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Comparative Study on Self-perceived Health of Parents of Children with Autism Spectrum Disorders and Parents of Non-disabled Children in Croatia

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Aim To assess self-perceived health of parents of children with autism spectrum disorders (ASD) in comparison with those of parents of non-disabled children.

Methods A total of 350 parents participated in the study: 178 parents of children with ASD (71% response rate) and 172 parents of non-disabled children matched by age, education, and place of living. Parents' self-perceived health was assessed using the Croatian version of the health status questionnaire SF-36, while socio-demographic information, chronic medical conditions, and needs were assessed by a general questionnaire.

Results For all dimensions of health, except physical health, parents of children with ASD had significantly poorer self-perceived health and reported significantly more deteriorated health in the last year than the control group ($P < 0.001$). They also reported more psychological disorders (11% vs 4.3%), which was the largest difference in specified chronic medical conditions. Hundred twenty six (71%) parents of children with ASD thought that enhancing different policy measures (economic, social, educational) could advance their and their children's health and well-being.

Conclusion Parents of children with ASD had poorer health than the control group in all components, except physical health. Because parents are the main providers of support for children with ASD, preserving parents' good health and well-being is a precondition for an optimal care for children. Therefore, current system for treating children with ASD in Croatia should also include permanent improvement of parents' health and well-being.

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Autism is defined as an organic developmental brain disorder that is manifested in difficulties in social interactions and communication, as well as unusual behaviors (1,2). Epidemiological report by the Centers for Disease Control in Atlanta, USA states that the prevalence rate of autism spectrum disorders (ASD) is 6.6 per 1000 births (3). One of the leading experts in autism epidemiology, E. Fombonne, performed a meta-analysis of 32 epidemiological studies of ASDs conducted between 1966 and 1991. Data were collected in 13 different countries on a sample of nearly 5 million. According to this research, of 10 000 live births, 13 people are born with autism and 3 people are born with Asperger syndrome. Another study found that 60 people of 10 000 live births had autism spectrum disorders (4). Global report of health status in European Union for 2007 mentions diverse diagnostic criteria for ASD and different methodology used in diagnosing, which produces different prevalence data. For example, the prevalence rate of children with ASD in the age group 5-11 was 57 per 10 000 in Cambridgeshire (United Kingdom), compared with 3.8 per 10 000 in the age group 3-14 in Nord-Trondelag (Norway), using the same criteria according to Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (5). Consequently, harmonization of the diagnostic criteria and methodology is needed.

In the Global Report, there is no data for Croatia, but they are available from the Croatian Disabilities Registry. Croatia regulates the collection of data on persons with ASD via the Croatian Disabilities Registry Act, according to which ASDs are distinguished as a separate disability category. The prevalence of ASD in child population (0-18 years) in Croatia is approximately 1 in 1000, 3 times more common in boys (6).

While care giving is considered to be a normal parental duty, providing the high level of care required by a child with long-term functional limitations can become burdensome and may impact both physical and mental health of the parents. A series of studies has been published about subjective health and health-related quality of life of family caregivers. Studies on family caregivers of people with chronic health problems revealed higher level of burden, stress, and depression (7). Although it has been argued that all chronic illnesses and disabilities of children can negatively affect health-related quality of life of the parents, each disease presents unique challenges (8,9). According to some authors (10,11), parents of children with ASD are a particularly vulnerable group as they take over practically the entire burden of family care for their severely disabled child. Parenting children with ASD was related to the impaired well-being of parents (12) and their higher morbidity of anxiety, depression (11,13), and obsessive compulsive symptoms (14). Caregivers also reported somewhat lower marital happiness, disturbed family cohesion, and adaptability (15).

In the process of deinstitutionalization of persons with intellectual disorders, parents of children with ASD become a key factor in improving the functioning of their children (16). According to the latest guidelines on therapy and rehabilitation of children with ASD (daily lifetime therapy) and in order to achieve harmony in all aspects of the child's life, parents assume a very important role in the child's rehabilitation process (17,18). For parents to be able to care for their child with ASD and contribute to the quality of their child's rehabilitation process, they need to be of good health themselves, as this care exerts great psychological and physical efforts (19). Therefore, preserving parents' good health and well-being is a precondition for an optimal care for the child. Poor caregiver health may contribute to recurrent hospitalizations (19) and out-of-home placements for children with chronic conditions and disabilities (20-22).

Therapy and rehabilitation of persons with ASD in Croatia is mostly administered in the Zagreb Autism Center, where this study was conducted. The Center has its branch offices in Split, Rijeka, and Nova Gradiška. The same institution administers rehabilitation and therapeutic services for 333 persons. The inpatient unit accommodates 89 patients, 37 of whom never have contact with their parents. Including persons with ASD into day therapeutic rehabilitation programs while being placed in the care of the family is in line with the global trends of care and social inclusion of persons with ASD (23,24).

Because of these trends and the finding that over 80% of persons with ASD in Croatia live with their families (6), it is necessary to assess the health of parents of disabled children. The purpose of the present study was to examine self-assessed health and chronic medical conditions in parents of children with ASD and compare them with parents of non-disabled children. The hypothesis was that parents of children with ASD, because of the increased requirements of child care, have lower self-perceived health and greater chronic medical conditions' load, which may contribute to more frequent chronic diseases in comparison with parents of non-disabled children.

PARTICIPANTS AND METHODS

Participants

The study included 178 parents of children with ASD (diagnosed under code F84 of International Classification of Diseases, Tenth Revision) with median age of 43 years (range 27-83), 105 (59.0%) of whom were mothers and 73 (41.0%) were fathers. The control group comprised 172 parents of non-disabled children, with median age of 42 years (range 24-82), 101 (58.7%) of whom were mothers and 71 (41.3%) were fathers. The majority of respondents in both groups were married. About a third of respondents had university education (37.1%), with a distribution over all educational fields (Table 1). There was no difference between the groups with respect to family status, education level, and age. The sample included 83.7% of parents of male children with ASD and 16.3% of parents of female children with ASD. Necessary sample size was calculated using the power analysis with the power of the test of 90% at the level of significance $\alpha = 1\%$.

Parents of children with ASD were contacted through the Croatian Autism Center in Zagreb and its branch offices in Rijeka, Split, and Nova Gradiška, and educational centers for children with disability in Pula and Osijek in the period from October 2006 to June 2007. The Center's database of users was the basis for a sample frame. Targeted sample were the parents whose children were at the time clients of the centers. The research was conducted in 29 Croatian municipalities. Parents were approached at parents' meetings and individually when they came to the Center (if they did not attend the meetings) and informed on the purpose of the study by the project leader. Questionnaires were distributed by the Centers' staff and project leader personally to both mothers and fathers who agreed to participate in the study. Altogether 250 questionnaires were distributed to parents. Each questionnaire included a cover letter with information about the research. There were 178 parents (71%) who completely filled out the questionnaire within the given deadline. The original plan was to have both of the parents fill out the questionnaire. However, some 20% fewer fathers responded. The matching control group of parents was based on the following characteristics of the group of parents of children with ASD: sex and age of children (±5 years), parents' age group (±5 years), educational background of parents, and municipality of residence. Data collection for the control group was organized as part of the primary health care in primary schools in municipalities of residence of parents with children with ASD in the period from July 2007 to May 2008. Participants for the control group were selected to match the parents from the ASD group.

TABLE 1. Demographic data of the study participants

	No. (%) of parents of		
Characteristic	child with ASD (n = 178)	non-disabled child (n = 172)	*P*
Mother	105 (59)	101 (58.7)	0.886†
Father	73 (41)	71 (41.3)	
Family status:			
both parents	158 (88.7)	156 (90.7)	0.675†
single parent	20 (11.2)	16 (9.3)	
Education level:			
primary	17 (9.6)	13 (7.6)	0.729†
secondary	96 (53.9)	91 (52.9)	
university	65 (36.5)	68 (39.5)	
Median age (min-max, years)	43 (27-83)	42 (24-82)	0.822‡

*ASD – autism spectrum disorders.
†χ^2 test.
‡Man Whitney U-test.

Measures

Parents' self-perceived health was assessed using the Croatian version of the health status questionnaire SF-36 (25,26). SF-36 is a multi-purpose, short-form health survey, that consists of 36 questions (25). It represents a theoretically based and empirically verified operationalization of 2 general health concepts, physical and psychological, and their 2 general manifestations, functioning and well-being. Accordingly, the questionnaire contains 4 types of scales or 4 conceptually different measures of health. They refer to the following assessments or indicators of health: 1) functioning at the behavioral level; 2) perceived well-being; 3) limitations connected with social life and the realization of central life roles; and 4) direct personal perception of total health. Each of the questionnaire items refers to one of the following 8 different health indicators (24): physical functioning (10 items); role-physical, referring to the limitations in performing important life roles due to physical health (4 items); bodily pain (2 items); general health (5 items); vitality and energy (4 items); social functioning (2 items); role-emotional, referring to the limitations in performing important life roles due to emotional problems (3 items); mental health, referring to the absence of anxiety and depression (5 items); and 1 final self-evaluated health transition item (5 levels from "much better than a year ago" to "much worse than a year ago"), which is not used in the score of any of the scales but is useful in estimating an average change in health status over a year before its administration. Five questionnaire scales – physical functioning, role-physical, bodily pain, social functioning, and role-emotional – define health as the absence of limitations and inability, so they represent continual and one-dimensional health measures. The 3 remaining scales – general health, vitality, and mental health – are bipolar, meaning that they measure a much wider range of negative and positive aspects of health. The physical functioning, role-physical, and bodily pain scales refer to the general factor of physical health, and social functioning, role-emotional, and mental health scales measure psychological health. Scales of vitality and general health are moderately connected with both factors. The total result is shown in the form of the profile defined with 8 points that represent the measure of individual aspects of health transformed into a standardized score from 0 (minimum) to 100 (maximum). On all scales, higher results indicate better subjective health. Psychometric validation of the Croatian version of the SF-36 revealed good psychometric properties (26). The Croatian version of SF-36 questionnaire was licensed to Andrija Štampar School of Public Health and the permission for using it was obtained. Furthermore, parents filled out a general questionnaire containing 3 parts: demographic part (sex, age, marital status, parent educational background, and child's sex and age); health part including questions on self-reported chronic medical conditions; and the part on the needs and type of help needed to advance their health and well-being.

Statistical analysis

Descriptive statistics was used to present data on sex, age, family status, and education level of study participants. Original results from health status questionnaire SF-36 were transformed according to authors' algorithm, which results in 8 health dimensions. The differences in self-perceived health between the 2 groups were assessed with Mann-Whitney U test since distributions were not normal. Difference in distributions of categorical data was tested with χ^2 test. Statistical analysis was performed by statistical software Statistica, version 7.1 (27).

RESULTS

For all dimensions of health, except for physical health, there was a significant difference in self-assessed health between parents of children with ASD and parents of non-disabled children (Table 2). The worst dimensions of health in parents of children with ASD were energy, vitality, and social functioning dimension. Sixty two (35%) parents of children with ASD reported that their health deteriorated in the last year, which is 18% higher than in parents of non-disabled children ($\chi^2_4=17.500$, $P=0.002$) (Table 3). Furthermore, 73 (41%) parents of children with ASD stated that they suffered from a chronic medical condition, compared with 52 (30%) parents of non-disabled children. Due to data distributions with small frequencies in several categories, test statistics was not performed. However, most common chronic medical conditions listed by parents of children with ASD were those of the musculoskeletal system and connective tissue (21.2%) and circulatory system (17.3%), while parents of non-disabled children reported medical conditions of respiratory system (27.1%). Furthermore, 20 (11%) parents of children with ASD suffered from psychological disorders (F00-F99 ICD-10 code group), which is 6.7% more than among parents of non-disabled children. This was the largest difference in specified chronic medical conditions between the groups (Table 4). Seventy-one percent of parents of children with ASD thought that enhancing economic, social, educational policy measures could advance their and their children's health and well-being.

TABLE 2. Eight health status dimensions and significance of difference between parents of children with autism spectrum disorders (ASD) and parents of non-disabled children

Health dimension	Score for the parents of (median, interquartile range): child with ASD	non-disabled child	P*
Physical functioning	80.0 (40.0)	80.0 (30.0)	0.118
Role physical	75.0 (78.5)	100.0 (25.0)	<0.001
Role emotional	66.7 (100)	100.0 (33.3)	<0.001
Social functioning	55.6 (22.3)	77.8 (22.2)	<0.001
Mental health	52.0 (22.0)	72.0 (20.0)	<0.001
Vitality/Energy	50.0 (30.0)	60.0 (15.0)	<0.001
Bodily pain	60.0 (40.0)	70.0 (30.0)	<0.001
General health	57.0 (27.0)	67.0 (20.0)	<0.001

*Man Whitney U-test.

TABLE 3. Frequency distribution for the item change in health during the last year for parents of children with autism spectrum disorders (ASD) and parents of non-disabled children

Change in health during the last year	No. (%) of parents of: child with ASD	non-disabled child
Much worse	10 (5.6)	2 (1.2)
Somewhat worse	52 (29.4)	27 (15.7)
About the same	96 (54.2)	115 (66.8)
Somewhat better	11 (6.2)	20 (11.6)
Much better	8 (4.5)	8 (4.7)

TABLE 4. **Chronic medical conditions reported by parents of children with autism spectrum disorders (ASD) and parents of non-disabled children, according to the International Classification of Diseases Tenth Revision (ICD-10) disease group**

	No. (%) of parents of	
Group of disease according to ICD-10 (code)	child with ASD	non-disabled child
Communicable and parasitic diseases (A00-B99)	2 (1.6)	1 (1.4)
Neoplasms (C00-D48)	6 (4.7)	2 (2.9)
Endocrine, nutritional and metabolite diseases (E00-E90)	19 (15.0)	9 (12.8)
Mental and behavioral disorders (F00-F99)	14 (11.0)	3 (4.3)
Diseases of the nervous system (G00-G99)	8 (6.3)	3 (4.3)
Diseases of the eye and ear (H00-H95)	3 (2.4)	2 (2.9)
Diseases of the circulatory system (I00-I99)	22 (17.3)	10 (14.3)
Diseases of the respiratory system (J00-J99)	8 (6.3)	19 (27.1)
Diseases of the digestive system (K00-K93)	14 (11.0)	5 (7.1)
Diseases of the skin and subcutaneous tissue (L00-L99)	1 (0.8)	3 (4.3)
Diseases of the musculoskeletal system and connective tissue (M00-M99)	27 (21.2)	11 (15.7)
Diseases of the genitourinary system (N00-N99)	3 (2.4)	2 (2.9)
Total	127 (100)	70 (100)

DISCUSSION

Our study demonstrated that parents of children with ASD reported significantly poorer self-perceived health in all dimensions, except in physical health, than parents of non-disabled children. Their energy and vitality and social functioning were particularly deteriorated. The only dimension of health in which there was no difference from parents of non-disabled children was physical health. This can be explained by the fact that 71% of surveyed parents of children with ASD were younger than 50. Especially important is the fact that even 35% of parents of children with ASD perceived their health as worse than last year, which is 18% higher than among parents of non-disabled children. Moreover, 41% of parents of children with ASD, in comparison with 30% of parents of non-disabled children, reported having a chronic medical condition, with about 3 times higher frequency of psychological disturbances than among parents of non-disabled children. This was the largest difference in specified chronic medical conditions between the groups.

All these facts are consistent with other studies (10-13), which indicate that parents of children with ASD are particularly vulnerable and that parenting of such children is related to parents' impaired well-being. In order for the care of disabled family member to have a positive effect on the family (17,28,29), several parameters are needed: harmonious family relationships, high socio-economic status, and the community which supports such families. Unfortunately, in Croatia it is difficult to satisfy these requirements, since the percentage of divorce in families with children with ASD is about 2% higher than in families with healthy children. Furthermore, Croatia is a post-war country with a low gross domestic product and one of the poorest countries in Europe (30). Also, the worst dimensions of health in parents of children with ASD are energy, vitality, and social functioning dimensions. This all indicates possible deviations from the parameters that, according to Yau and Li-Tsang (28), guarantee the highest quality of parenthood to a disabled child.

All these findings, and especially the fact that health of parents with children with ASD is compromised, present a potential threat to the optimal care for the child (19-22). A great majority (71%) of parents of children with ASD believes that enhancing different social, economic, and health policy aspects, as well as streamlining the legislature, would improve their and their children's health and quality of life. Parents from our study gave a series of proposals for achieving this goal. These measures include sensitization and education of the society on the issue of ASD, advancing the educational system and integration of children with ASD in the society, categorizing autism as 100% disability and claiming the pertaining rights, advancing the organizational aspects focusing on better service staffing and accommodation for children with ASD, and introducing personal assistants and legal provision for mothers with the caregiver status. All these measures may directly or indirectly improve the health of parents of children with ASD.

There are some factors, associated with the methodology used in our study, that limit the generalizability of our results. The sample of parents was not randomly selected from an open population; we included only those parents with children in the Autism Center who voluntary answered the questionnaire. The group of parents of children with ASD was thus pre-selected, comprising those who already received support through Centers. We are aware that sample selection did not include those parents who were either dislocated or unable to use the Centers. According to Croatian register (6), there are about 800 persons with diagnosed ASD living in Croatia, and about 1/3 of them visits the Center. So, we may expect to find even more difficulties and health problems in the population of all parents of children with ASD.

Special attention is devoted to improving the well-being of caregivers (31-33). Organized support for family caregivers benefits not only the patient, but also the caregiver and the health care team (34,35). Croatia has regulations on disabled persons, but these do not define or give enough significance to disability in ASD persons and persons with other intellectual disorders. It should be pointed out that ASD, like other intellectual disorders, is not covered by a single legal provision determining the degree of disability. Completing legal provisions, familiarizing parents with their rights, as well as interdepartmental cooperation, combined with empathy for disabled persons, could result in improving the position of persons with ASD and their families. In addition to streamlining the legislation, it is necessary to stress the importance of early diagnostics of pervasive developmental disorders, application of a suitable life-long approach, as well as giving support to the family and experts included in the treatment (36,37). Appropriate treatment and psycho-social support should be provided before the health of parents becomes seriously compromised. Such measures, besides encouraging a positive attitude in the society, may improve the well-being of autistic persons and their families. Additional attention should be focused on the especially vulnerable groups of parents of children with ASD, whose needs for support and help are greater than the needs of other parents.

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