Impacts of Co-Occurring ADHD Symptoms on Critical Markers of Outcome for Autistic Adults

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ABSTRACT

Outcomes for autistic adults are generally poor across multiple foundational metrics, including quality of life and activities of daily living. Co-occurring psychiatric conditions, including depression and anxiety, contribute to these poor outcomes. Attention-deficit/hyperactivity disorder (ADHD) is one of the most common co-occurring conditions in autistic individuals, yet its association with adult outcomes is largely unknown. 628 autistic adults (18-83 years; 58% female) recruited from the Simons Foundation Powering Autism Research for Knowledge cohort completed questionnaires on demographics, co-occurring mental health conditions, activities of daily living and subjective quality of life. After controlling for age, birth-sex, socioeconomic status, autistic traits, and ADHD medications, ADHD symptoms explained an additional 2 to 9% of variance across activities of daily living and all domains of subjective quality of life. This is the first study to demonstrate an association between self-reported ADHD symptoms and lower activities of daily living and subjective quality of life ratings by autistic adults. These findings highlight that additional research and better supports for co-occurring ADHD symptoms may be critical to enhancing independence and quality of life for autistic adults.

KEYWORDS: autism, attention deficit hyperactivity disorder, daily living skills, adult, quality of life

INTRODUCTION

Adult outcomes in autism spectrum disorder (hereafter ‘autism’) are generally poor across many foundational metrics, such as objective and subjective quality of life (e.g., health, social relationships, independent living, employment/vocation, adequate supports) (Graham Holmes et al., 2020; Roux et al., 2015). A primary contributor to these poor outcomes is co-occurring psychiatric conditions (Lawson et al., 2020). One of the most frequently co-occurring psychiatric disorders for autistic¹ youth is attention-deficit/hyperactivity disorder (ADHD) (Brookman-Frazee et al., 2018; Simonoff et al., 2008); nevertheless, its role in outcomes for autistic adults has not been examined.

Thirty-seven percent of autistic adults rate themselves as meeting diagnostic criteria for ADHD (Johnston et al., 2013), which is much higher than the self-reported rate of ADHD in the general adult population (2.5%) (Simon et al., 2009). This self-report rate in adulthood overlaps with prevalence rates found in autistic youth (Leyfer et al., 2006; Simonoff et al., 2008; Yerys, 2017). In addition, autistic youth with more ADHD symptoms experience greater adaptive functioning impairments (Lyall et al., 2017; Yerys et al., 2009, 2019) and are rated by informants (Graham Holmes et al., 2020; Sikora et al., 2012) and themselves (Graham Holmes et al., 2020) as having a lower quality of life. Whether similar patterns persist into adulthood is unclear, as there is an absence of research on the presence of co-occurring ADHD symptoms and their impacts on adaptive functioning and quality of life in autistic adults (Yerys, 2020). This study seeks to address this research gap.

Enhancing adaptive functioning and subjective quality of life are two critical research priorities for autistic adults and autistic self-advocacy groups (Autistic Self Advocacy Network, 2020;

¹ Here, we use identity-first language (e.g., “autistic adult”) or neutral language (“on the autism spectrum”) instead of person-first language (e.g., “adult with autism”) based on what most stakeholders prefer (Kenny et al., 2016).

Autistica, 2017; Gotham et al., 2015). With respect to adaptive functioning, there is a particular need to focus on improving activities of daily living in adulthood—self-care, domestic, and community living skills—as these skills allow people to live independently. Prior research has shown that among 2-21 year old autistic youth greater co-occurring ADHD symptoms are associated with fewer activities of daily living at home and in school settings (Lyall et al., 2017; Sikora et al., 2012; Yerys et al., 2009, 2019). With respect to quality of life, a large sample (N>2000) of children ages 2 through 17 enrolled in the Autism Treatment Network were split between those with and without ADHD, and children in the autism+ADHD group were reported to experience lower overall health-related quality of life, school functioning, physical functioning, emotional functioning, and social functioning (Sikora et al., 2012). Despite these robust findings, it is not yet known if the detrimental impacts of co-occurring ADHD in autistic people continue into adulthood.

The present study fills this gap in the literature by being the first investigation of the relationship between self-reported ADHD symptoms and outcomes—activities of daily living and subjective quality of life—among autistic adults. Based on the pediatric literature, we hypothesized that increasing ADHD symptoms would be associated with greater functional impairments, reflected in lower activities of daily living and lower subjective quality of life ratings across multiple domains of functioning. We also hypothesized that the association between ADHD symptoms and these adult outcomes would be maintained after controlling for individual characteristics (age, sex assigned at birth, education, autistic traits, ADHD medication status) and socioeconomic status (household income). We examined this hypothesis by evaluating continuous ratings of ADHD symptoms and their associations with activities of daily living and subjective quality of life. This approach was taken to examine whether the range of ADHD symptoms from

mild (and insufficient for a diagnosis) to clinically meaningful ADHD symptoms have an impact on activities of daily living and subjective quality of life.

METHOD

Participants

Simons Foundation Powering Autism Research for Knowledge (SPARK; Feliciano et al., 2018) Research Match was utilized to recruit autistic participants for this study. 628 (59% female) autistic adults ranging in age from 18-83 ($M=38.6$) years were included in analyses. These adults were designated as “independent” by SPARK meaning that they can consent for themselves and thus are unlikely to have a co-occurring intellectual disability. Inclusion in the SPARK registry requires that participants have an autism spectrum disorder diagnosis given by a medical/clinical professional. Providing further validation for these clinical diagnoses, 95% of the sample met screening criteria (scores >65) on the Autism spectrum Quotient-Short Form (AQ-28; Hoekstra et al., 2011). For detailed demographic characteristics of the sample, see Table 1. This project was declared exempt by the institutional review board at George Washington University.

[Table 1 here]

Measures

Predictor

Adult ADHD Self-Report Scale (ASRS; Kessler et al., 2005). The ASRS is a well-validated, self-report measure designed to screen for adult ADHD. Participants are asked to report on the previous 6 months, responding on a 5 option Likert scale (“Never” to “Very Often”) for each

item. Part A (6 questions) of the scale includes screening items that are most indicative of adult ADHD, with higher scores indicating greater ADHD symptoms. The final questions of the scale provide additional information concerning ADHD behaviors but are not as effective at predicting diagnosis. The ASRS has shown high internal consistency (Cronbach's $\alpha=0.88$) and high concurrent validity with clinician-rated assessments of ADHD symptoms (Cronbach's $\alpha=0.84$) (Adler et al., 2006), as well as high test-retest reliability for both total ($r_s=0.78$) and item-by-item ($r_s=0.61-0.79$) scores (Silverstein et al., 2018). Here, we assigned a number value to each category (e.g., "Never"=0, "Sometimes"=1, etc.), and used the sum of the scores from the 6 screening questions of Part A (range 0-24) as the independent variable. Higher scores denote more frequent and impairing ADHD symptoms.

Outcomes

Waisman Activities of Daily Living (W-ADL; Maenner et al., 2013). The self-report version of the 17-item W-ADL was used to assess independence in performing activities of daily living (Bishop-Fitzpatrick et al., 2017). Participants responded on a 3-point Likert scale (0=Does not do at all; 1=Does with help; 2=Independent, or does on own). Items of the W-ADL are summed to generate a total score ranging from 0 to 34, with higher scores representing greater independence in activities of daily living. It has robust internal reliability (Cronbach's $\alpha=0.81$; Bishop-Fitzpatrick et al., 2017). It was also highly reliable over time with weighted kappas ranging from 0.92 to 0.93 (Maenner et al., 2013). Here, we used the total score as a dependent variable with higher scores indicating more independence.

World Health Organization Quality-of-Life-BREF module (WHOQOL-BREF; The WHOQOL Group, 1998). The WHOQOL-BREF is an abbreviated version of the WHOQOL-100; it has 26-items across 4 domains—Physical Health, Psychological Health, Social Relationships, and Environmental Health—and 2 overall questions about quality of life. Higher scores indicate greater quality of life. It has robust psychometrics with acceptable internal consistency (Cronbach’s alphas=0.73-0.86 across domains), discriminant validity between ‘ill’ and ‘well’ respondents (all domain $ps < 0.001$), test-retest reliability ($rs = 0.66-0.87$), and factorial validity favoring the 4-factor solution (The WHOQOL Group, 1998). Here, we used the mean score from each domain (range 1-5) as a dependent variable. Higher scores indicate higher subjective quality of life.

Autism Spectrum Quality-of-Life (ASQoL; McConachie et al., 2018). The ASQoL consists of 9 items, answered on a 5-point Likert scale (1=Not at All/Never, 5=Totally/Always). A total ASQoL score is calculated by averaging the responses to the initial 8 items of the survey. A final ninth item, which asks about ‘autistic identity,’ is not included in the calculation of the total ASQoL score. Higher ASQoL total scores indicate better subjective autism spectrum quality of life. Here, we used the total mean score (range 1-5) from the ASQoL as a dependent variable.

Covariates

Autism Spectrum Quotient-28 item (AQ-28; Hoekstra et al., 2011). The 28-item self-report version of the AQ was used to measure autistic features on a 4-point Likert scale (1=definitely agree to 4=definitely disagree). The mean AQ-28 item score, with higher scores indicative of greater autistic features, was used as a covariate here. The AQ-28 has demonstrated good validity

and reliability, and acceptable to good internal consistency in autism samples (Cronbach's $\alpha=0.77-0.86$) (Hoekstra et al., 2011).

Household Income. Participants reported on annual household income based on 9 categories, ranging from \$20,000 to \$160,000 per year. Participants could also indicate that they did not know their annual household income, or that they preferred not to disclose this information.

ADHD Medications. Participants reported on their medication usage at the time of study completion. Each participant received a code indicating whether they reported current ADHD medication usage. ADHD medications included central nervous system stimulants (e.g., methylphenidate) as well as non-stimulant medications (e.g., atomoxetine).

Data Analysis

Multiple linear regressions examined associations between continuous ADHD symptoms and activities of daily living, Physical Health, Social Relationships, Environmental Health, and Autism Spectrum quality of life, after controlling for the effects of age, sex assigned at birth, socioeconomic status, ADHD medication usage, and autistic traits. All raw scores were transformed to z-scores prior to analyses. Bonferroni corrections were applied to the regression analyses (adjusted threshold: $p<.01$; .05/5 regression analyses) to account for multiple comparisons. We report z-scores and standardized beta coefficients for ADHD symptoms as measures of effect size.

RESULTS

ADHD symptoms contributed significant variance to activities of daily living and quality of life. Increasing ADHD symptoms (even after accounting for the effects of all covariates and an adjusted p value) were significantly associated with less independent activities of daily living ($\beta=-0.25$, $t=-6.21$, $p<.001$, $\Delta R^2=.06$) as well as lower quality of life in the domains of physical health ($\beta=-0.31$, $t=-8.51$, $p<.001$, $\Delta R^2=.09$), psychological health ($\beta=-0.28$, $t=-7.23$, $p<.001$, $\Delta R^2=.07$), social relationships ($\beta=-0.15$, $t=-3.69$, $\Delta R^2=.02$), and environmental health ($\beta=-0.31$, $t=-8.36$, $p<.001$, $\Delta R^2=.09$). See Table 2.

[Table 2 here]

DISCUSSION

The current study is the first to document the detrimental links between co-occurring ADHD symptoms and critically important outcomes for autistic adults. Utilizing self-ratings to tap into the lived autistic experience, this investigation revealed greater ADHD symptoms were associated with diminished independence in activities of daily living and lower subjective quality of life among autistic adults. Taken together, the current study fills an important gap in the literature, documenting the potential negative impact of ADHD during adulthood, and raises several issues that need to be addressed during the neglected period of adulthood in autism.

The present study provides an important new lead by showing that ADHD symptoms explain variance in activities of daily living in autistic adults. Our findings converge with a robust literature demonstrating the same association in preschoolers (Lyall et al., 2017; Sikora et al., 2012) through age 21 (Sikora et al., 2012; Yerys et al., 2009; 2019). However, the present findings may also seem counterintuitive because ADHD symptoms abate in many non-autistic individuals by early adulthood (Sibley et al., 2017). It is plausible that the abatement of ADHD

symptoms could be accompanied by a lack of an association with activities of daily living for autistic adults. Our findings demonstrate that this is not the case and highlight co-occurring ADHD as a potential stumbling block to achieving optimal independence levels in adulthood.

The present study is the first to use self-ratings, tapping into the lived experience of autistic adults, to link greater ADHD symptoms to lower quality of life during adulthood. This is important because the literature on subjective quality of life among autistic adults highlights a consistently lower rating compared to both adult psychiatric populations and non-autistic adults (Barneveld et al., 2014; Graham Holmes et al., 2020; McConachie et al., 2018). However, our study raises an important point that has been described previously: lower ratings of quality of life cannot be solely attributed to autism—other factors can and will play a role (Michael, 2021). That ADHD associates with quality of life in adulthood should not be a surprise for two reasons: 1) ADHD symptoms in non-autistic adults are associated with greater distress and lower physical, psychological, social, and environmental quality of life (Nicastro et al., 2018), and 2) ADHD's influence may be outsized in adulthood because there are higher expectations for independence and fewer structural supports (caregivers, educational system) in place for adults than children (Ishler et al., 2021; Shattuck et al., 2011).

Although the current study is the first of its kind and includes a large sample of autistic adults, possible limitations should be considered. This study relied on self-report; thus, inclusion of other informant reports could have provided convergent validity, particularly the severity of ADHD symptoms and their association with outcome measures. Additionally, the autistic adults participating in this study were cognitively capable of completing the study independently; it remains an open question whether the observed relationships between ADHD symptoms and

functional outcomes would be of a similar magnitude in autistic adults with more cognitive challenges.

This study indicates that targeting ADHD symptoms in autistic adults and curbing their severity may have important implications for improving both independent living and quality of life. To that end, it will be critical to address several issues in future research to improve our support of autistic adults. We must address how access to care for ADHD, and treatment effectiveness for ADHD symptoms during childhood and into adulthood relates to these critical outcomes. We must also determine whether there are critical windows in childhood and adolescence for intervening on ADHD symptoms in the life of an autistic individual to blunt these negative outcomes in adulthood, or whether we can reverse negative outcomes with successful treatment in adulthood. Furthermore, it will be important to examine other critical risk and protective factors that may influence the trajectory of activities of daily living and quality of life for autistic individuals across their lifespan, including genetic vulnerabilities, trait vulnerabilities (e.g., emotion dysregulation), parenting factors, socioeconomic status, and other social determinants of health.

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Table 1. Participant Characteristics and Mean Self-Report Ratings

Constructs	N=628
Age <i>M</i> (SD)	38.6 years (13.7)
Range	18-83 years
Birth-Sex (Female:Male)	369:259
Race and Ethnicity	
<i>Race</i>	
Asian	8
Black/African-American	12
More than one Race	55
Native American/Alaska Native	5
White	535
Other	12
Missing	1
<i>Ethnicity</i>	
Latinx	55
Non-Latinx	562
Unknown	10
Missing	1
Household Income	
< \$20,000	208
\$20,0001 – \$35,000	116
\$36,000 – \$50,000	87
\$51,000 – \$65,000	34
\$66,000 – \$80,000	57
\$81,000 – \$100,000	37
\$101,000 – \$130,000	33
\$131,000 – \$160,000	24
\$161,000+	32
Missing	96
AQ-28 <i>M</i> (SD)	84.1 (11.6)
Met AQ-28 Screening Criteria (yes:no)	594:34
On ADHD Medication (yes:no:missing)	93:438:97
ASRS Total Raw Score (Part A) <i>M</i> (SD)	12.7 (5.0)
W-ADL Total Raw Score <i>M</i> (SD)	30.6 (4.4)

WHOQOL-BREF-Physical Health Mean Item Score (SD)	3.44 (0.8)
WHOQOL-BREF-Psychological Health Mean Item Score (SD)	3.07 (0.8)
WHOQOL-BREF-Social Relationships Mean Item Score (SD)	3.10 (1.0)
WHOQOL-BREF-Environmental Health Mean Item Score (SD)	3.6 (0.7)
ASQOL Mean Item Score (SD)	3.2 (0.8)

ADHD=Attention Deficit/Hyperactivity Disorder; ASRS=ADHD Self-Report Scale; W-

ADL=Waisman Activities of Daily Living; ASQOL=Autism Spectrum Quality of Life

Table 2. Regressions of activities of daily living and quality of life domains on control variables and ADHD symptoms

	W-ADL					Physical Health					Psychological Health				
	B ^a	SE	95% CI	β	t	B ^a	SE	95% CI	β	t	B ^a	SE	95% CI	β	t
Baseline Model:	$R^2=0.07$, $F=8.77$, $p<0.001$					$R^2=0.16$, $F=22.84$, $p<0.001$					$R^2=0.10$, $F=13.04$, $p<0.001$				
Age	0.04	0.01	[0.02, 0.06]	0.16	3.90 ^b	-0.05	0.03	[-0.11, 0.01]	-0.07	-1.77	0.03	0.03	[-0.03, 0.09]	0.04	0.92
Sex at Birth	0.01	0.01	[-0.01, 0.04]	0.06	1.40	-0.13	0.03	[-0.19, -0.08]	-0.18	-4.68 ^b	-0.04	0.03	[-0.10, 0.02]	-0.06	-1.43
Household Income	0.04	0.01	[0.02, 0.06]	0.16	3.91 ^b	0.15	0.03	[0.09, 0.20]	0.19	5.09 ^b	0.08	0.03	[-0.02, 0.14]	0.10	2.59 ^c
Medications	-0.00	0.01	[-0.02, 0.02]	-0.01	-0.31	-0.10	0.03	[-0.16, -0.05]	-0.14	-3.73 ^b	-0.07	0.03	[-0.13, -0.01]	-0.93	-2.41 ^c
AQ	-0.04	0.01	[-0.06, -0.02]	-0.16	-3.87 ^b	-0.15	0.03	[-0.21, -0.10]	-0.20	-5.37 ^b	-0.20	0.03	[-0.26, -0.14]	-0.26	-6.70 ^b
Test Model:	$\Delta R^2=0.06$, $\Delta F=38.59$, $\Delta p<0.001$					$\Delta R^2=0.09$, $\Delta F=72.45$, $\Delta p<0.001$					$\Delta R^2=0.07$, $\Delta F=52.25$, $\Delta p<0.001$				
Control Covariates															
ADHD Self-Report Scale	-0.06	0.01	[-0.08, -0.04]	-0.25	-6.21 ^b	-0.28	-0.03	[-0.29, -0.18]	-0.31	-8.51 ^b	-0.21	0.03	[-0.27, -0.16]	-0.28	-7.23 ^b
	Social Relationships					Environmental Health					Autism Spectrum QOL				
	B ^a	SE	95% CI	β	t	B ^a	SE	95% CI	β	t	B ^a	SE	95% CI	β	t
Baseline Model:	$R^2=0.06$, $F=7.47$, $p<0.001$					$R^2=0.16$, $F=23.18$, $p<0.001$					$R^2=0.20$, $F=30.82$, $p<0.001$				
Age	-0.12	0.04	[-0.20, -0.04]	-0.12	-2.98 ^d	-0.02	0.03	[-0.07, 0.04]	-0.02	-0.56	-0.10	0.03	[-0.15, -0.04]	-0.12	-3.20 ^b
Sex at Birth	0.04	0.04	[-0.03, 0.12]	0.04	1.09	-0.02	0.03	[-0.07, 0.04]	-0.02	-0.56	-0.07	0.03	[-0.13, -0.01]	-0.09	-2.40 ^c
Household Income	0.08	0.04	[0.00, 0.16]	0.08	2.06 ^c	0.25	0.03	[0.20, 0.31]	0.36	9.50 ^b	0.19	0.03	[0.13, 0.24]	0.24	6.54 ^b
Medications	-0.01	0.04	[-0.09, 0.06]	-0.01	-0.32	-0.03	0.03	[-0.08, 0.03]	-0.04	-1.01	0.01	0.03	[-0.05, 0.06]	0.01	0.32
AQ	-0.17	0.04	[-0.25, -0.10]	-0.18	-4.47 ^b	-0.13	0.03	[-0.18, -0.08]	-0.18	-4.80 ^b	-0.26	0.03	[-0.32, -0.20]	-0.34	-9.06 ^b
Test Model:	$\Delta R^2=0.02$, $\Delta F=13.60$, $\Delta p<0.001$					$\Delta R^2=0.09$, $\Delta F=69.86$, $\Delta p<0.001$					$\Delta R^2=0.09$, $\Delta F=57.22$, $\Delta p<0.001$				
Control Covariates															
ADHD Self-Report Scale	-0.14	0.04	[-0.22, -0.07]	-0.15	-3.69 ^b	-0.22	0.03	[-0.27, -0.16]	-0.31	-0.26 ^b	-0.21	0.03	[-0.25, -0.14]	-0.27	-7.56 ^b

ADHD=Attention Deficit/Hyperactivity Disorder; AQ=Autism Spectrum Quotient; QOL=Quality of Life; W-ADL=Waisman Activities of Daily Living.

^a= All reported unstandardized coefficients and their 95% confidence intervals are z-scores.^b= $p \leq 0.001$ ^c= $p < 0.05$ ^d= $p < 0.01$