



Autism Spectrum Disorders in an Upper-Middle Income Country



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Abstract

The detection of Autism Spectrum Disorders (ASD) in Mexico has been a challenge. Parents, health and educational professionals lack knowledge of key symptoms causing delay in diagnosis, intervention and early treatment. Almost 76% of parents (N=92) expressed their first concern at 23.8 (SD=13.1) months, with a mean diagnosis delay of 41.8 (SD=35.2) months. The referral for a specialized assessment was suggested by medical doctor (35.8%), followed by teachers (27.4%), and psychologists (17.9%). Three professionals were contacted to obtain a formal diagnosis. Parents lose average 6.3 days of work per month to attend for their children's treatment appointments. Our findings can help develop better health and educational services to achieve timely diagnosis, and early intervention treatment.

Keywords: Diagnostic delay; Autism spectrum disorders; México; Economic burden

Introduction

In México, the prevalence of autism has been poorly studied, until [1], reported a prevalence rate of 0.89% (95% CI, 0.62-1.1%) for León, Guanajuato; in the same study, 70% of parents of children with ASD had concerns about their atypical development between 18 and 36 months of age, almost half of them had a first contact with health services at 24 to 36 months, but a formal diagnosis was reached between 36-60 months of age, or after, in 80% of the families. These data are consistent with a retrospective study (N=323) from a Mexican neurological center showing that the mean age of detection was 4 years old and the primary cause of parental concern was language delay or regression in 60% of the children [2].

Many studies show that most parents detect the signs and symptoms of ASD before 24 months of age [3-5] but the formal diagnosis is made 2 to 4 years later [6]. The delay is longer in low and middle-income countries compared to high-income countries (5.5-6 years vs. 4) [7]. Among Hispanics there is an

important lack of knowledge concerning developmental delays affecting the awareness and demand for assessment [8-10].

The diagnostic process is stressful, complex and difficult, this makes parents postpone [9,11-13], and when complaints are expressed to pediatricians many prefer to wait until the child is older to refer for assessment and lack important information about the early symptoms of autism [14] in contrast pediatricians in other countries are the first professional to refer for treatment [12,15].

In addition, in Mexico and Latinamerica very few diagnostic and screening instruments for autism have been formally validated [16-23]. Most centers use non-validated Spanish versions of these tools which were designed in Anglo-Saxon countries and have cultural biases that diminish their effectiveness when applied in countries with different languages than English such as the M-Chat or have different cutoff points like the ABC [17,24], or different total mean values compared to the original studies [19].

Moreover, timely diagnosis gives the opportunity to assess other siblings or family members with attenuated forms of the disorder and to receive genetic counselling. The age of detection, and other variables may differ depending on the recruitment setting, this is why we are interested in knowing the characteristics of children seeking attention in a psychiatric outpatient service. The aim of this study is to improve this knowledge which will be useful for the planning of services and public policy for this population.

Material and Methods

Type of design

A descriptive, prospective, cross-sectional observational study was conducted.

Sample

Participants were patients with a confirmed diagnosis of Autism Spectrum Disorder through a semi-structured clinical interview based on DSM-IV criteria and diagnostic instruments such as ADI-R, and/or CARS administered by an experienced child psychiatrist.

Procedure

Parents of children and adolescents (N=135) with a confirmed ASD diagnosis were invited to participate in the survey, with a response rate of 78.7%.

Measuring instruments

A survey was completed by the parents (Table 1).

Table 1: Sociodemographics and other variables of the study

	Autism (%) 50 (52.6)	Asperger (%) 26 (27.4%)	PDDNOS (%) 19 (20%)	Total ASD (%) 95(100)
Male N (%)	42 (84.0)	21 (80.8)	12 (63.2)	75 (78.9)
Age (years/months) M(SD)				
Child***	78.8(32.4)	108.7 (41.7)	100.4 (54.0)	91.3 (41.9)
Father	37.7 (7.1)	37.8 (6.6)	41.2 (8.6)	38.5 (7.4)
Mother*	33.8 (5.8)	34.3 (6.5)	39.8 (10.8)	35.1 (7.4)
SES (SD)	5.6 (3.0)	5.0 (0)	6.5 (2.0)	5.8 (2.7)
Monoparental family N(%)	8 (16.3)	10 (40.0)	6 (31.6)	24 (28.8)
ASD cause of separation/divorce N (%)	4 (57.1)	2 (20)	2 (33)	8 (34.8)
Initial concern yes/no N (%)*	48 (96)	26 (100)	18 (94.7)	92 (96.8)
Age in months of first concern M(SD)	21.0 (11.6)	26.2 (15.2)	27.8 (11.8)	23.8(13.1)
# Professionals before diagnosis M(SD)†	3.2 (3.5)	3.3 (3.0)	3.5 (2.6)	3.3 (3.2)
Diagnosis delay (months) M(SD)	35.4 (30.1)	42.4 (28.3)	55.1 (48.6)	41.8(35.2)
Other Previous diagnosis (%)	26 (52)	15 (57.6)	7 (36.8)	48 (50.5)
Comorbid non psychiatric illness N (%)	5 (10)	5 (19.2)	1 (5.3)	11 (11.6)
Medication prescribed for this illness N (%)	5 (10)	2 (8)	1 (5.3)	8 (8.5)
Medications prescribed for ASD M(SD)	1.5 (0.9)	1.6 (1.0)	1.6 (0.8)	1.5 (0.94)
Cost of medications in Dollars††	75.9 (57.8)	53.9 (44.6)	109.0 (52.6)	77.1(56.05)
Minimum wage (4.6 Dlls/day) # of days	16.51 (12.5)	11.73 (9.71)	23.7 (11.43)	16.7 (4.18)
Other therapies yes/no N (%)	29 (58)	18 (69.2)	8 (42.1)	55 (57.9)
Cost of therapies in Dollars M(SD)††	55.7 (54.7)	38.9 (34.0)	33.8 (24.2)	48.1 (46.9)
Minimum wage (4.6 Dlls/day) # days M (SD)	12.1 (11.91)	8.4 (7.4)	7.36 (5.2)	10.4 (10.2)
Days of work lost/ month M (SD)	7.0 (11.4)	3.4 (3.8)	8.5 (12.4)	6.3 (10.2)

Note: SES: Number of lights bulbs inside the household; †11.76% reported not having consulted any professional before receiving a formal diagnosis. ††2007 average exchange rate; *p≤.05, **p≤.01, p≤***.001

Statistical analysis

Group differences in categorical variables such as sex, subtype of ASD, type of family (monoparental vs. other) ASD as cause of separation (yes/no), initial concern yes/no, other previous dx (yes/no), comorbidity with non psychiatric disorders (yes/no), medication prescription (yes/no), other therapies (yes/no) were analyzed through chi square. Quantitative variables such as parents and child age, age of first concerns, number of professionals consulted, diagnosis delay in months, number of medications prescribed, cost of medication, minimum wage per day, cost of therapies, days of work lost per month were analyzed through analysis of variance (ANOVA).

Result

Sociodemographics

Twelve participants were removed from the study due to incomplete survey data. The final sample consisted of 95 children with autism spectrum disorder, of whom 78.9% (N=75) were male, with an average age of 91.3 months (SD 41.9).

Parental age

The mean age of the parents in the total sample and all subgroups was higher for the father compared to the mother: 38.5(7.4) vs. 35.1(7.4), PDDNOS 41.2(8.6) vs. 39.8(10.8), Asperger 37.8(6.6) vs 34.3(6.5) and the Autism 37.7(7.1) vs. 33.8(5.8) years (Table 1).

Developmental concerns

Most of the parents (96.8%) had preoccupations about their child development, percentage was higher in the Asperger group (100%), followed by Autism (96%) and PDDNOS (94.7%). The mean age of parental concern for the total sample was 23.8 months, the earliest concern was in the Autism group at 21 months, followed by the Asperger group at 26.2 months and the PDDNOS group at 27.8 months.

Referral for assessment

School and health professionals who referred the children for specialized assessment were physicians in 38.2% of cases, followed by teachers (27.4%), and psychologists (19.1%). Close relatives suggested that the child should be evaluated by an expert in 7.9% of cases, and 5.6% of children were assessed at the request of their parents.

Diagnosis

A formal diagnosis for the total sample was made until 41.8 months of age, for Autism at 35.4, Asperger at 42.4 and PDDNOS at 55.1. Almost half of the children receive a previous diagnosis other than ASD being ADHD the most common diagnosis.

Cost of treatment

The number of medications prescribed was between 1.5 and 1.6. The average cost of medication was between 53.9 and 109 dollars (dlls); in 2007 the daily minimum wage (dmw) in

Mexico was 4.6 dlls, so in order to buy medication for one month, parents would have to earn between 11.73 and 26.7 dmw. In addition, parents reported that 57.9% of the children with ASD receive additional behavioral and language therapy, with an average cost of 48.1 dlls per month, meaning that they would have to earn a corresponding 10.4 dmw. The average cost of the combined treatment (medications, language, behavioral and other therapies) would be 27.1 dmw.

Work productivity losses

Most of the mothers answered the survey, 46% them were housewives, the rest (54% N=51) reported losing between 3.5 and 9.5 days of work per month to attend for the children's medical appointments.

Discussion

In this study, we investigated the diagnosis delay in children with ASD and associated factors in a clinical sample.

Sociodemographics

As other studies we found a higher ratio of males vs. females 4:1 [25-29]. However, a recent study reported that the most reliable ratio between sexes is 3:1 given the higher risk of females to be underdiagnosed [30].

Almost 29% of the families were monoparental, from these 34.8% considered having a child with ASD was a major reason for separating, but there is no evidence that children with ASD are at increased risk for living in a household not comprised of 2 parents [31]. However, the percentage reported in this study is higher compared to the general population of Mexico; 16.8% in 2010 and 21% in 2015 [32].

Parental age

The average age of the parents at time of conception for the total sample was 30.9 vs. 27.5 for fathers and mothers respectively. This figure is higher than the age of the first pregnancy for Mexican women which is 21.1 years [33], and 24 for men for their first child [34].

The role of advanced maternal age in ASD has not been well established; evidence show that women above 40 and below 19 have a higher risk for having a child with ASD [35-38]. The association is stronger for the father's age [39,50]; but the causal effects of the parental age for elevating the risk of autism are still unknown [41].

Developmental concerns

Consistent with other studies [51-53], nearly 97% of the respondents had preoccupations concerning their child's development. The average age of first concern was 23.8 months for the total sample, which was earliest in the Autism group (21.0) compared to Asperger and PDDNOS (26.2 and 27.8) these results are consistent with other studies [12,54-56] but inconsistent with other [3].

Referral for assessment

On average, parents contacted 3.3 health professionals before receiving a reliable diagnosis; which was similar for all groups, consistent with other studies [26,56,57]. We must point out that access to mental health services in Mexico City is much better compared to other states of the country. In 2012, half of the board certified child psychiatrists (N=223) practiced in Mexico City [58,59].

Professionals who were more likely to refer patients for a clinical assessment were medical doctors (35.8%), teachers (27.4%) and psychologists (17.9%). Our results suggests that teachers play a significant role in the identification and referral of children with autism as mentioned by other researchers [60,61].

Compared to a Spanish study where the majority of the families took the initiative for seeking attention [62], only 5.6% of Mexican parents had the same initiative. The important role of relatives has been noted finding that frequent interaction with grandparents lowers the age of recognition by 5 months [63].

Diagnostic delay

The diagnostic delay in months for the total sample was 41.8 months (range 1-182), for Autism 35.4, for Asperger 42.4 and for PDDNOS 55.1; although it is important to note that our results do not reflect the general situation in Mexico. Our results are similar to other studies in which parents usually recognize symptoms of autism before 24 months of age and the mean age at diagnosis ranges from 38 to 120 months [2,64-72].

Contrasting with Asperger and PDDNOS, several studies report autism is consistently diagnosed earlier, probably due to its more severe and earlier symptoms [60,73,74]. Diagnostic delay persists even in high income countries which is 3.5 years between the first healthcare professional contact and the formal diagnosis of ASD in the United Kingdom [60], this is consistent with other studies reporting a time lag of nearly three years in receiving a diagnosis [60,65,68,75,76].

In Mexico reasons for this delay might be different, for example, a common practice is to withhold the diagnosis of autism from patients and parents in the educational and medical sector; this unethical practice reflects the stigma around mental health disorders [77,78]. Lack of knowledge is also a common problem in Mexico, as in other countries [14,79,80] substitute comma for a dot. Also, many family physicians lack training in diagnosis and do not know where to refer patients with autism; moreover, they are unfamiliar with screening tools and reported having little time to perform this type of assessment [81].

Studies from high income countries have a reported that only 6% of mental health providers feel comfortable providing a diagnosis of ASD and very few have training to conduct assessment for this disorder [82]. Since Mexico has similar problems, in 2018, the Mexican government reformed the law to

include a formal and early diagnosis as a fundamental right for people with ASD and their families [83].

Cost of treatment

Most parents reported their children received a mean of 1.5 medications with an average cost of 77.1 dlls per month representing 16.4 dmw. We also demonstrated a negative impact on the availability of the caregivers to work as reported in other studies [84]. In general, parents spend more time and money on their children and consequently earn less.

The mean number of medications prescribed was similar for all groups, but, contrary to our expectations the PDDNOS group spent the most on medications prescribed (\$109.0 dlls) representing 23.7 dmw. Usually the PDDNOS is a diagnosis assigned to individuals with milder forms of autism. A possible explanation is that the PDDNOS group had higher SES so probably their physician chose to prescribe more medications and with a higher cost.

In Mexico, the Seguro Popular [85], covers psychiatric care for ASD comprising a wide range of medications, melatonin to treat sleep disorders commonly associated with autism is not included despite its usefulness and minimal side effects [86], it also leaves out genetic testing, counselling, diagnostic and psychological testing, language and occupational therapy, and intensive behavioral treatment. In contrast, in the United States, health coverage of early intensive behavioral intervention (EIBI) for children with autism spectrum disorder (ASD) is increasingly becoming the norm [87,88].

Limitations

The information was collected in a clinical child psychiatric setting which does not reflect the condition of the problem in the general population. As mentioned earlier, it would be important to perform similar studies in the community, in rural settings and other Mexican states. The study sample had access to lower prices for medications and therapies, families not attending the same institution would probably have more expenses. Another important limitation was the lack of measurements of intellectual quotient in the majority of children, so we could not analyze the effect of this important variable in the diagnostic delay and costs in general. Future studies should focus on the diverse complex trajectories' parents follow to get a formal diagnosis and treatment.

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