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Alimentary Tract

Impact of inflammatory bowel diseases on working life: A French nationwide survey

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ABSTRACT

Background: Inflammatory bowel diseases (IBD) affect working-age patients. Data was lacking concerning the impact on working life.
Aims: The French IBD patient association conducted a nationwide survey to assess the burden of IBD at work.
Methods: An online survey was performed in 2016, targeting IBD patients working or having worked previously. The results were compared to those observed in the general population.
Results: Data from 1410 IBD patients were analyzed (62% Crohn's disease, 35% ulcerative colitis). Four-fifth of respondents were actively employed. Half of them stated that working with IBD was a problem. Compared to the general population, IBD employees had higher rates of permanent contracts, public employment but also of part-time contracts, and highly graduated patients were less likely to reach high qualified jobs. Among the disabling symptoms at work, fatigue was the most frequent (41%) followed by diarrhea (25%) and fecal incontinence (18%). Despite these difficulties, 76% were satisfied with their job. Most patients shared their IBD diagnosis with their colleagues, but 25% of them regretted it.
Conclusion: IBD has a strong negative impact on working life. While work satisfaction remains high, IBD affects career plans, highlighting the need for supporting measures to improve patients' work experience.

1. Introduction

Inflammatory bowel diseases (IBD) are chronic disorders responsible for many digestive symptoms. Extra-intestinal manifestations (EIMs) are also common in both Crohn's disease (CD) and ulcerative colitis (UC) [1]. Consequently, IBD can affect psychological, family, social and professional dimensions of patients' life, leading to poor quality of life [2,3], and disability [4]. Fatigue is one of the well-known factors involved [5,6].

In France, approximately 220,000 persons suffer from IBD, with a peak onset of 15–35 years of age [7], and many of them carry out an occupational activity. Few studies have already investigated the impact that IBD can have on patients' ability to work, but mainly as part of a more overall quality of life or disability assessment [8,9]. The Work Productivity and Activity Impairment Questionnaire (WPAI) is a generic tool specifically devoted to work disability [10,11]. It has been used in some IBD studies [12–14], demonstrating that both UC and CD can have a high impact on work productivity. Furthermore, it has been showed that work disability can lead to heavy indirect costs in IBD patients [15,16].

However, data was still lacking concerning a more detailed patients' perception of the disease-related burden at work. In this respect, the French national IBD patients' association, called Association François Aupetit (AFA), has performed, in collaboration with medical experts, a nationwide survey to assess the issues faced by IBD patients at work.

2. Patients and methods

2.1. Study design

The survey was designed in three phases: a qualitative phase enabling the construction of the questionnaire, a quantitative online survey, followed by a last qualitative step (focus groups).

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Here we present the results of the quantitative survey. The online survey was posted on the AFA website. The AFA communicated about the study *via* their magazine, and on Facebook and Twitter. This phase was conducted over 4 weeks from March to April 2016, targeting both AFA and non-AFA affiliated patients. Patients of both sexes, aged over 18, with an established diagnosis of IBD (CD, UC or IBD unclassified), currently working or having worked previously, were qualified to respond to the survey. Questionnaires with unfilled items were removed from the sample. The objective was to collect at least 1000 filled-in questionnaires.

The questionnaire included 68 questions in total (see Supplementary Material). Socio-demographic data were first collected including: gender, age, region of residence, last completed degree, family status. Clinical data were also collected including: type of IBD, disease duration, evolutionary course, previous and ongoing disease-related treatments, history of intestinal resection, and presence of stoma. Patients had to self-evaluate disease severity thanks to a semi-quantitative 3-grade scale broken down as "mild", "moderate" or "severe". They also had to determine the frequency of flare-ups as defined by recurrence of digestive and/or extra-intestinal symptoms. Twenty-four questions assessed patient's former and present professional activity and the impact of IBD on their professional career. Work satisfaction was defined on a 4-grade scale broken down as: "very satisfied", "satisfied", "not very satisfied", "not at all satisfied", likewise optimism about professional future which could be defined as "very optimistic", "optimistic", "pessimistic", "very pessimistic". Seven questions focused on the communication about IBD at work, and the last 17 questions assessed the consequences of IBD on the ability to work and perform regular activities, including the five questions of the WPAI questionnaire over the past seven days.

2.2. Data analysis

Categorical variables were described by percentages and continuous variables by mean ± standard deviation (SD).

WPAI scores measuring IBD patients' work and activity over the past 7 days were calculated, broken down as follows: WPAI 1: absenteeism rate; WPAI 2: efficiency loss rate (or presenteeism); WPAI 3: productivity loss rate (absenteeism and presenteeism); WPAI 4: overall activity impairment. Each WPAI sub-score ranges from 0 to 100%.

The results were compared to those observed in the general population, derived from nationwide surveys performed by the "Institut Français de l'Opinion Publique" (IFOP). Quota on age, gender, region and profession were used to ensure the representativeness of the sample.

A segmentation (or classification) analysis was performed based on questionnaire replies in order to identify different typological profiles of IBD patients according to respondents' perception of their disease and its impact on their professional life. Classification – also called typology – is part of the advanced analytics tools that are used for decades in research, especially market research. The aim is to identify, through the analysis of multiple variables, study subgroups or clusters characterized by specific attitudes or behaviors. The benefit of using this type of analysis is that it summarizes an important amount of data collected. Statistically speaking, the aim of this classification is to create subgroups within a group through minimizing the intra-group variance (to create subgroups that are as homogeneous as possible) and to maximize inter-group variance (to create subgroups that are as different as possible from each other). For this project, the "classical typology" program on the analytical software Coheric Analytics SPAD® has been used. The technique involves a sequence of two multivariate statistical techniques: a multiple correspondence analysis of variables (MCA), followed by the clustering of respondents in several subgroups according to the approach names "mixed classification" that uses the WARD method and the K-MEANS cluster analysis.

Table 1
Demographic and clinical characteristics of respondents (n = 1410).

Demographic and clinical data	Total (n = 1410)
Sex, n (%)	
Female	1070 (76)
Type of IBD	
Crohn's disease, n (%)	875 (62)
Ulcerative colitis, n (%)	496 (35)
IBD unclassified, n (%)	39 (3)
Age (years), mean (SD)	38 (10.1)
18–29 years old, n (%)	297 (21)
30–39 years old, n (%)	547 (39)
40–49 years old, n (%)	350 (25)
50–59 years old, n (%)	175 (12)
60 years old and over, n (%)	41 (3)
Disease duration (years)[a]	
<1 year, n (%)	55 (4)
1–9 years, n (%)	632 (45)
> 10 years, n (%)	723 (51)
Disease activity[b]	
Mild disease, n (%)	203 (14)
Moderate disease, n (%)	748 (53)
Severe disease, n (%)	385 (27)
Evolutionary course of the disease activity	
Chronically active, n (%)	177 (13)
>1 flare-up per month, n (%)	157 (11)
1 flare-up per month, n (%)	118 (8)
≥1 flare-up per year, n (%)	484 (34)
<1 flare-up per year, n (%)	474 (34)
Previous surgery, n (%)	471 (33)
Previous colostomy, n (%)	66 (5)
Ongoing IBD-related treatment[c]	
Aminosalicylates, n (%)	418 (30)
Immunosuppressants, n (%)	400 (28)
Anti-TNF therapy, n (%)	573 (41)

IBD: Inflammatory bowel disease; SD: Standard deviation; TNF: Tumor necrosis factor.

[a] Disease duration was captured by brackets so that the precise distribution is not available.

[b] 6% of patients did not express any opinion on this issue.

[c] Missing data for 19 patients.

2.3. Ethics approval and informed consent

All patients gave their informed consent when participating in the web-based survey. This survey was declared to the "Commission Nationale Informatique et Libertés" (CNIL).

3. Results

3.1. Respondents' characteristics

3.1.1. Demographic and clinical characteristics

Over one month, 1410 French IBD patients responded to the online survey. Among them, 60% were affiliated to the AFA. Demographic and clinical characteristics are summarized in Table 1. Twenty-seven percent were active smokers, and 16% were taking antidepressants or anxiolytics.

3.1.2. Socio-professional characteristics

Socio-professional characteristics are summarized in Table 2. Forty-one percent of all respondents (44% of male respondents, 40% of female respondents) had a high school education background as compared to 25% in the general French population (27% of male population, 24% of female population). The main professional sectors included health and social activities (21%), services (14%), trade (12%) and industry (8%).

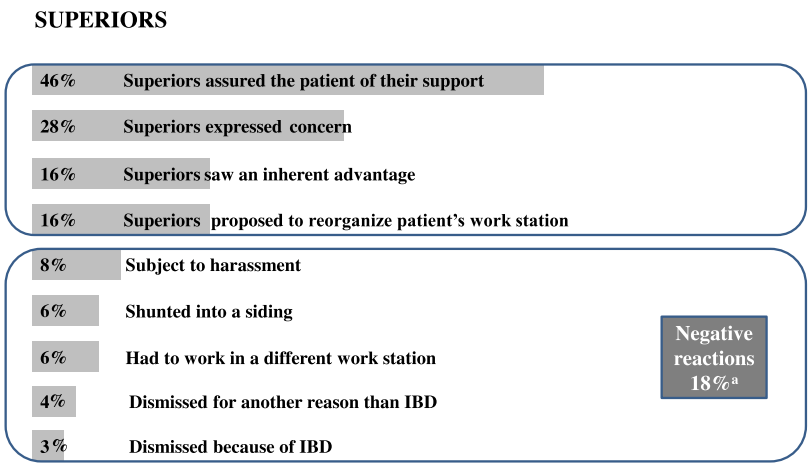

Fig. 1. Superiors' reaction after receiving patient's IBD diagnosis.
The reaction was mostly supportive: superiors assured the patient of their support in 46% of cases, expressed concern in 28% or saw an inherent advantage in 16% of cases, and 16% of respondents were proposed to reorganize their work station. However, some of these patients experienced a negative reaction from their hierarchy (18%): 8% were subject to harassment, 6% were shunted into a siding, 6% had to work in a different work station, and even 7% were dismissed (3% because of IBD, 4% for another reason).
[a]Patients could have more than one response.

Table 2
Socio-professional characteristics of IBD respondents compared to the general population.

Socio-professional data	IBD respondents (n = 1410)	General population[a]
Professional status		
Actively employed, n (%)	1126 (80)	–
Unemployed, n (%)	98 (7)	–
Disability leave, n (%)	64 (5)	–
Retired, n (%)	22 (2)	–
Without work for another reason, n (%)	100 (7)	
Type of employment contract[b]		
Permanent contract, n (%)	921 (82)	74
Temporary contract, n (%)	136 (12)	12
Agency work ("interim"), n (%)	9 (1)	2
Without any contract, n (%)	60 (5)	12
Public employment, n (%)[b]	411 (37)	29
Part-time contract, n (%)[b]	293 (26)	19
Work satisfaction[b]		
Very satisfied, n (%)	171 (15)	74
Satisfied, n (%)	685 (61)	–
Dissatisfied, n (%)	270 (24)	26

IBD: Inflammatory bowel disease; IFOP: Institut Français de l'Opinion Publique.
[a] Data from IFOP database.
[b] This part of the analysis focuses on respondents working at the moment of the survey (n = 1126).

3.2. Descriptive results

This part of the analysis focuses on respondents working at the moment of the survey (n = 1126).

3.2.1. IBD patients seek job security but a full-time workload can be difficult

Compared to the general population, actively employed respondents had higher rates of permanent work contracts and public employment, but also a higher rate of part-time contracts (Table 2). In average, IBD employees had been working in 3.4 (± 2.7) different companies. More than half of them (61%) had a stable professional course, *i.e.* a mean stay in the same company ≥ 3 years for those with < 10 years of professional experience, or ≥ 5 years for those with ≥ 10 years of experience.

3.2.2. IBD impacts patients' career

Many respondents declared that IBD changed their original career plan: 15% had to renounce to their initial choice, 24% chose a job they adjusted according to their disease. IBD patients with high degree of education accessed less frequently to highly skilled jobs than the general population (39% *versus* 64%). Thirty-nine percent also declared that their disease induced changes in the course of their career: among them, 25% felt that the choice of jobs was limited, 15% considered that IBD was a barrier to get a job, 11% declared having been dismissed because of IBD. Forty-five percent of respondents declared that IBD restricted their career development, and 43% asserted that their disease prevented them from fulfilling missions they should have been able to perform. Moreover, 68% thought they had to push themselves beyond their professional limits and 49% declared that their career had become a second priority because of IBD. Overall, half of respondents stated that living with IBD at work was a problem. Only 37% affirmed that they encountered no career difficulties at all, 19% that they had no impact on their working life.

3.2.3. Main symptoms impacting working life

Fatigue was the most frequent of these symptoms (41%) followed by diarrhea (25%) and fecal incontinence (18%). Pain and anxiety and/or depression were less frequent, reported by 10% and 3% of respondents, respectively.

Diarrhea and fecal incontinence episodes could be highly problematic, both at work and in public transport. Therefore, 75% of respondents chose to drive to work, and three-quarters of them stayed in a workplace close to home: 77% had less than one hour's commuting-time *versus* 65% in the general population. According to respondents, all these symptoms could also be responsible for indirect consequences on work productivity, such as a slower working pace and a perceived degraded quality of work.

3.2.4. Optimism about professional future and job satisfaction

More than half of respondents (59%) were optimistic about their professional future, as compared to 66% of the general population. Seventy-two percent felt that their chances of finding a new job would be low; among them, 80% thought that this would be, completely or partially, related to IBD.

However, 76% of respondents were generally satisfied with their occupational situation, which was similar to the general population (74%), but 80% of dissatisfied patients attributed it to IBD. Overall, IBD patients had a better perception of their professional situation than the general population, except for three selected items: work-related stress (68% *versus* 54%), balance between working and

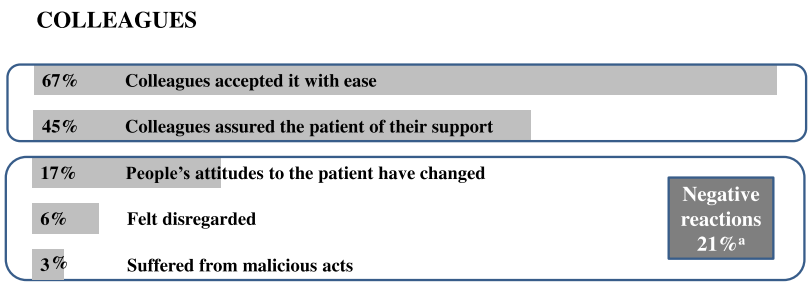

Fig. 2. Colleagues' reaction after receiving patient's IBD diagnosis.
Colleagues reacted in a positive way for the majority of them: 67% accepted it with ease, and 45% assured the patient of their support. However, 21% of respondents received a negative feedback from their co-workers: people's attitudes to the patient have changed in 17% of cases, 6% of patients suffered from malicious acts, and 3% felt disregarded.
[a]Patients could have more than one response.

Table 3
Comparison of WPAI scores according to the self-perception of disease severity by the patient.

WPAI scores/disease severity	Total (n = 1336)[a]	Mild (n = 203)	Moderate (n = 748)	Severe (n = 385)
WPAI 1: absenteeism rate (%)	10.9	5.8	9.8	15.2
WPAI 2: efficiency loss rate (%)	34.3	25.4	32.6	42.7
WPAI 3: productivity loss rate (%)	36.0	26.1	34.4	44.4
WPAI 4: overall activity impairment (%)	46.9	35.1	45.5	56.0

WPAI: Work productivity and activity impairment questionnaire.
[a] 6% of patients did not express any opinion on this issue.

personal lives (66% of satisfied respondents *versus* 75% of the general population), and safety conditions at work (57% of satisfied respondents *versus* 65% of the general population).

3.2.5. Informing colleagues about IBD

Most respondents shared their IBD diagnosis with their superiors (immediate superior: 74%, indirect supervisors: 57%), mainly to justify their frequent sick leaves. The human resources manager (46%), the staff representative (19%) and the union representative (18%) were less frequently informed. Fig. 1 illustrates superiors' reaction after the announcement of the diagnosis.

Most patients also communicated with their colleagues (closest colleagues: 85%, others: 26%), who reacted in a positive way for the majority of them. Fig. 2 summarizes colleagues' reactions after receiving IBD diagnosis.

Eighty-four percent of respondents informed their occupational physician about their IBD, but only 67% of them were satisfied with the solutions that have been proposed.

Of the 89% of respondents who shared the IBD diagnosis in their working environment, 25% regretted having done so.

3.2.6. WPAI scores

While absenteeism rate (WPAI 1) was low at 11%, efficiency loss rate (WPAI 2) and productivity loss rate (WPAI 3) were more important, respectively 34% and 36%. Overall activity impairment (WPAI 4) was relatively high (47%). WPAI scores were proportional to the disease severity (Table 3).

3.3. Respondents' profiles

Five typological profiles were identified among the respondents.

The "fighters" (18%): patients with severe IBD who control it completely despite heavy symptoms. They are elder people with a stable job.

The "positives" (24%): patients with moderate IBD who cope well with their disease despite the difficulties they face. They are quite young, not yet stable in their job, but have a permanent full-time contract.

The "spared" (16%): patients with mild IBD without any impact on their professional life. They are quite young, with high degree of education, and have a permanent full-time contract.

These three groups are satisfied with their professional life and optimistic about their future.

The "vulnerables" (22%): patients with severe IBD with important impact on their professional life. They encountered professional difficulties to such an extent that they had to change their career orientation.

The "outcasts" (20%): patients with severe IBD who completely disrupted their professional life. Most of them are unemployed.

The two latter groups are dissatisfied with their professional life and are pessimistic about their future. They are in a precarious situation.

3.4. Patients' rights: the disabled worker status

The majority of respondents (82%) felt that they were poorly informed about their rights as workers with a chronic disease. More than half of respondents (68%) nonetheless knew that they had the right to get a disabled worker status, but only 29% of them were actually aware of the benefits that this status could provide. Almost three-quarters of respondents (72%) already had (53%) or wanted (19%) to get this specific status while 28% rejected it.

3.5. Key improvements expected by IBD patients at work

Most respondents wanted their job to be adjusted if needed (65%) and demanded more flexibility in the management of their working hours (64%), 60% requested a more easily accessible "therapeutic part-time" employment and 58% would like to do home-based tele-work. Sixty-one percent asked for large information campaigns reaching out to all professional workers; the same proportion would like to have their medical examinations during working time.

4. Discussion

To the best of our knowledge, this survey is the first study to investigate, exclusively and in great detail, the impact of IBD on

working life in a large nationwide cohort of 1410 patients. We showed that IBD can affect career plans and work productivity. IBD patients often complain about fatigue and work-related stress, although most patients remain satisfied with their job.

Some of our results are consistent with previous studies, especially the BIRD study, recently performed in a French nationwide cohort of 1185 IBD patients, that assessed all dimensions of patient-reported outcomes (PROs) [4]. However, the BIRD study did not explore in depth the impact of IBD on working life, only focusing on WPAI scores. This patient population was similar to ours, the only differences being the proportion of women and the median age, respectively lower (61.5%) and higher (45 years old).

The WPAI scores were not exactly similar in both cohorts, but the larger proportion of women might explain the higher scores in our cohort, as the female gender has been described as a factor associated with work disability [4,17].

Fatigue emerged as a major symptom in both studies: in our survey 41% of actively employed respondents reported fatigue as the most disabling symptom at work, while 47.4% complained of overall tiredness in the BIRD study, with a strong inverse correlation between overall work impairment and the FACIT-F (Functional Assessment of Chronic Illness Therapy-Fatigue) score. This finding is also consistent with a systematic review published in 2010, reporting fatigue in about 45% of patients with IBD in remission [5]. In an American study, the prevalence of fatigue was lower (26.4%), but fatigued patients reported more work impairment [6].

Beyond confirming this data, our survey explored other larger dimensions of IBD patients' working life. It appeared that they seek more secure professional course than the general population, as respondents had a higher rate of permanent work contracts and public employment. In parallel, they have a higher rate of part-time contracts, reflecting the difficulties they face in assuming a full-time workload. This is consistent with the results of a Dutch study [18].

Our survey also investigated the symptoms that specifically affect patients' working life. Apart from fatigue, diarrhea and incontinence appeared to be extremely disabling, leading patients to set up avoiding strategies. Another study showed that IBD patients have to develop strategies and environmental supports at work [19]. According to patients, all these symptoms could also impact their work productivity, as confirmed in another study by De Boer *et al.* [20]. In the same vein, our study also demonstrated that work disability is proportional to inflammatory bowel disease severity, as it has already been shown in rheumatology for arthritis [21–25], and in pneumology for chronic obstructive pulmonary disease [26–28] and asthma [29,30].

Despite all these negative impacts, most patients in our cohort reported a high degree of satisfaction concerning their job. However, work-related stress was more frequently reported by IBD patients as compared to the general population. Stress at work is reported in other publications but data is not homogenous. In a Swiss cohort of more than 1500 IBD patients, the prevalence of job stress was remarkably low (5.7%), but three factors were associated with a higher level: female gender, full-time contract, and extra-intestinal manifestations [31]. In a Canadian survey, IBD was rated as a highly frequent source of stress by 20–30% of patients with persistently active symptoms compared to 1–2% of patients in clinical remission, however work, as well as finances and family were equal sources of stress [32].

Our study identified five typological profiles, showing that IBD patients may have very different work experiences, half of them being slightly affected by the disease in their working life, while the other half is pessimistic and dissatisfied with both professional and personal lives. This finding confirms that a stable employment is a key driver of quality of life in IBD patients, as it has already been described in other studies [20,33].

This survey also demonstrated that most IBD patients communicate about their disease with their hierarchy and colleagues. Although the reaction was mostly supportive, about one-fifth of patients experienced a negative reaction, highlighting the need for a better understanding of IBD in companies. In addition to large information campaigns to the attention of professional workers, this survey reports other concrete needs that patients expressed to improve their working condition, such as an increased flexibility in their job, and a more appropriate medical care at work.

Some parameters were nevertheless not or little investigated in this survey. Our study did not explore factors associated with productivity loss as it was outside the scope of the research. However, this data is available from other publications. A recent review identified eight factors associated with work disability: extreme ages, female gender, lower education, disease activity, disease course (penetrating and perianal disease), previous surgery, but also comorbidities and corticosteroid use [17]. Another study conducted in a Hungarian cohort of 443 IBD patients confirmed that young age, previous surgery and arthralgia are associated with a higher risk of disability pension [34].

Moreover, most patients now receive biological treatments. In our survey, 41% of respondents received anti-TNF treatments. However, the correlation between these treatments and patients' working experience was not investigated, while several publications reported positive effects of these treatments on work productivity [35–40].

Finally, it should be noted that selection and participation bias might be quite significant in this type of web-based survey. Indeed, our cohort included a vast majority of female respondents with a mean age of 38 years old, and 80% of them assessed disease severity as moderate or severe. This sample of respondents may not be representative of the overall IBD population as they might possess certain traits which potentially result in biased estimates. In addition, this survey is based on a French population and it may be difficult to extrapolate our results to other countries, all the more so as our cohort represents only 0.6% of the 220,000 people suffering from IBD in France.

In conclusion, this survey assesses in depth the impact of IBD on working life, providing data about patients' perception of their professional life. Although most patients are satisfied with their job, IBD may affect career plans, work productivity, and induce work stress. Fatigue is the most disabling symptom. Supporting measures are needed to improve patients' work experience.

Conflict of interest

IFOP is a market research and opinion poll company. They intervene for a number of clients including on behalf of clients of the Life Science Industry, in the frame of paid contracts.

The other authors declare that they have no competing interests.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at https://doi.org/10.1016/j.dld.2019.01.024.

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