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IBD-related work disability in the community: Prevalence, severity and predictive factors. A cross-sectional study

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Abstract

Background and aims: Data on the prevalence of work disability in patients with inflammatory bowel disease (IBD) are heterogeneous. As most studies have been performed in selected, often severe, IBD patients, the true prevalence of disability in the community remains controversial. The aim of this cross-sectional study was to evaluate the prevalence and severity of disability and its predictive factors in a community-based IBD population.

Patients and methods: Patients recorded in the community-based IBD register at the Hospital Universitario de Burgos were contacted. After informed consent they completed a set of questionnaires including demographic, clinical, disability and quality of life data. The statistical study was performed using SPSS 21.

Results: A total of 293 patients were included – 151 Crohn's disease (CD), 142 ulcerative colitis (UC), 137 female, mean age: 45 ± 11 years, mean time since diagnosis: 10.6 ± 11 years. Twelve patients (4.1%) had a work-disability pension. In addition, 93 (32%) of all patients had an officially recognized disability degree, which was generally moderate ($n = 73$, 25%) or severe ($N = 16$, 5%). Age, time since IBD diagnosis, CD, perianal disease, incontinence, active disease, the need for anti-TNF or psychological treatment, previous surgeries and the number of diagnostic tests and medical visits in the previous year were predictors of disability. Major predictors of qualifying for a disability pension were age, IBD activity, incontinence, need for biological drugs and ostomy.

Conclusion: Mild to moderate work disability is frequent in IBD. However, only a minority of patients develop severe disability qualifying them for a pension.

Keywords

Disability, inflammatory bowel disease, Crohn's disease, ulcerative colitis

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Introduction

Crohn's disease (CD) and ulcerative colitis (UC) are both chronic inflammatory bowel diseases (IBD). Both diseases alternate flares with periods of remission. Complications requiring hospitalization and surgery are not uncommon.[1]

Persistent activity, repeated flares and surgeries, and the adverse effects of medical treatment can lead to permanent work disability. As the incidence of the disease is highest at young ages, work disability represents a major social impairment for IBD patients.[2,3]

Rates of reported disability vary widely.[4] In a Norwegian cohort, the rate of IBD patients receiving

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disability pensions was 8.5%, similar to that in the population as a whole.[5] In general, the overall prevalence of work disability ranges from 1.3% to 50%[2,5–13] depending on the setting in which disability was measured and on how it was defined.[14,15] For example, 25% of patients included in a pivotal study for an anti-tumor necrosis factor (TNF) drug—A Crohn's disease Clinical trial Evaluating infliximab in a New Long-term Treatment regimen in patients with fistulising Crohn's disease (ACCENT I) trial—were receiving a disability pension.[11] In general, most of the studies have been performed in selected populations, and community data are scarce.[4,7,10]

Factors determining work disability are unclear. Although work disability has been generally related to the severity of IBD, the roles of other factors such as age, sex or educational level, to mention a few examples, remain controversial.[16]

In addition, although the degree of disability is a continuum, previous studies have not provided data on disability severity. The Spanish social security system provides coverage for the entire population via two complementary programs. Social Security Disability Insurance (SSDI) covers workers who have contributed to the SSDI system. Patients with disability receive pensions covering the inability to work in their profession (occupation-only disability) or the inability to work at all (absolute disability). The second program is an independent evaluation system that rates disability in both working and non-working people on a 100% scale. Patients must voluntarily request evaluation and the recognition of disability qualifies them for tax reductions and other advantages. However, only patients with a high degree of disability ($\geq 55\%$) who lack additional economic resources are awarded disability pensions, which tend to be very small.[17] Combining data from the two systems could provide insights not only into the prevalence but also the severity of IBD-related work and general disability.

Finally, the Hospital Universitario de Burgos (HUBU) provides care for a population of 258,792 individuals in northern central Spain (Castille and León).[18] The hospital provides all specialized care in the reference area. Due to the hospital's characteristics and its geographical location, patient referrals from or to other hospitals are rare. Private practice is limited in this area and, in general, severe diseases, including IBD, are referred to the hospital. The IBD unit at the HUBU keeps an updated community-based register of IBD patients including data on patients controlled at three of the four private practices in the area. It also attends to most of the patients with IBD, thus allowing the evaluation of IBD-related disability in the community.

The aim of the present study was to describe the prevalence, severity and the predictive factors of IBD-related work and general disability in a well-characterized community-based population in Spain.

Patients and methods

Patients

From January 2012 to June 2013, all patients registered in the IBD community-based database at the HUBU were evaluated for inclusion in a cross-sectional study. Exclusion criteria were:

1. Age below 18 or over 67 years.
2. Inability to understand or complete the questionnaires.
3. Refusal to give written informed consent to participate in the study.
4. IBD diagnosed six months or less before inclusion.

Methods

After receiving a full explanation of the project, patients signed informed consent and were asked to complete a set of questionnaires. Patients self-reported demographic data and IBD classification according to the Montreal classification.[19] Activity of the disease was determined using the Harvey-Bradshaw score[20] for CD and the modified Mayo score for UC.[21]

Disability was evaluated in the questionnaire on the basis of the patient's working status, receipt of a disability pension and, if so, its type (occupation-only or all-work disability) and official recognition of their disabled status. In accordance with Spanish law, the degree of disability was graded as mild ($< 33\%$), moderate ($\geq 33\%$ to $< 55\%$) or severe ($\geq 55\%$).[17]

Patients were also asked about certain variables, which had been associated with disability in previous studies.[5–13,16] They were interviewed again if necessary and medical reports were reviewed to check the completeness and accuracy of clinical data in order to avoid missing data. Finally, all patients filled out the validated Spanish version of the shortened Inflammatory Bowel Disease Quality of Life questionnaire IBDQ-9[22,23] and the EuroQol-5 questionnaire.[24] IBDQ-9 is a shortened version of the IBDQ-36 item-specific quality-of-life questionnaire. Both the original IBDQ-36 and the shortened version have been validated in Spanish.[22,23] EuroQol-5 is a generic quality-of-life instrument that has been extensively validated and used.[24] It was evaluated as suggested by Shaw et al.[25,26]

Data on the degree and rates of disability in the general population in the area were obtained from the Spanish Statistics Institute,[27] the Ministry of Employment and Social Security[28] and from the

yearly economic summary of the Chamber of Commerce of Burgos.[29]

Statistical methods

Continuous variables were given either as means ± SD or as medians and interquartile ranges. Proportions were given as percentages ±95% confidence intervals (CI). The Mann-Whitney test was used to compare continuous variables, and the Chi-square test for proportions; p values lower than 0.05 were considered significant. Comparisons of sample prevalence to the reference population were given as odds ratios (OR) and 95% CI.

Univariate and multivariate analyses were performed to identify the factors related to either receiving a disability pension or having a recognized degree of disability. Logistic regression using both an enter and backward method was performed for the multivariate analysis. Calculations were performed using SPSS 21 (Hewlett Packard, Chicago, IL, USA). The study was reported in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) recommendations.[30]

Ethical issues

The ethics review boards of the participating hospitals approved the study. Patients gave written informed consent before entering the study. All study procedures were performed in accordance with the Helsinki Declaration.[31] Personal data were coded before the analysis to preserve confidentiality and were managed according to the Spanish Protection of Personal Data Act of 1999.

Results

Patients

A total of 400 patients were registered in the HUBU IBD database. Prevalence of IBD in the population was 154.56 per 100,000 habitants, in the range of previously published studies in Spain.[32,33] Of the patients recorded, seven were younger than 18 and 63 were over 67. Of the remaining 330 patients, 22 declined to participate, seven had been diagnosed in the last six months, and four were unable to complete the questionnaire—two because of intellectual disability and two because of insuperable language barriers. Additionally, five patients did not fill out the questionnaires completely and were also excluded. Finally, 293 patients—151 CD and 142 UC—were included in the study (Figure 1).

Demographic and clinical characteristics of patients are shown in Table 1. In summary, 137 (47%) of the series were female, the mean age was 45.5 years, mean follow-up since diagnosis was 10.6 years and most patients were in remission or had very mild symptoms: Harvey-Bradshaw score was ≤ 5 in 112 (74%) and ≤ 7 in 128 (85%) CD patients, and the modified Mayo score was ≤ 2 in 95 (67%) and ≤ 4 in 126 (89%) UC patients. Fifteen percent of patients were receiving anti-TNF treatment.

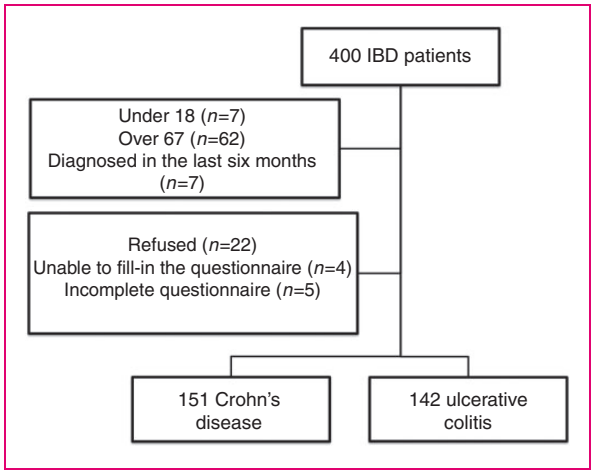

Figure 1. Flow diagram of the patients included in the study. IBD: inflammatory bowel disease.

Work status and degree of disability

A total of 214 IBD patients (73%) were actively employed, 12 (4.1%) were receiving a work-disability pension, 16 (5.5%) were unemployed and 11 (3.8%) prematurely retired. The remaining patients (13.6%) were homemakers ($n = 30$) or students ($n = 10$).

Of the 12 patients (4.1% of the whole series) receiving a work-disability pension, four had occupation-only disability and the remaining eight were considered to be unable to perform work of any kind. The rate of disability was similar in CD ($n = 7$, 4.6%) and UC ($n = 5$, 3.5%) patients. Of these 12 patients, seven stated that the disability was related mainly to the IBD, in two it was related to mixed causes (among which IBD was an important factor) and in three, the disability was due to unrelated diseases. Consequently, only 2.4%–3.1% of the whole patient population had an IBD-related work disability severe enough to qualify for a disability pension.

The rate of IBD patients receiving a disability pension compared with those actively working (5.4%) was twice the rate observed in the general working population in the province of Burgos (2.7%); OR was 2.07 (95% CI: 1.16 to 3.72, $p = 0.014$).[28,29]

Ninety-three patients (31.8%) had an officially recognized degree of disability, which ranged from

Table 1. Characteristics of patients

	All IBD ($n=293$)	CD ($n=151$)	UC ($n=142$)
Age (years, mean ± SD)	45.5 ± 11	43.1 ± 11	48 ± 10.2
Female (*n* (%))	137 (47)	70 (46)	67 (47)
Time since IBD diagnosis (years, mean ± SD)	10.6 ± 8.8	12 ± 9	9.3 ± 7
Age at diagnosis (≤ 16 y/17–40 y/ ≥ 40 y, (*n*))		7/113/31	
CD location: ileal/colonic/ileocolonic/isolated upper (*n*)		61/33/52/5	
Behavior (nonstricturing, nonpenetrating/stricturing/penetrating (*n*))		60/61/22	
Perianal disease (*n* (%))		44 (29)	
Harvey-Bradshaw (mean ± S.D)		4.1 ± 3.2	
UC location (proctitis/left-sided/extensive (*n*))			40/52/50
Modified Mayo score (mean ± S.D)			2.2 ± 1.9
Immunosuppressive treatment (*n* (%))	146 (50)	100 (66)	46 (32)
Anti-TNF treatment (*n* (%))	43 (15)	31 (21)	11 (8)
Previous resection (0/1/2/3 or more)	226/51/11/5	90/45/11/5	136/6/0/0
Perianal surgery (0/1/2 or more)		109/28/14	
Ileostomy/ ileo-anal pouch (*n*)		12/0	4/2

IBD: inflammatory bowel disease; CD: Crohn's disease; UC: ulcerative colitis; TNF: tumor necrosis factor.

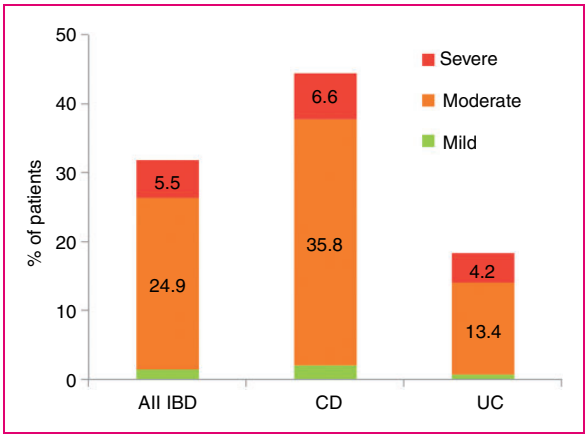

Figure 2. Distribution of disability according to its severity and type of diseases.
IBD: inflammatory bowel disease; CD: Crohn's disease; UC: ulcerative colitis.

24% to 100%. Most of the disabilities were graded as moderate (≥ 33% to < 55%) or severe (≥ 55%) The rate and the severity of disability were higher in CD than in UC patients ($p < 0.001$) (Figure 2). The patients attributed the disability to their IBD in 64 cases (69%), to mixed causes in 23 (25%) and to diseases other than IBD in six (7%).

Factors related to disability

Univariate analysis found that variables related to having a disability pension were age, IBD activity, the need for anti-TNF treatment, fecal incontinence and having an ostomy (Table 2).

Predictive factors for any grade of disability were having CD rather than UC, fecal incontinence, number of surgeries, number of medical visits and diagnostic tests performed in the previous year, use of anti-TNF, need for psychological treatment, low quality of life measured with either EQ-5D or IBDQ, age at inclusion in the study, time since the diagnosis of the disease and IBD activity (Table 2).

Time since IBD diagnosis was one of the most powerful predictors of disability. The degree of disability clearly increased with time (Figure 3).

Multivariate analysis to determine independent predictive variables for having a work-disability pension was not performed, because the low number of events precluded adequate analysis. The multivariate analysis for determining independent factors related to having any degree of disability, selected time since IBD diagnosis, need for an anti-TNF drug, number of previous surgeries and number of diagnostic procedures during the previous year (Table 3).

Discussion

The present study shows that one-third of IBD patients present some degree of disability and that the degree of disability increases in patients with long-standing disease. The findings reflect the progressive course of IBD.[34] However, rates of severe disability qualifying for disability pensions were low. In our series, only 4% of patients received a disability grant, a figure far

Table 2. Factors related to having a disability pension or a recognized degree of disability in the univariate analysis

	Disability pension			Any disability		
	Yes ($n=12$)	No ($n=281$)	p	Yes ($n=93$)	No ($n=200$)	p
Age (mean ± SD)	55 ± 8	45.2 ± 11	0.004	47 ± 11	45 ± 11	0.10
Female/male (n)	4/8	133/148	NS	44/49	93/107	NS
Education (primary/high school/university) (n)	5/1/6	62/119/100	0.09	24/36/33	43/84/73	NS
Age at IBD diagnosis (mean ± SD)	34.5 ± 11	35 ± 16	NS	31.8 ± 11	35.8 ± 11	0.005
Time since IBD diagnosis (mean ± SD)	19.8 ± 13	10.2 ± 8	0.12	14.9 ± 9	8.7 ± 8	0.000
CD/UC (n)	7/5	140/137	NS	67/26	84/116	0.000
Extensive disease (ileocolic CD, pancolitis) (n (%))	9 (75)	186 (66)	NS	58 (62)	137 (69)	0.03
IBD activity (Harvey > 5, Mayo modified > 3) (n (%))	7 (58)	77 (27)	0.03	42 (45)	42 (21)	0.000
Perianal disease (n (%))	2 (17)	42 (15)	NS	24 (26)	20 (10)	0.000
Fecal incontinence (n (%))	6 (50)	59 (21)	0.03	30 (32)	35 (18)	0.004
Ileostomy/colostomy (n (%))	3 (25)	13 (5)	0.01	9 (10)	7 (4)	0.08
Immunosuppressive drugs (n (%))	7 (58)	137 (49)	NS	53 (57)	91 (46)	0.054
Anti-TNF (n (%))	6 (50)	35 (13)	0.01	29 (31)	13 (7)	0.000
Need for psychological treatment (n (%))	3 (25)	38 (14)	NS	25 (27)	16 (8)	0.000
EQ-5D (mean ± S.D.)	0.83 ± 0.2	0.87 ± 0.1	NS	0.82 ± 0.1	0.89 ± 0.1	0.000
IBDQ-9 (mean ± S.D.)	36.4 ± 9	47.7 ± 10	0.04	44.3 ± 9	48.9 ± 10	0.000
Number of previous surgeries (mean ± SD)	0.91 ± 1	0.49 ± 1	NS	1.1 ± 1.7	0.22 ± 0.7	0.000
Previous year days of sick leave (mean ± SD)	–	–	–	27.4 ± 71	14.3 ± 46	0.12
Previous year diagnostic studies (mean ± SD)	4.5 ± 4	3.2 ± 3	NS	4.4 ± 4	2.7 ± 3	0.000
Hospitalization days; previous year (mean ± SD)	1.8 ± 6	3.2 ± 12	NS	2 ± 6	5.6 ± 19	NS
Previous year medical visits (mean ± SD)	1.8 ± 2	1.4 ± 3	0.09	1 ± 6	2.3 ± 5	0.01

IBD: inflammatory bowel disease; CD: Crohn's disease; UC: ulcerative colitis; TNF: tumor necrosis factor; EQ-5D: EuroQol-5 questionnaire; IBDQ-9: Inflammatory Bowel Disease Quality of Life questionnaire.

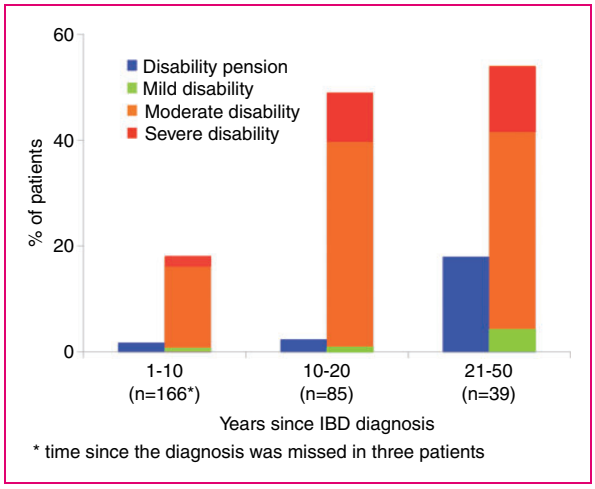

Figure 3. Prevalence and severity of disability according to time since inflammatory bowel disease (IBD) diagnosis.

below that observed in the prospective series by Høivic et al.,[7] who reported that 16.6% of patients had disability benefits. Differences between the series may be due either to differences in the patient population or to differences in the study settings. Regarding the patient population, Høivic et al.'s patients were evaluated at diagnosis between 1990 and 1993 and then between 2000 and 2003 after a 10-year follow-up period. As the use of biological drugs has been reported to reduce rates of disability in IBD patients,[35] a first possibility is that the disability rates could have been higher 10 to 20 years ago, before biological drugs were fully available. In fact, the rate of severe disability qualifying for a pension observed in patients with more than 20 years of disease in our study was 18%, very similar to the rate described by Høivic et al.[7] 10 years ago. It is possible, therefore, that the unavailability of effective treatments 20 years ago has increased the rate of surgery and the sequelae of the disease. As regards the setting, barriers to access may vary notably between different national SSDIs.

Our study is one of the first to present data on the rates of moderate to severe disability in IBD patients not qualifying for pensions. This approach gives a more complete picture of the topic and clearly shows that disability is frequent and increases with time: After 10

Table 3. Variables related to having a degree of recognized disability in the multivariate analysis

	B	SE	Wald	Sig.	Exp (B)
Time since IBD diagnosis	0.082	0.018	21.320	0.000	1.086
Anti-TNF (*n* (%))	−1.566	0.429	13.328	0.000	0.209
Number of previous surgeries	0.531	0.166	10.193	0.001	1.701
Number of diagnostic studies during the previous year.	0.104	0.047	4.858	0.028	1.110

IBD: inflammatory bowel disease; TNF: tumor necrosis factor.

years of disease, nearly 50% of individuals had some degree of recognized disability.

The study also highlights the difficulty of measuring disability. Although theoretically objective, the degree of disability secondary to IBD is modulated by many personal and social factors. Notably, only three of the 16 patients with an ostomy were receiving a disability pension. Furthermore, around one-third of patients with an ostomy were working actively and had never requested any disability evaluation. This highlights three important points. First, work disability depends on the physical and psychological requirements of a particular occupation, that is, the job profile diagram. Second, social background and personal attitudes and beliefs strongly modulate the degree of disability induced by a given physical alteration. Third, and as a consequence of these two points, measuring disability is extremely difficult and inevitably imprecise.

With regard to factors related to disability, the study shows that disability is more frequent in CD than in UC. This finding is in accordance with precious studies.[14,15] By contrast, rates of severe disability were similar, probably because a proportion of patients with UC will require a highly disabling total colectomy. In addition to having CD, the study highlights that two major groups of parameters modulate disability in IBD: factors related to severe disease, and surgical sequelae. Factors related to severe disease were the need for biological medication, persistent disease activity despite treatment, and need for a high number of explorations and medical visits during the previous year or a history of multiple surgeries. Surgical disabling sequelae include, for example, fecal incontinence or having an ostomy. In general, the factors described in our study agree with those found in previous studies.[2,7,9–17,36] Contrary to previous reports, however, we did not find associations between gender, educational level or type of employment and disability.

The study has certain limitations. We may have underestimated the real degree of disability by not including in the disabled group patients with severe disturbances such as having an ostomy or fecal incontinence but who had not requested either a disability pension or a formal evaluation for disability. Whether these patients—who probably do not consider themselves to be disabled—should be considered disabled is a difficult question. In addition, although the HUBU IBD database included all patients known to have IBD in the community using both hospital and primary care data, we could not be entirely sure that a few patients with inactive disease had not been missed. Conversely, it is theoretically possible that the database might have missed patients who received an ostomy or an ileo-rectal anastomosis for colonic disease years ago and had not been followed further for their IBD. In conclusion, both over- and underestimations of the disability rates are possible, although the number of patients missed is probably very low. Finally, the concession of disability pensions data in Spain[37] shows a marked geographical variability, suggesting a degree of inequity in the system. As a result, the award of disability pensions may not reflect exactly the true degree of disability of IBD patients: More objective evaluation tools would help to measure disability more accurately and might also help to increase equity.[37]

The present study confirms that disability is frequent in patients with long-term IBD, and so its prevention is important. Whether early aggressive treatment can prevent the evolution to refractory disease and the development of complications requiring surgery needs further investigation. In addition, determining the objective criteria related to disability could help medical evaluators and evaluation agencies to award disability benefits to patients in a more equitable manner.

In conclusion, work disability is frequent in IBD, although after 10 years of disease only a minority of patients develop severe disability requiring a pension. Degrees of disability increase with the time of evolution of the disease. Major sources of disability were persistent disease activity and long-term surgical sequelae.

What is already known about this subject?

- The prevalence of inflammatory bowel disease (IBD)-related work disability is not well known.
- Factors associated to work disability are also not well established.
- There are few data regarding minor degrees of disability.

What are the new findings?

- After 10 years of disease, only 4.1% of patients qualified for a disability pension.
- However, 32% of patients had some grade of officially recognized disability.
- Age, active disease despite treatment, the need for biological drugs, having an ostomy, and incontinence are the major predictors of severe disability.

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Conflict of interest

Xavier Calvet has served as a speaker, consultant and advisory member and has received research funding from MSD and Abbvie.

Beatriz Sicilia has nothing to declare.

Fernando Gomollón has served as a speaker, consultant and advisory member and has received research funding from MSD and Abbvie.

Alexis Ramos has nothing to declare.

Adoración Sastre has nothing to declare.

Jaume Motos has nothing to declare.

Albert Villoria has served as a speaker, consultant and advisory member and has received research funding from MSD and Abbvie.

Mercedes Vergara has nothing to declare.

Ariadna Figuerola has nothing to declare.

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Authorship statement

Alexis Ramos: acquisition of data, drafting the article and final approval of the version to be published. Xavier Calvet: conception and design, analysis and interpretation of data, drafting the article and final approval of the version to be published.
Beatriz Sicilia: conception and design, acquisition of data, and final approval of the version to be published. Mercedes Vergara: analysis and interpretation of data and final approval of the version to be published.
Adoración Sastre: acquisition of data and final approval of the version to be published. Ariadna Figuerola: acquisition of data, analysis and interpretation of data and final approval of the version to be published.
Jaume Motos: Interpretation of data and approval of the final version to be published.
Albert Villoria: analysis and interpretation of data, and approval of the final version to be published. Fernando Gomollon: conception and design, critical revision for important intellectual content and approval of the final version to be published.

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