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Sticking With It: Psychotherapy Outcomes for Adults with ASD in a College Counseling Center Setting

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Sticking With It: Psychotherapy Outcomes for Adults with ASD

in a College Counseling Center Setting

Emily Irene Anderberg

A thesis submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of

Master of Science

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ABSTRACT

Sticking With It: Psychotherapy Outcomes for Adults with ASD in a College Counseling Center Setting

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Young adults with autism spectrum disorders (ASD) experience high rates of comorbid mental health concerns in addition to distress arising from the core symptoms of autism. Many adults with ASD seek psychological treatment in outpatient facilities in their communities that are not specifically geared towards individuals with ASD. However, few studies have looked at the effectiveness of standard psychotherapeutic care in adults with ASD. This study aims to discover how individuals with autism spectrum disorders fare in psychotherapy within a college counseling setting compared to their neuro-typical peers. Clients with ASD ($n = 94$) or possible ASD ($n = 109$) were identified from counseling center case notes and the Outcome Questionnaire-45 (OQ) was used to track distress at each session. Clients with ASD showed no difference in level of distress at intake compared to their neuro-typical peers ($n = 29,326$) and improved about the same amount from pre- to post-treatment. However, students with ASD stayed in treatment for significantly more sessions than neuro-typical clients. Overall, adult therapy clients with autism spectrum disorder appear to benefit from typical counseling center services as much as their neuro-typical peers. They also tend to stay in therapy longer than their peers. Results are discussed with implications for counseling centers and future research directions.

Keywords: autism spectrum disorder, counseling, treatment, outcomes, adults

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Introduction

Autism spectrum disorder (ASD) is characterized by impairments in social communication and a restricted, repetitive pattern of interests and behaviors which emerge in early childhood and endure into adulthood. Contrary to previous beliefs, many adults with ASD are able to, and choose to, attend university. One study estimated that students with ASD make up between 0.7 and 1.9% of their university's undergraduate population (White, Ollendick, & Bray, 2011). Many of these students come to college undiagnosed with ASD and struggle significantly with the social, academic, and self-care aspects of college life (White, Ollendick, & Bray, 2011). In addition to college-specific concerns, adults with ASD experience high levels of comorbid psychiatric disorders (White, Oswald, Ollendick, & Scahill, 2009). About 40% of adults with ASD experience at least one anxiety disorder (commonly social anxiety disorder, obsessive compulsive disorder, and specific phobias; Van Steensel, Bögels, & Perrin, 2011; White, Oswald, Ollendick, & Scahill, 2009) and around 50% experience clinical depression (Bakken et al., 2010). Like their neuro-typical peers, many college students with ASD seek out psychotherapy for social and emotional difficulties at their university counseling center (Kitzrow, 2003).

However, little is known about how adults with ASD respond to psychotherapy. Several randomized controlled trials have shown that CBT is efficacious for treating anxiety disorders in adults with ASD (Russell et al., 2013; Hesselmark, Plenty & Bejerot, 2013; Wood et al., 2015). Several others have examined CBT in children and adolescents (Scattone & Mong, 2013; Sukhodolsky, Bloch, Panza & Reichow, 2013) or in smaller case-studies of adults (Cardaciotto & Herbert, 2005; Hare, 1997). Outside of traditional CBT, one study has shown that a modified version of mindfulness-based therapy is efficacious for adults with ASD and comorbid anxiety or

depression (Spek, van Ham & Nyklicek, 2013). However, this field of study has not yet moved towards effectiveness trials. Additionally, while many studies use protocols specifically modified for adults with ASD, most adults with ASD will receive psychotherapy that is more general and counseling services when they present at their local clinic. Thus, little is known about the therapy outcomes of adults with ASD in their communities.

The present study aims to begin to fill these gaps in the research literature by utilizing a large college counseling center dataset to investigate the psychotherapy outcomes of young adults with ASD. We aim to investigate the therapy experience of college students with ASD from several angles: 1) Do students with ASD and neuro-typical students present to therapy with similar levels of distress? 2) Do they stay in therapy for the same amount of sessions? 3) Do they receive the same reduction in distress as their peers from pre- to post-treatment? 4) Do their change trajectories in therapy match those of neuro-typical students? The answers to these questions should begin to illustrate how adults with ASD fare in psychotherapy treatment as usual in their communities and provide direction for clinics and counseling centers aiming to better serve young adults on the spectrum.

Method

Participants

This study was conducted from archival records of students who had received treatment at the Brigham Young University Counseling and Psychological Services Center (CAPS) between 1993 and 2015. All participants had given consent at the time of their treatment for their records to be used for archival research. The therapy case notes (N = 271,343) for these students were searched for key terms: autism, Asperger, autistic, ASD, PDD, and spectrum. This search

identified 1,043 notes containing one or more of these terms. Two independent raters then read each therapy note and categorized the content into one of three categories: student has reportedly been diagnosed with ASD (confirmed ASD, CASD), student was possibly diagnosed or is pursuing an evaluation of ASD (possible ASD, PASD), or student's record does not indicate ASD (neuro-typical, TYP). The raters then met together with the research team to discuss the discrepant ratings and agree upon a final rating. The raters agreed on 93% of their initial ratings. Using this process, we identified 94 individuals who have ASD and 109 individuals who may have ASD. We then compared the therapy participation and outcome statistics for these individuals with those of the neuro-typical students who attended therapy at CAPS during that time period. The demographic characteristics of the three groups in this study appear in Table 1. Neuro-typical students with demographic characteristics (religion, nationality, marital status, etc.) that did not match any students in the ASD groups were removed (N=11,466). For example, all students in the confirmed ASD and probable ASD groups identified as belonging to a single religion (Church of Jesus Christ of Latter Day Saints; LDS) and thus all non-LDS students in the neuro-typical group were removed to provide a semi-matched control group. This type of matching was performed to utilize the large data set while still ensuring the groups were demographically similar.

Setting

All participants received treatment as usual at the university counseling center (CAPS), delivered in individual or group therapy formats. Counseling sessions involve a wide variety of theoretical orientations (e.g., cognitive-behavioral, acceptance and commitment therapy, interpersonal). At this clinic, students who request counseling are assigned to the first available

psychologist or doctoral student, and they receive treatment as usual according to that clinician's theoretical orientation. Specific requests such as for a specific therapist gender or therapeutic orientation are granted if available. Additionally, students can be referred to a psychotherapy group or biofeedback services. Clients treated at CAPS present with a variety of problems and symptoms, ranging from home-sickness and adjustment disorders to personality disorders. Clients in the current study presented for personal and emotional concerns rather than for academic or career counseling.

Measures

Outcome Questionnaire (OQ-45). Client distress levels were evaluated using the Outcome Questionnaire 45 (OQ-45; Lambert et al., 2004), a 45-item self-report measure developed to track client progress and outcomes during psychotherapy. All clients were asked to complete the OQ-45 shortly before each session, either at home or in the waiting room. The OQ-45 has been validated for a range of clinical and non-clinical populations. Lambert and colleagues (2004) report an internal consistency of .93 and a test-retest reliability (3-weeks) of .84. The OQ-45 has demonstrated sensitivity to change in client functioning during psychotherapy (Vermeersch, Lambert, & Burlingame, 2000; Vermeersch et al., 2004). OQ items are scored on a 5-point scale (0: never, 1: rarely, 2: sometimes, 3: frequently, 4: almost always), which yields a total score from 0 to 180. High scores indicate more distress, and thus as clients improve, scores decrease. Typically, scores above 63 represent a clinical population (Kadera, Lambert, & Andrews, 1996). The standard deviation for this measure is 15 points, and 14-point increases or decreases are considered reliable change (Lambert et al., 2004).

Data Cleaning and Analysis

Due to the large time span and size of the data set, there is a significant amount of missing data. Students may neglect to fill out an OQ score for a session attended or skip questions. Because of the relatively small sample size of ASD clients involved in this study and since there were no conceptually compelling reasons to exclude participants with missing data, we included all data available for each analysis. For each subject, a new “course of treatment” was started if there was more than a 90 day gap between sessions. One difficulty of this complex data set is that session notes and information do not always coordinate by date with the OQ. Not every appointment required that the subject complete an OQ, especially if there was more than one appointment in a week. Furthermore, the OQ was not always completed on the same day as the session. Ultimately, each OQ score was associated with the closest appointment within 3 days of the survey completion date.

We used general linear models and Kruskal-Wallis (nonparametric rank-based ANOVA) to determine the difference in mean total OQ score and mean number of sessions between groups while controlling for several covariates (age, initial OQ, gender, marital status, ethnicity, and year). We also used a repeated measures mixed model with total OQ as the response variable; gender, marital status, and age as fixed effects; and subject as a random effect.

Results

Initial OQ

To determine whether students with ASD presented with similar levels of distress to their neuro-typical peers, we performed an ANOVA comparing the first-session OQ scores of the three groups: confirmed ASD (CASD; $M = 67.7$, $SD = 26.3$), probable ASD (PASD; $M = 69.4$,

$SD = 26.2$), and neuro-typical (TYP; $M = 66.7$, $SD = 23.7$). We found no significant differences between groups on initial OQ, $F(2, 29584) = 1.14$, $p = .32$. Students with ASD and neuro-typical students tend to present for therapy with comparable levels of general distress.

Time in Therapy

Because the data were positively skewed (as some clients stay in therapy for a very large number of sessions), we performed a Kruskal-Wallis rank sum test to determine whether time in therapy (within each course) differed between groups. Table 2 shows the means and standard deviations of number of sessions completed for each course. Kruskal-Wallis p-values show that the three groups were different in the length of their clients' first course of therapy. Follow-up pairwise tests indicated that the confirmed ASD group was in therapy significantly longer than the neuro-typical group ($p < .001$) and the possible ASD group was also in therapy significantly longer than TYP ($p < .001$). Overall, it appears that when they first come to therapy (course 1), students with ASD tend to stay for more sessions on average than their peers.

Additionally, as early dropout is a significant problem in the general therapy population, we looked at the percentage of clients attending only one session. In neuro-typical group, 27% ($N = 7858$) only attended one session. However, only 19% ($N = 18$) of the CASD group and 17% ($N = 18$) of the PASD group stayed for only one session.

Change from Pre- to Post- Treatment

We conducted an ANOVA to determine whether the average change from first to last session within the first course of therapy differed between the three groups, controlling for gender, marital status, country of residence, ethnicity, year of therapy, and age. Descriptive

statistics for OQ change, including means, quartiles, and minimums and maximums, are included in Table 3. On average, all groups showed improvement in therapy (reduction in OQ from beginning to end of therapy), and there were no significant differences between groups, $F(2, 21689) = .581, p = .56$. Students with ASD and possible ASD improved about the same amount as their neuro-typical peers from the beginning to end of each course of treatment.

We also performed a regression analysis with initial OQ as the explanatory variable and final OQ as the response variable to determine the degree to which initial OQ predicts final OQ. The overall slope was 0.64, indicating a strong relationship between initial and final, such that for every 1 point increase in initial OQ, final OQ increases by 0.62 points. There were no significant differences in slope between the three groups, indicating that initial OQ predicts final OQ in all groups. The more distressed a client is at the beginning of therapy, the more distressed they are at the end, even after controlling for demographic variables.

Change Trajectories

We performed a repeated measures mixed model with total OQ as the response variable and with diagnosis, session number, and the interaction between these as explanatory variables of interest. In addition we controlled for other covariates including gender, marital status, country of citizenship, ethnicity, and age. The repeated measures analysis also accounted for within subject correlations. Since we are interested in the trajectory of total OQ and we don't believe the trajectory is strictly linear, we included cubic terms for session number, which allows the trajectory a more complex path. The interaction between cubed session number and diagnostic status was significant for both CASD ($p < .001$) and PASD ($p = .002$), indicating that the cubic trajectories for both ASD groups are significantly different from the trajectory of the

TYP group. Figure 1 shows the lowest curves of the change trajectories for all three diagnostic groups, stopping at each group's average number of sessions to their lowest OQ score. Results of the mixed model suggest that these trajectories are significantly different from one another. The CASD group and PASD groups appear to take more sessions than the TYP group to reach their lowest OQ scores. Overall, the change trajectories of students with ASD and their peers are significantly different from one another, with the ASD group making slower progress towards their lowest point and taking significantly more sessions to reach this point.

Discussion

The current literature has a dearth of information on therapy outcomes for adults with ASD, especially in college counseling centers and other typical psychotherapy settings. This study of college students with ASD presents new findings about counseling processes and outcomes in this population.

In order to better understand where students with ASD were starting in therapy we investigated OQ scores at the first appointment. Students with ASD or possible ASD in our sample presented with the same amount of initial overall distress as their neuro-typical peers. Thus, on average, they are not waiting to seek services when they are very highly distressed or coming to therapy for very minor concerns. Rather, they are seeking therapy for a similar level of distress to that of their peers. We have not yet explored the nature of clients' presenting problems, though this is an important area for future study.

Once they present to therapy, students with ASD are staying in therapy for a larger number of sessions than their neuro-typical peers. In fact, within their first course of therapy students with ASD attended about twice as many sessions as neuro-typical students.

Additionally, only 18% of students with ASD dropped out of therapy after only one session compared to 27% of the neuro-typical group. This is very encouraging and indicates that the ASD group is willing to stick with therapy once they start. This may be occurring for several reasons. First, individuals with ASD tend to prefer structure and predictability and thus may continue to keep their appointments when other students may lapse due to a busy schedule or other demands. Second, clients with ASD may not feel relief as quickly and thus remain in therapy for longer in order to feel as though their course of therapy was successful.

This latter hypothesis is supported by the change trajectories of the three groups. Students with ASD improved about as much in therapy as their neuro-typical peers. The ASD groups both had a median improvement of 6 points during each course of therapy, and the TYP group similarly improved about 7 points. However, the ASD group stayed in therapy longer, and, as Figure 1 shows, it took longer for them to reach their lowest OQ scores. This change trajectory was significantly different from the trajectory of neuro-typical clients. Overall, it may be taking more sessions for clients with ASD to feel comfortable in therapy and begin to feel relief, but they are willing to stick with therapy while this slower change occurs.

This study has several important implications for individuals with ASD and their treatment providers. First, counseling centers should be aware that students with ASD are visiting their clinics and have need of their services. Second, clients with ASD should be encouraged to stick with therapy even if they don't see immediate results, as it appears that it may just take longer for the treatment to reach its peak influence. Third, session caps at counseling centers likely are detrimental to students with ASD, who generally take almost twice as long to make their biggest improvements in therapy. Finally, counselors should be aware that

therapy may look a little different with their clients on the spectrum, but they have the potential to improve in therapy just as much as their neuro-typical peers.

This study has several limitations that may make results difficult to generalize broadly. First, the ASD group was not confirmed with a formal diagnosis but was instead identified by mentions made of their diagnostic status in therapy case notes. While the raters agreed overwhelmingly on which category to place flagged participants in (possible, confirmed, or neuro-typical), this does not necessarily mean that the diagnosis is accurate. For example, if a case note mentioned that the client had been diagnosed with autism as a child, this participant was placed into the confirmed group, even though it is possible that the client was misdiagnosed, was mistaken about their history, or no longer meets criteria. However, as this was archival research, formal confirmation of the diagnosis was not a reasonable undertaking. Additionally, the demographic characteristics of our sample were fairly limited. We used college students who self-presented for treatment. Thus, results may not directly extend to adults with lower cognitive capacities, of older age, or those brought to therapy by a parent or other service provider. Our sample is also overwhelmingly white/Caucasian (90%) and of one religious group (LDS, 100%), which, while representative of the sampled university community, is not representative of most other populations in the US.

This study was conducted in order to better understand the outcomes of adults with ASD participating in counseling. Due to the relative lack of research in this area, there remain many topics that should be explored in future research endeavors. With our current data set, we would like to investigate the subscales of the OQ-45 to determine if clients with ASD show a different pattern of distress than their peers. We would also like to explore the progress of those in group therapy versus those in individual therapy, as there may be a difference in the duration of

treatment or the change trajectories of these two groups. Future studies should explore therapy outcomes for other adult ASD populations and settings, such as with older or less cognitively able adults, in community mental health centers, and in marital or family therapies. Within the college counseling center population, it would be helpful to know the therapy utilization rates of those formally diagnosed with ASD, as well as investigating outcomes of therapies targeting core symptoms of ASD (social skills training) versus comorbid disorders and symptoms (anxiety, depression, etc.). The current study represents a necessary first step in understanding the processes and outcomes of adults with ASD utilizing college counseling center services.

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Appendix

Table 1 *Demographic Characteristics of Study Groups*

| | TYP | CASD | PASD |
|----------------------------|-------------|----------|----------|
| Total | 29326 | 94 | 109 |
| <u>Gender</u> | | | |
| M | 12278 (42%) | 67 (71%) | 72 (66%) |
| F | 17048 (58%) | 27 (29%) | 37 (34%) |
| <u>Marital Status</u> | | | |
| Married | 13560 (46%) | 13 (14%) | 24 (22%) |
| Single | 15766 (54%) | 81 (86%) | 85 (78%) |
| <u>Citizenship Country</u> | | | |
| USA | 28282 (96%) | 92 (98%) | 104 (5%) |
| Unknown | 665 (2%) | 2 (2%) | 1 (.9%) |
| CAN | 257 (.8%) | 0 (0%) | 1 (.9%) |
| SKO | 97 (.3%) | 0 (0%) | 1 (.9%) |
| HK | 21 (<.1%) | 0 (0%) | 1 (.9%) |
| ARM | 4 (<.1%) | 0 (0%) | 1 (.9%) |
| <u>Ethnicity</u> | | | |
| WHI | 23090 (79%) | 82 (87%) | 98 (90%) |
| CAU | 3303 (11%) | 0 (0%) | 1 (.9%) |
| HIS | 1267 (4%) | 2 (2 %) | 4 (4%) |
| ASN | 717 (2%) | 4 (4%) | 2 (2%) |
| AMI | 260 (.9%) | 3 (3%) | 0 (0%) |
| PAC | 256 (.9%) | 2 (2%) | 2 (2%) |
| BLK | 191 (.6%) | 0 (0%) | 1 (.9%) |
| Unknown | 133 (.4%) | 1 (1%) | 0 (0%) |
| OTH | 109 (.4%) | 0 (0%) | 1 (.9%) |
| <u>Age</u> | | | |
| Mean | 22.2 | 21.52 | 21.57 |
| SD | 3.17 | 3.64 | 2.75 |

Table 2. Mean (SD) Number of Sessions Within Course.

| | |
|------------|-------------|
| <i>TYP</i> | 4.89 (6.5) |
| CASD | 9.96 (17.8) |
| PASD | 7.13 (7.8) |
| p-value* | <0.001 |

*Kruskal-Wallis p-value

Table 3. *Change in OQ During the First Course (Initial OQ – Final OQ)*

| | TYP | CASD | PASD |
|--------|------|-------|-------|
| Min | -107 | -64 | -69 |
| Q1 | -21 | -20.3 | -16.5 |
| Median | -8 | -6 | -6 |
| Q3 | 3 | 2 | 3 |
| Max | 118 | 40 | 36 |
| Mean | -9.7 | -9.4 | -7.9 |
| SD | 19.7 | 19.9 | 19.9 |

**Negative numbers indicate reductions in distress*

Figure 1. Average OQ across sessions by group

