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A preliminary evaluation of internalized stigma and stigma resistance in inflammatory bowel disease

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Abstract

Illness stigmatization among inflammatory bowel diseases (IBDs) is poorly understood. We aim to characterize internalized stigma and stigma resistance in IBD patients, and evaluate their relationships to outcomes. A total of 191 IBD patients reported internalized stigma, resistance, demographic and clinical information, and several outcomes: health-related quality of life (HRQOL), psychological distress, self-esteem, and self-efficacy. Overall 36% experienced internalized stigma and 88% moderate to high stigma resistance behaviors. Internalized stigma strongly related to poorer outcomes while resistance demonstrated a weaker, opposite effect. Internalized stigma and stigma resistance are important considerations for IBD outcomes. Interventions to reduce internalized stigma and leverage resistance are warranted.

Keywords

illness stigmatization; inflammatory bowel diseases; internalized stigma; patient outcomes; psychosocial functioning

Introduction

An unfortunate comorbidity of many chronic illnesses is stigmatization (e.g. Fry and Bates, 2011; Halding et al., 2011; Jenerette and Brewer, 2010; Kotrulja et al., 2010). In the last several decades, health-related stigma, defined as ‘social disqualification of individuals and populations who are identified with particular health problems’ (Weiss et al., 2006), has become an important public health issue. Recently, support for a five-factor structure of the stigma construct was proposed (Bresnahan and Zhuang, 2011). This model postulates that the distinct dimensions of stigma include labeling, negative attributions, distancing, status loss, and perceived controllability of the disease. Research about health-related stigma has focused predominately on illnesses such as HIV/AIDS, tuberculosis, leprosy, epilepsy, and mental illness (Juniarti and Evans, 2010; Van Brakel, 2006; Weiss et al., 2006). The effects of health-related stigma are consistent across these diseases and include negative effects on quality of life, self-esteem, well-being and participation in social activities (Juniarti and Evans, 2010; Van Brakel, 2006; Weiss et al., 2006).

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In mental illness, HIV, and leprosy research, the stigma construct consists of three main components: enacted stigma; perceived stigma; and internalized stigma (Link et al., 2004; Stevelink et al., 2011). *Enacted stigma* is the actual discriminatory behaviors by others toward those in the stigmatized group. These behaviors are defined as labeling, stereotyping, and discrimination, and are associated with a discrepancy in power between the groups. *Perceived stigma* reflects the subjective awareness of stigma. It is identified as an emotional response to enacted stigma and may lead to feelings of isolation or exclusion (Moore et al., 2008; Sayles et al., 2007). *Internalized stigma* (IS) reflects the degree to which an individual is in agreement with existing social stigma and stereotypes regarding certain conditions.

Internalized stigma, in particular, has been linked to reduced self-esteem, reduced self-efficacy, and reduced motivation for pursuing life-goals and/or necessary treatment (Corrigan et al., 2009; Ritsher and Phelan, 2004; Sayles et al., 2008; Tsang et al., 2010) However, the construct of *stigma resistance behaviors* (SRB) is a fourth factor that may protect an individual from the consequences of IS. Stigma resistance is defined as 'the experience of resisting or being unaffected by internalized stigma' (Ritsher et al., 2003: 36) and has been identified as an important consideration when evaluating the effects of stigma among chronic conditions such as schizophrenia (Sibitz et al., 2011), obesity (Puhl and Brownell, 2003), and HIV/AIDS (Buseh and Stevens, 2006).

Inflammatory bowel diseases (IBDs) are chronic, relapsing-remitting autoimmune diseases of the digestive tract (Podolsky, 1991). The most common IBD diagnoses are Crohn's Disease (CD) and Ulcerative Colitis (UC), with a worldwide prevalence ranging from 250–500 per 100,000 and rising (Molodecky et al., 2011). The clinical etiology, symptoms, and treatments of IBDs can cause significant physical and psychosocial burdens for patients (Casati and Toner, 2000; Farrell and Savage, 2010). The IBDs are characterized by bowel symptoms (i.e. prolonged or sudden diarrhea), chronic abdominal pain, fatigue, and sometimes 'extraintestinal' conditions such as eye inflammation, rashes and fistulae. Treatment regimens can be intensive, sometimes involving injectable drugs or multiple medications that must be taken throughout the day (Kozuch and Hanauer, 2008). All of these qualities of the IBDs lend them to the potential for psychosocial distress and stigmatization.

Although previous research examining the psychosocial aspects of IBD has identified certain disease-related concerns (e.g. energy, loss of control, body image, isolation, feeling dirty, feeling burdensome, feeling inadequate) which may contribute to stigmatization in IBD patients (Casati and Toner, 2000; Casati et al., 2000; De Rooy et al., 2001; Drossman et al., 1991), to date only one study has directly examined the role of stigmatization in IBD (Taft et al., 2009). Perceived stigma was identified in a majority of IBD patients and it significantly predicted problems with self-esteem, self-efficacy, medical adherence, quality of life, anxiety, and depression. Stigma was consistent across both CD and UC, and was associated with disease complexity and symptom frequency (Taft et al., 2009).

The current study expands upon the understanding of stigmatization in IBD by evaluating the potential impact of IS and SRB in patients with this disease. There are three goals of the present study. First, we aim to evaluate the presence of IS and SRB in the IBD population. Second, we seek to characterize the demographic and clinical correlates to

IS and SRB. Third, we aim to examine the relationships between IS and SRB and the following commonly assessed IBD patient outcomes: (1) psychological distress, including anxiety, depression, and somatization (Nahon et al., 2012); (2) disease specific health-related quality of life (Pallis et al., 2004); (3) global self-esteem (Lindfred et al., 2008); and (4) disease-specific perceived self-efficacy (Keefer et al., 2011).

Methods

Participants were recruited from two sources: (1) via an outpatient, university-based gastroenterology clinic; (2) via online support message boards, Craigslist, and a social networking website. The IBD diagnosis was confirmed via electronic medical record for clinic patients; online participants provided self-report information about their IBD diagnosis. Participants completed a series of questionnaires. Clinic patients had the option to complete the survey via paper and pencil or using the same web-based system as those recruited online. Cookies were used to prevent online participants from completing the survey more than once, with internet protocol (IP) address logging and review to identify duplicate entries for removal.

Measures

Sociodemographic information.—Age, gender, ethnicity, education, marital status, state of residence, population of home town.

Clinical information.—IBD diagnosis, years diagnosed, remission status, flare frequency, most recent flare severity, steroid dependence, surgical history, ostomy presence, extraintestinal symptoms, current medications, physician appointment frequency.

Stigma factors.—The Internalized Stigma Scale for Mental Illness (ISMI) is a 29-item self-report measure of the degree to which participants believe or internalize stigmatizing attitudes about mental illness or people with mental illness (Ritsher et al., 2003). For this study, the ISMI was modified so that ‘mental illness’ was replaced with ‘inflammatory bowel disease’ or ‘IBD.’ One question was changed because it was not applicable to the study sample (‘People with mental illness tend to be dangerous’ was modified to ‘People with IBD tend to be dirty’). Items are ranked on a four-point Likert Scale (0 = Strongly Disagree to 4 = Strongly Agree). The ISMI yields five subscales: alienation (‘I feel out of place in the world because I have IBD’); social withdrawal (‘I don’t socialize as much as I used to because my IBD might make me look or behave “weird”’); discrimination (‘People ignore me or take me less seriously just because I have IBD’); stereotype endorsement (‘People with IBD cannot live a good, rewarding life’); and SRB (‘Living with IBD has made me a tough survivor’). Scale scores are classified by four ranges (minimal, mild, moderate, severe). Internalized stigma scores are calculated using four of the five subscales, with SRB excluded. Stigma resistance is calculated separately using its single subscale. Higher scores indicate greater IS and SRB. The ISMI demonstrates good reliability (high internal consistency $\alpha = 0.90$, test–retest reliability $r = 0.92$) and validity, including when modified for medical populations (Stevelink et al., 2011). In the present sample, internal consistency for the four IS subscales was excellent ($\alpha = 0.94$) and fair for SRB ($\alpha = 0.61$).

Health-related quality of life.—HROOL was assessed using the Inflammatory Bowel Disease Questionnaire (IBDQ) (Guyatt et al., 1989). The IBDQ is a 32-item self-report questionnaire that evaluates the person's bowel and systemic symptoms as well as social and emotional functioning over the last two weeks. Questions are rated on a seven-point Likert scale. The IBDQ demonstrates excellent reliability and validity and is widely used in IBD research. Higher scores denote better functioning.

Psychological distress.—The Brief Symptom Inventory-18 (BSI-18) assessed participant's level of depression, anxiety, and somatization over the past week (Derogatis and Melisaratos, 1983). The BSI-18 is an 18-item measure of global psychological functioning with three subscales. Participants respond to questions on a five-point Likert scale (Not at All to Extremely). Higher scores represent poorer psychological functioning. Established clinical cutoff scores for significant pathology are ≥ 13 for women and ≥ 10 for men on all subscales. The BSI-18 demonstrates good reliability (Cronbach's α for global severity = 0.89; somatization = 0.74; depression = 0.84; anxiety = 0.89) and validity.

Self-esteem.—The Rosenberg Self-Esteem Scale (RSES) is a 10-item self-report measure of global self-esteem (Rosenberg, 1965). It consists of 10 statements related to overall feelings of self-worth or self-acceptance. The RSES is a well-established measure self-esteem with good reliability and validity.

Perceived self-efficacy.—The IBD Self Efficacy Scale (IBDSES) evaluated the degree to which participants believe in their ability to cope with demands related to managing their IBD (i.e. perceived self-efficacy (Keefer et al., 2011). The IBDSES is a 29-item self-report measure that evaluates self-efficacy related to managing stress and emotions, managing medical care, managing symptoms, and maintaining remission. Questions are rated on a five-point Likert scale and higher scores denote greater self-efficacy. The IBDSES demonstrates good reliability and validity.

Ethical considerations

This study was approved by the institutional review board of Northwestern University. All participants completed informed consent prior to participation.

Analysis

Data were entered into the Statistical Package for the Social Sciences v19 (IBM-SPSS, Chicago IL) for analysis. Preliminary tests for normal distribution, outliers, and missing data were conducted. Cronbach's α coefficient measured reliability of the ISMI in the IBD sample. Independent measures *t*-tests and one-way ANOVA with Tukey's HSD post-hoc testing evaluated any differences between demographic groups for study variables. Bonferroni correction was set to $p \leq .01$ for mean comparisons to avoid Type 1 error. Pearson's correlations evaluated the relationships between IS and SRB and the study outcomes HRQOL, psychological distress, self-efficacy, and self-esteem. Finally, stepwise regression analyses evaluated the relationship between IS, SRB, and these patient outcomes.

Results

Sample characteristics

One hundred and ninety-nine participants consented to the study. Of these, 191 completed all measures (96% completion rate). Demographic and clinical data of the study sample are presented in Table 1. The majority of the sample was married, college-educated Caucasian females with CD who were recruited online.

Prevalence of internalized stigma and stigma resistance

Overall, 36% of our sample reported the presence of IS about their IBD diagnosis, while 88% reported at least moderate SRB (Table 2).

We used a series of one-way ANOVA and independent samples *t*-tests to evaluate differences in stigma factors between demographic and clinical variables. Participants with less educational attainment reported more discrimination experiences ($F(4, 190) = 4.83$, $p = .001$) and were less likely to engage in SRB ($F(4, 190) = 5.04$, $p = .001$) than those with higher degrees. Post-hoc comparisons using the Tukey HSD test indicated that the mean scores for people with a high school education for both discrimination ($M = 1.92$, SD = .66) and SRB ($M = 2.88$, SD = .57) were lower than people with a college degree ($M = 1.51$, SD = .47 and $M = 3.26$, SD = .51). Independent sample's *t*-tests demonstrated that people in remission reported significantly less alienation ($t(189) = –2.58$, $p = .01$), stereotype endorsement ($t(189) = –3.26$, $p = .001$), discrimination ($t(189) = –2.70$, $p = .007$), social withdrawal ($t(189) = –2.62$, $p = .009$) and more SRB ($t(189) = 3.99$, $p = .000$). Participants with extraintestinal symptoms experienced greater discrimination ($t(189) = 2.51$, $p = .01$). Differences were also found for urban versus rural living ($F(2, 190) = 4.11$, $p = .01$) with people living in an urban environment reporting more stereotype endorsement ($M = 1.48$, SD = .40) than rural ($M = 1.22$, SD = .26). No significant differences were found for stigma factors for the remaining clinical or demographic variables.

Internalized stigma, stigma resistance, and patient outcomes

Lastly, we analyzed the relationship between IS, SRB, and IBD patient outcomes (HRQOL, psychological distress, self-efficacy, and self-esteem). Both IS and SRB were modestly correlated with all patient outcomes (r = –.72 to .65, all $p < .01$) (Table 3). These relationships were larger than the association between flare severity with HRQOL and global psychological distress, the only outcomes that yielded a significant relationship with flare severity.

Next, a series of stepwise linear regression analyses were performed (Table 4). Because flare severity had a significant correlation to HRQOL and psychological functioning, it was entered into the first step of the regression equation for these two outcome variables while IS and SRB were entered simultaneously in step 2. For the remaining outcome variables, only IS and SRB were entered into the regression equation.

Internalized stigma was a significant predictor for all four outcomes. The largest relationship was found between IS and decreased self-esteem with 52% of the variance explained.

Internalized stigma explained 28% of the variance in decreases in HRQOL and 37% of the variance in increases in global psychological distress when controlling for recent flare severity. Stigma resistance behaviors demonstrated a small but protective relationship with these outcome variables. For example, SRB accounted for 5% of the variance in improved self-esteem and self-efficacy, respectively, and 1% of the variance in greater HRQOL. Stigma resistance was not significantly associated with global psychological distress.

Discussion—The current study is the first to evaluate internalized stigma and stigma resistance behaviors among patients with IBD. We found that approximately one-third of our sample reported some degree of internalized stigma, which parallels research on individuals with severe mental illness (West et al., 2011) and HIV/AIDS (Sorsdahl et al., 2011). Most participants experienced minimal to mild levels of IBD IS. Alienation and social withdrawal were experienced more often than endorsement of stereotypes about people with IBD, while one quarter of participants reported some experiences with discrimination because of their illness.

A large majority of participants use SRB, endorsing such items as ‘Living with IBD has made me a tough survivor’ and ‘I can have a good, fulfilling life despite having IBD’. These findings suggest that while IBD patients may perceive that others hold negative attitudes toward IBD and experience discrimination, the majority are able to engage in behaviors that resist internalization of IBD stigma. Qualitative research on SRB among persons with HIV reveals that people are able to resist HIV stigma by adopting a meaningful new role or social identity (Goudge et al., 2009). This change serves to demonstrate the individual’s social value in ways that offset marginalization that occurs by being labeled as having a particular disease. Individuals in our sample may be involved in meaningful activities with patient advocacy groups or other organizations that, in turn, offset the impact of IBD stigma (Shepanski et al., 2005).

In general, demographic variables were not significantly different for reported stigmatization when corrected to prevent Type 1 error. However, we did observe that participants who were less educated and living in an urban environment were predisposed to increases in IS. These findings are similar to those among persons with severe mental illness, where a negative relationship existed between education level and stereotype endorsement (West et al., 2011). While no differences were seen by IBD diagnosis, remission status appears to play an important role in the internalization of stigma and utilizing SRB. This finding differs from the previous study on IBD stigma perceptions, which were consistent across remission status (Taft et al., 2009). Patients who have extraintestinal symptoms also report greater stigma internalization suggesting that this internalization may be situational and related to illness activity and severity. Healthcare providers should be mindful that patients with these demographic and clinical backgrounds may be more susceptible to stigma internalization and its effects, and that the degree of stigma internalization may be related to the patient’s current clinical presentation; longitudinal research would serve to better understand how IBD stigma evolves over time.

Similar to other chronic illnesses (Van Brakel, 2006; Vyavaharkar et al., 2010), IS in IBD patients is an important consideration when understanding degradations in patient

reported outcomes. For example, overweight persons report increased depression, poorer weight loss outcomes (Wott and Carels, 2010) and reduced HRQOL (Lillis et al., 2011) when they experience interpersonal or self-stigma. Patients with genital herpes also exhibit psychological distress related to internalized stigma, which in turn results in increased disease activity and poorer outcomes (Merin and Pachankis, 2011). In the present study, IBD patients with greater internalized stigma reported reduced HRQOL and increased psychological distress. As has been found among persons with mental illness (Livingston and Boyd, 2010), IBD patients who experience internalized stigma are also more likely to have poorer self-esteem and illness-related self-efficacy. These findings are consistent with those for perceived stigma in IBD patients, which was also related to reduced HRQOL, poorer psychological functioning, and decreased self-esteem and self-efficacy (Taft et al., 2009). Future research should evaluate what propels an IBD patient from the *perception* that others hold negative attitudes toward IBD to actually assimilating these beliefs into their own self-image (IS).

There are some limitations to the current study that should be taken into consideration when evaluating the results. First, our sample provided information via self-report measures which are subject to response bias. We also utilized online recruitment, which prevented confirmation of the IBD diagnosis in the entire sample. While we did not find significant differences for study variables between recruitment sources, previous research has shown that patients with IBD recruited online may report greater psychological distress (Jones et al., 2007). To measure IS we utilized a measure that was validated in the mental illness population. Reliability statistics were above acceptable standards for the modified version of the ISMI in this study. However validation of this measure in IBD would ensure proper measurement of the stigma construct. Finally our sample is from an almost entirely Caucasian background; caution should be used when applying these results to other racial or ethnic groups.

The results of this study encourage the development of interventions to reduce the effects of IS in patients with IBD, thereby potentially improving IBD outcomes. The nature of stigmatization lends itself well to targeted psychological intervention, especially cognitive-behavioral strategies that challenge patients' beliefs and assumptions around IBD and disability. Evaluation of what factors contribute to the internalization of stigma perceptions is an important first step. Also, understanding what cognitive processes occur to instill the protective SRB that are associated with better outcomes is warranted. As the results of this study are preliminary, further research into understanding the phenomenon of illness stigma among IBD patients is necessary and would benefit the multidisciplinary understanding of IBD patient outcomes.

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Table 1.

Demographic and clinical characteristics of study sample.

Demographic variable	***N*=191**	**IS**[a]	**SRB**[a]
Age	38.7 (12.3) *		
Recruitment source			
Online	69%	1.81 (.52)	3.08 (.52)
Clinic	31%	1.65 (.51)	3.07 (.55)
Gender			
Female	71%	1.79 (.52)	3.10 (.53)
Male	29%	1.69 (.51)	3.02 (.52)
Marital status			
Married	60%	1.71 (.49)	3.13 (.51)
Not married	40%	1.75 (.52)	3.02 (.57)
Race			
Caucasian	95%	1.75 (.52)	3.10 (.52)
Non-Caucasian	5%	1.93 (.54)	2.69 (.54)
Town population			
Urban	55%	1.80 (.51)	3.07 (.48)
Suburban	34%	1.78 (.53)	3.06 (.54)
Rural	11%	1.47 (.44)	3.20 (.71)
Education			
College or above	64%	1.67 (.49)	3.17 (.52)
Less than college	36%	1.93 (.53)	2.92 (.50)
Clinical variable			
IBD diagnosis			
Crohn’s Disease	66%	1.79 (.55)	3.09 (.52)
Ulcerative Colitis	34%	1.70 (.46)	3.06 (.54)
Remission			
Yes	49%	1.64 (.50)	3.23 (.48)
No	51%	1.87 (.52)	2.93 (.54)
Flare frequency			
Minimum once/year	69%	1.82 (.53)	3.07 (.51)
Less than once/year	31%	1.62 (.48)	3.10 (.56)
Ostomy			
Yes	12%	1.99 (.59)	3.08 (.51)
No	88%	1.82 (.51)	3.10 (.49)
Extraintestinal symptoms			
Yes	70%	1.81 (.50)	3.08 (.48)
No	30%	1.65 (.54)	3.07 (.62)
Fistulizing disease			

Demographic variable	***N*=191**	**IS**[a]	**SRB**[a]
Yes	21%	1.83 (.55)	3.17 (.43)
No	79%	1.74 (.51)	3.05 (.55)
Years w/IBD	9.8±9.6		
Recent flare rating (out of 10)	6.6±2.6		

Notes:

[*] Presented as Mean (SD).

[a] Out of total possible score of 4.0. Higher score indicates greater level of stigma factor.

Table 2.

Participant reported internalized stigma and stigma resistance behaviors.

	Minimal (%)	Mild (%)	Moderate (%)	Severe (%)
Alienation	52	22	19	7
Stereotype endorsement	92	8	–	–
Discrimination experiences	77	16	6	1
Social withdrawal	59	23	14	4
Total internalized stigma	64	29	7	–
	Minimal (%)	Mild (%)	Moderate (%)	High (%)
Stigma resistance behaviors	4	8	42	46

Table 3.

Correlation coefficients for flare severity, stigma factors, and outcome variables.

	1	2	3	4	5	6	7
1. Internalized stigma	–						
2. SRB	−.42**	–					
3. HRQOL	−.54**	.34**	–				
4. Global psych	.62**	−.31	−.77**	–			
5. IBD self-efficacy	−.56**	.43**	.66**	−.62**	–		
6. Self-esteem	−.72**	.52**	.46**	−.61**	.62**	–	
7. Flare severity	.05	.00	−.21**	.14*	−.05	−.05	–

Note:

* $p < .05$

** $p < .01$.

Table 4.

Regression analyses for internalized stigma, stigma resistance and flare severity with patient outcomes.

Model	Variable	Adjusted R^2	β	d.f.	*F*	*p*
HRQOL (IBDQ)						
1	Flare severity	.04	−.21	1,190	9.05	.003
2	Internalized stigma	.32	−.53	2,190	45.02	.000
3	Stigma resistance	.33	.15	3,190	32.28	.000
Global psych (BSI-18) *						
1	Flare severity	.01	.13	1,190	3.18	.08
2	Internalized stigma	.38	.61	2,190	59.90	.000
IBD self-efficacy (IBD-SES)						
1	Internalized stigma	.31	−.56	1,189	87.21	.000
2	Stigma resistance	.36	.23	2,189	53.09	.000
Self-Esteem (RSES)						
1	Internalized stigma	.52	−.72	1,190	206.10	.000
2	Stigma resistance	.57	.26	2,190	128.13	.000

Note: Flare severity entered in step 1 for HRQOL and Global psych. IS and SRB entered in step 2 using a stepwise method. IS and SRB entered using a stepwise method for IBD self-efficacy and self-esteem. Adjusted R squared and standardized beta coefficients are presented.

*Stigma resistance was not significant and removed from the regression model.