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ORIGINAL ARTICLE

Survey for caregivers of people in the autism spectrum in Chile: first concerns, age of diagnosis and clinical characteristics

Encuesta para cuidadores de personas del espectro autista en Chile: primeras preocupaciones, edad del diagnóstico y características clínicas

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What do we know about the subject matter of this study?

At the time of publication of this paper, there are no reports on caregivers' perception of the concerns and age of diagnosis of individuals on the autism spectrum.

What does this study contribute to what is already known?

It highlights the wide gap between the age of first concerns of the parents and the medical ASD diagnosis, which means a critical loss of treatment opportunities and may jeopardize the chances of a better future prognosis.

Abstract

Autism Spectrum Disorders (ASD) are neurodevelopmental disorders of increasing prevalence. People with ASD have multiple health, education, and community needs, yet there is little information about their situation in Chile. **Objective:** To learn about the demographic and clinical characteristics, caregiver's first concerns, and age of diagnosis of ASD individuals. **Patients and Method:** Participants were parents/caregivers of ASD persons, who answered the Caregiver Needs Survey, developed by Autism Speaks specifically for this purpose, and translated into Spanish. The survey is comprised of 4 sections: demographic information, characteristics of the ASD individual, past and present use of Health and Education Services, and parents/caregivers' perceptions of satisfaction, impact, stigma,

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and quality of life. Data from the first two sections are reported in this paper. **Results:** The survey was answered by 291 caregivers (86% mothers) of 291 mostly male ASDs (89%), aged between 1-40 years (X: 10.4 SD: 6.1). The average age of parents' first concerns was 29.2m (SD: 23.8) where the main ones were: interaction difficulties (79.4%), unusual response to sensory stimuli (69.8%), behavioral problems (65.3%), unusual gestures/movements (64.3%), and lack of eye contact (63.6%). The average age of diagnosis was 58m (SD: 36.5), with an average delay of diagnosis of 29m. The diagnosis was most frequently made by pediatric neurologists (44.7%), child psychiatrists (19.2%), and pediatricians (5.5%). The most frequent comorbidities were language impairment, cognitive deficit, and behavioral problems. **Conclusions:** The late age of diagnosis of ASD and the large gap between the age of first concerns and diagnosis, represent a critical loss of treatment opportunities and jeopardize the chances of a better long-term outcome.

Introduction

The increasing prevalence of Autism Spectrum Disorders (ASD), with current alarming figures up to 1:54 children aged 8 years[1], is a phenomenon that affects all regions worldwide, regardless of cultural, socioeconomic, or ethnic factors[2,3]. There is strong evidence on the relevance of early detection, both in intensive, appropriate, and timely interventions that result in significant improvements in cognitive and verbal skills and changes in developmental pathways, leading to a reduction in deficits[4,5].

Many factors play a role in delaying diagnosis, including the severity of symptoms, socioeconomic status, parental concerns about initial manifestations, and family access to health and education systems[5-7]. Although there are ASD children with more subtle characteristics that become evident at school age, many cases can be reliably diagnosed by trained medical professionals at about age 2[8]. Diagnosis in boys is four times more frequent than in girls[3], although the increasing detection of a less marked clinical phenotype in girls has reduced this proportion[9].

Hispanic families living in the USA face more difficulties in accessing diagnosis and health care than the non-Hispanic population, and general practitioners consider more difficult to diagnose children from these families[10]. A survey for caregivers of 758 families, from Southeast European countries, carried out by Daniels[11], shows that despite the results vary among countries, there are deficiencies in the timely diagnosis and the satisfaction and access to therapeutic interventions.

In Chile, as well as in other Latin American countries, there is little available information about the characteristics of ASD individuals, their families, and their access to timely diagnosis. These data are essential for decision-makers to develop effective public policies for this group[12].

This study is part of a collaborative work of the Latin American Autism Spectrum Network (REAL) integrated by professionals from universities and institutions in six Latin American countries. Its purpose is to collect information that allows a better understanding of the situation and needs of ASD people in Chile and thus contribute to the development of strategies aimed at improving the quality of life of ASD individuals and their families.

The objective of this work is to describe the sociodemographic and clinical characteristics, first concerns of the parents, age at diagnosis, and the professional who makes it, in order to help recognized the situation of ASD people and their families in Chile.

Patients and Method

Survey development

Autism Speaks, through its Global Autism Public Health (GAPH) Initiative, developed the Caregiver Needs Assessment Survey to assess the needs of affected families[13]. This survey is intended for parents or caregivers of individuals with a clinical diagnosis of Autism Spectrum Disorder (ASD), Pervasive Developmental Disorder (PDD), Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS), Asperger's Syndrome, or Autism Disorder. The survey can be answered through personal, telephone, or on-line interview and takes around 30 minutes to complete.

The survey consists of four sections and, if the respondent indicates that she/he has more than one child with ASD, the respondent should answer regarding the oldest child. The first section includes general and demographic information (relationship to the child, race/ethnicity, education, city of residence, etc.).

The second section includes specific questions related to the characteristics of the ASD child (age, diagnosis, first caregiver's concerns, age at diagnosis, and the professional who made the diagnosis). Respondents had to estimate according to the following categories: *a) current general functioning level of the ASD child:* mild, moderate or severe impairment; *b) current verbal skills:* no verbal skills, isolated words, 2-3 word phrases, sentences of more than 4 words, complex sentences; and *c) Intelligence Quotient or Developmental Quotient:* moderate to severe delay, mild delay, average, above average. This section also considered questions regarding which professional made the diagnosis (pediatrician, psychologist, neurologist, psychiatrist, primary care physician, nurse, multidisciplinary team, other).

The third section addresses the use and access to Health and Education Services. Caregivers had to indicate which services they have ever used and which they currently use. The final section asks about caregivers'/ parents' perception of satisfaction regarding access to services and unmet needs, the impact on the family and caregiver of having an ASD child, the perception of stigma or self-stigma, and finally, questions about the quality of life. Sections 1 and 2 are the subject of this publication.

Country-level implementation

A national coordinator was responsible for the implementation of the survey, supported and technically assisted by the REAL, the WHO, and Autism Speaks. The work consisted of a pilot study with 12 families, preparation of the survey, its translation and back translation for wide dissemination, and was approved by the Ethics Committee. In addition, the implementation included the selection of population sources data to be surveyed, the sampling frame, delivery of the surveys to the recipient organizations or individuals, and the collection of the completed surveys.

This study was approved by the Human Research Ethics Committee of the Faculty of Medicine, University of Chile in line with the Declaration of Helsinki. An informed consent and study description were provided online immediately before the survey. Participation was voluntary and anonymous. There was no monetary compensation for participation.

Participants

The target population was caregivers of ASD individuals in Chile. Due to the lack of available records of the target population for selecting individuals or units for the study, we used a complete list of service providers, which included organizations that provide any type of interventions aimed at ASD individuals. Many other sources were used to identify the target population.

Based on the authors' clinical, academic and research experience, a preliminary list of potential organizations was created and then added public information from online searches. Organizations that met the eligibility criteria were contacted by email and received the primary contact list. Using snowball sampling, organizations on the list were asked to recommend other organizations not identified in the primary search, until reaching saturation.

The survey was sent by email in all cases, completed at home (90%), at institutions providing health or educational services, or at parent organizations. Around one-fifth of the respondents (21.9%) needed assistance to complete the survey.

Results

The final sample was composed of 291 participants.

Caregivers' characteristics

Table 1 shows the characteristics of the caregivers. All respondents live in Chile and most of them were mothers of ASD individuals (86.3%). Regarding educational level, 63.2% of the participants have higher education. Most of the families resided in urban areas: Metropolitan Region (including Santiago, the capital and most populated city (49.8%)), Valparaiso (10.8%), and Antofagasta (7.2%). 15% of the group surveyed reported having at least one other member in the household diagnosed with ASD.

Regarding the health care system used, the respondents reported using the public health system (31.6%), the private one (57%), or the institutional one (9.6%). In Chile, this last category includes the institutional hospitals of the armed forces and other guild institutions, such as the *Hospital del Profesor*.

Characteristics of ASD individuals

Table 2 shows the characteristics of ASD individuals. Most individuals were males (89%), aged between 1 and 40 years (average 10.44 - SD 6.05). The average age at diagnosis was 58.0 months (SD 36.5), and the median was 46 months.

All individuals met one of the diagnostic categories of autism: ASD (36.4%), Asperger's syndrome (29.6%), and PDD (14.8%). Regarding the estimated level of deficit in general functioning (impairment severity), the respondents reported 7.2% as severe, 39.2% moderate, and 39.9% mild. In relation to the verbal skills level, about one-third of the individuals presented non-verbal communication or with a verbal skills level not higher than that of a two-year-old child; 12% were able to formulate sentences of more than four words, and 53% could complete complex sentences. Concerning the IQ or psychomotor development (PD) level reported by professionals, respondents reported that 53% of individuals had an IQ/PD at or above the average range, and 25.8% reported mild, moderate, or severe delay. 61.2% of the individuals presented behavioral problems.

First Concerns and Diagnosis

The first concerns of the caregivers appeared at 29.2 months on average (SD 23.8). In 69% of the cases, one of the parents, mainly the mother, was the first one to detect atypical characteristics. Among 18 possible concerns, the caregivers mention 9 (SD ± 4.5) on average; 15% mention four or less, and half of them mention ten or more. Figure 1 shows how often each concern was reported by caregivers. The most frequent concern was the difficulty in interacting with others (79.4%). Other concerns present in more than 50% of the sample were an unusual response to sensory stimuli (69.8%), behavioral difficulties (65.3%), unusual gestures/movements (64.3%), lack of eye contact (63.6%), repetitive interests (58.4%), lack of understanding of non-verbal communication (56.4%), speech/language delay (55.3%), and not speaking like other children of the same age (50.9%). The least mentioned concerns were medical problems (17.5%), gross motor problems (32.0%), difficulties in learning new things (alphabet, numbers) (32.8%), absence of speech (35.1%), and loss of speech or other skills (35.1%).

The diagnosis was made by a health professional in 95% of the sample (Figure 2). Pediatric neurologists were the professionals most frequently mentioned in the diagnosis of ASD (44.7%), followed by child psychiatrists (19.2%), and professional teams (17.2%). Pediatricians diagnosed 5.5% of the total cases.

Discussion

This study is the first step to systematically assess the characteristics of ASD patients in our country from the point of view of their caregivers. These data provide valuable information on the characteristics of ASD patients and their families, the detection of developmental difficulties by the parents, age, and diagnostic characteristics. This information provides the basis for the development of health and education strategies and policies.

This sample by convenience shows a bias towards a socioeconomic group of caregivers that is above the national average in many of the descriptive variables such as a higher proportion of urban versus rural families[14]; a higher educational level where 60% of caregivers report having a university or higher degree, compared with 21% of the Chilean population[15]; and 57% of the caregivers are affiliated to a private health care system versus 20% of the average Chilean population[16]. In addition, the factors before mention allow us to expect better use of digital tools, which facilitate the adequate completion of this survey. In contrast, other caregivers would have a higher difficulty accessing or completing the survey due to less experience with digital systems. Therefore, the information collected possibly reflects an advantageous reality compared with the situation of most families in our country.

We must consider the time window of the data collected given the wide age range of the ASD individuals in the families surveyed. The males to females ratio (8.9:1.1) reported may be attributed to underdiagnosis of ASD in females, something that has been reverted in recent years by recognizing different and subtle expressions of the condition depending on gender[9]. The variations observed in the diagnostic categories are due to the temporal evolution of the diagnosis and classification concepts[1,11,17].

Presenting 40-50% of individuals with minor speech impairments, average IQ, and only mild deficiencies in functioning, the level of general functioning, speech, and IQ/PD reported in this sample is similar to that reported in recent epidemiological studies in the USA[3] and may be related to the socio-economic and cultural bias of this sample.

Table 1. Characteristics of 291 parents/caregivers of 291 individuals with ASD

Relationship of the respondent to the person with ASD	N (%)
• Mother	251 (86.2)
• Father	32 (11.0)
• Grandparents	2 (0.7)
• Other	6 (2.1)
Respondent Educational level	N (%)
• None	1 (0.3)
• Incomplete Primary School	1 (0.3)
• Complete Primary School	3 (1.0)
• Secondary School	51 (17.5)
• Tertiary School/Technical level	51 (17.5)
• Professional Degree	128 (44.0)
• Post Graduate	56 (19.2)
Other Parent Educational level	N (%)
• None	2 (0.7)
• Incomplete Primary School	3 (1.0)
• Complete Primary School	3 (1.0)
• Secondary School	57 (19.6)
• Nivel Terciario	42 (14.4)
• Professional Degree	126 (43.3)
• Post Graduate	52 (17.9)
• don't know	6 (2.1)
Place of Residence	N (%)
• Metropolitan Region	145 (49.8)
• Other Regions	133 (45.7)
• no answer	13 (4.5)
Health Care Providers	N (%)
• Public Health	92 (31.6)
• Institutional	28 (9.6)
• Private Health	166 (57.1)
• Other	5 (1.7)

On the other hand, the prevalence of intellectual disability in ASD individuals shows a tendency to decrease over time. Previous estimates of 70-75%, have been gradually decreased, and are currently around 30-40%. Among those, 20-30% presents borderline intellectual functioning, and around 40-50% are within the normal range. This trend is largely attributable to better recognition of the condition and the inclusion of a wider phenotypic spectrum, with mildly affected and/or better adaptive functioning cases[18].

One of the most important findings of this survey is the late age at diagnosis (58 months), with an average interval of more than two years between the parents' first concern and the time of diagnosis. At 24 and 36 months, 59% and 79% of the caregivers, respectively, reported having a major concern about their child's development, however, only 12.2% and 37.4% of the children had been diagnosed up to that point. This worrying delay in identifying ASD individuals is also observed and subsists in developed countries such as the USA, the United Kingdom, and Canada, despite the increased awareness in identifying early signs, where the age at diagnosis is still between 4 and 5 years with a temporal trend towards earlier identification[7].

The severity of symptoms, better socioeconomic status, greater parental concern, and previous interactions with health and education systems are factors that have shown a consistent association with earlier diagnosis. A recent publication of this same survey applied in Southeastern Europe to 789 caregivers, including Albania, Bulgaria, Croatia, and Turkey, showed an average age of 24.4 months for the first concerns, very similar to the Chilean survey, however, the age of diagnosis was earlier (40 months). This difference with our study could be attributable to a younger sample and a lower level of functioning[11].

Montiel[19] conducted the only study of ASD children in Latin America which, similar to the above, shows that the parental concerns appear early at 17 months, but the diagnosis takes 3 years on average (53-54m). Salomone[20] studied a sample of 23 European countries, composed of 1,410 children aged less than 7 years, where he found age at diagnosis of 42 months, with considerable variation between countries, ranging from 33 to 50 months. Children with better verbal skills were identified later, especially if they were female. This supports the idea of a more subtle manifestation in females and that children with milder symptoms are diagnosed later[7,11,19-21].

In this study, the age of first parental concern averaged two years before diagnosis, around 30 months of age, which is higher than that reported in the literature[11,22,23]. The percentage of parents who recognize some developmental alteration before age 1 (18.2%) and before age 2 (59%) is lower than that observed in other studies. Publications from studies of different designs and populations report an average age range of first concerns between 14 and 24 months, with about one-third of parents reporting first concerns at age 1, and three-quarters at age 2[11,22-28]. The delay observed in this sample in recognizing difficulties would indicate a lesser awareness of early social, developmental, and emotional milestones, specifically the warning signs of autism, compared with other developmental milestones such as the motor one.

Table 2. Caregiver-reported characteristics of 291 individuals with ASD

Gender	N (%)
• Male	259 (89.0)
• Female	32 (11.0)
Age (y), mean (SD)	10.44 (6.05)
Range (y)	1-40
Current diagnosis	N (%)
• Autism Spectrum Disorder	106 (36.4)
• Pervasive Developmental Disorder	43 (14.8)
• Asperger Syndrome	86 (29.6)
• Autism/Autistic Disorder	28 (9.6)
• Pervasive Developmental Disorder NOS	28 (9.6)
Current level of functioning/severity	N (%)
• Mild impairment	116 (39.9)
• Moderate impairment	114 (39.2)
• Severe impairment	21 (7.2)
• don´t know	29 (10.0)
• no answer	11 (3.8)
Current verbal abilities	N (%)
• Non-verbal	38 (13.1)
• Single words only	25 (8.6)
• Two or three-word phrases	35 (12.0)
• Sentences > 4 words	35 (12.0)
• Complex sentences	155 (53.3)
• no answer	3 (1.0)
IQ/DQ* Estimation	N (%)
• Severe/Moderate delay	29 (10.0)
• Mild delay	46 (15.8)
• Average	88 (30.2)
• Above average	68 (23.4)
• don´t know	50 (17.2)
• no answer	10 (3.4)
Current Behavioural Problems	N (%)
• Yes	178 (61.2)
• No	113 (38.8)
Age at first concerns (m), mean (SD)	29.2 (23.8)
Age at diagnosis (m), mean (SD)	58.0 (36.5)

*IQ/DQ: Intellectual Quotient /Developmental Quotient

It is important to highlight that the pediatrician

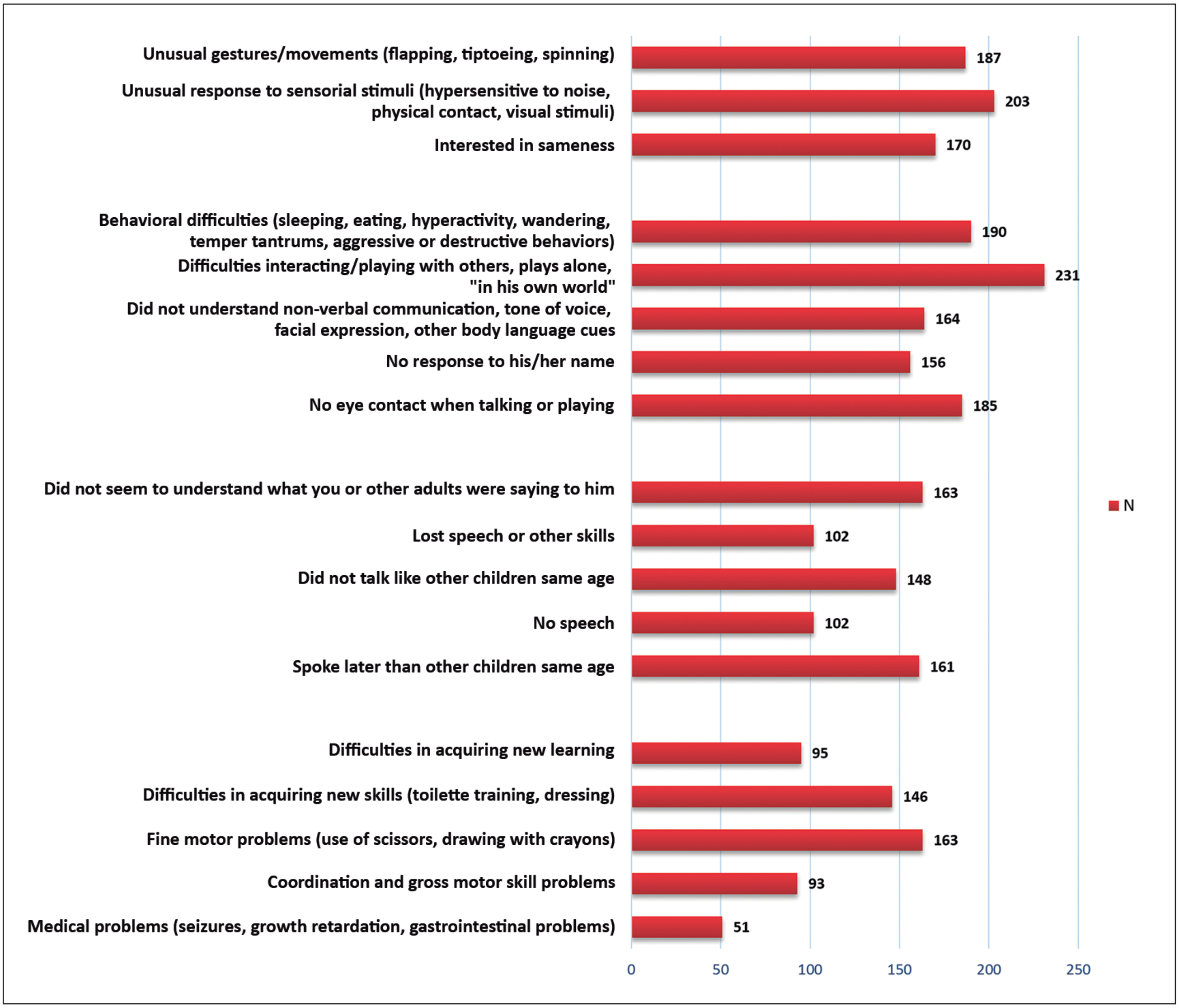

Figure 1. Nature and frequency of first concerns reported by caregivers in 291 individuals with ASD.

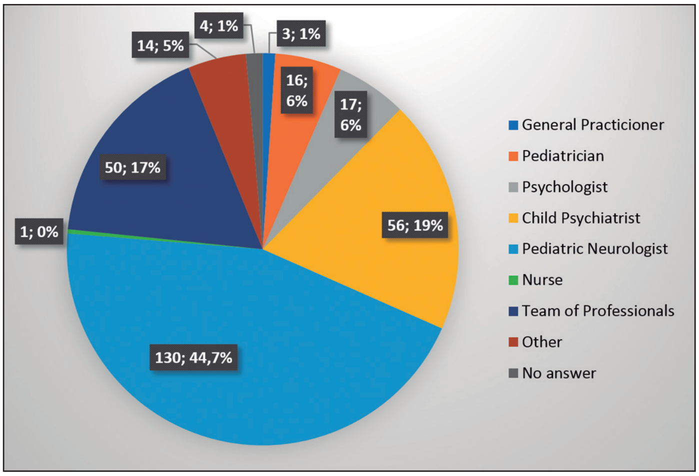

Figure 2. Professional who diagnosed Autism Spectrum Disorder in 291 individuals with ASD.

only diagnosed 5% of this sample. Considering that the pediatric consultation is a critical instance for the recognition and timely diagnosis of ASD and that pediatricians are the first professionals that parents refer their concerns to, they are the ones who should provide them with reliable guidance. In addition, their responsiveness is a determining factor in initiating an adequate diagnostic and therapeutic process. In contrast, missing this important opportunity to suspect or make the diagnosis means missing an unrecoverable therapeutic window that will have a decisive impact on the long-term prognosis. Some studies show that factors such as the lack of adequate training in developmental disorders or reluctance to burden parents by validating their concern lead them to adopt a passive behavior[29].

Diagnosing ASD is often a long and difficult process involving many actors including the child, family, pediatrician, specialists, and therapists, among others. The physician plays a key role in providing parents with a clear understanding of the process involved in obtaining a diagnosis of ASD, helping them to expand social networks, and guiding them to smooth interaction with existing care structures associated with ASDs[30,31].

Within the limitations of this study, it should be noted that it is a convenience sample, which, in this case, has a bias towards a group with a higher socioeconomic level than the average Chilean population and, therefore, reflects "the best situation" of ASD individuals in Chile.

The wide window of time detected in this sample which includes from babies to adults, calls into question the effect of changes in time that influence many, if not all, of the variables studied. In addition, it is worth mentioning that the reliability of this information is limited because it is a testimony of the respondents that is not verifiable. Since the collected information comes from caregivers, does not allow us to accurately confirm diagnoses or the current state of functioning and adaptation of ASD individuals. It has been noted that parents' estimates of the cognitive levels of their ASD children appear to be more inaccurate at higher levels of functioning[18].

These results can guide other research, focusing on priority areas for establishing health policies and actions in this population. One of the most immediate actions is early diagnosis and reducing the time gap between caregivers' first concerns and diagnosis, in health services related to children and adolescents.

In future studies, it will also be important to use new methodologies for collecting information and data in the most disadvantaged sectors of society (rural, low educational level, etc.) in order to transversally understand the reality. There is also a need to carry out studies by age group (children aged under two years, 2 to 5, 6 to 12, 12 to 18, and over 18), given the different developmental characteristics and services provided in the country.

Chile is a country with a long tradition of public health. Studying child growth and development has been a priority area. However, the emphasis of monitoring has been on psychomotor development and specific cognitive milestones, but not on socioemotional and communication development. Only recently, ASD has become a relevant topic for society and the media and has been gradually introduced in health programs and the academic curricula of this area. The data collected in this research are extremely important to consider in the different kinds of care, needs, and mental health situation of ASD individuals.

Conclusions

In Chile, this is the first exploratory descriptive study of caregivers, mostly parents, of ASD individuals. Their conditions in Chile are more unfavorable than that observed in similar studies conducted in southern European countries[11] regarding characteristics, age of first concerns, and delay in diagnosis.

The sample of this survey in Chile is mainly made up of caregivers with higher socioeconomic and educational levels, and with better access to digital media. Despite this, the results of this study show important indicators such as the two and a half years of delay in clinical diagnosis after the first parental concern, generating fewer opportunities for the overall/comprehensive development of these children and thus affecting their later prognosis. Possibly, the health and education systems do not adequately address early diagnosis, which is reflected in the limited participation of pediatricians in the timely detection of ASD.

Ethical Responsibilities

Human Beings and animals protection: Disclosure the authors state that the procedures were followed according to the Declaration of Helsinki and the World Medical Association regarding human experimentation developed for the medical community.

Data confidentiality: The authors state that they have followed the protocols of their Center and Local regulations on the publication of patient data.

Rights to privacy and informed consent: The authors have obtained the informed consent of the patients and/or subjects referred to in the article. This document is in the possession of the correspondence author.

Conflicts of Interest

Authors declare no conflict of interest regarding the present study.

Financial Disclosure

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