

Original Article

Women's Earnings are more Affected by Inflammatory Bowel Disease than Men's: A Register-Based Swedish Cohort Study

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Abstract

Background and Aims: Patients with inflammatory bowel disease [IBD] are subject to more work disability than the general population. We aimed to estimate the monetary cost of IBD for the individual through assessment of earnings in relation to diagnosis.

Methods: Through linkage of national registers, we identified patients aged 30–55 years at first IBD diagnosis in Sweden in 2002–2011, and same-sex IBD-free siblings. We estimated taxable earnings and disposable income from 5 years before to 5 years after diagnosis.

Results: The 5961 patients [27% Crohn's disease, 68% ulcerative colitis, 4.3% IBD unclassified] had similar taxable earnings to their 7810 siblings until the year of diagnosis, when earnings decreased and remained lower than for siblings during follow-up. The adjusted difference in earnings over the entire 5-year period after diagnosis was –5% [–8212€; 95% confidence interval: –11 458 to –4967€]. The difference was greater in women than in men, and greater in Crohn's disease than in ulcerative colitis. When stratifying for sex and IBD subtype and comparing earnings during each year of follow-up, median annual earnings were lower in women with Crohn's disease and ulcerative colitis than in their sisters during all years of follow-up, whereas the men had similar annual taxable earnings to their brothers. Disposable income was similar between patients and siblings during the investigated time period.

Conclusion: From the year of diagnosis and at least 5 years onwards, patients with IBD had 5% lower earnings than siblings, mainly explained by differences between women with IBD and their sisters. However, there were no differences in disposable income.

Key Words: Income; earnings; inflammatory bowel disease; IBD; Crohn's disease; ulcerative colitis

1. Introduction

Inflammatory bowel disease [IBD], comprising Crohn's disease, ulcerative colitis and IBD unclassified, has peak incidence in working-age individuals.¹ Due to its chronic and relapsing nature with periods of debilitating symptoms, need for regular physician visits,² and sometimes medical or surgical treatments in the hospital,^{3,4} the disease has the potential to affect an individual's lifelong economic situation. For society, IBD is associated with high costs, both direct medical costs and indirect costs from productivity losses.^{5–12}

Previous studies have shown that patients with IBD are subject to more sick leave,^{13–18} disability pension^{13–22} and unemployment^{14,23} than the general population. Another measure of labour market attachment and impact on the individual patient is the development of earnings. A number of studies have shown negative associations between chronic diseases and earnings,^{24–27} but this has not been investigated in patients with IBD. Earnings reflect professional career development and can show changes in work ability not captured through sick leave days, such as a reduction from full-time to part-time work, a move to a less demanding and strenuous position within the same firm, or a change of occupation.

We aimed to assess the monetary cost of IBD for the individual by investigating the development of taxable earnings and disposable income during the years before and after diagnosis of Crohn's disease, ulcerative colitis and IBD unclassified.

2. Methods

2.1. Study design

In this cohort study we compared patients with incident IBD and same-sex siblings without IBD diagnosis with regard to annual earnings.

2.2. Setting

In Sweden health care is tax-funded with universal access to care.²⁸ The Swedish social insurance system covers individuals who live or work in Sweden and includes benefits and allowances for families with children, people who are ill and people with disabilities.²⁹

2.3. Data sources

The personal identity number assigned to all residents allows for linkage of registers containing national data on demographics, morbidity, histopathology and socioeconomic variables [Supplementary Table 1].

2.4. Participants

2.4.1. Patients with IBD

We used International Classification of Disease [ICD] codes [Supplementary Table 2] in national registers to identify incident cases of IBD during 2002–2011 aged 30–55 years at diagnosis who had same-sex siblings. The age limit was chosen to enable estimation of earnings from 5 years before to 5 years after diagnosis, based on the assumption that most individuals have finished their education at age 25 years, and that many older workers retire from age 60 years and onwards. We requested either two or more records of IBD in the National Patient Register³⁰ or one or more record of IBD in the National Patient Register plus a colorectal biopsy record suggestive of IBD from the Swedish ESPRESSO Biopsy cohort.³¹ We have

previously shown that the positive predictive value for IBD with two or more IBD diagnoses is 93%³⁰ and 95% with one IBD diagnosis and a colorectal biopsy showing inflammation.³² The IBD subtype definition was based on the first two diagnostic listings [or when combined with a colorectal biopsy, on the first IBD ICD diagnosis], and patients with listings of both Crohn's disease and ulcerative colitis, or a listing of IBD unclassified [IBD-U] were defined as IBD-U and included in the IBD group.³³

2.4.2. Reference group

As a comparison group we used IBD-free same-sex siblings aged 30–55 years. The siblings had to be alive and free of IBD on the date of diagnosis of the index patient and stopped contributing person-time as reference individuals if and when they were diagnosed with IBD.

2.5. Variables

The main outcome was taxable earnings. Secondary outcome was personalized disposable household income, reflecting standard of living. Disposable income is the sum of all income [from different sources] minus taxes paid. It includes earnings, benefits due to sick leave, unemployment and disability, as well as other types of income [Supplementary Table 3]. Information on taxable earnings and disposable income was extracted from the LISA database, which holds information on compensations from employment, entrepreneurial activities, studies, national military service, illness, parental leave, unemployment, labour market activity, rehabilitation, partial retirement, early retirement, retirement, occupational pension, annuities, social assistance and private pensions for all Swedish residents.³⁴

Comorbidities were based on diagnostic listings in the Patient Register at any time point up to the year of IBD diagnosis/match [Supplementary Table 4].

2.6. Statistical methods

Follow-up started 5 years before fulfilment of diagnostic inclusion criteria. Stratification for age [30–39, 40–49 or 50–55 years], length of education [0–9, 10–12, >12 years, or unknown] and year of IBD onset [2002–2003, 2004–2005, 2006–2007, 2008–2009, 2010–2011] was based on the date of the first diagnostic record. Follow-up ended at death, emigration or 10 years after start of follow-up, whichever came first.

Taxable earnings and disposable income were summed for each calendar year in relation to diagnosis/match year, converted to Euros and inflation-adjusted to the year 2019. We present results as median values with 95% confidence intervals [CIs], as data were not normally distributed. The differences between patients and siblings in taxable earnings and disposable income were calculated through quantile regression [median regression using the QUANTREG procedure in SAS³⁵]. We present absolute differences, as well as differences adjusted for age and education, in addition to the matching variable sex. The adjustment variables were predetermined. We present results as adjusted median differences, and 95% CIs were obtained using resampling.

We also compared each patient with IBD to his/her same-sex sibling and categorized them as having annual taxable earnings that were more than 2% higher, within –2 to 2% difference, or at least 2% lower than the sibling.

All statistical tests were two-sided, and $p < 0.05$ was considered statistically significant. We used statistical software from SAS [version 9.2; SAS Institute Inc.].

2.7. Ethics

The regional ethics committee in Stockholm approved the study [DNR 2007/785-31/5; 2011/1509-32; 2012/601-32; 2015/0004-31; 2015/615-32; 2014/1287-31/4]. Since this was a register study, consent from the patients was not necessary.

3. Results

We identified 5961 patients with incident IBD aged 30–55 years between 2002 and 2011, who had in total 7810 same-sex siblings [Supplementary Figure 1; Table 1].

The mean age of patients was 42.1 years in of siblings was 42.7, that is the siblings were on average 6 months older [Table 1]. The majority of patients had ulcerative colitis [68%], followed by Crohn's disease [27%], and IBD-U [4.3%]. High-school education [10–12 years of education] as the highest education level was the most common [53%], 45% were married and 98% were born in a Nordic country. Compared to siblings, the patients had more often been diagnosed with psychiatric disease [4.7 vs 3.6%], rheumatoid arthritis [0.8 vs 0.4%] and primary sclerosing cholangitis [0.9 vs 0.1%] before first IBD diagnosis. The year before diagnosis the proportion unemployed was similar between patients and siblings [9.2% vs 9.4%], as well as the proportion with no taxable earnings [12.7% vs 12.4%]. More patients with Crohn's disease had no taxable earnings the year before diagnosis [15.4%, Supplementary Table 5] than patients with ulcerative colitis [11.4%, Supplementary Table 6].

Of the 5961 patients with IBD, 5915 [99%] had available data from 5 years before diagnosis, and 5848 [98%] had at least 5 years of follow-up.

3.1. Taxable earnings

Median annual taxable earnings were similar in patients with IBD and siblings 5 years before diagnosis [Figure 1]. Patients with Crohn's disease had lower median taxable earnings than siblings 5 years before diagnosis [Supplementary Figure 2], but in patients with ulcerative colitis median taxable earnings were similar to those of their siblings [Supplementary Figure 3]. During the year of diagnosis, taxable earnings decreased for the IBD patients and remained lower than in siblings during the entire follow-up period. The trend of decreasing taxable earnings compared to siblings was seen from the year of diagnosis and onwards in all age groups [Supplementary Figure 4] and in all categories of education [Supplementary Figure 5]. The differences remained 5–10 years after diagnosis [Supplementary Figure 6].

Over the entire 5-year period following diagnosis, the adjusted difference between patients with IBD and siblings was –5% [–8212€; 95% CI: –11 458 to –4967€] [Supplementary Table 7]. The difference was larger between women with IBD and sisters [–9778€; –13 640 to –5917€] than between men with IBD and brothers [–6569€; –11 483 to –1655€]. The differences were also larger in patients with Crohn's disease [–10 701€; –18 091 to –3310€] than in patients with ulcerative colitis [–6427€; –10 198 to –2657€]. The largest difference between patients and siblings [9%] was found in women with Crohn's disease: –12 703€ [–22 468 to –2937€].

When stratifying for IBD subtype and sex, there were differences between women with Crohn's disease and ulcerative colitis and their sisters, but no significant differences between men with Crohn's disease and ulcerative colitis and their brothers [Figure 2].

Around 50% of the patients with IBD had a same-sex sibling with at least 2% higher taxable earnings during the 1st to 5th year

following diagnosis, 6% had a sibling with similar [–2 to 2% difference] taxable earnings, and 44% had a sibling with lower [at least 2% lower] taxable earnings [Supplementary Figure 7].

3.2. Disposable income

Annual median personalized disposable household income was similar in patients with IBD and same-sex siblings before and after diagnosis/match year [Figure 3]. Patients with Crohn's disease had similar disposable income to their siblings [Supplementary Figure 8], whereas patients with ulcerative colitis had higher disposable income than siblings during several years both before and after diagnosis [Supplementary Figure 9]. Disposable income in patients with IBD was similar to that of siblings over calendar periods [Supplementary Figure 10].

4. Discussion

This nationwide cohort study set in a high-income country with comprehensive social insurance systems covering all residents shows that patients with IBD had 5% lower taxable earnings than siblings during the 5-year period following diagnosis, but that the disposable income of IBD patients was not lower than in siblings. The patients' lower taxable earnings were thus compensated through the Swedish social security system. The differences were larger in women than in men and greater in Crohn's disease than in ulcerative colitis. The largest difference in taxable earnings was between women with Crohn's disease and their sisters.

That women are at increased risk of sick-leave and disability has been reported in previous studies of patients with Crohn's disease,^{14,16,17,19,20,36,37} ulcerative colitis,³⁸ as well as in the general population,³⁹ and sickness absence can explain the lower earnings found in this study. It should be noted, however, that all our comparisons were between same-sex siblings. Why women [compared to men] seem to be more affected by an IBD diagnosis is not known, but similarly a diagnosis of type I diabetes was reported to have a more pronounced negative effect on earnings for women.²⁴ Generally, sex differences regarding sickness absence have been explained by poorer self-reported health,³⁹ greater levels of mental distress,^{39,40} sickness associated with pregnancy,⁴¹ family life issues,⁴² lower wages³⁹ and more unfavourable working conditions³⁹ among women. A greater impact of IBD on health-related quality of life has been reported in women compared to men in both Crohn's disease^{36,43} and ulcerative colitis.⁴⁴ Our results highlight that women with IBD, and especially women with Crohn's disease, are in greater need of support, which needs to be acknowledged by the healthcare system.

Patients with Crohn's disease had lower taxable earnings than their siblings already 5 years before diagnosis [Supplementary Figures 2 and 3], a difference that was not observed in patients with ulcerative colitis. Diagnostic delay could partly explain these findings. For Crohn's disease, the time between onset of symptoms and Crohn's disease diagnosis has been reported up to 7 years, whereas for ulcerative colitis this time is usually only a few months.^{45–51}

In this study, the patients were followed for up to 5 years after diagnosis, which may be too short an observation time. It may take some time for the individual to fully experience the impact of the disease on work performance, and the extent to which the disease justifies a reduction in work effort, and then make the appropriate adjustments. It is possible that IBD affects a person's choice of work, but it is difficult to establish in detail what type of work would be preferable. However, as a sensitivity analysis,

Table 1. Characteristics of patients with inflammatory bowel disease [IBD] and their sex-matched IBD-free siblings

Variable	IBD	IBD-free siblings	<i>p</i> -value ^a
N	5961	7810	
Sex, <i>n</i> [%]			0.89
Women	2928 [49.1%]	3827 [49.0%]	
Men	3033 [50.9%]	3983 [51.0%]	
Age at index date [years]			
Mean [SD]	42.1 [6.7]	42.7 [6.5]	<0.001
Median [IQR]	41.8 [36.4–47.6]	42.7 [37.4–48.0]	<0.001
Range, min–max	30.0–55.0	30.0–55.0	–
Categories, <i>n</i> [%]			
30–39	2469 [41.4%]	2921 [37.4%]	<0.001
40–49	2569 [43.1%]	3615 [46.3%]	
50–55	923 [15.5%]	1 274 [16.3%]	
Index year, <i>n</i> [%]			0.59
2002–2003	1617 [27.1%]	2194 [28.1%]	
2004–2005	1193 [20.0%]	1581 [20.2%]	
2006–2007	1031 [17.3%]	1352 [17.3%]	
2008–2009	1098 [18.4%]	1405 [18.0%]	
2010–2011	1022 [17.1%]	1278 [16.4%]	
IBD subtype, <i>n</i> [%]			
Crohn's disease	1634 [27.4%]	–	–
Ulcerative colitis	4069 [68.3%]	–	–
IBD unclassified	258 [4.3%]	–	–
Comorbidities, <i>n</i> [%] up until IBD diagnosis/match			
Cardiovascular disease	67 [1.1%]	66 [0.8%]	0.10
Diabetes mellitus	114 [1.9%]	143 [1.8%]	0.73
Psychiatric disease	283 [4.7%]	284 [3.6%]	0.001
Rheumatoid arthritis	45 [0.8%]	33 [0.4%]	0.01
Primary sclerosing cholangitis	51 [0.9%]	6 [0.1%]	<0.001
Education, <i>n</i> [%]			0.26
≤9 years	822 [13.8%]	1154 [14.8%]	
10–12 years	3171 [53.2%]	4111 [52.6%]	
>12 years	1960 [32.9%]	2528 [32.4%]	
Unknown	8 [0.1%]	17 [0.2%]	
Country of birth, <i>n</i> [%]			0.11
Nordic country	5846 [98.1%]	7628 [97.7%]	
Non-Nordic country	115 [1.9%]	182 [2.3%]	
Married, <i>n</i> [%]			0.13
Yes	2664 [44.7%]	3591 [46.0%]	
No	3 297 [55.3%]	4 219 [54.0%]	
Unemployed, <i>n</i> [%] year before diagnosis/match			0.71
Yes	550 [9.2%]	735 [9.4%]	
No	5 411 [90.8%]	7 075 [90.6%]	
Annual taxable earnings [1000€, inflation adjusted to 2019] year before diagnosis/match			
Mean [SD]	25.2 [22.0]	25.7 [20.4]	0.16
Median [IQR]	25.4 [11.3–34.0]	25.9 [13.5–34.1]	0.04
Range, min–max	0–574	0–422	–
<i>N</i> [%] with no taxable earnings	755 [12.7%]	968 [12.4%]	0.63
Mean [SD] annual earnings by age categories [1000€]			
30–39 years	23.8 [17.7]	24.1 [17.4]	0.57
40–49 years	26.1 [24.7]	26.7 [21.7]	0.29
50–55 years	26.5 [24.4]	26.6 [22.6]	0.89
Annual personalized disposable household income [1000€, inflation adjusted to 2019] year before diagnosis/match			
Mean [SD]	17.6 [15.3]	17.2 [10.9]	0.12
Median [IQR]	15.5 [11.4–21.2]	15.2 [11.2–20.8]	0.06
Range, min–max	0–728	0–260	–
<i>N</i> [%] with no disposable income	33 [0.6%]	37 [0.5%]	0.51
Calendar years of follow-up, <i>n</i> [%]			
Year 0	5961 [100%]	7810 [100%]	–
Year 1	5934 [99.5%]	7796 [99.8%]	0.003
Year 2	5910 [99.1%]	7770 [99.5%]	0.01
Year 3	5895 [98.9%]	7735 [99.0%]	0.40
Year 4	5871 [98.5%]	7711 [98.7%]	0.23
Year 5	5848 [98.1%]	7688 [98.4%]	0.13

SD, standard deviation; IQR, interquartile range.

^aChi-squared test for categorical variables, and Student's *t*-test or Wilcoxon rank-sum test for continuous variables.

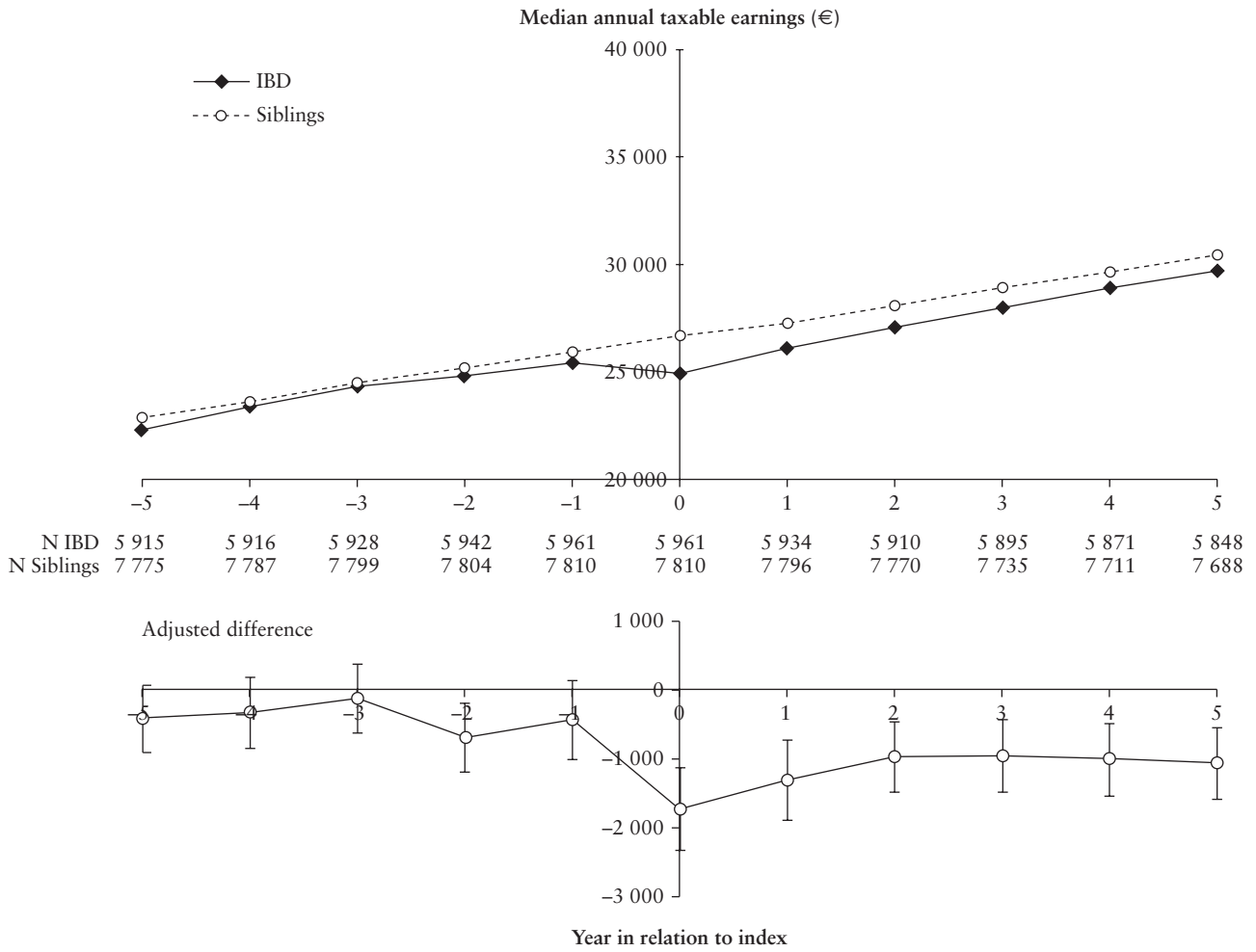


Figure 1. Median annual taxable income in patients with inflammatory bowel disease (IBD) and sex-matched IBD-free siblings.

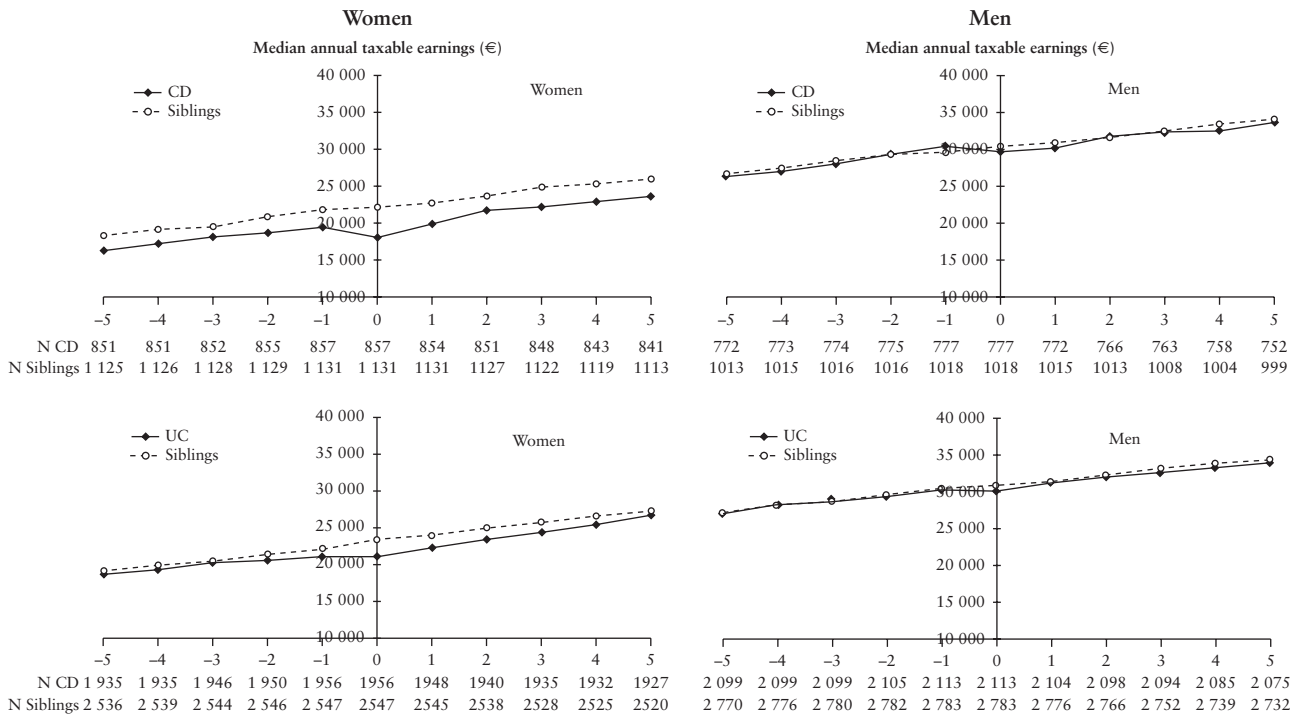


Figure 2. Median annual taxable income in women and men with ulcerative colitis (UC) and Crohn's disease (CD) and sex-matched IBD-free siblings.

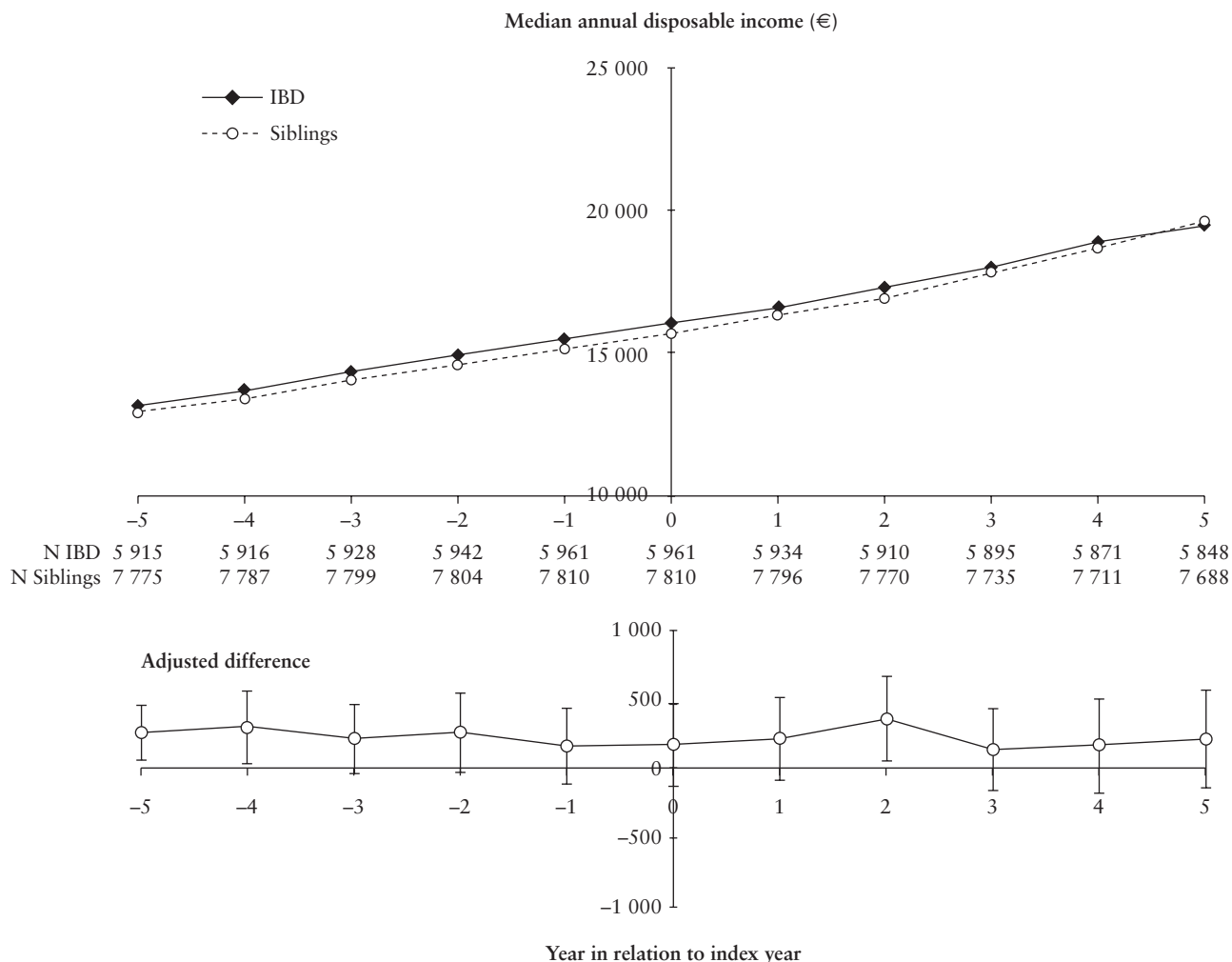


Figure 3. Median annual personalized disposable household income in patients with inflammatory bowel disease (IBD) and sex-matched IBD-free siblings.

we extended the follow-up time to 10 years after diagnosis, and the differences between IBD patients and siblings remained also during the 5th to the 10th year following diagnosis [Supplementary Figure 6].

The social security system in Sweden is more extensive than in many other countries. The expenditure on social protection per head in 2011 was 11 359€, compared to an EU average of 7294€, and the proportion of general government contributions was 15.4%, compared to 12.0% in the EU.⁵² The impact from the disease on the disposable income of IBD patients is likely to be larger in countries with less comprehensive social security systems and job security. However, it is also possible that a system where it is easier to dismiss an employee and where workers get very little or no sick leave compensation would generate smaller differences in earnings; that is, patients with IBD would work while sick to a higher degree.

The social security system in Sweden was subject to major changes during the study period, both regarding regulations and praxis. In 2003, early retirement was abolished and in 2008 the so-called *rehabilitation chain* was introduced, requiring that after 6 months of full or part-time sick leave, the ability of the individual to work must be assessed regardless of the age, education level or adaptive difficulties of the individual. Even though the national cost for social security has decreased radically since a peak in 2005, the

disposable income for IBD patients did not decrease from 2005 and onwards.

4.1. Strengths and limitations

A major strength of the present study is the population-based design and access to data from routine clinical practice entered prospectively in virtually complete registers. In contrast to other studies, we did not rely on patient-reported data. In previous studies patients with IBD have been compared with closely matched IBD-free individuals from the general population.^{53,54} In an effort to adjust for further unmeasured confounding from genetic, socioeconomic and lifestyle factors we chose to compare with same-sex siblings without IBD, a group that should be genetically and socio-demographically similar.

There are limitations regarding the generalizability of our results, because social security systems and job security regulations differ among countries. Therefore, our results in absolute terms may not be generalizable to other countries. Other limitations include a lack of granular data explaining why the patients with IBD had lower earnings. We know that patients with IBD have more sick-leave and disability than the general population, but other potential explanations include lower wages, poorer career development, and personal choice of working hours and sector of the labour market.

4.2. Implications

Although our findings show that patients with IBD had lower taxable earnings than their siblings, and that a comprehensive insurance system such as that in Sweden to a large extent compensates for the lost earnings due to illness, for most patients there was not a significant impact on their earnings. On the other hand, it is clear that a minority of patients, particularly women with Crohn's disease, will pay a high price for their disease. Social insurance does not fully compensate for lost earnings [in Sweden, compensation is at most 80% of the monthly salary]. Increasing utilization of these compensation systems over time can result in increasing differences in total earnings not only during working years, but also thereafter, as retirement compensation is based on accumulated life earnings.

5. Conclusion

During the first 5 years after diagnosis the adjusted difference in taxable earnings between patients with IBD and same-sex siblings was -5%. However, for most patients there was not a significant impact on earnings. Women with Crohn's disease and ulcerative colitis had lower annual earnings than their sisters during the entire follow-up, whereas men with Crohn's disease and ulcerative colitis had similar earnings to their brothers. The Swedish social security system compensated for differences in earnings, leading to similar disposable income for IBD patients and their siblings.

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Conflict of Interest

Authors' declaration of personal interests

A.H.E. and J.S. have worked on projects at the Karolinska Institutet and SWIBREG partly financed by grants from Ferring and Jansen. J.E.L. coordinates a study on behalf of the Swedish IBD quality register [SWIBREG], which has received funding from Jansen corporation. O.O. has been principal investigator on projects at Karolinska Institutet, partly financed by investigator-initiated grants from Janssen and Ferring, and Karolinska Institutet has received fees for lectures and participation on advisory boards from Janssen, Ferring, Takeda and Pfizer. O.O. also reports a grant from Pfizer in the context of a national safety monitoring programme. J. H. has served as speaker and/or advisory board member for AbbVie, Celgene, Celltrion, Dr. Falk Pharma and the Falk Foundation, Ferring, Hospira, Janssen, MEDA, Medivir, MSD, Olink Proteomics, Novartis, Pfizer, Prometheus Laboratories, Sandoz, Shire, Takeda, Thermo Fisher Scientific, Tillotts Pharma, Vifor Pharma and UCB, and received grant support from Janssen, MSD and Takeda. P.M. has received fees for lectures from Ferring, Abbvie, Takeda, Otsuka, MSD, MEDA and Nutricia, and has served as an advisory board member for Norgine. C.N. and K.W. have no disclosures.

Author Contributions

Conception and design: A.H.E., O.O. Acquisition of data: O.O. and J.E.L. Statistical analysis: J.S. Interpretation of data: All authors. Drafting the manuscript: A.H.E. Critical revision for intellectual content: All authors. Final

approval: All authors. Accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved: All authors. Guarantor of article: O.O.

Availability of data

The data underlying this article cannot be shared publicly due to privacy of individuals who participated in the study.

Supplementary Data

Supplementary data are available at *ECCO-JCC* online.

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