

Evaluation of Acceptance and Commitment Therapy (ACT) for Mothers of Children and Youth with Autism Spectrum Disorder

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Abstract Mothers of children with autism spectrum disorder (ASD) often face high levels of stress. While there have been interventions for parents of children with ASD targeting their parenting skills, there have been fewer studies that aim to target the psychological or physical well-being of the mothers themselves. This study included mothers of children with ASD to cofacilitate acceptance and commitment therapy (ACT) to other mothers of children with ASD. The intervention consisted of one evening session and a full-day workshop, followed by a refresher session 1 month later. Of the 33 mothers that enrolled in the study, 29 attended all three sessions and completed the outcome measures. Significant changes were observed over time in terms of depression, stress, social isolation and physical health scores. Post hoc analyses showed reductions in stress and depression and improvements in physical health which were maintained at follow-up. Results suggest that a brief parent-facilitated ACT group intervention may be effective in improving the mental and physical health of mothers of children with ASD.

Keywords Psychological acceptance · Mothers · Autism spectrum disorder · Mindfulness · Acceptance and commitment therapy

Introduction

It is well recognized that parents of children with autism spectrum disorder (ASD) experience higher levels of stress than other parents and that they are at greater risk for mental health problems (Dykens et al. 2014; Estes et al. 2009; Miodrag and Hodapp 2010; Taylor and Warren 2012). Until this point, most of the research aimed at parents of children with ASD has been focused on parent interventions to directly benefit the child. Significantly less attention has been paid to interventions which target parent functioning separately from the needs of their child. Common parent-focused interventions include informal parent-led support groups, cognitive behavioral therapies, mindfulness-based therapies, and respite care (Neece and Lima 2016).

There are now over a dozen studies focused on the impact of mindfulness- and acceptance-based approaches and their impact on parent functioning for parents of children with a variety of disabilities (Whittingham 2014), with several of these studies focused on parents of children with ASD specifically (Cachia et al. 2016). The majority of these interventions are modifications of mindfulness-based stress reduction (MBSR; Kabat-Zinn 2003). A second approach, acceptance and commitment therapy (ACT), has been less frequently studied. ACT focuses on six key processes: acceptance, cognitive defusion, being present, self-as-context, values, and committed action (Hayes et al. 1999). While ACT does incorporate mindfulness, it relies less upon formal mindfulness practice than an intervention like MBSR. ACT may have particular relevance to parenting children with ASD; ACT can be particularly useful in caregiving situations that involve

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challenging aspects that may be unchangeable (Losada et al. 2015). It recognizes that caregiving can stir up negative emotions, which can lead parents to cope by avoiding these emotions. It proposes that the acceptance of negative emotions, rather than experiential avoidance, will lead to less emotional distress in the long term (Hayes et al. 1999) and offers parents an alternative way to relate to their emotional experience. It also helps them to take action and commit toward their personal values including self-care, something parents may neglect or sacrifice when faced with the stresses of parenting. It may also appeal to certain parents because it is framed more broadly than an intervention which strictly teaches mindfulness skills. Some parents may like the brief format of the group with a broad parenting focus.

Blackledge and Hayes (2006) published the first ACT intervention study targeted toward parents of children with ASD. In this project, 15 mothers and 5 fathers attended a two-day group ACT workshop, for a total of 14 h of therapy. During this workshop, participants were encouraged to reflect on their personally held values, participate in extensive cognitive defusion exercises, and engage in discussions about cognitive control strategies. Parents reported significant improvements in general distress, depression, and overall health scores from pretreatment to follow-up 3 months later.

Since the Blackledge and Hayes' (2006) study, two studies with small samples focused specifically on parents of children with ASD from Iran and India (Joeekar et al. 2016; Poddar et al. 2015), and both described reductions in depressed mood. Reid et al. (2016) completed a qualitative study with five mothers of children with an intellectual disability and challenging behavior. In this study, mothers reported increased emotional well-being, as well as a new mindfulness-based outlook on negative emotions and challenges. They also appreciated meeting others in a similar situation to themselves. Finally, Whittingham et al. (2016) demonstrated that a parent training intervention for parents of children with cerebral palsy containing 4 h of embedded ACT led to improvements in parent and child functioning. This study was the only randomized control trial (RCT), but it did not study the effects of ACT alone as ACT was integrated within a psychoeducational parenting program.

We were interested in building upon the original Blackledge and Hayes' (2006) study with a Canadian cohort of mothers of children and youth with ASD. This group was unique in two ways; although many groups have included primarily mothers as opposed to fathers, this group was targeted specifically toward mothers. In addition, facilitators of this group were parents of children with ASD themselves (two mothers and one father). Building upon a recent study completed by Dykens et al. (2014), which demonstrated that parents of children with developmental disabilities could be trained to become therapists delivering parent-targeted psychological interventions to other parents, we trained previous

group participants to become group facilitators. This paper reports on the clinical outcomes of this brief parent-facilitated ACT intervention.

Method

Participants

Participants were recruited through local autism service agencies and autism family organizations in a large urban setting and surrounding areas. Mothers of school-age children and adolescents (<22 years) living in the Toronto area with proficiency in English to complete measures and take part in the intervention were eligible to participate. In total, 33 mothers participated in one of three ACT groups held between June 2015 and February 2016, and of these, 29 provided completed questionnaires. Mothers were diverse in terms of sociodemographic and cultural background and in terms of child age and diagnosis (see Table 1). Notably, about one third of mothers had more than one child with ASD. Hence, child clinical and demographic information was based on each child with ASD, and not just one child per mother.

Procedure

Mothers were recruited for this intervention through information flyers distributed electronically by various organizations in the region providing autism services, and interested participants were invited to contact the research coordinator by telephone or e-mail. All mothers with children of age 3 to 21 with a diagnosis on the autism spectrum were eligible to participate, so long as they had sufficient English to participate in the group and complete the surveys. Potential participants were then screened for eligibility and offered additional information on the intervention and research component. Eligible and interested participants completed a consent form and baseline questionnaire in the week prior to attending the first day of intervention. Measures were completed again 1 month later, just prior to the “refresher” evening, and a third time 8 weeks after the “refresher” evening. Questionnaires were completed online. Participants received 50 dollars (Canadian) to support childcare and transportation costs, as well as 50 dollars (Canadian) honorarium for questionnaire completion at the three time points. This project was approved by associated hospital- and community-based research ethics boards.

Intervention Description

The ACT intervention involved the use of experiential group exercises with the aim of increasing defusion and acceptance of difficult thoughts and emotions arising from being a parent, enhancing a mindfulness stance and a transcendent sense of

Table 1 Parent and child demographic variables

Parent demographics	<i>N</i> = 29	Percentage
Age of parent		
Range	26–59	
Mean	44.76	
SD	6.86	
Marital status		
Not married (single, separated/divorced, widowed)	8	27.5
Language spoken at home		
English	24	82.7
Born in Canada		
Yes	16	55.2
Another child with ASD		
Yes	11	37.9
Child demographics*	<i>N</i> = 40	Percentage
Age of child		
Range	3–20	
Mean	10.40	
SD	4.36	
Gender of child		
Male	33	82.5
Female	7	17.5
Diagnosis		
Asperger syndrome	5	12.5
High functioning autism	10	25.0
PDD-NOS	2	5.0
Autism	23	57.5

*Numbers for child demographics based on all children with ASD in family

observer-self, and facilitating reconnection and commitment to one's values, including valued activities other than parenting. The intervention was delivered in a group format consisting of one evening session followed by a full-day session and a second “refresher” evening session 1 month later. This format was based on previous work adapting ACT exercises for group therapy among clinical and nonclinical populations, including individuals with chronic pain (Fung and Zurowski 2008), depression, anxiety, and HIV and mental health stigma (Fung et al. 2011; Fung and Zurowski 2016). The adapted intervention for parents of children and youth with ASD was first piloted in fall 2010 and facilitated by two psychiatrists (Fung and Zurowski) in collaboration with the first author, who had expertise in working with families of children with ASD. This was refined over the course of 3 years and four parent workshops with encouraging results, as reported by Lunsky et al. (2012).

In the first evening, parents were facilitated to get to know one another, oriented to the purpose and nature of the

workshop, and introduced to ACT concepts through a brief didactic presentation and two group exercises. Over the next day, through brief mindfulness exercises (e.g., *leaves-on-a-stream*) and additional ACT experiential activities, parents further refined their learning. A typical ACT experiential activity consisted of a paired or large group activity, followed by debriefing that linked the experience with ACT processes and parenting stress. For example, a single object was placed in the center of the group, and all participants were invited to make observations about it. During debriefing, we explored our capacity and natural tendency to “fuse”, forming evaluations, attributions, projections, and judgments about the object (e.g., “it feels lonely being in the center”). The identification of the fusion process was then related to the critical judgments we might form about ourselves and others including our spouses and children, as well as the experience of and reaction to judgments from others (e.g., “you should have parented your child better”). At the end of this day, parents made commitments to do something over the next month consistent with their values. Parents met 1 month later to report back on their progress working toward their values and reflecting on their efforts. The ACT model was reviewed and parents participated in a mindfulness activity and an ACT exercise on the self-as-context, ending with a closure activity. For further details on the intervention, see Fung et al. (2017).

Based on clinical observation and participant feedback on the cohesive in-group effect related to one of the facilitators being himself a father with a child with ASD (KF), all intervention groups in the current study were co-led by this father along with two mothers of children with ASD who were trained to become leaders as part of the study design. Both mothers had participated previously in the original ACT parent workshops described above, expressed interest in becoming involved, and subsequently received formal training to facilitate ACT exercises (Fung et al. 2017). This training included completion of 40 h of continuing education in ACT at a local university, in addition to 4 h of practical training with the senior facilitator (the father), as well as planning and debriefing meetings before and after each intervention group. One of these mothers was a registered nurse working in the field of developmental disabilities and the other worked as a family support worker in a community agency.

Measures

The depression and stress subscales from the Depression Anxiety Stress Scale (DASS-21; Henry and Crawford 2005) were used to assess perceived depression and stress experienced in the previous week. The 7-item subscales each provide a total score between 0 and 21, using 4-point Likert scale ranging from “did not apply to me at all” (0) to “applied to me very much, or most of the time” (3). In the current sample, the

depression and stress subscales had Cronbach alpha levels of 0.89 and 0.88 at baseline, respectively.

Isolation and health subscales from the Parenting Stress Index 4th edition (PSI-4; Abidin 1995) were administered to measure perceived social isolation and physical health. Items were rated on a 5-point Likert scale from “strongly agree” (1) to “strongly disagree” (5), yielding total scores for each subscale. Higher scores on the 6-item isolation subscale were indicative of greater social isolation from friends or family and having a small support network (e.g., “I feel alone and without friends”). The 5-item Health subscale assessed current physical health (e.g., “since I had my child, I have often been sick,” or “I have problems sleeping, and I often feel tired during the day”). Internal consistencies for the isolation and health subscales in the current sample were 0.80 and 0.88 at baseline, respectively.

Participants also completed an intervention satisfaction measure (e.g., workshop relevancy, helpfulness, usefulness). Nine items were measured on a 5-point Likert scale with 1 being “strongly disagree” and 5 being “strongly agree.” The nine scaled items were followed by open-ended questions asking participants to share their challenges attending the intervention, favorite aspects, ideas for changing the group, and other comments or concerns.

Data Analyses

Within-subjects repeated measures analysis of variance (ANOVA) evaluated change in outcome measures across the three time points (pretreatment, posttreatment, and follow-up). Significant results were followed by pairwise comparisons for pretreatment to posttreatment, pretreatment to follow-up, and posttreatment to follow-up with Bonferroni corrections applied. Only data from the 29 mothers who completed measures at all three time points were included in these analyses.

Results

Means and standard deviations of the study variables at pretreatment, posttreatment, and follow-up are shown in Table 2. Mauchly’s test indicated that the assumption of sphericity had been not been violated for any measures. ANOVA results identified that time had a significant effect on depression

($F(2, 54) = 9.76, p < 0.001, \eta_p^2 = 0.27$), stress ($F(2, 54) = 18.17, p < 0.001, \eta_p^2 = 0.40$), social isolation ($F(2, 54) = 4.36, p = 0.02, \eta_p^2 = 0.14$), and physical health ($F(2, 54) = 8.10, p = 0.001, \eta_p^2 = 0.23$).

Subsequent pairwise comparison results for outcome measures are presented in Table 3. Bonferroni-corrected contrasts revealed that depression, stress, and health significantly improved from pre to post and from pre to follow-up, although not between post and follow-up. Thus, a significant change was achieved postassessment and maintained at follow-up. Contrasts were not significant for social isolation scores, although there was a trend toward a significant change from pre to post ($p = 0.06$).

With regard to participant satisfaction, feedback forms were available for 16 workshop participants. The vast majority agreed or strongly agreed with the positively worded statements (e.g., “I thought the workshop content was of interest,” “I felt supported and valued throughout the workshop”), with an average of 94.5% agreement or strong agreement across the nine statements. Through the open-ended items, mothers described the workshop atmosphere as welcoming and warm and valued the opportunity to connect with others who had similar experiences. For example, one mother noted that she was “able to express without judgment,” and another mother appreciated “meeting other mothers in similar circumstances and bonding with them.” Multiple mothers reported that ACT concepts and tools were presented in a dynamic and comprehensible manner, and as one mother described, “information was presented in a manner that kept you waiting for the next spoken word....” The mothers perceived the program as a priority but also reported challenges in balancing workshop attendance with their full schedules and other logistical difficulties (e.g., securing childcare, transportation).

Discussion

This exploratory study adds to the growing literature on the benefits of parent-focused interventions on parent health and well-being. The current study suggests that ACT for parents is feasible, with ease of recruitment, excellent attendance, and high satisfaction ratings. In addition, changes were observed from pre to post and maintained over the short-term follow-up period for three of the four of the clinical outcomes targeted. Unique

Table 2 Outcome measures postintervention

Measure	Pre <i>M</i> (<i>SD</i>)	Post <i>M</i> (<i>SD</i>)	Follow-up <i>M</i> (<i>SD</i>)	<i>F</i> (<i>df</i>)	<i>p</i> value
DASS stress	12.14 (4.89)	8.79 (4.61)	8.04 (4.36)	18.17(2, 54)	<0.001
DASS depression	8.54 (5.41)	6.14 (3.97)	5.29 (5.07)	9.76(2, 54)	<0.001
PSI health	16.04 (5.20)	13.93 (4.02)	14.00 (3.98)	8.10(2, 54)	0.001
PSI isolation	18.36 (5.11)	16.32 (3.40)	16.54 (3.99)	4.36(2, 54)	0.02

Table 3 Pairwise comparisons from pre to post, post to follow-up, and pre to follow-up assessments on the outcome measures

Measure	Mean difference	Standard error	<i>p</i> value	Confidence intervals of the mean differences
DASS stress				
Pre to post	3.36	0.81	0.001	1.29 ± 5.42
Post to follow-up	0.75	0.60	0.669	−0.78 ± 2.28
Pre to follow-up	4.11	0.75	0.000	2.19 ± 6.02
DASS depression				
Pre to post	2.39	0.86	0.029	0.20 ± 4.59
Post to follow-up	0.86	0.63	0.550	−0.75 ± 2.64
Pre to follow-up	3.25	0.78	0.001	1.25 ± 5.25
PSI health				
Pre to post	2.11	0.59	0.004	0.61 ± 3.61
Post to follow-up	−0.07	0.62	1.00	−1.65 ± 1.50
Pre to follow-up	2.04	0.58	0.005	0.559 ± 3.51
PSI isolation				
Pre to post	2.04	0.81	0.054	−0.02 ± 4.10
Post to follow-up	−0.21	0.61	1.00	−1.76 ± 1.34
Pre to follow-up	1.82	0.84	0.116	−0.32 ± 3.96

features of this intervention were its short length, parent facilitation, and a focus specifically on mothers.

The majority of mindfulness- and acceptance-based parent intervention studies have focused on formal mindfulness training, typically MBSR, and are typically held weekly. Two challenges with such interventions are the emphasis on formal practice, which can be difficult for some parents to find time for, and also the ongoing time commitment over many weeks, when life can be unpredictable and when childcare coordination might be a challenge. The broader approach of ACT compared to MBSR or MBCT may appeal to parents who are interested in some support and skill building, but not as open to learning meditation. The requirement to commit to regular formal practice, which is part of MBSR or MBCT, is not as emphasized in ACT. A brief intervention model such as the one presented in this study may have better attendance than a group held over a longer period of time and still lead to some change in clinical outcomes. For example, even the additional 4 h of ACT offered to parents of children with cerebral palsy led to additional improvements not seen in parents who received a standard parent training intervention without the ACT component (Whittingham et al. 2016), suggesting that brief interventions may still have substantial impact. What has yet to be studied is whether the degree of change and the types of change observed in a briefer intervention are equivalent to what occur in more traditional mindfulness-based programs. It would be important to examine which type of intervention can best engage parents and which leads to better attendance and clinical outcomes in the short and long term. Ultimately, it will be important to determine how to best match interventions to parent characteristics.

Several studies have shown that interventions such as this lead to reduced stress and improved mental health, but no studies of ACT have measured self-reported physical health. The improvements in physical health we reported are similar to improvements reported in MBSR-based interventions (Grossman et al. 2004), but with less time commitment. It would be important to explore whether a brief intervention such as ACT could also lead to changes in objective physical health measures, such as cortisol ratings or blood pressure. Because ACT also focuses on values and increasing behaviors consistent with values, it is possible that through ACT, parents would commit to implementing more health behaviors which might be driving these changes, such as eating differently or prioritizing physical exercise. Anecdotally, several mothers reported at the 1-month follow-up that they had invested in such activities.

This study demonstrated that participation in a brief intervention may lead to improvement in social isolation among mothers of children with ASD. This is an important variable to study because of the sense of commonality with others that can benefit mothers. While the improvement observed in our study was small, it is possible that it would be more evident in a larger cohort. Similarly, it is also possible that the social isolation subscale underestimates the sense of social connection forged within the group itself, as its items tend to focus on relationships with individuals outside of the therapy group. An indication of the strength of social connection forged is reflected in the commitment that the cohort of women made to continue meeting monthly with each other to practice ACT after the intervention ended. This group continues to meet 1 year later, and future research may follow these women over the longer term.

While parent-to-parent models have proven successful in a support group setting (Singer et al. 1999), this study included trained parents as ACT facilitators. It would be important to compare clinical outcomes and group satisfaction in a similar group facilitated by nonparent clinicians or a combination of parent and nonparent clinicians. Including parents may not only be beneficial to participants, it is also one way to employ a group of individuals who may have difficulties becoming gainfully employed because of caregiving responsibilities. This was also discussed in the larger RCT of MBSR by Dykens et al. (2014). This approach of encouraging family caregivers to be teachers is increasingly recognized as important in the broader caregiving literature (The Change Foundation 2015). Future work should consider how to refine the parent training process and determine what teachable skills are required in order to successfully facilitate this type of intervention.

In contrast to studies targeted toward parents more generally, we opted to restrict our intervention to mothers and to frame it as such—“mom to mom.” Although mothers are more likely to participate in parent interventions than fathers (three previous studies in this field were 100% mothers, the fourth was 97%), the theme of motherhood was explicit for this group. It would be interesting to study whether there are unique benefits to bringing mothers together. For example, this type of group allowed mothers in different types of relationships or not in a relationship to feel more equal to one another. Thus, this format may potentially offer a unique way to foster a type of connection not otherwise possible, such as in a mixed-couples group.

Limitations

Several limitations need to be considered in interpreting the results of this initial pilot investigation. The follow-up period for the current study was only 8 weeks. It would be important to study whether changes are maintained over a longer period of time. Future research could also formally examine treatment fidelity with this model, which we did not do with this study, because the lead clinician also designed the intervention. Additionally, there was no active treatment control group. We do not know whether these same outcomes would have been observed in a group of mothers participating in a different type of intervention held over the same time period. Self-reported improvement and satisfaction may simply reflect the positive experience mothers had attending workshops in the presence of other parents, including parent facilitators, and may not be attributable to the actual content of the intervention. As well, clinical outcomes were all based on self-report, and future studies could include biological measures of health or stress. Although profiles of participating moms were diverse both culturally and socioeconomically, this study cannot comment on benefits for mothers who did not

participate, nor can it speak to the impact of a similar intervention on fathers or other caregivers. Finally, although there is some suggestion that unique features of this group (focus on moms, parents as facilitators) were beneficial, we would only know if this is the case if these components were explicitly studied. Additionally, with one father and two mothers co-facilitating, we do not know the impact of both types of parents as facilitators versus just mothers to mothers.

Taking these limitations into account, it is important to continue to develop, refine, and evaluate parent interventions because of the vital role parents play in the lives of their children and their potential to help one another. Lessons that can be learned through interventions where families are part of the research team can help to develop a family-centered practice agenda.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Ethics Statement This study was approved by the institutional IRBs at the University Health Network and Surrey Place Centre.

Informed Consent Informed consent was obtained from all participants included in this study.

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