Original Article

Role of Parents in Meeting the Educational Needs of Children with Autism Spectrum Disorders

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Abstract

Introduction: Autism Spectrum Disorders (ASD) are making an important emerging public health problem and increasing alarmingly in recent times. The role of parents is of paramount importance in meeting the educational needs of their special children with ASD.

Objective: To find out the role of parents in meeting the educational needs for their children with ASD.

Methods: This descriptive type of cross sectional study was carried out to find the role of parents in meeting the educational needs for their children with ASD among the 61 purposively selected respondents who were attended to Autism Center in BSMMU, Dhaka and Proyash School, Dhaka Cantonment. The data were collected through face to face interview by semi structure questionnaire.

Results: This study revealed that the mean age of the children was 6.65 years with SD±2.763 years, 72.1% children with autism were male and 27.9% of them were female. In this study maximum 39.3% of mothers were HSC qualified and 50.8% of fathers were graduated, 80% mothers were housewife and 20% were in service. It was found that among the children about 52.5% were detected abnormality within first 18 months of age and about 47.5% were detected after 18 months of age. The association between age of first abnormality detection and mother's educational level was statistically significant (p=.025). The present study also reveals that 82% of mother had knowledge about autism, 88.5% of them feels that their children need special education for taking care. It was found in the study about 70.5% mother spent more than 4 hours time/day for taking care of their children at home whereas 29.5% of them spent 1-4 hours of time/day and detection of abnormality of the children was delayed among less educated mothers in comparison to educated mothers.

Conclusion: All this findings suggests that parent's educational needs for taking care of their children with ASD. In this aspect in-depth study on broader perspective is needed for more accurate description of the problem.

Key words: Autism spectrum disorders, Knowledge about autism, Special education, Role of parents, Obstacle for seeking care.

Introduction

Autism is a neural developmental disorder characterized by deficits in social interaction and communication and by restricted and repetitive behaviour. The neurological disorder sets in with the first three years of life and impacts on information processing in the brain by altering how nerve cells and their synapses connect and organize.[1] However, the word was first used by the Swiss psychiatrist, Eugen Bleuler, in 1911 and this concept evolved enormously since then. The word "autism" was first used by Leo Kanner in 1943, later his work along with eleven individuals who displayed socially withdrawn behaviours. Leo Kanneris usually believed to be the first person to employ the term in the way we understand it today. Autism literally means "aloneness," or living in one's own world.[2] In severe cases, young children may not interact with others, or treat people as objects. In milder cases it involves difficulty understanding and relating to others, and difficulty understanding other people's perspectives and emotions.[3]

ASD is associated with three primary symptoms, these are (1) lack of social interaction, (2) deficits in language and (3) odd, routine, or repetitive behaviours. These symptoms are often present before the age of two.[2] The definition of autism as per the diagnostics and statistical manual (DSM-IV-TR) is "the presence of markedly abnormal or impaired development in social interaction, communication and a markedly restricted repertoire of activity and interests".[3] Lack of social interaction can express in various ways that includes aloof to others, a little to no pretend play in early childhood, minimal eye contact, impaired sharing interest or an incapability to read social cues. Lack of communication often include late or regression of language development, confined ability to initiate or sustain conversations, or use of idiosyncratic language.

Restricted interests or a desire for repetition can manifest as wanting to hear the same song or watch the same movie

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repeatedly, using self-stimulating behaviours such as hand flapping or head nodding, or being preoccupied with parts of objects as opposed to focusing on the object as a whole.[3]

Specific early intervention is very much important to treat child with ASD. To get maximum benefits, the parents, treating doctors and specialists should discuss what is best for the child. In this regard, parents should be educated behavioural techniques so that they can participate in all aspects of their child's care and treatment. Special education classes are available for autistic children. Medication can be recommended to treat specific symptoms such as seizures, hyperactivity, extreme mood changes, or self-injurious behaviours.[4] Sometimes treatment is complicated by emergent symptoms such as irritability and other co-morbid situations which may warrant targeted treatment. Individual aims for management vary for different children and may involve combinations of medical and related therapies, educational therapies, behavioural therapies, allied health therapies and complementary and alternative medicine (CAM) therapies.[5]

In Bangladesh, number of children with ASD is increasing and making a serious emerging public health problem. The diagnosis of autism has increased six fold over the past decade in Bangladesh.[6] There is no cure for ASDs and no global consensus on which intervention strategy is most effective. Lifelong care is often required to maximize functional independence and quality of life by minimizing the core autism spectrum disorder features, facilitating development and learning, promoting socialization, reducing maladaptive behaviours and educating and supporting families.[7]

There is a significant role in both parents and school for their children's mental health care. Teacher's assessment is predictive of the child's subsequent mental health. Parent's and Teachers' knowledge of mental health should be increased and clear-cut instructions should be provided for them by health care professionals.[8] Neurodevelopmental disorders as like ASD takes severe toll on the affected family and also society in the long run for the resource poor country like Bangladesh. Therefore, it is indeed a necessity to find out the role of parents for their children with autism attending specialized centers.[9-11]

Materials and Methods

It was a descriptive type of cross-sectional study. The study was undertaken at center for Neurodevelopment and Autism in Children, BSMMU, Dhaka and Proyash School, Dhaka Cantonment, Dhaka. It was conducted for a total period of twelve months commencing from January 2014 to December 2014. The sample was taken purposively and sample size was 61. The respondents were the mothers of children with autism who came to the centers with their children. A semi-structured questionnaire was developed by using the selected variables according to the specific objectives. Pretesting was done at Sishu Bikash Kendra, Dhaka Sishu Hospital. The data was collected after having permission from the authority of Centre for Neurodevelopment and Autism in Children, Bangabandhu Sheikh Mujib Medical University (BSMMU), Dhaka and Proyash School in Dhaka Cantonment, Dhaka. The participants were briefed properly about the objectives of the study and freedom for participating in the study. The research was conducted in full accord with ethical principle. All data were checked thoroughly after collection. Data processing and analysis were done by using SPSS version 20. For inferential statistics Chi-squre test was done to see the level of significance and $p<0.05$ was considered to be significant.

Table-I: Distribution of respondents by demographic characteristics (n=61)

Characteristics		n	%
Age (Years)	1-5	24	39.3
	6-10	31	50.8
	11-15	6	9.8
Sex	Male	44	72.1
	Female	17	27.9
Place of residence	Urban	50	82
	Rural	11	18
Father's Occupation	Cultivation	4	6.6
	Service	39	63.9
	Business	18	29.5
Mother's Occupation	Housewife	49	80
	Service	12	20
Educational level (Father)	SSC	3	4.9
	HSC	10	16.4
	Graduation	31	50.8
	Post-graduation	17	27.9
Educational level (Mother)	Class VIII	4	6.6
	SSC	13	21.3
	HSC	24	39.3
	Graduation	17	27.9
	Post-graduation	3	4.9

Mean age of children was 6.65 years and SD±2.763 years. Out of 61 children, 31(50.8%) belonged to 6-10 years of age, 24(39.3%) were 1-5 years of age and 6(9.8%) were in 11-15 years of age, 44(72.1%) were male and 17(27.9%) of them were female and 82% were from urban area and 18% were from rural area. Among the respondent, 49(80%) mothers were housewife and 12(20%) of them were in service. It was found that among the respondents 31(50.8%) of father's educational level were graduate, 17(27.9%) were post graduate and 10(16.4%) were HSC qualified and 24(39.3%) mother's educational status were HSC, 17(27.9%) were graduate and 13(21.3%) were SSC qualified.

Table-II: Information related to time of recognition of children with ASD (n=61)

Age of abnormality detection by parents (In months)	n	%
Up to 18	32	52.5
Above 18	29	47.5
Age of diagnosis (Months)		
18	7	11.5
24	23	37.7
30	20	32.8
36	9	14.8
48	2	3.3

Table-II shows that among the respondent 32(52.5%) of children with autism were detected first abnormality within 18 months of age and 29(47.5%) were detected first abnormality above 18 months of age and among the children 23(37.7%) were diagnosed at 24 months of age, 20(32.8%) were diagnosed at 30 months of age and 9(14.8%) at 36 months of age.

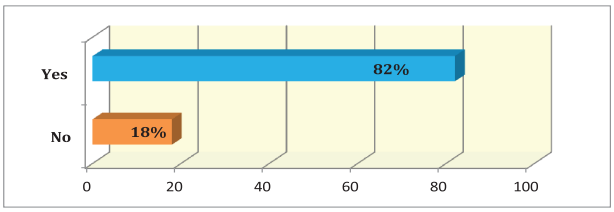

Figure-1: Distribution of knowledge of the respondent about the problem of the children (n=61).

This study showed 50(82%) of the mothers had knowledge about autism and 11(18%) had no knowledge about autism.

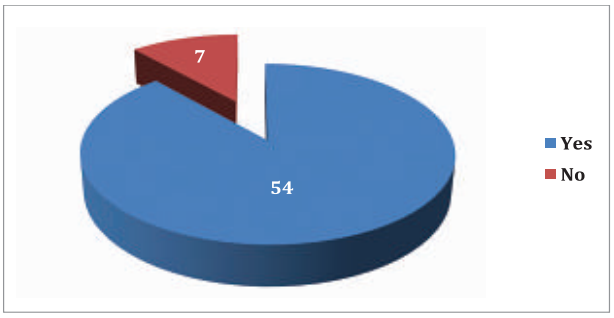

Figure-2: Distribution of knowledge of the respondent about special educational need (n=61).

Table-III: Distribution of the children about time spent at home by mother and father (n=61)

Time spend by mother (Hours/day)	n	%
Up to 2	10	16.4
2-4	8	13.1
4-6	35	57.4
6-8	8	13.1
Time for taking care by father(hour/day)		
1	25	41
2	33	54.1
3	3	4.9

Among the respondent 35(57.4%) of mother spent 4-6 hours/day at home, 10(16.4%) spent up to 2 hours/day, 8(13.1%) spent 6-8 hours/day of time and among the respondent 33(54.1%) father were spent about 2 hours of time and 25(41%) of father were spent 1 hour.

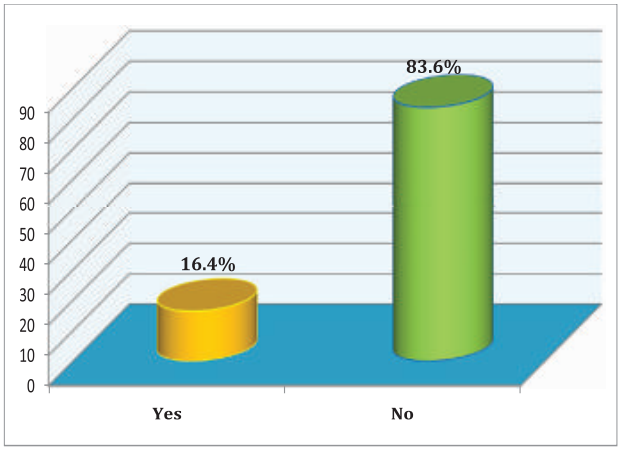

Figure-3: Distribution of the respondent by any obstacles for seeking care (n=61).

Among the parents, 51(83.6%) had no obstacles for seeking care for the children and 10(16.6%) were faced some difficulty for seeking care.

Table-IV: Association between age of first abnormality and mother's education (n=61)

Age of first abnormality detection (year)	Mother's education		Total	Test statistics
	Up to SSC	Up to SSC		
Up to 1.5	5	27	32(52.5%)	x^2=5.020
Above1.5	12	17	29(47.5%)	df=1
Total	17(28%)	44(72%)	61(100%)	p=.025

Among 61 respondents, 52.5% were detected first abnormality within 1.5 years and 47.5% were detected first abnormality after 1.5 years. Among the respondent 28% of mother's educational level were up to SSC and 72% of mother's were above SSC. The association between mother's education and age of first abnormality is statistically significant (p=.025).

Discussion

In the present study, it was found that among the children with ASD, 51% belonged to 6-10 years of age and 39% were 1-5 years of age. The mean age was 6.65 years with SD±2.763 years. This finding is not consistent with the study finding conducted by Newschaffer et al[12] where they found 66% children were 1-5 years and 18.5% were in age group 7-11 years.

This study result revealed that 72% child were male and rest of 28% of the children were female. This study finding is similar to to the study finding of Anderson, Larson and

Wuorio[13] where it was found that among the children 70% was male and 30% were female. The study reveals that among the parents about 39% mother's educational qualification were HSC, 28% were graduate and 21% were SSC qualified. Among the fathers 51% were graduate, 28% were post graduate and 16% were HSC qualified. This finding is not consistent with the study finding conducted by Zaman et al.[6]

This study showed that 80% mothers were housewife and 20% mothers were in service. This study result is more or less similar to the result of the study conducted by Rahman et al. This study showed among the children with ASD 38% were diagnosed at 2 years of age, 33% were diagnosed at 2.5 year of age and 15% at 3 years of age. This result is consistent with the result of CDC and also nearer to the result of Zaman et al.[6] The study reveals that 38% were started treatment at 2 years of age, about 30% started at 3 years of age and 25% started treatment at 2.5 years of age. This result is also nearer to Zaman et al.[6]

In this study, most of the mothers (82%) had knowledge about the problem of the children and 18% had no knowledge about the problem of the children. The association between mother's education and age of first abnormality is statistically significant. The high percentage of knowledge was found in the literate group which is supported by the study conducted by Mandelbaum et al.[14]

Among the respondents, about 88% feels that special education is required for their child for improvement and 12% had no idea about it. This result is also nearer to the result of the study conducted by Zaman et al.[6] In this study, 57% mother spent 4-6 hours time per day, 16% were spent up to 2 hours time per day and 13% were spent 6-8 hours time per day. This finding is not similar with the study conducted by Zaman et al[6] where they found 55% were regular to the centre and 36% mother spent. 4-6 hours time. In this study, 54% father spent 2 hours time per day for taking care of the children, 41% spent only 1 hour time per day for caring the children. Among the respondents 84% had no obstacles for seeking care for the children and 16% were faced some difficulty for seeking care. This finding is more or less similar to the study conducted by NIMH.[15]

Conclusion

It was intended to understand that parents role in meeting the educational needs of children with autism are related to selected important social factors, parents education and knowledge about autism, economic and demographic factors. In this study it has been observed that serving mother spent less time in comparison to no serving (housewives) mothers for taking care of their children, most rural parents faces obstacle for seeking care of the children and detection of abnormality of the children was delayed among less educated mothers in comparison to educated mothers. To ensure the family support to the children with autism physicians and other health care professionals can provide support to parents by educating them about Autism Spectrum Disorders. However, very limited number of researches were carried out nationally and data from national survey are really scarce and as such the study might have less comparatively discussed and might be lack of overall reflection of the country's scenario as a whole but hopefully it will generate some information which can serve as baseline data for further in-depth study in broader perspective.

Limitations of the Study

As sample size was small, the findings of the study may not represents the whole population of Bangladesh. Sampling was done purposively due to limited time and number of respondents availability.

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