Growing older with autism: A qualitative study

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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

Research on older people with autism is very limited. Given the gap in the literature, this study sought to explore the lived experiences of older people with autism.

Part 1 comprises a systematic review of autobiographical memory in adults with autism. Fourteen studies were identified and evaluated. Overall, individuals with autism retrieved fewer specific personal memories and took longer to access specific memories on cueing tasks relative to typical controls. However, the role of mood and the influence of methodological factors on autobiographical memory in adults with autism are not adequately understood.

Part 2 comprises a qualitative empirical study of the lived experience of autism in older age. Thirteen older people with autism participated in semi-structured interviews, which were subsequently analysed using thematic analysis. Findings indicated that the experiences of older people with autism were characterised by loneliness and longing for connection. Prior to diagnosis individuals had some awareness of difficulties, attributed to intrinsic differentness. Diagnosis provided a new framework for understanding differentness and prompted a process of life review and externalisation, whereby negative past experiences could be reattributed to autism as opposed to the self. Autism groups were highly valued, offering opportunities for acceptance and belonging.

Part 3 comprises a discussion of issues pertaining to conducting qualitative research in this field. Topics explored include personal assumptions and how these evolved over the course of the research, difficult aspects of the interview process, reflections on findings and ideas for future research.

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Part 1: Literature Review

What is the nature of autobiographical memory in adults with autism?

A systematic review

Abstract

Aims: Autobiographical memory, the recollection of past personal experiences and personal semantic knowledge, is fundamental to everyday functioning. It has been suggested that individuals with autism show reduced episodic personal memories. This paper aims to systematically review the literature regarding autobiographical memory in people with autism.

Methods: A systematic search was conducted on three databases for studies pertaining to autobiographical memory and autism. In total, 14 empirical studies were identified and evaluated.

Results: The diversity of methodologies used made direct comparisons difficult. Overall, there was evidence that adults with autism generate fewer specific autobiographical memories and take longer to access specific memories on cueing tasks compared to typical controls. The role of mood and the influence of methodological factors on autobiographical memory performance in adults with autism are not adequately understood.

Conclusions: This review found evidence to support diminished episodic autobiographical memory in autism but the influence of mood and methodological factors on test performance require further investigation. Future research studies could benefit from using larger sample sizes to ensure adequate power, drawing on a broader range of approaches to eliciting and measuring memories, and using depressed and typical controls.

Introduction

Autism spectrum disorder is a lifelong developmental condition characterised by social communication impairments and restricted, repetitive interests or behaviours (American Psychiatric Association [APA], 2013). Previously construed as divisible into discrete diagnostic categories (APA, 2000), more recently the concept of a single autism spectrum has replaced these categories with the understanding that the same core symptoms vary in severity between individuals (APA, 2013). This review will use the word 'autism' to describe individuals with any autism spectrum diagnosis and without comorbid learning disability (i.e. IQ in the normal range or above). Autobiographical memory and approaches to its measurement will first be described before considering the nature and pertinence of personal memory in autism.

Autobiographical Memory

Autobiographical memory is memory that pertains to the self and refers to an individual's recollection of past events and experiences (Kopelman & Kapur, 2001; Lind, 2010). Although often used synonymously with episodic memory (Raes et al., 2007), episodic memory is considered a broader construct, incorporating both personal memories and performance on particular learning tasks, such as word-list recall (Kopelman & Kapur, 2001). In line with recent theorists (e.g., Conway, 2005; Raes et al., 2007), this review advocates that autobiographical memory is best understood as a personal memory system comprised of semantic and episodic facets. The semantic facet consists of an individual's store of general personal information (e.g., schools attended, friends' names), while the episodic facet pertains to memories of particular events which are situated in time and space (e.g., the day I took my driving test) and accumulated over the course of a person's life (Piolino, Desgranges, Benali, &

Eustache, 2002). This episodic facet of autobiographical memory is characterised by autonoetic awareness, whereby individuals can mentally travel through time to relive a past event, rich in contextual information, including spatiotemporal and sensory-perceptual details (Tulvig, 1985). A feeling of remembering, as distinct from simply knowing, is therefore thought to distinguish episodic from semantic autobiographical memory. The current neuropsychological understanding of autobiographical memory holds that memory for personal experiences and more semantic personal knowledge exist relatively independently, with differential impairments reported (e.g., Eslinger, 1998; Tulving, Schacter, McLachlan, & Moscovitch, 1988).

Personal memory is understood as a hierarchical memory system, with autobiographical knowledge ranging from abstract, semantic material to specific personal events (Raes et al., 2007). This view of autobiographical memory is reflected in the Self-Memory System (SMS; Conway & Pleydell-Pearce, 2000). According to the SMS, a continuous hierarchy exists with personal representations ranging from life story themes (e.g., relationships, work), to lifetime periods (e.g., my time in university), to general events (e.g., attending lectures), to particular episodic memories (e.g., first lecture). When individuals are requested to retrieve a specific autobiographical memory, typically in response to word cues, retrieval is conceptualised as a staged process, starting with more semantic material and moving towards event-specific information (Conway & Pleydell-Pearce, 2000; Williams et al., 2007).

Autobiographical memory is central to human functioning, facilitating a person's sense of self, identity, orientation, continuity across time, social intimacy and ability to pursue goals in light of prior problem-solving (Conway & Pleydell-Pearce, 2000; Nelson & Fivush, 2004; Prebble, Addis, & Tippett, 2013; Raes, Hermans,

Williams, & Eelen, 2007; Williams et al., 2007). With respect to identity formation, autobiographical memory is thought to facilitate connections between discrete moments, enabling individuals to subjectively interpret their memories and integrate them into a coherent life story (Schechtman, 1994). The reminiscence bump, the phenomenon whereby personal memories from adolescence and early adulthood are overrepresented in recall tasks, is a robust finding in autobiographical memory research (Fitzgerald, 1988, 1996). It is believed to be the result of privileged encoding of experiences concerning Eriksonian psychosocial stages of development (e.g., Erikson, 1959), particularly identity formation in the second decade of life and formation of intimate relationships in the third (Holmes & Conway, 1999).

Over the past quarter of a century, autobiographical memory research has demonstrated that the way in which people remember past experiences has consequences for psychological functioning, namely whether the past is recalled in specific or general ways. A specific memory is characterised by spatiotemporal specificity (Peeters, Wessel, Merckelback, & Boon-Vermeeren, 2002), typically defined as a personal experience that lasted no longer than a single day (e.g., the day I passed my driving test). Overgeneral memory, on the other hand, initially described by Williams and Broadbent (1986), refers to the phenomenon whereby more general memories (e.g., driving lessons) are retrieved following a request for specific memories. Overgeneral memory is related to the aetiology and perpetuation of depression (Sumner, 2012; Williams et al., 2007).

Autism and Autobiographical Memory

It is perhaps surprising that it is only in the past decade that research has begun to explore personal memory in autism given the pertinence of autobiographical memory

to social and interpersonal functioning, which individuals with autism typically find difficult (Blacher, Kraemer, & Schalow, 2003). Additionally, high rates of depression have been reported in adults with autism, with 75% experiencing at least some degree of current depression (Hill, Berthoz, & Frith, 2004) and 70% of young adults reporting at least one episode of major depression (Lugnegård, Hallerbäck, & Gillberg, 2011). Given this increased vulnerability to depression and the role of overgeneral autobiographical memory in the maintenance of depression (Sumner, 2012), exploration of personal memory in autism seems of considerable importance.

Research with children with autism indicates reduced episodic and semantic personal memory (Bruck, London, Landa, & Goodman, 2007; Goddard, Dritschel, Robinson, & Howlin, 2014), while in adulthood it is suggested that episodic personal memory remains reduced but semantic personal memory is intact (Klein, Chan, & Loftus, 1999). This is in line with the general memory profile in autism, characterised by episodic memory deficits alongside spared semantic memory (Ben Shalom, 2009).

There are a number of plausible mechanisms that might underlie reduced episodic personal memory in autism. Reduced theory of mind, or the ability to infer mental states to predict and explain behaviour, is a robust finding in autism (Baron-Cohen, 2001; Baron-Cohen, Leslie, & Frith, 1985). Theory of mind is related to personal memory retrieval in clinical samples (Corcoran & Frith, 2003), and evidence from neuroimaging suggests that a core neural network underlies theory of mind and personal memory (Spreng, Mar, & Kim, 2008). The suggestion that individuals with autism are less able to reflect on their own mental states (Frith & Happé, 1999), have under-elaborated self-concepts and show a reduced self-reference effect at encoding (Lind, 2010), might mean that personal events are less likely to be tagged as personally significant, making self-relevant memory retrieval more difficult.

In addition to self-related processes, cognitive processing styles generally may have a role to play with respect to autobiographical memory in autism. In studies of (non-autobiographical) general memory in autism, the ability to hold together in memory the discrete features that characterise a particular episode appears diminished (Bowler, Gaigg, & Gardiner, 2014). Applied to the retrieval of personal experiences, this would suggest a tendency towards more fragmented personal recollections and storage of memories as isolated events rather than within a broader framework (Bowler et al., 2014). This would also be consistent with a weak central coherence account of autism, characterised by difficulty integrating local details into a global whole (Happé & Frith, 2006). Furthermore, a propensity to process information locally rather than globally might have implications for executive control, thought to be involved in autobiographical memory retrieval (Dalgleish et al., 2007) and one of the components hypothesised to underlie overgeneral memory (Williams, 2006). Executive control encapsulates the set of cognitive processes required for planning, initiating, sequencing and monitoring goal-directed behaviour in the face of distracting information (Williams, 2006).

Given the theoretical plausibility and possible implications of reduced autobiographical memory in autism, the present study sought to determine the nature, characteristics and correlates of autobiographical memory in adults with autism. Specifically, this review will investigate:

- What aspects of autobiographical memory have been measured in autism?
- Is autobiographical memory reduced in individuals with autism relative to controls?
- Do individuals with autism show a pattern of recollection consistent with the reminiscence bump?

- What factors have been found to correlate with autobiographical memory performance in autism?

Method

Studies had to meet a number of criteria in order to be eligible for inclusion:

1. The study must relate to personal memories. Studies should specifically index memory for personal events or self-relevant semantic memory.

2. Clinical participants must have a diagnosed autism spectrum disorder.

3. Clinical participants must not have comorbid learning disability. Participants should have verbal and intellectual abilities within or above the normal range, irrespective of whether language was initially delayed. Participant groups should have mean verbal IQ of 70 or above, or when information on verbal IQ is unavailable, mean full-scale IQ of 70 or above. Verbal IQ is privileged here because autobiographical memory is associated with language development (Nelson & Fivush, 2004) and studies of autobiographical memory typically require verbalisation of memories.

4. The mean age of participants must be 18 years or older.

5. The study must have a comparison group.

6. Studies must be peer-reviewed journal articles and written in English.

7. Studies using any experimental or naturalistic design, employing at least one qualitative or quantitative measure of autobiographical memory must be considered for inclusion.

Search Strategy

In March 2015, a systematic literature search was conducted in the PsychINFO, MEDLINE, and Web of Science databases in order to identify all studies relating to autism and autobiographical memory. Title, abstract and keyword searches were employed, and no filters were applied to the search. The search structure consisted of two sets of terms, each with a number of variants, specified below:

1. Autism

   (autis* OR asperger* OR pervasive development* disorder* OR PDD*

   OR ASD OR ASC OR development* disorder*)

   AND

2. Autobiographical memory

   (autobiographical memor* OR episodic memor* OR personal memor*).

The searches on PsychINFO, MEDLINE and Web of Science databases generated 116, 85 and 209 papers respectively. Following de-duplication, there were 254 papers.

Article Selection

All titles and abstracts of the 254 papers were read to check whether they met inclusion criteria. Thirty-eight papers could not be excluded on the basis of examination of title and abstract alone and were consequently read in full; 26 papers were subsequently excluded. The majority of these were excluded on the basis that they did not specifically index memory for personal events or self-relevant semantic knowledge. Others were eliminated because the clinical sample did not have a mean age of at least 18 years, or because they were theoretical or review papers. Where there was a query

about a paper's eligibility for inclusion in the review, two experienced researchers were consulted to reach a consensus according to inclusion criteria.

This left a total of 12 papers for inclusion in the review. See Figure 1.1 for a flow chart of inclusion and exclusion of papers. Of these, two papers each reported results from two studies, which were therefore appraised separately, leaving a total of 14 studies for inclusion. Reference lists of the papers that met inclusion criteria were examined to ascertain whether any further papers were eligible for inclusion. No additional studies were identified.

Figure 1

Diagram to Illustrate the Search Process

Records identified through
database searching
(n=410)

Additional records identified
through other sources
(n= 0)

Records after duplicates removed
(n=254)

Records screened
(n=254)

Records excluded
(n=191)

Full-text articles assessed
for eligibility
(n=38)

Full-text articles
excluded, with reasons
(n= 26)
————

No reference to personal
events/ self-relevant
knowledge (n=13)

Child/adolescent sample
(n=6)

Review/theoretical paper
(n=4)

Non-empirical paper
(n=1)

Past and future events
scores combined (n=1)

No comparison group
(n=1)

Papers included in
narrative review
(n=12)
————

Papers reporting two
studies (n=2)

Studies included in
narrative review
(n=14)

Critical Appraisal

For the included studies, the primary researcher independently extracted the data and assessed risk of bias using a modified version of the Newcastle-Ottawa scale for nonrandomised case-control studies, as employed by Herzog et al. (2013; see Appendix A for scale). The Newcastle-Ottawa scale comprises a 'star system', whereby a study is judged on three areas: the selection of cases and controls (maximum: five stars), the comparability of groups (maximum: two stars), and ascertainment of the exposure or outcome of interest (maximum: three stars). A total score was obtained by adding the number of stars in each category, with a higher score indicating better methodological quality. A maximum of ten stars could be assigned per study. A score of six or more on the Newcastle-Ottawa scale has previously been considered indicative of high levels of methodological quality (Leonardi-Bee, Smyth, Britton, & Coleman, 2008). Queries were resolved by consultation with research supervisors.

Results

A total of 14 studies from 12 papers met criteria for inclusion. This review was only concerned with the sections of research that met inclusion criteria; i.e., those that pertain to the autobiographical memory of individuals with autism. Table 1.1 provides a summary of the 14 studies.

Table 1.1
Characteristics and Results of Included Studies

Authors (year)	Diagnosis [Criteria; measure]	N (male)	Study aims	Mean age in years (SD)	Mean ability (SD/range) [Test]	Autobiographical memory test	AM dependent variable(s)	Main findings
Goddard, Howlin, Dritschel, & Patel (2007)	AS (n=36), HFA (n=1). [not specified]	AS: 37 (30) CG: 39 (31)	To investigate AM and social problem-solving in adults with ASD and controls.	ASD: 25.35 (6.51) CG: 21.26 (3.23)	ASD: VIQ 98.27 (18.53) FSIQ 97.59 (17.48) CG: VIQ 98.15 (20.45) FSIQ 99.44 (18.37) [WASI]	1. AM cueing task (5 positive emotion, 5 negative emotion, 5 neutral cues). 2. After providing ideal problem-solving strategy on MEPS, participants asked to report any thoughts/images.	1. Latency to first word of each response, specificity (specific or categoric/extended). 2. Propensity to retrieve any AM during MEPS. AM coded as above.	ASD fewer specific AM and longer latencies to retrieve specific AM. Emotional cues (versus neutrals) facilitated specificity for CG only. No group difference in tendency to retrieve AM during problem-solving.
Crane & Goddard (2008)	AS (n=14), HFA (n=1) [not specified]	ASD: 15 (12) CG: 15 (12)	To assess episodic and semantic aspects of AM, establish extent of deficit	ASD: 37.87 (12.63) CG: 32.73 (17.54)	ASD: VIQ 110.87 (16.86) FSIQ 114.33 (14.39) CG: VIQ 106.53 (15.03) FSIQ 111 (15.83) [WASI]	1. Episodic and semantic AM interview (4 life periods). 2. AM fluency task: asked to generate events and people's names (4 life periods), 90s limit. 3. Short interview task re personal episodic memories	1. Episodic AM: 3-point specificity scale (3=specific in time and place). Semantic AM: Max score 6 for each life period depending on volume of information. 2. Volume of memories generated in time limit. 3. Coded for volume of narrative, qualitative aspects.	1. No difference in overall AM. Bump in episodic and semantic AM in secondary school, 5-years post-school for CG only. 2. ASD fewer episodic AM overall, no difference in semantic. Both groups more episodic AM for secondary school compared to pre-school. CG bump in semantic AM at secondary school, 5-years post school. 3. No group difference in volume of narrative; ASD fewer specific memories than CG. No difference on qualitative. aspects.
Crane, Goddard, & Pring (2009 – Study 1a)[a]	AS (n=25), HFA (n=3) [ICD-10 or DSM-IV (records reviewed); AQ]	ASD: 28 (14) CG: 28 (14)	To assess accessibility of specific and general personal knowledge re currently and non-currently pursued goals.	ASD: 41.57 (16.49) CG: 40.53 (17.20)	ASD: VIQ 115.39 (12.10) FSIQ 117.18 (13.47) CG: VIQ 110.68 (13.35) FSIQ 115.11 (11.67) [WASI]	1. General event knowledge task: asked if experienced particular events (yes/no). 2. Event specific knowledge task: cue-word task related to goal items (self-concordant/non-self-concordant/non-goal).	1. Mean latency to general event knowledge for goal/non-goal, except where participants had not experienced goal item. 2. Mean number of specific AM overall and latency to specific AM as function of goal type.	1. ASD longer to access general event knowledge across goal type. Both groups faster to access knowledge re self-concordant goals. 2. ASD fewer specific AM overall. Goal cues facilitated speed of event-specific knowledge relative to non-goal for CG only.
Crane, Goddard, & Pring (2009 – Study 2)[a, b]	AS (n=18), HFA (n=2) [ICD-10 or DSM-IV (records reviewed); AQ]	ASD: 20 (10) CG: 20 (10)	To extend results of Crane et al. (2009 - Study 1) by examining general event knowledge.	ASD: 36.55 (11.62) CG: 35.45 (11.75)	ASD: VIQ 114.20 (12.27) FSIQ 113 (13.69) CG: VIQ 111.05 (10.70) FSIQ 112.50 (8.85) [WASI]	Revised version of AM cueing task: asked to report category of events, at speed.	Mean number of general AM and latency to general AM as function of goal type.	No group difference re overall number or latencies to general AM. Goal cues facilitated accessibility of general event knowledge compared to non-goal cues, no effect of goal self-concordance, similar across groups.

Table 1.1
Characteristics and Results of Included Studies(continued)

Authors (year) [study]	Diagnosis [Criteria; measure]	N (male)	Study aims	Mean age in years (SD)	Mean ability (SD/range) [Test]	Autobiographical memory test	AM dependent variable(s)	Main findings
Crane, Goddard, & Pring (2010)[b]	AS (n=18), HFA (n=2) [ICD-10 or DSM-IV (records reviewed); AQ]	ASD: 20 (10) CG: 20 (10)	To establish whether ASD could distinguish between self-defining/everyday memories; explore memory content, meaning making.	ASD: 36.55 (11.62) CG: 35.45 (11.75)	ASD: VIQ 114.20 (12.27) FSIQ 113 (13.69) CG: VIQ 111.05 (10.70) FSIQ 112.50 (8.85) [WASI]	Participants asked to describe 5 self-defining memories, 5 everyday memories. Memories rated on MCQ.	Total number of memories, narrative length, specificity, theme, reference to emotion, sensory elements, focus on self/other, meaning making.	Groups equally able to distinguish self-defining/everyday memories. CG more self-defining memories relative to everyday; no such pattern in ASD. No group difference on MCQ. ASD fewer specific AM overall. Memories qualitatively similar overall, but ASD less meaning from narratives.
Lind & Bowler (2010)	All HFA (AS or AD) [ICD-10, DSM-IV; ADOS, AQ]	ASD: 14 (11) CG: 14 (11)	To test hypothesis that individuals with ASD have diminished episodic AM and episodic future thinking.	ASD: 41.38 (12.71) CG: 43.83 (10.39)	ASD: VIQ 107.86 (12.37) FSIQ 105.86 (14.52) CG: VIQ 110.71 (15.75) FSIQ 108.57 (18.20) [WAIS-III-UK]	Cue task: asked to remember event that happened during specified time period (today, yesterday, week ago, month ago, year ago, 5y ago, 10y ago). MCQ completed.	Descriptions coded as episodic memory or error (omissions/general memories). Episodic AM scores based on proportion of specific AM described. Point of view, autonoetic awareness (MCQ)	ASD group recalled/imagined sig. fewer specific events, less likely to take field perspective, more likely to take observer perspective. No group difference in autonoetic awareness.
Tanweer, Rathbone, & Souchay (2010)	AS [DSM-IV; AQ]	ASD: 11 (9), CG: 15 (4)	To investigate whether AM in ASD are characterized by fewer episodic 'remembered' events	ASD: 34.1 (11.1) CG: 32.7 (9.5)	ASD: VIQ 109.55 (11.26) FSIQ 112.64 (8.76) CG: VIQ 108.47 (10.99) FSIQ 110.68 (8.94) [WASI]	1. Asked to provide AMs from 3 time periods (A=0-17y; B=last 5y; C=last 12m), with particular themes in each period (e.g., family event). 2. R/K paradigm (R/'remember' response = conscious recollection, autonoetic awareness)	1. AMs scored on 4-point episodic scale (4=specific event situated in time/space, plus sensory details). 2 scores for each time period: overall total (incl. specific and generic information), strictly episodic total (i.e. scored 4). 2. Proportion of R, K responses	ASD fewer memories overall, fewer episodic AM overall and across all periods. ASD lower proportion of R across A and B periods compared to CG; recency effect for both groups (more R in period C).
Crane, Pring, Jukes, & Goddard (2012 – Study 1)[c]	AS (n=16), HFA (n=2) [DSM-IV or ICD-10 (records reviewed); AQ]	ASD: 18 (12) CG: 18 (12)	To explore effects of manipulating imageability and frequency of word cues on AM retrieval.	ASD: 37.17 (13.59) CG: 37 (14.04)	ASD: VIQ 115.11 (9.07) FSIQ 114.00 (13.26) CGs: VIQ 116.39 (7.48) FSIQ 117.39 (8.22) [WASI]	AM cueing task: 1. Cue words varied in imageability (low/high), frequency (low/high). 2. Visual, tactile, auditory condition: Cue words varied in imagery modality (odor, tactile, auditory).	Memories coded as specific/not, latencies to specific memory retrieval (max 30s).	1. ASD marginally fewer specific memories than CG (non sig.), longer to retrieve (sig). High imageability = more AM, faster retrieval for both groups. No effect of frequency on speed/specificity. 2. ASD fewer specific AMs, longer to retrieve. More specific AM to cues high in visual imagery relative to tactile or auditory across groups.

Table 1.1
Characteristics and Results of Included Studies(continued)

Authors (year) [study]	Diagnosis [Criteria; measure]	N (male)	Study aims	Mean age in years (SD)	Mean ability (SD/range) [Test]	Autobiographical memory test	AM dependent variable(s)	Main findings
Crane, Pring, Jukes, & Goddard (2012 – Study 2)[c]	ASD – diagnostic categories not specified [DSM-IV or ICD-10; AQ]	ASD: 18 (10) CG: 18 (10)	To explore speed and specificity of AM retrieval using cues of different sensory stimuli.	ASD: 41.78 (15.27) CG: 39.50 (13.27)	ASD: VIQ 116.22 (11.09) FSIQ 118.17 (10.74) CG: VIQ 111.78 (11.19) FSIQ 114.89 (11.75) [WASI]	AM cueing task: 1. Odour, image and word cue condition (odour stimuli in covered glass jars.) 2. Auditory, image and word cue condition (auditory stimuli = 3s audio clip).	Memories coded as specific/error (memory failures, general categoric AM, general extended AM). Mean latencies to retrieval (max 30s).	1. ASD fewer specific AM, longer to retrieve across modality. Both groups longer to retrieve AM to odour cues relative to image, word. ASD more categoric AM. 2. ASD fewer specific AM, longer to retrieve across modality; ASD more categoric AM. Both groups longer to retrieve AM to auditory cues compared to image, word.
Chaput et al. (2013)	AS [DSM-IV-TR]	AS: 15 (15) CG: 15 (15)	To investigate self-awareness in AS through episodic AM assessment, linguistic markers of self-awareness in narratives.	AS: 19.3 (6.1, 13-33) CG: 21.0 (6.5)	ASD: VIQ 109.9 (17.4) FSIQ 103.5 (12.9) CG: VIQ 116.5 (21.5), FSIQ 109.2 (16.4) [WASI]	Adapted episodic memory test of autobiographical past (semi-structured questionnaire). Used 3 life periods (childhood, adolescence, past 12 months).	Total AMs overall (incl. specific and generic information). Total strictly episodic AMs (i.e. achieved max score on 4-point episodic scale; max=specific AM, located in time, place with personal details).	ASD fewer AM overall, fewer episodic AMs (i.e. scored 4). Family-related vocabulary and possessive pronouns less frequent in ASD interviews than CG.
Crane, Lind, & Bowler (2013a)	AS (n=18) [DSM-IV or ICD-10; ADOS, AQ]	ASD: 18 (13) CG: 18 (13)	To explore past event recollection and future event simulation compared to CG.	ASD: 40.12 (13.94) CG: 44.80 (11.59)	ASD: VIQ 109.94 (19.14) FSIQ 107.81 (10.30) CG: VIQ 111.72 (14.48) FSIQ 110.27 (15.72) [WAIS-III-UK]	Sentence completion AM task: SCEPT ('I still remember well how…'). Asked to recall memory of past event to complete sentence (11 total). Not explicitly asked to recall specific event. SCEPT returned electronically.	Response coded for degree of specificity (omissions, semantic associates, extended events, categoric events, specific event).	No group difference when generating past or future events: more specific events when recalling past events compared to imagining future, more semantic associates when imagining future events compared to recalling past. Depression scores not correlated with performance for either group.
Crane, Goddard, & Pring (2013b)	AS (n=25), HFA (n=3) [ICD-10 or DSM-IV (records reviewed); AQ]	ASD: 28 (14) CG: 28 (14)	To explore potential correlates of AM performance (depressed mood, rumination, WM, ToM).	ASD: 41.57 (16.49) CG: 40.53 (17.20)	ASD: VIQ 115.39 (12.10) FSIQ 117.18 (13.47) CG: VIQ 110.68 (13.35) FSIQ 115.11 (11.67) [WASI]	AM cueing task: 5 positive emotion, 5 negative emotion and 5 neutral words.	Number of specific AM, errors (categoric/extended memories, memory failures) as first responses, mean latencies to specific AM retrieval (max 60s).	ASD fewer specific AMs, longer to retrieve AM than CG. ASD higher depressed mood, rumination than CG; lower ToM and WM. Categoric AM related to depressed mood, rumination in CG only. Specific AM related to ToM and WM in ASD; not related to depressed mood, rumination.

Table 1.1
Characteristics and Results of Included Studies(continued)

Authors (year) [study]	Diagnosis [Criteria; measure]	N (male)	Study aims	Mean age in years (SD)	Mean ability (SD/range) [Test]	Autobiographical memory test	AM dependent variable(s)	Main findings
Kristen, Rossmann, & Sodian (2014)	AS (n=13), HFA (N=4), atypical autism (n=3) [ICD-10; AQ]	ASD: 20 (15) CG: 20 (14)	To investigate relationship between ToM for self (mind-mindedness) and other and AM.	ASD: 28.25 (11.57) CG: 29.30 (11.12)	ASD: VIQ 105.20 (15.61) PIQ 100.82 (22.11) CG: VIQ 105.00 (9.72) PIQ 103.85 (14.10) [PIQ=CFT, VIQ=MWT-B]	1. Semi-structured interview: asked to retrieve specific AM (4 life periods: preschool, primary school, secondary school to 18y, >18y). 2. Asked to recall 2 semantic AMs from each period (e.g., names, addresses).	1. 4-point scale of specificity (max=specific AM located in time/space with contextual detail); 2 episodic AM scores (overall, lifetime period). 2. Rated according to volume of information; 2 semantic AM scores (overall, lifetime period) calculated.	Semantic and episodic AM unrelated for both groups. Reduced specificity and quantity of AMs across lifespan for ASD; semantic AM also reduced but smaller effect size. For ASD only, positive relationship between mind-mindedness for self and episodic AM. No relationship between ToM (for other) and AM.
Lind, Williams, Bowler, & Peel (2014)	AD (n=5), AS (n=22) [ICD-10, DSM-IV-TR; AQ, ADOS (n=19), SRS-2]	ASD: 27 (21) CG: 29 (22)	To investigate underlying basis of deficits in episodic memory and episodic future thinking.	ASD: 35.46 (13.23) CG: 33.25 (16.15)	ASD: VIQ 111.59 (15.08) FSIQ 112.37 (16.36) CG: VIQ 112.97 (12.06) FSIQ 114.07 (11.01) [WASI]	Cue task: asked to describe particular events (12 total, incl. past, future, fictitious conditions) on cue cards (e.g., how you spent your last birthday). Questionnaire on salience, sense of presence, integrated nature of description.	'Composite experiential index' (richness/detail score, ranged 0-60). Calculated by combining description content (spatial references, presence, sensory, thought/emotion/action), sense of presence, perceived salience, spatial coherence.	ASD lower CEI across personally experiences past episodes, future events and fictitious scenes conditions. For both groups, higher CEI for descriptions of past events than for future events or fictitious scenes.

Note. ASD = autism spectrum disorder group; AD = Autistic disorder; ADOS = Autism Diagnostic Interview Observation Schedule (Lord et al., 2000); AM = autobiographical memory; AQ = Autism-spectrum Quotient (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001); AQ-*k* =Autism-spectrum Quotient (evaluated German short version); AS = Asperger's syndrome; CFT-R = Culture-Fair Test 20-R; CG = comparison group (typical adults); CEI = composite experiential index; DSM-IV-TR (APA, 2000); ICD-10 (World Health Organisation [WHO], 1993); Incl. = including; HFA = high-functioning autism; K = known; M = month(s); MCQ = Memory Characteristics Questionnaire (Johnson, Foley, Suengras, & Raye, 1988); MEPS = Means-End Problem-Solving Test; MWT-B = Mehrfachwahl-Wortschatztest (German multiple choice vocabulary test); R = remembered; R/K remember/know; SCEPT = The Sentence Completion of Events from the Past Test (Raes et al., 2007); Sig., = significantly; Specific = single event that lasted less than a day; SRS-2 = Social Responsiveness Scale, Second Edition (Constantino & Gruber, 2012); ToM = theory of mind; TST = Twenty Statements Task (Kuhn & McPartland, 1954); WASI = Wechsler Abbreviated Scale of Intelligence (Weschler, 1999a); WAIS-III-UK, Weschler Adult Intelligence Scale – Third UK Edition (Weschler, 1999b); WM = working memory; Y = year(s).
[a] Two separate studies from same paper; study 1 described as Crane et al. (2009 - Study 1, p. 559) and study 2 as Crane et al. (2009 - Study 2, p. 566).
[b] Same sample used in both studies
[c] Two separate studies from same paper; study 1 described as Crane et al. (2012 - Study 1, p. 2101) and study 2 as Crane et al. (2012 - Study 2, p. 2105).

1. Design and Sample Characteristics

All studies that met criteria for the review were cross-sectional. Sample sizes ranged from 11 (Tanweer, Rathbone, & Souchay, 2010) to 37 (Goddard, Howlin, Dritschel, & Patel, 2007) for autism groups and 14 (Lind & Bowler, 2010) to 39 for controls (Goddard et al., 2007). Although these samples seem typical of autism research, they are objectively small. No study provided a power calculation, and a few authors suggested that their studies are likely to have been under-powered. It is therefore possible that non-significant findings were the result of Type II error. Furthermore, the numerous analyses conducted by some studies (e.g., Kristen, Rossmann, & Sodian, 2014) raise questions about whether significant findings were the result of Type I error.

Mean verbal IQ for autism groups ranged from 98 (Goddard et al., 2007) to 116 (Crane, Pring, Jukes, & Goddard, 2012 – Study 2), and from 98 (Goddard et al., 2007) to 116 (Chaput et al., 2013; Crane et al., 2012 – Study 1) for controls. Overall, study samples tended to have mean verbal and full-scale IQ scores towards the higher end of average, as shown in Table 1.1. All but two studies took place in Britain; the others took place in France (Chaput et al., 2013) or Germany (Kristen et al., 2014).

2. Approaches to Measurement

    2.1 Autism measures.

Studies used a variety of approaches to establishing autism diagnosis. Most studies specified the diagnostic criteria used, such as the DSM-IV (APA, 2000), DSM-V (APA, 2013) or ICD-10 (WHO, 1993); reviewed clinical records and used at least one measure as an additional diagnostic check (Crane, Goddard, & Pring, 2009 – Study 1, 2010, 2013 – Study 1; Crane, Lind, & Bowler, 2013b; Crane et al., 2012 - Study 1, 2012 - Study 2; Kristen et al., 2014; Lind & Bowler, 2010; Lind, Williams, Bowler, &

Peel, 2014; Tanweer et al., 2010). The majority of these used the Autism-Spectrum Quotient (AQ; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001), and three used the Autism Diagnostic Interview Observation Schedule (ADOS; Lord et al., 2000) in addition to the AQ (Crane et al., 2013a; Lind & Bowler, 2010; Lind et al., 2014). One study described the diagnostic tests upon which participants' diagnoses were based and consequently did not administer additional diagnostic screens (Chaput et al., 2013). Two studies stated that participants had a formal diagnosis but did not specify the diagnostic criteria used, did not review participant records nor administer a screening test to confirm diagnosis (Crane & Goddard, 2008; Goddard et al., 2007).

2.2 Measuring autobiographical memories.

Studies employed various ways of quantifying the autobiographical memories generated by participants. Some studies coded memories as either specific (i.e. a single personal event that lasted no longer than a day) or not, and counted the volume of specific memories recalled within a time limit (Crane et al., 2009 - Study 1, 2010, 2012; Goddard et al., 2007; Lind et al., 2010). Others employed a more sophisticated coding system, in which responses were classified according to degree of specificity/generality (Crane et al., 2013a, 2013b; Goddard et al., 2007). Over-general categoric memories (reoccurring events) or extended memories (a single event but lasting longer than a day) were usually distinguished using this framework.

A three or four-point specificity/episodic scale was employed by four studies (e.g., Chaput et al., 2013; Crane & Goddard, 2008; Kristen et al., 2014; Tanweer et al., 2010), with higher scores awarded to specific memories located in time and place and with personal details, such as thoughts, feelings and sensory details. These studies

counted the number of strictly episodic autobiographical memories, i.e. memories achieving maximum scores.

Only two studies explicitly explored autobiographical semantic memory (Crane & Goddard, 2008; Kristen et al., 2014). Both studies requested particular autobiographical information, such as names and addresses, from specified lifetime periods. Participants' responses were coded according to the volume of information provided.

3. General Limitations of Studies

The results of this review must be considered in the context of a number of methodological concerns. All studies are observational and thus have inherent biases, notably selection biases. The tool used to determine risk of bias was an adapted version of the Newcastle-Ottawa scale, which has been widely used in evaluating observational studies (Stang, 2010). Table 1.2 displays results of the quality assessment. Eleven of the studies included in the review achieved at least six stars on the Newcastle-Ottawa assessment, indicating reasonably high methodological quality overall (Leonardi-et al., 2008). Regarding sample selection, most studies used a convenience sampling method and all failed to describe the comparability of respondents and non-respondents, suggesting the possibility of a self-selection bias. Additionally, the possibility of respondents tending to provide only what were considered socially acceptable memories was not considered in any study. In light of these biases, the results of this review should be considered tentative.

Table 1.2
Results of the Newcastle-Ottawa Quality Assessment Scale Adapted for Cross-Sectional Studies

Study	Selection (max=5)				Comparability (max=2)	Outcome (max=2)		Category Total	Total Quality Score
	Representativeness	Sample size	Non-respondents	Ascertainment of exposure	Based on design and analysis	Assessment of outcome	Statistical test		
Goddard et al. (2007)					**	**		Selection: 0 Comparability: 2 Exposure: 2	4
Crane & Goddard (2008)					**	**		Selection: 0 Comparability: 2 Exposure: 2	4
Crane et al. (2009 - Study 1)				**	**	**	*	Selection: 2 Comparability: 2 Exposure: 3	7
Crane et al. (2009 - Study 2)				**	**	**	*	Selection: 2 Comparability: 2 Exposure: 3	7
Crane et al. (2010)				**	**	**	*	Selection: 2 Comparability: 2 Exposure: 3	7
Lind & Bowler (2010)				**	**	**	*	Selection: 2 Comparability: 2 Exposure: 3	7
Tanweer et al. (2010)				**	**	*	*	Selection: 2 Comparability: 2 Exposure: 2	6
Crane et al. (2012 - Study 1)				**	**	**	*	Selection: 2 Comparability: 2 Exposure: 3	7
Crane et al. (2012 - Study 2)				**	**	**	*	Selection: 2 Comparability: 2 Exposure: 3	7
Chaput et al. (2013)				**	**	*		Selection: 2 Comparability: 2 Exposure: 1	5

Table 1.2
Results of the Newcastle-Ottawa Quality Assessment Scale Adapted for Cross-Sectional Studies

Study	Selection (max=5)				Comparability (max=2)	Outcome (max=2)		Category Total	Total Quality Score
	Representativeness	Sample size	Non-respondents	Ascertainment of exposure	Based on design and analysis	Assessment of outcome	Statistical test		
Crane et al. (2013a)				**	**	**		Selection: 2 Comparability: 2 Exposure: 2	6
Crane et al. (2013b)				**	**	**		Selection: 2 Comparability: 2 Exposure: 2	6
Kristen et al. (2014)				**	**	**		Selection: 2 Comparability: 2 Exposure: 2	6
Lind et al. (2014)				**	**	**	*	Selection: 2 Comparability: 2 Exposure: 3	7

Note. * = quality star, denotes that condition is satisfied. Absence of star indicates condition not satisfied. A study was given a maximum of one star for each item of the Outcome category and three of the four items of the Selection category (two stars awarded for 'ascertainment of exposure' item). A maximum of two stars can be allocated for Comparability.

4. Autobiographical Memory Specificity

Specificity refers to the recall of a single event, lasting no longer than a day (e.g., 'the day I passed my driving test'). Three approaches to eliciting specific memories were used; a cueing paradigm, a written sentence completion measure and requests to remember experienced events from specified time periods. These are discussed in detail in the sections that follow.

4.1 Cueing paradigm.

Six studies looked at memory specificity using a cueing paradigm (Crane et al., 2009 - Study 1, 2012 - Study 1, 2012 - Study 2, 2013b; Goddard et al., 2007; Lind & Bowler, 2010), in which individuals were presented with a cue, typically one word, to which they were instructed to recall a specific personal memory, at speed. All studies defined what constituted a specific memory for participants, provided practice trials to ensure understanding and prompts to specific memory retrieval during testing if initial memories were not specific. All of these studies found that individuals with autism produced fewer specific memories overall compared to controls, suggesting a specificity deficit in the autobiographical memories of individuals with autism.

4.2 Other methodologies.

In addition to the above cueing tasks and excluding studies which explored recollection across lifetime periods (discussed below), two further studies looked at memory specificity using different methodologies (Crane et al., 2013a; Lind & Bowler, 2010). One study found that individuals with autism generated fewer specific memories than controls on a task requiring participants to remember personally experienced events from seven time periods (as distinct from lifetime periods), ranging from today to ten

years ago (Lind & Bowler, 2010). This study defined specific memories and provided practice trials. The other study, using a larger sample but obtaining a slightly lower score on the quality assessment, did not define specific memories, explicitly request or prompt for specificity (Crane et al., 2013a). Using a written sentence-completion measure ('I remember well how…'), completed at home in the absence of an experimenter, this study found no difference with respect to specificity between autism and control groups (Crane et al., 2013a). This is in direct contrast to most studies reported here, and the findings might be the result of an insufficiently sensitive measure of episodic personal memory. On the other hand, the study is unique in that it did not require verbalisation of memories or interaction with an experimenter, so results might represent a truer picture of autobiographical memory in the absence of social interaction and verbalisation requirements.

5. Latency to Specific Autobiographical Memory Retrieval

Five studies which employed a cueing paradigm also calculated latency to specific memory retrieval, with latencies typically accounting for the time it took to generate a specific memory spontaneously or following prompting (Crane et al., 2009 - Study 1, 2012 - Study 1, 2012 - Study 2; 2013b; Goddard et al., 2007). Time limits of 30 to 60 seconds were imposed; maximum times were recorded if a participant failed to retrieve a specific memory. All studies found that autism groups took significantly longer to access specific memories compared to controls. One study explicitly requested general memories (e.g., 'attending lectures'), as distinct from specific memories (e.g., 'my first lecture'), and found no difference in response latencies between autism and control groups (Crane et al., 2009 - Study 2). This study obtained a high Newcastle-Ottawa score, suggesting high methodological quality. Latency-related findings overall

suggest that individuals with autism are equally able to access memories at the general level, but have greater difficulty accessing the database of event-specific memories.

6. Patterns of Autobiographical Memory Retrieval

Studies employed various approaches to explore patterns of retrieval, either as a function of cue type or across lifetime periods. These are considered in further detail below.

6.1 Impact of cue type on specificity and latency.

Five studies explored the effects of manipulating cue type on speed and specificity of memories retrieved (Crane et al., 2009 - Study 1, 2012 - Study 1, 2012 - Study 2, 2013b; Goddard et al., 2007). One study looked at speed of general (categoric) memory retrieval as a function of cue type (Crane et al., 2009 - Study 2). In particular, studies explored the impact of emotional valence, personal goals, imageability and sensory modality on patterns of autobiographical memory retrieval.

Two studies used cues that varied in emotional valence, with five positive, five negative and five neutral words used (Crane et al., 2013b; Goddard et al., 2007). Emotional cues (compared to neutral cues) facilitated retrieval of specific memories for controls but not for the autism group in one study (Goddard et al., 2007), but this was not replicated in a subsequent study (Crane et al., 2013b). While Crane et al. (2013b) achieved a higher quality assessment score, the larger sample used by Goddard and colleagues (2007) was perhaps better powered to detect memory specificity differences between groups. No significant effects of emotional valence were found with respect to latency to retrieval for autism or control groups in either study (Crane et al., 2013b; Goddard et al., 2007).

Two studies used cues that varied with respect to personal goals, with three self-concordant goal cues, three non-self-concordant goal cues and three non-goal cues employed (Crane et al., 2009 - Study 1, 2009 - Study 2). Personally pursued goals were identified one week prior to testing; self-concordance was based on self-ratings of intrinsic motivation and perceived importance. Goal cues, irrespective of whether these had been rated as self-concordant, were found to facilitate speed of specific memory retrieval over non-goal cues for controls only (Crane et al., 2009 - Study 1). When explicitly requested to retrieve general as opposed to specific memories, goal cues facilitated accessibility of general event knowledge relative to non-goal cues across both groups (Crane et al., 2009 - Study 2). Again, there was no effect of self-concordance. This suggests that while specific and general autobiographical knowledge were organised around goals for controls, this relationship was only observed for general memories in the autism group.

Two studies looked at the effects of experimental manipulations on speed and specificity of personal memories (Crane et al., 2012 - Study 1, 2012 - Study 2). While the autism group generated fewer specific memories overall and took longer to do so, cue-based experimental manipulations had a similar effect on the performance of both groups (Crane et al., 2012 - Study 1, 2012 - Study 2). Cue words high (versus low) in imageability facilitated speed and specificity of memories for both groups, and word cues high in visual imagery facilitated specificity and speed of personal memories relative to words high in tactile or auditory imagery (Crane et al., 2012 - Study 1). When the sensory modality of cues was manipulated, using odour, image, auditory and word-based cues, again a similar pattern of performance was observed in both groups. Participants across groups took longer to retrieve memories to odour cues compared to image or word cues, and to auditory cues compared to image or word cues (Crane

et al., 2012 - Study 2). Considered together, results here suggest that while individuals with autism generate fewer specific memories and take longer to do so overall, qualitative patterns of retrieval in response to cue type are broadly similar to those of controls.

6.2 Patterns of autobiographical memory across lifetime periods.

Four studies used a semi-structured interview to elicit episodic and semantic personal memories across lifetime periods (Chaput et al., 2013; Crane & Goddard, 2008; Kristen et al., 2014; Tanweer et al., 2010). Of these, the Chaput et al. (2013) study did not report the pattern of recollection across time periods. The study by Tanweer and colleagues (2010) was limited by a very small sample size and by an overly broad 'lifetime speriod A' (0-17 years), which meant that any bump in identity-related memories from adolescence could not be isolated. Statistical issues in the German study (Kristen et al., 2014) limit conclusions with respect to recollection patterns; the use of MANOVA is questionable in light of the lack of correlation between episodic and semantic personal memories in either group, violating the multicollinearity assumption.

With these methodological and statistical issues in mind, and despite a sample size of only 15 participants in each group, greatest emphasis was given to the results of the study by Crane and Goddard (2008), in which the average age of the autism group was 37 years. Using a semi-structured interview task, a pattern of recall whereby more episodic and semantic memories were recalled in the adolescent and early adulthood lifetime periods relative to other lifetime periods was observed for controls only. Using the same sample but employing a test of autobiographical memory fluency, in which individuals were requested to generate events (episodic) and

people's names (semantic) from the same lifetime periods as used in the semi-structured interview, a similar pattern of semantic recollection was again found in controls only. The autism group produced fewer episodic autobiographical memories overall, but both groups reported significantly more episodic memories for the secondary school period compared to the pre-school period. Overall, although a low quality score and wide variability in the performance of the autism group limits confidence, it can be tentatively concluded that individuals with autism do not show patterns of recall characteristic of the reminiscence bump.

7. Characteristics of Autobiographical Memories

Retrieved autobiographical memories were considered with respect to the consciousness accompanying recall and qualitative aspects of memory content. These characteristics are considered in detail in the section that follows.

7.1 Consciousness accompanying recollection.

Four studies explored experiential aspects of recollection using a variety of methodologies (Crane et al., 2010; Lind & Bowler, 2010; Lind et al., 2014; Tanweer et al., 2010). All obtained a score of at least six on the quality assessment indicating low risk of bias. Two studies used the self-report Memory Characteristics Questionnaire (MCQ; Johnson et al., 1988); one to confirm the distinction between self-defining and everyday memories (Crane et al., 2010) and the other to assess autonoetic consciousness (a feeling of remembering/re-experiencing) and the propensity to take an observer versus a field perspective in recollection (Lind & Bowler, 2010). Both autism and control groups rated self-defining memories higher on the MCQ than everyday memories, in terms of how well they were remembered,

vividness, emotionality and thought frequency (Crane et al., 2010), suggesting that the quality of recollective experience was comparable across groups. Similarly, Lind and Bowler (2010) found no group difference in the tendency to report a feeling of reliving/experiencing when remembering. However, with respect to perspective, although both groups were more likely to report taking a field over an observer perspective when remembering, controls were eight times more likely to take a field over an observer position while individuals with autism were 2.4 times more likely to take such a perspective (Lind & Bowler, 2010).

One study used the remember/know paradigm to investigate recollective experience (Tanweer et al., 2010). Using this paradigm, participants indicate whether they subjectively 'remember' a memory, suggesting conscious recollection of a specific event and thus autonoetic awareness, or simply 'know', suggesting familiarity in the absence of conscious recollection. Individuals with autism gave a greater proportion of 'know' memories across lifetime periods A (0-17 years) and B (last 5 years, excluding last 12 month) compared to controls (Tanweer et al., 2010). Both groups showed a recency effect, with a greater proportion of 'remember' responses in period C (last 12 months). However, large confidence intervals, particularly for period B, suggest wide variation in performance. Another study, using a larger sample size and employing an 'experiential index' score based on a composite of memory content and subjective ratings found that individuals with autism had significantly lower scores than controls when remembering past events (Lind et al., 2014). Unfortunately, the subcomponents of the index score were collapsed across past, future and imagined experimental conditions for subsequent analyses, so any further group differences in experiential aspects of remembering past personal events in particular were not explored.

Taken together, and despite limited sample sizes across studies, the bulk of the evidence seems to suggest that the self-reported recollective experience of people with autism is similar to that of typical controls. Methodological issues mean that any conclusions regarding remembered/known patterns of recollection across the lifespan are premature, but this is worthy of further research using larger samples.

7.2 Memory content.

Three studies looked at the content of memory narratives (Chaput et al., 2013; Crane et al., 2010; Crane & Goddard, 2008). One study found that individuals with autism were less likely than controls to use possessive pronouns or family-related words compared to controls (Chaput et al., 2013), suggesting a reduced self-focus and emphasis on others. However, the inclusion of some adolescents in this sample is a substantial limitation. The most frequently used words for the autism sample were school-focused (year, class, school), suggesting that the preoccupations of adolescents dominated overall, thereby limiting generalizability to adults. Contrary to this study and using entirely adult samples, two studies found no difference between autism and control groups in terms of self-focus versus other-focus (Crane & Goddard, 2008; Crane et al., 2010). No group differences were observed with respect to references to emotions or sensory elements in either study, although individuals with autism were significantly less likely to report learning a lesson or gaining an insight from their self-defining memories (Crane et al., 2010). However, participants were only asked to describe a memory, not to report on lessons learned, so it is conceivable that individuals with autism were equally able to derive meaning from their memories but just failed to report it. Given the methodological issues pertaining to sample age range in the study by Chaput and colleagues (2013), the studies by Crane and colleagues

(2010; Crane & Goddard, 2008) are more methodologically robust. It can therefore be tentatively concluded that memory content is broadly similar for adults with autism and typical adults.

8. Correlates of Autobiographical Memory

Seven studies looked at possible correlates of autobiographical memory (Crane & Goddard, 2008; Crane et al., 2013a, 2013b; Goddard et al., 2007; Lind & Bowler, 2010; Lind et al., 2014; Kristen et al., 2014). Correlates explored included theory of mind, mind-mindedness, social problem-solving, mood, episodic future imagining and particular aspects of cognition, including working memory and visual memory. These are discussed in detail below.

8.1 Mind-mindedness.

One study, which obtained a score of six on the critical appraisal tool indicating sound methodological quality, explored the relationship between autobiographical memory and mind-mindedness for self, calculated as the proportion of responses to open-ended requests for participants to describe themselves that were categorised as mental descriptors (Kristen et al., 2014). Mind-mindedness for self was significantly positively correlated with volume of episodic autobiographical memories for the autism group; no such relationship was observed for controls or for semantic personal memories for either group.

8.2 Theory of mind.

Three studies looked at theory of mind performance and remembering past events (Crane et al., 2013b; Kristen et al., 2014; Lind et al., 2014). All of which obtained a

score of at least six on the quality assessment indicating low risk of bias,. However, one study combined episodic personal memory and future thinking scores in correlational analyses with theory of mind (Lind et al., 2014), so this study was not further considered. The Strange Stories paradigm (e.g., Happé, 1994) was used to measure theory of mind in two studies (Crane et al., 2013b; Kristen et al., 2014). The German version of the reading the mind in the eyes test (Baron-Cohen, Wheelwright, Hill, Raste, & Plumb, 2001) was used as an additional theory of mind measure by Kristen and colleagues (2014). Neither approach to measurement correlated with episodic or semantic personal memory performance in the German study (Kristen et al., 2014), although the small sample size suggests that this study might have been underpowered to detect subtle differences. Using a larger sample, a significant positive relationship was found between theory of mind and specific autobiographical memory retrieval in the autism group only, but this no longer reached significance when the effects of IQ were controlled for (Crane et al., 2013b). Theory of mind tests were possibly inadequately sensitive in both studies, leading to low variance on scores, which might have influenced these surprising findings. In light of the above findings on mind-mindedness, it is unfortunate that a measure of introspection was not included in the Crane et al. (2013b) study. Broadly, it seems that the relationship between theory of (other) mind and autobiographical memory performance, if present, is not robust, and reduced ability to reflect on own mental states might be more strongly associated with personal memory performance.

8.3 Social problem-solving.

One study explored the relationship between autobiographical memory and performance on a vignette-based social problem-solving task (Goddard et al., 2007),

using specific autobiographical memory on a cueing task and tendency to retrieve any memories (specific, categoric, extended, general knowledge) during the problem-solving task as memory variables. This study obtained a low score with respect to methodological quality and did not employ an autism measure to distinguish between the groups, limiting confidence in findings. As expected, the autism group demonstrated poorer performance on the social problem-solving task compared to controls. Retrieval of specific memories on the cueing task was correlated with generating solutions to problems that evolved over time for the autism group only. There was no overall group difference in terms of propensity to retrieve any memories during problem-solving. Participants were not explicitly asked to retrieve memories during this task; rather they were asked to report on any thoughts that occurred to them during the problem-solving process. For controls, failing to retrieve any memory during problem-solving was associated with generating poor quality solutions to problems; this association was not observed in the autism group. This suggests that problem-solving performance for individuals with autism was independent of the retrieval of past experiences, indicating a difference between groups in terms of tendency to draw on past experience to dynamically problem-solve in social situations.

8.4 Mood.

Two studies, both of which obtained a score of six on the Newcastle-Ottawa quality assessment, looked at mood as a possible correlate of autobiographical memory (Crane et al., 2013a, 2013b). The studies differed in their approach to measuring autobiographical memory, with one study using a cueing task (Crane et al., 2013b), and therefore defining, practicing and prompting for specific memories, and another using a written sentence-completion task ('I still remember well how…') without

explicit instruction to retrieve specific memories (Crane et al., 2013a). No group difference was observed with respect to depression scores in the study employing the sentence-completion approach and depression scores were not correlated with personal memory performance for either group (Crane et al., 2013a). Contrary to this and using a larger sample, adults with autism had significantly higher depression scores in the study employing the cueing paradigm (Crane et al., 2013b). In this study, depression scores did not correlate with autobiographical memory specificity or latency for either autism or control groups, but higher depression scores were associated with a tendency to retrieve general (categoric) memories in controls only. Given that 10 (out of 28) participants in the autism group and none of the control group scored in the severe depression range in this study, and the robust finding of reduced memory specificity in depressed samples (Williams & Broadbent, 1986), the effects of autism versus depression on autobiographical memory specificity cannot be separated. It is possible that the presence or absence of depression affects specificity of memories differently for individuals with autism, but this cannot be concluded on the basis of comparison with a substantially less depressed control group.

8.5 Cognition.

Three studies explored particular aspects of cognition and their association with autobiographical memory (Crane & Goddard, 2008; Goddard et al., 2007; Kristen et al., 2014). With respect to working memory, higher working memory scores were linked to greater personal memory specificity and lower general memory retrieval for autism and control groups alike (Crane et al., 2013b). Individuals with autism had greater difficulty than controls with visual memory, performance on which was positively correlated with access to specific autobiographical memories for the autism

group only (Goddard et al., 2007), although this finding should be considered tentative in light of the low quality assessment score. No correlations were observed between autobiographical memory and verbal fluency in either group (Crane & Goddard, 2008), but again low methodological quality limits confidence. Kristen et al. (2014) reported a positive correlation between delayed logical memory and episodic and semantic autobiographical memory, but this study performed numerous analyses without accounting for Type I error and did not report specific p values.

Broadly, it seems that working memory is linked to autobiographical memory specificity in adults with autism and typical adults alike, while visual memory might be more specifically involved in specific memory retrieval in adults with autism only. Given that these findings are based on only one study of questionable methodological or statistical quality apiece, replication is warranted.

8.6 Future oriented imagination.

Two studies of high methodological quality investigated the relationship between remembering the past and imagining the future (Crane et al., 2013a; Lind & Bowler, 2010). The studies differed with respect to eliciting autobiographical memories, with one study describing and practicing specific memory retrieval before requesting verbal accounts of events that happened/will happen (Lind & Bowler, 2010). In contrast, the other study neither defined nor explicitly requested specific memories/future events (Crane et al., 2013a). A sentence-completion measure was used in past and future conditions (e.g., 'Next year…'), and participants completed the test at home without an experimenter present. The former study found that episodic memory scores were strongly and positively related to imagining future events in controls but not among individuals with autism (Lind & Bowler, 2010), while the latter found no significant

relationship between proportions of specific events generated in past or future conditions for either group, nor was there a difference in the strength of correlation between the groups (Crane et al., 2013a). Both studies were limited by small samples, but the discrepancy in findings is likely to be a product of the very different approach to eliciting autobiographical memories employed by the studies.

Within each study, patterns of memory and future thinking in individuals with autism were similar to controls. Both groups showed better episodic remembering than episodic future imaging, likely reflecting the increased cognitive demands involved in constructing a future event (Lind & Bowler, 2010), and both groups showed a higher proportion of specific events and a lower proportion of semantic associates (personal overgeneral semantic information) in the past events condition relative to the future events condition (Crane et al., 2013a). One further study also looked at past and future events but used an experiential dependent variable as opposed to a more direct measure of autobiographical memory (Lind et al., 2014), so this study was not considered.

Discussion

This review identifies and summarises the evidence regarding autobiographical memory in autism, its characteristics and correlates. The included studies varied in their approach to eliciting and measuring autobiographical memory, and therefore results could not be easily integrated. Broadly, it seems that individuals with autism generate fewer specific memories and take significantly longer to retrieve specific memories in studies employing a cueing paradigm. However, recollective experience, memory content and patterns of retrieval as a function of cue type were broadly similar across autism and control groups. Across lifetime periods, it seems adults with autism

do not show the reminiscence bump pattern of episodic and semantic personal memory characteristic of typical controls, although this finding needs replication on larger and older samples. Firm conclusions cannot be drawn regarding the mechanisms associated with personal memory retrieval in adults with autism. Working memory, visual memory and mind-mindedness were associated with number of specific autobiographical memories, but these results are based on only one study each and should be considered tentative.

The absence of even a subtle personal memory deficit using a sentence completion methodology (Crane et al., 2013a) suggests that results showing reduced specific autobiographical memories in adults with autism might be a product of methodology as opposed to a true reflection of autobiographical memory ability. It is unlikely that the lack of a time limit facilitated compensation for problems in spontaneous specific memory retrieval, given that participants were unlikely to be deliberately searching for specific memories in the absence of an explicit request to do so. A more likely possibility is that not explicitly asking for specific memories meant that specificity did not increase for controls, raising clear questions about the validity of the cueing paradigm employed by most studies reviewed here. Cueing tasks have been criticised for possibly missing non-clinical participants' typical style of generative memory recall, with extensive instructions, practice trials and prompting for specificity leading to a low incidence of overgeneral memories in non-depressed samples (Conway & Pleydell-Pearce, 2000; Raes et al., 2007). It is therefore possible that the cueing approach improved the specificity of memories generated by controls in the studies reviewed here, as opposed to showing a true deficit in adults with autism.

The equivalent performance of individuals with autism and controls in a study which required participants to write their memories at home without an experimenter

present (Crane et al., 2013a) also raises broad questions regarding the impact of verbalisation of memories and the social context of testing on autobiographical memory performance. It is possible that participants with autism experienced social anxiety in the context of verbalising their personal memories to a researcher, thereby potentially overshadowing true autobiographical memory ability. Additionally, most approaches to eliciting episodic autobiographical memories in the studies reviewed here can arguably be considered open-ended cognitive tasks, dependent upon participants' capacity to grasp task requirements and respond to the social expectations of the researcher (Crane et al., 2010), with which individuals with autism have particular difficulty (White, Burgess, & Hill, 2009).

Regarding the correlates of autobiographical memory, the finding that theory of mind was not robustly associated with autobiographical memory performance after partialling out the effects of IQ was perhaps surprising, but is in line with previous research that did not meet criteria for inclusion in this review (Adler, Nadler, Eviatar, & Shamay-Tsoory, 2010). Previously found to correlate in clinical samples (Corcoran & Frith, 2003), the failure to find such an association in individuals with autism suggests that non-significant findings might be a result of small samples and inadequate power. Non-significant findings might also be a reflection of insufficient sensitivity of theory of mind tasks, given that high-functioning individuals with autism are often able to pass the most complex laboratory-based theory of mind tasks (Happé, 1994), but are frequently unable to dynamically employ it in their daily lives (Frith, Happé, & Siddons, 1994). The positive association between theory of own mind (mind-mindedness for self) and episodic autobiographical memory needs replication in light of the numerous analyses conducted (Kristen et al., 2014). It is possible that reduced ability to reflect on mental states of self and other (Frith & Happé, 1999) is

associated with diminished autobiographical memory performance, but that tests of mind-mindedness are more sensitive to this in high-functioning adult samples.

With regards to mood, despite higher depression scores for adults with autism, access to specific memories did not seem compromised by a tendency towards retrieving categoric memories to the degree that has been found in depressed 'neurotypical' samples (Crane et al., 2013b), and negative emotion cues did not facilitate recall (Goddard et al., 2007). Goddard et al. (2007) suggested that self-focus may be a less prominent marker of encoding for individuals with autism compared to controls, reducing the probability of an overgeneral ruminative retrieval style but still limiting the accessibility of specific experiences. This is in line with the comparable access to general memories in response to goal cues across autism and control groups, but reduced access to specific memories in the autism group only (Crane et al., 2009 - Study 1, 2009 - Study 2). However, the relationship between autobiographical memory and depression is highly complex. Reduced autobiographical memory specificity is not simply a mood-dependent feature of depression; rather it seems to be a stable retrieval style of depressed and formerly depressed people (Peeters et al., 2002). Comparing adults with autism to significantly less depressed typical adults is therefore problematic with respect to separating out the effects of mood and autism on specificity and latency of autobiographical memory. Furthermore, most studies reviewed here failed to account for mood at all, a substantial issue given the high rates of depression in individuals with autism (Hill et al., 2004; Lugnegård et al., 2011).

Regarding semantic autobiographical memory, the two studies that investigated semantic autobiographical memory (Crane & Goddard, 2008; Kristen et al., 2014) did so as part of combined episodic and semantic tasks and it is therefore likely that the two memory types interacted during testing. The tendency for tests of

semantic autobiographical memory to focus on social elements, such as names of people from particular life periods, is potentially problematic in that people with autism do not demonstrate an instinctive preference for social stimuli (Klin, Jones, Schultz, Volkmar, & Cohen, 2002).

Limitations

The results of this review must be understood in the context of a number of methodological concerns. Of note, the systematic search retrieved only 12 papers (reporting on 14 studies) that met inclusion criteria for the current review, and review findings are therefore restricted by the limited number of included studies. Furthermore, the variation in approaches to eliciting and measuring autobiographical memory presented a challenge to integrating findings in a coherent review. A critical appraisal tool was used to ensure that the quality of evidence was as transparent as possible, but ratings by more than one researcher would have enhanced credibility with regards to the quality assessment. Performing the search on three different databases and an additional manual search likely reduced a possible identification bias in this review, but unpublished articles or grey literature were not searched for and consequently there is a risk of publication bias. With this in mind, no other systematic reviews of this topic were found and so the results may be of interest to professionals working with people with autism and other researchers.

Clinical Implications

The possibility of reduced autobiographical memory is of considerable significance for individuals with autism, given that sharing personal experiences is often central to the development of social relationships. Individuals with autism might have difficulty

thinking of particular personal memories to share in conversation, when they need to be accessed quickly, dynamically and without a specific request, which might contribute to the social difficulties they experience (Blacher et al., 2003). Furthermore, personal memories are likely to be important to in vivo social problem-solving (Conway & Pleydell-Pearce, 2000; Nelson & Fivush, 2004; Sumner, 2012; Williams et al., 2007), and difficulties mobilising specific personal memories might mean that problems remain unresolved. The use of social skills groups, which are reportedly often used but rarely evaluated in routine clinical practice (Howlin & Yates, 1999), might benefit from an autobiographical memory component. This might involve instruction on retrieving more specific memories high in contextual detail, facilitation of sharing personal memories in the group, and using past personal experiences of group members as templates for problem solving.

The lack of a reminiscence bump pattern of recollection compared to typical controls suggests that the development of a coherent sense of narrative identity might be affected in adults with autism, with possible implications for mental health longitudinally (e.g., Adler, Chin, Kolisetty, & Oltmanns, 2012). Additionally, given the reduced specificity of autobiographical memory in individuals with autism and the relationship between overgeneral memory and the aetiology and perpetuation of depression (Sumner, 2012), problems with respect to coherent identity development and overgeneral memory might help explain the high rates of depression in people with autism (e.g., Hill et al., 2004; Lugnegård et al., 2011). Clinicians should be mindful of this in therapeutic contexts and consider working with individuals to move from retrieval of overgeneral memories to more event-specific memories, and to draw on specific memories to develop a more coherent self-narrative.

The finding that adults with autism generate fewer specific personal memories might be suggestive of a more global reduction in episodic memory performance, which is in line with previous research (Bowler et al., 2014). This might mean that individuals with autism might have greater vulnerability to age-related conditions which affect episodic memory, such as Alzheimer's disease (Gold & Budson, 2008). Additionally, clinicians should be mindful of the possibility of premorbid diminished episodic memory in individuals with autism when assessing for conditions such as Alzheimer's disease.

Future Research

Future studies should consider using larger samples and a broader range of approaches to eliciting and measuring autobiographical memory. Particularly useful might be the Sentence Completion of Events from the Past Test (Raes et al., 2007), which would reduce the effects of social context and verbalisation on autobiographical memory performance, or the Autobiographical Memory Interview (Kopelman, Wilson, & Baddeley, 1989), which would allow inferences to be drawn regarding the pattern of recollection over lifetime periods and the degree to which the reminiscence bump is a feature of the recall pattern of adults with autism. With respect to measurement of retrieved memories, most studies in this review employed an all or nothing approach to scoring, with responses either belonging to a defined scoring category (e.g., specific memory, semantic associate) or not. This does not allow for much nuance and cannot fully account for the variability of events within each category. For instance, an event lasting two days is clearly more specific and less extended than an event lasting a fortnight, but these event types would not be differentiated in the studies reviewed

here. A more finely-grained coding system, perhaps employing a continuum approach to specificity, might be useful in future research.

Regarding possible correlates of autobiographical memory performance, the finding that performance on visual memory was related to accessibility of specific autobiographical memories (Goddard et al., 2007) is worthy of further research. Difficulties with visual memory have previously been documented in autism (Blair, Frith, Smith, Abell, & Cipolotti, 2002) and findings reported by Goddard et al. (2007) suggest that visual processing difficulties might contribute to autobiographical memory deficits. More sensitive theory of (own/other) mind tasks should be employed, and greater care should be taken to measure central executive functioning (Williams, 2006). Regarding rumination and overgeneral memory, matching on the basis of presence or absence of depression would be useful in investigating the possible role of mood and rumination on autobiographical memory in autism.

Conclusions

The available evidence shows that adults with autism take longer to access their personal memory database and tend to report fewer specific memories. However, it is not possible to conclude that this is a deficit in autobiographical memory per se, given the questionable sensitivity of the cueing paradigm which is overrepresented among the studies reviewed here. The finding of equivalent performance in adults with autism and controls when the social context and the need to verbalise memories were removed from testing emphasises the importance of taking a pluralistic approach to accessing autobiographical memory in future research. To extend research on autobiographical memory in autism, the next step is to include more sensitive designs that account for mood and limit the influence of social context and verbalisation.

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Part 2: Empirical Paper

Growing older with autism: A qualitative study

Abstract

Aim: Originally conceptualised as a disorder of infancy or early childhood and with relatively recent recognition of the lifelong nature of autism, research on getting older with the disorder is very limited. This study contributes to this nascent literature by exploring the experiences of older people with autism.

Method: The study was qualitative in approach. Thirteen older people with autism participated in semi-structured interviews about their experiences of diagnosis, loneliness and getting older. Interview data were analysed using thematic analysis. Quantitative measures of mood and loneliness were also completed to further contextualise experiences.

Results: Experiences of older people with autism were characterised by longing for connection, isolation and loneliness. Prior to diagnosis individuals had some awareness of difficulties, attributed to intrinsic differentness, and engaged in a deliberate process of reducing the visibility of this difference. Diagnosis prompted a process of life review and externalisation, whereby negative past experiences could be reattributed to autism as opposed to the self. Autism-specific support and social groups were highly valued, offering opportunities for belonging, acceptance and safety.

Conclusions: Growing older with autism was generally experienced as difficult and lonely. Individuals continued to experience substantial social challenges throughout adulthood and made considerable efforts to ameliorate these difficulties. Diagnosis offered a new framework for understanding difficult past experiences. These results highlight the need for greater support for this population with respect to reducing loneliness and improving access to diagnosis.

Introduction

Autism spectrum disorder is a developmental condition characterised by social communication impairments and the presence of restrictive, repetitive behaviour and interests (American Psychiatric Association [APA], 2013). Initially construed as a disorder of infancy and early childhood, the impairments of autism are now understood to last a lifetime, with similar prevalence rates across the lifespan (Baird et al., 2006; Brugha et al., 2011). There have been substantial changes to the definition of autism and a broadening of diagnostic criteria since Kanner's (1943) original description. The concept of a single autism spectrum has recently replaced previous diagnostic categories, with the understanding that the same core symptoms vary in severity between individuals (APA, 2013). In line with a single spectrum, this paper will use the word 'autism' to describe individuals with any autism spectrum diagnosis and, unless otherwise specified, those without comorbid learning disability (i.e. IQ in the normal range or above).

Research on getting older with autism is limited. The first cohort of children diagnosed with autism (Kanner, 1943) are now in old age, meaning that until recently there was no opportunity to study the course of autism across the lifespan. Consequently very little is known about the characteristics of older people with autism, their lifespan trajectories or needs (Piven & Rabins, 2011). Given the ageing population in western countries, increasing diagnosis rates (King & Bearman, 2009) and the high cost associated with the condition (Järbrink & Knapp, 2001; NICE, 2012), a number of recent reviews have emphasised the importance of investigating outcomes for older people with autism (Happé & Charlton, 2012; Perkins & Berkman, 2012; Piven & Rabins, 2011; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004).

Autism in Adulthood

Given the dearth of empirical research on autism in older age (discussed below), a brief consideration of what is known about the disorder in adulthood is perhaps useful. Follow-up studies of adults diagnosed with autism as children, encompassing the full range of intellectual functioning, suggest that intellectual ability and earlier language development are associated with better outcomes in adulthood (Billstedt, Gillberg, & Gillberg, 2007; Howlin, Goode, Hutton, & Rutter, 2004). However, the broadening of diagnostic criteria since the 1950s means that such samples are likely to reflect more severe cases with language impairment and comorbid learning disability (Happé & Charlton, 2012). For individuals of normal IQ diagnosed in adulthood, a Swedish consecutive referrals study found very high rates of psychiatric comorbidity, particularly mood and anxiety disorders (Hofvander et al., 2009). Regarding psychosocial outcomes, two thirds of the sample had graduated upper secondary school and a quarter college or university, and half of individuals aged over 23 years lived independently (Hofvander et al., 2009). In terms of daily occupation, 43% were studying or employed, while the remainder had either no organised daily activities, were unemployed, on sick leave or in receipt of a medical pension. A small minority (16%) were in long-term relationships.

These heterogeneous outcomes are consistent with previous review findings which emphasised that a subgroup of high-functioning individuals with autism go on to have favourable psychosocial outcomes (Selzer et al., 2004), although the means by which such outcomes are achieved are poorly understood. Some proposed mechanisms include knowledge gained through experiences of coping in the past, as well as increased self-awareness of 'differentness' and subsequent motivation to adapt behaviour (Perkins & Berkman, 2012). This self-awareness hypothesis is supported by

some qualitative research (Müller, Schuler, & Yates, 2008), which found that adults with autism (aged 18 to 62 years) described improved social understanding with time as they engaged in deliberate efforts to ameliorate social difficulties.

Autism in Older Age

Information on older people with autism is extremely scarce, primarily comprising a small number of case studies of Asperger's syndrome in older adulthood (James, Mukaetova-Ladinska, Reichelt, Briel, & Scully, 2006; Naidu, James, Mukaetova-Ladinska, & Briel, 2006) and an in-depth account of Kanner's first autism case study in *Atlantic* magazine, who is now in his late 70s (Donovan & Zucker, 2010). The autism case studies (James et al., 2006; Naidu et al., 2006) describe men aged between 66 and 83 years, all of whom had been referred to a clinic for other difficulties. Patterns of social interaction and behaviour associated with autism were observed in all cases. Despite chronic histories of interpersonal problems, most individuals had married, raised a family and had jobs for most of their adult lives (James et al., 2006; Naidu et al., 2006).

The *Atlantic* article (Donovan & Zucker, 2010) described the case of Donald, 10-years-old when originally described by Kanner (1943). Institutionalised briefly as a child, Donald went on to graduate from high school, attend college and work as a bank teller. He remained in his home town throughout his life, where he is accepted and enjoys local respect for his maths abilities (Donovan & Zucker, 2010). Donald's story and the case studies described above suggest that some older people with autism can have good outcomes, although the individual or contextual factors which facilitate favourable outcomes are as yet unknown.

Typical Ageing and Quality of Life

Of particular relevance to growing older with a disorder characterised by social impairments is the body of literature on the importance of social health for wellbeing in older age (Phelan, Anderson, LaCroix & Larson, 2004). Social isolation, the observable lack of relationships or social interaction, can be considered distinct from loneliness, which is perceived social isolation or subjective distress resulting from inadequate social relationships (Victor, Scrambler, Bond, & Bowling, 2000). In typical ageing the two factors are associated with poorer health (Berkman, 2000; Cohen, 2004) but they are not highly correlated (Coyle & Duggan, 2012; Perissinotto, Stijacic Cenzer, & Covinsky, 2012). Loneliness has been linked to depression (Cacioppo, Hughes, Waite, Hawkley, & Thisted, 2006), functional decline and mortality (Perissinotto et al., 2012).

Whether the effects of social isolation and loneliness hold for individuals with autism is not known. It is conceivable that isolation might be possible in autism in the absence of loneliness if time spent in pursuit of special interests is fulfilling (Happé & Charlton, 2012). Quantitative findings of younger people with autism suggest that this is unlikely, however, with high levels of loneliness reported in a sample of male adolescents (Lasgaard, Nielsen, Eriksen, & Goossens, 2010). Qualitative research also suggests that individuals with autism experience considerable loneliness in adulthood (Müller et al., 2008). In a sample of 18 adults with autism, all but one participant expressed a sense of profound isolation as a defining feature of their experience and all but three described a longing for greater emotional intimacy (Müller et al., 2008).

The Present Study

Given the dearth of research on older people with autism, this study is exploratory in nature. It focuses primarily on the lived experience of being an older person with autism, with a qualitative approach facilitating the development of a nuanced, in-depth understanding. Qualitative methodology has been successfully used in a small number of studies on the experiences of adolescents and adults with autism (Griffith, Totsika, Nash, & Hastings, 2011; Hurlbutt & Chalmers, 2002, 2004; Huws & Jones, 2008; Müller et al., 2008; Portway & Johnson, 2005; Punshon, Skirrow, & Murphy, 2009).

This study sought to explore the following broad research questions:

- What is the lived experience of older people with autism?

- How do older people cope with autism symptoms?

- What are participants' experiences of loneliness and isolation?

Method

Setting

Recruitment took place via one National Health Service (NHS) adult autism diagnostic clinic, a National Autistic Society (NAS) social group and two autism support groups in London. Nine individuals who had been diagnosed at the autism diagnostic clinic and had consented to being contacted regarding UCL research projects on autism were identified by the service as meeting eligibility criteria. They were contacted by letter (Appendix B), which explained the nature and purpose of the research and invited individuals to contact the researcher if they were interested in participating. Four individuals were recruited via this service. Of three older people attending the NAS social club, two met eligibility criteria and both participated. Five individuals were

recruited via a large support group in inner London and two via a smaller activity-focused autism group in outer London. It was not possible to track how many people received information about the study at these groups.

Ethical Approval

Ethical approval for this study was granted by the UCL Research Ethics Committee (see Appendix C for statement of approval).

Participants

In order to be eligible to participate in the study, individuals had to meet the following criteria:

1. Have a formal diagnosis of an autism spectrum disorder: for those not recruited via the NHS clinic this was established based on self-report, with participants providing the name of their diagnosing clinician and service. An autism screening measure was also used to further confirm diagnostic status. Participants were not excluded purely on the basis of low scores on this measure.

2. Be considered 'older' (defined as over 50 years).

3. Be able to communicate verbally and in English: this was established informally, typically during the first phone or face-to-face conversation with a participant.

4. Be resident in the UK.

5. Not have a comorbid learning disability: this was established based on self-report. If the researcher queried intellectual functioning based on apparent adaptive functioning or educational history, a prior psychological report of

intellectual ability was sought (occurred in one case; participant met criteria and participated).

Procedure

The researcher had a telephone conversation with individuals who expressed interest in the study to ensure they met inclusion criteria (by discussing formal diagnosis, confirming age and residence, and informally assessing verbalisation ability) and to schedule a time to meet. Most interviews took place in participants' homes, a few took place in a small conference room in UCL and one took place in an office in a participant's place of work. Participants read the study information sheet (Appendix D) and written informed consent was obtained for each participant (Appendix E). Demographic information was then collected before proceeding to the interview, which was audio-recorded and lasted an average of 1 hour 20 minutes. Open-ended semi-structured interview questions were employed flexibly and worded conversationally, sometimes being omitted or adapted according to the demands of the particular interview. Participants then completed a number of quantitative measures. Debriefing and details of local services were offered at the end of the interview (Appendix F). Participants were paid £20 to compensate them for their time; one participant declined payment.

Materials

Demographic information.

Demographic information regarding participants was collected via a demographic form which was developed for the study (Appendix G). This was also used to ensure that participants met all inclusion criteria.

Quantitative measures.

Autism.

The Autism Spectrum Quotient (AQ; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001) is a 50-item self-report screening measure of autistic traits (Appendix H). Scores of 32 or higher are suggestive of clinical levels of autism symptoms (Baron-Cohen et al., 2001), although more recently a lower score of 26 has been recommended as a useful clinical cut-off (Woodbury-Smith, Robinson, Wheelwright, & Baron-Cohen, 2005). This was used to confirm participants' diagnostic status. The AQ has good test-retest reliability (Baron-Cohen et al., 2001) and 83% discriminant validity (Woodbury-Smith et al., 2005).

Anxiety and depression.

The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) is a 14-item self-report screening questionnaire for anxiety and depression (Appendix I). The measure has good psychometric properties when used with adults and older adults (Mykletun, Stordal, & Dahl, 2001). The measure contains two 7-item subscales, one for anxiety and one for depression. Scores on both subscales range from 0 to 21, with higher scores indicative of greater symptomatology. Scores are differentiated according to severity, comprising normal (0-7), mild (8-10), moderate (11-15) and severe ($\geq$16) classifications (Snaith & Zigmond, 1994).

Loneliness.

The de Jong Gierveld Loneliness Scale (de Jong Gierveld & Kamphuis, 1985) is an 11-item self-report measure of loneliness (Appendix J). Scores range from 0 to 11, with higher scores indicative of greater loneliness. The scale is a valid and reliable

instrument for measuring overall loneliness in older people (Pinquart & Sorensen, 2001). Scores are differentiated according to severity of loneliness, comprising not lonely (0-2), moderate (3-8), severe (9-10), and very severe (11) classifications (de Jong Gierveld & van Tilburg, 1999).

Qualitative measure.

A semi-structured interview schedule (Appendix K) was developed for the study, designed in line with available guidance (Turner, 2010) and further refined with input from an older person with autism known to one of the research supervisors. It consisted of open-ended questions worded in a conversational style. It began with broad information regarding how participants had come to know of autism, before exploring the context of their decision to initiate the diagnostic process and what the diagnosis had meant for them. It also explored ageing, social support and how participants imagined their lives in the coming years and decades.

Qualitative Data Analysis

The interviews were transcribed in full and any identifying information removed. The data were analysed according to Braun and Clarke's (2006) approach to thematic analysis. As a theoretically-flexible method for exploring patterns in data, allowing for a detailed account of the lived experiences of individuals with particular clinical conditions (Braun, Clarke, & Terry, 2015), this was considered an appropriate analytic approach.

Thematic analysis is composed of six stages of coding and theme development (Braun & Clarke, 2006). The primary researcher read and re-read the whole data set, noting any initial observations (phase one). She then methodologically coded the data,

identifying key features (phase two; see Appendix L for a full list of initial codes), which were then studied for wider patterns of meaning (phase three). Following a process of review (phase four), emerging themes were refined, described and named (phase five), resulting in three overarching themes. The writing of this paper constituted the last phase of analysis. Vivid, compelling extracts were selected to illustrate themes and the fit between the data and the researcher's understanding of them (Elliott, Fischer, & Rennie, 1999). Data extracts are identified with participant number to show that themes are grounded in a wide variety of accounts. Filler words (e.g., 'um') and repeated words were removed from the extracts to enhance readability.

The analysis was guided by an essentialist/realist epistemological approach. This allows the researcher to theorise experience, meaning and motivations in a straightforward way, with language understood to reflect and enable individuals to articulate meaning and experience (Braun & Clarke, 2006). The data were analysed in an inductive 'bottom up' way, whereby the themes identified were strongly related to the data. Themes were identified at the semantic interpretive level, focusing on the explicit, surface-level aspects of interview data. Analysis incorporated both descriptive and interpretative components, with an attempt to theorise the significance of themes and their broader meanings and implications (Braun & Clarke, 2006). A rich thematic description of the entire data set was considered paramount, given that autism in older age is an under-researched area and participants' views on getting older with the diagnosis were unknown (Braun & Clarke, 2006).

Trustworthiness.

Multiple steps were taken to ensure the trustworthiness of results (Elliott et al., 1999). The research process was transparently presented, efforts were made to contextualise

the study and its participants, and quotes were employed to vividly illustrate themes to enable readers to critically judge the value and transferability of findings. The author wrote a subjectivity statement (see below) to describe her personal biases (Preissle, 2008). Triangulation was used to enhance trustworthiness (Carlson, 2010), whereby qualitative findings were contextualised with quantitative measures of some of the phenomena of interest. Further, a qualified clinical psychologist experienced in qualitative research separately coded four transcripts, followed by a process of comparison of interpretations, consensus building and elaboration of themes with the primary researcher. Respondent validity was not sought due to time constraints.

Subjectivity statement.

I am a white Irish working class trainee clinical psychologist in my late twenties. My interest in the experiences of people with autism stems from my clinical experience working with children and adults with low-functioning and high-functioning autism in diagnostic and therapeutic contexts. Nobody in my immediate or extended family has a diagnosed autism spectrum disorder. My prior assumptions included the idea that life for many people with autism would be characterised by high levels of stress, anxiety and difficulty, but that diagnosis would be experienced as helpful. I also assumed that individuals with more positive life experiences would be those who had found partners and perhaps found employment in their field of interest. I attempted to 'bracket' these personal assumptions while conducting the research (Barker, Pistrang, & Elliott, 2002).

Results

Participant Characteristics

As described in Table 2.1, 13 individuals met eligibility criteria and took part in the study. Of these, 10 were male (mean age 62.1 years) and three were female (mean age 54.7 years). All participants were white and all but two were British. All but three reported experiencing at least one mental health problem in their lives, the most common of which were depression and anxiety. All were diagnosed with autism in adulthood, with formal diagnosis obtained an average of six years prior to participating in this study. Three participants did not score above the clinical threshold of 26 on the AQ, which is in line with reported discriminant validity (Woodbury-Smith et al., 2005). A diagnostic report was observed for one of these cases; diagnostic status was based on self-report for the other two individuals, and further verbally confirmed by a social group leader in respect of one of these. Self-report ratings of anxiety and loneliness were high amongst this group, with all participants rating themselves as lonely and all but one indicating at least mild levels of anxiety.

Table 2.1
Participant Characteristics and Scores on Quantitative Measures

ID	Gender	Age group	Diagnosis	AQ	Years since diagnosis	Relationship status	Living status	Employment status (current/former employment)	Educational level attained	Loneliness	Depression	Anxiety
P1	M	60s	AS	35	13	Married	With spouse	Part-time (professional)	Bachelor's degree	Moderate	-	Mild
P2	F	50s	HFA	44	1	Single	With sibling	Unemployed (>10 years)	Some university	Moderate	Severe	Severe
P3	M	60s	HFA*	17	16	Single	Supported housing	Unemployed (>10 years)	Some secondary school	Moderate	-	Moderate
P4	M	50s	HFA*	31	3	Single	Supported housing	Unemployed (>10 years)	Some secondary school	Severe	-	Moderate
P5	F	50s	AS*	34	1	Single	Independent	Part-time (clerical)	Bachelor's degree	Moderate	-	Mild
P6	M	50s	AS	19	3	Single	Private house share	Part-time (charity)	Master's degree	Moderate	-	Mild
P7	M	60s	HFA	36	20	Single	Independent	Medically retired (clerical)	Some secondary school	Moderate	-	Moderate
P8	M	70s	AS	30	9	Single	Supported housing	Medically retired (clerical)	Some secondary school	Very severe	Moderate	Severe
P9	M	50s	AS*	36	1	Cohabiting	With partner	Medically retired (professional)	Bachelor's degree	Moderate	-	Mild
P10	M	60s	HFA	20	7	Single	Independent	Retired (self-employed, skilled)	Bachelor's degree	Moderate	-	-
P11	M	60s	AS	30	5	Married	With spouse, children	Fulltime self-employed (professional)	Bachelor's degree	Severe	-	Mild
P12	F	60s	AS	45	3	Divorced	With child, other family members	Fulltime informal carer	Some secondary school	Moderate	Mild	Severe
P13	M	60s	AS*	35	5	Single	Independent	Retired (unemployed >10 years)	Bachelor's degree	Very severe	-	Severe

Note. * = diagnostic status confirmed via NHS clinic or observation of diagnostic report; - = absence of depression or anxiety, see method; Anxiety, see method; AQ, see method; AS = Asperger's syndrome; Depression, see method; F = female; HFA = high-functioning autism; Loneliness, see method; M = Male.

Qualitative Findings

Analysis led to the generation of three overarching themes with 10 constituent subthemes (see Table 2.2). An example of a coded transcript excerpt is provided in the appendices (Appendix M). Themes are described and illustrated with quotes in the section that follows.

Table 2.2
Inductively Developed Themes, Subthemes and Prevalence Rates

Overarching theme		Subtheme	Prevalence* (n)
1. Difference	1.1	Realisation of differentness	Typical (11)
	1.2	Reducing visibility of difference	Variant (6)
2. Life review	2.1	Understanding the past	General (13)
	2.2	Externalising autism	Typical (8)
	2.3	Self-acceptance	Variant (5)
	2.4	Using knowledge of autism	Variant (7)
3. Longing for connection	3.1	Isolation and loneliness	Typical (9)
	3.2	Positive aspects of isolation	Variant (6)
	3.3	Reaching out (pre-diagnosis)	General (12)
	3.4	Reaching out (post-diagnosis)	Typical (10)
	3.4.1	Shared understanding	Variant (7)
	3.4.2	Social comparison and interpersonal learning	Variant (5)
	3.4.3	Discovering new abilities	Rare (2)

Note. *General = theme applies to all or all but one of participants (12-13); typical = theme applies to more than half of participants (8-11); variant = theme applies to up to half of participants (3-7); rare = theme applies to one or two participants (1-2).

1. Difference.

This overarching theme described how, prior to diagnosis and usually in adolescence and early adulthood, most participants went through a process of noticing and acknowledging their difference from peers. They then took steps to reduce the visibility of this difference so as to fit in with wider society.

1.1 Realisation of differentness.

The gradual realisation of differentness typically began in childhood and intensified in adolescence, abetted by experiences of bullying in secondary school and the lack of anything to which this could be attributed other than a vague notion of intrinsic difference. Participants often perceived some difference in how they were treated

compared to their peers, as exemplified in the following excerpt: *I was treated differently, I was perceived differently from the age of five*. (P2). In the absence of alternative explanations, this initial perception of difference seemed to be located internally. This grasping for explanation in the face of a perceptible but not understood difference can be seen in the following quote:

> *The very first time I thought I was different maybe in that way but I didn't know why, was when I was eight years old in '66. When they didn't put me up to the junior school from the primary school. And I thought, 'Oh, why are they doing that? What's wrong with me?' And prior to that, I would not have questioned my development, so to speak.* (P4)

Experiences of being bullied during secondary school, commonly reported among participants, reinforced the idea of differentness. Again, individuals were without explanation for why this happened to them and were unable to attribute it to something tangible:

> *I didn't know what to think. But I just thought I was different and that was it. But not… I didn't know why. I'd no idea why. But sometimes if the bullying got really bad and I used to get really upset, I used to think, 'Why do they always pick on me? Why? It's not fair. What have I done wrong? Why?'* (P12)

It is important to note that not all participants articulated that they had an early understanding that they were somehow different. Some were aware that family members or teachers perceived them as different, in the absence of their own conscious acknowledgement of differentness. For a minority of participants, the difference was not noticed until early adulthood. For example, following difficulty keeping up with co-workers, one participant described an early adulthood realisation of differentness:

I think I had a welfare officer, social worker, whatever, and things may have started

fitting together, you know. (P3)

1.2 Reducing outward difference.

Following the development of an understanding that they were somehow different, and

sometimes without fully understanding what this difference was, participants engaged

in a process of studying their peers carefully and emulating their social performance

to better fit in socially. The process of studying is described in the following excerpt:

But I watched people talking and then got close and earwigged what they were

saying. And then matched what they were saying to their gestures. (P10)

Individuals worked hard at applying what they had learned, practising gesture, voice

intonation and emphasis, and developing a repertoire of potential conversational

material based on their observations. One man, who had been unaware of his social

difficulties until they were pointed out by a colleague, described the practice

component of this process:

And I worked in front of a mirror, in the bathroom, in the lounge. I had

imaginary people in front of me that I was talking to. I used my arms to

gesticulate. (P9)

Similarly, participants developed a better understanding of acceptable and

unacceptable conversational material. One man summarised how he applied this

knowledge thus:

I try to be very careful of what I'm saying. You see, because certain things you

mustn't - somebody says there's certain subjects you mustn't speak of. Try very

hard, don't say the thing which is concerning politics or religion. (P8)

Over time, learned social skills required less conscious application and became more habitual, enabling participants to outwardly fit in:

> *When you emulate things long enough they become a habit. So they become – you actually outwardly become exactly like everybody else. But you aren't. You never – you never forget. You're never not autistic.* (P10)

However, while social skills were advantageous with respect to fitting in and participating socially, interaction retained a performance quality and individuals still felt a distance between themselves and those with whom they interacted:

> *And I think it made me seem as though I was more normal. And if I... And I tried to smile like they smiled. And I think it helped me up to a point, to mix up with other people. But all the time I was hiding my true self. That was the problem. Inside I was feeling sort of bad. I wasn't really supposed to be like that. But it got me sort of with other people and that. 'Cause I never went out. Never went out to a pub in my life until I was about 46.* (P12)

2. Life review.

This overarching theme was prominent in the accounts of all participants. It described a process of reviewing the past in light of new information, specifically the autism diagnosis, followed by a process of externalising autism so that autism and the self were experienced as separate entities, with the aims of autism sometimes at odds with those of the self. Individuals applied their new knowledge of autism to improve social performance and participation.

2.1 Understanding the past.

This subtheme involved using the diagnosis as a lens through which to view aspects of one's past and ways of interacting with the world that had hitherto been beyond explanation. Experiences such as bullying, academic failure, occupational difficulties and problems making and maintaining relationships could be understood in a new light on the basis of diagnosis. The process of understanding past experiences in light of diagnosis is exemplified in the following excerpt:

> *I mean, after the sort of diagnosis and learning what it was about, sort of almost every day I'd think of some incident way back. Ah yes, that happened because I was Asperger. I mean, it doesn't happen so much these days 'cause there's less of the incidents but occasionally it still does.* (P1)

In particular, the autism label enabled individuals to understand their social difficulties from a new perspective. For example, one participant described how autism helped him to understand some difficult experiences in his past: *Oh, bullying and sort of not fitting in and all that kind of thing. Yeah, trying to get on with other people and all this sort of thing.* (P7). This understanding pertained to friendships and romantic relationships alike, but the understanding it offered regarding romantic relationships seemed to particularly resonate for some participants. One man, who had recently been diagnosed, described how he was beginning to consider the influence of autism on his romantic life:

> *And it always seems to me that I'm the person who ends up by myself. All the time. Throughout my life. I'm the – I'm always the guy that's sitting alone. And I wonder whether that's to do with this Asperger's thing.* (P13)

For one participant, the process of grappling with the past and understanding previous difficulties in light of autism was experienced as painful and isolating:

So it was looking back and then suddenly realising there was this genetic connection and great feelings of inadequacy - that I must've been a really bad carer for my parents when they were terminally ill. And, just having to psychologically, on your own, reassess you whole life. And at the age of 53 it's going back a long way. (P2)

For most, however, life review offered opportunities for discovery and was generally positively experienced. The autism diagnosis revealed aspects of the past that had been negatively experienced but not understood, and the diagnosis seemed to facilitate retrieval of latent memories from childhood and adulthood alike. One woman recounted the way in which the autism label facilitated her understanding of her past:

Ah, I see! That's why people thought I was different. That's why they used to keep starting on me and I used to get mixed up and my life seemed to be completely different to other people's. That's why! And it all sort of fitted into place like a jigsaw. (P12)

The explanation provided by the autism diagnosis facilitated a new interpretation of personal struggles, helping to reduce the associated distress. The impact of this new way of understanding is exemplified in the following account:

Well, for example, you have an explanation why is it you find it difficult to meet people and relate to them. Once you have a few explanations, you find things smooth themselves out a bit. (P8)

Similarly, the diagnosis served to reduce shame around particular aspects of behaviour, unusual interests or perceived inadequacy with respect to some life goals:

Just that label, getting it last year, saying I've got a degree of autism. I knew it wouldn't be a cure or anything but it just explains those one or two things about your character. Like I've got this, like, secret world of animals and I

have stories about them. And I used to be sort of - inside I used to feel ashamed

about it. (P9)

2.2 Externalising autism.

The process of life review seemed to enable participants to consider autism as somewhat separate from their true selves, almost as something that sometimes got in the way of occupational, social or romantic success. Autism provided a plausible explanation for why things went wrong or why individuals failed to reach their full potential, meaning that difficulties could be attributed to autism rather than to the self. One man, who used the song lyric, 'sometimes my mind and I don't get along very well,' to understand the relationship between his autism and his sense of self, described the separateness of autism in the following way:

> *It's like a mind within a mind. Or a mind outside a mind that's kind of*
>
> *influencing your behaviour in a way that you don't want to.* (P13)

Similarly, another participant spoke of autism as an unpleasant but not malevolent behavioural feature, as opposed to a core aspect of the self:

> *And autism is not made to make social relationships wonderful. It is a condition*
>
> *that is meant to make social relationships more difficult. And that could also*
>
> *bring you in awkward situations and things like that. And you happen not to*
>
> *worry about that too much and just see it as an autism thing.* (P6)

The attributing of negative experiences to autism was positively experienced, allowing individuals to absolve themselves for what were previously perceived as personal shortcomings. The relationship between one's autism and wider society became the locus of potential distress, as exemplified in the following account of diagnosis:

It's a good thing to have happen. Because it makes you realise that all the problems you've had in the past you can put it down to one reason. And it's nothing to do with you yourself; it's because the other people don't understand why you're like that. And if they were to understand more why, they probably wouldn't carry on to you and harm you and upset you so much if they understood. (P12)

2.3 Self-acceptance.

Getting older and having the autism label facilitated a greater level of self-acceptance among participants. The re-evaluating of one's life when considered within an autism framework can be seen in the following quote:

I'm not pressurising myself to be like everyone else. You know, it doesn't matter if I like being on my own, living on my own. That's fine. It's 'cause I - you know, people with Asperger's are like that. So I can feel like I'm not somebody who's failed to have a relationship, failed to have children, failed to hold down a job or get to a higher position in a job. (P5)

Some individuals noted that the pressures of navigating the social world reduced with increasing age, which meant that older age may have been less stressful irrespective of the autism diagnosis:

'Cause I mean, when you're young you've got to make friends, you've got to find a partner, find a job and take exams and all this sort of thing. But when you're older you don't have those pressures, maybe. I think that makes a difference. (P7)

2.4 Using knowledge of autism.

Individuals were able to use their understanding of autism to capitalise on their strengths, as seen in the following account:

> *And there was a lot of suffering going on as a result of not actually understanding the fact that, you know, the nature of it. That certain things would be easy for me and certain things would be a struggle. And If I could learn to do the easy things and not do the struggle-y bits, which are almost impossible...* (P11)

Similarly, the awareness of differences in thinking style compared to 'neurotypical' people facilitated an appreciation of particular thinking styles associated with autism versus those of 'neurotypicals':

> *It shows me why I think the way I do. And why other people do not appear to be logical. And do not appear to be, in a sense, coherent. For example, their cognitive, what do you call it, dissonance, where they believe opposite things at the same time.* (P10)

Knowledge about autism facilitated a greater understanding of particular autism traits, such as special interests, playing out in the social realm. Individuals were able to draw on this knowledge and regulate their social performance accordingly:

> *But I realise I am very passionate and I tend to go on about these things a bit. And other people don't really know what I'm talking about. And I'm just, if you like, at the moment, checking that in myself. It doesn't mean I'm necessarily going to stop doing it, but...* (P13)

For most participants, diagnosis seemed to be experienced as benign. There was one participant, however, for whom the knowledge and increased awareness gained by virtue of the diagnosis was experienced as socially debilitating:

And then of course I started sort of making mistakes, even more mistakes talking to people because I was even more anxious and socially inept. Because I was so self-conscious with that diagnosis. (P2)

3. Longing for connection.

This overarching theme suggested that most participants perceived themselves to be isolated and experienced a subjective sense of loneliness. However, being alone also allowed participants the opportunity to pursue particular interests, which were highly valued. Subthemes pertaining to reaching out describe how participants made a conscious effort to socialise or acquire friends, particularly in early adulthood (pre-diagnosis), and later to meet other people with autism (post-diagnosis).

3.1 Isolation and loneliness.

A sense of isolation and loneliness permeated the accounts of most participants, as can be seen in the following excerpt:

I go back years but I remember once, I was 27, I said to my mother, 'I really feel lonely.' I said, 'I don't expect a girlfriend per se; if only I had somebody to talk to this evening. Man, woman, old or young, just for a conversation.' She said, 'I don't know what to suggest you do.' In those days you could phone the Citizens Advice Bureau up and get them to find somebody to talk to in the old days. (P7)

Isolation seemed to be a defining feature of growing up and getting older with autism, which became no less distressing with advancing years:

See, I never had many friends when I was younger. So I think in a way it's sort of prepared me for being on my own. Although I don't like it much. I've never liked it. (P12)

In the context of limited social networks, people particularly focused on the lack of one significant, anchoring relationship in their lives, describing a sense of longing:

I think I'm a born loner, quite frankly. And even no matter... Maybe I'm not the kind of person to have a life. Oh, I'd love it, with a person that would understand me. (P4)

Observations of the social connectedness of others threw participants' isolation into sharp relief, emphasising their aloneness. Such situations were endured with distress:

The summertime is worse for me than the winter. 'Cause it seems that more and more people are included in family and groups of friends or partners or whatever. And it seems I'm the excluded one. (P13)

Loneliness seemed reduced for the three study participants who were married or cohabiting, suggesting that one close relationship served to buffer the effects of social isolation. One participant described his relationship with his partner as follows:

He's very, very good. He's very perceptive. And he knows all my changes of mood. They're not extreme, but he knows when I'm having difficulties or when I'm anxious. (P9)

However, even for those in long-term relationships, isolation and a sense of disconnection or being cut off from other people was still a feature of their experience:

It's not to do with not having friends and stuff like that. It's to do with I just feel that I'm totally isolated in myself. I don't know what to say to anyone; I can't connect. (P11)

For participants that had worked, a job seemed to have afforded some degree of social contact in a structured context. While the social aspects of working were often a source of anxiety, the loss of that social contact and narrowing of their social opportunities following retirement was perceptible:

> *But in the last five, ten years, as I've got old, I've found that I want to do less and less and less and less. And see less people. And do things which are a bit more comfortable.* (P9)

3.2 Positive aspects of isolation.

Although most participants described themselves as socially isolated, aloneness was sometimes framed positively in that it allowed uninterrupted pursuit of hobbies and interests:

> *You know, where does lonely stop and isolated begin? I mean, I quite like my own company in some ways. Given that I'm quite hard-driven in my enthusiasm for certain things.* (P13)

The pursuit of interests allowed for immersion in the subject and experiences of mastery and achievement. It also offered participants a place of safety, which was in contrast with their anxiety-laden experiences of trying to engage with the social world. The differences between the pursuit of interests and experiences of failure and rejection with respect to engaging socially can be observed in the following quote:

> *I'm interested in machines. I can master them, if you like. I can understand them. I can relate to them. I can relate to machines better than I can people. Machines do not put you down. They don't criticise you. They don't hurt you and they don't make you cry. Not generally. People do that.* (P4)

3.3 Reaching out (pre-diagnosis).

Prior to diagnosis, many participants had made deliberate efforts to engage with people, usually in quite structured settings. They sometimes joined clubs related to interests and deliberately set about making friends, particularly in early adulthood. Structured activities or social gatherings with definite start and end points were preferred, serving to facilitate social interaction:

> *It was a structured thing and I felt rather more comfortable with that. So yeah, we sort of did – we were meeting around another activity. If I'm not focused on trying to be friendly with someone it's actually easier to be friendly with them.* (P11)

Just one participant reported that his negative experiences of participating in the social world prompted him to withdraw:

> *So I got to a stage where I was so used to being mistaken by others, misinterpreted, misunderstood; I thought, well, sod it. If you're going to misunderstand me, I'm not going to even, going to… I just closed off later on in life. I just thought, sod it.* (P4)

3.4 Reaching out (post-diagnosis).

Post diagnosis, most participants had some involvement in autism groups or had occasion to meet other people with autism. For some, this was an attempt to increase their social engagement generally, as noted by P10 when he said, "It's a day out like anything else." For most, it was a deliberate attempt to gather additional information about autism and how it applied to them. To demonstrate the different facets of this subtheme, the following account has been further divided into smaller subthemes pertaining to involvement with others with autism.

3.4.1 Shared understanding.

Meeting others with autism offered a sense of shared experience and understanding, which was lacking in their usual limited social networks. The importance of universality of experience and the sense of acceptance it endowed can be seen in the following quotes:

The people, some of them are on my wavelength. (P3)

You're accepted. You don't have to sort of hide anything. (P7)

Because they don't – the Asperger's people don't pick on you. Or take the rise out of you. And laugh at you. And get confused by what you say or something. Because they're similar themselves. And they're quiet; quieter sort of people. Sort of thing like I am, sort of thing. And it made me feel better. (P12)

Universality of experience and the pursuit of information were core to people's commitment to the groups, while emotional support or friendship-seeking seemed less important:

And I do feel like, yeah, well, they're in the same boat as me. Yeah, so, but I don't feel like - I don't socialise with them that much. I think a lot of people there don't, you know, don't go there to make friends. (P5)

Of course, autism groups were not without challenges. The difficulty of running a group for people with social difficulties is described in the following extract:

If I say the group is a group of misfits who are bound not to get on with each other, I mean, that's a bit of an exaggeration but it's not the recipe for success, forming an Asperger group. (P1)

Similarly, another participant recounted difficulties initiating meaningful conversation with group members, due to a focus on restricted topics*:*

I found that I was getting rebuffed or I was making them angry because I'd just say, 'Well, I liked Dr Who when I was a child but I don't really think it's a programme for adults.' (P2)

3.4.2 Social comparison and interpersonal learning.

Some individuals were shocked by the level of impairment exhibited by some people with autism, and strove to establish their place in the autism hierarchy:

There were obviously people who were severely incapacitated by it. Who hardly spoke a word and were kind of - they had to have other people there with them as well. And on the other end – at the other end of the spectrum, I suppose - there were, there was a guy there was doing a course at the university. And he seemed extremely lucid. So it's very difficult to see where I fit into. (P13)

This allowed some participants an opportunity to engage in a process of social comparison with other people with autism, enabling them to notice particular strengths they possessed by comparison. Reframing one's own circumstances in light of comparing oneself to another can be seen in the following quote, in which a man described his discovery that a fellow group member struggled hugely with public transport:

And I don't have these difficulties at all. And I travel around London quite easily. That's what my passion is, to travel around London. (P6)

Attending autism groups allowed certain aspects of experience to be normalised and understood in the context of autism:

While we were just talking about various things, them saying, 'Oh, I have a problem with babies and noise.' And I used to be ashamed of that. You know,

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years ago, I'd just think perhaps I'm being intolerant to children or kids or babies. And the whole group said, 'No, we find it difficult.' (P9)

The groups also allowed participants an opportunity for interpersonal learning, by applying knowledge gained through interacting with others to their own circumstances:

They might come up with some problems they've – 'What do I do about this?' And I'm like, this is what you do. And then, so I apply it to myself. That's what I ought to do about myself. (P8)

3.4.3 Discovering hidden abilities.

For two participants, both of whom were recruited via a small autism group in outer London, the discovery of hitherto unknown abilities, such as using metaphor, reading or creatively writing, was very powerful in their accounts. The discovery of a formerly hidden ability can be seen in the following extract:

Everything used to just go into a blur and I just couldn't concentrate. And she [group facilitator] said lots of people are like that with Asperger's. And the ones – she has a book club. And different books are given. And I've read about - must be about five or six books now! (P12)

The focus on something tangible (e.g., a book) facilitated the use of social skills in the absence of an overt focus on social skills:

That's where we're focused on – it might be book club and we're focused on the book. But if you listen to the discussion on the book, it's very flowing and we can be really supportive. (P11)

Discussion

Using a qualitative interview-based method, this study sought to explore the lived experiences of older people with autism. The study is unique in providing a nuanced portrait of the experiences of growing older with autism and it adds significantly to the nascent knowledge in this area. Overall, quantitative and qualitative findings illustrate the isolation, loneliness and longing for connection inherent in getting older with autism. A recognition of differentness earlier in life in the absence of anything tangible to which this could be attributed was experienced as painful, with diagnosis helping to explain this difference and offering a new framework in which to understand past experiences. Autism-specific groups were highly valued by participants, allowing for a sense of shared experience and acceptance.

Differentness

Consistent with the present findings, an awareness of difference when comparing themselves to 'neurotypical' peers has been previously documented in interview-based research with people with autism (Huws & Jones, 2015; Müller et al., 2008; Punshon et al., 2009), as well as qualitative analyses of the written accounts of individuals with autism (Jones, Quigney, & Huws, 2003; Williams, 2004). However, qualitative research with younger people (aged 16 to 21 years) who attended a college for people with autism did not indicate an awareness of difference prior to diagnosis disclosure (Huws & Jones, 2008), which raises the possibility that an examination of childhood experiences in adulthood leads to a retrospective perception of differentness as opposed to the more lifelong awareness of differentness described in the present study. Alternatively, the lack of awareness of differentness among the younger sample might

be a reflection of greater severity of autism and possibly a consequent delay in noticing and acknowledging differentness.

The finding that people engaged in a deliberate and effortful process to train themselves in the art of social interaction to the point that it became habitual is consistent with previous qualitative research in the US (Müller et al., 2008) and the UK (Griffith et al., 2011), and in qualitative analyses of the writings of individuals with autism (Williams, 2004). Similar to the present findings, prior research demonstrated that participants made substantial efforts to compensate for autism by developing their social/self-awareness (Müller et al., 2008) or to present a 'false self' to others (Griffith et al., 2011). The US sample tended to educate themselves by reading books and articles about autism or joining social skills or autism support groups (Müller et al., 2008), while those in the current study learned social skills by studying people or practising in more naturalistic settings. This is possibly reflective of the older age and consequently the absence of the autism label as a frame of reference until later life for most participants in this study, leaving them grappling with remedying their social difficulties without autism-related guidance for most of their lives.

Life Review and Externalisation

The process of reviewing one's life through the lens of the autism diagnosis was ubiquitous among participants in this study. Painful aspects of experience that had hitherto not been understood could now be explained using an autism framework, helping to integrate disparate experiences into a more coherent narrative, reduce self-blame and reattribute some responsibility for these experiences to the diagnosis. The explanatory power of the diagnosis has previously been documented in qualitative

interviews with adults with autism (Punshon et al., 2009) and young people with autism (Huws & Jones, 2008), facilitating an understanding of previous life events, particular difficulties and experiences. This process of review seems comparable to reminiscence, whereby remembering the past is thought to be a means of achieving ego integrity and resolving inner conflicts (Butler, 1963). The idea of integrative reminiscence seems of particular pertinence to participants in this study, whereby individuals seek to accept negative past events and reconcile the discrepancy between the actual and the ideal, facilitating a review of the causes and consequences of negative past experiences (Watt & Cappeliez, 2000).

The finding that participants in the present study engaged in a process of externalising autism is similar to previous qualitative research with individuals with autism in middle adulthood (aged 37 to 57), in which Asperger syndrome was considered separate to participants' core or real selves (Griffith et al., 2011). This process of externalisation bears a striking similarity to the narrative therapy practice of 'externalising the problem', in which individuals are helped to define their problems as separate from their identities (White & Epston, 1990; Carr 1998). Reappraising the problem and the person as separate entities facilitates the interruption of the dominant, problem-saturated story of the person's identity and the internalising of personal agency, thereby allowing for increased visibility and accessibility of options for resolving difficulties (Carr, 1998; Tomm, 1989; White & Epston, 1990). In the present study, knowledge regarding and externalisation of autism seemed to allow for increased accessibility of possible strategies to improve current social performance. It is possible that reappraisal also allows for an acknowledgement and appreciation of the positive aspects of autism, such as particular thinking styles that differ to those of

'neurotypicals', described in the present study and a sample of people with autism in middle adulthood (Griffith et al., 2011).

Isolation and Longing for Connection

Qualitative and quantitative findings illustrate the loneliness and isolation of older people with autism. The present findings are strikingly similar to a previous qualitative studies of the experiences of adults with autism (Müller et al., 2008). Intense loneliness and a longing for connection and intimacy with others were found in both studies. It is also notable that one of the first case studies of Asperger's syndrome in later life had loneliness as a presenting complaint (James et al., 2006). While not explicitly referencing loneliness, other qualitative studies have also documented a desire to 'fit in' and engage socially (Hurbutt & Shalmers, 2002; Huws & Jones, 2015), suggesting a felt sense of the absence of social relationships and a desire to ameliorate this. The present results are also in line with quantitative studies which found high levels of loneliness among children (Bauminger, Shulman, & Agam, 2003) and adolescents with autism (Lasgaard et al., 2010). Taking these qualitative and quantitative studies into account, in addition to the present findings, it seems that isolation and loneliness might be an almost inescapable element of growing up and getting older with autism.

Peer Support

Accessing a network of other people with autism was very important for participants, allowing them to feel understood, accepted and safe. In contrast to the findings of Müller et al. (2008), autism support groups were not used for the explicit purpose of learning social skills. Rather, interactions at autism-specific groups did not seem to have the perceived distance and the performance quality that tended to characterise

interaction with the 'neurotypical' world. Similar to the qualitative findings of Punshon and colleagues (2009), meeting others with autism seemed to afford individuals the experience of 'fitting in' which had hitherto been absent from their lives. The information provided at these groups and the realisation that others faced similar problems clearly held meaning for individuals, fostering a sense of belonging and providing an environment in which individuals could engage in interpersonal learning. Universality, imparting information, interpersonal learning and cohesion represent four group therapeutic factors (Yalom & Leszcz, 2005).

The importance of autism groups can also be understood with reference to social comparison theory, which involves the process of acquiring social information, considering it with respect to the self and reacting to comparisons (Festinger, 1954; Wood, 1996). In evaluating their place in the hierarchy of impairment, individuals could engage in a downward social comparison with those who demonstrated greater impairment (Wills, 1981), possibly helping them to feel better about their own situation. Downward social comparisons have been previously documented in the accounts of younger people with autism, with participants positioning themselves as better with respect to degrees of autism and ability observed in others (Huws & Jones, 2015). Representing their own autism as less severe might heighten subjective well-being and enable individuals to maintain a more positive self-identity (Huws & Jones, 2015).

Limitations

With respect to representativeness of the sample, while the gender ratio is similar to that reported in previous studies of high-functioning adults with autism (e.g., Baron-Cohen, Jolliffe, Mortimore, & Robertson, 1997), it is possible that participants were

not necessarily representative of older people with the diagnosis. The recruitment procedure, which partly relied on local autism support and social groups, may have inadvertently biased recruitment towards those who had accepted their diagnosis and were committed to it. While additionally recruiting via a diagnostic clinic might have negated this effect somewhat, participants recruited in this manner were in the minority. Similarly, the study procedure itself may have biased selection in favour of those with a willingness to engage socially with a researcher.

Interviewing older people with autism was not without its challenges. The interview schedule required the discussion of abstract concepts, emotions, social difficulties and perspective taking, known to be challenging for individuals with autism (Cridland, Jones, Caputi, & Magee, 2015). It was sometimes difficult to redirect conversation from special interests or lengthy discussion of specific past experiences, and consequently the quantity of interview data relevant to the research topic varied between individuals. At the stage of data analysis, it is possible that the ideas of more articulate individuals with good introspective and verbalisation abilities were overrepresented during coding and theme development, particularly as just one researcher was involved in the initial stages. The researcher attempted to negate this to a degree by triangulating qualitative and quantitative data, triangulating the perspectives of two researchers on a subset of transcripts, ensuring that the voices of all participants were included in the write-up of this paper and, where appropriate, the use of disconfirming case analysis (Yardley, 2008).

The lack of themes pertaining to family support or family understanding of autism post-diagnosis was perhaps surprising. Participants did not seem particularly close to their families of origin in this sample, which is possibly a reflection of participants' age and independence. Broadly, it appeared that for family members, the

diagnosis tended to either simply confirm something already assumed or they did not seem to thoroughly engage with it. However, it is possible that the questions used to access this aspect of experience in the interview schedule were overly reliant on individual theory of mind ability (Baron-Cohen, Leslie, & Frith, 1985), requiring individuals to focus on the perspectives of others, thereby perhaps placing excessive cognitive demands on participants and hindering a thorough exploration of family support.

Interview data overall tended to have a contemporary focus with limited exploration of recent decades of life or consideration of the future. While participants used their diagnosis to understand difficult experiences in childhood, adolescence and early adulthood, interview data were not particularly rich with respect to middle adulthood, which limited the degree to which the experiences of older participants could be compared to younger participants. This might be a reflection of the occupational and marital status of many participants; unemployment and the absence of a partner perhaps meant that some lifecycle transitions simply did not apply, and that life may not have changed remarkably over the middle adulthood years. Or perhaps it is a product of the suggested reduction in temporally extended self-awareness in individuals with autism, with proposed impairments in re-experiencing past states of self and pre-experiencing the future (Lind, 2010). Efforts were made to make questions about recent years and decades more concrete as the interviews progressed but this had little impact on data richness.

Implications for Practice

The considerable loneliness, isolation and anxiety in the present study suggests an urgent need for greater support for older people with autism. The qualitative findings

reported here provide some contextual explanation for the high levels of anxiety and depression among individuals with autism (Hofvander et al., 2009; Hill, Berthoz, & Frith, 2004; Lugnegård, Hallerbäck, & Gillberg, 2011). There is a lack of empirically supported mental health treatments for people with autism, and official guidelines recommend adapting existing treatments for common mental health problems by making them more concrete and structured, with greater emphasis on visual and written information (NICE, 2012). Based on the present study, the use of externalisation might be useful in therapeutic work with this population, either as part of a narrative approach or embedded within other therapeutic approaches. One case study of a 13-year-old boy with Asperger's syndrome found that externalising (anger) visually and concretely was effective, and seemed to facilitated the development of a therapeutic relationship (Cashin, 2008).

The findings of this study highlight the importance and helpfulness of diagnosis for individuals with autism. For most participants in this study, the idea of autism had first been mentioned to them by somebody involved in their care, either a support worker or health professional. Ensuring that all relevant professionals (education, employment, housing, health, social care, third sector) are cognisant of autism symptoms, the local autism pathway and how to access services is of considerable importance, in line with NICE guidelines (2012). Mental health professionals involved in the diagnosis of autism should routinely assess for social isolation and brief post-diagnostic support might be paramount for socially isolated cases.

Membership of local autism groups, which facilitated access to autism-related information and others who shared their experience was highly valued by participants in this study. Information on local groups should be routinely provided to individuals

following diagnosis. This is likely to go some way towards alleviating social isolation and loneliness, and target the need for information and access to others with similar experiences.

On a broader level, rates of unemployment were high in this sample, which is consistent with previous research (Bernard, Harvey, Potter, & Prior, 2001; Hofvander et al., 2009), and many participants expressed distress regarding their perceived career failures. Given the high cost to the economy in terms of lost productivity (NICE, 2012) and the high cost to individuals in terms of isolation and negative self-appraisal, greater availability and use of specialist supported employment programmes seems of crucial importance.

Recommendations for Future Research

This is the second qualitative study to document high levels of social isolation, loneliness and a desire for interpersonal connection in adults with autism (Müller et al., 2008). Due to time constraints, theoretical sampling and member checking could not be conducted to confirm and further explore these findings for participants. Future research should seek to further explore loneliness in this population, with particular reference to potential morbidity and mortality effects, the degree to which social network size predicts loneliness, and possible protective factors (e.g., having one confiding relationship, meaningfulness of special interests).

The present study has described the importance of membership of autism support and social groups for older people with autism. Informational support and the element of universality of experience appeared crucial for participants, but this occurred in the context of profound isolation and loneliness for many. Given the social difficulties inherent in autism, participants' commitment to support groups was

perhaps surprising. Future research should seek to qualitatively and quantitatively explore what, if anything, these groups provide over and above social contact.

The finding that consciousness of difference did not occur until late adolescence or adulthood for some participants is of some theoretical interest. Frith and Happé (1999) have previously proposed autism might be characterised by reduced introspective awareness, and just as individuals with autism arrive at explicit theory of (other) mind via a slow, laborious process, so too they may arrive at theory of (own) mind, or self-consciousness. It is possible that capacity for in-depth conscious reflection based on their emotional experiences, such as the distress associated with experiences of being bullied, occurs later for individuals with autism. This line of inquiry is worthy of further exploration, particularly as later development of introspective awareness likely means that conceptualisations of differentness are delayed, along with any consideration of options that might help alleviate social difficulties.

Conclusions

The quantitative and qualitative findings of this study illuminate the anxiety, loneliness and longing for interpersonal connection that seem to characterise navigating a life with autism. Prior to diagnosis the only explanation for difficulties available to participants was one of intrinsic differentness, and the findings reported here emphasise the helpfulness of diagnosis in terms of reappraising this difference, along with painful past experiences. Diagnosis allowed individuals to separate autism from their sense of self, and they sought to use their newfound knowledge of autism to improve social performance. Membership of autism-specific groups was highly valued, characterised by a sense of belonging, shared experience and acceptance.

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Part 3: Critical Appraisal

Critical Appraisal

This appraisal focuses on the main issues which arose during the research. Firstly, I will describe the way in which my assumptions may have affected the research process, followed by an account of how these assumptions evolved over the course of data collection. I will then describe particular difficulties with respect to the interviews, my responses to some aspects of data collection and some personal reflections on the research findings.

Initial Personal Assumptions

I came to this project with a number of assumptions which may have may have influenced the research project from genesis to completion. My assumptions may well have attracted me to the research topic to begin with, informed the choice of methodology, how the interviews were conducted and how long was devoted to particular aspects of experience, and the generation of themes. It is acknowledged that researchers have assumptions that reflect their experiences, values and beliefs, and that these will inevitably influence their work (Preissle, 2008). Through acknowledging these assumptions, as in the Subjectivity Statement (Preissle, 2008) in the empirical paper, attempts to 'bracket' these assumptions (Barker, Pistrang, & Elliott, 2002) and striving to be transparent throughout, I hope that I have produced a richly contextualised account of the lived experiences of older people with autism. It is entirely possible that another researcher might have approached the study with different assumptions and produced alternative but equally valid findings. In the sections that follow, I will firstly describe the background to my assumptions before considering how they evolved over the course of the research.

Benefits of social connection.

The first assumption that I brought to this research was that social involvement is an entirely good thing and that to be without means to necessarily suffer. This assumption was likely informed by a variety of factors: my background, in that I am from a village in southwest Ireland with a strong sense of community and focus on inclusiveness, elements which I've internalised as important; my own positive experiences of social involvement; and my clinical psychology training, in which social relationships and support are viewed as fundamental to emotional wellbeing.

Diagnosis as helpful.

Secondly, I came to this study with a belief in the helpfulness of diagnosis. While I am aware of the potential pitfalls of diagnosis, including the possibility of activating self-stigma and stigmatising reactions from family, friends and professional networks, I believed that in the case of a lifelong neurodevelopmental disorder the explanatory power of diagnosis would be largely beneficial. Despite substantial heterogeneity in autism presentations between individuals, my assumption was that a diagnostic label would facilitate greater understanding of interpersonal difficulties, both for individuals with autism and also for their social networks. The diagnostic label would enable those close to the individual to explain away unusual social behaviour, serving to reduce conflictual interaction and facilitate greater inclusion.

Outcomes as context-dependent.

Thirdly, from clinical work with people with autism both here and in Ireland, as well as prior research experience with families of children with autism, I think I may have approached this research study with a pessimistic view of outcomes for adults on the

spectrum. Although over the course of clinical work I have met adults with autism who were functioning well in their lives, I tended to attribute this to contextual factors such as having found the 'right' partner and the 'right' job (e.g., requiring substantial attention to detail, limited emphasis on teamwork and ideally a focus on an individual's special interest).

Changes to Assumptions as the Research Progressed

Some of my assumptions, described above, evolved over the course of the research as a result of meeting older people with autism. The changes to my assumptions are considered in detail below.

Benefits of social connection.

With respect to my first assumption, that of social connection being inherently good, I believe that this study largely confirmed for me the importance of social connection throughout the lifespan. Prior to beginning the study, however, I had given little consideration to the idea that time spent alone could be intrinsically positively experienced. Despite considerable isolation and loneliness, participants reported valuing opportunities to pursue special interests, affording experiences of safety, mastery and achievement, and serving to reduce anxiety levels:

> *I feel valued. I get on with things. I mean, I'm very good with my hands. I'm good at metal work, woodwork, leather craft, plastics. Not so much cobblering. Watches. Clocks. Gramophone motors I can repair 'cause I like technology, albeit somewhat old-fashioned technology. That's all the things I've done in the past. I did wiring. Practical electrics. Whatever. And I excel in those things. I absolutely excel. And I know my stuff.* (P4)

I find the word I've been thinking of lately, the way I regard life, is rather monochromatic. Lacking colour and magic. Outside of my fascination with music really; the kind of constant. (P13)

Time spent in pursuit of special interests was meaningful for participants, and the sense of safety and purpose it provided was in stark contrast to efforts to participate socially, which were often characterised by misunderstanding, anxiety and rejection.

Diagnosis as helpful.

With respect to the helpfulness of diagnosis, this assumption seemed to hold only for individuals with autism; it did not appear to influence understanding or support from their families or wider social networks. This was surprising, as I had assumed that once symptoms such as unusual social behaviour could be explained away as autism-related, interactions between the individual with autism and others would improve. I also had an idea that most people would approach diagnosis from a confirmation-seeking standpoint, whereby formal diagnosis would be preceded by self-diagnosis. In fact, this was true for only a small minority of participants. Most approached diagnosis from a position of vague curiosity, which meant that prior to diagnosis they had not given any real consideration to the diagnostic label and how it might apply to their particular life story. It was therefore for these individuals that formal diagnosis seemed particularly helpful, offering a truly new framework in which to understand prior difficulties. There was, however, a sense of lost opportunity in some participants' accounts of their diagnoses, with the sense that the diagnosis might have been of greater use earlier in life:

Well, I mean, if I had a diagnosis say as a teenager, well, they might have been - might have been able to put me in the right direction. It might have made life,

that - just that bit easier. It might have done. I'm not saying it would have done

but it might have done. (P7)

Only one participant appeared to find diagnosis a negative experience: *I was trying to*

turn off that emotion of just being completely shocked and disappointed in myself, I

suppose. (P2). This served as a substantial challenge to my assumption regarding

diagnostic helpfulness. In this instance diagnosis had been just one year old and

occurred in the context of no prior self-consideration of autism and a very limited

social network. It is therefore possible that the label might yet be perceived as useful,

but contextual factors at the time of seeking and obtaining diagnosis did not support

positive adjustment.

Outcomes as context-dependent.

My third assumption related to a negative view of likely outcomes for individuals with

autism. This was largely borne out by the research findings, with most participants

reporting isolation, loneliness and anxiety. A minority had jobs either currently or prior

to turning 65, and just three were in long-term relationships. I was surprised that

loneliness and anxiety seemed to apply to those who had partners just as it did to those

who were more isolated, however. It might be that participants with a long-

term/marital partner were less emotionally lonely, but that this occurred in the context

of considerable social loneliness. Emotional loneliness refers to the lack of an intimate

attachment while social loneliness is the lack of a wider social network, which

typically fosters a sense of belonging and companionship (Dykstra, 2009; Weiss,

1973).

It therefore seems that one close relationship was insufficient to compensate

for an otherwise very limited social network. It is also possible that sustaining that one

close relationship was challenging in and of itself, or that existing social participation was hard won and demanding of continued effort and upkeep. One participant, P11, who was married with children, self-employed and enjoyed his job, described building and maintaining relationships as a lifelong struggle:

I think it's the most difficult part for me. Of life. Even though there are certain things, other things that seem very difficult as well, the relationship side is the most difficult and the most unpredictable.

He compared his difficulty pursuing and sustaining relationships to the apparent ease and spontaneity with which 'neurotypicals' navigated the social world:

One of the things that I envy a bit in the neurotypical life - I don't envy a lot of the things in it at all - but that's one of the things I envy. It's that sort of relaxed, easy-going attitude to it.

It might be that irrespective of the presence or absence of one close relationship, for individuals with autism social participation is simply characterised by effort. The lack of predictability inherent in interaction means that attempts to participate socially are inevitably anxiety-laden, with social involvement something that must be deliberately worked on and maintained rather than something that might be enjoyed in the moment.

Difficulties with the Interview Process

Interviewing individuals with social difficulties was not without its challenges. These included an occasional focus on restricted topics of special interest, challenges associated with interviewing participants with less reflective ability, and the limitations of the interview schedule. These are discussed further in the sections that follow.

Special interests.

The first issue pertains directly to autism. During some interviews it was very difficult to redirect participants to the interview from lengthy descriptions of special interests or very detailed accounts of particular experiences. Attempts to interrupt this flow of information were usually futile, and often I found myself just accepting that the description would continue through to its natural conclusion. I usually felt bored and very frustrated during these moments, both with the participant and with the prospect of having to later invest considerable time transcribing lengthy accounts of matters irrelevant to my research topic. The following marks the beginning of a long account by P4 on the changing system of vehicle registration in Britain:

> *'Cause when you've got used to a particular system... And I was used to at least six of the previous systems until now. Now registration marks on motor vehicles now have the five-one system now. In Britain anyway. You had a similar system in Ireland not so long ago, I think. '87 they started doing the '87, D for Dublin; the '87, then the letter for where it came from, all that. Right, that was one thing. But what happened in this country is that they went from numbers to letters as serials.*

My frustration during such accounts likely compromised my ability to remain receptive and reflective. During transcription I noticed that I sometimes seemed to rush through the interview questions that followed participants' accounts of special interests, or failed to ask follow-up questions regarding potentially informative aspects of experience. This suggests that my frustration with the amount of time that had been devoted to these topics impacted on my ability to attend fully to participants' subsequent accounts of matters directly relevant to the research.

Reflective ability.

In addition to the difficulties around managing the time devoted to special interests or overly detailed accounts of specific experiences, a minority of participants seemed to struggle to reflect on their experiences, or perhaps the questions I asked failed to adequately access the level of reflection I sought. This apparent difficultly reflecting on past experiences can be seen in the following excerpt, where a participant is talking about his realisation that he was different based on difficulties at work and the involvement of a social worker and welfare officer:

Researcher	And then how come the social worker or the welfare office got involved?
P3	That I'm not too sure. It's just so, um, so involved, you know.
Researcher	It's a long time ago.
P3	So much so, you're kind of like, unless, yeah… I had some more information. I can't really mention it in the book. 'Cause writing a book, you have – you've got to elaborate.
Researcher	Ok.
P3	And the book's got to be clear.
Researcher	Mm.
P3	It's got to flow.
Researcher	Mm.
P3	Well, to a point anyway. 'Cause, um, I think most people who write books have to have it edited, or – not edited but, you know, knocked into shape.
Researcher	Ok. I'm just going to bring you back to the end of school and when you were doing the tailoring job…

The above excerpt is an example of the tendency of a minority of participants to respond vaguely or tangentially to some questions, sometimes bringing conversation back to a topic with which they were more comfortable or which interested them to a greater degree, P3's autobiography in this case. At the transcribing stage it became clear to me that this style of response elicited in me a tendency to ask more closed or multiple-choice style questions, with me doing most of the conversational pedalling. This served to keep the interview broadly on-topic but the information obtained possibly reflects my interests and assumptions more than it reflects the participants' own views of their lives. This strategy may also have impacted on the quality and nuance of the data collected for these participants. As a consequence, the views of less reflective individuals were possibly underrepresented following analysis.

Based on the above excerpt, it might also be that P3 did not understand my question or did not want to acknowledge that he did not know the answer. Or perhaps he knew the answer but was unable to articulate it. Booth and Booth (1996) describe the challenges of interviewing participants who struggle to communicate articulately. They state that while this may originate in restricted language skills it may be overlaid by other factors, such as self-esteem, learned compliance, loneliness and experiences of oppression (Booth & Booth, 1996). As data collection progressed, I began to allow extra time prior to beginning an interview to chat informally to participants. This seemed to demonstrate to participants that I was keenly interested in their perspectives and possibly helped reduce their anxiety during the interview itself. It also usually allowed for some brief informal discussion of special interests or recent specific events. This likely validated the importance of these subjects for participants but helped ensure that they did not come to dominate the recorded interview.

Limitations of the interview schedule.

The semi-structured interview schedule was designed to facilitate discussion of experiences leading up to and following diagnosis, perceptions of others regarding the diagnosis, transitions typical of older age (retirement, deteriorating health, loss and bereavement) and worries and hopes for the future. The interview schedule did not seem to work particularly well with respect to older age transitions and considering the future. Regarding the former, the transition-related aspects of the interview were added following consultation with an older person with autism. In hindsight, while such transition-related topics made intuitive sense, it is likely that they were of particular concern to that individual at that particular time in his life (contemplating retirement, recently returned from a stay in hospital characterised by lack of understanding and struggling with hospital routine). They therefore reflected his experience specifically more so than the concerns of older people with autism generally, given that most did not have jobs and few reported worrying about health.

Future-oriented questions also seemed challenging for participants. Some participants seemed to consider the future with a general sense of resignation but appeared to have difficulty accessing specific concerns or hopes:

No, frankly, I haven't really got hopes for the future. I can't say there's much I can do now. (P8)

I don't feel anything. It's just... You just breathe, you just eat, you shop, and... [Sighs] (P9)

When I was very young I had aspirations of being a writer and all sorts but it never happened. And as I got older I sort of accepted things as they were, just, sort of. (P7)

The difficulty with accessing specific future-related content might be the result of genuine acceptance, resignation and a sense of powerlessness over the future, or it may exemplify the suggested impairment in episodic future thinking in individuals with high-functioning autism (Lind & Bowler, 2010). Following discussion of this observation with research supervisors, more concretely-framed questions were subsequently used (e.g., specifying a future age and considering how things might be the same or different). Regardless, responses to future-oriented questions largely remained vague and overgeneral.

Personal Reflections

With respect to my personal reactions to the interview process, I found interviewing frequently frustrating and sometimes distressing, emotional responses which are likely to have compromised my ability to remain reflective. These topics are considered in greater detail below.

Social isolation.

As discussed above, at the commencement of this research study I had a number of assumptions. While at an intellectual level I had assumed that older people with autism might tend to be more socially isolated, I was perhaps unprepared for the extent of this and for its emotional impact. Some participants reported occasional phone contact with family members, with face-to-face interaction limited to professional networks, such as GPs and support workers. One man's closest relationship was with his support worker, who visited fortnightly:

> *Comes round every two weeks. And 'cause he's a writer, we tend to talk. He's*
> *more of a jazz fan than I am. We talk about literature quite a lot. And the*

hurdles we face in trying to write different material. So that's quite nice.

'Cause it gives me a... Obviously we talk about things like setting up these

meetings with GPs and this clinic and whatever. But a lot of the time we - I

suppose if he wasn't working in that capacity, I'd regard him as a friend. But

at the same time I'm aware there are certain boundaries that you can't really

cross over. (P13)

While it is important to note that relationships with support workers were perceived as very supportive and were highly valued by individuals in this study, I often found participants' reports of their lack of family or friendship networks and consequent dependence on professional networks quite bleak. This resulted in occasional feelings of hopelessness regarding society generally and particularly the consequences of a highly individualised society for individuals with existing disability.

Poverty and getting older.

Given the high levels of unemployment in this sample, some participants lived in very impoverished circumstances. One woman I visited lived in an extremely bare council flat, with little furniture beyond a mattress and a small table. She described her sense of her status in society as follows:

Well, I suppose it's chronic poverty and at the moment it's the bedroom tax.

And I think it's, you know, the – in, like, in America, 'no country for old men'

– it's the worst time to be depressed, to not be a social achiever. Not to be Type

A; a Type A person. So I think we live in very aggressive, go-getting times. And

I feel very much now the underclass. And I was told by the speech therapist

that the Asperger's people in the borough of [borough name], they are mostly

unemployed and long-term unemployed and depressed. Because they are

isolated and economically... It's like economic apartheid. (P2)

During interviews such as this, I often felt angry and quite hopeless about the state of society. It also caused me to question the usefulness of the notion of 'successful ageing'. Successful ageing, according to Rowe and Kahn's (1997) framework, involves low probability of disease and disability, sustaining a high degree of physical and cognitive functioning, and meaningful engagement in life. The present sample, by definition socially impaired, reported chronic mental health problems, isolation, and difficulties with employment and relationships, thereby failing to 'meaningfully engage'. There is clearly no place for individuals with existing disability in this narrow, exclusionary conceptualisation of ageing, and instead this framework appears to speak only to the experiences of privileged groups (Dillaway & Byrnes, 2009). Furthermore, given that ageing is fundamentally a dynamic, contextual process, dependant on the current and past conditions of people's lives, this framework is inherently problematic in that it focuses the locus of responsibility to successfully age upon the individual (Dillaway & Byrnes, 2009). In turn, this suggests that those who fail to achieve this gold standard of ageing do so due to an apparent lack of effort, serving to reduce the onus on society to provide supports when people are economically or socially dependent, and to diminish the state's duty to reduce social and structural inequalities (Dillaway & Byrnes, 2009; Martinson & Berridge, 2015). With social justice in mind, this framework cannot be said to account for the lived experiences of older people with autism or to serve their needs in the present sociopolitical climate, suggesting the need for a new and broader discourse on ageing.

Autism as an invisible disability.

In contrast to the lack of reflection described above, many of the individuals interviewed had excellent verbalisation abilities and most had adequate eye-contact. At times, I noticed myself forgetting that a participant had autism, perhaps until they described a recent social situation characterised by misunderstanding. One woman, who had largely excellent verbalisation skills and maintained good eye-contact throughout the interview, described a recent attempt to compliment an overweight stranger on her swimming ability:

> *I said, 'You remind me of a whale.' But I didn't mean a whale. I meant a dolphin. And she was a very good swimmer. And she called me thick. But I didn't mean to say that to her, like, I meant to be friends with her and nice to her. But she thought I was being rude to her.* (P12)

At moments like this I was reminded of the specific perils of a non-obvious disability. In addition to subjective social difficulties, including misunderstanding social rules and implicit meanings, individuals with autism also have to contend with difficulties arising from others' perceptions of their social mistakes, possibly resulting in experiences of being misunderstood, bullied and ostracised (Portway & Johnson, 2005). Most people with whom an individual with autism informally interacts are unlikely to be cognisant of the problems arising from autism. This means that unusual behaviour cannot be explained away, likely leading to poor social judgements and reducing the likelihood of further engagement with the individual. The theme of difference reported in Part 2 might be the result of a complex interplay between self-perception and the negative perceptions of others based on unusual social behaviour. This has implications throughout the lifespan, from unhappy experiences of schooling

and bullying by peers during adolescence to occupational underachievement in adulthood.

Reflections on Research Findings

I thought the importance of access to other people with autism was one of the more surprising findings, given the social impairments that define the disorder. Qualitative approaches would have much to contribute in terms of identifying the factors that autism groups provide that individuals' usual social networks do not. Given the level of isolation experienced, it might just be that social groups provide social contact that is otherwise in very short supply in their lives, and provide it in a form that is most palatable to individuals with autism, i.e., structured, planned, with definite start and end points. It seemed more than this, however, whereby interactions with other people with autism did not have the performance quality that characterised interaction with 'neurotypicals'. The suggestion that focusing on something tangible (e.g., a book) facilitated social interaction and cohesion by reducing overt focus on social performance was also surprising. Qualitative approaches would be helpful in isolating additional facilitators of social interaction in autism groups, which would have relevance for the implementation of groups in clinical and third sector settings.

The helpfulness of diagnosis with respect to reconsidering difficult past experiences and facilitating an externalisation of responsibility for such experiences was striking. It is hard not to imagine that earlier diagnosis might have been more helpful in terms of facilitating self-understanding earlier in life and perhaps accessing specialist support, particularly with respect to finding suitable employment. Some participants were already retired at the time of diagnosis, which meant that any

opportunities to better understand or manage difficult aspects of their pre-retirement jobs or to find suitable employment that capitalised on their strengths were lost.

Beyond employment, the finding that autism was perceived as external to the self was interesting in terms of post-diagnostic adjustment and incorporating the diagnosis into an individual's sense of identity. This is worthy of further exploration, and an in-depth longitudinal case-study approach to post-diagnosis adjustment and identity change would be very informative in this regard.

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Appendix A:

Adapted Newcastle-Ottawa Scale

Adapted Newcastle-Ottawa Scale for Cross-Sectional Studies

Selection: (Maximum 5 stars)

1) Representativeness of the sample:
   a) Truly representative of the average in the target population. * (all subjects or random sampling)
   b) Somewhat representative of the average in the target population. * (non-random sampling)
   c) Selected group of users.
   d) No description of the sampling strategy.

2) Sample size:
   a) Justified and satisfactory. *
   b) Not justified.

3) Non-respondents:
   a) Comparability between respondents and non-respondents characteristics is established, and the response rate is satisfactory. *
   b) The response rate is unsatisfactory, or the comparability between respondents and non-respondents is unsatisfactory.
   c) No description of the response rate or the characteristics of the responders and the non-responders.

4) Ascertainment of the exposure (risk factor):
   a) Validated measurement tool. **
   b) Non-validated measurement tool, but the tool is available or described.*
   c) No description of the measurement tool.

Comparability: (Maximum 2 stars)

1) The subjects in different outcome groups are comparable, based on the study design or analysis. Confounding factors are controlled.
   a) The study controls for the most important factor (VIQ/FSIQ). *
   b) The study control for any additional factor. * (e.g., age)

Outcome: (Maximum 3 stars)

1) Assessment of the outcome:
   a) Validated measurement tool. **
   b) Non-validated measurement tool, but the tool is available or described.*
   c) No description of the measurement tool.

2) Statistical test:
   a) The statistical test used to analyze the data is clearly described and appropriate, and the measurement of the association is presented, including confidence intervals and the probability level (p value). *
   b) The statistical test is not appropriate, not described or incomplete.

Note:

This scale has been adapted from the Newcastle-Ottawa Quality Assessment Scale for cohort studies to perform a quality assessment of cross-sectional studies for the systematic review, 'What is the nature of autobiographical memory in autism? A Systematic Review.'

Assessment of the outcome: Two stars awarded when autobiographical memory transcripts were rated by two researchers blind to autism/control condition.

Appendix B:

Letter to participants
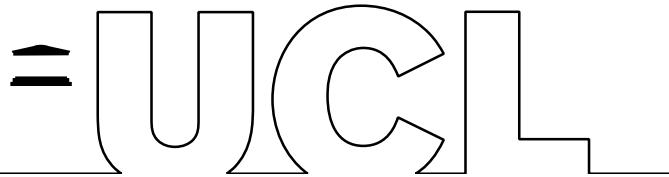
≙UCL

**Research Dept. of Clinical,
Educational and Health
Psychology**
1-19 Torrington Place
University College London
Gower Street
London WC1E 6BT
12 September 2014

[Name]
[Address]

Dear Mr/Ms [Surname],

We are contacting you as you were diagnosed as having Asperger's syndrome in the [NHS service name] Diagnostic Service and at the time consented to having your name kept on a research register. We are doing some research on growing older with ASD (study ref: 5446/001, approved by UCL Research Ethics Committee) and we are looking for volunteers with diagnosed autism spectrum conditions aged over 50 years to participate in one interview about your experiences of growing older with the diagnosis and to complete some rating scales and assessments of cognitive function (your thinking, reasoning and memory abilities). Participation will be treated confidentially. If you would like any further information or you would like to volunteer, please contact me directly (details enclosed). You will be reimbursed £20 for your time. Please find enclosed an information sheet, which contains further information regarding the study.

Yours sincerely,

Aoife Hickey
Trainee Clinical Psychologist

Appendix C:

Statement of ethical approval

UCL RESEARCH ETHICS COMMITTEE
GRADUATE SCHOOL OFFICE
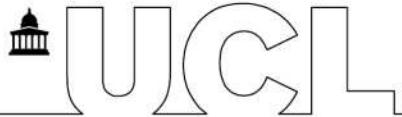
Dr Joshua Scott
Research Department of Clinical, Educational and Health Psychology
UCL

24th March 2014

Dear Dr Scott

<u>**Notification of Ethical Approval**</u>
<u>**Project ID: 5446/001: An exploratory study of growing older with autism**</u>

In my capacity as Chair of the UCL Research Ethics Committee (REC) I am pleased to confirm that your study has been approved by the UCL REC for the duration of the project i.e. until June 2015.

Approval is subject to the following conditions:

1. You must seek Chair's approval for proposed amendments 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'.

The form identified above can be accessed by logging on to the ethics website homepage: http://www.grad.ucl.ac.uk/ethics/ and clicking on the button marked 'Key Responsibilities of the Researcher Following Approval'.

2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. Both non-serious and serious adverse events must be reported.

    Reporting Non-Serious Adverse Events
    For non-serious adverse events you will need to inform Helen Dougal, Ethics Committee Administrator (ethics@ucl.ac.uk), within ten days of an adverse 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 of the Ethics Committee 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.

    Reporting Serious Adverse Events
    The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator 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. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.

On completion of the research you must submit a brief report (a maximum of two sides of A4) of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

With best wishes for your research.

Yours sincerely
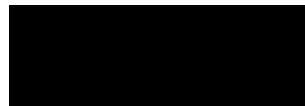
Professor John Foreman
Chair of the UCL Research Ethics Committee

Cc:
Dr Jason Crabtree & Aoife Hickey, Applicants
Professor Pasco Fearon, Head of Department

Appendix D:

Information sheet

≃UCL
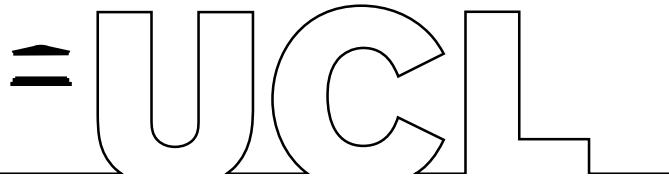
**Information Sheet for Older People (over 50 years) with an
Autism Spectrum Disorder (ASD)**

Title of Study: Exploratory Study of Growing Older with ASD

Researcher	Aoife Hickey	a.hickey.12@ucl.ac.uk
		Tel. [mobile number]
Research Supervisors	Dr Joshua Stott	j.stott@ucl.ac.uk
		Tel. 0207 679 5950
	Dr Jason Crabtree	j.crabtree@ucl.ac.uk
		Tel. 0207 679 5950
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 Aoife 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 [mobile number] or **a.hickey.12@ucl.ac.uk**.

What is this study about?
The aim of this study is to explore what it is like to grow older with an ASD (i.e. high-functioning autism, Asperger's syndrome or PDD-NOS). In particular, we want to understand how people cope with ASD, how ASD impacts on mental health, experiences of loneliness and isolation, and how people manage the changes that happen in older age.

Why is this study being done?
The goal of this study is to understand the experience of growing older with ASD. Although a lot of research has been done with younger people with ASD, very little research has looked at what it is like to grow older with the diagnosis. If we know more about the experience of growing older with ASD, then we may be able to help people with ASD do well in their old age and cope better with difficulties related to ageing.

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. We will spend some time talking about your experiences of getting an ASD diagnosis, what this has meant for you and the people close to you, how you cope with your ASD symptoms and manage the changes that occur as people get older. This conversation will be taped using a digital recorder. You will also be asked to complete some questionnaires about your ASD symptoms and mental health, 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 or the tape of your interview. 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 be asked to participate in one interview with us, which will focus on you, your ASD and getting older. We would like to ask you some questions about how you deal with your ASD, what your ASD has been like over time, whether you experience

any mental health difficulties (e.g., depression, anxiety) or loneliness, and how you manage the changes that happen in older age (e.g., retirement, loss of parents, deteriorating health). This interview will be recorded and it will be transcribed later. You will also be asked to complete some short questionnaires about your ASD and mental health. Finally, you will also 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, the study does involve talking about disability, mental health and older age, which might be upsetting for some people. If you become distressed during the interview, we can take as many breaks as you need or we stop the interview or 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 what it is like to grow older with ASD. Although there will be no immediate benefit for the participants taking part in this study, we hope that their 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 up until the interview has been transcribed (around one month from now). 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 in the average results of questionnaires and tests, not in the scores of any individual participant. Similarly, we are interested in themes across many participants' accounts of growing older with ASD, rather than one individual participant's interview.

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 [mobile number] or by email at **a.hickey.12@ucl.ac.uk** 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 E:

Consent form
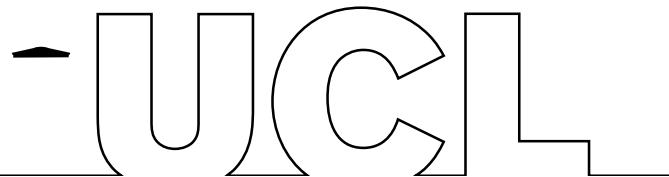
Consent Form for Older People (over 50 years) with an ASD Spectrum Disorder

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, until such time as the taped interview is transcribed (around one month from now).

☐ 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 my participation will be recorded using a digital audio recorder and I consent to use of this material as part of the project.

☐ 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 of the results. Confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications.

☐ I understand that I am being paid for my assistance in this research and that some of my personal details will be passed to UCL Finance for administration purposes.

☐ 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 F:

Debriefing form
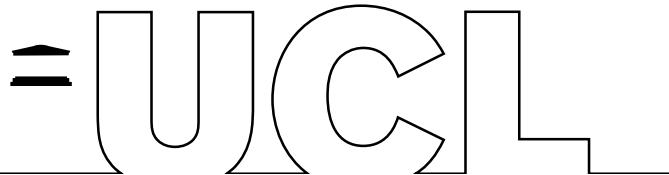
Debriefing From

This study is concerned with exploring what it is like to grow older with an ASD (e.g., high-functioning autism, Asperger's syndrome or PDD-NOS). In particular, we want to understand how people cope with ASD, how ASD impacts on mental health, experiences of loneliness and isolation, and how people manage the changes that happen in older age.

How was this investigated?
In this study, you were asked to participate in one recorded interview, which focused on you, your ASD and getting older. You also completed some short questionnaires about your ASD and mental health. Finally, we did some assessments of your memory and general cognitive functioning, which includes thinking and reasoning abilities.

Why is it important to study growing older with ASD?
Although a lot of research has been done with younger people with ASD, very little research has looked at what it is like to grow older with the diagnosis. If we know more about the experience of growing older with ASD, then we may be able to help people with ASD do well in their old age and cope better with difficulties related to ageing.

What if I want to know more?
If you would like to know more about growing older with ASD, the National Autistic Society have some information on their website:

http://www.autism.org.uk/gettingon

http://www.autism.org.uk/ageing

They also have a confidential helpline: 0808 800 4104. Lines are open 10am-4pm, Monday to Friday, and calls are free from landlines and most mobiles.

If you feel distressed about anything we talked about today, please speak with your GP.

If you would like any further information on this research, please contact me or my research supervisors (contact details below).

Researcher	Aoife Hickey	a.hickey.12@ucl.ac.uk **Tel.** [mobile number]
Research Supervisors	Dr Joshua Stott	j.stott@ucl.ac.uk **Tel.** 0207 679 5950
	Dr Jason Crabtree	j.crabtree@ucl.ac.uk **Tel.** 0207 679 5950
Address	Research Dept. of Clinical, Educational and Health Psychology 1-19 Torrington Place, University College London Gower Street, London WC1E 6BT	

Thank you again for your participation

Appendix G:

Demographic questions

Demographic Questions

Date of birth:

Age in years:

Gender: Male

Female

Ethnicity:

Country of birth:

Diagnosis:

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 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 highest status occupation?

Partner's current/most recent occupation:

Partner's highest status occupation:

Current household income:

Native language:

Number of siblings:

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

Appendix H:

Autism-Spectrum Quotient

The Adult Autism Spectrum Quotient (AQ)

Ages 16+

Name:.. Sex:...

Date of birth:................................. Today's Date................................

How to fill out the questionnaire

Below are a list of statements. Please read each statement <u>very carefully</u> and rate how strongly you agree or disagree with it by circling your answer.

DO NOT MISS ANY STATEMENT OUT.

Examples

E1. I am willing to take risks.	definitely agree	slightly agree	(slightly disagree)	definitely disagree
E2. I like playing board games.	definitely agree	(slightly agree)	slightly disagree	definitely disagree
E3. I find learning to play musical instruments easy.	definitely agree	slightly agree	slightly disagree	(definitely disagree)
E4. I am fascinated by other cultures.	(definitely agree)	slightly agree	slightly disagree	definitely disagree

1. I prefer to do things with others rather than on my own.	definitely agree	slightly agree	slightly disagree	definitely disagree
2. I prefer to do things the same way over and over again.	definitely agree	slightly agree	slightly disagree	definitely disagree
3. If I try to imagine something, I find it very easy to create a picture in my mind.	definitely agree	slightly agree	slightly disagree	definitely disagree
4. I frequently get so strongly absorbed in one thing that I lose sight of other things.	definitely agree	slightly agree	slightly disagree	definitely disagree
5. I often notice small sounds when others do not.	definitely agree	slightly agree	slightly disagree	definitely disagree
6. I usually notice car number plates or similar strings of information.	definitely agree	slightly agree	slightly disagree	definitely disagree
7. Other people frequently tell me that what I've said is impolite, even though I think it is polite.	definitely agree	slightly agree	slightly disagree	definitely disagree
8. When I'm reading a story, I can easily imagine what the characters might look like.	definitely agree	slightly agree	slightly disagree	definitely disagree
9. I am fascinated by dates.	definitely agree	slightly agree	slightly disagree	definitely disagree
10. In a social group, I can easily keep track of several different people's conversations.	definitely agree	slightly agree	slightly disagree	definitely disagree
11. I find social situations easy.	definitely agree	slightly agree	slightly disagree	definitely disagree
12. I tend to notice details that others do not.	definitely agree	slightly agree	slightly disagree	definitely disagree
13. I would rather go to a library than a party.	definitely agree	slightly agree	slightly disagree	definitely disagree
14. I find making up stories easy.	definitely agree	slightly agree	slightly disagree	definitely disagree
15. I find myself drawn more strongly to people than to things.	definitely agree	slightly agree	slightly disagree	definitely disagree
16. I tend to have very strong interests which I get upset about if I can't pursue.	definitely agree	slightly agree	slightly disagree	definitely disagree
17. I enjoy social chit-chat.	definitely agree	slightly agree	slightly disagree	definitely disagree
18. When I talk, it isn't always easy for others to get a word in edgeways.	definitely agree	slightly agree	slightly disagree	definitely disagree
19. I am fascinated by numbers.	definitely agree	slightly agree	slightly disagree	definitely disagree

20. When I'm reading a story, I find it difficult to work out the characters' intentions.	definitely agree	slightly agree	slightly disagree	definitely disagree
21. I don't particularly enjoy reading fiction.	definitely agree	slightly agree	slightly disagree	definitely disagree
22. I find it hard to make new friends.	definitely agree	slightly agree	slightly disagree	definitely disagree
23. I notice patterns in things all the time.	definitely agree	slightly agree	slightly disagree	definitely disagree
24. I would rather go to the theatre than a museum.	definitely agree	slightly agree	slightly disagree	definitely disagree
25. It does not upset me if my daily routine is disturbed.	definitely agree	slightly agree	slightly disagree	definitely disagree
26. I frequently find that I don't know how to keep a conversation going.	definitely agree	slightly agree	slightly disagree	definitely disagree
27. I find it easy to "read between the lines" when someone is talking to me.	definitely agree	slightly agree	slightly disagree	definitely disagree
28. I usually concentrate more on the whole picture, rather than the small details.	definitely agree	slightly agree	slightly disagree	definitely disagree
29. I am not very good at remembering phone numbers.	definitely agree	slightly agree	slightly disagree	definitely disagree
30. I don't usually notice small changes in a situation, or a person's appearance.	definitely agree	slightly agree	slightly disagree	definitely disagree
31. I know how to tell if someone listening to me is getting bored.	definitely agree	slightly agree	slightly disagree	definitely disagree
32. I find it easy to do more than one thing at once.	definitely agree	slightly agree	slightly disagree	definitely disagree
33. When I talk on the phone, I'm not sure when it's my turn to speak.	definitely agree	slightly agree	slightly disagree	definitely disagree
34. I enjoy doing things spontaneously.	definitely agree	slightly agree	slightly disagree	definitely disagree
35. I am often the last to understand the point of a joke.	definitely agree	slightly agree	slightly disagree	definitely disagree
36. I find it easy to work out what someone is thinking or feeling just by looking at their face.	definitely agree	slightly agree	slightly disagree	definitely disagree
37. If there is an interruption, I can switch back to what I was doing very quickly.	definitely agree	slightly agree	slightly disagree	definitely disagree
38. I am good at social chit-chat.	definitely agree	slightly agree	slightly disagree	definitely disagree

39. People often tell me that I keep going on and on about the same thing.	definitely agree	slightly agree	slightly disagree	definitely disagree
40. When I was young, I used to enjoy playing games involving pretending with other children.	definitely agree	slightly agree	slightly disagree	definitely disagree
41. I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant, etc.).	definitely agree	slightly agree	slightly disagree	definitely disagree
42. I find it difficult to imagine what it would be like to be someone else.	definitely agree	slightly agree	slightly disagree	definitely disagree
43. I like to plan any activities I participate in carefully.	definitely agree	slightly agree	slightly disagree	definitely disagree
44. I enjoy social occasions.	definitely agree	slightly agree	slightly disagree	definitely disagree
45. I find it difficult to work out people's intentions.	definitely agree	slightly agree	slightly disagree	definitely disagree
46. New situations make me anxious.	definitely agree	slightly agree	slightly disagree	definitely disagree
47. I enjoy meeting new people.	definitely agree	slightly agree	slightly disagree	definitely disagree
48. I am a good diplomat.	definitely agree	slightly agree	slightly disagree	definitely disagree
49. I am not very good at remembering people's date of birth.	definitely agree	slightly agree	slightly disagree	definitely disagree
50. I find it very easy to play games with children that involve pretending.	definitely agree	slightly agree	slightly disagree	definitely disagree

Developed by:
The Autism Research Centre
University of Cambridge

Appendix I:

Hospital Anxiety and Depression Scale

Hospital Anxiety and Depression Scale (HADS)

Read each item and circle the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

I feel tense or 'wound up':	A
Most of the time	3
A lot of the time	2
Time to time, occasionally	1
Not at all	0

I feel as if I am slowed down:	D
Nearly all of the time	3
Very often	2
Sometimes	1
Not at all	0

I still enjoy the things I used to enjoy:	D
Definitely as much	0
Not quite so much	1
Only a little	2
Not at all	3

I get a sort of frightened feeling like 'butterflies in the stomach':	A
Not at all	0
Occasionally	1
Quite often	2
Very often	3

I get a sort of frightened feeling like something awful is about to happen:	A
Very definitely and quite badly	3
Yes, but not too badly	2
A little, but it doesn't worry me	1
Not at all	0

I have lost interest in my appearance:	D
Definitely	3
I don't take as much care as I should	2
I may not take quite as much care	1
I take just as much care as ever	0

I can laugh and see the funny side of things:	D
As much as I always could	0
Not quite so much now	1
Definitely not so much now	2
Not at all	3

I feel restless as if I have to be on the move:	A
Very much indeed	3
Quite a lot	2
Not very much	1
Not at all	0

Worrying thoughts go through my mind:	A
A great deal of the time	3
A lot of the time	2
From time to time but not too often	1
Only occasionally	0

I look forward with enjoyment to things:	D
A much as I ever did	0
Rather less than I used to	1
Definitely less than I used to	3
Hardly at all	2

I feel cheerful:	D
Not at all	3
Not often	2
Sometimes	1
Most of the time	0

I get sudden feelings of panic:	A
Very often indeed	3
Quite often	2
Not very often	1
Not at all	0

I can sit at ease and feel relaxed:	A
Definitely	0
Usually	1
Not often	2
Not at all	3

I can enjoy a good book or radio or TV programme:	D
Often	0
Sometimes	1
Not often	2
Very seldom	3

Scoring:
Total score: Depression (D) _____ Anxiety (A) _____
0-7 = Normal
8-10 = Borderline abnormal (borderline case)
11-21 = Abnormal (case)

Questions relating to anxiety are indicated by an 'A' while those relating to depression are shown by a 'D'. Scores of 0-7 in respective subscales are considered normal, with 8-10 borderline and 11 or over indicating clinical 'caseness'

Appendix J:

De Jong Gierveld Loneliness Scale

11-Item De Jong Gierveld Loneliness Scale

Please indicate for each of the statements the extent to which they apply to your situation, the way you feel now. Please circle the appropriate answer.

The following statement serves as an example: "There is actually no one with whom I would want to share my joy or sorrow." If you experience these feelings in exactly the same way, please circle the answer "yes!" as shown below.

1. There is always someone I can talk to about my day-to-day problems	yes!	yes	more or less	no	no!
2. I miss having a really close friend	yes!	yes	more or less	no	no!
3. I experience a general sense of emptiness	yes!	yes	more or less	no	no!
4. There are plenty of people I can rely on when I have problems.	yes!	yes	more or less	no	no!
5. I miss the pleasure of the company of others	yes!	yes	more or less	no	no!
6. I find my circle of friends and acquaintances too limited	yes!	yes	more or less	no	no!
7. There are many people I can trust completely	yes!	yes	more or less	no	no!
8. There are enough people I feel close to	yes!	yes	more or less	no	no!
9. I miss having people around	yes!	yes	more or less	no	no!
10. I often feel rejected	yes!	yes	more or less	no	no!
11. I can call on my friends	yes!	yes	more or less	no	no!

Appendix K:

Semi-structured interview schedule

Semi-structured Interview Schedule

Experience of diagnosis:

Where did you first hear about autism?
> When did you start to think that autism might apply to you? OR
> What made somebody else think that it might apply to you?
> What was it that made you/them think this?
> What prompted you to seek a diagnosis?

Did finding out that you had autism change how you saw/understood yourself?
> *Prompts:* explanation for symptoms, difficulties with social interaction, maintaining relationships

Did finding out that you had autism change how other people understood you?

Living with autism symptoms:

Would you say that your autism symptoms have changed over time?
> *Prompts:* restricted interests/behaviours, social interaction, communication

What kind of things do you do to help cope with autism symptoms?
> *Prompts:* information, use of online forums/support groups, restricting repetitive behaviour to particular contexts, managing social anxiety, attending more structured activities, etc.

Relationship and support needs:

To whom do you turn for support?
> *Prompts:* practical support, emotional support, information/advice

How would you describe the quality of your relationships with other people?
> *Prompts:* Family/friends/partner/other, satisfaction with relationships, specific challenges in relationships, strategies to manage challenges, changing nature of relationship difficulties over time, qualities of most significant relationship, frequency/nature of contact, someone to talk to about day-to-day things, someone to call on re specific problem, feeling close/connected/empty, etc.

Do you have times where you feel lonely or isolated?

What prompted you to seek information/support online OR at a community support/advocacy group?
> *Prompts:* Was there anything you found useful about meeting other people with autism?

Transitions and the future:

What transitions/changes are happening for you at the moment?
> *Prompts:* Retirement, loss of parents/family support, poor health

What are your hopes for the future?

What kind of advice would you give to somebody who has been recently diagnosed with autism?

Appendix L:

Initial codes and examples

Initial codes with brief description and examples

Initial codes	Code description	Examples from interview data
Applying autism now	Attempt to apply knowledge of autism to improve social skills dynamically or to catch a social mistake quickly after it happened. This included informing other people about the diagnosis so as to ease social difficulties.	And sometimes, yeah what's really shocking is that sometimes the - they are obvious - that many obvious things many people know, which I have only found out, I think the last, the last two years. And that's a bit shocking sometimes. And so in the sense, yeah, autism is also - it's also about not understanding social situations and sometimes it seems that I don't understand them at all. Although now I do. But the - it was quite shocking that there are many things which most people have known from - probably from their teenage years. That I only start to understand them now. And, but yes, especially how to relate to people and how to look to people. (P6) When I first got it I did feel like, oh, I should tell people - I should tell everybody. Now I'm thinking maybe I'll pick and choose who I tell. I'll tell people if I really need to. If I've got a problem with something and it's to do with my Asperger's clearly and there isn't another reason, then I need to let them know. (P5)
Autism groups	This code referred to the perceived benefits of attending autism-specific social groups. Informational component and universality of experience perceived as particularly important.	You have similar experiences or similar, you know, you've been through similar things or… I mean, even though we're all different and we've all got completely different, you know, you know, someone finds this difficult, that easy, and you could have a group of ten and we'd all find something different that's difficult and we'd all find something different that's easy. So we don't seem to match up at all. But somehow we all do match up. Because it's that somehow the nature of why, why we have the difficulty is the same, but it just manifests in different ways. (P11) It is the information. Yes. I really believe – 'cause I know it's neurological and to be told that we have a different type of brain and different type of neuro wiring and hormonally and now they know sensory - that became a big relief. (P2)
Autism success stories	Referred to both knowledge of positive aspects of autism (such as attention to detail, focus, and how these could potentially be beneficially applied) and knowledge of successful examples of people with autism (i.e. found partner and job, famous people with autism).	So, there are things like attention to detail, being able to be good at proof reading, good memory, I can't remember all the things in the list. Certainly in this job, understanding and having a good memory for planning law is very useful. (P1) 'Cause somebody might have autism and they may have managed to hold down a successful job, they've managed to find themselves a partner and have children and everything. (P7)
Autism symptoms	Referred to increase in 'meltdowns' reported in older age. Patterns (e.g., specific getting up routine) seen as useful, not problematic, but difficulty with change to pattern. Subjects of particular interest could change over time, but not intensity of interest.	'Cause with me, I get very cross occasionally when things don't go my way. Very, very cross. (P8) I don't like change generally. So I have a pattern for doing things. A rhythm for, yeah, everything has a rhythm, a time. And if that's changed, I do get thrown. (P9)
Difference	Realisation of difference from peers. Elements that seemed to come effortlessly to 'neurotypicals' were experienced as very challenging – attributed internally but vaguely. Efforts made to remedy outward difference.	Each and every – years, oh the years after, the decades after, I've noticed how different I am to other people. Mentally and emotionally and… Well, I say emotionally, perhaps more so mentally. And how I react to particular situations. Social situations mainly. (P4) And, but yeah, she also knew from the very start that I was, she met me just after she first started to meet my brother. She knew from the first that I was different. (P6)

Initial codes	Code description	Examples from interview data
Externalising	Difficult aspects of past experience (e.g., bullying) or pervious experiences of perceived failure (e.g., finding a job, making and sustaining friendships, finding a partner) attributed to autism as opposed to self following diagnosis.	I mean, I was in a bad situation before I got my job and my diagnosis. I was really at my wits end about my life and the state I was in. Not understanding why I was such a – I felt like a failure at everything. Felt like – see, that's another thing - that I always felt like I'd failed at everything and now I feel like as far as, like, somebody with Asperger's goes, I'm probably near to, you know, as good as it gets. In some ways, you know? I've managed to hold down a job, you know, I've got friends, you know. A friend, anyway. Yeah, so give me a whole different perspective on myself. (P5)
Getting older	Difficulties easing with passing of time; reduced stress, anxiety, emphasis on 'fitting in' or needing to achieve particular milestones.	You know, I have the issue ahead of me. Probably, I mean, I may suddenly die of a heart attack and I've solved the problem so to speak. But, you know I've been saying to the NAS and as part of their aging project, you know, I mean if somebody could have a book or a website or something with just experiences of a dozen Asperger people who've retired, or even, like me, carried on – well, I could look at those experiences; ok, yes, that was a good idea or I wouldn't think of doing that or, you know, whatever. (P1)
		I wanted to fit in so much. I mean, you, as you get older you haven't got that pressure to fit in as much. That's the bit, the best thing really about being a bit older. (P5)
		But my personal attitude towards myself and my predicaments as appropriate, such as they were, had changed so much. It was almost a case of, oh well, there you are. Sort of thing. Don't worry about it. (P4)
Interests	Interests still actively pursued, although not necessarily same interest throughout life. Time spent engaged in interests experienced as meaningful and served to reduce anxiety.	Sometimes I can, I can take my mind off the anxiety by keeping myself busy. Sometimes I quite like to do ironing or hand sewing as a way of just something a bit repetitive. (P5)
		P: I like to make things like the triffid. Things like that, other things. And all sorts of things like that. I like doing – making clothes, if I can. Or doing some knitting. R: And how does that help, Asperger's-wise? P: It takes my mind off of things that I usually worry about. 'Cause I worry a lot. (P12)
Invisibility	Having an invisible disability – not immediately obvious to others	And that's another thing that annoys me. Not just being autistic but being like that and any other ways that I am different, it's not immediately obvious. People totally misread me. (P4)
Isolation	Felt sense of isolation, loneliness. Some alone time valued, particularly for purpose of pursuing interests.	I'm not lonely when I'm by myself. It's not an issue, it's not a problem for me. I can be by myself quite a lot. And be very happy. I mean not permanently by myself, but I can spend quite a lot of time by myself. (P11)
		See, I never had many friends when I was younger. So I think in a way it's sort of prepared me for being on my own. Although I don't like it much, I've never liked it. (P12)
Learning social skills	Attempt to reduce visibility of outward difference. Observation of and learning from others, practiced and applied in social settings.	Communication skills, you don't learn 'em overnight. It takes years. And it comes with education, you know. (P3)
		I realised there was something wrong. What was happening was my intellect was developing and my emotional was developing but differently. Like different boxes. And I deliberately integrated them myself. 'Cause I realised this was a malfunction of some sort. (P10)
		So anyway. I mentioned this to somebody else, who says, 'Let me give you a tip. Don't get chatting to strangers, particularly older folk. They might have thought you were tapping them for money.' (P8)

Initial codes	Code description	Examples from interview data
Life review	Looking back on life in light of knowledge gained from diagnosis. Realisation that particular experiences that had not be previously understood could be attributed to autism.	Well, I was glad. It explained quite – it explained why I did very badly at school. And it explained also why I never mixed socially and the rest of it. (P8)
		It just, well, it just gave me a reason why I was having so many problems with relationships and employment. (P7)
Post diagnosis response	Diagnosis as important, facilitating life review, understanding social difficulties. Biological understanding useful.	But by this time, when this was diagnosed, I thought, oh, great, fine, fair enough, and I realistically recognised, as I was told at the time, that this is a condition that one is born with. And you have it from birth to grave, basically. I understood that. And I thought, fine. That's great. In so far as, I know I can't change it. So there's no point in making a song and dance about it and jumping up and down about it so I just said, ok, fine. Wonderful. At least I know, now know where I stand. I know something that I did not know in my younger life. (P4)
		Well, before I used to think that I'm just a useless, stupid person. Haven't got any brain or anything. And now I think because I've been speaking to [group facilitator] and other people, I have. I have got a brain, my own type of brain. My own things I like to do. Just because I'm – I do different things and like, you know, act differently maybe, and say different things in a different way, then it doesn't mean that I'm stupid and useless sort of thing. (P12)
Stigma	Noticing negative behavioural and communicative features of autism in others.	Well. Some of them can't even interact. 'Cause of lack of social skills. Lack of communication skills. I'm learning all the time. (P3)
		Sometimes there's a clash of ideas. I mean, a lot of - a lot of Aspies, so to speak, they have their pet things. I mean, I have my pet things but mine are factual. Not fictional. A lot of them are into sci-fi and all this bloody crap. (P4)
		A lot of autistic people I have found – my experience, not universal necessarily – are so up their own arses they don't see anything else. (P10)
Wanting social contact	Seeking out company of other people for connection, friendship, intimacy. Effortful process earlier in adulthood and prior to diagnosis; post-diagnosis facilitated by access to autism-specific groups.	I'd like to meet more people, I'd like to do… I'd like to get friendly with a lady, if I could. But I don't think my chances are very good. (P8)
		But it's the sort of things I'd…. It's about… One of the things that I envy a bit in the neurotypical life. I don't envy a lot of the things in it at all. But that's one of the things I envy. It's that sort of relaxed, easy-going attitude to it. Whereas for me it's a bit more difficult for me to deal with that. (P11)
		The summertime is worse for me than the winter. 'Cause it seems that more and more people are included in family and groups of friends or partners or whatever and it seems I'm the excluded one. And I don't know how much of that is due to the fact of this Asperger's factor. 'Cause you can't see yourself, you can't see it on this outside. So you don't know really. (P13)

Initial codes	Code description	Examples from interview data
Understanding from others	Autism diagnosis seemed to be greeted with ambivalence by family members. For some, it seemed to confirm something long-suspected, and thus diagnosis itself was not truly new information. Lack of understanding regarding autism observed in interaction with mental health professionals. Informing others of diagnosis could sometimes help explain behaviour that could otherwise be considered rude.	I think the main difficulty is that people you meet might not take your autism seriously. That's a - that's a bit of a problem. And yeah, so for some people it's quite obvious that I have it while for other people, they don't believe it. And I heard somebody who said recently, the only different I see with other people is that you have a stammer. (P6)

The last psychiatrist I spoke to, Dr [name], was very young, very inexperienced, at [service]. And he kept telling me that I didn't have empathy. And I was having to explain to him, no, that that's a psychopath. We don't have social skills but we're not, you know, I don't have a lack of empathy. (P2)

And you tell people and sometimes they, you know, you get extra special treatment, which I kind of like, but it actually before people could be quite nasty to me when I was at university. 'Cause I'd talk, you'd talk and then they'd say shut up. You'd say, but you said talk. And I took it literally. Which is a very autistic thing. You take things literally. And when they realised I was autistic they didn't say shut up so often. (P10) |

Appendix M:

Example of coded transcript

	Transcript	Codes
Researcher	Do you still fall back on avoidance to a fair degree, or are there other things that you would also use now?	
Participant	Um, well the trouble is now I'm post diagnosis, I was hit by this massive hyper, um, self-consciousness. And it was so debilitating. Because, um, before the diagnosis I was in ignorance and, um, I just couldn't cope with that. I felt like every time I did anything, I was so self-aware that I was doing it wrong, that people wouldn't pick up the signals, that there was, um, something different about me. And, um, I was, I was just amazed. I thought how have people not picked up on it? You know, yet five year olds could pick up on it. I asked the psychiatrist that. I said, how can, you know, the junior, the five-year-olds know that I'm different but so many psychiatrists and psychologists keep misdiagnosing me. Um, up to the age of 52. So, um, and my coping strategies eventually, with more and more responsibility, less and less support, um, decades of poverty, um, sort of the stress of that, stress of being a carer for, um, terminally ill parents, um, having a brother who's manic depressive and a lot of that depression may be caused by the fact that he'd a sibling who he just couldn't understand. Just couldn't relate to. And he knew that other people thought I was an eccentric. Um, and that's a polite way of putting it. Um…	Increased self-consciousness Hyper-awareness, social anxiety Reflection on difference Lack of social support, isolation Limited family support Lack of understanding by family
Researcher	So there's been a kind of accumulation of stressors?	
Participant	Accumulation of stress. And just exhaustion because, um, if it wasn't named after Hans Asperger, um, I would call it constant anxiety syndrome. Because, um, I'm very much where it's a hyper-sensory, um, reaction, and I think up till very recently - and there's only a few people in the field - they think it's hyper-sensory, they think we're hyper. And I'm very aware of the sensory overload. And the fact that it's only this year that the sensory aspect has been recognised medically when it's so obvious to, um, us on the spectrum. It would always be something we'd say, like the fluorescent light's giving us a migraine, um, in the workplace or at school. Or in hospitals. Um, we could see the lights flickering. Um, noises would be much louder. And they have an echo which continues. Um…	Constant anxiety Sensory overload
Researcher	With the forum, what do you find useful about that? The forum meaning the [name of group] group, is it?	
Participant	Yeah.	
Researcher	Yeah.	
Participant	Um, well I met you and I've met people in the scientific research, which is very reassuring because to know there was a hormonal basis, um, for the fact that it made me less sociable. And one of the reasons I was bullied at school was because they had typical schoolgirl crushes on the pop stars of the day. So you were either a David Bowie fan or Marc Bolan, Bay City Rollers. And you were meant to spend all your money on magazines that had pictures of them, you could put on your bedroom wall. And so you'd be literally beaten up for not, um, having these ridiculous crushes on these sort of pop stars. And spending the little money you had on all these magazines. And I didn't go through that phase. An adolescent phase. And that caused me to get bullied an awful lot. And people make all sorts of assumptions about your sexuality because they just don't get that you've, you just don't, um… I think it's quite common, but, as the scientists said, because we don't have that sort of hormone that gives us the sort of adolescent crushes or romantic notions. Um, that – I think that's why we sort of gravitate to animals, 'cause they're so much easier to interact with. Um, than sort of humans because they're so, um… So when I became so super self-conscious it was then I started getting very anxious and nervous and then of course I started sort of making mistakes, even more mistakes talking to people because I was even more anxious and socially inept because I was so self-conscious with that diagnosis.	Reassurance of medical basis External attribution? Bullying Noticing difference Life review? Tangible (medical) explanation for difference Social challenges Anxiety Post-diagnostic response Applying diagnosis dynamically?