On mindfulness and autism

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Chapter 1
General Introduction
The development of children with autism spectrum disorder (ASD) deviates from a typical development. Children with ASD have social communication and interaction deficits, for example in using and understanding nonverbal communication and in socio-emotional reciprocity. Also, they show restricted, repetitive behavior patterns or interests. These autism symptoms are present to such an extent that they cause impairments in important areas of functioning, such as at school and in social life (American Psychiatric Association [APA], 2013). A different style of information processing is theorized to underlie these symptoms. The information processing of children with ASD is atypical in three areas. Firstly, children with ASD experience difficulties in theory of mind, the ability to assess mental states of others (Baron-Cohen, 2001). Secondly, children with ASD often experience difficulties in executive functioning, namely in planning, inhibition, working memory, and cognitive flexibility (Hill, 2004). Thirdly, they have a hyper focus on details and experience difficulties in combining these details into a coherent representation, resulting in a weak central coherence (Happé & Frith, 2006). Also, children with ASD often experience hyper- or hyposensitivity to sensory stimuli (APA, 2013). Atypical attention of children with ASD, such as impaired disengagement and orienting of attention and a decreased ability to filter distractors, may play an important role in the development of the information processing and behavioral symptoms in autism (Allen & Courchesne, 2001; Keehn, Müller, & Townsend, 2013; Keehn et al., 2016; Landry & Parker, 2013). Although these deviations in information processing and behavior often lead to having a great eye for detail and being honest and straightforward in social interaction, they also lead to difficulties in building and maintaining social relationships and organizing daily activities such as traveling with public transport and performing schoolwork.

On top of the autism symptoms, 70% of the children with ASD have symptoms that meet the criteria for at least one comorbid disorder (Simonoff et al., 2008). Common comorbid disorders in ASD are anxiety disorders, attention-deficit/hyperactivity disorder (ADHD), oppositional defiant disorder (ODD), obsessive-compulsive disorder (OCD), and depressive disorder (Leyfer et al., 2006; Simonoff et al., 2008; Van Steensel, Bögels, & De Bruin, 2013). The symptoms of children with ASD are also highly demanding for their parents. Parenting stress and parental mental health problems are higher in parents of children with ASD compared to parents of children who are typically developing or have other disabilities (e.g., Hayes & Watson, 2013; Van Steijn, Oerlemans, van Aken, Buitelaar, & Rommelse, 2014), which in turn further increases children’s comorbid internalizing and externalizing symptoms (Bauminger, Solomon, & Rogers, 2010; Hastings, 2002).

The population prevalence of ASD is estimated to be 0.76%, based on 37 studies from across the world, with the highest prevalence between the age of 5 and
20 years (Baxter et al., 2015). Some studies even indicate a prevalence of 2.6% in children of 7 to 12 year old (Kim et al., 2011). The prevalence of ASD, the need for support of children with ASD, and the burden for their parents lead to high costs for society. Costs of health care are estimated to be three times higher for children with ASD compared to children without ASD (Croen, Naijar, Ray, Lotspeich, & Bernal, 2006). Estimates of total costs, including non-health care costs such as loss of parents' paid work and extra help at school, mount up to 27 times higher compared to typically developing children (Van Steensel, Dirksen & Bögels, 2013). Lost productivity and adult care contribute largely to the costs of ASD for society (Ganz, 2007). Therefore, the development and investigation of treatment options for children and adolescents with ASD and their parents seems valuable for these families and for society as a whole.

Several treatment approaches are employed to diminish the impact of ASD on children's development and functioning. Almost half of the children with ASD receive pharmacological treatment (Madden et al., 2017). Although some psychotropic medications are effective in reducing restricted and problem behaviors, the significant adverse effects, such as weight gain and drowsiness, limit their application (McPheeters et al., 2011). Children with ASD respond equally well to placebo as to some medications, whereas the adverse effects of these medications are larger (King et al., 2009), so the risks of medication may exceed their benefits. Various behavioral treatments are based on an applied behavior analysis (ABA) approach, including early intensive behavioral intervention and pivotal response treatment. ABA improves the adaptive behavior, social interaction, and cognitive functioning of children with ASD (e.g., Reichow, 2012; Smith & Iadarola, 2015), but this approach is studied mainly for young children up to 7 years old with (mild) intellectual disability and consists of an intensive long-lasting program, which is not applicable and feasible for all families with ASD. Also, although positive gains have been reported one to 4 years after treatment, little is known about the outcomes of ABA-based programs in later stages of childhood (Matson & Konst, 2013). Social skills trainings commonly are group-based trainings that improve social competence, but results on quality of life are mixed (Cappadocia & Weiss, 2011; Reichow, Steiner, & Volkmar, 2013). Also, generalization of learnt skills to daily life is often difficult and under-studied (White, Keoning, & Scahill, 2007). Cognitive behavior therapy for anxiety effectively reduces anxiety in children with ASD (e.g., Storch et al., 2013; Van Steensel & Bögels, 2015), but this treatment is not focusing on other symptoms than comorbid anxiety. Research on other employed approaches, such as psychomotor therapy or systemic family therapy targeting both children with ASD and their family members is very limited (Spain et al., 2017). Thus, the evidence-based treatment options for ASD are
sparse, and most of the investigated approaches target young children or target one aspect of ASD, such as either social skills or comorbid anxiety. Also, most treatment options focus on the child, either directly or by training parents in carrying out an intervention. Given the reciprocal relationship between children's internalizing and externalizing symptoms and parenting stress in ASD (Bauminger et al., 2010; Hastings, 2002), targeting both parents and children could yield the most sustainable effects. Therefore, clinical practice could benefit from the development and thorough investigation of new non-pharmacological treatment approaches that focus on the broad symptomatology of children with ASD and on both the child and parental level.

Mindfulness provides a holistic approach to improve mental health and functioning, so could target the broad symptomatology of children with ASD and their parents. Mindfulness is defined as the self-regulation of attention to present-moment experiences, such as senses, thoughts, feelings, and bodily sensations, and to approach these experiences with an open, curious, non-judgmental and accepting attitude (Bishop, Lau, et al., 2004; Kabat-Zinn, 1994). In mindfulness-based programs (MBPs) participants cultivate this by practicing mindfulness meditations, applying these practices to daily living, and engaging in inquiry of their experiences. MBPs are founded on Buddhist traditions of training the mind to develop greater awareness and thereby greater understanding of self and others, which allows for developing skillful ways to relate to experiences instead of reacting automatically. This is combined with psychological theory and science, aiming for evidence-based practices and empirically-based theoretical models on the causes and maintenance factors of human distress and how to relieve it (Crane et al., 2017). Within this framework various MBPs have been developed, of which Mindfulness-Based Stress Reduction (MBSR) and Mindfulness-Based Cognitive Therapy (MBCT) are the most well-known and investigated programs. MBSR was developed for and improves mental health problems in people with chronic pain, stress, and other diseases (Baer, 2003; Bohlmeijer, Prenger, Taal, & Cuijpers, 2010), and is also effective in reducing stress, depression and anxiety symptoms, and improving quality of life of healthy people (Khoury, Sharma, Rush, & Fournier, 2015). MBCT was developed for and reduces the risk of relapse in people with recurrent depression (Kuyken et al., 2016; Ma & Teasdale, 2004). The effects of MBPs are superior to active controls, and comparable to other evidence-based treatments for various mental health problems (Farb et al., 2018; Goldberg et al., 2018; Kuyken et al., 2015). Also, mindfulness-based parenting programs could reduce parental stress, parental, and child psychopathology (Bögels, Hellemans, van Deursen, Römer, & van der Meulen, 2014; Meppelink, de Bruin, Wanders-Mulder, Vennik, & Bögels, 2016). Therefore, children with ASD and their parents might benefit from an MBP.
The rationale for developing a program based on mindfulness for children with ASD and their parents consists of multiple parts. Firstly, an MBP might improve the underlying information processing and attention problems of children with ASD. In MBPs children practice to regulate their attention. They train to focus and sustain their attention on a specific object, such as the breath, and to inhibit impulsive and automatic reactions to distractions (Bishop, Lau, et al., 2004; Hölzel et al., 2011). By reflecting on their experiences, noticing automatic impulses, and not responding to these impulses, children practice to respond with awareness and self-control instead of impulsively. This could improve the executive functioning difficulties (Zelazo & Lyons, 2012). Moreover, children train to switch their attention from one object to another, and to widen and narrow the focus of their attention (Bishop, Lau, et al., 2004; Lutz, Slagter, Dunne, & Davidson, 2008). They also learn to observe internal and external experiences from a distance as rising and passing events, i.e., to decenter from these experiences (Kabat-Zinn, 1994; Segal, Williams, & Teasdale, 2013). This could improve difficulties in hypersensitivity, disengagement of attention, and central coherence. Furthermore, children with hyposensitivity could benefit from MBP by training awareness of bodily sensations and external stimuli. In addition, in MBPs children train awareness and understanding of emotional and thought processes and may thereby improve their understanding of mental states of others as well (Block-Lerner, Adair, Plumb, Rhatigan, & Orsillo, 2007), thus an MBP might improve their theory of mind.

Secondly, an MBP might improve the social communication and interaction symptoms of ASD. Increased awareness of the present-moment includes increased awareness of the interactions with other people in the present-moment. If children are less overwhelmed and react less to distractions such as sounds or ruminative thoughts, they are better able to attend to others and their interactions with them (Samuel, 2009). Also, increased awareness and understanding of the mental states of others allows for anticipating to the behavior and reactions of others, which contributes to better relationships. In addition, increased awareness may lead to an increased recognition of how their own behaviors affect others. Furthermore, open and nonjudgmental awareness of emotions may lead to acceptance of other people’s emotions as well and thereby facilitates empathic responding (Block-Lerner et al., 2007).

Thirdly, an MBP might reduce the stress and comorbid symptoms of children with ASD. Children with ASD show an enhanced responsivity to stressors, such as medical procedures and interacting with peers (Corbett, Schupp, Simon, Ryan, & Mendoza, 2010; Spratt et al., 2012). The transactional stress model explains that stress arises when the encountered demands of people are higher than their coping
abilities, which leads to physical and psychological stress responses, including tension, frustration, depression, and anxiety (Lazarus & Folkman, 1984). As the demands in a social environment are high for children with ASD, and they experience difficulties in coping with sensory stimuli, this model may explain the high comorbidity of internalizing and externalizing problems. Also, a heightened stress response is related to deteriorated social functioning in ASD (Bishop-Fitzpatrick, Mazefsky, Minshew, & Eack, 2015; Corbett et al., 2014), and precede increased internalizing symptoms such as depression and anxiety in children during their development (Guerry & Hastings, 2011; Kuhlman, Olson, & Lopez-Duran, 2014). In an MBP participants practice to relate less judgmental, more open and accepting towards sensory stimuli, thoughts, feelings, and bodily sensations. They also learn that these experiences are passing events which can be viewed from a distance, and they learn to switch their attention from these experiences back to an anchor such as the breath (Kabat-Zinn, 1994; Segal et al., 2013). Thereby, in MBPs, participants increase their coping abilities through self-regulation to deal with stressful experiences (Kabat-Zinn, 1982). Thus, an MBP could increase the coping abilities of children with ASD, which could in turn improve their social functioning and reduce their comorbid internalizing and externalizing symptoms.

Fourthly, an MBP might reduce the parental stress and mental health problems of parents of children with ASD. Child behavior problems are related to parental stress and mental health problems, but this relation is less strong for parents with higher levels of mindfulness, mindful parenting, acceptance, and self-compassion (Jones, Hastings, Totsika, Keane, & Rhule 2014; Neff & Faso 2015; Weiss, Cappadocia, MacMullin, Viccili, & Lunskey 2012). Just as for children, an MBP may increase the coping abilities of parents as well, which could reduce their stress and mental health problems. In addition, parents are likely to have autism symptoms themselves, because heritability in ASD is 80% (Lichtenstein, Carlström, Råstam, Gillberg, & Anckarsäter 2010) and autism symptoms of children are related to autism symptoms of their parents (Constantino & Todd, 2005). Thus, just as for children with ASD, an MBP may decrease the social communication and interaction problems of their parents. Furthermore, if parents in an MBP practice their awareness and understanding of emotional and thought processes, this may improve their understanding of the mental states of their children and increase their ability of taking the perspectives of their children. In a mindful parenting training, parents practice an open, nonjudgmental, and accepting awareness of their children. This could help to see how their child really is and tailor their parenting to what their child needs to develop, instead of projecting expectations of how children should typically develop on their child. Also, they practice to notice their automatic reactions in parenting, and
Mindful parenting training reduces both parental and child psychopathology (Bögels et al., 2014). Thus, an MBP for parents of children with ASD may reduce their stress, mental health problems, and autism symptoms, improve the parent-child relationships, and reduce the emotional and behavior problems of their children.

Research into MBPs for children with ASD or their parents is in its beginning stages. Results of series of single-case studies showed that adolescents with ASD reduced their physical aggression by using a mindfulness meditation practice when their aggression was triggered (Singh, Lancioni, Manikam et al., 2011; Singh, Lancioni, Singh et al., 2011). In a pilot study with six parent-child dyads, mothers were trained in mindfulness and in turn trained their children. This program increased maternal mindfulness and family quality of life, and reduced parenting stress and children’s internalizing and externalizing problems for most participating families (Hwang, Kearney, Klieve, Lang, & Roberts, 2015). In another pilot study 23 adolescents and 29 parents participated in an MBP with parallel sessions for the adolescents and for their parents. The results indicated an increase in adolescents’ social responsiveness and quality of life, and a decrease in rumination, but no change in worry and mindful awareness. Also, the results indicated an increase in parents’ mindful awareness and mindful parenting, and a decrease in parenting stress, laxness and verbosity (De Bruin, Blom, Smit, van Steensel, & Bögels, 2015). Several randomized controlled trials (RCTs) were conducted to investigate MBPs for only the parents of children with ASD. Compared to a wait-list control group, parents that had participated in MBSR experienced reduced stress and depression and increased life satisfaction. Also, they experienced reduced behavior problems of their children (Neece, 2014). Other RCTs indicated that parents of children with ASD benefit more from an MBP than from a skills-based parent training (Ferraioli & Harris, 2013) or a positive psychology training (Dykens, Fisher, Taylor, Lambert, & Miodrag, 2014). In addition, an RCT investigating an MBP for adults with ASD showed a reduction in depression, anxiety, and rumination and an increase in positive affect compared to the wait-list control group (Spek, van Ham, & Nyklíček, 2013). Together, the emerging research into MBPs for children with ASD and their parents encourages further investigation of this treatment approach.

The MYmind program

Four of the five studies in this dissertation investigated the MYmind program. This program is a 9-week MBP for youngsters with ASD and their parents. The program is based on the MBSR program (Kabat-Zinn, 1982) and the MBCT program (Segal et al., 2013). As in these programs, in the MYmind program each session consists of educating theory, practicing meditations, inquiry discussions about the
meditations, and discussing home practices. The program includes various meditations based on MBSR and MBCT, such as the raising exercise, the breathing meditation, the body scan, yoga practices, the 3-minute breathing space, and the thoughts meditation. Adjustments are made to tailor the program to children, ASD, and to parents of children with ASD. The program cultivates present-moment attention, non-judgmental awareness of bodily sensations, thoughts, and feelings, and responding with awareness to distressing and difficult experiences instead of reacting automatically. The themes of the MYmind program consist of attention, attention for the body, for the breath, for stress, for external distractors, for internal distractors, for feelings of self and others, for changes, and for mindfulness after the training.

The adjustments for the children are based on the MYmind program for youth with ADHD (Van der Oord, Bögels, & Peijnenburg, 2012; Van de Weijer-Bergsma, Formsa, de Bruin & Bögels, 2012). The program contains playful exercises to educate theory on attention, stress, external distractors such as sounds, and internal distractors such as thoughts. For example, in a walking exercise children walk like a ragdoll, with all their muscles relaxed, and then like a robot, with all their muscles tensed. The differences in bodily sensations are discussed and examples are given how these bodily sensations can help us to recognize how we feel and what we need. Meditations are shorter than in MBSR and MBCT; the breathing meditation is 5 minutes at the beginning of the program and becomes 10 minutes, and the body scan is no longer than 20 minutes. In addition, several exercises are adjusted for children. For example, a body scan in which each body part is stretched and relaxed is practiced first to make it easier to be aware of the different body parts. Another example is the weather report meditation, in which children and parents are asked to become aware of their feelings and then describe their feelings or ‘internal weather’ in terms of a weather report. Also, the 3-minute breathing space for children contains the first two steps of the three-step breathing space in MBCT (Segal et al., 2013), to keep it more simple.

The adjustments for the ASD population are inspired by the MBP for adults with ASD (Spek et al., 2013) and on conversations with children with ASD that took part in the first groups of MYmind. Verbal guidance during the meditations is more direct, less metaphoric, and in general less than standard in MBSR or MBCT meditations, because some children with ASD misinterpret the standard verbal guidance or are distracted by the verbal guidance. If metaphors are used, such as viewing thoughts as trains passing by a station to explain how thoughts arise and pass by and can be viewed from a distance, time and attention is paid to explain the metaphor. A ninth session is added to allow for more rehearsal. In addition, the program includes theory and practices on coping with specific situations which are
difficult or stressful for children with ASD, such as dealing with changes, disturbing sounds, repetitive thoughts, and awareness of feelings. In the inquiry discussions about the meditations, two direct questions are asked, namely “Was this exercise enjoyable, neutral, or uncomfortable for you?” and “Whereby can this practice help you?”, if children experience difficulties in answering open questions about their experiences.

The parent sessions were based on the Mindful Parenting program developed by Bögels and Restifo (2014), a manual for parents of children with all kinds of disorders with sessions lasting 3 hours. Parallel to the children’s sessions, in MYmind the parenting sessions last 1.5 hours. The program includes theory and practices to cultivate awareness of automatic reactions towards the child's behavior and to respond non-automatically, dealing with parenting stress and stressful parenting situations, and open-mindedness, acceptance, and compassion towards the child and the child’s difficulties and needs. Also, the program includes theory and practices to cultivate awareness of parents’ own boundaries and bringing acceptance and self-compassion in their parenting. To cultivate this, in addition to the standard MBSR and MBCT meditations, the program includes mindful parenting meditations in which specific obstacles and needs of parents of children with ASD are visualized (e.g., a meditation on dealing with the frustration of your child that wants to wear a specific set of clothes which are in the washing machine), and self-compassion practices.

Objectives

The aims of this dissertation were to investigate if, for what, and how an MBP, and more specifically the MYmind program, could benefit children with ASD and their parents. We used multiple methods to investigate these objectives. Chapter 2 addresses whether mindfulness can increase empathy, including mind reading, empathic responding, and prosocial behavior. We used a randomized experiment with adults comparing a 5-minute mindfulness meditation to a relaxation and a mind wandering exercise. In doing so, we investigated whether the effects of a brief mindfulness meditation on empathy were due to mindfulness-specific mechanisms or due to stress-reduction approaches in general. Also, we investigated whether the effects depended on autistic or narcissistic traits.

The next chapters consist of the studies we conducted to investigate the MYmind program. They took place in a clinical setting; the participating families were referred to the mental health care centers that provided the MYmind program and participated in our studies. Chapter 3 presents a repeated measures study investigating if changes in child- and parent-reported social communication problems, emotional and behavioral functioning, mindful awareness, and parenting were present directly after, 2 months after, and 1 year after the MYmind program. Chapter 4
addresses whether children with ASD show atypical attention compared to typically developing children, and whether the MYmind program could improve their attention systems, using an objective assessment of attention and a typically developing control group. Chapter 5 presents a qualitative study in which we explored how mindfulness works for families with ASD, examining the research question which change processes are involved in the MYmind program according to the experiences of the children and parents. Chapter 6 presents a series of single-case studies in which we investigated the effects of MYmind for adolescents with ASD and comorbid internalizing disorders using a person-centered approach. Also, we investigated how changes were related to each other over time. Finally, Chapter 7 provides an overall discussion of all previous chapters in which the results are integrated and interpreted. Also, this chapter provides recommendations for future investigations and clinical applications on mindfulness and autism.