

Stigma and irritable bowel syndrome: a taboo subject?

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This Review highlights the stigma associated with irritable bowel syndrome and its impact on patient care and clinical outcomes. Stigma around irritable bowel syndrome is prevalent among the general public, health-care professionals, and co-workers, and is often related to poor understanding of the condition. Furthermore, stigma is associated with unsatisfactory outcomes for people with irritable bowel syndrome, including increased health-care use, psychological distress, and impaired quality of life. Comparative studies suggest that stigma is much higher for irritable bowel syndrome than it is for inflammatory bowel disease, a so-called organic gastrointestinal disorder with overlapping symptomatology. In this Review, we discuss the lack of interest in irritable bowel syndrome among members of the general public and health-care professionals, and the need for it to be better understood. These problems should be addressed by appropriate educational strategies to raise awareness and by relevant interventions.

Introduction

Irritable bowel syndrome (IBS) is a functional gastrointestinal disorder characterised by abdominal pain, abnormal bowel function, and bloating, in the absence of structural abnormalities.¹ As the most common functional gastrointestinal disorder worldwide, with an estimated prevalence of about 11%,² IBS accounts for up to 50% of all gastrointestinal consultations.³ Despite the high prevalence of this disorder, uncertainty about its pathophysiology persists. Current understanding is that the causation is probably multifactorial, with studies showing visceral hypersensitivity,^{4,5} abnormal gut microflora,⁶ abnormal gut motility,⁵ and aberrant CNS processing of painful stimuli.⁷ Importantly, psychological factors, including stress,⁸ are not directly implicated in the pathophysiology, but are known to exacerbate symptoms.

Stigmatisation of a medical condition often arises when a person with a disease or condition is associated with socially undesirable features of a disease (eg, faecal incontinence), which result in stereotyping.⁹ The resulting labelling of and discrimination against stigmatised individuals and their medical condition often lead to social exclusion.⁹ Patients can experience stigmatisation directly from others, termed enacted stigma. The other types of stigma—perceived and internalised stigma—both result from indirect negativity towards and discrimination against people with the condition by others. Unfortunately, IBS is a condition with many features that increase the likelihood of stigmatisation. These include its unclear causation, the paucity of effective treatment options, high rates of psychiatric comorbidities,¹⁰ and the erroneous belief that it is a purely psychosomatic illness.^{11,12} Moreover, bowel-related symptoms are considered taboo by many people,¹³ and patients with IBS are vulnerable to stigmatisation from family members and work colleagues because of their unpredictable bowel habits and fear of incontinence. Indeed, many patients withdraw from daily activities or new situations.¹⁴ In addition, presenteeism in the workplace—when an individual is at work but ineffective—is common in IBS.¹⁵

Patients with IBS have reported that their abdominal pain severity is similar to that of childbirth,¹⁶ and this pain

can lead to hopelessness and suicidal thoughts.^{17,18} The pain is often difficult to control, leading to analgesic escalation and counterproductive overprescribing of opioids.^{19,20} People with IBS also frequently visit many different physicians and might even be subjected to unnecessary abdominopelvic surgeries, including histology-negative appendectomy, cholecystectomy, and hysterectomy, because of misdiagnosis of the cause of pain.^{21–23} These unnecessary procedures can increase frustration and, as a result, patients can become vulnerable to stigmatisation from health-care professionals who have not found organic explanations for their symptoms.

The aim of this Review is to evaluate the evidence for stigmatisation in IBS and its detrimental effects on patients and clinical outcomes. We searched for articles relating to stigmatisation and IBS, and after excluding 313 articles that did not meet the search strategy inclusion criteria, we identified 20 relevant papers (figure; table). These studies encompassed three different but interrelated concepts of stigma. Five studies deal with enacted stigma, four concern internalised stigma, and six address perceived stigma, with the other five studies including a combination of these types of stigma. In this Review, we define each of the three types of stigma and summarise the key findings of the 20 studies.

Enacted stigma

Enacted stigma refers to the extent to which patients experience stigma from others. These experiences can be associated with stereotyping, discrimination, negative acts, and expressions of negative beliefs, and can come from the general public or in a health-care setting, potentially leading to unfair treatment, inadequate care, or the blaming of the patient for their illness.^{41,43}

In the largest study to date, an online survey of 392 members of the general public, Taft and colleagues⁴¹ compared enacted stigma towards IBS, inflammatory bowel disease (IBD), and adult-onset asthma. Participants were recruited via social media platforms and a dedicated research website and were presented with clinical vignettes in a randomised manner. Participants represented all geographical regions of the USA, and most were white (326 [83%] of 392) and non-Hispanic (313 [80%] of 392).

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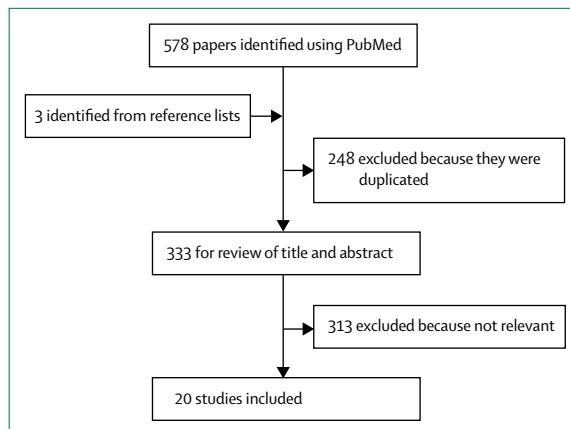


Figure: Flow diagram for literature review of stigma in irritable bowel syndrome

The researchers evaluated enacted stigma using a 30-item enacted stigma scale questionnaire, which was completed by all participants on the basis of their reaction to the clinical scenarios. Enacted stigma was significantly higher for IBS than for IBD and controls with adult-onset asthma ($p=0.000$). Furthermore, although all three groups were matched for gender, men with IBS were significantly more stigmatised ($p<0.001$) than men with asthma. No further differences between stigma levels and gender were found. Although the degree of familiarity with IBD was inversely associated with stigma levels, this association was much weaker for IBS. Members of the public who were found to be more empathetic (via a scoring tool, the Interpersonal Reactivity Index) expressed significantly less enacted stigma towards all three conditions than those who were not.⁴¹ 44 participants in this study with IBS or IBD were randomly allocated to rate a clinical vignette related to their own condition, and, unsurprisingly, patients with IBS or IBD showed reduced enacted stigma towards their own condition. These participants were therefore removed from the enacted stigma analyses.

Of concern, enacted stigma also comes from the clinicians who care for patients with IBS. Consistent with Taft and colleagues' observations that a person's gender could influence the degree of enacted stigma, a study by Hamberg and colleagues³¹ suggests that not only the gender of the patient, but also that of the clinician could influence reactions towards patients with IBS. This innovative study of 289 Swedish physicians during a national, written test examination, required them to describe the management of either a male or female patient with IBS, after being presented with otherwise identical cases except for the patient's gender. This case was a specially designed research question that all candidates were required to complete, having been randomly assigned a question on a specific gender. Surprisingly, physicians were more likely to question and investigate alcohol misuse for men with IBS than they were for women, whereas they were more likely to

question and investigate thyroid disease in women with IBS than they were for men. Female physicians were found to ask more questions to female patients than their male counterparts about previous medications and gynaecological problems, and sedating medications were most commonly prescribed to female patients by male physicians.³¹

Given these findings, Hamberg and colleagues³¹ suggest that male and female clinicians react differently to gender cues and have different preconceptions and differing patterns of gender bias, which seem to affect decision making and prescribing practice. Although the reasons for gender-dependent differences in attitudes towards patients with IBS in the study by Hamberg and colleagues remain unclear, some insight is provided by an anonymised survey of 60 physicians (30 men, 30 women) at a large university medical centre in the USA. Significantly more physicians reported that they find IBS more difficult to diagnose in women than in men (40 [67%] of 60 vs 19 [32%] of 60; $p=0.0003$), but more difficult to manage in men than in women (46 [77%] of 60 vs 28 [47%] of 60; $p=0.0014$).²⁵ These data could therefore explain to some extent why male patients with IBS are vulnerable to more enacted stigma than are women, and why clinicians' approach to management might vary partly depending on the patient's sex.

Further evidence for enacted stigma from health-care professionals comes from a UK-based qualitative study using in-depth, semistructured interviews with 12 clinicians (six gastroenterology clinicians of varying seniority and six general practitioners).²⁷ Overall, most clinicians reported either frustration with treating patients with IBS or intolerance of their personal characteristics, or both. Perhaps of most concern, however, was that gastroenterology clinicians had more negative views about IBS than did general practitioners. The reasons for their negative feelings included medical uncertainty and the struggle associated with ineffective treatments, and many reported frustration with the personalities of patients with IBS, who they often labelled with the terms neurotic or heartsink. However, some doctors in the study rejected these patient stereotypes, reporting that giving good explanations and using sensitive, sympathetic ways of communicating with patients was highly effective. One of the main limitations of this study is that it was unclear whether the seniority of the gastroenterology clinicians affected attitudes towards the patients.

Further evidence for enacted stigma towards patients with IBS from health-care professionals comes from a survey of 254 qualified nurses working in 18 hospitals in the UK.³³ Recruitment for this study was through opportunity sampling with surveys distributed to randomly selected hospitals that accepted a request to participate. Surveys were largely distributed by senior nursing personnel, and 10–30 completed questionnaires were received from each site. Most respondents had negative attitudes towards IBS, regardless of their

	Type of stigma	Population	Methods	Key findings
Björkman et al (2013) ²⁴	Internalised; perceived	Ten patients with Rome II IBS; tertiary clinic	Qualitative interviews, individually and in groups	Patients reported guilt, self-blame, embarrassment, shame, and perceived stigma and gender stereotyping from health-care providers
Borum (2002) ²⁵	Enacted	60 internal medicine physicians (30 male)	Survey of perceptions of ease of diagnosis and management of IBS	Doctors have gender-specific preconceptions about the difficulty of IBS diagnosis and management
Dancey et al (2002) ²⁶	Perceived	117 patients (54 male) with IBS diagnosed by a qualified doctor, recruited by two IBS charities	Mailed questionnaires including 11 item perceived stigma questionnaire, IBS-QoL scale, and illness intrusiveness ratings scale	Significant correlation between perceived stigma and decreased QoL in men ($r=-0.63$; $p<0.001$) and women ($r=-0.39$; $p<0.001$), but this association was stronger in men ($p=0.02$); perceived stigma correlated with illness intrusiveness in men ($r=0.62$; $p<0.001$) and women ($r=0.4$; $p<0.001$)
Dixon-Woods et al (2000) ²⁷	Enacted; perceived	Six gastroenterologists, six general practitioners, and 14 patients with IBS diagnosis from gastroenterology clinics	Qualitative, semistructured interviews	Gastroenterologists held more negative views towards patients with IBS than did general practitioners; positive interactions occurred when patients were taken seriously
Drossman et al (2009) ²⁸	Internalised	16 patients with Rome III IBS, recruited by the International Foundation for Functional Gastrointestinal Disorders	Qualitative, structured, and facilitated group discussions	Patients reported shame, avoiding others, losing out on things, and a sense of loss of living
Farndale et al (2011) ²⁴	Internalised; perceived	18 patients with either clinical diagnosis of IBS or Rome II or III criteria, identified from primary care database	Qualitative, semistructured interviews	Patients reported shame, embarrassment, alienation, and IBS being part of their identity; stigma perceived from health-care professionals; better experiences when health-care professionals were sympathetic
Håkanson et al (2009) ²⁹	Internalised	Nine patients with clinical IBS diagnosis, recruited from gastroenterology clinic	Qualitative, open-ended interviews	Patients reported altered self-image, shame, distrust of the body, feeling tired, self-blame, and making adaptations (independently of their health-care professionals) to deal with daily activities
Halpert et al (2011) ³⁰	Perceived	57 patients with Rome III IBS, recruited via IBS websites and advertisements by support groups	Baseline IBS-QoL scale and IBS-SSS, and qualitative, online, expressive writing, including what can be done to improve relationship between patient and health-care professional	Patients reported not being listened to and not trusting or being satisfied by their health-care professional, and expressed that listening and empathy from health-care professionals is important to maximise relationship's benefit
Hamberg et al (2004) ³¹	Enacted	289 trainee doctors taking a national examination with a research case included	Randomly allocated case studies (identical apart from patient's gender) with open-ended questions	Patient's and clinician's gender might affect physician's reactions to patients with IBS and influence clinical decision making, including prescribing practices
Jones et al (2009) ³²	Perceived	Patients with Rome II IBS (49 interviewed and 148 completing questionnaire)	Structured interviews to develop perceived stigma scale; patients completed 10-item perceived stigma scale questionnaire	57% of interviewees perceived stigma; patients report highest stigma from co-workers, employers, and friends; patients perceived lack of interest and understanding from others
Letson et al (1996) ³³	Enacted	254 qualified nurses from 18 hospitals	54-item questionnaire	Majority of nurses reported that patients with IBS were lazy and craved attention (87%), wasted doctors' time (92%), were unable to cope with life (84%), had low pain thresholds (78%), and that the condition was all in their minds (88%)
Looper et al (2004) ³⁴	Perceived	238 patients with functional somatic syndromes and comparable medical conditions (38 with IBS, 51 with IBD)	Perceived stigma measured by attitudes of others scale; comparison of patients with functional conditions vs similar organic disease	Patients with functional conditions perceived more stigma than did controls ($p<0.005$); no significant difference found between patients with IBS and IBD
McCormick et al (2012) ³⁵	Internalised; perceived	136 patients with chronic gastrointestinal conditions (38 with IBS, 47 with Crohn's disease, 33 with ulcerative colitis)	22 focus groups of 4–10 patients; qualitative, semistructured, open questions	Patients report questioning their self-identity, shame, embarrassment due to taboo symptoms, not being taken seriously by HCPs, and being told their condition is all in their heads
Mohebbi et al (2017) ³⁶	Internalised	12 patients with Rome 3 IBS, from three clinics in Iran	Qualitative, semistructured interviews	Patients report stigma through having a negative sense of self, shame, keeping their IBS a secret, and avoiding people through fear of being stigmatised
Quick et al (2015) ³⁷	Perceived	2625 adults aged 18–26 years (135 with a bowel disorder)	Online questionnaires including a self-esteem scale, depression scale, QoL scale, and perception of teasing scales	Young adults with symptoms of chronic bowel disorders were 1.5 times more likely to be "made fun of" ($p=0.018$) or "laughed at" because of their weight ($p=0.010$) than were healthy controls; they were also more likely to be upset by insults teasing their weight ($p=0.006$)
Raine et al (2004) ³⁸	Enacted	46 general practitioners	Qualitative analysis of group discussions of clinical scenarios and systematic review of mental health interventions, comparing CFS and IBS	General practitioners negatively stereotype patients with CFS more than they do for patients with IBS

(Table continues on next page)

	Type of stigma	Population	Methods	Key findings
(Continued from previous page)				
Taft et al (2014) ³⁹	Perceived; internalised	243 patients with Rome III IBS	Questionnaire study including adapted Internalised Stigma for Mental Illness Scale, IBS-QoL Instrument, perceived stigma scale for IBS, and the Patient-Reported Outcome Measurement Information System short-form anxiety and depression scales	Internalised stigma predicted impairment in QoL and psychological distress; patients reported perceived stigma from health-care professionals and co-workers and within their personal relationships
Taft et al (2011) ⁴⁰	Perceived	496 patients from a gastroenterology outpatient clinic (269 with IBS, 227 with IBD)	Online questionnaires including PSS-IBS, brief symptoms inventory-18, RSES, GSES, and SF-12	27% of patients with IBS report moderate to high levels of stigma, compared to 8% of patients with IBD ($p \leq 0.002$); stigma commonly comes from health-care professionals and co-workers; perceived stigma associated with negative outcomes such as depression; stigma from family and significant others associated with worst outcomes
Taft et al (2017) ⁴¹	Enacted	392 members of the general public, recruited via social media	Vignettes of asthma, IBS, and IBD patients presented electronically in randomised order; 30-point ESS questionnaire	Participants stigmatised patients with IBS more than they did patients with asthma and IBD ($p = 0.000$); reduced IBS stigma associated with higher levels of familiarity with the condition ($p < 0.05$) and more emotional empathy ($p < 0.01$)
Thompson et al (1996) ⁴²	Internalised	851 school children aged 11–17 years	20-item questionnaire about bowel symptoms and psychosocial factors	Compared with controls, children with IBS symptoms were more likely to report being different to others ($p = 0.002$), embarrassed to talk about their health ($p = 0.0001$), and that their health prevented them from going out with friends ($p = 0.03$)
IBS=irritable bowel syndrome. QoL=quality of life. IBS-SSS=IBS symptom severity scale. IBD=inflammatory bowel disease. CFS=chronic fatigue syndrome. PSS-IBS=perceived stigma scale-IBS. RSES=Rosenberg self-esteem scale. GSES=general self-efficacy scale. SF-12=short form 12-health status and outcomes. ESS=enacted stigma scale.				
Table: Summary of published studies on stigma against irritable bowel syndrome				

experience level or whether they had IBS themselves. Almost all nurses (232 [91%] of 254) suggested that patients with IBS “waste doctors’ time”.³³ Moreover, most nurses who participated thought that the condition is “all in their minds” (223 [88%] of 254) and that the patients were “lazy” and “craved attention” (220 [87%] of 254). Many participants (214 [84%] of 254) also said that patients with IBS are “unable to cope with life” and over three-quarters (198 [78%] of 254) said that patients with IBS have low pain thresholds.³³ 135 (53%) of the 254 nurses in this study also reported poor understanding of IBS among health-care professionals.

Another UK study took a qualitative approach to transcripts of group discussions with 46 randomly selected primary care doctors, who showed more positive attitudes to IBS than to chronic fatigue syndrome, which is another commonly stigmatised functional condition.³⁸ Analyses from the group discussions, done over an 8-month period, suggested less enacted stigma against IBS than against chronic fatigue syndrome. Potential reasons for this difference include the specific anatomical location of IBS, giving it a more understandable pathophysiology, and the characters of the patients; clinicians stated that patients with IBS seemed to “battle through” their condition more than those with chronic fatigue syndrome did.³⁸

Internalised stigma

Internalised stigma is when patients take on external, negative beliefs or attitudes about their condition, accepting them and applying them to themselves.⁴⁴

Internalising stigma can lead to depression and reduced self-esteem.^{45,46}

Several qualitative studies considering internalised stigma in patients with IBS have shown common themes. For example, a large proportion of patients report shame or embarrassment because of their IBS,^{14,28,29,35,42} taking on negative beliefs such as that the condition is their fault. Adopting this belief leads to patients blaming themselves²⁹ for various reasons, such as their eating habits or stress, and then feeling guilty.²⁴ Patients also felt alienated because of their IBS,^{14,36,42,39} and they reported an altered self-image, with some saying their illness made them feel “less attractive”²⁹ or that bloating changed their appearance, causing a feeling of self-disgust.³⁶ Some people felt shame or disgust because of the taboo surrounding their symptoms,^{29,35} and others reported reduced libido, avoidance of intimate relationships, and difficulty sharing everyday life with a partner.^{29,35} Patients often hid their IBS diagnosis from others, and some avoided people altogether,^{28,36,42} withdrawing from society and isolating themselves. Patients reported that these behaviours resulted from worrying that they might look or act strangely,³⁹ because of the fear and distress caused by the unpredictability of their symptoms.^{14,28} Similarly, and perhaps less recognised than studies of adults, a survey of 851 school children aged between 11 and 17 years from a single co-education high school in the UK revealed that a large proportion of children (133 [16%] of 851) have symptoms of IBS that affect their lives. Those affected were significantly more likely than controls to report

feeling “different”, “embarrassed”, or that their condition “prevented them going out with friends”.⁴² Adults with IBS also report that their IBS is disruptive to family, social situations, and relationships, to the extent that they lose out on experiences and opportunities, which they describe as a “loss of living”.²⁸

Although there is limited research on stigma against IBS in different cultures, Hispanic patients with IBS reported more stigma than did non-Hispanic participants in a North American study.³⁹ A study that used detailed, semistructured interviews with 12 Iranian patients with IBS at three Iranian university hospitals, during a 14-month period, revealed a high amount of internalised stigma,³⁶ suggesting that cultural differences could be relevant. Similar to the findings of studies of patients with IBS of European descent, Iranian patients with IBS described feeling shame, keeping their condition secret, or avoiding and hiding from society.³⁶ A Swedish study of nine patients with IBS from a hospital outpatient clinic, which used detailed, open interviews, suggested that there could even be gendered differences in the ways that people internalise stigma against IBS.²⁹ Men tended to feel “weaker” because of their condition, whereas women often felt guilty, believing the disease was their fault, or felt less attractive.²⁹ Patients in this study often described feelings of guilt or inadequacy because of their inability to live up to the high expectations of loved ones, such as parents feeling unable to look after their children.

Another North American study involved 104 university-based, gastroenterology outpatient clinic patients with IBS and 139 patients with IBS who fulfilled Rome III criteria and were recruited online from social media platforms. The study evaluated the effects of internalised stigma on psychological wellbeing, health competence, and health outcomes, using validated tools including the Irritable Bowel Syndrome Quality of Life Instrument, the Patient-Reported Outcome Measurement Information System short-form anxiety and depression scales, and the Internalised Stigma for Mental Illness Scale. The results of this study revealed that internalised stigma predicted 25–40% of the variance in psychological functioning, quality of life, health-care use, and health competence when controlling for stigma perception and disease variables.³⁹

Perceived stigma

Perceived stigma is the extent to which an individual with a disease feels that others hold negative beliefs or attitudes about or express negative behaviours towards their condition.^{41,45} This kind of stigma can be perceived in social interactions,³⁹ through teasing in school children,³⁷ and from health-care providers or co-workers.³⁹ Higher levels of perceived stigma can lead to reduced quality of life, self-esteem, and medication adherence, and increased psychological distress.³⁶

In a North American study of gastroenterology clinic patients and internet respondents with IBS, perceived

stigma was common, reported by 28 (57%) of 49 patients.³² Participants in this study underwent semistructured interviews, and a stigma scale was developed and subsequently validated in a further 148 patients with IBS. 25 (51%) of 49 patients with IBS reported that the public’s knowledge of IBS is low, and 22 (45%) thought their condition was not taken seriously by others. Moreover, 22 (45%) of 49 claimed that others imply that their symptoms are “self-inflicted” and 15 (31%) reported that others said the disease is “all in their head”.³² Furthermore, 31 (63%) of 49 patients limited the number of people to whom they disclose having IBS and 16 (33%) had limited roles at work because of their condition.

Patients with IBS perceive stigma from several groups of people, including within personal relationships³⁹ and in the workplace.^{32,40} Children and adolescents with chronic bowel disorders such as IBS might perceive substantially more stigma from classmates than do those without bowel disorders. This is suggested by an online survey of 2625 young adults aged between 18 and 26 years, in which people with chronic bowel disorders (76 patients with IBS, 25 patients with IBD, and 34 patients with coeliac disease) were 1.5 times more likely to recall being “made fun of” ($p=0.018$) or “laughed at” because of their weight ($p=0.010$) during childhood than people without bowel disorders.³⁷

Several studies report that stigma is often perceived from health-care professionals,^{14,39,40} with patients reporting that they feel as though they are not being listened to³⁰ or taken seriously,^{32,35} or that their IBS is trivialised.²⁷ These findings are consistent with the literature on enacted stigma in IBS already discussed. Women could be particularly exposed to perceived stigma from health-care professionals, with one study showing that women are commonly treated as though they are “whiny” or “neurotic” by their health-care providers.²⁴ Most patients with IBS have been shown to be dissatisfied with their health-care professional, as was highlighted by a US national survey of patients with IBS recruited via IBS-related websites and networks.³⁰ This study reported that positive comments made up only 22 (11%) of 197 patients’ comments about their relationship with their health-care provider, with a much higher proportion of negative comments (106 [54%] of 197).³⁰ Many patients have reported distrust of their clinicians.^{24,30} By contrast, patients who reported positive interactions described their doctors acting as if the patient had something worth treating, giving legitimate medical explanations, and being supportive and sympathetic.^{14,27}

Two studies on perceived stigma compared IBS and IBD. The largest study, using a series of questionnaires, compared perceived stigma in 269 patients with IBS and 227 patients with IBD.⁴⁰ Patients were recruited from a university hospital gastroenterology outpatient clinic in the USA and via online support message boards. This study found that IBS is far more stigmatised than IBD, with 73 (27%) of 269 patients with IBS reporting

moderate to high levels of perceived stigma, compared with just 18 (8%) of 227 patients with IBD. Disappointingly, health-care professionals were perceived to be the worst offenders, stigmatising IBS much more than IBD. The second study, based in a university teaching hospital in Canada, was limited by a smaller sample size of only 38 patients with IBS and 51 patients with IBD.³⁴ This study included data about several other functional conditions and controls, with patients recruited from different specialty clinics. Although no significant difference was found between perceived stigma against IBS and IBD, this study showed that patients with functional conditions perceived more stigma than controls did.³⁴

Perceived stigma in IBS is associated with worse outcomes,⁴⁰ increased depression,³⁴ and reduced quality of life.²⁶ One study suggested that perceived stigma affects quality of life through illness intrusiveness, which is when an illness affects involvement in valued activities and interests.²⁶ These negative clinical outcomes are associated most strongly with perceptions of stigma from family members and significant others.⁴⁰

Discussion

Despite progress in the understanding, diagnosis, and management of functional gastrointestinal disorders,⁴⁸ this Review—the first to cover all aspects of stigma—highlights that stigma is a major problem for patients with IBS (table). Research in this area consistently finds that stigma associated with IBS is both common and associated with substantially worse outcomes.

When considering strategies to reduce stigmatisation, it is striking that its detrimental effect on quality of life appears to be mediated by illness intrusiveness, with fear of stigmatisation from others often leading to the disruption of daily activities, absenteeism, and social withdrawal. Given the high prevalence of psychiatric comorbidities and suicidal thoughts present in patients with IBS,¹⁸ internalised stigma is a particularly important factor to address. Indeed, in other health conditions this type of stigmatisation is known to cause detrimental psychological effects and impairment of quality of life.^{49–53} Importantly, internalised stigma in IBS appears to be associated with perceived stigma from significant others and health-care professionals,³⁹ and our literature review suggests that stigma often comes from health-care professionals.^{27,33,39} In several studies, health-care professionals admitted that “medical uncertainty”, the struggle to find effective treatments, poor understanding, and misconceptions about the condition^{27,33} contributed to their frustration. Similar experiences have been reported by patients with gastrointestinal motility disorders.⁵⁴

This Review has identified an urgent need to improve training for health-care professionals in managing functional gastrointestinal and motility disorders, which is likely to be an effective way of reducing stigmatisation.

In addition to receiving better training in neurogastroenterology and motility disorders,^{55,56} health-care professionals caring for these patients should be provided with specific communication skills training to optimise the patient–provider relationship.⁵⁷ Such training would help them to avoid enacted and perceived stigmatisation during their consultations, which have consistently been shown to result in poor doctor–patient interactions, poor adherence to medication, reduced quality of life, anxiety, depression, and ultimately higher health-care use.^{27,30,32,40,39,47} Patients often think that their condition is trivialised or not taken seriously by their health-care professionals, with the implication that their illness is self-inflicted or all in their minds. As a result, many patients report dissatisfaction with consultations and a low level of trust in their doctors.

Traditionally, there have been few effective pharmacological options for patients with IBS, which could explain some of the difficulties experienced by health-care providers. In fact, the ineffectiveness of therapies has been cited as the reason for the relatively low pharmaceutical costs in IBS, with most of the expenditure consumed by recurrent outpatient attendance, hospital admissions, and significant indirect costs.⁵⁸ However, several novel medications have emerged, which have been shown to be effective in patients with moderate to severe IBS.⁵⁹ Two of these medications, eluxadoline for IBS-D⁶⁰ and lubiprostone for IBS-C,⁶¹ were initially approved in the UK and in Europe, but were subsequently withdrawn because of low demand and poor sales. Although the exact reasons for the poor uptake of these medications are unclear, the low interest in IBS among clinicians is likely to be an important factor.

Although there are few comparative studies, the apparent differences in stigma against IBS and IBD are striking. Despite sharing many symptoms, people with IBS clearly endure more stigma than do people with IBD.^{40,41} Similar associations have been observed in other functional conditions, which have been shown to be more stigmatised than comparable non-functional diseases.³⁴ There is also evidence that stigmatisation of chronic diseases could negatively influence the amount of research carried out into them.^{9,62,63} Research funding from national funding bodies is recognised as a major driver for scientific and medical progress, and it is therefore vital that resources are allocated proportionately to disease burden and prevalence.⁶⁴ Despite the prevalence of IBS being about 10 times higher than IBD, comparative studies on research funding in gastrointestinal diseases conducted in both North America and Europe have confirmed a marked disparity in funding, disproportional to disease prevalence and relative burden.^{58,64–66} Although the exact reasons for the substantial underfunding of IBS research relative to research IBD remains unclear, it is possible that stigmatisation is a factor. For example, previous work has shown that stigma and discrimination can lead to

Search strategy and selection criteria

DHV and MH completed a PubMed search to identify peer reviewed articles in English. The search terms “IBS”, “irritable bowel”, “functional bowel disorder”, and “spastic colon” were used in combination with the terms “stigma”, “stigmatisation”, “stigmatized”, “shame”, “stereotype”, “discrimination”, “prejudice”, “teasing”, “blame”, and “identity” using the “AND” operator. Search results were included up until Jan 31, 2019. All titles, abstracts, and reference lists from identified articles were assessed for relevance.

negative effects on public views about resource allocation.^{67,68} Single-disease charities and advocacy groups can have a large impact on policy and research funding,⁶⁹ and it might be harder for stigmatised diseases to achieve the same level of support from such organisations. Moreover, if a condition is seen as having a cause that “should be controllable by the patient”, it is possible that funding bodies might think such disorders are “less deserving” of resources.⁷⁰

In addition to raising awareness of stigmatisation of IBS, this Review has highlighted some areas for future research and development to address the problem. Reassuringly, stigmatisation was not universal among health-care providers in the studies covered, with some doctors and patients reporting good outcomes when stereotypes were avoided, communication was sympathetic and empathetic, and symptoms were legitimised.²⁷ Consequently, it could be valuable to try to identify what patients find most useful from an IBS consultation, to use this information for training purposes. As proposed in 2018 by the American Neurogastroenterology and Motility Society and the European Society of Neurogastroenterology and Motility, dedicated training for gastroenterology trainees and practicing gastroenterologists is a positive step, but it is in its infancy.⁷¹ It is also imperative that medical students are taught how to internally deal with their own frustration when confronted with a patient with negative tests and continuing gastrointestinal symptoms or any other unexplained medical symptoms, because not showing frustration is also likely to improve patients’ outcomes. In addition, IBS needs to have more prominence in the medical student curriculum and particularly in the final exam.⁷² If a student knows that IBS is very unlikely to feature in their exam, they are unlikely to take it seriously.

The studies presented here have also indicated that inadequate understanding and empathy among the general public are associated with stigmatisation. In other commonly stigmatised conditions, increasing levels of education and familiarity with a disease have been shown to reduce stigma and promote a more positive attitude towards the illness.^{73,74} Efforts to increase public understanding of IBS might, therefore, be effective in reducing enacted stigma. Finally, all of the

studies identified, with one exception, were done in white populations. Because IBS has a worldwide prevalence, it would be interesting to compare stigmatisation across different populations and to observe differences and their effects between areas.

In conclusion, IBS is associated with high levels of stigma, which detrimentally affects clinical outcomes. There is, therefore, an urgent need for further research into stigma and interventions to minimise this problem.

Contributors

DHV and MH did the literature review, MH wrote the manuscript, and PJW and DHV were involved in conception of the manuscript, helped write and revise the manuscript, and provided critical intellectual input.

Declaration of interests

DHV has acted as a consultant for Allergan Pharma and Shire, and PJW has acted as a consultant or received research funding from Danone, Allergan Pharma, Ironwood Pharma, and Salix Pharma, all outside of the submitted work. MH declares no competing interests.

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References

- Drossman DA. Functional gastrointestinal disorders: history, pathophysiology, clinical features, and rome IV. *Gastroenterology* 2016; **150**: 1262–79.
- Canavan C, West J, Card T. The epidemiology of irritable bowel syndrome. *Clin Epidemiol* 2014; **6**: 71–80.
- Gunn MC, Cavin AA, Mansfield JC. Management of irritable bowel syndrome. *Postgrad Med J* 2003; **79**: 154–58.
- Mertz H, Naliboff B, Munakata J, Niazi N, Mayer EA. Altered rectal perception is a biological marker of patients with irritable bowel syndrome. *Gastroenterology* 1995; **109**: 40–52.
- Kanazawa M, Palsson OS, Thiwan SI, et al. Contributions of pain sensitivity and colonic motility to IBS symptom severity and predominant bowel habits. *Am J Gastroenterol* 2008; **103**: 2550–61.
- Madden JA, Hunter JO. A review of the role of the gut microflora in irritable bowel syndrome and the effects of probiotics. *Br J Nutr* 2002; **88** (suppl 1): S67–72.
- Drossman DA, Camilleri M, Mayer EA, Whitehead WE. AGA technical review on irritable bowel syndrome. *Gastroenterology* 2002; **123**: 2108–31.
- Bennett EJ, Tennant CC, Piesse C, Badcock CA, Kellow JE. Level of chronic life stress predicts clinical outcome in irritable bowel syndrome. *Gut* 1998; **43**: 256–61.
- Link BG, Phelan JC. Stigma and its public health implications. *Lancet* 2006; **367**: 528–29.
- Lydiard RB, Falsetti SA. Experience with anxiety and depression treatment studies: implications for designing irritable bowel syndrome clinical trials. *Am J Med* 1999; **107**: S65–73.
- Walker EA, Katon WJ, Keegan D, Gardner G, Sullivan M. Predictors of physician frustration in the care of patients with rheumatological complaints. *Gen Hosp Psychiatry* 1997; **19**: 315–23.
- Homma M, Ishikawa H, Kiuchi T. Association of physicians’ illness perception of fibromyalgia with frustration and resistance to accepting patients: a cross-sectional study. *Clin Rheumatol* 2016; **35**: 1019–27.
- Atarodi S, Rafieian S, Whorwell PJ. Faecal incontinence—the hidden scourge of irritable bowel syndrome: a cross-sectional study. *BMJ Open Gastroenterol* 2015; **1**: e000002.
- Farnsdale R, Roberts L. Long-term impact of irritable bowel syndrome: a qualitative study. *Prim Health Care Res Dev* 2011; **12**: 52–67.
- Hungin AP, Chang L, Locke GR, Dennis EH, Barghout V. Irritable bowel syndrome in the United States: prevalence, symptom patterns and impact. *Aliment Pharmacol Ther* 2005; **21**: 1365–75.
- Agrawal A, Whorwell PJ. Irritable bowel syndrome: diagnosis and management. *BMJ* 2006; **332**: 280–83.
- Hitchcock LS, Ferrell BR, McCaffery M. The experience of chronic nonmalignant pain. *J Pain Symptom Manage* 1994; **9**: 312–18.

- 18 Miller V, Hopkins L, Whorwell PJ. Suicidal ideation in patients with irritable bowel syndrome. *Clin Gastroenterol Hepatol* 2004; **2**: 1064–68.
- 19 Pearson JS, Pollard C, Whorwell PJ. Avoiding analgesic escalation and excessive healthcare utilization in severe irritable bowel syndrome: a role for intramuscular anticholinergics? *Therap Adv Gastroenterol* 2014; **7**: 232–37.
- 20 Farmer AD, Ferdinand E, Aziz Q. Opioids and the gastrointestinal tract—a case of narcotic bowel syndrome and literature review. *J Neurogastroenterol Motil* 2013; **19**: 94–98.
- 21 Hungin AP, Whorwell PJ, Tack J, Mearin F. The prevalence, patterns and impact of irritable bowel syndrome: an international survey of 40,000 subjects. *Aliment Pharmacol Ther* 2003; **17**: 643–50.
- 22 Drossman DA, Leserman J, Hu JB. Gastrointestinal diagnosis, abuse history, and effects on health status. *Gastroenterology* 1996; **111**: 1159–61.
- 23 Longstreth GF. Avoiding unnecessary surgery in irritable bowel syndrome. *Gut* 2007; **56**: 608–10.
- 24 Björkman I, Dellenborg L, Ringström G, Simrén M, Jakobsson Ung E. The gendered impact of irritable bowel syndrome: a qualitative study of patients' experiences. *J Adv Nurs* 2014; **70**: 1334–43.
- 25 Borum ML. Physician perception of IBS management in women and men. *Dig Dis Sci* 2002; **47**: 236–37.
- 26 Dancy CP, Hutton-Young SA, Moye S, Devins GM. Perceived stigma, illness intrusiveness and quality of life in men and women with irritable bowel syndrome. *Psychol Health Med* 2002; **7**: 381–95.
- 27 Dixon-Woods M, Critchley S. Medical and lay views of irritable bowel syndrome. *Fam Pract* 2000; **17**: 108–13.
- 28 Drossman DA, Chang L, Schneck S, Blackman C, Norton WF, Norton NJ. A focus group assessment of patient perspectives on irritable bowel syndrome and illness severity. *Dig Dis Sci* 2009; **54**: 1532–41.
- 29 Håkanson C, Sahlberg-Blom E, Nyhlin H, Ternstedt B-M. Struggling with an unfamiliar and unreliable body: the experience of irritable bowel syndrome. *J Nurs Healthc Chronic Illn* 2009; **1**: 29–38.
- 30 Halpert A, Godena E. Irritable bowel syndrome patients' perspectives on their relationships with healthcare providers. *Scand J Gastroenterol* 2011; **46**: 823–30.
- 31 Hamberg K, Risberg G, Johansson EE. Male and female physicians show different patterns of gender bias: a paper-case study of management of irritable bowel syndrome. *Scand J Public Health* 2004; **32**: 144–52.
- 32 Jones MP, Keefer L, Bratten J, et al. Development and initial validation of a measure of perceived stigma in irritable bowel syndrome. *Psychol Health Med* 2009; **14**: 367–74.
- 33 Letson S, Dancy CP. Nurses' perceptions of irritable bowel syndrome (IBS) and sufferers of IBS. *J Adv Nurs* 1996; **23**: 969–74.
- 34 Looper KJ, Kirmayer LJ. Perceived stigma in functional somatic syndromes and comparable medical conditions. *J Psychosom Res* 2004; **57**: 373–78.
- 35 McCormick JB, Hammer RR, Farrell RM, et al. Experiences of patients with chronic gastrointestinal conditions: in their own words. *Health Qual Life Outcomes* 2012; **10**: 25.
- 36 Mohebbi Z, Sharif F, Peyrovi H, Rakhshan M, Naini MA, Zarshenas L. Self-perception of Iranian patients during their life with irritable bowel syndrome: a qualitative study. *Electron Physician* 2017; **9**: 5885–93.
- 37 Quick V, McWilliams R, Byrd-Bredbenner C. A case-control study of current psychological well-being and weight-teasing history in young adults with and without bowel conditions. *J Hum Nutr Diet* 2015; **28**: 28–36.
- 38 Raine R, Carter S, Sensky T, Black N. General practitioners' perceptions of chronic fatigue syndrome and beliefs about its management, compared with irritable bowel syndrome: qualitative study. *BMJ* 2004; **328**: 1354–57.
- 39 Taft TH, Riehl ME, Dowjotas KL, Keefer L. Moving beyond perceptions: internalized stigma in the irritable bowel syndrome. *Neurogastroenterol Motil* 2014; **26**: 1026–35.
- 40 Taft TH, Keefer L, Artz C, Bratten J, Jones MP. Perceptions of illness stigma in patients with inflammatory bowel disease and irritable bowel syndrome. *Qual Life Res* 2011; **20**: 1391–99.
- 41 Taft TH, Bedell A, Naftaly J, Keefer L. Stigmatization toward irritable bowel syndrome and inflammatory bowel disease in an online cohort. *Neurogastroenterol Motil* 2017; **29**: e12921.
- 42 Thomson S, Dancy CP. Symptoms of irritable bowel in school children: prevalence and psychosocial effects. *J Pediatr Health Care* 1996; **10**: 280–85.
- 43 Earnshaw VA, Quinn DM. The impact of stigma in healthcare on people living with chronic illnesses. *J Health Psychol* 2012; **17**: 157–68.
- 44 Steward WT, Herek GM, Ramakrishna J, et al. HIV-related stigma: adapting a theoretical framework for use in India. *Soc Sci Med* 2008; **67**: 1225–35.
- 45 Person B, Bartholomew LK, Gyaopong M, Addiss DG, van den Borne B. Health-related stigma among women with lymphatic filariasis from the Dominican Republic and Ghana. *Soc Sci Med* 2009; **68**: 30–38.
- 46 Gray AJ. Stigma in psychiatry. *J R Soc Med* 2002; **95**: 72–76.
- 47 Taft TH, Keefer L, Leonhard C, Nealon-Woods M. Impact of perceived stigma on inflammatory bowel disease patient outcomes. *Inflamm Bowel Dis* 2009; **15**: 1224–32.
- 48 Drossman DA, Hasler WL. Rome IV-functional GI disorders: disorders of gut-brain interaction. *Gastroenterology* 2016; **150**: 1257–61.
- 49 Heijnders M, Van Der Meij S. The fight against stigma: an overview of stigma-reduction strategies and interventions. *Psychol Health Med* 2006; **11**: 353–63.
- 50 Saunders B. Stigma, deviance and morality in young adults' accounts of inflammatory bowel disease. *Sociol Health Illn* 2014; **36**: 1020–36.
- 51 Ginsburg IH, Link BG. Psychosocial consequences of rejection and stigma feelings in psoriasis patients. *Int J Dermatol* 1993; **32**: 587–91.
- 52 Sirey JA, Bruce ML, Alexopoulos GS, Perlick DA, Friedman SJ, Meyers BS. Stigma as a barrier to recovery: perceived stigma and patient-rated severity of illness as predictors of antidepressant drug adherence. *Psychiatr Serv* 2001; **52**: 1615–20.
- 53 Kim SY, Kim JM, Kim SW, et al. Perceived stigma and quality of life in patients following recovery from delirium. *J Clin Psychiatry* 2017; **78**: e744–49.
- 54 Twist K, Ablett J, Wearden A, et al. Gastrointestinal dysmotility: a qualitative exploration of the journey from symptom onset to diagnosis. *Neurogastroenterol Motil* 2018; **30**: e13339.
- 55 Vasant DH, Radhakrishnan NV. Competency based medical education in gastrointestinal motility—the UK perspective. *Neurogastroenterol Motil* 2017; **29**: e12927.
- 56 Vasant DH, Sharma A, Bhagatwala J, Viswanathan L, Rao SSC. Apprenticeship-based training in neurogastroenterology and motility. *Expert Rev Gastroenterol Hepatol* 2018; **12**: 215–22.
- 57 Drossman DA. 2012 David Sun lecture: helping your patient by helping yourself—how to improve the patient–physician relationship by optimizing communication skills. *Am J Gastroenterol* 2013; **108**: 521–28.
- 58 Sandler RS, Everhart JE, Donowitz M, et al. The burden of selected digestive diseases in the United States. *Gastroenterology* 2002; **122**: 1500–11.
- 59 Corsetti M, Whorwell P. Novel pharmacological therapies for irritable bowel syndrome. *Expert Rev Gastroenterol Hepatol* 2016; **10**: 807–15.
- 60 Corsetti M, Whorwell P. New therapeutic options for IBS: the role of the first in class mixed μ -opioid receptor agonist and δ -opioid receptor antagonist (mudelta) eluxadoline. *Expert Rev Gastroenterol Hepatol* 2017; **11**: 285–92.
- 61 Drossman DA, Chey WD, Johanson JF, et al. Clinical trial: lubiprostone in patients with constipation-associated irritable bowel syndrome—results of two randomized, placebo-controlled studies. *Aliment Pharmacol Ther* 2009; **29**: 329–41.
- 62 Sharac J, McCrone P, Clement S, Thornicroft G. The economic impact of mental health stigma and discrimination: a systematic review. *Epidemiol Psychiatr Soc* 2010; **19**: 223–32.
- 63 Wilson A. Justice and lung cancer. *J Med Philos* 2013; **38**: 219–34.
- 64 Clerx E, Kupfer SS, Leffler DA. Disparities among gastrointestinal disorders in research funding from the National Institutes of Health. *Gastroenterology* 2017; **153**: 877–80.
- 65 Törnblom H, Simrén M, Barbara G, Niesler B. Funding for gastrointestinal disease research in the European Union. *Lancet Gastroenterol Hepatol* 2018; **3**: 593–95.
- 66 Peery AF, Crockett SD, Murphy CC, et al. Burden and cost of gastrointestinal, liver, and pancreatic diseases in the United States: update 2018. *Gastroenterology* 2019; **156**: 254–72.

- 67 Beck M, Dietrich S, Matschinger H, Angermeyer MC. Alcoholism: low standing with the public? Attitudes towards spending financial resources on medical care and research on alcoholism. *Alcohol Alcohol* 2003; **38**: 602–05.
- 68 Matschinger H, Angermeyer MC. The public's preferences concerning the allocation of financial resources to health care: results from a representative population survey in Germany. *Eur Psychiatry* 2004; **19**: 478–82.
- 69 Best RK. Disease politics and medical research funding: three ways advocacy shapes policy. *Am Sociol Rev* 2012; **77**: 780–803.
- 70 Skitka LJ, Tetlock PE. Allocating scarce resources: a contingency model of distributive justice. *J Exp Soc Psychol* 1992; **28**: 491–522.
- 71 Gyawali CP, Savarino E, Lazarescu A, et al. Curriculum for neurogastroenterology and motility training: a report from the joint ANMS–ESNM task force. *Neurogastroenterol Motil* 2018; **30**: e13341.
- 72 Corsetti M, Whorwell P. The global impact of IBS: time to think about IBS-specific models of care? *Therap Adv Gastroenterol* 2017; **10**: 727–36.
- 73 Corrigan PW, Green A, Lundin R, Kubiak MA, Penn DL. Familiarity with and social distance from people who have serious mental illness. *Psychiatr Serv* 2001; **52**: 953–58.
- 74 Angermeyer MC, Matschinger H. The effect of personal experience with mental illness on the attitude towards individuals suffering from mental disorders. *Soc Psychiatry Psychiatr Epidemiol* 1996; **31**: 321–26.

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