Outcomes in older adults with ASD:

Cross-sectional comparison between individuals over 50 years of age with and without ASD on cognitive measures.

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

To date, research concerning older adults with Autism Spectrum Disorder (ASD) has been very scarce. For that reason, this thesis aimed to examine characteristics of older adults with ASD.

The literature review (Part one) systematically reviewed studies regarding outcome of ASD in late adulthood in 6 areas: cognitive functioning, adaptive functioning, language, social functioning, comorbid difficulties and autism symptom severity. Ten empirical studies were identified and their findings were evaluated. As all the included studies were cross-sectional, longitudinal research is required to examine the age-related changes in individuals with ASD in all outcome areas.

The empirical paper (Part two) describes a quantitative study that compared cognitive and memory abilities between older adults with and without ASD over the age of 50. Impaired performance in processing speed and working memory was evident in older adults with ASD in the present study. However, according to the ageing literature, these deficits are also often found in neurotypical adults as they age. Therefore, longitudinal studies are warranted to explore how the combination of aging and ASD affect cognitive functioning.

The critical appraisal (Part three) comprises a discussion of issues and challenges arose during the process of conducting the literature review and empirical study. It considers how previous experiences influenced personal assumptions of the research project, how these assumptions have changed over the course of research, challenges arose during data collection and concludes with some personal reflections.

Impact Statement

ASD is known to be a lifelong neurodevelopmental disorder which is characterised by difficulties in social interactions as well as restricted, repetitive behaviour. Despite knowing the lifelong nature of ASD, it is striking that very limited research has been carried out with older adults with ASD. Therefore, this research project aimed to explore outcome in individuals with ASD as they enter late adulthood.

The present literature review systematically reviewed the literature concerning outcome of ASD in late adulthood in 6 domains: cognitive functioning, adaptive functioning, language, social functioning, comorbid difficulties and autism symptom severity. It was found that most of the included studies in the present review were interested in examining cognitive functioning in individuals with ASD but the findings were inconsistent. Whereas other outcome domains have not been researched thoroughly so no firm conclusions can yet be drawn upon the prognosis of ASD in late adulthood. The present review highlights the crucial need to address these gaps in the literature so as to provide a better understanding of the influence of ASD has on older adults and thus appropriate services can be developed to meet the unique needs of this population as they grow old.

One of the key reasons why there has been inconsistent findings regarding cognitive functioning in older adults with ASD is the use of less robust and comprehensive measures. To address that, the present empirical study employed the WAIS-IV and WMS-IV, which have high reliability and validity in assessing intellectual abilities and various memory abilities. In addition, the present study is also the first to look at IQ adjusted memory abilities in older adults with ASD and this allows more accurate interpretation of their memory abilities as the influence of any IQ differences between individuals can be controlled for. Results of the current study have great clinical implications for high functioning ASD population as they inform

us as to whether the difficulties they experienced in childhood and adolescence persist or abate as they grow older, and thus helping to inform services about which areas individuals with ASD require more support with at different life stages. The present findings indicate that deficits in processing speed and working memory, two of the impairments that are often observed in children and adults with ASD, seem to persist into late adulthood. Having said that, it is worth noting that these deficits are also commonly found in age-related cognitive decline in neurotypical adults. Therefore, longitudinal studies are warranted to explore the interplay between ageing and ASD and how they influence cognitive functioning over time in individuals with ASD.

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Part 1: Literature Review

Outcome in older adults with autism: A systematic review of literature

Abstract

Aims: Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that lasts a life-time. A lot of studies have been carried out to examine the impact of ASD in children and adolescents but only a handful of studies have looked at the prognosis of children and adolescents with ASD as they grow older. Hence, this paper aimed to systematically review the literature regarding prognosis of the ASD population in late adulthood.

Methods: A systematic literature search was carried out on two databases for studies concerning prognosis of ASD in late adulthood in the following outcome areas: cognitive functioning, adaptive functioning, language, comorbid difficulties, social functioning and autism symptom severity. Ten empirical studies were identified and their findings were evaluated.

Results: Most of the included studies had a relatively small sample sizes and they varied in their methods to assess the effect of ASD in late adulthood, even for the same outcome area. Therefore, their findings could not be integrated easily and thus making it difficult to generalise results to the wider ASD population. Seven of the ten included studies examined cognitive outcome in individuals with ASD but the findings were inconsistent. As other aspects of outcome have not been researched extensively, no firm conclusions can be drawn upon the prognosis of ASD in late adulthood.

Conclusions: This review provides some initial understanding of the outcome in individuals with ASD as they enter late adulthood. However, as all the included studies were cross-sectional, further longitudinal research is warranted to examine the age-related changes in individuals with ASD in all outcome areas.

1. Introduction

Individuals with Autism Spectrum Disorder (ASD) are often observed to have difficulties in social functioning and communication, as well as restricted and repetitive patterns of behaviour and interests. (American Psychiatric Association (APA) 1994, 2000; Geurts and Vissers, 2012; de Vries, 2015). The exact cause of ASD is yet to be determined and evidence suggests that the social and communication difficulties encountered by individuals with ASD tend to last a life time (Cederlund et al., 2008; Howlin et al., 2004; Geurts & Vissers, 2012). In the past, autistic disorder, Asperger's syndrome and pervasive developmental disorder not otherwise specified (PDD-NOS) were grouped together under the diagnosis of Pervasive Developmental Disorder. In 2013, the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) replaced these different categories with the overarching term 'ASD' which represents a single autistic spectrum in which individuals with ASD may present with similar core symptoms but vary in severity. The present review will use the term "Autism Spectrum Disorder (ASD)" to describe individuals with a diagnosis of autistic disorder, PDD-NOS or Asperger's Syndrome with and without any comorbid learning difficulties (i.e. IQ≥ 70). Previous reviews on outcomes for individuals with ASD in their adolescence or adulthood will be described first, followed by the prior reviews on outcomes in older adults with ASD.

1.1 Outcomes framework

ASD is a lifelong condition, however, only a small proportion of studies have been carried out to examine the prognosis of children and adolescent with ASD as they grow older. Magiati and colleagues (2014) conducted a critical review of studies that have addressed progress of children with ASD as they entered adolescence and early adulthood. They examined the prognosis of this population in terms of 6 domains; autism symptom severity, cognitive functioning, adaptive

functioning, language and communication, social integration and comorbid difficulties. This present review drew on Magiati and colleagues (2014)'s 6 domains to evaluate the characteristics of older adults with ASD.

1.2 Research on outcomes in ASD in adolescence and early adulthood

As a result of changes in diagnostic criteria and improved knowledge about the heterogeneity of presentation of ASD, prevalence estimates for ASD have been increasing over the past five decades (WHO, 2017). The rate of ASD diagnosis are not only rising in children, but also in adolescence and adulthood. Although there has been a lot of research into presentation of and intervention for ASD, only limited number of studies have examined the progress of children and adolescents with ASD who entered adulthood. (Magiati et al., 2014; Levy & Perry, 2011). Using the outcome framework described earlier, two reviews (Magiati et al., 2014; Levy & Perry, 2011) were conducted to look at prognosis for adolescents and adults with ASD in a number of domains including ASD symptom severity, cognitive functioning, language, social outcomes, comorbid difficulties and disorders, and adaptive functioning. Both reviews found great variations in many of the reported outcomes in adolescence and adulthood. For instance, some studies reported that social functioning, language skills and cognitive abilities remain stable but other studies reported deterioration in these domains. Having said that, adaptive functioning and severity of ASD symptoms were found to improve in most studies. It was suggested that small and highly heterogeneous sample, and the variability in measures and informants used to evaluate outcomes might have contributed to inconsistent findings on reported outcomes (Magiati et al., 2014; Levy & Perry, 2011).

1.3 Research on outcomes in ASD in late adulthood

There has been even less research on late adulthood with ASD. Therefore, it remains largely unknown as to whether the difficulties individuals with ASD

experience in their childhood and adulthood will persist through old age. Ageing itself already brings about many physical and psychological changes (Galluzzi et al., 2008; MacPherson et al., 2002; Beekman et al., 1998; Wolitzky-Taylor et al., 2010) and having the diagnosis of ASD might add another layer of complexity onto these changes (Patra, 2016). Therefore, it is important to gain a better insight into the prognosis of ASD in late adulthood so as to develop appropriate psychosocial and support interventions for this population (Patra, 2016; Lever and Geurts, 2016; Davids et al., 2016)

To date, four previous reviews were conducted with regards to outcome in ASD in late adulthood (Perkins & Berkman, 2012; Mukaetova-Ladinska et al., 2012; Patra, 2016; van Niekerk et al., 2011). Mukaetova-Ladinska et al (2012)'s review was descriptive and non-systematic. They summarised findings with regards to demographics, expected residential care needs, experiences of families/carers and cognitive assessment tools for individuals with ASD. van Niekerk et al. (2011) only identified three case reports in their literature search. Their review looked at the procedure used for diagnosing ASD in childhood and adulthood in the three case studies and then attempted to derive a more suitable procedure for diagnosing ASD in late adulthood. Perkins and Berkman (2012) included studies of middle aged (i.e. from mid 20s to late 40s) and older adults (i.e. above 50s) to review outcomes of aging adults with ASD in terms of ASD symptomatology, life expectancy and comorbidities, vocational, social and residential outcome. They found that ASD behavioural symptoms seem to be variable across lifespan and comorbidities can lead to a poorer quality of life. However, it is worth noting that neither their literature search process nor inclusion/exclusion criteria were sufficiently described. In addition, the majority of the studies included in Perkins and Berman's (2012) review focused on middle-aged adults with ASD rather than older adults with ASD. Patra (2016) systematically reviewed studies on healthcare issues and challenges experienced by older adults with ASD and found that ASD appears to have adverse

impact on both physical and psychological health. In addition, ASD behavioural symptoms, impairments in social functioning and communication seem to persist in late adulthood. There are also evidence suggesting that the lack of knowledge of ASD in healthcare professionals has an impact on both diagnosing ASD in older adults and the care received by older adults with ASD. Although Patra (2016)'s review aimed to evaluate studies concerning elderly with ASD, the author did not clarify the term 'elderly' or specify the age range in the inclusion criteria. Furthermore, the criteria for inclusion and exclusion were not described clearly and the review also did not evaluate the quality of the included studies.

1.4 Present Review

Given the limitations of the previous reviews, the fact that a number of new studies were published since the latest review in 2016 and the importance of understanding the unique needs of older adults with ASD in order to provide sufficient support, the present review aimed to extend these earlier reviews by: 1) updating previous reviews in the light of a number of recent relevant publications and 2) improving on methodology of previous reviews by a) systematically reviewing empirical studies that explored the effect of aging on individuals with ASD with clear inclusion and exclusion criteria; b) critically appraising quality of reviewed studies.

The present review aimed to explore the outcomes of older adults with ASD. In 2013, the National Autistic Society issued a report on ageing with autism and the report defined 'older' as over the age of 50. Previous research on adults with intellectual disability and autism also considered older people as over 50 years of age (Totsika, Felce, Kerr and Hastings, 2010). Hence, while it is recognised that this definition is at odds with many in the typically ageing literature, the present review also regarded individuals with ASD over the age of 50 as older adults.

2. Methods

2.1 Search Strategy

A systematic literature search was conducted in MEDLINE and PsycINFO up to and including 26th November 2017 so as to identify all the studies relating to outcome in older adults with ASD. Title, abstract and keywords searches were applied, and an age filter (including middle age (40-60); aged (65 years and older) or very old (age 85 years and older)) was also employed to the search. The search contained the following search terms, each with a number of variants, specified below:

1. Autism

   (autis* OR asperger* or ASD)

AND

2. Older Adults/Aging

   (old* OR elder* OR senior OR ageing)

The asterisk indicates truncation, in which enables the search to recognise different endings of the search terms. In order for studies to be identified in the above search, the title or abstract had to contain at least one search term from each of the two groups. Only studies that were written in English and published in peer-reviewed journals were included in the search. The searches on MEDLINE and PsychINFO databases identified 496 and 434 studies respectively. 120 paper were excluded due to duplication and thus leaving 810 studies. The titles and abstracts of the identified studies were then scanned to see if they were relevant to the topic of the present review. Following that, relevant studies were read in detail to determine if they met the inclusion criteria for the review.

2.2 Inclusion criteria

In order to be eligible for inclusion, studies had to fulfil the following inclusion criteria:

(i) Clinical participants must have an ASD diagnosis

(ii) Clinical participants must not have comorbid intellectual disabilities. All participants should have full-scale IQ of 70 or above.

(iii) All participants (clinical or control participants) have to be 50 years old or above

or

the age range of participants included people over the age of 50 and age was used as a predictor of outcome.

(iv) Studies needed to investigate behavioural and/or psychological outcome of individuals with ASD in late adulthood. In other words, studies needed to provide information in at least one of the 6 outcomes described in the framework above: Autism symptom severity; Cognitive ability; Adaptive functioning; Social outcomes; Comorbid difficulties and disorders; Language and communication.

(v) All studies need to report on quantitative research

(vi) Studies must employ at least one quantitative or behavioural measure of outcome to be considered for inclusion.

(vii) Studies must be written in English and published in a peer-review journal.

2.3 Article selection

All titles and abstracts of the 810 papers were read to decide whether they fulfil the inclusion criteria. 702 papers were eliminated on the basis of examination of title and abstract alone. The majority of the studies were excluded on the basis that they did not meet the age criterion or did not look at age as a predictor of outcome. Others were excluded because they did not include any behavioural measure of outcome or because they were review papers. When there was uncertainty as to whether a paper is eligible for inclusion for the present review, the research supervisor was consulted to decide if the paper fulfilled the inclusion criteria.

A total of 10 papers were included in the review. The PRISMA flow diagram (Figure 1) below illustrates the inclusion and exclusion of papers from the initial search results.

2.4 Critical Appraisal

For all the 10 included studies, the primary researcher evaluated quality of the studies with the quantitative scale of the QualSyst (Kmet et al, 2004). This scale is comprised of 14 items and it aims to evaluate quality of quantitative studies with different study designs. Each of the 14 QualSyst items is scored as either not been met (0), partially met (1), totally met (2) or not relevant to the article being evaluated (N/A). An overall summary score (ranging from 0 to 1) can be calculated for each study by adding the all the item scores together and dividing it by the total possible score (i.e. 28 – (number of “n/a”) x 2) (Stott, Charlesworth and Scior, 2017). In addition, an overall rating of high (++), medium (+) or low quality was given with regards to both QualSyst rating and the researcher’s critical evaluation of the likelihood of the identified problems to alter a study’s key findings (Stott et al., 2017). When determining overall quality rating, more emphases were given to the researcher’s critical evaluation than the QualSyst rating. It was because QualSyst only covered basic components that were central to study quality (i.e. appropriate use of analysis, research question or objective is sufficiently described) as it aimed

to be a quality assessment tool that was suitable for a wide range of study designs. In addition, all items in QualSyst were of equal weight and thus all items were assumed to exert the same amount of influence towards the validity of a study's findings. However, arguably some components (i.e. controlled for confounding variables, conclusions are supported by the results) might have a bigger impact on the validity of a study's conclusions than others (i.e. interventional and blinding of subjects are reported, results are reported in sufficient details). Another area that was not evaluated thoroughly by QualSyst was the outcome measures that were employed by studies. For instance, more than half of the included studies in the present review compared cognitive functioning in individuals with and without ASD but even for the same cognitive function, i.e. working memory or executive functions, different studies used different sets of cognitive measures. Some studies only employed a single subtest to assess a particular cognitive domain, namely memory, and this greatly affected the validity of their findings. For these reasons, the primary researcher's critical evaluation put more emphasis on components that were not assessed thoroughly in QualSyst, for instance rationale for the choice of outcome measure, interpretation of results and whether the identified issues would change the study's main conclusion. By combining both QualSyst scores and the researcher's critical evaluation, an overall quality rating was given to each study depending on whether the identified issues would alter a study's main findings slightly (++, high quality) or moderately (+, medium quality) or greatly (-, low quality).

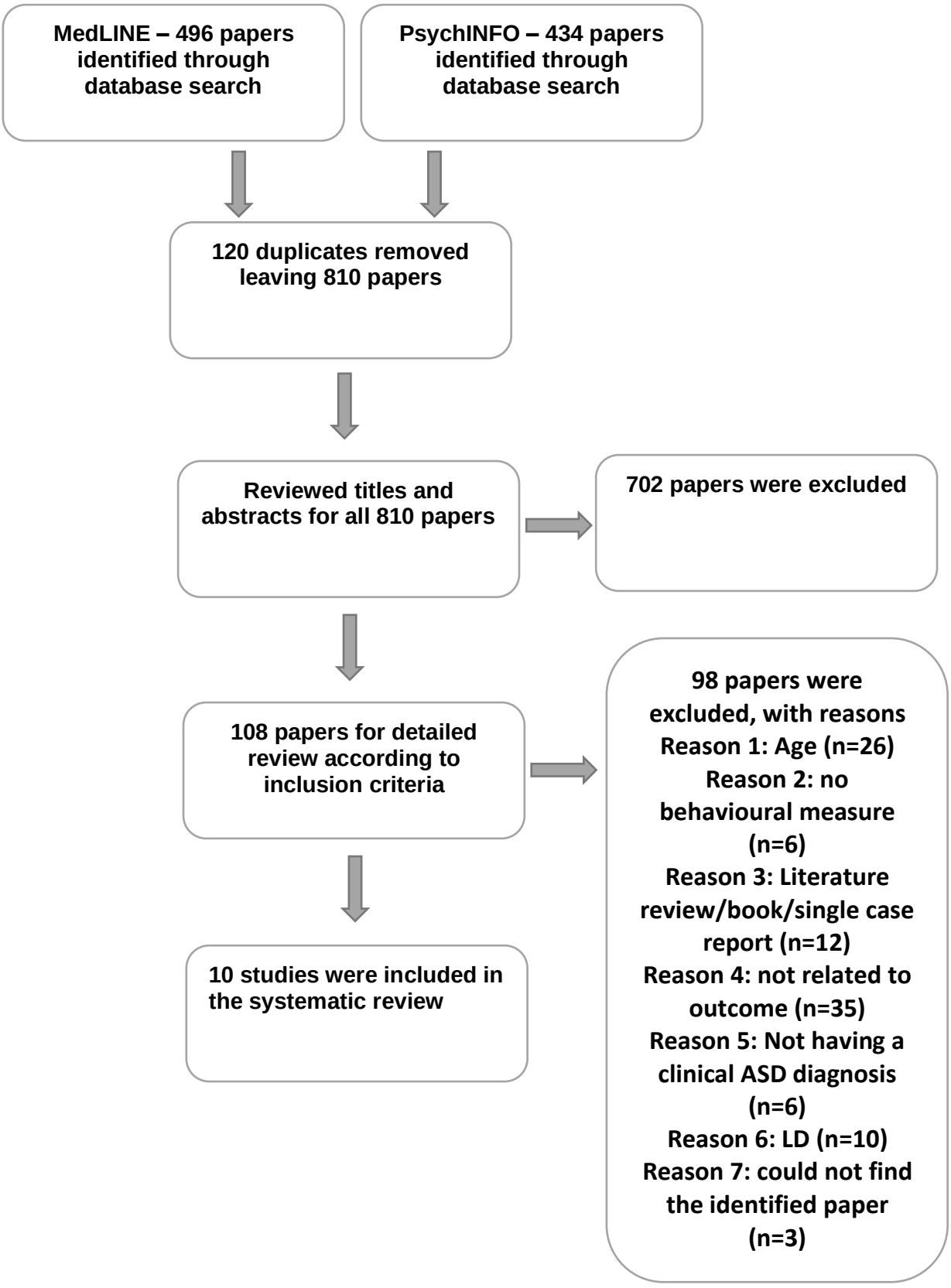
MedLINE – 496 papers identified through database search
PsychINFO – 434 papers identified through database search
120 duplicates removed leaving 810 papers
Reviewed titles and abstracts for all 810 papers
702 papers were excluded
108 papers for detailed review according to inclusion criteria
98 papers were excluded, with reasons
Reason 1: Age (n=26)
Reason 2: no behavioural measure (n=6)
Reason 3: Literature review/book/single case report (n=12)
Reason 4: not related to outcome (n=35)
Reason 5: Not having a clinical ASD diagnosis (n=6)
Reason 6: LD (n=10)
Reason 7: could not find the identified paper (n=3)
10 studies were included in the systematic review

Figure 1: PRISMA flow diagram to illustrate the Search Process

3. Results

For the 10 included studies, the current review only examined sections that fulfilled the inclusion criteria. For instance, Lever and colleagues (2017) examined interference control in two separate studies: Study 1 recruited young men with ASD whose age was between 18 to 36 years old; Study 2 looked at interference control across adult lifespan and hence recruited individuals with ASD from 19 to 79 years old. Therefore, only Study 2 of was included in the present review as it concerned with outcome in older adults with ASD whereas study 1 did not. Table 1 provides a summary of all the included studies.

3.1 Designs and Sample characteristics

All the studies that fulfilled the inclusion criteria for the review were cross-sectional. Sample sizes of the included studies ranged from 19 (Mayer & Heaton, 2014) to 138 (Lever & Geurts, 2016) for ASD group and 19 (Mayer & Heaton, 2014) to 170 (Lever & Geurts, 2016) for control group (CG). 6 out of the 10 studies had sample sizes with less than 40 participants for each of the ASD and control group and the other 4 studies had much larger sample sizes for both ASD and control groups, (over 100 participants in each group). None of the included studies provided information about an a priori power calculation and only one study commented that their study might be underpowered due to the small sample size. For that reason, it is possible that some non-significant findings, particularly in smaller studies were due to Type II errors. By contrast, 6 out of the 10 included studies employed a more stringent alpha to reduce the probability of Type I error.

Table 1: *Overview of studies included in the review*

Study no.	Author (year)	Diagnosis [Criteria; measure] IQ	N (male)	Study aims	Mean age in years (SD)	Type of Outcome	Measure	Main findings
1	Powell, P., et al (2017)	ASD [Prior Clinical diagnosis and ADOS-2 and SRS-2] Mean IQ ASD: 113.2 (9.5) CG: 113.1 (10.2)	ASD: 29 (24) CG: 30 (23)	To investigate any potential age-related cognitive differences between adults with ASD and typically developing (TD) controls.	ASD: 49.0 (11.7) CG: 48.7 (12.1)	Cognition	Category learning: WJ-CF Processing speed & Cognitive flexibility: Trail making test Immediate free recall and recognition memory: Rey Auditory Verbal Learning test	Both diagnosis and age were found to have a negative association with cognitive performance, whereby older age and having a diagnosis were associated with poorer cognitive performance. In comparison to the control group, age seemed to have a bigger impact on executive functioning in the ASD group.
2	Lever & Geurts (2016)	ASD [Prior clinical diagnosis of ASD according	ASD: 118 (83) CG: 118 (83)	To look at the impact of age has on cognition in	ASD: 47.6 (14.9) CG: 47.7 (15.4)	Cognition	Visual memory: WMS-III subtest – Visual Reproduction	Comparing to the controls, individuals with ASD performed better in visual

		to DSM-IV; ADOS >7 and AQ >26] Mean IQ ASD: 114.8 (16.9) CG: 114.3 (15.4) >50 Mean IQ ASD: 116.8 (16.4) CG: 116.1 (15.3)	Over 50 subgroup: ASD: 57 (44) CG: 56 (43)	individuals with ASD and explore whether age-related cognitive decline are exacerbated or lessened in ASD relative to TD controls.	>50 subgroup: ASD: 60.8 (6.9) CG: 61.5 (7.2)		Verbal memory: The Rey Auditory Verbal Learning Task (RAVLT) Generativity and semantic memory: COWART, Word naming subtest of the Groninger Intelligence Test (GIT) Theory of Mind (ToM): abbreviated version of the Faux Pas test Cognitive Failure Questionnaire	memory and poorer in both generativity and ToM. There was no significant group differences in verbal memory performance. However, deficits in ToM were not found in older adults (over 50 years of age) with ASD. Age-related cognitive decline in individuals with ASD was found to be lessened or similar to TD controls.
3	Lever, et al. (2017) – Study 2	Study 2: ASD [Prior clinical diagnosis of ASD according to DSM-IV criteria & ADOS-4 &AQ] Mean IQ ASD: 114.8 (16.9)	ASD: 118 (83) CG: 160 (91)	To examine the impact of age has on interference control in people with ASD across adulthood.	ASD: 47.6 (14.9) CG: 46.1 (16.5)	Cognition	Interference control: Simon Task Cognitive functioning: WAIS-III Vocabulary and Matrix reasoning	Across adult lifespan, people with ASD were found to make fewer mistakes. In general, individuals with ASD, in particular older adults with ASD, seemed to adopt a response strategy that values accuracy over speed.

		CG: 114.0 (16.5)						
4	Davids, et al. (2016)	ASD [Prior clinical diagnosis of ASD according to DSM-IV or DSM-5 criteria & ADOS] Mean IQ ASD: 106.3 (18.4) CG: 107.1 (15.6)	ASD: 36 (30) CG: 36 (30)	To compare executive functioning (EF) between individuals with ASD and TD controls on both objective and subjective EF measures.	ASD: 58.6 (7.8) CG: 59.4 (8.3)	Cognition	Autistic traits and symptoms: SRS-A Subjective EF: BRIEF-A General intellectual functioning: WAIS-IV-NL: Objective EF: Tower of London (TL-D), Zoo Map of BADS, COWAT (semantic verbal fluency tests and phonetic verbal fluency test)	Relative to the controls, ASD group reported more subjective EF impairments, but they did not show any impaired performance on objective EF task, except that they required longer time to complete the task.
5	Lever & Geurts (2016)	ASD [DSM-IV criteria & ADOS-4 & AQ] Mean IQ ASD: 113.8 CG: 113.3	Part I: ASD: 172 (116) CG: 172 (97) Part II: ASD: 138 (96) CG: 170 (97)	To investigate the prevalence of psychiatric symptoms and disorders in individuals with and without ASD across adult lifespan.	Part I: ASD: 46.7 CG: 46.0 Part II: ASD: 46.5 CG: 45.9	Comorbid difficulties and disorders	Part I: AQ, SCL-90 Part II: ADOS, shorten WAIS-III, MMSE and MINI	Results showed that despite marked psychological distress, psychopathology was less frequently occurred in older adults with ASD when compared to younger adults with ASD.

6	Lever et al. (2015)	ASD [Prior clinical diagnosis of ASD according to DSM -IV & ADOS-4 & AQ] Mean IQ ASD: 115.2 (16.9) CG: 113.3 (16.7)	ASD: 111 (79) CG: 164 (93)	To compare working memory (WM) performance between individuals with ASD and TD control across adult lifespan.	ASD: 47.5 (15.0) CG: 46.0 (16.5)	Cognition	Working memory: N-back	Apart from longer reaction time, ASD group exhibited similar level of WM performance to TD controls. Age seemed to have a negative association with WM performance for TD controls, whereby increase in age was associated with poorer WM performance. However, such association was not evident in ASD group.
7	Geurts & Vissers, (2012)	ASD [Prior clinical diagnosis of ASD, SRS or both] Mean IQ ASD: 109.5 (10.3) CG: 109.8 (7.9)	ASD: 23 (18) CG: 23 (18)	To explore cognitive functioning in older adults with ASD.	ASD: 63.6 (7.5) CG: 63.7 (8.1)	Cognition	Verbal Intelligence: The Dutch Adult Reading Test (DART) estimation of intelligence Processing speed: WAIS-III Digit Symbol – copy Attention: Sustained Attention to Response Test (SART)	Results indicated that older adults with ASD displayed deficits in working memory, sustained attention and fluency while other cognitive domains remained intact. Comparing to the controls, older adults with ASD appeared to have a different developmental pattern

							Working Memory: WMS-III subtest – Spatial Span Cognitive Flexibility: The Modified Card Sorting Test (MCST) & Trail Making Test (TMT) Planning: Tower of London Fluency: Controlled Word Association Test (COWAT) Visual Memory: WMS-III subtest Visual Reproduction Verbal Memory: The Dutch Version Rey Auditory Verbal Learning Task (RAVLT)	for fluency and visual memory.
8	van Heijst & Geurts (2015) - Study 2	ASD [Prior clinical diagnosis, Social Responsivene	ASD: 24 (19) CG: 24 (18)	To examine quality of life (QoL) in elderly with ASD and the	ASD: 63.7 (7.4) CG: 63.5 (8.0)	Social outcome	Quality of Life: RAND-36	Results showed that elderly with ASD reported significantly lower scores on QoL measure than the

		ss Scale Adult version (SRS-A) ≥60 or both] Mean IQ ASD: 109.5 (10.3) CG: 109.6 (7.8)		moderators of QoL (intelligence, ASD symptom severity, cognitive mistakes and psychological health).			Verbal Intelligence: The Dutch Reading Test (DART) Symptoms Severity: SRS-A Psychological health: Symptom Checklist (SCL-90) Cognitive Problems: Cognitive Failure Questionnaire (CFQ)	controls. Intelligence and symptoms severity were not found to influence QoL significantly. Psychological health or cognitive problems were not found to affect QoL after controlling for the effect of diagnosis.
9	Bastiaansen et al. (2011)	ASD [Prior clinical diagnosis of ASD according to DSM-IV and ADOS] Mean IQ ASD: 102.5 (14.81) CG: 101.5 (17.40)	ASD: 21 (21) CG: 21 (21)	To investigate if adults with ASD have deficits in the mirror neuron system and the relationship between mirror neuron system and social functioning in ASD population.	ASD: 30.6 (10.1) CG: 30.5 (9.8)	Social outcome	To assess level of social adjustment: Social Functioning Scale (SFS) – for both CG and ASD group Social domain of the ADOS – ASD group only	Results indicated that the mirror neuron system activity appears to have a positive relationship with age in individuals with ASD. In other word, increased mirror neuron system activity is associated with older age in ASD. Enhance mirror neuron activity was also coincided with changes in gaze behaviour and better social functioning.

10	Mayer & Heaton (2014)	ASD [Prior clinical diagnosis and ADOS] Mean IQ ASD: 113.37 (15.27) CG: 118.95 (10.84)	ASD: 19 (15) CG: 19 (15)	First, to examine the relationship between temporal changes and encoding and recall of speech. Second, to explore the potential associations between temporal processing performance and certain features of ASD (cognitive, clinical and behavioural difficulties that are characteristic of ASD)	ASD: 40.2 (11.3) CG: 38.3 (9.1)	Cognition	Cognitive Correlates: • Weschler Abbreviated Scales of Intelligence (WASI) • Peabody Picture Vocabulary Test (PPVT) • WM: WAIS-IV subtest Backward digit span Behavioural Correlates: • Communication Checklist-Self-report (CC-SR) • Adult/adolescent Sensory Profile (SP) Clinical Correlates: • Autism Quotient (AQ) • ADOS	Results showed that for both control and ASD groups, when presentation speed increased, fewer correct words were recalled. This effect was more pronounced in the older participants in the ASD group than in the control group. Auditory processing deficits in ASD may be due to difficulties that are characteristic of ASD, i.e. abnormal sensory profiles and deficits in social functioning and communication.

Table 1 details the main characteristics of the 10 studies included in the current review. Mean age for ASD group ranged from 30.6 (Bastiaansen et al., 2011) to 63.7 (Van Heijst & Geurts, 2015), and from 30.5 (Bastiaansen et al., 2011) to 63.7 (Geurts and Vissers, 2012) for the controls. Out of the ten included studies, seven studies had a mean age less than 50 for both ASD and control groups but they were still included in the current review as age was viewed as a continuum as per the inclusion criteria described above. In terms of gender, overall at least 70% of participants were male in the ASD group and at least 50% of participants were male in the control group. Mean IQ for ASD group ranged from 102.5 (Bastiaansen et al. 2011) to 115.2 (Lever et al., 2015) and from 101.5 (Bastiaansen et al., 2011) to 118.95 (Mayer & Heaton, 2014) for the controls. Eight of the included studies required participants to have a clinical diagnosis of ASD prior to the experiment as well as scoring above cut-off on autism measures, i.e. Autism Diagnostic Observation Scale (ADOS) or Autism Quotient (AQ). The other two studies (Van Heijst & Geurts, 2015; Geurts & Vissers, 2012) had a less stringent inclusion criteria for their ASD participants, their participants only needed to fulfil either one of these criteria. Almost all the studies (8 studies) took place in Netherlands and the remaining two studies, one took place at North Carolina (Powell et al., 2017) and the other took place in the United Kingdom (Mayer & Heaton, 2014).

3.2 General Limitations of studies

QualSyst (Kmet et al., 2004) was used to evaluate the quality of all the included studies in the review. Table 2 illustrates the details of the quality assessment of each study. Seven of the included studies were rated as medium to high quality. Most studies had a small sample size (i.e. below 40 participants per group) and no study provided any information, i.e. power calculation, to justify their sample size. Lastly, all included studies were cross-sectional so while their findings can provide information as to how those ageing with ASD are different to younger

adults or older adults without ASD at a particular point in time, no firm conclusion can be drawn on how age-related changes unfold across lifespan in individuals with ASD.

Table 2: Quality of included studies

Study	Qualsyst score – score/number of items, (ratio of score to items)	Main limitations	Rating of overall quality
Powell et al. (2017)	17/22 (0.77)	Small sample size and power was not calculated; recruitment source for the control group was not described clearly; one goal is not followed up in discussion ; study design only partially addressed the study question	-
Geurts & Vissers (2012)	18/22 (0.82)	Small sample size and power was not calculated; orders of measures not counterbalanced;	+

Bastiaansen, et al. (2011)	17/22 (0.77)	Small sample size, power was not calculated; stimuli were not presented in a counterbalanced order; unclear as to where the controls were recruited; no autism measure was given to the controls to ascertain that they did not have ASD; only male participants were recruited in both control and ASD groups; multiple comparisons with no corrections for Type 1 error	+
Mayer et al. (2014)	18/22 (0.82)	Intellectual disability status was not checked although full IQ was measured for both groups (cut off set at IQ≥ 70 but others generally set it to ≥ 80); limited description of how the control group was recruited; Small sample size, power was not calculated; multiple comparisons with no corrections for Type 1 errors	-
Lever et al. (2015)	21/22 (0.95)	Power was not calculated	++
Lever et al. (2016)	21/22 (0.95)	Power was not calculated	++

Van Heijist & Geurts (2015)	17/22 (0.77)	Power was not calculated; small sample size; age range was not clearly defined in inclusion criteria; measures were mainly self-reported; measures were not administered in an counterbalanced order; unclear as to where and how the control and ASD groups were recruited; multiple correlations with no corrections for Type 1 error	-
Davids et al. (2016)	21/22 (0.95)	Small sample size; power was not calculated; exclusion criteria for control was not described clearly; order of neuropsychological tests was not counterbalanced between participants; ASD sample was only recruited from a specialized ASD outpatient clinic which might have led to selection bias	+
Lever et al. (2017)	20/22 (0.91)	Power was not calculated although the sample size seemed large enough; exclusion criteria were not described clearly stated; multiple correlations with no corrections for Type 1 error	+

Lever & Geurts (2016)	20/22 (0.91)	Power was not calculated although the sample size seemed appropriate; exclusion criteria was not explained and stated clearly; long testing duration might cause fatigue effect and thus influence results	+

Note: ++ = High quality; + = medium quality and – = low quality

3.3 Outcomes

Of the six outcomes described in the outcome framework, only three outcomes were examined in the reviewed studies: cognitive abilities (7 studies); social outcome and social integration (2 studies) and comorbid difficulties and disorders (1 study). None of the reviewed studies examined autism symptom severity, adaptive functioning or language and communication. Below is a more detailed discussion of each of the outcomes:

3.3.1 Cognitive abilities

Cognitive abilities were examined in seven studies (Lever & Geurts, 2016; Davids, et al., 2016; Lever et al., 2015; Powell et al., 2017; Geurts & Vissers, 2012; Lever et al., 2017; Mayer & Heaton, 2014). Findings from these seven studies are summarized for each of the following cognitive domains: visual and verbal memory, working memory, executive function, processing speed, Theory of Mind, auditory processing and attention.

3.3.1.1 Visual and Verbal Memory

In total, three studies looked at the age and diagnosis related differences in visual and verbal memory (Powell, et al 2017; Lever & Geurts, 2016; Geurts & Vissers, 2012). In particular, Geurts and Vissers (2012) examined differences in both visual and verbal memory performance between typically developing (TD) older adults and older adults with ASD. Lever and Geurts (2016) first looked at differences in visual and verbal memory between individuals with ASD and TD controls aged 20-79 years old and then they re-ran all the analyses on a subgroup of participants who were 50 years of age or older to see if they could find similar results. Powell and colleagues (2017) compared verbal memory performance between younger and older adults of ASD and also with TD controls. All three studies employed the Rey-Auditory Verbal Learning Task (RAVLT; Rey, 1964; van den Burg, Saan & Deelman,

1985) to assess performance in verbal memory between ASD and control group. Of the three studies, two did not find significant difference in verbal memory performance between the two groups (Geurts & Vissers, 2012; Lever & Geurts, 2016). Whereas Powell and colleagues (2017) found that in general, younger participants performed better than older participants and that individuals with ASD had poorer performance compared to those without ASD. All three studies found that age has a significant negative association with verbal memory but did not find any evidence for age by diagnosis interaction. Hence, increasing age may lead to a decrease in verbal memory performance for both controls and ASD group (Powell et al., 2017).

In terms of visual memory, Geurts and Vissers (2012) did not find any significant group differences on either immediate or delayed recall between ASD and control group. Geurts and Vissers (2012) also performed exploratory regression analyses to explore if age had a different influence for ASD and control group on visual memory. They found a significant age by diagnosis interaction for visual memory and by visual inspection it was suggestive that age seemed to have a bigger impact on visual memory performance in the ASD group than in control group (double jeopardy aging pattern). However, with a larger and older sample and also the same visual memory measure (Visual Reproduction subtest of WMS-III), Lever and Geurts (2016) could not replicate Geurts and Vissers (2012)'s findings, instead they found evidence that individuals with ASD outperformed those without ASD in immediate recall of visual memory. Specifically, they found that overall performance in visual memory in individuals with ASD did not significantly change over age whereas for those without ASD, visual memory performance tended to be poorer in older participants. Having said that, when Lever and Geurts (2016) re-ran the analyses with a subset of participants who were over 50 years of age, the effect of age was similar for both control and ASD groups and that the age by diagnosis interaction was no longer significant for visual memory. In the light of Lever and

Geurts (2016)'s findings, it is suggested that aged-related cognitive differences characteristics of typical aging seem to be reduced or parallel in individuals with ASD but longitudinal studies were warranted to confirm this.

One possible reason to account for these conflicting results is the heterogeneity of ASD. Another possible reason for the differing results might due to the fact that participants with ASD in Lever and Geurts's (2016) study had higher IQ than participants with ASD in Geurts and Vissers's (2012) study. There is evidence that some of the memory difficulties that individuals with ASD experience, especially those in the high functioning range, only become apparent when task difficulty is increased (Boucher, 2001). In other words, participants over 50 in Lever and Geurts's (2016) study might still have difficulties in visual memory relative to typically developing older adults, but because their relatively higher average IQ, their difficulties were not apparent with the visual reproduction subtest of WMS-III. Their difficulties might be more apparent with a more difficult visual memory measure.

In summary, in the light of current evidence of two higher quality studies (Lever & Geurts, 2016; Geurts & Vissers, 2012), it seems that there is no relative differences between typically developing older adults and older adults with ASD in terms of verbal memory. Furthermore, there are initial suggestions that any decrement in verbal memory performance observed in those with ASD is likely to be part of ageing rather than due to ASD specifically. However, longitudinal evidence are required to ascertain this finding. In terms of visual memory, the evidence is less clear but the higher quality study (Lever & Geurts, 2016) suggested that there is no apparent differences in this domain either.

3.3.1.2 Working Memory

Working memory (WM) refers to the ability to hold information temporarily so as to enable for further processing and manipulation (Baddeley, 2003; Cowan,

2014; Lever et al., 2015). Two studies compared working memory performance between ASD and control group (Geurts & Vissers, 2012; Lever et al., 2015).

Geurts and Vissers (2012) used the Spatial Span subtest from Wechsler Memory Scale – III (WMS-III; Wechsler, 1987, 2002) to measure visuo-spatial working memory of individuals with and without ASD. Their results indicated that TD controls outperformed the ASD group. Lever et al. (2015) investigated WM performance in individuals with ASD by using the N-back task. Results demonstrated that apart from longer reaction time, individuals with ASD showed similar level of WM performance to those without ASD. This was again inconsistent with Geurts and Vissers's (2012) study. One possible reason for the different findings might due to the use of different measure to assess WM. Geurts and Vissers (2012) used Spatial Span task from WMS-III, this task aimed to examine visuo-spatial WM and this aspect of WM was found to be impaired in children and adults with ASD (Geurts et al., 2004; Zinke et al., 2010). Whereas Lever and colleagues (2015) employed the N-back task which used simple pictures as stimuli, but because they were easy to name, participant might have used verbal strategies, which could have helped individuals with ASD to perform better as they generally perform well in tasks with obvious verbal stimuli, i.e. letters (Koshino et al., 2005; Williams et al., 2005). In keeping with previous findings in typical ageing (Sander et al., 2012), Lever and colleagues (2015) revealed some evidence that poor WM performance is associated with increasing age in individuals without ASD. In light of the findings from their regression analyses, Lever et al. (2015) suggested that such age-related pattern in WM performance seem to be different in individuals with ASD, in which better performance was associated with increasing age. However, Lever et al.'s (2015) study was cross-sectional in nature and thus this finding should be interpreted carefully and longitudinal studies are warranted to verify their findings.

In summary, there is no general consensus as to whether there is significant difference in working memory performance between individuals with ASD and those

without. However, there are some evidence indicating that adults with ASD tend to performed better in tasks related to verbal working memory than those assessing visuo-spatial working memory. In addition, the higher quality study (Lever et al., 2015) revealed initial suggestions that better WM performance seems to be related to increasing age for ASD population but longitudinal studies are needed to confirm such findings.

3.3.1.3 Executive Functioning

Executive functioning (EF) refers to a range of cognitive functions that are required for complex and goal-directed behaviour. Deficits in EF are commonly observed as people age (Friedman, Nessler, Cycowicz, & Horton, 2009; Verhaeghen & Cerella, 2002). In addition, previous studies showed that children, adolescent and adults with ASD also exhibited some similar EF deficits, i.e. problems with planning and unable to shift attention flexibly (Geurts et al. 2004; Granader et al. 2014; Landa and Goldberg 2005; Kenworthy et al. 2008; Rosenthal et al. 2013; Wallace et al. 2016; Wilson et al. 2014; Davids et al., 2016). Of the seven studies, four studies explored EF in older adults with ASD.

In a study of medium quality, Geurts and Vissers (2012) administered Modified Card Sorting Test (MSCT; Nelson 1976) and the Trail Making Test (TMT; Reitan and Wolfson, 1985) to assess cognitive flexibility. They also used Tower of London of the Drezel University (ToL-DX; Culbertson and Zillmer 2001) to measure planning capacities. Their results indicated that ASD and control group did not differ significantly on MSCT, TMT and ToL-DX performance. Furthermore, their findings from regression analyses indicated that both age and age by diagnosis interaction were not significant predictors of performance in cognitive flexibility and planning. It was suggestive that age seemed to have similar impact on cognitive flexibility and planning domains in both ASD and control groups, however longitudinal studies are required to verify this.

Another study of medium quality (Davids et al., 2016) specifically looked at executive functioning in older adults with ASD by comparing objective performance on EF measures with subjective EF complaints. They employed the Zoo Map of the Behavioural Assessment of Dysexecutive Syndrome (BADS) (Wilson et al., 1996) and German version of Tower of London (TL-D) task (Tucha & Lange, 2004) to measure problem solving, cognitive flexibility and planning. A Dutch version of the Behaviour Rating Inventory of Executive Functioning – Adults (BRIEF-A; Roth et al. 2005, Dutch translation Scholte and Noens, 2011) was used as a subjective EF measure which was completed by both participants and their close relatives/partners. Results indicated that no significant differences in performance were found between ASD group and control group across all objective EF measures (the TL-D, Zoo Map). Instead there is evidence to suggest that those with ASD might have better executive functioning than TD older adults. Older adults with ASD were also found to report more subjective EF complaints than TD controls on BRIEF-A.

In a study rated as of low quality, Powell and colleagues (2017) used a letter-number switching subtest from Delis-Kaplan Executive Function System (D-KEFS; Delis-Kaplan et al., 2001) to tap cognitive flexibility and the Woodcock – Johnson Concept Formation Test (WJ-CF; Woodcock et al, 2001) to assess category learning. They found no significant group differences in category learning but the TD controls outperformed individuals with ASD in cognitive flexibility. In addition, increased age in adults with ASD was found to be related to poorer performance in cognitive flexibility whereas age was not a significant predictor of cognitive flexibility for TD controls.

Lever and colleagues (2017 – Study 2) investigated EF in terms of reactive and proactive control of interference in adults with ASD across lifespan by using a visual Simon task (Simon, 1969). In each trial during the visual Simon Task, the visual stimuli (i.e. a circle) appeared on either the right or left side of the computer

screen. The circle was in either blue or green and each colour was associated with a specific response key. The blue circle required a right-hand response whereas the green circle demanded a left-hand response. The trial was considered as congruent if the colour of the circle appeared on the same side as the associated response key. Conversely, trials were considered as incongruent when the colour of the circles did not appear on the same side as the associated response keys.

Despite slower response time, individuals with ASD displayed more accurate responses when compared with age and IQ matched TD controls in both congruent and incongruent trials. Given that adults with ASD displayed slower and more accurate responses, it was suggestive that adults with ASD tended to adopt a different response strategy, for instance more conservative and careful, than the controls. During the testing session, individuals with ASD also expressed that they preferred accuracy over fast response time, even though researchers reiterated that both accuracy and speed were equally important. Their findings also showed that there was also a difference in response strategy between older adults with ASD and younger adults with ASD, whereby older adults with ASD tended to employ a more conservative response strategy than young adults with ASD who did not adopt the same accuracy over speed bias (Lever et al., 2017).

One explanation for the inconsistency in findings above is that the above studies did not clearly state the definition of executive functioning. This was an important issue because the authors chose different sets of cognitive measures based on the definition of EF they adhered to. For instance, Davids and colleagues (2016) assessed EF in terms of cognitive flexibility, planning ability and priority setting, whereas Lever and colleagues (2017) only looked at interference control.

In general, higher quality studies concurred with the view that executive functioning is not impaired in older adults with ASD. In light of Lever and colleagues (2017)'s findings, perhaps one reason for unimpaired performance executive functioning in older adults with ASD is the occurrence of accuracy over speed bias.

Fluency

Measures of verbal fluency tap both executive functioning and language abilities (Davids. et al, 2016; Schmand et al., 208; Lever and Guerts, 2016). Three of the seven studies compared performance in fluency between individuals with and without ASD.

In a study of medium quality, Geurts and Vissers (2012) used an adapted version of the Controlled Word Association Task (COWAT; Benton and Hamsher, 1976) to measure phonemic verbal fluency. It was found that the controls produced significantly more correct words than ASD group, indicating that older adults with ASD seemed to experience more difficulties in generating novel responses.

In another study of medium quality, Lever and Geurts (2016) assessed phonemic fluency with COWAT (Benton and Hamsher, 1989) and evaluated semantic fluency with the Word Naming subtest of the Groninger Intelligence Test (GIT; Luteijn and Barelds, 2004). The controls outperformed the ASD group in both semantic and phonemic fluency. In addition, there was neither a significant effect of age nor a significant interaction effect of age and group on fluency performance. This is to say, fluency performance was not affected by age, and this pattern was similar in both ASD and control group.

In a study of medium quality, Davids et al. (2016) also employed shorter version of COWAT to assess both semantic and phonemic fluency in TD control and ASD group. No significant group differences were found in both semantic and phonemic fluency.

The discrepancy in findings between Davids et al. (2016) and other studies (Geurts & Vissers, 2012; Lever & Geurts, 2016) might due to the complexity of the semantic and phonemic fluency tasks used because participants in both Geurts and Vissers (2012) and Lever and Geurts's (2016) study were asked to produce words starting with 3 letters for 1 minute each but Davids et al. (2016) adopted a shorter version of the same fluency task in which they only asked participants to name

words with 1 letter for 1 minute. Thus, the fluency tasks in Davids et al.'s (2016) might be more prone to ceiling effects and less sensitive to differences.

In summary, the evidence appears to suggest that older adults with ASD have relatively poorer semantic and phonemic fluency. However, tentative findings from Lever and Geurts (2016) suggest that these deficits are present throughout lifespan and that the difference in fluency performance between control and ASD groups may not increase with age. Nonetheless, longitudinal work is needed to confirm this.

3.3.1.4 Processing Speed

Processing speed refers to the mental and motor speed in which an individual can solve non-verbal problems. Processing speed also corresponds to competency in planning, organising, motor control and coordination of visual and motor abilities (Groth-Marnat & Wright, 2016). It is important to assess processing speed in older adults with ASD because processing speed is often reduced as neurotypical adults age and impaired in individuals with ASD (Salthouse, 2004; Salthouse & Meinz, 1995; Geurts & Vissers, 2012; Geurts et al., 2008; Spek et al., 2008).

In a study of medium quality, Geurts and Vissers (2012) employed Digit Symbol-Copy from WAIS-III (Wechsler, 2002) to assess processing speed and they did not find any significant differences between the controls and ASD group.

In another study of medium quality, Davids and colleagues (2016) used processing speed index (PSI) scores of the Dutch version of the WAIS-IV (WAIS-IV-NL; Welchsler, 2008; Wechsler, 2012) to assess speed of information processing and they also did not find any significant differences between the two groups.

In a study rated as low quality, Powell and colleagues (2017) employed three subtests, which were visual scanning, number sequencing and letter sequencing, from Delis-Kaplan Executive Function System (D-KEFS; Delis et al., 2001) to

assess processing speed in individuals with ASD and those without ASD. Results indicated that ASD group has poorer processing speed performance than the controls.

The discrepancy in findings from the above studies might due to the use of different measures to assess processing speed, which could vary in difficulty. Another reason for the conflicting findings might be the difference in the average participant's age. The average participant's age in Powell et al. (2017) was about 10 years younger than the other two studies (Geurts and Vissers, 2012; Davids et al., 2016). Since the participants in the other two studies were much older, they might have already experienced decline in processing speed as a result of normal ageing as suggested in the ageing literature (Salthouse, 1991, 1996, 2009; Verhaeghen & Salthouse, 1997). Therefore, it is possible that no group differences were found because both the control and ASD groups displayed deficits in processing speed as a result of normal ageing process.

In summary, findings from two higher quality studies (Geurts & Vissers, 2012; Davids et al., 2016) are suggestive that there is no difference in processing speed between TD older adults and older adults with ASD. Potential reasons for the inconsistent results between studies are the use of different measures and the vast difference in participant's mean age.

3.3.1.5 Theory of Mind

Lever and Geurts (2016) was the only study that evaluated advanced Theory of Mind (ToM) for individuals with and without ASD. They assessed advanced ToM by using a shorter version of the Faux Pas Test (Spek, Scholte & Van Berkelaer-Onnes, 2010; Stone, Baron-Cohen & Knight, 1998). Overall, the controls were found to have better performance in ToM than ASD group. However, when only comparing a subset of participants whose age were above 50 in both groups, no significant group differences were found in ToM performance.

3.3.1.6 Auditory Processing

One study (Mayer & Heaton, 2014) investigated the impact of temporal changes in encoding and recall of speech in individuals with and without ASD. No significant overall group differences were found when comparing accuracy and recall time between individuals with ASD and TD controls. This study also explored whether behavioural (communication difficulties; sensory profile), cognitive (IQ; receptive vocabulary, WM) and clinical correlates (AQ; ADOS) were associated with auditory temporal processing in individuals with and without ASD by using regression analyses. A significant positive relationship was found between age and perceptual disturbance in ASD group but such relationship was not evident the control group. In other words, as individuals with ASD age, they may be more likely than TD controls to be affected by age-related processing effects (i.e. cognitive slowing) and thus reducing levels of word recall when presentation speed increases. Having said that, these findings should be interpreted with caution as they were based on a cross-sectional study. Therefore, no firm conclusions about the impact of ageing on auditory processing in individuals with ASD can be made yet.

3.3.1.7 Attention

Geurts and Vissers (2012) administered the Sustained Attention to Response Test (SART; Robertson et al., 1997) to assess attention in older adults with and without ASD. They found that there was no significant group differences in mean reaction time for correct responses and frequency of missing a correct response. However, it was observed that older adults with ASD tended to make more incorrect responses than TD older adults.

3.3.2 Social outcomes & social integration

Two studies looked at social outcomes and social integration in adults with ASD. One of them focused on quality of life (QoL) in older adults with ASD (van

Heijist & Geurts, 2015), while the other focused on the social functioning and its link with brain activities in adults with ASD (Bastiaansen et al., 2011).

A large difference in QoL was found between older adults with and without ASD in which older adults with ASD reported much lower QoL scores (van Heijist & Geurst, 2015) than those without ASD. IQ and symptom severity were not found to have an effect on QoL and this might due to the fact that all participants had normal to above average IQ and that the small sample size might lead to insufficient power to detect the effect. In addition, psychological problems or cognitive problems were also not found to have any significant effect on QoL after controlling the effect of diagnosis.

Previous research has suggested that the core social difficulties in ASD might stem from dysfunction of the mirror neuron system (lacoboni & Dapretto, 2006; Rizzolatti et al., 2008; Rizzolatti et al., 2009 ; Williams, et al. 2001; Dinstein et al., 2008; Southgate & Hamilton, 2008). In addition, hypoactivation of the inferior frontal gyrus (IFG) when processing facial expression is hypothesized to be the reason for the deficit in the mirror neuron system in children in ASD. By using fMRI with dynamic facial expressions stimuli and measuring level of social adjustment with Social Functioning Scale (SFS), Bastiaansen et al. (2011) explored if such deficit persists in adulthood and also the relationship between autistic symptoms, IFG activity and social behaviour in adults with ASD. Results showed that increased IFG activity during the perception of facial expression was positively associated with age in individuals with ASD but not in TD controls. The increase in IFG activity was also associated to improvement in social functioning and changes in gaze behaviour. Based on their findings, Bastiaansen and colleagues (2011) tentatively concluded that social functioning may improve as individuals with ASD age due to the increase in IFG activity but longitudinal studies are required to substantiate such conclusion.

3.3.3 Comorbid difficulties and disorders

Evidence has suggested that the occurrence of psychiatric problems is less frequent among the older individuals in the general population (Lever & Geurts, 2016; Beekman et al., 1998; Wolitzy-Taylor et al., 2010) but it is not known as to whether this also applies to individuals with ASD. Lever and Geurts (2016) looked at psychiatric symptoms and disorders across adult lifespan (young, middle-aged and older adults) in ASD. Adults with ASD across all three age groups reported more psychological symptoms and distress than their TD comparison groups but the levels of distress and symptoms reported were similar to a polyclinic psychiatric patient group in another study (Arrindell and Ettema, 2005). Almost 80% of adults with ASD reported to receive a diagnosis of a psychiatric disorder at least once throughout their lives and that depression and anxiety disorders are the two most common psychiatric disorders experienced by this population. In keeping with previous findings from the typical ageing literature (Bijl et al, 1998; Kessler et al., 2005), Lever and Geurts (2016) also found evidence suggesting that psychiatric problems are less prevalent in older adults with ASD when comparing to younger adults with ASD.

4. Discussion

The present review critically evaluated evidence from 10 studies that examined the impact of age in individuals with ASD in relation to six outcome areas: adaptive functioning, language and communication, severity of ASD symptoms, cognitive functioning, social outcomes and comorbid difficulties and disorders – with studies found only relating to three of these: cognitive functioning, social outcomes and comorbid difficulties and disorders. The included studies generally had a relatively small sample sizes and they varied in their approaches in investigating the impact of ASD in late adulthood, even for the same outcome area. Therefore, their findings

cannot not be integrated easily and were difficult to generalize results to a wider ASD population.

In general, for some cognitive functions, for instance fluency, visuo-spatial working memory, there appears to be a difference between older adults with ASD and TD older adults, where older adults with ASD tend to do worse. For other cognitive functions, for instance executive functioning, processing speed, ToM, verbal and visual memory, either no difference was found or in some cases those with ASD performed better than those without ASD. While longitudinal studies are needed to assess this fully, there are few significant age by diagnosis interaction effects suggesting that there is not a 'double jeopardy' effect (Lever & Geurts, 2016; Geurts & Vissers, 2012; Powell et al., 2017; Lever et al., 2015), whereby having a diagnosis of ASD increases impact of age on cognition (Geurts & Vissers, 2012). Indeed, there are some studies (Lever & Geurts, 2016; Lever et al., 2015), which suggest that cognition may improve with age in those with ASD relative to TD controls, but longitudinal studies are required to assess the relationship between ageing and cognitive functioning in older adults with ASD over time.

There are many inconsistencies in findings and the disparity between findings of different studies might in part be due to the small sample sizes and thus a potential selection bias. Furthermore, the use of different measures to assess the same cognitive domain might be another reason for the inconsistent findings. Another possible reason why age-related deficits were not found is that the overall average age of the recruited samples was relatively young and age-related deficits may not be evident even in TD adults until much later (above 65 years old). To have a better insight into the impact of aging on cognitive functioning in individuals with ASD, there is a pressing need for conducting a longitudinal study with a larger and older sample (i.e. above 65 years of age).

Qualitative impairments in social interaction is a core feature of ASD but little is known as to whether such impairments remain stable, worsen or improve over

time. Baastiannsen et al. (2011) provided some evidence to illustrate that mirror neuron system activity was enhanced with age in individuals with ASD and this also coincided with changes in gaze behaviour and improvements in social functioning as measured by Social Functioning Scale. ToM, the ability attribute mental states to oneself and others and thus to be able to understand and predict others' behaviour, plays a vital role for everyday social interaction and children and adolescent with ASD are often found have deficits in ToM (Chung et al., 2014). However, a recent study (Lever & Geurts, 2016) found that older adults with ASD (over 50 years of age) did not display any significant impairment in ToM when compared to TD controls. Across the lifespan, individuals with ASD reported poorer QoL comparing to TD controls and that psychological and cognitive problems did not have a significant impact on QoL after controlling the presence of ASD (van Heijst & Geurts , 2015). In addition, results from another recent study (Lever & Geurts, 2016) indicated that although older adults with ASD experience high level of distress, prevalence rate of psychiatric problems at their age (above the age of 55) is not as high as the prevalence rate in younger adults with ASD. In general, there are some suggestions that non-cognitive outcomes seem to improve in older adults with ASD relative to younger adults with ASD, however, all of these results are found in only one cross-sectional study each and therefore they should be considered as provisional.

4.1 Limitations of the present review

The present review suffers from some limitations which complicate the interpretation of the results. Of note, only 10 studies fulfilled the inclusion criteria after the systematic search, and thus evaluation of findings with regards to outcome in older adults with ASD was limited due to the small number of included studies. This review originally aimed to only look at studies that examined outcome in older adults (over the age of 50) with ASD. However, as there were only very limited

number of studies that were done with this particular population, the review also included studies that the age range of their samples covered individuals over the age of 50 and looked at age as a predictor of outcome. Although these studies included individuals over the age of 50 in their sample, they often did not specify how many of these individuals were in the sample. Hence, this made it difficult to ascertain if their findings were representative of individuals with ASD in late adulthood. Furthermore, the current review excluded studies that included individuals with ASD and co-occurring intellectual disabilities so as to focus specifically on ASD without the extra complication of having an intellectual disability. Yet, this might also limited the representativeness of the results of this review as most individuals with ASD also have intellectual disabilities (Matson & Shoemaker, 2009).

Furthermore, the variation in approaches in assessing different aspects of outcome in adults with ASD posed a challenge to the integration of results in a systematic review. Comprehensive assessment of the identified studies against the inclusion and exclusion criteria and quality assessment were completed by one researcher. Upon reflection, although quality assessment of all the included studies was done with the use of a quality assessment tool (QualSyst) together with primary researcher's critical appraisal, the overall quality rating of each study was dependent more on the researcher's critical appraisal than the overall QualSyst score. It was because QualSyst,was noticed that it only covered very fundamental components of study quality. Authors who developed QualSyst also admitted that the items included in the QualSyst scale are subjective as the items reflect their own conception of the key components that are instrumental in study quality (Kmet et al., 2004). For that reason, while using overall QualSyst rating as a guide to ensure the included studies were at least of minimum quality standard, the overall quality ratings were largely determined by the researcher's critical appraisal as the researcher could also incorporate aspects that were not assessed by QualSyst

thoroughly and decided to what extent the identified issues would alter the study's main findings. However, again the researcher's appraisals could also be considered as subjective as there was only one researcher carried out the quality assessment. The reliability of the assessment of articles and quality assessment would be enhanced if they could be carried out by more than one researchers. Finally, unpublished articles or grey literature were not searched so there might also be a risk of publication bias.

4.2 Clinical Implications

Despite knowing the lifelong nature of ASD, it is striking that very limited research has been carried out to examine if there is any changes to the deficits in individuals with ASD as they grow old. As evident in the present review, no studies were identified in the systematic search with regards to the adaptive functioning, language and autism symptom severity. In particular, severity of ASD symptoms is considered as one of the predictors that contributes to adults outcomes (van Heijst & Geurts, 2015). Therefore, there is a pressing need to address these gaps in the literature so as to provide a comprehensive understanding of how aging impacts on functioning in older adults with ASD and enable the development of support and service that meet the unique needs of this population.

It is also worth noting that at present there are no validated tools to measure QoL in individuals with ASD and only one study investigated QoL of older adults with ASD (van Heijst & Geurts, 2015) by using a generic measure of QoL. The QoL measure that van Heijst and Geurts (2015) used mainly focused on health-related QoL, which was just one aspect of QoL, rather than assessing positive well-being or QoL in general. Although older adults with ASD over the age of 50 were found to report poorer health-related QoL (van Heijst & Geruts, 2015), it did not necessarily equate poor outcome in all other QoL domains (Wikman et al., 2011). Hence, a measure of broader QoL, i.e. Control, Autonomy, Self-realization and Pleasure-19

Scale (CASP-19; Hyde et al., 2003) should be used to examine the impact of ASD has on QoL in older adults with ASD.

No firm conclusions can yet be drawn with regards to how age impacts cognition in ASD. However, the possibility raised in a number of studies that some cognitive deficits may remain stable across lifespan or that ASD may safeguard age-related decline in certain cognitive domains are of substantial significance for individuals with ASD and requires robust investigation in longitudinal studies. To date, no evidence indicates cognition deteriorates at a faster rate in ASD population so there is no evidence for ASD to be considered as a risk for dementia. If there are different developmental patterns in different cognitive domains, healthcare professionals can possibly help individuals with ASD to draw on their cognitive strength and perhaps can also use those strengths to compensate for the domains that they have deficits in.

Of note, there is some limited evidence in the current review to suggest that non-cognitive outcomes, for instance social functioning and comorbid psychiatric difficulties or disorders, are improved in older adults with ASD relative to younger adults with ASD. These findings have immense implications for service planning as they help to inform services which areas individuals with ASD require more support with at different life stages.

4.3 Future research

All studies included in the review were cross-sectional and they constituted an important attempt in investigating the impact of ageing in individuals with ASD. However, in order to look at how an individual ages and the potential differences in the ageing trajectories between individuals with and without ASD, longitudinal studies are needed. Therefore, longitudinal studies will be a necessary next step to study the nature of age-related changes in cognition, social functioning and comorbid difficulties in individuals with ASD. In addition, given the dearth of

research on non-cognitive outcomes, i.e. autism symptom severity, adaptive functioning and language and communication, more research on these domains are warranted so as to gain a more thorough understanding of prognosis of individuals with ASD as they enter late adulthood. Furthermore, as mentioned earlier the inconsistent findings in cognitive outcome might be caused by the types of measure used. Therefore, future studies should pay special attention in the selection of measures to assess level of functioning in different cognitive domains.

4.4 Conclusion

While a lot of research has been conducted with children and adolescent with ASD, only a handful of studies have been carried out with older adults with ASD and thus very little is known about ASD in late adulthood. As ASD is a lifelong condition, there is an urgent need to address this gap in the literature so as to understand the unique needs of older adults with ASD and also how best to support them. More than half of the included studies in this review looked at the cognitive outcome in individuals with ASD whereas other aspects of outcome have not been researched extensively. Despite the discrepancy in results between studies regarding how age impacts different cognitive domains in individuals with ASD, the available evidence in this review concurs with a general idea that older adults with ASD are largely performing at a similar level as TD controls. However, due to the cross-sectional nature of all the included studies, no firm conclusions can yet to be drawn upon the relationship between ageing and ASD. Hence, it warrants future research to adopt more sensitive longitudinal designs to examine these unanswered questions further.

In addition, although cross sectional evidence preliminarily indicates that individuals with ASD may have better social functioning and ToM as they grow older, older adults with ASD were also found to report poorer QoL. However, all these findings should to be considered tentatively because they are based on only

one study each. This review not only provides some initial insights into how aging impact on different aspects of outcome in individuals with ASD, but also emphasises the urgency to conduct longitudinal studies to analyse the nature of age-related changes among individuals with ASD.

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Part 2: Empirical Paper

Cross-sectional comparison between individuals over 50 years of age with and without ASD on cognitive measures.

Abstract

Aim: To compare cognitive and memory abilities between older adults with and without ASD over the age of 50.

Method: In total, 57 older adults who had an IQ ≥70 took part in the current study. 29 of them received a diagnosis of ASD prior to the study and the remaining 28 individuals who did not have ASD were considered as typically developing (TD) controls. Participants' cognitive and memory abilities were assessed by Wechsler Adult Intelligence Scale-IV (WAIS-IV) and Wechsler Memory Scale-IV (WMS-IV) respectively. WAIS-IV index scores, WMS-IV index scores and IQ adjusted WMS-IV index scores were analysed to explore if there were any significant differences between the controls and ASD group.

Results: Older adults with ASD were found to have poorer performance in processing speed and visual working memory, whereas for all other cognitive and memory domains they performed at a similar level as TD controls. No variables were found to confound the relationship between diagnosis and index scores performance.

Conclusions: Impaired performance in processing speed and visual working memory in children and adults with ASD seems to persist in late adulthood as older adults with ASD also displayed similar difficulties in present study. However, at the same time, deficits in processing speed and working memory are also associated with age-related decline in neurotypical adults. Therefore, longitudinal studies are warranted to explore how the combination of ageing and autism affects cognitive functioning in older adults with ASD.

1. Introduction

1.1 Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that is marked by impaired social functioning and communication as well as restricted patterns of behaviours and interests (American Psychiatric Association 2013a; Geurts & Vissers, 2012). Previous research has suggested that such social and communication difficulties tend to persist across lifespan in individuals with ASD (Cederlund et al., 2008; Howlin et al., 2004; Geurts & Vissers, 2012).

Prior to DSM-5 (American Psychiatric Association 2013a), there were different subgroups under the diagnosis of Autism, including Autistic disorder, High Functioning Autism (HFA), Asperger Syndrome (AS), Pervasive developmental disorder not otherwise specified (PDD-NOS). Asperger Syndrome (AS) was originally distinguished from the other subgroups by the absence of delay in language development and the presence of normal level of cognitive functioning (American Psychiatric Association, 2000). The DSM-5 (American Psychiatric Association 2013a), substituted these different subgroups with an all- encompassing term “ASD” that denotes an autistic spectrum in which individuals with ASD may present with similar key autistic symptoms but varying in levels of severity.

The present study will use the term ASD to describe individuals with a diagnosis of autism, HFA, AS or PDD-NOS and have an IQ $\geq$ 70 without any comorbid learning difficulties. The reason for choosing an IQ $\geq$70 as a cut-off is that an IQ<70 is the diagnostic criteria for an intellectual disability in DSM-5 (American Psychiatric Association, 2013b) and it is also the current inclusion criteria for NHS learning disability services (Moss, 2015).

1.2 Cognitive profiles of children, adolescents and younger adults with ASD

A lot of research has been carried out to investigate the impact of ASD on different aspects of cognition in children and adolescents, particularly in executive function (EF). Evidence suggests that many children, adolescents and young adults with ASD demonstrate some deficits in EF, mainly in planning and cognitive flexibility (Geurts et al., 2009; Hill, 2004a; Pennington & Ozonoff, 1996; Sergeant et al., 2002). Findings with regards to whether these EF deficits tend to persist or abate as children with ASD grow older are rather mixed but it is suggested that there are different developmental pathways for different domains of EF (Happe et. al., 2006; Pellicano, 2010; Geurts & Vissers, 2012).

Researchers have also investigated memory difficulties in children and younger adults with ASD. For episodic memory, a recent review (Boucher, Mayes and Bigham, 2012) indicated the ability of young individuals with ASD to recognise verbal and visual non-social related stimuli seems to be unimpaired or even superior to those without ASD. Nevertheless, for recognition and free recall of social stimuli, the findings are less consistent. For instance, individuals with HFA displayed no deficits in both immediate and delayed recall of non-social related stimuli but different results were found when social-related stimuli were used. Evidence for working memory performance is also mixed, but, in general, adolescents with ASD tend to find spatial working memory and more complex memory tasks more challenging than their typically developing (TD) peers (Barendse et al., 2013) and such impairments are still observed in adulthood (Sachse et al., 2013).

Furthermore, processing speed is also found to be another common area of weakness in children with ASD (Geurts et al., 2008; Oliveras-Rentas, et al., 2012; Mayes and Calhoun, 2008). However, several recent studies employed a processing speed task which was free from motor demands and found that children with ASD did not display any impairment in processing speed but performed at a

similar level as TD children (Wallace et al., 2009). It is therefore suggested that the conflicting results might due to the use of different processing speed tasks (motor or non-motor tasks) and more research is required to reconcile these findings (Oliveras-Rentas et al., 2012).

In summary, there is some evidence for impairments in executive functioning (Brunsdon & Happe, 2014; Hill, 2004b), working memory (Barendse et al., 2013) and processing speed (Geurts et al., 2008; Oliveras-Rentas, et al., 2012; Mayes & Calhoun, 2008) in children and adolescents with ASD.

1.3 Cognitive profiles of older adults with ASD

While a lot of research has been conducted regarding cognitive difficulties encountered by children and young adults with ASD, cognitive functioning of older people with ASD has hardly been studied although the prevalence of ASD in old age is actually similar to the prevalence of ASD in childhood (approximately 1% (Brugha et al. 2011)). To date, only a handful of studies (Geurts and Vissers, 2012; Lever and Geurts, 2016; Davids, Groen, Berg, Tucha & Balkom, 2016) explored the cognitive profiles of individuals with ASD above 50 years of age. These studies are cross-sectional and thus any conclusions regarding the impact of ageing on cognition are necessarily be speculative. All of these studies looked at memory abilities in older adults with ASD, partly because of the fact that memory deficits are an early feature of the most common form of dementia (Alzheimer's Disease) and it remains unclear whether having an ASD diagnosis might constitute a protective or risk factor for dementia or whether they are completely unrelated (Salthouse, 2004; Bowler et al., 2009; Goh & Park, 2009; Geurts & Vissers, 2012). In general, it is tentatively proposed by authors in the field (Geurts & Vissers, 2012) that developing a better understanding of the cognitive profiles of older adults with ASD will aid our understanding of potential cognitive decline in this group, (although this will need to

be confirmed through longitudinal work) and tailoring of psychosocial and support interventions for them.

Geurts and Vissers (2012)'s study was the first study that looked at cognitive functioning in people over the age of 50 with ASD by comparing them to TD controls on cognitive measures. They found that participants with HFA displayed deficits in fluency, sustained attention and working memory fluency while no impairment was evident in other cognitive domains (Geurts and Vissers, 2012). Powell and colleagues (2017) also revealed evidence that individuals with ASD had poorer performance in verbal memory, processing speed and cognitive flexibility when compared to the controls.

However, several other studies (Levers and Geurts, 2016; Davids et al., 2016; Lever et al. 2015) found conflicting results regarding the cognitive deficits encountered by individuals with ASD in late adulthood. With a larger and older sample, Levers and Geurts (2016) could not replicate Geurts and Vissers's (2012) findings as Lever and Geurts (2016) did not find any impaired visual memory performance in older adults with ASD. Instead, Levers and Geurts (2016) found that in comparison to TD controls, older adults with ASD had better performance in visual memory tasks, poorer performance in fluency tasks and no significant differences were found in verbal memory performance. In contrast, Davids et al. (2016) did not find any significant deficits in fluency in older adults with ASD and again this was not in keeping with Geurts and Vissers (2012)'s and Lever and Geurts (2016)'s findings. Likewise, Lever and colleagues (2015) were unable to replicate Geurts and Vissers (2012)'s findings in impairment in working memory in older adults with ASD. Instead, Lever et al. (2015) found that despite longer reaction time, no significant differences in working memory performance were found between ASD and control groups and that older age in ASD group seemed to be related to better working memory.

1.4 Reasons for discrepancy in results between studies

One possible reason to account for these conflicting results is the use of different measures by different studies to assess the same cognitive domains, i.e. working memory and fluency, as different tasks differ in terms of their complexity leading to the varying patterns of result (Toichi, 2008; Boucher, 2001). In addition, although many studies aimed to measure 'memory', memory is not a unitary construct and the different memory tests employed by different studies actually measured different aspects of memory. For instance, Lever et al. (2015) and Geurts and Vissers (2012) both aimed to assess working memory (WM) performance in individuals with ASD but they used very different measures to do so. Geurts and Vissers (2012) used Spatial Span subtest from WMS-III which tap the visuo-spatial aspect of WM. By contrast, Lever and colleagues (2015) employed N-back task in which the used picture stimuli were easy to name and thus verbal WM was assessed. Hence, the inconsistent results might be due to the fact that the two studies measured different aspects of WM and thus conflicting results are not surprising. In addition, heterogeneity of ASD (de Veries & Geurts, 2014, Lever et al., 2015) might also play a part in contributing to the inconsistent pattern of results.

Furthermore, the discrepancy of results between studies may also be due to measure reliability, because most studies only used one single subtest to measure each memory domain they assessed. This is not a reliable way to measure memory domains nor does it have good content validity (Crawford et al., 2012). Consequently, given the conflicting findings and these issues, the main aim of the present study was to employ the gold standard measure of memory abilities, Wechsler Memory Scale – Fourth Edition (WMS-IV), to compare the memory profiles of individuals over 50 years of age with and without ASD. WMS-IV not only has a good content validity as it measures many key areas of memory, but it also includes several subtests tapping each aspect of memory in which greatly enhances reliability (Crawford et al., 2012). In addition, as the present study also employed

Wechsler Adults Intelligence Scale – Fourth Edition (WAIS-IV), to measure our participants' intellectual abilities, WMS-IV scores can be adjusted for participants' intellectual abilities. This allows more accurate interpretation of participants' memory abilities as the influence of any IQ differences between samples can be controlled for.

To author's knowledge, the present study is also the first study that has used WAIS-IV to look at the impact of ASD on the different indices of WAIS-IV in people in late adulthood. This is of importance as adolescents and young adults with ASD tend to display unusual intellectual ability profiles, particularly in relation to processing speed and working memory (Sachse et al., 2013), and these are also two key aspects of intellectual ability that are affected in ageing in typically developing adults (Salthouse, 2012; Nyberg et al., 2012; Geurts, 2016). By using WAIS-IV, the gold standard measure of intellectual abilities, we could explore whether the impaired cognitive abilities, namely processing speed and working memory, which are commonly found in younger adults with ASD, would also be observed in a cross-sectional comparison between older adults with and without ASD.

1.5 The Present Study

With the use of WAIS-IV and WMS-IV, the present study aimed to compare intellectual and memory abilities in individuals with and without ASD in late adulthood. A recent policy report on ageing with autism by the National Autistic Society (2013) defined 'older' as over 50 years of age. Previous research on adults with intellectual disabilities and ASD also defined older people as over 50 years of age (Totsika, Felce, Kerr and Hastings, 2010). Therefore, the present study considered individuals over the age of 50 as older adults. However, previous evidence suggests that age-related cognitive decline in TD individuals only begins to occur at about 60 years old (Nilsson et al., 2009; Treitz et al., 2007; Geurts &

Vissers, 2012). Although in the present study individuals over the age of 50 were referred as older adults, it was acknowledged that they were indeed in a 'young old' category when compared to the general population and ageing literature.

In summary, research regarding the cognitive profile of people over 50s with an ASD diagnosis is still in its early stages; therefore, further research is needed to improve our understanding of memory and intellectual abilities of this particular population. Previous research in this field either only looked at the cognitive profiles of people with ASD in late adulthood without making any comparisons with a control group (Islam, 2016) or compared cognitive profiles of older adults with and without ASD but with less robust and comprehensive measures (Geurts & Vissers, 2012; Lever & Geurts, 2016; Davids et al., 2016). Hence, this study used more robust, valid and reliable measures to compare cognitive profiles of individuals over 50 years of age with or without ASD systematically. In the light of conflicting findings from previous research, this study aimed to address the following questions:

1) Are there significant differences between people aged over 50 with and without ASD in indices of the WAIS-IV? It is hypothesised that similar to younger people with ASD, older adults with ASD will have lower scores in processing speed and working memory indices relative to typically developing controls.

2) Are there significant differences between people aged over 50 with and without ASD in WMS-IV memory indices when a) memory index scores are adjusted for IQ and b) memory index scores are not adjusted for IQ? There are no specific hypotheses made regarding potential differences in performance in different memory domains between older adults with and without ASD due to the contradictory findings in the literature related to this.

2. Method

2.1 Power analysis

Power analysis for this study was informed by the study conducted by Geurts and Vissers (2012), who looked at which cognitive abilities in individuals over 50 years of age with and without ASD. Their results suggested that older adults with ASD exhibited deficits in working memory with a large effect size of $\eta^2 = 0.17$. A power calculation was carried out using G Power (Faul, Erdfelber, Lang & Buchner, 2007) giving an estimated sample size of 26 participants to provide 80% power with an alpha level of 0.05, to detect a large effect size.

2.2 Participants

ASD Group

Data on 26 individuals aged 50 or above with an ASD diagnosis were collected by a former trainee clinical psychologist for her thesis (Islam, 2016). Of the 26 participants that were diagnosed with ASD, 12 were recruited from participants who had taken part in a previous ASD study (Hickey, Crabtree, & Stott, 2017) and consented to be contacted for future research. The remaining 14 ASD participants were recruited from an autism research register at UCL and community based groups (i.e. Clearer Perspectives and Bridging the Gap Group, Asperger London Area Group (ALAG)). In the present study, 2 more participants with ASD were recruited from community-based advocacy/support groups for people with ASD and advertisement on online ASD forums. The inclusion criteria were as follow: fluent English speakers aged 50 years old or above with an official ASD diagnosis. Of the 28 participants in the ASD group, 23 of them reported to have a diagnosis of Asperger Syndrome, 3 of them reported to have a diagnosis of High-functioning Autism and the remaining two reported to have a diagnosis of Autism Spectrum Disorder. Participants were excluded from the present study if they reported to have

any current or history of other cognitive problems, global or specific learning or sensory disability that would prevent them from engaging easily with the test material.

Control Group

29 typically developing individuals were recruited for this study through community groups (e.g. University of the Third Age) and advertising on online platforms. All participants were fluent English speakers aged 50 years old or above and had an IQ of 70 or above. Participants in ASD group recruited by the former trainee clinical psychologist (Islam, 2016) were generally high functioning, therefore the present study actively tried to recruit an IQ matched control group by recruiting in University of Third Age, professional institutions and workplace, i.e. law firms. None of the 29 control participants reported any current or history of any cognitive problems, global or specific learning or sensory disability that would prevent them from engaging easily with the test material. All control participants completed Adult Autism Spectrum Quotient (AQ; Baron-Cohen et al., 2001) to screen for ASD. Demographics and AQ results are reported in Table 1 below in the results section.

2.3 Materials

2.3.1 Demographic information

Participants' demographic information, (age, gender, ethnicity, education level), was collected by a demographic questionnaire (Appendix A) that was designed for the present study.

2.3.2 Quantitative measures

Autism-Spectrum Quotient (AQ)

AQ (Baron-Cohen, Wheelwright, Skinner, Martin & Clubley, 2001) is a self-report questionnaire measure of autistic traits with good test-retest reliability (Baron-

Cohen et al, 2001; Baron-Cohen et al., 2006 & Hoekstra et al., 2008). It consists of 50 questions that look at individual's behaviour and ability in 5 domains: attention switching, communication, social skills, attention to detail and imagination. Individuals can pick one of the four possible responses (definitely disagree, slightly disagree, slightly agree and definitely agree) for each item. Total scores on the AQ can range from 0 to 50, where the higher the score, the more autistic traits the individual has. The clinical cut-off value of AQ is ≥ 32 and screening cut-off value is ≥16 (Baron-Cohen et al. 2001). AQ has been replicated across different ages (Auyeung et al. 2008) and cross-culturally (Hoekstra et al. 2008 & Wakabayashi et al. 2006). This measure was used primarily in the current study to assess for potential diagnoses of ASD in control participants (clinical cut-off of AQ ≥ 32) and as such it was only given to the controls.

2.3.3 Neuropsychological tests

Wechsler Adult Intelligence Scale – Fourth Edition (WAIS – IV)

WAIS-IV (Wechsler, 2008) is the current gold standard measure of intellectual abilities. It has high validity and reliability to assess cognitive ability in adolescents and adults (for ages 16 – 90) (Climie & Rostad, 2011). In total, WAIS – IV has 15 subtests, 10 of which are 'core' and they contribute to six composite scores: Verbal Comprehension Index (VCI), Perceptual Reasoning Index (PRI), Working Memory Index (WMI), Processing Speed Index (PSI), General Ability Index (GAI) and Full-Scale IQ (FSIQ). Scaled scores are calculated for each subtest and standard scores are derived for each composite score. In the current study, all participants completed 10 core subtests.

Wechsler Memory Scale – Fourth Edition (WMS –IV)

WMS-IV (Wechsler, 2009) is the gold standard measure of various memory abilities in adolescents and adults (for ages 16 – 90) and a good range of evidence indicates that it is a reliable and valid measure (Horne & McDonald, 2012). It consists of ten subtests, which contribute to five primary index scores: Auditory Memory Index (AMI), Visual Memory Index (VMI), Visual Working Memory Index (VWMI), Immediate Memory Index (IMI) and Delayed Memory Index (DMI).

IQ adjusted memory index scores can be obtained in the form of Contrast Scaled Scores (CSS). CSS helps to evaluates if a memory index score is unexpectedly high or low given the examinee's intellectual level compared to other examinees with similar intellectual level. To obtain CSS, first General Ability Index (GAI) needs to be calculated based on two of the WAIS-IV index scores: VCI and PRI scores. With the use of GAI scores and raw WMS-IV index scores, CSS for each domain of memory abilities can then be derived. CSS can range from 1 to 19, with a mean of 10 and a standard deviation of 3. A CSS of 7 (16^{th} percentile relative to examinees with similar General Ability) implies that that particular memory index is abnormally low relative to the examinee's GAI. Whereas a score of 13 or more (84^{th} percentile relative to examinees with similar General Ability) indicates that the examinee's memory index score is unexpectedly high compared with his/her GAI. (Wechsler, 2009; Groth-Marnat & Wright, 2016).

2.4 Procedure

Once participants had volunteered to take part in the study, they were contacted by the researcher by telephone or email to arrange a convenient time to meet with the researcher. Participants were given the options to carry out the testing session either at UCL, their homes or their offices. On the testing day, participants were first asked to read the information sheet of the present study (Appendix B) and then they were asked to complete an informed consent form (Appendix C) and a demographic

questionnaire. After that, they were tested with WAIS-IV and WMS-IV. To minimize order effects, the order in which WMS-IV and WAIS-IV were administered was counterbalanced across participants. Participants in the control group also completed the AQ to assess the presence of any autistic traits. Following successful completion of the testing session, all participants were sent a brief report about their performance in different cognitive domains.

2.5 Ethical Approval

The present study was approved by the UCL Research Ethics Committee (please refer to Appendix D for statement of ethical approval).

2.6 Data Analysis

A between subject design was employed. At the beginning, data were evaluated as to whether they met assumptions of parametric statistical tests. If assumptions were met, parametric tests were used. If assumptions were violated, necessary steps were taken to try to resolve the violations of the assumptions or non-parametric tests were used. Depending on whether data (transformed or otherwise) met parametric assumptions, independent sample t-tests or Mann Whitney U were used to compare the different index scores across different cognitive domains between ASD and control groups. As two of the participants in the control group scored higher than the clinical cut-off score in AQ, all analyses were performed again without them as a sensitivity analysis to see if that would change the results. Due to the multiple comparisons made between groups across different cognitive domains, the risk of Type I error was heightened. For that reason, Bonferroni corrected *p*-values were employed to control for Type I error.

To assess whether any demographic variables confound the relationship between diagnosis and index scores performance, first correlation analyses were conducted between demographic variables and index scores when there was a

significant group difference in index scores performance. Following that, demographic variables that were significantly correlated with index score performance would then be entered into exploratory regression equations to examine if these variables significantly influenced the relationship between diagnosis and index scores performance.

3. Results

3.1 Participant Characteristics

In total, 57 individuals took part in the current study (31 of whom were recruited and tested this year and the other 26 participants were recruited and tested by a former trainee clinical psychologist for her thesis (Islam, 2016). Of these, 29 did not have a diagnosis of ASD and 28 had a diagnosis of ASD. Table 1 summarizes participants' characteristics and differences in demographics between the controls and ASD group. The groups did not differ significantly from one another in age or overall IQ. The distribution of participants' ages and IQs was shown Figure 2 and Figure 3 respectively. In addition, no significant group differences were found in ethnicity and level of education. However, there was a significant difference in gender between ASD and control group, $x^2(1) = 9.65$, $p<0.01$.

In terms of AQ, 27 control participants scored less than the clinical cut-off score of 32 (Baron-Cohen et al., 2011) whereas the remaining two had a score of 36. All participants were included in the analysis first and sensitivity analysis was then conducted without the two control participants whose AQ scores exceeded the clinical cut-off score. No significant differences were found between the results from first analysis and the sensitivity analysis.

Table 1: *Characteristics of ASD participants and matched controls*

Description	Group	
	ASD (n=28)	Control (n=29)
Age[a]		
Median	61	63
(Range)	(50 – 72)	(50 – 68)
Gender*[b]	22M/ 6F	11M/ 18 F
IQ[c]		
Mean	113.39	119.76
(SD)	(18.11)	(11.96)
Ethnicity[d e]		
White/Non-white	25/3	25/4
Education[b f]		
No higher education/higher education	7/21	7/22
AQ		
Mean	-	18.62
(SD)		(7.67)

*p=0.05

a = Mann-Whitney U-test was used

b = chi-square test was used

c= Independent-sample t-test was used

d = The number between slash indicates number of participants who are white/who are non-white.

e = Fisher's exact test was used

f = The number between slash indicates number of participants who did not receive higher education/those received higher education. According to the National Qualification Framework (NQF), individuals who achieved NQF level 4 (i.e. above A-levels) are considered as receiving higher education and the present study also adopted the same framework in assessing whether participants had higher education.

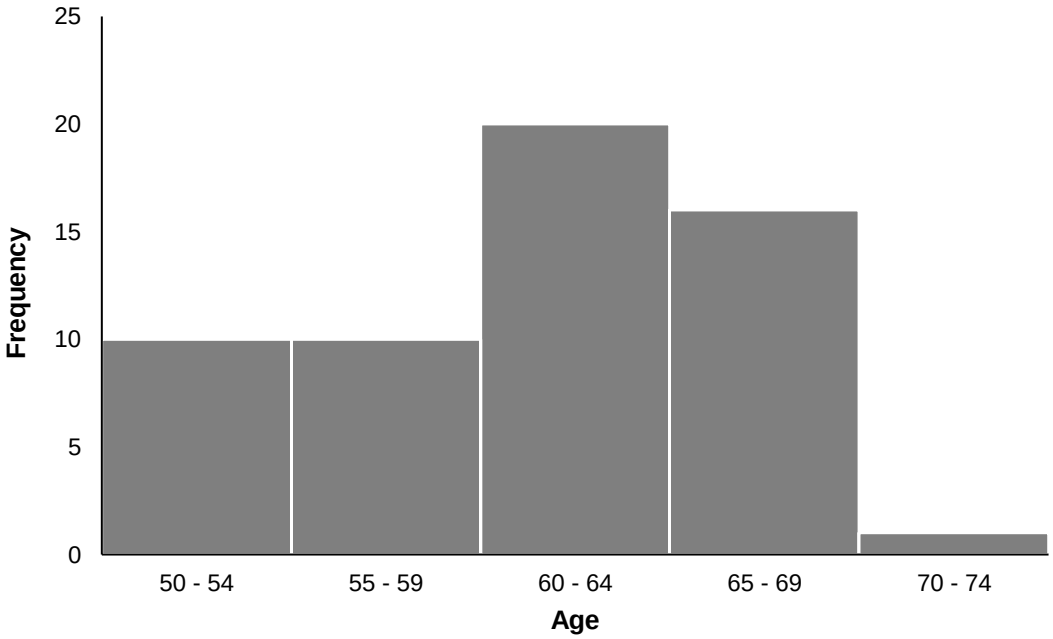

Figure 1. Distribution of participants' ages

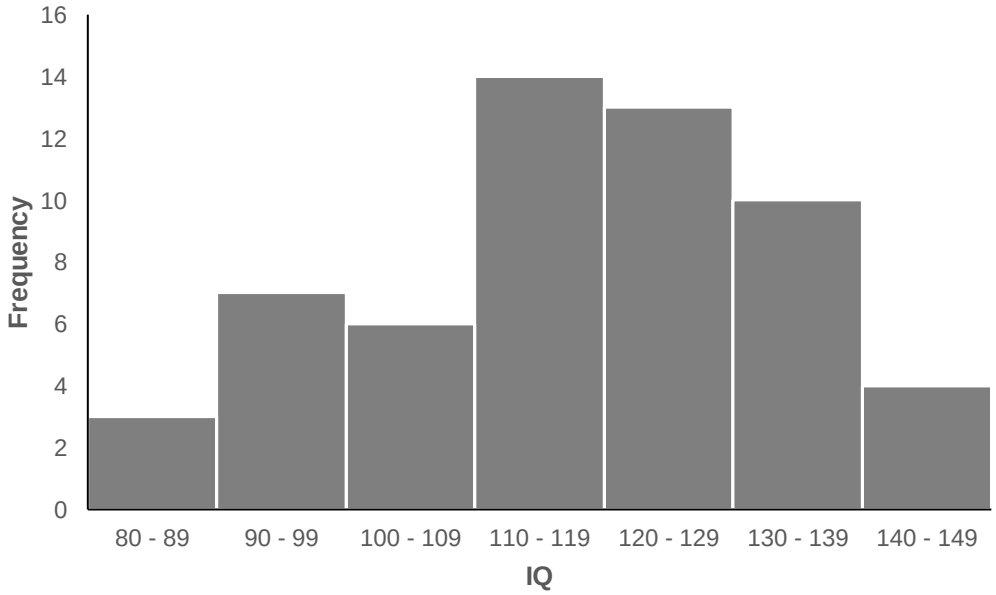

Figure 2. Distribution of participants' IQ

3.2 Intellectual abilities

Table 2 summarises participants' WAIS-IV index scores across different cognitive domains. Independent-samples t-tests were employed to compare scores in Verbal Comprehension Index (VCI), Perceptual Reasoning Index (PRI) and Processing Speed Index (PSI) between the two groups. Three outliers were identified in Working Memory Index (WMI) scores and after winsorizing (substitution of the outliers with the next highest value in each domain that was not an outlier), all assumptions required for conducting independent-sample t-test were met and winsorized data was also analysed using a t-test. Four group comparisons were conducted and thus the Bonferroni corrected *p*-value is 0.0125. There was a statistically significant difference in PSI scores between the two groups, with control group (M=111.17, SE = 2.50) scoring higher than the ASD group (M= 99.39, SE = 2.90), t (55) = 3.08, p=0.003, d = 0.87. The only domain that the ASD group had a higher mean index score than the controls was VCI but the difference was not found to be significant and the effect size of the difference was also considered as small (d = 0.23). There were no statistically significant differences between groups in other domains.

Table 2: *Group comparisons on each WAIS-IV index score*

	Control *n* = 29	ASD *n* = 28	*p*-value	Effect size (Cohen's d)	Total sample *N*=57
WAIS-IV Index Scores Mean (SD)					
Verbal Comprehension Index	113.79 (11.75)	116.54 (15.47)	0.45	0.23	115.14 (13.65)
Perceptual Reasoning Index	119.34 (13.83)	111.14 (18.08)	0.06	0.59	115.32 (16.44)
Working Memory Index	118.52 (14.16)	114.25 (16.87)	0.33	0.30	116.42 (15.56)
Processing Speed Index	111.17 (13.49)	99.39 (15.33)	0.003*	0.87	105.38 (15.48)

* $p<0.0125$ indicating significant *p*-value after Bonferroni correction

3.3 Memory abilities

When all assumptions were met, independent-samples t-tests were used to determine if there were significant differences between ASD and control groups in Auditory Memory Index (AMI), Immediate Memory Index (IMI) and Delayed Memory Index (DMI) respectively. Both Visual Memory Index (VMI) and Visual Working Memory Index (VWMI) had an outlier, thus the method of winsorizing was used to minimise the influence of the outlier. After winsorizing the extreme scores in VMI and VWMI, all assumptions for conducting independent-samples t-tests were met. Five group comparisons were conducted and thus the Bonferroni corrected *p*-value is 0.01. Table 3 summarises participants' WMS-IV index scores across different

domains after winsorizing. There was a statistically significant difference in Visual Working Memory domain between the two groups, with control group (*M* = 116.55, *SE* = 2.60) scoring higher than the ASD group (*M* = 102.86, *SE* = 3.45), *t* (55) = 3.19, *p*=0.002, *d*=0.98.

Table 3: *Group comparison on each WMS-IV index score*

	Control *n* = 29	ASD *n* = 28	*p*-value	Effect Size (Cohen's d)	Total sample *N*=57
WMS-IV Index Scores Mean (SD)					
Auditory Memory	114.41 (15.03)	108.96 (18.02)	0.22	0.36	111.74 (16.65)
Visual Memory[a]	107.00 (17.51)	98.29 (14.45)	0.05	0.50	102.72 (16.53)
Visual Working Memory[a]	116.55 (14.02)	102.86 (18.24)	<0.01*	0.98	109.82 (17.50)
Immediate Memory	112.00 (15.94)	104.00 (17.23)	0.07	0.50	108.07 (16.93)
Delayed Memory	112.97 (15.85)	105.11 (18.68)	0.09	0.50	109.11 (17.59)

* p<0.01 indicating significant p-value after Bonferroni correction
a = The scores were winsorized due to extreme outliers.

3.4 IQ adjusted memory abilities: Contrast Scaled Scores

Table 4 summarises participants' contrast scaled scores (CSS) across different memory domains. Independent-samples t-test was used to determine if there were significant differences in CSS of Auditory Memory Index (AMI) between ASD and control groups. For the CSS in the other four memory indices, none of the them were normally distributed even after attempts at transformation or winsorizing of outliers. Consequently, Mann-Whitney U tests were employed to determine whether there were any significant group differences in CSS in the four memory indices

(VMI, VWMI, IMI and DMI). In total, five group comparisons were conducted and thus the Bonferroni corrected *p*-value is 0.01.

As with non-adjusted memory index scores, there was a statistically significant difference found in the in CSS of Visual Working Memory domain between the two groups, in which control group performed better than ASD group. This is to say CSS of VWMI was statistically significantly higher in control group (Mdn= 11.00) than in ASD group (Mdn=8.00), U = 200.00, z =-3.30, p<0.01, r = 0.43.

3.5 Sensitivity analysis

There were two control participants scored above the clinical cut-off scores of 32 in AQ, therefore all the analyses were re-run excluding them from the control group to see if the results would differ. The analyses with and without that 2 participants yielded the same results.

Table 4: *Group comparison on each WMS-IV Contrast Scaled Score*

	Control *n* = 29	ASD *n* = 28	*p*-value	Effect Size	Total sample *N*=57
WMS-IV Contrast Scale Scores					
Auditory Memory[a]					
Mean	12.10	10.86	0.19	0.40[c]	11.49
(SD)	(3.07)	(3.90)			(3.53)
Visual Memory[b]					
Median	10.00	8.00	0.10	0.22[d]	8.00
(Range)	(4.00 – 17.00)	(3.00 – 13.00)			(3.00 – 17.00)
Visual Working Memory[b]					
Median	11.00	8.00	<0.01*	0.43[d]	10.00
(Range)	(6.00 – 16.00)	(1.00 – 17.00)			(1.00 – 17.00)
Immediate Memory[b]					
Median	11.00	9.5	0.17	0.18[d]	10.00
(Range)	(5.00 – 16.00)	(1.00 – 16.00)			(1.00 – 16.00)
Delayed Memory[b]					
Median	11.00	9.00	0.09	0.22[d]	10.00
(Range)	(6.00 – 18.00)	(2.00 – 19.00)			(2.00 – 19.00)

a = Independent-samples t-test was used to compare the mean index scores between ASD and control group
b = Mann-Whitney U test was employed to compare the medians of index scores between ASD and control group
c = Effect size was calculated in the form of Cohen's d, where *d*=0.2 (small effect); *d*=0.5 (medium effect) and *d*=0.8 (large effect size).
d = Effect size was calculated in the form of Pearson's correlation coefficient (*r*), where *r* = 0.10 (small effect); *r*=0.30 (medium effect) and *r*=0.50 (large effect).
* *p*<0.01, indicating significant p-value after Bonferroni correction

3.6 Exploratory Regression

For the two significant differences between groups (the PSI of the WAIS-IV and the VWMI of the WMS-IV), it was assessed whether any demographics variables were significantly correlated with PSI and VWMI index score performance (Table 5). Following that, exploratory hierarchical regression was used to examine whether these associations confounded the relationship between diagnosis and index score performance. For PSI, the only demographic variable associated with performance was gender (r =0.26, p=0.048). For VWMI, no demographic variables were associated with performance. Consequently, one hierarchical multiple linear regression was performed with gender entered first as a predictor of PSI performance and with diagnosis entered afterwards. Table 6 summarises the results of this hierarchical regression. The full model of gender and diagnosis to predict PSI scores (model 2) was statistically significant, R^2= 0.16, F (2, 54) = 5.17, p<0.01; adjusted R^2 = 0.13. The addition of diagnosis to the prediction of PSI scores (model 2) led to a statistically significant increase in R^2 of 0.09, F (1,54) =5.88, p<0.05. This significant increase in R^2 suggested that diagnosis was a significant predictor of PSI performance, independent of any influence of gender. In addition, gender was no longer a significant predictor when diagnosis was added to the model, indicating that diagnosis account for more variances in PSI scores than gender. Inspection of the regression coefficients indicated that having a diagnosis of ASD is negatively associated to PSI performance.

Table 5: *Correlations between demographic variables and Processing Speed Index scores and Visual Working Memory Index scores*

Cognitive and Memory abilities		*n*	Demographic Variables			
Test	Domain		Age	Gender	Education	Ethnicity
WAIS-IV	PSI	57	0.10	0.26*	-0.03	0.18
WMS-IV	VWMI	57	0.18	-0.11	-0.14	-0.02

*$p<0.05$

Table 6: *Hierarchical Multiple Regression predicting PSI scores from Gender and Diagnosis*

	PSI			
	Model 1		Model 2	
Variable	B	β	B	β
Constant	93.75**		104.78**	
Gender	8.19*	0.26*	3.95	0.13
Diagnosis			-10.18*	-0.33*
R^2	0.07		0.16	
F	4.10*		5.17**	
ΔR^2	0.07		0.09	
ΔF	4.10*		5.88*	

*$p<0.05$

**$p<0.01$

4. Discussion

With the use of WAIS-IV and WMS-IV, the present study compared cognitive and memory abilities between individuals with and without ASD over the age of 50. The impact of potential variables that might confound the relationship between diagnosis and participants' performance was also investigated.

4.1 Summary and interpretation of results

4.1.1 Intellectual abilities

In the present study, older adults with ASD were found to be performing at a similar level as those without ASD on verbal comprehension, perceptual reasoning and working memory. However, at the same time, they also had significantly lower scores in processing speed index compared to the controls. This finding is in keeping with results reported by Spek and colleagues (2017) who also found that old adults with ASD performed significantly poorer than TD older adults. Impairment in processing speed was also found in previous studies with children and adults with ASD (Geurts et al., 2008; Spek et al., 2008; Powell et al., 2017). Deficits in processing speed are suggestive of difficulties in processing and integrating visual information and then responding to this information. Poor performance in processing speed in individuals with ASD might be due to weak central coherence and problems with top-down processing, in which both are characteristics of individuals with ASD (Happe, 2005; Shah & Frith, 1993; Spek et al., 2008). Spek and colleagues (2017) also tried to unpick what contributed to the impairment in processing speed in older adults with ASD. By looking at their participants' performance on the two processing speed subtests on WAIS-III, they found that older adults of ASD (aged 60 or above) only displayed impairment in one of the subtests, Digit symbol-coding (DSC) subtest, but not the Symbol Search (SS) subtest. Whereas an opposite pattern of result was evident in adults with ASD, where impairment was found in SS subtest not in DSC subtest (Spek et al., 2009). It

was therefore hypothesized that the underlying factors of impairment in processing speed are different for adults and older adults with ASD. Spek et al. (2017) also hypothesised that impaired processing speed performance, especially in DSC subtest, in older adults with ASD might be associated with impairment in cognitive flexibility and inclination to persevere (Rumsey and Hamburger, 1988).

Another potential explanation of poorer processing speed performance in older adults with ASD is that they have a tendency to adopt a more careful and conservative response strategy. This hypothesis is supported by a previous study (Lever et al., 2017) that looked at inference control in individuals with ASD as their findings showed that middle-aged and older adults with ASD seemed to employ a more conservative response strategy than young adults with ASD who did not adopt the same accuracy over speed bias. Similarly, it is possible that older adults with ASD in the present study adopted the same strategy when they approached the processing speed subtests and thus resulting in lower PSI scores compared to the controls.

4.1.2 Memory abilities

Older adults with ASD performed at a similar level to those without ASD on auditory memory, visual memory, immediate memory and delayed memory, but differed in visual working memory. Similar pattern of results was found for IQ adjusted memory scores, in which typically developing older adults outperformed older adults with ASD on visual working memory domain.

Previous findings suggests that age-related cognitive decline and working memory performance might be influenced by several factors, for instance decline in sensory functioning, poorer interference control and reduced processing speed (Salthouse, 1996; Baltes & Lindengerger, 1997; Hasher & Zacks, 1988). Some of these factors are also known to be characteristics of ASD, therefore it is possible that working memory performance in older adults with ASD represents a ‘double

jeopardy' effect of ASD, whereby ASD may have an additional negative impact on age-related cognitive decline.

To date, there has not been a consistent pattern of results as to whether working memory is impaired in individuals with ASD. The use of different measures to assess working memory seemed to be one of the explanations of the discrepancy of results. For instance, Geurts and Vissers (2012) found deficits in visual working memory in older adults with ASD, whereas Lever et al. (2015) revealed similar level of working memory performance in individuals with ASD and the controls. Geurts and Vissers (2012) used Spatial Span task from WMS-III, which aimed to examine visuo-spatial WM and this aspect of WM was found to be impaired in children and adults with ASD (Geurts et al., 2004; Zinke et al., 2010). Whereas Lever et al. (2015) employed the N-back task which used simple pictures as stimuli, but because they were easy to name, participant with ASD might have used verbal strategies, which could have helped them perform better as they generally perform well in tasks with obvious verbal stimuli. i.e. letters, (Koshino et al., 2005; Williams et al., 2005). This may also explain why ASD group in the present study performed at a similar level as the control group on working memory index (WMI) in WAIS-IV as the two WMI subtests are Digit Span and Arithmetic which might have allowed them to use verbal strategies to help them to perform better. Whereas the two visual working memory index (VWMI) subtests in WMS-IV, they aim to tap the visuo-spatial aspect of WM. The stimuli in both subtests are uncommon symbols that cannot be named easily and thus it might be more difficult for participants with ASD to employ any verbal strategies that would help them to remember the stimuli. Consequently, the results support the interpretation that older adults with ASD may have worse visual but not verbal working memory than the controls.

4.2 Strength and limitation

4.2.1 Strengths

Strengths of this study pertain to the use of gold standard test battery measuring both cognitive and memory abilities. One of the reasons why there has been inconsistent findings regarding cognitive and memory abilities in older adults with ASD is the use of less robust and comprehensive measures. Therefore, the present study employed the WAIS-IV and WMS-IV, which have high reliability and validity in assessing intellectual abilities and various memory abilities. In addition, the present study is also the first to look at IQ adjusted memory abilities which allows more accurate interpretation of participants' memory abilities as the influence of any IQ differences between individuals can be controlled for. Furthermore, all participants with ASD in the present study were over the age of 50 and there has only been a handful of studies that explored cognitive functioning in individuals with ASD over the age of 50.

4.2.2 Limitations

There are several limitations to the present study. Participants were all in the normal to high functional range without any co-morbid intellectual disabilities in order to focus specifically on ASD without the confounding factor of having an intellectual disability. However, this might limit the representativeness of the present findings as most individuals with ASD have co-occurring intellectual disabilities (Matson & Shoemaker, 2009).

Secondly, although the National Autistic Society (2013) and previous research converged upon the idea that individuals with ASD aged 50 or above are considered as older adult, age-related cognitive decline in TD individuals only begins to occur at 60 years old (Nilsson et al., 2009; Treitz et al, 2007; Geurts & Vissers, 2012). Therefore, it may best to consider the current findings are concerned with a 'young old' ASD group and so future studies should be conducted to check if

they can replicate the present findings with an older sample (aged 60 or above). It is worth noting that the present study was cross-sectional rather than longitudinal and thus no firm conclusions can yet be drawn as to how cognition changes as individuals with ASD age. Nonetheless, the current sample gave some initial insight into the cognitive and memory abilities in individuals with ASD as they entered late adulthood.

Thirdly, there were more female than male participants in the control group, whereas a reverse pattern was observed in the ASD group. As mentioned in the result section, gender was found to be associated with processing speed performance. Therefore, future studies should try to achieve similar male to female ration in both ASD and control group so as to minimize any potential variables that might confound the relationship between diagnosis and cognitive performance, though our results did not suggest that gender influenced the current findings significantly.

In addition, we recruited participants with ASD if they reported that they received a clinical diagnosis of ASD prior to the study. However, we did not employ other diagnostic measures, i.e. AQ and ADOS, to ascertain whether their ASD diagnoses were accurate. On reflection, the Autism Quotient (AQ) could have given to participants with ASD to verify their diagnosis as the controls were asked to complete AQ prior to the experiment.

Another limitation is related to the design of the present study. On average, each participant took about 3.5 hours to complete all the cognitive tests and a fatigue effect might have presented as a result of long testing duration. However, as the order of the neuropsychological tasks was counterbalanced between participants, and that both control and ASD groups took about the same amount of time to complete tests, therefore this effect was likely to be equivalent across groups.

4.3 Clinical Implications and Future Research

By considering the cognitive and memory abilities of older adults with ASD, this study furthers our understanding of the levels of cognitive functioning in this particular population and it also allows us to examine whether the cognitive impairments they experienced in childhood and adolescence persist. Processing speed performance has been found to be closely related to levels of independence in daily functioning (Davids et al., 2016; Gothe et al., 2014; Marshall et al., 2011; Bell-McGinty et al., 2002; Jurado & Rosselli 2007), hence more research into processing speed could be of utility in promoting independent living in ASD. With better knowledge of cognitive functioning in older adults with ASD, the development of intervention and services for this population can be facilitated so as to meet their needs. Apart from intellectual and memory abilities, future studies should also explore executive functioning and Theory of Mind in individuals with ASD as they age. Not only because these are the two areas that children and adolescent with ASD experience difficulties with, but they also have implications in social and daily functioning.

Furthermore, deficits in processing speed and working memory were evident in children and adults with ASD (Geurts et al., 2004; Zinke et al., 2010; Geurt et al., 2008; Spek et al., 2008; Powell et al., 2017). The present findings indicate that these deficits seem to persist when this population enter late adulthood. To date, all studies, including the present study that investigated cognitive functioning in older adults with ASD were cross-sectional and no longitudinal studies have yet been conducted to examine the cognitive changes in this population as they age. For that reason, longitudinal studies are warranted to explore how the combination of ageing and ASD affects cognitive functioning over time in individuals with ASD.

4.4 Conclusion

To the author's knowledge, this is the first study that has employed gold-standard measures to compare cognitive profiles between individuals with and without ASD over the age of 50. It is also the first known study to assess memory abilities in older adults with ASD with IQ adjusted memory scores. Compared to TD older adults, older adults with ASD displayed poorer performance in processing speed and visual working memory and they performed at a similar level to those without ASD in all other cognitive and memory domains. Longitudinal studies are needed to further our understanding of the potential impact of the ageing and ASD on cognition.

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Part 3: Critical appraisal

1. Introduction

This appraisal discusses some of the issues and challenges arose during the process of the present research. The first section will cover how my previous experience and personal assumptions might have influenced the present study and also how these assumptions have changed over the course of the research. Following that, I will discuss challenges I encountered during the data collection process, my response to the challenges and conclude with some personal reflections on the whole research process.

2. Previous experience, personal assumptions and the current research project

2.1 Previous experience

It is recognised that most researchers have assumptions that incorporate their past experience, attitude and principles and all these will have an inevitable influence on their work. (Preissle, 2008). I very much agree with this idea as I think my initial assumptions and hypotheses about ASD and this study were greatly influenced by my previous experience working with children with ASD. My first experience working with individuals with ASD was when I shadowed a clinical psychologist, who specialised in working with children with ASD or ADHD, during my undergraduate degree. I recalled that there was one session that I spent the whole hour playing cars with a young boy with ASD but throughout the hour no matter how hard I tried to initiate a conversation with him, he never replied to me in actual words but only mimicking the sound of the engines. I could not help but wonder what would happen to this child when he grew up if he could never manage to have proper conversations with others. Even if his IQ is within the normal range, I started to ponder as to whether he would be able to achieve as much as other individuals who also have similar IQ. At the same time, by meeting with the parents whose children were diagnosed with ASD, I gained a better insight about the

challenges they encountered on a day to day basis. After that internship and I accumulated more experience working with children with ASD, I gradually developed an assumption that ASD not only tends to have a negative impact to the children's development, but it also contributes to marked distress in the parents and carers of children with ASD. According to previous research, there is evidence for impairment in executive functioning (Brunsdon & Happe, 2014; Hill, 2004), Theory of Mind (ToM; Yirmiya et al., 1998), processing speed (Geurts et al., 2008) and working memory (Barendse et al., 2013) in children and adolescent with ASD. Impairment in executive functioning has been identified to be the main reason for causing problems in activities of daily living and processing speed has also been found to be the key factor that predicts independence in daily functioning (Gothe et al., 2014; Bell-McGinty et al., 2002; Marshall et al. 2011; Davids et al., 2016; Jurado & Rosselli 2007). In addition, deficits in ToM is also found to be closely associated with impaired social functioning. These findings further strengthened my belief that the cognitive challenges encountered by children with ASD experiences would continue to have a marked impact on their lives as they grow older. This assumption has attracted me to the research topic from the beginning as I would like to gain a better insight into the prognosis of individuals with ASD in their late adulthood.

2.2 Changes in assumption as the research proceed

The topic of my literature review is to systematically review studies that looked at prognosis of individuals with ASD when they enter late adulthood. As mentioned earlier, my understanding of ASD and my previous experience working with children with ASD and their family contributed to my assumption that the outcome of ASD in adulthood and late adulthood would be fairly poor. At the beginning of the research project, I started to read around articles concerning ageing and ASD. The ageing literature acknowledged that neurotypical adults demonstrated age-related decline in several cognitive domains, for instance, processing speed (Verhaeghen &

Cerella, 2008), working memory (Braver and West 2008), the ability to learn new information and to recall them (Old & Naveh-Bejamin, 2008) as they age. Meanwhile, evidence also indicates that human brains will undergo several structural changes as a result of normal ageing, for instance reliable reduction in the volume of multiple brain structure and decreases in structural integrity of white matter and neuroreceptors (Park & Reuter-Lorenz, 2009; Park & Goh, 2009; Goh & Park, 2009). Furthermore, the cognitive difficulties experienced by individuals with ASD at younger ages are indeed largely overlapped with those encountered by typically ageing adults (Lever & Geurts, 2016). With this new information in mind, it further reinforced my initial assumption and that ASD might have an additional adverse effect on age-related cognitive decline. Individuals with ASD may experience a steeper decline in cognitive functioning when comparing to those without ASD in the process of normal ageing as individuals with ASD have been experiencing similar cognitive deficits since young and that ageing may exacerbate these deficits even more.

2.2.1 Literature Review

When I finished my initial literature search, I was struck by how little research has been conducted with older adults with ASD while so many resources have been put into research concerning children and adolescent with ASD. To date, excluding the present study, only four studies specifically looked at outcome in individuals with ASD over the age of 50. However, within these four studies, there is a discrepancy in results as to whether older adults with ASD function at a similar level as typically developing older adults. Although all these studies are cross-sectional in nature and longitudinal research is required to verify their findings, there is some initial evidence (Lever & Geurts, 2016; Lever et al., 2015) to suggest that cognition may improve with age in older adults with ASD relative to typically developing older adults. By doing the literature search made me realised that perhaps the initial assumption I

had was premature as I was only focusing on finding evidence that supports my assumptions and assumed that all ASD symptoms would only remain unchanged or become worse over time. Furthermore, the safeguard hypothesis (Geurts & Vissers, 2012), whereby ASD may indeed "protect" age-related cognitive decline, also made me reflect on the negative connotations I had given to ASD and that I have never considered the potential benefits that ASD might bring.

2.2.2 Recruiting participants

Another major incident that made me reconsider my initial assumption about the prognosis of individuals with ASD in their late adulthood was when I tried to recruit participants for the research study in one of the Asperger London Area Group (ALAG)'s monthly meetings. I remembered that alongside the meeting, there was also a small exhibition of the drawings that one of the ALAG members (who was diagnosed with Asperger's Syndrome) did and he also gave a presentation of his work at the start of the meeting. I was very impressed by the fine art pieces and the presentation by that ALAG member and he did not come across as an individual with ASD at all as he had great verbalisation abilities and good eye contact. I think what struck me most was his great achievement in his career which was the total opposite of my initial assumption of the negative impact of ASD could have on individuals. This again reminded me of the heterogeneity of presentation of ASD which made me wonder about the validity of my initial assumption of this population and that I should adopt a less pessimistic view on the prognosis of ASD in late adulthood.

2.2.3 Data collection and present findings

My experience of administering neuropsychological tests with older adults with ASD was indeed no different than when I administered the tests with older adults without ASD. When I did the tests with older adults with ASD, sometimes I noticed

myself forgetting that the participant had ASD. In addition, findings from the present study indicated that older adults were not found to have a global impairment in cognitive functioning, in particular they demonstrated some impairments in both processing speed and visual working memory. Impairment in processing speed and working memory are also often found in neurotypical adults as they age. Therefore, it still remains unclear as to whether the deficits in these cognitive domains are specific to ASD or as a consequence of normal ageing process.

3. Challenges arose during the process of data collection

The present study aimed to compare the cognitive profiles between individuals with and without ASD over the age of 50. The data collection for the ASD sample was already largely completed by a former trainee in 2016 and therefore the main focus for this study was to recruit and collect data from a group of typically developing older adults that matched the age and level of functioning of the ASD group. That was indeed a particular challenge for me as I am an international trainee and therefore I only have limited links to native English speakers over the age of 50s. In addition, I was worried that the long testing duration (at least 3 hours) might also be another reason that might put people off so I was hoping that I could offer some monetary incentive to participants to compensate for their time and effort. However, as most of the research money was spent on purchasing the neuropsychological test forms, it was not possible to offer any monetary incentive or to cover for participants' travel expenses. For these reasons, initially I was quite pessimistic as to whether I could recruit enough participants for the study. Fortunately, my supervisor, Dr Joshua Stott, has links with an organisation, University of the Third Age, which then allowed me to recruit almost all the controls for the current study from there. To my surprise, when I contacted the potential participants, almost all of them were not concerned about whether they would be paid for their participation or the long testing duration. They expressed interest in

taking part in my study because they had a genuine interest in knowing more about their cognitive abilities. Besides, quite a number of them also mentioned that they were interested to participate because they knew someone with ASD and so they hoped that their participation could help individuals with ASD to get the support they needed.

Compared to the recruitment process with typically developing controls, recruiting older adults with ASD was more difficult. Although recruiting older adults with ASD was not the main aim for the present study as we already had sufficient data for the ASD group, we still hoped to recruit more if possible so as to increase the power of the study. I tried to recruit more older adults with ASD by attending their local support group meeting or through online ASD forum but the response rate was not great and I only managed to recruit two more participants for the ASD group. One possible reason for that might be due to the fact that the rate of ASD diagnosis still remains low in late adulthood as there is no proper ASD screening and diagnostic tools for elderly people (van Niekerk et al., 2011). In addition, it might be possible that a lot of older adults who meet the diagnostic criteria for an ASD diagnosis but were not diagnosed properly earlier in life due to the lack of awareness of ASD as ASD was only included in the psychiatric classification system about three decades ago (van Niekerk et al., 2011). Therefore, it is very likely that ADS is rather underdiagnosed in older adults and thus it is very difficult to recruit older adults with a confirmed diagnosis of ASD.

Another main challenges that I encountered in this study was to keep participants engaged throughout the long testing duration. On average, each participant took approximately 3 hours to complete all the neuropsychological tests and questionnaires. Very often, participants reported feeling very exhausted after completing the first half of the tests and appeared to be quite unmotivated to complete the remaining tasks. To help participants to be able to perform at their best, I often offered them a break if I noticed them starting to lose focus and also

gave them more encouragement as they approached the more challenging tasks. However, most participants preferred to finish the tests as soon as possible rather having multiple breaks or breaking the testing session into two.

3.1 What I would have done differently

As mentioned earlier, ASD is highly likely to be underdiagnosed in older people and thus making it more difficult to recruit these individuals in the community. For that reason, I am wondering if it would be more helpful to work with NHS autism diagnostic clinics more closely in the recruitment process. For instance, to identify potential participants in the diagnostic clinic through clinicians working there. Besides, more work could also be done to develop better tools to diagnose ASD at old age and to promote the awareness of ASD in the community so as to reduce the likelihood of underdiagnosing of ASD in older people.

Due to limited human resources and time, most of the time I could only offer one testing session to each participant. If it is possible to have more than one researcher to administer the tests, I would have broken down the testing session into two sessions instead of aiming to complete everything in one long session in order to ensure that participants are trying their best to complete all the tasks and minimise the risk of fatigue effect.

Besides, I was the only researcher who responsible for both administrating neuropsychological tests with participants and also scoring of the tests. I was aware that the assumptions I had about ASD might have created potential bias when I administered and scored the tests. For that reason, I think it might be best if administration and scoring of tests could be carried out by different researchers. At the same time, I would have introduced blind scoring, in which the markers will not know the group identity of each participant so as to minimise any potential biases arise in the process of administration and scoring of neuropsychological tests.

4. Reflections

On reflection, the present study played a significant role in reshaping my beliefs about ASD and the prognosis of ASD in late adulthood. At the beginning of the project, I started off with the assumption that ASD had a negative impact on many aspects in life and that the difficulties individuals with ASD encounter would only persist or even exacerbate as they age. These assumptions were largely informed by my previous experience working with children with ASD as well as their parents. However, my assumptions of the impact of ASD has on individuals have evolved over the course of the research project. This experience also made me become more aware of how my personal experience and assumptions may have influenced the present study, for instance informed the research questions and hypotheses, scoring and interpretation of test results. At the same time, it also made me recognised the importance of acknowledging these assumptions while adopting a more receptive attitude to findings that might contradict my initial assumptions so as to minimise any potential biases that might occur at any phase of the research project.

While I was administrating neuropsychological tests with participants, I noticed that each participant had their own strategy to approach the tasks, especially for tasks that assess memory abilities. However, the present study only compared cognitive functioning between older adults with ASD and those without based on the index scores. These scores enabled us to carry out comparisons between groups on a quantitative level but they could not capture any qualitative information, for instance strategy used when approaching particular memory task, during the testing process. I think it will be extremely useful if we could also incorporate qualitative information in the analysis as it would then allow us to look at the different strategies participants employed and to examine the relationship between strategy and test performance. Furthermore, it will also be very interesting

to explore if there are any differences between the strategies used by individuals with ASD and those without ASD.

Another major thing that has struck me in this research project is the lack of research in examining outcome in individuals with ASD as they enter late adulthood. Despite the paucity of research in older adults with ASD, huge amount of resources has been put into research concerning children and adolescents with ASD. Research on ASD seems to come to a halt at the point that this population reaches early adulthood and it seems that there is a lack of interest in exploring the prognosis of these individuals in later adulthood. I keep thinking what may have contributed to this phenomenon and I wonder if it is due to the fact that ASD is underdiagnosed amongst older people and thus recruiting and conducting studies with them are deemed to be more difficult. To date, the diagnosis of autism was only officially included in the psychiatric classification system about three decades ago and thus it is possible that many older people have ASD but they have not been properly diagnosed. Therefore, there is a pressing need to have a better diagnostic procedure for ASD in older people, not only to aid the development of services and intervention, but also to facilitate research with this population. The dearth of research concerning the prognosis of ASD as individuals enter late adulthood warrants urgent attention as evidence has indicated that there's a huge overlap between the cognitive challenges experienced by individuals with ASD at younger age and those faced by neurotypical adults as they age. Furthermore, a lot of physical and psychological changes occur in the process of normal ageing and having a diagnosis of ASD might exert a different influence upon these changes. For this reason, it is vital to gain a more thorough understanding of the interplay between ageing and ASD in order to develop appropriate support to meet the needs of individuals with ASD as they grow old. Given the lack of research concerning ASD in late adulthood, I am honoured to contribute a little in exploring cognitive abilities in older adults with ASD. I do sincerely hope that more research will be

conducted in the near future to help to close this gap in literature and to inform services to provide support that meets the needs of older adults with ASD.

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Appendix A:

Demographic Questionnaire

Demographic Questions

Date of birth	
Age in years and months	
Gender	Male Female
Ethnicity	
Country of birth	
Age at receiving diagnosis	
Diagnosing clinician/service	
Any other mental health diagnoses?	Yes No
If yes, what diagnoses?	
Marital status	Single/ never married Married Cohabiting Separated Divorced Widowed
Number of children	
Highest level of education attained	
Age at which you left fulltime education	
Current living arrangements	Living alone/single Married/cohabiting Children living in the house
Employment	Fulltime Part time Sick leave (long term) Disablement pension Retirement pension Not working/unemployed Never worked Student Other

Current occupation (or last occupation prior to retirement)	Professional Managerial and technical Skilled (non-manual/manual) Partly skilled Unskilled
If not current occupation, what was your highest status occupation?	
Partner's current/most recent occupation	
Partner's highest status occupation	
Current household income	
Native language	
If not English, how long have you been speaking English?	
Do you have siblings?	Yes/No
If yes, how many?	
Birth order	
Do you consider yourself to be a religious person?	Yes/No
If YES, what is your religion?	
How would you rate your general health status?	Very good Quite good Neither good nor poor Quite poor Poor
Handedness	Left-handed Right-handed Ambidextrous
Vision	20/20 uncorrected vision Contact lenses Glasses Vision problems
Any hearing difficulties?	

Appendix B:

Information Sheet

Information sheet 1 – for individuals without ASD

Information sheet 2 – for individuals with ASD

Information Sheet for Healthy Volunteer (over 50 years of age) without Autism Spectrum Disorder (ASD)

Title of Study: Comparison between the cognitive profiles of individuals over 50 years of age with and without an ASD diagnosis

Researcher	Venus Tse
Research Supervisors	Dr Joshua Stott
	Tel.
	Dr Jason Crabtree
	Tel.
Address	Research Dept. of Clinical, Educational and Health Psychology 1-19 Torrington Place University College London Gower Street London WC1E 6BT

Hi, my name is Venus and I would like to invite you to take part in our research study. Before you decide whether you would like to take part, it is important for you to know what the research is about and what it will involve. Please read this information carefully and discuss it with others if you wish. If there is anything that is unclear, or if you would like some more information, you can contact me on or

What is this study about?
We are looking for people over the age of 50 without a diagnosis of Autism Spectrum Disorder (ASD) to take part in a study. The main aim of this study is to compare the thinking, reasoning and memory abilities of people over the age of 50 with and without ASD.

Why is this study being done?
Although a lot of research has been done with younger people with autism, very little research has looked at or compared cognitive profile of older people with and without autism even though autism is just as common in older people as it is in younger people. By developing a better understanding of the memory and cognitive abilities of older adults with ASD will aid understanding of potential cognitive decline in this group and tailoring of psychosocial and support interventions for them.

What will happen if I take part?
If you are happy to take part in this study, we will meet for about two to three hours, ideally in your own home, but elsewhere if you so choose. You will be asked to complete some questionnaires about ASD symptoms, and we will do some assessments of your memory and general cognitive functioning, which includes thinking and reasoning abilities. It is important for you to know that no one else apart from the researchers in this study will have access to the results of these assessments and questionnaires. Participating will take around two to three hours in total. You will be offered breaks and you can opt to participate over two sessions instead of one, if you wish.

What will I be asked to do?
You will also be asked to about your demographic details and to complete some short questionnaires. You will then be asked to do some tasks where I ask you to think about things, memorise things and perform certain tasks. If you agree to take part you will be asked whether you are happy to be contacted about participation in future studies. Your participation in this study will not be affected should you choose not be re-contacted.

Are there any risks in taking part?
We do not anticipate any significant risks to people taking part in this study. However, some tests of ability may be perceived as complex and arduous by participants. If you become distressed during the tests, we can take as many breaks as you need or we stop the test entirely. The study has been approved by the UCL Research Ethics committee.

What are the potential benefits?
We hope that with your help and that of other older people with ASD we will develop a better understanding of the cognitive profiles of people with ASD in late adulthood. Although there will be no immediate benefit for the participants taking part in this study, we hope that your participation will benefit other people with ASD as they age.

Do I have to take part in this study?
It is entirely up to you whether or not you take part in this study. If you do decide to take part, you will be asked to sign a consent form. If you decide now, or at a later date, that you do not wish to participate in this research, you are free to withdraw your participation. If you wish to stop or withdraw your participation, you do not need to give a reason.

Will information about me be available to anyone?
All information collected from you during the course of this research will be kept strictly confidential, unless required by law. For example, the police authorities will not have access to our research records. It is important for you to know that we are interested the average results of questionnaires and tests, not in the scores of any individual participant.

How to contact the researchers
You can ask any questions that you have about the study. If you have a question that you didn't think of now, you can ask it later. You can contact me on or by email at if you need any more information about the study. If, for some reason, you cannot reach me, you can contact my research supervisors (contact details above).

Please discuss the information above with others if you wish and ask us if there is anything that is not clear or if you would like more information. It is up to you to decide whether to take part or not; choosing not to take part will not disadvantage you in any way. If you do decide to take part you are still free to withdraw at any time and without giving a reason.

All data will be collected and stored in accordance with the Data Protection Act 1998.

Thank you for taking the time to read this information sheet.
Your help makes our research possible.

Information Sheet for Individuals (over 50 years of age) with Autism Spectrum Disorder (ASD)

Title of Study: Comparison between the cognitive profiles of individuals over 50 years of age with and without an ASD diagnosis

Researcher	Venus Tse **Tel.**
Research Supervisors	Dr Joshua Stott **Tel.** Dr Jason Crabtree **Tel.**
Address	Research Dept. of Clinical, Educational and Health Psychology 1-19 Torrington Place University College London Gower Street London WC1E 6BT

Hi, my name is Venus and I would like to invite you to take part in our research study. Before you decide whether you would like to take part, it is important for you to know what the research is about and what it will involve. Please read this information carefully and discuss it with others if you wish. If there is anything that is unclear, or if you would like some more information, you can contact me on or .

What is this study about?
We are looking for people over the age of 50 with a diagnosis of Autism Spectrum Disorder (ASD) to take part in a study. The main aim of this study is to compare the thinking, reasoning and memory abilities of people over the age of 50 with and without ASD.

Why is this study being done?
Although a lot of research has been done with younger people with autism, very little research has looked at or compared cognitive profile of older people with and without autism even though autism is just as common in older people as it is in younger people. By developing a better understanding of the memory and cognitive abilities of older adults with ASD will aid understanding of potential cognitive decline in this group and tailoring of psychosocial and support interventions for them.

What will happen if I take part?
If you are happy to take part in this study, we will meet for about two to three hours, ideally in your own home, but elsewhere if you so choose. You will be asked to complete some questionnaires about your ASD symptoms, and we will do some assessments of your memory and general cognitive functioning, which includes thinking and reasoning abilities. It is important for you to know that no one else apart from the researchers in this study will have access to the results of these assessments and questionnaires. Participating will take around two to three hours in total. You will be offered breaks and you can opt to participate over two sessions instead of one, if you wish.

What will I be asked to do?
You will also be asked to about your demographic details and to complete some short questionnaires. You will then be asked to do some tasks where I ask you to think about things, memorise things and perform certain tasks. If you agree to take part you will be asked whether you are happy to be contacted about participation in future studies. Your participation in this study will not be affected should you choose not be re-contacted.

Are there any risks in taking part?
We do not anticipate any significant risks to people taking part in this study. However, some tests of ability may be perceived as complex and arduous by participants. If you become distressed during the tests, we can take as many breaks as you need or we stop the test entirely. The study has been approved by the UCL Research Ethics committee.

What are the potential benefits?
We hope that with your help and that of other older people with ASD we will develop a better understanding of the cognitive profiles of people with ASD in late adulthood. Although there will be no immediate benefit for the participants taking part in this study, we hope that your participation will benefit other people with ASD as they age.

Do I have to take part in this study?
It is entirely up to you whether or not you take part in this study. If you do decide to take part, you will be asked to sign a consent form. If you decide now, or at a later date, that you do not wish to participate in this research, you are free to withdraw your participation. If you wish to stop or withdraw your participation, you do not need to give a reason.

Will information about me be available to anyone?
All information collected from you during the course of this research will be kept strictly confidential, unless required by law. For example, the police authorities will not have access to our research records. It is important for you to know that we are interested the average results of questionnaires and tests, not in the scores of any individual participant.

How to contact the researchers
You can ask any questions that you have about the study. If you have a question that you didn't think of now, you can ask it later. You can contact me on or by email at if you need any more information about the study. If, for some reason, you cannot reach me, you can contact my research supervisors (contact details above).

Please discuss the information above with others if you wish and ask us if there is anything that is not clear or if you would like more information. It is up to you to decide whether to take part or not; choosing not to take part will not disadvantage you in any way. If you do decide to take part you are still free to withdraw at any time and without giving a reason.

All data will be collected and stored in accordance with the Data Protection Act 1998.

Thank you for taking the time to read this information sheet.
Your help makes our research possible.

Appendix C:

Consent form

Consent Form

Please tick (✓) appropriate box:

☐Yes, I would like to participate in this study.

☐No, I do not want to participate in this study.

If Yes, please complete the following:

☐I have read the Information Sheet and I understand what the study involves.

☐I understand that I do not have to take part in this study if I do not want to.

☐I understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately.

☐I have had the opportunity to ask any questions I wish to ask.

☐ I consent to the processing of my personal information for the purposes of this research study.

☐ I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

☐ I understand that the information I have submitted will be published as a report and I will be sent a copy. Confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications.

☐ I agree that my non-personal research data may be used by others for future research. I am assured that the confidentiality of my personal data will be upheld through the removal of identifiers.

☐ I agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.

☐ I have the names and telephone numbers of the research team in case I have any queries in the future.

☐ I would like to be contacted regarding future studies regarding getting older with an ASD spectrum disorder.

Name: Date:

Signature: _____

Appendix D:

Ethics Approval document

UCL RESEARCH ETHICS COMMITTEE
ACADEMIC SERVICES

12th July 2017

Dr Joshua Stott
Research Department of Clinical, Educational and Health Psychology
UCL

Dear Dr Stott

Notification of Ethical Approval
Re: Ethics Application 11161/001: Comparison between the cognitive profiles of individuals over 50 years of age with and without an ASD diagnosis

I am pleased to confirm in my capacity as interim Chair of the UCL Research Ethics Committee (REC) that your study has been approved by the UCL REC until **28th September 2018.**

Approval is subject to the following conditions:

Notification of Amendments to the Research
You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form':
http://ethics.grad.ucl.ac.uk/responsibilities.php

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Chair or Vice-Chair of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Final Report
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

Academic Services, 1-19 Torrington Place (9th Floor),
University College London
Tel: +44 (0)20 3108 8216
Email: ethics@ucl.ac.uk
http://ethics.grad.ucl.ac.uk/

With best wishes for the research.

Yours sincerely

Professor Michael Heinrich
Interim Chair, UCL Research Ethics Committee

Cc: Dr Jason Crabtree & Venus Wing Sum Tse