

<https://doi.org/10.33878/2073-7556-2023-22-2-40-48>



Clinical features and quality of life of patients with idiopathic megacolon

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ABSTRACT

AIM: to assess the quality of life (QoL) of patients with idiopathic megacolon and its relationship with clinical and diagnostic features.

PATIENTS AND METHODS: the retrospective study of clinical features and diagnostic tests results included 81 patients with idiopathic megacolon/megarectum (2004–2022). The diagnosis of megacolon/megarectum was confirmed with a barium enema, Hirschsprung's disease was excluded based on anorectal manometry and (if needed) rectal Swenson biopsy. The QoL was assessed by IBSQOL questionnaire; clinical symptoms were assessed with a point scale. **RESULTS:** the quality of life in patients with idiopathic megacolon has most affected energy (emotional and physical) and physical role (work/main activity). In univariate analysis the significant correlation was revealed between QoL and age, sex, rate of defecation without assistance, rate of integral parameters "abdominal discomfort" and "defecation difficulties", duration of anamnesis, Wexner constipation scale rate and gut transit time ($p < 0,05$). In the same time, the presence or absence of constipation or anal incontinence (leakage), colon and rectum sizes (based on barium enema), parameters of defecography and rectal compliance test have not correlated with a QoL. No significant difference of QoL in patients added to conservative treatment and operated. Due to multivariate analysis (multiple linear regression) the age and rate of "abdominal discomfort" and "defecation difficulties" were only independent factors affected quality of life.

CONCLUSION: in terms of quality of life, idiopathic megacolon has the greatest impact on general tone and ability to perform basic professional activities. Independent factors that statistically significantly affect the assessment of quality of life are the age of patients and the severity of symptoms of abdominal discomfort and defecation disorders.

KEYWORDS: Idiopathic megacolon, idiopathic megarectum, quality of life

CONFLICT OF INTEREST: The authors declare no conflict of interest

FOR CITATION: Aleshin D.V., Achkasov S.I., Sushkov O.I., Shakhmatov D.G., Evgeniy S. Surovegin, Fomenko O.Yu. Clinical features and quality of life of patients with idiopathic megacolon. *Koloproktologia*. 2023;22(2):40–48. (in Russ.). <https://doi.org/10.33878/2073-7556-2023-22-2-40-48>

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Received — 22.11.2022

Revised — 13.01.2023

Accepted for publication — 17.05.2023

INTRODUCTION

Idiopathic megacolon is a chronic enlargement of the large intestine for which it is not possible to identify a clear etiological factor. The prevalence of idiopathic megacolon is unknown, but it is generally considered to be a fairly rare condition. So, according to Knowles, C.H. et al. (2003), 1,600 patients suffering from chronic constipation were treated at the Royal London Hospital for 10 years. Only 20 of them had megacolon/megarectum detected during the examination [1]. At the same time, since, on the one hand, constipation and

symptoms of abdominal discomfort are the main manifestation of megacolon, and, on the other, special tests are needed for its diagnosis, it can remain unrecognized in a significant part of cases, passing under the mask of irritable bowel syndrome or slow-transit constipation, and, according to a number of authors, makes up to 10–20% of patients with refractory constipation [2]. However, this is a separate group of patients with an excellent algorithm for diagnosis and treatment, a significantly higher risk of complicated course and, accordingly, significantly wider indications for surgery [3].

Table 1. *The width of the lumen of various parts of the colon is normal*

Part of the large intestine (<i>n</i> = 160)	Lumen width (min-max, cm)	
	Achkasov, S.I., 2003 (<i>n</i> = 160)	Preston DM, Lennard-Jones JE, et al., 1985 (<i>n</i> = 50)
Caecum	4.0 — 9.0	—
Ascending colon	2.5 — 9.0	5.0 — 9.3
Transverse colon	2.5 — 8.5	4.5 — 8.3
Descending colon	1.5 — 6.0	3.7 — 7.1
Sigmoid colon	1.5 — 6.0	3.3 — 6.3
Rectum	4.5 — 8.5	2.2 — 6.5

Currently, according to the systematic review by Cuda, T. et al. 2018 [4] and our analysis of the PubMed database for the subsequent period (2018–2022), there is no data in the literature on the quality of life of patients with idiopathic megacolon. Therefore, the purpose of the study was to assess the quality of life of patients with idiopathic megacolon and its relationship with the clinical picture and the results of diagnostic tests.

PATIENTS AND METHODS

A retrospective analysis of the quality of life, clinical picture and check-up results of 81 patients with idiopathic megacolon/megarectum, observed in the Ryzhikh National Medical Research Center of Coloproctology from 2004 to 2022, was carried out.

Currently, there are no generally accepted criteria for the diagnosis of idiopathic megacolon/megarectum. This study included patients whose diagnosis was established on the basis of barium exam (irrigoscopy) if the width of one or another part of the large intestine exceeded the normal parameters determined earlier in our clinic during barium exam morphometric study [5]. These parameters are very close to the results of the second of the two currently available studies of the normal size of the large intestine, performed at the Royal London Hospital (Table 1) [6].

The idiopathic nature of megacolon/megarectum was confirmed by excluding Hirschsprung's disease according to irrigoscopy, anorectal manometry (*n* = 76) and, if necessary, a full-thickness biopsy of the rectal wall by Swenson (*n* = 7). Extra-intestinal causes of megacolon were also excluded.

The study did not include patients with stomas who had previously undergone colorectal resections in other clinics for megacolons and had applied to our Center for stoma takedown.

The IBSQOL questionnaire was used to assess the quality of life (QoL). It was developed in 1997 by a group of German researchers led by Dr. Hahn, B.A. with the support of the pharmaceutical company Glaxo Wellcome and recommended for use at the World Congress of Gastroenterologists in Rome in 1999 [7]. The IBSQOL questionnaire includes 30 questions with gradation of answers on a point scale (from 1 to 5 or from 1 to 6 points). These questions are grouped into 9 sections reflecting the impact of intestinal symptoms on various aspects of human life: 1) emotional sphere; 2) mental health; 3) sleep; 4) tone; 5) physical activity; 6) nutrition; 7) social activity; 8) main activity; 9) sexual relations.

A point assessment is made for each section and in total. Domain indicators are calculated as a percentage of the best possible total score for this section and thus range from 0 to 100:

The total score is calculated as the average of the indicators by section:

Table 2. Scale of assessment of symptoms of abdominal discomfort and defecation disorder

Symptoms of abdominal discomfort	None	Very rarely	Sometimes	Often	Most of the time	Always
Symptoms of difficult defecation	None	Very rarely (0–25% of defecations)	Sometimes (25–50% of defecations)	Often (50–75% of defecations)	Most of the time (75–100% of defecations)	Always
Duration of defecation	Less than 5 min.	5–15 min.	16–30 min.	Over 30 min.		
Points	0	1	2	3	4	5

Table 3. Scale of assessment of the safety of an independent stool and the urge to defecate

Is there an independent stool (without using laxatives, enemas, candles, manual aids):	No	Very rarely	Sometimes	Often	Most of the time	Always
Urge to defecate	No	Very rarely	Sometimes	Often	Most of the time	Always
Points	0	1	2	3	4	5

The lower the score, the worse the quality of life. When analyzing the relationship of QoL with the clinical picture, signs such as gender, age, anamnesis data (duration of disease, the history of volvulus, surgical procedures) and the following symptoms: the presence or absence of constipation, independent stool, urge to defecate, anal incontinence (leakage), defecation rate, symptoms of abdominal discomfort and difficulties with defecation, were taken into account.

In addition, clinical manifestations were assessed using a special questionnaire with a gradation of frequency-severity of symptoms, which allowed to do a quantitative analysis on a point scale. Previously, we used this questionnaire to assess the severity of clinical symptoms in patients with chronic constipation [8]. For the convenience of the analysis, some of the symptoms were conditionally grouped into two integral indicators: “abdominal discomfort” and “defecation disorder”. “Abdominal discomfort” included symptoms such as belching, nausea, vomiting, bloating, rumbling in the abdomen, heaviness in the abdomen, abdominal pain. The indicator “defecation disorder” was determined by the duration of defecation and complaints about “difficulties with defecation”, “the need for intensive straining during

defecation”, “feeling of incomplete emptying”. The value of both indicators was calculated as a simple sum of points for each of the symptoms (Table 2).

In addition to the symptoms of abdominal discomfort and defecation disorder, the duration of symptoms and the preservation of the urge to defecate, the preservation of an independent stool and the defecation rate without enemas and laxatives were evaluated on a point scale (Tables 3–5).

In addition, the questionnaire made it possible to assess the intensity of constipation on a modified Wexner scale. Its differences from the original version were minimal and consisted in the gradation of the severity of difficulties with defecation and the feeling of incomplete emptying not in 5 (0–4 points), but in 6 (0–5 points) step scale.

The analysis of the relationship of the quality of life assessment was carried out with the following signs of diagnostic tests:

- irrigoscopy ($n = 81$)
 - o the width of the large intestine
 - o the length of the sigmoid and transverse colon
 - o the multiplying of the maximal width by the length of the sigmoid colon is a conditional indicator with which we tried to more accurately

Table 4. *The scale of assessment of the defecation rate*

Defecation rate (if you do not use laxatives, enemas, candles)	3 times a week or more	Twice a week	Once a week	Less than 1 time a week	Less than 1 time a month
Points	5	4	3	2	1

Table 5. *Anamnesis duration assessment scale*

Duration of symptoms (years)	Up to 1 year	1-5	6-10	11-20	Over 20
Points	1	2	3	4	5

Table 6. *Estimation of transit time for the gastrointestinal tract in points*

Transit time (hours)	Up to 24	24-48	49-72	73-96	Over 96
Points	1	2	3	4	5

take into account the correlation of symptoms with the size of the intestine.

It should be noted that not in all patients it was possible to measure the length of the sigmoid and transverse colon and the multiplying of width by length due to the imposition of intestinal loops on irrigograms.

- Defecography ($n = 52$)
 - o residual volume (V_{RES})
 - o defecation Time (T_{DEF})

For technical reasons, the defecation time during defecography was recorded in 47 out of 52 patients who underwent this study.

- Transit time of barium suspension through entire GI tract for 5 days ($n = 52$). In the statistical analysis, the severity of transit disorders was estimated in points (Table 6). In addition, the presence or absence of distal delay, that is, predominant contrast delay in the sigmoid colon and rectum, was taken into account.
- Reservoir function of the rectum test ($n = 40$)
 - o maximum tolerated volume (MTV, ml)
 - o index of the maximum tolerated volume (IMTV) — the ratio of the maximum tolerated volume to the amount of residual rectal pressure created by it
 - o adaptation coefficient ($\Delta V/\Delta P$) is the ratio of volume increase to residual pressure increase from the sensitivity threshold to the maximum tolerated volume.

In 8 patients, when examining the reservoir function of the rectum, only the volumes of air injected into the rectal balloon corresponding to the sensitivity thresholds were recorded, without taking

into account the residual rectal pressure created by them. Therefore, the calculation of the index of the maximum tolerated volume and the coefficient of adaptation was impossible. In another 12 cases, it was not possible to calculate the adaptation coefficient due to the fact that patients were unable to differentiate the first threshold of rectal sensitivity to filling.

STATISTICAL ANALYSIS

Statistical analysis was performed using the Statistics program, version 13.3. Given the abnormal distribution, Spearman's criterion was used for correlation analysis, and differences in binary data were evaluated using the Mann-Whitney criterion. Multivariate analysis was carried out using multiple linear regression equations. The differences were recognized as statistically significant at $p < 0.05$.

RESULTS

An analysis of the assessment of the QoL by patients with idiopathic megacolon according to the domains of the IBSQOL questionnaire showed that the lowest indicators were characteristic of general tone and ability for the main professional activity (Fig. 1).

This indicates that the disease had the greatest impact on these areas of life. In the relevant sections of the questionnaire, patients often noted a

feeling of emotional and physical fatigue, agreed with the statement that the disease interferes with their ability to work successfully, forces them to avoid certain types of work, “does not allow them to do the work as they would like”.

The relationship of the total quality of life assessment (Σ_{IBSQOL}) with clinical symptoms and the results of diagnostic tests was evaluated using Spearman's correlation analysis for rank values (Table 7) and the Mann-Whitney test for qualitative (binary) features (Table 8).

As can be seen from Table 7, the final QoL score (Σ_{IBSQOL}) decreased statistically significantly with the age of patients, as well as with an increase in the integral indicators “abdominal discomfort” and “defecation disorder”. The value of Σ_{IBSQOL} also depended on the gender of patients — in men it was significantly higher than in women (Table 8). The safety of an independent stool, assessed both in points and as a binary sign (yes/no), a high defecation rate without using laxatives and enemas correlated with a significantly higher final IBSQOL rating. In addition, a significant inverse correlation of the QoL level with the duration of anamnesis, the intensity of constipation on the Wexner scale and the degree of transit disorders was revealed according to the study of the transit of barium suspension in the gastrointestinal tract (Table 8).

At the same time, neither the presence or absence of constipation or anal incontinence (leakage), nor the size of the large intestine according to irrigoscopy, as well as the results of other objective diagnostic methods, with the exception of transit time test, correlated with the overall assessment of quality of life. The quality of life also did not significantly differ in patients who got conservative treatment and those who were later operated on. At the same time, the volvulus in the history, although it was one of the main indications for surgical treatment, nevertheless, turned out to be associated with a significantly higher Σ_{IBSQOL} index (Table 8).

Factors that demonstrated a significant correlation with the assessment of QoL were included in a multivariate analysis performed using multiple linear regression. As can be seen from Table 9, only the age and severity of the indicators “abdominal discomfort” and “defecation disorder” turned out to be independent factors significantly influencing the assessment of QoL by patients. Neither gender, nor the defecation rate without laxatives and enemas, nor the intensity of constipation on the Wexner scale, as well as the degree of transit disorders, have demonstrated an independent effect on the quality of life.

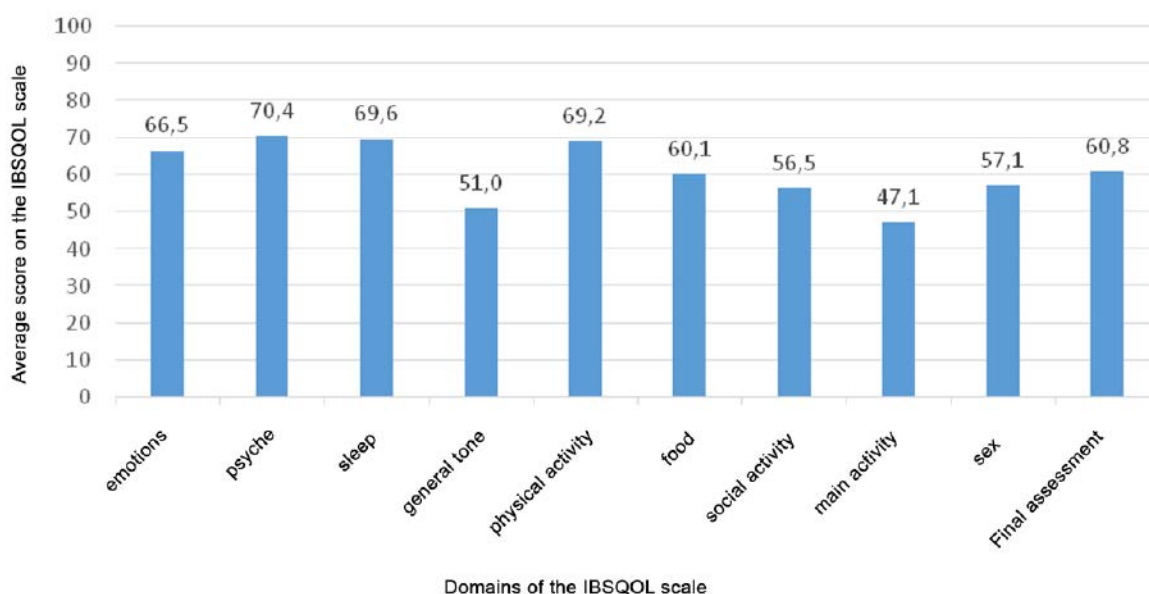


Figure 1. Health related quality of life measured with IBSQOL scales and summary index (mean rate)

Table 7. Relationship of the final QoL assessment (Σ_{IBSQoL}) with clinical signs and examination results (rank signs — Spearman correlation)

Sign		<i>n</i>	<i>R</i>	<i>p</i>
Age		81	−0.22	0.04
Independent stool (points)		80	0.46	0.000
Defecation rate		77	0.24	0.04
Urge to defecate		79	0.19	0.09
“Abdominal discomfort”		78	−0.55	0.000
“Defecation disorder”		78	−0.44	0.000
Duration of anamnesis		80	−0.26	0.02
Constipation intensity (Wexner scale)		79	−0.50	0.000
Ирригоскопия Irrigoscopy	Sigmoid colon length	44	0.09	0.56
	Transverse colon length	10	−0.24	0.51
	Width of the rectum	65	−0.18	0.16
	Width of the sigmoid colon	56	0.07	0.59
	Width × length of the sigmoid colon	36	0.06	0.71
	Width of the transverse colon	23	−0.30	0.16
Transit time through the gastrointestinal tract		52	−0.33	0.02
Defecography	T_{DEF}	47	0.07	0.64
	V_{RES}	52	0.04	0.79
Reservoir function of the rectum	MTV	40	−0.01	0.96
	I_{MTV}	32	0.08	0.66
	$\Delta V/\Delta P$	20	0.21	0.37

Note: *R* is Spearman's rank correlation coefficient

Table 8. The relationship of the final assessment of QoL (Σ_{IBSQoL}) with clinical and diagnostic signs (binary signs — Mann-Whitney test)

Sign	<i>n</i>	<i>Z</i>	<i>p</i>
Gender	81	2.01	0.04
Complaints of constipation (yes/no)	81	−1.0	0.31
Independent stool (yes/no)	81	2.17	0.03
Anal incontinence (leakage) (yes/no)	71	−0.28	0.78
History of volvulus in the anamnesis (yes/no)	81	1.97	0.049
Surgical treatment in the future (yes/no)	81	1.20	0.23
Distal delay (passage through the gastrointestinal tract)	44	0.36	0.72

Note: *Z* — confidence criterion

Table 9. Independent factors affecting $\sum_{IBSQOL}$ (multiple linear regression)

Sign	β	p
Age	-0.25	0.009
Gender	1.89	0.56
Independent stool (points)	1.45	0.74
Defecation rate	-1.79	0.22
"Abdominal discomfort"	-1.21	0.000
"Defecation disorder"	-0.99	0.008
Duration of anamnesis	0.68	0.59
History of volvulus in the anamnesis (yes/no)	3.86	0.25
Constipation intensity (Wexner scale)	0.44	0.41
Transit time through the gastrointestinal tract	-1.12	0.59

Note: $R^2_{\text{regression rate}} = 0,377-0,399$, $p < 0,000$; β — regression coefficients; $R^2_{\text{regression rate}}$ — coefficient of determination

DISCUSSION

The influence of a particular disease on the quality of life of patients is becoming an increasingly urgent problem of modern medicine. Moreover, this applies to such a basically benign condition as idiopathic megacolon. In the case of uncomplicated clinical picture, megacolon does not pose a significant threat to the health of patients and assumes, first of all, conservative treatment. At the same time, even the most successful therapy is not able to normalize the size of the intestine. Accordingly, the treatment is mainly aimed at making the life of patients with megacolon as convenient as possible. In such conditions, it is the assessment of the quality of life that is one of the determining criteria for the effectiveness of therapy. And the inability to achieve an acceptable quality of life is a reason to consider the feasibility of surgical treatment. But on the other hand, in order to predict the effectiveness of surgery, it is necessary to understand which factors have the most significant impact on the assessment of quality of life and to what extent our diagnostic methods allow us to evaluate these factors.

Currently, there are no questionnaires designed specifically to assess the quality of life of patients with idiopathic megacolon. In this paper, we used the IBSQOL questionnaire. This disease is a specific questionnaire, in the sense that it was

developed to assess the impact of irritable bowel syndrome on the quality of life. In our opinion, its use in patients with megacolon is quite justified, since the symptoms of these two conditions are very close. And since the diagnosis of irritable bowel syndrome is established based on the analysis of symptoms and is not so much a final diagnosis as a stage in understanding the patient and a guide to prescribing a certain type of treatment, patients with idiopathic megacolon often begin their journey to doctors just under the "mask" of IBS. In addition, the use of the IBSQOL questionnaire allowed us to compare the quality of life of patients with idiopathic megacolon and patients with chronic constipation not associated with large intestine enlargement. The results of this analysis will be the subject of subsequent publications. The disadvantage of using a disease-specific questionnaire, in contrast to a general questionnaire, such as, for example, SF-36, is the inability to compare the quality of life of patients with population data or with the effect on QoL of other diseases. At the same time, IBSQOL allows to assess the impact of megacolons on various areas of life and identify the most affected areas. The analysis showed that the idiopathic megacolon has the greatest impact on the overall tone and ability to perform the main professional activity. This is the difference from irritable bowel syndrome, which is characterized by a predominant influence on the emotional sphere, that is, the degree of life satisfaction due to the disease [7].

As for the relationship between quality of life and clinical symptoms, as well as the results of diagnostic tests, a statistically significant correlation of the final assessment of IBSQOL was found with the age and gender of patients, the safety of an independent stool, the magnitude of the indicators “abdominal discomfort” and “defecation disorder”, the independent defecation rate, the duration of anamnesis, the intensity of constipation according to the Wexner scale and the severity of transit violations. At the same time, neither the presence or absence of constipation or anal incontinence (leakage), nor the size of the large intestine according to irrigoscopy, as well as the results of other objective examination methods, with the exception of transit studies, correlated with the overall assessment of quality of life. The quality of life also did not significantly differ in patients who were prescribed conservative treatment and those who were later operated on. On the one hand, this is not surprising, given that the main indication for surgery in the presence of idiopathic megacolon/megarectum was a complicated course of the disease (volvulus, formation of fecal stones). On the other hand, the absence of differences indicates a minor impact of complications on the quality of life. Moreover, the quality of life of patients with a history of volvulus turned out to be even significantly better than in patients who did not face such a problem.

In multivariate analysis, only the age and severity of the indicators “abdominal discomfort” and “defecation disorder” turned out to be independent factors significantly influencing the assessment of QoL by patients.

Neither gender, nor the defecation rate without laxatives and enemas, nor the intensity of constipation on the Wexner scale, as well as the degree of transit disorders, have demonstrated an independent effect on the quality of life.

We hope to present an analysis of the relationship between the clinical manifestations of idiopathic megacolon and the results of objective methods for assessing the anatomical and functional state of the large intestine in the future. The unavoidable limitations associated with the observational and retrospective nature of this study require caution in interpreting its results. Nevertheless, there is a discouraging lack of a

significant relationship between QoL and the results of diagnostic tests. It should also be noted that, despite the statistical significance of the dependencies found in the multivariate analysis, the coefficient of determination of the obtained multiple linear regression did not exceed 0.4 (Table 9). In our opinion, this indicates the presence of factors that have a significant impact on the quality of life of patients with idiopathic megacolon, but which we were unable to identify either in the analysis of clinical symptoms or in the check-up of patients. Thus, the methods available to us for assessing the condition of patients, both clinical and instrumental, do not allow us to predict with any confidence the effect, in particular, of surgery on the quality of life. Accordingly, in the case of uncomplicated megacolon, the intention to improve the quality of life is a dubious reason for active surgical approach.

CONCLUSION

From the point of view of the quality of life, the idiopathic megacolon has the greatest impact on the overall tone and ability to perform the main professional activity. Independent factors that statistically significantly affect the assessment of quality of life are the age of patients and the severity of symptoms of abdominal discomfort and defecation disorders.

AUTHORS CONTRUBUTION

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Processing of the material: *Denis V. Aleshin*

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