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Original research paper

NEGATIVE EMOTIONAL STATES AND QUALITY OF LIFE IN PARENTS OF CHILDREN WITH AUTSTIC SPECTRUM DISORDER

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Abstract

Prevalence of autistic spectrum disorders is constantly increasing. Considering the lack of institutionalized support for guardians, it has been noticed that parents of children with ASD more often experience negative emotional states, such as depression, anxiety and stress, and perceive their quality of life to be lower than the parents of typically developing children. The aim of our research was to compare the level of depression, anxiety, stress and quality of life in parents of children with ASD and parents of children without developmental difficulties.
The research was quantitative, a socio-demographic questionnaire was used, as well as DASS-21 and WHOQOL scales. There were 78 participants, of which 39 parents of children with ASD (members of „Djeca svjetlosti“ Banja Luka and EDUS Sarajevo), and 39 parents of children without developmental difficulties. F-test was used for comparison of results in the depression, anxiety, stress and quality of life scales between the two groups.
It was found that there were statistically significant differences in the level of depression ($F=3.72$, $p<.01$), anxiety ($F=4.51$, $p<.01$) and stress ($F=3.47$, $p<.01$), in a way that negative emotion levels were higher in parents of children with autistic spectrum disorder. As far as the perceived quality of life is concerned, the only statistically significant difference was found in the domain of psychological health ($F=-3.22$, $p<.01$), in the way that the parents of typically developing children had higher level of perceived satisfaction in this domain.

Recommendations made on the basis of these results are that mental health professionals should be educated for work with emotional problems affecting parents of children with autistic spectrum disorders, in order to make treatment be more comprehensive and efficient.

Key words: autistic spectrum disorder, parents, stress, anxiety, depression, quality of life.

Introduction

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), autistic spectrum disorder is a superior term that includes autism, Asperger's syndrome and unspecified autistic spectrum disorder. Autistic spectrum disorders are complex disorders typically emerging in the first three years of life and encompass different aspects of psychological functioning. A characteristic of this type of disorder is that it permeates several important areas of development – reciprocal social reactions and communication, and also includes stereotypical behavioral patterns. Social relations are disturbed in terms of the inability to use non-verbal behavior in order to develop social interactions and peer relationships appropriate to the level of development. The absence of spontaneous attempts to share pleasure and interests with others, as well as lack of social and emotional reciprocity are noted. Qualitative impairment in communication is reflected in the delay or absence of speech development, difficulties in conversation reciprocity, repetitive speech, inability to imitate the game, and the lack of a symbolic game in general. In the sphere of behavior, the problem is manifested in a preoccupation with one or more stereotyped and restricted patterns of behavior, stereotyped and repetitive motor mannerisms, and preoccupation with parts of objects (1).

Although parents are increasingly involved in the therapeutic work with children with autistic spectrum disorders, a majority of researches is still mostly focused only on the outcomes of working with children, while little is still known about the effect of the whole situation on the family.

Some studies show that taking care of a child with autistic spectrum disorder, considering the wide range of problems faced, often results in high levels of stress, depression and anxiety in parents (2-5).

It has been found that in addition to the fact that parents of children with autism spectrum disorder have more expressed symptoms of depression, anxiety and stress than parents of healthy children, mothers of autistic children have more expressed symptoms of stress and depression than fathers (2). Other studies (6) show that half of parents of children with ASD express anxiety, while two-thirds are clinically depressed. De Sousa (7) finds that most mothers of children with autism have moderate to severe depression, unlike mothers of children with mental retardation who have scores on the scale range from mild to moderate depression.

It was noticed that depression, stress and anger among mothers of autistic children were intensified if they were unemployed or worked fewer hours (8). It is possible that such a state is a consequence of a greater number of hours spent with

an extremely demanding child, little interaction with adults, and also the reduced income.

Apart from negative emotional states, which can occur in parents of children with ASD, one of the important factors that should be paid attention to is the perception of quality of life. The World Health Organization (WHO) defines quality of life as one's own perception of the position in a specific cultural, social and environmental context (9). In addition to objective factors, such as social, economic and political, quality of life is also influenced by subjective perception and assessment of physical, material, social and emotional well-being. A subjective perception of quality of life is influenced by a value system of an individual, which is one of the reasons why the level of self-assessment of quality of life is, on average, stable and positive, regardless of the external events. This is confirmed by various research. Therefore, an assumption is being developed about the existence of a mechanism thanks to which the perception of subjective quality of life is maintained at a certain level. Best known is the Cummins' theory of homeostasis of subjective quality of life (10). The theory assumes that there is a mechanism of homeostasis that acts as a control system in which a person perceives his or her own well-being within the range strictly specific to the individual, and maintains a subjective quality of life of the individual and the level of satisfaction within the positive values (10). The normative range of population in the world is between 60% and 80%, and even the lowest values are above 50% (11). Based on these results and in accordance with the theory of homeostasis, it can be assumed that the perception of quality of life is a stable construct, and that the conditions that abruptly reduce or increase the subjective perception of quality of life cannot disturb its level in the long term. The general decline in the level of perceived quality of life is possible in situations when adverse impacts are so powerful that exceed coping strategies of the individual, which leads to the breakdown of homeostasis. It is believed that this can be a result of severe chronic pain and care for a family member suffering from a serious incurable disease. It is believed that the parents of children with autistic spectrum disorders, due to the characteristics of the disorder itself, are exposed to particularly high level of stress, and it is assumed that their perception of the quality of life will be lower. A group of Swedish authors came to the conclusion that mothers of children with autism have a lower perception of quality of life in the domain of health (12), while the Croatian sample study showed that the quality of life of parents of autistic children is lower in all domains (13). In addition, because of the numerous treatments, parents of children with autism have more financial problems, which further contributes to the level of stress (14). However, attention must also be paid to the possibility that care for a disabled family member can lead to a greater cohesiveness of the family. Given the results stated, as well as the fact there have been no studies of this type in our geographical area, as the aim of our research we have decided to compare the severity of symptoms of depression, anxiety and stress, as well as the level of quality

of life in parents of children with autistic spectrum disorder and parents of children without developmental difficulties.

Based on previous research, assumed is the following:

– Negative emotional states such as depression, stress and anxiety are more expressed in parents of children with autism (2-5)
– Negative emotional states are more expressed in mothers than in fathers of children with autistic spectrum disorders (2);
– Parents of children with autism, compared to parents of typically developing children, have lower levels of perceived quality of life (12, 13).

Method

Sample

The sample of the study was a convenience sample of 78 participants. 39 participants were parents of children diagnosed with some type of autistic spectrum disorder, all members of the associations „Djeca svjetlosti“ in Banja Luka or EDUS in Sarajevo. Besides that, 39 other participants were parents of children without developmental disorders, so they consisted a healthy control group. This sample has been drawn from elementary school, and consisted of parents whose children were of the same age as children with ASD. The groups were relatively homogeneous in age (M=36.51 in group of parents of children with ASD, M=34.72 in control group). The structure of the sample by gender is presented in Table 1. Most of the sample were couples, but in several cases, father weren't available for examination. Only two women were single mothers, there were no men as single parents.

Table 1 Structure of the sample by gender and group

	Men	Women	Total
Parents of children with ASD	17	22	39
Parents of children without disorders	15	24	39
Total	32	46	78

Instruments

In order to collect data on participants, their dominant emotional states and perception of the quality of life, the following instruments were used:

- *Questionnaire on socio-demographic data* – created for the needs of this study; it consists of 17 items; first nine questions relating to parents (years of age, working, marital and housing status), while eight questions were related to the child (age, diagnosis, most prominent problems);

- *Questionnaire for the assessment of depression, anxiety and stress DASS-21* (15, 16) – a questionnaire that provides a quantitative measure of distress on three

axis of depression, anxiety and stress. It consists of 21 items that describe negative emotional symptoms. Participants state how often they felt these symptoms during the past week, expressing the degree of agreement on a four-degree Likert-type scale (from 0 – never, to 3 – almost always). Reliability of each subscale obtained on the original sample of the test authors was very high (Cronbach's alpha – depression 0.91; anxiety 0.84; stress 0.90). On a Serbian sample, internal consistency of the scale was high (Cronbach's α = .92) (16).

- *Quality of Life Questionnaire of the World Health Organization WHOQOL bref (9)* – consists of two items that measure the overall quality of life, and 24 items related to the assessment of quality of life in four domains (physical health, psychological health, social relations and environment). Level of agreement with each statement is determined by five-degree Likert-type scale. The scale has a high correlation with the WHOQOL-100 (r-.89), as well as high reliability and internal consistency obatained on original sample. The Croatian version of the questionnaire was used.

Design

The research is non-experimental, conducted by a survey. The research design is multivariate.

Variables

The research included three groups of variables:

– socio-demographic variables – in order to define the structure of the sample;
– variables related to negative emotional states (level and category of depression, anxiety and stress) - numeric variable operationalized through the results on the DASS-21 scale
– variables related to quality of life – numeric variable, operationalized through the results on the scale WHOQoL

Procedure

A sample of parents of children with autistic spectrum disorder was gathered in associations "Djeca svjetlosti" in Banja Luka and EDUS in Sarajevo. During their introduction in the work of support group, respondents were given questionnaires with the explanation how to complete them.

Parents of children without developmental disorders were interviewed in a primary school in Banja Luka, on arrival at a parent – teacher meeting.

Results

AdH1) It is assumed that parents of children with autism have more expressed negative emotional states such as depression, anxiety and stress.

The results show that there are statistically significant differences in the level of expression of negative emotional states between parents of children with autistic spectrum disorders and parents of children with typical development. Differences were evident in the area of all three measured emotional states – depression (F=3.72, p<.01), anxiety (F=4.51, p<.01) and stress (F=3:47, p<.01), wherein negative emotional states were higher among parents of children with autistic spectrum disorder. Results can be seen in Table 2 in the appendix.

AdH2) It is assumed that negative emotional states are more expressed in mothers than in fathers of children with Autism Spectrum Disorders (Merkaj, Kika, Simaku, 2013).

The results show that, although differences in experiencing negative emotional states between mothers and fathers of children with autism do exist, they are not statistically significant. The following scores were obtained for the depression scale (F=.693, p=.09), anxiety (F=.856, p=.23) and stress (F=.001, p=.25). Detailed results are shown in Table 3 in the appendix.

AdH3) It is assumed that parents of children with Autism Spectrum Disorder, compared to parents of children who are typically developing, have lower levels of perceived quality of life.

As for the perception of quality of life, statistically significant difference was found only in the domain of psychological health (F=-3.22, p<.01), in a way that the higher degree of satisfaction in this area experience parents of children who are typically developing. There were no statistically significant differences in other domains (Table 2 in the appendix).

Discussion

The aim of our research was to compare the prominence of negative emotional states (depression, anxiety, and stress) and perception of the quality of life in parents of children with autistic spectrum disorder and parents of typically developing children. In line with previous research on this topic, three hypotheses were defined.

The first assumption that negative emotional states are more expressed among parents of children with autistic spectrum disorder, compared to the general population, has been confirmed. It is evident that depression, anxiety and stress are more prominent in parents of children with autism. These results are consistent with those available in the literature (2, 3, 4, 5), and are expected due to the continuous stress to which parents are exposed, and which is related to characteristics of the disorder itself, frequent rejection in the social environment as well as the lack of institutionalized care for children and psychological support to parents.

The second hypothesis that negative emotional states are more expressed in mothers than in fathers of children with autistic spectrum disorders was not confirmed

in our study, which is not in line with the existing findings (2). Regardless of the fact that mothers are the ones who spend almost all the time with children, taking care of everything – from basic to the special needs of the child, as well as taking care of the household and other family members, differences in the prominence of negative emotional states, when compared to fathers, are not statistically significant. This result may be a consequence of fathers being often too preoccupied with acquiring financial conditions for the provision of additional treatments for children with autism, which contributes to the severity of their stress and consequences which this exposure brings. Additionally, families with the child who has a developmental disorder are often forced to move from their place of permanent residence into larger cities where expert services are more accessible, thereby creating an extra pressure on fathers, who are often the only employed in the family. Nevertheless, in table 3 we can see the trend that levels of negative emotions are substantially higher in mothers than fathers of children with ASD, although they are not statistically significant. This may be due to small sample size, and should be examined in further studies using larger sample.

The third hypothesis that parents of children with autism, compared to parents of typically developing children, have lower levels of perceived quality of life is only partially confirmed, and statistically significant difference was found in the domain of psychological health. Such a result was expected, given the increased scores on the symptomatic scales that indicate high presence of negative emotional states such as depression, anxiety and stress in the population of parents with autistic children.

Limitations of this research are, first and foremost, related to the number of respondents being restricted by their membership in associations for support to children with autism. In the future research, it would be desirable to include parents of children with autistic spectrum disorders who are not members of any of the existing associations. Besides that, it would be important to compare this group of parents with parents of children with other developmental disorders (mental retardation, ADHD, Down Sy. etc.).

Recommendations arising from the results of our research would be referred to the establishment of the support groups for parents of children with autism spectrum disorder, as well as to raising awareness of the need for the training of professional staff working with children with disabilities, in order to recognize and treat emotional problems of parents and guardians of these children.

Conclusions

Research has shown that there is a significant difference between the group of parents of children with autistic spectrum disorder and parents of children with typical development. In parents of children with autism spectrum disorder there are significantly higher levels of stress, depression and anxiety. Perception of the quality of life differs in the domain of psychological health, in a way that it is lower in parents of children with developmental difficulties.

Exactly for this reason, professionals from different professions (psychiatrists, psychologists, social workers, occupational therapists) who work in institutions that care for children with autistic spectrum disorders, should be trained to recognize and treat the negative emotional states of parents. Parents should be involved in individual and/or group counseling programs to learn how to cope with stress that is inevitably associated with caring for a child with autism spectrum disorder.

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APPENDIX

Table 2 Differences in scores on scales according to the groups of parents

	Group of parents	Arithmetic mean	F	Sig. (2-tailed)
QOL environment	autism	3,4647		
	healthy children	3,4071	,013	,666
QOL social relations	autism	3,7521		
	healthy children	3,9487	2,270	,260
QOL psychological health	autism	3,6795		
	healthy children	4,1538	,965	,002
QOL physical health	autism	4,0476		
	healthy children	4,1832	,055	,321
Level of depression	autism	8,9744		
	healthy children	3,2821	21,422	,000
Level of anxiety	autism	8,9231		
	healthy children	2,4103	26,988	,000
Level of stress	autism	14,6667		
	healthy children	8,4103	,525	,001

Table 3 Differences in scores on scales in the group of parents of children with autistic spectrum disorder, by gender

	Gender	Arithmetic mean	F	Sig. (2-tailed)
QOL environment	Male	3,5441		
	Female	3,4034	,079	,485
QOL social relations	Male	3,9020		
	Female	3,6364	,421	,336
QOL psychological health	Male	3,9314		
	Female	3,4848	,191	,042
QOL physical health	Male	4,1681		
	Female	3,9545	,118	,282
Level of depression	Male	6,3529		
	Female	11,0000	,693	,099
Level of anxiety	Male	7,0588		
	Female	10,3636	,856	,230
Level of stress	Male	12,8235		
	Female	16,0909	,001	,251

NEGATIVNA EMOCIONALNA STANJA I KVALITET ŽIVOTA RODITELJA DJECE SA POREMEĆAJEM AUTISTIČNOG SPEKTRA

Apstrakt

Prevalencija poremećaja autističnog spektra je u stalnom porastu, a s obzirom na manjak institucionalizovane podrške starateljima, primijećeno je da roditelji djece sa problemima ove vrste češće doživljavaju negativna emocionalana stanja kao što su depresivnost, anskioznost i stres, te da kvalitet života doživljavaju lošijim nego roditelji djece koja se tipično razvijaju. Cilj našeg istraživanja je uporediti jačinu simptoma depresivnosti, anksioznosti i stresa, kao i stepen kvaliteta života kod roditelja djece sa poremećajem autističnog spektra i roditelja djece bez razvojnih smetnji.

Istraživanje je kvanitativno, korišteni su upitnik socio-demografskih podataka, skala DASS-21 i skala WHOQOL. Ispitano je 78 ispitanika, od čega 39 roditelja djece sa poremećajem autističnog spektra (članovi udruženja „Djeca svjetlosti“ u Banjoj Luci i EDUS u Sarajevu), te 39 roditelja djece bez razvojnih smetnji. F-testom su upoređeni rezultati na skalama depresivnosti, anksioznosti, stresa i kvaliteta života kod navedene dvije grupe.

Utvrđeno je da postoje statistički značajne razlike u nivou depresivnosti ($F = 3.72$, $p < .01$), anksioznosti ($F = 4.51$, $p < .01$) i stresa ($F = 3.47$, $p < .01$), pri čemu su negativna emocionalna stanja viša kod roditelja djece sa poremećajem autističnog spektra. Kod doživljaja kvaliteta života, statistički značajna razlika je pronađena samo u domenu psihološkog zdravlja ($F = –3.22$, $p < .01$), i to tako da veći stepen zadovoljstva u ovoj oblasti doživljavaju roditelji djece koja se tipično razvijaju.

Preporuke koje proizlaze iz rezultata ovog istraživanja su da bi profesionalci u oblasti mentalnog zdravlja trebali biti obučeni za rad na emocionalnim problemima sa kojima se suočavaju roditelji djece sa poremećajima autističnog spektra, kako bi tretman bio efikasniji i obuhvatniji.

Ključne riječi: poremećaj autističnog spektra, roditelji, stres, anksioznost, depresija, kvalitet života.