What are we going to do with you? Gastroenterology service providers' perceptions of 'difficult to manage' IBD patients

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BACKGROUND: This paper reports the results of a systematic survey of members of a clinical gastroenterology service to determine their perceptions of patients with inflammatory bowel disease (IBD) who were deemed to function poorly and were difficult to manage clinically.
OBJECTIVES: To assess objectively the defining characteristics of this perceived subgroup of patients who are encountered in virtually all gastroenterology services.
METHODS: A sample of gastroenterologists and gastrointestinal surgeons (n=10), as well as gastrointestinal nurses (n=19), was surveyed regarding their beliefs about the characteristics of patients with IBD who they judged to be extremely 'difficult to manage'. A survey was developed to assess patient characteristics (eg, symptom presentation, narcotic over-reliance, interpersonal behaviour and illness behaviour) and the emotional impact that this perceived patient group has on individual staff members as well as on the functioning of the gastrointestinal team.
RESULTS: The data indicated that patients with IBD who were perceived to be poorly functioning were viewed to have high levels of dysfunctional behaviour. In particular, negative behaviours (eg, manipulative interpersonal behaviours and excessive illness behaviours) were noted. Not only were these categories of behaviours high in frequency, but survey participants also rated these categories of behaviour to be highly distinct from those of typical patients with IBD. Moreover, this perceived patient group was

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reported to have a negative impact on individual staff and on the gastrointestinal team, and participants confirmed that they experience significant frustration and hostility when they work with these patients.

CONCLUSIONS: These data, if replicated, confirm the general clinical opinion that a small subgroup of 'difficult to manage' and poorly functioning patients with IBD exists. These patients appear to differ from typical patients with IBD in interpersonal characteristics more than in medical characteristics. If follow-up research, which is currently underway by the authors' group, shows that groups of poorly functioning gastrointestinal patients and typical gastrointestinal patients actually differ in measures of illness behaviour, then novel treatment approaches to improve the clinical services that are provided to these patients can be developed.

Key Words: *Dysfunctional IBD patient, Emotional impact, Team functioning*

Qu'allons-nous faire de vous ? Les perceptions des dispensateurs de services gastroentérologiques face aux personnes atteintes d'une MII ‹‹ difficiles à prendre en charge››

HISTORIQUE : Le présent article rend compte des résultats d'un sondage systématique auprès des membres d'un service de gastroentérologie clinique afin d'établir leurs perceptions des patients atteints d'une maladie inflammatoire de l'intestin (MII) réputés peu fonctionnels et difficiles à prendre en charge d'un point de vue clinique.

OBJECTIFS : Évaluer avec objectivité les caractéristiques déterminantes de ce sous-groupe perçu de patients, observé dans pratiquement tous les services de gastroentérologie.

MÉTHODOLOGIE : Un échantillon de gastroentérologues, de chirurgiens en gastroentérologie (n=10) et d'infirmières en gastroentérologie (n=19) ont été sondés au sujet de leur opinion relative aux caractéristiques des personnes atteintes d'une MII qu'ils considèrent extrêmement " difficiles à prendre en charge ". Un questionnaire a été élaboré pour évaluer les caractéristiques des patients (p. ex., présentation des symptômes, dépendance excessive aux narcotiques, comportement interpersonnel et comportement face à la maladie) et les effets affectifs de ce groupe perçu de patients sur les membres du personnel et sur le fonctionnement de l'équipe gastro-intestinale.

RÉSULTATS : Les données indiquent que les patients atteints d'une MII perçus comme peu fonctionnels étaient considérés comme présentant un comportement dysfonctionnel important. En particulier, des comportements négatifs (p. ex., comportements interpersonnels manipulateurs et comportements excessifs face à la maladie) ont été soulignés. Non seulement ces catégories de comportements étaient-elles très fréquentes, mais les répondants les ont-elles comme très distinctes de celles des patients habituels atteints d'une MII. De plus, les répondants ont indiqué que ce groupe perçu de patients a un effet négatif sur chaque membre du personnel et sur l'équipe gastro-intestinale et ils ont confirmé ressentir une grande frustration et beaucoup d'hostilité lorsqu'ils travaillent avec ces patients.

CONCLUSIONS : Ces données, si elles sont répliquées, confirment l'opinion clinique générale selon laquelle il existe bel et bien un petit sous-groupe de patients atteints d'une MII " difficiles à prendre en charge " et peu fonctionnels. Ces patients semblent différer des patients habituels atteints d'une MII par leurs caractéristiques interpersonnelles plutôt que par leurs caractéristiques médicales. Si des recherches de suivi, actuellement menées par le groupe d'auteurs, démontrent que les mesures de comportement face à la maladie des groupes de patients gastro-intestinaux peu fonctionnels diffèrent de celles des patients gastro-intestinaux types, de nouvelles démarches de traitement pourraient être mises au point pour améliorer les services cliniques fournis à ces patients.

The brain-gut connection is all too familiar to gastroenterologists. One of the major consequences of this complex, but active, interplay is that psychosocial factors have a strong impact on the level of functioning in patients with inflammatory bowel disease (IBD), at times equalling the impact of disease activity. There is a discrepancy, however, between our growing knowledge of interventions (surgical and medical) to treat disease activity and knowledge of interventions to manage quality of life and functional ability. There is a need to understand better the factors that underlie a patient's level of functioning with IBD. We have begun this process with a focus on the extreme group of 'difficult to manage' IBD patients. Anecdotal reports indicate that many gastroenterology services have observed a small group of IBD patients who have a great deal of difficulty functioning out of hospital and/or without frequent medical intervention. Two interesting observations about this group of patients include their ubiquitous nature (virtually all gastroenterology programs appear to have had experience with such patients) and the difficulty that clinicians encounter in managing these patients' symptoms; however, little systemic or academic attention has been given to this group of patients. We are much more likely to hear about these individuals during informal discussions among gastroenterology clinicians than during formal rounds or at conference proceedings; however, these patients can occupy a significant amount of a clinician's time and a service's resources. A recent audit of our gastroenterology service (Queen Elizabeth II Health Sciences Centre, Halifax, Nova Scotia) indicated that 1% of the IBD population accounted for 10% of admissions. Patients in the 'difficult to manage' group averaged 50 radiological procedures each, and one patient underwent more than 120 radiological investigations. Patients frequently left the hospital against a physician's medical advice and lodged complaints about their treatment. Further, as a group, these patients were often perceived to be narcotic dependent. Because such patients have not, to our knowledge, been formally studied, the extent to which they actually differ from more typical IBD patients is unclear. 'Difficult to manage' patients may have more complex biomedical disease than typical IBD patients, or they may be more difficult to manage for psy-

chosocial reasons. The first step in understanding what makes management difficult is to investigate the perceived characteristics of such patients. Do different clinicians hold similar opinions and have similar experiences? If yes, this warrants follow-up investigations that will evaluate patients directly. If no consensus can be established, the perceptions of the clinicians in our survey may reflect bias.

Over the past two decades, research to explore the role of psychosocial factors in IBD has begun. Drossman and colleagues (1-7) have been the most prolific at incorporating psychosocial factors into conceptualizations of IBD. Drossman (8) highlighted the need to avoid a 'functional' versus 'organic' perspective and encouraged the adoption of a biopsychosocial model. He provided evidence for the role of stress and coping in the presentation of IBD patients. In keeping with this evidence, our group found that IBD patients' quality of life, especially those with Crohn's disease, is highly influenced by psychosocial factors (9-12). Based on his research, Drossman (4,13) proposed a strategy for managing refractory functional gastroenterology disorders. In his strategy for care, he advocated such principles as basing diagnosis on the presence of positive symptoms, minimizing the number of procedures that are conducted, understanding the psychosocial contributions to the illness, focusing on the quality of the patient-physician relationship and establishing appropriate referral networks.

Although past research has laid a foundation for exploring the important roles of psychological issues in patients with IBD, it has not assessed directly the factors that contribute to functionality. To accomplish this, we began our series of investigations by systematically assessing the opinions of our gastroenterology service providers with regard to the characteristics that were perceived to distinguish the extreme group of poorly functioning IBD patients from typical IBD patients. We also sought to explore the impact of working with this select group of patients on staff and team functioning.

PATIENTS AND METHODS

Data in this study were collected by survey. Survey items were generated to assess three domains (patient behaviour, impact on staff and impact on team), using a series of focus groups that consisted of gastroenterologists, surgeons and gastroenterology nurses.

Patient behaviour

The 'patient behavior' section of the survey comprised 51 items. The items involved the rating of patient behaviours in the emergency room (ER), on the inpatient floor, at the time of discharge and after discharge. Clinicians were asked first to think about their collective experiences working with poorly functioning IBD patients. They were then asked to list the essential characteristics that, in their minds, defined those patients as a group (ie, a prototype). After they had done so, they were asked to keep this prototype in mind while they completed this section of the questionnaire. Because the authors wanted to assess general attitude, they did not provide specific case information or identify a specific group of well-known patients. To do so would have restricted the range of responses (by anchoring them to specific patients) and, therefore, would have increased the likelihood of agreement between staff.

For each of the items in this section, two ratings were made, each on five-point Likert scales that contained descriptive anchors. First, participants rated the frequency with which poorly functioning patients displayed poor behaviour (1 = never, 3 = sometimes and 5 = always). Second, they rated the extent to which the behaviour differed from that of typical gastroenterology patients (1 = not different, 3 = somewhat different and 5 = completely different). Finally, items were categorized, on rational grounds, into the following five subscales (see Appendix 1 for full list of symptoms).

- Symptom presentation (13 items): These items dealt with the most common physical symptoms associated with IBD, including pain, change in bowel habits, bloody stool, nausea, vomiting, bloating, anorexia and dehydration.

- Narcotic over-reliance (12 items): These items assessed behaviours such as requesting pain medication, frequency of as required medication, familiarity with the details of narcotic administration, dosing, etc, and reports of instant relief from pain.

- Interpersonal behaviour – general (five items): These items assessed interpersonal behaviours on the hospital floor, such as being very 'at home' in the hospital, bringing in one's own comforts, and being overly familiar with the staff and setting.

- Interpersonal behaviour – manipulative (five items): These items assessed behaviours that were seen by staff to be manipulative, such as the perception that patients were playing staff members off of one another and frequently switching primary care physicians – items that indicated that patients were overly familiar with staffing patterns (for example, knowing which doctor was on call at a given time).

- Illness behaviour (13 items): These items focused on behaviours that suggested a perception that the patient shows investment in being ill, such as dwelling on symptoms and disease, recounting details of surgery with the suggestion of pleasure, showing little interest in discharge or home situation, and quickly returning to the ER after discharge.

TABLE 1
Average ratings and standard deviations of the frequency of patient behaviour and the extent of difference between 'difficult to manage' patients with inflammatory bowel disease (IBD) and typical IBD patients

	Frequency of behaviour	Extent of difference from typical patient
Symptom presentation, mean (SD)	3.62 (0.49)	3.34 (1.19)
Narcotic over-reliance, mean (SD)	4.35 (0.64)	3.74 (0.86)
Interpersonal behaviour: General, mean (SD)	4.25 (0.58)	3.84 (0.90)
Interpersonal behaviour: Manipulative, mean (SD)	4.42 (0.54)	4.11 (0.79)
Illness behaviour, mean (SD)	4.02 (0.54)	4.12 (1.13)

Impact on staff

The 'impact on staff' section of the survey focused on the emotional impact that working with poorly functioning IBD patients had on gastroenterology staff. The degree to which these patients elicited various emotions from staff members was assessed using an adaptation of the Profile of Mood States (POMS) (14), and 10 items assessed the degree of frustration that was experienced when gastroenterology staff members worked with these patients. The POMS is a 64-item scale that assesses the following emotional domains – depression/dejection, confusion, tension/anxiety, anger/hostility, fatigue and vigour. Domain scores were calculated by summing the number of emotions that were endorsed within each category. The percentage of items that were endorsed in that category was analyzed. The questions that focused on frustration assessed, on a seven-point Likert scale (1 = not at all frustrating, 4 = somewhat/sometimes frustrating and 7 = extremely frustrating), the degree of frustration that was felt by staff as a result of the following perceptions – that a gap exists between expressed distress and objective measures of disease, that patients search for validation of their symptoms, that there is a patient dependency on medical staff, that patients lack personal responsibility for getting better, that patients have conviction in being ill, that patients have an attitude of entitlement to be cared for by others, that patients avoid assuming healthy roles, that patients exhibit excessive 'sick role' behaviours and that excessive time is required to manage these patients.

Impact on interdisciplinary team

The final section of the survey addressed the issue of team functioning that was associated with poorly functioning gastroenterology patients. The following issues were rated, using a seven-point Likert scale, in terms of the frequency of occurrence (1 = not at all, 4 = sometimes and 7 = very often) – patient elicits conflict within the team, the extent of support from other team members when dealing with these patients, the ability to discuss the patient with team members, and the extent to which the respondent believes that his or her opinions are respected by the team.

PROCEDURE

Two versions of this questionnaire were developed – one for gastroenterology nurses and one for gastroenterology physicians. The content of the questionnaires was identical, with the exception of the discipline-specific referents. The nurses' questionnaire was distributed to the nursing unit managers of two inpatient floors for gastroenterology service. The nursing unit managers made their staff aware of the study and supported the completion of the survey (ie, time during the nurses' shifts was made available for completing the survey). The physician questionnaires were distributed to the gastroenterology division staff members (n=10) and the gastroenterology surgeons (n=3) by the gastroenterology division head.

RESULTS

Sample

Of the 60 nurses who could have participated, 19 returned the survey (32% response rate). Of the 13 physician surveys that were distributed, 10 were returned (77% response rate). The total sample of surveys was 29. Of the nurses, all were female. All but one of the physicians was male. There was a sex differences in degree status, as was expected (χ^2=14.28, P<0.001). Further, nurses (70% of whom had diplomas and 30% of whom had a Bachelor of Science in Nursing) were younger (mean age of 34.93 years) than physicians (mean age of 45.44 years; t=3.26, P<0.005). Although nurses averaged fewer years of total experience (mean of 12.75 years) and gastroenterology-specific experience (mean of 7.25 years) than physicians (mean total experience of 16.71 years and mean gastroenterology experience of 12.86 years), these differences did not reach conventional levels of significance (P> 0.05).

Group differences for nurses and physicians

Before analyzing the results of the three sections for the total sample, the nurses' and physicians' surveys were compared to determine whether there were significant differences between the two groups. Comparisons were done on an item-by-item basis using a series of *t* tests. Despite the potential for significant compounding of the error rates

TABLE 2
Number of items in each subscale of the Profile of Mood States (POMS), average number endorsed by participants and percentage of items endorsed by participants in each subscale

	Number of items in subscale	Average number of items endorsed	Percentage of items endorsed
Depression/dejection	15	3.97	26.4
Confusion	7	1.86	26.6
Tension/anxiety	9	3.11	34.6
Anger/hostility	12	5.74	47.8
Fatigue	7	3.00	42.8
Vigour	8	1.52	19.0

with such a large number of individual *t* tests, in no case was there a significant difference in the item rating between the nurses and physicians. As a result, the samples were combined for the analyses reported below.

Patient behaviour

Recall that participant ratings of patient behaviour were made on a five-point Likert scale, with two ratings obtained for each item – the frequency of the behaviour and the extent to which the behaviour differed from that of the typical gastroenterology patient. Average ratings for each patient behaviour, as well as standard deviations, are shown in Table 1.

These data indicate that poorly functioning patients were frequently seen to display dysfunctional behaviour and that these behaviours were seen as distinct from those of typical gastroenterology patients. In terms of frequency of behaviour, with the exception of symptom presentation, the mean frequency rating was very high (greater than 4, on a five-point scale). As well, these ratings were consistent across the sample, as indexed by the low standard deviations (less than 0.65). Mean ratings were all greater than the midpoint for the extent to which the poorly functioning patient's behaviour was seen as distinct from the average gastroenterology patient's behaviour. For symptom presentation, these behaviours differed somewhat from those of average gastroenterology patients. Narcotic overreliance and general dysfunctional interpersonal behaviour also differed between groups, but neither of these scale scores was extreme. On the manipulative interpersonal behaviour and excessive illness behaviour scales, however, the average rating was quite extreme (again, greater than 4, on a five-point scale).

Impact on staff

To assess the negative impact that the poorly functioning patients had on the gastroenterology staff, participants completed a modified version of the POMS and a series of items to assess frustration level.

POMS: The POMS scale assessed the degree to which 'difficult to manage' patients elicited various emotions from survey participants, and was modified such that the response format was changed to yes or no. Results were reported as the percentage of items that were endorsed by participants within each subscale (Table 2). On average, almost half of the items on the anger/hostility and fatigue subscales were endorsed. Approximately one-third of the items on the tension/anxiety, depression/dejection and confusion subscales were endorsed. In contrast, the survey participants endorsed less than one-fifth of the items on the vigour subscale. These data reflect the negative emotional impact that the poorly functioning gastroenterology patients had on participants, and anger/hostility and fatigue were the primary emotions that were elicited by working with those patients.

Level of frustration: Participants rated, on a seven-point Likert scale (1 = no frustration or distress, 4 = moderate frustration or distress, and 7 = extreme frustration or dis-

TABLE 3
Average level of frustration experienced and standard deviation

Item	Mean rating (1-7)	Standard deviation
Disability greater than objective disease	5.33	1.69
Patient searching for validation of illness	5.07	1.61
Dependency on medical staff	5.31	1.56
Lack of personal responsibility for getting better	5.90	1.52
Conviction that seriously ill	5.41	1.45
Attitude of entitlement to be cared for	5.39	1.57
Avoidance of healthy roles	6.10	1.01
Behaviours that sustain a sick role	5.86	1.39
Time required to manage patient	6.52	0.74

tress), the level of frustration they experienced in reference to nine specific behaviours that were displayed by poorly functioning patients. For the frustration items (Table 3), all means were greater than five, with relatively small standard deviations, which indicated that a high level of frustration was consistent across patient behaviours. The highest ratings of frustration were with respect to the amount of time that was required to manage those patients (mean 6.52), that the patients avoided healthy roles (mean 6.10) and that the patients did not demonstrate a personal responsibility for getting better (mean 5.90). Participants also rated the amount of personal distress they experienced in working with 'difficult to manage' patients, and the average rating was 5.66 (SD 1.59), which attested to significant distress in participants as a result of working with this group of patients.

Impact on interdisciplinary team

Participants rated, on seven-point Likert scales (1 = not at all, 4 = sometimes and 7 = very often), several items that assessed team functioning. For the item that assessed the frequency with which poorly functioning patients elicit conflict within the team, the average score was 5.59 (SD 1.35). Further, when asked how often the participants felt supported by their colleagues, the average rating was 3.55 (SD 1.64), which was less than 'sometimes'. A similar rating of the extent to which the participants felt that their opinions were valued by their colleagues received an average rating of 4.45 (SD 1.53). Finally, when asked to rate the extent to which the treatment that participating members were administering was effective, the average rating was 3.14 (SD 1.55).

DISCUSSION

These results represent a first attempt to quantify the experience of gastroenterology staff members who worked with a subgroup of IBD patients who were viewed to be poorly functioning and difficult to manage. A number of conclusions can be drawn from these data. Our findings support the widespread agreement that a small group of poorly functioning IBD patients exists, and it is perceived that these patients can be distinguished from typical IBD patients. Participants were able to characterize this group of patients in terms of particular patient characteristics, in terms of the emotions that were elicited in working with such patients and in terms of the impact that such patients had on the functioning of the gastroenterology team.

With respect to behavioural presentation, a number of dimensions that reflect symptom experience, narcotic overreliance, general and manipulative interpersonal behaviour, and illness behaviour were assessed. Interestingly, the patients who were perceived to be poorly functioning were rated as distinct from typical IBD patients, based more on characteristics of manipulative behaviour and illness behaviour than on symptom presentation or narcotic overreliance. The frequency of all categories of behaviour was generally high (greater than four of five for all categories, except symptom presentation); however, ratings of the extent to which behaviours differed from those of more typical IBD patients were strongest for the dysfunctional behaviour scales (manipulative and excessive illness behaviour). If these findings are replicated and validated, they might suggest that illness behaviour issues may be central to IBD patients' abilities to function well.

It is likely that similar groups of poorly functioning patients also exist with other chronic diseases. The fact remains, however, that little is understood about those patients. To plan more efficacious interventions, it behooves us to examine scientifically the factors that are associated with poor functioning.

The data on the impact that poorly functioning IBD patients had on staff indicated that working with this group of patients aroused significant frustration and hostility. The item analysis of the level of frustration demonstrated that these patients have an extreme and consistent negative impact on staff. Participants experienced these patients to elicit high levels of conflict and low levels of support among team members. Further, participants perceived themselves to be of little help to these patients. It seems that these 'difficult to manage' patients bring out the worst in gastroenterology staff.

Although these data reveal interesting and potentially useful findings, the results must be interpreted with caution because they speak to staff opinion and not to patient characteristics per se. In fact, these data might be interpreted as confirmation that gastroenterology staff are biased against a subgroup of IBD patients. Do the findings exist in the minds of the staff (bias) or in the behaviour of the patients (excessive illness behaviour)? Before proceeding, follow-up research must confirm that patients who are identified as dysfunctional do, indeed, differ from typical IBD patients. We are currently completing such a study. We have assessed a small group (n=15) of patients who were judged to be representative of the extreme group of poorly functioning and 'difficult to manage' IBD patients. We randomly selected a matched-yoked control sample from our general population of IBD patients. These patients will be compared on a wide range of biomedical, social and psychological factors. If no systematic differences can be found, there is a possibility that the poorly functioning group is, in fact, unfairly perceived.

Although further research is clearly needed, this study represents an attempt to elucidate factors that contribute to functionality, or lack thereof, in patients with IBD. The results of this first step in our investigation indicate that it is possible, from a medical viewpoint, to distinguish the extreme group of poorly functioning IBD patients from typical IBD patients. Based on the perception of highly expert staff, it appears that poorly functioning patients are very difficult to manage. Given the negative impact that this group has on staff, the potential problem of bias against these patients, and implications for quality of care and for service provision, need to be further explored.

APPENDIX 1
Survey items

Symptom presentation (13 items)
- Increase in pain upon presentation in emergency room
- Increase in bowel movements upon presentation in emergency room
- Decrease in bowel movements upon presentation in emergency room
- Bloody stool upon presentation in emergency room
- Distended stomach upon presentation in emergency room
- Nausea upon presentation in emergency room
- Vomiting upon presentation in emergency room
- History of Colitis/Crohn's disease upon presentation in emergency room
- Dehydration upon presentation in emergency room
- Anorexia upon presentation in emergency room
- Patient is mobile on the hospital floor

Narcotic over-reliance (12 items)
- Requesting pain medications upon presentation in emergency room
- Narcotics are given as required 3 to 4 h by injection
- Patient knows the narcotic and dosage
- Patient requests Gravol (Carter-Horner, USA) with narcotic
- Patient is not afraid of needles
- Patient offers to help facilitate injection (eg, tissue to dab area)
- Calls before narcotics are due to give nurses time
- Sets alarms for narcotics
- Wakes up specifically for narcotics
- Returns to floor in time for narcotics
- Narcotics provide instant symptom relief
- When narcotics changed from intramuscularly to orally, patient is ready to leave

Interpersonal behaviours – general (five items)
- Patient is at home in hospital
- Patient brings in own comforts (eg, pillow, bedding)
- Patient knows how hospital functions
- Patient knows all staff (cleaners to food service)
- Patient knows menu and extra food items in fridge

Interpersonal behaviours – manipulative (five items)
- Patient tries to engage sympathy of staff and other patients
- Patient plays staff off one another ("you're nicer than...")
- Patient frequently changes primary physicians
- Patient knows nurse and physician shift changes
- Patient reports increase in pain when on-call physician is on duty

Illness behaviour (13 items)
- Offering medical advice to other patients in the hospital
- Being overly compliant
- Being overly assertive (want things done their way)
- Focusing only on the negative aspects of prognosis
- Recounting details of surgeries
- Dwelling on disease and symptoms
- Describing themselves as unlucky
- Never inquiring about date of discharge
- Not discussing home situation
- Not discussing losses associated with not being home
- Presents problems at home that curtail discharge
- Patient does not keep follow-up appointments
- Patient quickly returns to emergency room in distress

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