

Short communication

Prevalence of autistic spectrum disorders in Tripoli, Libya: the need for more research and planned services

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معدل انتشار اضطرابات الطيف الذاتوي (التوحد) في طرابلس، ليبيا: الحاجة إلى المزيد من البحوث ومن الخدمات التخطيطية
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الخلاصة: لا تتوفر المعطيات حول الذاتوية (التوحد) في ليبيا. وقد أجرى الباحثان دراسة مستشفى المرتكز في عيادة النماء العصبي في مستشفى الخضراء في طرابلس، من أجل تقدير معدل انتشار اضطرابات الطيف الذاتوي (التوحد) بين الأطفال الذين يزورون العيادات. وشمل التقييم جميع الأطفال المحوّلين إلى العيادة المذكورة بين عامي 2005 و2009 بتشخيص اضطرابات الكلام واللغة أو بصعوبات سلوكية. وبلغ العدد الإجمالي للأطفال الذين شوهدوا في العيادات خلال الفترة 2005-2009، 38 508 منهم 180 طفلاً لديهم سوابق تأخر الكلام واللغة أو الصعوبات السلوكية أو كليهما؛ وقد شُخص مئة وثمانية وعشرون من هؤلاء الأطفال المئة والثمانين على أنهم مصابون باضطراب الطيف الذاتوي (التوحد)؛ تسعة وتسعون منهم لديهم ذاتوية (توحد) مدرسية؛ مما يجعل معدل الانتشار حوالي 4 لكل ألف؛ وكانت نسبة الذكور إلى الإناث في اضطرابات الطيف الذاتوي (التوحد) 4 إلى 1. وفي الذاتوية (التوحد) على وجه الإجمال: 4.5 إلى 1. وكان العمر الأكثر مشاهدة في الأطفال المراجعين للعيادة هو 2-5 سنوات (58%) منهم 56% أحضروا للعيادة بعد 6-18 شهراً، من بدء الأعراض. فعلى الأطباء أن يأخذوا الذاتوية (التوحد) في الحسبان عندما يُجرّون التشخيص التفريقي في أي طفل يراجع باضطراب في الكلام واللغة، أو بصعوبات سلوكية أو كليهما.

ABSTRACT Data on autism are lacking for Libya. We conducted a hospital-based study in the Neurodevelopment Clinic of Al-Khadra Hospital in Tripoli to estimate the prevalence of autistic spectrum disorders in children attending the clinic. All children referred to the clinic between 2005 and 2009 with a diagnosis of speech and language disorders or behavioural difficulties were assessed. There were 38 508 children in total seen during 2005–09, 180 of whom had a history of delayed speech and language and/or behavioural difficulties. Of the 180, 128 children were diagnosed with autistic spectrum disorder: 99 had classical autism, giving the prevalence of about 4 in 1000. The male:female ratio for autistic spectrum disorders was 4:1 and for autism was 4.5:1. The most common age at presentation was 2–5 years (58%) and 56% presented 6–18 months after the onset of symptoms. Physicians should consider autism in the differential diagnosis of any child presenting with a speech and language disorder and/or behavioural difficulties.

Prévalence des troubles du spectre autistique à Tripoli (Libye) : intensifier les travaux de recherche et les services planifiés

RÉSUMÉ Les données sur l'autisme sont rares en Libye. Nous avons mené une étude hospitalière auprès d'enfants consultant dans un service en neurologie du développement de l'hôpital Al-Khadra à Tripoli pour estimer la prévalence des troubles du spectre autistique. Tous les enfants orientés vers l'établissement entre 2005 et 2009 et ayant reçu le diagnostic de troubles de la parole et du langage ou présentant des difficultés comportementales ont été examinés. Au total, 38 508 enfants ont été examinés entre 2005 et 2009, parmi lesquels 180 avaient des antécédents de retard de développement de la parole et du langage et/ou des difficultés comportementales. Parmi ces 180 enfants, 128 ont reçu le diagnostic de troubles du spectre autistique : 99 souffraient d'un autisme classique, correspondant à une prévalence de 4:1000. Le rapport entre les garçons et les filles pour les troubles du spectre autistique était de 4:1 et pour l'autisme classique de 4,5:1. L'âge le plus fréquent des patients à la première consultation se situait entre deux et cinq ans (58 %) et 56 % ont été examinés entre 6 et 18 mois après l'apparition des symptômes. Les médecins devraient envisager l'autisme comme diagnostic différentiel chez tout enfant présentant des troubles de la parole et du langage et/ou des difficultés comportementales.

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Introduction

Autism is a spectrum disorder with cases ranging from a relatively mild problem with social interaction to more severe difficulties in behaviour, such as not speaking, following rigid routines and social isolation. It is estimated that around 1 in 100 children between 5 and 9 years of age have autism [1–3]. Studies in developed countries have reported up to 60 cases per 10 000 children aged 0–16 years of all forms of autistic spectrum disorders (ASDs) [4]. Comparable figures, however, are not available for Libya [5,6].

The important historical observation about autism is that it was unknown in ancient culture and even up to the 19th century. It just “appeared” some 60 years ago [7]. Leo Kanner, was first to describe autism in 1943 [8] and, in 1944, Hans Asperger also described children with similar symptoms [9].

While there is extensive information about autism in many industrialized nations, data on autism are greatly lacking in Libya. Therefore, we aimed to estimate the prevalence of ASD in children referred to the Neurodevelopment Clinic of Al-Khadra Hospital in Tripoli so as to increase the awareness of these conditions among physicians and the need to consider autism when dealing with children presenting with speech and language disorder (SALD).

Methods

This was a hospital-based study. Children were identified as having an ASD through screening of all children referred to the Neurodevelopment Clinic of Al-Khadra Teaching Hospital, Tripoli, Libya between 2005 and 2009 with the diagnosis of delayed speech and language, no speech or language or behavioural difficulties. Children were reviewed, scored and classified by a clinician (AZ) as having ASD if they displayed behavioural abnormalities

consistent with DSM-IV for diagnosing [10] i) autism, ii) pervasive developmental disorder not otherwise specified (PDD-NOS), including atypical autism, or iii) Asperger disorder [11].

The Neurodevelopment Clinic is a regular weekly clinic at the paediatric outpatient department of Al-Khadra Teaching Hospital where 25 to 30 children (0–16 years) are seen per session. It is a consultant-led clinic (AZ) in addition to having 1 registrar, 1 senior house officer and a nurse. The clinic serves Tripoli, its suburbs and other hospitals, and receives referrals from other regions in Libya. The clinic does not care for all children with other neurological problem in the region.

Results

In total there were 38 508 children seen in the paediatric outpatient department between 2005 and 2009. In total 180 (0.48%) children were referred to the Neurodevelopment Clinic with history of delayed speech and language or behavioural difficulties. Of these 180, 128 children met the

diagnostic criteria for ASD (71%): 99 (55%) children had classic autism, 21 (12%) had PDD-NOS, 6 (3%) had Asperger syndrome and 2 (1%) had Rett syndrome. In addition, 32 (18%) of the 180 children had isolated speech and language delay, 13 (7%) had other diagnoses and 7 (4%) had sensorineural deafness (Table 1).

The prevalence of ASD was 1 in 332 children seen at the paediatric outpatient department (approximately 3 per 1000 children) and the prevalence of autism was 1 in 257 children seen (approximately 4 per 1000 children). The prevalence was based on period prevalence estimates of ASD for children of all age groups attending the Neurodevelopment Clinic. The sex ratio for ASD was 4 males to 1 female and for autism was 4.5 males to 1 female.

The age at presentation to the Neurodevelopment Clinic varied from as early the first year of life (3%) to as late as > 10 years (5%). The most common age at presentation was between 2 and 5 years (58%), the median age was 4 years and 6 months. No sex difference was observed.

Table 1 Final diagnosis of children referred to the clinic with speech and language disorders

Diagnosis	No. (n = 180)
Autism	99
PDD-NOS	21
Asperger syndrome	6
Rett syndrome	2
Isolated speech and language delay	32
Other diagnoses	13
Mental retardation	6
Ehlers–Danlos syndrome	1
Prader–Willi syndrome	1
Infantile spasms	1
Gratification disorders	1
Angelman syndrome	1
Fragile-X syndrome	1
ADHD	1
Sensorineural deafness	7

PDD-NOS = pervasive developmental disorder not otherwise specified; ADHD = attention-deficit hyperactivity disorder.

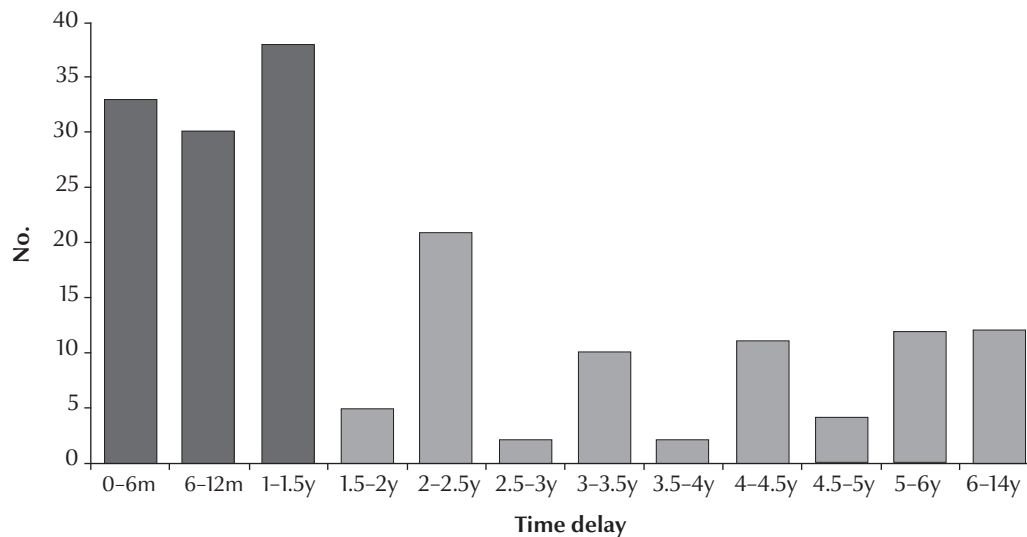


Figure 1 Time delay between the onset of symptoms and the presentation to the Neurodevelopment Clinic of Al-Khadra Hospital

The time delay between the onset of symptoms and presentation to the Neurodevelopment Clinic is shown in Figure 1. Of the 180 children referred to the clinic, 101 (56%) presented between 6 and 18 months after the onset of symptoms, while 24 (13%) presented 5 years after the onset of symptoms. Again no sex difference was seen.

Of the 180 children, 135 (75%) had a normal hearing test [mean brainstem auditory evoked potentials (BAEP)], 7 (4%) had severe sensorineural deafness and 4 (2%) had mild hearing loss. In 34 (19%) children, the results of BAEP were not available.

As regards magnetic resonance imaging (MRI) scans, 112 (62%) children had normal MRI scans while 14 (9%) had abnormalities; in 53 (29%) children the results of the MRI scan were not available. Of the 128 children with ASD, 88 (69%) had mental retardation. The most commonly documented early developmental concerns were for language followed by social concerns. In addition, 123 of the 128 children with ASD demonstrated abnormal preoccupation with television programmes.

Discussion

To the best of our knowledge, this is the first study in Libya on autism with a high response rate and cooperation from the parents. We believe our sample is representative of the Libyan population because, despite the large size of Libya, it is mostly desert with few medical services and thus most of the health services and specialized clinics in which these children and families are seen are concentrated in Tripoli.

Because ASDs are diagnosed on the basis of behavioural criteria and clinicians might apply criteria differently to arrive at a diagnosis of autism and related subtypes, determining prevalence is challenging [12–14]. The methodology in our study gave an ASD prevalence of 1 in 332 children (approximately 3 per 1000 children) and an autism prevalence of 1 in 257 (approximately 4 per 1000 children) for children attending our clinic. These figures are significantly lower than other larger studies in developed countries [15–17] and probably do not reflect the true prevalence of the disease in our community because of the lack of proper research facilities, lack of awareness and social stigma associated with the disease

which make detection of cases difficult, particularly early detection.

The proportion of children with ASD who had cognitive impairment ($IQ \leq 70$) was 69% which is consistent with reports from other studies [18]. In our children, 7 (4%) had sensorineural deafness and 12 (7%) had isolated speech and language disorder. This is a significant number and highlights the fact that every child with speech and language delay must have a proper hearing test and should be assessed by an expert as soon as possible to confirm or refute a diagnosis of ASD. Males outnumbered females by a ratio of 4 to 1 for ASD and 4.5 to 1 for autism; this is generally consistent with the sex distribution of autism given in developed countries [4,19].

The time delay between the onset of symptoms and presentation to our clinic varied considerably. Some families sought advice very late; this could be due to many factors such as the belief that the child will talk eventually, reluctance to make the problem known, and lack of information about ASD. We found no sex difference for age of recognition and age at presentation to the Neurodevelopment Clinic. This is consistent with Daley's study conducted in India [11] but differs from Al-Salehi et

al's findings in a study conducted in Saudi Arabia which reported that females were older at the time of evaluation than males [6]. Over 80% of the families reported severe temper tantrums and frustration if they interfered with the child when watching television programmes, which supports the findings of Waldman and Nicholson that early childhood television viewing may be an important trigger for autism [20].

Based on the prevalence of autism in the United States (0.2%), it has been estimated that there may be around 11 000 people with autism in Libya [21]. These extrapolated data may be highly imprecise, but they indicate the need for further investigation to obtain more accurate figures in order to identify the true extent of the problem and be able to devise strategies and intervention programmes to address it.

Conclusion

There has been a true and significant increase in autism prevalence worldwide. To date, the health and education authorities have not paid enough attention to this serious epidemic and its present and future impact. Many of those being diagnosed are still not in any

form of education or any form of early intervention programme. The biggest problem in any developing country, including Libya, is the lack of awareness of the parents and hence the lack of early interventions that may be available. Special education is rarely started early enough and even if, against all difficulties, a child gains a place in the school, the majority only start at 6 or 7 years, by which time they are "fixed observers". It is very important therefore that all paediatricians and primary health care providers consider autism when dealing with children presenting with speech and language delay.

It is possible to take the view that there are far worse medical problems than autism in many developing countries including Libya or that there are other problems that can be helped by simple procedures and the prevalence of autism is low so why divert scarce resources and efforts to this condition. There are indeed many other paediatric problems in Libya and other developing countries but autism is such a severe disability for both the individual and his/her family that every professional in the field of paediatrics must positively contribute to highlighting the problems to ensure that adequate resources are

available for care of children with such conditions in developing countries.

Not only are published data on autism lacking in Libya, they are scarce across the region and more studies and information are needed on all aspects of ASDs. For example, it would be interesting to know if any country in the Region has managed to solve the problem of provision of proper services for children with hearing difficulties and behavioural problems including autism.

Although our findings are preliminary, hospital based and the first to be conducted in Libya, they indicate the need for decision-makers to plan services and research the problem of ASDs countrywide.

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Mental health atlas 2011

The World Health Organization's (WHO) Project Atlas is aimed at collecting, compiling, and disseminating information on global mental health resources. The WHO *Mental health atlas 2011* presents updated information from 184 WHO Member States on available resources for treatment and prevention of neuropsychiatric disorders globally, by WHO region, and by income group. The Atlas 2011 shows that mental health resources within most countries remain inadequate. Moreover, resources across regions and different income levels are substantially uneven, and in many countries resources for mental health are extremely scarce. In comparing Atlas 2005 and 2011 there is some evidence of a small gain in mental health human resources. However, these gains are largely in high- and middle-income countries and not in low-income countries. Results from *Mental health atlas 2011* reinforce the urgent need to scale up resources for mental health care within countries.

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