Mindfulness-Based Interventions for Individuals with Autism Spectrum Disorder and Their Caregivers

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Bachelor of Environmental Management (Honours)
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Thesis submitted to fulfil the requirements for the combined degree of
Doctor of Philosophy / Master of Psychology (Clinical)

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September 2023

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List of Original Publications Arising From the Research

The following publications have been included in the body of this thesis. They are presented with all relevant tables and figures in Chapters 3, 4 and 5 respectively. Tables and figures that appeared as supplementary material with each article appear in the Appendices section at the end of this thesis.

Hartley, M., Dorstyn, D., & Due, C. (2019). Mindfulness for children and adults with autism spectrum disorder and their caregivers: A meta-analysis. *Journal of Autism and Developmental Disorders, 49*, 4306–4319. https://doi.org/10.1007/s10803-019-04145-3

Hartley, M., Due, C., & Dorstyn, D. (2021). Barriers and facilitators to engaging individuals and families with autism spectrum disorder in mindfulness and acceptance-based therapies: A meta-synthesis. *Disability and Rehabilitation*, 44(17), 4590-4601. https://doi.org/10.1080/09638288.2021.1921859

Hartley, M., Dorstyn, D. & Due, C. (2022). Challenges encountered with a mindfulness app: Lessons learnt from a pilot randomized trial involving caregivers and individuals with autism, *Research in Autism Spectrum Disorders*, 96, 1–9. https://doi.org/10.1016/j.rasd.2022.101991

List of Presentations

Hartley, M. (2019, September 24). *Mindfulness for children and adults with autism and their caregivers: A meta-analysis* [Poster presentation]. Faculty of Health and Medical Sciences Florey Postgraduate Research Conference, The University of Adelaide.

Hartley, M. & Dorstyn, D. (2019, October 24–26). Mindfulness for children and adults with autism and their caregivers: A meta-analysis. In I. I. Kneebone (Chair), *Psychological interventions for children with neurodevelopmental disorders and their carers* [Symposium]. 40th National Conference of the Australian Association for Cognitive and Behaviour Therapy. Adelaide, Australia.

Abstract

This thesis examines the application and effectiveness of mindfulness-based interventions (MBIs) for both individuals with autism spectrum disorder (ASD) and their primary caregivers. Emerging research shows that conventional MBIs can be effective in providing relief from mental health symptoms, such as depression and anxiety. However, questions remain regarding the effectiveness of MBIs across the lifespan of autistic individuals, the perception of MBIs among these individuals and their families, and the most effective way to disseminate MBIs to this population.

MBIs are attracting increasing attention in ASD research, partly because they cultivate an awareness and non-judgemental attitude towards difficult thoughts, feelings, and bodily sensations: aspects that are challenging for those with ASD, given their difficulties in sensory processing and emotional regulation. Issues with both access and affordability of mental health care have also been noted by this cohort. In this context, eHealth—the use of technology in mental health care—offers promise as a flexible service delivery option. To date, however, little research has explored eHealth as a mental health tool for ASD.

This thesis presents three studies, the first being a high-quality meta-analysis of 10 controlled and quasi-experimental studies ($N_{\text{participants}} = 574$) which evaluated mental health and wellbeing outcomes for autistic children and adults and their caregivers following MBI participation. Positive small to large effects (g range = 0.39 to 0.87) were reported by autistic adults and caregivers. The mental health benefits of MBI reported by autistic children were smaller in magnitude (g range = 0.22 to 0.43). These findings were, however, limited by the methodological quality of included studies. The small group of studies, which primarily involved caregivers, also precludes the ability to generalise the findings to the broader ASD population.

A second study, a qualitative meta-synthesis of the mindfulness intervention literature for ASD, provides further context to these meta-analytic findings. Based on 10 studies ($N_{\text{participants}}$ = 224), key themes focusing on the facilitators and barriers to mindfulness training were identified. Overall, individuals reported improved self-awareness and self-regulation with MBI. The group-based therapy format also provided a supportive environment and motivated participants to practise. However, home practice was seen as a key barrier. Equally problematic was the time commitment required for therapy combined with the demands of managing a child's ASD behaviours.

An intervention study, based on the findings of Studies 1 and 2, was then trialled to evaluate the feasibility and effectiveness of, a commercially available smartphone application based on mindfulness principles, Smiling Mind, for individuals affected by ASD. Distraction and boredom were key obstacles to app use reported by these children, while caregivers noted competing time commitments as a barrier to ongoing use. Participant interviews did, however, highlight positive attitudes to the use of Smiling Mind. That said, app use tended to be directed towards meeting specific goals, such as helping to promote better sleep for their child rather than the development of mindfulness skills per se.

In combination, the findings of these three studies suggest that MBI, particularly when offered via eHealth, has potential as a flexible method for improving the general wellbeing of autistic individuals and their caregivers. Despite an increased interest in mindfulness approaches, however, research on its application with ASD remains preliminary. Ultimately, significant methodological refinements are still needed to develop a robust picture of the application and effectiveness of MBI and its flexible delivery in this population.

Overview of Thesis

The structure of this thesis follows the University of Adelaide Graduate Research School's 'thesis by publication' guidelines for a PhD. This structure was selected to enable the timely dissemination of research in peer-reviewed academic journals and the presentation of each study in a structure that progresses naturally between each chapter.

Chapter 1 provides the context to this thesis by backgrounding ASD, including changes to diagnostic criteria and prevalence over time. The aetiology and epidemiology of ASD are also discussed, with a focus on primary physical and mental difficulties experienced by diagnosed individuals and those who care for them. Evidence-based psychological treatments are then explored, with a focus on cognitive behavioural therapy (CBT) as the primary tool used by clinicians and the promise of mindfulness-based techniques for treating specific features that present in ASD.

Chapter 2 introduces the concept of eHealth as an online tool for disseminating mental healthcare to individuals and communities. The advantages and pitfalls of this mode of service delivery are explored, and the adaptation of both CBT and mindfulness treatments to an eHealth format are discussed. Finally, evidence to leverage the combined advantages of both mindfulness and eHealth is presented, with a focus on useful treatment features that may be of specific benefit to those with ASD.

Chapter 3 presents Study 1, 'Mindfulness for Children and Adults With Autism Spectrum Disorder and Their Caregivers: A Meta-analysis'. This study, published in the *Journal of Autism and Developmental Disabilities*, synthesises quantitative research examining the effectiveness of MBIs for autistic children and adults. The findings are discussed in the context of the research quality of this body of evidence.

Chapter 4 presents Study 2, 'Barriers and Facilitators to Engaging Individuals and Families With Autism Spectrum Disorder in Mindfulness and Acceptance-Based Therapies: A

Meta-synthesis' published in the journal *Disability and Rehabilitation*. In this study, the qualitative literature on MBIs for ASD is summarised and critiqued. The findings highlight the diverse therapy experiences of persons affected by ASD, including the factors that facilitated or impeded their involvement in mindfulness training.

Chapter 5 presents Study 3, a pilot randomised controlled trial to evaluate the use and preliminary effects of the Smiling Mind app on the wellbeing of autistic children and adults and their caregivers. An abbreviated version of this study titled 'Challenges Encountered With a Mindfulness App: Lessons Learnt From a Pilot Randomised Trial Involving Caregivers and Individuals With Autism', was published in the journal *Research in Autism Spectrum Disorders* and is provided in Appendix A.

Chapter 6 concludes the thesis with a discussion of the overall findings and implications of the research program.

All journal manuscripts are formatted in accordance with the overall thesis, which follows the publication style of the American Psychological Association (7th edition) and meet the word limit of the respective journal. Consistent with the current APA style, as well as the evolution of disability language, this thesis adopts a combination of person-first (i.e., person with autism) and neuroaffirming or identity-first language (e.g., 'autistic person; Dunn & Andrews, 2015). This thesis was edited by Wendy Monaghan Editing Services, and editorial intervention was restricted to Standards D and E of the *Australian standards for editing practice*. All references for the manuscripts are included in the reference list at the end of the thesis for logical continuity. A citation for the published article is included in each of the prefaces to Chapters 3, 4 and 5.

Certificate of Original Authorship

I, Matthew Hartley, certify that this work contains no material that has been accepted for the award of any other degree or diploma in my name, in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name, for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and, where applicable, any partner institution responsible for the joint-award of this degree.

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I acknowledge the support I have received for my research through the provision of an Australian Government Research Training Program Scholarship.

Signature: Date: 12 September 2023

Acknowledgements

This thesis is the culmination of nearly 20 years of planning and study. Therefore, unsurprisingly, many people played a part helping me achieve its completion, but unfortunately, it is not possible to thank everyone. My biggest thanks go to my PhD supervisors: Associate Professors Diana Dorstyn and Clemence Due. Their skill in balancing expert advice, encouragement and patience elevates student supervision to an art form. I am truly thankful for having the opportunity to work and learn from two such outstanding people.

I am grateful to the other Master and PhD students for their encouragement during field placements and thesis writing and for sharing experiences through our psychology training, particularly Hugh, Jemima, Christianna, Michelle, Mara, and Susan. I am also thankful to the many psychology staff at the University of Adelaide for their support throughout my years studying in the department.

To my parents, Geoff and Sue Hartley, this journey could never have been completed without your encouragement, which has sustained our family through challenging moments. You have been unwavering in your support, even through your own challenges, and I'm humbled by your generosity and love.

To my friends Craig, Mike and Steve, thanks for listening and empathising when I doubted myself or just needed to vent with someone. Your support has helped me endure, and I'm grateful we continue to share the experiences of life together.

To my family, Theresa, Jayden, and Talia, thank you for supporting and encouraging me, making me laugh (and cry). The distractions and difficulties, excitement, and joy of being in a family with you has been the delight of my life, and I wouldn't change it for the world.

Outline of Candidature

The current thesis represents work undertaken as part of the requirements of a combined Doctor of Philosophy / Master of Psychology (Clinical) degree at the University of Adelaide, South Australia. This program (equivalent 4 years full time) combines a Master of Psychology (Clinical) course load (equivalent 2 years full time) with a Doctor of Philosophy research load (equivalent 3 years full time). The three published papers presented in this body of work, along with seven masters-level subject courses, three clinical placements and a mini-placement (with a combined total of over 2,000 contact hours) were completed within a 4-year candidature timeframe. The final year of candidature was completed concurrent with part-time clinical work as a provisional psychologist within the Department of Child Protection, South Australia. The standard level of funding allotted for PhD support was provided by the University of Adelaide and the School of Psychology, allowing for recruitment costs and conference registration. The university provided additional administrative support, including licences to access the websites that hosted online data collection (Survey Monkey software). During the period 2018 to 2021 inclusive, a stipend was also provided by the University as part of an Australian Government Research Training Program Scholarship.

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List of Abbreviations

ACT	acceptance and commitment theory
ADHD	attention deficit hyperactivity disorder
ASD	autism spectrum disorder
CASP	Critical Appraisal Skills Programme
CBT	cognitive behavioural therapy
CI	confidence interval
DASS	Depression Anxiety Stress Scales
DSM	*Diagnostic and Statistical Manual of Mental Disorders*
MAAS	Mindful Attention Awareness Scale
MBCT	mindfulness-based cognitive therapy
MBI	mindfulness-based intervention
MBPBS	mindfulness-based positive behaviour support
MBSR	mindfulness-based stress reduction
PDD	pervasive developmental disorders
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-analyses
QoL	Quality of Life
RCI	reliable change index
RCT	randomised control trial
SMD	standardised mean difference
SWB	subjective wellbeing
WHO	World Health Organisation

Chapter 1: Management of Mental Health in Autism Spectrum Disorder

Overview

Individuals living with autism spectrum disorder (ASD) show unique, complex behavioural and social impairments in addition to high rates of co-occurring mental health problems (King, 2016; Prosperi et al., 2021; Zaboski & Storch, 2018). Parents of autistic children have also reported experiencing stress, depression, and anxiety symptoms, often in response to their child's behaviour problems or care needs (Bitsika & Sharpley, 2021; Schnabel et al., 2020). Evidence-based psychological interventions that focus on managing children's mental health in conjunction with parental wellbeing can help to reduce the mental health difficulties experienced by both, with resultant positive impacts on the quality of life for the broader family unit (Hartley et al., 2019; Yu et al., 2019). Third-wave approaches that focus on mindfulness exercises and acceptance of difficult thoughts and emotions have shown promise for these families, as well as for autistic adults (Ridderinkhof et al., 2018a). To date, however, there has been little research on the perspectives and experiences of both the autistic individuals and their caregivers when receiving this therapy.

This chapter provides context for this thesis on mindfulness for autistic individuals, which includes children (17 years of age or younger) and adults (18 years of age or older), and their caregivers. Core diagnostic features, presenting characteristics and epidemiology are first discussed, followed by the strengths and pitfalls of traditional cognitive behaviour therapy (CBT) as a mental health intervention for this group. Mindfulness, a psychotherapy that incorporates elements of cognitive therapy and meditation, is then introduced as a uniquely suited practice to help autistic individuals and their families develop skills to better regulate their reactions to stressful situations. Finally, the available research on mindfulness therapies is critiqued, and critical gaps in the research with ASD groups are highlighted.

ASD

Evolving Diagnostic Criteria

ASD is a lifelong neurodevelopmental disorder that causes significant social, communication and behavioural challenges (American Psychiatric Association, 2013b; World Health Organisation, 2020). First described in 1943 by psychiatrist and physician Leo Kanner as a profound emotional disturbance, autism was characterised by (a) significant difficulties with social interaction and (b) resistance to change and insistence on sameness (Rosen et al., 2021). Kanner's speculations led to the belief that autism was a form of early-stage schizophrenia. Later research discredited this theory by confirming autism's biological basis by reason of its frequent association with epilepsy, onset during adolescence, and substantial heritability (Rosen et al., 2021).

Official recognition of autism as a psychiatric disorder occurred in the third edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III; (American Psychiatric Association, 1980). The DSM-III included a new class of conditions: the pervasive developmental disorders (PDD). These conditions included the diagnoses of infantile autism, characterised by social difficulties and specific behaviours that occur before 30 months of age; childhood-onset PDD, where problems occur between 30 months and 12 years of age; and atypical PDD, for presentations that fit neither of the previous diagnoses (American Psychiatric Association, 1980).

However, more diagnostic flexibility was needed to account for symptom differences depending on developmental stage. The revised DSM-III-R subsequently adopted 16 detailed criteria, grouped within three broad domains: communication, social communication and restricted interests / resistance to change (American Psychiatric Association, 1987). At least eight criteria, with a minimum of two from the social domain, needed to be met for a diagnosis of autism. This structure was retained in the DSM-IV, the first edition to categorise autism as a spectrum disorder. In addition to autism and PDD-NOS (PPD not otherwise specified), DSM-IV added Asperger's disorder as a diagnosis. Modifications to the DSM-V criteria were subsequently made based on research in the intervening period. A key argument was that the DSM-IV criteria could not provide precise and reliable diagnostic and prognostic outcomes for ASD (Wiggins et al., 2019).

In response to this criticism, DSM-V refined its ASD criteria into two primary domains of core characteristics, with three levels of severity (Rosen et al., 2021). To be diagnosed, a person had to have persistent deficits in both (a) social communication and interaction *and* (b) restricted, repetitive behaviours (American Psychiatric Association, 2013b). As an example of a deficit in social communication, an individual with ASD may have fluent verbal and written language skills, but their use of language in social situations may appear odd and unusual. They may also lack the ability to read typical conversational cues, making conversation with others awkward. Those with more severe forms of ASD have minimal verbal and written language skills and typically initiate few social interactions. Restricted and repetitive behaviours exhibited by these individuals may then manifest as an impaired ability to switch or change tasks or activities without becoming emotionally dysregulated, resulting in ritualised verbal or nonverbal behaviour (American Psychiatric Association, 2013b).

The ASD domains outlined in DSM-V provide a more comprehensive description of a person's presentation. Each domain is further classified on a 3-point scale indicating the level of support that a person needs: Level 1 ('Requiring support'), Level 2 ('Requiring substantial support') or Level 3 ('Requiring very substantial support'). Clinicians are also required to specify cognitive skills (e.g., with accompanying intellectual disability), alongside comorbid psychiatric disorders (e.g., anxiety, depressive disorders), language disorders and/or medical conditions that overlap with ASD and can exacerbate symptom severity (e.g., epilepsy, gastrointestinal disorders, sleeping difficulties; (Hudson et al., 2018; Lever & Geurts, 2016; Mannion et al., 2013; Soke et al., 2018).

There is evidence that the DSM-V criteria have improved the diagnostic sensitivity and specificity of ASD, particularly for preschool children, who commonly display restricted and repetitive behaviours as part of typical cognitive development. That is, DSM-V criteria reliably differentiate non-spectrum behaviours from ASD behaviours (Christiansz et al., 2016; Mazurek et al., 2017). Nonetheless, diagnostic challenges remain, particularly when determining an individual's level of significant impairment. For example, a clinician could delay diagnosis if an individual's impairment does not quite meet the criteria but would run the risk of the individual's mental health deteriorating. The alternative is to take a pathological view of ASD by diagnosing early, although doing so would risk stigmatising those with minimal impairment by labelling them with a 'disorder' (Jellett & Muggleton, (2021). Diagnosis is further complicated if an individual with ASD meets different levels of severity across the two domains (social communication vs. behavioural), making their support requirements challenging to determine (Weitlauf et al., 2014). A further criticism of the DSM-V is that the criteria for restricted interests and repetitive behaviours are also relevant to children with intellectual disability, children who experience severe deprivation, and typically developing children with average intelligence—all of which can increase the potential for false-positive diagnoses (Van Wijngaarden-Cremers et al., 2014). Despite these issues, the clinical debate surrounding development of DSM-V criteria for ASD has led to much-needed changes in society's conceptualisation of this disorder. From an earlier medical model that focused on notions of 'normality', the DSM now adopts a holistic biopsychosocial approach, whereby individual differences are valued and interventions are tailored to the individual's choices so as to better leverage their strengths (Vivanti & Messinger, 2021).

Aetiology

The causes of ASD appear to be multifaceted. There is evidence that ASD is moderately heritable with longitudinal studies indicating significant impact from environmental, genetic and epigenetic mechanisms (Hallmayer et al., 2011; Waye & Cheng, 2018). The suggestion is that typical neural dendritic spine development is interrupted, with interferences in synaptic plasticity and dysfunction within synapses—like that found in intellectual disability (Bailey et al., 1995; Joensuu et al., 2018; Waye & Cheng, 2018; Weiner et al., 2017). Animal models also suggest that altering synaptic composition and dendritic spine formation in mice produces core ASD features, such as fixed behaviours, poorer social interaction, anxiety and hyperactivity (Joensuu et al., 2018). Additional predictors implicated in the development of ASD include advanced parental age; birth complications associated with trauma, ischemia, or hypoxia; and prenatal health of the mother (Joensuu et al., 2018; Modabbernia et al., 2017). The aetiology of ASD development therefore remains an active field of research (Thapar & Rutter, 2020; Waye & Cheng, 2018).

Epidemiology

The prevalence of ASD has increased exponentially since the 1970s: from 1 in 5,000 in 1975 to around 1 in 110 in 2009 (Weintrab, 2011). More recent reviews of world-wide epidemiological studies (i.e., between 1994 and 2019) have indicated an average prevalence as high as .72% (95% CI=0 .61 - 0.85) - which equates to approximately 1 in 145 children. (Myers, 2019; Talantseva et al., 2023). Estimates based on data from the United States of America demonstrate an increase to one in every 44 8-year-olds, with the age of first assessment around 36 months: a decrease from the 51 months found in earlier studies (Bent et al., 2017; Maenner et al., 2021). However, this statistic has been disputed, with the worldwide prevalence estimated to be one in 132 when adjusting for between-study variance in survey methods across different countries (Baxter et al., 2015). In Australia, available studies estimate prevalence around .05% (Icasiano et al., 2004; Parner et al., 2011) with ASD comprising approximately 30% of National Disability Insurance Scheme participants who currently receive funded support for a disability, making it the most commonly diagnosed disability in the country (National Disability Insurance Agency, 2020). Explanations for the global increase in ASD diagnoses are not straightforward. The increase could be accounted for by societal factors, such as increased public and clinician awareness and education about autism, as well as access to diagnostic resources and changes to diagnostic criteria (King & Bearman, 2011; King et al., 2009; Liu et al., 2010; Mazumdar et al., 2013; Myers, 2019).

Gender Ratio

One peculiarity of ASD is the gender pattern, with more males than females being diagnosed at a ratio of approximately 3:1 (Loomes et al., 2017; Van Wijngaarden-Cremers et al., 2014). The gender difference is even more striking when considering variations in intelligence: specifically, a 1:1 male:female ratio has been noted when severe cognitive impairment is present; this increases to an 8:1 male:female ratio among individuals with an average to high IQ (Goldman, 2013). Plausible genetic and hormonal mechanisms may explain this male bias, which is also observed in other neurodevelopmental disorders, such as attention deficit hyperactivity disorder (ADHD) and conduct disorder (Rivet & Matson, 2011; Schaafsma & Pfaff, 2014; Thapar & Rutter, 2020). However, reported gender differences in ASD may also reflect clinician assumptions based on typical male presentations, including more externalising behaviours (e.g., insistence on sameness, repetitive interests, slow in developing language skills), while females with subtle clinical features are missed (Goldman, 2013; Lockwood Estrin et al., 2020).

Age discrepancies in this gender ratio have also been noted. In particular, the 5.5:1 male to female ratio of ASD seen in childhood drops to 2:1 in adolescence and early adulthood (Goldman, 2013; Rutherford et al., 2016). Again, this discrepancy may reflect a bias in screening criteria towards the male presentation of overt characteristics, such as lack of facial expressions, lack of imaginative play, and repetitive behaviours—features not always present, or present to the same extent, in females with ASD (Beggiato et al., 2017; Campbell et al., 2014; Fombonne, 2020). Researchers have also argued that females with ASD may redirect their interests to focus on people rather than objects or activities and may have higher social motivation, more social interactions, and better-developed language skills than similarly aged boys (Lai & Szatmari, 2020). Under-diagnosis in girls may also be due to their ability to mask poor social understanding by imitating others' speech and social interaction (Goldman, 2013; Rivet & Matson, 2011). Although this compensatory behaviour works for younger girls, it becomes ineffective once social demands become higher during their teenage years, leaving girls at risk of significant social difficulties (Lai & Szatmari, 2020; Lockwood Estrin et al., 2020). This masking behaviour may result in a delayed or missed diagnosis and is often accompanied by significant mislabelling of ASD characteristics as 'other conditions', mental health difficulties, feelings of disempowerment, or adjustment issues (Leedham et al., 2020). That said, there is also evidence that the severity of ASD is similar between sexes (Prosperi et al., 2021). Nonetheless, females' phenotypical expression is characterised by less internalising and externalising problems compared with males (Lockwood Estrin et al., 2020). Hence, diagnostic methods that rely on externalising characteristics, such as the DSM, may perpetuate misdiagnosis based on gender stereotypes (i.e., girls labelled as shy rather than socially unresponsive, a closer match to diagnostic criteria) and expectancy bias (i.e., clinicians may minimise characteristics of autism in females, given its lower incidence in this group; (Lai & Szatmari, 2020; Lockwood Estrin et al., 2020; Prosperi et al., 2021).

Mental Health and ASD

Autistic Children, Adolescents and Adults

Much of the available research on ASD has, to date, focused on diagnosis and treatment for children and adolescents; a subgroup that typically shows higher levels of anxiety and depressive disorders than the general population. Up to 50% of children and adolescents have comorbid anxiety and ASD, although rates as high as 79% have also been reported (Kent & Simonoff, 2017). This percentage is in stark contrast to the 2–24% anxiety prevalence range estimated for neurotypical children and adolescents (Kent & Simonoff, 2017; Merikangas et al., 2009; Mingins et al., 2021). Similarly, rates of depression are four times higher in autistic children than children in the general population (Hudson et al., 2018).

Less well understood, but equally critical, is the mental health of autistic adults, including individuals who are diagnosed in adulthood. Prevalence rates of ASD in adult populations are still significant, with one study estimating the rate to be 9.8 per 1,000– comparable to the prevalence rate in children (Baxter et al., 2015; Brugha et al., 2011). Concerningly, lack of diagnosis often leads to poor longer-term mental health in these individuals. A gender disparity is also present: female autistic adults are more likely to be diagnosed later in life, have higher intellectual ability, higher risk of poor mental health but more likely to respond to psychological treatment (Begeer et al., 2013; Hickey et al., 2018; Leedham et al., 2020).

Individuals diagnosed with ASD as adults have often initially attributed their difficulties with social interaction to their own inadequacies, precipitating poor mental health. A diagnosis may provide a sense of relief, with an explanation for their social and behavioural uniqueness, thereby motivating them to access additional supports (Hickey et al., 2018; Leedham et al., 2020). The impact of ASD across the lifespan is unclear, however. There is evidence to suggest that autistic adults over 50 years of age show improved health, due to a significant decline in neuropsychiatric characteristics (Wise et al., 2017). Other studies indicate that older autistic adults experience poor health (Rydzewska et al., 2019) . However, Croen et al., (2015) found that young autistic adults had approximately 3 times the rate of depression and five times the rate of suicide attempts compared with controls. That said, autistic adults do experience physical difficulties associated with the ageing process, such as poorer executive functioning, adaptive functioning and quality of life compared with neurotypical peers (Tse et al., 2021). Alongside these health difficulties, challenges in relation to work and relationship difficulties are often experienced by autistic adults (Howlin, 2021; Odom et al., 2021).

Caregivers of Autistic Children

Given the complexity of ASD, it is not surprising that parents and informal caregivers (i.e., individuals or couples who provide the majority of care needs, usually without payment) of diagnosed children have consistently reported higher levels of depression, anxiety and stress compared with caregivers of neurotypical children or even children with physical disabilities (Bitsika & Sharpley, 2017; Hayes & Watson, 2013; Keenan et al., 2016; Weiss et al., 2015). Studies have found rates of moderate to severe depression ranging from 10% to 34% among these caregivers—a rate well below that seen among the general population (Bitsika & Sharpley, 2021; Gatzoyia et al., 2014; Kessler et al., 2003). Moderate to severe anxiety is also much higher in caregivers with autistic children, with estimates of around 17% compared with the general population occurrence—which is closer to 3% (Bitsika & Sharpley, 2021; Kessler et al., 2012). Behavioural and emotional problems in autistic children are a crucial driver of caregiver mood, resulting in both immediate stress and long-term ruminative worry about their child's future. Additionally, ASD symptom severity directly contributes to caregiver fatigue, which, in turn, can reinforce challenges in coping and further exacerbate anxiety and depression (Chan et al., 2018; Giovagnoli et al., 2015; Seymour et al., 2013). Further it has been observed that a broader autism phenotype (BAP), a subclinical set of personality and behavioural features believed to have a genetic predisposition to autism, is correlated with increased parenting stress and depression compared to normative samples (Ingersoll & Hambrick, 2011; Ingersoll et al., 2011).

Compounding caregiver stress are situational factors, including a reduced ability to socialise due to their child's behaviour or needs, little or no ability to choose support services, strained co-parental relationships, and high financial costs associated with their child's therapy. For example, in Australia alone, the cost of physical therapy (e.g., occupational therapy, speech pathology) for a child with ASD equates to approximately A$35,000 per year (Horlin et al., 2014; Sim et al., 2018). Obtaining a diagnosis is a further source of significant stress. This stress might be due not only to worry about characteristics but also the advocacy that caregivers often need to undertake to ensure that clinicians and specialists take their concerns seriously (Boshoff et al., 2018, 2019). Caregivers of autistic children have tended to report similar characteristics and experiences, including distress, social phobia, and social stigma associated with their child's diagnosis—although mothers have also reported higher levels of optimism and perceived quality and quantity of social support (Bitsika et al., 2013; Ingersoll et al., 2011; Willis et al., 2016; Zhou et al., 2018). However, other factors found to influence caregiver anxiety, particularly the role of the co-parent and ASD symptom severity, are not uniformly significant across studies (Sim et al., 2018; Voliovitch et al., 2021). It is likely that gender differences are associated more with parental role (e.g., primary vs. secondary caregiver) rather than gender differences *per se* (Hartley et al., 2014; Sim et al., 2018).

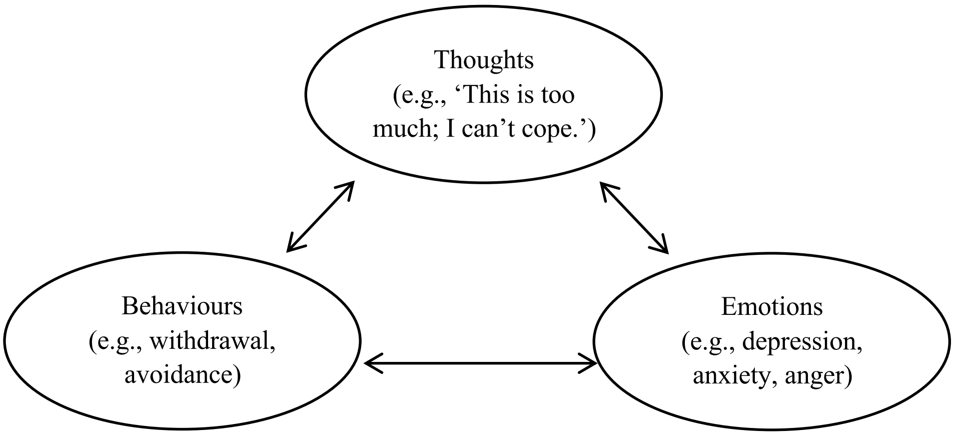
CBT and ASD

Psychological approaches can support autistic individuals as well as help caregivers develop resilience to the uncertainty of a positive diagnosis and any additional parental stressors (Leedham et al., 2020; McGrew & Keyes, 2014; Peer & Hillman, 2014; Su et al., 2018). Psychological interventions informed by a cognitive behavioural framework are a commonly used treatment approach for ASD across the lifespan though modifications to standard CBT for autistic individuals may be adopted (K. Cooper et al., 2018; David et al., 2018; Ung et al., 2015; Weston et al., 2016) . Although significant progress has been made in pharmacological approaches, antipsychotics (e.g., risperidone) and antidepressants (e.g., fluoxetine) show the only tangible benefits for individuals on the spectrum (e.g., reduced irritability and aggression). These medical treatments also come with significant side effects, such as weight gain, nausea, and agitation, with some even exacerbating behavioural difficulties (Henneberry et al., 2021; Taylor, 2016; Vasa et al., 2016). As such, psychological interventions remain a key approach for autistic individuals and their caregivers.

CBT, informed by philosophical and psychological theories about cognition and behavioural models for treating mental health disorders, was first outlined by American psychiatrist Aaron Beck in the 1960s. He observed that dysfunctional thinking (e.g., ‘I am a bad person’) was common to all psychological disorders and could significantly affect feelings (e.g., sadness) and behaviour (e.g., physical inactivity; see Figure1). Beck reasoned that if individuals developed strategies to create more-realistic thinking patterns, significant decreases in negative emotions and behaviours would result (Beck, 2021). A key aspect of CBT, then, is to help individuals examine the validity of their negative thoughts, words, or images in an objective way. That is, a person assesses the content of their beliefs, whether these beliefs are realistic and whether an alternative idea might be more appropriate, with resultant positive changes to their mood (Beck, 2021).

Figure 1

Basic CBT Model Highlighting the Reciprocal Relationship Between Thoughts, Emotions and Behaviours (Adapted From (Beck, 2021)



Although the evidence base for CBT is strong (for a recent review, see (David et al., 2018; Knapp et al., 2015), this therapy approach is not without its challenges. A key criticism is that CBT relies heavily on cognitive skills, including recognising emotions and understanding others' perspectives, and metacognitive abilities—skills that are typically impaired in persons with ASD (Behzadpoor & Pouretemad, 2021). CBT's requirement for introspection also places the onus on the individual to assume responsibility for undertaking treatment and sitting with uncomfortable feelings, such as increased anxiety, insecurity, and hopelessness (Berk & Parker, 2009; Schermuly-Haupt et al., 2018). Moreover, those with ASD are more likely to become emotionally overwhelmed during therapy. This reaction can, potentially, contribute to feelings of guilt if expected outcomes do not materialise and, in turn, reduce self-efficacy and increase anxiety (Berk & Parker, 2009; Schermuly-Haupt et al., 2018).

The application of CBT for persons with ASD requires some modifications to accommodate for differences in individuals' cognitive and language abilities (Lake et al., 2020; Ung et al., 2015; Vasa et al., 2014). In particular, visual representation of core CBT principles is vital to improving the feasibility of CBT for adolescents with ASD. Common visual strategies include the use of a 'stress-o-meter', which depicts green, yellow and red zones to explain the concept of emotional regulation, behavioural activities (e.g., a daily walk) to provide psychoeducation on relaxation, and video modelling of exposure instructions and tasks (Blakeley-Smith et al., 2021). Similar adaptations have been recommended for autistic adults, with CBT therapists reporting a need to implement more structure during sessions, reduce the use of metaphors, and rely on visual materials to lessen the emphasis on language abilities (K. Cooper et al., 2018; Vasa et al., 2016). Conversely, behavioural strategies typically focus on assessing the function of specific behaviours and replacing these behaviours with appropriate equivalents. For a person with ASD, this might involve learning a proactive coping strategy, such as taking time out and retreating to a quiet room to calm down instead of physically acting out (Leaf et al., 2021). Similarly, social behaviour might be modelled through explicit teaching instructions, via video or with peers in a group setting (Leaf et al., 2021).

When adopted with children and adolescents with ASD, such modifications have produced favourable mental health outcomes. For example, individual and group-based CBT programs have been effective in reducing anxiety symptoms, compared to waitlist controls (Sharma et al., 2021; Ung et al., 2015). There are, however, some caveats to this research. Comorbid mental health disorders (e.g., obsessive-compulsive disorder, psychosis), a common feature of ASD presentations known to negatively impact psychological treatment efficacy, are not routinely reported (Simonoff et al., 2013; Simonoff et al., 2008; Weston et al., 2016). Moreover, although meta-analyses have identified significant pre–post reductions in child anxiety with CBT, as determined by clinician reports, only minor or negligible gains have been reported by caregivers (Sharma et al., 2021; Ung et al., 2015). Clinicians' expertise in distinguishing features of anxiety from those of ASD may explain this result. For adolescents with ASD, CBT also appears to produce similar beneficial effects for mental health as does nondirective supportive counselling (Murphy et al., (2017). These findings echo research with neurotypical adults, where brief CBT (six to seven sessions) produced equally small reductions in depression and anxiety symptoms as general counselling with a focus on learning or reactivating problem-solving skills (Cape et al., 2010; King et al., 2014). The suggestion is that evidence-based psychotherapies should be considered when CBT is either ineffective, unsuitable, or not acceptable to the patient (King et al., 2014). In comparison, modified CBT for predominantly male adults aged 18–65 years with ASD has contributed to large and significant improvements in self-reported social anxiety and mood (Spain et al., 2017, Spain, Sin, et al., 2015). However, more research is needed before these findings can be generalised to the wider, heterogenous population with ASD. In summary, some autistic individuals appear to report improvements in aspects of mental health with CBT, yet this research remains limited in scope and quantity.

Mindfulness Interventions

CBT's narrow and structured focus on problem cognitions and behaviours has drawn criticism in recent years. Indeed, many mental disorders have broader life impacts; thus, a need to think flexibly is required (Hayes, 2004; Hayes & Hofmann, 2021). In response to these limitations, 'third-wave' cognitive behavioural therapies have been developed. These therapies draw upon concepts from classical conditioning and operant learning associated with 'first wave' approaches as well as cognition and information processing associated with 'second wave' therapies. Third-wave CBT targets thought *processes* rather than thought *content*. The aim is to teach attention and acceptance practices and, in turn, to change the responses to distressing psychological and emotional symptoms rather than eliminate them altogether (Hayes & Hofmann, 2021).

Third-wave methods emphasise mindfulness as a strategy, defined as an ‘awareness that emerges through paying attention on purpose, in the present moment, and non-judgementally to the unfolding of experience moment by moment’ (Kabat-Zinn, 2003, p. 145). Mindfulness practice involves systematically training the mind by focusing attention on a single sensation at any one moment (e.g., concentrating on the rhythm and flow of breathing, the way the breath feels on each inhale and exhale), while fostering an attitude of acceptance towards emotions, thoughts or external events (Segal et al., 2013).

Extensively practised in Buddhist traditions, mindfulness-based intervention (MBI) has gained significant popularity in Western psychology research and practice. One of the first pioneered programs was mindfulness-based stress reduction (MBSR), which was developed by Jon Kabat-Zinn in the 1970s as a complement to conventional medical treatment for chronic pain and stress disorders (Baer, 2003; Kabat-Zinn, 2003; Kabat-Zinn et al., 2017; Segal et al., 2013). A typical MBSR program consists of weekly 2-hour, 30-minute meetings over 8 weeks followed by a day of silent retreat. Weekly meetings have a unique theme upon which to base the group discussion (e.g., perception and creative responding). Group sessions also allow for up to an hour of formal meditation practice followed by an hour of discussion to cultivate mindfulness skills. Mindfulness exercises are taught under the initial guidance of an expert teacher. This guidance gradually reduces, with participants meditating in increased silence with each session. Participants learn basic mindfulness practices, such as awareness of the breath and use of mindfulness while walking and eating. Daily practice is a critical element of MBSR, with a minimum of 45 minutes of home practice required per day, 6 days per week (Kabat-Zinn et al., 2017).

Another MBI, developed by Segal et al. (2013) in the 1990s, is mindfulness-based cognitive therapy (MBCT). MBCT, originally termed ‘attention-control training’, was designed as a time-limited treatment for individuals with recurrent major depressive disorder.

MBCT adopted the MBSR 8-week group structure as a template and incorporated concepts from CBT (e.g., reality testing of automatic thoughts). MBCT therefore combines recognising and redirecting automatic negative thoughts with the third-wave strategies of mindfulness and acceptance to prevent dysfunctional automatic thoughts from precipitating further depressive episodes (Baer, 2003; Rieger, 2014). Although MBCT homework incorporates more specific reflection on how participants' thoughts link with depression, compared with MBSR (e.g., automatic thoughts questionnaire, working wisely with unhappiness and depression), MBCT participants are still encouraged to set aside 1 hour per day for home practice (Segal et al., 2013).

Mindfulness for Neurotypical Individuals

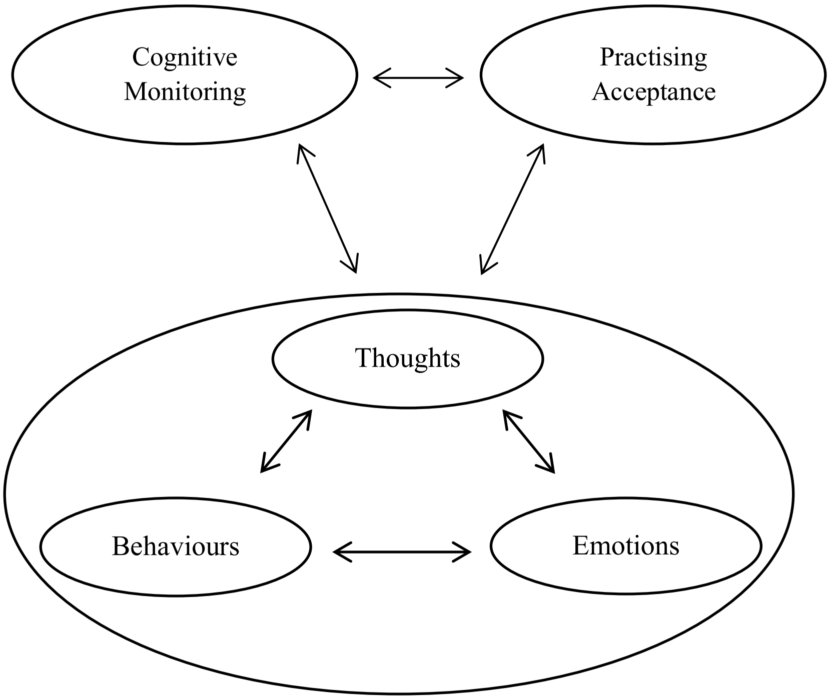
Mindfulness research has expanded considerably over the last three decades. There is now sufficient research literature to conduct meta-analyses on various mental processes and disorders to determine the effectiveness of MBIs. Indeed, these approaches have demonstrated superiority to placebo and active controls, producing moderately positive (Cohen's $d = 0.3$ to 0.5) effect sizes in anxiety, depression and quality-of-life outcomes across clinical and healthy adult populations—effects that are comparable to those associated with pharmacological treatments (Creswell, 2017; Goldberg et al., 2018; Khoury et al., 2015; Lindsay & Creswell, 2017). Evidence for mindfulness in persistent mental illness, such as psychosis, is also promising, albeit preliminary (Potes et al., 2018; Shapero et al., 2018).

Theoretically, mindfulness is proposed to improve emotional clarity and reduce rumination, worry and emotional reactivity while increasing meta-awareness and self-compassion, all of which contribute to positive mental health and wellbeing more broadly (Batink et al., 2013; D. Cooper et al., 2018; van der Velden et al., 2015). In addition, improvements to cognitive function occur through cognitive monitoring, which allows effective identification of emotional states, and the practice of acceptance, thereby enabling more-flexible responses to emotional stimuli (Lindsay & Creswell, 2017).

Monitor and acceptance theory provides a possible mechanism of action for mindfulness. According to this theory, ongoing monitoring of present-moment experiences and an acceptance orientation are critical to intervention efficacy (see Figure 2). Specifically, attention monitoring is responsible for control and regulation of affect, while acceptance helps to lower reactivity to negative affect (Lindsay & Creswell, 2017).

Figure 2

How Monitoring and Acceptance Theory Relate to CBT



One implication of this theory is that both positive and negative affect increase as attention skills develop, increasing awareness of both good and bad stimuli and affirming the importance of acceptance skills to help moderate increased stress reactions. This may partially explain why individuals can have negative meditation experiences, including severe and adverse impacts (e.g., agitation, fear, panic, depression, dissociation; (Lindahl et al., 2017). Research with the general population has identified adverse outcomes from initial mindfulness meditation training, including depletion of mental resources, increased short-term cortisol activity and reduced pain tolerance (Creswell et al., 2014; Evans et al., 2014). In addition, mindfulness practice may dampen positive emotions through the same neural pathways as those used when regulating negative emotions (Britton, 2019; Kral et al., 2018). Some of these adverse effects are likely due to the additional effort involved in learning a new therapeutic approach, suggesting that supervision by a practitioner and a period of adjustment may be necessary when undertaking training (Lindahl et al., 2017; Lindsay & Creswell, 2017).

Efficacy of Mindfulness

Active research is currently investigating the relationship between increased intensity and duration of mindfulness, akin to a dose–response relationship. To date, there is little evidence that larger doses of mindfulness enhance efficacy. Rather, the efficacy of an MBI appears to correlate with higher participant engagement, greater homework frequency, and the opportunity for feedback from either a trained therapist or an app (Firth, Torous, Nicholas, Carney, Pratap, et al., 2017; Parsons et al., 2017; Strohmaier, 2020). There are also no consistent findings on the relationship between the length of time engaged in mindfulness practice and the psychological outcomes (Creswell, 2017; Fox et al., 2014; Goldberg et al., 2017; Strohmaier, 2020). Although longer interventions appear to be more beneficial, substantial improvements have been demonstrated after a single 5-minute session (Creswell, 2017; Howarth et al., 2019; Strohmaier, 2020). This latter research suggests that the benefits from mindfulness may follow a nonmonotonic or inverted U-shaped curve, with too little being ineffective, too much being harmful and the optimum being somewhere in the middle (Britton, (2019).

Neuroimaging studies provide further insights into brain structure and brain function alterations, with mindfulness training a plausible mechanism for observed behavioural changes. Regular mindfulness practice is associated with positive neural activation pattern changes in brain regions typically associated with pathophysiologies (e.g., prefrontal cortex, basal ganglia; (Vignaud et al., 2018)). Structurally, brain regions that are altered in meditators include areas critical to meta-awareness (frontopolar cortex / BA 10), exteroceptive and interoceptive body awareness (sensory cortices and insula), memory consolidation and reconsolidation (hippocampus), self and emotion regulation (anterior, midcingulate and orbitofrontal cortex), and intra- and interhemispheric communication (Fox et al., 2014). The reduced activity noted in the amygdala and prefrontal cortex is of particular interest because both are crucial for regulating emotion and behaviour—aspects with which autistic individuals have considerable difficulty (Conner et al., 2019; Holzel et al., 2013; Taren et al., 2015).

Limitations of Mindfulness Research

To date, MBI studies have predominantly adopted a quantitative design. Such designs, particularly the 'gold standard' randomised controlled trial (RCT), are necessary to investigate efficacy claims, conduct trial comparisons between different MBIs and conduct meta-analyses to determine treatment efficacy for a specific population (Vancampfort et al., 2021). Nonetheless, many quasi-experimental and nonrandomised control studies evaluating the feasibility or application of mindfulness have claimed efficacy despite not including any type of control group—a criticism levelled at psychological science in general (Dimidjian & Segal, 2015; Goldberg et al., 2017; Van Dam, van Vugt, Vago, Schmalzl, Saron, Olendzki, Meissner, Lazar, Kerr, et al., 2018).

The accuracy and validity of the evaluations of MBIs have also been called into question. Despite the availability of MBSR or MBCT protocols to ensure a standardised approach, MBIs are characterised by significant differences in mindfulness usage (e.g., formal vs. informal mindfulness exercise), frequency and duration of meditations, intervention length and experience of the teacher (Dimidjian & Segal, 2015; Goldberg et al., 2017; Van Dam, van Vugt, Vago, Schmalzl, Saron, Olendzki, Meissner, Lazar, Kerr, et al., 2018). A further limitation for MBI research, in general, is a failure to report critical aspects of treatment fidelity, including participants' adherence to the intervention and the amount of guidance provided during home practice—information that is essential for determining dose–response relationships (Lloyd et al., 2018). Researchers have therefore urged caution in utilising MBIs for mental health disorders until the quality of research and explanatory mechanisms are more robust (Farias & Wikholm, 2016).

Given the above issues with quantitative research into MBIs, and since many quantitative designs with ASD groups are not sufficiently powered to detect statistically significant change, qualitative research into MBIs should be considered. Qualitative research can highlight positive and helpful experiences when undertaking mindfulness practice from the perspective of participants, such as increased emotional and physical awareness, greater self-acceptance, and acceptance of others. Negative experiences are also highlighted, from mild discomfort when undertaking meditation practice to psychological symptoms that are more severe, including the reliving of past trauma and the exacerbation of anxiety or depression (Cairns & Murray, 2015; Hartley et al., 2021; Wyatt et al., 2014).

Less common, but equally valuable, are mixed-method approaches. These approaches often probe individuals' experiences of mindfulness practice through interviews or surveys while incorporating quantitative measures to examine which outcomes occur with mindfulness training, both objectively and subjectively (Fish et al., 2016; Lindahl et al., 2017). Mixed-methods research therefore allows the researcher to benefit from both the contextualised insights of qualitative data and the generalisable, externally valid insights of quantitative data**.** When evaluating mindfulness, a combination of both quantitative and qualitative data can help with the identification of not only who benefits most from mindfulness but also in what circumstances (Farias & Wikholm, 2016; Lindahl et al., 2017).

Mindfulness for ASD

The modest amount of available literature evaluating mindfulness for ASD groups is promising. MBIs are increasingly being used to teach self-observation and regulation skills to autistic individuals, helping to reduce negative self-judgement and intrusive thoughts and emotions (Baer, 2003; Byrne et al., 2020; Byrne & O'Mahony, 2020; Pahnke et al., 2014).

Mindfulness training can help regulate regions of the brain, such as the amygdala, that contribute to emotional dysregulation in those with ASD as well as to symptoms of depression, anxiety and stress among caregivers (Lindsay & Creswell, 2017). Mindfulness training has successfully reduced aggressive and noncompliant behaviour and improved social communication in adolescents and autistic children (Singh, Lancioni, Singh, et al., 2011; Singh et al., 2006; Singh et al., 2014b; Spek et al., 2013b). MBSR has even been found to be as effective as CBT in managing anxiety, depression and stress symptoms in adults with high-functioning ASD (R. L. Cachia et al., 2016; Sizoo & Kuiper, 2017). There is also evidence that mindfulness can help with emotional regulation in these adults in the longer-term (Conner & White, 2018a; Kiep et al., 2015). However, many of the studies exploring mindfulness training in ASD have used small samples focusing on mother–child dyads with high-functioning children. Whether these results can be generalised to the broader, clinically diverse ASD population remains to be determined.

Caregivers of autistic children have also reported mental health benefits after engaging in mindfulness practice over several weeks (Dykens et al., 2014; Ferraioli & Harris, 2013). Moreover, studies that have examined the impact of children and their caregivers simultaneously using mindfulness, or caregivers learning and then teaching mindfulness to their children, have demonstrated positive results (Hwang et al., 2015; Ridderinkhof et al., 2018a). The suggestion is that improving parental wellbeing by teaching them mindfulness skills has flow-on benefits for their children (Neece, 2014).

Many criticisms of the mindfulness literature focused on the general population also apply to mindfulness approaches for ASD. Specific limitations include the reliance on uncontrolled study designs, lack of validation for altering manualised MBSR or MBCT protocols, and poor recording of participant treatment fidelity (Renee L. Cachia et al., 2016; R. L. Cachia et al., 2016). In addition, ASD studies have seldom explored the experiences of individuals who reported little or no benefit from mindfulness (Ridderinkhof, Bruin, et al., 2019; Ridderinkhof et al., 2018a; Salem-Guirgis et al., 2019) or of those who experienced discomfort or distress (Hwang & Kearney, 2015; Ridderinkhof, Bruin, et al., 2019). Further complicating this research is that studies that treat autistic children and their caregivers jointly have difficulty in identifying mindfulness as the only mechanism for change. That is, improved caregiver wellbeing may also be due to the parent–child interaction itself (Neece, 2014; Ridderinkhof et al., 2018a). Improvements in caregivers' mental health may even be due to group interaction with like-minded peers more so than to the mindfulness exercises themselves (Reid et al., 2016). Researchers examining mindfulness and autistic individuals must therefore carefully choose their methods to prevent unintentional confounds that reduce the reliability and validity of results.

Summary

ASD is a complex neurological disorder that has increased in prevalence over time, partly due to refined diagnostic criteria and increased awareness of the disorder. This increased prevalence has implications for health policy and practice, with caregivers facing significant stress navigating health and education systems for their child's physical and mental health symptoms and comorbidities. Although evidence-based psychological approaches, such as CBT, remain the default treatment, they typically require modification so that autistic individuals can effectively engage with the therapy material. More recently, a shift has occurred towards mindfulness as an acceptance-based therapy that can help to improve cognitive mechanisms, particularly attention and emotional regulation, in this child and adult group. As with CBT, mindfulness programs need careful design to include adequate clinician training and monitoring of individual participant experiences to ensure effective results. To date, however, the research on mindfulness training for autistic individuals remains limited in scope. The following chapter further explores adaptations to mindfulness for autistic individuals, with a focus on its application in a digital setting. The potential to access mindfulness training through computers or smartphones may help to overcome experimental limitations found in current mindfulness studies as well as address treatment accessibility difficulties identified by families living with ASD.

Chapter 2: eHealth Interventions and Autism

Overview

Internet access is ubiquitous in many areas across the world, particularly in middle- to high-income countries. The COVID-19 pandemic accelerated this access, with some 4.9 billion people, or 65% of the world population, now using the internet (International Telecommunication Union, 2021). In Australia in 2016-17, more than 8.6 million households had access to the National Broadband Network with 97% of households with children aged under 15 years having internet access (Australian Bureau of Statistics, 2018b). As of June 2021, almost 5 million (over 86% of households) had mobile broadband services (Australian Bureau of Statistics, 2018b; Australian Competition and Consumer Commission, 2021). The rising use of the internet offers access to new information and provides an opportunity to address current shortfalls in existing mental health care reported by vulnerable groups, including individuals and families living with ASD (Bennett et al., 2020; Sutherland et al., 2019). To date, little is known about the application and effectiveness of internet technologies in managing mental health difficulties in this cohort.

This chapter explores the development of the internet as a platform for mental health services and supports, commencing with the rationale for adapting evidence-based psychotherapies to deliver them digitally (also referred to as ‘eHealth’). The chapter then focuses on MBIs and how they are uniquely suited to an eHealth format. Lastly, the chapter discusses eHealth for ASD and whether such an intervention based on mindfulness principles may alleviate some of the mental health issues that autistic individuals (including children and adults) and their primary caregivers experience. The chapter concludes with an outline of the primary aims for this thesis based on research opportunities identified in the current literature.

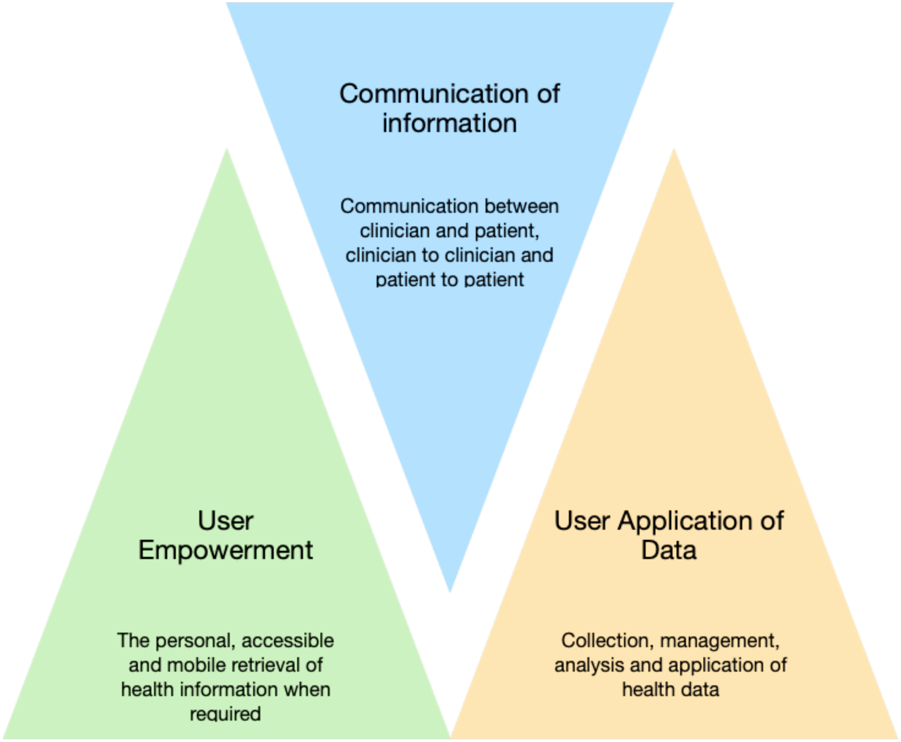
EHealth Defined

Eysenbach (2001) first used the term *eHealth* to denote the intersection of health information, medicine, public health, and businesses and services networked to digital information and communication technologies. In addition to using different digital platforms (i.e., mobile or desktop formats), eHealth encompasses both self- and clinician-guided formats. Eysenbach's (2001) definition has since been expanded to include a broad range of health services, including electronic healthcare delivery platforms and systems (telemedicine), electronic communication between practitioners and patients (telehealth), and even the provision and support of health services through mobile devices and smartphones (mhealth; (Meier et al., 2013). Despite notable differences in scope, each of these services theoretically share the essential components of eHealth proposed by Shaw et al. (2017) — namely, (a) empowering individuals to access information and monitor and track their health, (b) enabling intra- and intercommunication between clinicians and their patients, and (c) the collection, management and use of patient data to inform patient health choices (see Figure 3). Shaw et al. (2017) not only conceptually clarified the components of eHealth but also integrated these components into a framework, helping to standardise the discussion of eHealth across research disciplines.

Notably, few eHealth interventions adopt all three of Shaw et al.'s (2017) proposed components. As a result, the eHealth literature is characterised by numerous ill-defined and inconsistent terms and definitions (Meier et al., 2013; Oh et al., 2005; Shaw et al., 2017). One example is e-mental health, a subgroup of eHealth, which has been alternatively described as telemental health, telepsychology, telepsychiatry and even computerised psychotherapy (Aboujaoude et al., 2015; Massoudi et al., 2019). For this thesis, the term *eHealth*, originally proposed by Shaw et al (2017), is used to represent the breadth of technologically adapted psychological interventions.

Figure 3

Key Components of eHealth and Their Intersection (Adapted From (Shaw et al., 2017)



Development of eHealth

The use of computers to deliver psychotherapy offers an exciting opportunity to expand the range and repertoire of available mental health services. One of the first systems was a manualised version of CBT developed by Ghosh et al. (1984) to treat agoraphobia. CBT could be administered in three ways: self-guided instruction in a printed manual, automated (computer-led) format, or in-person with a therapist. Two key factors motivated the development of Ghosh et al.'s (1984) computer-administered program: (a) evidence that phobia severity and intensity could improve with frequent exposures and (b) demand for mental health treatment outstripping therapists' limited availability. In this context, a self-administered program offered the potential to alleviate the demand for therapists, reduce therapy wait times and even improve patient outcomes (Ghosh et al., 1984).

As computer technology has advanced, and its usage increased, so too has the evidence for various digital tools in mental health care, including video conferencing, dedicated webpages, and mobile smartphone applications (or ‘apps’)—each with varied effects (Luo et al., 2020). For example, a combination of internet and smartphone approaches have been used to effectively manage depression in clinical and nonclinical patient groups, with significant symptom reduction compared with waitlisted controls (Josephine et al., 2017). Mental health interventions delivered via the internet (i.e., webpages accessed through a web browser) have also been shown to benefit those with mild and moderate depression (Tokgöz et al. (2021). Similarly, apps have demonstrated some success in managing anxiety ($g = 0.19$, 95% CI: 0.07–0.31, $p = < 0.05$) and depressive disorders ($g = 0.22$, 95% CI: 0.10–0.33, $p = < 0.05$; (Firth, Torous, Nicholas, Carney, Pratap, et al., 2017; Firth, Torous, Nicholas, Carney, Rosenbaum, et al., 2017). In their meta-analysis of 19 smartphone interventions targeting a broad range of mental health issues, Weisel et al. (2019) even reported significant benefit for depression outcomes based on smartphone apps specifically designed for comprehensive self-administration ($g = 0.33$, 95% CI: 0.10–0.57, $p = < 0.05$; Weisel et al., 2019). The suggestion is that self-guided apps may provide a more coherent and consistent treatment than a combination of app use, in-person feedback, and clinician guidance (Firth, Torous, Nicholas, Carney, Pratap, et al., 2017).

The increasing reliance on self-administered therapy among available eHealth trials is worth considering. Research on eHealth typically includes some level of participant self-help in contrast to the active therapy component of a psychotherapy, such as CBT (Andersson & Titov, 2014; Hedman et al., 2012; Meier et al., 2013). EHealth’s emphasis on self-guidance and self-care has some advantages. First, allowing psychological therapy to be entirely self-administered removes both time restrictions and location restrictions, thereby improving patient access to psychotherapy and/or allowing clinicians to be present at times or locations previously unavailable (Hedman et al., 2012). Time and location constraints are particularly relevant for people residing in rural and regional areas, where service access may be limited. Similarly, people with transportation restrictions due to a disability or those from low socioeconomic backgrounds, who typically experience social inequities in utilising outpatient (face-to-face) psychotherapy, could benefit from the accessibility and affordability that eHealth offers (Hedman et al., 2012; Meier et al., 2013). Second, patients have the potential to make therapy progress with eHealth regardless of whether a clinician is present, because they have access to therapeutic resources, schedules, and assessments which can be stored and reviewed at their leisure. In this sense, the pace and content of eHealth can be adapted by the individual as required (Andersson & Titov, 2014; Domhardt et al., 2019; Hedman et al., 2012). Third, the format of eHealth is flexible and allows for a variety of digital formats, including desktop web browsers, emails, text messages, video conferences and mobile applications (Aboujaoude et al., 2015; Bennett et al., 2020; Hedman et al., 2012). Similarly, eHealth can be delivered in a pre-recorded or web-based format, ensuring the same content and delivery for each client. Lastly, there is an emphasis on eHealth being a time-limited intervention, ranging from a few weeks to no more than 6 months (Flujas-Contreras et al., 2019; MacKinnon et al., 2022; Thongseiratch et al., 2020). These latter elements remove the phenomena of therapist drift typically seen in face-to-face therapy, whereby therapists' intervention delivery skills inadvertently drift away from evidence-based techniques (Andersson & Titov, 2014; Waller & Turner, 2016).

However, there are limitations with eHealth. Maintaining user engagement remains problematic, despite the accessibility of apps indicated by the high number of downloads (Baumel, Muench, et al., 2019; Borghouts et al., 2021). Factors such as the perceived usefulness of an app, level of participant guidance provided, and how well an app connects participants socially can lead to significant attrition rates in smartphone trials, thereby impeding the reliability and validity of findings (Linardon & Fuller-Tyszkiewicz, 2020). Indeed, study dropout rates as high as 48% have been reported in the app literature (Torous et al., 2020). Adult participants have also reported low levels of computer knowledge and skills alongside low motivation as significant impediments to completing eHealth trials, particularly when having to balance other life demands, such as work and family (Hermes et al., 2019).

Further concerns have been raised about the lack of evidence-based eHealth interventions (Marshall et al., 2020). In a comprehensive review of 121 apps targeting anxiety in children and adolescents, it was found that only 23% used evidence-based treatment principles, such as CBT (Bry et al., 2018). Similarly, apps marketed for stress reduction have been found to contain few instructions regarding use or proper functionality and limited or no quality information about their efficacy (Baumel et al., 2020; Coulon et al., 2016; Mani et al., 2015; Weisel et al., 2019). Of more concern is the trend of using scientific language to sell these apps, with some even relying on anecdotal evidence or lived experience to validate their claims (Larsen et al., 2019). This lack of validation is, in part, a function of the relatively faster speed of technological development compared with the rate of scientific evaluation, with ‘gold standard’ large-scale RCTs for eHealth taking on average 5.5 years to complete (Torous et al., 2017; Wang et al., 2020). Given the low cost of entry for many app developers, the majority will never be able to afford the cost of a clinical trial (Bauer et al., 2020). Importantly, guidelines have been developed to determine which apps may prove helpful as an adjunct therapy. These guidelines examine the evidence for app efficacy and reinforce the importance of ensuring ongoing, individual monitoring of app usage (Bennett et al., 2020; Fish et al., 2016; Wang et al., 2020).

Finally, difficulties in establishing a therapeutic alliance when delivering psychotherapy via eHealth have been the subject of some debate. There is some evidence that eHealth leads to poorer outcomes due to limited or absent verbal or nonverbal cues which can impede rapport between clinician and client (Sucala et al., 2012). At the same time, it is argued that the therapeutic alliance is not as important when using eHealth given that client outcomes rely on the quality of online content rather than the clinician's skill set (Andersson & Titov, 2014; Sucala et al., 2012).

Efficacy of eHealth Across the Lifespan

When reviewing the eHealth evidence base, potential moderators of intervention effectiveness need to be considered. For example, preference of electronic device used varies with age, younger generations preferring smartphones while older adults tend to prefer desktops and laptops (Bauer et al., 2020). Importantly, a variety of eHealth tools have been used and adapted to deliver psychotherapy across the lifespan, with promising results. Examples include eHealth internet or app-based skills-building interventions to teach and enhance positive parenting strategies for managing disobedience, fighting, and aggression in young children (birth to 6 years), while concurrently alleviating parental stress (Flujas-Contreras et al., 2019; MacKinnon et al., 2022; Thongseiratch et al., 2020). Alongside improvements to caregivers' mental health (*g* range = 0.40 to 0.46; Flujas-Contreras et al. (2019), eHealth studies have noted small to moderate positive treatment effects for child anxiety (MacKinnon et al., 2022; Thongseiratch et al., 2020). However, samples in these studies were typically characterised by a higher proportion of female caregivers (up to 80%), thereby reducing the generalisability of the findings. That said, females more so than males do appear to rely on eHealth when searching for, and engaging with, health-related information and services and are, therefore, more likely to report health improvements as a result of their help seeking (Escoffery, 2018; Kontos et al., 2014; Victorson et al., 2020).

The available data on eHealth for adolescents is also positive. Internet-delivered CBT for social anxiety disorder involving key therapy strategies, such as exposure and safety behaviour avoidance, has been shown to significantly relieve anxiety (*d* = 0.64; 95% CI: 0.27–1.01) and depressive symptoms (*d* = 0.47; 95% CI: 0.07–0.88; (Nordh et al., 2021). School-based CBT programs delivered via CD-ROM have also been successful at improving depression symptoms compared with CD-ROM–based psychoeducation alone, with over 80% of students recommending the program (Stasiak et al., 2014). Meta-analytic findings confirm these results. In their review of 21 meta-analyses focusing on various eHealth tools for young people aged 4 to 25 years, Hollis et al. (2017) found that most adolescents and young adults with depression and anxiety reported clinical benefits with CBT-based eHealth, including internet and computerised or app interventions, compared with waitlisted peers or even another active treatment (e.g., problem-solving therapy). Notably, however, those with chronic psychosis, an eating disorder, or a neurodevelopmental disorder (e.g., ADHD, autism) have reported little benefit with eHealth (Hollis et al., 2017). Interestingly, eHealth interventions with children and adolescents appear to be beneficial without clinician involvement (Gindidis et al., 2018). Somewhat paradoxically, however, young people reported a preference for a mentor or guide to provide them with encouragement when undertaking eHealth and a preference for face-to-face therapy (Hollis et al., 2017). This finding suggests that adolescents and young adults likely require a nuanced and flexible approach that takes into consideration the preferences of the individual whenever possible.

Research on the application and effectiveness of eHealth with adults is more extensive. In a unique meta-analysis, Luo et al. (2020) compared eHealth cognitive therapy for adults (18–65 years) with mild to moderate depression across 17 studies with weekly face-to-face cognitive therapy. Depressive severity was substantially reduced in the eHealth group (standardised mean difference [SMD] = 1.73), although there was substantial variation across eHealth implementations of CBT (delivered via telephone, internet, or computer), type of control group (active vs. inactive control), and treatment population (general population vs. treatment-resistant groups). In comparison, other meta-analyses have reported small and often nonsignificant improvements in general wellbeing for adults with eHealth ($g = 0.18$ to 0.29; Bennett et al. (2020). Moreover, global ratings such as quality of life, functionality, and participant satisfaction have shown similar degrees of change among adults, regardless of whether the treatment arm involved eHealth or another active control (e.g., internet-delivered psychoeducation, online discussion groups; (Domhardt et al., 2019). Similar findings have been demonstrated with older adults (65+ years), with the suggestion that eHealth interventions may need to incorporate some form of social interaction (e.g., messaging, group discussion boards) for those who have less experience with mobile devices (Gould et al., 2021).

In sum, there is growing evidence that eHealth can be effectively adapted for children, adolescents, and adults, using a variety of digital tools. Results indicate a positive change in anxiety, depressive, and stress symptoms in particular. Treatment effectiveness does, however, appear to be facilitated by human guidance, as shown by the success of telehealth-based eHealth. How this guidance is incorporated into therapy, including the degree of either clinician or parental involvement does, however, vary considerably.

Mechanisms of Change in eHealth

It can be challenging to identify the most important and influential components of eHealth, given the wide range of technologies and interventions that this approach covers. This range includes differences in the degree of therapist guidance provided. Domhardt et al. (2019) reported superior results for guided eHealth interventions for anxiety compared with online problem-solving therapy or psychoeducation controls (SMD = 1.67). Interestingly, the frequency of clinician guidance (frequent vs. infrequent), the qualifications of instructors or the type of therapeutic approach (e.g., CBT vs. psychodynamic and interpersonal therapy) appear to have no significant influence on outcomes between groups (Domhardt et al., 2019). Similarly, Josephine et al. (2017) found intervention adherence rates were similar for mobile-based systems for depression (63% adherence), regardless of whether the intervention included clinician input. In one of the most recent comprehensive reviews of the eHealth literature involving 65 meta-analyses, Bennett et al. (2020) reported a significant association between fewer sessions (< 9) over extended periods (> 6 weeks) and higher engagement. Treatment engagement was higher if participants set reminders for doing their sessions and homework (Bennett et al., 2020). That said, intervention effects were greater when some form of clinician contact was present, regardless of whether this contact included infrequent email contact, time-limited phone calls or limited face-to-face contact.

The potential for digital placebo effects also needs to be considered—an effect that appears to be more pronounced with app interventions. This includes smaller positive outcomes for eHealth apps compared with active controls (e.g., psychoeducation, $g = 0.22$, 95% CI: 0.10–0.33, $p = < 0.05$) than inactive controls (e.g., waitlisted controls, $g = 0.56$, 95% CI: 0.38–0.74, $p = < 0.05$), as reported by adults with mild to moderate depression (Firth, Torous, Nicholas, Carney, Pratap, et al., 2017). Notably, participants in these studies were drawn from the general population and presented with subclinical, comorbid, or primary depressive symptoms. These studies therefore reflect a range of participant experiences with mild to severe symptomatology. Interestingly, smartphone apps that have incorporated a human component of feedback have demonstrated smaller treatment effects ($g = 0.24$, 95% CI: 0.09–0.39, $p = 0.002$) than self-contained apps ($g = 0.48$, 95% CI: 0.27–0.69, $p = < 0.001$), possibly because smartphone-only interventions are specifically designed for comprehensive self-administration (Firth, Torous, Nicholas, Carney, Pratap, et al., 2017).

CBT and eHealth

EHealth interventions have typically used techniques and principles taken from conventional psychological treatments, which are then adapted based on the technology used. However, these adaptations require validation to ensure treatment remains effective for users. As CBT has a robust evidence base, it has been readily adapted for eHealth (Deady et al., 2017; Torous et al., 2017). In one of the first eHealth trials to incorporate CBT, Fitzgerald and Werner (1996) noted improved behavioural and emotional regulation in two students with intellectual disability and ASD. More-recent reviews have shown a wider diversity of eHealth applications for delivering CBT. In their review of 10 RCTs, Deady et al. (2017) reported significant reductions in depression, anxiety, and stress symptoms with eHealth. Key cognitive strategies included self-monitoring, cognitive restructuring and problem-solving. Notably, reminders and homework feedback were not consistently applied across the included studies (Deady et al., 2017). However, whilst Deady et al. (2017) noted positive effects for both anxiety (SMD = 0.31, 95% CI: 0.10, 0.52; $p = 0.004$) and depression (SMD = 0.25, 95% CI: 0.09, 0.41; $p = 0.003$) with eHealth, the magnitude of treatment change for depression was smaller than that reported by Cuijpers et al. (2007); SMD = 0.42, 95% CI: 0.23–0.60, $p = < .01$). The type of cognitive strategy used in these trials appears to have some influence, with Levin et al. (2018) reporting similar positive change in self-criticism with apps that used cognitive diffusion, such as acceptance and commitment theory (ACT; d ranging from 0.76 to 1.06) and cognitive restructuring (i.e., CBT; d ranging from 0.80 to 1.61). It is therefore argued that a combination of acceptance-based emotion regulation and behavioural activation techniques are necessary when CBT is delivered via the internet or an app (Cuijpers et al., 2019). Indeed, activities centred around behavioural activation (including exposure tasks, acceptance-based relaxation techniques and activity scheduling) have shown the most impact in reducing depressive symptoms among clinical populations when the activities are delivered in an app (Torous et al. (2017). Other cognitive mediators such as positive beliefs, perceived control and changes in rumination and negative thinking have also been deemed critical to the effectiveness of eHealth (Domhardt et al., 2021).

There is, however, some concern that the commercial viability of an app may threaten the RCT as a methodology. In other words, apps can become outdated very quickly, potentially resulting in commercial opportunities being exploited by app developers while awaiting evaluation for trial results (Torous et al. (2017). It is therefore recommended that researchers and clinicians rely on evidence-based criteria when selecting apps, such as ensuring that apps are based on evidence-based therapies, the app content aligns with established treatment guidelines, and reminders—either automated or received directly from a clinician—are incorporated to help improve engagement (Bakker et al., 2016; Wang et al., 2020).

Despite these positive findings, alongside CBT's status as the 'gold standard' for psychological therapies (Hedman et al., 2012), there are limitations to the CBT approach in eHealth. One issue is that the clinician is not always present to monitor progress. As such, therapy cannot be adjusted to suit the changing needs and goals of the client (Gratzer and Khalid-Khan (2016). When designing exposure hierarchies for anxiety in an online environment, for example, without therapist guidance it can be difficult to elicit detailed fears and worries and to set appropriate exposure tasks (Spence et al. (2008). A further issue is that because eHealth is typically conducted with minimal or no clinician consultation, a detailed exploration of reasons for treatment resistance or noncompliance is not possible. This limited exploration of client motivation and engagement issues risks ineffective results for the client and possibly even harm from the intervention (Gratzer & Khalid-Khan, 2016; Spence et al., 2008). These difficulties are compounded by an unwillingness to complete session homework regardless of the number of reminders provided to participants (Spence et al. (2008). Indeed, the flexibility of online treatment makes it easy to delay or defer homework when other priorities arise, a key issue identified by several eHealth studies framed by CBT (Lee et al., 2021; Peros et al., 2021). Interestingly, more-recent eHealth interventions that have adopted third-wave therapies with acceptance components, such as MBCT and ACT, have demonstrated significantly less attrition or dropout (15.6%) than conventional CBT (26.1%; (Linardon & Fuller-Tyszkiewicz, 2020).

Mindfulness and eHealth

As the use of eHealth applications has expanded, so too has the digitisation of MBI. An app format is particularly suited to this therapy framework, primarily because of the ease and feasibility of unguided online meditation sessions to help regulate negative thoughts and feelings (Mikolasek et al., 2018; Morrison et al., 2017; Taylor et al., 2014). In a major update to their previous meta-analysis (Sommers-Spijkerman et al., 2021; Spijkerman et al., 2016), Sommers-Spijkerman et al. (2021) reviewed 97 RCTs involving online or app-based mindfulness interventions for clinical adult populations, with significant and positive effects noted for anxiety (g = 0.26, 95% CI: 0.18–0.33; $p < .001$), depression (g = 0.34, 95% CI: 0.18–0.50; $p < .001$) and stress (g = 0.44, 95% CI: 0.32–0.55; $p < .001$). Of interest, treatment effects were higher for studies based on acceptance-based therapies such as MBSR, MBCT and ACT, suggesting that similar mindfulness frameworks may be equally effective. There is also evidence that mental health improvements can occur in as little as 7 to 10 days with popular (commercialised) meditation apps, such as *Calm*, *Headspace* and *Smiling Mind* (Clarke & Draper, 2020; Flett et al., 2018; Howells et al., 2016), making eHealth apps an efficient and feasible addition to face-to-face mental health treatment.

There is less evidence for the effectiveness of mindfulness-based eHealth with children. One reason for this may be that online or app-based programs are predominantly self-directed and require significant parental commitment to complete, particularly in the absence of clinician appointments (MacDonell & Prinz, 2017; Thongseiratch et al., 2020). In contrast, research on the effectiveness of mental health apps for older adolescents and young adults is increasing (Leech et al., 2021). App-based meditation and mindfulness have been associated with beneficial effects among university students. For example, Flett et al. (2018) reported significant improvements in depressive symptoms, adjustment, resilience and mindfulness among university students following 10 days of using a mindfulness app. However, improvements in mental health through the use of a mindfulness app somewhat depend on the user's understanding of how to engage with mindfulness exercises; those who mistakenly perceive mindfulness as a passive process—rather than as an active process of focusing one's attention—may find that their distress increases (Clarke and Draper (2020).

Methodological limitations also compromise this research, weaknesses that reflect the eHealth literature more broadly (Goldberg et al., 2017). Studies have typically not reported or examined participants' treatment fidelity to an intervention, thereby preventing accurate analysis of the actual dose of eHealth that participants receive. Additionally, self-reported data indicate that some participants complete only around 40% of sessions (Gál et al., 2021; Sommers-Spijkerman et al., 2021). Poor app designs exacerbate this low engagement, with only a small percentage of mindfulness apps for children and adults rating acceptably on objective quality scales for app aesthetics, engagement, functionality, and quality of information (Mani et al., 2015; Nunes et al., 2020). These factors contribute to high nonadherence, between-study heterogeneity, and the risk of publication bias for meta-analyses reporting positive outcomes. Moreover, these methodological considerations limit the generalisability of available results to young and midlife adults (aged 18–60 years), who have not been routinely studied in eHealth mindfulness trials (Gál et al., 2021; Sommers-Spijkerman et al., 2021; Victorson et al., 2020).

To counteract some of these difficulties, Fish et al. (2016) developed a set of guidelines for investigating mindfulness delivery via eHealth designed to help strike a balance between intervention effectiveness and attrition minimisation. At a study design level, it is recommended that participants' experiences be explored using qualitative methods so that modifications can be made that will address their identified concerns about eHealth (Fish et al., 2016). Qualitative studies provide additional information on intervention effectiveness, including details on the strengths and weaknesses of an intervention and the reasons for nonadherence and attrition—both of which are problematic in current eHealth studies (Hartley et al., 2021; Linardon & Fuller-Tyszkiewicz, 2020).

Fish et al. (2016) also suggested that core mindfulness techniques, such as mindful breathing and body scanning, be included to aid comparison to MBSR and MBCT approaches. Specific suggestions regarding app duration and length are additionally proposed, including a minimum intervention length of 4 weeks encompassing about 30 minutes of practice 6 days per week and incorporating a variety of teaching and homework material formats, such as text, video, and audio (Fish et al., 2016). Notably, systematic reviews and meta-analyses have reported that 30 minutes of daily home practice is the average that participants complete during 8 weeks of MBSR; many find even this time commitment difficult to maintain and accordingly reduce home-practice requirements further (Boggs et al., 2014; Parsons et al., 2017). Although brief app interventions have shown benefit, sustained benefits over time have typically been associated with interventions over a longer period (Parsons et al., 2017). That said, practice quality (e.g., time spent in the present moment) appears to improve outcomes, regardless of the intervention period (Creswell, 2017; Goldberg et al., 2014). Moreover, given that mindfulness outcomes likely follow a normal distribution, the dose of mindfulness can be too little or too much depending on the individual (Britton, 2019). Flexibility in developing this testing regime is therefore necessary to find the optimal session duration and frequency for each person (Britton, 2019; Fish et al., 2016).

EHealth and ASD

Although eHealth options for ASD are still in the preliminary stage, this format does appear to be a feasible option for this group, in terms of helping to improve accessibility and usability of health care services. Particular focus has been on the use of eHealth to develop language capabilities. For example, unguided portable computer forms (e.g., tablets) have been more successful in helping autistic children acquire verbal communication skills than have guided picture exchange or voice output techniques (Lorah et al., 2015). Digital platforms and technologies, such as smartphone text messaging systems, have also helped caregivers maintain weekly contact with clinicians who provide real-time feedback on adolescent ASD behaviours and can provide on-the-spot guidance, when required (Chen et al., 2017). However, researchers have urged caution in adopting eHealth interventions for autistic individuals too quickly because these interventions may not have been developed to apply across the range of symptom presentations and may target only specific or limited skill sets (Allen et al., 2016; Kim et al., 2017; Lorah et al., 2015). Moreover, studies indicate that less than 5% of apps developed or targeted to ASD show evidence for efficacy claims, making choosing an evidence-based app difficult for clinicians and autistic individuals (Kim et al., 2017).

Given these caveats, it is perhaps not surprising that eHealth interventions for autistic individuals have primarily focused on clinician delivery of allied health assessments or therapy via video conferencing software. This format has been used to successfully deliver ASD diagnostic evaluations, thereby minimising ASD assessment service delays that are typically seen due to increased service demand and low levels of access to clinicians—an issue exacerbated by the COVID-19 pandemic (Matthews et al., 2021). Importantly, ASD assessments can be successfully conducted through eHealth, with in-person assessment required for less than 10% of cases involving younger (5- to 11-year-old) children with subtle characteristics or those with attentional problems, or to address technical glitches (Matthews et al., 2021). eHealth can also be tailored to target the development of specific skills. For example, in their systematic review of available ehealth studies for adolescents with ASD, Lamash et al. (2022) identified improvements in daily living and social skills alongside reduced anxiety and increased quality of life and social understanding. Another systematic review of 55 studies revealed comparable results between face-to-face psychological interventions involving a combination of CBT, functional and social communication and life-skills training, and the same interventions delivered via video conferencing for ASD (Ellison et al. (2021). Notably, a number of these studies relied on the involvement of caregivers, who supported and encouraged their children during the interventions. However, when using videoconferencing, clinicians must adapt their delivery to ensure successful outcomes for clients with ASD, including the need to address parent–child interactions that may occur off camera. Examples of such modifications include managing participants who get distracted by household activities during the intervention, allowing additional session time to build rapport and setting expectations for online session behaviour (e.g., appropriate eye contact with the camera; (Hepburn et al., 2016; Lee et al., 2021; Peros et al., 2021). Clients may also be required to video record and upload homework for clinician evaluation prior to each session to ensure that therapy goals are being met (Hepburn et al., 2016). It should be noted that some, but not all, clinicians have expressed scepticism regarding the reliability and validity of assessments that are conducted with these modifications. Indeed, assessments conducted via eHealth must rely heavily on parental or participant rapport given there are reduced opportunities for the clinician to directly observe deficiencies, particularly in individuals' social awareness (Spain et al., 2022).

For these reasons, researchers have recently turned to smartphone apps that could potentially be used without clinician involvement to increase the accessibility of psychological treatments for those affected by ASD. To date, however, no research has been conducted on the feasibility and effectiveness of psychological app interventions for ASD. Interestingly, caregivers of autistic children have reported high acceptability of eHealth modalities (e.g., assessments for diagnosis and accessing information on healthy lifestyles), with service users rating some eHealth services higher than face-to-face consultations with clinicians in terms of feasibility and satisfaction (Ellison et al., 2021; Lamash et al., 2022; Matthews et al., 2021; Singh et al., 2021). Such findings reflect the accessibility advantages of eHealth for a parent group who have reported structural and financial barriers to accessing professional mental health treatment (Matthews et al., 2021).

Early and targeted access to psychological treatment for this group is a particularly pertinent issue in Australia. Here, the National Disability Insurance Scheme, which began in 2013 and is overseen by the Australian Government, provides financial support for individuals and families with significant and permanent disabilities (National Disability Insurance Scheme Act 2013). Recent data from this scheme indicate that ASD is the largest single funded disability, accounting for around 30% of funded disabilities (not including ASD as a secondary diagnosis; (National Disability Insurance Agency, 2020, 2021). Additionally, the Australian Bureau of Statistics (Australian Bureau of Statistics, 2018a) reported that over 40% of autistic individuals report an unmet need for assistance with cognitive or emotional tasks; the largest unmet need in the survey. Research on ASD in Australia indicates that autistic children or intellectual disability have a high need for information and medication or counselling, but that only a small proportion are able to access the required services (Johnson et al., 2018). A parliamentary inquiry for services for people with ASD identified long wait times, with the wait for diagnostic services averaging between 12 and 18 months for young children, and treatment services for autistic adults being extremely rare (Edwards et al., 2017). These findings highlight the need for research and development in eHealth treatments for ASD, and their applicability across a wide variety of age groups.

Summary

As internet accessibility has increased, so too has the potential to reach vulnerable groups that otherwise may not have the capacity for or access to professional mental health supports. Although the evidence for eHealth interventions is still developing, interventions based on conventional cognitive and behavioural techniques appear to show efficacy across age groups and mental health conditions, particularly for anxiety and depression. There are, however, limitations with eHealth, particularly regarding participant engagement and difficulties for research to maintain its relevance due to rapid technological change. Nonetheless, eHealth has demonstrated early positive results with those affected by ASD. However, to reduce cognitive load requirements typically encountered with CBT techniques and the complex presentations commonly seen in ASD, simplified formats of eHealth need to be considered. In this context, MBIs, with their growing evidence base, may be an option. An app-based intervention may help autistic individuals and their families develop mindfulness skills in ways that are more conducive to incorporating therapy skills into their daily schedule. Although examining a mindfulness-based app for research purposes poses some methodological complexities, available recommendations provide a framework for rigorous testing of mindfulness apps (Fish et al. (2016).

Current Research

Chapters 1 and 2 highlighted some of the challenges in managing the cognitive, emotional, and behavioural characteristics and sequelae that come with a diagnosis of ASD. A key issue is the suitability of evidence-based psychological treatment approaches, such as CBT, to promote the mental health of individuals and their families coping with the extra demands that may come with ASD. A further issue for these individuals and families concerns the availability of psychological treatment. Indeed, the rising number of individuals diagnosed with ASD has seen a subsequent demand for treatment services. EHealth services that adopt mindfulness-based approaches offer a possible solution to both these issues, by offering a treatment approach suitable for the unique treatment demands of autistic individuals while also providing wider accessibility than traditional face-to-face therapy. To date, there is little to no research validating the adaptation of mindfulness techniques to a technology-based platform for this cohort. Rather, research into eHealth treatments for ASD has been limited to the evaluation of telehealth for assessment or treatment or apps for language and social-communication–based learning, rather than mental health applications.

The current research addresses this gap by investigating the effectiveness of mindfulness programs for mental health outcomes—particularly symptoms of depression, anxiety, and stress—among autistic individuals and their caregivers. The feasibility of eHealth as an avenue to provide an evidence-based mindfulness therapy was also explored. The specific aims of this research were threefold:

- to quantitatively summarise the available literature on mindfulness programs for autistic children, adolescents, and adults as well as their caregivers (Study 1)
- to qualitatively summarise the available literature on the experiences of both autistic children and adults, as well as their caregivers, when undertaking mindfulness and, in turn, potentially identify program components that are deemed most helpful or difficult for this cohort (Study 2)

- to pilot test the feasibility and suitability of a commercially available and well-established mindfulness app to improve the mental health of autistic individuals and their families (Study 3).

To address these aims, a mixed-methods framework was used. First, a quantitative and systematic literature review, with meta-analysis, was conducted to explore the psychological effects of mindfulness interventions for ASD-affected populations (Chapter 3: Study 1). The results, which were subsequently published, provided preliminary evidence for the use and effectiveness of MBCT- and MBSR-based MBIs with autistic children and adults and their caregivers. This was followed by a second comprehensive review of the qualitative literature in this area, a meta-synthesis, to explore experiences of mindfulness among autistic children and adults and their caregivers and caregivers (Chapter 4: Study 2). This second study, which was also published, identified important considerations for adapting mindfulness interventions, based on aspects that participants found helpful and less helpful. The final study (Chapter 5: Study 3) adopted these considerations in a pilot RCT to test the feasibility and potential effects of a mindfulness app, Smiling Mind. Modifications to treatment duration and requirements were made during this trial to suit the needs of autistic individuals and of their caregivers. Recruitment challenges provided some interesting insights that were incorporated into a subsequent publication, which outlines practical strategies for future eHealth trials with ASD groups. Due to publishing requirements, the complete study is presented in Chapter 5, with the published version (a brief report) included in Appendix A.

Chapter 3: Study 1

Mindfulness for Children and Adults With Autism Spectrum Disorder and Their Caregivers: A Meta-analysis

Research Communication

Findings from this research were communicated as *Mindfulness for Children and Adults with Autism Spectrum Disorder and Their Caregivers: A Meta-analysis* (Poster presentation) at the following national and international forums:

- a poster presentation at the national 12th Florey Postgraduate Research Conference (Adelaide, Australia), 2018
- an oral presentation to the National Conference of the Australian Association of Cognitive Behaviour Therapy, October 25, 2019.

Statement of Authorship

Title of Paper	Mindfulness for Children and Adults with Autism Spectrum Disorder and Their Caregivers: A Meta-analysis	
Publication Status	✓ Published ☐ Submitted for Publication	☐ Accepted for Publication ☐ Unpublished and unsubmitted work written in manuscript style
Publication Details	Hartley, M., Dorstyn, D., & Due, C. (2019). Mindfulness for Children and Adults with Autism Spectrum Disorder and Their Caregivers: A Meta-analysis. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-019-04145-3	

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Name of Principal Author (Candidate)	Matthew Hartley		
Contribution to the Paper	Conceptualisation of study, created database search terms and queries, reviewed articles and synthesised data, Utilised statistical software package to complete data analysis and prepared results. Wrote paper and prepared manuscript for publication		
Overall percentage (%)	80%		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	31st Jan 2023

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);

ii. permission is granted for the candidate in include the publication in the thesis; and

iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

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Contribution to the Paper	Assessed with conceptualisation of study, reviewed short-listed articles, reviewed raw data and assisted with data analysis and results. Contributed to editing draft manuscript for publication.		
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Preface

As outlined in Chapter 1, mindfulness holds promise as a psychological treatment approach for those with ASD. To date, however, the magnitude of treatment effect associated with mindfulness for autistic children and adults and their caregivers remains unclear. There are several reasons for this knowledge gap. The ASD literature is characterised by study numbers that are often small and underpowered, making it difficult to determine statistically significant positive change in comparison to a control condition. These small samples may also be subject to confounds, such as placebo effects or sample bias. Additionally, autistic individuals require modifications to conventional MBSR and MBCT protocols to account for their unique characteristics, such as reduced metaphor usage, shorter session length, and smaller group sizes to minimise social anxiety. Such modifications then make it difficult to have a direct equivalence comparison between conventional MBIs and the modified version.

The following study (Study 1) addressed these issues by using meta-analytic techniques to synthesise the published literature on mindfulness interventions targeted to autistic children and adults and their caregivers. The primary aim was to provide reliable effect-size estimates to confirm the efficacy of various MBIs on mental health symptoms reported by this cohort. A secondary aim was to summarise and critically evaluate the quality of the literature. In combination, these findings not only provide preliminary evidence of the efficacy of MBIs for individuals on the autism spectrum and their caregivers but also suggest ways to improve future MBI research with this group.

Mindfulness for Children and Adults with Autism Spectrum Disorder and Their Caregivers: A Meta-analysis

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Abstract

Mindfulness-based therapies are rising in popularity. However, evidence for their effectiveness in reducing psychological distress and enhancing wellbeing for families living with ASD is limited. A systematic search identified 10 independent studies, involving a pooled sample of 233 autistic children and adults and 241 caregivers. Hedges' *g* effect sizes with associated 95% confidence intervals, in addition to heterogeneity, were calculated using a random-effects model. Caregivers, children and adults who received mindfulness all reported significant gains in subjective wellbeing (SWB) immediately post-intervention. Available data indicated intervention effects were maintained at 3-month follow-up. Mindfulness presents a promising intervention strategy in ASD populations; however, more controlled research is required to determine its precise efficacy for affected families and subgroups.

Keywords: systematic review, subjective wellbeing, parents, intellectual disability, mental health

Introduction

Up to 70% of children and young people living with ASD experience a comorbid mental health problem or disorder, most commonly anxiety and depression (Lever & Geurts, 2016) or a combination of the two (Simonoff et al., 2008). Circumstantial anxiety in autistic children may be compounded by parental anxiety (Weiss et al., 2015). Autistic adults also self-report moderate to severe depressive and anxiety symptoms (Nah et al., 2018). Given that mood disturbances have a major adverse impact on everyday functioning in this cohort (Mazzone et al., 2013), strategies to manage and enhance SWB, including both positive and negative emotional feelings (Diener et al., 1999; Luhmann et al., 2012), are critical.

One promising strategy is mindful awareness, or nonjudgemental attention to the present moment (Kabat-Zinn, 2003). Mindfulness interventions have been shown to reduce psychological distress and facilitate wellbeing in general and clinical populations (for recent reviews see (Blanck et al., 2018; Perestelo-Perez et al., 2017; Potes et al., 2018; Wang et al., 2018). The suggestion is that interventions such as MBSR and MBCT can increase emotional clarity by reducing depressive rumination and preventing a downward spiral of negative thoughts (Baer, 2003; D. Cooper et al., 2018; Perestelo-Perez et al., 2017).

Evidence to support the effectiveness of mindfulness interventions targeted to families affected by ASD is promising, albeit preliminary (Renee L. Cachia et al., 2016). Mindfulness interventions have been successful in reducing aggressive and noncompliant behaviour, and improving social communication in children and adolescents with high-functioning ASD (Singh, Lancioni, Singh, et al., 2011; Singh et al., 2006; Singh et al., 2014b). Mindfulness interventions have also shown promise in the management of psychological distress in adults with high-functioning ASD (Sizoo & Kuiper, 2017; Spek et al., 2013a), even assisting emotional regulation over time (Conner & White, 2018b; Kiep et al., 2015). Similarly, caregivers of children with a neurodevelopmental disability who have practised mindfulness have reported psychological improvements in levels of depression, although changes in perceived stress have not been consistent (Dykens et al., 2014; Ó Donnchadha, 2018). Interestingly, the application of mindfulness in parallel for caregivers and their autistic children has demonstrated reciprocal improvements to the mental health of both groups (de Bruin et al., 2015; Ridderinkhof et al., 2018a), although there is suggestion that noted improvements to child wellbeing may be due solely to gains experienced by caregivers (Neece, 2014). Indeed, further research is required to determine whether gains in wellbeing for autistic children can be directly attributed to the intervention itself, changes due to childhood development or to improvements in the caregiver's mental health (Renee L. Cachia et al., 2016; Neece, 2014; Ridderinkhof et al., 2017).

A quantitative review of mindfulness and ASD research would help to consolidate the current evidence and inform a comprehensive picture of mindfulness and its application to the ASD population. Only recently has a meta-analysis been attempted in this area, when Nicollet et al. (2016) pooled data from four studies involving autistic adults who received a joint mindfulness and cognitive behavioural intervention. Participants reported a significant ($p = 0.04$), albeit small reduction in anxiety (Nicollet et al., 2016). Other systematic reviews indicate some support for mindfulness in autistic adults and their caregivers (Renee L. Cachia et al., 2016; R. L. Cachia et al., 2016; Donnchadha, 2018a; Hourston & Atchley, 2017), although effect sizes have not been routinely calculated.

The current review utilises meta-analytic techniques to integrate and summarise available data on the effectiveness of mindfulness interventions for families living with ASD to a standard effect size. The combined findings will help address the following research questions: Are mindfulness interventions effective in enhancing subjective wellbeing (SWB) for subgroups affected by ASD? If so, what are the short-term (i.e., pre- to immediately post-intervention) and longer-term (i.e., post-intervention to follow-up) effects for children, adults and their caregivers?

Methods

Protocol Registration

The protocol for this systematic review and meta-analysis is registered on the PROSPERO database (ID No. CRD42018103208).

Selection Criteria

Population

Eligible studies had to include children (of any age) or adults with a primary diagnosis of ASD, autism, Asperger’s or pervasive developmental disorder (consistent with criteria listed in the *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition; (American Psychiatric Association, 2013a) or their caregivers. Studies where the primary diagnosis involved a mixed cohort of ASD and intellectual or developmental disabilities were excluded.

Intervention

Studies had to evaluate an MBI, where the primary focus was fostering increased mindfulness in participants, defined as a purposeful nonjudgemental awareness of ongoing present experience (Kabat-Zinn, 2003). This included MBSR- and MBCT-based programs, with allowance for some modification when applied to the specific needs of individuals with ASD. Interventions where mindfulness training was only one component of the intervention program were not included. The intervention had to be delivered by a trained practitioner (e.g., nurse, psychologist, psychiatrist) and could include a combination of conventional face-to-face therapy and formal home practice—the latter considered a cornerstone of mindfulness training (Kabat-Zinn, 2003).

Outcomes

Intervention effectiveness had to be evaluated using a standardised, multi-item measure of SWB. SWB is a broad multifaceted concept encompassing self-evaluation of positive and negative affect in addition to evaluations of life satisfaction (Diener et al., 1999). Self-report outcomes from children, adults and caregivers were examined. Parental proxy reports of their child's SWB, which are routinely used as an alternative source of information in the ASD literature (Knuppel et al., 2018), were eligible.

Study Design

Given that mindfulness research in the ASD cohort is still preliminary (Renee L. Cachia et al., 2016; R. L. Cachia et al., 2016), both quasi-experimental and RCTs were included. Studies had to utilise a repeated-measures design, whereby SWB was assessed at baseline (i.e., pre-intervention), immediately post-intervention and, if possible, at follow-up. Only studies published in the English language, or with an English translation, were eligible. Finally, studies had to provide sufficient quantitative data to calculate effect sizes in the form of Hedges' *g* (e.g., means, standard deviations, *p* values, *t* tests). Qualitative studies, including case studies ($N < 5$), were excluded in this review because the primary focus was on the calculation, and comparison, of effect-size estimates.

Database Searches

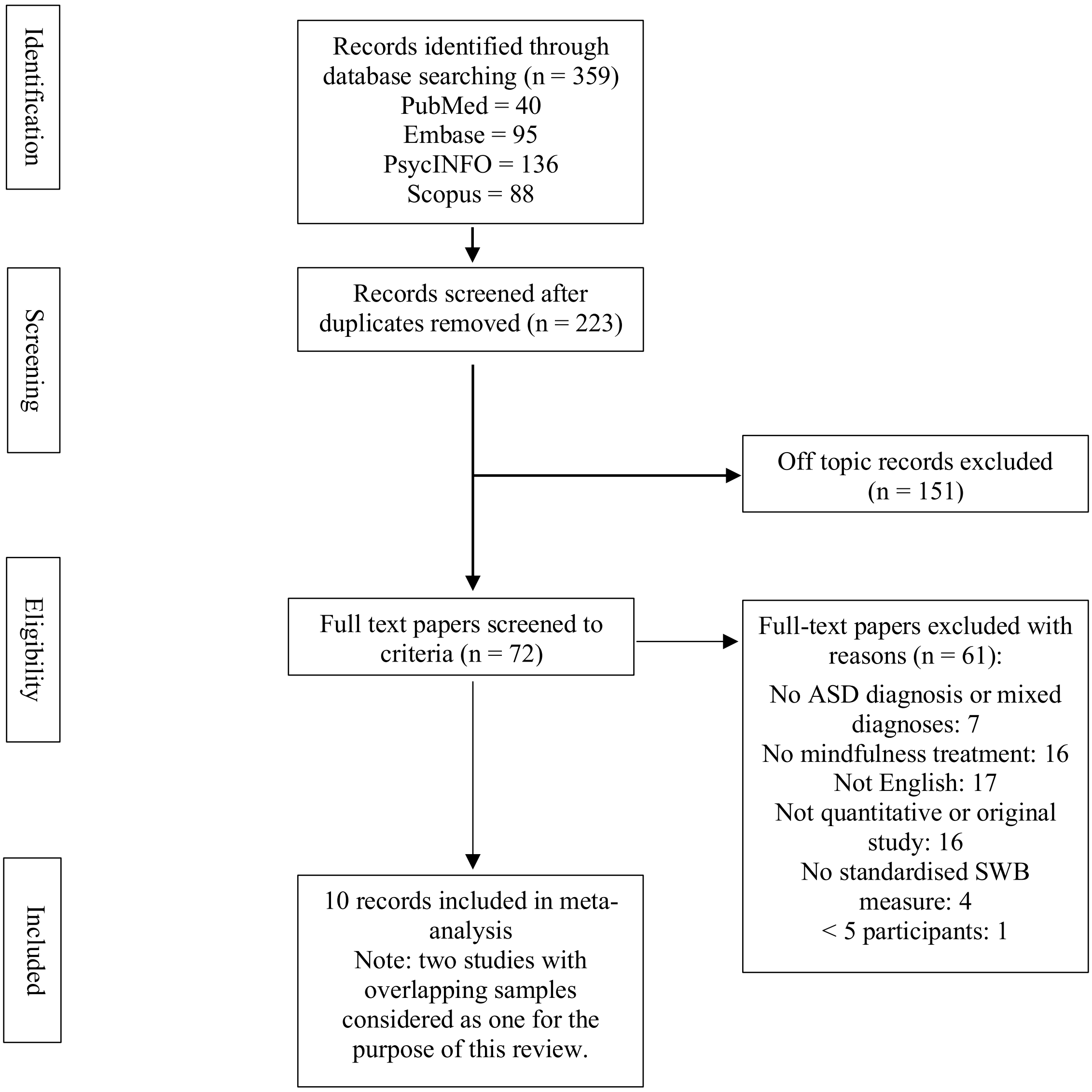
Embase, PsycINFO, PubMed and Scopus were searched from database inception to April 2018. A research librarian provided guidance in specifying a search strategy unique for each database. Search terms were deliberately kept broad, with keywords focused on general variants of 'ASD' or 'mindfulness', to ensure that all relevant articles were captured (see Appendix B). Reference checks of all included studies, in addition to relevant systematic and narrative reviews (Renee L. Cachia et al., 2016; R. L. Cachia et al., 2016; Donnchadha, 2018a; Hourston & Atchley, 2017; Paz & Wallander, 2017a; Spain et al., 2015), were conducted to ensure no data were missed. No additional studies were located through citation searching.

Study Selection

The article-screening process was conducted by the first author (MH) using EndNote software, as outlined by Peters (2017) and is outlined in Figure 4. Of 260 abstracts and titles screened, the full text of 72 potential studies were subsequently examined and rechecked against the inclusion criteria. Eleven studies met all inclusion criteria. Two articles (Rayan & Ahmad, 2016, 2017) appeared to utilise the same cohort of participants and, following confirmation with the study authors, were treated as one study. This resulted in a final sample of 10 independent studies. A second reviewer, a doctoral student in psychology, assessed a random selection of 50 (12%) articles to determine reliability in the screening process. Moderate interrater agreement was demonstrated ($\kappa = .6$; (Viera & Garrett, 2005). Disagreements were resolved with consensus discussion.

Figure 4

PRISMA Flow Diagram Outlining Study Selection (Moher et al., 2009)



Note. PRISMA = Preferred Reporting Items for Systematic Reviews and Meta-analyses.

Quality Assessment

Quality assessment was undertaken in accordance with the method outlined by Reichow et al. (2008) and consistent with previous systematic reviews involving ASD cohorts (Renee L. Cachia et al., 2016; Donnchadha, 2018a). Studies were assessed against six primary indicators necessary for research validity (e.g., control conditions, attrition, statistical tests). Each indicator was defined on a trichotomous scale: high (2), acceptable (1) or unacceptable quality (0). Eight secondary indicators, which are not required but can strengthen research validity, were also ranked on a dichotomous scale: evidence (1) or no evidence (0). For a study to receive an overall ranking of 'adequate' or higher it must receive at least four high-quality primary ratings, no unacceptable primary rankings, and evidence of two secondary rankings (Reichow et al., 2008).

Data Extraction and Management

Consistent with the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA; (Moher et al., 2009), key data were extracted from each study and managed in Meta-Essentials as outlined by Suurmond et al. (2017). These data included study characteristics (e.g., sample size, gender), intervention characteristics (e.g., frequency and duration of mindfulness intervention) and effect size data (e.g., means, standard deviations for each measure of SWB utilised by a study). Data extraction was performed by the first author (MH) and checked by the second author (DD).

Statistical Analysis

Effect size data were analysed using the software package Meta-Essentials (Suurmond et al., 2017). Hedges' *g* effect sizes were calculated for each individual, pre–post measure reported by a study. Hedges' *g* weights each group's standard deviation by its sample size, rather than the pooled standard deviation for the two groups, thereby allowing for correction of a potential upward bias due to small sample sizes (Borenstein et al., 2009; Ellis, 2010). The calculation of *g* involved several steps. First, where a study utilised multiple measures of SWB, effect estimates for each measure were individually calculated and then averaged. Effects were also standardised across measures: a positive *g* indicated an improvement in SWB following mindfulness, whereas a negative *g* indicated a deterioration. Second, given the variation in study design, effect sizes were calculated separately for within-group (i.e., quasi-experimental, dependent samples) and between-group (i.e., RCTs) study designs. When computing *g* from studies with a two-group repeated-measures design, the pre–post correlation is required in order to impute the within-groups standard deviation from the standard deviation of the difference. As studies did not routinely report this data, a conservative estimate of $r = .7$ was used, based on within-group test–retest correlations for the standardised measures utilised in this review (*r* range: typically > .7; see Appendices C and D).

Third, effect sizes were grouped and pooled into six categories reflective of the unique study populations and timeframes examined: ASD children post-intervention, ASD children follow-up, ASD adults post-intervention, ASD adults follow-up, Caregiver post-intervention, Caregiver follow-up. Prior to being pooled, effects were weighted by the respective study's inverse variance (g_w). This weighting gives preference to studies with larger samples, thereby accounting for an upward bias that is typically associated with effect estimates based on small sample sizes (Borenstein et al., 2009). Interpretation of *g* was based on Cohen's (1977) criteria, with values of 0.2, 0.5 and 0.8 representing small, medium and large intervention effects. In addition, 95% confidence intervals (CIs) were calculated to determine the precision of each *g*, while *p* values determined the statistical significance of each effect. A random-effects model was used for these analyses (Cummings, 2012)see Appendix E for individual measure *g* values.)

To address heterogeneity, the I^2 was calculated. This index reflects the proportion, or percentage, of variance in effect-size estimates attributable to real differences in effect size (Higgins et al., 2003). Finally, Orwin's fail-safe N (N_{fs}; (Orwin, 1983) was calculated to test for publication bias (criterion effect size = .2). The larger the N_{fs} value the more tolerant the effect is of excluded null results (Rosenthal, 1979). A recommended minimum N_{fs} was additionally computed by the formula $5k + 10$, where k is the number of studies included in the meta-analysis (Ellis, 2010; Rosenthal, 1979).

Results

Sample Characteristics

The pooled sample included 454 individuals (see Table 1): 74 children (mean age 13.7, SD = 2.3), 139 autistic adults (mean age = 38.4, SD = 10.3), and 241 caregivers (mean age 37.5, SD = 5.9). Female participants slightly outnumbered males (237f:217m) due to the higher proportion of female caregivers (162f:79m). In comparison, there were more male participants (child and adult) with ASD (75f:138m), consistent with the typical ASD profile (Rivet & Matson, 2011; Schaafsma & Pfaff, 2014). Five of seven studies excluded ASD participants with an IQ less than 85. Additional exclusions, stipulated by seven studies, were participants with genetic, neurodevelopmental, psychopathological or drug and alcohol disorders, those who had been institutionalised or had changes to medication during the study. Anxiety and depression were included comorbidities in two studies (Kiep et al., 2015; Spek et al., 2013a).

Study Characteristics

Studies originated from the Netherlands ($N_{studies}$ = 5) or the United States ($N_{studies}$ = 3), with single studies from Jordan, Australia and Spain (see Table 2). Both MBSR ($N_{studies}$ = 3) and MBCT ($N_{\text{studies}} = 5$), or a combination of both frameworks ($N_{\text{studies}} = 2$), were evaluated. Active comparison interventions ($N_{\text{studies}} = 3$; e.g., CBT, skills-based parenting, mindfulness for noncaregiver group) or waitlist controls ($N_{\text{studies}} = 2$) were utilised in five studies, with the remaining studies adopting a quasi-experimental pre–post design.

Over 40 individual measures of SWB were reported across the 10 studies (see Table 2). Most commonly this included quality-of-life indices (e.g., Beach Centre Family Quality of Life Scale), measures of general wellbeing (e.g., World Health Organization Five Well-Being Index), behavioural and emotional regulation (e.g., Child Behavior Checklist, Parenting Scale), stress and distress (e.g., Parenting Stress Scale), and mindfulness (e.g., Five Facet Mindfulness Questionnaire). Less common were specific measures for anxiety, depression, mood, autism behaviours, rumination and worry. Measures for caregivers and autistic adults were primarily self-reported. Intervention outcomes for children were based on a combination of child and parent responses (de Bruin et al., 2015; Hwang et al., 2015; Ridderinkhof et al., 2018a).

Mindfulness Interventions

Interventions occurred on a weekly basis, in group or individual format. Session duration typically ranged from 1.5 to 2.5 hours. This included brief interventions delivered over a 5-week timeframe (Rayan & Ahmad, 2016, 2017) and intense programs, lasting over 12 months (Hwang et al., 2015). Total clinician time ranged from 6.5 to 28 hours, with additional resources provided for the practice of mindfulness skills at home (e.g., mindfulness recording on CD). Intervention attendance was approximately 80% or above when reported (Conner & White, 2018b; de Bruin et al., 2015; Ferraioli & Harris, 2013; Rayan & Ahmad, 2016, 2017), with fidelity to home practice monitored by three studies (Conner & White, 2018b; Hwang et al., 2015; Rayan & Ahmad, 2017).

Modifications to mindfulness training were detailed for autistic adults. These modifications included a reduction in the use of metaphors and a lessening of cognitive therapy elements (Conner & White, 2018b; Kiep et al., 2015; Spek et al., 2013a); shortened (60- minute) sessions and 20-minute meditations, a preference for individual-based rather than group therapy, and a focus on emotional regulation rather than depression (Conner and White (2018b). Similarly, Sizoo and Kuiper (2017) paced their MBSR program over 13 weeks of 1.5 hour sessions in order to provide a slower pace of intervention delivery. Sessions were also modified to clarify text, similar to MBCT modifications, such as reducing the use of metaphors. For autistic children and their caregivers, elements from both MBCT and MBSR were utilised with some adaptations (de Bruin et al., 2015; Ridderinkhof et al., 2018a). This included shortening sessions from 2.5 to 1.5 hours, a focus on applying mindfulness to stressful situations and increasing the total number of sessions from eight to nine. Finally, an overview of the mindfulness intervention was provided at the beginning of the program, contra to normal practice (de Bruin et al., 2015), to reduce feelings of insecurity in child participants.

Practitioners delivering the interventions were typically mental health professionals (mental health nurse, clinical psychologist) who had undertaken additional training in mindfulness (de Bruin et al., 2015; Hwang et al., 2015; Rayan & Ahmad, 2016, 2017; Ridderinkhof et al., 2018a; Ruiz-Robledillo et al., 2015). Notably, practitioner qualifications and training were not always specified. Seven studies outlined management and monitoring of intervention fidelity, which ranged from training supervision (de Bruin et al., 2015), unannounced supervisory visits during delivery (Sizoo & Kuiper, 2017), and third-party recording and assessment of intervention fidelity criteria (Conner & White, 2018b; Ferraioli & Harris, 2013; Hwang et al., 2015; Rayan & Ahmad, 2016, 2017; Ridderinkhof et al., 2018a). Where measured, high (> 80%) practitioner-training fidelity rates were reported

(Conner & White, 2018b; Ferraioli & Harris, 2013; Hwang et al., 2015; Rayan & Ahmad, 2016, 2017; Ridderinkhof et al., 2018a).

Table 1

Characteristics of Included Studies

Lead author (year)	Country	Design	Sample characteristics				Framework	Duration	Control/ comparison	SWB measures
			Target group	Male	Female	Mean age (years)				
Conner (2018)	USA	Quasi-experimental	Adults	7	2	20	MBCT	8 weekly 2.5 hr sessions, 8 hr retreat	N/A	DERS OQ
de Bruin (2015)	The Netherlands	Quasi-experimental	Children	17	6	16	MBCT & MBSR	9 weekly 1.5 hr sessions, with self-practice	N/A	AQ MAAS-A PSWQ RRS WHO-5 SRS FFMQ IM-P PS PSI
			Caregivers	11	18	51				
Ferraioli (2013)	USA	Quasi-experimental	Caregivers	5	10	N/A	MBCT	8 weekly 2 hr sessions	Skills-based parenting	PSI-SF GHQ
Hwang (2015)	Australia	Quasi-experimental	Children	5	1	11	MBSR	Mothers: 8 weekly 2.5 hr sessions, 2-month self-practice. Children: 12-month period	N/A	FMI PSS1 BFQOL CBCL
			Caregivers	0	6	40				

Lead author (year)	Country	Design	Sample characteristics				Framework	Duration	Control/ comparison	SWB measures
			Target group	Male	Female	Mean age (years)				
Kiep (2015)	The Netherlands	Quasi-experimental	Adults	34	16	40	MBCT	9 weekly 2.5 hr sessions, 40–60 mins of self-practice	N/A	SCL-90-R RRQ GMS
Rayan (2016, 2017)	Jordan	RCT	Caregivers	31	73	40	MBCT	33 hrs of intervention, in person and self-practice	No intervention	WHOQOL CERQ DASS-21 MAAS-A
Ridderinkhof (2018)	The Netherlands	Quasi-experimental	Children	36	9	13	MBCT & MBSR	9 weekly 1.5 hr sessions with self-practice	N/A	SRS CAMM ASEBA CSQ-CA CSRQ WHO-5 PSS1 PSI PS IM-P SCS
			Caregivers	31	43	37				
Ruiz-Robledillo (2015)	Spain	Quasi-experimental	Caregivers	1	12	44	MBSR	9 weekly 2 hr sessions with self-practice	MBSR (for non-caregivers)	STAI-S POMS STAEI-2 ESS GHQ BDI ZBI ASQ

Lead author (year)	Country	Design	Sample characteristics				Framework	Duration	Control/ comparison	SWB measures
			Target group	Male	Female	Mean age (years)				
Sizoo (2017)	The Netherlands	Quasi-experimental	Adults	38	21	37	MBSR	13 weekly 90-min sessions	CBT	HADS GMS SRS-A RRQ IBI MAAS-A
Spek (2013)	The Netherlands	RCT	Adults	14	27	42	MBCT	9 weekly 2.5 hr sessions, 40–60 mins daily meditation	Waitlist control	SCL-90-R RRQ GMS

Note. AQ = Autism Questionnaire; ASEBA = Achenbach System of Empirically Based Assessment; ASQ = Autism Spectrum Quotient; BDI = Beck Depression Inventory; BFQOL = Beach Family Quality of Life; CAMM = Children's Acceptance and Mindfulness Measure; CBCL = Child Behaviour Checklist; CERQ = Cognitive Emotion Regulation Questionnaire; CSQ-CA = Chronic Stress Questionnaire for Children and Adolescents; CSRQ = Chronic Sleep Reduction Questionnaire; DASS = Depression Anxiety Stress Scales; DERS = Difficulties in Emotion Regulation Scale; ESS = Somatic Symptoms Scale; FFMQ = Five Facet Mindfulness Questionnaire; FMI = Freiburg Mindfulness Inventory; GHQ = General Health Questionnaire; GMS = Global Mood Scale; HADS = Hospital Anxiety and Stress Scale; IBI = Irrational Beliefs Inventory; IM-P = Interpersonal Mindfulness in Parenting Scale; MAAS-A = Mindful Attention and Awareness Scale; OQ = Outcome Questionnaire; POMS = Profile of Mood States; PS = Parenting Scale; PSI = Parenting Stress Index; PSS1 = Parenting Stress Scale; PSS = Perceived Stress Scale; PSWQ = Penn State Worry Questionnaire; RCT = randomised control trial; RRQ = Rumination Reflection Questionnaire; RRS = Ruminative Response Scale; SCL-90-R = Symptom Checklist-90 – Revised; SCS = Self-Compassion Scale; SRS = Social Responsiveness Scale-Adolescents; STAEI-2 = State-Trait Anger Expression Inventory; STAI-S = State-Trait Anxiety Inventory; SWB = subjective wellbeing; WHO-5 = World Health Organization Five Well-Being Index; WHOQOL-BRIEF = World Health Organization Quality of Life Assessment; ZBI = Zarit Burden Inventory.

Quality Assessment

Primary Quality Indicators

Table 2 presents results from the quality assessment. Sample demographics (PC), primary and secondary outcomes (IV, DV), and appropriate statistical tests (RQ, ST) were generally reported in full, minimising reporting bias. However, the majority of studies involved pilot or proof-of-concept trials based on a single-group design (CC). The two RCTs that were included (Rayan & Ahmad, 2016, 2017; Spek et al., 2013a) therefore received adequate research quality ratings, while each of the remaining studies received a weak quality rating.

Secondary Quality Indicators

The uncontrolled, nonrandomised (RA) studies presented a high risk of selection bias. Only Ridderinkhof et al. (2018a) reported interobserver agreement, although the psychometric properties of included measures were routinely reported. Of the two included RCTs, only Spek et al. (2013a) reported part blinding of researchers to randomisation, considered a crucial method of preventing both researcher and participant expectancy bias from influencing results (Pelham & Blanton, 2013), although difficult to methodologically control in psychotherapy research (Berger, 2015; Shean, 2014). Fidelity (F) to intervention protocols, attendance and home practice were monitored by all studies, though only three studies specifically assessed homework compliance (Conner & White, 2018b; Hwang et al., 2015; Rayan & Ahmad, 2017) and seven studies reported monitoring of practitioner compliance with intervention protocols (Conner & White, 2018b; de Bruin et al., 2015; Ferraioli & Harris, 2013; Hwang et al., 2015; Rayan & Ahmad, 2016, 2017; Ridderinkhof et al., 2018a; Sizoo & Kuiper, 2017), which was > 80% when reported. No study recorded an attrition rate (A) above 30%. This may, in part, be attributed to the relatively high ratio of therapists to participants (i.e., approximately 1:11). In addition to the use of small samples and the exclusion of participants with low-functioning autism (exclusion of IQ < 80 or intellectual disability), there was a disproportionate representation of either males or females in the participant groups, thereby limiting the generalisability of the findings (GM). Most studies ($N_{\text{studies}} = 9$) were underpowered (i.e., minimum *N* of 64 per group required to detect a medium effect size; Ellis, 2010), with the exception of Kiep et al. (2015). Consequently, studies were unable to unequivocally affirm the efficacy of mindfulness. All studies were considered to meet the minimum criteria for social validity outlined in Reichow et al. (2008).

Table 2

Assessment of Included Studies Based on Quality Indicators by Reichow et al. (2008)

Lead author (date)	Primary quality indicators						Secondary quality indicators								Overall rating
	PC	IV	CC	DV	RQ	ST	RA	IOA	BR	F	A	GM	ES	SV	
Conner (2018)	2	1	0	2	2	0	0	1	0	1	1	1	0	1	Weak
de Bruin (2015)	2	1	0	2	2	1	0	1	0	1	1	1	1	1	Weak
Ferraioli (2013)	1	2	0	2	2	1	1	0	0	1	1	0	1	1	Weak
Hwang (2015)	1	1	0	2	2	0	0	1	0	1	1	1	0	1	Weak
Kiep (2015)	2	1	0	2	2	2	0	1	0	0	1	1	0	1	Weak
Rayan (2016, 2017)	2	2	1	2	2	1	1	1	0	1	1	1	1	1	Adequate
Ridderinkhof (2017)	2	2	0	2	2	1	0	1	0	1	1	1	1	1	Weak
Ruiz-Robledillo (2015)	2	2	0	2	2	0	0	1	0	0	1	1	0	1	Weak
Sizoo (2017)	2	2	0	2	2	1	0	1	0	1	1	1	0	1	Weak
Spek (2013)	2	2	1	2	2	1	1	1	1	0	1	1	1	1	Adequate

Note. PC = participant characteristics; IV = independent variable; CC = comparison condition; DV = dependent variable; RQ = analysis linked to research question; ST = statistical tests; RA = participant random assignment; IOA = interobserver agreement; BR = blind rating; F = fidelity; A = attrition; GM = generalisation or maintenance; ES = effect size; SV = social validity.
Primary quality indicators: 2 = high quality, 1 = acceptable quality, 0 = unacceptable quality.
Secondary indicators: 1 = evidence, 0 = no evidence.

Effectiveness of Mindfulness

Quasi-experimental Studies

Effect sizes for each study, categorised according to participant group (child, adult, caregiver) and assessment time frame (pre–post intervention vs. follow-up), are displayed in Table 3. Pooled effect estimates revealed consistent short- and longer-term gains in SWB across all groups. However, these results were associated with low N_{fs} values, suggesting a high probability of publication bias.

Autistic children demonstrated the smallest post-intervention gains in SWB, regardless of whether mindfulness was conducted with the child and caregiver concurrently (de Bruin et al., 2015; Ridderinkhof et al., 2018a) or with the child alone (Hwang et al., 2015). Consistent medium effects were noted at 2-month follow-up, suggesting that gains were not only consistent across studies but maintained once the intervention had ceased.

Autistic adults reported small to medium positive changes in SWB following MBSR or MBCT, with slightly larger gains noted at follow-up. However, between-study variation in effect-size estimates was noted. Specifically, Kiep et al. (2015) demonstrated very large and positive effects from mindfulness but also individual differences in participant responses to mindfulness, as indicated by the wide CI range. Notably, Kiep et al. (2015) targeted participants reporting symptoms of depression, anxiety and rumination, potentially enhancing the effectiveness of treatment. Sizoo and Kuiper (2017) and Conner and White (2018b) also identified positive effects immediately post-intervention and again at follow-up, although these effects were small to medium in magnitude.

Caregivers reported large to medium gains in SWB with mindfulness. Again, these results were characterised by heterogeneity, indicating real differences in effect-size outcomes. For example, Ferraioli and Harris (2013) reported large intervention effects but noted baseline group differences, with intervention participants reporting higher levels of parenting stress and poor general health in comparison to the skills-based comparison group, suggestive of possible sample and selection bias effects. Ruiz-Robledillo et al. (2015) and Hwang et al. (2015) also found high to moderate gains in SWB in their small samples. In comparison, Ridderinkhof et al. (2018a) and de Bruin et al. (2015) reported significant, albeit small, intervention effects with their larger, more representative caregiver samples.

Randomised Control Trials

As shown in Table 4, both RCTs reported significant gains with an adapted MBCT program. This included large gains in SWB for autistic adults (Spek et al., 2013a) and medium gains for caregivers post-mindfulness (Rayan & Ahmad, 2016, 2017). These results need to be interpreted cautiously, given that they are based on only two studies.

Table 3

Standardised Mean Differences (Hedges' g) in SWB Across ASD Cohorts: Single-Group Designs

Category	Lead author (date)	N	g	95% CI		p	I^2	N_{fs} (Min. N)
				Lower	Upper			
ASD children post-intervention	Ridderinkhof (2017)[b]	45	.23	.15	.31	< .001		
	de Bruin (2015)	23	.18	.04	.32	.010		
	Hwang (2015)	6	.16	−.17	.49	.350		
	Total g_w		.22	.15	.28	< .001	0.00	0 (25)
ASD children follow-up	Ridderinkhof (2017)[b]	45	.45	.37	.53	< .001		
	de Bruin (2015)	23	.32	.09	.55	.008		
	Total g_w		.43	.35	.52	< .001	5.33	2 (20)
ASD adults post-intervention	Kiep (2015)[c, d]	50	2.22	.85	3.89	.009		
	Sizoo (2017)	59	.38	.26	.50	< .001		
	Conner (2018)[a]	9	.36	.24	.48	< .001		
	Total g_w		.39	.23	.55	< .001	58.17	3 (25)
ASD adults follow-up	Kiep (2015)[c, d]	50	2.53	.57	4.50	.011		
	Sizoo (2017)	59	.50	.38	.62	< .001		
	Conner (2018)[a]	9	.35	.17	.53	< .001		
	Total g_w		.46	.22	.70	< .001	66.46	4 (25)
Caregivers post-intervention	Ferraioli (2013)	15	1.70	1.52	1.88	< .001		
	Ruiz-Robledillo (2015)	13	1.04	.63	1.45	< .001		
	Hwang (2015)	6	.60	.27	.93	< .001		
	Ridderinkhof (2017)	74	.33	.25	.41	< .001		
	de Bruin (2015)	29	.30	.14	.46	< .001		
	Total g_w		.79	.23	1.36	.006	98.08	15 (35)
Caregivers follow-up	Ferraioli (2013)	15	1.09	.44	1.74	.001		
	Ridderinkhof (2017)[b]	74	.40	.32	.48	< .001		
	de Bruin (2015)	29	.32	.12	.52	.001		
	Total g_w		.42	.23	.62	< .001	60.07	3 (25)

[a] Standard error for 95% CIs calculated from variance in submeasures from a single measure.

[b] Follow-up measures used 2-month follow-up data only.

[c] Effect size calculated using SDs from submeasures due to inconsistencies with reported total measure SDs.

[d] This study included data from 20 participants included in Spek et al., (2013) intervention group.

Table 4

Standardised Mean Differences (Hedges' g) in SWB Across ASD Cohorts: RCTs

Category	Lead author (date)	*N*	*g*	95% CI		*P*	N_{fs} (Min. *N*)
				Lower	Upper		
ASD adults post-intervention	Spek (2013)	41	.87	.65	1.09	< .001	3 (15)
Caregiver post-intervention	Rayan (2016, 2017)	104	.43	.21	.65	< .001	1 (15)

Discussion

This meta-analysis synthesises the data from 10 independent studies that targeted mindfulness to autistic children and adults and/or their caregivers. The findings provide preliminary evidence for the effectiveness of MBSR and MBCT with this population, with significant short-term improvements in SWB noted and maintained up to 3 months post-intervention. These results are, however, tempered by the high risk of methodological and publication bias identified in this research.

Interestingly, autistic children demonstrated less short-term benefit from mindfulness in comparison with adult cohorts. However, this same group also experienced large SWB gains at follow-up. This may be due to the indirect effects of mindful parenting, with research identifying reductions in child aggressive and self-injurious behaviours in addition to modest improvements in child attention span when parents practise mindfulness (Neece, 2014; Singh et al., 2007; Singh et al., 2006; Singh et al., 2014b). The inclusion of one or both caregivers in the child's therapy may, therefore, change the child's responsiveness to a psychological intervention such as mindfulness.

Reliable moderate to high gains in SWB were also noted for autistic adults post-intervention and even at follow-up (Spek et al., 2013a). The child and adult ASD cohorts examined in this review were, however, biased towards males, a demographic that has been associated with higher rates of depression in ASD populations (Gotham et al., 2015). Research with neurotypical children also suggests that mindfulness may be more effective for females than males, due to better engagement with intervention (Bluth et al., 2017). Future ASD research should aim to balance study sample cohorts for gender as far as practicable, or at least examine SWB in specific age cohorts, in order to account for potential differences in intervention outcomes (Rivet & Matson, 2011; Worley & Matson, 2011). Future research might also consider including lower-functioning individuals in order to determine the effectiveness of mindfulness across the autism spectrum, particularly given that those with higher intelligence have reported higher rates of depressive symptoms (Hudson et al., 2018).

Similarly, caregivers reported significant short- and longer-term gains in SWB regardless of study design. There is, however, the possibility that the primarily female sample experienced severe levels of distress, as has been consistently shown in the ASD research (Bitsika et al., 2013; Willis et al., 2016) and, in turn, may report greater benefit from a stress management intervention such as mindfulness than their male counterparts. This is not definitive, as studies examining links between ASD severity, depression, anxiety and gender in caregivers have demonstrated mixed results (Bitsika et al., 2013; Ferraioli & Harris, 2013; Hudson et al., 2018; Strang et al., 2012; Willis et al., 2016). However, it does highlight a need to screen for participant depression levels.

Methodological Limitations

While these results are encouraging, a number of methodological limitations were encountered during study screening and data analysis. From a methodological perspective, we were unable to statistically assess critical differences in alterations to standard MBSR and MBCT protocols or practitioner experience, training and delivery on effect-size estimates as single-group designs do not account for group or therapist interaction effects (Cachia et al., 2016; Ridderinkhof et al., 2018a; Ruiz-Robledillo et al., 2015; Sizoo & Kuiper, 2017). RCTs are particularly important to minimise potential between-group differences. This includes the impact of child developmental factors or gains in caregivers' SWB on child SWB (Cachia et al., 2016; de Bruin et al., 2015). Similarly, studies did not consistently provide details relating to child ASD symptom severity or comorbidity. Child ASD severity has been linked to poorer mental health of caregivers (Ingersoll & Hambrick, 2011). In addition, comorbidity of mental health disorders, most commonly anxiety and depression, can be as high as 70% in children and 40% in autistic adults (Lever & Geurts, 2016; Nah et al., 2018). Providing these key sample parameters would allow moderator analyses to be conducted to determine the efficacy of mindfulness interventions for subgroups (Benn et al., 2012).

The lack of controlled research does, however, reflect a more general criticism of mindfulness research, which has been previously assessed as making only modest gains in methodological quality over the last two decades (Goldberg et al., 2017). The difficulty in working with ASD cohorts also needs to be considered. Caregivers find it difficult to adhere to interventions due to competing time commitments (Ruiz-Robledillo et al., 2015). Consequently, study methodologies may need to be simplified or weakened to accommodate ASD participants (Sizoo & Kuiper, 2017). Perceptual barriers also exist where mindfulness is not seen as a practical or helpful skill in dealing with ASD behavioural issues (R. L. Cachia et al., 2016; Ferraioli & Harris, 2013). Future studies could investigate service delivery methods that minimise time and resource commitments of participants, such as technology-facilitated mindfulness (Fish et al., 2016).

Our broad operationalisation of SWB also prevented a more nuanced examination of the mental health issues specific to each sample cohort. While SWB is a useful concept when identifying general positive wellbeing outcomes from diverse measures, it obfuscates the specific aspects of SWB that benefit most from mindfulness. For example, there is evidence that anxiety (Zaboski & Storch, 2018), depression (Hudson et al., 2018; Simonoff et al., 2008) and maladaptive behaviours, such as aggression (Singh, Lancioni, Manikam, et al., 2011; Singh, Lancioni, Singh, et al., 2011), are prevalent issues for individuals with ASD, whereas stress and depression are more pertinent issues for caregivers (Demir et al., 2008; Hayes & Watson, 2013; Neece, 2014). Our broad definition of SWB was, however, justified because measures of SWB are often intercorrelated (Diener et al., 1999) and an indicator of intervention effectiveness. Nonetheless, future research might consider narrowing the range of measures by focusing on the specific mental health difficulties experienced by the subgroup of interest (i.e., child or adult with ASD vs. caregiver), as outlined in the systematic review conducted by McConachie, Livingstone, et al. (2018). Further research to develop a measure of SWB specific to ASD is also needed in order to adequately capture unique features (including cognitions) present in this group. Indeed, included studies relied on measures developed for neurotypical individuals (McConachie, Mason, et al. (2018); (Milton & Bracher, 2013). Such research might incorporate a mixed-methods approach to provide important insight into the efficacy of mindfulness (Robertson et al., 2018).

Conclusions

MBIs appear to mitigate a number of interpersonal and mental health issues that impact on SWB in autistic children and adults and their caregivers. Further quantitative research is required to confirm the positive effects reported in this review in addition to the generalisability of these findings across a wider demographic of the ASD population. This includes future controlled trials to help account for intervention effects in addition to exploring potential gender differences in treatment response.

Compliance to Ethical Standards

Acknowledgements: The authors would like to thank Maureen Bell, Research Librarian at the University of Adelaide, in addition to Susan Staub and Belinda Fuss for assistance with the database searching, interrater reliability calculations and manuscript suggestions respectively. Thanks also to Henk van Rhee, Erasmus University, for guidance and technical assistance with Meta-Essentials. We also thank the authors of included studies who kindly responded to our requests for additional data.

Funding: This work was supported by an Australian Government Research Training Program Scholarship.

Conflict of interest: The authors declare they have no conflict of interest.

Ethical approval: This article does not contain any studies with human participants or animals performed by any of the authors.

Chapter 4: Study 2

Barriers and Facilitators to Engaging Individuals and Families With Autism Spectrum Disorder in Mindfulness and Acceptance-Based Therapies: A Meta-synthesis

Statement of Authorship

Title of Paper	Barriers and Facilitators to Engaging Individuals and Families With Autism Spectrum Disorder in Mindfulness and Acceptance-Based Therapies: A Meta-synthesis
Publication Status	✓Published ☐ Submitted for Publication ☐ Accepted for Publication ☐ Unpublished and Unsubmitted work written in manuscript style
Publication Details	Hartley, M., Due, C., & Dorstyn, D. (2021). Barriers and facilitators to engaging individuals and families with autism spectrum disorder in mindfulness and acceptance-based therapies: A meta-synthesis. *Disability and Rehabilitation*, *44*(17), 4590–4601. https://doi.org/10.1080/09638288.2021.1921859

Principal Author

Name of Principal Author (Candidate)	Matthew Hartley		
Contribution to the Paper	Conceptualisation of study, created database search terms and queries and conducted searches, reviewed articles and synthesised data, completed data analysis and prepared results. Wrote paper and prepared manuscript for publication.		
Overall percentage (%)	80		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the		
Signature		Date	31st Jan 2023

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate in include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Clemence Due		
Contribution to the Paper	Assisted with conceptualisation of study, reviewed short-listed articles, reviewed raw data and assisted with data analysis and results. Contributed to editing draft manuscript for publication.		
Signature		Date	31st Jan 2023

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Contribution to the Paper	Assisted with conceptualisation of study, assisted with data analysis and results. Contributed to editing draft manuscript for publication.		
Signature		Date	31st Jan 2023

Please cut and paste additional co-author panels here as required.

Preface

The meta-analysis outlined in Chapter 3 identified positive small ($g = 0.22$) to large ($g = 0.79$) benefits for autistic children and adults and their caregivers who undertook MBI. However, included studies in this meta-analysis typically focused on measures of wellbeing (e.g., Beck Depression Inventory) that may not capture important aspects of participants' experience of mindfulness sessions. Moreover, the range of effect sizes identified ($g_{\text{range}} = 0.22$ to 0.79) suggest that individuals' experiences with mindfulness vary: some persons with ASD and/or their caregivers benefit from this therapy, others do not. An exploration of these individual experiences may identify difficulties or barriers to effective mindfulness practice not identified in quantitative research, as well as provide unique insight into aspects of mindfulness training uniquely helpful to the ASD cohort.

The following study (Study 2) used qualitative techniques to synthesise the published mindfulness literature targeting autistic children and adults and their caregivers. Key themes raised by participants taking part in MBI were examined, including whether they experienced any benefits in relation to either their ASD characteristics or to their role as caregiver. Potential barriers that these participants faced when developing mindfulness skills were also examined. It was anticipated that these combined findings would help to inform the development of mindfulness programs specifically targeted to those with ASD. The available research was also critically appraised to better understand how future studies could be enhanced and refined to ensure robust research outcomes.

Barriers and facilitators to engaging individuals and families with Autism Spectrum Disorder in mindfulness and acceptance-based therapies: A meta-synthesis

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Abstract

Third-wave psychological therapies can benefit individuals and families living with ASD. To date, little is known about individuals' perceptions and experiences of therapy. This meta-synthesis aimed to capture participants' own experiences and reflections of mindfulness and acceptance-based therapies, including potential barriers and facilitators to therapy engagement. Most of the 10 included studies targeted caregivers ($N_{\text{studies}} = 3$) or involved dyadic parent–child interventions ($N_{\text{studies}} = 6$), with a single study involving autistic adults. Caregivers highlighted the challenge of completing daily mindful practice and the need to adapt homework length and frequency around their busy lifestyles. Autistic adults also identified therapy barriers; however, the data were less robust, providing only preliminary observations of this group. All three participant groups commented on the psychological benefits of therapy as a key facilitator (i.e., enhanced self-awareness, self-regulation, self-care). Peer support provided in group-based therapy was seen as an added benefit. Future research should examine the application of mindfulness therapies to autistic adults, given that little is currently known about this cohort's therapy experiences. Further research is also needed to explore whether traditional mindfulness approaches can be effectively modified to accommodate the ongoing cumulative daily demands these families experience.

Keywords: systematic review, subjective wellbeing, parents, intellectual disability, mental health

Introduction

A growing evidence base exists for the use of third-wave cognitive behavioural therapies, which share an emphasis on mindfulness and acceptance, to manage mental health difficulties among populations affected by developmental disabilities (Osborn et al., 2020; Ridderinkhof et al., 2018a; Singh et al., 2019) and, more specifically, ASD (Hartley et al., 2019). Mindfulness involves the practice of purposely focusing attention on the present moment without judgement, achieved through formal or informal meditation practices (Creswell, 2017; Kabat-Zinn et al., 2017). Examples include using the body to develop awareness through yoga or bringing mindfulness to everyday activities (e.g., eating, walking; (Kabat-Zinn et al., 2017; Stefan & David, 2020). Mindfulness also involves an attitude of acceptance towards unwanted thoughts and feelings rather than avoiding or changing them (Kabat-Zinn, 2003; Kabat-Zinn et al., 2017; Wielgosz et al., 2019).

Individual studies suggest that regular mindfulness practice can help to reduce symptoms of major depression and social anxiety (Lever & Geurts, 2016; Simonoff et al., 2008) and promote general wellbeing (Hartley et al., 2019; Semple, 2019), not only for children and adults diagnosed with ASD but also their caregivers. Further evidence by recent systematic and narrative reviews indicated improvements in parental wellbeing and child behaviour (i.e., reduced aggression and rumination, improved social behaviour) with mindfulness training, regardless of whether a controlled (Hartley et al., 2019) or pre–post study design was used (Renee L. Cachia et al., 2016; Hourston & Atchley, 2017; O Donnchadha, 2018).

Research about ASD has typically adapted highly manualised teaching approaches from MBSR and MBCT into unique ASD-focused MBIs. For example, de Bruin et al. (2015) modified the length of their MyMind therapy sessions by adding a mindful parenting component. Further adaptations for those with ASD include reducing the idiomatic language common to mindfulness teaching (i.e., metaphor usage), slowing the pace and delivery of teaching materials, and extending the number of sessions to increase repetition of the material (Conner & White, 2018b; Spek et al., 2013a). Similar adaptations to ACT and dialectical behaviour therapy have been trialled for parent, child and adult groups, with promising results (Corti et al., 2018; Hahs et al., 2019; Hartmann et al., 2012; Pahnke et al., 2019). The use of brief home-based mindfulness practice has even been trialled with some success (e.g., 30 minutes daily; (Parsons et al., 2017). However, such modifications contrast with traditional high-dose MBSR curriculums (i.e., eight weekly 3-hour sessions in conjunction with 45–60 minutes of daily mindfulness practice; (Kabat-Zinn et al., 2017; Santorelli, 2014). Indeed, it is argued that practice quality is a more important mediator of positive outcomes, at least for the general population, than total time spent in mindful practice (Goldberg et al., 2020; Strohmaier, 2020). Equally critical to outcomes is the mindfulness teacher—those with knowledge and experience of ASD can effectively adapt training materials and presentation to an individual's cognitive needs and, thereby, improve therapy impact (de Bruin et al., 2015; Spek et al., 2013a).

Such modifications to mindfulness treatment—while offering a tailored approach for those with ASD—may also compromise training integrity (Hwang & Kearney, 2015). Notably, reviews in this area have relied on quantitative data (R. Cachia et al., 2016; Renee L. Cachia et al., 2016; Hartley et al., 2019; Hourston & Atchley, 2017; Semple, 2019). A qualitative approach, which provides a detailed focus on the nuances and lived experiences of research participants and offers them opportunity to provide feedback on their own terms (rather than through precategorised responses), may help to clarify how mindfulness and acceptance-based treatments work for families living with ASD (Elliott, 2010; Ridderinkhof, de Bruin, et al., 2019; Rodgers & Elliott, 2015). To date, only two meta-syntheses have been conducted on mindfulness—neither of which examined people with ASD or those caring for people with ASD. Cairns and Murray (2015) reviewed seven MBCT studies targeted to adults with recurrent depression. Post-treatment gains included a greater self-awareness and self-acceptance of one's feelings and behaviour (Cairns & Murray, 2015). Peer and therapist support provided in a group format was also seen as beneficial. These findings were replicated by Wyatt et al. (2014), who examined the personal experiences of MBIs for various mental illness types (e.g., major depression, schizophrenia, eating disorders). Both reviews also identified significant challenges that participants faced in developing mindfulness skills, particularly difficulty understanding core therapy concepts and allocating time for regular home practice of mindfulness skills.

In summary, individuals and families with ASD face emotional and behavioural challenges, which mindfulness and acceptance-based therapies may assist in managing. The present review supplements our previous meta-analysis (Hartley et al., 2019) by examining personal accounts of mindfulness and acceptance training among individuals with ASD and their caregivers, helping to clarify not only barriers to treatment but also ways to promote mindfulness practice among this group. The following research questions are addressed in this synthesis: How do individuals (both adults and children) with ASD and their caregivers describe their experiences of undertaking a mindfulness or acceptance program? And what, if any, impacts do these therapy approaches have on their daily lives?

Methods

Protocol Registration

This systematic review was registered with the International Prospective Register of Systematic Reviews (PROSPERO No. CRD42020149415).

Selection Criteria

In addition to being published in English, in a journal, studies had to meet the following criteria.

Population

The sample involved children and adults (of any age) with a primary diagnosis of ASD, autism, or a historic diagnostic category (Asperger's or pervasive developmental disorder) consistent with criteria listed in the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2013, or equivalent) or their caregivers. Studies where the primary diagnosis involved a mixed cohort of ASD and intellectual or developmental disabilities were excluded. Although these criteria cover a very wide range of ages and challenges for each group, it was deemed necessary to include as many viewpoints as possible to contrast the ways in which mindfulness is experienced in this population. Additionally, it was important to include caregivers, given the reciprocal relationship between parental and child wellbeing (Bauminger et al., 2010; Lewallen & Neece, 2015).

Intervention

Studies had to evaluate mindfulness-based training with formal meditation (i.e., MBSR, MBCT) or a mindfulness-informed program (e.g., ACT, dialectical behavioural therapy; (Creswell, 2017; Wielgosz et al., 2019).

Outcomes

Qualitative data about participants' beliefs and experiences of mindfulness training were required. This data could be in the form of formal interviews, screening or exit interviews, focus group transcripts, online discussion forum quotes, or participants' open-ended responses to questionnaires and/or surveys.

Study Design

Primary qualitative, quantitative or mixed-methods studies were included. Dissertations, which often include rich qualitative data and are considered an important source of information for review syntheses, were also eligible (Lefebvre et al., 2019).

Database Searches

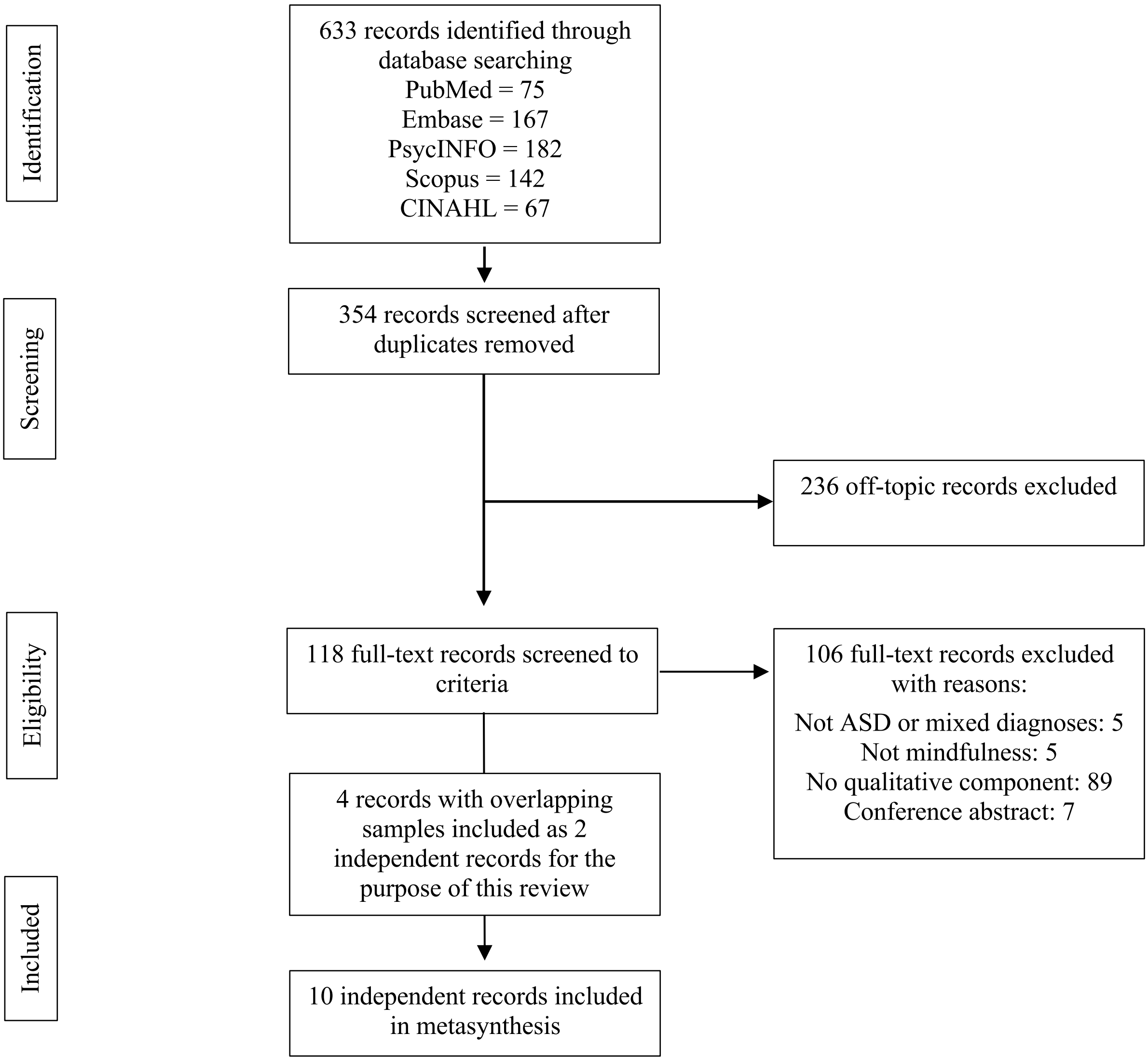
The CINAHL, Embase, PsycINFO, PubMed and Scopus databases were searched from inception to July 2020. Search strategies were developed in consultation with an expert research librarian and were tailored to each database, with key terms relating to the population ('autism') and intervention ('mindfulness') in focus (see search term logic grid in Appendix F). Reference checks of included studies and relevant systematic and narrative reviews (Renee L. Cachia et al., 2016; R. L. Cachia et al., 2016; Donnchadha, 2018a; Hourston & Atchley, 2017; Paz & Wallander, 2017b; Spain et al., 2015) were also undertaken, although no further studies were identified through this process.

Study Selection

The first author (MH) undertook preliminary title and abstract screening using EndNote software (Peters, 2017). First, records from each database search were imported into separate group folders. Duplicate records across all database searches were then identified (via the 'Find duplicates' command), with further duplicates identified and removed manually into a separate group folder. This process resulted in 354 unique records, the titles and abstracts of which were manually screened against the inclusion criteria. Off-topic records (e.g., non-ASD studies) were subsequently relocated to a separate EndNote folder. One hundred and eighteen potentially eligible studies were identified, and their full texts rescreened against the inclusion criteria, with discussion and consensus agreement on the final articles among all three authors. During this process, four records based on two independent studies were identified: the book form of a mixed-methods study (Hwang & Kearney, 2015) was included as it provided qualitative data not available in the published article (Hwang et al., 2015). The second study included a thesis (Beck, 2018) and corresponding published article (Beck et al., 2020), with data from both records used. In addition, two studies using an overlapping sample population were included: Ridderinkhof, de Bruin, et al. (2019) conducted full qualitative interviews on a subset of participants from their earlier study, which included brief participant responses (Ridderinkhof et al. (2018a). The final sample included 10 independent studies (see Figure 5).

Figure 5

PRISMA Flow Diagram Outlining Study Selection (Moher et al., 2009)



Quality Assessment

Quality ratings for each study were undertaken by the first author (MH), and audited by the second (CD), using the 10-item Critical Appraisal Skills Programme (CASP, 2018) checklist. Each study was evaluated according to each of three CASP domains: Section A considers the aims of each study and the qualitative method, design, recruitment, data collection and researcher bias; Section B examines ethical considerations, data analysis and findings; Section C focuses on the beneficial value a study contributes. Each question requires either a positive (+) or negative (−) rating corresponding to their level of quality (i.e., + high quality). In addition to CASP ratings, interview questions, where studies made them available, were examined in order to identify the type of data collected and any potential biases in each study (see Appendix G).

In order to assess the reporting quality of the six primarily quantitative studies, the Mixed Methods Appraisal Tool (v2018) was used. A preliminary rating was initially undertaken by the first author (MH) and then evaluated and refined by all three authors. This tool comprises 19 criteria across five different study types (qualitative, randomised, nonrandomised, descriptive and mixed-methods studies) and has been validated for content validity (Hong et al., 2019). Studies are evaluated against the appropriate study type criteria (e.g., qualitative studies are assessed against qualitative criteria 1.1–1.5) and allocated 'yes', 'no' or 'can't tell'. Rather than calculate a numerical score, results are examined in context for a more representative interpretation of study quality (Hong et al., 2019).

Data Extraction, Management and Analysis

Data extraction and initial thematic analysis were performed by the first author (MH), with preliminary themes and analysis reviewed and revised by the second (CD). Full-text records were loaded into NVivo 12 software (Trigueros-Cervantes et al., 2018) and qualitative data coded according to broad themes, as per thematic analysis and meta-synthesis protocols (Braun & Clarke, 2006, 2013; Finlayson & Dixon, 2008). Themes were evaluated for relevance to the study's research questions and demonstrated common features across the coded extracts, with relevant quotes and data extracts for supporting evidence. Themes were required to be internally coherent, with any discrepancies in the data (e.g., if the findings of the studies led to different results or experiences of mindfulness) noted. Overall, an inductive data-driven approach was adopted, whereby the authors developed, discussed and refined themes with consideration to the varieties of experience across the different participant groups (caregivers, autistic children and adults), without a pre-existing theoretical framework (Braun & Clarke, 2006). Discussion helped clarify where the authors identified similarities and differences between groups and where insufficient or incomplete data prevented robust identification of participant experiences. To ensure transparency and personal reflexivity, the first author (MH) maintained a research journal to catalogue thoughts about the coding and analysis process and discussed issues with the second author as the analysis progressed (Braun & Clarke, 2013). Refinement of themes occurred between all three authors at regular scheduled intervals during the analysis process. Discussions typically focused on whether themes adequately described the experiences reported in extracts. Where authors disagreed on themes, extracts were examined for additional context in their original source material and agreement reached by consensus.

Results

Sample Characteristics

The pooled sample comprised 224 individuals: 131 caregivers and 93 individuals (81 children, 12 adults) with ASD. Two studies sourced participants based on diagnosis or referral from a clinician (Kennedy, 2018; Salem-Guirgis et al., 2019), two conducted confirmatory testing of ASD (Ridderinkhof et al., 2018a; Ridderinkhof, de Bruin, et al., 2019), with the remainder recruiting participants from a registered disability agency (Beck, 2018; Beck et al., 2020; Quirk, 2018; Reid et al., 2016; Singh et al., 2014a; Singh et al., 2007) or clinician/agency referral (Hwang & Kearney, 2015). There was a higher proportion of female caregivers (*n* = 97; mother, grandmother, aunt), children (5–17 years; *n* = 81) and males with higher functioning ASD, child or adult (*n* = 76) (i.e., exclusions of those with IQ below 70–80, (Ridderinkhof et al., 2018a; Ridderinkhof, de Bruin, et al., 2019; Salem-Guirgis et al., 2019). Studies typically excluded children with a diagnosis of psychotic or behavioural disorders, suicide risk or participants undergoing concurrent psychological treatment. Not all studies reported participants' education or work status (Hwang & Kearney, 2015; Quirk, 2018; Reid et al., 2016; Singh et al., 2014a; Singh et al., 2007). Where these data were available, they indicated that caregivers had completed primary (*n* = 2, 1.5%) or secondary school (*n* = 22, 17%), with the majority having a post-secondary education (*n* = 83, 63%), including a trade, business or university qualification. Caregiver work commitments included full-time (*n* = 39, 30%) or part-time employment (*n* = 36, 27%), with the remainder being homemakers, unable to work due to disability or unemployed (*n* = 21, 16%). Autistic children attended a special education school (*n* = 6, 7%), primary or high school (*n* = 70, 86%) or college or university (*n* = 2, 2%). Autistic adults had completed high school (*n* = 2, 17%), trade school or college (*n* = 4, 33%) or held a bachelor's degree (*n* = 4, 33%) or advanced degree (*n* = 2, 17%).

Study Characteristics

Most studies had been published within the last 5 years and were based in high-income countries (see Table 5). These included four qualitative studies (Kennedy, 2018; Quirk, 2018; Reid et al., 2016; Ridderinkhof, de Bruin, et al., 2019), a single mixed-methods study (Hwang & Kearney, 2015) and five quantitative studies (Beck, 2018; Beck et al., 2020; Ridderinkhof et al., 2018a; Salem-Guirgis et al., 2019; Singh et al., 2014a; Singh et al., 2007). Semistructured or informal interviews were the most common data collection method, used by eight studies (Beck, 2018; Beck et al., 2020; Hwang & Kearney, 2015; Kennedy, 2018; Quirk, 2018; Reid et al., 2016; Ridderinkhof, de Bruin, et al., 2019; Singh et al., 2014a; Singh et al., 2007), followed by post-intervention surveys with open-ended questions (Ridderinkhof et al., 2018a; Salem-Guirgis et al., 2019). A single study included transcripts from online group meetings and comments on social media (i.e., Facebook; (Hwang & Kearney, 2015).

Mindfulness and Acceptance-Based Training

Dyadic programs, targeting caregivers and their child, were evaluated in six studies (Hwang & Kearney, 2015; Ridderinkhof et al., 2018a; Ridderinkhof, de Bruin, et al., 2019; Salem-Guirgis et al., 2019; Singh et al., 2014a; Singh et al., 2007), while three recruited caregivers alone (Kennedy, 2018; Quirk, 2018; Reid et al., 2016) and a single study involved autistic adults only (Beck, 2018; Beck et al., 2020). In seven studies, MBSR was the primary intervention—used on its own or in combination with other MBIs (MBCT, ACT and mindfulness-based positive behaviour support [MBPBS]). Training formats ranged from 1.5 to 2.5 hour weekly group-based sessions delivered over 8 to 9 weeks (Beck, 2018; Beck et al., 2020; Kennedy, 2018; Quirk, 2018; Ridderinkhof et al., 2018a; Salem-Guirgis et al., 2019) to individual weekly sessions delivered to caregivers over 3 months, with self-monitoring of mindful practice for a further 12 months (Hwang & Kearney, 2015; Singh et al., 2014a; Singh et al., 2007). A single study evaluated an intensive ACT program, delivered in two 4-hour sessions over two consecutive weekends (Reid et al., 2016). Another study interviewed participants about their previous mindful training experiences, which included a range of unspecified MBIs (Quirk, 2018).

The amount of home practice set for participants, including the time or specific nature of homework, was not routinely detailed, although some studies required 30–60 minutes of daily mindfulness (Beck, 2018; Beck et al., 2020; Kennedy, 2018; Singh et al., 2014a). Mindfulness was delivered by teachers who were reported to have appropriate experience and training while continuing in their own mindful self-practice. Years in self-practice differed between studies, from as little as 1 year (Ridderinkhof et al., 2018a; Ridderinkhof, de Bruin, et al., 2019) to as many as 40 years (Singh et al., 2014a). Five studies did not provide details on trainer experience (Kennedy, 2018; Quirk, 2018; Reid et al., 2016; Salem-Guirgis et al., 2019; Singh et al., 2007).

Quality Assessment

As seen in Table 6, all studies provided a clear statement of their research aims (CASP question 1), although only five provided details of their qualitative methodology (CASP question 2). Seven studies justified their research design (CASP question 3). Recruitment strategies (CASP question 4) and data collection were also explained and justified (CASP question 5). However, only three studies explicitly addressed the role of researcher bias (CASP question 6), and two did not explain how ethical standards (e.g., informed consent, confidentiality) were maintained for their research (CASP question 7). Five studies demonstrated evidence of adequate qualitative data analysis (CASP question 8), and most provided a clear statement and explanation of their findings (CASP question 9). All studies identified the valued contribution of their findings to mindfulness and autism research in general (CASP question 10).

Results from the Mixed Methods Appraisal Tool assessment for six studies are shown in Table 7. All studies provided a clear research rationale (S1) and appropriate data to address it (S2). However, only one provided sufficient qualitative methods, data and interpretation to answer their research question (CASP Item no.1.1–1.5). Methodological details were reported, aside from the criteria relating to experimental confounds (3.4; e.g., blinded participants, personnel, outcome assessment), given the difficulty in conducting a true double-blind RCT study for psychotherapy (Shean, 2014). Finally, studies justified their methodology (5.1), although only one effectively integrated both qualitative and quantitative components (5.2–5.5).

Qualitative Methods

Qualitative data were gathered from a variety of sources: open-ended questionnaires (Ridderinkhof et al., 2018a; Salem-Guirgis et al., 2019), informal interviews (Beck, 2018; Beck et al., 2020; Singh et al., 2014a; Singh et al., 2007), semistructured interviews (Hwang & Kearney, 2015; Kennedy, 2018; Quirk, 2018; Reid et al., 2016) and online group meetings and/or comments on social media (Hwang & Kearney, 2015). Participants were asked about their experiences of mindfulness and acceptance, including whether they found the training and subsequent practice helpful, which components were most beneficial or challenging, and any changes that may have occurred in their relationships during or after training (see Appendix H).

Table 5

Characteristics of Included Studies

Lead author	Country	Design	Sample characteristics				Framework	Duration	Qualitative component	Stated qualitative method
(Study reference)			Target group	Male	Female	Mean age (years)				
Beck (Beck, 2018; Beck et al., 2020)	USA	Quantitative quasi-experimental	Autistic adults	9	3	38	MBSR	8 x weekly 2.5 hr sessions, 7.5 hr retreat	Informal exit interviews	None specified
Hwang (Hwang & Kearney, 2015)	Australia	Quantitative quasi-experimental	Caregiver & child with ASD	0 5	6 1	40 11	MBSR	Mothers: 8 x weekly 2.5 hr sessions, 2-month self-practice. Children: 3 weeks of 3 sessions, 12-month period	Semistructured interviews, online meetings, Facebook comments	Thematic analysis
Kennedy (Kennedy, 2018)	USA	Qualitative	Caregiver		7	44	MBI	8 x weekly sessions	Semistructured interviews	Grounded theory
Quirk (Quirk, 2018)	USA	Qualitative	Caregiver		9	Not reported	MBSR & MBIs	Based on participants' earlier mindfulness experience	Semistructured interviews	Thematic analysis
Reid (Reid et al., 2016)	UK	Qualitative	Caregiver		5	Not reported	ACT	2 x 4 hr workshops, 1 week apart	Semistructured interviews	Thematic analysis

Lead author (Study reference)	Country	Design	Sample characteristics				Framework	Duration	Qualitative component	Stated qualitative method
			Target group	Male	Female	Mean age (years)				
Ridderinkhof[a] (Ridderinkhof, de Bruin, et al., 2019)	Netherlands	Qualitative	Caregiver & autistic children	11 8	20 6	44 12	MBCT & MBSR	9 x weekly 1.5 hr sessions, with self-practice	Semistructured interviews	Grounded theory
Ridderinkhof (Ridderinkhof et al., 2018a)	Netherlands	Quantitative repeated measures	Caregiver & child with ASD	31 36	43 9	37 13	MBCT & MBSR	9 x weekly 1.5 hr sessions, with self-practice	Post-treatment questionnaire	Content analysis
Salem-Guirgis (Salem-Guirgis et al., 2019)	Canada	Quantitative within-subjects	Caregiver & child with ASD	3 19	20 4	50 16	MBCT & MBSR	9 x weekly 1.5 hr sessions, with self-practice	Post-treatment questionnaire	Not specified
Singh (Singh et al., 2007)	USA	Quantitative quasi-experimental	Caregiver & child with ASD	0 4	4 0	27 5	MBSR-based	12 x weekly 2 hr sessions, 52 weeks mindful practice with child	Informal interviews	Not specified
Singh (Singh et al., 2014a)	USA	Quantitative quasi-experimental	Caregiver & child with ASD	0 3	3 0	40 17	MBPBS-based	2 hr pretraining, 8 x weekly 1-day sessions, 48 weeks mindful practice with child	Informal Interviews	Not specified

[a]Not counted in participant totals as participants were sourced from a previous study population by Ridderinkhof (Ridderinkhof et al., 2018a).

Table 6

Quality Assessment Using CASP Framework

Lead author	CASP item no.									
	1	2	3	4	5	6	7	8	9	10
Beck (Beck, 2018; Beck et al., 2020)	Yes	No	+	−	−	−	+	−	−	+
Hwang (Hwang & Kearney, 2015)	Yes	Yes	+	+	+	−	+	−	+	+
Kennedy (Kennedy, 2018)	Yes	Yes	+	+	+	+	+	+	+	+
Quirk (Quirk, 2018)	Yes	Yes	+	+	+	+	+	+	+	+
Reid (Reid et al., 2016)	Yes	Yes	+	+	+	−	+	+	+	+
Ridderinkhof (Ridderinkhof et al., 2018a)	Yes	No	+	−	−	−	+	+	+	+
Ridderinkhof (Ridderinkhof, de Bruin, et al., 2019)	Yes	Yes	+	+	+	+	+	+	+	+
Salem-Guirgis (Salem-Guirgis et al., 2019)	Yes	No	−	+	+	−	+	−	−	+
Singh (Singh et al., 2007)	Yes	No	−	+	−	−	−	−	+	+
Singh (Singh et al., 2014a)	Yes	No	−	+	+	−	−	−	+	+

Note. CASP = Critical Appraisal Skills Programme.
+ = yes; − = no.

Table 7

Quality Assessment Using the Mixed Methods Appraisal Tool Framework

Lead author	Mixed Methods Appraisal Tool item no.																
	S1	S2	1.1	1.2	1.3	1.4	1.5	3.1	3.2	3.3	3.4	3.5	5.1	5.2	5.3	5.4	5.5
Beck (Beck, 2018; Beck et al., 2020)	Yes	Yes	−	−	/	/	/	+	+	+	−	+	+	−	−	−	−
Hwang (Hwang & Kearney, 2015)	Yes	Yes	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Ridderinkhof (Ridderinkhof et al., 2018a)	Yes	Yes	−	−	/	/	/	+	+	+	−	+	+	−	−	−	−
Salem−Guirgis (Salem-Guirgis et al., 2019)	Yes	Yes	−	−	/	/	/	+	+	+	−	+	+	−	−	−	−
Singh (Singh et al., 2007)	Yes	Yes	−	−	/	/	/	+	+	+	−	+	+	−	−	−	−
Singh (Singh et al., 2014a)	Yes	Yes	−	−	/	/	/	+	+	+	−	+	+	−	−	−	−

Note. + = yes; − = no; / = can’t tell

Overview of Themes

Two broad categories, comprising 10 themes in total, were identified across the 10 studies (see Table 8). This included four key barriers to therapy engagement and six benefits or facilitators to therapy. Therapy barriers, particularly difficulties in establishing a routine alongside other personal and physical barriers (e.g., therapy cost, time, travel) were only identified by caregivers and autistic adults. In saying this, caregivers provided the richest range of experiences—not only highlighting the limitations but also the improvements with therapy. Conversely, children focused their comments on therapy facilitators. Importantly, all three groups recognised the personal and positive effects of mindfulness. Individual themes, with supporting quotations, are discussed in more detail below.

Table 8

Identified Categories and Themes Relating to Treatment Barriers and Facilitators, and Participant Groups That Reported Each Theme for Each Study

	Theme	Participant category		
		Caregiver	Child with ASD	Adult with ASD
Barriers	Stressors	(Hwang & Kearney, 2015; Kennedy, 2018; Quirk, 2018; Reid et al., 2016; Singh et al., 2014a; Singh et al., 2007)		
	Expectations and perceptions	(Quirk, 2018; Reid et al., 2016; Singh et al., 2014a; Singh et al., 2007)		
	Establishing a routine	(Hwang & Kearney, 2015; Kennedy, 2018; Quirk, 2018; Reid et al., 2016; Salem-Guirgis et al., 2019; Singh et al., 2007)		(Beck, 2018; Beck et al., 2020)*
	Other barriers	(Kennedy, 2018; Quirk, 2018)		(Beck, 2018; Beck et al., 2020)*
Facilitators	Self-awareness	(Hwang & Kearney, 2015; Kennedy, 2018; Quirk, 2018; Reid et al., 2016; Ridderinkhof et al., 2018a; Ridderinkhof, de Bruin, et al., 2019)	(Hwang & Kearney, 2015; Ridderinkhof et al., 2018a; Ridderinkhof, de Bruin, et al., 2019)	(Beck, 2018; Beck et al., 2020)*
	Self-acceptance	(Kennedy, 2018; Quirk, 2018; Reid et al., 2016; Ridderinkhof et al., 2018a; Ridderinkhof, de Bruin, et al., 2019)	(Ridderinkhof et al., 2018a; Ridderinkhof, de Bruin, et al., 2019)	(Beck, 2018; Beck et al., 2020)*
	Self-regulation	(Hwang & Kearney, 2015; Kennedy, 2018; Quirk, 2018; Reid et al., 2016; Ridderinkhof et al., 2018a; Ridderinkhof, de Bruin, et al., 2019; Salem-Guirgis et al., 2019;	(Hwang & Kearney, 2015; Ridderinkhof et al., 2018a; Ridderinkhof, de Bruin, et al., 2019; Salem-Guirgis et al., 2019)	(Beck, 2018; Beck et al., 2020)*

Theme	Participant category		
	Caregiver	Child with ASD	Adult with ASD
	Singh et al., 2014a; Singh et al., 2007)		
Self-care	(Hwang & Kearney, 2015; Kennedy, 2018; Quirk, 2018; Reid et al., 2016)		(Beck, 2018; Beck et al., 2020)*
Sharing experiences in the group	(Kennedy, 2018; Quirk, 2018; Reid et al., 2016; Ridderinkhof et al., 2018a; Salem-Guirgis et al., 2019)	(Ridderinkhof et al., 2018a; Salem-Guirgis et al., 2019)	(Beck, 2018; Beck et al., 2020)*
Changes in self and others	(Hwang & Kearney, 2015; Kennedy, 2018; Quirk, 2018; Reid et al., 2016; Singh et al., 2014a; Singh et al., 2007)		

Note. *Data included from both the thesis and published article from Beck (Beck, 2018; Beck et al., 2020).

Category 1: Barriers to Developing Skills in Mindfulness and Acceptance

Theme 1: Stressors

Caregivers were the only group to report stressors as a barrier. Studies prompted caregivers to reflect on whether training had brought changes in their lives and relationships, such as altering feelings of stress (see Appendix H). Life stressors, including their child's aggressive behaviours and/or comorbid psychological disorders, were seen to have a detrimental impact on parental mental health. Partner or broader family ill-health, family separation, work stress, ageing and personal sickness were also noted. These stressors were compounded by the struggle and isolation that many felt from parenting a child with special needs and, ultimately, impaired their ability to engage in self-care:

> I'm realising now that I focus so much on her that I forgot me, and that's important too, I need to give to me … 'cause I had nothing left, I got to the point I had nothing left. (Caregiver, quoted in Quirk, 2018, p. 70)

Theme 2: Expectations and Perceptions

Caregivers reported initial difficulties in learning to become more mindful and accepting, difficulties that were not found in the experiences of autistic children and adults. Previous exposure to psychological therapies for their child's problematic behaviour, in particular, contributed to this negative perception. Some even expressed doubts about how effective mindfulness would be compared with traditional behaviour management techniques (Singh et al., 2007; Singh et al., 2014b). Others reported some initial difficulties in readjusting their mindset:

> The challenge, in the beginning was to really think, do I really have to do this stuff? … Kinda more realising that yes, I need to do this stuff, 'cause yes, it really does work, it's really helping me. (Caregiver, quoted in Quirk, 2018, pp. 64–65)

One caregiver perceived that mindfulness, as a non-western practice, could invoke negative reactions and judgements from others, which in turn might act as a barrier to considering this treatment option for themselves or their child:

> And I wouldn't even put the word yoga because people from different backgrounds come and, uh, for example, if my husband, if he sees the word yoga he will just like turn it away. (Caregiver, quoted in Quirk, 2018, p. 73)

Theme 3: Establishing a Routine

The challenge of developing a regular mindfulness practice routine was identified by caregivers and autistic adults:

> In terms of the mindfulness part and relaxation part for myself, I think that was more difficult to implement. And I still have trouble with that and finding time or making time to do that. (Caregiver, quoted in Kennedy, 2018, pp. 65–66)

This challenge was particularly true for caregivers who found it difficult to engage their autistic children in mindfulness (Hwang & Kearney, 2015) or for whom home practice was often impractical due to their child's special care needs:

> Everything with him takes up a lot of time and anything that I can do when he's not there I've only got a small window to do it in and it mounts up. (Reid et al., 2016)

Others noted the difficulty of maintaining home mindful practice due to discomfort (Ridderinkhof, de Bruin, et al., 2019), becoming overwhelmed by emotion (Hwang & Kearney, 2015) or because they had never tried to sit quietly and focus before (Quirk, 2018). Both caregivers and autistic adults became frustrated and anxious when they did not meet their own practice goals (Beck, 2018; Hwang & Kearney, 2015). However, once established, daily mindfulness practice became easier to maintain over time (Hwang & Kearney, 2015; Singh et al., 2014b).

Homework was often adapted around participants' lifestyles, either by reducing the time taken for home exercises or by using more informal meditations. For example, one caregiver noted, 'I try to incorporate breathing meditation as we drive to school each day' (Hwang et al., 2015, p. 108). However, many participants indicated that they struggled to maintain their mindful practice once training was complete. For example, participants made comments such as, 'I honestly rarely do it at home' (caregiver, quoted in Quirk, 2018, p. 65) and 'It is more difficult to maintain without the group' (caregiver, quoted in (Salem-Guirgis et al., 2019).

Theme 4: Other Barriers

Caregivers additionally described practical barriers to training, such as time and travel inconvenience, childcare requirements and unfamiliarity with the training provider. Cost was a specific barrier mentioned in four studies—two of which charged a subsidised fee for an external facilitator to deliver mindfulness training (Kennedy, 2018; Quirk, 2018). Time and travel inconvenience were identified by autistic adults.

Category 2: Improvements From Mindfulness Training

Theme 1: Self-Awareness

While improvements in self-awareness were acknowledged by autistic adults, caregivers and autistic children found that mindfulness enhanced their awareness of the present moment in particular, which became easier with further training:

> Even now without thinking about it, I try and just stay in this present moment. So give all my attention to whatever I'm doing at that time, whereas before I would be thinking of the next thing I have to do. (Kennedy, 2018)

As a result of increased awareness, many also reported experiencing increased enjoyment with whatever was happening in the present moment (Quirk, 2018), such as not having to worry about how, or if, they were going to achieve their daily tasks or feeling concern about future stressors (Kennedy, 2018). An increased awareness of mind and body sensations, including feelings of negativity, stress and anger as well as physical symptoms (e.g., fast breathing, irregular heartbeat, physical aches and pains) was additionally noted. Children also indicated that being aware of negative stimuli helped to alleviate any physical stresses:

> I better feel the distraction in my body. When I feel it, I mostly try to prevent it, when I am doing something important … I feel like it is ... bubbling … *And how do you*

> *notice that earlier, the bubbling*? That is because I earlier feel and know what is happening in my body. (Ridderinkhof, de Bruin, et al., 2019)

An increased awareness of what others were saying or feeling was noted. Caregivers, in particular, noticed improvements in the quality of interactions with their child by enjoying the present interaction or activity and having a better understanding of their child's behaviour (Hwang & Kearney, 2015; Kennedy, 2018; Quirk, 2018; Ridderinkhof, de Bruin, et al., 2019; Singh et al., 2014b).

Theme 2: Self-Acceptance

The second theme, predominantly reflected in caregivers but also in autistic children and adults, was the ability to accept one's present circumstances, including with fewer judgemental thoughts. As one caregiver said, mindfulness led to 'less judgment too, for myself and others. I mean, that's been a real great thing' (quoted in Quirk, 2018, p. 72).

Acceptance and nonjudgement were especially important for caregivers, who found a greater appreciation of their child and the difficulties that their child faced:

> I now look at him in a different way, that's something that helped me with the class. And I see him not like a child, he's a person, an individual. (Caregiver, quoted in Kennedy, 2018, p. 62)

Autistic children also reported the ability to be more self-accepting:

> Previously I was very strict on myself … Now it is just being kind to myself. Like: Hey, it may all be there, I do not need to change it. It is troublesome for a while, but I don't really have to change it. (Ridderinkhof, de Bruin, et al., 2019)

Theme 3: Self-Regulation

Improvements to active self-regulation were frequently endorsed as important by all three groups. This typically involved pausing and taking deep breaths or doing a short meditation during or after a challenging situation before consciously choosing to act in a more productive way. For autistic children, using a breathing space or a meditation was one way to calm themselves when they began to recognise that their emotions were escalating: ‘The breathing space. I often did that one. I do that one when something goes wrong’ (Ridderinkhof, de Bruin, et al., 2019).

Another child described the ability to physically remove themselves from anxiety-inducing situations:

> It has helped me to learn to be in the moment and know that it is okay to walk out of a situation, to breathe, and then go back into that situation whatever it may be. (Salem-Guirgis et al., 2019)

Caregivers reported that self-regulation, as a result of being more mindful, enhanced their parenting skills, particularly their ability to place healthy boundaries on their children while remaining in control of the situation and their responses. For example:

> It helps me in not getting completely stressed out. Sometimes this is acute, when the children do something or when they get into a fight. Then I take just one moment before I respond. (Ridderinkhof, de Bruin, et al., 2019)

Theme 4: Self-Care

Self-care, or the ability to look after one’s own physical and mental wellbeing, was identified as a treatment facilitator by both caregivers and autistic adults. In the case of caregivers, overcoming self-criticism, forgiving themselves, taking time for themselves, accepting their limitations and acknowledging they were doing their best with their child were critical to self-care, yet seldom practised. For example:

> I just really learned don’t compare yourself to anybody. You’re trying your best. Just have that compassion to yourself. Even if you make the mistake, forgive yourself. (Caregiver, quoted in Kennedy, 2018, p. 59)

Autistic adults observed that learning mindfulness skills helped to enhance their self-worth: ‘It made me feel like I’m more human even though I’m not perfect’ (Beck et al., 2020).

Theme 5: Sharing Experiences in the Group

Gaining connection and support from peers was seen as a key benefit of group-based training, particularly for caregivers and children and, to some extent, for autistic adults. Caregivers found that the group format helped them establish and maintain regular mindful practice while learning to appreciate other families’ struggles. One commented, ‘We could actually talk about the fact that some of our kids hit and punch … we usually can’t talk about [these things] anywhere else’ (Reid et al., 2016). Autistic children also appreciated this format:

> I was able to meet other autistic people for the first time in my life, which finally made me feel like I wasn’t alone. There are others like me out there.’ (Salem-Guirgis et al., 2019)

Theme 6: Changes in Self and Others

This theme, only reported by caregivers, reflected the significant and positive changes seen in a child’s behaviour due to caregivers’ learning core mindfulness skills (e.g., ability to regulate their emotions and remain calm). For example:

> What I see more of lately, because I don’t push to meltdown point anymore. I used to push to meltdown point and then she would bite or whatever. (Hwang & Kearney, 2015)

Positive changes in family functioning were additionally reported. The family environment was described as calmer, with children listening more readily and becoming interested in joint mindful practice with their caregivers.

Discussion

This meta-synthesis examined personal accounts of mindfulness and acceptance training from individuals with ASD and their caregivers. Caregivers, the group that presented the richest data, commented on the need to adapt standard home-practice protocols to their circumstances in addition to time and cost concerns. Despite the time and energy commitment required for therapy, however, all three cohorts identified factors contributing to their engagement—particularly, enhanced self-awareness of thoughts and feelings while remaining calm and nonjudgemental. Caregivers additionally highlighted the importance of training to improve acceptance of themselves as well as of their child in helping enhance wellbeing in the family unit. The therapeutic value of group peer support, as an opportunity to facilitate dialogue and provide role modelling, was also noted by all participants.

The aforementioned psychological facilitators of therapy are consistent with theoretical neural models of mindfulness action on body awareness, attention and emotion regulation (Holzel et al., 2011). The resultant positive changes that caregivers noted in their family members is an equally important finding. This finding mirrors that found in our quantitative review of the literature (Hartley et al., 2019): as caregivers become more aware of their children's emotions, they are able to adapt their parenting style, resulting in reduced family arguments and disagreements, with less aggression and more compliance from their diagnosed child. The relationship between caregiver and child engagement appears to be reciprocal: those caregivers who were committed to mindfulness and acceptance-based approaches helped to positively influence their child's engagement in these therapies, but they also benefited personally from having their child attend training. This is in line with research highlighting the key role of caregiver engagement and support in improving a child's behavioural and emotional dysfunction (Chan & Neece, 2018; Kasperzack et al., 2020).

Peer support and validation was another highlight for caregivers. Connecting with others was seen as a key incentive not only for attending therapy (e.g., participants reporting greater empathy for fellow group members) but also for maintaining continued home practice (Beck, 2018; Hwang & Kearney, 2015; Kennedy, 2018; Quirk, 2018; Reid et al., 2016; Ridderinkhof et al., 2018a; Ridderinkhof, de Bruin, et al., 2019). Group support and discussion is considered a necessary part of traditional mindfulness training (Kabat-Zinn, 2003; Kabat-Zinn et al., 2017). In saying this, caregivers who received individualised training also reported benefits (Hwang & Kearney, 2015; Singh et al., 2007; Singh et al., 2014b). These findings highlight the need to carefully screen and engage caregivers prior to commencing any psychotherapy to determine not only their needs and suitability for therapy but also the appropriate mode and structure of treatment.

The few studies that provided data for autistic children did not report barriers to mindfulness, possibly because children typically have less responsibility than adults do and rely on their caregivers for support or because the caregivers minimised the barriers for their children. The exhaustion and lack of self-care consistently reported by many caregivers is indicative of the significant effort spent easing any difficulties experienced by children. As with caregivers, benefits with both group therapy and individual therapy formats were noted. While children identified peer support and validation during group-based mindfulness training as important (Beck, 2018; Hwang & Kearney, 2015; Kennedy, 2018; Quirk, 2018; Reid et al., 2016; Ridderinkhof et al., 2018a; Ridderinkhof, de Bruin, et al., 2019), those with high behavioural needs responded positively to tailored mindfulness training (e.g., (Conner & White, 2018b; Hwang & Kearney, 2015; Singh et al., 2007; Singh et al., 2014b). These findings echo those of previous research, with greater caregiver involvement indicative—but not determinative—of better outcomes for children (Hwang & Kearney, 2015; Meppelink et al., 2016; Neece, 2014; Ridderinkhof et al., 2018a).

Reported experiences from adults, although the least explored (Beck, 2018; Beck et al., 2020), were consistent with those described by caregivers. This finding may possibly reflect the high level of responsibility faced by this group, in comparison with younger peers, in scheduling mindfulness training in their own lives. However, while reports of training were typically positive among this group, and homework completions described as ‘exemplary’ by clinicians delivering mindfulness, autistic adults still reported feeling stressed or guilty when home-practice requirements were not met each day. Notably, studies with neurotypical individuals have reported an increase in anxiety with mindfulness training, largely due to the stringent home-practice requirements (Clarke & Draper, 2020). Given that individuals with ASD are more prone to anxiety (Maddox & White, 2015; van Steensel et al., 2011), there may be a need to modify the standard MBSR curriculum to individual need, by developing a meditation schedule that is convenient and suitable to that person (Spek et al., 2013a), scheduling one-on-one mindfulness training (Conner & White, 2018b) or personalised reminders to practise—strategies that have been successfully used with caregivers (Rayan & Ahmad, 2016). Future research should continue to examine whether training requirements can also be reduced (e.g., reducing the length of sessions and home practice) in order to derive the same, or similar, improvements to standard mindfulness training.

Indeed, alternative ways of incorporating mindful practice into one’s daily routine were deemed essential in order to help caregivers overcome the difficulties of maintaining regular mindful practice at home (Beck, 2018; Hwang & Kearney, 2015). This was particularly true for caregivers who received individual training—a format typically associated with higher home-practice requirements (Hwang & Kearney, 2015; Singh et al., 2007; Singh et al., 2014b). While increased intensity and duration of mindfulness practice is likely to produce larger effects (Creswell, 2017), consistent with a ‘dose–response’ effect

(Creswell, 2017; Goldberg et al., 2020; Strohmaier, 2020), it is equally important for people to learn to use skills when stressed or upset. In this context, intermittent mindful practice may be beneficial for those who are time poor (Clarke & Draper, 2020). Similarly, if individuals are experiencing undue stress in their lives, they may not have the energy required for mindfulness practice (Spek et al., 2013a). Technology tools offer another option to support engagement in mindfulness interventions, by augmenting face-to-face training and guiding home practice. In particular, smartphone mindfulness apps have shown potential to reduce anxiety in as little as 10 days (Clarke & Draper, 2020; Flett et al., 2018; Howells et al., 2016), something that highly stressed individuals may gain benefit from (Creswell & Lindsay, 2014), although these findings remain preliminary.

Limitations

Several limitations need to be acknowledged, many a reflection of the methodological limitations that characterised the included studies. First, we acknowledge that although an expert librarian assisted in the customised database searches, a single author conducted the preliminary screening of articles. Second, the quantitative studies included in this review were not designed to meet qualitative standards. Indeed, only five of the included studies had a robust qualitative methodology (Hwang & Kearney, 2015; Kennedy, 2018; Quirk, 2018; Reid et al., 2016; Ridderinkhof, de Bruin, et al., 2019). However, it was deemed necessary to evaluate all possible studies on the topic of mindfulness and acceptance, as applied to ASD, in order to provide a comprehensive review of existing research in this area. Third, variability in the delivery, duration, intensity and/or practice requirements of the mindfulness-based (e.g., MBSR, MBIs) and mindfulness-incorporated (e.g., ACT) approaches examined may have influenced participants' experiences. For example, awareness formed the primary focus of training in some studies (i.e., MBSR, MBIs; (Hwang & Kearney, 2015; Singh et al., 2014a; Singh et al., 2007)) or was taught in conjunction with cognitive behavioural techniques in others (i.e., MBCT, ACT; (Reid et al., 2016; Ridderinkhof et al., 2018a; Ridderinkhof, de Bruin, et al., 2019; Salem-Guirgis et al., 2019)). Similarly, the relative effects of group- and individual-based interventions for persons with ASD, both of which were associated with benefits but also barriers, requires further examination (Anclair et al., 2017; Sizoo & Kuiper, 2017). Equally important are details relating to the experience level (with ASD or mindfulness) of the practitioner, which is known to influence both intervention quality and effect (Bennett-Levy, 2019).

Fourth, sample characteristics may have contributed to the reported facilitators. As is common in ASD research, included studies were biased towards female caregivers and males with ASD (Hartley et al., 2019; Rivet & Matson, 2011; Schaafsma & Pfaff, 2014)—subgroups that show high levels of anxiety and stress compared with the general population and, therefore, may be more likely to demonstrate therapeutic change (Creswell & Lindsay, 2014; Hayes & Watson, 2013; Keenan et al., 2016; Lever & Geurts, 2016; Zaboski & Storch, 2018). A more comprehensive picture of mindfulness as experienced by autistic children and adults is needed. Indeed, for autistic children, the noted facilitators could be attributed to typical developmental changes, improved caregiver wellbeing or simply the opportunity to engage in a joint activity with their caregivers (de Bruin et al., 2015; Ridderinkhof et al., 2018a). Future studies focusing solely on the experiences of individuals with ASD would also be a welcome addition to the field; the available data for this group did not provide sufficient richness to enable an exploration of themes with any confidence and should, therefore, be treated as a preliminary representation of this cohort. Indeed, the single study that focused on autistic adults provided only a summary of their interview data with few quotes contained. Consequently, key contextual information (e.g., major themes identified, number of participants identifying with each theme, divergent themes) may have been missed.

Finally, studies seldom explored the experiences of individuals who reported no benefit or change from mindfulness and acceptance (Ridderinkhof et al., 2018a; Ridderinkhof, de Bruin, et al., 2019; Salem-Guirgis et al., 2019), or from those who experienced discomfort or distress (Hwang & Kearney, 2015; Ridderinkhof, de Bruin, et al., 2019). While uncomfortable experiences are considered part of the experience of therapeutic change (Creswell, 2017), serious adverse impacts, such as agitation, fear, anxiety, panic and depression, can occur (Creswell, 2017; Lindahl et al., 2017; Wyatt et al., 2014). The lack of detail around adverse experiences has led to criticism of mindfulness research as an ideology rather than an evidence-based practice (Farias & Wikholm, 2016; Farias et al., 2016). Importantly, studies are beginning to examine these data to better understand who benefits most from mindfulness and in what circumstances or contexts (Clarke & Draper, 2020; Farias & Wikholm, 2016).

Conclusions

Experiences of mindfulness and acceptance training reported by individuals with ASD and their caregivers are consistent with the experiences reported in other clinical populations. Key facilitators include enhanced self-awareness, better management of negative thoughts and disruptive or problematic behaviours, and the motivating effects of group-based practice. The findings also highlight a need to explore creative and flexible ways to help this cohort engage in regular mindful home practice over time, a treatment aspect considered to be most difficult to maintain. The effectiveness of modifications to traditional mindfulness training and practice for ASD-affected populations, in addition to an examination of why some participants experience little or no benefit, are future research priorities.

Compliance to Ethical Standards

Acknowledgements: The authors would like to thank Maureen Bell, Research Librarian at the University of Adelaide, for assistance with the database searching. We also thank the authors of included studies who kindly responded to our requests for additional data.

Funding: This work was supported by an Australian Government Research Training Program Scholarship.

Conflict of interest: The authors declare they have no conflict of interest.

Ethical approval: This article does not contain any studies with human participants or animals performed by any of the authors.

Chapter 5: Study 3

Challenges Encountered With a Mindfulness App: Lessons Learnt From a Pilot Randomised Trial Involving Caregivers and Individuals With Autism

Preface

Studies 1 and 2 evaluated the current evidence base for mindfulness research and its effectiveness and acceptability among individuals and families with ASD. Both studies provided promising evidence for this third-wave psychotherapy. Suitably designed mindfulness programs appear to provide caregivers, and autistic children and adults greater awareness of their emotional states as well as strategies to self-regulate uncomfortable emotions and enhance their wellbeing.

Both studies also identified a need for additional controlled research in this area as well as a need to consider alternative forms of service delivery to promote treatment engagement. A pilot study was subsequently developed to test the feasibility and preliminary effects of an eHealth mindfulness program for individuals with ASD using a commercially available and well-established smartphone app, Smiling Mind, whose programs closely follow an MBSR structure. Ease of use and the benefit of having a basic MBSR program accessible at any time were key reasons for the selection of an app intervention based on an evidence-based psychotherapy. A further benefit of Smiling Mind is that it was developed in consultation with psychologists and it provides programs tailored to specific age groups. Moreover, Smiling Mind has the ability to track user participation in mindfulness sessions as an index of engagement.

The study followed a mixed-methods design as per the recommendations outlined by Fish et al. (2016). Specifically, participants were surveyed before and after the mindfulness program and then interviewed to better understand their perceptions and experiences of the program. However, despite endeavouring to follow best practice guidelines for pilot RCTs (Fish et al., 2016), feedback from disability service providers during the consultation phase indicated that additional modifications to the study requirements were required to motivate and maintain participants' engagement. The main concern raised was that the study requirement of 6 days a week of mindfulness practice over 5 weeks was not feasible due to participants' competing time constraints directly related to the child's care needs—a key issue for families with young autistic children. A post-hoc deviation from the study design was therefore necessary, with the mindfulness practice requirement reduced to a minimum of 5 days, although participants could engage in additional sessions if they desired.

Additional challenges were then encountered during recruitment and data collection. Limitations with access to the Smiling Mind database made it difficult to reliably extract user data from the app's central database, limiting app-use statistics to five participants (two of whom were caregiver–child dyads) - undermining a key element in our study design. The paper that follows was originally submitted for publication. Comments from the Editor indicated that although the article was suitable for the journal, the challenges encountered and lessons subsequently learnt during the trial would be of more benefit to readers. The article was subsequently published as a brief report. Chapter 5 outlines the full article as it was originally submitted, with the published report version provided in Appendix A.

Challenges Encountered With a Mindfulness App: Lessons Learnt From a Pilot Randomised Trial Involving Caregivers and Individuals With Autism

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Abstract

Background: Smartphone applications (apps) can make mental health support more accessible to autistic children and their caregivers. However, there remains a lack of established data on the use and impact of psychology-based apps with this group.

Methods: Using a mixed-methods design, we evaluated the feasibility and preliminary effects of a self-guided MBSR app, Smiling Mind, for autistic children and adults and their caregivers. First, participants were randomly assigned to Smiling Mind (n = 8) or an attention-control condition (n = 8) for 1 or 5 weeks. Pre–post measures targeted mindfulness (Mindful Attention Awareness Scale), wellbeing (WHO-5), and distress (Depression Anxiety Stress Scales–21 item). Individuals' trial experiences were subsequently explored using semi-structured interviews (n = 3). Those who registered interest but did not complete the study were surveyed about barriers to their participation (n = 33).

Results: Reliable change indices indicated positive change among 50% (n = 4) of app participants compared with 25% (n = 2) in the control group. Caregivers identified competing time commitments as a key barrier to app use. Autistic individuals reported distraction and boredom as key obstacles to developing mindfulness skills. Nonetheless, overall experiences of using Smiling Mind were positive.

Conclusions: Use of an evidence-based smartphone app as part of a broader mental health program may help to support the general wellness of individuals living with ASD. Future studies with this group need to consider their research design, particularly strategies to promote study recruitment and engagement.

Keywords: mobile applications, caregivers, wellbeing, mindfulness, children, autism

Introduction

The promise of 24/7 access to mental health care via the internet has fuelled research in the use of smartphone applications or ‘apps’ (Cuijpers et al., 2009; Massoudi et al., 2019; Meier et al., 2013). In addition to tailored health information, resources and anonymity, app interventions provide patients the freedom to self-pace their treatment (Cowpertwait & Clarke, 2013; Kuijpers et al., 2013). Meta-analytic studies also confirm consumer satisfaction with mental health apps, alongside moderate improvements in symptoms of distress (i.e., reduced depression, anxiety, and stress symptoms) and quality of life (Bennett et al., 2020; Gál et al., 2021; Linardon, 2020).

Individuals and families living with ASD may benefit from using a mental health app, given their increased rates of mental health disorders (Hudson et al., 2018; Mingins et al., 2021; Schnabel et al., 2020). App interventions can also help to address issues of treatment accessibility, with caregivers citing competing time demands, emotional burden, treatment cost and limited availability of providers as key barriers to mental health care (Hartley et al., 2021).

To ensure effectiveness, the content of an app needs to be evidence based (Baumel et al., 2020; Qu et al., 2020). Well-established therapies, such as mindfulness meditation to focus and regulate one’s thoughts and feelings, are particularly well suited to an app format (Mikolasek et al., 2018; Morrison et al., 2017; Taylor et al., 2014). Notably, mental health improvements have been identified in as little as 10 days with leading meditation apps such as Calm, Headspace, HeadGear and Smiling Mind (Clarke & Draper, 2020; Deady et al., 2020; Flett et al., 2018; Howells et al., 2016) To date, however, trials evaluating these apps have not always considered the influence of digital placebo effects, or the likelihood of positive mood changes occurring due to interaction with technology (Firth & Torous, 2019; Linardon, 2020; Torous & Firth, 2016; Torous et al., 2020; Van Dam, van Vugt, Vago, Schmalzl, Saron, Olendzki, Meissner, Lazar, Gorchov, et al., 2018). Moreover, few apps have been evaluated with consideration of the specific requirements of autistic individuals and their caregivers, such as being easily accessible and low cost.

The present study is, to our knowledge, one of the first to evaluate both usability and effectiveness of a commercially available mindfulness app, Smiling Mind, for autistic children and adults and their caregivers. Specific aims were to determine: (a) app suitability, based on time and usage preferences of this group, and (b) the comparative effects of Smiling Mind on SWB versus an attention-control condition. The study involved two stages. First, a pilot RCT was conducted to determine suitability of the Smiling Mind app. Individuals' experiences of using the app, in addition to potential modifications required to design a future full-scale trial RCT, were also explored (Eldridge et al., 2016; Fish et al., 2016). Those who registered an interest in the study but were unable to complete the app evaluation were then surveyed to examine the key barriers that prevented their participation and which adjustments, if any, may have improved their engagement.

Methods

Protocol Registration

Ethical approval for this project was provided by the University of Adelaide Human Research Ethics Committee (RCT: H-2019-036, Survey: 19–95). A protocol for the RCT was prospectively registered with the Australian and New Zealand Clinical Trials Registry (ACTRN12619000584134).

Participants

Children (aged 11–17 years) and adults (aged 18+) with ASD, and their caregivers, were eligible to participate. Additional requirements included fluency in written and spoken English, as well as access to a smartphone or computing device with internet connectivity. Participants who disclosed untreated mental illness or symptoms on study enrolment were excluded and referred to their general (medical) practitioner for follow-up.

Measures

Sociodemographic variables (e.g., age, gender) in addition to self-reported information about ASD diagnosis, mental health history (i.e., previous pharmacological or psychological treatments, prior experience with mindfulness meditation) and current life stressors (e.g., physical illness, COVID-19 related stress) were obtained on study enrolment. For the RCT, three standardised measures of psychological functioning were additionally administered at baseline and immediately following the intervention.

Mindful Attention Awareness Scale

This 15-item Mindful Attention Awareness Scale (MAAS) measures an individual's ability to be mindful, or the ability to attend to the present moment (Brown and Ryan (2003); (Osman et al., 2016). Both adult (MASS-A) and child (MAAS-C) versions were utilised. Respondents are asked to rate how frequently they engage in low-level mindfulness activities (e.g., ‘I do jobs or tasks automatically without being aware of them’) on a 6-point Likert scale from 1 (*almost always*) to 6 (*almost never*). Scoring is reversed for the MAAS-C. Item scores are summed, with greater levels of mindfulness represented by higher scores for children and lower scores for adults. Consistent with previous research with clinical, child and adolescent populations, good reliability was demonstrated in the present study (Cronbach’s alpha = .82; (Brown & Ryan, 2003; Lawlor et al., 2013).

Depression Anxiety Stress Scales–21

Based on the original Depression Anxiety Stress Scales (DASS; (Lovibond & Lovibond, 1995), the 21-item version is designed to measure the negative emotional states of depression, anxiety and stress. Items are rated on a four-point Likert scale from 0 (*did not apply to me at all*) to 3 (*applied to me very much of the time*) and can be summed to produce a composite measure of distress: higher scores represent greater symptom severity. Missing data for two DASS-21 items were imputed with an average value derived from the remaining items (UNSW, 2018). The factor structure of the DASS-21 has been successfully replicated in children and adolescents (Szabo, 2010; Szabó & Lovibond, 2006; Tully et al., 2009) and has demonstrated utility as a mental health screening tool for autistic adults (Nah et al., 2018). In this study, Cronbach’s alpha was .9 for the total DASS-21.

World Health Organization Five Well-Being Index

The well-established questionnaire, the World Health Organization Five Well-Being Index (WHO-5), has been used as a measure of general wellbeing in research with children, adolescents, and adults (Allgaier et al., 2012; Topp et al., 2015). Participants are asked to rate five items on a 6-point scale from 0 (*at no time*) to 5 (*all of the time*). Higher scores represent better wellbeing, with scores below 13 indicative of low wellbeing (Allgaier et al., 2012). Cronbach’s alpha was an acceptable .88 in the present study.

Treatment Satisfaction

Smiling Mind participants rated their satisfaction with the app using a single item, indicating the degree to which they found the app helpful (1 = not at all helpful to 5 = extremely helpful).

Treatment Fidelity

All participants were asked to estimate the weekly frequency with which they either accessed the Smiling Mind app or spent a period in 'quiet time'. These data were supplemented with end-user data—namely, the time and date that specific meditations on Smiling Mind were used and the duration of use.

Smiling Mind Intervention

The Smiling Mind smartphone app, developed by a not-for-profit organisation Smiling Mind Pty Ltd is available free of charge on both the App Store and Google Play. The app follows an MBSR format, offering both formal (e.g., body scan, mindful breathing) and informal (e.g., eating, sleep, gratitude, and relationships) meditation exercises (see Appendices H and I). These exercises are designed to be self-guided, with content and duration modified to suit different demographics and preferences (e.g., school-age children vs. adults, classroom vs. workplace setting) by psychologists involved in the app development. Smiling Mind has been highly rated for ease of use (Mani et al., 2015), with suitability demonstrated in paediatric settings (Weekly et al., 2018) as well as the broader population (Flett et al., 2018).

Consistent with mindfulness practice recommendations (Fish et al. (2016), the initial protocol specified an intervention length of 10 minutes per day, for 3 days per week over 5 weeks. After 4 months of recruitment, this requirement was modified to 10 minutes per day over 1 week. This post-hoc deviation to the study protocol was in response to feedback from participating agencies suggesting that the shorter time frame was less onerous, and therefore practicable, for families with ASD. This need for brief (i.e., 7-day) app interventions has precedence (Clarke & Draper, 2020). Participants who completed the assessments and intervention received a $A20 shopping voucher to compensate them for their time.

Attention Control (Quiet Time)

Those assigned to the control group were instructed to engage in quite activity on their smartphone in a manner of their choosing (e.g., viewing social media, listening to music) for a period of 1 or 5 weeks. This attention-control condition resembled real-world smartphone usage (Baumel, Edan, et al., 2019) and accounted for the positive placebo effect that smartphone use may have on mood (Firth, Torous, Nicholas, Carney, Rosenbaum, et al., 2017; Torous & Firth, 2016). On study completion, the control group was encouraged to access the Smiling Mind app at their leisure.

Barriers to Participation Survey

A purposely designed questionnaire was administered to those who registered an interest but did not complete the RCT. In addition to demographic details, three questions with prepopulated response options were included focusing on individuals' reasons for requesting study information (e.g., 'I would like help for anxiety or stress, I have a child that needs help dealing with anxiety or stress'), what prevented them from participating (e.g., 'It was just one too many things to think about'; 'The information provided was too complicated'); and what, if any, additional incentives may have helped maintain their engagement (e.g., 'I would prefer mindfulness training from someone I trust like an autism services provider'; 'I need more information on the app and Smiling Mind'). An 'Other' category allowed participants the opportunity to elaborate on their answers.

Procedure

Randomised Control Trial

In addition to advertising the study on social media, 13 statewide autism support provider bodies across Australia were emailed an invitation to participate, with nine agreeing to post links to the study website, participant information and consent form (see Appendix N, O and P) on their webpage and/or in their e-newsletter. Recruitment continued for 12 months (March 2019 to March 2020).

Those interested in the study contacted the first author (MH) for further information and were required to return a signed consent form for themselves and their child (if applicable). Consenting participants were subsequently emailed a hyperlink to the baseline (Time 1) survey hosted by SurveyMonkey. Following receipt of the completed survey, participants were assigned a unique sequential number based on the time and date they responded. Group allocation (1:1 ratio) was performed using a computer-generated program (www.randomizer.org) overseen by the first author (MH) (see Figure 6).

Participants assigned to the Smiling Mind group were provided with written and video instructions on app set-up and meditation program selection. Autistic adults and caregivers were asked to first undertake the Mindfulness Foundations program, which comprises some 28 meditations focusing on core mindfulness concepts (e.g., body scan and mindful breathing, thoughts and emotions). Children and adolescents were instructed to choose the relevant age-group program (i.e., 10–12 years old; 13–15 years old), each of which contained 40 shortened meditations. Participants were encouraged to complete the meditation sessions in the order that they appeared in the Smiling Mind app and to complete at least one meditation per day. It was not a requirement to complete all meditations in the program, although they could if they wished too. Those who completed both assessments and intervention received a A$20 shopping voucher to compensate for their time.

Interviews

Five participants, all caregivers of autistic children, indicated they were available for an interview. Three provided informed consent and were contacted. Interviews were semistructured with six main questions examining their experiences of being involved, including the least beneficial aspect of the Smiling Mind app, noted changes in their thinking or behaviour during the study, and suggestions for improvement. Each question had prompts and examples to help facilitate discussion (see Appendix J). Telephone interviews were conducted by the first author (MH) and ranged from 25 to 51 minutes in duration (M = 34:44). Interviews were recorded and transcribed by the interviewer, with a copy of the written transcript sent to each participant to confirm accuracy.

Barriers to Participation Survey

Participants who registered but did not complete the RCT were emailed an invitation to a follow-up survey. Following written consent, they were emailed the survey link. A reminder email was sent after 2 weeks. Those who completed the survey entered into a draw to receive one of five A$20 gift cards.

Analyses

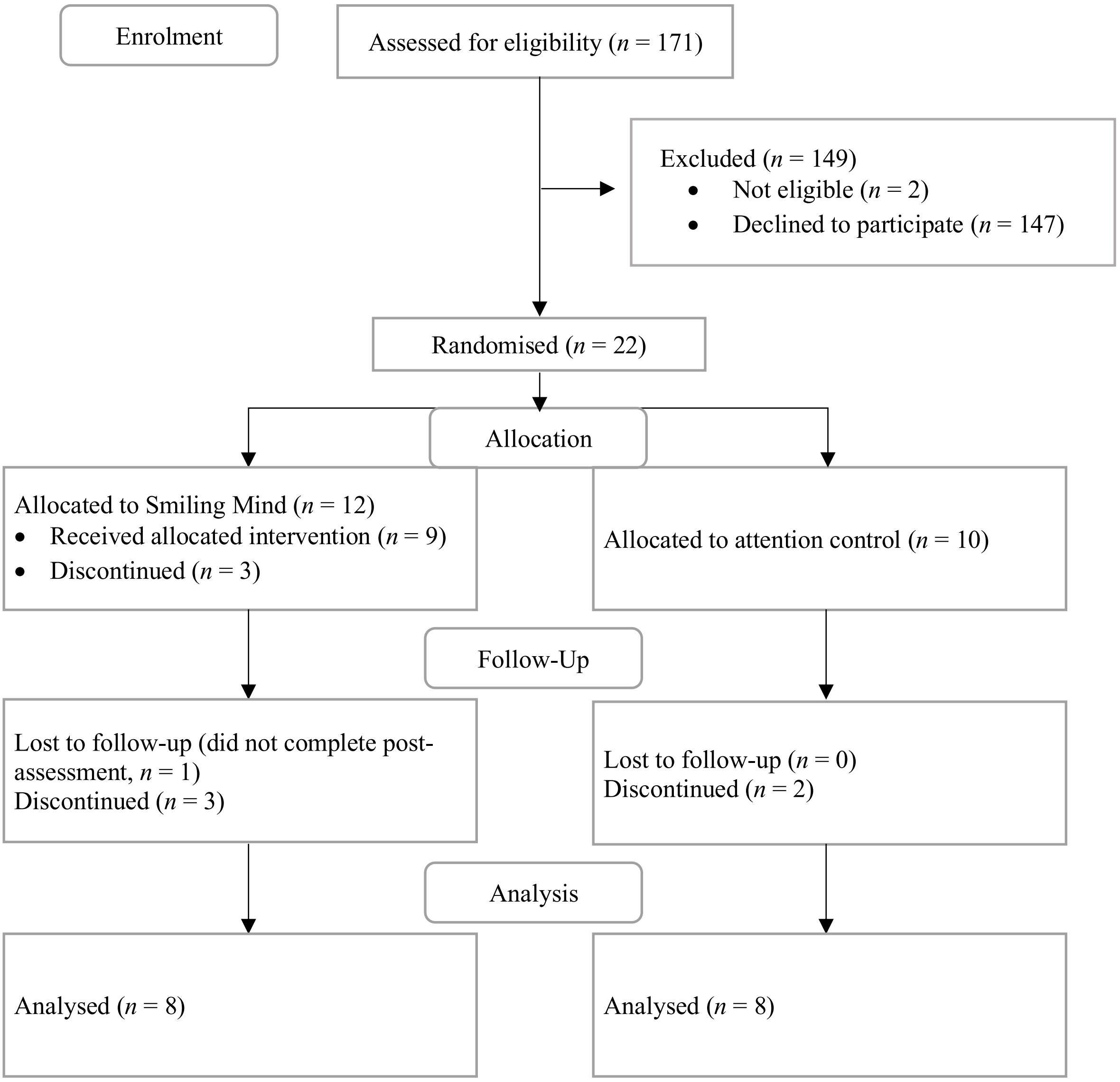
Pre- and post-comparisons for each participant on each repeated measure (MAAS, DASS-21, WHO-5) were examined using reliable change indices (Jacobson & Traux, 1991; Morley & Dowzer, 2014). This method determines whether the magnitude of change in participant scores is large enough to be statistically reliable. Reliable change is calculated by examining the mean and standard deviation of pre- and post-scores with a significant reliable change index (RCI) being at least two standard deviations higher or lower than the group mean. RCIs were calculated using the Excel template developed by the Center for Clinical Informatics (Brown et al., 2015).

Interviews were drawn upon to provide brief case studies of the three consenting caregivers (Flyvbjerg, 2006), with the view to explicating their unique experiences of mindfulness, for themselves or their child. To develop these case studies, transcripts were first analysed with NVivo 12 software (Trigueros-Cervantes et al., 2018). A directed content analysis approach was used to evaluate participant responses on the usefulness of the Smiling Mind app, including whether responses were consistent with or contradicted previous research findings and to identify limitations or extensions to application of mindfulness for this group (Hsieh & Shannon, 2005).

Finally, survey data were summarised using descriptive statistics (i.e., percentage responses to each question), with content analysis of 'Other' category text responses providing further context to barriers that may not have been identified in the multiple-choice questions (see Appendices K, L and M).

Figure 6

CONSORT 2010 Flow Diagram for Randomised Pilot and Feasibility Trials (Eldridge et al., 2016)



Results

Sample Characteristics

A total of 16 individuals, primarily caregivers (*n* = 11, *M* = 42 years) who identified as Caucasian and female, completed the RCT (see Table 9). Also included were two children (*M* = 12 years) and three adults (*M* = 35 years) with ASD. In addition to autism as a primary diagnosis, secondary diagnoses were self-reported, (*n* = 9) namely developmental diagnoses (e.g., ADHD, *n* = 5), dyslexia (*n* = 1), dysgraphia (*n* = 1), speech delay (*n* = 1), sensory or auditory processing disorders (*n* = 3) and mental health comorbidities (i.e., anxiety *n* = 5, depression *n* = 1). Fifteen participants had previously accessed pharmacological, psychological or counselling support, with seven continuing this treatment (2 adults, 5 autistic children). Most (*n* = 11) identified using some form of mindfulness in the last 12 months, the detail of which was not described. Of note, six participants (4 intervention, 2 controls) described experiencing one or more concurrent stressors during the study, namely isolation due to the COVID-19 health crisis (2 caregivers), moving house (2 caregivers), family difficulties (3 caregivers), and medication changes (1 adult with ASD).

Smiling Mind Activity and Feedback

Four participants completed the 5-week trial. However, self-reported data indicated some variation in the weekly frequency of mindfulness practice—from a single meditation (*n* = 1) to multiple sessions (range: 3–4 sessions; *n* = 3)—predominantly accessed in the afternoon or at night (*n* = 12). All but one participant in the 5-week trial group completed the minimum three sessions. Engagement was more problematic in the 5-day trial, with none of the four participants allocated to this program completing the minimum five sessions.

User-end data from Smiling Mind, where this was available (see Tables 10 & 11), highlighted variable use. Overall, 37 discrete meditations were accessed, typically from midday onwards (i.e., between 12 pm and 11:59 pm, *n* = 28) but also early morning (between 12 am and 11:59 am, *n* = 9). Meditation programs relating to sleep were popular, accounting for nearly half the total recorded meditation time. Notably, the introductory Mindfulness Foundations program, a requisite module for all parent and adult intervention participants, was only accessed by one adult with ASD.

Answers to the single-item satisfaction scale were generally positive, with participants reporting that the Smiling Mind app was somewhat helpful (*n* = 5) or extremely helpful (*n* = 3). Open-ended responses (*n* = 6) confirmed this: ‘It really is such a high quality, powerful app’ (Caregiver; Participant 6). Barriers to engagement were, however, identified. Two caregivers commented that the lack of variation in meditations made it difficult to keep their children interested, for example: ‘My son used the app and was happy to chill out to it … but he started to become bored with it’ (Participant 15). An adult with ASD also found that they were easily distracted while practising meditations: ‘I could only manage short bursts with the Smiling Mind app’ (Participant 3). Another caregiver reported that her daughter enjoyed Smiling Mind but would have preferred longer meditations: ‘We found it good for help with resting and she specifically loved the Thought Catcher. Very short bedtime ones could be longer’ (Participant 7).

Control-Group Activity

Control participants reported a total of 58 sessions of quiet time. This activity included reading or viewing books, websites, news or social media (*n* = 7) or quietly self-reflecting (*n* =1). Three participants completed their required number of sessions, regardless of whether they were allocated to the 1- or 5-week trial. The remaining five participants completed two to four sessions in the 5-day trial.

Table 9

Baseline Characteristics of Total Sample

Demographics	Child	Adult	Caregiver
Gender			
Male	1		
Female	1	1	11
Not specified		2	
Mean age (*SD*)	12 (1.4)	35 (10)	42.4 (8)
Level of education			
Post-graduate degree		1	3
Degree or diploma		1	7
High school		1	1
Primary school			
Not yet completed	2		
ASD severity level*			
Level 1 (mild)	1	1	1
Level 2 (moderate)	1		6
Level 3 (severe)		1	2
Don’t know		1	2
Secondary diagnoses*	1	2	7
Previous treatment*			
No			1
Yes	2	3	8
Length of time since treatment*			
Current	1	3	3
< 12 months			4
> 12 months	1		3
Previous experience of mindfulness			
Yes	1	3	9
No	1		2

* Reflects data for ASD child (either self-reported or reported by caregiver).

Table 10

Total Meditation Time for Each Smiling Mind Program

Program name	Users	Number of users*	Number of meditations accessed	Total time (mins)
Introduction to Mindfulness	Caregiver/child/adult	3	16	39
Mindfully Together	Caregiver/child	1	3	28
Mindfulness Foundations	Adult/caregiver	2	17	81
Sleep for Kids	Caregiver/child	1	5	65
Sleep	Adult/caregiver	2	5	75

* Smiling Mind data available for only five participants due to technical issues with app user login.

Table 11

*Total Meditation Time for Each Smiling Mind User**

User	Users	Intervention length	Number of meditations accessed ^	Total time (mins)
User 1	Caregiver	5 weeks	3	4
User 2	Adult	5 weeks	16	110
User 3	Caregiver/child	5 days	6	6
User 4	Caregiver/child	5 days	11	139
User 5	Caregiver	5 days	8	29

* Smiling Mind data are only available for five participants due to technical issues with app user login.
^ The number of unique meditations accessed, not the number of times a user listened to the same meditation.

Reliable Change Associated With Smiling Mind Versus Quiet Time

Table 12 lists the change indices for each group and psychological measure. For Smiling Mind, participants (25%) reported positive and reliable change in either dispositional mindfulness (MAAS, RCI: > .69), mood (DASS-21 RCI: > 8.9), and/or general wellbeing (WHO-5 RCI: > 4.4). A possible dose–response effect was noted, with three of the four participants allocated to the 5-week trial reporting positive reliable change. This included a caregiver who reported the highest number of average weekly sessions, coinciding with improvements across all measures.

The control group had mixed responses to quiet time. One caregiver reported negative change for the MAAS, or greater difficulty entering into a mindful state at 1 week post (RCI: > .67). However, two other caregivers reported improvements on the DASS (RCI: > 9.7) or the WHO-5 (RCI: > 6.2) over this same period of time. The single child and adult with ASD in this group did not report meaningful effects with quiet time.

Table 12

Reliable Change Scores and App (or Quiet Time) Usage per Participant

Group	MASS RCI	DASS-21 RCI	WHO-5 RCI	Participant	Duration	No. sessions per week
Smiling Mind						
Participant 2	0.7^	−3.5	−1.0	Child	5 weeks	3
Participant 3	−0.3	−4.5	−1.0	Adult	5 days	3
Participant 5	−0.1	1.0	4.0	Adult	5 weeks	3*
Participant 7	0.2	−4.3	4.0	Caregiver	5 days	1*
Participant 10	0.0	−5.3	2.0	Caregiver	5 days	1*
Participant 11	−0.5	−13.3^	1.0	Caregiver	5 days	2*
Participant 14	0.5	−13.3^	4.0	Caregiver	5 weeks	1
Participant 15	1.0^	−14.2^	6.0^	Caregiver	5 weeks	4
Quiet Time						
Participant 1	−0.2	4.5	−6.0	Child	5 days	2
Participant 4	−0.3	−0.2	−1.0	Adult	5 days	5
Participant 6	0.5	−20.5^	4.0	Caregiver	5 days	5
Participant 8	−0.5	4.3	−3.0	Caregiver	5 days	3*
Participant 9	0.3	−8.8	8.0^	Caregiver	5 days	4*
Participant 12	−0.9^	2.0	4.0	Caregiver	5 days	2
Participant 13	0.0	0.0	2.0	Caregiver	5 days	2
Participant 16	0.3	−2.5	3.0	Caregiver	5 weeks	7

Note. MAAS RCI = Mindfulness Awareness and Attention Scale (higher scores reflect improvement); DASS-21 RCI = Depression Anxiety Stress Scales (lower scores reflect improvement); WHO-5 RCI = World Health Organization Five Well-Being Index (higher scores reflect improvement).
^ Denotes reliable change.
* Participant identified a stressor occurring during the trial.

Case Studies

Three female caregivers agreed to discuss their experiences of using the Smiling Mind app for themselves and their families.

Case Study 1: Fiona

‘Fiona’ is a parent of two girls, aged 6 and 8, one of whom has ASD (‘Jane’). Fiona indicated that her family had previous experience with mindfulness apps (for ‘about 2 years’). She decided to participate because her previous app was no longer available—

highlighting the importance of both availability and stability of apps for consistent practice. Fiona noted that using Smiling Mind resulted in Jane relaxing prior to going to bed and even sleeping better. However, she also found that Jane tended to become fixated on repeating specific meditations or on specific aspects of the meditation, rather than working her way through the suggested program. Fiona noted that this was because Jane 'feels really comfortable' with that meditation—suggesting that autistic children may prefer to use the same meditation multiple times.

Fiona used mindfulness regularly, on her own and with her children to help them sleep:

> Because we do it every night like at bed, it's a ritual in our house, we kind of read, go to bed and then lay there and I put the meditation on the [inaudible], and I have to lay with my daughter anyway until she goes to sleep.

While using the app was helpful, Fiona felt that the meditations were too brief in duration for Jane:

> I reckon at least 10 to 15 minutes, I think, that's a good time to, for them to breath, wind down and then, Yeah, kinda just go, you've told a little story now, now it's time for you to go to sleep, you know, 5 minutes is not long at all for a child to wind down and what not.

Fiona found that both of her children were able to listen to and understand the meditation instructions, although they would both fixate on certain aspects rather than on developing a mindful practice:

> Um, they listened to them and followed them. One thing my daughter did say was, the one she listens to all the time, she [the meditation] says the same word, quite a lot, …

> I was like this, we are to just listen to it not count the words, but, yeah, so I think, yeah, in her eyes, it's a bit annoying that it says the same thing over and over.

Fiona highlighted that completing the meditations in Smiling Mind was equally beneficial for her own wellbeing, even though she primarily used the meditations with her daughter, Jane:

> I'm laying with them ,and is this [the meditation] making me think a little bit more about how I am feeling at the time, and I suppose after I did kind of, just, well actually I do feel a lot more chilled.

In summary, Fiona found the Smiling Mind meditations pleasant and relaxing, helping calm her children before bedtime. She found that her daughter with ASD, Jane, was more comfortable repeating the same meditation each night. Although Fiona found Smiling Mind to be beneficial, her focus appeared to be helping her children relax rather than developing mindfulness skills for herself.

Case Study 2: Leanne

'Leanne' is a caregiver of two children: a male aged 11 with ASD ('Jarrad') and a female aged 8 without ASD. Leanne said that she was a long-time mindfulness user, having 'actually been teaching (preschool) children mindfulness'. Like Fiona, Leanne was hopeful that mindfulness would improve Jarrad's quality of life. Leanne found that both her children benefited from the mindfulness sessions. Similar to Fiona, she reported this benefit despite using the Smiling Mind meditations designed for children:

> Even if I didn't get to that real deep place of relaxation, I would walk away, come away from it going yeah I need that … I'm a much better person for it, and with my children I also noticed straight after they were much calmer as well. I wish it would last longer … I mean like, the residual effects of the children being calm.

Leanne had difficulty completing daily mindfulness practice, particularly in finding available time for herself but also in scheduling practice time depending on her son's state of mind:

> Then of course not just finding the time, whether or not Jarred would be, you know, compliant, so if there was something happening for him at that particular time, so, yeah, that was my biggest challenge.

As with Fiona, Leanne noted that her son, Jarrad, initially found the meditations engaging. However, he also found the shorter meditations (e.g., < 10 mins, The Bubble Journey) somewhat repetitive, and yet concentrating through longer meditations (i.e., > 10 mins) was equally difficult:

> He struggled to get through the sessions, I mean for him very short … and I think the bubble one which they keep referring to was actually for a younger group of children, I think it was only five or ten minutes … I remember on a couple of occasions that we, we tried something different that was longer, we, he just didn't get there, and so the shorter ones was better, but then he got bored with it.

Leanne did highlight strengths with Smiling Mind, particularly its design, ease of use and the narrator's tone and pacing. However, she suggested that increasing the amount of imagery and customising voices could potentially help Jarrad improve his ability to focus:

> I think it would be good to have, and this actually was some feedback that Jarrad gave me was, different people, like, it was, I really think that … whoever's voice was on there was very calming and relaxing and appropriate but it would be good to perhaps have other options as well, maybe during the different meditations.

In summary, Leanne found Smiling Mind beneficial for both herself and her children. Similar to Fiona, she tended to focus on her son's use of meditations more so than her own and on the importance of relaxation rather than on consolidating learnt mindfulness skills. Her son, Jarrad, had difficulty developing mindful practice skills; he became easily distracted and bored with the app's content.

Case Study 3: Betty

'Betty' is a caregiver for her two autistic children, a 15-year-old female 'Emilie' and 8-year-old male, 'John'. As with Fiona and Leanne, she was interested in how the use of Smiling Mind might benefit her family: 'I'm a big advocate for ASD kids and adults … and looking for ways to help my kids and myself.' Betty was time poor: she home-schooled her children while managing their transportation to therapy groups. She was impressed with the layout and usability of Smiling Mind in addition to the app's consideration of the unique sensitivities of those on the autism spectrum—features that helped to ease her initial apprehension about trying something new:

> When you're on the spectrum and you, you don't know what things are going to be like, and I think from that very first word, it gives you this sense of comfort, so I found the voice and the, the meditations themselves really, really good.

This sense of comfort was reflected in other aspects of the app, where the overall feeling of meditations was muted and did not overwhelm the senses:

> The sounds that he used, the background music, everything, all the little chimes and everything where not too overwhelming from a sensory point of view, and it had the right effect.

Betty found that each of her children benefited from Smiling Mind, albeit at different times of the day:

> I think I found the best time of day for him was prior to getting started with our schoolwork, my daughter on the other hand, a teenager … struggles with sleep … so I found for her late night for her to listen to it.

Betty noted that both Emilie and John required her encouragement to use the Smiling Mind app. While Betty and her son, John, benefited from this use, John was not motivated to use the app without her:

> If I listen to it before I go to bed, I go to sleep easier … I go through and choose one that I think … that he can just, yeah, focus in on that to get him in a calmer place, so as we go, he'll hopefully use it himself more independently, but he's not that independent with a lot of things at this point.

Betty also mentioned that her daughter, Emilie, was more open to using Smiling Mind because it had no specific association with ASD, thereby removing the sense of stigma associated with formal therapy:

> We're at that weird age where she doesn't want the label … You don't want to hang out with other ASD people, you just want to fit in to society with your peers and go undetected, so this is something she can do, and no one has to know about … so there's, there's no stigma attached to it in that way.

In summary, Betty was enthusiastic about Smiling Mind due to its low sensory impact and lack of stigma. As with Fiona and Leanne, Betty focused primarily on the benefits of the app for her children although acknowledged that Smiling Mind had a calming effect for herself. She identified some difficulty in getting her children to use the app independently.

Barriers to Participation Survey

The majority (85%) of participants who were assessed as being eligible for the RCT declined to participate. Reasons for dropout were not cited. Thirty-three who had registered interest did, however, respond to a follow-up survey. Similar to RCT participants, most identified as female (94%), with a mean age of 42 years. The majority were also caregivers (73%), although autistic adults (6%) also responded to the survey. A significant proportion (21%) did not identify which group they belonged to. ASD severity, whether rated for themselves or for their child, was considered to be mild (18%), moderate (58%), severe (9%) or unknown (15%). A sizeable number (58%) also identified comorbid psychological disorders (e.g., ADHD, sensory processing disorder). Most (60%) had had previous exposure to a form of mindfulness.

Reasons for responding to the initial study invitation (Question 1) centred on a desire to learn self-management skills to better manage their own anxiety (39%) or that of their child's (70%). General interest and curiosity in mindfulness itself was also noted (36%). Few (6%) had prior experience with the Smiling Mind app, with the offer of learning a free app an incentive for some (6.1%). Of those who provided 'Other' text responses (12%), an interest in supporting research into ASD treatment was expressed.

Reasons for not participating in the RCT (Question 2) overwhelmingly included having too many things to think about (51.5%) or insufficient time (30.3%). Some found the study information or the Smiling Mind app itself too complicated (12.1%), while others stated a preference for guided support from a mindfulness teacher (9%). There was also a preference to use the free app without participating (6.1%), while a small proportion (3%) wanted immediate benefits to help their situation. Interestingly, none expressed concerns about sharing their app data or commented on whether mindfulness was a useful skill to learn. Over half (51.5%) who provided additional comments highlighted issues with time (e.g., too busy or forgot about the trial; 35%). Logistical and technical issues with the study were also cited (29%), including difficulty with using the app and confusion or angst with the study processes, such as children not meeting the minimum age eligibility requirements (24%) or being very resistant or too anxious to participate (12%).

Suggestions for promoting participation in future studies (Question 3) included a preference for in-person mindfulness training by a trusted provider, such as an autism or disability service, or participation in a group setting with other families (45.5%). Others desired more information about the Smiling Mind app or the benefits of mindfulness (45%), while 18% preferred financial incentives (e.g., gift vouchers). Text responses (42%), again, highlighted the need for additional time to complete the study in order to accommodate busy schedules (64%) along with improved clarity regarding study eligibility, registration and consent (22%) and a need to include incentives that were appealing to teens with ASD (14%), although no examples of such incentives were provided.

Discussion

This pilot study examined the suitability of the Smiling Mind mindfulness app for autistic individuals and their caregivers. The app's effectiveness in managing self-reported wellbeing was also explored. Our preliminary results are consistent with reliable and positive changes noted among app users more so than among control participants. Interviews with caregivers also highlighted the suitability of Smiling Mind for both themselves and their children, although caregivers noted that their child with ASD had difficulty concentrating during meditations. This, in addition to the follow-up responses provided by those who did not complete the study, suggests that strategies to increase app engagement and user retention are required.

The findings highlight a number of issues for consideration when designing future app evaluation trials with ASD groups. The high trial attrition we encountered is consistent with previous disability research (Ahmed et al., 2020; Bakker et al., 2018; Haas et al., 2016;

Hochheimer et al., 2016). In the present study, lack of time and poor child compliance (i.e., problems coping with wandering or distracted thoughts) made it difficult for participants to complete the minimum number of mindfulness practice sessions—a finding echoed in our recent meta-synthesis of this research (Hartley et al., 2021). Moreover, caregivers reported typically selecting those meditations that helped them in specific and immediate ways rather than following a prescribed order. For example, the Thought Catcher meditation in the Smiling Mind app helped them to focus on calming their children prior to bedtime, indicating the importance of achieving daily practicalities while also benefiting their child (Haas et al., 2016).

In addition to improved retention, improved engagement strategies are needed. One potential solution lies in gamified mindfulness apps, or mindful gaming, whereby simple game mechanics (e.g., different levels that unlock prizes) can help maintain a person's motivation and interest while also developing a meditation habit. Additional strategies targeting autistic individuals might include content that can easily be imitated and repeated by children (e.g., favourite character song or phrase) as well as opportunities for social networking with peers online (Camargo et al., 2019; Martins et al., 2020; Sliwinski et al., 2018).

Notably, proponents of app-based interventions typically highlight efficacy, low cost and availability as key benefits, without evaluation of real-world engagement and attrition (Baumel, Edan, et al., 2019; Baumel, Muench, et al., 2019; Linardon & Fuller-Tyszkiewicz, 2020). The additional constraints of time reported by our sample of families living with ASD often precluded daily mindfulness practice and may compound anxiety for some (Clarke & Draper, 2020; Hartley et al., 2021; Hudson et al., 2018; Masefield et al., 2020; Schnabel et al., 2020; Vasa et al., 2020). Further research is needed to explore how conventional mindfulness practices can be effectively modified to best meet the needs of individuals and families with ASD, particularly given that intermittent practice can still lead to benefits in wellbeing (Clarke & Draper, 2020; Lunsky et al., 2017).

A need for additional information on the benefits of Smiling Mind, and of mindfulness in general, was also indicated, with 45% of those who responded to our follow-up survey desiring this information. A key aspect of traditional MBSR and MBCT is psychoeducation, including discussion of key mindfulness concepts and the goals, objectives and client responsibilities in this program, not only to promote perceived utility but also intention to participate or practice mindfulness skills (Crandall et al., 2019; Kabat-Zinn, 2003; Kabat-Zinn et al., 2017; Singh et al., 2014a). This psychoeducation might also help to correct or modify participants' app usage, with many caregivers in our study commenting that they relied on familiar—rather than effective—usage patterns (i.e., use of the same meditations), a reliance that may cause caregivers to disengage (Martins et al., 2020; Parks et al., 2012).

Limitations

Participant recruitment was a major limitation in this study, with quantitative data lacking sufficient experimental power and only three caregivers participating in follow-up interviews to provide case studies, potentially leading to selection bias. While our recruitment strategy was broad, encompassing all ASD state or territory service providers and Facebook advertising, direct contact with primary care providers (e.g., general practitioners, care managers, support workers)—who are often a first point of contact for many caregivers concerned about research participation (Beadle-Brown, Ryan, et al., 2012)—might have assisted recruitment. Streamlining communication of study information and protocols should also be considered, given the noted complications with signup, the misunderstandings over eligibility requirements and the suggestion that autistic individuals can find aspects of electronic communication confusing (Beadle-Brown, Ryan, et al., 2012; Haas et al., 2016).

Future research might also incorporate the offer of phone or video calls to build trust and reduce anxiety about participation (Beadle-Brown, Ryan, et al., 2012; Haas et al., 2016).

Methods for electronically testing and tracking session fidelity for individual app users could be improved. Recent app studies are beginning to track treatment fidelity using targeted in-app metrics (Flett et al., 2020). As noted in this trial, however, technical difficulties with user login details contributed to incomplete app usage statistics. Data collection pathways therefore need to be verified to ensure data integrity and user privacy; otherwise, the researcher runs the risk of incomplete datasets (Carter et al., 2015; Jokinen et al., 2021). A related issue is how to best monitor fidelity of mindfulness practice through apps. Conventional assessment tools developed to assess the integrity of mindfulness training (e.g., ‘Mindfulness-Based Interventions: Teaching Assessment Criteria’ (Crane, 2018; Crane & Hecht, 2018) will likely require adaptation for this context.

Finally, the post-hoc deviation in our delivery of the Smartphone app, while appropriate in pilot and feasibility trials, impacted on our determination of intervention efficacy (Eysenbach & Consort-Ehealth-Group, 2011). Future comparative effectiveness trials are needed to examine the impact of different time arrangements on mindfulness training, including apps with simplified short-term training (e.g., 5–10 days) or more-standard long-term training (e.g., 8 weeks; Parsons et al. (2017)). While greater time in mindfulness has produced larger effects, there is also evidence that mindfulness can be beneficial even when practised sporadically (Clarke & Draper, 2020; Creswell, 2017; Lunsky et al., 2017).

Conclusions

The present findings suggest that Smiling Mind has potential for autistic individuals and their caregivers. However, lifestyle complexities associated with ASD, including caregivers’ available time, compliance of children and distraction during sessions, need to be considered in order to maintain participants’ engagement and, ultimately, facilitate the development of mindfulness skills. Future research should also focus on methodological concerns, such as verifying the practice of core mindfulness skills and the fidelity of user app data through a combination of self-reported and objective (app) data.

Compliance to Ethical Standards

Research ethics: The authors declare that all research involving human participants was conducted only by the informed consent of participants and complied with the ethics approval given by the University of Adelaide Human Research Ethics Committee.

Acknowledgements: The authors would like to thank Novita (SA), Autism SA, Autism NT, Autism Queensland, ASPECT (NSW), AMAZE (Vic.), Marymead Autism Centre (ACT) and Smiling Mind for their support of this project.

Funding: This work was supported by an Australian Government Research Training Program Scholarship.

Conflict of interest: The authors declare they have no conflict of interest.

Chapter 6: Conclusion

Overview

This thesis has presented a research agenda that aimed to examine the effectiveness of mindfulness programs on mental health outcomes among autistic children and adults and their caregivers, with a particular focus on the application of eHealth MBIs. This research used a mixed-methods approach, incorporating summaries of quantitative and qualitative literature—while also rating research quality. A further aim was to explore participant experiences with MBI and, potentially, identify unique enablers or impediments to mindfulness practice. Using this information, a pilot trial was designed to explore the feasibility and preliminary effects of using a well-established, evidence-based mindfulness app to manage mental health symptoms, and promote wellbeing, among autistic individuals and their families or caregivers.

Chapters 1 and 2 provided key background information for the research agenda. A brief history of ASD was outlined, including its initial description, the evolution of diagnostic criteria in the DSM, ASD causes and distribution in the population, and current evidence-based psychological treatments. Mindfulness-based techniques were outlined and described as uniquely suited to treating specific ASD presentations. The concept of eHealth was then introduced, followed by an examination of its advantages and pitfalls when used for mental health applications. The adaptation of mindfulness to an eHealth format to leverage service accessibility and provide features that may be of specific benefit to ASD populations was then discussed.

Study 1, presented in Chapter 3, quantitatively summarised and critically appraised the methodological quality of existing research examining the effects of MBIs on psychological outcomes for autistic children and adults and their caregivers. Positive small to large effects were reported by all three groups. Notably, autistic children experienced the least benefit. These findings need to be considered in the context of methodological difficulties, particularly unvalidated modifications to manualised MBSR and MBCT protocols, the reliance on quasi-experimental and uncontrolled designs, and limited details about ASD symptom severity and comorbidity— all of which restricted the extent to which the findings can be generalised to the wider, heterogenous ASD population.

Chapter 4 presented Study 2, a meta-synthesis that explored the experiences and perceptions of mindfulness training among autistic children and adults and their caregivers. Overall, participants reported improved self-awareness and self-regulation as key benefits. The group-based setting was seen to have particular benefits, by providing a supportive environment which helped to normalise participants' experience whilst also acting as a reminder for ongoing mindfulness home practice. However, length of home practice required by the mindfulness interventions was cited as a key barrier, especially for time-poor caregivers. Studies were, however, characterised by variability in their mindfulness delivery and practice, sample bias towards female caregivers and males with ASD, and little or no discussion of negligible or negative impacts of mindfulness.

Chapter 5 presented the complete dataset for the third and final study, the published version of which is provided in Appendix A. This original study evaluated the use of the Smiling Mind mindfulness app for autistic children and adults and caregivers. Intervention participants accessed this app over a period of 1 to 4 weeks and were compared to an attention control group of peers who engaged in 'quiet time'. Although problems with recruitment limited between-group analyses, reliable change indices identified large and individual pre–post changes across psychological outcomes among the Smiling Mind group. Obstacles to app use were also collected as part of this study. For autistic individuals these barriers included boredom and distraction. For caregivers, as in the meta-synthesis (Study 2), lack of time was a key barrier to regular app use. Follow up interviews conducted with caregivers did, however, highlight the importance that they placed on the app to assist with specific behavioural goals for their child (e.g., improving sleep). The findings of this pilot trial highlight the need for further research into the application and effectiveness of smartphone apps that are based on evidence-based principles for ASD populations. The findings also highlight a need to factor improved recruitment practices and participant engagement into future research to ensure robust data on mindfulness delivered via eHealth.

The present chapter discusses the implications of the combined findings of this research. Future research avenues are discussed, including the importance of considering the positive and (if any) adverse effects of mindfulness training and practice for individuals and their families. Further opportunities for eHealth to increase access to psychological treatments for this population are then explored.

Effect of MBIs on the Wellbeing and Experiences of Those Affected by ASD

The aim of the research agenda was to summarise the available quantitative and qualitative literature on MBIs for autistic children and adults and their caregivers (Studies 1 and 2). This included a quality review of relevant literature via the use of published quality indicators (i.e., CASP, 2018; Reichow et al. (2008); (Hong et al., 2019)), to quantify the effect of MBIs on participants' wellbeing and examine their experiences, including what helped or restricted the development of mindfulness skills.

Study 1 identified both short- and longer-term improvements across mental health outcomes with MBI—more so for adults and caregivers than for children. Autistic children found home practice, when conducted alone, difficult. Engagement with peers or caregivers helped motivate them to complete mindfulness homework tasks. These children also required at least some emotional co-regulation with their caregiver (Salem-Guirgis et al., 2019; Drusedau et al., 2021; Singh et al., 2014). Research indicates how important mindful parenting, or parenting practiced with awareness and compassion, is for children. Mindful parenting has been shown to significantly reduce caregiver stress and child behavioural problems (Neece, 2014). Study1 and 2 also found MBIs coupled with behavioural support training for caregivers produced gains to caregiver mental health, alongside reductions in aggressive and disruptive behaviours from autistic children (Singh et al., 2007; Singh et al., 2014; Singh et al., 2019). These findings are perhaps indicative of how impactful caregivers' self-regulation and parenting skill are to a child's emotional state. Children's outcomes are more likely to show variability, in part due to their dependence on caregivers' emotional wellbeing but also differences in who is assessing the child's characteristics (Hwang & Kearney, 2015; Meppelink et al., 2016; Neece, 2014; Ridderinkhof et al., 2018a) The small to large effect sizes identified in Study 1 compare favourably with outcomes from previous systematic reviews of MBIs, not only for autistic individuals and their caregivers (Renee L. Cachia et al., 2016; R. L. Cachia et al., 2016; Donnchadha, 2018b; Hourston & Atchley, 2017) but also for clinical populations (Blanck et al., 2018; Chu et al., 2018; Goldberg et al., 2018; Perestelo-Perez et al., 2017; Wang et al., 2018).

Study 2 builds on these findings and indicated that caregivers, autistic children and adults tended to find MBIs beneficial for both wellbeing and mental health; a finding also consistent with non-ASD populations (Cairns & Murray, 2015; Wyatt et al., 2014). Improvements in awareness, attention and emotion regulation were identified as particularly important outcomes in Study 2. The resulting improvements in caregivers' wellbeing also had flow-on benefits for the family, including reduced aggression and more compliance from autistic children. Group formats for mindfulness delivery were seen to be beneficial, by encouraging mindfulness skill development through social connection. Group MBI also had the added benefit of allowing participants to share their experiences while gaining understanding and acceptance from each other. This benefit did, however, have repercussions, with many individuals struggling to continue practice once the group connection ceased.

Indeed, recent studies undertaken with other patient populations (i.e., those with a primary mental health diagnosis, such as major depression or an anxiety disorder) indicate that ongoing therapist guidance and feedback is not only helpful but necessary in maintaining positive outcomes (Sommers-Spijkerman et al., 2021).

Results of Studies 1 and 2 confirm a generally positive trend seen when MBI is targeted to autistic individuals. That is, all age groups reported positive change in wellbeing and mental health immediately post-intervention and at follow-up. Similar findings have been reported in mental health research with adults (Blanck et al., 2018; Chu et al., 2018; Goldberg et al., 2018; Perestelo-Perez et al., 2017; Wang et al., 2018). The focus on developing acceptance is critical to improving self-esteem for individuals on the autism spectrum, by helping to relieve stress induced by social and behavioural difficulties (Francis et al., 2021). Developing self-acceptance is especially important for those who are diagnosed with ASD later in life, particularly females who spend significant time and effort trying to ‘fit in’ socially, often unsuccessfully, leading to significant stress and poor self-esteem (Leedham et al., 2020; Sim et al., 2018). Studies 1 and 2 further suggest that the flexibility of MBIs may accommodate a diverse range of ages and maladaptive behaviours across the autism spectrum. As already noted in Chapter 1, the ‘gold standard’ mental health therapy, CBT, has shown less consistent results across age groups affected by ASD (Sharma et al., 2021). This is because effective CBT relies heavily on cognitive skills that are either absent or inhibited in autistic individuals. Consequently CBT goals require significant adaptation to an individual’s cognitive profile in order to attain maximum benefit (Behzadpoor & Pouretemad, 2021).

The additional tensions faced by individuals and families with ASD when trying to adapt their lifestyle around the specific challenges associated with ASD create unique complications for psychotherapy. Importantly, the research in this thesis highlights that MBIs can provide a holistic approach to address the difficulties posed by an ASD diagnosis. As with many neurodevelopmental disorders, a diagnosis of ASD affects the whole family unit, thus requiring a high level of skill and responsiveness by caregivers to manage (Koukouriki et al., 2021; Moffitt et al., 2021). Further, the level of psychological distress experienced by autistic individuals and their caregivers when compared with those with other neurodevelopmental disorders (e.g., Down syndrome, cerebral palsy, intellectual disability; Hayes & Watson, 2013) is higher. Indeed, the stigma around ASD often leads to negative self-evaluations and self-worth, affecting the family's social activities and relationships (Chan & Leung, 2021; Hayes & Watson, 2013). In addition to psychological distress a range of additional impacts on caregivers have been identified such as reduced cognitive capacity, sleep difficulties, poor physical health, and poor memory performance - all of which are likely to impact not only on their parenting but their ability to engage in psychotherapy (Lovell et al., 2021; Lovell et al., 2019; Schnabel et al., 2020).

The combination of studies presented in the current research program indicates that MBIs can address many of the challenges associated with ASD for autistic individuals, as well as their primary caregivers. First, MBIs provide a framework of support and guidance to help participants learn about themselves and their behaviours. With the support of the group or a dedicated teacher, participants can normalise their experience and find peer support by sharing their experiences, thus helping minimise any shame they may experience associated with ASD behaviours and challenge any internalised stigma they experience (Ridderinkhof et al., 2019). While this support is helpful in a therapeutic context, it does raise questions regarding the important role of human interaction on mindfulness exercises. Human interaction, through either group or individually guided contexts, is a key component of MBI treatment (Kabat-Zinn et al., 2017). Group participants in the individual studies examined in the meta-analysis (Study 1) and meta-synthesis (Study 2) reported that the peer interaction experienced in group settings was just as beneficial as the mindfulness exercises themselves, if not more so (Kennedy, 2018; Quirk, 2018; Salem-Guirgis et al., 2019; Ridderinkof et al., 2019). That said, individually guided participants in Study 2 did report positive impacts, perhaps indicating that only some human interaction is necessary (Hartley et al., 2021; Singh et al., 2007; Singh et al., 2014b). Similar findings have been reported by Sommers-Spijkerman et al., (2021), with online MBIs that involve limited clinician interaction, either in person or electronically, having superior effects over unguided treatment.

To date, however, it remains unclear whether group interaction provides a benefit independently of mindfulness practice or whether it facilitates individuals' mindfulness participation. For example, caregivers of autistic individuals may find group MBIs most beneficial, given that group sharing and support are important for their wellbeing (Kennedy, 2018; Quirk, 2018; Salem-Guirgis et al., 2019; Ridderinkof et al., 2019). Conversely, autistic individuals may find group situations confronting, hence why MBI delivered on an individual basis has shown promising results (Conner & White, 2018b). While a level of human interaction appears important for best-case outcomes with MBIs, issues of training fidelity and lack of RCTs continue to dominate the discussion with respect to research quality (Goldberg, Riordan, et al., 2022; Goldberg et al., 2017). Nonetheless, future MBI research should account for the influences of human interactions in their findings by detailing the components most beneficial in MBI training, then examining how these components can be adapted to suit the specific needs of members of the ASD community.

A second issue relating to MBI that participants in this research program identified was the flexibility of this approach. Most engaged in meditation and learnt skills when necessary, rather than daily – as required by conventional MBI training (Kabat-Zinn, 2003; Kabat-Zinn et al., 2017). Indeed, for the participants across Studies 1 to 3, consistent practice could have been detrimental given the additional pressure of completing another activity, or unrealistic expectations regarding the improvement MBIs may provide on mental health

(Britton, 2019; Clarke & Draper, 2020). The results of caregiver and child studies also show that responding to children's behaviours with mindful awareness can be more effective in reducing dysregulated behaviours than behavioural interventions - suggesting that emotional co-regulation may be more important than mindfulness skill development for autistic children (Singh et al., 2007; Singh et al., 2014b). Mindful parenting approaches are achieved by training caregivers to provide mindfulness practices and principles to their autistic children, whilst also allowing them to respond to their child flexibly, compassionately, and in the moment. In this way, mindfulness practices can help caregivers cater to their child's individual needs, further reducing stress for themselves and children, by removing enforcement with inflexible behaviour plans (Singh et al., 2007; Singh et al., 2014b). In Study 2, caregivers also engaged in their own mindful practice when and where they could, depending on circumstances at the time – implying that use of MBIs can be context dependent. That is, individuals find benefit with MBI uniquely suited to their personal circumstances and psychological profile (Bitsika & Sharpley, 2021; Sahdra et al., 2017). This finding is encouraging, particularly as the opportunity to customise treatment has been shown to be important to self-efficacy which, in turn, promotes individuals' wellbeing (Beadle-Brown, Hutchinson, et al., 2012).

These reflections on the current research program highlight a broader trend in the field of psychology, which has seen a movement from protocol-based therapies to process-based approaches. Psychological therapy has typically adopted a standardised approach to treating mental disorders, by assuming that working with underlying thoughts and feelings is secondary to eliminating the symptoms through behaviourist learning principles (Hayes & Hofmann, 2021). For example, MBSR and MBCT approaches set uniform minimum time limits for meditation for all participants—both in session and as homework—because more time spent in home practice is inferred to lead to greater benefit (Creswell, 2017). In contrast, process-based approaches focus on developing individuals' cognitive flexibility, rather than administering standardised, identical interventions across individuals with different therapeutic needs (Hayes & Hofmann, 2021). Research is uncovering significant limitations with the uniform approach. For example, mindfulness practice appears to benefit only around 25% of a trial population (Parsons et al., 2017). Longer practice times have been linked to negative outcomes (e.g., emotional dissociation, sleep inhibition), whereas shorter infrequent practice is showing benefit (Clarke & Draper, 2020; Goldberg et al., 2020; Parsons et al., 2017). The suggestion is that the quality of mindfulness practice is more important than quantity Higher levels of participant engagement, homework frequency and direct face-to-face contact with a trained therapist have also been shown to positively impact treatment outcomes of MBIs, although the magnitude of this effect appears to vary depending on participants' conscientiousness and motivation to change (Creswell, 2017; Fox et al., 2014; Goldberg et al., 2017; Parsons et al., 2017; Strohmaier, 2020). Such insights are encouraging because they suggest that the effectiveness and practicality of MBIs can be further enhanced for individuals affected by ASD when tailored to their specific needs (Britton, 2019).

This additional requirement to examine individual differences and responses to MBI, however, creates some difficulties for researchers, who already face challenges developing robust methodologies for evaluating psychotherapies without degrading study quality. For example, a key mindfulness process is that of bringing one's attention to the present moment, often by focusing on specific body sensations (Lindsay & Creswell, 2017). However, sensory sensitivities are a common comorbid feature of ASD. That is, certain experiences, such as odours or loud noises, may cause discomfort or sometimes panic (Robertson & Simmons, 2018). In the context of ASD, the recording of individuals' specific responses to MBI material is required to reduce aversive sensations and increase positive sensations for beneficial outcomes. Indeed, studies examining meditation-related adverse events have recommended screening participant sensitivities beforehand to maximise the benefits of MBIs, while minimising risks (Goldberg, Lam, et al., 2022). Another example is the changes in sleep propensity noted in mindfulness participants, with meditation practice promoting or inhibiting sleep, depending on practice amount (Britton et al., 2010; Britton et al., 2014). For those with ASD, where sleep difficulties are common, using mindfulness to aid sleep onset will need to be carefully monitored to ensure mindfulness activity is beneficial. Consideration of attentional biases that autistic individuals tend to display towards positive and negative stimuli - biases which may underlie their anxiety symptoms - is also important (Bergman et al., 2020; Milosavljevic et al., 2017). For example, those with a predisposition toward negative stimuli (e.g., fear of animals; Barry et al., 2015), may require a change in administering MBIs to avoid becoming overwhelmed. In this case, therapy may need to focus on bias modification or distraction by focusing the client on non-threatening aspects of the feared object or situation or engaging them in other tasks while the stimulus is present (Barry et al., 2015; Britton, 2019).

These examples indicate that targeted therapeutic goals are important when evaluating MBI and that recording a comprehensive set of variables that are likely to affect treatment outcomes is necessary to facilitate individualised therapy safely and effectively. Researchers are now adopting the use of additional statistics, such as the reliable change indices, in addition to group averages and effect sizes (as highlighted in Study 3), to describe clinical changes in wellbeing whilst also accounting for individual differences (Aizik-Reebs et al., 2021; Baer et al., 2019; Britton, 2019). Further work to develop tailored MBIs is however required to focus research on issues specific to their application for autistic individuals and their caregivers, as has been done with other focused MBIs such as for chronic pain, drug addiction and relationship enhancement (Creswell, 2017; Dimidjian & Segal, 2015).

Mixed Methods Improve Validity of MBI and ASD Research

This research program deliberately made use of mixed methods. Although current intervention research continues to favour quantitative approaches, the use of both quantitative and qualitative research methods in this thesis highlights how critical the use of diverse methods is to improve validity in both mindfulness and ASD-based research fields. This is due to the different methodological strengths that quantitative and qualitative approaches bring, as well as their differing but complementary ability to capture a breadth of participant data and human experiences (McConachie, Livingstone, et al., 2018; Stefan & David, 2020).

This flexible approach is proving crucial in a variety of ways, not least of which includes the validation of new mindfulness constructs. Indeed, current measures that are used to evaluate adverse events during mindfulness training, such as the MAAS (Brown & Ryan, 2003), unintendedly skew towards positive outcomes (Britton, 2019; Britton et al., 2021; Goldberg et al., 2016). Further benefits are seen when developing measures of wellbeing and quality of life for individuals affected by ASD, such as the autism-specific quality of life instrument (ASQoL; McConachie, Mason, et al., 2018), which was developed to supplement the well-established WHOQoL-BREF. Whereas conventional research characterises neurotypical constructs, such as minimal social contact and monotonous or repetitive work tasks, as indicators of poorer wellbeing, the ASQoL characterises wellbeing as a neurodiverse construct, whereby undertaking repetitive tasks and minimal social interaction are seen as a benefit because they fit typical ASD behaviours (Ayres et al., 2018; Sáez-Suanes & Álvarez-Couto, 2021). Measures for autistic children and adults can also be supplemented by caregiver-report which, while not replacing self-reported data, can provide an alternative perspective on QoL (Knuppel, Telleus, et al., 2018). Notably, ASD assessment tools developed without mixed methods have often focused on quantifying internalising and externalising behaviours (e.g., anxiety, depression, emotional dysregulation), thus failing to incorporate individuals’ strengths into the assessment processes. As a result, individuals and caregivers may develop negative and pathologising self-evaluations from their assessment experiences (McConachie et al., 2015). Importantly, any research concerning ASD – whether quantitative, qualitative or mixed methods - requires ongoing consultation and collaboration with the ASD community to validate tools and measures that capture all aspects of their experiences (McConachie, Mason, et al., 2018).

This research program also identified qualitative methods as essential for examining the long-term outcomes for participants, including delineating any experiences associated with MBI training and that may have been discomforting or genuinely adverse (Baer et al., 2019; Coronado-Montoya et al., 2016; Fish et al., 2016; Goldberg, Lam, et al., 2022). The use of qualitative methods in this thesis allowed for exploration of participants’ experiences using the app (Study 3), how they and their children responded to using app-based mindfulness, and the difference in responses depending on the age, gender, or ASD severity. For example, noting that autistic children preferred to repeat familiar meditations, that meditations were chosen based more on practicalities for children (e.g., improving sleep onset) than engaging in mindful practice, or that caregivers had little time to devote to their own practice, provided greater understanding of the perception of eHealth MBIs in a real world context. These insights facilitate understanding of how intervention practices can be adjusted to engage participants more fully when contributing to eHealth MBI studies; nuances that would be missed in solely quantitative approaches.

Guidelines for eHealth MBI research clearly identify mixed-methods research as critical for evaluating participant outcomes because this approach provides an excellent mechanism to improve research designs through detailed participant feedback (Fish et al., 2016). This is especially true due to more recent investigations identifying a range of negative outcomes from MBIs across meditation traditions, and the realisation that accounting for individual experiences is necessary due to variation in outcomes indicating benefit from mindfulness likely exists on a spectrum (Britton, 2019; Lindahl et al., 2017). This is also true of eHealth where mixed-methods allows exploration of experiences of both clinician and participant, resulting in improvements to both (McLean et al., 2021). It follows that a mixed-methods approach should be the default study design when investigating the impact of a psychotherapy, such as mindfulness, on autistic individuals.

eHealth MBI Research Advantages and Opportunities

Research into MBIs has had considerable difficulty removing the influence of human-interaction effects from the research outcomes, making it challenging to determine the key components of an effective intervention (Goldberg et al., 2017; Maxwell et al., 2015). One methodological benefit in using an eHealth format for MBI, as done in Study 3, is the ability to maintain both the quality and integrity of pre-recorded teaching materials, thereby preventing variability in mindfulness teacher training, competence or interaction with participants—key criticisms of current MBI research (Goldberg et al., 2017). Use of eHealth can, therefore, help researchers isolate and measure interaction effects. For example, it is possible to separate the effects of human-guided MBIs delivered via eHealth ($g = 0.42$) compared to unguided approaches ($g = 0.21$); an outcome not achievable with conventional in-person MBI (Sommers-Spijkerman et al., 2021). If done carefully, eHealth MBIs could account for group interaction effects, thus improving study quality. A further advantage of eHealth is that is can be used to track the treatment fidelity of participants' 'homework' as sessions can be verified by collection of app metadata (Sommers-Spijkerman et al., 2021). That said, Study 3 highlighted difficulties with accessing such data. Confounds with eHealth applications also need to be considered. Indeed, caregivers in Study 3 reported that allocating 10 minutes a day to themselves to meditate was a rare luxury. The simple act of taking time for one's self-care can, itself, have a positive effect on mood. Future eHealth studies could potentially look at how variation in the application of a MBI affects individual outcomes, such as perceived stress, social participation, level of self-determination and independence – variables associated with improved social and behavioural outcomes in autistic individuals as well as reduced caregiver stress (Beadle-Brown, Hutchinson, et al., 2012).

Although we noted participants non-adherence to the study protocol in Study 3, previous research has shown that long term engagement with eHealth apps remains low among general and clinical populations (Baumel, Muench, et al., 2019; Cavanagh et al., 2013; Mani et al., 2015). Research on improving engagement and retention with interventions through eHealth is being examined through gamification of apps, user-interface design, and improved social networking abilities with specific attention focused on individuals, particularly autistic children (Camargo et al., 2019; Constain M et al., 2019; van Schalkwyk et al., 2017). There is evidence that autistic children have specific media preferences and habits (e.g., repeatedly viewing the same video, imitation of characters speech); aspects which may be used to facilitate educational or regulation strategies (Martins et al., 2020; Salem-Guirgis et al., 2019). In addition, the use of social media by adolescents with ASD has been found to facilitate higher friendship quality, suggesting that the incorporation of social media in eHealth apps may help to promote intervention adherence (van Schalkwyk et al., 2017). Gamification and engaging interface designs within eHealth interventions have also been associated with improved adherence and learning outcomes in primary health care (Bindoff et al., 2016; Birk & Mandryk, 2019; LeRouge et al., 2016; Ryan et al., 2017). Preliminary findings even suggest that mindful gaming, where specific elements of games that engage mindful awareness are emphasised, can promote adherence to mindful practice, and overcome distraction, discomfort, and boredom (Sliwinski et al., 2015, 2017, 2018). Use of these elements in ASD-targeted eHealth will be critical to improving retention rates in research and allied health settings.

eHealth in ASD Mental Health Service Delivery

The present research program extended the eHealth literature for ASD by piloting an eHealth MBI, the Smiling Mind app (Study 3). Using a mixed-methods approach, app use was examined at over the short-term (i.e., 1 week to 5 weeks). The purpose, here, was to examine pre-post changes in wellbeing and mental health, not only for the larger group but also for individuals. Despite widespread interest from community ASD groups, the study ultimately lacked sufficient participants to examine group differences. Although there was more-positive change in RCI values in the Smiling Mind group, the results were not robust enough to indicate an effect (whether positive or negative) from app use. Importantly, caregiver interviews provided insight into how Smiling Mind was used and perceived by these families. Both individuals and caregivers identified benefits, particularly in helping both autistic children and adults to relax before sleep. Caregivers also found the use of Smiling Mind helpful in calming themselves. However, unlike other qualitative studies (e.g., Kennedy, 2018, Quirk, 2018), caregivers did not identify benefits such as increased self-awareness or improved self-regulation, possibly due to allocating less time to the use of Smiling Mind or due to the less formal format with briefer sessions. While tracking users' activity with the app was trialled to determine participant fidelity and the mindfulness activity that users engaged with most, accurate data analytics on users' app usage were not made available to the student researcher. Future research projects must verify user data acquisition, storage, and retrieval pathways, accurately tracing them through the eHealth system via the use of 'dummy data', thus ensuring participant data is not mishandled or made irretrievable by the system. Finally, when surveying users who expressed initial interest but ultimately did not participate in the pilot, respondents indicated their desire to deal with uncomfortable feelings such as anxiety, for themselves or their child, as their main interest. However, caregivers' high stress levels and lack of time prevented participation. These findings are consistent with participant reports identified from the meta-synthesis in Study 2.

The most consequential learning from Study 3 was that, despite the high level of interest and enthusiasm initially expressed by research partners for the project, it did not translate into participant enrolments, nor did the majority recruited follow the mindfulness meditations prescribed, reflective of the unique impediments of ASD research (Beadle-Brown, Ryan, et al., 2012). While a comparative strength of the project was the range of disability service providers and autistic individuals engaged nation-wide, primarily through online or social media channels, this did not translate into enrolled participants. This result is a stark contrast to other studies that have successfully recruited participants through social media (Ahmed et al., 2020; Sanchez et al., 2020). Some of the reluctance to participate may be explained by the significant manual processes involved in enrolment (e.g., lengthy participant information sheets, manual signing of formal consent forms) which, although were necessary ethical safeguards, may also hinder recruitment due to the perceived complexity (Beadle-Brown, Ryan, et al., 2012). Additionally, the small financial incentive offered to encourage enrolment as well as the convenience of the eHealth intervention were not sufficiently motivating for participants to enrol (Haas et al., 2016; Hood et al., 2022). Although caregivers reported a particular interest in the project, many also felt unable or unwilling to commit to the research, even with the project's focus on flexibility to accommodate their lifestyle. This amotivation was reflected in participant survey responses, where a perceived lack of time and 'being busy' were identified as major hurdles rendering the intervention infeasible in the eyes of participants regardless of how effective it may have been (Dimidjian & Segal, 2015). Regardless, using Smiling Mind in an eHealth format did provide an opportunity to evaluate an app that was familiar to many, and allowed participants autonomy in how they chose to interact with the app. Increasing participant autonomy with interventions is known to have a positive influence over study participation and engagement (Beadle-Brown, Hutchinson, et al., 2012). For ASD populations, recruitment of participants through dedicated clinics or disability agencies as their starting point showing larger study samples (Harkins et al., 2010; Rayan & Ahmad, 2016; Ridderinkhof et al., 2018b). Unfortunately, this approach was not feasible within the timeframe of the current research program. Careful planning of time and resources will be required in future studies to enable collaboration with clinics and service providers allowing for collection of larger participant samples. This may be particularly beneficial as research indicates autistic individuals are more likely to participate in research which is inclusive of the broader autistic community from the study planning stage onwards, allowing them to participate and discuss the findings with the researchers and other participants (Haas et al., 2016). Furthermore, engaging with clinicians who are familiar with the need of autistic individuals and can be sensitive to their specific concerns, can help to motivate and facilitate collaborative autism research (Haas et al., 2016).

That participants did not follow the mindfulness meditation playlist outlined in the study materials is also intriguing. Rather than automatically and sequentially moving through the meditations in the app, most chose to repeat the meditations that tended to align with their specific needs, such as relaxation or unwinding before sleep, and did not engage in mindfulness specifically. One possibility is that the study materials required too much time and effort to consult when participants wanted immediate, short-term relief from their symptoms—a plausible explanation given that those interviewed were unable to remember details of the specific meditation exercises that they had accessed. A second possibility is that participants misunderstood the concept of mindfulness, preferring instead to focus on meditation activities that seemed more likely to solve their problem directly rather than on developing mindfulness skills (Hartley et al., 2021). Indeed, many in Study 3 reported a familiarity with mindfulness, yet only some were able to describe mindfulness concepts, such as self-awareness and self-control. Those with little familiarity with mindfulness may prefer behavioural interventions (e.g., using positive or negative reinforcement strategies to reduce targeted child behaviours), which they may consider to be more practical than mindfulness techniques (Ferraioli & Harris, 2013; Singh et al., 2007; Singh et al., 2014b).

The behaviour of participants in Study 3 may also be explained by the picture emerging from current MBI literature, with social aspects of these interventions considered to be critical to individual outcomes (Hanley et al., 2022). Although conventional MBIs have always incorporated a social component, online MBIs show greater effectiveness and lower attrition rates when a clinician is available to provide guidance and regular feedback on their progress (Sommers-Spijkerman et al., 2021; Torous et al., 2020). It may be that the opportunity to engage online with peers while undertaking training (e.g., in a discussion forum or chat room) may be warranted; a method which has been successfully used to support caregivers undertaking individual MBI training and their autistic children (Hwang & Kearney, 2015).

Conclusion

Overall, this thesis has added valuable knowledge to our understanding of the use of MBIs with ASD populations and their caregivers. Specifically, this thesis has highlighted the aspects of MBI's which can potentially help this cohort to develop skills that promote their sense of wellbeing and quality of life but also in providing encouragement and normalisation of their experience through social interaction. The present thesis has also shown the potential of eHealth MBIs to further support autistic children and adults and their caregivers with flexible acceptance-based approaches. Further research can extend these findings with respect to delineating the role of human interaction during the intervention and which eHealth platform (mobile app, website, etc.) facilitates the best outcomes.

This chapter has outlined the significance of this research program in contributing to our understanding of ASD and the suitability of MBIs, particularly when delivered via eHealth. Evidence that MBIs can improve the wellbeing of autistic individuals across the lifespan as well as the mental health of caregivers, continues to grow, as evident by Studies 1 and 2. The pilot trial outlined in Study 3 adds to this evidence base by examining individuals' experiences with MBIs using a mixed-methods approach. The use of this approach within an eHealth framework also provides a template for future studies to refine. Future research programs will, however, need to focus on improving participant recruitment through deeper researcher and clinician involvement to support participants through the intervention. Improved participation can, in turn, help reduce uncertainty regarding study outcomes and support comprehensive analysis of individuals' unique emotional and behavioural traits, allowing modification of eHealth MBIs and, ultimately, help to maximise mental health outcomes.

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Appendices

Appendix A: Study 3 – Challenges Encountered With a Mindfulness App: Lessons Learnt From a Pilot Randomised Trial Involving Caregivers and Individuals With Autism

Statement of Authorship

Title of Paper	Challenges Encountered With a Mindfulness App: Lessons Learnt From a Pilot Randomised Trial Involving Caregivers and Individuals With Autism
Publication Status	✓ Published ☐ Accepted for Publication ☐ Submitted for Publication ☐ Unpublished and unsubmitted work written in manuscript style
Publication Details	Hartley, M., Dorstyn, D., & Due, C. (2022). Challenges encountered with a mindfulness app: Lessons learnt from a pilot randomized trial involving caregivers and individuals with autism. Research in Autism Spectrum Disorders, 96. https://doi.org/10.1016/j.rasd.2022.101991

Principal Author

Name of Principal Author (Candidate)	Matthew Hartley		
Contribution to the Paper	Conceptualisation of study, development of study method, recruitment of participants, collected and analysed data, completed data analysis and prepared results. Wrote paper and prepared manuscript for publication.		
Overall percentage (%)	80		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the		
Signature		Date	31st Jan 2023

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate in include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Diana Dorstyn		
Contribution to the Paper	Assessed with conceptualisation of study, reviewed short-listed articles, reviewed raw data and assisted with data analysis and results. Contributed to editing draft manuscript for publication.		
Signature		Date	31st Jan 2023

Name of Co-Author	Clemence Due		
Contribution to the Paper	Assessed with conceptualisation of study, reviewed raw data and assisted with data analysis and results,. Contributed to editing draft manuscript for publication.		
Signature		Date	31st Jan 2023

Please cut and paste additional co-author panels here as required.

Challenges Encountered With a Mindfulness App: Lessons Learnt From a Pilot Randomised Trial Involving Caregivers and Individuals With Autism

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Abstract

Background: We undertook a trial to examine the feasibility of a self-guided mindfulness app, Smiling Mind, for children and adults with autism spectrum disorder (ASD) and their parents. The trial encountered problems in recruitment, enrolment, and retention, which are described here.

Methods: Of 169 eligible participants, only 22 consented and were randomly assigned to Smiling Mind (n = 12) or an attention-control condition (n = 10). A further six participants withdrew during the study. Barriers to trial participation were subsequently explored through semistructured interviews to form case studies and a follow-up survey.

Results: Interview and survey data highlighted parents' competing time commitments as a key barrier to participation. For autistic children and adults, distraction and boredom were major challenges to engagement.

Conclusions: A number of modifiable variables in our recruitment procedures and intervention design ultimately resulted in a sample size that was too small to draw any firm conclusions. Future ASD research can maximise sampling by broadening recruitment strategies and partnering with community services and schools. Engagement in mindfulness could also be improved by incorporating regular communication to motivate time-poor participants.

Keywords: smartphone, parents, mindfulness, children, autism

Introduction

Mental health smartphone applications or ‘apps’ may offer benefit to individuals and families living with autism spectrum disorder (ASD): a group that experience problems with treatment accessibility alongside increased rates of mental health disorders (Hudson et al., 2018; Masefield et al., 2020; Mingins et al., 2021; Schnabel et al., 2020; Vasa et al., 2020). In addition to anonymity, mental health apps encourage self-paced treatment (Cowpertwait & Clarke, 2013; Kuijpers et al., 2013). Secular mindfulness, developed on evidence-based psychological principles and used to focus and regulate one’s thoughts and feelings, is well suited to an app format with user satisfaction and acceptability demonstrated among the general population (Gál et al., 2021; Sommers-Spijkerman et al., 2021). However, evaluations of real-world psychological app trials have largely ignored the specific requirements of individuals with ASD, with less than 5% of ‘autism’ apps having empirical evidence supporting their use (Baumel, Muench, et al., 2019; Kim et al., 2017; Linardon & Fuller-Tyszkiewicz, 2020).

We intended to address this research gap by evaluating a commercially available mindfulness app, Smiling Mind, for autistic children and adults and their primary caregivers. We were particularly interested in whether this group would find a mindfulness app helpful. However, we encountered significant recruitment and engagement difficulties, which limited any analysis of the app’s effectiveness. In this brief report, we describe lessons learnt from follow-up interviews and surveys with eligible participants, which may help to improve the likelihood of success of future intervention studies with this cohort.

Methods

Registration and Design

Following ethics approval (University of Adelaide Human Research Ethics Committee: H-2019-036, H-2019-95) and protocol registration (ACTRN12619000584134), consenting participants were randomly assigned (1:1) to the Smiling Mind app or an attention control using a computer-generated program (www.randomizer.org).

Sample

Children (11–17 years) and adults (18+ years) with ASD and their parents, grandparents, or foster parents were targeted. Fluency in written and spoken English and access to a smartphone device with internet connectivity were additional requirements. Those who disclosed untreated mental illness on enrolment were excluded and referred to their medical practitioner.

Intervention

The Smiling Mind app (www.smilingmind.com.au) follows a self-guided MBSR framework, offering formal (e.g., body scan, mindful breathing) and informal (e.g., eating, sleep, gratitude and relationships) meditation exercises, which have been highly rated for ease of use across settings and age groups (Mani et al., 2015; Weekly et al., 2018). Participants were provided with written and video instructions on app set-up, with a requirement to practise core mindfulness concepts via the app’s Mindfulness Foundations program (e.g., body scan, mindful breathing, noticing thoughts) for a minimum of 10 minutes per day, for 3 days per week over 5 weeks. After 4 months of recruitment, this requirement was reduced to 10 minutes per day over 1 week. While appropriate for a pilot feasibility trial and consistent with other brief app interventions (Clarke & Draper, 2020), this change impeded any evaluation of intervention efficacy (Eysenbach & Consort-Ehealth-Group, 2011).

Attention Control

The control group was instructed to engage in daily quiet activity on their smartphone in a manner of their choosing (e.g., reading news, social media, listening to music) for 10 minutes per day for a period of 1 or 5 weeks. This attention-control condition resembled real-world smartphone usage (Baumel, Muench, et al., 2019)

Measurements

Participants completed a baseline survey online, detailing background information (i.e., sociodemographics, ASD diagnosis, mental health history) and validated measures of psychological wellbeing. Intervention participants additionally rated their satisfaction with Smiling Mind (1 = *not at all helpful* to 5 = *extremely helpful*) and estimated the weekly frequency with which they accessed the app. These data were supplemented with Smiling Mind app data (i.e., time and date that specific meditations were used and duration of use).

Recruitment

Thirteen community autism support providers across Australia were identified via the Google search engine, Facebook and Autism Alliance Australia, and emailed an invitation to participate. Of these, nine agreed to disseminate the study material. Enrolment was slower than expected, despite offering a small financial incentive (A$20 shopping voucher), with six participants in the first 3 months, followed by 10 over the next 9 months (March 2019 to March 2020). A follow-up survey was administered to those who had initially expressed an interest in the study, but later withdrew, focusing on individuals' reasons for requesting study information, obstacles to participation, and suggestions to maximise engagement in future research. Survey participants entered a draw to receive one of five A$20 gift cards.

Analyses

The resulting small sample size and diffuse intervention methods (1 week vs. 5 weeks) limited analyses of our pre–post outcome data.[1] Instead, we focused on patterns of app use, interviews (Appendix Q) and survey data. Interview transcripts were analysed with NVivo 12 software (Trigueros-Cervantes et al., 2018) and provided brief case studies, explicating caregivers' unique experiences of mindfulness for themselves or for their child (Flyvbjerg, 2006). Survey data were summarised with descriptive statistics, alongside content analysis of free text responses (see Appendices K, L and M).

Results

Sample Characteristics

Sixteen eligible participants consented to the RCT (see Figure A1), including mothers and grandmothers (*n* = 11), children (*n* = 2) and autistic adults (*n* = 3; see Table A1). The majority (*n* = 15) had accessed pharmacological or psychological support in the last 12 months (*n* = 11). Six participants (4 intervention, 2 controls) reported experiencing concurrent life stressors during the trial (e.g., moving house, family difficulties, medication changes).

Smiling Mind Activity and Feedback

Frequency of practice varied from a single meditation (*n* = 1) to multiple sessions (range: 3–4 sessions; *n* = 3), with all participants in the 5-week trial completing the minimum three sessions. No participants assigned to the 5-day trial completed the minimum five sessions. Available end-user data indicated meditation programs relating to sleep (*n* = 5) were most popular. The Mindfulness Foundations program, a requisite module, was accessed by

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[1] Outcome data are available from the first author, on request.

only one adult with ASD. Participants rated the Smiling Mind app as somewhat helpful ($n = 5$) or extremely helpful ($n = 3$).

Figure A1

CONSORT 2010 Flow Diagram for Randomised Pilot and Feasibility Trials (Eldridge et al., 2016)

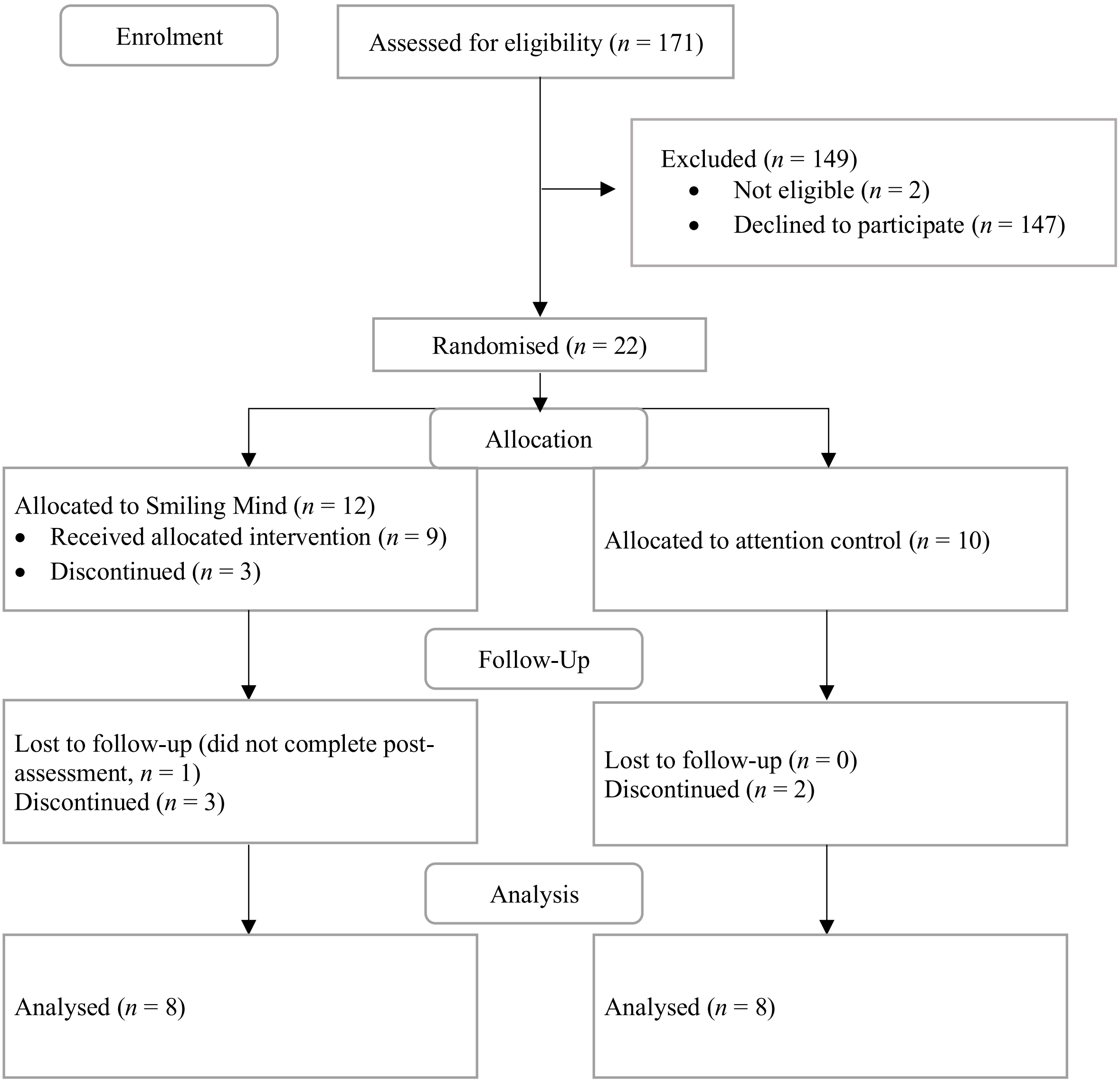

Table A1

Baseline Characteristics of Sample

Demographics	Child	Adult	Caregiver[1]
Gender			
Male	1		
Female	1	1	11
Not specified		2	
Mean age (*SD*)	12 (1.4)	35 (10)	42.4 (8)
Level of education			
Post-graduate degree		1	3
Degree or diploma		1	7
High school		1	1
Primary school			
Not yet completed	2		
ASD severity level*			
Level 1 (mild)	1	1	1
Level 2 (moderate)	1		6
Level 3 (severe)		1	2
Don’t know		1	2
Secondary diagnoses*	1	2	7
Previous treatment*			
No			1
Yes	2	3	8
Length of time since treatment*			
Current	1	3	3
< 12 months			4
> 12 months	1		3
Previous experience of mindfulness			
Yes	1	3	9
No	1		2

[*] Reflects data for ASD child (either self-reported or reported by caregiver).

Case Studies

'Fiona'

Fiona had had previous experience with mindfulness apps (for 'about two years') and decided to participate because her previous app was no longer available, highlighting the importance of both availability and stability of apps for consistent practice. Fiona used mindfulness with her children to help them sleep, including her 11-year-old daughter with ASD (Jane):

> We do it every night like at bed, it's a ritual in our house, we kinda of read, go to bed and then lay there and I put the meditation on the [inaudible], and I have to lay with my daughter anyway until she goes to sleep.

Although she primarily used the meditations with Jane, Fiona recognised that this practice was equally beneficial for her own wellbeing:

> [The meditation] is this making me think a little bit more about how I am feeling at the time, and I suppose after I did kind of, just, well actually I do feel a lot more chilled.

Fiona did, however, note that the meditations were too brief for Jane:

> I reckon at least ten to fifteen minutes, I think, that's a good time to, for them to breath, wind down and then, Yeah kinda just go, you've told a little story now, now it's time for you to go to sleep, you know, five minutes is not long at all for a child to wind down.

'Leanne'

Similar to Fiona, Leanne was familiar with mindfulness practice, having taught this to preschool children. She also used the app with her children and reported benefit:

> Even if I didn't get to that real deep place of relaxation, I would walk away, come away from it going yeah I need that … I'm a much better person for it…and with my children – I also noticed straight after they were much calmer as well.

However, Leanne had difficulty scheduling practice time for herself and her 11-year-old son Jarrad:

> Then of course not just finding the time, whether or not Jarrad would be, you know, compliant, so if there was something happening for him at that particular time, so, yeah, that was my biggest challenge.

As with Fiona, Leanne commented that the shorter meditations (e.g., < 10 mins) were somewhat repetitive for Jarrad, while concentrating through longer meditations was equally difficult for him:

> He struggled to get through the sessions … I remember on a couple of occasions that we tried something different that was longer, we, he just didn't get there, and so the shorter ones was better but then he got bored with it.

Leanne found the narrator's tone and pacing appealing, although suggested that increasing the amount of imagery and customising voices in the app might help Jarrad to focus:

> This actually was some feedback that Jarrad gave me … whoever's voice was on there was very calming and relaxing and appropriate but it would be good to perhaps have other options as well, maybe during the different meditations.

'Betty'

Betty home-schooled a 15-year-old ('Emilie') and 8-year-old ('John') and managed their therapy appointments. She was impressed with the layout and usability of Smiling Mind and the app's unique sensitivities for those on the autism spectrum:

> When you’re on the spectrum and you, you don’t know what things are going to be like, and I think from that very first word it gives you this sense of comfort, so I found the voice and the, the meditations themselves really, really good … not too overwhelming from a sensory point of view, and it had the right effect.

Betty reported that both of her children benefited from Smiling Mind, albeit at different times of the day:

> I think I found the best time of day for him was prior to getting started with our schoolwork; my daughter on the other hand, a teenager … struggles with sleep … so I found for her late night for her to listen to it.

However, John, in particular, required his mum’s encouragement to use Smiling Mind:

> I go through and choose one that I think … that he can just, yeah, focus in on that to get him in a calmer place, so as we go he’ll hopefully use it himself more independently, but he’s not that independent with a lot of things at this point.

Betty’s daughter Emilie was more open to using Smiling Mind as it had no specific association with ASD, thereby removing the stigma associated with formal therapy:

> We’re at that weird age where she doesn’t want the label … You don’t want to hang out with other ASD people, you just want to fit in to society with your peers and go undetected, so this is something she can do, and no one has to know about… so there’s, there’s no stigma attached to it in that way.

Follow-Up Survey

Of 138 who provided their contact details, 33 responded to a follow-up survey (see Appendices K, L and M). Many indicated a desire to participate in the trial to better manage their own anxiety (39%) or that of their child’s (70%) as well as a general interest and curiosity in mindfulness (36%). Reasons for not participating, overwhelmingly, included having too many things to think about (51.5%). Over half (51.5%) had forgotten about the trial. Logistical issues included children not meeting the minimum age criterion or being too resistant or anxious to participate (29%). A preference for in-person mindfulness training by a trusted provider (e.g., autism-specific service) and for participation in a group setting with other families (45.5%) was also noted. Others desired more information about Smiling Mind and/or the benefits of mindfulness (45%). Text responses (42%) highlighted the need for additional time to accommodate busy schedules (64%), improved clarity regarding study eligibility and registration (22%), and incentives that were appealing to teens with ASD (14%), although no specific examples were provided.

Discussion

This pilot study was designed to examine the suitability of a commercially available mindfulness app, Smiling Mind, for individuals with ASD and their caregivers. The trial encountered difficulties in recruitment, enrolment and engagement. Parent interviews and survey responses from all three groups highlighted problems with scheduling regular time for mindfulness practice as well as difficulties maintaining concentration and motivation during meditations, particularly for children.

The low recruitment rate, although consistent with difficulties encountered in disability research in general, indicates a need to recruit broadly. Direct contact with primary care providers, who are often a first point of contact for many caregivers, as well as partnerships with educators of school-age children on the spectrum, should be considered (Ahmed et al., 2020; Beadle-Brown, Ryan, et al., 2012; Haas et al., 2016). Research registers (e.g., Prolific) can also expedite enrolment, although a fee is typically associated with this access.

Survey responses further highlighted some reluctance in engaging with ‘mindfulness’. The offer of phone or video calls to build trust and reduce anxiety about participation may have improved communication with participants, particularly for those individuals who find aspects of electronic communication confusing (Beadle-Brown, Ryan, et al., 2012; Haas et al., 2016).

Lack of time and poor child compliance made it difficult for parents to complete the recommended number of mindfulness practice sessions, a finding echoed in previous research (Hartley et al., 2021). Verbal guidance when undertaking mindfulness training may increase the perceived utility and intention to practise learnt skills (Crandall et al., 2019; Hartley et al., 2021; Sommers-Spijkerman et al., 2021). Early psychoeducation could also clarify goals, objectives and individual responsibilities in order to successfully complete a skills-based psychological app, such as Smiling Mind.

Improved app engagement strategies for autistic children should also be considered. Gamification features (e.g., rewards and personalisation options) may motivate use, particularly among autistic children and adults (Camargo et al. (2019). Content that can easily be imitated and repeated by children (e.g., favourite character song or phrase) or online opportunities for social networking may also motivate use, although the group format may not suit everyone (Camargo et al., 2019; Hartley et al., 2021; Martins et al., 2020; Sliwinski et al., 2018).

Finally, methods for electronically testing and tracking session fidelity for individual app users could be improved. Recent studies have accessed in-app metrics for this reason (Flett et al., 2020). We had problems accessing these data, resulting in incomplete usage statistics. Ideally, data collection pathways need to be verified upfront; otherwise, the researcher runs the risk of incomplete datasets (Carter et al., 2015; Jokinen et al., 2021). Future app research should incorporate tech support, separate from the actual content of the app intervention, to ensure data integrity.

Conclusions

The present trial identified important and preventable factors that can be used to promote recruitment and engagement in future mindfulness trials involving individuals and families living with ASD. These include forming collaborations with primary care and education providers to improve access to eligible participants, verifying the practice of core mindfulness skills at the outset, maintaining engagement through ongoing interactions, and improving data collection processes.

Research Ethics: The authors declare that all research involving human participants was conducted only with the informed consent of participants and complied with the ethics approval given by the University of Adelaide Human Research Ethics Committee.

Acknowledgements: The authors would like to thank Novita (SA), Autism SA, Autism NT, Autism Queensland, ASPECT (NSW), AMAZE (Vic.), Marymead Autism Centre (ACT) and Smiling Mind Pty Ltd. for their support of this project.

Funding: This work was supported by an Australian Government Research Training Program Scholarship

Conflicts of interest: the authors declare they have no conflict of interest

Appendix B: Study 1 – Search Terms Used in Database Searches

Database	Search Terms
PubMed	child development disorders, pervasive[mh] OR autis*[tiab] OR asperger*[tiab] OR ASD[tiab] OR pervasive developmental disorder*[tiab] AND mindfulness[mh] OR mindful*[tiab] OR meditation*[tiab] OR acceptance and commitment therap*[tiab] OR dialectical behavior therap*[tiab]
PsycINFO	exp autism spectrum disorders OR autis*.ti,ab OR asperger*.ti,ab OR ASD.ti,ab OR pervasive developmental disorder*.ti,ab AND exp mindfulness OR mindful*.ti,ab OR meditation*.ti,ab OR “acceptance and commitment therap*”.ti,ab OR “dialectical behavio?r therap*”.ti,ab
Embase	‘autism’/exp OR autis*:ti,ab OR asperger*:ti,ab OR ‘pervasive developmental disorder*’:ti,ab AND ‘mindfulness’/exp OR mindful*:ti,ab OR meditation*:ti,ab OR ‘acceptance and commitment therap*’:ti,ab OR ‘dialectical behav* therap*’:ti,ab
Scopus	TITLE-ABS (autis* OR asperger* OR "pervasive developmental disord*" OR "child development disord*") AND TITLE-ABS ("mindful*" OR "meditation*" OR "acceptance and commitment therap*" OR "dialectical behaviour therap*")

Note. ABS = Australian Bureau of Statistics.

Appendix C: Study 1 Test–Retest Reliability of Measures Included in Meta-analysis

Measure		Participant group	Test–retest Reliability	Study
AQ	Autism Questionnaire	Child (caregiver report)	-	Hoekstra et al., (2011)
ASEBA ASR	Achenbach System of Empirically Based Assessment – Adult Self-Report	Adult	0.83–0.94	Achenbach & Rescorla (2001)
ASEBA CBCL-	Achenbach System of Empirically Based Assessment – Child Behaviourism Checklist	Child (caregiver report)	0.95	Achenbach & Rescorla (2003)
ASQ	Autism Spectrum Quotient	Caregiver	0.70	Baron-Cohen et al. (2001)
BDI	Beck Depression Inventory	Caregiver	0.60	Nolen-Hoeksema (2000)
BFQOL	Beach Family Quality of Life	Caregiver	0.41–0.82	Hoffman et al. (2006)
CAMM	Children's Acceptance and Mindfulness Measure	Child	-	Greco et al., (2011)
CERQ	Cognitive Emotion Regulation Questionnaire	Caregiver	0.41–0.59	Garnefski et al. (2001)
CSQ-CA	Chronic Stress Questionnaire for Children and Adolescents	Child	-	de Bruin et al., (2017)
CSRQ	Chronic Sleep Reduction Questionnaire	Child	0.78	Meijer (2008)
DASS	Depression Anxiety Stress Scales	Caregiver	-	-
DERS	Difficulties in Emotion Regulation Scale	Adult	0.68–089	Gratz & Roemer (2004)

Measure		Participant group	Test–retest Reliability	Study
ESS	Somatic Symptoms Scale	Caregiver	-	-
FFMQ	Five Facet Mindfulness Questionnaire	Caregiver	0.61–0.84	Veehof et al. (2011)
FMI	Freiburg Mindfulness Inventory	Caregiver	0.80	Trousselard et al. (2010)
GHQ	General Health Questionnaire	Caregiver	0.68	Quek et al. (2001)
GMS	Global Mood Scale	Adult	0.80–0.82	Spindler et al. (2009)
HADS	Hospital Anxiety and Stress Scale	Adult	0.62–0.74	White et al. (1999)
IBI	Irrational Beliefs Inventory	Adult	0.79	Al-Heeti et al. (2012)
IM-P	Interpersonal Mindfulness in Parenting Scale	Caregiver	-	-
MAAS-A	Mindful Attention and Awareness Scale	Child, Adult, Caregiver	0.81	Brown & Ryan (2003)
OQ	Outcome Questionnaire	Adult	0.78–0.84	Lambert et al. (1996)
POMS	Profile of Mood States	Caregiver	0.65–0.74	McNair & Heuchert (2005)
PS	Parenting Scale	Caregiver	0.84	Arnold et al. (1993)
PSI	Parenting Stress Index	Caregiver	0.84	Abidin (1995) in Dardas & Ahmad (2014)
PSS	Parenting Stress Scale	Caregiver	0.85	Berry & Jones (1995)
PSS	Perceived Stress Scale	Caregiver	0.85	Cohen et al. (1983)

Measure		Participant group	Test–retest Reliability	Study
PSWQ	Penn State Worry Questionnaire	Child	0.92	Meyer et al. (1990)
RRQ	Rumination Reflection Questionnaire	Adult	-	-
RRS	Ruminative Response Scale	Child	0.67	Nolen-Hoeksema (2000)
SCS	Self-Compassion Scale	Caregiver	0.93	Neff (2003)
SCL-90-R	Symptom Checklist-90 – Revised	Adult	0.68–0.83	Derogatis (1994)
SRS	Social Responsiveness Scale	Child/Caregiver, Child (caregiver report), Adult	-	-
STAEI-2	State-Trait Anger Expression Inventory	Caregiver	-	Spielberger (1999)
STAI-S	State-Trait Anxiety Inventory	Caregiver	0.65–0.86	Spielberger et al. (1983)
WHO-5	World Health Organization Five Well-Being Index	Child/Caregiver	0.88	Sibai et al. (2009)
WHOQOL-BRIEF	World Health Organization QOL Assessment	Caregiver	0.66–0.87	The WHOQOL Group (1998)
ZBI	Zarit Burden Inventory	Caregiver	-	-

Appendix D: Study 1 – References for Measure Test–Retest Reliability

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Appendix E: Study 1 –Calculated Hedges’ *g* Values For All Study Measures

Category	Lead author (date)	Measures	*g*	95% CI		*p*
				Lower	Upper	
ASD children post-intervention	Ridderinkhof (2018)	SRS	0.31	0.08	0.55	0.042
		CBCL internalising	0.34	0.11	0.58	0.042
		YSR internalising	0.13	−0.10	0.36	0.043
		CBCL externalising	0.21	−0.02	0.44	0.043
		YSR externalising	0.20	−0.03	0.43	0.043
		CBCL attention	0.31	0.08	0.55	0.042
		YSR attention	0.22	−0.02	0.45	0.043
		RRS	0.43	0.19	0.67	0.041
		CSQ-CA	0.20	−0.03	0.43	0.043
		CSRQ	0.06	−0.17	0.29	0.043
		WHO-5	0.34	0.11	0.58	0.042
		CAMM	0.02	−0.21	0.25	0.043
	de Bruin (2015)	MAAS-A	0.25	-0.08	0.58	0.143
		WHO-5	0.53	0.18	0.88	0.132
		RSS	0.33	0.00	0.66	0.141
		PSWQ	0.04	−0.28	0.36	0.146
		AQ	0.04	−0.28	0.36	0.146
		SRS Total	0.01	−0.31	0.33	0.146
		AQ Total	0.09	−0.24	0.41	0.146
	Hwang (2015)	CBCL Total T2-T3	0.16	−0.50	0.81	0.208
ASD children follow-up	Ridderinkhof (2017)	SRS	0.32	0.09	0.56	0.042
		CBCL internalising	0.37	0.14	0.61	0.042
		YSR internalising	0.49	0.25	0.73	0.041
		CBCL externalising	0.42	0.18	0.66	0.041
		YSR externalising	0.55	0.30	0.80	0.040
		CBCL attention	0.43	0.19	0.67	0.041
		YSR attention	0.56	0.31	0.81	0.040
		RRS	0.70	0.44	0.95	0.038
		CSQ-CA	0.62	0.37	0.87	0.039
		CSRQ	0.28	0.04	0.51	0.042
		WHO-5	0.39	0.16	0.63	0.042
		CAMM	0.36	0.13	0.60	0.042
ASD children follow-up	de Bruin (2015)	MAAS-A	0.02	−0.30	0.34	0.147
		WHO-5	0.61	0.25	0.96	0.139
ASD children follow-up	de Bruin (2015)	RSS	0.89	0.50	1.27	0.131
		PSWQ	0.27	−0.06	0.60	0.145
		AQ	0.06	−0.27	0.38	0.147
		SRS	0.32	−0.01	0.65	0.145

Category	Lead author (date)	Measures	*g*	95% CI		*p*
				Lower	Upper	
		AQ	0.14	−0.18	0.47	0.146
ASD adults post-intervention	Kiep (2015)	Wellbeing	0.57	0.34	0.81	0.170
		Anxiety Rumination	3.36	2.80	3.93	0.165
		Positive Affect	2.74	2.26	3.22	0.167
	Sizoo (2017)	HADS-A	0.75	0.44	1.06	0.056
		HADS-B	0.40	0.11	0.68	0.064
		GMS-P	0.24	−0.04	0.51	0.066
		GMS-N	0.33	0.05	0.61	0.065
		SRS-A	0.27	−0.01	0.54	0.066
		RRQ	0.51	0.22	0.80	0.062
		IBI	0.24	−0.04	0.52	0.066
		MAAS	0.38	0.10	0.66	0.064
	Conner (2018)	DERS Total	0.36	−0.19	0.91	0.065
		Outcome Questionnaire	0.36	−0.19	0.91	0.065
ASD adults follow-up	Kiep (2015)	Wellbeing	0.54	0.31	0.77	0.170
		Anxiety Rumination	3.61	3.01	4.21	0.164
		Positive Affect	3.47	2.89	4.06	0.164
	Sizoo (2017)	HADS-A	0.74	0.43	1.05	0.057
		HADS-B	0.71	0.40	1.01	0.058
		GMS-P	0.55	0.26	0.85	0.061
		GMS-N	0.51	0.22	0.80	0.062
		SRS-A	0.27	−0.01	0.55	0.066
		RRQ	0.53	0.24	0.82	0.061
		IBI	0.28	0.00	0.56	0.065
		MAAS	0.47	0.18	0.76	0.063
	Conner (2018)	DERS Total	0.35	−0.20	0.89	0.066
Caregiver post-intervention	Ferraioli (2013)	PSI-SF	1.62	0.49	2.75	0.219
		GHQ	1.80	0.58	3.03	0.196
	Ruiz-Robledillo (2015)	Total Symptoms	2.10	0.73	3.48	0.101
		PGH Somatic Symptoms	1.06	0.17	1.96	0.173
		PGH Anxiety and insomnia	0.99	0.13	1.86	0.178
		PGH Social dysfunction	0.87	0.05	1.68	0.188
		PGH Severe Depression	0.46	−0.24	1.16	0.216
		Total Perceived health	1.43	0.38	2.47	0.144
	Hwang and Kearney (2015)	Mindfulness	1.01	0.14	1.88	0.124
		Parenting Stress	0.43	−0.26	1.13	0.187
		Quality of Life	0.50	−0.21	1.21	0.180
	Ridderinkhof (2017)	SRS-A	0.19	0.00	0.37	0.057
		ASR internalising	0.31	0.12	0.49	0.056
		ASR externalising	0.39	0.20	0.57	0.056

Category	Lead author (date)	Measures	*g*	95% CI		*p*
				Lower	Upper	
Caregiver post-intervention	Ridderinkhof (2017)	ASR attention	0.26	0.07	0.44	0.057
		PSS	0.43	0.24	0.61	0.055
		PSI-C	0.21	0.02	0.39	0.057
		PS-O	0.54	0.35	0.74	0.054
		IM-P	0.42	0.23	0.60	0.055
		SCS-SF	0.28	0.09	0.46	0.056
	de Bruin (2015)	WHO-5	0.33	0.04	0.62	0.200
		PS-Total	0.10	−0.19	0.38	0.208
		PSI-C	0.20	−0.09	0.49	0.205
		FFMQ Total	0.56	0.25	0.87	0.187
		IM-P Total	0.34	0.05	0.64	0.200
Caregiver follow-up	Ferraioli (2013)	PSI-SF	0.81	0.01	1.60	0.346
		GHQ	1.48	0.41	2.56	0.238
	Ridderinkhof (2017)	SRS-A	0.08	−0.10	0.26	0.057
		ASR internalising	0.46	0.27	0.66	0.055
		ASR externalising	0.50	0.31	0.70	0.054
		ASR attention	0.28	0.09	0.46	0.056
		PSS	0.35	0.16	0.53	0.056
		PSI-C	0.39	0.20	0.57	0.056
		PS-O	0.64	0.44	0.84	0.053
		IM-P	0.50	0.31	0.70	0.054
		SCS-SF	0.38	0.19	0.56	0.056
	de Bruin (2015)	MAAS-A	0.02	−0.30	0.34	0.147
		WHO-5	0.61	0.25	0.96	0.139
		RSS	0.89	0.50	1.27	0.131
		PSWQ	0.27	−0.06	0.60	0.145
		AQ	0.06	−0.27	0.38	0.147
		SRS	0.32	−0.01	0.65	0.145
		AQ	0.14	−0.18	0.47	0.146

Appendix F: Study 2 – Search Terms Used in Database Searches

Database	Search terms
PubMed	child development disorders, pervasive[mh] OR autis*[tiab] OR asperger*[tiab] OR ASD[tiab] OR pervasive developmental disorder*[tiab] AND mindfulness[mh] OR mindful*[tiab] OR meditation*[tiab] OR acceptance and commitment therap*[tiab] OR dialectical behavior therap*[tiab]
PsycINFO	exp autism spectrum disorders OR autis*.ti,ab OR asperger*.ti,ab OR ASD.ti,ab OR pervasive developmental disorder*.ti,ab AND exp mindfulness OR mindful*.ti,ab OR meditation*.ti,ab OR “acceptance and commitment therap*”.ti,ab OR “dialectical behavio?r therap*”.ti,ab
Embase	‘autism’/exp OR autis*:ti,ab OR asperger*:ti,ab OR ‘pervasive developmental disorder*’:ti,ab AND ‘mindfulness’/exp OR mindful*:ti,ab OR meditation*:ti,ab OR ‘acceptance and commitment therap*’:ti,ab OR ‘dialectical behav* therap*’:ti,ab
Scopus	TITLE-ABS (autis* OR asperger* OR "pervasive developmental disord*" OR "child development disord*") AND TITLE-ABS ("mindful*" OR "meditation*" OR "acceptance and commitment therap*" OR "dialectical behaviour therap*")
CINAHL	MH autism OR TI autis* OR AB autis* OR TI asperger* OR AB asperger* OR TI ‘pervasive developmental disorder*’ OR AB ‘pervasive developmental disorder*’ AND MH Mindfulness OR TI Mindful* OR AB Mindful* OR TI ‘Dialectical Behaviour Therap*’ OR AB ‘Dialectical Behaviour Therap*’ OR TI ‘Dialectical Behavior Therap*’ OR AB ‘Dialectical Behaviour Therap*’ OR TI ‘Dialectical Behaviour Therap*’ OR TI Acceptance and Commitment Therap*’ OR AB ‘Acceptance and Commitment Therap*’

Note. ABS = Australian Bureau of Statistics.

Appendix G: Study 2 – Questions to Participants in Interviews or Surveys

Lead author (date)	Questions
Beck (2018, 2020)	• If you were to have a conversation with a person with autism spectrum disorder who is considering this mindfulness program what would you tell them about the mindfulness program? • What facilitators did you experience as a result of this group? • What problems did you experience as a result of this group • How did this group impact your daily life? • What did you learn about yourself as a result of this group?
Hwang & Kearney (2015)	• Reviewed qualitative data taken from an online group forum and face-to-face meetings with individual participants that indicated the level and characteristics of engagement in mindfulness practice.
Kennedy (2018)	• What are your three biggest stressors at the moment? • Previously you stated that **insert responses to pre-program question here** were your biggest stressors. How are these things now? Describe your experience in the mindful parenting course? • What was the most useful aspect of the course for you? • What did you not find helpful about the course? • What would you consider to be the advantages and disadvantages of taking the course in a group format? • How would you describe your relationship with your child?
Quirk (2018)	• Can you describe for me the type of mindfulness training you have participated in and why you were interested in it? • What were the most challenging and most rewarding aspects of the training? • Can you describe for me what your home practice looks like and any challenges you've faced when trying to establish your home practice? • Can you please describe for me specific ways mindfulness training and practice have impacted your daily life and your relationship with your family? • What has been the biggest lesson you have learnt from mindfulness training and practice? • What advice would you give other parents of children with autism about mindfulness training and practice? • Is there anything else you would like to add?

Reid (2016)	• General information about whether the participant had attended any similar workshops before, and whether they attended both of the sessions. • What their experience and emotional wellbeing was before the workshops. • Their experiences of the parent wellbeing workshops. • Recommendations for future workshops.
Ridderinkhof (2019)	• What does mindfulness mean to you? • How did you experience the mindfulness training? • Has anything changed for you through the mindfulness training? If so, what? • How does mindfulness help you? • Has anything changed for your mother/father/co-parent/child through the mindfulness training? If so, what?
Ridderinkhof (2018)	• What, if anything, they learnt. • What, if any, changes they experienced their opinions about the MYmind program. • What, if anything, has changed in the relationship with their child.
Salem-Guirgis (2019)	• How helpful the MyMind program was. • Did you experience any barriers while participating in the MyMind program?
Singh (2007)	Interviews focused on: • meditation practice • use of mindfulness in daily life • social interaction with their children • relationship with their spouses • mindfulness versus previous training in other forms of intervention • personal growth • hopefulness
Singh (2014)	Participants provided an evaluation of their mindfulness-based practices and perceived outcomes of participation in the MBPBS program. Interviews focused on three key issues: • gaily meditation practice • the MBPBS program • personal growth

Appendix H: Study 3 – Meditation List for 10–12 Year Olds

Meditations for 10–12 year olds	Session	Type	Duration
	Lesson	Our Internal Weather	1:00
Mindfulness 101 – The Land of Mindfulness	Meditation	The Bubble Journey	7:25
	Meditation	Daily Mindfulness Guide	5:23
	Activity	Rock the Boat	3:26
Mindfulness 102 – Breath	Meditation	Belly Breathing	6:20
	Meditation	Daily Mindfulness Guide	5:23
	Activity	A Mindful Hug is the Shortest Distance Between Friends	2:22
Mindfulness 103 – Exploring Sounds	Meditation	Exploring Sounds	6:50
	Meditation	Daily Mindfulness Guide	5:23
	Activity	A Few Mindful Activities to Choose From	2:08
Mindfulness 104 – The Senses	Meditation	Exploring Tastes	5:58
	Meditation	Daily Mindfulness Guide	5:23
	Activity	Count Your Senses!	2:15
Mindfulness 105 – A Relaxing Bubble Journey	Meditation	A Longer Bubble Journey	9:23
	Meditation	Daily Mindfulness Guide	10:29
	Activity	Mirror Movement	1:47
Mindfulness 106 – Thoughts and Feelings	Meditation	My Internal Weather	6:09
	Meditation	Daily Mindfulness Guide	10:29
	Activity	Under the Sea	1:17
Mindfulness 107 – A Wish For Me	Meditation	The Wish Tree	6:30
	Meditation	Daily Mindfulness Guide	10:29
	Activity	Exploring Your Elements	3:05
Mindfulness 108 – Empathy and Kindness	Meditation	The Wish Tree – Revisited	6:48
	Meditation	Daily Mindfulness Guide	10:29
Mindfulness 201 – Curiosity	Meditation	Curiosity and Play:	6:33
	Meditation	Daily Mindfulness Guide – Body Scan 5:00	5:00
	Meditation	Bitesize Curiosity and Play	3:00
Mindfulness 202 – Mindful Listening	Activity	Take Home Activity – Noticing Nature	0:15
	Meditation	Mindful Listening: 10–12 Years	4:47
	Meditation	Daily Mindfulness Guide – Breath and Sounds	5:00
	Meditation	Bitesize Mindful Listening	3:00

Meditations for 10–12 year olds	Session	Type	Duration
Meditations for 10–12 year olds	Session	Type	Duration
	Activity	Take Home Activity – Mindful Listening	10:00
Mindfulness 203 – Mindful Learning	Meditation	Mindful Learning: 10 – 12 Years	5:12
	Meditation	Daily Mindfulness Guide – Empathy and Kindness	5:00
	Meditation	Bitesize Mindful Learning	2:52
	Activity	Take Home Activity – Mindful Learning	10:00
Mindfulness 204 – Emotions	Meditation	Emotions: 10 – 12 Years	6:35
	Meditation	Daily Mindfulness Guide – Body Scan	5:00
	Meditation	Bitesize Emotions	2:55
	Activity	Take Home Activity – Drawing Your Internal Weather	10:00
Mindfulness 205 – Mindful Movement	Meditation	Mindful Movement: 10–12 years	6:45
	Meditation	Daily Mindfulness Guide – Breath and Sounds	5:00
	Meditation	Bitesize Mindful Movement	2:46
	Activity	Take Home Activity – Mindful Movement	10:00
Mindfulness 206 – Sleep	Meditation	Sleep and Thoughts	6:22
	Meditation	Daily Mindfulness Guide – Empathy and Kindness	5:00
	Meditation	Bitesize Sleep and Thoughts	3:00
	Activity	Take Home Activity – Starry Sky	10:00
Mindfulness 207 – Gratitude	Meditation	Gratitude	6:00
	Meditation	Daily Mindfulness Guide – Body Scan	5:00
	Meditation	Bitesize Gratitude	3:00
	Activity	Take Home Activity – Thank You	10:00
Mindfulness 208 – Self-Compassion	Meditation	Self-Compassion	6:27
	Meditation	Daily Mindfulness Guide – Breath and Sounds	5:00
	Meditation	Bitesize Self-Compassion	3:00
	Activity	Take Home Activity – Self Portrait	10:00

Appendix I: Study 3 – Smiling Mind Mindfulness Foundations Sessions

Adults	Session	Type	Description	Duration
The Breath	Meditation	Body Scan	Bring awareness of the different parts of the body.	8:03
	Meditation	Exploring the Breath	This is a general meditation that can be listened to daily.	7:04
	Activity	Are You Still Breathing	This activity reminds you to check in with your breath.	1:36
	Activity	Are You Really Listening	This activity guides you through mindfully listening to someone else.	2:45
Sounds and Taste	Meditation	Breath and Sounds	This exercise trains your attention muscle by asking you to be curious about things that are present.	11:31
	Meditation	Body Scan Bubble Journey	This is a general meditation that you can listen to daily.	7:03
	Activity	Mindful Eating	A mindful eating exercise.	5:57
	Activity	Where Did My Food Come From	Can you imagine what it took to get a piece of fruit into your hand, ready to eat?	2:32
Thoughts	Meditation	Breath and Thoughts	Our minds are thought machines that roam wild when left to their own devices.	10:13
	Meditation	One Minute Body Scan	Use this tool to cultivate mindfulness by tuning into your body throughout the day.	4:17
	Meditation	Body Scan Bubble Journey	This is a general meditation that you can listen to daily.	7:03
	Activity	A Legal Alien	Try taking a step back from your thoughts and observing them from a distance.	1:32
Emotions	Meditation	Breath and Emotions	This meditation practice is dedicated to bringing awareness to emotions and emotional experiences.	7:02
	Meditation	Breath and The Body	This is a general meditation that can be listened to daily. It encourages curious exploration of your sense through a body scan.	10:19
	Activity	Feeling Emotions In Your Body	This activity provides a tool to practice bringing mindfulness into experiencing emotions.	2:12
	Activity	Finding Your Inner Master	Imagine your role model or "master" giving you advice. What would they tell you?	4:28
Everyday Mindfulness	Meditation	Short Mindfulness Practice	Use this exercise to place a comma in your day.	3:41
	Meditation	Breath and The Body	This is a general meditation that can be listened to daily. It encourages curious exploration of your sense through a body scan.	10:19
	Activity	Choosing To Do Things Mindfully	50 activities that you can do mindfully each day!	4:45
	Activity	Bonus Practice	Try exploring how your breath changes throughout the day.	1:22
Curiosity	Meditation	Curiosity and Beginner's Mind	This lesson meditation connects you with your sense of curiosity.	6:32
	Meditation	Body Scan	This is a general meditation you can listen to daily.	5:00
	Meditation	Extended Meditation (20 Minutes)	Practice mindfulness more independently with longer periods of silence and less guidance.	20:06
	Activity	Connecting with Nature	This activity is about connecting with nature. Doing so, helps reduce stress and improve mental wellbeing.	0:15
Stress	Meditation	Stress	This lesson meditation is designed to help you understand your stress response.	6:58

Adults	Session	Type	Description	Duration
	Meditation	Breath and Sounds	This is a general 5 minute meditation that uses breath and sounds to practice being mindful. You can listen to this daily.	5:00
	Meditation	Extended Meditation (20 Minutes)	Practice mindfulness more independently with longer periods of silence and less guidance.	20:06
	Activity	Journaling Exercise	Write down anything that you feel is stressing you out this week and why.	0:15
Sleep and Gratitude	Meditation	Sleep: Starry Night	This meditation will help prepare you for a good night's sleep.	7:44
	Meditation	Sleep: Body Scan	This meditation will help prepare you for a good night's sleep.	8:20
	Meditation	Gratitude and Joy	This meditation connects you with the feeling of gratitude.	5:08
	Meditation	Extended Meditation (30 Minutes)	Practice mindfulness more independently with longer periods of silence and less guidance.	28:44:00
	Activity	Practising Gratitude	This activity is that might help you transform your thoughts and feelings about the day.	0:15
Relationships	Meditation	Relationships	This meditation is designed to help you become more mindful in your interactions with the important people in your life.	6:27
	Meditation	I Wish For Me	Explore another wonderful way of putting a smile on your mind, by making friendly wishes for yourself.	6:10
	Meditation	I Wish For You	You can share love and happiness with the people you care for by sending them friendly wishes.	7:19
	Meditation	Extended Meditation (30 Minutes)	Practice mindfulness more independently with longer periods of silence and less guidance.	28:44
	Activity	Write a Letter	This week, write a letter to yourself, and then to someone else letting them know what you appreciate about them.	0:15
Mindful Listening	Meditation	Mindful Listening: Mindsurfing	This meditation uses music and sound to bring you into the present moment.	7:12
	Meditation	Mindful Listening: Dreamtime	This meditation uses music and sound to bring you into the present moment.	7:12
	Meditation	Extended Meditation (45 Minutes)	Practice mindfulness more independently with longer periods of silence and less guidance.	43:43
	Activity	Mindful Conversations	Listening is one of the most important skills in life that helps you notice more about your environment and other people.	0:15

Appendix J: Study 3 – Qualitative Interview Schedule

Question	Prompt
Could you tell me about your experiences of being involved in the Smiling Mind study?	How easy was it to follow each mindfulness session? How did you find using the app? What was your experience of having scheduled time for mindfulness?
What was least beneficial aspect of the intervention, and why?	What did you find annoying? What did you find uncomfortable? Was anything confusing or unclear?
Have you seen any changes in your thinking or behaviour after using the app?	How do you see yourself now compared with before? How aware are you of your own everyday behaviours? Have you noticed any other changes? (How is this different to other mindfulness programs you have tried?)
Any additional comments on the use of the Smiling Mind app or the meditations used in this app?	How did you find using the app? How easy was it to find and use a meditation? Do you have any suggestions for improving the app? (Did you use the introductory videos?)
What motivated you to complete the intervention?	What motivated you? What benefits did you think would occur by taking part? What motivates you now?
What changes would improve the study?	How did you find the duration of the study? Would you use the app with guidance from a mentor or in a group? Were you able to schedule time to complete the sessions? Were the sessions too long/too short? Did you find yourself rushing to complete them? What would happen if you did it again?

Appendix K: Study 3 – Responses to Barriers to Participation Survey, Question 1

Question 1. What were the two most important reasons for registering your interest in this trial?

Response	%
I have a child that needs help dealing with anxiety or stress.	69.7
I would like help for anxiety or stress.	39.4
It seemed interesting.	36.4
I just need something to help my situation.	27.3
Other (responses below)	12.1
• I'm an autistic parent to 2 autistic children and another who has anxiety. I support research into ASD. • I have done some reading on mindfulness and thought it would be a good thing to try. • It can't be any worse than doing nothing, right? • It was a great research question.	
I have undertaken mindfulness training before.	6.1
It didn't cost anything.	6.1
I've used Smiling Mind before.	6.1

Appendix L: Study 3 – Responses to Barriers to Participation Survey, Question 2

Question 2 What prevented you from participating?	
Response	%
It was just one too many things to think about.	51.5
Other (responses below) • There was no category that fit my circumstances: an autistic parent. • I totally forgot about the study. • I don't have a printer to complete the form. • We were told we were not ellegable [sic]. • It just came at a particular busy period. I'm disappointed to have missed out. • I'm so sorry I actually want to do it I just got busy and forgot about it. • I missed the part that there was an app involved. • Focusing on the anxiety at high stress times can be more difficult. We had a holiday and starting high school. I didn't start it early enough to help with these, only emphasise that there was anxiety. • Too much else happening in life at the time, with 2 young kids on the autism spectrum. • My daughter was out of preferred age range. • I fully intended to apply and participate, but had too many things going on – and missed it. • I couldn't easily get into/onto the app. • My child did not make the age requirements. • My (ASD) daughter didn't want to participate and as I was mostly wanting her to be involved, there was no point. • Consent forms arrived later. I didn't find a direct link to download the app. I was confused about the registration process. I didn't think my child would use it. • My child didn't fit the age group; I signed up not knowing this. • I didn't realise the trial had started.	51.5
I don't have the time.	30.3
I needed more support from someone who's used mindfulness before.	9.1
The information provided was too complicated.	9.1
The app was free so I tried it without participating.	6.1
The Smiling Mind app was too confusing to use.	3.0
Mindfulness takes too long to work.	3.0

Appendix M: Study 3 – Responses to Barriers to Participation Survey, Question 3

Question 3: Is there anything that would have helped you participate?	
Response	%
Other (responses below)	42.4
• Better timing.	
• Clarity around whether I participate as an autistic person or parent of autistic people.	
• I needed the time which I have a bit more now.	
• Electronic permission forms.	
• Just tricky time.	
• Maybe a longer time period to allow participation, or other types of reminder prompts.	
• Remembering to do it.	
• Different time of year.	
• It was literally just a matter of having way too many things to do and not enough time – was very keen to participate.	
• Greater age range.	
• We ended up needing to move house rather quickly, so we didn't have the time right then.	
• As stated above, my daughter didn't want to participate, no direct reason given but I am assuming it is because she currently doesn't want to do anything that connects her to autism, which she hates having.	
• Straightforward registration, consent and download all provided at the same time. Something to appeal to a teen with ASD and anxiety.	
• I was interested to participate, just didn't realise it had started.	
I need more information on the app and Smiling Mind.	33.3
I would prefer mindfulness training one-on-one with a person rather than an app.	27.3
A financial incentive.	18.2
Something that can help my situation immediately.	15.2
I need more information on how useful mindfulness might be.	12.1
I would prefer mindfulness training from someone I trust like an autism services provider.	12.1
I would prefer mindfulness training in a group format where I can be with others in the same situation as me.	6.1
There is nothing that would help me participate.	6.1

Appendix N: Survey Information Sheet for Adults with ASD

SURVEY INFORMATION SHEET FOR ADULTS WITH ASD

PROJECT TITLE: Evaluating the Smiling Mind smartphone app for individuals with Autism Spectrum Disorder and their caregivers

Dear Participant,

You are invited to participate in a research project being conducted by the University of Adelaide in collaboration with a mindfulness application maker, Smiling Mind.

What is the project about?

We are testing the effectiveness of the Smiling Mind meditation app on wellbeing for individuals with autism spectrum disorder (ASD) and their parents/caregivers. We want to know if regular use of this app can help people manage feelings of stress, anxiety and depression.

Who is undertaking the project?

The project will form the basis of a research degree in psychology being undertaken by Matthew Hartley at the University of Adelaide, under the principle supervision of Dr. Diana Dorstyn. The project involves collaboration from Smiling Mind, a not-for-profit company that has developed the popular Smiling Mind mindfulness app. The following information is to help you decide whether or not you would like to take part. Please note that there is no guarantee that use of this app will improve your mental health.

Why am I being invited to participate?

You are being invited because you are

- An adult with a diagnosis of Autism Spectrum Disorder, AND you are
- Fluent in spoken and written English

What am I being invited to do?

Participation in this project involves a number of steps

- Complete a brief online survey. The survey asks questions about your wellbeing.
- You will then be randomly assigned to one of two groups. The first group, the “intervention group”, will be asked to download and use the Smiling Mind app for at least 20 minutes per day, over 5 days. You can, of course, use the app more often than this during the study period.
- The remaining participants will be the “control group”. If you are assigned to this group, you will be asked to spend up to 20 minutes per day to sit quietly on your own and to use your smartphone, as you normally would, over 5 days.
- After 5 days you will receive a link to complete a further online survey.
- The same survey will be sent to you a final time, 1 month later.

If you wish, you can leave your details to participate in a follow-up interview to share your experiences about taking part in the project.

How much time will my involvement in the project take?

This study requires a small regular time commitment of at least one 20 minute session each day for 5 days. In addition, the brief online survey that you will complete three times over the course of the study, depending on which group you are allocated too, will take approximately 20 minutes to complete each time.

Participants who nominate to discuss their experiences of the study may be invited for an interview that will take approximately 1 hour. You do not have to take part in this interview.

When is the project taking place?

The recruitment phase of the project is anticipated to commence mid-May and be completed by December 2019

Are there any risks associated with participating in this project?

We do not expect any side effects from participating in this research project. However, if at any time you begin to feel uncomfortable or upset while completing the questionnaire, or while accessing the Smiling Mind app, you should cease immediately. Please also contact the Student Researcher to inform of your withdrawal from the study (matthew.hartley@adelaide.edu.au).

Counselling support can be arranged by contacting your local GP for assessment for a mental health care plan to access to a mental health professional.

Other sources of counselling support that you may wish to consider are:
Lifeline on 13 11 14
Kids Helpline on 1800 551 800
MensLine Australia on 1300 789 978
Beyond Blue on 1300 22 46 36

What are the potential benefits of the research project?

We hope to show that daily practice of mindfulness, with the guidance of a smartphone app, can help to improve wellbeing for children and adults with ASD and their caregivers

Can I withdraw from the project?

Participation is completely voluntary, and you can withdraw from the study at any time.

What information will be collected?

As part of your participation, we ask that you complete a short survey that will ask questions about:

- Your age, gender, postcode, contact email address and questions related to your ASD diagnosis, as well as any previous therapies you may have undertaken
- We will also collect the following information from Smiling Mind:
  The date and time of each mindfulness session you access on the Smiling Mind app, and The name of the session and how you feel before and after each session.

  Please note location tracking is ***NOT*** used in the Smiling Mind app.

What will happen to my information?

Confidentiality and privacy: Data collected from the online surveys will remain anonymous and de-identified.

Storage: All participant data will be stored on a secure university network drive to which only the researchers will have direct access and kept up to 5 years

Publishing: Any published work will only use group, not individual data.

Sharing: All participants, if they choose, will be provided a brief summary of the research findings at the end of the project

Your information will only be used as described in this Information Sheet and it will only be disclosed according to the consent provided, except as required by law.

Who do I contact if I have questions about the project?

You can contact the Student Researcher, Matthew Hartley, matthew.hartley@adelaide.edu.au or the Principle Investigator, Dr. Diana Dorstyn, diana.dorstyn@adelaide.edu.au, with any queries about the project.

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2019-036). This research project will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research (2007; updated 2018). If you have questions or problems associated with the practical aspects of your participation in the project or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. If you wish to speak with an independent person regarding concerns or a complaint, the university's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat by phone:+61 8 8313 6028), email: hrec@adelaide.edu.au, or post: Level 4, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000.

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

If I want to participate, what do I do?

Contact Matthew Hartley (matthew.hartley@adelaide.edu.au) who will provide you with instructions on how to participate in the study.

Yours sincerely,

Mr Matthew Hartley (PhD candidate)
Dr Diana Dorstyn (Senior Lecturer)
Dr Clemence Due (Senior Lecturer)

Appendix O: Human Research Ethics Committee Consent Form

Human Research Ethics Committee (HREC)

CONSENT FORM – Surveys and Intervention

1. I have read the attached Information Sheet and agree to take part in the following research project:

Title:	Evaluating the Smiling Mind smartphone app for individuals with Autism Spectrum Disorder and their caregivers
Ethics Approval Number:	**H-2019-036**

2. I have had the project, so far as it affects me, and the potential risks and burdens fully explained to my satisfaction by the research worker. I have had the opportunity to ask any questions I may have about the project and my participation. My consent is given freely.

3. I have been given the opportunity to have a member of my family, or a friend, present while the project was explained to me.

4. Although I understand that the purpose of the research project is to improve the quality of health/medical care, it has also been explained that my involvement may not be of any benefit to me.

5. I agree to participate in the activities as outlined in the participant information sheet.
   Please Note: This form does not provide consent for an interview, a separate consent form will be provided for those who nominate for interviews.

6. I consent to Smiling Mind providing data on my use of the Smiling Mind app to the researchers only for the purpose of this research project.

7. I understand that I am free to withdraw from the project at any time and that this will not affect medical advice in the management of my health, now or in the future.

8. I have been informed that the information gained in the project may be published in a journal article/thesis/news article/conference presentations/ etc.

9. I have been informed that in the published materials I will not be identified, and my personal results will not be divulged.

10. I understand my information <u>will not</u> be used for future research purposes:

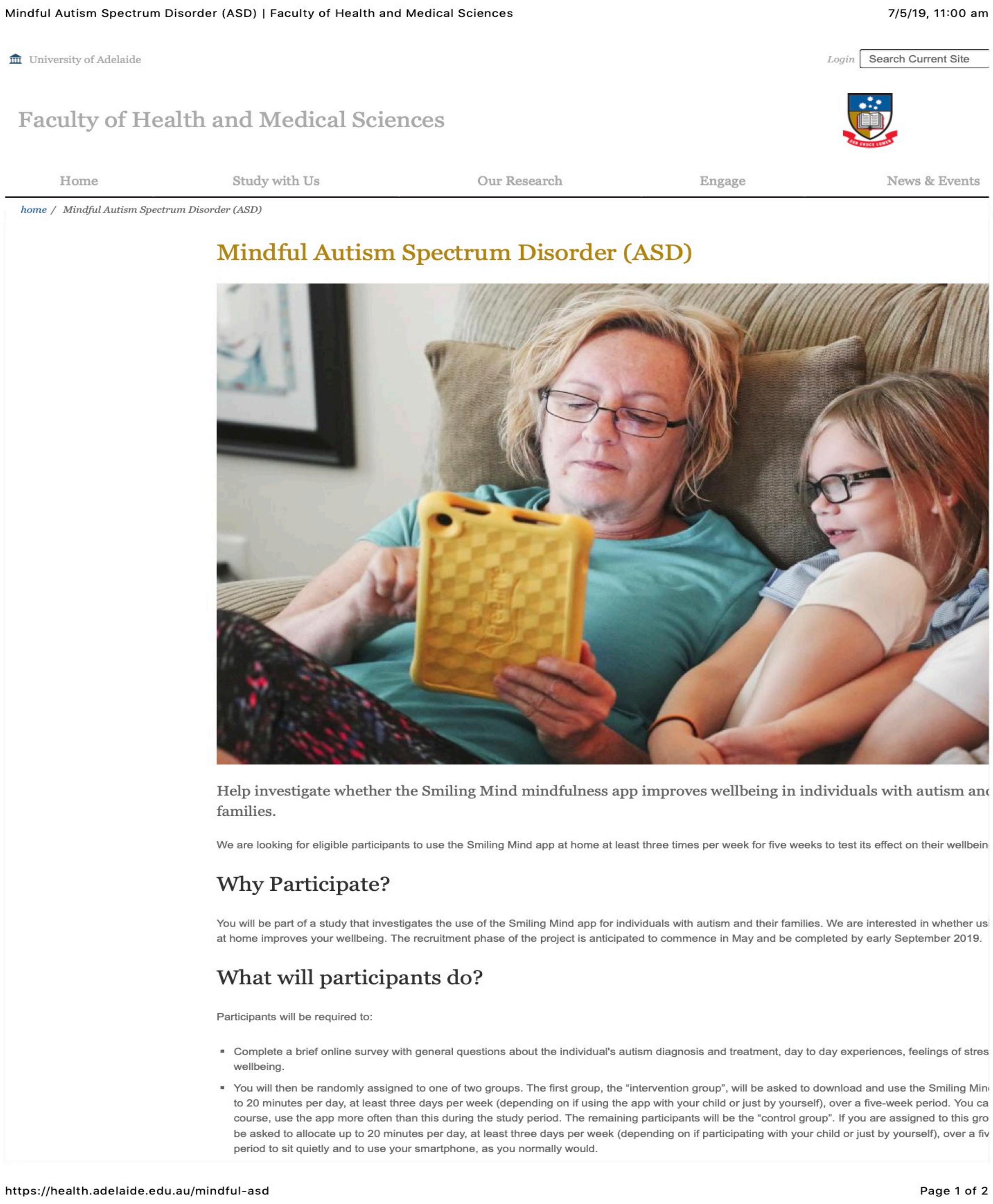
11. I understand my information will only be disclosed according to the consent provided, except where disclosure is required by law.

12. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

Participant (Adult with ASD) to complete:

Name: _________________________Signature: ____________________________ Date: _____________

Appendix P: Smiling Mind Recruitment Landing Site



Mindful Autism Spectrum Disorder (ASD) | Faculty of Health and Medical Sciences 7/5/19, 11:00 am

Faculty of Health and Medical Sciences

Mindful Autism Spectrum Disorder (ASD)

Help investigate whether the Smiling Mind mindfulness app improves wellbeing in individuals with autism an
families.

We are looking for eligible participants to use the Smiling Mind app at home at least three times per week for five weeks to test its effect on their wellbein

Why Participate?

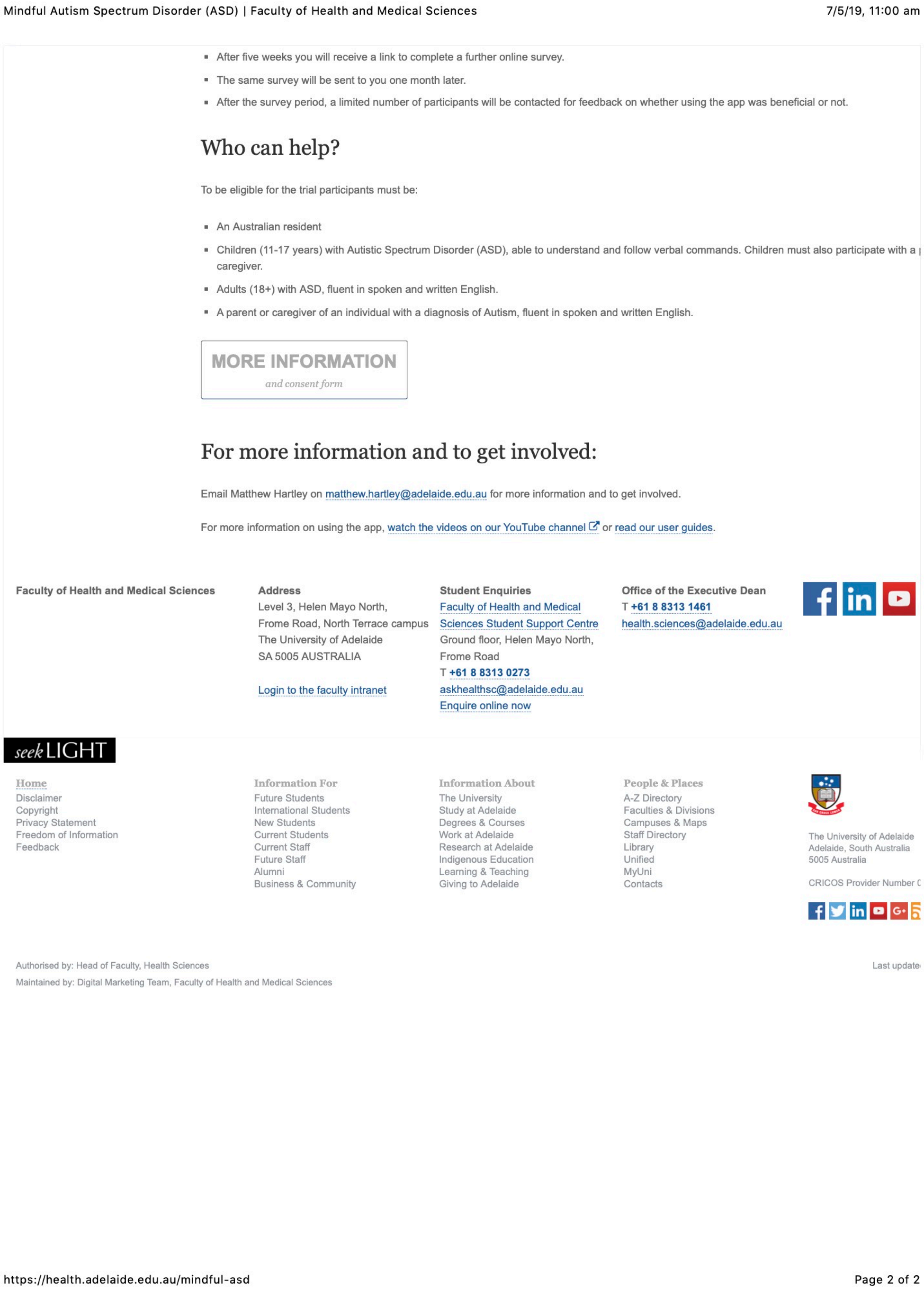
You will be part of a study that investigates the use of the Smiling Mind app for individuals with autism and their families. We are interested in whether us
at home improves your wellbeing. The recruitment phase of the project is anticipated to commence in May and be completed by early September 2019.

What will participants do?

Participants will be required to:

- Complete a brief online survey with general questions about the individual's autism diagnosis and treatment, day to day experiences, feelings of stres
wellbeing.
- You will then be randomly assigned to one of two groups. The first group, the “intervention group”, will be asked to download and use the Smiling Min
to 20 minutes per day, at least three days per week (depending on if using the app with your child or just by yourself), over a five-week period. You ca
course, use the app more often than this during the study period. The remaining participants will be the “control group”. If you are assigned to this gro
be asked to allocate up to 20 minutes per day, at least three days per week (depending on if participating with your child or just by yourself), over a fiv
period to sit quietly and to use your smartphone, as you normally would.

https://health.adelaide.edu.au/mindful-asd Page 1 of 2



Mindful Autism Spectrum Disorder (ASD) | Faculty of Health and Medical Sciences 7/5/19, 11:00 am

- After five weeks you will receive a link to complete a further online survey.
- The same survey will be sent to you one month later.
- After the survey period, a limited number of participants will be contacted for feedback on whether using the app was beneficial or not.

Who can help?

To be eligible for the trial participants must be:

- An Australian resident
- Children (11-17 years) with Autistic Spectrum Disorder (ASD), able to understand and follow verbal commands. Children must also participate with a caregiver.
- Adults (18+) with ASD, fluent in spoken and written English.
- A parent or caregiver of an individual with a diagnosis of Autism, fluent in spoken and written English.

MORE INFORMATION
and consent form

For more information and to get involved:

Email Matthew Hartley on matthew.hartley@adelaide.edu.au for more information and to get involved.

For more information on using the app, watch the videos on our YouTube channel or read our user guides.

Faculty of Health and Medical Sciences

Address
Level 3, Helen Mayo North,
Frome Road, North Terrace campus
The University of Adelaide
SA 5005 AUSTRALIA

Login to the faculty intranet

Student Enquiries
Faculty of Health and Medical
Sciences Student Support Centre
Ground floor, Helen Mayo North,
Frome Road
T **+61 8 8313 0273**
askhealthsc@adelaide.edu.au
Enquire online now

Office of the Executive Dean
T **+61 8 8313 1461**
health.sciences@adelaide.edu.au

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CRICOS Provider Number

Authorised by: Head of Faculty, Health Sciences
Maintained by: Digital Marketing Team, Faculty of Health and Medical Sciences

Last update

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