

A systematic review of disease-related stigmatization in patients living with inflammatory bowel disease

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Abstract: Chronic illness stigma is a global public health issue. Most widely studied in HIV/AIDS and mental illness, stigmatization of patients living with inflammatory bowel disease (IBD), chronic autoimmune conditions affecting the digestive tract, has garnered increasing attention in recent years. In this paper, we systematically review the scientific literature on stigma as it relates to IBD across its three domains: perception, internalization, and discrimination experiences. We aim to document the current state of research, identify gaps in our knowledge, recognize unique challenges that IBD patients may face as they relate to stigmatization, and offer suggestions for future research directions. Based on the current review, patients living with IBD may encounter stigmatization and this may, in turn, impact several patient outcomes including quality of life, psychological functioning, and treatment adherence. Significant gaps exist related to the understanding of IBD stigma, providing opportunity for future studies to address this important public health issue.

Keywords: inflammatory bowel disease, stigma, discrimination, systematic review

Introduction

Inflammatory bowel diseases (IBDs), which include Crohn's disease (CD) and ulcerative colitis (UC), are chronic immune-mediated, inflammatory diseases of the digestive tract characterized by abdominal pain, rectal bleeding, diarrhea, and fatigue.¹ In some cases, extraintestinal symptoms such as eye or skin inflammation and joint pain are present.² Perianal fistulas occur in ~30% of IBD patients and may be a considerable source of distress.³ Incidence and prevalence rates of IBD are increasing globally.⁴ Treatment options for IBD include oral and injectable medications and intravenous infusions, often used in combination to induce remission as defined by symptoms, endoscopic appearance, and biomarkers.¹ Surgical interventions are common, with the cumulative risk for surgery 7 years after diagnosis being 29% for CD and 13% for UC.^{5,6}

The physical, psychological, social, and financial ramifications of IBD are substantial, and the understanding of the role of illness stigma in these effects is minimal. Psychosocial functioning including reduced health-related quality of life,⁷⁻¹⁰ increased depression and anxiety,¹¹⁻¹⁶ and relational^{17,18} and social issues¹⁹ are common. These impacts can be due to the illness itself or side effects from some IBD medications (eg, corticosteroids) or surgery.^{20,21} Social withdrawals,²² feelings of being different from others,²³⁻²⁵ and degradations in body image^{23,26} have all been reported. Psychosocial impacts of IBD result in poorer patient reported outcomes including increased health care utilization,^{27,28} reduced treatment adherence,^{29,30} and increased disease activity.³¹⁻³³

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Financially, people living with IBD pay ~3,000 to 6,000 USD more annually for health care costs than those without IBD.³⁴ Aggregate annual estimates of total direct health care costs for IBD range from 500 million USD (UC) to 2.3 billion USD (CD).³⁵ Indirect costs from lost productivity and similar issues related to IBD are also in billions of dollars.^{35–37} Poor IBD self-management contributes to increased financial burdens, and improving illness self-management via improvements in IBD-related self-efficacy, streamlining communication between physician and patient, and increasing patient buy-in to treatments all demonstrate improvement in patient outcomes.^{38–41} While stigma has not been directly studied in relation to IBD self-management, it is associated with decreases in self-esteem and self-efficacy⁴² suggesting that stigma may be associated with poorer disease management.

Chronic illness stigmatization, most notably characterized in mental health^{43–45} and HIV/AIDS^{46–48} research, is a common and global social issue.⁴⁹ While the majority of research in this area is in the aforementioned conditions, other chronic illnesses such as cancers,^{50–52} hepatitis C,^{53–55} epilepsy,^{56–58} leprosy,^{59–61} and obesity^{62–65} have well-documented stigmatization. Illness stigma has a myriad of public health implications including limiting access to medical care, increasing treatment nonadherence, increased psychological distress, decreased self-esteem and self-efficacy, and increased illness symptoms.^{66–73} The construct of stigma has evolved since Erving Goffman's seminal work defining stigma as a state of "spoiled identity" brought on being "deeply discredited" and socially rejected for having a particular trait.⁷⁴ In 2001, Link and Phelan⁷⁵ expanded the stigma model to include a convergence of labeling, prevailing cultural beliefs, disconnection of the stigmatized from others, and loss of social status combined with discrimination experiences. Research into stigma remains steady, with several hundred studies being published per year over the past decade.

Prevailing stigma theory delineates stigma into three domains: perceived or felt stigma, where the individuals sense that others hold negative attitudes or beliefs toward them or their condition; enacted stigma, or actual discriminatory experiences; internalized or self-stigma, or belief by the stigmatized individuals that negative attitudes or stereotypes about their condition are true and apply to them.⁷⁶ A fourth and adaptive domain, stigma resistance, has been captured via research utilizing the Internalized Stigma Scale for Mental Illness by Boyd et al.⁷⁷ In any particular individual, one to all four of these stigma domains may be at play, and the

relationships between each and patient outcomes are well documented.^{49,70,78–81}

Jones et al⁸² identified six traits of a condition or trait that lend it to stigmatization: concealability, variability in course, aesthetic qualities, disruptiveness, origin, and perceived threat. Of these, the severity of the illness and a perception that the condition was caused by behavior of its bearer are most likely to predict stigmatization.⁸³ Based on these parameters, combined with the social taboo related to bowel symptoms in most cultures, IBD is susceptible to illness-related stigma. The severity of IBD varies by patient, but as a whole IBD is considered a serious illness with complex medical regimens to keep inflammation and symptoms in a state of remission, including the use of intravenous infusions (eg, infliximab and vedolizumab). While the etiology of IBD is better understood today as an immune-mediated disease, historically IBD was viewed as a psychosomatic illness with personality traits that made an individual susceptible to its occurrence. The notion that a person could develop CD due to "obsessional behavior" lends it to stigmatization.⁸⁴ Today, multiple triggers of disease onset and/or activity are identified including infection, antibiotic use, smoking, low mood, nonsteroidal anti-inflammatory drug use, and stress.⁸⁵ Perceived stress, negative mood, and stressful life events are often associated with IBD flares.⁸⁵ Identifying psychological reasons for disease activity is important, yet brings with it the potential for others to view IBD symptoms as under the person's control due to a lack of ability to manage his or her psychological state or stress levels.

Initial inquiries into stigmatization of gastrointestinal illness occurred with the irritable bowel syndrome (IBS). Stigma studies in IBS find that a significant percentage of patients report some illness stigmatization.⁸⁶ However, differences in the etiology between IBS and IBD (ie, functional vs organic) lend themselves to potential differences in stigmatization.⁸⁷ Some patients with IBD are also diagnosed with IBS when their CD or UC is considered to be in remission via physiological markers yet the patient continues to exhibit symptoms.⁸⁸ Unfortunately, to date, no studies exist evaluating stigma experiences in IBD patients diagnosed with IBS. To date, no current reviews of illness stigmatization exist for IBD. In this review, we evaluate the three primary stigma domains and the relationship of each to patient outcomes, disease management, and course.

Systematic review

A literature search of studies published in English between 1985 and July 2015 was performed via the online databases

PubMed, PsycINFO, and Google Scholar. The 1985 cutoff was selected based on the seminal Jones et al study which better defines stigma as it relates to chronic medical illness.⁸² The following keyword combinations were used: 1) inflammatory bowel disease, Crohn's Disease, ulcerative colitis combined using the "AND" operator with 2) stigma, stigmatized, stigmatization, discrimination, prejudice, stereotype, shame, bullying, blame, and teasing (eg, "Crohn's disease" AND "stigmatization"). Article titles and abstracts were screened for relevance and full-text articles retrieved for a more detailed review. Reference lists of identified articles and book chapters were also reviewed for additional studies. Unpublished manuscripts and dissertations are not included. Articles identified via the database searches were reviewed by the authors for relevance to the stigma construct and those not specifically addressing stigma were removed from the final review. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram for the literature search is outlined in Figure 1.

Identified studies

Twenty-six studies are reviewed. The majority was published in the USA and evaluate perceived stigma (15 studies). Four studies evaluate internalized stigma, five evaluate enacted stigma, and two evaluate more than one stigma domain. Adult and child/adolescent studies of stigma were included. Specific measures of health-related stigma are abundant and summarized elsewhere.⁸⁹ The findings are organized by the three stigma domains (Table 1).

Perceived or felt stigma

The most widely studied of the stigma domains in IBD is perceived or felt stigma, with 84% of participants in a recent study reporting some perceived stigma.⁴² Several studies report persons living with IBD having concerns about how others see them,^{25,26,90} feeling different than others,²⁶ feeling shame,⁹¹ and feeling discredited, including by medical providers.^{26,87} For example, hospitalized patients requiring pain management report being labeled as a difficult patient,

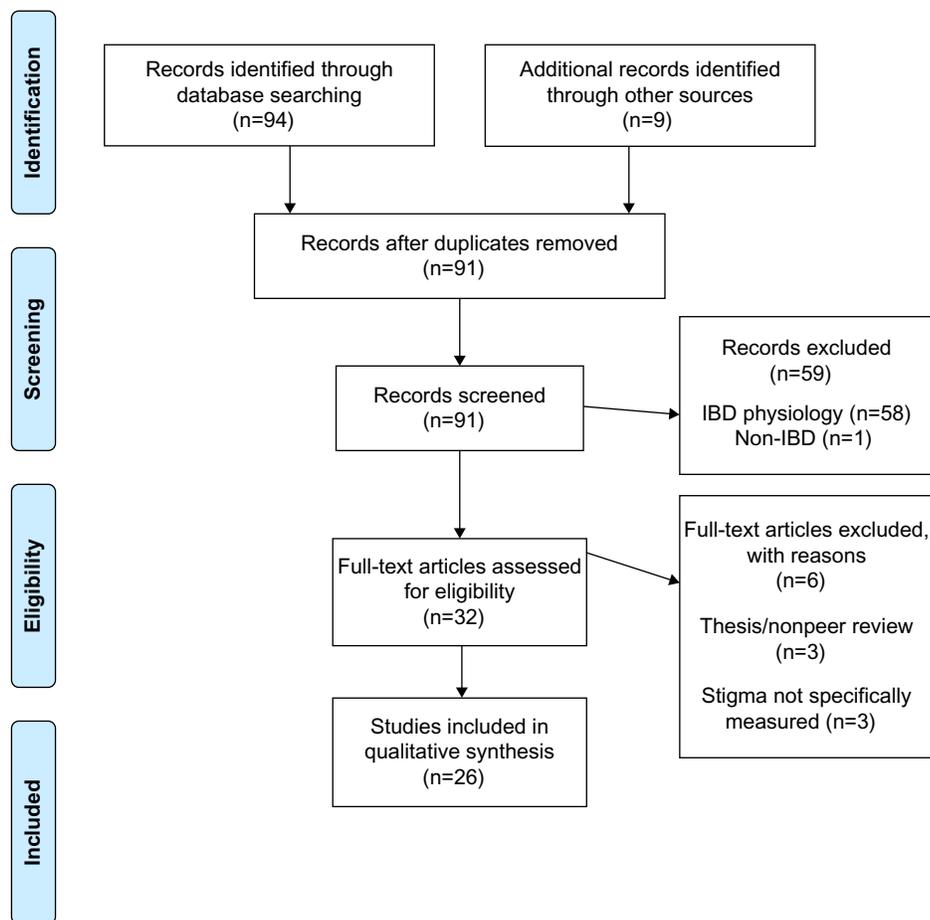


Figure 1 PRISMA flow diagram for systematic review of stigmatization in inflammatory bowel diseases.

Abbreviations: IBD, inflammatory bowel disease; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

Table 1 Relevant studies of inflammatory bowel disease (IBD) stigmatization

Authors	Study description	No of subjects	Stigma measured	Key findings
Bernhofer et al ⁹²	Qualitative interview of pain experiences during hospital stay	16	Perceived	Labeled as difficult, needy, drug-seeking, unable to tolerate pain properly
Czuber-Dochan et al ⁹⁴	Qualitative interview health care professionals perceptions of IBD-related fatigue	20	Enacted	Frustration and poor understanding of IBD-related fatigue
Dibley and Norton ⁹⁰	Mixed qualitative interview, cross-sectional survey of experiences with fecal incontinence	611	Perceived	Concerns about how others view IBD, increased social withdrawal/isolation to protect from potential shame
Frohlich ⁹⁹	Qualitative interview of coping with IBD-related stigma	17	Perceived	Feelings of guilt from being a burden, feeling of relief after disclosure to safe others
Saunders ⁹⁸	Qualitative interview of stigma experiences	4	Perceived	Nondisclosure due to embarrassment from symptoms, challenges related to passing as normal
Czuber-Dochan et al ⁹³	Qualitative interview of fatigue experiences	46	Perceived	Health care providers have little understanding of IBD-related fatigue
Danielsen et al ¹¹⁰	Qualitative interview of impact of ostomy on quality of life	15	Internalized	Positive experiences with ostomy, feeling in control of disease management
Taft et al ¹¹³	Cross-sectional survey of internalized stigma/stigma resistance	191	Internalized	33% report internalized stigma, alienation, and social withdrawal most common; the majority engage in stigma resistance behaviors
Taft et al ⁸⁷	Cross-sectional survey comparing perceived stigma in irritable bowel syndrome (IBS) and IBD	496	Perceived	IBS patients report greater stigma than IBD, larger impact on patient outcomes for stigmatized IBD patients
Taft et al ⁴²	Cross-sectional survey measuring perceived stigma	211	Perceived	84% report some perceived stigma. Stigma increases psychological distress, decreases quality of life
Voth and Sirois ¹⁰⁹	Cross-sectional survey of self-blame and adjustment	259	Internalized	Self-blame about IBD correlates with poorer outcomes
Smith et al ¹¹¹	Cross-sectional survey of stigma of ostomy	195	Internalized	Ostomy contributes to feelings of shame, self-stigma
Finlay et al ¹⁰¹	Cross-sectional survey of racial minority experiences	148	Perceived	Caucasians are more likely to disclose IBD status than African-Americans
Looper and Kirmayer ¹⁰⁵	Cross-sectional survey of felt stigma in functional vs organic illnesses	89	Perceived	Perceived stigma is significantly correlated with poorer psychological functioning; no difference in stigma perception between IBS and IBD
Krause ⁹¹	Qualitative interview of social representations of IBD	19	Internalized	Many patients report feelings of shame related to their IBD diagnosis and symptoms
Daniel ²⁶	Qualitative interview of young adult experiences	5	Perceived, enacted, internalized	Feel others think they use IBD for secondary gain, poor body image/damaged, feel different, feel discredited, shame, concerns about disclosure
de Rooy et al ⁹⁵	Cross-sectional survey of IBD patient concerns	241	Perceived	Older patients, women, patients with ulcerative colitis, lower educational level report greater stigma
Levenstein et al ²⁵	Cross-sectional survey of IBD patient concerns	2,002	Perceived, internalized	Body stigma, feeling dirty, concerns of being a burden reported in patients living in multiple countries
Moskovitz et al ¹⁰⁶	Cross-sectional survey of social support and surgical outcomes	86	Perceived	Poor social support is correlated with worse surgical outcomes
Mayberry ¹¹⁵	Cross-sectional survey of personnel managers and workplace discrimination	195	Enacted	30% would not provide leave for outpatient care. IBD impacts promotion decisions in 8% of managers. 60% would make accommodations
Moody et al ¹⁰⁴	Cross-sectional survey of social implications of childhood IBD	64	Perceived	50% of students report teachers unsympathetic toward IBD
Mayberry et al ¹⁰²	Cross-sectional survey of workplace/education discrimination	116	Enacted	50% of patients with Crohn's disease had trouble finding work compared to 24% of controls
Moody et al ¹⁰⁰	Cross-sectional survey of employer attitudes toward IBD	53	Enacted	25% of employers would not continue to employ people if they developed IBD, 30% would not provide time off work to attend appointments
Drossman et al ²³	Questionnaire validation of IBD patient concerns	991	Perceived	Body image, concerns about being a burden, feeling dirty or smelly common concerns
Salter ¹⁰⁸	Qualitative interview of stigma of ostomy	7	Internalized	Ostomy increases self-stigma, shame, body image issues
Wyke et al ¹⁰³	Cross-sectional survey of workplace discrimination	170	Perceived, enacted	81% disclosed IBD, 80% coworkers, 77% employers generally helpful about IBD

needy, that they cannot tolerate pain properly, or are inappropriately seeking narcotic painkillers (ie, drug-seeking patients).⁹² Fatigue is a commonly reported IBD symptom and patients report significant social impact with little understanding from their medical providers.⁹³ A follow-up inquiry by the same author with health care providers found that considerable frustration and difficulty in understanding IBD-related fatigue was common,⁹⁴ indicating a significant disconnect between providers and patients. Older patients, especially women and patients with UC, tend to report greater disease felt stigma as do patients with lower educational backgrounds.^{95,96} Stigma perceptions appear to be stable whether the disease is active or in remission and do not appear to vary between UC and CD.²³

As IBD is a concealable illness, the issue of disclosure is a salient concern for many patients. Individuals living with concealable conditions may opt to “pass” as someone without a chronic illness or “cover” by downplaying the severity of its symptoms.^{97,98} Most often, persons living with IBD report nondisclosure due to embarrassment related to its symptoms.⁹⁸ Fears of the threat of incontinence, bowel sounds, or urgency while in public can have significant negative impacts on patients’ social interactions, often leading to withdrawal and isolation as to protect themselves from potential shame.^{26,90} Passing can be challenging, especially when the patient must use the toilet multiple times per day,⁹⁸ so covering is more often employed especially to “safe others”. Guilt about being a burden to others and stoicism may also contribute to nondisclosure.^{26,99} Concealment is often associated with reduced communication, interactions, and transactions with others thereby increasing feelings of isolation and depression. Disclosure can yield positive results, providing a sense of relief from the stress of keeping IBD hidden and mitigating the effects of stigma.⁹⁹

As can be expected, experiences with IBD disclosure vary considerably. Some patients report being very open about their condition while others may tend to keep it hidden except with family and close friends.⁹⁹ Disclosure in employment settings comes with its own unique challenges.¹⁰⁰ Racial differences exist, with Caucasians more likely than African-Americans to disclose their IBD status to their employer or fellow employees.¹⁰¹ The reactions in occupational settings are mixed. A 1992 study of patients with CD found that 37% of patients currently employed felt their employer did not need to know about their IBD and 30% were in favor of active concealment. Additionally, 24% felt IBD had limited their employment prospects including avoiding seeking a promotion or being denied promotion because of their illness.¹⁰² Conversely, a 1988 study found the majority of participants reported high workplace

disclosure (81%), and that 80% of coworkers and 77% of employers had been generally helpful.¹⁰³ These significantly different findings on employer attitudes may be related to a wide variability in employment culture as a whole, geographic differences in health-related stigma, or the level of familiarity that surveyed employers had with IBD. It highlights that IBD patient experiences with perceptions of negative attitudes from employers will likely vary widely, highlighting the importance of inquiring about each individual’s experience in a clinical setting. Academic and school settings also present challenges for people living with IBD. In one study, 50% of children reported that their teachers were unsympathetic toward their illness.¹⁰⁴ Another study found that 21% of college-aged students found lecturers to be indifferent and 8% found them to be hostile toward their disease.¹⁰²

Perceived stigma in IBD patients is associated with several outcomes including increases in psychological distress,^{42,105} decreases in health-related quality of life, reduced medication adherence, and decreased self-esteem and self-efficacy.⁴² Patients who perceive poor social support prior to surgery report poorer quality of life after the procedure.¹⁰⁶ If the surgical intervention results in an ostomy, quality of life may improve in some patients in that they feel more in control of their illness¹⁰⁷ while others may experience an increase in both perceived and internalized stigma.¹⁰⁸ Simply perceiving that others hold these negative attitudes is sufficient to degrade patient well-being. Whether or not the individual internalizes the stigma can lead to even greater distress, and thus, is an important line of inquiry in stigma research.

Internalized or self-stigma and stigma resistance

Internalized or self-stigma may be related to the poorest outcomes of the three stigma domains in that patients apply negative attitudes and stereotypes to themselves rather than rejecting them as false. Internalized stigma includes alienation, stereotype endorsement, discrimination experiences, and social withdrawal.⁷⁷ Patients with IBD report feeling damaged,²⁶ especially as it relates to physical changes from the disease or its treatments (eg, weight loss or gain, stunted growth, and skin rashes). Self-blame regarding the onset of IBD or the presence of its symptoms postdiagnosis is associated with poorer adjustment to the illness.¹⁰⁹ The presence of an ostomy can contribute to self-stigma in some cases,^{110,111} while in others it produces positive results including feelings of satisfaction with their illness management.¹¹²

One study specifically evaluates internalized stigma and stigma resistance in IBD.¹¹³ Overall, 33% of people

living with IBD report internalized stigma with alienation and social withdrawal being the most common. In general, IBD patients report mild levels of internalized stigma while a larger majority report stigma resistance attitudes and behaviors suggesting that while IBD patients perceive others hold stigmatizing views, they tend to not incorporate them into their sense of self. Levels of internalized stigma are associated with lower educational levels, residing in an urban setting, and having extraintestinal symptoms. Unlike stigma perception, patients who identified themselves as in remission reported less internalized stigma and greater use of stigma resistance behaviors. Internalized stigma in IBD patients predicts reduced health-related quality of life, poorer self-esteem and self-efficacy, and increased psychological distress. These findings are similar to internalized stigma studies in other patient populations.^{53,70,114}

Enacted stigma

Studies on enacted stigma in IBD are limited. Patients report many people simply do not understand IBD, which may cause some to accuse persons with IBD of exaggerating their condition for secondary gain.²⁶ In 1992, Mayberry found that 50% of CD patients compared to 24% of matched healthy controls had significant trouble finding work and long-term unemployment exceeding 6 weeks.¹⁰² Mayberry¹¹⁵ evaluated employer attitudes and practices toward people living with CD. Only two out of 35 companies would reject candidates because of IBD. However, 33 of 35 would rely on preemployment medical examinations to make hiring decisions and 8% said IBD would negatively impact promotion consideration. Sixty percent would support employee experiencing a relapse by providing a lighter work period and 16% would pay for private care; 30% would not extend paid leave time for outpatient appointments. Due to the dearth of studies on enacted stigma in IBD patients, additional research is important to close the gaps in the understanding of how common enacted stigma is, what the more common sources of discrimination are, and how enacted stigma influences outcomes.

Discussion

Based on the results of this review, IBD is susceptible to stigma because of its concealability, embarrassing symptoms, and historical view of IBD being a psychosomatic condition. The most commonly studied type of stigma is perceived stigma, evident in 17 studies and demonstrating that the majority of IBD patients perceive stigma from their peers, significant others, colleagues, and physicians.⁴² Perceived stigma is the easiest construct to identify, but may have less

to do with outcomes than “deeper” levels of stigma such as internalized or enacted. For example, patients who perceive stigma but do not internalize it may utilize coping strategies that would be found in any stigma-reducing intervention technique (eg, cognitive reframing). Future research could probably shift away from perceived stigma at this point and focus on other forms.

Internalized stigma, or the incorporation of stigmatizing beliefs and attitudes into one’s sense of self, is potentially the most detrimental to IBD outcomes because it results in declines across physical and psychological functioning more than perceived stigma. In other disease groups, similar findings are noted.⁷⁷ As IBD requires substantial self-management to maintain remission, adhere to medications, follow disease surveillance protocols (eg, colonoscopy and regular laboratory testing), vaccination, and other health guidelines, stigma could potentially interfere with self-care. Internalized stigma may be the most modifiable form of stigma through cognitive and behavioral therapies, if it is detected early and remediated.

Considerably less is known about enacted stigma in IBD and is an important area for future research. Enacted stigma evaluated in other conditions demonstrates that it is a very important aspect of public health and health systems.^{44,116,117} Whether it is subtle “weeding” out of an employee who is chronically ill or more direct (eg, refusing to allow an IBD patient to use the restroom), enacted stigma requires a comprehensive intervention.

Measurement of stigma and related factors is critical to proper detection and potential intervention – unfortunately, the construct itself, when present, makes it hard to measure. One tool specific to IBD is the Perceived Stigma Scale for IBD, adapted from the Perceived Stigma Scale for IBS,⁸⁶ which allows for quick assessment of stigma perceptions among IBD patients during routine visits. However, as we saw earlier, poor quality of life, poor treatment adherence, or low disease knowledge may also point to stigmatizing beliefs about IBD and when present, the provider should query for perceived stigma. Regardless, it is important for health care providers to ask patients about the social implications of their disease so that they may be referred to appropriate resources, including clinical health psychologists, to help mitigate the potential impacts of stigma on patient outcomes.

The development of stigma interventions has occurred for other chronic conditions,^{46,118–121} and while their efficacy in reducing stigma is mixed, these interventions have merit. The RAND Corporation and the American Psychological Association have described theoretically-based multicomponent

approaches to reducing stigma in mental illness which could be applicable to IBD.¹²² These include training interventions for health professionals and the general public, which provide information on the causes of the disease (not stress or diet, but an immune-inflammatory reaction), treatments (infusions, surgeries, and ostomies), and experiences of people living with the disease (people with CD and ostomies can be athletes, like Matt Light, David Garrard, and Kevin Dineen). Educational interventions seem to hold the longest staying power when they are enhanced with a direct interpersonal contact strategy (having a guest speaker with UC or a panel discussion between IBD patients from different backgrounds).¹²³ Finally, mass media campaigns can deliver similar antistigma, educational messages although the impact of these is hard to evaluate. Patient advocacy groups have already emerged to help destigmatize IBD (eg, The Great Bowel Movement, www.thegreatbowelmovement.org) and research into their benefit could be an important next step.

Disclosure

The authors report no conflicts of interest in this work.

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