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Disease-specific self-efficacy in the eosinophilic gastrointestinal disorders

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Abstract

Eosinophilic gastrointestinal disorders (EGIDs) are chronic inflammatory conditions with increasing global prevalence. Self-efficacy is important for patients' ability to manage chronic disease. We sought to evaluate disease-specific self-efficacy in the EGIDs via a modified version of the Inflammatory Bowel Disease Self-Efficacy Scale (IBD-SES). Ninety-one Participants reported demographic, clinical, and psychosocial variables. The IBD-SES demonstrated excellent reliability and validity in this population. Self-efficacy was higher in men, patients with less severe disease, and those who had consulted a dietitian. The IBD-SES is a useful measure of disease-specific self-efficacy in the EGIDs. Further research is necessary to understand the role of self-efficacy in the management of these illnesses.

Keywords

adults; chronic illness; eosinophilic gastrointestinal disorders; perceived control; self-efficacy

Introduction

Eosinophilic gastrointestinal disorders (EGIDs) are chronic inflammatory diseases of the gastrointestinal tract that affect 25–50 per 100,000 people in the United States (Spergel et al., 2011). The underlying mechanism of the EGIDs is believed to be an abnormal increase in the number of *eosinophils* (white blood cells) in the mucosa of the digestive system (Liacouras et al., 2011) in reaction to some environmental stimulus, the most common of which is food. These eosinophils permeate the lining of the gastrointestinal tract and cause multiple symptoms depending on the location of infiltration and include abdominal pain, diarrhea, acid reflux, difficulty swallowing, nausea, and vomiting (Verheijden and Ennecker-Jans, 2010; Oh and Chetty, 2008). EGIDs can occur in the esophagus (eosinophilic esophagitis (EoE)), stomach (Gastritis), small intestine (Enteritis), large intestine (Colitis), or in multiple locations (Gastroenteritis); however, to date, EoE is the most commonly diagnosed of the EGIDs.

Over the past decade, EGIDs have gained increased attention among medical professionals due to steadily rising global prevalence rates (Soon et al., 2013). Once believed to be

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primarily a pediatric disease, EGID rates in adults are on the rise (Liacouras et al., 2011). Accurate diagnosis can be challenging and often involves several invasive procedures. Current treatments for EGIDs are intensive but often not satisfactorily effective. They may involve dietary management, corticosteroids, steroid-sparing anti-inflammatory agents, or a combination of these (Assa'ad, 2009; Liacouras, 2003; Liacouras et al., 2011; Oh and Chetty, 2008; Pratt et al., 2008). Dietary treatments include food elimination, formula-based diets, or gastric tube feedings.

To identify foods that may be triggering the eosinophilic reaction, patients often must eliminate the top eight allergy-producing foods (dairy, soy, eggs, wheat/gluten, peanuts, tree nuts, fish, and shellfish) for several weeks. They then systematically reintroduce one food at a time to their diet, and those foods that cause symptoms are permanently removed from the person's diet. In some patients, additional foods beyond the top eight are involved in invoking inflammatory responses, leading to complicated reintroduction trials and potential for considerable dietary impact. EGID treatments require proper adherence, lifestyle changes, and careful management of side effects. Despite this, there are relatively few research studies that have focused on the psychosocial factors associated with EGIDs and illness outcomes (Henry et al., 2012; Taft et al., 2012).

In Health Psychology research, *self-efficacy* (SE) is an important factor in adherence and disease management. SE is the social-cognitive construct that refers to an individual's perception of his or her capability to perform certain tasks or to achieve desired results (Bandura, 1977). This construct is distinct from actual ability and is closely associated with motivation to make and maintain behavioral changes (Kelly et al., 1991). Research in chronic illnesses such as cancer (Hoffman, 2012; Mystakidou et al., 2012), multiple sclerosis (Fraser and Polito, 2007; Young et al., 2012), HIV (Kamen et al., 2013), and inflammatory bowel disease (IBD; Keefer et al., 2011; Taft et al., 2013) suggests that SE may be an important predictor of physical and psychosocial outcomes. Furthermore, the association between high SE and successful behavior changes has been studied extensively in various health behaviors such as smoking cessation (Martinez et al., 2010), weight loss (Hankonen et al., 2013; McKee, 2013; Warziski et al., 2008), and adherence to medical treatments (Brus et al., 1999).

The goal of the current research study is to evaluate disease-specific SE in a sample of EGID patients using a validated measure of SE in patients with IBD (Keefer et al., 2011). Since IBD and EGIDs are both chronic inflammatory gastrointestinal diseases, we hypothesize that the Inflammatory Bowel Disease Self-Efficacy Scale (IBD-SES) will be a reliable and valid measure of disease-specific SE for EGIDs.

Methods

Participants

Adults aged 18–70 years diagnosed with EGIDs for at least 6 months were recruited through three ways as follows: via email to members of a US-based patient advocacy group, advertising to social media support groups, and a university-based outpatient gastroenterology practice. Clinic participants were recruited during routine visits to

their gastroenterologist and completed paper-based questionnaires that measured disease-specific and general perceived SE, health competence, depression, and anxiety. Non-clinic participants completed the same questionnaires via a secure third-party survey provider.

Measures

IBD-SES (29 items) measures disease-specific SE for patients with IBD. Items are rated on a 10-point Likert scale with 10 being “totally sure,” 5 being “somewhat sure,” and 1 being “not sure at all.” The IBD-SES is divided into four subscales: (1) managing stress and emotions, (2) managing medical care, (3) managing symptoms and disease, and (4) maintaining remission. Questions were changed to reflect SE related to EGIDs by changing “IBD” to “EGID” (e.g. “Take the medications to prevent a flare up of your EGID as directed?”) and bowel symptoms to “EGID symptoms” (e.g. “Keep EGID symptoms from interfering?”). One question was added to the Managing Medical Care section to gauge SE related to dietary treatment: “Follow a diet to prevent a flare up of your EGID as directed?” Higher scores on the IBD-SES indicate greater SE. Internal consistency of the IBD-SES is excellent (Cronbach’s $\alpha = 0.96$).

Perceived Health Competence Scale (PHCS; 8 items) measures patients’ perceived ability to manage health outcomes. Higher scores on the PHCS reflect higher perceived health competence (PHC). This scale has good internal consistency (Cronbach’s α ranged from 0.82 to 0.90 across samples), construct validity, and test–retest reliability (Smith et al., 1995).

General Self-Efficacy Scale (GSES; 10 items) measures perceived ability to cope with various life demands (Schwarzer and Jerusalem, 1995). Higher scores reflect higher SE (i.e. more positive perceptions of one’s ability to cope with life’s demands). The GSES has been shown to have high reliability, stability, and construct validity in multicultural studies (Cronbach’s α ranged from 0.76 to 0.90 across samples) (Luszczynska et al., 2005).

National Institutes of Health–Patient Reported Outcomes Measurement Information System (NIH-PROMIS) short-form: Emotional Distress–Depression (8 items) assesses self-reported negative mood (sadness and guilt), views of self (self-criticism and worthlessness), and social cognition (loneliness and interpersonal alienation), as well as decreased positive affect and engagement (loss of interest, meaning, and purpose). Each question has five response options ranging in value from one to five (Pilkonis et al., 2011).

NIH-PROMIS short-form: Emotional Distress–Anxiety (8 items) measures self-reported fear (fearfulness and panic), anxious misery (worry and dread), hyperarousal (tension, nervousness, and restlessness), and somatic symptoms related to arousal (racing heart and dizziness). Each question has five response options ranging in value from one to five (Pilkonis et al., 2011).

Demographic and Clinical Information was collected for each participant and includes gender, age, race, ethnicity, education level, marital status, insurance status, income, EGID diagnosis, duration, symptom activity, symptom severity, medical appointments and

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

Statistical analyses

Data from the online and clinic samples were pooled and exported to SPSS 20.0 for analyses. Data were tested for normality prior to analyses, and significance was set at $p < .05$. Descriptive statistics were calculated for all demographic and clinical variables. To test the reliability of the IBD-SES in this sample, Cronbach's α and Guttman Split-Half reliability were measured for the total score and each subscale, accordingly. Relationships between scores on the IBD-SES and the additional psychosocial measures were evaluated via Pearson's correlations to determine construct validity. Finally, a series of independent samples t -tests were conducted to understand group differences in self-efficacy for demographic and clinical variables.

Results

Sample characteristics

In this sample of 91 EGID patients (Table 1), 74 percent were women, 92 percent were non-Hispanic White, 49 percent were married, and 79 percent had private insurance. Their mean age was 36.6 years (standard deviation (SD) = 11.27 years), and mean years of education was 15.05 years (SD = 3.49 years). In all, 47 percent were recruited through online support groups, 27 percent were from the patient advocacy group, and 26 percent were from the gastroenterology clinic. Similar to disease prevalence rates, the majority (65.9%) of the sample had EoE. In all, 70 percent of participants were currently experiencing EGID symptoms and did not consider themselves in remission.

On average, participants experienced active symptoms 5.1 days per week, had between one and two endoscopies in the past year, and had seen their primary EGID physician four times in the past year. For treatment, the majority of participants (77%) used prescription medications to treat their EGID. In all, 76 percent used a dietary treatment at some point during the course of their illness, with 60 percent having done so in the 3 months prior to the study. Half of the sample had seen a dietitian, and 15 percent had consulted a psychologist as part of their EGID management.

Reliability and validity of IBD-SES

Internal consistency of the 30-item IBD-SES in this sample was excellent (Cronbach's $\alpha = 0.96$, Guttman Split-Half = 0.89; Table 2). Subscales also demonstrated superior reliability with Cronbach's α ranging from .89 (Managing Medical Care) to .96 (Managing Stress & Emotions). Guttman Split-Half scores ranged from 0.68 (Managing Medical Care) to 0.93 (Managing Stress & Emotions).

Convergent validity was evidenced by modest and significant correlations with each of the questionnaires in our assessment battery (all $p < .01$). The largest correlation was with PHC ($r = 0.74$), followed by inverse relationships with depression ($r = -0.514$) and anxiety ($r =$

−0.469). The smallest relationship was with general SE, indicating that EGID-specific SE is only somewhat related to general belief in abilities in other life domains ($r = 0.31$).

Relationship between SE and demographic/clinical variables

Next, we sought to understand how demographic and clinical variables may relate to levels of EGID-specific SE (Table 3). We found significant differences in SE for gender and marital status; men scored significantly higher than women, $t(75) = 2.65$, $p < .05$, and married participants scored significantly higher than those who were not married, $t(78) = 2.02$, $p < .05$. Specifically, men reported more confidence in managing stress/emotions, managing symptoms/disease, and maintaining remission. Married participants felt more confident in managing medical care.

Symptom variables that were correlated with the IBD-SES included number of symptomatic days per week ($r = -0.33$, $p < .01$), most recent flare severity ($r = -0.31$, $p < .01$), and disruptiveness of EGID flares symptoms ($r = -0.33$, $p < .01$). The participant's number of endoscopies and number of doctor's appointments in the past year were not significantly correlated with IBD-SES scores.

Disease activity is also related to levels of SE, with participants currently experiencing symptoms reporting significantly lower SE, $t(78) = 2.71$, $p < .01$ and those who considered themselves in remission having significantly higher SE, $t(78) = -3.98$, $p < .01$. Specifically, symptomatic participants scored lower on managing stress/emotions and managing symptoms/disease. Participants in remission scored higher on SE in these domains as well as for maintaining remission. Finally, those participants who had worked with a dietitian about their EGID reported significantly higher levels of SE, $t(78) = -2.08$, $p < .05$, specifically related to managing stress. No significant differences existed for the remaining demographic or clinical variables.

Discussion

The results of this study provide preliminary evidence that the IBD-SES may be a valid and reliable measure of disease-specific SE for EGID patients, although further validation efforts are necessary. We report excellent internal reliability and convergent validity with several validated measures. Given the rigorous nature of medical treatments for EGIDs, the importance of adherence to these regimens, and the need for self-management of their condition, a validated measure of patient SE is an important addition to EGID outcome research. The four subscales of the IBD-SES (managing stress/emotions, managing symptoms/disease, maintaining remission, and managing medical care) provide an additional level of understanding of specific SE domains and increased opportunity to tailor interventions for individual patients.

In this sample, we found that men felt more in control of managing stress and emotions, their symptoms/disease, and maintaining remission than women. Psychological theory on SE has repeatedly demonstrated gender differences in SE favoring males (Gecas, 1989). However, data on gender differences for health-related SE are somewhat mixed and appear to vary depending on the patient population. For example, male college students report lower

levels of SE related to HIV protection than their female peers (Dekin, 1996) while women report less SE related to pain tolerance (Jackson et al., 2002; Vierhaus et al., 2011), weight control (Presnell et al., 2008), and participating in cardiac rehabilitation activities (Schuster and Waldron, 1991). Although the gender differences found in this sample suggest higher SE in male EGID patients compared to female patients, further research with equal numbers of men and women is necessary.

Research into the patient–provider relationship in EGIDs may provide insights into our observed gender differences. Previous studies have demonstrated that positive patient–provider interactions foster greater overall confidence (Johnson et al., 2006) and that greater patient satisfaction levels are associated with greater disease-specific SE (Zachariae et al., 2003). Interestingly, gender differences exist in healthcare experiences (Hall et al., 1994), and women may be less likely to be satisfied with their medical care (Elliott et al., 2012). We found that participants in our sample who had more integrated care (i.e. worked with a dietitian) felt better able to manage stress related to their EGID, suggesting that quality of care is an important aspect to SE levels in this patient population.

Our results also showed that marital status was related to levels of SE, with married participants reporting greater SE, especially as it relates to managing their medical care. These findings are similar to other chronic conditions including scleroderma (Buck et al., 2010), rheumatoid arthritis (Tewary, 2008), and cardiovascular disease (Waltz and Badura, 1988). The role of positive social support in health outcomes is well documented. Marital quality is an important consideration in understanding its relationship to SE and health outcomes (Tewary, 2008). While we did not measure this construct, it is likely that participants in this study have adequate spousal support regarding their condition. Further research into social relationships and their effects on EGID outcomes is warranted.

Disease activity was also related to levels of SE, which is congruent with data from other patient populations including rheumatoid arthritis (Sperber et al., 2013), cancers (Mystakidou et al., 2012; Porter et al., 2002), and sickle cell disease (Edwards et al., 2001). Participants in self-reported remission and those who were not currently experiencing symptoms reported greater confidence in their ability to manage stress/emotions, to manage their disease, and to maintain remission. Logically, participants whose disease has responded to treatment interventions feel in greater control of their condition. Those with more symptomatic days per week, greater symptom severity, and more disruption to their daily life due to EGID reported significantly lower SE.

It appears that women, participants in active disease states (i.e. with current symptoms or not in remission), participants with less immediate social support (i.e. unmarried), and participants who lack integrated care demonstrate lower SE. These patient groups may benefit from interventions targeted specifically at increasing SE in order to improve physical and psychosocial outcomes (e.g. medication adherence or overall quality of life), as has been demonstrated in other chronic illnesses (Bandura, 1977; Brus et al., 1999; Fraser and Polito, 2007; Hoffman, 2012; Keefer et al., 2011; Kelly et al., 1991; Martinez et al., 2010; Mystakidou et al., 2012; Warziski et al., 2008; Young et al., 2012). Specifically, cognitive behavioral therapy (CBT) interventions are shown to increase SE in patients with many

chronic conditions (Edinger et al., 2001; O’Leary et al., 1988; Redondo et al., 2004), and may benefit patients with EGIDs.

According to Bandura’s (1977) theory of SE, people are more likely to avoid tasks that they believe to be beyond their capabilities. Applied to this research study, it is possible that participants with lower disease-related SE will be less motivated to engage in proper self-management of symptoms and medical treatments. As such, interventions to increase SE in EGID patients may be a useful tool for physicians, nurses, dietitians, and health psychologists. One effective technique that has been used to increase SE in other patient populations is motivational interviewing (MI) (Chariyeva et al., 2012; Walpole et al., 2011). A total of 15 percent of our sample had met with a therapist regarding their EoE; however, no significant relationship existed between this and disease-specific SE. As there are many approaches to psychotherapy, and we did not assess the types of interventions used, we cannot draw any conclusions about the effectiveness of psychotherapy in this population. However, future studies may explore the role of evidence-based psychological interventions, such as MI and CBT, to increase SE in the EGID populations.

There are limitations to this study that should be considered when interpreting its results. The majority of our participants were non-Hispanic White, college-educated females with private health insurance, who live in the United States. Caution should be used when applying these results to ethnic minorities, those from lower socioeconomic statuses, and those outside of the United States. Our study sample also did not match previous data on gender distributions of EGIDs, which indicate that males are more likely to be diagnosed than females (Liacouras, 2003; Soon et al., 2013). Methodologically, this study used a cross-sectional design and did not evaluate test–retest reliability of the IBD-SES. Longitudinal studies would help better understand the patterns of SE in this patient population over time and throughout treatment.

The sample size of this study was adequate for the statistical analyses; however, it was substantially smaller than the original IBD-SES study, which had a sample size of 172 (Keefer et al., 2011). Finally, a percentage of our participants were recruited online, and therefore, we could not validate a self-reported EGID diagnosis.

This study is the first to report on disease-specific SE in a cohort of patients living with EGIDs. While the results are preliminary, they highlight the importance of evaluating SE in this patient population and to consider the impact that low SE may have on disease course. Further research into this relationship is needed, with the ultimate aim to guide potential patient interventions to maximize SE and improve patient-reported outcomes.

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Table 1.

Demographic and clinical description of study sample.

	Total sample (<i>N</i> = 91)
Age ^a	36.60 years (11.27)
Female gender ^b	67 (76.3%)
Race: non-Hispanic White ^b	84 (92.3%)
Marital status: married ^b	43 (47.3%)
Insurance: private insurance ^b	71 (78%)
Education ^a	15.05 years (3.49)
Recruitment source ^b	
Online, other	41 (45.1%)
Online patient advocacy	24 (26.4%)
Gastroenterology clinic	23 (23.1%)
Type of illness ^b	
Eosinophilic esophagitis	60 (65.9%)
Eosinophilic gastroenteritis	17 (18.7%)
Eosinophilic colitis	5 (5.5%)
Eosinophilic gastritis	3 (3.3%)
Disease and treatment	
Days/week symptoms ^a	5.08 days (1.95)
Most recent flare severity (1–10)	5.87 (2.46)
Disruptiveness of flare symptoms (1–10)	6.01 (2.69)
Experiencing current symptoms ^b	64 (70.3%)
Not in remission ^b	63 (69.2%)
Consulted dietitian ^b	45 (49.5%)
Consulted psychologist ^b	14 (15.4%)
Endoscopies in past year ^a	1.62 (1.48, 0–7)
Physician visits past year ^a	4.02 (4.64, 0–30)
Dietary treatment past 3 months ^b	55 (60.4%)
Prescription medicine past 3 months ^b	70 (76.9%)

^aContinuous variables are reported as mean (standard deviation (SD)).^bCategorical variables are reported as frequency (%).

Table 2.

Reliability statistics for IBD-SES in EGID sample.

	Cronbach's α	Guttman Split-Half
IBD-SES total	0.96	0.89
Managing stress/emotions subscale	0.96	0.93
Managing medical care subscale	0.89	0.68
Managing symptoms/disease subscale	0.95	0.91
Maintaining remission subscale	0.91	0.85

IBD-SES: Inflammatory Bowel Disease Self-Efficacy Scale; EGID: eosinophilic gastrointestinal disorder.

Table 3.Independent *t*-test for group differences on total IBD-SES scores and subscale scores.

IBD-SES Scale, mean (SD)					
	Total	Managing stress	Managing medical care	Managing symptoms/disease	Maintaining remission
Gender					
Male	7.46 (1.7)	7.52 (1.7)	8.26 (2.1)	7.06 (2.6)	6.56 (2.10)
Female	6.42 (1.8)	6.14 (1.8)	7.70 (2.0)	5.01 (2.3)	5.59 (2.48)
<i>t</i>	2.65 *	2.49 *	1.01	3.30 **	1.58
Marital status					
Married	6.94 (1.7)	6.84 (2.1)	8.38 (1.7)	5.88 (2.4)	6.08 (2.4)
Unmarried	6.14 (1.9)	6.11 (2.2)	7.25 (2.2)	5.15 (2.6)	5.58 (2.4)
<i>t</i>	2.02 *	1.48	1.13 *	1.33	0.94
Current EGID symptoms					
Yes	6.22 (1.8)	6.17 (2.3)	8.42 (1.6)	5.06 (2.4)	6.69 (2.0)
No	7.45 (1.5)	7.36 (1.8)	7.61 (2.2)	6.85 (2.3)	5.53 (2.5)
<i>t</i>	2.71 **	2.13 *	1.5	291 **	1.89
Current remission					
Yes	7.77 (1.4)	7.75 (1.5)	7.67 (2.0)	7.47 (2.2)	7.37 (1.6)
No	6.09 (1.7)	6.01 (2.3)	8.25 (2.1)	4.80 (2.2)	5.27 (2.4)
<i>t</i>	-3.98 **	-3.97 **	-1.11	-4.76 **	-4.51 **
Dietitian use					
Yes	6.92 (1.7)	6.98 (2.2)	7.51 (2.3)	5.07 (2.4)	5.45 (2.6)
No	6.08 (1.9)	5.88 (2.1)	8.08 (1.9)	5.88 (2.6)	6.14 (2.2)
<i>t</i>	-2.08 *	-2.28 *	-1.25	-1.45	-1.28

IBD-SES: Inflammatory Bowel Disease Self-Efficacy Scale; EGID: eosinophilic gastrointestinal disorder; SD: standard deviation.

* $p < .05$;** $p < .01$.