

Depression in independent young adults on the autism spectrum: Demographic characteristics, service use, and barriers

Autism

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Abstract

Depression is a common problem for adults on the autism spectrum, but little is known about depression-related service receipt in this group. To understand depression diagnostic and treatment status better, we collected information on current depressive symptoms, depression diagnosis, and treatment status of 315 young adults with a childhood diagnosis of autism from the Simons Foundation Powering Autism Research for Knowledge registry. About two-thirds (65.4%) of the adults had been diagnosed with depression, and 46.7% currently met clinical cut-offs for depression on depressive symptoms measures. Among the currently depressed, the majority (83.0%) had a formal depression diagnosis. Despite being no more likely than males to be currently depressed, females (biological sex) were more likely to have received a depression diagnosis. As for depression treatment, 58.5% of currently depressed adults were currently being treated, and 68% had previously received treatment. Medication was the most common form of treatment, followed by individual therapy. Likelihood of receiving depression treatment was higher among those with a formal depression diagnosis and with higher levels of education. Adults reported several barriers to accessing treatment for depression, including financial and insurance issues, accessibility to appropriate care, and professionals' lack of understanding about depression in autism.

Lay abstract

Depression is common among adults on the autism spectrum, but little is known about the extent to which these adults living in the community access diagnostic and treatment services for depression. To address this gap, we surveyed 315 adults on the autism spectrum on depression symptoms, diagnosis, and services. About half of the sample had scores on standard depression measures that suggested they were currently depressed ($n = 147$, 46.7%). Among the currently depressed, most of them had received a depression diagnosis from a professional. Depressed females were about 3.5 times more likely than depressed males to have a depression diagnosis. More than half of the currently depressed adults on the autism spectrum reported receiving depression treatment at the time of the study, while about two-thirds had previously received treatment. Those with a depression diagnosis were more likely to have received treatment, and those who had some education beyond high school were more likely to be currently receiving treatment. Financial and insurance issues were the most common barriers that adults reported in accessing treatment for depression.

Keywords

depression diagnosis, depression treatment, service barriers, sex differences

Poor mental health is an urgent concern for adults on the autism spectrum (Cusak & Sterry, 2016; IACC, 2017), contributing to increased risk for suboptimal long-term outcomes (D. K. Anderson et al., 2014; Lawson et al., 2020; Magiati et al., 2014). Depression is particularly prevalent, with reported rates of lifetime diagnosis as high as 77% (Au-Yeung et al., 2019; Fombonne et al., 2020; Hollocks et al., 2019; Hudson et al., 2019; Joshi et al., 2013; Lai

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et al., 2019; Lugnegaard et al., 2011). Unfortunately, while increased awareness of this problem has led to calls for action (Gotham et al., 2020), few studies have investigated the current depression service landscape among depressed adults on the autism spectrum. This information is critical to identify disparities and improve access to care for this extremely vulnerable population.

Many previous studies on depression in autism have relied on samples from outpatient clinics or autism specialty centers, and have typically focused on estimating rates of lifetime diagnosis (i.e. whether an individual *ever* received a depression diagnosis (Hollocks et al., 2019; Hudson et al., 2019)). Relatively little is known about the extent to which depressed adults on the autism spectrum living in the community at large have been diagnosed with and/or treated for depression. This information is necessary for understanding gaps in services. The few studies that have focused on community samples suggest high unmet mental health needs. For example, analyses of post-high school service use among young adults on the autism spectrum in the National Longitudinal Transition Study 2 (NLTS-2) showed that about 35% received mental health services, with an even smaller percentage receiving services targeting depression (Shattuck et al., 2011). This rate of service receipt is much lower than what would be expected given estimated rates of depression (i.e. more than 70% lifetime diagnosis), and may reflect problems with mental health service access. Another survey of individuals on the autism spectrum and their caregivers on a waiting list for community-based services found that more than half (52.8%) of the sample had unmet needs for mental and behavioral health services (Schott et al., 2020).

These unmet service needs may result from service access barriers. Families of individuals on the autism spectrum often experience physical, emotional, and financial burdens accessing mental and behavioral health services (Ganz, 2007; Keefer et al., 2018), with common barriers, including cost and insurance, service accessibility, and logistics (Taylor & Henninger, 2015). Furthermore, a recent qualitative analysis found that adults on the autism spectrum perceived professionals as lacking knowledge about mental health problems in autism, resulting in delays in getting appropriate services (Camm-Crosbie et al., 2019). More specific information on barriers accessing depression services may suggest potential target areas for improvement, ultimately reducing mental health service disparities in this population (Crane et al., 2019).

Enhanced understanding of individual-level factors related to service receipt could also improve access to services for those on the autism spectrum. Studies on depression service status in the general population indicate that individuals from racial and ethnic minority groups or with lower education levels experience higher rates of unmet needs (Alegría et al., 2008; Simpson et al., 2007; Todd & Teitler, 2019). In autism samples, difficulty accessing

autism-related diagnostic and treatment services is especially pronounced for those from lower socio-economic status (SES) and/or racial/ethnic minority households (Mandell et al., 2002; Taylor & Henninger, 2015). However, most of these studies surveyed all service types together (e.g. housing services, vocational services, financial support) and did not focus specifically on depression or mental health services. In addition, differences in depression diagnosis based on biological sex (as distinct from gender/gender identity, which refers to one's sense of oneself as male, female, or non-binary gender) are consistently observed in the general population, with females being more likely than males to receive a diagnosis (Altemus et al., 2014; Crick & Zahn-Waxler, 2003; Eid et al., 2019). While studies of children on the autism spectrum found little evidence of sex differences in co-occurring psychiatric conditions (including depression; Brereton et al., 2006; Hurtig et al., 2009; Lai et al., 2019; Mayes et al., 2011; Menezes et al., 2018), information from adult samples is even more limited. In fact, no study to date has directly assessed demographic factors associated with diagnostic or treatment services for depression, specifically, among depressed adults on the autism spectrum.

This study collected information from young adults on the autism spectrum about current depressive symptoms, depression diagnoses, current, and past treatment services for depression, and service barriers. We aimed to answer the following: (1) How likely are autistic adults with elevated levels of depressive symptoms to have received a depression diagnosis, and what demographic factors are associated with having received a depression diagnosis? (2) How likely are autistic adults with elevated depressive symptoms to be receiving treatment for depression, what types of treatments are they receiving, and what factors are associated with receiving treatment? and (3) What are the specific barriers to accessing depression services reported by autistic adults with elevated depressive symptoms?

Method

Participants

Participants for the online survey were recruited through the Simons Foundation Powering Autism Research for Knowledge (SPARK) research match registry, which includes registrants across the United States (SPARK Consortium, 2018). Email invitations were sent to 700 independent adult (i.e. legally responsible for oneself) SPARK registrants who met the following inclusion criteria: (1) able to complete self-report and consent for themselves (as evidenced by previously completed online surveys); (2) age between 18 and 35 years; (3) received an autism diagnosis from a professional before age 18; and (4) completed the Background History Questionnaire at initial SPARK registration between 2017 and 2020. In this study,

Table 1. Characteristics of the young adult sample.

		Whole sample (N = 315)	Currently depressed (N = 147)
		Frequency (%)	Frequency (%)
Biological sex	Male	165 (52.4)	71 (48.3)
	Female	150 (47.6)	76 (51.7)
Gender identity	Male	163 (51.8)	70 (47.6)
	Female	133 (42.2)	64 (43.5)
	Non-binary	13 (4.1)	10 (6.8)
	Agender	2 (0.6)	1 (0.7)
	Bigender	1 (0.3)	1 (0.7)
	Transgender	2 (0.6)	1 (0.7)
Race	White	259 (82.2)	115 (78.2)
	African American	11 (3.5)	6 (4.1)
	Asian	4 (1.3)	4 (2.7)
	Multi-racial	36 (11.4)	19 (12.9)
	Other	5 (1.6)	3 (2.0)
Ethnicity	Non-Hispanic	287 (91.1)	131 (89.1)
	Hispanic	28 (8.9)	16 (10.9)
Relationship status	Single	198 (62.9)	83 (56.5)
	Dating	65 (20.6)	36 (24.5)
	Married	39 (12.4)	22 (15.0)
	Separated	1 (0.3)	1 (0.7)
	Civil partnership	2 (0.6)	1 (0.7)
	Other	10 (3.2)	4 (2.7)
Any children	No children	278 (88.3)	128 (87.1)
	With children	37 (11.8)	19 (12.9)
Highest education level	Some high school	12 (3.8)	8 (5.4)
	GED diploma	12 (3.8)	9 (6.1)
	High school graduate	97 (30.8)	44 (29.9)
	Trade or vocational school	26 (8.3)	18 (12.2)
	Associate degree	31 (9.8)	14 (9.5)
	Some college	66 (21.0)	34 (23.1)
	Baccalaureate degree	55 (17.5)	15 (10.2)
	Graduate/professional degree	18 (5.7)	5 (3.4)
Employment Status	No paid employment	152 (48.3)	74 (50.3)
	Paid full-time employment	61 (19.4)	24 (16.3)
	Paid part-time employment	101 (32.1)	49 (33.3)
		N, mean (SD), range	N, mean(SD), range
Age at the survey		315, 26.33 (4.64), [18.1, 35.9]	147, 26.40 (4.67), [18.1, 35.7]
Age of autism diagnosis (in years)		315, 8.74 (4.63), [0.50, 17.92]	147, 9.03 (4.55), [0.50, 17.92]

we chose to only include those aged 18–35, who received an autism diagnosis before age 18, to account for at least some of the massive heterogeneity that characterizes samples of adults on the autism spectrum. Besides, this age range has been shown as a particularly challenging time for adults on the autism spectrum (Shattuck et al., 2011, 2012) and a sensitive period for developing mental health problems in the general population (Zivin et al., 2009).

Out of 700 eligible registrants contacted, 315 adults completed the full survey with the recruitment goal of 300. Of those who completed the full survey, 147 (46.7%) were categorized as *currently depressed* based on their scores on depressive symptom measures and constituted the primary

analytic sample. Note that these individuals were not assessed for a formal depression diagnosis in our study; they are identified as *currently depressed* due to clinically significant elevations in depressive symptoms (see below for further details). Table 1 presents the characteristics of the whole sample and the *currently depressed* analytic sample.

Measures

SPARK registry information. As part of the SPARK registration process, participants provided background information (e.g. demographics, diagnostic history). Age of autism

diagnosis and race/ethnicity variables were derived from the registry database, and used to describe the characteristics of the sample.

The *young adult current status form* is a questionnaire designed by the study team to gather data on current life circumstances, such as relationship and employment status, education, and information related to depression symptoms, diagnoses, and treatments. Participants reporting a previous depression diagnosis were asked to provide details (i.e. age of diagnosis, professional who gave the diagnosis). Those not reporting a previous depression diagnosis were asked whether they had ever felt depressed and/or had ever been asked by a professional about depression. All participants were asked whether they had ever received mental health services related to depression, and whether they had ever encountered barriers accessing depression services (“Have you encountered any barriers when seeking help for depression or depressive disorders? If so, please specify.”).

Beck Depression Inventory-II (BDI-II; Beck et al., 1996) is a 21-item self-report instrument assessing mood during the last 2 weeks in individuals aged 13 and older, with items scored on a scale of 0–3 indicating four different levels of severity. A total score of 0–13 corresponds to a minimal level of depressive symptoms, 14–19 to mild, 20–28 to moderate, and 29–63 to severe. A cut-off score of 20 has been shown to have good sensitivity (0.81–0.85) and specificity (0.83–0.92) for a clinical diagnosis of depression (Dozois et al., 1998; Kumar et al., 2002). The BDI-II showed good internal consistency of 0.95 in the current sample and good psychometric properties in a previous study of adults on the autism spectrum (Z. J. Williams et al., 2020). While Z. J. Williams et al. (2020) generated autism-specific norms and screening categories for the BDI-II based on their sample, we chose to rely on the well-established convention of the original BDI-II scoring because (1) BDI-II showed good psychometric properties in autism and (2) we observed high agreement (~90%) between the original scoring and Z. J. Williams et al. (2020) scoring in the current sample when the categories were dichotomized (i.e. “likely depressed and above” and “moderate and above” considered as currently depressed).

Depression Anxiety Stress Scale (DASS; Lovibond & Lovibond, 1995) consists of 42 items describing emotional symptoms (on a scale of 0–3) and generates three scores for depression, anxiety, and stress based on self-report. The DASS showed good internal consistency within the scales (range: 0.84–0.91; Lovibond & Lovibond, 1995). The depression scale was used in this analysis. Recommended cut-offs on the depression scale are as follows: 0–9 is normal range, 10–13 is mild, 14–20 is moderate, 21–27 is severe, and above 28 is extremely severe (Lovibond & Lovibond, 1995). A cut-off of 14 showed a sensitivity of 0.86 and specificity of 0.56 for detecting a clinical diagnosis of depression (Nieuwenhuijsen et al., 2003) and corresponds to the 88th percentile in a

normative sample (Crawford & Henry, 2003). In this study, the DASS showed excellent internal consistency, with Cronbach’s alpha of 0.96. The DASS has been previously used with adults on the autism spectrum (Cage et al., 2018; Maddox & White, 2015). In addition, average scores and frequencies meeting clinical cut-offs on the anxiety scale (scores of 10 or higher are considered moderate level and above) and stress scale (scores of 19 or higher are considered moderate level and above) are reported to provide further information on the overall mental health characteristics of the overall sample.

In the current analysis, participants whose scores exceeded the cut-offs for a moderate level of depression on either the BDI-II (cut-off of 20) or the depression scale (DASS) (cut-off of 14) were considered to be *currently depressed*. The scores on the two depression measures were highly correlated ($r = 0.89$), indicating good convergent validity, but each captured unique cases (see results). As the focus of this study was to understand community depression services status, both scales were included to increase the sensitivity to identify adults with clinically elevated depressive symptoms who were likely in need of services. Although high scores on these instruments do not equate to a diagnosis, scores above cut-offs on one or both measures indicate a high likelihood that an individual would meet criteria for a clinical diagnosis of depression (Dozois et al., 1998; Kumar et al., 2002). See Supplementary Table S1 for characteristics of the subsamples who met cut-offs on the BDI-II ($n = 136$) and DASS ($n = 119$), and Supplementary Table S2 for BDI-II and DASS descriptive statistics for the current sample.

Procedures

Participants who responded to the email invitation were directed to a webpage to provide electronic informed consent. Then, they accessed a secure platform to complete the online survey. Both before and after the survey, participants were reminded about the anonymity of the survey, and were provided mental health resources and encouraged to reach out to professionals in their community if they needed help. Upon survey completion, participants received a US\$25 e-gift card for their participation. All study procedures were approved by the Internal Review Board at the authors’ institutions.

Analysis

Data analyses were conducted using statistical software, SAS 9.4. First, preliminary analyses were conducted: (1) to assign participants to the *currently depressed* category based on BDI-II and DASS scores; (2) to describe basic demographic information of the whole sample and the *currently depressed* sample, and to compare demographic characteristics between the *currently depressed* and *not currently depressed* (i.e. scoring below the cut-off on

Table 2. Results of logistic regression on current depression treatments among the currently depressed ($n = 147$).

		aOR	95% confidence limits	p
Race	Racial and ethnic minority	Reference	–	–
	Non-Hispanic White	1.84	[0.78, 4.36]	0.167
Sex	Male	Reference	–	–
	Female	0.68	[0.31, 1.47]	0.327
Depression diagnosis	No depression diagnosis	Reference	–	–
	Received depression diagnosis	17.76	[5.09, 61.95]	<0.0001
Educational level	High school and less	Reference	–	–
	Above high school degree	3.03	[1.36, 6.74]	0.007
Employment	Unemployed	Reference	–	–
	Employed	0.63	[0.30, 1.34]	0.231

aOR: adjusted odds ratio.

both depression screeners); and (3) to examine the correlations between scores from the BDI-II and DASS subscales. For the purpose of this study, the main analyses focus on the *currently depressed* subsample. Information about rates of depression diagnoses and treatment among those *not currently depressed* can be found in the Supplemental materials.

To address questions about diagnostic services, rates of lifetime depression diagnosis among *currently depressed* young adults (based on current symptoms measures) were generated. Logistic regression was conducted to examine the impact of possible demographic factors on the receipt of depression diagnosis among the *currently depressed*. Given that adults could have received a depression diagnosis at any time prior to data collection (e.g. several months to several years before participating), we chose “stable” demographic variables to avoid confounds related to timing: race (non-White as the reference group) and biological sex (male as the reference group). “Transient” demographic characteristics, such as education or employment, which might have changed between the time of depression diagnosis and the time of participation in this study (e.g. education could have been attained before OR after the depression diagnosis), were not included in this model to examine who had received a depression diagnosis.

To address questions about treatment services, the frequency of different types of depression treatments received (both currently and previously) were tabulated. Logistic regressions were conducted separately: one for any *current* depression treatment and the other for any *previous* depression treatments. For the *current* treatment receipt model, the stable demographic variables (i.e. race and biological sex), transient indicators of *current* SES (i.e. education level and employment status), and depression diagnosis were entered into the model (see Table 2). Similarly, due to concerns about confounds related to timing, for the *previous* treatment receipt model (in which treatment could have happened at any time), only time-independent “stable” demographic factors (i.e. race and biological sex) and

depression diagnosis¹ were included (see Table 3). For all three logistic models (i.e. depression diagnosis, current depression treatment, and previous depression treatment), we included biological sex instead of gender/gender identity because (1) theoretical rationale for including gender/gender identity instead of biological sex for examining depression services in adults on the autism spectrum is still limited and (2) 19 adults in our sample reported gender/gender identify different from their biological sex and our sensitivity analysis showed that gender functioned similarly to biological sex in models predicting depression diagnosis and treatments in the current sample.

Finally, to address questions about treatment barriers, we first generated the frequency of adults reporting barriers in the *currently depressed* sample, and then coded and analyzed their open-ended responses about specific barriers to accessing depression-related services. The first author and a research assistant both reviewed the open-text responses independently, and then a coding scheme of common themes was generated using the inductive approach (all the codes are listed in Table 5). The two coders independently assigned codes to each individual response, and then resolved coding discrepancies (7 disagreements out of 78 codes assigned, 91% reliable) through consensus discussion. A frequency table was generated for the commonly mentioned barriers.

Results

Depression diagnosis among the currently depressed

As indicated above, a total of 147 out of 315 (46.7%) young adults in the current sample met the cut-off for a moderate level of current depression on either the BDI-II and/or the DASS (see Table 1 for demographics of the *currently depressed* sample). Among the *currently depressed* adults, 108 (73.5% out of 147) met the cut-offs on both measures, 28 (19%) only met the cut-off on the BDI-II,

Table 3. Results of logistic regression on previous depression treatments among the currently depressed ($n = 147$).

Previous depression treatment status		aOR	95% confidence limits	p
Race	Racial and ethnic minority	Reference	–	–
	Non-Hispanic White	0.77	[0.29, 2.10]	0.614
Sex	Male	Reference	–	–
	Female	1.25	[0.54, 2.88]	0.603
Depression diagnosis	No depression diagnosis	Reference	–	–
	Received depression diagnosis	27.54	[7.47, 101.49]	<0.0001

aOR: adjusted odds ratio.

and 11 (12.2%) only met the cut-off on the DASS. The *currently depressed* group ($n = 147$) did not differ from the *not currently depressed* ($n = 168$) in any of the listed demographic variables ($ps > 0.05$). In addition, out of 315 young adults, 42.9% reported moderate anxiety or above and 32.7% reported moderate stress or above on the DASS (see Supplementary Table S2 for detailed descriptive statistics).

The majority of the *currently depressed* group reported having received a depression diagnosis ($N = 122$, 83%), with most of them diagnosed by a psychiatrist ($N = 64$) or a psychologist ($N = 35$); see Supplementary Table S3 for details about previous depression diagnoses. Among the 122 *currently depressed* adults who had received a previous depression diagnosis, the average age at the first depression diagnosis was 15.26 years ($SD = 5.40$ years). Meanwhile, nearly one-fifth of the *currently depressed* adults ($N = 25$, 17% out of 147) reported that they had never received a formal diagnosis of depression; however, almost all of them reported that they had wondered if they were depressed (24 out of 25, 96%) with two-thirds having been previously asked about depression or depressive symptoms by a professional (17 out of 25, 68%, see Supplementary Table S3).

Logistic regression analysis revealed that among *currently depressed* adults, females were more likely than males to have received a formal depression diagnosis (adjusted odds ratio (aOR) = 3.44, 95% confidence interval (CI): 1.33–8.90; $p = 0.01$); specifically, 91% of the *currently depressed* females versus 74.7% of *currently depressed* males had ever received a depression diagnosis. Race was not significantly associated with likelihood of depression diagnosis (aOR = 1.41, 95% CI: 0.52–3.83, $p = 0.50$).

Depression treatment receipt among currently depressed adults

Among *currently depressed* adults, 123 (83.7%) reported having received treatment for depression, with 86 (58.5%) adults currently in treatment. Logistic regression

results showed that receiving a formal diagnosis of depression was significantly associated with greater odds of depression treatment receipt both currently (67.2% with diagnosis vs 16% without a diagnosis were receiving current treatments; see Table 2 for regression results) and previously (79.5% with diagnosis vs 12% without diagnosis received previous treatments; see Table 3 for regression results). In addition, education levels significantly predicted who was currently receiving treatment for depression. Those who had completed any amount of postsecondary education were more likely to be in treatment than those with education levels of high school or below.

Depression treatment types. Medication use was the most frequently reported treatment for depression in our sample, followed by individual therapy (see Table 4). Group therapy for depression was much less frequently used than medication and individual therapy. Other depression treatments reported include electroconvulsive therapy, residential treatment center, and online counseling. Moreover, one-fifth ($n = 30$, 20.4%) of those in the *currently depressed* group reported receiving more than one type of treatment currently, with 29 receiving both medication and individual therapy.

Depression service barriers

Among *currently depressed* adults, nearly one-half ($n = 60$) reported having experienced barriers to depression-related services. Nevertheless, 82.9% of the 60 adults who reported barriers had a depression diagnosis, 55.3% were currently receiving treatment, and 65.8% had previously received treatment. Of the 60 adults who reported barriers, 54 provided open-ended responses that were grouped into eight themes (see Table 5). The most frequently mentioned barrier was financial issues and insurance coverage, with more than half of these adults bringing up struggles trying to pay for the services they needed (see Table 5). For example, one participant described the financial struggle to access care while being unemployed:

Table 4. Types of depression treatment received among the currently depressed ($n = 147$).

Types of treatment	Time received	With depression diagnosis ($n = 122$)	Without depression diagnosis ($n = 25$)
Medication	Currently	72 (59.01%)	4 (16%)
	Previously only	37 (30.33%)	1 (4%)
	Never	13 (10.66%)	20 (80%)
Individual therapy	Currently	37 (30.33%)	1 (4%)
	Previously only	45 (36.89%)	0
	Never	40 (32.79%)	24 (96%)
Group therapy	Currently	4 (3.28%)	0
	Previously only	16 (13.11%)	0
	Never	102 (83.61%)	25 (100%)

Table 5. Commonly mentioned barriers to depression-related services among the currently depressed.

Themes	Frequency (% out of 54)
Financial and insurance issues	32 (59.26%)
Accessibility of care/a good fit	15 (27.78%)
Professional's lack of understanding	10 (18.52%)
Logistics (e.g. scheduling, transportation)	7 (12.96%)
Difficulty describing and explaining feelings	5 (9.26%)
Symptoms preventing them from seeking care	5 (9.26%)
Side effects, majorly medications	3 (5.56%)
Family members' lack of understanding	1 (1.85%)

One individual might mention multiple barriers in their responses, and each of those barriers was coded and counted in the frequency table. Thus, percentages add up to more than 100.

I originally had a therapist, but since I am unemployed, I could not afford to continue therapy long-term. Especially with my insurance doubling this year, [. . .], I cannot afford to receive help anymore. I just take my anti-depressants and struggle through it, since I cannot get access to any other helpful sources.

Another person shared the difficulty of finding providers who accept Medicaid:

[The] majority do not accept Medicaid. So, it's all rumor hunting and waiting so long that you practically give up with no hope.

Besides the financial burden, participants also brought up the issue about limited accessibility of appropriate care. One young adult shared that

The lack of providers in my area who were willing to treat me and had the time to treat me because there are so many people who need services.

One shared their thoughts about the difficulty in finding therapists who understand co-occurring autism and depression:

Most therapy is geared for neuro-normative people. Therapists struggle [to] understand that I am Autistic and what being Autistic means.

Other barriers mentioned by young adults included logistics (such as finding transportation and coordinating schedules), difficulties describing their feelings to professionals and labeling their emotions (e.g. alexithymia), other co-occurring symptoms (e.g. fatigue, anxiety, and fear) preventing them from seeking care, treatment side effects, and family members' lack of understanding.

Discussion

This study adds to a growing body of literature indicating significantly elevated rates of depression in young adults on the autism spectrum. Taking together results of depression measures (i.e. current symptoms) and reports of previous diagnoses, we found a current depression rate of 47% (based on well-validated measures of depression symptoms) and a lifetime rate of 65% (based on self-reported depression diagnoses). Though falling within the large range of prevalence estimates reported in previous studies, these rates are higher than many previous studies (meta-analysis by Hollocks et al. (2019) found a pooled estimate of 23% for current depression and 37% for lifetime depression). Several factors might have contributed to the relatively high rate of depression and depression diagnosis reported here. First, adults experiencing depressive symptoms may have been more likely to volunteer for this study given that our recruitment materials specifically mentioned our interest in understanding depression in autism. Second, studies have found that individuals on the autism spectrum with higher cognitive/language abilities (i.e. similar to participants in this study, who were all capable of providing self-reports) are more likely to experience depression (Hollocks et al., 2019; Hudson et al., 2019; Sterling et al., 2008), at least as measured by standard instruments. Furthermore, the sex ratio in the current sample was close to 1:1, with a much higher percentage of females than most previous studies (Hudson et al., 2019;

though this percentage is generally consistent with online samples of adults on the autism spectrum (Taylor et al., 2019)). Given our findings that females were more likely than males to have received a depression diagnosis, the large number of females in this study might have contributed to higher rates of depression diagnosis (Lai et al., 2019). Finally, with the intention of capturing as many adults as possible who might be in need of depression services, we classified an adult as being *currently depressed* if they met the cut-offs on either of two well-established depressive symptoms measures; however, some of these adults might not meet the diagnostic criteria for a clinical diagnosis of depression.

While the finding of sex differences in depression diagnosis mirrors what has been long observed in the general population (Crick & Zahn-Waxler, 2003; Kessler et al., 1993), it is inconsistent with previous studies in autism where no sex differences in depression symptoms or diagnosis were found (Hudson et al., 2019; Lai et al., 2011). It is possible that the balanced sex ratio of a relatively large sample in this study lends more power to detect sex differences than previous analyses. Furthermore, the similar proportion of males and females in the *currently depressed* (male:female = 1:1.07) and *not currently depressed* (male:female = 1.27:1) groups suggests that this finding (females being 3.44 times more likely to receive depression diagnosis) is not driven by sex differences in base rates of elevated depressive symptoms, but rather a reflection of sex differences in depression identification (91% of the *currently depressed* females (vs 74.7% *currently depressed* males) had a depression diagnosis). Admittedly, future studies are needed to replicate the finding and to investigate how sex might affect depression in autism. Still, the current findings suggest that similar biases may exist for depression screening and diagnostic processes for males on the autism spectrum as for males in the general population.

In addition to biological sex, future research will also want to consider the role of gender/gender identity when examining depressive symptoms, diagnosis, and related treatment among individuals on the autism spectrum. A growing body of research suggests that gender identity (and particularly non-binary gender) is related to a greater risk for mental health problems (Meyer, 2003), and individuals on the autism spectrum are more likely than those in the general population to be gender diverse (Dewinter et al., 2017; Warrier et al., 2020). In the future, it will be important to consider how gender identity interplays with biological sex (e.g. gender incongruence) in the study of depressive symptoms, depression diagnoses, and access to depression services in the autism population.

The high concordance between instrument classifications and clinical diagnoses of depression in this study suggests that mental health professionals in the community (e.g. psychiatrists, psychologists) were able to identify

depression in adults on the autism spectrum. Given that these adults have higher needs for healthcare services in general (Cummings et al., 2016; Weiss et al., 2018), some may have had more frequent interactions with healthcare professionals which increased likelihood of receiving a depression diagnosis when experiencing elevated levels of depressive symptoms. However, for the 17% of *currently depressed* adults who had never received a depression diagnosis, most had been concerned that they might be depressed, and 68% of them also reported that professionals had asked them about depression and depressive symptoms. This indicates that a subset of adults on the autism spectrum may fail to receive appropriate diagnoses even when depression is suspected by the patient and/or the provider. With depression diagnosis being the only factor associated with likelihood of receiving treatment both currently and previously in this study, it is critical to maximize the sensitivity of diagnostic procedures for identifying depression in this group. Future studies should examine the demographic and symptom characteristics of individuals who reported depressed feelings but were missed by depressive symptoms measures and/or professional diagnoses. For example, issues around symptom overlap, diagnostic overshadowing, and non-prototypical symptom representations may interfere with the ability to accurately detect depression in a subset of depressed adults on the autism spectrum (Au-Yeung et al., 2019; Cassidy et al., 2018; Pezzimenti et al., 2019; Rosen et al., 2018).

Of those who were *currently depressed* based on the BDI and/or DASS scores, over one-half were currently receiving treatment, with medication being the most common form of treatment, followed by individual psychotherapy. Many adults were receiving more than one treatment, with the most common combination being medication and individual psychotherapy. Though higher than the service receipt rate in the general population (Olsson et al., 2016), the fact that only half of those who were *currently depressed* were receiving current treatment is still alarming considering the dire consequences of untreated depression in autism (i.e. higher suicidality and more hospital visits; Cassidy et al., 2020; Hirvikoski et al., 2016). As has been found in the general population (Todd & Teitler, 2019; Witt et al., 2011), education level was significantly associated with current treatment status. It is possible that individuals with higher education might be better equipped to access or advocate for care. However, with limited data in this study, it is hard to conclude *how* education level might have impacted treatment access, as other confounding socio-economic factors (e.g. income, occupation) were not examined simultaneously.

Barriers accessing depression services could also have created delays or left those in need untreated. The barriers identified in this study overlapped with findings from previous studies on general service barriers in autism (C. Anderson & Butt, 2018; Camm-Crosbie et al., 2019;

Taylor & Henninger, 2015), and mental health service barriers in the general population (e.g. high service cost and limited access; Rowan et al. 2013; Saxena et al., 2007). Our findings highlight implications for policy, practice, and research. Specifically, advocacy is needed for policy changes to address barriers around the financial burden, insurance coverage (e.g. Medicaid), and accessibility to care (e.g. the limited number of professionals in low resourced areas). Early identification and continued monitoring of depressive symptoms could provide in-time support before the symptoms become too impairing for individuals to seek or benefit from help. Specifically, for those on the autism spectrum, treatment strategies to facilitate the individuals' communication of mood, feelings, and experiences may also be helpful to make sure they feel they are being heard and validated. Furthermore, identifying strategies to help professionals understand, identify, and treat depression in autism earlier and better should be a focus of future research and training efforts (Maddox et al., 2019, 2020). Unfortunately, treatments for depression in autism, especially among adults, have shown limited effectiveness (Chandrasekhar & Sikich, 2015; Kiep et al., 2015; Lake et al., 2014; Sizoo & Kuiper, 2017; Spain et al., 2015; K. Williams et al., 2013), suggesting continued high risk for poor outcomes even among those who are able to access treatment.

There are several limitations to be considered in this study. Researchers have raised concerns about application of depression measures designed for the general population to autism samples, and have called for psychometric analyses and validation studies specifically within autism (Cassidy et al., 2018; Gotham et al., 2015). We selected measures that show good psychometric properties in both general population and autism samples, and found that scores based on the autism-specific norms (Z. J. Williams et al., 2020: BDI-II in autism) showed high agreement with conventional BDI-II scoring used in our study. Still, meeting cut-offs on depressive symptom measures is not the same as meeting criteria for a clinical diagnosis of depression. Furthermore, though commonly used in prevalence studies of depression, self-reported diagnoses (e.g. depression) have shown low consistency with medical chart review (alpha range: 0.3–0.4) in the general population (Leikauf & Federman, 2009), indicating possible reliability issues with self-reported depression diagnosis.

Characteristics of the study sample should also be considered when interpreting our findings. Inclusion in this study was limited to adults with a childhood diagnosis of autism. This decision was made to help manage the extreme heterogeneity that characterizes adults on the autism spectrum, including known differences in sample characteristics associated with age of diagnosis (see Huang et al., 2020 for review), which complicates understanding of how findings may apply to different groups of adults. Future research will need to determine whether our results also apply to adults who received an autism diagnosis later

in life, or who self-identified as being on the autism spectrum. In a similar vein, our sample only spans early adulthood, leaving a large proportion of middle-age and older adults out of the current analysis. Therefore, the current findings might not be generalizable to older adults, especially considering that even more service barriers were reported by older adults in the general population (Unützer, 2002).

Though we did not find significant racial disparities in either depression diagnosis or treatment, we were limited in our ability to detect meaningful effects of race based on the fact that about 80% of the current sample was white. More diverse samples are needed to investigate inequities in depression service access among adults on the autism spectrum. In addition, the two SES variables included only measured the current education level and employment status and might not be reflective of the *actual* SES of the sample over time given that 28.6% ($N = 42$) of the young adults who were *currently depressed* were still in school. Therefore, we were not able to evaluate the potential effects of SES on lifetime depression diagnosis and previous treatment receipt without chronologically consistent information on SES.

Despite these limitations, a significant strength of this study is the use of a community sample from a national autism research registry, which may address some of the sampling biases inherent in clinically ascertained samples of adults presenting with mental health complaints. Moreover, the relatively large sample allowed us to examine different types of depression experiences (such as those who were *currently depressed* with or without a depression diagnosis), while many autism studies are underpowered to examine such nuances in depression-specific service experience. We also moved beyond the simple descriptions of depression service status and examined the effects of individual demographic variables on services receipt, providing insights into possible depression service disparities in this vulnerable population. Furthermore, the juxtaposition of quantitative data with open-ended responses to questions about barriers allowed us to develop a deeper understanding of the barriers experienced by these adults in accessing the depression treatments that they desired. Findings point to the need for future research to examine the depression treatment experiences of other adults on the autism spectrum (e.g. those who are diagnosed as adults; those who are gender diverse), as well as the need for more effective treatments to ameliorate depressive symptoms in this group. Thus, this study highlights a number of avenues for future research and advocacy to improve depression services for adults on the autism spectrum.

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Community involvement

All study procedures and documents were reviewed and approved by the Community Advisory Council (CAC) of self-advocates and family members from the autism community organized by the SPARK research match registry.

Consent for publication

All participants provided informed consent to be part of the study and are aware that the findings of the current study will be published. No details, images, or videos relating to an individual person are reported in the current manuscript.

Data availability

Data included in the current study are available on the SPARK Research Match registry hosted by Simons Foundation. Interested researchers can get approval and obtain the SPARK population dataset described in this study by applying at <https://base.sfari.org>.

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Supplemental material

Supplemental material for this article is available online.

Note

1. Out of 147, 125 reported an age of previous depression treatment after the age of depression diagnosis age; excluding the remaining 22 who reported treatment onset prior to depression diagnosis did not change the significant findings.

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