The impact of socio-demographic and clinical factors on the quality of life and disease acceptance in patients with Crohn's disease

Anna Gawor1ABCDEF, Daria Lelek2ABCDEF, Lucyna Ścisło1DEF, Joanna Chrobak-Bień1DEF

1Institute of Nursing and Midwifery, Faculty of Health Sciences, Jagiellonian University – Collegium Medicum, Krakow, Poland, Head: prof. Tomasz Brzostek MD PhD
2Jagiellonian University – Collegium Medicum, Krakow, Poland
3Department of Nursing and Midwifery, Department of Conservative Nursing, Faculty of Health Sciences, Medical University of Lodz, Poland, Head: prof. Maria Kózka MD PhD

ABSTRACT:

Introduction: Crohn's disease (CD) is a chronic inflammatory disorder of the gastrointestinal tract characterized by periods of remission and exacerbations of varying severity. The symptoms include: abdominal pain, diarrhea, flatulence, nausea, loss of appetite, weight loss, weakness, and changes in body temperature. Treatment is based on a combination of nutritional treatment and pharmacotherapy. Sometimes surgery can be necessary. The quality of life and disease acceptance are essential elements of the functioning of people with CD.

Aim: The aim of the study is to analyze the factors affecting the quality of life and the level of disease acceptance in patients suffering from Crohn's disease.

Material and methods: The study was conducted in a group of 46 patients diagnosed with Crohn's disease. The study was carried out using the proprietary questionnaire, AIS, and WHOQOL-BREF.

Results: The study group was dominated by young people. The average age of respondents was 34.28. The quality of life and the level of CD patients' disease acceptance were at an average level. The average score obtained by respondents in the Acceptance of Illness Scale (AIS) was 28.37. The study revealed a significant impact of disease acceptance level on the respondents' assessment of quality of life.

Conclusions: Patients' quality of life and level of disease acceptance are influenced by demographic factors and the clinical course of disease. Older patients after several surgeries for CD should receive more intensive psychological care. Health education of patients with CD regarding disease, self-care, and skillful support are key in increasing the assessment of quality of life and the level of disease acceptance. Further research is required in a larger group of patients with CD subject to surgical treatment.

CONCLUSION: Crohn's disease, disease acceptance, quality of life

ABBREVIATIONS

AIS – Acceptance of Illness Scale
CD – Crohn's disease
WHO – World Health Organization

INTRODUCTION

Crohn's disease (CD) is a chronic inflammatory disorder of the gastrointestinal tract. Full-thickness and most often granulomatous inflammation can develop anywhere in the digestive tract. The most common locations are the terminal ileum, the ileocecal valve, and the cecum. The initial inflammatory process covers the mucosa and spreads to the remaining layers of the gastrointestinal wall. This leads to intestinal fibrosis and destruction; it is also possible to develop strictures and fistulas [1, 2]. The peak incidence falls between 15 and 35 years of age, but disease symptoms may appear at any age. There were no differences in incidence between women and men [3]. The current incidence of CD in Western Europe and North America is estimated at 5–10 cases per 100,000 per year [4]. According to the data reported by the National Crohn's Disease Registry, 6,324 patients were registered in Poland in 2019 [5]. However, a family history of Crohn's disease was proven [6]. The etiology of CD has not been fully understood yet. Genetic, environmental, immunological factors, and the bacterial flora of the gastrointestinal tract are argued to be significant factors in the pathogenesis and development of disease [4, 7]. The genetic predisposition to CD can be determined before the onset of symptoms. Detection of mutations within specific genes may be the basis for assuming the possibility of disease [8]. The course of disease varies and depends on individual cases. About 40% of patients experience a gradual reduction in the severity of symptoms after initial exacerbation. One third of patients experience a wave-like course of disease characterized by consecutive periods of exacerbation and remission. One fifth of patients has consistently more or less severe symptoms. The least common form of disease is initially characterized by low activity followed by a rapid increase in disease symptoms [8]. CD can cover the entire gastrointestinal tract, but in 90% of cases it is limited to three areas: only the small intestine, only the large intestine, or in a mixed form simultaneously the small and large intestine. Inflamed sections of the intestine alternate with sections which are unaffected. Patients often have local complications in the form of abscesses, fistulas or strictures [6]. Some patients develop fistulas: usually perianal, less often enterocutaneous [2]. The perianal form of disease significantly reduces the quality of life, sometimes to a much greater extent than in other clinical groups. Numerous scientific studies have confirmed an increased risk of colorectal cancer among people suffering from inflammatory bowel diseases, including CD. The risk of disease
Acceptance of illness and adaptation are among the key concepts used in medical psychology. Both adaptation and acceptance of the disease have a significant impact on patients’ quality of life. The term “acceptance” is tantamount to consenting to something, as well as adopting an opinion, view, judgment, attitude or behavior [12]. Adaptation means adjusting to the role of a diseased person, the ability to cope with the disease with all its consequences, especially negative ones, as well as the effects which the disease has on the patient’s life. Acceptance allows for adapting to a new situation of disease and living with it [13]. Numerous scientific studies demonstrate that the fact that patients accept the disease reduces negative emotional reactions, which in turn improves their physical and mental comfort and increases the quality of life [14]. The aim of the study is to analyze the factors affecting the quality of life and the level of disease acceptance in patients suffering from CD.

MATERIAL AND METHODS

The study was conducted at the Department of General Surgery, Oncology, Gastroenterology and Transplantology at the University Hospital in Krakow between July 2019 and March 2020, and included 46 patients. The basic conditions for participation were: diagnosed Crohn’s disease and the patient’s free and informed consent to participate in the research study. The study was carried out in accordance with Declaration of Helsinki. Data were collected by means of the survey method. The questionnaires used were: the author’s questionnaire, the Acceptance of Illness Scale (AIS) and the WHOQOL-BREF quality of life assessment. The author’s questionnaire contained socio-demographic data (sex, age, place of residence, professional activity) and clinical data (duration of disease, treatment method, additional symptoms). Acceptance was measured using the Acceptance of Illness Scale (AIS) in the adaptation of Zygfryd Juczyński, which measures the degree of disease acceptance and can be used for any disease. The scale contains eight statements that describe the disease consequences in a negative manner and concern: limitations resulting from the disease, reduced self-esteem, lack of self-sufficiency, the inability to pursue one’s own interests, and a sense of dependence on other people. Each question contains a 5-point scale, where 1 means complete consent, and 5 means complete disagreement with the given statement. The sum of possible points ranges from 8–40. The scale has no standards. However, the most common assumption is that a result below 20 means no or poor acceptance, 20–30 means a medium degree of acceptance, while a score above 30 means a high level of disease acceptance [12]. The WHOQOL-BREF questionnaire developed by the World Health Organization (WHO) was used to assess the respondents’ quality of life. It is an abbreviated version of the WHOQOL 100 scale. Patient quality of life is assessed by means of 26 questions concerning four aspects: physical, mental, social, and environmental. The questionnaire does not have a scale for interpreting the results. The higher the score in a given domain, the better the quality of life [13]. In order to better visualize the results, raw results are summarized and transformed into a 4–20-point scale. An additional statistical method was used to analyze the collected data. Statistical analysis was prepared using the SPSS Statistics software and the Microsoft Office package. The numerical and/or percentage values of individual response variants are presented as tables or bar graphs. Quantitative variables are presented in the table containing measures of central tendency and dispersion. For the purpose of statistical analyses, the significance level was set at 0.05 (p = 0.05). The significance of relationships between nominal variables was checked using the chi-square test of independence by means of the following formula, where Oi – observed value; Ei – expected value:

\[ \chi^2 = \sum_{i=1}^{n} \frac{(O_i - E_i)^2}{E_i} \]

The expected value was calculated using the following formula:

\[ E_{expected} = \frac{(row\ sum)(column\ sum)}{(total\ sum)} \]

Independent sample t test was used for quantitative variables to determine the difference between two independent means. On the other hand, the significance level of differences between more than two quantitative unconnected variables was checked using one-way analysis of variance. The results were subjected to statistical analysis, processed, and presented in tables.

RESULTS

The study included 46 participants aged between 19 and 52. The average age was 34.28, with a median 32.5, and the standard deviation 8.74. Most respondents were men (52.2%), while the percentage of women was slightly lower (47.8%).

The mean duration of Crohn’s disease in the studied group of 46 patients was 9 years, with a standard deviation of 5.04, and a mean value of 8.5. The minimum value was 2 years and the maximum was 20. A significant number of respondents stated that they had family members suffering from CD (17.4%). The most common initial symptoms were: abdominal pain (82.6%), loss of appetite (78.3%), rapid weight loss (54.3%), and abdominal distension (43.5%). Currently, the vast majority of respondents reported that they experienced abdominal pain (90.9%), while relatively numerous groups complained of abdominal distension (38.6%), fevers (31.8%), and loss of appetite (27.3%). A significant number of respondents stated that they had comorbidities (23.9%) such as: hypertension, diabetes, hyperthyroidism, hypothyroidism, and discopathy. People who reported comorbidities were over 30 years of age. The respondents reported that during the study they used:
Respondents who had been ill for more than 10 years were operated for CD much more often than the remaining respondents. For the majority of respondents, the purpose of the current visit to the surgical ward was resection of the inflamed intestine (58.7%), while the remaining respondents mentioned other reasons for hospitalization, such as: removal of an abscess (21.7%), removal of a fistula (8.7%), strictureplasty (6.5%), and restoration of gastrointestinal continuity (4.3%).

The study showed that the average score obtained by the respondents in AIS was 28.37 ± 6.16. Therefore, it can be concluded that the level of disease acceptance among the studied group was average. The average assessment of the quality of life (on a scale from 1 to 5) based on WHOQOL-BREF was 3.07 ± 0.71, while the respondents’ average level of satisfaction with one’s health was 2.20 ± 0.69. Further analysis of the data obtained for the age criterion revealed statistically significant differences in the following scales: AIS disease acceptance level \( [t (44) = 3.750; \ p < 0.01] \), quality of life assessment \( [t (44) = 2.322; \ p < 0.05] \), somatic domain \( [t (44) = 2.250; \ p < 0.05] \), psychological domain \( [t (44) = 2.115; \ p < 0.05] \), social domain \( [t (44) = 2.331; \ p < 0.05] \). It has been shown that respondents up to 35 years of age have a higher quality of life and accept their illness to a higher extent than respondents over 35. Moreover, they better assess their functioning in the somatic, psychological, and social domains.

The analysis of data using Student’s t-test for independent samples showed significant differences in the mean results obtained in the following scales, depending on marital status: disease acceptance level \( [t (44) = -3.472; \ p < 0.01] \), quality of life assessment \( [t (44) = -3.586; \ p < 0.01] \), level of satisfaction with one’s health \( [t (44) = -2.607; \ p < 0.05] \), somatic domain \( [t (44) = -3.142; \ p < 0.01] \), psychological domain \( [t (44) = -2.380; \ p < 0.05] \), social domain \( [t (44) = -3.621; \ p < 0.01] \). Married respondents assessed their quality of life, degree of disease acceptance and level of satisfaction with their health worse than single respondents or those living in informal relationships. Moreover, married persons are characterized by worse functioning in somatic, psychological, and social life.

Depending on the level of education, there was a significant difference in the mean results obtained in the assessment of quality of life in the environmental domain scale \( [t (44) = -2.060; \ p = 0.045] \). The respondents with higher education obtained a much higher result.

The further part of detailed data analysis revealed no significant differences in the mean results obtained in the analyzed AIS and WHOQOL-BREF scales in relation to the professional activity of respondents. The subsequent portion of the statistical analysis used Student’s t-test for independent samples. Statistical analysis did not reveal any statistically significant differences in the mean scores recorded in the analyzed AIS and WHOQOL-BREF scales, depending on the financial situation of respondents. There were no statistically significant differences in the mean scores obtained in the analyzed AIS and WHOQOL-BREF scales, depending on the place of residence.

Analysis by means of Student’s t-test for independent samples showed a significant difference in the mean results obtained in all
The respondents suffering from comorbidities obtained significantly lower results on the scales mentioned above than the other respondents.

One-way analysis of variance showed significant differences in mean results depending on the number of hospitalizations of respondents for the following scales: disease acceptance level \[F (2; 43) = 3.618; p < 0.05\], quality of life assessment \[F (2; 43) = 6.115; p < 0.01\], somatic domain \[F (2; 43) = 7.353; p < 0.01\], psychological domain \[F (2; 43) = 3.996; p < 0.05\], social domain \[F (2; 43) = 5.854; p < 0.01\]. The highest results in the above scales were recorded in patients hospitalized 1–2 times, while the lowest among respondents hospitalized over 4 times.

The study revealed significant differences in mean scores depending on the need for surgery for CD for the following scales: disease acceptance level \[t (44) = -2.484; p < 0.05\], quality of life assessment \[t (44) = -2.745; p < 0.01\], somatic domain \[t (44) = -3.857; p < 0.001\], psychological domain \[t (44) = -3.066; p < 0.01\], Social Domain \[t (44) = -4.167; p < 0.001\]. The respondents who were operated on due to CD obtained significantly lower results in all the above scales than the other respondents. Correlation analysis showed significant positive relationships between the level of disease acceptance and assessment of the quality of life \((r = 0.810; p < 0.001)\), the level of satisfaction with one’s health \((r = 0.581; p < 0.001)\), as well as the quality of life in the somatic \((r = 0.857; p < 0.001)\), psychological \((r = 0.819; p < 0.001)\), social \((r = 0.645; p < 0.001)\), and environmental domains \((r = 0.736; p < 0.001)\). With the increase in the level of disease acceptance, the respondents’ quality of life, as well as their level of satisfaction with their health, improved.

**DISCUSSION**

Assessment of the quality of life and acceptance of disease by patients are essential elements affecting overall therapy. This is especially important in chronic diseases, when patients struggle with the disease and its consequences for many years. The level of adaptation to the disease affects the patients’ perception of quality of life. Assessment of the quality of life is a subjective evaluation of each patient and depends on a number of factors, e.g., demographic status, character traits, personality or the value system of a given person.

The study was conducted in a group of 46 patients aged 19–52 during hospitalization for surgical treatment. The level of disease acceptance and the level of quality of life among the patients included in the study were at an average level. On the other hand, the level of the respondents’ satisfaction with their health was unsatisfactory. Moreover, it was shown that the level of disease acceptance is affected by: age, marital status, duration of disease, comorbidities, number of previous hospitalizations, previous surgical procedures, well-being, and negative emotions among the respondents. The level of satisfaction with one’s health status depended on: gender, marital status, duration of disease, well-being, and negative emotions. Assessment of the quality of life was affected by: gender, age, marital status, disease duration, comorbidities, number of hospitalizations, previous surgical procedures, well-being, and negative emotions. Analysis of respondents’ quality of life for individual WHOQOL-BREF domains revealed that each domain (somatic, psychological, social, environmental) is influenced by: disease duration, well-being, and negative emotions. Moreover, the somatic, psychological and social

| Tab. III. The level of disease acceptance, assessment of the quality of life, level of satisfaction with one's health and assessment of the quality of life in individual domains depending on marital status (N = 46). |
|---|---|---|---|---|---|---|---|
| **MARITAL STATUS** | **MARRIED** | **NOT MARRIED** | **STUDENT T TEST** |
| **M** | **SD** | **M** | **SD** | **t** | **p** |
| Level of disease acceptance | 26.50 | 5.48 | 32.64 | 5.62 | -3.472 | < .001 |
| Assessment of quality of life | 2.84 | 6.3 | 3.57 | 6.5 | -3.586 | < .001 |
| Level of satisfaction with one’s health | 2.03 | 5.9 | 2.57 | 7.6 | -2.607 | < .012 |
| Somatic domain | 11.63 | 2.37 | 14.14 | 2.80 | -3.142 | < .003 |
| Psychological domain | 13.97 | 2.04 | 15.57 | 2.24 | -2.380 | < .022 |
| Social domain | 15.38 | 2.50 | 18.36 | 2.73 | -3.621 | < .001 |
| Environmental domain | 15.28 | 1.82 | 16.50 | 2.24 | -1.947 | < .058 |

Source: prepared by the authors

| Tab. IV. The level of disease acceptance, assessment of the quality of life, level of satisfaction with one’s health and assessment of the quality of life in individual domains depending on education (N = 46). |
|---|---|---|---|---|---|---|---|
| **EDUCATION** | **VOCATIONAL/ SECONDARY** | **TERTIARY** | **STUDENT T TEST** |
| **M** | **SD** | **M** | **SD** | **t** | **p** |
| Level of disease acceptance | 27.36 | 6.27 | 29.94 | 5.82 | -1.405 | < .167 |
| Assessment of quality of life | 2.93 | 7.2 | 3.28 | 6.7 | -1.655 | < .105 |
| Level of satisfaction with one’s health | 2.21 | 6.3 | 2.17 | 7.9 | -2.27 | < .021 |
| Somatic domain | 12.07 | 2.94 | 12.89 | 2.37 | -0.989 | < .328 |
| Psychological domain | 14.29 | 2.51 | 14.72 | 1.67 | -1.650 | < .519 |
| Social domain | 16.36 | 2.67 | 16.17 | 3.29 | -2.17 | < .030 |
| Environmental domain | 15.18 | 1.91 | 16.39 | 2.00 | -2.060 | < .045 |

Source: prepared by the authors

the analyzed scales, depending on the duration of Crohn’s disease: disease acceptance level \([t (44) = 3.877; p < 0.001]\), quality of life assessment \([t (44) = 4.024; p < 0.001]\), level of satisfaction with one’s health \([t (44) = 2.503; p < 0.05]\), somatic domain \([t (44) = 4.294; p < 0.001]\), psychological domain \([t (44) = 3.142; p < 0.01]\), social domain \([t (44) = 2.548; p < 0.05]\), environmental domain \([t (44) = 3.174; p < 0.05]\). The respondents who had been ill for a maximum of 10 years obtained significantly higher results on all scales than those who had been ill for over 10 years.

The further part of analysis revealed a significant difference in the results obtained in the following scales, depending on the presence of comorbidities: disease acceptance level \([t (44) = 2.769; p < 0.01]\), quality of life assessment \([t (44) = -2.410; p < 0.05]\), somatic domain \([t (44) = -3.239; p < 0.01]\), psychological domain \([t (44) = -3.075; p < 0.01]\). The respondents suffering from comorbidities obtained
domains are separately influenced by: age, marital status, number of previous hospitalizations, and previous surgical procedures. The somatic and psychological domains were influenced by comorbidities, while separately the environmental domain was shown to be affected by the respondents’ education level. There was no evidence of the influence of professional activity, financial situation and place of residence on the quality of life. Moreover, it has been shown that the level of satisfaction with one’s health and the quality of life increases with the increase in the level of disease acceptance. The issue of the quality of life among patients suffering from CD is often overlooked, both by the patient’s environment and the medical staff caring for him, which is mentioned by the study by Bążk et al. on the assessment of the quality of life in patients with CD. The main reasons are the lack of sufficient knowledge about the tools used to assess quality of life, as well as gaps in theoretical knowledge about the disease itself. A comprehensive assessment of the quality of life should take into account various aspects of the patient’s life, especially those related to his functioning on the physical, mental and social level, as well as related to the well-being and severity of disease symptoms [15]. The respondents’ average quality of life was moderate, so it can be concluded that the conducted study and the study by Bążk et al. provided similar conclusions.

Similar results to those from the author’s study were obtained by Bączyk et al. on the basis of a study from 2007. At that time, the study included 30 patients suffering from IBD, among whom 18 had been diagnosed with CD. The respondents were of a similar age to those participating in the authors’ study. Quality of life assessment was also performed using the WHOQOL-BREF questionnaire. In the research carried out by Bączyk et al. [16] the respondents’ average quality of life, average level of satisfaction with one’s health status, as well as the means obtained after summarizing the score for functioning in the physical, mental, social and environmental domains were similar to the results obtained in the authors’ study. Chrobak-Bień et al. conducted a study in a group of 50 patients whose mean age was close to that of the respondents obtained in this study, in which AIS was used as a research tool. The results obtained for both studies were almost at the same level and indicated an average degree of disease acceptance. The same results regarding the influence of selected features on the level of patients’ disease acceptance were obtained for: gender, education level, and professional activity. The above-mentioned features have no effect on the degree of assessment by patients in AIS. Different results were noted in terms of age. The study conducted by Chrobak-Bień et al. demonstrated that age did not affect the assessment of disease acceptance, while analysis of the results of this study provided grounds to conclude that the younger the patient’s age, the better his acceptance of the disease. Similar conclusions were shown in surgical treatment in both studies. On the basis of the conducted study, Chrobak-Bień et al. analyzed the impact of disease acceptance on the patients’ quality of life. In addition to the author’s questionnaire and the AIS scale, they used the SF-36 questionnaire. The conclusions were the same as in the case of this study. The higher the degree of disease acceptance, the higher the respondents’ quality of life [17].
REFERENCES


