WILEY AP&T Alimentary Pharmacology & Therapeutics

Impacts of perianal disease and faecal incontinence on quality of life and employment in 1092 patients with inflammatory bowel disease

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Summary

Background: Patient reported outcomes regarding perianal disease and faecal incontinence in the community-based inflammatory bowel disease population are poorly described.

Aims: To determine the impacts of perianal disease and faecal incontinence on quality of life and employment in inflammatory bowel disease patients.

Methods: For this cross-sectional study, a comprehensive survey was sent out to members of the Dutch National Crohn's and Colitis patient organisation. Validated questionnaires regarding faecal incontinence and active perianal disease were used to estimate its prevalence's. The effect on the quality of life (36-Item Short Form Survey) and on employment status (multivariate binary regression analysis) was assessed in this inflammatory bowel disease population.

Results: A total number of 1092 returned questionnaires (58% responders) were used for analysis; 750 respondents (69%) were female; mean age was 47 years (IQR 35-59). In 621 patients (57%) Crohn's disease, in 422 (39%) ulcerative colitis and in 49 (4%) patients unclassifiable inflammatory bowel disease was self-reported. The 114 patients (10%) with a stoma were excluded for continence related analyses. Faecal incontinence was reported in 555 patients (57%), was comparable between the different inflammatory bowel disease diagnoses and affected all 36-Item Short Form Survey subscales adversely (incontinence vs continence: Physical functioning 75 vs 84, $P < 0.0001$; Limitations due to physical health 49 vs 63, $P < 0.0001$; Limitations due to emotional problems 49 vs 64, $P < 0.0001$; Energy/fatigue 47 vs 53, $P < 0.0001$; Emotional well-being 71 vs 74, $P = 0.005$; Social functioning 63 vs 73, $P < 0.0001$; Pain 66 vs 75, $P < 0.0001$; General health 41 vs 48, $P < 0.0001$). Active perianal disease was reported in 39% Crohn's disease, 16% ulcerative colitis (84% fissures) and 20% unclassifiable inflammatory bowel disease patients. Faecal incontinence was more common in patients with perianal disease (67% vs 53%, $P = 0.003$). When correcting for age, disease duration, inflammatory bowel disease-related surgery and faecal incontinence, active perianal disease was independently affecting employment (OR 0.67; 95% CI 0.50–0.91; $P = 0.01$).

Conclusions: Faecal incontinence and perianal disease are quality of life determining factors. Faecal incontinence needs more attention among clinicians, and development of new (drug) therapies needs to be focussed on perianal disease.

1 | INTRODUCTION

Inflammatory bowel disease (IBD) mainly comprises Crohn's disease (CD) and ulcerative colitis (UC). It is well known that these relatively common conditions consume significant healthcare resources,[1,2] and may compromise patient's quality of life.[3] As the diseases are chronic, symptoms of most concern to the patients have to be characterised and treatment needs to be guided by quality of life above all else. However, a large proportion of patients is not able to express potentially important information to their physician with regard to their complaints,[3] and almost 50% report that their physician does not ask about the impact of their symptoms on quality of life.[4] Awareness amongst clinicians is needed regarding complaints causing the highest burden in this population, to prioritise treatment and development of new therapeutic strategies.

Faecal incontinence, usually defined as the uncontrolled loss or liquid of solid stool, is one of the concerns reported by IBD-patients.[5] Its prevalence amongst the IBD-population, which has only been investigated in five studies to date, is estimated between 20% and 38% in tertiary centers[6–9] and even up to 74% in a community-based population.[10] The latter has only been reported once, precluding reliable data on community-based prevalence numbers of faecal incontinence and its association with quality of life. In a cross-sectional study, only 3% of patients had a medical diagnosis of faecal incontinence, whilst 36% reported complaints.[11] Indisputably, the anal function warrants (medical) attention and physicians (gastroenterologist and colorectal surgeons, in particular) need to ask actively.

Perianal disease (ie, fissures, fistulas, abscesses and stenosis) occurs in a considerable group of patients with CD, and is associated with a more extensive and complicated disease behaviour.[12] The prevalence of these, usually embarrassing, complaints is reported in a wide range, partly due to a variety of used definitions.[13] The limited number of studies addressing this have mainly focussed on tertiary populations,[14] hence a community-based, more accurate estimation has barely been reported.[15,16] If documented, anal pain and discomfort seem unfavourable factors compromising quality of life,[17] and self-reported depressive symptoms are frequently concomitantly observed,[18] underlining the negative impact on quality of life.

In this cross-sectional study, we aimed to survey the prevalence of faecal incontinence and perianal disease, and related its occurrence with perceived quality of life, in a large population-based cohort of members of the Dutch Crohn's and Colitis patients' organisation (CCUVN).

2 | METHODS

2.1 | Study population

In October 2016, CCUVN had a total membership database of 10 047 patients. A comprehensive, anonymised study questionnaire (Data S1) was sent out online (via a purpose-designed secure website) by the CCUVN in January 2015 and October 2016 to a panel which consisted of 1710 CCUVN patients (1206 female) in October 2016. The panel is represented by patients who gave consent to participate in online surveys with regard to disease-related subjects, which are carried out several times a year. A reminder was sent out to nonresponders after 3 weeks. In addition, a link to the questionnaire was added to the monthly CCUVN newsletter of January 2015. Inclusion criteria were age over 18 years old and a self-reported diagnosis of IBD.

2.2 | Questionnaires

The close-ended survey included a self-reported IBD diagnosis (CD, UC or 'IBD-U' if the type of disease was not classifiable by the patient, or if UC was reported with the presence of small bowel disease), perianal disease activity index,[19] St. Marks incontinence score,[20] 36-Item Short Form Survey[21] and the faecal incontinence quality of life questionnaire.[22] Faecal incontinence was defined as the involuntary loss of liquid or solid stool at least once per month. Active perianal disease was described as a score of ≥1 for the category "Type of perianal disease" on the perianal disease activity index. An additional questionnaire was developed to collect data with regard to basic and disease characteristics, and previously performed (IBD-related) surgical interventions.

2.3 | Statistical analysis

Patients with CD, UC and IBD-U were characterised by the use of descriptive statistics. Continuous variables were described as means with interquartile ranges (IQR), categorical variables as percentages. Differences between continuous variables were studied with the use of the Student's t test and chi-square was used for categorical variables. One-way ANOVA was used for comparison of continuous variables between >2 groups. All patients had complete data for the basic characteristics (age, sex, type of disease [CD, UC, IBD-U], disease localisation and stoma surgery). For variables with missing data, multiple imputation was performed using the Markov Chain Monte Carlo method (total variables missing 2.4%; job description 0.1%; operational procedures 0.6%; age at diagnosis 1.7%; influence of IBD on job description 2.4%; 36-Item Short Form Survey 2.5%; effect of IBD on productivity at work during the past 6 months 3.4%; sick leave during the past 6 months because of IBD 3.6%; St. Marks incontinence score 4.7%; perianal disease activity index 5.8%; faecal incontinence quality of life questionnaire 7.1%). As a total of 52% of patients had a complete dataset, multiple imputations are appropriate technique or imputation of missing data.[23] Little's MCAR test was performed for determining whether missing values were missing completely at random.[24] Ten imputed data sets were created and pooled. Patients with a stoma were excluded in continence-related analyses. Basic and disease characteristics which were associated with employment status ($P < 0.10$) were included in the multi-variable logistic regression model to identify independent associated

factors ($P < 0.05$ considered statistical significant), with results presented as effect sizes (Odds Ratio) with 95% CI. Statistical analysis was performed using SPSS Statistics version 21 (IBM Corp, Armonk, NY, USA).

2.4 | Ethical statement

This study was initiated by the CCUVN. The members of the selected panel gave consent to participate in anonymous health-related surveys.

3 | RESULTS

3.1 | Patient population

A total of 1120 patients responded to the questionnaire. Of these patients, 997 (91%) were member of the CCUVN panel, resulting in a response rate of 58%. The other 95 (9%) responded the questionnaire via the CCUVN newsletter. Twenty-eight patients were excluded due to the age of <18 years (n = 14), lack of information regarding their diagnosis (n = 11), and missing basic characteristics (n = 3). The remaining 1092 patients were slightly younger (47 vs 48 years; $P = 0.02$) compared to the 9100 CCUVN patients (91%) who registered their age and gender; there was no difference in gender (69% vs 66% females; $P = 0.06$). Demographics, disease characteristics and previously performed IBD-related surgery of the 1092 patients are shown in Table 1 (CD = 621; UC = 422; IBD-U = 49). Overall, 376 female patients (50%) had at least one vaginal delivery. CD patients were younger than UC patients (46 vs 49 years; $P = 0.001$). They were diagnosed with CD at a younger age than UC patients (32 vs 38 years; $P < 0.0001$), and had a longer disease duration compared to IBD-U patients (14 vs 9 years; $P = 0.011$). CD patients underwent more often IBD-related abdominal surgery (CD 44%, UC 10% and IBD-U 12%; $P < 0.0001$). Active perianal disease was reported by 244 CD patients (39%), 69 UC patients (16%) and 10 IBD-U patients (20%). Of these, a total of 58 UC patients (84%) reported anal fissures only. Perianal surgery was predominantly performed in CD patients (fistula surgery 19%; abscess surgery 20%), although also reported amongst the UC population (fistula surgery 2%; abscess surgery 3%).

3.2 | Faecal incontinence

To describe the prevalence of faecal incontinence, all patients with a stoma were excluded (CD = 92, UC = 19, IBD-U = 3). Faecal incontinence was reported in 555 patients (57%) (306 CD patients [58%], 225 UC patients [56%] and 24 IBD-U patients [52%], Table 2). The mean St. Marks incontinence score was higher in CD patients compared to IBD-U patients (9 vs 7; $P = 0.011$). Faecal incontinence was frequently associated with a flare-up in all types of diagnoses (CD 42%; UC 56%; IBD-U 42%), more often in UC compared to CD patients ($P = 0.005$). Furthermore, a total of 125 CD (41%), 78 UC (35%) and 9 IBD-U patients (38%) reported faecal incontinence episodes during periods of remission in addition. Twenty-three per cent of CD patients who underwent perianal surgery reported that symptoms of faecal incontinence were related to the perianal surgery. Quality of life on all of the four faecal incontinence quality of life subscales (ranging 0-4) was affected, regardless the type of diagnosis. As shown in Table 3, incontinent patients reported a lower 36-Item Short Form Survey score on all different subscales compared to continent patients (Physical functioning 75 vs 84, $P < 0.0001$; Limitations due to physical health 49 vs 63, $P < 0.0001$; Limitations due to emotional problems 49 vs 64, $P < 0.0001$; Energy/fatigue 47 vs 53, $P < 0.0001$; Emotional well-being 71 vs 74, $P = 0.005$; Social functioning 63 vs 73, $P < 0.0001$; Pain 66 vs 75, $P < 0.0001$; General health 41 vs 48, $P < 0.0001$). Patients with an age over 65 were excluded to assess the impact of faecal incontinence on daily work. Less incontinent patients reported a paid job (65% vs 74%; $P = 0.002$).

3.3 | Perianal disease

Patients from all diagnoses (CD, UC and IBD-U) with perianal disease (n = 323) were compared to IBD patients without perianal disease (n = 769) with regard to their quality of life, employment and the association with faecal incontinence (Table 4). Patients with perianal disease reported a lower 36-Item Short Form Survey score on all different subscales (Physical functioning 74 vs 80, $P < 0.0001$; Limitations due to physical health 47 vs 57, $P = 0.001$; Limitations due to emotional problems 47 vs 57, $P = 0.0002$; Energy/fatigue 44 vs 52, $P < 0.0001$; Emotional well-being 69 vs 73, $P = 0.001$; Social functioning 60 vs 69, $P < 0.0001$; Pain 62 vs 72, $P < 0.0001$; General health 39 vs 45, $P < 0.0001$). Restriction of sexual activities was reported amongst more than two-third of the patients with perianal disease (no restriction 31%; slight restriction 28%; moderate limitations 25%; marked limitations 12%; unable to engage in sexual activities 4%).

Patients with an age over 65 were excluded to assess the impact of perianal disease on daily work. Less patients with perianal disease reported a paid job (61% vs 69%; $P = 0.004$), and a higher proportion of patients with perianal disease reported that their job type was a result of their IBD (34% vs 21%; $P < 0.0001$). Patients with perianal disease were more likely to report sick leave during the past 6 months (48% vs 36%; $P = 0.007$), and the effect of their IBD on their work productivity during the past 6 months was reported to be higher on a 0-10 Likert scale (4.6 vs 3.9; $P = 0.01$).

Subsequently, patients with a stoma were excluded to analyse the prevalence and impact of faecal incontinence on quality of life in IBD patients with perianal disease compared to other IBD patients. Faecal incontinence was more commonly reported amongst patients with perianal disease compared to patients without perianal disease (67% vs 53%; $P = 0.003$). In addition, incontinent patients with perianal disease reported a lower quality of life on all of the four different faecal incontinence quality of life subscales.

TABLE 1 Demographics, disease characteristics and previously performed IBD-related surgery of the total group (*n* = 1092)

Variable	Crohn's disease	Ulcerative colitis	IBD not classifiable by patient
Number of patients	621 (57%)	422 (39%)	49 (4%)
Gender			
Female	459 (74%)	262 (62%)	29 (59%)
Vaginal delivery	214 (47%)	145 (55%)	17 (59%)
1	71 (33%)	44 (30%)	8 (47%)
2	104 (49%)	84 (58%)	6 (35%)
3	29 (14%)	12 (8%)	0
4	9 (4%)	3 (2%)	3 (18%)
>4	1 (0.5%)	2 (2%)	0
Male	162 (26%)	160 (38%)	20 (41%)
Age—years[a] (mean, IQR)	46 (34-57)	49 (37-61)	46 (35-57)
Age at diagnosis—years[b] (mean, IQR)	32 (30-41)	38 (26-48)	37 (29-46)
Disease duration—years[c] (mean, IQR)	14 (10-19)	12 (3-19)	9 (2-13)
Disease location			
Oesophagus/stomach	44 (7%)	0	3 (6%)
Small bowel	173 (28%)	0	6 (12%)
Large bowel	181 (29%)	357 (85%)	30 (61%)
Rectum	142 (23%)	65 (15%)	16 (33%)
Small and large bowel	244 (39%)	0	9 (18%)
IBD-related abdominal surgery[d]	272 (44%)	40 (10%)	6 (12%)
Bowel resection	219 (35%)	8 (2%)	3 (6%)
Subtotal colectomy	31 (5%)	18 (4%)	2 (4%)
Ileal pouch-anal anastomosis	11 (2%)	11 (3%)	1 (2%)
Abscess	56 (9%)	3 (0.7%)	0
Stoma	92 (15%)	19 (5%)	3 (6%)
Active perianal disease			
No	377 (61%)	353 (84%)	39 (80%)
Yes	244 (39%)	69 (16%)	10 (20%)
Perianal surgery			
Fistula			
Surgery	121 (19%)	8 (2%)	2 (4%)
Seton	61 (10%)	1 (0.2%)	0

(Continues)

TABLE 1 (Continued)

Variable	Crohn's disease	Ulcerative colitis	IBD not classifiable by patient
Abscess			
Surgery	124 (20%)	11 (3%)	0

[a]Crohn's disease patients younger than ulcerative colitis patients (*P* = 0.001).
[b]Crohn's disease patients diagnosed at younger age than ulcerative colitis patients (*P* < 0.0001).
[c]Crohn's disease patients longer disease duration than not classifiable IBD-patients patients (*P* = 0.011).
[d]Crohn's disease patients underwent more frequently abdominal surgery than ulcerative colitis patients (*P* < 0.0001) and not-classifiable IBD-patients (*P* < 0.0001).

3.4 | Employment status—binary regression analysis

As faecal incontinence was more commonly reported amongst patients with perianal disease, a multivariate binary regression analysis was performed to investigate the independent impact of both complaints on employment status. The results in Table 5 show that perianal disease (Odds Ratio 0.71; 95% CI 0.53-0.95; *P* = 0.02) and faecal incontinence (Odds ratio 0.68; 95% CI 0.51-0.90; *P* = 0.007) are both independently affecting employment status (no paid job = 0 vs paid job = 1), when corrected for the presence of a stoma. Table S1 shows a univariate analysis of all basic characteristics and other factors with a possible effect on employment status. Age (Odds ratio 0.95; 95% CI 0.94-0.96; *P* < 0.0001), age at diagnosis (Odds ratio 0.98; 95% CI 0.97-0.99; *P* < 0.0001), disease duration (Odds ratio 0.96; 95% CI 0.95-0.97; *P* < 0.0001), subtotal colectomy (Odds ratio 0.31; 95% CI 0.16-0.57; *P* = 0.0002), Ileal pouch-anal anastomosis (Odds ratio 0.47; 95% CI 0.20-1.12; *P* = 0.09), abdominal abscess surgery (Odds ratio 0.53; 95% CI 0.30-0.92; *P* = 0.02), stoma (Odds ratio 0.63; 95% CI 0.41-0.95; *P* = 0.03), active perianal disease (Odds ratio 0.66; 95% CI 0.50-0.88; *P* = 0.004), perianal surgery (Odds ratio 0.63; 95% CI 0.45-0.90; *P* = 0.01) and faecal incontinence (Odds ratio 0.65; 95% CI 0.49-0.86; *P* = 0.002) were all affecting employment status.

Disease duration and age at diagnosis (*P* < 0.0001), and active perianal disease and perianal surgery (*P* < 0.0001) were highly correlated variables, therefore age at diagnosis and perianal surgery were not added to the final model. In the multivariate model (Table S1), age (Odds ratio 0.96; 95% CI 0.94-0.97; *P* < 0.0001), subtotal colectomy (Odds ratio 0.37; 95% CI 0.17-0.80; *P* = 0.01) and active perianal disease (Odds ratio 0.67; 95% CI 0.49-0.91; *P* = 0.01) were independently affecting employment status. Faecal incontinence lost its effect in this model (*P* = 0.15) due to the addition of age, as incontinent patients were older compared to continent patients (47 vs 42 years; *P* < 0.0001).

TABLE 2 Prevalence of faecal incontinence (≥ monthly) and associated quality of life. Patients with a stoma were excluded in this analysis

Variable	Crohn's disease	Ulcerative Colitis	IBD not classifiable by patient	P-value
Stoma				
No	529 (85%)	403 (95%)	46 (94%)	<0.0001*
Female	397 (75%)	251 (62%)	27 (59%)	
Male	132 (25%)	152 (38%)	19 (41%)	
Yes	92 (15%)	19 (5%)	3 (6%)	
Faecal incontinence				
Number of patients	306 (58%)	225 (56%)	24 (52%)	0.60
Female	242 (79%)	162 (72%)	13 (54%)	
Vaginal delivery	129 (53%)	97 (60%)	8 (62%)	
Male	64 (21%)	63 (28%)	11 (46%)	
Liquid stool				
≥ monthly, < weekly	161 (53%)	196 (87%)	21 (88%)	
≥ weekly	40 (13%)	22 (10%)	2 (8%)	
Solid stool				
≥ monthly, < weekly	102 (33%)	83 (37%)	10 (42%)	
≥ weekly	9 (1%)	9 (4%)	1 (4%)	
St. Marks incontinence score (mean, IQR)	9 (7-12)	9 (7-11)	7 (5-8)	0.011**
Related to:				
Flare	130 (42%)	125 (56%)	10 (42%)	0.005*
Remission	125 (41%)	78 (35%)	9 (38%)	0.40
Nutrition	71 (23%)	47 (21%)	1 (4%)	0.09
Perianal surgery	15 (23%)	1 (8%)	0	
Faecal incontinence quality of life (mean, IQR)				
Lifestyle	3.0 (2.4-3.7)	2.9 (2.3-3.5)	2.8 (2.2-3.5)	0.16
Coping/behaviour	2.3 (1.7-2.8)	2.3 (1.8-2.8)	2.3 (1.7-2.9)	0.68
Depression/self-perception	2.8 (2.3-3.3)	3.0 (2.6-3.4)	2.8 (2.3-3.2)	0.30
Embarrassment	2.8 (2.3-3.3)	3.0 (2.3-3.3)	2.8 (2.3-3.3)	0.14

*Differences between Crohn's disease and ulcerative colitis remained significant after Bonferroni correction (P < 0.017).
**Differences between Crohn's disease and IBD-unknown remained significant after Bonferroni correction (P < 0.017).

4 | DISCUSSION

In this community-based IBD population, we observed that more than half of patients reported involuntary loss of faeces at least once per month, regardless of their diagnosis. Even if all nonresponders would be classified as continent, which seems implausible, still 35% of the population would report symptoms of faecal incontinence. Other key findings were that active perianal disease was frequently reported amongst the CD (39%) population, and that regular episodes of faecal incontinence were more common in patients with active perianal disease. Furthermore, faecal incontinence and active perianal disease were affecting quality of life on all 36-Item Short Form Survey subscales, and active perianal disease (corrected in a multivariate regression analysis) had a negative effect on employment status.

Community-based numbers of faecal incontinence in IBD patients have sparsely been described; in one study, a prevalence of faecal incontinence up to 74%, was reported, based on a questionnaire with a response rate of only 33%.[10] The authors estimated a prevalence of 24% if all nonrespondents were classified as continent. In a tertiary population, faecal incontinence may be more prevalent, as these patients may have more a complicated disease course which potentially increases the risk of faecal incontinence. A prevalence of 28% in 108 consecutive IBD patients of a tertiary CD out-patient clinic has indeed been reported.[7] Twenty-six per cent of a referral out-patient population in South Asia reported complaints of faecal incontinence, in a study in which patients with previous traumatic anal injury, concomitant neurological disorders or psychiatric illnesses were excluded.[8] In a previous study, we reported a prevalence of 20% in a complex CD population,[9] using the same definition as in this study. These findings imply that the prevalence in this study may be overestimated (albeit still worrisome), which might be explained by a more than average engaged population consisting of self-selected patients being member of a patient organisation, whom already signed up for surveys. Nevertheless, physicians need to be pro-active in

TABLE 3 Quality of life in patients with symptoms of faecal incontinence (≥ monthly) compared to those without

Variable	Incontinent	Continent	P-value
SF-36 (mean, IQR)			
Physical functioning	75 (65-95)	84 (75-100)	<0.0001
Limitations due to physical health	49 (0-100)	63 (25-100)	<0.0001
Limitations due to emotional problems	49 (0-100)	64 (33-100)	<0.0001
Energy/fatigue	47 (30-65)	53 (35-75)	<0.0001
Emotional well-being	71 (60-84)	74 (64-88)	0.005
Social functioning	63 (50-75)	73 (63-100)	<0.0001
Pain	66 (45-80)	75 (68-90)	<0.0001
General health	41 (25-55)	48 (30-65)	<0.0001
Number of patients ≤ 65 years	483 (87%)	379 (90%)	
Job description			0.002*
No job	121 (25%)	67 (18%)	
Paid job	312 (65%)	282 (74%)	
Voluntary work	50 (10%)	30 (8%)	

*Differences between patients with (65%) and without symptoms of faecal continence (74%) with a paid job remained significant after Bonferroni correction (P < 0.017).

questioning IBD patients for symptoms of faecal incontinence, as this distressing complaint is reported by a substantial proportion of patients.

Remarkably, faecal incontinence was reported during periods of both flare-ups as well as in remission. In addition, up to one-third of the incontinent patients reported involuntary loss of solid stool, corroborating that faecal incontinence not only occurs during periods of active disease which has not been reported previously in the IBD population. In patients with active disease, diarrhoea and proctitis can be considered as contributing factors to faecal incontinence. In remission, previously performed bowel resections, perianal fistula surgery, and also rectal fibrosis associated with a decreased rectal compliance are associated with an increased risk.[9,10] Besides these disease specific factors, other frequently related causes of faecal incontinence (traumatic delivery, pudendal neuropathy, neurological diseases) may also be responsible for the complaints. If active disease has been excluded, treatment can be started with fibre supplements and physiotherapy ± biofeedback. In patients in whom conservative management has failed, additional anorectal physiology testing (eg, anorectal manometry, rectal sensation/compliance tests, endoanal ultrasonography and defaecography) might be considered,[25] and a multidisciplinary approach with gastroenterologists, gynaecologists and colorectal surgeons can be worthwhile to determine the best treatment strategy.

Perianal disease (fistulas in particular) remains a challenging problem in patients with CD. Since the advent of the tumour necrosis factor antagonists, some improvement of fistula treatment has been achieved. Results from the ACCENT II trial have shown that infliximab is considered effective in up to 36% at a follow-up of 54 weeks,[26] and adalimumab therapy was associated with increases in fistula closure over time in the open label-extension study of the CHARM.[27] Another recent treatment option is mesenchymal stem cell therapy, which, at week 52, appeared to be beneficial in (not too) complex perianal fistulas in approximately 56% of CD patients as compared to 39% success in controls, who were only operated upon.[28] In this patient group, potentially surgical treatment may remain an alternative, but likewise often an unsuccessful therapeutical option. Fissures that are resistant to conservative treatment may also require surgery, such as lateral internal sphincterotomy, which in itself may induce faecal incontinence, particularly in women.[29] In addition, the association between anal stenosis and faecal incontinence has been described previously.[30]

We have shown that patients with perianal disease more frequently reported symptoms of faecal incontinence, which emphasises the demand for development of new nonsurgical treatment options, as perianal surgery in this group is discouraged. Furthermore, patients with active perianal disease reported a diminished quality of life and a higher rate of work disability as a result of their disease. This implied that perianal disease may cause an economic burden.[2,31] It needs to be taken into account that more aggressive luminal disease, especially in the colon or rectum, may also play a role in this, as it is related to perianal disease.[12] To assess the exact impact of perianal disease on healthcare costs, a health-economics analysis will be needed, as previously performed by the COIN study group.[1]

We acknowledge that there were methodological limitations to conducting this study. First, the survey was sent to a panel of self-selected CCUVN patients. As approximately 80 000 people in the Netherlands suffer from IBD, one of eight is member of the patient association. The panel consisted of patients who signed up voluntary to complete disease-related questionnaires. Hence, the group may be represented by patients who are more dedicated to report their complaints or have more severe disease. This potential bias always needs to be considered when health-related outcomes are interpreted. Second, the patients were asked to report their disease characteristics themselves and no additional clinical (or endoscopic) information was used to confirm the diagnosis, previously performed disease-related interventions or current disease activity. Third, we acknowledge the limitations of the perianal disease activity index to assess the prevalence of active perianal disease. From our perspective, this tool is appropriate to indicate whether perianal disease is currently active or not. However, the questionnaire cannot be used to estimate the prevalence of the different types of perianal disease (fissures/fistula), as scores for different types are added up to the same category. Fourthly, we used an online questionnaire to address the research questions, although it has been demonstrated that Internet-respondents generally report a poorer quality of life than patients recruited from clinic.[32]

Bearing in mind the limitations, we were still able to show the impact of faecal incontinence and perianal disease on quality of life. Assessment of these conditions among the community based population using patient reported outcome according to the terminology of the US Food & Drug Administration has barely been performed to date. To assess the specific effect of these embarrassing

TABLE 4 Quality of life and symptoms of faecal incontinence (≥ monthly) in all patients with and without perianal disease. Patients with a functioning stoma were excluded in continence related analyses

Variable	Perianal disease	Non-perianal disease	P-value
Number of patients	323 (30%)	769 (70%)	
Crohn's disease	244 (39%)	377 (61%)	
Ulcerative colitis	69 (16%)	353 (84%)	
IBD not classifiable by patient	10 (20%)	39 (80%)	
Quality of life			
SF-36 (mean, IQR)			
Physical functioning	74 (60-80)	80 (70-95)	<0.0001
Limitations due to physical health	47 (0-100)	57 (0-100)	0.001
Limitations due to emotional problems	47 (0-100)	57 (0-100)	0.0002
Energy/fatigue	44 (25-60)	52 (35-70)	<0.0001
Emotional well-being	69 (56-84)	73 (64-88)	0.001
Social functioning	60 (50-75)	69 (50-88)	<0.0001
Pain	62 (45-78)	72 (58-90)	<0.0001
General health	39 (25-55)	45 (30-60)	<0.0001
Number of patients ≤ 65 years	300 (93%)	678 (88%)	
Job description			0.004*
No job	84 (28%)	146 (22%)	
Paid job	183 (61%)	465 (69%)	
Voluntary work	33 (11%)	68 (10%)	
Result of their IBD	102 (34%)	144 (21%)	<0.0001
Sick leave during the past 6 months	87 (48%)	166 (36%)	0.007
Effect of IBD on productivity at work (Likert 0-10)	4.6 (2-7)	3.9 (1-7)	0.01
Number of patients without a stoma	273 (85%)	705 (92%)	
Faecal incontinence			
Number of patients	182 (67%)	373 (53%)	0.003
Liquid stool			
≥ monthly, < weekly	152 (84%)	326 (88%)	
≥ weekly	28 (15%)	36 (10%)	
Solid stool			
≥ monthly, < weekly	64 (35%)	130 (35%)	
≥ weekly	8 (4%)	12 (3%)	
SMIS (mean, IQR)	10 (7-12)	9 (7-11)	0.18
Faecal incontinence quality of life			
Lifestyle	2.8 (2.2-3.5)	3.0 (2.5-3.6)	0.04
Coping/behaviour	2.1 (1.6-2.5)	2.4 (1.9-2.9)	0.04

(Continues)

TABLE 4 (Continued)

Variable	Perianal disease	Non-perianal disease	P-value
Depression /self-perception	2.7 (2.2-3.1)	3.0 (2.6-3.4)	0.03
Embarrassment	2.7 (2.3-3.3)	3.0 (2.3-3.3)	0.04

*Differences between patients with (61%) and without perianal disease (69%) with a paid job remained significant after Bonferroni correction (P < 0.017).

TABLE 5 Univariate and multivariate binary regression analysis of variables and its associations with employment (no paid job = 0 vs paid job = 1)

Variable	Univariate		Multivariate	
	Odds Ratio (95% CI)	P-value	Odds Ratio (95% CI)	P-value
Stoma				
No	Reference	—	Reference	—
Yes	0.63 (0.41-0.95)	0.03	0.68 (0.44-1.03)	0.07
Active perianal disease				
No	Reference	—	Reference	—
Yes	0.66 (0.50-0.88)	0.004	0.71 (0.53-0.95)	0.02
Faecal incontinence				
No	Reference	—	Reference	—
Yes	0.65 (0.49-0.86)	0.002	0.68 (0.51-0.90)	0.007

complaints, the use of patient reported outcome is essential, as the status of a patient's health condition is reported without amendment or interpretation by a clinician or by anyone else. As such, this methodology might provide more accurate results on the burden compared to results collected by physicians only.

In conclusion, faecal incontinence and perianal disease are frequently occurring in IBD patients, leading to an unmet need in terms of therapeutic options. Awareness amongst physicians is needed to ask actively for complaints of faecal incontinence, and development of new therapies needs to be focussed on treatment of perianal disease, taking patient reported outcomes into account when describing its efficacy.

ACKNOWLEDGEMENT

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