


SHORT REPORT

Perceived helpfulness of depression treatments among young adults with autism

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Abstract

Currently available treatments for depression show limited effectiveness in adults with autism spectrum disorders (ASD) based on measures of symptom changes and clinician impressions. Perceived helpfulness is another metric that has been found to be useful for understanding treatment outcomes in the general population, but it has not yet been explored in adults with ASD. Thus, the current study collected online survey data to examine patient-perceived treatment helpfulness in a sample of 144 adults with ASD who reported that they were currently receiving community-based treatment for depression. Findings indicate that while there was variability in the levels of perceived helpfulness for both medication and individual therapy, most adults with ASD perceived treatment to be at least moderately helpful. Notably, adults with ASD reported having been in treatment for a prolonged duration (5 to 6 years). Ordinal logistic regression models showed that adults with more depressive symptoms perceived treatments to be less helpful (i.e., medications: odds ratio [OR] = 0.92, 95% confidence interval [CI] = 0.89–0.95; individual therapy: OR = 0.95, 95% CI = 0.92–0.99). Moreover, women perceived medication as more helpful than men (OR = 2.33, 95% CI = 1.13–4.82). Other individual (i.e., age, race, education level) and treatment (i.e., treatment length, concurrent treatment) characteristics were not significantly associated with perceived helpfulness. These findings suggest that future studies may want to use perceived helpfulness, in addition to traditionally used objective outcomes, to understand patients' treatment experience and evaluate depression treatments for adults with ASD.

Lay summary: Adults with autism are much more likely to be depressed than those without autism; therefore, effective depression treatments are necessary to improve mental health outcomes in this group. This online survey study found that most adults with autism felt that the depression treatments they were receiving in the community (i.e., medication and individual therapy) were helpful. Females and those with fewer symptoms of depression felt treatments were more helpful compared with males and those with more symptoms of depression. Our findings suggest that when examining whether treatments for depression are effective, it may be important to measure adults' feelings about the helpfulness of the treatments in addition to measuring changes in symptoms of depression.

KEYWORDS

depressive symptoms, individual therapy, measure, medication, treatment helpfulness

INTRODUCTION

Depression is significantly more common in adults with autism spectrum disorders (ASD) than in the general

population (Hasin et al., 2018; Hollocks et al., 2019; Joshi et al., 2013). To date, clinicians treating depressed adults with ASD have relied on interventions that are established for the general population (Howes

et al., 2018), with medication and psychotherapy most commonly used (Zheng et al., 2021). While the number of published studies about the use of these treatments in adults with ASD has increased over the past decade (Gotham et al., 2020; Keefer et al., 2018), evidence of their effectiveness in this population is limited (White et al., 2018).

Studies of depression treatments for adults with ASD commonly employ objective measures of treatment effectiveness, including standard self- and informant-report measures of depressive symptoms or clinician ratings of severity and improvement (Spain et al., 2015; Taylor, 2016; Weston et al., 2016). Less common are “subjective” outcomes, such as perceived helpfulness, which are often utilized in the general population to measure treatment acceptance and effectiveness (Harris et al., 2020; Lippens & Mackenzie, 2011). Perceived helpfulness captures aspects of treatment effects and acceptability that are unique from more “objective” outcomes. Studies in the general population have shown that when patients perceive depression treatment to be helpful, they are more likely to follow through with the treatment (adherence) (Lippens & Mackenzie, 2011), to be satisfied with the treatment (Alang & McAlpine, 2020), to benefit from the treatment or recover (Ojala & Wheeler, 2012), and to seek and utilize future treatments when in need (Colman et al., 2014; Edlund et al., 2002).

While previous studies have included subjective measures such as “usefulness” or satisfaction to examine social validity and feasibility of treatments from the perspectives of adolescents with ASD and their parents (Conner et al., 2019; de Bruin et al., 2015; Shaffer et al., 2019), only one study to our knowledge has specifically examined perceptions of medication treatment among adults with ASD (Coleman et al., 2019), and no study to date has evaluated perceived helpfulness of depression treatment in this group. Given that adults with ASD are at elevated risk of mental health problems and often experience difficulties accessing services (Hollocks et al., 2019; Joshi et al., 2013; Shattuck et al., 2011, 2012), evaluating perceived helpfulness from their perspectives could offer new insights about the effectiveness and acceptability of community depression treatments.

Further, understanding individual correlates of perceived helpfulness could provide additional information about what is likely to be perceived as most helpful by which patients. For example, studies on perceived helpfulness of depression treatment in the general population have found patients’ helpfulness ratings to be associated with various demographic characteristics (e.g., age, sex, education levels), as well as depression symptom severity (e.g., self-rated levels of depression), and depression treatment status (e.g., whether receiving multiple treatments at the same time) (Alang & McAlpine, 2020; Harris et al., 2020).

The current study sought to describe the perceived helpfulness of different types of depression treatment,

and individual correlates of perceived helpfulness, among a community sample of adults with ASD.

METHOD

Participants

Participants for the online survey were recruited through the Simons foundation powering autism research for knowledge (SPARK) research match registry (SPARK Consortium, 2018) as part of a larger study (Zheng et al., 2021). Independent adults between 18 and 35 years who had received a childhood ASD diagnosis and were capable of providing self-reports were invited. A sample of 315 adults with ASD participated (see Table S1 for further descriptions of the whole sample). In the current analysis, the subsample who reported currently receiving treatment(s) for depression ($N = 144$, 45.7% out of 315) was included (see Table 1 for sample characteristics). The study procedures were approved by the institutional review boards at the authors’ institutions.

Measures

Demographic information, including age, biological sex, race/ethnicity, and highest education level attained, was collected as part of the online survey designed by the study team.

Depression treatment status and perceived helpfulness. Participants reported whether they were currently receiving any type of depression treatments (“Are you currently receiving treatment for depression?”). If yes, they were asked whether they were currently receiving each of the following types of depression treatments: medication, individual psychotherapy, group therapy, and others. For each treatment they were receiving, they were asked the length (in months) and perceived helpfulness (“How helpful has [treatment type] been so far?” on a five-point scale “Not at all,” “Slightly,” “Moderately,” “Very,” “Extremely”).

Current depressive symptoms were measured by the self-report Beck Depression Inventory-II (BDI-II) (Beck et al., 1996). The 21 groups of statements in the BDI-II are assigned scores on a scale of 0 to 3, with higher scores indicating greater depression symptom severity. The BDI-II has good psychometric properties among adults with ASD (Williams et al., 2020) and showed good internal consistency (Cronbach’s Alpha = 0.95) in the current sample.

Analysis

First, the frequencies of treatment types, levels of perceived helpfulness, and the descriptive statistics of

TABLE 1 Characteristics of adults who reported currently receiving depression treatment ($N = 144$)^a

		Mean (<i>SD</i>)	Range
	Age at the survey	26.68 (<i>SD</i> = 4.76)	18.1–35.7
	Age at the ASD diagnosis	9.35 (<i>SD</i> = 4.80)	0.5–17.92
		Frequency	%
Biological sex	Male	68	47.22
	Female	76	52.78
Gender identity	Male	69	47.92
	Female	62	43.06
	Non-binary	9	6.25
	Agender	1	0.69
	Bigender	1	0.69
Race	Other	2	1.39
	White	121	84.03
	African American	4	2.78
	Asian	2	1.39
	Multi-racial	15	10.42
Ethnicity	Other	2	1.39
	Non-Hispanic	131	90.97
	Hispanic	13	9.03
Highest education level	Some high school	3	2.08
	GED diploma	5	3.47
	High school graduate	43	29.86
	Trade or vocational school	12	8.33
	Associates degree	16	11.11
	Some college	37	25.69
	Baccalaureate degree	23	15.97
	Graduate/professional degree	5	3.47

Note: The current analytic sample shares comparable demographic characteristics with the full study sample ($N = 315$; 47% Male, 78% White, 41% with high school degree or less, with insignificant chi-square results, $ps < 0.05$) and the larger SPARK registry sample of independent young adults with childhood diagnosis of ASD. In the larger SPARK sample, there are 52% Male, 81% White, and 37% with high school degree or less.

treatment length were described for each type of treatment. The perceived helpfulness (Wilcoxon test) and treatment length (paired t test) were compared between medication and individual therapy among those receiving both treatments. Then, separate ordinal logistic regression models were fitted to examine potential factors associated with the perceived helpfulness ratings of each type of depression treatment. With limited frequencies reported for group therapy ($N = 4$) or other treatment ($N = 3$), regression models were fitted for medication and individual therapy only. Variables included in the models were demographic characteristics, depression-related variables, and treatment-related factors (for details, see Tables 2 and 3). We coded the status of receiving both medication and individual therapy and included the concurrent treatment status in the perceived helpfulness models to explore whether receiving another treatment at the same time would have an effect on the perceived helpfulness of the specific treatment under investigation. Given the limited frequencies of the “Not at all” helpful

category for both medication ($N = 2$) and individual therapy ($N = 1$), the “Not at all” category was collapsed with the “Slightly” category for both treatment types for ordinal logistic regression. Odds ratios were generated for all the factors based on the regression results.

RESULTS

Of the 144 adults with ASD who reported currently receiving any treatment for depression, 122 (85%) were currently receiving medication, 68 (47%) individual therapy, and four (2.7%) group treatments. Forty-seven (33%) were receiving both medication and individual therapy simultaneously, with three of them also getting group treatment (there were no statistically significant demographic differences between those receiving medication only, individual therapy only, and both, see supplementary materials). Adults who were taking medication for depression reported that they had been on medication for an average duration of about

TABLE 2 Results from the ordinal logistic regression of perceived helpfulness of medication (n = 122)

Variables	Categories	Odds ratio	95% Wald confidence limits	p
Race	Racial and Ethnic Minority	Reference	—	—
	Non-Hispanic White	2.37	(0.90, 6.24)	0.081
Sex	Male	Reference	—	—
	Female	2.33	(1.13, 4.82)	0.022 ^a
Educational level	High school and less	Reference	—	—
	Above high school degree	2.03	(0.92, 4.45)	0.078
Concurrent medication	Individual therapy only	Reference	—	—
	Individual therapy and medication	1.08	(0.53, 2.21)	0.826
Age	(Continuous)	1.03	(0.96, 1.12)	0.404
Treatment length	(Continuous)	1.00	(1.00, 1.01)	0.815
Depressive symptoms	(Continuous)	0.92	(0.89, 0.95)	<0.001 ^a

^aIndicating statistical significance.**TABLE 3** Results from ordinal logistic regression of perceived helpfulness of individual therapy (n = 68)

Variables	Categories	Odds ratio	95% Wald confidence limits	p
Race	Racial and ethnic minority	Reference	—	—
	Non-Hispanic white	0.53	(0.17, 1.62)	0.267
Sex	Male	Reference	—	—
	Female	1.43	(0.57, 3.58)	0.443
Educational level	High school and less	Reference	—	—
	Above high school degree	1.34	(0.52, 3.48)	0.547
Concurrent medication	Individual therapy only	Reference	—	—
	Individual therapy and medication	0.80	(0.30, 2.14)	0.657
Age	(Continuous)	0.97	(0.89, 1.07)	0.567
Treatment length	(Continuous)	1.01	(1.00, 1.01)	0.137
Depressive symptoms	(Continuous)	0.95	(0.92, 0.99)	0.006 ^a

^aIndicating statistical significance.

6 years (Mean = 71.66 months [*SD* = 68.08], Median = 50 months, Range: 1 to 288 months), while those currently receiving individual therapy reported that they had been in treatment for about 5 years on average (Mean = 57.69 months [*SD* = 68.84], Median = 35 months, Range: 1 to 300 months). Overall, most perceived both medication and individual therapy to be “Moderately” and “Very” helpful, with more adults perceiving individual therapy to be either “Slightly” or “Extremely” helpful than medication (see Figure 1). Among those who received both treatments (*N* = 47), there were no statistically significant differences in treatment durations (*p* = 0.493) or perceived helpfulness (*p* = 0.903) between medication and individual therapy.

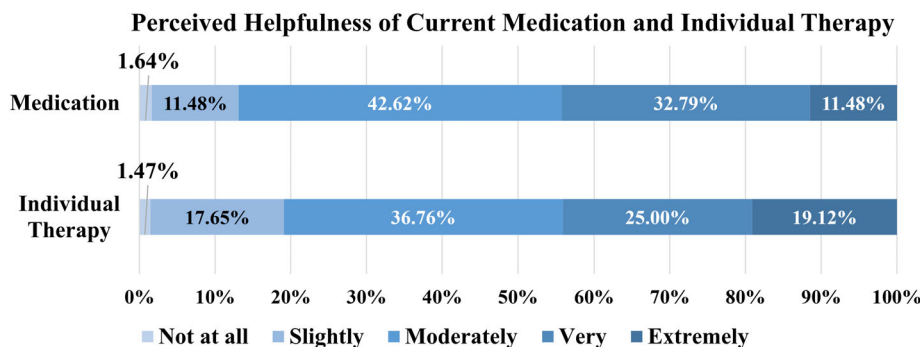
Results from the regression models for both medication and individual therapy showed that self-reported levels of depressive symptoms were negatively associated with perceived helpfulness of both medications (Table 2) and individual therapy (Table 3). That is, adults with more depressive symptoms were less likely to report high levels of perceived helpfulness. Sex was the only other

significant indicator for the perceived helpfulness of medication, with women more likely to perceive medication to be more helpful (Table 2) than men. The other factors (i.e., age, race, education level, treatment length, and concurrent treatment received) did not significantly predict perceived helpfulness for either treatment (see Tables 2 and 3).

DISCUSSION

Adults with ASD are greatly in need of effective depression treatment services. Yet, research establishing the effectiveness of currently available treatment approaches has lagged far behind this need. The current study introduces perceived helpfulness as a potentially useful metric for understanding depression treatment effectiveness in adults with ASD. Our findings indicate that while the perceived helpfulness of depression treatments varied widely, most adults in this community sample perceived medication and individual psychotherapy as moderately

FIGURE 1 Perceived helpfulness of current medication and individual therapy



helpful or better, indicating that the “subjective” effectiveness of community treatments for depression was mostly satisfactory.

Investigation of potential correlates of perceived helpfulness found that adults with ASD with more self-reported depressive symptoms were less likely to perceive treatments as helpful, which is consistent with findings from the general population (Alang & McAlpine, 2020; Hemmis et al., 2015). It is possible that individuals starting with more depressive symptoms were less likely to perceive treatment as helpful (regardless of the objective effectiveness of treatments), or that treatments were indeed less helpful for more depressed individuals and/or those presented with more complex cases of depression. However, given that we only have one timepoint, it is impossible to determine the directionality of the effect, highlighting the need for longitudinal work in this area.

Another factor associated with perceived helpfulness of medication was biological sex. While there were no sex differences in frequencies of receiving medications or levels of self-reported depressive symptoms in this sample (see supplementary materials), it is possible that similar to women in the general population, women with ASD also respond better to depression medication than men (Sramek et al., 2016; Trivedi et al., 2006; Weissman, 2014). Further, following patterns in the general population (Lippens & Mackenzie, 2011), higher levels of perceived helpfulness may lead women with ASD to be more likely than men to persist with and benefit from depression treatments.

Of those who received individual therapy, a high proportion (69%) also reported using medication. However, unlike general population findings (Alang & McAlpine, 2020; Harris et al., 2020), receiving medication and individual therapy concurrently was not significantly associated with the level of perceived helpfulness of either type of treatment. Previous studies collected one overall rating of perceived helpfulness for participants receiving multiple treatments, whereas we asked participants to rate each type of treatment separately. It is possible that receiving medication and psychotherapy concurrently does not necessarily change the perceived

helpfulness of each separate treatment, but rather the overall perceived helpfulness.

Notably, the average lengths of treatment for medication and individual therapy were reported to be 6 and 5 years, respectively. These long averages far exceed the length recommended by clinical guidelines of 16 to 20 therapy sessions over 3 to 4 months for individual psychotherapy (American Psychological Association, 2019; National Institute for Health and Care Excellence, 2009) and the 12-month duration of medication necessary to prevent relapses as shown in research (Geddes et al., 2003). One possibility for such prolonged treatment durations is that adults with ASD might experience persistent depression that requires ongoing treatment. Unfortunately, such prolonged treatment durations are not compatible with insurance-based care systems, nor are they realistically sustainable given the ever-growing population of depressed adults with ASD and a limited number of providers. Alternatively, it is also possible that depression treatment might not work as well for adults with ASD (White et al., 2018), and thus, it takes them longer to make sufficient progress to “graduate” from the treatment. Together with the lack of association between treatment duration and helpfulness, these results indicate that being in treatment for a long time does not mean the treatment is effective or is perceived to be more helpful. Measuring perceived helpfulness could provide the information needed to increase individualization based on specific patient needs and to identify which specific “elements” of treatment are most helpful for particular groups of patients.

There are several limitations to consider for the current study. First, our findings are limited by the characteristics of the sample. Specifically, only independent young adults with a childhood diagnosis of ASD were recruited. Thus, findings might not be applicable to individuals who received an ASD diagnosis later in life or those who cannot self-report. Also, given that our sample was recruited from a national registry and was majorly White, these adults might be more connected to resources and enjoy better service access than other adults in the community, who might not have the same level of resources. Therefore, their perspectives of the helpfulness of depression treatment might not be

representative of the larger ASD adult population. Further, the current study did not collect detailed information on previous treatment experience or current treatment characteristics (e.g., numbers and types of medications and individual therapy), making examination of treatment-related nuances and histories impossible. Future studies should include careful profiling of depression treatments over time to understand the elements perceived as most helpful by adults with ASD. Future studies should also consider the possible impact of other mental health problems and other treatments adults with ASD might be receiving.

In general, most adults with ASD perceived the depression treatments they were receiving to be helpful, regardless of age, race/ethnicity, and education level. Yet, previous studies find limited evidence of these treatments effectively alleviating depressive symptoms in adults with ASD. Further investigation of the associations between “subjective” perceived helpfulness and “objective” depressive symptom changes could provide a fuller picture of how current treatments work, and thus, inform treatment planning and individualization: for example, it may be that levels of perceived helpfulness “mediate” adults’ symptom changes in responses to certain depression treatments. In summary, perceived helpfulness could be a useful construct to study depression treatment outcomes in addition to conventional objective measures of effectiveness (e.g., symptom reduction), and has potential utility in predicting patient behaviors related to depression treatment in ASD.

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AUTHOR CONTRIBUTIONS

All authors contribute to the manuscript significantly to be listed as an author. Shuting Zheng and Somer L. Bishop conceptualized the study. Shuting Zheng led the data collection, designed and conducted the analysis, and drafted the full manuscript. Julie Lounds Taylor, Ryan Adams, and Florencia Pezzimenti provided substantive edits to the manuscript. All authors reviewed and approved the final draft. Julie Lounds Taylor and Somer L. Bishop secured the funding for the study.

ETHICS STATEMENT

The study protocol and procedures were approved by institutional review boards at the authors' institutions. All participants provided written informed consent before taking part in the study.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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