The quality of life in parents raising children with an autism spectrum disorder from Poland, Belarus and France

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ABSTRACT

Purpose: To assess the health-related quality of life (HRQL) in parents of children with autism spectrum disorder (ASD).
Materials and methods: The sample consisted of 83 families with children with ASD, including 30 families from Poland, 25 from Belarus, and 28 from France. Parental HRQL was surveyed with the World Health Organization Quality of Life–BREF (WHOQOL–BREF) and KINDL^R questionnaires.
Results: This study showed that Polish parents reported the lowest quality of life according to the WHOQOL–BREF. Parents from Belarus reported slightly worse HRQL than parents from France, though other aspects of quality of life (e.g, social sphere, somatic sphere) did not differ significantly between these parents. Parents from Poland also reported lower HQOL according to the KINDL^R questionnaire, while parents from Belarus had a higher HQRL in the mental, physical, and self-esteem domains compared to parents from Poland and France. **Conclusion:** Parents from Poland with children with ASD reported lower HRQL both on the WHOQOL–BREF and KINDL ^{R} questionnaires compared to parents from Belarus and France.
Key words: autism spectrum disorder, children, parents, quality of life

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INTRODUCTION

Autism occurs in all parts of the world, and it affects people of different nationalities and from different social groups. Interestingly—and unfortunately—the number of people with this disorder is still growing.

Statistical data from the California Health and Services Agency estimate that the rate of diagnosis of autism spectrum disorder (ASD) increased from 5.78/10,000 in 1987 to 14.9/10,000 in 1994. A 2012 review of global prevalence estimates ASD found a median of 62 cases per 10,000 people [1]. In Poland and Belarus, there are no complete statistics of ASD. Based on the 2000 report developed by the Synapsis Foundation, the problem relates to about 10,000 children and adolescents in Poland [2]. France has made autism the national focus for the year 2012 and the Health Ministry now evaluates the rate of autism to be 60 per 10,000 (1 out of 150) [3].

Children and adolescents with ASD have social and communication impairments and behavior difficulties, and many will also present comorbid psychiatric conditions, including attention deficit hyperactivity disorder (ADHD) and externalizing and internalizing disorders [4,5]. A considerable number of studies show that parents of children with ASD report higher stress levels and depression than parents of children without ASD [6]. It has also been shown that families of children with ASD experience more parenting stress than families with children diagnosed with other disabilities (e.g, Down syndrome, cerebral palsy, intellectual disability) [7]. The amount of stress experienced by parents of children with ASD may be influenced by the severity of the child's condition. Higher autism symptomatology and a greater number of co-occurring psychiatric disorders in the child are associated with an increased risk for current treatment of maternal depression and a lower maternal quality of life [8]. Moreover, parents also experience impaired physical functioning, tiredness, or exhaustion.

Furthermore, several studies confirm that parents of children or adolescents with ASD have impairments in health and social relationships [9, -11]. Weiss [12] reported that many parents of children with ASD experienced feelings of intense anger, guilt, depression, or anxiety most of the time. Moreover, these feelings were frequently expressed in psychosomatic problems.

Quality of life (QoL) is a measure of an individual's wellbeing that includes multiple domains of functioning and is being increasingly recognized as an important construct to use in the study of developmental disabilities [13]. Assessment of QoL is important in medical practice, to improve the doctor-patient relationship, in assessing the effectiveness of different treatments, in health services evaluation, in research and in policy making [14].

A general, negative influence of the child's disease on health-related quality of life (HRQOL) of parents can be assumed [15]. The WHOQOL-BREF is an international cross-culturally comparable quality of life assessment instrument. The measurement of HRQoL includes all essential aspects of physical, psychological, and social well-being, which contribute to the overall health status as defined by the World Health Organization (WHO). The WHOQOL-BREF is widely used both in healthy and sick people [16].

Another frequently used instrument for the assessment of children's HRQoL is the KINDL^R questionnaire. It includes indicators for physical, psychological, family, social, and school wellbeing and self-esteem [17]. There are several factors that affect the HQRL in parents of children with ASD, including child's age, autism severity, problematic behavior, economic and education status of parents, depression in parents, and anxiety. However, little is known about the effects of culture on the HQRL in parents of children with ASD. Autism appears to be a strong candidate given its biological underpinnings. However, the existing literature of case reports and limited ethnographic studies suggest that the most accurate view of autism is as a biological condition that is culturally shaped in terms of symptoms and overall nature. Research on developmental disorders within a cultural context and in non-Western countries have received limited attention from both experts in the fields of autism and medical anthropology [18]. Although autism occurs in all cultures and countries, most of the published researches have come from Western countries. There are limited number of studies that compare the HQRL in parents raising children with ASD from different countries. Furthermore, to the best of our knowledge, no study on the quality of life has been conducted on parents of children with ASD from three different countries (Poland, Belarus, and France).

The purpose of this study was to explore the HQRL in parents of children suffering from ASD as evaluated by the KINDL^R and WHOQOL-BREF questionnaires.

MATERIALS AND METHODS

Participants

The analysis included 83 families, including 30 families from Poland, 25 families from Belarus and 28 families from France (Table 1). The following inclusion criteria were: living together with the child now and throughout the period of the disability and being biological parents. Each child had to meet the criteria of ASD diagnosis on DSM-IV and was examined by a child psychiatrist or psychologist. ASD duration was a minimum of three

years. In contrast, exclusion criterion was the lack of diagnosed ASD and the parents consent. In Poland, families were recruited from the Polish Association "Wspólny Świat" of the Centre for Therapy and Diagnosis of Autistic Children in Biała Podlaska. In Belarus, families were recruited from Центркоррекционно-развивающего обучениияреабилитации in Brestand. In France, families were from the Association of Parents of Autistic Children in the department of DeuxSevres-Centre Hospitalier in Niort.

Measures

Parental WHOQOL – BREF

The standardized WHOQOL–BREF quality of life questionnaire, in the original languages of Polish, Russian and French, was used [18]. The WHOOOL–BREF questionnaire is used to assess the quality of life of both healthy individuals and patients in clinical practice and covers the following areas of quality of life: physical, mental, social relationships and functioning in the community. Individual assessment of a patient is made in each of these four domains and includes the following aspects:

- In the physical domain (domain 1 - DOM1): activities of daily life, dependence on medication and treatment, energy and fatigue, mobility, pain and discomfort, rest and sleep, and ability to work;
- In the domain of psychology (domain 2 - DOM2): appearance, negative feelings, positive feelings, self-esteem, spirituality, religion, personal faith, thinking, learning, memory, and concentration;
- In the domain of social relationships (domain 3 - DOM3): personal relationships, social support, and sexual activity;
- In the domain of functioning in the community (domain 4 - DOM4): financial resources, freedom, physical and mental security, health and health care (availability and quality), home environment, the possibility of acquiring new information and skills, opportunities for and participation in recreation and rest, physical environment (pollution, noise, traffic, climate), and transportation.

In addition, the WHOQQL–BREF test also includes questions which are analyzed separately. Question 1 (WH01) addresses individual overall perception of quality of life and question 2 (WH02) examines individual overall perception of the respondent's own health. Responses are recorded on a 5-point scale (score range 1-5). In each of the areas you can get a maximum of 20 points.

The results of the various fields have a positive direction (the higher the score, the higher the quality of life) (WHOQOL–BREF: Introduction, Administration, Scoring and generic version of the assessment [18].

The KINDL^R questionnaire was also used in the original languages Polish, Russian and French, provided by the University Medical Center Hamburg-Eppendorf Center for Psychosocial Medicine, Department of Child and Adolescent Psychiatry, Psychotherapy and Psychosomatics (KINDL^R questionnaire language versions; [19]. The KINDL$^{\mathbf{R}}$ questionnaire is used to study the sense of quality of life among children and young people and focuses on the key dimensions of health: mental health, physical condition, social relationships and daily functioning. In the present study, we used a version for parents: Form A: Kiddy–KINDL for children between 4 and 7 years of age and Form B: Kid–KINDL for children between 8 and 16 years of age. Both forms of the questionnaire contain 40 items (Likert scale) on four dimensions: psychological well-being—Psyche (mind): 11 questions, physical—Soma (body): 9 questions, social relations—Polis: 9 questions, and daily functioning: 11 questions.

In the version for youth ages 8–16, we added seven additional positions to the 40 basic ones: psychological well-being—Psyche (mind): 14 questions; physical—Soma (body): 11 questions; social relations—Polis: 11 questions; and daily functioning: 11 questions. The respondent had to mark answers (on a scale of five) which corresponded to his/her experience from the previous week. It was also possible to transform all scales in order to obtain a value from 0 to 100. The higher the value, the better quality of life is reflected [19]

Procedure

The study was conducted between from 2011–2012. A total of 30 questionnaires were distributed in Poland and 30 were returned. In Belarus 30 questionnaires were distributed and 25 were returned, and in France 30 questionnaires were distributed and 28 were returned.

Statistical analysis

Due to the nature of the data, an appropriate tool for statistical inference was the chi-square test for independence. Analysis of the results obtained using the WHOQOL–BREF quality of life questionnaire and KINDL^R questionnaire consisted in the presentation of the average, median (middle value) and standard deviation. In order to determine a variation in the distribution of quality of life among the three countries, Kruskal-Wallis test was used. The critical level for all tests of significance was $<.05$.

RESULTS

Demographic data for the sample is presented in Table 1. Groups did not significantly differ in child age, gender, age of the mother and

father, and place of residence, and all of the parents and children were Caucasian. In general, mothers who were surveyed were younger (36.2 ± 6.7 years) than their spouses (39.4 ± 7.5).

Table 1 Sociodemographic data

	Poland n=30	**Belarus n=25**	**France n=28**
Child Age (mean)	8.4 ± 3.4	9.2 ± 3.7	8.0 ± 2.7
Gender (% male)	63.3%	84.0%	60.8%
Mothers	93.3	100%	89.2%
Fathers	6.7%	-	10.8%
Mother's Age (years)	38.4 ± 6.8	36.0 ± 6.2	34.1 ± 6.5.
Father's Age (years)	42.7 ± 8.0,	38.1 ± 6.9	37.1 ± 6.4
Urban areas	57.%	88%	74.1%
Rural areas	43.3%	12%	25.9%

Significant differences in quality of life (the WHOQOL–BREF) between respondents from Poland, Belarus, and France were found. Parents from Poland had the lowest HQRL when compared to parents from Belarus and France. The HQRL (somatic, psychological, and social domains) did not differ between the parents of Belarus and France. Only parents from Belarus reported significantly lower HQRL in terms of community domain when compared to parents from France. Details are shown in Table 2.

Table 2. The quality of life WHOQOL-BREF in parents of children with autism spectrum disorder from Poland, Belarus and France

Quality of life WHOQOL-BREF	**Country**								
	Poland *n*=30			**Belarus *n*=25**			**France *n*=28**		
	$\bar{x}$	Me	*s*	$\bar{x}$	Me	*s*	$\bar{x}$	Me	*s*
Somatic field	52.7 ***	50.0	15.5	64.6	66.1	16.3	67.1	67.9	13.1
Psychological field	55.6*	50.0	18.6	62.3	66.7	15.7	67.1	66.7	10.8
Social field	54.2***	50.0	16.8	71.2	75.0	18.2	72.3	75.0	13.2
Community	49.7***	48.4	13.8	58.1#	60.9	15.1	67.5	65.6	14.0

***p= <0.001 *vs* parents from Belaurs and France; * p< 0.01 vs parents from Belaurs and France; #p= 0.028 *vs* parents from France; $\bar{x}$ - mean Me- mediana; *s* – standard deviation

In terms of the assessment of mental or physical conditions and self-esteem, the most favorable answers were given by a group of Belarusians (KINDL^R). Family relationships for parents from France prevailed, and parents from Poland reported their mental and physical condition and satisfaction with family life to be better than their or self-esteem or the social relations of their children (Table 3).

Table 3. The quality of life KINDL^R in parents of children with autism spectrum disorder from Poland, Belarus and France

KINDL questionnaire	**Country**								
	Poland *n*=30			**Belarus *n*=25**			**France *n*=28**		
	$\bar{x}$	Me	*s*	$\bar{x}$	Me	*s*	$\bar{x}$	Me	*s*
Physical condition	60%*	56%	12%	72%	69%	21%	59%*	63%	15%
Mental state	60% #	59%	13%	70%	75%	17%	65%	63%	13%
Self-esteem	48% ***	44%	11%	67%	63%	12%	54%	56%	11%
Family	60% ***	56%	19%	74%	81%	17%	82%	81%	12%
Social relations	44% **	38%	15%	59%	63%	16%	59%	63%	20%
School	55%	56%	16%	65%	69%	15%	60%	63%	15%

***p< 0.001 *vs* parents from Belaurs and France; ** p< 0.01 *vs* parents from Belaurs and France; * p<0.05 *vs* parents from Belarus; $\bar{x}$ - mean Me - mediana; *s* – standard deviation

DISCUSSION

The results indicate that parents (vast majority of mothers: 93.3% from Poland, 100% from Belarus, and 89.2% from France) of children with ASD are at an increased risk of impaired physical and psychological well-being. Parents from Poland had the lowest HRQL scores when compared to parents from Belarus and France. In contrast, parents from France and Belarus had similar HQRL scores. Our findings are consistent with previous studies in relation to the QoL in of parents with children with ASD [8-10].

The observed differences of the HQRL between parents from three countries might be partially explained in the context culture. Culture is defined as the characteristic ways in which people of certain group perceive and interact with their environment. Moreover, it is the external expression of people's mental life in the form of language, beliefs, customs, technology, human relationship, and many other factors [20]. Illness behavior is the way that mental illness is recognized, labeled, explained and treated within any particular culture.

Although Poland, Balarus and France belong to Europe, they differ in their values, beliefs, customs, social relationships and economic burdens. Belarus is located in the Eastern Europe, Poland is located in the Central Europe and France is located in the Western Europe. There are differences in the culture, economy, and medical care system between these countries. It is known that the impaired maternal HRQL of children with ASD is related to symptoms of hyperactivity [15].

In the present study, we did not evaluate autism severity in children. Difficulties and problems encountered in families with children with autism are similar for families with children with chronic illnesses. Parents of children with chronic disorders also have impaired HQRL in their physical functioning and mental health.

Cappe et al. [21] found that the QoL of parents raising children with autism also experience emotional disorders and difficulties coping with stress. These results are consistent with our findings. There are differences in the stress level of parents and HQRL between mothers and fathers of children with ASD [22].

However, we did not compare the HRQL of mothers and fathers because almost all parents were single mothers.

A child with a disability is a serious restriction for parents in terms of their relationships with other people, and also with the surrounding world. Parents raising children with ASD often report impairment in social relationships (contacts with family members and friends). These findings are consistent with what we found in the present study.

Using a KINDL^R questionnaire, we found significantly impaired social relations reported by the parents, with the social relations being most impaired in parents from Poland.

In a recent study in Poland, Czenczek et al. [23] evaluated the HQRL of parents with children with autism using Questionnaire SF -36. The research proves there exists reduced levels of functioning in parents in areas of life such as general health, mental health, social functioning, physical and mental functioning, energy, and vitality.

It should be emphasized that parents of children with autism systematically report QoL variables differently than other parents.

Parents of children with autism have a higher prevalence of autism-related traits and other psychopathologies than the general population [24].

In the present study, we did not evaluate autism-related traits in the parents of children with ASD).

Limitations and Future Directions

First, the number of patients were small. Second, we did not analyze the economic and education status of the surveyed parents. Third, we did not analyze the HQORL of the parents in correlation with the autism severity displayed in their children. Further research is required to determine the HQRL of parents with children with ASD in correlation with their economic and education status, as well as autism severity.

CONCLUSIONS

We found differences in the HQRL of parents raising children with ASD in three European countries, mainly Poland, Belarus, and France. Parents of children with ASD from Poland reported the lowest HQRL in both questionnaires, the WHOQOL – BREF and KINDL^R, while parents from France and Belarus had similar HQRL results.

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Conflicts of interest

The authors declare that they have no conflicts interests.

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