AN EVALUATION OF ACCEPTANCE AND COMMITMENT THERAPY WORKSHOPS FOR PARENTS OF AUTISTIC CHILDREN

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Abstract

Emerging research shows that Acceptance and Commitment Therapy (ACT) may improve mental health for caregivers. This dissertation sought to understand outcomes and experiences for parents of autistic individuals following participating in a 3-day ACT group workshop. Workshops were co-led by other trained parents of autistic people and professional clinicians.

In Study 1, parents (*N*=54) were randomly assigned to either complete a brief group-based ACT intervention or remain on the waitlist. Participants completed surveys immediately prior to randomization, and 3-, 7-, and 17-weeks post-randomization. Mixed effects linear models testing group x time interaction indicated the Treatment group demonstrated greater post-intervention improvements than the Waitlist group in parent depression and family distress. Treatment group parents also reported greater short-term gains in positive affect and personal goal attainment, compared to the Waitlist group. Although there was no significant group x time interaction for other outcomes, stress, defusion, and experiential avoidance showed improvement for the Treatment group, but not the Waitlist group, at post-intervention. All Treatment group improvements were maintained at follow-up. Results suggested that a brief ACT group intervention is efficacious for improving some aspects of mental health for parents of autistic children.

In Study 2, 15 parents who had previously attended the ACT workshop participated in individual interviews, focusing on parents' experiences in a group with a co-facilitation model, and their perspectives about who should facilitate interventions for parents of autistic people. Using a qualitative thematic analysis approach, overall themes identified included the importance of a group environment in which trust is created through establishing credibility of the program and ensuring emotional safety. This environment allowed for parents to be able to fully participate in the workshop by sharing experiences, feeling open minded and hopeful, and focusing on what is important to them. Participants discussed behaviours, knowledge, and skills that they value in facilitators, that both parent leaders and professional clinicians can contribute, as well as emphasizing the unique value that the parent leader brought to the group. Findings lend themselves to developing best practices around creating effective and supportive interventions for parents of autistic people.

Dedication

For Ari. You give me the perspective I need to work hard at what's most important, and joy in all moments in between.

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To my endlessly supportive supervisor, Dr. Jonathan Weiss, thank you for the time and effort you put toward helping me grow as a researcher and clinician. I feel incredibly lucky to have had the benefit of your mentorship, guidance, and vision throughout this program. Most of all, thank you for your kindness and patience as I navigated this last chapter.

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Publication Disclosure

Study 1 was published under the citation below in May 2023. The article is included in this dissertation under Open Access from SAGE Publications Inc, allowing the embedding of full published journal articles in a dissertation, including where the dissertation will be posted in any electronic Institutional Repository or database, provided all re-use is non-commercial and appropriately credits the journal using the full citation information. Also see: *https://us.sagepub.com/en-us/nam/journal-author-archiving-policies-and-re-use*.

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Chapter One: Introduction

General Introduction

The Needs of Parents of Autistic Children

Parents of autistic children can experience high levels of stress, anxiety and depression, and levels of chronic stress have been shown to surpass levels experienced by parents of children with other developmental disabilities (Bitsika & Sharpley, 2004; Davis & Carter, 2008; Estes et al., 2009). Often, involving parents in interventions for autistic children is done with the aim of helping parents better support their children, such as teaching parents the same skills children are learning in social skills or mental health therapies to increase generalizability of learning (e.g., Karst et al., 2015; Reaven et al., 2015; Weiss et al., 2018) or providing interventions focused on parenting competence or skills (e.g., Kuravackel et al., 2018; Tellegen & Sanders, 2014). Notably, even when parent well-being is not the focus of intervention, parents of autistic children have been shown to report small improvements in their own positive coping and depression following participation in their children's therapy (Maughan & Weiss, 2017).

Parents raising an autistic child report a wide diversity of experiences. Rewards and positive impacts, such as learning through experiences, family closeness and strength, sense of meaning and personal growth (Kayfitz et al., 2010), feelings of great joy (Myers et al., 2009), and valuing their children's many strengths and positive traits (Cost et al., 2021) are reported when parents are asked. On the other hand, many parents report declines in well-being and functioning, possibly connected to the common experience of caring for their child involving having to majorly adjust or limit time spent in work, social, and personal activities (Meirsschaut et al., 2010). Parents can experience difficult thoughts and feelings that are a response to these real challenges and other stressful aspects of parenting, such as feeling isolated or disconnected from “a normal way of life” (Woodgate et al., 2008, p. 1078) and many of these challenges for parents can persist over the lifespan (Seltzer et al., 2011). The experience of parenting when a child has autism is multifaceted, and it follows that supporting parents to improve their own well-being would require parent-focused support that recognizes the complex nature of the experience.

The Acceptance and Commitment Therapy Approach

Acceptance and Commitment Therapy (ACT) is an intervention framework that focuses on helping individuals to develop awareness and acceptance of difficult experiences and commit to behaviours that are in service of their values (Hayes et al., 2006). The overall aim of ACT interventions is not to decrease psychological symptoms, problems, or distress, but to increase one’s effectiveness in pursuing values that are personally meaningful, even in the context of difficult symptoms or circumstances (Harris, 2006). Interventions using ACT incorporate experiential activities, mindfulness exercises, didactic teaching, and use of metaphor to illuminate concepts, with the aim of fostering the development of psychological flexibility, a key component of mental health and wellness that involves six core interrelated psychological processes (Hayes et al., 2006): *Acceptance* encompasses the process of experiencing painful thoughts, emotions, and private experiences, rather than avoiding them. The avoidance of thoughts or emotions is referred to as experiential avoidance. *Contact with the present moment* involves being mindfully present in the here-and-now, rather than focusing on the past or future. *Defusion,* in contrast to cognitive fusion, is the ability to observe one’s thoughts as separate from oneself, rather than reacting to them as though they are facts. *Self-as-context* is an awareness of and ability to access the part of the self that can observe one’s inner experiences without becoming invested in them. This allows one to detach from negative concepts about the self. The core process of *values* involves clarifying and connecting with one's personally held values that they hold most meaningful. The last process involves taking *committed action* toward these values, even when problems or symptoms arise (Hayes et al., 2006).

Interventions incorporating the ACT framework may be more relevant to parents of children with autism than therapy modalities that aim to decrease problems or symptoms, or that focus on problem-solving or altering thinking patterns. Not only has psychological acceptance been shown to be an important protective factor in the well-being of parents of autistic children (e.g., Jones et al., 2014; Weiss et al., 2012), but there is also evidence that these parents are prone to use more avoidance coping strategies (Sivberg, 2002), which is associated with more stress and mental health problems than other ways of coping (Hastings et al., 2005).

Interventions that incorporate ACT have begun to be used in some studies with parents of autistic children (for detailed reviews see Magnacca et al., 2021; Yao et al., 2023), with preliminary work demonstrating that ACT can reduce various markers of stress and depression in this group. Using within-subjects research designs, post-intervention improvements for parents have been demonstrated in depression, overall distress, avoidance, and cognitive fusion (Blackledge & Hayes, 2006); anxious symptoms and quality of life (Poddar et al., 2015); stress, perceived physical health, and social isolation (Lunsky et al., 2018); and cognitive fusion, psychological flexibility, and values-consistent action (Fung et al., 2018b). Little qualitative research has been conducted on ACT for parents of autistic children, but in one study, parents described in post-treatment interviews a better ability to cope with stress, increased emotional well-being for themselves and their child, and the ability to take a different, more mindful, perspective on their difficulties (Reid et al., 2016). Last, in the only randomized controlled trial (RCT) to date testing the efficacy of ACT for parents of autistic children, nine parents receiving

Applied Behaviour Analysis (ABA) participated in a 4-hour ACT workshop, compared to nine parents who received ABA only (Hahs et al., 2018). The ACT group demonstrated significantly greater improvements, compared to the ABA-only group, in self-reports of mindfulness, experiential avoidance, cognitive fusion, consistency toward personal values, and depression, but no follow-up measurement was employed.

Dissertation Overview

This dissertation aimed to contribute to the body of work on ACT for improving markers of mental health and well-being in parents of autistic children by addressing current research gaps in this area. First, ACT has not yet been evaluated in parents of autistic children using a randomized controlled design, to test the effects of ACT while controlling for time, with a large enough sample to both increase generalizability to the larger population of parents of autistic children and have sufficient power to detect small effects. Second, interventions using ACT for parents of autistic children may have benefits beyond the parent, to the child and broader family context, and studies testing its efficacy have not yet assessed these potential effects. Third, most of the studies evaluating ACT primarily involve mothers, and broadening the sample to include fathers is important to understand whether and how the ACT approach affects a broader group of parents of autistic children. Fourth, as ACT is meant to improve psychological flexibility processes and positive functioning while not necessarily decreasing symptoms, it is essential that evaluations of ACT include measurement of change in positive aspects of parent functioning as well, rather than focusing only on whether it reduces problems or deficits. Last, very little is known about what parents of autistic children prefer and experience regarding parent-focused supports, as there have been no studies that directly ask or interview parents about this topic. As more interventions are being developed and delivered to improve mental health in parents of autistic children, parent voices must be included in this process.

It is essential to better support the well-being of parents of autistic children by providing interventions that directly target parents themselves, and that are brief and accessible enough that it is realistic and feasible for parents to participate. Emerging studies on the ACT intervention are promising, and there is a need to build on this existing research on ACT to support its continued use in parents of autistic children. This dissertation approached this first, by using a larger-scale randomized trial of the ACT intervention to compare outcomes between the treatment and an untreated control group, and second, by exploring the perspectives and experiences of parents who participated in the intervention.

Study 1

In this dissertation, Study 1 tested the efficacy of a three-session ACT workshop developed for parents of autistic youth (Fung et al., 2018a), using an RCT design, for improving parent well-being, and child and family functioning. The manualized workshop, entitled 'Caring for the Caregiver' was developed by researchers and clinicians, with the first author also a parent of an autistic child. It was first delivered and tested using a repeated-measures design with mothers of children with autism (Fung et al., 2018b; Lunsky et al., 2018). Study 1 is the first RCT of this brief ACT intervention for parents of autistic children, and one of few studies of parent interventions more generally that include fathers as participants as well. The workshop used a co-facilitation model, in which each workshop was led by at least one parent of an autistic person, in addition to a professional clinician. Both types of facilitators were trained in delivering the ACT workshop, and parent-peer facilitators had additionally completed the workshop in the past as participants. The Treatment group that completed the program immediately following randomization was compared against a Waitlist control condition. The aims of Study 1 were to understand whether the ACT workshop was efficacious for improving mental health, positive functioning, and personal goal attainment in parents of autistic children; for improving the mental health of children of participating parents; and for improving overall family functioning, relative to the waitlist condition.

Study 2

In this dissertation, Study 2 used a qualitative study design to examine the experiences and perspectives of a subset of parents who had previously participated in the ACT workshop as part of the larger RCT. Following the completion of the RCT, 15 parents participated in semi-structured interviews about their experiences in the workshop, and about their perspectives on the intervention delivery model and facilitators. The first aim of Study 2 was to learn what is most important to parents of autistic people regarding the facilitators of their group interventions. The second aim was to understand how parents viewed the co-facilitation model of the ACT workshop, in which trained parents of autistic people and professional clinicians delivered the intervention together. A qualitative thematic analysis revealed constructs related to what parents of autistic people value in interventions in which they participate. From the qualitative data, a conceptual framework was created that outlined how facilitator qualities, skills, experiences, and behaviours affect the group environment and the overall experiences of participants, in ACT interventions for parents of autistic people.

Chapter Two: Study 1: Parent, Child, and Family Outcomes Following Acceptance and Commitment Therapy for Parents of Autistic Children: A Randomized Controlled Trial

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Abstract

Emerging research shows that Acceptance and Commitment Therapy (ACT) may improve mental health for caregivers. Parents of autistic children, adolescents, and adults (N=54) were randomly assigned to either complete a brief group-based ACT intervention or remain on the waitlist. Participants completed surveys immediately prior to randomization, and 3-, 7-, and 17-weeks post-randomization. The primary outcome was depression symptoms and secondary outcomes included stress, goal attainment, positive affect, ACT psychological processes, child mental health and family functioning. Mixed effects linear models testing group x time interaction indicated the Treatment group (n=27) demonstrated greater post-intervention improvements than the Waitlist group (n=27) in parent depression (p=.03, d=-0.64) and family distress (p=.04, d=-0.57). Treatment group parents also reported greater short-term gains in positive affect (p=<.001, d=0.77) and personal goal attainment (p=.007, d=0.80), compared to the Waitlist group. Although there was no significant group x time interaction for other outcomes, stress (b=-2.58, p=.01), defusion (b=-3.78, p=.001), and experiential avoidance (b=-4.22, p=.01) showed improvement for the Treatment group, but not the Waitlist group, at post-intervention. All Treatment group improvements were maintained at follow-up. Results suggest that a brief ACT group intervention is efficacious for improving some aspects of mental health for parents of autistic children.

Parent, Child, and Family Outcomes Following Acceptance and Commitment Therapy for Parents of Autistic Children: A Randomized Controlled Trial

Parents of autistic children[1] commonly experience greater levels of stress, anxiety and depression compared to parents of children who do not have a disability, and their levels of chronic stress have been shown to surpass levels experienced by parents of children with other developmental disabilities (Bitsika & Sharpley, 2004; Estes et al., 2009). Given the high stress experienced by parents of autistic children (Hayes & Watson, 2013), it follows that parents would experience their own challenges that require parent-focused support.

Acceptance and Commitment Therapy (ACT) has emerged as an intervention with a strong evidence base supporting its use for caregivers (Han et al., 2021). The ACT framework focuses on helping individuals improve psychological flexibility, which involves increasing openness and mindful awareness in the present moment, and acceptance of difficult experiences (Hayes et al., 2006). The overall aim of ACT is not to decrease psychological distress, but to increase one's effectiveness in pursuing values that are personally meaningful, even in the context of difficult symptoms or circumstances (Harris, 2006). In addition to rewards and positive impacts of raising an autistic child that many parents report (Kayfitz et al., 2010), parents of autistic children also describe making significant adjustments to their lives to support their child's care, such as career changes, or devoting very limited time to social or personal activities (Meirsschaut et al., 2010). They may have difficulty navigating inaccessible care systems, unsupportive social systems, or adjusting to a parenting experience that can involve a

[1] We recognize that there are many viewpoints with respect to selecting language to describe autism and other disabilities. We use identity-first language to reflect the preference of many autistic adults and their family members (Botha et al., 2023; Kenny et al., 2016).

high level of daily childcare demands (Meirsschaut et al., 2010). As a result, parents may experience difficult thoughts and feelings in response to these real challenges and stressors. Acceptance, therefore, may be a more appropriate framework than treatment modalities that focus on problem-solving. The use of psychological acceptance has also been shown to be an important protective factor in the well-being of parents of autistic children (Jones et al., 2014; Weiss et al., 2012). In addition, parents of autistic children report that they employ more avoidance coping (i.e., cognitive distancing/minimizing; escape behaviours) than parents of children without autism, which may be related to increased strain on the family system (Sivberg, 2002). Avoidance coping, although sometimes adaptive in the short term, is associated with increased stress and mental health problems over time (Hastings et al., 2005). As such, these parents may benefit from interventions that help decrease the use of psychological avoidance and promote psychological acceptance.

There is a growing literature demonstrating the effectiveness of ACT among parents of autistic children. In the first published study of ACT for parents of autistic children, Blackledge and Hayes (2006) delivered a two-day workshop to 20 parents. Participants demonstrated post-intervention improvements in self-reported depression, distress, experiential avoidance, and cognitive fusion. In another study, two 4-hour ACT workshops were delivered to five mothers of children with intellectual and developmental disabilities who displayed high levels of challenging behaviour (Reid et al., 2016). Analysis of post-intervention interviews revealed that parents reported a better ability to cope with stress, increased emotional well-being for themselves and their child, and the ability to take a more mindful perspective on their difficulties. In a multiple baseline repeated measures analysis of three mothers of autistic children who participated in six 90-minute sessions of ACT, parents increased in their use of values-guided behaviours (Gould et al., 2018) post-training and six months later.

In India, Poddar and colleagues (2015) delivered ACT individually to five mothers of autistic children over 10 sessions. Improvements in parent self-reports of depressive and anxious symptoms, psychological flexibility, and quality of life were noted post-intervention. In Iran, an 8-week group ACT intervention provided to 12 mothers was superior to 8 weeks of individual counselling for reducing self-reports of depression and experiential avoidance, although group assignment was not random (Joekar et al., 2016).

In a study with a slightly larger sample, Lunsky and colleagues (2018) delivered a brief ACT workshop to 29 mothers of autistic children and young adults. In addition to having ACT expertise, facilitators were also parents of autistic children. Post-intervention, improvements were seen in parents' self-reports of depression, stress, perceived physical health and social isolation, and improvements in all but social isolation were maintained at follow-up. A second study of this cohort reported that mothers also indicated improvements in cognitive fusion, psychological flexibility, and values-consistent action, which were maintained at follow-up (Fung et al., 2018b).

One of the only randomized controlled trials (RCTs) of ACT for parents focused on parents of children with cerebral palsy, where researchers added a 4-hour ACT training for parents who were already receiving a parenting intervention, compared to a randomly-assigned waitlist control group and a parent training only group. The addition of ACT training resulted in improved parent reports of child quality of life and reduced parental depression and stress, compared to the waitlist group (Whittingham et al., 2015). This study did not compare receiving only ACT to a control condition, making it difficult to determine the relative impact of ACT on the improvements observed. In the only RCT to date testing the efficacy of ACT for parents of autistic children (age 5-13), nine parents receiving Applied Behaviour Analysis (ABA) participated in a 4-hour ACT workshop, compared to nine parents who received ABA only (Hahs et al., 2018). The ACT group demonstrated significantly greater improvements compared to the ABA-only group in self-reports of mindfulness, experiential avoidance, cognitive fusion, consistency toward personal values, and depression, but no follow-up was employed.

ACT has yet to be evaluated in parents of autistic children using both a randomized controlled design and a large enough sample to increase generalizability to the larger population of parents of autistic children. Further, while there is evidence that in families of autistic children, parent-focused interventions can also serve to improve child behaviour and mental health (Neece, 2014; Singh et al., 2006; Singh et al., 2014) and family adjustment (Tonge et al., 2006), no studies have examined child and family outcomes following ACT interventions for parents. Finally, as ACT is meant to improve psychological flexibility and positive functioning while not necessarily decreasing symptoms, it is essential that evaluations of ACT include outcome measures which assess positive aspects of parent functioning as well, rather than focusing only on reduction of problems.

Aim

The current study tested the efficacy of a brief, manualized group-based ACT workshop developed for parents of children, adolescents, and adults[2] with neurodevelopmental disabilities, including autism. A randomized controlled design compared a Treatment group that completed the program immediately to a Waitlist control condition. The primary outcome was reduction in

[2] The term *children* will subsequently be used to refer to participating parents' autistic children, regardless of the age of the child, adolescent, or adult.

parent depression, and secondary outcomes included other aspects of parent mental health, positive functioning, and goal attainment. We also investigated the extent to which the intervention impacted the mental health of children of participating parents, and overall family functioning. We predicted that parents who were offered the ACT program would report improvements in their mental health, positive functioning, goal attainment, and in their child's mental health and family's functioning, relative to the waitlist condition.

Method

Participants

Participants included 54 parents of autistic children, adolescents, and adults ages 3 to 34 years. To be included in the study, parents had to provide documentation of their child's autism diagnosis from a health care practitioner qualified to diagnose autism in Ontario, Canada (i.e., clinical psychologist, pediatric/general practitioner physician, or psychiatrist). Additional inclusion criteria were the ability to speak English and identify therapy goals, and no prior exposure to ACT.

Program Description

The intervention was a three-session workshop based on ACT principles, developed by Fung and colleagues (2018b), and described in detail by Lunsky and colleagues (2018). The first session involved a 3-hour introduction to the ACT processes, and participants were introduced to mindfulness through an experiential guided imagery exercise. The second full-day session occurred the following day and included didactic, experiential, and mindfulness activities to demonstrate the concepts of ACT, and linked material to the experience of parenting an autistic person. Guided activities were interspersed with paired sharing, group discussion and videos. At the end of session 2, participants committed to engaging in one action that aligned with their values. A 3-hour refresher session was conducted one month later.

Measures

Sample Characteristics

The parent-report *Social Communication Questionnaire–Lifetime version* (SCQ; Rutter & Bailey, 2003) was used to measure autism symptoms. The parent-report *Scales of Independent Behavior–Revised* Short Form (SIB-R; Bruininks et al., 1996) measured adaptive functioning. The SIB-R uses a standard score (M=100, SD=15, Range: 0-200).

Primary Outcome

Depression. Symptoms of depression were measured using the 7-item Depression subscale of the *Depression Anxiety Stress Scale–21* (DASS-21; Lovibond & Lovibond, 1995). Item responses reference the past week and use a four-point scale (0=Never to 3=Almost Always). Subscale scores can fall into the ranges of normal, mild, moderate, severe, or extremely severe. These severity labels characterize the range of scores in the population; a mild score does not indicate mild level of disorder and is below the typical severity of those seeking help (Lovibond & Lovibond, 1995). Therefore, a “moderate” score (7 or higher) was used to define depression of clinical concern. Internal consistency for Depression was good in the current sample (α=0.89).

Secondary Outcomes

Parent Mental Health and Positive Functioning. The 7-item Stress subscale of the DASS-21 was used to measure symptoms of stress. Internal consistency was α=0.84 in the current sample.

Two subscales of the *Parenting Stress Index–Fourth Edition* (PSI-4; Abidin, 1995) were used. The 6-item Isolation subscale measures perceived social isolation and the 5-item Health subscale measures perceived physical health in relation to parenthood. Parents were asked to reference the past week. Items were rated on five-point scale (1=Strongly Agree to 5=Strongly Disagree). The PSI-4 has been previously used with parents of autistic children (Feinberg et al., 2014; Lunsky et al., 2018; Thullen & Bonsall, 2017). In this sample, internal consistency was acceptable (Isolation α=0.76, Health α=0.70).

The *Positive & Negative Affect Schedule* (PANAS; Crawford & Henry, 2004) is a 20-item measure that assesses respondents' experiences of different positive and negative emotions over the past week. Only the positive affect subscale was used, which has items that include 10 positive (i.e., active, determined) mood words, and respondents report the extent to which they experienced each mood over the last week (1=Not at all to 5=Extremely). The PANAS demonstrated excellent internal consistency in the current sample (α=.90 for Positive Affect) and in previous studies with parents of autistic children the Positive Affect subscale has been associated with other positive parental outcomes (e.g., optimism, psychological well-being; Ekas et al., 2010).

To assess goal attainment, at screening, participants identified three goals they hoped to attain through completing the workshop. At baseline, goals were refined with the assistance of a clinically-trained graduate student to ensure they were Specific, Measurable, Attainable, Relevant, and Timed, and *Goal Attainment Scaling*, a procedure typically used in rehabilitation intervention, was used to track progress (Bovend'Eerdt et al., 2009). For each goal, operationalized definitions were created to describe the participant's target behaviors if their goal was achieved (0), slightly exceeded (+1), greatly exceeded (+2), not quite achieved (-1) or nowhere near (-2), to create an individualized reference guide. At each assessment time point, participants were electronically sent their guide, which they referenced to select the number that represented their progress toward each goal.

For the analysis, participants' highest goal attainment score at each time point was used (i.e., the goal for which the participant indicated the highest achievement rating for could differ between time points). We analyzed participants' highest achieved goal (and thus the goal they were prioritizing) rather than totaling achievement of all goals, as the three goals may not have been considered equally important to participants. Focusing in on one priority goal allowed for examination of what meaningful change in one area could look like. Other research using goal attainment scaling has found utility in selecting the highest-ranking goal for analysis (Jennings et al., 2018; McGarrigle & Rockwood, 2020). To capture the effect of the program on whether goals were attained or not, the resulting values were dichotomized into 0 (*not quite achieved* or *nowhere near achieved*) and 1 (*achieved* or *slightly exceeded* or *greatly exceeded*). Past research on goal scaling has also analyzed reports in this manner (e.g., Jennings et al., 2018; Chiarello et al., 2020).

ACT Process Measures. The *Acceptance & Action Questionnaire-II* (AAQ-II; Bond et al., 2011) was used to measure psychological flexibility and acceptance. The AAQ-II is a 7-item questionnaire on which items are rated on a 7-point scale to provide an overall score. Higher scores indicate greater levels of acceptance and less experiential avoidance. The AAQ-II showed excellent internal consistency, α=.92. The AAQ and AAQ-II have been used previously in studies of parents of autistic children (Blackledge & Hayes, 2006; Hahs et al., 2018, respectively).

The *Valued Living Questionnaire* (VLQ; Wilson et al., 2010) is a two-part questionnaire that measures the extent to which respondents are in contact with their chosen values in everyday life. First, the participant indicates the importance they place on 10 life areas (e.g., friendship, work, spirituality), on a 10-point scale from Not at all important to Very important. In the second part, they indicate how consistent their actions currently are in each valued area on a 10-point scale, ranging from Completely inconsistent to Completely consistent. In this sample, the VLQ demonstrated acceptable internal consistency (Importance α=.69, Consistency α=.83, Valued Living Composite α=.76). The VLQ has been used in other studies with parents (Fung et al., 2018b).

The *Cognitive Fusion Questionnaire* (CFQ; Gillanders et al., 2014) is a 7-item measure used to assess the degree to which respondents report currently feeling distressed by, getting caught up with, or struggling to let go of thoughts. Statements are rated on a 7-point Likert scale (1=Never true to 7=Always true). Internal consistency was excellent in the current sample, α=.93. The CFQ has been used in studies of parents of autistic children (Hahs et al. 2018; Fung et al., 2018b).

The *Bangor Mindful Parenting Scale* (BMPS; Jones et al., 2014) is a 15-item questionnaire that measures parents' degree of mindfulness in their parenting and interactions with their children. Respondents rate items on a 4-point scale (0=Never true to 3=Always true). It has been used previously in studies of parents of children with autism and other disabilities (Lunsky et al., 2015). Internal consistency for the total score was α=.79 in the current sample.

Youth Mental Health and Family Functioning. The *Strengths & Difficulties Questionnaire* (SDQ; Goodman, 2001) assesses mental health difficulties broadly in children and youth. In line with SDQ guidelines, when administered at baseline, parents were asked to reference the past 6 months, and at subsequent time points the reference period was the past 1 month. The measure has subscales for Emotional Symptoms, Conduct Problems, Hyperactivity-Inattention, Peer Problems, Prosocial Behaviour, Impact, and Total Difficulties. Respondents provided item ratings on a 3-point scale (1=Not true to 3=Certainly true). Internal consistencies were acceptable for most subscales of the SDQ in the current sample, ranging from α=.69 to .72, except Peer Problems (α=.46). The SDQ is often used in studies of autistic children (Allik et al., 2006; Chalfant et al., 2007).

The *Brief Family Distress Scale* (BFDS; Weiss & Lunsky, 2011) was used to obtain a measure of the current level of crisis parents perceive in their family. Respondents indicate, on a scale from 1 to 10, which numbered statement most accurately represents the state of their family's current distress. Statements range from 1= *everything is fine, my family and I are not in crisis at all*, 5= *things are very stressful, but we are getting by with a lot of effort*, 10= *we are currently in crisis, and it could not get any worse*. The BFDS has been used in other studies of parents of children with developmental disabilities (Hastings, 2016; McKenzie et al., 2017).

The General Functioning subscale of the *McMaster Family Assessment Device* (FAD; Epstein et al., 1983) was used as a measure of family functioning over the past two weeks. Responses for each of the 12 items are provided on a 4-point scale, ranging from Strongly agree to Strongly disagree. This tool has been used in parents of children with disabilities (Brown et al., 2015) and had good internal consistency (α=.82) in the current sample.

Procedure

Recruitment

The study was approved by ethics boards at York University, the Centre for Addiction and Mental Health, and Surrey Place in Toronto, Ontario. This study was registered prior to data collection with the ISRCTN registry (97093664). See Supplemental Table 1 for the CONSORT Checklist. Participants were recruited from postings on websites of child autism community agencies, autism service e-newsletters, and referrals from the community between January-November 2019. Interested parents were invited to participate in a telephone screening interview to assess eligibility. For participants who met screening criteria, study procedures were explained, and written informed consent was obtained. As shown in Figure 1, 77 participants were screened, with 7 excluded for not meeting inclusion criteria, and 7 declining to participate. Power analyses using G*Power 3.1 indicated that a sample size of 55 would be sufficient to detect medium effects. No participants reported experiencing harm from participation in the trial.

Randomization

Following the baseline appointment, the first author randomized parents into either the Treatment or Waitlist group using online randomization software (Urbaniak & Plous, 2015). Participant randomization was stratified by gender, to ensure approximately equal numbers of males and females in each group. Sixty-three participants were randomized. If partners participated together, one was randomly excluded from the analysis (n=9), leaving 27 in each group. Parents in the Treatment group participated in their assigned ACT workshop within two weeks. Waitlisted parents participated in the intervention after the follow-up time point.

Study Design

Following participant screening, baseline data were collected within two weeks prior to the commencement of the workshop. Parents completed demographic and evaluation measures online, and goals were defined during a phone appointment. Child social communication abilities and adaptive functioning were assessed at baseline; the SCQ was administered online, and the SIB-R was completed during the phone appointment in interview format.

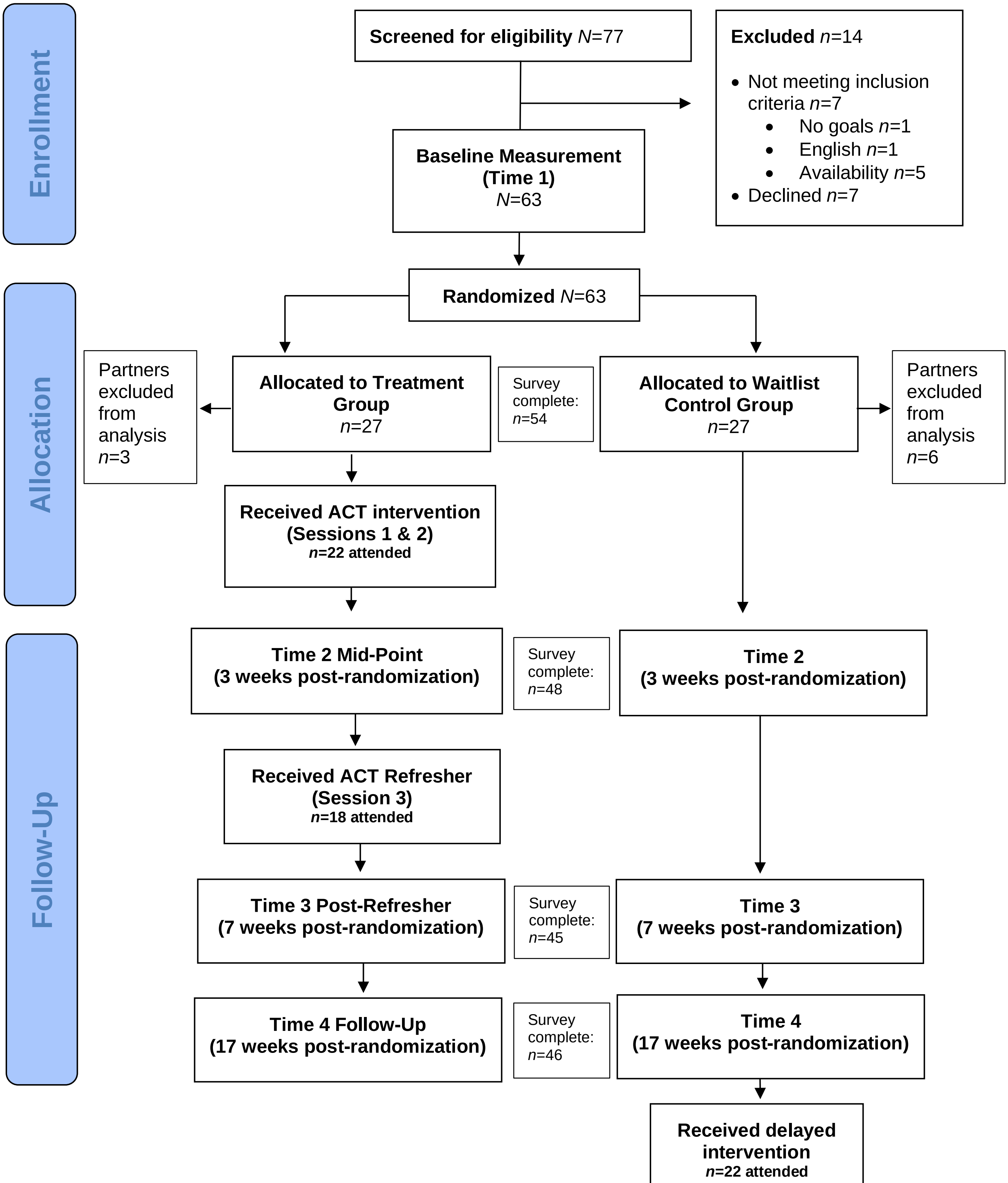
All outcome measures (DASS-21, PANAS, PSI-4, AAQ-II, VLQ, CFQ, BMPS, BFDS, FAD, SDQ, goal attainment) were administered online at 7-weeks post-baseline (post-refresher/ Time 3) and 17 weeks post-baseline (follow-up/Time 4). The primary outcome measure (DASS-21 Depression), as well as four additional brief measures (DASS-21 Stress, PANAS, BFDS, goal attainment) were re-administered at the mid-point of treatment (3 weeks post-randomization/Time 2). These measures were selected to obtain a brief snapshot of four areas of functioning (i.e., mental health, positive functioning, family distress, and behaviour change) immediately after the first two intervention sessions/wait. Following Time 4 data collection, the Waitlist group participated in the intervention.

Community Involvement

Families of autistic individuals were involved in this study. Parents of autistic people designed the intervention (Fung et al., 2018a) and co-facilitated every workshop, working in partnership with clinicians. No autistic people were involved in the research process.

Figure 1

CONSORT Flow Diagram



Data Analysis

Using SPSS version 27, we performed a series of linear mixed effects regression analyses at each post-treatment time point of the relationship between Group and each outcome measure (DASS-21 Depression, DASS-21 Stress, PANAS, PSI-4, AAQ-II, VLQ, CFQ, BMPS, BFDS, FAD, SDQ). As fixed effects, we entered Group (Treatment/Waitlist), Time (2 levels: Baseline and Time 2 or 3), and Group x Time interaction into the model. The interaction directly tested whether Treatment and Waitlist groups showed a different pattern of change in outcome measures at the different study time points. As random effects, we included an intercept for subjects to account for repeated measurements. Mixed effects models accommodate for missing values using the maximum likelihood method, and therefore, this analysis included all randomized participants (N=54 [9 partners excluded]).

Cohen's *d* effect sizes were calculated using the difference in change scores between Treatment and Waitlist groups, divided by the pooled standard deviation at baseline. Effect size magnitudes were defined as: negligible (<0.20), small (0.20-0.49), medium (0.50-0.79), and large (≥0.80) (Cohen, 1992).

Differences between the Treatment and Waitlist groups in their goal attainment (i.e., goal achieved/not achieved) was tested using Pearson chi-square analyses. Missing goal attainment values were imputed in SPSS using multiple imputation, including all demographic variables, baseline scores, and variables in the analysis as predictors. Chi-squared values from 10 imputed datasets were pooled in R using the MIcombine.chisquare function from the miceadds package (Enders, 2010). This function produces a combined statistic, which is approximately F-distributed. Odds ratio was used as the effect size measure.

Two analyses included treatment completers only from the Treatment group (n=18), who completed the full 3-day intervention with refresher, in addition to all Waitlist participants (*n*=27). First, for depression, the number of participants in each group who moved from the clinical to non-clinical range was calculated at Time 2 and Time 3. The interaction between Group and improvement to the non-clinical range was tested using Pearson chi-square analyses. Second, to assess whether improvements were maintained at 4-month follow-up (only possible for the Treatment group), linear mixed effects regression analyses were performed on treatment completers (*n*=18) with Time (2 levels: Time 3 and Time 4) as the fixed effect, and subjects' intercept as a random effect.

Results

Baseline Demographics

There were no significant differences in participant characteristics at baseline (see Table 1). Participants were 83% female, two thirds had completed university, and approximately one third were currently taking psychotropic medication. All 54 participants completed the survey at Time 1. At Time 2, 48 participants completed the survey (88.9%), at Time 3, 45 participants (83.3%), and at Time 4, 46 participants (85.2%).

Table 1

Group Differences in Parent and Child Characteristics at Baseline

Variable	Treatment *n*=27	Waitlist *n*=27	*t* or χ^2	*p*
Parents				
Age *M* (*SD*)	47.11 (7.66)	49.56 (9.80)	t=-1.02	.31
Range	36-66	32-69		
Sex *n (%)*			χ^2=1.20	.27
Female	24 (88.9%)	21 (77.8%)		

Male	3 (11.1%)	6 (22.2%)		
Marital status *n* (%)			χ^2=0.91	.34
Married/common law	19 (70.4%)	22 (81.5%)		
Single/divorced/separated	8 (29.6%)	5 (18.5%)		
Current sleep/psychotropic medication			χ^2=4.21	.12
Yes	6 (22.2%)	12 (44.4%)		
No	20 (74.1%)	12 (44.4%)		
Missing	1 (3.7%)	3 (11.1%)		
Current individual/group/family therapy			χ^2=4.60	.10
Yes	8 (29.6%)	4 (14.8%)		
No	10 (37.0%)	16 (59.3%)		
Missing	9 (33.3%)	7 (25.9%)		
Ethnicity *n* (%)			χ^2=8.36	.40
Chinese	2 (7.4%)	2 (7.4%)		
East Asian	0	1 (3.7%)		
Filipino	0	1 (3.7%)		
South Asian	0	2 (7.4%)		
Black	1 (3.7%)	0		
White	20 (74.1%)	19 (70.4%)		
Latin American/Hispanic	1 (3.7%)	0		
Other/Prefer not to answer	3 (11.1%)	2 (7.4%)		
Education *n* (%)			χ^2=1.89	.26
High school graduate	1 (3.7%)	1 (3.7%)		
Graduated college	6 (22.2%)	5 (18.5%)		
Some university	2 (7.4%)	3 (11.1%)		
Graduated university	10 (37.0%)	7 (25.9%)		
Post-graduate degree	8 (29.6%)	11 (40.7%)		
Household income (CAD) *n* (%)			χ^2=3.18	.53

<$50,000	2 (7.4%)	2 (7.4%)		
$50,000-$99,999	8 (29.6%)	6 (22.2%)		
$100,000-$149,999	5 (18.5%)	5 (18.5%)		
≥$150,000	10 (37.0%)	8 (29.6%)		
Prefer not to answer	2 (7.4%)	6 (22.2%)		
Children				
Age *M* (*SD*)	15.07 (7.92)	14.07 (7.77)	t=0.47	.64
Range	3-34	3-27		
Sex *n* (*%*)			χ^2=1.03	.31
Female	7 (25.9%)	4 (14.8%)		
Male	20 (74.1%)	23 (85.2%)		
Years since autism diagnosis *M* (*SD*)	7.26 (7.80)	8.35 (7.11)	t=-0.47	.64
Range	0-33	1-22		
Ethnicity *n* (*%*)			χ^2=5.02	.66
Indigenous	0	1 (3.7%)		
Chinese	1 (3.7%)	1 (3.7%)		
South Asian	0	2 (7.4%)		
Black	1 (3.7%)	0		
White	22 (81.5%)	21 (77.8%)		
Other/prefer not to answer	3 (11.1%)	2 (7.4%)		
SIB-R Standard Score *M* (*SD*)	75.63 (27.75)	63.41 (36.64)	t=1.38	.17
Range	12-118	0-124		
SCQ Total Score *M* (*SD*)	18.56 (6.81)	19.78 (5.73)	t=-0.71	.48
Range	6-32	11-29		

SIB-R Scales of Independent Behaviour–Revised; *SCQ* Social Communication Questionnaire.

Primary Outcome

Depression

At Time 2 (mid-point), following the main two-day workshop, parents in the Treatment group demonstrated significant reductions in depression scores (b=-3.21, p=.001), whereas these improvements were not seen for the Waitlist group (b=0.46, p=.51), with a large Time x Condition interaction (see Table 2). At Time 3 (post-refresher), the Treatment group showed sustained reductions in depression scores (b=-2.60, p=.03) and the Waitlist continued to show no reduction in depression (b=0.08 p=.88), with a medium Time x Condition effect.

In the Treatment group, 18 participants completed the full 3-day intervention, including the refresher. Improvements observed in the Treatment group were maintained at 4-month follow up, with no differences among treatment completers between Time 3 and Time 4 depression scores (b=-0.14; p=.90; see Supplemental Table 2 for Time 4 analyses).

Improvement from Clinical to Non-Clinical Range. Out of 18 treatment completers, 12 had depression scores in the moderate or higher range at baseline. Of the 12, 10 parents entered the non-clinical range for depression by Time 2 (83%), and 8 remained non-clinical by Time 3 (67% improvement). In the Waitlist group, none of the 10 participants who were in the clinical range at baseline moved to the non-clinical range at Time 2, and 3 became non-clinical by Time 3 (30%). At Time 2, there was a significant interaction between Group and moving to the non-clinical range (χ^2 (1)=15.28, p=<.001), which attenuated by Time 3 (χ^2 (1)=2.93, p=.09). By Time 3, two Waitlist participants originally in the non-clinical range moved to a clinical score on the depression subscale, as did one Treatment group participant.

Table 2

Primary Outcome for Treatment and Waitlist Groups from Baseline Using Linear Mixed Effects Model

Measure	EMM (SE)		Time x Condition Effect	*p*	*d*
	Treatment	Waitlist			

DASS-21 Depression					
Baseline	7.12 (0.95)	5.48 (0.57)			
Time 2	3.91 (0.57)	5.95 (0.87)	$F(1, 48.31)=10.53$	**.002**	-0.87
Time 3	4.53 (0.97)	5.56 (0.82)	$F(1, 48.08)=5.02$	**.03**	-0.64

DASS-21 Depression Anxiety Stress Scale.

Secondary Outcomes

Parent Mental Health & Positive Functioning

Values for between-group analyses for all secondary outcomes can be found in Supplemental Table 3. There was no significant Time x Condition effect for stress at Time 2 or Time 3. At Time 2, while the Treatment group did not have a significant reduction in stress from baseline, there was a trend toward reduction (b=-1.67, p=.07), which was not observed in the Waitlist group (b=0.22, p=.80). At Time 3, significant improvements in stress from baseline were observed in the Treatment group (b=-2.58, p=.01), but not for the Waitlist group (b=-0.99, p=.17). At follow-up, maintenance of the improvements in stress between baseline and Time 3 was seen, with no significant changes from Time 3 to Time 4 for treatment completers (b=0.67, p=.43).

At Time 2, there was a significant Time x Condition interaction for positive affect, with a small effect size. The Treatment group showed an increase in positive affect (b=2.76, p=.02), whereas the Waitlist group had lower positive affect at Time 2 (b=-2.95, p=<.001). At Time 3, there was no treatment effect observed for positive affect.

At Time 3, there was no significant Time x Condition interaction for parenting stress-related health, but there was a trend toward more improvement in the Treatment group (b=-0.89, p=.16) than the Waitlist group (b=0.84, p=.20). For isolation, there was no Time x Condition effect, nor any within-group change for either group.

Goal Attainment. At Time 2, 81.9% of the Treatment group had met at least one of their goals, compared to 43.0% of the Waitlist group, and there was a significant association between Group and goal attainment, $F(1, 461.41)=7.47$, $p=.007$, $d=0.80$. Based on the odds ratio, the odds of achieving or exceeding one's goal was 5.99 times higher if in the Treatment group than in the Waitlist group (95% CI:1.73, 20.70). This association was not present at Time 3, $F(1, 394.16)=1.45$, $p=.23$, $d=0.33$ or at Time 4, $F(1, 637.51)=0.12$, $p=.73$, $d=0.09$. At Time 3, 75.2% of the Treatment group was achieving or exceeding their goal, compared to 58.1% for the Waitlist group.

ACT Process Measures

There was no Time x Condition effect for any ACT process measures. Looking at within-group change for each group, improvements were observed in the Treatment group for experiential avoidance ($b=-4.22$, $p=.01$) and cognitive fusion ($b=-3.78$, $p=.001$), whereas none were observed for the Waitlist group ($b=-0.86$, $p=.56$ and $b=-2.03$, $p=.11$ respectively). There was no significant within-group change for valued living or mindful parenting at Time 3 for either group. At 4-month follow-up, maintenance of the Treatment group's improvements between baseline and Time 3 was seen for experiential avoidance. While not significant, there was also a trend toward further improvement ($b=-2.76$; $p=.07$). There was change observed in cognitive fusion, indicating further improvements since Time 3 for the Treatment group ($b=-2.44$, $p=.04$).

Family Functioning and Youth Mental Health

Between baseline and Time 2, being in the Treatment group was associated with reductions in family distress ($b=-1.09$, $p=<.001$), not seen for the Waitlist group ($b=-0.31$, $p=.13$). The Time x Condition effect was significant with a small effect size. At Time 3, a medium Time x Condition effect was seen for family distress, with parents in the Treatment group (*b*=-1.00, *p*=.001) demonstrating greater improvement compared to the Waitlist group (*b*=-0.10, *p*=.77). At 4-month follow-up, maintenance of the improvements in family distress between baseline and Time 3 was seen, with no significant changes from Time 3 to Time 4 for treatment completers (*b*=0.05, *p*=.77). There was no within-group change or Time x Condition effect for general family functioning or youth mental health.

Discussion

The current study used an RCT design to test the efficacy of a brief, group-based ACT intervention for mothers and fathers of autistic children, adolescents, and adults. Overall, the intervention resulted in gains for parents, with the greatest treatment effects observed for parent depression and family distress, which were maintained at the four-month follow-up. Parents also reported short-term gains with respect to personal goal attainment, and small changes in positive affect. Although there was no significant Group x Time interaction for stress, cognitive fusion, and experiential avoidance, all these outcomes showed improvement, with small effect sizes, for the Treatment group at post-intervention, while the Waitlist group did not improve; these within-group changes were also maintained at follow-up. Parents did not report any significant improvements with respect to mindful parenting, valued living, overall family functioning, or child mental health.

Parent Mental Health & Positive Functioning

The most consistent treatment effect was seen for parent depression. These findings align with previous studies of ACT for parents of autistic people (Blackledge & Hayes, 2006; Joekar et al., 2016; Lunsky et al., 2018; Poddar et al., 2015), wherein parent self-reports of depression decreased post-intervention. In our study, 67% of Treatment condition participants with clinical levels of depression were in the normal range at Time 3, compared to only 30% of those in the Waitlist condition. While Blackledge and Hayes had some evidence for cognitive defusion as a mediator for depression improvements, and studies of ACT in other populations also show post-treatment defusion mediating changes in depression (Zettle et al., 2011), our sample showed less change in defusion than found in prior research. Fung and colleagues (2018b) did report that post-ACT intervention improvements in mental health for mothers of autistic children were mediated by improvements in values-consistent action. Although our sample did not show change in their reports of how consistently they acted in accordance with their values, they did in action toward individually-set goals, which could underlie the changes in depression observed. Additional research with a larger cohort of participants would help to better elucidate the relationship between valued living, goals, cognitive fusion, and depression in parents of autistic youth.

Conversely, no significant differences between groups for stress were reported. Parents of autistic children can experience chronic stressors, including high levels of mental health problems in their autistic youth (e.g., Simonoff et al., 2008). Indeed, in the current study, the average child mental health problems score was in the "very high" range, including specific conduct problems ranging from "raised" to "high," and the overall impact of these problems in the "very high" range. These family characteristics may require targeted interventions before pronounced differences are seen in parents' personal experience of stress.

Parents who participated in ACT had greater increases in positive affect compared to the Waitlist group at Time 2, though the effect was small and dissipated by Time 3. The link between positive affect and perceived social support in parents of children with disabilities has been repeatedly demonstrated (Findler et al., 2016; Smith et al., 2012), and it follows that positive affect would increase immediately after an intensive workshop designed to allow parents with similar experiences to connect. This may not have been maintained as time passed, without sustained social connections or ongoing engagement with the material.

Goal attainment, similarly, showed a large group difference at Time 2, which was no longer apparent at Time 3. At Time 2, the Treatment group was six times more likely to report achieving or exceeding one of their goals, with 82% of the Treatment parents and only 43% of the Waitlist parents indicating goal achievement. Recent research on goal attainment indicates that ongoing progress is most likely when goals are set just slightly out of reach, balancing challenge while preventing discouragement (Chevance et al., 2021). Further, ACT encourages parents to shift their behaviour to align with their most closely held values. Since many Treatment group participants had already achieved or exceeded their highest-rated goal just after the workshop weekend, they might have benefitted from re-setting their goals higher after reaching them, or based on values they identified and prioritized in the workshop. Last, as the highest-rated goal may have differed at different time points, we cannot say whether attainment of a particular goal was maintained for each participant at subsequent measurement times, only that many reported attaining at least one of their goals.

ACT Psychological Processes

In terms of the four ACT psychological processes, cognitive fusion and experiential avoidance showed small improvements in the Treatment group only, though not to a degree that resulted in a Group x Time interaction, and there was no change in mindful parenting or valued living. As shown in other studies of ACT interventions, some process-related changes take several months to become evident, particularly with respect to behaviour change (González-Menéndez et al., 2014; Kohtala et al., 2017). Further, for mindfulness-based interventions, there is a strong relation between degree of mindfulness practice at home and amount of improvement in mindfulness and well-being (Carmody & Baer, 2008; Greenberg et al., 2018; Parsons et al., 2017). Published ACT manuals emphasize the importance of home practice (Hayes, 2005), and it is generally established that practice is beneficial to maximize effects of psychotherapy in general (Hoet et al., 2018). A weekly format with regular homework check-ins, or individual support, might support more practice and therefore greater change in behaviour.

Family Functioning & Child Mental Health

More distal outcomes of family functioning and child mental health were also assessed. There were strong consistent treatment effects for family distress (BFDS). Although the intervention is not intended to attenuate family crises, participants in ACT are encouraged to change their relationship to their internal and external experiences. The BFDS asks parents to provide a broad appraisal of how difficult their current situation is and post-intervention, parents might have appraised their circumstances in a different light. It is also possible that reductions in distress occurred following experiences that were not sufficiently captured in our process measures. For instance, participants engaged in positive, supportive, and relaxing activities, possibly providing a sense of greater ability to cope with stressors or a temporary sense of relief, translating into shifts in their experience of distress. Further, through engaging with fellow group members in similar situations, and sharing experiences of distress, it is possible that participants received important informal social support that helped them to manage the stressors in their lives. Results do not support the hypothesis that a brief ACT workshop would result in changes in more general family functioning and child mental health. The factors affecting mental health problems are complex and multifaceted, with many unrelated to parenting behaviour or parent mental health and requiring more direct management to result in improvement (White et al., 2018).

Strengths & Limitations

This study had many strengths. This was one of only two RCTs testing the efficacy of ACT for improving well-being in parents of autistic children, allowing us to elucidate treatment effects of ACT while controlling for time and repeated measurements. In addition, the inclusion of a follow-up assessment ensures that longer-term program effects are captured. The heterogeneity of the sample, in terms of including fathers, as well as parents of autistic children spanning a range of ages, socio-communication functioning, and adaptive skills, is also a strength, and improves generalizability of findings to more parents of autistic people.

There are also key limitations to our study. Participants were recruited mainly through autism service agencies, and many were already receiving supports and services for their child, which may limit generalization to families who do not have any support, or who are unwilling to potentially wait 4 months to receive the program. Twenty-two Treatment group participants completed the main intervention weekend, and four were unable to attend the refresher one month later, leaving only 18 full "treatment completers." Additionally, all outcomes were assessed through subjective parent report, which could potentially influence the validity of results or limit some effects of the intervention being captured. Further, the high average level of household income and parent education, limited racial/ethnic diversity, and relatively low levels of parent mental health problems in this cohort limits the conclusions that can be drawn regarding the effect of ACT for parents with less education, with varying cultural backgrounds, or with greater need.

Conclusion

Given the higher levels of distress experienced by parents of autistic individuals compared to parents who do not have a child with a disability (Keenan et al., 2016), it is crucial to identify brief, effective and accessible supports. This study aligns with the growing body of research that suggests that ACT can benefit parents across multiple domains. Important next steps are to understand more about parents' experiences in the workshop to learn which aspects of the intervention are most useful. This might include a measure of social connection in the group. Future trials might also compare different modes of intervention delivery (i.e., weekly versus brief intensive format, in-person versus virtual delivery) as well as the effect of practice or longer-term support, on outcomes. Additionally, studies may consider implementing assessments of children and families from a secondary reporter, such as a teacher or other parent, or youth self-report. Lastly, it would be important to include a longer follow-up time point in additional RCTs of ACT.

Chapter Three: Study 2: What Matters about Group Facilitators of Parent Interventions and Why? Experiences of Parents of Autistic People

Abstract

Group interventions to support well-being are emerging for parents of autistic children, youth, and adults. While studies of parent interventions have implemented various models of facilitation, including groups led by parent-peer facilitators, and those led by professional clinicians, there has been no investigation into how parents experience different facilitation models or what is important to parents about the facilitators of their groups. Using a qualitative research approach (thematic analysis), 15 parents who had previously attended 3-day Acceptance and Commitment Therapy (ACT) group workshops, which were co-led by trained parents of autistic people and professional clinicians, participated in individual interviews. Interviews focused on parents' experiences in a group with a co-facilitation model, and their perspectives about who should facilitate interventions for parents of autistic people. Overall, participants described the importance of a group environment in which trust is created through establishing credibility of the program and ensuring emotional safety. This environment allowed for parents to be able to fully participate in the workshop by sharing experiences, feeling open minded and hopeful, and focusing on what is important to them. They discussed behaviours, knowledge, and skills that they value in facilitators, that both parent leaders and professional clinicians can contribute, as well as emphasizing the unique value that the parent leader brought to the group. Findings are discussed as they pertain to creating effective and supportive interventions for parents of autistic people.

What Matters about Group Facilitators of Parent Interventions and Why? Experiences of Parents of Autistic People

As the importance of addressing the mental health and wellness of parents of autistic children has received more attention, therapies have been developed, most often administered by professional clinicians (e.g., Blackledge & Hayes, 2006; Reid et al., 2016). There have also been interventions that are facilitated or co-facilitated by other parents of autistic people (e.g., Dykens et al., 2014; Lunsky et al., 2018). Studies evaluating programs with a peer model report that participants can take advantage of parent-to-parent rapport provided by peer facilitators, and that peer facilitators seem to be able to easily understand and relate to participants' experiences (Dykens et al., 2014). Involving a parent facilitator who has lived experiences parenting an autistic child could be especially helpful in interventions for parents of autistic people, because these parents often report difficult experiences with professionals (Osborne & Reed, 2008).

There have been different ways of implementing a combined peer-professional intervention model for parents of autistic people. One approach involves trained parent-peers delivering the intervention to participants, along with some professional or clinician support. For example, Dykens and colleagues (2014) compared the efficacy of a brief mindfulness program to a positive psychology intervention for improving distress in mothers of children with autism and other neurodevelopmental disabilities; both programs were facilitated by trained peer mentors. Similarly, Hock and colleagues (2022) implemented a parent-peer-delivered co-parenting program for parents of children recently diagnosed with autism, in which the facilitators were solely parent-peers, who had been trained and supported by study researchers and clinicians. Other studies use clinicians only to deliver interventions but incorporate "parent advisors," that is, trained parents who are present and contribute during sessions. In one such example, Lunsky and colleagues (2021) had professional clinicians deliver a mindfulness-based workshop to parents of autistic people, with parent advisors present for all sessions, participating in exercises and sharing their experiences.

In another approach, Lunsky and colleagues (2018) provided an Acceptance and Commitment Therapy (ACT) intervention designed to support parents of autistic children, in which the workshop was co-created by parents of autistic people along with professional researchers and clinicians (Lunsky et al., 2018). Parent-peer facilitators, who had previously participated in the workshop and were subsequently trained, delivered the program to mothers of autistic children, along with a psychiatrist who was also a parent of an autistic child. In a recent qualitative study examining the experiences of clinician and caregiver leaders of a co-delivered ACT intervention for autism parents, program leaders described the benefit of complementary contributions when leaders, through their different roles, brought a diversity of experiences and skillsets to facilitation (Lake et al., 2024). There is currently no study that investigates parents' experiences and preferences regarding professional-led and/or peer-facilitated interventions. Interventions using this type of combined model, in which content is co-developed and co-facilitated by peers and professional clinicians, could be a starting point to understand more about the value of each facilitator role when supporting parents of autistic people.

For other caregiver populations, a few studies have compared different facilitation models in terms of effectiveness only. Toseland and colleagues (1990) found that for caregivers of adults with chronic disabilities, different patterns emerged depending on the outcome variable measured. Specifically, professional-led groups demonstrated superiority in terms of improvement in psychological symptoms, while peer-led groups in increasing social supports, and similar improvements were found for personal change (e.g., positive appraisals, interpersonal relationships). Perlick and colleagues (2011) demonstrated that a caregiver peer-led family education intervention was superior to a clinician-led one for caregivers of patients with schizophrenia, in terms of reducing feelings of self-blame and guilt. These studies indicate that there is still much to be learned about how different types of facilitators influence intervention experiences for caregivers.

Going beyond professional training and role, the individual qualities (e.g., personality, attitudes) and skills of intervention facilitators may have important implications for effectiveness. Therapist effects, defined as the proportion of therapy outcome variance that can be attributed to individual therapist factors, have been shown to amount to as much as 29% (Johns et al., 2019). In psychotherapy interventions broadly, therapist factors, including relational qualities (e.g., ability to express empathy, warmth, positive regard), interpersonal skills in challenging situations, professional self-awareness, and attitudes toward therapeutic work, have been shown to be associated with psychotherapy outcomes (Anderson et al., 2009; Heinonen & Nissen-Lie, 2020). There is little known about therapist qualities and skills that are important for therapy outcomes in interventions for parents of autistic people specifically, and an important first step would be to hear from parents themselves about their intervention experiences and what characteristics they value in facilitators.

Given an absence of prior research on optimal facilitators and facilitation models in interventions for parents of autistic people, a qualitative approach is most appropriate to begin to explore parent experiences and perspectives on this topic. Qualitative research imposes fewer restrictions on the type of information that can be collected and is useful when the focus is to better understand a participants' experience, as opposed to classifying, measuring, or predicting (Josselson, 2013). Qualitative research has been used successfully with parents of autistic children to capture the perspectives of parents themselves on issues such as how parents cope over time (Gray, 2006), their lived parenting experiences (Woodgate et al., 2008), and receiving a diagnosis of autism (Midence & O'Neill, 1999). As well, editorials have emphasized that qualitative research holds an equally important place in our knowledge and understanding of autism as quantitative research (Bölte, 2014).

As part of the randomized controlled trial (RCT) of Acceptance and Commitment Therapy (ACT) for parents in Study 1, parents of autistic individuals participated in workshops co-led by one or more professional clinicians and one or more trained parents of autistic people (parent-peers). The intervention was a three-session workshop based on ACT principles, developed by Fung and colleagues (2018b), and described in detail by Lunsky and colleagues (2018). The workshop was developed through a partnership between researchers and parents of autistic people, with the manual's first author being a psychiatrist, researcher, and a parent of an autistic child. The current study (Study 2) was an investigation of how a subset of parent participants experienced this co-facilitation model, to learn what is important to them regarding the facilitators of their interventions, using a qualitative study design. Study 2 addressed the following two broad research questions:

1) How do parents of autistic people experience having both a parent-peer and a clinician facilitate their intervention?
2) What is important to parents of autistic people regarding the facilitators of their group interventions?

These questions focused on understanding what parents of autistic people value in interventions in which they participate. By revealing constructs applicable to this topic, the aim was to create a starting point for a model of effective intervention facilitation for parents of autistic people. This theoretical model can help inform research and clinical decisions about whom should facilitate interventions for parents of autistic people.

Method

Participants

Participants were recruited from a pool of 51 parents of autistic children, youth and adults; these parents completed the 3-day ACT workshop as part of the larger RCT. For the RCT, parents were recruited from postings on websites of several child autism community agencies, autism service e-newsletters, and referrals from the community. Overall, 77 parents responded and participated in a screening call. After screening, 63 participants were randomized in the study, and 51 parents participated in the full workshop. In total, 15 parents of autistic children, youth, and adults participated in interviews. All parents in Study 2 met the same inclusion criteria as outlined in the Study 1 RCT, including documentation of their child's autism diagnosis from a qualified health care practitioner, fluency in English, no prior participation in an ACT intervention, and the ability to identify personal goals. In total, 14 mothers and one father were interviewed, who ranged in age from 36 to 69 years (M = 49.5; SD = 8.25). Parents had an autistic child ranging from 3 to 27 years of age (M = 15.0; SD = 8.05), and 13 out of 15 children of participating parents were male (86.7%).

Procedure

Parents were invited to participate in interviews by email invitation, which outlined that the researchers were interested in parent perspectives about the facilitators of the ACT workshop in which they participated. Nineteen participants, who had completed the ACT RCT workshops, initially expressed a desire to participate, and four did not reply to the follow up emails sent to schedule interviews, leaving 15 parents. Parents who wished to take part in an interview were asked to sign an informed consent form outlining the risks and benefits of the study. A phone interview was scheduled at parents' convenience. Phone interviews were audio-recorded and transcribed verbatim. The interviews took between 30 and 45 minutes. Participants were reimbursed $25.00 CAD for their time upon completion of the interview.

Coding and Analysis

Interviews were conducted using a semi-structured format. An interview guide (see Appendix D) was used to provide guidance and structure to the interview. A semi-structured design allows for the flexibility recommended when working with families in which a member has autism, to allow participants to focus on issues that are meaningful to them, to permit sharing a diversity of ideas outside of a set of expected responses, and to limit researcher control over how participants express their experiences (Cridland et al., 2015). The interview guide was developed by the first author, who attended and observed all six of the Study 1 ACT workshops, as well as previous ACT workshops for parents of autistic people. The interview guide was reviewed and refined by other team members involved with the research and clinical delivery of the workshop. The guide included broad questions about parents' experiences in the group and what makes a "good facilitator," as well as more specific questions about the respective contributions of the professional clinician and parent-peer, perspectives on the co-facilitation model, and how facilitators affected parents' experience in the workshop.

The chosen qualitative approach was a thematic analysis, coded using a grounded theory-informed protocol. This framework was used, as opposed to other qualitative methodologies, because the goal of the investigation was to develop a theoretical understanding of what is important to parents about the facilitators of their groups in the social context of a combined parent- and clinician-led ACT group. Using the coding process described by Charmaz (2006), themes were generated from the text using an inductive/data-driven approach. No specific theories were used a priori to inform or understand the participants' experience, which is appropriate when there is not enough existing research to form strong prior theoretical assumptions (Glaser & Strauss, 1967; Strauss & Corbin, 1990). In this way, observations from the data can be used to derive codes and themes in a bottom-up fashion.

First, the transcript was divided into meaning units, or segments of text containing a full and discrete thought. This is an adaptation of the original grounded theory protocol, in which line-by-line coding is used (Glaser & Strauss, 1967). Using open coding, each unit of meaning was labeled with tentative category names based on the strongest ideas in the meaning unit. These lower-order categories were clarified by creating a definition for each, with category labels and definitions refined throughout coding. These categories were then subject to further analysis and then reduced, with meaningfully related categories clustered by theme. A constant comparative method of analysis was used to generate themes from the data. Using this method, themes become more abstract through comparing data points to other data points, comparing categories to other categories, and then comparing categories to concepts (Charmaz, 2006).

Coding was undertaken by the first author, although was supported through informal consultation with some members of the research and clinical team. Throughout the coding process, the first author engaged in memo-writing of thoughts that arose at each step of analysis on the phenomenon of study. Memo-writing occurred at the following times: immediately after each interview to reflect on the interview experience, while listening to the audio of the interview, throughout the process of transcribing, and during coding and analysis.

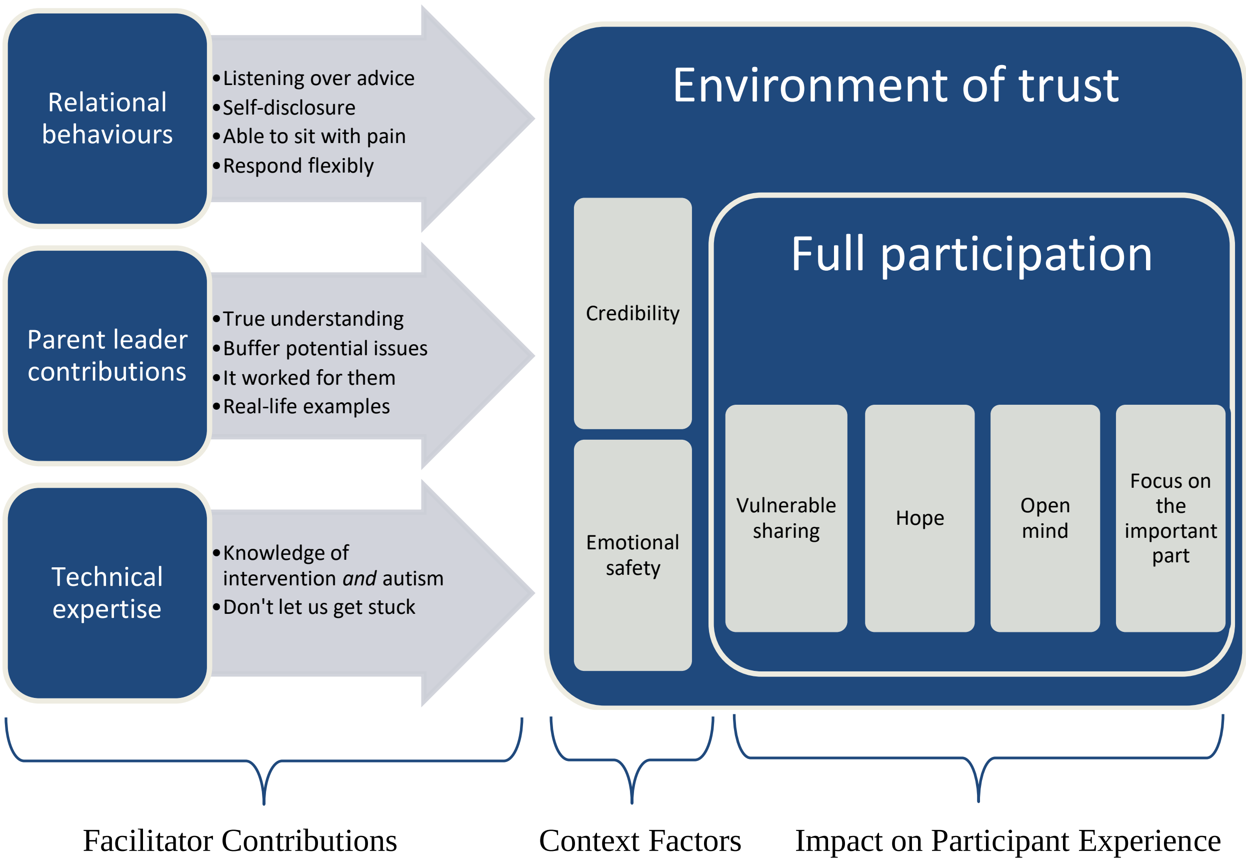
Results

Overall Findings

The thematic analysis resulted in five themes and 16 subthemes that could be categorized under three broad domains: 1) facilitator contributions, 2) context factors, and 3) impact on participant experience. From the data, a conceptual model emerged that provides a framework for understanding what is valued by parents of autistic children about the facilitators of their interventions, and why these factors are important to them (Figure 1). Parents emphasized that an environment in which there is trust established (context) is crucial for allowing them to fully participate and learn in the group (impact). They described which facilitator factors led to creating that type of environment (facilitator contributions), including a range of leader behaviours, skills, knowledge, and perspectives that were most valued by parent participants. The domain of facilitator contributions contained the greatest number of codes.

Figure 1

Model Depicting the Impact of Facilitators on Group Context and Participant Experiences in Interventions for Parents of Autistic Children



Although participants shared their perspectives about the value that each facilitator type brought to the group, most comments referred to *general* facilitator contributions that mattered to parents, which were irrespective of facilitators' formal "role" (i.e., parent-peer or professional clinician). There was no clear impression that the majority of participants had a preference for either role over the other; rather, most were able to name a leader who stood out to them personally and reflect on why that was. In fact, it was suggested that almost all valued facets of a leader could be provided by any facilitator with the appropriate traits, skills, and training. Thus, facilitator contributions are grouped by theme, rather than divided by role, except for the theme of *parent leader contributions*, which describes a particular set of contributions that only the parent-peer leader brought. In the descriptions below, themes are specified with headings, with subthemes designated with italics. Ellipses within quotes signify that text was removed as it was not pertinent to the analysis. Other quotes are verbatim, with minor edits for clarity. Any information identifying participants or group facilitators was removed. This includes references to the gender of group facilitators; because only one leader was male, all pronouns have been changed to they/them/their.

Facilitator Contributions

Relational Behaviours

When participants described facilitator contributions, all described approaches to communication and interpersonal behaviours. That is, specific relational behaviours, or ways in which group leaders connected with participants, were highly valued by parents. Almost all participants described a good facilitator as someone who can convey a sense of empathy through listening. One participant noted, "my voice felt heard and really validated." Many parents explained that they had received a great deal of unhelpful advice throughout their parenting journey (sometimes which did not consider their child's unique needs), and they came into the workshop wary about receiving advice they had already tried, or that was invalidating or irrelevant to their situation specifically parenting their autistic child. The subtheme *listening over advice* captures the emphasis parents placed on facilitators being able to listen well without providing suggestions:

> "There was never any sort of suggestions about, 'oh well maybe you should have tried this' or 'maybe you could have done that,' or, 'did you ever think about doing this instead?' It was just… they listened."

Participants reflected on the value of facilitators engaging in *self-disclosure*, including leaders' own personal or family experiences with autism, whether or not the facilitator was a parent themselves. Some referred to the emotional impact of hearing a group leader's experience:

> "[Facilitator] used a lot of [their] own personal experiences when talking in the group. It makes you more at ease, more calm."

Others noted that hearing self-disclosure from a facilitator was "powerful." Self-disclosure could also involve a leader acknowledging their own position and limitations:

> "[Clinician] was pretty up front about the fact that [they don't] have someone diagnosed on the autism spectrum as a child but [they] had good insights and was not presumptuous about parenting, or any of it. [They were] insightful and thoughtful and acknowledged, you know, the limits of [their] experience."

There was great value placed on the strength of facilitators to be *able to sit with pain,* that is, be able to hear about a challenge or a painful experience and demonstrate that they could handle it, without trying to change or fix it. One participant spoke about a facilitator who "gave me space to be whatever I am in the moment. I loved when [Facilitator] intervened and said, 'guys, don't save her.'" Another parent spoke about how powerful it was to be able to share painful experiences and be met with compassion: "instead of pull away, [Facilitator] draws closer." There was also a reflection on how facilitators were able to convey their personal tolerance, that is, to "be comfortable in those vulnerable times when people are sharing their struggles, and to be okay with that."

Some parents described valuing group leaders' ability to *respond flexibly* to participants. This sometimes referred to bending and accommodating to the specific needs and dynamic of the group, such as spending more time on a particularly relevant topic or one that needed more clarification. Flexibility also came up when participants spoke about how it was important for leaders to be open-minded to participant experiences and perspectives, especially when they were different from their own. The idea was raised that having "a rigid way of thinking about things" or "too narrow a view of the best way to do this [i.e., to parent]" would interfere with facilitation. Another participant shared that they have noticed the tendency of other parents to "see the world through the prism of your own experience with your own kid." As such, participants valued "the ability to hold different views or admit when you don't understand."

Parent Leader Contributions

Some behaviours and perspectives that were highly valued by participants were those unique contributions from parent leaders. The most frequently cited benefit of having a parent leader was that they demonstrated a *true understanding* of participants' experiences. Several parents felt that understanding requires authentic lived experience. For example:

> "Unless you've been through it, you don't really know."
>
> "You can read all about it; until you live it you don't understand it."
>
> "If you don't have the lived experience, it's very easy to tell somebody something, and not realize they cannot do it."

One parent spoke about the added comfort of not having to provide a lot of explanation or backstory to be understood:

> "That's just the benefit of having a person who's experienced it – they kind of get it right from the start without even knowing the specifics of each family or family member."

Another parent took this further, suggesting that there was an easy shared understanding between parent participant and parent-peer leader that could be communicated almost intuitively:

> "I can say one word and [they] knew exactly what I'm talking about without me further explaining myself."

When parents were asked more generally about their opinions about the co-facilitation model, some gave examples of how the presence of a parent-peer leader helped to *buffer potential issues* that have previously arisen for them in interactions with those who do not have an autistic child. For example, one parent spoke about negativity they hear frequently in the "little comments that people will often make without even realizing it," noting, "that can be hard." Another parent explained that upon arrival on the first day of the workshop, hearing the parent-peer(s) introduce themselves quelled fears or biases related to past challenging experiences with professionals:

> "I think for a lot of people with kids with autism, you go through a lot of different medical professionals. And unfortunately, you have some negative experiences along the way for a lot of people. And so, to have a clinician be the only person… it's hard to be open to that because of those negative experiences along the way."

Participants felt excited about the idea of being taught by someone who had similarities to them, and who had found the ACT concepts helpful. One parent communicated that, "when you see somebody else that you know has been through this and has something that's successful, there's hope that, okay, it can work for me too." This implicit endorsement message that *it worked for them,* was important to many participants in helping them feel confident about the relevance of the ACT intervention to their own lives:

> "Wow, these tools work if the parent is willing to do it, is willing to engage in the ACT strategies, right?"

Furthermore, having a parent-peer facilitator speak about their own experiences in relation to the intervention content meant that participants received *real-life examples* of when and how to connect ACT principles to the same types of experiences that a parent participant might face:

> "[Facilitator] would bring in [their] own personal experiences – memories of when [they] first started doing ACT, or a scenario where [they've] had to use the ACT techniques. And I just found that really reinforced the information and made it a little more real than just hearing the theory of it."

Another parent described a particular moment when they felt that the content began to resonate clearly:

> "When [Facilitator] listed all [their] personal experiences about that, that moment in the group… it just really was impactful for me and I think let me open my head more, too… It's a different type of therapy for sure, but… piecing the tools that were provided with [Facilitator]'s real-life experience just kind of pulled it so together for me."

Technical Expertise

Participants often referred to expertise that was more technical in nature that leaders demonstrated, such as specific intervention knowledge, and skills related to managing a group. Although these types of expertise were often demonstrated by clinicians, participants noted that they believed well-trained parent leaders could also offer some of these contributions as well. Participants often spoke about the knowledge that was required to lead a group, with facilitators needing to "know their material inside out." For this group, parents shared that facilitators should have in depth *knowledge of intervention* ***and*** *autism*, with both topics being equally important. Facilitators had to be knowledgeable enough about the intervention to be able to "put it into everyday talk for people to understand," clarify more difficult concepts, and respond to participant questions. Parent participants also expected facilitators to also have enough experience and understanding of autism, either through their personal life or working with families professionally. They wanted leaders who could "understand the different systems that parents interact with." One participant, referring to a facilitator who demonstrated knowledge and understanding of both ACT and autism, noted:

> "[Facilitator] was more natural and genuine in conveying the ACT material because [they] knew it. And it was so, embedded in [them], it was so innate that [they] could convey the material seamlessly."

Another area of experience noted to be important was group leadership and problem management skills. Most comments that made up these subthemes were in response to questions asking about the value that clinicians bring; however, some participants noted that they observed parent-peers who were skilled in these behaviours. The subtheme, *don't let us get stuck*, captures both the experience and skill in leading a group, and the ability to manage problems or crises if they emerged. This included experience and skill around managing time and maintaining a balance between "listening and teaching." It was important to parents that one group member was not allowed to monopolize the group and that discussions did not veer into tangents that were only helpful to one individual. For example:

> "[Facilitators] were able to keep control of the group, but in a respectful way. I'm just thinking of certain moments like when it could've very easily been taken over by certain personalities, or certain situations, or certain stories and they were able to… bring everybody back on track."

Some parents felt that good group leadership also encompassed the confidence to manage problems or issues if they came up, with the ability to "jump in and stop something" when needed. They noted that if a crisis had arisen, such as an upset participant or conflict between group members, they want to know that there is someone leading who is trained to manage that, when responding to questions about the value that clinicians or clinical training could bring.

Context Factors

Environment of Trust

During discussions about facilitators, participants spoke about the resulting group environment that was created. Parents described a sense of trust that was established in the group, in that they felt they could trust the facilitators and the content that they presented. Under this theme, two subthemes were identified, capturing the aspects of the group context that parents valued and that contributed to building their trust.

First, parents discussed that the facilitators contributed to parents' belief that the program had *credibility*. That is, participants spoke about having the underlying belief that ACT was a valid intervention that would be useful to them. Some participants noted that it was the clinician presence that contributed to this sense of credibility:

> "I liked the fact that there was a clinician there as well because in my mind, it sort of made this a valid thing to be doing."

> "I think it's the professionalism and the validity that was brought with the clinician being part of the group, being a facilitator…That led me to feel more comfortable in some ways."

Others felt reassured by the presence of both clinicians and parent-peers:

> "From the get-go there was a sense of competency, knowledge base, and a broad range of experiences that were in the room, from having those different lenses."

> "I think you get more buy in, and you get more credibility with both."

Second, there was emphasis that the qualities and contributions of facilitators created *emotional safety* for participants, whereby parents felt the environment was a safe one to be able to take risks such as expressing themselves and asking questions in the group. The sense that there was emotional safety in the environment increased comfort levels and helped participants overcome barriers to participation. For example, one parent spoke about how they typically would remain quiet in a group setting:

> "I tend to be a bit of an observer…you do need to gain my trust for me to feel comfortable speaking."

Another parent referenced that a particular facilitator's warmth and authenticity had the following effect:

> "It promoted my ability to share vulnerable parts of my parenting that were unpleasant. And that's the environment [Facilitator] really facilitated for me."

Impact on Participant Experience

Full Participation

Finally, many of parents' comments were about why it matters to have skilled and understanding facilitators who have the ability generate a safe therapeutic environment. Parents spoke about the importance of being able to fully participate and learn during the group, without being held back. One component of full participation identified was *vulnerable sharing* of personal experiences, thoughts, and feelings. Parents noted that the feelings and experiences they shared with the whole group, or in pairs, were often difficult or sensitive:

> "The thing about ACT is that there's a lot of personal exposure and sharing. You share a lot of personal information… you put yourself in an emotionally vulnerable space."

Parents felt that they benefitted from hearing the perspectives and experiences of other parents, as well as being able to share their own with the group:

> "If you didn't really fully participate, you wouldn't really understand it, or I think you would get a lot more from it if you were really able to be comfortable opening up and sharing with the other person and sharing with the group."

Some parents reflected on their ability to access *hope* during the workshop, which increased their ability to participate fully in the group. Parents believed that in order to benefit when participating in the intervention activities, "you have to have hope for your future, and you have to believe the intervention will help." Simply having the group led by a parent peer was helpful for one participant: "Seeing a parent leader who is doing ok and whose child is doing ok – that gives me hope." Some participants described taking this feeling home with them after completing the workshop, noting: "one of the things that I took with me was a sense of hope," and "the load feels lighter."

Parents reflected that, as a participant, being able to have an *open mind* was important with respect to their ability to fully access and apply the intervention content. Many spoke to the idea that some ACT concepts, such as the practice of noticing and accepting painful experiences without attempting to fix or change them, could initially feel difficult to consider. Some noticed differences in their perspective: "my thinking shifted, approaching these issues shifted." Parents noted that the impact of good facilitation and sense of safety and credibility in the group was that they were able to open their mind during the workshop and take in new ideas:

> "You feel more open to accepting some of the things that they were saying and being willing to try it and being willing to, you know think okay, this might help me in my life."

Parents spoke about their experience in this intervention of being able to *focus on the important part*. That is, when they entered the group, they had a sense that there was a shared understanding in the room about many of their experiences and needs. It was a relief "not having to explain the whole baseline stuff," noted one participant. Others commented that they did not have to justify their experiences or perspectives, with one parent sharing that typically, “if someone doesn’t get it, you go into convincing mode.” By not having to spend time and energy explaining or convincing, parents had their resources freed up to learn, process and use the ACT material.

Discussion

Parents of autistic people are beginning to participate in interventions focused on their own well-being, and this study is among the first to provide insight into parents’ perspectives on their experiences in these interventions and with the people who facilitate them. In this study, interviews were conducted with parents who had participated in Acceptance and Commitment Therapy (ACT) group workshops that were co-led by parent-peers and professional clinicians. From the qualitative data, a conceptual model emerged that depicted, for this context, what parents value in their group leaders, and how those factors impact the group environment and participant experiences.

Facilitator Contributions

The practice of involving parent-peers in the facilitation of interventions for parents of autistic children is an emerging practice in research, with parent-peers being involved to different degrees (e.g., see Dykens et al., 2014; Lunsky et al., 2018; Hock et al., 2022). The current study is one of the first attempts to understand parent perspectives on this practice generally, and to ask about the qualities of parent leaders that matter to participants. This study, which had both parent-peers and professional clinicians present and involved throughout the workshops, is also the first attempt to understand parent perspectives about facilitators within a co-designed and co-facilitated ACT program. Parents described several personal qualities, behaviours, skills, and experiences that they observed in the leaders of their groups. In terms of what parents highly valued, it was relational behaviours, such as listening well and with empathy, hearing participants' difficult experiences without trying to change or fix them, responding with flexibility, and sharing their own experiences, that were mentioned by all participants. Many of these characteristics reflect aspects of therapist behaviours that have been described as necessary for therapeutic change. For instance, frameworks of counselling communication skills required for effective work with clients have described similar concepts of reflection, accurate empathy, self-disclosure, and flexibility as key components of what counsellors can do to help support clients (Kuntze et al., 2009). These characteristics also reflect the 'first pathway' of the contextual model of common factors (Wampold, 2001; Wampold, 2015), which involves therapist behaviours that create a foundation for the 'real relationship' between a therapist and a client; a genuine relationship based on caring and empathy in which client and therapist accurately perceive and understand one another. (The 'second pathway' involves therapist behaviours that address client expectations and hope, while the 'third pathway' consist of the specific ingredients of the chosen therapy that benefit the client by fostering skills, strengths, and healthy actions; Cuijpers et al. 2019). Common factors are seen as any factors that can contribute to client improvements, and that are common across different treatments. Lambert (2013) groups common factors into domains of Support, Learning, and Action, representing the sequence of change in successful therapy. The facilitator contributions that emerged in the current study fit squarely into the first domain, Support, which encompasses those initial relationship factors and supportive functions (e.g., therapist expertise, identification with therapist, positive relationship, therapist empathy) that precede change in beliefs, attitudes, and actions.

Intervention Context

Participants shared that the emotional environment in which the group took place was crucial to their overall experience. Comments reflected participants' need for emotional safety, with examples of how that type of group environment allowed for them to demonstrate more vulnerability and active engagement. These findings align with existing perspectives on group therapy processes that emphasize the importance of group context. Yalom (1995) proposed that an important task of group leaders is to create a culture in the group (group climate) that is cohesive, allowing group members to feel warmth and comfort, feel that they belong, and believe that they are valued and accepted in the group. Kivlighan and Tarrant (2001) tested Yalom's theory that group climate is the mechanism of effective outcomes for group members, mediating the effect of group leader actions. Forty-one therapists completed end-of-session ratings of how much focus they placed on various therapeutic tasks in 8-session groups with 233 adolescents with behaviour challenges. A higher therapist focus on creating a safe atmosphere in the group was positively related to the group climate becoming more active and engaged over time, which in turn was related to participants perceiving higher benefits of the therapy. In the current qualitative study, the theme of emotional safety in the environment, and the emphasis that participants placed on it, fits well with existing conceptualizations of a cohesive group climate. At the same time, the context of ACT, which requires some level of vulnerability to participate in experiential and paired sharing activities, may pull for greater need for this type of safe atmosphere compared to some other therapeutic modalities.

For parents of autistic children, the context of the intervention may have even more significance. Parents of autistic children tend to use more avoidance coping strategies (e.g., behavioural disengagement, self-blame, distraction) than other parents (Lai et al., 2015), and having a more avoidant style has been shown to negatively impact engagement in therapy, as these clients may need more reassurance of acceptance from others before participating

(Edelman & Chambless, 1995). In addition, parents of autistic children may have had difficult experiences when navigating care systems, coping with unsupportive social systems (Meirsschaut et al., 2010), or have had their feelings invalidated by service providers (Stahmer et al., 2019). It follows that these experiences could increase hesitancy around sharing difficult experiences in an intervention setting, and these parents may place a high value on a group environment that fosters a sense of trust, safety, and credibility. Indeed, participant interviews in the current study reflected these types of past experiences contributing to their approach to entering and participating in the group.

Impact on Participants

In addition to facilitator and context conditions, parents spoke about how they experienced a sense of hope through group processes, that things will be "okay" and that they intervention will be helpful, and they valued this feeling as an outcome in and of itself. As noted above, the contextual model of common factors in fact prescribes hope as a 'second pathway' toward client healing (Wampold, 2001), and participant voices in the current qualitative study provide support for this process. Empirical quantitative research also supports the important role of hope. In families of children with intellectual disabilities, including those with autism, mothers with higher "trait hope" (i.e., the belief that one will be able to find ways to achieve their goals), had lower levels of depression, and hope predicted higher levels of positive affect in both mothers and fathers (Lloyd & Hastings, 2009). As well, Faso and colleagues (2013) looked at factors predicting well-being in parents of autistic children, finding again that higher levels of hope predicted lower levels of depression and greater reported life satisfaction. Parents in the current study were able to identify specific ways that the intervention conditions allowed them to engage in the workshop. In addition to feeling hopeful about the future, parents described personal experiences such as vulnerable sharing with others, opening up to new ideas, and freeing themselves from expectations to explain or justify, in order to focus on ACT content. These experiences have similarities to those included in Lambert's (2013) second domain of common therapy factors, Learning. Following Support, the Learning stage in therapy involves changes in one's beliefs and conceptualizations of problems, and includes common factors such as corrective emotional experiences, acquiring insight, and adjusting one's expectations. In theory, these experiences lead to clients taking action toward change.

Limitations & Future Directions

This study is an important first step in understanding the experiences of parents of autistic children attending ACT group therapy. A strength of the current qualitative study is that the sample consisted of parents who experienced a facilitation model that comprised both parent leaders and clinicians. This created the opportunity to gain participant insights about the contributions of each leader role and about the co-facilitation model more generally. This study also had several limitations. To start, ACT involves didactic skills teaching, experiential learning, and participant sharing. Current findings may not apply to participants in groups that are more group process-oriented, psychoeducational, or longer-term. In addition, as the interviewer was involved in multiple aspects of the project, including recruitment and data collection, and was present in the workshops, there is a risk that participants provided less critical feedback of groups and facilitators than they otherwise might have with an outside interviewer. Further, in the current sample, the children of participating parents spanned a wide age range, from preschool-age to young adulthood. Parents of older and younger autistic children might value different qualities and behaviours of facilitators depending on past service experiences, but this nuance was not explored in the current study. Lastly, it is possible that this sample of caregivers who chose to participate in interviews differed in important ways from the larger population of autism parents. This sample was recruited from postings on websites of child autism community agencies, autism service e-newsletters, and referrals from the community, and therefore participants were already connected in some way to the autism service community. Additionally, those who chose to participate in a randomized controlled trial, and then further engage in an interview, may have had either a higher need for support, or greater capacity to engage in intervention, or both, compared to the broader population of autism caregivers. This limitation could be partly addressed by routinely including an interview component as part of data collection for larger intervention trials.

There are many research avenues to extend this work. Future qualitative studies might explore parent perspectives in interventions that are led by only parent-peers, or only professional clinicians. Although the presence of both facilitator types allowed participants to consider the impact of both roles, it would be important to understand how much of their experience was unique to this co-facilitation model, and which aspects of their experience was related to the ACT modality specifically. Future quantitative work could compare different leadership models in terms of participant satisfaction and improvement in markers of well-being and mental health. An exploration into the impact of facilitator gender, as well as the interaction of gender and other aspects of identity and demographics (e.g., cultural viewpoints, age, etc.) might also shed light on how other aspects of facilitation and representation help to further support positive participant experiences or are valued by participants.

Clinical Implications

As the availability of programs to support the mental health and well-being of parents of autistic people is increasing, so too has variability in types of interventions and delivery models.

Along with evidence on efficacy, parent input on aspects of intervention facilitation that they value, and that they experience positively, can help make decisions about how programs can be optimally delivered to suit the needs of the population they serve. The current study reveals that parents value many aspects of parent-professional-delivered ACT groups. Specifically, many contributions can be made by both parent-peers and professional clinicians that can help parents of autistic children feel emotionally safe to actively engage in an ACT workshop, including facilitator self-disclosure, acknowledging their own limitations, and providing active and warm listening over advice and problem-solving. There may also be unique and important contributions made by parent-peers, which suggests it may be important to consider ways in which partnerships with parent advisors, parent co-facilitators, or parent co-developers could enhance interventions.

Within the context of supporting families of autistic children, parents can experience support and wellness in interventions, and with intervention facilitators, that cultivate relational and hope-related common psychotherapy factors. These common factors likely set the stage for parents to benefit from the 'third pathway' of therapeutic change (Wampold, 2015) – the ACT processes that participants are invited to experience during the process of these groups. Beyond ACT, many of the specific facilitator contributions, context factors, and positive experiences that parents identified as important, could plausibly be incorporated into other mental health and well-being interventions for parents of autistic children, whether those interventions use a parent-professional, parent-peer, or more traditional clinician facilitation model. It is crucial to incorporate the perspectives of parents of autistic children, in order to continue to develop and strengthen mental health supports available for this group.

Chapter Four: General Discussion

Summary of Dissertation Findings

Study 1 Summary

This dissertation contributed to an enhanced understanding of the effects for parents of autistic children of participating in interventions focused on their own well-being, when an Acceptance and Commitment Therapy (ACT) approach is used. Study 1 implemented a Randomized Controlled Trial (RCT) design to test the efficacy of a brief ACT intervention for mothers and fathers of autistic children, youth, and adults. Parent participants completed measures immediately prior to randomization (Baseline/Time 1), and at 3 weeks (Time 2), 7 weeks (Time 3), and 17 weeks post-randomization (Time 4). These measurement time points corresponded to pre-intervention, one week, one month, and three months after the workshop weekend, comparing Treatment group participants to a Waitlist group that had not yet received the intervention. Measures assessed parents' self-reports of their own individual mental health, positive functioning, personal goal attainment and ACT psychological processes, as well as of their family's functioning and level of current distress, and of their child's mental health.

The ACT intervention resulted in parent-reported improvements, with one of the largest treatment effects observed for parent depression. Sixty-seven percent of Treatment condition participants with clinical levels of depression were in the normal range at Time 3, compared to only 30% of those in the Waitlist condition, and overall, there was significantly greater improvement in Treatment group compared to the Waitlist group at Time 2, which was maintained at Time 3. These results align with previous studies of ACT for parents of autistic people (Blackledge & Hayes, 2006; Joekar et al., Lunsky et al., 2018; Poddar et al., 2015), wherein parent self-reports of depression decreased post-intervention. On the other hand, there were no significant differences in parent-reported stress between groups at post-intervention/wait. Although more improvement in stress had been expected, our results were similar to those of another study that delivered ACT to a self-selected subset of parents who were already receiving a child-focused early intervention; Corti and colleagues (2018) also found no significant time x treatment interaction between their ACT treatment group and the control group. Parents of autistic children can experience chronic stressors, such as high levels of mental health problems in their autistic youth (e.g., Simonoff et al., 2008), which may require targeted interventions that focus on both supporting parent and addressing stressors, before more pronounced differences are likely to be reported in parents' personal experience of stress. In our sample, parent reports of overall child mental health problems and the impact of those problems were on average in the "very high" range, which is a factor that tends to be associated with high levels of parenting stress (Huang et al., 2014), and may lessen the impact of brief parent focused interventions. In one intervention for autistic children that included parent involvement, pre-intervention parent stress levels moderated effects on parents, whereby parents with higher initial stress showed more improvement in their sense of efficacy post-intervention if their child participated in a lower intensity program, whereas parents with low initial stress reported higher post-treatment sense of efficacy if their child received a higher intensity intervention (Estes et al., 2021). For some parents, adjusting the intensity or dose of their own intervention may be important, as is considering the intensity of any concurrent programming their child is involved in during the study.

In Study 1, parents who participated in ACT had greater increases in positive affect compared to the Waitlist group at Time 2, though it was an effect that dissipated by Time 3. The link between positive affect and perceived social support in parents of children with disabilities has been repeatedly demonstrated (i.e., Findler et al., 2016; Smith et al., 2012) and it follows that positive affect would increase immediately after an intensive weekend workshop designed to allow parents with similar experiences to connect. This may not have been able to be maintained as time passed after the group, without sustained social connections or ongoing engagement with the ACT material. Goal attainment, similarly, showed a large group difference at Time 2, which was no longer apparent at Time 3. At Time 2, the Treatment group was six times more likely to be achieving or exceeding one of their goals, with 82% of the Treatment parents and only 43% of the Waitlist parents indicating goal achievement. At Time 3, a slightly smaller proportion of Treatment parents indicated that they were achieving or exceeding their goals, and more Waitlist parents had begun to achieve their goals. Studies on goal attainment indicate that ongoing progress is most likely when goals are set just slightly out of reach, balancing challenge while preventing discouragement (Chevance et al., 2021). Since many Treatment group participants had already achieved or exceeded their goal when assessed immediately after the workshop weekend, they might have benefitted from readjusting their original goals to create more challenge or based on values identified during the workshop.

In terms of the ACT psychological processes, there were no group x time treatment effects for values-guided behaviour or mindful parenting. As shown in other studies of ACT, some changes in these markers of psychological flexibility take several months to become evident, especially those that involve behaviour change (González-Menéndez et al., 2014; Gould et al., 2017; Kohtala et al., 2017). In a study of ACT for parents of children with developmental disabilities, changes in parenting behaviour were reported at 6 months follow-up, but not earlier, when participants were assessed immediately post-intervention (Whittingham et al., 2015). When values-directed overt behavior is measured in parents of autistic children following ACT, the largest effects have been observed more than 6 months post-training (Gould et al., 2017). In the only other RCT of ACT (Hahs et al., 2018), while a mindfulness measure of awareness and attention (Mindful Attention Awareness Scale) showed more improvement in the treatment group compared to the control, another mindfulness measure assessing a non-judgmental and accepting approach (Frieburg Mindfulness Inventory) did not show a treatment effect. The current results may therefore reflect an insufficient shift in some aspects of mindfulness, contributing to an overall nonsignificant result. At the same time, in this dissertation, cognitive fusion and experiential avoidance showed improvements in the Treatment group and not in the Waitlist group (though not to a degree that resulted in a significant group x time interaction). Overall, cognitive fusion and avoidance differ from valued living and mindfulness in that the former assess thoughts and feelings, while the latter address actions. Through all ACT workshop activities, clients are encouraged to reconsider their relationship to their thoughts and feelings, resulting in a perspective shift that may result in measures assessing one's internal experiences to be most sensitive to change.

In Study 1, the more distal outcomes of family functioning and child mental health were assessed at post-intervention and follow-up. There were strong consistent treatment effects in parent responses to a measure that asked for a broad appraisal of how difficult their current family crisis experience is. Although the intervention is not intended to address or attenuate family crises, participants in ACT are encouraged to change their relationship to their internal and external experiences. Whether or not families experienced actual change in their circumstances post-intervention, parents might have been better able to reflect on their circumstances and see them in a different light. Study 1 results do not support the hypothesis that a brief ACT workshop would result in actual change in more general family functioning and child mental health. The factors affecting mental health problems are complex and multifaceted, with many unrelated to parenting behaviour or parent mental health and require more direct management to result in improvement (see White et al., 2018 for a review). It may also be that since the bidirectional relationship between parent and child mental health in families with autism is often reflected over a longer period (e.g., Zaidman-Zait et al., 2020), any effect on children because of changes in parent distress might have only been evident if assessed after a longer follow-up period.

Study 2 Summary

Since the first published study of ACT for parents of autistic children in 2006 (Blackledge & Hayes), there has been a surge of studies of implementing interventions using ACT and other modalities to improve and support the well-being and mental health of this group (for reviews see Da Paz & Wallander, 2017; MacKenzie & Eack, 2022). Existing studies have focused on the effectiveness of these types of interventions for influencing improvements in measures of parent wellness. In parallel, there has been some work done in which interventions for parents of autistic children are beginning to include parent-peers to various degrees in both content development and program delivery (e.g., see Dykens et al., 2014; Lunsky et al., 2018; Lunsky et al., 2021, Hock et al., 2022). The effectiveness of these well-being interventions for parents of autistic children that has been the focus of that research, and there has been less exploration of parents' perspectives on the approach to facilitation used.

In Study 2, a subset of parents who had participated in the ACT workshop as part of the RCT were interviewed regarding their experiences in the group and their perspectives on group facilitators, who had delivered the workshop as part of a trained team that included both parent-peers and professional clinicians. The aim of Study 2 was to begin to develop a theoretical understanding of what is important to parents about the facilitators of their groups in the social context of a combined parent-peer-led and professional clinician-led ACT group workshop. Study 2 also aimed to understand the qualities of group leaders that matter most to parents, and about their opinions on having both types of facilitators lead their group. Interviews were coded using a grounded theory-informed protocol, and the resulting qualitative data were analysed using a thematic analysis approach, by which several overarching themes and subthemes emerged.

Themes included facilitator contributions (i.e., behaviours, knowledge, and skills that both parent leaders and professional clinicians brought), in addition to unique aspects of facilitation that the parent leader contributed. Participants emphasized their need to be in a group environment in which trust is created through establishing credibility of the program and ensuring participants' emotional safety. These contributions of the facilitators and qualities of the group environment seemed to allow for parents to be able to fully participate in the workshop by sharing experiences, feeling open minded and hopeful, and focusing on what is truly important to them. From the data, a model emerged that depicted this process, with facilitator qualities and behaviours influencing the group environment, which in turn led to participants feeling they had enhanced experiences during the group.

Relational behaviours were valued in facilitators, such as those communication and interpersonal behaviours that therapists and facilitators use to connect with clients. The behaviours that parents discussed and the impact they felt those behaviours had on them were not unlike 'common therapy factors' often described in clinical training and research. These common factors comprise a set of communication and relationship building skills that span all therapeutic modalities and are crucial for therapist-client relationship building and, therefore, therapeutic change. Although these behaviours are taught to clinicians as part of most therapy skills training (Kuntze et al., 2009; Fife at al., 2014), parents in Study 2 discussed that they observed and valued these behaviours (e.g., listening with empathy and without trying to 'fix', responding with flexibility, sharing personal experiences) in both parent-peer and clinician leaders. Parents also shared that they valued specific contributions of parent-peer facilitators, such as the authentic understanding obtained through shared experiences that they conveyed to participants, and the sense that if ACT 'worked' for them, as leaders with these shared life experiences, then perhaps it can 'work' for group members as well.

In addition to specific behaviours, skills and qualities of facilitators, parent participants described a more general sense of the type of group environment that was important to them and that allowed them to feel comfortable. They valued a group environment that evoked both a sense that the workshop was trustworthy and credible, and that gave participants the feeling of emotional safety. Parents spoke about the ways in which facilitators fostered and maintained a group culture of that nature. Researchers and clinicians emphasize that group culture, or group climate, greatly impact actual outcomes for participants (Yalom, 1995). In Study 2, these group environment themes could have emerged because of qualities of the intervention (e.g., the ACT overall framework or specific ACT content delivered), the co-facilitation model with inclusion of both parent-peers and clinicians, or the specific needs of parents of autistic children. Parents spoke about the effect of feeling trust and credibility in the intervention, in that they were able to approach the workshop with active engagement, the sense of increased hope for themselves, and the ability to identify what was truly important for them focus on in the workshop. Indeed, parents of autistic children may have their own unique needs, strengths and vulnerabilities when it comes to participating in interventions, based on past experiences with service systems, patterns of resilience and coping, and the wide spectrum of needs and presentations in autistic people.

The qualitative themes emerging in Study 2 led to a conceptual framework, outlining a process by which facilitator qualities, skills, experiences, and behaviours affect the group environment and the overall experiences of participants. This framework could be further refined with additional interview data from parents of autistic people who participate in parent-focused well-being interventions. Future research can help illuminate how parents of autistic people think about different types of facilitators, and whether the qualitative results from this study are specific to the ACT modality, to this parent-peer co-designed and co-facilitated approach to delivery, or to some combination or other factor. Further, this study speaks to the need for more qualitative approaches to intervention research for parents of autistic people, as the complexities identified in our Study 2 findings were not reflected in the quantitative results found in Study 1.

Conclusion

Research Implications

This dissertation included one of only two RCTs to date testing the efficacy of ACT for improving markers of well-being in parents of autistic children. While other studies have looked at post-treatment outcomes for parents following participation in ACT, randomly assigning parents to a Treatment or Waitlist group demonstrated treatment effects of ACT when controlling for change over time and repeated measurements. The sample of parents used, which included fathers, as well as participating parents having autistic children that ranged in age from 3 to 34 years and presenting with a wide range of social-communication and adaptive living skills, improves the generalizability of findings to be applied to a broader subset of parents of autistic people. This dissertation also speaks to the importance of measuring positive outcomes when evaluating the impact of ACT, as many changes observed (e.g., positive affect, goal attainment) may reflect the ACT aim of increasing positive values-driven behaviours and thriving even in the presence of symptoms or challenges.

This dissertation also extended quantitative findings by learning more about the values and needs of participating parents, using mixed methods design. As such, this dissertation is an important first step in understanding the experiences of parents of autistic children attending ACT group therapy. A strength of the Study 2 qualitative study is that the sample consisted of parents who experienced a facilitation model that was composed of both parent leaders and clinicians. This created the opportunity to gain participant insights about the contributions of each leader role and about the co-facilitation model more generally.

This dissertation had several limitations. First, while Study 1 included a longer follow-up assessment than has been used in many previous studies, an even longer follow-up period would be advantageous in future work, allowing for observation of effects that, if present, would take longer to develop (e.g., changes in child mental health, changes in ACT psychological processes). Additional limitations to this dissertation include the sample of participants having many families who were already receiving supports and services for their child, relatively low levels of parent mental health problems, as well as on average participants having high household incomes and education levels, which may limit the ability to generalize findings to those families with higher need and fewer resources. Lastly, there is the potential that self-selection bias could have affected the results of these studies. Interventions and supports for autism parent well-being and mental health are not routinely offered in many communities, despite high interest and need, and parents often cite supports to be unavailable or inaccessible (Avery et al., 2022). Participants were recruited from autism community postings and websites, and some were on waitlists to receive other services for their child. It may be that this sample of parents was different from those who were not already connected to the autism service system, and from those without the capacity to participate in a randomized trial. It is also possible that caregivers who chose to participate had a higher need for or motivation to pursue intervention than other caregivers who are less likely to seek parent-focused supports.

Although the current full sample of 63 parents who completed baseline measures and were randomized is larger than many studies of ACT for parents of autistic individuals, some did not complete the full workshop and measures. Additional research with a larger cohort of participants would help to better elucidate the relationship between ACT psychological processes and aspects of mental health in parents of autistic youth. All quantitative outcomes were assessed through subjective parent report, which could potentially influence the validity of results or limit some effects of the intervention being captured. Additional studies of ACT could implement assessments of children and families from a secondary reporter, such as a teacher (for youth outcomes) or other family member (for parent and other family outcomes).

In terms of limitations to Study 2, ACT is unique in that it involves didactic skills teaching, experiential learning, and participant sharing. The themes and process that emerged might not apply to participants in other types of therapy groups or workshops. Last, it is possible that parents of older and younger autistic children might value different qualities and behaviours of facilitators depending on past service experiences, but this nuance was not explored in the current study.

In addition to addressing methodological limitations, there are other qualitative and quantitative research avenues to extend the findings from this dissertation. Future qualitative studies might explore parent perspectives in interventions that are led by only parent-peers, or only professional clinicians. Although the presence of both facilitator types allowed participants to consider the impact of both roles, it would be important to understand how much of their experience was unique to the co-facilitation model. In addition, future quantitative work could compare different leadership models in terms of participant satisfaction and improvement in markers of well-being and mental health. An exploration into the impact of facilitator gender, as well as the interaction of gender and other aspects of identity and demographics (e.g., cultural viewpoints, age, etc.) might also shed light on how other aspects of facilitation and representation help to further support participant experiences or are valued by participants.

Clinical Implications

The increased time demands on families of autistic children (Sawyer et al., 2010) make it important to have interventions that are accessible and brief, to allow a greater range of parents to participate. In addition to changes in format, interventions in some treatment modalities have begun to adjust the facilitator role, identifying the utility of having other parents of autistic children lead interventions for parents. Much of the knowledge gained from this dissertation can be applied to clinical work with parents of autistic children. This dissertation demonstrated that there are impacts for parents when they participate in a brief weekend ACT workshop focused on their well-being. These findings can be applied to supporting parents of autistic individuals in clinical settings, whereby brief interventions could possibly be useful and feasible with the resources available to community agencies. At the same time, given that the Study 1 RCT resulted in larger upfront changes that attenuated over time, it would be important to identify how to better support parents to engage with the material following intervention completion. Findings from these studies suggest that it is meaningful for parents to have other parent-peers involved in intervention facilitation, and specific subthemes identified from participant interviews could be considered when working clinically with parents of autistic children.

Future Directions

Given the higher levels of distress experienced by parents of autistic individuals compared to parents who do not have a child with a disability (Keenan et al., 2016), it is crucial to identify and further develop brief, effective, and accessible supports that focus on parents themselves. This dissertation study aligns with the growing body of research that suggests that ACT can benefit parents across multiple domains. It also extends findings to explore experiences for parents in the workshop and with intervention facilitators. This type of investigation into parents' preferences, values and perspectives can help further refine intervention delivery for parents of autistic children, in order to best suit the needs, strengths and vulnerabilities of this group, and continue strengthen mental health supports for this group.

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Appendix A: Study 1 Supplemental Table 1

CONSORT Checklist of Information to Include when Reporting a Randomised Trial

Section/Topic	Item No	Checklist item	Reported on page No
Title and abstract			
	1a	Identification as a randomised trial in the title	7
	1b	Structured summary of trial design, methods, results, and conclusions (for specific guidance see CONSORT for abstracts)	8
Introduction			
Background and objectives	2a	Scientific background and explanation of rationale	9-12
	2b	Specific objectives or hypotheses	12-13
Methods			
Trial design	3a	Description of trial design (such as parallel, factorial) including allocation ratio	19
	3b	Important changes to methods after trial commencement (such as eligibility criteria), with reasons	N/A
Participants	4a	Eligibility criteria for participants	13
	4b	Settings and locations where the data were collected	18-19
Interventions	5	The interventions for each group with sufficient details to allow replication, including how and when they were actually administered	13-14
Outcomes	6a	Completely defined pre-specified primary and secondary outcome measures, including how and when they were assessed	12-18, 20
	6b	Any changes to trial outcomes after the trial commenced, with reasons	N/A
Sample size	7a	How sample size was determined	18
	7b	When applicable, explanation of any interim analyses and stopping guidelines	N/A
Randomisation:			
Sequence generation	8a	Method used to generate the random allocation sequence	18
	8b	Type of randomisation; details of any restriction (such as blocking and block size)	18
Allocation concealment mechanism	9	Mechanism used to implement the random allocation sequence (such as sequentially numbered containers), describing any steps taken to conceal the sequence until interventions were assigned	18

Implementation	10	Who generated the random allocation sequence, who enrolled participants, and who assigned participants to interventions	18
Blinding	11a	If done, who was blinded after assignment to interventions (for example, participants, care providers, those assessing outcomes) and how	N/A
	11b	If relevant, description of the similarity of interventions	N/A
Statistical methods	12a	Statistical methods used to compare groups for primary and secondary outcomes	22-23
	12b	Methods for additional analyses, such as subgroup analyses and adjusted analyses	22-23
Results			
Participant flow (a diagram is strongly recommended)	13a	For each group, the numbers of participants who were randomly assigned, received intended treatment, and were analysed for the primary outcome	18
	13b	For each group, losses and exclusions after randomisation, together with reasons	18
Recruitment	14a	Dates defining the periods of recruitment and follow-up	19
	14b	Why the trial ended or was stopped	N/A
Baseline data	15	A table showing baseline demographic and clinical characteristics for each group	23-25
Numbers analysed	16	For each group, number of participants (denominator) included in each analysis and whether the analysis was by original assigned groups	21-22
Outcomes and estimation	17a	For each primary and secondary outcome, results for each group, and the estimated effect size and its precision (such as 95% confidence interval)	23-29
	17b	For binary outcomes, presentation of both absolute and relative effect sizes is recommended	26, 28
Ancillary analyses	18	Results of any other analyses performed, including subgroup analyses and adjusted analyses, distinguishing pre-specified from exploratory	92-94
Harms	19	All important harms or unintended effects in each group (for specific guidance see CONSORT for harms)	19
Discussion			
Limitations	20	Trial limitations, addressing sources of potential bias, imprecision, and, if relevant, multiplicity of analyses	33
Generalisability	21	Generalisability (external validity, applicability) of the trial findings	33
Interpretation	22	Interpretation consistent with results, balancing benefits and harms, and considering other relevant evidence	29-33
Other information			
Registration	23	Registration number and name of trial registry	19
Protocol	24	Where the full trial protocol can be accessed, if available	N/A
Funding	25	Sources of funding and other support (such as supply of drugs), role of funders	N/A

Appendix B: Study 1 Supplemental Table 2

Follow-up Change for Treatment Completers from Time 3 to Time 4 Using Linear Mixed Effects Model

Measure	EMM (SE)		Time Effect	*Effect from Baseline b (SE)*	*p*
	Time 3	Time 4			
DASS-21 Depression	5.19 (1.11)	5.06 (0.74)	F (1, 18) = 0.02, d = -0.03	-0.14 (1.06)	.90
DASS-21 Stress	7.00 (1.09)	7.67 (0.95)	F (1, 18) = 0.66, d = -0.17	0.67 (0.82)	.43
PANAS	27.63 (2.00)	29.06 (1.83)	F (1, 17.09) = 1.19, d = 0.17	1.43 (1.31)	.29
BFDS	4.45 (0.38)	4.50 (0.45)	F (1, 17.94) = 0.09, d = 0.03	0.05 (0.17)	.77
CFQ	25.67 (1.81)	23.22 (1.60)	F (1, 18) = 5.20, d = -0.33	-2.44 (1.07)	**.04**
AAQ-II	20.20 (1.90)	17.44 (1.61)	F (1, 17.15) = 3.65, d = -0.35	-2.76 (1.44)	.07^{+}
BMPS	26.19 (1.30)	27.61 (1.29)	F (1, 17.31) = 2.19, d = 0.26	1.42 (0.96)	.16
PSI-4 Health	14.83 (0.73)	14.94 (0.86)	F (1, 18) = 0.03, d = 0.03	0.11 (0.70)	.88
PSI-4 Isolation	16.00 (0.65)	16.10 (0.77)	F (1, 18) = 0.02, d = 0.02	0.10 (0.71)	.89
FAD	27.73 (1.51)	27.94 (1.47)	F (1, 17.06) = 0.07, d = 0.05	0.21 (0.78)	.79
SDQ Impact	4.92 (0.52)	4.67 (0.65)	F (1, 18) = 0.28, d = -0.09	-0.25 (0.48)	.60
VLQ Composite	43.88 (3.39)	45.24 (3.88)	F (1, 17.31) = 0.21, d = 0.09	1.36 (2.96)	.65

DASS-21 Depression Anxiety Stress Scale; *PANAS* Positive and Negative Affect Schedule; *BFDS* Brief Family Distress Scale; *CFQ* Cognitive Fusion Questionnaire; *AAQ-II* Acceptance & Action Questionnaire; *VLQ* Valued Living Questionnaire; *BMPS* Bangor Mindful Parenting Scale; *PSI-4* Parenting Stress Inventory; *FAD* McMaster Family Assessment Device; *SDQ* Strengths and Difficulties Questionnaire.

Appendix C: Study 1 Supplemental Table 3

Secondary Outcomes for Treatment and Waitlist Groups from Baseline Using Linear Mixed Effects Model

Measure	EMM (SE)		Time x Condition Effect	*p*	*d*
	Treatment	Waitlist			
DASS-21 Stress					
Baseline	9.26 (0.81)	8.35 (0.76)			
Time 2	7.59 (0.83)	8.57 (0.89)	F (1, 50.49) = 2.32	.13	-0.46
Time 3	6.68 (0.93)	7.36 (0.72)	F (1, 50.89) = 2.00	.16	-0.38
PANAS					
Baseline	27.59 (1.51)	29.30 (1.31)			
Time 2	30.35 (1.41)	26.34 (1.37)	F (1, 50.10) = 18.38	**<.001**	0.77
Time 3	29.47 (2.00)	28.64 (1.43)	F (1, 45.57) = 1.70	.20	0.34
BFDS					
Baseline	5.00 (0.37)	4.82 (0.22)			
Time 2	3.91 (0.31)	4.51 (0.30)	F (1, 49.12) = 5.88	**.02**	-0.49
Time 3	4.00 (0.33)	4.72 (0.38)	F (1, 46.31) = 4.29	**.04**	-0.57
CFQ					
Baseline	27.41 (1.70)	27.37 (1.39)			
Time 3	23.63 (1.57)	25.34 (1.47)	F (1, 49.97) = 1.13	.29	-0.22
AAQ-II					
Baseline	22.70 (1.74)	21.04 (1.34)			
Time 3	18.48 (1.68)	20.18 (1.40)	F (1, 50.43) = 2.50	.12	-0.41
BMPS					
Baseline	25.11 (1.05)	26.70 (0.96)			
Time 3	26.72 (1.07)	26.38 (0.84)	F (1, 48.18) = 1.30	.26	0.28

VLQ Composite					
Baseline	44.07 (2.95)	48.07 (2.58)			
Time 3	46.20 (3.19)	46.26 (3.58)	*F* (1, 46.75) = 1.13	.29	0.27
PSI-4 Health					
Baseline	15.52 (0.78)	14.74 (0.77)			
Time 3	14.63 (0.74)	15.58 (0.90)	*F* (1, 47.45) = 3.73	$.06^{+}$	-0.42
PSI-4 Isolation					
Baseline	17.93 (0.85)	18.33 (0.34)			
Time 3	16.67 (0.76)	18.50 (0.91)	*F* (1, 49.50) = 1.30	.26	-0.32
FAD					
Baseline	27.89 (0.93)	26.41 (0.88)			
Time 3	26.57 (1.26)	26.72 (0.91)	*F* (1, 46.73) = 1.43	.24	-0.34
SDQ Impact					
Baseline	4.85 (0.52)	4.37 (0.38)			
Time 3	4.95 (0.52)	4.06 (0.49)	*F* (1, 46.26) = 0.25	.62	0.17

DASS-21 Depression Anxiety Stress Scale*; PANAS* Positive and Negative Affect Schedule; *BFDS* Brief Family Distress Scale; *CFQ* Cognitive Fusion Questionnaire; *AAQ-II* Acceptance & Action Questionnaire; *VLQ* Valued Living Questionnaire; *BMPS* Bangor Mindful Parenting Scale; *PSI-4* Parenting Stress Inventory; *FAD* McMaster Family Assessment Device; *SDQ* Strengths and Difficulties Questionnaire.

Appendix D: Study 2 Interview Guide

Opening Questions

1. Please tell me about your experiences with the facilitators of your Acceptance & Commitment Therapy (ACT) workshop.

2. How would you define a **good facilitator**? What would you hope for and expect from them?

Decision-Making Around Group Participation

3. Do you recall being informed that facilitators would consist of both parents of children with autism, and professional clinicians? If so, did this make a difference with regard to your desire to participate in the workshop? What if you had been told the facilitators would be only parents, or only clinicians?

Specific Questions about Clinicians and Parent Facilitators in ACT

4. Did one facilitator stand out for you? [Why were those qualities important for you? How did they affect your experience in the program? What was it like to (experience these things)]

5. Do you feel that some facilitators were more or less effective than others? [Remind participant of who the facilitators were, and status (i.e., senior/junior, parent/clinician]

6. Can you share your perspective on any value, and/or particular qualities/experiences clinicians bring to group facilitation? What about any value/qualities/experiences that parents bring? Any drawbacks?

7. What, if anything, do you think is helpful, or did you like, about using a combined parent- and clinician-led model? [If parents did like it, ask whether it was helpful for ACT specifically, or would be helpful for other groups as well]. What, if anything, do you think is unhelpful, or could be a drawback, of using combined model?

Experiences Outside of ACT

8. What have been your experiences in the past (i.e., before the ACT workshop) of being in programs led by clinicians? What about programs led by parents of children with autism or other disabilities? [Would you have preferred that there had been parents/clinicians present?]

Ending Questions

9. What are your preferences, in terms of future programs that you participate in, for having them led by parents, professional clinicians, or both?

10. What, if anything, did you get out of participating in ACT? Was there anything you found to be unhelpful or difficult?

11. What advice would you give to program developers/agencies/organizations who are selecting leaders for group therapy programs for parents of people with autism?

12. [Orient back to big question]. Is there anything that I have not asked about that you wish to add, or think is important for me to know?