



International Foundation for Functional Gastrointestinal Disorders

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Overview

Functional gastrointestinal (GI) disorders significantly impact health related quality of life, or “HRQOL,” as it’s called in medical literature. This impact is obvious to anyone who has a functional gastrointestinal GI disorder, or to any provider who cares for people with these disorders. For example, studies have shown that some patients with irritable bowel syndrome (IBS), the most common functional GI disorder, have a HRQOL that is significantly worse than patients with diabetes or even patients with severe kidney disease requiring dialysis. In light of this finding, the American College of Gastroenterology, among other societies, suggest that healthcare providers carefully monitor the HRQOL of their patients in order to help guide treatment decisions.

However, this suggestion assumes that clinicians are capable of assessing HRQOL in their patients with functional GI disorders in the first place. To the contrary, some studies indicate that many (but by no means all) providers do a poor job of eliciting their patients’ agendas, addressing their patients’ fears and concerns, and accurately assessing the impact of functional GI disorder symptoms on their overall health status. Patients, in turn, indicate that this shortcoming leads them to become dissatisfied with their care, largely because they feel like their providers are not really listening, or are asking all the wrong questions. In light of this observed provider-patient disconnect, it is critical for physicians and patients with functional GI disorders to:

- (1) Understand the concept of HRQOL,
- (2) Recognize why knowing about HRQOL is important in clinical practice,
- (3) Understand how HRQOL is measured,
- (4) Know how HRQOL in functional GI disorders compares to HRQOL in other medical disorders, and
- (5) Learn how to estimate HRQOL in everyday clinical practice to help direct care.

The purpose of this article is to address each of these 5 clinically important topics.

Understanding HRQOL

Although interest in HRQOL has only recently gained a central focus in clinical research and everyday clinical care, the notion of HRQOL is not recent. Over 50 years ago the World Health Organization defined health in its charter constitution as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” This landmark definition broke from the narrow view that health is simply the absence of disease or pathology, and instead offered a new view – namely that health is a concept that covers several areas of well-being simultaneously. The modern concept of HRQOL is a direct descendent of the World Health Organization definition in that HRQOL is now thought to encompass three fundamental areas: (1) physical health, (2) psychological health, and (3) social health. A balanced measure of HRQOL can capture all of these areas and summarize them in a single number (see Measuring HRQOL, below).

Importance of HRQOL in Clinical Practice

There are at least four reasons why measuring HRQOL is relevant in clinical practice. Each is important toward improving patient outcomes.

The effect of symptoms – First, any experienced health care provider knows that the things doctors measure do not always correspond with how the patient is actually *feeling*. For example, in diabetes, doctors usually measure the “hemoglobin A1C” levels, which is a way of monitoring blood sugar. This number is often used to help make treatment decisions, like how aggressively to treat the diabetes, or whether to change to a new medication. But the problem is that some patients may have great hemoglobin A1C numbers, but still feel listless or depressed despite their favorable lab values. In contrast, others with unfavorable levels may nonetheless feel upbeat and vigorous. Similarly, an IBS patient with 3 daily bowel movements may share the same problems at work (like difficulty getting the job done because of the constant bother of symptoms) as another IBS patient with 6 daily bowel movements. So in both examples the traditional outcome measured by healthcare providers (e.g., hemoglobin A1C levels, bowel movement frequency) fails to capture other aspects of health. Unfortunately, many doctors are trained to consider just the usual outcomes, but might not think more broadly about how the disease is affecting the patients from a professional, psychological, or social standpoint as well. In other words, just asking about bowel movement frequency, bloating, or stomach pain, although important, is not enough to fully understand how disease is affecting a patient. It’s only part of the picture.

The outcome values – A second reason to measure HRQOL is that not only do traditional biological outcomes miss key aspects of health, but also patients rarely value these outcomes in the same manner as providers. For example, patients with high blood pressure often fail to share the same enthusiasm as their providers in achieving specific blood pressure goals, but are quick to comply with therapy when their blood pressure leads to headaches or dizziness. Similarly, some patients with chronic constipation could care less if their therapy allows them to achieve an increase of 1 or 2 more bowel movements per day, but care greatly if the improvement also allows them to eat dinner without worrying about all the consequences of their food selection. Measuring HRQOL directly acknowledges that patients often value different outcomes than their providers.

The burden on society – Third, HRQOL is a key component to understanding the true burden of any disease. Traditional measures of disease burden include the prevalence of a disease (i.e., “how many people have this disease”), direct and indirect expenditures of a disease (i.e., “how much does this disease cost health care systems and society at large”), and the worker productivity decrements related to a disease (i.e., “how does this disease affect people at work”). However, in order to fully appreciate the true burden of a disease, it’s also important to appreciate the HRQOL decrement engendered by the disease. The notion of “weighting” diseases not only by their cost and prevalence but also by their HRQOL reduction has an innate sense of fairness and is a fundamental principle of health

economics. The last part is important, because it suggests that societies and health providers are willing to spend more money to cure diseases that severely impact HRQOL than diseases that only moderately impact HRQOL. For this reason alone it's critical to carefully understand the HRQOL reduction of various diseases, because that information may have policy implication when it comes to setting up a healthcare budget.

The burden on the patient – Fourth, HRQOL is especially important in diseases that are marked by morbidity or illness, but not mortality or death. If we only emphasized the care of diseases that kill people, then most of the world would be without treatment, since, thankfully, many diseases do not cause death. Fortunately, the functional GI disorders, like IBS, are not mortal diseases. But that does *not* mean that they are not important, or that they are just a “nuisance” that should be blown off. To the contrary, as we'll see below, functional GI disorders can severely affect patients HRQOL. So without measuring HRQOL, it would be unfair just to say that these disorders are nothing more than a “nuisance” because they are not mortal diseases.

This is distinguished from diseases where HRQOL really has no important role, such as in patients with an acute life-threatening disease. These are conditions where rapid treatment must be rendered, regardless of how the HRQOL is affected at the moment of illness. For example, nobody sits around measuring HRQOL in someone with an active ulcer bleed or a gallstone obstruction. In contrast, HRQOL has large clinical relevance in patients with chronic disorders like migraine headache, fibromyalgia, or depression. The functional GI disorders share characteristics with these latter conditions, since they uniformly affect quality but not quantity of life. Thus, failing to acknowledge HRQOL in chronic conditions like functional GI disorders is a dangerous approach, because it tends to minimize the importance of these conditions.

Measuring HRQOL

HRQOL is usually measured with patient questionnaires, which doctors or researcher call “instruments.” HRQOL instruments collect data across several areas of health, including physical, psychological, and social functioning. HRQOL instruments are generally classified as either “generic” or “disease-targeted.” Generic instruments are questionnaires developed to measure HRQOL across many different conditions. In contrast, disease-targeted instruments are questionnaires designed to target one or more specific related conditions. Examples of generic instruments include the Short Form-36 Health Survey (SF-36) and the Sickness Impact Profile (SIP). For example, the SF-36 has been used to measure health in over 100 conditions ranging from hepatitis C to colon cancer to IBS. As with other balanced HRQOL measures, the SF-36 measures health across several areas, including mental, physical, and social health. The instrument includes 36 items that are organized into 8 discrete scales, such as “physical functioning,” “vitality,” or “bodily pain.” Each scale can be scored from 0 to 100, with higher scores indicating a better HRQOL. So this way, any patients can be assigned a set of actual numbers to measure their HRQOL, a bit like a vital sign. The SF-36 is particularly useful in functional GI disorders since it captures areas that are deemed important by patients with these disorders, including bodily pain, energy/fatigue, and social functioning. In particular, the SF-36 contains several items pertaining to “vital exhaustion,” including the degree of feeling “full of life,” feeling “worn out,” and feeling “tired” (see below for more on this). Because vital exhaustion is thought to be a critical component of the biology of disorders like IBS, the SF-36 is an example of an appropriate

generic instrument to use in measuring HRQOL in functional GI disorders.

There have been several disease-targeted instruments developed to measure HRQOL in functional GI disorders. These instruments vary in content, length, and degree of data supporting their validity for use in clinical practice. Of the multiple disease-targeted instruments in functional GI disorders, the Irritable Bowel Syndrome Quality of Life (IBS-QOL) questionnaire, originally developed by Patrick and Drossman, has the most extensive data supporting its validity. In particular, the IBS-QOL can be used to measure patient HRQOL over time, and the change in IBS-QOL scores often correlate with other important features of health. So that way, providers might use the IBS-QOL to follow how their patients are doing from visit to visit, rather than just relying on the usual vital signs such as temperature, heart and respiratory rate, or blood pressure. In addition, the IBS-QOL has been used in clinical treatment trials to help determine whether specific therapies improve HRQOL. This type of information is critical, because treatments that improve only one or two symptoms, although potentially useful, might not be useful if they can't actually make patients' HRQOL better at the same time. So having a measure like the IBS-QOL is extremely useful to help test new treatments as they arise.

Along these lines, it should be noted that HRQOL is a little different from “severity.” Disease severity is a different concept from disease HRQOL, and this distinction is currently undergoing research. One thing is clear, however: a good measure of HRQOL should also correspond with severity. In other words, as a patient's “severity” gets worse, their HRQOL should get worse as well and vice versa. Future research will aim to better understand what patients mean by “severity,” and will try to create instruments that can capture the idea of severity, in addition to measuring HRQOL.

Comparing HRQOL in Functional GI Disorders to Other Medical Disorders

Several studies have compared HRQOL in patients with functional GI disorders versus either healthy patients or patients with non-functional GI disorder medical disorders. Most of the data have been collected in patients with IBS. For example, a review by Wells et al. demonstrated that patients with IBS scored consistently lower on all 8 sub-scales of the SF-36 compared to a “normal” non-IBS group. Another study found that patients with IBS have the same physical HRQOL on the SF-36 as patients with diabetes, and a lower physical HRQOL compared with patients with depression or acid reflux disease. Perhaps more surprisingly, mental HRQOL scores on the SF-36 were lower in IBS than in chronic kidney disease – a condition marked by considerable physical and mental disability. Thus, it is unquestionable that many patients with functional GI disorders have a very low HRQOL, and thus failing to recognize this problem could undermine the physician-patient relationship and lead to dissatisfaction with care.

Estimating HRQOL in Clinical Practice

Despite all these academic and practical reasons to measure HRQOL, most providers don't do it. There are several reasons why. First, many providers find it burdensome. In order to accurately measure HRQOL, providers must perform a thorough evaluation of multiple physical, psychological, and social areas of health. This takes time. Validated HRQOL instruments like the SF-36 or IBS-QOL are designed to capture information from each of these areas of health in order to establish a broad and balanced portrait of a patient's unique HRQOL. However, these

measures are primarily designed for research purposes, and clinicians rarely have the time or inclination to assess HRQOL with this degree of detail. Second, most healthcare providers, including gastroenterologists, have not received training in how to perform a complete “biopsychosocial” evaluation, in which they take the time not only to ask about individual physical symptoms (like bloating, diarrhea, constipation, pain, etc.), but also take the time to understand whether and how the disease causes emotional or social distress. Indeed, studies have shown that this type of history-taking is rarely performed. Third, many providers think that knowing HRQOL is clinically “inactionable.” In other words, they’re not sure how the information can help them take care of their patients, as opposed to knowing individual symptoms, like bloating, diarrhea, or pain.

In light of this reality it is important to arm providers with a concise list of questions that can help them rapidly understand their patients HRQOL. Moreover, it’s important to show how knowing this information can help drive treatment decisions by allowing providers to gain better insight into their patients’ overall health.

Towards that end, several studies have identified factors that can help providers understand their patients HRQOL in functional GI disorders. The most consistent predictor of HRQOL is the *severity* of the predominant symptom. Data from several studies indicate that HRQOL decreases in lockstep with increasing severity, as previously mentioned. So it’s important not only to identify the predominant symptom of patients with functional GI disorders, but also to understand the severity of the predominant symptom. For example, a doctor might ask, “What is the main symptom that is bothering you?” The answer can help understand what treatments to recommend, but does not necessarily get at HRQOL. But the following additional question can help with understanding HRQOL, “How *bad* is that symptom; for example, is it ‘mild,’ ‘moderate,’ or ‘severe?’” We’ll come back to an example of one of these questions below.

There are some other questions doctors can ask. For example, we have found that the duration of symptom flares (more than 24 hours versus less than 24 hours) is an important predictor of HRQOL. In addition, HRQOL is highly associated with patients’ overall mood, energy level, and whether or not they are anxious. Perhaps most importantly, we have seen that HRQOL is highly related to something called “vital exhaustion,” which includes symptoms like “tiring easily,” “feeling low in energy,” and having a “low sexual drive.” In contrast, we have found that HRQOL is actually *not* determined by specific gastrointestinal symptoms (e.g., diarrhea, constipation, bloating, dyspepsia), degree of previous gastrointestinal evaluation (e.g., previous flexible sigmoidoscopy or colonoscopy), or any demographic characteristics (e.g., gender, age, marital status).

Taken together, these findings suggest that rather than focusing exclusively on individual bowel symptoms such as stool frequency, stool characteristics, or sub-type of IBS, and potentially misleading clinical factors such as age or disease duration, providers might be better served to focus their brief patient encounter on gauging global/overall symptom severity, addressing anxiety, and identifying and eliminating factors contributing to vital exhaustion in IBS. This may occur through teaching management and relaxation skills, developing a greater sense of self-efficacy by encouraging control over IBS symptoms, promoting appropriate lifestyle modifications (i.e.,

diet, exercise, quitting smoking), and allowing patients to recognize their own limitations.

But none of this will happen if providers fail to measure overall HRQOL. So we have recently tried to help in this cause by creating a very short questionnaire that can be used in everyday clinical practice. The idea is that the questionnaire can be administered in the waiting room, and a nurse can quickly score the results and put it on the doctor’s intake sheet like a “vital sign.” This type of information, in fact, may be much more valuable in functional GI disorders than the typical vital signs.

B.E.S.T. Questionnaire

Based on previous research, including interviews with patients, experts, and our own database studies, we created a questionnaire with only 4 questions. Most patients fill out the questionnaire in less than 1 minute, and a nurse can score it in under 30 seconds using a simple algorithm. The score ranges between 0 and 100, where 100 is the “worst” score, and 0 is the “best” score. In fact, we call this questionnaire the “B.E.S.T.” score, because the 4 questions stand for B.E.S.T. (not necessarily because this is the “best” way to measure HRQOL!):

- (1) How **B**ad are your bowel symptoms?
- (2) Can you still **E**njoy the things you used to enjoy?
- (3) Do you feel like your bowel symptoms mean there’s something **S**eriously wrong?
- (4) Do your bowel symptoms make you feel **T**ense?

We found that the score on the B.E.S.T. instrument was an excellent “stand-in” for the IBS-QOL, suggesting that the instrument could give a quick snap-shot of overall HRQOL. Future research will aim to better understand how this score works over multiple follow-up visits, and to better understand how having this information can improve not only provider decision-making, but also the overall patient-provider relationship.

Ultimately, the whole purpose of having questionnaires like this is to improve patient care by bridging the gap between providers and their patients. If doctors can learn what questions to ask, and if patients can provide the right information, then this exchange might be more valuable than any vital sign or individual symptoms could ever provide. That’s the motivation for measuring HRQOL in functional GI disorders.

Further Reading

Spiegel BMR, Naliboff B, Mayer E, Bolus R, Chang L. Development and initial validation of a concise point-of-care IBS severity index: the 4-item “BEST” questionnaire. *Gastroenterology* 2005;130:S1040.

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