

## Prospective Study

## Faecal incontinence and health related quality of life in inflammatory bowel disease patients: Findings from a tertiary care center in South Asia

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### Abstract

**AIM:** To analyze the frequency and severity of faecal incontinence (FI) and its effect on the quality of life (QOL) in inflammatory bowel disease (IBD) patients.

**METHODS:** All patients who attended surgical and medical gastroenterology outpatient clinics in a tertiary care center with an established diagnosis of either ulcerative colitis (UC) or Crohn's disease (CD) over a period of 10 mo were included in this study. Before enrollment into the study, the patients were explained about the study and informed consent was obtained. The patients with unidentified colitis were excluded. The data on demographics, disease characteristics, FI (Vaizey score), and quality of life (IBD-Q) were collected. Data were analyzed using SPSS version 21.

**RESULTS:** There were 184 patients (women = 101, 54.9%; UC = 153, 83.2%) with a female preponderance for UC (male/female ratio = 1:1.5) and a male preponderance for CD (male/female = 2:1). Forty-eight (26%) patients reported symptoms of FI. Among the patients with FI, 70.8% were women ( $n = 34$ ) and 29.2% were men ( $n = 14$ ) with an average age of 52.7 years (range, 20-78 years). Average age of onset of FI was 48.6 (range, 22-74) years. Ten percent ( $n = 5$ ) reported regular FI.

Incontinence to flatus was seen in 33.3% ( $n = 16$ ), to liquid faeces in 56.2% ( $n = 27$ ), to solid faeces in 6.2% ( $n = 3$ ) and to all three in 4.1% ( $n = 2$ ). Twenty-one percent ( $n = 10$ ) complained of disruption of their physical and social activity. There was no association between FI and type of IBD. Significant associations were found between FI and age ( $P = 0.005$ ) and gender ( $P < 0.001$ ). QOL in our cohort of patients was significantly affected by FI.

**CONCLUSION:** In our study, nearly a quarter of patients reported FI. There was a significant correlation between FI and QOL. Therefore, enquiring about FI in IBD patients can lead to identification of this debilitating condition. This will enable early referral for continence care in this group of patients.

**Key words:** Inflammatory bowel disease; Quality of life; Faecal incontinence; Crohn's disease

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**Core tip:** This was a prospective study involving 184 patients with inflammatory bowel disease (IBD). It was designed to analyze the frequency and severity of faecal incontinence (FI) and its effect on the quality of life (QOL) in IBD patients in a tertiary care center. In our study, nearly 25% of patients reported the symptoms of FI. There was a significant correlation between FI and QOL. Therefore, enquiring about FI in IBD patients can lead to identification of this debilitating condition.

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## INTRODUCTION

Faecal incontinence (FI) is defined as the involuntary passage of solid or liquid stools, which is a hygienic and social problem<sup>[1]</sup>. It is a devastating personal and social problem which causes emotional distress leading to social isolation and loss of self-confidence<sup>[2]</sup>. The prevalence rates of FI in the community vary between 2.2%-15% in adults<sup>[3-7]</sup>. It is widely accepted that many patients with anal incontinence do not seek medical advice, thus making the true prevalence uncertain. Therefore under-reporting is common due to social embarrassment<sup>[8,9]</sup>.

FI can lead to social isolation. It also can adversely affect ability to maintain relationships, occupation and self-esteem aspects of the quality of life (QOL)<sup>[10,11]</sup>. Ulcerative colitis (UC) and Crohn's disease (CD) are chronic inflammatory conditions related to the gastrointestinal tract. There is a paucity of knowledge of FI in patients with inflammatory bowel disease (IBD), except in patients

with fistulas and those who underwent restorative proctocolectomy with an ileal pouch<sup>[12]</sup>. FI is also known to be associated with vaginal delivery in women<sup>[13,14]</sup>. In addition, in both genders, FI can be associated with a range of pelvic floor disorders and perianal surgeries (e.g., haemorrhoidectomy and sphincterotomy)<sup>[15,16]</sup>.

The only estimation of FI in IBD is from patients attending special clinics and the data from the Crohn's and Colitis Foundation of the United Kingdom, and the incidence ranged from 22%-33.5%<sup>[17-19]</sup>. No previous study has reported on FI among patients with IBD in Sri Lanka or in South Asia.

Therefore, the main aim of this study was to determine the frequency and severity of FI, and its effect on QOL in IBD patients who presented to a tertiary care center in Sri Lanka, which is a South Asian country.

## MATERIALS AND METHODS

### Patients and methods

This study was conducted at the National Hospital of Sri Lanka, which is a tertiary care hospital. The patients were interviewed prospectively over a period of 10 mo. Before the interview, the patients were educated about the study and informed consent was obtained. All the patients who attended outpatient clinics with an established histological diagnosis of either UC or CD were included in the study. Diagnosis of IBD was made based on clinical, endoscopic, radiological and histological findings. Age younger than 18 years, lack of cooperation, diagnosed psychiatric illness, being too ill to participate, patients with neurological disorders and those with a previous traumatic anal sphincter injury were excluded from the study. The study was approved by the ethics review committee of the hospital.

All IBD patients were interviewed using an interviewer administered questionnaire, which consisted of two parts. The first part consisted of personal details of the patients including socio-demographic data, disease characteristics, management details and history. The second part of the questionnaire included FI severity (Vaizey score)<sup>[20]</sup> and quality of life (IBD-Q) score.

### FI

FI was assessed based on Vaizey score with a four point scale: Never, rarely, sometimes, and regularly. Vaizey score was selected because it has shown high clinical validity and utility<sup>[20]</sup>. The Vaizey Incontinence questionnaire consists of seven questions. A score of 0 suggests no problems with bowel continence and a score of 24 suggests very severe problems with incontinence.

### QOL

IBD-Q32 evaluates QOL in four main aspects (bowel symptoms, emotional health, systemic symptoms and social symptoms). Cumulative score reflects the overall QOL. For each aspect under specific category, score varies from one to seven. Score of one indicates very poor QOL and that of seven indicates excellent QOL. Total IBDQ

**Table 1** Demographic characteristics of the study population *n* (%)

	Total IBD	UC	CD
Age at the diagnosis (yr)			
≤ 10	2 (1.1)	1 (0.7)	1 (3.2)
11-19	17 (9.2)	13 (8.5)	4 (12.9)
20-29	42 (22.8)	25 (16.3)	17 (54.8)
30-39	53 (28.8)	49 (32.0)	4 (12.9)
40-49	39 (21.2)	36 (23.5)	3 (9.7)
50-59	21 (11.4)	19 (12.4)	2 (6.5)
60-69	8 (4.3)	8 (5.2)	-
70-79	2 (1.1)	2 (1.3)	-
Gender			
Male	83 (45.1)	62 (40.5)	21 (67.7)
Female	101 (54.9)	91 (59.5)	10 (32.3)
Education			
Primary (Grade 1-5)	40 (21.7)	35 (22.9)	5 (16.1)
Secondary (Grade 6-13)	118 (64.1)	101 (66.0)	17 (54.8)
Higher (University or above)	26 (14.1)	17 (11.0)	9 (29.0)
Employment			
None	72 (39.1)	64 (41.8)	8 (25.8)
Student	11 (6.0)	11 (7.2)	-
Labourer	63 (34.2)	50 (32.7)	13 (41.9)
Professional	38 (20.7)	28 (18.3)	10 (32.3)

IBD: Inflammatory bowel disease; UC: Ulcerative colitis; CD: Crohn's disease.

score can range from 32 (very poor QOL) to 224 (perfect HRQOL).

Both IBDQ and Vaizey score were selected because of their simplicity and precision, which make those ideal for clinical practice to identify patients who require specialist help and in the clinical research setting to provide a sensitive measure of FI<sup>[20,21]</sup>.

### Statistical analysis

The associations between categorical data were examined using  $\chi^2$  test. The association between categorical variables and IBDQ-32 scores was determined using Student's *t*-test. Factors statistically significant in the univariate analysis were included in a multivariate regression model to examine their associations with FI score and QOL. The differences were considered significant when  $P \leq 0.05$ . Data were analyzed using SPSS (Version 21, Chicago, IL, United States).

## RESULTS

### Demographic and disease characteristics

There were 184 patients (M:F = 83:101) with a mean age of 44.5 (range, 20-78) years. The majority of patients (83.2%,  $n = 153$ ) had UC. The mean duration of disease was 8.17 (range, 1-28) years, while 33.7% ( $n = 62$ ) of patients had IBD for more than 10 years. The participation rate of our population was high (184/188 = 97.87%). The majority of UC patients were female, with a male to female ratio of 1:1.5. A male preponderance was noted in CD (male to female ratio = 2:1). None of our patients had a positive family history. Mean age at diagnosis for UC was 36.3 (range,

**Table 2** Descriptive statistics for the four domains and overall score of the IBDQ-32 and categories

	Minimum (Reference)	Maximum (Reference)	Mean
IBDQbowel	10	56	22.33
IBDQSystemic	6	34	12.5
IBDQEmotional	18	84	34.87
IBDQSocial	5	35	12.3
IBDQTotal	51 (32)	215 (224)	94.28

7-71) years. The patients with CD were diagnosed at a significantly younger age than UC patients ( $27.35 \pm 10.22$  years vs  $38.14 \pm 13.05$  years,  $P < 0.0001$ ). Peak age of onset was in the fourth decade for UC and in the third decade for CD (Table 1). Out of females ( $n = 101$ , UC = 91, CD = 10), the majority were unmarried ( $n = 55$ , UC = 47, CD = 8). Out of married females ( $n = 46$ ), 25 had undergone lower segment caesarian sections and 10 had undergone vaginal deliveries, while 11 had no childbirth yet. There were no females with ongoing pregnancy in our sample.

### QOL

The mean of IBDQ-32 scores of enrolled patients was 94.28 (51 to 215). Mean IBDQ scores of bowel symptoms, systemic, emotional, social categories of IBDQ are shown in Table 2. The social symptom and systemic symptom categories had the lowest HRQOL scores (12.3 and 12.5, respectively).

There was no significant difference between CD and UC, with regard to the mean IBDQ-32 (80.26 for CD and 79.52 for UC,  $P = 0.778$ ) or mean Vaizey score (UC 13.79 vs CD 14.45,  $P = 0.629$ ). Also, there was no significant difference in mean scores of bowel symptom (21.11 vs 22.39,  $P = 0.220$ ), systemic (12.46 vs 12,  $P = 0.560$ ) social (11.91 vs 11.10,  $P = 0.297$ ) and emotional symptoms (34.04 vs 34.77,  $P = 0.607$ ) between the two categories of UC and CD.

### Determinants of QOL

Although females had a slightly higher mean IBDQ score (79.9 vs 79.34), it was not statistically significant ( $P = 0.769$ ). In subgroup analysis, there was no significant difference in the four aspects of IBDQ categories ( $P > 0.05$ ). Females had significantly higher incontinence scores than males (mean Vaizey score 79.9 vs 79.34,  $P < 0.05$ ).

Twenty-six (14.1%) patients of the total study population underwent surgical treatment. In the UC group, 8.5% ( $n = 13$ ) underwent surgical treatment, the commonest surgical procedure was restorative proctocolectomy ( $n = 12$ ) and one patient underwent sigmoid colectomy. IBD patients who underwent surgery had significantly higher IBDQ bowel (23.48 vs 21,  $P < 0.05$ ) and IBDQ total scores (81.83 vs 79.34,  $P < 0.05$ ) compared to the patients who were on long-term medical management. However, the difference

**Table 3** Details of surgical procedures for inflammatory bowel disease

Surgical procedure	Indication	n (%)
UC		
Restorative proctocolectomy and ileoanal pouch	Steroid resistance-7 Atypia on histology-4 Sigmoid colon cancer-1	12 (7.8)
Sigmoid colectomy	Stricture of sigmoid colon	1 (0.7)
CD		
Drainage and fistulectomy	Perianal abscess and fistula	1 (3.2)
Fistulectomy and repair	Recurrent enterocutaneous fistula	1 (3.2)
Incision and drainage	R/Ischiorectal fossa abscess	1 (3.2)
Repair of the fistula	Enterocutaneous fistula	2 (6.4)
R/hemicolectomy and ileo transverse anastomosis	Strictures of the colon	4 (12.9)
Total colectomy and ileostomy	Strictures of colon	2 (6.4)
Repair of the fistula	Recto vaginal fistula	1 (3.2)
Strictureplasty, R/hemicolectomy and ileo transverse Anastomosis	Two long segment narrowings -distal ileum multiple narrowings > 10 in jejunum and proximal ileum and strictures of ascending colon	1 (3.2) -

UC: Ulcerative colitis; CD: Crohn's disease.

**Table 4** Correlation between quality of life components and incontinence scores

Association	Pearson correlation coefficient (Rho value)
IBDQbowel vs Vaizey score	0.74
IBDQSystemic vs Vaizey score	0.13
IBDQEmotional vs Vaizey score	0.09
IBDQSocial vs Vaizey score	0.3
IBDQTotal vs Vaizey score	0.61

of incontinence scores was not significantly different between the two groups.

Mean IBDQ-emotional and IBDQ-social scores had significant association with the extent of colonic involvement by the disease. The mean total IBDQ scores did not show significant differences in relation to education level ( $P = 0.676$ ), age ( $P = 0.343$ ), duration ( $P = 0.884$ ), extent of IBD ( $P = 0.92$ ) or current symptoms of the disease ( $P = 0.3$ ).

The relationships between psychosocial, clinical, and demographic variables and the overall score of IBDQ-32 are shown in Table 3.

### FI vs QOL

The extent of colitis was significantly associated with the Vaizey scores ( $P = 0.002$ ), where patients with distal colitis had higher scores. Association of total IBDQ and Vaizey score was statistically significant ( $P < 0.001$ ). Pearson correlation was performed to determine the correlation between Vaizey score and components of QOL scores and total IBD-Q score. QOL scores for emotional and systemic components showed a weak association ( $Rho < 0.3$ ), QOL score of social component showed a moderate association ( $Rho 0.3-0.7$ ) and that of bowel symptoms showed a strong association ( $Rho > 0.7$ ) (Table 4).

## DISCUSSION

It is noted that the incidence of IBD is increasing in the Asian population<sup>[22,23]</sup>. They are among the group of chronic disorders associated with periods of remission and unpredictable relapses. QOL measurement is especially pertinent in IBD, because it is a chronic disabling disease<sup>[24]</sup> which commonly occurs in early adulthood and hence affects all aspects of life, mainly physical, social and psychological. The peculiarities of chronic disease over acutely resolving conditions are that they often have a long-term negative effect on the emotional and social life, which are most of the time not visually apparent<sup>[25]</sup>. Feeling dirty and smelly following loss of bowel control, with resultant offensive body odours, unfulfilled potential in the work place and issues related to sexual relationships were the highly ranked concern in a survey of patients with IBD<sup>[26]</sup>.

In addition, fear of loss of bowel control and its unpredictability can lead to a profound effect on the individual's behaviour. In the majority of patients with IBD, this factor can lead to an avoidance of routine social events or impairment of daily activities<sup>[27,28]</sup>. Recent work by Daniel *et al*<sup>[27]</sup> and Hall *et al*<sup>[29]</sup> showed that these patients only attend places with toilet facilities or avoid public places all together.

Our results showed that IBD patients who underwent surgery for UC and CD had significantly higher IBDQ bowel (23.48 vs 21,  $P < 0.05$ ) and IBDQ total scores (81.83 vs 79.34,  $P < 0.05$ ) than those who was on long-term medical management. This may be due to the long-term symptom relief and avoidance of chronic medicine intake leading to more convenient life style. According to our results, higher Vaizey scores were associated with lower IBDQ scores ( $P < 0.001$ ). This shows that the fear of anal incontinence and its unpredictability had a profound effect on the individual's day-to-day activities. In our study, we found important variables significantly

related with lower QOL, suggesting that HRQOL analysis has an important role in understanding the true impact of the disease on patients. QOL score of social component showed a moderate association ( $\rho$  0.3-0.7) and QOL of bowel symptom component showed a strong association ( $\rho > 0.7$ ) with FI. This shows the significant impact of incontinence on social activities.

In conclusion, FI has adverse effects on social, emotional and other aspects of QOL in patients with IBD. Given the availability of specialist FI interventions and support, we recommend that sensitive questioning regarding FI should be part of routine disease surveillance in the outpatient setting to cater for this unmet need.

## COMMENTS

### Background

Severity and impact of faecal incontinence (FI) on quality of life (QOL) of inflammatory bowel disease (IBD) are not widely investigated. In general FI has adverse effects on daily activities, hence on QOL. The current study was designed to evaluate the severity and frequency of FI and its effect on QOL in IBD patients presented to a tertiary care center in a South Asia country.

### Research frontiers

This study has showed that FI has more adverse effects on social, emotional and other aspects of QOL in IBD. Given the availability of specialist FI interventions and support, the authors recommend that sensitive questioning regarding FI should be part of routine disease surveillance in the outpatient setting.

### Innovations and breakthrough

Current literature suggests various strategies to improve the management and outcome of chronic diseases such as IBD. This study provides evidence on improvement QOL by considering the FI as an important aspect of the management.

### Applications

This study has showed that FI correlates with HRQOL in IBD patients. Therefore, these aspects should be addressed to improve the management of these patients having this chronic disease.

### Terminology

FI is defined as the involuntary passage of passage of solid or liquid stools, which is a social and hygienic problem. Ulcerative colitis/Crohn's disease are chronic IBD affecting gastrointestinal tract.

### Peer-review

A well-timed piece with pertinent clinical insight, and the information provided is relevant and could be interesting enough to warrant readers' attention.

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