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Self-reported prospective and retrospective memory among middle aged and older autistic and non-autistic people

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Abstract

Objective: Self-reported memory difficulties are common among older adults, but few studies have examined memory problems among autistic middle-aged and older people. The current study examines self-rated prospective (PM) and retrospective (RM) memory difficulties and their associations with age in middle-aged and older autistic and non-autistic people.

Methods: 350 autistic people (58% assigned-female-at-birth; age-range: 40-83 years) and 350 non-autistic adults matched on age, birth-sex and education level were included in the analysis. Participants completed the Prospective and Retrospective Memory Questionnaire (PRMQ) which includes questions about PM vs. RM (memory type), environment-cued vs. self-cued (cue), and short vs. long delay (delay).

Results: Autistic people reported significantly more PM and RM difficulties than the comparison group. Both groups reported more difficulties with PM (vs. RM), self-cued (vs. environment-cued), and short (vs. long) delay. No significant interactions were observed. Among autistic people, younger age was associated with reporting more PM and RM difficulties, but this pattern was not observed among non-autistic people.

Conclusions: Autistic people may be at reduced risk for memory problems as they age, compared to their same-age non-autistic peers. Further studies are required to explore the association between self-reported memory challenges and memory task performance among autistic older people.

Introduction

Autism Spectrum Disorder (ASD, henceforth autism) is a lifelong neurodevelopmental condition characterised by differences in social communication and presence of restricted and repetitive behaviour (American Psychiatric Association, 2013). Autistic people often demonstrate differences in cognitive abilities including difficulties in some aspects of memory compared to non-autistic comparison groups (Desaunay et al., 2020). Both retrospective (recall of information) and prospective (remembering to perform a future action) memory task performance difficulties have been observed among autistic compared to non-autistic adults (Altgassen et al., 2012; Kretschmer et al., 2014; Landsiedel et al., 2017), although use of cues and other task-specific characteristics may reduce or eliminate difficulties.

Autistic people tend to demonstrate better retrospective memory on tasks involving cues, recognition (as opposed to recall) and visual (compared to verbal) information (Landsiedel et al., 2017). For prospective memory, autistic people tend to perform better on event-based (perform an action in response to an occurrence, cued by the environment) compared to time-based (perform an action at a given time, often self-generated) cues (Williams et al., 2014). Importantly, research suggests that autistic people perform poorly on ecologically-valid tasks (i.e., those that mimic real-world) compared to lab-based tasks (Altgassen et al., 2012; Kretschmer et al., 2014)). These findings among autistic people suggest real-world difficulties with prospective memory that may affect daily functioning (Altgassen et al., 2012; Landsiedel et al., 2017).

Retrospective and prospective memory difficulties are also common in later life (generally considered to be 60 years and older) among non-autistic people (Maylor et al., 2002). Importantly, self-reported memory difficulties among older people are associated with both lower objective memory performance and real-world outcomes in the form of higher depression symptomatology and less independence in activities of daily living (Horn et al., 2018; Ryu et al., 2016). Therefore, self-reported memory problems represent a potentially potent marker of everyday cognitive skills. Prospective memory in particular is hypothesised

to be important for maintaining independence in later life (Ihle et al., 2012; Maylor et al., 2002).

The Prospective and Retrospective Memory Questionnaire (PRMQ; Crawford et al., 2003) is a self-rating scale which disentangles different aspects of memory in everyday life. The PRMQ prospective memory scale has been shown to be significantly associated with prospective memory task performance in some (Kliegel & Jager, 2006), but not all, studies (Rönnlund et al., 2011; Williams et al., 2014). In the general population, the PRMQ reveals fewer retrospective compared to prospective memory difficulties (Smith et al., 2000). Unlike memory task performance, self-rated memory abilities do not generally decline with age (which is thought to reflect comparison between self and similar age peers), and age associations have not been observed on the PRMQ (Crawford et al., 2003; Smith et al., 2000). We are aware of only one study that has explored self-reported memory difficulties among autistic young adults. In a small sample, autistic young adults (n=17) reported more memory difficulties than a non-autistic comparison group, and both groups reported more prospective (compared to retrospective) memory problems (Williams et al., 2014). However, we are not aware of any study that has explored self-reported prospective and retrospective memory concerns among autistic older people. This study examined differences in self-reported prospective and retrospective memory between middle-aged and older autistic people and a matched (on age, birth-sex and education level) comparison group; and examined associations with age in each group.

Methods

Participants

Participants were a group of 40+ year old autistic adults recruited online via Simons Foundation Powering Autism Research (SPARK; SPARK Consortium, 2018) Research Match service, and a comparison group from a publicly available dataset (https://osf.io/ak5pb/) recruited as part of a population survey conducted by UK researchers

and hosted by the British Broadcasting Corporation (BBC; Logie & Maylor, 2009; https://womaac.psy.ed.ac.uk/).

The autistic adults took part in a larger online study of adult development/aging, provided informed consent, and were compensated $25 for their time. The study was approved by the local institutional review board and followed procedures in accordance with the Declaration of Helsinki. 398 autistic people started the Prospective and Retrospective Memory Questionnaire (PRMQ). Forty-eight participants in the SPARK sample were excluded due to one or more of the following: lacking a clinical autism diagnosis (n=3), previous traumatic brain injury (n=15), report of dementia or stroke (n=13), missing items on the PRMQ (n=15), and/or missing educational information necessary for participant matching (n=2). Note, no participant reported brain tumour or other serious neurological disorder; seven people reported having a diagnosis of epilepsy. The final sample included 350 autistic individuals aged 40-83 years who had completed the PRMQ. For participant details see Table 1.

The autistic adult sample was composed of “independent” adults as designated by SPARK. These adults can consent for themselves and thus are unlikely to have a co-occurring intellectual disability. None of the participants in the current study reported intellectual disability as a prior medical diagnosis on their health history questionnaire. In order to be included in the SPARK registry, participants were required to have self-disclosed a diagnosis of ASD given by a medical/clinical professional. (Note, self-disclosure of diagnosis has been shown to be accurate in a sample of the SPARK dataset; Fombonne et al., 2022). To further validate the ASD clinical diagnosis information provided, participants completed the 28-item self-report Autism spectrum Quotient-28 (AQ28; Hoekstra et al., 2011). Scores >65 are considered to be above the cut-off indicating a positive screen for ASD. 97.4% of participants in the current sample scored >65.

Participants for comparison were leveraged from a study conducted in collaboration with the BBC between May 2006 and April 2009 (Logie & Maylor, 2009). The study was promoted via a television documentary, a popular television guide, and various radio and

television shows. Data was collected from 408,938 participants, aged 8 to 90 years old, from over 180 countries and is freely available to use (https://osf.io/ak5pb/). Data was filtered to retain participants aged 40-84 with information on home country, resulting in 83,383 participants. Using home country as a proxy for being fluent in English, we excluded participants (n=6,120) where English was not used as a primary language in the home country (i.e. not used, used only for education, or described as a second language according to Eberhard et al., 2021). People who had missing items on the PRMQ (n=1,847) or missing educational information (n=607) were also excluded. The final dataset of 74,809 was used as input to MatchIt in R (Ho et al., 2011; https://cran.r-project.org/web/packages/MatchIt/). Participants in the BBC sample were matched one-to-one to the SPARK sample based on age, sex assigned at birth and education level.

The final comparison group comprised 350 people aged 40-79 years old (see Table 1 for demographic details for the broader BBC sample aged 40 years and older, and the final sample evaluated in this study). The resulting matched samples did not significantly differ for age ($t(698)=1.60$, $p=.11$) or educational attainment ($\chi^2(4)=3.91$, $p=.42$). The samples differed for sex ratio and although this difference was statistically significant ($\chi^2(1)=8.89$, $p=.003$) the effect was small in magnitude $V=0.11$.

Measures

Demographic Information

Participants provided detailed demographic information including age, sex assigned at birth, and highest educational level. Educational level was coded as 1=None, 2=Primary School, 3=Secondary or High School, 4=Technical or Vocational College, 5=Other College, 6=Graduate with a university/college degree, 7=Postgraduate or professional degree.

PRMQ

The PRMQ is a 16-item self-report measure examining prospective (8 items, e.g. “Do you decide to do something in a few minutes and then forget to do it?”) and retrospective (8

items, e.g. “Do you fail to recognize a place you visited before?”) memory problems (Crawford et al., 2003). Items were also classified as memory being environment-cued (e.g. “Do you forget to buy something you planned to buy, even when you see the shop?”) or self-cued (e.g. “Do you forget something you were told a few minutes before?”), and as reflecting short delays (e.g., “Do you look at something without realizing you have seen it moments before?”) or long delays (“Do you forget what you watched on television the previous day?”). The response to each item is on a six-point Likert scale (1-Very rarely, 2-Rarely, 3-Occasionally, 4-Somewhat often, 5-Often, 6-Very often), and was recoded to a 5-point scale by collapsing responses of 4s and 5s together and recoding responses of 6 into 5s. Total scores range between 16 and 80, and scores for the Retrospective Memory (RM) and Prospective Memory (PM) scales are between 8 and 40 each, with higher scores indicating more memory problems. The PRMQ has good internal consistency: Cronbach’s alphas for Total score=0.89, PM score=0.84, and RM score=0.80; and no evidence that age or gender impact scores (Crawford et al., 2003). Alphas for the current study indicated good internal consistency for both the autistic (Total alpha=0.93, PM alpha=0.91, RM alpha=0.85) and non-autistic (Total alpha=0.90, PM alpha=0.86, RM alpha=0.80) groups.

Data Analysis

An ANOVA was conducted including between (autistic vs. non-autistic group), and within (retrospective/prospective; self-/environment-cue; long/short delay) subject factors, and interaction effects. Pearson’s correlations were conducted to explore the associations between memory (PRMQ total, RM, and PM scores) and age.

Results

ANOVA

Main effects: A significant difference was observed between the autistic and non-autistic groups ($F=29.22$, $p<.001$), with autistic adults self-reporting more memory difficulties than non-autistic adults. Significant main effects were also observed for memory type

(F=357.19, p<.001), cue (F=360.38, p<.001) and delay (F=213.78, p<.001). More difficulties were reported for prospective compared to retrospective memory, for self- versus environment-cued recall, and for short versus long delays.

Interactions: No significant interactions with group were observed (group x memory, F=2.09, p.149; group x cue, F=1.21, p=.271; group x delay, F=.192, p=.661).

Sex assigned at birth: If sex assigned at birth is included as a covariate in the analyses, the pattern of results remains unchanged.

Correlational analyses

A significant negative correlation was observed between age and total PRMQ score, for the autism group (r=-0.18, p<.001) but no association was found in the non-autistic group (r=0.015, p=.78). Separate correlational analyses were run for each memory type. Autistic people report fewer prospective (r=-0.18, p<.001) and retrospective (r=-0.16, p<.001) memory problems with older age; whereas no age associations are observed for non-autistic people (prospective memory, r=-0.017, p=.76; retrospective memory, r=0.047, p=.38).

Fisher's r-to-z statistic was used to assess whether the difference between the correlations reached statistical significance. The correlation with age was significantly greater for the autism (compared to the comparison group), for total (z=-2.59, p=.001), prospective (z=-2.17, p=.03) and retrospective (z=-2.75, p=.006) memory.

Discussion

To date, little is known about self-reported memory problems in middle-age or later life for autistic people. However self-reported memory problems may be important markers for future cognitive decline and have a significant impact on everyday functioning. In this study, autistic middle-aged and older people reported more memory difficulties than similar aged non-autistic people. Autistic people (and non-autistic people) reported more difficulties for prospective than retrospective memory, self- compared to environment-cued memories, and short compared to long delays. These findings are consistent with the one previous

study of self-reported memory among autistic young adults (Williams et al., 2014). However, no significant interactions between group and memory condition were observed (in keeping with findings in Williams et al., 2014). This indicates that although autistic people reported more memory difficulties than non-autistic people, the pattern of memory problems by memory type, cue, and delay were similar between the two groups. This finding is somewhat different to previous studies that have suggested that autistic people perform better on memory tasks utilising environment (or event-based) cues compared to self-cues in lab-based studies (Altgassen et al., 2012; Williams et al., 2014). However, environmental cues do not appear to be beneficial for autistic people in naturalistic studies (Altgassen et al., 2012; Kretschmer et al., 2014), which may be more similar to self-reported memory difficulties measured here.

Older age was associated with fewer self-reported prospective and retrospective memory problems for the autistic group but not for the non-autistic group. This may indicate that autistic adults are less susceptible to memory difficulties with ageing when compared to non-autistic similar aged peers. Whether autistic people are accurately describing a lack of memory decline or are better at managing typical age-related changes due to lifelong strategy use, is not yet clear. A recent study of autistic older people suggests convergent validity between the PRMQ and the AD8 (which queries change in a number of domains and abilities including memory and cognition, Klein et al., 2023). This suggests that autistic older people are consistently reporting their cognitive abilities but does not tell us whether their perceptions are borne out in performance-based testing. It is worth noting that the current finding of worse self-reported memory among autistic people, is not entirely consistent with studies using performance-based memory measures. Autistic older people demonstrate poorer performance on some aspects of memory but not others (Lever & Geurts, 2015; Torenvliet et al., 2021). However, it is also possible that some differences in results reflect any number of factors, including cohort effects, with only the healthiest older autistic people volunteering to take part in research studies.

Results of this study should be considered within the scope of several strengths and limitations. The participants in the autistic and non-autistic groups were recruited to different studies, and matched on age, birth-sex, and educational level. Although both studies included the PRMQ as an online questionnaire within a larger study, there may be differences between the groups related to recruitment strategy. Intellectual ability was not measured in either study. However, the cognitive demands of participation in both studies indicate that the samples are unlikely to reflect the population as a whole, and this may be particularly important for the autism group which did not include individuals with a co-occurring intellectual disability. However, a clear strength is that this study includes a large number of autistic people from under-represented groups in research, namely people assigned female at birth and middle-aged and older people.

To our knowledge this is the first study to describe self-reported prospective and retrospective memory difficulties among middle-aged and older autistic people. Autistic middle-aged and older people report more memory problems compared to peers, but these are negatively correlated with age. Given that self-reported memory difficulties are indicative of future memory problems and lower quality of life (Ryu et al., 2016; Schmitter-Edgecombe et al., 2011), lower self-rated memory performance in adulthood is particularly worrying for older autistic people. Whether memory aids or training could be targeted as interventions to support older autistic people is not yet clear. Further studies are required to explore the association between self-reported memory problems and memory task performance among autistic older people, whether autistic people are more accurate describing memory difficulties than age-matched comparison groups, and whether longitudinal data replicates the suggested “improvement” in memory with age among autistic people.

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Table 1: Autistic versus non-autistic adults' demographic characteristics and Prospective and Retrospective Memory Questionnaire scores.

	Autistic Adults (SPARK) *N*=350	**Non-Autistic Adults (BBC Matching 1:1)** BBC *N*=350	**Non-Autistic Adults (BBC dataset aged over 40 before matching)** BBC *N*=74,809
Age, years			
Mean (SD)	51.66 (8.91)	52.75 (9.1)	51.04 (8.5)
Median (Range)	49.92 (40.08-83.33)	51 (40-79)	49 (40-84)
Comparison to SPARK data		$t(698)=1.60$, $p=.11$	$t(75157)=1.36$, $p=.17$
Sex, n (%)			
Female	203 (58.0%)	241 (68.9%)	47,715 (63.8%)
Male	147 (42.0%)	109 (31.1%)	27,094 (36.2%)
Comparison to SPARK data		$\chi^2(1)=8.89$, $p=.003$	$\chi^2(1)=5.04$, $p=.025$
Gender identity, *n* (%)			
Gender diverse	18 (5.1%)		
Cisgender	331 (94.6%)	--	--
Not reported	1 (0.3%)		
Race and Ethnicity			
Race, n *(%)*			
Asian	7 (2.0%)		
Black/African American	10 (2.9%)		
More than one race	33 (9.4%)	--	--
Native American/Alaskan Native	5 (1.4%)		
Other	7 (2.0%)		
White	288 (82.3%)		
Ethnicity, n *(%)*			
Hispanic/Latinx	24 (6.9%)		
Not Hispanic/Latinx	322 (92.0%)		
Unknown	4 (1.1%)		

Education, *n* (%)			
Primary School	13 (3.7%)	13(3.7%)	487 (0.75%)
Secondary School/High School	26 (7.4%)	26 (7.4%)	21,605 (28.9%)
Technical, Vocational or Other College	108 (30.9%)	132 (37.7%)	24,472 (32.7%)
Graduate with University or College Degree	104 (29.7%)	92 (26.3%)	14,604 (19.5%)
Post-graduate or Professional Degree	99 (28.3%)	87 (24.9%)	13,641(18.2%)
Comparison to SPARK data		$\chi^2(4)=3.91$, $p=.42$	$\chi^2(4)=142.95$, $p<.001$
PRMQ scores Mean (SD)			
Prospective Memory	24.07 (7.79)	21.43 (5.02)	
Retrospective Memory	21.01 (6.93)	18.81 (4.7)	
Environment-Cued	21.38 (7.05)	18.81 (4.63)	
Self-Cued	23.7 (7.57)	21.42 (4.86)	
Short Delay	23.46 (7.4)	21.1 (4.91)	
Long Delay	21.61 (7.17)	19.14 (4.67)	

* Note that gender identity, race and ethnicity were note available for the BBC non-autistic dataset.

Figure 1: Scatterplots for associations between self-reported prospective and retrospective memory scores and age for autistic versus non-autistic adults.