



## **IBS and Quality of Life**

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Health problems are not limited to medical symptoms. Two individuals with the same medical diagnosis and identical or equally severe symptoms can have a health problem of a very different magnitude associated with their medical condition. This is because the impact of a medical condition on a person's life can vary greatly from one individual to the next. How much of a burden illness is on each patient's life depends on several factors. It is becoming widely recognized that in order to understand the burden of illness on a patient and find the most effective treatment for medical conditions, one must take into account changes in quality of life that occur in association with a person's illness and recovery. Health-related quality of life (HRQOL) has become an important topic in medical research.

The impact of irritable bowel syndrome (IBS) and other functional gastrointestinal disorders (FGID) on the quality of life of patients has often been underestimated by physicians and researchers, because people with these disorders do not face direct threat to their life and are not disabled in any obvious ways. For the same reasons, friends and family members of individuals with functional GI disorders may underestimate the impact these disorders can have on a person. But, in fact, research has now shown that these disorders often have a very substantial impact on the patients' quality of life, which is important for anybody who interacts with people with this diagnosis.

## **THREE BASIC APPROACHES TO MEASURING THE HRQOL IMPACT OF MEDICAL CONDITIONS**

Various methods have been devised to measure quality of life among medical patients. In 1995, it was estimated that more than 300 disease-specific questionnaires and more than 70 general surveys (applicable to many different health conditions) had been used for this purpose in various studies<sup>(1)</sup>. There are essentially three methods for measuring quality of life. The simplest is the so-called global approach, where people are directly asked to rate their quality of life, for example, on a 10 point scale from "very poor" to "excellent". The obvious problem with this kind of method, although it has been used often, is that individual patients may take very different factors into account in deciding on a rating and the ratings obtained may not be comparable from person to person.

A second approach, which has been the most common one in IBS research until recently, is to use questionnaires that are designed to evaluate the general functional status of the person. Two such widely used questionnaires are

the Sickness Impact Profile (SIP) (2), which measures many aspects of a person's daily functioning, and the Medical Outcomes

Study Short Form 36 (SF-36) (3), which inquires about factors such as the person's activity level, severity of pain, general health, and social, physical and mental functioning. The advantage of such general measures is that they can be applied to a wide variety of diseases and disorders, and make it possible to compare statistically how much different medical conditions affect quality of life.

However, a problem with using general questionnaires is that they do not include questions about specific ways in which particular disorders can impact life. They may, therefore, miss unique and important aspects of how a particular disorder affects a person's well-being and functioning. For example, difficulty with being far away from a restroom may significantly impair the quality of life of some people with IBS but not affect people with many other disorders. For this reason, it is often necessary to use disease-specific questionnaires to fully evaluate the quality-of-life impact of a particular health condition. These questionnaires are made for the evaluation of one medical condition only, and they are designed to cover as many of the different ways that the condition affects a person's life as possible.

Another important consideration in measuring HRQOL is what aspects of a person's experience and life condition should be included. Due to the multitude of methods that are in use, the content can vary quite a bit. Some questionnaires, for example, measure the severity of physical symptoms and wrap this into the quality-of-life calculation.

Doing so, however, might overlook the possibility that some people can have severe symptoms without much impact on their life. Also, some approaches primarily measure objective functioning, such as the ability to work and engage in social and relationship activities, but do not include emotional factors that may make life miserable, such as worry or feeling of loss or isolation due to having the disorder.

Although it is a matter of opinion exactly what should be measured to determine overall HRQOL, most researchers agree that it is a broad-ranging phenomenon that should encompass emotional well-being, the ability to be physically active, and the ability to function normally in personal and social activities and close relationships. Many investigators now choose to include more than one quality-of-life questionnaire in their research studies, typically both a general and a disease-specific one, in order to maximize their detection of important HRQOL changes and avoid missing something important.

## **NEW AND BETTER WAYS TO STUDY QUALITY OF LIFE IN IBS**

Quality of life research has reached prominence as a research topic in the study of IBS only within the last five years. Despite this late start compared to research on some other medical conditions, it has now become a topic of great interest to many who study IBS. This heightened attention to HRQOL in the disorder is reflected in the development of several questionnaires to measure quality of life specifically in IBS. One of the first of these was the IBS-QOL (Irritable Bowel Syndrome-Quality of Life) questionnaire (4,5).

Other questionnaires that also have been published and scientifically validated (tested to ensure they are reliable and truly measure what they are supposed to measure) include the similarly named Irritable Bowel Syndrome Quality of Life Questionnaire (IBSQOL)<sup>(6)</sup>, the Irritable Bowel Syndrome Questionnaire (IBSQ), and the IBS-36<sup>(7)</sup>. The Functional Digestive Disorders Quality of Life Questionnaire (FDDQL)<sup>(8)</sup> is designed to be used both for IBS and Functional Dyspepsia. As a result of the burst of activity in this area, there

are now several excellent methods available that are custom-tailored to measuring the impact of IBS on individuals who have the disorder.

## **WHAT DETERMINES HOW MUCH IBS AFFECTS QUALITY OF LIFE?**

Research studies are beginning to identify some of the factors that influence quality of life in IBS. Some of the findings to date are:

- The frequency and severity of symptoms affects HRQOL in IBS. The more severe the IBS symptoms are, and especially abdominal pain, the poorer the overall quality of life tends to be<sup>(9,10)</sup>. Patients with mild IBS may not have worse overall quality of life than the general population<sup>(11)</sup>.
- Having other medical conditions along with IBS, such as headaches, back pain or fibromyalgia, worsens quality of life measurably. Sperber and his co-investigators<sup>(12)</sup> found that HRQOL is significantly worse for patients who have both IBS and fibromyalgia, compared to those who only have IBS. Recent research at our Center suggests that the negative effect of coexisting conditions becomes especially pronounced when patients have more than one other condition in addition to IBS<sup>(9)</sup>.
- Presence of multiple non-gastrointestinal physical symptoms is associated with worse quality of life. Some individuals with IBS experience a large number of physical symptoms that have no apparent direct relationship with the central symptoms of IBS. These extra symptoms seem to be associated with worse quality of life when they are particularly numerous<sup>(9,13)</sup>.
- One study, by Hahn, Yan and Strassels<sup>(14)</sup>, indicates that IBS may impact the lives of people to different degrees in different countries. These researchers found that IBS in patients in England had a more severe impact on their quality of life, measured both on the IBSQOL and SF-36 questionnaires, compared to patients in the U.S.
- Depression worsens quality of life in IBS, and this effect seems to be independent of the severity of IBS symptoms<sup>(13)</sup>.
- Research is also beginning to show that some factors that one might think would influence how much impact IBS has on quality of life make no difference. For example, bowel symptom pattern does not appear to play a role in this regard: IBS patients with constipation-predominant, diarrhea-predominant and alternating bowel activity patterns suffer similar degrees of quality-of-life impairment<sup>(11)</sup>. Gender also appears to make little difference. Men and women suffer similar overall HRQOL impairment due to IBS<sup>(15)</sup>.

## **IMPAIRMENT IN QUALITY OF LIFE IN IBS COMPARED TO OTHER MEDICAL CONDITIONS**

Several studies have made side-by-side comparisons of the quality-of-life status of individuals with IBS and other disorders. Although the findings are mixed, they have surprised some investigators, because they tend to show that IBS patients suffer quality of life impairment that is equal or greater than seen in some serious and even lifethreatening chronic medical conditions:

- Frank and colleagues published a paper<sup>(16)</sup> reporting that, on the average, IBS patients have worse quality of life than individuals with asthma, gastroesophageal reflux disease (GERD) or migraine headaches, but have better quality of life than patients with rheumatoid arthritis and panic disorder.
- Gralnek and colleagues found<sup>(17)</sup> that IBS patients had worse quality of life than individuals with GERD, but better than patients with clinical depression. They also reported that IBS patients fare worse in several aspects of quality of life (measured by the SF-36) compared to patients with diabetes mellitus and endstage renal disease, both of which are life-threatening conditions.

- A review by Wells, Hahn and Whorwell (18) indicates that impairment of many aspects of life in IBS -- such as energy level, social functioning and general health is similar to that of clinical depression (except for mental functioning, which is better in IBS), and that IBS patients have worse overall quality of life than patients with Type II diabetes.

## **EFFECTS OF IBS TREATMENTS ON QUALITY OF LIFE**

Most researchers studying treatments for IBS now assess the change in quality of life associated with treatment for IBS in addition to quantifying changes in bowel symptoms.

Doing this provides a better understanding of the difference IBS treatments really make in ways that are important to the patient.

Studies indicate that effective treatments of IBS, both drugs and psychological therapies, neutralize the quality of life impairment due to IBS (5,11). One of the most promising discoveries is that lasting quality-of-life improvement, remaining long after the treatment ends, can be achieved from psychological treatments for IBS. Quality-of-life improvement after hypnosis treatment, for example, is still evident years later (19,20).

Creed et al (21) recently found in a large study that IBS patients who were treated with interpersonal psychotherapy enjoyed lasting enhancement in quality of life even though their IBS symptoms were no better than before. This observation underscores the notion that impairment in quality of life is somewhat independent from symptom severity and is not an inevitable consequence of symptoms.

## **THE FUTURE OF QUALITY-OF-LIFE RESEARCH IN IBS**

Much work remains to be done to clarify what factors cause the substantial impairment in HRQOL seen in IBS, and to identify ways to minimize this impact on patient lives. For example, personality variability and the different strategies individuals use to cope with the disorder are likely to partly determine the amount of quality-of-life impairment they suffer, but little is known about these factors at the present time.

Despite these and other unanswered questions, the recent focus on HRQOL has provided progress in the field, in part because it has made the research more patient-centered.

Impaired quality of life is now understood to be a large component of the health problem of IBS. Future efforts to find better treatments for IBS will aim not only to improve bowel symptoms, but also to help patients achieve a quality of life equal to those without the disorder.

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