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Self-Reported Cognitive Decline Among Middle and Older Age Autistic Adults

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Declarations

Conflicts of Interest:
None.

Abstract

Very little is known about autistic adults as they age. Early evidence suggests a potentially high risk for dementia and atypical cognitive decline in autistic middle and older age adults. Research in the general population indicates that self-reported cognitive decline may predict future dementia earlier than performance-based measures. Nevertheless, self-report dementia screeners have not been used to date in autism research. In a sample of middle and older age autistic adults (N=210), participants completed a self-rated dementia screener, the AD8, to describe the rate of cognitive decline, examine associations of cognitive decline with age, educational level, sex designated at birth, and autistic traits, and document the psychometrics of a dementia screener in autistic adults. We found high rates of cognitive decline with 30% of the sample screening positive. The most common symptoms were declining interest in leisure activities, and increases in everyday problems with thinking, memory, and judgment. There was evidence that autistic individuals designated female at birth may be more vulnerable to cognitive decline than autistic individuals designated male at birth. Notably, reports of cognitive decline did not vary by age or educational level. Modestly elevated autistic traits were found in those screening positive versus negative for cognitive decline. Finally, the dementia screener showed good psychometrics, including convergent validity with an independent measure of current memory problems. These results could signal an emerging public health crisis in autistic adults as they age, and support the potential utility of self-report measures for early screening for cognitive decline in this population.

Lay Summary: This study used a self-report dementia screener to look at increasing problems in thinking and memory in middle and older age autistic adults. Rates of thinking and memory problems were high, with 30% of the autistic adults reporting experiences of cognitive decline. Autistic individuals designated female at birth and adults with greater autistic traits were more likely to screen positive for likely cognitive decline.

Introduction

Advancing age is associated with increased risk for cognitive decline, which can have subtle impacts (i.e., Mild Cognitive Impairment [MCI]) or can result in frank interference with daily functioning (i.e., dementia). The term dementia encompasses changes in the brain leading to memory loss and impaired cognition from a variety of causes, including vascular dementia, frontotemporal dementia, Parkinson's Disease, and Alzheimer's Disease. MCI may be an early sign of Alzheimer's Disease or another neurodegenerative condition, but not all cases of MCI progress into dementia (Gale et al., 2018). The most common form of dementia, Alzheimer's Disease, is increasingly common in countries with rapidly aging populations, and thus has important implications for public health (Alzheimer's Association, 2022). In addition to increasing age, other risk factors for developing dementia include poor cardiovascular health, genetic markers, medication use, depression at any age, low educational attainment, and decreased social participation, among others (Bellou et al., 2016; Hugo & Ganguli, 2014). Sex designated female at birth is also an important risk factor of Alzheimer's Disease, with a 20% lifespan risk in those assigned female vs. a 10% lifespan risk in those assigned male at birth (Soria Lopez et al., 2019), which may be due to longer lifespan among women and the effects of menopause (e.g., neuroendocrine and cognitive changes; Scheyer et al., 2018).

We are essentially naive as to how cognitive aging progresses in autism spectrum disorder (ASD), including the risk for dementia. Previous research utilizing Medicaid claims data has identified prevalence rates of early-onset dementia (onset before age 65) as 2.6 times higher in ASD than in the general population. The prevalence of early-onset dementia was 4.04% in autistic individuals without co-occurring intellectual disability, compared to 0.97% in the general population (Vivanti et al., 2021). Strikingly, the estimate of the mean age of early-onset dementia

for autistic adults without intellectual disability was 49 years, about 5 years earlier than the

general population (Vivanti et al., 2021). In Medicare claims data, 25.2% of autistic adults ages

65 and older received diagnoses of "cognitive disorders", an increase of 20 percentage points (or

an over 4-fold increase) compared to estimates in the general population (Hand et al., 2020).

While information from claims data is important to identify areas of research need, claims data

only indicates a diagnosis was made without providing details about symptom presentation.

Further limitations of relying solely on findings from claims data include the reliance on

diagnostic codes that may lack validation, as well as the grouping of diagnoses together to study

prevalence (e.g., all cognitive disorders ["delirium, dementia, amnesia, and 'other' cognitive

disorders"] are grouped together in Hand et al., 2020). Although claims data findings offer

insight into a particular risk among autistic adults for developing Alzheimer's Disease and other

dementia diagnoses with varying cognitive symptoms, there is limited research on the

experiences of cognitive decline and on dementia symptom presentation in this population.

When conceptualizing MCI and dementia in the context of autism during adulthood, it is

important to differentiate between cognitive impairments present across the lifespan (e.g.,

challenges in executive function), and age-related cognitive decline occurring over time. Based

on cross-sectional studies, there is some indication of increasing age-related cognitive problems

that could be indicative of MCI or dementia among autistic adults, though evidence is mixed thus

far. For example, in two studies using the same performance-based screening task, one found

more features of MCI among autistic adults than non-autistic adults (Powell et al., 2017: ages 30-

67 years, ASD group n=29) whereas the other did not (Groot et al., 2021: ages 30-73 years, ASD

group n=51). In the study that identified increasing age-related cognitive problems on a

performance-based measure of MCI, there were no differences between autistic and non-autistic

younger adults, suggesting that the diverging associations between age and performance were unlikely due to cognitive differences in ASD present earlier in development (Powell et al., 2017). Similarly, in studies examining executive function, a critical component of cognition that declines with age in the general population (e.g., Cepeda et al., 2001; Fisk & Sharp, 2004), some studies have found increasing age-related cognitive inflexibility (one area of executive function) across adulthood in autistic vs. non-autistic adults (Powell et al., 2017). Other studies show parallel age-related differences in this aspect of cognition in these groups (Geurts & Vissers, 2012: ages 51-83 years, ASD group *n*=23; Torenvliet et al., 2022: ages 30-89 years, ASD group *n*=88) as well as episodic memory (Lever & Geurts, 2016: ages 20-79 years, ASD group *n*=118). In a longitudinal study of verbal memory in autistic and non-autistic adults (Pagni, Walsh et al., 2021: ages 18-71 years, ASD group n=106), declines in verbal memory were found in 33% of the autistic sample over a span of two to three years, compared to only 4% of the non-autistic sample. Previous research in this area is limited by relatively few cognitive aging studies that incorporate longitudinal designs or that focus specifically on MCI or dementia risk in ASD, and most existing studies involve small sample sizes with diminished statistical power. Nevertheless, there is some preliminary evidence, albeit mixed, for divergent age-related cognitive differences in ASD.

Looking beyond performance on cognitive tasks, there is increased recognition of the importance of self-report assessments as early symptoms of cognitive decline may not always be observable to an informant. Though measures of subjective cognitive impairment and subjective memory complaints (SMCs) are often associated with objective tests of cognitive decline in the general population (Dardenne et al., 2017), SMCs may be an early indicator of later cognitive decline. Indeed, SMCs, even in the absence of objective memory problems, serve as a useful tool

for the early identification of cognitive impairment in non-autistic populations (Choe et al., 2018; Wasef et al., 2021). Self-reported cognitive problems have shown predictive power in identifying future dementia of all types (Jessen et al., 2010; Rönnlund et al., 2015), though depressive symptoms, another risk factor for dementia, may be predictive of SMCs (Gruters et al., 2019; Eramudugolla et al., 2012). In a meta-analysis of longitudinal studies following people with SMCs but no objective cognitive problems, it was found that those with SMCs were twice as likely to develop dementia, compared to those having no SMCs (Mitchell et al., 2014). In a recent study, a self-reported measure of increased cognitive problems effectively distinguished between those with no memory problems, MCI, and dementia (Kasai et al., 2021). The measurement of SMCs enhances the early detection of individuals at risk of developing dementia by identifying those that may be experiencing subclinical or very early stages of dementia. Benefits of early detection include earlier access to medical care and treatments to prevent or delay disease progression, an opportunity for individuals and their families to plan for the future, and access to treatments to manage symptoms and improve quality-of-life (Rasmussen & Langerman, 2019).

The limited work that has been conducted examining cognitive decline in autistic adults has used validated, performance-based measures to assess age-related differences in cognition among autistic adults (Geurts & Vissers, 2012; Groot et al., 2021; Powell et al., 2017). No prior study has utilized a self-report screener for dementia or experiences of cognitive decline. The utility of self-reports in autistic individuals has been demonstrated in other areas of clinical research, including executive function and related cognitive domains (Geurts et al., 2020; Kenworthy et al., 2022; Lever & Geurts, 2016). Previous research has identified increased self-reported cognitive problems in autistic adults (Lever & Geurts, 2016), in addition to high

concordance between self and informant reports of executive function difficulties (Kenworthy et al., 2022), which demonstrates autistic people are able to accurately report on their own cognitive challenges.

Current research suggests that autistic adults are at increased risk for dementia, and self-report measures are an unexplored tool to identify increases in cognitive problems as an early marker for dementia risk in autistic adults (Mitchell & Shiri-Feshki, 2009). Therefore, the present study aims to: 1) describe the rates and profiles of self-reported cognitive decline, 2) examine associations of age, educational level, sex designated at birth, and autistic traits with self-reported increases in cognitive decline, and 3) document the psychometrics of one self-report measure of cognitive decline (i.e., the AD8; Galvin et al., 2005, Galvin et al., 2007) in a sample of middle and older age (MOA) autistic adults, including both internal consistency reliability and convergent validity with a self-report measure of memory problems. Based on prior research, we expect to find overall high rates of self-reported cognitive decline in autistic adults, greater self-reported increases in cognitive decline in autistic individuals designated female at birth, less evidence for cognitive decline in autistic individuals with a Bachelor's degree or higher, and good convergent validity between self-reported cognitive decline and self-reported current memory difficulties. In addition, we will explore the association between age and cognitive decline with a prediction that cognitive decline will be fairly consistently reported across middle and older adulthood in ASD.

Methods

Participants

In the present study, 210 autistic MOA adults (89 males, 121 females) were recruited online through Simons Powering Autism Research (SPARK), Research Match as part of a

follow-up study (see Charlton et al., 2022; Geurts et al., 2022) two years after the completion of the original study (December 2021-January 2022). The final sample of 210 represents 55% of the original sample invited to participate (n=385) and includes those who completed all study measures.

All participants were designated by SPARK as "independent" autistic adults, indicating they were able to consent to the research study for themselves and therefore were unlikely to have an intellectual disability. All participants were required by SPARK to self-disclose a diagnosis on the autism spectrum given by a medical or clinical professional. Diagnoses on the autism spectrum in the SPARK sample have been validated using electronic medical records, with 98.8% confirmation of diagnoses (Fombonne et al., 2022). In the current study, 99% of participants scored above the AQ28 cutoff (>65) indicative of ASD. Consistent with other online self-report survey research in autistic adults, the sample included a relatively high proportion of participants designated female at birth (Rubenstein & Furnier, 2021; Rødgaard et al., 2022) compared to population-based estimates for autistic children (Maenner et a., 2021) and adults (Dietz et al., 2020). The study was approved by The George Washington University Institutional Review Board (IRB) and all participants provided informed consent. The age range of participants was 42 to 81 years, with a mean age of 55.63 (SD=9.44). See Table 1.

[Table 1]

Measures

Demographic Information

Participants provided information on age, educational level, sex designated at birth, race, ethnicity, and current medication use.

Increases in Cognitive Problems

Participants completed self-ratings of the AD8 (Galvin et al., 2007). The AD8 is a

measure of individual change "over the last several years" in memory, orientation, judgment, and

function, as they relate to the presence of cognitive problems. The AD8 is sensitive to early

cognitive change indicative of very mild (i.e., early) dementia and was designed to distinguish

between individuals with no dementia (i.e., normal aging) and those with very early stages of

dementia. The AD8 includes 8 items, rated as *"Yes", "No",* or *"Don't know"* to indicate

whether individuals have experienced changes in thinking and memory (e.g., "Repeats the same

things over and over (questions, stories, or statements)") or daily activities (e.g., "Less interest in

hobbies/activities"). Items rated as *"Yes"* are summed to obtain the AD8 total score. The AD8

measures cognitive changes over the past several years, but does not measure the exact age of

symptom onset or severity of these cognitive challenges. Previous research on the AD8 has

identified that cut-offs of 2 for informant reports and 1 for self-reports maximize sensitivity and

specificity to indicate likely cognitive impairment (Galvin et al., 2007). In clinic samples, the

informant-report AD8 has been moderately to strongly correlated with gold-standard clinical

dementia ratings and performance on objective neuropsychological tests (Galvin et al., 2006).

Previous research including self-reported AD8 scores in non-autistic samples has found good

diagnostic performance with sensitivity ranging from 80% to 85% and specificity ranging from

59% to 74% (Chin et al., 2013; Galvin et al., 2007). The self-report version of the AD8 has

demonstrated fair discriminative validity with an area under the ROC curve (AUC) of .78

(Galvin et al., 2007). The AD8 has also been shown to be similarly effective between males and

females, as well as White and Black participants (Galvin et al., 2007). For the current study,

analyses were conducted using not only the AD8 total score, but also cutoffs of ≥ 1 and ≥ 2 to

reflect the conventional cutoff for self-report (Galvin et al., 2007) and a higher-threshold cutoff (Galvin et al., 2005).

Autistic Traits

Participants completed the Autism Quotient-28 (AQ28; Hoekstra et al., 2011) during the first wave of data collection, two years prior, and was not repeated at the current wave of data collection. The AQ28 is a 28-item self-report measure of autistic traits, with higher scores indicating more traits. The AQ28 has demonstrated good internal consistency in autistic samples (alpha=.77-.86; Hoekstra et al., 2011). In the current study, the AQ28 total score was used as a covariate in Aims 2 and 3.

Convergent Validity of the AD8

Current subjective memory complaints were measured using the Prospective-Retrospective Memory Questionnaire (PRMQ; Smith et al., 2000), which permits the assessment of the convergent validity of the AD8. The PRMQ is a 16-item self-report measure of the frequency of current cognitive problems in both prospective (e.g., "Do you decide to do something in a few minutes' time and then forget to do it?") and retrospective memory (e.g., "Do you fail to recall things that have happened to you in the last few days?"). Questions about memory failures are rated on a 5-point scale (*"Very Often", "Quite Often", "Sometimes", "Rarely", or "Never")*. Total scores range from 16 to 80, with higher scores representing a greater frequency of memory mistakes or failures. Previous research on the PRMQ self-report has demonstrated high internal consistency (Cronbach's alpha=.89; Crawford et al., 2003) and discriminant validity among groups with and without Alzheimer's Disease (Smith et al., 2000). The PRMQ has been used in previous research with autistic adults to assess memory complaints (Landsiedel & Williams, 2020; Williams et al., 2014). Thus, the PRMQ as a measure of current

memory problems allowed for the assessment of convergent validity with changes in thinking and memory over the last several years as quantified by the AD8. The current study used the PRMQ total score in analyses.

Data Analysis

All analyses were performed using SPSS Version 28. Descriptive statistics for overall and item-level AD8 data and one-sample t-tests comparing the current sample to a USA population-based sample (Passler et al., 2021) were used to address Aim 1. Results are presented using both higher-threshold (≥ 2) and conventional self-report (≥ 1) cutoffs on the AD8. To examine age, educational level, and sex differences in both overall and item-level self-reported increases in cognitive problems (Aim 2), t-tests and chi-square tests were used. T-tests were also used to examine differences in autistic traits (AQ28) by AD8 screening status. If AQ28 scores differed for AD8 screen positive and screen negative groups, follow-up analysis of covariance (ANCOVA) was then used to examine age differences based on AD8 screening status after controlling for AQ28 scores. To address Aim 3, Cronbach's alpha was used to examine the internal consistency reliability of AD8 responses (Galvin et al., 2006), and Pearson's correlations between total scores for the AD8 and PRMQ were used to examine convergent validity. If AQ28 scores were associated with AD8 scores, partial correlation was used to examine the association between AD8 and PRMQ total scores after controlling for AQ28 scores.

Results

Aim 1: Rates and profiles of self-reported cognitive decline

The mean AD8 total score for the entire sample was 1.39 (SD=2.03, range=0-8). Using a higher-threshold cutoff of ≥2, 30% of autistic middle-aged and older adults screened positive for experiencing increasing cognitive problems over the last several years (i.e., cognitive decline) as reported on the AD8. Using the instrument's conventional and recommended self-report cutoff of ≥1, 48.9% of the sample screened positive for experiencing cognitive decline. See Table 2 for screening status by various cutoff scores.

[Table 2]

Item-level examination of the AD8 revealed that the most commonly endorsed symptoms indicating a change in the past several years were less interest in leisure activities (Interest; 29.5% of the sample, n=62), everyday thinking and/or memory problems (Consistency; 27.8%, n=58), judgment problems (Judgment; 20.7%, n=43), and forgetting appointments (Appointments; 19.7%, n=41). Less commonly endorsed symptoms of cognitive decline included trouble with learning to use appliances or tools (Appliances; 12.4%, n=26), trouble handling complex finances (Finances; 11.5%, n=24), repeating things (Repeats; 11%, n=23), and trouble remembering the correct month or year (Orientation; 7.1%, n=15). When profiles of symptom endorsement were compared between the MOA autistic adults in the current study and a USA population-based sample (Passler et al., 2021; See Figure 1), there were significant differences in judgment problems (p=.016), less interest in leisure activities (p=.004), trouble handling complex finances (p=.033), forgetting appointments (p=.007), and everyday thinking and/or memory problems (p=.002), with elevated endorsement rates among the MOA autistic adults in the current study.

[Figure 1]

Aim 2: Associations with self-reported increases in cognitive decline

There were no significant sex or age differences in item-level responses on the AD8. Using a

higher-threshold cutoff (≥ 2), there were no significant sex differences between the autistic

groups screening positive or negative, $\chi2(1,N=210)=1.27$; $p=.26$, $w=.08$. Using a cutoff of ≥1,

there was a marginally significant sex difference in screening status, $\chi2(1,N=210)=3.62$; $p=.057$,

$w=.13$ (see Figure 2), with 54% of females and 40% of males screening positive on the AD8.

[Figure 2]

There were no significant age differences between the autistic groups screening positive or

negative using either cutoff on the AD8 (see Table 3). Age was not correlated with the total

AD8 score in the entire sample ($r=-.02$, $p=.73$) nor only among the adults screening positive

using a cutoff of ≥1 ($r=-.02$, $p=.87$; $n=101$) or ≥2 ($r=-.07$, $p=.57$; $n=63$). There were also no

significant differences in educational level between the autistic groups screening positive or

negative using a cutoff of ≥1, $\chi2(1,N=209)=.004$; $p=.95$, $w<.01$, or ≥2, $\chi2(1,N=209)=.53$; $p=.46$,

$w=.05$, on the AD8. Further, there were no significant differences in total AD8 score between

those who had completed a bachelor's degree or higher and those who had not completed a

bachelor's degree $t(118)=1.09$, $p=.28$, $d=.17$.

[Table 3]

Higher autistic trait ratings were found for autistic adults screening positive compared to those

screening negative using a cutoff of ≥1, $t(207)=-1.65$, $p=.05$, $d=-.23$, and a higher-threshold

cutoff of ≥2, $t(207)=-3.12$, $p=.001$, $d=-.47$ on the AD8 (See Table 4). Similarly, AQ28 total score

and AD8 total score were significantly but only modestly correlated with one another overall

($r=.19$, $p<.01$). An ANCOVA revealed no main effect of screening status on age using a cutoff

of ≥ 1 ($F(1, 206)=.27$, $p=.61$, $\eta_p^2=.001$) or using a cutoff of ≥ 2 ($F(1, 206)=.23$, $p=.63$, $\eta_p^2=.001$), even after controlling for the effect of AQ28 score.

[Table 4]

Aim 3: Psychometrics of the AD8

The psychometric properties of the AD8 were examined through internal consistency and convergent validity. Participants who endorsed "Don't Know" for an item ($n=53$) were excluded from internal consistency analyses. The AD8 demonstrated good internal consistency, with a Cronbach's alpha of .84. Inter-item pairwise correlations ($n=176$-204) for the AD8 ranged from $r=.28$-.59 (see Table 5). Convergent validity between AD8 total score and PRMQ total score was assessed through a Pearson's correlation and was statistically significant and of moderate to large effect size ($r=.49$, $p<.001$). Even after controlling for autistic traits (AQ28), partial correlations showed a relationship of the same magnitude between AD8 total score and PRMQ total score, $r_{partial}(206)=.49$, $p<.001$.

[Table 5]

Discussion

This study was the first to examine self-reported cognitive decline in MOA autistic adults in one of the oldest age samples reported to date. In line with the literature on the prevalence and incidence of early-onset dementia in autistic adults (Vivanti et al., 2021), we found high rates of subjective complaints of cognitive decline in the current sample of autistic adults, with an average age of those reporting cognitive decline in their mid-50s. Commonly endorsed symptoms included declining interest in leisure activities, and everyday problems with thinking,

memory, and judgment. There were no significant sex differences between the autistic groups screening positive or negative when using a higher-threshold cutoff, but those designated female at birth may be more vulnerable to cognitive decline when using the recommended lower-threshold self-report cutoff. Rates of cognitive decline did not differ by age or educational level, and age was not significantly correlated with cognitive decline. Autistic traits were modestly correlated with subjective complaints of cognitive decline, and those screening positive on the dementia screener (AD8) had marginally greater autistic traits compared to those screening negative. However, controlling for autistic trait ratings did not alter findings reported here. Finally, the self-reported dementia screener used here (AD8) demonstrated good psychometric properties among MOA autistic adults, including strong internal consistency, similar to previous validation studies of the measure with non-autistic older adults (Galvin et al., 2006) and good convergent validity through moderate associations with the PRMQ. Overall, these findings signal an increasing need for providers to screen for cognitive decline and associated dementia risk in MOA autistic adults, and for our healthcare system to prepare to address the needs of autistic adults with increasing cognitive challenges. These screenings, especially those leveraging the use of self-report, will aid the early detection of dementia in autistic adults whose symptoms may be subtle. This early screening will allow autistic adults to have timely access to the care and treatment planning they need to promote well-being and quality-of-life.

In the current study, high rates of cognitive decline were identified, with 30% of MOA autistic adults screening positive on the dementia screener (AD8) using the higher-threshold cut-off (≥ 2). The rates of cognitive decline identified in our sample converge with reports of the increased likelihood of dementia and other similar cognitive challenges among autistic adults (Hand et al., 2020; Vivanti et al., 2021), though more research on large population-based

samples is needed to establish prevalence rates of cognitive decline and dementia risk in MOA autistic adults. The present findings suggest that rates of cognitive decline may be high among autistic adults, and this may signal a risk for future MCI or dementia. In a USA population-based sample of adults who were on average 10 years older than the present sample, 23.4% of adults screened positive on the self-reported AD8 using a cutoff of ≥2, compared to the 30% here (Passler et al., 2021). Similar profiles of symptom endorsement were observed in the population-based non-autistic sample and in MOA autistic adults in the current study, though when significant differences in endorsement rates occurred, they were always elevated in the MOA autistic adults. For example, declining interest in leisure activities and everyday problems with thinking, memory, and judgment were the most commonly endorsed symptoms, while forgetting the month or year was the least common symptom in both groups, though in both cases, rates were significantly elevated in the MOA autistic adults (Passler et al., 2021; see Figure 1). Adults in the population-based sample who screened positive were older than those that screened negative, with an average age of 65.48 (SD=8.57), and were more likely to be female, be less educated, and have higher rates of cardiovascular problems and depression (Passler et al., 2021). Notably, previous research using this self-report instrument has focused on its discriminative ability among severity levels of dementia, and therefore has focused on adults considerably older than those in the present study (Chin et al., 2013; Galvin et al., 2007; Kasai et al., 2021).

Item-level findings demonstrated that monitoring changes in daily activities/functioning may aid early diagnosis and treatment planning for autistic adults at risk for experiencing cognitive decline. Decreasing interest in leisure activities, including hobbies, was the most commonly reported symptom. Reduced engagement in hobbies is associated with increased risk of dementia in the general population (Almeida-Meza et al., 2021). It may be that hobbies, and

associated participation in daily activities, become too cognitively taxing, or withdrawal from activities may be associated with apathy common in late-life depression. It is also possible that the COVID-19 pandemic influenced these declines in interest in activities, although in data collected in the general population before COVID-19, this was also the most commonly reported symptom (Passler et al., 2021). More research is needed to better understand how these symptoms unfold in everyday life for autistic people, and how COVID-19 may have influenced symptom presentation and cognitive aging in MOA autistic adults. Other common symptoms were increasing everyday thinking and memory problems, and forgetting appointments. The endorsement of these items could indicate increases in working, episodic, and prospective memory problems associated with cognitive decline. Evidence on whether declines in working memory are divergent in autistic adults compared to non-autistic adults is mixed (Geurts & Vissers 2012; Lever et al., 2015), while episodic memory performance appears similar for autistic and non-autistic adults, even as they age (Desaunay et al., 2020; Lever & Geurts 2015). Problems with judgment and trouble handling complex finances may be indicative of executive function challenges previously documented among autistic adults (Davids et al., 2016; Wallace et al., 2016), and may become exacerbated by cognitive decline as autistic adults age. In non-autistic samples of older adults with MCI, SMCs appear related to daily living impairment and depressive symptoms (Ryu et al., 2016). Given the high prevalence of depression in autistic adults (Hudson et al., 2019), and associated cascading effects of psychomotor slowing in thinking, memory, and judgment; future research should examine the effects of depression on cognitive aging in autistic adults.

Age was weakly correlated with the total score on the dementia screener (AD8), indicating that cognitive decline is consistently reported across ages from middle to older

adulthood in ASD. The average age of adults with likely cognitive decline was 56.27 years, using a higher-threshold cutoff. Our findings identifying cognitive decline starting as early as middle-adulthood converges with evidence of an earlier onset of dementia in autistic older adults (average age of 49 years) compared to the general population (Vivanti et al., 2021). However, while the AD8 measures the presence of self-reported increased cognitive problems, it does not capture the severity of cognitive problems or the exact timing of symptom onset. Thus, an endorsed symptom may worsen over time, but may not be captured by this screening measure. Educational level was also not indicative of increased cognitive problems. Further research is necessary to examine symptom trajectories across the adult lifespan and following the onset of cognitive decline, and continue to examine the role of education and how to promote cognitive reserve in autistic adults.

No significant sex differences in screen-positive rates were identified when using a higher-threshold cutoff; however, when using the conventional cutoff for self-report, autistic individuals designated female at birth were more likely to screen positive than autistic individuals designated male at birth. These elevated cognitive complaints in females align with a recent study of Medicare-enrolled older autistic adults in which the prevalence of cognitive disorders was 28.1% for females and 23.8% for males (Hand et al., 2020). Further research is necessary to examine how experiences of cognitive aging may differ between autistic individuals designated male versus female at birth, especially in older adulthood. This is important given that the lifetime risk of Alzheimer's Dementia is higher in females due to a variety of factors (Li & Singh, 2014), including the impact of the loss of estrogen during menopause on cognition leading to memory challenges.

In examining associations between autistic traits and cognitive decline, a weak but significant correlation was identified between autistic traits rated two years earlier and signs of cognitive decline indicated by a dementia screener. However, even after controlling for autistic traits, our findings on cognitive decline and current memory problems remained the same. Thus, it is unlikely that the dementia screener (AD8) and measure of memory failures (PRMQ) were simply reflecting ASD symptom severity instead of cognitive decline. However, one challenge in the field moving forward is how to disentangle dementia symptoms from autistic traits and associated cognitive features (e.g., Rhodus et al., 2022). Speculatively, our observation that greater autistic traits at an earlier time point were associated with greater self-reported cognitive declines could indicate that those with elevated autistic traits are more likely to show cognitive declines in the future. Although, our current study lacked the concurrent or longitudinal data to rigorously evaluate this hypothesis, a recent study of non-autistic older adults with dementia showed that elevated autistic traits were associated with earlier age of dementia onset and more severe cognitive impairment (Rhodus et al., 2020). The autistic traits most common in this sample of non-autistic adults with dementia were across social, communication, and routinized behavioral domains (e.g., not initiating with peers, not requesting to get needs met, engaging in ritualistic behavior, responding negatively to routine changes; Rhodus et al., 2020). Thus, future research incorporating longitudinal designs should examine cognitive trajectories in autistic adults and the association between autistic traits and cognitive decline.

Finally, the psychometric properties of the measure of self-reported dementia symptoms used here (AD8) in MOA autistic adults were found to be good. Therefore, we provide preliminary evidence that the AD8 is a reliable and valid measure of changes in cognitive problems indicative of cognitive decline in autistic adults who are able to complete self-report

measures. The AD8 demonstrated good internal consistency, which was comparable to that reported in non-autistic samples (Galvin et al., 2006). Additionally, the AD8, a measure of increasing cognitive problems over time, and the PRMQ, a measure of current memory difficulties, were moderately strongly associated with one another, validating the AD8 as a measure of cognitive difficulties in MOA autistic adults.

Limitations of the current study are present, including the exclusion of autistic adults with intellectual disability, lack of ethnoracial and educational diversity within the sample, the relatively high proportion of females to males included in the study, and the relatively low proportion of individuals above the age of 75. The current study chose to rely solely on self-report to identify more subtle early changes indicative of cognitive decline and examine the subjective experiences of older autistic adults. This approach aligns with required assessment for cognitive impairment at annual wellness visits through Medicare beginning with direct observation and patient report. The focus on self-report prevented the inclusion of autistic adults who are not able to independently complete self-report measures; however, future studies could incorporate use of informant report measures validated for adults with intellectual disability. While informant-report cognitive screening measures have been validated in the general population (e.g., AD8; Galvin et al., 2005) and in adults with intellectual disability (e.g., Deb et al., 2007), they have not been validated in autistic adults to date. While future research needs to include autistic individuals across the entire spectrum, the current finding that even in a sample of "independent" autistic adults there are high rates of early onset cognitive decline addresses concerns that cognitive decline is associated with intellectual disability rather than ASD per se. Future research on cognitive decline in older autistic adults with co-occurring intellectual disability and the development of associated measures is warranted. The current sample was also

limited by the inclusion of predominantly White ethnoracial identities and the majority of

participants (66%) had a college degree or higher; thus, future research is needed with samples

that are representative of the general population. Further, the present sample was drawn from the

SPARK sample which has higher rates of autistic individuals designated female at birth than

current diagnostic rates in ASD (Maenner et al., 2021). However, the enrichment for individuals

designated female at birth in the present study could also be considered a strength of this

research, especially given that the ASD literature predominantly focuses on individuals

designated male at birth and given the increased risk of dementia among females in the general

population (Li & Singh, 2014). Though this study represents one of the oldest age samples

within ASD research, the number of individuals over the age of 75 ("old-old") in the study (n=1)

was also a limitation, given links between advancing age and dementia risk in the general

population. Extant information on older autistic adults is sparse, which is perhaps unsurprising

given that initial descriptions of ASD were first published only ~80 years ago (Kanner, 1943;

Asperger, 1944). The current research was not able to differentiate between biological or

environmental explanations for cognitive decline or early onset dementia. For example, living

alone (Desai et al., 2020) and educational level (Bellou et al., 2016) have been identified as risk

factors of dementia in neurotypical older adults**. Future research may examine the effects of

psychosocial and physical determinants of health on cognitive aging, including community

participation, living situation, employment, social connections, co-occurring physical and mental

health conditions, and medication use in MOA autistic adults.

Overall, findings showed high rates (30%) of self-reported cognitive decline among

MOA autistic adults. Further, autistic individuals designated female vs. those designated male at

birth may be more vulnerable to cognitive decline. The use of self-ratings of cognitive decline

using the AD8, which we have shown to be psychometrically sound for autistic adults without intellectual disabilities, revealed particular concerns for decreasing interest in hobbies, and increasing everyday problems with thinking, memory, and judgment. The high rates of MOA autistic adults reporting cognitive decline indicate that 1) dementia screenings for autistic adults should begin in middle adulthood and 2) the possibility of an emerging public health crisis for autistic adults–our healthcare system needs to be equipped to meet an increasing call for services for MOA autistic adults. Early screening for cognitive decline in cognitively-able autistic adults using self-report will enable early access to care, treatment planning, and ultimately, improved quality of life as autistic adults age.

Abbreviations: ASD: Autism Spectrum Disorder, MCI: Mild Cognitive Impairment, MOA: Middle and older age, AD8: 8 Item Dementia Screener, PRMQ: Prospective-Retrospective Memory Questionnaire, AQ28: Autism Quotient-28

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Table 1
Participant demographic information and descriptive statistics for primary measures.

Measure	M or *n*	SD or %	Range	Total *n*
Age	55.62	9.46	42-81	210
Sex Designated at Birth				210
Male	89	42%		
Female	121	58%		
Level of Education				209
Less than a Bachelor's Degree	72	34%		
Bachelor's Degree or Higher	137	66%		
Race				210
White	175	83.30%		
Black	3	1.40%		
Asian	6	2.90%		
Multiracial	17	8.10%		
Other	9	4.30%		
Ethnicity				208
Hispanic or Latino	8	3.80%		
Not Hispanic or Latino	198	95.2%		
Don't Know	2	1.00%		

AD8 Total Score	1.39	2.03	0-8	210
PRMQ Total Score	39.60	12.99	16-74	209
AQ28 Total Score	87.41	10.49	65-109	209

Note. No participants reported that they were using cognitive-enhancing medications (i.e., use of Donepezil, Galantamine, Rivastigmine, or Memantine indicated for treatment of memory and thinking symptoms in mild, moderate, or severe dementia due to Alzheimer's or Parkinson's) at the time of data collection.

PRMQ=Prospective-Retrospective Memory Questionnaire (Smith et al., 2000); AQ28=Autism Spectrum Quotient-28 (Hoekstra et al., 2011).

Table 2

AD8 Screening Status by Cutoff

AD8 Cutoff	Positive Screen
1	48.9%
2	30.0%
3	23.3%
4	14.7%

Table 3
Average Age in Years by AD8 Screening Status

AD8 Cutoff	Mean Age in Years (SD)		
	Positive AD8 Screen	Negative AD8 Screen	Difference
≥1	55.23 (9.72)	56.06 (9.16)	$t(208)=-.63, p=.26, d=.09$
≥2	56.27 (8.75)	55.35 (9.74)	$t(208)=-.67, p=.52, d=.01$

Table 4
AQ28 Total Score by AD8 Screening Status

AD8 Cutoff	Mean AQ28 Total Score (SD)		
	Positive AD8 Screen	Negative AD8 Screen	Difference
≥1	88.65 (11.07)	86.27 (9.84)	*t*(207)=-1.65, *p*=.05, *d*=-.23
≥2	90.78 (9.76)	85.95 (10.49)	*t(207)*=-3.12, *p*=.001, *d*=-.47

Table 5
AD8 Inter-Item Correlations

		Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8
Item 1: Judgment	*r*	–							
N range = 177-188									
Item 2: Interest	*r*	.44**	–						
N range = 182-201									
Item 3: Repeats	*r*	.57**	.47**	–					
N range = 177-192									
Item 4: Appliances	*r*	.47**	.39**	.52**	–				
N range = 183-200									
Item 5: Orientation	*r*	.29**	.35**	.28**	.44**	–			
N range = 185-204									
Item 6: Finances	*r*	.59**	.34**	.36**	.40**	.44**	–		
N range = 184-202									
Item 7: Appointments	*r*	.46**	.37**	.31**	.48**	.36**	.55**	–	
N range = 184-201									
Item 8: Consistency	*r*	.50**	.38**	.43**	.43**	.44**	.46**	.47**	–
N range = 176-190									

** Correlation is significant at the 0.01 level (2-tailed).

Figure Legends

Figure 1. Percentage endorsements for each item of the AD8 in the current sample of middle and older age autistic adults and in a population-based sample of non-autistic older adults (Passler et al., 2021).
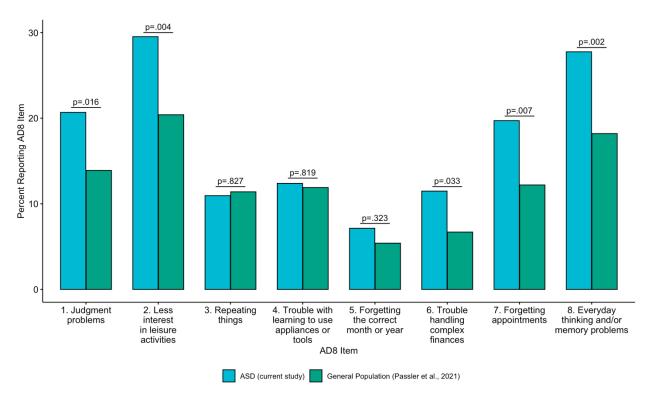
Figure 2. AD8 screening status by sex designated at birth.