

## The challenges of people with autism spectrum disorder in adulthood: An integrative review



<https://doi.org/10.56238/uniknowindevolp-117>

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### ABSTRACT

This study aimed to identify the main challenges faced by people with Autism Spectrum Disorder (ASD) in adult life. This is an integrative review covering articles published between 2017 and 2022, available on the following databases: Scopus, PubMed and Virtual Health Library. After selecting and organizing the studies, the corpus consisted of eight articles that addressed these challenges of adults with ASD and their experiences in the field of health, polypharmacy, socialization and the correlation with other psychiatric disorders. The studies contributed to an understanding of the problems faced by the group, in addition to their needs and perceptions, pointing to the lack of support in the transition to adult life, the lack of professional qualification in assisting people with ASD and the lack of adaptations to the environment towards individuals, contributing to the increase of mental disorders and social isolation.

**Keywords:** Autism Spectrum Disorder, Adult Health, Standard of Care.

## 1 INTRODUCTION

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), autism, currently referred to as Autism Spectrum Disorder (ASD), can be conceptualized as a complex developmental disorder that influences and compromises the individual's behavioral habits, whether in language, communication and/or related to social interaction (APA, 2014).

In 2020, the Centers for Disease Control and Prevention (CDC) pointed out that 1 in 36 children is diagnosed with autism. In addition, the World Health Organization (WHO) estimates that 1% of the world population has ASD and in Brazil, this number can reach 3.9 million Brazilians diagnosed (GERALDO, 2020).



Within the complexity of ASD there are levels of support that vary according to the functional impairment and dependence of the individual. At level or grade 1, people present less impairment when compared to others, being more functional and mild, requiring less support from family members or health professionals. At level 2 the losses are more apparent, and there may be communication deficits, repetitive behaviors, sensitivity to light or sounds and, therefore, need greater support. People diagnosed with level 3 have greater functional impairment, so that social interaction is extremely limited, repetitive behaviors are more significant and there is great intellectual and language impairment, and may not even communicate through speech and, therefore, the individual becomes more dependent and needs more substantial support (APA, 2014).

Thus, people with ASD face several challenges in their daily lives, mainly due to the way they are seen by society, with prejudices and associated stereotypes. However, according to the Brazilian Law of Inclusion of Persons with Disabilities, it is known that integration is a right of all, guaranteed by law, in which it is intended to ensure and promote conditions of equality, with the purpose of social inclusion and citizenship (BRASIL, 2015).

In addition to prejudice, individuals with autism face barriers to work in the labor market and universities, due to the lack of structure of services such as: limitations in communication, socialization, professional disqualification of institutions and lack of investment to receive this group, implying in the humanization of care. (HARMON, 2011; BONTEMPO, 2009; CHRISTMAS, 2022).

In Brazil, there are few studies that address the inclusion of autistic people (LEOPOLDINO, 2015; SALGADO, 2014). Thus, this research is justified by the gap still existing in the literature about the production of scientific research aimed at the difficulties faced by individuals with ASD in adulthood. In addition, the theoretical and practical contributions of the work are focused on the production of knowledge about the theme, serving to subsidize health professionals, as well as society, in the provision of humanized, holistic, collaborative and qualified care to adults with ASD and their caregivers. In this sense, this research aimed to identify the main challenges faced by people with ASD in adult life.

## 2 METHODOLOGY

This is an integrative literature review type research, in which the following guiding question was established: what are the challenges faced by people with ASD in adult life?

The review included the following libraries and education databases for literature screening: Scopus Database and PubMed search engines and the Virtual Health Library (VHL). It is noteworthy that its database of articles is among the world's leading research databases.

The searches covered studies between 2017 and 2022 and the following descriptors were adopted: "Autism Spectrum Disorder", "Adult Health" and "Standard of Care", and their respective



versions in the English languages, articulated by the Boolean operator AND. As an exclusion criterion, articles such as experience reports and literature reviews were eliminated. The articles that were selected answered the guiding question, were published in full and are available free of charge on electronic platforms in the languages Portuguese, English and Spanish.

A total of 2,329 articles were obtained by searching for keywords with the Boolean operator, and 665 articles were found in the Scopus database, 738 articles in the PubMed search engine and 665 articles in the VHL search engine, of which 1375 were single articles and 954 were duplicated. We selected those who contemplated the adult with ASD, who were freely accessible through the CAFE and who answered the guiding question, resulting in 82 articles that concomitantly met these criteria. Another selection cycle was carried out and categorized into the topics "Assistance of health professionals", "Polypharmacy", "Socialization and behavior", "Psychiatric disorders", and 21 articles were identified, of which only 8 were included in the review because they addressed the objective of the study.

The data of the 8 articles were organized in a spreadsheet with the following items: title of the article, year of publication, authors, countries, title of the journal, participants of the research and description of the theme of the articles containing objective, methodology and results, as recommended by Pagotto, Bachion and Silveira (2013) regarding the elaboration of an instrument for the extraction of data from the articles, the absolute and relative frequency of each variable was presented, using tables and tables. Subsequently, the descriptive analysis of the data contained in the spreadsheet and presentation of the results were performed.

### 3 RESULTS AND DISCUSSION

The articles used for this review were published between 2018 and 2022, being 2022 (2), 2021 (2), 2019 (2) and 2018 (2), with no articles selected in 2020.

Table 1- Articles on the main challenges faced by people with ASD during adult life

	<b>Title</b>	<b>Authors/Year</b>	<b>Newspaper</b>
1	Opportunities for Inclusion and Engagement in the Transition of Autistic Youth from Pediatric to Adult Healthcare: A Qualitative Study	Ames, Mahajan, Davignon, Massolo, Croen (2022)	Journal of Autism and Developmental Disorders
2	Current and Lifetime Somatic Symptom Burden Among Transition-aged Autistic Young Adults	Williams, Gotham (2022)	Autism
3	Health profiles of adults with ASD: Differences between women and men	DaWalt, Taylor, Movaghar, Hong, Kim, Brilliant, Mailick1 (2021)	Autism



4	Modified CBT for social anxiety and social functioning in young adults with autism spectrum disorder	Bemmer, Boulton, Thomas, Larke, Lah, Hickie, Guastella (2021)	Rev. Molecular Autism
5	Examining Primary Care Health Encounters for Adults With Autism Spectrum Disorder		American Journal of Occupational Therapy
6	Eating Problems in Men and Women with an Autism Spectrum Disorder	Stein Duker, Kim, Pomponio, Mosqueda, Pfeiffer (2019)	Journal of Autism and Developmental Disorders
7	Health Concerns and Health Service Utilization in a Population Cohort of Young Adults with Autism Spectrum Disorder	Spek, Rijnsoever, Laarhoven, Kiep (2019)	Journal of Autism and Developmental Disorders
8	Addressing medical needs of adolescents and adults with autism spectrum disorders in a primary care setting	Weiss, Isaacs, Diepstra, Wilton, Brown, McGarry, Lunsy (2018)	Autism

Source: Prepared by the authors (2023).

The research carried out in these articles allowed us to understand what were the main challenges faced by people with ASD as adults from different thematic and methodological lines.

The theme involved the identification of barriers to medical care, the prevalence of mental disorders and somatic symptoms, eating problems and socialization in the different scenarios to which people with ASD were inserted.

The authors adopted different methodological approaches to respond to their objectives, with semi-structured interviews; application of a modified version of the *Patient Health Questionnaire-15* through the SPARK platform; interventionist approach through comparison with control group using SWEAA; application of questionnaires; use of *software* to analyze data and identify differences in the socio-demographic characteristics of the groups; analysis through electronic health records; and application of modified cognitive-behavioral therapy technique in the groups.

Table 2- Participants with ASD, Objective, Methodology and Conclusion

Authors	Goal	Participants	Methodology	Conclusion
Saqr, Braun, Porter, Barnette, Hanks (2018)	Identify barriers to access to medical consultations.	126 patients seen at The Ohio State University's <i>Center of Autism Services and Transition</i> and a focus group of 10 adults.	Semi-structured interview and application of the MRCI scale.	The pre-consultation evaluation made it possible to identify and circumvent barriers that hinder the regularity of consultations in primary care. Many of the patients use medications with psychotropic effects, requiring communication with the doctor to avoid drug interactions.
Williams, Gotham (2022)	To evaluate the prevalence of somatic symptoms in	290 adult SPARK members diagnosed with ASD before the age of 18.	Application of the modified version of the <i>Patient Health Questionnaire-15</i>	Adults with ASD have a higher somatic burden than the general population. Higher level of burden was associated with female gender, higher level of



	adults with ASD.		via the SPARK platform.	ASD, depression, anxiety and quality of life. The impact of somatic symptoms on health care and morbidity are imprecise, but it is an indicator of the quality of life of these individuals.
Spek, Rijnsoever, Laarhoven, Kiep (2020)	Assess the presence of eating problems in people with ASD.	89 individuals with ASD recruited from the <i>Autism Information Center</i> and the Lister institution.	Comparison with a control group of 68 neurotypical people using SWEAA translated into Holland.	Individuals with ASD of both sexes report difficulty adapting eating behaviors in the presence of other people and performing two activities simultaneously during the meal, preferring not to interact socially. Men with ASD who live alone have a greater preference for certain foods and have rituals for eating, while women with ASD have greater problems in rituals, perceptual sensitivity and difficulty in social interaction.
Duker, Kim, Pomponio, Mosqueda, Pfeiffer (2019)	Identify barriers and strategies to implement primary care meetings.	People with ASD, caregivers and primary health care providers of adults with ASD, totaling 78 people.	Data collection from questionnaire.	Adults with ASD and caregivers have barriers to primary care, with sensory discomforts and cost being the main concerns, as well as difficulty communicating with providers. Interdisciplinary collaboration with occupational therapists can help patients, caregivers, and the interdisciplinary team increase primary health care encounters.
Weiss, Isaacs, Diepstra, Wilton, Brown, McGarry, Lunsky (2018)	To compare the health profile of adults with ASD between 18 and 24 years of age and neurotypical or with other developmental disabilities.	5,095 individuals with ASD, 10,487 people with other developmental disabilities, and 393,263 neurotypical people.	Use of <i>software</i> to analyze data and identify differences in the socio-demographic characteristics of the groups.	Young adults with ASD need a different plan of care than the general population and those with other developmental disabilities, especially in the area of mental health. Early diagnosis and intervention of psychiatric disorders in young people with ASD should be enhanced to ensure mental health and prevention of psychiatric illness.
DaWalt, Taylor, Movaghar, Hong, Kim, Brilliant, Mailick (2021)	To investigate the hypothesis that women with ASD have a worse health status than men with ASD and neurotypical women.	2,119 adults with ASD and 21,870 neurotypical adults in the control group.	Analysis of the Marshfield electronic health record of ASD patients and the control group.	Women with ASD have a higher risk and poorer quality of health. There is double risk related to nutrition, sleep, neurological disorders and psychiatric conditions. There is greater use of health services by women with ASD than men with ASD or neurotypical women.
Bemmer, Boulton, Thomas, Larke, Lah, Hickie, Guastella (2021)	To evaluate the benefits, tolerance, and acceptability of cognitive behavioral therapy in young adults with ASD.	78 adolescents and young adults.	Modified cognitive behavioral therapy was performed in a group for eight weeks.	Participants in cognitive behavioral therapy reported improvements in socialization and psychiatric disorders, with strong acceptance from participants and with important clinical utility.



Ames, Mahajan, Davignon, Massolo, Croen (2022)	Identify how interventions should meet the needs of youth with ASD, caregivers, and health care providers during the transition to adulthood.	39 participants, being 7 young people with ASD alone, 7 pairs of young people with ASD together with their caregivers, 10 caregivers alone and 8 health providers.	Semi-structured telephone interview.	Stakeholders reported a precarious transition process, in which there is a lack of shared health decision, consultations, and early transition planning that benefits young people with ASD in this process.
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Source: Prepared by the authors (2023).

From the analysis of the studies included for this review, the main challenges faced during adulthood were categorized into thematic lines, since there were similar and complementary contents in the selected articles. Thus, divided into 4 themes: inefficiency in the care of health professionals; polypharmacy and its challenges; socialization and isolation; and the relationship between psychiatric disorders and ASD.

### 3.1 THEME 1: INEFFICIENCY IN THE CARE OF HEALTH PROFESSIONALS

According to the studies of Saqr *et al.* (2018), medical clinic consultations in primary care for patients with ASD tend to be problematic due to the delay in the waiting room and the difficulty of communication during the anamnesis and physical examination, causing moments of intense stress during these activities. In addition, the process of social interaction with the medical team is reported as a negative feedback loop, due to anxiety and difficulty concentrating in autistic patients (SAQR *et al.*, 2018).

This barrier between primary care professional and patient during the transition to adulthood presents several challenges related to care, especially the difficulty in maintaining patient participation in the health system and good relationship with professionals, resulting in a greater predisposition to chronic diseases and mental disorders (AMES *et al.*, 2022).

For Ames *et al.* (2022), the transition of the person with ASD to adulthood is marked by the desire for bodily autonomy, exercising control over who can examine and touch them in health environments. This patient-professional interaction directly influences the acceptance of care and the follow-up of quality care. However, there is a flaw present in the communication between caregivers or family members and professionals, since this independence is not provided in an absolute way for them, making this assistance even more difficult (AMES *et al.*, 2022).

Under another approach, individuals with ASD have more clinical and mental health problems when compared to other people, in addition to being more likely to use health services, especially hospital services (CROEN *et al.*, 2015).



According to the study by Weiss *et al.* (2017), adults with autism have a greater predisposition to follow up with a general practitioner, pediatrician, psychiatrist, neurologist, gastroenterologist, in addition to visiting emergency units and hospitalization for psychiatric reasons, because these individuals tend to have more diagnoses focused on basic needs. Despite this, there is a dissatisfaction on the part of autistic individuals regarding the care and assistance provided by professionals (LIPTAK *et al.*, 2006).

On the other hand, there are reports from health professionals who also mention the difficulty in feeling and providing comfort when caring for adults with ASD (PATEL; O'HARE, 2010). The studies of Steim *et al.* (2019) demonstrate that the communication of health professionals and the team represents a challenge for adults with ASD, once the lack of qualification of specialists in dealing with these individuals is present and that sometimes interprets in a negative way the aggressive and anxious behaviors in the waiting room environment and in the consultation itself.

### 3.2 THEME 2: POLYPHARMACY AND ITS CHALLENGES

It is known that there is no specific treatment for autism that can reverse the case, as well as there is no evidence that the various pharmacological interventions that exist and are adopted in the current medical scenario are really beneficial for the patient with ASD (NETO; BRUNONI; CYSNEIROS, 2019). However, studies show the early introduction of these drug therapies, in which more than 50% of individuals start using drugs between 0 and 2 years of age, often associated with the use of more than 3 medications, with antipsychotics, antidepressants, anticonvulsants and stimulants being the most common (ARIMA, 2009).

In the study by SARQ *et al.* (2022), the use of various medications associated or not with the direct treatment of ASD was identified, the most common being selective serotonin and serotonin-noradrenaline reuptake inhibitors, benzodiazepines, atypical antipsychotics, antiepileptics, sleep stimulants, laxatives, antihypertensive drugs and non-stimulant ADHD treatment. It was pointed out as a great challenge, the reduction of risks of the most complex medical regimens aimed at the potential adverse effects of the drugs, in which there are prescriptions with different dosages, schedules and effects and sometimes the process of acceptance and effectiveness of the treatment are not achieved due to the deficiency in the doctor-patient communication (SARQ *et al.*, 2022).

On the other hand, according to Durker *et al.* (2019), adults with ASD have difficulty in going to the pharmacy to acquire the drug treatment, as well as to follow it properly at the correct time and at the return of the medical consultation to analyze if the therapy is being beneficial. The study had the collaboration of adults with ASD (34) and their caregivers (31) and, regarding this problem, 26.5% (9) of the adults and 45.4% (15) of the caregivers reported difficulty in following the use of the various drugs, which is due to the existing barrier in the communication and prescription of an individualized



care plan for adults with ASD in consultations focused on primary care, likewise as described in the study by Sarq *et al.* (2022), in which sometimes doctors prescribe a complex drug regimen to be followed, not seeking to simplify or explain the use of drugs to be used daily to patients and their caregivers (DURKER *et al.*, 2019; SARQ *et al.*, 2022).

It is important to highlight that although pharmacological therapy is the therapy of choice by a large part of the medical profession, its use should not be adopted for all patients without adapting to their real needs, since the use of drugs inappropriately can aggravate the clinical picture or cause severe drug interactions, placing the patient, who no longer receives adequate guidance from professionals, at a higher degree of risk (SARQ *et al.*, 2022; GRANDSON; BRUNONI; CYSNEIROS, 2019).

### 3.3 THEME 3: SOCIALIZATION AND BEHAVIORS

Food, in addition to involving nutritional issues, is an event of fraternity and sensory stimulation. In the study by Spek *et al.* (2019), adults with ASD reported difficulties focused on eye contact, adaptation of food, socialization and multitasking, being more likely to choose to eat alone and not to interact socially at mealtimes. In this sense, repetitive and restricted behaviors, in addition to sensory sensitivity at the time of socialization, favor the comorbidity of Social Anxiety Disorder, through the constant fear of negative reactions to the deficit of social interaction characteristic of the spectrum (BEMMER *et al.*, 2021; KEIFER *et al.*, 2020).

Individuals with ASD interpret facial expressions at a slower speed and more inaccurately, that is, the social reasoning to interpret socio-emotional situations is slower when compared to neurotypical individuals (KEIFER *et al.*, 2020). In this sense, they need greater effort to socialize during the meal, since sharing attention in situations of multitasking and presence of sensory stimuli impairs the performance of cognitive functions and appropriate responses, further distancing neurotypical people, reinforcing negative social experiences (SPEK *et al.*, 2019; KEIFER *et al.*, 2020; BEMMER *et al.*, 2021).

In this sense, Wallace *et al.* (2018) associates the characteristics of ASD with high rigid food selectivity and neophobia, which is the fear or refusal of new foods, preferring specific foods and often not rich in nutrients. This behavior is intensified in individuals who live alone, who have a greater preference for certain foods and behavioral rituals, than those who have company at home, largely due to the support and development of skills (SPEK *et al.*, 2019).

### 3.4 THEME 4: PSYCHIATRIC DISORDERS AND ASD

Adults with autism have higher rates of depression and anxiety (CROEN *et al.*, 2015; FORTUNA *et al.*, 2016). It was identified in Williams and Gotham's (2022) research that total symptom





burden was strongly associated with anxious complaints, exhibiting slightly lower correlations with levels of autistic traits.

Thus, a correlation was also present between depressive or anxious symptoms and the following factors: older age, female gender and high levels of autistic traits. In this context, most symptoms began in adolescence or adulthood (GRANT *et al.*, 2021; MAZUREK *et al.*, 2019; HINZ *et al.*, 2017; KOCALEVENT *et al.*, 2013).

It was identified in the study by Saqr *et al.* (2018), the prevalence of some psychiatric disorders in patients with ASD in the age group of 15-29 years, in which each individual, in most cases, presented more than one disorder, namely: intellectual disability (49%), ADHD (49%), anxiety (52%) and depression (31%). In addition, the study by Weiss *et al.* (2018), demonstrated that sleep disorders are more prevalent in those affected by ASD, compared to population controls.

According to the study by Walt *et al.* (2021), women with ASD are more likely to develop neurological disorders and psychiatric disorders when compared to men. The diagnostic process in women experiences more challenges when compared to the diagnosis in males, since they are more likely to camouflage their symptoms, which is reflected by the older age of the first diagnosis of ASD in females compared to males (GREEN *et al.*, 2019; LAI *et al.*, 2017; BEGEER *et al.*, 2013; SHATTUCK *et al.*, 2009).

Thus, depression and anxiety were identified as central concerns in the quality of life among adolescents and adults with ASD, particularly during the transition to adulthood, since these rates are higher in this public. In addition, it is noticed, from the studies, that autistic individuals have a higher risk of developing health problems and mental disorders, and this characteristic is a greater predictor of disability, reduced quality of life and difficulties in daily functioning (JOSHI *et al.*, 2013).

#### **4 FINAL CONSIDERATIONS**

In view of the studies discussed in this review, it was observed the scarcity in the scientific production in the scope of the challenges faced by people with ASD, especially research with a young-adult public, representing a gap in this field. In addition, it is recommended for future work to sensitize and highlight adults within the spectrum, since, mostly, the research focuses only on the childhood phase, however, eventually these children became adults and continued with follow-up with the multidisciplinary team.

These studies have contributed to a better understanding of the main challenges faced by people with ASD in adulthood, focusing on their needs and perceptions. It was possible to observe the prevalence of mental disorders, especially depression and anxiety in this group, directly interfering in their quality of life. In addition, the difficulties related to socialization imply in eating behaviors, since



the interaction in this circumstance can cause moments of intense stress, suffering and anguish, causing them to opt for social isolation.

From another perspective, the deficiency in the provision of care services to individuals with ASD, with a focus on communication, also contributes to a greater risk of the unwanted effects of polypharmacy, since medical practice usually uses various pharmacological resources for the treatment of autism, sometimes with no real need, and does not seek to simplify and make possible the understanding of the therapy for patients and their caregivers.

In addition, the existing barriers of care provided by health professionals during consultations in primary care, whether initially in the waiting room with the excess of sounds in the environment, the physical structure of the place, since individuals with ASD have greater sensitivity to light and sounds, as well as problems related to lack of communication and their behavioral challenges, make it difficult to establish a bond between professional and patient.

Thus, the need for continuing education for health professionals about Autism Spectrum Disorder is reinforced, in order to understand what autism is, its signs and symptoms, its comorbidities and its treatment, whether pharmacological and/or with other therapeutic measures, so that they can be able to intervene in moments of crisis and offer individualized care, adopting interventions that qualify the care provided to this group.

In addition, the study enables a better understanding of the theme for society, that is, how to deal with the needs of adults with ASD and favor relevant information to understand and help in their development. Moreover, it corroborates for the academic sphere by providing information through scientific data, which contributes and motivates the production of new academic research.



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