

Autism Spectrum Disorders in Older Adulthood: The Current State of Research

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Introduction

The term ‘autism’ was first described in the 1900s to describe schizophrenic-like symptoms in children. The term was not commonly used until the 1960s when psychiatrists and pediatricians began using the diagnosis to explain abnormal child development. Autism first appeared in the Diagnostic and Statistical Manual III in the 1980s, which provided more specific diagnostic criteria, such as difficulty with communication and socialization, marked mannerisms, and repetitive or ritualistic behaviors (Evans, 2013). Autism was later identified as a spectrum disorder and was renamed autism spectrum disorder (ASD) in the 1990s. This change expanded the diagnostic criteria to accommodate a wider range of abilities and symptoms (Zeldovich, 2018).

ASD has historically been studied and diagnosed in childhood, so there is a gap in knowledge of ASD diagnoses, interventions, and prevalence in adulthood and late life. However, since the first significant waves of ASD diagnoses occurred in the 1960s and 1980s, there are now opportunities to research aging with ASD. The purpose of this literature review is to examine the current state of research on autism spectrum disorders in older adults, identify areas of weakness in the research, and provide recommendations for improvement.

Methods

The Multi-Search tool through the University of Georgia Libraries was used to locate appropriate sources for this review of the literature. Key search terms were “autism” OR “asd” OR “autism spectrum disorder” AND “older adults” OR “elderly” OR “seniors” OR “geriatrics.” Results were limited to peer-reviewed articles published within the last five years to ensure

relevance and provide a clear picture of current research on ASD in older adulthood. Six articles were selected to be reviewed.

Results

In the selected literature, three articles highlighted health disparities faced by older adults with ASD, and three articles examined the effects of aging on functional ability or independence.

Health Disparities

There are significant health disparities that impact older adults with ASD. While life expectancy for the average American is about 78 years, individuals with ASD have a much lower life expectancy, at only 54 years (Roestorf et al., 2019). As such, the articles in this review defined 50 as the age marker for older adulthood for individuals with ASD. The lower life expectancy of adults with ASD can likely be explained by the high prevalence of comorbid physical and mental health conditions (Bishop-Fitzpatrick & Rubenstein, 2019; Roestorf et al., 2019). One retrospective cohort study, which examined the health profiles of adults aged 40 to 88 with ASD, found a high prevalence of various health conditions, including immune conditions, sleep disorders, psychiatric disorders, cardiovascular diseases, and gastrointestinal diseases in older adults with ASD (Bishop-Fitzpatrick & Rubenstein, 2019). The health gap that exists also worsens with age, and all-cause mortality for older adults with ASD is disproportionately high at every age (Roestorf et al., 2019). The high burden of physical and mental health issues for older adults with ASD can likely be attributed to two main factors. First, health care delivery may be of lower quality for individuals on the spectrum, especially in adulthood, since healthcare professionals are not adequately trained to work with people who have developmental disorders like ASD unless they are working in pediatrics (Bishop-Fitzpatrick

& Rubenstein, 2019). Additionally, individuals with ASD may have difficulty adhering to doctors' recommended courses of treatment and lifestyle changes because individuals with ASD often struggle with changes, especially those impacting their preferred routines and lifestyle choices (Amanullah et al., 2020).

A systematic review of the health outcomes of older adults with ASD identified participation in activities of interest to be a protective factor against anxiety and depression, and it also suggested that individuals diagnosed earlier in life had greater adaptive skills to navigate changes associated with aging, such as declines in memory, executive function, and communication (Amanullah et al., 2020). In this way, having an autism diagnosis earlier in life can be beneficial to older adults, as they are better equipped to handle issues of cognitive decline in aging.

Aging and Functional Ability

In understanding the independence and functional abilities of older adults with ASD, three studies examined executive functioning, communication, cognitive decline, and disabilities in activities of daily living. Older adults with ASD have a lower baseline for independence in daily functioning as compared to their neurotypical counterparts. However, a retrospective cohort study found that levels of support required for older adults with ASD changed very little over time (Wise et al., 2020). This finding suggests that functional ability does not drastically change as individuals with ASD advance in age.

Similarly, a matched control study showed that older adults with ASD had comparable results for executive functioning tasks as compared to neurotypical adults of the same ages. However, older adults with ASD required more time for planning and executing tasks, and they were more likely to report problems or complaints relating to executive functioning in daily life (Davids et al., 2016). Researchers concluded that the greater frequency of executive functioning-

related issues for older adults with ASD is likely related to time pressures imposed on them by others (Davids et al., 2016).

Finally, in a cross-sectional survey of 142 caretakers of older adults, researchers found commonalities in the presentation of symptoms of Alzheimer's Disease and ASD. Older adults in the sample who displayed traits characteristic of ASD were more likely to experience cognitive impairment at an earlier age, and cognitive impairment was more likely to be severe (Rhodus et al., 2020). Results of this study concluded that there is likely a connection between early-onset dementia and ASD traits in older adults, but there is a need for further research on this connection.

Gaps in the Literature

ASD in older adulthood is under-researched. Most of the studies that were found in search results and used as references in the selected articles were focused on ASD in childhood. Research has expanded slightly to explore how ASD presents in adults, and how it may impact certain realms of life such as relationships and employment (Bennett, 2016). However, ASD in late life is largely unstudied. This is partially due to the history of ASD being diagnosed in childhood and the diagnostic criteria being written with a focus on children (Bennett, 2016). There is little information on what ASD looks like in adulthood and late life, so it is difficult to diagnose adults and difficult to study ASD in adulthood.

Additionally, the articles in this review almost exclusively examined high functioning adults with ASD, which means a significant portion of the autism spectrum has not been considered in the research. Individuals who are nonverbal, intellectually disabled, or have

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difficulty with interpersonal communication need to be involved in research on ASD in older adulthood.

Another issue common to the existing literature is the gender disparity in autism research. Each of the studies included in this review had a greater proportion of males than females, and some studies had great differences in the populations, such as the retrospective cohort study of older adults with ASD that included 60 men and only 14 women (Wise et al., 2020). The lack of representation of women with ASD is part of a larger disparity in diagnoses, as males are four times more likely to receive an autism diagnosis than females (Centers for Disease Control and Prevention, 2018). This does not mean that females are less likely to be on the autism spectrum, but it does mean that males with ASD are more likely to receive a diagnosis than females with ASD (Bennett, 2016).

Recommendations for Researchers

The first recommendation is to utilize different ASD diagnostic tools for different populations. The current DSM-V diagnostic criteria are written and focused on adolescents, and it is most effective in identifying ASD in that subpopulation (Bennett, 2016). There are other tools for screening and diagnosing ASD, such as the Autism Quotient and the Autism Spectrum Disorder in Adults Screening Questionnaire (ASDASQ) which are both designed for adults. These tools are important to use because ASD often presents differently in adulthood than in childhood, so researchers should examine what ASD looks like in adults and continue developing and updating diagnostic tools for ASD in adults and older adults. Evaluating ASD in girls and adult women is also an important next step for research, as females are

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underrepresented in ASD literature. A more informed understanding of ASD in females will help in developing diagnostic tools that can improve diagnoses for females and reduce the diagnosis disparity.

There is also a need for longitudinal studies of people with ASD so that researchers can better understand how ASD may change over time, particularly in late life. Many of the studies that were reviewed used cross-sectional or retrospective designs, but these studies are limited in what they can conclude about the effects of aging with ASD. A longitudinal study that follows a cohort of adults with ASD over several years may be useful in providing information on health outcomes, quality of life, and what ASD looks like in later life.

Lastly, it would be beneficial for researchers to make surveys or measurement tools inclusive for highly impaired, nonverbal, or non-communicative individuals with ASD. Accessibility is important, especially when working with individuals with disabilities, and this matters because inaccessible research tools will produce inaccurate results. One study included in this review had caregivers complete survey items for the older adults they look after, and this is one way that individuals with communication difficulties can be better included in ASD research (Rhodus et al., 2020).

Conclusion

Research on ASD in older adulthood is in its early stages. There are many opportunities for continuing research to better understand how aging impacts individuals with ASD and how to best support older adults with ASD. Upon reviewing the literature, it is recommended that further research focus on improving diagnostic tools for different populations, conducting longitudinal

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research to examine ASD over time, and emphasizing accessibility in research so that the full spectrum of ASD in older adults can be studied and represented.

References

- Amanullah, S., Rajeh, A., & Sivakumar, K. (2020). An overview of autism in the elderly [Review Article]. *Asian Journal of Psychiatry*, 48.
<https://doi.org/10.1016/j.ajp.2019.101897>
- Bennett, M. (2016). 'What is life like in the twilight years?' A letter about the scant amount of literature on the elderly with autism spectrum disorders [Letter to the editor]. *Journal of Autism and Developmental Disorders*, 46(5), 1883. <https://doi.org/10.1007/s10803-016-2710-z>
- Bishop-Fitzpatrick, L., & Rubenstein, E. (2019). The physical and mental health of middle aged and older adults on the autism spectrum and the impact of intellectual disability [Article]. *Research in Autism Spectrum Disorders*, 63, 34-41.
<https://doi.org/10.1016/j.rasd.2019.01.001>
- Centers for Disease Control and Prevention. (2018). *Autism Spectrum Disorder (ASD) Data and Statistics*. <https://www.cdc.gov/ncbddd/autism/data.html>
- Dauids, R., Groen, Y., Berg, I., Tucha, O., & Balkom, I. (2016). Executive Functions in Older Adults With Autism Spectrum Disorder: Objective Performance and Subjective Complaints [Article]. *Journal of Autism & Developmental Disorders*, 46(9), 2859-2873.
<https://doi.org/10.1007/s10803-016-2831-4>
- Evans, B. (2013). How autism became autism: The radical transformation of a central concept of child development in Britain. *History of the human sciences*, 26(3), 3-31.
<https://doi.org/10.1177/0952695113484320>
- Rhodus, E. K., Barber, J., Abner, E. L., Duff, D. M. C., Bardach, S. H., Caban-Holt, A., Lightner, D., Rowles, G. D., Schmitt, F. A., & Jicha, G. A. (2020). Behaviors

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Characteristic of Autism Spectrum Disorder in a Geriatric Cohort With Mild Cognitive Impairment or Early Dementia. *Alzheimer Disease & Associated Disorders*, 34(1), 66-71.

<https://search.ebscohost.com/login.aspx?direct=true&AuthType=ip,shib&db=edo&AN=141964543&site=eds-live&custid=uga1>

Roestorf, A., Bowler, D. M., Deserno, M. K., Howlin, P., Klinger, L., McConachie, H., Parr, J.

R., Powell, P., Van Heijst, B. F. C., & Geurts, H. M. (2019). “Older Adults with ASD: The Consequences of Aging.” Insights from a series of special interest group meetings held at the International Society for Autism Research 2016–2017 [Article]. *Research in Autism Spectrum Disorders*, 63, 3-12. <https://doi.org/10.1016/j.rasd.2018.08.007>

Wise, E. A., Smith, M. D., & Rabins, P. V. (2020). Correlates of daily functioning in older adults with autism spectrum disorder [Article]. *Aging & Mental Health*, 24(10), 1754-1762.

<https://doi.org/10.1080/13607863.2019.1647138>

Zeldovich, L. (2018). *The evolution of ‘autism’ as a diagnosis, explained.*

<https://www.spectrumnews.org/news/evolution-autism-diagnosis-explained/>