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Using acceptance and commitment training in the support of parents of children diagnosed with autism

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Keywords

Using, acceptance, commitment, training, support, parents, children, diagnosed, autism

Disciplines

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Using Acceptance and Commitment Training in the Support of Parents of Children Diagnosed with Autism

John T. Blackledge and Steven C. Hayes

Keywords: Chronic mental disorders; collaborative recovery model; treatments

Abstract

Objectives: *Parents of autistic children face enormous challenges, but very little attention has been paid to their psychological needs. Acceptance and Commitment Therapy (ACT) has previously been tested with parents as part of a comprehensive package, but not yet alone. The present study used a within-subject, repeated measures design to test the effects of a 2-day (14 hour) group ACT workshop on 20 normal parents/ guardians of children diagnosed with autism. Parents were assessed three weeks before the workshop, one week before, one week after, and three months after. No significant change occurred while waiting for treatment, but pre to post improvements were found on the Beck Depression Inventory-II (BDI-II), and the Global Severity Index (GSI) of the Brief Symptom Inventory (BSI). Significant pre to follow-up improvements were observed on the BDI-II, BSI, and the General Health Questionnaire-12. Processes measures of experiential avoidance and cognitive fusion also changed and there was some evidence that these changes mediated outcomes seen. Results suggest that ACT may have promise in helping parents better adjust to the difficulties in raising children diagnosed with autism.*

1. INTRODUCTION

Autism is a debilitating disorder, not only to the children who suffer from it, but to their parents. The parents of autistic children experience high levels of chronic stress (DeMyer, 1979; Holroyd, Brown, Wikler, & Simmons, 1975), even more so than parents of Downs Syndrome and psychiatrically diagnosed children (Holroyd & McArthur, 1976; Wolf, Noh, Fisman & Speechley, 1989). The parental feelings that come with autism would be a challenge to anyone. Parents tend to feel responsible and blamed for their children's conditions, guilty and ashamed, and feel even hatred, anger, and blame toward their partners for their perceived responsibility (Konstantareas, 1990).

Mothers of children diagnosed with autism feel frustrated, anxious, and tense more often than mothers of non-disabled and Down syndrome children (Rodrigue, Morgan, & Geffken, 1990), and both parents tend to be exhausted and pessimistic about the future (DeMyer, 1979; DeMyer & Goldberg, 1983).

Given such observations, it is not surprising that these parents have high rates of depressive and anxiety disorders (Breslau & Davis, 1986). Most researchers feel that such pathology is largely “secondary or reactive to the stress and special non-normative adaptations” these children require (Konstantareas, 1990, p. 60).

The state of treatments for parents of children diagnosed with autism differs little now from what was offered 20 years ago: “The common thread that ties most of these intervention strategies together is that their focus is . . . either directly or indirectly on the developmentally disabled child” (Intagliata & Doyle, 1984, p. 4). In other words, the psychological needs of parents themselves are largely ignored. For example, while parent training is widespread, the focus in this training is managing the autistic child. The handful of attempts to address the needs of parents of autistic children (Micheli, 1999; Samit, 1996; Davidson & Dossier, 1982) are methodologically weak, and two of these approaches imparted little more than parenting skills training (Micheli, 1999; Samit, 1996).

Acceptance and Commitment Therapy (ACT; Hayes, Strosahl, & Wilson, 1999) seems particularly applicable to the psychological situation faced by these parents. The difficult thoughts and feelings faced by these parents are not necessarily exaggerated or inaccurate given the extreme and unrelenting challenges these children present. As Singer, 1993 specifically noted (p. 213), for that reason parents often experience traditional cognitive and emotional change strategies as invalidating. Acceptance presents itself as an especially relevant alternative approach, particularly because many of these children’s problems are unlikely to change, at least quickly. Rather than challenging the content of difficult thoughts and feelings, ACT emphasizes acceptance of unpleasant emotions, defusion from difficult thoughts, clarification of the client’s personally held values and corresponding goals, and enhancement of the client’s effectiveness in moving toward those values and goals. This collection of targets seems well suited to the parental stress caused by disabled children. ACT has been successfully used to treat a variety of specific psychological problems (see Hayes, Masuda, Bissett, Luoma, & Guerrero, 2004, for a review) including anxiety and stress (Bond & Bunce, 2000; Twohig & Woods, in press; Zettle, 2003), pain (Dahl, Wilson, & Nilsson, in press), substance use (Gifford, Kohlenberg, Hayes, Antonuccio, Piasecki, Rasmussen-Hall, & Palm, in press; Hayes, Wilson, Gifford, Bissett, Piasecki, Batten, Bird, & Gregg, in press), depression (Zettle & Hayes, 1986; Zettle & Raines, 1989), and burn out (Hayes, Bissett, Roget, Padilla, Kohlenberg, Fischer, Masuda, Pistorello, Rye, Berry, & Niccolls, in press). The current study was designed to produce preliminary data on the effectiveness of a two-day ACT intervention on the depression and distress experienced by parents of children diagnosed with autism, and to provide beginning data on the mechanisms of action of this intervention. Given the preliminary nature of this work and the chronic nature of the challenges faced, a within-group design was used, in which a baseline rate of change was established and then compared to the changes produced by the intervention and retained through follow-up.

2. METHOD

2.1 Participants

The 20 participants in the study were recruited from 3 different geo-graphical regions (the areas surrounding Reno, Nevada, Sacramento, California, and San Francisco, California). English-speaking parents with autistic children were mailed written descriptions of the proposed intervention along with an invitation to participate. There was no attempt to reach only clinically distressed parents, and the intervention was not presented as therapy. Rather it was presented as a supportive, sharing experience that might help parents better cope with the challenges and stress of raising a child diagnosed with autism. The intent was to reach the more normal mainstream of parents in this situation, in part because the long-term goal is to see whether ACT might be included as a normal part of support services for parents in this situation. Letters of support from the directors of their respective programs or agencies were included when possible, and the parents were encouraged to ask the investigator, or staff at the appropriate treatment center or advocacy agency, any questions they had about the nature of the study and the intervention. Parents expressing a desire to participate in the study were then mailed the appropriate consent forms and asked to sign and return these consent forms. Seven parents participated in the Sacramento workshop, six and three parents (respectively) participated in the two San Francisco Bay Area work-shops, and four parents participated in the Reno workshop.

2.2 Measures

Assessment devices used for the study consisted of six self-report instruments, in addition to demographic information. Two self-report instruments measured therapeutic mechanisms of change thought to be active in ACT, and four measured outcomes in the domains of general distress, depression, and perceived control over child behaviour.

2.2.1 Outcome Measures. The Global Severity Index (GSI) from the Brief Symptom Inventory (BSI; Derogatis & Melisaratos, 1983) is a widely used and reliable general measure of psychological distress. Its 53 items cover a broad range of psychological symptoms (e.g., specific items ask how much respondents are distressed by “feeling blue,” having “difficulty making decisions,” and having “the idea that someone else is controlling your thoughts”).

The Beck Depression Inventory–II (BDI; Beck, Steer, & Brown, 1996) is a reliable and very well-known self-report measure of depression. Its 21 items deal with affective, behavioural, and cognitive aspects of this disorder.

The General Health Questionnaire-12 (GHQ-12; Goldberg, 1978) is a 12 item self-report instrument that reliably screens for general psychiatric problems. The GHQ includes items on self-esteem (e.g., “Have you recently felt that you couldn’t overcome your difficulties?”), stress (e.g., “Have you recently lost much sleep over worry?”), and active coping (e.g., “Have you recently been able to face up to your problems?”).

The Parental Locus of Control Scale (PLOC; Campis, Lyman, & Prentice-Dunn, 1986) is a reliable self-report of parenting ability. In order to test for possible generalization from a distress-oriented intervention to parenting performance, a 10-item subscale of the PLOC was used that assessed parents' perceptions of their child management effectiveness. Sample items include "My child's behaviour is sometimes more than I can handle," and "Sometimes when I'm tired I let my children do things I normally wouldn't".

2.2.2 Process Measures: Two self-report instruments assessing ACT-specific processes were used in the study. The Acceptance and Action Questionnaire-9-item version (AAQ; Hayes, Strosahl, Wilson, Bissett, Pistorello, Toarmino, Polusny, Dykstra, et al., in press) measures experiential avoidance, cognitive fusion, and difficulty in acting in the present of negative private events. Sample items include, "I'm not afraid of my feelings", "When I evaluate something negatively, I usually recognize that this is just a reaction, not an objective fact", and "I am able to take action on a problem even if I am uncertain what is the right thing to do." Reliability is on the low end of the range considered adequate for a short scale (Cronbach's alpha = .7; Hayes, Strosahl et al., in press). The AAQ has been shown in some controlled studies to covary with ACT outcomes (e.g., Bond & Bunce, 2000), to covary with a wide range of applied out-comes (Hayes, Strosahl, et al., in press), to predict poor outcomes over as long as a year period (Bond & Hayes, 2003), and to predict poor responses to emotional challenges (e.g., Karekla, Forsyth, & Kelly, in press).

The Automatic Thoughts Questionnaire (ATQ; 30 items; Cronbachal-pha = .97; Hollon & Kendall, 1980) measures the frequency of automatic negative statements about the self. The ATQ was modified to include the believability of automatic thoughts assuming that they occurred (1 = "not at all believable" to 7 = "completely believable") – that is, controlling for frequency. Higher scores on the ATQ-B indicate higher levels of cognitive fusion. Previous research has shown excellent internal reliability of the ATQ-B (Cronbach's alpha = .96; Bissett, 2002). The ATQ-B has also been shown to covary with ACT outcomes (Zettle & Hayes, 1986), and to covary with such applied problems as severity of substance abuse (Bissett, 2002).

2.2.3 Adherence: All 52 hours of the group workshops were videotaped and partitioned into 1-hour segments by the primary author. Thirty percent of these tapes (a total of 16 hours) were randomly evaluated by trained raters using an adherence scale adapted for use in this study.

2.3 Design

A within subject, repeated measures design was used, with a total of four assessment points. For each cohort, the first assessment point occurred three weeks before the intervention, and the second assessment point occurred one week before the intervention. A third assessment was completed one week after each workshop, and the final assessment was completed three months after each workshop.

2.4 Procedure

Each two-day workshop involved a total of 14 hours of instruction, group participation, and experiential exercises drawn largely from Hayes et al. (1999). The last workshop lasted only 10 hours since two of the three participants had a medical conflict during the last two hours of each workshop day. In the remaining three workshops, 14 out of the remaining 17 participants received the entire intervention. One participant did not attend the second day of the workshop for unknown reasons. Two participants left after the first two hours, which was largely orientation, saying that they had come thinking the intervention was on a specific aspect of parenting skills, not parental distress.

2.4.1 Treatment Delivery and Assessment. The full assessment package was given to each cohort three weeks prior to treatment (phase 1), one week prior to treatment (phase 2), one week following the last day of the workshop (phase 3), and three months after the post-treatment assessment (phase 4), for a total of four assessments per cohort. Assessment packages were mailed out prior to each assessment point, with instructions to complete each packet and mail it back to the experimenter by the designated date. At the beginning of each assessment week, the experimenter called individual participants to remind them to complete the assessment. Participants who had not completed and returned an assessment by the designated deadline were again called and reminded. By the time the study was completed, 11% of assessments had not been returned.

2.4.2 Workshop Design. Due to the group workshop format (which allowed less individualized treatment than individual psychotherapy) and the non-clinical status of some of the workshop participants, the intervention may be more appropriately called *Acceptance and Commitment Training* as opposed to *Therapy*. However, material used in the workshop was fundamentally the same as material used in individual ACT psychotherapy protocols. All workshops were facilitated by the primary author. After an introduction regarding the nature and purpose of the workshop, participants were asked to clarify personally held values following an experiential exercise (the “funeral exercise”; Hayes et al., 1999) designed to facilitate this process. An interactive *creative hopelessness* discussion was conducted to get clients in touch with their unworkable emotional and cognitive control strategies. This was followed by extensive use of cognitive defusion techniques and exercises designed to disrupt the verbal aspects of participants’ unpleasant and disabling emotions (e.g., experiential distinctions between *descriptions* and *evaluations*, facilitation of an observer perspective through mediation-like exercises and metaphors highlighting the distinction between *self as context* and *self as content*, etc.). Additional defusion work also occurred in the next stage of the workshop, which primarily involved several experiential exercises and metaphors designed to facilitate participant acceptance of difficult emotions and cognitions. Common ACT exercises from Hayes et al. (1999) such as the “tin can monster,” the “physicalizing,” and the “looking for Mr. Discomfort” exercises were used in this portion of the workshop. Participants were then introduced to making behavioural commitments in the face of discomfort and discouraging thoughts using techniques like the “eye contact” and “choice vs. decision” exercises. Finally, thorough participant values assessment and clarification was facilitated by an interactive discussion of the nature of goals, actions, barriers, and values, including personalized examples of each category.

3. RESULTS

3.1 Characteristic of the Sample

Fifteen females and five males participated in the study, with an average age of 42.85 (ranging from 25 to 66 years). Nineteen of 20 participants reported being married or in a committed long-term relationship; five married couples participated. Seven participants reported having obtained a high school education, while 11 reported having attended college and two reported having received advanced degrees. Twelve of the participants described themselves as White or Caucasian, six as Hispanic, and two as Asian/Pacific Islander. All participants reported having only one child or dependant diagnosed with a developmental disability (all were Autism Spectrum Disorder), and participants had an average of 2.25 children (ranging from one to six children).

3.1.1 Pre-Treatment Distress. Scores of 18, 27, and 34 on the BDI-II indicate mild, moderate, and severe Major Depressive Episodes, respectively (Steer, Brown, Beck, & Sanderson, 2001). Pre-treatment (Phase1) means indicated an average BDI-II score of 13.95, ranging from 3 to 36, with seven participants registering scores of 15 or higher and five participants registering scores of 18 or higher. Two participants exceeded the cut off score indicating severe depression, one participant exceeded the cut off score indicating moderate depression, and two participants exceeded the cut off score indicating mild depression.

In the general population the average GSI is .30, with a standard deviation of .31 (Derogatis & Melisarotos, 1983). Phase 1 GSI scores averaged 0.71 and ranged from 0.04 to 2.23.

GHQ-12 scores averaged 18.2 at Phase 1 and ranged from 11 to 28. Scores of 11 or higher predict the existence of one or more psychological diagnoses with nearly 80% sensitivity and specificity (Goldberg, Gater, Sartorius, Ustun, Piccinelli, Gureje, & Rutter, 1997).

PLOC scores averaged 19.95 at Phase 1 and ranged from 10 to 33. A mean score of 31 (recall that higher scores mean lower perceived efficacy) was observed in a sample of parents requesting professional help with parenting (Campis et al., 1986). Given the relatively good scores on the PLOC, this measure was dropped from further analysis.

The recruitment strategy followed in this study was designed to obtain a normal sample of parents facing the stress of raising a child diagnosed with autism. That appears to characterize this group. Looking across the outcome measures, these parents believed that they were relatively effective in child management (perhaps not surprising given that most had already received training and support from various agencies), but most were still distressed. Their mean GHQ score would predict the presence of at least one psychiatric diagnosis, for example, and the GSI score on average was about 1.3 standard deviations above the mean. Only a minority was depressed, and only a few participants were severely distressed. Overall, this sample appears to be a relatively healthy sample of parents experiencing the stress of raising an autistic child.

3.2 Adherence

Sixteen of 52 1-hour tapes (31%) were randomly selected and rated for the presence of eight ACT-consistent processes on a five point scale (from “not at all” to “extensively”). The eight processes were designed to cover all of the major areas of the workshop, and included ratings of:

(1) therapist metaphor use; (2) therapist attempts to enact experiential acceptance; (3) therapist efforts to elucidate the problematic nature of client emotional/cognitive control efforts; (4) exploration of previous client change efforts; (5) therapist use of language conventions intended to en-act cognitive defusion; (6) encouragement of clients to make and keep behavioural commitments; (7) facilitation of client values and goals clarification; and (8) therapist attempts to help clients discriminate their *selves-as-context*. Each hour-long segment was scored by two graduate students familiar with ACT and trained to use the rating system by the primary author. Inter-rater reliability across these 16 tapes was 0.93. All of the tape segments had “considerable” to “extensive” emphasis on at least one (sometimes two) ACT processes, with the exception of one taken from very first hour of a workshop (consisting of introductory and orienting remarks). Furthermore, each of the eight processes addressed by the coding system received this level of emphasis on at least three of the 16 tapes. This shows that all of the expected processes were covered and the segments were indeed focused on ACT processes.

3.3 Data Analysis

Because most of the measures used were not normally distributed, non-parametric Wilcoxon signed-ranked tests were used to assess process and outcome effects. Planned contrasts were made between phases 1 and 2, 1 and 3, and 1 and 4. This allowed us to assess first whether time alone was likely to alter these measures (phase 1 compared to phase 2), and then against that backdrop to examine pre to post (phase 1 compared to 3) and pre to follow-up changes (phase 1 compared to phase 4). A failure to find significant changes between the two pre-intervention phases, combined with such changes from pre to post or pre to follow-up would provide controlled evidence of an intervention impact. In all tests, only p values of .05 or less were interpreted. The pre- to post- and pre- to follow-up tests were one-tailed since directional predictions had been made.

No correction was used for multiple comparisons since the study used only three outcome measures and had clear outcome predictions. Given the relatively small N, and the use of the standard alpha level of .05 throughout, further restriction of alpha levels would also result in an under-powered test, substantially increasing the risk of a Type II error, which seem particularly undesirable given the state of the literature.

3.4 Analysis of Outcomes

TABLE 1: Phase Means for the Outcome Measures

Measure	PHASE	Mean	Std. Error
BDI	1	13.95	2.32
	2	12.05	2.27
	3	9.75	1.82
	4	10.00	2.16
GSI	1	.71	.16
	2	.65	.14
	3	.42	.10
	4	.54	.12
GHQ	1	18.20	.86
	2	18.70	.87
	3	16.85	.86
	4	17.45	.88

GHQ-12 ($z(20) = -1.43, p = ns$). Significant pre to follow-up improvements were found for the BDI-II ($z(20) = -2.52, p = .006$, one-tailed), the GSI ($z(20) = -2.03, p = .021$, one-tailed), and the GHQ-12 ($z(20) = -1.67, p = .048$, one-tailed).

3.4.1 Magnitude of Results. While statistically significant outcome changes were seen, the average changes were not large. BDI-II scores changed an average of about four points from pre-treatment to post-treatment and follow-up, for example. It should be remembered, however, that the mean BDI-II score in this group of normal parents was below the cut off for depression. In order to more fully understand the impact of the intervention we will now explore the magnitude of the results with those who were above or approaching clinical cut offs for the BDI (for brevity's sake we will not repeat these analysis with other major outcome measures, but the pattern was similar for these areas as well).

If we consider just the five participants with BDI-II scores 18 or above at baseline, their mean BDI-II scores were 29.6, 26, 19.8, and 20.6 across the four phases. These pre-post changes are larger than that seen in the overall analysis (approximately ten points) and the retention of improvement from post to follow-up is very good (reflecting a pre-follow-up change of nine points). If these values are subjected to the same Wilcoxon signed-ranks test used in the main analysis, no significant difference is found for Phase 1 to Phase 2 changes ($z(5) = -1.22, p = ns$), but significant changes are found for Phase 1 to

Phase 3 ($z(5) = -1.83, p = .034$, one-tailed), and Phase 1 to Phase 4 ($z(5) = -2.06, p = .02$, one-tailed). Conversely, the same means for participants with initial scores below 18 were 8.73, 7.4, 6.4, and 6.47. None of these changes are significant, although the pre to post ($z(15) = -1.61, p = .054$, one-tailed) and pre to follow-up ($z(15) = -1.60, p = .054$) comparisons are very close, in part because participants just below the score of 18 also did very well. If the participants who began with BDI-II scores just below the clinical cut off are added (i.e., BDI \checkmark 15), the division among participants is similarly clear. The mean BDI-II scores for this group were 25.4, 21.3, 15.4, and 15.6 across the four phases. If these values are subjected to the same Wilcoxon signed-ranks test used in the main analysis, no significant difference is found for Phase 1 to Phase 2 changes ($z(7) = -1.58, p = ns$), but significant changes are found for Phase 1 to Phase 3 ($z(7) = -2.20, p = 0.014$, one-tailed), and Phase 1 to Phase 4 ($z(7) = -2.38, p = .008$). Conversely, the same means for participants with initial scores below 15 were 8.6, 12.2, 10.4, and 12.6. None of these changes are close to significance. This overall pattern shows that improvement is occurring primarily in participants in the clinical range or just below, not among those well into the non-clinical range, and that among these the changes are fairly substantial.

3.5 Analysis of Process Variables

There were two process measures of ACT concepts: the AAQ, which measures experiential avoidance, and the ATQ-B, which measures cognitive fusion. Phase means are shown in Table 2. At baseline only a minority of this group was emotionally avoidant. Phase 1 AAQ scores averaged 32.6 and ranged from 20 to 47. The average AAQ score in a non-clinical population is 38; the average clinical population score is 42 (Hayes, Strosahl et al., in press). Phase 1 ATQ-B scores averaged 73.5 at Phase 1, ranging from 31 to 151. Previous research has shown that the internal reliability of the believability of thoughts scale added to the ATQ are also excellent (Cronbach's $\alpha = .96$; Bissett, 2002). The ATQ-B has also been shown to covary with ACT outcomes (Zettle & Hayes, 1986), and to covary with such applied problems as severity of substance abuse (Bissett, 2002).

TABLE 2: Phase Means for the Process Measures

Measure	PHASE	Mean	Std. Error
AAQ	1	32.55	1.75
	2	31.25	1.75
	3	32.30	1.65
	4	31.00	1.68
ATQ-B	1	73.50	8.18
	2	68.15	9.54
	3	61.95	8.88
	4	63.40	9.07

As with the outcome measures, these two measures were examined using Wilcoxon signed-ranks tests for planned comparisons on each measure between phases 1 and 2, 1 and 3, and 1 and 4.

Changes from Phase1 to Phase2 were first examined to see if any of the measure improved due to time alone. Neither the AAQ ($z(20) = -1.35, p = ns$), nor the ATQ-B ($z(20) = -1.47, p = ns$) showed significant changes. From pre to post, the ATQ-B improved ($z(20) = -2.07, p = .02$, one-tailed), but the AAQ did not ($z(20) = -.31, p = ns$). From pre to follow up, statistically significant improvement was found for both the AAQ ($z(20) = -1.72, p = .043$, one-tailed), and the ATQ-B ($z(20) = -1.81, p = 0.035$, one-tailed).

3.6 Meditational Analyses

The particular design used in this study does not allow for a straight-forward application of popular methods of meditational analysis (e.g., Baron & Kenny, 1986) since there is no control group and it is thus not possible to regress treatment on outcome with the mediator factored out. However, the logic of meditational analysis can be approximated.

In order to give changes in mediators time to impact outcomes, in this part of the analysis we are focused on outcomes assessed at follow-up and mediators assessed at post-assessment. Since the AAQ did not improve at post, we examined the possible meditational role of defusion as assessed by the ATQ-B, given that it showed no statistically significant change from Phase 1 to 2 but did in Phases 1 to 3. Table 3 shows that the post scores for the ATQ-B correlate significantly with all three outcomes at follow-up (range: .42 to .57). These findings together with the previously reported pattern among outcome measures (i.e., lack of statistically significant changes from Phase 1 to 2 and the statistically significant change from Phase 1 to 4) provide preliminary evidence of mediation but a higher test (Barron & Kenny, 1986) is that the improvement seen in follow-up outcomes should be reduced or eliminated when the mediator is factored out. When the ATQ-B post scores were used as a covariate, none of the follow-up differences in outcomes remained. Unfortunately assessment was not frequent enough to detect possible changes in process variables *before* outcomes changes occurred and for that reason this meditational result must be viewed only as suggestive.

TABLE 3: Spearman's rho between the Post ATQ-B and Follow Up Outcomes

Post workshop processes	BDI-II	GHQ-12	GSI
ATQ-B	.57**	.42*	.52**

* $p < .05$; ** $p < .01$

4. DISCUSSION

Overall, these results provide evidence that ACT improved psychological outcomes in a group of parents with children diagnosed with autism. Most of the gains achieved were retained over a 3 month period. ACT also reduced experiential avoidance and cognitive fusion. There was some evidence that the latter played a role in the outcomes obtained. This pattern of results provides preliminary support both for ACT as a technology that can help ameliorate the psychological distress of parents with autistic spectrum children, and for the model of distress that underlies ACT.

Process analyses reveal that both measures changed significantly from pre-treatment to follow-up, and that ATQ-B post-treatment scores are also significantly different from pre-treatment. The small and delayed impact on AAQ scores might be both because this group had relatively normal AAQ scores to begin with and because (like the GHQ) the active coping component of the AAQ may take time to develop. There is evidence that the ATQ-B, which assesses the ACT concept of cognitive fusion (i.e., the “believability” of thoughts) mediated ACT outcomes.

There are several limitations to this discussion. It was a small trial, with only 20 participants. Half of the participants were couples, there was an 11% assessment non-completion rate, and there was no formal control group. As a result, the study could not control for expectancy, social support, or other generally helpful psychosocial processes that are inherent in any treatment. The process measures provide some reassurance that the effects seen here fit the treatment model, but it is not possible to make up fully for the lack of random assignment to a well-crafted control condition.

Many of the participants were not highly distressed according to the measures used here. This is not surprising given that the purpose of the study was to examine the impact of an ACT workshop on a sample of normal parents facing the challenges inherent in raising a child with a diagnosis of autism but this further reduced the power of the study. The outcomes observed may be interesting in that light, however, because workshops such as these could readily be integrated into normal parent training and similar interventions commonly used with these parents. A workshop format was used because of concerns that the often extreme demands on their time and energy resulting from their parental role might make multi-session therapy impractical. It is probably easier for parents to schedule one weekend away than a few hours every week for several weeks. Furthermore it seemed that time-limited, group interventions may be a more realistic intervention choice for agencies interested in providing direct care to the parents whose children they treat. The relatively low drop out rate (3 of 20 participants) and the relatively good outcomes provides support for these decisions.

The process measures used for the study were not optimal. The believability scale of the modified ATQ has been used as a process measure for ACT for 18 years (Zettle & Hayes, 1986) but there are only very limited reliability data available (e.g., Bissett, 2002) and even more limited validity data. The nine-item AAQ used in the study is designed more for population-based studies than as a process measure, and its psychometric properties are only adequate (Hayes et al., in press). The AAQ and ATQ-B are also very general process measures. In other ACT studies, process measures designed to address the specific areas targeted have generally been more effective, especially as mediators of change (e.g., acceptance of diabetes-related feelings or thoughts for diabetes management using ACT: Gregg, 2004; acceptance of

smoking-related feelings or thoughts for smoking cessation using ACT: Gifford et al., in press; defusion from stigmatizing thoughts for stigma reduction using ACT: Hayes, Bissett et al., in press). Because of the very general processes measures used in the present study, it is unknown whether participants improved at accepting difficult emotions and defusing from problematic thoughts associated with parenting a disabled child. Development of such a measure would be useful for future use of this intervention.

The intervention itself may have benefited from the inclusion of more specifically focused defusion and acceptance techniques. Fairly general ACT methods were used in this study. Parents themselves applied these exercises to their parenting difficulties, but it probably would have been more effective to use more therapist-provided examples and exercises dealing specifically with the cognitive and affective barriers associated with parenting. For example, participants could have been asked to focus systematically on the difficult choice points presented to these parents by their children, and defusion and acceptance work could then have focused more on these issues.

Other innovations might also help increase the impact of the intervention. One or two follow-up sessions might have been scheduled in the months following the intervention. Such sessions (perhaps consisting of a few hours each) could focus on further clarifying participants' values, correcting misperceptions about techniques and strategies taught in the initial workshop, and identifying and defusing additional cognitive barriers to effective action that were not sufficiently targeted during the work-shop. Follow-up sessions such as these might be more effective if they were conducted individually, as values clarification and identification and defusion of problematic cognitions can be complicated and thus benefit from individualized attention.

Finally, measurement of changes in various aspects of psychological distress may not provide the best test of the effectiveness of ACT, a treatment whose most important professed goal is increased effectiveness in pursuing personally meaningful values and goals. While decreases in various types of psychological distress are a very welcome occurrence they are not a substitute for more behavioural measures. Attempts are currently being made to develop assessment measures that validly and reliably assess values-consistent behaviour (e.g., Wilson & Murrell, in press). Development of such an instrument should be very useful in assessing the effects of ACT.

5. CONCLUSION

Prior to this study, ACT had never been tested empirically with parents of children diagnosed with autism. The present study provides evidence that it can be effective with this population and suggests that larger, better controlled studies should now be pursued.

Parents of children diagnosed with autism face enormous challenges. There has been an explosion of research on how to help these children: it is time for the needs of the parents to receive serious attention.

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