

Analysis of factors affecting the quality of life of those suffering from Crohn's disease

Authors' Contribution:

A – Study Design
B – Data Collection
C – Statistical Analysis
D – Data Interpretation
E – Manuscript Preparation
F – Literature Search
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ABSTRACT:

Introduction. Crohn's disease is an inflammatory bowel disease of unknown etiology. Its chronic nature, as well as symptoms of intestinal and overall significantly impedes the daily functioning of patients. Alternately occurring periods of exacerbation and remission are the cause of reduced quality of life of patients. Understanding the factors that caused the decrease in the quality of life, it allows us to understand the behavior and the situation of the patient and the ability to cope with stress caused by the disease.

Aim of the study. The aim of the study was to analyze the factors affecting the quality of life of people with Crohn's disease.

Material and methods. The study group consisted of 50 people diagnosed with Crohn's disease. Respondents were treated at the Department of General Surgery and Colorectal Medical University of Lodz and Gastroenterological Clinic at the University Clinical Hospital No. 1 in Lodz. Quality of Life Survey was carried out by a diagnostic survey using a research tool SF-36v2 and surveys of its own design.

Results. Analysis of the results demonstrated that the quality of life of patients with Crohn's disease was reduced, especially during exacerbations. Evaluation of the quality of life of respondents in physical terms was slightly higher than in the mental aspect. Higher education subjects and the lack of need for surgical treatment significantly improves the quality of life.

Conclusions. The occurrence of chronic disease reduces the quality of life of respondents. Elderly patients are better able to adapt to the difficult situation caused by the disease. The quality of life of women and men is at a similar level and patients in remission of the disease have a better quality of life of patients during exacerbations.

KEYWORDS:

quality of life, Crohn's disease, disease activity

INTRODUCTION

Crohn's disease (CD) belongs to the group of inflammatory bowel diseases of hitherto unknown etiology. The disorder is characterized by segmental inflammatory lesions affecting the entire intestinal wall. The lesions may occur in any segment of the gastrointestinal tract. Most commonly, however, they are located within the terminal ileum (40-50%) while the lowest incidence of the disease is observed within the upper gastrointestinal tract.

Despite the fact that the etiopathogenesis of CD has not been fully elucidated, genetic, environmental, as well as immune factors are considered to be the main causes of the disorder. Crohn's disease is observed at all geographical latitudes in individuals of all racial origins. The highest increase in morbidity rates is observed in the developed countries including the US, Canada, and Western Europe [1]. The lowest morbidity rates are observed in Africa and Asia. Currently, the morbidity rate in the European Union amounts to about 5 cases per 100,000 patients each year [2]. Despite the fact that CD is a disease that affects mainly young patients (within their second and third decade of life), first symptoms may appear at any age.

Due to its chronic character, CD is a remittent-relapsing disease that impairs everyday functioning and inescapably reduces the quality of life of the patients [3]. Once diagnosed, the disease persists throughout the patient's life. Besides the treatment of the primary disease, contemporary medicine has another objective of impro-

ving the patients' quality of life. The World Health Organization (WHO) defines the quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" [4]. Negative perception of the disease being incurable favors the onset of depression and further to deterioration of the patient's clinical status. Chronic diseases are also associated with reduced motivation to keeping fit and adapting to the realities of the disease. Acceptation of the disease is tantamount to accepting the limitations and potential impairment caused by this disease. A common consequence of the hitherto incurable CD consists in depressed mood which is caused not only by the basic clinical symptoms of the disease but also to the associated emotional and psychological problems. Despite the efforts of experts, the treatment of these problems is not always successful [5-8]. Therapeutic problems may be due to the lack of appropriate knowledge on the disease as well as the lack of knowledge of the quality of life assessment tools. The consequences amount to acceptance of limitations caused by the disease, lower self-reliance feeling of dependence on others and reduced self-esteem [9]. Obtaining appropriate information on the quality of life deficits as experienced by the patients facilitates better understanding of their behavior and strategies for coping with everyday life and the stress caused by the disease.

The quality of life is associated with the acceptance of the disease and adaptation to the new situation in the patient's life which has

a significant impact on further well-being of the patient [10]. The assessment of the quality of life of patients coping with chronic diseases including the CD facilitates identification of factors having the largest impact thereon. Information on health-related quality of life facilitates taking up measures to improve the quality of patient care. The objective of the study was to analyze the factors affecting the quality of life in Crohn's disease patients.

MATERIAL AND METHODS

The study population consisted of 50 residents of Łódzkie voivodeship previously diagnosed with Crohn's disease. One half of the study group (25 patients) consisted of patients hospitalized at the Department of General and Colorectal Surgery of the Medical University of Łódź. The remaining 25 subjects consisted of subjects treated at the specialist Gastroenterology Clinic at the University Clinical Hospital No. 1 in Łódź. Participation in the study was voluntary and anonymous, and the subjects were informed accordingly. The study started in July 2016 following an approval being obtained from the Bioethics Committee of the Medical University of Łódź (decision no. RNN/177/16/KE dated 14 June 2016). The study was completed on 31 January 2017. The study was conducted in line with the guidelines of Declaration of Helsinki.

The study design consisted of patients being administered the Short Form (36) Health Survey version 2 (SF-36v2) along with a proprietary study questionnaire. Quality of life was assessed using the Polish language version of the licensed SF-36v2 form (Student License Agreement QM035225 – CT177402- OP052598).

The questionnaire allows to comprehensively capture the subjective feelings of patients while the license, standardization and professional translation ensure the reliability of results. The SF36v2 questionnaire consists of 11 questions and facilitates the assessment of the quality of life in individual domains including physical functioning (PF), role limitations due to physical problems (RP), bodily pain (BP), general health perception (GH), vitality (VT), social functioning (SF), mental health (MH), role limitations due to emotional problems (RE), and health transition (HT). The above categories are grouped into two main summaries: the physical component summary (PCS) including PF, RP, BP, and GH and the mental component summary (MCS) including VT, SF, RE, and MH [11, 12]. The quality of life is assessed in each domain using a 0 to 100 scale. The higher the score, the higher the quality of life. No reference standards are available for SF-36v2 and therefore one may not conclude whether the results of responders correspond to a high or a low quality of life. One may only compare individual domains to identify the areas of the best and the poorest quality.

Our proprietary questionnaire consisted of 22 questions regarding the duration of the disease, symptoms, complications, treatment and demographic variables.

The statistical analysis of quantitative (i.e. numerical) variables consisted of calculation of means, standard deviations, medians, quartiles as well as the minimum and maximum values.

Qualitative (i.e. non-numerical) variables were summarized by the numbers and percentages of occurrence of each particular value. Quantitative variables were compared between the two groups

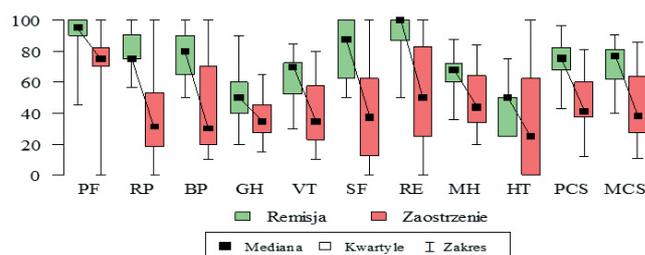


Fig. 1. Quality of life of the patients depending on the stage of the disease.

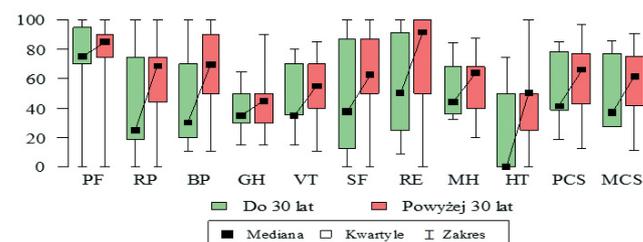


Fig. 2. The quality of life of patients, depending on age.

using the Student's t-test (when variables followed the normal distribution curve within the groups) or using the Mann-Whitney's U-test (when normal distribution could not be observed). The comparison of quantitative variables between three and more groups was made using the analysis of variance (ANOVA) (when variables followed the normal distribution curve within the groups) or using the Kruskal-Wallis test (when normal distribution could not be observed). Post-hoc analyses using Tukey's HSD test (for normal distributions) or Dunn's test (for non-normal distributions) were carried out for statistically significant differences being observed in the comparisons. Normal distribution of variables was verified using the Shapiro-Wilk's test. The significance level was defined as 0.05; all values with $p < 0.05$ were considered to be significantly correlated. The analyses were carried out using the R software version 3.3.2.

RESULTS

Responses were obtained from all patients over the entire scheduled study period. The results were subjected to statistical analyses and subsequently processed and presented as tables and figures.

The study population consisted of 25 male and 25 female patients. The mean age of the entire group was 35.72 (SD=10.78) years. The mean age of the female subpopulation was 29.92 as compared to 27.72 in the male subpopulation. The youngest responder was 20 years old while the oldest one was 69 years old. Most responders (90%) declared to be residents of urban areas. More than one half of the responders had higher educational background (56%) as compared to 36% of responders with medium educational background and 8% of responders with vocational educational background. The vast majority of the subjects (86%) were professionally active, with 6% studying, 6% receiving disability pension due to the disease and 1 person (2%) being retired. The mean duration of the disease was 5.92 (SD=4.59) years. The vast majority of subjects (94%) were aware of the negative health consequences of smok-

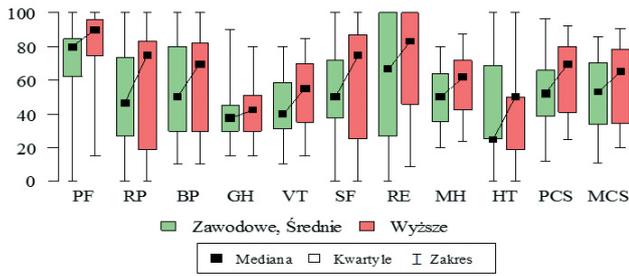


Fig. 3. The quality of life of patients, depending on education.

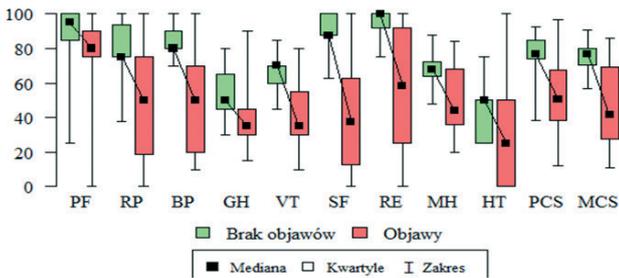


Fig. 4. Quality of life of patients, depending on the symptoms.

ing and did not smoke cigarettes or other tobacco products. Table 1 presents the clinical characteristics of the study population.

The next part of the study consisted in the statistical analysis of the quality of life of CD patients in individual domains. The best scores were provided in PE, RE, and PCS domains while the lowest scores were most prevalent in VT, GH, and HT domains. The responders scored slightly lower with regard to the mental component summary (MCS) as compared to the physical component summary (PCS). Table 2 illustrates the quality of life scores for individual domains.

Out of the entire study population, 19 patients were in remission while the remaining 31 patients were in the active phase of the disease. The statistical analysis of the data on the quality of life of patients depending on the disease phase (remission vs. exacerbation) revealed $p < 0.001$ for the PE, RP, BP, GH, VT, SF, RE, MH, PCS, and MCS domains; this means that the quality of life of patients depended on the phase of the disease. The quality of life was higher in remittent patients than in those experiencing an exacerbation (Chart 1). The HT domain was the only one in which no correlation between the disease phase and the quality of life was observed ($p = 0,12$).

The statistical analysis of data revealed no statistically significant differences between the patients' gender and the quality of life. Further analysis of data focused on verification of a potential statistically significant correlation between the age and the quality of life of patients. The comparisons of scores in the BP, SF, RE, and HT domains had p values of less than 0.05, i.e. The quality of life in those domains was age-dependent. The quality of life increased with age as evident in the group of patients above the age of 30. The results are presented in Chart 2.

Further statistical analysis focused on the relationship between the educational background and employment on the quality of life of responders. Only 4 patients in the study group had vocational

Tab. 1. Clinical characteristics of the study group.

FEATURE	N	%	
Disease form	Remission	19	38
	Mild	12	24
	Moderate	13	26
	Severe	6	12
Impact of the disease on the chosen job	Yes	23	46
	No	26	52
	Not applicable**	1	2
Job change required due to the disease	Yes	13	26
	No	36	72
	Not applicable**	1	2
The impact of the disease on the relationships with others	Very strong	1	2
	Strong	11	22
	Some	21	42
	None	17	34
Negative impact on family relationships	Very strong	0	0
	Strong	2	4
	Some	28	56
	None	20	40
	Very satisfied	6	12
	Satisfied	16	32
Satisfaction of patient's private life	Neither satisfied nor dissatisfied	20	40
	Dissatisfied	8	16
Sources of knowledge on the disease*	TV, Internet	37	74
	Physician, nurse	45	90
	Patient associations	14	28
	Books, press	22	44
Clinical symptoms	Other (studies, other patients)	3	6
	Perianal fistulae	7	14
	Internal fistulae	3	6
	Anal fissures	3	6
	Abscesses	8	16
	Intestinal stenosis	17	34
	Anemia	13	26
	Skin lesions	15	30
	Arthritis	14	28
	Iritis	0	0
Surgical procedures due to the disease	None of the above	13	26
	None	22	44
	Once	18	36
	Twice	7	14
Types of earlier surgical procedures*	3 times	3	6
	Small intestinal resection	8	16
	Large intestinal resection	12	24
	Abscess	8	16
	Inflammatory abdominal tumor	0	0
	Fistulae	7	14
	Other (sigmoidoceleal resection, intestinal stenosis plasty)	2	4

* The percentages do not add up to 100 due to the multiple answers being allowed.
 ** The patient never worked

educational background and were this group was combined with that consisting of patients with medium educational background. A $p < 0.05$ value was observed in the PF domain which means that physical functioning depended on the educational background of patients. Patients with higher education were shown to present with better quality of life scores than patients with vocational or medium education (Chart 3). Three individuals within the study population were students, another 3 received disability pensions while another 1 subject was retired. All these subjects were combined in a group of “non-working” subjects. All the p scores exceeded 0.05 for all domains of the SF36v2 survey demonstrating that the quality of life of the patients did not depend on their occupational activity (Table 3).

Further study focused on the analysis of the quality of life depending on the experienced clinical symptoms (including non-gastrointestinal symptoms). Comparisons of PF, RP, BP, GH, VT, SF, RE, MH, PCS, and MCS showed $p < 0.05$ for all types of symptoms experienced by the subjects. Patients experiencing no additional, non-gastrointestinal symptoms reported higher quality of life scores. Only within the HT domain the clinical symptoms had no impact on the quality of life of the responders ($p = 0.171$). The results of the study are presented in Chart 4.

Patients were divided into three groups according to their responses to one of the questions in the proprietary questionnaire pertaining to the history of surgical treatment for CD. The first group consisted of surgical treatment-naïve patients. The second group consisted of subjects with the history of one surgical procedure whereas the third group consisted of subjects who had undergone two or more surgical procedures due to their primary disease. The statistical analysis revealed $p < 0.05$ for the PF, RP, BP, GH, VT, SF, RE, MH, PCS, and MCS domains; this means that the quality of life of patients depended on the history of surgical treatment. Post-hoc analysis was performed to examine the observed correlation in more detail. It showed that in every of the aforementioned domains, patients naïve to surgical treatment reported higher quality of life scores compared to patients who had undergone surgeries. The results of the analysis are presented in Chart 5.

DISCUSSION

As a chronic disease, CD has a significant and multifactorial impact on every domain of human life. It forces patients to change their lifestyles while simultaneously causing trouble in performing their daily duties and social roles. The problem is all the more important that the disease largely affects young individuals who just start their professional careers and establish their families. The chronic character of CD together with clinical symptoms occurring in a recurrent, severe and oftentimes unpredictable fashion gastrointestinal tract as well as in other organs significantly reduces the quality of life of individuals affected by the disease. Ability to maintain self-reliance in everyday activities, improvement in one's well-being, and pursuit to improve one's abilities and the quality of life should constitute a measure the efficacy and control provided by therapeutic and rehabilitation approach [13,14].

As demonstrated in our studies, patients with remittent disease reported better quality of life than patients experiencing exacerbations of the disease. This result was consistent with observations

Tab. II. Quality of life domains

DOMAIN	MEAN	SD	MEDIAN	MIN	MAX	Q1	Q3
PF	77,4	24,91	82,5	0	100	75	95
RP	54,25	30,94	56,25	0	100	20,31	75
BP	56,8	29,45	55	10	100	30	80
GH	41,2	17,72	40	15	90	30	50
VT	48,5	22,11	50	10	85	35	70
SF	54,75	33,3	50	0	100	28,12	87,5
RE	67,33	33,11	75	0	100	33,33	100
MH	54,4	19,12	56	20	88	36	68
HT	39	29,95	37,5	0	100	25	50
PCS	58,58	21,1	63,08	12,31	96,92	38,85	78,08
MCS	55,02	23,21	56,92	10,77	90,77	34,23	76,54

Q1, Q3 – quartiles

made in other studies by other authors. In a study conducted in several hospitals in Spain, Casellas et al. observed a deterioration in the quality of life of patients with active (i.e. Exacerbated) disease as compared to patients in remission [15]. A Polish study by Andrzejewska et al. [16] examined the quality of life of patients with Crohn's disease. In a group of 92 responders with inflammatory bowel disease, 41 patients were diagnosed with CS. The results were indicative of the quality of life being worse in disease exacerbation as compared to remission [16]. As a chronic disease, CD often leads not only to physical, but also to psychosocial disabilities. As shown by the results of our study, the responders scored slightly lower with regard to the mental component summary (MCS) as compared to the physical component summary (PCS). In 2008, a Swedish research group conducted a study to demonstrate that most frequent complains reported by CD patients pertained to limitations due to lack of vitality and intensity of disease symptoms, particularly pain [17]. In another study carried out to assess the quality of life of patients with inflammatory bowel diseases Henrich and Herschbach demonstrated that this population of patients is characterized by lack of satisfaction in individual domains of life (relaxation, rest, energy level, physical condition) that increased with the increased activity of the disease [18].

Despite the fact that CD may occur in patients of any age, two peak incidence age ranges are observed, the first between the age of 15 and 35 and the second after the age of 60 [19,20]. In our own study, a larger part of responders was relatively young (mean age 35.72 for the entire population) and had a higher educational background (56%). The analysis of the impact of age on the quality of life of patients showed that the quality of life increased with patients' age. This correlation may be due to the financial as well as professional status of patients becoming more stable as they grow older. Individuals after the age of 30 commonly had their life partners and children who were able to provide provided unmeasurable support in their disease. Similarly, Bączyk et al, demonstrated that individuals above the age of 30 and with higher educational background reported higher quality of life scores with regard to intestinal symptoms as well as the systemic and emotional functioning [21]. However, the cited study revealed no statistically significant correlation between the area of residence or the gender and the quality of patient's life. The results of our own study confirm these observations.

Tab. III. Quality of life of patients, depending on the activity

DOMAIN	PROFESSIONAL ACTIVITY	N	MEAN	SD	MEDIAN	MIN	MAX	Q1	Q3	P*
PF	Working patients	43	77,56	26,15	85	0	100	75	95	0,398
	Non-working patients	7	76,43	16,76	80	45	95	70	87,5	
RP	Working patients	43	55,81	32,17	68,75	0	100	21,88	81,25	0,325
	Non-working patients	7	44,64	21,17	50	18,75	75	28,12	56,25	
BP	Working patients	43	58,84	29,94	70	10	100	30	80	0,231
	Non-working patients	7	44,29	24,4	50	20	90	25	50	
GH	Working patients	43	42,21	16,84	40	15	90	30	50	0,215
	Non-working patients	7	35	22,91	35	15	80	17,5	40	
VT	Working patients	43	50,47	22,41	55	10	85	35	70	0,101
	Non-working patients	7	36,43	16,76	35	15	70	30	37,5	
SF	Working patients	43	57,56	33,65	62,5	0	100	37,5	87,5	0,128
	Non-working patients	7	37,5	27	37,5	0	87,5	25	43,75	
RE	Working patients	43	70,93	32,5	83,33	0	100	41,67	100	0,067
	Non-working patients	7	45,24	29,99	50	8,33	100	25	54,17	
MH	Working patients	43	55,91	19,33	60	20	88	38	70	0,207
	Non-working patients	7	45,14	15,95	40	36	80	36	44	
HT	Working patients	43	40,12	29,95	50	0	100	25	50	0,498
	Non-working patients	7	32,14	31,34	25	0	75	12,5	50	
PCS	Working patients	43	59,64	21,83	64,62	12,31	96,92	38,46	78,46	0,585
	Non-working patients	7	52,09	15,52	50,77	40	84,62	41,54	53,08	
MCS	Working patients	43	57,21	23,35	61,54	10,77	90,77	36,92	76,92	0,158
	Non-working patients	7	41,54	18,38	36,92	27,69	81,54	31,54	40,77	

*Mann-Whitney's test

Crohn's disease has a significant impact on all domains of patients' lives. It puts limitations to their emotional, social and professional functioning which in consequence leads to low self-esteem and lack of life satisfaction. In Poland, the available statistical data on the occupational activity of patients with inflammatory bowel diseases are not abundant. However, we know that 35% of male patients with ulcerative colitis and 42% patients affected by the same disease end their professional career before the statutory retirement age [22]. A Canadian study showed that a significant percentage (16.5%) of female CD patients who had been professionally active at the moment of diagnosis were unemployed or received a pension due to being incapable of working. The results of our studies do not match those by other authors. The analysis of our results shows that the professional activity of responders had no impact on their quality of life.

We were also able to demonstrate that the occurrence of intestinal problems and troublesome non-gastrointestinal symptoms is an important factor responsible for significant deterioration of the quality of life.

Similar results were published by Cassellas et al., who observed a significant impact of pain and discomfort on the quality of life of the responders [15]. A significant percentage of patients (65.9%) experiencing disease exacerbation reported pain and discomfort. Bernklev et al. also demonstrated that the incidence of gastrointestinal problems had a significant impact on the quality of life of the patients. The more often the patients reported gastrointestinal problems, the lower were their quality of life scores.

As demonstrated in our study, the type of treatment also has a significant impact on the quality of life of CD patients. The quality

of life scores reported by the group of responders undergoing conservative treatment were better than those reported by patients undergoing surgical treatment. Bączyk et al. also demonstrated low overall quality of life scores reported by patients with inflammatory bowel diseases undergoing treatment in surgical departments [21].

As shown by our study, the quality of life is affected by a number of factors including the phase of the disease, age, presence of clinical symptoms and the treatment regimen. Further studies are required to assess the impact of other aspects such as disease duration, pharmacological treatment regimens and adverse effects associated with these regimens.

CONCLUSIONS

1. The main factor reducing the quality of life of patients with Crohn's disease consists of chronic gastrointestinal and non-gastrointestinal complaints. A negative impact of the above was observed mainly in relation to the mental component summary.
2. Patients in remission reported significantly better quality of life scores compared to patients with active disease.
3. The lowest quality of life scores were observed in patients below the age of 30 and with medium or vocational educational background.
4. No correlation between gender and the reported health-related quality of life could be observed.

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