

Autism in Older Adults

Introduction

Autism is a lifelong developmental disorder that affects how people perceive, communicate, and interact with others (National Autistic Society, 2022). Autism is often referred to as a spectrum condition, because of the various ways it can impact on people and the different level of support that people with the disorder require (Department of Health & Social Care, 2021). Autism can be defined as a “neurodevelopmental disorder characterised by impairment of reciprocal social interaction and communication and restricted repetitive behaviours” and it is estimated that 1 in every 100 people in the UK have autism (Wing, 1997; Department of Health & Social Care, 2021). Although autism is among the most common of the neurodevelopmental disorders, little is known about older adults with autism (OAWA) (Piven and Rabins, 2011). Previously, autism had been predominantly labelled as a disorder of childhood, however, evidence now shows that autism is a lifelong condition. Autism was scientifically described for the first time in the 1940s and the children that were studied then are now entering into their older adult years, but little is known about the characteristics and needs of these specific individuals (Piven and Rabins, 2011).

This assignment aims to explore autism in older adults by discussing the limitations of the current research and analysing challenges that may arise in an ageing population of autistic adults. Most research studies focus on autism in children, because generally autism tends to be identified at a young age, but there does not appear to be the same amount of interest in the children with autism who inevitably age into OAWA. The research is limited, but there are some recent studies which have been more focused on the OAWA age group. This assignment will explore the recent research which highlights numerous risks that OAWA are more susceptible to in comparison to the general population. The author will critically analyse the evidence of the risks associated with OAWA including neurodegenerative disease, psychiatric disorders and misdiagnosis and specific physical health conditions. The author

will also discuss how current practice in working with autistic adults could be enhanced and improved upon in future practises.

Misdiagnosis and late diagnosis

In the general population an older adult is defined as someone over the age of 65, however, when discussing people with autism an older adult is defined as an autistic adult over the age of 50 years old (Roestorf *et al*, 2019). During this assignment the author will be using these same criteria as this is what the limited researched defines an OAWA as being.

Throughout the literature there is mixed opinions on whether it is appropriate or not to diagnose autism in older adults. James *et al* (2006) presented a case series of older adults (aged 67–84 years) suspected to have Asperger's disorder. These patients had been previously diagnosed with mood and anxiety disorders and labelled as treatment resistant, which led to them receiving unnecessary, lengthy clinical psychiatric care that was not clinically indicated for their diagnosis of autism. James *et al* (2006) concluded that although there is argument for not diagnosing an OAWA if they have lived a life with relatively few issues, it would be helpful to have the diagnosis to accurately understand and support the person should they begin to experience significant changes to their mood or mental state and to avoid unsuitable medical or psychosocial treatment. In this case presentation all the subjects were males which, along with a small sample size, is a limitation to the study. Although historically autism has been perceived as more prevalent in men (Driver and Chester, 2020), recent statistics suggest that the ratio of men to women with autism is now 1:3.

Another study by Stagg and Belcher examined the lived experience of nine older adults (between the ages of 52 and 54) who received a late diagnosis of autism. The participants reported feeling acutely aware of being different as children and described experiencing peer rejection and isolation (Stagg and Belcher, 2019) along with feeling "alien" to everyone else around them. The participants reported feelings of "relief", "eureka moments" and "increased self-awareness" following their diagnosis. Overall, they described the diagnosis as a positive outcome which allowed them to better understand their past and

better prepare for their future. The study sample is small, but there was fair representation of gender throughout; five females and four males.

The literature describes a phenomenon known as “diagnostic overshadowing”, which contributes to under-recognition of autism, late diagnosis, and the misdiagnosis of mental health disorders, particularly in older females (Lai *et al.*, 2015; Zener, 2019). There appears to be a lack of understanding and knowledge surrounding the signs and symptoms of autism in older adults, especially females, which can lead to common misdiagnosis such as borderline personality disorder (BPD) (Carpenter *et al.*, 2019; Dell’Osso *et al.*, 2018), obsessive compulsive disorder (OCD) or attention deficit hyperactivity disorder (ADHD) (Zener, 2019; Driver and Chester, 2020). Delaying or misdiagnosing a person puts them at higher risk of not receiving the correct support that they need (Zener, 2019).

Despite the numerous advantages of diagnosing autism in older adults, the literature suggests that there are also reasons why people would not seek a diagnosis. For the older population, autism may still be seen as an acute mental illness with large stigma attached to it. Autism was once considered exceedingly rare and profoundly debilitating, however, we now know that it is increasingly common and presents on a spectrum of abilities (Grinker, 2020). Rather than a mental illness, autism is now described as “neurodiversity”, with people who do not have autism being referred to as “neuro-typical”. This helps reduce the stigma attached, but some, if not most of the older population may struggle to accept the new terminology due to long-standing beliefs and opinions. Older adults may also find that a diagnosis of autism could largely impact their perception of themselves and who they are. Taylor’s (1983) cognitive adaptation model discusses this area of self-awareness by stating that people who are faced with life-changing information must re-evaluate their whole sense of self and subsequently their future goals. This awareness can be life-changing and difficult to accept for most adults, but more-so for someone approaching the later stages of their lives. Recently, children and their families are well supported following a diagnosis of autism however this does not appear to be the case for our older adult population, with OAWA often report receiving inadequate support post-diagnosis (Bancroft *et al.*, 2012).

To spread awareness of misdiagnosis and late diagnosis of OAWA, the author explored assessment tools which are recommended. NICE guidelines (National Institute for Health and Clinical Excellence, 2012) suggest the following assessment tools for assessing an adult for autism who do not have a diagnosed learning disability; the Adult Asperger Assessment (Baron-Cohen *et al*, 2005), the ADI-R (Lord *et al*, 1994), the ADOS-G (Lord *et al*, 2000), the Asperger Syndrome Diagnostic Interview (Gillberg *et al*, 2001) and the Ritvo Autism Asperger Diagnostic Scale – Revised (Ritvo *et al*, 2011). The author aims to promote the use of these assessment tools whilst assessing patients who exhibit behaviours which might be indicative of an autism diagnosis rather than a label of personality disorder or a treatment resistant psychiatric disorder. The author chose to discuss these tools within a multi-disciplinary team discussion to raise awareness and educate staff about misdiagnosis and late diagnosis of autism in OAWA. Interestingly, there was not much awareness of these tools within the older adult mental health team, including lack of knowledge on how to administer or access them. This highlights a huge gap in autism awareness and diagnostic criteria which may lead to inappropriate treatment decisions for the OAWA population.

Psychiatric disorders

It has long been recognised that people with autism experience more mental health problems than the general population (White *et al.*, 2009). Recent studies of mortality, illness, and suicide among autistic adults are alarming. Autistic adults appear to die much earlier than the general population, and they seem to be more vulnerable to certain medical problems too (Robison, 2019). Suicide and depression are more common for people with an autism diagnosis than in the general population which suggests a growing mental health crisis within the autistic community that is not being recognised or treated effectively (Robison, 2019). Nylander *et al* (2018) identified high prevalence of anxiety, mood disorders and psychotic disorders in OAWA. They conducted a study of 601 Swedish OAWA and concluded that 381 OAWA (63.4%) had been in contact with specialised psychiatric care and 151 (25%) had been in-patients during the period examined. Lever and Geurts (2016) conducted a similar study of 48 OAWA (55-79 years old) and found that although OAWA did show high

rates of psychiatric disorders, they had fewer psychiatric diagnoses than younger adults with autism. This study sample is small and was based on self-reports of psychiatric disorders rather than Nylander et al (2018) who based their research on formal diagnosis of psychiatric disorders.

Sedgewick (2021) completed a study of psychiatric disorders in autism on 948 adults with autism aged 18-81 years old. They noted that this group of people suffered from psychiatric disorders such as anxiety, depression and eating disorders. They concluded that autistic individuals suffer with anxiety due to numerous reasons, but specifically highlight that their sensory sensitivities and social engagement challenges have a large impact. These challenges impact on how individuals interact with their peers and surroundings, increasing rates of social isolation and limited support, leading to increasing levels of anxiety and distress. Sedgewick (2021) notes that autistic adults suffer with depression more than the general population and suggests that this may be due to the high levels of unemployment, homelessness, and higher levels of domestic abuse (Griffiths *et al*, 2019). These statistics also suggest that depression is more common for those with autism due to their inability to interact with their peers in a “socially acceptable” way, leading to negative reactions from peers and thus increased social isolation. “Camouflaging” is phenomenon which describes how autistic individuals try to hide their autistic traits to interact with neuro-typical’s, this has been identified as something that causes high rates of suicide in autistic adults due to the high level of mental strain it can cause (Hull *et al*, 2019). The data described in Sedgewick (2021) study was taken from self-reports, which means that the formal diagnoses of anxiety and depression cannot be verified, however they did use widely used assessment tools such as the HADS-A and HADS-D (Zigmond and Snaith, 1983). Another limitation is that the study covers a wide age-range and does not break down the different data based on age, so it is difficult to assess whether there is a discrepancy between adults of working age and OAWA.

Overall, the data regarding psychiatric disorders in OAWA remains limited but there are advances in the research in recent years. Given that there is good evidence to suggest that psychiatric disorders are more prevalent in adults with autism, it can be assumed that this follows through into later life. Ageing can

affect a person's mental health and well-being due to a range of factors such as grief (parents/care-givers deaths), change in social circumstance (retirement) and age-related health conditions which may cause pain or discomfort can have a knock-on effect to someone's mental well-being (World Health Organisation, 2017).

Neurodegenerative disorders

There is limited evidence and research on the age-related cognitive changes in OAWA, however, there are frequent references to executive functioning deficits in autistic people, which appear to worsen as they age. This is noted to be the same for people with autism and those with a comorbid intellectual disability (Lever *et al*, 2015; Rosenthal *et al*, 2013).

In 2021 a study was conducted assessing the prevalence and incidence of early-onset dementia among adults with autism and concluded that adults with autism under the age of 65 were approximately 2.6 times more likely to be diagnosed with dementia (Vivanti *et al*, 2021). This was the first study to examine the prevalence of dementia in older adults with autism, therefore this area of interest remains under-researched. Although Vivanti *et al*'s (2021) study is recent, the results are alarming. It is well known that there is a link between dementia and Down syndrome, which has led to research uncovering a partial overlap and a potential biological link between the two disorders. This has created an increased availability and understanding of interventions that can support those with a diagnosis of both dementia and Down syndrome (Hartley *et al*, 2015). The same could be done regarding autism and dementia if the research was expanded upon.

We are an ageing population and if the research is correct, there will be many OAWA who develop dementia and subsequently require further specialised care and even care placement. The vast majority of those with a dementia diagnosis eventually require long-term nursing care placements due to their increasing care needs which cannot be met at home (Alzheimer's Society, 2021). The staff in these homes may have a great understanding of dementia but may lack the education and understanding of a co-existing autism diagnosis. This highlights the further need for more education and wide-spread

understanding of the disorder, for those within a caring profession to better care for the OAWA population. Dementia care training is mandatory in most healthcare settings, but this is not the case for autism training. More needs to be done to promote the understanding of OAWA so that we can care for them in a way that promotes their individuality and adapts to their needs, rather than treat the “symptoms of dementia” which may have been a lifelong trait. As with autism, people with a dementia diagnosis experience symptoms such as impairments of executive functioning, motor functioning and social interaction (Liang and Carlson, 2020). This must be considered when assessing an OAWA who may be developing a neurodegenerative disorder, as at their baseline they may have experienced these deficits.

Physical health comorbidities

There is little research into the physical health outcomes of OAWA specifically, however, the author aims to highlight the current research around physical health problems that are prevalent in this specific population. As most of the research discusses “adults” with autism, the author will explore the likely outcomes of ageing alongside these more prevalent physical health complaints. In 2016 a systematic review of the physical health of adults with autism found that they were at higher risk of cardiovascular problems such as obesity diabetes and hyperlipidaemia and at much higher risk of gastrointestinal issues (Cashin *et al*, 2016). Similarly, a study conducted of OAWA in 2018 found higher prevalence of most health conditions, including motor problems, cardiovascular issues, hyperthyroidism, and neurological disorders (Bishop-Fitzpatrick *et al.*, 2018). The study did however highlight that OAWA showed to be at lower risk of metastatic cancer, hypertension, and alcohol abuse. Limitations to this study were that the electronic health record (HER) data that they used to complete the study may have contained inaccurate or incomplete data (Bishop-Fitzpatrick *et al.*, 2018).

In a case-controlled analysis of case records by Tyler *et al* (2011), it was identified that a population of adults with autism diagnosed with hypertension or hyperlipidaemia were less likely be prescribed treatment for their health condition compared to a control group of people without an autism diagnosis.

Tyler *et al* (2011) also noted that adults with autism were prescribed psychotropic medication significantly more often than the those without autism. Their study also showed that adults with autism had higher prevalence of experiencing constipation, which is something that older adults without an autism diagnosis suffer with regularly, therefore it is likely to be something that our OAWA population suffer from too. Given the barriers with OAWA and communication, something as simple as constipation could cause significant discomfort and cause unnecessary agitation and upset in the OAWA group if they were unable to identify their symptoms. Although there is limited data on OAWA specifically, this data shows that if adults of working age are being subjected to this then it is statistically likely that the OAWA population would experience the same. Wright (2015) also reports that people with autism are about 3 times more likely to have constipation. Wright (2015) states that people with autism are 1.4 times more likely to be overweight. Obesity is mentioned throughout the literature, as children with autism have been identified as being more likely to become obese than children without autism (Cashin et al, 2016). People with autism tend to have restricted diets and therefore from childhood they suffer from obesity which continues through into adulthood. Obesity puts a strain on joints which may cause further discomfort to OAWA as they age, as joint pain is a symptom of ageing also.

Cashin et al (2016) describes why autistic adults may experience increased challenges with their physical health. They may experience restricted physical activity, may not engage effectively in weight management, may exhibit restricted dietary intake, may suffer with poor sleep and lack of knowledge of sleep hygiene and may be affected using long-term psychotropic medication. Given that all these challenges occur throughout the lifespan of a person with autism, it is obvious that as the person ages the challenges that they have dealt with throughout their lifetime will undoubtedly have a lasting impact on their physical health.

The author can identify numerous challenges that OAWA population face regarding their physical health and its treatment and management. OAWA may find attending a review with their GP overwhelming and therefore avoid it altogether, they may not have the resources or ability to physically make an

appointment with their GP, they may not have a clear understanding or perception of their own symptoms and therefore not recognise the need for a physical health review. OAWA may find communicating their needs difficult and therefore will go unnoticed and untreated. The author proposes that there should be more support in the community for OAWA, especially those who live independently or with little social support. It is important that the NHS recognises the difficulties that occur in accessing primary care services for those with an autism diagnosis and therefore the need to make appropriate adjustments. There needs to be more awareness of the risks associated within the older adult population and more-so the OAWA population who are at significantly higher risk of physical health co-morbidities and premature death. Primary care services may benefit from internal autism-specialist clinicians who could identify and treat these common conditions that people with autism suffer from.

Conclusion

As highlighted above, OAWA appear to be more susceptible to a range of co-existing health conditions which are having a negative impact on their quality of life and overall life expectancy. Mental illness, physical health co-morbidities and neurodegenerative disorders are among just a few of the co-existing health conditions that research has identified as being a clinical concern for this population (Roestorf et al, 2019). Unnecessary medical treatment for a misdiagnosed psychiatric illness may also be exacerbating the physical health co-morbidities that have been highlighted. Inappropriate treatment combined with lack of mental health resources and support is having a largely negative impact on the lifespan of OAWA, with the literature stating that OAWA die younger than the general population. These figures are alarming and need to be addressed.

Although the research on OAWA remains limited, thankfully there are some recent studies which explore the challenges and complications associated for this group of people. This positively suggests that it is an area of research that is becoming more widely discussed. Roestorf *et al* (2019) discussed how future research and healthcare interventions may benefit OAWA as they age, which

the author agrees are imperative to the future of the care of OAWA. The needs highlighted for future autism care included; increased opportunities for education and training around autism for all healthcare workers, improved awareness of adaptations that can be implemented within healthcare settings (as there remains a large focus on “treatment” under the biological model of care rather than adaptation which is more suitable for autistic individuals who do not have treatable or changeable characteristics), increased understanding within primary care of autism to support with appropriate diagnosis and signposting, increased support in post-diagnosis of autism especially for OAWA. There are many obstacles in achieving this, including funding and education opportunities, however the author believes that if the above-mentioned improvements could be implemented, then the care of those OAWA would be much improved and this would subsequently reduce burden on services, improve patient well-being and overall quality of life

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