

© 2016 Elvira Mujkanovic, Haris Memisevic, Edin Mujkanovic, Sadata Zecic, Inga Biscevic

This is an Open Access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>) which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original work is properly cited.

ORIGINAL PAPER

Mater Sociomed. 2016 Aug; 28(4): 288-291

MOTHERS' SATISFACTION WITH TREATMENT OPPORTUNITIES FOR THEIR CHILDREN WITH AUTISM SPECTRUM DISORDER IN BOSNIA AND HERZEGOVINA

Elvira Mujkanovic, Haris Memisevic, Edin Mujkanovic, Sadata Zecic, Inga Biscevic

Faculty of Health Sciences, University of Sarajevo, Bosnia and Herzegovina

Corresponding author: Elvira Mujkanovic, MD. Faculty of Health Sciences, University of Sarajevo, Bosnia and Herzegovina

ABSTRACT

Aim: The goal of this study was to examine the general satisfaction of mothers of children with autism spectrum disorder (ASD) with treatment opportunities for their children in Bosnia and Herzegovina. An additional goal was to assess the level of mothers' satisfaction with their own involvement in the creation and implementation of Individual Education Plans. **Methods:** The sample consisted of 98 mothers of children with ASD. Mothers answered to questions related to their perceived satisfaction with treatment options. **Results:** The results of this study indicated that mothers are generally satisfied with educational opportunities for their children (61.2%). However, their satisfaction with involvement in the creation and implementation of Individual Education Programs was much lower (35.7%). Most comments of the mothers were that the treatment options should be more widely available and that the educational programs could be improved. **Conclusions:** Parents of children with ASD should have more information on the treatment options available for their children. More educational opportunities need to be offered to children with ASD in Bosnia and Herzegovina.

Key words: autism spectrum disorder, mothers, children with autism, treatment opportunities.

1. INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by persistent deficits in social communication and social interaction. It is also accompanied by restrictive, repetitive patterns of behavior (1). The symptoms of ASD are manifested in the early developmental period, usually before the age of 3. Although there have been some advancements in determining biological causes of ASD, the exact causes are still hard to pinpoint due to a wide variety of potential causative factors (2, 3). Another focus of research, besides etiology, has been focused on finding the potential biological substances that could alleviate the ASD symptoms. Although there are some promising biological treatments for ASD on the horizon, such as the use of oxytocin (4), the best available options for treating ASD symptomatology remain psycho-educational. There are a number of psycho-educational treatments available that proved to be very efficacious in reducing the symptoms and improving the cognitive and educational outcomes of children with ASD. One of the best known and probably the most researched such treatment is the Applied Behavior Analysis (ABA). Ever since the seminal work of Lovaas

(5), the interest in this method had grown rapidly and the evidence of its efficacy keep accumulating. There are numerous instructional methods that originated from ABA and they also seem to be very promising (6). Besides ABA based instructional approaches to learning, there is a plethora of other, more or less scientifically validated approaches to learning in children with ASD. Some of the best known such approaches include TEACCH (Teaching and Education of Autistic and Communication Handicapped Children (7), Denver model (8, 9) and PECS (Picture Exchange Communication System). There are also numerous other methods, purported to be beneficial for children with ASD, but for which scientific proofs are not that strong or are missing.

This vast selection of therapeutic modalities, all claiming to be greatly efficacious by their creators, represents a great challenge for parents of children with ASD. Parents have to choose which treatment they will select for their child, fearing at the same time that they may be missing on something "better". Thus, it is not surprising that families raising children with ASD have higher level of stress compared to families raising typically developing children (10, 11). In the same line, parents of children with ASD have higher stress

levels than parents of children with other developmental disabilities (12).

The goal of the present study is to examine the perceived level of satisfaction of mothers of children with ASD with available educational treatments in Bosnia and Herzegovina and their satisfaction with their own involvement in the creation of Individual Education Programs for their children.

To date, the research on ASD in Bosnia and Herzegovina has been very scarce. To the best of authors' knowledge there are no studies on any aspect of autism in Bosnia and Herzegovina published in peer reviewed journals. There are no studies dealing with the prevalence of children with ASD in Bosnia and Herzegovina, although the international trends show that the prevalence is increasing (13). The same trend is probably present in Bosnia and Herzegovina as well, as the numbers of children with diagnosed ASD who are enrolling in the special and regular schools in Bosnia and Herzegovina is increasing.

Prior to realization of goals of this study, let us briefly introduce the readers with the current situation regarding the education of children with ASD in Bosnia and Herzegovina.

B&H context

Children with ASD usually receive the formal diagnosis of ASD at the Neuropsychiatry departments at the University Clinical Centers in Sarajevo, Banja Luka, Mostar and Tuzla. Parents state that the procedure of getting the diagnosis is very stressful and the diagnosis is insufficiently explained to them. After receiving the formal diagnosis, parents are referred to Educational institutions (such as special preschools and schools), and to Non-governmental organizations (NGOs) that offer some kind of treatment to children with ASD. In the city of Sarajevo, there are two special schools that provide preschool services to children with ASD and couple of NGOs that provide treatments to these children. Most of the treatments offered are scientifically validated such as Applied Behavior Analysis. However, parents also state as the problem that these treatments offered at the NGOs are expensive and represent an additional financial burden for them.

Bosnia and Herzegovina has a very complex political structure. It consists of two entities (Federation B&H and Republic of Srpska) and Brcko district. Furthermore, FB&H is divided in 10 Cantons, one of which is Canton Sarajevo. Each of these political entities has their own Ministry of education and legislature covering education, so there are 13 Ministries of Education and same number of Educational laws. Although, most of these laws are affirmative regarding the education of children with special needs, they are not fully implemented in practice. As an example of this, Educational Law in Canton Sarajevo states that every child with special needs will receive necessary specialized support from special education teacher and speech therapists. Currently there are no special education teachers or speech therapists employed in regular schools in Canton Sarajevo. According to the law, children with special educational needs are children with intellectual, hearing, visual and motor disability. There is no separate category for children with ASD, although there are some initiatives to expand this list to be more aligned with the IDEA (Individuals with disabilities education act) categories of children eligible for

special education services.

As there is a shortage of scientific literature examining the position of parents of children with ASD, we wanted to fill this gap by examining one important segment, namely the satisfaction of mothers with treatment options and services for their children with ASD in Canton Sarajevo, Bosnia and Herzegovina. In addition to this, we examined whether there are differences in attitudes of mothers in regard to type of school the child is attending (preschool or elementary) and educational level of the mother.

2. METHODS

Participants

The sample for this study involved 98 mothers of children with ASD from Sarajevo Canton. Children were receiving a variety of services: a) attending regular kindergartens; b) attending specialized kindergartens, c) attending regular schools and d) attending Special schools. As we wanted to test mothers' attitudes in relation to two independent variables, the sample was divided in two groups: a) mothers of preschool children with ASD (67 or 68.4%) and b) mothers of school-aged children with ASD (31 or 31.6%). The other independent variable was education level and sample was divided in two groups: a) mothers who finished elementary and high school (63 or 64.3%) and b) mothers who finished faculty and higher (35 or 35.7%).

Instrument and Procedure

Total of 120 mothers were given customary designed, 12 questions long questionnaire regarding many aspects of perceived knowledge and support in the areas such as legislature, existing service and supports, satisfaction with expert support services etc. Out of 120, 98 mothers returned the questionnaires. The satisfaction level was measured with 5 point Likert scale ranging from 1 (strong disagreement) to 5 (total agreement). For the purposes of this study, we selected 2 questions to ask the mothers regarding the current aspects of educational treatment that is offered to their children:

- I am satisfied with the level of treatment opportunities at the educational institutions;
- I am included in the creation and implementation of individual education programs for my child. We explained that all data are anonymous and mothers signed an informed statement to participate in the study.

Statistical analysis

Data were presented descriptively through frequencies and percentages. The hypotheses were tested by Chi-squared test. An alpha level of .05 was set for all statistical tests. Data were analyzed with computer program SPSS v.13 for Windows.

3. RESULTS

The first goal of this study was to examine the satisfaction level of mothers with the treatment opportunities their children are receiving at the educational institutions and NGOs that provide education and rehabilitation treatments to children with ASD. Descriptive analysis is shown in table 1.

Strongly disagree N %	Disagree N %	Undecided N %	Agree N %	Strongly agree N %
19 19.4	18 18.4	1 1	29 29.6	31 31.6

Table 1. Distribution of mothers' answers on the item: I am satisfied with the treatment opportunities for my child

As can be seen from the table the answers were divided. Total of 60 mothers (61.2%) were satisfied with the available expert services at the educational institutions, as compared to 37 mothers (37.8%) who were not satisfied. There was only one neutral answer, so the mothers were pretty confident in their answers.

We then compared the differences in attitudes in relation to the mothers' educational level and in relation to whether the children attended preschool or school institutions. In testing the potential differences, the Strongly disagree and Disagree answers were merged in the category **Disagree** and answers Strongly agree and Agree were merged in the category **Agree**. In the case of mother's educational level, there was only one undecided answer so it was not included in the analysis. The results are shown in Table 2.

Education level	Disagree N %	Agree N %
Mothers who finished elementary and high school	22 35.5	40 64.5
Mothers who finished faculty and higher degrees	15 42.9	20 57.1
Setting		
Mothers of preschool children	27 40.9	39 59.1
Mothers of elementary school children	10 32.3	21 67.3

Table 2. Satisfaction with the treatment opportunities in relation to mother's educational level and type of setting the child attends.

In relation to mothers' educational level it can be seen that both groups are mostly satisfied with the available expert services at the schools. Slightly higher percentage of mothers with higher level of education are not satisfied with the expert services.

According to the Chi-square test, there were no statistically significant differences in the attitudes of mothers towards satisfaction with expert services at the educational institutions in relation to their educational level, $X^2(1, N=97) = 0.51; p = .47$.

Further it can be seen that more mothers of elementary school children (67.7%) are satisfied with expert supports than are mothers of preschool children (59.1%). However, according to the Chi square test, these differences are not statistically significant, $X^2(1, N=97) = 0.67; p = .41$.

The second question of the survey regarded the satisfaction of mothers with their involvement in the creation and implementation of Individual Education Programs. The descriptive results are shown in Table 3.

Strongly disagree N %	Disagree N %	Undecided N %	Agree N %	Strongly agree N %
24 24.5	23 23.5	16 16.3	28 28.6	31 7.1

Table 3. Distribution of mothers' answers on the item: I am satisfied with my involvement in the creation and implementation of Individual Education Programs

As can be seen from the table, only 35.7% of mothers agreed with the statement. For this item there were many mothers who were undecided on the issue and almost half of the mothers disagreed with the statement. In Table 4 we compared the attitudes of mothers in relation to the educational level and type of setting the child was attending.

Education level	Disagree N %	Undecided N %	Agree N %
Mothers who finished elementary and high school	31 49.2	10 15.9	22 34.9
Mothers who finished faculty and higher degrees	16 45.8	6 17.1	13 37.1
Setting			
Mothers of preschool children	30 44.8	8 11.9	29 43.3
Mothers of elementary school children	17 54.8	8 25.8	6 19.4

Table 4. Satisfaction with the involvement in program creation and implementation in relation to mother's educational level and type of setting the child attends.

It can be seen from the table that the answers were distributed equally in regard to the mothers' educational level and there no statistically significant differences between them ($X^2(2, N=98) = 0.11; p = .97$). However, there were statistically significant differences in the distribution of answers between mothers of preschool and mothers of school children ($X^2(2, N=98) = 6.3; p = .042$). Significantly larger percentage of mothers of preschool children was satisfied with their involvement in programs for their child in comparison with mothers of school children.

4. DISCUSSION

The goal of this study was to assess the satisfaction of mothers of children with ASD with the treatment opportunities in Canton Sarajevo, Bosnia and Herzegovina. An additional goal was to assess the impact of mothers' level of education and type of setting the child attends on the attitudes. The results of this study indicated that majority of mothers were satisfied with the treatment opportunities. More than 60% of them were happy with the treatment options offered to their children. Distribution of these answers was the same regardless of the education level of the mothers or of the age of the child (preschool or school aged). The results of this study are in line with an earlier study confirming that there was no effect of child's age, ethnicity and household income on the satisfaction of mothers with educational provision (12). Earlier research has shown that the services for children with ASD received at preschool and elementary school differ. For example in a study by Wei et al. (14) the authors found that children with ASD attending elementary school had higher odds of receiving appropriate physical education and customized computer software but lower odds of receiving learning strategies supports compared to preschool children with ASD. Our results confirmed this finding in a way that mothers of preschool children were more satisfied with their involvement and implementation of Individual Education Programs than mothers of school aged children with ASD.

Regardless of the perceived satisfaction with the educational opportunities, mothers of children with ASD are faced

with many challenges in their everyday lives (15). In this study, besides providing answers to the items in the survey, mothers were also asked to name some of the greatest obstacles that they are facing with in their everyday lives. The most frequent answers to that question were discontent with medical services, reluctance of medical staff to diagnose the child and refer it to the adequate educational institution. Many parents believe they lost valuable time in hospitals instead of receiving appropriate psycho-educational interventions. We believe it is of utmost importance that pediatric clinics should immediately refer any child suspected of having ASD and children with ASD to the appropriate educational centers that offer evidence-based psycho-educational interventions to these children. More attention should also be given to social supports to parents of children with ASD, as these supports can significantly reduce the amount of stress (16). It is very important to develop programs aimed at providing emotional and social supports to parents of children with ASD in Bosnia and Herzegovina and these supports should be incorporated in the daily activities of centers for education and rehabilitation.

In line with the results of this study, it would be important to find out how to improve educational opportunities for children with ASD, so even more parents would be satisfied with them. One way to do this would be through the educational trainings to parents, so the parents can feel more confident in choosing the educational options for their child. Mothers in this study would like to be more involved in the creation and implementation of the educational program for their child. Some of the comments that these mothers made were that the Individual Education Programs are not well-adjusted to the needs of their child and that the existing Programs should be more detailed about the educational goals.

Lastly, let us mention some of the limitations of this study. A number of important variables that could potentially have an impact on mother's attitudes were not taken into consideration such as: marital status, partner support, monthly income etc. These factors could affect mothers' satisfaction level. As was done in some other studies (17), we did not ask the mothers about the ideal educational placement for their child. Future research should examine the above mentioned factors.

5. CONCLUSION

We believe there should be more trainings and seminars for parents of children with ASD, where the parents would learn more about the effective programs for children with ASD and would be more empowered to select the ones that are scientifically validated.

- Conflict of interest: none declared.

REFERENCES

1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (DSM-5). American Psychiatric Pub. 2013.
2. Landrigan PJ. What causes autism? Exploring the environmental contribution. *Curr Opin Pediatr.* 2010; 22(2): 219-25.
3. Constantino JN, Charman T. Diagnosis of autism spectrum disorder: reconciling the syndrome, its diverse origins, and variation in expression. *Lancet Neurol.* 2015; 15(3): 279-91.
4. Yatawara CJ, Einfeld SL, Hickie IB, Davenport TA, Guastella AJ. The effect of oxytocin nasal spray on social interaction deficits observed in young children with autism: a randomized clinical crossover trial. *Mol Psychiatry.* 2015; 1-7.
5. Lovaas OI. Behavioral treatment and normal educational and intellectual functioning in young autistic children. *J Consult Clin Psychol.* 1987; 55(1): 3-9.
6. Anderson SR, Romanczyk RG. Early intervention for young children with autism: Continuum-based behavioral models. *Res Pract Persons Severe Disabl.* 1999; 24(3): 162-73.
7. Schopler E, Reichler RJ. Parents as cotherapists in the treatment of psychotic children. *J Autism Child Schizophr.* 1971; 1(1): 87-102.
8. Rogers SJ, Hayden D, Hepburn S, Charlifue-Smith R, Hall T, Hayes A. Teaching young nonverbal children with autism useful speech: A pilot study of the Denver model and PROMPT interventions. *J Autism Dev Disord.* 2006; 36(8): 1007-24.
9. Dawson G, Jones EJ, Merkle K, Venema K, Lowy R, Faja S, Kamara D, Murias M, Greenson J, Winter J, Smith M. Early behavioral intervention is associated with normalized brain activity in young children with autism. *Journal of the American Academy of Child & Adolescent Psychiatry.* 2012; 51(11): 1150-9.
10. Miranda A, Tárraga R, Fernández MI, Colomer C, Pastor G. Parenting Stress in Families of Children with Autism Spectrum Disorder and ADHD. *Except Child.* 2015; 82(1): 81-95.
11. Davis NO, Carter AS. Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *J Autism Dev Disord.* 2008; 38(7): 1278-91.
12. Bromley J, Hare DJ, Davison K, Emerson E. Mothers supporting children with autistic spectrum disorders social support, mental health status and satisfaction with services. *Autism.* 2004; 8(4): 409-23.
13. Newschaffer CJ, Falb MD, Gurney JG. National autism prevalence trends from United States special education data. *Pediatrics.* 2005; 115(3): e277-82.
14. Wei X, Wagner M, Christiano ER, Shattuck P, Jennifer WY. Special education services received by students with autism spectrum disorders from preschool through highschool. *J Spec Educ.* 2014; 48(3): 167-79.
15. Estes A, Munson J, Dawson G, Koehler E, Zhou XH, Abbott R. Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism.* 2009; 13(4): 375-87.
16. Boyd BA. Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus Autism Other Dev Disabl.* 2002; 17(4): 208-15.
17. Kasari C, Freeman SF, Bauminger N, Alkin MC. Parental perspectives on inclusion: Effects of autism and Down syndrome. *J Autism Dev Disord.* 1999; 29(4): 297-305.