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**Assessment of quality of life and physical and mental health in children and adolescents with coeliac disease compared to their healthy peers**

Процена квалитета живота и менталног здравља у деце и адолесцената са целијакијом и њихових здравих вршњака

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## Assessment of quality of life and physical and mental health in children and adolescents with coeliac disease compared to their healthy peers

Процена квалитета живота и менталног здравља у деце и адолесцената са целијакијом и њихових здравих вршњака

### SUMMARY

**Introduction/Objective** Strict gluten-free diet for life is the only treatment for patients with coeliac disease. Limited selection of food options can cause problems in acceptance by their peers and affect their quality of life.

The aims of this paper was to examine the subjective experience of the quality of life in children and adolescents with coeliac disease and obtain a comprehensive picture of physical and mental impairments and social functioning compared to their healthy peers.

**Methods** The investigation was conducted as a cross-sectional study. It included 116 respondents aged 5–18 years with coeliac disease and 116 healthy children of similar age and gender. A Serbian version of Paediatric Quality of Life Inventory (PedsQL) was used as an instrument for measuring of quality of life in children. Descriptive statistics were calculated to analyse all results, while T-test was used to compare them.

**Results** The mean value of total PedsQL score was lower in the coeliac disease patients ( $75.89 \pm 20.35$ ) than in the controls ( $86.35 \pm 11.13$ ). Additionally, the experimental group reported lower all PedsQL Scale scores than the control group in the domains of psychosocial, school, social and emotional functioning. However, there was no statistically significant difference on the physical health scale. These results were the same in all age groups among both males and females.

**Conclusions** The disturbance of health-related quality of life in children and adolescents with coeliac disease is significant and the quality of life is lower if compared to their healthy peers.

**Keywords:** Coeliac disease, children, quality of life

### САЖЕТАК

**Увод/Циљ** Строго контролисана и доживотна безглутенска дијета је лек за пацијенте са целијакојом. Ограничен избор хране им ствара проблеме у прихватању од вршњака и може имати утицај на квалитет живота и психички статус.

Циљ овог рада је био да испита субјективан доживљај квалитета живота деце и адолесцената са целијакијом и добје целовиту слику о нарушености њиховог физичког и психичког здравља и социјалног функционисања у односу на здраве вршњаке.

**Метод** Истраживање је спроведено по типу студије пресека. Обухваћено 116 испитаника узраста од 5–18 година са целијакијом и 116 здраве деце сличне према узрасту и полу. Српска верзија Педијатријског упитника о квалитету живота *PedsQL* је коришћена као инструмент мерења квалитета живота код деце. Дескриптивни подаци израчунати су за све резултате, док је т-тест коришћен да их упореди.

**Резултати** Средња вредност од укупног броја бодова на *PedsQL* тесту била је нижа у групи деце и адолесцената са целијакијом ( $75.89 \pm 20.35$ ) него у контролној групи ( $86,35 \pm 11,13$ ). Експериментална група је такође имала ниже резултате *PedsQL* теста у односу на контролну групу у доменима психосоцијалног, школског, социјалног и емоционалног функционисања. Није нађена статистички значајна разлика у домену показатеља физичког здравља. Ови резултати су били исти код дечака и девојчице за све узрасте.

**Закључак** Квалитет живота повезан са здрављем деце и адолесцената са целијакијом значајно је нарушен у поређењу са здравим вршњацима.

**Кључне речи** Целијакија, деца, квалитет живота

### INTRODUCTION

Coeliac disease is a chronic inflammatory disease of multifactorial aetiology which results from a polygenic predisposition and gluten exposure [1]. The only scientifically proven beneficial treatment is strict lifelong adherence to a gluten-free diet [2]. Limited selection of food options, illness-based social inequality if compared to others, illness-induced stress and the disease treatment can all affect the quality of life. Children, especially if they are ill, can show very intense emotional reactions. This can affect their social functioning because of their feelings of shame; children can avoid contacts and having meals with others and, on the other hand, their peers sometimes may have a problem in social acceptance of celiac patients [3, 4].

Health-related quality of life is a subjective feeling of the impact of health on various aspects of life and is focused on children's everyday functioning. However, one of the biggest problems in assessing the quality of life in children is the specificity of their age and whether "their opinion should be taken into account" [5]. Measurement of health and quality of life in children is very complex and associated with various methodological problems. Worldwide previous research indicates that the quality of life of a sick child is significantly influenced by social, psychological and emotional aspects, apart from the physical ones [6]. Developmental psychologists believe that children aged 5-7 years are able to answer specific questions about their pain, mood and feelings, likes and dislikes, fears induced by certain phenomena, anxiety and delight, while at the age of 9 or 10 years, they can perform self-assessment and analyse their behaviour [7, 8].

The aim of this paper was to investigate the difference between the subjective experience of the health-related quality of life in children and adolescents with coeliac disease and their healthy peers and to obtain a comprehensive picture of their physical and mental impairments and social functioning in comparison to their healthy peers.

## METHODS

The investigation was conducted as a cohort, observational and cross-sectional study. The study included 116 subjects aged 5 to 18 years who had been diagnosed with coeliac disease and who complied with a gluten-free diet for at least a year. The control group consisted of 116 healthy respondents who meet the basic age and gender matching criteria with the examined group. The survey of children with coeliac disease was conducted within regular gastroenterological follow-ups. The selection of respondents for the control group was made using random sampling from the basic set of pre-school, primary and secondary school children from Belgrade. Children with coeliac disease and comorbidity (Hashimoto thyroiditis, Diabetes mellitus, etc.) were excluded from the study.

Paediatric Quality of Life Questionnaire (PedsQL) was the instrument employed for assessing the quality of life (QOL). There were different versions for three age groups (5-7, 8-12 and 13-18 years). Each version had 23 questions sorted into 4 categories, and answers were graded on a 5-point scale. The survey used a variety of Likert-scaled questions: 0—never, 1—almost never, 2—sometimes, 3—often, and 4—always. The scales were: Emotional functioning (8 questions), Social functioning (5 questions), School functioning (5 questions) and Physical functioning (5 questions). The questions from the first three scales gave the score of Psychosocial Health, while the last scale was the score of Physical Health. The mean values of results were converted to scale values from 0 to 100, where the higher score indicated better QOL. If more than 50% of the answers were missing, the result was not taken into account. PedsQL was culturally adapted and validated in the Serbian language [9, 10].

The questionnaires with brief instructions were given to children and adolescents to fill in, offering the assistance in completing if needed. Parents took an active part in the group of respondents

aged 5-7 years. The examination was carried out in the presence of the study authors, nurses and – in the control group – psychologists or pedagogues.

Descriptive statistics were calculated for all questionnaire scores. Independent samples *T*-test was used to compare PedsQL scores for various groups. The *P* value <0.05 was considered statistically significant. The amount of missing data was 2.6%.

The study was reviewed and approved by the Ethics Committee of the Institute of Mother and Child Health "Dr Vukan Čupić" in Belgrade and the University Children's Hospital in Belgrade. According to the ethical requirements, all respondents were informed in writing about the study goals and use of the data obtained exclusively for scientific purposes, providing the guarantee of anonymity of all the received data and identity of the respondents.

## RESULTS

The basic demographic data of the examined groups has been shown in Table 1.

**Table 1. Demographic characteristics of participants.**

Parameters	Celiac Disease (n = 116)	Control Group (n = 116)
<b>Age group, n (%)</b>		
5–7 years	22 (19.0)	14 (12.1)
8–12 years	44 (37.9)	48 (41.4)
13–18 years	50 (43.1)	54 (46.5)
<b>Gender, n (%)</b>		
Male	39 (33.6)	47 (40.5)
Female	77 (66.4)	69 (59.5)

The mean value of PedsQL total score was lower in the coeliac disease group than in the control group. Additionally, the coeliac disease group reported lower all PedsQL Scale scores than the control group. However, there was no statistically significant difference on the Physical health scale (Table 2).

**Table 2. Children's and healthy peers Pediatric Quality of Life Inventory General Scale Scores.**

PedsQL	Groups	$\bar{x} \pm SD$	CI 95%		<i>p</i> ( <i>t</i> -test)
			LL	UL	
<b>Emotional functioning</b>	Celiac disease	71.29±25.01	66.69	75.89	<0.05
	Healthy peers	84.66±15.40	81.82	87.49	
<b>Social functioning</b>	Celiac disease	81.55±24.02	77.13	85.97	<0.05
	Healthy peers	93.97±9.88	92.15	95.78	
<b>School functioning</b>	Celiac disease	73.81±24.04	69.32	78.29	<0.05
	Healthy peers	88.28±13.69	85.76	90.79	
<b>Physical health</b>	Celiac disease	76.75±25.31	72.10	81.41	0.100
	Healthy peers	81.44±17.13	78.29	84.59	
<b>Psychosocial health</b>	Celiac disease	74.91±21.31	71.00	78.83	<0.05
	Healthy peers	88.97±10.74	86.99	90.94	
<b>Total</b>	Celiac disease	75.89±20.35	72.14	79.63	<0.05
	Healthy peers	86.35±11.13	84.30	88.39	

Females scored PedsQL higher than males in both groups, with the exception noted in the Emotional functioning scale. Both, males and females from the control group tended to rate the PedsQL scores higher than the coeliac disease group. Among males, differences were statistically significant on four of six scores with no difference on the Emotional functioning and the Physical health scales. Among females, differences were significant on five of six scores with no difference on the Physical health scale (Table 3).

**Table 3. Children's and healthy peers Pediatric Quality of Life Inventory General Scale Scores according to gender.**

PedsQL	Groups	Gender	$\bar{x}\pm SD$	<i>T</i> test ( <i>p</i> )	<i>T</i> <sub>Male</sub> ( <i>p</i> )	<i>T</i> <sub>Female</sub> ( <i>p</i> )
<b>Emotional functioning</b>	Celiac disease	Male	73.08±24.86	0.587	0.100	<0.05
		Female	70.39±25.21			
	Healthy peers	Male	80.90±15.43	0.061		
		Female	86.56±15.14			
<b>Social functioning</b>	Celiac disease	Male	76.03±27.77	<0.05	<0.05	<0.05
		Female	84.35±21.54			
	Healthy peers	Male	93.59±9.10	0.772		
		Female	94.16±10.30			
<b>School functioning</b>	Celiac disease	Male	68.78±25.75	<0.05	<0.05	<0.05
		Female	76.25±22.94			
	Healthy peers	Male	84.74±18.03	<0.05		
		Female	90.06±10.56			
<b>Physical health</b>	Celiac disease	Male	74.48±28.29	<0.05	0.693	0.065
		Female	78.61±23.64			
	Healthy peers	Male	75.24±18.95	<0.05		
		Female	79.58±15.32			
<b>Psychosocial health</b>	Celiac disease	Male	71.45±23.20	<0.05	<0.05	<0.05
		Female	76.67±20.21			
	Healthy peers	Male	86.41±11.84	<0.05		
		Female	90.26±9.97			
<b>Total</b>	Celiac disease	Male	72.92±21.71	<0.05	<0.05	<0.05
		Female	77.39±19.61			
	Healthy peers	Male	82.53±12.19	<0.05		
		Female	88.28±10.10			

The coeliac disease group reported lower all PedsQL Scale scores than the control group across all ages, five of six scales were different. However, there was no difference on the Physical health scale in each age subgroup. Also, the biggest difference in each domain of quality of life was observed among the youngest age groups (Table 4).

## DISCUSSION

Our study included more female participants, which is in line with the results of other surveys. Namely, the authors have noticed that female population is more likely to suffer from coeliac disease (1.3-2:1) [1, 11]. In our cohort, nearly 45% of children with coeliac disease belong to the older age group. This is understandable considering the easier cooperation with them, a longer period of treatment in most of them and a better understanding of the disease.

To our knowledge, this is the first study in Serbia to show the differences between the subjective experiences of quality of life dealing with the health of children with coeliac disease in comparison to their healthy peers. While considering individual QOL domains, the lower value can be noticed on five of six PedsQL scores, with the exception of physical functioning. This should be taken with a grain of salt, because, in most cases, the endangering of physical health is usually experienced only through some disabilities. On the other hand, the results of some studies indicate that the timely

diagnosis of the disease and gluten-free diet as coeliac treatment do not really affect physical health [11–15].

**Table 4. Children's and healthy peers Pediatric Quality of Life Inventory General Scale Scores according to age.**

PedsQL	Groups	Age (years)	x±SD	T <sub>5-7</sub> (p)	T <sub>8-12</sub> (p)	T <sub>13-18</sub> (p)
<b>Emotional functioning</b>	Celiac disease	5-7	59.09±34.90	<b>&lt;0.05</b>	<b>&lt;0.05</b>	<b>&lt;0.05</b>
		8-12	74.55±23.10			
		13-18	73.80±19.89			
	Healthy peers	5-7	81.36±18.85			
		8-12	89.55±13.29			
		13-18	81.80±14.66			
<b>Social functioning</b>	Celiac disease	5-7	74.55±30.04			
		8-12	85.23±19.97			
		13-18	81.40±24.16			
	Healthy peers	5-7	90.45±11.74			
		8-12	95.57±6.92			
		13-18	94.10±10.96			
<b>School functioning</b>	Celiac disease	5-7	47.89±29.36	<b>&lt;0.05</b>	<b>&lt;0.05</b>	<b>&lt;0.05</b>
		8-12	81.93±19.77			
		13-18	76.50±18.27			
	Healthy peers	5-7	88.18±16.22			
		8-12	90.91±12.91			
		13-18	86.00±13.01			
<b>Physical health</b>	Celiac disease	5-7	79.30±32.40	0.251	0.387	0.390
		8-12	78.34±24.63			
		13-18	77.88±22.66			
	Healthy peers	5-7	81.82±10.37			
		8-12	82.46±19.47			
		13-18	80.38±17.54			
<b>Psychosocial health</b>	Celiac disease	5-7	58.33±26.82	<b>&lt;0.05</b>	<b>&lt;0.05</b>	<b>&lt;0.05</b>
		8-12	80.57±18.74			
		13-18	77.23±17.06			
	Healthy peers	5-7	86.67±13.21			
		8-12	92.01±9.47			
		13-18	87.30±10.18			
<b>Total</b>	Celiac disease	5-7	65.29±26.56	<b>&lt;0.05</b>	<b>&lt;0.05</b>	<b>&lt;0.05</b>
		8-12	79.79±18.62			
		13-18	77.11±17.32			
	Healthy peers	5-7	84.98±11.10			
		8-12	88.69±11.52			
		13-18	84.89±10.66			

Dietary restrictions in a gluten-free diet limit various daily social activities including travel and entertainment. They often have to explain why they should not consume gluten-containing food, which often attracts their peer's attention. Teenagers are expected to have more difficulties in adhering to diet due to their rebellious behaviour and the pressure and influence of the society, especially when they have meals at school, visit their friends, go to parties and excursions, etc. There are also difficulties in purchasing gluten-free products; they are often not sufficiently secure and easily accessible, and their price is still a burning issue. All this can be frustrating and bothering for children and can lead to dietary neglect and worsen the disease [14–18].

The emotional functioning of children with coeliac disease is significantly lower in comparison to healthy children. Sick children can show very intense emotional reactions. Similarly, some studies

showed that childrens with coeliac disease had more negative emotions (anger, sorrow, aggression, jealousy) than their healthy peers [17–19].

Adaptation to school, completing school obligations and belonging to various groups are significant indicators of normal development and functioning of children with chronic illness. Because of their strict adherence to dietary regimens and regular medical follow-ups children do not attend school normally, they need to miss classes, they fail to attend out-of-class activities and lose interaction with their peers. The results of some studies showed that the affected children also express concern about their absence from school, separation from peers, feeling of dissimilarity and they express the increased need for care and assistance from others [17, 19]. Also, there was often the lack of understanding the nature of their illness reflected by some teachers and peers [20].

Observing the sample in our study by gender, we found that girls had higher results than boys, with the exception of emotional functioning. The observation of girls only suggests the conclusion that there were differences between groups in every scale, except in the physical health scale, and the observation of boys showed no differences only in emotional functioning and physical health. The results of other researchers are contradictory, some indicated that there is no difference between boys and girls [21, 22], but there are also studies presenting lower quality of life in girls with coeliac disease [23, 24].

Observing coeliac respondents in our study by age, we conclude that they reported a lower level of quality of life in all scores and in all age groups if compared to the control group. The most pronounced deviations were in the youngest age groups. This must be taken with caution, given that in this age parents mostly assisted in giving answers and they do not often have a realistic view when it comes to their children. Surprisingly enough, the greatest difference would be expected to appear between adolescents, considering their peer's pressure and busy lifestyle, which contributes to a greater reliance on packaged foods that often contain gluten [4, 12, 14, 18, 25].

The assessment of the health-related quality of life (HRQoL) is increasingly recognized as a very important measure of the overall outcome of treatment. Self-reporting on the quality of life allows the examination of factors that affect the illness and treatment from the child's aspect. Dietary changes and the implementation of a gluten-free diet can be difficult, costly and socially unaccepted due to social constraints, and this creates difficulties in managing the dietary regimen and therefore can exert a negative impact [26–29]. After establishing a definite diagnosis of the disease and the start of a gluten-free diet rapid recovery takes place, and the quality of their life becomes similar to their healthy peers [12, 30].

## CONCLUSION

Compared to healthy children, the quality of life in children with coeliac disease in all age categories is disturbed in every domain where the quality of life can be measured and observed, except physical functioning. Girls with coeliac disease have a better quality of life than boys.

For a healthy life with coeliac disease and for successful adaptation and re-socialisation of the patients, it is necessary to improve the knowledge about the disease through additional education, to provide the patients with greater choice of gluten-free products, to encourage both patients and their peers to accept the necessary changes and, of course, to provide psychological support.

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