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The Impact of IBD on Ability to Work and Study. A Patient Perspective.

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Abstract

Purpose

The aim of this study was to explore the multifaceted ways in which inflammatory bowel disease (IBD) negatively affects working life and studies.

Material and Methods

IBD patients were identified by diagnosis codes from the hospital records of a Finnish University Hospital. Patients were sent questionnaires via mail and text messages. Respondents, being 561 patients, formed the sample. Hospital records and data of medications were combined to questionnaire data.

Results

Over a fifth of the patients reported having to change their job due to IBD, whereas a third of the sample had to modify their work due to IBD. On average, they had changed jobs once. Most common modifications were to do fewer hours or work during different hours, decreasing the physical burden of their work and moving their workplace closer to a toilet. Around a fifth of the sample' studies were negatively influenced by IBD. Interestingly, clinical parameters or sex did not affect the probability of job modifications, changes or negative effects on studies.

Conclusions

IBD has a considerable negative impact on many patients' studies and working life that extends beyond commonly studied absenteeism and presenteeism.

Key words: IBD, Crohn's disease, ulcerative colitis, working life, work

Introduction

Inflammatory Bowel Diseases (IBD), comprising Crohn's disease (CD) and ulcerative colitis (UC), are chronic, inflammatory, relapsing disorders of the gastrointestinal tract that significantly impact the lives of those affected (1,2). Although the disease may be diagnosed at any age, the peak age of onset for IBD is 16 to 35 (3,4). Thus, it can potentially have a long-lasting negative impact on a patient's working life. Physical symptoms, such as abdominal pain, diarrhoea and fatigue, poses substantial challenges to individuals' working lives. The unpredictable nature of these diseases, characterised by fluctuating periods of remission and exacerbation, can lead to frequent absences, reduced productivity and a profound overall negative impact on patients' working life. Moreover, the stigma associated with gastrointestinal symptoms, coupled with the stress of managing a chronic illness, can exacerbate mental health issues further complicating the ability to maintain a stable and fulfilling work life (5-7).

It is known that IBD significantly affects patients in many aspects of their life, and the inflammatory bowel disease questionnaire (IBDQ)-questionnaire has been found to be an effective tool for assessing these effects. IBD can negatively affect patients' ability to work in many ways, for example, by causing sick leave (absenteeism) and working while sick (presenteeism). These aspects of negative impact on working life due to IBD have been relatively well-documented previously (7-10). IBD is also known to cause early retirement (11,12), and studies have shown that patients with IBD are more likely to be unemployed than that of the control population (13,14).

Overall, also from this same study population, the different types of negative impact of IBD on patient's working life have been studied earlier (15,16). Furthermore, the ongoing challenges posed by IBD often necessitate changes in job roles or workplaces as well as negatively affect the patient's studies and chosen field. To our knowledge, these negative effects have not been reported in previous studies.

The aim of this study was to explore the multifaceted ways in which IBD negatively affects working life and studies.

Material and methods

Patient sample

The study was conducted at Turku University Hospital located in the Hospital District of Southwest Finland. This district encompasses 28 municipalities with a combined population exceeding 470,000 residents. Researchers retrospectively gathered data on patients diagnosed with Crohn's disease (CD) and ulcerative colitis (UC) identified by the ICD-10 (International Classification of Diseases, tenth revision) codes K50 and K51, respectively. The data collection covered a one-year period from September 1, 2015 to August 31, 2016. To be included, patients needed to have had at least one outpatient clinic visit or hospitalisation due to IBD within this timeframe. Exclusion criteria included patients who had passed away before data collection, those under 18 years old and individuals residing outside the hospital district. This resulted in a study sample of 2,208 patients (17).

In July 2018, a questionnaire was mailed to a randomised half of the initial sample (1,104 patients). To boost response rates, SMS reminders were sent, and the questionnaire was resent in September 2018 to non-respondents. Additionally, a QR code was included in the mailings and SMS messages to allow participants to complete the survey online. If a participant completed the questionnaire more than once, only the first submission was included in the study. Thirty-one patients, who did not provide a written consent, were excluded, along with two respondents who reported not having IBD. The final study sample included 561 patients resulting in a response rate of 50.8%. Non-responders were significantly younger (43.2 years) when compared to the responders, but no differences in the distribution of sexes or CD compared to UC were found.

Questionnaire

In the questionnaire, patients were asked of their demographic background, to describe their current or last occupation or profession and if they were currently employed, studying, unemployed or pensioners with multiple choices allowed. From the description of their last occupation, categorization was made with separate parameters being: (1) Blue-collar worker, (2) White-collar worker, (3) Management position and (4) Self-employed. In the analysis, a white-collar worker and Management position were combined. The information on how many years 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.

Data of the perceived need to change their work were collected with the following questions: Have you needed to switch jobs due to inflammatory bowel disease after it was diagnosed? Yes or No. If yes, how many times ___. If yes, why?_____ From this open-ended question, the answers were categorised to three categories (Table 1). Data of the perceived need to modify their work were collected with the following questions: Have you needed to modify your work due to inflammatory bowel disease after it was diagnosed? Yes or No. If yes, how many times _____. If yes, how? _____ From this open question, the answer was categorised into five different groups as described in Table 1.

As the questions regarding changes and modification in work did not have a specific timeframe, the entire patient sample was used in all the analysis and not just the currently employed or studying.

The effect of IBD on respondents' studies was assessed with three questions. Patients were only asked to respond to the questions if they were currently studying or were studying while having been diagnosed with IBD. Thus, only respondents to these questions were included in the analysis regarding the effect of IBD on studies. The first question was: Has IBD affected the field of your studies? Yes or No. Then: Has IBD slowed the progress of your studies? Yes or No. And lastly: Has inflammatory bowel disease weakened your academic performance? Yes or No.

The translated, official, licenced IBDQ32-questionnaire was included in the questionnaire. The IBDQ32-questionnaire has been validated in several instances and in different languages (18-20). The IBDQ-score was calculated as a sum of all 32 questions with a lower score representing a worse quality of life ranging from 32 to 224.

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 and medication use.

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. In statistical analyses, subjects who had modified their work were compared to subjects who did not modify their work, and, respectively, in subjects that had changed their work or had not changed their work. All analyses were performed in SPSS version 25 (SPSS Inc., Chicago, IL, USA).

Results

The final patient sample was 561 patients, who were on average 53 years old. Half of them were male, and a little over one third were diagnosed with CD and the rest with UC. Most of the patients were currently employed in mostly white-collar jobs. The detailed characteristics and demographics are displayed in Table 2.

Over a fifth of the patients reported having to change their job due to IBD (Table 2). On average, they had changed jobs once most often because the job got too hard despite the modifications made. The patients that reported having to change jobs were on average ten years younger than patients who had been able to stay in their jobs (Table 2). Clinical parameters, such as faecal-calprotectin values, hospitalizations, use of biological medications or the diagnosis UC/CD, did not have an effect on the likelihood of having to change jobs (Table 2).

Almost a third of the sample reported having to modify their work due to IBD (Table 2). The most common modifications were to work for fewer hours or to work during different hours, decreasing the physical burden of their work and moving their workplace closer to a toilet (Table 3). The patients who reported having modified their work due to IBD were on average statistically significantly younger and had a statistically significantly lower quality of life according to the IBDQ-questionnaire (Table 2). However, the use of biological medications, hospitalisation, faecal-calprotectin values or the diagnosis (UC/CD) did not have a significant effect on the likelihood of work modifications. Patients who reported having modified their jobs also reported statistically significant more working while sick (Presenteeism). Interestingly, almost three quarters (73%) of patients who had changed their jobs reported as having a need to also modify it.

IBD also influenced patients' studies, as 16.0% of respondents felt that IBD had an impact on the field of study and 18.6% of the respondents experienced a delay in their studies, whereas only 7.5% replied that IBD had weakened their academic success. Patients whose studies were negatively affected by any means had a significantly lower quality of life compared to those whose studies were not affected (IBDQ-score 147.7 and 179, respectively, $p<0.01$).

Discussion:

IBD patients reported that their disease had a significant negative impact on patients' studies and working life as over a third of the patients in this study reported significant changes or modifications to their jobs. This subject has not been well studied, maybe because it is difficult to monetize these negative effects in economic terms. It was notable that these negative effects were observed similarly in both UC compared to CD and in men and women. Also, the need to change and to modify their jobs was accumulated in the same patients, while also having a lower quality of life.

The persistent symptoms of IBD can cause chronic fatigue, pain and diarrhoea, 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 (21). One of the most prominent negative effects of IBD on work life is absenteeism. Individuals with IBD often experience higher rates of sick leave compared to their healthy counterparts (8). In addition to absenteeism, presenteeism—where individuals are physically present at work but are unable to perform at their full capacity due to illness—also plays a significant role in diminishing work productivity. Both absenteeism and presenteeism due to IBD has been studied over several occasions (7-11,22), and thus, we did not focus on these aspects of working life in this study. Overall, the absenteeism and presenteeism in our study seem somewhat similar compared to many of these earlier studies. A review article on the disability caused by IBD also covered work disability (23). However, the focus was mainly on disability pension and employment rates with also some mentions on absenteeism. Interestingly, Rogala et al. reported that even though the employment rates seemed

similar in IBD and non-IBD populations, there was a three-fold increase in short-term disability amongst IBD population compared to those in the control sample (24). This was reported as reduced activity at work/home and requiring extra effort due to illness. This further implies that this issue has not previously been studied thoroughly enough.

Furthermore, the ongoing challenges posed by IBD often necessitate changes in job roles or workplaces. Many individuals find themselves needing to shift to less physically demanding roles or seeking positions that offer more flexible working conditions, such as remote work or adjustable hours (25). For some, this may mean accepting lower-paying jobs or positions with fewer responsibilities, which can have an impact on career progression and financial stability. In more severe cases, individuals may need to change their occupation entirely and opt for work that accommodates their health needs but may not align with their skills, experience or professional aspirations. This can lead to a loss of professional identity and a sense of career dissatisfaction (25). In our study, the IBD patients who changed their jobs were significantly younger. It might be that the younger patients are still finding their place in their working life and career path or that they are overall more insecure about their chronic condition. One small study from Puerto Rico reported recently that 38% of rather young IBD patients felt that the disease limited their work goals, and one-fifth felt discriminated at work (26). Their patient sample consisted of 120 IBD patients with average age of 27 years, and the study group used both qualitative and quantitative data. These results were similar to our study emphasising the need to take into account the changes and modifications at the workplace. To our understanding, no other studies about the job changes or changes made in the working place has been published.

By design, the patient sample in this study covered IBD patients throughout different stages of their disease and represents an average IBD patient. Thus, the results can be thought to be somewhat generalizable to IBD patients overall. We tried to seek a comprehensive approach and also, used hospital data records for acquiring information on laboratory results, hospitalizations and medication use in addition to the questionnaire. Furthermore, in our study, the patients were provided an open-ended question and asked to use their own words to describe how the work had been negatively affected by IBD. If ready-made lists had been used, there would have been a possibility that some of those that are important to the patients could have been omitted. The study group feels that we have been able to acquire information from the patient's perspective, which is important to remember, especially when discussing chronic diseases. However, our study would have benefitted from a larger sample size, which maybe would have enabled more in-depth subgroup analyses.

Both clinicians and employers should ask about their IBD patient's overall quality of life and their ability to perform work duties. The IBDQ32 does not specifically assess patients' working life or studies (18-20). However, IBDQ scores implicated a lower quality of life in patients that had modified their jobs due to IBD and in those whose studies were negatively affected.

This study had limitations. First, the response rate of 50.8% was found to be sufficient. However, the non-responders were significantly younger, which could have had a clear impact on the results. It could be that the younger people would have even more disruptions made in their working place because of their illness. It is also possible that the questionnaire was answered by the most affected patients, thus overestimating the negative effects compared to an average IBD population. On the other hand, it may have been useful to have a control group without IBD giving the possibility to quantify to what extent IBD patients experienced negative effects on their work. However, this would have meant a similar survey for the control group, which might seem peculiar and could be difficult to receive enough responses. By asking if the negative effect was due to IBD, we tried to isolate IBD from other factors.

The findings of this study underscore the significant and multifaceted impact of Inflammatory Bowel Diseases on individuals' working lives. IBD not only affects physical health but also extends its influence into professional domains creating substantial challenges for those who suffer from these chronic conditions. Being able to work is important not only to the patient but also to society. Work is

important to the patient both mentally and financially. Having a disability that impairs work ability is known to reduce a patient's health-related quality of life (27). The cumulative effect of these challenges often results in a reduced quality of work life for individuals with IBD leading to a potential decline in overall life satisfaction. It is crucial for employers and policymakers to recognize the unique needs of employees with IBD and to implement supportive workplace practices. These might include offering flexible work schedules, providing reasonable accommodations and fostering an inclusive work environment that reduces stigma and supports mental well-being.

Conclusions:

IBD has a considerable negative impact on many patients' studies and working life that extends beyond commonly studied absenteeism and presenteeism. Future research should focus on understanding these challenges in detail and developing interventions that effectively reduce the impact of IBD in the workplace.

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Data Availability Statement

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

Disclosure statement

Authors have no conflicts of interest to declare.

Authors' contributions:

Concept and design: AM, RR, MV, KM.

Acquisition of data: AM, RR, KM.

Analysis and interpretation of data: AM, KM.

Drafting of Manuscript: AM, KM.

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Table 1. Descriptions of categorisations of the open questions

Categorization of the question concerning switching jobs.				
1. The employer did not agree to the proposed changes.		2. Despite changes, the job got too difficult to handle due to IBD.		3. Some other reason.
Categorization of the question concerning modifications in work.				
1. The physical load of the job was reduced.	2. Modifying the field of work or retraining.	3. The psychological burden was reduced.	4. Workplace was moved closer to a toilet.	5. Working hours were modified.

Table 2. Patient characteristics and demographics in all patients and those who have had to modify their work as well as those who have had to change their work. Mean values and SD in parenthesis or number and percentages in parentheses where applicable

	All, n=561	Modified work, n=164	Changed work, n=105
Age	53.17 (15.7)	47.7 (13.3)*	44.8 (13.5)*
Employed	321 (57.2%)	115 (70.1%)	83 (79%)
Blue Collar	138 (41.4%)	29 (33.0%)	43 (36.1%)
White Collar	176 (52.8%	54 (51.4%)	67 (56.3%)
Unemployed	37 (6.6%)	14 (8.5%)	12 (11.4%)
Student	25 (4.5%)	6 (3.7%)	5 (4.8%)
Pensioner	211 (37.6%)	43 (26.2%)	16 (15.2%)
Male	284 (50.6%)	90 (54.9%)	62 (59%)*
Crohn	201 (35.8%)	55 (33.5%)	34 (32.4%)
IBD years	17. (11.0)	16.4 (10.4)	16.2 (11.3)
IBDQ-score	171.5 (34.0)	165.4 (37.2)*	171.1 (34.7)
Biological use	67 (11.9%)	27 (16.5%)	17 (16.2%)
Hospitalization	22 (3.9%)	7 (4.3%)	4 (3.8%)
Highest Calpro	652.0 (1119.1)	673.1 (1078.0)	831.8 (1318.6)
Surgery	117 (20.9%)	33 (20.1%)	20 (19%)
Absenteeism last month (days)	1.8 (6.2)	2.2 (6.3)	2.6 (7.3)
Presenteeism last month (Hours)	7.7 (41)	14.5 (69.1)*	8.0 (19.6)

*$p<0.001$

Statistical comparisons between modified work and not modified work or changed work or have not changed work.

Table 3.

The proportions (in %) of patients' responses on how their work was modified (data available of 132 patients out of 164 who had modified their work by 80%)

Decreasing physical burden	Changing job field	Decreasing psychological burden	Moving workplace closer to toilet	Reducing working hours
29% (n=38)	9% (n=12)	10% (n=13)	20% (n=27)	32% (n=42)