Facing Stress: Coping Strategies, Resilience and Mental Health

Outcomes in Autistic Adults

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List of Abbreviations

ACCESS Program – Acquiring Career, Coping, Executive control, Social Skills Program

ACE – Adverse Childhood Events

ACT – Acceptance and Commitment Therapy

ADHD - Attention Deficit Hyperactivity Disorder

ALSAA - Australian Longitudinal Study of Autistic Adults

ANN – Artificial Neural Network

APA - American Psychiatric Association

AQ-Short – Autism Spectrum Quotient-Short

ASD – Autism Spectrum Disorder

AUD – Australian Dollar

AutismCRC - Cooperative Research Centre for Living with Autism

AutismNT – Autism Northern Territory

AutismQLD – Autism Queensland

AutismWA – Autism Western Australia

Brief COPE – Brief Coping Orientation to Problems Experienced

CBT - Cognitive Behavioural Therapy

CD-RISC10 – 10 item Connor-Davidson Resilience Scale

COR – Conservation of Resources

COVID-19 – Coronavirus-19

CYRM-SR-28 – Child and Youth Resilience Measure Self Report – 28 item

DSI – Daily Stress Inventory

DSM-5 Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition

EI – Emotional Intelligence

EMA – Ecological Momentary Assessment

ER – Emotion Regulation

FCQ – Fear of Coronavirus Questionnaire

GAD-D - Generalized Anxiety Disorder-Dimensional Scale

HPA - Hypothalamic-Pituitary-Adrenal

ICD-10 - International Classification of Diseases 10th Revision

ID – Intellectual Disability

IU – Intolerance of Uncertainty

LGBTQI - Lesbian, Gay, Bisexual, Transgender, Queer and Intersex

MBI – Mindfulness Based Intervention

NSCH – National Survey of Children's Health

OTARC – Olga Tennison Autism Research Centre

PDD-NOS - Pervasive Developmental Disorder-Not Otherwise Specified.

PHQ-9 - Patient Health Questionnaire-9

PSS-10 – 10 item Perceived Stress Scale

PTG – Post Traumatic Growth

PTSD – Post Traumatic Stress Disorder

QoL – Quality of Life

RAP-ASD – Resourceful Adolescent Program – Autism Spectrum Disorder

RBP – Resilience Builder Therapy Program

READY - Resilience and Activity for every DaY

RPAAS – Resilience Pathways in Autistic Adults Study

SASLA - Study of Australian School Leavers with Autism

STEPS - Stepped Transition in Education Program for Students with ASD

TAFE – Technical and Further Education

TLRE - Transforming Lives Through Resilience Education

TMSC – Transactional Model of Stress and Coping

WEMWBS – Warwick Edinburgh Mental Well-being Scale

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Thesis Abstract

There is consensus surrounding the poor mental health outcomes experienced by many autistic adults. The non-autistic literature suggests that high stress represents a key contributor to the development and maintenance of psychopathology but individual resources such as coping and resilience have the potential to mitigate the effects of stress on mental health, accounting for individual differences across mental health outcomes. Despite emerging research showing high stress in autistic adults, investigations of coping and resilience in this population are scarce. The aim of this thesis was to examine coping strategies and resilience, and their associations with stress, mental health and well-being in an autistic adult population. Six empirical studies were conducted to address this over four overarching aims. The studies examined the: 1) validity of the Brief COPE to examine coping patterns; 2) cross-sectional and longitudinal associations between coping strategies and mental health outcomes; 3) stress-moderating role of coping strategies on psychological well-being; and 4) inter-relationships between coping strategies and resilience in relation to stress and mental health in autistic adults. Overall, the results demonstrated the validity of a six-factor structure for the Brief COPE in autistic adults. Disengagement coping and engagement coping strategies represented risk and protective factors respectively in relation to mental health outcomes, both cross-sectionally and longitudinally. However, while engagement coping strategies moderated the effects of stress on well-being, disengagement coping strategies did not. Joint examination of coping and resilience revealed the mediating role of coping strategies in resilience-mental health relationships, as well as coping-resilience profiles characterising autistic adults at risk for high stress. Together, these results highlight the significance of coping and resilience patterns of autistic adults for their mental health and well-being, the importance of capturing these patterns, and their potential usefulness in the development and design of stress and mental health supports for this population.

Publications Reproduced in the Thesis

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Statement of Authorship

This thesis includes work that has been submitted, accepted or published for journal publication. This thesis comprises six empirical papers and as such, several other individuals have contributed to these articles; see table below for detailed contributions. For all empirical papers, I conceptualised the rationale for the research, conducted data analyses and produced all the written material. Manuscripts 1 (Chapter 6), 2 (Chapter 7), 3 (Chapter 8) and 5 (Chapter 10) utilised secondary data from two longitudinal Australian autistic adult studies: longitudinal Study of Australian School Leavers with Autism (SASLA) and the Australian Longitudinal Study of Autistic Adults (ALSAA). During my candidature, SASLA was overseen by Professor Amanda Richdale, Dr Lauren Lawson and Alex Haschek, and ALSAA by Professor Julian Trollor and Dr Samuel Arnold. Manuscripts 4 and 6 (Chapters 10 and 12) were derived from the Resilience Pathways for Autistic Adults Study (RPAAS). I managed all aspects of research for RPAAS, including study design, recruitment of participants, data collection, analysis and the write up of associated manuscripts. I formatted all manuscripts, submitted them to specific journals and incorporated revisions where necessary. Beyond the empirical studies, I also provided the conceptual and theoretical framework for this thesis.

SASLA and ALSAA empirical manuscripts (Chapters 6, 7, 8 and 10)		
Co-authors	Contributions	Percentage of Contribution
Melanie Muniandy	Conception and design of study, analysis and interpretation of research data, drafted manuscripts and incorporated revisions	70%
Amanda L. Richdale & Lauren P. Lawson	Acquisition of research data, contribution of knowledge, critically reviewing and revising manuscripts	20%
Julian N. Trollor & Samuel R. C. Arnold	Acquisition of research data, contribution of knowledge and manuscript revision	10%
RPAAS empirical manuscripts (Chapters 9 and 11)		
Melanie Muniandy	Acquisition of research data, conception and design of study, analysis and interpretation of research data, drafted manuscripts and incorporated revision	70%
Amanda L. Richdale & Lauren P. Lawson	Contribution of knowledge, critically reviewing and revising manuscripts	30%

Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis accepted for the award of any other degree or diploma. No other person's work has been used without due acknowledgment in the main text of the thesis. This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution. All research procedures reported in this thesis were approved by the La Trobe University Human Ethics Committee (SASLA: HEC14-095 and RPAAS: HEC19443) and University of New South Wales Human Research Ethics Committee (ALSAA: HC15001).

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Chapter 1: General Introduction

Chapter Overview

This chapter provides a brief overview of Autism Spectrum Disorder (ASD), including its characteristics, aetiology and prevalence. The focus of this thesis is on the autistic adult population. A review on autism in adulthood and adult outcomes is provided, concluding with co-occurring mental health conditions and psychological well-being, and highlighting the high stress faced in autistic adults, which may be a risk factor for poor mental health in this population. Within the context of stress, a case is then made for the importance of coping strategies and resilience, which might underlie mental health outcomes in autistic adults. The chapter concludes with an overview of the current project and the structure of this thesis.

1.1. Autism Characteristics, Aetiology and Prevalence

Autism Spectrum Disorder (ASD; hereafter referred to as autism) can be referred to as a collection of neurodevelopmental disorders typically characterised by pervasive impairments in reciprocal social communication and social interactions, as well as restricted, repetitive and stereotyped patterns of behaviour (APA, 2022)[1]. While most autistic individuals experience challenges and difficulties across these broad domains, there remains great heterogeneity within the autism phenotype, with differences in the severity, manifestations and presentations of autistic traits across this population (Masi et al., 2017). Autistic symptomatology trajectories are said to change across age and time (Howlin et al., 2014; Siebes et al., 2018; Taylor & Seltzer, 2010); however, most individuals diagnosed with autism in childhood will continue to meet the diagnostic criteria for autism in adulthood (Howlin et al., 2004).

The current prevalence estimates of autism are 1 - 1.68% of the general population (Baio et al., 2018; Baxter et al., 2015; Zeidan et al., 2022), a rate which has

[1]At present, there is no one single term that is preferred by all individuals on the autism spectrum. As is the preference of the autistic community (e.g., Bottema-Beutel et al., 2021), this thesis will use identity-first language (i.e., autistic person) rather than person-first language (i.e., person with autism). The term 'autism spectrum disorder' (ASD) will be used when referring to the diagnostic criteria, where relevant.

risen significantly in the last decade and most notably in high income countries (Elsabbagh et al., 2012). The increase in prevalence can be due to several factors, including increased autism awareness in the community and by clinicians, the broadening of the diagnostic criteria for autism, service availabilities, and improved ability to identify and diagnose autism in young children (Hertz-Picciotto & Delwiche, 2009; Lundström et al., 2015; Masi et al., 2017). A comparable prevalence in autistic adults of 1- 2% has been reported (Brugha et al., 2016; Dietz et al., 2020); however autism prevalence studies in adulthood have been limited to date. Increasingly, adults are seeking and obtaining autism diagnoses (Huang et al., 2020), reflecting the sizable proportion of individuals who had previously slipped through the diagnostic net in childhood and referred to as the 'lost generation' (Lai & Baron-Cohen, 2015). Many of these adults may have been previously diagnosed with learning difficulties (Brugha et al., 2011), Attention Deficit Hyperactivity Disorder (ADHD) or psychiatric disorders (Geurts & Jansen, 2012; Happé et al., 2016), which may have served as a barrier to receiving an autism diagnosis given the complexities of differential diagnosis (Lai & Baron-Cohen, 2015).

Autism has a strong genetic component, with its heritability being well-established (De Rubeis & Buxbaum, 2015; Tick et al., 2016). A population-based cohort study of over 2 million Swedish children reported that the probability of an autism diagnosis for those with an autistic sibling was 12.9%, and 59.2% for monozygotic twins (Sandin et al., 2014). Other twin studies report the heritability of autism to be over 80% (Colvert et al., 2015; Sandin et al., 2017). Indeed, a meta-analysis of twin studies in autism found that heritability estimates ranged between 64% and 91% (Tick et al., 2016). Although a myriad of genetic variations is said to be associated with autism (e.g., De Rubeis et al., 2014), the proportion of cases attributable

to a given aetiology is relatively small (Buxbaum, 2022). Most cases do not have an identifiable genetic cause, suggesting that environmental factors also play a role in the aetiology of autism (Hallmayer et al., 2011; Mandy & Lai, 2016).

A strong male bias remains in autism, with a sex ratio of approximately 3-4 males to every female frequently reported in childhood and adolescence (Loomes et al., 2017; Zeidan et al., 2022). Possible contributing factors for this sex bias include sex-specific biological factors (see review by Werling & Geschwind, 2013), more 'masking' of autistic symptoms in females (i.e., hiding autistic characteristics to 'pass' as non-autistic; Lai et al., 2020), and a male-centric operationalisation of autism and associated diagnostic instruments, resulting in the under-recognition, misdiagnosis or delayed diagnosis of females (Giarelli et al., 2010; Lai et al., 2017). In adults, the male to female sex ratio is suggested to be smaller (1.8-2:1; Hofvander et al., 2009; Rutherford et al., 2016), likely reflecting changing clinical practices and the improvement of identification of autistic females in adulthood (Jensen et al., 2014). Nevertheless, while although autistic adults comprise a significant and growing proportion of the population, most research to date has focused on autistic children and their families, warranting more prioritising of and support for the autistic adult population.

1.2. Outcomes in Adulthood

With the rise of the neurodiversity movement within the autism community, there has been a shift away from a medical, deficit-focused model of autism which has traditionally focused on individual deficits and impairments. Autism is celebrated as a natural human variation and an inseparable aspect of one's identity which needs no 'cure' (Kapp, 2020; Kapp et al., 2013). The positive reframing of autism has empowered autistic people to accept and embrace their autistic identities and has been associated with positive outcomes such as improved mental health, self-esteem and a sense of

belonging in autistic adults (Cage et al., 2018; Cooper et al., 2017; Leedham et al., 2020).

Nevertheless, when considering adult outcomes more broadly, many autistic adults

continue to face challenges in independent living, education, employment and forming or

maintaining relationships (Anderson et al., 2014; Eaves & Ho, 2008; Henninger &

Taylor, 2013; Howlin & Magiati, 2017; Howlin et al., 2013), and may face significant

mental health challenges (e.g., Hollocks et al., 2019).

With respect to living arrangements, less than half of autistic adults report living

independently and many rely on regular family support and assistance (Anderson et al.,

2014; Sosnowy et al., 2018). Although young autistic adults report aspirations to live

away from home, have a place that they can feel in control of, and make their own

decisions, a lack of employment opportunities, financial independence and possible

difficulties in managing a household were noted as some of the barriers to more

autonomy and independent living (Sosnowy et al., 2018). Encouragingly, a recent

Australian study found that 78% of cognitively able autistic adults aged 25 years or older

($N = 221$) reported living alone, with a partner or with others (Arnold et al., 2019),

suggesting that independent living is possible with the appropriate support.

As autistic adolescents transition into adulthood and exit formal schooling

systems, engagement in educational and vocational activities are reported to be low and

continues to decline over time. A 10-year longitudinal examination of educational and

vocational activities in autistic adults ($N = 161$) found a reduction in participation of

these activities over the surveyed time period, suggesting that the low engagement in

educational and vocational activities remains relevant to the wider autistic adult

population and is not unique to the 'transition years' post school (Taylor & Mailick,

2014). Compared to their non-autistic peers, fewer autistic adults enrol in or complete

tertiary education (ABS, 2018; Newman et al., 2011; Shattuck et al., 2012; Wei et al.,

2013) and young autistic adults are more likely to attend technical and further education (TAFE) or community college and to study part-time (Flower et al., 2021). Autistic adults highlight access to support services, academic accommodations and good relationships with staff and peers as key to their success in these higher educational contexts (Sosnowy et al., 2018). However, disclosing an autism diagnosis is complex and many find it difficult to disclose their autism diagnoses and access the support available (Anderson et al., 2018; Cai & Richdale, 2016).

Studies examining the employment experiences of autistic adults highlight the considerable challenges in successfully gaining and retaining employment (Hedley et al., 2017a), presenting significant barriers for autistic adults to achieve financial independence (Howlin & Moss, 2012). Rates of unemployment are high in autistic adults (Baldwin et al., 2014; Chen et al., 2015; Roux et al., 2017) and they are more likely to work part-time, reduced hours, or are employed for work they are overqualified for. In Australian-based studies, 37- 46% of employed autistic adults were underemployed by skill level (skills exceeded the occupational skill level needed for their job) or hours worked (desired more working hours; Baldwin et al., 2014; Harvery et al., 2021), and only 57% of adults reported being in open employment, with 11% having no activity (Arnold et al., 2019). While key barriers to successful employment include communication difficulties, co-occurring conditions, stigma, and a lack of understanding of autism and access to services (Black et al., 2020; Chen et al., 2015), autistic adults report inclusivity, responsibility, career advancement, allocation of job tasks on par with their skills and abilities, as well as a supportive and structured work environment as key facilitators for their successful employment (Scott et al., 2015).

Despite being motivated to have friendships and sustain lasting social relationships (Bargiela et al., 2016; Sedgewick et al., 2019), a relatively small percentage

of autistic adults report having meaningful friendships or romantic relationships (Billstedt et al., 2011; Howlin & Moss, 2012), with many adults experiencing high levels of social isolation (Howlin et al., 2013; Orsmond et al., 2013) and loneliness (Ee et al., 2019; Hedley et al., 2018; Mazurek, 2014). Autistic adults report difficulties with navigating majority social norms, noting that their friendships tended to stem from finding others from the autistic community who were accepting of their social differences (Sosnowy et al., 2019). Indeed, autistic individuals have better interactional rapport and feel more understood when with other autistic people, compared to being with non-autistic people (Crompton et al., 2020a, 2020b; Macmillan et al., 2019). Social relationships are bi-directional; non-autistic individuals also report difficulties in interpreting the mental states and social cues of autistic individuals (Edey et al., 2016; Sheppard et al., 2016) and are less willing to interact with them (Sasson et al., 2017). To make friends and be more socially accepted, autistic individuals often resort to compensatory strategies to mask their autistic behaviours, which can be strenuous and stressful (Bargiela et al., 2016; Hull et al., 2017).

While the existing literature suggests suboptimal outcomes for many in the autistic adult population, it is important to acknowledge that many of these outcomes are framed in environments where societal structures, such as attitudinal barriers and limited accommodations in employment or educational contexts, can impede on autistic individuals' ability to thrive. The autistic community are a minority within a non-autistic society governed by majority societal norms, and living outside of any majority can lead to stress (Crompton et al., 2020a). It is thus not surprising that there is demonstrated high stress and frequent stressful encounters in autistic adults compared to the general population (Baron et al., 2006; Bishop-Fitzpatrick et al., 2015, 2017; Gillott & Standen, 2007). Although core autistic traits related to social difficulties may predispose autistic

adults to more stressful encounters and experiences, much of the challenges and stress experienced by this population is externally imposed. Concerningly, autistic adults face frequent experiences of stigma and discrimination, and are at an increased vulnerability of being bullied and victimised (Griffiths et al., 2019; Johnson & Joshi, 2016). Not only would these negative experiences be inherently stressful, they are also likely to deter autistic adults from disclosing their diagnoses, resulting in limited access to supports or accommodations (Thompson-Hodgetts et al., 2020) and increasing masking behaviours, resulting in negative outcomes such as burnout and mental health difficulties (Cage & Troxell-Whitman, 2019; Hull et al., 2021; Mantzalas et al., 2022; Raymaker et al., 2020).

1.3. Mental Health Outcomes in Autistic Adults

A range of co-occurring mental and physical health conditions have been reported in the autistic adult population (APA, 2022). Autistic adults are at a disproportionate likelihood of developing psychopathological conditions, particularly anxiety and depression (e.g., Lever & Geurts, 2016). In a study with 1,507 autistic adults, the prevalence of a co-occurring diagnosis of anxiety (29.13%) or depression (25.75%) was significantly higher compared to the prevalence of anxiety (9.1%) or depression (9.89%) in the non-autistic adults (n = 15,070; Croen et al., 2015). Similarly, a recent systematic review and meta-analysis of studies with autistic adults found that the current and lifetime pooled prevalence was 27% and 42% for any anxiety disorder, and 23% and 37% for depression respectively (Hollocks et al., 2019). Relatedly, suicidal ideation, which is strongly associated with mental ill-health such as depression (Hedley et al., 2017b), is reported to be approximately nine times more prevalent in autistic adults compared to the general population (Cassidy et al., 2014; Hirvikoski et al., 2016).

Although these negative indicators of mental health form an essential part to

understanding the mental health outcomes for autistic adults, it is also important to consider the positive facets of psychological health, such as mental well-being. As a construct, mental well-being represents more than just the absence of mental ill-health; it reflects a combination of both hedonic (i.e., pleasure and happiness) and eudaimonic (i.e., fulfilment, realising one's potential) well-being (Ryan & Deci, 2001). Positive relationships, personal growth, life purpose and autonomy are among the core dimensions of mental well-being, capturing perceptions of both feeling and functioning well (Ryff, 2014; Stewart-Brown et al., 2009). Rather than being on separate ends of a continuum, the positive and negative facets of mental health are related yet distinct, with different antecedents and impact on overall outcomes (Suldo & Shaffer, 2008; Teismann et al., 2018). Mental well-being has also been noted to play a protective role against mental ill health in autistic and non-autistic samples (Hedley et al., 2019; Teismann et al., 2018; Wilhelm et al., 2010). While studies in autism have predominantly focused on the negative facets of mental health, there is increasing research suggesting poor well-being in autistic adults, as demonstrated through either a direct measure of positive well-being (e.g., Cage et al., 2022; Hedley et al., 2019; Lawson et al., 2020) or as inferred through measures of quality of life, self-esteem, anxiety or depression (e.g., Cooper et al., 2017; Mazurek, 2014).

Nevertheless, a comprehensive understanding of the factors or mechanisms which may underlie these poor mental health outcomes in autistic adults is limited. A range of predictors of mental health in the autistic adult population have been reported to date, including sex, autistic traits, social connectedness and support, emotion regulation strategies and sleep efficiency (Bailey et al., 2020; Cai et al., 2019; Hedley et al., 2019; Henderson et al., 2021; Maitland et al., 2021). However, the ways in which stress and stress-related constructs such as coping strategies and resilience may be

implicated in the mental health of autistic adults is unknown. This is surprising given

that the wider stress literature suggests that stress represents a significant risk factor for

poor mental health outcomes, and the potential for related constructs such as coping

strategies and resilience to mitigate some of the negative effects of stress.

1.4. Stress, Coping and Resilience in Autism

Stress can be implicated in an array of poor health outcomes (Thoits, 2010). The

detrimental effects of stress on psychological health have been well documented in the

wider stress literature, with frequent stressor encounters and higher perceptions of stress

associated with poorer psychological health such as elevated levels of anxiety and

depression, or reduced well-being (Catabay et al., 2019; Gomes et al., 2016; Juruena et

al., 2020; Lu et al., 2019). Despite the scarce literature, comparable associations in

autism have also been reported where higher perceptions of stress and more frequent or

traumatic encounters with stressors are related to higher distress, more emotional

problems, lower well-being and poorer quality of life in autistic youth and adults (Botha

& Frost, 2020; Hong et al., 2016; Khor et al., 2014; Moseley et al., 2021; Taylor &

Gotham, 2016).

Nonetheless, not all who are faced with high stress report poor mental health

outcomes. Aside from environmental and stressor-related factors, there are individual

factors, such as coping strategy use and resilience, which can intervene in the stress-

strain relationship, mitigating the effects of stress, and resulting in better outcomes than

would otherwise be expected given the stressful circumstances (Catabay et al., 2019;

Dardas & Ahmad, 2013; Hu et al., 2015). These inter-relationships are particularly

relevant when considering the autistic adult population, given the research

demonstrating high stress and frequent stressor encounters, and consensus surrounding

increased poor mental health outcomes in these adults. Considering the limited coping

and resilience literature in autism research to date, especially in autistic adults, a more extensive examination of coping strategies and resilience in relation to stress and mental health outcomes in autistic adults is pertinent, as this can help inform the design of stress and mental health support and intervention options in this population.

1.5. The Current Research

This thesis presents findings from a cohesive series of studies, with the overarching aim of examining coping strategy use and resilience, and their associations with stress and both positive and negative mental health outcomes in autistic adults. The thesis begins with an overview of the existing literature on stress and coping (Chapter 2) and resilience (Chapter 3). The overall research rationale, aims and specific objectives for each of the six empirical studies is delineated in Chapter 4, before an overview of the methodological details across the empirical studies is described in Chapter 5. Chapters 6 to 11 present empirical studies, in the form of manuscripts published in, or submitted to peer-reviewed scientific journals. Finally, Chapter 12 presents a general discussion and interpretation of thesis findings and implications, considering overall strengths and limitations, and offering potential directions for future empirical and clinical work.

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Chapter 2: Literature Review - Stress and Coping

Chapter Overview

This chapter is divided into two parts, with the aim of providing an overview of the stress (Part 1) and coping (Part 2) literature, focusing primarily on components relevant to the research presented in this thesis, including theoretical models that provided the conceptual framework for this thesis. Drawing evidence from both the autistic and non-autistic literature, both parts begin with broader discussions of the constructs of stress and coping, including their conceptualisations and measurement, their associations with mental health outcomes, and the role of coping strategies in the stress process. Following this, a more in-depth overview of the current state of stress and coping research in autism is provided. The chapter concludes with a summary of what is known with regards to stress and coping in the autistic population to date, as well as current gaps in the literature.

Stress (Part 1)

2.1. Stress Models and Conceptualisations

Stress is an ubiquitous term in modern society, often used to reflect negative experiences associated with a range of stressful encounters and stressors, from minor hassles and irritants that can characterise daily life, to pervasive traumas and phobias (Robinson, 2018). The Transactional Model of Stress and Coping (TMSC; Lazarus & Folkman, 1984) posits that upon encountering a stimulus or event, a series of cognitive appraisals takes place between an individual and their environment. These appraisals reflect the cognitive processes through which events and stimuli are ascribed meaning (Boyd et al., 2009; Lazarus & Folkman, 1984). Referred to as primary appraisal, individuals are first said to evaluate the degree of relevance, meaning or threat an encounter might have to their well-being (Dewe & Cooper, 2007). Specifically, events are appraised as: 1) benign-positive, if they are thought to have a positive effect; 2)

irrelevant, if they have no significance; or 3) stressful, if they are likely to harm, threaten or challenge one's well-being.

A range of factors, both event-related (e.g., nature, severity or intensity) and individual-related (e.g., personality traits, past encounters with event) can influence the primary appraisal of stimuli and events. Those appraised as stressful or threatening (hereafter referred to as a 'stressor') represent the intermediary step that precedes the initiation of a stress response (Lebois et al., 2016) and the secondary appraisal process. During secondary appraisal, individuals determine their course of action in managing the stressor and/or the emotions evoked, which involves the evaluation of available coping resources and the potential success of one's ability to manage or resolve the event (Lazarus & Folkman, 1984). Coping resources refer to social and personal characteristics, internal and external to the individual (e.g., self-efficacy, coping style, resilience and social support) that may support their ability to cope more effectively in the face of adversity and stressful encounters (Pearlin & Schooler, 1978). Thus, it is the combination of events appraised as threatening to one's well-being, and their demands outweighing one's ability and resources required to cope, that results in the experience of stress (Lazarus & Folkman, 1984).

Stress can therefore be conceptualised as a dynamic process between an individual and their environment, where the processes of cognitive appraisals and subsequent coping responses have the potential to intervene and influence the stressor-stress relationship, contributing to individual differences in experiences of stress and its subsequent outcomes. Central to this model is the emphasis that it is the subjective perceptions of stress, rather than the nature of the event itself, that elicit the deployment of coping strategies (Lazarus, 1991). Individuals are thus depicted as active agents who can influence the impact and consequence of stressors through the use of behavioural,

cognitive and emotional strategies (Quine & Pahl, 1991). The outcomes that follow these experiences of stress are influenced and shaped by the selection, use and effectiveness of coping strategies used in response to a stressor (Lazarus & Folkman, 1984).

2.2. Stress and Mental Health Outcomes

A wide range of negative health outcomes are associated with experiences of stress, including heart disease, cancer and chronic fatigue syndrome (see Cooper & Quick, 2017). Foundational to the stress-health link are the physiological and biological changes that occur when the body is faced with a stressor. Stressors disrupt the equilibrium of internal systems (Pacak & Palkovits, 2001), inducing the fight or flight response (e.g., Sakakibara et al., 2016) as the body attempts to maintain internal consistency, also referred to as homeostasis. Major biological pathways are activated when stressors are encountered, including the hypothalamic-pituitary-adrenal (HPA) axis and the sympathetic nervous system (Black, 1994; Moynihan, 2003), initiating a cascade of stress responses and physiological changes. These changes include increased arousal, alertness, attention and vigilance, the suppression of nonessential bodily functions (e.g., metabolism, digestive and reproductive systems), and the release of adrenaline, cortisol and noradrenaline into the bloodstream, as well as increased heart rate and blood pressure.

To cope with the stressor, cognitive and behavioural regulatory strategies are implemented, and if well managed, the stressor passes, stress responses cease, and internal systems readjust and return to their normal states. However, prolonged and repeated activation of the stress response through chronic stressor exposure, or an inability to effectively cope or adapt to stressors, can lead to allostatic load (McEwen & Stellar, 1993). Allostatic load reflects the cumulative effect of stressful encounters and their physiological consequences on the individual, including a heightened risk for

physical and psychological disorders (Guidi et al., 2021). This leads to the accumulation of 'wear and tear' on the body and is a 'cost' of adaptation (McEwen, 2003). Allostatic load has been associated with increased psychopathology in both general and clinical populations (Juster et al., 2011; Kobrosly et al., 2014).

The deleterious effects of stress on psychological health and well-being being are particularly well documented in the wider stress literature (Lazarus & Folkman, 1984; Pillow et al., 1996; Seiffge-Krenke, 2000). Increased appraisals and perceptions of stress are associated with increased loneliness, anxiety, depression, post-traumatic stress disorder (PTSD), and reduced well-being (Catabay et al., 2019; Gomes et al., 2016; Kwag et al., 2011; Lu et al., 2019). The severity, frequency and intensity of stressors encountered, including their cumulative nature, can influence the ways in which stress impacts mental health. Indeed, experiences of stressful life events often precede the onset of depressive episodes (Hammen, 2005; Paykel, 2003), and cumulative exposure to lifetime stress has been significantly related to increased symptoms of anxiety and depression, as well as reduced well-being (e.g., McLoughlin et al., 2021; Slavich et al., 2019; Toussaint et al., 2016).

Chronic stress levels, through exposure to intense and acute stressors or frequent and enduring stressors (Cohen et al., 2007), are an important determinant in the manifestations of psychopathology such as anxiety, depression and PTSD (e.g., Bali, 2015; Cohen et al., 2007; Qu et al., 2012). Similarly, relatively minor encounters, such as daily hassles and irritants, may also be detrimental to mental health and well-being over time, given that these events occur more frequently than major life events and thus have potential to permeate the realities of everyday life (Lazarus & Folkman, 1984; Pillow et al., 1996; Seiffge-Krenke, 2000; Serido et al., 2004).

Nevertheless, despite the negative outcomes typically associated with stress, not all individuals who experience stress will go on to have poor psychological health outcomes. While some individuals may be more vulnerable to the negative effects of stress, others cope, adjust and successfully recover from their stressful experiences with their mental health intact. It has been argued that it is not only the direct effects of stress on mental health, but also the indirect effects of intervening factors such as one's sensitivity or vulnerability to stress, as well as coping resources and abilities, that can determine psychological health and well-being outcomes (Bali, 2015; de Kloet et al., 2005). When considering the autistic adult population, the associations between stress and mental health outcomes are particularly important given the elevated rates of co-occurring mental health conditions reported in autistic adults (e.g., Croen et al., 2015; Hand et al., 2020) and there is a need to better understand factors which may contribute to this.

2.3. Stress in the Autistic Population

From the general population literature, it is clear that a myriad of individual and environmental factors affect the stress process; thus it is reasonable to expect that population-related factors would similarly influence stressful encounters and experiences of stress in those with a disability or other minority groups. Indeed, the disability literature suggests that individuals with disabilities face a wide range of stressors and unique sets of challenges that are often magnified by factors related to the nature of their disability (Groomes & Leahy, 2002; Iwasaki & Mactavish, 2005). Relatedly, disability and minority populations are often faced with experiences of stigma and discrimination (e.g., Bahm & Forchuk, 2009; Karlsen & Nazroo, 2002) which can bring about unique stressors, increased exposure to stressful life events, and higher overall stress. Referred to as 'minority stress' (Meyer, 2001), the stress associated with social disadvantage faced

by minority groups can lead to adverse health outcomes (Meyer & Frost, 2013; Schwartz & Meyer, 2010). These population-unique stress experiences are particularly relevant when considering autistic individuals, as there are likely to be characteristics, predispositions and vulnerabilities unique to autism, both internal and external to the individual, which may influence or shape the stressful encounters and subsequent stress-related outcomes faced by this population.

To date, stress research in the autistic population has predominantly explored stress from a physiological perspective, such as through the examination of biological stress markers (e.g., cortisol) or arousal levels (e.g., cardiovascular reactivity) in response to stress (Bishop-Fitzpatrick et al., 2017; Corbett et al., 2009; Lydon et al., 2016). In contrast, the literature surrounding the psychological stress experienced by autistic individuals is limited. Although there is burgeoning research on the psychological stress experienced by parents, caregivers or family members of autistic individuals (e.g., Bonis, 2016; McStay et al., 2014; Orsmond & Seltzer, 2009), relatively less is known about the stress experienced or perceived by autistic individuals themselves.

Current research suggests there is greater stressor exposure and increased levels of perceived stress in the autistic adult population. For example, a comparison study measuring the extent of exposure to, and perceived severity of life stressors in autistic (n = 127) and non-autistic adults (n = 104) found that autistic adults experienced more cumulative stressors across a range of life domains such as work, housing, health and relationships (Moseley et al., 2021). Further, the autistic adults in this study perceived these stressors as more stressful than the non-autistic adults, even once stressor exposure was controlled for. Mirroring these findings, other recent studies have also found higher perceived stress in autistic adults compared to the general population (McLean et al., 2021; McQuaid et al., 2022). Indeed, higher autistic traits have been associated with

increased perceptions of stress in both autistic and non-autistic samples (Hirvikoski &
Blomqvist, 2015), with autistic adults reporting higher overall perceived stress compared
to non-autistic adults (Bishop-Fitzpatrick et al., 2015, 2017; Hirvikoski & Blomqvist,
2015). These elevated levels of stress reported in autistic adults do not appear to be
affected by stress measurement type (i.e., occurrence of stressful life events, levels of
perceived stress or biological stress responses; Bishop-Fitzpatrick et al., 2017), response
mode (i.e., self-reported or interview-observed stress; Bishop-Fitzpatrick et al., 2015) or
co-occurring intellectual disability (ID; Gillott & Standen, 2007).

Research from the broader autism literature also offers important insights into the
challenges and difficulties faced by autistic adults, which may in turn place these
individuals at an increased vulnerability for high stress. Autistic adults face significant
challenges in their everyday lives (Shattuck et al., 2012; Smith et al., 2012; Taylor &
Seltzer, 2011), encountering difficulties in vocation and higher education, accessing
services, managing multiple responsibilities and adapting to transition changes (First et
al., 2016). Autistic adults frequently identify daily living skills as a priority area for
research, services and support (Gotham et al., 2015; Pellicano et al., 2014). The frequent
and varied stress and challenges faced by autistic individuals in their daily lives
(Twachtman-Cullen, 2006) may also be further exacerbated by autism-related
characteristics (Gillott & Standen, 2007; Howlin & Moss, 2012). Autistic traits such as
social communication difficulties, behavioural inflexibilities, sensory sensitivities, and
intolerance to uncertainty can impede an individual's ability to successfully navigate
through everyday social roles, contexts and demands, predisposing them to increased
experiences of stress (Groden et al., 1994; Kerns et al., 2015). In an examination of
dimensions of stress in autistic individuals, Groden et al. (2001) identified events
characterised by social / environmental interactions, unpleasant events, sensory / personal

contact or anticipation/ uncertainty as autism-specific sources of stress (Groden et al., 2001).

The environment in which autistic individuals operate is also likely to influence the stressors they encounter. Concerningly, autistic individuals are at a greater likelihood of being victimised (Cappadocia et al., 2012), bullied (Sterzing et al., 2012) or targeted for exploitation (Fisher et al., 2013). Autistic children and adolescents are as much as four times more likely to be bullied compared to their non-autistic peers (van Roekel et al., 2010; Wainscot et al., 2008; Zablotsky et al., 2014), and although friends can play a protective role in reducing this risk, friendships are often lacking amongst autistic children. Compared to non-autistic adults, autistic adults report a higher vulnerability to negative life experiences across multiple domains such as childhood and adulthood victimisation, employment, finances, the criminal justice system and social services (Griffiths et al., 2019). In employment, autistic adults frequently report being discriminated against, with rates of discrimination being positively associated with the degree of autism traits (Johnson & Joshi, 2016). The enduring experiences of being targeted and discriminated against from childhood through adulthood constitute a pervasive phenomenon likely to result in chronic stress over time. These experiences are not dissimilar to the accumulated stress burden noted in other marginalised or minority groups (e.g., Troxel et al., 2003), with reports of more frequent stressful life events and greater appraisals of threat reported in these groups (e.g., Pieterse & Carter, 2007).

Relatedly, frequent experiences of societal stigma and discrimination may deter autistic individuals from disclosing their autism diagnoses, resulting in limited access to support and accommodations that may be needed (Thompson-Hodgetts et al., 2020). Autistic individuals also report attempts to 'mask' or 'camouflage' their social difficulties to be accepted, increase connections, avoid stigma, and meet family, social or

other societal expectations (Hull et al., 2017). 'Masking' or trying to portray a non-autistic persona (Bargiela et al., 2016; Tierney et al., 2016) involves copying others and controlling one's behavioural expression to compensate for social and communication difficulties (Dean et al., 2017), and can be strenuous and challenging to one's identity (Bargiela et al., 2016). Thus, hiding one's true self through the constant need to be self-aware, self-monitor, monitor others' reactions and self-evaluate throughout daily interactions can result in elevated levels of stress (Hull et al., 2017).

Overall, emerging stress research in autism and the broader autism literature offer significant insight into the cascade of individual and environmental factors that collectively shape and contribute to the challenges and stress faced by autistic individuals. As highlighted earlier, in addition to high and cumulative life stress, autistic adults are also subject to population-unique, minority stress, which forms an additional stress burden (Botha & Frost, 2020). Autistic burnout, a phenomenon characterised by persistent chronic exhaustion, loss of skills and lower tolerance to stimuli, is said to be the consequence of this chronic life stress in autistic individuals (Raymaker et al., 2020). A cumulation of life stressors related to, or exacerbated by being autistic, barriers to receiving support and an imbalance between demands and coping resources, interwoven with the lack of awareness and stigma surrounding autism, can contribute to the onset and maintenance of autistic burnout, which can have dire consequences for the quality of life and mental health in the autistic population (Mantzalas et al., 2022; Raymaker et al., 2020). Therefore, an in-depth examination of experiences and perceptions of stress in autistic adults, and the ways in which stress might be implicated in the psychological health and well-being of this population is pertinent.

2.3.1. Stress and Mental Health Outcomes in Autism

Increasing evidence suggests that high stress levels are associated with poor outcomes more broadly in the autistic population. For example, in autistic adolescents aged 12 – 18 years, more frequent occurrences of daily hassles were associated with increased parent-reported emotional and behavioural problems (Khor et al., 2014). In autistic adults, higher levels of perceived stress have been related to increased social disability (i.e., reduced level of social functioning; Bishop-Fitzpatrick et al., 2017), decreased quality of life (Hong et al., 2016; McLean et al., 2021; McQuaid et al., 2022), poor sleep quality (McLean et al., 2021) and less independence in daily living (McQuaid et al., 2022). A few recent studies have also examined the relationship between stress and mental health outcomes in autistic adults.

Cumulative stressful life events and trauma in 36 autistic youth transitioning into adulthood (i.e., exiting high school) were said to be implicated in mood and depression symptomatology, with almost 90% of those with mood symptomatology having experienced a traumatic event compared to 41% of those without mood symptomatology (Taylor & Gotham, 2016). In adulthood, Moseley et al. (2021) examined lifetime exposure to 55 major stressors across numerous life domains (e.g., education, work, housing, health, relationships and life-threatening situations) and the perceived severity of these stressors in 127 autistic adults aged 19-73 years. They found that higher perceived stressor severity was related to poorer physical health, decreased social support, increased psychological distress and increased loneliness in their sample of autistic adults, supporting the detrimental impact of stress on health. In a recent examination of minority stress (e.g., victimisation, everyday discrimination, internalised stigma and physical concealment of autism) in 111 autistic adults, Botha and Frost (2020) found that minority stress formed an additional stress burden in these adults, and

that minority stress consistently predicted lower well-being and elevated distress, above and beyond the effects of general stress. Nevertheless, the ways in which other aspects of stress such as general perceived stress, or stress associated with daily hassles might relate to mental health outcomes, especially positive facets of mental health such as well-being, in the autistic adult population have not yet been examined.

As noted in Chapter 1, a range of factors is proposed to be implicated in the high prevalence of co-occurring mental health conditions in the autistic population. It is possible that collectively, these factors represent a population-unique vulnerability to poor mental health outcomes (e.g., Helverschou et al., 2011; Kerns et al., 2015) in autistic individuals, resulting in an increased susceptibility to the detrimental mental health consequences of stress. Diathesis-stress models such as the stress-vulnerability-coping model (Zubin & Spring, 1977) can be useful in framing the relationship between stress and mental health outcomes in groups who may already be vulnerable to poor mental health such as autistic adults.

2.4. The Stress-Vulnerability-Coping Model

The stress-vulnerability-coping model posits that individuals are endowed with a degree of vulnerability that represents a threshold for the development of psychopathology (Ingram & Luxton, 2005). Vulnerability in this model refers to unique biological, psychological or social factors that contribute to the susceptibility of experiencing mental ill-health. As exposure to challenging circumstances (i.e., stressors) and experiences of stress increase, so do the risks for psychopathology. However, it is the interaction between vulnerability and precipitating stress that determines whether individuals cross the threshold into a psychological disorder (Zubin & Spring, 1977). Thresholds for psychopathology therefore vary between individuals, depending on their unique vulnerabilities and experiences of stress. Originally used to explain the aetiology

of schizophrenia, the stress-vulnerability-coping model has since been adapted and

applied to broader areas of mental health including depression (Colodro-Conde et al.,

2018; Eberhart & Hammen, 2010).

Figure 1

The interaction between vulnerability and stress in predicting mental illness (Zubin &
Spring, 1977). Reprinted with permission (Appendix A)
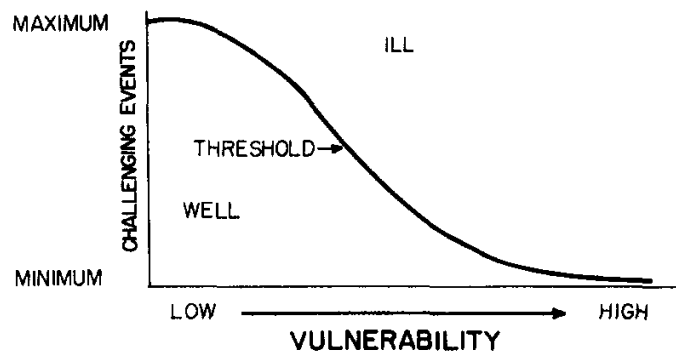
As depicted in Figure 1, if the stress evoked by stressors and challenging

encounters remains below the vulnerability threshold, the consequences of stress on

mental health are maintained within the limits of what is considered 'normal' (i.e.,

functioning 'well'). Given the proposed heightened vulnerability to poor mental health

outcomes in autistic adults, it is possible that experiences of stress, even relatively minor

stressors such as daily hassles, may create sufficient conditions for vulnerability

thresholds to be crossed, resulting in the increased susceptibility for the onset of mental

ill-health and poor well-being.

Available coping resources and abilities are vital determinants of stress

perceptions and stressor impact (Lazarus & Folkman, 1984). The 'coping' aspect of the

model is the point where there is potential to 'shift' individuals above or below their

vulnerability threshold. Although stressful experiences are common predecessors to poor

mental health, the ways in which individuals cope can intervene within the stress-mental

health relationship. Coping abilities, competence and efforts employed to manage stress, if effective, can reduce the risk of the development of psychopathological symptoms (Zubin & Spring, 1977). Despite a potentially increased susceptibility to the negative mental health consequences of stress in autistic individuals, adaptive coping strategies may have the potential to help buffer some of the negative effects of stress, maintaining these individuals below their vulnerability thresholds, and thus protecting their mental health. In contrast, maladaptive coping strategies may further exacerbate the negative effects of stressful encounters on mental health, pushing these individuals above their thresholds, at which point their risk for mental ill-health and poor well-being is at its highest.

In the following section, an overview of the construct of coping in response to stress, its associations with mental health outcomes, and how this may be applicable in the context of autism is provided.

Coping (Part 2)

2.5. Coping Conceptualisations and Approaches

The construct of coping can be described as cognitive and behavioural efforts exerted by an individual to manage internal and external demands that are perceived to exceed their current resources (Lazarus & Folkman, 1984). The literature has broadly operationalised coping in one of two ways: as a state or a trait. The state approach assumes that an individual's coping strategy use is a specific, flexible situational response that depends on the nature of demands and resources during a particular stressful transaction. Accordingly, different coping strategies are evoked during different stressful encounters, as well as during different phases of a single stressful episode (Folkman & Lazarus, 1985). The state approach therefore assumes little consistency or stability in an individual's use of coping strategies across situations. In contrast, the trait

approach proposes that individuals develop habitual ways of dealing with stress over time and that these dispositions influence the choice of coping strategies used across stressful encounters (e.g., Carver & Scheier, 1994; Moos & Holahan, 2003). From this perspective, relatively stable traits (e.g., personality and perceptual styles) and coping skills, as well as prior coping experiences, play a role in characterising the everyday manner in which individuals approach events in their lives (Roth & Cohen, 1986), including how they cope across stressful situations (Endler & Parker, 1994). Research that conceptualises coping as a trait broadly examines coping strategy use in response to stress, assuming a degree of stability in coping strategies used during stressful encounters.

Conceptualising coping as situation-specific does not consider individual factors that can contribute towards the habitual ways in which individuals cope. On the other hand, approaching coping as a trait places little emphasis on contextual and situational factors which can influence the availability, usefulness or appropriateness of coping strategies in a stressful situation. Coping is likely both situational and dispositional (Bolger, 1990; Carver et al., 1989; Ptacek et al., 2006), a result of personal predispositions and environmental contingencies. Both perspectives offer valuable insights into the ways in which stress is responded to, echoing the sentiments of Parker and Endler (1996, p.15) "Both situational and stylistic variables have been found to play roles in specific coping responses. We believe the coping area will have made a substantial advance when researchers assess routinely both types of coping variables".

While there are benefits to considering coping as both situational and dispositional, due to the limited coping literature within autism to date, coping is approached from a dispositional perspective in this thesis. This allows for the broader, more general examination of coping strategies used by autistic adults whilst limiting the

degree of individual differences that can result from measuring situational coping, such as the non-comparability of stressful events under consideration (e.g., magnitude, significance, controllability, or changeability of events) and the subsequent levels of stress elicited (Penley et al., 2002).

2.6. Coping Categorisations and Measurements

Coping responses encompass several actions and strategies that individuals use to deal with stressful encounters, and are attained by a plethora of behaviours, cognitions, and perceptions (Pearlin & Schooler, 1978; Skinner et al., 2003). Although many attempts have been made to reduce the number of overarching coping categories within which individual coping strategies can be nested, the best way to organise individual coping strategies into a broader architecture has not yet been agreed upon (Carver & Connor-Smith, 2010). To date, numerous classifications have been employed in the coping literature (see review by Skinner et al., 2003), with coping dichotomies based on the orientation of strategies being among the most used approaches. Thus, approach or engagement coping refers to strategies such as problem solving, planning, and positively reappraising a situation, orient and focus towards managing the source of stress and feelings of distress. In contrast, avoidance and disengagement coping reflect strategies that orient away and disengage from the stressor or evoked feelings of distress, such as self-distraction and being in denial (Compas et al., 2001, 2006a; Herman-Stahl et al., 1995; Roth & Cohen, 1986).

However, it is possible that the use of only two overarching categories fails to adequately reflect the myriad of coping strategies available (Aldwin, 2007; Connor-Smith et al., 2000; Skinner et al., 2003), forcing a wide range of coping strategies, with differing purposes or foci, to be operationalised under the same coping construct. For example, strategies characterised by seeking social support from others, turning to

religion or spiritual beliefs, or actively planning and problem solving may all be

considered approach coping on the surface and categorised as such, despite being quite

distinct. Further, coping categories are not always mutually exclusive. Distracting

oneself as a means of coping may be considered avoidant or disengaging if the intention

is to avoid the problem altogether, but potentially approach or engagement if the aim is

to temporarily calm down and collect one's thoughts. Importantly and perhaps most

relevant when examining coping strategies in the autistic community, imposing a

classification of coping strategies defined by the non-autistic population does not

account for population-specific intricacies which may influence the ways in which

individual strategies group together within these over-arching coping categories.

Relatedly, classifications of coping strategies from a person-centred perspective

have been increasingly used in the wider coping literature to better capture the

multidimensionality of coping as a construct. When faced with stressful encounters,

individuals are likely to employ a combination of coping strategies, using them in

conjunction with one another, rather than single coping strategies in isolation (Doron et

al., 2013, 2014; Eisenbarth, 2012). Coping profiles are used to classify individuals into

subgroups based on their different combinations of coping strategies through employing

person-focused approaches such as cluster analysis. Across varying measurements of

coping strategies, methodologies and samples, three to four coping profiles are typically

reported, where the profiles are characterised by the dominance of some coping

strategies over others or the frequency with which most strategies are used. For

example, Doron et al. (2013) identified three coping profiles in a non-clinical adult

sample ($N = 334$) across a range of cognitive coping strategies: 'adaptive copers',

'avoidant copers' and 'low copers'. The 'adaptive copers' demonstrated high use of

strategies such as acceptance and positive reappraisals; the 'avoidant copers', high use

of strategies reflecting catastrophising, rumination and blaming others; while the 'low copers' showed infrequent use across all coping strategies.

More recently, in response to the Coronavirus-19 (COVID-19) pandemic, Pété et al. (2022) derived four coping profiles to differentiate groups of French adult athletes (N = 526) based on their coping patterns: high use of problem solving and cognitive restructuring strategies ('engaged coper'), high use of avoidant strategies ('avoidant copers'), moderate use of cognitive restructuring and distraction ('self-reliant copers'), and moderate use of support seeking ('active and social copers'). Similarly, three coping profiles were derived in a Slovenian adult sample (N = 1,347) during the first wave of the COVID-19 pandemic: the 'engaged profile' characterised by the predominant use of active approach-oriented strategies; the 'avoidant profile', which demonstrated high use of avoidant strategies; and the 'disengaged profile', which demonstrated low use of most coping strategies (Kavčič et al., 2022). The use of coping profiles may be especially useful in the autistic adult population, given the heterogeneity in behaviours, strengths, challenges and outcomes commonly reported. This approach also allows for the identification of unique coping patterns amongst autistic adults, and allows for the exploration of how these profiles may differently associate with stress and mental health outcomes.

2.7. Associations between Coping and Mental Health Outcomes

The link between use of coping strategies and mental health has been extensively examined across clinical and non-clinical samples. Generally, active responses to stress using approach-engagement coping strategies have been associated with more positive mental health outcomes such as improved psychological adjustment, well-being, and life satisfaction, as well as reduced internalising and externalising symptoms (Compas et al., 2006b; Connor-Smith et al., 2000; Dijkstra & Homan, 2016;

Greenglass & Fiksenbaum, 2009; Jaser et al., 2005; Meyer, 2001; Suldo et al., 2008).

Conversely, more passive responses through the employment of avoidance-disengagement coping strategies have been consistently related to more negative mental health outcomes such as higher levels of anxiety and depression, reduced life satisfaction and poorer psychological adjustment (Carver et al., 1989; Dijkstra & Homan, 2016; Friedman-Wheeler et al., 2008; Suldo et al., 2008). Furthermore, a meta-analysis that examined the associations between coping and physical and psychological health in non-clinical populations noted similar patterns, where approach-oriented coping strategies such as problem solving were related to better health outcomes, while avoidant, disengagement coping strategies such as distancing, wishful thinking and avoidance were related to poorer physical and psychological outcomes (Penley et al., 2002).

Nevertheless, the associations between coping and mental health outcomes are likely to be more complex, dynamic and reciprocal. Although disengaging and avoiding stressors may induce the intrusion of stress-related thoughts and emotions, pre-empt more effective coping efforts (Taylor & Stanton, 2007), and predict higher levels of distress in the long term (Rayburn et al., 2005), coping through avoidance and disengagement may be beneficial in certain circumstances. Disengaging or avoiding a stressful situation can be helpful when the situation is not amenable to change, or when it offers individuals the opportunity to temporarily redirect their attention elsewhere, calm down and gather their thoughts (Carver & Connor-Smith, 2010; Heckman et al., 2004; Patry et al., 2007; Taylor & Stanton, 2007). Further, although theoretical perspectives of coping note the effect of coping strategies on the development and maintenance of psychological symptoms (e.g., Carver et al., 1989; Folkman & Lazarus, 1986), the reverse is also possible, where psychopathological symptoms may influence

or reflect the choice of individual coping strategies. This is particularly relevant to avoidant, disengagement coping strategies, given that responses characterised by avoidance are central in anxiety and depressive disorders (e.g., Newman & Llera, 2011; Trew, 2011).

While longitudinal studies that examine approach and avoidance coping strategies as antecedents to mental health states generally report positive and negative effects respectively on outcomes such as depression, anxiety, affect and levels of distress, most studies also note a bi-directional relationship (Aldwin & Revenson, 1987; Billings et al., 2000; Holahan et al., 2005; Lin & Leung, 2010; Nielsen & Knardahl, 2014; Suldo et al., 2008). These findings underscore the influence of mental health on coping strategy use and thus the importance of controlling the effects of baseline mental health when attempting to explicate the unique predictive role of coping on subsequent mental health outcomes longitudinally.

Relatedly, prospective studies that examine longitudinal changes in coping strategy use (i.e., an increase or decrease between time points) report its predictive role on subsequent levels of mental health. For example, in adults presenting at a trauma centre, an increased use of engagement coping strategies over a one-year period was related to lower levels of depressive and post-traumatic symptoms at follow-up, while an increase of disengagement coping over this time was related to higher depressive and post-traumatic symptoms at follow-up (Booker et al., 2020). Similarly, in female crime victims, an increase in coping through social withdrawal over three months was associated with higher post-traumatic symptoms at follow-up, while coping through emotional expression over time was related to reduced post-traumatic symptoms at follow-up (Gutner et al., 2006). These studies highlight not only the malleability of coping strategy use over time, but that individual coping trajectories (i.e., an increase or

decrease of strategy use over time) can also play an essential role in determining mental health outcomes.

2.8. Stress-moderating Role of Coping

As noted earlier in this chapter, the relationship between stress experienced and mental health outcomes is not linear, especially when individual factors such as coping strategy use, among others, are considered (Grant et al., 2006). Coping strategies used in response to stress can influence mental health both directly or indirectly, through their potential to moderate the relationship between stress and mental health. As discussed in the stress-vulnerability-coping model, some coping strategies may operate as a protective factor, buffering the negative effects that stress can have on mental health outcomes, while other coping strategies might operate as a risk factor, exacerbating the negative effects of stress.

Research on the moderating role of coping strategies in the relationship between stress and various outcomes have reported mixed findings. For example, primary control coping (e.g., problem solving) and secondary control coping (e.g., positive thinking) strategies have been found to buffer the relationships between vulnerability to stress, such as sociotropy (i.e., heightened concern about what others think and an overvaluation of social relationships and approval of others; Beck, 1983) and symptoms of anxiety and depression, whilst disengagement coping (e.g., avoidance) was noted to amplify these relationships (Connor-Smith & Compas, 2002). Some studies support the stress-exacerbating role of avoidance coping (Cheng et al., 2012; Young & Limbers, 2017), but in contrast, others report the opposite, proposing that avoidance coping can buffer the negative effects of stress (Dardas & Ahmad, 2013). Similarly mixed findings are noted for approach-oriented coping strategies, which have been reported to both mitigate (Cheng et al., 2012; Suldo et al., 2008) and exacerbate (Hill & Hoggard, 2018; Patterson,

2003) the effects of stress on psychological symptoms, distress, well-being, and life satisfaction in a range of samples.

The heterogeneity across study samples, outcome measures, the stress context and measurement of coping strategies can undoubtedly contribute to inconsistent findings concerning the effectiveness and impact of coping strategy choices. The different study samples used in prior research are likely to experience varying stress levels and contexts, which may influence both the role and effectiveness of the coping strategies elicited. Indeed, it is possible that active, approach coping strategies may buffer the effects of more amenable stressors such as those that arise from job insecurities (Cheng et al., 2012) or educational demands (Suldo et al., 2008), but exacerbate the effects of more uncontrollable stressors, such as those related to racial discrimination (Hill & Hoggard, 2018) or confronting situations faced during police work (Patterson, 2003). Further, the different ways in which coping strategies are categorised and the measures used to encapsulate mental health in a given context (e.g., symptoms of ill-health, measures of well-being, work engagement, life satisfaction) are likely to further contribute to the discrepant findings across studies.

When considering autistic adults, understanding the roles of coping strategies, including the ways in which they may buffer or exacerbate the effects of stress in this population is vital. As discussed in Part 1 of this chapter, autistic adults experience frequent stressful encounters and report high levels of stress in their everyday lives. This is particularly concerning given the deleterious effects stress can have on mental health and well-being. However, stressor encounters and experiences of stress cannot be eliminated, they can only be minimised at best (Khor et al., 2014). Coping strategies, however, can be developed, and strategies that are more adaptive for autistic adults have the potential to play a promotive, protective, or stress-buffering role. Therefore, a more

comprehensive understanding of coping in autistic adults may help ascertain patterns of use of coping strategies, and the various pathways through which coping strategies might associate with mental health outcomes in the autistic adult population.

2.9. Coping Research in the Autistic Population

2.9.1. Coping and Emotion Regulation

A large proportion of coping research conducted in the autistic population has focused on coping in parents, caregivers and family members of autistic individuals (e.g., Lai & Oei, 2014; Seymour et al., 2013; Zablotsky et al., 2014). While there are suggestions that overall, coping is poor in the autistic population (Groden et al., 2001; Hirvikoski & Blomqvist, 2015), research examining coping strategies used in response to stress by autistic individuals, particularly adults, remains limited. This scarcity of coping research in autistic individuals is nevertheless complemented by literature in the associated area of emotion regulation (ER).

Coping and ER are closely related constructs, with some overlap in the strategies examined across the two areas. Coping strategies that aim to manage or regulate emotional components of stressful encounters (i.e., emotion-focused coping) are not unlike ER strategies. Additionally, strategies involving cognitive or positive reappraisals of situations and emotional suppression or expression are typically examined in both areas of research. Despite these overlaps however, the constructs of coping and ER are said to remain distinct, with the intended focus of the strategies, and the contexts in which the strategies are employed, being key points of divergence (see review by Compas et al., 2014). The focus of coping strategies can encompass managing the source of stress, as well as its associated emotions, whereas the focus of ER strategies is typically on managing and regulating emotions. While the use and measurement of coping strategies are limited to the context of stress, ER strategies are deployed in

stressful or non-stressful contexts, in response to experiences of both positive and

negative emotions.

Given the limited coping literature in the autistic population, some discussion on

ER, particularly in relation to autistic adults, is included in this chapter where appropriate

to provide additional perspectives regarding regulatory processes in autistic individuals

more generally, as well as in response to stressful encounters. However, it is important to

note however, that some ER studies in the autism literature (e.g., Pouw et al., 2013;

Rieffe et al., 2011, 2014) have operationalised coping as a component of ER, instead of a

distinct construct. These studies also measure strategies used in response to unpleasant,

challenging or negative life encounters, instead of emotions or the emotional impact of

events, and utilise the term 'coping strategies' rather than 'emotion regulation strategies'.

To maintain consistency and to avoid misrepresenting these studies, the same coping

terms as employed by the authors were used in this chapter when discussing these

studies.

2.9.2. Coping Themes in Autism

Several studies have examined the coping of autistic individuals in the context of

bullying, peer victimisation and stigma. For example, Bitsika and Sharpley (2014)

recorded a range of strategies used in response to bullying experiences in a sample of

autistic boys ($N = 48$, mean age = 9.9 years), from walking away and reciprocating

(verbally and physically), to avoidance. These strategies, however, were reported as

ineffective in helping the boys feel better or reducing their levels of distress. Similarly,

Altomare et al. (2017) examined coping strategies in 38 autistic youth aged 8 to 13 years

in response to bullying and peer victimisation scenarios, where coping strategies were

grouped into either approach or avoidance coping. Approach coping captured active

methods to change the situation (e.g., telling an adult, problem solving) and included

externalising behaviours such as physical aggression, while avoidance coping

encompassed more passive strategies aimed at avoiding the situation (e.g., ignoring or

walking away). Altomare et al. also noted a lack of responses suggestive of seeking

social support from peers, which may be consistent with the literature surrounding

limited friendships and social networks in autistic individuals (e.g., Petrina et al., 2014).

Finally, in the context of stigma, a systematic review across 27 studies identified

camouflaging, selective disclosure and self-advocacy, positive reframing, and

reconstructing one's identity as among the most common coping strategies used by

autistic individuals ($N = 2,151$) aged 11-73 years (Han et al., 2021).

   Other qualitative studies in autistic adult samples have identified key coping

themes across a range of contexts. For example, in a French-based study, Dachez and

Ndobo (2018) explored the ways in which 31 autistic adults aged 15-53 years coped both

currently and retrospectively across a range of experiences, including discrimination,

their autism diagnostic process, social relationships and employment. Coping through

engagement in special interests, militancy (against deficiency-centred definitions of

autism), obtaining a diagnosis, seeking support from 'atypical' friends and animals,

normalisation (by masking their difficulties), intellectualisation (by finding meaning or

explanations for events) and using humour were identified as key coping strategies in this

sample. In particular, engaging in special interests was considered to be avoidance-

oriented, allowing individuals to escape reality, calm down and manage their emotions.

Some similarities were noted by Ghanouni and Quirke (2022), who explored the coping

and resilience experiences among the autistic adult community ($N = 22$; 13 autistic

adults, five parents, and four service providers), where engaging in recreation and leisure

(i.e., incorporating breaks), seeking emotional support (e.g., through support groups) and

adopting the use of technology (e.g., for socialisation, daily activities) were among the

main coping themes that emerged. Finally, in autistic adolescents transitioning into adulthood (13 autistic youth, 19 caregivers), coping through accessing support from community services, family and friends and seeking opportunities for self-determination were reported to be most helpful (First et al., 2016).

Together, these findings suggest that autistic adults utilise a large range of coping strategies to manage stressful encounters. In particular, appearing to disengage, by engaging in special interests, and recreation and leisure activities may be beneficial in helping them to recuperate and refocus, especially when feeling overwhelmed or distressed.

2.9.3. Potential Maladaptive Coping Pattern

Although it can appear reductionist to label certain coping strategies as more adaptive than others without considering the contextual and situational factors associated with stressful encounters, there is a maladaptive pattern of coping strategy use that is alluded to in the autistic population. This pattern is based on evidence suggesting a reduced use of active, approach-oriented coping strategies in autistic children and youth compared to their non-autistic peers across various contexts.

2.9.3.1. Coping Strategy Comparison Studies

Numerous cross-sectional comparison studies between autistic and non-autistic individuals report findings that support a pattern of reduced active, approach-oriented coping strategies. For example, Bauminger (2004) identified use of two main coping strategies in response to feelings of jealousy in 16 autistic and 17 non-autistic children (mean ages = 11.14 years and 11.51 years, respectively), labelled situation-activity coping (i.e., modifying the situation to make it more pleasant) and cognitive-mentalistic coping (i.e., distracting or occupying oneself with other things). This study found that the autistic children used significantly fewer situation-activity coping strategies, but a

comparable number of cognitive-mentalistic coping strategies, compared to the non-autistic children.

Similarly, in response to common, daily, negative events, Rieffe et al. (2011) noted that their sample of 11-year-old autistic children ($N = 66$) used fewer adaptive coping strategies (e.g., planning and acceptance) but similar amounts of maladaptive coping strategies (e.g., catastrophising and self-blame) as their non-autistic peers ($N = 118$). Most recently, Corbett et al. (2021) examined experiences of stress and coping strategy use in 61 autistic and 61 non-autistic youth (mean age of 13 years) in response to the COVID-19 pandemic. They found that the autistic youth endorsed less primary control engagement coping (e.g., emotional expression or regulation, problem solving) and secondary control engagement coping (e.g., acceptance, cognitive restructuring) strategies, but more disengagement coping strategies (e.g., avoidance, being in denial) compared to the non-autistic group. While these studies identified a tendency to use avoidant, disengagement coping strategies in autism, all three studies utilised cross-sectional data.

Supporting the cross-sectional data, Rieffe et al. (2014) examined coping strategies in 81 autistic and 131 non-autistic youth (aged 8-15 years at baseline) in response to 'if something bad happened' across three time points, with nine-month intervals. They found that compared to the non-autistic sample, the autistic youth used fewer approach coping strategies (e.g., tell a family member, find a solution) but similar avoidant coping strategies (e.g., do something to forget the problem, say that I don't care) at all three time points. In contrast, Pouw et al. (2013) found no differences in the use of approach, avoidant or maladaptive coping strategies in response to 'if something bad happened' among a group of autistic ($n = 63$) and non-autistic ($n = 57$) boys of similar ages (8-13 years). The lack of group differences in this latter study may be related to

their sample being limited to only boys or the different groupings of coping strategies used in the two studies. Indeed, while the aforementioned studies, including Rieffe et al. (2014), categorised individual coping strategies into overarching dichotomies (adaptive-maladaptive coping or approach-avoidance coping), Pouw et al. further separated avoidance coping (e.g., do something to forget the problem) from maladaptive coping (e.g., get angry, throw or hit something) in their study.

Drawing briefly from the autistic adult ER literature, less frequent use of adaptive strategies (i.e., cognitive reappraisal) and more use of maladaptive strategies (i.e., suppression) have also been noted in autistic adults, compared to non-autistic adults (see review by Cai et al., 2018a). In a study examining cognitive ER strategy use in 121 autistic and 121 non-autistic adults, Bruggink et al. (2016) found that the autistic adults used fewer positive reappraisals and more blaming of others compared to the non-autistic adults. Samson et al. (2012) also found reduced use of reappraisal strategies and higher use of suppression strategies in autistic adults compared to non-autistic adults ($n = 27$ in each sample). Samson et al. further noted that the autistic adults expressed less self-efficacy in their ability to reappraise their emotions. Difficulties in taking alternative mental perspectives in autistic individuals may lead to their perception of cognitive reappraisal strategies being ineffective, subsequently contributing to a reduced use of reappraisal strategies. Indeed, the review by Cai et al. (2018a) posited that autistic individuals not only have difficulties in regulating their emotions but also report a reduced effectiveness in the strategies they employ to do so.

2.9.3.2. Coping Measurement Considerations

It is plausible that the apparent increased use of maladaptive patterns of coping strategies observed in autistic individuals has been influenced by grouping coping strategies into the overarching categories typically imposed on both the autistic and non-

autistic samples in previous research. Utilising the same factor structure of a coping measure normed for the general population, across both autistic and non-autistic groups assumes that the ways in which individual coping strategies are perceived and utilised, and the functions which they might serve, are identical across both autistic and non-autistic individuals. This does not account for population-unique factors which might influence how individual coping strategies operate or group together, and thus influence the composition of overarching coping categories in each population.

The most parsimonious structure that best represents the categorisation of coping strategies in a given sample is commonly identified using factor analytical procedures. Coping strategies that do not strongly relate to their corresponding coping category are typically removed, resulting in the coping categories and their constituent items being distinct, conceptually clear, and meaningful to the study sample. It is reasonable to expect that autism, an important aspect of one's identity, can bring in autism-specific factors that shape stress experiences and the coping strategies used in response. Rather than imposing a coping category structure derived from the general population, utilising a coping factor structure validated for use in the autistic population has the potential to capture autism-specific aspects or presentations of coping. This is similarly noted in measures of other constructs validated for use in the autistic population (e.g., Cassidy et al., 2018; McConachie et al., 2018). However, to date, no coping measures have been validated for use in the autistic adult population.

Further, it is also possible that some coping strategies which may appear avoidant or maladaptive on the surface (e.g., walking away or distracting oneself) are considered an 'active' strategy for autistic individuals by allowing them to calm down and collect their thoughts (e.g., Carver & Connor-Smith, 2010). Indeed, the qualitative coping studies reviewed here have alluded to the possible benefits of such strategies in autistic

samples, at least in the short-term (Dachez & Ndobo, 2018; Ghanouni & Quirke, 2022). Therefore, to better establish the potential adaptiveness (or maladaptiveness) of specific coping strategies in autistic individuals, it is important to define coping categories in a way that is relevant to autistic individuals and then examine the ways in which individual coping strategies are associated with both positive and negative mental health outcomes in this population.

2.9.4. Coping Strategies and Mental Health Outcomes in Autism

To date, research surrounding the relationships between coping strategy use and mental health outcomes in autistic children and adolescents has produced relatively mixed findings. Consistent with reports in the broader coping literature, some studies find associations between higher use of avoidance and disengagement coping strategies and poorer psychological outcomes. For example, in a study exploring the relationship between parent- and self-reported coping strategies and behavioural and emotional problems in autistic adolescents ($N = 31$, aged 12-18 years), Khor et al. (2014) found that a disengagement coping style was significantly associated with increased behavioural and emotional problems, regardless of respondent. Similarly, when examining coping strategies and internalising problems in 11-year-old autistic ($n = 66$) and non-autistic ($n = 118$) children, maladaptive coping strategies were related to increased internalising symptoms in both groups (Rieffe et al., 2011). However, neither of these studies found a significant relationship between adaptive, approach coping strategies and improved psychological outcomes in their autistic samples, although Rieffe et al. (2011) did note this association in their non-autistic sample.

In exploring coping strategies and depressive symptoms in autistic ($n = 63$) and non-autistic ($n = 57$) boys aged 9-15 years, Pouw et al. (2013) found that in both samples, maladaptive coping strategies were related to increased depressive symptoms,

while approach coping strategies were related to decreased depressive symptoms. However, contrary to the wider literature, this study also found that more use of avoidance coping strategies (which were categorised separately to maladaptive coping strategies) was related to *fewer* depressive symptoms, but only in the autistic group, raising the possibility that coping through avoidance might be useful for autistic individuals. The potential adaptiveness of avoidance coping in autistic children was further supported by Rieffe et al. (2014), who examined the longitudinal relationship between coping strategies and depressive symptoms in autistic ($n = 81$) and non-autistic youth ($n = 131$). In this study, increased use of *both* approach and avoidance coping strategies over time contributed to reduced depressive symptoms in both samples.

The literature surrounding ER strategies and mental health outcomes in the autistic population offers further insight into this area, and in line with the coping literature, also highlights the inconsistencies across study findings. For example, in a sample of 121 autistic and non-autistic adults aged 18 to 62 years, Bruggink et al. (2016) found that while maladaptive cognitive strategies (e.g., self-blame and catastrophising) were predictors of higher anxiety and depression in both groups, some adaptive strategies (e.g., acceptance) also predicted increased symptoms of anxiety. Further, a study with 25 autistic and 23 non-autistic youth aged 12 to 19 years found that voluntary engagement strategies (e.g., changing the situation, acceptance) were associated with lower levels of internalising symptoms in both groups, whereas involuntary strategies characterised as both engagement (e.g., rumination, impulsive action) and disengagement (e.g., emotional numbing, inaction) were related to higher levels of internalising symptoms in both groups (Mazefsky et al., 2014). These studies highlight that not all engagement strategies are equivalent, nor equally helpful, and that there are engagement strategies (e.g., rumination) which may be active and approach-oriented in their focus, yet maladaptive in

nature. These could include not only the involuntary and reactionary strategies noted in Mazefsky et al., but also others such as substance-use (e.g., Ullman et al., 2013), which although not an uncommon protective response to stressors and feelings of distress, is generally found to be ineffective over time.

ER studies that have examined cognitive reappraisal (i.e., to modify emotions and experience) and suppression (i.e., to avoid expression of emotions) strategies in the autistic population have shown more consistency in their findings. For example, Samson et al. (2015) found that reduced use of cognitive reappraisal was related to increased maladaptive behaviours in 31 autistic youth between the ages of 8 and 20 years. Similarly, in 121 autistic adolescents and adults aged 14-79 years, Cai et al. (2018b) found that adaptive (i.e., cognitive reappraisal) and maladaptive (i.e., suppression) ER strategies were negatively and positively related to symptoms of depression respectively. A further examination of potential interactions between the two strategies in autistic adults suggested that high use of reappraisal strategies may act as a buffer against the effects of suppression strategies on mental health, highlighting the importance of also exploring the use of strategies *relative* to each other, rather than merely in isolation (Cai et al., 2018b). Given that the ER strategies characterised by reappraising or reinterpreting stressful situations and the expression or suppression of distress are also examined in the coping literature, it might be that these strategies, as well as their interactions, might similarly relate to mental health and other stress-related outcomes in autistic adults in the context of coping with stress.

From the coping-mental health studies conducted in autistic samples to date, it is difficult to hypothesise how coping strategies used in response to stress may associate with mental health outcomes in autistic adults and if these associations might differ from those found for non-autistic adults. The extent to which findings from studies largely

conducted with autistic youth may be applicable to autistic adults is unclear. While ER

studies in autistic adults might suggest the adaptiveness of some strategies (e.g.,

reappraisals) over others (e.g., emotional suppression), it is not known if comparable

coping strategies will operate similarly in the context of stressful encounters. Indeed, it is

possible that coping strategies may interact differently with stress in autistic adults, with

the potential for approach-oriented or avoidant-oriented coping strategies to mitigate or

moderate the effects of stress on mental health.

2.10. Chapter Conclusions

Overall, the stress and coping literature in the autism population remains limited

to date. While there is emerging research surrounding the increased vulnerability of

autistic individuals to stressful encounters, relatively little is known about perceptions of

stress in autistic adults, and how these might relate to mental health outcomes. Similarly,

the mixed findings across coping studies conducted in the autism population are

exacerbated by inconsistencies in coping categorisations and measurement, the context of

strategy use, sample characteristics and study design, making it challenging to

substantively cumulate or compare current study findings. Additionally, coping-mental

health studies in autism to date have almost exclusively focused on the negative aspects

of mental health (e.g., anxiety, depression, internalising symptoms) without including

measures of positive mental health such as psychological well-being. It is probable that

coping strategies differentially relate to these different aspects of mental health.

It is also possible that the combination of individual coping strategies that make

up overarching coping categories differ between autistic and non-autistic adults. Utilising

a coping measure that is validated and reliable for use in autistic adults is imperative to

best capture patterns of coping strategy use in response to stress in this population.

Understanding the mechanisms underlying coping and both positive and negative mental

health in the context of stress is also vital, as this may present significant points at which coping supports and interventions can be used to potentially reduce the adverse mental health risks associated with stress in autistic adults.

When considering the context of stress more broadly, resilience represents another key construct that is related to coping strategies and has potential to influence mental health and well-being outcomes. Thus, an in-depth exploration of resilience, its associations with stress, coping and mental health outcomes, as well as resilience research in autism is provided in the following chapter.

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Chapter 3: Literature Review - Resilience

Chapter Overview

As Chapter 2 presented an overview of coping strategies in the context of stress, the aim of this chapter is to provide a broad overview of resilience, including its definitions and the contexts of resilience research. The ways in which resilience is operationalised as a construct in the literature (i.e., a trait, process or outcome) is also discussed, ultimately focussing on the trait approach when considering the autistic adult population. Associations between resilience, stress, coping and mental health outcomes are considered, and a more detailed discussion on the current state of resilience research in autism in light of the limited literature to date is provided. The chapter concludes with a summary of resilience research in autism and highlights potential areas for future research pertinent to the autistic adult population.

3.1. Definitions of Resilience

The term resilience originates from the Latin word *resilire*, meaning 'to jump back' or 'to recoil'. First applied in the field of physics to demonstrate 'the ability to bounce or spring back into shape', the term resilience has been similarly used in psychology to depict an individual's capacity to 'bounce back', adapt and maintain normal functioning in the face of risk factors and adversity (Bonanno, 2004; Luthar et al., 2006; Rutter, 2012; Smith et al., 2010). Risk factors represent factors that threaten adaptive functioning and are related to an increased likelihood of a specified negative outcome (Masten, 2007; Narayan et al., 2015; Tusaie & Dyer, 2004). Exposure to adverse and stressful life events constitutes such risk factors, given their associations with maladjustment and compromised adaptation across numerous contexts (Riley & Masten, 2005; Schetter & Dolbier, 2011). Nevertheless, the extent of negative outcomes associated with risk factors varies across individuals, and there are those who when exposed to similar risks, appear to be less affected, adjust, and report better than expected

outcomes given their circumstances (Lemery-Chalfant, 2010; Luthar & Cicchetti, 2000; Masten, 2001). Rather than being invulnerable to their difficult circumstances, these individuals are said to bend yet subsequently recover (Garmezy, 1993) and are able to maintain a stable equilibrium in the face of stress (Bonanno, 2004), thus exemplifying resilience.

3.2. Contexts of Resilience Research

Resilience research was historically rooted in the context of childhood adversities such as poverty, maltreatment or neglect, where there were children who exhibited developmentally appropriate cognitive development and adaptive functioning or better than expected mental health outcomes, despite being at risk for the contrary (e.g., Garmezy & Rutter, 1983; Werner & Smith, 1992). This risk context of resilience research was later broadened to include chronic or life-threatening illnesses and the occurrences of acute traumatic life events (e.g., wars and natural disasters) where demonstrations of individual adjustment, quality of life and post-traumatic growth symptoms were used to ascertain individual resilience (e.g., Aldwin et al., 1994; Farber et al., 2000).

More recently, resilience research has been conducted in the context of more common and modest disruptions and challenges embedded in everyday life, such as daily hassles (e.g., Almeida, 2005; Ong & Leger, 2022). Daily hassles refer to frequent or continuous, minor stressors that arise out of day-to-day living. These everyday stressors are disruptive, with the frequency of their occurrences associated with negative outcomes such as psychological distress and psychopathology (Asselmann et al., 2017; Serido et al., 2004). Examining resilience in relation to daily hassles operates under the premise that for most people, adversities they have encountered are likely to be embedded in their everyday life, rather than in the occurrence of single, major disasters (Davis et al., 2009).

Although these daily events may be minor, they have the potential to accumulate, creating more persistent and chronic stress over time and increasing the likelihood for individuals to experience detrimental outcomes (Zautra, 2003).

The context of stressors that permeate daily life is particularly relevant when considering vulnerable, minority or clinical populations that may not only be presented with population-unique stressors but also be faced with circumstances composed of multiple, co-occurring stressors, resulting in chronic stress (e.g., Meyer, 2003). For example, individuals of low socio-economic status may be disadvantaged by experiencing multiple stressors (i.e., financial stress, familial stress, poor health status and psychological distress) and having limited resources such as reduced life control, reduced access to education, less social support and poorer social cohesion (Leadbeater et al., 2005; Mulder et al., 2011). Indeed, access to internal and contextual protective factors typically associated with increased resilience and adaptability can be more elusive in these populations. Similarly, clinical populations such as children with ID may be more vulnerable to poor developmental outcomes and psychopathology associated with their cognitive impairments, have reduced access to protective personal and external protective factors, and be at an increased risk for considerable personal, social and economic disadvantages (Emerson et al., 2010; Gilmore et al., 2014).

It can be argued that the unique, co-occurring stressors and thus chronic stress faced by individuals in minority and/or disadvantaged populations are not unlike those experienced by individuals in the autistic population. As discussed in Chapter 2, autistic adults experience heightened levels of stress, frequent stressor encounters and additional stress burdens (i.e., minority stress related to autism). While a diagnosis of autism is not an adversity (Lai & Szatmari, 2019), these experiences of stress, in addition to the broader pervasive difficulties and challenges often faced by autistic individuals, can be

considered a form of adversity (Climie et al., 2013), placing a range of outcomes such as the mental health and well-being of autistic adults at risk. The abilities and processes enlisted by autistic individuals in order to overcome these stressful circumstances may therefore reflect varying degrees of resilience (Lai & Szatmari, 2019; McCrimmon & Montgomery, 2014).

3.3. Approaches to Resilience as a Construct

At its most fundamental level, resilience research strives to understand how some individuals do well despite experiencing challenges and adversity. This represents a significant paradigm shift away from focusing on risk factors and the development of disease, towards that of strength development and maintenance of health (Limmer & Schütz, 2022). As noted by Modesto-Lowe et al. (2011, p.519), "Resilience shifts the focus from "What is wrong?" to "What can make it right?". As a construct however, resilience can be operationalised as either a trait, process or outcome (Fletcher & Sarkar, 2013), with the ways in which resilience is conceptualised subsequently informing decisions surrounding how it can be best measured.

As a trait, resilience can be viewed as a constellation of attitudes, characteristics and skills connoting general resourcefulness, flexibility, tolerance of negative affect, and an action-oriented approach to solving problems which can enable individuals to adapt, or even thrive, despite difficult circumstances (Bonanno, 2004; Campbell-Sills et al., 2006; Connor & Davidson, 2003; Eisenberg et al., 2004; Maddi, 2005; Richardson, 2002; Skodol, 2010; Tugade & Fredrickson, 2004). Resilience has been described as an 'adaptive stress resistant personal quality' (Ahern et al., 2008, p. 32), and while traditionally suggested to reflect an intrinsic and stable individual characteristic, more recent conceptualisations note that resilience can be both innate and acquired over time, malleable yet relatively stable (Connor & Davidson, 2003; Hu et al., 2015; Joyce et al.,

2018). Indeed, individual resilience has been found to be responsive to targeted

interventions (e.g., Steinhardt & Dolbier, 2008) and can be influenced by social factors

(van Kessel, 2013). Single self-report resilience measures such as the Connor-Davidson

Resilience Scale (CD-RISC; Connor & Davidson, 2003) or The Resilience Scale

(Wagnild & Young, 1993) are typically used to assess individual resilience and are also

helpful in establishing changes in resilience levels pre- and post-interventions (e.g.,

Schachman et al., 2004). Resilience as a trait can be viewed as a dynamic personal

resource comprised of personality characteristics, abilities and learned skills that can

accumulate over time, facilitate positive adaptation to stressors and promote

psychological health and positive outcomes (Jackson et al., 2007; Smith et al., 2010;

Wagnild & Young, 1993).

Resilience as a process is not directly measured but inferred through measures of

risks and outcomes. Specifically, resilience is considered to be present when there is

evidence of both positive outcomes and risk exposure (Luthar et al., 2000). The resilience

process, also referred to as the process of adaptation (Chmitorz et al., 2018), consists of

the complex interaction of factors related to risk, outcome and protective factors that lie

at the individual, family and community levels (Fergus & Zimmerman, 2005; Masten,

2001; Windle, 2011). Of particular interest is the identification of protective factors, both

internal and external to the individual, which buffer the negative effects of risks and

contribute towards more positive outcomes. For example, in a study where resilience was

determined in a sample of transgender adolescents and young adults using measures of

stigma and mental health outcomes, protective factors such as school connectedness,

family connectedness and friend support were identified as helpful in reducing the

likelihood of negative mental health outcomes, thus facilitating resilience (Veale et al.,

2017). In the context of child maltreatment, protective factors at the individual (e.g.,

internal locus of control, optimism, less self-blame) and family (e.g., stable family environment, supportive relationships) levels have been frequently linked with resilience (Afifi & MacMillan, 2011).

Resilience operationalised as an outcome is typically demonstrated by an immediate outcome measure following adversity. This may include maintenance of positive functioning, absence of psychopathological symptoms and / or evidence of recovery following adversity, despite individuals having been at increased risk of reporting the contrary (e.g., Alim et al., 2008; Luthar & Zelazo, 2003; Mancini & Bonanno, 2009; Rutter, 2006). For example, in samples of children exposed to trauma, those who reported low levels of PTSD (Peltonen et al., 2014) or demonstrated developmentally appropriate adaptive functioning such as finishing high school, absence of substance abuse or dependence, and evidence of social activity (DuMont et al., 2007) were considered resilient. In conceptualising resilience as an outcome, whether individuals are characterised as resilient is dependent not only on the type of outcome measure used but also on the time of measurement. For example, what might be considered a suitable outcome indicative of resilience immediately after an adverse event (e.g., low levels of distress), may be different to that considered suitable in the longer term (e.g., high psychological well-being), highlighting that immediate outcomes are not usually final endpoints and may also play a mediator role for longer-term outcomes (Schetter & Dolbier, 2011).

Despite these differences in resilience conceptualisations, there is general convergence in the literature acknowledging resilience to be the product of complex interactions, within and between individuals and their environment (Ungar & Theron, 2020). Importantly, across the conceptual discrepancies, resilience remains an important

contributor to an individual's ability to face, adapt to and recover from stress, underscoring its potential to promote and foster positive mental health outcomes.

3.4. Resilience, Stress and Mental Health Outcomes

Between the encounter of stressors and outcomes lies the stress regulation process, encompassing internal and external resources that interact with and influence aspects of stressful experiences, and how individuals respond or cope (Rossi et al., 2007). Resilience is one such internal resource. Individual differences in resilience can therefore account for variations in stress responses and subsequent outcomes, including resistance to and recovery from stressful situations (Fredrickson et al., 2003; Ong et al., 2006; Tugade & Fredrickson, 2004). Indeed, resilience is implicated at several levels of the stress process, such as stressor appraisals, cognitions in response to emotions, and the selection of coping strategies, which then result in either positive or negative responses and outcomes (Fletcher & Sarkar, 2013; Fletcher & Scott, 2010).

As outlined in the Transactional Model of Stress and Coping (Chapter 2), individuals undergo a series of cognitive appraisals after exposure to a stressor. Resilient individuals, who tend to be more optimistic about their abilities and have a higher sense of control and self-esteem, are more likely to appraise events more positively and as less threatening, resulting in lower levels of stress experienced (Kaiseler et al., 2009; Major et al., 1998). Resilience has been proposed as an important predictor of stress, where increased levels of resilience are associated with lower levels of both perceived stress and chronic stress, as well as a reduced frequency of daily hassles and stressful life events (Cowden et al., 2016; García-León et al., 2019; Kermott et al., 2019; Onan et al., 2019; Pinquart, 2009; Rahimi et al., 2014; Smith et al., 2010).

Resilience also represents a key characteristic in the promotion and maintenance of mental health. As an individual resource, resilience may positively moderate the

meaning of, or regulate reactions in response to stressful encounters, which in turn can positively impact stress-related outcomes such as mental health and well-being. When considering the ways in which resilience might foster mental health, resilience can play both a protective role, by reducing the negative effects of stress or moderating its impact on mental health (Gloria & Steinhardt, 2016; Wingo et al., 2010), as well as an ameliorative role, by promoting stress recovery (García-Secades et al., 2017; Russell et al., 2021).

Drawing parallels from an 'immunity' framework based on resistance to somatic disorders, Davydov et al. (2010) proposed three underlying resilience mechanisms in the promotion of good mental health: 'health protection', 'harm reduction' and 'health promotion', which were analogous to 'immune barriers', 'somatic recovery' and 'strengthening of immune system' respectively. Resilience has the potential to attenuate or limit the negative impact of stressors on mental health outcomes (health protection), accelerate the recovery process and aid individuals in 'bouncing back' following adversity (harm reduction), and improve individual capacity to deal with subsequent threats and stressors in the future (health promotion). Thus, as discussed in Chapter 2, it is not simply the occurrence of stressors, but how individuals respond to stressors, that impacts their physical and psychological health.

Positive associations between resilience and mental health outcomes have been demonstrated in individuals across varying contexts and across the lifespan. For example, in samples of adults described as at-risk for poor mental health (e.g., emerging adults transitioning out of welfare, African American mothers, and women with previous history of cancer), increased levels of resilience have been associated with decreased symptoms of anxiety and depression (Goldstein et al., 2013; Mitchell & Ronzio, 2011; Scali et al., 2012). Similarly, in samples of college students and bereaved adults,

increased resilience has been associated with higher life satisfaction, positive affect and psychological well-being (Mak et al., 2011; Pidgeon & Keye, 2014; Rossi et al., 2007; Xing & Sun, 2013).

Across childhood and adulthood (ages 6- 60 years), a meta-analysis by Hu et al. (2015) found robust associations between higher trait resilience and improved mental health outcomes. Similarly, meta-analyses that examined the associations between resilience and mental health in adults aged 60 and older have identified comparable relationships between higher resilience and better mental health, as indicated by measures of anxiety, depression, quality of life and well-being (Färber & Rosendahl, 2020; Wermelinger Avila et al., 2017). The protective and promotive role of resilience in relation to mental health outcomes has also been noted across varying physical health contexts. Specifically, meta-analyses examining resilience in individuals with chronic diseases such as diabetes and rheumatoid arthritis (Cal et al., 2015), life-threatening diseases (Tamura et al., 2021), and somatic illnesses (Färber & Rosendahl, 2018) have reported inverse relationships between resilience and symptoms of anxiety and depression, as well as positive relationships between resilience and quality of life (QoL). Together these results highlight the universal protective role of resilience against ill health across age and contexts.

As discussed in Chapter 1, there is an increased vulnerability to poor mental health outcomes in autistic adults as evidenced by the high prevalence of anxiety and depression (e.g., Hollocks et al., 2019; Lai et al., 2019) and lower well-being (e.g., Hedley et al., 2019; Lawson et al., 2020) compared to that of the general population. Given the high stress and frequent stressor encounters reported in autistic adults, and the deleterious effects of stress on mental health as addressed in Chapter 2, an in-depth examination of resilience alongside other stress-related constructs such as coping is

important to help elucidate the ways in which the effects of stress can be mitigated, and positive mental health outcomes promoted in this population.

3.5. Resilience and Coping as Individual Resources

As noted earlier in this chapter, resilient individuals tend to be more optimistic and confident in their skills and abilities, including their coping abilities (Nicholls et al., 2011). They also are more likely to appraise stressor encounters as less threatening and more manageable (Seery et al., 2010). It is therefore unsurprising that studies examining the associations between resilience and coping report that individuals with higher resilience more frequently employ coping strategies that are approach-oriented and problem-focused, and less frequently utilise avoidant and emotion-focused coping strategies (Campbell-Sills et al., 2006; Chen, 2016; Folkman & Moskowitz, 2004; Fullerton et al., 2021; Moore et al., 2017; Sagone & De Caroli, 2014; Secades et al., 2016; Thompson et al., 2018).

At this juncture, it is important to distinguish between the constructs of resilience and coping. Although resilience is closely aligned with and conceptually related to coping, the two constructs are considered to be distinct (Campbell-Sills et al., 2006; Meyer, 2015; Van Vliet, 2008). While resilience reflects characteristics related to how individuals approach, respond and adapt to challenging circumstances, coping refers to the reactionary cognitive and / or behavioural strategies employed following an encounter appraised as stressful. Resilience influences the stress process at numerous stages and typically augurs a positive outcome for the individual, such as the maintenance of positive emotions or improved recovery from stressful encounters (Ong et al., 2006; Tugade & Fredrickson, 2004). In contrast, as described in Chapter 2, coping strategies can be adaptive or maladaptive in nature, and thus the subsequent coping outcomes may be positive or negative, depending on the nature and effectiveness of

coping strategies, and contextual factors surrounding the stressful encounter (Fletcher &

Sarkar, 2013; Folkman & Moskowitz, 2004). Importantly, while they remain distinct,

both resilience and coping can either ameliorate or aggravate the effects of adverse and

stressful experiences (Skodol, 2010), representing two malleable resources that

individuals can develop, build on and draw from when faced with stressful

circumstances.

3.5.1. The Conservation of Resources Model

When conceptualising resilience and coping strategies as individual resources, a

useful framework to consider, which might provide a framework to explain the

variability in stress responses and outcomes in autistic adults, is the Conservation of

Resources model (COR; Hobfoll, 1989, 2011). Central to COR theory is that individuals

strive to acquire, retain, foster and protect resources. Resources in the context of the

COR model can refer to tangible objects (e.g., a house), personal resources (e.g., traits,

skills or characteristics), conditions (e.g., employment) or energy (e.g., knowledge)

valued by the individual, or which serve as a means of attaining goals and additional

resources. Resource loss is considered more salient than resource gain, where the

negative impact of loss is proposed to be disproportionately higher than the positive

impact of resource gain (Hobfoll, 2011). Individuals are therefore motivated to invest in

their resources (referred to as their 'resource caravans') and develop a resource surplus to

offset the possibility of future losses (Frydenberg, 2017).

Stress occurs when there is a loss (or threat of loss) of resources, or when an

individual's investment of resources is not adequately returned. For example, a

workplace conflict with a colleague may lead to loss of personal (e.g., self-esteem,

confidence), energy (e.g., time and mental energy) and condition (e.g., strained

relationship) resources, resulting in heightened feelings of stress. Thus, when confronted

with stressors, individuals strive to prevent net loss of resources (Hobfoll, 1989). As

depicted in Figure 1, the process of resource conservation is a result of broader life

circumstances and resource-loss events (Buchwald & Schwarzer, 2010). Individuals

endowed with greater resources are less vulnerable to the negative impact of resource-

loss events, can utilise available resources to better cope, can replenish or re-invest their

resources, and may offset the circumstances which lead to future resource losses, a

cyclical process referred to as 'gain spirals'. On the other hand, individuals lacking in

resources may be less equipped to successfully adapt, might experience more losses that

are unlikely to be replenished and are less likely to gain new resources during recovery.

This process, where initial losses lead to further losses, is referred to as 'loss spirals'

(Hobfoll, 1989; Zwiebach et al., 2010). Augmenting and optimising the use of resources

is therefore key.

Figure 1

Processes of resources conservation (Buchwald & Schwarzer, 2010). Reprinted with
permission (Appendix B)
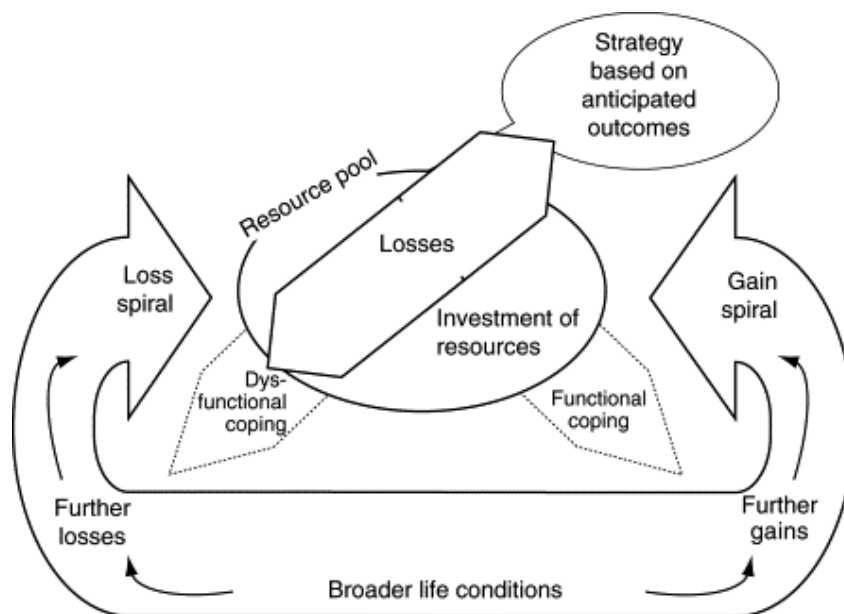
Personal resources form part of an individual's resource pool and can mitigate the relationship between encounters with stressors and the subsequent stress experienced (Frydenberg, 2017). It is conceivable that autistic adults with higher resilience and more adaptive coping strategies in their 'resource pool' may be less vulnerable to the impact of stressors, experience less resource loss, and as a result, experience less stress and fewer stress-related negative outcomes. These individuals may appraise events as less threatening, be more confident in their coping abilities, use more adaptive coping strategies, and anticipate positive outcomes. Following successful outcomes, other resources may be invested or cultivated, such as more refined use of coping strategies, or improved self-confidence or self-esteem, which may then positively influence future stressor encounters, increasing the opportunity for gain spirals.

The environment in which the individual operates (or 'caravan passageways') also plays a role in the maintenance and development of their resource caravans. Though many such environmental circumstances (e.g., socio-economic status, safety, availability of employment) are beyond the control of individuals and their families, nurturing, resource-enriching environments can help foster and protect resources, whereas impoverished and resource-scarce environments might obstruct or detract from resources (Hobfoll, 2011). Ultimately, people differ in their individual resources as they do their environmental resources. Investing and developing resilience and adaptive coping strategies alongside other resources, in addition to creating a more accommodating and resource-nurturing environment for autistic adults may be useful in enabling autistic adults to be better equipped and to better adapt, increasing their likelihood of reporting positive outcomes in the context of stress.

3.5.2. Inter-relationships between Resilience and Coping Strategies

The ways in which resilience and coping strategies interact can in turn have implications for mental health outcomes. One potential underlying mechanism may be that the positive effects of resilience on mental health are mediated through the selection of coping strategies used in response to stressful encounters. Indeed, the mediating role of coping strategies in associations between resilience (or resilience-related traits) and outcomes such as mental health, post-traumatic growth, and PTSD symptoms has been demonstrated in the broader stress and trauma literature and in diverse samples such as undergraduate students, firefighters, adults presenting at an emergency department, Israeli army recruits and women faced with infertility (Florian et al., 1995; Griva & Anagnostopoulos, 2010; Groth et al., 2019; Ogińska-Bulik & Kobylarczyk, 2016; Thompson et al., 2018; Yu et al., 2014). These studies suggest that higher resilience is associated with a range of improved outcomes, and that resilience might also facilitate the use of more adaptive coping strategies, consequently contributing to these improved outcomes. While it is plausible that coping strategies may similarly mediate the resilience-mental health relationship in the autistic adult population, the inter-relationships between resilience, coping strategies and mental health in autism research have not been examined to date.

In addition to resilience-coping interactions at a construct level, investigating the relationship between resilience and coping in autistic adults at an individual level would be complementary. Characterising individual patterns of resilience and coping through the use of 'profiles' can account for coping strategies used in combination, rather than in isolation, and how these combinations of coping strategies might differentially relate to varying levels of resilience. As discussed in Chapter 2, individual coping profiles can be derived using cluster analytical procedures and reflect patterns of coping strategy use,

including the relative ratio, or potential dominance, of some coping strategies over others. Such coping profiles have been noted to differ across measures of stress as well as psychological health outcomes (Doron et al., 2014; Eisenbarth, 2012; Gaylord-Harden et al., 2008).

The ways in which resilience profiles are derived is dependent on how resilience is conceptualised in a given study. For example, individuals may be characterised as 'low resilience' or 'high resilience' based on scores from a single resilience measure (e.g., Kumar et al., 2010; Prince-Embury & Steer, 2010) or a composite of factors closely related to resilience such as hardiness and self-efficacy (Wilson et al., 2016). In contrast, other studies categorise individuals as resilient based on different patterns of adjustment. For example, using measures of PTSD symptoms and post-traumatic growth to indicate adjustment, Tillery et al. (2016) derived three resilience profiles in groups of youth with and without cancer, 'resilient high-growth', 'resilient low-growth' and 'distressed'. In a sample of children exposed to intimate partner violence, Graham-Bermann et al. (2009) derived four profiles of adjustment, 'severe adjustment problems', 'struggling', 'depression only' and 'resilient' based on a combination of internalising and externalising symptoms measures, self-worth and social competence.

Despite being relatively unexamined in the literature, a combination of coping-resilience profiles may be useful in demonstrating how coping strategies and resilience patterns may co-occur in autistic adults at an individual level. Further, there could be autistic adults who report high levels of resilience but utilise a combination of coping strategies that are not typically considered 'adaptive', or vice-versa. Utilising a person-centred approach to characterise autistic adults based on their coping-resilience patterns would be important given the heterogeneity within autism and the need to understand individual-level characteristics that may confer risk for or protection against outcomes

such as stress. Person-centred approaches would also enable the identification of individuals at the highest risk for poor outcomes, and allow for personalised support and intervention options.

3.6. Resilience in Autism: Employing a Trait Approach

In the context of autistic adults, resilience in this thesis is approached from a trait perspective, representing a dynamic individual resource of characteristics, attributes and skills that can facilitate the ways in which autistic adults face, adapt to, and recover from stressful and adverse encounters. Although an in-depth understanding of resilience operationalised both as a process and an outcome in autistic adults is also important, risk factors and outcome measures that are relevant, meaningful, and able to capture the essence of resilience in this population are difficult to quantify.

With respect to resilience as a process, there is limited research in the general population surrounding the magnitude of events and experiences, or the thresholds of exposure required to constitute adversity or a risk factor (Leadbeater et al., 2005). Further, not all adverse or stressful contexts have a clearly defined beginning and end. While some researchers might employ a threshold-dependent definition of adversity, others consider *any* hardship or difficulty as adversity (Fletcher & Sarkar, 2013). As described in Chapter 2, autistic individuals face increased encounters with adverse events and experience high levels of stress, in addition to autism-unique stressors. It is thus unclear which measure, or combination of measures, might best represent risk factors in the study of resilience in autistic adults.

With respect to positive outcomes, these need to be conceptually relevant to the risk or adversity under examination (Luthar et al., 2015). In the general population, various criteria have been utilised to quantify positive outcomes in adults, such as 'normative' adult standards or 'behaviourally manifested social competence, or success

at meeting stage-salient developmental tasks' (Luthar & Cicchetti, 2000, p. 858).

However, these outcomes tend to have an emphasis on individual and relationship

capacities (e.g., academic success, employment, involvement in relationships, and

independent living; Goldstein et al., 2013; Newman et al., 2011) and do not always

consider the sociocultural context in which an individual operates (Ungar & Liebenberg,

2011). Given the large heterogeneity in outcomes reported in the autistic adult

population, indicators of this nature may not adequately capture or appropriately reflect

the full range of desired adult outcomes in this population.

      While other outcomes such as having a functional role in society, independence

with or without support, adequate daily living skills, psychological well-being, and

physical health and safety may be suitable indicators of success in the autistic adult

population (Henninger & Taylor, 2014), the appropriate stringency for outcome criteria

required to indicate 'success' remains subjective. This has been similarly noted in the

broader resilience literature, where some researchers posit that individuals need to

demonstrate success or competence across multiple adjustment domains to be considered

resilient, while others stipulate that competence in one domain is sufficient to

demonstrate resilience (Luthar et al., 2000).

      Employing a trait approach to resilience in this thesis thus allows for a broader

examination of resilience in the autistic adult population, one that is neither limited to

specific contexts or circumstances of stress and adversity nor confined to particular

measures of outcome and adjustment. This broad approach is in line with the limited

resilience research in autism to date, which is discussed in the following section and

complements the dispositional approach held in relation to coping, as discussed earlier in

Chapter 2.

3.7. Resilience Research in the Autism Literature

Resilience research in autistic individuals is relatively limited to date, with most research in the autistic population having focused on resilience in parents, caregivers, and families (Bekhet et al., 2012; Bitsika et al., 2013; Gardiner et al., 2019). Encouragingly however, resilience in autism represents an emerging area of research, with growing discussions surrounding risk-outcome pathways and the identification of protective factors at individual and environmental levels that may facilitate the maintenance of positive outcomes and adaptation for autistic individuals (Elsabbagh, 2020; Lai & Szatmari, 2019). In addition, given the ongoing COVID-19 pandemic and its impact on the autism community (e.g., educational and vocational challenges, reduced access to clinical services and support, and disrupted home and leisure routines), the need to examine and foster resilience and coping in autism has been underscored as highly pertinent (Ameis et al., 2020; Baweja et al., 2022).

This overall scarcity of resilience research and lack of resilience measures validated for use in the autistic population was also recently highlighted by Clark and Adams (2021) in a systematic review of resilience studies conducted in autistic children and children with ID (aged 5- 17 years) over a 20-year period (1999-2019). Further, it was noted that there is both growing interest and research surrounding resilience interventions for autistic children and adolescents (e.g., Habayeb et al., 2017; Mackay et al., 2017). While these interventions often have a range of targeted outcome areas (e.g., social competence, emotional functioning, coping and adaptive skills, psychopathological symptoms) in addition to resilience, an in-depth examination or clear conceptualisation or measurement of resilience as a construct is usually lacking.

In the following discussion of the resilience literature in autism, the ways in which resilience is conceptualised in each study is addressed to aid study interpretability

and to draw patterns across the varied resilience research conducted in autism to date. Though not always explicitly defined, many of the resilience studies in the autism literature to date have conceptualised and measured resilience from a trait-like perspective, by either utilising a single resilience measure, or assessing a range of characteristics or factors, to demonstrate levels of individual resilience. Drawing findings from a range of quantitative studies, the next section first considers the potential low levels of resilience in autistic samples, associations between resilience and other individual resources such as emotional intelligence (EI), and the protective role of resilience against negative outcomes. This is followed by a more in-depth discussion surrounding adversity, resilience and coping in autistic adults based on current qualitative study findings available to date.

3.7.1 Low Resilience in Autistic Samples

Several studies have alluded to potentially low levels of resilience in autistic individuals compared to their non-autistic peers. Significant inverse relationships have been reported between autistic traits and levels of resilience in both autistic and non-autistic samples. In a study with 212 (193 male) non-autistic adolescents aged 14-17 years, where resilience reflected the degree to which an individual's resources (i.e., their sense of mastery and relatedness) exceeded their emotional reactivity to stress, higher levels of autistic traits were associated with lower resilience (McCarthy et al., 2020). Similarly, in samples of adults with high autism traits ($n = 201$) and adults from the general population ($n = 1,553$), where resilience was characterised by individual attributes such as personal competence, acceptance, secure relationships, self-reliance, and emotion regulation, the extent of autism traits was inversely associated with resilience in both samples (Taylor et al., 2022).

Studies that have examined group differences in resilience between autistic and

non-autistic samples have shown inconsistent findings. For example, in a US-based comparison study, Rigles (2017) utilised telephone interview data from the National Survey of Children's Health (NSCH) between 2011 and 2012 to examine adverse childhood events (ACE), resilience (referred to as 'resiliency') and health outcomes in 1,188 autistic and 43,003 non-autistic children aged 7-16 years. In this study, resilience was quantified based on parent-report across three items (i.e., child showing interest and curiosity to learn new things, stays calm and in control when faced with challenges, and finishes task and follows through with plans). In addition to more experiences of ACE, the autistic children had lower resilience compared to the non-autistic children. Further, while increased ACE was related to decreased resilience in the non-autistic children, the levels of resilience in the autistic children remained unchanged despite changes in ACE.

Montgomery et al. (2008) examined 'resilience factors' in autistic male youth (N = 20; age 16-21 years), where resilience factors were defined as traits and characteristics that reflect a sense of mastery (e.g., optimism, competence, self-efficacy), relatedness (e.g., trust, support, tolerance with others) and emotional reactivity (e.g., sensitivity, recovery, impairment from emotional events). Based on parental report, the autistic youth had lower levels of resilience, particularly lower emotional resilience (i.e., high emotional reactivity), in addition to higher resistance to change, immaturity in daily living skills and difficulties in utilising support systems to overcome adversity, compared to same-aged population norms (Montgomery et al., 2008). In contrast, in a younger sample examining the same 'resilience factors', McCrimmon et al. (2016) reported no significant differences in any of the resilience factors (i.e., sense of mastery, relatedness and reactivity) between 20 autistic and 20 non-autistic children aged 8-12 years (95% male). This lack of group differences in resilience was noted again in McCrimmon et al. (2018), where no group differences in any resilience factors between boys aged 8-12

years with clinical diagnoses of autism or ADHD, and those who were typically developing (*n* = 18 per group) were found.

A possible explanation for the discrepancies in findings of resilience levels in autism may be related to the type of reporting utilised in these studies. Indeed, only studies using parental report (Montgomery et al., 2008; Rigles, 2017) demonstrated significantly lower resilience in the autistic children and adolescents, whereas studies using self-report (McCrimmon et al., 2016, 2018) reported no group differences between the autistic and non-autistic children. Alternatively, these discrepancies may be related to age, where resilience decreases from childhood to adolescence. Indeed, compared to childhood, adolescence involves transitional changes and increased introspection, which may impact how adolescents evaluate their resilience (Sun & Stewart, 2007). It is also possible that the younger autistic children may be less able to accurately report their resilience (Hu et al., 2015). Nevertheless, it is difficult to generalise the autism study findings to autistic adults given that the prior study samples were primarily children and adolescents, some of which were almost exclusively male. Further, the degree of potential overlap between reduced resilience as measured in these studies and broader autistic traits (e.g., behavioural inflexibility and dysregulation, difficulties in managing social networks) makes it unclear if autistic traits may have been a confounding factor in the measurement of resilience in these studies. Given the limited resilience studies in autism, the ways in which these study findings may be applicable to the autistic adult population remains unknown.

3.7.2. Associations between Resilience and Emotional Intelligence

Several resilience studies have examined the associations between resilience and EI in autistic children and youth, proposing that capitalising on individual strengths and resources, such as EI, may in turn promote other resources such as resilience. EI refers to

how individuals identify, perceive, use and regulate their own emotions and those of others (Brasseur et al., 2013). Although both EI and emotion regulation (ER) are involved in emotion management more broadly, ER encompasses specific processes and strategies used by individuals to modify or maintain their emotional responses, whereas EI represents a major resource that can foster the development of ER-related skills (Zysberg & Raz, 2019). EI is implicated in stress management, and it is plausible that an individual's ability to appraise, process and utilise emotional information may subsequently have an influence on their resilience in the face of stress. Thus examining EI literature in autism may provide insights into resilience in this population.

Studies have examined EI from either a trait-perspective, encompassing a constellation of emotional, self-perceived, behavioural dispositions and abilities, including interpersonal, intrapersonal, adaptability and stress management domains which can influence one's ability to cope with environmental demands, or an ability-perspective, covering the capacity to perceive, access, understand and generate emotions that assist in enhancing emotional knowledge and the regulation of affect. Strong positive associations between trait-based EI and various aspects of resilience have been reported in 20 autistic males aged 16 to 21 years (Montgomery et al., 2008) and in a predominantly male sample of autistic children aged 8-12 years ($N = 20$, McCrimmon et al., 2016 and $N = 18$; McCrimmon et al., 2018). Similarly, McCarthy et al. (2020) reported positive associations between EI and resilience in 212 non-autistic adolescents aged 14 to 17 years. Autistic traits were also found to mediate different dimensions of the EI-resilience relationship, suggesting that the ways in which EI associates with resilience may be in part explained by the degree of autistic traits (McCarthy et al., 2020). Specifically, individuals who were better at emotion recognition, expression and

management, as well as the understanding of emotions in others tended to have fewer

autistic traits and in turn, reported higher resilience.

Overall, these EI-resilience studies highlight the inter-relationships between EI

and resilience as individual resources, suggesting that addressing one resource has the

potential to promote another. This may be similarly the case when considering the

constructs of coping and resilience in the autistic population, where facilitating resilience

in autistic individuals may promote more adaptive coping strategy use or vice versa. As

discussed in Chapter 2, coping and emotion-related constructs such as ER can be related

but also distinct in their focus and the contexts in which these strategies are deployed

(Compas et al., 2014). While there has been increasing literature on ER and strategies

used to up or down-regulate positive and negative emotions in autistic adults (see review

by Cai et al., 2018), little remains known about the types or frequency of use of coping

strategies in response to stressors and situational demands faced in this population.

Further, as noted earlier in this chapter, the relationships between resilience and coping

strategies in the autistic population have remained unexplored.

3.7.3. Protective Role of Resilience against Poor Outcomes

Concordant with the broader literature, resilience has been suggested to play a

protective role in reducing the severity or frequency of a range of poor outcomes in the

autistic population, such as emerging school refusal and poor mental health.

3.7.3.1. Emerging School Refusal.

Within the context of bullying experiences, Bitsika et al. (2022) explored

psychological resilience and its associations with emerging school refusal in a sample of

58 autistic boys aged 5 to 16 years in primary ($n = 36$) and secondary ($n = 22$) schools.

Psychological resilience was defined as an individual's capacity to cope with and resist

the harmful effects of stress, encompassing personal traits that promote rebounding from

and positive adjustments to challenging situations. Findings suggested that total

psychological resilience, particularly items relating to the ability to control negative

thoughts and to remain calm when angry, was inversely related to emerging school

refusal, but only in the older sample. Developmental differences may explain these

differences in relationships across the two school samples. The significance of emotional

elements of resilience may be stronger in children than in adolescents, in relation to

outcomes such as school refusal. It is also possible that adolescent boys may have more

refined cognitive capacities that not only help modify the context or impact of bullying

experiences, but also reduce the need to avoid school (Bitsika et al., 2022).

3.7.3.2. Physical and Mental Health.

Across autistic children, adolescents and adults, higher levels of resilience using

varying definitions and measurements have been related to improved physical and mental

health outcomes. For example, in children, psychological resilience as defined above in

Bitsika et al. (2022) was inversely associated with symptoms of anxiety in a sample of 39

autistic boys aged 7 to 12 years (Bitsika & Sharpley, 2014). Similarly, Rigles (2017)

found positive associations between resilience and improved health. Specifically, the

potential moderating role of autism trait severity (quantified as mild, moderate or severe)

in the relationship between resilience and both physical and mental health in a combined

sample of autistic and non-autistic children ($N = 56,746$) aged 7 to 16 years was

examined. Findings suggested that this interaction was not significant, indicating that the

ways in which resilience was inversely associated with physical and mental health in

autistic and non-autistic children were the same. Considering the findings on inverse

relationships between resilience and autistic traits reported earlier, it is possible that

while autistic traits are directly and separately related to resilience (McCarthy et al.,

2020; Taylor et al., 2022) and health outcomes, they do not moderate resilience-health

relationships.

In adolescents and adults, Onyishi and Sefotho (2019) examined the relationship between resilience and depressive symptoms in 68 Nigerian autistic adolescents and young adults aged 12 to 23 years. Resilience was measured using the Child and Youth Resilience Measure (CYRM-SR-28) across three subscales: individual skills, relationship with caregivers and contextual factors (Liebenberg et al., 2012). Findings from this study suggested that a low total resilience score was a strong indicator for high depressive symptoms, where the individual factors subscale emerged as the strongest predictor. This suggests that fostering resilience, particularly through the development of individual factors, may be helpful in buffering depressive symptoms in autistic adolescents and adults (Onyishi & Sefotho, 2019). Likewise, in their pooled sample of adults with high autism traits ($n = 201$) and adults from the general population ($n = 1,553$), Taylor et al. (2022) found that higher resilience was associated with fewer symptoms of both anxiety and depression. Additionally, higher resilience predicted a weakened relationship between autistic traits and depression (but not anxiety), suggesting that resilience may be more important in providing a protective role against depression rather than anxiety.

Only one resilience study in the autistic population to date has included a positive measure of mental health (i.e., positive mental well-being; Hwang et al., 2020). In addition to exploring the relationship between resilience and both negative and positive mental health outcomes, Hwang et al. (2020) also investigated the factor structure and psychometric properties of the 10-item Connor-Davidson Resilience Scale (CD-RISC10) in a sample of 95 autistic adults with a mean age of 44 years. Consistent with the broader literature, higher levels of resilience were related to improved well-being and reduced symptoms of anxiety and depression in these autistic adults. Additionally, the unidimensional structure of the CD-RISC10 was found to be a reliable and valid measure

of resilience in this sample, capturing the individual ability to thrive despite adversity

(e.g., adapting to change, bouncing back after hardship, and handling unpleasant

feelings). Importantly, Hwang et al. (2020) further noted that given the vulnerability to

stressful and negative life events in autistic adults, a more in-depth understanding of the

relationship between resilience and coping strategies was needed.

Taken together, these studies indicate the potential for resilience to operate as a

protective factor against a range of negative outcomes, particularly mental health

outcomes, in the autistic population. Nevertheless, there are few resilience studies

conducted to date, most of which have focused on autistic children and youth, with only

one study conducted with autistic adults (i.e., Hwang et al., 2020). Understanding the

ways in which resilience might be implicated in the mental health and well-being of

autistic adults, as well as establishing possible mechanisms underlying these

relationships is pertinent to addressing the high stress and poor mental health outcomes

reported in this population.

3.7.4. Resilience, Adversity and Coping

Two qualitative studies to date have explored resilience experiences and

perspectives in the autistic adult population, providing some in-depth understanding of

the adversity and challenges faced by autistic individuals, coping mechanisms utilised

and the ways in which resilience might manifest and be further fostered in autistic

individuals.

In a qualitative study exploring the meaning of childhood adversity and resilience

in four autistic adults aged 19 to 27 years (three women, one non-binary), Heselton et al.

(2022) identified themes related to the negative effects of adversity and factors associated

with resilience building. A range of childhood adversities (e.g., bullying, rejection and

abuse, internal dysregulation and behavioural challenges) were experienced by the

participants and were noted to result in social disconnection, mental health challenges, suicidal ideation, emotional distress, a poor sense of self, and difficulties in adult relationships. The participants also shared that their resilience developed over time, through growth and as they transitioned into adulthood, with several internal and external factors contributing to their overall resilience. In particular, 'safe spaces', both external (e.g., being a part of accepting communities) and internal (e.g., being able to immerse themselves in their interests and talents), represented a place of refuge for these autistic adults, providing safety and escape from adversity, while allowing them to foster aspects of their identity and individual strengths (e.g., self-understanding, determination, pride) and develop resilience.

Only one qualitative study thus far has jointly examined resilience and coping strategies in autistic individuals. Ghanouni and Quirke (2022) explored autistic adult (N = 13, aged 27 to 53 years) and stakeholder (i.e., five parents and four service providers) experiences of coping and resilience, where three major factors that affect the development of coping and resilience were identified: societal expectations and conformity, adjusting daily routines, and learning over time. All participants felt that autistic adults were faced with the pressures of having to conform to societal expectations and standards (e.g., independent living, employment) and that they were often targets of biases and negative attitudes. Coping mechanisms included incorporating breaks, leisure and recreation activities into daily routines, seeking emotional support from support groups, and the use of technology to assist with socialisation and daily activities (e.g., grocery shopping, task reminders). The participants also believed in the ability of autistic adults to develop and learn resilience and coping skills over time by identifying and cultivating their strengths and acknowledging and addressing their weaknesses, triggers and trauma, as well as a broader need for improved education and

advocacy in the autistic population.

Drawing from these two qualitative studies, it is evident that autistic adults experience a range of stressful encounters and adversities throughout their lifetime, and these experiences can have a profound impact on their lives. Fostering individual strengths such as coping mechanisms and a sense of self, and addressing weaknesses, triggers and past trauma have been reported as helpful. Studies that utilise a quantitative approach to further examine resilience and coping in autistic adults would not only complement these reported qualitative experiences, but may also uncover underlying mechanisms between resilience and coping strategies, and how these might be implicated in the experience of stress and other stress-related outcomes in the autistic adult population.

3.8. Chapter Conclusions

Resilience represents an important element in the framework of mental health promotion. As an individual resource, resilience can influence the stress process, having potential implications for levels of perceived stress and selection and use of coping strategies, as well as positively impacting outcomes such as mental health and well-being. However, resilience literature in the autistic population, particularly in adulthood, is scarce to date. Considering the breadth of stress and adversity faced by this population and the poor mental health outcomes frequently reported, a better understanding of resilience as a construct in autistic adults, and its associations with stress, coping and mental health is important.

The examination of resilience in autistic adults represents a strength-based approach to understanding the ways in which autistic adults face and respond to both stressors and adversity. While a few recent autism studies have indicated the potential protective role that resilience may have against poor mental health, not all have utilised a

resilience-specific measure to assess resilience in their autistic samples. Moving forward to best capture and measure resilience in autistic adults, utilising a measure that has been validated for use in this population is important. In addition, examining the ways in which resilience associates and interacts with closely-related constructs such as coping and stress would be vital for a more in-depth understanding of this understudied area in the autism literature. Better insights into these inter-relationships have the potential to offer valuable information concerning the personalisation and development of resilience supports and interventions, with the twin aims of reducing stress and protecting the mental health and well-being of autistic adults more broadly.

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Chapter 4: Research Rationale and Aims

Chapter Overview

The rationale, aims and hypotheses for each study included in this doctoral thesis is outlined in this chapter. The overarching aim of this thesis was to build on the limited but emerging literature on coping and resilience, and their associations with stress, mental health and well-being in autistic adults. This was systematically addressed by first examining a commonly utilised, existing coping measure and establishing a factor structure for autistic adults using a large autistic adult sample (Chapter 6; Study 1). Using the factor structure derived in Study 1, the associations between coping strategies and mental health outcomes were then investigated cross-sectionally in autistic and non-autistic adults (Chapter 7; Study 2), and longitudinally over a two-year period in autistic adults (Chapter 8; Study 3). Following these studies, an in-depth examination of the potential stress-moderating role of coping strategies on psychological well-being in autistic adults was conducted (Chapter 9; Study 4). Finally, the inter-relationship between coping strategies and resilience was explored, first in relation to mental health outcomes using a variable-focused approach (Chapter 10; Study 5) and then in relation to stress, using a person-focused approach (Chapter 11; Study 6). Addressing four main aims (see Figure 1 below), these six studies take the form of manuscripts published in or submitted to peer-reviewed scientific journals (5 published, 1 under review).

Figure 1

Overarching aim of thesis, addressed by four main aims and their respective chapters
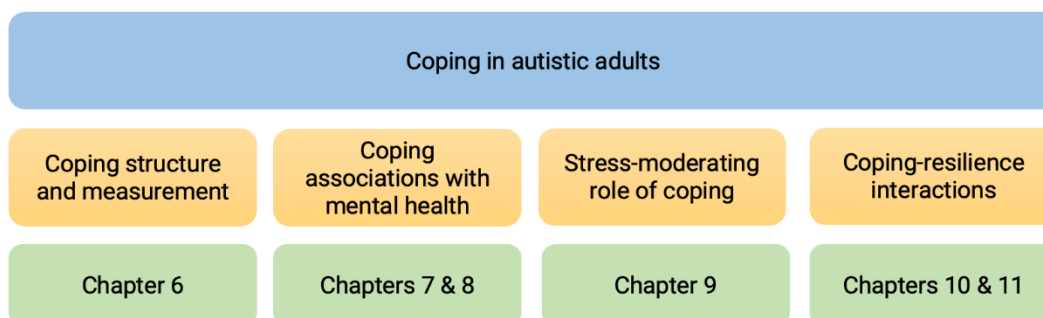
Aim 1: Determine factor structure of the Brief COPE and its validity for use in autistic adults (Chapter 6).

As discussed in Chapter 2, coping studies conducted in the autistic population have been limited, with inconsistent findings in relation to patterns of coping strategy use and associations between coping strategies and mental health outcomes. Further, there is not yet a standardised coping measure that is validated for use with autistic adults. Utilising factor structures and item compositions that have been validated and normed with samples from the general population can be problematic as these structures may fail to capture intricacies in the use and grouping of coping strategies which may be unique to autistic individuals. Indeed, it is plausible that there are autism-specific factors that influence stressor encounters, experiences of stress and the subsequent selection, use and effectiveness of coping strategies in this population.

The Brief COPE (Carver, 1997) is a commonly employed, 28-item coping measure covering a wide range of individual coping strategies. While originally suggested to have fourteen overarching coping subscales, more recent studies across a range of samples have obtained more parsimonious factor structures, identifying fewer, broader coping dimensions captured by the Brief COPE (e.g., Benson, 2010; Kapsou et al., 2010; McLoughlin, 2019). Nevertheless, no consensus on the ideal factor structure has been reached, although conceptual and structural similarities have been derived across these samples (see review by Krägeloh, 2011). To best capture the coping responses in autistic adults, it is imperative to first establish and utilise a Brief COPE factor structure that has been validated for use with autistic adults. This approach also addresses the concerns raised by the autistic adult community that measures validated for non-autistic individuals may not adequately reflect the experiences of those in the autism

community, nor fully capture the autism-specific aspects of constructs (Nicolaidis et al., 2020).

Thus, the aim of Study 1 was to determine the most parsimonious factor structure of the Brief COPE that best represented the use of coping strategies in a sample of autistic adults, and to establish its psychometric properties. Using a non-autistic adult comparison sample, differences in factor structure and factor composition at the item-level between the two samples was also examined. Given the exploratory nature of this study and the lack of consensus in the factor structure of the Brief COPE from the literature, no specific hypotheses were made regarding the factor structures that would emerge for each sample.

Aim 2: Examine cross-sectional and longitudinal associations between coping strategies and mental health outcomes in autistic adults (Chapters 7 and 8).

Compared to the general population, poor mental health outcomes are commonly reported in the autistic adult population (see Chapter 1). Autistic adults report a high prevalence of co-occurring mental health conditions, such as anxiety and depression, as well as reduced well-being (Hedley et al., 2019; Hollocks et al., 2019; Joshi et al., 2013; Lawson et al., 2020). As noted in Chapter 2, exposure to stressors and experiences of stress can have a detrimental impact on individual mental health and well-being (Nelas et al., 2016; Ribeiro et al., 2018; Watson et al., 2008). This is particularly concerning for autistic adults, given the high levels of stress and increased vulnerability to negative life events in this population (e.g., Gillott & Standen, 2007; Griffiths et al., 2019). The ways in which an individual copes and the coping strategies they use in response to stressors have the potential to play a protective role, buffering the negative effects of stress on mental health and well-being (Compas et al., 2001). However, as noted in Chapter 2, research surrounding the relationships between coping strategies and mental

health outcomes in the autistic population is limited, with inconsistent findings, and no studies to date have examined these relationships in autistic adults. While there is strong evidence from the broader coping literature that coping strategies characterised by avoidance and disengagement tend to relate to poorer mental health, and coping strategies that are approach-and engagement-oriented relate to better mental health, it is not known if the same associations exist among autistic adults. Further, no coping studies in autism to date have examined both the negative and positive aspects of mental health outcomes in relation to coping strategy use. In addition to both these facets of mental health providing a more holistic picture of mental health outcomes in autistic adults, it is also possible that coping strategies may differentially relate to positive and negative facets of mental health. Importantly, understanding coping-mental health relationships in autistic adults can help identify coping strategies which may operate as risk or protective factors in relation to mental health outcomes in this population.

Thus, the aim of Chapter 7 was to examine the concurrent associations between coping strategies and mental health outcomes (i.e., depression, anxiety and well-being) in autistic and non-autistic adult samples using the Brief COPE factor structures identified in Chapter 6. Comparing the results for the autistic and non-autistic samples allowed for the exploration of coping-mental health associations which may be unique to the autistic adults. Based on the current coping literature, disengagement coping was expected to be positively related with depression and anxiety, and negatively related with psychological well-being in both samples. Conversely, engagement coping was expected to be negatively related to depression and anxiety, and positively related to psychological well-being. No predictions were made with regard to any remaining coping categories identified in Chapter 6 or the potential group differences between the two samples.

As discussed in Chapter 2, coping strategies represent a malleable individual resource which can be developed and honed. Longitudinal coping studies in the wider literature suggest that mental health and well-being at follow-up can be predicted by both baseline levels of coping strategies (Nielsen & Knardahl, 2014; Thompson et al., 2018) and changes in these levels over time (e.g., Booker et al., 2020). Capturing coping trajectories over time and understanding their relationships with mental health outcomes can be particularly useful in informing stress and coping-related support and intervention options in autistic adults. Indeed, the efficacy of coping strategy interventions in promoting adaptive coping strategies in non-autistic samples has been encouraging, with more effective coping patterns (i.e., increased problem-solving strategies, reduced avoidant strategies), and lower symptoms of depression, negative affect and perceived stress demonstrated post intervention (Steinhardt & Dolbier, 2008). However, only one longitudinal coping-mental health study has been conducted in the autistic population to date, where mean use of engagement coping strategies, as well as an increase of both engagement and disengagement coping strategies over time, were found to predict fewer depressive symptoms in autistic children at follow-up (Rieffe et al., 2014).

The aim of Chapter 8 was to explore the longitudinal relationship between coping strategies and mental health (i.e., depression, anxiety and well-being) in the autistic adult population. Specifically, baseline levels of coping strategies and the change in coping strategy use over time were examined as potential predictors of subsequent mental health outcomes in a sample of autistic adults two years later. It was expected that after controlling for baseline levels of mental health, both higher baseline and an increase in disengagement coping strategies would be significant predictors for worse mental health outcomes at follow-up, while higher baseline and an increase in engagement coping strategies would predict better mental health outcomes at follow-up.

Aim 3: Investigate the potential stress-moderating role of coping strategies in relation to psychological well-being in autistic adults (Chapter 9).

As discussed in Chapter 2, exposure to stressor encounters and stressful experiences have been linked with detrimental outcomes in mental health and well-being within the wider literature (Buser & Kearney, 2017; Seiffge-Krenke, 2019). This is particularly relevant to autistic adults, given the emerging research suggesting high stress and frequent stressful encounters (Bishop-Fitzpatrick et al., 2017; Moseley et al., 2021), and the consensus surrounding poor mental health outcomes (Hollocks et al., 2019; Joshi et al., 2013) in autistic adults. Nevertheless, not all individuals who experience stress report poor mental health and reduced well-being. Individual use of coping strategies has the potential to moderate the relationship between stress and its subsequent outcomes. Specifically, some coping strategies may operate as a protective factor, buffering the negative effects of stress on mental health, while others can be a risk factor, exacerbating the effects of stress on mental health (Ahles et al., 2016; Dardas & Ahmad, 2013; Suldo et al., 2008). However, the potential stress-moderating role of coping strategies in relation to psychological well-being has not yet been examined in the autistic population.

The aim of Chapter 9 was to provide an initial examination on the potential moderating role of coping strategies on the associations between stress and psychological well-being in autistic adults. It was hypothesised that coping strategies would moderate the relationship between stress and psychological well-being. Specifically, it was predicted that engagement coping would play a stress-buffering role, weakening the relationship between stress and well-being, whereas disengagement coping would play a stress-exacerbating role, strengthening the relationship between stress and well-being.

Aim 4: Explore the interactions between coping strategies and resilience in relation to stress and mental health outcomes in autistic adults (Chapters 10 and 11).

Although coping and resilience are distinct, both constructs are conceptually related in that they can ameliorate or aggravate the impact and subsequent outcomes of stressful encounters (Skodol, 2010). As alluded to in Aims 2 and 3, the ways in which individuals cope and their use of coping strategies in response to stressors play a pertinent role when considering mental health outcomes. Similarly and as discussed in Chapter 3, resilience also represents a key characteristic in the promotion and maintenance of good mental health (e.g., Goldstein et al., 2013; Scali et al., 2012), with positive associations between levels of resilience and mental health and well-being (see meta-analysis by Hu et al., 2015). These relationships have been similarly noted in the autistic population, where higher levels of resilience were associated with better mental health and well-being in a sample of autistic adults (Hwang et al., 2020).

Resilience is implicated at various stages of the stress process, including the selection of coping strategies (Fletcher & Sarkar, 2013). Individuals who report higher levels of resilience also tend to report more use of active and engagement-oriented coping strategies, while those with lower levels of resilience more commonly report using passive and disengagement-oriented coping strategies (e.g., Moore et al., 2017; Thompson et al., 2018). Extending this further, it is plausible that coping strategies play a mediating role in the resilience-mental health relationship, and that the influence of resilience on use of coping strategies may in turn have subsequent implications for mental health outcomes. However, the ways in which coping strategies and resilience may be associated, and the potential for coping to mediate the relationship between resilience and mental health in the autistic population has not yet been examined.

The aim of Chapter 10 was to explore the inter-relationships between trait resilience, coping strategy use and mental health outcomes in autistic adults. Specifically, the associations between coping strategies and resilience, and the potential mediating role of coping strategies on the relationship between resilience and mental health outcomes were examined. Higher levels of trait resilience were expected to be related to higher use of engagement coping strategies and lower use of disengagement coping strategies. Both disengagement coping and engagement coping were expected to mediate the concurrent relationship between resilience and levels of anxiety, depression and psychological well-being.

Both coping strategy use and resilience can potentially impact levels of perceived stress. For example, coping strategies that are approach and engagement-oriented have been associated with lower stress, and coping strategies that are avoidant and disengagement-oriented with higher stress (Dabrowska & Pisula, 2010; Reeve et al., 2013). Although the ways in which resilience and coping strategies may be associated on a variable level have been explored in the general population (e.g., Moore et al., 2017; Thompson et al., 2018), less is known about how resilience and coping strategies may interact at an individual level, where these strategies are likely to be used in combination with each other, rather than in isolation (Eisenbarth, 2012). Coping profiles are typically used to characterise individuals based on their unique combination of coping strategies, and resilience profiles to capture varying individual patterns of resilience (Prince-Embury & Steer, 2010). Given the inter-relationships between coping and resilience more broadly, it is plausible that distinct coping-resilience profiles exist, depicting specific combinations of coping and resilience profiles, and that these coping-resilience profiles may differ across levels of stress. However to date, coping-resilience profiles have yet to be examined in either autistic or non-autistic populations.

The aim of Chapter 11 was to characterise distinct coping and resilience subgroups using a person-focused approach and to examine the ways in which these profiles relate to concurrent experiences of stress in autistic adults. Considering both the novelty of coping-resilience profiles in the broader literature and the limited coping and resilience literature in autism research to date, there were no specific predictions in relation to the profiles that would be derived. However, it was hypothesised that individuals who reported high resilience, high engagement coping and low disengagement coping would experience lower stress compared to those characterised by low resilience, low engagement coping and high disengagement coping.

The next chapter provides the general methodology for the six empirical studies, including recruitment, participant characteristics, procedures, measures and statistical analyses.

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Chapter 5: General Methods

Chapter Overview

The six empirical chapters in this thesis utilised data from three survey projects: 1) the longitudinal Study of Australian School Leavers with Autism (SASLA); 2) the Australian Longitudinal Study of Autism in Adulthood (ALSAA); and 3) the Resilience Pathways in Autistic Adults Study (RPAAS), an empirical project designed specifically for this thesis. Funded by the Cooperative Research Centre for Living with Autism (Autism CRC), both SASLA and ALSAA worked in close collaboration to allow for a lifespan approach to be taken in identifying unique profiles of younger and older Australian autistic adults through a questionnaire-based, prospective collection of longitudinal information (SASLA: baseline, 12 and 24 months; ALSAA: baseline and 24 months). While SASLA broadly aimed to capture the profiles of Australian autistic students through transitional periods (e.g., from school to tertiary education/ adult life, or from tertiary education to adult life), ALSAA aimed to provide a comprehensive profile of autistic adults through a focus on physical and mental health, participation in society and healthy ageing. Each empirical chapter presented in this thesis has been published in or submitted to scientific journals. As a streamlined description of methods used is provided in the relevant chapters, the aim of the current chapter is to provide a more comprehensive overview of the methodological details (i.e., research design, participants, measures and procedures) across all six chapters.

5.1. Participants

5.1.1. Recruitment

Longitudinal Study of Australian School Leavers with Autism (SASLA).

As part of the Autism CRC, SASLA was designed in 2014 to follow Australian autistic and non-autistic adolescents and young adults over a 2-year period. Data

collection began in 2015 where participants were adolescents and young adults aged 15-25 years, and parents and carers of autistic young people, recruited into one of the four groups: 1) formally diagnosed autistic participants without co-occurring ID, self-report; 2) formally diagnosed autistic participants with co-occurring ID, caregiver- report; 3) carers of autistic adolescents and young adults aged 15-25 years, self-report and 3) non-autistic control participants, self-report.

In October 2014, SASLA organised an adult forum consisting of presentations and panel discussions, which allowed for autistic adults, their caregivers and service providers to share their lived experiences with the wider community. This forum not only further informed decisions surrounding the focus of research areas for SASLA, but also allowed for the promotion of the study and beginning the recruitment of potential participants. The recruitment period for the baseline survey for SASLA occurred between April 2015 and June 2018. Potential participants were primarily recruited through the dissemination of promotional materials across Australia through a wide range of channels, including autism-specific research centres and participant registries (e.g., Olga Tennison Autism Research Centre), autism support networks (e.g., Aspergers Victoria, Amaze, Alpha Autism, Aspect, Autism QLD), tertiary education institutions, secondary and special education institutions and social media (e.g., Facebook, Twitter and websites). To allow for further snowball sampling, recruited participants were also encouraged to share information about the study within their own networks. To boost recruitment and to retain participants for the full duration of the study, participants recruited from August 2017 were offered a AUD30 e-voucher upon completion of the final survey.

Australian Longitudinal Study of Autism in Adulthood (ALSAA)

Similarly as part of the Autism CRC, ALSAA was developed in conjunction with SASLA in 2014 to follow Australian autistic and non-autistic adults aged 25 years and over with a follow-up at 2-years. Data collection began in 2015 where adults based in Australia aged 25 years and over were recruited by ALSAA into one of the following groups: 1) formally diagnosed autistic adults without ID, self-report; 2) formally diagnosed autistic adults with ID, caregiver-report; 3) adults who believed they were autistic, but without a formal diagnosis of ASD, self-report; 4) non-autistic control participants, self-report; and 5) carers of autistic adults, self-report.

Participants were recruited into ALSAA for baseline data collection between July 2015 to November 2017. Similar to SASLA, potential participants were recruited into ALSAA through nation-wide dissemination of promotional materials via a range of avenues; this included autism-specific organisations and service providers, autism self-advocacy groups, universities, allied health, psychology and medical centres, aged-care and disability service providers, carer organisations and online communities for older Australians. If agreeable, recruited participants were also encouraged to share information about the study within their networks to allow for snowball sampling. ALSAA also developed a research advisory network (consisting of autistic adults and carers), who not only ensured that the survey and measures were relevant and valid to the autistic adult population, but also assisted with snowball sampling. The ALSAA advisory network were paid AUD30 per hour for consultation, with a maximum limit of 2 hours per consultation task. Both SASLA and ALSAA collaborated on the range of questionnaires in each study at baseline and 24 months, allowing for significant overlap in measures.

Resilience Pathways in Autistic Adults Study (RPAAS)

RPAAS was a questionnaire-based online study of Australian autistic adults aged 18 years and over, developed specifically for this thesis in 2018. Ethics approval was obtained in late 2019 before data collection began in mid-2020. Targeted recruitment efforts were aimed at Australian-based autistic adults without co-occurring ID, aged 18 years and above, with proficiency in English. An AUD10 e-gift voucher was also offered as a thank you for participation. As the study and recruitment period occurred during the COVID-19 pandemic, recruitment efforts were focused online, using e-mail and various online platforms. Recruitment flyers (Appendix C) were distributed where appropriate. A range of recruitment avenues were identified and utilised; these include:

- Olga Tennison Autism Research Centre (OTARC) participant registry, newsletter and online channels: Autistic individuals aged 18 years and above were e-mailed information about the study and were invited to participate by contacting the PhD Candidate. Information on the study was also advertised on OTARC's website, newsletter and social media.

- Autism CRC: The PhD Candidate liaised with the Autism CRC's marketing and communications team to create a recruitment page on the Autism CRC website. Subsequent promotion was done via the Autism CRC's newsletter, eNews, Facebook and Twitter pages.

- Autism-specific organisations: To maximise representativeness across the Australian states, numerous Australia-wide autism organisations were approached, such as Aspect, Autism QLD, Autism NT, Autism Tasmania and Autism WA. If agreeable, information and promotional materials were provided.

- Autistic peer support groups: Peer support groups such as Different Journeys and Aspergers Victoria were contacted and subsequently provided with study

information to be shared with their group members via newsletters and social

media pages. The PhD Candidate also recorded a short Zoom video promoting

the study for an Aspergers Victoria youth meetup on 29 July 2020.

- Australian-based autism researchers and research groups: Information on the

study was shared within the Autism CRC Adulthood research program (Core

Program 3), which consisted of autism researchers from a range of Australian

universities. Several research groups were also approached to promote the study

within their networks (e.g., Curtin Autism Research Group).

- Social media: A 'Resilience Pathways in Autistic Adults' Facebook page was

created, acting as a centralised location for information about the study and

included the PhD Candidate's contact details. Interested individuals were able to

follow the page and share this with others with relative ease.

- Snowballing and word of mouth: Autistic adults and/or friends and family of

autistic adults known to the PhD Candidate were approached. Participants and

potential participants who had contacted the PhD Candidate regarding the study

were also encouraged to share information about the study with others, where

appropriate.

5.1.2. Sampling

Across the six empirical chapters, the four main aims of this thesis were

addressed using a combination of data from SASLA and ALSAA, or RPAAS. To

measure autistic traits, all participants completed the Autism Spectrum Quotient-Short

(AQ-Short; Hoekstra et al., 2011). Autistic participants in the studies presented in this

thesis were included if they reported a clinical diagnosis of autism and indicated they did

not have an ID. An overview of the data used for each chapter, including further

information about the participants and samples can be seen in Table 1.

Table 1

Sample information by empirical chapter

Data utilised	Chapters 6 and 7		Chapter 8	Chapter 9	Chapter 10	Chapter 11
	SASLA and ALSAA		SASLA and ALSAA	RPAAS	ALSAA	RPAAS
Sample	Autistic	Non-autistic	Autistic	Autistic	Autistic	Autistic
N	255	165	87	86	78	86
Age (years; *M, SD,* range)	35.98; 15.32; 15 - 80	33.80; 15.39; 15 -77	38.80; 15.41; 16 - 80	40.76; 13.47; 19 - 74	46.60; 12.67; 27 - 84	40.76; 13.47; 19 - 74
Female/ Male/ other	136; 108; 11	127; 38; 0	48; 37; 2	57; 29; 0	42; 30; 6	57; 29; 0
AQ-Short (*M, SD*)	85.93 (10.45)	51.62 (8.40)	At baseline: 86.06 (12.70)	87.96 (9.52)	89.41 (11.53)	87.96 (9.52)
Self-reported diagnosis[a] (*n*; %)						
ASD	72; 28.2		20; 23	56; 65.1	15; 19.2	56; 65.1
Autistic Disorder	2; 0.4		1; 1.1	-	1; 1.3	-
Asperger's Syndrome	138; 54.1	N/A	52; 59.8	28; 32.6	50; 64.1	28; 32.6
High Functioning Autism	39; 15.3		10; 11.5	1; 1.2	9; 11.5	1; 1.2
PDD-NOS	3; 1.2		1; 1.1	1; 1.2	-	1; 1.2
Infantile autism	1; 0.4		-	-	-	-
Missing	-		3; 3.4	-	3; 3.8	-

Note. [a]These represent self-reported diagnosis; some of these diagnosis labels no longer exist in the current DSM or ICD-10 classification systems; Chapter 6: Brief COPE factor structure; Chapter 7: Cross-sectional coping-mental health associations; Chapter 8: Longitudinal coping-mental health associations; Chapter 9: Stress-moderating role of coping; Chapter 10: Inter-relationships between coping, resilience and mental health; Chapter 11: Coping-resilience profiles and experiences of stress

5.2. Measures

All three surveys comprised a comprehensive set of questions and standardised questionnaires capturing a range of information including stress, coping, traits and behaviours, social networks, mental health, psychological well-being and quality of life. Questionnaires were considered based on acceptable psychometric properties, use in prior research, and where possible, having been validated for use in the autistic population. Measures selected for the empirical chapters were informed by the thesis aims and current gaps in the autism literature, as well as the previous use of measures across both normative and clinical populations, including the autistic population where possible. Only measures utilised in this thesis are described below. A full description of SASLA and ALSAA can be seen in Richdale et al. (2022) and Arnold et al. (2019a), respectively. An overview of measures used for each chapter presented in this thesis can be seen in Table 2, while the internal consistencies of the measures in each chapter are presented in Table 3 at the end of this section.

Demographic information. Demographic information collected in SASLA and ALSAA included age, sex, ethnicity, educational status, autism diagnosis, co-occurring mental health conditions and English-speaking status. Several demographic items across SASLA and ALSAA were differently worded or included different options (e.g., gender, ethnicity, educational status), which made it difficult to collate and report some demographic data which utilised pooled data from both projects for Chapters 6, 7 and 8. RPAAS measured basic demographics (e.g., age, sex, gender, autism diagnosis, and Australian state of residence) as well as exposure to COVID-19 infection (i.e., a diagnosis of COVID-19 in self, family or extended network).

Table 2

Measures used in each empirical chapter

Measures	Chapters					
	6	7	8	9	10	11
Autism traits (AQ-Short)	✓	✓	✓	✓	✓	✓
Coping (Brief COPE)	✓	✓	✓	✓	✓	✓
Resilience (CD-RISC 10)	✗	✗	✗	✗	✓	✓
Mental Health						
Depression (PHQ-9)	✓	✓	✓	✗	✓	✗
Anxiety (DSM-5 GAD-D)	✗	✓	✓	✗	✓	✗
Well-being (WEMWBS)	✓	✓	✓	✓	✓	✗
Stress						
Daily Hassles (DSI)	✗	✗	✗	✓	✗	✓
General Perceived Stress (PSS)	✗	✗	✗	✓	✗	✓
COVID-19						
COVID-19 related stress	✗	✗	✗	✓	✗	✓
COVID fear (FCQ)	✗	✗	✗	✓	✗	✓

AQ-Short Autism Spectrum Quotient -Short; *Brief COPE* Brief Coping Orientation to Problems Experienced; *CD-RISC 10* Connor-Davidson Resilience Scale- 10 item *PHQ-9* Patient Health Questionnaire-9; *DSM-5 GAD-D* Diagnostic and Statistical Manual of Mental Disorders-5 Generalized Anxiety Disorder Dimensional Scale; *WEMWBS* Warwick-Edinburgh Mental Well-being Scale; *DSI* Daily Stress Inventory; *PSS* Perceived Stress Scale; *FCQ* Fear of Coronavirus Questionnaire

Autism traits. The Autism Spectrum Quotient-Short (AQ-Short; Hoekstra et al., 2011) is a 28-item abridged version of the 50-item full self-report questionnaire (Baron-Cohen et al., 2001) designed to measure levels of autism traits quantifying the ASD phenotype. There are five subscales within this measure: fascination with numbers/ patterns, preference for routine, difficulties with social skills, switching difficulties, and difficulties with imagination. Each item is scored on a 4-point Likert scale ranging from *definitely agree* (1) to *definitely disagree* (4), with higher scores indicating increased

autism traits. With the inclusion of reverse-scored items (13 items), the individual scores

are summed to generate a total AQ-Short score, where a cut-off score above 65 has high

sensitivity and specificity with a clinical diagnosis of ASD (.97 and .82 respectively;

Hoekstra et al., 2011).

Coping. The Brief COPE (Carver, 1997) is a 28-item, abbreviated version of the COPE

inventory (Carver et al., 1989), utilised to measure coping strategies used in response to

stressful encounters. Ratings are made on a 4-point Likert-type scale ranging from *I*

haven't been doing this at all (1) to *I've been doing this a lot* (4). Fourteen 2-item coping

subscales are said to make up the Brief COPE, however factor analytic methods are also

recommended by the author to obtain more parsimonious factor structures relevant to a

given sample. A six-factor structure (i.e., engagement, support-seeking, disengagement,

substance-use, humour and religious coping) using a large sample of autistic adults was

identified in Chapter 6. This factor structure was subsequently used for all remaining

empirical chapters in this thesis. The Brief COPE can be used to measure dispositional

coping (i.e., typical or habitual use of coping strategies) and situational coping (i.e.,

coping strategies used in response to a particular, specified stressor). The research in this

thesis measured coping from a dispositional perspective.

Resilience. The CD-RISC 10 (Campbell-Sills & Stein, 2007) is the 10-item abridged

version of the 25-item Connor-Davidson Resilience Scale (Connor & Davidson, 2003),

used to measure aspects of trait resilience such as tolerance of negative affect,

adaptability to change, self-efficacy and action-oriented approach. Respondents rate

items on a 5-point scale from *not true at all* (0) to *true nearly all the time* (4). The sum of

items generates a total score, where higher scores reflect greater resilience. The CD-

RISC 10 has reported good construct validity and psychometric properties, and has been recently validated as suitable for use in the autistic adult population (Hwang et al., 2020).

Depression. The Patient Health Questionnaire-9 (PHQ-9; Kroenke et al., 2001) is a 9-item questionnaire, a module from the full PHQ (Spitzer et al., 1999), designed to screen for the presence of depressive symptoms across normative and clinical samples. Items assess a range of experiences, including sleep disruption, experiences of displeasure, negative thoughts and appetite. Respondents are asked if they were bothered by each item over the last two weeks such as 'feeling down, depressed or hopeless' or 'little interest or pleasure in doing things', where items are scored on a 4-point scale ranging from *not at all* (0) to *nearly every day* (3). A total PHQ-9 score is obtained using the sum of items, where a score of ≥ 10 is indicative of major depression, with high sensitivity (.88) and specificity (.88). The PHQ-9 has been used extensively across samples and is validated for use in the autistic population (Arnold et al., 2019b).

Anxiety. The DSM-5 Generalized Anxiety Disorder Dimensional Scale (DSM-5 GAD-D; Lebeau et al., 2012) is a 10-item, self-report measure designed to measure the presence of general anxiety symptomology, developed alongside other DSM-5 measures such as social anxiety disorder, specific phobia, agoraphobia and panic disorder. Items broadly encompass cognitive and physical symptoms related to fear and anxiety as well as escape and avoidance behaviours. Each item is negatively worded and rated on a 5-point Likert-type scale ranging from *never* (0) to *all of the time* (4), where the sum of items generates a total score. Higher scores indicate greater anxiety severity, and a total score >14 has been reported to indicate significant or clinical levels of anxiety with good sensitivity and specificity (.73; Beesdo-Baum et al., 2012).

Psychological Well-being. Comprising 14 items, the Warwick-Edinburgh Mental Well-being Scale (WEMWBS; Tennant et al., 2007) is designed to capture positive aspects of mental health, including positive emotions, positive functioning (e.g., self-acceptance, competence and autonomy) and satisfying personal relationships. Using a 5-point Likert scale from *none of the time* (1) to *all of the time* (5), respondents report their experiences over the last two weeks to the positively worded items (e.g., 'I have been feeling optimistic about the future' or 'I've been feeling interested in other people'). Items are summed to obtain a total score, where a higher score is indicative of higher well-being. The WEMWBS has reported high internal consistency across a range of samples (α range: .89-.93; Lloyd & Devine, 2012; Tennant et al., 2007).

Daily hassles. The Daily Stress Inventory (DSI; Brantley et al., 1987) consists of 58 items and is designed to measure the occurrence of daily events typically viewed as stressful and unpleasant in the last 24 hours, and if an event has occurred, the perceived stressfulness of the event on a 7-point Likert-type scale ranging from *occurred but was not stressful* (1) to *caused me to panic* (7). Three daily scores can be derived using the DSI: 1) Frequency: the number of events that have occurred; 2) Sum: the sum of the total stress of events that have occurred; and 3) Average stress of events: sum divided by the frequency. The DSI has reported good convergent, divergent validities and internal consistencies (α: .83 and .87, for frequency and sum scores respectively; Brantley et al., 1987).

General perceived stress. The Perceived Stress Scale (PSS-10; Cohen & Williamson, 1988) is the abridged version of the original 14-item PSS (Cohen et al., 1983), designed to measure the degree to which individuals perceive aspects of their lives to be uncontrollable, unpredictable and generally stressful. Respondents are asked about the

frequency of certain feelings and thoughts over the last month, rated on a 5-point scale ranging from *never* (1) to *very often* (5). Examples of items include 'felt nervous and stressed', 'been angered because things were outside your control' and 'felt that you were on top of things'. A total score can be obtained using the sum of items; cut-off scores are commonly used in the literature to suggest low (0 - 13), moderate (14 - 26) and high (27 - 40) levels of stress. Excellent internal consistency has been reported for the use of PSS-10 in numerous samples (α: .91; Mitchell et al., 2008; Wu & Amtmann, 2013), including autistic adult samples (α: .82 - .87; Bishop-Fitzpatrick et al., 2017; Evers et al., 2022).

COVID-19 related stress. Given the geographical spread of potential participants across Australia, the uneven spread of COVID-19 infections across Australian states and territories during the time RPAAS was conducted, and thus the variability in exposure and potential for infection across participants, stress directly related to contracting the COVID-19 virus was not measured. Instead, perceptions of stress in major life domains (i.e., employment, education, living situation and social relationships) as a result of disruptions and changes due to COVID-19 and its associated State or Territory Government-regulated restrictions were measured and reported (Chapters 9 and 11). Respondents were first asked if they had experienced a change or disruption in each domain (i.e., 'Since the COVID-19 pandemic, have you experienced changes in your __?'). Those who indicated 'Yes' were then asked to provide details of these changes and report their levels of perceived stress (if any) as a result of these changes (i.e., 'Overall, how stressful do you perceive these changes in your __ to be?') on a 5-point Likert scale from *not stressful at all* (1) to *extremely stressful* (5). Respondents who indicated 'No' to changes in any domain were assigned a score of 0 in this domain. A total stress over COVID disruption score ranging from 0 to 20 was created using the sum of scores across each domain.

Fear of COVID-19. Fear associated with COVID-19 was assessed using the Fear of Coronavirus Questionnaire (FCQ; Mertens et al., 2020). This questionnaire consisted of eight statements which examined relevant components of fear (e.g., worry, attentional biases, avoidant behaviour) specifically in relation to COVID-19. Items were rated on a 5-point Likert scale, which ranged from (1) *Strongly disagree* to (5) *Strongly agree*. A higher total score on the FCQ indicates a higher fear of COVID-19. To date, good internal consistency of the FCQ has been reported in several studies (α= .77 and .80; Mertens et al., 2020; Vos et al., 2021).

5.3. Procedures

SASLA and ALSAA

Institutional ethics approval for SASLA was received from the La Trobe University Human Ethics Committee (Approval #HEC14-095). Upon expression of interest via e-mail or telephone, potential participants were provided with the participant information statement and consent forms via e-mail. Potential participants were also screened for study eligibility, which included being 15-25 years old and living in Australia. Participation in the study via self-report required proficiency in English and adequate cognitive capabilities, both of which were ascertained during correspondence with the individual and / or their caregivers. For the autistic group, formal diagnosis of ASD was confirmed through either self- and / or parent-report. Once participants agreed to participate in the study, they were added to a secure participant database and were asked to provide informed consent in writing. For individuals younger than 18 years, parental consent was also obtained. Upon receiving consent, a personalised survey link via Qualtrics (Qualtrics, 2014) was provided. Participants were also given the option of a paper version of the survey. The online survey could be completed over more than one sitting within two, consecutive, four-week periods, with the survey being split (Batches 1 and 2) to reduce

Table 3

Internal consistencies for measures for samples within each empirical chapter

Measures	Chapters 6 and 7		Chapter 8		Chapter 9	Chapter 10	Chapter 11
	Autistic	Non-autistic	Autistic (T1)	Autistic (T2)	Autistic	Autistic	Autistic
Autism traits (AQ-Short)	.81	.76	.86	.89	.81	.86	.81
Coping (Brief COPE)							
Engagement coping	.86	.89	.85	.89	.77	.88	.77
Support-seeking coping	.88	.87		-	-	-	-
Disengagement coping	.76	.80	.75	.78	.76	.79	.76
Substance-use coping	.95	.94		-	-	-	-
Humour coping	.82	.83		-	-	-	-
Religious coping	.78	.83		-	-	-	-
Resilience (CD-RISC 10)	-		-		-	.93	.88
Depression (PHQ-9)	.89	.90	.90	.93	-	.92	-
Anxiety (DSM-5 GAD-D)	.90	.88 (Chapter 7 only)	.87	.88	-	.87	-
Well-being (WEMWBS)	.92	.92	.91	.93	.88	.93	-
Daily hassles (DSI)							
Frequency of events	-		-		.91	-	.91
Sum of stress	-		-		.92	-	.92
Perceived Stress (PSS)	-		-		.90	-	.90
COVID Stress	-		-		.86	-	.86
Fear of Coronavirus (FCQ)	-		-		.79	-	.79

AQ-Short Autism Spectrum Quotient -Short; *Brief COPE* Brief Coping Orientation to Problems Experienced; *CD-RISC 10* Connor-Davidson Resilience Scale- 10 item
PHQ-9 Patient Health Questionnaire-9; *DSM-5 GAD-D* Diagnostic and Statistical Manual of Mental Disorders-5 Generalized Anxiety Disorder Dimensional Scale;
WEMWBS Warwick-Edinburgh Mental Well-being Scale; *DSI* Daily Stress Inventory; *PSS* Perceived Stress Scale; *FCQ* Fear of Coronavirus.

potential participant burden, after which the survey link would expire and require reactivation by a member of the SASLA team. Incomplete surveys were also followed up with reminder e-mails. SASLA participants were followed up one and two years after baseline survey completion; the survey was not split at either follow-up.

Similarly, ALSAA received institutional ethics approval through the University of New South Wales Human Research Ethics Committee (Approval #HC15001). Potential participants expressed their interest in the study via e-mail, telephone or by submitting an expression of interest form online. Study eligibility included being 25 years or older, living in Australia and being proficient in English for those participating via self-report. The autistic group in ALSAA consisted of adults with a formal diagnosis of ASD (which was confirmed through self- or carer-report), as well as adults who believed themselves to be autistic but did not have a formal diagnosis; only those with a formal diagnosis were used for the studies presented in this thesis. Once eligibility was ascertained, participants were sent an anonymous, personalised link to the questionnaires via Qualtrics. Consent forms were included at the beginning of the survey, with checkboxes available for participants to indicate their consent. The option for paper versions of questionnaires and consent forms was also provided if this was preferred. ALSAA participants were followed-up once after baseline survey completion, two years later.

RPAAS

Institutional ethics approval was granted from the La Trobe University Human Ethics Committee (Approval #HEC19443; Appendix D) for RPAAS. Individuals interested in participating in the study expressed their interest via e-mail. More information (i.e., participant information statement; see Appendix E) about the study was subsequently provided, queries were addressed, and participants screened for eligibility

(e.g., age, ASD diagnosis, no ID). ASD diagnoses and the absence of co-occurring intellectual disability were determined via self-report. Once agreeable, participants were sent an e-mail with an embedded study link via Research Electronic Data Capture (REDCap). Consent forms were included (Appendix F) at the beginning of the survey for participants to provide informed consent before starting the survey. Once consent was indicated, participants were directed to the survey. As the survey was anonymous and could not be linked back to participants who had previously expressed interest, it began with an eligibility screening page, which checked again that participants met the study inclusion criteria. Those who met the screening criteria continued with the survey.

Given the online nature of the study and the financial reward (in the form of an AUD10 e-voucher) offered upon survey completion, several strategies were also put into place to screen out potential 'bots' or automated survey fillers from true participants. Specifically, the 'bot' screening items included on the eligibility page were: 1) Three fill-in-the-blank statements (two multiple choice, one with open-ended text), allowing responses with nonsensical answers or those consisting of random characters to be screened out; 2) Consistency checks (Jones et al., 2015) by including two related questions (i.e., by asking for date of birth and age in years) to establish consistency of answers; and 3) Simple cognitive challenge tasks through the use of reCAPTCHA (Liu & Wronski, 2018). Once these tasks were passed, participants were automatically directed to the survey items.

Contact details for the PhD Candidate and supervisory team were provided prior to the start of the survey should any concerns arise while participants were completing the survey. Respondents were able to take breaks while completing the approximately 30-minute survey as long as their browser remained open. Upon survey completion, support information was provided (see Appendix G) if respondents had any concerns

about their responses, were feeling distressed or felt that they needed support. The research team's contact details were provided again should respondents have felt the need to reach out. At this stage, respondents were given the option to be re-directed to a new page where they could enter an e-mail address of choice to receive the AUD10 e-voucher (nine participants opted out of receiving this e-voucher). Importantly, this re-direction allowed separation between survey responses and potentially identifying participants' e-mail addresses, thus maintaining the anonymity of the survey.

5.4. Statistical Analyses

As detailed in Chapter 4, this thesis had four main aims. These aims are also noted individually across the six empirical chapters (Chapters 6 to 11), with statistical analyses conducted using SPSS v27 (IBM Corp Armonk, NY, US), the PROCESS macro v3.5 in SPSS (Hayes, 2018) and R version 4.1.0. An overview of the analyses in relation to these chapters is described below; for more detailed information, please refer to the statistical analyses section of the respective chapters.

Aim 1: Determine the factor structure of the Brief COPE and its validity for use in autistic adults (Chapter 6)

The factor structure of the Brief COPE was first determined using principal axis factoring (with oblique rotation). This helped to identify the underlying coping structure that best represented the coping responses of our samples of autistic and non-autistic adults. This also allowed for preliminary examination of differences in factor structure and item composition within each coping factor between the two samples, potentially identifying aspects in the grouping of coping strategies that may be unique to autistic adults. Through correlation analysis, convergent and divergent validities of conceptually

relevant coping factors were determined using measures of depression and well-being respectively.

Aim 2: Examine cross-sectional and longitudinal associations between coping strategies and mental health outcomes in autistic adults (Chapters 7 and 8)

The aim of Chapter 7 was to determine how the coping factors identified in Chapter 6 were cross-sectionally related to mental health outcomes. Correlation analysis was first conducted between these six coping factors and positive and negative aspects of mental health (i.e., depression, anxiety and well-being) in both the autistic and non-autistic samples. Coping factors significantly associated with each mental health outcome in each sample were subsequently explored as potential predictors[1] in the respective hierarchical multiple regression models. Analysing the potential predictive roles of coping between the two samples separately also allowed for the examination of potential between-sample differences in patterns of coping-mental health. Following this, the next step was to focus on the autistic adult sample and examine coping-mental health associations longitudinally, which was addressed in Chapter 8.

Given the associations between baseline mental health and subsequent mental health outcomes indicated in the autism literature (e.g., Hedley et al., 2019), it was also important to control for baseline mental health when examining the associations between coping and mental health over time. Baseline (T1) and follow-up (T2) scores were compared across key variables using *t*-tests, while correlation analysis was used to examine associations between T1 coping strategies and T2 mental health outcomes. To explore the predictive role of T1 coping strategy on T2 mental health, hierarchical multiple regression was conducted. Specifically, T1 coping strategy and change in use of coping strategy over time (T1 to T2) were entered as potential predictors, while controlling for T1 mental health. Following this, as a post-hoc analysis, a coping ratio

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[1]Rather than imply causality, the terms 'predict' or 'predictors' used to describe the role of coping strategies refer to the extent to which coping strategies may account for variances in mental health outcomes.

variable was created to capture the use of coping strategies *relative* to each other. This variable was then entered as a potential predictor in the multiple regression models.

Aim 3: Investigate the potential stress-moderating role of coping strategies in relation to psychological well-being in autistic adults (Chapter 9)

The broader literature frequently reports negative associations between stress and well-being (e.g., Seiffge-Krenke, 2019). Coping strategies have the potential to moderate this relationship, by buffering or exacerbating the effects of stress on well-being (Ahles et al., 2016; Suldo et al., 2008). In Chapter 9, the relationship between stress and well-being in a sample of autistic adults was first examined using correlation analysis. For a multi-dimensional approach to measuring stress, a stress composite variable was created, capturing the general sense of stress and stress over daily hassles. The potential moderating role of coping strategies in the relationship between stress and well-being was subsequently examined through two moderation analyses, with engagement coping and with disengagement coping.

Aim 4: Explore the interactions between coping strategies and resilience in relation to stress and mental health outcomes in autistic adults (Chapters 10 and 11)

Coping and resilience are distinct but conceptually relevant constructs when considering the stress process and stressful encounters (Skodol, 2010). The ways in which coping and resilience are related and might interact were examined using variable- and person-centred approaches. In Chapter 10, the inter-relationships between coping, resilience, and mental health outcomes in autistic adults were first explored using correlation analyses. The potential for coping strategies to play a mediating role in the associations between resilience and mental health was subsequently tested using mediation analyses. Using a person-centred approach, Chapter 11 empirically derived coping-resilience profiles that may exist within a sample of autistic adults using k-means

cluster analysis. Potential differences in how these profiles or clusters were related to

levels of stress (i.e., daily hassles, general perceived stress and COVID-related stress)

were then examined using one-way analysis of variance (ANOVA).

5.5. Overall Design

An overall visual depiction of the six studies presented in this thesis, their

contribution to the four main aims of the thesis, statistical analyses conducted, study

design and data utilised is provided in Figure 1.

Figure 1

Thesis components: aims, chapters and main study details

Research aims	Chapters	Statistical analyses	Study design	Data
Coping structure and measurement	**Chapter 6** Factor structure and psychometric properties of the Brief COPE in autistic older adolescents and adults	Pearson's correlation; Principal axis factoring	Cross-sectional	SASLA & ALSAA data
Coping associations with mental health	**Chapter 7** Associations between coping strategies and mental health outcomes in autistic adults	Pearson's correlation; Hierarchical multiple regression; t-tests		
	Chapter 8 Longitudinal role of coping strategies on mental health outcomes in autistic youth and adults		Longitudinal	
Stress-moderating role of coping	**Chapter 9** Stress and well-being in autistic adults: exploring the moderating role of coping	Pearson's correlation; Moderation analysis	Cross-sectional	RPAAS data
Coping-resilience interactions	**Chapter 10** Inter-relationships between trait resilience, coping strategies and mental health outcomes in autistic adults	Pearson's correlation; Mediation analysis		ALSAA data
	Chapter 11 Coping-resilience profiles and experiences of stress in autistic adults	K-means cluster analysis; ANOVA		RPAAS data

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Chapter 6: Factor structure and psychometric properties of the Brief COPE in autistic older adolescents and adults

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Factor structure and psychometric properties of the Brief COPE in autistic older adolescents and adults

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A R T I C L E I N F O

A B S T R A C T

Background: Autistic adults experience high levels of stress, which may negatively affect their mental health. However, research into coping with stress in this population is limited, with no coping measures specifically validated for use in the autistic population.

Method: Utilising data from two Australian longitudinal adult studies, exploratory factor analysis was conducted to determine the factor structure that best represented the use of coping strategies in a sample of autistic adults ($N = 255$) using the Brief COPE. Mental health and well-being measures were used to provide information on psychometric properties. To explore potential intricacies in factor structure that may be unique to autistic adults, a preliminary subjective comparison with a non-autistic adult sample ($N = 165$) was also conducted.

Results: A six-factor solution, with high internal reliabilities, best represented the use of coping strategies in the autistic adult sample. Good convergent and divergent validities for the conceptually relevant coping factors were also reported. Subjective comparisons raise the possibility of some similarities (e.g., support-seeking coping strategies) and differences (e.g., the use of self-distraction coping strategies) in factor structures between the autistic and non-autistic samples.

Conclusions: This study provides an initial validation of the Brief COPE in autistic adults and supports its usefulness in assessing coping strategies in response to stress in this population. Findings also have potential implications for informing intervention services for autistic individuals, given the known relationships between the coping of stress and broader outcomes, such as mental health.

1. Introduction

There is consensus in the literature that outcomes for autistic adults are generally poor. Many adults on the autism spectrum face challenges in areas of employment, independent living and forming or maintaining relationships (e.g. Baldwin, Costley, & Warren, 2014; Eaves & Ho, 2008; Howlin & Magiati, 2017; Mazurek, 2014). A sense of loneliness is prevalent (Ee et al., 2019; Hedley, Uljarević,

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Foley, Richdale, & Trollor, 2018; Jobe & White, 2007) and co-occuring mental health conditions are common (Gillott & Standen, 2007; Hofvander et al., 2009; Joshi et al., 2013; Stewart, Barnard, Pearson, Hasan, & O'Brien, 2006), with significantly higher prevalence rates of anxiety and depression in the autistic population compared to that of the general population (Croen et al., 2015; Hollocks, Lerh, Magiati, Meiser-Stedman, & Brugha, 2018; Maddox & White, 2015). Research suggests that exposure to stressful experiences and how one copes with stress and challenges can have a substantial impact on one's well-being, mental health and functioning (Cheng, Lau, & Chan, 2014; Evans & Kim, 2013; Lazarus & Folkman, 1984; Littleton, Horsley, John, & Nelson, 2007). This is especially relevant to autistic individuals, who have been suggested to experience higher levels of stress (Bishop-Fitzpatrick, Mazefsky, Minshew, & Eack, 2015; Groden et al., 2001), more frequent stressful encounters (Baron, Groden, Lipsitt, & Groden, 2006; Gillott & Standen, 2007) and poorer overall coping (Hirvikoski & Blomqvist, 2015) compared to the general population. Indeed, emerging literature have suggested significant associations between levels of stress and outcomes such as quality of life and social functioning in autistic adults (Bishop-Fitzpatrick, Minshew, Mazefsky, & Eack, 2017; Bishop-Fitzpatrick, Smith DaWalt, Greenberg, & Mailick, 2017; Hirvikoski & Blomqvist, 2015; Hong, Bishop-Fitzpatrick, Smith, Greenberg, & Mailick, 2016).

Coping can be conceptualised as cognitive and behavioural efforts to manage external and/or internal demands that have been perceived to exceed one's resources (Lazarus & Folkman, 1984). Coping strategies, when used effectively, have been depicted to play a critical protective role in buffering the negative effects of stress on one's health and well-being (Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001; Skinner, Edge, Altman, & Sherwood, 2003). Avoidance-oriented coping strategies (e.g., disengagement, denial, distracting oneself) are often strongly associated with higher levels of internalising and externalising symptoms, increased psychological distress and poor psychological well-being (Aldwin & Revenson, 1987; Carver, Scheier, & Weintraub, 1989; Friedman-Wheeler, Haaga, Gunthert, Ahrens, & McIntosh, 2008; Nielsen & Knardahl, 2014). Conversely, although less consistently, approach-oriented coping strategies (e.g., problem-focused, engagement and positive reappraisals) have been generally associated with positive life outcomes such as increased positive affect, fewer depressive symptoms, reduced distress and better well-being (Billings, Folkman, Acree, & Moskowitz, 2000; Mayordomo-Rodríguez, Meléndez-Moral, Viguer-Segui, & Sales-Galán, 2015; Nielsen & Knardahl, 2014; Sharkansky et al., 2000). Although coping has been suggested by some to be a process that is dynamic and specifically tailored to specific demands of a stressful event (e.g., Lazarus & Folkman, 1984), more stable individual traits such as personality have also been found to influence or interact with coping strategy selection directly, by facilitating or constraining the use particular strategies, or indirectly, by influencing the efficacy of coping strategies (Connor-Smith & Flachsbart, 2007).

There has been extensive literature surrounding the coping of parents and families of autistic individuals (e.g., Benson, 2010; Hastings et al., 2005; Lai, Goh, Oei, & Sung, 2015; Orsmond, Kuo, & Seltzer, 2009), where a range of coping strategies and resources are reported to be utilised in response to the higher parenting and caregiving stress typically reported in this population (e.g., Hayes & Watson, 2012). However, coping studies conducted in relation to autistic individuals themselves remain limited. Several studies that compared the use of coping strategies between autistic and non-autistic children and adolescents (referred to as youth hereafter) reported fewer adaptive and approach coping strategies in autistic youth, but that both groups used similar levels of maladaptive and avoidance coping strategies (Bauminger, 2004; Rieffe et al., 2011; Rieffe, De Bruine, De Rooij, & Stockmann, 2014). In a sample of autistic adults ($N = 60$), Bishop-Fitzpatrick, Smith DaWalt et al. (2017) found that participation in recreational activities may serve as an important coping mechanism against the negative effects of perceived stress on their well-being. Other studies explored the relationships between the use of coping strategies and various outcomes in autistic youth. Consistent with the broader coping literature, coping strategies characterised by avoidance and disengagement were related to increased emotional problems and internalising symptoms in autistic youth (Khor, Melvin, Reid, & Gray, 2014; Rieffe et al., 2011), although the reverse was noted by Pouw, Rieffe, Stockmann, and Gadow (2013) where avoidant coping was related to reduced depressive symptoms in autistic boys. Further, in a longitudinal study with 81 autistic youth aged 9–15 years, Rieffe et al. (2014) found no associations between average use of avoidance coping and depressive symptoms, but did report that an increase in avoidance coping over time was related to fewer depressive symptoms. The relationship between coping strategies characterised by approach and engagement with mental health have been mixed, with studies reporting either a positive (Pouw et al., 2013; Rieffe et al., 2014) or a lack of relationship (Khor et al., 2014; Rieffe et al., 2011), not unlike what is reported in other populations (for a review, see Taylor & Stanton, 2007).

The scarcity of coping studies conducted particularly in the autistic adult population is concerning given the high levels of stress reported in this population (e.g., Bishop-Fitzpatrick et al., 2015; Bishop-Fitzpatrick, Minshew et al., 2017; Hirvikoski & Blomqvist, 2015; Hong et al., 2016). Further, as there has yet to be a standardised coping measure validated for use in the autistic population, it is unclear whether the coping categories used in the previous studies best represented the coping strategies used in their autistic samples. It is plausible that there may be intricacies in the construct of coping that are unique to autistic individuals. Autism, an aspect of one's identity, may introduce other autism-specific factors that influence the types of encounters faced, how these encounters are appraised, and subsequently how or which coping strategies are elicited in response. For example, autistic individuals, many of whom use social camouflaging techniques to fit in to social situations (Hull et al., 2017) may be particularly vulnerable to social-related stress. This heightened vulnerability may be comparable to that reported in sociotropic individuals (i.e., those with strong concern for social acceptance, maintaining relationships and avoiding rejection), who have been found to utilise fewer engagement coping strategies (e.g., problem solving, adapting) and more disengagement coping strategies (e.g., avoidance, denial) in response to social stress (Connor-Smith & Compas, 2002).

In the related area of emotion regulation, autistic adults have been suggested to overall report more difficulties regulating their emotions, and a tendency to display a maladaptive pattern of strategy use (e.g., Bruggink, Huisman, Vuijk, Kraaij, & Garnefski, 2016; Cai, Richdale, Uljarević, Dissanayake, & Samson, 2018; Samson, Huber, & Gross, 2012; Swain, Scarpa, White, & Laugeson, 2015). In particular, when examining cognitive emotion regulation strategy use, Bruggink et al. (2016) found that autistic adults reported reduced use of positive reappraisals and increased use of blaming others, compared to non-autistic adults. Similarly, Samson et al.

(2012) reported that their autistic adult sample utilised fewer positive reappraisals and more supressing of emotion-related behaviours. These findings of reduced adaptive emotion regulation strategies may provide an indication of potential reduced use of adaptive coping strategies in response to stress in autistic adults. Although coping and emotion regulation are conceptually similar, coping can be considered narrower in that its strategies are elicited solely in response to events that are stressful, yet broader in that it incorporates strategies that are not solely emotion-focused (Compas, Jaser et al., 2014). While both constructs may be complimentary in providing a better picture surrounding behavioural regulatory processes more generally (see Compas et al., 2017), given the high levels of stress reported in autistic adults, the present study focuses on the coping strategies used in response to stressful situations.

In a meta-analysis across a 12-year period and 2,000 empirical studies, Kato (2015) found that the COPE inventory (Coping Orientation to Problems Experienced; Carver et al., 1989), including its brief and revised versions, was the most widely used coping measure (rate of use: 20.2 %) across a diverse range of populations. A notable distinction that sets the COPE apart from many other coping measures is its theoretical basis; it is specifically guided by models of stress (Lazarus & Folkman, 1984) and behavioural self-regulation (Carver & Scheier, 1982). An abbreviated version, the 28-itemed Brief COPE (Carver, 1997) was later developed, and consists of 14 coping subscales (i.e., active coping, acceptance, planning, positive reframing, use of instrumental support, use of emotional support, self-distraction, behavioural disengagement, self-blame, humour, denial, venting, religion and substance-use coping), comprising of two items each. The Brief COPE has several strengths, including its coverage of a wide range of coping responses, relative ease of completion and minimal participant burden.

In attempts to achieve a more parsimonious understanding of the use of coping strategies across a range of samples, various studies have found that some of the Brief COPE's fourteen coping subscales appear to cluster together to form fewer, broader underlying coping dimensions. Despite some overlap and conceptual similarities in the factors that emerged across these studies, a systematic review on factor analytic studies using the Brief COPE (Krägeloh, 2011) revealed no clear consensus on the number of underlying coping dimensions extracted. Instead, depending on the sample, a range of coping factors of between two and 12, with a median of six, is typically retained. While the different factor structures across various populations such as parents of autistic children, adolescents in response to cyberbullying and undergraduate university students (e.g., Benson, 2010; Ebert, Tucker, & Roth, 2002; McAuliffe, Cordier, Vaz, Thomas, & Falkmer, 2017; McLoughlin, 2019) tend to report acceptable psychometric properties (i.e., Cronbach alpha range: .70–.85 and convergent and divergent validities demonstrated using measures of anxiety, depression and well-being), these disparate factor structures and the ways in which they are conceptualised may limit the ability to make meaningful comparisons across samples or studies, underscoring the importance of exploring the underlying coping structure in a given sample. Thus, while the Brief COPE is useful in its current form, further exploration surrounding its factor structure is warranted before its use in the autistic adult population.

The main aim of the current study was to explore the factor structure and psychometric properties of the Brief COPE in a large sample of autistic older adolescents and adults (hereafter referred to as adults). Taking into account the scarcity of coping research in this population, this study allowed us to examine the utility of a widely used coping measure in an autistic sample and to explore underlying coping dimensions that best represent their use of coping strategies. Given the substantial evidence on the associations between coping and psychological health and well-being outcomes, some of which were described earlier, we utilised mental health and well-being measures to provide preliminary information on psychometric properties, specifically its convergent and divergent validities. To capture both the negative and positive facets of well-being, we used a measure of depressive symptoms and of positive mental well-being. Finally, utilising a non-autistic adult sample, a secondary aim was to potentially identify coping intricacies that are unique to autistic adults using a preliminary exploration of similarities and differences between the two groups in their emergent factor structures on the Brief COPE.

2. Method

2.1. Participants and procedures

Secondary data from two longitudinal Autism CRC Australian-wide studies, the Study of Australian School Leavers with Autism (SASLA) and Australian Longitudinal Study of Adults with Autism (ALSAA; for cohort details, see Arnold, Foley et al., 2019), with a target age range of 15–25 years, and over 25 years respectively, were utilised.

2.1.1. Autism CRC SASLA and ALSAA studies

SASLA and ALSAA are prospective, questionnaire-based, longitudinal cohort studies that were developed in close collaboration in 2014. Consultation with the autistic population and autistic advisors were utilised to inform the study designs and identify research priority areas. SASLA and ALSAA comprised of three participant groups: autistic adults, non-autistic general community comparison adults, and carers of autistic adults. Participants who self-identified as being autistic but did not have a formal diagnosis (representing the 'lost generation' of autistic adults; Lai & Baron-Cohen, 2015) were also recruited to the ALSAA study. Formally diagnosed participants were asked to provide details of their diagnosis (e.g., diagnostic label, year of diagnosis and diagnosing practitioner details). The Autism Quotient-Short (AQ-Short; Hoekstra et al., 2011) cut-off score was also used to support the diagnostic status.

One primary aim of SASLA and ALSAA was to identify and comprehensively describe the profiles of autistic adults in Australia and to compare them to non-autistic adults. The overlap of measures between the two studies has allowed for an adulthood lifespan approach to be taken from late adolescence to older adulthood. To date, pooled data from SASLA and ALSAA have been used to explore a range of areas including anxiety, depression, suicidal ideation, quality of life, cognitive reappraisal, and sleep, as well as psychometric scale validation in autistic adults (Arnold, Uljarević et al., 2019; Cai, Richdale, Foley, Trollor, & Uljarević, 2018; Hedley et al.,

2018; Jovevska et al., 2020; Lawson et al., 2020; Uljarević et al., 2019).

Following ethics approval from the relevant university ethics committees, both studies recruited primarily through advertisements via social media, participant registries, Autism-specific organisations, autism self-advocacy groups, disability organisations, educational institutions, and employment services. Potential participants were sent the participant information and consent form online, as well as information and consent forms for parent/ guardians for those under 18 years. After providing consent, participants were sent a personalised link to access the online survey on Qualtrics (www.qualtrics.com). All hard copy participant information, consent forms and surveys were provided upon request.

2.1.2. The present study

The present study utilised pooled SASLA and ALSAA data from formally diagnosed autistic adults and non-autistic community comparison adults. At the time of this study, a total of 573 participants (344 autistic adults; 229 non-autistic adults) self-reported their responses and completed both the Brief COPE and AQ-Short. Autistic participants who reported a co-occurring intellectual disability ($n = 34$), scored below the cut-off score of 66 on the AQ-Short ($n = 24$) and non-autistic participants who scored above 65 on the AQ-Short ($n = 64$) were not included in our sample. All participants in the autistic sample reported a clinical diagnosis of autism; participants who felt they were autistic but did not have a formal diagnosis ($n = 31$) were not included. Following data cleaning in both samples as per the criteria above, the final sample for analysis consisted of 255 autistic adults (108 males, 136 females, 11 other/missing, Mage = 35.98, SDage = 15.32, range: 15–80 years) and 165 non-autistic adults (38 males, 127 females, Mage = 33.80, SDage = 15.39, range: 15–77 years).

2.2. Measures

2.2.1. Coping strategies

The Brief COPE (Carver, 1997) is a 28-item, abbreviated version of the COPE inventory (Carver et al., 1989), where two items make up one of the 14 coping subscales. Ratings are made on a 4-point Likert-type scale ranging from *I haven't been doing this at all* (1) to *I've been doing this a lot* (4). While adequate internal reliabilities for the 14 subscales were reported by the author, we did not utilise these subscales. Instead, we used the 28 individual items to explore the underlying coping categories that best represented our samples and report the internal reliabilities of these. The Brief COPE can be used to assess dispositional coping (general coping style) or situational coping (for a specific stressor or event). In this study, the dispositional format was utilised.

2.2.2. Depressive symptoms

The Patient Health Questionnaire-9 (PHQ-9; Kroenke, Spitzer, & Williams, 2001) is a 9-item questionnaire developed to detect the presence of depressive symptoms, including experiences of displeasure, sleep disruption, appetite and negative thoughts. Items are scored on a 4-point scale ranging from *not at all* (0) to *nearly every day* (3). Total PHQ-9 score is obtained using the sum of items (range from 0 to 27), where a score of ≥ 10 is indicative of major depression, with high sensitivity (.88) and specificity (.88). The internal consistency and Cronbach alpha values for the PHQ-9 in the current autistic and non-autistic samples was 0.893 and 0.899 respectively. The PHQ-9 has been recently validated for use in autistic adults, reporting its suitability in measuring depressive symptoms in this population (Arnold, Uljarević et al., 2019).

2.2.3. Psychological well-being

The Warwick-Edinburgh Mental Well-being Scale (WEMWBS; Tennant et al., 2007) is comprised of 14-items scored on a 5-point Likert scale from *none of the time* (1) to *all of the time* (5). It captures positive aspects of mental health, including positive emotions, functioning and satisfying interpersonal relationships, where a higher score indicates a higher level of positive mental well-being. The WEMWBS has reported high internal consistency (α range: .89–.93; Lloyd & Devine, 2012; Tennant et al., 2007). High Cronbach alpha values for the WEMWBS were also noted in the current autistic and non-autistic samples, at 0.916 and 0.923 respectively.

2.3. Statistical analyses

In the absence of an existing or pre-conceived factor structure from the literature, an exploratory approach was undertaken to examine the factor structures of the Brief COPE in both the autistic and non-autistic samples. Each sample consisted of pooled data from the SASLA and ALSAA studies for the autistic and non-autistic groups respectively. Exploratory factor analysis was conducted using principal axis factoring with an oblique rotation (Promax) to allow for correlation among the derived factors. A combination of the scree test (Cattell, 1978), number of eigenvalues greater than 1.0 (Field, 2005; Kaiser, 1960), proportion of variance explained and conceptual interpretability of factors (Raykov & Marcoulides, 2011) was taken into account when deciding on the number of factors to be retained. The factor structures for both samples were first examined independently by each of the authors before consensus on the most parsimonious structures for each sample was reached. Items with factor loadings greater than 0.4 were assigned to a specific factor, while items that failed to meet this threshold, or loaded greater than 0.4 on more than one factor, were eliminated from further analyses. Using the sum of scores of its constituent items, a total score for each coping factor was obtained.

To determine the reliability of the factor structure obtained in the autistic sample, internal consistencies for each coping factor were reported using standardised Cronbach's alpha coefficients, where values greater than 0.7 were deemed acceptable (Nunnally & Bernstein, 1994). Due to several variables violating the assumptions of normality, all subsequent analyses were bootstrapped with 2, 000 resamples and 95 % bias-corrected and accelerated (BCa) confidence intervals to provide more robust statistics (Tabachnick,

Fidell, & Ullman, 2007). Bivariate correlations between conceptually relevant coping factors with total PHQ-9 and WEMWBS scores were examined to determine convergent and divergent validities. Finally, to subjectively compare factor structures between the two samples, we first determined whether conceptually similar factors emerged across both groups and if so, we compared their item compositions. All data analyses were run using The Statistical Package for the Social Sciences (SPSS) version 25.

Table 1
Factor loadings of the Brief COPE in autistic and non-autistic samples.

Factors	Autistic (N = 255)						Non-autistic (N = 165)					
	1	2	3	4	5	6	1	2	3	4	5	6
%Variance	22.60	11.41	7.68	6.23	5.82	4.44	25.90	11.05	7.54	6.55	4.81	3.99
Cronbach's alpha	.86	.88	.76	.95	.82	.78	.89	.87	.80	.94	.83	.83
[14] I've been trying to come up with a strategy about what to do	**.813**	.003	.126	.009	−.120	.004	**.712**	.177	.050	−.002	−.193	.000
[7] I've been taking action to try to make the situation better	**.753**	.067	−.085	−.053	−.017	−.061	**.624**	.171	−.137	.106	−.053	.079
[25] I've been thinking hard about what steps to take	**.718**	.083	.166	−.082	−.031	.021	**.597**	.157	.073	−.104	−.087	.135
[2] I've been concentrating my efforts on doing something about the situation I'm in	**.661**	.184	−.062	.056	−.172	−.095	**.650**	.097	−.133	.130	−.162	.072
[24] I've been learning to live with it	**.615**	−.188	.000	−.006	.131	−.023	**.699**	−.142	.083	−.075	.176	−.070
[20] I've been accepting the reality of the fact that it has happened	**.603**	−.068	−.032	.043	.073	−.118	**.642**	−.046	−.015	−.057	.281	−.062
[17] I've been looking for something good in what is happening	**.547**	−.072	−.058	.006	.176	.211	**.623**	−.047	−.184	−.028	.247	.179
[12] I've been trying to see it in a different light, to make it seem more positive	**.543**	−.039	−.192	.111	.074	.208	**.780**	−.018	−.089	−.030	.043	−.117
[9] *I've been saying things to let my unpleasant feelings escape*	.305	.136	.048	.072	.070	.033	.272	.191	.152	.076	.003	.013
[5] I've been getting emotional support from others	−.136	**.857**	−.022	.026	.063	.052	−.024	**.790**	.030	.014	−.057	−.176
[10] I've been getting help and advice from other people	.080	**.847**	−.031	−.049	−.075	−.053	−.015	**.849**	−.015	.045	−.028	.042
[23] I've been trying to get advice or help from other people about what to do	.005	**.846**	.064	−.028	−.081	.037	−.166	**.897**	.009	−.041	.135	.084
[15] I've been getting comfort and understanding from someone	−.041	**.816**	−.101	.023	.080	.009	.096	**.757**	−.034	−.107	.009	−.125
[21] I've been expressing my negative feelings	.143	**.445**	.126	.030	.112	−.026	−.012	**.550**	.059	.005	.129	.103
[26] I've been blaming myself for things that happened	.033	.000	**.796**	−.121	−.014	−.051	.163	.054	**.778**	.004	−.184	.004
[13] I've been criticizing myself	.132	−.072	**.728**	−.140	.009	−.088	.108	.055	**.801**	−.067	−.036	−.063
[16] I've been giving up the attempt to cope	−.187	.029	**.668**	.091	.084	.049	−.188	−.072	**.612**	−.028	.082	.190
[6] I've been giving up trying to deal with it	−.134	−.008	**.562**	.151	.006	.008	−.154	−.043	**.709**	.034	.129	−.058
[8] I've been refusing to believe that it has happened	−.015	.000	**.440**	.076	−.036	.108	*.009*	*.114*	*.359*	*.250*	*.068*	*−.054*
[3] *I've been saying to myself "this isn't real*	.085	−.083	.388	.156	−.119	.116	−.011	.114	.078	.275	.164	.106
[1] *I've been turning to work or other activities to take my mind off things*	.060	.056	.338	.001	.099	.015	**.628**	−.226	.144	.040	−.041	−.113
[19] *I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping*	.034	.139	.248	.076	.160	.037	.409	−.028	.341	.025	.107	.095
[11] I've been using alcohol or other drugs to help me get through it	.054	−.023	.063	**.950**	−.066	−.036	.021	−.067	.026	**.865**	−.018	−.029
[4] I've been using alcohol or other drugs to make myself feel better	.005	.021	.028	**.920**	.023	−.046	−.012	−.027	−.033	**.993**	.028	−.006
[18] I've been making jokes about it	.053	.047	.001	.022	**.936**	−.071	.162	.054	.010	.023	**.756**	−.078
[28] I've been making fun of the situation	.041	−.006	.046	−.070	**.710**	.013	−.035	.054	.006	.023	**.809**	.009
[22] I've been trying to find comfort in my religion or spiritual beliefs	−.084	.023	.082	−.069	−.079	**.878**	−.023	−.092	.083	−.027	−.080	**.905**
[27] I've been praying or meditating	.103	.015	.002	−.020	.025	**.732**	−.017	.016	−.058	.013	.024	**.761**

3. Results

3.1. Factor structure in autistic sample

The Kaiser-Meyer-Olkin (KMO) verified the sampling adequacy for the analysis, KMO: 0.773, while Bartlett's test of sphericity indicated sufficient correlation between each item for factorability, $x^2(378) = 3176.36$, $p < .001$. Assumptions of non-multicollinearity were also met. All 28 coping items were included in the first EFA. The 'elbow' in the scree plot, eigenvalues more than 1.0, proportion of variance explained, and interpretability of factors were considered when deciding the most parsimonious model. Consensus among the authors was reached and a six-factor model was retained.

Four coping items were removed due to low factor loadings (< 0.4): two self-distraction coping strategies (items 1 and 19; i.e., "I've been doing something to think about it less, such as going to the movies, watching TV, reading, daydreaming, sleeping or shopping" and "I've been turning to study, work or other activities to take my mind off things"), one venting coping strategy (item 9; i.e., "I've been saying things to let my unpleasant feelings escape") and one denial coping strategy (item 3; "I've been saying to myself it isn't real"). No significant cross-loadings or negative loadings were noted. With these four items removed, the six-factor solution was repeated and accounted for 58.18 % of total variance.

The first factor extracted was best described as *Engagement coping*. It consisted of eight items: Planning (items 14 and 25), Active Coping (items 2 and 7), Positive Reframing (items 12 and 17) and Acceptance (items 20 and 24) coping strategies. The second factor which embodied *Support-seeking coping* had five items, consisting of Emotional Support (items 5 and 15), Instrumental Support (items 10 and 23) and one Venting (item 21) coping strategies. The third factor, best characterised as *Disengagement coping* also comprised five items: Self-Blame (items 13 and 26), Behavioural Disengagement (items 6 and 16) and Denial (item 8) coping strategies. The remaining fourth, fifth and sixth factors that emerged were Carver's original two-itemed subscales, *Substance-use coping* (items 4 and 11), *Humour coping* (items 18 and 28) and *Religious coping* (items 22 and 27). Individual factor loadings, percentage variance and Cronbach's alpha for each of the six extracted factors are reported in Table 1.

3.2. Reliability and validity in the autistic sample

All six factors in the autistic sample yielded good reliabilities, with the internal consistencies for all factors meeting the 0.7 threshold (α range = 0.75–0.95; see Table 1). To determine convergent and divergent validities, bivariate correlations between coping factors that were conceptually more adaptive (i.e., engagement coping) or maladaptive (i.e., disengagement coping and substance-use coping) and total PHQ-9 and WEMWBS scores were calculated. Convergent validity was demonstrated by significant positive correlations between engagement coping and WEMWBS ($r = .151$, BCa 95 % CI = .003, .304), disengagement coping and PHQ-9 ($r = .671$, BCa 95 % CI = .595, .736), and substance-use coping and PHQ-9 ($r = .280$, BCa 95 % CI = .140, .410). Divergent validity was demonstrated by significant negative correlations between disengagement coping and substance-use coping with WEMWBS ($r= -.529$, BCa 95 % CI = -.619, -.426 and $r= -.195$, BCa 95 % CI = -.310, -.075 respectively). There was agreement in significance determined by BCa 95 % CI values and adjusted p-values once controlling for multiple comparisons in all correlations except for the weak relationship (i.e., small effect size) between engagement coping and WEMWBS that was not significant with the adjusted p-value. Correlations between the six coping factors and the PHQ-9 and WEMWBS in the autistic sample are presented in Table 2.

3.3. Factor structure comparison

In the non-autistic sample, consensus was also reached that a six-factor should be retained (KMO: 0.793, Bartlett's test: $x^2(300) = 2200.72$, $p < .001$), accounting for 59.9 % of variance. Three items were removed due to factor loadings less than 0.4 (items 3, 8, and 9: "I've been saying to myself 'this isn't real'", "I've been refusing to believe that it has happened" and "I've been saying things to let my unpleasant feelings escape" respectively). All individual factor loadings, Cronbach's alpha and percentage of variance explained for the non-autistic sample can be seen in Table 1. Based on the similarities of coping items that make up the six factors in this sample, we labelled these six factors as we did in the autistic sample. Minor differences were noted in the item composition of engagement coping

Table 2

Pearson's Bootstrapped Correlations of study variables in autistic sample ($N = 222$).

	1.	2.	3.	4.	5.	6.	7.
1. Engagement coping	-						
2. Support-seeking coping	.455*	-					
3. Disengagement coping	.018	.069	-				
4. Substance-use coping	.136*	.085	.259*	-			
5. Humour coping	.254*	.190*	.146	.091	-		
6. Religious coping	.287*	.147	-.111	-.083	-.060	-	
7. PHQ-9	.034	.024	.671*	.280*	.060	-.089	-
8. WEMWBS	.151	.102	-.529*	-.195*	.117	.125	-.655*

Two thousand bootstrapped samples; 95 % BCA confidence intervals that do not cross zero are in bold and significance based on *$p < .008$ (Bonferroni adjustment) also noted.

PHQ-9 Patient Health Questionnaire-9; *WEMWBS* Warwick-Edinburgh Mental Well-being Scale.

and disengagement coping factors between the two samples. Specifically, the two self-distraction coping strategies (items 1 and 19) loaded onto engagement coping in the non-autistic sample, but not in the autistic sample, while a denial coping item (item 8) was included in the disengagement coping factor in the autistic sample, but not in the non-autistic sample. The remaining factors (support-seeking, substance-use, humour and religious coping) comprised identical items in the two samples.

4. Discussion

To date, there has been a lack of studies that have investigated the psychometric properties of a coping measure within the context of autistic adults. The present study sought to examine the Brief COPE's factor structure using a large sample of autistic adults in order to: (1) determine the most parsimonious structure that best represented the use of coping strategies in autistic adults; (2) examine the scale's psychometric properties to determine its suitability for use in this population; and finally (3) compare the factor structure with that of a sample of non-autistic adults to potentially identify coping characteristics that may be unique to autistic adults. Our results suggest that a six-factor structure best represented the use of coping strategies in our sample of autistic adults. This is consistent with previous studies suggesting the presence of fewer, broader underlying dimensions of coping compared to Carver's original taxonomy of 14 subscales. Although the number and labelling of the factors that emerged across various studies in the literature may differ, there has been relative consistency in approximately three broad dimensions being extracted (Kapsou, Panayiotou, Kokkinos, & Demetriou, 2010), which are conceptually similar to: 1) active, positive or engagement coping, 2) support-seeking coping, and 3) avoidance, denial or disengagement coping (e.g., Kapsou et al., 2010; Miyazaki, Bodenhorn, Zalaquett, & Ng, 2008; Mohanraj et al., 2015; Pozzi et al., 2015; Snell, Siegert, Hay-Smith, & Surgenor, 2011). We found this to also be the case in our sample of autistic adults, where results indicated three broader coping dimensions (i.e., engagement coping, support-seeking coping and disengagement coping) and three more specific ones (i.e., substance-use coping, humour coping and religious coping).

The engagement and disengagement coping subscales that emerged in our autistic sample comprised of coping strategies oriented towards and away from the stressor and its associated distress respectively. While engagement coping is comprised of strategies that involve dealing with the stressor and distress in an engaged and constructive manner (e.g., planning, problem solving or positive reappraisal), disengagement coping, in contrast, is comprised of strategies that are not only avoidant in nature (e.g., being in denial) but also what is typically seen to be negative or less than helpful thoughts and behaviours (e.g., blaming oneself or giving up). Both these factors map closely to the engagement-disengagement coping dimensions reported in the literature (see Compas et al., 2001), and thus were labelled as such. The remaining four coping subscales (i.e., support-seeking, substance-use, humour and religious coping) are more self-explanatory in their labelling and emerged as distinct factors, supporting some of the criticisms in the coping literature that the use of coping dichotomies alone (e.g., problem-emotion focused, approach-avoidance, engagement-disengagement, adaptive-maladaptive coping) may be too simplistic, and that additional coping categories are needed to more adequately capture and measure the myriad of coping strategies people use when dealing with stress (Carver et al., 1989; Connor-Smith, Compas, Wadsworth, Thomsen, & Saltzman, 2000; Skinner et al., 2003).

Although several weak to moderate correlations suggest that these six factors are not completely mutually exclusive, they remain conceptually distinguishable, representing different ways of coping and though unexplored in the present study, may serve different purposes in the coping process. In particular, the presence of a moderate correlation between engagement coping and support-seeking coping (r = .455; BCa 95 % CI: .336, .559) was not surprising, given that people who are more inclined to engage and actively cope during a stressful situation may also be similarly motivated to seek practical advice and help (instrumental support) or emotional comfort (emotional support) from others. The other weak associations between these coping subscales also support the notion that rather than engaging in coping strategies in isolation, individuals are likely to employ a variety of coping strategies when responding to stressful events (Carver et al., 1989) or even during different phases of a stressful event (Folkman & Lazarus, 1985).

In addition to good internal consistencies as indicated by Cronbach alpha values, the coping subscale that was most conceptually relevant to health and well-being outcomes, as informed by the literature (i.e., disengagement coping) was found to be associated with both higher levels of depressive symptoms and lower levels of well-being, demonstrating acceptable convergent and divergent validities. The weak association (and disagreement in significance determined by confidence intervals and adjusted p values) between engagement coping, which is usually considered adaptive, and increased well-being was also noted. This may be in line with the general inconsistencies noted between engagement coping and improved mental health and well-being, where to an extent, the effectiveness of such strategies may rely on situational factors (e.g., whether the event was amenable to change). While we examined coping strategy use from a dispositional perspective, it may be informative for future research to also explore situational coping strategies, to be able to explore this relationship further.

It was not surprising that the five coping strategies related to self-blame, behavioural disengagement and denial loaded together onto the disengagement coping factor, given their general avoidant and maladaptive nature. Although it should be acknowledged that coping strategies in and of themselves may not be intrinsically adaptive or maladaptive across all contexts, the evidence in the literature suggests that coping strategies that are avoidant or disengaging in nature are more likely to be linked to poorer health and well-being, including depression (e.g., Benson, 2010; Ottenbreit & Dobson, 2004; Penland, Masten, Zelhart, Fournet, & Callahan, 2000). While there may be benefits from distancing oneself from a stressful situation, such as to collect one's thoughts or to calm down, these benefits appear to be short-lived (Carver & Connor-Smith, 2010), and in the long run, avoiding the problem can promote an increase in intrusive thoughts about the stressor, anxiety and negative mood (Najmi & Wegner, 2008). Additionally, the long term or habitual use of avoidant coping strategies may be detrimental in that it may impede the emergence or use of more adaptive coping strategies.

When comparing the six-factor structures between the two samples, we found minor differences and some similarities in terms of

item composition. A notable difference was the inclusion of self-distraction coping strategies in the engagement coping subscale for the non-autistic sample, but not in the autistic sample. Though these two items were dropped from further analyses in the autistic sample, they did appear to load highest on the disengagement coping subscale (factor loadings of 0.338 and 0.248 for items 1 and 19 respectively). It is plausible that coping strategies that involve distracting oneself or re-directing one's attention towards other activities may be construed as adaptive or constructive in non-autistic adults, but less so in autistic adults. It may be worthwhile for future studies to explore the role, effectiveness and possible resources required to efficiently engage in self-distraction coping strategies in response to stress in autistic individuals. Further, both samples appeared to have identical items in the support-seeking, substance-use, humour and religious coping subscales, raising the possibility that these four coping subscales, and what they might mean across both samples, may be fairly consistent. However, it is important to note that due to the current lack of consensus in factor structures previously identified in the literature (to test model fit against), we were not able to conduct a more objective comparison between our two samples (e.g., confirmatory factor analysis or multi-group factorial invariance analysis) and that our comparison of factor structures at this stage, was exploratory at best.

4.1. Limitations and future directions

The data presented in this study suggest a six-factor structure for the Brief COPE in a large sample of autistic adults, with a wide age-range. The results provide preliminary evidence of the utility of the Brief COPE in this population. Given the exploratory nature of this study, it would be beneficial for future studies to confirm this six-factor structure across other large samples within the autistic population. Several limitations need to be taken into account when considering our findings. First, our autistic sample did not include autistic individuals with co-occuring intellectual disability, and thus is not representative of the general autistic adult population. While informant reports can be a valuable source of information, some of the coping strategies included in the Brief COPE are cognitive or covert in nature, and as a result, may not be as easily observed by others. Indeed, coping studies that utilised self- and parental-reports for example, have found the cross-information associations to be somewhat mixed (e.g., Compas, Desjardins et al., 2014; Jaser et al., 2005).

Second, both our samples had more female participants than would be typically representative. Although this is in line with the general female overrepresentation in online studies and surveys in autistic adult samples (e.g., Mason et al., 2018) and other samples more generally (e.g., Rao & Donaldson, 2015), the ways in which the gender differences may affect the factor loadings in each sample is not known. While the literature surrounding gender differences in coping strategy use in the broader population has yielded some inconsistent findings (e.g., Brougham, Zail, Mendoza, & Miller, 2009; Ptacek, Smith, & Dodge, 1994), with mostly small effect sizes reported when present (Matud, 2004), less is known about how this might apply in the autistic population. It would be useful for large scale future coping studies to explore potential structural invariance across genders in autistic individuals. Third, due to the online nature of the SASLA and ALSAA studies, independent assessments to confirm autism diagnosis was not possible, although all autistic participants did self-report a formal diagnosis of autism and only those meeting the cut-off score on the AQ-Short were included. Finally, this study only explored coping strategies from a dispositional perspective, rather than in response to specific stressful events. While there is suggested to be relative stability of coping responses over time, the exact strategy elicited in a particular situation also relies on contextual factors. Future research may also consider including both dispositional coping and situational specific coping measures.

4.2. Implications

This study demonstrates the validity and reliability of using the Brief COPE to capture coping responses in response to stress in autistic adults, where the six-factor structure obtained may be appropriate for use in this population. Further investigations into the ways in which autistic individuals cope with stress will be able to inform intervention programs and better support autistic adolescents and adults when faced with stressful situations. For example, when considering stress management in autistic adults, it has been proposed that the engagement in and access to recreational activities may be particularly useful (Bishop-Fitzpatrick, Smith DaWalt et al., 2017). In addition, support programs can be further tailored to suit autistic individuals, including identifying potential barriers in utilising certain coping strategies, or addressing the types of stressful situations faced by the autistic individuals on a regular basis. Indeed, it has been recently suggested the chronic life stress faced by autistic individuals often result in 'autistic burnout', a term used to describe long-term, pervasive state of exhaustion (Raymaker et al., 2020).

5. Conclusion

This is the first study to examine the factor structure of the Brief COPE in autistic adults. Our results suggest that a six-factor structure (i.e., *engagement coping, support-seeking coping, disengagement coping, substance-use coping, religious coping* and *humour coping*) best represented our sample, and good psychometric properties were found. Our study provides an initial validation of the Brief COPE in autistic adults and may prove useful when assessing use of coping strategies in response to stressful events in this population. Though future research is warranted, we also raise the possibility of similarities and differences in the use of coping strategies, such as self-distraction strategies, between autistic and non-autistic adults.

Author contributions

MM conceived the study, conducted data analysis and wrote the paper. ALR and LPL supervised the work, contributed to the planning and design of the study and provided comments on the paper. SRCA and JNT provided intellectual feedback. All authors except MM were involved in the recruitment and management of the two longitudinal studies used in this paper. All authors examined the factor structures independently before a consensus was reached, read and commented on the paper prior to submission.

Declaration of Competing Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

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Chapter 7: Associations between coping strategies and mental health outcomes in autistic adults

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RESEARCH ARTICLE

Associations between coping strategies and mental health outcomes in autistic adults

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Abstract

Compared to the general population, mental health difficulties are commonly reported in autistic adults. However, the ways in which coping strategies are associated with mental health and well-being in this population remain unknown. Further, we do not know if, and if so, how these associations might differ to that of non-autistic adults. In this study, we hypothesized that in both our autistic ($N = 255$) and non-autistic ($N = 165$) adult samples, disengagement coping strategies (e.g., denial) would relate to poorer mental health and well-being, while engagement coping strategies (e.g., problem solving) would relate to better mental health and well-being. Regression analyses revealed that higher use of disengagement coping strategies was significantly associated with higher levels of anxiety and depression, and lower levels of well-being in both samples. In contrast, increased use of engagement coping strategies was associated with better well-being, but only in the autistic sample. Our results contribute to the characterization of negative and positive mental health outcomes in autistic adults from a coping perspective, with potential to offer novel information regarding coping strategies to consider when addressing support options for mental health difficulties in the autistic adult population.

KEYWORDS
adults, autism spectrum disorders, coping strategies, mental health, well-being

ASSOCIATIONS BETWEEN COPING STRATEGIES AND MENTAL HEALTH OUTCOMES IN AUTISTIC ADULTS

Autism spectrum disorder (ASD) is a collection of neurodevelopmental conditions that are typically characterized by difficulties in social communication, interactions and restricted, repetitive and stereotyped patterns of behavior (American Psychiatric Association, 2013). In the autistic adult population, poor mental health is frequently reported (Gillott & Standen, 2007; Hofvander et al., 2009; Joshi et al., 2013; Skokauskas & Gallagher, 2010; White & Roberson-Nay, 2009), with higher prevalence of anxiety and depression among autistic adults compared to the general population (Hollocks et al., 2019; Maddox & White, 2015).

Exposure to stress and how one copes has a substantial impact on mental health and overall functioning (Cheng et al., 2014; Evans & Kim, 2013; Lazarus & Folkman, 1984; Littleton et al., 2007; Taylor & Stanton, 2007). Coping strategies can play a protective role by buffering the negative effects of stress on health and well-being (Compas et al., 2001). This is especially relevant to autistic individuals, who report both high perceived and observed stress (Bishop-Fitzpatrick et al., 2017; Groden et al., 2001), frequent stressful encounters (Baron et al., 2006; Gillott & Standen, 2007), and an increased vulnerability to negative life experiences (Griffiths et al., 2019). However, research surrounding stress and coping in the autistic population remains scarce, especially in adults. While understanding the experiences of stress is important, the occurrence of stressful events can only be minimized at best. Coping strategies on the other hand, can be developed or honed (Khor et al., 2014). Thus, a more comprehensive understanding surrounding coping and its relation to mental

health is pertinent for developing appropriate supports in this population.

Coping, mental health and well-being

Coping can be defined as cognitive and behavioral efforts to manage external and/or internal demands perceived to exceed one's resources (Lazarus & Folkman, 1984). Coping strategies are commonly classified into dichotomies, based on (1) intended functions: to directly alter the source of stress (i.e., problem-focused coping) or alleviate feelings of distress (i.e., emotion-focused coping; Folkman & Lazarus, 1980); and (2) orientation: strategies oriented towards the stressor and distress (i.e., approach or engagement coping) or away (i.e., avoidance or disengagement coping; Compas et al., 2001; Herman-Stabl et al., 1995; Roth & Cohen, 1986). Despite the usefulness of coping dichotomies, there is evidence to suggest that these categories are oversimplified and are unable to adequately capture the myriad of coping strategies (Carver et al., 1989; Connor-Smith et al., 2000; Skinner et al., 2003). Studies across non-autistic samples examining the factor structure of widely used coping measures, such as the Brief COPE (Carver, 1997) typically identify more than two coping dimensions (see review by Krägeloh, 2010). Similarly, in a study with autistic adults, six coping dimensions were identified using the Brief COPE, two of which closely mapped onto engagement/approach and disengagement/avoidance coping (labeled 'engagement coping' and 'disengagement coping' respectively), while the other four coping dimensions (i.e., support seeking, substance-use, humor and religious coping) remained distinct (Muniandy et al., 2021a).

Across a range of non-autistic samples in cross-sectional studies, avoidance and disengagement coping strategies are consistently associated with poorer mental health, such as higher anxiety and depression, and poorer psychological adjustment (Carver et al., 1989; Friedman-Wheeler et al., 2008; Penley et al., 2002). In contrast, approach and engagement coping strategies tend to be associated with more positive life outcomes, including reduced internalizing and externalizing symptoms, as well as improved well-being (Compas et al., 2006; Connor-Smith et al., 2000; Jaser et al., 2005; Meyer, 2001). While the relationships between coping and mental health are likely complex, dynamic, and reciprocal to an extent, longitudinal studies that have examined coping strategies as antecedents to mental health note the positive and negative effects of approach and avoidance coping strategies respectively, on psychological symptoms, affect and levels of distress (Aldwin & Revenson, 1987; Billings et al., 2000; Lin & Leung, 2010; Nielsen & Knardahl, 2014). Similarly, changes in engagement and disengagement coping strategy use over time (i.e., an increase or decrease between time points) are suggested to predict subsequent depressive and posttraumatic

symptoms (Booker et al., 2020; Gutner et al., 2006), demonstrating not only the possibility for coping strategies to impact mental health, but also the malleability of coping strategies and thus their potential responsiveness to intervention.

To better understand the relationships between coping and mental health outcomes, it is important to consider both the negative (e.g., anxiety, depression) and positive (e.g., positive affect, happiness) facets of well-being. Rather than two opposing sides, these aspects of well-being are noted to be separate, with distinct predictors and effects on overall functioning (Huppert & Whittington, 2003; Keyes, 2000; Suldo & Shaffer, 2008). Positive well-being has also been suggested to protect individuals from the effects of negative well-being, in autistic (Hedley et al., 2018) and non-autistic (Teismann et al., 2018; Wilhelm et al., 2010) samples. It is plausible that coping strategies may associate differently with these different aspects of mental health and well-being.

Coping research in the autistic population

Although the general sentiment is that stress levels are high in autistic individuals (Bishop-Fitzpatrick et al., 2015; Hirvikoski & Blomqvist, 2015), research examining coping in the autistic population is limited. Further, most coping research has focused on autistic children. While there is not yet a cohesive picture on the developmental shifts in coping (Skinner & Zimmer-Gembeck, 2007), coping strategies have been suggested to become more cognitively elaborate and their use more situationally differentiated as children transition into adolescence (see review by Zimmer-Gembeck & Skinner, 2011). Increased use of numerous forms of cognitive coping and active, approach-oriented coping have been noted from adolescence into adulthood (Leipold et al., 2019; Syed & Seiffge-Krenke, 2015), suggesting a further broadening of coping repertoires and flexibility in use with age (Zimmer-Gembeck & Skinner, 2011). However, age-related patterns in coping across the span of adulthood are not well established (Yancura & Aldwin, 2008), with studies across different age groups and contexts proposing varying age trajectories for differently conceptualized and measured coping strategies (e.g., Blanchard-Fields et al., 2004; Vannucci et al., 2018). It is therefore unclear the extent to which study findings on coping in autistic children are applicable to autistic individuals during transitions into adulthood and beyond, a developmentally different age range to the studies conducted in this population to date.

The lack of coping research in the autistic adult population is however complemented by research in the related area of emotion regulation. The constructs of coping and emotion regulation are closely associated, with a degree of overlap in the strategies examined. Indeed, coping strategies addressing the emotional aspects of stressful

events or the regulation of emotions (e.g., emotion-focused coping) are not dissimilar to emotion regulation strategies, and strategies characterized by cognitive reappraisal and emotional suppression (or expression) are typically examined in both areas of research. However, the focus and the context in which these strategies are employed, and therefore measured, in the coping and emotion regulation literatures represent key points of divergence (see review by Compas et al., 2014). Specifically, coping strategies are measured with the broader focus of modifying and managing stressors as well as the emotions associated with stressful encounters, whereas the focus of emotion regulation strategies is solely on managing emotions. On the other hand, the measurement of coping strategies is limited to contexts of stress, while emotion regulation measures strategies used in response to both positive and negative emotions, in both stressful and non-stressful circumstances. Given the limited coping studies in the autistic population, some emotion regulation research, especially in autistic adults, is also considered here, providing some insights into the regulatory processes in this population more generally, including responses to stress.

There is evidence to suggest a maladaptive pattern of coping strategy use in the autistic population. Several studies report that autistic children and adolescents (referred to as youth hereafter) use fewer adaptive and approach coping, but similar maladaptive and avoidance coping strategies compared to non-autistic youth (Bauminger, 2004; Rieffe et al., 2011; Rieffe et al., 2014). In contrast, Pouw et al. (2013) found no differences in approach, avoidant or maladaptive coping strategies between autistic and non-autistic children. It is important to note that Rieffe et al. (2011, 2014) and Pouw et al. (2013) conceptualized coping as an aspect of emotion regulation, rather than a distinct construct. These studies use the term 'coping strategies' and include coping-like measures to assess strategy use in response to unpleasant or negative life events, rather than to regulate emotions or the emotional impact of such events. In the interest of consistency, we utilize the same coping terms as used by the authors when discussing these studies.

Similar maladaptive patterns can be drawn from emotion regulation studies in the autistic adult population, where autistic adults report fewer adaptive strategies (e.g., cognitive reappraisal) but more maladaptive strategies (e.g., suppression) compared to non-autistic adults. Indeed, a review by Cai et al. (2018) suggests that autistic individuals have more difficulties in emotion regulation, lower effectiveness in utilizing these strategies, and depict a general maladaptive pattern of strategy use, compared to non-autistic individuals. In a comparison study exploring habitual cognitive emotion regulation strategy use in autistic and non-autistic adults, the autistic sample was noted to utilize more strategies that reflect blaming others, and fewer strategies indicative of positively reappraising situations (Bruggink et al., 2016). Similarly,

Samson et al. (2012) found that autistic adults used less dispositional cognitive reappraisal strategies to change the emotional impact of events, and more expressive suppression strategies to inhibit emotion-related behaviors compared to non-autistic adults. Other forms of coping implicated in the autistic population include consuming alcohol (Kronenberg et al., 2014; Sizoo et al., 2009), engaging in special interests and humor (Dachez & Ndobo, 2018) and a reduced use of support-seeking coping strategies (Altomare et al., 2017).

Studies examining associations between coping and mental health in autistic individuals have reported inconsistent findings. Similar to the broader coping literature, increased disengagement and maladaptive coping strategies have been related to increased emotional problems and internalizing symptoms in autistic youth (Khor et al., 2014; Pouw et al., 2013; Rieffe et al., 2011). However, contrary to what is typically reported in the general population, avoidance coping has been associated with fewer depressive symptoms in autistic boys (Pouw et al., 2013) and youth (Rieffe et al., 2014), raising the possibility that avoidance coping may be beneficial for autistic youth (Pouw et al., 2013). Similarly, findings surrounding the use of approach, engagement type coping strategies in autistic samples have also been mixed, with studies reporting positive (Pouw et al., 2013; Rieffe et al., 2014) or no associations (Khor et al., 2014; Rieffe et al., 2011) between these strategies and improved mental health. While coping has recently been suggested to play a mediating role in the relationship between trait resilience and mental health in autistic adults (Muniandy et al., 2021b), a more in-depth understanding of how various coping strategies relate to mental health outcomes, and how this may compare to non-autistic adults is needed.

Overall, the existing literature on how autistic adults cope with stress is scarce. In addition to the paucity of coping studies, the few studies that exist report such mixed findings that it is difficult to form a cohesive picture on coping strategy use, or their associations with mental health outcomes in autistic adults. Variability in sample characteristics, coping measures (e.g., cognitive or behavioral strategies), coping categories and their constituent strategies, coping context (e.g., specified stressor, hypothetical situations or general stress) and outcome measures, make it impossible to cumulate or compare these findings in a meaningful way.

The present study

The main aim of the present study was to examine coping strategy use in autistic adults and determine associations between strategy use and both positive (well-being) and negative (anxiety, depression) mental health outcomes. Using a sample of non-autistic adults for comparison purposes, a secondary aim was to explore coping

characteristics and associations that may be unique to autistic adults. Given the scarcity of coping studies in autism across adulthood, we felt it was pertinent to employ a broad perspective and utilize a large sample of autistic adults across a wide age-range to capture the entire span of adulthood (i.e., emerging adults to older adults). Relatedly, coping was assessed more generally, using a dispositional (i.e., strategies usually employed across stressful situations), rather than a situational approach (i.e., strategies utilized in response to a specific encounter), allowing us to limit individual differences such as variability in stressful encounters. Coping strategies were grouped into six categories (i.e., engagement, support seeking, disengagement, substance-use, humor and religious coping) in both the autistic and non-autistic adult samples, as informed by the six-factor structures previously identified in Muniandy et al. (2021a).

Based on existing coping studies in non-clinical populations, we hypothesized that in both samples: (1) disengagement coping would be positively correlated with depression and anxiety, and negatively correlated with well-being, and (2) engagement coping would be negatively correlated with anxiety and depression, and positively correlated with well-being. Due to limited literature, no hypotheses about the remaining four coping categories were made.

METHODS

Participants

We utilized secondary data from the Autism CRC's two longitudinal, Australian-wide adult studies, the Study of Australian School Leavers with Autism (SASLA; see Flower et al., 2019 and Lawson et al., 2019) and the Australian Longitudinal Study of Autism in Adulthood (ALSAA; see Arnold, Foley, et al., 2019). SASLA and ALSAA are questionnaire-based, prospective, longitudinal cohort studies that were designed in close collaboration in 2014. To establish research priority areas, community consultation was undertaken by SASLA and ALSAA using an autistic adult forum and a national collaboration of researchers, clinical health providers and an advisory network (which included autistic individuals, parents and organizations). After determining key research areas, which included mental health and well-being, continued consultation throughout the conduct of the online survey helped ensure that the studies were remained relevant and accessible for the autistic population.

The targeted participant age range for SASLA and ALSAA were 15–25 years, and 25 years and over, respectively, allowing for a lifespan approach to be taken in identifying comprehensive profiles of young and older Australian autistic adults. Both SASLA and ALSAA consisted of three groups of autistic and non-autistic participants: (1) autistic participants without co-occurring

intellectual disability (ID); (2) autistic participants with co-occurring ID and their carers; and (3) non-autistic control participants. ALSAA also included an additional group of participants who self-identified as autistic but did not have a formal diagnosis of autism. Only autistic participants without co-occurring ID and non-autistic control participants were included in the present study.

A total of 573 participants (344 autistic individuals; 229 non-autistic individuals) completed the Brief COPE, and Autism Spectrum Quotient (AQ-Short; Hoekstra et al., 2011), a measure of autism traits. All autistic participants self-reported a clinical diagnosis of ASD, including year of diagnosis and type of diagnosing clinician. Participants excluded from the study were autistic individuals who scored<66 on the AQ-Short ($n = 24$), reported an intellectual disability ($n = 34$), or believed they were autistic but did not report receiving a clinical ASD diagnosis ($n = 31$), and non-autistic individuals who scored >65 on the AQ-Short ($n = 64$). The final sample comprised of 255 autistic (108 males, 136 females, 10 other, one missing; $M_{age} = 35.96$, SD = 15.32) and 165 non-autistic individuals (38 males, 127 females; $M_{age} = 33.80$, SD = 15.39) aged 15–80 years. In analyses where gender was examined or controlled for, participants who did not report their gender ($n = 1$) or identified as gender 'other' ($n = 10$) were removed due to small sample sizes. While both groups were of comparable age [$t (417) = -1.403$, $p = 0.161$], the non-autistic group consisted of more females [$x^2 (1) = 19.33$, $p < 0.001$] compared to the autistic group.

Procedures

Following university ethics approvals, informed consent was obtained from all participants, in addition to parental consent for individuals under 18 years. Both studies recruited participants through a wide range of channels, including research participant registries, autism-specific organizations, forums, support networks and self-advocacy groups, educational institutions, employment services, psychology and allied health private practices, online autism communities and social media. All participants provided demographic information and answered the questionnaires online using Qualtrics (Qualtrics, 2014), or through a paper copy, upon request. The data used in this study represents a cross-section (i.e., baseline) of the data collected by SASLA and ALSAA between 2015 and 2018.

Measures

Autism traits

The AQ-Short (Hoekstra et al., 2011) is a 28-item abridged version of the original AQ (Autism Quotient; Baron-Cohen et al., 2001) measuring autism traits.

Scored on a 4-point Likert scale ranging from definitely agree (1) to definitely disagree (4), higher scores indicate increased autism traits. A score >65 has high sensitivity and specificity with a clinical diagnosis (0.97 and 0.82, respectively; Hoekstra et al., 2011). Good Cronbach alpha values were noted in the current autistic (0.81) and non-autistic (0.76) samples.

Coping behavior

The Brief COPE (Carver, 1997) is a 28-item, abbreviated version of the COPE inventory (Carver et al., 1989). Ratings are on a 4-point Likert-type scale ranging from I have not been doing this at all (1) to I have been doing this a lot (4). Six coping categories were utilized based on Muniandy et al. (2021a), where all categories had good internal consistencies in both the autistic (α range: 0.76–0.95) and non-autistic (α range: 0.80–0.94) samples.

Depression symptoms

The Patient Health Questionnaire-9 (PHQ-9; Kroenke et al., 2001) is a 9-item questionnaire measuring depressive symptoms in the past 2 weeks. Items are scored on a 4-point scale ranging from not at all (0) to nearly every day (3). A total score is obtained using the sum of items, with a score ≥ 10 being indicative of major depression, with high sensitivity (0.88) and specificity (0.88). The PHQ-9 has been recently validated for use in the autistic population (Arnold, Uljarević, et al., 2019). High Cronbach alpha values were found in the current autistic and non-autistic samples, at 0.89 and 0.90, respectively.

Anxiety symptoms

The DSM-5 generalized anxiety disorder dimensional scale (DSM-5 GAD-D; Lebeau et al., 2012) is a self-report, 10-item measure assessing symptoms of anxiety in the past month. Items are rated on a 5-point Likert-type scale ranging from never (0) to all of the time (4). Items are summed to give a total score, with higher scores indicating greater anxiety. A total score >14 indicates significant or clinical levels of anxiety (Beesdo-Baum et al., 2012). Good internal reliabilities were found for the current autistic (0.90) and non-autistic (0.88) samples.

Psychological well-being

The Warwick-Edinburgh Mental Well-being Scale (WEMWBS; Tennant et al., 2007) comprises 14-items, scored on a 5-point Likert scale from none of the time (1) to all of the time (5). It captures positive aspects of mental health, including positive emotions and functioning in the past 2 weeks, where higher scores indicate higher well-being. The WEMWBS has reported high internal consistency (α range: 0.89–0.93; Lloyd & Devine, 2012; Tennant et al., 2007). Similarly, high internal consistencies were noted in the current autistic (α: 0.92) and non-autistic (α: 0.92) groups.

Data analysis

All tests were two-tailed, with p values <0.05 considered statistically significant. Due to non-normal distribution for some variables, subsequent analyses were performed with 2000 re-samples bootstrapping and 95% bias-corrected and accelerated (BCa) confidence intervals to allow for more robust statistics (Tabachnick & Fidell, 2013). Differences in variables between the two groups were analyzed using bootstrapped, independent samples t-tests, and Cohen's d effect sizes are reported. As discussed earlier, the present study examined six coping categories in both samples (i.e., engagement, support seeking, disengagement, substance-use, humor and religious coping) based on the six-factor structure previously identified in Muniandy et al. (2021a). As noted in Muniandy et al., while these six coping categories were conceptually similar, the number of items (i.e., individual coping strategies) included in each coping category was not always identical across the samples (see Supplemental Table S1). Thus, the mean score (rather than total score) for each coping category was used when comparing coping strategy use between samples. Correlational analysis was conducted to examine the pattern of relationships between demographics (age, gender), autism traits (AQ-Short), total scores of coping strategy use (engagement, support seeking, disengagement, substance-use, humor and religious coping), mental health (PHQ-9, DSM-5 GAD-D) and well-being (WEMWBS) separately for the autistic and non-autistic groups.

To examine the cross-sectional predictors of the mental health outcomes, three hierarchical multiple regression analyses with 2000 bootstrapped re-samples for PHQ-9, DSM-5 GAD-D and WEMWBS were conducted separately for the autistic and non-autistic groups. Demographics, autistic traits and coping strategies significantly associated with each outcome measure were entered into each model as potential predictors. These domains were entered into the models over three steps, with relevant demographic variables at Step 1, autism traits at Step 2, and coping strategies at Step 3. As autistic traits and broader mental health outcomes are associated (e.g., Cassidy et al., 2018; Schiltz et al., 2021), entering autistic traits separately at Step 2 allowed us to observe the amount of variance (R^2 change) in mental health accounted for by autistic traits, once demographics were controlled for. Similarly, entering the relevant coping strategies for each mental health outcome last in each model allowed us to examine any additional

variance explained by these coping variables once the contributions of demographics and autistic traits were accounted for. Predictor variables were examined for multicollinearity by assessing the variance inflation factor (VIF < 10) and tolerance statistic (1/VIF > 0.1) values. Case wise diagnostics were also examined to check residuals for bias. Using the criterion of ± 3.29 (Tabachnick & Fidell, 2013), no univariate outliers were identified in the autistic sample, while three were noted in the non-autistic sample. Multivariate outliers were examined using a combination of Mahalanobis' distance, Cook's distance and leverage values, where several outliers were identified in each regression model. However, removing these participants from the analyses did not significantly change the total amount of variance explained and as such, they were retained. All three models in both samples met the assumptions on linearity, independence of residuals, homoscedasticity and normal distributions of residual errors. All data analyses were run using The Statistical Package for the Social Sciences (SPSS) version 25 (IBM Corp. 2017).

RESULTS

Descriptive statistics

Descriptive statistics and bootstrapped independent samples *t*-tests for the study variables for the autistic and non-autistic samples are presented in Table 1. Significant group differences were demonstrated by BCa confidence interval values that did not cross zero. There was also agreement in significance indicated by BCa 95% CI values and *p*-values. Several differences between the autistic and non-autistic groups with moderate to large effect sizes were noted. The autistic group reported higher autism traits (AQ-Short), disengagement coping, depressive and anxiety symptoms (PHQ-9 and DSM-5 GAD-D), as well as lower well-being (WEMWBS).

Correlation analyses

Table 2 presents the results from the correlation analyses for each sample. Of particular interest were the associations between demographic variables, autism traits and coping strategies with depression, anxiety and well-being. Several significant relationships were noted in both groups. Higher autism traits, disengagement coping and substance-use coping scores were significantly associated with higher levels of depressive symptoms and anxiety, and lower well-being across both samples. Further, all but one coping strategy (humor coping) was positively associated with increased anxiety symptoms in the non-autistic group, while engagement coping was positively associated with increased well-being in the autistic group only.

Multiple regression analyses

All regression coefficients, standard errors and BCa 95% confidence intervals for the three models in both samples can be found in Tables 3, 4, and 5.

As can be seen in Table 3, the final models in the autistic and non-autistic samples accounted for 46.5% and 43.5% of variance in depression respectively. For the autistic sample, the final model was significant, $F (4, 225) = 48.96$, $p < 0.001$, with gender, autism traits and disengagement coping identified as significant unique predictors. In the non-autistic sample, the final model was also significant, $F (5,150) = 23.06$, $p < 0.001$, with age and disengagement coping being significant independent predictors in the final model.

For anxiety, as noted in Table 4, demographics, autism traits and coping strategies were significant predictors in the final models of both the autistic [$F (6, 226) = 32.62$, $p < 0.001$] and non-autistic [$F (7,139) = 21.49$, $p < 0.001$] samples, with the models accounting for 46.4% and 52.0% of variance in each group respectively. Specifically, in the autistic group, age, gender, autism traits and disengagement coping were significant unique predictors in the final model, while age, autism traits, support seeking, disengagement and substance-use coping were significant, unique predictors in the non-autistic sample.

Finally, as reported in Table 5, a total of 35.5% and 38.1% of variance in well-being were accounted for in the final models of the autistic [$F (4, 216) = 29.70$, $p < 0.001$] and non-autistic [$F (4,157) = 24.12$, $p < 0.001$] groups respectively. In the autistic group, autism traits, engagement and disengagement coping were identified as significant unique predictors in the final model, while in the non-autistic group, age, autism traits, disengagement and substance-use coping were significant predictors in the final model.

DISCUSSION

The aim of this study was to examine the associations between coping strategies and mental health outcomes in samples of autistic and non-autistic adults. We noted more frequent use of disengagement coping strategies in the autistic sample, but similar use of engagement coping strategies, when compared to the non-autistic sample. Although it is possible that the increased propensity to disengage in the autistic sample may be related to the high levels and varying sources of stress faced by this population, it may also represent a maladaptive coping pattern in response to stress in autistic adults. Indeed, there is existing literature regarding a potential maladaptive pattern of coping and emotion regulation strategy use in the autistic population more broadly (e.g., Bruggink et al., 2016; Rieffe et al., 2011; Rieffe et al., 2014; Samson et al., 2012); however, what

T A B L E 1   Descriptive statistics and bootstrapped between-group comparisons

Variables	Autistic ($N = 219$) Mean (SD)	Non-autistic ($N = 143$) Mean (SD)	Between group comparisons			
			t (360)	p value	BCa 95% CI	d
Autism traits (AQ-Short)	85.93 (10.45)	51.62 (8.40)	32.92	<0.001	**32.500, 36.043**	3.54
Engagement coping	2.45 (0.68)	2.38 (0.70)	0.88	0.377	−0.081, 0.214	0.10
Support-seeking coping	2.21 (0.76)	2.22 (0.75)	−0.12	0.907	−0.176, 0.162	−0.01
Disengagement coping	1.95 (0.69)	1.54 (0.61)	5.91	<0.001	**0.274, 0.549**	0.64
Substance-use coping	1.38 (0.80)	1.34 (0.65)	0.47	0.640	−0.120, 0.180	0.05
Humor coping	1.77 (0.86)	1.79 (0.85)	−0.30	0.762	−0.212, 0.147	−0.03
Religious coping	1.64 (0.85)	1.48 (0.79)	1.70	0.09	−0.030, 0.335	0.18
Depression (PHQ-9)	9.93 (6.85)	4.73 (4.65)	8.07	<0.001	**3.948, 6.431**	0.85
Anxiety (DSM-5 GAD-D)	14.14 (8.37)	6.00 (5.40)	11.05	<0.001	**6.718, 9.531**	1.11
Well-being (WEMWBS)	40.08 (9.69)	52.22 (7.97)	−12.44	<0.001	**−13.992, −10.235**	−1.34

Note: Two thousand bootstrapped resamples; 95% bias-corrected and accelerated confidence intervals (BCa 95% CI) that do not cross zero are in bold and significance based on p are also noted.

Abbreviations: AQ- Short, Autism Spectrum Quotient-Short; DSM-5 GAD-D, Diagnostic and Statistical Manual of Mental Disorders-5 Generalized Anxiety Disorder Dimensional Scale; PHQ-9, Patient Health Questionnaire-9; WEMWBS, Warwick-Edinburgh Mental Well-being Scale.

constitutes a 'maladaptive pattern' varies between studies. Disengagement coping, as defined in the current study, has some overlap with maladaptive emotion regulation strategies such as self-blame (Bruggink et al., 2016; Rieffe et al., 2011) and coping strategies such as avoidance coping (Rieffe et al., 2014). Similarly, there is some overlap between engagement coping, as defined in the current study, and other adaptive emotion regulation strategies such as cognitive and positive reappraisals (Bruggink et al., 2016; Samson et al., 2012) and coping strategies such as approach coping and adaptive coping (Rieffe et al., 2011; Rieffe et al., 2014). Despite these overlaps, our study findings offer insight into coping strategy use in response to stressful events in the autistic adult population, an age range that has not yet been examined to date. Consistent with the wider literature on suboptimal levels of mental health in autistic adults (e.g., Hollocks et al., 2019; Maddox & White, 2015), we also found that the autistic adult sample reported higher anxiety and depression, and lower well-being compared to the non-autistic adult sample.

As hypothesized, the associations between increased disengagement coping and higher levels of depression and anxiety, as well as reduced well-being were evident in both samples (Table 6). This is consistent with the broader literature where maladaptive, disengagement and avoidant type coping strategies are associated with poorer mental health and well-being (e.g., Friedman-Wheeler et al., 2008; Kapsou et al., 2010; Schmidt et al., 2005; Spira et al., 2004). Regarding studies with autistic samples, our finding was consistent with some prior research (Khor et al., 2014; Rieffe et al., 2011) but not all, as increased use of avoidance coping has also been related to reduced depression (Pouw et al., 2013; Rieffe et al., 2014). While speculative, inconsistencies with the latter two studies could be related to differences

in gender compositions, where Pouw et al. (2013) only included boys in their sample ($N = 66$), study design, as Rieffe et al. (2014) only identified a negative relationship when examining coping longitudinally, or the measurement of coping itself, where both studies examined coping responses to 'if something bad happened'. Importantly, our findings highlight the associations between disengagement coping and mental health outcomes in autistic adults, a developmental age not explored in previous studies.

Our second hypothesis in relation to the association between engagement coping and mental health outcomes was not supported. Increased engagement coping was not associated with lower depression or anxiety in either group but was related to higher anxiety ($r = 0.233$) in the non-autistic group. Further, though increased engagement coping was positively associated with higher well-being in the autistic group, this was not the case in the non-autistic group (Table 6). This positive relationship between engagement coping and well-being in the autistic group was particularly noteworthy, given that coping studies conducted in autistic samples to date have not explicitly examined positive aspects of mental health. Two studies did, however, report a relationship between approach, engagement-type coping and lower depressive symptoms in autistic youth (Pouw et al., 2013; Rieffe et al., 2014) which may well be an indication of higher well-being. Future work should consider both the positive and negative facets of mental health, as our results suggest that these constructs may be differently associated with coping strategies.

The lack of relationship between engagement coping and well-being in the non-autistic sample in this study was unexpected. This discrepancy between the two groups may be related to the types of stressful events that were being considered, as to an extent, the effectiveness

TABLE 2   Pearson's bootstrapped correlations of study variables for autistic (lower shaded section; $n = 209$) and non-autistic (upper unshaded section; $n = 143$) groups

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.
1. Gender[a]	–	−0.001	**−0.182***	0.144	**0.200***	0.047	−0.053	−0.102	**0.169***	−0.028	0.077	0.091
2. Age	0.044	–	−0.166*	−0.098	−0.069	−0.138	0.024	**−0.331****	0.015	**−0.276****	**−0.260****	**0.290****
3. Autism traits (AQ-Short)	**0.179****	**0.386****	–	−0.020	−0.152	**0.174***	0.001	0.005	0.014	**0.199***	**0.252****	**−0.341****
4. Engagement coping	**0.165***	**0.228****	0.113	–	**0.510****	**0.154**	0.106	**0.400****	**0.251****	0.132	**0.233****	0.020
5. Support-seeking coping	0.045	−0.068	0.002	**0.465****	–	**0.275****	−0.024	**0.269****	0.135	0.103	**0.343****	−0.030
6. Disengagement coping	0.049	0.088	**0.216****	0.036	0.062	–	**0.226****	0.103	0.114	**0.528****	**0.615****	**−0.442****
7. Substance-use coping	−0.028	**0.154***	**0.184****	0.127	0.071	**0.271****	–	0.129	−0.076	**0.278****	**0.327****	**−0.276****
8. Humor coping	0.046	0.019	0.006	**0.267****	**0.204****	**0.161****	0.095	–	0.153	**0.231****	0.134	−0.018
9. Religious coping	**0.162***	0.133	−0.014	**0.289****	**0.142***	−0.107	−0.087	−0.051	–	0.012	**0.183***	0.137
10. Depression (PHQ-9)	**0.153***	0.056	**0.273****	0.040	−0.010	**0.681****	**0.279****	0.083	−0.093	–	**0.683****	**−0.653****
11. Anxiety (DSM-5 GAD-D)	**0.144***	−0.128	**0.231****	0.087	**0.158***	**0.640****	**0.274****	0.123	−0.018	**0.748****	–	**−0.580****
12. Well-being (WEMWBS)	−0.060	−0.122	**−0.302****	**0.148***	0.116	**−0.523****	**−0.198***	0.090	0.124	**−0.655****	**−0.546****	–

Note: Two thousand bootstrapped re-samples; BCa 95% confidence intervals that do not cross zero are in bold and significance based on p values (*) are noted.

Abbreviations: AQ-Short Autism Spectrum Quotient-Short; DSM-5 GAD-D, Diagnostic and Statistical Manual of Mental Disorders-5 Generalized Anxiety Disorder Dimensional Scale; PHQ-9, Patient Health Questionnaire-9; WEMWBS, Warwick-Edinburgh Mental Well-being Scale.

[a]Positive direction indicates female.

*$p < 0.05$; **$p < 0.01$.

TABLE 3 Two thousand bootstrapped re-samples linear regression models predicting depression in autistic and non-autistic samples

Depression (PHQ-9)

Autistic ($N = 229$)	B	SE B	β	BCa 95% CI	$R^2 (\Delta R^2)$	Non-autistic ($N = 155$)	B	SE B	β	BCa 95% CI	$R^2 (\Delta R^2)$
Step 1					0.027*	Step 1					0.103**
Gender	2.196	0.904	0.163	**0.420, 3.931**		Age	−0.113	0.023	−0.321	**−0.161, −0.071**	
Step 2					0.091 (0.064**)	Step 2					0.140 (0.037*)
Gender	1.556	0.894	0.116	−0.233, 3.283		Age	−0.098	0.023	−0.279	**−0.144, −0.055**	
Autism traits	0.164	0.040	0.257	**0.085, 0.246**		Autism traits	0.126	0.044	0.198	**0.043, 0.211**	
Step 3					0.465 (0.375**)	Step 3					0.435 (0.294**)
Gender	1.572	0.708	0.117	**0.266, 2.964**		Age	−0.057	0.019	−0.163	**−0.095, −0.022**	
Autism traits	0.083	0.031	0.131	**0.021, 0.147**		Autism traits	0.063	0.036	0.099	−0.004, 0.126	
Disengagement	1.210	0.101	0.606	**1.015, 1.405**		Disengagement	0.979	0.179	0.481	**0.651, 1.369**	
Substance-use	0.264	0.255	0.063	−0.239, 0.803		Substance-use	0.564	0.329	0.135	−0.058, 1.267	
						Humor	0.357	0.209	0.119	−0.088, 0.755	

Note: BCa 95% confidence intervals that do not cross zero are in bold.

Abbreviation: PHQ-9, Patient Health Questionnaire-9.

*$p < 0.05$, **$p < 0.001$.

T A B L E 4 Two thousand bootstrapped re-samples linear regression models predicting anxiety in autistic and non-autistic samples

Anxiety (DSM-5 GAD-D)

Autistic ($N = 232$)	B	SE B	β	BCa 95% CI	R^2 (ΔR^2)	Non-autistic ($N = 146$)	B	SE B	β	BCa 95% CI	R^2 (ΔR^2)
Step 1					0.048*	Step 1					0.060*
Age	−0.072	0.031	−0.134	**−0.134, −0.007**		Age	−0.084	0.023	−0.244	**−0.128, −0.041**	
Gender	2.936	1.075	0.176	**0.840, 5.072**							
Step 2					0.106(0.057**)	Step 2					0.105 (0.045*)
Age	−0.120	0.033	−0.223	**−0.183, −0.055**		Age	−0.071	0.022	−0.208	**−0.112, −0.034**	
Gender	2.187	1.068	0.131	**0.234, 4.156**		Autism traits	0.137	0.043	0.215	**0.050, 0.222**	
Autism traits	0.205	0.055	0.260	**0.095, 0.309**							
Step 3					0.464(0.358**)	Step 3					0.520(0.415**)
Age	−0.137	0.025	−0.255	**−0.187, −0.087**		Age	−0.048	0.021	−0.141	**−0.090, −0.010**	
Gender	2.143	0.836	0.128	**0.559, 3.709**		Autism traits	0.114	0.040	0.179	**0.037, 0.188**	
Autism traits	0.111	0.043	0.141	**0.029, 0.194**		Engagement	−0.018	0.050	−0.023	−0.122, 0.083	
Support-seeking	0.214	0.118	0.097	−0.023, 0.466		Support-seeking	0.337	0.105	0.239	**0.133, 0.525**	
Disengagement	1.427	0.134	0.574	**1.169, 1.706**		Disengagement	0.981	0.167	0.440	**0.630, 1.335**	
Substance-use	0.435	0.290	0.083	−0.101, 0.966		Substance-use	0.994	0.294	0.237	**0.427, 1.679**	
						Religious	0.390	0.239	0.114	−0.061, 0.846	

Note: BCa 95% confidence intervals that do not cross zero are in bold.

Abbreviation: DSM-5 GAD-D, Diagnostic and Statistical Manual of Mental Disorders-5 Generalized Anxiety Disorder Dimensional Scale.

*$p < 0.05$, **$p < 0.001$.

TABLE 5 Two thousand bootstrapped re-samples linear regression models predicting well-being in autistic and non-autistic samples

Well-being (WEMWBS)

Autistic (N = 220)

	B	SE B	β	BCa 95% CI	R² (ΔR²)
Step 1					0.089**
Autism traits	−0.275	0.056	−0.298	**−0.382, −0.161**	
Step 2					0.355 (0.266**)
Autism traits	−0.186	0.049	−0.202	**−0.281, −0.088**	
Engagement	0.349	0.105	0.196	**0.133, 0.582**	
Disengagement	−1.354	0.190	−0.480	**−1.739, −0.957**	
Substance-use	−0.284	0.339	−0.047	−0.947, 0.398	

Non-autistic (N = 161)

	B	SE B	β	BCa 95% CI	R² (ΔR²)
Step 1					0.099**
Age	0.172	0.042	0.315	**0.092, 0.260**	
Step 2					0.200 (0.101**)
Age	0.134	0.041	0.244	**0.054, 0.221**	
Autism traits	−0.326	0.073	−0.326	**−0.468, −0.171**	
Step 3					0.381 (0.180**)
Age	0.103	0.039	0.189	**0.029, 0.191**	
Autism traits	−0.248	0.064	−0.248	**−0.367, −0.116**	
Disengagement	−1.218	0.236	−0.376	**−1.708, −0.733**	
Substance-use	−0.1029	0.526	−0.155	**−2.009, −0.105**	

Note: BCa 95% confidence intervals that do not cross zero are in bold.
Abbreviation: WEMWBS, Warwick-Edinburgh Mental Well-being Scale.
*$p < 0.05$, **$p < 0.001$.

of engagement coping strategies (e.g., problem solving, planning) can depend on whether the stressful events under consideration were amenable to change (Taylor & Stanton, 2007). While this study examined coping strategies from a dispositional perspective, it may prove useful for future research to also explore situational coping strategies and the controllability of the stressful event when investigating engagement coping strategies. Also of note was the significance of support-seeking coping in relation to anxiety in the non-autistic sample only. Similarly reported in other studies (e.g., Thorne et al., 2013; Vierhaus & Lohaus, 2009), it is plausible that turning to others for support and comfort may also include elements of avoidance, impeding the development of more effective, independent coping strategies (Thorne et al., 2013). An in-depth exploration of the roles and underlying motivation for using support-seeking coping strategies in the autistic population would be insightful.

Findings from the current study highlight several coping areas that may warrant and benefit from further investigation in the autistic population. In particular, given that disengagement coping was associated to both positive and negative mental health outcomes in both samples, it would be interesting to investigate whether diagnosis or group membership may moderate the relations between disengagement coping and mental health. Additionally, it will be important to explore the use of disengagement coping strategies in autistic adults in more detail. It is plausible that disengagement coping strategies may serve different functions or be beneficial in some way in the autistic population, which may explain the greater endorsement of these strategies reported in our autistic adult sample. Disengaging from stressful encounters can be helpful in the short-term, by allowing individuals to calm down and collect their thoughts, or in response to uncontrollable contexts, where there is little that can be done to amend the situation (Carver & Connor-Smith, 2010; Taylor & Stanton, 2007). Autistic individuals may disengage or remove themselves from stressful situations to avoid further input, stimulation (Halim et al., 2018) or sensory overload (Crane et al., 2009). Further, not all disengagement coping strategies are equivalent. Though not captured in the current study, positive distraction for example, may be construed as adaptive if used temporarily to redirect attention elsewhere (e.g., 'planned breathers'; Patry et al., 2007), or as maladaptive if used primarily to avoid a situation, with no intention of returning to deal with it more directly (Waugh et al., 2020; Wolgast & Lundh, 2017). Future studies that examine the use, meanings, and underlying intentionality of coping strategies in autistic adults would further complement our research, providing a deeper understanding of coping strategy use in this population.

Overall, in a large sample of autistic adults across a wide age range, our findings show that disengagement coping was associated with poorer mental health outcomes (i.e., depression, anxiety, and well-being), while

TABLE 6 Summary of significant findings in relation to coping predictors from regression analyses

| Predictor coping variables | Mental health outcomes | | | | | |
| | Depression (PHQ-9) | | Anxiety (DSM-5 GAD-D) | | Well-being (WEMWBS) | |
	Autistic	Non-autistic	Autistic	Non-autistic	Autistic	Non-autistic
Engagement coping	–	–	–	–	✓ (+)	–
Support-seeking coping	–	–	–	✓ (+)	–	–
Disengagement coping	✓ (+)	✓ (+)	✓ (+)	✓ (+)	✓ (−)	✓ (−)
Substance-use coping	–	–	–	✓ (+)	–	✓ (−)
Humor coping	–	–	–	–	–	–
Religious coping	–	–	–	–	–	–

Note: (+) and (−) reflect positive and negative directions of association respectively.

engagement coping was associated with higher well-being. These results suggest that the use of specific coping strategies is important when addressing mental health outcomes for autistic adults. It is possible that helping autistic adults to utilize more adaptive coping strategies (i.e., reduce disengagement coping and increase engagement coping) may positively influence mental health outcomes. However, it is not possible to know if maladaptive coping strategy use contributed to the development of poor mental health, or if the presence of poor mental health influenced or reflected the choice of maladaptive coping strategies in a cross-sectional study such as ours. The use of longitudinal data in future studies would be imperative in confirming the direction of these relationships. Nonetheless, our cross-sectional findings make an important contribution to the characterization of both positive and negative mental health outcomes in the autistic adult population from a stress and coping perspective, a perspective that is limited in the autism literature to date.

Our findings are in line with increasing calls for the need to develop evidence-based interventions for autistic adults with a focus on coping and managing stressful events (e.g., Bishop-Fitzpatrick et al., 2015; Hirvikoski & Blomqvist, 2015). Taking a holistic approach and incorporating other stress-related constructs such as resilience could also be beneficial since these constructs are interrelated (Muniandy et al., 2021b). While there are several intervention programs tailored for autistic adults such as ACCESS (Oswald et al., 2018) and STEPS (White et al., 2017) that do include coping skills, these programs remain quite broad and cover a range of target areas. A way forward may be to co-design intervention programs with the autistic community to specifically focus on their experiences of stress (e.g., addressing frequently faced stressful encounters) and coping strategy use (e.g., identifying potential barriers in utilizing certain coping strategies). Although the present study explored the habitual ways in which individuals cope, contextual factors of specific stressful situations can also impact the use of coping strategies (e.g., Folkman & Lazarus, 1985). Relatedly, varying ages or stages throughout adulthood may influence coping behavior, not only in the use of coping strategies, but also sources of stress, social roles and demands, as well as coping resources. Future work that takes account of age or developmentally related differences, as well as examines situational coping and the stability of coping dispositions across specific stressors, would be particularly helpful in improving the sensitivity and personalization of support options in the autistic adult population.

When considering our findings, several limitations need to be considered. First, our autistic sample only included autistic adults without an intellectual disability, with the ability to self-respond to the questionnaire items, thus is not representative of the autistic population more broadly. Although self-report measures can be influenced by biases (e.g., social desirability bias), the cognitive, internal and covert nature of several items on the Brief COPE, as well as mental health measures, may make it difficult for these constructs to be observed and accurately reported by others. Despite differences in coping strategy use between self- and parent-reports in autistic adolescents (aged 12–18 years), Khor et al., 2014 noted that the associations between coping and behavioral and emotional problems were consistent regardless of respondent. It would be insightful for future studies to similarly utilize cross-respondent reporting to ascertain the convergence of coping responses in autistic adults, and whether coping-mental health associations may differ as a function of respondent in this age group. Both samples in this study also had an overrepresentation of female participants (55.7% in the autistic group and 77% in the non-autistic group), not unlike the general female overrepresentation in online studies in autistic adult samples (e.g., Kapp et al., 2013) or other populations more generally (e.g., Rao & Donaldson, 2015). Gender differences in coping strategies have been reported to be inconsistent (e.g., Brougham et al., 2009; Ptacek et al., 1994) and if present, tend to report small effect sizes (Matud, 2004; Tamres et al., 2002). Given the few weak correlations ($r < 0.2$) noted between coping strategies and gender in both groups in the present study, the effects of gender were not explored further.

Third, although all autistic participants reported a clinical diagnosis of ASD and met the cut-off score on the AQ-Short, independent assessments to confirm diagnosis of ASD was not possible due to the online nature of the studies and the geographical spread of recruitment. Fourth, our data were cross-sectional. While an important first step in exploring the associations between coping strategies and mental health outcomes in this population, future studies that are longitudinal would allow for the predictive value of coping on mental health to be more clearly examined, while controlling for baseline mental health. Finally, stress was not measured in the present study. Although coping was approached from a dispositional perspective, it is plausible that different types or levels of overall stress may influence coping strategy use, or the associations between coping strategies and mental health. It would be beneficial for future coping studies to account for variabilities in stress to further understand how coping strategies relate to mental health.

CONCLUSION

This study is among the few that have examined coping strategies in autistic adults, and their relation to mental health outcomes. To our knowledge, this study is also the first to examine these relationships alongside a comparison sample of non-autistic adults. Our results showed associations between disengagement coping and overall poorer mental health in both groups, while engagement coping was associated with better well-being in the autistic group. Given the high prevalence of mental health difficulties in autistic adults, this study offers novel information regarding coping strategies for consideration when addressing support and intervention options for mental health difficulties in autistic adults, suggesting a focus on reducing disengagement coping and increasing engagement coping strategies.

CONFLICT OF INTEREST
The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

ETHICS STATEMENT
The study was conducted under ethical approvals from La Trobe University Human Research Ethics Committee (HEC14-095) and the University of New South Wales Human Research Ethics Committee (HC15001), and in accordance with the ethical standards of the National Health and Medical Research Council (NHMRC).

DATA AVAILABILITY STATEMENT
The data supporting this study arose from two longitudinal studies funded by Autism CRC (https://www.autismcrc.com.au), which owns the intellectual property in these data. Please contact Autism CRC concerning data availability (research@autismcrc.com.au).

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Chapter 8: Brief Report: Longitudinal Role of Coping Strategies on Mental Health Outcomes in Autistic Youth and Adults

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BRIEF REPORT

Brief Report: Longitudinal Role of Coping Strategies on Mental Health Outcomes in Autistic Youth and Adults

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Abstract

The stress literature suggests that coping strategies are implicated in mental health outcomes. However, the longitudinal relationship between coping strategies and mental health in the autistic adult population has not yet been examined. This 2-year longitudinal study examined the predictive role of both baseline and change in coping strategy use over time (i.e., an increase or decrease) on anxiety, depression, and well-being after 2-years in 87 autistic adults aged 16 to 80 years. Controlling for baseline mental health, both baseline and increase in disengagement coping strategies (e.g., denial, self-blame) predicted higher anxiety and depression, and lower well-being, while an increase in engagement coping strategies (e.g., problem solving, acceptance) predicted higher well-being. These findings extend the current coping literature in autistic adults, offering insight into mental health support and intervention options.

Keywords Adults · Autism spectrum disorder · Coping strategies · Mental health

There is consensus surrounding elevated rates of co-occurring mental health conditions in the autistic population (Lever & Geurts, 2016), with a recent meta-analysis reporting the prevalence for any *current* anxiety disorder and depression in autistic adults to be considerably higher than that of the general population (Hollocks et al., 2019). Multiple risk factors associated with poor mental health have been identified, including autistic traits, female gender, emotion dysregulation, intolerance of uncertainty, loneliness, dissatisfaction with social supports and sleep difficulties (Cai et al., 2018; Garcia-Villamisar & Rojahn, 2015; Hedley et al., 2018; Jovevska et al., 2020). However, research surrounding the roles of stress and coping which may underlie poor mental health in autistic adults is limited to date.

It is well established in the general literature that exposure to stressful or adverse events is significantly associated with reduced mental health and well-being (e.g., Cheng et al., 2014; Taylor & Stanton, 2007). Stress can increase risks for psychopathology and distress for both autistic (Botha & Frost, 2020; Moseley et al., 2021) and non-autistic samples (de Frias & Whyne, 2015; Marin et al., 2011). Coping strategies have the potential to mitigate some of the negative effects of stress. Given the high levels of perceived stress (Bishop-Fitzpatrick et al., 2015), daily stressors (Higgins et al., 2021) and increased susceptibility to negative events (Griffiths et al., 2019) in the autistic population, the investigation of coping in autistic adults is critical.

Coping refers to cognitive or behavioural strategies utilised to manage the demands of encounters perceived as stressful (Lazarus & Folkman, 1984). Coping can be classified into engagement or disengagement strategies, based on whether the strategy is directed towards or away from the source of stress and associated feelings of distress (Compas et al., 2001). Engagement coping encompasses approach-oriented strategies that actively address the stressor and alleviate feelings of distress (e.g., planned problem solving, positive reappraisal), while disengagement coping reflects avoidance-oriented strategies that aim to escape or avoid these (e.g., denial, behavioural disengagement; Carver & Connor-Smith, 2010). Across a range of studies using both

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cross-sectional and longitudinal data, avoidant and disengagement coping strategies are frequently associated with negative health outcomes, including internalizing (Friedman-Wheeler et al., 2008) and post-traumatic symptoms (Thompson et al., 2018), psychological distress (Littleton et al., 2007; Nielsen & Knardahl, 2014) and maladjustment (Duongdao & Roesch, 2008). Conversely, though less consistently, approach and engagement coping strategies are related to positive health outcomes such as improved physical health (Park & Adler, 2003), social functioning (Tiet et al., 2006) and quality of life (Gattino et al., 2015), and reduced depression (Friedman-Wheeler et al., 2008).

In autism, coping and mental health studies are limited, with inconsistent findings. In autistic children and youth, most have reported associations between increased disengagement coping strategies and increased internalising symptoms and emotional problems (Khor et al., 2014; Pouw et al., 2013; Rieffe et al., 2011). In contrast, others have found that disengagement coping is related to reduced depressive symptoms in samples of autistic boys ($N = 63$; Pouw et al., 2013) and autistic youth ($N = 81$; Rieffe et al., 2014). Similarly, mixed findings are noted with engagement coping, where increased use of these strategies has been related to improved mental health in some studies (Pouw et al., 2013; Rieffe et al., 2014), and a lack of relationship reported in others (Khor et al., 2014; Rieffe et al., 2011). In autistic adults, one cross-sectional study to date has examined relationships between coping strategy use and mental health, where disengagement coping was associated with poorer mental health (i.e., higher depression and anxiety, lower well-being) and engagement coping was related to higher mental well-being (Muniandy et al., 2022a).

The limited coping studies in autistic adults is nevertheless complemented by the emotion regulation (ER) literature. Though closely related, with some strategy overlap, coping and ER remain distinct in both focus and the context in which these strategies are deployed (see Compas et al., 2001 for a review). At this juncture, it is worth noting that Rieffe et al. (2011, 2014) and Pouw et al. (2013) conceptualised coping as a feature of ER rather than a distinct construct, and examined strategy use in response to life events and negative experiences, instead of to regulate the emotional impact of such events. To avoid misinterpretations, we use the same coping terms here as utilised by the authors when addressing these studies.

In autistic adults, some studies report associations between maladaptive ER strategies (e.g., self-blame) and adaptive ER strategies (e.g., positive refocusing), with higher and lower internalising symptomatology respectively ($N = 121$; Bruggink et al., 2016). Others found that emerging autistic adults with co-occurring mood and anxiety disorders demonstrated more involuntary engagement ER strategies (e.g., rumination, emotional arousal) and fewer voluntary engagement ER strategies (e.g., problem solving, emotional control), compared to those without these co-occurring conditions ($N = 27$; Charlton et al., 2020). In examining ER relationships with mental health, Cai et al. (2018) noted the significance of considering suppression strategies relative to reappraisal strategies (i.e., an ERQ ratio), where a higher ERQ ratio was related to higher anxiety and depression in autistic adults ($N = 61$), highlighting the importance of considering relative use of ER strategies as contributors to psychopathology in autism. It is not yet known if relative use of coping strategies may be similarly significant when considering the mental health outcomes in autistic adults.

To date, only one coping-mental health study has utilised a longitudinal study design with autistic individuals (Rieffe et al., 2014). Across three time points (9-month intervals), Rieffe et al. (2014) found that both mean use and an increase in engagement coping strategies over time predicted subsequent fewer depressive symptoms in both autistic and non-autistic children aged 9–15 years. Further, and contrary to what is typically reported in the broader literature, an increase in disengagement coping strategies over time was related to fewer depressive symptoms in both samples. However, longitudinal coping-mental health relationships in autistic adults have not yet been examined. It is unclear the extent to which the results found in autistic youth (Rieffe et al., 2014) might apply to adults. As Rieffe et al. (2014) did not control for baseline depression, it is not known whether the predictive power of coping strategies would have held once the effects of prior depressive symptoms were accounted for. Indeed, prior and current psychopathology symptoms are said to be important predictors of future psychopathology symptoms in autistic and non-autistic adults (Hedley et al., 2019; Gallagher et al., 2018).

The current study aimed to examine the predictive role of baseline coping and change in coping strategies over time on follow-up mental health outcomes 2-years later (i.e., depression, anxiety and well-being) in a sample of autistic older adolescents and adults (hereafter referred to as adults), while controlling for baseline mental health. It was hypothesised that both higher baseline and increased use of disengagement coping over time would predict lower mental health outcomes at follow-up, whereas higher baseline and an increase in engagement coping would predict better outcomes at follow-up.

Methods

Participants and Procedures

The sample was 87 autistic adults aged 16 to 80 years (37 males, 48 females, 2 missing; $M_{age} = 38.80$, $SD_{age} = 15.41$), recruited through the nationwide longitudinal online studies, the Study of Australian School Leavers with Autism (SASLA; see Flower et al., 2019 and Lawson et al., 2019) and the Australian Longitudinal Study of Autism in Adulthood (ALSAA; see Arnold et al., 2019). All autistic participants had no co-occurring intellectual disability and self-reported a current diagnosis of autism, which was corroborated by an above-threshold Autism-Spectrum Quotient-Short Form score (AQ-Short; Hoekstra et al., 2011). At baseline, 41.4% of the sample reported a co-occurring diagnosis of depression, while 52.9% reported a diagnosis of anxiety. Completed educational levels were some or all of high school (25.3%), certificate or diploma (19.5%), undergraduate degree (23%) and post graduate degree (21.8%) (missing: 10.3%). Using postcode-based Socioeconomic Index for Areas (SEIFA) as a proxy for socioeconomic disadvantage, the mean decile of 6.69 ($SD = 2.66$; range = 1–10, where 1 represents the lowest 10% of areas and 10 the highest 10%) indicated that the sample was slightly above average compared with the Australian population.

Both SASLA and ALSAA undertook community consultation to determine key research areas (e.g., mental health and well-being), which was maintained throughout the studies to help ensure that the surveys were relevant and accessible to the autistic adult population. Following ethical approvals, recruitment for both studies involved numerous channels including autism-specific organisations and forums, clinicians, support groups and educational institutions. Participants provided informed consent, with those aged below 18 years also providing parental consent. Following this, participants completed the surveys online or by post. The present study utilised secondary data from both SASLA and ALSAA, comprising both baseline (T1) and 2-year follow-up (T2) data. Since data collection for SASLA and ALSAA was still ongoing during this time, an accurate participant attrition rate could not be provided.

Measures

Autism Quotient-Short (AQ-Short; Hoekstra et al., 2011) 28-items scored on a 4-point Likert scale from *definitely agree* (1) to *definitely disagree* (4) to establish levels of autism traits. A cut-off score > 65 has high sensitivity and specificity

with a clinical diagnosis of ASD (0.97 and 0.82 respectively; Hoekstra et al., 2011).

Brief COPE (Carver, 1997) 28-items scored using a 4-point Likert-type scale from *I haven't been doing this at all* (1) to *I've been doing this a lot* (4) to assess coping strategy use. Engagement and disengagement coping strategies were examined based on the factor structure validated for use in autistic adults identified in Muniandy et al. (2021).

Patient Health Questionnaire-9 (PHQ-9; Kronke et al., 2001) Depressive symptoms were established using 9-items scored on a 4-point scale from *not at all* (0) to *nearly every day* (3). The PHQ-9 has been validated in autistic adults (Arnold et al., 2020).

DSM-5 Generalized Anxiety Disorder Dimensional Scale (DSM-5 GAD-D; LeBeau et al., 2012) 10 items were rated on a 5-point Likert-type scale ranging from *never* (0) to *all of the time* (4) to capture cognitive and physical symptoms of fear and anxiety.

Warwick-Edinburgh Mental Well-being Scale (WEMWBS; Tennant et al., 2007) 14-items were scored on a 5-point Likert scale from *none of the time* (1) to *all of the time* (5) to determine levels of mental well-being.

Total scores for the PHQ-9, DSM-5 GAD-D and WEMWBS were obtained by summing the items; higher scores indicated more symptoms of anxiety or depression and better well-being respectively.

Data Analysis

All variables were continuous except gender which was dichotomous (male/female). As disengagement coping and PHQ-9 violated assumptions of normality, subsequent analyses were performed with 2,000 resamples bootstrapping and 95% bias-corrected and accelerated (BCa) confidence intervals (Tabachnick & Fidell, 2013). Changes in variable scores over time (i.e., from T1 to T2) were explored using paired samples *t*-tests, including Cohen's *d* effect size. The relationships among variables were examined using Pearson correlation analyses. Three hierarchical regression models were used to investigate the longitudinal predictors for each of the three mental health outcomes at 2-years. There was no evidence of multicollinearity. One univariate outlier was identified using a criterion of ±2.58 standard deviations from the mean (Field, 2013) in one model (WEMWBS), however removing this participant from the analyses did not significantly change the results and they were retained. No multivariate outliers were identified using Mahalanobis'

distance, Cook's distance and leverage values. In each model, the predictor variables were age, gender, and AQ-short (Step 1), respective baseline mental health outcome (Step 2), T1 engagement coping and disengagement coping (Step 3) and change (Δ) in engagement and disengagement coping (Step 4). As part of a post hoc analysis, the predictive role of both coping strategies *relative* to each other was examined, through creating a coping ratio variable (i.e., engagement score divided by disengagement score). The multiple regression models were re-run using the same predictors at Steps 1 and 2, but with T1 coping ratio at Step 3 and change in coping ratio over time at Step 4.

Results

Descriptives and Correlation Analyses

All scales had good to excellent internal consistency at both T1 (α range: 0.75–0.91) and T2 (α range: 0.78–0.93). Descriptive information and bootstrapped comparisons between T1 and T2 scores are presented in Table 1, where at the group level, no significant changes from T1 to T2 were noted for key variables. As seen in Table 2, higher T1 disengagement coping was correlated with higher anxiety and depression, and lower mental well-being at T2, while T1 engagement coping was not significantly associated with T2 mental health outcomes.

Predictors of Follow-Up Mental Health Outcomes

Results from the multiple regression models are presented in Table 3. For depression, the final model [$F(8, 66) = 23.90$, $p < .001$] accounted for 74.3% of variance in T2 PHQ-9 scores, where higher T1 depression and T1 disengagement coping, and an increased use of disengagement coping over time significantly predicted higher T2 depressive scores.

In the final model for anxiety, [$F(8, 65) = 21.73$, $p < .001$], 72.8% of variance in T2 GAD-D scores was accounted for, where lower age, higher autistic traits, T1 anxiety and T1

disengagement coping, as well as an increase of disengagement coping over time were significant unique predictors.

For mental well-being, the final model [$F(8, 67) = 28.65$, $p < .001$] accounted for 77.4% of variance in T2 WEMWBS scores. Lower autistic traits and T1 disengagement coping, reduced use of disengagement coping over time, higher T1 well-being and increased use of engagement coping over time, were significant predictors for improved well-being at follow-up.

Following these findings, the coping ratio variable was examined as a potential predictor for T2 mental health outcomes. The final models for PHQ-9, GAD-D and WEMWBS scores at T2 were all significant and accounted for 64.4% [$F(6, 68) = 20.47$, $p < .001$], 63.2% [$F(6, 67) = 19.20$, $p < .001$] and 66.7% [$F(6, 69) = 23.07$, $p < .001$] of variance respectively. Lower age and male gender were significant predictors for higher T2 anxiety, while higher autistic traits predicted higher T2 anxiety and lower T2 well-being. All three T1 mental health outcomes significantly predicted their respective outcomes at T2. In relation to coping, higher T1 coping ratio (i.e., higher engagement coping relative to disengagement coping) was a significant predictor for lower T2 anxiety and higher T2 well-being. Additionally, an increase of coping ratio over time (i.e., increase in engagement coping, decrease in disengagement coping, or both over time) predicted lower T2 depression, lower T2 anxiety and higher T2 well-being (see Table 4).

Discussion

The present study provides the first longitudinal examination of relationships between coping strategies and mental health outcomes in autistic adults, where baseline and change in coping strategies over time were explored as mental health predictors at a 2-year follow-up. Findings show: (1) significant associations between higher baseline disengagement coping and poorer mental health outcomes 2-years later; (2) increase in disengagement coping over time uniquely predicted poorer mental health 2-years later; and (3) increase in

Table 1 Descriptive statistics and comparisons between baseline (T1) and follow-up (T2)

Variable	T1	T2	Bootstrapped comparisons[1]		
	M (*SD*)	M(*SD*)	*t* (69)	BCa 95% CI	*d*
Autism traits (AQ-Short)	86.06 (12.70)	85.97 (14.10)	0.107	-1.543, 1.772	-0.02
Engagement coping	19.36 (5.31)	20.30 (5.86)	-1.684	-2.021, 0.171	0.21
Disengagement coping	10.01 (3.56)	9.44 (3.47)	1.561	−0.086, 1.243	-0.19
Depression (PHQ-9)	10.13 (7.21)	10.30 (7.77)	− 0.255	-1.512, 1.243	0.03
Anxiety (DSM-5 GAD-D)	14.77 (8.10)	13.49 (8.25)	1.607	− 0.157, 2.757	-0.20
Well-being (WEMWBS)	39.33 (9.93)	40.87 (10.49)	-1.551	-3.636, 0.414	0.19

2000 bootstrapped resamples; *AQ-Short*: Autism Spectrum Quotient-Short; *PHQ-9*: Patient Health Questionnaire-9; *DSM-5 GAD-D*: Diagnostic and Statistical Manual of Mental Disorders-5 Generalized Anxiety Disorder Dimensional Scale; *WEMWBS*: Warwick-Edinburgh Mental Well-being Scale

Table 2 Pearson's correlational analyses for demographics and variables at T1 and T2

	Age	Gender	T1 AQ	T2 AQ	T1 Engage	T2 Engage	T1 Disengage	T2 Disengage	T1 PHQ-9	T2 PHQ-9	T1 GAD-D	T2 GAD-D	T1 WEM-WBS
Gender	-0.002	-											
T1 AQ-Short	0.448**	0.094	-										
T2 AQ-Short	0.468**	0.0116	0.881**	-									
T1 Engage	0.078	-0.017	-0.098	-0.049	-								
T2 Engage	-0.023	0.022	-0.189	-0.195	0.653**	-							
T1 Disengage	0.226	-0.019	0.365**	0.398**	-0.112	-0.224	-						
T2 Disengage	0.149	-0.151	0.347*	0.348**	-0.116	-0.055	0.626**	-					
T1 PHQ-9	0.186	0.063	0.413**	0.396**	-0.047	-0.101	0.701**	0.516**	-				
T2 PHQ-9	0.132	0.011	0.456**	0.446**	-0.058	-0.054	0.578**	0.741**	0.722**	-			
T1 GAD-D	0.027	0.016	0.346**	0.290*	0.159	0.094	0.602**	0.313**	0.773**	0.560**	-		
T2 GAD-D	0.025	-0.070	0.480**	0.458**	0.008	0.016	0.629**	0.673**	0.617**	0.776**	0.672**	-	
T1 WEMWBS	-0.340**	0.010	-0.572**	-0.552**	0.296**	0.410**	-0.529**	-0.389**	-0.616**	-0.508**	-0.499**	-0.455**	-
T2 WEMWBS	-0.197	0.040	-0.581**	-0.533**	0.218	0.350**	-0.541**	-0.722**	-0.535**	-0.804**	-0.392**	-0.684**	0.673**

Pearson's correlational analyses for demographics and variables at T1 and T2

2000 bootstrapped resamples; 95% BCA confidence intervals that do not cross zero are in **bold** (*p*-value significance are also identified; *p < .05, **p < .01)

AQ-Short: Autism Spectrum Quotient-Short; *Engage*: Engagement coping; *Disengage*: Disengagement coping; *PHQ-9*: Patient Health Questionnaire-9; *DSM-5 GAD-D*: DSM-5 Generalised Anxiety Disorder Dimensional Scale; *WEMWBS*: Warwick-Edinburgh Mental Well-being Scale

engagement coping strategies over time predicted improved mental well-being 2-years later. Further, examination of a coping ratio demonstrated that higher use of engagement coping *relative to* disengagement coping strategies, and an increase in this ratio over time, predicted overall improved mental health outcomes 2-years later.

Significant relationships between higher baseline disengagement coping, increased depressive and anxiety symptoms and decreased mental well-being 2-years later suggest that disengagement coping may be a risk factor for poor mental health in autistic adults. This is consistent with longitudinal findings in the general population (Nielsen & Knardhal, 2014; Taft et al., 2007; Thompson et al., 2018), and extends cross-sectional findings in autistic adults to date (Muniandy et al., 2022a). The lack of significant relationship between baseline engagement coping and improved well-being at follow-up was unexpected. However, engagement coping is most effective in response to malleable, controllable stressors (Carver & Connor-Smith, 2010) and as the measurement of coping strategies was not stressor- or situation-specific in the current study, it is possible that our sample was more frequently faced with uncontrollable stressors. Further, the impact of engagement coping strategies may have diminished over time (Nielsen & Knardhal, 2014) and thus may not have been not adequately captured in our 2-year time-lag snapshot.

Our findings also indicated that both higher baseline and increase in disengagement coping over time predict increased depression and anxiety, and lower well-being at follow-up, even after baseline mental health outcomes are controlled for. This suggests that regardless of current mental health, individuals who frequently use disengagement coping or are on a trajectory of increasing use of these strategies, or both, are at a heightened risk of future poor mental health and well-being. Further, increased use of engagement coping over time (but not baseline levels) predicted better mental well-being at follow-up. This suggests that rather than the absolute level of prior or current engagement coping use, it is the increase in their use over time, or newly acquired engagement coping strategies, that may assist in promoting the future mental well-being of autistic adults. These findings are concordant with studies in the general population which have specifically demonstrated the predictive role of changes in coping strategy use over time (Booker et al., 2020; Gutner et al., 2006; Kim et al., 2003), highlighting that coping trajectories in addition to baseline coping, are important predictors for mental health and other stress-related outcomes.

While our results are inconsistent with those of Rieffe et al. (2014), who found that increases in both approach and avoidance coping over time predicted reduced depressive symptoms at follow-up in autistic youth, there are many

Table 3 Linear regression models predicting T2 mental health outcomes

	T2 Depression (PHQ-9)			T2 Anxiety (GAD-D)			T2 Well-being (WEMWBS)		
	β	BCa 95% CI	R² (ΔR²)	β	BCa 95% CI	R² (ΔR²)	β	BCa 95% CI	R² (ΔR²)
Step 1			0.187			0.283			0.303
Age	−0.113	−0.194, 0.082		−0.307	**−0.282, −0.055**		0.136	−0.101, 0.297	
Gender	−0.014	-3.602, 2.705		−0.122	-5.222, 0.858		0.085	-2.519, 6.263	
T1 AQ-Short	0.466	**0.154, 0.442**		0.580	**0.241, 0.551**		−0.596	**−0.718. −0.325**	
Step 2			0.572 (0.385**)			0.567 (0.284**)			0.543 (0.240**)
Age	−0.084	−0.140, 0.052		−0.182	**−0.199, −0.010**		0.164	−0.027, 0.279	
Gender	−0.059	-3.355, 1.234		−0.180	**-5.750, −0.457**		0.048	-2.598, 4.772	
T1 AQ-Short	0.201	**0.014, 0.233**		0.346	**0.105, 0.355**		−0.299	**−0.438, −0.086**	
T1 MH	0.674	**0.559, 0.925**		0.580	**0.428, 0.751**		0.579	**0.400, 0.823**	
Step 3			0.579 (0.007)			0.629 (0.061**)			0.585 (0.042*)
Age	−0.089	−0.143, 0.046		−0.241	**−0.225, −0.048**		0.165	−0.027, 0.291	
Gender	-0.48	-3.358, 1.594		−0.135	-5.038, 0.341		0.042	-2.566, 4.521	
T1 AQ-Short	0.191	**0.003, 0.229**		0.326	**0.097, 0.333**		−0.287	**−0.434, −0.075**	
T1 MH	0.596	**0.362, 0.947**		0.364	**0.116, 0.612**		0.437	**0.211, 0.746**	
T1 Engage	−0.013	−0.250, 0.219		0.044	−0.182, 0.321		0.038	−0.267, 0.403	
T1 Disengage	0.116	−0.339, 0.818		0.339	**0.287, 1.307**		−0.245	-1.409, 0.053	
Step 4			0.743 (0.164**)			0.728 (0.099**)			0.774 (0.188**)
Age	−0.055	−0.100, 0.042		−0.201	**−0.183, −0.041**		0.111	−0.026, 0.189	
Gender	0.043	-1.261, 2.624		−0.097	-4.098, 0.648		−0.063	-3.759, 0.952	
T1 AQ-Short	0.114	−0.022, 0.158		0.244	**0.059, 0.263**		−0.181	**−0.285, −0.051**	
T1 MH	0.523	**0.316, 0.848**		0.403	**0.186, 0.641**		0.389	**0.253, 0.606**	
T1 Engage	0.007	−0.204, 0.222		0.060	−0.155, 0.336		0.092	−0.132, 0.478	
T1 Disengage	0.396	**0.428, 1.305**		0.507	**0.732, 1.582**		−0.492	**-2.009, −0.914**	
Δ Engage	−0.022	−0.292, 0.184		−0.007	−0.280, 0.319		0.189	**.077, 0.809**	
Δ Disengage	0.475	**0.906, 1.535**		0.369	**0.566, 1.393**		−0.509	**-2.453, -1.146**	

Note. *T1*: Baseline; *T2*: Follow-up; *AQ-Short*: Autism Spectrum Quotient-Short; *MH*: Respective mental health outcome (i.e., T1 Depression, T1 Anxiety or T1 Well-being), *Engage*: Engagement coping; *Disengage*: Disengagement coping; Δ *Engage*: Change in engagement coping over time; Δ *Disengage*: Change in disengagement coping over time

2000 bootstrapped resamples; 95% BCA confidence intervals that do not cross zero are in **bold**;

*$p < .05$, **$p < .01$

Table 4 Final linear regression models for T2 mental health outcomes with coping ratio as a predictor

	T2 Depression (PHQ-9)			T2 Anxiety (GAD-D)			T2 Well-being (WEMWBS)		
	β	BCa 95% CI	R²	β	BCa 95% CI	R²	β	BCa 95% CI	R²
			0.644			0.632			0.667
Age	−0.098	−0.133, 0.027		−0.189	**−0.191, −0.020**		0.140	−0.044, 0.264	
Gender	0.004	-2.062, 2.150		−0.139	**−0.4884, −0.049**		−0.006	-3.031, 3.111	
T1 AQ-Short	0.144	−0.009, 0.189		0.269	**0.053, 0.314**		−0.264	**−0.371, −0.112**	
T1 MH	0.632	**0.501, 0.868**		0.561	**0.381, 0.757**		0.391	**0.213, 0.633**	
T1 Coping ratio	−0.160	-2.250, 0.127		−0.226	**-3.081, -0.026**		0.341	**1.327, 4.903**	
Δ Coping ratio	−0.279	**-3.478, -1.267**		−0.227	**-3.648, −0.716**		0.330	**2.504, 5.339**	

Note. Coping ratio: total engagement coping/ disengagement coping scores

2000 bootstrapped resamples; 95% BCA confidence intervals that do not cross zero are in **bold**

methodological differences between the two studies which may account for these differences, including sample characteristics (autistic adults vs. a collapsed sample of autistic and non-autistic youth), study design and duration (two time-points vs. three; 2-years vs. 18-months), coping context (in response to past stressful events vs. 'if something bad happened'), and the inclusion of non-coping variables (i.e., worry and rumination). Further, as only the present study controlled for the influence of baseline mental health, it is not known the extent to which prior depressive symptoms might have accounted for or influenced follow-up depressive symptoms in the Rieffe et al. (2014) study.

The significance of coping ratio (engagement coping/disengagement coping) as a predictor of mental health highlights that individuals tend to utilise a repertoire of coping strategies to varying degrees, and that these strategies may interact. We found that higher coping ratio (i.e., higher use of engagement relative to disengagement coping) and an increase in this coping ratio over time (i.e., increasing engagement coping, reducing disengagement coping, or both) significantly predicted better mental health outcomes 2-years later. It is possible that engagement coping plays a protective role by buffering some of the negative effects of disengagement coping on mental health. Alternatively, the positive effects of engagement coping on mental health may to an extent be overridden or suppressed in individuals who utilise high levels of disengagement coping strategies. These findings mirror the emotion regulation literature which suggests that adaptive strategies (reappraisal) may buffer the effects of maladaptive strategies (suppression), and that strategies used in conjunction with each other may act jointly on the mental health and well-being of autistic adults (Cai et al., 2018). It would be useful for future research to capture the ways in which coping strategy usage might co-occur in autistic individuals, and how these may relate to stress-related outcomes.

Other noteworthy findings include the significance of higher autistic traits as a predictor for higher anxiety and lower well-being, supporting the positive associations between autistic traits and psychopathological symptoms previously reported in autism (e.g., Garcia-Villamisar & Rojahn, 2015; Lever & Geurts, 2016). Lower age as a predictor for higher anxiety in the current sample, was consistent with some autistic adult studies (Lever & Geurts, 2016), but not others (Uljarević et al., 2020), and this may be due to the different age groupings across the studies. Finally, male gender as a predictor for higher anxiety (only in the coping ratio model) was unexpected, and in contrast to the literature on increased propensity for anxiety in female autistic adults (Lever & Geurts, 2016; White et al., 2009). However, this gender effect was not stable across the other regression models, with only minimal differences in mean DSM-5 GAD-D scores between males and females in the current sample (male: 13.44; female: 12.60). Future work examining potential differential patterns in coping ratios in male and female autistic adults, and their relationships with mental health would be insightful in teasing out these coping mechanisms further.

Overall, our findings demonstrate that considering various aspects of coping strategy use (i.e., snapshots, trajectories and ratios) is useful in providing a more comprehensive understanding of the impact of coping on mental health outcomes in autistic adults. Establishing coping profiles based on patterns of coping strategy use can help identify autistic adults who may be at risk for developing poor mental health in the future; similar profiles have been used to examine risk for high stress in autistic adults (Muniandy et al., 2022b). Further, the predictive role of coping trajectories reflects a degree of malleability in coping strategy use over time. This suggests that individual use of coping strategies is amenable to change and thus can be responsive to coping interventions. Indeed, interventions with an emphasis on patterns of coping strategy usage are increasingly recommended (Garcia, 2010), where aims to reduced maladaptive, disengagement coping strategies and promote adaptive, engagement coping strategies have been shown to be efficacious in various populations to date (Craig et al., 2018; Steinhardt & Dolbier, 2008). A joint focus of decreasing or limiting the use of disengagement coping whilst building on the repertoire and effectiveness of engagement coping strategies may be effective in treating anxiety and depressive symptoms, and may improve well-being in autistic adults.

Despite our novel findings, there are some limitations to this study. The relatively small sample size may have resulted in our analyses only being sufficiently powered (power = 0.80) to detect a large effect size ($f^2 = 0.35$), warranting replication using a larger sample. While there were more female participants (male: female ratio of 1:1.3) compared to the gender ratios reported in the autistic adult population (i.e., 1.8–2.6:1; Posserud et al., 2021; Rutherford et al., 2016), this female overrepresentation or 'reversed sex ratio' is commonly observed in survey-based autism studies (Rodgaard et al., 2022). Although gender was controlled for in the regression models, it would be beneficial to examine these longitudinal associations within male and female samples, in order to identify any possible gender differences. Coping strategies were limited to engagement and disengagement coping as informed by the broader coping literature. Other coping strategies (e.g., support-seeking or religious coping) should be examined as potential predictors of mental health outcomes in autistic individuals. Finally, while the current study employed a broader, exploratory approach, it would be important for future studies to capture information such as individual treatments (e.g.,

type, duration, medication) and exposure to stressors (e.g., occurrence of major life events, daily hassles) to establish whether coping-mental health associations in autistic adults may differ as a function of these factors.

This is the first study to have examined longitudinal associations between coping strategy use and mental health outcomes in a sample of autistic adults across a large age range, contributing to the limited coping literature in autism to date. These results indicate that coping strategies used in response to stressors remain important predictors of mental health and well-being in autistic adults, regardless of prior mental health. In line with the growing calls for interventions to address coping skills and stress management more generally in the autistic population (Bishop-Fitzpatrick et al., 2015; Hirvikoski & Blomqvist, 2015), coping strategies represent an important potential intervention target for enhancing the mental health trajectories of autistic adults.

Declarations

Conflict of Interest The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

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Chapter 9: Stress and Well-being in Autistic Adults: Exploring the Moderating Role of Coping

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Stress and Well-being in Autistic Adults: Exploring the Moderating Role of Coping

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Abstract

The wider stress literature points to negative associations between stress and well-being. Similarly, the use of engagement coping strategies and disengagement coping strategies in the face of stress are related to improved and reduced well-being respectively. However, in the autism population stress and coping research is limited to date, and the extent to which coping may moderate the relationship between stress and well-being is not known. Using data from an Australian online study, we explored the potential moderating (i.e., buffering or exacerbating) role of coping in the relationship between stress and well-being in a sample of autistic adults ($N = 86$). Our findings indicated that increased stress was associated with lower well-being. Further, moderation analyses showed that while both engagement coping (e.g., problem solving, positive appraisal) and disengagement coping (e.g., self-distraction, being in denial) strategies had significant positive and negative direct effects on well-being respectively; engagement coping also had an indirect, buffering effect on well-being through its interaction with stress. Our results illustrate the different underlying mechanisms by which coping strategies may associate with stress and well-being. They also highlight the potential protective role of engagement coping strategies, which can be incorporated in the promotion and maintenance of well-being in autistic adults.

Keywords Autism · Coping · Stress · Well-being · Adults

Stress and Well-being in Autistic Adults: Exploring the Moderating Role of Coping

Autism Spectrum Disorder (ASD) refers to a complex neurodevelopmental condition typically characterised by pervasive impairments in social communication and restricted, repetitive and stereotyped patterns of behaviour (American Psychiatric Association, 2022). There is strong consensus concerning the high rate of poor mental health in the autistic adult population (Hollocks et al., 2019; Joshi et al., 2013). Indeed, the prevalence of co-occurring mental health conditions, particularly anxiety and mood disorders, is significantly higher in autistic adults compared to that in the general population (Lai et al., 2019), with lifetime rates of psychiatric conditions reported to range between 37% and 79% in autistic adults (Croen et al., 2015; Hollocks et al., 2019; Lever & Geurts, 2016).

In autism, a deficit-model approach has been predominantly employed in the examination of outcomes such as mental health, where the presence or absence of psychopathology or mental ill health is considered indicative of negative and positive states of mental health respectively. However, individuals with co-occurring psychopathology are more than the sum of their symptoms (Duckworth et al., 2005) and a unidimensional, deficit approach fails to capture positive experiences and functioning. Encouragingly, recent studies are increasingly exploring the complementary, positive facets of mental health such as psychological well-being (hereafter referred to as well-being). Well-being as a construct takes account of subjective interpretations of an individual's emotional, cognitive and psychological functioning (Keyes et al., 2002), encompassing positive aspects of life such as happiness, positive affect, fulfilling relationships and life satisfaction (Dodge et al., 2012; Tennant et al., 2007).

Outside of the autism literature, an array of advantages across multiple life domains including health behaviours and outcomes (Blanchflower et al., 2013; Kim et

al., 2014), social relationships (Oishi et al., 2009) and work performance (Tenney et al., 2016) have been associated with well-being. Further, well-being has been said to play a potential protective role against the effects of negative mental health such as depression in both autistic and non-autistic samples (Hedley et al., 2018; Layous et al., 2011; Teismann et al., 2018; Wilhelm et al., 2010). Considering the suboptimal levels of well-being increasingly reported in autistic adults (e.g., Lawson et al., 2020), examining potential factors that may influence well-being in autistic individuals is vital.

Exposures to, and experiences of stress have been frequently linked with detrimental outcomes in mental health and well-being within the wider literature (e.g., Buser & Kearney, 2017; Gillett & Crisp, 2017; Seiffge-Krenke, 2019). Although the occurrence of stressors (i.e., internal or environmental conditions) can exert strain on resources (Halbesleben et al., 2014; Hobfoll, 1989), it is the subsequent appraisal of the stressor's significance and demands, in light of available resources, that determines the extent to which psychological stress is experienced (Epel et al., 2018; Lazarus & Folkman, 1984). Stress can arise from a range of circumstances and therefore can be measured across multiple domains, from the stress over minor events that characterise everyday life (i.e., daily hassles) to the overall sense of stressfulness in life (i.e., general perceived stress).

Although general and domain-specific stress are linked and likely to co-occur, these measures are also said to assess different facets of the stress experience (e.g., Luo et al., 2021; Stawski et al., 2008; van Eck et al., 1998). Indeed, individuals with high general perceived stress may still have varied stress reactivity and responses across different contexts and life domains (Morgan et al., 2014). It is reasonable to assume that high general perceived stress, in addition to high domain-specific stress, may place individuals at an increased susceptibility to the detrimental mental health consequences

of stress. Aggregating information across both general and domain-specific stress may therefore be useful in forming a more multi-dimensional representation of stress by considering both general perceived stress and the potentially cumulative nature of stressful experiences represented by daily hassles together.

Stress in autistic adults

Compared to the general population, autistic adults are more vulnerable to encountering daily hassles, both stressful and adverse life events (Bishop-Fitzpatrick et al., 2017; Griffiths et al., 2019; Moseley et al., 2021; Twachtman-Cullen et al., 2006), and experience higher levels of perceived stress (Bishop-Fitzpatrick et al., 2017; Hong et al., 2016). Further, higher levels of autistic traits have been associated with increased perceived stress in both autistic and non-autistic samples (Amos et al., 2019; Hirvikoski & Blomqvist, 2015). Heightened stress in the autistic population is also evidenced by research on 'autistic burnout', characterised by experiences of chronic exhaustion due to the accumulation and build-up of life stressors which exceed coping abilities (Mantzalas et al., 2021; Raymaker et al., 2020). High stress has been associated with increased emotional and behavioural difficulties in autistic youth (Khor et al., 2014), anxiety and depression (Evers et al., 2022), increased psychological distress and poorer physical health (Moseley et al., 2021), reduced social functioning (Bishop-Fitzpatrick et al., 2015) and poorer quality of life (Bishop-Fitzpatrick et al., 2017; Hong et al., 2016) in autistic adults. More frequent occurrences of stigma-related stressors were also associated with lower well-being and psychological distress in autistic adults (Botha & Frost, 2020). However, to our knowledge, the ways in which levels of perceived stress, rather than the occurrence of stressors, might relate to psychological well-being in autistic adults has not yet been examined.

To understand the mechanisms in the relationship between stress and well-being in autistic adults, it is also worth examining individual resources that may play an interactive (i.e., moderating) role on the stress and well-being relationship. One such resource that can moderate the relationship between stress and its outcomes is coping (Campbell-Sills et al., 2006). Coping refers to the ways in which cognitive and behavioural coping strategies are utilised in response to stressful encounters (Carver et al., 1989). While coping strategy use can be classified in a myriad of ways (Skinner et al., 2003), the distinction between engagement and disengagement coping strategies is one that is commonly made (e.g., Compas et al., 2001; Connor-Smith et al., 2000). Engagement coping refers to active strategies that aim to resolve the stressor and/or regulate feelings of stress (e.g., problem solving, positive reappraisals) while disengagement coping strategies aim to avoid these (e.g., behavioural disengagement, denial). Across autistic and non-autistic adult samples, increased use of engagement coping strategies has been linked to reduced anxiety and depressive symptoms, as well as improved well-being, positive affect and life satisfaction, whereas disengagement coping has been often related to increased poor mental health, negative affect, distress and reduced well-being (Compas et al., 2017; Evers et al., 2022; MacCann et al., 2012; Milas et al., 2021; Muniandy et al., 2022a, 2023; Schäfer et al., 2017).

Given these associations between coping and mental health outcomes, it is plausible that the relationship between stress and its consequential strain is influenced by coping strategy use. Indeed, there is evidence supporting the moderating role of numerous forms of coping (e.g., engagement coping, avoidance or disengagement coping, social support coping and religious coping) in associations between stress and indicators of mental health (e.g., anxiety, depression), life satisfaction and quality of life (Ahles et al., 2016; Connor-Smith & Compas, 2002; Dardas & Ahmad, 2015; Greer,

2011; Suldo et al., 2008). To date, only one study has examined the moderating role of coping strategies in the stress-mental health relationship in the autistic adult population. In samples of autistic (n = 149) and non-autistic (n = 147) adults, Evers et al. (2022) examined the role of broadly defined adaptive (e.g., planning, positive reframing, seeking social support and religion) and maladaptive (e.g., behavioural disengagement, self-blame, substance use and self-distraction) coping strategies in the context of stress and symptoms of anxiety and depression. They found that adaptive coping strategies did not moderate the relationship between perceived stress and symptoms of anxiety and depression for either sample, while maladaptive coping strategies moderated the stress-depression relationship for the non-autistic group only (Evers et al., 2022).

As far as we know, no study has examined the moderating role of coping in the relationship between stress and psychological well-being in autistic adults. Establishing whether coping strategy use may buffer or exacerbate the relationship between stress and well-being in autistic adults is crucial not only in understanding the aetiology of psychological well-being in autistic adults, but also in informing support and intervention options to develop resilience in the face of stress (e.g., Troy & Mauss, 2011).

The present study

The aims of the present study were two-fold: (1) to examine the associations between stress and well-being, and (2) to explore the potential moderating role of coping strategies (i.e., engagement and disengagement coping) on the relationship between stress and well-being in a sample of autistic adults. To capture stress in a multi-dimensional way, a composite stress score was created (i.e., an aggregate of perceived stress related to general and daily life). It was hypothesised that increased stress would relate to lower levels of well-being in our sample of autistic adults. Further, coping

strategies were expected to play a moderating role, with engagement and disengagement coping buffering and exacerbating the effects of stress on well-being respectively.

Methods

The present study was conducted during the second wave of the ongoing coronavirus (COVID-19) pandemic in Australia between June and November 2020. While it was not within the aims of the study to examine the health impact of the pandemic, information on the fear of COVID-19 and stress associated with COVID-19 disruptions in major life domains was captured. This is detailed below and further discussed later to provide additional context to the overall stress experienced by our sample of autistic adults during this time.

Participants

Participants were recruited through an online study where the inclusion criteria were that they resided in Australia, were aged 18 years or older, and self-reported a clinical diagnosis of ASD (including details such as specific diagnosis, year of diagnosis and the type of diagnosing health professional) without a co-occurring intellectual disability. To support diagnosis, the cut-off score on the Autism-Spectrum Quotient Short (AQ-Short) was used, where only participants scoring 65 and above were included in the sample. The final sample consisted of 86 autistic adults (66% female; $M_{age} = 40.76$, $SD_{age} = 13.47$) aged 19- 74 years. One participant reported having had a COVID-19 diagnosis.

Procedures

After ethics approval by the La Trobe University Human Ethics Committee (#HEC19443), a wide range of recruitment channels was utilised to recruit formally diagnosed autistic adults living in Australia. These included national and state-based autism specific organisations, autistic peer support groups, online autism communities,

and participant databases from autism research organisations. Following an expression of interest, potential participants were given more information on the study, and once agreeable, an online link to the survey on REDCap (Research Electronic Data Capture; Harris et al., 2009) was provided. This link included an eligibility page and consent forms, where once consent was indicated, participants were automatically directed to the beginning of the survey.

Measures

Autism traits

The Autism Quotient-Short (AQ-Short; Hoekstra et al., 2011) is a 28-item questionnaire designed to measure levels of autism traits. Scored on a 4-point Likert scale from *definitely agree* (1) to *definitely disagree* (4), higher scores suggest higher autism traits. Items are summed to generate a total score, where a score of 65 and above has high sensitivity and specificity (0.97 and 0.82 respectively) with a clinical diagnosis of ASD (Hoekstra et al., 2011). Good internal consistency was also noted for the sample in the present study (α: 0.81).

COVID Fear

The 8-item Fear of Coronavirus Questionnaire (FCQ; Mertens et al., 2020) was used to examine components of fear (e.g., worry, avoidant behaviour, attentional biases) in relation to the COVID-19 pandemic. Items are rated on a 5-point Likert scale, from (1) *Strongly disagree* to (5) *Strongly agree,* where a higher total score suggests a higher fear of COVID-19. The FSQ has been reported to have good internal consistency in adult samples to date (α: 0.77 – 0.80; Mertens et al., 2020; Vos et al., 2021), including in the current sample (0.79).

COVID Stress

Due to the uneven spread of COVID-19 infections and exposures across Australian states and territories, the authors developed questions to measures stress over pandemic-associated disruptions in major life domains rather than examine stress related to contracting COVID-19. To measure stress over changes in employment, education, living situation and social relationships, a yes/no item "Since the COVID-19 pandemic, have you experienced changes in your_____?" was used. Those who indicated 'yes' were asked to rate the stress due to this change from (1) *Not stressful at all*, to (5) *Extremely stressful*. Those who indicated no change in any domain were assigned a score of 0 for that domain. A total COVID disruption stress score was calculated using the sum of stress reported over the four domains (range: 0- 20). The COVID stress score had good internal consistently in the current sample (α: 0.86) and has been previously used in Muniandy et al. (2022b).

Daily Hassles Stress

The Daily Stress Inventory (DSI; Brantley et al., 1987) contains 58 items, where respondents indicate the occurrence of daily events and rate the perceived stress for each event on a 7-point Likert scale ranging from *Occurred but was not stressful* (1) to *Caused me to panic* (7). The average stress over daily hassles can be determined by dividing the sum of stress scores by the number of events that occurred (Brantley et al., 1987). Excellent internal reliabilities for the DSI (i.e., sum of stress scores and frequency of events occurred; α values: 0.92 and 0.91 respectively) were noted in the current sample.

General Perceived Stress

The Perceived Stress Scale (PSS-10; Cohen & Williamson, 1988) is designed to measure the degree to which individuals appraise demands in their lives as stressful. Frequency of

stressful thoughts and feelings in the last month are rated on a 5-point Likert scale

ranging from *never* (1) to *very often* (5). Excellent internal reliability for the PSS has

been reported in non-autistic (α: 0.90; Mitchell et al., 2008; Wu & Amtmann, 2013) and

autistic adults (α: 0.82; Evers et al., 2022), including the current sample (α: 0.90).

Coping Strategies

The Brief COPE (Carver, 1997) is a 28-item measure to assess frequency of coping

strategy use on a 4-point Likert scale ranging from (1) *I haven't been doing this at all* to

(4) *I have been doing this a lot*. The six-factor structure for the Brief COPE for autistic

adults (Muniandy et al., 2021a) was used in the present study; two of the coping factors

were examined: the 8-item engagement coping (e.g., "I've been taking action to try to

make the situation better") and 5-item disengagement coping (e.g. "I've been giving up

the attempt to cope") subscales. These subscales were selected based on their strong

associations with stress and well-being in the wider coping literature, and showed good

internal consistencies in the current sample (α values: 0.77 and 0.76 respectively).

Psychological well-being

The Warwick-Edinburgh Mental Well-being Scale (WEMWBS; Tennant et al., 2007)

contains 14 items to assess aspects of positive mental well-being over the last two weeks.

Items are rated on a 5-point Likert scale ranging from *none of the time* (1) to *all of the*

time (5), where a total score is generated using the sum of scale items. The WEMWBS

has been previously used in autistic samples, with high internal consistency noted (α

values: 0.85 - 0.92; Hedley et al., 2019), including the current sample (α: 0.88).

Data Analysis

To examine variable distributions, tests of normality using the Kolmogorov-

Smirnov statistic were conducted; COVID-stress and disengagement coping scores were

positively skewed, while COVID-fear scores were negatively skewed. To account for

distributional non-normality, the subsequent Pearson r correlation analysis to examine

the associations between study variables was bootstrapped with 2,000 resamples.

To allow for moderator effects to be best detected, relationships between the

predictor (i.e., stress, coping) and outcome variables (i.e., well-being) should be

significant (Frazier et al., 2004). Neither COVID stress nor COVID fear were associated

with well-being (see Table 1), thus were not included in the composite stress score or the

moderation models. To obtain a more multi-faceted indicator of stress, a composite stress

score was created comprising stress measures significantly associated with well-being.

Given the significant relationship between general perceived stress (PSS) and daily

hassles (DSI) stress with well-being (WEMWBS), both stress scores were standardised

to z-scores and subsequently summed, where each domain was weighted equally in its

contribution to the composite stress score. Data screening showed no evidence of

multicollinearity based on the variance inflation factor (VIF <10) and tolerance statistic

(1/VIF> 0.1) values. There were no univariate outliers based on casewise diagnostics

(criterion of $\pm$ 3.29; Tabachnick & Fidell, 2013), while three multivariate outliers were

identified using a combination of Mahalanobis distance, Cook's distance and leverage

values. However, as removing these participants from the analyses did not significantly

change the total amount of variance explained, they were retained.

To ascertain whether coping strategies interacted with stress in the prediction of

well-being, moderation analyses were performed using the PROCESS macro v3.5.3 for

SPSS (Hayes, 2018). The potential moderating roles of engagement coping and

disengagement coping were examined in two separate models, with stress and coping as

the independent variables and well-being as the dependent variable. As age, sex and

autistic traits were not significantly associated with well-being (Table 1) they were not

included as co-variates. Power analysis using G*Power3 (Faul et al., 2007) indicated that

for a small effect size ($d = 0.20$), alpha value of 0.05, power of 0.90 and three predictors in each model (i.e., stress, coping strategy, stress x coping strategy), a minimum sample size of 75 participants was required. All data analyses were run using The Statistical Package for the Social Sciences (SPSS) version 25 (IBM Corp. 2017).

Results

Descriptive and correlation analyses

Descriptive statistics and correlations can be seen in Table 1. General perceived stress (PSS) was relatively high in the current sample, with most total PSS scores categorised as moderate (48.8%) or high (40.7%). Both general perceived stress and daily stress were negatively related to well-being and positively related to disengagement coping. Although a large proportion of participants (86%) experienced changes and disruptions in at least one of the four life domains measured, COVID-stress was only moderately associated with general stress and was not significantly associated with any other variables. COVID-fear was not associated with any of the study variables.

Moderation analysis

The first moderation analysis explored the moderating role of engagement coping in the relationship between stress and well-being. The final model was significant, F (3, 74) = 22.11; $p < 0.001$, and explained 47.3% of the variance in total well-being. As depicted in Figure 1(a), both stress [b (*SE*) = -2.42 (0.415), 95% CI: -3.234 to -1.590, $t = -5.826, p < 0.001$] and engagement coping [b (*SE*) = 0.57 (0.182), 95% CI: 0.204 to 0.928, $t = 3.119, p = 0.003$] significantly predicted well-being. Further, the interaction between stress and engagement coping was also significant [b (*SE*) = 0.21(0.084), 95% CI: 0.038 to 0.374, $t = 2.439, p = 0.017$) with small effect size ($\Delta R^2 = 0.04$), suggesting that engagement coping moderates the relationship between stress and well-being.

Table 1

Study variables (M, SD, range) and Pearson's 2,000 bootstrapped re-samples correlations for sample (n = 78)

Variables	Range	M (SD)	1	2	3	4	5	6	7	8	9
1. Age	19-74	40.76 (13.47)	1								
2. Sex[a]	-	-	-.183								
3. Autism traits	67-112	87.96 (9.52)	.010	.043							
4. COVID-19 fear	15-38	26.80 (5.90)	.088	.028	-.005						
5. COVID-19 stress	0-20	5.56 (4.62)	-.191	.094	-.067	.160					
6. Daily hassles stress	2.5- 6.6	4.32 (0.91)	-.038	**.235***	**.252***	.169	.173				
7. General stress	6-39	24.80 (6.96)	-.111	.088	**.226***	.058	**.364****	**.617****			
8. Engagement coping	12-29	20.80 (4.11)	.141	.109	-.070	.059	-.036	-.194	-.186		
9. Disengagement coping	5-19	9.60 (3.47)	-.084	-.137	**.220**	.080	.141	**.348****	**.562****	**-.316****	
10. Well-being	0-37	18.40 (7.48)	-.121	.043	-.208	-.016	-.064	**-.465****	**-.581****	**.421****	**-.524****

Note. BCa 95% confidence intervals that do not cross zero are in **bold**; significance based on *p*-values (*) are also noted.

$^*p < 0.05$; $^{**}p < 0.01$; [a]Positive direction indicates female

Figure 1

Moderation models of stress on well-being by use of engagement coping strategies (a)
and disengagement coping strategies (b)

(a)

(b)
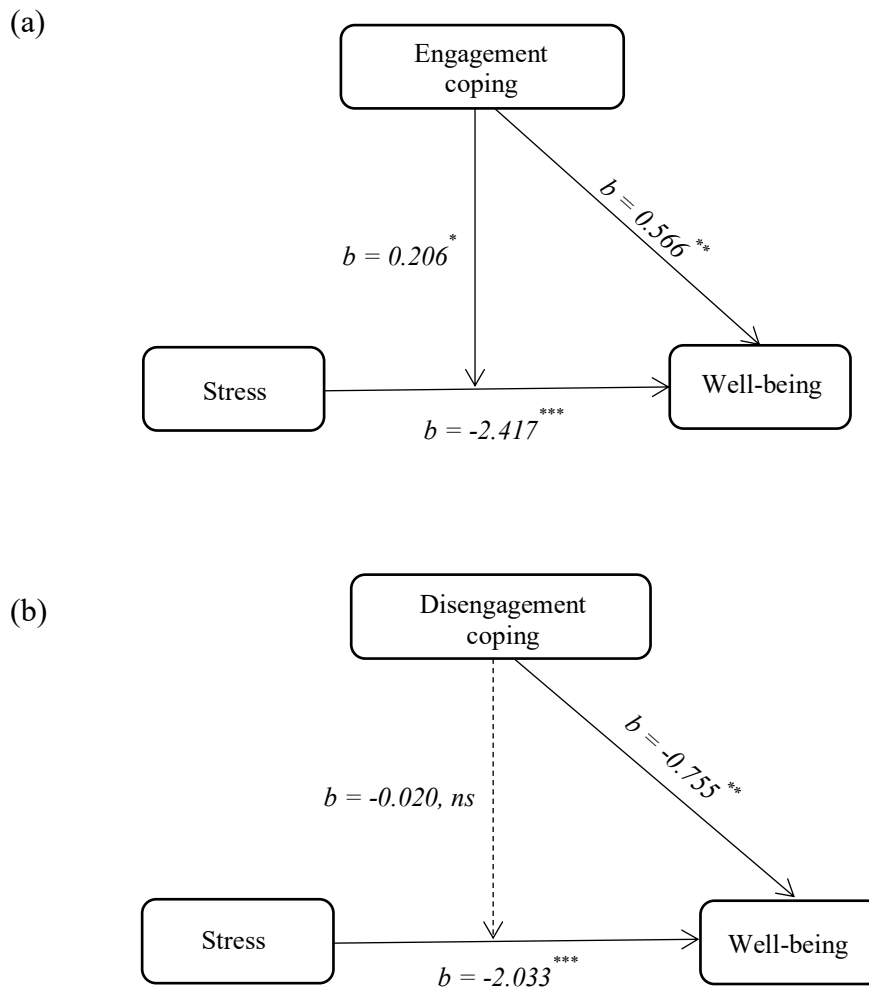
Note. *b* values correspond to the unstandardised regression coefficients *p* < .05; **p
<.01; ***p <.001; *ns*: not significant

The second moderation analysis explored the potential moderating role of

disengagement coping in the relationship between stress and well-being. The final model

was significant, $F (3, 74) = 17.09$; $p < 0.001$, and explained 40.9% of the variance in total

well-being. As seen in Figure 1(b), stress [b (*SE*) = -2.03 (0.496), 95% CI: -3.022 to -

1.044, $t = -4.095$, $p < 0.001$] and disengagement coping [b (*SE*) = -0.76 (0.276), 95% CI:

-1.306 to -0.205, $t = -2.732$, $p = 0.008$] significantly predicted well-being. However, the

Figure 2

Interaction of engagement coping (a) and disengagement coping (b) on the relationship between stress and well-being

(a)

(b)
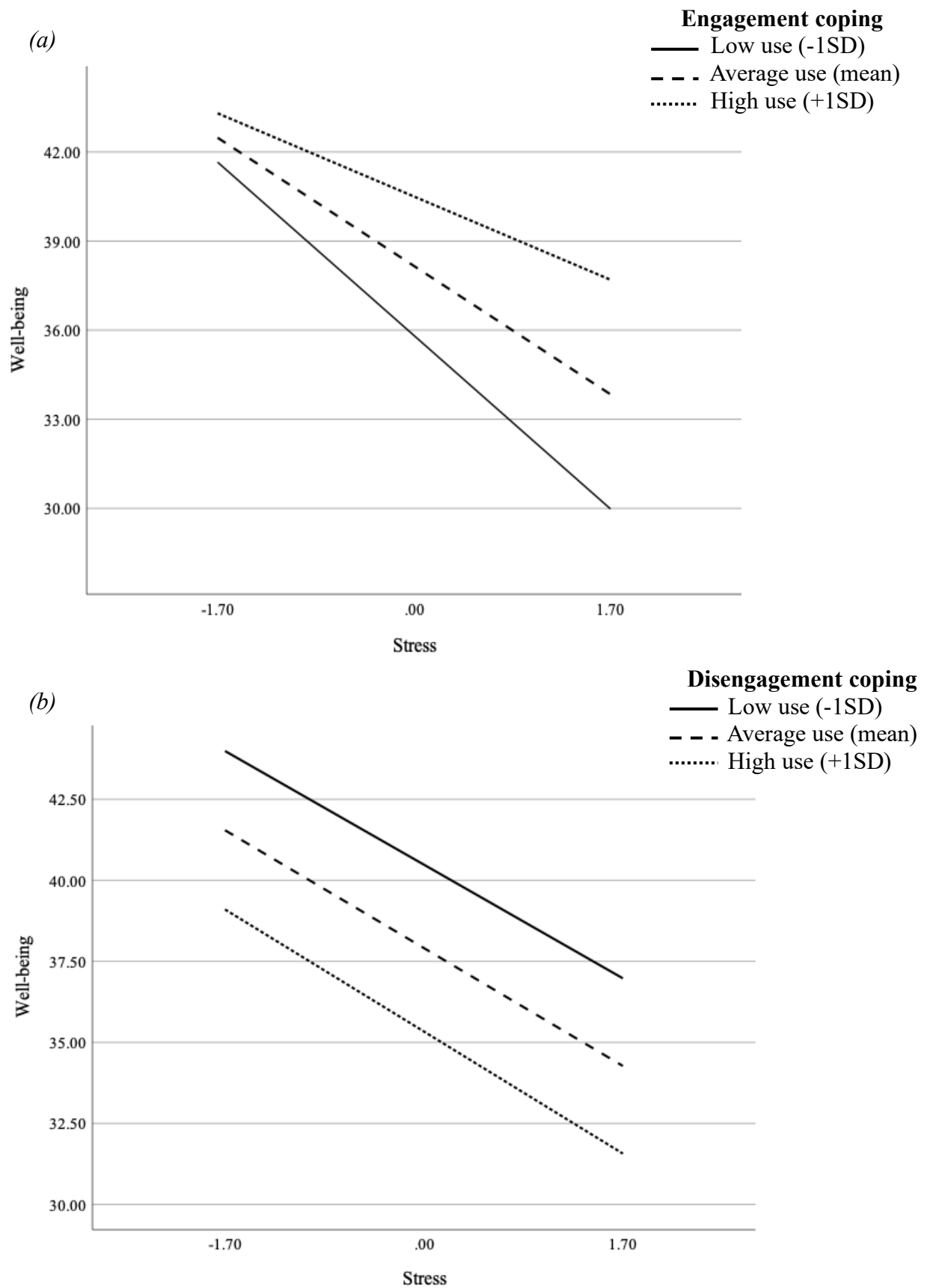
interaction between stress and disengagement coping was not significant [b (SE) = -0.02 (0.110), 95% CI: -2.392 to 0.200, t = -0.179, p = 0.859], suggesting that disengagement coping did not moderate the relationship between stress and well-being.

Graphical representations using simple slopes of the interactions between stress and each coping strategy (by using the ±1 standard deviation approach) are presented in Figure 2. As noted in both Figures 2(a) and 2(b), the effects of stress on well-being were consistently negative, regardless of coping strategy used. However, as seen in Figure 2(a) the effect of stress on well-being is larger (i.e., the slope is steeper) in individuals with low levels (-1SD from mean) of engagement coping compared to those with high levels (+1SD from mean) of engagement coping strategies. In contrast, visual inspection shows the non-moderating role of disengagement coping on well-being Figure 2(b). The effect of stress on well-being using low, average or high disengaging coping strategies appears unchanged, as depicted by the paralleled slope lines.

Discussion

The present study examined the associations between stress and psychological well-being in autistic adults and explored the potential moderating role of coping strategies that may underlie these associations. Our findings showed that stress was inversely associated with well-being in our sample of autistic adults. We also found that although both engagement and disengagement coping were independently associated with levels of well-being, only engagement coping was a significant moderator of the relationship between stress and well-being.

As hypothesised, and consistent with findings in the wider stress literature (e.g., Buser & Kearney, 2017; Gillett & Crisp, 2017; Slavich et al., 2019), increased stress was related to reduced well-being in the current sample of autistic adults. While stress has been related to poorer outcomes such as emotional or behavioural difficulties,

psychological distress, anxiety, depression and quality of life in autistic youth and adults to date (Bishop-Fitzpatrick et al., 2015, 2017; Evers et al., 2022; Khor et al., 2014), the present study extends these findings by examining its relationship with psychological well-being, an association which has not previously been examined in autistic individuals. Through the use of a composite stress score, we also attempted to capture some of the cumulative and multidimensional aspects of stress. Our findings indicate that stress is a risk factor for poor well-being in autistic adults, contributing to the dearth of well-being studies in this population to date.

As disruptions to routine and adapting to changes in the face of uncertainty can be challenging for autistic adults (Cassidy et al., 2020), and pandemic-related changes and disruptions have been found to predict increased psychological distress in autistic adults (Bal et al., 2021), it was noteworthy that neither stress associated with COVID-19 disruptions nor COVID fear were related to coping strategies or well-being. This may be related to the timing of the study, which coincided with the second wave of COVID-19 in Australia (June to October 2020). As the lockdowns and associated changes and disruptions, many of which were still present outside of lockdown periods, began during the first wave of COVID (March to May 2020), some disruptions may have stabilised and become a routine part of daily life. The stressful impact on well-being may have thus reduced by the time the second wave began. Nevertheless, the significant relationship between COVID-19 stress and general perceived stress (PSS), which reflects overall stressfulness in one's life, suggests that the PSS could also have captured some of the stress related to COVID-19 pandemic disruptions during this time.

Our hypothesis surrounding the moderating role of coping strategies in the relationship between stress and well-being was partially supported. As predicted, engagement coping significantly moderated the relationship between stress and well-

being, consistent with the stress-buffering role of engagement, approach-oriented coping

strategies noted in previous studies in non-autistic groups (e.g., Cheng et al., 2012; Suldo

et al., 2008; Yip et al., 2008). However, it was not consistent with Evers et al. (2022)

who found no moderation effect for adaptive coping on stress-mental health relationships

(anxiety and depression). This may be due to Evers et al. investigating the negative facets

of mental health, as engagement and approach-oriented coping strategies may be more

important when considering positive aspects of mental health (Muniandy et al., 2022a).

Other reasons for the lack of moderating role reported in Evers et al. could be related to

having defined 'adaptive coping' using the Brief COPE item-composition typically used

for non-autistic adult samples. In the present study, engagement coping was one of the

six factors from the Brief COPE validated for autistic adults (Muniandy et al., 2021a),

comprising active strategies that aim to ameliorate or reframe stressors (e.g., problem

solving, positive reappraisals) and manage emotional responses (e.g., acceptance).

In contrast, while the use of disengagement coping strategies was a significant

independent predictor of well-being, it did not play stress-exacerbating role in the stress

and well-being association as hypothesised. Significant direct effects of disengagement

coping on well-being suggest that although this form of coping remains a risk factor for

poor well-being, the degree to which this strategy is used (i.e., low or high use) does not

strengthen or weaken the relationship between stress and well-being as in the current

sample. The findings are also consistent with the recent report that maladaptive coping

strategies do not moderate stress-mental health relationships in autistic adults (Evers et

al., 2022). While some non-autistic coping literature also shows an absence of

moderating effects for coping strategies reflective of avoidance and disengagement on

stress-mental health relationships (e.g., Barnes & Lightsey Jr, 2005; Suldo et al., 2008),

others have reported a significant moderating role (e.g., Cheng et al., 2012; Evers et al.,

2022; Gillett & Crisp, 2017). A speculative explanation for the lack of a moderating role for disengagement coping in the current study could be the controllability of sources of stress. Despite the detrimental effects of disengagement coping strategies on psychological outcomes in the long term, temporary disengagement can be helpful in the context of stressors that are uncontrollable or non-amenable to change (e.g., Boxer et al., 2012; Carson & Polman, 2010). As the COVID-19 pandemic would constitute such an uncontrollable stressor, it is possible that disengaging, at least temporarily, would not exacerbate the effects of stress.

Our findings have several implications for the design of coping supports and mental health interventions for autistic adults. First, there may be benefit in focussing on and developing and honing the use of adaptive (i.e., engagement) coping strategies. Although coping skills are sometimes broadly addressed in mental health interventions in the autistic adult population (Oswald et al., 2018; White et al., 2017), we propose that the development of coping appraisals (such as distinguishing malleable and non-malleable aspects of stressors) and the use of coping strategies (i.e., increasing engagement coping, reducing disengagement coping strategies) may be important as both intervention targets and outcome measures. Relatedly, in laying the foundation for more adaptive coping appraisals and strategy use, it would be pertinent to also build coping resources such as improving self-esteem and resilience, which can interact with coping processes and foster the use of more engagement, approach-related coping (Leandro & Castillo, 2010; Muniandy et al., 2021b; Taylor & Stanton, 2007).

The stress-buffering role of engagement coping noted in the present study suggests that it is particularly beneficial in the context of high stress. Taking a multi-perspective approach aimed both at remedial and preventative action, it would be important to identify both autistic adults currently experiencing high stress, as well as

situations likely to elicit high levels of stress in this population. In addition to measures of stress, coping-resilience profiles can be helpful in identifying autistic individuals most at risk for experiencing high levels of stress (Muniandy et al., 2022b). While subject to individual differences, challenging periods in adulthood such as experiencing the 'services cliff' as autistic adolescents exit child and adolescent service systems, and transitions such as those into post-secondary education and employment (Howlin & Moss, 2012; Shattuck et al., 2011; Volkmar et al., 2017) are likely to invoke high levels of stress if left unmanaged. Importantly, tailored coping interventions adapted to suit the autistic population are recommended, including consultation with the autistic community.

While our results offer important information for better supporting the well-being of this population, there are also several limitations to our findings which should be considered. First, given the cross-sectional nature of the data, it is possible that the pattern of results could be explained via other causal relationships. For example, autistic adults who report higher well-being may simply, generally perceive life to be less stressful. Although our study and the interpretation of our findings were theory-driven and based on the stress-buffering models, future work utilising a longitudinal design could ascertain the causal directions of the reported associations. Second, our study sample is not representative of the autistic adult community more broadly given that it was limited to autistic adults without an intellectual disability with a larger proportion of female participants (66%) than typically found. Although sex was not significantly related to well-being, women did report more stress over daily hassles, thus, it would be informative for future research to explore potential sex discrepancies in the stress-moderating role of coping strategies. Third, while the current study took a general and broad approach in exploring the moderating roles of engagement and disengagement

coping, there are other coping strategies beyond these which may significantly interact in the stress-well-being relationship in autistic adults. Relatedly, although different sources of stress were considered, more in-depth details about the context in which stress occurred were not captured. Future work can extend our findings by exploring a wider range of coping strategies (or repertoire of strategies) across specific, high stress-invoking situations relevant to the autistic population.

In conclusion, this is the first study to assess the moderating role of two coping strategies, engagement and disengagement, in the relationship between stress and the positive facets of mental health, psychological well-being, in autistic adults. Given the scarcity of stress and well-being research in the autistic adults to date, our findings offer some novel insights into the potential for engagement and disengagement coping strategies to act as resilience and risk factors respectively in the promotion of positive well-being for autistic adults.

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Chapter 10: Inter-relationships between trait resilience, coping strategies, and mental health outcomes in autistic adults

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RESEARCH ARTICLE

Inter-relationships between trait resilience, coping strategies, and mental health outcomes in autistic adults

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Abstract

Resilience has been depicted as a key characteristic in the promotion of mental health in the face of stress and adversity. Despite high levels of stress encountered in the autistic population, resilience studies remain scarce. Using data from an Australian longitudinal adult study, this study explored the inter-relationships between trait resilience, coping, and mental health in a sample of autistic adults (N = 78). In particular, we examined the relationship between resilience and use of coping strategies, and the potential mediating role of coping strategies in the relationship between resilience and mental health outcomes. Our findings suggested that increased use of engagement coping (e.g., problem-solving, positive appraisal) and decreased use of disengagement coping (e.g., self-blame, being in denial) strategies were associated with higher levels of resilience. Further, mediation analysis results suggest that disengagement coping mediated the associations between resilience and all three mental health outcomes (i.e., depression, anxiety, and well-being), while engagement coping strategies mediated the relationship between resilience and well-being only. Our results illustrate that coping strategies may be an important mechanism in explaining the resilience-mental health relationship in autistic adults, highlighting the importance of considering stress-related constructs together (i.e., trait resilience and coping) when addressing support and intervention options for mental health difficulties in the autistic adult population.

Lay Summary

This research explored how resilience and coping strategies influence the mental health and well-being of autistic adults. We found that resilient autistic adults used more engagement coping strategies, less disengagement coping strategies, and reported better mental health and well-being. Considering stress-related factors together (i.e., resilience and coping) offers a novel perspective to mental health difficulties in autistic adults and may be a vital step in the development of support options in this population.

KEYWORDS
adults, autism, coping, mental health, resilience, stress

INTRODUCTION

There is increasing research to suggest that autistic individuals experience higher stress (e.g., more stressful encounters and life events, higher perceived and observed stress) compared to the general population (Baron et al., 2006; Bishop-Fitzpatrick et al., 2017; Gillott & Standen, 2007; Groden et al., 2001; Hirvikoski & Blomqvist, 2015). Traits typically associated with autism, such as social and communication difficulties, behavioral inflexibility, and sensory sensitivities, may make it particularly challenging for autistic individuals to navigate through their social environments, thus predisposing them to increased experiences of stress (Gillott &

Standen, 2007; Groden et al., 2006; Kerns et al., 2015; Meyer et al., 2006). Further, feelings of acceptance, or lack thereof, by external sources can make autistic individuals "socially vulnerable" (Fisher et al., 2013), significantly contributing to stress (Cage et al., 2018). While many autistic individuals may attempt to "camouflage" their autistic traits in order to blend in, the constant need to be self-aware and to monitor oneself that camouflaging involves, can be highly strenuous and detrimental to mental health (Bargiela et al., 2016; Cage et al., 2018; Hull et al., 2017). Conversely, co-occurring mental health conditions frequently reported in this population (e.g., social anxiety and possible fear of negative evaluations; Maddox & White, 2015), may also further promote camouflaging. These stressful exposures, in addition to an increased vulnerability to negative life experiences in autistic adults (e.g., unemployment, discrimination, victimization, financial exploitation, and hardship; Griffiths et al., 2019; Johnson & Joshi, 2016; Taylor et al., 2015) are likely to result in chronic or traumatic levels of stress (Kerns et al., 2015) as well as burnout over time (e.g., Raymaker et al., 2020).

To date, both perceived and parent-observed levels of stress have been associated with poor outcomes such as reduced social functioning and quality of life (QoL) in autistic adults with and without an intellectual disability (Bishop-Fitzpatrick et al., 2015, 2017, 2018; Hong et al., 2016). Findings across a range of non-autistic populations suggest that enduring forms of stress can have detrimental implications on mental health and well-being (de Frias & Whyne, 2015; Mark & Smith, 2012; Steinhardt et al., 2011; Thoits, 2010). Stress exposure that is chronic or perceived as uncontrollable can give rise to, or exacerbate symptoms of affective disorders (Hammen et al., 2004; Marin et al., 2011; McGonagle & Kessler, 1990). This may be particularly relevant when considering the high prevalence of co-occurring mental health conditions in autism. Indeed, Eaves and Ho (2008) found that 77% of their autistic adult sample reported an additional mental health diagnosis, including anxiety, depression, and bipolar disorder. Furthermore, with anxiety and mood disorders being the most common, lifetime rates for psychiatric conditions are reported to range between 37% and 79% in the autistic adult population (Croen et al., 2015; Hollocks et al., 2019; Lever & Geurts, 2016; Uljarević et al., 2019). Thus, in attempts to further understand the mechanisms that may underlie affective disorders in autistic adults, it may prove useful to examine constructs associated with the management of, and responses to stressful events, such as resilience and coping.

Resilience commonly refers to the ability to both "bounce back" (Masten, 2001; Rutter, 1987) and move forward in the face of adversity (Bonanno, 2004). In essence, individuals exposed to adversity or risk (i.e., circumstances that are typically associated with maladjustments in various life domains) tend to report poorer or less than ideal outcomes across multiple aspects of life. However, some individuals with similar exposures appear to report outcomes better than would be expected given their circumstances (Lemery-Chalfant, 2010; Luthar & Cicchetti, 2000; Masten, 2001). There are wide discrepancies in the conceptualization and operationalization of resilience in the literature, where resilience is commonly viewed as a trait, process or outcome (for a review, see Fletcher & Sarkar, 2013). 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 (e.g., Bonanno, 2004; Connor & Davidson, 2003; Skodol, 2010). These attributes are both innate and acquired, relatively stable, and yet can change over time or be influenced by environmental factors (Connor & Davidson, 2003; Hu et al., 2015; Joyce et al., 2018). Resilience as a process refers to the interaction between adversity, outcome, and protective/promotive factors, where the presence of resilience is inferred through reports of positive outcomes despite experiences of adversity (e.g., Fergus & Zimmerman, 2005). As an outcome, resilience is assessed based on an immediate outcome, such as the absence of symptoms or the presence of positive outcomes following adversity (e.g., Luthar & Zelazo, 2003). The present study approached resilience from a trait perspective. As the discrepancies in conceptualizations and thus measurements across studies can pose difficulties in making comparisons or drawing conclusions meaningful to the present study, only studies that have conceptualized resilience as a trait are discussed here.

In a range of non-autistic samples, resilience has been depicted as a key characteristic that moderates the negative effects of various stressors and promotes well-being in the face of adversity (Goldstein et al., 2013; Mitchell & Ronzio, 2011; Scali et al., 2012). A recent meta-analysis across 60 studies examining the relationships between trait resilience and mental health reported that resilience had strong positive associations with aspects of mental well-being, such as positive affect and life satisfaction (Hu et al., 2015). Conversely, they reported negative associations between resilience and mental ill health, such as anxiety and depression. It is conceivable that the clinical symptomatology, associated difficulties, and aforementioned high-stress levels experienced by autistic individuals may constitute elements of risk or adversity, therefore predisposing autistic individuals to poorer outcomes (Climie et al., 2013; Lai & Szatmari, 2019) including mental health difficulties. Nevertheless, not all autistic adults go on to manifest poor outcomes (e.g., Billstedt et al., 2011; Howlin et al., 2004). Heterogeneity in the autistic population is commonly reported, with reports of varying strengths and difficulties, co-occurring conditions, and achievements across different areas of functioning (Levy & Perry, 2011; Magiati et al., 2014; Szatmari et al., 2015). These uneven outcome

profiles suggest that there may be resilience-related factors influencing the trajectories of autistic individuals. Examining resilience in the autistic population would enable a more comprehensive understanding of the ways in which autistic individuals face and respond to stress. Further, taking a resilience perspective allows a shift from a deficit-based model, where the focus is on deficits and impairments, toward a strengths-based model, which focuses on strengths and positive attributes that enable autistic individuals to thrive.

To date, few studies have explicitly explored resilience as a construct within the autistic population. Autistic youth aged 16 to 21 years reported higher levels of vulnerability in several aspects of resilience, including traits such as lower emotional resilience, higher resistance to change, increased withdrawal, as well as difficulties in using support systems to overcome adversities, compared with their non-autistic peers (Montgomery et al., 2008). A possible explanation for this may be that some aspects of resilience overlap with traits commonly reported in autistic individuals (e.g., behavioral inflexibility). However, other studies reported no significant differences in resilience traits between autistic children and their peers (McCrimmon et al., 2016, 2018). More recently, Hwang et al. (2020) validated the use of the abridged Connor-Davidson Resilience Scale (CD-RISC 10; Campbell-Sills & Stein, 2007) with robust psychometric properties in a sample of autistic adults. In this study, increased resilience was associated with improved positive well-being and reduced levels of negative aspects of well-being, as is reported in other populations. However, neither the relationship between resilience and coping, nor the inter-relationships between resilience, mental health, and coping have been examined in the autistic population to date.

Though conceptually related, the constructs of resilience and coping are proposed to be distinctively different (Campbell-Sills et al., 2006; Van Vliet, 2008). Resilience positively influences the stress process at multiple stages (e.g., appraisals of a potential stressor, or selection of coping strategies) and typically augurs a positive outcome for the individual, such as the maintenance of optimism or positive emotions (Dawson & Pooley, 2013; Tugade & Fredrickson, 2004). 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; Folkman & Moskowitz, 2004). Though varying classification systems exist (see Skinner et al., 2003 for a review), engagement coping strategies are active coping attempts typically aimed at resolving the stressor and/or its associated distress, while disengagement coping strategies are aimed at avoiding these. Previous work in both autistic and non-autistic samples has associated engagement coping with better well-being, increased positive affect and self-esteem, and fewer

depressive symptoms (Billings et al., 2000; Compas et al., 2001; Rieffe et al., 2014; Sharkansky et al., 2000; Varni et al., 2012), while disengagement coping strategies are related to higher anxiety and depression, increased distress and reduced well-being (Friedman-Wheeler et al., 2008; Khor et al., 2014; Nielsen & Knardahl, 2014; Rieffe et al., 2011).

Although both resilience and coping have the potential to ameliorate or aggravate the impact of adverse and stressful experiences (Skodol, 2010), it is plausible that resilience may also influence the coping process. An individual's beliefs about themselves and the world in which they operate may influence how they cope with stressful events (Lazarus, 1999). There is research to suggest that resilient individuals, who tend to have a more positive view and a stronger belief in themselves, their abilities, and circumstances (Schoon & Bynner, 2003) are more likely to engage in active, task-oriented coping strategies whereas those who are less resilient tend to use more passive and avoidant coping strategies (Campbell-Sills et al., 2006; Eschleman et al., 2010; Li, 2008; Moore et al., 2017; Sagone & De Caroli, 2014; Sexton et al., 2010; Thompson et al., 2018). Extending this further, it may then be reasonable to suggest that the influence of resilience on the selection of coping strategies, may in turn have implications for mental health and well-being. In other words, the positive influence of resilience on mental health may be explained, at least partly, by the ways in which one copes with stress. The potential mediating role of coping in the resilience-outcome relationship has been explored in the broader stress and trauma literature, where coping has been demonstrated to mediate the relationship between resilience and mental health, post-traumatic growth (PTG) and post-traumatic stress disorder (PTSD) symptoms (Florian et al., 1995; Ogińska-Bulik & Kobylarczyk, 2016; Thompson et al., 2018; Yu et al., 2014). Exploring the potential mediating role of coping strategies in the relationships between resilience and mental health outcomes in autistic adults may be particularly important in informing the development of effective mental health support from a stress-related perspective.

The main aims of this study were to: (a) examine the associations between trait resilience and coping strategy use, and (b) explore the potential mediating role of coping strategy in the resilience-mental health relationship, in a sample of autistic adults. Characterizing the inter-relationships between resilience, coping, and mental health outcomes (i.e., anxiety, depression, and well-being) in autistic adults is particularly pertinent given the high levels of mental health difficulties reported and the need for tailored and targeted mental health interventions in this population. Based on previous findings from normative and other clinical populations, we hypothesized that: (a) higher levels of resilience would be associated with increased use of engagement coping and reduced use of disengagement coping strategies, and (b) coping

strategies would mediate the relationship between resilience and mental health outcomes.

METHODS

Participants

Participants were recruited through the Australian Longitudinal Study of Adults with Autism (ALSAA), a nationwide longitudinal survey funded by the Cooperative Research Centre for Living with Autism (Autism CRC), which had a target age range of 25 years and older (for cohort details, see Arnold, Foley, et al., 2019). Follow-up data were utilized for the present study, as the resilience measure (i.e., CD-RISC-10; Campbell-Sills & Stein, 2007) was not included in the first wave. At the time of this study, 78 autistic adults had completed the 2-year follow-up survey. All participants self-reported that they had received a clinical diagnosis of an ASD, including their specific diagnosis, year of diagnosis and details of the diagnosing professional. The final sample consisted of 78 autistic individuals (30 males, 42 females, 6 other) aged 27 to 83 years (M_{age} = 46.60 years, SD_{age} = 12.67). To maintain a balanced ratio in terms of gender composition, participants who reported their gender as "other" ($N = 6$) were omitted from analyses where gender was implicated.

Procedures

After ethics approval by the University of New South Wales Human Research Ethics Committee (No. HC15001), recruitment into ALSAA began in 2015 and is currently ongoing. Recruitment was conducted through a variety of channels including state-based organizations, research participant databases, educational institutions, self-advocacy and support groups, psychology and allied health practices, online autism communities, and social media. Potential participants aged 25 years and over, and based in Australia who expressed interest received participant information and a consent form. After eligibility screening, participants were mailed a paper copy or emailed a Qualtrics (Qualtrics, 2018) link to the online survey, depending on their preference. The data utilized in this study represents cross-sectional data collected at the 2-year follow-up.

Measures

Autism traits

The AQ-Short (Hoekstra et al., 2011) contains 28-items and is a self-report measure to assess autistic traits. Responses are made on a 4-point Likert scale from *definitely agree* (1) to *definitely disagree* (4),

where a higher score indicates increased autistic traits. The sum of items generates a total AQ-score, where a cut-off of 65 has high sensitivity and specificity with a clinical diagnosis of ASD (0.97 and 0.82, respectively; Hoekstra et al., 2011).

Coping behavior

The Brief COPE (Carver, 1997) is the 28-item abbreviated version of the COPE Inventory (Carver et al., 1989), designed to measure coping strategy use. Items are scores on a 4-point Likert scale from *I have not been doing this at all* (1) to *I've been doing this a lot* (4). As informed by factor analytic procedures in a large sample of autistic adults (Muniandy et al., 2021), we utilized two higher order coping dimensions (i.e., engagement coping and disengagement coping) as these were most significantly associated with mental health outcomes in the wider coping literature. The eight-item engagement coping subscale is characterized by active attempts at managing a situation or associated emotions (e.g., "I've been trying to come up with a strategy about what to do" or "I've been accepting the reality of the fact that it has happened"), while the five-item disengagement coping subscale involves strategies to avoid or distance oneself from the stressor or evoked feelings (e.g., "I've been giving up the attempt to cope" or "I've been refusing to believe that it has happened"). A total score for each subscale is obtained using the sum of its constituent items.

Resilience traits

The Connor-Davidson Resilience Scale (CD-RISC 10; Campbell-Sills & Stein, 2007) is the abridged version of the CD-RISC (Connor & Davidson, 2003), designed to measure aspects of resilience such as personal competence, positive acceptance of change, and tolerance of negative affect. The measure contains 10 items rated on a 5-point Likert scale from *not true at all* (0) to *true nearly all the time* (4). Total scores are obtained through the sum of items, where higher scores reflect greater resilience. The CD-RISC-10 has good construct validity and psychometric properties (Campbell-Sills & Stein, 2007), high internal consistency (Cronbach's alpha = 0.85–0.88; Campbell-Sills & Stein, 2007; Scali et al., 2012) and has been recently validated for use in the autistic population (Hwang et al., 2020).

Depression symptoms

The Patient Health Questionnaire-9 (PHQ-9; Kroenke et al., 2001) is a nine-item, self-report measure used to assess the presence of depressive symptoms. Items are scored on a 4-point scale from *not at all* (0) to *nearly every day* (3), where a higher score indicates higher levels

of depressive symptomatology. The sum of items produces a total score, where scores ≥10 indicate major depression, with high sensitivity and specificity ($\alpha = 0.88$ for both; Kroenke et al., 2001), as well as good test–retest reliability (0.84). This measure has been recently validated for use in the autistic population (Arnold, Uljarević, et al., 2019).

Anxiety symptoms

The DSM-5 Generalized Anxiety Disorder Dimensional Scale (DSM-5 GAD-D; LeBeau et al., 2012) is a 10-item, self-report measure that assesses anxiety symptomatology. Each item is rated on a 5-point Likert-type scale ranging from *never* (0) to *all of the time* (4). A total score can be created by summing the scores on the 10 items, where higher scores indicate greater anxiety severity. A total score > 14 has been reported to indicate significant or clinical levels of anxiety (Beesdo-Baum et al., 2012).

Psychological well-being

The Warwick-Edinburgh Mental Well-Being Scale (WEMWBS; Tennant et al., 2007) is a 14-item measure designed to capture positive mental well-being such as positive emotions and functioning, over the last 2 weeks. Items are scores on a 5-point Likert scale, from *none of the time* (1) to *all of the time* (5). An overall score is calculated by totaling the scores for each item, where a higher score indicates a higher level of mental well-being. The WEMWBS has reports of good content validity and high internal consistency (α range: 0.89–0.93; Lloyd & Devine, 2012; Tennant et al., 2007).

Data analysis

All scales had good to excellent internal reliabilities in the current sample (α range: 0.78–0.93; see Table 1). Tests of normality using Shapiro–Wilk statistic were conducted to examine variable distribution, where AQ-Short and disengagement coping were negatively skewed and PHQ-9 positively skewed. The subsequent correlation analysis to explore associations between variables of interest was thus bootstrapped with 2000 resamples to account for distributional non-normality. Data screening showed no evidence of multicollinearity using the variance inflation factor (VIF <10) and tolerance statistic (1/VIF > 0.1) values. No univariate outliers were identified using case wise diagnostics with a criterion of ±3.29 (Tabachnick & Fidell, 2013), while one multivariate outlier was identified using a combination of Mahalanobis distance, Cook's distance, and leverage values. However, removing this participant from the analyses did not significantly change the total amount of variance explained and as such, they were retained.

Mediation analyses were performed using the PROCESS macro v3.4 for SPSS (Hayes, 2018). Levels of depression, anxiety, and well-being were examined in separate models as the dependent variable, with resilience as the independent variable and use of coping strategies (i.e., engagement coping, disengagement coping, or both) as mediators. Gender was considered as a potential covariate in the mediation models, given the apparent oversampling of female participants compared to what is typically representative in the autistic population (i.e., male-to-female ratio at 3:1; Loomes et al., 2017). Due to the prerequisite of significant associations between the proposed mediator(s) and both the dependent and independent variables when testing mediation (Hayes, 2018), disengagement coping was utilized in all

T A B L E 1 Descriptive statistics

	n data	α	*n* (%) or M (*SD*)	Range
Gender	78	-		-
Male			30(38.5%)	
Female			42 (53.8%)	
Other			6 (7.7%)	
Age	78	-	46.60 (12.67)	27.17–83.58
AQ-short	78	0.86	89.41 (11.53)	58–112
Engagement coping	71	0.88	20.55 (5.62)	8–32
Disengagement coping	72	0.79	9.38 (3.37)	5–18
CD-RISC 10	78	0.93	20.79 (9.00)	0–40
PHQ-9	75	0.92	10.41 (7.28)	0–27
DSM-5 GAD-D	76	0.87	12.82 (8.02)	0–34
WEMWBS	73	0.93	40.66 (10.12)	14–64

Abbreviations: AQ-short, Autism-Spectrum Quotient-Short; CD-RISC 10, Connor-Davidson Resilience Scale-10 item; PHQ-9, Patient Health Questionnaire-9; DSM-5 GAD-D, Diagnostic and Statistical Manual of Mental Disorders-5 Generalized Anxiety Disorder Dimensional Scale; WEMWBS, Warwick-Edinburgh Mental Well-Being Scale.

T A B L E 2   Pearson's 2000 bootstrapped resamples correlations for key variables

	Age	Gender (female)	AQ-short	Engage	Disengage	CD-RISC10	PHQ-9	DSM-5 GAD-D
Gender (female)	−0.216							
AQ-short	0.07	−0.013						
Engagement	−0.211	−0.01	**−0.266***					
Disengagement	0.043	**−0.369****	0.211	−0.091				
CD-RISC10	−0.121	0.176	**−0.347****	**0.471****	**−0.443****			
PHQ-9	0.008	−0.215	**0.298***	−0.158	**0.703****	**−0.369****		
DSM-5 GAD-D	−0.093	**−0.274***	**0.370****	−0.178	**0.634****	**−0.494****	**0.766****	
WEMWBS	−0.039	0.203	**−0.341****	**0.425****	**−0.703****	**0.532****	**−0.793****	**−0.705****

Note: BCA 95% confidence intervals that do not cross zero are in bold.
Abbreviations: AQ-Short, Autism Spectrum Quotient-short; Engagement, engagement coping; Disengagement, disengagement coping; CD-RISC10, Connor-Davidson Resilience Scale-10 item; PHQ-9, Patient Health Questionnaire-9; DSM-5 GADD, DSM-5 Generalized Anxiety Disorder Dimensional Scale; WEMWBS, Warwick-Edinburgh Mental Well-Being Scale.
$^*p < 0.05$, $^{**}p < 0.01$.

three models, while engagement coping was only used in the well-being model. Mediation analyses were carried out using 5000 bootstrapped resamples and bias-corrected methods. The significance of the mediator (indirect effect) was established when the direct effect of resilience on mental health was reduced or became non-significant, in the presence of a coping strategy as a mediator. All data analyses were run using The Statistical Package for the Social Sciences (SPSS) version 25 (IBM Corp., 2017).

RESULTS

Descriptive statistics are presented in Table 1 while bivariate correlations are in Table 2. Approximately half of our sample (48.6%) met the threshold score of 10 on the PHQ-9 for major depression, while 43.1% met the cut-off score of 14 for significant anxiety on the DSM-5 GAD-D. Significant intercorrelations among resilience and mental health outcomes (depression, anxiety, and well-being) were noted. While disengagement coping strategies were related to mental health outcomes in the

expected directions, use of engagement coping strategies was only significantly associated with levels of well-being.

In the first mediation model, the relationship between CD-RISC10 and PHQ-9, mediated by disengagement coping was explored. As seen in Figure 1, this mediation model was supported, with significant indirect effects of resilience on depression through disengagement coping ($B = −0.245$, $SE = 0.067$, BCa 95% CI [−0.377, −0.107]). The variance accounted for PHQ-9 by CD-RISC10 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.

The second model explored the potential mediating role of disengagement coping in the relationship between CD-RISC10 and DSM-5 GAD-D. As seen in Figure 2, this mediation model was also supported. There was a significant indirect effect of resilience on anxiety, through disengagement coping ($B = −0.197$, $SE = 0.071$, BCa 95% CI [−0.351, −0.073]), with an increase of variance in DSM-5 GAD-D from $R^2 = 0.256$ to $R^2 = 0.436$ when disengagement coping was added as a mediator in the model.
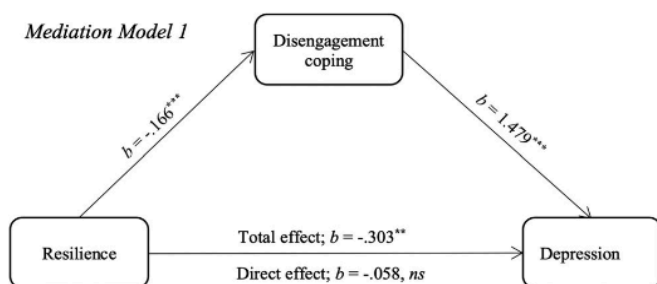

F I G U R E 1   Mediation Model 1 depicts the relationship between resilience and depressive symptoms, mediated by the use of disengagement coping strategies. *B* values correspond to unstandardized regression coefficients. $^*p < 0.05$; $^{**}p < 0.01$; $^{***}p < 0.001$; *ns*: not significant
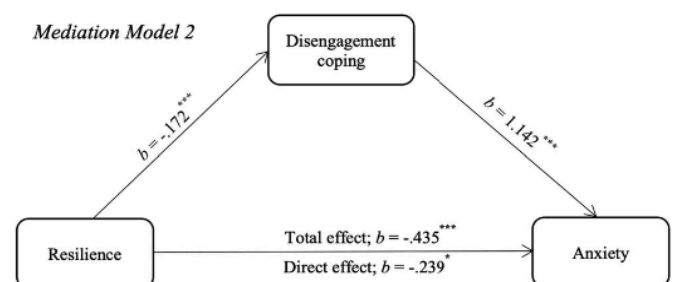

F I G U R E 2   Mediation Model 2 depicts the relationship between resilience and anxiety symptoms, mediated by the use of disengagement coping strategies. *B* values correspond to unstandardized regression coefficients. $^*p < 0.05$; $^{**}p < 0.01$; $^{***}p < 0.001$; *ns*: not significant
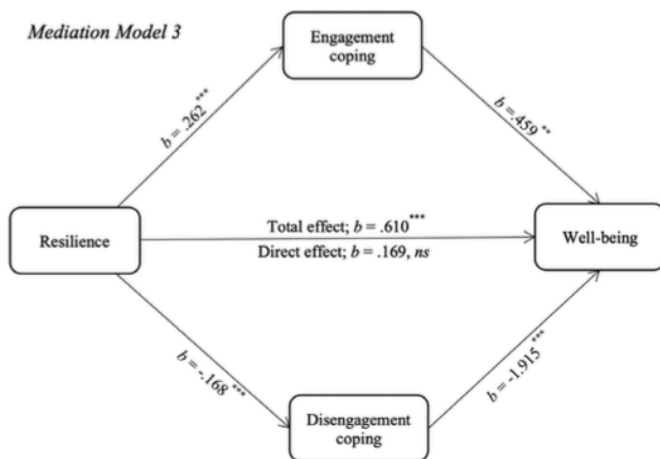
FIGURE 3 Mediation Model 3 depicts the relationship between resilience and well-being, mediated by the use of both engagement coping and disengagement coping strategies. B values correspond to unstandardized regression coefficients. $^*p < 0.05$; $^{**}p < 0.01$; $^{***}p < 0.001$; ns: not significant

The third model explored the mediating role of coping in the relationship between CD-RISC10 and WEMWBS, with both engagement and disengagement coping as potential mediators. As is seen in Figure 3, this parallel mediation model was supported, with significant indirect effects through disengagement coping ($B = 0.321$, $SE = 0.082$, BCa 95% CI [0.140, 0.471]) and engagement coping ($B = 0.120$, $SE = 0.058$, 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 contrast between the two coping strategies in terms of their mediating effects was not significant, $B = -0.201$, $SE = 0.098$, BCa 95% CI (-0.374, 0.021). The direct effect of resilience on well-being was no longer significant at this point, indicating full mediation.

Gender and AQ-Short had some significant correlations and were considered as potential covariates in the mediation models. However, the inclusion of gender and AQ-Short in the mediation models did not substantively change the results in the models. Minimal changes in total variance explained were noted ($R^2 = 0.526$, $R^2 = 0.466$, and $R^2 = 0.639$) and the mediation effects ($B = -0.219$; $B = -0.161$; $B_1 = 0.265$, and $B_2 = 0.115$) remained significant in the PHQ-9, DSM-5 GAD-D and WEMWBS models, respectively.

DISCUSSION

While there is some evidence in the literature to suggest that coping strategies used in response to stressful events can impact mental health and well-being in the autistic population, little is known about resilience in autistic individuals. To date, the inter-relationships between resilience, coping strategies, and mental health

outcomes, and whether coping strategies may be the mechanism that explains, at least partly, the positive association between resilience and mental health, remain unexplored. The present study aimed to examine: (a) the relationship between trait resilience and coping strategies, and (b) the potential mediating role of coping strategies in the trait resilience-mental health relationship, in a sample of autistic adults. Our findings suggest that higher resilience was related to increased use of engagement coping and reduced use of disengagement coping respectively. We also found that coping strategies played a significant mediating role in the relationship between resilience and mental health outcomes, where disengagement coping mediated the associations between resilience and all three mental health outcomes, while engagement coping strategies mediated the resilience-well-being relationship only.

The significant correlations between resilience and coping strategy use in our sample of autistic adults is consistent with the broader resilience literature, where resilience has been positively associated with active, approach-oriented coping strategies, and negatively associated with passive, avoidant coping strategies when faced with stressful events (e.g., Campbell-Sills et al., 2006; Moore et al., 2017; Thompson et al., 2018). Indeed, coping characterized by being problem-focused and goal-oriented has been suggested to reflect that of a "resilient coping pattern" (Sinclair & Wallston, 2004). Autistic adults who perceive themselves as resilient are likely to appraise stressful events as more controllable and manageable, thus utilizing engagement coping that reflects strategies which actively respond to the situation. Conversely, less resilient autistic adults are more likely to feel overwhelmed or perceive stressful events as uncontrollable, and therefore use coping strategies that reflect avoidance and disengagement. The characterization of resilient autistic adults by their coping style is a vital step in investigating the resilience construct, a relatively unexplored though emerging area of research in the autistic population. Further, these results add another perspective to the increasing literature surrounding stress and burnout experienced in the autistic population, where it would be useful to consider not just the stressful experiences and coping strategies utilized, but also understanding how autistic individuals face, adapt to, and perhaps grow from stressful encounters.

As hypothesized, coping strategies played a significant mediating role in the associations between resilience and mental health outcomes. Specifically, in our sample of autistic adults, the use of coping strategies is the mechanism that fully explains the relationship between resilience and both depressive symptoms and well-being, and partially explains the relationship of resilience with anxiety symptoms. Autistic adults in our sample who evaluated themselves as more resilient, utilized more adaptive coping strategies (more engagement, less disengagement coping strategies), which were then associated with

improved mental health and well-being. These results complement previous research in other populations, which has noted the significance of coping as a mediator in the relationships between resilience and mental health outcomes (e.g., Florian et al., 1995; Sojo & Guarino, 2011) and other outcome measures, including quality of life, PTG and PTSD symptoms (Ogińska-Bulik & Kobylarczyk, 2016; Thompson et al., 2018; Yu et al., 2014). Importantly, the potential for coping strategies to be at least part of the "conduit" through which resilience affects mental health outcomes in autistic adults has important clinical implications when addressing mental health support and intervention programs.

Interventions addressing stress and the management of stress have the potential to improve the quality of life in the autistic adult population (Bishop-Fitzpatrick et al., 2018). When considering mental ill health in the autistic population from a stress perspective, it may be helpful to take a combined approach when designing and implementing support or intervention programs by focusing on the development of both resilience and adaptive coping skills. Such an approach is supported by the reported effectiveness of interventions targeting both resilience and coping in improving overall well-being reported in non-autistic populations (e.g., Burton et al., 2010; Steinhardt & Dolbier, 2008). This finding offers support to current psychosocial approaches targeting anxiety and depression in the autistic population, which may already incorporate elements of resilience and coping, such as cognitive behavioral therapy (CBT) or mindfulness-based intervention (MBI). Indeed, a recent systematic review and meta-analysis of resilience programs and interventions in a diverse range of samples (e.g., individuals with depression, new migrants, veterans) has found the utilization of a CBT approach and mindfulness techniques to be particularly effective in promoting levels of resilience (Joyce et al., 2018). It may be therefore beneficial for current CBT and MBI approaches to place a larger emphasis on these stress-related constructs (i.e., resilience, coping strategy use). Further, resilience training as a preventative measure, tailored to particular transitional periods where autistic individuals are more likely to experience increased stress (e.g., entering adulthood, or the workforce), may also be useful.

There is also a need for a more tailored approach in the design of programs and intervention for the autistic population. Indeed, our findings suggest an emphasis on minimizing the use of disengagement coping strategies, as this may impede the emergence or development of engagement coping strategies. It may prove useful to uncover underlying motivations in utilizing disengagement coping strategies that may be specific to the autistic population. Indeed, young autistic adults have been reported to more likely remove themselves from mounting stress to avoid further input or stimulation, compared to non-autistic adults who engaged in distraction or relaxation coping strategies instead (Halim et al., 2018). Further, identifying frequently faced stressful events and negative life experiences that autistic individuals are especially vulnerable to, including potential barriers or resources required in developing trait resilience or coping strategies in this population, would be vital areas to address. While the present study examined resilience from a trait perspective, it would also be important for future research to consider resilience as a process, and examine the interplay of individual and contextual factors (e.g., adversity, stress, social support) that may enable or hinder the achievement of a "good outcome" in the face of adversity.

We would particularly advocate that the design of stress-related intervention programs be done in collaboration with the autistic community. As noted by Benevides et al. (2020), there is a great need to identify the preferred approaches to intervention alongside autistic adults, with these practices being adapted for, and led by autistic individuals, allowing participants to define their own goals and outcomes. Various autism-specific adaptations to interventions have been reported in the literature to date, including using a range of communication methods, allowing parents or significant others to play an active role, using personalized and more visual outcome measures, as well as eliminating the use metaphors or imaginative language (Spain & Happé, 2019; Spek et al., 2013).

It was noteworthy that disengagement coping strategies mediated the relationship between resilience and all three mental health outcomes, while engagement coping strategies was only a significant mediator in the relationship between resilience and well-being. The significance of engagement coping to well-being but not the negative indicators of mental health (i.e., anxiety, depression) is not dissimilar to what is reported in the coping literature, where rather than being on opposing sides, engagement and disengagement coping strategies may be distinct categories of coping that simply differentially predict negative and positive indicators of mental health (Taylor & Stanton, 2007). Future research may consider exploring the roles of other coping categories beyond what was measured in the present study, particularly proactive coping. Proactive coping incorporates a positive, future-oriented approach where individuals anticipate potential stressors, acting in advance to prevent them from occurring (Greenglass & Fiksenbaum, 2009). Perceived control and self-efficacy are some of the key aspects of proactive coping which may also be similarly reflected in resilient individuals.

This is the first study to assess the inter-relationships of both resilience and coping strategy use in relation to mental health and well-being in autistic adults, offering significant implications for designing interventions to better support the mental health of this population. The study also encompassed a large age range of autistic

adults, where the lack of significant associations between age and other variables of interest suggest that these findings may be applicable to the entire span of adulthood in the autistic population. However, due to the exploratory nature of this study, several limitations should be considered. The primary limitation is that the data are cross-sectional in nature and it is possible that other causal relationships could explain the observed pattern of results. For example, autistic adults with more depressive or anxiety symptoms may view themselves as less resilient. Thus, these preliminary findings present a basis to conduct larger longitudinal research to examine the direction of these relationships over time. Our analyses also may have been underpowered given the sample size. Although the use of bootstrapping methods can improve the robustness in assessing mediation effects in sample sizes such as ours (Shrout & Bolger, 2002), replication using a larger sample is recommended. Third, we did not include a measure of stress or adversity. It is plausible that individual differences in stress experienced can influence the underlying mechanisms of trait resilience, coping, and mental health. While the increased vulnerability to poorer outcomes in the autistic population as a whole formed the premise of the current study to explore the associations between these constructs, it would be beneficial for future research to account for varying levels or types of stress experienced in order to unpack these relationships further. Our sample only included autistic adults without an intellectual disability, with the ability to self-respond to the questionnaire items, and thus is not representative of the wider autistic adult population. Though informant reports can be a valuable source of information, some of the coping strategies and resilient traits questions are cognitive or covert in nature, and as a result, may be difficult to interpret or be observed by others. We had an overrepresentation of female participants (58.3%), as commonly occurs in online survey studies in both autistic and non-autistic adults (e.g., Kapp et al., 2013; Nicolaidis et al., 2013). While including gender as a covariate in the mediation models did not substantively change the results or the mediation effects observed, it may prove useful for future studies to explore possible gender discrepancies using a larger sample. Finally, although all autistic participants explicitly indicated a clinical diagnosis of ASD (including reporting the year the diagnosis occurred, diagnosing medical professional and their diagnostic label), independent assessments to confirm diagnosis were not possible due to the online nature of the studies and the geographical spread of recruitment. However, given the study's extensive questions, as well as its lengthy and voluntary (non-reimbursable) nature, we believe that there is minimal risk of inappropriate responding by individuals without a diagnosis (Hwang et al., 2020).

In conclusion, the present study offers novel insights into characterizing the inter-relationships between trait resilience, coping, mental health, and well-being in autistic adults. Our findings corroborate a growing body of evidence that suggest the importance of considering stress-related constructs in the autistic population. We also highlight the importance of considering both resilience and coping strategies in informing support and intervention programs to protect and improve the mental health of autistic adults. Low trait resilience and a disengagement coping style can be used as markers of vulnerability to psychopathology and have the potential to help identify autistic individuals at risk. While still an emerging area of research, addressing the high prevalence of mental health difficulties in autism using a strength-based approach and constructs such as resilience may help contribute toward the positive shift in attitudes toward autism more generally.

CONFLICT OF INTERESTS
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Chapter 11: Coping-resilience profiles and experiences of stress in autistic adults

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RESEARCH ARTICLE

Coping-resilience profiles and experiences of stress in autistic adults

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Abstract
Emerging studies allude to high stress in autistic adults. Considering the detrimental impact of stress on health outcomes, examining individual resources which may influence the extent to which stress is experienced (e.g., coping and resilience) is vital. Using a person-focused approach, this study aimed to identify coping-resilience profiles, and examine their relations to general perceived stress and daily hassles in a sample of autistic adults ($N = 86$; aged 19–74 years). Cluster analysis identified four coping-resilience profiles (i.e., *high cope/ low resilience*, *low cope/ high resilience*, *engage cope/ high resilience*, and *disengage cope/ low resilience*). The *high cope/ low resilience* and *disengage cope/ low resilience* groups had significantly higher general perceived stress than the remaining groups. No significant group differences were noted in relation to daily hassles. Jointly addressing coping and resilience may be beneficial on the perceived stress experienced in autistic adults. The use of coping-resilience profiles may also allow for the personalization of stress management and support options in the autistic adult population.

Lay summary
High stress is increasingly reported in autistic adults. As stress can impact individual health, examining how autistic individuals cope with stress, and their resilience when faced with stressful events, is important. In this study, we grouped 86 autistic individuals aged 19–74 years based on their coping and resilience patterns. We then compared these groups across their general sense of stress and stress over daily hassles. Four coping-resilience groups were identified, where those demonstrating a combination of high disengagement coping strategy use and low resilience reported the highest general sense of stress. These results suggest that a joint focus on coping strategies and resilience may be beneficial in understanding the stress experienced in autistic adults. Characterizing individuals based on their coping-resilience patterns can inform support services, personalize stress management options and identify individuals who may be at risk for experiencing high stress in the autistic adult population.

KEYWORDS
adults, autism spectrum disorders, coping, resilience, stress

Stress can be conceptualized as person-environment transactions where demands placed on the individual are appraised as either taxing or exceeding the resources necessary to cope (Lazarus & Folkman, 1984). Stressors, by definition, demand and/or deplete resources (Halbesleben et al., 2014; Hobfoll, 1989) and it is the relative ratio between perceived demands and personal resources that determines the extent to which an individual experiences stress (Epel et al., 2018). Across a range of clinical and nonclinical samples alike, high stress has been established as a risk factor for detrimental outcomes in both physical and mental health, well-being, and quality of life (e.g., Cohen et al., 2007; Edman et al., 2017; Nelas et al., 2016; Ribeiro et al., 2018; Watson et al., 2008). These associations may

be particularly relevant to the autistic population considering the high prevalence of co-occurring physical health issues (Croen et al., 2015; Jones et al., 2016), mental health conditions (Hollocks et al., 2019; Lai et al., 2019), and poor quality of life (Lawson et al., 2020; Mason et al., 2018; van Heijst & Geurts, 2015).

Although there is a substantial degree of research on physiological correlates of stress (e.g., cortisol) in the autistic population (e.g., Corbett et al., 2009; Lydon et al., 2016), less is known about subjective evaluations of stress across contexts in autistic individuals. Indeed, central to experiences of stress are not only encounters with stressors, but also the ways in which they are subsequently perceived or appraised (Lazarus & Folkman, 1984). Stressful encounters and events are typically assessed using measures of life events or daily hassles. While the occurrences of stressful major life events (e.g., divorce, major illness) can undoubtedly invoke stress and require significant adjustments, there is also potential for minor stressors and hassles that characterize daily life to be enduring, reoccurring and to have a cumulative impact over time (Kanner et al., 1981; Lazarus & Folkman, 1984; Wheaton et al., 2013). On the other hand, the subjectivity of stressful experiences, influenced by individual differences in stressor appraisals and coping resources, is captured through measures of perceived stress. Perceived stress measures may be broad, tapping into how unpredictable, uncontrollable and overloaded individuals might generally perceive their lives to be (Cohen et al., 1983) or context-specific, such as in response to specific events or encounters in various life domains.

Emerging studies in the autistic population have alluded to elevated levels of stress and frequent stressful encounters (e.g., Gillot & Standen, 2007; Kerns et al., 2015). Autistic individuals are suggested to be at increased risk for experiencing more frequent and varied stressful encounters in their daily lives (Twachtman-Cullen et al., 2006), as well as more frequent occurrences of stressful life events (Bishop-Fitzpatrick et al., 2017; Moseley et al., 2021) than non-autistic individuals. Autistic adults also report higher levels of perceived stress compared to non-autistic adults (e.g., Bishop-Fitzpatrick et al., 2015, 2017), with higher autistic traits associated with increased levels of perceived stress in autistic adults (Hirvikoski & Blomqvist, 2015). Relatedly and concerningly, autistic adults are also at an increased vulnerability for experiencing adverse life events such as bullying, discrimination, victimization and exploitation (Griffiths et al., 2019; Johnson & Joshi, 2016), all of which are likely to result in more intense and ongoing, chronic levels of stress over time. Indeed, autistic adults have described the accumulation of these negative experiences as traumatic, resulting in poor mental health outcomes (Benevides et al., 2020).

Studies examining associations between various measures of stress and resultant outcomes in the autistic population show findings concordant with those of the wider literature. For example, an increase in parent-reported frequency of daily hassles in autistic youth was related to an increase in behavioral and emotional problems for these youth (Khor et al., 2014). This is consistent with findings illustrating the cumulative impact of daily stressors and their negative consequences for physical and psychological health in a range of non-autistic populations (Beasley et al., 2003; Mroczek et al., 2015; Charles et al., 2013; Seiffge-Krenke, 2000; Sin et al., 2015). Similarly, associations between elevated perceptions of stress and a range of poor outcomes have also been reported in autistic adults, particularly in relation to poorer social functioning, greater social disability, and reduced quality of life (Bishop-Fitzpatrick et al., 2015, 2017; Hong et al., 2016).

To further understand the experiences of stress in the autistic population, it is also important to consider the influence of psychosocial resources, which reflect intervening factors that can moderate the meaning of, or regulate reactions to stressful encounters (Lazarus & Folkman, 1984). Individual differences in stress experiences in response to otherwise objectively equal stressors can be largely due to differences in the nature and availability of individual and environmental resources (Lazarus & Folkman, 1984). While many environmental circumstances (e.g., socio-economic status, availability of employment) may be difficult to control (Hobfoll, 2011), there are some individual resources that are malleable. Examples of these resources include coping and resilience, both of which can impact the stress process through their influence on stressor appraisals and coping abilities (Dabrowska & Pisula, 2010; Muller & Spitz, 2003; Smith et al., 2010).

Coping reflects the use of specific cognitive and behavioral strategies in response to stressful encounters (Folkman & Moskowitz, 2004). While many classifications of coping strategies exist (see Skinner et al., 2003), engagement coping often represents active coping strategies that focus on resolving the stressor and/or feelings of stress (e.g., problem solving, positive reappraisals), whereas disengagement coping strategies (e.g., behavioral disengagement such as giving up attempts to cope, being in denial) focus on avoiding these, in autistic and non-autistic samples (e.g., Compas et al., 2001; Muniandy et al., 2021a). From a dispositional perspective, coping reflects the habitual ways in which individuals use strategies from their coping repertoire to respond to stressful encounters (Carver et al., 1989).

Use of coping strategies can be influenced by personal disposition, coping skills as well as prior coping experience (Endler & Parker, 1994), highlighting that coping is modifiable and responsive to targeted intervention (e.g., Compas et al., 2010). The coping literature in autistic adults is limited to date, however this scarcity is complemented by the emotion regulation literature. Although coping and emotion regulation are related, with some overlap in strategies examined, emotion regulation

strategies are used across stressful and non-stressful contexts as well as in response to positive and negative emotions, whereas coping strategies are only deployed in response to stressors, and typically negative emotions associated with stressful encounters (see review by Compas et al., 2014).

Resilience can be defined as the ability to 'bounce back', adaptat, and/or the maintenance of normal functioning despite exposure to stress and adversity (Luthar, 2006; Rutter, 2012; Smith et al., 2010). As a construct, resilience can be operationalized as a trait, process or outcome (Fletcher & Sarkar, 2013). Resilience as a trait encapsulates a continuum of individual attitudes, characteristics and learned skills that denotes general hardiness, resourcefulness and the ability to withstand and flexibly adapt to the changing demands of stressful experiences (Block & Block, 1980; Connor & Davidson, 2003; Skodol, 2010; Smith et al., 2010). These traits are suggested to be both innate and acquired, stable yet malleable (Hu et al., 2015; Joyce et al., 2018). Indeed, resilience traits can be influenced by social factors such as social support (van Kessel, 2013) and are modifiable through targeted interventions (e.g., Steinhardt & Dolbier, 2008). Resilience operationalized as a process captures the interaction of adversity, outcomes, and protective factors, where evidence of adversity and reports of positive outcomes infer the presence of resilience (e.g., Fergus & Zimmerman, 2005). As an outcome, resilience is demonstrated through an immediate outcome measure such as the presence of favorable behavior, maintenance of functioning or the absence of psychopathological symptoms in the context of risk or adversity (e.g., Luthar & Zelazo, 2003). In this study, resilience was approached from a trait perspective, representing a dynamic individual resource that can facilitate the ways in which individuals face, adapt to, and recover from stress.

Both coping and resilience can either ameliorate or aggravate the experiences of stress (Skodol, 2010). Coping strategies characterized as engagement-oriented have been linked to reduced stress, whereas coping strategies that are disengaging in nature have been associated with increased stress (Brougham et al., 2009; Cherkil et al., 2013; Dabrowska & Pisula, 2010; Muller & Spitz, 2003; O'Brien et al., 2012; Reeve et al., 2013). Similarly, resilient individuals, who are likely to have a more optimistic outlook and a stronger belief in their abilities (Schoon & Bynner, 2003), have reported higher resistance to stress (Ong & Bergeman, 2004), lower perceived and chronic stress, and fewer occurrences of stressful life events (Cowden et al., 2016; García-León et al., 2019; Rahimi et al., 2014; Wilks, 2008). Although higher engagement coping, lower disengagement coping and higher levels of resilience traits have been separately associated with improved outcomes such as better mental health and well-being in autistic adults (Hwang et al., 2020; Muniandy et al., 2022), the ways in which coping and resilience may relate to stress in autistic adults

have not yet been examined. Given their malleability, coping strategies and resilience may be important resources that can be developed and honed through support and intervention to mitigate some of the stressful encounters faced by autistic individuals.

The inter-relationship between coping and resilience has been noted in autistic and non-autistic samples, where higher resilience is associated with increased use of engagement coping strategies, and lower resilience with disengagement coping strategies (Campbell-Sills et al., 2006; Moore et al., 2017; Muniandy et al., 2021b; Thompson et al., 2018). However, little is known about how coping and resilience in autistic people might co-occur at an individual level. There is increasing evidence to suggest that an individual's beliefs about a stressful encounter can subsequently influence their ability to cope effectively (Crum et al., 2013). Utilizing a person-focused approach such as cluster analysis in a given sample may help to identify distinct coping-resilience profiles, which are characterized by individual patterns of coping strategy use and levels of resilience.

Increasingly used in the wider coping literature, the classification of individuals based on their coping profiles operates under the premise that during a stressful encounter individuals utilize coping strategies in conjunction with one another, rather than in isolation (Eisenbarth, 2012; Garnefski et al., 2001; Sideridis, 2006). Coping profiles are typically determined using cluster analytical procedures on a measure of coping strategy use, allowing the identification and description of subgroups based on their unique combinations of coping strategies (e.g., Doron et al., 2014; Steele et al., 2008; Tolan et al., 2002). These distinct combinations of coping strategies that make up these coping profiles have been found to associate differently with a range of outcome measures including stress, and psychological and physical health outcomes (Doron et al., 2014; Eisenbarth, 2012; Gaylord-Harden et al., 2008). Coping profiles suggesting 'risk' for poor outcomes on health indicators are identified and subsequently can be used to shape intervention designs and efforts. To date, coping profiles have not been examined in the autistic population.

Large variability exists in the ways in which resilience profiles are derived in the literature, which is not unexpected given the heterogeneity in the operationalizations of resilience as a construct. Resilience profiles have been determined through cluster analytical procedures on single resilience measures (e.g., Kumar et al., 2010; Prince-Embury & Steer, 2010), a combination of characteristics typically associated with resilience (e.g., hardiness, self-efficacy, coping, and social support; Wilson et al., 2016), or a combination of risk (e.g., stressful life events, low income) and positive adjustment (e.g., competence, absence of psychopathology) measures. In this latter approach, individuals who demonstrate high risk and good adaptation or adjustment are typically grouped into

the 'resilient' profile (e.g., Gerber et al., 2013). As far as we know, the specific combination of coping profiles and resilience profiles (i.e., coping-resilience profiles) has not been examined in autistic or non-autistic samples thus far. This is surprising given the increasing evidence surrounding the associations between these two constructs at the variable level.

Considering the high stress and poor health-related outcomes reported for autistic adults, the examination of coping-resilience profiles can help further our understanding of the ways in which coping and resilience might co-occur within autistic individuals. Determining how these profiles may differentially relate to experiences of stress may also be especially useful in the tailoring of support options based on an individual's unique disposition to, and risk of stress.

CURRENT STUDY

The main aim of the current study was to identify coping-resilience profiles in a sample of autistic adults using a person-focused approach, and to examine their relationships with experiences of stress (i.e., general perceived stress and daily hassles stress). Although there were no specific hypotheses regarding the profiles that would be derived due to the novelty of coping-resilience profiles in the general population and the scarcity of coping and resilience literature in autism research to date, it was expected that individuals characterized by high resilience, high engagement coping and low disengagement coping would report lower levels of general perceived stress and daily hassles stress. In contrast, individuals with low resilience, low engagement coping and high disengagement coping were expected to report higher stress.

METHODS

The current study was conducted during the ongoing coronavirus pandemic (COVID-19; June to November 2020). Although examining stress, coping and resilience specifically in response to COVID-19 was not the aim of the study, additional information on COVID-19 associated fear and stress was captured and is included at different points in this manuscript where relevant, to provide further context to the overall stress experienced by our sample during this period.

Participants

The participants consisted of 86 autistic adults (29 males, 57 females, $M_{age} = 40.76$, $SD_{age} = 13.47$, range: 19–74 years). They all resided in Australia and self-reported a formal diagnosis of ASD, including their specific diagnosis, year of diagnosis, and details of their diagnosing professional. The inclusion criteria were autistic adults aged 18 years and above, with a formal diagnosis of autism, who were based in Australia, and were proficient in English.

To ensure that participants understood the study requirements and were able to provide informed consent, only individuals who self-reported not having a co-occurring diagnosis of intellectual disability on the study eligibility page, were included in the study. The Autism-Spectrum Quotient Short (AQ-Short) was also used as an inclusion criterion, where only participants who met criteria for ASD on the AQ-Short (>65; Hoekstra et al., 2011) were included in the sample for analysis. Participant demographic information is presented in Table 1.

Procedures

Following institutional ethics approval from La Trobe University Human Ethics Committee (HEC19443), recruitment for the study targeted formally diagnosed autistic adults through a range of channels, including Australian and state-based autism organizations (e.g., Autism CRC, Autism Queensland), autism-specific service providers, and participant databases from various autism research organizations. Upon expression of interest, the study information statement and an online link to REDCap (Research Electronic Data Capture; Harris et al., 2009) were provided to potential participants. The online link included an eligibility page, where once the criteria were met and informed consent indicated, participants were automatically directed to the start of the survey. The online survey included questions on basic demographics and a range of questionnaires encompassing experiences of stress, coping and resilience, psychological well-being and quality of life. Upon study completion, all participants were offered the option of receiving a $10 e-voucher. Participants who agreed to this were re-directed to a new page, where an e-mail address of choice could be provided.

MEASURES

Autism traits

The Autism Quotient-Short (AQ-Short; Hoekstra et al., 2011) is a 28-item abbreviated version of the 50-item AQ screening questionnaire (Baron-Cohen et al., 2001) widely used to measure autistic traits. Using a 4-point Likert, scale ranging from *definitely agree* (1) to *definitely disagree* (4), higher scores are indicative of increased autism traits. A total score can be generated using the sum of the individual items, where a total cut-off score greater than 65 has high sensitivity (0.97) and specificity (0.82) with a clinical diagnosis of ASD (Hoekstra et al., 2011). A high Cronbach alpha value (0.81) was found in the current study.

TABLE 1   Demographic information

		M (SD; range) N or frequency
N		86
Age		40.76 years (13.47; 19–74 years)
Sex designated at birth	Male	29 (33.7%)
	Female	57 (66.3%)
Gender identity	Male	28 (32.6%)
	Female	47 (54.7%)
	Genderqueer or non-conforming	8 (9.3%)
	Different identity	1 (1.2%)
	Missing	2 (2.3%)
Self-reported diagnoses	Autism spectrum disorder	56 (65.1%)
	Autistic disorder	0
	Asperger's syndrome	28 (32.6%)
	High functioning autism	1 (1.2%)
	Pervasive developmental disorder–not otherwise specified	1 (1.2%)
Age of diagnoses (years)	1–10	11 (12.8%)
	11–20	11 (12.8%
	21–30	13 (15.1%)
	31–40	19 (22.1%)
	41–50	23 (26.7%)
	51–60	3 (3.5%)
	61–70	5 (5.8%)
	Missing	1 (1.2%)
Australian state of residence	Victoria	47 (54.7%)
	New South Wales	17 (19.8%)
	Western Australia	4 (4.7%)
	South Australia	6 (7.0%)
	Queensland	9 (10.5%)
	Tasmania	1 (1.2%)
	Australian Capital Territory	2 (2.3%)
COVID-19		
Diagnosed with COVID-19	Self	1 (1.2%)
	Close family or friends	1 (1.2%)
	Extended family or friends	5 (5.8%)
Had COVID-19 symptoms	Self	15 (17.4%)
	Close family or friends	10 (11.6%)
	Extended family or friends	8 (9.3%)
Since the COVID-19 pandemic, experienced changes and disruptions in	Employment	47 (54.7%)
	Education	19 (22.1%)
	Living situation	38 (44.2%)
	Social relationships	48 (55.8%)

COVID-19 fear

Fear of COVID-19 was assessed using the Fear of Coronavirus Questionnaire (FCQ; Mertens et al., 2020), which contained eight statements to assess components of fear (e.g., worry, attentional biases, avoidant behavior) in relation to COVID-19. The items tap into aspects of fear such as threat of infection in themselves (e.g., 'For my personal health, I find the virus to be much more dangerous than the seasonal flu') and in others (e.g., I am worried that friends or family will be infected), precautionary and safety behaviors to prevent infection (e.g., I take more precautions compared to most people to not become infected), as well as attentional biases (e.g., I am

constantly following all news updates regarding the virus). Rated on a 5-point Likert scale, ranging from (1) *Strongly disagree* to (5) *Strongly agree*, a higher total score indicates a higher fear of COVID-19. A total score is derived using the sum of the eight item scores. To date, good internal consistency has been reported in other studies ($\alpha = 0.77$ and 0.80; Mertens et al., 2020; Vos et al., 2021), including the present sample ($\alpha = 0.79$).

COVID-19 stress

Considering the uneven spread of COVID-19 exposures and infections across Australia due to variable and changing state and territory border closures and lockdowns during the time of study, it was deemed unsuitable to measure stress directly related to contracting COVID-19. Rather, the authors developed questions to measure perceived stress in major life domains as a result of COVID-19 and its associated movement restrictions. Stress associated with COVID-19 disruptions and changes in major life domains (i.e., employment, education, living situation and social relationships) was assessed with a yes/no item "Since the COVID-19 pandemic, have you experienced changes in your_____?". Respondents who indicated a change in any of the domains were then asked to specify details of the change and the extent of stress experienced because of this change on a 5-point Likert scale from (1) *Not stressful at all*, to (5) *Extremely stressful*. Participants who indicated no change in any domain were assigned a score of 0 in this domain. A total COVID-19 stress score was derived using the sum of stress over the four domains, where scores ranged from 0 to 20. The internal consistency for the total COVID-19 stress score in the current sample was 0.86.

Coping strategies

The Brief COPE (Carver, 1997) is a 28-item abbreviated version of the original COPE inventory (Carver et al., 1989) where use of coping strategies is measured using a 4-point scale ranging from (1) *I have not been doing this at all* to (4) *I have been doing this a lot*. A 6-factor structure for the Brief COPE has been reported for autistic adults by Muniandy, Richdale, Trollor, and Lawson (2021a), with good internal consistencies across all six coping subscales (Engagement coping: 0.86, Support-seeking coping: 0.88, Disengagement coping: 0.76, Substance-use coping: 0.95, Humor coping: 0.82 and Religious coping: 0.78). In the present study, the 8-item engagement coping (e.g., "I've been trying to come up with a strategy about what to do") and 5-item disengagement coping (e.g. "I've been refusing to believe that it has happened") subscales (Supplementary Table A1) were examined given their strong associations with stress in the wider non-autistic coping literature (e.g., Arsenio & Loria, 2014; Coiro et al., 2017; Yang

et al., 2008). The total score for each subscale is obtained by summing the constituent items, where higher scores reflect more frequent use of the respective coping strategy. Both the engagement coping and disengagement coping subscales had good internal consistencies, with alpha values of 0.77 and 0.76 respectively in the current sample.

Resilience

The Connor-Davidson Resilience Scale-10 (CD-RISC-10; Campbell-Sills & Stein, 2007) is the 10-item abridged version of the CD-RISC (Connor & Davidson, 2003), designed to assess various aspects of resilience such as hardiness (e.g., 'I am able to adapt to changes when they occur or 'I tend to bounce back after illness, injury or other hardships') and persistence (e.g., 'I believe I can achieve my goals, even if there are obstacles'). Items are rated on a 5-point scale ranging from (0) *not true at all* to (4) *true nearly all the time*. A total resilience score is obtained using the sum of items, where a higher score reflects higher levels of resilience. The CD-RISC-10 has good construct validity (Campbell-Sills & Stein, 2007) and high internal consistency is reported in the general population ($\alpha = 0.85$ in Campbell-Sills & Stein, 2007; $\alpha = 0.88$ in Scali et al., 2012). It has also been validated for use in an autistic adult sample, with high internal consistency ($\alpha = 0.92$; Hwang et al., 2020). High internal consistency was found for the current sample (Cronbach's alpha = 0.88).

General perceived stress

The Perceived Stress Scale (PSS-10; Cohen & Williamson, 1988) is a shortened version of the original PSS (Cohen et al., 1983), used to evaluate the degree to which individuals appraise their lives as generally stressful. Respondents rate the frequency of certain feelings and thoughts over the last month on a 5-point scale ranging from *never* (1) to *very often* (5). Cut-off total scores are commonly used in the literature to suggest low (0–13), moderate (14–26) and high (27–40) levels of stress. Good to excellent internal reliability has been reported for the PSS-10 in adults from the general ($\alpha = 0.91$; Mitchell et al., 2008; Wu & Amtmann, 2013) and the autistic population ($\alpha = 0.87$, Bishop-Fitzpatrick et al., 2018; $\alpha = 0.76$, Hong et al., 2016), as was the case in the present study (0.90).

Daily hassles stress

The Daily Stress Inventory (DSI; Brantley et al., 1987) is a 58-item self-report measure that allows respondents to indicate the occurrence of daily events often viewed as

stressful or unpleasant, and has been used extensively across clinical (e.g., Felsten, 2004; Houle et al., 2012) and non-clinical populations (e.g., Bell & D'zurilla, 2009; Winzeler et al., 2014). Upon indicating the occurrence of an event, individuals rate their perceived stressfulness on a Likert-type scale ranging from *Occurred but was not stressful* (1) to *Caused me to panic* (7). Three scores are derived from the DSI: (1) Frequency: the number of stressful events experienced; (2) Sum: total stress across events; and (3) Average stress: the average stress experienced over an event, calculated by dividing the sum of stress by the frequency of events (Brantley et al., 1987). Cronbach alpha for the frequency of events and the sum of stress in the present study were 0.91 and 0.92, respectively.

Measures related to autism traits (AQ-Short) and COVID-19 (FCQ and COVID-19 stress) provided further information about the sample characteristics. To derive coping-resilience profiles, coping (Brief COPE) and resilience (CD-RISC-10) scores were utilized, while the subsequent associations between these profiles and experiences of stress were examined across three measures of stress (PSS, Average Daily Hassles stress and COVID-19 stress).

Data analysis

Descriptive statistics were used to report levels of stress while associations between key variables in the study were examined using correlation analyses. To empirically derive resilience-coping profiles based on similar patterns of coping strategy use and resilience in the current sample, cluster analysis was conducted. As the measures of coping and resilience were differently scaled, all scores were standardized to z-scores prior to cluster analytic procedures (e.g., Macnab et al., 2001; Vesanto, 2001). An intra-cluster sum of squared distances scree plot was produced using R version 4.1.0, where the apparent plateau

or 'elbow' in the plot indicated the optimal number of clusters (k; Everitt & Hothorn, 2011). Cluster validity was evaluated using an average Silhouette coefficient threshold of ≥ 0.5 (Dalmaijer et al., 2022; Kaufman & Rousseeuw, 1990). The value of k was then utilized in the k-means cluster analysis conducted in SPSS version 27.0.0 with the default 10 iterations, to characterize participants according to their patterns in coping strategy use and resilience. The derived clusters and their compositions were subsequently examined to ensure meaningful interpretation (Rapkin & Luke, 1993).

To explore cluster-level differences, Pearson's chi-square for independence tests and one-way analysis of variance (ANOVA) with post-hoc tests via Bonferroni were utilized to explore cluster-level differences in variables of interest. Effect size measure for each ANOVA was determined using Eta squared (η^2), where 0.01 was interpreted as a small, 0.06 as a medium, and 0.14 as a large effect. As several variables violated the assumptions of normality, bootstrapping analysis using 2000 resamples and 95% bias-corrected and accelerated (BCa) confidence intervals (CI) were applied to the correlation analyses and ANOVAs for more robust statistics (Field, 2013). In these analyses, BCa confidence intervals that do not include zero demonstrate statistically significant estimates (Hayes, 2009). Missing data were pairwise excluded where possible, with the exception of bootstrapped analyses, which require list wise exclusion.

RESULTS

Descriptive and correlation analyses

Descriptive statistics and correlations are provided in Table 2. Relatively high levels of general perceived stress were noted in the sample, with total PSS scores primarily ranging from moderate to high (low, 5.8%; moderate, 48.8%; high, 40.7%). The mean frequency of daily hassle
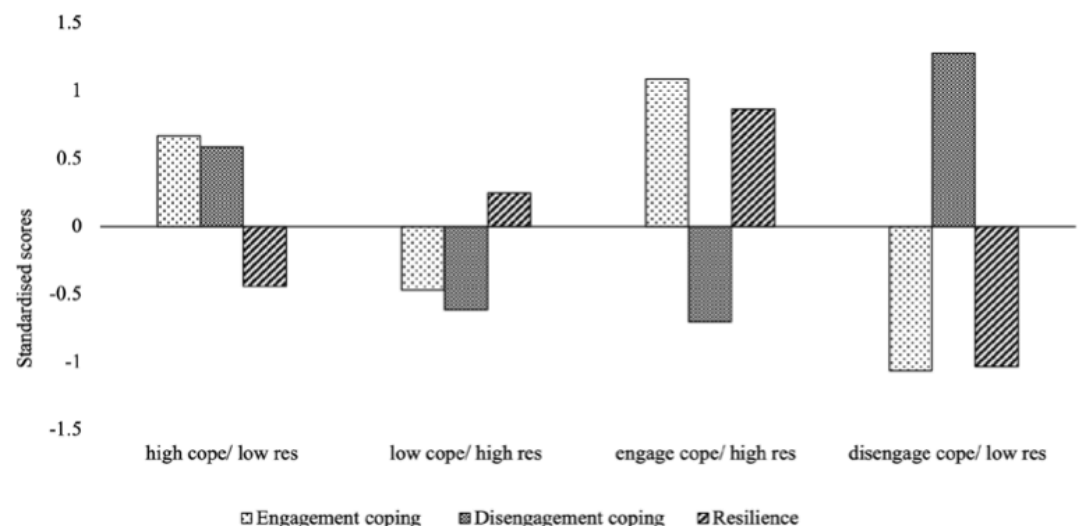

FIGURE 1 Composition of standardized scores for engagement coping, disengagement coping and resilience across the four groups

TABLE 2 Study variables (*M*, *SD*, range) and Pearson's 2000 bootstrapped re-samples correlations for full sample ($n = 80$)

Variable	Range	M (SD)	1	2	3	4	5	6	7	8	9	10
1. Age	19–74	40.76 (13.47)	—									
2. Se[a]	—	—	−0.217	—								
3. Autism traits	67–112	87.96 (9.52)	−0.004	0.060	—							
4. COVID-19 fear	15–38	26.80 (5.90)	0.110	0.022	0.011	—						
5. COVID-19 stress	0–20	5.56 (4.62)	**−0.212**	0.114	−0.052	0.153	—					
6. Daily hassles frequency	2–45	16.62 (9.48)	**−0.232***	0.026	0.063	**0.220**	**0.409****	—				
7. Daily hassles average stress	2.5–6.6	4.32 (0.91)	−0.095	**0.267***	**0.264***	0.151	0.195	**0.340****	—			
8. Perceived stress	6–39	24.80 (6.96)	−0.172	0.129	**0.236***	0.037	**0.379****	**0.344****	**0.639****	—		
9. Engagement coping	12–29	20.80 (4.11)	0.143	0.110	−0.054	0.077	−0.032	0.060	−0.185	−0.180	—	
10. Disengagement coping	5–19	9.60 (3.47)	−0.119	−0.119	0.199	0.041	0.144	**0.341****	**0.351****	**0.561****	**−0.329****	—
11. Resilience	0–37	18.40 (7.48)	0.019	−0.020	**−0.315****	0.007	−0.060	−0.099	**−0.334****	**−0.528****	**0.385****	**−0.610****

Note: BCa 95% confidence intervals that do not cross zero are in **bold** and significance based on p-values (*) are noted.

*$p < 0.05$.

**$p < 0.01$.

[a]Positive direction indicates female.

TABLE 3 Descriptive statistics (M, SD) for each coping-resilience profile

	High cope/low resilience ($n = 15$)	Low cope/high resilience ($n = 27$)	Engage cope/high resilience ($n = 20$)	Disengage cope/low resilience ($n = 18$)
	M (SD)	M (SD)	M (SD)	M (SD)
Age	40.84 (10.41)	36.63 (11.07)	47.55 (14.34)	39.89 (15.90)
Female (%)	8 (53.3)	20 (74.1)	15 (75)	11 (61.1)
Autism traits	89.87 (10.04)	86.30 (8.99)	86.60 (9.98)	90.78 (8.97)
COVID-19 fear	28.27 (6.33)	26.41 (6.06)	26.65 (6.03)	25.67 (5.90)
COVID-19 stress	7.00 (5.71)	4.70 (3.94)	5.00 (4.23)	6.00 (5.43)
Daily hassles frequency	19.47 (13.62)	14.59 (8.03)	15.50 (7.59)	18.72 (10.13)
Daily hassles average stress	4.28 (1.14)	4.22 (0.82)	4.09 (0.85)	4.73 (0.93)
Perceived stress	27.00 (6.35)	22.41 (5.73)	21.70 (7.55)	29.22 (5.64)
Engagement coping	23.53 (2.39)	18.89 (2.19)	25.25 (2.00)	16.44 (2.53)
Disengagement coping	11.60 (1.92)	7.41 (1.78)	7.10 (1.59)	14.00 (2.50)
Resilience	15.20 (6.69)	20.37 (5.06)	25.00 (5.00)	10.78 (5.30)

events encountered was 16.62 (possible range: 0–58) and the average daily hassles stress was 4.32 (possible range: 1–7).

General perceived stress was positively correlated with all other stress measures (i.e., daily hassles frequency and stress, and COVID-19 stress). Higher use of disengagement coping was associated with increased general perceived stress and average daily hassles stress, whereas higher levels of resilience were related to reduced general and daily hassles stress. Coping strategies and resilience were not significantly associated with either COVID-19 fear or COVID-19 stress.

Coping-resilience profiles

Four clusters were identified based on the examination of the intra-cluster sum of squared distances scree plot indicating a plateau or 'elbow', silhouette figures, and interpretability of clusters. The first group ($n = 15$) was characterized by high use of *both* coping strategies (i.e., Engagement and Disengagement coping), and low Resilience; hereafter labeled *high cope/ low resilience*. The second group ($n = 27$) was labeled *low cope/ high resilience*, reflecting low use of *both* coping strategies and high Resilience scores *relative* to the coping scores reported in this cluster. The third group ($n = 20$) reported high use of Engagement coping but low use of Disengagement coping, and high Resilience, and was subsequently labeled *engage cope/ high resilience*. The fourth group ($n = 18$) was labeled *disengage cope/ low resilience*, considering the high Disengagement coping, but low use of Engagement coping, and low Resilience scores. The composition of scores for each cluster can be seen in Figure 1 and Table 3. Standardized score composition for each cluster by sex is presented in the Supplemental (Figure A1).

Profile-differences across variables

Profile-differences across key variables are presented in Table 3. There were no between-group differences in relation to participant sex ratio [x^2 (3) = 2.752, $p = 0.431$], autistic traits, [F (3, 76) = 1.15, $p = 0.333$] or COVID-19 fear [F (3,76) = 0.527, $p = 0.665$]. While individuals in the *low cope/ high resilience* group were younger than the *engage cope/ high resilience* group [F (3, 76) = 2.74, $p = 0.049$], no other significant age differences between the groups were noted.

In relation to stress, significant profile differences were noted in general perceived stress, with large effect size [F (3, 76) = 6.40, $p = 0.001$, $\eta^2 = 0.20$]. As illustrated in Figure 2, the *high cope/ low resilience* group had higher general perceived stress compared to the *low cope/ high resilience* (BCa 95% CI = 0.62, 8.41) and *engage cope/ high resilience* (BCa 95% CI = 0.89, 9.97) groups. Likewise, the *disengage cope/ low resilience* group reported higher general perceived stress compared to the *low cope/ high resilience* (BCa 95% CI = −9.92, −3.59) and *engage cope/ high resilience* (BCa 95% CI = −11.76, −3.57) groups. No significant profile differences were noted across average daily hassles stress [F (3, 76) = 1.74, $p = 0.167$] or COVID-19 stress [F (3, 76) = 0.899, $p = 0.446$].

DISCUSSION

The primary aim of this study was to characterize the individual patterns of coping strategy use and resilience in a sample of autistic adults and subsequently examine its relationship with levels of general perceived stress and daily hassles stress. We also examined whether COVID-19 fear or COVID-19 related stress impacted our
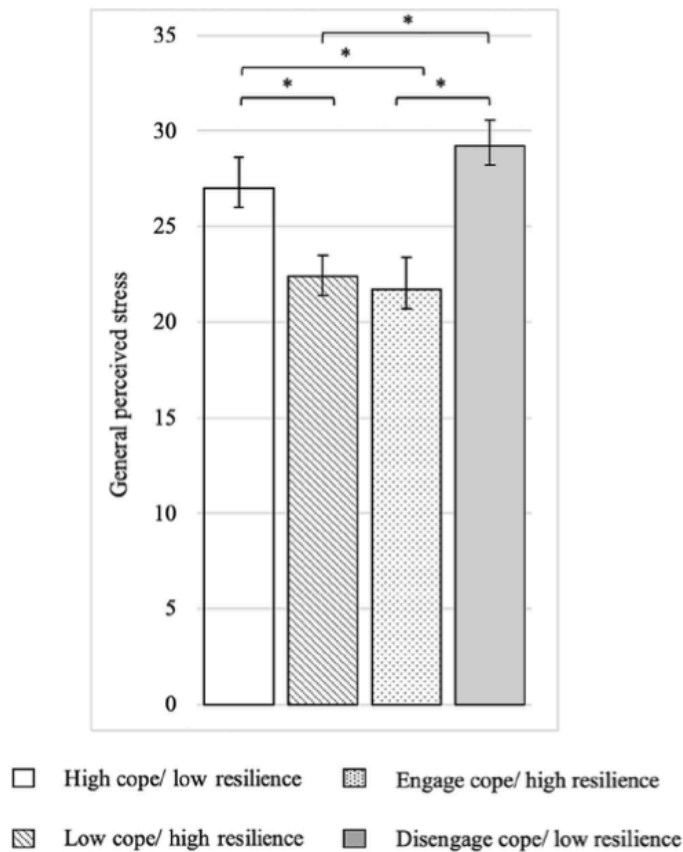
FIGURE 2 Profile differences in relation to general perceived stress. Bars represent stress scores (+/− *SE*). Bracketed bars with an asterisk (*) are significantly different.

findings. Based on the distribution of resilience, engagement coping and disengagement coping scores, four profiles were derived: *high cope/ low resilience*, *low cope/ high resilience*, *engage cope/ high resilience*, and *disengage cope/ low resilience*. Both the *high cope/ low resilience* and *disengage cope/ low resilience* groups reported significantly higher general perceived stress compared to the *low cope/ high resilience* and *engage cope/ high resilience* groups. However, no significant profile differences were found in relation to average daily hassles stress, COVID-19 related stress, or COVID-19 fear.

Relatively high levels of general perceived stress were noted in the current sample, with almost half the autistic adults (48.8%) reporting moderate stress, and more than a third (40%), high stress, corroborating findings of previous research surrounding high perceived stress in autistic adults (e.g., Bishop-Fitzpatrick et al., 2018; Bishop-Fitzpatrick et al., 2017; Hirvikoski & Blomqvist, 2015). The significant positive associations between general perceived stress and the other context-specific stress measures (i.e., daily hassles and COVID-19 stress) also suggests the influence of stress over specific contexts in an individual's overall sense of life stressfulness, and vice-versa. Thus, the measure of general perceived stress seems to have captured aspects of context-specific stress related to daily

life and COVID-19 pandemic disruptions in our sample of autistic adults during this time.

Daily hassles stress in the current sample (mean stress: 4.32) appeared relatively higher than population norms to date (i.e., score range of 2.22–2.59; Bell & D'zurilla, 2009; Brantley et al., 1987; Houle et al., 2012; Winzeler et al., 2014), although the frequency with which these hassles occurred (mean frequency: 16.62), while at the high end, was within the range of those reported for other adult samples (i.e., range: 9–17; Brantley et al., 1987; Orsega-Smith et al., 2004; Winzeler et al., 2014). As far as we know, this is the first study that captured a snapshot of both the frequency and stress of daily hassles in a sample of autistic adults; previous research has only explored daily hassles in autistic youth (Khor et al., 2014). These findings suggest that although autistic adults may not necessarily face an increased number of hassles and irritants in their everyday life, these encounters, as well as life in general, are perceived as more stressful. Future studies may benefit from measuring daily hassles in autistic adults over an extended period (e.g., using a weekly/ monthly hassles log or momentary time sampling) to examine potential changes in, or accumulation of hassles over time.

The four distinct profiles (i.e., *high cope/ low resilience*, *low cope/ high resilience*, *engage cope/ high resilience*, and *disengage cope/ low resilience*) identified through patterns of coping and resilience closely align with coping profiles identified in numerous non-clinical samples to date (e.g., Doron et al., 2014; Gadreau & Blondin, 2004; Seiffge-Krenke & Klessinger, 2000; Smith & Wallston, 1996). Indeed, although labeled differently, four coping profiles, characterized by both low and high use of *all* coping strategies, and the relative emphasis/de-emphasis of some strategies over others, have been commonly reported. This suggests that relying solely on the dominance of, or preference for some coping strategies over others does not adequately account for the ways in which individuals cope. There are individuals who use various strategies within their repertoire to similar degrees (i.e., both sparingly or frequently), as noted in our low and high cope groups. These findings mirror those reported in the autism emotion regulation literature where individuals are said to employ a repertoire of dispositional emotion regulation strategies that vary in nature and approaches, and that considering a combination of strategies is important in determining their joint impact on outcome measures (Cai et al., 2018). Our results not only complement the growing use of person-centered approaches in the coping literature (e.g., Freire et al., 2020; Hasselle et al., 2019), but our inclusion of resilience provides an additional dimension, indicating that while individuals may use a combination of coping strategies, these combinations may also co-occur differently with resilience, supporting the supposition that coping and resilience are inter-related and multidimensional in nature.

As hypothesized, the *engage cope/high resilience* group reported significantly less general perceived stress compared to the *disengage cope/low resilience* group. To remind the reader, *engage cope* reflects high use of engagement coping and low use of disengagement coping, whereas *disengage cope* refers to high use of disengagement coping and low use of engagement coping. While coping styles characterized by active, approach-oriented coping (i.e., high engagement, low disengagement coping) and high resilience are personal resources that have been separately associated with lower stress (e.g., Dabrowska & Pisula, 2010; Ong & Bergeman, 2004), it is plausible that the combination of both, as endorsed by some individuals, is beneficial in a cumulative manner in relation to individuals' stress experiences. This is congruent with the Conservation of Resources theory (Hobfoll 2002; Hobfoll et al., 2018), which postulates that individuals with high personal resources (e.g., high resilience) may further acquire, develop and preserve new resources (e.g., engagement coping strategy repertoire) making them less vulnerable to stress, whereas those with low resources (e.g., low resilience) may be on a downward spiral of losing resources (e.g., disengaging as a means of coping), making these individuals even more vulnerable to stress. In the context of stress in autistic adults, focusing on and developing engagement coping, reducing disengagement coping and improving resilience in conjunction with each other may be especially beneficial in creating an 'upward spiral' of resource gain (Hobfoll, 2002, 2011).

Differences in average daily hassles stress and COVID-19 stress between the *engage cope/high resilience* group and the *disengage cope/low resilience* group did not reach statistical significance. The lack of profile differences in these latter measures of stress may be related to them being context specific. Indeed, as coping-resilience profiles in the present study were derived using coping and resilience scores measured using a dispositional approach, it is possible that potential discrepancies in context-specific stress, if any, would be best-captured using coping and resilience measures that are also situation-specific. It may be worthwhile for future studies to examine situational coping-resilience profiles in response to specific stressful encounters to continue unpacking the relationships between coping, resilience, and stress in the autistic population. Further, although unexamined in and beyond the aims of the current study, there are constructs such as perceived control (Dijkstra & Homan, 2016; Ong & Bergeman, 2004) and self-efficacy (Benight & Cieslak, 2011; Hamill, 2003) which may impact both coping and resilience. Exploring these constructs in the context of stressful encounters may further elucidate the mechanisms that underlie the associations between coping and resilience, and subsequent levels of perceived stress in the autistic population.

Of particular interest was the *low cope/ high resilience* group, which formed about a third (33.8%) of the sample

and the relatively low levels of stress reported across the three stress measures. This 'low coper' profile, reflecting a low use of both coping strategies, is not uncommon in the literature and has been similarly noted in other samples to be associated with relatively good outcomes such as reduced stress, pain, depressive and emotional symptoms, and higher personal adjustment (Aldridge & Roesch, 2008; Doron et al., 2014; Smith & Wallston, 1996; Steele et al., 2008). It is possible that the low use of engagement coping in the *low cope/ high resilience* group may have been buffered by both a similarly low use of disengagement coping and high resilience, with resulting lower stress. Nevertheless, the cross-sectional data in our study limits our ability to establish the direction of these relationships and it is just as possible that individuals who perceive less stress in their lives simply have less to cope with, and thus utilize all coping strategies to a lesser extent. Longitudinal data in future studies would be especially important in determining the directions of these relationships. Similarly, we note that the *low cope/ high resilience* group was younger in age compared to the *engage cope/ high resilience* group. While this might indicate the broadening of coping strategy repertoire with age, future longitudinal research may be better able to ascertain the stability of coping-resilience profiles over time, and whether individual profile membership may change with age.

A key practical implication from this study is the need for personalization of stress support and intervention options. Although not all autistic adults experience high stress, the use of coping-resilience profiles could help identify those at highest risk of experiencing stress (i.e., *disengage cope/ low resilience* or *high cope/ low resilience* groups), especially during times when stress may be expected (e.g., transitional periods, occurrence of significant life changes). Based on coping-resilience profiles, individual-specific aspects of coping and resilience can be determined and addressed according to individual need. For example, autistic individuals characterized by the *high cope/ low resilience* profile may be more susceptible to high perceived stress and may therefore benefit from interventions focusing on reducing disengagement coping tendencies and increasing resilience (thus shifting them towards a lower stress risk profile). On the other hand, individuals presenting with an *engage cope/ high resilience* profile may not be at risk for high perceived stress and may not require coping strategy or resilience-related support at the time of assessment.

Beyond this, these profiles can also be useful in providing an initial snapshot of an individual's current repertoire of coping strategies and levels of resilience, subsequently informing more in-depth discussions with them surrounding self-beliefs, experiences of recovery after challenging events, effectiveness of and motivations behind preferred coping strategies, as well as potential barriers which may impede the use of certain coping strategies. It is possible for example, that disengagement

coping strategies, which are frequently endorsed in the autistic population (e.g., Muniandy et al., 2022), may be helpful for autistic adults in a way that was not captured in the present study. Indeed, disengaging from stressful encounters, at least briefly, may be beneficial in allowing individuals to avoid further input, stimulation or sensory overload (Crane et al., 2009; Halim et al., 2018).

Interventions in autistic adults have largely focused on reducing symptoms of co-occurring mental health conditions (Benevides et al., 2020). Although some of these may already incorporate elements of coping and resilience among their areas of focus (McGillivray & Evert, 2014; Oswald et al., 2018), interventions with an explicit focus on stress reduction and management in autistic adults are relatively limited. Further, while there are promising programs referred to as resilience interventions with autistic youth (e.g., Resourceful Adolescent Program–Autism Spectrum Disorder, RAP-ASD; Shochet et al., 2022 or Resilience Builder Therapy Program, RBP; Habayeb et al., 2017), these interventions do not incorporate resilience as a primary target or outcome measure. As far as we know, stress interventions are yet to be designed and conducted in autistic adults, which specifically target and measure coping strategy use and resilience.

Our consideration of resilience in addition to coping in autistic adults supports the increasing focus on stress reappraisal and mindset interventions in the wider stress-management literature (e.g., Hagger et al., 2020; Jamieson et al., 2018), which aims for stressors to be re-interpreted as challenging, enhancing and to be approached (rather than threatening, deleterious and to be avoided), not unlike the characteristics reflected in resilience. For example, interventions which focus on identifying and altering maladaptive thinking or disem-powering interpretations of situations (e.g., catastrophising or overgeneralizing) can help reduce the likelihood of individuals succumbing to their stressful encounters or feeling defeated, thus enhancing their resilience levels. A joint focus on coping strategies would allow individuals to build on their coping strategy repertoire, limit the use of unhelpful coping strategies (e.g., alcohol use), and improve self-efficacy surrounding their coping abilities. Indeed, there is evidence surrounding the effectiveness of interventions targeting both resilience and coping in improving overall well-being across non-autistic samples (Burton et al., 2010; Steinhardt & Dolbier, 2008). In particular, the use of Cognitive Behavioral Therapy (CBT) and mindfulness-based approaches has been noted to be effective in the promotion of resilience and resilience-related factors (such as coping) in the general population (Joyce et al., 2018).

When considering the autistic adult population, stress interventions focusing on coping and resilience, through the incorporation of mindfulness-based approaches (e.g., acceptance, being calm and present) and CBT-based approaches (e.g., cognitive appraisals and

flexibility, problem solving skills) can be beneficial in fostering adjustments to stressful encounters (Helmreich et al., 2017), and may result in reduced perceived stress and other negative stress-related outcomes. Such interventions would be best designed in collaboration with the autistic community, where suitable adaptations (e.g., communication methods, use of language; Spain & Happé, 2019; Spek et al., 2013), as well as potential autism-unique considerations for promoting coping and resilience may be identified. For example, given that a sense of social inclusion and belonging has been highlighted by autistic adults as important in their development of resilience and coping (Ghanouni & Quirke, 2022), fostering positive relationships and building support systems for autistic adults may be an important area of focus. It would also be useful for these interventions to utilize coping and resilience measures using psychometric tools that have been validated for use in this population, such as the Brief COPE and CD-RISC-10.

Considerations, limitations and future directions

The COVID-19 pandemic continues to be an evolving phenomenon. While there is emerging evidence to suggest its deleterious effects on stress and well-being in autistic individuals (e.g., Ameis et al., 2020; Corbett et al., 2021), the impact of the pandemic will inevitably vary between individuals (Hedley et al., 2021). This is not unlike other contexts in stress research, where despite the use of specific measures of stress and stressor encounters, there remains individual differences in other sources of stress that may be unexamined and unaccounted for. The present study was uniquely placed in the presence of the COVID-19 pandemic, a large-scaled, universal stressor faced by all study participants. Further, our incorporation of general and dispositional measures was useful in limiting the impact of contextual factors and individual differences across the examination of stress, coping, and resilience.

While the present study addresses several current gaps in the autism literature, it also includes some limitations. First, due to the relatively modest sample size, replication using a larger sample to evaluate the robustness of the four coping-resilience profiles is recommended. Although there are no clear rules-of-thumb regarding minimum sample sizes in cluster analytical procedures (see Sarstedt & Mooi, 2014 or Dalmaiher et al., 2022), a larger sample of autistic adults could improve generalizability of our results. Larger sample sizes may be more sensitive to stress differences in relation to daily hassles, or may be able to detect statistically significant stress differences between the two higher perceived stress groups (i.e., *disengage cope/ low resilience* and *high cope/ low resilience*), and the two lower perceived stress groups (*engage cope/ high resilience* and *low cope/ high*

resilience). Such studies may also allow for more reliable comparisons of coping-resilience profiles across other demographic measures such as adult life stages (e.g., young adults vs older adults), as well as other measures more commonly used to characterize the autistic population (e.g., IQ, adaptive functioning, quality of life).

Next, while the present study measured coping by examining the use of engagement and disengagement coping strategies given their associations with stress in the literature, future studies should consider exploring other coping strategies as they may interact differently with resilience. For example, the use of proactive coping, which involves the anticipation of potential stressors and the incorporation of future-oriented strategies to prevent these from occurring (Greenglas & Fiksenbaum, 2009) may be similarly reflected in more resilient individuals.

Third, our sample included an overrepresentation of female participants (66%), as is similarly reported in online survey studies in autistic and non-autistic samples (e.g., Kapp et al., 2013; Nicolaidis et al., 2013). While the lack of sex differences between the profiles suggests that group-differences were not influenced by sex, it may prove useful for future studies with larger samples to characterize coping-resilience profiles separately in males and females to confirm whether or not sex-differences in patterns of coping strategy use and levels of resilience d exist. Relatedly, it would be important for future research to examine stress and stress-related constructs such as coping and resilience within the context of gender diversity. From an intersectionality perspective, it is possible that gender diverse autistic individuals have unique experiences of stress, or reflect different patterns of coping strategies, compared to cisgendered autistic individuals. Additionally, although the constructs of coping, resilience, and perceived stress are commonly examined together in the broader stress literature, it is possible that there are conceptual overlaps between these constructs, which could artificially inflate the relationships between coping-resilience profile membership and levels of perceived stress. Item-level comparisons across the measures used here did not identify items identical enough to warrant item deletions, however, future research to determine the distinctiveness of these stress-related constructs and the extent of any potential overlap, both at the conceptual- and item-levels in the autism population may be warranted.

Finally, the cross-sectional nature of the data limits our ability to draw causal conclusions. Although we can conclude that individual levels of resilience and coping patterns may confer risk in response to levels of stress experienced, it is equally possible that experiences of stress can influence the resilience and coping strategies used. Indeed, experiences of extreme or chronic stress are likely to impact individual abilities and resources, subsequently influencing the individual's capacities to both withstand and to cope with demands (e.g., Cicchetti &

Rogosch, 2009; Schetter & Dolbier, 2011). Although extreme levels of stress were not indicated in any of our stress measures, future work with a longitudinal design would allow for a deeper understanding of the associations between resilience and coping patterns, and stress in autistic adults.

CONCLUSION

In conclusion, the present study offers significant insight into coping and resilience patterns in relation to stress in autistic adults, an otherwise limited area of research in this population. Our findings suggest distinct patterns of coping strategies and resilience on an individual level across four distinct profiles, where autistic adults characterized by the *disengage copel low resilience* and *high copel low resilience* profiles are likely to be at highest risk for elevated stress and may benefit most from stress-related intervention. Jointly addressing coping and resilience may positively impact the degree of stress experienced by autistic adults, and in turn, has potential to cascade positively into other areas of life such as physical and psychological health, well-being and quality of life.

CONFLICT OF INTEREST
The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT
The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT
Ethics approval was provided by La Trobe University Human Ethics Committee (HEC19443).

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

Chapter 12: General Discussion

Chapter Overview

The overarching aim of this thesis was to explore and build on the limited yet emerging literature on coping and resilience, and their relationships with stress and mental health outcomes in autistic adults. Despite the consensus that both poor mental health and psychological well-being commonly occur in the autistic adult population, a comprehensive understanding of potential contributing factors, particularly from a stress perspective, has been lacking (Chapter 1). Autistic adults face greater exposure to negative life events and elevated levels of perceived stress, with higher levels of stress associated with poorer outcomes (Chapter 2; Part 1). Nevertheless, the coping literature in autism to date has focused almost exclusively on coping strategy use in autistic children and adolescents (Chapter 2; Part 2). Further, none of these prior coping studies utilised coping measures validated for use in autistic individuals, making it unclear if autism-specific aspects of coping were appropriately captured. Resilience research in the autistic population has been similarly scarce, with the underlying associations between resilience and coping, and how they might relate to stress and mental health in autistic adults not yet known (Chapter 3). These literature gaps informed the theoretical and analytical frameworks employed in the empirical work presented in this thesis.

As the results of each empirical study presented in this thesis have been discussed in detail in their respective chapters, the purpose of this concluding chapter is to present a broader synthesis of the findings and an overarching discussion within the wider context of the relevant literature. As a reminder, an overview of the six empirical chapters and a summary of their findings is provided next (Table 1). In the following sections, a summary and implications of the study findings, reflections on the current research's strengths and limitations, as well as suggestions for future empirical and clinical directions are discussed.

Table 1

Research aims, empirical chapters and summary of chapter findings

Research aims	Chapters	Summary of chapter findings
Coping structure and measurement	Chapter 6 (Study 1): Factor structure and psychometric properties of the Brief COPE in autistic older adolescents and adults	Exploratory factor analysis on the Brief COPE identified six-factor coping structures in both autistic and non-autistic adults, with minor item discrepancies, validating the use of the Brief COPE in the autistic adult population.
Coping associations with mental health	Chapter 7 (Study 2): Associations between coping strategies and mental health outcomes in autistic adults	Cross-sectional multiple regression analyses highlighted the role of engagement coping as a protective factor and disengagement coping as a risk factor for poor mental health outcomes in autistic adults.
	Chapter 8 (Study 3): Longitudinal role of coping strategies on mental health outcomes in autistic youth and adults	Longitudinal (2-year) analyses supported the predictive role of coping on follow-up mental health while accounting for baseline mental health, as well as demonstrating the significance of changes in coping strategy and the usefulness of coping ratios in relation to follow-up mental health.
Stress-moderating role of coping	Chapter 9 (Study 4): Stress and well-being in autistic adults: exploring the moderating role of coping	Moderation analyses showed the moderating role of engagement coping but not disengagement coping in the stress-well-being relationship in autistic adults. Engagement coping played a stress-buffering role but disengagement coping strategies did not play a stress-exacerbating role on well-being.
Coping-resilience interactions	Chapter 10 (Study 5): Inter-relationships between trait resilience, coping strategies and mental health outcomes in autistic adults	Mediation analyses revealed the mediating role of coping strategies in the resilience-mental health relationship in autistic adults. Disengagement coping mediated the relationship between resilience and depression, anxiety and well-being, whereas engagement coping only mediated the relationship between resilience and well-being.
	Chapter 11 (Study 6): Coping-resilience profiles and experiences of stress in autistic adults	Cluster analysis identified four distinct coping-resilience profiles based on coping strategy and resilience patterns in autistic adults. These profiles were differentially associated with levels of general perceived stress.

12.1. Mental Health Outcomes and Experiences of Stress

As previously discussed in Chapter 1, mental ill-health is prevalent in the autistic adult population (Griffiths et al., 2019; Hollocks et al., 2019; Maddox & White, 2015), with higher levels of anxiety and depression symptomatology compared to the general population (Brody et al., 2018; Buck et al., 2014; Remes et al., 2016). Similarly high levels of anxiety and depression were noted across the studies in this thesis. Specifically, across Chapters 6, 7, 8 and 10, 44.8% – 48.6% of autistic adults met the clinical cut-off for depression on the Patient Health Questionnaire-9 (PHQ-9), while 39.1% - 45.5% met the clinical cut-off for anxiety on the DSM-5 Generalised Anxiety Disorder Dimensional Scale (DSM 5 GAD-D). These proportions are significantly higher than found for the non-autistic adults in Chapters 6 and 7, where only 17.6% and 10.9% met the clinical cut-off scores for depression and anxiety, respectively. When considering psychological well-being, the autistic adults in Chapter 7 reported significantly lower well-being on the Warwick Edinburgh Mental Well-being Scale (WEMWBS) compared to the non-autistic adult sample, with even lower WEMWBS scores reported by the autistic adults in Chapter 9. Thus, using both negative (anxiety and depression) and positive (psychological well-being) mental health indicators, findings across these studies support poorer mental health outcomes reported in the autistic adult population to date.

As noted in Chapter 2, autistic adults more frequently face life stressors and negative life events (Moseley et al., 2021) and experience a greater number and more varied everyday hassles compared to non-autistic individuals (Twachtman-Cullen, 2006). Perceptions of overall stress in life are also higher among autistic adults compared to non-autistic adults (Bishop-Fitzpatrick et al., 2015, 2017a; Hirvikoski & Blomqvist, 2015), even when the frequency or intensity of stressor encounters are controlled for (Moseley et al., 2021). Measures of stress were included in Chapters 9 and 11, capturing

general perceptions of stress (Perceived Stress Scale; PSS), frequency and stress over daily hassles (Daily Stress Inventory; DSI), as well as perceived stress of COVID-associated changes in major life domains (i.e., employment, education, living situation and social relationships). Consistent with the extant literature in autism, relatively high levels of perceived stress were reported in the study sample, with more than a third (40%) of autistic adults reporting high stress and almost half (48.8%) moderate stress. The mean PSS score reported in the sample of autistic adults (24.80) was high and comparable to the sample of autistic adults in McQuaid et al. (2022; $N = 713$, mean PSS score $= 22.81$), whose stress scores were noted to be significantly higher than that of the general population.

The frequency of daily hassles encountered by autistic adults in the reported studies was somewhat elevated but within the range of daily stressors faced by other adult samples (e.g., Orsega-Smith et al., 2004; Winzeler et al., 2014). While this may appear inconsistent with the notion that autistic individuals face more frequent negative events and stressor encounters, there are several possible explanations. Groden et al. (2001) noted that encounters characterised by social interactions, sensory difficulties and uncertainty can be particularly stressful for autistic individuals. It is possible that daily hassles that tap into these areas are not adequately captured by the DSI, an index of daily stressors developed and normed for the general population. For example, although the DSI has items that reflect interpersonal problems (e.g., 'argued with another person' or 'criticised or verbally attacked'), it does not include items that capture anticipation or uncertainty surrounding social interactions, or having to socialise in unfamiliar environments, both of which may be sources of stress for autistic individuals.

Additionally, as the Resilience Pathways of Autistic Adults Study (RPAAS) was conducted during the ongoing COVID-19 pandemic, the likelihood of encountering some

of the events listed in the DSI, such as 'Spoke or performed in public', 'Dealt with a rude waiter/ salesperson' or 'Experienced unwanted physical contact (e.g., in crowds)' would have been reduced, particularly in the face of the Australian COVID lockdowns. Nevertheless, perceived stress over daily hassles in the autistic adult sample was higher than population norms reported to date (e.g., Houle et al., 2012; Winzeler et al., 2014), suggesting that these daily hassles, even if not encountered more frequently, were perceived as more stressful by autistic adults. In relation to the COVID-associated changes in major life domains, autistic adults reported these changes and disruptions as ranging from moderately stressful to very stressful; a more detailed discussion of this is provided next in Section 12.2.

Together, these stress findings suggest high levels of perceived stress among autistic adults, where the positive associations between the broader (general perceived stress) and context-specific (daily hassles, COVID stress) measures of stress might indicate the bi-directional influence and overlap between these different contexts of stress. In addition, higher stress measured using a composite stress variable (PSS, DSI) in Chapter 9 was related to reduced well-being, suggesting the role of stress as a potential risk factor for poor mental well-being in autistic adults. This finding supports findings in the autism (e.g., Moseley et al., 2021) and broader stress literature (e.g., Gomes & Teixeira, 2016; Lu et al., 2019), highlighting how perceived stress may at least partially account for the suboptimal levels of well-being in this population.

12.2. COVID-19 Pandemic Considerations and Implications

As the ongoing COVID-19 pandemic continues to be an evolving situation, its long-term impact and repercussions in the autism community are not yet fully understood and are likely to be complex and influenced by individual differences (Baweja et al., 2022; Maljaars et al., 2022; Oomen et al., 2021). Despite some evidence for a decline in

mental health in autistic adults (Pellicano et al., 2021), others reported stable (Adams et al., 2021) or improved (Bundy et al., 2022; Fancourt et al., 2021) mental health during the pandemic. RPAAS (Chapters 9 and 11) was conducted during the height of the COVID-19 pandemic and government-regulated 'lockdowns' in Australia. Nevertheless, psychological well-being as measured by the WEMWBS (37.85) in Chapter 9 was comparable to the large autistic adult sample used in Chapters 6 and 7 (40.08), conducted pre-pandemic.

A small percentage of the RPAAS adult sample reported personal exposure to COVID, with 1.2% ($n = 1$) having been diagnosed with COVID, while 7% ($n = 6$) reported diagnoses of COVID in friends and/ or family. Although COVID fear, as measured by the FCQ in the autistic adults was comparable to that of other non-autistic adult samples (e.g., Mertens et al., 2020; Vos et al., 2021), level of fear was not significantly related to outcome measures such as stress or well-being. While this is inconsistent with other studies reporting associations between COVID fear with stress and mental health such as anxiety and depression (Bitan et al., 2020; Fitzpatrick et al., 2020; Vos et al., 2021), it is important to note that many of these studies utilised data collected during the early stages of the pandemic, when stress and mental health would have been most impacted. RPAAS was conducted between June to November 2020, during the second COVID wave in Australia (June to October 2020). It is possible that by this time, while people remained fearful of COVID, the impact of this fear on mental health and well-being had waned. Further, during the time RPAAS was conducted, the COVID infection rate in Australia was relatively lower (i.e., 0.25 – 21.08 new cases per million people) compared to other countries such as the United States (60.89 – 530.57) and the United Kingdom (5.49 – 375.23) in this time (Mathieu et al., 2020).

When considering COVID-related changes and disruptions, most (n = 74; 86%) autistic adults in RPAAS experienced changes and disruptions in at least one of four life domains: employment, education, living situation and social relationships. Interestingly, the autistic adults who experienced changes and/or disruptions in employment (including working conditions and arrangements) reported significantly better well-being than those who did not experience such changes. The increased well-being associated with employment changes supports the employment literature concerning autistic adults, where they have voiced their preferences for the provisions of more workplace adjustments and accommodations such as working from home, less social expectations and more work flexibility (Baldwin et al., 2014; Harvery et al., 2021). This finding not only suggests that pre-pandemic work conditions and expectations have been suboptimal for autistic adults, but that they may also have been detrimental for their psychological well-being.

Like mental health outcomes, there was an inherent amount of heterogeneity in the perceptions of stress over pandemic-related disruptions. Although some research reported high stress in the autistic population due to pandemic-related factors such as the lack of clarity in relation to ever-changing governmental guidelines (e.g., Pellicano et al., 2021) or financial and employment uncertainties (e.g., Bundy et al., 2022; Goldfarb et al., 2021), others noted that the pandemic helped reduce stressors characterised by social obligations and sensory overload (Oomen et al., 2021). Of note across Chapters 9 and 11 was that nearly 40% of adults reported changes in social relationships as 'very stressful'. Although social distancing and isolation may be considered somewhat 'common' for some autistic individuals, as may be reflected by limited social networks (Orsmond et al., 2013) and increased rates of loneliness (Ee et al., 2019), there is a difference, and

consequently, a difference in associated stress, when individuals are forced into self-isolation out of a public health necessity (den Houting, 2020).

To encapsulate total stress over pandemic-associated disruptions and changes across the four life domains, a COVID stress score was calculated; however COVID stress due to these disruptions was not related to levels of well-being. Approximately 55% of RPAAS participants lived in the state of Victoria, which had the longest and most restrictive lockdowns in Australia. It may be that by the time RPAAS was conducted (June – November 2020), the impact and stress of these disruptions, which began in March 2020, had reduced. The easing of restrictions towards the end of this time (October 27th 2020) could have also reduced the negative impact on the well-being of later participants.

Nevertheless, as summarised by Bundy et al. (2022, pg. 1766) 'it is likely the pandemic's impact on autistic people has been complex, variable and perhaps not unequivocally negative'. Chapters 9 and 11 were uniquely placed within a large-scale, global pandemic faced by all study participants. This is not dissimilar to other contexts in stress research more broadly, where despite a common group or societal stressor experienced by all, there will always be individual differences in other sources of stress or other confounding factors which remain unexamined or unaccounted for. Considering this heterogeneity in experiences of stress and mental health, understanding how individual resources such as coping strategies and resilience may relate to and influence these high levels of stress and poor mental health outcomes is therefore pertinent.

12.3. Coping Strategies and Resilience in Autistic Adults: Summary and Implications of Findings

As seen in Table 1, the present thesis had four main aims, which were addressed across six empirical studies reported in Chapters 6 to 11. This section provides a

discussion of these results and their implications.

12.3.1. Coping Patterns in Autistic Adults

Exploratory factor analysis of the 28-item Brief COPE in Chapter 6 suggested a conceptually similar six-factor structure in both the autistic and non-autistic adult samples (Engagement, Support-seeking, Disengagement, Substance-use, Humour and Religious Coping). The six coping factors are in line with the median number of six extracted coping factors (range of two to 12) reported in a systematic review of factor analytic studies using the Brief COPE (Krägeloh, 2011). Consistent with other studies (e.g., Kapsou et al., 2010; Pozzi et al., 2015), three broader coping categories were also noted in both adult samples characterised by: 1) active, approach-oriented engagement strategies, 2) seeking emotional and/or instrumental support from others, and 3) passive, avoidance-oriented disengagement strategies. In particular, the engagement and disengagement coping categories in both samples reflected coping strategies directed towards and away from a stressor and/ or its associated emotions respectively, mapping closely to the engagement-disengagement coping dimensions reported in the wider coping literature across non-autistic samples (Compas et al., 2012; Dijkstra & Homan, 2016). While there have been discrepancies in coping categories identified and examined in the wider literature, Carver and Connor-Smith (2010) concluded that 'the distinction that appears to have greatest importance is engagement vs. disengagement' (p.687), reflecting the two key coping categories reported in Chapter 6.

Although six conceptually similar coping factors were found in the autistic and non-autistic samples, minor item-level discrepancies across the factor structures highlighted the importance of utilising measures and tools validated specifically for autistic populations to capture population-unique differences. Of particular note was the use of self-distraction coping strategies (i.e., 'I've been turning to work or other activities

to take my mind off things' and 'I've been doing something to think about it less such as going to the movies, watching TV, reading, daydreaming, sleeping or shopping'), which for the non-autistic adults loaded on the Engagement Coping factor, but for autistic adults, loaded highest on the Disengagement Coping factor (albeit were dropped from the scoring due to low strength <0.4). It is possible that distracting oneself and refocusing one's attention on other activities as a means of coping is interpreted as active and constructive in non-autistic adults, but not in autistic adults. The difference in interpretation may be related to how preferred activities are broadly framed within and outside of autism. While focused interests and activities in non-autistic individuals are typically described as hobbies and are said to facilitate positive outcomes, these activities have a more negative connotation in autism, referred to as 'special interests', and are often described as unusual, intense or an obsession (Jordan & Caldwell-Harris, 2012; Nowell et al., 2021; Winter-Messiers, 2007).

Although most coping research suggests that strategies characterised by features of avoidance and disengagement are primarily unhelpful (Carver & Connor-Smith, 2010; Zimmer-Gembeck & Skinner, 2016), Waugh et al. (2020) proposed that positive distraction coping strategies can be adaptive, particularly those involving engagement in leisure activities that induce positive emotions or orient individuals towards neutral targets. While activities used with the intention to avoid a stressor can have a detrimental impact on outcomes in the long term, leisure activities used as 'planned breathers' or short-term distractions can help allow individuals time to calm down and regulate themselves (Patry et al., 2007; Tsaur & Tang, 2012). In autism, participation in leisure and recreational activities can help autistic youth cope with the stresses of life (Folta et al., 2022) and buffer the impact of stress on quality of life (Bishop-Fitzpatrick et al.,

2017b). However, the short- versus long-term impact of these activities as a coping strategy is not known.

Thus, it is not the activity per se but the intention underlying the use of such activities as coping strategies that may determine their impact on short- and long-term outcomes. Indeed, there are differences in the short- and long-term impact of coping strategies. Avoidant coping strategies may be an adaptive response to uncontrollable stress in the short-term but can lead to negative consequences such as prolonged stress and unresolved trauma in the long-term (Newman et al., 2011). Although not captured using the Brief COPE, coping studies that determine the duration of and intention behind the use of specific coping strategies (e.g., disengagement) in autistic adults would provide a better understanding of the role and meaning of such coping strategies, and therefore their subsequent impact on outcomes.

Using the Brief-COPE factor structure obtained in Chapter 6, coping patterns in autistic and non-autistic adults were examined in Chapters 7 to 11. In Chapter 7, across the six coping categories in both the autistic and non-autistic samples, engagement coping strategies were used most often, and substance-use coping strategies least often. Further, comparisons of coping patterns between the autistic and non-autistic adults revealed significantly higher use of disengagement coping strategies in the autistic sample. However, both autistic and non-autistic adults reported comparably high use of engagement coping strategies. The elevated use of avoidant, disengagement coping strategies in autistic adults aligns with coping and emotion regulation strategy patterns reported in the broader autism literature (e.g., Bruggink et al., 2016; Rieffe et al., 2014; Samson et al., 2012). These findings indicate that while autistic adults may utilise active, engagement coping strategies when faced with stressful encounters as frequently as in the general population, they also report higher use of avoidance and disengagement coping

strategies. Thus, considering several coping strategies in conjunction with each other, rather than each in isolation is important as it may provide a more holistic picture of coping patterns in autistic adults.

Indeed, individuals are likely to utilise a repertoire of coping strategies, to differing degrees, at varying stages of a stressful encounter (Folkman & Lazarus, 1985). It is also probable that differing coping strategies interact, where the effects of some coping strategies may be suppressed or enhanced when used alongside other coping strategies. As noted in Chapter 2, the use of coping profiles considers the concurrent use of coping strategies, characterising individuals based on their unique patterns and combinations of coping strategies (e.g., Doron et al., 2014; Steele et al., 2008). Methods such as using a 'coping ratio' (relative use of engagement coping strategies to disengagement coping strategies; Chapter 8) or coping profiles (identification of subgroups based on differing coping patterns; Chapter 11) are ways to begin unpacking the roles of coping strategies in relation to stress and mental health outcomes in autism.

12.3.2. Risk and Protective Factors: Disengagement Coping and Engagement Coping Strategies

Mirroring the broader coping literature, findings across Chapters 7 to 9 showed that higher use of disengagement coping strategies was related to poorer mental health outcomes (i.e., higher depression and anxiety, and lower well-being) in autistic adults, both cross-sectionally and longitudinally. It was also observed in Chapter 8 that increased use of disengagement coping strategies over a two-year period significantly predicted poorer mental health outcomes at follow-up, even when prior levels of mental health were accounted for. These results suggest autistic adults who report high use of disengagement coping strategies, or who are on a trajectory of increasing use of such strategies over time, may be placed at higher risk for poor mental health outcomes in the

future. Results from Chapters 7 to 9 also indicated that high use of engagement coping strategies was cross-sectionally and longitudinally associated with better psychological well-being in autistic adults. As further noted in Chapter 8, it was the *increase* in engagement coping strategy use over time that significantly predicted higher well-being at follow-up, compared with baseline levels. These findings suggest that high use of engagement coping, increasing the frequency of engagement coping strategies or broadening the repertoire of such strategies may contribute to the promotion of psychological well-being in autistic adults.

These risk and protective roles of disengagement and engagement coping strategies, respectively in relation to mental health align with findings from the wider, non-autistic literature (e.g., Coiro et al., 2017; Kapsou et al., 2010; Saxon et al., 2017). The differential significance of engagement and disengagement coping strategies in relation to positive and negative mental health indicators also supports findings from other non-autistic coping literature to date (e.g., Fino et al., 2022; MacIntyre et al., 2020; Taylor & Stanton, 2007). Although the significance of engagement coping to improved well-being was not replicated in the non-autistic adult sample (Chapter 7), the item composition of engagement coping differed between the autistic and non-autistic samples, where self-distraction coping strategies were included in engagement coping for the non-autistic adults but not for the autistic adults (Chapter 6). Thus, although distracting oneself to focus on other activities was interpreted more positively by non-autistic adults (i.e., loaded on engagement coping) and therefore construed as constructive, these self-distraction coping strategies may not necessarily lead to better well-being. Alternatively, engagement coping strategies may be more important for the promotion of psychological well-being in autistic adults compared to non-autistic adults.

Having independently established the relationships between engagement and disengagement coping strategies and mental health outcomes for autistic adults, the relative use of both coping strategies and how this might predict follow-up mental health outcomes was examined in Chapter 8. Findings revealed that a higher coping ratio at baseline, that is, an increase in engagement coping relative to disengagement coping, at baseline significantly predicted lower anxiety and better well-being at follow-up, while an increase in the coping ratio over time significantly predicted lower depression and anxiety, and better well-being at follow-up. These findings suggest that jointly addressing both coping strategies, that is, increasing engagement coping and decreasing disengagement coping (i.e., increasing an individual's coping ratio score) may have the most beneficial impact on mental health and well-being for autistic adults. The importance of considering the multi-dimensional nature of coping aligns with reports from the emotion regulation literature, whereby adaptive and maladaptive ER strategies have been found to jointly impact the mental health and well-being of autistic adults (Cai et al., 2018).

When examining the role of coping strategies in the context of stress (Chapter 9), although disengagement coping strategies had a significant, negative, main effect on well-being, these strategies did not play a stress-moderating (i.e., stress-exacerbating) role. The lack of a moderating relationship indicates that although autistic adults with high use of disengagement coping strategies consistently reported lower well-being than those with low use of these strategies, the high use of disengagement coping strategies did not further exacerbate the negative effects of stress on their well-being. Thus, the extent to which disengagement coping strategies were used (i.e., low or high use) did not impact the relationship between stress and well-being in these autistic adults. The lack of a stress-exacerbating role for disengagement coping strategies mirrors some existing

coping literature (e.g., Barnes & Lightsey Jr, 2005; Coiro et al., 2017; Evers et al., 2022; Suldo et al., 2008) but not others (e.g., Gillett & Crisp, 2017; Yip et al., 2008), highlighting the inconsistencies and heterogeneity across study samples, coping strategy and outcome measures, as well as stress contexts in the literature. A further explanation for these inconsistencies may be related to the potentially complex nature and underlying intentions of disengagement coping strategies where, as discussed in Section 12.3.1, such strategies are not necessarily inherently maladaptive and may have the potential to provide some relief and distance from current stressors.

In contrast, engagement coping strategies positively associated with well-being and moderated the impact of stress on well-being, depending on the level of stress reported. Thus, engagement coping strategies played a stress-buffering role, mitigating the negative effects of stress on well-being. Autistic adults who reported lower use of engagement coping strategies showed a sharper decline in their well-being as levels of stress increased, compared to those with higher use of engagement coping strategies. These findings are in line with other adult studies which note the stress-buffering role of coping strategies that are approach and engagement-oriented (e.g., Cheng et al., 2012; Suldo et al., 2008) but are inconsistent with Evers et al. (2022) who did not find adaptive coping strategies to moderate the stress-mental health relationship in autistic adults. A likely reason for this latter inconsistency may be related to the measures of mental health, where Evers et al. examined negative facets of mental health (i.e., anxiety and depression), while Chapter 9 explored psychological well-being, a positive facet of mental health. As reported in Chapters 7 and 8, and in line with the wider coping literature (e.g., Fino et al., 2022; Taylor & Stanton, 2007), coping strategies can differentially relate to positive and negative aspects of mental health. Developing and harnessing the use of engagement coping strategies in autistic adults, particularly in the

context of high stress, may therefore prove particularly beneficial for promoting well-being.

Overall, the coping-mental health literature in autism has almost exclusively focused on autistic children and adolescents to date, with inconsistent findings across these studies. Findings from Chapters 7 to 9 represent the first studies to demonstrate the role engagement and disengagement coping strategies may play for the mental health of autistic adults concurrently, prospectively and jointly, illustrating the differential associations across coping strategies with positive and negative aspects of mental health. While engagement coping strategies did not directly relate to anxiety or depression in the samples of autistic adults here, it is possible that these strategies can indirectly impact negative facets of mental health through improved well-being. Indeed, there is evidence for well-being acting as a buffer against depression in autistic adults (Hedley et al., 2019). The results of this thesis underscore the importance of capturing patterns of coping strategies in autistic adults to better understand individual vulnerability to poor mental health outcomes. Although a reduction in disengagement coping strategies may be similarly useful across all stress levels, higher use of engagement coping strategies may be especially useful in the contexts of high stress, or in anticipation of a highly stressful event. Support options with a focus on facilitating the reduction of disengagement coping strategies and enhancing engagement coping strategies in autistic adults have the potential to promote positive mental health outcomes in this population.

12.3.3. Coping and Resilience Interactions in Relation to Stress and Mental Health

Consistent with reports in the broader literature (Moore et al., 2017; Thompson et al., 2018), findings from Chapters 10 and 11 suggested that resilience was related to more frequent use of engagement coping strategies and less frequent use of disengagement coping strategies in two different autistic adult samples. In considering

potential underlying mechanisms for mental health outcomes in autistic adults, mediation analyses in Chapter 10 showed that coping strategies mediated the relationship between resilience and mental health outcomes, where disengagement coping strategies mediated the relationship between resilience and mental health outcomes (i.e., depression, anxiety and well-being). In contrast, engagement coping strategies mediated the relationship between resilience and well-being only.

These results are in concordance with those in the wider stress and trauma literature (Thompson et al., 2018; Yu et al., 2014), where coping strategies have been reported to mediate not only the associations between resilience and psychological outcomes, but also symptoms of post-traumatic stress disorder (PTSD) and post-traumatic growth (PTG). Considering the emerging literature surrounding PTSD in autistic adults (e.g., Haruvi-Lamdan et al., 2020; Stewart et al., 2022), the investigation of coping-resilience mechanisms that underlie PTSD, especially in autistic adults, would be beneficial in informing evidence-based support options for this population. Importantly, the findings from this thesis suggest coping strategies can operate as a conduit through which resilience affects mental health outcomes in autistic adults, where less helpful disengagement coping strategies can be exacerbated by low levels of resilience, and that engagement coping strategies may be promoted through high levels of resilience.

Patterns of coping and resilience at an individual level were explored for the first time using cluster analytical procedures (Chapter 11), where four subgroups of autistic adults with distinct coping-resilience profiles were identified: *high cope/ low resilience*, *low cope/ high resilience*, *engage cope/ high resilience* and *disengage cope/ low resilience*. Although this study represents the first investigation of coping-resilience profiles in autistic adults, the cluster characterisations complement the wider coping

literature, where coping profiles have been identified based on the frequency of strategy use, and the emphasis of some strategies over others (e.g., Achnak & Vantilborgh, 2021; Doron et al., 2014; Gaudreau & Blondin, 2004). In particular, the composition of the *engage cope/ high resilience* and *disengage cope/ low resilience* profiles is consistent with previous work identifying that high resilience groups infrequently adopt disengagement coping strategies (Yi-Frazier et al., 2010). Together these results highlight that autistic adults demonstrate comparable inter-relationships between coping and resilience to non-autistic adults. However, it is not yet known whether the composition of adults falling into each coping-resilience profile or the relationships between these profiles and outcomes, may differ between autistic and non-autistic adults.

Several significant group differences in relation to general perceived stress across the four coping-resilience profiles were found. The largest difference was noted between the *engage cope/ high resilience* group and *disengage cope/ low resilience* group, with the former group reporting significantly lower levels of stress than the latter. This difference in stress levels suggests that autistic adults demonstrating high engagement coping, low disengagement coping, and high resilience patterns perceive and report lower stress compared to those characterised by low engagement coping, high disengagement coping and low resilience. Drawing back to the Conservation of Resources theory (Hobfoll, 2011) discussed in Chapter 3, it is plausible that resources such as engagement coping patterns and high resilience are cumulatively beneficial in supporting autistic adults in how they encounter, perceive and experience stress, and can thus reduce the stress experienced by these adults.

Differences in daily hassles and COVID stress across the four profiles did not reach statistical significance. It is possible that the dispositional approach to measuring coping strategy use and resilience was not sensitive enough to capture individual

differences in specific stress contexts. Indeed, the usefulness or effectiveness of coping

strategies may differ across varying contexts of stress, where for example, engagement

coping strategies, particularly those which are problem-focused (e.g., problem solving,

planning), can be more effective in the context of stressors that are controllable and

amenable to change (Taylor & Stanton, 2007). Deriving situational, as opposed to

dispositional coping-resilience profiles, in response to specific contexts may be useful in

further understanding relationships between coping, resilience and stress across various

contexts in autism. Alternative methods such as ecological momentary assessment

(EMA) or experience sampling methods (ESM), which consist of repeated

measurements, can also help explore the dynamic and nuanced relationships between

coping, resilience and stress both within and across time, allowing for the examination of

dynamic and temporal relationships among these constructs.

Together, Chapters 10 and 11 demonstrate significant inter-relationships between

coping strategies and resilience, suggesting that the choice of coping strategies and level

of resilience in autistic adults represent key factors implicated in stress and mental health

outcomes. These findings underscore the importance of examining resilience alongside

coping strategies in autistic adults and indicate that enhancing resilience whilst

simultaneously addressing coping, by improving the use of engagement coping strategies

and reducing disengagement coping strategies, has the potential to reduce overall risk for

stress, thus promoting better mental health and well-being in this population.

12.4. Considerations and Limitations

Prior to the research reported here, the literature on coping and resilience in

autism had been scarce. As noted earlier, the small number of prior studies focused

exclusively on autistic children and adolescents and their applicability to autistic adults

was thus unknown. Determining the most parsimonious factor structure for the Brief

COPE using a large sample of autistic adults (Chapter 6) and then using this factor structure in subsequent research studies (Chapters 7 to 11) ensured that coping patterns in the autistic adults were appropriately captured. The six studies reported here represent the first research to examine both coping and resilience patterns and their relationship with stress and mental health in the autistic adult population. The large age range of autistic adults in these studies and the use of two different samples of adults, strengthened the generalisability of the findings reported. Generalisability was further complemented using dispositional measures to examine coping strategies, resilience and perceived stress in autistic adults across all studies, allowing for the broad exploration of these constructs without the heterogeneity that comes with context or situation-specific approaches. Together, these provide key insights into the understanding of coping and resilience and how they can impact stress and mental health in autistic adults, providing directions for future research to examine these constructs across more specific contexts.

Using valid measures is necessary to capture potential autism-unique presentations of the constructs under examination and address the concerns of the autistic adult community regarding the use of standardised measures that may not adequately capture their experiences (Nicolaidis et al., 2019). Thus, it was important that the measures used to examine coping and resilience were validated for use in the autistic population. A strength of this thesis was the focus on validating a measure of coping for use with autistic adults (Brief COPE) and using other validated measures where possible; the resilience measure (CD-RISC10) utilised here had been previously validated in autistic adults (Hwang et al., 2020a), supporting its use in appropriately capturing resilience in this population, as had the PHQ-9 measure of depression (Arnold et al., 2020). These measures strengthened the validity of the current findings, with clear potential for informing clinical work and supports in this population.

Another key strength of this thesis was the strong methodological approach using longitudinal, multi-dimensional, and variable- and person-focused approaches to investigate the relationships between coping strategies, mental health, stress and resilience. This thesis presents the first longitudinal examination of coping-mental health associations while accounting for prior mental health to highlight the unique predictive role of coping strategies (Chapter 8). Further, while the variable-centred approach in Chapter 10 provided a parsimonious way to examine associations between coping, resilience and mental health, contributing to the generalisability of its findings to the autistic adult population more widely, the person-centred approach in Chapter 11 complemented this by identifying the dynamics of emergent subgroups of autistic adults based on their coping strategy use and level of resilience, providing a more nuanced understanding of coping-resilience patterns in this population.

Although there is consensus regarding the poor mental health outcomes for many autistic adults, most mental health research has used negative indicators of mental health, whereas much less is known about the positive aspects of mental health. All studies in this thesis which examined mental health outcomes (Chapters 6 to 10) incorporated a positive mental health measure (i.e., well-being), while Chapters 6 to 8 and 10 also included negative indicators of mental health (anxiety and depression). The use of both negative and positive indicators of mental health provided a more holistic understanding of the mechanisms underlying poor mental health and well-being in the autistic adult population, where coping strategies were found to differentially relate to positive and negative indicators of mental health. Across the studies, higher well-being was consistently associated with both increased use of engagement coping strategies and reduced use of disengagement coping strategies, highlighting the potential for well-being

in the autistic adult population to be promoted through addressing both these coping strategies.

While this research was novel and offered new perspectives with respect to mental health and its relationships with coping, resilience and stress in the autistic adult population, there are some limitations across the series of studies that should be acknowledged and are summarised here. First, the data collected across each study relied on participant self-report. While some raise concerns over the accuracy of autistic individuals in identifying their emotional states (Berthoz & Hill, 2005), others have found that autistic individuals can report their internal states and aspects of life in a valid and reliable manner (e.g., Shipman et al., 2011). An alternative is informant report, but not all constructs are easily observable by others (e.g., cognitive coping strategies and aspects of resilience, internalised moods and feelings). There is also a risk of informants misinterpreting the internal states of autistic adults based on what is observed externally, particularly if masking behaviours are involved. While the use of self-report measures for autistic adults provides one method to examine the reported associations, research incorporating multi-method or multi-informant measurement approaches may help capture coping and resilience from different perspectives and in identifying potential differences as a function of respondent methods.

Relatedly, due to the online nature of the studies, self-reported autism diagnoses could not be confirmed. Several measures were in place to account for this. Recruitment efforts for the SALSA, ALSAA and RPAAS were conducted predominantly through autism-specific organisations, groups and communities, maximising the chances of reaching autistic individuals. All autistic participants also provided details about their diagnoses, including the year of diagnosis, diagnostic label, and diagnosing professionals. Further, as rigour can be increased through the inclusion of an autism

questionnaire (Bal & Lounds Taylor, 2019), the AQ-short was used as a measure of autistic traits in all six empirical studies. These measures, in addition to the extensive and voluntary nature of the surveys, minimised the risk of inclusion of individuals without an autism diagnosis.

There was also an overrepresentation of female autistic adults across the studies compared to what is reported in the wider autistic population (male: female ratio of 1.8-2.6:1; Posserud et al., 2021; Rutherford et al., 2016). This 'reverse sex ratio' in survey-based autism studies (Rødgaard et al., 2022) has been similarly reported in autistic adult studies more broadly (e.g., 67% females in Gilmour et al., 2012; 59% in Hull et al., 2020; estimated 65% in Kapp et al., 2013; 58% in Lawson et al., 2020; 59% in Nicolaidis et al., 2013). Relatedly, although gender identity information was collected, examination of coping and resilience in non-binary groups was not possible due to the very small numbers present across the studies. From an intersectionality perspective, examining these constructs in gender diverse autistic adults would be important, as it is likely that gender diverse individuals face unique stressors related to their multiple minority identities, which may then differently relate to coping strategies and resilience. All studies were representative across age, with few or no sex differences in the findings. Future research incorporating more males and gender diverse individuals is needed to clearly ascertain whether sex and gender differences related to coping and resilience exist.

While the coping-mental health studies were both cross-sectional and longitudinal, demonstrating the characterisation and predictive role of coping strategies in relation to mental health and well-being in autistic adults, the temporal priority of coping strategies over mental health outcomes in the longitudinal study is not sufficient to infer causal directions. Similarly, the coping-resilience studies (Chapters 10 and 11)

relied on cross-sectional data. Thus, the direction of the associations and how they relate to mental health outcomes (Chapter 10) and stress (Chapter 11) in autistic adults cannot be confirmed. There is great heterogeneity in the design and findings of similar studies in non-autistic samples. Some studies note the mediating role of resilience in the coping-mental health relationship (rather than the mediating role of coping in the resilience-mental health relationship) or that stress might predict the types of coping strategies used (rather than vice-versa). For example, chronic or extreme levels of stress can impact and influence an individual's ability to withstand and cope with the demands encountered (Cicchetti & Rogosch, 2009; Schetter & Dolbier, 2011). Although the current studies provided a step toward characterising coping and resilience in relation to mental health and stress in autistic adults, longitudinal and randomised experimental designs are necessary to delineate these mechanisms further.

12.5. Future Implications

The high stress, frequent adverse life experiences and heightened vulnerability to stressful life events found in autistic adults (e.g., Griffiths et al., 2019; Moseley et al., 2021) constitute elements of risk or adversity, placing this population at an increased likelihood of experiencing poor mental health outcomes. Their stress-related vulnerability, combined with the limited research in coping and resilience in autistic adults, formed the premise underlying the investigation of stress, coping, resilience and mental health in this thesis. The general and dispositional approaches adopted with these variables allowed for a broader, exploratory examination of these constructs. Given the limited research to date, it was important to first explore *how* different levels of stress, coping, resilience, and mental health were inter-related, rather than *why*.

As engagement coping strategies were found to play a stress-buffering role in the context of high stress, ascertaining highly stressful contexts in autistic adults could help

identify situations in which engagement strategies may be best promoted. High stress

contexts may include adverse social experiences such as peer victimisation (Cappadocia

et al., 2012), transitions into adulthood (Taylor & Gotham, 2016), disclosure of autism

diagnosis (Thompson-Hodgetts et al., 2020) or experiences of discrimination (Johnson &

Joshi, 2016). Determining a priori the events and contexts considered 'stressful' can be

problematic, as there may be autism-unique factors that lead objectively benign events to

being perceived as stressful, and likewise, a seemingly stressful event perceived as

benign. It is likely that methodological approaches using co-production frameworks will

be most successful in establishing commonly reported stressful encounters and contexts

in autistic adults, including details such as the controllability of such events or

amenability to change. Investigating how coping and resilience are used within these

defined contexts would provide opportunities to unpack situational-specific coping

strategies and resilience for autistic adults, including examining coping and resilience

stability across contexts.

From a methodological perspective, there are other statistical approaches which

can provide a more in-depth examination of coping and resilience and / or the

relationships between them in autism. For example, network analysis can be useful in

determining the inter-relatedness between coping and resilience, and the extent to which

they are distinct or may overlap in autism. It can also identify important 'bridge nodes',

which have the potential to influence both coping and resilience, forming the basis for

guiding support and therapeutic interventions in autism. Indeed, a network analysis on

coping and resilience in non-autistic adults found that the use of social support coping,

active coping, planning and goal efficacy may prove important in impacting both coping

and resilience in these adults (Van der Hallen et al., 2020). Relatedly, the use of artificial

neural networks (ANN) allows for the incorporation of multiple variables (e.g., coping

strategies, resilience, nature of stressors, individual and contextual demographic variables) to create predictive models of stress (e.g., Bekesiene et al., 2021; Morales-Rodríguez et al., 2021), which could assist in identifying and subsequently target key stress predictors in the autistic population.

The strong associations and the predictive role of engagement and disengagement coping strategies in relation to positive and negative aspects of mental health in autistic adults found across the empirical studies in this thesis support reports surrounding the associations between ER strategies and internalising symptomatology in the autistic adult population (Bruggink et al., 2016; Cai et al., 2018). Coping and ER are closely related constructs with both shared and distinct features (see review by Compas et al., 2014). However, and not unlike in the non-autistic literature, the two areas of work have remained separate and disconnected in autism. Future research incorporating both constructs has the potential to disentangle the connections and overlap between coping and ER in autism. In the context of network analysis, community analysis can be used to group ER and coping items based on their inter-connectedness, determining the extent of overlap or distinctness between the two constructs. Alternatively, it would be informative to examine underlying mechanisms between coping and ER and their relationship with stress and stress-related outcomes. For example, coping strategies may mediate the relationship between ER and stress in autistic adults, as demonstrated in some non-autistic literature, where aspects of ER facilitate the use of coping strategies, which in turn predicts burnout, perceived stress and psychological distress (Chan, 2006; Nizielski et al., 2013; Schäfer et al., 2020).

A further question surrounds the issue of diversity across the autism spectrum. While there is great heterogeneity in the cognition of autistic adults (e.g., Magiati et al., 2014), this thesis focused on more cognitively able autistic adults. There is little research

on stress, coping strategies and resilience in autistic adults with a co-occurring intellectual disability. Additionally, minority stress associated with autism forms an additional stress burden for autistic adults, contributing to poor well-being and high distress, above and beyond the effects of general stress (Botha & Frost, 2020). This disproportionate stressor exposure and experience of stress may be compounded for autistic adults who may also be members of other minority groups. Referred to as the 'double jeopardy hypothesis' (Ferraro & Farmer, 1996), individuals who are a part of several minority groups (e.g., LGBTQI, ethnicity, female gender) are likely to experience the additive effects of these different identities. Thus, autistic adults who are female, gender non-conforming or belong to an ethnic minority group are likely to experience elevated stress and more varied stressor encounters compared to male autistic adults who are not a part of other minority groups. Similarly, socioeconomic status differences can influence individuals' access to resources and the ability to leverage supports within their communities (Sassu & Volkmar, 2023). Socioeconomic disadvantage, reduced financial or social capital, and less access to professional services and support can impact not only the types and levels of stress autistic adults experience but may also influence their use of coping strategies and resilience.

Emerging discussions on intersectionality in autism continue to highlight the diverse and distinct experiences of marginalised autistic communities and the differential outcomes associated with these interwoven elements of individual experiences and identities (Sassu & Volkmar, 2023; Saxe, 2017). Although the studies presented in this thesis provided information on sex, gender diversity and socioeconomic status (by proxy of postcodes) to characterise the autistic adults in the studies, only male/ female associations could be explored. Future research identifying specific stressors, societal barriers and stressful experiences arising from intersecting identities within the autistic

population, and how coping and resilience may play a protective role against the negative, health-related consequences is required.

The Conservation of Resources (COR) model posits that individuals are motivated to acquire, build on and protect their resources and that individuals with greater resources are less vulnerable to the detrimental impact of resource-loss events, such as stress (Hobfoll, 1989). It would be beneficial for future research to extend the findings of this thesis to examine the relationships between coping and resilience in autistic adults alongside other individual- and environmental-level factors to understand how these factors may interact and impact stress and stress-related outcomes in this population. Indeed, there are several other areas of research that may influence or be influenced by coping and resilience but were beyond the scope and aims of this thesis. For example, emotional intelligence (EI), which is suggested to be lower in autistic adults (Brady et al., 2014; Robinson et al., 2020), may have a significant influence on resilience (McCarthy et al., 2020) and stress and burnout (Zysberg et al., 2017). Intolerance of uncertainty (IU), the predisposition to react negatively to uncertain, unexpected, or unpredictable events (Buhr & Dugas, 2006) is reported to be elevated in autistic adults (Hwang et al., 2020b; Vasa et al., 2018) and can be a predictor for anxiety and stress (Hwang et al., 2020b; Oglesby et al., 2016).

Similarly, psychological flexibility, a central component of executive functioning, reflects abilities to switch between tasks, shift attention and adjust behaviours according to a changing environment (Dajani & Uddin, 2015). Aspects of inflexibility in relation to routine and transitions, as well as restricted, repetitive and stereotyped patterns of behaviour observed in autism, are related to psychological inflexibility, which can lead to co-occurring mental health challenges such as anxiety and depression (Factor et al., 2016; Gloster et al., 2017; Stratis & Lecavalier, 2013). Beyond individual factors,

examining the types and perceptions of social support would be insightful, as autistic adults have highlighted the importance of a sense of social inclusion and belonging in developing their resilience and coping (Ghanouni & Quirke, 2022).

When considering the experiences of stress and resultant mental health outcomes more broadly in autistic adults, it is important to acknowledge that stress is often socially imposed on autistic individuals. As noted in Higgins et al. (2021, p.6), it is akin to "being in a world that is not your world". Social and environmental factors such as a lack of support in the workplace, harmful sensory environments, and experiences of stigma and discrimination faced by autistic individuals represent both 'structural' and 'psycho-emotional' disablism (Reeve, 2014), and can significantly contribute to autistic stress and burnout (Mantzalas et al., 2022). Therefore, determining how contextual factors, such as workplace adjustments and supports, or experiences of discrimination or bullying at work, contribute to stress in autistic adults is critical to creating supportive and understanding work environments for these adults. Environments such as these would represent environmental resources, which in addition to individual resources such as coping strategies and resilience, can be drawn from by autistic adults during times of stress.

12.6. Clinical Directions

Clinically, there are calls to develop and establish evidence-based stress support and interventions suitable for autistic adults (Bishop-Fitzpatrick et al., 2015; Hirvikoski & Blomqvist, 2015). While there remain important environmental and systemic factors that need to be addressed to reduce the stress imposed on this population, addressing individual resources such as coping strategies and resilience, as demonstrated by findings across the studies in this thesis, can serve as a basis for developing individualised stress and mental health supports in autistic adults. In doing so, the coping strategies, and the

items that make up these strategies, will need consideration. The literature also indicates that autism-specific adaptations and modifications to support and intervention programs, including input from autistic adults (e.g., Spain & Happé, 2020), is necessary to improve the accessibility and success of such support options in the population. Autistic adults emphasise the need for intervention options to be adapted for, evaluated with, and led by autistic individuals to ensure their relevance and appropriateness of use in the autistic community (Benevides et al., 2020).

Although a few programs designed for autistic adolescents and adults have incorporated coping strategies (*STEPS*; White et al., 2017) and / or resilience (e.g., *Think Well, Feel Well, Be Well,* McGillivray & Evert, 2014; *ACCESS*, Oswald et al., 2018) amongst a range of other target areas, support and intervention programs focusing explicitly on coping and resilience in autistic adults are limited. There are additional support programs used in the autistic population referred to as resilience interventions (e.g., *Resourceful Adolescent Program–Autism Spectrum Disorder, RAP-ASD*; Shochet et al., 2022 or *Resilience Builder Therapy Program, RBP*; Habayeb et al., 2017); however, resilience as a construct is not fully incorporated as an intervention target or as a measurable outcome in these programs. The results from this thesis highlight that autistic adults who utilise more disengagement coping strategies, less engagement coping strategies, and demonstrate low resilience are more likely to demonstrate higher stress and poorer mental health and well-being, highlighting that coping strategies and resilience represent key malleable points for intervention. Therefore, developing interventions with a combined approach of focusing on the development of engagement coping strategies, reducing the use of disengagement coping strategies and enhancing resilience in autistic adults, and from a preventative approach, in children and

adolescents, may be beneficial in managing stress and mitigating negative stress-related outcomes in these populations.

Though not yet explicitly explored in the context of autistic adults, the efficacy of resilience-based programs that focus on resilience and coping strategies have been reported in several non-autistic adult samples (First et al., 2018; Steinhardt & Dolbier, 2008). Of note are two group-based resilience interventions in adults: *Transforming Lives Through Resilience Education (TLRE;* Steinhardt & Dolbier, 2008) and *READY; Resilience and Activity for every DaY* (Burton et al., 2010), both of which have shown encouraging results in reducing stress and promoting resilience, adaptive coping strategy patterns, mental health and well-being. While differing in content and approaches, both programs have been used in clinical and non-clinical samples and may be useful in providing a framework for the design of coping and resilience-related supports in the autistic adult population.

The *TLRE* (Steinhardt & Dolbier, 2008) is a four-week, two-hourly, group psychoeducational intervention designed to reduce stress, enhance resilience, facilitate adaptive coping mechanisms, and promote other protective resources (e.g., positive affect and self-esteem) during periods of heightened stress. Compared to pre-intervention, at post-intervention, adults participating in the *TLRE* reported increased resilience, more frequent use of problem-solving strategies, fewer avoidant strategies (Herbert & Manjula, 2022; Steinhardt & Dolbier, 2008), lower depressive symptoms, negative affect and stress (Steinhardt & Dolbier, 2008), and larger stress-related growth (Dolbier et al., 2009). In clinical samples, adults with HIV participating in *TLRE* reported improved resilience and mood (Fazeli et al., 2022), while adults with diabetes who undertook a combination of *TLRE* and nutrition education showed improvements in resilience and

perceived stress, although these changes did not reach statistical significance (Steinhardt et al., 2009).

If appropriately adapted and modified in consultation with autistic adults, the *TLRE* may be a suitable support option for autistic adults currently experiencing or anticipating a period of high stress. Given the stress-buffering role of engagement coping strategies in the context of high stress, developing and building on such strategies, which include planning, active problem solving, acceptance and positive reframing, would be particularly useful. It is also important to consider the specific intervention target areas, as a target of improving psychological well-being in autistic adults would suggest a focus on increasing engagement coping strategies and resilience, and reducing disengagement coping strategies, whereas a target of reducing anxiety and depressive symptomatology might require a focus on disengagement coping strategies and resilience.

As indicated by the results in Chapter 11, ascertaining and profiling autistic adults based on their coping and resilience patterns may help identify those most vulnerable to stress and subsequently mental health difficulties. The *READY* Program is a resilience training program which aims to enhance resilience and psychological flexibility through the incorporation of Acceptance and Commitment Therapy (ACT) processes and Cognitive Behaviour Therapy (CBT); the program can be tailored to specific contexts (Burton et al., 2009, 2010) and modified for clinical samples (e.g., Pakenham et al., 2018). Evaluations of *READY* have demonstrated improvements in resilience, well-being, QoL, stress and mindfulness in clinical (e.g., Pakenham et al., 2018; Ryan et al., 2020) and non-clinical (e.g., Burton et al., 2010) adult samples. Encouragingly, CBT has been found to be efficacious in promoting psychological health (Spain & Happé, 2020; Spain et al., 2015), and ACT may promote adaptive functioning skills (Byrne & O'Mahony, 2020), reduce perceived stress and increase quality of life (Pahnke et al.,

2019, 2022) in autistic adults. Further, Pahnke et al. (2019) provide some useful tips for modifying an ACT program for autistic adults, including adapting examples to be more relevant, individual support after each session, extended psychoeducative material and colour coding of materials to provide better structure.

A potential *READY* program adaptation for autistic adults may be to use small groups of autistic adults, based on the autistic adults' differing risks to high stress. The use of coping-resilience profiles may be useful here to group those with comparable coping and resilience patterns and potentially similar stress-related circumstances together, allowing for the content and pace of the program to be tailored to suit a group's needs. Establishing pre-program coping-resilience profiles can also inform more in-depth discussions surrounding experiences of stressful events, underlying motivations and the effectiveness of coping strategies, as well as barriers and enablers of these strategies. Although the 'active coping strategies' target in the *READY* program do not appear to focus on specific coping strategies (with the exception of physical activity), a specific focus on engagement and disengagement coping strategies may be useful in autistic adults.

Regardless of the type of coping and resilience support, it is important to acknowledge that autism is a spectrum condition and as attested by qualitative literature to date (Kerns et al., 2022), there is heterogeneity in the precipitators and presentations of stress in this population. A one-size-fits-all approach to coping and / or resilience intervention is therefore unlikely to be useful. There remains a great need for the design of any supports to be conducted in collaboration with autistic individuals (Benevides et al., 2020), allowing for preferred approaches, adaptations, considerations and outcomes to be identified and incorporated into these intervention programs, ensuring their relevance and appropriateness to the autistic community. Depending on the needs and

preferences of the autistic adults, the development of both group- and individual-based approaches to coping and resilience support is required.

12.7. Conclusion

This thesis presented findings from a comprehensive series of six studies, with the overarching aim of examining patterns of coping strategies in the context of stress in autistic adults, its relationships with resilience, and the role of coping and resilience in relation to stress and mental health outcomes. This research shows that in autistic adults, (1) the Brief COPE is a valid and useful measure to examine coping patterns; (2) both disengagement coping and engagement coping are important predictors of mental health and well-being; and (3) resilience and coping strategies are strongly inter-related, and together, characterise stress and mental health outcomes. When examined in more depth, underlying coping strategies in relation to stress differed, with engagement coping strategies moderating the effects of stress on well-being, while disengagement coping did not. Changes in coping patterns over time also demonstrated the dynamic nature of coping strategy use in autistic adults, its malleability and therefore its potential responsiveness to coping-specific supports and intervention. Finally, the associations between coping strategies and resilience suggest strong inter-relationships between the two constructs, and their joint contribution to stress, mental health and well-being. Thus, the work presented here provides novel insights in the context of stress in the autistic adult population, informing the development and design of coping-based supports to improve the stress and mental health outcomes of autistic adults.

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Appendix C – RPAAS Recruitment Flyer

Resilience Pathways in Autistic Adults

How do stress-related factors impact the well-being of autistic adults? How are autistic adults affected by the current COVID-19 pandemic?

What are some protective factors that may help buffer the negative effects of stress?

Through this research, we hope to better understand the different pathways that lead to better well-being in autistic adults.

Who can participate?

✓ Adults **with** a diagnosis of Autism without co-morbid intellectual disability

✓ Aged 18 years and above

✓ Fluent in English

✓ Living in Australia

What is involved?

✓ Complete a brief online screening survey to determine your eligibility for the study

✓ Complete an online questionnaire about your autism diagnosis, the impact of COVID-19, stressful events you may have experienced, your wellbeing and sense of self, how you cope and experience stress, your social support and networks, as well as your quality of life. This will take about 30 minutes

✓ As a thank you, you can choose to receive a $10AUD Coles e-gift voucher upon completion of the survey

For more information or to get involved

Please contact

Melanie Muniandy
Olga Tennison Autism Research Centre, La Trobe University

Ph: (03) 9479 2891

E-mail:
m.muniandy@latrobe.edu.au

La Trobe University Human Ethics Committee approval:
[HEC19443]

Appendix D – RPAAS Ethics Approval

Human Ethics   📁 Inbox - LTU STAFF   16 December 2019 at 11:04 AM   Ⓗ

HEC19443 - New Application - Approved   Details

To: Amanda Richdale,   Cc: M.Muniandy@latrobe.edu.au,   Lauren Lawson

** This is an automatically generated email, please do not reply. Contact details are listed below.**

Dear Amanda Richdale,

The following project has been assessed as complying with the National Statement on Ethical Conduct in Human Research. I am pleased to advise that your project has been granted ethics approval and you may commence the study.

Application ID: HEC19443
Application Status/Committee: University Human Ethics Committee

Project Title: The Resilience Project: perspectives and pathways to well-being in autistic adults

Chief Investigator: Amanda Richdale

Other Investigators: Melanie Muniandy, Dr Lauren Lawson

Date of Approval: 16/12/2019
Date of Ethics Approval Expiry: 16/12/2024

The following standard conditions apply to your project:

- Limit of Approval. Approval is limited strictly to the research proposal as submitted in your application.

- Variation to Project. Any subsequent variations or modifications you wish to make to your project must be formally notified for approval in advance of these modifications being introduced into the project.

- Adverse Events. If any unforeseen or adverse events occur the Chief Investigator must notify the UHEC immediately. Any complaints about the project received by the researchers must also be referred immediately to the UHEC.

- Withdrawal of Project. If you decide to discontinue your research before its planned completion, you must inform the relevant committee and complete a Final Report form.

- Monitoring. All projects are subject to monitoring at any time by the University Human Ethics Committee.

- Annual Progress Reports. If your project continues for more than 12 months, you are required to submit a Progress Report annually, on or just prior to 12 February. The form is available on the Research Office website. Failure to submit a Progress Report will mean approval for this project will lapse.

- Auditing. An audit of the project may be conducted by members of the UHEC.

- Final Report. A Final Report (see above address) is required within six months of the completion of the project.

You may log in to ResearchMaster (https://rmenet.latrobe.edu.au) to view your application.

Should you require any further information, please contact the Human Research Ethics Team on:
T: +61 3 9479 1443l E: humanethics@latrobe.edu.au.

Warm regards,

Human Research Ethics Team
Ethics, Integrity & Biosafety, Research Office

Appendix E – RPAAS Participant Information Statement

Participant Information Statement

Resilience Pathways in Autistic Adults		
The research is being carried out in partial fulfilment of Doctor of Philosophy under the supervisions of Prof Amanda Richdale and Dr Lauren Lawson. The following researchers will be conducting the study:		
Role	**Name**	**Organisation**
PhD Candidate	Melanie Muniandy	Olga Tennison Autism Research Centre School of Psychology & Public Health
Research funder	This research is supported by in kind support by La Trobe University.	

1. **What is the study about?**
   You are invited to participate in a study investigating resilience and how autistic adults cope or recover from setbacks in life. We hope to understand the different pathways that are associated with well-being in autistic adults and identify protective circumstances that may buffer the negative effects of stress on well-being.

2. **Do I have to participate?**
   Being part of this study is voluntary. If you want to be part of the study, we ask that you read the information below carefully and ask us any questions.

   You can read the information below and decide at the end if you would like to participate. If you decide not to participate, this won't affect your relationship with La Trobe University or any other listed organisation.

3. **Who is being asked to participate?**
   You have been asked to participate because:
   - You are an adult aged 18 years and above with a diagnosis of Autism Spectrum Disorders with no associated intellectual disability
   - You are fluent in English
   - You live in Australia

4. **What will I be asked to do?**
   If you want to take part in this study, we will ask you to complete an anonymous online survey consisting on information about your autism diagnosis, stressful events you may have experienced, your well-being and sense of self, how you cope and experience stress, your social support and networks, and your quality of life. Given the recent COVID-19 outbreak, we will also ask about how this pandemic may have impacted your life. It will take approximately 30 minutes of your time to be a part of this study.

5. **What are the benefits?**
   The benefit of you taking part in this study is that you will be contributing towards furthering the understanding of well-being trajectories in autistic adults, and potentially identifying circumstances or factors that may help autistic individuals thrive. The expected benefit to society in general is that the strength-based perspective employed in this research may help contribute towards the positive shift in attitudes towards autism more generally. As a thank you for participating, you can choose to receive a $10AUD Coles e-gift voucher sent to the e-mail address provided upon completion.

6. **What are the risks?**
   With any study there are (1) risks we know about, (2) risks we don't know about, and (3) risks we don't expect. We have listed the risks we know about below. This will help you decide if you want to be part of the study.

   Some of the questions, especially surrounding perceived and experienced stress may be confronting or distressing some people. If you experience something that you aren't sure about, please contact us immediately, so we can discuss the best way to manage your concerns. You will find our contact details at the bottom of this page. Information on support options will be made available at the end of the survey, should you require this.

Participant Information Statement

7. **What will happen to information about me?**
   We will collect and store information about you in ways that will not reveal who you are. This means that you cannot be identified in any type of publication from this study.

   We will keep your information indefinitely after the project is completed.

   We will collect, store and destroy your data in accordance with La Trobe Universities Research Data Management Policy which can be viewed online using the following link: https://policies.latrobe.edu.au/document/view.php?id=106/.

   At the end of the survey, you will be invited to join the OTARC Participant Registry. Please note that you are under no obligation to do so. If you agree, you will be directed to the OTARC website where demographic information you provide will be stored in the registry. These will not be linked back to your survey responses. The information you provide is personal information for the purposes of the Privacy and Date Protection Act 2014 (Vic). You have the right to access personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the Information Privacy Act.

8. **Will I hear about the results of the study?**
   You will be able to read about the results of this study on the Olga Tennison Autism Research Centre's blog (http://otarc.blogs.latrobe.edu.au/). However, given the anonymity of this study, we will not be able to contact you personally to let you know when this has occurred. Results from this study is also likely to be reported or published in a thesis, journal articles, research reports or conference presentations.

9. **What if I change my mind?**
   If you no longer want to complete the questionnaire, simply close the web browser. However, we would not be able to withdraw your responses made until that point or after you have completed and clicked the 'Submit' button. As this is an anonymous survey, we are not able to link you with your questionnaire responses. Your decision to withdraw at any point will **not** affect your relationship with La Trobe University or any other organisation listed.

10. **Who can I contact for questions or want more information?**
    If you would like to speak to us, please use the contact details below:

Name/Organisation	Position	Telephone	Email
Prof Amanda Richdale	Chief Investigator	03-9479 1742	a.richdale@latrobe.edu.au

11. **What if I have a complaint?**
    If you have a complaint about any part of this study, please contact:

Ethics Reference Number	Position	Telephone	Email
HEC19443	Senior Research Ethics Officer	+61 3 9479 1443	humanethics@latrobe.edu.au

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Appendix F – RPAAS Consent Form

Consent Form – Declaration by Participant

I (the participant) have read understood the Participant Information Statement, and any questions have been answered to my satisfaction. I agree to participate in the study, I know I can withdraw at any time up until the 'Submit' button is clicked. I understand that the researchers would not be able to withdraw any responses made due to the anonymity of this survey.

I agree information provided by me during the project may be included in a thesis, presentation and published in journals on the condition that I cannot be identified.

I would like my information collected for this research study to be:
☐ Only used for this specific study;
☐ Used for future related studies;
☐ Used for any future studies

I agree, start questionnaire

Appendix G – RPAAS Support Information

<u>Before the start of the survey</u>

Should any concerns arise while you are responding the survey, please contact us so we can discuss the best ways to manage your concerns.

Student Investigator:	Melanie Muniandy	+61 03 9479 2891 m.muniandy@latrobe.edu.au
Chief Investigator:	Prof Amanda Richdale	+61 03 9479 1742 a.richdale@latrobe.edu.au
Associate Investigator:	Dr Lauren Lawson	+61 03 9479 2463 l.lawson@latrobe.edu.au

- -

<u>At the end of the survey</u>

If are concerned about your responses to any of these questions, or are feeling distressed, we recommend contacting any of the mental health services listed below:

Crisis Support Line:

- Lifeline Australia (24 hours): 13 11 14, www.lifeline.org.au

Mental Health Information Lines:

- Beyond Blue (24 hours): 1300 22 4636 or www.beyondblue.org.au
- SANE (9am to 5pm): 1800 187 263 or www.sane.org

You can also find a list of local support services by state and territory at:

https://www.healthdirect.gov.au/mental-health-services-by-state-and-territory. Alternatively, you can make an appointment with your regular medical practitioner/family doctor to further discuss your concerns and other available supports.

If there is anything you are not sure about, please contact us so we can discuss the best ways to manage your concerns.

Student Investigator:	Melanie Muniandy	+61 03 9479 2891 m.muniandy@latrobe.edu.au
Chief Investigator:	Prof Amanda Richdale	+61 03 9479 1742 a.richdale@latrobe.edu.au
Associate Investigator:	Dr Lauren Lawson	+61 03 9479 2463 l.lawson@latrobe.edu.au

Appendix H – Permission to Include Published Manuscript in Thesis (Chapter 6)

Factor structure and psychometric properties of the Brief COPE in autistic older adolescents and adults

Author: Melanie Muniandy, Amanda L. Richdale, Samuel R.C. Arnold, Julian N. Trollor, Lauren P. Lawson

Publication: Research in Autism Spectrum Disorders

Publisher: Elsevier

Date: June 2021

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