

Outcomes for Adolescents and young Adults with Autism Spectrum Disorder: General Social Functioning

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Abstract

Background: Earlier reports from different parts of the world reported fair to poor outcome of ASD in adolescence and young adult life.

Method: Eighty children diagnosed as ASD from a public clinic and a day care centre for adolescent made the study sample. 59, (73%) of sample's mothers were contacted by telephone 10-15 year after diagnoses to assess their children general social functioning and behaviour. Children were not seen or examined.

Results: Sample mean age was 17.3 year–St Dev. 4.8 year, and mean age at diagnosis was 3.2 year. Male, female ratio was 4:1. Almost all attended day care programs for ASD and 10% are in regular school. A quarter of cases had friends and all were living with their families. None are married or hold a regular job. Researcher scored more small gains while mothers reported more substantial gains.

Discussion and conclusion: 10-15 year outcome of children with ASD showed mixed results. Parents reported considerable benefits in social adjustment in half of the sample in comparison in quarter by independent researcher. Reasons for such difference were discussed. In future, we need to expand the follow up duration and use measurable parameters to assess benefits.

Keywords: ASD; Adolescence; Young adult; Outcome; Social; Bahrain

Introduction

Today adolescents and young adult persons with Autism Spectrum Disorder (ASD) enjoy better opportunities than their predecessors. They have a better chance to be diagnosed early, receive special education, behavioural intervention, early school education and live with their families rather than institutions.

The beginning of adulthood often involves significant changes in educational, vocational, housing, and interpersonal domains and the development of new roles and identity formation. Such changes are especially more stressful for adolescents with ASD and their families due to inherent difficulty of coping with change for persons with ASD. Additionally, the heterogeneity of ASD may make it challenging for families to develop clear expectations for the future. Finally, there are an increasing number of individuals with autism spectrum disorders entering adulthood; it is still unclear how the disorder impacts individuals later in the life course.

Earlier reports from Europe, North America and Japan regarding adolescents with ASD revealed poor social adjustment for the majority [1-5]. Many remained in institutions for mentally ill people, lived in isolation, with very low work capacity skills level. Some studies identified good intellectual ability and the presence of speech at age 6

year were found to be good prognostic factors [2,6] and associated with better outcome. Many received medications and up to 40% developed seizures disorders after puberty [7]. Little is known about the social functioning of young adult and older individuals with ASD. Treatment for people with ASD has advanced in recent years and this needs to be taken into account when interpreting results from such studies.

Most cases reported in the above studies were diagnosed in the 70's and 80's of the last century, with varied intellectual cognitive abilities and age of diagnosis. Furthermore, they were a heterogeneous group of multiple neuro-developmental diagnoses, different level of function and age at diagnosis. It was not clear what type of interventions was received and whether all of them treated in the same way.

Therefore, the conclusion remarks of these studies; should be taken with caution and may not be relevant to recently diagnosed cases. Recent outcome studies used prospective design and focused on benefits of certain programs and intervention of short duration [8-13].

The purpose of the present study was to assess the global functioning and behavior of a cohort of ASD patients diagnosed in childhood and were later examine into their adolescence and young adult life in a developing country.

Methods

Bahrain is an archipelago situated in the Arabian Gulf region, east of Saudi Arabia. It covers an area of approximately 765 Km² and has an estimated population of 1.33 million in 2013. Annually, nearly 30 new cases of suspected ASD are diagnosed in Child Adolescent Psychiatric Unit (CAPU) in the Psychiatric Hospital, Bahrain. The prevalence of ASD was reported the 4.3 per 10000 populations by one-time registry method [14]. The diagnosed cases were referred to three major community rehabilitation centres under the umbrella of Bahrain Association of Intellectual Disabilities and Autism (BAIDA), (Al Wafer centre, Al Rashad centre and the Youth Club depending on their age group). The centres utilize Applied Behaviour Analysis–Sensory Integration–Miller Method, diet restriction program and social and leisure activities as intervention for their clients.

Design

Cross-sectional, prospective design study.

Sample

All cases of children diagnosed with Autism Spectrum disorder in the year 2005–2006 according to DSM-IV Revised criteria and attended (CAPU) and others with the same diagnosis enrolled in Al Rashad Center for autism at the time of data collection constitute the study sample, n=80 [15].

Fifty-nine (73.8%) parents, mostly mothers, were contacted and interviewed over the telephone. Twenty-one families could not be reached, because of change of contact numbers. None refused to participate. The missed families did not differ from those contacted by mean age–sex distribution or social class. There were no exclusion criteria. Al Rashad center is day care center for adolescents with ASD (age 12–21 year).

Procedures

The families of identified sample were contacted by telephone 10-15 years after diagnosis of autistic disorder. A special data collection form was designed for the study in order to provide structure to the interviews. The form contains demographic of parents and cases, history of use of rehabilitation services, history of other treatment methods, the current general social functioning and behaviour. The researcher, who was independent to cases, also asked the parents, Center’s staff and examined cases files to determine the benefits gained over the study period.

Parent’s social class was constructed following a modified version of Redlech and Hollangshhead five level scale [16].

Research approval was obtained from the Management Board Committee, BAIDA and ethical committee secondary care, Ministry of Health, Kingdom of Bahrain. Participation was voluntary and no participant was forced to participate in the interviews. By agreeing to participate in the interviews subjects consented the use of the data for scientific purposes only.

Analysis

Data were entered into SPSS version 22 for analyses. Analyses were primarily descriptive; Chi square was used to assess statistical differences wherever applicable using 0.05 level as significant. Due to small numbers, social classes were grouped into two groups, high

(Class 1+2+3) and low Class 4+5), and benefits into two groups, no change or little benefits verses major benefits.

Results

Sample description–Table 1 shows the following

Item	No	%	
Age	Range	Mean	
At follow-up	15-33 Year	17.3	
At diagnoses	2-12 Year	3.7	
Sex	Male	47	79.7
	Female	12	20.3
Comorbidity	ASD alone	37	62.7
	ASD and ID	19	32.2
	ASD with other	3	5.1
Education received	Kindergarten	34	57.6
	School	19	32.2
	Rehabilitation		
	Day care centres	57	96.6
	Coaching	23	39
	Intervention		
	Medication	35	59.3
	Diet program	18	30.5
	Others	14	23.7
	Birth Rank	First	27
Last		22	37.3
Other		10	16.9
Social class	Class 1	3	5.1
	Class 2	12	20.3
	Class 3	30	50.8
	Class 4	9	15.3
	Class 5	5	8.5
Parental blood Relationship	First degree relations	34	57.6
	2nd degree relations	8	13.6
	No Relations	17	28.8

Table 1: Sample description.

Fifty-nine mothers completed the interviews. Child age at this data collection ranged between 15-33 years. with a mean age of 17.3 year and St. Deviation of 4.8. Cases were diagnosed as ASD in the age range of 2-12 years with a mean age of 3.7 years. Male outnumbered females

by a ratio of 4:1. Two third of the sample have ASD only and one third ASD combined with intellectual disability. Almost half, (57.6%) had attended day care center for autism for more than 10 years and one third 32.2% attended regular school in addition for variable duration. almost all 96.6% attended day-care program for children with ASD for more than 6 years, while another 39% received extra coaching by trained specialists such as oxygen therapy, oil massage and sports. More than half the sample (59.3%) received medication to control their hyperactivity and or aggression, 30% diet restriction program and 23% other types of intervention. At present twenty-five cases (42.4%) were staying at home while another 47.5% still attending day-care centre for youth with ASD and another (10.2%) are in regular school system. Fourteen cases, (23.7%) developed seizure disorders during adolescent period. Nearly half of the cases (45.2%) are first-born children and 22 (37.3) ranked last. Furthermore, 21 (35.6%) of fathers and 25 (42.4%) of mothers hold either university degree or higher while 21 (35.6%) father and 17 (28.8%) had completed high school education.

Half of fathers were employed (57.6%) in comparison to 30.5% of mothers. Retired fathers constitute 39% in comparison to 8.5% retired mothers. Housewife employment was (60.3%). Social class distribution showed a large proportion were middle class (50.8%) Almost half of the sample had consanguineous marriage of first degree relation (57.6%), in addition to 13.6% who had 2nd degree blood relation. Only one third of the sample where the parents were not blood related.

The vast majority of cases (88.1%) had relationship within family members and a quarter (25.4%) had relationship with persons outside the family. None of the cases died, are married or live alone or hold a steady job during the follow up period.

As far as general social functioning is concerned (Table 2).

Item	No	%
Current Status*		
Staying at home	25	42.4
Attending day care center	28	47.5
Going to school	6	10.2
Relationships		
With family only	52	88.1
Having friends	15	25.4
*Non were married, working or living independently		

Table 2: Sample general social functioning.

As far as benefits from rehabilitation or intervention (Table 3), quarter of the families reported no change, another quarter little charge and nearly half reported considerable improvement. The researcher assessment of improvement or benefits gained over the years was more in favour of little improvement in (40%) no change in 35.6% and major improvement in only 23.7%.

Social class and birth order did not seem to significantly impact outcome.

Factor	Little or no change	Major change	OR	95% CI	P Value	Total
Benefit by						
Relatives (mothers)	33	36				
			2.5	1.1495-5.5794	0	59
Researcher	45	14				
Gender						
Male	24	23				
					0.121	59
Female	9	3				
Social Class						
High-class 1,2,3	26	7				
					0.417	59
Low-class 4,5	19	7				
Birth Rank						
1st	15	18				
					0.583	59
Others	12	14				

Table 3: Rehabilitation benefits by factors

Discussion

The majority of followed up cases were adolescents or young adults who were diagnosed at early childhood. The average duration of follow up was nearly 15 years following diagnoses. Males outnumbered females by 4:1; this is similar with other earlier reports [17]. Comorbidity is usually high with ASD but in it was rather low in this sample. What appear to be unusual was early exposure to structural learning such as kindergarten and primary education. Even after 15 years at least 10% were still in regular normal stream schooling. Almost all of cases attended day care program specific for ASD training and rehabilitation beside other types of coaching like sport activity and life skill training. Many children received medications mostly tranquilizer, requested by centre staff for younger age children in order to control their hyperactivity, and antiepileptic for older children with seizure disorders. Diet restriction, gluten free and casein free, is available at day care centres. It is an option intervention available for families. Last birth rank presentation constituted more than a third of the cases. This might give support to the findings related to the role of parental age as a risk factor for ASD found in several worldwide reports [18,19]. Half of the cases were from middle class background – class 3. Social class were not found to be associated factor with ASD even if some linkage reported in certain reports [20]. The number of parents with shared blood relationship was very high, much more than reported in Bahrain [21]. This goes with widely accepted fact about the genetic factor underlying the etiology of ASD. Many parents and especially mother have high education status, compared to mothers of children with intellectual disabilities which was reported in others studies [20]. The rate of employed and housewife's mothers was similar to that in population [22].

Results of the study are similar to other studies which found the progress of ASD social adaptation in their families and the community at large is rather fair to poor [1,2,12]. Many remained isolated with little contact outside the family members, unemployed, single and living with their families. The fact that a quarter of the sample made friends outside their families is an important finding especially if we realized that the base line function is probably low judging from the heterogeneity and severity of disability among the sample. The mean age of the sample was 17 years; persons at this age are more likely to be single, unemployed and living with the families. It might need a longer follow up period to assess these aspects of social adjustment or improvement.

Nearly half of mothers believed that their children showed considerable gains in social life compared to researcher who recognized improvement in only quarter of cases. Mother assessment included behaviour at home and in the community while the researcher depended on reviewing files notes and what day care staff mentioned about behavior and social adjustment in their own environment. In addition, certain type of behavior may probably become more evident in day care centers such as aggressive or oppositional acts. Other explanation for the difference lies with the researcher assessment of progress as whenever he is unsure and cannot judge, and then he was likely to mark them as little or no changes.

The social gains were not associated with gender, social class, birth rank of the child, comorbidity and type of intervention. This study is similar to other studies in this regard [7].

Study Limitations

The sample included children with different cognitive abilities and wide age range at diagnoses

Cases were not evaluated at the time of data collection regarding mental status or cognitive abilities.

Benefits were determining entirely on subjective mother's own assessment and not according to clear parameters.

Twenty-seven per cent of the sample was lost to follow-up. These patients may have had more negative outcome.

Conclusion and Future Suggestion

In a cohort of 59 children with ASD followed up 10-15 years later, showed mixed results of general social functioning. They were living with their families, 10% attending – regular school and half of cases still going to day care centers. in spite of the fact that none of them get married or engaged in regular job, their parents were happy with the improvement in relationship and behavior in half of the sample. The outcome in social functioning seen to be better than what was reported in old studies and reflect improvement from the continuous long term rehabilitation efforts [13]. As the sample mean age was only 17 years, we need probably to examine these children after a long duration and well in their young adult life to assess factors such as intimate relationship and employment.

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