

Survey Regarding the Need of Intensive Training Workshops for Autism Community

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ABSTRACT

Aim: To determine the importance and need of intensive training workshops for autism related community

Study design: Cross sectional study

Place and duration of study: WAPDA Teaching Hospital and Asad Clinic (Eye & Pediatrics Centre) from January 2014 to January 2015

Methodology: In this study we needed 3 groups. In the first group all those 100 parents whose children were already diagnosed of Autism spectrum disorder and children age range was between 3 to 12 years were included without any discrimination of their education level. Second group included 100 professionals. Professionals were defined as those persons who were actively involved in management of children with autism either independently or in supervision with some experts or institute for at least 1 year. Professionals comprised of speech & language pathologist, main stream teachers, clinical and applied psychologist and special educationists. In the 3rd group, 100 doctors were included and majority of these were pediatricians and doctors from Medical and Allied and General Practitioners. Parents who were doctors were excluded from this group. Chi Square was applied & p-value ≤ 0.05 was considered as significant.

Result: In the first group of parents, 52 did not attend any workshop and 13 had no knowledge at all. While in the second group of professional, 50 did not attend any seminar or training workshop and 14 had no knowledge at all. In the 3rd & most educated group of doctors 63 doctors did not attend any seminar or workshop and 21 had no knowledge at all. While doctors had poor knowledge regarding autism management followed by professional and then parents.

Conclusion: Our study, we have observed that most educated and most influential group has lack of training and knowledge regarding autism management in spite of their interest in autism so emphasis should be given to intensify the frequency of autism training workshops for better understanding & management of affected community.

Keywords: Autism, knowledge, seminars, professional

INTRODUCTION

Autism is a brain disorder that begins in early childhood and persists throughout adult hood. It affects three crucial areas of development, communication, social interaction and behavior issues. It is about four times more common in boys than girls; it can affect children of all races and social classes with autism spectrum disorder (ASD). This makes understanding of ASD and its best therapies very difficult. Early diagnosis and early intensive management prior to age of 3-5 years may improve the prognosis and make them more functional. Children are not being diagnosed with ASD early enough. This is usually due to lack of training of related professional on autism specific screening strategies¹. Knowledge and awareness about childhood autism diagnosis and management is low among healthcare professionals².

Autism is becoming an epidemic and is believed to be one of the fastest growing disabilities in childhood and there is a lot variation among healthcare professionals regarding autism diagnosis and management and majority has very poor knowledge regarding practical autism management strategies.³ There is a lot impact on an individual and his or her family after receiving a diagnosis of autism spectrum disorder and they definitely need autism related professionals to guide them timely and properly. In this very critical stage both in the life of a child and his family when they are to manage and support themselves and their affected child, it is really disheartening that most of health care professionals have little or no exposure regarding autism management strategies⁴.

It is very important to understand that delay in diagnosis or misdiagnosis not only hinder the implementation of effective and timely intervention strategies for the deserving child but can also lead to

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poor collaboration of parent and health care providers^{3,5}.

Parent may get distracted in alternative treatments and quality time of affected and deserving child get wasted, so it becomes very crucial to provide optimal services on behalf of health care professionals to affected families and help in reducing the burden & stress associated with autism and its management and it is very important to improve the baseline knowledge of childhood autism among healthcare professional not only for timely management but for the better collaboration of parents and their therapist. The aim of study was to determine the need of intensive training workshops for the autism community and help our children and families effectively.

MATERIALS AND METHODOLOGY

This cross sectional descriptive study was conducted in Paediatric Department WAPDA Teaching Hospital and Asad pediatric sand eye clinic Lahore from January 2014 to January 2015. A total of 300 participants were included and we divided them into 3 groups comprising of parents, professionals and doctors. All 100 parents irrespective of their education status were included and their children had already been diagnosed as ASD (Autism Spectrum Disorder) and were being managed. In the second group of 100 professionals, majority consisted of speech and language pathologist, followed by clinical & applied psychologists & special educationists. We also included main stream inclusive teachers involved in teaching and management of children diagnosed with autism. In the 3rd group of 100 doctors, majority were pediatricians but also included doctors from Medical & Allied mainly and general practitioners as well. Parents who were professionally doctors were excluded from this group.

A standardized Performa was made with the questioners about the level of exposure to autism related seminars and workshops and evaluate the knowledge regarding autism diagnosis and management strategies. While doing knowledge assessment of these, certain criteria were made based on questionnaire and were classified in 4 groups as poor, fair, good, and no knowledge at all.

Every group was enquired about the diagnosis and strategies of management in 10 standard questions. Group, who answered at least 5 questions out of 10 and 2 out of 5 questions included A&B, was classified as group with good knowledge. While group who was able to answer only 3 questions out of 10 and one of 3 questions included A or B at least, was classified as group with fair knowledge. And the group who tried to answer at least any 2 out of any

10 listed questions other than A or B of that proforma questionnaire was classified as group with poor knowledge and the group that did not know anything from A-J was classified as group with no knowledge at all.

Questions were:

- Autism diagnosis by identifying its basic clinical features , DSM 5 criteria (some base line) /CHAT scoring ;(at least some basic knowledge of autism features mentioned in above two methods).
- Behavior management by ABA (applied behavior)
- Some knowledge of IEP (individualized education plan) by portage guide, CARS scoring or ABELL –R (Curriculum guide and scoring system)
- Speech & language therapy
- Sensory Integration therapy
- Visual strategies
- Medical management /biomedical interventions (diet modifications)
- PECS and TEACCH etc (visual strategies of management for communication and transitions)
- Self Help and physical medicine related to motor part of management
- Occupational Therapy
- Knowledge of main stream inclusive schooling
- Relationship development Intervention/Floor time, (social) any other methodology.

RESULTS

In the first group of parents, 52 did not attend any workshop or seminars on autism while only 9 parents out of 100 had exposure to more than 2 autism intensive training workshops in the last 2 years and when their knowledge was assessed we found that 13 parents had no knowledge at all about autism teaching and management . While in the second group of professionals, 50 did not attend any seminar or training workshop and about 11 professionals had attended more than 2 intensive training workshops in last 2 years and 14 had. 11 professionals had good knowledge, 33 with fair knowledge and 42 were labeled as professionals with poor knowledge and 14 had no knowledge at all .In the 3rd & most educated group of doctors 63 doctors did not attend any seminar or workshop and 21 had no knowledge at all , 52 doctors had poor knowledge 23 had fair knowledge and 4 doctors had good knowledge of autism teaching methodologies and management. We found that doctors had poor knowledge regarding autism management followed by professional and then parents.

Table 1: Comparison of age and seminar related information in all study groups

	Study Group		
	Parents	Professionals	Doctors
Seminar attended (P value <0.001)			
<2 (in 2 years)	22	27	26
>2 (in 2 years)	26	7	7
Training workshop (P value 0.030)			
<2 (in 2 years)	10	23	11
>2 (in 2 years)	9	11	4
Not attended any seminars / workshop	52	50	63

Table 2: Comparison of knowledge in all study groups

	Level of knowledge assessed in study groups			
	No Knowledge	Poor	Fair	Good
Parents	13	24	34	27
Professionals	14	42	33	11
Doctors	21	52	23	4

P value <0.001

DISCUSSION

Mean age of participant was 32 for parents and 27 years for professionals and 30 year for doctors. In the second group majority of the participant were speech and language therapist followed by clinical psychological and special educationist. Another study also showed the similar results¹. It was also noticed that 43 professionals were working independently as home based tutors and 57 were working in affiliation with some institution or under the supervision of some expert. Regarding attendance rate at workshops and seminars in the last 2 years, there was maximum attendance of professionals, followed by parents and then doctors. Results are consistent with another study done to see knowledge and training in autism community^{1,6}. While we were assessing the knowledge level among 3 groups, it was observed that majority of doctors and professionals were not properly aware of autism and its management strategies. This is also in consistent with another study^{3,7}. This lack of knowledge and decreased attendance rate in autism related workshops and conferences may be due to lack of interest, lack of facilitation and motivation at the personal or institute level, there may be unsatisfying knowledge of speaker and low quality of training workshops that could influence the autism community specially health care providers. By intensive trainings of professionals we can not only direct and guide the parent mediated intensive interventions but also help in reducing the potential level of stress and depression by sharing their burdens^{8,9}. Affected families may have questions about medical therapy, nutritional supplements and diet, sleep issues, allergy and immune functions and gut problems so it is very

important to train the most educated group of doctors as well¹⁰. Knowledge is power we can empower the autism community through parent and professional trainings¹¹ and better developmental out comes by early intensive interventions¹².

CONCLUSION

Our study has assessed the knowledge and training of autism community in general and has shown that most educated and most influential group has lack of training and detailed knowledge of autism management although they have got interest in knowing autism. So emphasis should be given to increase the frequency and quality of training workshops and conferences at the physician level for early diagnosis and timely referral to subspecialties.

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