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Impact of pediatric inflammatory bowel disease on caregivers' work productivity: A multicenter study by the SEGHNP

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Abstract

Objectives/Background: Pediatric inflammatory bowel disease (PIBD) poses significant challenges not only to patients but also to their families, particularly affecting the work productivity of caregivers. This Spanish multicenter study aims to elucidate the extent of this impact.

Materials and Methods: A cross-sectional, multicenter study was conducted between February 2021 and June 2023, involving parents or caregivers of PIBD patients aged 10–18 years. The study utilized the Work Productivity and Activity Impairment (WPAI) questionnaires alongside assessing disease activity and socioeconomic status to quantify work productivity loss and its economic implications.

Results: The study included 370 patients from 37 centers, highlighting a significant loss of work productivity among caregivers, especially mothers. The global unemployment rate was notably higher in this group compared to national averages (22.9% vs. 13.8%), particularly among females (30.7% vs. 13.7%), with absenteeism and presenteeism rates (26.4% and 39.9%) significantly impacting the caregivers' ability to work. The study also identified active disease and treatment with biologics or steroids as risk factors for increased work productivity loss.

Conclusions: Caregivers of children with inflammatory bowel disease face considerable challenges in maintaining employment, with a notable economic impact due to lost work hours. The findings underscore the need for targeted support and interventions to assist these families, suggesting potential areas for policy improvement and support mechanisms to mitigate the socioeconomic burden of PIBD on affected families.

KEYWORDS

absenteeism, children, chronic illness, presenteeism, WPAI

Víctor Manuel Navas-López and Javier Martín de Carpi are co-seniors authors.

1 | INTRODUCTION

Pediatric inflammatory bowel disease (PIBD), encompassing both Crohn's disease and ulcerative colitis, presents a significant challenge for children and adolescents globally.[1–3] The healthcare demands for PIBD patients are elevated, entailing more frequent diagnostic tests, biologic infusions, outpatient visits, and hospital admissions.[4] Beyond the immediate health implications for young patients, PIBD often imposes substantial burdens on their families, extending to various aspects of daily life, including parental employment.[5–8] The employment dynamics of parents or caregivers of children with inflammatory bowel disease (IBD) represent a crucial yet underexplored domain, warranting thorough investigation and understanding.[9–11]

The management of PIBD demands substantial time and energy from caregivers, who often find themselves navigating a complex landscape of medical appointments, treatments, and caregiving responsibilities while striving to maintain their professional commitments.[4,12,13] Balancing these demands can pose substantial challenges, leading to disruptions in employment and financial stability. Furthermore, the emotional toll of witnessing a child's illness and the uncertainty surrounding its management can exacerbate the stress experienced by caregivers, further impacting their ability to sustain employment.[14–18]

Despite the growing recognition of the multifaceted impact of PIBD on families, empirical research specifically focusing on the labor repercussions for caregivers remains limited. Existing studies have primarily focused on clinical outcomes and disease management, with comparatively fewer addressing the socioeconomic dimensions, particularly the effects on parental employment. Therefore, there is a critical need for comprehensive research that investigates the extent and nature of employment-related challenges faced by caregivers of children with IBD.

This article aims to provide an investigative perspective on the labor implications experienced by caregivers of PIBD patients. Through an in-depth analysis of relevant data sources, we endeavor to identify the key factors influencing parental employment, including factors associated with disease severity, treatment modalities and socioeconomic status. Additionally, we will explore the impact of parental employment disruptions on family financial well-being.

The objectives were to evaluate the impact of PIBD on the work and daily activities of parents or caregivers of patients, as well as the economic repercussions secondary to potential loss of working hours.

What is Known

- Pediatric inflammatory bowel disease (PIBD) imposes substantial burdens on the patients and their families, extending to various aspects of daily life, including parental employment.

What is New

- Our study shows that caregivers of children with inflammatory bowel disease face considerable challenges in maintaining employment, with a notable economic impact due to lost work hours.
- Two independent variables (being mother of a child with active disease) were significantly associated with work absenteeism, presenteeism, and the impact on nonwork activities.
- These findings highlight the need for targeted interventions to alleviate the economic strain associated with managing this condition.

2 | METHODS

Multicenter and cross-sectional study (February 2021 to June 2023) with the inclusion of parents or caregivers of patients with PIBD aged 10–18 years diagnosed according to Porto criteria.[19] Members of the Spanish Society of Pediatric Gastroenterology, Hepatology, and Nutrition (SEGHNP) were requested to recruit p-IBD families that where under follow-up in their hospitals. The treating physician was responsible for explaining the project, obtaining the corresponding informed consents and registering the patients and parents/caregivers' data. In the two-parent families, both caregivers were invited to participate. The Work Productivity and Activity Impairment (WPAI)-Caregiver questionnaires for Crohn's disease or ulcerative colitis[4,20–22] were handled in printed form to the parents/caregivers of the patients, as appropriate, using the translated and validated version for the Spanish population.[23] These patients had participated in the validation and cross-cultural adaptation project of the IMPACT-III, whose methodology has already been published by our group.[24] Parents/caregivers were asked to complete them in the hospital or take them home and return them on the next visit. They were requested to time the number of minutes needed to fulfill them and record it in the form. We recorded the following patients' clinical data: sex, age at diagnosis and at the time of participation, the disease activity using PUCAI (Pediatric Ulcerative Colitis Activity Index)[25] and wPCDAI (weighted Pediatric Crohn's Disease Activity Index),[26] the phenotype according to the Paris classification,[27] the medical treatment followed at the time of the study, and the PGA (physician's global assessment). Active disease was defined as PUCAI ≥ 10 or wPCDAI ≥ 12.5 (Table 1). Additionally, the following caregivers' work-related variables were asked and recorded: level of education, occupational category according to the National Institute

TABLE 1 Demographical and medical characteristics of PIBD patients ($n = 370$).

Male sex, *n* (%)	207 (56)
Age at diagnosis, years, median (IQR)	11.3 (8.7–13.3)
Time to diagnosis, months, median (IQR)	3.1 (1.3–6.9)
Disease duration from diagnosis, years, median (IQR)	2.4 (1.2–4.9)
Age at assessment, years, median (IQR)	14.4 (12.4–16.1)
Type of IBD, *n* (%)	
CD	226 (61.1)
UC	128 (34.6)
IBD-U	16 (4.3)
Paris classification UC + IBD-U, *n* (%)	144 (38.9)
E1: ulcerative proctitis	11 (8)
E2: left-sided UC (distal to splenic flexure)	27 (19)
E3: extensive (hepatic flexure distally)	10 (7)
E4: pancolitis (proximal to hepatic flexure)	95 (66)
Severity (severe defined by PUCAI ≥ 65)	
S0: never severe	95 (66)
S1: ever severe	49 (34)
Paris classification CD, *n* (%)	226 (61.1)
Age at diagnosis (years)	
A1a: 0 to <10	77 (34)
A1b: 10 to <17	149 (66)
Location	
L1: distal 1/3 ileal +/− limited cecal disease	52 (23)
L2: colonic	29 (13)
L3: ileocolonic	144 (64)
L4a: upper disease proximal to ligament of Treitz	40 (18)
L4b: upper disease distal to the ligament of Treitz and proximal to distal 1/3 ileum	11 (5)
Behavior	
B1: nonstructuring nonpenetrating	187 (83)
B2: structuring	23 (10)
B3: penetrating	11 (5)
B2–B3: structuring and penetrating	5 (2)
P: perianal disease modifier	61(27)
Growth	
G0: no evidence of growth delay	169 (75)
G1: growth delay	57 (25)
PUCAI at assessment, median (IQR)	0 (0–10)
Patients in remission, *n* (%)	108 (75)
wPCDAI at assessment, median (IQR)	0 (0–10)
Patients in remission, *n* (%)	179 (79.2)
Current treatments *n* (%)	
Biologics	114 (30.8)
Immunosuppressants	165 (44.6)
Corticosteroids	22 (6)
5-ASA	125 (33.7)
Other (dietary treatment, granulocytapheresis, antibiotics, and oral nutritional supplements)	103 (27.8)
PGA	
Normal	259 (70)
Mild	52 (14)
Moderate	37 (10)
Severe	22 (6)

Abbreviations: 5-ASA, 5-aminosalicylic acid; CD, Crohn's disease; IBD, inflammatory bowel disease; IBD-U, unclassified inflammatory bowel disease; IQR, interquartile range; PGA, physician's global assessment; PIBD, pediatric inflammatory bowel disease; PUCAI, Pediatric Ulcerative Colitis Activity Index; UC, ulcerative colitis; wPCDAI, weighted Pediatric Crohn's Disease Activity Index.

of Statistics (INE), and professional situation at the time of completing the questionnaires (salaried, unemployed, self-employed, etc.) (Table 2). The average annual salary for each occupational group was recorded based on the latest available INE data for the year 2020. To estimate the economic loss in the previous week due to PIBD, we first adjusted the average annual salary according to the average salary increase of 2.9% in 2021 and 2% in 2022 compared to previous years. The cost of average hourly labor was calculated considering the 1723 annual hours established by the collective agreements that came into effect in 2022 in our country.[28,29] The economic loss in the previous week due to PIBD was estimated. Our rate of absenteeism was compared with the national rate provided by the INE in the fourth quarter of 2022, which amounted to 6.1% (4.6% due to temporary incapacity and 1.5% without medical leave).[30]

Data were collected and stored using the electronic data capture tools REDCap® (Research Electronic Data Capture) with the license from the SEGHNP.[31] Technical support was provided by the AEG-REDCap Support Unit, shared with the Spanish Association of Gastroenterology (AEG). REDCap® is a secure web application designed for data capture in research studies, providing an intuitive interface, audit trails to track data manipulation, as well as procedures for exporting to common statistical packages and importing from external

TABLE 2 Educational level, occupational group, and parental situation.

Educational level, *n* (%)	**Total (*n* = 635)**	**Women (*n* = 342)**	**Men (*n* = 293)**	***p***
No studies	11 (1.7)	5 (1.5)	6 (2)	0.763
Primary education or equivalent	112 (17.6)	58 (17)	54 (18.4)	0.705
General secondary education, first cycle	85 (13.4)	39 (11.4)	46 (15.7)	0.448
Professional education, second cycle	71 (11.2)	35 (10.2)	36 (12.3)	0.906
General secondary education, second cycle	99 (15.6)	54 (15.8)	45 (15.4)	0.366
Higher professional education	62 (9.8)	37 (10.8)	25 (8.5)	0.128
University education or equivalent	195 (30.7)	114 (33.3)	81 (27.6)	0.018
Occupational group (INE categories), *n* (%)	**Total (*n* = 563)**	**Women (*n* = 298)**	**Men (*n* = 265)**	***p***
Management of companies and public administration	18 (3.2)	7 (2.3)	11 (4.2)	0.346
Technicians and scientific professionals	135 (24)	85 (28.5)	50 (18.9)	0.003
Technicians and support professionals	54 (9.6)	24 (8.1)	30 (11.3)	0.414
Administrative employees	71 (12.6)	45 (15.1)	26 (9.8)	0.024
Workers in restaurant services, personal services, protection, and sales	123 (21.8)	85 (28.5)	38 (14.3)	0.0001
Skilled workers in agriculture and fishing	2 (0.4)	0 (0)	2 (0.8)	-
Artisans and skilled workers in manufacturing industries, construction, mining, extractive industries, metallurgy, machinery construction, graphic arts, textiles, food processing, cabinetmakers, artisans, and others	58 (10.3)	10 (3.4)	48 (18.1)	0.0001
Operators and assemblers of fixed installations and machinery and drivers and operators of mobile machinery	33 (5.9)	3 (1)	30 (11.3)	0.0001
Unskilled workers	69 (12.3)	39 (13.1)	30 (11.3)	0.279
Professional situation, *n* (%)	**Total (*n* = 620)**	**Women (*n* = 335)**	**Men (*n* = 285)**	***p***
Salaried: Person working for someone else, with a fixed or occasional work contract	373 (60.2)	185 (55.2)	188 (66)	0.877
Unemployed: Person not working and actively seeking employment, either if they have had paid work before	142 (22.9)	103 (30.7)	39 (13.7)	0.0001
Self-employed: Person working for themselves but without a constituted company	54 (8.7)	16 (4.8)	38 (13.3)	0.003
Part-time salaried	23 (3.7)	19 (5.2)	4 (1.4)	0.002
Business owner with salaried employees: Person with their own company and employees under their charge	21 (3.4)	10 (3)	11 (3.9)	0.827
Temporary layoff or employment regulation	3 (0.5)	2 (0.6)	1 (0.4)	0.564
Part-time work: when working dedication is less than 7/8 h daily	2 (0.3)	0 (0%)	2 (0.7)	-
Cooperative worker: Person working in a cooperative as a cooperative partner	2 (0.3)	0 (0%)	2 (0.7)	-

Abbreviation: INE, National Institute of Statistics.

sources. Data from the INE related to the absenteeism rate in the fourth quarter of 2022 were also consulted.

WPAI outcomes were expressed as impairment percentages, with higher numbers indicating greater impairment and less productivity. The WPAI instrument is a six-items questionnaire (Q1: currently employed; Q2: hours missed due to specified problem; Q3: hours missed for other reasons; Q4: hours actually worked; Q5: degree problem affected productivity while working; and Q6: degree problem affected regular activities) with a recall period of the past 7 days: one question (Q1) requires a dichotomous answer (yes/no) and five questions (Q2–Q6) require the inclusion of a numerical value (i.e., number of hours missed, or degree of work or regular activities repercussion from 0 to 10). Based on the responses to the six items, four scores are derived: absenteeism, presenteeism, work productivity, and nonwork-related activity impairment. The scores were multiplied by 100 to express them in percentages. The formulas for calculating work and activity impairment were as follows: (1) percent work time missed due to problem (absenteeism): Q2/(Q2 + Q4); (2) percent impairment while working due to problem (presenteeism): Q5/10; (3) percent overall work impairment due to problem: Q2/(Q2 + Q4) + [(1 − (Q2/(Q2 + Q4))) × (Q5/10)] and (4) percent activity impairment due to problem: Q6/10.[32]

The study was approved by the Ethics Committee of the promoting center, and all parents/caregivers, as well as patients over 12 years old, signed the corresponding informed consents.

2.1 | Statistical analysis

Variables with a normal distribution were expressed as mean ± standard deviation, and those without a normal distribution as median and interquartile range (IQR). We employed the Kolmogorov–Smirnov test to evaluate the normality of the distribution. We employed the chi-square test for comparing the proportions. To compare the variables with a normal distribution, we used the Student's *t*-test and the Mann–Whitney *U* test in those without normal distribution. We considered a $p < 0.05$ as statistically significant. We constructed predictive models using univariate and multivariate (MV) logistic regression tests. To construct the model, only those variables that presented statistically significant differences or a trend ($p < 0.15$) in the univariate analysis, along with the variables that, based on the theoretical or empirical knowledge, were considered related to the dependent variable and were included on the MV. We measured the magnitude of the association between the model's predictive variables and the dependent variable with the odds ratio (OR) and its corresponding 95% confidence interval (CI). The data were analyzed using the statistical package SPSS®, version 24.0 for Windows® (SPSS Inc.).

3 | RESULTS

A total of 370 patients with PIBD from 37 participating centers were included. The clinical characteristics of the patients included in the study are shown in Table 1. Among the 370 patients, 318 (85.9%) lived with both parents/caregivers, while the remaining 52 (14.1%) lived with a single parent or another relative. This indicated that the potential number of questionnaires to be collected was 688, with this study receiving 635 responses, equating to a 92.3% response rate. Parental data regarding their occupational characteristics and educational levels are reflected in Table 2.

As shown in Table 2, the unemployment rate was significantly higher in women compared to men (30.7%, 95% CI [26.0–35.9] vs. 11.6%, 95% CI: [8.6–15.5], $p < 0.0001$).

3.1 | Absenteeism

Out of the 382 parents/caregivers whose information was valid for analysis, 281 (73.6%, 95% CI: 68.9–77.3) reported no work absenteeism, with 80% (95% CI: 66.2–89.1) of couples where one parent works versus 75.8% (95% CI: 70.2–80.6) when both caregivers work (χ^2, $p = 0.343$). Among the other 101, the absenteeism rate was 11.1% (IQR: 5.2–19.4), with no differences between couples where both members worked and those where only one worked (11.1%, IQR: 6.5–12.8 vs. 11.1%, IQR: 6.0–20.0, $p = 0.411$). In couples where both caregivers worked, there were no differences in absenteeism based on gender (women: 11.3%, IQR: 6.4–20.7 vs. men: 9.1%, IQR: 5.2–16.6, $p = 0.399$), Table 3. There were no differences in the number of hours lost in the last week based on the couple's working situation (both work vs. one works)—4 h (IQR: 2–8) versus 4 h (IQR: 2–8), $p = 0.706$. This resulted in a total of 688.5 h lost in the week (median of 4 h [IQR: 2–7]). The median economic loss in the last week was 61.2€ (IQR: 40–116), representing 22.7% (14.8%–43.1%) of the minimum interprofessional salary. The total amount of economic loss in our series in the last week reached 8420.20€ (equivalent to 31.2 times the minimum weekly interprofessional salary in 2022 in Spain).

3.2 | Presenteeism

There were data from 404 parents/caregivers. Among them, 243 (60.1%, 95% CI: 55.3–64.8) did not report presenteeism at work. Presenteeism was higher in women (64.6% vs. 35.4%, $p = 0.0001$). Of the other 161 caregivers, the percentage of presenteeism was 30% (IQR: 20–60), being higher in couples where both caregivers worked (39 [30.0–48.8] vs. 28 [IQR: 20.1–31.7], $p = 0.0001$), with no differences found

TABLE 3 Predictive variables for work absenteeism and presenteeism.

Variable	Univariate OR (95% CI)	*p*	Multivariate OR (95% CI)	*p*
Predictive variables for work absenteeism[a]				
Couple's job situation (both work)	3.1 (2.3–4.1)	0.0001	-	-
Full-time job	5 (1.4–17.2)	0.011	-	-
Active employee	7 (2.9–16.4)	0.0001	4.4 (1.4–13.5)	0.008
Active disease[b]	2.1 (1.3–3.5)	0.003	3.5 (2.3–5.4)	0.0001
Mothers	2.3 (1.4–3.7)	0.001	2.4 (1.4–4.1)	0.001
Treatment with intravenous anti-TNF	1.7 (1.03–2.8)	0.036	2.5 (1.3–4.6)	0.002
Predictive variables for work presenteeism. Dependent variable: Presenteeism[c]				
Mothers	1.5 (1.05–2.4)	0.028	-	-
Active employee	1.9 (1.02–3.8)	0.042	-	-
Absenteeism	21.8 (11.4–41.5)	0.0001	21.9 (11.3–42.4)	0.0001
Steroid treatment	3.4 (1.4–8.2)	0.005	3.3 (1.06–10.2)	0.039
Biological drug treatment	1.9 (1.2–3.0)	0.003	2.4 (1.3–4.4)	0.003

Abbreviations: CI, confidence interval; NPV, negative predictive value; OR, odds ratio; PPV, positive predictive value; PUCAI, Pediatric Ulcerative Colitis Activity Index; TNF, tumor necrosis factor; wPCDAI, weighted Pediatric Crohn's Disease Activity Index.

[a]Hosmer and Lemeshow test: $p = 0.574$; Cox–Snell R^2: 0.329. Nagelkerke R^2: 0.439; sensitivity: 25 (15–37); specificity: 91 (86–94); NPV: 79 (74–84); PPV: 45 (29–62); positive likelihood ratio 3.04 (1.7–5.6); negative likelihood ratio: 0.84 (0.75–0.94). The model shown here is significant, explaining between 0.329 and 0.439 of the dependent variable, and correctly classifies 75.6% of cases.

[b]PUCAI > 10 or wPCDAI ≥ 12.5.

[c]Hosmer and Lemeshow test: $p = 0.960$; Cox–Snell R^2: 0.311. Nagelkerke R^2: 0.420; sensitivity: 57 (48–65); specificity: 93 (89–96); NPV: 76 (70–81); PPV: 85 (76–91); positive likelihood ratio: 8.9 (5.2–15.5); negative likelihood ratio: 0.45 (0.37–0.55). The model shown here is significant, explaining between 0.311 and 0.420 of the dependent variable, and correctly classifies 78.9% of cases.

between mothers and fathers (30% [IQR: 17.5–60] vs. 30% [IQR: 20–57.5], $p = 0.812$). This amounted to a total of 1890.5 weekly hours of presenteeism (median 8 h [IQR: 4.4–17.6]). The median economic loss in the last week was €128.8 (IQR: €76.5–€264.5); 47.8% (28.4%–98.2%) of the minimum interprofessional salary. The total amount reached €27,625.1 (equivalent to 102.6 times the minimum interprofessional salary in 2022 in Spain). There were no differences in the number of hours lost in the last week based on the couple's working situation (both work vs. one works), 8 h (IQR: 4.5–17.6) versus 16 h (IQR: 8.4–20), $p = 0.185$.

3.3 | Loss of work productivity

There are data from 383 parents/caregivers. Of these, 215 (56.5%, IQR: 51.4–61.2) do not report loss of work productivity. Of the 166 caregivers, the percentage of loss of work productivity was 30.5% (IQR: 15.8–60.0). The percentage of loss of work productivity was similar in both types of families, with two active members 32% (IQR: 17.2–67.4) versus those with only one active member, 34.3% (IQR: 10.5%–50%), $p = 0.551$, and there were no differences regarding the parent/caregiver (mothers: 33.3% [IQR: 14.2–67.4] vs. fathers 31% [IQR: 19.5–70.3], $p = 0.877$) (Table 4).

3.4 | Impact on nonwork-related activity

There are data from 510 parents/caregivers. Among them, 305 (59.8% [IQR: 55.4–63.9]) do not report impairment of activity. Of the other 205, the percentage of loss of nonwork-related activity was 30% (IQR: 20–60). The percentages of impairment of nonwork-related activity were similar in families without any active family member, with one, or two active caregivers (50% [IQR: 20–70] vs. 50 [IQR: 20–60] vs. 30 [IQR: 20–50], $p = 0.119$). It was higher in women than in men (40% [IQR: 20–60] vs. 30% [IQR: 20–50], $p = 0.128$).

4 | DISCUSSION

Our study uncovered a disparity in unemployment rates among parents/caregivers of patients compared to the general Spanish population according to the INE data

TABLE 4 Predictive variables for loss of work productivity and for Impact on nonwork-related activity.

Variable	Univariate OR (95% CI)	*p*	Multivariate OR (95% CI)	*p*
Predictive variables for Loss of work productivity[a]				
Mothers	1.7 (1.1–2.6)	0.01	1.8 (1.2–3.0)	0.007
Type of parental activity (employee)	1.8 (0.9–3.4)	0.076	2.1 (1.2–3.4)	0.042
Active disease[b]	1.8 (1.1–2.9)	0.012	2.0 (1.2–3.4)	0.009
Steroid treatment	3.2 (1.3–7.9)	0.013	3.6 (1.2–10.4)	0.016
Predictive variables for Impact on nonwork-related activity[c]				
Mothers	1.4 (1.0–2.3)	0.039	1.5 (1.0–2.2)	0.039
Active disease[b]	2.2 (1.5–3.4)	0.0001	2.4 (1.6–3.6)	0.0001

Abbreviations: CI, confidence interval; NPV, negative predictive value; OR, odds ratio; PPV, positive predictive value; PUCAI, Pediatric Ulcerative Colitis Activity Index; wPCDAI, weighted Pediatric Crohn's Disease Activity Index.

[a]Hosmer and Lemeshow test: $p = 0.581$; Cox–Snell R^2: 0.072; Nagelkerke R^2: 0.097; sensitivity: 25 (18–33); specificity: 92 (87–95); NPV: 62 (56–67); PPV: 72 (57–83); positive likelihood ratio: 3.4 (1.9–6.1); negative likelihood ratio: 0.8 (0.7–0.9). The model shown here is significant, explaining between 0.072 and 0.097 of the dependent variable, and correctly classifies 63.7% of cases.

[b]PUCAI > 10 or wPCDAI ≥ 12.5.

[c]Hosmer and Lemeshow test: $p = 0.422$; Cox–Snell R^2: 0.043; Nagelkerke R^2: 0.059; sensitivity: 35 (29–42); specificity: 81 (76–85); NPV: 65 (60–70); PPV: 56 (47–65); positive likelihood ratio: 1.9 (1.4–2.5); negative likelihood ratio: 0.8 (0.7–0.9). The model shown here is significant, explaining between 0.043 and 0.059 of the dependent variable, and correctly classifies 62.9% of cases.

(22.9% vs. 13.8%), particularly among females (30.7% vs. 13.7%). The unemployment rate among females in our series was double the national average, suggesting that some caregivers may cease working to prioritize the care of their children affected by PIBD.[33] This finding aligns with the observation that managing a chronic illness such as PIBD often requires substantial caregiving responsibilities, potentially necessitating one parent to leave the workforce.[9,10]

The existing legislative framework in Spain, such as Royal Decree 1148/2011,[34] provides some support for those caring for children with serious illnesses, including cancer. This decree allows one parent to reduce their working hours by up to 50% to care for their child, with an accompanying economic subsidy equivalent to 100% of the established base pay for temporary disability. However, it is noteworthy that neither this decree nor its subsequent amendment in Order TMS/103/2019 explicitly includes IBD as a qualifying condition for this governmental benefit.[35] Consequently, caregivers of PIBD patients may need to utilize other types of leave to attend to their child's care needs, further exacerbating their employment-related challenges.

The absenteeism rate among the studied population quadrupled the national average in 2022 (26.4% vs. 6.1%), underscoring the unique challenges faced by caregivers of patients with PIBD. The absenteeism rates in our sample were similar to those found by other authors.[4,36,37] This substantial disparity between general population and PIBD caregivers reflects the considerable demands placed on these caregivers, including frequent medical appointments, medication management, and the need for ongoing emotional support. The significantly higher absenteeism rate emphasizes the high impact of PIBD on parental employment and underscores the urgent need for targeted support measures to address the specific needs of this vulnerable population. In relation to the factors influencing absenteeism in our series, we found that absenteeism was significantly higher among female employees whose children's disease were not in remission and receiving intravenous anti-tumor necrosis factor treatment. While it is true that the infusion time of IFX can be shortened,[38] the time involved in managing hospital admission, peripheral vein cannulation, and subsequent infusion requires the patient to remain in the center for no less than 3 h. In this sense, the therapeutic options currently available, both orally and subcutaneously,[39] can influence this relevant aspect. Two significant aspects of the univariate model are that absenteeism was higher in couples where both partners were employed and in those working full-time.

This situation is compounded by our findings on presenteeism, which indicates that parents/caregivers may be physically present at work but are not fully productive due to the demands of caring for a child with PIBD. Presenteeism rates, 39.9%, were similar to those published by Klomberg et al. (34.7%) and Stawowczyk et al. (35.5%), and can have significant implications for workplace productivity and may contribute to feelings of stress and burnout among affected caregivers.[4,37] Therefore, the absence of specific provisions for PIBD in existing legislation underscores

the need for policy reforms to better support families managing chronic pediatric illnesses. The risk factors for presenteeism were having had previous absenteeism and the patient receiving treatment with biologics or steroids. This indicates that, often, the leaves that caregivers can take to attend to their children's needs are clearly insufficient. The impossibility of managing steroid treatment (which may indicate a moderate-severe acute episode) makes presenteeism more prevalent. Presenteeism, like workplace absenteeism, was higher among women. This may be due to the fact that they tend to spend more time caring for patients. We also found that when both caregivers work, this work impact is shared; however, when only one works, they may delegate the caregiving and thus the concerns arising from the sick child. On the other hand, if only one works, they bear the family's economic support and therefore cannot afford for their child's illness to affect them at work.

The loss of work productivity in our series was 43.5%, slightly lower than previously reported.[4] In our series, we observed that the rate of work productivity loss was higher among employed women, specifically mothers of children with active disease being treated with steroids with no effect of disease duration as were shown by Klomberg et al.[4]

If we analyze the impact on nonwork activities (40.2%), it was more significant on mothers of children with active diseases. This suggests that the burden of caregiving and household chores primarily falls on them, leading to a decreased availability of time for leisure or relaxation activities.

In our study, two independent variables (being mother of a child with active disease) were significantly associated with work absenteeism, presenteeism, and the impact on nonwork activities. There was no correlation found with the duration of the disease, consistent with the findings reported in the study by Klomberg et al.[4] The percentage of patients with normal PGA was slightly lower than the percentage of patients in remission according to PUCAI and wPCDAI (Table 1). This may reflect the fact that physicians consider symptoms like tenesmus and fatigue that are not included in those activity indexes.

A limitation of our study relates to the timing of questionnaire collection, which was carried out in the hospital and pertained to the preceding week. This means that if a patient is currently hospitalized or has recently experienced a relapse, it is likely due to circumstances that could introduce bias into the responses provided. Another limitation concerns the design of our study; being cross-sectional, it assessed various health status points across different individuals, thereby preventing a dynamic analysis of disease progression and its impact. Data previously published have demonstrated a reduction in work impairment figures at 3 and 12 months postdisease onset compared to baseline conditions. This highlights the critical need for longitudinal studies to assess the impact of disease on work productivity and the daily activities of patients effectively.[4,40]

However, the multicentric design with almost 40 participating centers, including PIBD patients from different Spanish regions and sociocultural backgrounds, makes these data generalizable.

In conclusion, our study underscores the significant economic burden faced by parents/caregivers of children with IBD, characterized by higher rates of unemployment and presenteeism compared to the general population. The lack of explicit recognition of PIBD in existing governmental support schemes further exacerbates the challenges faced by affected families. Addressing these disparities requires a multifaceted approach, including legislative reforms to include PIBD as a qualifying condition for support benefits, as well as workplace accommodations to support caregivers in balancing work and caregiving responsibilities effectively. By implementing these measures, policymakers can better support families affected by PIBD and alleviate the economic strain associated with managing this chronic condition.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

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