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Chapter 13

Ageing when being Autistic

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The Case of a 73 Year Old Autistic Woman

C. is a woman of 73 years of age and she is autistic. She received her diagnosis at the age of 67, right after she retired from her job in a specialised art book store. She has a partner (no children) of whom she takes care as he had a series of strokes. C. comes from a family of six children, and was always a loner. She loved to read and was as long as she can remember interested in the arts. Her favourite art period was, and is, the Dutch Golden Age, and she knows everything there is to be known about Rembrandt, Rubens, Vermeer et cetera. As a child, she did have one friend who was, like her, a fanatic art fan. At both middle and high school she was bullied a lot and it was a relief when she was allowed to study art history at the university. Here she was among like-minded people and met her husband. As an adult she lived a quiet life with her husband and her work in the art store was a perfect match. C. has a history of depressive periods and is rather anxious especially when expected to meet (new) people. After her retirement she became fully depressed and hardly left her house. In this period her husband had his first stroke. He could not talk or move anymore, but she realised this only after a couple of days. She thought he was fooling her. Only after consulting her neighbour she called the GP. Her days are now filled with reading, and taking care of her husband and the only other person she talks to are her neighbour and her psychologist. C. is worried what will happen when her husband dies. She does not feel it is good to live on her own much longer, but at the same time she is scared what will be waiting for her when she has to move to a home for older adults. She does not like to be touched, cannot deal with specific sounds, and unexpected changes in her daily schedule.

Changes in physical health, cognitive processes, daily routines, social environment, and future prospects are a normative part of the ageing process for all adults. However, differences among people in the timing and course of these changes are large. We are just beginning to learn how people with an autism spectrum condition (ASC)[1] diagnosis are affected by the normative ageing process and by ageing-related changes associated with ASCs.

An ASC is a lifelong developmental disability characterised by challenges in social interactions and communication, difficulties dealing with unpredictability, and sensory sensitivities (Lai & Baron- Cohen, 2015). In the DSM-5 (American Psychiatric Association, 2013) this is referred to as autism spectrum disorder. To meet this criteria people need to have persistent problems in two domains: (1) Social communication and social interaction across multiple contexts, as manifested currently or by history and (2) Restricted, repetitive patterns of behaviour, interests, or activities. Importantly, although these characteristics need to be present during early development, they may fully manifest when social demands exceed the limited capacities. Moreover, overt characteristics could be masked later in life by strategies learnt during development. This is of importance as in late adulthood there are roughly two groups of autistic adults: (1) Adults with a childhood diagnosis of ASC and (2) Adults who received their diagnosis (or self identify) during (late) adulthood.

In the earliest couple of decades after autism was described in the research literature the prevalence was estimated to be low (around 0.04%, Lotter, 1966). Nowadays, the estimated prevalence of ASC is approximately 1% (e.g. Brugha et al., 2011) irrespective of age, although some studies estimate preva- lence to be as high as 3% (Fombonne, 2018). Moreover, where before it was thought that the male: female ratio was 4:1, currently it is believed to be 3:1 or even less skewed (Loomes, Hull, & Mandy, 2017). The percentage of individuals with a co-occurring intellectual disability has also changed; initial estimates were approximately 70%, but current estimates are 11–26% (Rydzewska et al., 2018). These three major changes in autism-related figures are likely to be caused by the broadening definition and improved recognition of autism. The change in the definition of autism is sometimes a crucial factor in understanding observed differences across studies and across age

cohorts. However, the majority of autism research has focused on children, teens, and young adults (Mukaetova-Ladinska et al., 2012), but fortunately in the last decade autism in older people is gaining research attention.

The first descriptions of older autistic adults were case reports of late diagnoses (James, Mukaetova-Ladinska, Reichelt, Briel, & Scully, 2006), n=5 [age range 67-84];(Naidu, James, Mukatoeva-Ladinska, & Briel, 2006), n=1 [66 years]; (van Niekerk e.a., 2011) n=3 [age range 72-83]). Since these case reports a few larger data-rich studies have been published, but the majority of papers on older autistic adults describe the need for research about this specific age group (Barber, 2015; Happé & Charlton, 2012; Michael, 2016; Perkins & Berkman, 2012; Roestorf et al., 2019). The dominant view (often implicitly) expressed in these articles is that autistic adults have an increased risk of accelerated ageing (i.e. steeper age- related physical and mental deterioration). A recent qualitative study (Hickey, Crabtree, & Stott, 2018) of 13 autistic adults diagnosed in adulthood, over 50 years of age (range 53–71), concluded that various challenges faced by older adults are similar among autistic adults independent of their age. Moreover, being autistic is seen as a vulnerability factor for early onset cognitive ageing or neurodegenerative diseases like dementia. People with an ASC diagnosis seem to have shortened lifespans and are more likely to be physically less healthy than those without ASC (e.g. Bishop-Fitzpatrick & Rubenstein, 2019; Croen et al., 2015; Hirvikoski et al., 2016). Additionally, well known age-related vulnerability for cognitive decline such as low social participation and physical activity, stress, and having more than one diagnosis (mental and/or physical) are prevalent among autistic adults. This demonstrates that autism is not just a transient developmental phase in childhood and that it is of relevance to focus on old-aged autistic adults. So, there is a need for more knowledge regarding ageing in autistic adults because (a) little is known and (b) what is known so far seems worrying. In the current chapter we will focus on the recent findings on late adulthood of autistic adults regarding ASC characteristics, well-being, mental and physical health, the ageing brain, and cognitive ageing.

General Well-being/Outcomes

There is an ongoing discussion about how to best measure well-being in autistic adults and account for the impact of the specific lived experiences (e.g. McConachie et al., 2018). In general well-being and quality of

life can be measured in a number of different ways, either objectively (based on relationships with family members, neighbourhood resources, housing, and physical and mental health) (Bishop- Fitzpatrick et al., 2016) or subjectively reported by either parents (or other relatives/partners) and autistic adults.

A relatively large body of research finds that a small majority of autistic adults achieve 'good' objective well-being, as defined by normative outcomes in the domains of housing, work, and relationship status, but many individuals' outcomes are less positive (for review, see (Henninger & Taylor, 2013; Magiati, Tay, & Howlin, 2014). Objective well-being may be considered better when a broader range of objective outcomes, including relationships with family members, neighbourhood resources, and physical and mental health are taken into account (Bishop-Fitzpatrick et al., 2016). Subjective well-being is reported to be low according to either parents (or other relatives/partners) and autistic adults themselves (Hong, Bishop-Fitzpatrick, Smith, Greenberg, & Mailick, 2016; van Heijst & Geurts, 2015) on a broad range of life domains, such as psychological and physical health, access to care, living circumstances when compared to adults without ASC (e.g. Bishop-Fitzpatrick, Mazefsky, & Eack, 2018). However, findings of a few recent studies do suggest otherwise (Deserno et al., 2019; Hong et al., 2016; Moss, Mandy, & Howlin, 2017). For example the autistic adults' self-reported well-being seems to be similar to adults without an ASC diagnosis (Hong et al., 2016; Moss et al., 2017). The participants in these studies often did not have a co-occurring intellectual disability, while the prevalence of intellectual disabilities was often high in older studies. Hence, ASC itself might not be the relevant factor here, but the associated physical and mental problems as well as the person-environment fit might be much more important (Rubenstein & Bishop-Fitzpatrick, 2019). This is especially likely so for those that have an (above) average intellectual level.

Notably, much of the existing research on well-being and quality of life focuses on autistic people in early to middle adulthood. We know comparatively little about well-being and quality of life for autistic people near the end of life: a recent meta-regression of studies examining quality of life in autistic adults identified a mean age across studies of 35.64 years (Kim & Bottema-Beutel, 2019). Fortunately, studies of quality of life in the three largest cohorts (Bishop-Fitzpatrick, Mazefsky, & Eack, 2018; Deserno, Borsboom, Begeer, & Geurts, 2017; McConachie et al., 2018) studied to date include autistic adults up to the age of 91 years.

While not studied systematically yet, one worry for older autistic individuals and their loved ones is how well-being and quality of life might change in later-life. Notably, existing service systems designed to support the needs of older adults in the general population may not suit the specific needs of older autistic adults. For instance, housing for the elderly might not be suited for the needs of autistic people. Nursing care may also pose specific challenges because it is often provided in communal settings which could be problematic for older autistic adults with sensory sensitivities. Staff and clinicians in nursing facilities receive little to no training on the specific needs of autistic adults. Access to care and housing are both important themes for well-being, and differences across countries exist. For example the health care system in the United States, is rather different from the health care system in Scandinavia. Cross- cultural and cross-health-care system comparisons can help us examine and resolve potential disparities in care.

ASC Characteristics

The diagnostic status seems relatively stable from childhood to middle adulthood, and even when diagnostic criteria are no longer met both ASC symptomatology and associated challenges often persist (Bastiaansen et al., 2011; Magiati et al., 2014; Totsika, Felce, Kerr, & Hastings, 2010). However, apart from a few exceptions (e.g. Bastiaansen et al., 2011; Esbensen, Seltzer, Lam, & Bodfish, 2009; Totsika et al., 2010), the majority of the 'older' adults participating in adult ASC studies were in their (late) forties or early fifties. Interestingly two separate cross-sectional studies examining 18–55 year olds (Happé et al., 2016) and 19–79 year olds (Lever & Geurts, 2018) with an ASC diagnosis, both showed increasing autistic traits (using the Autism Quotient; AQ) with age up to the end of middle age after which these seemed to decrease in the 55□□group (Lever & Geurts, 2018). However a further study of those aged from 18 to over 60[2] also using the AQ, showed no evidence of age-differences in autistic traits (Siebes, Muntjewerff, & Staal, 2018). In studies examining autistic traits in those without an ASC diagnosis, no significant age-associations were observed in either those referred for possible, but not confirmed ASC diagnosis aged 18–55 (Happé et al., 2016) or in typical adults aged 61–88 years old (Wallace, Budgett, & Charlton, 2016). Whether in senescence specific behaviours or ASC characteristics arise or

disappear cannot be answered based on these cross-sectional studies. The qualitative study by Hickey, Crabtree and Stott (2017) suggests no crucial alterations in ASC traits with age. Late diagnosed autistic adults are often those with higher IQ. Moreover, a clinical observation is that older autistic adults are often better at blending in due to camouflaging / masking; (b) better at coping with being different; and (c) more at ease with being different and, therefore, less reluctant to overtly showing so called autistic behaviour.

When working in old-age care, it would be beneficial when one is aware and accepting of specific (a)typicalities which are more often observed in autistic adults. For example, many autistic adults experience hypo- and hypersensitivities. Recognising that these sensitivities can co-exist, but can also suddenly change from hypo- to hypersensitivity or vice versa may lead to improved care. For example, sensitivity to fabrics can be the cause of sleeping problems. Also, not responding to others does not imply a lack of interest, but can be a way to deal with overwhelming sensory input. During their life, autistic adults have often disentangled how to deal with their sensitivities (e.g. wearing sunglasses indoors to protect from light sensitivity), so acceptance of their own chosen solutions is recommended. Moreover, many autistic adults have had negative experiences with health care workers and/or have been bullied in the past. It is, therefore, crucial to provide safety and recognition. Importantly, one needs to realise that autism might have not been recognised yet in older individuals. Typical instruments used in adulthood (like the AQ and Autism Observational Schedule [ADOS] module 4) can be used, but diagnosis primarily relies on an extensive interview with the person and someone who has known them for a long time. There is, unfortunately, no golden standard for assessing ASC in older individuals.

Physical and Mental Health

Autistic adults show a wide range of highly prevalent mental (Houghton, Ong, & Bolognani, 2017; Lever & Geurts, 2016b; Nylander, Axmon, Björne, Ahlström, & Gillberg, 2018) and physical health conditions (Bishop-Fitzpatrick & Rubenstein, 2019; Croen et al., 2015; Fortuna et al., 2016; Houghton et al., 2017). It is largely unclear whether these conditions have the same etiological origin as ASC or result from living with ASC (Rubenstein & Bishop-Fitzpatrick, 2019). Nonetheless, the association of a wide range of serious health

conditions with ASC likely grows stronger with increasing age as many prevalent health conditions are common among older adults. The most commonly associated physical health conditions are immune conditions, sleep disorders, cardiovascular disease, and gastro- intestinal conditions (e.g. Bishop-Fitzpatrick & Rubenstein, 2019; Croen et al., 2015; Fortuna et al., 2016; Houghton et al., 2017). Importantly, some physical health conditions such as cardiovascular risk factors and disease increase the risk of developing not only Vascular Dementia, but also Alzheimer's Disease or Mixed Dementias (Langa, Foster, & Larson, 2004). The most commonly associated mental health conditions are anxiety, mood, and psychotic disorders (Houghton, Ong, & Bolognani, 2017; Lever & Geurts, 2016b; Nylander, Axmon, Björne, Ahlström, & Gillberg, 2018). In old-age care, it is important to always assess potential associated health conditions as autistic adults might not experi- ence or express their own health concerns in the same way as adults from the general population. Moreover, eating patterns might need extra attention as eating disorders are prevalent in people with ASC as people can experience difficulties with knowing when to eat, might not recognise the feeling of being hungry/thirsty, or have very specific requirements regarding food. Alertness regarding changes in health status is crucial to prevent serious outcomes. Standardised regular assessment of the aforemen- tioned conditions is recommended, as is monitoring for health conditions that present with ASC at an earlier age than in the general population.

The assumption of accelerated ageing is, as previously discussed, partly based on the observed increased risk for neurodegenerative diseases in autistic adults (Bishop-Fitzpatrick & Rubenstein, 2019; Croen et al., 2015; Starkstein, Gellar, Parlier, Payne, & Piven, 2015). For example the prevalence of dementia (type unspecified) was much higher in autistic adults over 18 years of age (2.26%) as compared to controls (0.5%) (Croen et al., 2015). Also in a group of autistic adults aged 40–88 years dementia was highly prevalent (5%) (Bishop-Fitzpatrick & Rubenstein, 2019). Seemingly contrasting findings has been observed in a study by Oberman and Pascual-Leone (2014) as in their study only 3.8% of the autistic older adults had an additional dementia diagnosis (<3.8%), while the estimated prevalence of dementia in the total sample was 13%. This observation of dementia in the total sample is remarkably high, which calls into question the validity of the comparison group. Nonetheless, findings are not yet consistent and, unfortunately, no distinction regarding the type of dementia has been made.

Another known neurodegenerative disorder which seems to be more prevalent in autistic adults

compared to individuals in the general population is Parkinson's disease. Croen and colleagues (2015) found a Parkinson's disease prevalence of 0.93% compared to 0.05% in adults without ASC in a study of adults aged 18+. In a much smaller study, Starkstein and colleagues (2015) reported a prevalence of Parkinsonism between 16% and 32% in autistic adults over 40 years of age. This is remarkably high as in the general population of adults over 65 years of age, the prevalence of Parkinson's disease is approximately 2.6% (de Rijk et al., 1997). Whether these preliminary observations of prevalent neurodegenerative disease in autistic people are evidence of *accelerated* or *early* ageing (i.e. a parallel ageing pattern) remains to be determined. Either way, it will be difficult to disentangle whether the observed behavioural and physical problems associated with neurodegenerative disease are an intrinsic part of ASC or not. Again it is recommended that there is extra alertness to the possibility of developing neurodegenerative disorders in older autistic adults, and that neurodegenerative disease may present at earlier ages or progress more quickly.

Brain and Cognition

Atypical brain development is considered to be at the start of the different developmental trajectories observed in autistic people. The idea is that early atypical brain development (Courchesne, Campbell, & Solso, 2011; Donovan & Basson, 2017) has cascading effects on cognitive development. The major hypothesis is that there is less connectivity (i.e. reduced white matter microstructure) across different brain areas. In old-age, increasing age is associated with a reduction in white matter microstructure (e.g. Damoiseaux, 2017; Westlye et al., 2010), which in turn relates to reduced cognitive performance (e.g. Jolly et al., 2016; Tomimoto, 2015). Developmental studies across the lifespan show that white matter microstructure development follows an inverted u-shape with white matter developing until the 30s and then declining after □50 years of age (e.g. Damoiseaux, 2017; Westlye et al., 2010). Longitudinal studies of white matter microstructure in ageing show widespread age-related decline across the brain over even short time periods (i.e. 2 years, Barrick, Charlton, Clark, & Markus, 2010). Brain studies in old aged autistic adults are virtually non-existent. Only a few small imaging studies have focused specifically on middle and old aged autistic adults (e.g. Baxter et al., 2019; Braden et al., 2017; Koolschijn, Caan, Teeuw, Olabarriaga, & Geurts, 2017; Koolschijn & Geurts, 2016). Based

on these findings, one can carefully conclude that no major differences are apparent with respect to brain volume and cortical thickness in autistic compared to non-autistic individuals. However, functional activation patterns still differ between autistic and non-autistic groups, and white matter microstructure may even show increased risk of decline in autistic adults compared to neurotypical controls (although note the small age-associations in neurotypical controls in this study). Given that these are all cross-sectional studies, longitudinal studies are crucial to determine whether this is indeed the case and how this relates to cognition.

Others have suggested that the neurobiological make up (i.e. atypical brain development) of those with an ASC will actually protect against cognitive ageing (Oberman & Pascual-Leone, 2014). The hypothesis is that their brain is hyper plastic (quickly modulating synaptic connections in reaction to environ- mental changes) and, therefore, for a longer period protected against cognitive decline as age-related reductions in brain plasticity has been related to cognitive decline. The 'autistic' brain is, according to the authors, too plastic during development which is beneficial during ageing as older individuals with a lack of plasticity (hypo-plastic) are more prone to develop dementia. A way to learn about brain development is indeed to focus on the prevalence of neurodegenerative diseases (see previous section), but measuring cognition is yet another approach to address brain ageing.

The cognitive challenges autistic individuals often encounter as children (e.g. slower information processing, decreased cognitive flexibility) are the domains that are especially sensitive to cognitive ageing (Geurts & Vissers, 2012; Happé & Charlton, 2012). Additionally, aspects of the cognitive profile of autistic children and young adults shows striking resemblance with cognitive profiles of older adults without ASC (Bowler, Gaigg, & Gardiner, 2014). This ageing analogy implies that we can learn from the cognitive ageing literature to understand autistic information processing, as younger autistic adults cognitive profiles mimic those of older adults without ASC. However, the observation of an old-age cognitive profile in young or middle aged autistic adults has also led to the assumption of accelerated cognitive ageing in (old) autistic adults.

There are a handful of cognitive studies including middle and old aged autistic adults and findings are inconsistent. On a group level the majority of studies find hardly any differences in cognitive profile (Davids, Groen, Berg, Tucha, & van Balkom, 2016; Geurts & Vissers, 2012; Lever & Geurts, 2016a), whereas others did

observe some subtle cognitive differences (Baxter et al., 2019; Braden et al., 2017; Powell, Klinger, & Klinger, 2017). Autistic older adults do consistently report more cognitive challenges (Davids et al., 2016; Lever & Geurts, 2016a; van Heijst & Geurts, 2015), but this is often not reflected in their performance on cognitive tasks. Moreover, hardly any evidence in these cross-sectional studies has been observed for accelerated cognitive ageing although some findings do suggest that, if anything, executive control processes are at risk. So far findings across executive function tasks are rather inconsistent. In contrast, parallel cognitive ageing trajectories seem to be more likely at an older age. This implies that the observed cognitive profile of middle-aged autistic adults is similar to old aged non-autistic adults (i.e. the ageing analogy). Interestingly, there is also some early evidence that older autistic adults experience fewer cognitive challenges compared to older non-autistic adults, which would fit with an idea of (learned) beneficial cognitive strategies. A caveat of all aforementioned studies is that the majority of the autistic participants had an IQ within or above the normal range. So, ageing patterns might be different with conditions often present (see earlier section) in autistic adults. To this point, there seems to be most evidence for parallel cognitive ageing, but longitudinal studies are needed to determine the actual changes in cognition.

Based on one seminal, but small, longitudinal ASC study (Howlin, Savage, Moss, Tempier, & Rutter, 2014), one can argue that the developmental trajectories for adult outcomes for people who were diagnosed with ASC approximately 30 years ago, are too diverse to have a single overall conclusion. While, for example, some participants had a relatively good cognitive outcome (no change in intellectual level or a slight increase), other participants' aggressive behaviour was so severe that their intellectual ability could not be assessed (Howlin, Savage, Moss, Tempier, & Rutter, 2014). Actually, none of these individuals ever developed language above a 3-year level. Hence, it is likely that old-age cognitive-trajectories will be diverse among the group of older autistic adults.

The future challenge is to disentangle who is at risk for accelerated cognitive ageing and who is somehow protected. For now results imply that it is worthwhile to assess cognition regularly in order to ensure that someone's unique profile of cognitive strengths and weaknesses will be known and potential deterioration (or improvements) will be noticed. However, there is no typical 'autistic' cognitive profile in old-aged autistic

adults.

Conclusion

Given the newness of the literature on ageing in autistic people, we must take care not to draw strong conclusions. However, both qualitative and quantitative data do suggest that older autistic adults encounter a wide range of physical and mental health challenges typically associated with ageing. We identified three key issues:

1. More research that fully and carefully characterises the social, physical, and cognitive ageing pro- cess for autistic people is warranted
2. It is likely that autism is associated with more physical and mental health conditions; this warrants extra care for older autistic people and autism-specific training for physicians and other clinicians who practice with older adults
3. Age-related neurodegenerative diseases are hard to distinguish from the well-established physical, mental, and cognitive challenges older autistic adults experience. Hence, in old-age care this warrants thorough assessment

We, therefore, argue that when being autistic or when working with autistic older adults one needs to be aware of the so called old-age profile which middle aged autistic adults can exhibit. Autistic adults may experience, perform, and impress as being older when considering their actual age. It is of import- ance that autism knowledge is used to adjust typical old-age solutions in order to meet the needs of middle-aged and older autistic individuals.

Footnotes

[1] In this chapter we will refer to adults with an ASC diagnosis as 'autistic adults' because recent research indicates that identity-first language (as opposed to person-first language) is the terminology adults themselves prefer (Kenny et al., 2016). Moreover, this terminology fits well with the idea of both ASC as neurodiversity and being a disability. We do, however, acknowledge that preferences related to use of identity-first versus person- first language are heterogeneous and that some autistic adults, their loved ones, and their service

providers may have differing preferences related to language use.

[2] Although the sample sizes were smaller in those over 50 and the maximum age is not reported (18-30, n=175; 30-40, n=125; 40-50, n=135; 50-60, n=87;>60, n=40).

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Suggested Readings

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