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## Moving beyond perceptions: internalized stigma in the irritable bowel syndrome

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### Abstract

**Background**—Internalized stigma (IS) is an important construct in the chronic illness literature with implications for several patient reported outcomes. To date, no study exists evaluating IS in patients with the irritable bowel syndrome (IBS).

**Methods**—Two hundred and forty three online and clinical participants completed the following questionnaires: the IS scale for mental illness (ISMI; modified for IBS), perceived stigma scale for IBS, NIH-PROMIS Anxiety and Depression Scales, IBS quality of life scale, and the Perceived Health Competence Scale. Demographical and clinical data were also collected.

**Key Results**—The modified ISMI was reliable and valid in this population. Participants reported both perceived and IS. Alienation was most reported, followed by social withdrawal and discrimination experiences. IS predicted 25–40% of the variance in psychological functioning, quality of life, healthcare utilization, and health competence when controlling for stigma perception and disease variables. IBS patients perceived more stigma from personal relations than healthcare providers. Hispanic participants reported more perceived stigma, indicating there may be cultural differences in IBS-related stigma experience. Symptom severity, disruptiveness, and treatment choices are also implicated in stigma perception and internalization.

**Conclusions & Inferences**—Patients with IBS report both perceived and IS with alienation most reported. However, IS significantly predicts several patient outcomes when controlling for PS. Cultural and illness traits may influence how stigma is perceived and internalized. Future research is warranted.

### Keywords

internalized stigma; irritable bowel syndrome; patient outcomes; perceived stigma

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#### AUTHOR CONTRIBUTION

TT was responsible for study design, data collection, statistical analyses, and final manuscript preparation. MR, KD, and LK assisted with data interpretation and manuscript preparation.

#### CONFLICTS OF INTEREST

The authors have no competing interests to disclose.

## INTRODUCTION

Functional somatic syndromes are chronic conditions characterized by persistent physical symptoms but lack any known pathological basis. Irritable bowel syndrome (IBS) is one of the most costly and common functional bowel disorders with significant impact on an individual's quality of life.<sup>1,2</sup> Current IBS prevalence estimates range from 10% to 22% in western populations<sup>1,3</sup> and the individual costs associated with IBS can be upwards of 5500 USD spent per year,<sup>4</sup> while the annual societal burden is ~20 billion USD.<sup>2</sup>

Stigma is social devaluation or discrimination based on negative stereotypes of a population with a particular characteristic.<sup>5</sup> Chronic illness stigma is a continuing public health issue with several detrimental effects on important patient reported outcomes (PROs).<sup>6–13</sup> One predominant theory illustrates three types of stigma: experienced, perceived, and internalized.<sup>14</sup> Experienced stigma is characterized by an outside group displaying biased or prejudiced attitudes toward a stigmatized population. However, perceived stigma relates to an individual's intuition of discriminatory behaviors displayed by others. The final subtype, internalized stigma (IS), is the level in which an individual endorses various stereotypes about their condition. While a person would need to perceive stigmatizing behaviors or attitudes to internalize them, prior studies in other populations show that only some individuals go on to internalize these attitudes into their own schema. Indeed, some patients actively resist stigma toward their illness.<sup>15,16</sup>

Internationally, the Rome III criteria set the current and primarily symptom-based diagnostic standard for IBS in the absence of organic pathology.<sup>17</sup> Bloating, bowel fluctuations or urgency, and abdominal pain are commonly associated with reduced quality of life in IBS patients, while other factors such as dietary restrictions, sleep disruption, emotional distress, and daily activity limitations contribute as well.<sup>18</sup> In addition, the ambiguous cause of IBS, its ability to be concealed, and uncertain symptom course can lead to misinformation or confusion, further causing elevated levels of stigma.<sup>19</sup> High psychiatric comorbidity and perceptions of physical or emotional disability contribute to the notion that IBS is psychological, which can increase the risks of stigmatization,<sup>20</sup> making this an important area of inquiry.

Previous research in this area has indicated patients with IBS report some perceived stigma.<sup>10,19</sup> With a lack of obvious biomarkers, IBS patients can experience a lack of understanding about their disorder from family members, significant others, and healthcare providers.<sup>21,22</sup> Complex psychological processes lead some individuals to adopt these negative beliefs into their self-concept, leading to additional degradations in well-being. Individuals who have internalized the stigma toward their condition feel shame because they are more likely to endorse stereotypes and believe them to be accurate descriptions of themselves. Most IS research centers on HIV/AIDS, cancer, obesity, and mental illness with consistent results in that IS increases depression<sup>12,23</sup> and anxiety,<sup>23,24</sup> reduces healthcare utilization,<sup>25</sup> decreases self-esteem,<sup>23,26</sup> self-efficacy,<sup>27</sup> and treatment adherence,<sup>12,28</sup> and leads to poorer health-related quality of life<sup>24</sup> and disease outcomes.<sup>9,10,27,29,30</sup> To date, stigma research for IBS has focused only on stigma perceptions and not whether patients tend to internalize, or believe, the negative attitudes they perceive others to hold toward

them and their illness. No research exists that evaluates how IS may influence IBS patient outcomes. We aim to evaluate IS and its relationship with stigma perception, and how each may impact psychological well-being and health competence, or a patient's perceived ability to manage health outcomes, in this population.

## METHODS

Potential study participants were recruited via a university-based outpatient gastroenterology clinic and from online sources (Facebook, Twitter, message boards: [www.ibsgroup.org](http://www.ibsgroup.org), [www.healingwell.com](http://www.healingwell.com)). Clinical participants completed paper-based questionnaires, while online participants completed the same measures via a secure, third party survey provider. The IBS diagnosis was confirmed for clinical patients using Rome III criteria by a gastroenterologist; Rome III modular screening questions were used for online participants prior to being able to complete study. After obtaining informed consent, participants completed a series of self-report questionnaires.

### Demographical and clinical background

Demographical variables included gender, race, ethnicity, age, marital status, education, income, and primary health insurance. Clinical variables included IBS subtype (Diarrhea, Constipation, or Mixed), diagnosis duration, symptom duration prior to diagnosis, symptom frequency ('When your IBS is active please indicate how many days per week, on average, you experience IBS symptoms') and severity ('On a scale of 1 to 10, please rate how SEVERE your IBS symptoms have been over the past 3 months [on average]'), disruption to daily ('On a scale of 1 to 10, please indicate how DISRUPTIVE your IBS symptoms are to your daily activities in the last 3 months') and social activities ('On a scale of 1 to 10, please indicate how DISRUPTIVE your IBS symptoms are to your social life in the last 3 months'), openness to disclosing IBS ('On a scale of 1 to 10, please rate how open you are to discussing your IBS with others'), treatments for IBS in past 30 days (prescription, over-the-counter, dietary supplements, and other complimentary/alternative methods), and physician visits for IBS in past year.

### Perceived health competence survey (PHCS)<sup>31</sup>

The PHCS provides a measure of patients' perceived ability to manage health outcomes. Higher scores on the PHCS reflect higher perceived health competence. This scale has good internal validity (Cronbach's alphas ranged from 0.82 to 0.90 across samples), construct validity, and test-retest reliability.

### Irritable bowel syndrome-quality of life (IBS-QOL)<sup>32</sup>

The IBS-QOL is a 30-item self-report measure of health-related quality of life and addresses 10 domains: emotional health, mental health, health belief, sleep, energy, physical functioning, diet, sexual relations, social, and physical functioning. Higher scores indicate better quality of life. The IBS-QOL demonstrates good reliability and validity across several studies.

### NIH-PROMIS short form anxiety & depression scales<sup>33</sup>

The Anxiety scale measures self-reported fear (fearfulness, panic), anxious misery (worry, dread), hyperarousal (tension, nervousness, restlessness), and somatic symptoms related to arousal (racing heart, dizziness). The Depression scale assesses self-reported negative mood (sadness, guilt), views of self (self-criticism, worthlessness), and social cognition (loneliness, interpersonal alienation), as well as decreased positive affect and engagement (loss of interest, meaning, and purpose). For both scales, each question has five response options ranging in value from one to five. Higher scores denote greater psychological distress.

### Internalized stigma for mental illness scale (ISMI)<sup>34,35</sup>

The ISMI assessed the degree to which participants believe or internalize stigmatizing attitudes about IBS. The ISMI is a 29-item self-report measure with items ranked on a 4-point Likert Scale (Strongly Disagree to Strongly Agree). The ISMI yields four stigma subscales: alienation ('I feel out of place in the world because I have [IBS]'), social withdrawal ('I don't socialize as much as I used to because my [IBS] might make me look or behave "weird"'), discrimination ('People discriminate against me because I have [IBS]'), and stereotype endorsement ('People with [IBS] cannot live a good, rewarding life'). An optional fifth subscale for stigma resistance was not used in this study. Scale scores are classified by four ranges (minimal, mild, moderate, and severe). For this study, the term 'mental illness' was replaced with 'Irritable Bowel Syndrome' or 'IBS'. One question was changed due it not being applicable to the study sample ('People with mental illness tend to be dangerous' was modified to 'People with IBS tend to be dirty'). Higher scores indicate greater IS with a maximum score of 4.0 for each scale. The ISMI demonstrates good reliability (Cronbach  $\alpha$  0.81–0.94, Test–Retest reliability 0.62–0.92) and validity across multiple languages and cultures,<sup>33</sup> including when modified for medical populations (to date: eating disorders, epilepsy, inflammatory bowel disease [IBD], leprosy).<sup>33</sup>

### Perceived stigma scale for IBS (PSS-IBS)<sup>21</sup>

The PSS-IBS is a 10-item questionnaire designed to measure perceived stigma in IBS patients that focuses on disclosure, attitudes and knowledge about IBS, illness validity, seriousness, and blame (Table 4). These items produce an overall stigma score and two subscale scores: significant others (family, friends, and spouse) and healthcare providers (physicians, nurses, and staff). Higher scores indicate greater levels of perceived stigma. Preliminary findings suggest that the PSS-IBS is a valid and reliable measure of patient-perceived stigma.<sup>10,21</sup> Three scores are calculated by summing the values for each item and dividing by the number of questions answered for each scale. Maximum possible score for each scale is 5.0.

This study was reviewed and approved by the institutional review board of Northwestern University. All data were obtained anonymously.

### Statistical analyses

Online data were exported to SPSS version 20 (IBM-SPSS, Inc., Chicago, IL, USA) and combined with the paper-based questionnaire data for analyses. Tests for normal

distribution were conducted to identify need for non-parametric tests. Descriptive statistics evaluated the demographical and clinical variables of the sample. Independent samples *t*-tests and *Z*-tests for two proportions evaluated differences between online and clinical participants. Reliability of the ISMI and PSS-IBS was evaluated using Cronbach's  $\alpha$  and Guttman split-half reliability statistics. Validity of these scales was evaluated by Pearson's correlations with clinical and patient outcome data. Mean plus standard deviation scores were calculated for each scale of the ISMI and PSS-IBS with Pearson's correlations evaluating the relationship between perceived and IS. A series of Independent Samples *t*-tests and one-way ANOVA were used to explore significant differences between categorical demographical and clinical variables for perceived and IS, as well as differences in levels of perceived stigma from personal relationships and medical providers. To correct for Type I error from multiple comparisons, statistical significance was set a  $p = 0.01$  for these analyses. Four separate hierarchical regression analyses determined the relationship between both stigmas and patient outcomes. Variables were entered in a block fashion and yielded three models: model 1 contained only perceived stigma, model 2 included perceived and IS, and model 3 added four illness severity variables (symptom severity, symptom frequency, social disruption, daily activity disruption). Variation inflation factor values were set at or below 10 to test for multicollinearity and Durbin-Watson statistic evaluated autocorrelation (range 0–4). R square, change in R square, and change in model significance are reported for each model. Statistical power was set at 0.80 for multivariate analyses.

## RESULTS

A total of 243 participants completed the study. For online participants, 34 who consented to the study did not finish all of the questionnaires (completion rate: 80%). The sample was mostly female, Caucasian, non-Hispanic, and college educated (Table 1). All data were normally distributed. There were some significant differences between recruitment sources. The online sample was more likely to be Caucasian or use dietary supplements, while the clinical sample was more likely to have constipation predominant or mixed IBS, have seen a dietitian or therapist as part of their IBS treatment, and reported more frequent and more severe symptoms (Table 1).

### Reliability and validity of ISMI & PSS-IBS

Prior to conducting statistical comparisons, we evaluated the reliability and validity of the ISMI and PSS-IBS in our sample. Overall, both measures demonstrated excellent internal consistency both for the total scale and subscale scores (Table 2). All values were above the standard acceptability cutoff of 0.70, indicating the ISMI and PSS-IBS reliably measured the two stigma constructs in this sample. Validity was supported for both measures by significant positive correlations with IBS symptom severity and frequency, disruptiveness, psychological distress and degradation of HRQOL, and significant negative correlations with perceived health competence (Table 3). Internalized stigma was moderately and positively correlated with perceived stigma from significant others ( $r = 0.55, p < 0.001$ ) and healthcare providers ( $r = 0.36, p < 0.001$ ). Correlations between IS subscales and total perceived stigma ranged from  $r = 0.41$  to  $r = 0.49$ , all  $p < 0.001$ , indicating separate but related constructs.

## Stigma perception and internalization

Overall, participants reported both stigma perception and internalization (Table 2). Participants perceived more stigma from personal relationships than from healthcare providers. Item-level analyses of the PSS-IBS showed that these differences occurred for all items except being treated differently or having opportunities limited (Table 4). For IS, the highest mean scores were for alienation and social withdrawal, and lowest score for stereotype endorsement.

We conducted an exploratory analysis of differences between categorical demographical and clinical variables for perceived and IS scores. Ethnicity, recruitment source, and certain treatments demonstrated significant differences in stigma perception. Hispanic participants ( $N = 22$ ) reported more perceived stigma for both personal relationships ( $M = 2.90$  vs  $1.67$ ),  $t(196) = 9.24$ ,  $p = 0.000$  and healthcare providers ( $M = 2.30$  vs  $1.19$ ),  $t(197) = 7.62$ ,  $p = 0.000$ . Online participants ( $N = 139$ ) perceived significantly more stigma from significant others ( $M = 2.92$  vs  $1.75$ ),  $t(205) = 8.91$ ,  $p = 0.000$  and medical providers ( $M = 2.33$  vs  $1.27$ ),  $t(206) = 7.32$ ,  $p = 0.000$ . Patients who use supplements ( $N = 102$ ) reported greater perceived stigma from healthcare providers ( $M = 2.60$  vs  $2.11$ ),  $t(112) = 2.58$ ,  $p = 0.01$ , while those who had seen a therapist ( $N = 112$ ) in the past 3 months reported significantly lower perceived stigma from both personal relationships ( $M = 1.90$  vs  $2.86$ ),  $t(205) = -6.93$ ,  $p = 0.000$  and healthcare providers ( $M = 1.37$  vs  $2.30$ ),  $t(206) = -6.21$ ,  $p = 0.000$ .

For IS, only patients who used complementary and alternative (CAM) methods other than supplements or OTC medications (e.g., acupuncture, chiropractic medicine, massage;  $N = 44$ ) reported significantly more IS across several domains: Alienation ( $M = 2.30$  vs  $1.84$ ),  $t(118) = 2.74$ ,  $p = 0.007$ ; Stereotype Endorsement ( $M = 1.54$  vs  $1.27$ ),  $t(117) = 3.00$ ,  $p = 0.003$ ; Discrimination ( $M = 1.82$  vs  $1.40$ ),  $t(118) = 3.07$ ,  $p = 0.003$ ; and Social Withdrawal ( $M = 2.09$  vs  $1.65$ ),  $t(117) = 2.74$ ,  $p = 0.007$ . No significant differences were found for the other demographical and clinical variables.

## Relationship between stigma and patient outcomes

Modest positive correlations exist between both internalized and perceived stigma and the number of physician visits for IBS in the past year (Table 3). As this finding is contrary to some data on the relationship between stigma and healthcare utilization, we evaluated these correlations by recruitment source and found that these relationships remained significant for the online participants, but did not achieve significance while exhibiting negative relationships for the clinical sample.

Hierarchical regression analyses were first evaluated for multicollinearity and autocorrelation. Variation inflation factor values ranged from 1.3 (Sx Frequency) to 5.7 (Disruption Daily Activities), and were below the standard cutoff score of 10 for multicollinearity. Durbin-Watson statistics were all close to 2.0, ranging from 1.7 (HRQOL) to 2.3 (Depression), indicating no autocorrelation. Statistical power fell well above the 0.80 cutoff for each regression analysis. Both perceived and IS uniquely contributed to a percentage of the variance for all patient outcome variables (Table 5). The directionality of the standardized beta weights was as expected in that people who reported greater

stigma experienced more anxiety and depression, a greater negative impact on HRQOL, reduced perceived health competence, and increased healthcare utilization. Internalized stigma contributed almost twice the variance for increases in anxiety, depression, and poorer HRQOL than perceived stigma; for perceived health competence the effects were essentially equal. There was minimal weakening of the stigma relationship with these outcome variables when disease variables were considered, with the exception being the disruptiveness of symptoms on social activities affecting the relationship between stigma and HRQOL. For healthcare utilization, IS explained three times the variance than perceived stigma, with the relationship between stigma perception and physician visits becoming non-significant when IS was entered into the regression model. However, these relationships were brought to non-significance when other illness variables were entered into the third model.

## DISCUSSION

This is the first study to evaluate the presence of IS in IBS and its relationship with stigma perception and psychosocial PROs. The ISMI modified for IBS was a reliable and valid measure of IS in this sample. We found IBS patients reported both perceived and IS, with alienation being the most reported IS construct. The ISMI alienation scale gauges a person's experience of being less than a full member of society via items such as 'Having IBS has ruined my life' and 'I feel out of place in the world because I have IBS'.<sup>34</sup> Feelings of alienation and isolation are often reported in IBS patients<sup>18,36</sup> and negative interpersonal interactions may make IBS patients uncomfortable with discussing their condition, avoid activities,<sup>18</sup> experience greater stress, and have poorer HRQOL.<sup>37</sup>

Jones *et al.*'s 2009 pioneering study on perceived stigma in IBS found friends, family, and colleagues (i.e., significant others) were the more likely sources of stigmatizing interactions. In a 2011 study, stigma perception predicted poorer outcomes for both IBS and IBD patients.<sup>10</sup> Our current findings are congruent in that patients reported more stigma from significant others than medical providers, and perceived stigma was moderately correlated with increased anxiety and depression, and decreased HRQOL and health competence. However, perception is only part of the broader understanding of stigma in this patient population.

Previous research indicates IS has a potential role in determining several outcomes including treatment adherence, access to care, psychological and social functioning, and disease activity.<sup>35,38–40</sup> Specific to chronic gastrointestinal (GI) illness, IS is a predictor of poorer self-esteem, lower disease-specific self-efficacy, and greater psychological distress in patients with IBD.<sup>9</sup> Similar trends existed in our IBS sample, with IS accounting for 25–40% of the variance in anxiety, depression, HRQOL, healthcare utilization, and health competence when controlling for perceived stigma, illness severity, and symptom disruptiveness. As there are significant data to suggest mental illness contributes to stigma experiences, it is likely that individuals with increased levels of anxiety and depression may also report higher levels of stigma; our study design does not allow us to identify this bi-dimensional relationship and is an important consideration for future research.

The relationship between symptom severity and stigma is complex and mediated by other psychosocial variables<sup>41</sup>; thus, we cannot differentiate if having more severe IBS leads greater stigma or if stigma exacerbates IBS symptoms. Internalized stigma and perceived stigma from healthcare providers, but not personal relationships, are significantly correlated with more frequent, severe, and disruptive IBS symptoms. The importance of the patient–physician relationship is extensively studied, including in GI illness.<sup>42–45</sup> A majority of IBS patients report negative interactions from their medical providers<sup>45</sup> and significant disparities exist between what IBS patients need and what they receive from their physicians. Providers should be mindful of their approach with IBS patients to minimize behaviors that may be perceived as stigmatizing, especially with those with a more severe condition.

We found differences in who experiences IBS stigma by ethnicity, recruitment source, and treatment choices. Culture is an important determinant in how patients define and seek treatment for an illness, including IBS.<sup>46</sup> Data on racial and ethnic differences in IBS patients focus on HRQOL, epidemiology, and illness severity.<sup>47,48</sup> Differences exist between Hispanic and non-Hispanic patients in experiences with functional somatic symptoms<sup>49</sup> and health-related stigma.<sup>50,51</sup> We found Hispanic participants reported more perceived stigma from both personal relations and healthcare providers, however our Hispanic sample size is small and may not be sufficiently powered to accurately reflect these differences. Regarding the latter, sociocultural meanings and illness experience impact how symptoms are described<sup>46,52</sup> and disconnect between a medical provider and the Hispanic patient may contribute to perceptions of stigma. In addition, traditional health beliefs and practices are common and combined with Western medicine approaches in Hispanic cultures,<sup>53</sup> highlighting the importance of cultural competence in working with Hispanics with IBS. Additional research to understand differences in ethnic and racial experiences in this patient population is needed.

Participants recruited online perceived significantly more stigma than those recruited in the outpatient clinic. People who frequently use the internet tend to be more anxious, emotionally distressed, and lonely than those with less usage.<sup>54–56</sup> Patients with IBS and IBD recruited from online support communities report significantly poorer HRQOL and increased psychological distress than those from an outpatient clinic; it is logical online participants in our study report greater stigma. Online communities may provide a safe haven for the stigmatized, who otherwise feel alienated and isolated from others.<sup>57</sup> It is possible that our sample included a self-selected group with higher levels of stigma than the clinical sample. Healthcare social media is a rapidly expanding area,<sup>58–60</sup> and future studies should include its uses among IBS patients.

Differences in stigma also existed for treatment choices. Participants who regularly use non-prescription supplements identified greater perceived stigma from their healthcare providers. Irritable bowel syndrome patients use CAM therapies, including supplements, due to the limited number of efficacious treatments and a desire for a more natural approach.<sup>61</sup> However, due to lack of quality randomized clinical trials demonstrating the effectiveness of CAM for IBS, medical providers remain cautious before recommending this treatment



option.<sup>62,63</sup> Patients who use supplements may experience varying responses from their medical provider that may be deemed stigmatizing.

Patients who used other CAM methods, such as acupuncture, chiropractic medicine, or massage, reported significantly more IS. Feelings of alienation, social withdrawal, and discrimination (especially from healthcare providers), may draw a person to a more holistic approach regardless of documented efficacy.<sup>64</sup> Alternatively, IBS patients who are more distressed may seek any treatment possible to alleviate their condition,<sup>18</sup> engaging in potentially risky illness behaviors in an attempt to solve a seemingly unsolvable problem.<sup>65</sup> Finally, patients who recently saw a therapist reported significantly less perceived stigma from both personal relationships and from healthcare providers. There is wide and growing support for the use of behavioral therapies in the treatment of IBS.<sup>66–69</sup> Managing the negative effects of perceived and IS should be incorporated into these intervention for appropriately referred patients.

There are some limitations to the present study that should be taken into consideration when interpreting its results. We utilized a cross-sectional design and drew data from both online and clinical participants, which demonstrated some significant differences in symptom presentation and severity, as well as treatments used. Exploratory analyses were conducted to establish differences among groups for IS and PS, and thus should be interpreted with caution. While screening questions helped determine if an online participant had IBS, the diagnosis could not be confirmed. The majority of the participants (86%) were Caucasian, non-Hispanic women, so some discretion should be taken when applying these results to other ethnic or racial populations. Future studies should aim to obtain more diverse samples to determine how IBS stigma is influenced by cultural factors. Online participants with IBS may feel less support from others and decreased satisfaction with treatment options, which may bias their responses toward significantly more perceived stigma. Part of our sample population was recruited from a university-based GI clinic, indicating these participants actively sought specialized medical treatment for their IBS symptoms. It is possible these patients are more satisfied with treatment than their online counterparts, and therefore reported lower levels of perceived stigma from healthcare providers.

The results of the present study illustrate the impact IS has on IBS patients, significantly contributing to increased depression and anxiety, poorer reported quality of life, and decreased health competence when controlling for disease severity, intrusiveness, and stigma perception. Irritable bowel syndrome patients report more stigma from significant others, but stigma from healthcare providers is also an important consideration. Additional research, including longitudinal studies to understand how stigma and its relationship with PROs evolves over time, is needed. In the interim, psychological interventions for IBS should consider the role of IS in treatment and outcomes.

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### Key Messages

- Illness stigmatization, an important consideration in managing patient outcomes, has yet to be studied amongst IBS patients.
- Two hundred and forty three participants completed questionnaires about stigma experiences, beliefs, psychological function, quality of life, and health competence.
- Patients with IBS report both perceived and internalized stigma, and internalized stigma significantly predicts several patient outcomes.
- Cultural and illness traits may influence how stigma is perceived and internalized.

**Table 1**Demographical and clinical description of study sample ( $N = 243$ )

Demographical	Total sample	Online ( $n = 139$ )	Clinic ( $n = 104$ )
Female gender	86% (209)	89% (120)	83% (89)
Caucasian	88% (214)	95% (133)	76% (81)***
Non-Hispanic	91% (221)	95% (130)	85% (91)
Age (years)	38.7 ± 13.5	37.4 ± 13.1	40.2 ± 14.0
Married	42% (102)	41% (57)	57% (45)
College graduate	74% (180)	73% (102)	75% (78)
Household income \$50,000	47% (114)	49% (66)	46% (48)
Private insurance	69% (168)	68% (94)	71% (74)
<i>Clinical presentation</i>			
IBS subtype			
IBS-D	36% (87)	37% (51)	35% (36)
IBS-C	31% (75)	21% (29)	44% (46)**
IBS-M	33% (80)	42% (59)	20% (21)**
Diagnosis duration (years)	9.4 ± 8.5	9.3 ± 8.7	10.6 ± 6.3
Symptom duration prior to Dx (months)	45.2 ± 73.6	46.2 ± 75.2	25.9 ± 23.2
Symptom frequency (days per week)	5.4 ± 2.6	5.6 ± 2.4	7.4 ± 1.5*
Symptom severity (out of 10)	5.9 ± 2.4	5.8 ± 2.4	7.7 ± 2.4*
Symptom disruptiveness (out of 10)			
Daily activities	5.5 ± 2.6	5.4 ± 2.6	6.9 ± 3.1
Social activities	5.3 ± 2.9	5.3 ± 2.9	6.4 ± 3.3
Current IBS treatment			
Rx medication	36% (87)	30% (42)	43% (45)
OTC medication	53% (129)	58% (80)	47% (49)
Supplements	42% (102)	52% (72)	29% (30)**
Other CAM	18% (44)	20% (28)	15% (16)
No treatment	11% (27)	14% (20)	7% (7)
# physician visits past year for IBS	4.0 ± 3.9	3.8 ± 3.6	7.9 ± 6.4
Dietitian <sup>†</sup>	9% (22)	5% (7)	14% (15)*
Therapist <sup>‡</sup>	46% (112)	10% (14)	94% (98)***
Openness to disclosure of IBS <sup>§</sup>	5.6 ± 2.9	5.6 ± 2.9	7.0 ± 2.7

\*  $p < 0.05$ \*\*  $p < 0.01$ \*\*\*  $p < 0.001$ .

IBS-D: diarrhea predominant; IBS-C: constipation predominant; IBS-M: mixed presentation; Dx: diagnosis; Rx: prescription; OTC: over-the-counter; CAM: complimentary alternative medicine.

<sup>†</sup>Patients who saw dietitian for IBS in past 3 months.

<sup>‡</sup>Patients who saw therapist (Psychologist, Social Worker, Counselor) for psychotherapy related to IBS in past 3 months.

<sup>§</sup>Average response to item 'On a scale of 1 to 10, please rate how open you are to discussing your IBS with others'.

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**Table 2**

Reliability statistics and mean scores for ISMI &amp; PSS-IBS

	Cronbach $\alpha$ <sup>*</sup>	Guttman Split-Half Coefficient <sup>†</sup>	Mean (SD)
ISMI (Entire Scale) <sup>‡</sup>	0.91	0.88	1.61 (0.53)
Alienation	0.86	0.84	2.00 (0.72)
Social Withdrawal	0.87	0.86	1.74 (0.67)
Stereotype Endorsement	0.76	0.80	1.33 (0.38)
Discrimination Experience	0.86	0.82	1.45 (0.55)
PSS-IBS (Entire Scale) <sup>§</sup>	0.95	0.76	2.08 (1.01)
Significant Others	0.93	0.92	2.30 (1.06)
Medical Providers	0.93	0.91	1.74 (1.09)

<sup>\*</sup>,<sup>†</sup> Measures of consistency and stability for overall scale score and each subscale. Standard acceptable cutoff is 0.70.

<sup>‡</sup> Maximum score is 4.0.

<sup>§</sup> Maximum score is 5.0.

Correlates of stigma perception and internalization with IBS symptoms and psychosocial outcomes

**Table 3**

	Sx FREQ	Sx SEV	Sx disrupt (ADL)	Sx disrupt (SOC)	ANX	DEP	HRQOL impact	PHC	MD visits
Alienation	0.28	0.38	0.53	0.56	0.54	0.67	0.74	-0.40	0.31
Stereotype endorsement	0.27	0.29	0.44	0.46	0.46	0.63	0.59	-0.36	0.27
Discrimination experience	0.17 <sup>NS</sup>	0.28	0.44	0.46	0.46	0.58	0.63	-0.37	0.28
Social withdrawal	0.26	0.37	0.52	0.46	0.54	0.66	0.74	-0.40	0.35
Perceived stigma – PR	0.12 <sup>NS</sup>	0.15 <sup>NS</sup>	0.39	0.40	0.43	0.54	0.59	-0.30	0.25
Perceived stigma – HCP	0.30	0.27	0.29	0.33	0.47	0.44	0.41	-0.36	0.18 <sup>NS</sup>

NS: Non-significant; all other  $p < 0.01$ . FREQ: symptom frequency; SEV: symptom severity; ADL: symptom disruption to daily activities; SOC: symptom disruption to social activities; ANX: anxiety; DEP: depression; HRQOL: health-related quality of life; PHC: perceived health competence.

**Table 4**Mean (SD) item-level perceived stigma scores with independent samples *t*-test comparisons of stigma sources

PSS-IBS item	Significant others	Healthcare providers	<i>t</i>	<i>p</i>
Not taken seriously	2.5 ± 1.3	2.2 ± 1.4	2.29	0.02
Believed to be more 'in my head' than physical	2.4 ± 1.5	2.0 ± 1.5	2.75	0.006
Something I keep hidden	2.1 ± 1.5	1.2 ± 1.2	6.83	<0.0001
Caused by something I'm doing	2.4 ± 1.5	2.0 ± 1.4	2.84	0.005
Cannot be as open as I'd like	2.5 ± 1.4	1.6 ± 1.4	6.62	<0.0001
They do not have enough knowledge about	3.2 ± 1.3	2.4 ± 1.6	5.65	<0.0001
Not interested in hearing about	2.8 ± 1.4	1.8 ± 1.4	7.35	<0.0001
Causes them to treat me differently	1.7 ± 1.4	1.5 ± 1.4	1.47	0.14
Don't understand when I need to change plans	2.5 ± 1.4	2.0 ± 1.7	3.30	0.001
Limit my opportunities because of severity of IBS	1.7 ± 1.4	1.6 ± 1.7	0.66	0.51
Total perceived stigma	2.4 ± 1.1	1.82 ± 1.2	8.66	<0.0001

Hierarchical multiple regression analyses of impact of stigma on psychosocial function and healthcare utilization

Table 5

	Anxiety $\beta$	Depression $\beta$	HRQOL $\beta$	PHC $\beta$	MD visits $\beta$
Model 1					
Perceived stigma	0.52 <sup>***</sup>	0.58 <sup>***</sup>	0.60 <sup>***</sup>	-0.41 <sup>***</sup>	0.20 <sup>*</sup>
<i>Model Sig</i>	***	***	***	***	*
<i>R</i> <sup>2</sup>	0.27 <sup>***</sup>	0.33 <sup>***</sup>	0.36	0.16 <sup>***</sup>	0.04 <sup>*</sup>
Model 2					
Perceived stigma	0.28 <sup>**</sup>	0.27 <sup>***</sup>	0.28 <sup>***</sup>	-0.26 <sup>*</sup>	-0.14
Internalized stigma	0.42 <sup>***</sup>	0.53 <sup>***</sup>	0.59 <sup>***</sup>	-0.25 <sup>*</sup>	0.36 <sup>**</sup>
<i>Model Sig</i>	***	***	***	*	***
<i>R</i> <sup>2</sup>	0.37 <sup>***</sup>	0.51 <sup>***</sup>	0.60 <sup>***</sup>	0.19 <sup>*</sup>	0.11 <sup>***</sup>
<i>R</i> <sup>2</sup>	0.11 <sup>***</sup>	0.18 <sup>***</sup>	0.24 <sup>***</sup>	0.04 <sup>*</sup>	0.07 <sup>**</sup>
Model 3					
Perceived stigma	0.28 <sup>**</sup>	0.30 <sup>***</sup>	0.20 <sup>**</sup>	-0.26 <sup>*</sup>	-0.10
Internalized stigma	0.40 <sup>***</sup>	0.58 <sup>***</sup>	0.38 <sup>***</sup>	-0.25 <sup>*</sup>	0.15
IBS frequency	-0.01	-0.07	-0.08	-0.04	0.13
IBS severity	0.07	0.26 <sup>*</sup>	0.12	0.04	0.14
Disruption ADL	0.16	-0.20	0.17	-0.16	0.07
Disruption SOC	-0.17	-0.07	0.23 <sup>*</sup>	0.15	0.24
<i>Model Sig</i>	ns	ns	***	ns	***
<i>R</i> <sup>2</sup>	0.36	0.52	0.73	0.17	0.29
<i>R</i> <sup>2</sup>	0.01	0.03	0.15	0.01	0.22

\*  $p < 0.05$

\*\*  $p < 0.01$

\*\*\*  $p < 0.001$ .

$\beta$ : standardized beta weight; ADL: activities of daily living; SOC: socialization; HRQOL: health-related quality of life; PHC: perceived health competence.