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# Young Adult Patients With Paediatric-Onset Inflammatory Bowel Disease Have a Higher Educational Level and a Higher Employment Rate Than the General Population

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**Keywords:** Crohn's disease | education | inflammatory bowel disease | profession | ulcerative colitis

## ABSTRACT

**Background & Aims:** There are few published data on the impact of paediatric-onset inflammatory bowel diseases on education and employment. The objective of the present cross-sectional study was to assess the educational level and occupational status of adult patients with paediatric-onset inflammatory bowel diseases from the EPIMAD Registry.

**Methods:** The inclusion criteria were (i) a diagnosis of paediatric-onset (< 17 years at diagnosis) inflammatory bowel diseases, and (ii) age 25 or over at the time of study. The patients answered a self-questionnaire on their educational level and profession. The data were compared with those of the general population of the same age and geographic area.

**Results:** Three hundred and sixty-one patients (286 with Crohn's disease and 75 with ulcerative colitis) filled out and returned the questionnaire. The median [interquartile] age was 15.0 [12.9; 16.3] years at diagnosis and 34.2 [29.6; 39.5] years at the time of the study. Patients were more likely to have a higher education degree than the general population (57% vs. 41%, $p < 0.0001$). The unemployment rate was significantly lower among study participants than among the general population (9% vs. 15%, $p = 0.001$). Salaried patients were significantly more likely to be employed in the healthcare sector (14% vs. 9% in the general population; $p = 0.005$) and in the public sector (34% vs. 22% in the general population; $p < 0.0001$).

**Conclusion:** Our results showed that relative to the general population, patients with paediatric-onset inflammatory bowel diseases have a higher educational level and a higher employment rate, and are more likely to work in the healthcare and public sectors.

**Abbreviations:** CD, Crohn's disease; HBI, Harvey-Bradshaw Index; IBD, inflammatory bowel disease; INSEE, *Institut National de la Statistique et des Etudes Economiques* (French National Institute of Statistics and Economic Studies); IQR, interquartile range; SCCAI, Simple Clinical Colitis Activity Index; SIBDQ, Short Inflammatory Bowel Disease Questionnaire; UC, ulcerative colitis.

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For a complete listing of the EPIMAD study group, see the Acknowledgments section.

**Summary**

- Summarise the established knowledge on this subject
  - The relationship between paediatric-onset IBD and academic or professional difficulties is not well studied. Frequent school or work absences may negatively impact education and employment opportunities.
  - Yet, patients may develop coping strategies that help them succeed academically and professionally. Studies suggest that they achieve at least average or above-average education levels.
- What are the significant and/or new findings of this study?
  - Patients with paediatric-onset IBD were more likely to have a higher education degree and a higher employment rate as compared to the general population, demonstrating a true ability to cope with the disease.
  - Patients were more often employed in the healthcare and public sectors.
  - Those who faced difficulties during studies had lower educational levels, highlighting the need for better support.

## 1 | Introduction

The incidence of paediatric inflammatory bowel disease (IBD) has increased dramatically over the last few decades [1, 2]. Paediatric-onset IBD is usually considered to account for between 10% and 25% of incident IBD cases (depending on the upper age limit used in the definition of onset, which ranges from 15 to 20) and is associated with a high morbidity rate. Patients with paediatric IBD often present with a more aggressive clinical course, more extensive disease, and more frequent complications (such as nutritional impairment, delayed puberty, growth retardation, disability, and the need for surgery) [3–6]. These patients also experience more IBD-related hospital admissions than their adult-onset counterparts [7].

IBD follows a chronic relapsing-remitting course and thus significantly impacts the patients throughout their lives. Furthermore, adolescent patients are affected by IBD during a period that is critical in terms of their education and career plans. As with many chronic illnesses, IBD has a significant impact on a child's or adolescent's physical, emotional and social development. Furthermore, it is well established that the symptoms of IBD worsen a patient's quality of life (QoL) [8, 9].

The putative relationship between paediatric-onset IBD and difficulties during studies or with future employment has not been extensively studied. On one hand, one can hypothesise that the recurrent and sometimes long absences from school or work associated with disease exacerbations have severe negative impacts on a person's education or employment. On the other hand, the affected adolescents might develop coping strategies that enable them to succeed more readily in higher education and at work. The latter hypothesis would be coherent with reports showing that people with paediatric-onset IBD have an above-average or at least average educational level [10–17]. The objective of the present study was therefore to assess educational levels and employment rates in young adult patients with paediatric-onset IBD in comparison to members of the general population of the same age range and sex.

## 2 | Patients and Methods

### 2.1 | Study Population

The main study inclusion criteria were (i) documentation in the EPIMAD registry (see below), (ii) Inflammatory Bowel Disease (IBD) diagnosed before the age of 17, and (iii) age 25 or over at the time of study (to ensure that all participants had completed their education). The EPIMAD registry was initiated in 1988 and has been described in detail elsewhere [18]. Briefly, all gastroenterologists and paediatric gastroenterologists practicing in the private or public sectors in northern France ($n$ = 265) have reported on all patients consulting for the first time for symptoms suggestive of IBD. On a regular basis (three times a year, on average), staff from the EPIMAD office visit the gastroenterologists' offices and collect information from the patients' medical records. The final diagnosis of IBD is made by two expert gastroenterologists according to previously published and validated criteria [18].

### 2.2 | Data Collection

Patients were contacted from November 2019 to December 2020 by postal mail and asked to fill out a self-questionnaire concerning their highest educational qualification or degree, their age on obtainment of the highest educational qualification or degree, profession, current occupational status, socioprofessional category, work disability status, previous and ongoing medical treatments, previous surgery related to IBD, the presence of stoma, disease activity (according to the Harvey-Bradshaw Index (HBI) for patients with Crohn's disease (CD) and the Simple Clinical Colitis Activity Index (SCCAI) for patients with ulcerative colitis (UC), and quality of life (QoL) according to the Short Inflammatory Bowel Disease Questionnaire (SIBDQ) [19–21]. Active disease was defined as an HBI > 3 for CD or an SCCAI > 2 for UC. QoL was defined as 'poor' (with a SIBDQ score below 45), 'normal' (with a SIBDQ score between 45 and 60) or 'high' (with a SIBDQ score over 60) [22]. Patients were also asked about the impact of IBD on their choice of educational courses, the progress of their educational courses, and their choice of profession.

Professions were classified according to the socio-professional categories defined by the French National Institute for Statistics and Economic Studies (*Institut National de la Statistique et des Etudes Economiques* (INSEE)).

The study questionnaire was specifically designed for the present research. To facilitate comparisons with data on the general population, the questions on education level and occupation were taken from the questionnaire used in the INSEE national

population census. The questionnaires used in the present study to assess quality of life and disease activity have been validated in the literature. The study questionnaire was first tested on 40 patients and then modified if required.

Demographic and clinical characteristics at diagnosis were extracted from the EPIMAD registry's database: age, sex, the date of diagnosis, the time interval between symptom onset and diagnosis, clinical presentation at diagnosis, and any family history of IBD. The CD's location was defined according to the Montreal classification [23] as pure ileal involvement (L1), pure colonic involvement (L2), ileocolonic involvement (L3) and/or upper gastrointestinal disease (L4, which could be combined with L1, L2 or L3). Patients with ileocaecal involvement were classified as L3. The presence or absence of perianal lesions was noted. The CD's behaviour was not assessed because this variable has only been recorded since 2008. The UC's location was defined according to the Montreal classification as proctitis (with disease limited to the rectum (E1)), left-sided colitis (with disease limited to the colon below the splenic flexure (E2)), or extensive colitis (with involvement of the colon beyond the splenic flexure (E3)).

To avoid multiple entries and ensure anonymity, an identifier number was assigned to each patient and affixed to each questionnaire sent out. Patients who had not sent back the completed self-questionnaire within 2 months were chased up by mail and asked again to participate in the study.

### 2.3 | Definition of Outcomes

The definitions used in the present study were taken from the INSEE 2020 census of the population in France.

Educational level was defined as the highest educational qualification or degree obtained in five groups: (i) No formal education or primary education only; (ii) junior secondary education; (iii) short vocational secondary education; (iv) upper secondary education (a baccalaureate high school leaving certificate, or equivalent) and (v) higher education. The latter category was subdivided into 2 years of higher education, 3 or 4 years of higher education, and five or more years of higher education.

The occupational status was defined as the participant's primary situation at the time of the study: employed, apprentice or paid trainee, student or unpaid trainee, unemployed, retired, or homemaker. The occupied labour force was defined as all people exercising a profession or helping other people in their work (whether paid or not): employed people, apprentices, trainees, employed students, and employed retirees (Supporting Information S1: Figure S1). The labour force was defined as the occupied labour force plus the active unemployed population (i.e. unemployed people actively looking for work). The unemployment rate was defined as the number of unemployed people as a proportion (in percentage) of the labour force.

Professional occupations were classified with regard to the six socioprofessional categories defined by the INSEE: (i) farmers; (ii) craftspeople, shopkeepers, and managers; (iii) executives and intellectual professions; (iv) intermediate professions; (v) employees; and (vi) workers. Healthcare professionals were defined as physicians, dentists, pharmacists, nurses, and other healthcare providers.

### 2.4 | Reference Data

Reference data for the general population of the same age and sex and from the same geographic area were obtained from the INSEE population census database (for reference data on the educational level, occupational status, socioprofessional category and unemployment rate) and 'all employees' database (for employment in the public and in the healthcare sector). The reference year for these data was 2019.

### 2.5 | Statistical Analysis

Data management and statistical analysis were carried out using SAS software (version 9.4, SAS Institute Inc., Cary, NC, USA). The threshold for statistical significance was set to $p \leq 0.05$.

Quantitative variables were quoted as the mean (standard deviation) or the median [interquartile range (IQR)], depending on the distribution. Qualitative variables were quoted as the frequency (percentage). Missing data were removed from the analysis. The numbers of missing data are given in the tables or in table footnotes.

In order to evaluate non-response bias, the respondents and non-respondents were compared with regard to their clinical and demographic characteristics at diagnosis. To assess differences in the socio-economic level, we examined the FDEP09 deprivation index [24] and the level of urbanisation of the place of residence at diagnosis.

Given that our patient population was likely to differ from the general population with regard to the age and sex distribution, we stratified our sample [25] by five-year age group and by sex so that (i) it was consistent (in terms of proportions) with the 2019 INSEE national census population and (ii) intergroup comparisons were not biased by differences in the age and sex distributions. Below, the tables give the raw and adjusted rates and the text presents the adjusted rates only. The paediatric-onset IBD population and the reference general population were compared by applying chi-square tests of comparison to a theoretical proportion (goodness of fit test) taking into account post-stratification weights. Theoretical proportions were those observed in reference data.

The study protocol was approved by an independent ethics committee (*CPP Nord-Ouest IV*, Lille, France; reference: 2017 A003397 46).

## 3 | Results

### 3.1 | Response Rate

A total of 1076 patients registered in the EPIMAD database met the inclusion criteria. Of these, 207 were lost to follow-up, 19

had died since the diagnosis of IBD, and 5 had a complicated personal situation (e.g. incarceration) and so were not contacted (Supporting Information S1: Figure S2). Ultimately, 845 patients were contacted by mail. One hundred patients no longer lived at the mailing address given in the database, and 361 patients (286 with CD and 75 with UC) sent back the completed questionnaire: this corresponded to 34% of the eligible patients, 43% of the patients sent a questionnaire (including those with an incorrect mailing address), and 48% of the patients who actually received the questionnaire. The patients filled out the self-questionnaire between November 2019 and June 2021.

### 3.2 | Clinical and Demographic Characteristics of the Patients

Forty-seven percent ($n$ = 170) of the respondents were men (Table 1). The median [IQR] age was 15.0 [12.9; 16.3] years at diagnosis and 34.2 [29.6; 39.5] at the time of the study. The median disease duration was 20.7 years [15.7; 26.1]. Seventy-nine percent ($n$ = 286) of respondents had CD. At the time of the study, about half of the patients with CD had an ileocolonic involvement ($n$ = 158, 57%), 32% had an upper disease ($n$ = 93), and 23% had anoperineal lesions ($n$ = 23). Half of the patients with UC had an extended disease (E3, $n$ = 36, 49%).

Forty-three percent of the patients ($n$ = 141) were in remission at the time of the study, 52% ($n$ = 168) had active disease, and 5% ($n$ = 16) had severe disease. The median QoL rating was 54 [45; 61]. Twenty-three percent ($n$ = 79) of the patients had a low QoL, 51% ($n$ = 172) had a normal QoL and 26% ($n$ = 88) had a high QoL (Table 1).

### 3.3 | Comparison of Respondents and Non-respondents

The differences in age and sex between respondents and non-respondents were not statistically significant. Seventy-nine percent ($n$ = 286) of the respondents and 74% ($n$ = 527) of the non-respondents had CD ($p$ = 0.047). Concerning the patients with CD, L4 involvement was significantly more common among respondents (32%, $n$ = 93) than among non-respondents (24%, $n$ = 127; $p$ = 0.010). Concerning the patients with UC, the disease was significantly more extensive in respondents than in non-respondents: E1, E2 and E3 locations were reported in 12%, 38% and 49% of the respondents and 31%, 30% and 38% of the non-respondents ($p$ = 0.007). In order to assess a potentially biased relationship between response status and socio-economic status, we compared respondents and non-respondents with regard to the deprivation index (in quintiles) and the level of urbanisation of the place of residence (Table 1). The intergroup difference in the deprivation index was not statistically significant ($p$ = 0.162). However, the intergroup difference in the urbanisation level was significant ($p$ = 0.036); relative to non-respondents, respondents were more likely to live in a rural area than the general population (22% vs. 28%, respectively) and less likely to live in a densely populated area (38% vs. 32%, respectively).

### 3.4 | Educational Level

For the 359 patients having finished their formal education, the median [IQR] age at highest diploma was 22 [19; 24] years (Figure 1a and Supporting Information S1: Table S1). Compared with the general population, patients had a higher educational level; the proportions with a degree from a higher education establishment were 41% and 57% ($p$ < 0.0001).

### 3.5 | Professional Status

The great majority of the patients (82%, $n$ = 294) were in work at the time of the study (Table 2). Five of 294 patients were on sick leave or maternity/paternity leave at the time of the study.

The labour force comprised 91% ($n$ = 327) of the patients; this proportion was similar in the general population (90%, $p$ = 0.578) (Table 3). Among the labour force population, the unemployment rate was lower among the patients than in the general population (9% vs. 15%, respectively; $p$ = 0.001). Ninety-one percent ($n$ = 271) of the occupied labour force were salaried employees, and 82% ($n$ = 238) had full-time work; these proportions were similar in the general population (92% ($p$ = 0.927) and 84% ($p$ = 0.172), respectively).

The distribution of socioprofessional categories in the patient group differed significantly ($p$ < 0.0001) from that in the general population (Figure 1b and Supporting Information S1: Table 2). Indeed, the proportion of executives and higher intellectual professions and the proportion of intermediate professions were higher in the patient group than in the general population (22% vs. 16%, and 41% vs. 28%, respectively).

A total of 115 (32%) patients were officially registered as disabled. The proportion in the labour force population was lower for patients with a disability (84%, $n$ = 97) than for patients without a disability (93%, $n$ = 230; $p$ = 0.006). The unemployment rate was higher among patients with a disability (11%, $n$ = 11 out of 97) than among patients without a disability (9%, $n$ = 20 out of 230), although this difference was not statistically significant ($p$ = 0.456).

Of the salaried patients, 37% ($n$ = 100, 3 missing data) had informed their employer about their disease, 72% ($n$ = 192, 1 missing data) had informed their work colleagues, and 83% ($n$ = 219, 7 missing data) had informed their occupational physician.

### 3.6 | Factors Associated With a Higher Educational Level

Disease activity and quality of life at the time of the study were the only factors significantly associated with educational level. In a univariate analysis, active disease and low quality of life were negatively associated with a higher educational level (odds ratio [95% confidence interval (CI)] = 0.47 [0.30; 0.75] for active disease vs. remission, $p$ = 0.001; 0.44 [0.26; 0.77] for low QoL vs. normal QoL, $p$ = 0.003; and 1.20 [0.50; 2.05] for high QoL vs.

**TABLE 1** | Clinical and demographic characteristics of patients with paediatric-onset IBD overall, and a comparison of respondents ($n = 361$) and non-respondents ($n = 715$). Significant differences are given in bold.

| | Total ($n = 1076$) | Respondents ($n = 361$) | Non-respondents ($n = 715$) | *p*-value | Missing data |
|---|---|---|---|---|---|
| Individual characteristics | | | | | |
| Male sex | 535 (49.7%) | 170 (47.1%) | 365 (51.0%) | 0.220 | 0 (0.0%) |
| Age at diagnosis (y)[a] | 15.0 [12.7; 16.2] | 15.0 [12.9; 16.3] | 15.1 [12.7; 16.2] | 0.842 | 0 (0.0%) |
| Disease duration (y)[a] | 20.5 [15.4; 25.9] | 20.7 [15.7; 26.1] | 20.5 [15.3; 25.8] | 0.666 | 0 (0.0%) |
| Age at the time of the study (y)[a] | 34.2 [29.6; 39.5] | 34.2 [29.6; 39.5] | 34.2 [29.6; 39.5] | 0.926 | 0 (0.0%) |
| Disease | | | | | |
| CD | 813 (75.6%) | 286 (79.2%) | 527 (73.7%) | **0.047** | 0 (0.0%) |
| UC | 263 (24.4%) | 75 (20.8%) | 188 (26.3%) | | |
| Family history of IBD | 133 (12.4%) | 54 (15.0%) | 79 (11.0%) | 0.066 | 0 (0.0%) |
| Extra-intestinal symptoms | 158 (14.7%) | 63 (17.4%) | 95 (13.3%) | 0.068 | 0 (0.0%) |
| Disease activity | | | | | 36 (10.0%) |
| Remission | | 141 (43.4%) | | | |
| Active disease | | 168 (51.7%) | | | |
| Severe disease | | 16 (4.9%) | | | |
| SIBDQ | | 54 [45; 61] | | | 22 (6.1%) |
| Low QoL | | 79 (23.3%) | | | |
| Normal QoL | | 172 (50.7%) | | | |
| High QoL | | 88 (26.0%) | | | |
| CD (at diagnosis) | *n = 813* | *n = 286* | *n = 527* | | |
| Disease location | | | | | |
| L1 | 130 (16.6%) | 51 (18.3%) | 79 (15.7%) | 0.629 | 30 (2.8%) |
| L2 | 197 (25.2%) | 70 (25.1%) | 127 (25.2%) | | |
| L3 | 456 (58.2%) | 158 (56.6%) | 298 (59.1%) | | |
| Upper location (L4) | 220 (27.1%) | 93 (32.5%) | 127 (24.1%) | **0.010** | 0 (0.0%) |
| Perineal lesions | 50 (6.1%) | 23 (8.0%) | 27 (5.1%) | 0.100 | 0 (0.0%) |
| UC (at diagnosis) | *n = 263* | *n = 75* | *n = 188* | | |
| Disease location | | | | | |
| E1 | 67 (26.0%) | 9 (12.3%) | 58 (31.3%) | **0.007** | 5 (1.9%) |
| E2 | 84 (32.6%) | 28 (38.4%) | 56 (30.3%) | | |
| E3 | 107 (41.4%) | 36 (49.3%) | 71 (38.4%) | | |
| Characteristics of the place of residence at diagnosis | | | | | |
| Deprivation index | | | | | |
| 1st quintile | 137 (12.8%) | 58 (16.2%) | 79 (11.1%) | 0.162 | 5 (0.5%) |
| 2nd quintile | 149 (13.9%) | 46 (12.8%) | 103 (14.4%) | | |
| 3rd quintile | 137 (12.8%) | 48 (13.4%) | 89 (12.5%) | | |
| 4th quintile | 152 (14.2%) | 51 (14.2%) | 101 (14.2%) | | |
| 5th quintile | 496 (46.3%) | 155 (43.3%) | 341 (47.8%) | | |
| Level of urbanisation | | | | | |
| Densely populated | 388 (36.2%) | 115 (32.1%) | 273 (38.3%) | **0.036** | 5 (0.5%) |
| Intermediate density | 424 (39.6%) | 141 (39.4%) | 283 (39.7%) | | |
| Rural | 259 (24.2%) | 102 (28.5%) | 157 (22.0%) | | |

Abbreviations: CD, Crohn's disease; QoL, quality of life; SIBDQ, short inflammatory bowel disease questionnaire; UC, ulcerative colitis; y, years.
[a]Median [IQR].

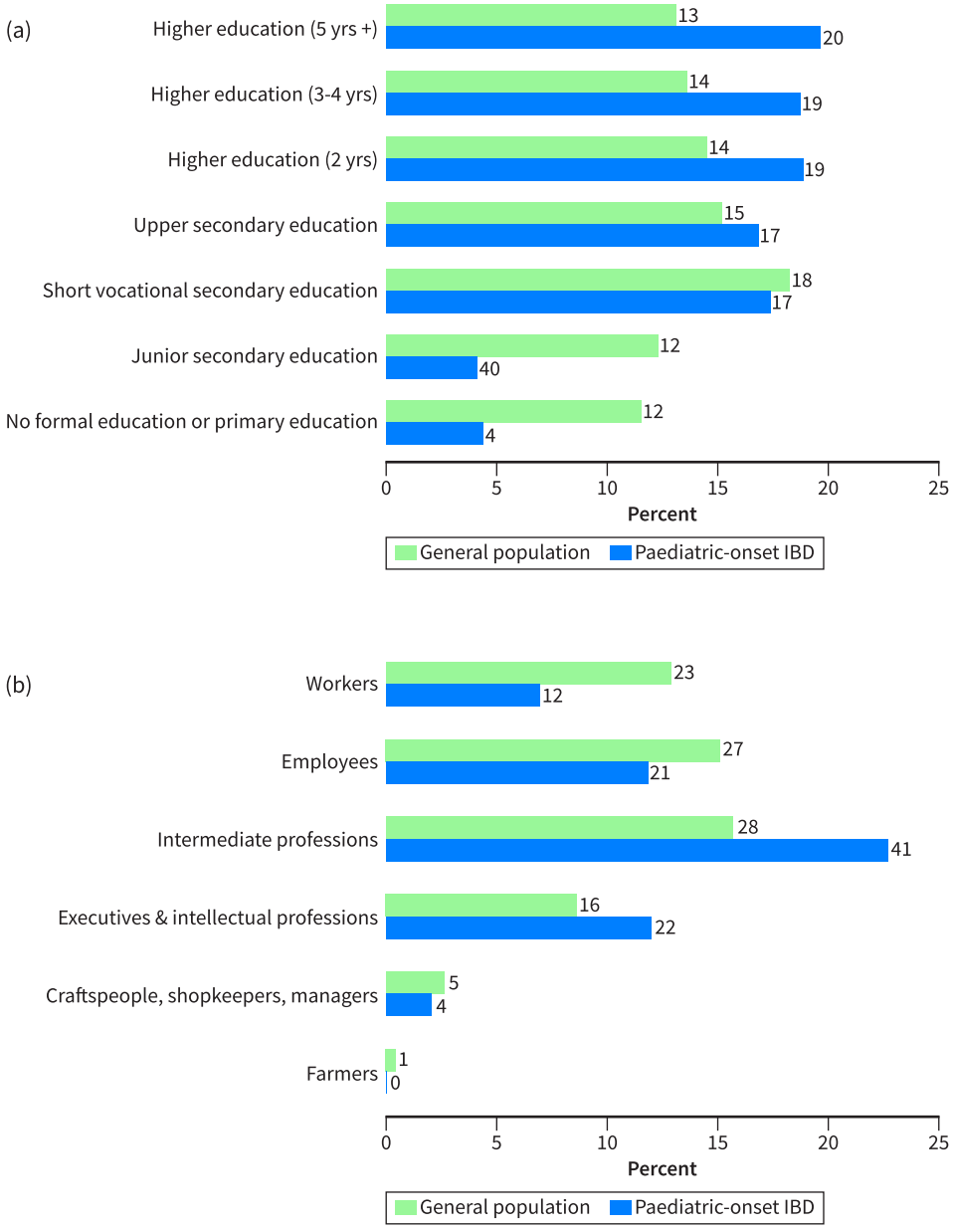


**FIGURE 1** | The highest educational qualification or degree obtained (Panel a) and the socioprofessional categories in the occupied labour force population (Panel b) among patients with paediatric-onset IBD versus the general population.

**TABLE 2** | Main occupational status of the patients with paediatric-onset IBD at the time of the study ($n$ = 361).

| | | Paediatric-onset IBD patients ($n$ = 361) | | |
|---|---|---|---|---|
| | | **Frequency** | **Raw rate** | **Adjusted rate** |
| Labour force population | Exercising a profession | 294 | 81.5% | 82.3% |
| | Apprentice or paid trainee | 2 | 0.5% | 0.5% |
| | Unemployed job seeker | 31 | 8.6% | 7.9% |
| Out of the labour force | Student or unpaid trainee | 2 | 0.5% | 0.4% |
| | Other unemployed[a] | 32 | 8.9% | 8.9% |
| Total | | 361 | 100% | 100% |

[a]Including homemakers and people with a disability.

**TABLE 3** | Professional status in patients with paediatric-onset IBD versus the general population.

| | Patients with paediatric-onset IBD ($n$ = 361) | | | Reference data ($n$ = 1,827,384) | $p$-value |
|---|---|---|---|---|---|
| | Frequency | Raw rate | Adjusted rate | | |
| Labour force population | 327 | 90.6% | 90.7% | 89.8% | 0.578 |
| Unemployed | 31 | 9.5% | 8.7% | 15.0% | 0.001 |
| Occupied | 296 | 90.5% | 91.3% | 85.0% | |
| Salaried job[a] | 271 | 91.5% | 90.5% | 91.7% | 0.927 |
| Full-time job[b] | 238 | 81.8% | 81.6% | 84.5% | 0.172 |

[a]The proportion of salaried employees was estimated for the occupied labour force.
[b]Data were missing for five participants. The proportion of full-time workers was estimated for the occupied labour force.

normal QoL, $p$ = 0.499). Young age (< 10 years) at diagnosis, sex, type of IBD, disease location at diagnosis, previous surgery, and previous treatment with an anti-TNF, immunosuppressant or corticosteroid were not associated with a higher education.

### 3.7 | The Patients' Perception of the Impact of IBD on Their Education and the Choice of a Profession

Thirty-two percent of the patients ($n$ = 117) believed that their IBD had influenced their educational choices, 61% ($n$ = 219) felt that their IBD had influenced the progression of their education, and 36% ($n$ = 130) felt that their IBD had influenced their choice of a profession.

It is noteworthy that the educational level was associated with the patient's feelings about the influence of the disease on their educational choices (Figure 2a, $p < 0.001$) and the progression of their education (Figure 2b, $p$ = 0.008). Indeed, patients who said that IBD had influenced their educational choices or the progression of their education were more likely to have a lower educational level.

The patients' free-forms and written comments were also analysed. It is noteworthy that only 66% ($n$ = 238) of the patients gave free-form, plain-language comments on their education and/or profession. The main IBD-related educational difficulty faced by patients was absenteeism (mentioned by 136 patients, i.e. Fifty-seven percent of those having given free-form comments; Figure 3a). It is noteworthy that 10 (4%) patients mentioned a lack of school support and only three patients mentioned that their educational courses had been adapted as a function of their health. The main consequences of these difficulties were academic delays ($n$ = 37, 15%) and dropping out of school or university ($n$ = 28, 12%, Figure 3b). The age on obtainment of the highest educational qualification or degree (Supporting Information S1: Table S1) appeared to match the ages expected for each educational level.

The patients mentioned the following criteria for their choice of a profession, in decreasing order of importance: office work/seated work/a non-physical job ($n$ = 21, 9%), the need for an easy access to a toilet ($n$ = 17, 7%), the exclusion of incompatible occupations ($n$ = 14, 6%), specifically adjusted working hours/rest periods ($n$ = 11, 5%), job security/salaried employment/civil servant ($n$ = 8, 3%), no travel ($n$ = 8, 3%), ability to take leave ($n$ = 8, 3%), and a no-pressure occupation ($n$ = 5, 2%) (Figure 3c). The incompatible occupations most frequently mentioned were teaching, firefighting or serving in the army or police. Interestingly, 18 (8%) patients stated that their disease had had a positive impact on their educational and professional choice: the time spent in hospital or in a medical environment made them want to work in the healthcare sector. This result was confirmed by the quantitative data from the self-questionnaire: 17% ($n$ = 56) of the labour force had a job in the healthcare sector. Fourteen percent ($n$ = 43) of the salaried patients worked in the healthcare sector, compared with 9% (according to the INSEE) in the general population ($p$ = 0.005). Furthermore, 34% ($n$ = 85) of the salaried patients worked in the public sector, compared with 22% in the general population ($p < 0.0001$).

## 4 | Discussion

Our assessment of a sample of patients with paediatric-onset IBD from a population-based registry showed that the latter's employment rate was significantly higher than that of members of the general population of the same age and from the same geographic area. Furthermore, the educational level was higher among patients with paediatric-onset IBD than among the general population. It is noteworthy that patients with paediatric-onset IBD were more likely to be working in the healthcare sector and in the public sector.

Many studies have investigated the impact of adult-onset IBD on the patients' education and professional status. In contrast, patients with paediatric-onset IBD have not been extensively assessed in this respect, and the few published studies have often had small sample sizes [10, 11, 13, 14, 16]. The evaluation criteria also differed from one study to another: the educational level, school attendance and/or school performance, part-time working, the unemployment rate, and earnings.

Most of the literature data show that the educational level distribution is similar in patients with paediatric-onset IBD versus the general population [11, 13–16, 26]. Our results are in line with two studies that found a higher educational level in patients with paediatric-onset IBD. In Canada, El Matary et al. compared 112 adult patients with paediatric-onset IBD (76 with CD and 36 with UC or with IBD unclassified) diagnosed between 1978 and 2007 with a control group of 565 age- and sex-

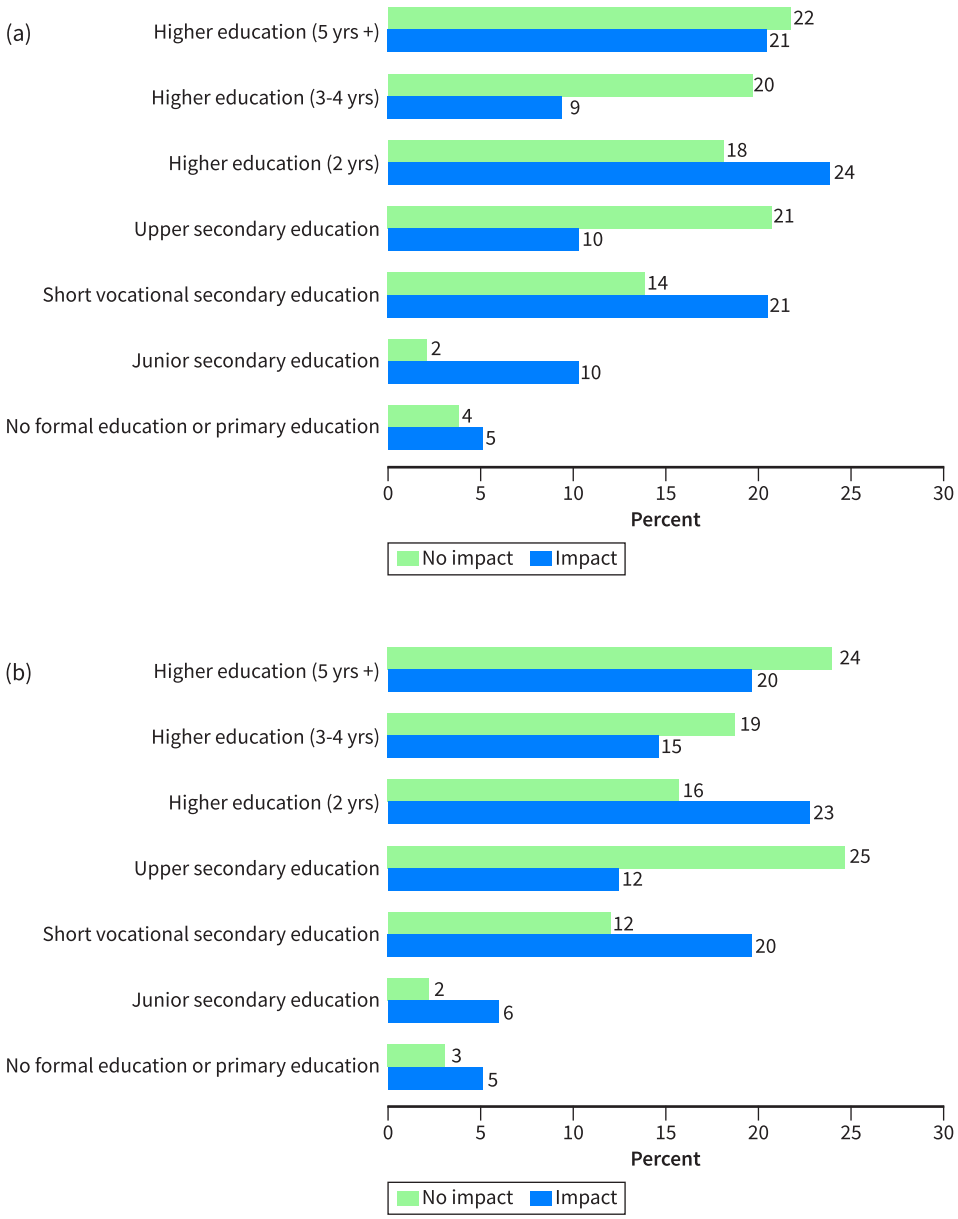


**FIGURE 2** | Relationship between the highest educational qualification or degree obtained and the reply concerning the impact of IBD on educational choices (Panel a) and the progression of education (Panel b) among patients with paediatric-onset IBD.

matched adults free of chronic disease [16]. The IBD patients were significantly more likely to have a university degree (88%) than the control group (73%) ($p < 0.01$). In Denmark, a study based on administrative data compared 3178 patients with paediatric-onset IBD (1344 with CD and 1834 with UC) with 28,204 individuals from a matched population-based cohort; the hazard ratio (95% CI) for achieving an upper secondary educational level was higher among patients with IBD (1.14 [1.07; 1.21) for CD and 1.16 [1.10; 1.23] for UC) [17]. In our study, the only factors associated with a higher educational level were quality of life and disease activity at the time of the study. However, the association between current disease activity and past disease activity - which might have influenced educational choices in the past - is hard to demonstrate. In our study, the educational level was not associated with the patients' clinical characteristics at diagnosis, including age, disease location, previous surgery, and previous treatment with an anti-TNF, immunosuppressant or corticosteroid. These results are in line with a Canadian study of 337 patients with paediatric-onset IBD, in which age at diagnosis, surgery, hospital admissions, and the need for corticosteroid therapy or any other therapy had no impact on the patients' educational level [15].

In our study, the major practical difficulty encountered by patients during their education was absenteeism. This is in line with the results of a study of 50 IBD adolescents and 42 control adolescents in Ohio; the investigators found that 20% of the patients with IBD and only 4% of control subjects were absent from school for more than 3 weeks per year ($p < 0.05$) [13]. In our study, a large number of patients also reported impairments in their social interactions. Likewise, Hummel et al.'s study of 62 patients with paediatric-onset IBD and 76 control subjects in The Netherlands reported that the patients were less likely to attend sports clubs ($p = 0.02$), go to nightclubs during

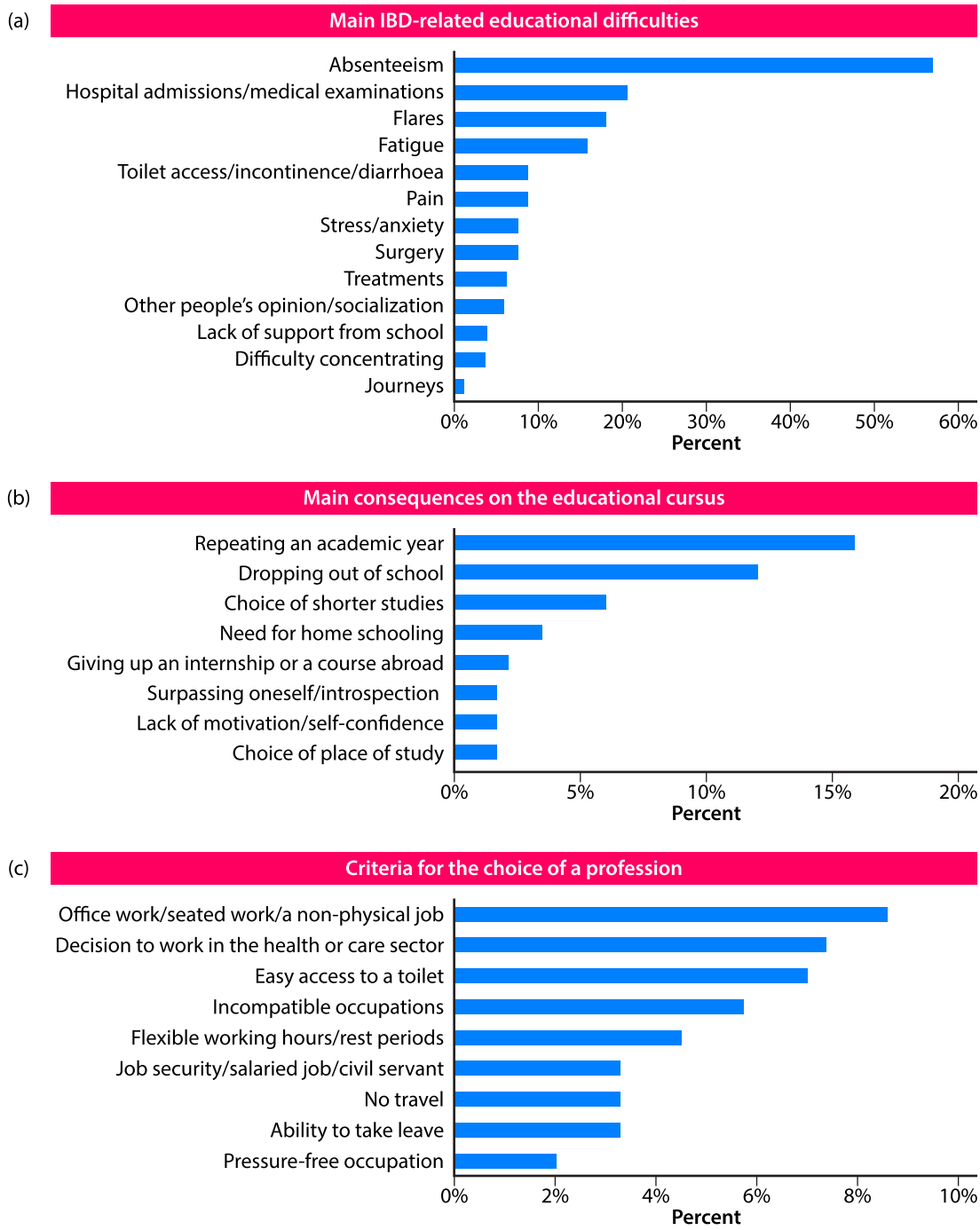


**FIGURE 3** | Data from the analysis of the patients' free-form, plain-language comments on the study questionnaire. The stated percentage corresponds to the proportion of patients having given free-form comments ($n$ = 238). (a) The main difficulties encountered during the patients' education. (b) The main impacts of IBD on the progression of patients' education. (c) The patients' criteria for choosing a profession.

high school ($p$ = 0.002), and have a romantic relationship ($p$ = 0.003) [14].

To the best of our knowledge, the present study is the first to find a higher employment rate among patients with paediatric-onset IBD. The literature data generally showed similar employment rates in patients with IBD versus the general population [10, 16, 26]. Conversely, Hummel et al. found that patients with IBD who had completed their university education were significantly less likely to be employed than controls (with employment rates of 25% and 57%, respectively; $p$ = 0.004) [14]. However, Hummel et al.'s study featured a small number ($n$ = 36) of patients having completed their education. It is noteworthy that according to a recent study in Sweden, young adults with IBD earned significantly less than matched individuals from the general population reference but had similar employment rates [26]. Unfortunately, data on earnings were not available in our study. Another study found that young

adults with IBD were more likely than control individuals to have a part-time job [12]. We did not confirm this because the frequency of full time working was similar in our patients with IBD versus the general population.

Interestingly, our patients with paediatric-onset IBD were more likely to work in the public sector and in the healthcare sector. To the best of our knowledge, the present study is the first to obtain these two results. The patients reported that being in frequent contact with healthcare professionals during their childhood made them want to help others. The choice of the public sector might be related to job security and greater provisions for sick leave.

Our study had a number of strengths. Firstly, the study data came from a well-documented population-based registry. Secondly, the patients had been diagnosed with IBD in childhood but were all aged over 25 at the time of the study; the fact that they had completed their education enabled us to study their socioprofessional status. Comparisons with the general control population were based on solid reference data from the INSEE (population census and employee databases) on people of the same age and in the same geographic area. Post-stratification of these data had only a limited impact on the results. Lastly, the study questionnaire used exactly the same questions as the census questionnaire, which facilitated direct comparisons of the groups' data.

Our study also had some limitations. Firstly, as in all studies based on a self-questionnaire, the results might have been subject to recall and non-response bias. However, the response rate was satisfactory (48% of the people who actually received the questionnaire), and we compared the characteristics at diagnosis of the respondents and non-respondents: no differences were observed, other than a slightly higher proportion of patients with CD, a higher rate of CD upper digestive tract involvement, and more extensive UC among the respondents. The last two points suggest that the respondent patients would be in favour of a more severe disease; hence, less severe disease cannot explain the higher employment rate and the higher educational level observed in the patients with IBD versus the general population. The disease location at diagnosis was not associated with a higher educational level. Moreover, the proportion of people living in a rural environment at the time of diagnosis was higher among respondents than among non-respondents; this type of difference could potentially bias the results. According to a study by the French Ministry of Health, however, young people in rural areas are less keen to go to university than young people in urban areas [27]. Furthermore, young graduates in both environments have similar levels of access to employment. Therefore, we do not believe that the slight over-representation of patients from rural areas explains the favourable outcome (relative to the general population) observed here. Another limitation relates to the lack of data on the socio-economic status of the patients' parents. These variables might influence a person's educational level and professional future independently of the disease. However, it has been shown that patients suffering from paediatric-onset IBD have a similar socio-economic level to that of the general population [28]. Lastly, our data were limited to northern France and cannot be extrapolated to other regions of France or to other countries.

## 5 | Conclusion

Our results showed that relative to their control counterparts, patients with paediatric-onset IBD have a higher educational level and a higher employment rate—thereby demonstrating a true ability to cope with the disease. However, the patients who mentioned difficulties during their education had a lower educational level on average. The latter finding emphasises the need for a holistic approach to the treatment of children and adolescents with IBD, in order to minimise the relapse frequency and enable patients to follow a school curriculum that is as normal as possible.

### Author Contributions

**Hélène Sarter:** conceptualization, methodology, software, validation, formal analysis, data curation, visualization, writing-original draft. **Mathilde Le Coniac:** conceptualization, investigation, writing-review and editing. **Ariane Leroyer:** methodology, data curation, formal analysis, software, writing-review and editing. **Guillaume Savoye:** conceptualization, investigation, validation, funding acquisition, writing-review and editing. **Mathurin Fumery:** conceptualization, validation, investigation, funding acquisition, writing-review and editing. **Nathalie Guillon:** investigation, writing-review and editing. **Corinne Gower-Rousseau:** conceptualization, investigation, funding acquisition, validation, writing-review and editing. **Delphine Ley:** conceptualization, investigation, validation, writing-review and editing. **Dominique Turck:** conceptualization, investigation, funding acquisition, validation, writing-original draft.

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## Ethics Statement

The study protocol was approved by an independent ethics committee (*CPP Nord-Ouest IV*, Lille, France; reference: 2017 A003397 46).

## Consent

The authors have nothing to report.

## Conflicts of Interest

G.S. has served as a speaker for MSD France, Ferring France, Abbvie France, and Vifor France. C.G.R. has served as a speaker for Ferring France & International, Takeda France, Tillotts France, Janssen International, and MSD France. M.F. has received lecture fees or consultancy fees from MSD, Abbvie, Takeda, Ferring, Gilead, Celgene, Celltrion, Biogen, Amgen, Fresenius, Galapagos, Tillotts, Ferring, Janssen, Hospira, Pfizer, Arena, CTMA, and Boehringer. D.L. has received lecture fees from Abbvie and Sandoz. D.T. has received lecture fees from Sandoz. H.S., M.L., and A.L. have nothing to declare.

## Data Availability Statement

Data are available on reasonable request to the corresponding author.

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## Supporting Information

Additional supporting information can be found online in the Supporting Information section.