

# BRIEF COMMUNICATION

## Do We Know What Patients Want? The Doctor-Patient Communication Gap in Functional Gastrointestinal Disorders

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**BACKGROUND & AIMS:** Understanding patients' expectations at initial consultation for functional gastrointestinal disorders (FGIDs) might influence future health care utilization. Ideally, patients and doctors would have a common understanding of the issues involved. We sought to investigate this with matched questionnaires. **METHODS:** Patients' needs/expectations/understanding were compared with gastroenterologists' and general practitioners' awareness of these. Patients were followed up to investigate satisfaction with and outcomes of specialist consultation. **RESULTS:** Specialists underestimated the number and severity of patients' symptoms (in 43% and 41%, respectively), and patients and specialists had quite discordant views on what treatment would best suit their symptoms. Strikingly, only 1 of 13 patients available for follow-up agreed with or accepted the functional diagnosis, despite all being diagnosed by a specialist as having an FGID. **CONCLUSIONS:** In FGIDs there is a communication gap between patients and gastroenterologists. Importantly, at follow-up, patients do not acknowledge their FGID diagnosis. This communication gap and lack of acceptance of a functional diagnosis are likely to influence future management and health care utilization.

Functional gastrointestinal disorders (FGIDs) are extremely prevalent.<sup>1,2</sup> However, only a subset of patients consult their general practitioner (GP) or receive specialist referral.<sup>3</sup> Despite this, FGIDs account for ~30% of ambulatory care gastrointestinal consultations<sup>4</sup> and thus represent a large workload for gastroenterologists,<sup>3</sup> especially because many with FGIDs consult repeatedly.<sup>5</sup>

There appears to be an unacknowledged and unexplained divergence in the understanding and purpose of the specialist consultation between patients and doctors. Doctors regard reassessment as medically unnecessary where there is an existing FGID diagnosis,<sup>6</sup> whereas diagnosed patients return for review with the same cluster of symptoms. Previous research has examined concurrent psychopathology as driving this re-consulting behavior.<sup>7,8</sup> However, psychopathology accounts for only ~40% of the variation in FGID consulting behavior.<sup>9</sup>

When patients with FGIDs seek specialist consultation, it is often unclear to the gastroenterologist whether it is to diagnose the cause of symptoms, initiate or readjust treatment, or for other reasons. This lack of a clear mutual understanding of the role of specialist consultation might impair the effectiveness of

the encounter, because meeting patients' expectations at this time might be critical in modifying ongoing health care utilization.

Recent work in our department with FGID patients (irritable bowel syndrome [IBS] particularly) suggested that patients might have different views than doctors about the role of specialist consultation, although treating specialists' views were not specifically sought in this initial study.<sup>10</sup>

Therefore, here we aimed to (1) investigate the degree of concordance among patients presenting for assessment of FGIDs, their treating gastroenterologists, and referring GPs with regard to the referral, evaluation, and treatment process and (2) examine ongoing health care usage and ownership of the diagnosis after the specialist encounter.

### Methods

All referrals to a general adult gastroenterology outpatient department at a metropolitan hospital were screened for 6 months. Where referrals indicated a likely FGID, subjects were invited by mail to participate before their specialist consultation. Subjects were not considered if their referral indicated need for an interpreter, confounding comorbidities, or major psychosocial issues. Each patient-gastroenterologist pair independently completed a questionnaire (Appendix 1). After consultation with the gastroenterologist, each referring GP was invited to complete the same questionnaire.

After the episode of care, participants were asked a series of questions regarding their specialist consultation, how they felt about the care they received, and whether they had been given a diagnosis. Up to 3 attempts were made to contact each patient.

The study was approved by the Royal Adelaide Hospital Ethics Committee. Completion of a questionnaire signified consent.

The questionnaire was developed locally by one of the authors (E.F.) on the basis of previous qualitative work.<sup>10</sup> This is a novel 15-item measure to assess patient perceptions and opinions on 5 main themes: (1) areas and severity of life affected

**Abbreviations used in this paper:** FGID, functional gastrointestinal disorder; GP, general practitioner; IBS, irritable bowel syndrome.

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**Table 1.** Patient-Reported Symptom Burden and Doctors' Perception

	Patient report	Perceived by gastroenterologist	Perceived by GP
Number of FGID symptoms, median (range)	5 (1–11)	2 (1–5)	3 (1–11)
Symptom frequency, mean (SD) (1 = constant to 5 = never)	1.93 (0.87)	2.58 (1.07)	2.1 (1.17)
Pain severity, mean (SD) (1 = extreme to 5 = almost nothing)	2.7 (0.99)	3.04 (0.96)	3 (0.48)
Interference with daily life, mean (SD) (1 = severely to 5 = not at all)	3 (0.94)	3.31 (0.74)	3.31 (0.48)

SD, standard deviation.

by symptoms, (2) main reasons for symptoms, (3) best treatment approach, (4) ability to cope in the long-term, and (5) likelihood of using further health services.

Doctors completed the questionnaire from each patient's perspective. Thus it assessed doctors' accuracy in gauging patients' perceptions.

General health literacy was measured (REALM-R<sup>11</sup>). Two FGID-related words (diarrhea and flatulence) were added for heightened contextual relevance,<sup>11</sup> for a maximal score of 10.

## Results

### Participants

Invitations were sent to 75 referred patients. Only 31 attended their specialist appointment. Two opted out, and 2 had missing data, leaving 27 participants with a clinical FGID diagnosis (22 women), mean age, 37.3 years (range, 20–74; median, 32 years), where both patient and gastroenterologist completed questionnaires at initial consultation. Referring GPs for 13 of 27 subjects participated. Mean time from initial encounter to attempted follow up was ~20 weeks; only 13 of 27 patients were contactable. Clinician diagnoses were IBS, 15; functional dyspepsia, 5; functional abdominal pain, 2; other functional bowel disorder, 8; some with >1 diagnosis. Eleven gastroenterologists participated, age 26–63 years, 2 female. Thirteen GPs participated, 50% female (1 transgender); practice locations were city, suburban, and near country.

### Initial Consultation

Patient-reported symptom burden and doctors' perception of this are shown in Table 1. Although mean scores were similar among patients and doctors (Table 1), agreement in individual patient-doctor pairs was poor. In 82% of pairs, gastroenterologists underestimated patients' number of symptoms, were accurate in 11%, and overestimated this in 7%. Considering symptom frequency, gastroenterologists were accurate (41%) or underestimated (43%) patients' reports. Gastroenterologists either underestimated (41%) or were accurate (33%) in estimating how severely symptoms affected patients' lives, whereas GPs were either accurate (46%) or overestimated (39%) this. Gastroenterologists (48%) and GPs (46%) underestimated individual patients' reported pain level.

Patients viewed diet (45%) and the impact of stress and worry (38%) as prime causes of symptoms, and gastroenterologists were accurate in gauging this (concordance, 45%). Other patient-nominated causative factors included family history (27%), infection (24%), and "weak immune system" (10%).

Patients and doctors had discordant views on desirable/expected timelines for diagnosis, treatment implementation, and patients' ability to cope in the longer-term; concordance

rates among patients and doctors on these items ranged from ~8% to 56%.

Patients viewed a single operation (41%) or dietary modification (31%) as the most useful/desirable treatment for their symptoms. Gastroenterologists were more focused on symptom control, endorsing medication (41%), or managing stress and worry (28%).

GPs endorsed medication (14%) and managing stress and worry (10%) as preferred approaches. GPs (14%) also suggested other treatment modes including psychological, reassurance, and further investigations.

Awareness of diagnosis before the specialist consultation is shown in Table 2.

### Follow-Up

When asked directly whether they were given a diagnosis, only 1 of 13 patients agreed with the FGID diagnosis (IBS); 12 denied (or rejected) having been given an FGID diagnosis. Where dual physical and functional diagnoses (N = 2) were recorded (diverticulitis and IBS, reflux and IBS), subjects reported only the physical diagnosis, ignoring the FGID diagnosis.

Eight subjects had not further consulted for FGID symptoms, and 6 did not anticipate they would need to. Those reporting they had or would said it would mostly be with their GP and only with a specialist if again referred.

### Health Literacy

The mean health literacy score (n = 27) was 9.04 (range, 3–10). The score of the patient agreeing with her diagnosis was

**Table 2.** Prior Awareness of Diagnosis (Preceding Current Specialist Consultation)

	Concordance
Gastroenterologist and Pt	
Pt and gastroenterologist agree no prior diagnosis	15
Pt and gastroenterologist agree on previous diagnosis	1
Pt notes diagnosis, gastroenterologist does not	6
Gastroenterologist notes diagnosis, Pt does not	5
GP and Pt	
Pt and GP agree no prior diagnosis	5
Pt and GP agree on previous diagnosis	0
Pt notes diagnosis, GP does not	2
GP notes diagnosis, Pt does not	6

Pt, patient.

10, which did not differ from the 12 patients denying their diagnoses (mean, 9.6; range, 7–10).

## Discussion

In this novel study in FGIDs, we directly and concurrently examined the perceived needs/expectations of patients and whether their specialists and referring GPs are aware of these patient perceptions. Two striking findings were the high level of miscommunication between patients and specialists and the unexpected fact that only 1 patient owned/acknowledged the FGID diagnosis at follow-up.

Concordance between patients and doctors was acceptable in objective information such as past diagnosis. However, patient perceptions of symptom burden were underestimated by gastroenterologists, and patients' and specialists' views on the best treatment options diverged. Patients' beliefs that a single operation to uncover and treat "the cause" would be the most desirable treatment option are consistent with their lack of acceptance of the functional diagnosis and indicate a persisting expectation of finding a specific cause and thus a cure.

The most important finding was that the majority of patients diagnosed with an FGID did not "own" this diagnosis at follow-up. Patients either denied being given any diagnosis or, in the case of dual diagnoses, reported the physical diagnosis but not the FGID diagnosis. On further questioning, some patients allowed they had "sort of" been given a diagnosis of IBS; however, their language indicated skepticism about this as a "firm" or "real" diagnosis. The high levels of health literacy suggest that misunderstanding the diagnosis or associated medical terms is not the cause of this communication failure.

Although it is possible that patients did not own/accept the FGID diagnosis because it was not clearly given, this is unlikely. (1) Each FGID diagnosis was clearly both handwritten in case notes and typed in the letter sent to each GP, indicating high-level specialist confidence in diagnosis. (2) This would not account for subjects who, on further questioning, grudgingly agreed they had sort of been given a diagnosis. (3) We have active research in FGID, so specialists see FGID as valid diagnoses and are willing to give them explicitly. (4) The high health literacy makes it unlikely subjects were passive participants and left the consultation without "an answer." Although our questionnaire needs validation, it was simple and was easy to administer to patients and for doctors to complete, suggesting "face validity."

Others have recommended that physicians deal with FGID patients by addressing symptom severity and anxiety and by helping eliminate factors contributing to exhaustion by discussing coping mechanisms, relaxation, and lifestyle modifications.<sup>12</sup> Our results suggest that many patients might not be initially receptive to this approach. Thus, we might need to first take a step back and ensure that patients own their diagnosis before embarking on therapy.

Although most had not yet consulted other health professionals, the failure of our patients to acknowledge their diagnosis is likely to lead to unnecessarily seeking services for FGID symptoms in the future, because patients do not believe the symptoms are, as yet, adequately explained. This phenomenon

of a discarded diagnosis has important implications in FGIDs because it might underpin recurrent consultation.

## Supplementary Data

Note: to access the supplementary materials accompanying this article, visit the online version of *Clinical Gastroenterology and Hepatology* at [www.cghjournal.org](http://www.cghjournal.org).

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## Appendix 1

**Gastroenterological Treatment Expectations (GETE)  
Questionnaire Development  
SCALE DEVELOPMENT – PATIENT REPORT**

15-item questionnaire, allowing completion in 10–15 minutes — idea is that, eventually, this can be done in the waiting room prior to specialist consultation.

The GETE is designed to yield a patient profile, rather than a score(s) to be compared with norms or cutoff points.

The GETE is designed to assess three distinct areas or domains of patients' needs and expectations:

1. **PART A: Explication of symptoms (nature and impact): ITEMS 1–5**
2. **PART B: Investment in “ID of cause” (expectations of an answer): ITEMS 6–10**
3. **PART C: Treatment and Prognostics: The consult process (expectations of a solution): ITEMS 11–15**

The GETE

1. Please circle the **symptoms** you experience (you can circle as many as are relevant for you):
  - a. Diarrhea
  - b. Constipation
  - c. Bloating
  - d. Pain and discomfort
  - e. Wind
  - f. Weight loss or gain
  - g. Sleeplessness
  - h. Fatigue
  - i. Poor concentration
  - j. Loss of appetite
  - k. Lack of control (over wind, diarrhea, etc)
2. How would you describe the **frequency** of your symptoms?
  - a. Constant; they are always present
  - b. Fairly constant
  - c. Temporary; they are usually relieved after visiting the toilet
  - d. Infrequent, only now and then
3. How would you describe the level of **pain and discomfort** you experience from your symptoms?
  - a. Extremely high
  - b. High
  - c. Moderate
  - d. Slight
  - e. Almost nothing
4. Please indicate which **two** areas of your daily life are **most affected** by your symptoms (please number as “1” and “2”):
  - a. My physical health and fitness

- b. My diet and eating habits/choices
  - c. My mental well-being: feeling stressed, worried, unhappy
  - d. My social life, including my ability to go out
  - e. My family life, including stress or strain on spouse/children
  - f. My career, including loss of time/days due to symptoms
  - g. Other: \_\_\_\_\_.
5. How **severely** is your daily life affected by your symptoms?
  - a. Extremely severely
  - b. Severely
  - c. Moderately
  - d. Only slightly
6. Have you received **any diagnosis** for your symptoms in the past?
  - a. **No**, I was just told that \_\_\_\_\_.
  - b. **Yes**, the diagnosis was \_\_\_\_\_.
7. If you answered “**Yes**” to Question 6, **who** provided you with the diagnosis? \_\_\_\_\_.  
**Did you agree** with that diagnosis? (did it make sense to you)?
  - a. Yes
  - b. No
  - c. Not sure

**OR**

If you answered “**No**” to Question 6, do you expect that the gastroenterologist you are seeing **today** will be able to provide you with a clear diagnosis?

  - d. Yes
  - e. No
  - f. Not sure
8. Even if you *never* receive an “answer” to your symptoms, do you think you could still manage your symptoms in the long-term **without a diagnosis**?
  - a. Yes
  - b. No
  - c. Not sure
9. When you think about **possible causes or explanations** of your symptoms, which **two** of the following make the **most sense to you** (please number as “1” and “2”):
  - a. My family history
  - b. An infection of some sort
  - c. A weak immune system
  - d. The impact of daily stress and worry
  - e. Problems with my diet, including bad reactions to food
  - f. Other: \_\_\_\_\_.

10. During **what period of time** do you expect a clear diagnosis of your symptoms from the doctor you are seeing today?
- Today
  - Within 1 month
  - Within 3 months
  - After 6 months
  - More than 1 year
11. Have you ever tried any treatments, medicines, activities, supplements, or remedies to help with your symptoms in the past?
- No
  - Yes (please indicate) \_\_\_\_\_.  
If **“Yes”**, who recommended this treatment to you? \_\_\_\_\_.
12. Which of the following treatment approaches do you see as being **most useful or successful** for you?
- One operation to look at the internal damage
  - Changing my lifestyle: a better diet, more exercise, and/or quit smoking
  - Improving levels of stress and worry in my daily life
  - Taking medication until the problem goes away
  - Other: \_\_\_\_\_.
13. **When** do you feel a treatment of your symptoms should begin?
- From today
  - Within 1 month
  - Within 3 months
  - Within 6 months
  - Probably not for a year or more
14. If the gastroenterologist today said that there was no simple, clear, and easy treatment for your condition, would this be **acceptable to you**?
- Yes
  - No
  - Not sure
15. In seeking a treatment for your symptoms, would you be willing to seek treatment options from other allied health professionals (such as dietitians, naturopaths, acupuncturists)?
- Yes
  - No
  - Not sure; I would need more information
- Final Section to complete:**  
**Please hand back to the interviewer for your instructions:**
- Osteoporosis
  - Allergic
  - Jaundice
  - Anemia
  - Fatigue
  - Directed
  - Colitis
  - Constipation
  - Diarrhea
  - Flatulence
- Questionnaire complete – Thank You!