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PEOPLE IN BIOETHICS

Living with Irritable Bowel Syndrome: A significant impact on patients' everyday lives



KEYWORDS

Gastrointestinal disease;
 Irritable bowel syndrome;
 Abdominal pain;
 Diagnosis;
 Quality of life;
 Patient feedback

Introduction

Irritable Bowel Syndrome (IBS) is a chronic, disabling condition, characterized by abdominal pain and transit disorders divided into three categories [1]: IBS predominantly with Constipation (IBS-C), IBS predominantly with Diarrhea (IBS-D) and Mixed IBS, with alternating diarrhea and constipation (IBS-M).

This disease is not well known, although it affects nearly 3 million people in France (i.e., 5 to 10% of the population) [2]. No curative care is available to date.

The *Association des patients souffrant du SII* (APSSII) was set up in 2010 to end patient isolation by providing reliable information and useful resources for living with IBS. It has the support of many doctors and researchers.

This article presents the testimonies of two IBS patient-experts (IBS-C witness and IBS-D witness). It aims to demonstrate the impact of the disease on sufferers' daily lives: symptoms and effects, medical care (diagnosis and treatment), quality of life and perception of the disease (among the general public and healthcare professionals).

These testimonies are backed up by scientific data and corroborated by the opinion of a neurogastroenterologist specializing in IBS.

Testimonies from IBS sufferers

Symptoms and effects

The testimonies illustrate two particularly crippling cases of IBS.

IBS-C witness

IBS-C in this patient takes the form of irregular, painful and incomplete bowel movements, daily bloating and gas. The stools are hard and fragmented (Bristol stool chart type 1) [3], sometimes compacted (type 2). They are occasionally mushy during episodes of false diarrhoea (type 6).

Abbreviations: APSSII, *Association des patients souffrant du syndrome de l'intestin irritable* IBS French patients' organisation; FODMAPs, Fermentable Oligo-, Di-, Monosaccharides And Polyols; HCPs, healthcare providers; IBS, Irritable Bowel Syndrome; IBS-C, Irritable Bowel Syndrome with Constipation; IBS-D, Irritable Bowel Syndrome with Diarrhoea; IBS-M (the M stands for "mixed"), Irritable Bowel Syndrome with constipation and diarrhoea; SNFGE, *Société nationale française de gastro-entérologie*, a national French Association for Gastroenterology.

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The symptoms are accompanied by chronic abdominal pain and a feeling of permanent rectal distension. The witness also reports the following associated symptoms: chronic fatigue, hemorrhoidal attacks, difficulty wiping, irritation and bleeding.

In addition, the witness indicated that she is obliged to manage her schedule around her medical condition (complex organization). This significantly reduces the time left for personal activities and sleep.

IBS-D witness

Living with IBS-D diagnosed as severe means having to endure pain and diarrhoea each day (Bristol type 5–6) and a chronic episode every 3 days or so (Bristol type 7).

In concrete terms, this means organizing one's life and schedule around visits to the toilet, which occur up to 4 times per day in so-called "normal" times and 8 times during a flare-up. It also means having to deal with fecal emergencies, i.e. finding a toilet in less than 5 minutes, wherever you are, be it when traveling, in the workplace, the street or out in nature, etc. These traumatic episodes lead to a fear of being unable to control one's bowels, called laxophobia.

The witness also has to deal with the following symptoms: nausea, acid reflux, flatulence, belching, physical weakness, hemorrhoids and anal irritation.

The diagnosis

Scientific studies show that IBS is a late diagnosis disease. The average time between the onset of the first symptoms and diagnosis is 3.4 years [4] (7 years for the IBS-C witness and 5.2 years for the IBS-D witness). The age range of diagnosis is estimated to be between 30 and 40 years [5] (39 years for the IBS-C witness and 34 years for the IBS-D witness).

IBS-C witness

The witness has suffered from constipation since adolescence: occasional, then chronic since 2002 (age 22), aggravated by an episode of pyelonephritis that occurred at that age. She then noted an increase in the episodes of constipation, which became permanent from 2012 (age 32).

That same year, the witness consulted a gastroenterologist for the first time following a severe hemorrhoidal attack. An incision was necessary, but the constipation was not seriously treated: no recommendations were made apart from taking laxatives.

This lack of response led the witness to seek information on complementary treatments. At the same time, on the advice of a friend, the witness consulted a gastroenterologist who was aware of IBS: the diagnosis was finally made in 2019 (at the age of 39). The drug treatment was then adjusted to regulate the attacks.

The witness was also prescribed additional tests in 2021 (colonic transit time, rectal manometry, breathing test). An anismus was detected, without establishing to date whether IBS-C was the cause or consequence.

Table 1 Annual expenditure in euros, not reimbursed.

	IBS-C witness	IBS-D witness
Direct expenditure ^a	300	1000
Consultations, examinations, medication		
Additional treatments	1,200	150
Food for special dietary requirements	2000	2400
Total	3500	3550

^a The direct expenditure of sufferers is estimated at 756 euros per year, according to a scientific study [7].

IBS-D witness

The witness has suffered from diarrhea since childhood. She has experienced several bouts of uncontrollable diarrhea. The episodes of diarrhea increased in 2011 (age 29). The witness continued to manage this problem on her own because you often hear that it is "normal to have stomach aches".

As the situation became untenable in 2014, the witness consulted a gastroenterologist, who told her "it is most probably an irritable bowel. It's not a serious disease because it's in your head, so you shouldn't listen to the symptoms". The other gastroenterologists she consulted were of no greater help. The witness even began to feel guilty, thinking that it was all her fault.

In 2016, a serious event in the witness's life made her realize that she had to take care of her health and find solutions by herself. The discovery of Professor Sabaté's book [6] was a relief and proved to the witness that this disease is genuine and scientifically recognized. She was then diagnosed quickly.

Treatments

No curative care exists to date.

Only symptomatic treatment can be considered and existing solutions are often poorly reimbursed. As a result, patients have to bear significant expenses, as the two patients in this article can testify (Table 1).

Medicines

IBS-C witness

The treatment was based on oral osmotic laxatives and gas-releasing suppositories. Probiotics were not shown to have any significant effect.

IBS-D witness

The only medication that works is Loperamide, but the dosage is limited to 6 capsules per day. Also, it generates flatulence, which is totally incompatible with a satisfactory quality of life.

Antispasmodics have only a limited effect on pain.

Lastly, a probiotic and a treatment acting on permeability combined with a prebiotic can limit the intensity of the attacks.

Additional treatments

IBS-C witness

The witness combines holistic practices to better manage the symptoms: naturopathy, hypnosis, magnetism and yoga. These practices are essential for relief, but this can only be sustained through regular practice, which requires a significant investment of time and money. The witness is also interested in aromatherapy, which appears to reduce bloating.

IBS-D witness

Group self-hypnosis and meditation sessions helped the witness to calm the pain, but had no effect on stool frequency or consistency.

Food

Food plays a major role in sufferers' lives. Seventy-three percent of patients said that food was a trigger and 93% felt that it made symptoms worse. Eighty-seven percent of the witnesses interviewed found it particularly hard to stick to a diet [8].

IBS-C witness

The witness estimates that her diet triggers 70% of her symptoms. She follows a low FODMAP diet, which is complex and requires support. She still suffers from crises and eating disorders including appetite and weight loss, prolonged fasting and fear of eating.

IBS-D witness

Adopting a no-residue diet is the only way to manage symptoms and bad flare-ups, but this is particularly restrictive and frustrating.

This diet consists of limiting foods that increase the volume of stools and accelerate intestinal transit. Accordingly, the witness only eats starchy foods, lean meat and fish, with no added fat.

Impact on daily life

Professional life

A scientific study [9] shows IBS has a major impact on the professional life of 85% of sufferers, affecting their productivity at work. Discomfort was felt by 69% of patients who took part in the survey and 21.6% were prescribed time off work for a median of 5.5 days.

IBS-C witness

Chronic pain leads to drowsiness and drops in concentration, affecting the quality of work. The witness also has a tendency to retain gas because of being near others and using the same toilets. This exacerbates the pain and discomfort. In times of severe crisis, the witness is unable to go to work (estimate: 4 days off work per year).

IBS-D witness

Diarrhea is a taboo subject, so you have to constantly hide your symptoms and the consequences: having up to 8 bowel movements a day, staying on the toilet for a long time, finding a toilet away from your colleagues' office, holding in your flatulence. You also have to find excuses to explain your numerous absences from meetings and the office.

Being on business trips for several days/weeks means sharing daily life with colleagues, subordinates and superiors from breakfast to dinner. Having no control over meals means transit problems get worse.

Social life

The impairment of quality of life for IBS sufferers is judged to be equivalent to, or even greater in some respects, than other chronic conditions such as Crohn's disease, insulin-requiring diabetes and end-stage renal disease [10].

IBS-C witness

Poor understanding of the disorder means those around her do not understand what she is going through. They downplay her symptoms which are thought to be entirely psychosomatic. IBS is still very much a taboo subject, leading the witness to be withdrawn, making it hard to meet new people.

The witness also faces disappointment, as she regularly has to turn down invitations. This creates tension and frustration and IBS is largely responsible for narrowing down her social circle.

IBS-D witness

The witness feels that few people around her understand the impact that IBS has on her life. For example, restricting her activities due to pressing needs is often seen as a whim or a desire to stay at home.

The witness also has to constantly justify her diet and absences caused by IBS.

As a result, the witness has had to cut back on socializing with virtually anyone who does not suffer from IBS or really understand the reality of the condition.

Relationships and intimacy

IBS has a major impact on sufferers' relationships and intimacy.

IBS-C witness

The witness feels that her illness is not compatible with dating. When she is in a relationship, her partner is also affected: the whole household has to deal with isolation and frustration and work to a tight schedule that leaves no room for improvisation. She feels that her illness is an obstacle to letting go and to a fulfilling sex life.

IBS-D witness

When she first had IBS symptoms and then when they worsened, the witness was in a long-term relationship and her partner fully understood the difficulties she was experiencing on a daily basis. However, the witness does not know how to start a new relationship when diarrhea and flatulence are a daily occurrence.

Perception of the illness

IBS is often thought to be psychosomatic although it is "a genuine digestive disorder". Stress is not actually a cause, but an aggravating factor of the pathology [11].

IBS-C witness

The parts of the body affected by the disorder are still a source of shame and most people do not want to hear about it. The majority of patients continue to be stigmatized, just like people with any other form of disability.

The fact of "living only by and for one's stomach" considerably alters quality of life. The witness reports regularly feeling diminished and devalued, which leads to depressive episodes.

These two factors point to patient isolation, which alters confidence and self-esteem.

IBS-D witness

It is rarely possible to talk about the taboo symptoms of IBS without provoking disgust or ridicule. Very few people understand the reality of the disorder and its crippling effects. Although optimistic by nature, the witness feels that her psychological state is adversely affected by the many bouts of uncontrollable diarrhea.

The witness would prefer to have a psychosomatic illness because she could solve this problem in a certain number of psychotherapy sessions. But there are so many causes and factors that are totally beyond her control that she feels powerless to solve this problem.

The scientific opinion of a neurogastroenterologist specializing in IBS

These two detailed testimonies on the daily life of IBS patients perfectly illustrate what many patients can experience because of their symptoms with direct consequences related to pain, transit disorders and bloating. They also underline, what is less known by society and by healthcare professionals, a significant impact on relationships with others, in their intimacy and in the work environment, which can be a source of isolation and induce secondary depression.

These testimonials also show that different transit disorders can similarly impact the quality of life. They require permanent efforts to adapt to the disease on a daily basis and also have consequences on the patients' financial resources due to non or very low reimbursement of the various treatments.

I hope that the dissemination of these patients' courageous words will one day allow health professionals and society to better understand what patients experience, for better care and better recognition of this disease. This would only be fair considering the equivalent impact with other diseases that receive much more attention.

Conclusion

The testimonies of IBS sufferers, scientific data and the opinion of a neurogastroenterologist demonstrate the deficiencies in IBS care: late diagnosis, a lack of attentiveness and knowledge of IBS by healthcare practitioners and few

effective treatments. This explains why many patients feel that they are struggling to get diagnosed and treated.

The lack of knowledge and recognition of IBS amplifies the isolation of patients, whose quality of life is already severely impaired. There is a significant perception gap between their experience of the disorder and its portrayal in society.

This is why it is vital to conduct awareness-raising and outreach work on IBS among health professionals and the general public.

Medical care and financial support are also a major area for improvement, which requires recognizing IBS as a disabling illness in its own right. Medical staff should systematically receive training on IBS, research should be stepped up and reimbursement of certain types of treatment and care should be considered.

It is time for patients to feel they have access to support, help and advice as part of a proper care program.

Human and animal rights

The authors declare that the work described has not involved experimentation on humans or animals.

Informed consent and patient details

The authors declare that this report does not contain any personal information that could lead to the identification of the patient(s) and/or volunteers.

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Disclosure of interest

The authors declare that they have no competing interest.

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