

Quality of life in patients with Crohn's disease and ulcerative colitis. Comparative analysis

Jakość życia osób z chorobą Leśniowskiego-Crohna i wrzodziejącym zapaleniem jelita grubego. Analiza porównawcza

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Słowa kluczowe: wrzodziejące zapalenie jelita grubego, choroba Leśniowskiego-Crohna, jakość życia.

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Abstract

Introduction: Inflammatory bowel diseases are idiopathic chronic conditions of the gastrointestinal tract. The major types of IBD are Crohn's disease (CD) and ulcerative colitis (UC). They interfere with the daily life of those affected and may potentially cause lifelong disability.

Aim: To assess health-related quality of life and biopsychosocial functioning in a community-based sample of patients with inflammatory bowel disease and explore its association with gender, level of education, dwelling place, duration, type and phase of disease.

Material and methods: Fifty-one patients with ulcerative colitis and forty-one patients with Crohn's disease were involved in the study. Health related quality of life was assessed by a disease-specific instrument, a Polish version of Rating Form of IBD Patients Concerns (RFIPC) and by self made questionnaire.

Results and conclusions: It was confirmed that patients suffering from inflammatory bowel disease assessed their health related quality of life as low. Highest scores (the worst quality of life) were significantly associated with female gender, exacerbation of disease, short duration of disease, patients living in the country and patients with low level of education. Biopsychosocial functioning of most patients from these groups is gravely disturbed and thus require a particular attention in care and specialist treatment.

Streszczenie

Wprowadzenie: Nieswoiste zapalenia jelit (NZJ), do których zalicza się wrzodziejące zapalenie jelita grubego oraz chorobę Leśniowskiego-Crohna, są grupą idiopatycznych chorób przewodu pokarmowego o charakterze przewlekłym. Obie jednostki istotnie ograniczają życie chorego i potencjalnie mogą prowadzić do przewlekłej niepełnosprawności.

Cel: Ocena jakości życia oraz funkcjonowania biopsychosocjalnego pacjentów z NZJ, a także określenie związku między poziomem jakości życia chorych na NZJ a czynnikami, takimi jak: płeć, poziom wykształcenia, miejsce zamieszkania, czas trwania, rodzaj i stadium choroby.

Materiał i metody: Badaniem objęto 51 pacjentów z wrzodziejącym zapaleniem jelita grubego oraz 41 osób cierpiących na chorobę Leśniowskiego-Crohna. Jakość życia chorych oceniono na podstawie badania z użyciem polskiej wersji kwestionariusza obaw i lęków związanych z chorobą (RFIPC) oraz ankiety autorskiej.

Wyniki i wnioski: Stwierdzono, że subiektywna ocena jakości życia pacjentów z NZJ jest niska. Najwyższe wyniki z użyciem RFIPC, a tym samym najniższą jakość życia uzyskano wśród kobiet, osób w aktywnym stadium choroby oraz mieszkańców wsi, osób z niskim wykształceniem i osób z chorobą trwającą krócej niż 2 lata. Zauważono, że funkcjonowanie biopsychosocjalne większości pacjentów z tych grup jest poważnie zaburzone i dlatego wymaga szczególnej uwagi w procesie opieki i leczenia specjalistycznego.

Introduction

Inflammatory bowel disease (IBD) is a group of incurable, inflammatory diseases of gastrointestinal tract with alternating periods of remissions and flare-ups in its course. The major types of IBD are Crohn's disease (CD) and ulcerative colitis (UC). According to the data gathered by Krajowy Rejestr Chorych (National Register of Patients) there are about 5 thousand people suffering from Crohn's disease in Poland, and the number is growing [1]. While, there is no epidemiological data gathered about ulcerative colitis (UC) it can be assumed that the number of patients diagnosed with this disease is similar to the value noted in other European countries [2]. What is also similar to other countries, the incidence peak of IBD in Poland is between 20 and 40 years of age, that is in the period of highest professional and social activity of a person [3, 4]. Inflammatory bowel disease diseases may lead to chronic disability and thus influence health related quality of life (HRQoL) in people suffering from these diseases. Results of the research substantiate this claim and confirm that the HRQoL level among people, both with CD and UC, is far lower than that of healthy people [5, 6]. Lowered life quality shows not only as worse physical functioning, what would be the result of quite a severe IBD course, but also as psychosocial consequences of disease [7, 8].

HRQoL, due to its multi-dimensional and complex structure, requires to be assessed with the use of thorough, profiled research instrument, specially created to measure life quality in people with IBD. Questionnaire Rating Form of IBD Patients Concerns (RFIPC) developed by Drossman *et al.* meets these principles [6]. The questionnaire is an instrument for subjective assessment of psychosocial functioning of patients with IBD. It takes into consideration specific patients' anxieties and fears that result from IBD course and treatment and assesses their level against four indexes: impact of disease on every-day living, sexual intimacy, disease complications and self body-image connected with the stigma phenomenon [5, 6].

Aim

The aim of the research was to learn the impact of disease complaints on health related quality of life in patients with IBD.

Material and methods

A survey was conducted from December 2007 to November 2008. It was carried out in sample of 60 subjects recruited among patients being treated in Gastroenterologii, Żywienia Człowieka i Chorób

Metabolicznych Unit in Szpital Kliniczny nr 2 in Poznań (Gastroenterology, Human Nutrition and Metabolic Diseases Unit in the Clinic Hospital Nr 2 in Poznań) and in 32 members of Wielkopolskie Stowarzyszenie Colitis Ulcerosa i choroby Leśniowskiego-Crohna (Great Poland Association Colitis Ulcerosa and Crohn's Disease). A qualification criterion for patients was IBD diagnosis confirmed by clinical, histopathological and picture examination. All patients that took part in the research were adults. The character of the survey was completely anonymous.

The research instrument was a REIPC questionnaire [6]. The authors had adjusted the instrument culturally before they set about to proper researching. Patients were answering the RFIPC questionnaire by marking their answers on a visual-analogue 10 mm scale. From the final amount of points an arithmetic mean has been calculated, its value described the HRQoL level of the recipients. The result below the mean 38.7 points meant less anxieties and at the same time better life quality.

Additionally, an author's questionnaire was used in the survey that covered social-demographic data of patients, style of living and also type, duration and the phase of disease, intensification of symptoms, appearance of complications, administered drugs and coexisting diseases.

The psychometric quality of the instrument was evaluated by means of the Cronbach coefficient α statistic. The result for the whole questionnaire was 0.95, similar values were also obtained in individual areas [3].

Pearson's χ^2 test and Mann-Whitney U test were used to verify data.

Results

Ninety two respondents, 51 (55.43%) were diagnosed with UC and 41 (44.56%) with CD. The intensification of the disease process was observed in 52 patients (56.52%). The number of women with UC and CD was correspondingly the same, whereas men were more often diagnosed with UC (61.36 vs. 36.63%). The duration of disease in the population of subjects was analysed in three categories: less than 2 years – 26 respondents (28.26%), from 2 to 10 years – 44 (47.82%) and more than 10 years – 22 patients (23.91%). The age span was from 18 to 68, and the age mean of the respondents was – 36.6.

Most frequent complaints observed in respondents were: abdominal pain, diarrhoea and reduced well-being. As a result of disease 54 patients (58.69%) suffered from general and local complications like: anaemia, weight loss, osteoporosis, circumanal

changes, changes in the oral cavity and other. Statistically significant difference in the frequency of complications was observed in the case of weight loss and osteoporosis ($p = 0.0150$), they were more often in patients with CD than UC.

On the basis of data obtained from additional questionnaire the influence of IBD on every-day activities of respondents has been determined. The disease had the biggest impact – that is it hindered actual performance to a significant degree – on the following activities: going to school/work (41.30%), sleep (40.21%), physical activity (35.86%) and entertainment (34.78). It had the smallest impact on things like: sexual intimacy (52.17%) and personal hygiene practices (53.26%) (Table I).

On the basis of results obtained with the use of RFIPC questionnaire the HRQoL level in respondents has been calculated. The mean value of points in the population of subjects is 50.07 which means, according to the agreed scoring, that the mean evaluation of life quality of respondents was low. The general evaluation of life quality was conducted by analysing 25 questions in the questionnaire. They referred to the degree of anxiety felt within individual indexes: general disease impact, disease impact on sexual intimacy, disease complications and body stigma. Inflammatory bowel disease patients felt the strongest anxieties about development of cancer and having surgery or ostomy, hence health related quality of life in these patients was lower in the index of disease complications. The lowest level of anxiety, and at the same time the highest quality of life, was detected in the scope of possibility of having children, infecting others with the disease, and also being treated as “others”. The most satisfactory respondents’ life sphere was sexual intimacy (Table II).

Among subjects with low life quality women were those who dominated, they were no fewer than 83.33% (the mean RFIPC score – 61.84). Such a result had 43.18% men (the mean RFIPC score – 37.22). The mean RFIPC score for people in the remission phase of the disease was 33.83, which means high life quality, whereas the mean RFIPC score for patients during

disease exacerbation was almost half higher – 62.56 (low life quality). The quality of life in rural residents was lower (the mean RFIPC score – 59.57) than for urban residents (the mean RFIPC score – 44.75). In the three time-span divisions listed before a group with the lowest level of life quality was the group of patients with the disease for less than 2 years (the mean RFIPC score – 65.03). The research also took into consideration the education variability. Mean scores obtained with the use of RFIPC were as follows: respondents with primary education – 59.88, respondents with vocational secondary education – 57.54, respondents with secondary education – 52.04, respondents with university education – 39.83.

By means of statistical analysis (Pearson χ^2 test) the relationship between the level of life quality and disease duration ($p = 0.00015$), dwelling place (Mann-Whitney U test $p = 0.009078$), gender (Pearson χ^2 test

Table I. Influence of disease on every-day activities
Tabela I. Wpływ choroby na czynności dnia codziennego

Activities	The degree of impediment					
	none		medium		considerably	
	N = 92	100%	N = 92	100%	N = 92	100%
sleep	36	39.13	19	20.65	37	40.21
hygiene practices	49	53.26	21	22.82	22	23.91
sexual intimacy	48	52.17	17	18.47	27	29.34
physical activity	28	30.43	31	33.69	33	35.86
housework	38	41.30	29	31.52	25	27.17
cultivation of interests, hobby	38	41.30	23	25.00	31	33.69
meeting friends, family	38	41.30	29	31.52	25	27.17
entertainment	30	32.60	30	32.60	32	34.78
going to work/school	26	28.26	28	30.43	38	41.30

Table II. The level of health related life quality according to RFIPC in patients with IBD

Tabela II. Poziom jakości życia wg RFIPC wśród pacjentów z NZJ

The level of health related quality of life	General		Indexes							
			disease impact		sexual intimacy		complications		body stigma	
	N = 92	100%	N	100%	N	100%	N	100%	N	100%
low (result \uparrow 38.7)	59	64.13	60	65.21	43	46.73	64	69.56	52	56.52
high (result \downarrow 38.7)	33	35.86	32	34.78	49	53.26	28	30.43	40	43.47

$p = 0.00006$) and education (Pearson χ^2 test $p = 0.01549$) has been confirmed. No statistical relationship between the quality of life and the type of disease has been found (Pearson χ^2 test $p = 0.75733$).

Discussion

Inflammatory bowel disease are somatic diseases, their course is to a considerable degree conditioned by psychological and emotional factors. The subject literature has it that almost half of patients in the exacerbation disease phase signal difficulties in functioning resulting from such problems as: living under constant feeling of intensive stress, chronic anxiety, reduced well-being, depression [6, 9, 10]. Drossman *et al.* [6] proved in the research with the use of RFIPC that health related quality of life in patients with IBD is lower than in general population. What is more, they showed that there are differences in life quality between patients with UC and CD. Patients with CD, as compared to patients with UC showed more anxieties concerned with pain, suffering, being a burden to others, physical problems and the level of vitality. General life quality for patients with CD was much more lower than for patients with UC. In the own research no significant difference between life quality for patients with CD and UC were found. The quality of life was described by over half of patients (64.13%) as low (the mean RFIPC score – 50.07). Individual levels of anxiety differed only insignificantly from the Drossman *et al.* group [6]. Biggest anxieties in both groups concerned complications: development of cancer and having surgery or ostomy. High scoring in the RFIPC questionnaire (59.5), apart from anxieties listed before, also concerned an access to high quality health service. According to the data delivered by respondents this anxiety stemmed not only from the fear of not being able to reach a specialist but also from the possibility of getting treatment refund, professional approach of doctors to their disease and treatment process, and too narrow scope of health education concerning IBD. In the group of American patients such high level of this particular anxiety hasn't been detected. Whereas, latest publications from Canada [11] show that the level of satisfaction of patients with IBD with access to specialist service is not satisfactory as well. It is, most of all, the result of existence of barriers such as: lack of access to a specialist, time one has to wait for next visit and a feeling that care service does not meet patient expectations. An essential problem in the population of Polish patients with IBD is reduced professional activity. Wiercinska-Drapalo [3] concludes from her own research that 35% of men and 42% of women, both with UC and

CD, end their professional career before they reach retirement age. In own research percentage of patients not active professionally due to their health condition was 16.30% of all respondents. No statistical relationship between professional activity and factors like gender, disease duration or type of disease was noted. The only factor that determined professional situation of people with IBD was duration of disease exacerbation. The conclusion is that the decisive factor, as far as possibility of employment and actual professional activity are concerned, does not depend on the diagnosis itself but on the flare-up of the disease symptoms.

Conclusions

1. In the carried out research the subjective evaluation of health related quality of life was substantially influenced by: gender, dwelling place, education and exacerbation of the disease course. The type of disease had no impact.

2. Exacerbation of disease course hinders the performance of most every day activities, this has significant impact on deterioration of health related quality of life in patients with IBD.

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