

# Patient-Physician Relationship in Irritable Bowel Syndrome: Review on Empathy and Stigma

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## ABSTRACT

Irritable bowel syndrome (IBS) lacks a clear understanding of the disease's pathogenesis and effective treatments thus producing frustration among providers and patients, leading to the stigmatization of the disease and the patients with the syndrome. A literature search was performed to make a hermeneutical review on empathic patient-provider communication and IBS. The relationship is defined by partners being dependent on one another in the pursuit of obtaining good outcomes. It is a unique interaction depending not only on the individual qualities of each partner but also on the specific patterns of the patient-physician synergy. Empathy is crucial for any relationship. It helps to recognize the other as the other of myself, a person like me. Meanwhile, stigmatization results from identifying and labelling human differences and stereotyping persons who are linked to undesirable characteristics. IBS is at high risk of stigmatization in various contexts and settings including health care, causing patients and physicians misconceptions and distress, which in turn leads to the worsening of the disease in patients and burnout in physicians. Narrative-based medicine helps create a holistic perspective of a patient's problems and health, thus providing a tool for an empathic doctor-patient relationship that fosters mutual understanding and helps patients with IBS make sense of symptoms, increases their ability to manage their IBS in a psychologically flexible manner, subsequently helping them maintain their quality of life.

**Key words:** patient-physician relationship – empathy – stigma – irritable bowel syndrome.

**Abbreviations:** IBS: irritable bowel syndrome.

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## INTRODUCTION

Irritable bowel syndrome (IBS) has a heterogenic and multifactorial pathogenesis involving complex interactions between genetic, neuroendocrine, immunological, psychological, dietary, and environmental factors [1-3]. It is highly prevalent, as more than 40% of persons worldwide have functional gastrointestinal disorders affecting the quality of life and health care use [4-6]. It is associated with chronic abdominal pain, altered bowel habits, psychiatric comorbidities, such as anxiety and depression, and no “structural findings”

suggesting the functional origin of the disease [7-9]. At this point IBS is prone to be considered a less legitimate unexplained psychiatric disorder [1]. This common misunderstanding produces frustration among providers, leading to the stigmatization of the disease and the patients with the syndrome.

A comprehensive model of brain-gut-microbiome interactions has emerged in the past decade aiming to explain the nature of IBS as well as offer a basis for novel treatment options targeting microbiota, brain function, and other possible pathogenetic mechanisms [10-12]. Still there is not yet a breakthrough in this process, and gastroenterologists still encounter a large workload of gut-brain axis diseases. Functional gastrointestinal diseases account for about 30% of ambulatory care gastrointestinal consultations, especially because many consult repeatedly [13].

The relationship between patient and physician is thought to have a relevant role in treating IBS patients. Interventions targeting patient-provider interactions improve population health, patient experience, physician experience, and costs

[1]. It is an everyday practice of each physician, yet the complexity of the concept of relationship and various inside processes are not easy to describe and review in the terms of scientific methods. Some of the instruments are developed for use in medical health care disciplines, frequently based on dimensions of trust and empathy, much more are those aiming for therapeutic alliance in psychotherapy [14].

Since Darwin's time empirical studies have confirmed that the human ability to distinguish the internal affects of others, also known as empathy, assists in adaptive processes, such as conflict resolution, accommodative behavior, psychological adjustment, and communication effectiveness [15]. It is also known that not only the emotional ability to feel others, but effortful, careful systematic thinking generates even more accurate impressions than spontaneous, category-based conclusions [15, 16]. This leads to the hypothesis that empathy might be acquired.

The authors of this article searched for the available literature from various databases (PubMed, Willey online library, Taylor, and Francis online, Cochrane library) to make a hermeneutical review on empathy as a crucial part of the patient-physician relationship in IBS. Believing that this can lead to better clinical practice by nurturing awareness of the importance of empathy in the interaction with patients.

## PATIENT-PHYSICIAN RELATIONSHIP

The definition of relationship according to Finkel et al. [17] is that partners are dependent on one another in the pursuit of obtaining good outcomes and facilitating the aspiration of their most important needs and goals. This can be used to understand the interaction between patient and physician when they meet in the situation of a disease, fall into dependence and both seek a suitable outcome. The principle of uniqueness, meaning that relationship outcomes depend not only on the specific qualities of each partner but also on the unique patterns of the patient-physician synergy [17, 18]. The merging of two partners into a single psychological entity - the integration principle, and the way relationships change over time - the trajectory principle - are the main construct of every relationship [17]. Thus, it is not just the "style" of a doctor that determines the outcome of the interaction. The manner of a patient and the interaction of both must be considered as well [19].

Four steps of the doctor-patient relationship are described by Benedetti [18]. The first is "feeling sick". This is a starting point that triggers a motivated behavior aimed to suppress discomfort - the second step "seek relief". The third step is when the patient "meets the therapist". It is a special and unique social interaction in which the physician is expected to suppress discomfort. At this point expectations, beliefs, trust, and hope are key elements in the patient, whereas empathic and compassionate behavior represents the doctor [18, 19]. The fourth step, when the patient "receives the therapy", is of at most importance. The very act of administering a treatment is a psychological and social event that is sometimes capable of inhibiting a symptom such as pain, even though the treatment is fake, as it is known in the placebo studies [18, 20].

In 1927 Peabody [21] talked about the broader sense of medicine that includes the relationship of the physician with his

patient. He defined it as an art, based on the increasing extent of the medical science, but comprising much that still remains outside the realms of any science [21]. Later, the importance of the doctor-patient relationship was described by Balint [22] in 1955 as "the doctor as a drug." Special attention to this interaction is paid in the psychotherapy process. It is known that the quality of the treatment relationship and alliance is more important for patients' outcomes than the specific techniques applied [23-25].

Because of the heterogeneity of the phenomenon, it is not easy to apply a quantitative method for investigating human experience and behavior, most studies evaluating patient-physician relationship are of a qualitative nature [26-28]. To answer the question, quantitative methodologies use as many as 19 different instruments to study these relationships, along with qualitative studies examining illustrative case histories, physician or patient narratives, direct observation of doctor-patient interactions (audio or video recorded for later analysis), and semi-structured focus group discussions [14]. The situation reflects the emerging nature of this area of clinical practice though in psychotherapy it has been valued and studied from the beginning, starting with Freud [28, 29].

The relationship with a physician could be conceived as different from the relationship with a psychotherapist, as the goals and methods vary. However, the instruments originally developed in psychotherapy have also been used and validated in medical healthcare fields. Thus, the doctor-patient relationship must have commonalities with the therapist-patient relationship [14]. As reviewed by Ridd et al. [30] depth of patient-doctor relationship involves four main elements: knowledge, trust, loyalty, and regard. All these dimensions fit well within both concepts of interrelation [14].

In IBS the physician-patient relationship has been recognized as having an important therapeutic likewise as in all chronic diseases, regardless of any pharmacological treatment [31]. But the communication between the doctor and the client is frequently frustrating for both sides. Jayaraman et al. [32] suggest that the reasons for the breakdown in communication between IBS patients and their physicians are related to the diagnostic process, possession of the diagnosis, and treatment.

The advised proactive diagnostic approach based on history and physical examination alone (Rome criteria) is not accepted by many physicians and patients [32-34]. Additional tests for exclusion of the organic disease lead to the frustration of uncertainty because there is no test to confirm the IBS [32, 35]. There is often a discrepancy between the patient's beliefs about her illness and the burden of symptoms and the physicians' understanding, thus the diagnosis of IBS is rarely acknowledged [13]. Patients' and specialists' views on the best treatment options diverge in part because of a lack of effective treatments [13, 31, 36]. The qualitative studies of patient perspective on IBS reveal the incongruity of what is expected and what is received: "Don't just write me a prescription, but really get to know my problems and help out in natural ways." or "The first thing on the guidelines for treating IBS should be to acknowledge the patient and their symptoms" [37]. Such miscommunication can lead to disappointment, devaluation, and mistrust regarding patient-physician as well as physician-patient vectors.

## EMPATHY AND RELATIONSHIP

The concept of empathy is manifold. It can be characterized in the categories of philosophy, theology, developmental psychology, social and personality psychology, ethology, and neuroscience [38]. But despite the disagreements that arise from the different languages, the empirical data indicates empathy as the capacity of an observer to sense the emotions and feelings of another human being [38].

Empathy is a multidimensional process, involving at least two major components – emotional and cognitive. Emotional empathy is so-called experience sharing [39]. It is the ability to respond with an emotion similar to that of another person, even though the event that caused the emotion did not directly happen to us. It may include not only joyful feelings but sometimes personal distress, discomfort, and anxiety due to others [16, 39, 40].

Cognitive empathy on the other hand is the ability to understand and consider another individual's mental state and affects not necessarily feeling the same [39]. The accuracy of this process can be achieved by reading and interpreting multiple situational, verbal, and non-verbal cues or by asking participants to self-report regarding their abilities to understand emotions [40, 41].

Social empathy helps to recognize the other as the other of myself, a person like me with a subjective perspective, values, rights, and commitments thus enabling and maintaining bonds in everyday life [16, 42]. Clinical empathy involves an ability to understand the patient's situation, perspective, feelings, and attached meanings, to communicate that understanding and check its accuracy; as well as act on that understanding with the patient in a helpful way [25]. Likewise, Barrett-Lennard [43] described a model of clinical empathy as the 'empathy cycle'. It comprises the inner process of empathetic listening to another; the attempt to communicate an empathetic understanding of the other person's experience; and the client's actual perception of this communication [43].

There is a good correlation between empathy and the physician-patient relationship suggesting it to be of unquestionable importance in clinical practice [44-47]. Various studies have shown improved patient satisfaction and strengthened patient enablement, lowered patients' anxiety and distress, and significantly better clinical outcomes [44].

It is also claimed that physicians are not only more effective healers but enjoy more professional satisfaction when they practice with empathy [45]. Roter et al. [48] found that doctors with an engaged, psychosocially oriented communication style experience burnout less frequently than others [48]. Sattar et al. [49] reviewed that empathic concern was correlated with lower burnout scores, yet only in the situations where empathy was associated with compassionate but not distressful feelings. These findings address the complexity of empathy. We hypothesize the association to be associated with the differences in emotional and cognitive empathy. Yet to our knowledge, there are no such studies that investigate the interaction of two components of empathy in the process of the patient-physician relationship.

The placebo effect is one of the most known concepts associated with empathic patient-physician communication.

The mechanism of action of the placebo effect involves what is known as the empathy brain [18], activating various nuclei in the prefrontal cortex and their connections with the cerebral amygdalae, the limbic system, the thalamus, and the hippocampus, as shown by functional neuroimaging studies in patients and healthy volunteers [18, 50, 51]. An empathic doctor-patient interview triggers a series of complex psychoneuroendocrine mechanisms in the brain developed throughout human evolution and related to trust, pleasure, and positive expectations [52, 53]. When a treatment is given to a patient, be it sham or real, it is not administered in a vacuum, but in a complex set of psychological states and administered along with a complex set of psychosocial stimuli that tell the patient that a clinical improvement should be occurring shortly [18].

There is growing evidence that placebo could be a treatment option for IBS [54-59]. Studies of placebo without deception or so-called open-label placebo when the patient is told that the pills are inactive, have no medication, but "have been shown in rigorous clinical testing to produce significant mind-body self-healing processes" [57] show that placebo is superior to no pill control group and similar to those receiving double-blind placebo with greater improvement in IBS symptoms and meaningful clinical impact [57, 58]. Several possible mechanisms are linked to the patient such as psychosocial traits, e.g. visceral hypersensitivity [55] or genetic predisposition [56] but the patient-practitioner relationship seems to be the most robust component [59].

## STIGMA IN IBS

Stigmatization can be recognized as the opposite of empathy. As stated above empathy is a perception of another, an ability to recognize and understand the thoughts and feelings of others thus identifying another as a person like me with a subjective perspective, values, rights, and commitments [25, 60]. The process of stigmatization on the other hand results from people identifying and labelling human differences, stereotyping persons who are linked to undesirable characteristics. This separates "them" - the stigmatized group - from "us". When people are labelled, set apart, and linked to undesirable characteristics, a justification for devaluing, rejecting, and excluding them appears [42, 61].

It is not clear why some of the characteristics become marks of negative evaluations, be they visible or invisible, controllable, or not, linked to appearance, behavior, or group membership, but "power must be exercised" for stigmatization to occur [62, 63]. This defines stigma as a social construct [62]. As proposed by evolutionary scholars human beings use cognitive adaptation that helps group living by avoiding poor social exchange partners, joining cooperative groups, and avoiding those who are likely to carry communicable pathogens [64]. The main attributes that are possessed or thought to be possessed by stigmatized people are connected to body, social environment, but especially mental status [64, 65]. This might be a cause for different cultural beliefs of mental disorders, e.g. perceiving mental illness as personal weakness and lack of self-control in Asian and Latin American cultures, or as divine punishment as well as possession of evil spirits in Arab

and African societies. Even in Western countries where mental illness is recognized more as a health matter, there is a belief that one with mental health disorders could be dangerous or unpredictable [66]. It is observed that social stigma is bigger when illness is thought to be of behavioral or so-called mental cause [67, 68]. People living with various chronic illnesses, but especially those associated with mental health may encounter stigmatization – social devaluation or discrediting due to their illness - in their social environment, workplace, or even health care system [69-71].

Stigmatization is defined by three main processes: (a) perceived stigma - the negative or degrading perception of the disease or people with the disease, (b) internalized stigma – recognizing and accepting oneself with those negative beliefs and feelings associated with their stigmatized attribute, usually associated with shame, guilt, and diminished self-worth and (c) enacted stigma is associated with experiencing stereotyping, prejudice, and discrimination directed at those with the disease from others without the disease [72]. The last step is anticipated stigma - the expectance of experiencing stereotyping, prejudice, and discrimination directed at people with chronic illness from others in the future. Internalized and particularly experienced stigma is related to the greater anticipated stigma which in turn is associated with less care access and lower quality of life [73].

Stigmatization in IBS is common in various contexts and settings. Perceived stigma in IBS is associated with knowing that others imply that their symptoms are “self-inflicted”, or the disease is “all in their head”. This perception might affect social interaction by limiting the number of people to whom they disclose having IBS [74]. Patients with gut-brain interaction diseases might perceive stigma from several groups of people within personal relationships and the workplace, but also often from health care professionals [75-77]. Patients report that they feel as though they are unheard [37, 77] or not taken seriously [74] or that their IBS is trivialized [36]. In comparison with inflammatory bowel diseases, IBS is much more stigmatized especially by healthcare professionals [76]. High psychiatric comorbidity and the notion that IBS is psychological increase the risks of stigmatization, as there are significant data to suggest mental illness contributes to stigma experiences [78-80]. Likely, individuals having IBS with increased levels of anxiety and depression may also report higher levels of stigma.

As review by Ko et al. [81] patients with functional somatic syndromes such as IBS, fibromyalgia or chronic fatigue syndrome perceive or experience at least moderate levels of stigma/invalidation, but patients with comparable explained conditions [inflammatory bowel disease (IBD), rheumatoid arthritis, or multiple sclerosis] also perceive or experience stigma/invalidation. The data on differences between IBS and IBD were ambivalent. In one of the reviewed studies for IBD duration of illness was correlated with perceived stigma [82]. This might be because the progression of illness can include particularly stigmatizing changes such as colectomy and ileostomy, but also because IBD itself is considered a psychosomatic disease [83].

Internalizing stigma can lead to depression and reduced self-esteem [84]. As reviewed by Hearn et al. [85] several qualitative studies in the last two decades show a large proportion of patients with this type of stigma report shame

or embarrassment because of their IBS, e.g. “*I didn’t tell my husband – I don’t tell my friends... it’s embarrassing*” [86]. Adopting this belief leads to patients blaming themselves for various reasons, such as their eating habits or stress, and then feeling guilty. It is also associated with the feeling of uncertainty and coping mechanisms of control and empowerment [87]. Stress, on the other hand, has an impact on important physiological functions of the gut including gut motility, secretion, visceral sensitivity, and mucosal blood flow. In addition, stress modifies gut microbiota and enhances paracellular permeability [88]. Thus, anxiety is thought to be involved in the pathogenesis of gut-brain interaction diseases as the primary course as well as a complication following the gut symptoms so can go both directions [89]. The stigmatization of gut-brain interaction diseases or the patients with such conditions may have a negative impact on the progress of the disease.

Doctors in the presence of patients with IBS also experience uncertainty because of a lack of clear medical understanding of the disease’s origin as well as effective treatments [90]. “*Anyone gets frustrated with patients banging out symptoms, saying medication makes them worse, nothing makes them better, and ‘what are you going to do, doctor?’*” [90].

In Western societies, physicians tend to be stereotyped as aggressive, intelligent, error-free healers and as scientists “battling at all costs, death, and disease” [91]. Another popular stereotype is that of the physician as a “lone decision maker” [91]. When sufferers of medically unexplained disorders (such as IBS) cannot fit into the conceptual frame of biomedicine and therefore cannot meet health professionals’ expectations of what constitutes an illness, their personal legitimacy is undermined [92].

Doctors tend to cope with these situations by forming the rules of engagement governing their relationship with IBS patients, frequently predetermined by how patients accept the IBS diagnosis if they demand expensive and lengthy investigations or fail to cope or respond to treatment [90]. The study by Letson et al. [93] showed that nurses also carry negative attitudes toward IBS sufferers, for example, that those patients are not able to cope with life, or that they waste doctors’ time. Moreover, these attitudes were based not on experience but on knowledge of the stereotyped IBS character. However, even the older and more experienced nurses or those who themselves suffered from these complaints, or had attended study days on IBS, held similar attitudes [93]. It should be noted that studies of enacted stigma in patients with IBS are more than 15 years old. There are some positive shifts in the subject empathy and IBS awareness in recent times [94] but the true data is lacking.

## NARRATIVE MEDICINE

The concept of narrative medicine aims to remedy the feeling shared by many patients that “their doctors don’t listen to them or that they seem indifferent to their suffering” [95]. According to Charon [95], this feeling is the price of more and more technologically sophisticated medicine, which focuses on the biological disease itself rather than on the particular patient suffering from a specific disease.

Through the progress of the science in medicine, we gain a lot of knowledge that is considered verified and undoubted information about diseases, but we also need other kinds of knowledge, so-called hermeneutical knowledge allowing us to grasp something about the patient who is sitting in front of us that we cannot grasp otherwise [96]. This knowledge, however, can never be verified and always remains more or less subject of notion.

Narrative-based medicine assumes that patient narratives of illness can create a holistic perspective of a patient's problems and health not only by the presence of symptoms but also by how it affects everyday life, social interactions, feelings, etc. [97, 98]. The narrative is concerned with individuals, rather than simply reporting a clinical vignette thus encouraging empathy and promoting understanding and compassion between clinician and patient [97]. As well as it allows one to re-evaluate her life and construct meaning [97]. Distress, injury, disease, and loss generate suffering when they threaten meaning in the patient's personal narrative [99]. On the other hand, it is possible for individuals with chronic diseases to believe that their illness has led to the obtaining of positive qualities, including changed life priorities, appreciation for daily life, and more meaningful interpersonal relationships [87, 100].

There are no direct studies that evaluate the possible effect of narrative medicine on IBS, but some findings suggest that an empathic doctor-patient relationship which fosters mutual understanding and helps patients with IBS make sense of symptoms, increases their ability to manage their IBS in a psychologically flexible manner, subsequently helping them maintain their quality of life [101, 102].

## CLINICAL IMPLICATIONS

Empathy in the patient-provider relationship is significant in every medical situation, while in diseases of the gut-brain axis, it is of utmost importance. We dare say that a lack of empathy can devolve into stigmatization in patients with IBS and cause frustration in the diagnostic and therapeutic process. This leaves patients and physicians in misapprehension and distress, which in turn leads to the worsening of the disease in patients and burnout in physicians.

A lot of good practice advice is offered to foster meaningful connections with patients including active listening techniques, a patient-centered approach, exploring emotional cues by naming and validating the patient's feelings and using verbal and non-verbal communication manners [1, 28, 31, 103-106]. Taking action to alleviate the patient's suffering could be carried out through deep acting, by generating empathy and consistent emotional and cognitive reactions with the patient, similar to the method used by some stage and screen actors; surface acting by forming empathic behaviors toward the patient, without consistent emotional reactions, or both, thus helping patient belief in physician's empathy [45, 106].

To our understanding sometimes it is enough to meet your patient with IBS as a person with unique subjective perspectives, values, rights, and commitments. Try to use cognitive empathy attempting to understand and consider the patient's mental state and affects not necessarily feeling the same. This is known to serve creating and enjoying the unique

experience of interaction between two humans, something more than science – the art of relationship.

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