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## Stigmatization toward irritable bowel syndrome and inflammatory bowel disease in an online cohort

T. H. Taft<sup>1</sup>, A. Bedell<sup>1</sup>, J. Naftaly<sup>2</sup>, and L. Keefer<sup>3</sup>

<sup>1</sup>Northwestern University Feinberg School of Medicine, Chicago, IL, USA

<sup>2</sup>Rosalind Franklin School of Medicine, North Chicago, IL, USA

<sup>3</sup>Icahn School of Medicine, Mount Sinai Medical Center, New York, NY, USA

### Abstract

**Background**—Stigma is associated with many negative health outcomes. Research has examined perceived and internalized stigma in individuals with irritable bowel syndrome (IBS) and inflammatory bowel disease (IBD), but less has been done to evaluate levels of enacted stigma associated with these conditions. The aim of this study was to evaluate the presence of enacted stigma toward IBS and IBD in the general population compared to an adult-onset asthma (AOA) control group.

**Methods**—Participants were recruited via social media and a research-dedicated website and completed all measures online. Participants were randomized to one of six clinical vignettes: (i) IBD male, (ii) IBD female, (iii) IBS male, (iv) IBS female, (v) AOA male, or (vi) AOA female. Participants read the assigned vignette and then completed measures of emotional empathy, level of familiarity, and enacted stigma.

**Key Results**—Participants reported higher levels of enacted stigma toward IBS compared to both IBD and AOA. No differences in stigma were found between IBD and AOA. Higher levels of familiarity were most strongly correlated with reduced IBD-related stigma, with weaker but still significant correlations between level of familiarity and IBS and AOA. Higher levels of emotional empathy were associated with reduced stigma for IBD, IBS, and AOA.

**Conclusions & Inferences**—Individuals with IBS experience greater levels of enacted stigma compared to IBD and AOA. This finding is consistent with previous research that has shown greater levels of perceived and internalized stigma in IBS compared to IBD.

### Keywords

discriminatory behavior; enacted stigma; inflammatory bowel disease; irritable bowel syndrome; patient outcomes

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**Correspondence.** Tiffany H. Taft, Northwestern University Feinberg School of Medicine, Chicago, IL, USA. ttaft@northwestern.edu.

### CONFLICTS OF INTEREST

The authors have no competing interests to disclose.

### AUTHOR CONTRIBUTION

TT and JN were responsible for study design and data collection; TT performed the statistical analysis; TT and AB wrote the manuscript; JN and LK assisted with data interpretation and manuscript preparation.

## 1 | INTRODUCTION

Many individuals with chronic medical conditions experience stigma, or the labeling of a person as different or defective because of a perceived trait.<sup>1,2</sup> Research on stigma has focused primarily on mental health<sup>3,4</sup> and other chronic illnesses such as HIV/AIDS,<sup>5,6</sup> cancers,<sup>7,8</sup> epilepsy,<sup>9,10</sup> and obesity.<sup>11,12</sup> Stigma is associated with a multitude of negative health outcomes, including increased illness symptoms, psychological distress, and treatment non-adherence, and decreased self-esteem, self-efficacy, and access to medical care.<sup>13-16</sup> Stigma is frequently conceptualized into three domains: perceived, internalized, and enacted.<sup>17</sup> Perceived stigma refers to how an individual senses that others hold negative attitudes or beliefs toward oneself or one's condition. When an individual accepts negative beliefs regarding his/her illness and incorporates those beliefs into his/her own identity, this is known as internalized stigma. Enacted stigma refers to discriminatory acts or negative attitudes that one may experience as a result of his or her illness.

Irritable bowel syndrome (IBS) is a functional gastrointestinal disorder that is characterized by symptoms of pain, bloating, gas, and diarrhea or constipation, which are not associated with any known structural or tissue abnormalities. Inflammatory bowel diseases (IBD; Crohn's disease, ulcerative colitis) are chronic digestive diseases that present with symptoms similar to those found in IBS, but are associated with inflammation to all or some of the digestive tract. Due to societal taboos around discussions of bowel functioning, and historically viewing these disorders as psychosomatic, individuals with IBS and IBD may each experience stigma.

Research in IBS and IBD has previously been conducted for perceived and internalized stigma but is lacking in the area of enacted stigma.<sup>18-20</sup> One recent study of young adults with IBD found that the experience of perceived and enacted stigma frequently leads to patients choosing not to disclose or to attempt to conceal these conditions.<sup>21</sup> Research on perceived stigma in IBS and IBD showed that perceived stigma negatively impacts clinical outcomes, including increased depression and anxiety, lower quality of life, and reduced self-esteem and self-efficacy.<sup>20</sup> However, perceived stigma impacts these groups differently, as IBS patients were shown to perceive more stigma from their health care providers than patients with IBD. Internalized stigma in both conditions is associated with an increase in health care utilization and reductions in health-related quality of life, psychological functioning, and perception of health competence.<sup>18,22</sup>

In this study, we sought to evaluate stigmatizing attitudes (i.e., enacted stigma) toward patients with IBS and IBD in the general population, utilizing a validated experimental design in the HIV/AIDS literature.<sup>23,24</sup> This design features vignettes depicting individuals with IBS, IBD, and adult-onset asthma (AOA). As AOA historically has not been associated with high levels of stigmatization, it was chosen as a patient control group.<sup>25</sup> We hypothesize that participants will display greater stigma toward individuals with bowel disorders (IBS and IBD) than AOA. Based on previous research in perceived stigma toward functional disorders, we also hypothesize that participants will display greater stigma toward IBS than IBD.<sup>20,26</sup>

## 2 | METHODS

Potential participants were recruited via social media (Facebook, Twitter) and a research-dedicated website ([researchmatch.org](http://researchmatch.org)) between June and October 2014. Study questionnaires were administered online via the third party survey site [www.surveymonkey.com](http://www.surveymonkey.com). After obtaining informed consent, participants completed the following information:

### 2.1 | Demographic

Gender, race, ethnicity, education level, marital status, sexual orientation, employment status, geographic location, household income, and chronic illness status.

Participants were then randomized to one of six clinical vignettes: (i) IBD Male, (ii) IBD Female, (iii) IBS Male, (iv) IBS Female, (v) AOA Male, or (vi) AOA Female. The first paragraph of the vignette provided a brief description of each medical condition, followed by a description of a 28-year-old with that specific diagnosis (Appendix S1). After being presented with the clinical vignette, participants were asked to verify the name of the illness they just read about (IBS, IBD, or AOA). The following questionnaires were then administered:

**2.1.1 | Level of Familiarity Scale (Disease Specific; LOF)**—The LOF is an 11-item questionnaire that assesses a person's degree of contact with people living with a specific illness.<sup>27</sup> Participants are asked to check each item that applies (e.g., "I live with a person with Crohn's Disease," "A friend of the family has IBS."). Each item is scored for the level of intimacy (11=most intimate contact, 7=medium intimacy, 1=little intimacy.). If more than one item is endorsed, the highest level of intimacy item is recorded (Maximum score=11).

**2.1.2 | Enacted Stigma Scale (Disease Specific, ESS)**—The ESS is a 30-item, study-specific questionnaire adapted from three stigma scales: Explanatory Model Interview Catalogue (EMIC) stigma scale for the community, the Perceived Stigma Scale for IBS (PSS-IBS), and the Internalized Stigma of Mental Illness (ISMI) stereotype endorsement subscale.<sup>28</sup> The EMIC is a standard measure of illness stigma that has been modified for studies across multiple conditions.<sup>29</sup> The PSS-IBS is a measure of GI-specific illness perceptions; items were modified to capture enacted stigma (e.g., "My IBS is believed to be more "in my head" than physical" to "Most symptoms people with IBS/IBD/Asthma experience are more in their head than physical").<sup>30</sup> Items are rated on a 5-point Likert scale (Strongly Disagree to Strongly Agree); higher scores denote greater enacted stigma (Maximum score=150). The ISMI is a measure of internalized stigma with five subscales; the stereotype endorsement scale measures how much a person agrees with stigmatizing attitudes (e.g., "Negative stereotypes about IBS/IBD keep me isolated from the "normal" world."). The ESS demonstrated excellent reliability (Cronbach  $\alpha$ : IBS=0.90, IBD=0.88, AOA=0.81).

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### SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article.

**2.1.3. | Attributions Questionnaire (Disease Specific, AQ-9)**—The AQ-9 is 9-item measure of stereotype endorsement for a specific illness.<sup>31</sup> Each item corresponds with a stereotype factor from the long version of the questionnaire (AQ-27): Blame, Anger, Pity, Help, Dangerousness, Fear, Segregation, and Coercion. Items are rated on a 1 (none at all) to 9 (very much) point scale. Higher scores denote greater stereotype endorsement. The AQ-9 is used to confirm construct validity of the ESS only.

**2.1.4 | Interpersonal Reactivity Index (IRI)**—The IRI is a 28-item measure of an individual's degree of empathic capacity, or the ability to understand and share the feelings of another.<sup>32</sup> Items are rated on a 5-Point Likert Scale (Does Not Describe Me Well to Describes Me Very Well). Higher scores denote greater empathy.

## 2.2 | Statistical analyses

All responses from the online system were exported into SPSS v. 22 for analyses. Total scores and means for each questionnaire were computed. Data were evaluated for normal distribution and completeness, with incomplete subjects removed from the study sample. Descriptive statistics (percentages, mean [Standard Deviation]) evaluated the demographic characteristics of the participants. Reliability statistics (Cronbach alpha, Guttman statistic) evaluated the internal consistency and split-half reliability of the ESS (reported in Methods section above) and Pearson's correlation with the AQ-9 evaluated the construct validity of the ESS.

Participants' response to item 5 of the LOF indicated whether he or she had a diagnosis of IBS, IBD, or AOA; participants were dichotomously categorized (Yes/No) if their diagnosis matched the diagnosis of the patient they were rating (e.g., participant with IBD randomized to IBD patient group=Yes, participant with IBS randomized to AOA=No). These groups were compared prior to additional analyses to determine if significant differences exist that may influence enacted stigma. Pearson's correlations evaluated relationships between continuous demographic variables and study measures.

A series of independent samples *t*-tests and one-way Analysis of Variance (ANOVA) determined significant differences in mean scores for enacted stigma, level of familiarity, and emotional empathy for each demographic variable. Cohen's *d* evaluated estimates of effect size for enacted stigma between IBS and IBD, IBS and AOA, and IBD and AOA. Additional Pearson's correlations assessed relationships between stigma, level of familiarity, and emotional empathy. Stepwise linear regression evaluated the percentage variance in enacted stigma accounted for by diagnosis, level of familiarity, and emotional empathy (all variables entered in Step 1). Analysis of covariance (ANCOVA) measured the relationships between stigma, familiarity, and emotional empathy while controlling for any demographic variables with significant group differences. Finally, to evaluate differences by gender of the patient vignette IBS and IBD participants were matched to AOA gender controls for comparison. Based on Bonferroni correction, statistical significance was set to *P* .01 for *t*-tests and ANOVA to control for type 1 error due to multiple comparisons.

### 3 | RESULTS

Four hundred and twenty-four potential participants visited the study website and 420 consented. Of those, 392 completed all study questionnaires (93% completion rate). Participants were equally randomized across illness vignettes. Demographic characteristics are listed in Table 1. The majority of the sample was female, Caucasian, non-Hispanic, college educated, heterosexual, and employed at least part-time. All geographic regions of the United States were represented. One-third of participants had a chronic medical illness diagnosis.

The ESS was a reliable and valid measure of enacted stigma; reliability statistics for the ESS are reported above. The AQ-9 was strongly correlated with the ESS ( $r=.61$ ,  $P<.001$ ), supporting construct validity. Participants who were randomized to either the IBD or IBS vignette and self-disclosed having the same diagnosis they were rating (positive group) demonstrated significantly less enacted stigma than those who did not have the illness (IBD  $P<.001$ ; IBS  $P<.01$ ). No differences in enacted stigma were found for the AOA group and as such, diagnosis positive participants were excluded from enacted stigma analyses for IBS and IBD only. No differences existed between positive and negative diagnosis groups for emotional empathy for IBD, IBS, or AOA.

#### 3.1 | Levels of enacted stigma by illness

As a whole, participants reported significantly higher levels of enacted stigma toward IBS than IBD or AOA (Table 2). No differences existed for stigma between IBD and AOA ( $P>.05$ ). Effect sizes when comparing the three groups were small for IBD compared to AOA ( $d=0.26$ ), medium for IBS compared to IBD ( $d=0.52$ ), and large for IBS compared to AOA ( $d=0.79$ ). Only one difference in stigma level existed when comparing IBS and IBD patients to gender-matched AOA controls in that males with IBS were significantly more stigmatized than males with AOA ( $P<.001$ ). This comparison did not yield significant differences in females with IBS or males or females with IBD when compared to gender-matched AOA controls. Differences in enacted stigma did not exist between male and female patients for each illness group (e.g., IBS males vs IBS females) (Fig. 1).

#### 3.2 | Demographic differences in enacted stigma

Mean differences in enacted stigma by illness were compared for each categorical demographic variable shown in Table 1., with gender being the only variable demonstrating a significant difference. Specifically, male participants reported greater stigma toward IBD than women ( $P<.01$ ). These gender differences exist for IBS and AOA ( $P<.05$ ), however, they do not meet the level of significance set for this study. All other remaining demographic variables demonstrated no significant differences in levels of enacted stigma.

Next, we evaluated enacted stigma between male and female participants based on the gender of the patient in the vignette and found that male participants were more likely than female participants to stigmatize females with IBD and were more likely to stigmatize males with AOA (both  $P<.01$ ). Male participants also stigmatized males with IBD more than female participants, however, this finding was above significance for this study ( $P=.05$ ). No

differences exist in stigmatizing attitudes by participant gender for females with AOA, or for males or females with IBS.

### 3.3 | Relationship between level of familiarity, emotional empathy, and enacted stigma

Overall, participants were significantly more familiar with AOA than IBD and IBS ( $P<.001$ ), with similar levels of familiarity for IBS and IBD (Table 2). Higher levels of familiarity were most strongly correlated with reduced IBD-related stigma ( $r=-0.47$ ,  $P<.001$ ). Greater familiarity also correlated with less stigma in IBS ( $r=-0.24$ ,  $P<.05$ ) and AOA ( $r=-0.29$ ,  $P<.05$ ), however, the relationship was considerably weaker than that seen in the IBD group.

Levels of participant emotional empathy were consistent across illness groups. Participants who reported greater levels of emotional empathy were less likely to stigmatize each illness, with similar relationship sizes for IBD ( $r=-0.36$ ,  $P<.01$ ) and IBS ( $r=-0.33$ ,  $P<.01$ ), and a weaker yet significant relationship for AOA ( $r=-0.29$ ,  $P<.05$ ). Gender differences exist in levels of emotional empathy (male= $82.79 \pm 11.5$ , female= $90.23 \pm 12.9$ ,  $P<.001$ ), however, when controlling for gender in the relationship between emotional empathy and stigma, the relationship remained significant ( $P<.001$ ).

Results from the regression model suggest level of familiarity contributes most to the variance in enacted stigma ( $R^2_{\text{adj}}=0.16$ ; 16%), followed by emotional empathy ( $R^2_{\text{adj}}=0.08$ ; 8%). The illness being rated was excluded from the model.

## 4 | DISCUSSION

In this study, we utilized a validated experimental design to evaluate enacted stigma toward individuals with IBS and IBD. We hypothesized that enacted stigma would be greater toward IBS and IBD than for the AOA control group, and that the greatest enacted stigma would be toward IBS, due to its functional nature. In line with our hypothesis, IBS received the greatest amount of enacted stigma, which is consistent with results from existing research. In a recent study by our group,<sup>18</sup> there were greater levels of perceived stigma in individuals with IBS compared to those with IBD. Similarly, a 2004 study of functional somatic syndromes (FSS; including IBS) and matched medical controls groups (including IBD) found the FSS group perceived more stigma than the medical control group. We did not, however, find support for our prediction that there would be greater stigma toward IBD compared to AOA.

Effect sizes for IBS stigma compared to IBD and AOA demonstrate that IBS has a somewhat greater degree of stigma than a comparable condition (i.e., Crohn's disease) and much greater stigma than asthma, a relatively non-stigmatized illness. A 1996 meta-analysis of HIV/AIDS-related stigma found a modest effect size ( $d=0.45$ ) when compared to other stigmatized illnesses such as cancer, heart disease, and diabetes.<sup>33</sup> Research on workplace stigma toward obese individuals finds moderate effect sizes ( $d=-0.52$ ) compared with the non-obese.<sup>34</sup> Based on these data, IBS is at comparable risk for stigmatization as HIV and obesity; IBD is at considerably lower risk for stigmatization than these highly stigmatized groups, but at greater risk than asthma.

Participants with greater emotional empathy were less likely to stigmatize each illness, with a similar relationship size for IBS and IBD, and a small but significant relationship in AOA. Significant differences exist by participant gender in emotional empathy, with women demonstrating more emotional empathy than men. However, we found the relationship between emotional empathy and stigma remained after controlling for this gender difference.

Historically, many studies utilizing the vignette design studied HIV/AIDS-related stigma and prejudice, and have primarily been done outside of the USA<sup>35–39</sup> Some of these studies centered on disentangling stigma toward the HIV/AIDS diagnosis from stigma regarding its mode of transmission (e.g., men who have sex with men, injecting drug use, commercial sex, blood transfusion), particularly among health care workers.<sup>37,39,40</sup> In one study looking at prejudice among Chinese medical students, more prejudice was directed toward individuals who were injecting drug users or involved in commercial sex, regardless of whether they had AIDS or leukemia, than those who had contracted HIV from a blood transfusion.<sup>39</sup>

Similarly, studies conducted within the United States on obesity-related stigma show an association between stigma and perceived responsibility or control over development of the condition.<sup>41,42</sup> In a 2013 study, vignettes depicted individuals with anorexia nervosa, bulimia nervosa, binge eating disorder, major depressive disorder, and obesity.<sup>43</sup> Obese individuals were blamed more than individuals with any other condition, and both obese individuals and those with binge eating disorder were seen as more responsible for their condition due to perceived lack of self-discipline. Findings from both HIV/AIDS and obesity-related stigma literature align with the ideas presented in Jones et al.'s seminal work that postulated that the perception of responsibility for contracting an illness leads to greater stigma and prejudicial attitudes. Patients with IBS report attitudes related to “my IBS is all in my head” and “my IBS is caused by something I have done” implying controllability in illness.<sup>30</sup> Thus, others may perceive that IBS is caused by something people are doing, such as how they manage stress, the food they choose to eat, or other lifestyle factors that they are perceived to have control over.

Most stigma studies in the United States, have focused on mental illness. In a 2015 study, vignettes presented individuals with schizophrenia, depression, prescription pain medication addiction, and heroin addiction, and these were described as either being untreated or treated.<sup>44</sup> Participants endorsed more enacted stigma (e.g., less willingness to work closely with them at a job) toward individuals with untreated heroin addiction, depression, and schizophrenia compared to a control group. In the current study, IBS, a condition traditionally viewed as a psychosomatic condition associated with more anxiety, depression, and neuroticism compared to IBD and AOA was the most stigmatized.<sup>45–47</sup> This result is supported by the concept of level of peril, outlined by Jones et al.<sup>48</sup> Peril focuses on perceived dangers associated with stigmatized individuals, such as the threat of individuals with mental disorders engaging in a verbal or physical attack. In addition, this concept relates to how encountering stigmatized individuals makes us “starkly aware of our own frailty”.<sup>48</sup> Individuals with IBS in the current study may have been associated with a higher level of peril due to the association it has with mental health issues, such as anxiety, depression and neuroticism. Also, as IBS is a poorly understood condition, especially among

the lay community, it may be associated with greater peril than IBD which has more a definitive etiology and significantly lower prevalence rate than IBS.

Another vignette study of US college students showed that both younger students and those with less familiarity with mental illness were more likely to stigmatize and maintain social distance from mentally ill individuals.<sup>49</sup> In our study we found that higher levels of familiarity were associated with reduced stigma in individuals with IBD, and this was seen to a lesser, but significant, degree in IBS and AOA. Antistigma interventions and campaigns tend to focus on education aimed at addressing this level of familiarity.<sup>50,51</sup> Several patient advocacy groups exist for IBS and IBD (e.g., Crohn's & Colitis Foundation of America, International Foundation for Functional GI Disorders) and could be leveraged by clinicians to counteract IBD-and IBS-related stigma.

When comparing stigma scores for IBS and IBD to gender-matched controls, the only difference existed for males with IBS scoring higher than males with asthma. Previous research indicates that women are perceived as less responsible for their illnesses than men<sup>52</sup> and offered more support relative to men.<sup>53</sup> As IBS is more prevalent in women,<sup>54</sup> males with IBS may be the most prone to disease-related stigma. When evaluating the gender of the participant, male participants demonstrated the highest stigma levels across illness groups. Data are limited for evaluating gender differences in chronic illness enacted stigma, however, a 2008 study by Mosher et al.<sup>55</sup> found that there were no gender differences in stigma toward cancer patients, including in levels of control over their condition. Conversely, in a study of obesity, men are more likely to attribute obesity to a lack of willpower and reported greater dislike of obese individuals, and hold a greater overall weight bias.<sup>56</sup> Additional research in this area is warranted.

#### 4.1 | Limitations

The sample was racially homogeneous and was primarily comprised of non-Hispanic Caucasians. Additionally, the sample was highly educated. Further research with minority populations and with varying education levels is needed to determine how findings may differ in these groups. An additional limitation is due to the survey methodology of this study. As with all survey studies, there is the potential for participants to bias their answers for social desirability, but the anonymity of the online administration may have corrected for that potential. We do not know the overall rates of IBD, IBS, or AOA in our study sample. Based on those in the positive diagnosis group, IBS and AOA fell at or below national prevalence rates (IBS=6% based on Rome IV criteria, AOA=8%) while IBD was significantly higher than that found in the general population (less than 1% versus 7% of study sample). This may limit the generalizability of our findings to the broader US population.

Future studies should aim to evaluate perceived stigma in patients and enacted stigma in identified significant others, both interpersonal and health care providers, to determine the congruence of these phenomena. Evaluations of existing educational programs available via patient advocacy groups should be conducted in a more systematic way to measure stigma levels pre-and postintervention.



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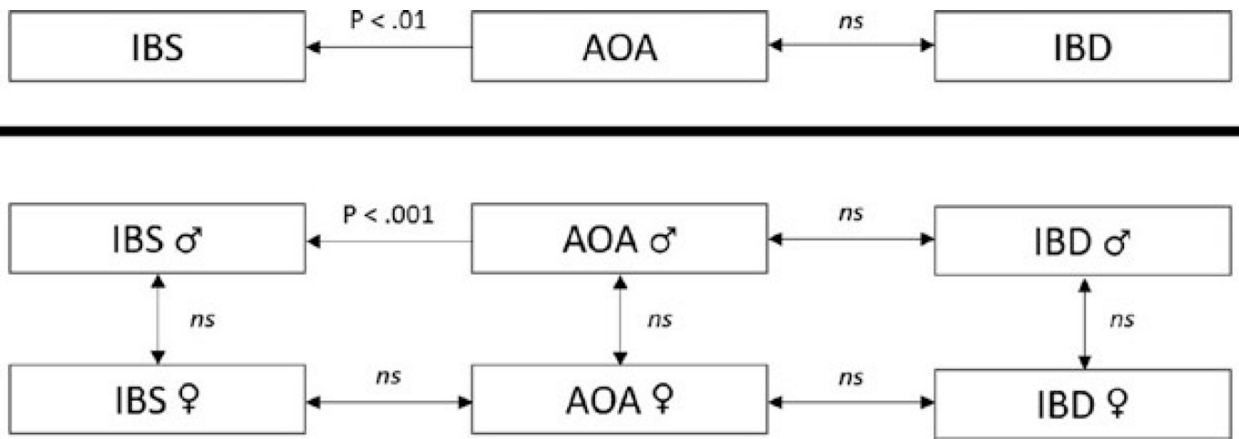
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### Key Points

- Chronic illness stigma is a salient issue in gastrointestinal disease. Enacted stigma, or discriminatory actions or attitudes, toward inflammatory bowel disease and irritable bowel syndrome (IBS) has yet to be evaluated.
- This study finds that patients with IBS, specifically males, experience the most enacted stigma from people in the general population even though people are generally equally familiar with both conditions.
- Irritable bowel syndrome patients report feeling stigmatized and this study corroborates that people without IBS hold negative attitudes toward the illness. Health care providers should be aware of the presence of stigma in IBS patients and its potential impact of patient outcomes.



**FIGURE 1.**  
Differences in enacted stigma by diagnosis and gender of patient vignette

**TABLE 1**

## Demographic characteristics of study sample

Variable	N=392
Gender	
Male	31.4% (123)
Female	68.4% (268)
Age (mean $\pm$ SD)	
	34.5 $\pm$ 12.1
Race	
Caucasian	85.3% (326)
African American	2.9% (11)
Other	14.7% (45)
Ethnicity	
Hispanic	18.5% (71)
Non-Hispanic	81.5% (313)
Married/Co-Habitating	50.5% (196)
Heterosexual	94% (358)
College Educated	71.5% (278)
Employed (at least part-time)	72.6% (283)
Geographic Location	
New England	6.6% (26)
Mid Atlantic	9.0% (35)
East North Central	23.0% (90)
West North Central	5.6% (22)
South Atlantic	12.5% (49)
East South Central	8.7% (34)
West South Central	5.6% (22)
Mountain	17.1% (67)
Pacific	6.4% (25)
Outside of USA	5.4% (21)
Household income >50 000 USD per year	54.8% (213)
Chronic illness diagnosis	32.4% (127)
Illness randomization	
IBD male	14% (55)
IBD female	18.1% (71)
IBS male	18.6% (73)
IBS female	15.6% (61)
AOA male	20.9% (82)
AOA female	12.8% (50)

Variable	N=392
Positive diagnosis <sup>a</sup>	
IBD	7.1% (28)
IBS	4.1% (16)
AOA	5.4% (21)

<sup>a</sup>Participant diagnosed with same illness assigned to rate via randomization as identified by Level of Familiarity Scale.

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Mean (SD) of enacted stigma, stereotype endorsement, level of familiarity, and emotional empathy by illness group

**TABLE 2**

	<b>IBD</b>	<b>IBS</b>	<b>AOA</b>	<b>F</b>	<b>P</b>
Level of familiarity	6.5 (3.8)	5.7 (3.8)	7.9 (2.6)	13.87	.000 <sup>a</sup>
Enacted stigma	45.6 (10.6)	51.9 (13.2)	43.1 (8.5)	18.57	.000 <sup>b</sup>
Stereotype endorsement	17.8 (5.5)	19.1 (7.6)	18.2 (6.2)	1.36	.258
Emotional empathy	88.1 (11.9)	86.3 (13.7)	89.3 (13.0)	1.45	.237

<sup>a</sup>AOA>both IBS and IBD.

<sup>b</sup>IBS>both IBD and AOA.