

Original Article

Psychological service needs of parents in the management of ASD

Mou Juliet Rebeiro¹, S M Abul Kalam Azad^{2*}, Abu Yusuf Mahmud³

¹Masters Student, Department of Clinical Psychology, University of Dhaka

²Associate Professor, Department of Clinical Psychology, University of Dhaka

³Assistant Professor of Psychology, Directorate of Secondary & Higher Education, Bangladesh

ABSTRACT: Background: Management of behavioral and emotional problems of children with autism spectrum disorders (ASDs) is a great concern for parents in a resource-poor country like Bangladesh. Parents' needs from professionals are very crucial in designing and delivering psychological service for this.

Objective: This study was aimed to find out psychological service needs of the parents of children (4-12 years old) with ASD.

Materials and Methods: A total of 27 parents who were the primary caregivers of the autistic children participated in the study during 2016. All the participants were selected from a school for special children in Dhaka. Permission from the respective authority was obtained and informed consent was taken from all the participants prior to data collection. Parents' responses were collected through interviews and severity of anxiety and depression of parents were determined using valid psychometric tools. Obtained quantitative data were analyzed using SPSS, version 20. and qualitative data were analyzed according to categorization of themes.

Results: 84.60% of the parents of younger children (4-6 years old) and 64.30% parents of the older children (7-12 years old) with ASD suffered from mild to profound levels of anxiety. The study also revealed that 84.60% of the parents of younger children and 78.60% parents of the older children (7-12 years old) with ASD suffered from mild to severe levels of depression. Parents of these children reported behavioral, communication, social and cognitive disturbances shown by the children with ASD. Most of the parents (46.2% parents of 4-6 years old children and 42.9% parents of 7-12 years old children with ASD) reported the need for psychological service over other services.

Conclusion: Despite receiving service from a special school for children with ASD, psychological services for both parents and children are critically needed for better care and management.

Keywords: Autism, psychological service, parenting

Article History

Received: 20 February 2019

Accepted: 19 May 2019



Scan the QR code to see the online version or, visit-

www.bioresearchcommunications.com

Corresponding author

S M Abul Kalam Azad
Associate Professor,
Department of Clinical Psychology,
University of Dhaka
Email: smazad@du.ac.bd
Mobile:

Citation: Mou Juliet Rebeiro, S M Abul Kalam Azad, Abu Yusuf Mahmud; Psychological service needs of parents in the management of ASD. *Biores Comm.* V5-(2). (744-749)

INTRODUCTION

Autism spectrum disorder (ASD) is a complex neuro-developmental disorder characterized by impaired social communication and social interaction and restricted, repetitive behaviors, interests, or activities that cannot be explained by another intellectual disability.⁽¹⁾ It has been estimated that about 1% of the world population, suffer from an autism spectrum disorder.⁽²⁾ Studies in Asia, Europe, and North America have identified individuals with ASD with an average prevalence of between 1% and 2%. The prevalence is increasing exponentially with rates as high as 1.5% in USA to 2.6% in South Korea.² In Bangladesh, a community based cross sectional study reported 0.8% prevalence of autistic disorder among children aged 5 to 17 years.^[3] In 2013, a pilot project utilizing community health workers to screen neuro-developmental disorders indicated overall prevalence of 0.155% for ASD where 3% for Dhaka city and 0.07% in rural areas.⁴

Parents often go through their own stages of grief after knowing their child has been diagnosed with ASD. Learning the child has this disorder may spark a sense of grief, sorrow, shock, or denial among parents. Parents with disabled children present higher levels of dysphoria, intense anger, guilt, depression and anxiety⁵. Parents of children with ASD report higher levels of parental stress than parents of children with other developmental disorders⁶. In Asian countries significant number of parents of children with ASD suffer from depression, for example, researchers⁷ in Turkey reported high rates (72%) of depression in mothers of children with autism. In another study conducted in a tertiary hospital of Pakistan reported that 89% mothers and 77% fathers of intellectually disabled children had anxiety and depression⁸. One researcher⁹ found that stress can cause depression and anxiety and when one parent experiences depression or anxiety, it elevates the stress level of the other parent, increasing that parent's susceptibility to depression or anxiety. Parental stress is influenced significantly by factors such as child's characteristics, parental resources and formal services. Parents of younger children diagnosed with ASD report significantly greater levels of stress than do parents of older children with ASD¹⁰. Formal services have been shown to be particularly helpful in providing stress relief for parents of children with ASD¹¹.

A pioneer author¹² wrote extensively about how the individuals go through five stages of grief. The five stages include denial, anger, bargaining, depression, and acceptance. These stages can also be applied to other grieving processes such as grief and loss associated with raising a child with ASD. Denial can be a strong emotion that often helps parents with their initial reactions and thoughts associated with learning their child has a disability. Denial often takes the form of feeling numb, shock, confused, dazed, and

bewildered. When parents are experiencing denial, it is quite common for parents to ignore or resist treatment recommendations because they are not ready to accept the implications and seriousness of the diagnosis. Therefore, parental denial of the child's diagnosis is one of the critical components of the psychological management for children with ASD.

Anger is another emotion parents may experience after hearing about their child's ASD diagnosis. Parents get angry and want answers as to why their child has ASD. The anger parents express may be directed towards their child's doctors or teachers at first because they are usually the ones informing the parents of the diagnosis¹³.

Another emotion parents may feel after hearing their child's ASD diagnosis is bargaining or guilt. Parents typically wonder if they did something that caused their child to have ASD and blame themselves for what happened to their child and if they did, what can they do to make their child not have ASD.

After experiencing feelings of denial, anger, and bargaining, many parents suffer some level of depression associated with the loss of their typical child. Parents may experience feelings of sadness, emptiness, irritableness, hopelessness, and tearfulness. In fact, depression is common in parents of children with ASD¹³.

Above global literature indicate that parents of children with ASD experience a host of negative emotions and it is crucial to identify their psychological service needs in our cultural context. In our country, parents of children with ASD also experience these negative emotions and face many difficulties managing their children. This study therefore aimed to explore the psychological service needs of parents for their children (4-12 years old) with Autism Spectrum Disorders (ASDs) in Dhaka, Bangladesh.

MATERIALS AND METHODS

The research was conducted on a sample of 27 parents (18 mothers and 9 fathers) of children with ASD. All of them were taken from a school for special children in Dhaka. The age of the respondents ranged from 24 to 40 with mean age 32.2 years and SD of 4.68. All of them were married and came from a higher middle class family.

To collect data for this study each of the parents was administered questionnaires comprising scales to measure anxiety and depression and some responses were taken through interview based on topic guide questions. Following instruments were used:

Anxiety Scale

Anxiety scale¹⁴ was used to find out level of anxiety among respondents. The scale consisted of 36 items in 5 point likert format which measure the severity of anxiety. Item analysis of this scale was done using 102

clinical and 102 non clinical subjects. The final scale was consisted of 36 items, selected on the basis of item total correlation and discrimination value (both significant at $\alpha = 0.01$). Experimental try out was conducted on 410 participants (207 clinical and 203 nonclinical). Split half reliability was 0.916 ($\alpha = 0.01$) and the Cronbach's alpha reliability was 0.9468. The test retest correlation ($r = 0.688$) was found to be significant. The content validity of the scale was ensured strictly following the sequential system model of scale development and by expert's input in different stages of item construction.

Depression Scale

A new scale of depression⁽¹⁵⁾ in the cultural context of Bangladesh was used. Depression scale is a five point rating scale consisting of 30 items. The response options were "not at all applicable (1)", "not applicable (2)", "uncertain(3)", "a bit applicable (4)", and "a totally applicable (5)". All items were scored in positive direction. Higher scores indicate higher level of depression. Highest score in this scale is 150 and lowest is 30. The split half reliability of the scale is $r=0.7608$ and test-retest reliability is $r=0.599$.

Topic guide

A topic guide was developed to collect parents' responses. The topic guide comprised of seven open ended questions containing understanding of the diagnosis, difficulties parents face in managing children, what particular services these parents require very much etc. All the questions were in plain Bangla language.

Procedure

Participants were selected by using purposive sample technique. The questionnaires were administered to

each participant individually. The demographic information was taken along with the questionnaire. Some responses of the participants were taken through interview using semi structured questionnaire. They were informed of the purpose of the present research and necessary rapport was established before administering questionnaire.

Ethical consideration: Ethical clearance was obtained from the Department of Clinical Psychology, University of Dhaka. Permission from school authority was obtained before conducting the study. Written informed-consents were taken from all participants. Each participant was assured that their answer will be completely anonymous and confidential and will be used for only research purpose. When the respondents completed the questionnaires, they were thanked for their kind participation.

The study was mainly quantitative in nature and topic guide questions were used as supplementary tool to collect data. Information collected through topic guide questions were coded and displayed according to their themes. Depression and anxiety scales were used to measure the severity of depression and anxiety among parents of children with ASD.

RESULTS

The objective of this study was to find out the psychological service needs of the parents of children with ASD. Obtained data were analyzed by using SPSS version 20 and qualitative findings are presented through a few tables with description.

Table 1. Anxiety severity of parents according to their children's age group

Anxiety severity level	Parents of younger children (4-6 years old)	Parents of older children (7-12 years old)
Below cut off point	2 (15.4%)	5 (35.7%)
Mild	7 (53.8%)	2 (14.3%)
Moderate	2 (15.4%)	2 (14.3%)
Severe	1 (7.7%)	2 (14.3%)
Profound	1(7.7%)	3 (21.4%)
Total	13 (100%)	14 (100%)

Table 1 shows the severity levels of anxiety for parents of younger children with ASD and for parents of older children with ASD.

Table 2. Depression severity of parents according to their children's age group

Depression severity level	Parents of younger children (4-6 years old)	Parents of older children (7-12 years old)
Below cut off point	1 (7.7%)	1(7.1%)
Minimal	1(7.7%)	2 (14.3%)
Mild	8 (61.5%)	6 (42.9%)
Moderate	2 (15.4%)	2 (14.3%)
Severe	1 (7.7%)	3 (21.4%)
Total	13 (100%)	14 (100%)

Table 2 shows the severity level of depression for parents of younger children with ASD and for parents of the older children with ASD.

Table 3. Problems reported by parents according to their children's age group

Nature of the Problem	Younger children (4-6 years old)	Older children (7-12 years old)
Behaviour Problems		
scream loudly	2 (15.4 %)	1 (7.1 %)
move body parts hands, legs	2 (15.4 %)	4 (28.6%)
jumping, throwing things	4 (30.8 %)	1 (7.1 %)
excessive stubbornness	3 (23.1 %)	2 (14.3 %)
clapping hands, making noises	1 (7.7%)	3 (21.4 %)
cannot stay same position for long	1 (7.7%)	3 (21.4 %)
Total	13 (100%)	14 (100%)
Communication Problems		
able to express necessity	2 (15.4 %)	5 (35.7 %)
unable to express necessity	3 (23.1%)	2 (14.3%)
very little ability to express	8 (61.5 %)	7 (50.0 %)
Total	13 (100%)	14 (100%)
Social Problems		
unable to adjust with other people	3 (23.1%)	6 (42.9 %)
unable to make friend	2 (15.4 %)	4 (28.6 %)
hit other children	1 (7.7 %)	1 (7.1 %)
dislike social gathering	7 (53.8 %)	3 (21.4 %)
Total	13 (100%)	14 (100%)
Cognitive difficulties in comparison with normal children		
very poor	9 (69.2 %)	6 (42.9 %)
poor	2 (15.4%)	5 (35.7 %)
medium	2 (15.4 %)	2 (14.3 %)
good	0 (00%)	1 (7.1 %)
Total	13 (100%)	14 (100%)

Table 3 displays the problems parents face managing their children with ASD based on interview.

Table 4. Service required by parents according to their children's age group

Service Need	Younger children (4-6 years old)	Older children (7-12 years old)
Psychological management	6 (46.2%)	6 (42.9%)
Physiotherapy	4 (30.8%)	5 (35.7%)
Occupational therapy	3 (23.1%)	3 (21.4%)
Total	13 (100%)	14 (100%)

Table 4 shows the type of professional services required by the parents of children with ASD based on interview.

DISCUSSION

The results of the present study showed that parents of children with autism spectrum disorders have clinical level of anxiety and depression. Severity of emotional problems are high in these parents as shown in Table-1 and Table-2. The findings are consistent with the findings of western studies^{16, 17}. In our socio-cultural context, parents of disable children are stigmatized¹⁸, participate less in social or recreational activities¹⁹ and as a result these parents suffer from emotional problems. 84.60% of the parents of younger children (4-6 years old) and 64.30% parents of the older children (7-12 years old) with ASD suffered from mild to profound levels of anxiety. The study also revealed that 84.60% of the parents of younger children and 78.60% parents of the older children with ASD suffered from mild to severe levels of depression. This finding is supported by previous¹⁰ study that found that parents of children 4 years old or younger who are diagnosed with ASD report significantly greater levels of stress than do parents of older children with ASD. Some parents in this study admitted that they only get supports from their school which is not enough for them in managing their children's psychological problems at home. Lack of adequate trained staffs in the school is the major cause of limited support parents receive. Parents thus struggle daily in the management of these children. As the Government of Bangladesh is not providing sufficient subsidies, poor financial situation of caregivers and the amount of social support caregivers have can cause stress and anxiety. A recent study concluded that stressors were not a direct predictor of negative outcomes, but that their influence was moderated by social support and coping style²⁰.

Table-3 shows that children with ASD exhibited multiple behavioral problems, communication related problems and social problems notably restlessness, poor adjustment and academic difficulties. Parents thus need some particular guidance and support from mental health professionals for better management of the challenges they face with their child with ASD. Professional service needs reported by these parents are presented in Table-4, where psychological service need was required by most of the parents.

CONCLUSIONS

This study revealed that a high percentage of parents of children with ASD suffer from mental health problems such as anxiety and depression due to raising their children. Professional service and parents' education and training on psychological management can reduce anxiety and depression in these parents.

REFERENCES

1. American Psychiatric Association, 2013. Diagnostic and statistical manual. 5th ed. Arlington, VA: American Psychiatric Association.
2. Center for Disease Control and Prevention. Prevalence of autism spectrum disorders. Autism and Developmental Disabilities Monitoring Network, 14 sites, United States; 2012. Retrieved from <https://www.cdc.gov/ncbddd/autism/data.htm>.
3. Rabbani M.G., Alam MF, Ahmed H.U., Sarkar M., Islam M.S., Anwar N., et al. Prevalence of mental disorders, mental retardation, epilepsy and substance abuse in children, 2009. Bangladesh J of Psychiatry, 23(1):11-53.
4. Hossain M.D., Ahmed H.U., Jalal Uddin M.M., Chowdhury W.A., Iqbal M.S., Kabir R.I., et al. 2017. Autism Spectrum disorders (ASD) in South Asia: a systematic review. BMC Psychiatry, 17(1):281.
5. Davis C., Rosswurm M. and Zane T. 2008. The cost of fad treatments in autism. Journal of Early and Intensive Behavior Intervention. 5(2):44-51.
6. Griffith, G. M., Hastings, R. P., Nash, S., & Hill, C. 2010. Using Matched Groups to Explore Child Behavior Problems and Maternal Well-Being in Children with Down Syndrome and Autism. Journal of Autism and Developmental Disorders. 40(5):610-619.
7. Firat, S., Diler, R., Avci, A., & Seydaoglu, G. 2002. Comparison of psychopathology in the mothers of autistic and mentally retarded children. Journal of Korean Medical Science, 17, 679-685.
8. Azeem, M. W., Dogar, I. A., Shah, S., Cheema, M. A., Asmat, A., Akbar, M., . . . Haider. 2013. Anxiety and Depression among Parents of

- Children with Intellectual Disability in Pakistan. *J Can Acad Child Adolesc Psychiatry*, 22(4), 290-295.
9. Rogers M. L. 2008. Can marital satisfaction of parents raising children with autism be predicted by child and parental stress. Doctoral Dissertation, 18. Retrieved from ProQuest LLC
 10. Osborne L. A and Reed P. 2010. Stress and self-perceived parenting behaviors of parents of children with autistic spectrum conditions. *Research in Autism Spectrum Disorders*. 4:405-414.
 11. Tehee E., Honan R. and Hevey D. 2009. Factors contributing to stress in parents of individuals with autistic spectrum disorders. *Journal of Applied Research in Intellectual Disabilities*. 22:34-42
 12. Kubler-Ross E. 1972. On death and dying. *JAMA* 1972; 221(2):174-179.
 13. Koegel, L., and LaZebnik, C. 2004. *Overcoming autism*. New York, NY: Penguin Group.
 14. Deeba F. and Begum R. 2004. Development of an anxiety scale for Bangladeshi population. *Bangladesh Psychological Studies*. 14:39-54.
 15. Uddin M.Z. and Rahman M. M. 2005. Development of a scale of depression for use in Bangladesh. *Bangladesh Psychological Studies*. 15:25-44.
 16. Harris S. 1984. The family and the autistic child: A behavioral perspective. *Family Relations* 1984. 33: 127-134.
 17. Dunn M. E., Burbine T., Bowers CA and Tantleff-Dunn S. 2001. Moderators of stress in parents of children with autism. *Community Mental Health Journal*. 37:39-52.
 18. Upadhyaya G. R. and Havalappanavar N. B. 2008. Stress in parents of the mentally challenged. *Journal of the Indian Academy of Applied Psychiatry*. 34: 53-59.
 19. Majumdar M, Da Silva P Y, Fernandes J. 2005. Stress and anxiety in parents of mentally retarded children. *Indian Journal of Psychiatry*. 47(3): 144-147.
 20. Gohel M., Mukherjee S. and Choudhary S. K. 2011. Psychosocial impact on the parents of mentally retarded children in Anand District. *Health line*. 2(2): 62