

Mindfulness, Self-Compassion, Parental Stress, Well-Being and Child Behaviour in
Neurodisability

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Executive Summary

This paper focusses on mindfulness in parents of children with neurodevelopmental disabilities, such as Autistic Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Tics, Tourette's Syndrome (TS) and/or intellectual disabilities.

Part I includes a systematic review of the literature exploring the comparative effectiveness of parent only mindfulness interventions and parallel parent and child mindfulness interventions, amongst parents of children with a range of neurodevelopmental disabilities (including ASD, ADHD, Tics, TS and/or intellectual disabilities). Previous reviews explored the effectiveness of mindfulness interventions amongst parents of children with ASD and those with a range of neurodevelopmental disabilities. However, it was not clear which type of interventions were more, less or equivalent in their effectiveness; parent only mindfulness interventions or parallel parent and child mindfulness interventions?

This review included a quality assessment of 13 studies using the Quality Assessment Tool for Quantitative Studies (QATQS). The inclusion criteria included a) studies that included a parent only mindfulness intervention or a parallel parent and child mindfulness intervention (including those based on Mindfulness Based Stress Reduction (MBSR), Mindfulness Based Cognitive Therapy (MBCT) and/or Mindful Parenting (MP), b) studies including parents of children 0-18 years with neurodevelopmental disabilities and c) studies including a pre and post outcome measure. Studies were excluded if they included a) parent training with an additional mindfulness component, b) typically developing children, those with developmental delay or looked after children and c) studies that were not peer reviewed or published.

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A narrative synthesis of the findings highlighted that there was sufficient evidence to support the effectiveness of both parent only and parallel interventions in reducing parental stress, in parents of children with ASD, ADHD. There was some evidence of reductions in parental stress amongst parents of children with comorbid neurodevelopmental disabilities. Parallel parent and child interventions had a positive impact on outcomes for children with ADHD such as reductions in ADHD symptoms, inattention, internalising and externalising difficulties. There was a lack of sufficient evidence to support parent only interventions having a positive impact on child outcomes.

In conclusion, further research is needed to establish whether parent only interventions have the potential to have a positive impact on child outcomes, in families of children with neurodevelopmental disabilities. Furthermore, RCT's comparing parent only and parallel parent and child interventions are needed to establish which are more effective for parental and child outcomes. Future studies should also explore the effectiveness of mindfulness interventions in parents of children with Tics/TS and intellectual disabilities.

Part II includes the empirical paper which explores mindfulness, self-compassion, parental stress, well-being and child externalising difficulties in parents of children with neurodevelopmental disabilities. Previous studies have shown that children with neurodevelopmental disabilities present with high rates of co-morbid neurodevelopmental disabilities, internalising difficulties (i.e. emotional) and externalising (i.e. behavioural) difficulties. Studies show that parents report higher levels of parental stress than parents of typically developing children. Emerging literature explores how mindfulness theory can be applied to the parenting context; mindful parenting (MP) to reduce parental stress and reactivity. Understanding the relationships between mindfulness, self-compassion, parental stress, well-being and child externalising difficulties in a neurodevelopmental sample is vital so that MP interventions can be tailored accordingly for specific groups. The current study

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aimed to a) explore relationships between mindfulness (trait and MP), self-compassion, parental stress, well-being and child externalising difficulties, amongst parents of children with neurodevelopmental disabilities (including ASD, ADHD, Tics, TS and intellectual disabilities), b) explore whether the relationship between parental stress and child externalising difficulties is mediated by mindfulness and to c) compare levels of mindfulness, self-compassion, parental stress, well-being and child externalising difficulties amongst parents of children with specific primary diagnoses (e.g. ASD, ADHD and Tics/TS).

The empirical study was a quantitative, cross sectional, correlational, questionnaire based study. Parents were eligible to take part if they had a child aged 0-17 years old with a diagnosis of a neurodevelopmental disability (ASD, ADHD, Stereotypies, Tics, TS and/or intellectual disability). Parents were recruited retrospectively and prospectively through two specialist neurodevelopmental NHS teams in London. This included a mail out to those being seen in clinic and those who had previously consented to participate in research and clinicians handing out study information sheets to parents seen in clinic. Parents were also recruited through national charities such as Tourette's Action, ADHD Foundation, Autism Research, Special Needs and Parents (SNAP) and public Facebook groups for parents of children with neurodevelopmental disabilities.

Parents made direct contact with the researcher by phone or email. Informed written consent was gained before parents went on to complete six questionnaires online or by post. These included measures of trait mindfulness (Five Facets of Mindfulness Questionnaire), MP (Interpersonal Mindfulness in Parenting Scale), self-compassion (Self-Compassion Scale), parental stress (Parental Stress Scale), well-being (WHO (Five) Well-Being Index) and child externalising difficulties (Strengths and Difficulties Scale). In total, 84 parents consented and took part in the study. Of these, 12 participants were recruited from NHS services and 72 were recruited through national charities and/or public Facebook group advertisements.

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Findings showed that higher levels of MP and self-compassion were significantly related to lower levels of parental stress. Higher levels of trait mindfulness and self-compassion were significantly related to increased parental well-being. Higher levels of MP were related to lower levels of child internalising difficulties and child externalising difficulties (although these findings did not remain significant after applying Bonferroni correction). Of the facets of MP, higher levels of self-regulation (i.e. non-reactivity) was significantly related to lower levels of child externalising difficulties and compassion for self and child was significantly related to lower levels of parental stress and child internalising difficulties.

The relationship between parental stress and child externalising difficulties was not mediated by trait mindfulness or MP. However, the reverse relationship was found, highlighting that the relationship between child externalising difficulties and parental stress was mediated by MP but not trait mindfulness. Thus, child externalising difficulties significantly related to parental stress via the capacity to draw upon MP practices or not. This highlights that MP may be important for parents to draw upon in the face of child externalising difficulties.

Between group analyses revealed that there were no significant differences between levels of trait mindfulness, parental stress and well-being in parents of children with a primary diagnosis of ASD, ADHD or Tics/TS. Lower levels of MP and self-compassion were found in parents of children with ASD and ADHD in comparison to parents of children with Tics/TS. Parents of children with ASD reported significantly higher levels of total child difficulties, internalising and externalising difficulties than parents of children with Tics/TS, and higher levels of total child difficulties and internalising difficulties than those with ADHD.

In conclusion, specific MP interventions are likely to be helpful interventions for parents of children with neurodevelopmental disabilities. Specifically, those with ASD who

report particularly high levels of child difficulties and low levels of MP. Increasing parent's mindful parenting levels through MP interventions are likely to improve parental stress levels in the face of high levels of child externalising difficulties. Mindful parenting interventions that support parents to foster non-reactivity and compassion towards their child and themselves are more likely to be helpful in improving parental stress and coping in the face of child internalising and externalising difficulties.

Part III includes an integration, impact and dissemination critical section. It aims to discuss how the review and empirical study are related yet distinct pieces of work and how they both uniquely contribute to the existing literature. The discussion will also include critical appraisal and reflections on the experience and decisions made during the systematic review and empirical study. It also discusses the potential impact of the review and empirical study and plans for dissemination.

I. Systematic Review

Effectiveness of Parent Only and Parallel Parent and Child Mindfulness Interventions
in Neurodisability

Abstract

Parents of children with neurodevelopmental disabilities report higher levels of parental stress and child behaviour difficulties than parents of typically developing children. Emerging literature has found that parents of children with neurodevelopmental disabilities report reduced parental stress and improved child behaviour following mindfulness interventions. However, it is not clear which are more effective: parent only mindfulness interventions or parallel parent and child mindfulness interventions. This review evaluates 13 studies that included: (a) a mindfulness intervention for parents, or a parallel parent and child mindfulness intervention (interventions were based on Mindfulness Based Stress Reduction (MBSR), Mindfulness Based Cognitive Therapy (MBCT), Mindful Parenting (MP) or a combination of these), (b) parents of children aged 0-18 years old with at least one neurodevelopmental disability (e.g. Autistic Spectrum Disorder, Attention Deficit Hyperactivity Disorder, Tics, Tourette's Syndrome, intellectual disability), and (c) a pre and post intervention outcome measure. A narrative synthesis of findings highlighted that both parallel parent and child mindfulness interventions and parent only mindfulness interventions led to significant reductions in parental stress. There was some evidence for parallel interventions having a positive impact on child outcomes (i.e. reductions in ADHD symptoms, internalising and externalising difficulties), in families with a child with ADHD. Less is known about the effectiveness of mindfulness interventions for parents of children with Autistic Spectrum Disorder, Tics/Tourette's Syndrome, intellectual disabilities and/or comorbid neurodevelopmental disabilities. Further research is needed to establish the possible benefits of parent only mindfulness interventions on child outcomes, in parents of children with a range of neurodevelopmental disabilities. Future research should also explore the effectiveness of mindfulness interventions in parents of children with Tics/TS and/or intellectual disabilities.

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Keywords: Mindfulness Based Stress Reduction, Mindfulness Based Cognitive Therapy, Mindful Parenting, Neurodevelopmental Disability

Introduction

Neurodisability

Prevalence rates suggest that 3-4% of children have a life-long neurodevelopmental disability that is present from birth or childhood (Blackburn et al., 2012). Neurodevelopmental conditions considered in this review include Autistic Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Tics, Tourette's Syndrome (TS) and/or intellectual disabilities. Children with these conditions present with a range of impairments. DSM-V categorises ASD to include persistent deficits in social communication and social interaction, across multiple contexts and accompanied by restricted, repetitive patterns of behaviour, interests or activities (American Psychiatric Association, 2013). In contrast, ADHD is defined as persistent patterns of inattention and/or hyperactivity-impulsivity that interferes with functioning or development (American Psychiatric Association, 2013). Tics are referred to as "sudden, rapid, non-rhythmic motor movements or vocalisations usually appearing in bouts whilst waxing and waning in frequency, intensity and type of tic" (Mills & Hedderly, 2014, p. 24). Tourette's Syndrome is defined as "tics that are multiple, with motor tics and a phonic tic present at some point over a period of at least one year" with symptoms occurring daily that occur before the age of 18 (Mills & Hedderly, 2014, p. 24). Finally, intellectual disabilities are defined as developmental conditions characterised by significant deficits in intellectual functioning and adaptive functioning (American Psychiatric Association, 2013).

Estimates suggest that ADHD is the most common neurodevelopmental condition affecting 1-2% of children (Blackburn et al., 2012), with ASD affecting at least 1% (Blackburn et al., 2012), TS affecting between 0.3-0.8% of school age children (Scahill, Sukhodolsky, Williams & Leckman, 2005; Hirtz et al., (2007) and intellectual disabilities affecting 2.91% of children in the UK (Emerson, Hastings, McGill, Pinney & Shurlock, 2014).

Parental Stress and Child Behaviour

Caring for a child with a chronic, lifelong neurodevelopmental disability has been linked to significant levels of parental stress, amongst parents of children with ASD, ADHD, Tics, TS and/or intellectual disabilities (Anastopoulous, Guevremont, Shelton & DuPaul, 1992; Baker-Ericzn, Brooknian-Frazee & Stahner, 2005; Deault, 2009; Dyson, 1996; Duarte, Bordin, Yazigi & Mooney, 2005; Estes, Munson & Dawson, 2009; Hayes & Watson, 2013; Van de Weijer-Bergsma, Formsma, DeBruin & Bögels, 2012; Montes & Halterman, 2007; Rao & Beidel, 2009; Roach, Orsmond & Barratt, 1999). High rates of child externalising (i.e. behavioural) difficulties have also been reported in children with ADHD, ASD and intellectual disabilities (Eisenhower, Baker & Blacher, 2005; Hartley, Sikora & McCoy, 2008; Johnston & Mash, 2001). Comorbid neurodevelopmental disabilities are common and associated with increased parental stress (Stewart, Greene, Lessov-Schlaggar, Church & Schlaggar, 2015) and child externalising difficulties (Goldin, Matson, Tureck, Cervantes & Jang, 2013; Rao & Landa, 2014; Sukhodolsky, Scahill & Zhang, 2003; Yerys et al., 2009). Studies have shown that parents of children with a neurodevelopmental disability and comorbid ADHD report increased child externalising difficulties than those without comorbid ADHD (Goldin et al., 2013; Sukhodolsky et al., 2003; Yerys et al., 2009;).

Parental stress has been linked to lower levels of parental self-efficacy (Coleman & Karraker, 1998). According to social cognitive theory, reduced parental self-efficacy reflects an individual's perceived ability to cope in situations that they feel incapable of changing (Bandura, 1977,1991). Lower levels of parental self-efficacy are likely amongst parents of children with neurodevelopmental disabilities given that the conditions are lifelong and require long term care. The literature highlights that the relationship between increased parental stress and lowered parental self-efficacy is reciprocal and perpetuating. Parental stress can have negative effects on parenting styles, the parent-child relationship and parental self-efficacy.

Specifically, increased parental stress is associated with reduced parental warmth (Bögels, Lehtonen & Restifo, 2010) and more reactive, automatic and rejecting parenting styles (Belsky, 1984; Webster-Stratton, 1990).

Correlational studies have explored how parental stress might relate to child externalising difficulties. Studies have shown that increased parental stress and reactivity predict increased child internalising (i.e. emotional) and externalising difficulties (Johnson & Reader, 2002; Hastings, 2002; Miller-Lewis et al. 2006). Furthermore, increased child externalising difficulties also predict increased parental stress (Beck, Hastings, Daley & Stevenson, 2004; Hassall, Rose & McDonald, 2005). This suggests that parental stress and child externalising difficulties have a mutually reciprocal relationship with one another (Neece, Green & Baker, 2012). Therefore, increased parental reactivity and stress can lead to and exacerbate child externalising difficulties, resulting in further parental stress (Neece et al., 2012; Pesonen et al., 2008;).

Parent Training

Historically, evidence-based parent training programmes based on psychosocial and behavioural models have been recommended as treatment for children presenting with ADHD or significant externalising difficulties (NICE, 2016). However, it is not clear whether these programmes are effective for parents of children with other neurodevelopmental disorders such as ASD, Tics, Tourette's, intellectual disabilities or comorbid neurodevelopmental disabilities. Previous studies have found that high levels of parental stress, depression and parental ADHD can limit the effectiveness of interventions (Forehand, Furey & McMahon, 1984; Osbourne, McHugh, Saunders & Reed, 2008; Psychogiou, Daley, Thompson & Sonuga-Barke, 2008; Robbins, Dunlop & Plenis, 1991; Reyno & McGrath, 2006; Strauss et al. 2012; Webster-Stratton, 1990;). Therefore, it is likely that parents with particularly high levels of parental

stress or those who have children with comorbid neurodevelopmental disabilities may not benefit from these programmes.

Mindfulness

To address this problem, researchers and clinicians have turned to the mindfulness literature to explore its possible effects on parental stress. The literature defines general levels of mindfulness (i.e. trait mindfulness) as “*paying attention in a particular way; on purpose, in the present moment, and non-judgementally*” (Kabat-Zinn, 1994, p. 4). Mindfulness theory suggests that the act of intentionally focusing on one’s attention, with a non-judgemental attitude, can foster adaptive coping responses to stressful situations. The effectiveness of Mindfulness Based Stress Reduction (MBSR) is established in reducing levels of distress in individuals suffering from long term, chronic physical illnesses (i.e. cancer, chronic pain) (Rosenzweig et al., 2010). MBSR has also been shown to reduce stress amongst clinical and non-clinical populations. (Grossman, Niemann, Schmidt & Walach, 2003; Ledesma & Kumano, 2008). Rather than attempting to reduce symptoms, MBSR focuses on observing, describing and accepting all experiences and/or sensations non-judgementally.

Mindful Parenting (MP)

Due to the potentially chronic nature of stress associated with parenting a child with neurodevelopmental disabilities, emerging research has explored how mindfulness might be applied to the parenting context. Mindful parenting (MP) has been defined as “*applying the practices of paying attention in an intentional and non-judgemental manner to one’s child and parenting*” during specific parent-child interactions (Kabat-Zinn and Zabat-Zinn, 1997 as cited in Beer, Ward & Moar, 2013, p. 103). Thus, MP is an example of state (i.e. situational) mindfulness, in contrast to one’s level of trait mindfulness which reflects a broader capacity to be mindful. Mindfulness theory suggests that in the context of parenting, an increased ability

to tune into and regulate one's own emotional states may result in more adaptive and less reactive responses to the child (Duncan, Coatsworth & Greenberg, 2009). The MP model (see p. 69) proposes that interventions may increase parental sensitivity, attunement and reduce reactivity and stress (Duncan et al., 2009). This is hypothesized to interrupt the unhelpful cycle of increased parental stress and reactivity that perpetuates child externalising difficulties and vice versa (Duncan et al., 2009; Patterson, 2002).

Components of Mindfulness Based Stress Reduction (MBSR) and Mindfulness Based Cognitive Therapy (MBCT) have been adapted to develop the MP programme (Bögels & Restifo, 2014). Emerging preliminary studies highlight that parents of children with neurodevelopmental disabilities completing mindfulness interventions report a range of positive outcomes. Some pre-post studies report reduced parental stress (DeBruin, Blom, Smit, van Steensel & Bögels, 2015; Hwang, Kearney, Klieve, Lang & Roberts, 2015; Neece, 2014; van de Weijer-Bergsma et al., 2012), reduced child problems (Hwang et al., 2015), reduced child anxiety (Hwang et al., 2015), reduced child ADHD symptomology (Neece, 2014; Van der Oord, Bögels & Peijnenberg, 2012), reduced parent ADHD symptomology (Van der Oord et al., 2012) and increased parental trait mindfulness (Hwang et al., 2015; Van der Oord et al., 2012). Of these, two studies included parents of children with ASD (DeBruin et al., 2015; Hwang et al., 2015) and three studies included parents of children with ADHD (Neece, 2014; van de Weijer-Bergsma et al., 2012; Van der Oord et al., 2012).

Critique of Literature

There are significant limitations to the current evidence base. Firstly, most studies are pre-post intervention design without use of control groups. Only one study used a wait list control group to control for the effect of time and repeated measurements (Van der Oord et al., 2012). Without the use of control groups, it is difficult to assess whether the effects are due to

the intervention itself or whether participants would have improved over time or due to other factors (e.g. child medication). It is also possible that with such small samples (ranging from 6 parent-children dyads (Hwang et al., 2015) to 46 parents (Neece, 2014) these studies may lack power to detect significant effects, thus reducing external validity. Secondly, the studies vary in the interventions they evaluate. Some studies include mindfulness interventions based on MP and others are adapted from or based on MBSR and/or MBCT or a combination of all three programmes. As a result, it is difficult to evaluate which aspects of the programmes are effective, and for whom. Thirdly, some studies include parent only mindfulness interventions, and others include parallel parent and child mindfulness interventions. This makes it difficult to determine which components (i.e. parent or child) are responsible for the outcomes and which component leads to the best outcomes for parents and children. Finally, some studies include parents of children with ADHD and others include parents of children with ASD. Little is known about the effectiveness of mindfulness interventions for parents of children with Tics/Tourette's Syndrome or those with comorbid neurodevelopmental disabilities. This limits the extent to which conclusions can be made about the effectiveness of mindfulness interventions for parents of children with a range of neurodevelopmental disabilities.

Current Review

To my knowledge, two systematic reviews have been published on mindfulness interventions for parents of children with neurodevelopmental disabilities (Cachia, Anderson & Moore, 2015; Petcharat & Liehr, 2016). The first review explored the effectiveness of mindfulness interventions in parents of children with ASD (Cachia et al., 2015). This review found support for the effectiveness of mindfulness interventions in reducing parental stress and increasing well-being as well as speculation about the potential effects on child behaviour. The second review explored the effectiveness of mindfulness interventions for parents of children with a range of neurodevelopmental disabilities (including ASD, ADHD, intellectual

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disabilities, developmental delay, developmental disabilities and cognitive or health impairments) (Petcharat & Liehr, 2016). This review concluded that mindfulness interventions increased parental mindful awareness, well-being, and reduced parental stress, anxiety, depression, and child behaviour (Petcharat & Liehr, 2016). However, this review included only five studies. This limits the extent to which these findings can be generalized to clinical settings. Furthermore, neither review sought to determine whether parallel parent and child mindfulness interventions are more, less or equally as effective as parent only mindfulness interventions, in families of children with neurodevelopmental disabilities.

The current review sought to address this gap in the literature. It aimed to explore the comparative effectiveness of parallel parent and child mindfulness interventions and parent only mindfulness interventions, in families with children aged 0-18 years old with a neurodevelopmental disability (including ASD, ADHD, Tics, TS and/or intellectual disabilities). Establishing the effectiveness of parent only and parallel parent and child interventions will develop the evidence base for mindfulness interventions in neurodevelopmental disability. Specifically, it will help to determine which intervention leads to improvements in child outcomes and highlight areas for future research.

Method

Search Strategy

A comprehensive literature search was conducted between June and July 2017 using Google Scholar and three electronic databases; Psych Info, Web of Science and PubMed.

Search terms included “mindful parenting” OR “mindfulness” OR “self-compassion” OR “mindfulness based stress reduction” AND “parents” OR “parenting” AND “neurodevelopmental disorders” OR “neurodevelopmental disability” OR “neurodevelopmental” OR “ASD” OR “Autistic Spectrum Disorder” OR “ADHD” OR “Attention Deficit Hyperactivity Disorder” OR “Tics” OR “Tourette’s” OR “intellectual disability” OR “learning disability”. The search terms were applied to “titles”, “abstracts” and “topics”.

Reference lists of included papers were checked for relevant papers.

Study Eligibility Criteria

The inclusion criteria for studies included a) a parent only mindfulness intervention or a parallel parent and child mindfulness intervention. Mindfulness interventions could be based on Mindfulness Based Stress Reduction (MBSR) (Kabat-Zinn, 2003) (Appendix 1), Mindfulness Based Cognitive Therapy (MBCT) (Segal, Williams & Teasdale, 2012) (Appendix 2) and/or Mindful Parenting (MP) programmes (Bögels et al., 2010) (Appendix 3), b) parents of children aged 0-18 years old with neurodevelopmental disabilities, including ASD, ADHD, Tics, Tourette’s, intellectual disabilities, and c) a pre-and-post intervention outcome measure.

There were no restrictions on date of publication or country. Exclusion criteria included a) studies that included parent training interventions with an additional mindfulness

component, b) studies involving typically developing children, children with developmental delay, or looked after children, and c) studies that were not peer reviewed or published.

Study Selection

The primary researcher reviewed all articles. Figure 1 highlights the process taken to identify the studies included in this review. The electronic search retrieved 155 articles. Of these, 59 articles were identified via Psych Info, 49 via Web of Science, 20 via Pub Med, 17 via Google Scholar and 10 additional studies were identified through reference lists of identified studies.

After duplicates were removed, 52 studies were screened by title and abstract. Nineteen studies were excluded using the exclusion criteria. Of these, six studies were excluded due to design, four studies were excluded due to publication status, three studies were excluded due to sample, two were excluded due to intervention type, one was a duplicate, two were abstracts and one was a non-intervention based book on MP.

A total of 33 studies were fully screened. A further 20 studies were excluded. Of these, ten studies were excluded due to sample, four studies were excluded due to intervention type, two studies were excluded due to design, two studies were excluded due to being incomplete, one was a duplicate, and one was a non-intervention based book.

A total of 13 studies were included for analysis.

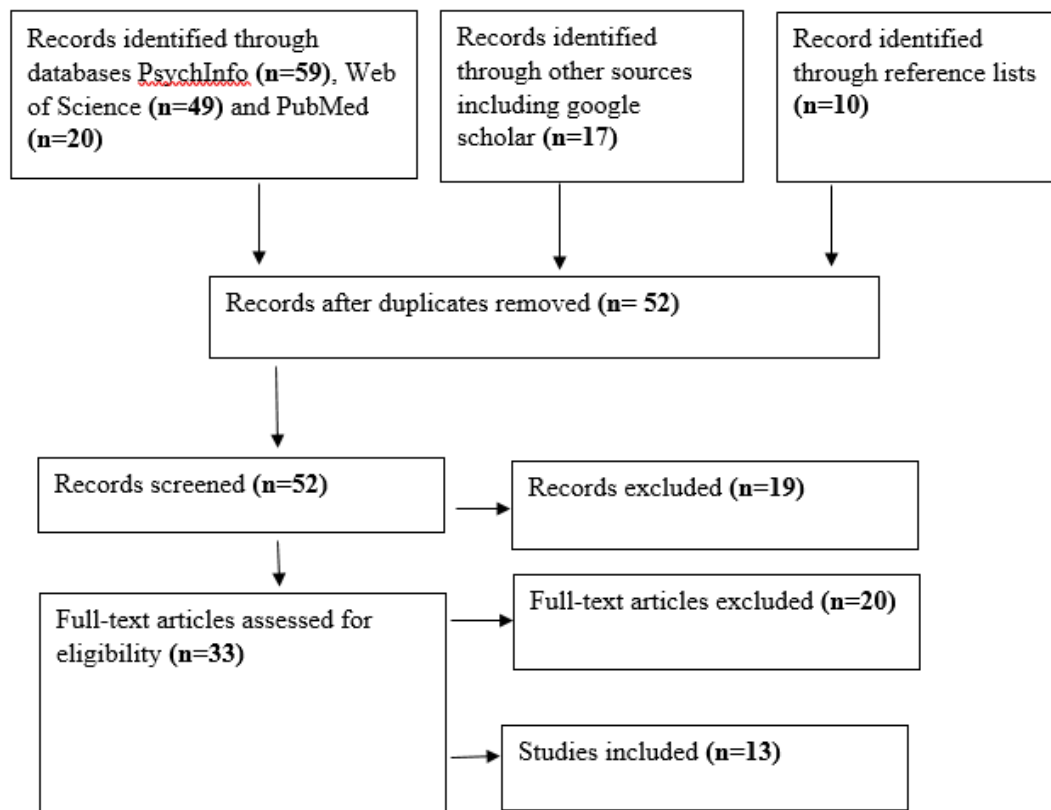


Figure 1: PRISMA diagram of process

Data regarding study design, country, sample, participants, intervention type, therapist training, results including effect sizes and overall quality ratings were extracted. Data are presented in Table 1 for all 13 studies.

Quality Assessment

The Quality Assessment Tool for Quantitative Studies (QATQS) developed by the Effective Public Health Practice Project (EPHPP; Thomas, 2003) was selected as a tool to assess the quality of each study (Appendix 4). It was chosen due to its ability to appraise and assess quantitative studies across eight domains including; selection bias, study design, confounders, blinding, data collection methods, withdrawals/drop-outs, intervention integrity and analysis. Applying this tool to each paper included providing a score for each question

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across six out of eight domains, as shown in Appendix 5. This results in a methodological rating of ‘weak’, ‘moderate’ or ‘strong’ for each domain, leading to an overall quality rating for all studies (presented in Table 1). An overall rating of ‘weak’ was determined if the study obtained two or more ‘weak’ ratings, ‘moderate’ was given if the study obtained one ‘weak’ rating and an overall rating of ‘strong’ was given to studies that were not assigned any ‘weak’ scores in any domain. Construct validity and content validity was reported to be acceptable (Thomas, Ciliska, Dobbins & Micucci, 2004). Inter-rater reliability was also found to be acceptable (Thomas et al., 2004).

Results

Of the 13 studies included, six were quasi experimental pre-post designs, four were multiple baseline or dyadic designs and three were randomised controlled trials (RCT's). Table 1 highlights each studies design, publication country, sample, participants, intervention type, therapist training, findings including effect sizes and overall quality rating.

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Table 1: Study characteristic of included studies

Title/Date	Country/ Design	Sample/ Participants	Intervention	Parent vs parent and child	Instructor	Measures	Outcomes	Effect size (ES) (Cohens <i>d</i>)	Overall Quality Rating
Bakhshayesh, Khishvand & Siavoshi (2015)	Iran RCT	N=36 children (aged 6-12 with ADHD) + parents	8 x 90 mins MP group for parents (Bögels et al., 2010) + child MBCT intervention (Segal et al., 2002) & adapted from (Van der Oord et al., 2009)	Parent and child intervent ion	CBT therapists with mindfulne ss experience and training	1.Connors Adult ADHD Rating Scale 2.Buri Parental Authority Questionnaire 3.Parental Stress Index	1. Child ADHD symptoms significantly reduced after child mindfulness training 2. Parental distress significantly reduced after parent mindfulness training 3. Significant improvements in child hyperactivity in parallel training group compared to the other two groups	1.0 (large ES)	M

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Title/Date	Country/ Design	Sample/ Participants	Intervention	Parent vs parent and child	Instructor	Measures	Outcomes	Effect size (ES) (Cohens <i>d</i>)	Overall Quality Rating
Benn, Akiva, Arel & Roeser (2012)	US Randomi sed waitlist control group	N=32 parents of children aged 5-19 with ASD/ADH D	5 x 2 hour MBSR group for parents	Parent intervent ion	Instructors with training in MBSR or MBCT	1.Five Facets Mindfulness Questionnaire 2.Percieved Stress Scale 3.State-Trait Anxiety Inventory (STAI) 4.Center for Epidemiological Studies Depression Scale (CES-D) 5.Positive and Negative Affect Schedule (PANAS) 6.Psychological Well-Being Scale	1. Significant reductions in parental stress, anxiety. Significant increases in mindfulness and self- compassion at post and 2 months follow-up	0.40 (medium ES), 0.52 (medium ES), 0.52 (medium ES), 0.40 (medium ES)	M

7. Self Compassion

Scale

8. Forgiveness

Scale

9. Interpersonal

Reactivity Index

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Title/Date	Country/ Design	Sample/ Participants	Intervention	Parent vs parent and child	Instructor	Measures	Outcomes	Effect size (ES) (Cohens <i>d</i>)	Overall Quality Rating
Bögels, Hoogstad & van Dun (2008)	Netherla nds Pre-post group design	N=14 adolescents aged 11-18 with ADHD, ODD/CD or ASD and their parents	8 x 1.5 hour parallel parent and child intervention, based on MBCT (Segal, Williams and Teasdale, 2002)	Parent and child intervention	Experienc ed CBT therapists with training in mindfulne ss	1.Child Behaviour Checklist 2.Youth Self Report 3.Children's Social Behaviour Questionnaire 4.Self Control Rating Scale 5.Subjective Happiness Scale 6.Mindful Attention and Awareness Scale	1. Improvements in child reported internalizing and externalizing difficulties, attention. Improved performance on attention tests 2. Parents reported improvements on child externalizing and attention 3. Improvements in overall child difficulties 8 weeks follow up, reported by child and parent	0.5 (medium ES), 1.1 (large ES), 1.0 (large ES), 0.5 (medium ES), 0.6 (medium ES) 0.3 (small ES), 0.3 (small ES) 0.4 (medium ES), 0.9 (large ES)	S

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Title/Date	Country/ Design	Sample/ Participants	Intervention	Parent vs parent and child	Instructor	Measures	Outcomes	Effect size (ES) (Cohens <i>d</i>)	Overall Quality Rating
Dehkordian, Hamid, Beshlideh & Honormand (2016)	Iran RCT	N=60 children aged 8-12 with ADHD	8 week group MP intervention for parents (Bogels et al., 2010) 8 x 60 min social thinking skills group for adolescents Exercise group for adolescents	Parent intervent ion	No detail about instructor training	1.Connors Parenting Rating Scale 2.Pediatric Quality of Life Questionnaire	1. Significant improvements in adolescent's quality of life 2. Significant improvements in adolescent's quality of life following parent MP training compared to control group	.34 (small ES) .61 (medium ES)	S

MINDFULNESS IN NEURODISABILITY

Title/Date	Country/ Design	Sample/ Participants	Intervention	Parent vs parent and child	Instructor	Measures	Outcomes	Effect size (ES) (Cohens <i>d</i>)	Overall Quality Rating
Haydicky, Schechter, Wiener & Ducharme (2013)	US Pre-post group design	N=18 adolescents aged 13-18 with ADHD and their parents	8 x 1.5 hours weekly parallel mindfulness intervention for parents and children	Parent and child intervent ion	Doctoral students with training in mindfulne ss	1.WASI 2.Conners 3.Revised Child Anxiety and Depression Scale (RCADS) 4.Stress Index for Parents of Adolescents 5.Family Assessment Device 6.Issues Checklist 7.Acceptance and Action Questionnaire (AAQ)	1.Reductions in adolescents' inattention, conduct problems 2. Reductions in parenting stress. 3. Significant increases in MP 3. Adolescents did not report improvements. 6. Additional reductions in parental stress at follow up	.62-.70 (medium ES) .55-.91 (medium- large ES) .82 (large ES) 1.01 (large ES)	W

8. Interpersonal
Mindful Parenting-
Inventory

MINDFULNESS IN NEURODISABILITY

Title/Date	Country/ Design	Sample/ Participants	Intervention	Parent vs parent and child	Instructor	Measures	Outcomes	Effect size (ES) (Cohens <i>d</i>)	Overall Quality Rating
Hwang, Kearney, Klieve, Lang & Roberts (2015)	Australia Dyadic design	N=6 mother and child dyads (aged 10-15 years old with ASD)	8 x 2.5 hours weekly mindfulness programme + 2 months self-practice + 8-week programme (mothers teach their children mindfulness)	Parent only intervent ion	Mindfulne ss programm e developer/ author	1.Frieberg Mindfulness Inventory (FMI) 2.Parental Stress Scale 3.Family Quality of Life (FQOL) 4.Child Behaviour Checklist	1. 5/6 mothers reported increased mindfulness after parent training. 3/6 reported further increases after child training 2. Reductions in parental stress after parent training and 5/6 mothers reported further reductions after child training. 3.Increased quality of family life after parent training and 3/6 further increases in family life		W

MINDFULNESS IN NEURODISABILITY

Title/Date	Country/ Design	Sample/ Participants	Intervention	Parent vs parent and child	Instructor	Measures	Outcomes	Effect size (ES) (Cohens <i>d</i>)	Overall Quality Rating
Rayan & Ahmad (2016)	Jordan Quasi experime ntal design with non- equivale nt control group	N=104 parents of children aged 1/2-17 with ASD.	5 x 1 hour weekly mindfulness intervention, adapted from Ferraioli and Harris (2013) and (Bögels & Restifo, 2013)	Parent only intervent ion	Clinical nurse specialist, certified in MBSR and own practice	1.Demographic survey 2.The World Health Organization QOL Assessment Brief 3.The Positive Stress Reappraisal Subscale of the Cognitive Emotion Regulation Questionnaire (CERQ) 4.The Mindful Attention Awareness Scale (MAAS)	1. Significant improvements in parental quality of life and trait mindfulness	.72 (large ES) and .48 (medium ES)	S

MINDFULNESS IN NEURODISABILITY

Title/Date	Country/ Design	Sample/ Participants	Intervention	Parent vs parent and child	Instructor	Measures	Outcomes	Effect size (ES) (Cohens <i>d</i>)	Overall Quality Rating
Singh, Singh, Lancioni, Singh, Winton and Adkins (2010)	US Multiple baseline design	N=2 mothers and their children aged 10-12 with ADHD	12 week mindfulness for parents + children	Parent and child intervention	Experienc ed mindfulne ss trainer	1.Parent rates compliance to requests 2.Parents rate satisfaction in interactions with child and subjective units of happiness	1.Child compliance increased 2.Training children in mindfulness positively enhanced mother-child interactions 3.Satisfaction in interactions increased with further increases following child training 4.Units of parental happiness increased in the same way		W

MINDFULNESS IN NEURODISABILITY

Title/Date	Country/ Design	Sample/ Participants	Intervention	Parent vs parent and child	Instructor	Measures	Outcomes	Effect size (ES) (Cohens <i>d</i>)	Overall Quality Rating
Singh, Lancioni, Winton, Singh, Curtis, Wahler & McAleavey (2007)	Multiple baseline design	N=3 mothers and children aged 4-6 years with developmen tal disabilities	12 x 2 hour one-to-one mindfulness training	Parents only intervention	Senior investigato r	1. Subjective Units of Parenting Satisfaction (SUPS) 2. Subjective Units of Interaction Satisfaction (SUIS) 3. Subjective Units of Use of Mindfulness (SUUM)	1. Reductions in child aggression, non- compliance and self- injury 2. Increases in mothers' satisfaction with their parenting skills and interactions with their children		W

MINDFULNESS IN NEURODISABILITY

Title/Date	Country/ Design	Sample/ Participants	Intervention	Parent vs parent and child	Instructor	Measures	Outcomes	Effect size (ES) (Cohens <i>d</i>)	Overall Quality Rating
Singh, Lancioni, Winton, Fisher, Wahler, McAleavey, Singh & Sabaawi (2006)	Multiple baseline design	N=4 mothers and their children aged 4-6 with ASD	12 x 2 hour one-to-one mindfulness training	Parent only intervention	Senior investigato r	1. Aggression (measured by observation) 2. Subjective Units of Parenting Satisfaction (SUPS) 3. Subjective Units of Interaction Satisfaction (SUIS) 4. Subjective Units of Use of Mindfulness (SUUM) 5. Perceived Parental Stress	1. Reductions in child aggression and increases in child social skills 2. Parents reported greater mindfulness practice, increased satisfaction with parenting, more social interactions with their children, and lower parental stress		w

MINDFULNESS IN NEURODISABILITY

Title/Date	Country/ Design	Sample/ Participants	Intervention	Parent vs parent and child	Instructor	Measures	Outcomes	Effect size (ES) (Cohens <i>d</i>)	Overall Quality Rating
Van der Oord, Bögels & Peijnenburg, 2011)	Netherla nds Quasi experime ntal pre- post design with waitlist control	N=22 parents and their children aged 8-12 with ADHD	8x 90 minute parallel parent + child intervention, based on MBCT (Segal et al.2002) and MBSR (Kabat-Zinn, 1990)	Parent and child intervent ion	Experienc ed CBT therapists with extensive mindfulne ss experience	1.Disruptive Behaviour Disorder Rating Scale (CBDRS) 2.Parental Stress Index (PSI) 3.The Parenting Scale 4.Mindfulness Attention and Awareness Scale (MAAS) 5.The ADHD Rating Scale (ARS)	1.Significant reductions in child inattention, child hyperactivity/ Impulsivity 3.Significant reductions in parental inattention/ hyperactivity and impulsivity 4.Significant improvements in mindful awareness 5.Significant reductions in parental stress and over reactivity from pre-follow up	.80 (large ES) .56 (medium ES) .36 and .56 (small ES) .28 (small ES) .57 (medium ES) ES) .85 (large ES)	S

MINDFULNESS IN NEURODISABILITY

Title/Date	Country/ Design	Sample/ Participants	Intervention	Parent vs parent and child	Instructor	Measures	Outcomes	Effect size (ES) (Cohens <i>d</i>)	Overall Quality Rating
Van de Weijer-Bergsma, Formsma, de Bruin & Bögels (2012)	Netherla nds Pre-post design	N=10 adolescents aged 11-15 with ADHD and their parents.	8 x 1.5 hour weekly mindfulness for adolescents (Bögels and Mindfulness in Schools Project) + parents MP intervention (Bögels et al. 2008)	Parent and child intervent ion	Interventio ns delivered by experience d CBT therapists who were experience d mindfulne ss practitione rs	1.Youth Self Report 2.Child Behaviour Checklist 3.Teacher Report Form 4.Behaviour Rating Inventory of Executive Functioning (BRIEF) 5.Mindfulness Attention Awareness Scale (MAAS) 6.Parental Stress Index 7.Parenting Scale	1. Borderline significant reductions in child attention problems and internalising symptoms 2. Significant reduction in child behaviour problems, reported by fathers only 3. Borderline significant improvements in child executive functioning reported by fathers	0.6 (medium ES), 0.4 (medium ES) and 0.2 (small ES) 1.0 (large ES) and 0.5 (medium ES)	S

	8.Flinders Fatigue Scale	4. Improvements in adolescent's performance on attention tests	0.9 (large ES)
	9.Subjective Happiness Scale		
	10.Computerised tests of attention	5. Fathers, but not mothers, reported reduced parenting stress	.7 (medium ES)
		6. Mothers reported reduced overreactive parenting, whereas fathers reported an increase	0.9 (large ES), 0.3 (small ES), 1.1. (large ES)
		7. No effect on mindful awareness for adolescents or parents	

MINDFULNESS IN NEURODISABILITY

Title/Date	Country/ Design	Sample/ Participants	Intervention	Parent vs parent and child	Instructor	Measures	Outcomes	Effect size (ES) (Cohens <i>d</i>)	Overall Quality Rating
Zhang, Chan., Ting & Wong (2017)	Hong Hong Pre-post design	N=11 children aged 8-12 with ADHD and their parents	8 x 90 minute group MP intervention for parents + child mindfulness, based on MBSR (Kabat-Zinn 1990) and MBCT (Segal et al. 2002)	Parent and child intervention	Experienc ed therapists in working with children with special needs and in providing group mindfulne ss	1.CONNORS continuous performance test 2.Test of everyday attention for children 3.The Eyberg child behaviour inventory 4.The Behaviour Rating Inventory of Executive Function 5.Parental Stress Index 6.Parenting Scale 7.Interpersonal Mindfulness in Parenting	1. Improvements on child attention tests. 2. Parental stress increased 3.No statistically significant reductions in parental stress or improvements in MP	.73 (medium ES)	M

W=Weak study quality rating, M=Moderate quality study rating, S=Strong quality study rating

Review of Studies

Intervention type/format/duration. All studies included at least a parent mindfulness intervention, based on one model or a combination of models, including MBSR (Kabat-Zinn, 2003), MBCT (Segal et al., (2012) and/or MP (Bögels & Restifo, 2014). All three programmes have similar aims, theoretical frameworks and content (See appendices 1-3 for programme overviews). The MP programme incorporates the formal practices from MBSR and MBCT such as body scan, mindfulness of the breath and body, yoga, mindful seeing and walking. All three programmes have a focus on the application of mindfulness in everyday life. However, MP interventions apply mindfulness to specific daily parenting experiences.

Interventions differed in their duration, length, therapist training and content. Studies also varied in the extent to which adaptations were made to improve the accessibility of interventions. For example, some studies adapted and tailored interventions for children and adolescents with ADHD.

Due to the differences in content, Table 2 highlights the models used and the different components of the intervention reported by each study. This highlights that four studies included interventions that were based on MBSR (Benn, Akiva, Arel & Roeser, 2012; Singh et al., 2006; Singh et al., 2007; Singh et al., 2010), three included interventions based on MP (Bakhshayesh, Khishvand & Siavoshi, 2015; Dehkordian, Hamid, Beshlideh & Honormand, 2016; Rayan & Ahmad, 2016; van de Weijer-Bergsma et al., 2012), two included interventions based on MBCT (Bögels, Hoogstad & van Dun, 2008; Haydicky, Schechter, Wiener & Ducharme, 2013), two studies used a combination of MBSR/MBCT and MP (Van der Oord., 2011; Zhang, Chan, Ting & Wong, 2017) and one study used Early Buddha teachings (Hwang et al., 2015). Of the few studies using a purely MP model; two studies included parents of

children with ADHD (Dehkordian et al., 2016; van de Weijer-Bergsma et al., 2012) and one included parents of children with ASD (Rayan & Ahmad, 2016).

The most commonly reported components were applying mindfulness to everyday life, practising homework, practising mindfulness of the breath and body, self-compassion and an emphasis on attention and awareness. The interventions based on MP incorporated some additional, consistent components such as parental patterns and schemas, stress and its relationship with conflict and parenting, love and limits, and elements of yoga.

MINDFULNESS IN NEURODISABILITY

Table 2: Models and components of interventions

Study	Parent only	Parent and child	Sample	Manual; MP, MBSR, MBCT	Autopilot/Awareness	Non-Reactivity	Self-compassion	Patterns and schemas	Stress, conflict and parenting (inc. rupture and repair/tuning into child emotional states	Love and limits	Meditation of breath	Meditation of body	Imagery	Communication/Interaction	Applying mindfulness to everyday life	Attention/Distraction	Attitude/Judging/Acceptance	Yoga	CBT/Psychoeducation	Boundaries	Homework/practice
Bakhshayesh, Khishvand & Siavoshi (2015)	✓		ADHD	MP	✓	✓	✓	✓	✓	✓	✓	✓			✓	✓	✓	✓			✓
Benn, Akiva, Arel & Roeser (2012)	✓		ASD/ADHD	MBSR	✓	✓		✓			✓	✓	✓		✓					✓	
Bögels, Hoogstad & van Dun (2008)		✓	ADHD/ASD	MBCT	✓	✓					✓	✓		✓	✓	✓	✓	✓			

MINDFULNESS IN NEURODISABILITY

Study	Parent only	Parent and child	Sample	Manual; MP, MBSR, MBCT	Autopilot/Awareness	Non-Reactivity	Self-compassion	Patterns and schemas	Stress, conflict and parenting (inc. rupture and repair/tuning into Love and limits	Meditation of breath	Meditation of body	Imagery	Communication/Interaction	Applying mindfulness to everyday life	Attention/Distractio	Attitude/Judging/Acepta	Yoga	CBT/Psychoeducation	Boundaries	Homework/practice
Dehkordian, Hamid, Beshlideh & Honormand (2016)	✓		ADHD	MP	✓	✓	✓	✓	✓	✓	✓			✓	✓	✓	✓			✓
Haydicky, Schecter, Wiener & Ducharme (2013)		✓	ADHD	MBCT	✓	✓				✓	✓		✓	✓	✓		✓	✓	✓	✓
Hwang, Kearney, Klieve, Lang & Roberts (2015)	✓		ASD	Early Buddha teachin gs						✓					✓		✓			

MINDFULNESS IN NEURODISABILITY

Study	Parent only	Parent and child	Sample	Manual; MP, MBSR, MBCT	Autopilot/Awareness	Non-Reactivity	Self-compassion	Patterns and schemas	Stress, conflict and parenting (inc. rupture and repair/tuning into child	Love and limits	Meditation of breath	Meditation of body	Imagery	Communication/Interaction	Applying mindfulness to everyday life	Attention/Distracton	Attitude/Judging/Acceptance	Yoga	CBT/Psychoeducation	Boundaries	Homework/practice
Rayan & Ahmad (2016)	✓		ASD	MP	✓	✓	✓	✓	✓	✓	✓	✓			✓	✓	✓	✓	✓		✓
Singh, Singh, Lancioni, Singh & Adkins (2010)		✓	ADHD	MBSR							✓	✓			✓						✓
Singh, Lancioni, Winton, Singh, Curtis, Wahler & McAleavey (2007)	✓		Comorbid	MBSR			✓		✓		✓			✓	✓	✓	✓		✓		✓

MINDFULNESS IN NEURODISABILITY

Study	Parent only	Parent and child	Sample	Manual; MP, MBSR, MBCT	Autopilot/Awareness	Non-Reactivity	Self-compassion	Patterns and schemas	Stress, conflict and parenting (inc. rupture and repair/tuning into child Love and limits	Meditation of breath	Meditation of body	Imagery	Communication/Interaction	Applying mindfulness to everyday life	Attention/Distracton	Attitude/Judging/Acceptance	Yoga	CBT/Psychoeducation	Boundaries	Homework/practice
Singh, Lancioni, Winton, Fisher, Wahler, McAleavey, Singh & Sabaawi (2006)	✓		ASD	MBSR			✓		✓		✓			✓		✓	✓			✓
Van der Oord, Bögels & Peijnenburg, 2011)		✓	ADHD	MBSR/ MBCT	✓	✓				✓	✓		✓	✓	✓	✓	✓	✓		✓

MINDFULNESS IN NEURODISABILITY

Study	Parent only	Parent and child	Sample	Manual; MP, MBSR, MBCT	Autopilot/Awareness	Non-Reactivity	Self-compassion	Patterns and schemas	Stress, conflict and parenting (inc. rupture and repair/tuning into child emotional states	Love and limits	Meditation of breath	Meditation of body	Imagery	Communication/Interaction	Applying mindfulness to everyday life	Attention/Distracton	Attitude/Judging/Acceptance	Yoga	CBT/Psychoeducation	Boundaries	Homework/practice
Van de Weijer-Bergsma, Formsma, de Bruin & Bögels (2012)	✓		ADHD	MP	✓	✓	✓	✓	✓		✓	✓			✓	✓	✓	✓			✓
Zhang, Chan, Ting & Wong (2017)	✓		ADHD	MP/ MBSR/ MBCT	✓	✓					✓	✓		✓	✓	✓		✓	✓	✓	✓

Six studies included parent only mindfulness interventions (Benn et al., 2012; Dehkordian et al., 2016; Hwang et al., 2015; Singh et al., 2006; Singh et al., 2007; Rayan & Ahmad, 2016). Seven studies included a parallel parent and child mindfulness intervention (Bakhshayesh et al., 2015; Bögels et al., 2008; De Bruin, Blom, Smit, van Steensel & Bögels, 2014; Haydicky et al., 2013; Singh et al., 2010; van der Oord et al., 2011; van de Weijer-Bergsma et al., 2012; Zhang et al., 2017).

All parent and child mindfulness interventions were conducted in group format in accordance with MBSR, MBCT and MP manuals. There were differences in the length and duration of interventions. Seven studies included eight 90-minute sessions (Bakhshayesh et al., 2015; Bögels et al., 2008; Dehkordian et al., 2016; Haydicky et al., 2013; van der Oord et al., 2011; van de Weijer-Bergsma et al., 2012; Zhang et al., 2017) in accordance with programme manuals. One study included an eight-week intervention of 2.5 hours per week (Hwang et al., 2015). Three studies included a 12-week mindfulness programme (Singh et al., 2006; Singh et al., 2007; Singh et al., 2010) and two studies included five-week interventions (Benn, Akiva, Arel & Roeser, 2012; Rayan & Ahmad, 2016).

Therapist training. All studies reported some information about therapist experience or training, with one exception (Dehkordian et al., 2016). Three studies reported that the interventions were delivered by the programme developer or the author of the study (Hwang et al., 2015; Singh et al., 2007; Singh et al., 2007b). This could introduce reporting bias. One intervention was delivered by a doctoral student (Haydicky et al., 2013). Other interventions were conducted by a clinical nurse specialist (Rayan & Ahmad, 2016) or experienced CBT therapists (Bakhshayesh et al., 2015; Bögels et al., 2008; Van der Oord et al., 2011; van de Weijer-Bergsma et al., 2012). Seven studies reported that therapists had experience in delivering mindfulness interventions (Bakhshayvand et al., 2015; Rayan & Ahmad, 2016;

Singh et al. 2010; Van der Oord et al., 2011; van de Weijer-Bergsma et al., 2012; Zhang et al., 2017). The information provided suggested that six studies included therapists with no formal mindfulness training or certification (Hwang et al., 2015; Singh et al., 2006; Singh et al., 2007; Singh et al., 2010; van de Weijer-Bergsma et al., 2012; Zhang et al. 2017). This is a significant limitation which limits confidence about treatment fidelity in these studies.

Research design. Three studies were randomised controlled trials (RCT's). Of these, one study compared the effectiveness of child only mindfulness, parent only mindfulness and parallel parent and child mindfulness interventions (Bakhshayesh et al., 2015). Another RCT compared a parent only mindfulness intervention (MP) with social skills training for children and exercise for children (Dehkordian et al., 2016). Both studies included parents of children, and children with ADHD. The final RCT compared the effectiveness of parallel parent and child mindfulness with a waitlist control group (Benn et al., 2012). This study included parents of, and children, with a range of comorbid neurodevelopmental disabilities.

Six studies were quasi experimental, pre-post intervention design studies (Bögels et al., 2008, Haydicky et al., 2013; Rayan & Ahmad, 2016; Van der Oord et al., 2011; van de Weijer-Bergsma et al., 2012; Zhang et al. 2017). Of these, one study used a non-equivalent control group (Rayan & Ahmad, 2016) and one study used a waitlist control group (Van der Oord et al., 2011). Four studies were multiple baseline designs/dyadic designs (Hwang et al., 2015; Singh et al., 2006; Singh et al., 2007; Singh et al., 2010).

Follow up. There was some variety in whether studies evaluated outcomes at follow up. Of the three RCT's, only one study assessed outcomes at 8 weeks follow up (Benn et al., 2012). Five pre-post intervention design studies included a follow up measurement, however these varied from 6 weeks (Haydicky et al., 2013), 8 weeks (Benn et al., 2012; Bögels et al., 2008; Van der Oord et al., 2011) and 16 weeks (van de Weijer-Bergsma et al., 2012).

Outcome measures. Nine studies included pre-post outcome measures that assessed both parental and child outcomes. Two studies included parent outcome measures only (Benn et al., 2012; Rayan & Ahmad, 2016), one study used parent and child reported outcome measures to assess child outcomes (Bögels et al., 2008) and one study used young person self-report measures alone (Dehkordian et al., 2016). Studies that included parallel parent and child mindfulness interventions used both parent and child outcomes (Bakhshayesh et al., 2015; Haydicky et al., 2013; Singh et al., 2010; Van der Oord et al., 2012; van de Weijer-Bergsma, 2012; Zhang et al. 2017). Studies that included parent only mindfulness interventions used either parent only outcomes (Benn et al., 2012; Rayan & Ahmad, 2016), child only outcomes (Dehkordian et al., 2016), or a combination of parent and child outcomes (Hwang et al., 2015; Singh et al., 2006, Singh et al., 2007).

Most of the studies used parent report questionnaires to assess parental and child outcomes. In addition, some studies used child report questionnaires (Bögels et al., 2008; Dehkordian et al., 2016; Haydicky et al., 2013; van de Weijer-Bergsma et al., 2012) and attention tests (van de Weijer-Bergsma et al., 2012; Zhang et al., 2017). Questionnaires varied between studies with some studies assessing the child's quality of life (Dehkordian et al., 2016), ADHD symptomology, compliance, child externalising difficulties (Bögels et al., 2008; van de Weijer-Bergsma et al., 2012), executive functioning (Haydicky et al., 2013), happiness and well-being (Bögels et al., 2008). One study also used the WASI to screen for intellectual functioning (Haydicky et al., 2013) and two studies used computerised tests of attention (van de Weijer-Bergsma et al., 2012; Zhang et al., 2017).

Parent report questionnaires varied significantly across studies. Most of the studies measured parental stress (Bakhshayesh et al., 2015; Benn et al., 2012; Haydicky et al., 2013; Hwang et al., 2015; Van der Oord et al., 2011; van de Weijer-Bergsma, 2012; Zhang et al., 2017), quality of life or happiness/satisfaction (Rayan & Ahmad, 2016; Singh et al., 2007;

Singh et al., 2006; Singh et al., 2010) or depression and anxiety (Benn et al., 2012). Studies measuring parental stress used the Perceived Stress Scale (PSS), the Parental Stress Inventory (PSI) or the Stress Index for Parents of Adolescents. A variety of measures were used to measure trait mindfulness, including the Freiberg Mindfulness Inventory (FMI), Acceptance and Action Questionnaire (AAQ) and Mindful Attention Awareness Scale (MAAS). The use of a variety of measures to assess the same construct makes comparisons between studies difficult and may limit the conclusions that can be drawn. Only one study assessed levels of MP with the Interpersonal Mindfulness in Parenting (IM-P) questionnaire (Zhang et al., 2017). The multiple baseline design studies asked parents to report subjective units of happiness, interaction, child compliance and/or child aggression (Hwang et al., 2015; Singh et al., 2006; Singh et al., 2007; Singh et al., 2010).

Sample. Of the parent only intervention studies, sample sizes ranged from 3-104 parents. A total of 247 parents completed parent only mindfulness interventions. Of the parallel parent and child interventions studies, sample sizes were smaller. They ranged from 2-36 parent and child dyads. A total of 113 parent and child dyads completed parallel parent and child mindfulness interventions.

Participant characteristics. Over half of the studies included in this review included parents of, and children with ADHD (Bakhshayesh et al., 2015; Dehkordian et al., 2016; Haydicky et al., 2013; Singh et al., 2010; Van der Oord et al., 2011; van de Weijer-Bergsma et al., 2012; Zhang et al., 2017). Six of these studies included parallel parent and child interventions (Bakhshayesh et al., 2015; Haydicky et al., 2013; Singh et al., 2010; Van der Oord et al., 2011; van de Weijer-Bergsma, 2012; Zhang et al., 2017) and one study included a parent only mindfulness intervention (Dehkordian et al., 2016).

Three studies included parent only interventions with parents of children with ASD (Hwang et al., 2015; Rayan & Ahmad, 2016; Singh et al., 2006). Three studies included parents

of children with comorbid developmental disabilities. Of these, one study included parents of children with comorbid ASD and ADHD (Benn et al., 2012). One study included parents of, and children with comorbid ADHD, Oppositional Defiant Disorder (ODD), conduct disorder (CD) or ASD (Bögels et al., 2008) and one study included parents of children with a range of neurodevelopmental disabilities (Singh et al., 2007). Of these, one study included a parallel parent and child intervention (Bögels et al., 2008) and two studies included parent only interventions (Benn et al., 2012; Singh et al., 2007).

No studies including parents of children with Tics, TS or intellectual disabilities were identified or included in this review.

All studies included parents of children aged 0-18 years old.

Recruitment. Recruitment methods varied somewhat, with some studies offering mindfulness interventions to families who had been referred to academic centres for diagnosis and treatment of ADHD (Van der Oord et al., 2011; van de Weijer-Bergsma et al., 2012) or referred via a mental health clinic (Bakhshayesh et al., 2015; Bögels et al., 2008), school (Benn et al., 2012; Dehkordian et al., 2016), or non-government organisation (Zhang et al. 2017). Other studies advertised the study online, via local psychology and MBSR networks (Hwang et al., 2015). This method of recruitment may introduce selection bias where people who have experience of or interest in mindfulness interventions may agree to take part. This potentially limits the external validity of the study if parents have lower levels of parental stress and child externalising difficulties. Two studies did not report enough information to determine the method of recruitment (Singh et al., 2007; Singh et al., 2010). One study contacted families to invite them to participate, however it was unclear in what setting recruitment occurred (Rayan & Ahmed, 2016). The final study reported that recruitment occurred at the request of parents, but it was not clear in what setting (Singh et al., 2006).

Attendance rates and withdrawals/drop outs. Completion rates across studies were very good, ranging from 71%-100%. Two RCT's did not provide data about dropout rates which may be suggestive of a 100% completion rate (Bakhshayesh et al., 2015; Dehkordian et al., 2006). The final RCT used payments as an incentive to complete the study, resulting in a 98.4% completion rate. However, a 15% drop out rate from post to follow up was reported (Benn et al., 2012).

Many small-scale studies reported a 100% completion rate, however they included between two to six parent-child dyads (Hwang et al., 2015; Singh et al. 2007; Singh et al., 2010). The study reporting the highest attrition rate (29%) included a sample of parents and children with a range of comorbid diagnoses such as ADHD, Oppositional Defiant Disorder (ODD), conduct disorder (CD) and ASD (Bögels et al., 2008). This may indicate that parallel mindfulness interventions are difficult for children with complex, comorbid neurodevelopmental disabilities to engage with.

Publication type/place. All 13 studies were published in peer-reviewed journals. Four studies were conducted in the United States of America, three in the Netherlands, three in the Middle East, one in Australia and one in Hong Kong. It was not possible to determine where two studies were conducted.

Results by Design

Parallel parent and child interventions. Of seven studies, six included parents of, and children with a diagnosis of ADHD (Bakshayesh et al., 2015; Haydicky et al., 2013; Singh et al., 2010; Van der Oord et al., 2011; van de Weijer-Bergsma et al., 2012; Zhang et al., 2017) and one study included parents of children with a variety of neurodevelopmental disabilities,

including ADHD, ASD, conduct disorder (CD) and oppositional defiant disorder (ODD) (Bögels et al., 2008). This highlights a lack of evidence exploring the effectiveness of parent and child mindfulness interventions, in parents of children with ASD and/or Tic/TS specifically.

These studies included one RCT (Bakhshayesh et al., 2015), five pre-post studies (Bögels et al., 2008; Haydicky et al., 2013; Singh et al., 2010; van de Weijer-Bergsma et al., 2012; Zhang et al., 2017) and one pre-post design with a waitlist control (Van der Oord et al., 2011),

There were mixed findings with regards to parental outcomes. One pre-post study reported improved MP in parents, of a large effect size (Haydicky et al., 2013) yet another study reported no change in MP (Zhang et al., 2017). However, the latter study included a smaller sample size and may have lacked power to detect an effect. Significant improvements in trait mindfulness, of a small effect size, were found compared to a waitlist control group in one study (Van der Oord et al., 2011). However, no changes in trait mindfulness were found in another pre-post study (van de Weijer-Bergsma et al., 2012).

Three of seven studies, using different designs, reported significant reductions in parental distress or stress, of medium to large effect sizes (Bakhshayesh et al., 2015; Haydicky et al., 2013; Van der Oord et al., 2012). In addition, one pre-post study reported a reduction in father's stress, but not for mothers (van de Weijer-Bergsma et al., 2012) and another reported an increase in parental stress (Zhang et al., 2017). Improvements in parental inattention, hyperactivity impulsivity, and reactivity were reported in one pre-post study, of a small effect size (Van der Oord et al., 2012). Two of seven studies reported a reduction in parental reactivity; one of which included a waitlist control group (van de Weijer-Bergsma et al., 2012; Van der Oord, et al., 2012).

Four of seven studies reported significant reductions in parent rated child ADHD symptoms, of small to large effect sizes (Bakhshayesh et al., 2015; Bögels et al., 2008; Haydicky et al., 2013; Van der Oord et al., 2011). Of these, three were pre-post design studies (Bögels et al., 2008; Haydicky et al., 2013; Van der Oord et al., 2011) and one was an RCT comparing parent only mindfulness (MP), parallel parent and child mindfulness (MP) and child mindfulness (Bakhshayesh et al., 2015). The RCT reported significant reductions in child ADHD symptoms in the parallel parent and child intervention group and the child mindfulness group, but not in the parent only mindfulness group. Significant improvements in child hyperactivity/impulsiveness (large effect size) and reductions in parental stress were reported in the parallel parent and child intervention group (Bakhshayesh et al., 2015). Significant reductions in parental stress were also found in the parent only intervention group. No significant improvements in parenting methods, parental distress and parent-child interactions were found in the child intervention group.

Furthermore, one pre-post study reported borderline significant findings, of a medium effect size (van de Weijer-Bergsma et al., 2012) and two pre-post studies reported improvements on child attention via neurocognitive tests (van de Weijer-Bergsma et al., 2012; Zhang et al. 2017). Three of seven studies reported significant reductions in child externalising difficulties; one with a large effect size (Bögels et al., 2008), one study reported improvements by fathers only, of a small effect size (van de Weijer-Bergsma et al., 2012) and a multiple baseline study reported significant improvements in child compliance (Singh et al., 2010). Child reported improvements in internalising difficulties were reported in two of seven pre-post studies, of medium to large effect sizes (Bögels et al., 2008; Haydicky et al., 2013).

Parent only interventions. Three of six studies included parents of children with ASD (Hwang et al., 2015; Rayan & Ahmad., 2016; Singh et al., 2006), one included parents of children with ADHD (Dehkordian et al., 2016) and two included parents of children with a range of neurodevelopmental disabilities (Benn et al., 2012; Singh et al., 2007). Of these, two were RCT's (Benn et al., 2012; Dehkordian et al., 2016), two were multiple baseline designs (Singh et al., 2006; Singh et al., 2007) and one was quasi experimental with a non-equivalent control group (Rayan & Ahmad., 2016).

Three of six studies, of varying designs, reported significant reductions in parental stress (Benn et al., 2012; Hwang et al., 2015; Singh et al., 2007). Of these studies, the RCT compared the effectiveness of a parent only MP intervention with a waitlist control group (Benn et al., 2012). They found significant reductions in parental stress and anxiety and increases in trait mindfulness and self-compassion (medium effect sizes) at post and 8 weeks follow up. A limitation of this study is that they failed to measure child outcomes. Therefore, it is unclear whether and how these effects for parents might relate to the parent-child relationship or child outcomes.

Three of six studies, of various designs (including one RCT, one quasi experimental study with a non-equivalent control group and a dyadic design study) reported significant increases in trait mindfulness, of medium effect sizes (Benn et al., 2012; Rayan & Ahmad, 2016).

Improvements in children's quality of life (Dehkordian et al., 2016), parental quality of life (Rayan & Ahmad, 2016), and family quality of life were reported in three of six studies (Hwang et al., 2015). The RCT compared the effectiveness of a parent only MP intervention with child social skills training and exercise (Dehkordian et al., 2016). Parents who engaged in MP training reported significant improvements in their adolescent's quality of life post intervention; an effect that was not found amongst the other two child focused interventions.

This highlights the potential for parent only interventions to have a positive impact on child outcomes. However, these outcomes are limited as they are based on parent's perceptions of their child's difficulties rather than self-report from adolescents.

Only two of six studies, of multiple baseline design, measured child outcomes reported reductions in child aggression and increases in parenting satisfaction (Singh et al., 2010; Singh et al., 2007).

Results by Participants

ADHD. Eight of 13 studies included parents of, and children, with ADHD. Five of eight studies reported significant improvements in child ADHD symptoms after completion of parallel mindfulness training, of medium to large effect sizes (Bakhshayesh et al., 2015; Haydicky et al., 2013; Van der Oord et al., 2011; van de Weijer-Bergsma et al., 2012; Zhang et al., 2017). One study reported a significant reduction in child externalising difficulties, of a small effect size (van de Weijer-Bergsma et al., 2012) and one study reported reduced child internalising difficulties (Haydicky et al., 2013).

Four of eight studies reported significant improvements in parental distress or stress, ranging from small to medium effect sizes (Bakhshayesh et al., 2015; Haydicky et al., 2013; Van der Oord et al., 2011; van de Weijer-Bergsma et al., 2012). However, this finding was only reported in fathers in one study, and parental stress worsened in another study (Zhang et al., 2017). Two of eight studies reported significant improvements in parental trait mindfulness, of a small effect size (Bakhshayesh et al., 2015; Van der Oord et al., 2011) and another study reporting improved parental reactivity in mothers only (van de Weijer-Bergsma et al., 2012).

ASD. Three of 13 studies, of varying designs, explored the effectiveness of parent only mindfulness interventions in parents of children with ASD (Hwang et al., 2017; Rayan &

Ahmad, 2016; Singh et al., 2006). One study reported significant increases in parental quality of life and trait mindfulness, of a large effect (Rayan & Ahmad, 2016). However, the lack of control group to compare this effect to makes it difficult to attribute these effects to the intervention alone. Another study reported increases in mindfulness and reductions in parental stress (Hwang et al., 2017). Both studies included different sample sizes, with only six parent-child dyads in Hwang et al.'s (2017) study and 106 parents in Rayan and Ahmad's (2016) study.

Tics/TS/intellectual disability. No studies including parents of, or children with Tics, TS, or intellectual disabilities were identified or included in this review.

Comorbid neurodevelopmental disabilities. Two studies included parents of children with comorbid neurodevelopmental disabilities. One study included a parallel parent and child intervention with parents of children with ADHD, ASD, CD and ODD (Bögels et al., 2008). They found significant improvements in child reported internalising and externalising difficulties, attention and mindful awareness. Parents also reported increased child attention and reduced child externalising difficulties (Bögels et al., 2008). The study evaluating a parent only intervention with parents of children with ASD and ADHD reported significant reductions in parental stress and anxiety and increased trait mindfulness and self-compassion, of medium effect sizes (Benn et al., 2012).

Results by Quality

Quality rating 'strong'. Five of 13 studies were given an overall quality rating of 'strong' (Bögels et al., 2008; Dehkordian et al., 2016; Rayan & Ahmad, 2016; Van der Oord et al., 2012; van de Weijer- Bergsma et al., 2012). Of these five studies, one was an RCT (Dehkordian et al., 2016), two were pre-post studies with a waitlist control or a non-equivalent control group (Rayan & Ahmad, 2016; Van der Oord et al., 2012) and two were pre-post designs (Bögels et al., 2008; van de Weijer- Bergsma et al., 2012). Three of these five studies included parallel

parent and child interventions (Bögels et al., 2008; Van der Oord et al., 2012; van de Weijer-Bergsma et al., 2012) and two studies included parent only interventions (Dehkordian et al., 2016; Rayan & Ahmad, 2012). All five studies reported significant reductions in child attention problems, of medium to large effect sizes. Two of five studies reported significant reductions in child internalising and externalising problems, of small to large effect sizes (Bögels et al., 2008; van de Weijer-Bergsma et al., 2012). Two of five studies reported significant reductions in parental stress and reactivity (Van der Oord et al., 2012; Van de Weijer-Bergsma et al., 2012). However, reductions in parental stress occurred for fathers only in one study (Van de Weijer-Bergsma et al., 2012) and reduced reactivity occurred for mothers only in the other study (van de Weijer-Bergsma et al., 2012). One of five studies reported significant improvements in parental mindful awareness, of a small effect size (Van der Oord et al., 2012). Another study failed to find any change in trait mindfulness for children or parents (van de Weijer-Bergsma et al., 2012).

Two of five studies included parent only interventions (Dehkordian et al., 2016; Rayan & Ahmad, 2016). Significant improvements in parental quality of life, of a large effect size, and significant increases in trait mindfulness, of a medium effect size was reported (Rayan & Ahmad, 2016). One study reported significant improvements in adolescent's quality of life, of a medium effect size (Dehkordian et al., 2016).

Quality rating 'medium'. Three of 13 studies achieved an overall quality rating of 'medium'. Of these, two studies included a parallel parent and child intervention (Bakhshayesh et al., 2015; Zhang et al., 2017) and one included a parent only intervention (Benn et al., 2012). Two of three studies, of varying designs, reported significant reductions in parental stress (Bakhshayesh et al., 2015; Benn et al., 2012) and one study reported an increase in parental stress (Zhang et al., 2017). Two of three studies reported significant reductions in child ADHD/attention difficulties (Bakhshayesh et al., 2015; Zhang et al., 2017). The RCT reported

significant reductions in child ADHD symptoms in both the child mindfulness group and the parallel parent and child mindfulness group. One of three studies reported a significant increase in parental anxiety, trait mindfulness and self-compassion, of a medium effect size (Benn et al., 2012). However, no significant reductions in trait mindfulness were reported in one study (Zhang et al., 2017).

Quality rating ‘weak’. Five studies were assigned an overall quality rating of ‘weak’ (Haydicky et al., 2013; Hwang et al., 2015; Singh et al., 2006; Singh et al., 2007; Singh et al., 2010). Two of five pre-post studies reported significant reductions in parental stress (Haydicky et al., 2013; Hwang et al., 2017). Two of five studies reported significant improvements in trait mindfulness (Hwang et al., 2017; Singh et al., 2006) and one study reported a significant increase in MP, of large effect size (Haydicky et al., 2013). Only one of five studies reported a significant reduction in child inattention and child externalising difficulties, of a medium to large effect size (Haydicky et al., 2013). Two of five studies, of multiple baseline design, reported reductions in child aggression and improved parental satisfaction (Singh et al., 2006; Singh et al., 2007). Two of five studies of multiple baseline design, reported increased child compliance following mindfulness interventions for parents (Singh et al., 2007; Singh et al., 2010).

Discussion

The aim of this review was to assess the comparative effectiveness of parallel parent and child mindfulness interventions and parent only mindfulness interventions, in families of children aged 0-18 years old with neurodevelopmental disabilities. Exploring whether parallel parent and child mindfulness interventions are more, less or equivalent in their effectiveness to parent only mindfulness interventions will develop the evidence base for mindfulness interventions in neurodisability and shed light on the specific components that lead to positive parental and/or child outcomes. This review aimed to address this gap in the literature that was identified by a previous review (Cachia et al., 2015). The current review had the potential to include studies including mindfulness interventions for parents of and children with ADHD, ASD, Tics/TS and/or intellectual disabilities. However, no studies including parents of and/or children with Tics, TS or intellectual disabilities were identified. This highlights a gap in the literature that future research should address.

Parental outcomes

This review highlighted sufficient evidence to support the effectiveness of both parallel parent and child mindfulness interventions and parent only mindfulness interventions in reducing parental stress, amongst parents of children with ASD and ADHD, with some evidence of reductions in parental stress for parents of children with comorbid neurodevelopmental disabilities too. These findings are confirmed by previous reviews that support the efficacy of mindfulness interventions in improving parental outcomes, both in parents of children with ASD (Cachia et al., 2015) and parents of children with a range of neurodevelopmental disabilities (Petcharat & Liehr, 2017).

Child outcomes

With regards to the possible impact of parallel mindfulness interventions and parent only mindfulness interventions on child outcomes, less is known. Preliminary studies have highlighted the enhanced benefits of parents undergoing mindfulness training and then providing mindfulness training to their children. One study reports that children's aggression reduced following parent training, and then improved further during subsequent child training (Singh et al. 2010). However, the multiple baseline design means that the effects of the parent training cannot be controlled for. Thus, it is difficult to determine whether these additional effects can be attributed to the child training, or the previous parent training. Aside from these small-scale findings, little is known about the potential effects of parent only mindfulness interventions on child externalising difficulties.

There is currently more evidence to suggest that parallel parent and child interventions have a greater impact on child outcomes than parent only interventions. Only one RCT was able to compare a child mindfulness intervention with a parent mindfulness intervention and a parallel parent and child mindfulness interventions. They recruited parents of, and children with ADHD (Bakhshayesh et al., 2015). This study found that those in the child mindfulness and parallel parent and child mindfulness groups reported significant reductions in child ADHD symptomology compared to the parent only mindfulness group. Those in the parent mindfulness and parallel parent and child mindfulness interventions reported significant reductions in parental distress (Bakhshayesh et al., 2015). This might suggest that parent mindfulness has a positive impact on parental stress, whilst the child mindfulness may have a positive impact on child ADHD symptomology. However, more RCT studies comparing the effectiveness of parallel and parent only interventions are needed to substantiate these claims.

Furthermore, a consistent trend in the literature was found to support the effectiveness of parallel parent and child mindfulness interventions in reducing ADHD symptoms and improving attention for children with ADHD. This was evident in six of seven studies, of varying designs, using a mixture of parent report questionnaires and child attention tests. In addition, internalising and externalising difficulties. Based on the current evidence, this suggests that parallel parent and child mindfulness are more effective than parent only interventions, in families where there is a child with ADHD. This evidence is in line with findings from other reviews that show that child mindfulness interventions result in reductions in child ADHD symptoms (Burke, 2009; Cairncross & Miller, 2016). However, it remains unclear whether the parent mindfulness or the child mindfulness leads to these outcomes. Further RCT's should directly compare parent, child and parallel interventions to address this gap.

Mindfulness theory suggests that increased parental stress and reactivity can perpetuate child externalising difficulties which can further exacerbate parental stress. The reciprocal relationship between parental stress and child behaviour noted in the literature would suggest that intervening at the parent level to reduce parental stress should produce positive effects in the parent-child relationship, parental stress and child behaviour. Findings from this review support the potential for parent only interventions to significantly reduce parental stress. There are also some preliminary findings of a possible impact on child externalising difficulties. However, this finding is based on very few multiple baseline studies (Singh et al., 2006; Singh et al. 2007). More research is needed to further substantiate the potential effect of parent only mindfulness interventions on child outcomes (i.e. internalising and externalising difficulties) in parents of children with neurodevelopmental disabilities.

Clinical Implications

The findings of this review have clinical implications for the evidence base and treatment for families of children with ADHD. Specifically, parallel parent and child mindfulness interventions may be effective in reducing parental stress, child ADHD symptoms, child internalising and externalising difficulties. There was a lack of studies evaluating the effectiveness of parent only mindfulness interventions on child outcomes, in parents of children with ASD and comorbid neurodevelopmental disabilities. As a result, it was not possible to address whether parent only or parallel parent and child interventions are more, less or equivalent in their effectiveness in families of children with ASD. Furthermore, there were no studies exploring the effectiveness of mindfulness interventions for parents of children with Tics/TS and/or intellectual disabilities. Given what the literature highlights about the increased comorbidities (Hayes & Watson, 2013; Reid, 2011; Mayes, Calhoun & Crowell, 2000), parental stress (Singer, 2006; Zhang, Chan, Ting & Wong, 2017) and child externalising difficulties (Blacher & McIntyre, 2006) within the neurodisability population, further research is needed with these groups. Addressing the issues discussed in this review will be important and may lead to different conclusions around the comparative benefits of parallel parent and child and parent only interventions.

This review highlighted that very few studies evaluated the effectiveness of specific MP interventions in families of children with neurodevelopmental disabilities. Given that MP applies mindfulness to the parenting context, it is possible that MP may lead to more effective outcomes for parents and children. Future research should evaluate the effectiveness of MP in parents of children with ASD, Tics/TS and intellectual disabilities with the use of control groups.

Strengths and limitations

The search strategy for the literature review was comprehensive. It aimed to capture studies that included interventions based on MBSR, MBCT and/or MP as well as studies that included parents of children with a range of neurodevelopmental disabilities. The search was conducted between June-July 2017. Therefore, the findings of this review are likely to be representative of the available literature during this time.

The search process initially highlighted additional studies that appeared to be relevant to this review. However, on closer examination they were excluded. Firstly, studies including parents of children with developmental delay were excluded. This was an important distinction to make to increase the external validity of the review and its applicability to clinical settings. Secondly, studies were excluded for including third wave cognitive behavioural therapies such as acceptance and commitment therapy (ACT). Thirdly, parent training interventions with enhanced mindfulness were also excluded. Thus, for the purposes of this review interventions were limited to those based on MBSR, MBCT and/or MP; all of which are 8-week group based manualised programmes. Lastly, it was surprising that some studies included parents of children with varied age ranges that spanned beyond 18 years. These studies were excluded as this review to protect the external validity of the review.

Nevertheless, there are limitations to this review. Firstly, the search strategy was conducted by the primary researcher only. This may raise questions about the extent to which this review reliability captures the relevant studies and could have implications for the conclusions that are drawn. Secondly, a second reviewer would have been helpful in quality assessing a sub-sample of studies to obtain an acceptable level of inter-rater reliability. Unfortunately, this was not possible within the timescales of this review. To address these

concerns, future reviews should include a second reviewer that blindly conducts the search strategy and a sub-sample of the quality assessments.

Another possible limitation of this review is the exclusion of non-peer reviewed studies. This increases the possibility of publication bias. The decision to exclude them was made to maintain a high level of quality amongst the included studies. This was particularly important given the limitations of the literature; including a lack of RCT's, use of control groups and a reliance on pre-post and multiple baseline design studies. Most of the studies were quasi experimental or pre-post designs without the use of control groups. This raises concerns about internal validity and the possible influence of extraneous variables. Therefore, we cannot be certain that the effects reported are due to the intervention itself and not due to other factors such as time. Secondly, none of the studies reported whether researchers and participants were blinded to the study. Therefore, it is possible that those participating in mindfulness interventions expected an effect and reported placebo effects. Thirdly, many of the studies interventions were delivered by clinicians or researchers without sufficient training in mindfulness. This raises concerns about the fidelity of the interventions across studies.

Lastly, there are limitations to consider with regards to the quality assessment tool used in this review. Specifically, the studies deemed to be 'strong' varied in their design from RCT to pre-post design studies (one with a non-equivalent control group and one waitlist control group) and pre-post studies without use of control groups. All 'strong' studies received no weak ratings across the domains. The fact that studies achieving a 'strong' rating varied substantially in design rating may speak to the relatively weak methodology of the studies in the literature or may highlight a limitation of the tool's ability to reliably distinguish quality between a mixture of study designs.

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To answer the review question fully RCT's that compare the effectiveness of parallel parent and child interventions, with parent only interventions and control groups are needed. Unfortunately, this review only contained one study that directly compared the effectiveness of parallel mindfulness interventions, with parent only and child only mindfulness interventions. Future RCT's are needed that compare parallel and parent only interventions in this way.

Another limitation of the literature exploring the effectiveness of parent only mindfulness interventions is that many studies failed to measure child outcomes. Therefore, it is possible that parent only mindfulness interventions have potential to positively impact on child outcomes. However, future studies should evaluate parental and child outcomes.

Most findings were consistently reported across studies (i.e. reductions in parental stress, child ADHD symptoms, child internalising and externalising problems). However, there were some variability in consistency of findings regarding changes in trait mindfulness. Studies used a variety of different tools to measure trait mindfulness, which may result in slightly different constructs being measured. Due to these limitations, there were not enough robust findings to conclude that mindfulness interventions led to significant improvements in overall levels of trait mindfulness. Future research should aim to use a consistent measure of trait mindfulness, as well as measuring MP.

Conclusions

There is evidence to suggest that parallel parent and child mindfulness are effective in reducing parental stress, child ADHD symptoms, child internalising and externalising difficulties, in families of children with ADHD. Less is known about the effectiveness of mindfulness interventions in parents of children with ASD, Tics/Tourette's Syndrome,

intellectual disabilities or those with comorbid neurodevelopmental disabilities. There is evidence to suggest that parent only mindfulness interventions have a significant impact on parental stress, but further research is needed to establish the possible benefits for child outcomes.

These findings have important clinical implications for practice. Firstly, parallel parent and child mindfulness interventions may be a helpful supplement to medication and/or parent training in the treatment of ADHD. They may be particularly helpful for parents suffering from high levels of parental stress, and/or mental health difficulties, or those who have ADHD themselves, whom may not benefit as much from standard behavioural evidence-based parenting programmes recommended by NICE guidelines (2016). Studies in this review reported high completion rates showing that these interventions are appropriate and feasible for parents and children with ADHD. However, some studies used reward systems to increase child compliance with the programme. Therefore, it is possible that children and adolescents with ADHD and comorbid neurodevelopmental disabilities might drop out of treatment without use of rewards. There are clearly implications for services around resources and costs in providing parallel parent and child group mindfulness interventions over 8 weeks.

Future research should include RCT's that evaluate the effectiveness of MP with parents of children with ASD, Tics/Tourette's and/or intellectual disabilities as well as with parents of children with comorbid neurodevelopmental disabilities, with a specific focus on possible child outcomes. Studies should use control groups to control for extraneous variables. RCT's that directly compare parallel parent and child mindfulness, parent only mindfulness and control groups, will be particularly helpful in developing the evidence base.

II. Empirical Paper

Mindfulness, Self-Compassion, Parental Stress, Well-Being and Child Behaviour in
Neurodisability

Abstract

Caring for a child with comorbid neurodevelopmental disabilities can be challenging due to the severity and nature of associated impairments and increased child externalising difficulties. Studies have consistently found that parents of children with a neurodevelopmental disability (including Autistic Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Tics, Tourette's Syndrome and intellectual disabilities) report increased parental stress compared to those of typically developing children. Mindfulness applied to the parenting context i.e. Mindful Parenting (MP) may help parents/caregivers to manage stress in the face of challenging behaviour. This cross sectional, correlational study aimed to a) explore the relationships between mindfulness, self-compassion, parental stress, well-being and child externalising difficulties, in parents of children with a range of neurodevelopmental disabilities, b) explore whether mindfulness mediates the relationship between parental stress and child externalising difficulties and c) to compare levels of mindfulness and self-compassion amongst parents of children with specific primary diagnoses (ASD, ADHD, Tics/Tourette's Syndrome). Results showed that higher levels of MP and self-compassion were significantly correlated with lower levels of parental stress. Higher levels of trait mindfulness and self-compassion were significantly associated higher parental well-being. The self-regulation facet of MP was significantly associated with lower levels of child externalising difficulties, whilst the compassion for self and child was significantly associated with lower levels of child internalising difficulties. Mindful parenting mediated the relationship between child externalising difficulties and parental stress. Parents of children with a primary diagnosis of ASD had significantly lower levels of MP, self-compassion and higher rates of child externalising difficulties compared to parents of children with a primary diagnosis of Tics/TS. Mindful parenting interventions may be helpful for parents of children with a range of

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neurodevelopmental disabilities who are experiencing high levels of parental stress and child externalising difficulties, specifically parents of children with ASD. Future research should evaluate the effectiveness of MP interventions in parents of children with neurodevelopmental disabilities using RCT's to further develop the evidence base.

Keywords: Mindfulness, Mindful Parenting, Parental Stress, Child Behaviour, Neurodevelopmental Disability

Introduction

Neurodevelopmental Disabilities

Prevalence rates in the United Kingdom suggest that 3-4% of children have a chronic, lifelong neurodevelopmental disability that is present from birth or early childhood (Blackburn, Read & Spencer, 2012). Neurodevelopmental disabilities occur due to delayed brain development which affects the development of language, cognition, emotion and motor behaviours (Millan, 2013). Conditions include Autistic Spectrum Disorder (ASD) defined as persistent deficits in social communication and social interaction and repetitive behaviour, interests or activities (American Psychiatric Association, 2013), Attention Deficit Hyperactivity Disorder (ADHD) defined as persistent patterns of inattention and/or hyperactivity-impulsivity that interferes with functioning or development (American Psychiatric Association, 2013), Motor Stereotypies defined as a “repetitive, non-functional disorder which interferes with normal activities or results in injury” (Mills & Hedderly, 2014, p23), Tics defined as “sudden, rapid, non-rhythmic motor movements or vocalisations usually appearing in bouts whilst waxing and waning in frequency, intensity and type of tic” (Mills & Hedderly, 2014, p. 24) and Tourette’s Syndrome (TS) defined as “tics that are multiple, with motor tics and a phonic tic present at some point over a period of at least one year” with symptoms occurring daily that occur before the age of 18 (Mills & Hedderly, 2014, p. 24). Finally, intellectual disabilities are characterised by significant deficits in intellectual functioning and adaptive functioning (American Psychiatric Association, 2013).

Estimates suggest that ADHD is the most common neurodevelopmental disability affecting 1-2% of children (Blackburn, Read & Spencer, 2012), with ASD affecting at least 1% (Blackburn et al., 2012) and TS affecting between 0.3-0.8% of school age children (Hirtz et al., (2007); Scahill, Sukhodolsky, Williams & Leckman, 2005).

Presenting Problems and Comorbidity

Children with neurodevelopmental disabilities have a range of difficulties which bring them and their families into contact with child and adolescent mental health services (CAMHS). They are known to have high levels of externalising difficulties (i.e. child behaviour difficulties) (Eisenhower, Baker & Blacher, 2005; Matson, Wilkins & Macken, 2008; McClintock & Oliver, 2003) and internalising difficulties (i.e. emotional difficulties) (Connor et al., 2003; Chang et al., 2007; Simonoff, et al., 2008). Furthermore, they are at increased risk of co-morbid neurodevelopmental disabilities (Reid, 2011) and/or intellectual disabilities (Burd, Freeman, Klug & Kerbeshian, 2005; Matson & Shoemaker, 2009; Mayes, Calhoun & Crowell, 2000). Across studies using different samples, 70% of children with ASD had an intellectual disability (Zoghbi & Bear, 2012), 78% met diagnostic criteria for ADHD (Lee & Ousley, 2006), 22% had an additional tic disorder and 11% had TS (Canitano & Vivanti, 2007).

Parental Stress in Neurodisability

Caring for a child with chronic, lifelong neurodevelopmental disabilities is known to be linked to increased levels of parental stress (Baker-Ericzn, Brooknian-Frazee & Stahner, 2005; Duarte, Bordin, Yazigi & Mooney, 2005; Hayes & Watson, 2013; Montes & Halterman, 2007; Rao & Beidel, 2009; Theule, Wiener, Tannock & Jenkins, 2010; Van de Weijer-Bergsma, Formsma, DeBruin & Bögels, 2012) and reduced parental well-being (Cooper, Robertson & Livingston, 2003; Donenbourg & Baker, 1993; Johnson, Frenn, Feetham & Simpson, 2011; Johnston & Mash, 2001) in parents of children with ASD, ADHD, Tics/TS and intellectual disabilities.

Parental stress has been defined in the literature as “*psychological distress that arises from the demands of parenting*” (Deater-Deckard, 1998, p. 314). A model of parental stress is

highlighted in Figure 1. It posits that child characteristics (i.e. child temperament, level of impairment, behavioural difficulties, severity), parental perception of child characteristics and the parent's availability of resources and support all contribute to the level of parental stress (Bluth, Roberson, Billen & Sams, 2013; Perry, 2004). Parental stress is thought to influence the parent's perceptions of their child's difficulties, as well as their perceptions of available support. Therefore, it is possible that reducing parental stress may lead to positive changes in the parent's perceptions of their child's difficulties and/or alter their relationship to the child's behaviour.

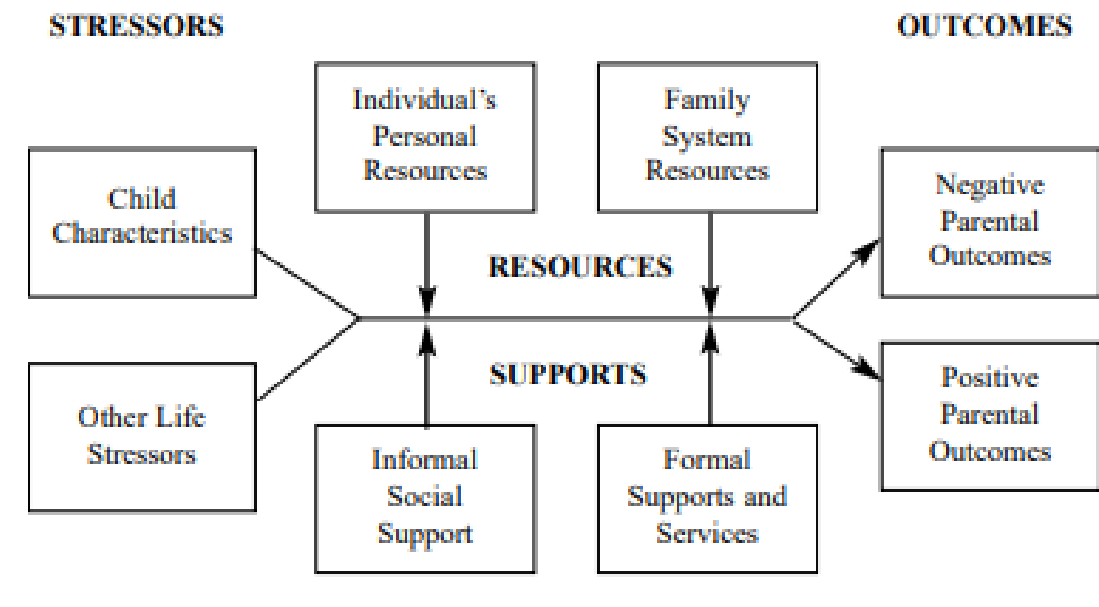


Figure 2: A model of stress in families of children with developmental disabilities (Perry, 2004)

Parents of children with neurodevelopmental disabilities report significantly higher levels of parental stress, anxiety and depression compared to parents of typically developing children (Hoffman, Sweeney, Hodge, Lopez-Wagner & Looney, 2009; Houser-Cram, Warfield, Shonkoff & Krauss, 2001; Miranda, Tarraga, Fernandez, Colomer & Pasotr, 2015;

Singer, 2006; Stewart, Greene, Lessov-Schlaggar, Church & Schlaggar, 2015; Zhang, Chan, Ting & Wong, 2017). This is thought to be due to increased family difficulties, reduced social support (Pisula, 2007; Sanders & Morgan, 1997) and increased child externalising difficulties. Furthermore, the literature suggests that parents of children with ASD experience even greater stress and child externalising difficulties than parents of children with Down's Syndrome, developmental disabilities and intellectual disabilities (Bouma & Schweitzer, 1990; Blacher & McIntyre, 2006; Brereton et al. 2006; Dabrowska & Pisula, 2010; Kasari & Sigman, 1997; Hayes & Watson, 2013). It is not clear why this is the case. However, some studies have suggested possible links to the social impairments (i.e. difficulties relating to others) and the restrictive/repetitive behaviours associated with ASD (Davis & Carter, 2008; Gabriels, Cuccaro, Hill, Ivers & Goldson, 2005).

Comorbid neurodevelopmental disabilities are known to exacerbate the range of impairments and externalising behaviours (Macmillan, 2014; Tureck, Matson, May & Turygin, 2012) which is likely to result in increased parental stress (Lecavalier, Leone & Wiltz, 2006). Of the few studies that have explored parental stress amongst parents of children with comorbid neurodevelopmental disabilities, the findings have been mixed. One study of 121 parents of children aged 5-9 years old found no significant differences in parental stress between a comorbid ASD and ADHD group compared to an ASD group and an ADHD group (Miranda et al., 2015). However, other studies suggest that increased ADHD symptomology is related to increased stress and child externalising difficulties in comorbid neurodevelopmental samples (Miranda et al., 2015; Stewart et al., 2015; Sukhodolsky, Scahill & Zhang, 2003).

Parental Stress and Parenting Styles

Parental stress has been shown to have negative effects on parenting and the parent-child relationship. Studies have shown that parental stress is associated with reduced parental

warmth (Bögels, Lehtonen & Restifo, 2010) and more reactive, automatic and rejecting parenting styles (Belsky, 1984; Webster-Stratton, 1990). Studies have shown that increased parental stress and reactivity predict increased child internalising and externalising difficulties (Hastings, 2002; Johnson & Reader, 2002; Miller-Lewis et al. 2006). Increased child externalising difficulties have also been found to predict increased parental stress (Beck, Hastings, Daley & Stevenson, 2004; Hassall, Rose & McDonald, 2005). This suggests that parental stress and child externalising difficulties have a mutually reciprocal relationship. Thus, increased parental reactivity and stress exacerbates child behaviour difficulties, resulting in further parental stress and reactivity and vice versa (Neece, Green & Baker, 2012; Pesonen et al., 2008).

Historically, evidence-based parent training programmes based on psychosocial and behavioural models have been recommended as treatment for parents of children presenting with ADHD or significant child externalising difficulties (NICE, 2016). These interventions support parents to develop skills in positive parenting and behavioural management that are based on social learning and social cognitive theories.

Social learning theories describe how parents can inadvertently reinforce undesirable behaviours through their sustained attention to them, resulting in an increase in their occurrence (Bandura, 1977). Social cognitive theory suggests that parents' self-efficacy (i.e. their ability to cope in difficult circumstances) may increase as parents develop skills to manage child behaviour difficulties. However, it is not clear whether these programmes are effective for parents of children with ASD, Tics, Tourette's, intellectual disabilities, and/or comorbid neurodevelopmental disabilities. Studies have found that high levels of parental stress, depression and parental ADHD can limit the effectiveness of interventions (Osbourne, McHugh, Saunders & Reed, 2008; Owens et al., 2003; Reyno & McGrath, 2006; Webster-Stratton, 1990). Therefore, it is likely that parents with particularly high levels of parental stress

or those who have children with comorbid neurodevelopmental disabilities may not benefit from these programmes.

Mindfulness

To address this problem, researchers and clinicians have turned to the mindfulness literature. Mindfulness has been defined as “*paying attention in a particular way, on purpose, in the present moment and non-judgmentally*” (Kabat-Zinn, 1994, p. 4). Early conceptualizations of mindfulness emphasize two key processes of change: attention (i.e. focus that is directed to conscious experience) and awareness (i.e. the process of monitoring one’s internal and external experiences) (Brown & Ryan, 2003). Although both are important aspects of consciousness, mindfulness has been described as a mental process whereby one’s attention and awareness to experience are heightened. Other theories have proposed that key mechanisms of change include a) attention (i.e. “paying attention”), b) intention (i.e. “on purpose”) and c) attitude (i.e. “non-judgementally”) (Shapiro, Carlson, Astin & Freedman, 2006). Alternative theories offer a five-factor model of mindfulness whereby five key facets contribute to one’s overall levels of trait mindfulness. These include a) acting with awareness, b) observing, c) describing, d) non-judging of inner experience and e) non-reactivity to inner experience (Baer et al., 2006; Carmody & Bear, 2008).

Mindful Parenting (MP)

Given the potentially long-term nature of parenting a child with neurodevelopmental disabilities, mindfulness interventions may be helpful for parents experiencing high levels of parental stress. Mindfulness has been applied to the parenting context; mindful parenting (MP) defined as “*applying practices of paying attention in an intentional and non-judgemental manner to one’s child and parenting over time*” during specific parent-child interactions

(Kabat-Zinn & Zabat-Zinn, 1997) cited in Beer, Ward & Moar, 2013, p. 103). The MP model is highlighted in Figure 2. It proposes that MP contributes to more adaptive parenting practices and positive parenting behaviours which result in improved parent-child communication, parent-child relationship and parental self-efficacy, which results in increased child emotional and behavioural well-being (Duncan, Coatsworth & Greenberg, 2009). MP includes five facets; a) listening with full attention¹, b) non-judgemental acceptance of self and child², c) emotional awareness of self and child³, d) self-regulation in the parenting relationship⁴ and e) compassion for self and child⁵ (Duncan et al., 2009).

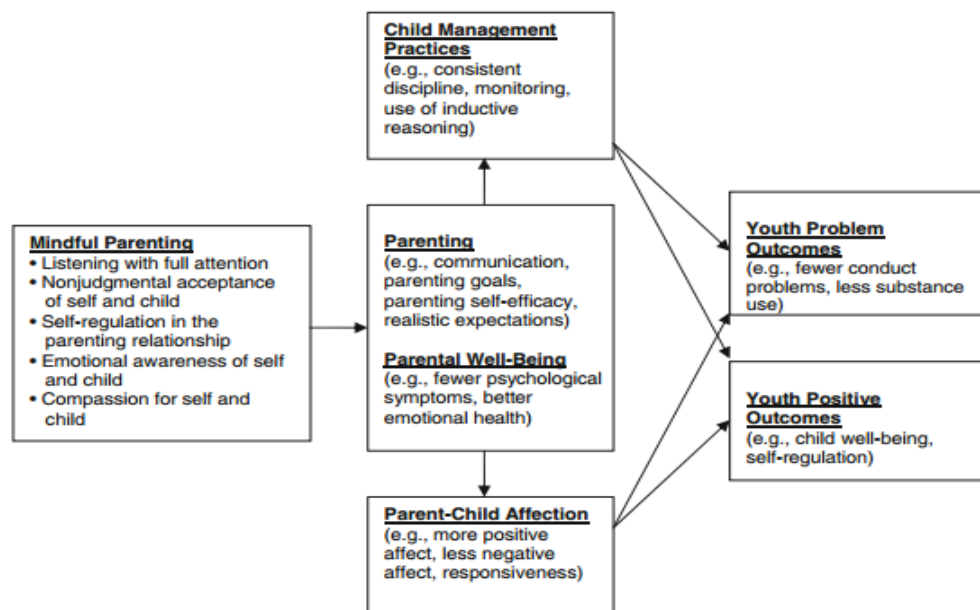


Figure 3: Model of MP (Duncan et al., 2009)

¹ Listening with full attention refers to the parent's capacity to sensitively attune to their child's needs and behaviours in the present moment.

² Non-judgemental acceptance of self and child refers to both the parental attributions and expectations that may influence specific parent-child interactions and the acknowledgement and acceptance of the challenges that come with parenting a child with neurodevelopmental disabilities.

³ Emotional awareness of the self and child refers to the process of bringing attention and awareness to both parental and child emotional states.

⁴ Self-regulation in the parenting relationship refers to the capacity to respond less reactively and the ability to choose parenting practices in line with one's parental values in specific parent-child interactions.

⁵ Compassion for self and child refers to both the capacity to respond to the child's needs and behaviour in a way that acknowledges and responds to their distress, as well as taking a forgiving, less harsh stance to one's own parenting practices.

Parental Stress and Child Behaviour

Patterson's coercion theory (2002) highlights how parental stress and parenting practices may influence child externalising difficulties. Studies have shown that harsh and coercive parenting styles are a risk factor for children developing conduct and behavioural problems (Smith et al., 2014). Furthermore, child externalising difficulties are known to elicit harsher, reactive parenting practices (Scaramella & Leve, 2004). Child externalising difficulties can elicit strong emotional responses from caregivers which may contribute to negative, harsh parenting practices, which serve to inadvertently reinforce the problematic behaviours over time (Smith et al., 2014). Escalating patterns of conflict between parent and child reinforces the externalising behaviours. Mindfulness theory acknowledges the role of parental stress in these unhelpful patterns of interaction between parent and child. Increased parental stress and parental reactivity serves to escalate or maintain child externalising difficulties and parental stress. Thus, children with neurodevelopmental disabilities and child externalising difficulties are more likely to have parents who experience high levels of parental stress and mental health difficulties, which may contribute to more reactive parenting practices, negative parent-child relationships and patterns of escalating conflict.

Mindfulness in Families of Typically Developing Children

Both trait mindfulness and MP have been described as potential psychological resources for parents to draw upon and/or develop as adaptive coping mechanisms (Folkman, 1997; Lazarus & Folkman, 1984). Amongst parents of typically developing children, higher levels of trait mindfulness and MP have been associated with lower levels of parental stress

(Corthorn & Milicic, 2016) and lower levels of child internalising⁶ and externalising difficulties⁷ (Parent, McKee & Rough, 2015). One facet of MP, non-judgemental acceptance, was specifically related to lower levels of adolescent internalising difficulties (Geurtzen, Scholte, Engels, Tak & Van Zundert (2014). This highlights the potential for MP to relate to both parental and child variables. These findings could have important implications for parents of children with neurodevelopmental disorders, whom experience high levels of parental stress and child internalising and externalising difficulties.

Mindfulness in Families of Children with ASD

To date, two correlational studies have begun exploring some of these relationships in parents of children with ASD. Higher levels of trait mindfulness were significantly associated with lower levels of parental stress, amongst 67 parents (Conner & White, 2014). Higher levels of MP were also significantly associated with lower levels of parental stress and reduced child externalising difficulties, amongst 28 parents of children with ASD (Beer et al., 2013). These preliminary findings suggest potentially important relationships between mindfulness, parental stress and child externalising difficulties, in parents of children with ASD. However, these findings may not be generalisable to clinic settings where children often present with high levels of comorbidities. No studies to date have explored the relationships between mindfulness (trait and MP), parental stress and child externalising difficulties, amongst parents of children with comorbid neurodevelopmental disorders.

To develop the evidence base for mindfulness interventions in neurodisability it is important to develop our understanding of what facets of trait mindfulness and MP may be

⁶ Internalising difficulties refer to children's emotional and peer difficulties

⁷ Externalising difficulties refer to children's behavioural difficulties

related to parental and child variables. This is crucial so that future MP interventions can be developed and tailored to meet the needs of parents of children with specific neurodevelopmental disabilities. One study has explored these relationships in 28 of parents of children with ASD (Beer et al., 2013). They found that two facets of MP: non-judgemental acceptance and compassion for self and child were significantly related to reduced parental stress. Three facets: non-judgemental acceptance, compassion for self and child and self-regulation were significantly related to reduced child externalising difficulties. Furthermore, compassion for self and child was significantly related to parental depression, anxiety and stress. This suggests the potential importance of compassion (within the parenting context) in both reducing stress and child externalising difficulties, in parents of children with ASD.

Furthermore, exploring potential mediating factors that may indirectly affect the relationship between parental stress and child behaviour will help to develop theoretical understanding of how mindfulness brings about change. To date, only one study has explored mediation, in 28 parents of children with ASD. They did not find a significant mediating effect for MP in the relationship between parental stress and child behaviour (Beer et al., 2013). However, this may be due to the small sample size and not having enough power to detect the effect; something which the present study seeks to address, in a broader neurodevelopmental sample.

Self-Compassion

Emerging literature suggests that in addition to trait mindfulness and MP, general levels of self-compassion may be associated with positive parental outcomes (i.e. increased well-being). Self-compassion is defined as *“being kind to oneself in times of difficulty, recognising*

the shared nature of human difficulty and being aware of but without ignoring or dwelling on perceived negative aspects of the self or life” (Neff & Faso, 2014, p. 2). Self-compassion is thought to be important for parents of children with ASD who are more likely to experience shame, guilt and self-blame in relation to their child’s condition and parenting (Gray, 1993; Fernandez & Arcia, 2004; Mak & Kwok, 2010). The link between self-compassion and mental health has been well evidenced in the general population. For example, a meta-analysis reported a large effect for the relationship between self-compassion and parental stress (Macbeth & Gumley, 2012). Although closely linked to trait mindfulness, self-compassion is a distinct construct that is comprised of three components⁸. It is also distinct to the compassion for self and child facet of MP, which taps into the parent’s capacity to be compassionate towards their child and themselves during specific parent-child interactions.

Studies using non-neurodevelopmental samples have shown that higher levels of self-compassion are associated with parents making more external attributions of their child’s behaviour (Legge & Kuyken, 2016). Parents high in self-compassion also exhibit less critical and reactive parenting styles (Psychogiou et al., 2016). Furthermore, increased parental self-compassion has been associated with reduced child internalising and externalising difficulties, in 333 parents at 16 months follow up (Psychogiou et al., 2016). However, these findings became nonsignificant after controlling for child gender, parent education and parental depression. In another study, higher levels of trait mindfulness, MP and self-compassion were related to lower parental stress (Gouveia, Carone, Canavarro & Moreira, 2016). These findings suggest that higher levels of self-compassion relate to reduced parental stress and may influence parental perception and/or management of child externalising difficulties. Bogel’s et

⁸ Self-compassion, as defined by Neff & Faso (2014) has three components; 1. Self-kindness versus self-judgement, 2. Common humanity versus isolation and 3. Mindfulness versus overidentification

al. (2010) hypothesize that reducing parental stress and improving self-compassion are two potential mechanisms by which change may occur via increased MP. Therefore, self-compassion is likely to play an important role for parents who are managing the demands of parenting a child with neurodevelopmental disabilities.

Little research to date has explored the potential role of self-compassion amongst parents of children with neurodevelopmental disabilities. One small scale study found that increased levels of self-compassion were associated with greater parental well-being and life satisfaction, in 51 parents of children with ASD (Neff & Faso, 2014). Preliminary qualitative data also confirms the potential importance of self-compassion for parents caring for a child with ASD given the particularly high levels of parental stress in this population (Neff, 2011). Despite this emerging literature, no research to date has explored the role of self-compassion in parents of children with comorbid neurodevelopmental disorders.

Current Study

The current literature suggests that trait mindfulness, MP and self-compassion are associated with parental outcomes (i.e. parental stress and well-being). Furthermore, there is some preliminary evidence to suggest that higher MP may be related to lower levels of child externalising difficulties. However, these findings relate to parents of children with ASD only. Little is known about whether they are generalisable to parents of children with comorbid neurodevelopmental disabilities. This is an important aim of the current study given the high rates of comorbidity, parental stress and child externalising difficulties in children with comorbid neurodevelopmental disabilities.

Therefore, the current study aims to build on Beer, Ward and Moar's (2013) findings by addressing issues of sample size and power and measuring trait mindfulness and self-compassion. The main objectives of the current study are to a) explore relationships between mindfulness (trait and MP), self-compassion, parental stress, well-being and perceived child externalising difficulties, in a broad neurodevelopmental sample, b) explore whether the relationship between parental stress and perceived child externalising difficulties is mediated by mindfulness (trait and MP) in a broad neurodevelopmental sample, and c) compare levels of mindfulness, MP and self-compassion amongst parents of children with primary diagnoses of ASD, ADHD and Tics/Tourette's Syndrome. It is predicted that:

- Higher levels of mindfulness, MP and self-compassion will be negatively associated with lower levels of parental stress, perceived child externalising difficulties and positively associated with parental well-being.
- Of the MP facets, two facets (non-judgemental acceptance of self and child and compassion for self and child) will be positively associated with parental well-being and negatively associated with parental stress. Three facets (non-judgemental acceptance of self and child, compassion for self and child and self-regulation) will be negatively associated with perceived child externalising difficulties.
- Mindfulness and MP will mediate the relationship between parental stress and child externalising difficulties.

Method

Design

This study was a retrospective observational study using a quantitative, cross sectional, questionnaire based, correlational design.

Participants

Parents. Participants included parents of children aged 4-15 years old, with at least one diagnosis of a neurodevelopmental disability (ASD, ADHD, Tics, Tourette's, Stereotypies, and/or intellectual disabilities). Participants were recruited from the United Kingdom between September-January 2018. The final sample consisted of 84 parents; some of whom included both parents from one family (N=5). Parents age ranged from 30-57 years old (M=42, SD=5.15). Eighty eight percent of the sample were mothers, 10% were fathers and 2% were adoptive fathers. Most of the parents reported being married (73%), 13% were in a long-term relationship, 10% were single and 5% were divorced. A large proportion of the sample (98%) included parents of White/White British/White Other ethnicity. Only 2% of the sample were of a Black/Black British ethnicity or other ethnicity. A large proportion of the sample were employed in some capacity (76%) and 24% were not employed. Of the sample, 78% were educated to A-Level equivalent or beyond.

Most parents taking part had two children (60%), 17% had one child, 17% had three children and 6% had more than three children. Of those that had more than one child, 25% reported that they had a second child with a disability.

Children. Of the 84 children in the sample, child age ranged from 5-15 years old (M=10.47, SD=2.43). Seventy six percent of the children were male and 24% were female children. Forty one percent of the sample had a primary diagnosis of ADHD, 26% had a primary diagnosis of

ASD and 26% had a primary diagnosis of Tics/Tourette's Syndrome and 7% had a primary diagnosis of Stereotypies. Fifty four percent of the sample had a comorbid neurodevelopmental disability. Of these, 27% had a comorbid ASD diagnosis, 7% had a comorbid ADHD diagnosis, 4% had a comorbid diagnosis of Tics/Tourette's Syndrome, 4% had a comorbid intellectual disability, 2% had a comorbid diagnosis of stereotypies and 56% ticked 'other'. Of those that ticked 'other', parents either reported that their children were awaiting a comorbid neurodevelopmental disability diagnosis or they had mental health difficulties and/or behavioural and/or physical health difficulties. These included anxiety, OCD, insomnia, self-harm/suicidality, oppositional defiant disorder, dyslexia, dyspraxia, sensory processing disorder, neurofibromatosis type 1, global developmental delay and other medical conditions such as hypermobility syndrome, congenital hypothyroidism, asthma.

Recruitment

Participants were recruited retrospectively and prospectively from two NHS teams; the children's Complex Neurodevelopmental Disability assessment service and the Tics and Neuro-developmental Movements (TANDeM) service at Guys and St Thomas Hospital. Approximately 150 families who had consented to be contacted for research purposes and who had previous contact with the TANDeM team were sent a study invite (Appendix 7) and study information sheet (Appendix 6). Other potential participants were handed out study information sheets in clinic prospectively. Participants were also recruited through online charities (e.g. Tourette's Action, Research Autism, ADHD Foundation) and online advertisements of the study through public Facebook groups for parents of children with neurodevelopmental disabilities.

All participants were advised to read the study information sheet and contact the researcher to discuss the research further, ask questions and provide informed consent. Those who agreed to take part were given the opportunity to complete the study questionnaires online via Qualtrics or by post. Informed consent (Appendix 8) was gained either electronically before participants proceeded to complete the study questionnaires via Qualtrics or in written format by completing and returning the consent form along with the study questionnaires.

A total of 134 parents expressed interest in completing the study. Of these, 82 (65%) went on to complete the questionnaires. Of these, 12 participants were recruited from NHS services, and the remaining 72 participants were recruited via charities and online advertisements. After completion of the study, participants were sent a debrief form (Appendix 9) and those who had consented to be contacted again for service user involvement were sent a copy of the research findings (Appendix 12) and an invitation to share their interpretations of the findings and recommendations for dissemination.

Power

Effect size calculations were based on similar correlational design studies using neurodevelopmental samples. Medium effects were found between compassion and parental stress ($r=0.48$) and between the non-judgemental facet of MP and parental stress ($r=0.35$), in 28 parents of children with autism (Bear et al., 2013). A large effect ($r=-0.54$ (95%CI = -0.57 to -0.51; $Z=-34.02$; $p<.0001$) was found in a meta-analysis of 14 studies, between self-compassion and parental mental health (Macbeth & Gumley, 2012). Calculations based on the observed R^2 for the relationship between MP, parental stress and child behaviour showed a large effect ($R^2=.309$) (Jones, Hastings, Totsika, Keane & Rhule (2014). Seventy participants were required, predicting a medium effect, with an alpha level of .05 and power of .80 (Cohen, 1992). For specific primary diagnosis analysis, expecting a large effect, with an alpha level of

.05 and power .80 (Cohen, 1992) 19 parents were required per group. Therefore, the current study was adequately powered.

Ethical Approval

This study was approved by the West Midlands – South Birmingham Research Ethics Committee and NHS Health Research Authority (HRA) in June 2017 (Appendix 10). Approval was also gained via self-certification through Royal Holloway, University of London's ethics board. Local Research and Development approval with Guys and St Thomas NHS Trust was also granted.

Measures

Copies of all six questionnaires are included in Appendix 11.

Five-facet mindfulness questionnaire (Baer, Smith, Hopkins, Krietemeyer & Toney (2006)). The Five Facets Mindfulness Questionnaire (FFMQ) is a self-report scale that measures individual's general levels of mindfulness in their daily lives. It is a 39-item scale with a 5-point Likert-type scale (ranging from 1 'never or very rarely true' to 'very often or always true') with total scores ranging from 39 to 195. The scale is composed of five facets (i.e. subscales). These include: observing (8 items; range 8-40), describing (8 items; ranging 8-40), acting with awareness (8 items; range 8-40), non-judging of inner experience (8 items; range 8-40) and non-reactivity (7 items; range 7-35). Scores for items 12, 16, 22 (describing), 5, 8, 13, 18, 23, 28, 34, 38 (acting with awareness), 3, 10, 14, 17, 25, 30, 35 and 39 (non-judging of inner experience) were reversed for scoring purposes. The scale was developed from a factor analysis of items from five mindfulness questionnaires (De Bruin et al., 2012).

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Good internal consistency has been reported for all five facets ($\alpha = 0.75-0.91$) in meditators, non-meditators, students, general population and parents of children with autism (Baer et al. 2006; Baer et al. 2008). Good construct validity is reported, evidenced by correlations ($r = .89$ between the Mindful Attention Awareness Scale and the acting with awareness facet of the FFMQ; $r = .75$ between the non-reactivity facet of the FFMQ and the Mindfulness Questionnaire) (Baer et al., 2008). Most mindfulness facets were significantly related to meditation experience. Meditators scored significantly higher than non-meditators (Baer et al., 2008). Partial evidence for the convergent validity was found due to moderate correlations ($r_s = .23$ to $.50$, $p < .05$) between FFMQ facets and a measure of psychological well-being. Cronbach's alpha for the FFMQ items in this study was 0.78.

Interpersonal mindfulness in parenting (IM-P) scale (Duncan, 2007). The Interpersonal Mindfulness in Parenting Scale (IM-P) measures an individual's tendency to apply mindfulness to parent-child interactions in day to day life. (Duncan, 2007). It is a 31-item five point-type Likert scale (ranging from 1 'never true' to 5 'always true'). Total scores range from 39 to 155. The scale is composed of five facets: listening with full attention (5 items; range 5-25), emotional awareness of self and child (6 items; range 6-30), self-regulation in parenting relationship (6 items; range 6-30), non-judgemental acceptance of self and child (7 items; range 7-35) and compassion for self and child (7 items; range 7-35). Scores for items 1, 9, 13, 19 (listening with full attention), 11, 12 (emotional awareness of self and child), 2, 5, 14, 29 (self-regulation/non-reactivity), 10, 23 (non-judgemental acceptance of self and child) and 15, 17, 26 (compassion for self and child) were reversed for scoring purposes.

Adequate internal consistency reliability is reported for all subscales and total score ($\alpha = 0.76-0.82$; 0.92) (Duncan, 2007). Adequate convergent and discriminant validity has been found in a sample of parents and young adolescents. Non-reactivity was most highly correlated

with self-compassion ($r=.53$), awareness had a strong inverse relationship with absent mindedness ($r=-.61$), non-judging had a strong inverse relationship with neuroticism ($r=.55$) and difficulties with emotion regulation ($r=.52$) (Duncan, 2007). MP was shown to be positively associated with, yet also distinct from levels of general mindfulness (Duncan, 2007). This is evident in findings of a one standard deviation increase in general mindfulness being associated with a .70 increase in MP (Duncan, 2007). MP also accounted for a substantial proportion of the variance in the parent-child affective quality and general child management, yet was independent from them (Duncan, 2007). Cronbach's alpha for the IM-P items in this study were .88.

Self-compassion scale (Neff, 2003). The Self-Compassion Scale (SCS) is a self-report measure of general levels of compassion towards the self (Neff, 2003). It is a 26-item scale using a 5-point Likert scale (ranging from 1 'almost never' to 5 'almost always') and total scores ranging from 26-130. The scale is composed of three dimensions; self-kindness versus self-judgement, sense of common humanity versus isolation and mindfulness versus over-identification. Scores for items 1, 8, 11, 16, 21 (self-judgement), 4, 13, 18, 25 (isolation), 2, 6, 20 and 24 (over-identified) were reverse scored for scoring purposes. Total scores and total mean scores were calculated for each domain, resulting in a total mean score (ranging from 0-5). Total mean scores between 1-2.5 indicate low self-compassion, 2.5-3.5 indicate moderate self-compassion and 3.5-5 indicate high self-compassion.

Good internal consistency reliability has been reported ($\alpha >.86$) (Neff, 2003). Good construct validity has been found, evidenced by the SCS being significantly negatively correlated with the self-criticism subscale of the DEQ ($r=.65$). The scale demonstrates convergent validity, evidenced by correlations with partner ratings. The scale has been found

to have discriminant validity due to no correlations found with social desirability (Neff, 2016). Cronbach's alpha for all items in this study is .94.

Parental stress scale (Berry & Jones, 1995). The Parental Stress Scale (PSS) is a self-report scale measuring the levels of stress experienced by parents in relation to their parenting role (Berry & Jones, 1995). It is an 18-item scale using a five-point Likert scale (ranging from 1 'strongly disagree' to 5 'strongly agree') with total scores ranging from 18-90. Lower scores indicate lower levels of parental stress and higher scores are indicative of higher levels of parental stress. Scores for items 1, 2, 5, 6, 7, 8, 17, 18 were reversed for scoring purposes.

Good internal consistency reliability has been reported ($\alpha = 0.83$) (Lee, 2012). Criterion-related validity was supported by predicted correlations with role satisfaction. Significant discrimination was found between mothers of children in treatment for emotional/behavioural difficulties and developmental disabilities compared to those not receiving treatment (Berry & Jones, 1995). Furthermore, validity is evidenced by correlations between the PSS and the total parenting stress index ($r = .75$, $P < .01$), total child domain ($r = .62$, $p < .01$) and total parent domain ($r = .72$, $p < .01$) of the Parental Stress Index (Berry & Jones, 1995). Cronbach's alpha for this study was .84.

WHO (Five) well-being index (Psychiatric Research Unit). The WHO (Five) Well-Being Index is a self-report scale measuring an individual's general well-being (Psychiatric Research Unit). It is a 5 item 5-point Likert Scale (ranging from 5 'all of the time' to 0 'at no time'), with total scores ranging from 0-25. A total score is derived from five items, with lower scores representing lower levels of well-being and higher scores representing higher levels of well-being. Raw scores were multiplied by four to generate a percentage score ranging from 0-100.

This measure has been shown to have adequate construct validity as a screening tool for depression and as an outcome measure (Topp, Ostergaard & Sondergaard, 2015). Analyses confirmed that the five items constitute a unidimensional scale whereby each item adds unique information about well-being (Topp, Ostergaard & Sondergaard, 2015). Cronbach's alpha for this study was .87.

Strengths and difficulties questionnaire (SDQ) (Goodman, 1997). The Strengths and Difficulties Questionnaire (SDQ) is a self-report scale, measuring children's emotional and behavioural difficulties (Goodman, 1997). It is a 25 item, 3-point Likert scale (ranging from 'not true' to 'certainly true') with total scores ranging from 0-40. It is composed of five domains: prosocial behaviour (5 items; range 0-10), emotional symptoms (5 items; range 0-10), conduct problems (5 items; range 0-10) and hyperactivity and peer problems (5 items; 0-10). Scores for items 7, 14, 15, 17, 18 were reversed. Total child difficulties were calculated by summing each sub-scale score, except for prosocial. A total internalising score was derived from the sum of the emotional and peer problems scales. A total externalising score was derived from the sum of the conduct and hyperactivity scales.

The SDQ is commonly used and is well validated in its ability to identify child internalising and externalising difficulties (Goodman, 1997). Good internal consistency reliability has been reported for total behaviour problems for children with autism ($\alpha = .78$ and $.80$ for mothers and fathers) (Jones, Hastings, Totsika, Keane & Rhule, 2014). Cronbach's alpha in this study was $.60$.

Data Analysis

The data were analysed using IBM SPSS Statistics Version 21. Twelve cases were excluded due to missing or incomplete data. Eighty-four complete cases were included for

analysis. All variables were normality distributed except for parent age. Thus, parametric tests were used, with a non-parametric test to explore the relationship between parent age and trait mindfulness. A total of six outliers were identified and removed from the analysis. Skewness and kurtosis were found to be within acceptable bounds (i.e. <2.58 or <3.29) for all study variables. Pearson's bivariate correlations and independent t-tests were conducted to explore relationships between demographic variables (including parent age, gender, employment, education, number of children, additional children with disabilities, child age, child gender) and the study variables (including parental trait mindfulness, MP, self-compassion, well-being, stress and child behaviour).

Pearson's bivariate correlations were used to explore the relationships between the study variables (trait mindfulness, MP, self-compassion, parental stress, well-being and child behaviour) and relationships between the facets of trait mindfulness and MP. Partial correlations were conducted to control for potential covariates including parent employment, child comorbidity and child gender. These correlations are included in brackets in Tables 5, 6 and 7. The Bonferroni correction was applied to all correlations to control for multiple testing. All correlations that remained significant at this level are highlighted in bold in Tables 5, 6, and 7. Mediation analyses were conducted using the PROCESS macro for SPSS (Hayes, 2013) using Hayes Bootstrapping. All data were checked for normality of distribution, homoscedasticity and independent errors. Histograms highlighted that data were normally distributed, scatterplots showed linearity between variables and Cook's distances test was conducted, showing that all cases were less than 1, indicating no outliers. All necessary assumptions for bootstrapped mediation analysis were met.

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Finally, an ANOVA and post-hoc independent t-tests were conducted to explore whether there were any significant differences in trait mindfulness, MP or self-compassion between parents of children with primary diagnoses of ASD, ADHD and Tics/TS.

Results

Demographic characteristics

Means and standard deviations for the sample are shown in Table 3. Thirty-four parents reported having a child with a primary diagnosis of ADHD, twenty-two had a child with a primary diagnosis of Tics or TS, twenty-one had a child with a primary diagnosis of ASD and six had a primary diagnosis of Motor Stereotypies. Forty seven percent (N=39) of the sample had no comorbid diagnosis and fifty three percent (N=44) had a comorbid neurodevelopmental disability.

*Table 3. Mean, standard deviation, percentages and medians for demographic data
(N=84)*

	Mean	SD	%	Median
Child age	10.47	2.43	-	11
Child gender				
Boys	-	-	76.2	-
Girls	-	-	23.8	-
Parent age	41.45	5.15	-	41
Parent gender				
Male	-	-	11.9	-
Female	-	-	88.1	-
Marital Status				
Single	-	-	9.5	-
Married	-	-	72.6	-

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	Mean	SD	%	Median
Long term relationship	-	-	13.1	-
Divorced	-	-	4.8	-
Parental ethnicity				
White/White	-	-	87.6	-
British/White Other	-	-	-	-
Black/Black British	-	-	1.2	-
Other	-	-	1.2	-
Parental employment				
Full time	-	-	27.4	-
Part time	-	-	27.4	-
Student/volunteer	-	-	3.6	-
Self-employed	-	-	21.4	-
Unemployed	-	-	20.2	-
Parents education level				
G.C.S.E or equivalent	-	-	22.6	-
A-Level or equivalent	-	-	29.8	-
Degree	-	-	29.8	-
Post-degree qualification	-	-	17.9	-

Pearson's bivariate correlations and independent t-tests were conducted to explore whether child age/gender, or parent age/gender were associated with trait mindfulness, MP, self-compassion, well-being, stress and child difficulties. All were non-significant except for a positive correlation between child gender and internalising difficulties ($r(83) = .239, p=.03$),

with higher rates reported for females. Significant bivariate correlations were found between child comorbidity and child internalising difficulties ($r=.283$, $p=.009$) and total child difficulties ($r=.231$, $p=.04$) but not child externalising difficulties ($r=.178$, $p=.105$). No significant differences were found between the number of children in the family and whether there were siblings with disabilities and parental stress and mindfulness levels. No significant differences were found between parental educational attainment and any of the parental variables.

Furthermore, no significant differences were found between parental employment and MP ($F(5,77) = 2.36$, $p=.05$), self-compassion ($F(5,77) = .814$, $p=.54$), parental stress ($F(5,78) = 1.31$, $p=.27$), parental well-being ($F(5,78) = 1.308$, $p=.27$), child internalising difficulties ($F(5,77) = 1.255$, $p=.29$) and child externalising difficulties ($F(5,78) = 2.357$, $p=.05$). However, there were significant differences in total child difficulties ($F(5,76) = 2.605$, $p=.03$) according to parental employment. That is, parents that were unemployed reported higher levels of total difficulties and externalising difficulties compared to those that were employed.

Relationships between mindfulness (trait and MP), self-compassion, parental stress, well-being and perceived child behaviour

Table 4 shows descriptive statistics (means, SD and range) for trait mindfulness, MP self-compassion, parental well-being and stress and child externalising difficulties. Parents in the sample reported relatively low levels of parental well-being ($M=40.14$, $SD=20.01$), with 64% percent of scores falling within the ‘low mood’ to ‘likely depression range’. Mean parental stress scores fell within the very high range. Mean self-compassion scores ($M=2.77$, $SD=0.54$) fell within the moderate range, with 27% of parents classified as ‘low self-compassion’, 66% as ‘moderate self-compassion’ and 7% as ‘high self-compassion’. No norms exist for trait mindfulness or MP but higher scores represent higher levels of mindfulness. The mean total

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child difficulties score fell within the very high range, indicating a high level of need in the sample.

Table 4: Descriptive statistics for parental mindfulness (trait and MP), self-compassion, parental well-being, stress and child externalising difficulties

Variables	N	M	SD	Range	(Possible range)
Trait mindfulness (FFMQ)	83	117.33	19.17	89	39-195
Observing (FFMQ)	84	24.40	6.34	30	8-40
Describe (FFMQ)	84	26.74	7.02	32	8-40
Awareness (FFMQ)	84	21.40	6.04	28	8-40
Non-judgemental (FFMQ)	83	25.58	7.03	32	8-40
Non-reactivity (FFMQ)	83	19.06	4.27	22	7-35
Mindful parenting (MP)	83	78.69	8.54	43	39-155
Listening with full attention (MP)	83	16.20	2.77	14	5-25
Emotional awareness (MP)	83	22.02	2.30	10	6-30
Non-reactivity (MP)	83	18.66	3.36	18	6-30
Non-judgemental (MP)	83	23.66	3.08	14	7-35
Compassion (MP)	83	22.45	3.16	14	7-35
Self-compassion	83	2.77	0.54	2.51	0-5
Parental well-being	84	40.14	20.01	84	0-100
Parental stress	84	45.89	9.12	46	18-90
Total child difficulties	82	22.61	5.50	24	0-40
Child internalising difficulties	83	9.89	3.94	19	0-20
Child externalising difficulties	84	12.25	3.76	16	0-20

Figure 4 highlights the breakdown of total child difficulties scores by primary diagnosis. This shows relatively high levels of total child difficulties across the three main

diagnostic groups, with higher rates amongst children with primary diagnoses of ADHD and ASD.

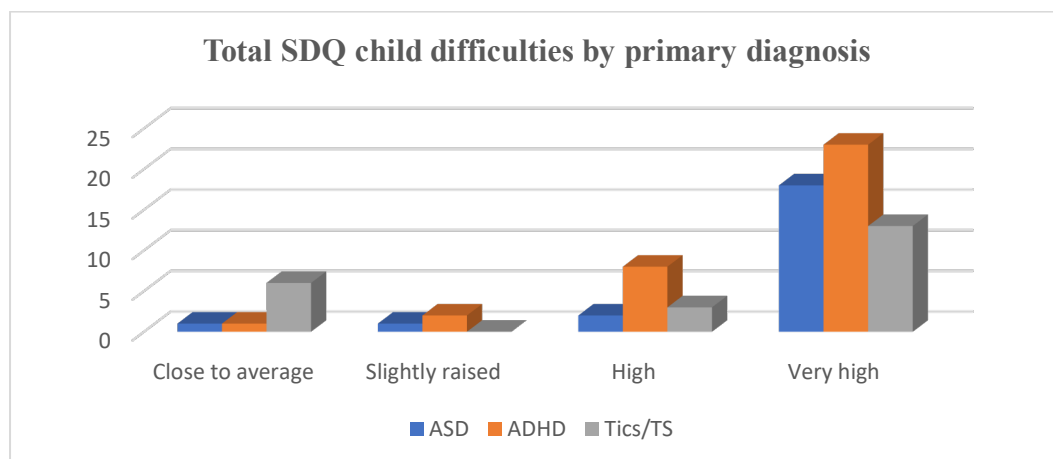


Figure 4: Total child difficulties scores by primary diagnosis

Pearson's product moment correlation coefficients between parental trait mindfulness, MP, self-compassion, parental stress, parental well-being, and perceived child difficulties are shown in Table 5. Overall, the correlations remained significant after controlling for potential covariates (child gender, comorbidity and parent employment) which are highlighted in brackets. A number of findings became non-significant after applying the Bonferroni correction ($p < .002$) to protect against multiple testing and the potential for Type 1 errors. Only those correlations which remained significant after Bonferroni correction (shown in bold) will be discussed.

Trait mindfulness was significantly positively correlated with self-compassion ($r(80) = .646, p < 0.01$) and parental well-being ($r(81) = .448, p < 0.01$) with a large effect size. That is, parents with higher levels of trait mindfulness reported higher levels self-compassion and well-being.

No significant correlation was found between MP and parental well-being ($r(83) = .154, p = .110$). However, MP was significantly negatively correlated with parental stress ($r(82) = -$

.417, $p < 0.001$) with a medium effect size and positively correlated with self-compassion ($r(82) = .394$, $p < .001$). In other words, parents who reported using more MP reported lower levels of parental stress and higher self-compassion.

Self-compassion was significantly positively correlated with parental well-being ($r(81) = .540$, $p < 0.01$) with a medium effect size. That is, higher levels of self-compassion among parents were related to higher levels of parental well-being. Furthermore, parental self-compassion was negatively correlated with parental stress ($r(81) = -.341$, $p < 0.01$) with a medium effect size. That is, parents who reported higher levels of self-compassion reported lower levels of parental stress.

A significant negative correlation was found between parental well-being and parental stress ($r(82) = -.451$, $p < 0.01$) with a large effect size. In other words, parents who reported greater well-being tended to experience lower levels of parental stress.

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Table 5: Pearson's correlation coefficients for parental mindfulness (trait and MP), self-compassion, well-being, stress and child externalising difficulties

	Trait mindfulness	Mindful parenting	Self-compassion	Parental well-being	Parental stress	Total difficulties	child internalising difficulties	Child externalising difficulties
Trait mindfulness	-	.397*** (.387***)	.648*** (.642***)	.475*** (.500***)	-.319** (-.311**)	-.205 (-.198)	-.276* (-.276*)	-.041 (.027)
Mindful parenting		-	.394*** (.380***)	.179 (.180)	-.430*** (-.414***)	-.205 (-.192)	-.243* (-.230*)	-.257* (-.242*)
Self- compassion			-	.530*** (.540***)	-.363*** (-.341***)	-.134 (-.107)	-.332** (-.312**)	.076 (.109)
Parental well- being				-	-.451*** (-.463***)	-.226* (-.223*)	-.240* (-.246*)	-.198 (-.169)

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	Trait mindfulness	Mindful parenting	Self-compassion	Parental well-being	Parental stress	Total child difficulties	Child internalising difficulties	Child externalising difficulties
Parental stress					-	.297** (.267*)	.326** (.280**)	.270* (.256*)
Total child difficulties						-	.759*** (.763***)	.695*** (.694***)
Child internalising difficulties							-	175 (.172)
Child externalising difficulties								-

***p<.001, **p<.01, *p<.05

Figures in brackets represent partial correlations after controlling for covariates (comorbidity, parental employment and child gender). Figures in bold remained significant after applying Bonferroni correction (p=.002)

Relationships between facets of trait mindfulness and parent and child variables

Table 6 highlights that, as expected, there were significant moderate sized correlations between trait mindfulness and all five facets of trait mindfulness, (all $r(81) = .494-.702$, $p < 0.01$). Trait mindfulness was significantly positively correlated with four of five facets of MP; including listening with full attention ($r(80) = .238$, $p < 0.05$), non-judgemental acceptance ($r(80) = .540$, $p < 0.01$), non-reactivity ($r(80) = .317$, $p < 0.01$) and compassion of self and child ($r(80) = .434$, $p < 0.01$). There was no significant association between trait mindfulness and the emotional awareness facet of MP ($r(80) = .185$, $p = .09$).

Bonferroni correction was used and only correlations which remained significant are described. Three facets of mindfulness (awareness, non-judgemental acceptance and non-reactivity) were positively associated with self-compassion ($r(82/83) = .391-.514$, all $p < .001$ or $p < .01$). One facet: describing, was positively associated with higher levels of parental well-being ($r(84) = .391$, $p < .002$).

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Table 6: Pearson's correlation coefficients for facets of trait mindfulness and study variables

Facets of trait mindfulness	Trait mindfulness	Mindful parenting	Self- compassion	Parental well- being	Parental stress	Total child difficulties	Child internalising difficulties	Child externalising difficulties
Observing	.494*** (.550***)	.259* (.289*)	.194 (.218)	.117 (.151)	-.094 (-.125)	.131 (.094)	.057 (.000)	.148 (.133)
Describing	.702*** (.686***)	.157 (.130)	.386** (.378**)	.428*** (.391***)	-.119 (-.105)	-.100 (-.039)	-.098 (-.068)	.022 (.112)
Awareness	.696*** (.679***)	.274* (.255*)	.393*** (.391***)	.375** (.333*)	-.261* (-.265*)	-.295** (-.256*)	-.207 (-.203)	-.225* (-.155)

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	Trait mindfulness	Mindful parenting	Self- compassion	Parental well-being	Parental stress	Total child difficulties	Child internalising difficulties	Child externalising difficulties	
Non- judgemental	.595*** (.609***)		.277* (.271*)	.499*** (.498***)	.196 (.198)	-.324** (-.305**)	-.232* (-.221)	-.362 (-.329)	-.056 (-.155)
Nonreactivity	.637*** (.679***)		.200 (.183)	.502*** (.514***)	.329** (.296**)	-.136 (-.134)	-.169 (-.149)	-.265 (-.272)	-.055 (-.003)

***p<.001, **p<.01, *p<.05

Correlations in brackets are those after controlling for child gender, parent employment and comorbidity. Those in bold remain significant after applying the Bonferroni correction at p<.002.

Relationships between facets of mindful parenting, parental stress, well-being and child behaviour variables

Table 7 highlights the relationships between the five facets of MP with the study variables. Only correlations that were significant after applying the Bonferroni correction are discussed.

As expected, there were significant positive correlations between MP (total score) and all five facets of MP including listening with full attention ($r(80) = .641, p < 0.01$), emotional awareness ($r(80) = .553, p < 0.01$), non-judgemental acceptance ($r(81) = .708, p < 0.01$), non-reactivity ($r(80) = .798, p < 0.01$) and compassion for self and child ($r(83) = .743, p < .001$). Of the five facets of MP, emotional awareness was not significantly correlated with any of the study outcomes. One facet: compassion for self and child, was negatively associated with lower levels of parental stress ($r(83) = .456, p < .001$) and child internalising difficulties ($r(83) = -.430, p < .001$). One facet: non-reactivity, was significantly negatively associated with child externalising difficulties ($r(80) = -.336, p < .001$). All of which had medium effect sizes.

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Table 7: Pearson's correlation coefficients for facets of MP and study variables

Facets of mindful parenting (MP)	Trait mindfulness	Mindful parenting	Self- compassion	Parental well-being	Parental stress	Total child difficulties	Child internalising difficulties	Child externalising difficulties
Listening with full attention	.238* (.196)	.649*** (.641***)	.094 (.062)	.173 (.127)	-.338** (-.320*)	-.272* (.088)	-.213 (.001)	-.314** (-.270)
Emotional awareness	.185 (.196)	.544*** (.553***)	.040 (.045)	-.157 (-.171)	-.044 (-.061)	.102 (.088)	0.35 (.001)	-.053 (-.047)
Non- judgemental acceptance	.540*** (.534***)	.714*** (.708***)	.537*** (.528***)	.262* (.244)	-.358** (-.344**)	-.122 (-.097)	-.182 (-.157)	-.125 (-.094)

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Facets of mindful parenting (MP)	Trait mindfulness	Mindful parenting	Self- compassion	Parental well-being	Parental stress	Total child difficulties	Child internalising difficulties	Child externalising difficulties
Nonreactivity	.317** (.305**)	.792*** (.798***)	.294** (.297**)	.215 (.209)	-.344*** (-.366***)	-.259* (-.275*)	-.082 (.121)	-.351*** (-.366***)
Compassion for self and child	.434*** (.417***)	.748*** (.743***)	.572*** (.565***)	.265* (.244*)	-.465*** (-.456***)	-.333** (-.325**)	-.434*** (-.430***)	-.239* (-.212)

***p<.001, **p<.01, *p=.05

Correlations in brackets are those after controlling for child gender, parent employment and comorbidity. Those in bold remain significant after applying the Bonferroni correction at p<.001.

Mediation Analysis

Mediation analyses were carried out using the PROCESS macro for SPSS (Hayes, 2013) using 5000 resamples and accelerated confidence intervals. This aimed to explore whether mindfulness (trait and MP) mediated the relationship between parental stress and child externalising difficulties. Table 8 highlights that no significant indirect effect was found between parental stress and child externalising difficulties through change in MP ($\beta=.03$, 95% CI $-.02, -.08$). However, a significant indirect effect of child externalising difficulties on parental stress through change in MP was found ($\beta=.25$, 95% CI $.03, .57$). These results suggest that mindful parenting had a significant mediating effect between child externalising difficulties and parental stress.

Table 8: Summary of mediation analysis showing the mediation effect of change in MP and trait mindfulness on child externalising difficulties

Independent variable	Mediating variable	Dependent variable	Effect of IV on DV	Effect of IV on M	Effect of M on DV	Direct Effect	Indirect Effect (a x b) 95% CI
(IV)	(M)	(DV)	(c)	(a)	(b)	(c*)	
Parental Stress	MP	Child Externalising Difficulties	.09	-.40	-.08 ^a	.06 ^a	.03 (-.02,-.08)
Parental Stress	Trait Mindfulness (Total FFMQ)	Child Externalising Difficulties	.12	-.68	.01 ^a	.13	-.01(-.05,-.04)

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Child	MP	Parental	.61	.26	-.42	.35 ^a	.25 (.03,-.57)
Externalising		Stress					
Difficulties							
Child	Trait	Parental	.69	-.21 ^a	-.15	.66	.03 (-.19,-.25)
Externalising	Mindfulness	Stress					
Difficulties	(Total						
	FFMQ)						

^a Non- significant results at 95% confidence interval

The figures below highlight the pathway of effects, with significant effects marked with *.

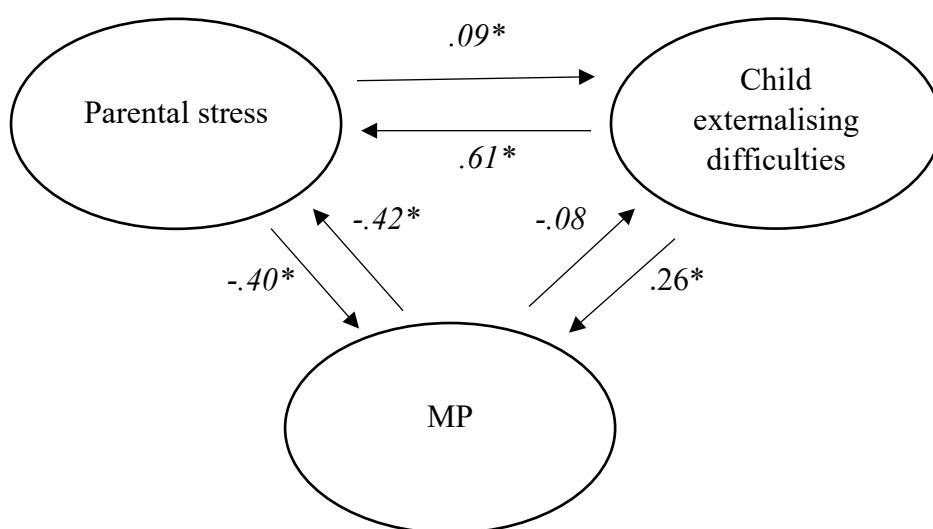


Figure 5: Visual representation of MP mediation effects

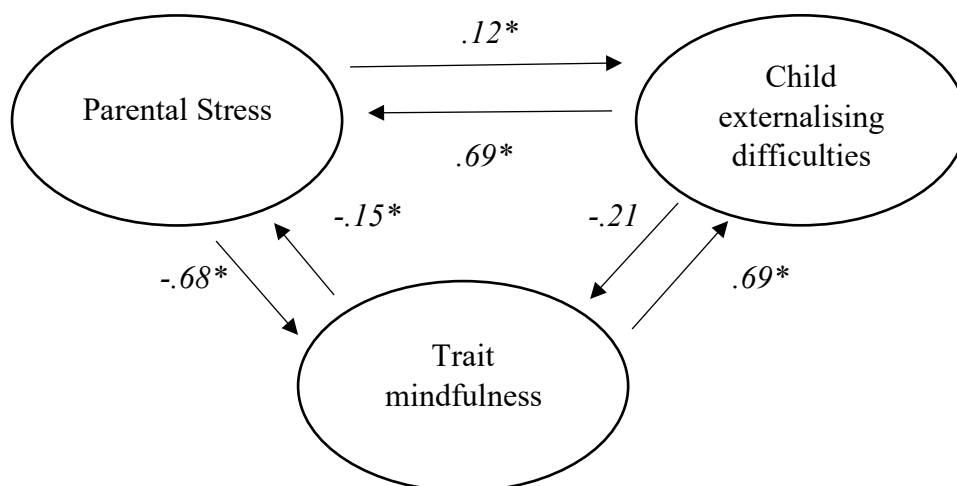


Figure 6: Visual representation of trait mindfulness mediation effects

Comparison of levels of trait mindfulness, MP and self-compassion according to primary diagnosis

Table 9 shows the comparative mean scores and standard deviations for all study variables, between those with a primary diagnosis of ASD, ADHD and Tics/Tourette's Syndrome. This highlights that the parents with children with a primary diagnosis of Tics/Tourette's Syndrome have higher mean scores for trait mindfulness, MP, well-being and lower child externalising difficulties.

Table 9: Descriptive statistics for parental mindfulness (trait and MP), self-compassion, well-being and child externalising difficulties according to primary diagnosis

Variables	Primary diagnosis of ASD (N=21)	Primary diagnosis of ADHD (N=34)	Primary diagnosis of Tics/Tourette's Syndrome (N=21)
	<i>Mean (SD)</i>	<i>Mean (SD)</i>	<i>Mean (SD)</i>
Trait mindfulness (FFMQ)	115.14 (23.63)	115.06 (18.9)	121.36 (16.54)
Observing (FFMQ)	25.77 (7.20)	23.09 (5.52)	25.55 (6.25)
Describing (FFMQ)	23.95 (8.20)	27.65 (5.91)	27.77 (6.63)
Non-judgemental (FFMQ)	20.23 (6.48)	25.06 (6.98)	22.50 (5.22)
Non-reactivity (FFMQ)	19.19 (4.80)	18.53 (3.89)	19.73 (4.10)
Mindful parenting (MP)	76.00 (9.97)	77.76 (9.17)	82.50 (7.92)
Listening with full attention (MP)	16.29 (3.05)	16.06 (3.15)	16.32 (1.99)
Emotional Awareness (MP)	21.76 (2.57)	21.82 (2.28)	22.55 (2.39)
Non-reactivity (MP)	18.77 (3.73)	18.15 (3.36)	19.36 (3.35)
Non-judgemental (MP)	23.24 (2.28)	23.35 (.65)	24.55 (2.72)
Compassion (MP)	21.24 (2.51)	22.03 (3.06)	24.27 (3.44)
Self-compassion	2.65 (3.80)	2.71 (0.56)	3.01 (0.45)
Parental well-being	36.18 (20.86)	39.3 (18.98)	43.45 (19.80)
Parental stress	47.41 (8.20)	46.06 (9.92)	44.59 (9.36)
Total child difficulties	25.68 (5.66)	22.24 (4.98)	20.65 (5.27)

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Child internalising difficulties	11.72 (3.61)	9.23 (4.01)	9.00 (4.12)
Child externalising difficulties	13.59 (4.09)	13.00 (2.51)	10.4

A one-way independent ANOVA was used to compare levels of trait mindfulness, MP and self-compassion between parents of children with a primary diagnosis of ASD, ADHD and Tics/Tourette's Syndrome. The three groups did not differ significantly on trait mindfulness ($F(2,74) = .826, p=.442$), parental stress ($F(2,75) = .505, p=.606$) or parental well-being ($F(2,75) = .753, p=.475$). However, there were significant differences in levels of MP ($F(2,74) = 3.447, p<.037$) and self-compassion ($F(2,75) = 3.545, p<.034$), total child difficulties ($F(2,73) = 5.169, p=.008$), total internalising difficulties ($F(2,74) = 3.283, p=.043$) and externalising difficulties ($F(2,75) = 5.484, p=.006$).

Post hoc independent sample t-tests highlighted a significant difference in MP levels between parents of children with a primary diagnosis of ASD and parents of children with a primary diagnosis of Tics/Tourette's Syndrome ($t(41) = -2.681, p=.01$). That is, parents of children with ASD had significantly lower levels of MP than parents of children with a primary diagnosis of Tics/Tourette's Syndrome. No significant difference in MP levels were found between parents of children with a primary diagnosis of ASD and parents of children with a primary diagnosis of ADHD ($t(53) = -.727, p=.47$). That is, levels of MP were lower in both parents of children with primary diagnoses of ASD and ADHD, but parents of children with ASD reached significance.

Furthermore, parents of children with a primary diagnosis of Tics/Tourette's had significantly higher levels of self-compassion compared to parents of children with primary diagnoses of ASD ($t(41) = .407, p=.007$) and parents of children with a primary diagnosis of ADHD ($t(54) = -2.086, p=.042$).

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Parents of children with a primary diagnosis of ASD reported significantly higher scores for total child difficulties ($t(40) = 2.972, p=.005$), internalising difficulties ($t(41) = 2.295, p=.027$) and externalising difficulties ($t(42) = 2.614, p=.012$) compared to parents of children with primary diagnoses of Tics/Tourette's Syndrome. They also reported significantly higher levels of total child difficulties ($t(54) = 2.397, p=.020$) and internalising difficulties ($t(53) = 2.313, p=.025$) compared to parents of children with primary diagnoses of ADHD, but no significant differences in externalising difficulties were found between these two groups ($t(54) = .671, p=.505$). Parents of children with a primary diagnosis of ADHD reported significantly higher levels of child externalising difficulties compared to parents of children with primary diagnoses of Tics/Tourette's Syndrome.

Discussion

The aims of this study were to a) explore relationships between mindfulness (trait and MP), self-compassion, parental stress, well-being and child externalising difficulties, in parents of children with neurodevelopmental disabilities, b) explore whether mindfulness (trait and MP) mediated the relationship between parental stress and child externalising difficulties and c) compare levels of mindfulness (trait and MP) and self-compassion between specific primary diagnosis groups, including ASD, ADHD and Tics/TS. A discussion of the findings in the context of theory and previous literature, along with the study's strengths and limitations, clinical implications and future research is presented.

The first aim of this study was to explore relationships between trait mindfulness, MP, self-compassion, parental stress, well-being and child externalising difficulties, in parents of children with neurodevelopmental disabilities. Findings showed some support for hypothesis one highlighting that higher levels of trait mindfulness, MP and self-compassion were significantly associated with lower levels of parental stress. The relationship between MP and parental stress reached a greater level of significance (of a similarly medium effect size) than previously found in 28 parents of children with ASD (Beer et al., 2013). The strength of this finding may be explained by the high rates of comorbidity in this study, which could mean that the parents in this sample are particularly vulnerable to high levels of stress and lower levels of MP. This fits with descriptive data highlighting relatively high levels of parental stress and 64% of the sample reporting low mood, or likely depression in this sample. These findings highlight the potential usefulness of interventions that target general mindfulness, MP and self-compassion, in parents who are caring for a child with neurodevelopmental disabilities.

More specifically, this study found that increased trait mindfulness and self-compassion were related to higher levels of parental well-being and lower levels of child internalising

difficulties. This suggests that levels of mindfulness and self-compassion may be linked to parental stress and bolster well-being in parents of children with ASD, ADHD and Tics and/or TS, as well being associated with lower levels of child internalising difficulties (although the latter did not remain significant after Bonferroni). This finding fits with emerging literature suggesting that self-compassion is a key mechanism of change in mindfulness interventions (Bögels et al. 2014) and theories stating that children develop emotional regulation skills through the responses of their caregivers (Neff, 2003). Thus, children with caregivers who have modelled self-compassion will have greater levels of self-compassion themselves; which serves as a protective factor for them against internalising difficulties.

Interestingly, although higher levels of trait mindfulness and self-compassion were related to lower child internalising difficulties, higher levels of MP were significantly associated with lower parental stress and lower levels of child externalising difficulties. This suggests that specific MP interventions may be more useful than general mindfulness interventions for parents of children with ADHD, ASD, Tics/TS, where there are high levels of parental stress and child externalising difficulties. However, it is important to note that the correlations between mindfulness (trait and MP) and child outcomes did not reach significance at $p < .002$ after applying Bonferroni correction to control for multiple testing and potential Type 1 errors. Emerging pre-post studies show that MP interventions lead to increases in parental stress and reductions in child externalising difficulties in parents of children with ASD and ADHD (Hwang et al., 2015; Neece, 2013). This highlights a potentially causal relationship whereby increasing parental MP levels appears to have an indirect effect on improving child externalising difficulties (as reported by parents post intervention). Since this study was correlational it was not possible to draw any causal links. However, future RCT's are needed to evaluate the possible effects of MP on parental and child outcomes.

Surprisingly, no significant effect was found between MP and well-being. This does

not fit with previous findings that highlight a negative correlation between MP and depression in parents of children with ASD (Beer et al., 2013). It is evident from the literature that trait mindfulness and well-being are positively correlated in community samples of meditators and non-meditators (Brown & Ryan, 2003; Cash & Whittingham, 2010; Keng, Smoshi & Robbins, 2011). It may be that the relationship between state mindfulness (i.e. MP) is less likely to be correlated with general well-being, and more likely to be correlated with parental depression.

Another aim of this study was to explore the relationships between the facets of MP, parental well-being, stress and child externalising difficulties. Four facets: non-judgemental acceptance, compassion for self and child, listening with full attention and self-regulation, were negatively associated with parental stress (although only compassion for self and child and self-regulation remained significant after applying the Bonferroni correction). Non-judgemental acceptance and compassion for self and child were previously found to be negatively associated with parental stress, in parents of children with ASD (Beer et al., 2013). It is possible that Beer et al. (2013) lacked power to detect all of these relationships, or that parents of children with comorbid neurodevelopmental disabilities with potentially higher levels of parental stress may need to draw on more facets of MP when faced with child externalising difficulties and parental stress.

The current study found that three facets of MP: listening with full attention, self-regulation and compassion, were negatively associated with lower levels of child externalising difficulties. Compassion for self and child was also significantly negatively associated with lower child internalising difficulties. After applying Bonferroni corrections, the negative correlation between self-regulation and child externalising difficulties remained significant, with a negative correlation between compassion for self and child internalising difficulties also remaining significant. These findings highlight that compassion for self and child and self-regulation (i.e. non-reactivity) may be key components of MP to focus on. These finding fits

with Patterson's (2002) theory that suggests that if parents can self-regulate their emotional experiences and respond (i.e. rather than react under stress) and take a compassionate stance to themselves and their child, they are more likely to sustain positive parent-child relationships and implement positive parenting practices. This is likely to reduce the likelihood of child externalising difficulties becoming reinforced over time.

The third aim was to explore whether the relationship between parental stress and child externalising difficulties was mediated by MP or trait mindfulness. Mindful parenting was found to be a mediating factor in the relationship between child externalising difficulties and parental stress. That is, child externalising difficulties significantly related to parental stress via the capacity to draw upon MP practices or not. This finding fits with theories highlighting that child externalising difficulties can be related to more reactive parenting styles which may exacerbate child externalising difficulties, parent-child conflict and increase parental stress (Patterson, 2002; Scaramella & Leve, 2004; Dishion, et al. 2003). Given that trait mindfulness did not mediate the relationship between child externalising difficulties and parental stress, parents of children with neurodevelopmental disabilities are likely to benefit from specific MP interventions rather than generic mindfulness programmes such as MBSR.

The final aim was to explore any significant differences amongst parents of children with ASD, ADHD and Tics/TS to determine whether these groups might require tailored interventions. Overall, parents did not significantly differ in their levels of trait mindfulness, parental stress or well-being. However, parents of children with primary diagnoses of ASD and ADHD had lower levels of MP and self-compassion than parents of children with Tics/TS. This may be because parents of children with ASD reported significantly higher levels of total child difficulties, internalising and externalising difficulties compared to parents of children with Tics/TS. They also reported significantly higher total child difficulties and internalising difficulties compared to parents of children with primary diagnosis of ADHD. Perhaps the

combination of high levels of internalising and externalising difficulties makes it more difficult for parents of children with ASD to draw upon MP skills in the face of these difficulties. Overall, these findings highlight a significant need for interventions that improve MP amongst parents of children with ASD. This fits with previous research highlighting parents of children with ASD as a particularly vulnerable group, both in terms of parents experiencing high levels of stress, depression and reports of increased child internalising and externalising difficulties.

It is interesting that despite having higher levels of self-compassion and MP, parents of children with Tics/TS had similar levels of parental stress as parents of children with primary diagnoses of ASD and ADHD. It may be that these parents are coping with different daily challenges and/or their children may present with fewer externalising difficulties. This may be explained by there being less stigma and self-blame associated with parenting a child with Tics or TS, than there might be for parents of children with ASD or ADHD who may have higher rates of externalising difficulties. This fits with studies suggesting that parents of children with externalising difficulties and disabilities report high levels of stigma and self-blame (Fernández & Arcia, 2004; Davis & Monaco, 2016). Although studies have highlighted that parents of children with TS report stigma, this is related to peers and teachers misunderstanding the condition (Rivera-Navarro, Cubo & Almazán, 2013). Future research may want to explore stigma and self-blame amongst parents of children with different neurodevelopmental difficulties to explain these differences.

The findings of this study suggest that child externalising difficulties predict MP but not trait mindfulness levels, and that child externalising difficulties predict parental stress via changes in MP. Thus, it makes sense that parents experiencing fewer child externalising behaviours may be more able to preserve their MP practices, even when experiencing relatively high levels of parental stress. Another hypothesis could be that, while ASD is a life-long condition, 80% of children with tics that appear before the age of ten will experience a

significant reduction or disappearance of their tics during adolescence and into adulthood. Evidence suggests that only 20% of this group will experience a worsening of tics into adulthood (Cath et al., 2011). This knowledge may influence parent's capacity to cope.

Strengths, Limitations and Future Directions

This study included a sample of parents of children with a range of neurodevelopmental disabilities. This is both a strength and limitation of the study. The literature on the impact of comorbidity on child behaviour and parental stress indicated a clear need for a study to explore the relationships between mindfulness and parent/child variables, in a broad neurodevelopmental sample. Therefore, the findings of this study can be generalised to clinic settings where high levels of comorbidities are common. However, there are limitations to including a broad neurodevelopmental sample. Firstly, it reduces the internal validity as the number of possible variables (e.g. comorbid neurodevelopmental, physical and mental health difficulties) that are not controlled for increases. Secondly, between group comparisons were based on parent's report of what they deemed to be their child's 'primary diagnosis'. Therefore, the children will have had varying comorbid diagnoses that were not controlled for. This limits the conclusions that can be drawn from the findings that explore differences between the three diagnostic sub-groups. Given the literature on comorbid ADHD with ASD resulting in increased child externalising difficulties, future research should explore the effectiveness of MP interventions in this population.

There are other limitations regarding the sample to consider. Firstly, the fact that participants were recruited from the NHS, charity organisations and public Facebook groups for parents of children with neurodevelopmental disabilities may have resulted in differences in participants socioeconomic status, intellectual ability, parental stress, mindfulness levels, previous experience or interest in mindfulness interventions amongst the sample. Due to the

small sample size of participants that were recruited from the NHS, statistical analyses were not deemed appropriate or meaningful. Therefore, it is possible that such differences exist within the sample which may affect the generalisability of the findings. It is also possible that the study attracted parents who had some understanding and/or practice of mindfulness which may reduce the external validity of the study. Previous mindfulness experience may impact on parent's baseline levels of trait mindfulness and MP and should be measured and controlled for in future studies.

There are also limitations to the cross-sectional nature of this study. The study findings tell us about the nature of relationships but cannot determine cause and effect relationships. Furthermore, given that cross-sectional data provides a snapshot in time, longitudinal studies may be helpful to better understand relationships over time.

Finally, there are limitations to parental self-report measures, which have the potential to introduce social desirability bias. For example, parents may not have wished to disclose their true levels of mindfulness and parental stress for fear of what this would mean for them as parents. The findings are also limited in that child internalising and externalising difficulties are measured by parental report. Therefore, future studies evaluating the effectiveness of MP interventions may want to incorporate parent and child outcome measures, or observation methods.

Clinical Implications

This study adds to an emerging body of literature that suggests that MP interventions may be helpful for parents of children with a range of neurodevelopmental disabilities who are experiencing high levels of parental stress and child externalising difficulties. Specifically, this study highlights that parents of children with a primary diagnosis of ASD are likely to experience high levels of parental stress and child internalising and externalising difficulties,

and lower levels of MP. This indicates a greater level of need for MP interventions for this specific group of parents. Mindful parenting interventions should have a specific emphasis on supporting parents/carers to foster non-reactive parenting and a compassionate stance to their child, and importantly, to themselves as parents. Further research (i.e. randomised controlled studies) should explore the effectiveness of MP groups for parents of children with ASD, and a range of neurodevelopmental disabilities, including those with more than one neurodevelopmental disability.

III. Integration, Impact and Dissemination

Integration

This paper aims to provide an overview of the research process. This includes a discussion of how the review and empirical study are distinct yet related pieces of work and a critical evaluation and reflection on the process of undertaking both parts, including any challenges, dilemmas and/or decisions made along the way.

The overall aim of this project was to develop the evidence base for mindfulness interventions in families of children with a range of neurodevelopmental disabilities, including those with Autistic Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Tics/Tourette's Syndrome (TS) and/or intellectual disabilities. Previous literature highlights that parents of children with neurodisabilities report significantly higher levels of parental stress and child behavioural difficulties compared to those without disabilities. Mindfulness theory suggests that intentionally focusing on one's attention, with a non-judgemental attitude, has the potential to reduce stress. Thus, emerging studies have begun to explore the potential effectiveness of mindfulness interventions for families of children with specific neurodisabilities, such as ADHD and ASD. Furthermore, emerging studies have begun to explore the relationships between mindfulness, parental stress and child behaviour, in parents of children with ASD.

The review and the empirical paper are related in that both pieces of work make distinct contributions to the literature on mindfulness in families of children with neurodisabilities. The review explored the effectiveness of mindfulness interventions in families of children with a range of neurodevelopmental disabilities. Specifically, this aimed to explore the comparative effectiveness of parallel parent and child mindfulness interventions and parent only mindfulness interventions, in families of children with neurodevelopmental disabilities.

MINDFULNESS IN NEURODISABILITY

To compliment this piece of work, the empirical paper aimed to a) explore the relationships between mindfulness (trait and MP), self-compassion, parental stress, well-being and child behaviour, in parents of children with a range of neurodevelopmental disabilities (including those with ASD, ADHD, Tics/TS and/or intellectual disabilities), b) compare levels of mindfulness (trait and MP), self-compassion, parental stress, well-being and child behaviour between specific diagnostic groups and to c) explore whether MP mediates the relationship between parental stress and child behaviour. The study contributes to the theoretical understanding of the relationships between these variables, in a comorbid neurodevelopmental sample. Specifically, exploring whether MP mediates the relationship between parental stress and child behaviour will help to better understand the nature of this relationship and potentially lead to specific intervention recommendations for parents of children with comorbid and specific neurodevelopmental disabilities.

I was drawn to this research area due to my previous experiences of working within Child and Adolescent Mental Health Teams (CAMHS) as well as my own personal experience of having a younger sibling with a diagnosis of ASD. As a result, I have an appreciation and understanding of the challenges that parents and families may face. These might include differences in how family members view the diagnosis, helpfulness of a diagnosis and the implications of it for the young person. Furthermore, my previous experiences of providing evidence-based parenting interventions to parents reporting high levels of child behavioural difficulties (including parents of children who may or may not have been diagnosed with oppositional defiant disorder, conduct disorder and/or ADHD) were also influential in how I came to be interested in this research area. During this work, I was struck by the lack of evidence base around the effectiveness of these programmes for parents of children with other neurodevelopmental disabilities such as ASD, Tics/TS and/or intellectual disabilities. There seemed to be a gap in provision and lack of appropriate support for these families.

Therefore, conducting research in an area that could potentially add to the evidence base for interventions for families of children with neurodevelopmental disorders appealed to me very much. Throughout my training I have developed knowledge and experience of using mindfulness in my work with clients and have seen the benefits it can have on psychological well-being, such as reducing stress and coping. Working in CAMHS settings has also highlighted to me the benefits of working directly with young people, and/or indirectly with their parents. For example, working with parents/carers often increases their understanding of their child's needs and supports their coping in the face of their child's difficulties. Therefore, the idea of a parents only intervention that applied mindfulness to the parenting context was interesting and theoretically I could see its potential value within this population.

Systematic Review

To compliment the empirical paper, it seemed appropriate to explore the literature on the effectiveness of mindfulness interventions for parents of children with neurodevelopmental disabilities. Specifically, to establish how much literature exists for different neurodevelopmental disabilities (ASD, ADHD, Tics/TS, intellectual disabilities) to determine whom mindfulness interventions may be effective for, and to inform directions for future research. However, I came across two relevant reviews in the literature (Petcharat & Liehr, 2016; Cachia, Anderson & Moore, 2016). One review looked at the effectiveness of mindfulness interventions in families of children with a range of neurodevelopmental disabilities (Petcharat & Liehr, 2016). There were some limitations to this review as it included only US studies between 2010-2016 and did not include families of children with Tics/TS. The second review looked into the effectiveness of mindfulness interventions for parents of children with ASD (Cachia, Anderson & Moore, 2016). Both reviews gave a narrative synthesis of

findings and did not use a quality assessment tool.

The literature contained a mixture of studies including those that evaluated the effectiveness of parent only mindfulness interventions and others that included parallel mindfulness interventions for parents and child. In the latter studies, it was difficult to know which outcomes were associated with which intervention; were these effects of the parent training, effects of the child training or a combination of both? I became curious about what effects parent only interventions and parallel interventions had on parental and child outcomes, and which were more effective in leading to parental and child outcomes. These questions led to the development of the review question; how do parent only mindfulness interventions compare in effectiveness to parallel parent and child mindfulness interventions? As a researcher with some knowledge but no prior experience of practising mindfulness I decided to enrol on to an 8-week Mindfulness Based Stress Reduction course. This provided me with personal experience of what an MBSR programme was like, including its benefits and challenges. I realised how hard it was to introduce regular home practise into my own life, and how much harder this was likely to be for parents managing multiple demands of parenting, working etc. Despite this, I thoroughly enjoyed making the time and space to attend the course and I was able to practise shorter exercises outside of the course. I found that I adopted a more compassionate, grateful and open approach to experiences, even those that I might perceive to be unpleasant experiences. It also taught me the benefit in sitting with and inviting uncomfortable, negative sensations which has helped me to develop personally and professionally.

Methodological Critique & Reflections

Search strategy. During the process of identifying search terms I became aware of the many different terms that referred to variations of mindfulness interventions in the literature. It

became clear that there would not be enough studies using the MP model, so I decided to include interventions that were based on MP, MBSR and/or MBCT. This felt appropriate as MP had been adapted from these programmes, and they are similarly offered in a group format, over 8 weeks. I decided that interventions referred to as Acceptance Commitment Therapy (ACT) would not be included as they were theoretically different and were less comparable. Furthermore, I decided that behavioural parent training programmes with additional mindfulness components should not be compared with a predominantly mindfulness intervention. I hope that by minimising the potential for too much difference between the interventions allows for a more reliable review. Despite these efforts, a number of differences remain which need to be kept in mind when interpreting the findings (e.g. study design, length and total time of intervention, level of training of facilitators).

A decision was made to exclude studies that were not peer-reviewed to allow for a certain level of quality. This led to the exclusion of four studies. A limitation of this approach may be that it introduces publication bias, whereby published studies may be more likely to produce positive findings.

Quality appraisal. Both reviews identified in the area were narrative reviews that included critical evaluation of the quality of the studies, their strengths and limitations. However, this approach could be open to researcher bias. To minimise this, I sought to use a quality assessment tool that would systematically help me to assess each studies quality. To support my decision making over which tool to use, I referred to a review of reviews that evaluated 194 tools (Deeks et al., 2003). This paper highlighted six tools which covered at least five to six internal validity domains; one of which could be used to assess health care interventions of randomised and non-randomised studies (Downs & Black, 1998). This tool was considered along with the Quality Assessment Tool for Quantitative Studies (QATQS) developed by the Effective Public Health Practice Project (EPHPP; Thomas, 2003). Both tools were rated by the

National Collaborating Centre for Methods and Tools as ‘strong’ and had acceptable content validity, construct validity and inter-rater reliability. As such, I piloted using both tools to quality assess a study. During this process I noticed that the Downs & Black (1998) tool was lengthy and provided a numerical score, whereas the QATQS tool gave a quality rating (i.e. weak, moderate or strong) for each domain and then an overall quality rating. I opted for the QATQS due its clarity and relevance to the types of studies included in my review (i.e. pre-post, multiple baseline, dyadic design). It seemed helpful in distinguishing between the quality of included studies, with only those not scoring ‘weak’ across any domain scoring an overall quality rating of ‘strong’, those scoring ‘weak’ on one domain scored an overall quality rating of ‘moderate’ and those scoring ‘weak’ on more than one domain scored an overall quality rating of ‘weak’. An important limitation of this review is that it was not possible within the timescales of this project to have a secondary rater, to obtain Kappa’s inter-rater reliability.

Empirical Study

Methodological Critique & Reflections

Service user involvement. During the initial phases of developing the research questions, I consulted with a parent of a child with autism, who had completed a MP programme in one of the NHS sites that I hoped to recruit from. I hoped that this consultation would help me to get a better sense of the challenges that parents face, as well as her experience of the intervention, and which facets of MP she found most helpful in managing her stress, as well as her child’s behaviour. She felt there needed to be a recognition that parenting a child with a disability is somewhat more challenging than parenting a typically developing child; something which is supported by the literature. She felt that all five facets of MP were useful in some way. For example, she felt that rather than assuming what her child was thinking or feeling,

listening with full attention enabled her to identify when her child was trying to communicate something through his or her behaviour. Developing skills in detecting the emotional experience of the child helped her to identify triggers and understand the emotions underlying behaviours. Self-regulation in the parent-child relationship seemed to be important for helping her and other parents to communicate with their children calmly, in the face of strong parental emotional experiences. Compassion for self and child was acknowledged to be important for both parent and child well-being. She felt that compassion for self and child was like non-judgemental acceptance, which she described as being important as all the parents in her group were quite hard on themselves. She described that parents tended to put their child first, leaving less space for them to be self-compassionate; a theme discussed by Neff & Faso (2014). There was a sense that attributing behaviours externally rather than internally (e.g. “it’s not my fault”) helped her to foster non-judgemental acceptance. Previous literature supports this idea that increased self-compassion results in parents being more likely to make external attributions to child behaviour (Legge & Kuyken, 2016).

What I found particularly striking was that she attributed the importance of specific facets with either parental or child outcomes. For example, she felt that non-judgemental acceptance and compassion for self and child were particularly helpful in managing parental stress; a theme confirmed by this study, with the addition of listening with full attention and self-regulation. Qualitative interviews with parents of children with ASD highlight that non-judgemental acceptance and compassion for self and child are domains that are particularly difficult for parents to foster (Beer, Ward & Moar, 2013). This might indicate specific areas for MP programmes to focus on. However, descriptive data from this study suggests that listening with attention and reactivity mean scores were the lowest facet scores amongst the sample. Furthermore, emotional awareness was felt to be particularly helpful in managing child

behaviour difficulties; a theme that was not confirmed by this study to be significantly related to child behaviour.

Recruitment. My initial plan was to recruit all participants retrospectively and prospectively from two teams in one NHS site. Based on previous response rates for questionnaire based studies, I anticipated recruitment to be complete within 3-5 months; the latter was based on a very conservative response rate. However, an initial mail out to 150 families yielded an 11% response rate, which translated into an 8% completion rate. I soon began to appreciate the number of steps involved in the recruitment process; from staff remembering to share information sheets in clinic, to parents having to make direct contact with me, to finding a convenient time to discuss the study and obtain consent, and finally for parents to find the time to complete the questionnaires. Recruitment continued to be slow, despite having been to visit and present to the teams. Furthermore, my external supervisor who worked within the neurodevelopmental team left, resulting in less of a presence and reminders for the staff. Due to these recruitment concerns, a decision was made to explore additional recruitment methods via charities and social media. Initially, I had concerns about whether this would attract a sample of parents who were coping better, or those who may not have the same level of need as families accessing a specialist service. It is possible that the families accessing NHS services experience higher levels of stress that may have got in the way of them being able to participate in research. This raises the question as to whether these families may differ in mindfulness levels, parental stress, well-being and child behaviour difficulties compared to the families that participated via local Charities/Facebook groups. However, you could argue that families whom are not currently accessing NHS services are just in need of support, or in greater need. This was supported by data showing high levels of parental stress, low well-being and high levels of child difficulties in this study sample. Comparisons were not made between those that were recruited via NHS services and those recruited via charities as the number of

those recruited from NHS services was too low for this to be meaningful. A limitation of this approach could be that the research attracted parents with interests and/or experience in mindfulness, or those who were at least motivated to know more.

Selection of measures. It felt important to include a measure of MP and trait mindfulness, given the potential differences between trait and state mindfulness in a specific context: MP. Previous studies have not included both measures (Beer, Ward & Moar, 2013) which this study wished to address. The Five Facet Mindfulness Questionnaire (FFMQ; Baer, Smith, Hopkins, Krietemeyer & Toney, 2006) is commonly used within research and its five-facet composition allows for relationships between facets to be explored. The Interpersonal Mindfulness in Parenting (IM-P; Duncan, 2007) is also the predominant measure of MP within the literature. Given emerging evidence about the potential importance of compassion in relation to one's parenting, there was a rationale for introducing a general measure of self-compassion; the Self Compassion Scale (Neff, 2003). Ideally, I would have used the Parenting Stress Index, in line with a body of literature. However, this was not possible within the budget constraints of this project and a freely available measure of parental stress was opted for; Parent Stress Scale (Berry & Jones, 1995). The WHO (Five) Well-Being Index (Psychiatric Research Unit) was chosen to measure well-being due to it being a relatively short but valid measure. The Strengths and Difficulties Questionnaires (SDQ; Goodman, 2005) was also used as it measures total child difficulties, as well as providing separate scores for internalising and externalising difficulties which was felt to be a helpful distinction to make.

Ethical considerations. Thoughtful consideration took place about the potential demands placed on parents of asking them to complete numerous lengthy questionnaires. Therefore, it was agreed that a maximum of six questionnaires would be used; with the decision to include a short measure of well-being. I was able to pilot their use with two parents who confirmed

their acceptability and the time taken to complete them. This informed how I explained the study and what it would involve for parents. I also wondered about how to make the questionnaires easily accessible to parents to fit around their busy lives and decided to give them the opportunity to complete them by post or online via Qualtrics. Most parents opted to complete the questionnaires online as it was quick and relatively straight forward. However, a small minority wished to complete by hand and returned them by freepost.

I was also aware of how difficult it might be for parents to find time to complete the questionnaires. Therefore, it felt ethical to be able to provide some form of incentive. I was able to provide three £25 vouchers, to three participants randomly selected by an online generator.

As a researcher and clinician, asking parents/caregivers to complete questionnaires on their levels of mindfulness, self-compassion, parental stress, well-being and child behaviour without offering them any form of support or signposting to relevant support or interventions felt uncomfortable. However, this was managed by adding the Patient Advice and Liaison Service (PALS) details to the study information sheet and using a debrief form which gave parents the opportunity to access counselling support through Evelina Hospital or to contact the principal research if they found anything about the study distressing.

Careful consideration was also given to how to approach recruitment via Facebook groups. A decision was made to create a Facebook group page advertising the research study; which was used to post advertisements on various charity and public parent group pages aimed at parents of children with neurodevelopmental disabilities.

Clinical Implications for Future Research, Theory and Practice

There are important clinical implications of the systematic review and the empirical study to consider. The review highlighted that both parent only mindfulness interventions and parallel parent and child mindfulness interventions are effective in reducing parental stress, amongst parents of children with a range of neurodevelopmental disabilities. On the whole, there was enough evidence to suggest that parallel interventions had a more positive impact on child outcomes (i.e. child ADHD symptoms, internalising and externalising difficulties) than parent only interventions, in parents of children with ADHD. Therefore, parallel interventions are likely to be effective in reducing parental stress and child difficulties in families where there is a child with ADHD. However, there is a lack of research looking at the indirect effects of parent only mindfulness interventions on child outcomes. This should be addressed by future research, as theory suggests that indirect change is possible via interventions that address reactivity and stress. There are many practical benefits of providing parent only interventions. Future RCT's should directly compare the effectiveness of a parallel and parent only intervention, in parents of children with ASD and other neurodevelopmental disabilities.

The empirical study has highlighted that increased trait mindfulness, self-compassion and MP are associated with reduced parental stress, in parents of children with comorbid neurodevelopmental disabilities. It also highlights that increased trait mindfulness and self-compassion are related to reduced child internalising difficulties, whereas increased MP seemed to be more related to reduced child externalising difficulties. However, these effects were not significant after controlling for Type 1 errors so need to be interpreted with caution. When looking at specific facets of MP and their relationships with child outcomes, higher levels of parental non-reactivity and compassion for self and child were associated with reduced child externalising difficulties, which remained significant after controlling for Type 1 errors. This suggests that increasing parent's MP practices: specifically compassion for self

and child and non-reactivity, may have indirect effects on child behaviour. Further research is needed to explore this with use of control groups.

This study has also shown that parental stress can have a negative impact on both MP and trait mindfulness. However, child behaviour difficulties directly affects parental stress via the ability to draw on MP or not. Therefore, levels of trait mindfulness and possibly self-compassion, may be remain relatively stable in the face of child behaviour difficulties, whereas MP levels are more likely to be affected. Therefore, parents of children with neurodevelopmental disabilities will require specific MP interventions, rather than generic MBSR programmes.

These findings fit with theories of mindfulness/MP that aim to break the automatic, transactional patterns of escalating conflict between parent and child that occurs outside of conscious awareness (Dumas, 2005). There is an emphasis on being able to distance oneself from negative emotions, leaving more room for non-judgemental consideration of one's own and child's behaviour. Duncan's (2009) model of MP proposes that if parents are able to draw upon MP practices, their self-efficacy improves. This results in a realistic appreciation of what their child can or cannot do as well as improved parental well-being. This leads to increased consistency with discipline and/or child behavioural management practices combined with increased parental positive affect. Both the increased ability to choose parenting practices in line with parental values and increased parental affect results in fewer child behavioural and emotional difficulties.

Future research should address the following:

- Intervention studies should use a variety of outcome measures to evaluate the effectiveness of MP interventions including measures of parental stress, well-being,

mental health and child internalising and externalising difficulties; ideally with a child or young person self-report measure.

- More randomised controlled trials with control groups are needed to evaluate the effectiveness of MP interventions; particularly for parents of children with ASD, Tics/TS and intellectual disabilities, and comorbid presentations.
- Randomised controlled trials to compare the effectiveness of parent only compared to parallel MP interventions; particularly in parents of children with ASD, Tics/TS and/or intellectual disabilities.
- Future studies should control for previous mindfulness practice.

Overall Conclusions

The critical evaluation and reflections provided in this paper highlights the decision-making process, and the inevitable strengths and weaknesses of the research conducted. It has highlighted the benefits and complexities of including parents of children with comorbid neurodevelopmental disabilities in research; but I hope that this provides a unique contribution to the literature where parents of children with ASD are acknowledged as a particular group in need of MP interventions. Furthermore, I hope that this research allows for more consideration and exploration of how MP interventions could be helpful for parents of other neurodevelopmental disabilities, including ADHD, Tics/TS, intellectual disabilities and comorbid presentations.

Impact

On a personal level, conducting this research project has deepened my interest in mindfulness interventions and strengthened my scientist practitioner approach. For example, sharing my knowledge and expertise with colleagues regarding the effectiveness of mindfulness for children with ADHD (a common presenting difficulty in my current Fostering, Adoption and Kinship Care placement) has also been impactful on a service level. This has led on to plans to pilot and evaluate a mindfulness group for children with ADHD.

On a service level, this research will add to the growing evidence base for the effectiveness of MP interventions for reducing parental stress and potentially having indirect effects on the parent-child relationship and children's outcomes. These findings are likely to have a useful impact on practitioners who work within neurodevelopmental teams in CAMHS services where the work involves the assessment and treatment of children up to 17 years old with a diagnosis of ASD, ADHD, Tics/TS, and/or other neurodevelopmental, mental health or physical health disabilities. I anticipate that this research will lead to more mindfulness and mindful parenting interventions being rolled out within specific neurodevelopmental CAMHS services in the future. I would also like to be involved in co-facilitating and evaluating the effectiveness of a MP intervention for parents of a range of neurodevelopmental disabilities, to further develop the evidence base and impact on interventions offered on a service level.

Furthermore, there is potential for MP interventions to have an impact on an individual, family and intergenerational level. This is supported by the MP model which aims to positively influence the parent-child relationship (Duncan, 2010). Child emotional and behavioural difficulties have been linked to poorer outcomes in later life, therefore there is a strong argument for MP interventions to be offered as early interventions. Furthermore, Bögels,

Lehtonen and Restifo (2010) argue that MP interventions may break the cycle of intergenerational parenting practices.

On a national level, charities for parents of children with ASD, ADHD, Tics/TS and intellectual disabilities could be instrumental in spreading the findings and increasing their impact.

Dissemination

I plan to disseminate the findings and discuss the implications of this study with the NHS sites that participated, as well as sharing lay summaries of the findings with charities that supported recruitment (such as Tourette's Action, ADHD Research, Research Autism, SNAP). Charities will then share the findings on their websites and via their social media platforms such as Facebook and Twitter pages. Lay summaries will also be shared with participants who expressed interest in hearing about the findings, and will be given opportunities to feedback and discuss them. It is hoped that this process of involvement will develop more thinking about the implications of the research. I also plan to disseminate the findings to the neurodevelopmental team at Tavistock Centre, who work with children and adults with neurodevelopmental disabilities and whom are interested in hearing about the study. I also plan to disseminate the research via Research Gate and share it with leading researchers in the field.

Plans for publication include attempts to publish at the highest impact journals with the potential to reach the most members. These may include the Journal of Consulting & Clinical Psychology, the Journal of Clinical Psychology or the Mindfulness Journal. The latter has an impact factor of 3.015, indicating a high level of potential impact. I also plan to present the research at the European Society for the Study of Tics annual conference and the British Paediatric Neurology Association annual conference.

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V. Appendices

Appendix 1: MBSR Group Programme

Session	Themes/Activities
1	Theory and evidence Mindful eating, mindful breathing, body scan, present moment awareness
2	Examining perceptions, assumptions and the individual view of the world Use of body scan to cultivate greater awareness of how individuals react to stress
3	Mindful hatha yoga, sitting meditation, walking meditation
4	Physiological basis of stress reactivity
5	Application of mindfulness in repeated unhelpful patterns
6	Interpersonal mindfulness
All day retreat	
7	Application and practise
8	Review

Appendix 2: MBCT Group Programme

Session	Themes/Activities
1	Automatic pilot, raisin Body Scan, daily mindfulness
2	Thoughts and feelings (cognitive) Body scan, pleasant event diary, 10 minute sitting
3	Mindful movement, unpleasant events diary, 3 min breathing space
4	Automatic thoughts (cognitive) Guided sitting meditation, 3 min breathing space with coping step
5	Sitting meditation (guided and unguided), 3 in breathing space
6	Moods, thoughts and alternative viewpoints (cognitive) Choice of practice, 3BS
7	Pleasure and mastery of activities (cognitive) Choice of practice, early warning signs, relapse prevention plan
8	Relapse prevention action plans (cognitive) Continuation of formal and informal mindfulness practice

Appendix 3: Mindful Parenting Programme

Session focus	Themes	In-session mindfulness practice	In-session mindful parenting practice	Home practice
1. Automatic pilot parenting	Rationale for non-reactive parenting	Bodyscan	Morning stress exercise	Bodyscan child as raisin
		Raisin		Mindful routine activity
	Automatic pilot			Mindful first bite
	Doing versus being mode			
2. Beginners mind parenting	Seeing child with beginner's mind	Bodyscan	Morning stress from perspective of a friend	Bodyscan
		Sitting meditation: breath		Sitting meditation: breath
	Attitude of kindness		Gorilla video	Mindful routine activity with your child
	Obstacles to practice	Seeing meditation	Gratitude practice	Savoring pleasant moments calendar
3. Reconnecting with our body as a parent	Expectations and interpretation			
	Body sensations	Yoga (lying)	Exploring bodily reactions to parenting stress	Yoga (lying)
	Awareness of pleasant events	Sitting meditation: breath and body		Sitting meditation: breath and body
	Watching the body during parenting stress	3-min breathing	Imagination parenting stress: self-compassion	3-min breathing

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	Recognising limits			Mindful activity with your child
	Self-compassion when we're stressed			Stressful moments calendar
4. Responding versus reacting to parenting stress	Awareness and acceptance of parenting stress	Sitting meditation: breath, body, sounds and thoughts	Fight-flight-freeze-dance	Yoga (standing)
	Grasping and pushing away	Yoga (standing)	Imagination parenting stress + 3-min breathing + doors	Sitting meditation: breath, body, sounds and thoughts
	How thoughts exacerbate stress	3-min breathing		3-min breathing under stress
	Responding rather than reacting to stress			Parenting stress calendar with 3-min breathing
				Autobiography
5. Parenting patterns and schemas	Recognising patterns from own childhood	Sitting meditation: breath, body, sounds and thoughts, emotions	Pattern recognition exercise	Sitting meditation: breath, body, sounds and thoughts
	Being with strong emotions		Holding strong emotions with kindness	Walking meditation
	Awareness of angry and vulnerable child modes and punitive and demanding parent modes	Walking meditation inside		3-min breathing when your child is behaving
				Parental stress calendar + schema mode recognition

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6. Conflict and parenting	Perspective taking, joint attention	Sitting meditation: choiceless awareness	Imagination: parent-child conflict + perspective, rupture and repair	Own 40-min practice
	Rupture and repair	Walking meditation outside		Rupture and repair practice
	Turning in to your child's emotional states			Breathing space when you..
7. Love and limits				Mindfulness day
	Compassion and loving-kindness	Loving-kindness	Imagination: limits	Own 40-min practice
				Bring in symbolic object
	Befriending yourself and your (inner) child	Self-compassion	Role-play: limits	Write narrative
			What do I need?	Mindful limit setting Loving-kindness
8. A mindful path through parenting	Awareness of limits			
	Mindful limit setting			
	Review of personal growth via symbolic objects or narrative	Bodyscan Loving-Kindness	Sharing process through symbolic objects or narrative	Own practice
	Looking to the future		Gratitude practice	
	Intentions for practice			

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	How can I care for myself (and my child)?			
Follow up session	Experiences, obstacles and renewed intentions for practicing mindful parenting	Bodyscan Stone meditation	Mountain meditation Wishing well	Own practice

Appendix 4: Quality Assessment Tool

QUALITY ASSESSMENT TOOL FOR QUANTITATIVE STUDIES



COMPONENT RATINGS

A) SELECTION BIAS

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?

- 1 Very likely
- 2 Somewhat likely
- 3 Not likely
- 4 Can't tell

(Q2) What percentage of selected individuals agreed to participate?

- 1 80 - 100% agreement
- 2 60 - 79% agreement
- 3 less than 60% agreement
- 4 Not applicable
- 5 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

B) STUDY DESIGN

Indicate the study design

- 1 Randomized controlled trial
- 2 Controlled clinical trial
- 3 Cohort analytic (two group pre + post)
- 4 Case-control
- 5 Cohort (one group pre + post (before and after))
- 6 Interrupted time series
- 7 Other specify _____
- 8 Can't tell

Was the study described as randomized? If NO, go to Component C.

No Yes

If Yes, was the method of randomization described? (See dictionary)

No Yes

If Yes, was the method appropriate? (See dictionary)

No Yes

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

QUALITY ASSESSMENT TOOL FOR QUANTITATIVE STUDIES



COMPONENT RATINGS

A) SELECTION BIAS

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?

- 1 Very likely
- 2 Somewhat likely
- 3 Not likely
- 4 Can't tell

(Q2) What percentage of selected individuals agreed to participate?

- 1 80 - 100% agreement
- 2 60 - 79% agreement
- 3 less than 60% agreement
- 4 Not applicable
- 5 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

B) STUDY DESIGN

Indicate the study design

- 1 Randomized controlled trial
- 2 Controlled clinical trial
- 3 Cohort analytic (two group pre + post)
- 4 Case-control
- 5 Cohort (one group pre + post (before and after))
- 6 Interrupted time series
- 7 Other specify _____
- 8 Can't tell

Was the study described as randomized? If NO, go to Component C.

No Yes

If Yes, was the method of randomization described? (See dictionary)

No Yes

If Yes, was the method appropriate? (See dictionary)

No Yes

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

F) WITHDRAWALS AND DROP-OUTS

(Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?

- 1 Yes
- 2 No
- 3 Can't tell
- 4 Not Applicable (i.e. one time surveys or interviews)

(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).

- 1 80 -100%
- 2 60 - 79%
- 3 less than 60%
- 4 Can't tell
- 5 Not Applicable (i.e. Retrospective case-control)

RATE THIS SECTION	STRONG	MODERATE	WEAK	
See dictionary	1	2	3	Not Applicable

G) INTERVENTION INTEGRITY

(Q1) What percentage of participants received the allocated intervention or exposure of interest?

- 1 80 -100%
- 2 60 - 79%
- 3 less than 60%
- 4 Can't tell

(Q2) Was the consistency of the intervention measured?

- 1 Yes
- 2 No
- 3 Can't tell

(Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?

- 4 Yes
- 5 No
- 6 Can't tell

H) ANALYSES

(Q1) Indicate the unit of allocation (circle one)

community organization/institution practice/office individual

(Q2) Indicate the unit of analysis (circle one)

community organization/institution practice/office individual

(Q3) Are the statistical methods appropriate for the study design?

- 1 Yes
- 2 No
- 3 Can't tell

(Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?

- 1 Yes
- 2 No
- 3 Can't tell

MINDFULNESS IN NEURODISABILITY

GLOBAL RATING

COMPONENT RATINGS

Please transcribe the information from the gray boxes on pages 1-4 onto this page. See dictionary on how to rate this section.

A	SELECTION BIAS	STRONG	MODERATE	WEAK
		1	2	3
B	STUDY DESIGN	STRONG	MODERATE	WEAK
		1	2	3
C	CONFOUNDERS	STRONG	MODERATE	WEAK
		1	2	3
D	BLINDING	STRONG	MODERATE	WEAK
		1	2	3
E	DATA COLLECTION METHOD	STRONG	MODERATE	WEAK
		1	2	3
F	WITHDRAWALS AND DROPOUTS	STRONG	MODERATE	WEAK
		1	2	3
				Not Applicable

GLOBAL RATING FOR THIS PAPER (circle one):

- | | | |
|---|----------|----------------------------|
| 1 | STRONG | (no WEAK ratings) |
| 2 | MODERATE | (one WEAK rating) |
| 3 | WEAK | (two or more WEAK ratings) |

With both reviewers discussing the ratings:

Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings?

No Yes

If yes, indicate the reason for the discrepancy

- | | |
|---|---|
| 1 | Oversight |
| 2 | Differences in interpretation of criteria |
| 3 | Differences in interpretation of study |

Final decision of both reviewers (circle one):

- | | |
|---|----------|
| 1 | STRONG |
| 2 | MODERATE |
| 3 | WEAK |

Appendix 5: Quality Assessment Table

	Selection bias			Study design				Confounders			Blinding			Data collection			Withdrawals and drop out			Global rating
	Q1	Q2	R	Q1	Q2	Q3	R	Q1	Q2	R	Q1	Q2	R	Q1	Q2	R	Q1	Q2	R	
Bakhshayesh, Khishvand & Siavoshi (2015)	1	5	M	Y	N	N	S	N	N/A	S	3	3	M	1	1	S	3	4	W	M
Benn, Akiva, Arel & Roeser (2012)	2	5	M	1Y	Y	Y	S	2	1	S	3	3	M	3	1	W	1	2	M	M
Bögels, Hoogstad, van Dun, Schutter & Restifo (2008)	2	1	M	5N	N	N	M	2	1	S	1	3	M	1	1	S	1	2	M	S
Dehkordian, Hamid, Beshlideh & Honarmand (2016)	1	5	M	Y	N	N	1	2	N/A	S	3	3	M	1	1	S	3	4	3	S
Haydicky, Schecter, Wiener & Ducharme (2013)	3	2	W	5N	N	N	M	3	4	W	3	3	M	1	1	S	1	2	M	W

MINDFULNESS IN NEURODISABILITY

Hwang, Kearney, Klieve, Lang & Roberts (2015)	3	5	W	6N	N	N	M	2	4	S	3	3	M	3	1	W	1	1	S	W
Rayan & Ahmad (2016)	2	2	M	2Y	N	N	S	1	1	S	1	3	M	1	1	S	1	1	S	S
Van der Oord, Bögels & Peijnenburg (2012)	2	1	M	N	N/A	N/A	W	2	N/A	S	1	2	W	1	1	S	1	1	S	W
Singh, Singh, Lancioni, Singh, Winton & Adkins (2010)	3	4	W	N	N	N	M	2	4	W	1	3	M	2	2	W	4	5	M	W
Singh, Lancioni, Winton, Singh, Curtis, Wahler & McAleavey (2007)	4	5	W	N	N	N	M	3	4	W	3	3	M	3	3	W	3	4	W	W
Singh, Lancioni, Winton, Fisher, Wahler & McAleavey (2006)	4	5	W	N	N	N	M	3	4	W	3	3	M	3	3	W	3	4	W	W

MINDFULNESS IN NEURODISABILITY

Van der Oord, Bögels & Peijnenburg (2011)	2	1	M	N	N	N	M	2	N/A	S	3	3	M	3	3		1	1	S	S
Weijer-Bergsma, Formsma, de Bruin & Bogels (2012)	2	1	S	N	N	N	M	2	N/A	S	1	3	M	1	1	S	1	1	S	S
Zhang et al. (2017)	1	5	M	5 N	N	N	M	2	1	S	3	3	M	3	1	W	1	1	S	M

Appendix 6: Study Information Sheet



Guy's and St Thomas' 
NHS Foundation Trust



Participant Information Sheet Version 4.0 22.05.2017

Study Title: Relationships between mindfulness, self-compassion, stress, well-being and child behaviour in neurodisability

We would like to invite you to take part in a research study. The study aims to explore relationships between mindfulness, self-compassion, parental well-being, stress and child behavioural difficulties, in parents of children with neurodevelopmental disorders (such as Autistic Spectrum Disorder, Attention Deficit Hyperactivity Disorder, Tics/Tourette's Syndrome, Intellectual Disability).

Before you decide whether or not to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with relatives, friends or members of your clinical team if you wish.

What do I do next if I wish to take part?

- Please contact the researcher, Melissa Clapp, Trainee Clinical Psychologist either by emailing her on Melissa.Clapp.2015@live.rhul.ac.uk or leaving a telephone message on **01784414012**. If leaving a message please make sure to say that you wish to speak with Melissa Clapp and leave a contact number and best day/time to contact you.
- The researcher will then contact you by telephone and give you the chance to ask questions before you decide whether to participate. Please ask if there is anything that is not clear, or you would like more information.

Part 1 (Purpose of the study and what will happen if you take part)

What is the purpose of the study?

Parents of children with neurodevelopmental disorders report higher levels of stress and child behavioural difficulties than parents of children without neurodevelopmental disorders. Evidence suggests that mindfulness (i.e. bringing present moment attention to day-to-day experience, in a non-judgemental way) may be related to lower levels of parental stress and reduced child behaviour problems.

MINDFULNESS IN NEURODISABILITY

This study will help to find out what aspects of mindfulness relate to lower parental stress, improved child behaviour and improved parental well-being. This will help to develop mindfulness programmes for parents of children with neurodevelopmental disorders and may lead to more groups for parents in the future.

Who is organising and conducting the research?

The research is being supervised by Dr Tamsin Owen and Dr Alice Emond, Clinical Psychologists, within the Paediatric Neurodisability Service at Evelina Hospital and Dr Lyn Ellett, Senior Lecturer in Clinical Psychology based at Royal Holloway University of London. The study is being carried out by Melissa Clapp, who is a Trainee Clinical Psychologist at Royal Holloway, University of London.

Why have I been invited?

The service that your child is being seen in has agreed to participate in this research study. This means that we are inviting you and other parents who are being seen in clinic, to read about the study and take part if you so wish.

Do I have to take part?

No. It is up to you to decide whether or not to take part. Not taking part will **not** affect your routine clinical care provided through Evelina Hospital.

What will happen to me if I take part?

You will speak to the researcher Melissa Clapp on the telephone. She will describe the study in more detail, go through this information sheet and check whether you want to take part or not. You would be free to withdraw from the study at any time, without giving a reason. Withdrawal or non-participation will not affect the standard of care your child receives or any future treatment in any way.

If you would still like to take part in the study, we will post an information sheet and six questionnaires to you to complete and return to us in a freepost envelope. Alternatively, the questionnaires will be available online. The questionnaires should take 30-35 minutes to complete. The questionnaires will ask you about:

- Your experience of being a parent of a child with a neurodevelopmental disorder
- Your general levels of well-being
- The extent to which you approach day-to-day tasks with mindfulness
- The extent to which you apply mindfulness in your interactions with your child
- Your child's strengths and difficulties including behaviour difficulties

There are no right or wrong answers, and you are free to decline to answer any question you do not feel happy to answer. You can complete the questionnaires from home or a convenient place.

Expenses and payments

Taking part in this study is voluntary and you will not be paid for your participation. However, if you choose to participate you will be entered into a raffle for the chance to win one of three £25 vouchers.

What are the possible disadvantages or risks of taking part?

We do not anticipate that there will be any disadvantages to taking part, except for the time commitment taken to complete the questionnaires.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get will help to develop mindfulness programmes for parents of children with neurodevelopmental disorders. It may also lead to more research exploring the effectiveness of mindfulness programmes for parents of children with neurodevelopmental disorders. This may lead to more mindfulness programmes being offered in the future.

What if there is a problem?

If you have any queries or concerns about the study please contact the researcher on 01784414012 in the first instance or Dr Tamsin Owen, Clinical Psychologist on 07939425461. Any complaints about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. More details on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice, and all information about you and your child will be handled in confidence. The details are included in Part 2.

This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2 (Details about taking part)

What will happen if I don't want to carry on with the study?

You are free to withdraw at any point, without giving a reason. Refusal or withdrawal of consent will **not** affect the current or future care your child receives at the Evelina Children's Hospital. You have the right to withdraw consent after it has been given, and to ask that your own data be destroyed.

What if there is a problem?

If you have a concern about any aspect of this study, you should speak to either Melissa Clapp (Researcher) or Dr Tamsin Owen (Clinical Psychologist), who will do their best to answer your questions (contact details are provided at the end of the information sheet). If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of this study, you may also contact Dr Lyn Ellett (Senior Lecturer in Clinical Psychology) on 01784 414049.

You can also contact the Patient Advice and Liaison Service (PALS) by:

MINDFULNESS IN NEURODISABILITY

Telephone: 0207 188 8801 Email: pals@gsst.nhs.uk

Letter: PALS, St Thomas' Hospital, Westminster Bridge Road, London, SE1 7EH

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for legal action for compensation, but you have to pay your own legal costs. Royal Holloway, University of London, is providing negligent and non-negligent indemnity cover for this research. The normal NHS complaints mechanisms will still be available to you.

Will my taking part in this study be kept confidential?

Yes. All data collected during the course of the study will be held according to the Data Protection Act (1998). All data collected will be anonymised and given a unique identification number. This means that only the researcher will know whose data belongs to whom. Your name and your child's name will not be disclosed to anyone else, and neither will you be identified in any report or publication.

All anonymised paper data will be stored securely in a locked filing cabinet that only Melissa Clapp or Dr Tamsin Owen will have access to. All data will be stored on a secure encrypted electronic storage device. On completion of the research, all data will be stored at Evelina London for up to five years. Signed consent forms will be stored securely at Royal Holloway University, and destroyed after two years.

What will happen to the results of the research study?

The results of the study will be written up as part of a Doctorate in Clinical Psychology. The results may also be published in a journal or presented at a conference. We will also offer you a summary of the findings.

Who has reviewed the study?

This study has been reviewed and given approval by the research subcommittee at Royal Holloway, University of London. The study has also been approved by the Guys and St Thomas' Research and Development Department. All NHS research is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests.

Further information and contact details

If you would like further information about taking part, please do not hesitate to contact Melissa Clapp in the first instance.

Melissa Clapp, Trainee Clinical Psychologist

Email: Melissa.Clapp.2015@live.rhul.ac.uk or leave a telephone message on 01784414012 stating the research name, your name, contact number and best day/time to reach you.

Dr Tamsin Owen, Clinical Psychologist

Email: tamsin.owen@gstt.nhs.uk or by phoning 020 7188 7188.

Thank you for considering taking part and/or taking time to read this sheet.

Appendix 7: Study Invite Letters



Dear Parent/Carer,

Re: A study exploring the relationships between mindfulness, parental stress/well-being and child behaviour in parents of children with neurodevelopmental disorders

We are writing to you because your child is under the care of the complex neurodevelopmental disorders team or the tics and neuro-developmental movements (TANDeM) team at Evelina Hospital.

We would like to invite you to take part in a study exploring how mindfulness relates to parental stress, well-being and child behaviour difficulties in parents of children with neurodevelopmental disorders (Autistic Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Tics or Intellectual Disability (ID)). This is important because we know that parents report high levels of stress and child behaviour difficulties. Therefore, it is important to consider the potential beneficial effects of mindfulness.

We hope to use the information from this research to:

- Find out what aspects of mindfulness might relate to parental stress and child behaviour
- Develop the evidence base for mindfulness programmes for parents of children with neurodevelopmental disorders
- Develop and tailor mindfulness programmes for parents of children with neurodevelopmental disorders

If you decide to take part, the study would involve you completing some questionnaires (these can either be posted to you or completed online). If you would like to know more about the study, please refer to and read the enclosed study information sheet.

Please be aware that it is up to you whether you would like to take part or not, and not taking part will not affect your child's routine care in any way.

Yours sincerely,

Dr Tamsin Owen

Clinical Psychologist

Appendix 8: Informed Consent Form



Guy's and St Thomas' **NHS**
NHS Foundation Trust



Centre Number:

Study Number:

Participant Identification Number:

CONSENT FORM FOR RESEARCH STUDY

Study Title: Relationships between mindfulness, self-compassion, parental stress, well-being and child behaviour in neurodisability

Version 1.0 (19.03.17)

Name of Chief Investigator: Melissa Clapp (Trainee Clinical Psychologist)

Name of Principal Investigator: Dr Tamsin Owen (Clinical Psychologist)

	Please initial to confirm
I confirm that I have read and understand the information sheet dated 19.03.17 (Version 1.0) for the above study.	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my or my child's medical care or legal rights being affected.	
The procedures regarding confidentiality have been clearly explained to me (e.g. anonymisation of data)	
I agree to take part in the above study	

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

When complete, 1 copy for participant: 1 copy for researcher site file: 1 (original) to be kept in medical notes.

Appendix 9: Debrief form



PARTICIPANT DEBRIEF FORM (Version 1.0 19.03.17)

Study Title: Relationships between mindfulness, self-compassion, parental stress, wellbeing and child behaviour in neurodisability

Thank you for taking part in the above research study.

Purpose of the research study

The purpose of this study is to explore relationships between mindfulness, mindful parenting, self-compassion, parental wellbeing, stress and perceived child behaviour, in parents of children with a range of neurodevelopmental disorders (including Autistic Spectrum Disorder, Attention Deficit Hyperactivity Disorder, Tic's and Intellectual Disability). Knowing more about these relationships is important because we hope it will help clinicians working in NHS services to develop and tailor mindful parenting interventions for parents and support greater provision of mindful parenting interventions in the long term.

Procedure

The study involves participants completing a brief information sheet and six questionnaires about themselves and their family. Questionnaires included questions around:

- Participants experiences of their parenting role in relation to having a child with a neurodevelopmental disorder
- Participants general levels of wellbeing
- Participants general tendency to be mindful (i.e. bringing attention to the present moment, in a non-judgemental way)
- Participants tendency to be mindful in interactions with their child
- Child's strengths and difficulties, including any behaviour difficulties

Support

If you were upset or distressed by participating in this study or participation has given you a reason to feel concerned or worried, we encourage you to discuss this further with:

Dr Tamsin Owen, Clinical Psychologist within the Tics and Neurodevelopmental Movements Team (TANDeM) based at Evelina London Children's Hospital (020 7188 7188)

- If you request you can be referred to the Evelina London's parent counsellors
- Alternatively, please see the Evelina website for other support <http://www.evelinalondon.nhs.uk/get-involved/support-groups.aspx>

Appendix 10: NHS & HRA Approval Letters



Health Research Authority

West Midlands - South Birmingham Research Ethics Committee

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

31 May 2017

Miss Melissa Clapp
Clinical Psychology Department
Royal Holloway, University of London
Egham, Surrey
TW20 OEX

Dear Miss Clapp

	Relationships between mindfulness, self-compassion, parental stress, wellbeing and child behaviour in neurodisability
REC reference:	17/WM/0189
IRAS project ID:	223605

Thank you for your letter of 29 May 2017 responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with

prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Contract/Study Agreement [Study Approval Letter]	v1	09 March 2017
Covering letter on headed paper [Covering letter]	v1	23 May 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor insurance/indemnity letter]	v1	20 April 2017
IRAS Application Form [IRAS_Form_28042017]		28 April 2017
Letters of invitation to participant [Clinician letter of invite]	v1	20 May 2017
Letters of invitation to participant [Clinician letter of invite]	v1	20 May 2017
Non-validated questionnaire [Participant Demographic Sheet]	v1	19 March 2017
Participant consent form [Consent Form]	v1	19 March 2017
Participant information sheet (PIS) [Debrief Form]	v1	19 March 2017
Participant information sheet (PIS) [Participant Information Sheet]	V4	20 May 2017
Research protocol or project proposal [Research Protocol]	v1	19 March 2017
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	v1	19 March 2017
Summary CV for supervisor (student research) [Principal Investigator CV]	v1	24 April 2017
Summary CV for supervisor (student research) [External Supervisor CV]	v1	10 February 2017
Summary CV for supervisor (student research) [External Supervisor CV]	v1	21 April 2017
Validated questionnaire [WHO5 Well-being Questionnaire]	V1	19 March 2017
Validated questionnaire [Parental Stress Scale]	V1	19 March 2017
Validated questionnaire [Self-Compassion Scale]	V1	19 March 2017
Validated questionnaire [Five Facets Mindfulness Questionnaire]	V1	19 March 2017
Validated questionnaire [Interpersonal Mindfulness Parenting Questionnaire]	v1	20 April 2017
Validated questionnaire [Strengths and Difficulties Questionnaire]	V1	19 March 2017

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research

Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

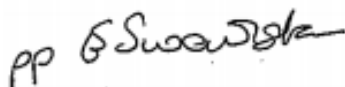
We are pleased to welcome researchers and R & D staff at our RES Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

17/WM/0189

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



Professor Paula McGee
Chair

Email: NRESCommittee.WestMidlands-SouthBirmingham@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: Ms Annette Lock

Dr Mays Jawad, Guys and St Thomas NHS Trust



Health Research Authority

Miss Melissa Clapp
Clinical Psychology Department
Royal Holloway, University of London
Egham, Surrey
TW20 OEX

Email: hra.approval@nhs.net

05 June 2017

Dear Miss Clapp

Letter of HRA Approval

Study title:	Relationships between mindfulness, self-compassion, parental stress, wellbeing and child behaviour in neurodisability
IRAS project ID:	223605
REC reference:	17/WM/0189
Sponsor	Royal Holloway, University of London

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

IRAS project ID	223605
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It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application

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procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **223605**. Please quote this on all correspondence.

Yours sincerely

Steph Macpherson
Senior Assessor

Email: hra.approval@nhs.net

Copy to: *Ms Annette Lock, Royal Holloway, University of London [Sponsor]*
Dr Mays Jawad, Guys and St Thomas NHS Trust [Lead NHS R&D]

Appendix 11: Measures

Five Facets of Mindfulness Questionnaire

Five Facet Mindfulness Questionnaire

Description:

This instrument is based on a factor analytic study of five independently developed mindfulness questionnaires. The analysis yielded five factors that appear to represent elements of mindfulness as it is currently conceptualized. The five facets are observing, describing, acting with awareness, non-judging of inner experience, and non-reactivity to inner experience. More information is available in:

Please rate each of the following statements using the scale provided. Write the number in the blank that best describes your own opinion of what is generally true for you.

1	2	3	4	5
never or very rarely true	rarely true	sometimes true	often true	very often or always true

- _____ 1. When I'm walking, I deliberately notice the sensations of my body moving.
- _____ 2. I'm good at finding words to describe my feelings.
- _____ 3. I criticize myself for having irrational or inappropriate emotions.
- _____ 4. I perceive my feelings and emotions without having to react to them.
- _____ 5. When I do things, my mind wanders off and I'm easily distracted.
- _____ 6. When I take a shower or bath, I stay alert to the sensations of water on my body.
- _____ 7. I can easily put my beliefs, opinions, and expectations into words.
- _____ 8. I don't pay attention to what I'm doing because I'm daydreaming, worrying, or otherwise distracted.
- _____ 9. I watch my feelings without getting lost in them.
- _____ 10. I tell myself I shouldn't be feeling the way I'm feeling.
- _____ 11. I notice how foods and drinks affect my thoughts, bodily sensations, and emotions.
- _____ 12. It's hard for me to find the words to describe what I'm thinking.
- _____ 13. I am easily distracted.
- _____ 14. I believe some of my thoughts are abnormal or bad and I shouldn't think that way.

- _____ 15. I pay attention to sensations, such as the wind in my hair or sun on my face.
- _____ 16. I have trouble thinking of the right words to express how I feel about things
- _____ 17. I make judgments about whether my thoughts are good or bad.
- _____ 18. I find it difficult to stay focused on what's happening in the present.
- _____ 19. When I have distressing thoughts or images, I "step back" and am aware of the thought or image without getting taken over by it.
- _____ 20. I pay attention to sounds, such as clocks ticking, birds chirping, or cars passing.
- _____ 21. In difficult situations, I can pause without immediately reacting.
- _____ 22. When I have a sensation in my body, it's difficult for me to describe it because I can't find the right words.
- _____ 23. It seems I am "running on automatic" without much awareness of what I'm doing.
- _____ 24. When I have distressing thoughts or images, I feel calm soon after.
- _____ 25. I tell myself that I shouldn't be thinking the way I'm thinking.
- _____ 26. I notice the smells and aromas of things.
- _____ 27. Even when I'm feeling terribly upset, I can find a way to put it into words.
- _____ 28. I rush through activities without being really attentive to them.
- _____ 29. When I have distressing thoughts or images I am able just to notice them without reacting.
- _____ 30. I think some of my emotions are bad or inappropriate and I shouldn't feel them.
- _____ 31. I notice visual elements in art or nature, such as colors, shapes, textures, or patterns of light and shadow.
- _____ 32. My natural tendency is to put my experiences into words.
- _____ 33. When I have distressing thoughts or images, I just notice them and let them go.
- _____ 34. I do jobs or tasks automatically without being aware of what I'm doing.
- _____ 35. When I have distressing thoughts or images, I judge myself as good or bad, depending what the thought/image is about.
- _____ 36. I pay attention to how my emotions affect my thoughts and behavior.
- _____ 37. I can usually describe how I feel at the moment in considerable detail.
- _____ 38. I find myself doing things without paying attention.
- _____ 39. I disapprove of myself when I have irrational ideas.

Interpersonal Mindfulness in Parenting Scale

MINDFULNESS IN NEURODISABILITY

Interpersonal Mindfulness in Parenting (IM-P) scale – Expanded version (Parent report)

The following statements describe different ways that parents interact with their children on a daily basis. Please tell me whether you think the statement is "Never True," "Rarely True," "Sometimes True," "Often True," or "Always True" for you. Remember, there are no right or wrong answers and please answer according to what <i>really reflects</i> your experience rather than what you think your experience <i>should</i> be. Please treat each statement separately from every other statement.	Never True	Rarely True	Sometimes True	Often True	Always True
1. I find myself listening to my child with one ear because I am busy doing or thinking about something else at the same time.	1	2	3	4	5
2. When I'm upset with my child, I notice how I am feeling before I take action.	1	2	3	4	5
3. I notice how changes in my child's mood affect my mood.	1	2	3	4	5
4. I listen carefully to my child's ideas, even when I disagree with them.	1	2	3	4	5
5. I often react too quickly to what my child says or does.	1	2	3	4	5
6. I am aware of how my moods affect the way I treat my child.	1	2	3	4	5
7. Even when it makes me uncomfortable, I allow my child to express his/her feelings.	1	2	3	4	5
8. When I am upset with my child, I calmly tell him/her how I am feeling.	1	2	3	4	5
9. I rush through activities with my child without being really attentive to him/her.	1	2	3	4	5
10. I have difficulty accepting my child's growing independence.	1	2	3	4	5
11. How I am feeling tends to affect my parenting decisions, but I do not realize it until later.	1	2	3	4	5
12. It is hard for me to tell what my child is feeling.	1	2	3	4	5
13. When I am doing things with my child, my mind wanders off and I am easily distracted.	1	2	3	4	5
14. When my child misbehaves, it makes me so upset I say or do things I later regret.	1	2	3	4	5
15. I tend to be hard on myself when I make mistakes as a parent.	1	2	3	4	5
16. When my child does something that upsets me, I try to keep my emotions in balance.	1	2	3	4	5
17. When times are really difficult with my child, I tend to blame myself.	1	2	3	4	5
18. When things I try to do as a parent do not work out, I can accept them and move on.	1	2	3	4	5
19. I am often so busy thinking about other things that I realize I am not really listening to my child.	1	2	3	4	5

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MINDFULNESS IN NEURODISABILITY

The following statements describe different ways that parents interact with their children on a daily basis. Please tell me whether you think the statement is "Never True," "Rarely True," "Sometimes True," "Often True," or "Always True" for you. Remember, there are no right or wrong answers and please answer according to what <i>really reflects</i> your experience rather than what you think your experience <i>should</i> be. Please treat each statement separately from every other statement.	Never True	Rarely True	Sometimes True	Often True	Always True
20. When I do something as a parent that I regret, I try to give myself a break.	1	2	3	4	5
21. In difficult situations with my child, I pause without immediately reacting.	1	2	3	4	5
22. It is easy for me to tell when my child is worried about something.	1	2	3	4	5
23. I tend to criticize myself for not being the kind of parent I want to be.	1	2	3	4	5
24. I pay close attention to my child when we are spending time together.	1	2	3	4	5
25. I am kind to my child when he/she is upset.	1	2	3	4	5
26. When I am having a hard time with parenting, I feel like other parents must have an easier time of it.	1	2	3	4	5
27. When my child is going through a difficult time, I try to give him/her the nurturing and caring he/she needs.	1	2	3	4	5
28. I try to understand my child's point of view, even when his/her opinions do not make sense to me.	1	2	3	4	5
29. When something my child does upsets me, I get carried away with my feelings.	1	2	3	4	5
30. I can tell what my child is feeling even if he/she does not say anything.	1	2	3	4	5
31. I try to be understanding and patient with my child when he/she is having a hard time.	1	2	3	4	5

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Self-Compassion Scale

HOW I TYPICALLY ACT TOWARDS MYSELF IN DIFFICULT TIMES

Please read each statement carefully before answering. To the left of each item, indicate how often you behave in the stated manner, using the following scale:

Almost never					Almost always
1		2	3	4	5
_____	1.	I'm disapproving and judgmental about my own flaws and inadequacies.			
_____	2.	When I'm feeling down I tend to obsess and fixate on everything that's wrong.			
_____	3.	When things are going badly for me, I see the difficulties as part of life that everyone goes through.			
_____	4.	When I think about my inadequacies, it tends to make me feel more separate and cut off from the rest of the world.			
_____	5.	I try to be loving towards myself when I'm feeling emotional pain.			
_____	6.	When I fail at something important to me I become consumed by feelings of inadequacy.			
_____	7.	When I'm down and out, I remind myself that there are lots of other people in the world feeling like I am.			
_____	8.	When times are really difficult, I tend to be tough on myself.			
_____	9.	When something upsets me I try to keep my emotions in balance.			
_____	10.	When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.			
_____	11.	I'm intolerant and impatient towards those aspects of my personality I don't like.			
_____	12.	When I'm going through a very hard time, I give myself the caring and tenderness I need.			
_____	13.	When I'm feeling down, I tend to feel like most other people are probably happier than I am.			
_____	14.	When something painful happens I try to take a balanced view of the situation.			
_____	15.	I try to see my failings as part of the human condition.			
_____	16.	When I see aspects of myself that I don't like, I get down on myself.			
_____	17.	When I fail at something important to me I try to keep things in perspective.			

- _____ 18. When I'm really struggling, I tend to feel like other people must be having an easier time of it.
- _____ 19. I'm kind to myself when I'm experiencing suffering.
- _____ 20. When something upsets me I get carried away with my feelings.
- _____ 21. I can be a bit cold-hearted towards myself when I'm experiencing suffering.
- _____ 22. When I'm feeling down I try to approach my feelings with curiosity and openness.
- _____ 23. I'm tolerant of my own flaws and inadequacies.
- _____ 24. When something painful happens I tend to blow the incident out of proportion.
- _____ 25. When I fail at something that's important to me, I tend to feel alone in my failure.
- _____ 26. I try to be understanding and patient towards those aspects of my personality I don't like.

MINDFULNESS IN NEURODISABILITY

Parenting Stress Scale

Parental Stress Scale

The following statements describe feelings and perceptions about the experience of being a parent. Think of each of the items in terms of how your relationship with your child or children typically is. Please indicate the degree to which you agree or disagree with the following items by placing the appropriate number in the space provided.

1 = Strongly disagree 2 = Disagree 3 = Undecided 4 = Agree 5 = Strongly agree

1	I am happy in my role as a parent	
2	There is little or nothing I wouldn't do for my child(ren) if it was necessary.	
3	Caring for my child(ren) sometimes takes more time and energy than I have to give.	
4	I sometimes worry whether I am doing enough for my child(ren).	
5	I feel close to my child(ren).	
6	I enjoy spending time with my child(ren).	
7	My child(ren) is an important source of affection for me.	
8	. Having child(ren) gives me a more certain and optimistic view for the future.	
9	The major source of stress in my life is my child(ren).	
10	Having child(ren) leaves little time and flexibility in my life.	
11	Having child(ren) has been a financial burden.	

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12	. It is difficult to balance different responsibilities because of my child(ren).	
13	The behaviour of my child(ren) is often embarrassing or stressful to me.	
14	. If I had it to do over again, I might decide not to have child(ren).	
15	I feel overwhelmed by the responsibility of being a parent.	
16	Having child(ren) has meant having too few choices and too little control over my life.	
17	I am satisfied as a parent	
18	I find my child(ren) enjoyable	

WHO Five Well-being scale



Psychiatric Research Unit
WHO Collaborating Centre in Mental Health

WHO (Five) Well-Being Index (1998 version)

Please indicate for each of the five statements which is closest to how you have been feeling over the last two weeks. Notice that higher numbers mean better well-being.

Example: If you have felt cheerful and in good spirits more than half of the time during the last two weeks, put a tick in the box with the number 3 in the upper right corner.

	<i>Over the last two weeks</i>	All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
1	I have felt cheerful and in good spirits	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
2	I have felt calm and relaxed	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
3	I have felt active and vigorous	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
4	I woke up feeling fresh and rested	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
5	My daily life has been filled with things that interest me	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0

Scoring:

The raw score is calculated by totalling the figures of the five answers. The raw score ranges from 0 to 25, 0 representing worst possible and 25 representing best possible quality of life.

To obtain a percentage score ranging from 0 to 100, the raw score is multiplied by 4. A percentage score of 0 represents worst possible, whereas a score of 100 represents best possible quality of life.

Strengths and Difficulties Questionnaire

Strengths and Difficulties Questionnaire

P 4-17

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child's behaviour over the last six months.

Child's Name

Male/Female

Date of Birth.....

	Not True	Somewhat True	Certainly True
Considerate of other people's feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless, overactive, cannot stay still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often complains of headaches, stomach-aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shares readily with other children (treats, toys, pencils etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often has temper tantrums or hot tempers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rather solitary, tends to play alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally obedient, usually does what adults request	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many worries, often seems worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has at least one good friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often fights with other children or bullies them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often unhappy, down-hearted or tearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally liked by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Easily distracted, concentration wanders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nervous or clingy in new situations, easily loses confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kind to younger children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often lies or cheats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Picked on or bullied by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often volunteers to help others (parents, teachers, other children)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thinks things out before acting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Steals from home, school or elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gets on better with adults than with other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many fears, easily scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sees tasks through to the end, good attention span	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you have any other comments or concerns?

Please turn over - there are a few more questions on the other side

MINDFULNESS IN NEURODISABILITY

Overall, do you think that your child has difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

No	Yes- minor difficulties	Yes- definite difficulties	Yes- severe difficulties
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you have answered "Yes", please answer the following questions about these difficulties:

- How long have these difficulties been present?

Less than a month	1-5 months	6-12 months	Over a year
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- Do the difficulties upset or distress your child?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- Do the difficulties interfere with your child's everyday life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
HOME LIFE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
FRIENDSHIPS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CLASSROOM LEARNING	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
LEISURE ACTIVITIES	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- Do the difficulties put a burden on you or the family as a whole?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Signature

Date

Mother/Father/Other (please specify:)

Thank you very much for your help

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Appendix 12: Summary of study findings



Study Title: Relationships between mindfulness, self-compassion, parental stress, wellbeing and child behaviour in neurodisability

What was the purpose of the study?

Parents of children with neurodevelopmental disorders report higher levels of stress and child behavioural difficulties than parents of children without neurodevelopmental disorders. Evidence suggests that overall levels of mindfulnessⁱ (i.e. bringing present moment attention to day-to-day experiences, in a non-judgemental way) and/or mindfulness applied to specific parent-child interactions (i.e. mindful parentingⁱⁱ) may be related to lower levels of parental stress and reduced child behaviour problems.

This study aimed to explore what aspects of mindfulnessⁱⁱⁱ relate to lower parental stress, child behaviour and improved parental wellbeing. This will help to develop and tailor mindfulness programmes for parents of children with neurodevelopmental disorders.

SUMMARY OF RESEARCH FINDINGS

- Parents reporting higher levels of **overall mindfulness**, **mindful parenting** and **self-compassion** generally reported lower levels of **parental stress**.
- Parents reporting higher levels of **overall mindfulness** and **self-compassion**^{iv} were more likely to report increased **parental wellbeing**.
- Parents who reported higher levels of **non-judgemental acceptance** and **compassion for self and child** (specific aspects of mindful parenting) were more likely to report higher levels of **wellbeing**.
- Parents with higher levels of **overall mindfulness** and **self-compassion** were more likely to report lower levels of **child emotional difficulties**.
- Parents reporting higher levels of **mindful parenting** were more likely to report lower levels of **child behaviour difficulties**. Specifically, **listening with full attention**, **non-reactivity** and **compassion for self and child** (specific aspects of mindful parenting) were related to lower **child behaviour difficulties**.
- Higher levels of **compassion for self and child** (a specific aspect of mindful parenting) was significantly related to lower **child emotional difficulties** and lower **child behaviour difficulties**.

- Parents of children with a primary diagnosis of ASD, ADHD or Tics/Tourette's Syndrome (TS) did not significantly differ in their overall levels of **mindfulness**, **parental stress** or **wellbeing**.
- Parents of children with a primary diagnosis of ASD reported significantly higher levels of **overall child difficulties**, **emotional difficulties** and **child behaviour difficulties** compared to those with a primary diagnosis of Tics/TS.
- Parents of children with a primary diagnosis of ASD reported significantly higher levels of **total child difficulties** and **emotional difficulties** compared to those with a primary diagnosis of ADHD.
- Overall, parents of children with a primary diagnosis of ASD reported lower levels of **mindful parenting** than parents of children with primary diagnoses of Tics/TS. Levels of **child behaviour difficulties** were similar between parents of children with a primary diagnosis of ASD and ADHD.
- Parents of children with a primary diagnosis of Tics/TS reported higher levels of **self-compassion** than parents of children with primary diagnoses of ASD and ADHD.
- **Child behaviour difficulties** had a significant impact on levels of **parental stress**, through changes in **mindful parenting**. In other words, **child behaviour difficulties** contribute to **parental stress** by reducing levels of **mindful parenting**.
- Findings show that if parents are able to draw on **mindful parenting** practices in the face of **child behaviour difficulties**, this may have a positive impact on **parental stress**.

CLINICAL IMPLICATIONS OF FINDINGS

- Mindful parenting group interventions may be helpful for parents of children with a range of neurodevelopmental disabilities who are experiencing high levels of parental stress and child behavioural difficulties.
- Parents of children with a primary diagnosis of ASD, in particular, are likely to benefit from mindful parenting interventions that aim to reduce parental stress and child behavioural difficulties.
- Mindful parenting interventions should have a specific emphasis on supporting parents/carers to foster a compassionate stance to their child, and importantly, to themselves as parents.
- Further research (i.e. randomised controlled studies) should explore the effectiveness of mindful parenting groups for parents of children with a range of neurodevelopmental disabilities, and those with more than one neurodevelopmental disability.



I would like to thank you once again for your participation in my research study. I welcome any feedback or interpretations that you might have about the findings or clinical implications, that would helpfully inform the write up of this study. Please contact Melissa Clapp (see details below)

Melissa Clapp, Trainee Clinical Psychologist

Email: Melissa.Clapp.2015@live.rhul.ac.uk or leave a telephone message on 01784414012 stating the research name, your name, contact number and best day/time to reach you.

Supervised by Dr Tamsin Owen, Clinical Psychologist

Email: tamsin.owen@gstt.nhs.uk or by phoning 020 7188 7188.

Thank you for taking part and for taking time to read this sheet.

ⁱ Overall mindfulness is defined as "paying attention in a particular way, on purpose, in the present moment and non-judgementally

ⁱⁱ Mindful Parenting (MP) is defined as "applying practices of paying attention in an intentional and non-judgmental manner to one's child and parenting over time" or the application of mindfulness in relation to specific parent-child interactions.

ⁱⁱⁱ Five aspects of mindful parenting include:

1. Listening with full attention (i.e. focused attention and awareness)
2. Non-judgemental acceptance of self and child (i.e. rather than referring to resignation, this refers to an overarching acceptance of whatever is happening at any given moment)
3. Emotional awareness of self and child (i.e. being aware of internal states of self and child)
4. Self-regulation in the parenting relationship (i.e. pausing before reacting and choosing how to approach the situation based on parental values)
5. Compassion for self and child (i.e. adopting a forgiving stance towards themselves, parenting and child)

^{iv} Self-compassion is defined as "being kind to oneself in times of difficulty, recognising the shared nature of human difficulty and being aware of but without ignoring or dwelling on perceived negative aspects of the self or life".