

REVIEWS

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Quality of Life in Inflammatory Bowel Disease

Jakość życia w nieswoistych zapaleniach jelit

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Abstract

Inflammatory bowel disease (IBD) is a chronic condition of unknown etiopathogenesis requiring continuous pharmacological treatment. Additionally, hospitalization and surgical intervention in the course of disease are often needed. Health-related quality of life in IBD is evaluated by general and IBD-specific questionnaires. Studies have shown significant correlation of the quality of life of patients with IBD with disease activity and significantly decreased quality of life during flares. Quality of life has become an important factor in evaluating the effectiveness of new therapeutic strategies in IBD (Adv Clin Exp Med 2009, 18, 1, 79–83).

Key words: quality of life, IBDQ, inflammatory bowel disease, Crohn's disease, ulcerative colitis.

Streszczenie

Nieswoiste zapalenia jelit (*Inflammatory Bowel Disease* – IBD) to przewlekłe choroby przebiegające z okresami zaostrzeń i remisji, wymagające stałego leczenia farmakologicznego, a często również hospitalizacji i interwencji chirurgicznych. Jakość życia związana ze zdrowiem u pacjentów z IBD jest badana za pomocą kwestionariuszy ogólnych oraz swoistych, opracowanych specjalnie dla tych chorych. Badania jednoznacznie wskazują na związek jakości życia z aktywnością choroby i istotne obniżenie jakości życia w okresie zaostrzeń. Ocena jakości życia związanej ze zdrowiem stała się istotnym elementem w badaniu skuteczności nowych strategii terapeutycznych w IBD (Adv Clin Exp Med 2009, 18, 1, 79–83).

Słowa kluczowe: jakość życia, IBDQ, nieswoiste zapalenia jelit, choroba Leśniowskiego-Crohna, wrzodziejące zapalenie jelita grubego.

Inflammatory bowel disease (IBD) is a group of chronic gastrointestinal diseases of unexplained etiopathogenesis and includes ulcerative colitis (UC), Crohn's disease (CD), and indeterminate colitis. Epidemiological studies in Western countries have shown a stable rate of incidence of UC and increased incidence of CD. IBD is also more often diagnosed recently in countries in which it was very rare. It is estimated that the average incidence of UC in Europe amounts to 10/100,000 inhabitants and of CD 5/100,000 inhabitants. The peak of incidence is observed between 15 and 25 years of age [1, 2]. IBD is thus most often diagnosed among young people, who are usually professionally active or studying and who are often planning to have children.

The course of inflammatory bowel disease is chronic, with typical flares and remissions. The typical manifestation of the flare includes diarrhea

with blood, fever, abdominal pain, malnutrition, and anemia and its symptoms. Active disease requires intensive pharmacological treatment, nutritional support, and often hospitalization and surgical interventions [3]. Moreover, patients with inactive disease are still often not fully symptom free and require chronic maintenance therapy or therapy protecting against future complications, such as osteoporosis or colorectal cancer. Additionally, it is important that a significant percentage of IBD patients develop extra-intestinal manifestations involving other organs and systems, i.e. joints, bones, skin, eyes, liver, and the biliary tract, which also influence quality of life. Furthermore, IBD patients run a higher risk of colorectal cancer.

Clinical symptoms, laboratory markers (e.g. erythrocyte sedimentation rate, C-reactive protein, fibrinogen, platelet count), endoscopic examina-

tions, and indexes combining clinical symptoms and the results of additional tests (e.g. the Crohn's Disease Activity Index (CDAI), Rachmilewitz index, Mayo index) are used to evaluate the activity of inflammatory bowel disease. Quality of life questionnaires have also become an integral and significant part of the assessment of patients with IBD.

Definition and Methods of Assessing Quality of Life

However often the term "quality of life" is used, it is still difficult to define. Considering inflammatory bowel disease it is necessary to limit this term to health-related quality of life (HRQoL). HRQoL is defined as the subjective assessment of a patient's physical, mental, and social state concerning his or her own experience of health and disease. Measurement of the quality of life is conducted with appropriate questionnaires and scales. General scales and scales dedicated to the certain diseases, so-called disease-specific scales, are available.

The SF-36 questionnaire (Medical Outcomes Study 36-item Short-Form General Health Survey) is an example of a general scale. It is constructed of 36 questions evaluating limitations in physical, social, and usual role activities caused by health, physical or emotional problems, as well as bodily pain, general mental health, vitality, and general health perceptions. The maximum score is 100, where a higher score number signifies a better quality of life [4].

The Inflammatory Bowel Disease Questionnaire (IBDQ) is a disease-specific scale used to assess quality of life in patients with inflammatory bowel disease. It was developed at McMaster University in Canada. The scale includes 32 questions assessing four areas: bowel symptoms (B), systemic symptoms, (S), emotional function (E), and social function (SF). Answers to the questions are given on a seven-point scale and the total score ranges from 32 to 224 points. A higher score signifies a higher quality of life.

Together with the conventional laboratory, endoscopic, and clinical markers and indices, quality of life has become an integral and important part of the assessment of new therapeutic strategies in clinical trials [5, 6]. For example, statistically significant improvement in QoL in patients who obtained clinical improvement or remission was found in the ACT 1 and ACT 2 (a clinical trial assessing the efficacy and safety of infliximab in moderate and severe ulcerative colitis, $n = 728$) [7].

Quality of Life in Inflammatory Bowel Disease

The clinical manifestation of inflammatory bowel disease is varied and mostly depends on the activity and type of disease. The Montreal classification of Crohn's disease includes the criteria age at onset, location of the disease in the gastrointestinal tract, and behavior of the disease (presence of strictures and fistulas). The Montreal classification of ulcerative colitis concerns the extent of inflammation in the large bowel [8]. Studies assessing QoL in IBD focus not only on comparisons with the quality of life in healthy people. The relationships between quality of life and many disease-related and other factors, such as disease activity, disease duration, age and gender of the patient, and treatment strategy, are also studied. Love et al. showed decreased quality of life in outpatients with inflammatory bowel disease compared with an age- and sex-matched healthy control group. Quality of life was worse not only globally, but in every studied area, with the strongest negative influence of bowel symptoms on quality of life. Then came emotional, social, and systemic components [9].

So-called short questionnaires have been developed to minimize the time needed to conduct and interpret scales. The Short Inflammatory Bowel Disease Questionnaire (SIBDQ) consists of 10 questions assessing the state of the patient during the two weeks before the visit. The questions in the short questionnaire concern the same areas as in the IBDQ: bowel symptoms, systemic symptoms, and emotional and social function. Irvine et al. showed that the SIBDQ is useful and reliable and allows detection of significant changes in health-related quality of life in patients with Crohn's disease and ulcerative colitis [10]. Similarly, Spanish authors have found that a worsening of quality of life associated with IBD exacerbation can be credibly evaluated with a short questionnaire (IBDQ-9). Casellas et al. conducted a study to compare the influence of the clinical and endoscopic activity of IBD on QoL in a group of 68 patients with IBD. The authors used two questionnaires: the IBDQ-36 and its shortened version IBDQ-9. They found that IBDQ-9 had good correlation with disease activity evaluated with clinical indexes (Rachmilewitz index in UC and Harvey-Bradshaw index in CD). The correlation was better for UC than for CD. The authors concluded that HRQoL may be equally appropriately assessed with the shortened questionnaire as with the conventional IBDQ-36. The major advantage of shortened ques-

tionnaires, i.e. saving the patients' and doctors' time, can result in their more frequent use in daily practice, especially in that they are important tools evaluating the effectiveness of treatment [11, 12]. Kiran et al. studied the usefulness of the Cleveland Global Quality of Life (CGQL) and its correlation with SF-36 and CDAI in CD patients. The authors showed that both the CGQL and SF-36 similarly correlated with CDAI. They also found that the CGQL is a simple measurement of quality of life in Crohn's disease [13].

Casellas et al. conducted a study to determine whether HRQoL at IBD onset differs from that in repeated relapses of the disease. The study group consisted of 120 patients with exacerbations of inflammatory bowel disease (57 with UC and 63 with CD). Every patient completed the IBDQ, EuroQol, and PGWBI. No differences between patients with the first diagnosis of IBD and patients with the next flare were found. The authors concluded that experience with the IBD flare does not influence the perception of quality of life during subsequent relapses of disease [14].

Andersson et al. studied the quality of life in 127 patients with Crohn's disease of the large bowel (56 men, 71 women, average age: 44 years). The control group consisted of 266 healthy individuals. Of the CD patients, 73.2% had undergone operation of the colon, 51.2% had inflammatory changes in the small bowel, and 72.4% had inactive disease. Compared with the control group, the patients with CD in remission had similar quality of life evaluated with SF-36 except for a lower score regarding the general state of health. Patients with active disease had lower scores in all areas assessed with SF-36. Taking into consideration age, gender, coexisting location in the small bowel, presence of a stoma, past surgical operations of the colon, disease activity, and duration and aggressiveness of disease, only disease activity was a prognostic factor for decreased quality of life. Although no differences between the HRQoL of the patients with Crohn's disease in remission and the healthy population were found, the authors observed negative influences of disease on parenthood, family life, and professional activity. Patients with Crohn's disease more often lived alone (68 vs. 78.4%) and did not have children (67.7 vs. 78%). They also more often used sick-leave and allowance. The authors concluded that the treatment strategies recently administrated in Crohn's disease allow most patients to lead a life the quality of which is not decreased [15].

In a review of 22 studies considering HRQoL in Crohn's disease, Cohen found that it is lower not only when compared with a healthy population, but also lower than in patients with ulcerative

colitis. Moreover, once again it was shown that quality of life correlates with the activity of disease and it decreases during exacerbations [16]. Casellas et al. studied the impact of disease phenotype according to the Vienna classification on HRQoL using three questionnaires (IBDQ, Psychological General Well-Being, EuroQol). The study group consisted of 198 patients. The authors did not find differences regarding age at diagnosis, disease location, and behavior. The lack of correlation between HRQoL and CD phenotype can be related to the low sensitivity of the tool measuring quality of life, which was demonstrated in previous studies indicating that SF-36 and PGWB were not able to distinguish between patients with inactive Crohn's disease and a control group. Simultaneously, the authors noted that disease-specific tests like the IBDQ can detect even small changes in HRQoL in inflammatory bowel disease. Thus in the cited study the influence of phenotype on HRQoL did not result from the test applied. Lower quality of life was, however, related to gender (women), a higher number of flares per year, and higher disease activity. Two independent factors influencing HRQoL which were the strongest in the studied group were disease activity and the number of relapses per year [17]. Similar results were achieved in a multicenter study of patients with inflammatory bowel disease at nine hospitals located in different regions of Spain. The authors used IBDQ and EuroQol in a group of 1156 patients (528 with UC and 628 with CD). Decreased quality of life correlated with disease activity, but not with the type of disease [18].

Japanese authors noted an interesting relation between quality of life and disease duration. They found that the strongest factor influencing quality of life in a group of 331 patients with ulcerative colitis was disease activity, regardless of disease duration. Although disease duration itself did not influence quality of life, it was shown that other factors impacting HRQoL changed with disease duration. Disease activity was the strongest factor disturbing quality of life among patients with disease duration of less than 5 years and who were on sick-leave, and hospitalization was the strongest factor among patients with disease duration of 5–9 years [19]. Zahn et al. also found that disease duration does not influence quality of life in ulcerative colitis and correlates with diseases activity evaluated by clinical and endoscopic indexes. The authors also showed that women did not experience worsened HRQoL, which was demonstrated in some other studies [20].

Vidal et al. suggested that psychological distress, regardless of disease activity, has a negative impact on quality of life in IBD patients, which

indicates the need for treatment of psychopathology parallel to the treatment of IBD [21].

Assessment of quality of life is an integral part of the evaluation of medical as well as surgical treatment. Coffey et al. assessed quality of life with the Cleveland Global Quality of Life in 64 patients after ileal pouch-anal anastomosis. Patients operated because of ulcerative colitis had higher quality of life than patients with familial adenomatosis or UC with pouchitis. Additionally, quality of life was influenced by the type of diet and the timing of intake. More than 95% of the patients complained about dietary restrictions [22].

Questionnaires for the assessment of quality of life have been adapted and validated for use in different languages and countries [23]. Han et al. confirmed that the IBDQ is a valid and reliable tool for assessing quality of life in patients with ulcerative colitis in England [24]. Watanabe et al. achieved similar results using the Japanese IBDQ in patients with ulcerative colitis after ileal pouch-anal anastomosis [25]. Leong et al. examined a group of 135 patients with IBD (59 with CD and 76 with UC) using the Chinese version of the IBDQ. The authors demonstrated good correlation of the IBDQ with SF-36 and clinical indexes of disease activity. Moreover, the capability of the IBDQ to distinguish between active and inactive disease was shown [26]. Ren et al. achieved similar results in a group of 92 patients with IBD [27].

Norman et al. studied quality of life in

200 patients with benign diseases of the gastrointestinal tract and the impact of malnutrition on quality of life. The largest groups consisted of patients with liver cirrhosis (n = 61) and inflammatory bowel disease (n = 69). The results showed that the quality of life of patients with ulcerative colitis was lower compared with patients with liver cirrhosis. However, the influence of malnutrition on quality of life was greater in the liver cirrhosis than in the IBD patients. The authors suggested the need for further studies to demonstrate whether nutritional intervention can improve quality of life [28]. Improvement of quality of life, in addition to the prevention and treatment of malnutrition and improvement of growth and development in children, is one of the goals of nutritional therapy in Crohn's disease according to ESPEN guidelines. Appropriate clinical trials investigating the influence of nutritional treatment on quality of life are missing, as it is believed that improving the nutritional state improves the general state [29].

The authors concluded that the most important factor influencing quality of life in inflammatory bowel disease is disease activity. Studies have shown significant decreases in quality of life in IBD patients with active disease compared with IBD patients in remission and healthy controls. Decreased quality of life was also observed in patients with a higher number of flares per year. IBDQ is the most often used tool for assessing quality of life in patients with inflammatory bowel disease.

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