Exploring a novel score to assess the Patient Perceived Burden of Disease in Crohn's Disease and Ulcerative Colitis – Crohn's Colitis Cure (CCC) Data Insights Program

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INTRODUCTION & AIM

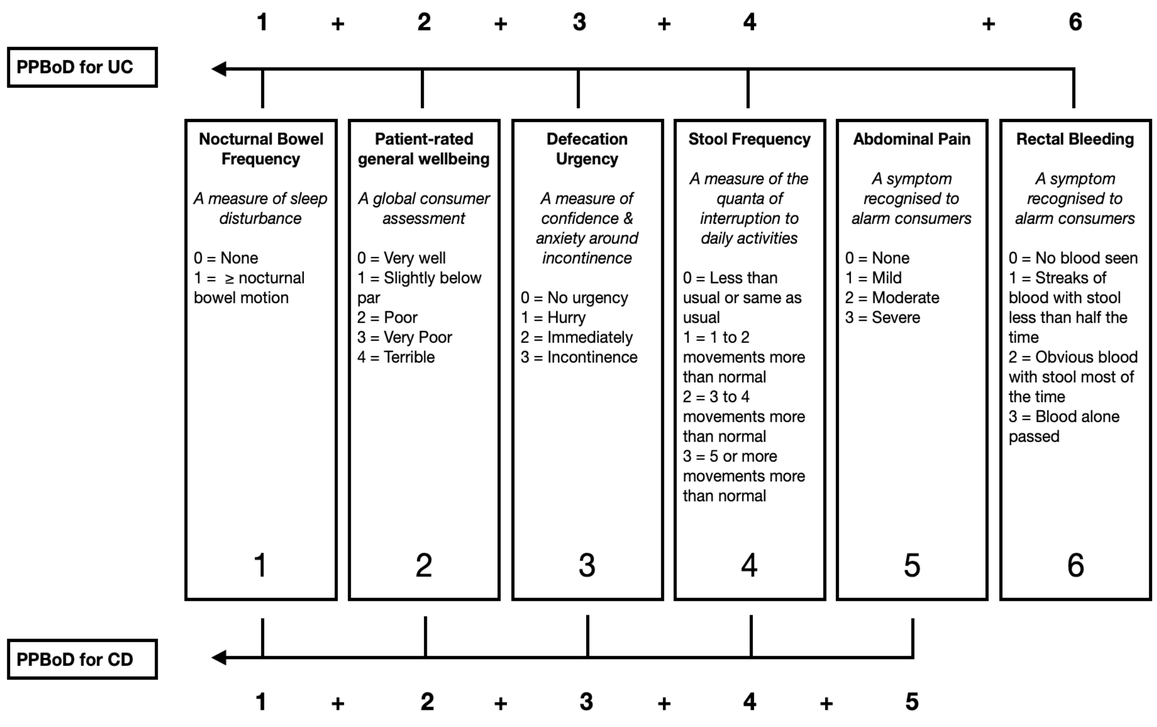
- The prevalence and burden of inflammatory bowel disease (IBD) is rising globally.
- We propose a novel score to capture and quantify the patient-perceived burden of disease (PPBoD) in IBD, in a large real-world Australasian cohort.
- Possible relationships amongst PPBoD, demographics, disease and treatment factors were explored.

METHOD

- Crohn's Colitis Care (CCCare) de-identified Clinical Quality Registry (CQR) was interrogated in April 2024.
- Adults with CD and UC across 19 IBD centres with an outpatient encounter in the last 14 months were included.
- A novel PPBoD score was designated for CD and UC.

RESULTS:

- **6,211** people with IBD were identified with a clinical assessment in the last 14 months.
- **57.2%,** (n=3551) had Crohn's Disease, **42.8%,** (n=2660) had Ulcerative Colitis.
- **4,308** people with IBD had sufficient data to calculate PPBoD.
- **82.5%** had either no or only mild PPBoD.



RESULTS - CONT:

- 73.6% resided in Australia (n=3171) and 26.4% in New Zealand (NZ) (n=1137). People living in **NZ had higher PPBoD**.
- **Females, active smokers and those who had used corticosteroids** in the last 14 months reported **higher PPBoD**.
- More people in Australia were on a Biologic or novel small molecule compared to NZ **(55.6% vs 39.2%).**
- The utilisation of aminosalicylates did not differ across PPBoD categories.
- **1530 (24.6%)** had a recent faecal calprotectin (FCP), people with no PPBoD were more likely to have biochemical remission (FCP < 100 mg/g).
- Data for endoscopic and radiological remission were available in **1391 (22.4%)** people; those with no PPBoD were more likely to be in remission.
- In people with **no PPBoD, 1.2% had any days out of role** due to IBD. Those with higher PPBoD had more days out of role.

	None n = 2208	Mild n = 1343	Moderate n = 453	Significant n = 304	p-value
Median Age, years (IQR)	40 (30-55)	43 (32-57)	42 (32-54)	39 (27-52)	
Female, n (%)	998 (45.3)	663 (49.6)	268 (59.3)	185 (61.1)	< 0.001
Median BMI, kg/m^2 (IQR)	25.5 (22.4-28.7)	26.1 (22.9-30.1)	25.6 (22.4-30.1)	25.2 (21.5-29.0)	
Currently smoking, n (%)	137 (6.2)	109 (8.1)	31 (6.8)	38 (12.5)	< 0.001
Advanced Therapy, n (%)	1214 (61.1)	775 (64.9)	265 (64.3)	179 (64.9)	< 0.001
Steroids, n (%)	180 (8.2)	135 (10.1)	89 (19.6)	90 (29.6)	< 0.001
Aminosalicylates, n (%)	829 (41.7)	468 (39.2)	153 (37.1)	113 (41.0)	0.26
Immunomodulator, n (%)	797 (40.1)	469 (39.3)	140 (34.0)	133 (48.2)	< 0.01
>1 days out of role due to IBD, n (%)*	24 (1.2)	68 (5.8)	50 (13.0)	69 (27.2)	< 0.001
Faecal calprotectin, <100 mg/g, n (%)*	503 (66.3)	257 (57.1)	101 (55.5)	42 (30.2)	< 0.001
Complete endoscopic and radiologic remission, n (%)*	333 (50.2)	203 (47.5)	74 (42.0)	30 (24.0)	< 0.001

*Percentage of those with available data.

CONCLUSIONS

- Within this geographically dispersed cohort, the majority had either no or mild PPBoD.
- Smoking, steroid therapy and days out of role were all indicators associated with significant PPBoD.
- Further studies are required to validate this novel score to assess PPBoD in IBD.

For more information contact: info@c-c-cure.org, or visit www.c-c-cure.org