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ORIGINAL ARTICLE

Inflammatory bowel disease: perceived impact on leisure-time activities

Kalle Mattila[a,b], Rasmus Rankala[c], Markku Voutilainen[c,d] and Anssi Mustonen[c]

[a]Department of Emergency Medicine, Turku University Hospital, Turku, Finland; [b]Department of Public Health, University of Turku, Turku, Finland; [c]Department of Internal Medicine, Turku University Hospital, University of Turku, Turku, Finland; [d]Department of Clinical Medicine, University of Turku, Turku, Finland

ABSTRACT

Objective: Inflammatory bowel disease, consisting of Crohn's disease and ulcerative colitis, is known to negatively impact an individual's quality of life. Leisure-time activities are an important part of life by creating and strengthening social networks. The aim of this study was to thoroughly evaluate the perceived impact of inflammatory bowel disease on leisure-time activities by quantifying limitations in activities caused by the disease.

Methods: A structured questionnaire, hospital records and national registers were combined to assess limitations caused by the disease in a patient's leisure-time activities. The final study sample was 561 patients.

Results: More than half of the patients (52.8%) reported that IBD had caused limitations in their leisure-time activities. Women perceived that their limitations were greater when compared to the reports by men. One-third of the patients (33.3%) reported reducing and 17.6% abandoning at least one leisure-time activity due to their disease. Most often mentioned activities that were reduced and abandoned were physical activities. The IBDQ32 score had a significant correlation with all of the studied outcomes. Laboratory tests results and the patient's age or the level of income did not correlate with limitations in leisure-time activities.

Conclusions: In conclusion, this study showed that patients with inflammatory bowel disease perceived a marked limitation in their leisure-time activities due to their disease.

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KEYWORDS
IBD; Crohn's disease; ulcerative colitis; leisure-time activities; limitation; IBDQ-score

Introduction

Inflammatory bowel diseases (IBD) are lifelong chronic diseases that can cause both gastrointestinal and systemic symptoms and are characterized by alternating periods of remissions and relapses with no curative treatment. IBD comprises of two main diseases, ulcerative colitis (UC) and Crohn's disease (CD) [1,2]. Its incidence and prevalence are increasing worldwide [3,4] with the prevalence being approximately 1% in Finland [5].

Previous studies have shown that IBD significantly affects patients in many aspects of their life. The negative effect is particularly severe during relapses, but even during remission, patients may not be entirely symptom-free and also during remission, gastrointestinal symptoms very often are the main factors that influence negatively on their quality of life [6]. IBD patients also worry about possible disease complications and other issues related to their illness [7]. Furthermore, IBD is known to cause mental conditions such as anxiety and depression [8–10].

Leisure-time activities are an important part of life by creating and strengthening social networks. They also can contribute to physical and mental health. A Canadian study, based on an online survey, showed that the majority of IBD patients felt that their diseases caused limitations in their leisure-time activities and interpersonal relationships [11]. In a European study from 25 different countries, 35% of the respondents reported that IBD kept them from pursuing intimate relationships [8]. Also, in a Finnish questionnaire study from 2009, 16.3% of the IBD patients felt that IBD symptoms greatly affected their leisure-time activities, while only 28.8% reported no limitation at all [12]. The study group also found that the IBDQ score correlated well with the perceived limitations in leisure-time activities.

It is likely that IBD patients benefit from physical training, because regular exercise could improve psychological health and reduce some disease symptoms and complications [13]. Both low-to-moderate and moderate-to-vigorous physical activity have been found to be beneficial also for health-related quality of life in people with IBD [14–18]. Due to the nature of the disease, it can easily be thought to cause limitations especially in sporty or physical leisure-time activities. One review study stated that the majority of reports to date have shown that patients with IBD have a low level of habitual physical activity relative to age- and sex-matched control groups [19]. An American study from 2016 reported that 44% patients limited their physical exercise due to IBD for

CONTACT Kalle Mattila kamatt@utu.fi TYKS, T-sairaala, Savitehtaankatu 1, Turku, Finland

reasons including fatigue, joint pain, embarrassment and weakness [20].

However, most of these studies mentioned above have briefly addressed the issue of leisure-time activities rather than trying to take a more comprehensive overview of this important aspect in living.

The aim of this study was to evaluate the perceived impact of IBD on leisure-time activities and to quantify the limitations caused by the disease.

Materials and methods

Patient sample

The study took place at Turku University Hospital in the Hospital District of Southwest Finland. The hospital district consists of 28 member municipalities with a total of over 470,000 residents. A retrospective data gathering of patients with diagnosis codes K50 for CD and K51 for UC according to ICD-10 (International Classification of Diseases, 10th revision) system were identified during a one-year period between 1 September 2015 and 31 August 2016. Patients must have had at least one out-patient clinic visit or hospitalization due to IBD during the time period. Patients who were deceased before the data gathering, patients under 18 years old and patients living outside the area of the hospital district were excluded. This produced a study sample of 2,208 patients.

A questionnaire was sent by mail in July 2018 to a randomized half (1,104 patients) of the original study sample. To improve the response rate, SMS reminders were sent to the patients. The questionnaire was also resent by mail in September 2018 to those who had not responded. A possibility to answer the questionnaire *via* internet was also provided using a QR code in the mailed questionnaire and SMS. If someone answered the questionnaire twice, only the first received questionnaire was accepted in the study. Thirty-one patients did not give written consent to the study and were excluded. Also, two of the respondents reported not having IBD and were thus excluded. In total, 561 patients, yielding a response rate of 50.8%, were included in the final study sample.

Questionnaire

In the questionnaire, patients were asked about their demographic background and the level of their monthly income. The information on how long ago the IBD diagnosis was made was also solicited. Previous surgical operations and whether they had a stoma at a given moment or at some point during their IBD were surveyed.

The subjects were asked to list their current leisure-time activities using their own words, and they were not provided with a predefined list of activities. These activities were later analyzed and grouped into three categories by the study group being 1. physical/sports, 2. difficulties getting to toilet and 3. other leisure-time activities. After this, the subjects were asked how many hours per week they currently spent on the leisure-time activities they had listed.

Patients were asked about how many hours per week IBD had reduced the time used on leisure-time activities. Patients were asked how much, on average, IBD was reducing their ability to perform in their leisure-time activities using a visual analogue scale (VAS) from 0 to 100, where 0 was labelled not at all and 100 as extremely. Patients were asked to list any leisure-time activities, which had been affected by IBD, by asking: *Have you been forced to reduce some leisure-time activities because of IBD? a) no and b) yes*, followed by: *If yes, which leisure-time activities?* _____. Next, they were similarly asked if they had been forced to give up completely some leisure-time activities due to IBD again listing any possible activities affected. When analyzing the reduction, the same 3 groups being 1. physical/sports, 2. difficulties getting to toilet and 3. other leisure-time activities were used.

The translated and officially licenced IBDQ32 questionnaire was included in the questionnaire [21], which has been validated in several instances and in different languages [22–23]. The IBDQ32-questionnaire uses a timeframe of two weeks prior to answering the questionnaire. The IBDQ score was calculated as a sum of all 32 questions with a smaller score representing a worse quality of life ranging from 32 to 224. For a detailed analysis, The IBDQ score was divided into four different health domains being bowel symptoms (questions: 1, 5, 9, 13, 17, 20, 22, 24, 26, 29), systemic symptoms (questions: 2, 6, 10, 14, 18), emotional function (questions: 3, 7, 11, 15, 19, 21, 23, 25, 27, 30, 31, 32) and social function (questions: 4, 8, 12, 16, 28).

For a comprehensive approach, we also acquired data from the Social Insurance Institution of Finland and the data from hospital records and combined them with the data solicited from the questionnaire. This data included laboratory results, hospitalizations, administration of biologics and the use of per oral glucocorticoids such as prednisone, prednisolone, methylprednisolone, hydrocortisone. From the laboratory tests, the lowest, highest and average values were taken at Turku University Hospital during the study period.

Ethical considerations

The ethical committee of The Hospital District of Southwest Finland approved the study. The patients received a written description of the sampling procedure and study purpose as well as the planned use and storage of the information they were to provide. This was followed by a description of the subject's rights according to the Helsinki declaration.

Statistical analyses

The statistical evaluation of the data was based on the Chi-Square test and Fisher's exact test for proportions and on the Student's t-test for mean. The Pearson coefficients of correlation were used to examine the degree of the relationship between two continuous variables. All analyses were performed in SPSS version 25 (SPSS Inc., Chicago, IL, USA).

Table 1. Patient characteristics.

	total
Total sample	561
Age	53.2 years
cd	201 (35.8%)
UC	360 (64.2%)
Clinical data	
biologics	67 (12.8%)
Corticosteroids	171 (32.9%)
antibiotics	31 (6.0%)
hospitalization	22 (4.2%)
ibdq score	172 (range 44–223, SD ± 34)
surgery due to ibd	117 (20.9%)
highest CRP	10 (range 1–276, SD ± 26)
Highest Calpro	652 (range 13–6000, SD ± 1119)

Results

In total 561 patients answered the questionnaire. The average age of the respondents was 53.2 years (20–93) and 49.4% of them were women; 35.8% had CD and 64.2% UC. The average IBDQ32-score was 172 (range 44–223, SD ± 34) (Table 1). The participants reported spending 11.8 h weekly doing leisure-time activities with men reporting slightly more than women. The most frequently mentioned leisure-time activity was physical activity (63.5% of the patients); however, CD patients participated less in physical leisure-time activities compared to UC patients (57.7% and 66.6%, respectively, $p < .05$).

More than half of the patients (52.8%) reported that IBD had caused a limitation in their leisure-time activities. Women felt that the limitations caused by IBD was greater compared to that reported by men with 42 compared to 30 on a 0–100 VAS scale, respectively ($p < .001$) (Table 2). Also, patients who had operations due to IBD reported greater limitations caused by their disease in their leisure-time activities (Table 2).

One-third of the patients (33.3%) reported reducing at least one leisure-time activity due to IBD. Of those who reported at least one reduced activity, these individuals had an average reduction of 1.6 activities and 5.7 h weekly. Most reductions in activities were physical activities (59.7%) and secondly, activities with difficulties getting to the bathroom (38.2%). In total, 17.6% of the patients reported abandoning at least one leisure-time activity due to IBD. Amongst them, the average amount of activities abandoned was 1.4 (range 1–6), and physical activities were most frequently abandoned (Table 3). Patients, who received biologics, had both statistically significant reduced and abandoned leisure-time activities compared to those patients who did not get biologics. Also, patients with CD were more likely to abandon leisure-time activities compared to patients with UC. In total, 43.7% of patients reported none of these limitations in their leisure-time activities due to IBD.

The IBDQ32 score and all its four different components, being bowel symptoms, systemic symptoms, emotional function and social function, had a significant correlation with all of the studied outcomes. Especially, the questions regarding social functions had a significant correlation with a perceived limitation ($r = -0.531$, $p < .001$), a reduction ($r = -0.369$, $p < .001$) and the abandonment of leisure-time activities ($r = -0.365$, $p < .001$). Also, there was a statistically significant correlation between how long ago the patient had been diagnosed with IBD and the reduction of leisure-time activities ($r = 0.090$ [$p < .05$] and $r = 0.108$ [$p < .05$], respectively).

None of the analyzed laboratory tests, such as for alaninaminotransferase, C-reactive protein, fecal calprotectin, hemoglobin and leucocytes, had a statistically significant correlation on perceived limitations, a reduction, or the abandonment of leisure-time activities. IBD also seemed to affect patients of all ages equally, as there was no statistical correlation with age on any of these three studied outcomes. Also, the patient's level of income did not correlate with these three types of perceived limitations in leisure-time activities.

Discussion

Our study indicates that IBD has a marked adverse impact on leisure-time activities. More than a half of the patients reported that IBD hampered their ability to do leisure-time activities with the effect being greater among women. One-third of the patients reported a reduction, and one-sixth reported the abandonment of at least one leisure-time activity due to IBD. The disease seems to impact relatively similarly all ages and both sexes. According to the authors' knowledge, there are no previous studies focusing on the detailed effects of IBD on leisure-time activities. In the present study, we tried to comprehensively cover the different problems that IBD could cause to the patients' leisure-time activities. Systematic sampling of the patients was expected to provide a sample that represented a typical IBD patient treated at Turku University Hospital's Gastroenterology clinic. The final sample size was considered sufficiently large to analyze the differences between subgroups.

IBD is known commonly to cause conditions such as abdominal pain, fever, diarrhea and fatigue, and the disease onset is usually at an early age [1,4]. The impairments can be thought to be particularly severe during relapses, but even during remission, patients can experience limitations due to IBD. Thus, it seems likely that IBD can cause significant limitations to a patient's leisure-time activities. However not many studies have put their focus on this important aspect of life.

In our study, more than a half of the patients reported that IBD caused limitations in their leisure-time activities. Two earlier studies, which only used one or two questions concerning leisure-time activities, have reported similar results. A Finnish questionnaire study from 2009 included one question to solicit information on how IBD had affected their leisure-time activities. In total, 16.3% of the IBD patients felt that IBD symptoms have greatly affected their leisure-time activities, and 51.7% reported somewhat affected, while the rest reported no impact at all [12]. The study group also found that the IBDQ score correlated well with the perceived limitations in leisure-time activities. A Canadian study reported in 2015 that among respondents with IBD, 64% reported a significant effect on leisure-time activities, and 52% reported a significant impact on their interpersonal relationships [11]. These proportions are slightly larger compared

Table 2. Weekly hours spent in leisure-time activities, the percentage of patients that reported disadvantage in leisure-time activities due to IBD and the average level of limitations amongst the patients, who reported a limitation due to IBD.

	Weekly hours spent in leisure-time activities	Perceived limitation in any leisure-time activity	Level of limitation (VAS scale 0–100)
All	11.5	52.8%	36
Men	12.5	53.3%	30***
Women	10.5	52.3%	42***
Crohn	11.6	54.6%	39
Colitis	11.5	51.8%	35
Biologics	11.3	64.6%*	37
No-biologics	11.7	51.6%*	36
Operated	14.7**	52.9%	46**
Not operated	10.6**	53.1%	34**

*$p < .05$, **$p < .01$, ***$p < .001$.
Otherwise statistically not significant.

Table 3. The proportion of patients that reported being forced to reduce and abandon leisure-time activities due to IBD.

	Reduced leisure-time activities	Reduced physicial activities	Reduced activities with difficulties getting to toilet	Reduced other leisure-time activities	Abandoned leisure-time activities	Abandoned physical activities	Abandoned activities with difficulties getting to toilet	Abandoned other leisure-time activities
All	33.3%	24.0%	11.8%	5.0%	17.6%	11.2%	5.5%	2.7%
Men	31.1%	22.5%	9.2%	2.8%*	15.1%	9.9%	6.1%	2.5%
Women	35.5%	25.3%	14.4%	7.2%*	20.0%	12.3%	4.9%	2.9%
Crohn	33.5%	21.4%	11.9%	7.5%*	22.3%*	15.4%*	7.5%	3.5%
Colitis	33.1%	25.2%	11.7%	3.6%*	14.9%*	8.6%*	4.4%	2.2%
Biologics	44.8%*	32.8%	11.9%	6.0%	26.2%	22.4%**	4.5%	6.0%
No-biologics	32.4%*	23.5%	11.7%	4.6%	16.7%	9.7% **	5.8%	2.2%
Operated	36.2%	26.5%	12.8%	4.4%	25.0%*	19.7%**	6.8%	4.3%
Not operated	32.9%	23.6%	11.3%	7.7%	16.0%*	9.0%**	5.3%	2.3%

*$p < .05$, **$p < .01$, ***$p < .001$.
Otherwise statistically not significant.

to our study. One possible explanation could be that their study population had a larger proportion of CD patients compared to our study. Our study results suggest that CD patients might experience a greater negative impact on leisure-time activities compared to UC patients, while CD patients reported being forced to completely abandon a leisure-time activity statistically significantly more often (Table 3).

It is important for the patient to be able to do physical exercise, while the low level of physical activity can have an adverse effect on overall health and increases the risk of developing many other chronic diseases. It is also unclear if a low level of physical activity may have contributed to the development of IBD possibly through a reduced modulation of pro-inflammatory cytokines [19]. Patients with IBD have a low level of habitual physical activity when compared to control groups [17,19,24]. A study from the United States reported that in 44% of their study population, IBD limited their exercise due to factors such as fatigue, joint pain and embarrassment [20]. Otherwise, their article mainly focused on how much and what kind of exercises IBD patients did. Furthermore, their study found no correlation between C-reactive protein and fecal calprotectin values and the amount of exercise done by the patients. However, they did not report about possible correlations with the patients who felt that IBD limited their exercise. Our study found no statistically significant correlation between any analyzed laboratory tests, such as alaninaminotransferase, C-reactive protein, fecal calprotectin, hemoglobin and leucocytes, and a perceived limitation, a reduction or in an abandonment of leisure-time activities. This finding emphasizes the fact that clinicians treating IBD patients should actively ask about their patients' quality of life, when at least the limitations in leisure-time activities do not correlate with the laboratory results.

In our study, patients receiving biologics had been forced to both reduce and abandon their leisure-time activities compared to those patients without biologics medication. Even though biologics have improved the overall treatment of IBD, our study indicates that patients receiving biologics still have a hindrance from IBD on their leisure-time activities. On the other hand, in Finland, biologics are mainly administered to IBD patients with a more severe disease presentation, and when other treatment methods are insufficient, it is probable that these patients experience more limitations in their leisure-time activities.

Overall, 43.7% of the patients in this study perceived no negative effects on their leisure-time activities due to IBD. This can be considered as a relatively positive result compared to previous studies conducted with patients with some other chronic diseases [25,26]. This could be explained by improvements in the medical therapies and the better availability of biologics. The nature of IBD, with its recurrent episodes of relapses and remissions, also differs somewhat from other chronic diseases and might thus also have a positive influence on the proportion of patients not affected compared to other chronic diseases.

It can be difficult when trying to assess limitations in leisure-time activities due to IBD in several ways. Firstly, there is no consensus about the timeframe that the questionnaires should span. Especially in IBD, the type and severity of symptoms experienced by patients can vary greatly over time. A

shorter time frame can minimize a patient's recall bias but is susceptible to the occurrence of infrequent events. Furthermore, particularly, in the patients who have had IBD for many years, it could be difficult to recall their performance in leisure-time activities before the disease onset. It is likely that the patient sample in this study covered IBD patients throughout different stages of their disease and represents accurately an average IBD patient. Thus, the results can be thought to be generalizable to IBD patients overall. Furthermore, the questionnaire was sent in early autumn and re-sent few months later, which may slightly impact the limitations on leisure-time activities due to a different season. The patients with different answering time frames were not analyzed separately. This may have a minor impact on the leisure activites between the different groups and can be seen as a limitation of this study.

Our study provides detailed information on how many hours patients with IBD participate in leisure-time activities. Some earlier studies amongst other chronic diseases have shown similar hours spent on leisure-time activities compared to our study [25,26]. Our study did not include any control cohort. However, this study attempts to provide detailed information by soliciting information on how much the patients thought, that their participation on leisure-time activities was decreased specifically due to IBD. The limitation of this method is that it might be difficult for some respondents to estimate the negative impact of IBD.

Different data collection methods may also influence the patient's answers. In our study, the patients were asked to use their own words to describe the leisure-time activities that had been negatively affected by IBD to such an extent that they had either been forced to reduce the amount of time spent doing these activities or abandoning them completely. If ready-made lists had been used for the leisure-time activities, there would have been a possibility that some of those that are important to the patients could have been omitted. Such lists could also have included leisure-time activities that were unimportant to the patients but may have been chosen if relevant activities were not listed. This would make the quantification of the impact more difficult and decrease the reliability of assessments. Also, when a patient actually has to write down a leisure-time activity, it is more likely that he/she actively engages in it compared to a situation where a ready-made list would be present. It is likely that our method of open-ended listing produced activity lists that may have more accurately reflected the activities actually enjoyed by the patients. However, it is not easy to group numerous different written leisure-time activities for subanalyses and it is possible that this phase of the study methods can cause uncertainty and possible bias.

Conclusions

In conclusion, this study showed that IBD patients perceived a marked negative effect on their leisure-time activities due to their disease.

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Author contributions

Concept and design: KM, RR, MV, AM; Acquisition of data: KM, RR, AM; Analysis and interpretation of data: KM, RR, AM; Drafting of Manuscript: KM; Critical revision: KM, RR, MV, AM; Final approval: KM, RR, MV, AM.

Disclosure statement

Authors have no conflicts of interest to declare.

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ORCID

Rasmus Rankala http://orcid.org/0000-0001-7264-6861

Data availability statement

The data underlying this article will be shared on reasonable request to the corresponding author.

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