context
	age
	sex
	education
	comorbid diagnoses
	inclusion / exclusion criteria
	comparison or control group details
Methodology	constructs explored (resilience / coping)
	construct definitions
	measurement tools
	autism diagnosis details
Analysis	associated factors explored
	method of analysis
Results	primary relevant findings

Data analysis

Narrative synthesis was used to analyse findings across studies. Initial themes were determined primarily with reference to the research questions, including the definition and measurement of resilience, coping and factors associated with these constructs. Following data extraction, further themes were identified through examination of patterns emerging from tabulated study characteristics and findings. Owing to heterogeneity of methodological and analytical approach in included papers, meta-analysis of findings was not undertaken.

Results

Figure 1 shows a flow diagram of the selection process. Before the full-text screening stage, the majority of studies were removed due to a focus outside the population of interest (autistic people under the age of 16, families, parents, carers, healthcare professionals). Reasons for exclusion at the full-text screening stage included samples with participants under the age of 16, lack of explicit focus on coping or resilience constructs, and insufficient information around diagnostic procedure for autism and intellectual disability. Seven studies met the criteria for inclusion in the final review, of which five focused on coping, one on resilience, and one explored the association between resilience and coping.

Research Question 1: Quality of included studies

Methodological quality as measured by the QATSDD (reported in full in Table 3) was fairly consistent across studies, with most falling in the ‘moderate quality’ range. Standardised scores ranged from 57.14% to 80.95%, with a mean rating of 68.71% (*SD* =

9.47). Only two studies scored in the 'high quality' range, with scores of 78.57% (Muniandy et al., 2021b) and 80.95% (Oswald et al., 2018). Mean scores for individual QATSDD items indicated that included studies suffered primarily from poor consideration of sample size and representativeness. Three papers (Hirvikoski & Blomqvist, 2015; Kronenberg et al., 2015; Muniandy et al., 2021b) made no explicit reference to the consideration of sample size prior

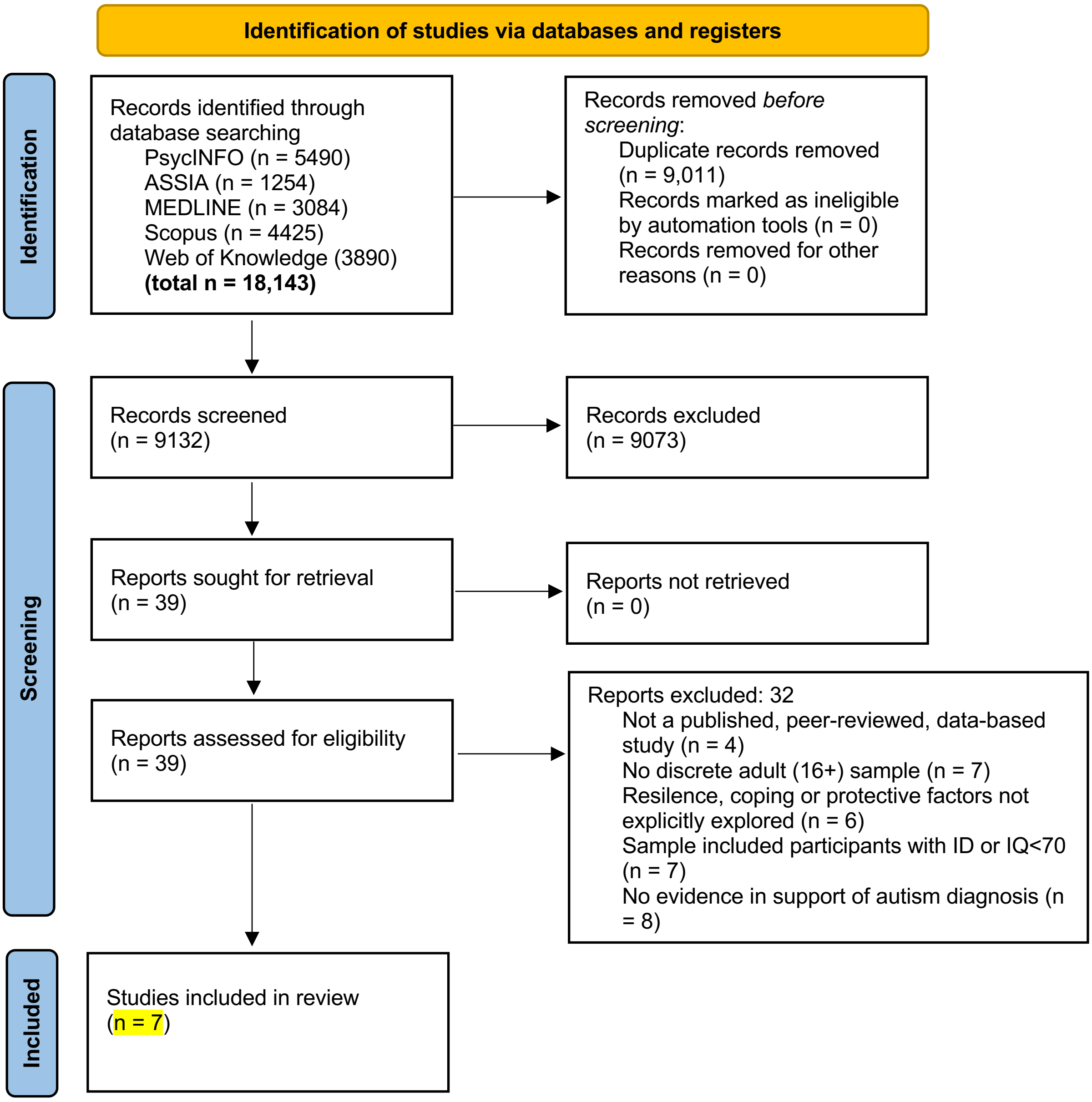

Figure 1. PRISMA flow diagram of study selection (Page et al., 2021)

Table 3 *Individual QATSDD item scoring per included study*

Criteria	Hirvikoski et al. (2015)	Khanna et al. (2014)	Kronenberg et al. (2015)	Montgomery et al. (2008)	Muniandy et al. (2021)	Oswald et al. (2018)	Renty & Roeyers (2007)	M (*SD*)
Explicit theoretical framework	**2**	**3**	**3**	**3**	**3**	**3**	**3**	**2.86** (0.38)
Statement of aims/objectives in main body of report	**3**	**3**	**3**	**3**	**3**	**3**	**3**	**3.00** (0.00)
Clear description of research setting	**3**	**3**	**3**	**3**	**3**	**3**	**3**	**3.00** (0.00)
Evidence of sample size considered in terms of analysis	**0**	**1**	**0**	**2**	**0**	**1**	**1**	**0.57** (0.79)
Representative sample of target group of a reasonable size	**1**	**2**	**1**	**1**	**1**	**2**	**1**	**1.29** (0.49)
Description of procedure for data collection	**2**	**2**	**2**	**1**	**3**	**2**	**1**	**1.86** (0.69)
Rationale for choice of data collection tool(s)	**2**	**2**	**1**	**1**	**3**	**3**	**3**	**2.14** (0.90)
Detailed recruitment data	**3**	**2**	**1**	**2**	**2**	**3**	**1**	**2.00** (0.82)

Statistical assessment of reliability and validity of measurement tool(s)	**0**	**2**	**2**	**0**	**3**	**1**	**3**	**1.57**	(1.27)
Fit between stated research question and method of data collection	**3**	**2**	**3**	**2**	**3**	**2**	**2**	**2.43**	(0.53)
Fit between research question and method of analysis	**2**	**3**	**3**	**2**	**3**	**2**	**2**	**2.43**	(0.53)
Good justification for analytic method selected	**2**	**3**	**2**	**2**	**3**	**3**	**3**	**2.57**	(0.53)
Evidence of user involvement in design	**0**	**0**	**0**	**0**	**0**	**3**	**0**	**0.43**	(1.13)
Strengths and limitations critically discussed	**2**	**3**	**2**	**2**	**3**	**3**	**3**	**2.57**	(0.53)
Total Score (/42)	**25**	**31**	**26**	**24**	**33**	**34**	**29**	**28.86**	(3.98)
%	**59.52**	**73.81**	**61.90**	**57.14**	**78.57**	**80.95**	**69.05**	**68.71**	(9.47)

to analysis. None of the studies included details of power analysis; however, four (Khanna et al., 2014; Montgomery et al., 2008; Oswald et al., 2018; Renty & Roeyers, 2007) described adjustments to effect sizes, alpha values, or numbers of regression model predictors, taking sample size into account. None of the included studies used sampling techniques to ensure comprehensive representation of the target population, and three (Hirvikoski & Blomqvist, 2015; Kronenberg et al., 2015; Montgomery et al., 2008) discussed this only in the limitations section. Other studies mitigated the impact of demographic imbalances by considering them in terms of analysis. Renty and Roeyers, (2007) used Pearson's correlations to screen for covariates prior to running regression analyses, Muniandy and colleagues (2021b) included gender as a covariate in mediation analysis, and two authors (Kronenberg et al., 2015; Oswald et al., 2018) used ANCOVA methods to control for demographic differences between autistic and control samples.

Procedures for data collection were described adequately in the majority of studies, but two (Montgomery et al., 2008; Renty & Roeyers, 2007) contained no information about how, where or when data was gathered. Whilst most studies provided a clear rationale for the choice of measures used, statistical assessment of the reliability of measures was variable. Two studies (Hirvikoski & Blomqvist, 2015; Montgomery et al., 2008) made no mention of reliability assessment for measures used; one study (Oswald et al., 2018) discussed reliability without assessing statistically.

With regard to study design and research setting, the QATSDD prioritises the clarity and transparency of reported details, and arguably is less sensitive to methodological limitations of specific designs (Fenton et al., 2015). Whilst all included studies scored highly on these criteria, all but one (Oswald et al., 2018) used a cross-sectional design, and none captured long-term outcomes. A majority of studies (n = 5) relied on recruiting participants from research contexts (schools, autism databases) or used convenience cluster sampling, while two (Hirvikoski & Blomqvist, 2015; Kronenberg et al., 2015) recruited from clinical contexts. More valid and reliable data might be obtained using epidemiological and random samples. The lowest scoring QATSDD item across studies concerned service user involvement in study design (item mean score 0.43, *SD* = 1.13), with only one study (Oswald et al., 2018) providing evidence to this effect.

Relative strengths of the papers included clear theoretical frameworks informing study aims, detailed description of research settings, good justification of analytical approach, and consideration of study limitations. No studies were excluded on the basis of quality assessment, but QATSDD item scores and methodological limitations were considered during narrative synthesis of findings.

Research Question 2: Definitions and measurement of resilience and coping

Definitions of resilience and coping

Despite considerable heterogeneity in the broader evidence base around ‘coping’ (Skinner et al., 2003), definitions of the construct showed a notable consistency across relevant studies (see Table 4). Four of the six studies exploring coping defined the construct in terms of the cognitive and behavioural strategies used by an individual to manage demands, with three (Khanna et al., 2014; Kronenberg et al., 2015; Muniandy et al., 2021b) referencing the same source in their definition (Folkman & Lazarus, 1980). The two remaining studies focused on coping self-efficacy, or the subjective perception of one’s own ability to cope with stressful situations.

Resilience was defined broadly in one study as the “qualities that contribute to positive adaptation in spite of the presence of risk factors or significant adversities”, and the authors emphasize the importance of both inter- and intra-personal factors in their

Table 4 *Definitions of resilience and coping across included studies*

Study	Construct explored (resilience / coping)	Definition and reference
Hirvikoski et al. (2015)	**Coping**	The individual's subjective perception of his or her ability to cope with the specific stressor, or perception of control, is crucial for the perception of distress (Karasek & Theorell, 1990)
Khanna et al. (2014)	**Coping**	Coping represents an individual's cognitive and behavioral attempt at managing stressful events (Folkman & Lazarus, 1980). Coping can be either problem-focused (also referred as 'adaptive coping') or emotion-focused (also referred as 'maladaptive coping'), with the former aimed at dealing with the problem and the latter aimed at regulating the emotions associated with the problem (Folkman & Lazarus, 1980).
Kronenberg et al. (2015)	**Coping**	Coping refers to the cognitive and behavioural efforts of individuals to manage their internal and external demands which are appraised as taxing or exceeding the resources of the individual (Folkman & Lazarus, 1980).
Montgomery et al. (2008)	**Resilience**	Resiliency may be defined as those qualities that contribute to positive adaptation in spite of the presence of risk factors or significant adversities (Masten, 1999)
Muniandy et al. (2021)	**Resilience, coping**	Resilience as a trait represents a constellation of attributes that connote general sturdiness, resourcefulness and flexibility, allowing one to thrive in the face of adversity (Connor & Davidson, 2003) Coping refers to the specific cognitive or behavioral strategies elicited in response to the demands of a stressful encounter, where the outcome may be positive or negative, depending on the effectiveness of the coping strategy utilized and contextual factors of the stressful encounter (Fletcher & Sarkar, 2013)
Oswald et al. (2018)	**Coping**	Coping self-efficacy (Bandura, 1994), or self-perceptions regarding one's own ability to cope effectively with life stressors and challenges
Renty & Roeyers (2007)	**Coping**	Coping (BC) refers to the cognitive and behavioral efforts family members employ to reduce or manage the demands on the family system (McCubbin & McCubbin, 1993)

conceptualisation (Montgomery et al., 2008). By contrast, the other paper approaches resilience from a ‘trait’ perspective, focusing on individual “attributes that connote general sturdiness, resourcefulness and flexibility, allowing one to thrive in the face of adversity” (Muniandy et al., 2021b).

Measurement of resilience and coping

All studies employed self-report quantitative measures of resilience and coping, and choice of measure varied considerably across studies with only one scale (The Brief COPE) used more than once. Characteristics and reliability statistics for measures used in included studies are presented in Table 5.

Two scales were used to measure resilience as a distinct construct. The Connor-Davidson Resilience Scale (CD-RISC 10; Campbell-Sills & Stein, 2007) is an abbreviated version of the original CD-RISC (Connor & Davidson, 2003), and comprises 10 items focusing on intra-individual attributes of resilience, or ‘hardiness’. A 5-point Likert scale measures endorsement of resilience traits such as ability to regulate emotion, optimism, self-efficacy, flexibility and cognitive focus under stress. Montgomery and colleagues (2008) chose to adapt The Resiliency Scales for Children and Adolescents (RSCA; Prince-Embury, 2008) for use with their sample of young autistic adults, making minor modifications to item wording with permission from the scale’s developers. In contrast to the CD-RISC 10, the RSCA operationalises resilience across three domains: Sense of Mastery, Sense of Relatedness, and Emotional Reactivity. Muniandy and colleagues (2021b) reported excellent reliability for the CD-RISC 10 in their sample of autistic adults (α = 0.93); while Montgomery and colleagues (2008) did not provide reliability statistics for their adapted version of the RSCA.

Table 5. *Description of resilience and coping measures used in included studies*

Measure	Target population	Mode of completion	Used in study	Subscales	No. of items	Cronbach's alpha
Connor-Davidson Resilience Scale (CD-RISC 10)	General population	Self-report Answered on a 5-point scale (0 = *not true at all* to 4 = *true nearly all the time*	(Muniandy et al., 2021b)		10	0.93[a]
The Resiliency Scales for Children and Adolescents	General population adolescents (15 – 18 years)[b]	Self-report Scoring information not reported	(Montgomery et al., 2008)	Sense of Mastery	[c]	[c]
				Sense of Relatedness	[c]	[c]
				Emotional Reactivity	[c]	[c]
Brief Coping Orientation to Problem Experiences	General population	Self-report Answered on a 4-point scale (1 = *I have not been doing this at all* to 4 = *I've been doing this a lot*	(Muniandy et al., 2021b)	Engagement coping	8	0.88[a]
				Disengagement coping	5	0.79[a]
			(Khanna et al., 2014)	Adaptive coping	16	0.77[a]
				Maladaptive coping[d]	12	0.73[a]
Ways of Coping Questionnaire[e]	General population	Self-report Answered on a 4-		Approach coping strategy	[c]	0.82[a]

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[a] Cronbach's alpha reported in a study sample with autism

[b] Minor modifications for older participants made to two items by study authors, with permission from scale creators

[c] Not reported in study

[d] Study authors removed two items relating to substance abuse in order to be sensitive toward study participants

[e] Study authors removed three items (14, 33, and 43) to improve the internal consistency of the subscales

		point scale (0 = *not used* to 3 = *used a great deal*	(Renty & Roeyers, 2007)	Avoidance coping strategy	[c]	0.64[a]
Perceived Stress Scale (Swedish version)	General population	Self-report Answered on a 5-point scale	(Hirvikoski & Blomqvist, 2015)	Distress	[c]	[c]
				Coping	[c]	[c]
Coping Self-Efficacy Scale	General population	Self-report Answered on an 11-point scale (anchor points: 0 = *cannot do at all*, 5 = *moderately certain can do*, 10 = *certain can do*)	(Oswald et al., 2018)	Use problem-focused coping	6	0.91[a]
				Stop unpleasant emotions and thoughts	4	0.91[a]
				Get support from friends and family	3	0.80[a]
Utrecht Coping List	General population	Self-report Answered on a 4-point scale (1 = *never* to 4 = *very often*	(Kronenberg et al., 2015)	Active problem solving	[c]	0.77[f], 0.82[g]
				Palliative reaction	[c]	0.58[f], 0.76[g]
				Avoidance	[c]	0.71[f], 0.73[g]
				Socialisation	[c]	0.83[f], 0.75[g]
				Passive reaction	[c]	0.70[f], 0.70[g]
				Expression emotions	[c]	0.65[f], 0.64[g]
				Reassuring thoughts	[c]	0.58[f], 0.70[g]

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[f] Cronbach's alpha reported in a study sample of patients with substance use disorder, with or without co-occurring autism and attention deficit hyperactivity disorder

[g] Cronbach's alpha reported in a study reference sample of non-autistic adults

Five scales were used to measure coping among the included studies. The Brief Coping Orientation to Problem Experiences (Brief COPE; Carver, 1997), a 28-item measure of coping styles, was used in two studies (Khanna et al., 2014; Muniandy et al., 2021b), with different factor structures applied in each. Khanna and colleagues (2014) used the structure applied by Meyer (2001), assessing coping styles across two subscales. The Adaptive Coping subscale incorporates attitudes and resources such as acceptance, humour, positive reframing and use of emotional support, while the Maladaptive Coping subscale includes items relating to avoidance-based or reinforcing tendencies like self-blame, disengagement, and substance abuse. Both subscales showed acceptable reliability (Adaptive α = 0.77; Maladaptive α = 0.73) in the study sample of autistic adults. The authors removed two items from the Maladaptive subscale relating to substance abuse out of sensitivity towards participants, but do not elaborate on how this may have affected psychometric properties of the Brief COPE in this sample. Muniandy and colleagues (2021b) draw instead upon their own previous factor analysis of the Brief COPE in a sample of autistic adults (Muniandy et al., 2021a), which may account for the superior reliability statistics achieved in their two subscales (Engagement α = 0.88; Disengagement α = 0.79).

The 66-item Ways of Coping Questionnaire (WOC; Folkman & Lazarus, 1988), used in one study (Renty & Roeyers, 2007), takes a similar approach by conceptualising coping along two strategy composites: Approach Coping and Avoidance Coping. The study authors removed three items (14, 33 and 43) in order to improve the internal consistency of the subscales, which remained variable in their sample of autistic adult males (Approach α = 0.82; Avoidance α – 0.64). One study (Hirvikoski & Blomqvist, 2015) assessed coping using the Swedish version of the Perceived Stress Scale (PSS; Cohen et al., 1983), a 14-item self-report measure comprising two subscales: *Distress* and *Coping*. The PSS *Coping* subscale measures endorsement of items such as “felt confident about your ability to handle your personal problems”, focusing specifically on an individual’s *perceived* coping ability. The study authors did not provide reliability statistics for the PSS in their sample. The Coping Self-Efficacy Scale (CSES; Chesney et al., 2006), used as an outcome measure in one RCT study (Oswald et al., 2018), is a 26-item measure of perceived ability to cope effectively with challenges. In the study sample of autistic adults, good to excellent reliability was demonstrated in each of the three subscales: Use problem-focused coping (α = 0.91), Stop unpleasant emotions and thoughts (α = 0.91) and Get support from friends and family (α = 0.80).

Finally, the Utrecht Coping List (UCL; Schreurs, 1993) was used to measure coping strategies in a sample of autistic adults with diagnoses of substance use disorders (Kronenberg et al., 2015). The UCL contains 47 items making up seven subscales: active problem solving, palliative reaction (distraction, substance use), avoidance, socialisation (seeking support from others), passive reaction (rumination, withdrawal), expressing emotions, and reassuring thoughts. Scores are summed to give an indication of an individual’s predominant coping styles. Reliability statistics in this study are provided only for a normative reference group and the combined patient sample, which included patients with substance use disorder with and without co-occurring autism and attention- deficit hyperactivity disorder (Kronenberg et al., 2015). Subscale reliability statistics showed considerable variability in both the patient group (α = 0.58 to 0.83), and the reference group (α = 0.64 – 0.82).

Research Question 3: Factors associated with resilience and coping in autistic adults

Study characteristics

A summary of study characteristics and primary relevant findings is presented in Tables 6 and 7. All included studies were conducted within the last 15 years, and only two papers were published earlier than 2014. Studies were conducted across six different countries, with two from the USA and one each from Sweden, The Netherlands, Belgium, Canada and Australia.

Descriptive, cross-sectional designs were used for all but one of the studies, which reported on a Randomised Controlled Trial (RCT) of an intervention promoting social skills and coping self-efficacy in a sample of autistic adults (Oswald et al., 2018). Participant samples were recruited from community settings in a majority of studies, frequently through the use of autism registries, advocacy groups, service user organisations, universities, clinics and social media channels. In two studies, participants were recruited from clinical settings, including a tertiary unit for neurodevelopmental disorders and an addiction care centre. Samples sizes showed considerable diversity, ranging from 20 to 291 and with a median of 25. Whilst all but one study recruited a majority of male participants, four had samples including 36-40% female participants.

Coping styles of autistic adults

Two studies directly compared measures of coping between autistic and non-autistic samples. Using the Coping subscale of the PSS as a broad measure of perceived coping, Hirvikoski and Blomqvist (2015) found that autistic adults reported significantly higher perceived

Table 6 *Characteristics of participants in included studies*

Authors (year published)	**N (autistic)**	**Age range (years)**	**Mean age (SD) in years**	**Male : female ratio (%)**	**Comorbid diagnosis**	**Comparison /control**
Khanna et al. (2014)	291	18-65	30.75 (11.88)	60.8 : 39.2	Other mental illness (36.8%)	None
Hirvikoski & Blomqvist (2015)	25	Not reported	34.08 (7.52)	60 : 40		28 non-autistic adults
Kronenberg et al. (2015)	31	Not reported	40	94 : 6	SUD*: 100%	SUD* alone (n = 50); SUD + ADHD** (n = 41)
Renty & Roeyers (2007)	21	35-54	43.52 (4.98)	100% male		None
Montgomery et al. (2008)	20	16-21	17.8 (1.2)	100% male		None
Oswald et al. (2018)	25	18-38	24.9 (6.1)	64 : 36	Anxiety: disorder (12%), borderline levels (12%), clinical levels (4%)	16 autistic adults (waitlist control),
Muniandy et al. (2021)	78	27.17-83.58	46.60 (12.67)	38.5 : 53.8 : 7.7 (other)	PHQ-9 Major depression (48.6%), DSM-5 GAD-D anxiety (43.1%)	None

*SUD = substance use disorder; **SUD + ADHD = substance use disorder with co-occurring attention deficit hyperactivity disorder

Table 7 *Characteristics and primary relevant findings of included studies*

Authors (year published)	**Location**	**Design**	**N (autistic)**	**Resilience / coping measures***	**Aim(s)**	**Main findings**
Khanna et al. (2014)	USA	Quantitative, cross-sectional	291	Brief COPE	To determine factors (including coping style) associated with physical and mental health-related quality of life (HRQOL) among autistic adults	Physical HRQOL was negatively correlated with maladaptive coping in autistic adults ($r = -0.216$, $p < 0.01$). Mental HRQOL was negatively correlated with autism severity ($r = -0.204$, $p < 0.01$) and maladaptive coping ($r = -0.355$, $p < 0.01$). In regression analyses, greater use of maladaptive coping was a significant negative predictor of physical HRQOL ($\beta = -0.298$, $p = 0.011$), and mental HRQOL ($\beta = -0.653$, $p < 0.001$). Adaptive coping did not emerge as a significant predictor in either model.
Hirvikoski & Blomqvist (2015)	Stockholm, Sweden	Quantitative, cross-sectional	25	PSS	To determine whether autistic traits are correlated with both perceived stress and perceived coping ability in autistic adults	Autistic adults scored significantly higher than non-autistic adults on measures of perceived stress ($t(40.01) = 3.40$, $p = 0.002$, $d = 0.95$) and perceived coping ability ($t(38.37) = 3.38$, $p = 0.002$, $d = 0.94$). In the combined sample, autistic traits were positively correlated with perceived stress ($r = 0.64$, $r^2 = 0.41$, $p < 0.001$) and poor perceived coping ability ($r = 0.63$, $r^2 = 0.40$, $p < 0.001$)
Kronenberg et al. (2015)	The Netherlands	Quantitative, cross-sectional	31	UCL	To explore which coping styles are displayed by adult substance use disorder	Compared to the SUD** group, SUD + ASD patients reported greater use of Passive Reaction ($d = -0.534$, $p = 0.22$) and less use of Reassuring Thoughts ($d = 0.560$, $p = 0.017$). Compared to the SUD + ADHD

					patients with and without co-occurring ADHD or autism; to compare coping styles with general population reference norms	group, SUD + ASD patients reported greater use of Passive Reaction, ($d = 0.511$, $p = 0.033$), and less use of both Reassuring Thoughts ($d = −0.713$, $p = 0.004$) and Expression of Emotions ($d = 0.511$, $p = 0.049$). Compared to population reference norms, SUD + ASD patients showed greater use of Passive Reaction ($d = -1.815$, $p < 0.01$), Palliative Reaction ($d = -1.200$, $p < 0.01$) and avoidance ($d = -0.987$), $p < 0.01$).
Renty & Roeyers (2007)	Ghent, Belgium	Quantitative, cross-sectional	21	WOC	To determine whether individual (psychosocial distress) and marital adaptation are related to problem-focused and avoidant coping strategies, social support, and autistic traits in autistic adult males	In bivariate correlation analysis, avoidance coping was positively correlated with psychosocial distress in autistic adult male partners ($r = 0.445$, $p < 0.05$). In regression analyses, coping strategy use was not a significant predictor of psychosocial distress over and above autism specific traits and social support.
Montgomery et al. (2008)	Alberta and Manitoba, Canada	Quantitative, cross-sectional	20	RSCA	To examine resilience as it relates to trait- and ability-based models of Emotional Intelligence in young adults with Asperger's syndrome	Trait-based Emotional Intelligence was correlated positively with the Sense of Relatedness subscale ($r = 0.644$, $p = .02$) and negatively with the Emotional Reactivity subscale ($r = –0.626$, $p = .003$) of the Resiliency Scales. The Stress Management subscale of Emotional Intelligence was negatively correlated with the Emotional Reactivity scale of the Resilience Scales ($r = –0.829$, $p < .001$). No statistically significant correlations were found between Ability-based Emotional Intelligence and resilience.

Oswald et al. (2018)	Sacramento, California, USA	Quantitative, RCT	25	CSES	To investigate the acceptability and efficacy of the Acquiring Career, Coping, Executive control, Social Skills (ACCESS) Program for young autistic adults	Although participants in the treatment group reported significant increases in measures of global adaptive functioning and self-determination, no significant group differences were found between baseline and post-treatment total coping self-efficacy scores. Participants in the treatment group reported significantly higher scores on the "Get support from friends and family" subscale of the CSES (change in mean score of 3.6, 95% CI 0.7-6.5, $p = 0.02$)
Muniandy et al. (2021)	Australia	Quantitative, cross-sectional	78	CD-RISC 10, Brief COPE	To examine the associations between trait resilience and coping strategy use; to explore the potential mediating role of coping strategy in the resilience-mental health relationship, in autistic adults.	Correlation analysis showed that Disengagement coping was positively associated with PHQ-9 depression scores ($r = 0.703$, $p < 0.01$), DSM-5 GAD-D anxiety scores ($r = 0.634$, $p < 0.01$), and negatively associated with WEMWBS wellbeing scores ($r = -0.703$, $p < 0.01$). Engagement coping was significantly positively correlated with wellbeing ($r = 0.425$, $p < 0.01$) only. Autistic traits were negatively correlated with engagement coping ($r = -0.266$, $p < 0.05$) and resilience ($r = -0.347$, $p < 0.01$) but not significantly related to disengagement coping. Resilience scores were negatively correlated with depression ($r = -0.369$, $p < 0.01$), anxiety ($r = 0.494$, $p < 0.01$) and positively with wellbeing ($r = 0.532$, $p < 0.01$). Resilience was correlated positively with the use of engagement coping strategies ($r = 0.471$, $p < 0.01$), and negatively with the use of disengagement strategies ($r = -0.443$, $p < 0.01$).

Mediation analysis model 1 showed significant indirect effects of resilience on depression through disengagement coping (β = -0.245, *SE* = 0.067, BCa 95% CI [-0.377, -0.107]). The variance accounted for in PHQ-9 depression scores by CD-RISC 10 resilience scores increased from $R^2 = 0.144$ to $R^2 = 0.491$ when disengagement coping was added as a mediator. The direct effect of resilience on depression was no longer significant at this point, indicating full mediation.

Model 2 showed a significant indirect effect of resilience on anxiety through disengagement coping (β = -0.197, *SE* = 0.071, BCa 95% CI [-0.351, -0.073]), with an increase of variance in DSM-5 GAD-D scores from $R^2 = 0.256$ to $R^2 = 0.436$ when disengagement coping was added as a mediator in the model.

Model 3 a showed significant indirect effect of resilience on wellbeing through disengagement coping (β = 0.321, *SE* = 0.082, BCa 95% CI [0.140, 0.471]) and engagement coping (β = 0.120, *SE* = 0.058, BCa 95% CI [0.028, 0.256]). The variance explained in WEMWBS increased from $R^2 = 0.294$ to $R^2 = 0.610$ when both mediators were added. The direct effect of resilience on wellbeing was no longer significant at this point, indicating full mediation.

* Brief COPE = Brief Coping Orientation to Problem Experiences (Meyer, 2001); PSS = The Perceived Stress Scale (Coping subscale) (Cohen et al., 1983); UCL = Utrecht Coping List (Schreurs, 1993); WOC = The Ways of Coping questionnaire (Folkman, 2013); RSCA = Resiliency Scales for Children and Adolescents (adapted) (Prince-Embury, 2008); CSES = Coping Self-Efficacy Scale (Chesney et al., 2006); CD-RISC 10 = The Connor-Davidson Resilience Scale (Campbell-Sills & Stein, 2007) ** SUD = substance use disorder; ** SUD = substance use disorder alone; SUD + ASD = autism with co-occurring substance use disorder; SUD + ADHD = substance use disorder with co-occurring attention deficit hyperactivity disorder

problems with coping than ‘neurotypical’ adults ($t(38.37) = 3.38$, $p = 0.002$, $d = 0.94$), as well as higher levels of distress ($t(40.01) = 3.40$, $p = 0.002$, $d = 0.95$). Significant positive correlations were also found between severity of autistic traits, and both levels of distress ($r = 0.64$, $r^2 = 0.41$, $p < 0.001$) and coping self-efficacy problems ($r = 0.63$, $r^2 = 0.40$, $p < 0.001$). The quality of this study (QATSDD rating 59.52%, moderate range) was impacted by a relatively small sample size, and since the authors failed to report reliability statistics for the PSS, findings must be interpreted with caution.

Kronenberg and colleagues (2015) explored the specific coping styles of substance use disorder (SUD) patients, comparing samples with co-occurring autism, ADHD and SUD alone. Autistic adult patients were found to use more ‘passive reaction’ or avoidant coping strategies (rumination, withdrawing, retreating, pondering, incapacity to act) in the face of challenges than both the SUD+ADHD ($d = 0.511$, $p = 0.033$) and the SUD alone patients ($d = -0.534$, $p = 0.22$). Autistic patients also reported significantly less use of ‘reassuring thoughts’ (self-encouragement, reassurance) than the SUD+ADHD group ($d = −0.713$, $p = 0.004$) and the SUD group ($d = 0.560$, $p = 0.017$), and less coping by ‘expression of emotion’ (annoyance, anger, letting off steam) than the SUD+ADHD group ($d = 0.511$, $p = 0.049$). Compared to population reference norms, SUD + ASD patients showed greater use of Passive Reaction ($d = -1.815$, $p < 0.01$), Palliative Reaction ($d = -1.200$, $p < 0.01$) and Avoidance ($d = -0.987$), $p < 0.01$). Study quality was in the moderate range (QATSDD rating 61.90%) owing to a small sample size, lack of clear procedural recruitment data and questionable appropriateness of measures used. Results are likely to have been affected by relatively low internal consistency in certain subscales of the UCL coping measure in the autistic sample ($\alpha = 0.58$ to 0.83)

Impact of different coping styles on outcome in autistic adults

Included studies reported a number of associations between different coping styles and various mental health outcomes in autistic adult samples. The use of 'maladaptive' coping styles such as disengagement, denial, self-blame, substance abuse and distraction were found to significantly predict lower mental ($\beta = -0.653$, $p < 0.001$) and physical ($\beta = -0.298$, $p = 0.011$) health-related quality of life (HRQOL) in a large-scale study of 291 autistic adults in the USA (Khanna et al., 2014). Muniandy and colleagues (2021b) detected similar associations: disengagement coping was found to be positively correlated with symptoms of depression ($r = 0.703$, $p < 0.01$) and anxiety ($r = 0.634$, $p < 0.01$), and negatively associated with wellbeing ($r = -0.703$, $p < 0.01$). Whilst both studies used the Brief COPE, different factor structures and subscales were used in analysis, which may account for differences in effect sizes reported. Muniandy and colleagues (2021b) reported superior reliability statistics for their subscales ($\alpha = 0.79$ to 0.88), which were drawn from a validation study with autistic adults (Muniandy et al., 2021a). Whilst both studies achieved relatively high QATSDD scores, Khanna and colleagues (2014) recruited a larger sample size for their study (n = 291). Broadly consistent with these findings, a study exploring the impact of coping styles and social support on individual and marital adaptation in autistic males found the use of 'avoidance' coping strategies to be associated with higher levels of psychosocial distress ($r = 0.445$, $p < 0.05$; Renty & Roeyers, 2007). This study achieved a slightly lower QATSDD rating (69.05%), owing to decreased sample size and representativeness.

Notably, whilst maladaptive and avoidant coping strategies were associated with *negative* outcomes in these studies, engagement strategies were not consistently correlated with positive outcome. No significant associations were found between engagement coping and HRQOL (Khanna et al., 2014) or levels of psychosocial distress (Renty & Roeyers, 2007), whilst Muniandy and colleagues (2021b) found an association with wellbeing only (r

= 0.425, $p < 0.01$) only. These findings may also be influenced by variable reliability in subscales of measures used. Renty and Roeyers (2007), for example, reported Cronbach's alphas of 0.82 for the Approach subscale of the Ways of Coping questionnaire, and 0.64 for the Avoidance subscale. These studies varied in choice of coping measure and approach to statistical analysis, which limits scope for direct comparison. Despite these differences, it is notable that the direction of relationships reported are broadly consistent across the studies.

Factors associated with resilience

Muniandy and colleagues (2021b) found that autistic traits as measured by the AQ-Short (Hoekstra et al., 2011) were negatively correlated with CD-RISC 10 resilience scores ($r = -0.347$, $p < 0.01$) in their sample of autistic adults. Both scales demonstrated strong reliability in this sample ($\alpha = 0.86 – 0.93$).

Montgomery and colleagues (2008) explored the role of Emotional Intelligence (EI) on resilience in a sample of young autistic adults. The construct of EI is operationalised across two sub-domains. 'Trait-based' EI is defined as "an array of non-cognitive capabilities, competencies, and skills that influence one's ability to succeed in coping with environmental demands and pressures" (Bar-On, 1997). Trait-based EI focuses on behavioural rather than cognitive aspects of emotional intelligence, and is measured by the Bar-On Emotional Quotient Inventory (Newsome et al., 2000), a self-report measure of emotionally and socially intelligent behaviour (Bar-On, 1997). By contrast, 'Ability-based' EI describes the higher-order cognitive strategies involved in identifying, appraising and regulating emotions (Mayer et al., 2000), and is measured by the Mayer-Salovney-Caruso Emotional Intelligence Test (MSCEIT; Mayer et al., 2002). In the absence of a control group, the study compared outcome data from a sample of 20 male autistic adults to previously published population norms. Trait-based Emotional Intelligence was found to be correlated positively with the Sense of Relatedness subscale ($r = 0.644$, $p = .02$) and negatively with the Emotional Reactivity subscale ($r = –0.626$, $p = .003$) of the Resiliency Scales. The Stress Management subscale of Emotional Intelligence was negatively correlated with the Emotional Reactivity scale of the Resilience Scales ($r = –0.829$, $p < .001$), and no statistically significant correlations were found between ability-based EI and resilience.

The quality rating of this study (57.14%) was the lowest of the included studies, suffering from a small and unrepresentative sample (n = 20, 100% male) and a lack of procedural information reported. The authors made alterations to the RSCA measure of resilience, and reliability statistics of subscales was not declared, limiting the interpretation of reported findings. In order to mitigate the impact of small sample size, the authors adopted a conservative alpha value of $p < .01$, and this may have resulted in false negative findings around the association between ability-based EI and resilient outcomes.

Interactions between coping style and resilience

One study (Muniandy et al., 2021b) examined the association between 'trait' resilience and use of coping strategy, hypothesising a mediating role of coping style in the relationship between resilience and mental health outcomes in a sample of autistic adults. CD-RISC 10 resilience scores were negatively correlated with depression ($r = -0.369$, $p < 0.01$), anxiety ($r = 0.494$, $p < 0.01$) and positively with wellbeing ($r = 0.532$, $p < 0.01$). Resilience was also correlated positively with the use of engagement coping strategies ($r = 0.471$, $p < 0.01$), and negatively with the use of disengagement strategies ($r = -0.443$, $p < 0.01$) as measured by the Brief-COPE. Moreover, the relationship between resilience and mental health outcomes was mediated by coping strategy use, with full mediation observed in the models of depression ($\beta = -0.245$, $SE = 0.067$, BCa 95% CI [-0.377, -0.107]) and wellbeing ($\beta = 0.321$, $SE = 0.082$, BCa 95% CI [0.140, 0.471]), and partial mediation in the model of anxiety (β = -0.197, *SE* = 0.071, BCa 95% CI [-0.351, -0.073]). Specifically, use of disengagement coping mediated associations between resilience and all three mental health outcomes, whilst engagement coping mediated the resilience-wellbeing (β = 0.120, *SE* = 0.058, BCa 95% CI [0.028, 0.256]) relationship only. This study achieved a 'high quality' QATSDD rating of 78.57%, and while the sample size (n = 78) was already large relative to other included studies, the authors employed bootstrapping methods to increase the robustness of more complex mediation analysis. However, sample representativeness was impacted by a lack of independent verification of autism diagnosis which may limit the reliability of findings to some degree.

Interventions targeting coping style in autistic adults

A single intervention study investigated the acceptability and efficacy of a program designed to enhance coping and social skills in autistic adults using an RCT design (Oswald et al., 2018). The Acquiring Career, Coping, Executive control, Social Skills (ACCESS) program is a group intervention adapted by researchers in the USA specifically for young autistic adults. Whilst the intervention targets a range of outcomes across several domains, it incorporates a specific module on coping with stress and anxiety using CBT-based strategies. Significant improvements were found in the treatment group compared with the wait-list control group on measures of global adaptive functioning and self-determination. Whilst no significant effect was found for composite scores on the Coping Self-Efficacy Scale (CSES), participants receiving the ACCESS intervention did report a significant increase in coping self-efficacy relating specifically to accessing support from family and friends (change in mean score of 3.6, 95% CI 0.7-6.5, p = 0.02). The study achieved the highest QATSDD quality rating overall (80.95%), with CSES subscales demonstrating good to excellent reliability (α = 0.80 – 0.91) and detailed description of procedures and service user involvement provided. However, the validity of findings is limited by a relatively small sample size (treatment n = 25, control n = 16) and somewhat reduced questionnaire response rate. Trial assessors were not blinded to treatment, and no long-term follow up data was gathered to measure post-treatment gains.

Discussion

Quality and limitations of studies

Findings reported in the included studies were frequently limited in their generalisability by samples lacking in size and representativeness. Whilst several studies demonstrated sufficient statistical power to reveal robust associations between severity of autism traits, specific coping strategy use and impact on mental health outcomes, it is likely that other relationships went undetected due to type II error. Samples in the included studies were affected by overrepresentation of participants who were male and highly educated, suggesting a need for future research to prioritise underrepresented groups. Whilst recent studies have suggested male-to-female ratios of 3:1 among autistic people (Loomes et al., 2017), controversy persists around diagnostic gender bias, and this may be perpetuated by unrepresentative sampling practices in research.

With the exception of one RCT, all included studies were cross-sectional by design, perhaps reflecting the nascent status of this growing evidence base. For this reason, causality cannot be inferred from reported associations between resilience traits, coping styles and outcomes for autistic adults. Recurrent findings suggested the benefits of engagement and approach-oriented coping strategies for autistic adults, but it may be that individuals with greater psychological wellbeing have greater capacity to enact these strategies. Similarly, whilst individuals showing higher trait resilience report less psychological distress, it is possible that those with symptoms of anxiety and depression may view themselves as less resilient. Long-term follow up data for interventions targeting resilience and coping skills may be particularly important for autistic adults, who may take longer to enact and embed behavioural skills than their non-autistic peers (Montgomery et al., 2008).

Specific findings

Variation in the measurement and conceptualisation of coping styles creates challenges for comparing findings in the included studies (Compas et al., 2001). This problem is not unique to coping research in autism. In a review of coping classification systems, Skinner and colleagues (2003) identified over 100 category systems and measures, highlighting the obstacles this creates in comparing and aggregating results across different studies. Conceptual overlap between categories of different coping measures was frequently observed, and reliability of subscales varied considerably. Despite these limitations, some broad trends were identified across included studies.

The most robust and consistent findings across the included studies concern the associations between broad dimensions of coping – engagement and disengagement styles – and mental health outcomes. Coping strategies focused on avoidance or disengagement from a specific challenge (denial, distraction, self-blame) were consistently correlated with high levels of psychological distress and low levels of wellbeing. These findings are consistent with the broader evidence base around coping, which suggests strong associations between avoidant coping styles and mental health difficulties (Görgen et al., 2014; Hedlund et al., 2010). Weaker associations – or no relationships at all – were found between approach coping styles (problem-solving, acceptance, reappraisal) and positive mental health outcomes.

Insufficient evidence is available to establish the reasons for this. It is possible that autistic adults employ idiosyncratic adaptive coping strategies that are not adequately identified by existing measures, most of which have been designed with general population samples in mind. The appropriateness and validity of generic psychometric scales has been raised as a concern in other areas of autism research (Kerns et al., 2015), with some authors calling for adapted measures to be used in future studies (Cassidy et al., 2018). Others have hypothesised a broader issue with the reliability of psychometric measurement in autistic individuals, some of whom may struggle to distinguish between qualitative item responses like ‘sometimes’ and ‘often’ due to cognitive inflexibility and concrete thinking styles (Kronenberg et al., 2015). Whilst reported reliability statistics of measures used in the included studies were generally acceptable, there was very little consistency in approaches to measuring coping and resilience, making direct comparison of findings impossible. Indeed, a limitation of the literature around coping and resilience in autism more broadly is the lack of psychometric measures validated for use in this population. Only in the last two years have relevant validation studies emerged (Muniandy et al., 2021a; Hwang et al., 2020), both of which were excluded from the present review due to inconsistency in sampling methodology and diagnostic procedure. It is suggested that future studies employ measurement tools that have more recently been validated in autistic adult samples, such as the Brief COPE (Muniandy et al., 2021a) and the CD-RISC 10 (Hwang et al., 2020). Cross-validation of self-report questionnaire data with objective report would facilitate more robust findings in line with the broader coping and resilience evidence base (Windle et al., 2011).

Another possibility is that approach coping strategies (as defined by generic measures) are less effective for the kinds of challenges faced by autistic people. Findings from the broader coping literature are equivocal: studies with some health populations have shown strong negative associations between active coping and psychological distress ((Sharkansky et al., 2000), while others have shown weak correlation or none at all (Morris et al., 2018). Early theories of coping suggested that active orientations like problem-solving are only effective in situations under which an individual has some degree of control (Lazarus, 1993), and it may be that the core difficulties associated with autism are felt to be more intrinsic and less malleable.

Resilience remains a particularly underdeveloped area of research in autistic adults, with only two relevant papers meeting the inclusion criteria for this review. As it stands, the construct of resilience in autistic adults as explored by existing studies is very narrowly defined in comparison to the broader resilience literature. Included studies operationalised resilience primarily as a collection of individual traits, in contrast to much of the contemporary literature which focuses on dynamic, interpersonal and context-specific processes (Masten, 1999; Ungar et al., 2013). Considering resilience in its ecological context is in keeping with the social model of disability (Dowling & Dolan, 2001) and can inform interventions to leverage sources of support around individuals in promoting positive outcome (Fergus & Zimmerman, 2004). Given that autistic adults may experience more stressful life events as well as more perceived stress (Bishop-Fitzpatrick et al., 2017), the paucity and limitations of existing resilience studies is concerning.

More encouraging are the reported emergent findings on coping style as a mechanism through which resilience predicts mental health in autistic adults. Similar findings have been reported in research with other health populations (Thompson et al., 2018) which suggest that the impact of resilience on mental health outcomes is mediated positively by active coping and negatively by avoidant coping. Future research should seek to replicate these findings in larger and more representative samples, using longitudinal methodology to elucidate the directionality of previously reported associations.

Limitations and implications

The findings of this systematic review should be interpreted in the context of several limitations. The search strategy and terms for this review were designed so as to achieve high sensitivity and low specificity in records identified, and indeed the number of papers initially returned through database searches was relatively high (n = 9132). Despite this, it is notable that the eligibility criteria led to the exclusion of many relevant papers, and that this was in part due to considerable variation in sampling methodology, definition of population, and diagnostic procedure. Whilst rigour and adherence to protocol in the systematic review process is important, the limitations of applying strict eligibility criteria in this instance should be also acknowledged. The existing evidence base was found to be characterised by inconsistent methodological and sampling procedures, leading to challenges in the systematic synthesis of findings. Relevant studies with important findings were excluded on this basis, and it is recommended that future studies prioritise sample representativeness and clarity in diagnostic verification. Secondly, since eligibility criteria specified peer-reviewed papers for inclusion to improve the quality of evidence, it is possible that publication bias occurred from excluded relevant studies. Thirdly, to limit sample heterogeneity, studies including participants with co-occurring diagnoses of intellectual disability (ID) were excluded from this review. It is estimated that at least one third of autistic people also have an ID diagnosis (Baio et al., 2018), and the reported findings cannot be generalised to this substantial sub-group. Fourthly, the method of assessing study quality was limited to ratings using the QATSDD tool. Whilst the QATSDD enables comparison of quality between diverse study designs, it has been criticised for lack of sensitivity to certain elements of quantitative methodologies such as randomisation bias, and for lack of item weighting (Fenton et al., 2015). Finally, while search terms were designed with high sensitivity in mind, it is possible that studies exploring distinct but related constructs – such as emotion regulation – would also contribute useful findings to the evidence base around coping and resilience.

These limitations notwithstanding, the results presented in this review have several implications for future research and clinical practice. Psychological interventions for autistic adults should aim to alleviate stress by reducing maladaptive coping strategies, which are associated with poor mental health outcomes and compromise trait resilience. Such strategies might include avoidance, denial, self-blame, and substance abuse, but it should be remembered that the efficacy of specific strategies is context dependent. The promotion of engagement coping strategies may also be beneficial for autistic adults, although further evidence is needed to support their role in decreasing distress. Increased use of problem-solving, cognitive reappraisal and acceptance may all improve outcomes for autistic adults, although future studies should aim to quantitatively evaluate the benefit of autism-specific coping strategies like support from 'atypical' friends and engaging in special interests. Coping research in autistic adults should aim to use validated measures such as the Brief COPE to aid comparison of findings across studies. The only validated measure of resilience in autistic adults is the CD-RISC 10, which assesses trait resilience only. Future studies should aim to validate measures tapping inter-individual domains of resilience such as social support, to aid the evaluation of novel interventions targeting resilience in this population.

Conclusions

This systematic review aimed to identify and synthesize findings from the existing evidence base on resilience and coping in autistic adults. Whilst only a small number of studies met the eligibility criteria for inclusion in the final review, the quality of these papers and the concordance between some findings suggest the emergence of a promising field of research. It is hoped that the present review will have utility in assessing the evidence base as it stands, and in guiding future research to complement existing findings.

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Psychological Wellbeing of Autistic Adults in the UK During the COVID-19 Pandemic

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(word count = 8000)

Prepared according to instructions for *Journal of Autism and Developmental Disorders* (see Appendix A)

Abstract

Social restrictions during the COVID-19 pandemic have led to an increase in mental health difficulties, but the impact on autistic adults is not well understood. 124 autistic adults and 51 non-autistic adults completed mental health measures over three months during the first wave of COVID-19. Linear mixed model analysis revealed increased levels of depression, anxiety, and decreased wellbeing in the autism group. Hierarchical regression analysis indicate that higher age and higher educational status significantly predicted greater increases in psychological distress over time in the autism group only. Policymakers and mental health services should consider risk factors unique to autistic adults during COVID-19. Further research is recommended to explore the underlying causes of vulnerability to stress during pandemic conditions.

Keywords

autism; adult; COVID-19; pandemic; mental health

Psychological Wellbeing of Autistic Adults in the UK During the COVID-19 Pandemic

The COVID-19 pandemic continues to create significant disruption and adversity in the lives of citizens worldwide. Since the World Health Organisation declared the crisis a global pandemic in March 2020 (World Health Organization, 2021a), governments have implemented varying degrees of social restrictions to mitigate the impact of widespread infection. Although lockdowns and social distancing measures have proven effective in reducing community transmission (Chaudhry et al., 2020), the secondary harm associated with these interventions has only gradually become more apparent (Zavlis et al., 2021).

Mental health impact of COVID-19

A wide range of empirical studies have now evidenced the negative mental health impacts of COVID-19 restrictions (Tsamakis et al., 2021; Xiong et al., 2020). Large-scale longitudinal studies have monitored the trajectory of mental health outcomes over the course of the pandemic and identified risk factors in general population samples (Pierce et al., 2021; University College London, 2021). Higher levels of anxiety, depression, and traumatic stress were reported during initial lockdowns relative to pre-pandemic levels (Huang & Zhao, 2020; Rajkumar, 2020), including in the UK (Shevlin et al., 2020). COVID restrictions have been associated with elevated levels of loneliness (McGinty et al., 2020), sleep disturbance (Huang & Zhao, 2020), and suicidal thoughts and behaviours (Ammerman et al., 2021). Data collected by the Office for National Statistics over the course of the pandemic has suggested that levels of anxiety and low mood in the population have been highest immediately after the imposition of national lockdowns (ONS, 2020). Symptoms of depression and anxiety in adults during the pandemic have been associated with younger age, lower socio-economic status, fewer educational qualifications, and coming from an ethnic minority background (University College London, 2021).

Early in the pandemic, it was suggested that specific groups may show increased vulnerability to the impacts of COVID restrictions. A position paper published in April 2020 gathered views from leading experts and people with lived experience, specifying the mental health consequences of lockdown for vulnerable groups as an immediate priority (Holmes et al., 2020). Recommendations were made for a co-ordinated approach to research into the psychological impact of COVID-19, including capturing mental health outcome data "in as close to real-time as possible", as well as identification of resilience and coping factors to inform ongoing intervention. Similar recommendations were made following previous pandemic outbreaks, with the suggestion that demographic variables like age, gender and socio-economic status may constitute significant risk and protective factors (Douglas et al., 2009). Disability has been highlighted as one of the factors most strongly associated with high levels of anxiety during the current pandemic (Office for National Statistics, 2020a), though the extent to which this reflects pre-existing disparities is unclear.

Experience of autistic adults and COVID-19

There is reason to believe that COVID-19 conditions may present particular challenges to autistic people, who can struggle with unexpected changes in routine (Wallace et al., 2016) and show decreased tolerance of uncertainty compared to non-autistic individuals (Maisel et al., 2016). Autism is a neurodevelopmental condition affecting how people perceive and interact with the world around them. Autistic people face everyday challenges with social interaction and social communication, and often show restricted or repetitive patterns of behaviour and interests (American Psychiatric Association, 2013).

Prevalence of autism in the UK general population is estimated to be around one in every 100 people (Brugha et al., 2011). Research from before the pandemic consistently found that autistic people are at elevated risk of adverse psychological outcomes (Kirsch et al., 2020; Lever & Geurts, 2016; Lugo-Marín et al., 2019), including higher rates of comorbid depression and anxiety (Hollocks et al., 2019; Uljarević et al., 2020). A recent systematic review reported prevalence rates of 20% for anxiety disorders and 11% for depression in autistic samples, compared with 7.3% and 4.7% respectively in the general population (Lai et al., 2019). Although overlap in diagnostic criteria may in part account for the reported co-occurrence of autism and psychiatric disorders (Halim et al., 2018), it has also been suggested that the core social difficulties associated with autism may precipitate the onset of psychological distress (Kerns et al., 2017). For example, previous research has indicated that young autistic people may experience anxiety specifically in relation to sensory sensitivity, fears around access to special interests, and in anticipation of changes to routine (Kerns et al., 2014). Autistic people face pre-existing barriers to accessing healthcare (Nicolaidis et al., 2015), and this may be further exacerbated by a general increase in demand for mental health services during the pandemic (World Health Organization, 2020).

Consistent with autism research more broadly, studies exploring the impact of COVID-19 conditions on children, families and carers appeared to take priority in the early stages of the pandemic. However, since the end of 2020, research focusing more on autistic adults has begun to emerge. A frequent finding has been the elevated risk of poor mental health outcomes in the autistic adult population during COVID (Bal et al., 2021; Lugo-Marín et al., 2021; Oomen et al., 2021). Much of the published evidence relates to early pandemic experiences, when social distancing measures required that data collection be carried out remotely. Using a cross-sectional survey design, researchers from the United Kingdom asked 51 autistic adults to rate the impact of COVID-19 measures on their mental health (Davidson et al., 2021); 35% of participants reported that their mental health had gotten “a little worse”, and 37% “a lot worse” (Davidson et al., 2021). Acknowledging that a need for rapid data collection had compromised the robustness of their design, the authors called for future research that included more representative samples as well as non-autistic comparison groups.

Findings around the effect of age on the relationship between COVID-19 and psychological distress in autistic adults have been equivocal. A US-based online survey of 396 autistic adults found that between March and June 2020 younger adults (aged 18-39), as well as females and those with personal experience of COVID-19, were at increased risk of psychological distress (Bal et al., 2021). Whilst these findings are broadly consistent with those from general population samples (University College London, 2021), the authors noted a higher proportion (45%) of autistic adults reporting psychological distress in the “moderate to severe range” than had been found in the general population (10.7%) using equivalent measures (Bal et al., 2021). Researchers from Spain explored the psychological impact of lockdown on autistic patients of all age groups at a single time point in May 2020, using historical medical records to draw comparisons with equivalent pre-pandemic measures (Lugo-Marín et al., 2021). Standardised clinical questionnaires covering a range of psychological symptoms were completed by a sample that included 35 autistic adult patients. In contrast to other research, findings indicated a broad improvement in psychological wellbeing following lockdown, with younger adults showing significantly greater improvement over time compared with older adults (Lugo-Marín et al., 2021).

Finally, a large-scale mixed-methods study exploring the psychological impact of COVID-19 on autistic adults was undertaken across three European countries including the United Kingdom (Oomen et al., 2021). 1044 adults, 613 of whom self-reported a diagnosis of autism, completed an online questionnaire including measures of depression and anxiety symptoms between April and May 2020. Results suggested significantly higher symptoms of psychological distress, as well as functional impact, in the autism group, with many participants also reporting a reduction in mental health support following the imposition of lockdown. The authors emphasised a need for further research focusing on the longer-term impact of lockdown on autistic adults.

Despite the alarming findings of increased risk for autistic people during COVID-19, it has also been suggested that unique resilience and protective factors may exist in this population. Due to existing challenges in social communication, a reduction in social contact (Davidson et al., 2021; Oomen et al., 2021) and environmental requirements (Lugo-Marín et al., 2021) may be preferable for some autistic people. Whilst identifying those most vulnerable to the detrimental impacts of the pandemic remains a priority, it is also important to understand factors and characteristics that promote psychological resilience in the face of such unique challenges. Elucidating both risk and protective factors may be crucial to inform service delivery and intervention targets, particularly in anticipation of the predicted surge of referrals to mental health services as the immediate physical threat of COVID-19 recedes (NHS Confederation, 2020).

Factors associated with psychological wellbeing during COVID-19

Concern around the psychological effects of COVID-19 on specific clinical populations focuses not only on the immediate impact of restrictions but also the longer-term implications for mental health needs and service provision. There is a need for services supporting autistic people to consider how they will cope with the ongoing stress and uncertainty of changing COVID-19 restrictions, as well as any support needs that may emerge in the aftermath of the crisis. A ‘resilience’ framework can be helpful in considering factors relating to psychological wellbeing in contexts of chronic stress (Masten, 2001).

Resilience

The term resilience has been used to describe the ability of an individual to achieve positive outcomes despite adversity, and to show flexibility and adaptiveness in stressful environments (Connor & Davidson, 2003). It may be conceptualised as a dynamic construct, incorporating individual factors such as thinking styles and coping self-efficacy, as well as interpersonal or relational factors like supportive relationships and social resources (Johnston et al., 2015). Although a lack of robust research evidence around resilience factors in autistic adults has been noted elsewhere in the literature (Hedley et al., 2019; Howlin & Magiati, 2017), resilience measures have more recently been validated in adult autistic samples (Hwang et al., 2020).

Some psychometric measures of resilience take a multifactorial approach, tapping both the individual personality traits that might predispose someone to a more resilient mindset as well as relational and environmental factors like levels of family support and external resources (Windle et al., 2011). As yet, however, those measures that have been validated in autistic adult samples – such as the Connor-Davidson Resilience Scale (CD-RISC; Connor & Davidson, 2003) take a unifactorial approach measuring ‘trait’ resilience only. Perception of social support is not measured by the CD-RISC but may represent an important factor to consider in the resilience of autistic adults during COVID. Indeed, previous studies have indicated the importance of social support in predicting mental health outcomes of general population samples under COVID-19 conditions (Li et al. 2021). Difficulties in accessing social support existed for autistic adults before the pandemic (Kerns et al., 2017) and there is reason to believe the sudden changes in routine and lifestyle brought about by the imposition of lockdown might exacerbate these difficulties (Kerns et al., 2014). For this reason, in the current study perceived social support will be considered and measured separately from resilience.

Social Support

There are further reasons to believe that the availability of social support may play an important role in the psychological wellbeing of autistic adults during COVID-19. A recent systematic review of factors related to psychosocial outcomes in autistic adults without a co-occurring intellectual disability suggested that, amongst other factors, low perceived social support is associated with poor outcomes (Zimmerman et al., 2018). Seeking social support has been identified as an effective coping strategy for autistic adults (Dachez & Ndobo, 2018), and has been shown to reduce psychological distress for individuals in the general population following previous natural disasters (Glass et al., 2009). Understanding the role of perceived social support in the novel context of the pandemic may have important implications for service provision.

Tolerance of Uncertainty

Finally, it is important to consider the role of tolerance of uncertainty in the psychological wellbeing of autistic adults in the context of COVID-19 restrictions. Existing research has suggested that autistic people find it more difficult to tolerate states of uncertainty, and that this can lead to increased rates of anxiety (South & Rodgers, 2017). Tolerance of uncertainty has previously been demonstrated to have a mediating role in the relationship between autism traits and anxiety in autistic adults (Maisel et al., 2016). The challenge of coping with uncertainty around COVID-19 for autistic adults was highlighted as a primary area of concern by international expert panels early in the pandemic (Cassidy et al., 2020). This has been borne out by subsequent research on the experience of autistic adults, with changes to routine, lack of clarity over safety guidance, and uncertainty around "what will happen next" frequently identified as detrimental to wellbeing (Davidson et al., 2021; Goldfarb et al., 2021; Oomen et al., 2021). Life during the COVID-19 pandemic has been characterised by uncertainty and unpredictability, in terms of the spread and health impacts of the virus as well as the changing levels of restrictions brought in to reduce infection. Previous theory and research would suggest that the mental health of autistic adults may be particularly susceptible to the influence of uncertainty, and it will be considered here as a primary predictor variable.

Current Study

As yet, there have been relatively few empirical studies exploring the psychological impact of pandemics on autistic adults. Given the now well-established impact of COVID-19 conditions on mental health outcomes, and the higher prevalence of mental health difficulties in autistic people, there is a need for greater understanding of the psychological wellbeing of autistic adults during the current pandemic, and factors predictive of resilience.

The aim of the current study was to capture longitudinal mental health outcomes in a sample of autistic adults in the UK over three months shortly following the initial outbreak of COVID-19. Whilst previous studies have investigated the psychological impact of COVID-19 in this population, to our knowledge none have quantitatively analysed trajectories of mental health outcomes over multiple time points across several months. Guided by recommendations made by previous researchers in the field, we aimed to recruit a large sample and include a control group of non-autistic individuals in order to compare trajectories of change over time. Gathering detailed demographic information and measures of related psychological constructs allowed for identification of variables associated with different trajectories. The following research questions were addressed:

1. How do trajectories of mental health outcomes (measures of depression, anxiety and wellbeing) of autistic adults in the UK change over a period of three months during the first wave of the COVID-19 pandemic?
2. How does the mean trajectory of mental health outcomes among autistic adults compare with that of non-autistic adults?
3. What factors are associated with greater change in mental health outcomes over time for autistic adults?

Due to the novel context and unpredictability of COVID, the direction of mental health outcome trajectories was not hypothesised. However, it was predicted that mean trajectories in the autism group would show a steeper decline, or smaller improvement, than the control group. An exploratory approach was taken to examine factors associated with change in outcomes over time, with demographic and predictor variables drawn from existing research.

Methods

Study Design

A longitudinal panel design using online surveys was selected to investigate the trajectories of mental health outcomes in autistic and non-autistic adults during the COVID-19 pandemic.

Participants

Participants were recruited using online invitations publicised through social media accounts, mailing lists and websites of autism and mental health charities in the UK. Those recruited in the early stages were encouraged to forward publicity to anyone they thought might be interested. Eligibility criteria are presented in Table 1. In the interests of maintaining transparency around research design, participants of both autism and control groups were recruited through the same channels, with the autism-specific focus of the research being made clear in all publicity materials. No incentives were offered for participation in the study, although it was emphasized that contributing data to the study would benefit research efforts around the wellbeing of autistic adults during the pandemic.

Table 1 *Participant inclusion and exclusion criteria*

Inclusion	**Exclusion**
Aged 18 years or over	Diagnosis of learning disability or cognitive impairment
English speaking	
Resident in the United Kingdom	Current formal diagnosis of schizophrenia, psychosis or bipolar disorder

Allocation to autism and control groups relied on self-report of formal diagnosis. Whilst the "gold standard" of diagnostic verification in autism research includes assessment by independent clinicians using standardised assessment tools, data collection was felt to be time-sensitive at the recruitment stage, and the process of diagnostic verification was expected to create further delay. In order to balance the ecological validity of collected data and the diagnostic validity of participant grouping, the Autism-Spectrum Quotient (AQ-50; (Baron-Cohen et al., 2001) was used to support participant self-report of autism diagnosis.

The distribution of AQ-50 scores initially found in the current control sample (*M* = 20.97, 95% CI 17.71, 24.23) was notably elevated in comparison to the reference norms found by previous general population samples (*M* = 16.94, 95% CI 16.4, 17.4; (Ruzich et al., 2015), including a cluster of scores at or above the clinical cut-off of 32 (Baron-Cohen et al., 2001). Although the AQ-50 has been found to yield relatively high false-positive rates (Ashwood et al., 2016), previous research has also suggested that autism may be underdiagnosed among the adult population in England (Brugha et al., 2011). It was speculated that the sampling methods used may have resulted in a higher number of undiagnosed autistic participants (for example, family members of diagnosed autistic adults) found in the control group. It seemed likely that those control group participants who scored highly on the AQ-50 represented a mixture of non-autistic and undiagnosed autistic individuals. For these reasons, a decision was made to exclude those control group participants who scored at or above the clinical cut-off of 32 (n=17) from the final analysis, with the aim of minimising confounding factors, maximising ecological validity and increasing representativeness across the samples. By contrast, the distribution of AQ-50 scores in the current autism group were very similar to those found in previous meta-analyses of autistic samples (Ruzich et al., 2015). It was therefore decided that self-report alone would be sufficient to determine allocation to the autism group.

The final sample of 175 participants included 124 adults in the autism group (mean age 39.84, *SD* = 12.47) and 51 adults in the control group (mean age 42.06, *SD* = 13.05). Both groups contained a relatively high proportion of female participants, with 88 (71.0%) in the autism group and 42 (82.4%) in the control group. Further demographic characteristics are presented in Table 2.

Table 2 *Demographic data by group*

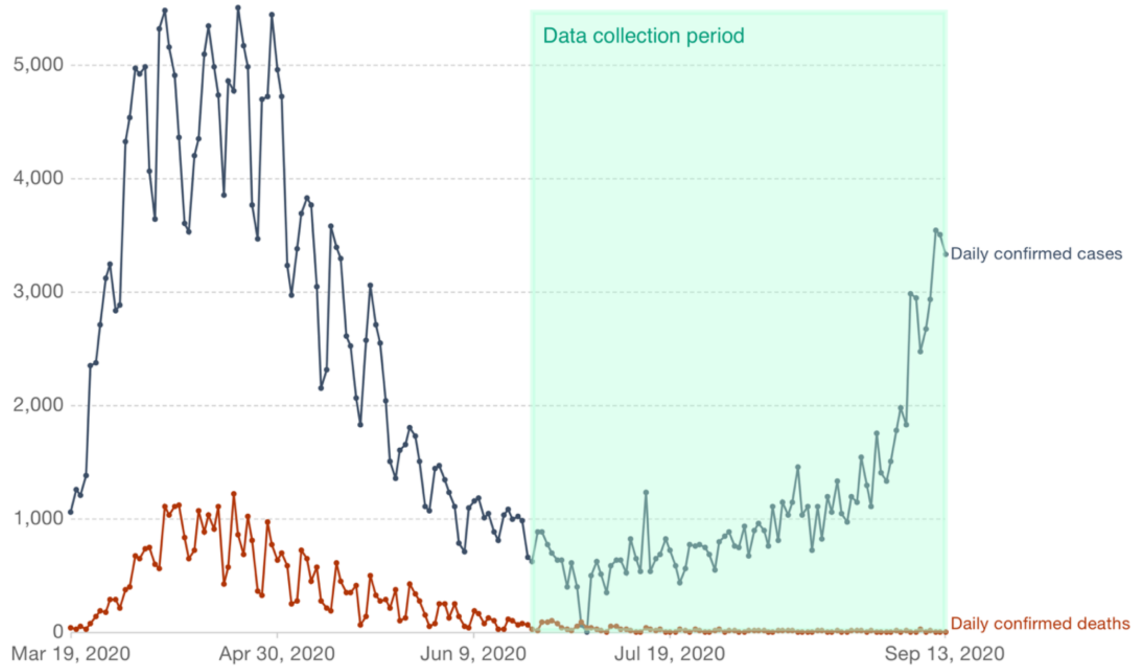
	Autism (n = 124)		**Control (n = 51)**	
	***M* (SD) / n (%)**		***M* (SD) / n (%)**	
Age (years)	39.84	(12.47)	42.06	(13.05)
Gender				
Male	21	(16.9%)	9	(17.6%)
Female	88	(71.0%)	42	(82.4%)
Transgender male	2	(1.6%)		
Transgender female	1	(0.8%)		
Gender variant / non-conforming	8	(6.5%)		
Prefer not to say / not listed	4	(3.2%)		
Education				
Doctorate	6	(4.8%)	3	(5.9%)
Masters	25	(20.2%)	22	(43.1%)
Undergraduate	42	(33.9%)	14	(27.5%)
Post-secondary (A-levels, etc)	21	(16.9%)	7	(13.7%)
Secondary (GCSEs, etc)	11	(8.9%)	2	(3.9%)
Vocational (Diploma, BTEC, etc)	15	(12.1%)	3	(5.9%)
None of these	4	(3.2%)		
Ethnicity				
White	118	(95.2%)	46	(90.2%)
BAME	3	(2.4%)	5	(9.8%)
Prefer not to say	3	(2.4%)		
Previous mental health diagnosis				
Yes	98	(79.0%)	16	(31.4%)
No	21	(16.9%)	35	(68.6%)
Unsure / prefer not to say	5	(4.0%)		
AQ-50 Total Score	40.15	(6.47)	14.39	(7.41)

Procedure

Ethical approval was obtained from the Cardiff University School of Psychology Research Ethics Committee. The study protocol was created in the few weeks following the initial outbreak of COVID in the UK, and it was felt that data gathering should begin as soon as possible in order to capture the most ecologically valid information. However, it was also important to ensure sufficient sample size for adequate power to be achieved using the planned Linear Mixed Model analysis, and to acquire full ethical approval for the project.

Once these criteria had been met, it was possible to begin data collection on 21st June 2020. It was estimated that twelve weeks would be sufficient to measure meaningful levels of change in outcome data, whilst minimising attrition. Therefore, data were collected over a period of twelve weeks from 21st June to 13th September 2020. This time period captured the end of the first wave of COVID-19 in the UK, and the start of the second wave (see Graph 1). Although there were many changes to guidance and restrictions during this time, social distancing rules remained in place.

A total of seven surveys were sent to participants through the online Qualtrics platform, at fortnightly intervals (see Figure 1). Participants were required to complete each survey within 5 days of distribution. Access to online surveys was contingent on each participant indicating informed consent and understanding of confidentiality and anonymity. Data were stored initially using the GDPR-compliant servers provided by the online survey platform, before being downloaded onto an encrypted USB device for local storage. The lead researcher consulted with the autistic staff members of a local community group, to seek advice on study design and appropriate wording for surveys and publicity material. Where possible, amendments were made in line with feedback before surveys were sent out.



Graph 1 Daily confirmed COVID-19 cases and deaths in the United Kingdom between 19th March and September 13 2020. Source: ourworldindata.org/coronavirus

Measures

Autism-Spectrum Quotient (AQ-50)

The Autism Spectrum Quotient (AQ-50; (Baron-Cohen et al., 2001) is a 50-item self-report questionnaire measuring identification with statements describing behaviours and attitudes reflecting core ASD traits. In addition to self-report of formal autism diagnosis, the AQ-50 was used as a screening tool to establish membership of the autistic or control groups. The AQ-50 has demonstrated adequate levels of test-retest reliability, and acceptable internal consistency across its five subscales (α = 0.63 - 0.77; Baron-Cohen et al., 2001)

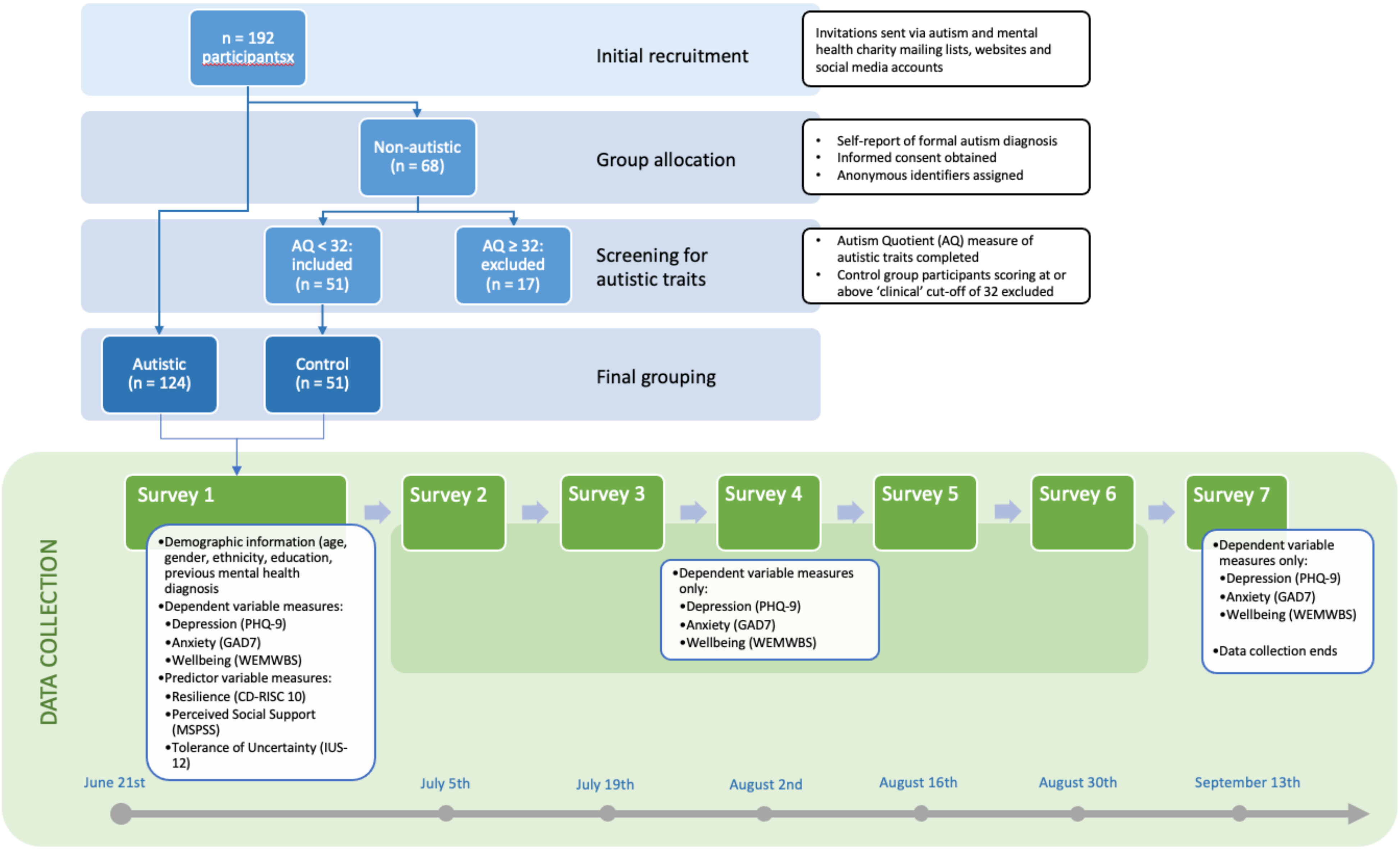


Figure 1 Flow chart showing recruitment process and data collection period

Patient Health Questionnaire (PHQ-9)

Depressive symptoms were measured using the Patient Health Questionnaire (PHQ-9). The PHQ-9 is routinely used in clinical practice (Kroenke et al., 2001) and has recently been found to have similarly strong psychometric properties in autistic and general population samples (Arnold et al., 2020). The 9 question items are derived from the Diagnostic and Statistical Manual (American Psychiatric Association, 2013) criteria for major depressive disorder, and combine to give a total score out of 27. The PHQ-9 has demonstrated strong psychometric properties, including good internal reliability ($\alpha = 0.89$; Kroenke et al., 2001).

Generalised Anxiety Disorder Scale (GAD7)

The Generalised Anxiety Disorder Scale (GAD7; Spitzer et al., 2006) is a seven-item measure of anxiety symptoms, with item scores combining to give a total out of a maximum of 21. The GAD7 has been validated in general population samples, showing strong internal consistency ($\alpha = 0.89$; Löwe et al., 2008), although its psychometric properties in autistic adult samples have not been studied.

Warwick-Edinburgh Mental Well-being Scale (WEM-WBS)

The Warwick-Edinburgh Mental Well-being Scale (WEMWBS) is a 14-item measure of subjective mental well-being and psychological functioning, comprising positively-worded question items (Tennant et al., 2007). Although the measure has not been specifically validated in autistic samples, in the general population it has shown excellent content validity and internal consistency (α = 0.91; Tennant et al., 2007).

Connor-Davidson Resilience Scale (CD-RISC 10)

A methodological review of resilience measures found no "gold standard" psychometric scale (Windle et al., 2011), but recommended the use of The Connor-Davidson Resilience Scale (CD-RISC; Connor & Davidson, 2003). The CD-RISC 10 is a self-report measure assessing predominantly intra-personal aspects of resilience such as tolerance of negative affect and acceptance of change. The scale has demonstrated good psychometric properties and high internal consistency in general population samples (α = 0.85-0.88; Campbell-Sills & Stein, 2007) and has recently been validated in a sample of 95 autistic adults (Hwang et al., 2020).

Intolerance of Uncertainty Scale (IUS-12)

The Intolerance of Uncertainty Scale (IUS-12; Carleton et al., 2007) is a twelve-item measure of anxiety relating to unknown situations. It has been used to demonstrate the mediating role of intolerance of uncertainty in the relationship between autism traits and anxiety in autistic adults (Maisel et al., 2016). The IUS has previously demonstrated strong psychometric properties including good internal consistency across subscales (α = 0.85; Carleton et al., 2007).

Multidimensional Scale of Perceived Social Support (MSPSS)

The MSPSS (Zimet et al., 1988) is a 12-item self-report scale measuring perceived availability of support across three domains: family, friends, and significant other. The MSPSS has shown to have high internal consistency and reliability (α = 0.88) in general population samples (Zimet et al., 1990), and has been used to measure perceived social support in autistic adults (Alvarez-Fernandez et al., 2017).

Data Analysis

All scales had good to excellent internal reliabilities in the current samples (α = 0.81 – 0.95; see Table 3). Growth curve analysis using Linear Mixed Models (LMMs) was chosen to address the primary research question. In the context of repeated-measures designs, LMMs can be used to estimate change over time in a dependent variable, accounting for both within-individual and between-individual variation (Shek & Ma, 2011).

Table 3. *Reliability (Cronbach's alphas) for measures in autism and control groups*

	Autism (n = 124)	**Control (n = 51)**
AQ-50	0.85	0.88
MSPSS		
Significant Other Subscale	0.95	0.93
Family Subscale	0.93	0.90
Friends Subscale	0.95	0.92
IUS-12		
Prospective Anxiety Subscale	0.83	0.89
Inhibitory Anxiety Subscale	0.86	0.90
CD-RISC 10	0.85	0.89
PHQ-9	0.87	0.81
GAD7	0.92	0.91
WEMWBS	0.92	0.92

LMMs (also known as ‘multi-level models’) are designed for the analysis of data which are structured hierarchically. In the current study, observations from individual time points (level 1) are ‘nested’ within individual participants (level 2), who themselves are nested within the two groupings of autistic and control (level3). In contrast to traditional methods – such as ANOVA, which evaluates change between groups by comparing a series of time-point pairings – LMMs aim to describe a *continuous* trajectory of change (Curran et al., 2010). Model parameters are estimated not only for the effect of participant grouping, but also for the individuals nested within that grouping. Separate data points for each individual are used to construct a “line of best fit”, yielding an intercept and gradient (or slope) that together define change trajectories across time for that individual (see Figure 2). The variance between individual and group-level trajectories can then be analysed using regression methods, to estimate the association between independent predictor variables and the rate of change in an outcome variable over time.

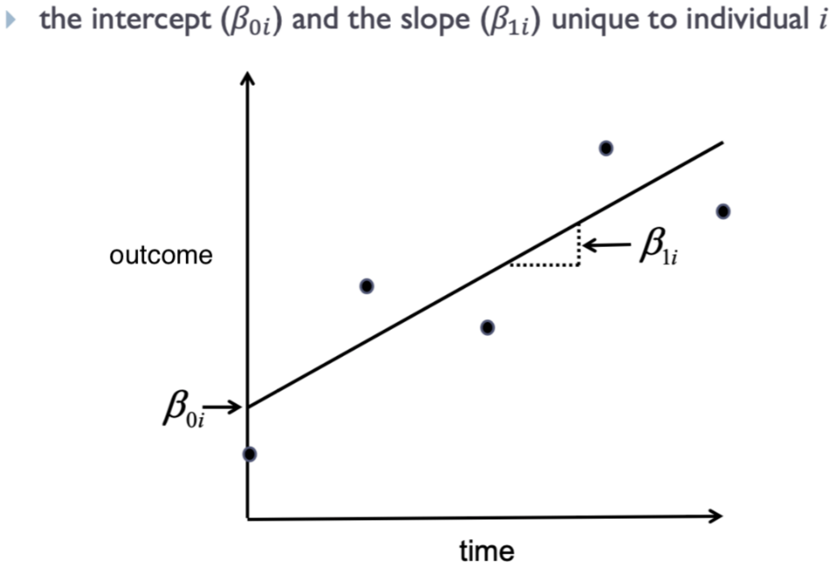


Figure 2 Linear mixed model estimated trajectory for individual change in outcome over time

LMMs can be thought of as an extension of the traditional linear regression model, which evaluates the relationship between a dependent variable (Y) and one or more independent variables (X) using the data from individuals (i):

$$Y_i = \beta_0 + \beta_1 X_i + \varepsilon_i$$

ε indicates the residual error, or deviation between the actual value and the predicted value, whilst β_0 indicates the 'starting point' or intercept value of Y when the values of all independent variables are 0. β_1 can also be thought of as the gradient, or slope, of the association between X and Y. These parameters are classified as 'fixed effects'.

LMMs extend this model by incorporating 'random effects' – parameters which are allowed to vary across the different contexts or 'levels' in the data structure (Walker et al., 2019). Whilst the simple linear model estimates only the parameters that define sample-level characteristics, LMMs can explore individual-specific variation in these parameters. In repeated measures designs, within-person differences at level 1 are modelled by estimating the outcome (Y) for individual (i) at time (t).

$$Y_{ti} = \beta_{0i} + \beta_{1i} X_{ti} + \varepsilon_{ti}$$

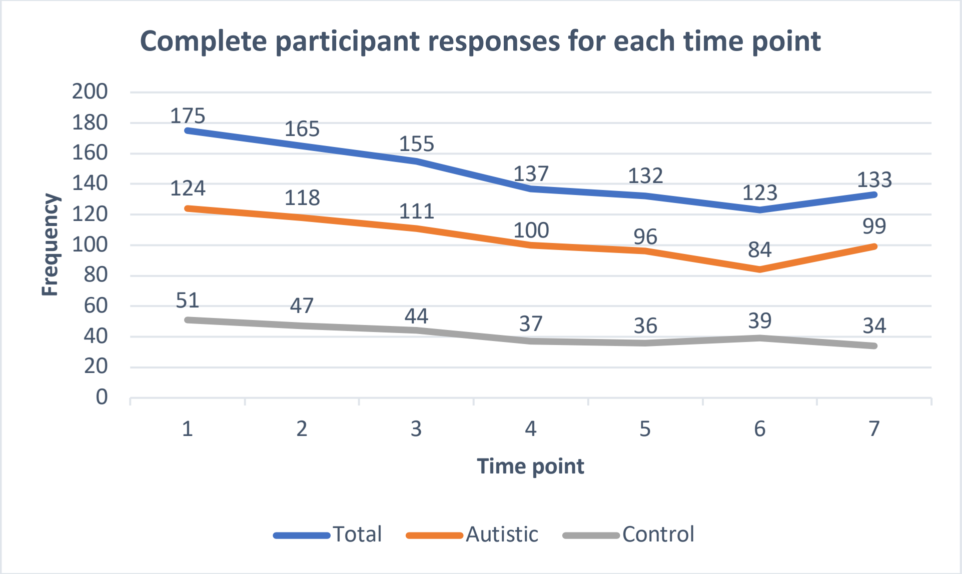
Between-person variability in the intercept (β_{0i}) and gradient (β_{1i}) at level 1 is modelled at level 2 by defining these parameters separately:

$$\beta_{0i} = \beta_0 + u_{0i}$$

$$\beta_{0i} = \beta_0 + u_{0i}$$

where β_0 and β_1 represent the overall mean intercept and gradient for the sample, whilst u_{0i} and u_{1i} denote the variability of individual intercepts and gradients around those means.

An advantage of using LMMs to analyse longitudinal data over more traditional methods is that these models can account for partially missing data (Curran et al., 2010), so long as missing data points are assumed to be "missing at random" in estimation methods. Random effects can be used to estimate longitudinal trajectories from observed values, even when data has not been captured for every time point. Graph 2 shows numbers of complete responses for each data point in the current sample. Whereas in traditional methods of statistical analysis imputation of missing data would be required, growth models can account for missing values by weighting the individual data points of participants according to the number of observations present. Participants at level 2 with a larger number of data points present in the data set at level 1 are weighted more heavily than those with higher levels of missing data. Estimates of individual trajectories can therefore be made even in participants cases where data points are missing.



Graph 2 Completed participant survey response numbers for each time point during the data collection period.

In order to answer the primary research question, the first stage of analysis involved constructing separate LMMs for the autism group and the control group, to estimate change trajectories in the outcome variables of depression, anxiety and wellbeing over time. The models estimated fixed effects for time, group and the interaction of time and group. Random effects were predicted for intercept per individual, and gradient over time. Visual inspection of trends suggested that a linear trend in time (rather than higher-order terms such as quadratic or cubic) would be sufficient. Furthermore, plots of effects were estimated to maximise interpretability and facilitate subsequent regression analysis. A restricted maximum likelihood approach was taken in fitting the LMMs, and Satterthwaite approximation was used for the degrees of freedom. An unstructured covariance matrix was used to model the covariance pattern in the models.

A two-stage hierarchical linear regression was performed to explore factors associated with trajectories in outcome between participants. Values for individual intercepts and slopes were estimated for each participant from each respective LMM, and slope values were used as the outcome variable for subsequent regression analysis. Choice of predictor variables was driven by existing research around mental health during COVID in general population samples, and by predicted clinical utility. Age and gender have been associated with measures of psychological distress across several COVID-19 studies (Office for National Statistics, 2020a; Pierce et al., 2021; University College London, 2021). Ethnicity was included as the disproportionate effects of COVID on individual from ethnic minorities had been widely reported at the time of data collection (Sze et al., 2020). Additional confounding variables were predicted to include previous mental health diagnosis, and educational level, both of which were included in the final regression model. It was expected that educational level may be a particularly significant factor, in light of recent research findings that psychological distress in autistic adults may relate to the gap between cognitive ability and adaptive functioning level (Kraper et al., 2017; Zukerman et al., 2021).

The approach to statistical analysis was determined with a view to maximising interpretability of Linear Mixed Model and regression results. Whilst it is possible to incorporate predictor variables into Linear Mixed Models themselves for direct comparison between groups (Walker et al., 2019), the resultant effect size estimates relate to group-level mean outcomes rather than values specific to individual participants. Performing separate regression analyses on individual slope values allows for a more fine-grain analysis of factors associated with individual variance in scores over time.

Model 1 included demographic variables (age, gender, ethnicity, educational level, and previous mental health diagnosis). Following inspection of descriptive statistics, and to aid interpretability, all demographic variables aside from age were collapsed into dichotomous or three-level categories. Gender was coded as male, female, or transgender / gender-non-conforming; ethnicity as either White background or Black, Asian or Minority Ethnic background (BAME); educational level either as undergraduate degree or higher, or as lower than undergraduate degree; and previous mental health diagnosis as ‘yes’ or ‘no’. Since demographic variables were predicted to influence outcomes more significantly, measures of resilience (CD-RISC 10 total score), perceived social support (MSPSS total score), and tolerance of uncertainty (IUS-12 total score) were incorporated in Model 2 as potential protective factors of interest.

The same two-stage regression was performed separately in the autistic and control groups, for each of the three outcome variables (depression, anxiety, and wellbeing slopes), resulting in a total of six models. Of primary interest were the factors relating to outcome variance in the autism group. Due to the imbalance in sample sizes between the autistic and control groups, it was predicted that running statistical tests to formally evaluate and compare effect sizes for predictor variables between the two groups would have a detrimental impact on model power (Kumle, 2021). For this reason, and to aid interpretability of findings, informal comparisons were made between the control group and autism group regression models. Evaluation of the models focused on the amount of variability in the outcome accounted for by each set of predictors, degree of improvement in model fit between each stage as measured by Akaike Information Criteria, and impact of each individual predictor on each of the three outcome variables. Inspection of residuals from model-estimated individual trajectories suggested no significant issues with assumptions of normality and constant variance. Multicollinearity between independent variables was assessed, and no significant issues were detected. Participants with data missing from the demographic and independent variables were excluded from the regression analysis, resulting in a total sample size of n=159 (autism group n=111, control group n=48).

Results

Research Question 1: How do trajectories of mental health outcomes change over time?

Results for each of the three Linear Mixed Models are summarised in Table 4. Significant effects were not found for time or for the interaction between group and time for any of the three outcome variables, suggesting that group-level mental health scores did not change significantly during the time of observation.

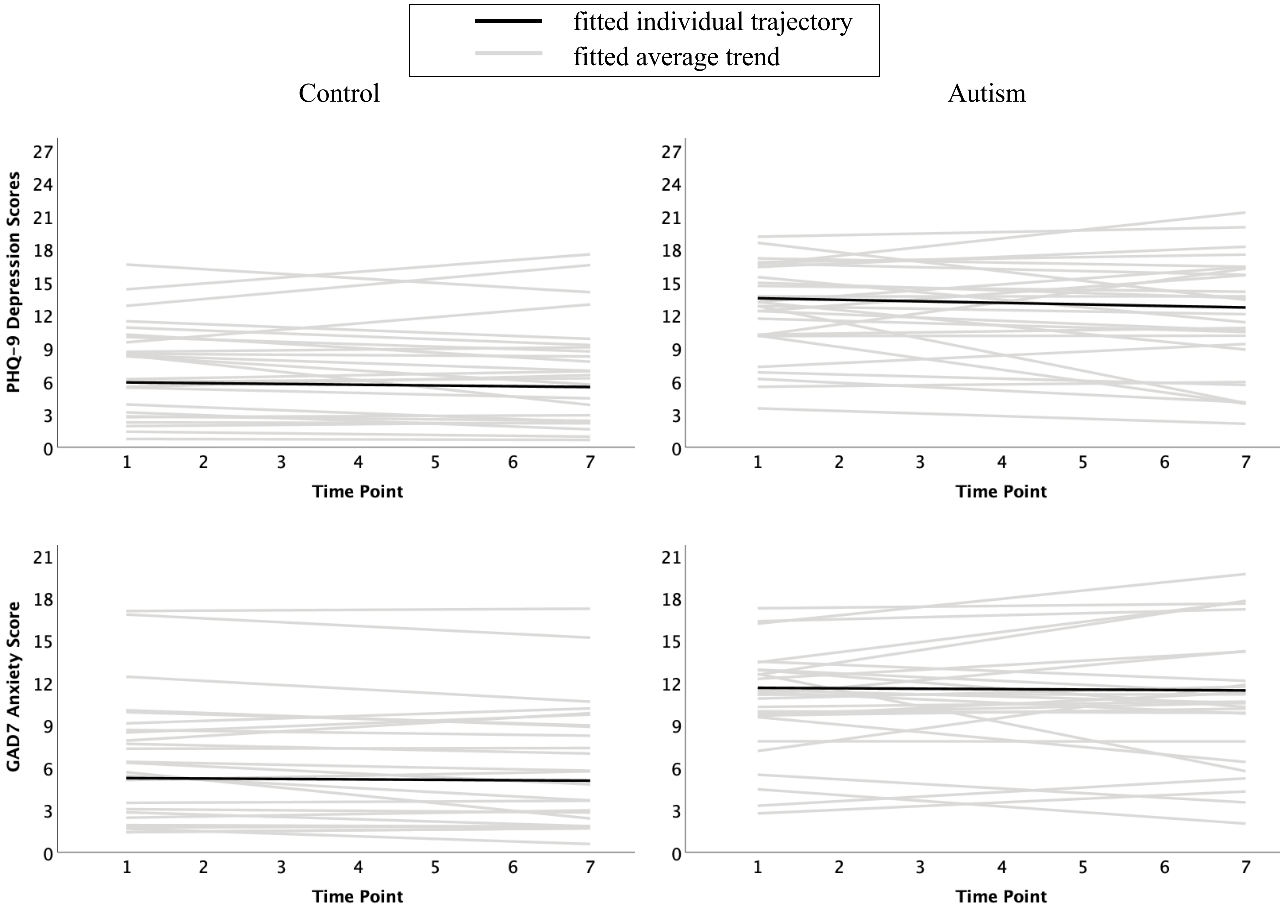
Table 4. L*inear Mixed Model results for dependent variables*

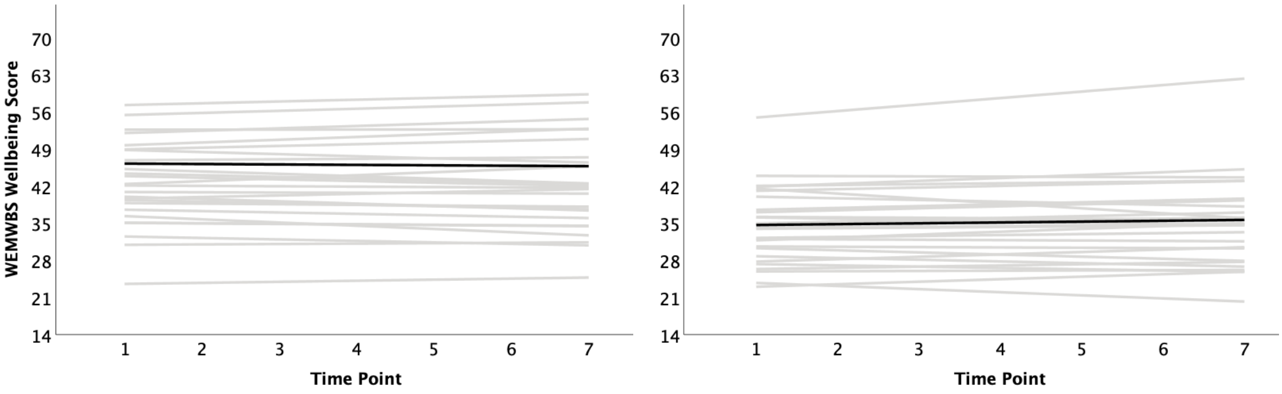
Outcome variable	**Parameter**	**Estimate**	**Test (*df*)**	***p***
Depression	Intercept	5.89	t = 7.06 (174.96)	
	Group (reference = control)	**7.64**	**t = 7.72 (174.53)**	**.001**
	Time	-0.07	t = -0.538 (158.54)	.592
	Group*Time	-0.07	t = -0.425 (158.10)	.671
Anxiety	Intercept	5.25	t = 6.98 (173.68)	.001
	Group (reference = control)	**6.39**	**t = 7.15 (173.38)**	**.001**
	Time	-0.35	t = -0.32 (152.42)	.747
	Group*Time	0.00	t = 0.26 (152.11)	.980
Wellbeing	Intercept	46.24	t = 36.00 (174.25)	.001
	Group (reference = control)	**-11.58**	**t = -7.59 (173.87)**	**.001**
	Time	-0.08	t = -0.41 (157.93)	.686
	Group*Time	0.23	t = 1.07 (157.25)	.286

Research Question 2: How do mean trajectories among autistic adults compare with those of non-autistic adults?

Graph 3 shows model-estimated group-level trajectories of depression, anxiety, and wellbeing. A significant main effect was found for group in each of the three outcome variables: depression ($\beta = 7.64$, $p < .01$), anxiety ($\beta = 6.39$, $p < .01$) and wellbeing ($\beta = -11.58$, $p < .01$). Autistic participants recorded mean PHQ-9 (depression) scores across time points that were 7.64 higher, GAD-7 (anxiety) scores that were 6.39 higher, and WEMWBS (wellbeing) scores that were 11.58 lower than control group participants.

Visual inspection of individual trajectory plots (see Graph 3) indicated that substantially more variability in slopes of autistic participants existed for all three outcome variables when compared with control group participants. In the control group, individual slopes indicate relatively little change over time in relation to the fitted average group trend. In the autism group, however, the average trend (and accordingly the group-level parameter estimate) appear to belie substantial variability; this is, individual autistic group participants showed greater levels and rates of both improvement and deterioration in mental health scores over time. This may indicate that the impact of COVID-19 restrictions on the mental health of autistic participants was more heterogenous. Whilst some autistic participants clearly showed greater levels of decline in psychological wellbeing than any control group participant, others conversely showed greater levels of improvement. This finding is consistent with existing pandemic research which suggests that some autistic people may in fact benefit from a decrease in the social demands of neurotypical environments during COVID-19 (Lugo-Marín et al., 2021).





Graph 3. Linear Mixed Model estimated individual trajectories and average trend for PHQ-9 depression, GAD7 anxiety and WEMWBS wellbeing scores per group. Black lines indicate model-estimate group-level trajectory for each group, with a subset of 25 randomly selected individual participant trajectories shown in grey.

Research Question 3: What factors are associated with greater change in mental health outcomes over time for autistic adults?

Depression

In the autism group, the demographic variables included in Model 1 contributed significantly to the regression model, accounting for 13% of the total variability in depression slopes ($R^2 = .13$, $F(6,104) = 2.49$, $p = .027$). Incorporating the predictor variables of resilience, perceived social support and tolerance of uncertainty at stage 2 explained an additional 3.5% of the total variability in depression slopes, although this change in R^2 was not significant ($R^2\Delta = 0.035$, $F(3, 101) = 1.41$, $p = 0.25$). Inspection of Akaike Information Criteria values indicated an improvement in fit over Model 1 (-110.330, -108.878). Model 2 itself significantly predicted depression slopes, with the eight predictors together accounting for 16% of the total variability ($R^2 = .16$, $F(9,101) = 2.15$, $p = .032$). Among the predictors in Model 2, only age ($\beta = .258$, $p = .011$*)* and educational level ($\beta = .187$, $p = .049$*)* were found to significantly (alpha = .05) predict depression slopes, whilst resilience and tolerance of uncertainty approached significance level. Specifically, higher age and having an undergraduate degree or higher were associated with greater increase in depressive symptoms over time.

By contrast in the control group, age was not found to be significantly associated with depression slopes. The association between educational status and outcome was marginally significant, and the direction of this relationship was reversed compared to the autism group (β = -.286, p = .064). For participants in the control group, having an undergraduate degree or higher appeared to represent a protective factor against increasing depressive symptoms over time. It should be noted that neither of the two regression models, taken as a whole, significantly predicted depression slopes in the control group. Table 5 presents more detailed output from the regression models for autistic and control groups.

Anxiety

In the autism group, the demographic variables included in model 1 accounted for 9% of the variability in anxiety slopes, although the model as a whole did not significantly predict outcome (R^2 = .09, F(6,104) = 1.76, p = .114). Although incorporating the predictor variables at stage 2 explained an additional 2% of variability in anxiety slopes, this change in R^2 was not significant ($R^2\Delta$ = 0.021, F(3, 101) = .803, p = 0.495). Among the predictors in Model 2, age was again found to significantly predict anxiety slopes (β = .258, p = .011) whilst all other variables did not reveal significant associations. Specifically, higher age was associated with greater increase in symptoms of anxiety over time. In the control group, neither of the regression models were found to significantly predict anxiety slopes. In contrast to the autism group, no significant relationship between age and anxiety slopes was found. Table 6 presents more detailed output from the regression models for autistic and control groups.

Wellbeing

In the autism group, the demographic variables included in model 1 accounted for 6% of the variability in wellbeing slopes, although the model as a whole did not significantly predict outcome ($R^2 = .06$, $F(6,104) = 1.14$, $p = .346$). Incorporating the predictor variables at stage 2 explained an additional 7% of variability in wellbeing slopes, and this change in R^2 was significant ($R^2\Delta = 0.07$, $F(3, 101) = 2.735$, $p = 0.048$). However, inspection of Akaike Information Criteria values did not indicate an improvement in fit over Model 1 (-132.887, -135.555). The eight predictors together in model 2 accounted for 13% of variability in wellbeing slopes, though this association was only marginally significant ($R^2 = .13$, $F(9,101) = 1.71$, $p = .097$). Among the predictors in Model 2, only tolerance of uncertainty was found to significantly predict wellbeing slopes ($\beta = .-0.18$, $p = .014$). Specifically, higher scores on the Intolerance of Uncertainty Scale were associated with greater decrease in wellbeing symptoms over time.

By contrast in the control group, tolerance of uncertainty was not found to be significantly associated with wellbeing slopes, whilst a small significant association was found for age ($\beta = -.0.02$, $p = .016$). For these participants, higher age was associated with greater increase in wellbeing scores over time. It should be noted that neither of the two regression models, taken as a whole, significantly predicted wellbeing slopes in the control group. Table 7 presents more detailed output from the regression models for autistic and control groups.

Table 5. *Hierarchical regression with depressive symptoms (PHQ-9) as outcome*

	Autistic (n=111)					**Control** (n=48)				
Model	*B*	*SE*	β	*95% CI*	*P*	*B*	*SE*	β	*95% CI*	*p*
Model 1										
Constant	-0.843	.222		[-1.283, -0.404]	.001	.388	.257		[-.131, .908]	.139
Age	**0.012**	.005	**0.247**	[0.003, 0.021]	**.011**	-.006	.005	-.204	[-.016, .003]	.190
Male	0.002	.165	0.001	[-0.326, 0.330]	.990	.221	.157	.217	[-.096, .539]	.167
TG/GNC	0.096	.172	0.052	[-0.245, 0.438]	.576					
BAME	0.144	.352	0.038	[-0.555, 0.843]	.684	-.086	.213	-.060	[-.516, .343]	.687
Degree	**0.263**	.116	**0.212**	[0.033, 0.492]	**.025**	**-.267**	.136	-.297	[-.541, .007]	**.056**
Prev-MH	0.083	.164	0.051	[-0.242, 0.407]	.614	-.041	.126	-.049	[-.295, .212]	.745
Model 2										
Constant	-1.856	.572		[-2.990, -0.722]	.002	1.036	.624		[-.226, 2.299]	.105
Age	**0.013**	.005	**0.258**	[0.003, 0.022]	**.011**	-.010	.006	-.309	[-.022, .002]	.101
Male	-0.065	.168	-0.040	[-0.399, 0.270]	.702	.159	.173	.155	[-.190, .508]	.363
TG/GNC	0.067	.175	0.037	[-0.279, 0.414]	.701					
BAME	0.128	.354	0.034	[-0.574, 0.830]	.719	-.164	.238	-.114	[-.646, .318]	.496
Degree	**0.232**	.117	**0.187**	[0.001, 0.464]	**.049**	**-.286**	.150	-.319	[-.589, .018]	**.064**
Prev-MH	0.126	.168	0.078	[-0.206, 0.459]	.454	.074	.176	.088	[-.282, .430]	.676
CD-RISC	0.016	.009	0.179	[-0.003, 0.034]	.099	-.001	.012	-.013	[-.025, .024]	.951
MSPSS	0.022	.044	0.049	[-0.066, 0.109]	.626	-.029	.068	-.077	[-.166, .107]	.665
IUS	0.014	.008	0.179	[-0.002, 0.029]	.093	-.012	.007	-.315	[-.027, .003]	.122

Note. *SE* = standard error; CI = confidence interval; TG/GNC = transgender/gender non-conforming; BAME = Black, Asian and minority ethnic background; Degree = undergraduate degree or above; Prev-MH = previous mental health diagnosis; CD-RISC = Connor-Davidson Resilience Scale; MSPSS = Multidimensional Scale of Perceived Social Support; IUS = Intolerance of Uncertainty Scale

Table 6. *Hierarchical regression with anxious symptoms (GAD7) as outcome*

	Autistic (n=111)					**Control** (n=48)				
Model	*B*	*SE*	β	*95% CI*	*P*	*B*	*SE*	β	*95% CI*	*p*
Model 1										
Constant	-.377	.139		[-.653, -.100]	.008	.047	.162		[-.280, .375]	.772
Age	.005	.003	.173	[-.001, .011]	.077	-.002	.003	-.120	[-.009, .004]	.442
Male	-.058	.104	-.058	[-.264, .148]	.575	.188	.099	.295	[-.012, .388]	.065
TG/GNC	-.096	.108	-.085	[-.311, .118]	.374					
BAME	.133	.221	.057	[-.306, .572]	.549	.038	.134	.043	[-.232, .309]	.777
Degree	.119	.073	.155	[-.026, .263]	.106	.025	.086	.044	[-.148, .198]	.773
Prev-MH	.109	.103	.109	[-.095, .313]	.290	-.068	.079	-.130	[-.228, .091]	.392
Model 2										
Constant	-.740	.362		[-1.458, -.021]	.044	.389	.395		[-.409, 1.187]	.331
Age	**.007**	.003	.219	[.000, .013]	**.035**	-.003	.004	-.142	[-.010, .005]	.448
Male	-.065	.107	-.065	[-.277, .147]	.544	.187	.109	.293	[-.034, .407]	.095
TG/GNC	-.073	.111	-.065	[-.293, .147]	.510					
BAME	.132	.224	.057	[-.312, .577]	.556	.049	.151	.054	[-.256, .354]	.747
Degree	.122	.074	.159	[-.025, .269]	.103	.010	.095	.018	[-.182, .202]	.917
Prev-MH	.124	.106	.124	[-.087, .334]	.247	-.055	.111	-.105	[-.280, .170]	.622
CD-RISC	.001	.006	.020	[-.011, .013]	.857	-.006	.008	-.178	[-.022, .009]	.422
MSPSS	.043	.028	.156	[-.013, .098]	.133	.003	.043	.012	[-.084, .089]	.947
IUS	.002	.005	.041	[-.008, .012]	.707	-.006	.005	-.250	[-.015, .004]	.224

Note. *SE* = standard error; CI = confidence interval; TG/GNC = transgender/gender non-conforming; BAME = Black, Asian and minority ethnic background; Degree = undergraduate degree or above; Prev-MH = previous mental health diagnosis; CD-RISC = Connor-Davidson Resilience Scale; MSPSS = Multidimensional Scale of Perceived Social Support; IUS = Intolerance of Uncertainty Scale

Table 7. *Hierarchical regression with wellbeing (WEMWBS) as outcome*

	Autistic (n=111)					**Control** (n=48)				
Model	*B*	*SE*	β	*95% CI*	*P*	*B*	*SE*	β	*95% CI*	*p*
Model 1										
Constant	.594	.200		[.197, .992]	.004	-.615	.307		[-1.234, .005]	.052
Age	-.005	.004	-.122	[-.013, .003]	.217	.013	.006	.336	[.001, .024]	.035
Male	-.064	.149	-.045	[-.360, .232]	.671	-.189	.188	-.156	[-.568, .190]	.320
TG/GNC	-.141	.155	-.088	[-.450, .167]	.366					
BAME	.003	.318	.001	[-.628, .635]	.992	-.246	.254	-.144	[-.759, .266]	.338
Degree	-.159	.105	-.147	[-.366, .049]	.132	.152	.162	.143	[-.175, .479]	.352
Prev-MH	-.141	.148	-.100	[-.434, .152]	.342	-.061	.150	-.061	[-.364, .241]	.685
Model 2										
Constant	1.552	.507		[.546, 2.558]	.003	-1.148	.742		[-2.649, .354]	.130
Age	-.005	.004	-.119	[-.014, .003]	.243	.017	.007	.463	[.003, .031]	.016
Male	.011	.149	.008	[-.286, .307]	.943	-.058	.205	-.048	[-.473, .358]	.781
TG/GNC	-.136	.155	-.085	[-.443, .172]	.383					
BAME	.111	.314	.034	[-.511, .733]	.725	-.045	.283	-.026	[-.618, .528]	.875
Degree	-.159	.104	-.147	[-.365, .046]	.128	.102	.178	.096	[-.258, .463]	.569
Prev-MH	-.105	.149	-.074	[-.400, .190]	.481	-.215	.209	-.215	[-.638, .208]	.310
CD-RISC	.000	.008	.004	[-.016, .017]	.967	-.014	.014	-.213	[-.043, .015]	.335
MSPSS	-.038	.039	-.099	[-.116, .040]	.333	.109	.080	.240	[-.054, .272]	.184
IUS	**-.018**	.007	-.269	[-.032, -.004]	**.014**	**.006**	.009	.131	[-.012, .024]	**.517**

Note. *SE* = standard error; CI = confidence interval; TG/GNC = transgender/gender non-conforming; BAME = Black, Asian and minority ethnic background; Degree = undergraduate degree or above; Prev-MH = previous mental health diagnosis; CD-RISC = Connor-Davidson Resilience Scale; MSPSS = Multidimensional Scale of Perceived Social Support; IUS = Intolerance of Uncertainty Scale

Discussion

This paper presents findings from a large UK sample of autistic adults during the COVID-19 pandemic, followed longitudinally with mental health outcomes captured at several time points over three months. Analysis using Linear Mixed Models allowed for the identification of individual-level variables associated with degree of change over time, and the inclusion of a control group allowed for comparisons to be drawn from a sample of non-autistic participants.

The findings from this study include novel and significant contributions to the emergent evidence base around the experience of autistic people under pandemic conditions. At the time of writing, waves of community infection from COVID-19 continue to affect countries across the world (World Health Organization, 2021b). Although national vaccination programs offer hope for an alternative to social distancing and lockdowns in combating the virus, the emergence of novel variants with higher transmission rates and potential vaccine-resistance suggests that a need for vigilance remains (Mishra et al., 2021). Should social restrictions need to be extended or reinstated, evidence gathered during the early stages of the pandemic will be necessary to inform future policy and intervention. Whilst swift, decisive action on a national scale was required following the initial outbreak of COVID-19, a more nuanced approach prioritising those most vulnerable to the effects of social restrictions may now be achievable. Findings from the present study suggest that autistic adults may be one such group, and offer a more granular analysis of individual risk factors in this population.

Differences in outcome between autism and control group

As anticipated, the current results indicate that symptoms of depression and anxiety were significantly higher in the autism group than the control group across all time points, whilst levels of wellbeing were lower. These findings are consistent with previous research conducted prior to the start of the pandemic, with elevated levels of depression and anxiety (Lai et al., 2019; Uljarević et al., 2020) found in autistic adults compared with general population samples. Results from the current study suggest that this disparity persists under pandemic conditions. However, whether or not the imposition of lockdown and social distancing has exacerbated pre-existing mental health inequalities cannot be answered conclusively without access to earlier data for comparison. A recent pre-pandemic study examining the psychometric properties of the PHQ-9 in a sample of autistic adults reported a difference of 1.54 between mean scores for autistic (*M* 6.56, *SD* = 5.59) and control (*M* 5.02, *SD* = 4.82) community samples (Arnold et al., 2020). It must be noted that sampling heterogeneity in the current study may have affected outcomes, and that differences in method of analysis makes comparison difficult. Nonetheless, the group effect detected for mean depression scores using the present LMM analysis ($\beta = 7.64$, $p = .001$) indicated a much larger discrepancy across time points than has previously been found (Arnold et al., 2020).

Changes in outcome over time

Perhaps more surprising was the finding that scores on all three dependent variables remained stable over the three-month period of data collection. Population studies suggest that the greatest impact on mental health occurs in the immediate aftermath of restrictions being imposed (Office for National Statistics, 2020a). Available research into the experience of autistic adults during COVID-19 suggests a similar pattern. Researchers from the USA found that while high levels of psychological distress were reported immediately after lockdowns were imposed in April 2020, they remained relatively stable two months later in June (Bal et al., 2021). A Spanish study involving a clinical sample of autistic adults found a decrease in stress and psychological problems as assessed by the Symptom Checklist 90 Revised (SCL-90-R) 8 weeks after the onset of lockdown, compared with pre-pandemic levels (Lugo-Marín et al., 2021). Highlighting that stress levels were instead elevated in caregivers of autistic adults, the authors speculate that some autistic people may benefit from a reduction in the social demands of neurotypical environments.

Results from the current study are also likely to have been influenced by ongoing changes in guidance, social restrictions, and reported levels of community transmission of COVID-19 during the period of data collection. Case numbers, hospitalisations and daily deaths in the UK had reached relatively low levels by the first data point in early June 2020 (UK Government, 2021). Restrictions gradually eased over the following weeks, with pupils returning to classes, workers returning to offices, non-essential shops re-opening, and the hospitality sector welcoming citizens into pubs, restaurants, and outdoor public venues (Institute for Government, 2021). By the seventh and final data collection point in mid-September case numbers had begun to rise again, and while daily deaths remained low, lockdowns were being imposed in local areas showing higher infection rates (Institute for Government, 2021). With so many time-dependent and potentially confounding variables present, a great deal of individual variation in psychological wellbeing might be expected. The observed mean trajectories between the autism and control groups may belie significant individual variation in observed outcomes.

Factors associated with change in outcome over time

Age, depression and anxiety

When interpreting the results of the regression analyses examining factors associated with change in dependent variables over time, it should be emphasized that these findings were derived from a relatively small sample size, particularly in the control group models. In addition, the research setting and context were in some senses unique to the period of data collection. As such, replicability of the reported findings is compromised, and accordingly any conclusions drawn from the current data must remain tentative.

Regression analysis of individual trajectories identified two variables significantly associated with outcome that were unique to the autism group. First, age was found to be a significant predictor of increasing symptoms of both depression and anxiety over time in the autism group. Higher age was found to be significantly associated with greater increases in depression and anxiety over time, whilst no association was found in the control group. This would appear to suggest that older age represents a unique risk factor for the development of psychological problems in autistic adults in the UK under COVID-19 conditions. Whilst findings from existing research vary, these results are consistent with some previously published studies. Measuring the effects of eight weeks of lockdown in autistic adults, (Lugo-Marín et al., 2021) reported improvement on all SCL-90-R subscales except for Anxiety in younger participants (under 30 years). In the older group (over 30 years) only the Interpersonal Sensitivity subscale measuring feelings of inadequacy and inferiority showed a significant decrease. Whilst the sample context differed from the present study, with participants drawn from clinical settings, the direction of association between age and distress is replicated. By contrast, (Bal et al., 2021) found higher levels of psychological distress in younger autistic adults immediately following lockdown in the USA, with scores remaining stable eight weeks later. The authors noted that those participants who indicated greater initial impact were less likely to respond to the second survey and suggested that patterns may change as the pandemic progresses. Whilst the present study employed a more longitudinal design foregrounding trajectory of change, national variation in pandemic impact, population age distribution and service availability are likely to have influenced results.

Whilst no association between age and depression or anxiety slopes was found in the control group, existing research suggests that the opposite trend may be found in the general population. The UCL *COVID-19 Social Study* has reported on mental health outcomes including depression (as measured by the PHQ-9) and anxiety (GAD7) periodically throughout the pandemic, including on a fortnightly basis during the data collection period for the present study (University College London, 2021). Whilst trajectories of depression and anxiety scores during this time are broadly similar with those found in the control group for the present study, the UCL study has consistently found higher rates in younger age groups (University College London, 2021). Reporting on older adult outcomes early in the pandemic, The Office for National Statistics similarly found higher average wellbeing scores and levels of happiness in adults aged over 60 than those aged under 60 (Office for National Statistics, 2020b). A large-scale UK study using latent-class trajectory analysis identified lower age as a predictor of deteriorating mental health between April and October 2020 (Pierce et al., 2021).

It remains unclear why increasing age would confer additional risk for autistic adults in particular. Children and young people have historically been prioritised in autism research, whilst studies exploring characteristics of older autistic adults is sparse (Roestorf et al., 2019). This dearth of research evidence may, in part, result from ongoing changes to the criteria, terminology and process around diagnosis of autism since the condition was first identified (Wise, 2020). A recent systematic review found evidence of elevated rates of co-occurring physical and mental health difficulties in older autistic adults compared to non-autistic peers (Tse et al., 2021). Higher rates of anxiety and depression have been reported in this population (Stewart et al., 2020), as well as schizophrenia, psychosis and personality disorders (Hand et al., 2020). However, a lack of autism awareness amongst professionals working with older adults may also result in misdiagnosis and underdiagnosis in this population, as core autistic traits are misinterpreted as symptoms of psychological distress (Brugha et al., 2011; Takara & Kondo, 2015). Significant barriers to accessing healthcare exist for older people (Prina et al., 2014), autistic people (Mason et al., 2019), and older autistic people in particular (Wright et al., 2019) under normal conditions, and these disparities in provision may have worsened during the pandemic. Results from the present study suggest that pre-existing disparities in research and clinical outcomes for older autistic adults continue to disproportionately impact this already vulnerable group.

Educational level and depression

Level of educational qualification was also found to be uniquely associated with trajectory of depression scores in the autism group. Whilst having an undergraduate degree or higher represented a protective factor in the control group, autistic participants at this level of education reported greater increases in depressive symptoms over time. The control group outcomes appear broadly consistent with existing research on population mental health outcomes during COVID-19. The UCL study has reported lower levels of depression (PHQ-9) scores in adults with a university degree compared to those with GCSEs or A-Levels only throughout the pandemic (University College London, 2021). A study tracking symptoms of depression and anxiety symptoms in 21,938 adults in England identified four distinct trajectory classes using growth mixture modelling (Saunders et al., 2021). Two classes showed worsening symptoms during full lockdown before diverging as lockdown eased;

participants recovering after this stage were more likely to have university degrees and higher income, suggesting that higher educational status was a protective factor in this sample.

It has previously been suggested that higher levels of intelligence are associated with increased risk for psychological difficulties in autistic people, including depression (Chandrasekhar & Sikich, 2015). Large-scale studies have shown that rates of depression are lower in autistic adults with an intellectual disability than in those without (Rai et al., 2018). A recent meta-analysis of depressive disorders in autism found higher Full Scale Intelligence Quotient scores to be associated with higher lifetime prevalence for depression and suggested that more intellectually able individuals may have greater awareness of autism-related difficulties (Hudson et al., 2019). While these findings have been partially supported by the results of the present study, further research is needed to understand why autistic adults with higher educational status are at higher risk of developing depressive symptoms in the context of pandemic conditions.

Other variables

Finally, it is noteworthy that no significant associations were found between the dependent outcomes and the three predictor variables of interest, except for wellbeing and tolerance of uncertainty. Whilst higher scores on the Intolerance of Uncertainty Scale were associated with decreasing wellbeing scores over time in the autism group, no such relationship was found in the control group. Whilst sample heterogeneity may account for a lack of identified associations, it is also possible that existing measures of social support (such as the MSPSS) and resilience (CD-RISC) are less sensitive to measuring these constructs in the novel context of COVID-19.

Strengths, implications and limitations

The present study contributes novel findings to the emergent evidence base around the experience of autistic adults during the COVID-19 pandemic. The identification of unique risk factors for this group has potentially important implications for both current policy and future clinical practice. As the effects of the pandemic continue to challenge populations and disrupt service provision, targeted intervention for vulnerable groups should remain a priority. Findings from the present study suggest that conclusions drawn from population-level research into the mental health impact of COVID may not hold true for autistic adults. Specifically, whilst greater age and educational achievement may act as protective factors in the general population, these same characteristics may represent risk factors for autistic adults.

The present study benefitted from a relatively large sample of autistic adults, a broad age distribution among participants, and a longitudinal design with multiple waves of data collection to strengthen the reliability of findings. To our knowledge, it is the first study to examine trajectories of mental health outcomes in autistic adults during COVID in this way. A further strength of this research was the representation of autistic people through consultation during the study design stage.

There are several limitations to consider around the present study, which offer additional opportunities for future research. Firstly, it was not possible to make a direct comparison of participant outcomes against pre-pandemic data. For this reason, the impact of COVID restrictions themselves on both measures of mental health outcomes and discrepancies between autistic and control groups can only be inferred through comparison with existing pre-pandemic literature. The ubiquity and variability of pandemic experiences makes COVID a challenging phenomenon to investigate, and it is possible that outcomes were influenced by a range of confounding factors. Similarly, it was not possible to capture outcome data from the first three months following the outbreak of COVID in the UK, and the degree to which the immediate impact of lockdown influenced outcomes remains unknown in the current sample.

Secondly, a lack of representativeness in recruited samples may affect generalisability of findings. Both samples were characterised by relatively high levels of educational attainment, a high proportion of female participants, and low numbers of participants from black or ethnic minority backgrounds. The autistic sample comprised a high proportion of participants with a previous mental health diagnosis, possibly due to a reliance on mental health charities in the recruitment process. However, existing research has found a higher proportion of co-occurring mental health difficulties in autistic populations (Lai et al., 2019; Uljarević et al., 2020) and the inclusion of these characteristics in regression models reduces the impact of confounding variables on reported findings. Findings from the regression analysis in the control group in particular must be interpreted with caution, due to a potential lack of representativeness resulting from the sampling methodology use. Elevated levels of autism traits as measured by the AQ-50 among participants in the initial control group suggest that they may not have been drawn from a representative sample population. Whilst the exclusion criteria used to screen out participants with significantly elevated levels of autistic traits may have mitigated against the impact of imprecise sampling, it remains a possibility that undetected confounding variables in this group influenced dependent variable outcomes.

Finally, the level of attrition over the 7 waves of data collection is likely to impact the reliability of the reported findings. Whilst the modelling procedures of Linear Mixed Models can account for high rates of participant dropout relative to more traditional methods of analysis (Curran et al., 2010; Walker et al., 2019), it remains a possibility that missing data is related to differences in outcome variables measured. It is also possible that regression analysis in the control group was underpowered by smaller sample size, and that this may have resulted in false negative findings for this group.

Conclusions

The present study offers detailed insight into the experience of autistic adults during the COVID-19 pandemic in the UK. The well-established finding that autistic adults are at greater risk of psychological distress and lower wellbeing is replicated in the present study in the context of COVID-19 restrictions. Although little group-level change was detected in mental health outcomes during the period of data collection, regression analysis of individual trajectories indicates the presence of unique risk factors in this group. Greater age and higher educational status, which may be protective factors against the development of mental health difficulties in the general population, were found to predict greater distress and lower wellbeing over time in our sample of autistic adults. These findings may have utility in guiding policy and clinical practice as many countries continue to grapple with the effects of COVID-19.

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Appendix A

Guidelines for journal submission

Instructions for Authors

Editorial procedure

Double-Blind Peer Review

MANUSCRIPT FORMAT

All JADD manuscripts should be submitted to Editorial Manager in 12-point Times New Roman with standard 1-inch borders around the margins.

APA Style

Text must be double-spaced; APA Publication Manual standards must be followed.

As of January 20, 2011, the Journal has moved to a double-blind review process. Therefore, when submitting a new manuscript, DO NOT include any of your personal information (e.g., name, affiliation) anywhere within the manuscript. When you are ready to submit a manuscript to JADD, please be sure to upload these 3 separate files to the Editorial Manager site to ensure timely processing and review of your paper:

- A title page with the running head, manuscript title, and complete author information. Followed by (page break) the Abstract page with keywords and the corresponding author e-mail information.
- The blinded manuscript containing no author information (no name, no affiliation, and so forth).
- The Author Note

Types of papers

Articles, Commentaries Brief Reports, Letters to the Editor

- The preferred article length is 20-23 double-spaced manuscript pages long (not including title page, abstract, tables, figures, addendums, etc.) Manuscripts of 40 double-spaced pages (references, tables and figures counted as pages) have been published. The reviewers or the editor for your review will advise you if a longer submission must be shortened.
- Special Issue Article: The Guest Editor may dictate the article length; maximum pages allowed will be based on the issue's page allotment.
- Commentary: Approximately 20-25 double-spaced pages maximum, with fewer references and tables/figures than a full-length article.
- A Brief Report: About 8 double-spaced pages with shorter references and fewer tables/figures. May not meet the demands of scientific rigor required of a JADD article – can be preliminary findings.
- A Letter to the Editor is 6 or less double spaced pages with shorter references, tables and figures.

  Style sheet for Letter to the Editor:

- A title page with the running head, manuscript title, and complete author information including corresponding author e-mail information
- The blinded manuscript containing no author information (no name, no affiliation, and so forth):-

  - 6 or less double spaced pages with shorter references, tables and figures

  - Line 1: "Letter to the Editor"

  - Line 3: begin title (note: for "Case Reports start with "Case Report: Title")

  - Line 6: Text begins; references and tables, figure caption sheet, and figures may follow (page break between each and see format rules)

Review your manuscript for these elements

1. Order of manuscript pages

Title Page with all Author Contact Information & Abstract with keywords and the corresponding author e-mail information.

Blinded Manuscript without contact information and blinded Abstract, and References

Appendix

Figure Caption Sheet

Figures

Tables

Author Note

Manuscript Submission

Manuscript Submission

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

Permissions

Authors wishing to include figures, tables, or text passages that have already been published elsewhere are required to obtain permission from the copyright owner(s) for both the print and online format and to include evidence that such permission has been granted when submitting their papers. Any material received without such evidence will be assumed to originate from the authors.

Online Submission

Please follow the hyperlink “Submit manuscript” on the right and upload all of your manuscript files following the instructions given on the screen.

Please ensure you provide all relevant editable source files. Failing to submit these source files might cause unnecessary delays in the review and production process.

Title page

The title page should include:

- The name(s) of the author(s)
- A concise and informative title
- The affiliation(s) and address(es) of the author(s)

- The e-mail address, telephone and fax numbers of the corresponding author

Abstract

Please provide an abstract of 120 words or less. The abstract should not contain any undefined abbreviations or unspecified references.

Keywords

Please provide 4 to 6 keywords which can be used for indexing purposes.

Text

Text Formatting

Manuscripts should be submitted in Word.

- Use a normal, plain font (e.g., 10-point Times Roman) for text.
- Use italics for emphasis.
- Use the automatic page numbering function to number the pages.
- Do not use field functions.
- Use tab stops or other commands for indents, not the space bar.
- Use the table function, not spreadsheets, to make tables.
- Use the equation editor or MathType for equations.
- Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Headings

Please use no more than three levels of displayed headings.

Abbreviations

Abbreviations should be defined at first mention and used consistently thereafter.

Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

Acknowledgments

Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

Body

- The body of the manuscript should begin on a separate page. The manuscript page header (if used) and page number should appear in the upper right corner. Type the title of the paper centered at the top of the page, add a hard return, and then begin the text using the format noted above. The body should contain:
- Introduction (The introduction has no label.)
- Methods (Center the heading. Use un-centered subheadings such as: Participants, Materials, Procedure.)
- Results (Center the heading.)
- Discussion (Center the heading.)

Headings

Please use no more than three levels of displayed headings.

Level 1: Centered

Level 2: Centered Italicized

Level 3: Flush left, Italicized

Footnotes

Center the label “Footnotes” at the top of a separate page. Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes. Type all content footnotes and copyright permission footnotes together, double-spaced, and numbered consecutively in the order they appear in the article. Indent the first line of each footnote 5-7 spaces. The number of the footnote should correspond to the number in the text. Superscript arabic numerals are used to indicate the text material being footnoted.

Author Note

The first paragraph contains a separate phrase for each author's name and the affiliations of the authors at the time of the study (include region and country).

The second paragraph identifies any changes in the author affiliation subsequent to the time of the study and includes region and country (wording: "authors name is now at affiliation".)

The third paragraph is Acknowledgments. It identifies grants or other financial support and the source, if appropriate. It is also the place to acknowledge colleagues who assisted in the study and to mention any special circumstances such as the presentation of a version of the paper at a meeting, or its preparation from a doctoral dissertation, or the fact that it is based on an earlier study.

The fourth paragraph states, "Correspondence concerning this article should be addressed to..." and includes the full address, telephone number and email address of the corresponding author.

Terminology

- Please always use internationally accepted signs and symbols for units (SI units).

Scientific style

- Generic names of drugs and pesticides are preferred; if trade names are used, the generic name should be given at first mention.
- Please use the standard mathematical notation for formulae, symbols etc.:Italic for single letters that denote mathematical constants, variables, and unknown quantities Roman/upright for numerals, operators, and punctuation, and commonly defined functions or abbreviations, e.g., cos, det, e or exp, lim, log, max, min, sin, tan, d (for derivative) Bold for vectors, tensors, and matrices.

References

Citation

Cite references in the text by name and year in parentheses. Some examples:

- Negotiation research spans many disciplines (Thompson, 1990).
- This result was later contradicted by Becker and Seligman (1996).
- This effect has been widely studied (Abbott, 1991; Barakat et al., 1995; Kelso & Smith, 1998; Medvec et al., 1999).

Authors are encouraged to follow official APA version 7 guidelines on the number of authors included in reference list entries (i.e., include all authors up to 20; for larger groups, give the first 19 names followed by an ellipsis and the final author's name). However, if authors shorten the author group by using et al., this will be retained.

Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text.

Reference list entries should be alphabetized by the last names of the first author of each work.

Journal names and book titles should be *italicized*.

If available, please always include DOIs as full DOI links in your reference list (e.g. "https://doi.org/abc").

- Journal article Grady, J. S., Her, M., Moreno, G., Perez, C., & Yelinek, J. (2019). Emotions in storybooks: A comparison of storybooks that represent ethnic and racial groups in the United States. *Psychology of Popular Media Culture, 8*(3), 207–217. https://doi.org/10.1037/ppm0000185
- Article by DOI Hong, I., Knox, S., Pryor, L., Mroz, T. M., Graham, J., Shields, M. F., & Reistetter, T. A. (2020). Is referral to home health rehabilitation following inpatient rehabilitation facility associated with 90-day hospital readmission for adult patients with stroke? *American Journal of Physical Medicine & Rehabilitation*. Advance online publication. https://doi.org/10.1097/PHM.0000000000001435
- Book Sapolsky, R. M. (2017). *Behave: The biology of humans at our best and worst*. Penguin Books.
- Book chapter Dillard, J. P. (2020). Currents in the study of persuasion. In M. B. Oliver, A. A. Raney, & J. Bryant (Eds.), *Media effects: Advances in theory and research* (4th ed., pp. 115–129). Routledge.
- Online document Fagan, J. (2019, March 25). *Nursing clinical brain*. OER Commons. Retrieved January 7, 2020, from https://www.oercommons.org/authoring/53029-nursing-clinical-brain/view

Tables

- All tables are to be numbered using Arabic numerals.
- Tables should always be cited in text in consecutive numerical order.
- For each table, please supply a table caption (title) explaining the components of the table.
- Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.
- Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

Each table should be inserted on a separate page at the back of the manuscript in the order noted above. A call-out for the correct placement of each table should be included in brackets within the text immediately after the phrase in which it is first mentioned. Copyright permission footnotes for tables are typed as a table note.

Appendix B

Systematic Review search syntax per database

Database	Syntax
PsycINFO, MEDLINE	((autis* or asperger* or "Pervasive developmental disorder*" or asd).mp. or exp autism spectrum disorders/) and ((resilien* or coping or hardiness or "protective factor*" or adversity or adaptiv* or adaptability).mp. or exp "resilience (psychological)"/ or exp coping behavior/)
ASSIA	(AB(autis* OR asperger* OR "Pervasive Developmental Disorder*" OR asd) OR TI(autis* OR asperger* OR "Pervasive Developmental Disorder*" OR asd) OR SU(autis* OR asperger* OR "Pervasive Developmental Disorder*" OR asd) OR TOC(autis* OR asperger* OR "Pervasive Developmental Disorder*" OR asd) OR OTI(autis* OR asperger* OR "Pervasive Developmental Disorder*" OR asd) OR IF(autis* OR asperger* OR "Pervasive Developmental Disorder*" OR asd) OR TM(autis* OR asperger* OR "Pervasive Developmental Disorder*" OR asd) OR MESH(autis* OR asperger* OR "Pervasive Developmental Disorder*" OR asd)) AND ((AB(Resilien* OR coping* OR adaptiv* OR adaptability OR hardiness OR "protective factor*" OR adversity) OR TI(Resilien* OR coping* OR adaptiv* OR adaptability OR hardiness OR "protective factor*" OR adversity) OR SU(Resilien* OR coping* OR adaptiv* OR adaptability OR hardiness OR "protective factor*" OR adversity) OR TOC(Resilien* OR coping* OR adaptiv* OR adaptability OR hardiness OR "protective factor*" OR adversity) OR OTI(Resilien* OR coping* OR adaptiv* OR adaptability OR hardiness OR "protective factor*" OR adversity) OR IF(Resilien* OR coping* OR adaptiv* OR adaptability OR hardiness OR "protective factor*" OR adversity) OR TM(Resilien* OR coping* OR adaptiv* OR adaptability OR hardiness OR "protective factor*" OR adversity) OR MESH(Resilien* OR coping* OR adaptiv* OR adaptability OR hardiness OR "protective factor*" OR adversity)) AND stype.exact("Scholarly Journals" OR "Trade Journals"))
Scopus	(TITLE-ABS-KEY (autis* OR asperger* OR "pervasive developmental disorder*" OR asd)) AND (TITLE-ABS-KEY (resilien* OR coping OR hardiness* OR "protective factor*" OR adversity OR adaptiv* OR adaptability)) AND (LIMIT-TO (DOCTYPE , "ar") OR LIMIT-TO (DOCTYPE , "re") OR LIMIT-TO (DOCTYPE , "ed"))
Web of Knowledge	(TS=(Autis* OR asperger* OR “Pervasive Developmental Disorder*” OR ASD) OR TI=(Autis* OR asperger* OR “Pervasive Developmental Disorder*” OR ASD) OR AB=(Autis* OR asperger* OR “Pervasive Developmental Disorder*” OR ASD) OR AK=(Autis* OR asperger* OR “Pervasive Developmental Disorder*” OR ASD) OR KP=(Autis* OR asperger* OR “Pervasive Developmental Disorder*” OR ASD)) AND (TS=(Resilien* OR coping* OR adaptiv* OR adaptability OR hardiness OR “protective factor*” OR adversity) OR TI=(Resilien* OR coping* OR adaptiv* OR adaptability OR hardiness OR “protective factor*” OR adversity) OR AB=(Resilien* OR coping* OR adaptiv* OR adaptability OR hardiness OR “protective factor*” OR adversity) OR AK=(Resilien* OR coping* OR adaptiv* OR adaptability OR hardiness OR “protective factor*” OR adversity) OR KP=(Resilien* OR coping* OR adaptiv* OR adaptability OR hardiness OR “protective factor*” OR adversity))

Appendix C

Systematic Review protocol

Background

Previous research has indicated that autistic adults are generally at higher risk of developing a range of mental health difficulties compared to the general population (Lai et al., 2019; Lugo-Martin et al., 2019). Many autistic people, however, demonstrate high levels of 'resilience' to the challenges of living in a neuro-typical world. The empirical evidence base has traditionally focused almost exclusively on risk factors that predict psychopathology and negative outcomes in autism (Szatmari, 2017). Conversely, an emergent research literature aims to explore psychological outcomes through the framework of resilience, "an interactive dynamic construct that considers protective factors and positive adaptation in adversity" (Stewart & Yuen, 2011).

A recent narrative review on risk and resilience in autism (Szatmari, 2018) calls for greater focus on protective factors in autism research, and qualitative studies involving autistic participants have indicated the importance of resilience to their quality of life (Guy et al., 2020). The resilience literature emphasises the interaction of individual and environmental factors in predicting outcome, which may yield novel data for services supporting autistic people (Lai & Szatmari, 2019). There may additionally be reason to believe that unique factors contribute to the coping strategies of autistic adults, including special interests and support from "atypical" friends (Dachez & Ndobo, 2018). Living in the current context of the COVID-19 pandemic may involve unique challenges for autistic adults (Ameis, Lai, Mulsant & Szatmari, 2020), and a resilience framework may help autistic people and those supporting them to mitigate current and future psychological strain.

The related but distinct concept of 'coping' refers to the specific strategies individuals use to manage demands that are perceived as stressful. Different coping strategies have been associated with mental health outcomes, and may support services in guiding intervention plans for health populations. Autistic adults experience increased levels of stress in comparison to the general population, and an understanding of coping may be beneficial for this population.

In support of the emerging evidence base around resilience and coping in autism, and to provide direction for future research efforts, the current paper will systemically review available studies which investigate the role of resilience and coping in the lives of autistic adults, and explore factors associated with these constructs.

Objective

To systematically review existing literature relating to resilience, coping and associated factors in autistic adults. The review will include any quantitative or qualitative study that presents evidence for the role of resilience, coping or related factors, in psychological outcomes and quality of life in autistic adults.

Review Questions

- How have the constructs of resilience and coping been defined, measured and explored in existing research involving autistic adults?
- What can existing studies tell us about factors associated with resilience and coping in autistic adults?
- What is the quality of available research evidence on the role of resilience and coping in psychological outcomes for autistic adults?

Search Strategy

Databases to be searched:

APA PsycInfo
Medline via OVID
Scopus
Web of Science
ASSIA

Reference searching

Hand searching will be performed through reference lists, related journals, and citations of articles in books.

Search Terms

Subject Heading	**Search terms**
Autism	Autis* **OR** asperger* **OR** "Pervasive Developmental Disorder*" OR ASD
AND	
Resilience	Resilien* **OR** coping* **OR** adapt* **OR** hardiness **OR** "protective factor*" **OR** adversity

Eligibility Criteria

Inclusion:

- Primary **published** research studies which measure or explore 'resilience', 'coping' and/or associated factors
- Peer-reviewed papers (including quantitative, qualitative, mixed-methods, single case design)
- English data based studies from any date
- Studies including participants aged 16 or over
- Participants report a formal diagnosis of ASD or supported through the use of a standardised autism screening tool)

Exclusion:

- Non-data based studies
- All participants under 16 years old
- Focus on the outcomes of others (family members / carers / health professionals.
- Diagnoses do not adhere to the inclusion criteria
- Data relevant to 'resilience', 'coping' or related constructs are not explicitly captured.

Screening and selection

All papers will be downloaded into Zotero referencing software and duplicates will be removed.The PRISMA flowchart will be used to measure searched studies against the inclusion / exclusion criteria.

Titles of all papers will assessed against exclusion criteria by CL. Papers remaining after exclusion criteria have been applied will progress to the next stage where abstracts will be screened. Full-texts of all remaining papers will be screened against exclusion criteria for inclusion in the quality assessment and data extraction stages. At each stage a second rater (JB), blinded to the other researcher's ratings, will additionally assess a random selection of 10% of the papers (titles, abstracts and full-texts). A Kappa statistic of inter-rater reliability will be reported, and any disagreements between raters will be resolved through discussion.

At the quality assessment stage, all remaining papers will be assessed by CL, with a randomly selected 25% of included papers additionally rated by JB. All disagreements on inclusion / exclusion will be discussed. Where agreement is not possible, the third rater will make the final judgement.

Data extraction

Once consensus has been reached on the reports to be included, data will be extracted independently by CL.

For all included reports, data to be extracted will be:

- Authors, year of publication, citation, country of study
- Research design, methodology used, study aim
- Details about the characteristics of the samples of the studies will be explored such as number of participants, age range, gender, comorbidity, type of autism diagnosis (autism, autism spectrum disorder)
- Details about how resilience, coping and related constructs are explored in samples of autistic adults, including measurement tools used and respondent type (parent, teacher, child self-report).

Risk of bias (quality) assessment

Study quality will be assessed using the Quality Assessment Tool for Studies with Diverse Designs (QATSDD).

Data Synthesis

A narrative synthesis detailing quality of included studies and a summary of factors associated with psychological resilience and coping in autistic adults will be presented.

References

Ameis, S.H., Lai, M., Mulsant, B.H. et al. Coping, fostering resilience, and driving care innovation for autistic people and their families during the COVID-19 pandemic and beyond. Molecular Autism 11, 61 (2020). https://doi.org/10.1186/s13229-020-00365-y

Ashley Guy, Rachel Harrell, Evangelina Rivera, Barbara Kornblau, Scott Robertson, Debora Oliveira; How Do Autistic Adults Define and Describe Resilience?. Am J Occup Ther 2020;74(4_Supplement_1):7411505204. https://doi.org/10.5014/ajot.2020.74S1-PO7512

Dachez, J., Ndobo, A. Coping Strategies of Adults with High-Functioning Autism: A Qualitative Analysis. J Adult Dev 25, 86–95 (2018). https://doi.org/10.1007/s10804-017-9278-5

Lai MC, Kassee C, Besney R, et al. Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. Lancet Psychiatry. 2019;6(10):819–829.

Lai MC, Szatmari P. Resilience in autism: Research and practice prospects. Autism : the International Journal of Research and Practice. 2019 Apr;23(3):539-541. DOI: 10.1177/1362361319842964.

Lugo-Marín et al., (2019) Prevalence of psychiatric disorders in adults with autism spectrum disorder: A systematic review and meta-analysis. Research in Autism Spectrum Disorders.59, 22-33.

Stewart DE, Yuen T. A systematic review of resilience in the physically ill. Psychosomatics. 2011 May-Jun;52(3):199-209. doi: 10.1016/j.psym.2011.01.036. PMID: 21565591.

Szatmari, P. (2018), Risk and resilience in autism spectrum disorder: a missed translational opportunity?. Dev Med Child Neurol, 60: 225-229. doi:10.1111/dmcn.13588

Appendix D: Systematic Review Quality Assessment Tool (QATSDD)

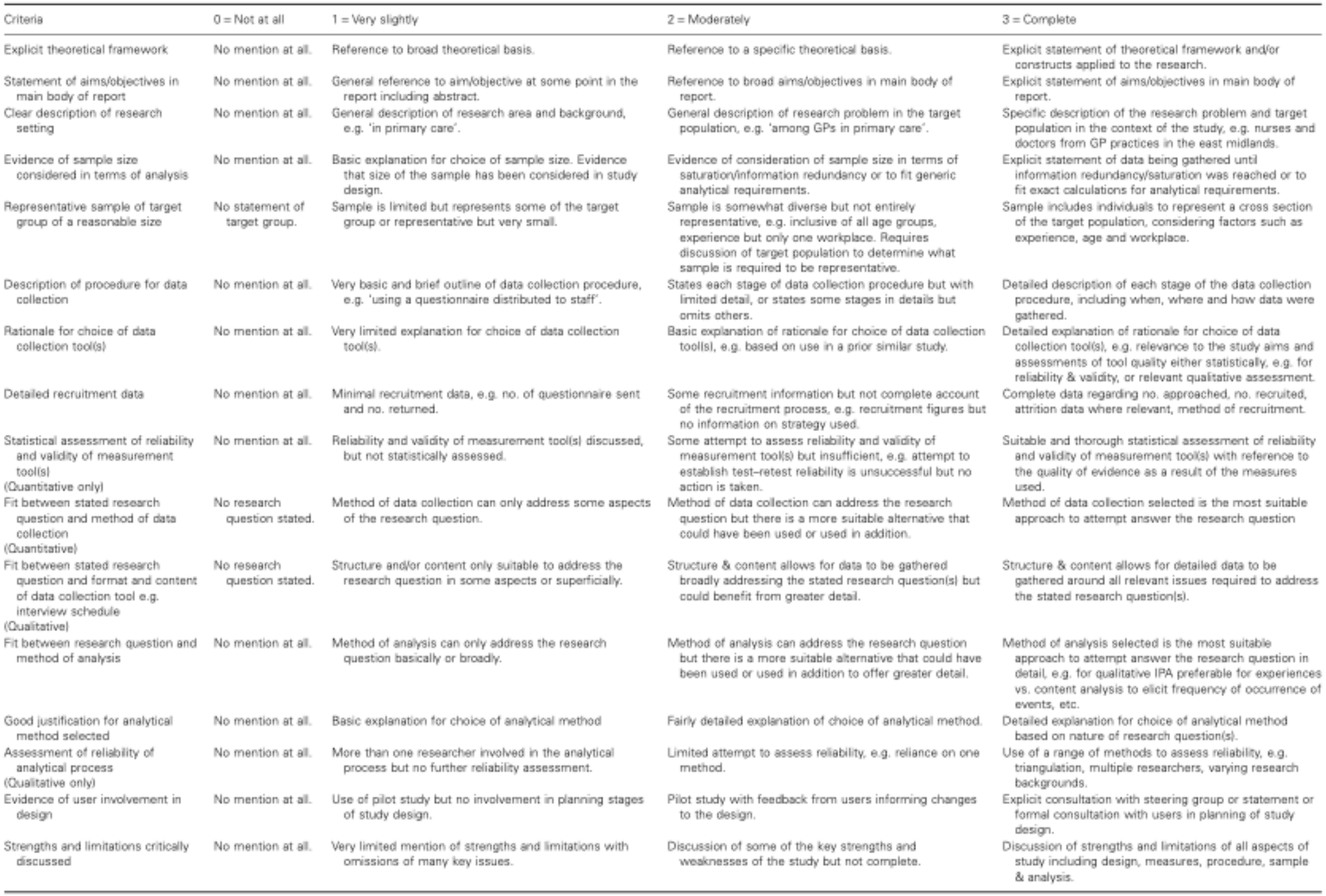


Table 1 Quality assessment tool and scoring guidance notes

Criteria	0 = Not at all	1 = Very slightly	2 = Moderately	3 = Complete
Explicit theoretical framework	No mention at all.	Reference to broad theoretical basis.	Reference to a specific theoretical basis.	Explicit statement of theoretical framework and/or constructs applied to the research.
Statement of aims/objectives in main body of report	No mention at all.	General reference to aim/objective at some point in the report including abstract.	Reference to broad aims/objectives in main body of report.	Explicit statement of aims/objectives in main body of report.
Clear description of research setting	No mention at all.	General description of research area and background, e.g. 'in primary care'.	General description of research problem in the target population, e.g. 'among GPs in primary care'.	Specific description of the research problem and target population in the context of the study, e.g. nurses and doctors from GP practices in the east midlands.
Evidence of sample size considered in terms of analysis	No mention at all.	Basic explanation for choice of sample size. Evidence that size of the sample has been considered in study design.	Evidence of consideration of sample size in terms of saturation/information redundancy or to fit generic analytical requirements.	Explicit statement of data being gathered until information redundancy/saturation was reached or to fit exact calculations for analytical requirements.
Representative sample of target group of a reasonable size	No statement of target group.	Sample is limited but represents some of the target group or representative but very small.	Sample is somewhat diverse but not entirely representative, e.g. inclusive of all age groups, experience but only one workplace. Requires discussion of target population to determine what sample is required to be representative.	Sample includes individuals to represent a cross section of the target population, considering factors such as experience, age and workplace.
Description of procedure for data collection	No mention at all.	Very basic and brief outline of data collection procedure, e.g. 'using a questionnaire distributed to staff'.	States each stage of data collection procedure but with limited detail, or states some stages in details but omits others.	Detailed description of each stage of the data collection procedure, including when, where and how data were gathered.
Rationale for choice of data collection tool(s)	No mention at all.	Very limited explanation for choice of data collection tool(s).	Basic explanation of rationale for choice of data collection tool(s), e.g. based on use in a prior similar study.	Detailed explanation of rationale for choice of data collection tool(s), e.g. relevance to the study aims and assessments of tool quality either statistically, e.g. for reliability & validity, or relevant qualitative assessment.
Detailed recruitment data	No mention at all.	Minimal recruitment data, e.g. no. of questionnaire sent and no. returned.	Some recruitment information but not complete account of the recruitment process, e.g. recruitment figures but no information on strategy used.	Complete data regarding no. approached, no. recruited, attrition data where relevant, method of recruitment.
Statistical assessment of reliability and validity of measurement tool(s) (Quantitative only)	No mention at all.	Reliability and validity of measurement tool(s) discussed, but not statistically assessed.	Some attempt to assess reliability and validity of measurement tool(s) but insufficient, e.g. attempt to establish test–retest reliability is unsuccessful but no action is taken.	Suitable and thorough statistical assessment of reliability and validity of measurement tool(s) with reference to the quality of evidence as a result of the measures used.
Fit between stated research question and method of data collection (Quantitative)	No research question stated.	Method of data collection can only address some aspects of the research question.	Method of data collection can address the research question but there is a more suitable alternative that could have been used or used in addition.	Method of data collection selected is the most suitable approach to attempt answer the research question
Fit between stated research question and format and content of data collection tool e.g. interview schedule (Qualitative)	No research question stated.	Structure and/or content only suitable to address the research question in some aspects or superficially.	Structure & content allows for data to be gathered broadly addressing the stated research question(s) but could benefit from greater detail.	Structure & content allows for detailed data to be gathered around all relevant issues required to address the stated research question(s).
Fit between research question and method of analysis	No mention at all.	Method of analysis can only address the research question basically or broadly.	Method of analysis can address the research question but there is a more suitable alternative that could have been used or used in addition to offer greater detail.	Method of analysis selected is the most suitable approach to attempt answer the research question in detail, e.g. for qualitative IPA preferable for experiences vs. content analysis to elicit frequency of occurrence of events, etc.
Good justification for analytical method selected	No mention at all.	Basic explanation for choice of analytical method	Fairly detailed explanation of choice of analytical method.	Detailed explanation for choice of analytical method based on nature of research question(s).
Assessment of reliability of analytical process (Qualitative only)	No mention at all.	More than one researcher involved in the analytical process but no further reliability assessment.	Limited attempt to assess reliability, e.g. reliance on one method.	Use of a range of methods to assess reliability, e.g. triangulation, multiple researchers, varying research backgrounds.
Evidence of user involvement in design	No mention at all.	Use of pilot study but no involvement in planning stages of study design.	Pilot study with feedback from users informing changes to the design.	Explicit consultation with steering group or statement or formal consultation with users in planning of study design.
Strengths and limitations critically discussed	No mention at all.	Very limited mention of strengths and limitations with omissions of many key issues.	Discussion of some of the key strengths and weaknesses of the study but not complete.	Discussion of strengths and limitations of all aspects of study including design, measures, procedure, sample & analysis.

Appendix E

Confirmation of ethical approval for empirical study

Dear Christopher,

The Ethics Committee has considered your revised PG project proposal: Psychological wellbeing and resilience among autistic adults in the UK during the COVID-19 pandemic (EC.20.05.12.6023R).

The project has been approved.

Please note that if any changes are made to the above project then you must notify the Ethics Committee.

Best wishes,
Adam Hammond

School of Psychology Research Ethics Committee

Cardiff University
Tower Building
70 Park Place
Cardiff
CF10 3AT

Tel: +44(0)29 208 70360
Email: psychethics@cardiff.ac.uk
http://psych.cf.ac.uk/aboutus/ethics.html

Prifysgol Caerdydd
Adeilad y Tŵr
70 Plas y Parc
Caerdydd
CF10 3AT

Ffôn: +44(0)29 208 70360
E-bost:psychethics@caerdydd.ac.uk

Appendix F

Participation invitation form

[To be included on the landing page of the online survey, Cardiff university logo displayed]

You are invited to take part in a research study exploring the mental health of people in the UK during the COVID-19 pandemic.

We are inviting people with and without a diagnosis of autism to take part, and we would really value your contribution.

The next page contains further details about the project and how you can get involved.

The lead researcher is working on this project as part of a doctorate training course in Clinical Psychology.

It is your choice if you want to take part. Your decision will have no effect on your current use of services.

If you decide to take part, you will be asked to complete an online questionnaire. You will be asked some questions about your mental health, and about your current living situation. It should take around 30 minutes to complete.

After you have completed the initial questionnaire, you will be sent another, much shorter questionnaire, every two weeks for the next three months. This should take less than 5 minutes to complete each time.

You will also have the option to take part in a short interview via video call, to find out more about how you have been coping during the pandemic. This is not mandatory – you may choose to complete the online surveys only.

Best wishes,

Chris Lewis

Trainee Clinical Psychologist,

School of Psychology, Tower Building, 70 Park Place, Cardiff, CF10 3AT.

e-mail: lewiscj16@cardiff.ac.uk

Appendix G

Participant Information Form

[To be displayed on second page of online survey, after clicking "continue" on Invitation landing page. Cardiff University logo to be displayed]

Title of study:	**Psychological wellbeing and resilience among autistic adults in the UK during the COVID-19 pandemic**
Principal Investigator:	Chris Lewis, Trainee Clinical Psychologist
Supervisors:	Dr John Fox, Consultant Clinical Psychologist Dr Rona Aldridge, Clinical Psychologist
Contact Details:	South Wales Clinical Psychology Doctorate, School of Psychology, Tower Building, 70 Park Place, Cardiff, CF10 3AT Email: lewiscj16@cardiff.ac.uk

We would like to invite you to take part in this research study to find out about the mental health of people in the UK during the COVID-19 coronavirus pandemic. The study aims to explore how current conditions (like social distancing measures) are affecting the mental health of autistic people, and whether this is different to the way it affects people who are not autistic.

You will be asked to complete an initial online survey, which should take approximately 30 minutes. After that, you will be sent a much shorter survey to complete every two weeks for the next three months. These fortnightly surveys should only take about five minutes to complete. When all of the information has been put together, the lead researcher will submit this study as part of his training in Clinical Psychology.

So that you can decide if you want to take part there is more information below about why the research is being done and what it will involve. Please take some time to read through and discuss with others if you wish. If you have any questions please contact us using the details above.

Thank you for reading the information and your interest in the study.

What the study is about

We want to find out how conditions around the COVID-19 coronavirus pandemic are affecting the mental health and wellbeing of people in the UK. The study will compare the experience of autistic people with people who are not autistic. We will be collecting information about how people's mood, anxiety levels and wellbeing change over the course of the pandemic.

We also want to find out about the ways people are coping with the current challenges, and what leads some people to be more resilient to stress during conditions like social distancing. We hope this information will help services to support those who may be struggling.

Why I have been chosen?

We contacted several charities and organisations to help us recruit people for this study. You may have seen the study advertised on social media or on a mailing list for one of these organisations. We are hoping that lots of people take part in this study, and your contribution would be really valuable.

Do I have to take part?

No. You only take part in the study if you want to. Even if you begin the survey or after you have completed several surveys, you can stop at any time without giving a reason. If you don't take part or decide to stop, it will not affect any services that you may be involved with.

What will happen

If you decide to take part, you will be directed to an initial survey on this website. The survey contains questions about your mental health, and the ways you cope with difficult situations. There are also general questions about your life at the moment. At no point will you be asked to submit any information that might identify you – your information will be kept secure and anonymous.

Once you have finished this survey, you will be sent another, much shorter survey to complete every two weeks for the next three months. These fortnightly surveys should only take about five minutes each to complete. This will help us understand how people's mental health changes over time.

We also hope to conduct longer interviews via phone or videocall with a small number of people at a later stage of the project. You can opt-in for the chance to be interviewed, but there is no requirement for you to do so.

The potential benefits and disadvantages of taking part

At the moment, there are lots of things we don't know about how the coronavirus pandemic is affecting people in the UK. If you choose to take part, your contribution will be very helpful for services supporting people who are most at need during the pandemic. It will also help services to prepare for any future periods of social distancing.

Will what I said be kept confidential?

If you take part in the study, all of the information that you give us will be kept confidential and anonymous. You will not be asked to provide any information that might identify you, and we will not be collecting contact details from participants. Instead, you will be provided with a unique identifier code when you begin the first survey – this will help us to join up your responses over the three month period.

The information you submit via the online survey platform will be transmitted securely through GDPR-compliant servers. The data will be downloaded directly from the survey platform by the lead researcher and stored on an encrypted, password-protected device. Only members of the research team listed above will view the data you provide, and this will be deleted following submission of the published paper.

The consent form is the only form that will have your name on it. It will be kept in a locked filing cabinet in the Cardiff University Clinical Psychology Department. Your interview will be typed up within a month and then the recording will be deleted. All of the information from the interview, including the background information sheet and the typed up interview will be numbered and contain made up names. All computer files will be password protected and only accessible by the lead researcher and her two supervisors listed below.

The data controller is Cardiff University and the Data Protection Officer is Matt Cooper – CooperM1@cardiff.ac.uk

The lawful basis for the processing of the data you provide is consent.

What will happen to the results of the study?

Your responses and those of other participants will be put together to try and understand how conditions around the COVID-19 pandemic are affecting the mental health of autistic people and people who are not autistic. The results will be submitted as part of the lead researcher's training in Clinical Psychology. They may also be written up and published in an academic journal. No information that could identify individuals will be used.

You can choose to receive an email notification from the online survey platform once the paper has been published, with a link to download the paper.

Who is sponsoring the research?

Cardiff and Vale University Health Board is funding the research and Cardiff University is sponsoring the research.

Who has said that the study is OK to go ahead?

The research study has been reviewed and approved by the School of Psychology Research Ethics Committee at Cardiff University. If you have any concerns or complaints about the research you can contact the School of Psychology Research Ethics Committee in writing at:

Secretary to the Research Ethics Committee School of Psychology
Tower Building
70 Park Place

Cardiff CF10 3AT

psychethics@cardiff.ac.uk
If you would like more information about the project, please feel free to contact us:

Chris Lewis

Trainee Clinical Psychologist, Postgraduate student. South Wales Doctoral Programme in Clinical Psychology 11th Floor, School of Psychology, Tower Building,
70 Park Place,
Cardiff,
CF10 3AT

Email: lewiscj16@cardiff.ac.uk

Research Supervisor: Dr John Fox, Consultant Clinical Psychologist

South Wales Doctoral Programme in Clinical Psychology Cardiff & Vale UHB

Email: FoxJ10@cardiff.ac.uk

Appendix H

Participant Consent Form

[To be displayed on third page of online survey, after clicking "continue" on Study Information page. Cardiff University logo to be displayed]

Title of study:	**Psychological wellbeing and resilience among autistic adults in the UK during the COVID-19 pandemic**
Principal Investigator:	Chris Lewis, Trainee Clinical Psychologist
Supervisors:	Dr John Fox, Consultant Clinical Psychologist Dr Rona Aldridge, Clinical Psychologist
Contact Details:	South Wales Clinical Psychology Doctorate, School of Psychology, Tower Building, 70 Park Place, Cardiff, CF10 3AT Email: lewiscj16@cardiff.ac.uk

[Participants will be required to click on tick boxes for each item below to indicate informed consent to take part in the study:]

1. I understand that my participation in this project will involve completing an online survey about my mental health during the COVID-19 pandemic, and that I will be notified to complete additional, shorter surveys every two weeks for a period of three months. ☒

2. I have read and understood the information provided on the previous page. ☒

3. I understand that participation in this study is entirely voluntary and that I can withdraw from the study at any time without giving a reason. This will not affect my access to services. ☒

4. I understand that I am free to ask any questions at any time. I can discuss any concerns with the lead researcher or the University Ethics Committee. ☒

5. I understand that the information provided by me will be kept securely and confidentially. I understand that this information will be held no longer than necessary for the purposes of this research. ☒

6. I understand that my name and other identifying details will not be collected as part of this study. ☒

7. I understand that I can opt-out of any future invitations to take part in follow-up interviews with the lead researcher. ☒

8. I understand that at the end of the study I will be provided with additional information and feedback about the purpose of the study. ☒

9. I agree to take part in the above study. ☒

10. I confirm that I am an adult of age 18 years or older ☒

I consent to participate in the study conducted by Chris Lewis, School of Psychology, Cardiff University with the supervision of Dr John Fox and Dr Rona Aldridge. ☒

Appendix I

Debriefing form for online survey

[To be displayed on final page of online survey, after clicking “submit responses”. Cardiff University logo to be displayed]

Title of study: **Psychological wellbeing and resilience among autistic adults in the UK during the COVID-19 pandemic**

Thank you for taking part in this study. The information that you have provided in your survey will be put together and analysed with the other surveys collected for this research. We hope that the results from this study will help us to understand how the COVID-19 pandemic is affecting the mental health of people in the UK, and how services can support those who are most in need. This information could be useful for services supporting autistic people to consider for future clients.

If you are experiencing mental health difficulties, please contact your GP for further support.

The information that you have submitted will be sent to the lead researcher, and will be stored securely on an encrypted, password-protected device. The information will only be viewed by members of the research team.

If you have any further questions please contact us:

Researcher: Chris Lewis

Trainee Clinical Psychologist, Postgraduate student

Lewiscj16@cardiff.ac.uk

South Wales Doctoral Programme in Clinical Psychology, 11th Floor, School of Psychology, Tower Building,
70 Park Place, Cardiff, CF10 3AT

If you have any concerns or complaints about the research you can contact the School of Psychology Research Ethics Committee in writing at:
Secretary to the Research Ethics Committee
School of Psychology, Tower Building

70 Park Place, Cardiff, CF10 3AT

psychethics@cardiff.ac.uk

Appendix VI:

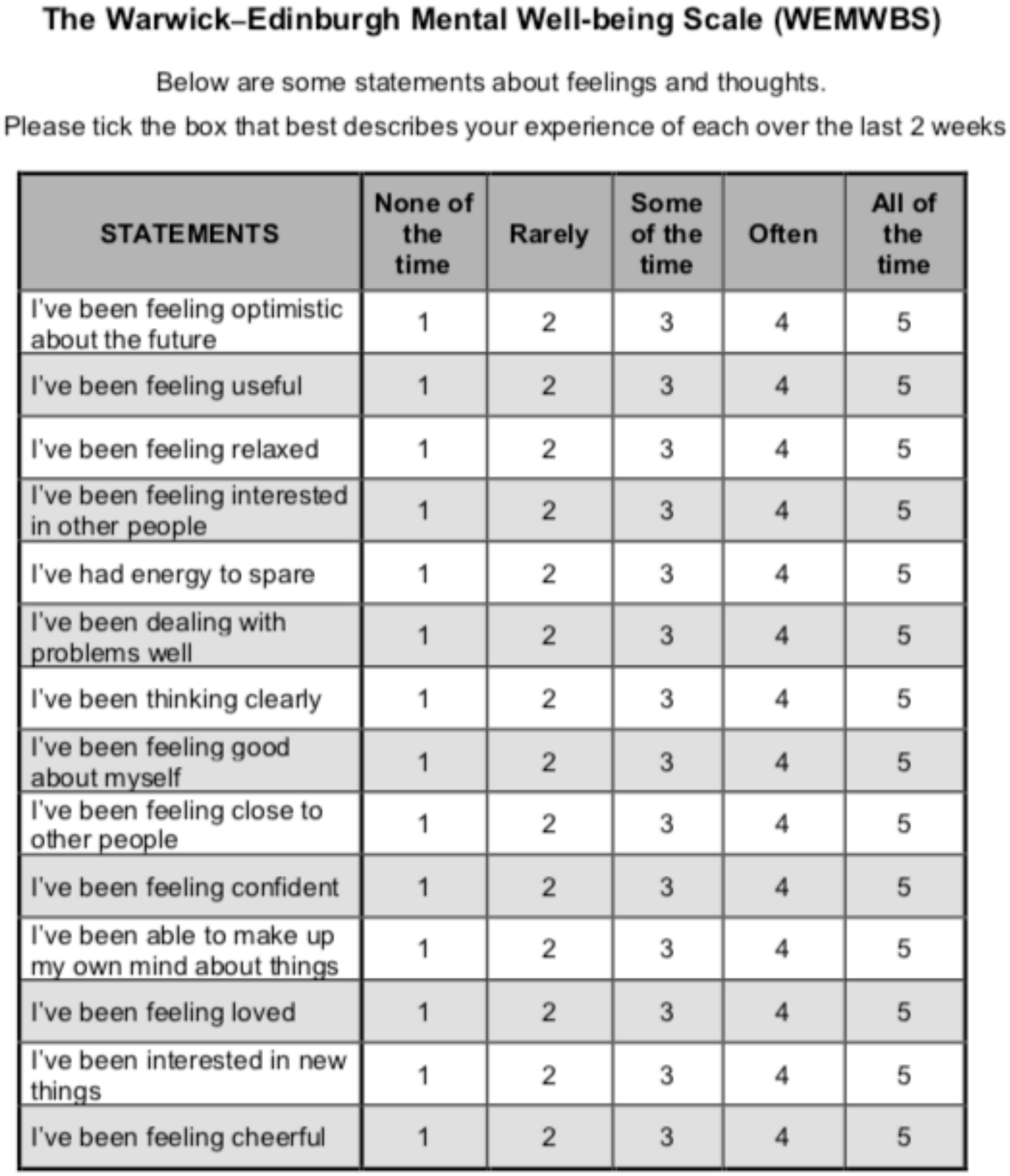
Measures included in online survey

Patient Health Questionnaire (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day	No response
1. Little interest or pleasure in doing things	☐	☐	☐	☐	☐
2. Feeling down, depressed or hopeless	☐	☐	☐	☐	☐
3. Trouble falling or staying asleep, or sleeping too much	☐	☐	☐	☐	☐
4. Feeling tired or having little energy	☐	☐	☐	☐	☐
5. Poor appetite or overeating	☐	☐	☐	☐	☐
6. Feeling bad about yourself - or that you are a failure or have let yourself or your family down	☐	☐	☐	☐	☐
7. Trouble concentrating on things, such as reading the newspaper or watching television	☐	☐	☐	☐	☐
8. Moving or speaking so slowly that people could have noticed. Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual	☐	☐	☐	☐	☐
9. Thoughts that you would be better off dead, or hurting yourself in some way	☐	☐	☐	☐	☐

Generalised Anxiety Disorder – 7 (GAD-7)

Over the last 2 weeks, how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day	No response
1. Feeling nervous, anxious or on edge	☐	☐	☐	☐	☐
2. Not being able to stop or control worrying	☐	☐	☐	☐	☐
3. Worrying too much about different things	☐	☐	☐	☐	☐
4. Trouble relaxing	☐	☐	☐	☐	☐
5. Being so restless that it hard to sit still	☐	☐	☐	☐	☐
6. Becoming easily annoyed or irritable	☐	☐	☐	☐	☐
7. Feeling afraid as if something awful might happen	☐	☐	☐	☐	☐



The Warwick–Edinburgh Mental Well-being Scale (WEMWBS)

Below are some statements about feelings and thoughts.

Please tick the box that best describes your experience of each over the last 2 weeks

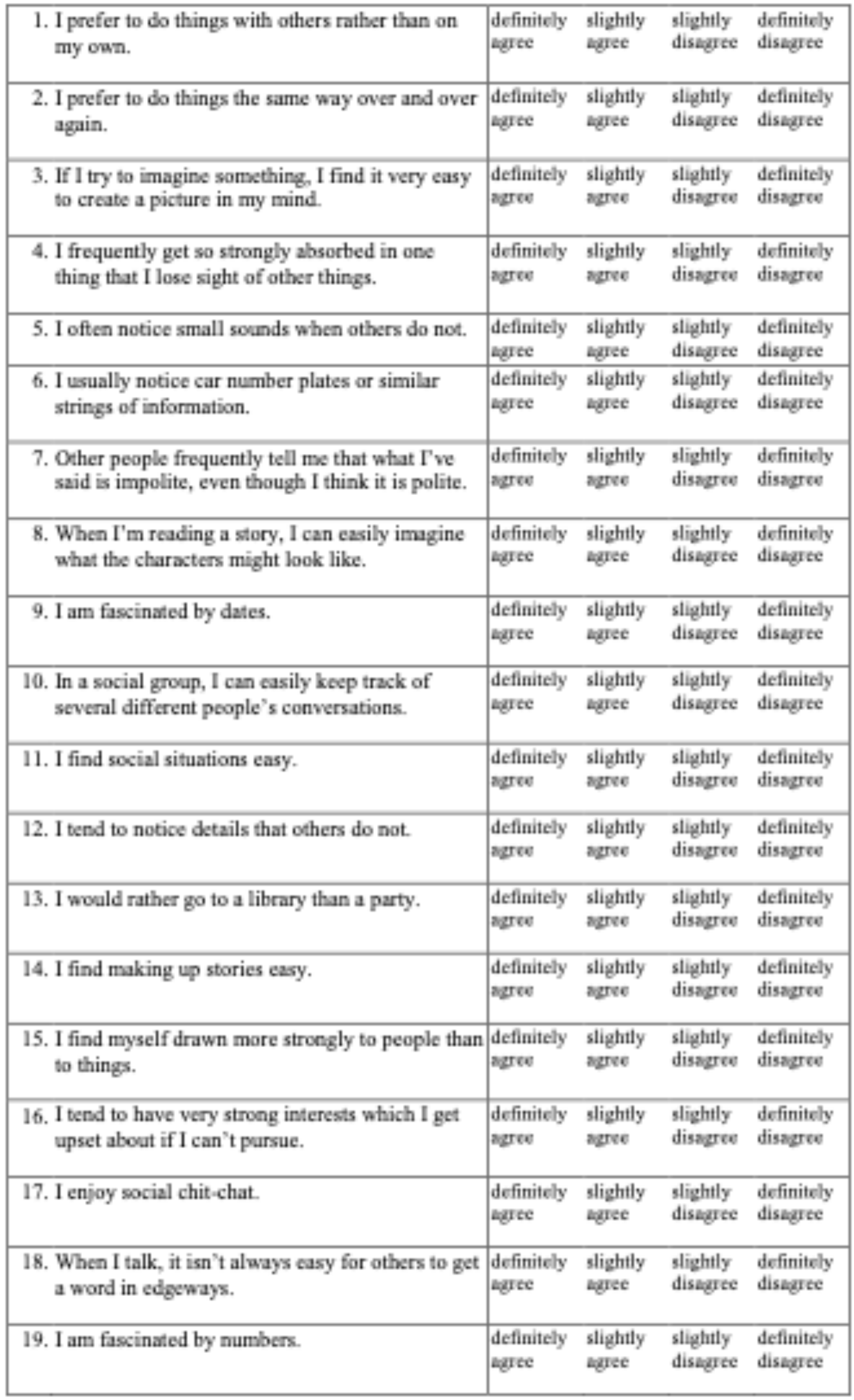
STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been feeling interested in other people	1	2	3	4	5
I've had energy to spare	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling good about myself	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been feeling confident	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5
I've been feeling loved	1	2	3	4	5
I've been interested in new things	1	2	3	4	5
I've been feeling cheerful	1	2	3	4	5

Intolerance of Uncertainty Scale (IUS-12)

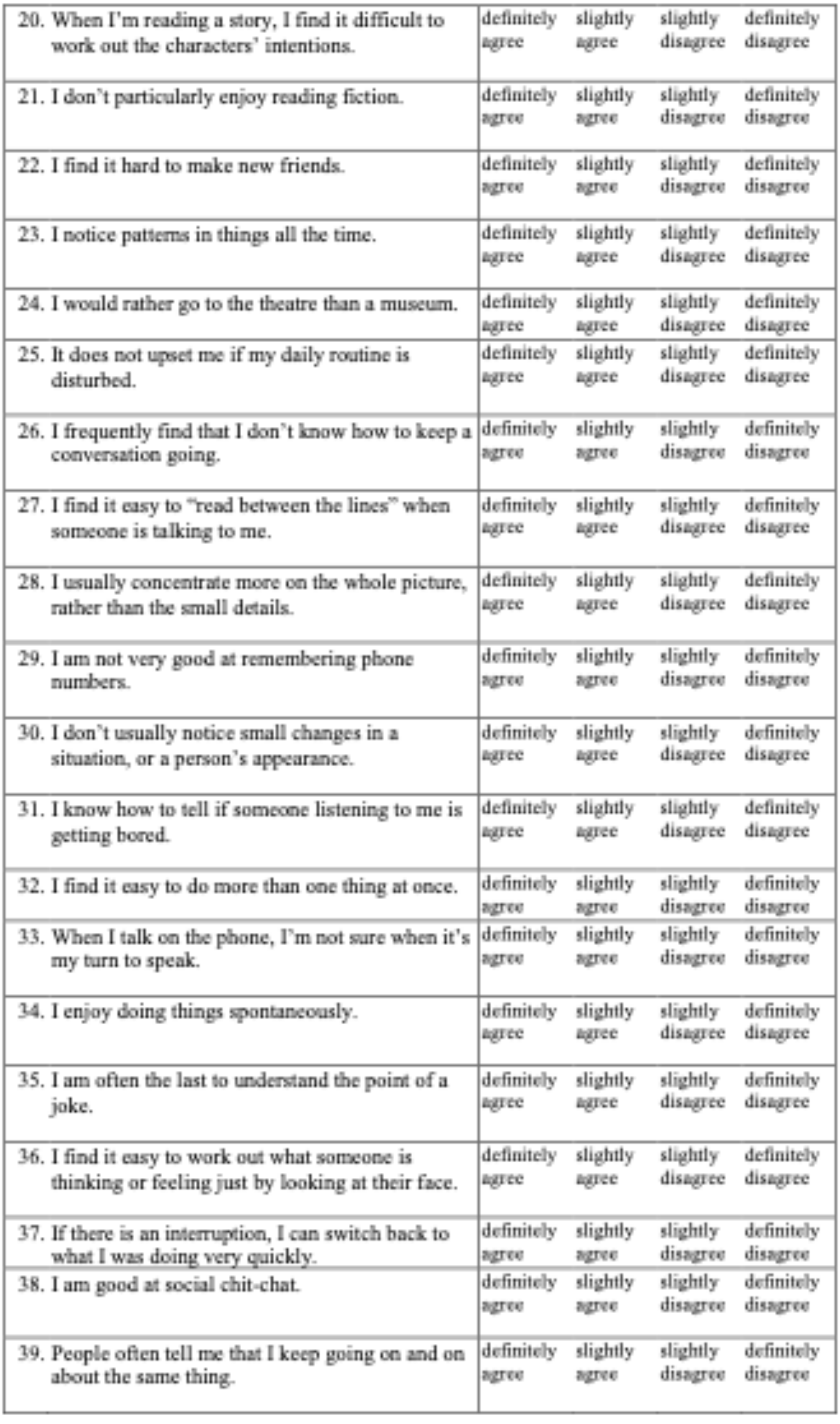
You will find below a series of statements which describe how people may react to the uncertainties of life. Please use the scale below to describe to what extent each item is characteristic of you. Please circle a number (1 to 5) that describes you best.

	Not at all characteristic of me		Somewhat characteristic of me		Entirely characteristic of me
1. Unforeseen events upset me greatly.	1	2	3	4	5
2. It frustrates me not having all the information I need.	1	2	3	4	5
3. One should always look ahead so as to avoid surprises.	1	2	3	4	5
4. A small unforeseen event can spoil everything, even with the best of planning.	1	2	3	4	5
5. I always want to know what the future has in store for me.	1	2	3	4	5
6. I can't stand being taken by surprise.	1	2	3	4	5
7. I should be able to organize everything in advance.	1	2	3	4	5
8. Uncertainty keeps me from living a full life.	1	2	3	4	5
9. When it's time to act, uncertainty paralyses me.	1	2	3	4	5
10. When I am uncertain I can't function very well.	1	2	3	4	5
11. The smallest doubt can stop me from acting.	1	2	3	4	5
12. I must get away from all uncertain situations.	1	2	3	4	5

Autism Quotient (AQ-50)



1. I prefer to do things with others rather than on my own.	definitely agree	slightly agree	slightly disagree	definitely disagree
2. I prefer to do things the same way over and over again.	definitely agree	slightly agree	slightly disagree	definitely disagree
3. If I try to imagine something, I find it very easy to create a picture in my mind.	definitely agree	slightly agree	slightly disagree	definitely disagree
4. I frequently get so strongly absorbed in one thing that I lose sight of other things.	definitely agree	slightly agree	slightly disagree	definitely disagree
5. I often notice small sounds when others do not.	definitely agree	slightly agree	slightly disagree	definitely disagree
6. I usually notice car number plates or similar strings of information.	definitely agree	slightly agree	slightly disagree	definitely disagree
7. Other people frequently tell me that what I've said is impolite, even though I think it is polite.	definitely agree	slightly agree	slightly disagree	definitely disagree
8. When I'm reading a story, I can easily imagine what the characters might look like.	definitely agree	slightly agree	slightly disagree	definitely disagree
9. I am fascinated by dates.	definitely agree	slightly agree	slightly disagree	definitely disagree
10. In a social group, I can easily keep track of several different people's conversations.	definitely agree	slightly agree	slightly disagree	definitely disagree
11. I find social situations easy.	definitely agree	slightly agree	slightly disagree	definitely disagree
12. I tend to notice details that others do not.	definitely agree	slightly agree	slightly disagree	definitely disagree
13. I would rather go to a library than a party.	definitely agree	slightly agree	slightly disagree	definitely disagree
14. I find making up stories easy.	definitely agree	slightly agree	slightly disagree	definitely disagree
15. I find myself drawn more strongly to people than to things.	definitely agree	slightly agree	slightly disagree	definitely disagree
16. I tend to have very strong interests which I get upset about if I can't pursue.	definitely agree	slightly agree	slightly disagree	definitely disagree
17. I enjoy social chit-chat.	definitely agree	slightly agree	slightly disagree	definitely disagree
18. When I talk, it isn't always easy for others to get a word in edgeways.	definitely agree	slightly agree	slightly disagree	definitely disagree
19. I am fascinated by numbers.	definitely agree	slightly agree	slightly disagree	definitely disagree



20. When I'm reading a story, I find it difficult to work out the characters' intentions.	definitely agree	slightly agree	slightly disagree	definitely disagree
21. I don't particularly enjoy reading fiction.	definitely agree	slightly agree	slightly disagree	definitely disagree
22. I find it hard to make new friends.	definitely agree	slightly agree	slightly disagree	definitely disagree
23. I notice patterns in things all the time.	definitely agree	slightly agree	slightly disagree	definitely disagree
24. I would rather go to the theatre than a museum.	definitely agree	slightly agree	slightly disagree	definitely disagree
25. It does not upset me if my daily routine is disturbed.	definitely agree	slightly agree	slightly disagree	definitely disagree
26. I frequently find that I don't know how to keep a conversation going.	definitely agree	slightly agree	slightly disagree	definitely disagree
27. I find it easy to "read between the lines" when someone is talking to me.	definitely agree	slightly agree	slightly disagree	definitely disagree
28. I usually concentrate more on the whole picture, rather than the small details.	definitely agree	slightly agree	slightly disagree	definitely disagree
29. I am not very good at remembering phone numbers.	definitely agree	slightly agree	slightly disagree	definitely disagree
30. I don't usually notice small changes in a situation, or a person's appearance.	definitely agree	slightly agree	slightly disagree	definitely disagree
31. I know how to tell if someone listening to me is getting bored.	definitely agree	slightly agree	slightly disagree	definitely disagree
32. I find it easy to do more than one thing at once.	definitely agree	slightly agree	slightly disagree	definitely disagree
33. When I talk on the phone, I'm not sure when it's my turn to speak.	definitely agree	slightly agree	slightly disagree	definitely disagree
34. I enjoy doing things spontaneously.	definitely agree	slightly agree	slightly disagree	definitely disagree
35. I am often the last to understand the point of a joke.	definitely agree	slightly agree	slightly disagree	definitely disagree
36. I find it easy to work out what someone is thinking or feeling just by looking at their face.	definitely agree	slightly agree	slightly disagree	definitely disagree
37. If there is an interruption, I can switch back to what I was doing very quickly.	definitely agree	slightly agree	slightly disagree	definitely disagree
38. I am good at social chit-chat.	definitely agree	slightly agree	slightly disagree	definitely disagree
39. People often tell me that I keep going on and on about the same thing.	definitely agree	slightly agree	slightly disagree	definitely disagree

40. When I was young, I used to enjoy playing games involving pretending with other children.	definitely agree	slightly agree	slightly disagree	definitely disagree
41. I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant, etc.).	definitely agree	slightly agree	slightly disagree	definitely disagree
42. I find it difficult to imagine what it would be like to be someone else.	definitely agree	slightly agree	slightly disagree	definitely disagree
43. I like to plan any activities I participate in carefully.	definitely agree	slightly agree	slightly disagree	definitely disagree
44. I enjoy social occasions.	definitely agree	slightly agree	slightly disagree	definitely disagree
45. I find it difficult to work out people's intentions.	definitely agree	slightly agree	slightly disagree	definitely disagree
46. New situations make me anxious.	definitely agree	slightly agree	slightly disagree	definitely disagree
47. I enjoy meeting new people.	definitely agree	slightly agree	slightly disagree	definitely disagree
48. I am a good diplomat.	definitely agree	slightly agree	slightly disagree	definitely disagree
49. I am not very good at remembering people's date of birth.	definitely agree	slightly agree	slightly disagree	definitely disagree
50. I find it very easy to play games with children that involve pretending.	definitely agree	slightly agree	slightly disagree	definitely disagree

Developed by:
The Autism Research Centre
University of Cambridge

Connor-Davidson Resilience Scale 25 (CD-RISC-25) ©

*For each item, please mark an "**x**" in the box below that best indicates how much you agree with the following statements as they apply to you over the last **month**. If a particular situation has not occurred recently, answer according to how you think you would have felt.*

		not true at all (0)	rarely true (1)	sometimes true (2)	often true (3)	true nearly all the time (4)
1.	I am able to adapt when changes occur.	☐	☐	☐	☐	☐
2.	I have at least one close and secure relationship that helps me when I am stressed.	☐	☐	☐	☐	☐
3.	When there are no clear solutions to my problems, sometimes fate or God can help.	☐	☐	☐	☐	☐
4.	I can deal with whatever comes my way.	☐	☐	☐	☐	☐
5.	Past successes give me confidence in dealing with new challenges and difficulties.	☐	☐	☐	☐	☐
6.	I try to see the humorous side of things when I am faced with problems.	☐	☐	☐	☐	☐
7.	Having to cope with stress can make me stronger.	☐	☐	☐	☐	☐
8.	I tend to bounce back after illness, injury, or other hardships.	☐	☐	☐	☐	☐
9.	Good or bad, I believe that most things happen for a reason.	☐	☐	☐	☐	☐
10.	I give my best effort no matter what the outcome may be.	☐	☐	☐	☐	☐
11.	I believe I can achieve my goals, even if there are obstacles.	☐	☐	☐	☐	☐
12.	Even when things look hopeless, I don't give up.	☐	☐	☐	☐	☐
13.	During times of stress/crisis, I know where to turn for help.	☐	☐	☐	☐	☐
14.	Under pressure, I stay focused and think clearly.	☐	☐	☐	☐	☐
15.	I prefer to take the lead in solving problems rather than letting others make all the decisions.	☐	☐	☐	☐	☐
16.	I am not easily discouraged by failure.	☐	☐	☐	☐	☐
17.	I think of myself as a strong person when dealing with life's challenges and difficulties.	☐	☐	☐	☐	☐
18.	I can make unpopular or difficult decisions that affect other people, if it is necessary.	☐	☐	☐	☐	☐
19.	I am able to handle unpleasant or painful feelings like sadness, fear, and anger.	☐	☐	☐	☐	☐
20.	In dealing with life's problems, sometimes you have to act on a hunch without knowing why.	☐	☐	☐	☐	☐
21.	I have a strong sense of purpose in life.	☐	☐	☐	☐	☐
22.	I feel in control of my life.	☐	☐	☐	☐	☐
23.	I like challenges.	☐	☐	☐	☐	☐
24.	I work to attain my goals no matter what roadblocks I encounter along the way.	☐	☐	☐	☐	☐
25.	I take pride in my achievements.	☐	☐	☐	☐	☐

Add up your score for each column 0 + ____ + ____ + ____ + ____

Add each of the column totals to obtain CD-RISC score = ____________________________

Multidimensional Scale of Perceived Social Support

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the "1" if you **Very Strongly Disagree**
Circle the "2" if you **Strongly Disagree**
Circle the "3" if you **Mildly Disagree**
Circle the "4" if you are **Neutral**
Circle the "5" if you **Mildly Agree**
Circle the "6" if you **Strongly Agree**
Circle the "7" if you **Very Strongly Agree**

		Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree
1.	There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2.	There is a special person with whom I can share joys and sorrows.	1	2	3	4	5	6	7
3.	My family really tries to help me.	1	2	3	4	5	6	7
4.	I get the emotional help & support I need from my family.	1	2	3	4	5	6	7
5.	I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6.	My friends really try to help me.	1	2	3	4	5	6	7
7.	I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8.	I can talk about my problems with my family.	1	2	3	4	5	6	7
9.	I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10.	There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11.	My family is willing to help me make decisions.	1	2	3	4	5	6	7
12.	I can talk about my problems with my friends.	1	2	3	4	5	6	7