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THE EFFECTS OF THE SOCIOECONOMIC STATUS OF SERBIAN FAMILIES CHILDREN WITH COELIAC DISEASE ON GLUTEN-FREE DIET

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UTICAJ SOCIOEKONOMSKOG STATUSA PORODICA U SRBIJI U KOJIMA ŽIVE DECA SA CELIJAKIJOM NA USPEH DIJETE BEZ GLUTENA

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ABSTRACT

Objective. To determine the effects of the socioeconomic characteristics of Serbian families with coeliac children (education level, employment, number of family members, monthly family income) on a gluten-free diet outcomes, as measured by serologic tests (tTG).

Methods. The sample included 116 parents and the same number of children and adolescents (N = 116) diagnosed with the coeliac disease who had followed a gluten-free diet for at least a year. Children were aged 5-18 years. The research was carried out at the University Children's Hospital in Belgrade and the Institute of Mother and Child Health "Dr Vukan Čupić" in Belgrade. The research was conducted during the period April-December 2016. The instruments used in the research were the Socioeconomic Survey Questionnaire and the Documentation Sheet, both specially designed for the purpose of this study.

Results. The results of our study have shown that the mean age of mothers was 39.6 years and fathers 43.4 years. Parent respondents reported completed secondary education in 58% (116) of all cases. 46.55% of mothers and 35.34% fathers of the examined children with coeliac disease were not permanently employed. 82.76% of parents were married. Four-member families were most common. Considering the specific needs, 51% of the parents perceived their income level as very low and low. Serologic tests confirmed the efficacy of the therapy in 25.86% (30/116) of the children.

Conclusion. The poor success of a gluten-free diet in the coeliac children and adolescents pointed out to the major impact of a lower socioeconomic status of their families. Taking into account all the difficulties in the implementation of a gluten-free dietary restrictions for children in Serbia, it becomes clear that the engagement of the whole society, and not just the members of their families, is necessary.

Key words: *Celiac disease; child; diet, gluten-free.*

SAŽETAK

Cilj istraživanja. Utvrditi ulogu koju socioekonomske karakteristike porodica dece sa celijakijom u Srbiji (nivo obrazovanja, zaposlenost, broj članova porodice, mesečni porodični prihod) imaju na rezultat uspeha terapije ishranom bez glutena, koji se meri serološkim testovima tTG .

Metode. Istraživanjem je obuhvaćen uzorak od N = 116 roditelja i isto toliko dece i adolescenata N = 116 s dijagnozom celijakije, koji su na bezglutenskoj ishrani minimum godinu dana. Deca su uzrasta 5–18 godina. Mesto istraživanja su Univerzitetska dečja klinika u Beogradu i Institut za zdravstvenu zaštitu majke i deteta Srbije „Dr Vukan Čupić", na Novom Beogradu. Vreme istraživanja obuhvata period od 1. aprila do 31. decembra 2016. godine. Korišćeni instrumenti istraživanja su Upitnik o socioekonomskim karakteristikama ispitanika i Dokumentacioni list, oba konstruisana za potrebe ovog istraživanja.

Rezultati. Rezultati istraživanja pokazuju da je prosečna starost majki ispitivane dece 39,6 godina, a očeva 43,4 godine. Srednju stručnu spremu ima 58% (116) roditelja. Stalni radni odnos nema 46,55% majki i 35,34% očeva dece sa celijakijom. U braku je 82,76% roditelja. Porodice su najčešće četvoročlane. Visinu prihoda u odnosu na specifične potrebe 51% roditelja procenjuju kao vrlo loše i loše. Serološki testovi provere uspeha terapije bili su pozitivni kod 25,86% (30/116) dece.

Zaključak. Nezadovoljavajući uspeh terapije dijetom bez glutena dece i adolescenata sa celijakijom ukazuje na veliki uticaj lošeg socioekonomekog statusa porodica u kojima žive. Uzimajući u obzir sve teškoće u sprovođenju bezglutenske ishrane dece u Srbiji, postaje jasno da je neophodno angažovanje i društva, a ne samo članova njihovih porodica.

Ključne reči: *celijakija; dete; bezglutenska ishrana.*

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INTRODUCTION

Coeliac disease is a chronic autoimmune disease characterized by the intolerance to the gluten protein in wheat, barley, rye and oats. There is a considerable heterogeneity in clinical presentation, from malabsorption with chronic diarrhoea, poor growth in children, abdominal distension and weight loss to non-specific signs and symptoms (1,2). The disease affects about 1% of the population and has a negative impact on various aspects of life, including physical and social functioning. In the last few decades, the awareness of the coeliac disease has been changing, and coeliac disease is becoming recognized as a worldwide problem affecting people of all ages (3,4,5). The exact number of people in Serbia affected with coeliac disease is not known since there are no official statistics, but experts claim that the expected number is the same as in other countries where the research has been conducted, in the range of 1/100. It is assumed that 35,000-70,000 people in Serbia have been diagnosed with coeliac disease (6). The treatment is carried out by a strict lifelong diet, avoiding wheat, rye, oats, barley and products containing them (7,8). A gluten-free diet for children with coeliac disease is demanding and may psycho-socially and financially affect both patients and their families. Non-adherence to diet for any reason deteriorates the health of these children, leading to numerous complications (9,10).

The objective of this research is to examine socioeconomic characteristics of the families with coeliac children such as education level, employment, marital status of parents, the number of family members, the family monthly income and the possible impacts on a gluten-free diet. The efficacy of the diet is assessed by serologic tests – antibodies to tissue transglutaminase IgA and IgG (tTG).

PATIENTS AND METHODS

The study included 116 parents (mother or father) and the same number of children aged 5-18 years diagnosed with coeliac disease. The survey was conducted from April 1 to December 31, 2016. The survey was carried out within the regular gastroenterological oversight at the University Children's Hospital in Belgrade and the Institute of Mother and Child Health "Dr Vukan Čupić" in Belgrade. The study, for which the parental consent had already been received, included children and adolescents aged 5-18 years who were diagnosed with coeliac disease and lived on a gluten-free diet for at least a year.

A structured questionnaire was specially designed for this survey, including the questions about socioeconomic characteristics of the respondents – age, residence, education, employment, workplace, marital status, the number of family members, the monthly income of the family, the respondents' self- assessment of their economic status.

The documentation sheet was filled in with the data taken from the records of medical institutions related to the results associated with tTG testing.

Testing Procedure started after brief instructions. All parents were given questionnaires to fill in anonymously and without time limits, explaining the aim of a scientific study and that it was not a diagnostic procedure. Each respondent was offered the assistance in completing the questionnaire if needed.

The study was approved by the Ethics Committee of the University Children's Hospital in Belgrade and the Institute of Mother and Child Health "Dr Vukan Čupić" in Belgrade. Satisfying the ethical requirements, all the respondents were informed about the basic objectives of the research and the exclusive use of data for scientific purposes, providing data confidentiality and anonymity of the respondents. The parents who agreed to participate in this study together with their children signed the consent forms that were required for the participation in the study. Description of numerical data was performed through classical methods of descriptive and inferential statistical methods. The analysis and data processing were performed using a software package for statistical analysis (Statistical Package for the Social Sciences - SPSSTM for Windows, version 23.0, 2015). The results have been presented in tables. In our research, we used the following descriptive statistics: the absolute frequency, percentage, median, arithmetic mean, mode, maximum/minimum, interquartile deviation, standard deviation, standard error and 95% confidence interval for both upper and lower range limits. Multiple response analysis was given along with the percentage of such responses (response frequency), as well as in relation to the percentage of informants who chose each of the possible answers (case frequency).

RESULTS

The study included 116 parents who accompanied their children for regular coeliac disease follow-ups to the health facility. The results are shown in Tables.

DISCUSSION

During the research, 88 (76%) mothers and 28 (24%) fathers accompanied their children for follow-ups. Mothers more often accompanied their children, and we cannot explain that by the fact that more fathers were full-time employed, because of the similar values in the sample distribution of the two variables – 53.5% of mothers and 60.34% fathers. The average age of the mothers was 39.6 years and the mean age of fathers was 43.4 years (Table 1). When comparing our results with the results of the study carried out in Italy which included 45 families with coeliac children, we concluded that similar results were

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obtained. Namely, the mean age of the parents was similar, the mothers' average age was 37 years and fathers' mean was 41.6 (11). The paternal age-specific data are very useful since coeliac children need their family support and middle-aged parents are more willing to learn more about the disease and its treatment, thus providing the children's safety and protection. Analysing the data of parental education, we found out that the highest percentage of parents completed secondary education (58%), 26% of them obtained a college or university degree, and primary school was the attainment of 9% of the parents. (Table 2). A higher educational degree was more common in mothers (28.45%) than in fathers (24.14%). Comparing our results with those obtained by Filippo T. in Italy, we concluded that the average educational status of the parents in the study was significantly different, since in their study parents with a higher educational degree made 43.3%, those with secondary education 54%, and elementary school education was completed by only 2.2% of the examined parents (11). The results of previous studies dealing with the quality of life of coeliac children and adolescents in the world literature have shown that the educational background of parents, especially mothers, appeared to be an important factor for the successful implementation of dietary guidelines, especially in children with coeliac disease. Addolorato G. et al reported that more educated parents took better care of the selection and preparation of gluten-free food and exerted more control over their children's adherence to a gluten-free diet (12). Some researchers figured out that low-level parental knowledge and their poor understanding of the importance of the diet lead to the non-compliance in children(11). Rajpoot P. et al also pointed out better results of a gluten-free diet in children whose mothers attained higher education due to their greater ability to understand their child's illness and collect necessary information (13,14). By analysing the employment of parents in our study, we realised that 46.55% of mothers and 35.34% of fathers of coeliac children were not employed on a full-time basis (Table 3). Parental unemployment, especially unemployed

Table 1. Descriptive statistics – age of parents of coeliac children

Age	*n*	*Min*	*Max*	*M* (*SD*)	*SE*	95% CI		*Mdn* (*IQR*)
						LL	*UL*	
Mothers	116	24	55	39.69 (6.23)	0.58	38.54	40.84	40.00 (8.00)
Fathers	112	28	61	43.14 (6.22)	0.59	41.98	44.31	43.00 (8.00)

Note: Number of respondents (n = 116); SE – standard error; CI – confidence interval; LL – lower limit; UL – upper limit.

Table 2. Comparative presentation of sample distribution according to parents' education level

Education level	mothers		fathers	
	n	%	*n*	%
Primary school	9	7.76	1	0.86
Craft education	4	3.45	12	10.34
High (secondary) school	69	59.48	6	5.17
Higher education	33	28.45	66	56.90
Missing data	1	0.86	28	24.14
			3	2.59

Note: Number of respondents (n = 116);

Table 3. Sample distribution according to employment of parents of coeliac children and adolescents

Employment	mothers		fathers	
	n	%	*n*	%
Employed	62	53.45	70	60.34
Unemployed	54	46.55	41	35.34
Missing data			5	4.31

Note: Number of respondents (n = 116);

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mothers, enabled that a stay-at-home parent exerted more control when implementing a gluten-free diet, especially over younger children. Some studies conducted in recent years in Europe showed that children were more likely to violate the diet when they are not under parental supervision during the selection of foods, food preparation and mealtime (15). Whitaker et al found that 36% of parents – study participants, had limited their participation in social activities after the coeliac disease had been diagnosed in their children (16). Rosen et al. found that the new way of life accepted by parents had a major impact on all family members, including the affected child (17). A child's illness is also an emotional burden for the parents that is easier to bear if shared among the partners. The results of our study have shown that the majority of 82.76% of the parents were married, 10.34% lived in cohabitation and 4.31% were divorced (Table 4). The results of an Indian study showed that family relationships are extremely important; that study also confirmed more faithful adherence to the diet regime in families with married parents (13). Some families affected by such a stressful life event – illness of a child, became more unified, developed and promoted family strengths and positively redefined the system of family values. However, some families, especially those that were vulnerable and at risk even before the illness of their youngest members was diagnosed, began to manifest clinically relevant symptoms requiring continuous psychological intervention. Filippo T. pointed out that the sincere and dedicated family support eased the child's adjustment to coeliac disease, and also improved its quality of life (11). In our research, the number of household members who live with coeliac children was mostly – four (Table 5). When it comes to the monthly income of the families and the self-assessment of their economic status, the results of our survey showed that 64% of the families lived with lower than average incomes, which was rated as very bad and bad material conditions in 51% of cases. (Table 6, 7) The implementation of the gluten-free diet can increase the cost of living of the family, causing difficulties in its everyday functioning, especially with more family members diagnosed with coeliac disease and the income lower than required. Namely, in a study conducted in the UK, the authors Zingoni F. et al found that children living in a poor socioeconomic environment were about two times more likely to be diagnosed with delay and possibly extremely difficult complications. This is so since the poorer population do not attend a doctor very often and even when the diagnosis is established, there is a greater possibility of non-adherence to a gluten-free diet due to their unfavourable financial situation for purchasing gluten-free products (18). The results of the studies conducted in India and the United States showed that

Table 4. Sample distribution by marital status

Marital status	*N*	%
Married	96	82.76
Divorced	5	4.31
Widow/-er	3	2.59
Non-marital union	12	10.34

Note: Number of respondents (n = 116);

Table 5. Sample distribution according to the number of household members

n	*Min*	*Max*	*Mo*	*M* (*SD*)
116	2	8	4	4.40 (1.21)

Note: Group of respondents (n = 116);

Table 6. Sample distribution according to monthly income

Monthly Income		
	n	%
Less than 10,000.00 RSD	3	2.59
10,000.00-20,000.00 RSD	18	15.52
21,000.00-30,000.00 RSD	28	24.14
31,000.00-40,000.00 RSD	21	18.10
More than 41,000.00 RSD	42	36.21
Missing data	4	3.4

Note: Number of respondents (n = 116)

Table 7. Sample distribution according to the amount of income in relation to needs (self-assessment of economic status)

Income in relation to needs	*N*	%
Very low	9	7.76
Low	42	36.21
Good	46	39.66
Very good	10	8.62
High	8	6.90
Missing data	1	0.86

Note: Number of respondents with coeliac disease (n = 116)

Table 8. Sample distribution of the efficacy of therapy using serologic tests in coeliac patients

Blood analyses confirming diet efficacy	*n*	%
Positive	30	25.86
Negative, i.e. Normal	86	74.14

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families with higher income per capita more strictly adhere to a gluten-free diet (13,19). Sarkhy A. et al in their study published in 2016 presented the attitude of 106 (93.8%) Saudi families regarding the very high price of gluten-free products and the profound effect of the diet on their family budget (20). Similar outcomes were presented by Singh and Whilan, discussing the availability and price of gluten-free products that are generally more expensive (21). Leffler and associates particularly emphasized that 51.3% of the patients considered high cost of a gluten-free diet to be an important issue for people with coeliac disease, because it is directly related to their ability to implement the necessary diet (22). Regular tTG serologic tests are appropriate in controlling the adherence to a gluten-free diet. Negative antibodies to tissue transglutaminase IgG and IgA (tTG) are reliable indicators of the strict adherence to the diet, while positive ones indicate dietary non-adherence and omissions. The serological blood tests in our respondents were positive at 25.86% (30/116) and negative i.e. normal at 74.14% (86/116) (Table 8). Only a trace of gluten in food is sufficient to produce damage to the mucosa of the small intestine and subsequent complications (23-25). The lack of awareness of the necessity of strict adherence to a gluten-free diet in children and adolescents can cause serious problems in the further course of the disease. In the study of Araujo and Araujo, some sufferers among adolescents stated that they used food with gluten because of the lack of alternatives and sometimes the lack of information on the foods they must not consume in public places (26). The supply of gluten-free food can be especially difficult for children who live in rural areas, suburbs and small towns. Other factors, as well, could adversely affect the dietary regime, including the unattractive taste of gluten-free foods and alternative crops, poor knowledge of the gluten-free diet, the difficulty of changing entrenched eating habits, incomplete or confusing labelling of gluten in food and drugs, limited availability of gluten-free restaurants and shops (27,28). In adolescents, peer influence has an important impact on non-adherence to the restrictive diet, as well as a hectic lifestyle relying on packaged foods that often contain gluten (29). In the implementation of the dietary regime, the most successful are those children and adolescents who live in families that completely cut out all gluten foods, so that the whole family use exclusively gluten-free food. Biagetti et al suggested that a gluten-free diet strongly affects the everyday social life of children and their parents (30). In a study of Roma et al, in a sample of 73 coeliac children aged 5-14.5 years, 58% adhered to the gluten-free dietary regime and 42% stated that they sometimes consciously ate foods with gluten because they could not understand the long-term effects of gluten on their health.

CONCLUSION

Children with coeliac disease need the support of their families in their adherence to a gluten-free dietary regime. It is important that their families and households include both parents. Higher education level and favourable financial situation are preferable. Poor social and economic status of the families with coeliac children in Serbia causes the failure in the implementation of the therapeutic diet. Given all the negative effects of gluten in coeliac patients, it is necessary that health professionals, food industry and the whole society put in a great deal of effort together.

ABBREVIATIONS:

IgA – immunoglobulin A

IgG – immunoglobulin G

tTG – tissue transglutaminase

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