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Prevalence of autism spectrum disorder in children in the Azores Islands (Portugal): sociodemographic and clinical profile

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Abstract
Prevalence studies are essential to provide objective indicators about Autism Spectrum Disorder (ASD) and are a source of information for public policies. This study aimed to estimate the prevalence of ASD among children in the Azores Islands (Portugal). Administrative data on the number of children with a proven diagnosis of ASD were collected from all schools. Parents completed a questionnaire about the child's sociodemographic characteristics, the diagnostic process, and clinical history. The overall prevalence of ASD in the Azores region was 9.92 per 1000 children, approximately equivalent to 1% (0.99). The prevalence of ASD in the Azores seems to be higher when compared with the global rate in Portugal, as well as with other regions of Europe. There appears to be a concentration of children with ASD in the region, and the results appear to support the hypothesis of a heritable predisposition to ASD.

Keywords ASD · Children · Prevalence · Portugal · Azores

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental condition currently defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013) as the presence of difficulties in two major areas: (i) social communication and interaction (ii) and restricted, repetitive patterns of behavior, interests, or activities. These difficulties must be present in the early developmental period and occur in several contexts, significantly affecting social, occupational, and other areas of functioning (APA, 2013). This condition can be complex to identify early, but some atypical behaviors can be noticed after six months (Bryson et al., 2007).

Through the 1980 s, autism was considered a rare condition, with a prevalence of less than 5/10,000 (e.g., Ritvo et al., 1989). However, from the 1990 s onwards, prevalence studies began to identify an increasing trend in prevalence rates (Özerk, 2017; Salari et al., 2022). For example, the Center for Disease Control and Prevention (CDC, 2023) indicates that in the year 2000 (children born in 1992), the prevalence of children with ASD in the United States was 1:150; in 2010 (children born in 2002) the prevalence was 1:68; in 2018 (children born in 2010) the prevalence was 1:44, and in 2023 it increased to 1:36. Also in Canada, studies indicate an increase in prevalence rates (e.g., Ouellette-Kuntz et al., 2012), 39% from 2003 to 2008 for children aged 2 to 4 years and an increase of 155% from 2003 to 2008 for children aged 10 to 14 years. In Norway, Surén et al. (2013) indicate a substantial increase in prevalence rates over the last few decades - from 1:2000 in 1970 and 1980 to

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1:1000 in 1990 and 2011 to 1:125. A more recent study by Özerk and Cardinal (2020) indicates that the national prevalence rate among Norwegian children aged 1–16 years was 1:340 in 2014, rising in 2016 to 1:297 in 2016, representing an increase of 14.9%. In Northern Ireland, the estimated prevalence of autism in school-age children increased from 1.2% in 2008/09 to 2.9% in 2017/18, an increase of 1.7% points (Irish Department of Health, 2018).

Globally, recent systematic reviews (e.g., Chiarotti & Venerosi, 2020; Bougeard et al., 2021; Özerk, 2017) and prevalence studies (e.g., Irish Department of Health, 2018; McConkey, 2020; Özerk & Cardinal, 2020) have indicated an increase in the prevalence of ASD among children worldwide. The World Health Organization itself (2022) indicates an increase in prevalence worldwide, from an estimated one child in 160 diagnosed with ASD in 2021 (Depastas & Kalaitzaki, 2022) to 1 in 100 children in 2022 (WHO, 2023). A more recent systematic review (Zeidan et al., 2022) of prevalence studies between 2012 and 2021 indicates the same values, 1:100.

Not disregarding the effective increase in rates, several explanations for this increase have been suggested, namely the advances in diagnostic and screening tools (Depastas & Kalaitzaki, 2022; Fombonne et al., 2021), broader definition of ASD, changes in diagnostic criteria, changes in research methods, and the increased awareness of ASD (Depastas & Kalaitzaki, 2022; Durkin & Wolfe, 2020; Fombonne et al., 2021; Nevison & Blaxill, 2017).

Another aspect to be highlighted is the variability of prevalence rates between and within countries at the regional level (Chiarotti & Venerosi, 2020; Özerk, 2017). Regarding the different regions of the world and countries, Chiarotti and Venerosi (2020) indicated that ASD rates (per 1000 children) in Europe varied between 4.2 in Italy and 31.3 in Iceland; in North America they varied between 10 (Canada) and 18.5 (United States), in the Middle East between 1.1. (Iran) and 15.3 (Lebanon region), in Asia between 0.8 (Bangladesh) and 93.0 (Japan region), and in Australia between 15.1 and 25.2.

In Europe, 14 countries participated in the European project "Autism Spectrum Disorders in Europe" (ASDEU) to estimate the prevalence of ASD in children aged 7–9 years. This study showed variations between 4.76:1000 (southeast of France) and 31.3:1000 (Iceland), which includes Portugal, with a study at the regional level identifying a prevalence of 5:1000 in the central region (Rasga et al., 2020). The only national study in Portugal was carried out by Oliveira et al. (2007), identifying an overall rate of 9.2:10.000 children (0.92:1000; 0.092%), with significant variations between regions - the lowest in the Algarve (2.4:10.000; 0.24:1000; 0.024%) and the highest in the Azores (15.6:10.000; 1.5:1000; 0.156%) (Oliveira et al., 2007).

It is also crucial to consider the role of parental knowledge about the diagnostic process (Hus & Segal, 2021; Sainsbury et al., 2023), as well as the variability of diagnostic procedures and practices that may exist depending on the country or region (Makino et al., 2021; Penner et al., 2018). Several studies indicate that one of the biggest challenges in informing parents or caregivers of the diagnosis is that they understand the diagnosis and how it was arrived at (Makino et al., 2021; Rogers et al., 2016). Parental understanding and awareness of diagnostic criteria may affect the identification and diagnosis of ASD (Wang et al., 2022; Zuckerman et al., 2014) and consequently influence variability in reported prevalence rates (Hus & Segal, 2021).

Furthermore, differences in diagnostic procedures, whether due to regional differences, the availability of qualified professionals, or the use of different instruments, also contribute to variability in rates and make comparisons between studies complex (Hus & Segal, 2021; Solmi et al., 2022; Talantseva et al., 2023). The variability in prevalence rates has been justified by methodological differences between studies (Chiarotti & Venerosi, 2020; Özerk, 2017), namely variations in the type of samples studied (children from different age groups; children from different levels of education), sample size and recruitment context; screening tools; and the procedures adopted to identify children with ASD. Some studies relied on existing administrative databases (special education or school data, health, or social records, combining data from multiple databases). Other studies integrated one or several steps to identify cases in underlying populations (DSM-based questionnaires or checklists administered to teachers, parents, or health professionals; reports of parent interviews; child assessment). So, these differences make it challenging to carry out comparative analyses of prevalence rates. In addition, there are cultural differences in the interpretation of children's behavior and awareness of the phenomenon (Özerk, 2017; Zeidan et al., 2022).

Regardless of these issues, prevalence studies are essential because they provide objective indicators on the dimension of ASD, its possible impact, and the necessary responses regarding health and education, anticipating the economic and social costs of the phenomenon. (Chiarotti & Venerosi, 2020; Özerk, 2017; Zeidan et al., 2022). Thus, they constitute a source of information for creating and developing public policies, raising the awareness of policymakers and the community in general for the phenomenon, and for the responses by the health and education services that are a priority. Prevalence data also reflect the status of services, including their ability to identify/diagnose and intervene and/or support responses for this population, allowing to signal improvements that should be considered by policymakers (Fombonne et al., 2021; Zeidan et al., 2022).

Children and adults with ASD are part of human diversity, and their dignity, freedom of choice and independence, non-discrimination, and full participation and inclusion in society must be safeguarded (United Nations Convention of the Rights of Persons with Disabilities, 2007). Full participation and inclusion in society require health services and adequate social and educational support that promotes the development and training of people with ASD. For this, information is needed on the prevalence rates of ASD among children, as well as its characterization, to plan and improve intervention responses in the field of physical and mental health and educational and social development.

The current study

In the last two decades, there has been a growing concern regarding obtaining ASD prevalence indicators, mainly in countries where the number of studies is smaller, such as Portugal. As mentioned earlier, this country has one study at the national level, with data collected in 1999/2000 (Oliveira et al., 2007), which identified the Azores as the region with the highest prevalence rate (15.6:10.000; 0.156%).

Later, within the scope of the ASDEU project, a study was carried out on the prevalence of ASD in the 2016/17 school year among children aged 7 to 9 years in the Central Region of Portugal (Rasga et al., 2020). The overall prevalence of ASD in the Center region was 0.5%, higher than that found in the study by Oliveira et al. (2007) in the 1999/2000 school year −0.125%. The authors suggested that the increase may result from changes in the diagnostic criteria introduced by the DSM-5, not being limited to the most severe manifestations of ASD.

Both studies (Oliveira et al., 2007; Rasga et al., 2020) indicate the need to develop further national and regional periodic studies to monitor and update ASD rates over the years. In the Azores region, the region with the highest prevalence rate in the 1999/2000 school year (Oliveira et al., 2007), the periodic collection of data on ASD should be the subject of special attention. However, after 20 years, no studies have been identified, so it is essential to update and identify the ASD prevalence rate in this region.

Thus, the present study aims to:

- Determine the prevalence of ASD in children in primary education in the Azores region.
- Obtain the sociodemographic and clinical characterization of children with ASD and discuss its implications.

Method

Data sources

The Azores archipelago comprises nine islands: Santa Maria, São Miguel, Terceira, Graciosa, São Jorge, Pico, Faial, Flores, and Corvo (see Fig. 1). The islands of the Azores have a population of around 236.657. The island of São Miguel concentrates most of the population (137.856), followed by Terceira (56.437), Faial (14.994), Pico (14.148), São Jorge (9.171), Santa Maria (5.414), Graciosa (4.391), Flores (3.793) and Corvo (430).

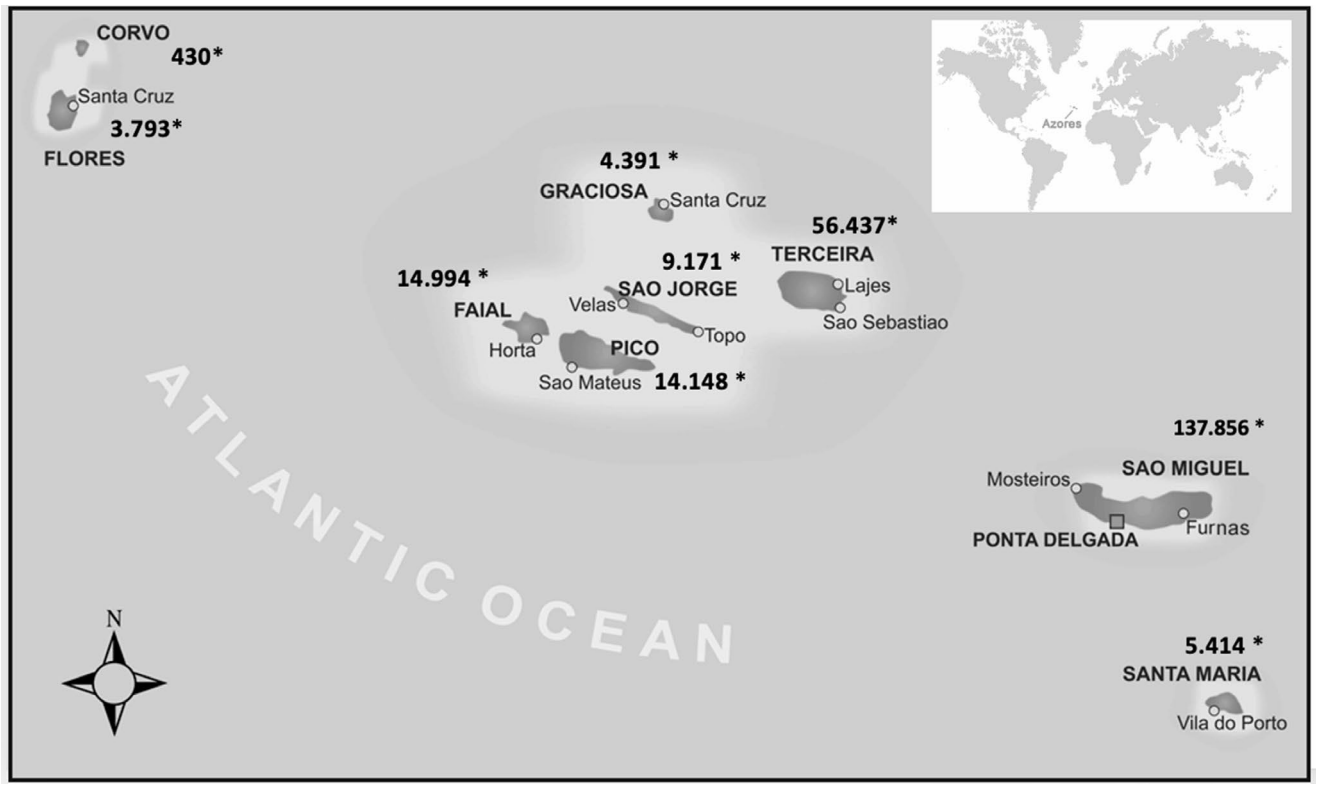
The present study exclusively includes primary school children living in the Azores in the 2018/2019 school year. It should be noted that in the Azores, as in mainland Portugal, primary education is compulsory, so all children of school age (including children who turn six by December 31, 2018) attend educational establishments. Given the smaller number of schools in the Azores, the study included all primary schools (public and private), seeking to cover all children diagnosed with autism spectrum disorders.

Case identification and data collection

The Ethics Committee of the University of the Azores approved the present study. The cases were identified based on the schools' administrative records. To this end, authorization was requested from the Regional Directorate of Education of the Azores (DREA) to access the number of children diagnosed with ASD per school and collect characterization data from the children's parents.

For the child to appear in the administrative records as having a diagnosis of ASD, it is necessary to signal special educational needs (by parents and/or teachers). However, the child does not need to demonstrate a compelling need to benefit from special education services, and it is only necessary to have a medical report indicating the diagnosis of ASD.

It is essential to clarify that, at the time of the study, the diagnostic process in Portugal did not follow a structured and standardized model, so there is no detailed information about the process and protocol used. What we can mention is that the diagnosis, preferably carried out by a multidisciplinary team (includes psychologist, speech therapist, occupational therapist, or special education teacher) led by a pediatrician, neuro pediatrician or child psychiatrist considers the child's developmental history, reported behavioral symptoms by caregivers, clinical observation and DSM-5 criteria, also integrating the administration of screening and diagnostic tests, such as the Autism Diagnostic Interview-Revised (ADI-R) and the Child Autism



*Population (the number of inhabitants per island)

Fig. 1 Azores islands and number of inhabitants per island

Rating Scale (CARS) (Oliveira et al., 2007). However, as already mentioned, there were no clear guidelines at the time of the study regarding the instruments to be used, such as the Autism Diagnostic Observation Schedule– 2nd edition (ADOS-2) or the ADI-R, considered golden measures (Hudock & Esler, 2022; Kamp-Becker et al., 2021; Le Couteur et al., 2008; Risi et al., 2006), so that the possibility is recognized that not everyone followed the same methodology to prepare the diagnosis. It should be noted that it was only in April 2019 that a directive (standard no. 002/2019 of 23/04/2019) was published by the General Directorate of Health (GDH) of Portugal for the Diagnosis and Intervention approach to Autism Spectrum Disorder in Pediatric and Adult Age (Direcção Geral da Saúde, 2019).

After authorization, the researchers contacted each educational institution, which provided the number of children with a proven diagnosis of ASD (that is, with a report or medical statement attesting to the diagnosis) and disclosed the study to parents and guardians to authorize their participation in the study to characterize children with ASD.

Parents who agreed to participate completed a questionnaire developed specifically for the study, focusing on sociodemographic information on the child and family, their clinical history, and the diagnostic process. The construction of the questionnaire was based on a review of the literature on ASD and the sociodemographic and clinical characteristics of children with ASD. Experts and professionals who work with children with ASD (child psychiatrists, psychologists, speech therapists) were also consulted to analyze the cultural sensitivity and appropriateness of the questions. Subsequently, comprehension tests were carried out with some parents and teachers of children with ASD (recruited through informal contacts of the researchers), being asked about the questions' meaning/interpretation and format. The comprehension tests resulted in some adjustments and refinements to some questions. In this way, it was ensured that parents would understand the questions as researchers expected.

Prevalence calculation

Official DREA statistics for the 2018/2019 (Governo dos Açores, 2019) school year were used to obtain the total number of children enrolled in primary education (across the Azores region and by island). It was impossible to establish the ratio by sex, given that the DREA statistical data does not explicitly discriminate the number of students by sex in primary education (it discriminates the educational level, ranging from the 1 st to the 9th grade). ASD prevalence rates

were calculated by dividing the number of children diagnosed with ASD by the total number of children enrolled in primary school (across the region and by island).

$$\mathrm{P\ (prevalence)} = \frac{\text{number of identified cases}}{\text{total population attending primary school}} \times 1000$$

The formula was adapted from 10,000 to 1000 children due to the small number of children attending primary school per island. Likewise, the formula for the confidence intervals considered 1000 and not 10.000 children, applying to the Azores region as a whole and by island.

$$\begin{aligned}&\text{Lower 95\% confidence limit} = \\ &\frac{\frac{1.96}{2} - \sqrt[2]{\text{No. Children ASD}+0{,}02}}{\text{total number of children in primary school}} \times 1000 \\ &\text{Upper 95\% confidence limit} = \\ &\frac{\frac{1.96}{2} + \sqrt[2]{\text{No. children ASD}+0{,}96}}{\text{Total number of children in primary school}} \times 1000\end{aligned} \quad (1)$$

Results

ASD prevalence rates in the Azores

Of the 10,892 children enrolled in primary education in the 2018/2019 school year, 108 were identified as having a diagnosis of ASD. Thus, the overall prevalence of ASD in the Azores region was 9.92 per 1000 children (cf. Table 1), approximately equivalent to 1% (0.99).

Given that the Azores archipelago comprises nine islands, an attempt was made to analyze the prevalence on each island, verifying a significant variability. The island of Corvo had the highest rate (1:19 children; 5.2%), followed by Santa Maria (5:222; 2.25%), Flores (2:123; 1.6%), and Graciosa (3:185; 1.6%). The island of Faial (5:571; 0.87%) and São Miguel (60:7799; 0.88) had the lowest rates.

It should be noted that the islands with the highest prevalence are those with a low population density and, therefore, a reduced total number of children in primary education (e.g., Corvo has 19 children in primary education). The rate established on the most populous island falls within the 95% CI of all the other islands, suggesting no significant difference between that rate and those of the other islands.

The sample is not random, but the total population of primary school children per island. In addition, the identification of cases of children with ASD was not the result of random sampling but rather effective identification in school records, integrating all cases of ASD from the outset. Thus, the risk of overestimation bias does not arise.

It should be noted that educational administrative records were not limited to children who demonstrated a compelling need for special education services (only their indication and proof of the diagnosis of ASD by medical statement). However, although this approach reduces the likelihood of not identifying children with less severe ASD, there may be cases of children who have not yet been signaled and, therefore, have not been diagnosed. So, the rate may be higher.

Characteristics of children diagnosed with ASD

Of the 108 children diagnosed with ASD, 82 parents agreed to participate in the study (see Table 1). Thus, 82 children were included in the characterization study, and 76% identified with ASD (see Table 2).

The sample comprised 82 participants, primarily male (N = 65, 79.3%), aged between 5 and 12 years (mean = 7.8, SD = 1.73). Considering this sample, the male-to-female ratio is approximately 3.82. It also should be noted that, despite the age range (5–12), all children are in primary school. There are children aged five because they entered in September when they were still five but would have turned

Table 1 Total number of children attending primary school in the azores, number of children diagnosed with ASD, number of children included in the sample, and prevalence estimates per 1000 children in the target population for the study 2018/2019 academic year

Island	Total population of primary school students	Nº of children identified at school diagnosed with ASD	not agree to participate	No. of children with ASD who participated	ASD prevalence per 1000 children*	Prevalence of ASD per 1000 children (95% confidence interval) **	% of ASD
Santa Maria	222	5	3	2	(5/222)*1000	22.52 (7.11–52.73)	2.52
São Miguel	6799	60	10	50	(60/6799)*1000	8.82 (6.72–11.37)	0.882
Terceira	2151	21	3	18	(21/2151)*1000	9.76 (6.04–14.93)	0.976
Graciosa	185	3	1	2	(3/185)*1000	16.22 (3.10–47.68)	1.622
São Jorge	299	3	1	2	(3/299)*1000	10.03 (2.08–29.50)	1.003
Pico	523	8	1	7	(8/523)*1000	15.30 (6.56–30.19)	1.530
Faial	571	5	5	0	(5/571)*1000	8.76 (2.78–20.50)	0.876
Flores	123	2	1	1	(2/123)*1000	16.26 (1.58–59.28)	1.626
Corvo	19	1	1	0	(1/19)*1000	52.63 (0.05–298.12)	5.263
TOTAL Azores	10,892	108	26	82	(108/10892)*1000	9.92 (8.14–11.97)	0.992

Table 2 Sociodemographic characterization of the sample (N= 82)

Variables	*n*	%	Mean	SD	Range
Sex (assigned to birth)					
Male	65	79.3			
Female	17	20.7			
Age			7.8	1.73	5–12
Position compared to siblings					
Youngest child	32	39			
Oldest child	19	23.2			
Middle child	6	7.3			
Only child	21	25.6			
Twin	4	4.9			
Main caregiver					
Mother	65	79.3			
Father	3	3.7			
Both	9	11			
Grandmother	4	4.9			
Other	1	1.2			
Caregiver qualifications					
Basic education	45	54.3			
High school	21	25.3			
University education	15	18.3			
No schooling	1	1.2			

six by December 2018. The older children did not pass the grade and were retained for one or two years.

The results also indicated that 39% (n= 32) were the youngest child in the family, and 27.5% (n= 11) were the only children. The primary caregiver of these children was the mother (79.3%, n= 65), and, for most, their highest level of education was either primary (54.8%; n= 45) or secondary (25.6%; n= 21) education.

Table 3 describes the diagnostic process, clinical history, and the medical background of the child's family. Regarding the level of the features of the ASD diagnosis, 53.7% (n= 44) were identified as having features of the mild level of ASD, 29.3% (n= 24) moderate level, and 3.7% (n= 3) severe. As for the diagnostic and clinical history, those who detected the first signs of ASD were most frequently the mother (62.2%, n= 51), followed by the educator/teacher (14.6%, n= 12). About the age at which the diagnosis was made, 3 is the age with the highest absolute frequency. At three years, more than half of the sample (54.9%) had a diagnosis.

When trying to analyze whether detection occurred earlier in girls or boys, it appears that despite the difference not being significant (see Table 4), the average age is higher in girls (M =4 years) compared to boys (M =3.72).

It should be noted that most children (62.2%; n= 51) did not receive support from an early intervention team. Those who did receive early intervention (37.8%, n= 31) started at an average age of 2.7 years (SD =0.8082).

The clinician responsible for the diagnosis was mainly a pediatrician (60.9%; n= 50), followed by a psychologist (23.2%; n= 19) and a child psychiatrist (14.6%; n= 12). The diagnosis was primarily performed in public health institutions (65.9%, N= 54). As for the evaluation protocol used to make the diagnosis, most parents did not know if it was applied (73.2%, N= 60). Most children did not take or had never taken medication to control symptoms associated with ASD (59.8%; n= 49), and most children (85.4%; n= 70) had no other associated medical condition (e.g., epilepsy, sensory disability, mental disability, etc.) at the time of this study.

Regarding the medical background of the child's family (Table 3), the majority (73.2%, N= 60) had no direct lineal relatives (grandparents, parents) diagnosed with ASD or any other family member with any neurological or psychiatric condition (73.2%; n= 60). Most (90.2%; n= 74) had no siblings with ASD and/or other type of disabilities.

Discussion

This study indicated an overall prevalence of ASD in the Azores Islands of 9.92 per 1000 children, which is equivalent to 0.99% (approximately 1%). Compared to the prevalence obtained in the 1999/2000 school year (15.6 per 10,000, equivalent to 1.56 per 1,000 children) (Oliveira et al., 2007), there seems to be an increase of 0.8% (0.156 to 0.99%). It should be noted that the current study's sample is not random but the total population of primary school children per island. So, the identification of cases of children with ASD was not the result of random sampling but rather the effective identification in school records, integrating, from the outset, all cases of ASD. Thus, the risk of overestimation bias does not arise.

The literature indicates that the higher rates are estimated by studies based on records-review surveillance, followed by studies with mixed designs, and the lowest rates are based on direct evaluation (Talantseva et al., 2023). So, rates tend to be lower for prevalence studies requiring in-person assessments. While notable methodologic differences in case definition exist between the Oliveira et al. (2007) study and the current study, with the former implementing direct assessment and the latter relying on administrative data, the several-fold increase in measured ASD prevalence between studies' results supports a high likelihood that these results indicate a meaningful increase in ASD prevalence.

Additionally, the higher prevalence rates in the Azores may reflect the age group studied, given that studies indicate that the identification of autism cases increases with school entry and that prevalence rates are higher among children aged groups 5/6–11/12 (Özerk, 2017), which the present study integrates.

It should be noted that the increase in the prevalence rate is in line with the most recent international studies and the

Table 3 Diagnosis, clinical history of the child, and family medical background

Diagnosis and clinical history - variables	*n*	%	Mode	Range
Features of ASD				
Mild	44	53.7		
Moderate	24	29.3		
Severe	3	3.7		
Does not know	11	13.4		
Who identified the early signs of ASD				
Mother	51	62.2		
Other family members	3	3.7		
educator/teacher	12	14.6		
Family's doctor	5	6.1		
Other healthcare professional	11	13.4		
The child's age when the diagnosis was made			3	1–9
Who made the diagnosis				
Pediatrician	50	60.9		
Child psychiatrist	12	14,6		
Family's doctor	1	1.2		
Psychologist	19	23.2		
The institution where the diagnosis was made				
Public health institution	54	65.9		
Private health institution	15	18.3		
Portuguese Association for Developmental Disabilities and Autism (APPDA)	9 3 1	11 3.7 1.2		
Private development center School				
Diagnosis is based on an evaluation protocol.				
Yes	13	15.9		
No	9	11		
Does not know	60	73.2		
The child participated in early intervention.				
Yes	31	37.8		
No	51	62.2		
Takes or has taken some psychopharmaceutical to control symptoms associated with ASD				
Yes	33	40.2		
No	49	59.8		
The child has other associated medical conditions				
Yes	9	11		
No	70	85.4		
Do not know	3	3.7		
Family medical background– variables				
Direct lineal relatives with ASD				
Yes	22	26.8		
No	60	73.2		
Siblings with ASD and/or other type of disability				
Yes	8	9.8		
No	74	90.2		
Any family member with neurological or psychiatric conditions				
Yes	22	26.8		
No	60	73.2		

Table 4 Age of ASD detection - comparison by sex (assigned to birth)

	Male (*n* = 65) M (SD)	Female (*n* = 17) M (SD)	t (27.211)	*p*
Age of ASD detection	3.729 *(1.7510)*	4 *(1.5812)*	−0.614	0.279

literature (Bougeard et al., 2021; McConkey, 2020; Özerk & Cardinal, 2020) that indicate this trend worldwide. This increase may be due to the diagnostic changes in the DSM 5 in 2013, which were no longer limited to the most severe expression of autism but included milder forms (Salari et al., 2022; Zeidan et al., 2022). However, it should be noted that this perspective is not widely accepted and is the subject of discussion in literature and research (King et al., 2014; Kulage et al., 2020). Some authors indicate that the DSM-5 criteria may exclude some cases previously diagnosed with Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS) or Asperger, especially children who have higher abilities or atypical symptoms (Kulage et al., 2020; McPartland et al., 2012; Smith et al., 2015). Thus, the DSM-IV criteria, being more comprehensive, can increase diagnoses but can also exclude some cases. This duality reinforces the need to adopt standardized protocols and robust measures, particularly validated and widely recognized instruments, to ensure more accurate, objective, and consistent diagnoses (Kulage et al., 2014).

Comparing the values found in the Azores with the results obtained from other studies carried out in other European countries at the regional level - and which resorted to administrative data from the region in age groups that integrate primary education (6–10 years old) - it seems that the Azores tend to show higher values. For example, two regional studies in Italy indicated 4.2:1000 and 4.3:1000 (cf. Chiarotti & Venerosi, 2020). Only the study in the region of Catalunya (Spain) that used administrative data on children aged 6–10 years (primary school age) indicates a higher rate −11.8:1000 (Pérez-Crespo et al., 2019).

Compared with national studies from other European countries that also used administrative data and integrated similar age groups, the prevalence of ASD in the Azores is also higher. For example, the study by Bachmann et al. (2018) in Germany indicates a prevalence of 6.0:1000 children. Also, compared with the prevalence rates in Europe indicated by a recent meta-analysis (Talantseva et al., 2023), between 0.5 and 0.73, the prevalence in the Azores is higher.

The prevalence rate also seems to be higher in the Azores compared to recent studies in other countries outside Europe that used administrative data. For example, a recent study in Colombia indicates a rate of 0.187% (García-Zambrano et al., 2022). Another study developed in Korea, which used data from the National Health Insurance Service (NHIS), indicates that of children born between 2007 and 2014,

about 0.9% were diagnosed with ASD by 2020 (Kim et al., 2021). Globally, the prevalence rate in the Azores, around 1%, is close to the worldwide estimate reported by the WHO (2022) and the review of prevalence studies between 2012 and 2021 (Zeidan et al., 2022).

Although the present study points to the higher prevalence of ASD in the Azores, it should be noted that the results derive from administrative records, which, in turn, are based on medical reports that attest to the diagnosis of ASD. As indicated in the method section, in Portugal, there were no clear guidelines regarding the diagnostic process and the instruments used at the time of the study. Therefore, it is possible that a standardized protocol or one with golden measures, such as the ADOS-2 or ADI-R, was not used. So, although administrative records allow greater scope in identifying cases, they also lead to limitations in the standardization of diagnoses. Therefore, the higher prevalence of ASD in the Azores must be analyzed in a contextualized way, and the specific diagnostic conditions mentioned must be considered. It is essential not to disregard the possibility of a higher prevalence resulting from the lack of uniform and standardized protocols in the diagnostic process.

Regarding the sample characterization, it was found that most children (79.3%) are male, with a ratio of 3.82:2, which aligns with most studies and systematic reviews (Posserud et al., 2021; Salari et al., 2022). Fombonne (2009) estimated a 4:1 male: female-gender ratio, and a systematic review indicates that the ratio is about 3:1 (Loomes et al., 2017). However, some authors have drawn attention to the possibility that ASD is underdiagnosed in girls (May & Williams, 2018AQ), given that historically, diagnostic criteria for ASD were based mainly on research involving male participants. So, the criteria may not fully capture the diverse ways in which autism can manifest in girls, and societal stereotypes about autism being more prevalent in boys can lead to underdiagnosis in girls.

Despite the limitation of standardization of the diagnostic process indicated above, we cannot fail to consider that the prevalence of ASD in the Azores region seems higher when compared with the global rate in Portugal and the remaining regions of the country and other regions of Europe. Thus, the question arises about the possibility of concentration of children with ASD in the region. The literature indicates that of all neurodevelopmental disabilities, ASD is considered one of the most hereditary (Newschaffer et al., 2007; Özerk, 2017; Robinson et al., 2011). Specifically on the Azores region, Oliveira et al. (2007) raised the possibility of some genetic specificity in its population - as it is a region with high consanguinity and a higher prevalence of recessive genetic conditions, such as ASD.

Analyzing the data from the present study, we can say that the findings from this study appear to support a heritable predisposition for ASD. Considering that the ASD prevalence identified in the current study is 1%, the fact that 26.8% of direct relatives also had ASD indicates a 26 times increased likelihood of having ASD. In addition, sibling studies typically identify rates of about 20% among younger siblings of children with ASD (Ozonoff et al., 2011). So, the fact that 10% of children identified had a sibling with ASD or other disability is not that low considering. Indeed, over 25% of children in this study were from single-child households, 23% were the oldest child, and younger children would not have as much time to access an ASD diagnosis, particularly considering the relatively young age range of children in the study.

Furthermore, we cannot disregard the possibility that family members were not diagnosed. On the one hand, there may be adult family members who were not evaluated and not diagnosed due to less awareness and recognition of the phenomenon a few decades ago and fewer means of diagnosis.

Another result to be highlighted is the fact that more than 85% indicate that the child does not have other associated medical conditions (although medical conditions associated with ASD are listed, such as epilepsy, sensory impairment, mental disability, etc.). In this context, the studies' results are inconsistent with other prior studies about co-existing medical, psychiatric, or developmental conditions (Bougeard et al., 2021). So, the results of this study indicate that most parents did not identify any concomitant condition. However, not identifying them does not necessarily mean they are absent. Parents may identify the symptoms of other medical conditions as symptoms of ASD without considering their differentiation.

It should also be noted that around 40.2% of children took medication to control symptoms associated with ASD, a high percentage. This result may be due to the open formulation of the question, with the types of medications not being listed. Thus, parents may have assumed any psychiatric medication to be specific medication to control ASD symptoms. When asked about the type of medication, they mainly indicate medication for anxiety and hyperactivity.

Regarding the identification and diagnosis of ASD, the mother primarily identifies the first signs. Mothers tend to take on more of the role of primary caregivers for children (Shrestha et al., 2023), especially in early childhood. This closer contact with the child allows mothers to be more attentive to behaviors and developmental milestones, increasing the likelihood of them being the first to identify atypical indicators of development.

The fact that pediatricians make most diagnoses (60.9%) reveals the central role of these professionals in child health. Pediatricians typically monitor the child's health and development from the first months of life (Alghamdi et al., 2023;

Dodson et al., 2022), which is why they are in a privileged position to identify early signs of ASD. They are also the professionals whom parents tend to turn to when they have concerns about their child's development (Dodson et al., 2022). Compared to pediatricians, psychologists make fewer diagnoses (23.2%), which may be due to the scarce number of these professionals in public health institutions and even in schools. Another reason may be the lack of resources and scarcity of psychologists specializing in ASD, limiting the diagnostic assessments that psychologists can carry out.

The lack of psychologists specializing in ASD in public health institutions and schools may mean that some diagnoses may be made by professionals who may not have the same depth of training and experience in recognizing signs of ASD, leading to less accurate diagnoses and, therefore, with implications for the necessary intervention measures. On the other hand, as most diagnoses are carried out by pediatricians, who are responsible for various child health problems, this may result in an overload of these professionals, with less time and resources dedicated to the thorough diagnosis and assessment of ASD. It should be noted that this is a complex process that requires detailed observation and multiple sessions, and it is recommended that it be carried out by a multidisciplinary team - which includes a psychology professional (Gerdts et al., 2018; Volkmar et al., 1999). The shortage of psychologists specializing in ASD limits the ability to create such teams, which may compromise the multidisciplinary and holistic approach needed for assessment and intervention in ASD - diagnoses may not reflect the full complexity of ASD and, therefore, affect the appropriateness of subsequent interventions.

Another aspect to highlight is that 73% of respondents report not knowing whether an assessment protocol was used to obtain the ASD diagnosis, which suggests that most parents do not seem to have sufficient knowledge about the ASD diagnosis process. Furthermore, 11% report that the diagnosis of ASD is not based on an assessment protocol, which may reflect the non-existence of such a protocol or a mistaken perception and/or lack of knowledge of the procedures and diagnostic criteria. This lack of knowledge may reflect insufficient information availability, communication difficulties about standardized diagnostic practices, or even difficulties understanding them. Some studies indicate that parents are often not fully informed or do not understand the specific criteria and procedures used in diagnosing ASD (Makino et al., 2021; Rogers et al., 2016), suggesting problems with communication or transparency on the part of professionals (Boshoff et al., 2019), whether due to the complexity of the diagnostic process (Boshoff et al., 2019; Hus & Segal, 2021) or even the scarcity of educational resources available to parents.

On the other hand, it is also worth remembering that in Portugal, it was only in April 2019 that the GDH created a standard for the assessment, diagnosis, and intervention of ASD (Direcção Geral da Saúde, 2019), which indicates the procedure and protocol to be used in the diagnostic evaluation of ASD. The data for the present study were collected in the 2018/19 academic year when the standard had not yet been created, so it is also possible that a structured protocol had not been applied at the time.

The standard above also postulates that a multidisciplinary team with training and documented experience in ASD must make the diagnosis. The team must include a pediatrician with experience in neurodevelopment and/or neuropediatrics and a child and adolescent psychiatrist, with the support of a psychologist, speech therapist, occupational therapist, special education and rehabilitation technician, nurse, and social worker. This standard, therefore, reinforces what was previously mentioned about the need to integrate specialized psychologists in the ASD assessment and diagnosis process.

It is also worth highlighting that the GDH standard recommends that the ASD diagnostic process follow standardized clinical steps focused on evaluating signs and symptoms. It considers the criteria of DSM-5, ICD-10 (International Classification of Diseases), or DC:0–5 (Diagnostic Classification Manual for Mental Health and Child Development Disorders), adapted to the child's age and context. The assessment includes direct clinical observation, analysis of clinical history, and use of complementary screening tools, with the Modified Checklist for Autism in Toddlers Revised with Follow-up (MCAT-R/F) indicated for children aged 16 to 30 months (Direcção Geral da Saúde, 2019).

However, although the standard emphasizes the importance of structured methods, there are no guidelines for the systematic use of gold standard instruments, such as the ADOS-2 and the ADI-R - which limits the standardization and comparability of diagnoses, national or international. Literature indicates that these instruments would provide greater objectivity and reliability to the diagnosis, reducing the likelihood of subjective interpretations by professionals and, therefore, the variability of diagnoses (Cicchetti et al., 2008; Hudock & Esler, 2022; Olsson et al., 2016; Zander et al., 2016). Furthermore, we cannot fail to mention that the ADOS-S was adapted for the Portuguese population only in 2023 (Gonçalves et al., 2023), and the ADIR-R has been translated into Portuguese from Portugal; however, there is still no publication of its adaptation.

Finally, it should be noted that most children who accessed early intervention were diagnosed before age 3. Considering that some authors argue that early intervention should start between 2 and 3 years of age (Zwaigenbaum et al., 2016), providing better results due to more remarkable

neuronal plasticity, this result seems to indicate the scarcity of resources in this area in the Azores, with the need for more significant investment in early intervention.

Implications

Without disregarding the limitations of the diagnostic process already reported at the time of data collection, the present study reveals a meaningful prevalence of ASD in the Azores among primary school children. It draws attention to the need to provide more services and intervention responses at this stage, namely in the school context. In addition, the data obtained on early intervention shows the scarcity of resources and services in the field for these children and families.

Although there are some Azores services available, these appear to be insufficient and/or not reaching all children and families with ASD. The services available in the Azores region stand out: the delegation of the Portuguese Association for Developmental Disorders in the Azores, located on the island of São Miguel, with the mission of promoting the quality of life and social integration of people with neurodevelopmental and neurodevelopmental disorders and autistic spectrum; the clinical consultation specialized in development, which includes ASD, at the public hospital of Ponta Delgada (Island of São Miguel) and the public hospital of Horta (Island of Terceira); the Azores Child and Youth Development Centre, located on São Miguel, private clinical service with social protocols, with specialized clinical assessment and intervention consultation for ASD.

Notably, most children who benefited from early intervention lived on the island of São Miguel, Ponta Delgada, or nearby locations. This finding may indicate the greater difficulty for children in more remote locations on the island of São Miguel and, even more so, on other islands to access early intervention services.

It can be concluded that, although some resources are available, they are concentrated around the principal city of the largest island in the Azores. Therefore, it seems essential to promote children's mobility from other islands and/or more remote regions to the services available in São Miguel (Ponta Delgada) or to create responses on other islands and/or regions.

Furthermore, the results allow us to conclude that there is a need for more significant investment in integrating psychologists into multidisciplinary teams that work with children with ASD. The lower participation of psychologists in the diagnosis of ASD compared to pediatricians, due to the scarcity of these specialized professionals in public health institutions and schools, indicates the importance of investing in the training, hiring, and integration of psychologists specialized in ASD. This investment will allow for a multidisciplinary approach, ensuring all children can access accurate diagnoses and effective interventions.

We must emphasize, too, that the results indicated parents' lack of knowledge or little understanding of the ASD diagnosis process. These data may reflect the need for more explicit information made available by health professionals or the difficulty in communication, possibly due to a lack of involvement or detailed explanation during the process. Diagnosing ASD is complex and can involve multiple sessions, which can be confusing for parents. Parents may need a clear explanation to understand the role of assessment protocols.

Therefore, this makes us reflect on the need to improve communication between health professionals and parents, ensuring they understand the diagnostic process and what it entails. Also, in this context, the psychologist's role can be essential in creating educational/informative programs aimed at parents or communicating and clarifying parents using clear and accessible language. The psychologist can help improve communication and decode medical language, making it easier for parents or caregivers to feel more informed and confident. Parents' knowledge and understanding of the ASD diagnosis are essential for their involvement and active participation in the ASD intervention process with their children.

The possibility of the high prevalence of ASD in the Azores being associated with the lack of standardization of assessment protocols and the non-use of internationally recommended gold-standard measures at the time of the study has been addressed. This allowed us to reflect, even today, on the need to improve the diagnostic process in Portugal. Standard 002/2019 from the Department of Health made significant advances, clearly establishing standardized clinical procedures based on internationally recognized diagnostic criteria (DSM-5, ICD-10, and DC:0–5). However, except the MCAT-R/F aimed at children between 16 and 30 months, it does not establish the systematic implementation of gold standard instruments, such as the ADOS-2 and the ADI-R or similar - which could provide the diagnosis greater consistency and objectivity. The recent adaptation of the ADOS-2 for the Portuguese population (Gonçalves et al., 2023) and the translation of the ADI-R represent significant advances. However, it is crucial to promote the adaptation of more instruments and, mainly, invest in training professionals to use them to guarantee their correct and consistent application in all diagnostic contexts. It would also be recommended that the implementation of established procedures and their results be monitored to evaluate their impact on diagnosis accuracy and the reduction of variability between professionals.

Finally, the limitations of the study must be mentioned. It is noteworthy that the identification of cases was based

only on the administrative records of the schools and that an evaluation protocol was not administered to confirm the diagnosis in the identified cases. The present study, namely the difficulty of concluding the increase in the prevalence rate in the Azores, reveals the need to update prevalence rates regularly but include an evaluation protocol to confirm the identified cases. It is also suggested that official data on the age range of children in each of the years that make up primary education be obtained to get comparable data (according to age) with more studies. Furthermore, to validate the genetic specificity of the population in this region, it would be pertinent to explore the existence of ASD better in siblings and other family members.

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Data availability The datasets generated and/or analyzed during the current study are not publicly available due to the investigators' commitment in the informed consent form that only the investigators involved in the study would have access to the data and that they do not make data available to third parties.

Declarations

Ethics approval The study was approved by the ethics committee of the University of Azores (Registration UAC/2019/8282; Report 32/2019). All procedures performed in the present study were under the ethical standards of the research committee and the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed consent Before collecting data, participants were informed in writing about the scope and aim of the study, the data protection regulations, the guarantee of protection of the data collected and its exclusive access by researchers involved in the study, and their right to refuse or withdraw from participation at any time. Informed consent was obtained from all participants.

Conflict of interest The corresponding author, on behalf of all authors, states that there is no conflict of interest.

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