

The impact of the disease on functioning of a family with an autistic child

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Introduction: Scientific communities are beginning to recognize more and more tension, burden and sometimes joy associated with caring for child with autism.

Purpose: To determine the impact of the disease on functioning of a family with an autistic child.

Material and Methods: We analyzed 83 families with children diagnosed with autistic disease, including 30 Polish families, 25 families from Belarus and 28 families from France. Parents filled in a questionnaire assessing their knowledge about problems associated with raising an autistic child.

Results: Parents from Poland found most difficult to accept the child's health condition, and families from France coped with the problem best. For all parents the dominant impression after hearing the diagnosis was shock, French parents were the least likely to associate the disease as a punishment for their sins, which in turn often occurred among respondents from Poland and Belarus. Parents from Belarus frequently complained about problems their autistic child had with learning (about ¾ of responses). While Polish parents surprisingly often

recognized as the most onerous carrying out procedures related to the treatment of the child, they often complained about depression, sadness, insomnia. Respondents from Belarus most frequently could enjoy every day. Among the behaviours of autistic children differentiating the examined countries were: disobedience (by far the least indications in France), persistence (the lowest percentage in Belarus) and lies (parents from Poland most often complained about that). Among the parents' reaction to the annoying and stressful child's behaviour the attempts to admonish and explain were dominant, but these were parents from Poland, who frequently admitted that they shout at the child.

Conclusions: Among parents' reaction to the annoying and stressful child's behavior is an attempt to admonish and explain, moreover, Polish parents frequently admit to shout at the child. There are differences in the perception of the problems of parents of autistic children in selected countries, like Poland, France, and Belarus.

Key words: Family, disease, disorder, autistic

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INTRODUCTION

Autism is a pervasive developmental disorder that is present in almost all communities. Characterized by abnormalities in social interaction, communication, and severe restrictions on the activities and interests. In the last decade the number of children with this diagnosis has increased dramatically to 15 people per 10 000, live births [1].

The first epidemiological studies of autism were completed in 1966 in the UK [2]. They were conducted by Lotter [2] in Middlesex County, and he made screening of all children between 8 and 10 years of age, using questionnaires that were sent to teachers and other professionals working with children. He examined a total of about 78,000 people and initially identified 135 potentially exposed to this disorder. Among this, group finally emerged 35 people who met the diagnostic criteria developed by Kanner (i.e., rigidity of patterns and behaviour and withdrawal from social relations, these symptoms occurred before the age of five years). In these studies, Lotter [2] estimated autism prevalence at approximately 4.5 / 10 000, and the ratio of autistic girls to boys described as 2.6 to 1.

According to the most current research on autism the average assumed rate of morbidity is the value of 20.6 / 10, 000 cases, with more than four fold predominance of boys over girls [3].

Scientific communities are beginning to recognize more and more tension, burden and sometimes joy associated with an autistic child care. The diagnosis of autism in a child means a very high level of stress to the parents. In many situations, this stress is accompanied by social and behavioral difficulties and feeling of guilt resulting from the attitude of the community, which attributes it to "bad upbringing of the child" by their parents [4]. In the past, parents blamed themselves for the birth of an autistic child and resigned from various therapy programs and education of that child. Children with autism were often left unnoticed, "hidden" in the house and diagnosed too late.

Parents struggling with problems of an autistic child in everyday life note that providing assistance to people with autism throughout the life is a reality which they have to face. Parents are overcome with fear and uncertainty about where to find loving, lifelong help that is available regardless of how difficult and abnormal behavior their children have. Thus, some experience paradoxical confusion of hope and despair. In addition, long-term and cumulative stress over time causes immense tension both in each of the parents, and between them, and affects the extended family and the relationship between them. A number of problems are piling up, and the consequence of living in tension can be sometimes depression,

anxiety, burnout. "Burn out "syndrome appears in them as a result of contact with a child who requires a large emotional, intellectual and physical input . "The burnout" syndrome among parents of autistic children often becomes the ground of conflict in marriage, partners derive less satisfaction from their relationship and finally, themselves as parents. These phenomena can certainly have an impact on the quality of life of families with an autistic child. In order to determine the impact of the disease on functioning of a family with an autistic child, the following issues were examined: the attitude to the disease, the reaction after receiving the diagnosis of the disease, difficulties in child care, the impact of the child's illness on the emotions of parents, stressful child's behaviour and reactions to it, the attitude of the community towards the child's illness.

MATERIALS AND METHODS

Parents of children diagnosed with autism were subjected to a questionnaire. Parents came from three European countries: Polish, Belarus and France, some efforts were necessary to keep the similar numerical structure due to the origin of respondents. The following criteria were established: living together with the child now and throughout the period of the disease, being biological parents recognized (according to the criteria of ICD 10 or DSM IV) and documented chronic disease, and its duration is a minimum of three years and the consent to the study. In contrast, the exclusion criterion was the lack of consent.

The analysis referred to 83 families, including 30 families from Poland, 25 families from Belarus and 28 families from France. Parents filled in a questionnaire assessing their knowledge about autism and problems associated with raising a child with autism. The questionnaire consisted of :

- the general section, consisting of seven questions, including those relating to, among other things: the age of the parents, place of residence, education, family structure, its financial situation, the use of additional financial assistance, the duration of the child's illness.
- 1st basic part - Evaluation of the impact of the disease on family functioning, consisted of nine questions, including those relating to, among other things: coming to terms with the child's disease, obtained help in the upbringing of the child, reactions to the diagnosis of the child disease, difficulties encountered in child care, the impact of the disease on the emotions of parents, children's behavior stressing their parents, their reaction to this behavior, the reaction of the community to the child's illness, assessment of self-esteem and self- evaluation of attitudes of a spouse to the child 's disease.

- 2nd basic part – The assessment of parents' knowledge about autism, consisting of eighteen questions, concerning, among other things: knowledge of the proportion of the population affected by autism, gender, the ability to recognize autism in adults, knowledge of the concept of the autistic spectrum, symptoms of autism, evaluation of myths about autism, the period in which to start therapy, opinions about the treatment of autism by special diet, the existence of effective medicine, the possibility of complete healing of autism, whether a single medical examination is sufficient to make the diagnosis of " autism ", sources of knowledge about autism, the need to expand knowledge in this field, preferred people who should pass on knowledge about autism to parents, topics in the field of autism which they would like to discuss, preferred forms of sharing that knowledge.

In order to determine whether the diversity between the attitudes to the disease among respondents from different countries is a non-accidental effect which reflects certain regularity, in particular, countries, an adequate statistical test was applied. Due to the nature of the data, an appropriate tool for statistical inference was the Chi-square test for independence. Based on the result of the test (the probability test p), which has been included in the table heading it was stated that the dependence between the country and the attitude to the disease was statistically significant. It was assumed that when $p \geq 0.05$ indicates that this is tested difference, dependence, the effect is not statistically significant; when $p < 0.05$ we can talk about statistically significant dependence (we mark this fact by*); when $p < 0.01$ it means highly significant relation (**); when $p < 0.001$ it means highly statistically significant correlation (***)

The study was conducted after obtaining the approval number RI-002/242/2009 bioethics committee of the Medical University of Bialystok.

RESULTS

Generally, the average age of fathers is 39.4 ± 7.5 , while the mothers 36.2 ± 6.7 . In Poland, the average age of fathers is 42.7 ± 8 , and mothers 38.4 ± 6.8 years. In Belarus, the average age of fathers is 38.1 ± 6.9 , and mothers 36 ± 6.2 . In France, the average age of fathers is 37.1 ± 6.4 , while the mothers 34.1 ± 6.5 years.

Generally, examined families lived in the city (53%), including 57.7 % of families from Poland, 88 % from Belarus and 25.9% from France. In the country lived a total of 41 % of the families surveyed, including 42.3% from Poland, 12 % from Belarus and 74.1 % from France. 6 % of respondents did not declare their place of living.

Fathers usually have vocational education (34.9%), secondary education (31.3%), higher education (26.5%) or BA degree (2.4%). 4.8 % of the fathers did not indicate their education. Mothers with secondary education make up 38.6 %, with higher education 25.3%, vocational education 21.7 % or BA degree 12%. 2.4% of mothers did not indicate their education.

In the study population, there were 85.5% of complete families, 12% of one-parent families and 2.4% of respondents did not specify clearly the structure of their family. The average duration of a child's illness was 6.8 ± 3.9 years, including an average of 7.9 ± 2.7 years in Poland, 7.2 ± 5.2 years in Belarus and 5.2 ± 3.2 in France.

Differences in the perception and coping with the disease, depending on the country of origin of the parents of an autistic child are presented below.

As it is shown in the table below (Table 1), Poland is a country where accepting child's medical condition for their parents is the most difficult. Respondents from France coped with this burden best.

Table 1 Attitude to the disease

Country	Reconciliation with the disease ($p = 0,0012^{**}$)			Total
	yes	no	Hard to say	
Poland	7 (17,5%↓)	9 (50,0%↓)	11 (64,7%↓)	27
Belarus	12 (30,0%↓)	7 (38,9%↓)	3 (17,6%↓)	22
France	21 (52,5%↓)	2 (11,1%↓)	3 (17,6%↓)	26
Total	40	18	17	75

Respondents were asked about their reaction after hearing the diagnosis of the child. While for all parents (regardless of a country), the shock was the dominant feeling, French parents least likely treated their autistic child as a punishment for their sins/guilt. However, such feelings were quite common among respondents

from Poland and Belarus. Table 2 contains the result of the chi-squared test of independence, by means of which we compared the incidence of indicating individual feelings after hearing the diagnosis, depending on the country.

Table 2. The reaction after receiving the diagnosis of the child's disease.

The reaction after receiving the diagnosis of the child's disease	Country						P value
	Poland		Belarus		France		
	N	%	N	%	N	%	
Shock	19	63.3%	17	68.0%	24	85.7%	0.1388
Anger and grief to the world	15	50.0%	9	36.0%	10	35.7%	0.4523
Disease as a punishment for the sins	13	43.3%	11	44.0%	1	3.6%	0.0009***
A relief after the diagnosis	8	26.7%	2	8.0%	3	10.7%	0.1119
A feeling of disappointing the family	4	13.3%	4	16.0%	4	14.3%	0.9611
Concidering placing the child in a health care center	2	6.7%	1	4.0%	1	3.6%	0.8374

Parents from Belarus frequently complained about educational problems their autistic child had (about ¾ of responses). Poles surprisingly often (compared to other nationalities)

recognized as the most onerous carrying out procedures related to the treatment of the child (Table 3).

Table 3. Difficulties in child care.

Difficulties in child care	Country						P value
	Poland		Belarus		France		
	N	%	N	%	N	%	
Child acquisition of independence	20	66.7%	21	84.0%	22	78.6%	0.3005
Learning difficulties	13	43.3%	18	72.0%	10	35.7%	0.0218*
Acquisition of knowledge about the disease	14	46.7%	5	20.0%	9	32.1%	0.1116
The need of treatments	13	43.3%	0	0.0%	1	3.6%	0.0000***
Hard to say	5	16.7%	3	12.0%	1	3.6%	0.2700

Polish parents more often than others complained about depression, sadness and insomnia as a result of the child's autism. In contrast, respondents from Belarus responded most strongly

that they can enjoy every day. The exact answers with distinguished statistical significance are given in Table 4.

Table 4. The impact of the child's disease on parents' emotions.

The impact of the child's disease on the emotions of parents	Country						P value
	Poland		Belarus		France		
	N	%	N	%	N	%	
Fatigue	23	76.7%	11	44.0%	20	71.4%	0.0280*
Sadness	22	73.3%	10	40.0%	8	28.6%	0.0019**
Irritation	13	43.3%	5	20.0%	13	46.4%	0.0972
I enjoy everyday	6	20.0%	17	68.0%	5	17.9%	0.0001***
Resignation from work	15	50.0%	4	16.0%	5	17.9%	0.0062**
Insomnia	16	53.3%	3	12.0%	4	14.3%	0.0005***
The lack of motivation to exercise	5	16.7%	7	28.0%	8	28.6%	0.4916
Jealousy of healthy children	8	26.7%	5	20.0%	4	14.3%	0.5046
Concern about the financial condition of a family	5	16.7%	7	28.0%	5	17.9%	0.5342
Does not affect	4	13.3%	2	8.0%	2	7.1%	0.6881
Hard to say	0	0.0%	1	4.0%	0	0.0%	0.3091

Among the behaviours of autistic children which differentiate responses of parents from France), by far the least indications of France), persistence (the lowest percentage in Belarus) and

different countries we can mention disobedience (by far the least indications of lies (most often complained about by parents from Poland) (Table 5).

Table 5 Stressful child's behaviour.

The most stressful children's behaviour	Country						P value
	Poland		Belarus		France		
	N	%	N	%	N	%	
Stubbornness	19	63.3%	6	24.0%	17	60.7%	0.0062**
Disobedience	17	56.7%	16	64.0%	6	21.4%	0.0034**
Disrespect	16	53.3%	9	36.0%	12	42.9%	0.4255
Untidiness	10	33.3%	7	28.0%	4	14.3%	0.2325
Recklessness	4	13.3%	4	16.0%	7	25.0%	0.4879
Quarrels	3	10.0%	8	32.0%	3	10.7%	0.0537
Rudeness	6	20.0%	3	12.0%	4	14.3%	0.6972
Lies	9	30.0%	3	12.0%	1	3.6%	0.0181*
Agression	0	0.0%	1	4.0%	0	0.0%	0.3091
Hard to say	2	6.7%	0	0.0%	3	10.7 %	0.2576

Among the parents' reaction to annoying and stressful child's behaviour dominated an attempt to admonish and explain, but it were parents

from Poland who frequently admitted to shout at the child (Table 6).

Table 6. Reactions to stressful child's behaviour.

Reactions to stressful child's behaviour	Country						P value
	Poland		Belarus		France		
	N	%	N	%	N	%	
We admonish	23	76.7%	14	56.0%	21	75.0%	0.1927
We shout	20	66.7%	6	24.0%	5	17.9%	0.0002***
We pretend not to see	9	30.0%	5	20.0%	2	7.1%	0.0874
We blame our spouse	7	23.3%	3	12.0%	6	21.4%	0.5349
We show disrespect	3	10.0%	2	8.0%	1	3.6%	0.6300
Hard to say	3	10.0%	2	8.0%	1	3.6%	0.6300

Parents from Poland more often than others pointed out that their child's autism caused that their friends turned their back on them, and this

reduced their social contacts and a greater distance of their acquaintances (Table 7).

Table 7. The attitude of the community to the child's disease.

The attitude of the community to the child's disease	Country						P value
	Poland		Belarus		France		
Family is supportive	20	66.7%	16	64.0%	25	89.3%	0.0653
Friends are kind	14	46.7%	18	72.0%	15	53.6%	0.1554
Family keeps distance	5	16.7%	0	0.0%	2	7.1%	0.0823
Acquaintances keep distance	5	16.7%	0	0.0%	1	3.6%	0.0390*
Family limited contacts	1	3.3%	0	0.0%	0	0.0%	0.4090
Acquaintances limited contacts	8	26.7%	3	12.0%	1	3.6%	0.0403*
Health care professionals are friendly	10	33.3%	9	36.0%	17	60.7%	0.0738
Health care professionals treat us as the necessary evil	5	16.7%	2	8.0%	1	3.6%	0.2274
The disease deepened feelings between spouses	3	10.0%	5	20.0%	3	10.7%	0.4909
The disease grew the spouses apart	3	10.0%	1	4.0%	3	10.7%	0.6312
Hard to say	2	6.7%	1	4.0%	0	0.0%	0.3940

In Tables 8 and 9 we listed the frequency of the declared attitudes towards the illness of a child. Significant differences related to the question of concerns about the future of the children and the

declaration that everything will be devoted to them. Both of these attitudes were significantly more frequent among respondents from Belarus.

Table 8. The attitude towards the child's disease.

The attitude towards the child's disease	Country						p
	Poland		Belarus		France		
I fear for the child's future	14	46.7%	22	88.0%	10	35.7%	0.0003***
I try to accept the situation	14	46.7%	15	60.0%	16	57.1%	0.5705
I will sacrifice everything for the child	10	33.3%	17	68.0%	10	35.7%	0.0185*
I limit contact with other people	10	33.3%	4	16.0%	4	14.3%	0.1515
I do not accept the disease	5	16.7%	3	12.0%	3	10.7%	0.7807
I try to hide deficiencies of the child	2	6.7%	1	4.0%	0	0.0%	0.3940
Currently i would not decide to raise a child	1	3.3%	0	0.0%	0	0.0%	0.4090
I consider placing the child in the health care center	0	0.0%	0	0.0%	1	3.6%	0.3701
Hard to say	6	20.0%	0	0.0%	0	0.0%	0.0033**

Table 9. The attitude of the spouse to the child's disease.

The attitude of the spouse to the child's disease.	Country						p
	Poland		Belarus		France		
Is trying to accept the situation	12	40.0%	15	60.0%	16	57.1%	0.2636
Will sacrifice everything to a child	6	20.0%	10	40.0%	11	39.1%	0.1860
Fears for the child's future	9	30.0%	9	36.0%	7	25.0%	0.6840
Limits contacts with other people	7	23.3%	3	12.0%	4	14.03%	0.4843
Does not accept the disease	6	20.0%	5	20.0%	2	7.1%	0.3132
Is trying to hide the deficiencies of the child	3	10.0%	2	8.0%	0	0.0%	0.2460
At the moment would not decide to raise a child	2	6.7%	1	4.0%	0	0.0%	0.3940
Is considering placing the child in the health care center	0	0.0%	0	0.0%	0	0.0%	1.0000
Hard to say	6	20.0%	0	0.0%	1	3.6%	0.0153*

DISCUSSION

Autism, like any other chronic disease, is becoming a part of the family system. Symptoms of autism are not only a burden, but they also organize family life and in special situations can stabilize disturbed by various processes homeostasis of the family system. Difficulties and problems encountered in families with an autistic child are characteristic for families with chronically ill children [5].

In the present study, families from Poland (26.7%) confirmed that friends have limited contact with them, the parents from Belarus declared a similar problem in 12.0% of cases and parents from France only in 3.6% of cases. Only

parents from Poland (3.3%) indicated limited contacts for their reason.

Pisula [6] points out that there are two main concepts explaining what happens to the parents of children with developmental problems, especially children with mental retardation. The first, known as the concept of mourning, assumes that after being informed of the child's disease their mothers experience deep sorrow, the great overwhelming sadness, fully comparable to the grief experienced by those whose child died [6]. This is closely related to the fact that expecting a healthy baby, they dream about and idealize the baby. A child that appears instead of the expected one, thus becomes a stranger, different from that ideal child. Unfortunately, as long as the mourning lasts, it is not possible to attach to a child who

really exists. Parents gradually come to its acceptance, and the process proceeding phases .

Solnit and Stark [cited after 6] have identified three phases of parents' adaptation to the thought that their child will remain disabled: shock, confusion and gradual adaptation.

In the present study, all parents frequently declared that at the time of diagnosis of autism in their child they felt shock (63.3% in Poland and 68 % in Belarus, 85.7% in France). They were the least frequently accompanied by the thought of putting a child to a health care center (6.7% from Poland, 4 % from Belarus, 3.6% from France).

Mc Daniel [5] draws attention to the fact that the illness of a child supports dysfunctional family systems. In the case of autistic children, the disease can trigger triangulation in the form of an excessive focus on the child in order to put off difficult issues in the relationship between spouses. In addition, we are often faced with a situation where one person takes over the role of a primary caregiver. As a result, other people keep distance, which may be the cause of a conflict between the carer (blamed for overprotection) and other individuals (blamed for the lack of commitment and understanding) [5].

The presence of a disabled child, especially mentally handicapped one, has a multidimensional impact on functioning of the family and is a major source of stress. The specificity of this stress lies in the specific nature of the requirements for the parents (caregivers) participating in the process of raising an ill child. Looking for a sick child requires devoting to the child a significant part of the time, energy and strength. Thus, the illness of a child has a significant impact on many areas of a family life, such as physical and social situations and the physical and mental health of its members. Parents are often forced to change life plans and objectives, which in turn leads to a feeling of frustration and depression.

In the present study, parents from Poland (76.7%) most often marked fatigue, which was similar in the case of parents from France (71.4%), and slightly less was declared by Belarusians (44.0 %); the feeling of sadness dominated in most cases (73.3%) of responses of Poles, slightly less among Belarusians (40.0%) and grief was felt by 28.6% of the French. Insomnia was also a significant factor affecting the quality of life of families caring for a disabled child. Polish parents constituted the vast majority, 53.3% opted for the criterion, French parents only in 14.3%, and parents from Belarus in 12.0%.

Beckman [cited for 7] stated that single mothers complained about feeling more stress than mothers living with a partner. However, in a study conducted previously by Bradshaw and Lawton [cited after 7] no differences between the levels of

stress among single-parent families and families with both parents were stated.

Admittedly the studies by Bristol and Gallager and DeMyer [cited after 7] took into account mothers of children with autism, however, in studies devoted to the fathers of these children it was revealed that they, too, are experiencing significant emotional and financial burden.

In the present study, most of the families were complete families. Noting the financial situation of families, the surveyed were asked about resigning from the job. Polish respondents were the largest group, i.e. 50.0 % of them gave up work to provide care for the ill child, parents from France did so to a much lesser extent (17.9%) and similarly responded Belarusian parents (16.0 %).

It should be noted [8] that parents of a child affected by autism, must first familiarize themselves with the disease, change their own mentality and adjust family habits so that they can receive a sick family member. A characteristic feature of parental stress is its permanent nature and the lack of prospects for a change. Stress affects the sensitivity of parents towards their children's needs, on the adequacy of their behaviour in relation to the signals coming from the child, the perception of the child, and also evokes the increasing tensions in the relationship between mothers and fathers, and between parents and siblings growing up in good health. Parents of autistic children, besides experiencing a sense of loss, grief and guilt, also feel helpless facing indifference shown by a child who reveals almost no signs of emotional attachment [8].

Professional literature, according to Randal and Parker [9] often defines them as stressed, helpless, constantly worried and frightened. Their sense of loneliness and isolation is also very clear, as well as anxiety about the future [9].

In the study of Lin et al. [10] the attention was paid to the mechanisms of coping with the disease soon after the diagnosis of the child, while waiting for free day care. Nine main coping mechanisms were singled out, which were divided into three basic categories: adaptation by a change in oneself's life, the development of assistance for children with autism and seeking support [10].

Osborne and Reed [11] indicate a strong relationship between parental stress and problems with child behaviour, when other factors were controlled, such as the level of severity of autism and intellectual functioning of the child. According to the authors [11] parental stress of having a small child with autism (2-4 years old) was the stronger factor enabling to predict the child's problems at a later stage, but such a dependence in case of older children was not found. According to the data of the study [11] the intensity of the symptoms of autism

have a stronger connection with stress felt by parents of young children (less than 4 years old). However, in contrast, the behavior problems of children are strongly correlated with parental stress among older children (over 4 years old). The authors conclude that parental stress can affect a child's behavior problems [11].

CONCLUSIONS

1. Functioning of a family with a sick child is subject to the biggest change in the sphere of social contacts, social and somatic sphere.
2. There are factors that have a significant impact on the functioning of the family, especially significant is stress, sadness, fatigue and insomnia.
3. Among parents' reaction to the annoying and stressful child's behavior dominates an attempt to admonish and explain, moreover, Polish parents also most frequently admit to shouting at the child.
4. There are differences in the perception of problems of autistic children's parents in selected countries, such as Poland, France and Belarus.
5. Definitely closer to each other in solving problems related to the care of a disabled child were France and Belarus. Poland slightly differed from these countries, particularly the significant differences concerned the question of coping with stress, perception of the quality of life of children and their own quality of life.

Conflicts of interest

The authors declared no conflicts of interest.

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