Learning to connect: a feasibility study of a mindfulness and compassion training for parents of children with autism spectrum disorder

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ABSTRACT

**Background:** Parents of children with Autism Spectrum Disorder (ASD) face unique challenges in caregiving that threaten their ability to take optimal care of themselves and their children. Numerous studies have investigated the stress experienced by parents of children with ASD, but fewer have aimed to enable parents to better cope with the challenges involved in raising a child with ASD. While there is strong rationale for implementing second-generation mindfulness-based interventions (SG-MBIs) for ASD, to the best of our knowledge no study to date has investigated the effects of these standardized programs in this population.

**Method:** We aimed to assess feasibility of CBCT® (Cognitively-Based Compassion Training) in parents of children with ASD (n=15). CBCT® is a SG-MBI of proven benefit for persons in several situations involving psychological stress. Participants completed measures of perceived stress –PSS–, children’s behavior –ABC–, acceptance of their child’s condition –AAQ–, empathy and compassion –IRI–, parent-child relationship –PSOC– and executive functions –BRIEF-A– at pre-and post-intervention, and two-month follow-up.

**Results:** CBCT participants demonstrated significant improvements in acceptance of their child’s condition, empathetic concern, parent-child relationship and cognitive flexibility. We also found a significant decrease in child’s symptoms and parenting stress. Overall results indicated that CBCT meets several criteria of feasibility for introduction into a clinical setting.

**Conclusions:** The current study extends the literature exploring the applications of mindfulness for ASD. These preliminary findings suggest that CBCT holds promise as a practical approach to promoting mental health and well-being in parents of children with ASD. Further clinical investigation into the role of SG-MBI for ASD is warranted.

**Keywords:** mindfulness, compassion, ASD
Introduction

Autism spectrum disorder (ASD) is a life-long neurodevelopmental disorder. It is characterized by persistent deficits in social communication and social interaction, along with repetitive and restricted patterns of interests and behaviour [1]. Furthermore, irritability, anxiety and aggression are common among individuals with ASD [2]. The impact of these difficulties extends beyond the diagnosed individuals, affecting their social environments (families, caregivers and communities). Indeed, parenting a child with ASD is associated with high levels of burden, depression, anxiety, and poorer self-perceived general health [3]. The prevalence of depression, anxiety, and emotional distress is higher among parents of children with ASD than in parents of typically developing children or parents of children with other neurodevelopmental disorders (i.e. intellectual disability or cerebral palsy) [4-10]. Besides, sub-clinical autistic symptoms and traits has consistently been observed in parents of children diagnosed with ASD with a frequency an order of magnitude higher than observed in the general population [11-13]. This fact has been named as the broader autism phenotype (BAP) [14]. Traits of BAP include aloofness, communication difficulties, poor social skills, impaired emotional recognition and diminished executive functioning [15,16]. Recent research has shown that the presence of autistic traits in mothers predicts disturbances in the social ability of their children with ASD [17].

While many studies have involved parents in their children’s treatment, fewer have provided them with the support they need for their own mental health [18,19]. Evidence from review studies highlight the benefits for parents of interventions targeting their mental health, but also report improvements in the nature of parent-child relationships [19,20]. Since parental stress interferes with the effectiveness of treatment for the child, improvement in children’s outcomes is to be expected. In this line of thinking, some pioneering studies have demonstrated how mindfulness training in mothers of children with ASD leads to an improvement in the behavior of the children [21-23].

In the last two decades, there has been an increased interest in mindfulness-based interventions (MBI). Compelling evidence, from hundreds of intervention studies, shows that training in Mindfulness is effective for promoting health and well-being both in the general population and in a wide range of clinical populations [24-26]. Mindfulness meditation involves a group of self-regulation practices “that focus on training attention and awareness in order to bring mental processes under greater voluntary control and thereby foster general mental well-being” [27]. MBI are typically classified into two generations of programs [28]. The first generation of mindfulness-based interventions –FG-MBI– of these is represented by the first standardized mindfulness programs, MBSR –mindfulness-based stress reduction and MBCT– mindfulness-based cognitive therapy [29,30]. On the other hand, the second generation of MBI –SG-MBI–, which have emerged in recent years, encompass a group of intervention programs characterized by the explicit training of self-compassion and compassion. Among them we can find MSC –mindful self-compassion, ABCT –attachment-based compassion therapy– and CBCT –Cognitively Based Compassion Training [31-33]. The research on the effectiveness of this “second wave” of MBI has shown that they are effective in improving mental health and social connection in both general and clinical populations [34-36].

Results from many studies have shown that first generation MBI are effective in promoting benefits for parents of children with ASD, as well as for the children themselves [20,23,37,38]. A recent review of randomized controlled trials (RCTs), reported large positive effects on the parents distress and general health [19,39-41]. Participation in mindfulness programs has also been associated with a decrease in stress of caregivers of individuals with other intellectual and developmental disabilities [42,43]. Although there is strong rationale to implement SG-MBI for ASD, no study to date has investigated the effects of these standardized programs in this population [44].

Cognitively Based Compassion Training (CBCT), is a SG-MBI that teaches mindfulness, active contemplation of loving-kindness, as well as empathy and compassion towards self and others. Unlike traditional mindfulness-based programs, and those with a component of self-compassion, CBCT aims directly to foster affection for, positive connection with, and acceptance and understanding of others. Training in CBCT has already been demonstrated to reduce immune inflammatory and emotional distress responses to psychosocial stressors [45,46]. It also enhances empathetic accuracy in reading emotions, including changes in the underlying neurobiology [47]. CBCT has the potential to be a valuable stress management technique in parents of children with ASD. It includes a detailed manual of procedures for instructors and students and is therefore an ideal methodology for the systematic study of the effects and possible benefits of meditation [33].

The benefits of SG-MBI to promote mental health and social connection in both general and clinical populations, and the lack of studies developed exclusively in parents of children with ASD led us to design the present study. We aimed to (a) explore the feasibility of using CBCT as a stress management intervention with parents of children with ASD, (b) examine a panel of specific instruments to evaluate the efficacy of CBCT, and (c) establish averages and variances of these measures to assist in determination of sample sizes for future studies of CBCT efficacy. Our evaluation of feasibility was based on criteria suggested by Bowen et al. [48]. We focused the present analysis on three of these: demand (the likelihood of the program to be chosen by the potential end-users), acceptability (to what extent the program is judged as satisfying by the recipients), and limited efficacy testing (whether the program shows promise of being successful with the intended population).

Method

Participants

Participants were recruited with flyers announcing a program of “stress-reduction training”. The word “meditation” was not employed in the flyer to circumvent confounds such as self-selection bias or prejudice. Instead, the term, “Cognitive
Training” was used. Flyers with information about the study were distributed at an Autism Center and autism-related social media or handed out directly by the Center’s Care Coordination personnel. The effectiveness of our recruitment efforts was one of the feasibility endpoints of the study; recruitment results are presented below, under “Measures of Feasibility”.

Fifteen parents of children with developmental disabilities (14 with ASD and one with Fetal Alcohol Syndrome –FAS) participated in the study. Inclusion criteria were: (a) being the parent of a child with special needs, and (b) having no change in psychotropic medication within the previous six months. Parents were also asked whether or not their child with special needs had had any change in their intervention six months prior to the training.

Demographics were recorded for 14 of the participants (excluding 1 mother who did not return the demographic questionnaire). All were adults, age averaging 45±5.9 years (M±SD). Twelve of the 14 were women. Twelve (85.7%) had at least four years of college. The sample was racially and ethnically diverse, with 50% being White and the remainder distributed nearly equally among African American, Asian, and Hispanic ethnicity. Only three parents came from single-parent households. Most families had two children; 11 (79%) of the families had only one child with special needs, while four (21%) had two. All but one of the participants’ children were reportedly verbal and with no intellectual disability.

**Procedure**

All participants were exposed to a standard course of CBCT training. CBCT sessions took place in a private classroom at the Autism Center or at a location nearby. Participants met once weekly during eight weeks for two hours and were encouraged to do homework consisting of mindfulness, self-compassion and compassion meditation practices between the sessions. The contents of the CBCT program and the procedure for assessing feasibility of CBCT training, including psychometric efficacy measures used to evaluate outcomes, are described below. Three successive cohorts of four, five and six parents participated in the study, resulting in 15 total. Participants were asked to complete questionnaires before and immediately after the program, eight weeks later, and two months following the study. All procedures were approved by the University Institutional Review Board. Informed consent was obtained for all participants. This study was registered with Clinical Trials (http://www.clinicaltrials.gov).

**CBCT® protocol**

The training program consists of six integrated modules geared toward teaching participants compassion through mindfulness practices, developed in 2012 [33]. Classes were led by a licensed clinical psychologist with expertise in developmental disabilities who was also certified in CBCT. Each session included instruction, discussion, and a 30 to 40-min long period of meditation. The six modules are summarized in Table 1.

Pacing of module presentation is fluid and tailored to each unique group of participants. The sequential nature of the modules prevents participants from benefitting from the intervention if they miss too many classes, so it was stipulated at the beginning of the training that participants missing more than three days (out of eight) would be encouraged to withdraw and start over when the course was offered at a later date. Information on attendance is presented below, under Acceptability and Satisfaction. In each session, participants are led through a series of meditation exercises and discussions that help them progressively cultivate attention skills, first, and then other-centered thoughts while overcoming self-focused thoughts. Topic overviews and their corresponding guided meditation recordings for at-home practice were made available online.

**Measures of feasibility**

We evaluated feasibility in three different areas of focus: demand for services and recruitment, acceptability and satisfaction, and limited efficacy testing [48]. Our measures consisted of analyses of recruitment, attendance, questionnaire submission, homework completion, surveys of participant satisfaction, and statistical analysis of questionnaires.

**Demand for services and recruitment:** In order to assess the feasibility of this area of focus, the number of participants who were a part of each step of the recruitment process was...
recorded. Participant and contact information were collected in oral interviews. Information about schedule preferences was also recorded if provided. Recruitment was conducted in three waves, yielding the three cohorts of participants, and was executed in the following steps: (a) distribution of advertisements through flyers, (b) registration of the name and contact information of interested participants, (c) conduct of an informational session for participants, and (d) scheduling of CBCT sessions according to availability of interested participants. Attendance at the informational session and classes was tabulated; this information was our primary measure of Demand.

Acceptability and satisfaction. Data was collected on attendance of the 15 participants enrolled in the study who signed a written consent form. Participants’ questionnaire responses were tabulated and weekly participant logs of the number of times and duration of meditation sessions outside class were summarized. Two months after the training, participants were reminded to submit follow-up questionnaires, and were also asked to rate their level of satisfaction with the program and whether they would recommend CBCT to a friend. There was also an open invitation without specific questions to share any information they wanted about their experience. Responses were provided by phone or email to an investigator who had not been part of the training and did not know personally any of the participants. Responses were labelled with an ID to maintain anonymity.

Although attendance, questionnaire completion, homework, and satisfaction were our primary measures of Acceptability, a rough qualitative analysis of a few personal accounts of the participants obtained by email was also conducted in order to gain a better understanding of their satisfaction with CBCT and self-perception of its impact on their functioning. Creswell [49] described qualitative design as a description of the lived experiences of a concept or phenomenon as told by several individuals. We attempted to follow this approach and analyzed the available participants’ personal reports focusing on what was experienced and how it was experienced [61].

Limited efficacy testing: Questionnaires were given to participants to complete pre-intervention (Time 1), post-intervention (Time 2), and at a two-month follow-up (Time 3). For the first cohort (cohort A), these were given to complete at home and return later in-person or by mail. For the second (B) and third (C) cohorts, parents were given the opportunity to fill out the Time 1 questionnaires at the Center after they consented to participate, and to stay after the last class to complete the Time 2 forms. Fourteen participants returned the questionnaires at Time 1. Six of the 15 participants completed measures at Times 1 and 2, and four participants completed most of the measures at Times 1, 2 and 3. For the fifteenth participant who consented to the study but did not return any questionnaires, only attendance is presented. In addition to demographics (age, gender, race/ethnicity, education level, family composition, child’s diagnosis), and rating of satisfaction, measures of the following variables were recorded: (a) perceived severity of the child’s symptoms; (b) stress and acceptance (c) empathy and compassion; (d) behavioral flexibility; and (e) parent-child relationship. A list of the instruments employed, together with a description of each can be found in Table 2.

Data analyses were performed using SAS v9.4 (Cary, NC); statistical significance was evaluated at the 0.05 level. Study efficacy was considered by gauging the pre-post change (delta-A) in psychology measure scores from Time 1 to Time 2. As previously noted, measures included a variety of subscale and total scores from the eight measures included in Table 2 (ABC, PSI, PSS, AAQ, IRI, MAAS, BRIEF, and PSC). Statistical significance of these changes was evaluated by means of paired t-tests. Effect sizes were calculated by dividing the mean pre-post measure difference by the standard deviation of the differences for each measure (Δ/SD), and interpreted via the standard Cohen’s d criteria, small ≥ 0.2, medium ≥ 0.5, and large ≥ 0.8 (δ). Only the six participants with both Time 1 and Time 2 data were included in the paired analysis. In addition, Time 1 differences in measure scores between those with higher attendance (more than 75% or six classes) and those with lower attendance (less than 75%) were analyzed via two-sample t-tests. These analyses, together with the demographic comparisons mentioned earlier, were carried out to assist in the characterization of individuals at higher risk for early attrition to inform future studies and are presented under acceptability and satisfaction in the results section.

Results

Demand for services and recruitment

As a measure of the demand for the program tested in this study, we tabulated measures of the response to the recruitment effort. These included the number of persons contacting the program staff in response to publicity, the percentage of these attending informational sessions, and the total number who began to participate in the program. After one month of publicity, 16 persons had contacted us and placed their names on the list of possible participants; at present, after about one year of publicity efforts, more than 50 persons have placed their names on the list. Out of those 50, 17 persons attended informational sessions, and of these 16 began the program, with one citing scheduling conflicts as a reason not to participate. Fifteen out of 16 participants met inclusion criteria. One female participant was excluded from the analysis because she reported a change in her psychotropic medication dosage in the previous six months, but she was still invited to participate in the program.

Acceptability and satisfaction

Attendance, questionnaire completion, and homework: To evaluate acceptability of the CBCT program we summarized the participation level of the parents in the study through their attendance at training sessions, their self-reported completion of homework (meditation sessions at home) and return of completed study questionnaires. As can be seen in Table 3, 4 of the participants attended 4 or fewer of the 8 training sessions and thus did not complete the program. The remaining 11 participants attended an average of 80.68% of the sessions. Of
Table 2. Questionnaires Used to Assess Efficacy

Perceived severity of the child’s symptoms
Aberrant Behavior Checklist, irritability subscale (ABC), used as an index of ASD-specific disability in similar studies [50,51].

Stress and acceptance
Parenting Stress Index/Short Form (PSI/SF) [52]. It includes three subscales: Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child. Perceived Stress Scale (PSS) [53].

Acceptance and Action Questionnaire (AAQ) [54]. A version that has modified elsewhere in relation to parenting a child with ASD was used [55]. Interpretation is reversed for results of the AAQ scale. Higher scores indicate lower acceptance.

Empathy and compassion
Interpersonal Reactivity Index (IRI), including four subscales: Perspective Taking, Fantasy, Empathic Concern, and Personal Distress [56].

Behavioral flexibility
Mindful Attention Awareness Scale (MAAS) [57].

Behavior Rating Inventory of Executive Function- Adult Version (BRIEF-A), with indexes: a) Behavioral Regulation and b) Metacognition, as well as a Global Executive Composite score [58]. Interpretation is reversed for results of the the BRIEF scales. Higher scores indicate lower behavioral flexibility.

Parent-child relationship
Parenting Sense of Competence Scale (PSOC) [59].

Table 3. Attendance, Questionnaires, Homework and Satisfaction

<table>
<thead>
<tr>
<th>ID</th>
<th>Attendance out of 8 (%)</th>
<th>Submitted Qs (out of 3)</th>
<th># of Weeks w/hm work log</th>
<th>Avg Practice Time/Week</th>
<th>Average Sessions/Week</th>
<th>Satisfaction (out of 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A_1</td>
<td>8 (100%)</td>
<td>2</td>
<td>7</td>
<td>76.16</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>A_2</td>
<td>6 (75%)</td>
<td>1</td>
<td>0</td>
<td>N/A</td>
<td>N/A</td>
<td>6</td>
</tr>
<tr>
<td>A_3</td>
<td>6 (75%)</td>
<td>1</td>
<td>0</td>
<td>N/A</td>
<td>N/A</td>
<td>7</td>
</tr>
<tr>
<td>A_4</td>
<td>5 (62.5%)</td>
<td>0</td>
<td>0</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>B_1</td>
<td>4 (50%)</td>
<td>1</td>
<td>2</td>
<td>73.00</td>
<td>7.00</td>
<td>7</td>
</tr>
<tr>
<td>B_2</td>
<td>7 (87.5%)</td>
<td>2</td>
<td>8</td>
<td>58.75</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>B_3</td>
<td>8 (100%)</td>
<td>3</td>
<td>8</td>
<td>47.61</td>
<td>9.78</td>
<td>7</td>
</tr>
<tr>
<td>B_4</td>
<td>7 (87.5%)</td>
<td>3</td>
<td>8</td>
<td>96.22</td>
<td>5.44</td>
<td>7</td>
</tr>
<tr>
<td>B_5</td>
<td>6 (75%)</td>
<td>3</td>
<td>8</td>
<td>59.56</td>
<td>12.11</td>
<td>7</td>
</tr>
<tr>
<td>C_1</td>
<td>8 (100%)</td>
<td>3</td>
<td>8</td>
<td>49.67</td>
<td>4.33</td>
<td>7</td>
</tr>
<tr>
<td>C_2</td>
<td>3 (30%)</td>
<td>1</td>
<td>0</td>
<td>N/A</td>
<td>N/A</td>
<td>7</td>
</tr>
<tr>
<td>C_3</td>
<td>3 (30%)</td>
<td>1</td>
<td>0</td>
<td>N/A</td>
<td>N/A</td>
<td>7</td>
</tr>
<tr>
<td>C_4</td>
<td>5 (62.5%)</td>
<td>1</td>
<td>5</td>
<td>103.20</td>
<td>8.60</td>
<td>N/A</td>
</tr>
<tr>
<td>C_5</td>
<td>5 (62.5%)</td>
<td>1</td>
<td>3</td>
<td>23.67</td>
<td>4.33</td>
<td>7</td>
</tr>
<tr>
<td>C_6</td>
<td>2 (25%)</td>
<td>1</td>
<td>0</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

1 The participant ID’s letter identifies their cohort, first (A), second (B), or third (C)
2 Participant A_4 was excluded from all efficacy assessments as she did not submit any questionnaires

Table 4. Time 1 Differences in Efficacy Measures at Time 1 Based on Attendance

| Measure, Mean (SD) | Time 1 Scores | P-Value; Effect Size
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td></td>
<td>N &lt;75% Visits</td>
<td>N ≥75% Visits</td>
</tr>
<tr>
<td>ABC Irritability</td>
<td>6 25.83 (8.86)</td>
<td>7 9.29 (5.59)</td>
</tr>
<tr>
<td>PSI – Defensive Responding</td>
<td>6 21.33 (7.55)</td>
<td>7 21.29 (5.56)</td>
</tr>
<tr>
<td>PSI – Parent Distress</td>
<td>6 34.83 (11.18)</td>
<td>7 31.71 (8.36)</td>
</tr>
<tr>
<td>PSI – Parent/Child Dysfunction</td>
<td>6 33.83 (17.97)</td>
<td>7 27.71 (10.86)</td>
</tr>
<tr>
<td>PSI – Difficult Child</td>
<td>6 42.5 (12.72)</td>
<td>7 38 (10.77)</td>
</tr>
<tr>
<td>PSI Total</td>
<td>6 111.2 (40.48)</td>
<td>7 97.43 (26.01)</td>
</tr>
<tr>
<td>PSS Total</td>
<td>6 25.33 (2.5)</td>
<td>8 20.25 (2.61)</td>
</tr>
<tr>
<td>AAQ Total</td>
<td>6 29.5 (10.41)</td>
<td>8 19 (9.67)</td>
</tr>
<tr>
<td>IRI – Perspective Taking</td>
<td>6 24.83 (6.24)</td>
<td>8 21 (4.11)</td>
</tr>
<tr>
<td>IRI – Fantasy</td>
<td>6 23 (7.21)</td>
<td>8 16.63 (5.18)</td>
</tr>
<tr>
<td>IRI – Empathic Concern</td>
<td>6 27.5 (4.93)</td>
<td>8 21 (4.21)</td>
</tr>
<tr>
<td>IRI – Personal Distress</td>
<td>6 15.5 (3.73)</td>
<td>8 12.75 (2.96)</td>
</tr>
<tr>
<td>MAAS Total</td>
<td>6 54 (15.75)</td>
<td>8 44.25 (5.82)</td>
</tr>
<tr>
<td>BRIEF – BRI SS</td>
<td>6 55.5 (8.17)</td>
<td>8 55.25 (5.5)</td>
</tr>
<tr>
<td>BRIEF – MI SS</td>
<td>6 55.17 (13.93)</td>
<td>8 57 (4.87)</td>
</tr>
<tr>
<td>BRIEF – GEC SS</td>
<td>6 83.33 (16.66)</td>
<td>8 84 (6.07)</td>
</tr>
<tr>
<td>PSOC Total</td>
<td>6 66.83 (16.58)</td>
<td>7 69.71 (8.3)</td>
</tr>
</tbody>
</table>

1 Attendance is an indication of Acceptability, one of the measures of feasibility.
2 Absolute Cohen’s d effect sizes calculated as (M2 - M1) / SDpooled
3 Cohen’s d cutoffs are small ≥ 0.2, medium ≥ 0.5, large ≥ 0.8
the 15 participants, 14 returned questionnaires at least at the first data point (Time 1), and six returned them at two data points (Times 1 and 2). Four of those six returned questionnaires at Times 1, 2, and 3. Six persons returned seven or all the requested homework logs, three returned between two and five logs, and six returned no logs at all. Those returning logs averaged 65.32 minutes of at-home meditation per week, distributed across 6.73 sessions weekly.

There were no significant demographic differences between those that attended < 75% of classes versus ≥ 75% of classes (data not shown). Time 1 differences in measure scores in the two groups are presented in Table 4. Significant differences and large effect sizes (≥ 0.8) suggest that parents who participated more perceived less severity in their child’s symptoms (ABC-I), were less distressed (PSS), and exhibited higher levels of empathy and compassion (IRI-empathic concern). No significant differences were observed in the AAQ, MAAS, and IRI Fantasy, and Personal Distress subscales, with large effect sizes ≥ 0.8; and a non-significant difference was also found for IRI-Perspective Taking, with a moderate effect size ≥ 0.5. (Please note that interpretation should be reversed for results of the AAQ scale; higher scores indicating lower acceptance).

**Satisfaction**

After the study was completed, participants were asked to rate their satisfaction with the program on a seven-point scale. As shown in Table 4, 12 persons responded; 11 rated their satisfaction as “7” (maximal) and 1 as “6.” All participants reported that “they would recommend it to a friend”; four of them added that they had already done so.

Our qualitative analysis of testimonials shared by five participants upon completion of the training indicates several common themes. Specifically, a general experience of self-growth and feeling of compassion toward self were reported by the participants. An increased sense of control, enhancement of coping skills, facilitation of interpersonal abilities, and broadening of perspective were also identified. For instance, one participant commented that “CBCT was to me what behavior intervention was to my children; it taught me a new, healthier way of being.” Another stated, “It is allowing me to take care of my son in a much healthier way.” A third extended her experience to an interaction with a provider, “My frustration with that provider dissolved when I started to think of her as another confused human being; she didn’t have the information I needed but I remained open enough to see that she could be helpful in other ways, and she was”.

In addition, themes related to a shared experience of participation in training were identified. In particular, the participants reported feeling validated, recognizing the universality of their difficulties, being more able to accept their feelings, and having hope in their capacity to face challenges. Finally, the experience of normalization of personal struggles was another theme revealed through this analysis. “The CBCT program shows we are human, we can be balanced,” shared one of the participants. And another one added, “Two weeks into CBCT I was told that something about me had changed; I was not so argumentative, something had opened up.” Refer to Table 5 for an eloquent testimony of one of our participants, as reported in Marchant (2016) [62].

**Limited efficacy testing**

As noted in the methods section, we administered eight questionnaires to examine five domains related to parental distress. These questionnaires were administered prior to CBCT training (Time 1) and immediately after CBCT (Time 2). In order to avoid the confounding effect of a different diagnosis, the parent of the child with FAS was excluded from the analysis of the measures including direct references to a child with special needs. There was also missing data for one participant in the MAAS questionnaire at Time 2. Accordingly, there were only five participants who answered the ABC-I, PSI, AAQ, MAAS, and PSOC and six who completed the PSS, IRI, and BRIEF at Time 2. Meaningful improvements were noted for these participants, as indicated by statistically significant differences in measure scores and large effect sizes (Table 6). Specifically, ABC-I and the PSI Defensive Responding, PSI Parent Distress, PSI Difficult Child, and PSI total scores all saw large decreases, with effect sizes > 1, and were statistically significant. Moreover, large improvements were found in the PSS and AAQ measures, as well as in the MAAS, BRIEF, and PSOC scores, each with significant p-values and effect sizes in excess of 1.5. Aside from the Empathetic Concern subscale, the IRI assessment was the only measure that failed to significantly improve over the course of study (Table 6). Overall there was (a) a decrease in perceived severity of the child’s symptoms (ABC-I), (b) a decrease in parent stress (PSS, PSI) and an increase in acceptance (AAQ),

Table 5. Testimony of CBCT Participant from Marchant (2016)

| “CBCT is now being taught in a range of communities at risk of stress, including breast cancer survivors, veterans with PTSD, native Americans – and autism carers. For Fhena, the course, led by Marcus centre psychologist Samuel Fernandez-Carriba, was a revelation. “The fog started clearing,” she says. During the course, Fhena says she realised that autism had come to define her children in her eyes. “All you see is a burden. It was robbing me of so much I could give to them.” Instead of being overwhelmed by her own stress and misery, she started to view the world from her kids’ perspective, and to see them as people in their own right. “In the class, I released a feeling of entitlement,” she says. “The feeling that I was supposed to have a life without these challenges.” She had always struggled with that provider dissolved when I started to think of her as another confused human being; she didn’t have the information I needed but I remained open enough to see that she could be helpful in other ways, and she was”. “Then I realized. These special beings were given to me because of what I put into the pot.” And with that single thought, much of the stress in Fhena’s life disintegrated. Instead of feeling bitter and resentful, “I’m enjoying being with them.” And her children have responded beautifully. “Every day there is a new blossoming,” she says. “Ahav is drawing crusieships in 3D detail. Analiel is writing 25 songs a day.” And the best moment of all, when Ahav said, “Mommy, I’m so proud of you. Because I know that you love me even more now.” |
(c) an increase in empathy and compassion (IRI-empathic concern) (d) an increase in behaviour flexibility (BRIEF-A, MAAS), and (e) improved parent-child relationships (PSOC).

**Discussion**

We provided CBCT to a group of parents of children with ASD as a community-based mental-health service for the purpose of (a) collecting empirical data on the feasibility of implementing this intervention, (b) exploring the appropriateness of several measures of parental stress, and (c) identifying measure-based psychometric properties for a future full-scale scientific efficacy study. The framework used was based on the suggestions of Bowen et al. [48] for evaluation of feasibility. We chose three areas of focus that that best matched the needs of our clinical program situation: demand, acceptability, and limited-efficacy testing.

**Demand**

There is a great demand for a stress reduction program in this population, as indicated by the large number of participants interested in being part of the recruitment list. Despite this high initial interest, there was less intention to use such a program in its current format, as judged by the attendance to the information session. Once participants attended the information session the rate of refusals was low; indeed, it took about 25 minutes to complete them. The number of returned questionnaires suggests these were not too cumbersome or lengthy; indeed, it took about 25 minutes to complete them. Sixteen participants enrolled in the program, with 15 meeting the inclusion criteria and signing the consent form. Eleven out of the 15 participants fully completed the program (i.e., missed three or less classes out of eight). Among these, satisfaction was very high for the 9 participants who completed the satisfaction survey. Three of the four parents who withdrew also agreed to fill out the satisfaction questionnaires and attended a session organized to inform about the results of this study. Our attrition of 26% (four out of 15) is higher than that reported in some parent-training interventions (approximately 10%) [63]. Parental motivation to participate in and complete the program may been attenuated by the absence of any well-defined anticipated benefit for the children. Most participants were married, from a high socioeconomic status, and had children who were only moderately impaired. Severity of the child’s symptoms may have also influenced attendance, as those who attended at least 75% of the classes reported lower symptomatology in their children and less perceived stress. The fact that all but one of the parents filled out Time 1 questionnaires suggests these were not too cumbersome or lengthy; indeed, it took about 25 minutes to complete them. The number of returned questionnaires decreased considerably at Times 2 and 3. For cohorts B and C, it was decided that questionnaires would be filled out during class time. This improved the number of completed questionnaires in cohort B but not C, of which only one person attended the last session. Participants who completed the training seemed to be highly engaged in homework. All but one of the nine participants who returned homework logs reported having engaged in practice.

**Acceptability**

Sixteen participants enrolled in the program, with 15 meeting the inclusion criteria and signing the consent form. Eleven out of the 15 participants fully completed the program (i.e., missed three or less classes out of eight). Among these, satisfaction was very high for the 9 participants who completed the satisfaction survey. Three of the four parents who withdrew also agreed to fill out the satisfaction questionnaires and attended a session organized to inform about the results of this study. Our attrition of 26% (four out of 15) is higher than that reported in some parent-training interventions (approximately 10%) [63]. Parental motivation to participate in and complete the program may been attenuated by the absence of any well-defined anticipated benefit for the children. Most participants were married, from a high socioeconomic status, and had children who were only moderately impaired. Severity of the child’s symptoms may have also influenced attendance, as those who attended at least 75% of the classes reported lower symptomatology in their children and less perceived stress. However, the PSI, a well validated scale for assessing parent stress, did not show any differences in the two groups.

**Table 6. Efficacy Measure Scores Before and After Eight Weeks of CBCT**

<table>
<thead>
<tr>
<th>Measure, Mean (SD)</th>
<th>N</th>
<th>Time 1</th>
<th>N</th>
<th>Time 2</th>
<th>Mean Diff (SD)</th>
<th>P-Value; Effect Size</th>
<th>Effect Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABC Irritability</td>
<td>5</td>
<td>8.6 (5.18)</td>
<td>5</td>
<td>5.4 (4.51)</td>
<td>-3.2 (1.48)</td>
<td>0.009; 2.16</td>
<td></td>
</tr>
<tr>
<td>PSI – Defensive Resoning</td>
<td>5</td>
<td>23.2 (5.4)</td>
<td>5</td>
<td>15.6 (5.03)</td>
<td>-7.6 (2.7)</td>
<td>0.003; 2.81</td>
<td></td>
</tr>
<tr>
<td>PSI – Parent Distress</td>
<td>5</td>
<td>35 (7.18)</td>
<td>5</td>
<td>24.6 (7.7)</td>
<td>-10.4 (4.93)</td>
<td>0.009; 2.11</td>
<td></td>
</tr>
<tr>
<td>PSI – Parent/Child Dysfunction</td>
<td>5</td>
<td>31.6 (10.31)</td>
<td>5</td>
<td>27.6 (8.56)</td>
<td>-4 (3.54)</td>
<td>0.065; 1.13</td>
<td></td>
</tr>
<tr>
<td>PSI – Difficult Child</td>
<td>5</td>
<td>43 (4.42)</td>
<td>5</td>
<td>35 (9.03)</td>
<td>-8 (3.54)</td>
<td>0.029; 1.50</td>
<td></td>
</tr>
<tr>
<td>PSI Total</td>
<td>5</td>
<td>109.6 (19.03)</td>
<td>5</td>
<td>87.2 (19.78)</td>
<td>-22.4 (7.4)</td>
<td>0.003; 3.03</td>
<td></td>
</tr>
<tr>
<td>PSS Total</td>
<td>6</td>
<td>20.83 (2.79)</td>
<td>6</td>
<td>10.33 (2.94)</td>
<td>-10.5 (3.59)</td>
<td>0.005; 1.95</td>
<td></td>
</tr>
<tr>
<td>MAAS Total</td>
<td>5</td>
<td>23.6 (6.1)</td>
<td>5</td>
<td>14.2 (1.92)</td>
<td>-9.4 (5.55)</td>
<td>0.019; 1.69</td>
<td></td>
</tr>
<tr>
<td>IRI – Perspective Taking</td>
<td>6</td>
<td>20.67 (2.94)</td>
<td>6</td>
<td>23.17 (3.25)</td>
<td>2.5 (3.78)</td>
<td>0.166; 0.66</td>
<td></td>
</tr>
<tr>
<td>IRI – Fantasy</td>
<td>6</td>
<td>17.5 (4.89)</td>
<td>6</td>
<td>14.17 (9.43)</td>
<td>-3.33 (9.77)</td>
<td>0.441; 0.34</td>
<td></td>
</tr>
<tr>
<td>IRI – Empathic Concern</td>
<td>6</td>
<td>20.5 (4.59)</td>
<td>6</td>
<td>24.5 (1.64)</td>
<td>4 (3.58)</td>
<td>0.041; 1.12</td>
<td></td>
</tr>
<tr>
<td>IRI – Personal Distress</td>
<td>6</td>
<td>13.17 (3.37)</td>
<td>6</td>
<td>11.5 (6.57)</td>
<td>-1.67 (6.22)</td>
<td>0.541; 0.27</td>
<td></td>
</tr>
<tr>
<td>MAAS Total</td>
<td>5</td>
<td>42.2 (4.92)</td>
<td>5</td>
<td>67 (10.39)</td>
<td>24.8 (9.01)</td>
<td>0.004; 2.75</td>
<td></td>
</tr>
<tr>
<td>BRIEF2 – BRI SS</td>
<td>6</td>
<td>55 (4.73)</td>
<td>6</td>
<td>45.53 (6.58)</td>
<td>-9.67 (5.21)</td>
<td>0.006; 1.86</td>
<td></td>
</tr>
<tr>
<td>BRIEF2 – MI SS</td>
<td>6</td>
<td>56 (5.33)</td>
<td>6</td>
<td>48.5 (5.05)</td>
<td>-7.5 (3.51)</td>
<td>0.003; 2.14</td>
<td></td>
</tr>
<tr>
<td>BRIEF2 – GEC SS</td>
<td>6</td>
<td>83.17 (5.60)</td>
<td>6</td>
<td>64.33 (6.53)</td>
<td>-18.83 (5.19)</td>
<td>&lt;0.001; 3.63</td>
<td></td>
</tr>
<tr>
<td>PSOC Total</td>
<td>5</td>
<td>68 (3.42)</td>
<td>5</td>
<td>79.8 (3.42)</td>
<td>11.8 (5.4)</td>
<td>0.008; 2.19</td>
<td></td>
</tr>
</tbody>
</table>

1Absolute Cohen’s d effect sizes calculated as Δ\text{time2} / Δ\text{time1}; small ≥ 0.2, medium ≥ 0.5, large ≥ 0.8

2Interpretation is reversed for results of the AAQ and the BRIEF scales. Higher scores indicate lower acceptance and lower behavioral flexibility, respectively.
outside class at least three times/week for about 10 minutes, a level of practice designated by others as “high” for CBCT [45].

**Limited efficacy testing**

Although our assessment of efficacy testing was limited and preliminary, there were significant improvements in all outcome variables: (a) a decrease in perceived severity of the child’s symptoms (ABC-I); (b) a decrease in parent stress (PSS, and four of five PSI scales) and an increase in acceptance (AAQ); (c) increase in empathetic concern (IRI subscale); (d) increase in behaviour flexibility (three BRIEF-A scales and MAAS); and (e) improved parent-child relationships (PSOC). Among the five parents of children with ASD who completed ABC, PSI and PSOC questionnaires, only one reported that her child had any changes in his intervention six months earlier, which suggests that these improvements were likely not associated with changes in their children’s intervention. We know as well that these results were not due to changes in the parents’ medication. Little can be said about maintenance of benefits as only four parents filled out follow-up measures. While these results are preliminary, we were able to estimate statistical parameters which will assist in determining optimal sample sizes for future studies. Overall, it seemed that for parents, meeting with other parents of children with ASD and a clinical psychologist for eight weeks while discussing CBCT brought some perceived benefits and was highly satisfying. This benefit is not the result of changes in the parents’ medication or their children’s intervention, as these remained constant.

**Limitations**

Two limitations for the generalizability of the study’s results are the small homogeneous sample size, and absence of a control group. The limited attendance even in view of the large demand must be addressed in future interventions. One possible explanation for the low attendance is that the intervention took place within a culture of parents seeking benefits for their children while ignoring their own needs, but who may not have realized that taking care of themselves may benefit those they care for. Furthermore, participants did not receive any compensation for their time, nor were they offered babysitting services for their children, nor was a remote tele-health option available as suggested by some parent-training studies [64].

The study lacked a scale of fidelity, which has now been developed for CBCT, as often used in RCTs to assess consistency. However, CBCT is highly standardized with manual-based protocols permitting consistent replication of the treatment by those who have undergone the rigorous teaching certification process. We were confident that procedures were consistent with the standardized manual because the lead teacher for all groups was a certified CBCT instructor with more than seven years of meditation practice with this protocol. The CBCT teacher training requires lifelong commitment to meditation practice and includes an eight-week introductory CBCT course, two one-week long retreats, an eight-week long practicum, and an eight-week long teaching assistantship.

**Conclusions**

In this study, we assess the feasibility of conducting CBCT with a community sample of parents of children with ASD. CBCT participants demonstrated significant improvements in acceptance of their child’s condition, executive functions, empathetic concern and the parent-child relationship. We also found a significant decrease in child’s symptoms and parenting stress. Overall results indicated that CBCT meets several criteria of feasibility for introduction into a clinical setting. Specifically, there was demand by parents for CBCT, as well an acceptance of and satisfaction with the intervention. This study adds to the literature of research that targets improving the mental health of these parents [19,20].

These preliminary findings suggest that CBCT holds promise as a practical approach to promote mental health and well-being in parents of children with ASD. In line with previous research we also found an improvement in the children’s symptoms by working only with parents. Recent research has suggested that mindfulness and compassion may constitute a neural training to strengthen the neural pathways underlying effective social engagement [65,66]. Further clinical investigation should explore the role of SG-MBI for ASD. Such interventions should always assess benefits in the children’s outcomes to help us better understand and treat ASD as a condition in which the full family system is involved. In the vast research on assessment and intervention for children with ASD, it is surprising how little attention has been given to the impact of the caregivers’ health and well-being on the course of treatment.

This study is novel in that it uses compassion meditation or CBCT as a stress-management technique. Eleven other studies have described mindfulness-based interventions for caregivers of individuals with ASD and, although some report benefits in compassion none employ specifically a SG-MBI or a compassion training protocol [20,39,40]. Previously published studies have reported benefits from CBCT, but none of these involved parents of children with ASD [67-69]. There are two complementary mechanisms that may explain how parents of children with ASD can benefit from training that includes mindfulness and compassion. First, the mindfulness part of the training leads to a greater control of mental processes and behavioral regulation. Second, the compassion component may enhance empathy and compassion in the parents, skills that may help them to connect with and take optimal care of themselves and their children.

Overall, we show that CBCT is feasible, that there is a demand, and that parents accept and are satisfied with the intervention. Our data also suggest that this intervention may decrease perceived symptoms of children with ASD, decrease parenting distress, increase acceptance of the child’s condition, increase parental cognitive flexibility, and improve parent-child interactions. The questionnaires we employed were not too demanding and we obtained useful psychometric information
that can provide a basis for future studies. Based on these preliminary results, a randomized clinical trial is now underway that includes additional behavioral and physiological measures to further explore feasibility and test the potential benefits of CBCT for parents of children with ASD.

Acknowledgments

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References


64. Vismara LA, Young GS, Rogers SJ. Telehealth for expanding the reach of early autism training to parents. *Autism Research and Treatment*. 2012.


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