



QUALITY OF LIFE IN CHILDREN WITH ULCERATIVE COLITIS

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ABSTRACT

The aim of the research is to analyze the results of an evaluation of the quality of life of children with ulcerative colitis depending on disease clinical characteristics. 15 children with UC were examined (8 boys and 7 girls, average age - 14.3 ± 1.4 years) Severity of the disease was determined using the Pediatric Ulcerative Colitis Activity Index (PUCAI), estimates of the quality of life of the children and their parents using PedsQL 4.0 Generic Core Scales. Observation of patients included in the study was carried out for a year, the studied parameters were evaluated at the beginning of the observation at the first examination, after 6 and 12 months. The study of QOL level revealed a decrease in the performance of various scales of the PedsQL 4.0 questionnaire, both when assessing children with UC and their parents. The remitting nature of the disease and its frequent relapses in pediatric patients with UC have a significant impact on the quality of life of children, in particular, the effect of the disease on their physical activity and schooling is shown. The search for associations between clinical manifestations and indicators of the quality of life of UC in children also showed the presence of a number of statistically significant inverse correlations. Study showed that subjective assessments of the quality of life of children and their parents largely coincided. The data indicate that, during the examination of children with IBD, the pediatrician should assess the presence of socio-psychological stress factors in each child, interview parents about the performance and attendance of the children at school. A mandatory component of the examination and management of patients with IBD should be monitoring the level of quality of life of children associated with health, since this category of patients is characterized by its significant decrease relative to the corresponding indicators in healthy peers.

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Inflammatory bowel disease (IBD) is a group of chronic diseases (Crohn's disease and ulcerative colitis), characterized by gastrointestinal tract mucous membrane inflammation, which is manifested by periods of exacerbation and remission [1-3]. The prevalence and incidence of IBD is increasing worldwide, in recent years its level has been from 4 to 11 cases per 100,000 population [4, 5]. At the age of up to 20 years, approximately 25-30% of patients are diagnosed with Crohn's disease (CD), and 20-25% have ulcerative colitis (UC) [3, 4].

The advances of recent decades in IBD treatment have significantly optimized approaches to the treatment of these patients. At the same time, the lack of accurate methods for predicting an effective individual IBD treatment strategy contributes to intensive research aimed at identifying genetic, serological and microbiological markers that allow such a prognosis [1, 4].

The results of a number of observational studies involving adult patients with IBD devoted to the study of disease outcomes indicate that the young age of the disease onset is associated with an increased risk of adverse outcomes, which confirms the importance of early treatment initiation in children, as well as the need for doctors to consider such an aspect as quality of life (QOL) of this category of patients [6-8].

A number of studies have been performed on the assessment of QOL of patients with IBD, and, according to their results, in most patients, including those with UC, its level is statistically significantly lower compared to the corresponding characteristics in the general population

[9-11]. It was shown that children and adolescents with IBD, including UC, are physically less developed and active compared to healthy peers [7, 8], they are characterized by disturbances in family relationships [6, 11], limited participation in social activities, disorders of the emotional spectrum, learning problems, more frequent missed classes [7].

Some authors believe that determining the level of QOL in patients with IBD can be used as a screening method [8], while researchers believe that the activity of the disease has a great influence on the QOL of these patients [10, 11]. Ojeda Z., Cofré S. (2018) proposed to consider the activity of the disease as a factor associated with the level of QOL. According to the authors, an understanding of what pathogenetic and clinical factors in patients with IBD are reliably associated with the QOL level will make it possible to justify the need to perform certain therapeutic measures. This, in turn, will allow to improve the quality of life of these patients [8].

No less important is another aspect. According to Ryan J. et al. (2013), the low level of QOL of patients with IBD is largely associated with an increase in the frequency of various diagnostic and treatment measures and, consequently, increased use of health resources [9]. In this regard, the early detection and treatment of these patients is important both in terms of improving clinical outcomes and clinical and economic efficiency - the use of health resources.

It should be noted that the above aspects remain almost unexplored to date.

The aim of the article is to analyze the quality of life of children with ulcerative

colitis depending on disease clinical characteristics.

Materials and methods. A single-center, open, prospective, non-randomized study was conducted at the University Children's Clinical Hospital in 2017-19. 15 children with UC were examined (8 boys and 7 girls, average age - 14.3 ± 1.4 years).

The selection of patients in the study was carried out according to the following inclusion criteria:

- age 8-18 years;
- diagnosis of UC, confirmed by clinical endoscopic and morphological data;
- informed consent signed by parents of the child

As non-inclusion were considered:

- achieved stable remission of the underlying disease at the time of the start of the study;
- the presence of concomitant diseases that could affect the course of the underlying disease, distort the clinical picture and results of laboratory and instrumental diagnostics;
- lack of ability (for any reason) to comply with all medical prescriptions, including the inability to attend scheduled visits and to complete all necessary research procedures;
- the refusal of the child or its parents to participate in this study and/or the refusal of the parents to sign the informed consent form.

Diagnoses were made on the basis of a comprehensive examination, including clinical and laboratory data and the results of an endoscopic examination based on the clinical recommendations of the Russian Gastroenterological Association and Russian Coloproctologists Association for the diagnosis and treatment of ulcerative colitis (2016). The severity of

the disease was determined using the clinical index of UC activity in children - Pediatric Ulcerative Colitis Activity Index (PUCAI). When calculating the PUCAI index, the following facts are taken into account: abdominal pain, rectal bleeding, stool consistency with most bowel movements, stool frequency in 24 hours, bowel movements during the night (any episode that caused an awakening), patient activity level.

The average duration of the disease in children with UC was 6.3 (2.9; 9.7) years.

In some children, extraintestinal manifestations of IBD were observed: primary sclerosing cholangitis in 4 (26.7%) patients, joint damage in 7 (46.6%) children, skin damage in 2 children (13.3%), interstitial lung disease and vasculitis in one child (6.7%). Combinations of several extraintestinal manifestations were noted in 5 children (33.3%).

Along with the traditional survey, in the process of observation, a comparative assessment of the quality of life was carried out using the PedsQL 4.0 Generic Core Scales questionnaire for the age group of 8-12 years, 13-18 years, the scales of which provide the opportunity to assess the level of quality of life of the child by the following components: physical activity, mood, communication, life at school. At the same time, QOL was independently evaluated both by children and parents. QOL parameters were evaluated in dynamics and compared with activity levels, duration of the disease, and the presence of extraintestinal manifestations.

All children received therapy in accordance with clinical recommendations with 5-ASA preparations (mesalazine, salofalk), 50-60 mg/kg/day. If necessary,

corticosteroids (prednisone, hydrocortisone, budesonide) and cytostatics (azathioprine, 6-mercaptopurine) were added (corrected) to therapy.

Observation of patients included in the study was carried out for a year, the studied parameters were evaluated at the beginning of observation at the first examination, after 6 and 12 months.

Among the limitations of the study was the limited volume of selection of patients, which was caused by the relatively low frequency of presentation of patients with the considered nosologies in real-life clinical practice during the period of the investigation.

Analysis of results was performed using Statsoft software packages STATISTICA 10 and Microsoft Excel 2016. The main characteristics and statistical criteria were selected when comparing them after studying the distribution of the attribute and comparing it with the Gaussian distribution by the Kolmogorov-Smirnov criterion. Since the revealed distribution of attributes differed from normal, non-parametric methods were used to further work with the obtained data. Quantitative data were described as Me (Q25; Q75), where Me is the median; Q25 and Q75 are the lower and upper quartiles, respectively. Qualitative parameters were presented as the frequency of occurrence of symptoms as a percentage of the total number of patients.

Comparison of quantitative indicators at different periods of observation in the studied samples of children with UC and their parents was carried out using the Wilcoxon criterion. To analyze differences in qualitative parameters, the chi-square and Fisher criteria were used.

The relationship between the charac-

teristics of the quality of life and disease activity level was searched for using correlational analysis with the calculation of the Spearman correlation coefficient, which was used for the distribution of attributes other than normal. Differences were considered statistically significant if “p” did not reach the threshold value of the level of statistical significance of the null hypothesis (alpha) equal to 0.05.

Results and Discussion. A significant lowering of QOL indicators (using the PedsQL 4.0 survey) was established for children with UC relative to the reference values for healthy children, which was characteristic for the evaluation of QOL both by the children and their parents. In the process of treatment, an increase in QOL level was observed against the background of a lowering in the activity of the pathological process (PICA index), the duration of the disease and presence of extraintestinal manifestations, on the one side, with values on the QOL survey scale (physical activity, mood, school education) – on the other. It was confirmed that the remitting character of the disease and its frequent relapses in pediatric patients with Crohn’s disease have a significant effect on QOL of patients.

The search for correlations between clinical manifestations and QOL indicators in children with UC also showed the existence of a series of statistically significant reverse correlations. The research showed that subjective evaluations of QOL by the children and their parents basically coincided.

In the course of examining children with inflammatory diseases of the intestine, the pediatrician must evaluate the QOL level, question the parents about the physical activity, performance and at-

tendance at school of the children. Monitoring of the health-associated QOL level of the children must become an essential component of the examination and management of these patients, because a significant lowering of these indicators is characteristic for them as compared with corresponding indicators in healthy peers. Taking into account aspects associated with QOL of these children can contribute to an increase in the effectiveness of early diagnostics of treatment and an improvement in treatment outcomes. The frequency of complaints in children included in the study is shown

Table 1

Dynamics of complaints (n = 15) during treatment (n /%)

Complaints	Beginning of observation		After 12 months	
	n	%	n	%
Weakness	11	73.3	4	26.7*
Memory impairment	5	33.3	3	20.0
Sleep disorders	6	40.0	3	13.3

Note: * - statistically significant differences ($p < 0.05$) compared with the indicators "Beginning of observation" (Fisher cr.)

in (Table 1). A survey of children and parents indicated that during the initial examination, the most frequent complaints were: general weakness during the day in 11 (73.3%) patients, memory loss in 5 (33.3%) children, sleep disturbances in 6 (40.0%) cases.

One year after the start of the observation, a marked decrease in the frequency of complaints was observed. Thus, 4 (26.7%) patients reported general weakness during the day, the value of this indi-

cator statistically significantly decreased relative to the initial level ($p = 0.010$). Sleep disorders were noted by 3 patients (20.0%), complaints of memory loss were recorded only in 2 patients (13.3%). The revealed differences between the last two indicators compared with the initial levels did not reach statistical significance ($p > 0.05$).

It was established that the activity of the disease in children with UC before the start of observation by the PUCAI in-

Table 2

PUCAI dynamics in children with UC (n = 15) during treatment, Me (Q25; Q75), points

Terms	PUCAI
Beginning of observation	52.5 (47.1; 58.8)
6 months	36.4 (27.0; 44.4)* ($p = 0.026$)
12 months	23.0 (16.6; 29.0)* ($p = 0.015$)

Note: * - statistically significant differences ($p < 0.05$) compared with the indicators "Before beginning of treatment" (Wilcoxon cr.)

dex was 52.5 (47.1; 58.8) points (Table 2). Subsequently, during the treatment process, a marked decrease in the values of this indicator was noted - after 6 months its value was 36.4 (27.0; 44.4) points and was statistically significantly ($p = 0.026$) below the corresponding initial level. Beyond that, the identified trend continued: 1 year after the start of observation, the index value was 23.0 (16.6; 29.0) and was statistically significantly lower than the PUCAI level before the inclusion of patients in the study ($p = 0.015$).

The baseline QOL values (at the initial examination) are given in **Table 3**. A significant decrease in the QOL levels was noted on all scales, which was characteristic both of the estimates given by children and their parents. The values of the indicators of the PedsQL 4.0 questionnaire in children with UC were lower than the reference values, which should be 100 points for a population of healthy children. At the same time, the level of the overall indicator of this questionnaire was 58.6 (44.4; 68.1) when assessed by children, and 70.1 (62.4; 88.1) points when evaluated by parents.

An assessment of QOL indicators dynamics for children with UC during the observation showed a statistically significant increase in the values of the indicators on all scales of the PedsQL questionnaire (**Table 4**). When evaluated by children, the value of the overall indicator scale of the questionnaire increased from 58.6 (44.4; 68.1) points to 69.1 (54.2; 75.8) after 6 months and was statistically significantly ($p = 0.017$) higher than that before the patients were included in the study. After 12 months, the level of this QOL parameter was 80.1 (69.1; 88.2) points, statistically significantly exceeding the value of the initial indicator ($p = 0.024$).

When assessing the QOL of children with UC by their parents, a similar, but less pronounced dynamics was observed, the value of the indicator was statistically significantly ($p = 0.008$) increased from the initial level of 70.1 (62.4; 88.1) points to 83.3 (64.2; 90.4) 9 points after 6 months after the start of observation. After 1 year, the value of this parameter was 86.3 (72.4; 92.0) ($p = 0.006$ relative to the initial value).

Table 3

Quality of life baseline levels in children with UC ($n = 15$), Me (Q25; Q75), points

QOL indicators questionnaire PedsQL 4.0	Questionnaire quality of life indicators PedsQL 4.0 Generic Core Scales	
	Children's assessment	Parents assessment
Physical activity	13.5 (9.2; 18,8)	15.2 (10.1; 21.5)
Mood	17.1 (14.6; 25,3)	19.0 (13,6; 24,0)
Communication	12.2 (7.8; 18.1)	14.1 (9.8; 20.6)
School life	15.5 (11.1; 19.8)	21.5 (17.7; 35.1)
General	58.6 (44.4; 68.1)	70.1 (62.4; 88.1)

Table 4

General indicators of the PedsQL 4.0 Generic Core Scales ($n = 15$) dynamic in the treatment process, Me (Q25; Q75), points

Questionnaire Scales	Beginning of observation	After 6 months	After 12 months
Children's assessment	58.6 (44.4; 68.1)	69.1 (54.2; 75.8)* ($p=0.017$)	80.1 (69.1; 88.2)* ($p=0.024$)
Parents assessment	70.1 (62.4; 88,1)	83.3 (64.2; 90.4)* ($p=0.008$)	86.3 (72.4; 92.0)* ($p=0.006$)

Note: * - statistically significant ($p<0.05$) differences compared with before the beginning of observation (Wilcoxon cr.)

Table 5

The relationship of Quality of life indicators with the PUCAI in patients with UC (Spearman correlation coefficients)

QOL indicators questionnaire PedsQL 4.0	PUCAI	Disease duration	Extraintestinal manifestations
Physical activity	-0.482* ($p=0,014$)	-0.412* ($p<0,001$)	-0.357* ($p=0.019$)
Mood	-0.383* ($p=0.029$)	-0.348* ($p=0.009$)	-0.284* ($p=0.032$)
Communication	-0.256 ($p=0.214$)	-0.305 ($p=0,176$)	-0.193 ($p=0,228$)
School life	-0.351* ($p=0.019$)	-0.208 ($p=0.124$)	-0.319* ($p=0.014$)
General	-0,424* ($p=0.005$)	-0,444* ($p=0.003$)	-0,397* ($p=0.011$)

Note: * - statistically significant Spearman correlation coefficients ($p<0.05$)

The revealed increase in QOL level occurred against the background of a decrease in the pathological process activity during treatment. This was also confirmed by the results of a search for the relationship of quality of life indicators with the clinical activity of UC, carried out using a correlation analysis. As can be seen from **Table 5**, the values of the PUCAI index in the examined children had inverse statistically significant correlations of moderate strength with the values of the QOL questionnaire scales - with physical activity ($R = -0.482$), mood ($R = -0.351$) and life in school ($R = -0.351$).

At the same time, there were no significant correlations for the "Communication" scale with the level of disease activity. The values of the PUCAI were negatively statistically significantly associated with the general indicator of the PedsQL 4.0 questionnaire ($R = -0.424$).

It was also found that the duration of the disease was statistically significantly negatively related to the indicator of the scale of physical activity ($r = -0.412$), mood parameters ($r = -0.348$), communication ($r = -0.305$) and the general indicator of the PedsQL 4.0 questionnaire ($r = -0.444$).

The presence of extraintestinal manifestations of the disease moderately negatively correlated with the levels of QOL scales: physical activity ($r = -0.357$), life at school ($r = -0.319$) and the general indicator of the questionnaire ($r = -0.397$).

Thus, the evaluation of QOL of patients included in the study demonstrated a decrease in the indicators of the various scales of the questionnaire PedsQL 4.0 when evaluated both by children with UC and their parents. The correlation analysis

data allows to conclude that the disease duration and the presence of extraintestinal manifestations should be considered as the main clinical characteristics affecting the QOL of children with UC. The study of QOL level revealed a decrease in the performance of various scales of the PedsQL 4.0 questionnaire, both when assessing children with UC and their parents. The remitting nature of the disease and its frequent relapses in pediatric patients with UC have a significant impact on the quality of life of children, in particular, the effect of the disease on their physical activity and schooling is shown. The search for associations between clinical manifestations and indicators of the quality of life of UC in children also showed the presence of a number of statistically significant inverse correlations. It should be noted that the effect of disease duration and therapy on QOL of this category of patients remains poorly understood. Despite the fact that in some studies the relationship could not be demonstrated [10], in other studies the authors showed that patients with long-term IBD have a lower level of QOL [12-14]. At the same time, our study found that the duration of the disease was statistically significantly negatively related to a greater extent to the indicator of the scale "Physical activity" and "Mood", as well as the general indicator of the questionnaire. Also, most of the scales of the PedsQL 4.0 questionnaire had significant inverse correlations with such characteristics of disease activity as the PUCAI index and the presence of extraintestinal manifestations of IBD.

Our study showed that subjective assessments of the quality of life by children and their parents largely coincide.

The important role of parents in managing children with IBD has been shown by Bramuzzo M. et al. (2019). According to the authors, changes in the psychological well-being of parents can affect the QOL level of these children. The study included children with IBD at the age of 8-18 and their parents, while the children answered the questionnaires of the HRQoL questionnaire, and the levels of distress, anxiety, depression, and pain were assessed in parents. To assess the correlation between indicators of parents and children, the method of single-variable and multiple regression analysis was used [15].

100 children were examined (45 with CD, 55 with UC), 90 mothers and 62 fathers of these children. Parents had a high level of distress, while the values of indicators characterizing the severity of anxiety, depression, and pain were relatively low. It was noted that the severity of parental distress had the most significant correlation with the level of QOL (according to HRQoL) in children, and was also associated with the activity of the disease and recent exacerbations of IBD. In multivariate regression analysis, it was

found that the contribution of “parental factors” to the variance of QOL in children was more than 20% [15].

We should agree with the authors’ conclusion on the necessity of implementation of measures aimed at correcting parental distress in the management of children with IBD. Also, our data indicate that, during the examination of children with IBD, the pediatrician should assess the presence of socio-psychological stress factors in each child, interview parents about the performance and attendance of school by the children. Unfortunately, at present, specialists rarely pay attention to the need to assess and correct QOL of children with IBD. A mandatory component of the examination and management of patients with IBD should be monitoring the level of quality of life of children associated with health, since this category of patients is characterized by its significant decrease relative to the corresponding indicators in healthy peers. Taking into account the aspects related to QOL of these children can contribute to early diagnosis, improve the course and outcome of the disease.

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РЕЗЮМЕ

Качество жизни детей с язвенным колитом

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Проведена оценка качества жизни детей с язвенным колитом. Обследовано 15 детей с ЯК (8 мальчиков и 7 девочек, средний возраст – 14.3±1.4 года). Выявлена статистически значимая отрицательная связь длительности заболевания с показателем физической активности, параметрами настроения, общения и общим показателем по опроснику PedsQL 4.0. Внекишечные проявления заболевания умеренно отрицательно коррелировали с уровнями следующих шкал КЖ: физической активностью, жизнью в школе и общим показателем по опроснику. Полученные данные позволяют заключить, что в качестве основных клинических характеристики, влияющих на КЖ детей с ЯК, следует рассматривать длительность заболевания и наличие внекишечных проявлений. Также полученные нами данные свидетельствуют о том, что субъективные оценки уровня качества жизни детей и их родителей в значительной степени совпадают. Обязательным компонентом обследования и ведения пациентов с ВЗК должен стать мониторинг уровня качества жизни детей, связанного со здоровьем, поскольку учёт аспектов, связанных с КЖ этих детей может способствовать ранней диагностике, улучшению течения и исхода заболевания.

Ключевые слова: воспалительные заболевания кишечника, язвенный колит, качество жизни, активность заболевания, внекишечные проявления, корреляционный анализ.

რეზიუმე**ცხოვრების ხარისხის დონე წყლულოვანი კოლიტის მქონე პაციენტებში**სიჭინავა ი. ვ.¹, იაბლოკოვა ე. ა.¹, ივარდავა მ. ი.²

¹ რუსეთის ფედერაციის ჯანდაცვის სამინისტროს უმაღლესი განათლების ფედერალური სახელმწიფო ავტონომიური საგანმანათლებლო დაწესებულება ი.მ. სეჩენოვის სახელობის მოსკოვის პირველი სახელმწიფო სამედიცინო უნივერსიტეტი (სეჩენოვის უნივერსიტეტი). ბავშვთა ჯანმრთელობის კლინიკური ინსტიტუტის ბავშვთა დაავადებათა კათედრა

² რუსეთის ფედერაციის ჯანდაცვის სამინისტროს ფედერალური სახელმწიფო ავტონომიური დაწესებულება „ბავშვთა ჯანმრთელობის ეროვნული სამედიცინო კვლევითი ცენტრი“

კვლევის მიზანია წყლულოვანი კოლიტის მქონე ბავშვების ცხოვრების ხარისხის დონის შესწავლა დაავადების კლინიკური ნიშნების ფონზე. პედიატრიული ცხოვრების ხარისხის დონის კითხვარით - PedsQL 4.0- წყლულოვანი კოლიტით დაავადებული ბავშვების ცხოვრების ხარისხის დონის შესწავლამ გამოავლინა დაბალი მაჩვენებელი, როგორც ბავშვებში, ასევე მათ მშობლებში. დაავადებისთვის დამახასიათებელი პერიოდული რეციდივები წყლულოვანი კოლიტის მქონე ბავშვებში უარყოფით გავლენას ახდენს მათი ცხოვრების ხარისხზე. კერძოდ, მათ ფიზიკურ აქტივობაზე და სასკოლო ცხოვრებაზე. კლინიკურ გამოვლინებებსა და ბავშვების ცხოვრების ხარისხის დონის ინდიკატორებს შორის კავშირის კვლევამ ასევე გამოავლინა სტატისტიკურად მნიშვნელოვანი ინვერსიული კორელაციების არსებობა. საკითხის შესწავლამ აჩვენა, რომ ბავშვებისა და მათი მშობლების ცხოვრების ხარისხის სუბიექტური შეფასებები დიდწილად ემთხვევა ერთმანეთს. კვლევის შედეგებით დადგინდა, რომ ნაწლავების ანთებით დაავადებული ბავშვების გამოკვლევისას, აუცილებელია პედიატრმა შეაფასოს თითოეული ბავშვის სოციალურ-ფსიქოლოგიური სტრესის ფაქტორები, გამოკითხოს მშობლები ბავშვების აკადემიური მოსწრების და გაკვეთილებზე დასწრების შესახებ. პაციენტების გამოკვლევისა და დაავადების მართვისას სავალდებულო უნდა გახდეს ბავშვების ცხოვრების ხარისხის დონის მონიტორინგი ჯანმრთელობის მდგომარეობასთან მიმართებაში, რადგან, როგორც გაირკვა, ამ კატეგორიის პაციენტებში ცხოვრების ხარისხის დონე ჯანმრთელი თანატოლების ცხოვრების დონის შესაბამის მაჩვენებლებთან შედარებით მნიშვნელოვნადაა შემცირებული.

საკვანძო სიტყვები: ნაწლავის ანთებითი დაავადებები, წყლულოვანი კოლიტი, ცხოვრების ხარისხი, დაავადების აქტივობა, ექსტრა-ნაწლავური გამოვლინებები, კორელაციის ანალიზი.