Patients with functional gastrointestinal and motility disorders experience waxing and waning chronic symptoms of uncertain etiology. In general, the disorders are not well understood. Lack of awareness may lead to social, economic, and emotional distress as well as failed therapeutic outcomes. An effective physician-patient relationship is a cornerstone to patient care. It begins with a positive diagnosis, reassurance, and education. Both the patient and physician will benefit from understanding symptoms within the context of the patient’s lived experiences.

Who among us wants to imagine, let alone live with, suffering a potentially disabling condition that is embarrassing to talk about, often invisible to others, misunderstood by the public and even many physicians, and often dismissed as a psychological problem. Those affected by the conditions understand this all too well. Living with chronic disorders means enduring illnesses characterized by unpredictable symptom episodes and disabling effects that are often accompanied by minimally effective treatments, social stigma, and isolation (3).

Patients may talk to their doctors about symptoms they experience, like gut pain, diarrhea, constipation, nausea, or vomiting. But the social, economic, and inner challenges experienced, as well as the individual potential lost is something that is seldom discussed.

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Individual physicians who hear the personal stories from the patients that he or she sees will undoubtedly do everything they can to relieve the suffering described. Each patient presents the clinician with the challenge to help reduce symptoms and improve quality of life. Nonetheless, there is also a broader challenge to the collective body of researchers and clinicians who care for these patients, and that is to move this field forward. Answers to questions about prevention and treatment, let alone cures, are few or nonexistent. We need to build broader awareness about these disorders, among multiple medical disciplines, so that signs and symptoms are recognized, diagnosis is swift and confident, and appropriate treatment plans implemented that take into consideration the patient’s lived experiences.

UNDERSTANDING THE PATIENT PERSPECTIVE

A patient seeking medical care may present with symptoms that are not at first recognized as being associated with a chronic functional or motility disorder. Symptoms may be attributed instead to something else. As a result, the patient’s search for help can become a frustrating and baffling experience. For example, it may begin with a misdiagnosis during a visit to an emergency room. Repeated visits may result in the patient, rather than the symptoms, being characterized as “difficult.” The patient, moving on to their primary care physician in an increasingly anxious search for help, may be confronted by an unconcerned attitude on the part of the caregiver to the chronic bowel symptoms, nausea or vomiting eroding the person’s daily life.

How unusual is this type of experience? It is all too common. In a quantitative survey of persons who reported a diagnosis of irritable bowel syndrome (IBS) conducted in 2002 by the International Foundation for Functional Gastrointestinal Disorders (IFFGD), 43% of respondents suffered five or more years with symptoms before a diagnosis of IBS was made (4). Patients with cyclic vomiting syndrome often go on for years without diagnosis (5). Misdiagnosis can lead to unnecessary tests and procedures. Patients and families both suffer. The patient expectation is for care and compassion. When that does not happen or diagnosis is vague, hope can change to fear, anger or despair. Patients may turn to unconventional treatments that promise easy solutions, but in the end do little except add to their frustration.

It is hoped that patients do not have to endure years of failed therapeutic encounters. Diagnostic procedures have improved over the past two decades. However, in many cases the patient with a functional or motility GI disorders who is seen by their primary care physician must be referred to an appropriate specialist before an accurate diagnosis is made.

The Rome criteria have made positive diagnosis of a functional GI disorder possible with little or no testing. The diagnosis of a motility disorder may come with a battery of tests. Patients submit to the tests with the hope of unlocking the mystery to their misery. It is important that patients fully understand the preparation for the test, what will happen during the test, and what to expect afterwards. Patients need to know why they are being tested and how the test results will affect them. Why is the test necessary for their diagnosis? Will the results affect their treatment plan?

In clinical practice, symptoms may be categorized as mild, moderate, or severe (6). Severity is something that continues to be a subjective measurement for many patients. A physician may view severity based on a concept of disease within a biomedical framework; the patient will likely understand severity within the framework of their lived experiences (7). The patient who lives with gastroparesis, for example, has an ever-present concern about maintaining weight and proper nutrition. Pharmacological agents may help manage the disorder, but come with their own set of side effects. Patients considered as the most severe live with the fear of gastric failure.

Patients who live with cyclic vomiting syndrome are overcome with the disorder when it takes control of their body. Somehow, they find the resolve to continue on and search for any clue that could help them manage the symptoms for this devastating condition. As with many of these disorders, they may endure not only impaired quality of their life, but also economic hardship as they fail to maintain their jobs or pay high medical costs as they search for answers to their problem (5).

Individuals with fecal incontinence must find and draw on inner strength in order to venture out into society day after day acutely aware that they live in a
world that is intolerant of the condition. Regardless of how many incontinent episodes they endure in any measured time period, they must manage the uncertainty of their disorder twenty-four hours a day, seven days a week, every day of their lives.

Irritable bowel syndrome impacts upon patients lives with differing degrees of severity. Symptoms wax and wane, can change over time and even appear contradictory. Painful and unpredictable, at its worst the condition is debilitating.

Table 1
Gastrointestinal functional and motility disorders

Motility Disorders (11):
- Esophagus
  - Achalasia
  - Diffuse esophageal spasm
  - Gastroesophageal Reflux Disease
- Stomach
  - Gastroparesis
  - Dumping Syndrome
- Small Intestine
  - Chronic intestinal pseudo obstruction
- Colon
  - Colonic Inertia
  - Functional rectosigmoid obstruction
  - Hirschsprung’s disease

Functional Disorders (6):
- Functional esophageal disorders
  - Functional heartburn
  - Functional chest pain of presumed esophageal origin
  - Functional dysphagia
  - Globus
- Functional gastroduodenal disorders
  - Functional dyspepsia
  - Postprandial distress syndrome
  - Epigastric pain syndrome
  - Belching disorders
    - Aerophagia
    - Unspecified excessive belching
  - Nausea and vomiting disorders
    - Chronic idiopathic nausea
    - Functional vomiting
    - Cyclic vomiting syndrome
- Rumination syndrome in adults
- Functional bowel disorders
  - Irritable bowel syndrome
  - Functional bloating
  - Functional constipation
  - Functional diarrhea
  - Unspecified functional bowel disorder
- Functional abdominal pain syndrome
- Functional gallbladder and Sphincter of Oddi (SO) disorders
  - Functional gallbladder disorder
  - Functional biliary SO disorder
  - Functional pancreatic SO disorder
- Functional anorectal disorders
  - Functional fecal incontinence
- Functional anorectal pain
  - Chronic proctalgia
  - Levator ani syndrome
  - Unspecified functional anorectal pain
  - Proctalgia fugax
- Functional defecation disorders
  - Dyssynergic defecation
  - Inadequate defecatory propulsion
- Functional disorders: neonates and toddlers
  - Infant regurgitation
  - Infant rumination syndrome
  - Cyclic vomiting syndrome
  - Infant colic
  - Functional diarrhea
  - Infant dyschezia
  - Functional constipation
- Functional disorders: children and adolescents
  - Vomiting and aerophagia
    - Adolescent rumination syndrome
    - Cyclic vomiting syndrome
    - Aerophagia
  - Abdominal pain-related functional gastrointestinal disorders
    - Functional dyspepsia
    - Irritable bowel syndrome
    - Abdominal migraine
    - Childhood functional abdominal pain
      - Childhood functional abdominal pain syndrome
  - Constipation and incontinence
    - Functional constipation
    - Nonretentive fecal incontinence
ADDRESSING PATIENT NEEDS

There are several underlying threads that connect those with a gastrointestinal functional or motility disorder. First, these are disorders that are uncomfortable and challenging to speak about. There is no socially acceptable way to discuss bowel habits or vomiting. The general public is neither well informed nor accurately informed about digestive health and disease (8). In response, individuals may develop strategies to cope such as avoidance, withdrawal, vigilance, and concealment. The degree to which these strategies are applied may vary from person to person, but each has its own associated personal cost that further adds to the social isolation or frustration felt by so many patients. Chronic illness impairs function in body, mind, and spirit; the demands imposed on individuals as they struggle to cope with their illness are never completely eliminated (3).

Symptoms, from the esophagus to the rectum, often are difficult for patients to describe. It may be hard for them to provide a clear picture of what they are experiencing. Furthermore, they may have lived so long with symptoms that they now accept them as “normal.” Many people will adapt to their symptoms, unaware of how many things they do each day, or have given up in their life, to accommodate their symptoms. A person may not realize this until asked, “How have your symptoms changed your life?”

Frequency of symptom episodes is a common measurement of severity. But while objective measurements are essential in making a diagnosis, alone they are not enough to measure the burden of illness for the patient. An experience related to me by a specialist treating a woman with fecal incontinence illustrates this point. The patient, when asked when she was last incontinent of stool, replied “Five years ago.” Why, if her episodes were so infrequent, was she seeking treatment for incontinence? After some probing, the patient disclosed that she had altered her life to the point where she rarely left her home and the close proximity of the bathroom. Thus, she avoided being incontinent. She had surrendered her quality of life to accommodate her symptoms. Within the context of her lived experiences, the true level of severity was revealed.

The importance of patient-physician communication cannot be overstated. It is critical that a physician inquire about how symptoms are affecting the patient’s life. Without exploring that aspect of the disorder, the true extent of the symptom complex cannot be understood.

Furthermore, patients are untrained observers. They tend to give inconsistent accounts of their symptom experience and bodily functions (7). They do not necessarily know how or what to talk about with their physician. The words they choose to describe symptoms may hold a different meaning for them than they do for the physician. For example, a patient may report diarrhea when in reality they are incontinent. They may have no idea that fecal incontinence is a medical condition. A few extra moments spent by the physician exploring the meaning of terms used by the patient can be a significant part of a satisfactory clinical outcome.

Second, patients often feel that their symptoms are not being taken seriously. At the extreme, this can be due to misdiagnosis. A patient discharged from an emergency room, for example, without a proper diagnosis because the personnel are ill informed about the symptoms of many of these disorders is particularly disheartening. More likely, a patient is left with many unanswered questions after being given a diagnosis with minimal explanation. To the patient, unsatisfactory explanations may be experienced as a denial of the legitimacy of their reported symptoms, an implication that negative test results mean an absence of cause, and a lack of understanding or belief in their suffering (9). Yet these are reoccurring themes for many patients with GI functional and motility disorders. It speaks to a larger issue of medical education and how best to serve patients in the future.

Third, patients want to feel connected with their care givers. The therapeutic doctor-patient partnership is critical for success. For those with severe motility disorders the solution may mean an invasive life-altering surgical treatment. I speak with thousands of patients. It is not uncommon for patients to find themselves being told, in a matter of fact way, that they will need some form of surgery or invasive procedure with little explanation from the physician. They are left stunned and confused, and leave the physician’s office anxious and fearful of what lies ahead for them.

A therapeutic partnership involves understanding by the physician of the patient’s illness experience, as well as educating the patient (10). Patients seeking
help need to feel that their care is truly a partnership with an empathetic physician who acknowledges the medical basis of their symptoms as well as their affect on daily living. For the patient with a chronic disorder of GI motility or function, an empowering doctor-patient relationship can be remarkably affirming and valuable (9). Empowerment provides the patient with a framework in which to understand their symptoms, remove self-doubt or blame, and identify factors that may contribute to symptoms which the patient can influence or control within the context of their own experiences. The physician and patient thus become allies in the management of the condition.

SUMMARY

Physicians generally understand illness in the context of signs and symptoms that point to a diagnosis. Patients, on the other hand, understand illness in the context of their daily living; experiences that give expression to their individual being and that extend outward to family, friends, employers, and others. These experiences do not point to a diagnosis, but they must be taken into account to understand the degree of severity of the illness and the best approach to treatment for individual patients. Successful management of the functional and motility disorders depends on both the physician and patient working together.

Physicians in multiple disciplines need better training and awareness of the GI functional and motility disorders. Patients benefit from a swift and confident diagnosis, reassurance, and education. Physicians need to understand the patient’s symptoms within the context of their daily lived experiences. Communicating effectively together, the patient and physician can work in partnership to formulate a management or treatment plan that will best affect a positive outcome.

References