

Autism in late adult and post-retirement life

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Research with older adults with Autism

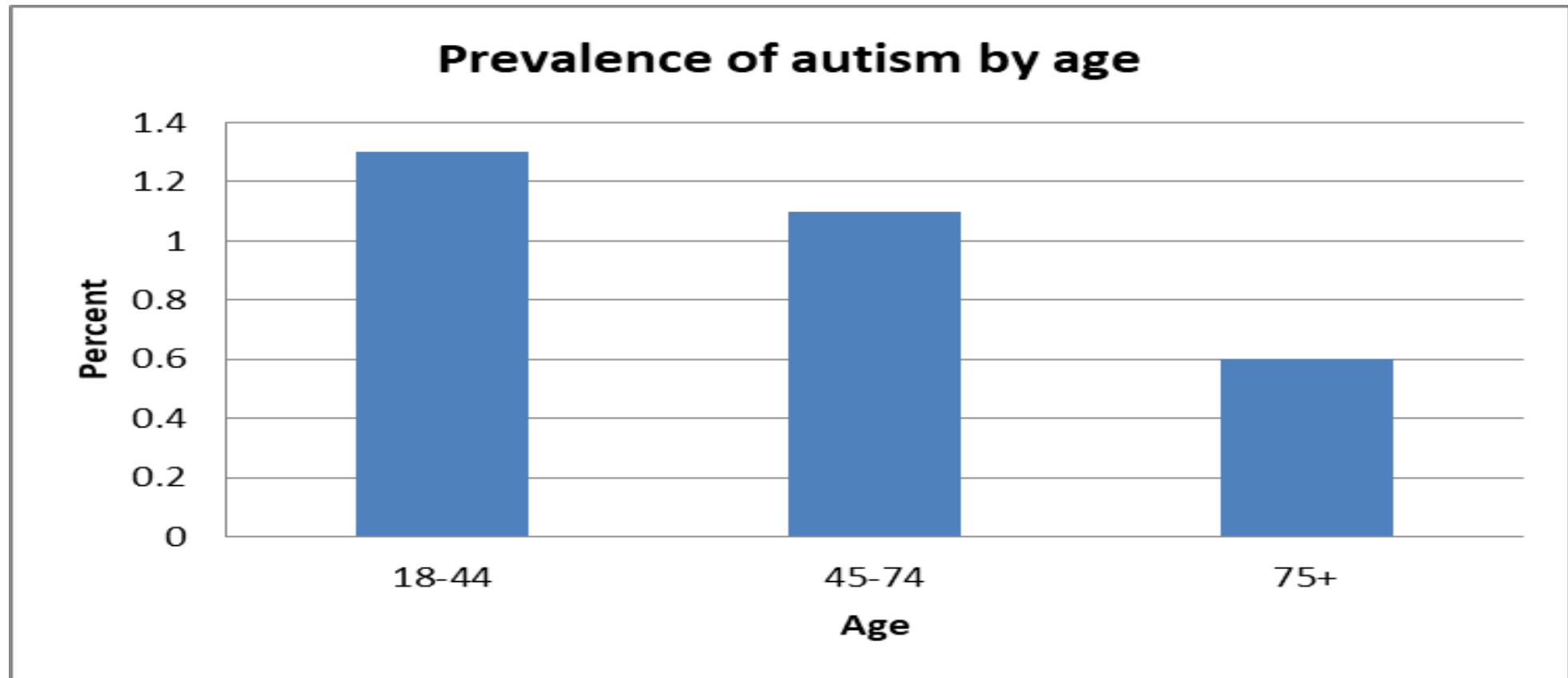
Research is scarce

- Autism only included as a psychiatric diagnostic classification around 3 decades ago
- Historically seen as a childhood and not life long diagnosis
- Focus of research on causes, diagnosis and treatment in children.
- Few adult diagnostic services until recently
- Issues with gaining early developmental history

Therefore comparatively far fewer older adults in receipt of a diagnosis and far less research.

Research important to assess unique needs of older adults with autism and their support needs.

Estimates of the prevalence of autism (Bruga et al. 2012)



Research in older adults with Autism

- Little known about risks to physical health, suggestion of increase risk of epilepsy, cardiovascular disease, diabetes and suicide (Coren et al. 2014).
- Risk of early mortality among people with autism is almost twice that of the general population, Hirvikoski et al. 2016).
- Less of a deterioration in mental health and quality of life in older adults with autism (Van Heijst and Guerts, 2015).

Research in older adults with Autism

- Risk of developing Alzheimer's disease possibly lower than general population (Barnard-Brak et al., 2019).
- Suggestion of similar patterns of strengths and weaknesses in memory to younger adults (Lever et al., 2015)



Experience of getting a diagnosis in older adults

Hickey, A., Crabtree, J., Stott, J. (2018)

*'Suddenly the first fifty years of my life made sense':
Experiences of older people with autism.*

Autism, 22, 357-367

13 people aged over 50 with a diagnosis of autism participated in semi-structured interviews about their experiences of diagnosis, social support and getting older. Also considered self reported depression and anxiety levels

Hickey, Crabtree & Stott, 2018

Levels of loneliness, depression and anxiety

ID	Gender	Age group	Loneliness	Depression	Anxiety
P1	M	60s	Moderate	-	Mild
P2	F	50s	Moderate	Severe	Severe
P3	M	60s	Moderate	-	Moderate
P4	M	50s	Severe	-	Moderate
P5	F	50s	Moderate	-	Mild
P6	M	50s	Moderate	-	Mild
P7	M	60s	Moderate	-	Moderate
P8	M	70s	Very severe	Moderate	Severe
P9	M	50s	Moderate	-	Mild
P10	M	60s	Moderate	-	-
P11	M	60s	Severe	-	Mild
P12	F	60s	Moderate	Mild	Severe
P13	M	60s	Very severe	-	Severe

Themes generated from thematic analysis

- Difference
- Life review
- Longing for connection

Difference

Prior to diagnosis, individuals had awareness of their difficulties, attributed these to intrinsic difference and many reported engaging in a deliberate process of reducing the visibility of this difference (camouflaging).

'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)

Difference

Once 'difference' was understood, individuals studied their peers and imitated their social skills. Over time, learned social skills became more habitual, enabling participants to 'fit in'.

'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'. (P12)

Life review: Understanding and reaching out

Diagnosis prompted a process of life review and externalisation, whereby past negative experiences were reattributed to autism as opposed to the self.

Deliberate effort to gather additional information by meeting others with autism

- Sense of shared experience and understanding
 - *You're accepted. You don't have to sort of hide anything. (P7)*
 - *The people, some of them are on my wavelength. (P3)*

Life review: Understanding and reaching out

Social comparison

- *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)*

Normalising

- *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. (P9)*

Gaining knowledge

- *They might come up with some problems they have – '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)*

Focusing on something tangible helped

- *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)*

Longing for connection: isolation and loneliness

- Defining feature of growing up and getting older with autism
- No less distressing as people got older
 - *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)*
- People particularly focused on the lack of a romantic relationship, describing 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)*
- Loneliness was less prominent in the accounts of the three study participants who had partners: one close relationship might help buffer effects of social isolation?
- ...But disconnection or being cut off were still features 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)*

Positive aspects of isolation

- Aloneness was sometimes framed positively
- Allowed uninterrupted pursuit of hobbies and interests, sense of achievement
 - *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)*
- A place of safety:
 - *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)*
- The potential of special interests to buffer distress
 - *A lot of [people with] Asperger's don't suffer from chronic depression because they have a narrow field of interest and they might have a job in that field of interest. Especially males. (P2)*

What might help reduce loneliness for people with autism?

- Autism-specific groups/community
 - Might be particularly important immediately post-diagnosis – highly valued by participants
- Many people on the spectrum develop ways of masking symptoms, but some do not and require help
 - Professional-led social skills - improving social knowledge and understanding, improving social functioning, reducing loneliness and potentially alleviating psychiatric symptoms (Spain & Blainey, 2015)
 - Can increase skills necessary to access community-based groups
 - Feedback on groups suggest participants want more explicit focus on romantic relationships (Spain & Blainey, 2014)
 - Emphasis on early intervention treatments means that interventions that might be important in adult life, such as dating skills, are under-developed (Shire, 2013)

What might help reduce loneliness for people with autism?

- Role of statutory services in developing support networks
 - Evidence from mental health groups of benefits of such groups (Crabtree et al, 2010)
- Consideration of models of care short term intensive vs long term low level
- Identification and diagnosis – still an issue, especially in older adults
- Bullying, abuse and stigmatisation – raising awareness
- Avoiding inappropriate friendships, mate hate, social vulnerability

Aging and cognitive functioning

- Aging in typically developed adults is associated with a decline in specific sub types of memory and cognitive functioning.
- Not clear how autism affects degree or type of cognitive change in autistic people as they age.
- Important to understand any changes as specific changes in cognitive functioning are an early indication of dementia in TD adults.

Tse, Crabtree, Islam & Stott (2019)

- Aim
- To compare cognitive and memory abilities between older adults with and without autism aged over 50.
- Cognitive ability assessed using the WAIS IV
- Memory ability assessed using the WMS IV
- 28 older adults with autism
- 29 Typically developed older adults

Group comparisons on each WAIS-IV Index Score

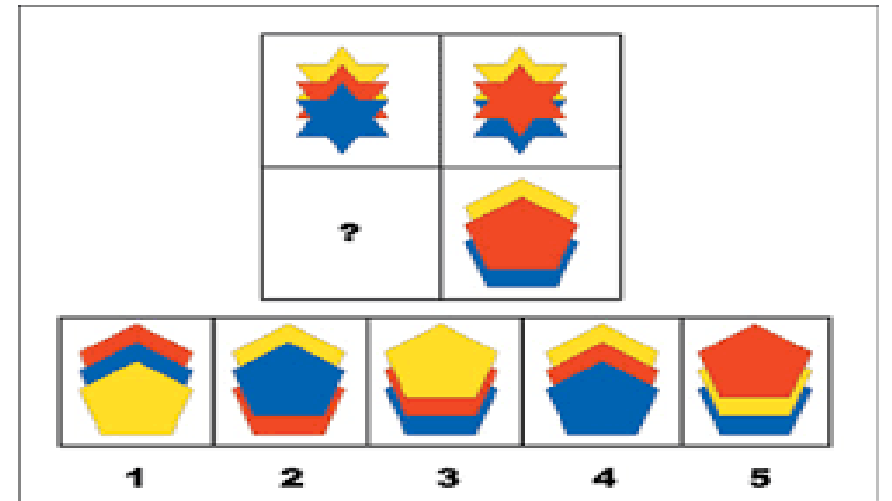
	Control <i>n</i> = 27	Autism <i>n</i> = 28	<i>p</i> -value	Effect size (Cohen's <i>d</i>)	Total sample <i>N</i> = 55
WAIS-IV Index Scores, Mean (SD)					
VCI	112.74 (11.27)	116.54 (15.47)	0.31	0.34	114.67 (13.59)
PRI	118.74 (13.96)	111.14 (18.08)	0.09	0.54	114.87 (16.49)
WMI ^a	116.85 (11.33)	114.25 (16.87)	0.51	0.23	115.53 (14.35)
PSI	111.30 (13.12)	99.39 (15.33)	0.003*	0.91	105.24 (15.38)

^aThe scores were winsorized due to extreme outliers

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

Group comparisons on each WAIS-IV Index Score

- The control group scored significantly higher than the autism group on processing speed.
- Trend for the control group to perform better on perceptual reasoning tasks
- Trend for those in the autism group to perform better on verbal comprehension



Group comparison on each WMS-IV Index Score

	Control <i>n</i> = 27	Autism <i>n</i> = 28	<i>p</i> -value	Effect Size (Cohen's <i>d</i>)	Total sample <i>N</i> = 55
WMS-IV Index Scores, Mean (SD)					
AMI	114.59 (15.56)	108.96 (18.02)	0.22	0.36	111.73 (16.94)
VMI ^a	106.85 (18.08)	98.29 (14.45)	0.06	0.47	102.49 (16.74)
VWMI ^a	116.40 (14.53)	102.86 (18.24)	<0.01*	0.93	109.51 (17.74)
IMI	111.63 (16.47)	104.00 (17.23)	0.10	0.46	107.75 (17.15)
DMI	113.41 (16.17)	105.11 (18.68)	0.08	0.51	109.18 (17.83)

^aThe scores were winsorized due to extreme outliers

**p* < 0.01 indicating significant *p*-value after Bonferroni correction

Group comparison on each WMS-IV Index Score

- On verbal working memory the control group scored significantly higher than the autism group.
- Overall trend for the autism group not to perform as well in all memory indices, but not significantly different from the control group.

Understanding cognitive differences

- Poorer performance in processing speed found across the life span in people with autism.
- Possibly due to executive functioning differences e.g. set shifting, focusing attention, disregarding unrelated details
- Also tendency to adopt a more careful and conservative response strategy (Lever et al., 2017)

Understanding memory differences

Suggestion that working memory may be linked to:

- sensory functioning,
- poorer interference control
- reduced processing speed

All linked to Executive Functioning (EF)

In conclusion...

- Cognitive and memory functioning in older adults with autism follow a similar profile to children and younger adults with autism.
- No evidence of increased risk of cognitive decline.
- Cognitive and memory functioning differences in individuals with autism appear to be linked to overall differences in executive functioning.

Questions?

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