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Survey to identify patient characteristics, treatment preferences and impact of inflammatory bowel disease (IBD) on quality of life across 7 countries in Europe

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BACKGROUND

- Inflammatory bowel disease (IBD), including Crohn's disease (CD) and ulcerative colitis (UC), is characterised by chronic inflammation of the gastrointestinal tract, with no cure currently available[1,2]
- The increasingly complex and diverse treatment paradigm for IBD suggests that along with clinical guidelines, patient engagement through shared decision-making engages patients in treatment decisions and optimises the chance of a chosen therapy matching their personal preferences[3]
- Adequate information and fair presentation of the trade-off between the risks and benefits of treatment are critical for patients' participation in medical decisions[3]
- This patient survey aimed to describe the demographics and clinical characteristics of respondents and patient-rated preferences towards existing treatment options and impact on quality of life (QoL); here, we present patient demographics, clinical characteristics, and impact of IBD on QoL

METHODS

Study design and population

A descriptive, observational, stated preference study consisting of an online, cross-sectional survey conducted across 7 European countries (see **Table 1**)

Patients aged ≥18 years who self-reported having CD or UC and being previously/currently treated for these conditions

October 2020 to January 2021

ClinicalTrials.gov identifier: NCT04597905

Data sources

- Data collected through an online, self-reported questionnaire via the Carenity platform[4] and partnerships with local organisations

Outcomes

- Patient demographics, clinical characteristics and impact of IBD on QoL

RESULTS

Patient demographics

- Overall, 686 patients (CD, 360; UC, 326) across 7 countries completed the survey (**Table 1**)

Table 1: Survey respondent demographics

	CD (n=360)	UC (n=326)
Sex, n (%)		
Female	259 (71.9%)	188 (57.7%)
Male	101 (28.1%)	138 (42.3%)
Age (years), mean (range)	48.0 (19.0–77.0)	50.0 (19.0–82.0)
Country of residence, n (%)		
France	106 (29.4%)	74 (22.7%)
UK	38 (10.6%)	71 (21.8%)
Spain	50 (13.9%)	40 (12.3%)
Italy	39 (10.8%)	55 (16.9%)
Netherlands	41 (11.4%)	27 (8.3%)
Belgium	34 (9.4%)	26 (8.0%)
Switzerland	52 (14.4%)	33 (10.1%)
Living area (approximate inhabitants), n (%)		
Very large (>1M)	39 (10.8%)	39 (12.0%)
Large (100,000–1M)	55 (15.3%)	62 (19.0%)
Medium (20,000–100,000)	95 (26.4%)	82 (25.2%)
Small (2,000–20,000)	114 (31.7%)	94 (28.8%)
Rural (<2,000)	57 (15.8%)	47 (14.4%)
Other	0 (0.0%)	2 (0.6%)
Highest educational level, n (%)		
PhD	7 (1.9%)	4 (1.2%)
Master's degree	32 (8.9%)	43 (13.2%)
Bachelor's degree	53 (14.7%)	50 (15.3%)
2-year university degree	54 (15.0%)	42 (12.9%)
Professional training[a]	23 (6.4%)	10 (3.1%)
High school diploma	142 (39.4%)	130 (39.9%)
Did not finish high school	33 (9.2%)	32 (9.8%)
Other	6 (1.7%)	9 (2.8%)
Not known	10 (2.8%)	6 (1.8%)

[a]Item not in the questionnaire but added from response to verbatim 'other'
CD, Crohn's disease; M, million; UC, ulcerative colitis; UK, United Kingdom

Patient clinical characteristics

- In patients with CD and UC, mean disease duration was 13.6 and 11.0 years and mean age at diagnosis was 33.0 and 38.0 years, respectively (**Table 2**)

Table 2: Survey respondent clinical characteristics

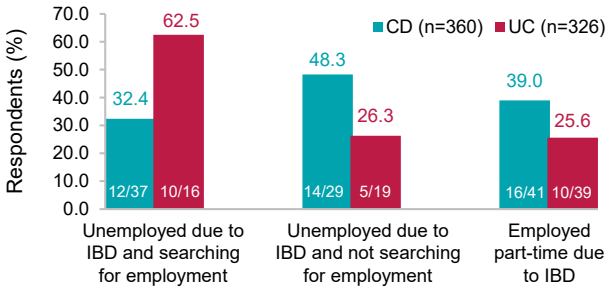
	CD (n=360)	UC (n=326)
Disease duration (years), mean (range)	13.6 (0.2–49.1)	11.0 (0.1–68.7)
Disease duration categories (years), n (%)		
≤2	42 (11.7%)	57 (17.5%)
3–5	45 (12.5%)	41 (12.6%)
6–10	67 (18.6%)	64 (19.6%)
>10	148 (41.1%)	107 (32.8%)
Not known	58 (16.1%)	57 (17.5%)
Age at diagnosis (years), mean (range)[a]	33.0 (6.0–70.0)	38.0 (4.0–75.0)
Age at diagnosis categories (years), n (%)[a]		
≤20	62 (20.5%)	21 (7.8%)
21–30	84 (27.8%)	80 (29.7%)
31–40	67 (22.2%)	67 (24.9%)
41–50	51 (16.9%)	38 (14.1%)
51–60	25 (8.3%)	39 (14.5%)
>60	13 (4.3%)	24 (8.9%)
Fistulising CD, n (%)	135 (37.5%)	NA
Pouch/stoma, n (%)	34 (9.4%)	33 (10.1%)
Affected localisation of the GI tract, n (%)		
Colon only	66 (18.3%)	NA
Ileum only	99 (27.5%)	NA
Rectum only	5 (1.4%)	63 (19.3%)
Colon and ileum	76 (21.1%)	NA
Colon, ileum and rectum	49 (13.6%)	NA
Ileum and rectum	15 (4.1%)	NA
Rectum and part of colon	31 (8.6%)	145 (44.5%)
Rectum and entire colon	NA	88 (27.0%)
Other and/or unknown	19 (5.3%)	30 (9.2%)
Currently treated for IBD, n (%)		
Receiving treatment	276 (76.7%)	256 (78.5%)
Receiving no treatment	84 (23.3%)	70 (21.5%)
Treatment for IBD, n (%)		
Previous		
Corticosteroids[b]	306 (85.0%)	269 (82.5%)
Advanced therapies/biologics	169 (46.9%)	72 (22.1%)
Immunomodulators[c]	156 (43.3%)	98 (30.1%)
Current[d]		
Corticosteroids[b]	124 (44.9%)	142 (55.5%)
Advanced therapies/biologics	173 (62.7%)	70 (27.3%)
Immunomodulators[c]	74 (26.8%)	69 (27.0%)

[a]Includes 302 (CD) and 269 (UC) patients; [b]Include methylprednisolone, prednisone, prednisolone, dexamethasone, hydrocortisone and budesonide only; [c]Include azathioprine, mercaptopurine, methotrexate, tacrolimus and cyclosporine; [d]Includes 276 (CD) and 256 (UC) patients
CD, Crohn's disease; GI, gastrointestinal; IBD, inflammatory bowel disease; NA, not applicable; UC, ulcerative colitis

Impact of IBD on employment status

- Overall, 11.7% and 7.7% of patients were either unemployed or partially employed due to their CD and UC, respectively (**Figure 1**)

Figure 1: Impact of IBD on employment status

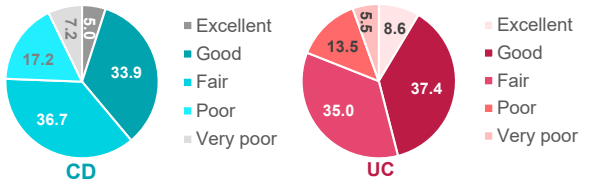


CD, Crohn's disease; IBD, inflammatory bowel disease; UC, ulcerative colitis

Impact of IBD on QoL

- Approximately 70% of patients in each group (CD or UC) described their current well-being as good or fair (**Figure 2**)

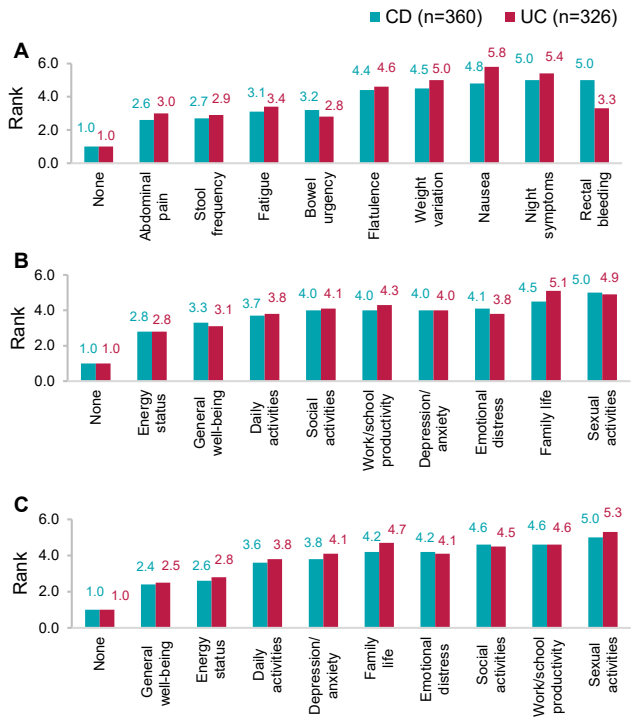
Figure 2: Impact of IBD on current general well-being



Data are presented as the percentage of patients (CD, n=360; UC, n=326)
CD, Crohn's disease; IBD, inflammatory bowel disease; UC, ulcerative colitis

- Abdominal pain, fatigue and stool frequency were ranked by 83% vs 73%, 79% vs 67% and 73% vs 72% of patients with CD vs UC, respectively, as the symptoms most impacting QoL (**Figure 3A**)
- Energy status, general well-being and daily activities were ranked by 79% vs 69%, 71% vs 71% and 61% vs 61% of patients with CD vs UC, respectively, as the aspects of daily life most impacted by IBD (**Figure 3B**)
- General well-being, energy status and daily activities were ranked by 75% vs 76%, 73% vs 69% and 54% vs 54% of patients with CD vs UC, respectively, as aspects of daily life for improvement through treatment (**Figure 3C**)

Figure 3: Impact of IBD on QoL measures—(A) Symptoms of IBD with the most impact on QoL, (B) aspects of daily life most impacted by IBD, and (C) aspects of daily life to be improved by treatment



Data are presented as mean rank. The ranks were based on a symptom ranking question (1, most impactful symptom; 2, second most impactful symptom; etc.) as judged by the respondents. None refers to 'no symptom'
CD, Crohn's disease; IBD, inflammatory bowel disease; QoL, quality of life; UC, ulcerative colitis

CONCLUSIONS

- Patients who completed this survey mainly comprised a middle-aged population with >75% of patients being currently treated for IBD
- CD was diagnosed at an earlier age and with a longer disease duration than UC
- While symptoms were different for patients with CD and UC, patients ranked similar aspects expected to improve the most by treatment
- These findings can support clinical decision-making and treatment strategies to improve treatment outcomes and patient QoL

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REFERENCES: 1. Fakhoury M, *et al. J Inflamm Res. 2014;7:113-120;* 2. Seyedian SS, *et al. J Med Life. 2019;12:113-122;* 3. Siegel CA. *Gut. 2012;61:459-465;* 4. Carenity. https://www.carenity.co.uk/.

DISCLOSURES: GF has received consultancy fees from MSD, Takeda, AbbVie, Janssen, Pfizer, Celltrion, Sandoz, Alfasigma, Samsung, Amgen, Roche and Ferring. NB-E and FB are employees of Takeda Pharmaceuticals International AG. PV is an employee of Carenity. EH has no potential conflict of interest to disclose.

ACKNOWLEDGEMENTS: This study was funded by Takeda Pharmaceuticals International AG. Medical writing support for the development of this poster was provided by Archana Patkar, PhD, of Cactus Life Sciences (part of Cactus Communications) and funded by Takeda Pharmaceuticals International AG. Authors retained full control of the poster content.

Presented at the 16th ECCO Virtual Meeting, July 2–3 & 8–10, 2021