

Autistic Spectrum Disorder today in Libya Five years' experience

**Professor Adel M Zeglam, MBBCh, DCh, FRCPCH, FRCPI,
Consultant Neurodevelopment Pediatrician,
Professor of Pediatrics and Child Health**

Al-Khadra Hospital

Tripoli, Libya

Dr. Marwa F. Al-Ogab, MBBCh

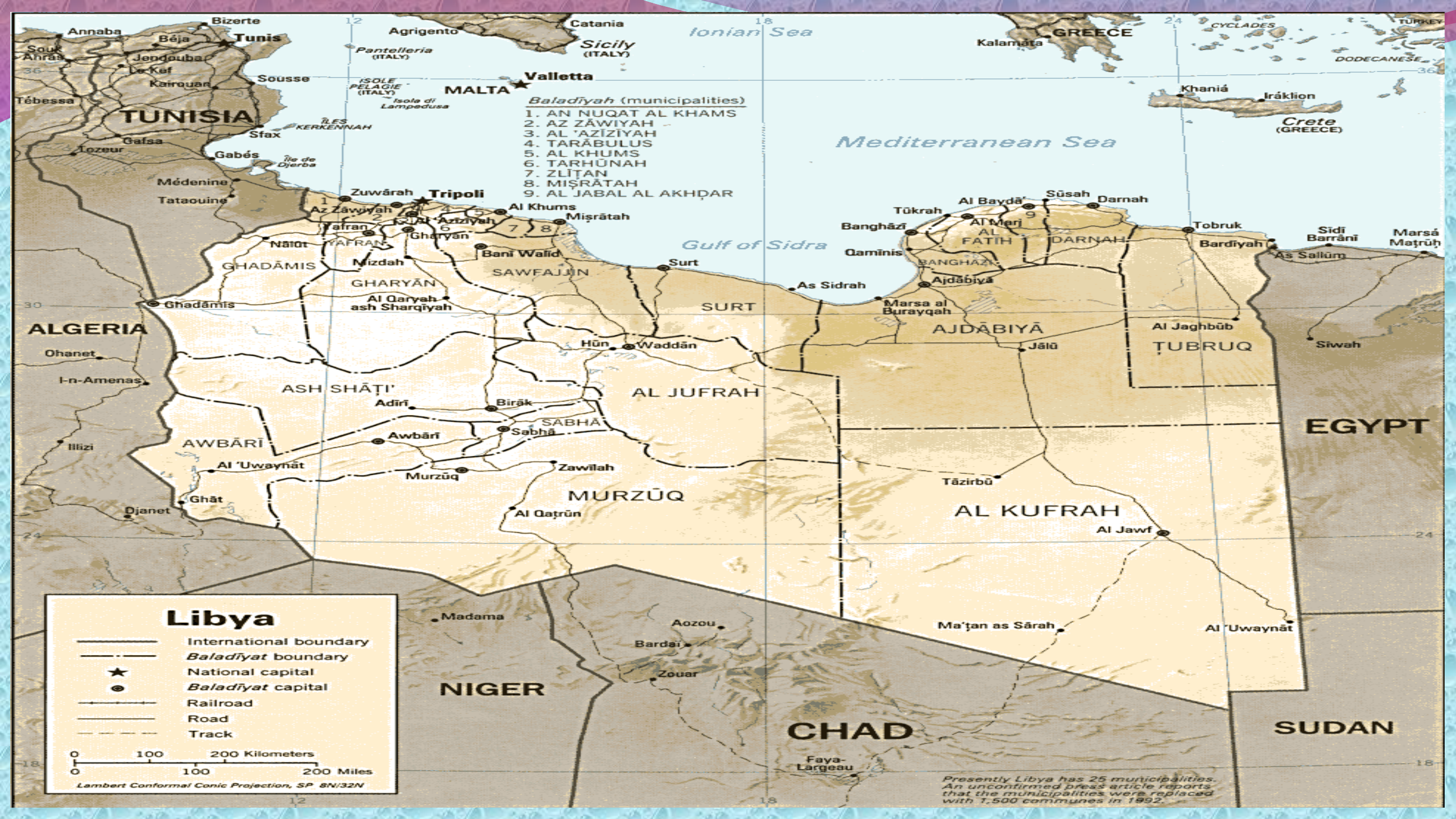
Community Pediatrician, Primary Health Care

Research Assistant

Tripoli, Libya

Al-Khadra Teaching Hospital, Tripoli, Libya





LIBYA

- Libya is situated in North Africa, stretching along the Mediterranean shoreline for nearly 2,000 kilometers. Its area is 1,775,500 square kilometers making it the fourth largest country in Africa. Egypt is on its eastern border; Sudan, Chad and Niger are to the south and Tunisia and Algeria lie to the west. Tripoli (the capital) is the country's major city.
- The total population of Libya was 6.18 million, with 39% of the population below the age of 15. More than half of the population is urban; most of them live in the coastal area in the main cities, namely Tripoli (2.4 million) and Benghazi (0.75 million). The estimated birth rate is 25.6 births per 1,000 populations (158,000 births per annum). Approximately 98.3% of all births are in health establishments. Infant mortality rate is 17.6 per 1,000 live births; under-five mortality is 20.1 per 1,000 population, with a growth rate of 1.83%. Life expectancy at birth is 72.5 years.
- Official language Arabic, but English used extensively. Islam is the official and dominant religion.
- Estimates of total literacy between 70 and 80 percent.
- It is estimated that 48.4% of marriages in Libya are consanguineous; 30% of the total marriages are between first cousins.

OVERVIEW

1. *Introduction*
2. *Aim of the study*
3. *Methodology*
4. *Results*
5. *Conclusion*
6. *Recommendation*

Autistic Spectrum Disorder

Autism spectrum disorder (ASD) is a range of complex neurodevelopment disorders characterized by:

- A.** Persistent deficits in social communication and social interaction across multiple contexts.
- B.** Restricted, repetitive patterns of behavior, interests, or activities.
- C.** Symptoms must be present in the early developmental period.
- D.** Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E.** These disturbances are not better explained by intellectual disability or global developmental delay.

Autism has reached epidemic proportions all over the world

The increasing number of children with this serious disorder will have an enormous effect on the community and economy.

Autistic Spectrum Disorder

- Very likely neurological in origin – not emotional, not the refrigerator mom.
- A disability which affects the way that people communicate and relate to those around them.
- 4 times more prevalent in boys.
- No known racial, ethnic, or social boundaries.
- No relation to family income, lifestyle.
- Autism impacts normal development of the brain in areas of social interaction and communication skills.
- Occasionally, aggressive and/or self-injurious behavior may be present.

“Autistic Spectrum Disorder (ASD) in Tripoli / Libya”

Comparative study 2011-2015

- A significant proportion of children with ASD are diagnosed in their preschool years. With the growing awareness of ASD it means therefore that children in their primary school years are more likely than ever before to be identified.
- Libya has witnessed an increase in the number of individuals being diagnosed with an autism spectrum disorder. For example, in over the past two years, the number of new diagnoses per year has increased, with more than 440 children newly diagnosed with an autism spectrum disorder in 2015. This increase in identified children with autism spectrum disorders has been observed in other parts of the world.

“*Autistic Spectrum Disorder (ASD) in Tripoli / Libya*”

Comparative study 2011-2015

The aims of the study were:

- Analyze comparatively the children with ASD between years 2011 and 2015.
- To provide decision—makers prevalence rates with which to describe the burden of the disorder throughout the country,
- To provide baseline statistics from which to measure patterns in prevalence over time,
- To ultimately help policy planners to adequately manage the provision of services required for these children living in our community.
- Increase the awareness among pediatrician and primary health care providers of the importance of considering autism when dealing with children presenting with speech and language disorders.

“Autistic Spectrum Disorder (ASD) in Tripoli / Libya”

Comparative study 2011-2015

Methods

Hospital based comparative study between year 2011 and year 2015 of all children referred to Neurodevelopment Clinic at AL-Khadra hospital (NDC-KH)/Tripoli/Libya with the diagnosis of either delayed speech and language, no speech or language or behavioral difficulties.

The diagnosis of autism was based on DSM-IV & V criteria supplemented by information obtained from parent and child's interviews, checklists (M-CHAT & ADI) and examination of hospital records. The assessments were conducted by the same consultant (AZ).

“Autistic Spectrum Disorder (ASD) in Tripoli / Libya”

Comparative study 2011-2015

Neuro-development clinic @ Al-Khadra hospital, Tripoli (NDC-KH)

- Regular weekly clinic.
- Al-Khadra Teaching hospital, POPD
- 30 – 35 patients per session.(0-16 years)
- Consultant led clinic. (AZ)
- One registrar, one SHO, nurse.
- Serves Tripoli , its suburbs, other hospitals, and other regions in Libya
- Receives referrals from other countries.
- Does not care for all children with epilepsy and other neurological problems in the region.

“Autistic Spectrum Disorder (ASD) in Tripoli / Libya”

Comparative study 2011-2015

Results

A comparison review of ASD diagnoses was made between the years 2011 and 2015. The total number of children seen in Paediatrics Out-patient Department (POPD) between year 2011 and 2015 were 306748 out of whom 3360 children were referred for ASD assessment and whose ages “ranged from younger than 2 years to 10 years of age”. ASD were diagnosed in 66% (2202 children). SCD were diagnosed in 110 children (3 %) which gives the prevalence of 7:1000. The male/female ratio of ASD remained almost the same between 2011 (3.6:1) and 2015 (3:1). The referral sources and procedures were similar during each of the data collection periods.

“Autistic Spectrum Disorder (ASD) in Tripoli / Libya“

Comparative study 2011-2015

Results	2011	2012	2013	2014		2015	
Speech and Language disorder	200	792	890	664		814	
Autistic Spectrum Disorder	166 83%	630 %79	608 68%	ASD	SCD	ASD	SCD
				358 %54	49 %7	440 %54	61 7%
Prevalence	1:90 11:1000	1:140 7:1000	1:166 6:1000	1:200 5:1000		1:178 6:1000	

Causes of referral to NDC

	ASD - 2015	Total number of children
No speech or language	171 – 39%	259 - 32%
Delayed speech and language	113 – 26%	258 - 32%
Lost speech	40 – 9%	57 - 7%
Unclear speech and language	13 – 3%	67 - 8%
Behavioral difficulties	33 – 8%	72 – 9%
???Autism	39 – 9%	46 - 6%
Poor social interaction	31 – 7%	55 - 6%
Epilepsy	5 – 1%	8 - 0.9%

Autistic Spectrum Disorder

Sex distribution 3 : 1

MALE (78%)

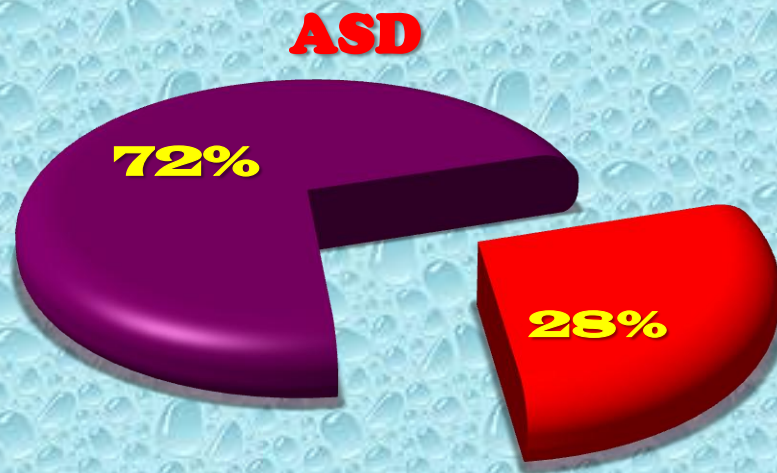
FEMALE (22%)



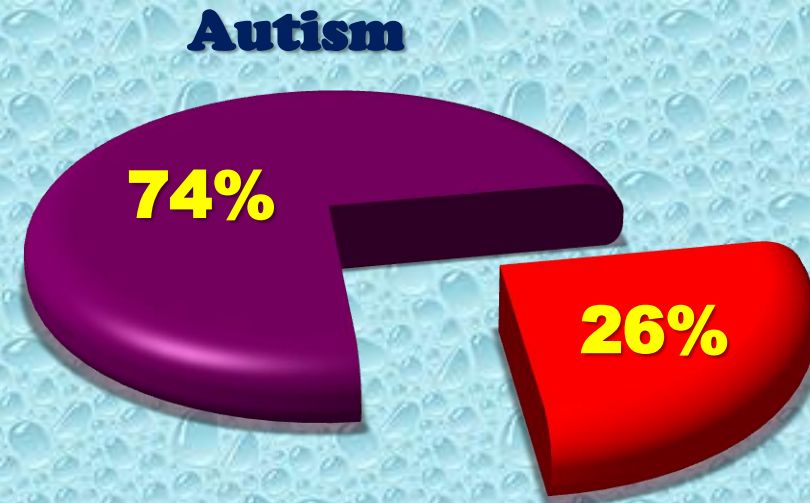
“Autistic Spectrum Disorder (ASD) in Tripoli / Libya”

Comparative study 2011-2015

Consanguinity



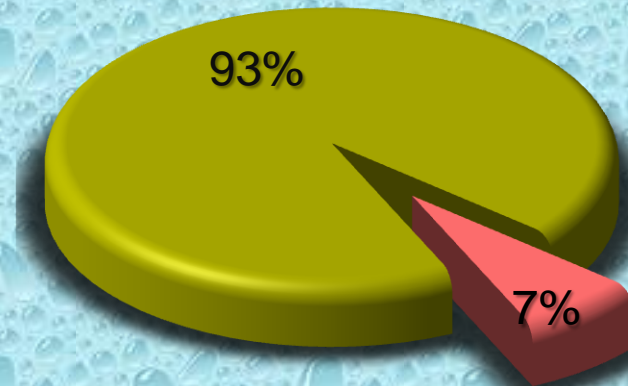
■ No ■ Yes



■ No ■ Yes

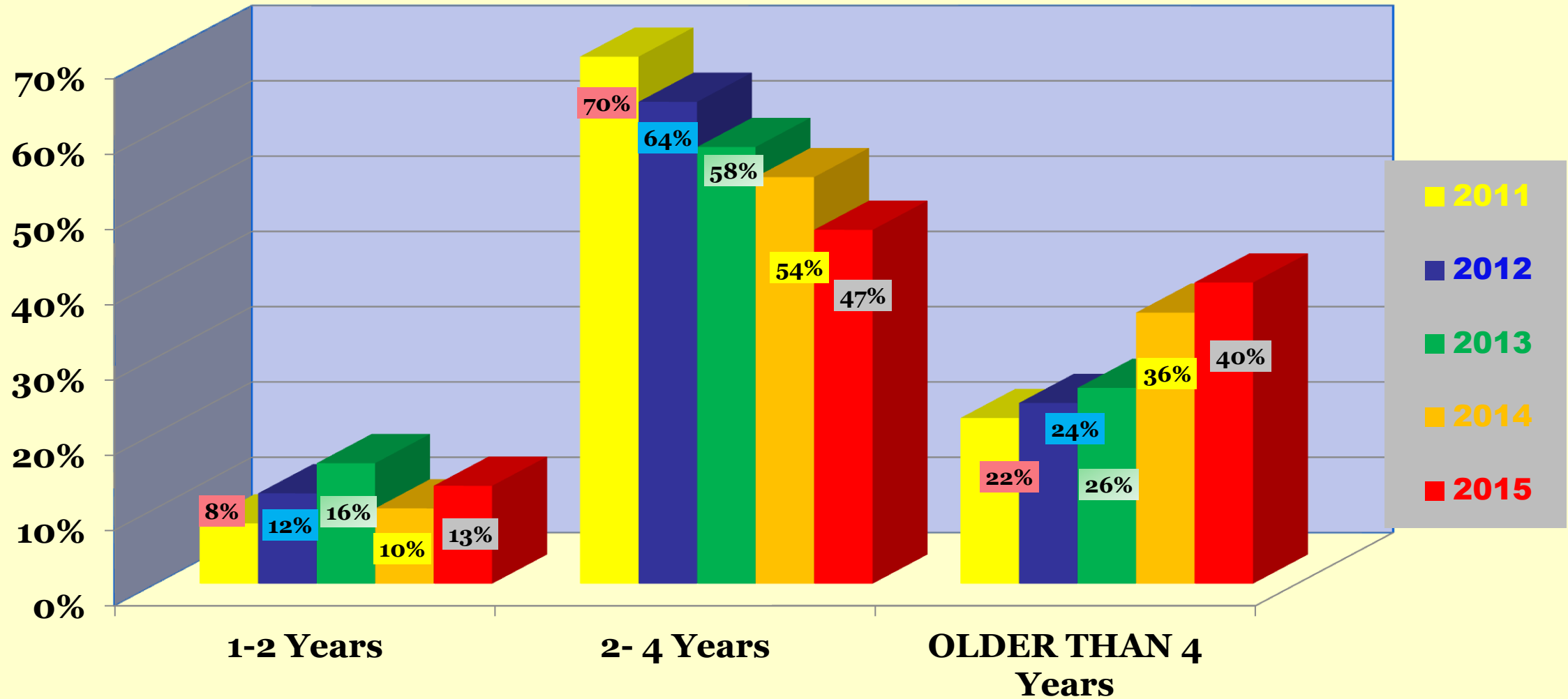
“Autistic Spectrum Disorder (ASD) in Tripoli / Libya”
Comparative study 2011-2015

Fetal distress (ASD)



■ Yes ■ No

Age of presentation to NDC 2011 - 2015

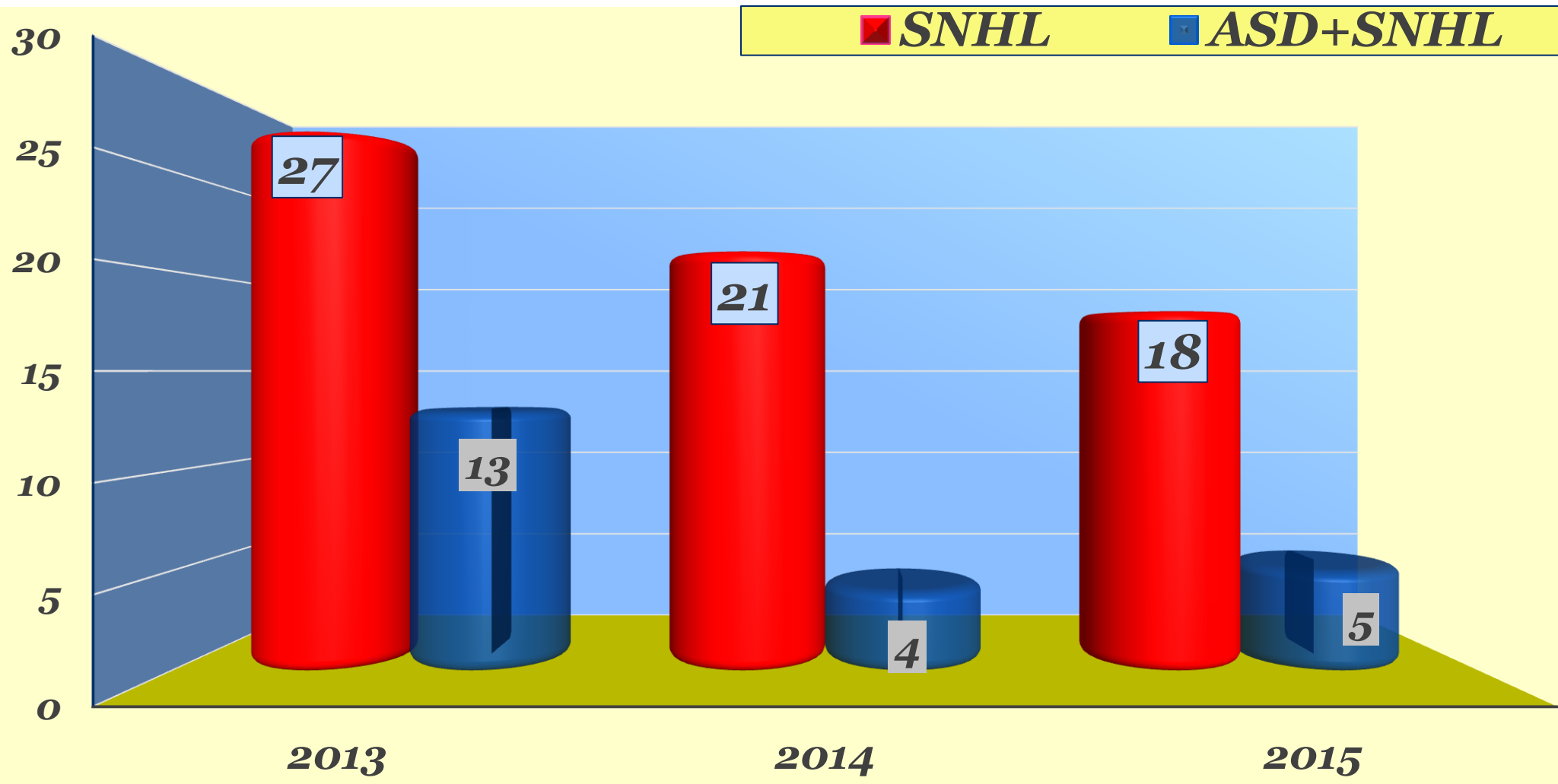


Type Of
MRI
abnormalities

n=70

MRI Brain	Number of patients	MRI Brain	Number of patients
Periventricular leukomalacia	16	MPS II	2
Ischemia	9	Gliotic Lesion Vascular in Nature	1
Arachnoid Cyst	6	dilated Virchow robins space	1
Brain Atrophy	9	NFI	2
Corpus Callosum Agenesis	6	cerebellar hypoplasia	1
Leukodystrophy	5	Arnold Chiari malformation	1
Hydrocephaly	4	loss of right temporal lobe volume	1
Pinealoblastoma	1	Moderate loss of pituitary volume	1
Dilated ventricles	3	Bilateral vascular legion	1

Number of children diagnosed with ASD and SNHL in relation to total number of children diagnosed with SNHL (66)



Autistic Spectrum Disorder (ASD) in Tripoli / Libya

Discussion

ASD is an important differential diagnosis of any “language disorder delayed or no speech and language, and behavioral difficulties”. It is often diagnosed late because of its peculiar presentation in children, has a wide spectrum of different behavioral pattern and the wrong belief from the side of the parents that the child will talk eventually .

A low index of suspicion and because the parents are shame and afraid of hearing the diagnosis are another causes of delayed diagnosis . Referral to professionals with experience in these sorts of problems saves time, money and prevents unnecessary investigations and treatment.

The presence of more than one child with autism in the same family may suggest a strong genetic basis.

Autistic Spectrum Disorder (ASD) in Tripoli / Libya

Discussion

The prevalence of the problem is probably higher and probably similar to that seen in USA and UK. No data were available from the Arab countries or other developing countries. Autism is an important differential diagnosis of any language disorder “and behavioral difficulties”. We highlights the need for accurate incidence and prevalence estimates in order to adequately plan for the current and future needs of people with an ASD, thereby enabling them to maximize their potential to participate in their communities. 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. *The deteriorating security situation and the ongoing armed conflict has had an adverse impact on Libya's health sector by hampering healthcare provisions.*

POINTS OF INTEREST

- six (6) children product of IVF (in- vitro fertilization)
- five (5) Schizophrenic parents .
- 82 children part of twins.
- 263 children are product of first degree consanguinity.
- 46 families have more than one child with autism.
- four (4) families have three autistic children.
- sixteen (16) families have twins with ASD.
- More than 80% of affected children obsessed with TOUYOUR ALJANNA (children songs) satellite channel .
- More than 60% of affected children put in front the TV set from as early as first few months of life.

RECOMMENDATIONS

1. *Access to timely and affordable diagnosis*

A time delay creates additional frustration and stress on family members who are living with the pressures of raising a child with an autism spectrum disorder.

2. *Early intervention for pre-school children*

Every child has access to a minimum 20 hours of autism-specific early intervention and family support per week. Further, no family should experience a waiting period of more than 3 months between diagnosis and early intervention service provision.

3. *Early schooling*

Children need to be supported with autism-specific educational services to consolidate their learning and communication skills .

4. *Improved data collection*

Mechanism for the national collation of data from multiple sources, with opportunities for diagnostic validation should be organized. This will assist with future research into the causes, diagnostic pathways, effective interventions and outcomes for individuals with ASD.

One final word, we found a very high rate of use of TV among children with ASD. Our study conclusively demonstrate that early exposure to TV can be one of the most important environmental trigger that account for the rise in prevalence of ASD in Líbya and probably in some other countries over the last five years. This study is being considered for publication.

Acknowledgment

The authors extend great thanks and appreciation to all the parents for their support and to all who has been involved in running this study. Thanks to my colleague doctors seniors and juniors for referring these children to the clinic.

References

1. Zeglam AM, Maouna A. Is there a need for a focused health care service for children with autistic spectrum disorders? A keyhole look at this problem in Tripoli, Libya. *Autism*. 2012; 16:337-9. doi: 10.1177/1362361310393535. [PubMed] [Cross Ref]
2. Zeglam AM, Maouna AJ. Prevalence of autistic spectrum disorders in Tripoli, Libya: the need for more research and planned services *East Mediterr Health J*. 2012; 18(2), 184-188.
3. Zeglam Adel M.; Al-Bloushi Haneen. Autism today in Libya: Is it a tip of an iceberg? (A comparative study). *Middle East Journal of Family Medicine*. Sep2012, Vol. 10 Issue 8, p34-38.
4. Baron-Cohen S, Scott FJ, Allison C, Williams J, Bolton P, Matthews F, Brayne C. Prevalence of autistic spectrum conditions. UK-based population study. *The British Journal of psychiatry* 2009; 194:500-509.
5. Baird G, Simonoff E, Pickles A, Chandler S, Loucas T, Meldrum D, Charman T. Prevalence of Disorders of Autistic Spectrum in population cohort of children in South East Thames: The Special need project. *Lancet* 2006; 368:179-181.
6. Lenoir P, Bodier C, Desombree H, Malvy J, Abeet J, Ould Taleb M, Sauvag D. Prevalence of Pervasive developmental Disorder. A review. *Encephale* 2009, Feb; 35(1):36-42. Epub 2008 Sep .23.
7. Yazbak FE. Autism in the United States: a perspective. *Journal of American Physician and Surgeons*, winter 2003; vol. 8 number 4.
8. Kanner L. Autistic disturbances of affective contact. *Nervous child* 1943; 217-250.
9. Asperger H. Die "Autistischen psychopathen" in kindesalter. *Archiv für Psychiatric and Nerven Krankheiten* 1914; 17:76-136.
10. Mankoski RE, Collins M, Ndosu NK, Mgalla EH, Sarwatt VV, Folstein SE "Etiologies of autism in case- sever from Tanzania" *J. Autism Dev Disord*. 2006; 36(8): 1039-51.
11. Al-salehi SM, AL-Hifty EH, Ghaziuddin M. Autism in Saudi Arabia: Presentation, Clinical Correlates and Comorbidity. *Transcult Psychiatry* 2009 ; 46 (2):340-7.
12. Daley TC. The need for cross-cultural research on pervasive developmental disorders. *Transcultural Psychiatry* (2004); 39(4), 532-551.
13. American Psychiatric Association. Diagnostic and statistical manual of mental disorders, 4thed. , text revision 2000; Washinton DC, American Psychiatric Association.
14. Yeargin-Allsopp M, Rice C, Karapurkar T. , Doernberg N ,Boyle C, Murphy C. Prevalence of autism in a US metropolitan area. *JAMA* 2003; 289: 49-55
15. Fombonne E. Is there an epidemic of autism? *Paediatric* 2001; 107:411-413.
16. Rice C, Baio J, Van naerden Braun K. Doernberg N., Meaney FJ, Kieby RS for the ADDM Network. A public Health collaboration for the surveillance of autism spectrum disorders (ASD) *Paediatric. Perinat Epidemiol* 2007. In Press.
17. Fombonne E. Epidemiologic surveys of autism and other pervasive developmental disorders: an update. *J. Autism Dev. Disorder* 2003; 33: 302-382.
18. Fombonne E. Epidemiologic surveys of autism and other pervasive developmental disorders, *Journal of clinical psychiatry* 2005; 66(supp. /10), 3-8.
19. American Psychiatric Association (APA), *Diagnostic and Statistical Manual of mental Disorders, forth edition, 1994*, Washington DC. APA.
20. Waldman M, Nicholson S, Adilor N. Does television cause autism?, Autism Prevalence and Precipitation Rates in California, Oregon, and Washington Counties. *Arch Pediatr Adolesc Med*. 2008; 162(11):1026-1034.
21. Us Census Burean, *International Data Base 2004; Wrong Diagnosis.com (WD.com)*.

THANKS
FOR
YOUR Kind
Attention

شكراً على
حسن الانتباه

