

ILLNESS STIGMA, BODY IMAGE DISSATISFACTION, THWARTED  
BELONGINGNESS, AND DEPRESSIVE SYMPTOMS  
IN YOUTH WITH INFLAMMATORY BOWEL DISEASE

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Abstract: Introduction: Elevated depressive symptoms are observed in youth with inflammatory bowel disease (IBD), and have been linked to perceived illness stigma and feelings of social isolation. One potential variable related to stigma that has received minimal attention in the pediatric IBD literature is *body image dissatisfaction*. Due to the stigmatizing nature of IBD, youth may feel self-conscious about their body image, which contributes to decreased feelings of social belongingness and ultimately depressive symptoms. The current study tested an *illness stigma*→*body image dissatisfaction*→*thwarted belongingness*→*depressive symptoms* serial mediation model, in which IBD stigma was hypothesized to indirectly influence youth depressive symptoms through the sequential effects of stigma on body image dissatisfaction and thwarted social belongingness. Methods: Youth with IBD ( $N=75$ ) between 10-18 years-old were recruited from a pediatric gastroenterology clinic and completed psychosocial measures. Disease severity was assessed by physician global assessment. Current medications and body mass index (BMI) data were collected. Results: Analyses revealed significant direct effects among the modeled variables and a significant serial indirect path for *illness stigma*→*body image dissatisfaction*→*thwarted belongingness*→*depressive symptoms* (effect = 0.81, 95% CI = .15 to 1.78), controlling for gender, BMI, and prednisone medication. Conclusions: Youth who perceive greater IBD stigma are more likely to experience increased body image dissatisfaction due to their IBD, which may engender feelings of social estrangement, and ultimately elevated depressive symptoms. Both stigma and body image dissatisfaction should be assessed and addressed in a multidisciplinary fashion by medical providers and mental health professionals.

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## CHAPTER 1

### INTRODUCTION

#### **Inflammatory Bowel Disease**

Inflammatory Bowel Disease (IBD) refers to a group of chronic autoinflammatory gastrointestinal diseases characterized by intermittent disease flares and aversive symptoms. There is currently no cure for IBD, thus treatment aims to manage inflammation to acquire and preserve symptom remission (Bernick & Kane, 2011). IBD and its treatment can have body-altering effects, such as growth deficits, delayed puberty, cushingoid appearance, skin lesions, and weight gain or weight loss (Bousvaros et al., 2006; Shikhare & Kugathasan, 2010). Growth deficits, which can lead to short stature or poor weight gain, are estimated to occur in 40-85% of youth with IBD (Gasparetto & Guariso, 2014; Shamir, Phillip, & Levine, 2007) and can be irreversible if left untreated prior to puberty (Wine et al., 2004).

#### **Psychosocial Adjustment to Pediatric IBD**

Because the clinical course and management of IBD are often undesirable and can have physically altering consequences, it is not surprising that youth are at an increased risk for poorer social functioning and emotional adjustment difficulties (e.g., Hommel, Denson, Crandall, & Mackner, 2008), with rates of depression as high as 20-25% (e.g., Clark et al., 2014; Gamwell et al., 2018; Hommel et al., 2008; Szigethy et al., 2004). Further, youth with IBD evidence

significantly higher rates of depressive disorders compared to youth with other types of chronic medical conditions, and poorer social functioning compared to youth without chronic medical conditions (Greenley et al., 2010). Because many symptoms of IBD are of a socially sensitive nature (Greenley et al., 2010; Lindfred, Saalman, Nilsson, Sparud-Linden, & Lepp, 2012; Mackner, Sisson, & Crandall, 2004), attention in the pediatric IBD literature has emphasized variables that capture the stigmatizing and embarrassing experience of IBD and their influence on youth social and emotional adjustment outcomes. Findings indicate that youth with IBD who perceive greater *illness stigma* feel more socially isolated and evidence elevated depressive symptoms (Gamwell et al., 2018; Roberts et al., 2020). Although these findings suggested that *decreased social belongingness* plays a significant role in the association between illness stigma and depressive symptoms, results also pointed to the need for examining additional variables to better understand the manner in which illness stigma negatively influences youth thwarted social belongingness and depressive symptoms.

### **Illness Stigma, Body Image Dissatisfaction, and Thwarted Belongingness**

One potential variable that may act as an intermediary mechanism to explain how illness stigma affects thwarted social belongingness and depressive symptoms is *body image dissatisfaction*. Body image dissatisfaction is a negative mental representation of one's body and appearance, as well as a negative perception of how others perceive one's body and appearance (McDermott et al., 2014). Specifically during childhood, body image dissatisfaction is known to play an important role in self-esteem and social identity, and has been shown to be associated with depressive symptoms in healthy youth (Ferreiro, Seoane, & Senra, 2011; Murray, Rieger, & Byrne, 2018). Findings also indicate that children and adolescents with chronic illnesses have less positive body images than healthy youth (Pinquart, 2013). Illness-specific body

dissatisfaction has been demonstrated as a prevalent concern in adults with IBD with up to two thirds of one study sample endorsing body image concerns, likely due to negative perceptions of unwanted physical changes from treatment and effects of the disease (Keefer & Kane, 2017; McDermott et al., 2015; Saha et al., 2015; Wabich et al., 2020). However, it is argued that body image may have differing effects and greater emotional influence in youth with IBD compared to adults because the IBD-specific undesirable physical changes are compounded with the stressors associated with physical maturation, emotional development, and body image acquisition during adolescence (Ruemmele & Turner, 2014).

Research from other pediatric populations (e.g., craniofacial conditions, obesity) has demonstrated that perceived stigma predicts body image concerns and heightened depressive symptoms (Crechand et al., 2020; Gray et al., 2011; Stevens et al., 2017). Body image dissatisfaction is also related to thwarted belongingness and perceived social isolation in adult populations (Forrest et al., 2016; Kwan et al., 2017). In addition, body image dissatisfaction due to IBD is a known predictor of depressive symptoms in adults with IBD (Keefer & Kane, 2017; McDermott et al., 2015; Saha et al., 2015) and in youth with IBD body image concern is correlated with depressive symptoms (Abdovic et al., 2013; Claytor et al., 2020; Cushman et al., 2021; Herzer, Denson, Baldassano, & Hommel, 2011a; Herzer, Denson, Baldassano, & Hommel, 2011b; Malik et al., 2013; Otley et al., 2006; Perrin et al., 2008). However, the disease features of IBD that may influence body image dissatisfaction and the mechanism(s) by which body image dissatisfaction impacts depressive symptoms remain under-studied areas in this population (Herzer et al., 2011; Ross, Strachan, Russell, & Wilson, 2011). Moreover, no known study has examined the potential contribution of IBD stigma to body image dissatisfaction and depressive symptoms in youth with IBD.

Given the potential embarrassing physical and appearance-altering effects of IBD and its treatment, youth with IBD may have an acute sensitivity to body image concerns. Thus, youths' perceptions of body image dissatisfaction may have particular relevance to illness stigma, thwarted social belongingness, and depressive symptoms. Specifically, although the relation between stigma and body image dissatisfaction has yet to be empirically examined in this population, it is possible that IBD stigma may drive existing body image concerns through heightened focus on the embarrassing aspects of the illness, especially those related to the negative impact of IBD on physical appearance. In other words, youth who experience embarrassment and stigma associated with their IBD may be more self-conscious of physical changes due to the illness and consequently, experience increased dissatisfaction with their physical appearance. Because body image is central to youth social and emotional development, heightened body image dissatisfaction may prompt feelings of social alienation and thwarted social belongingness, and increase the likelihood for youth to experience depressive symptoms.

### **The Present Study**

To examine these potential links, the current study tested an *illness stigma* → *body image dissatisfaction* → *thwarted belongingness* → *depressive symptoms* serial mediation model, whereby youths' perceptions of IBD stigma will be associated with heightened body image dissatisfaction and subsequent feelings of social isolation, and ultimately depressive symptoms. Thus, it is anticipated that greater youth perceptions of IBD stigma will convey a serial indirect effect on youth depressive symptoms through the sequential effects of IBD stigma on body image dissatisfaction and, in turn, the impact of body image dissatisfaction on thwarted social belongingness.

## CHAPTER II

### METHOD

#### **Participants and Procedure**

Participants consist of 75 youth with IBD between 10-18 years and their parent or legal guardian. A portion of the data completed by the current sample was included in previous studies examining the relationship of illness stigma to youth depressive symptoms connected by intermediary variables (i.e., health communication difficulties, IBD worry, illness intrusiveness). Participants were recruited from a pediatric gastroenterology clinic in the Southwest United States. Eligibility criteria include: youth diagnosis of IBD; child and parent English fluency; no documented cognitive deficits; child age between 10-18 years. Disease eligibility was determined by an attending pediatric gastroenterologist. Following youth and caregiver consent, participants completed self-report questionnaires during a scheduled outpatient appointment. Disease information, such as date of diagnosis, medications, and current disease severity were collected from medical chart review. Upon completion, participants received \$20 as compensation for participation.

## **Ethical Considerations**

All recruitment, consent, and data collection procedures have been approved by the hospital Institutional Review Board (IRB) and adhere to APA Ethical guidelines. Parent or legal guardians provided written and verbal consent for both their and their child's participation. Youth participants gave verbal and written assent if younger than 18 years of age, or consent if 18 years old.

## **Measures**

A background information questionnaire was used to obtain caregiver report of demographic information (e.g., child age, gender, race). A medical chart review was completed to gather disease-related information (e.g., medications, illness duration).

The *Stigma Scale-Child* (SS-C; Gamwell et al., 2018) assesses youth perceived stigma associated with IBD (e.g., “*How often do you feel embarrassed about your IBD?*”). The SS-C is an 8-item youth report measure on a 5-point Likert scale (1 = “*never*” to 5 = “*very often*”). A total score is calculated by summing the items, with higher scores indicating greater perceived illness stigma. The SS-C has demonstrated high internal consistency in previous samples of youth with IBD (Gamwell et al., 2018; Roberts et al., 2020) and in the current sample ( $\alpha = .87$ ).

The *Youth Body Image Questionnaire* (YBIQ) measures youth perceptions of body and appearance dissatisfaction (e.g., “*Do you feel dissatisfied/unhappy with how you look?*”). The YBIQ was adapted from the Body Image Scale (BIS; McDermott et al., 2014) which was designed to assess perceptions of body image dissatisfaction in adults with IBD. Specifically, the YBIQ was adapted to be developmentally appropriate for adolescents. The YBIQ has 8-items rated on a 4-point Likert scale (1 = “*not at all*” to 4 = “*very much*”). A total score is calculated by summing the items, with greater scores indicating greater perceptions of body image

dissatisfaction. The BIS has demonstrated good internal consistency in adults with IBD (McDermott et al., 2014) and the YBIQ in the current sample of youth with IBD ( $\alpha = .87$ ).

The *Interpersonal Needs Questionnaire-Thwarted Belongingness* subscale (INQ-TB; Van Orden, Witte, Gordon, Bender, & Joiner, 2008) evaluates youth self-report of social isolation and feelings of not belonging to a social group or connecting with others. The INQ-TB has 9-items (e.g., “*These days, I often feel like an outsider at school or with my friends*”) rated on a 7-point Likert scale (1 = “*not at all true for me*” to 7 = “*very true for me*”). A total score is calculated by summing the items, with higher scores representing greater perceived thwarted belongingness. The INQ-TB has demonstrated good internal consistency in pediatric IBD studies (e.g., Gamwell et al., 2018) and in the current sample ( $\alpha = .87$ ).

The *Children’s Depression Inventory-2<sup>nd</sup> Edition* (CDI-2; Kovacs, 2011) assessed youth self-report of depressive symptoms over the previous two-week period. The CDI-2 is a 28-item questionnaire rated on a Likert scale from 0 to 2, with higher scores indicative of more severe depressive symptoms (e.g., 0 = “*I am sad once in a while,*” 1 = “*I am sad many times,*” 2 = “*I am sad all the time*”). If a critical item was endorsed on the CDI-2, the pediatric psychologist in the gastroenterology clinic performed a suicide assessment to assure safety of the participants. A total score is calculated by summing the items. The CDI-2 has demonstrated good internal reliability in youth with IBD (e.g., Baudino et al., 2019; Gamwell et al., 2018; Roberts et al., 2020) and in the current sample ( $\alpha = .87$ ).

### **Data Analytic Plan**

Initial analyses examined rates of clinically elevated depressive symptoms, and compared mean values of our modeled variables as a function of clinical versus non-clinical levels of depressive symptoms. Zero-order correlations and *t*-tests were also conducted to determine

potential demographic and disease covariates. Additional preliminary correlation analyses examined the zero-order associations among the key study variables. Primary analyses were performed using PROCESS software version 3.4. Significance tests utilized 95% confidence intervals yielded from 5,000 bootstrapped regression resampling draws with replacement (e.g., Hayes, 2017) to examine the direct and indirect contributions of the independent variables (i.e., illness stigma, body image dissatisfaction, thwarted belongingness) to the primary dependent variable (i.e., youth depressive symptoms).



## CHAPTER III

### RESULTS

#### **Preliminary analyses**

Utilizing standard scoring guidelines, 20% of youth ( $n = 15$ ) endorsed clinically elevated CDI-2 depressive symptoms (i.e., raw scores  $\geq 14$ ; Kovacs et al., 2011). Further, SS-C, YBIQ, and INQ-TB scores were all significantly greater among youth who endorsed clinical levels of depressive symptoms (all  $p$ 's  $< .01$ ). Mean comparison analyses indicated no significant differences in CDI-2 by race, disease type, and medication type. Female youth exhibited greater depressive symptoms ( $p < .05$ ). No other significant relationships were demonstrated between CDI-2 and disease or demographic variables (see Table 2). Although BMI and steroid medications were not significantly correlated with depressive symptoms in the preliminary analyses, previous research has indicated that BMI and steroid use could play a role in body image dissatisfaction (Claytor et al., 2020). Consequently, BMI and steroid use were included along with youth sex as covariates in the primary analyses.

#### **Primary analyses**

Bootstrapped regression analyses (see Figure 1), revealed significant direct effects for *IBD stigma* on both *body image dissatisfaction* (path  $a_1 = 2.67$ , 95% CI = 1.49 to 3.85) and *thwarted belongingness* (path  $a_2 = 3.69$ , 95% CI = 0.68 to 6.69). Further, *body image*

*dissatisfaction* was associated with *thwarted belongingness* (path  $d_{21} = 0.92$ , 95% CI = 0.38 to 1.45), and *thwarted belongingness* had a direct effect on *depressive symptoms* (path  $b_2 = 0.33$ , 95% CI = 0.20 to 0.46). The direct effect of *IBD stigma* on *depressive symptoms* was not significant (path  $c' = -0.66$ , 95% CI = -2.30 to 0.99). Further, serial mediation results revealed a significant *IBD stigma*  $\rightarrow$  *body image dissatisfaction*  $\rightarrow$  *thwarted belongingness*  $\rightarrow$  *depressive symptoms* indirect effect (path  $a_1d_{21}b_2 = 0.81$ , 95% CI = 0.15 to 1.79). Thus, in addition to multiple independent direct effects among the modeled variables, results suggest that youth who encounter greater IBD-related stigma are more likely to experience heightened body image dissatisfaction, which in turn may give rise to feelings of social exclusion and ultimately depressive symptoms.

## CHAPTER IV

### DISCUSSION

In order to understand the role of body image dissatisfaction in adjustment difficulties in youth with IBD, the current study extended previous findings indicating illness stigma and body image dissatisfaction are associated with depressive symptoms in this population (Claytor et al., 2020; Cushman et al., 2021). Specifically, the study was the first to investigate the potential contribution of perceived stigma, body dissatisfaction, and thwarted belongingness in concert to depressive symptoms in youth with IBD. The serial mediation results indicate that youth who perceive greater illness stigma also experience increased perceptions of body image dissatisfaction due to their IBD, which in turn may engender feelings of social estrangement and elevated depressive symptoms (i.e., *illness stigma*→ *body image dissatisfaction*→ *thwarted belongingness*→ *depressive symptoms*).

Aligned with previous research demonstrating the effect of stigma on body image dissatisfaction across other pediatric populations (e.g., craniofacial conditions, obesity; Crecrand et al., 2020; Gray et al., 2011; Stevens et al., 2017), the current findings reveal the contribution of illness stigma to body image dissatisfaction in youth with IBD. These findings suggest that illness stigma may act as a driver of youth's negative perceptions of the influence of IBD on their physical appearance and physique. Further, body image dissatisfaction may act as a

mechanism through which illness stigma promotes social isolation and susceptibility to depressive symptoms. Thus, youth who perceive their IBD as stigmatizing may be more likely to attend to the embarrassing IBD-related experiences, including the influence of IBD on their appearance and body shape, thus potentially increasing body image dissatisfaction. Similar to studies in young adults (Forrest et al., 2016; Kwan et al., 2017), youth with increased body image dissatisfaction may be hypervigilant about their changes or distinctions in appearance due to IBD and its treatments, which may eventuate into feeling different and socially isolated from others. Thus, youths' negative perceptions of their physical appearance may contribute to feelings of social distance and ultimately poorer emotional functioning, particularly depressive symptoms. Importantly, findings occurred controlling for BMI and steroid use, suggesting that illness stigma and body image dissatisfaction influence social isolation and emotional adjustment independent of body mass and steroid treatment.

### **Clinical Implications**

The current findings demonstrate several potential areas to prevent and treat adjustment difficulties in youth with IBD. Medical professionals serve as front-line agents to determine the youth with IBD at risk for adjustment concerns and those in need of formal mental health consultation and therapy services (Keethy et al., 2014). The significant percentage of youth with clinically elevated levels of depressive symptoms emphasizes the need for routine screening during IBD clinic visits for illness stigma, body image dissatisfaction, and depressive symptoms. Further medical professionals may have opportunities to prevent potential adjustment difficulties by discussing the physical changes due to IBD, body image concerns, ways in which to flexibly manage IBD symptoms, and continued engagement in social activities (e.g., face-to-face and virtual support groups, IBD camps; Keethy et al., 2014; Salazar et al., 2014)

Because illness stigma and body image dissatisfaction are amenable to clinical intervention, our results could inform treatment efforts designed to address the social and emotional challenges imposed by IBD. Cognitive behavioral treatments have been documented as effective for treating depressive symptoms in youth with IBD (e.g., illness education, cognitive restructuring, behavioral activation; problem-solving/coping skills; Szigethy et al., 2007; 2015). However, the integration of IBD stigma (e.g., adapting self-stigmatizing cognitions; Heijnders & van der Meij, 2006) and body image specific coping skills (e.g., modifying negative cognitions about appearance, exposure and response prevention activities despite appearance concerns; Greenberg et al., 2010; Tremblay & Limbos, 2009) with current evidenced-based cognitive behavioral treatments for depressive symptoms may further booster potential coping skills and reduce maladaptive illness perceptions. Further, providing evidenced-based treatments in interdisciplinary pediatric gastroenterology clinics positions medical and mental health providers to consult and collaborate allowing for early identification of adjustment and body image concerns and systematic intervention (Herzer-Maddux et al., 2013; Mackner et al., 2020; Wong et al., 2018).

### **Limitations**

The current study is qualified by several limitations. Despite the sample demographics paralleling that of other pediatric IBD studies (e.g., Greenley et al., 2010; Reed-Knight et al., 2016), the sample was largely Caucasian youth from middle to upper socioeconomic backgrounds and possessing quiescent disease activity. Also, the modest sample size may increase the potential that extreme cases may have influenced the results; however, the bootstrapping and resampling statistical process lessens the possibility for Type I error and limits the influence of outliers (Creedon & Hayes, 2015; Hayes & Scharkow, 2013). Further, the cross-

sectional data collection of the current study prevents a definitive interpretation of the variables temporal order (Maxwell & Cole, 2007). The self-report measure of body image dissatisfaction specific to pediatric IBD was adapted from a body image dissatisfaction measure in adult IBD to be developmentally appropriate for our participant age range. Thus, the current measure has not been psychometrically investigated in youth with IBD; however, the original version has demonstrated strong psychometric properties in adults with IBD, and the current version revealed good internal consistency in our sample. In addition, previous mental health diagnoses and psychological intervention history were not gathered and potentially could have resulted in systematic elevations and/or response bias in our modeled variables. Finally, data were collected exclusively via self-report, potentially amplifying the associations among variables due to shared method variance (Holmbeck et al., 2002). However, analyses indicated a number of independent direct associations, which increases confidence that the observed effects reflect independent variance (versus shared variance) among the variables.

### **Summary and Future Directions**

Youth with IBD experience several appearance and body altering symptoms due to their illness. Youths' heightened body image dissatisfaction due to IBD is likely an outgrowth of the stigma associated with those symptoms because illness stigma may increase youths' focus on these symptoms, especially during this developmentally vulnerable time. This study reveals body image dissatisfaction as a potential means by which illness stigma relates to thwarted belongingness and depressive symptoms. Because parent illness appraisals may increase negative perceptions about IBD symptoms (Baudino et al., 2020; Roberts et al., 2019) and youths' body image (Phares et al., 2004; Seo et al., 2020), future studies examining these variables in concert could potentially shed light on additional points of intervention for

addressing depressive symptoms in this population. Further, peer victimization has been identified as an important stressor in the social lives of youth with IBD (Roberts et al., 2021), thus research is needed to examine the interplay of peer victimization with stigma, body image dissatisfaction, thwarted belongingness, and depressive symptoms in this population. More generally, our findings are consistent with previous calls for integrated medical and psychological services in multidisciplinary clinic settings to promote the reciprocal exchange of information between gastroenterologists and mental health professionals that allows for accurate identification and coordinated management of youth at risk for emotional difficulties.

## CHAPTER V

### GRANT APPLICATION FOR STIGMA, BODY IMAGE, AND DEPRESSIVE SYMPTOMS IN PEDIATRIC CROHN'S DISEASE

#### **Background**

Crohn's disease (CD) is a type of inflammatory bowel disease (IBD) in which chronic inflammation and ulceration can be observed in any part of the digestive tract. CD can be chronically debilitating, require life-long treatment, and if left untreated can lead to life-threatening complications (Bousvaros et al., 2006). Approximately 25% of CD diagnoses are during childhood and affect 58 out of every 100,000 youth in the United States (Day, Ledder, Leach, & Lemberg, 2012; Kappelman, Moore, Allen, & Cook, 2013), with incidence rates continuing to climb (Benchimol et al., 2011). CD involves invasive symptoms, such as pain, diarrhea, malnutrition, bloody stool, and frequent bathroom use. In addition, CD and its treatment can have body-altering effects, such as growth deficits, delayed puberty, cushingoid appearance, skin lesions, and weight gain or weight loss (Bousvaros et al., 2006; Szigethy, McLafferty, & Goyal, 2010). Growth deficits are estimated to occur in 40-85% of youth with CD (Gasparetto & Guariso, 2014; Shamir, Phillip, & Levine, 2007). There is currently no cure for CD, thus the focus of treatment is geared toward managing inflammation to achieve and maintain symptom remission (Bernick & Kane, 2011).



Because the clinical course and management of CD are often arduous and aversive, it is not surprising that youth are at an increased risk for psychosocial adjustment difficulties (e.g., Hommel, Denson, Crandall, & Mackner, 2008), with rates of depression as high as 20-25% (e.g., Clark et al., 2014; Gamwell et al., 2018; Hommel et al., 2008; Szigethy et al., 2004). Further, in a mixed sample of youth with CD and ulcerative colitis (UC), Greenley et al. (2010) found significantly higher rates of depressive disorders compared to youth with other types of chronic medical conditions, and poorer social functioning compared to youth without chronic medical conditions. Although clinically elevated levels of depressive symptoms appear to be equally distributed across CD and UC in pediatric samples (Szigethy et al., 2004; Vaisto, Aronen, Simola, Ashorn, & Kolho, 2010), the adult IBD literature provides suggestive evidence that depressive states and deteriorating disease course are more closely associated in CD relative to UC (Alexakis, Kumar, Saxena, & Pollok, 2017). Thus, whereas rates of elevated depressive symptoms may not differ between youth with CD or UC, the long-term impact of depressive symptoms on disease outcomes may be greater in CD populations. Given the prevalence of elevated depressive symptoms, and the potential long-term impact of depression on disease outcomes, the identification of determinants of depressive symptoms in youth with CD could guide clinical interventions aimed at improving psychological functioning.

Although authors have identified some psychosocial factors associated with youth emotional adjustment beyond the influence of objective disease status (e.g., parenting stress; Guilfoyle, Gray, Herzer-Maddux, & Hommel, 2014), there is a paucity of empirical research examining psychosocial variables that contribute to poorer youth emotional adjustment outcomes in pediatric CD (Schuman, Graef, Janicke, Gray, & Hommel, 2013). Interestingly, because many symptoms of CD are of a socially sensitive nature (Greenley et al., 2010; Lindfred, Saalman,

Nilsson, Sparud-Linden, & Lepp, 2012; Mackner, Sisson, & Crandall, 2004) recent attention in the pediatric literature has begun to emphasize variables that capture the stigmatizing and embarrassing experience of CD and their influence on youth social and emotional adjustment outcomes. However, few empirical data exist in the pediatric CD literature regarding these types of variables.

In one of the only known studies of this kind, Gamwell et al. (2018) found evidence indicating that youth with IBD who perceive greater *illness stigma* feel more socially isolated and evidence elevated depressive symptoms. Although findings from Gamwell et al. suggested that *decreased social belongingness* plays a significant role in the association between illness stigma and depressive symptoms, results of their study also pointed to the need for examining additional variables to better understand the manner in which illness stigma negatively impacts youth depressive symptoms. One potential variable related to stigma that has received attention in the pediatric IBD literature is *body image dissatisfaction* (Ross, Strachan, Russell, & Wilson, 2011). Body image during childhood is known to play an important role in self-esteem and social identity, and body dissatisfaction has been shown to predict depressive symptoms in healthy youth (Ferreiro, Seoane, & Senra, 2011; Murray, Rieger, & Byrne, 2018). Findings also indicate that children and adolescents with chronic illnesses have less positive body images than healthy youth (Pinquart, 2013), and youth with CD have significantly greater body image concerns relative to youth with UC (Herzer, Denson, Baldassano, & Hommel, 2011; Perrin et al., 2008). Thus, the negative effects of CD on physical appearance may adversely impact youths' body image and, like illness stigma, contribute to both feelings of social alienation and depressive symptoms. Although suggestive evidence indicates that body image dissatisfaction may be associated with depressive symptoms in youth with IBD, body image remains an under-studied

area in this population (Herzer et al., 2011; Ross et al., 2011). Moreover, no known study has examined the precipitants of body image or the manner in which body image dissatisfaction impacts depressive symptoms in youth with CD.

## **Objectives**

Given the observed prevalence of depressive symptoms in youth with CD, research is needed to examine variables associated with the subjective experience of CD that could provide insight into emotional adjustment outcomes. It is suspected that greater youth perceptions of stigma related to CD contribute to increased body image dissatisfaction, prompting feelings of social estrangement and an increased vulnerability for experiencing depressive symptoms. Thus, youths' perceptions of illness stigma may lead to heightened body dissatisfaction, which engenders feelings of social isolation and ultimately depressive symptoms. Because both stigma and body dissatisfaction can be addressed by clinicians, results of this study could inform interventions designed to alleviate some of the emotional challenges experienced by youth with CD. The goal of this study is to examine the direct and indirect contributions of illness stigma, body dissatisfaction, and thwarted social belongingness to depressive symptoms in a sample of 80 youth diagnosed with CD.

Aim 1: Replicate previous findings (Gamwell et al., 2018) demonstrating the mediating role of thwarted social belongingness in the relation between illness stigma and depressive symptoms, focusing exclusively on youth with CD.

Hypothesis 1: It is hypothesized that a significant *illness stigma* → *thwarted belongingness* → *depressive symptom* mediation path will be observed in an independent sample of youth with CD, establishing the replicability of previous findings observed in mixed CD/UC groups of youth.

Aim 2: Extend existing findings to investigate a serial mediation model that examines the mediating role of youth body dissatisfaction in the *illness stigma* → *thwarted belongingness* → *depressive symptom* indirect association.

Hypothesis 2: It is hypothesized that youth body dissatisfaction will mediate the association between illness stigma and social thwarted belongingness, resulting in a significant *illness stigma* → *body dissatisfaction* → *thwarted belongingness* → *depressive symptom* serial mediation path. Thus, perceived illness stigma will confer an indirect effect on youth depressive symptoms via serial indirect effects of youth illness stigma on body dissatisfaction and thwarted social belongingness.

## **Method**

### **Participants and Procedures**

Participants will include 80 youth with CD between 10-18 years and their parent or legal guardian. Participants will be recruited from the pediatric gastroenterology clinic at The Children's Hospital at the University of Oklahoma Health Sciences Center (OUHSC). Eligibility criteria include: youth diagnosis of CD; child and parent English fluency; no documented cognitive deficits; child age between 10-18 years. Disease eligibility will be determined by an attending pediatric gastroenterologist. Graduate student research assistants (i.e., the graduate student principal investigator and two additional graduate students) will recruit all participants in the gastroenterology clinic. Following youth and caregiver consent, participants will complete self-report questionnaires during a scheduled outpatient appointment. The pediatric gastroenterologist will also provide disease information, such as date of diagnosis, global assessment (PGA), Pediatric Crohn's Disease Activity Index (PCDAI), and current disease status. All recruitment, consent, and data collection procedures have been approved by the

OUHSC IRB and adhere to APA Ethical guidelines. Upon completion, participants will receive \$20 as compensation for participation.

Dr. Chaney's lab will be the primary research lab for this study and is located in the psychology department at Oklahoma State University (OSU). Dr. Chaney's lab maintains a collaborative working relationship with the OUHSC Gastroenterology Clinic whose providers have expressed enthusiasm and support of this project and its potential clinical implications.

### **Measures**

A background information questionnaire will be used to obtain caregiver report of demographic information (e.g., child age, gender, race). The pediatric gastroenterologist will provide global disease severity and disease status information at the time of recruitment, as well as date of diagnosis and prescribed medications.

The *Stigma Scale-Child* (SS-C; Gamwell et al., 2018) will assess youth perceived stigma associated with CD (e.g., "How often do you feel embarrassed about your IBD?"). The SS-C was adapted from the Child Stigma Scale (CSS; Austin, MacLeod, Dunn, Shen, & Perkins, 2004) originally designed for youth with epilepsy. The SS-C is an 8-item youth report measure on a 5-point Likert scale (1 = "never" to 5 = "very often"). A total score is calculated by summing the items, with higher scores indicating greater perceived illness stigma. The SS-C has demonstrated high internal consistency in previous samples of youth with IBD (Gamwell et al., 2018).

The *Youth Body Image Questionnaire* (YBIQ) will assess youth perceptions of body and appearance dissatisfaction (e.g., "Do you feel dissatisfied/unhappy with how you look?"). The YBIQ was adapted from the Body Image Scale (BIS; McDermott et al., 2014) which was designed to assess perceptions of body dissatisfaction in adults with IBD. Specifically, the YBIQ

was adapted to be developmentally appropriate for adolescents. The YBIQ has 8-items rated on a 4-point Likert scale (1= “not at all” to 4 = “very much”). A total score is calculated by summing the items, with greater scores indicating greater perceptions of body dissatisfaction. The BIS has demonstrated good internal consistency in adults with IBD (McDermott et al., 2014).

The *Interpersonal Needs Questionnaire-Thwarted Belongingness* subscale (*INQ-TB*; Van Orden, Witte, Gordon, Bender, & Joiner, 2008) will assess youth self-report of social isolation and feelings of not belonging to a social group or connecting with others. The *INQ-TB* has 9-items (e.g., “*These days, I often feel like an outsider at school or with my friends*”) rated on a 7-point Likert scale (1 = “not at all true for me” to 7 = “very true for me”). A total score is calculated by summing the items, with higher scores representing greater perceived thwarted belongingness. The *INQ-TB* has demonstrated good internal consistency in pediatric IBD studies (e.g., Gamwell et al., 2018).

The *Children’s Depression Inventory-2<sup>nd</sup> Edition* (*CDI-2*; Kovacs, 2011) will assess youth self-report of depressive symptoms over the previous two-week period. The *CDI-2* is a 28-item questionnaire rated on a Likert scale from 0 to 2, with higher scores indicative of more severe depressive symptoms (e.g., 0 = “*I am sad once in a while,*” 1= “*I am sad many times,*” 2 = “*I am sad all the time*”). A total score is calculated by summing the items. The *CDI-2* has demonstrated good internal reliability in youth with IBD (e.g., Gamwell et al., 2018).

### **Data Analytic Plan**

Initial zero-order correlations and *t*-tests will determine potential demographic and disease covariates. Additional preliminary correlation analyses will examine the zero-order associations among the key study variables, such as the PCDAI and body dissatisfaction. Primary analyses will be performed with the structural equation software *Mplus* version 7.31

(Muthén & Muthén, 1998-2012). Significance tests will utilize 95% confidence intervals yielded from 5,000 bootstrapped regression resampling draws with replacement (e.g., Hayes, 2013) to examine the direct and indirect contributions of the independent variables (i.e., illness stigma, body dissatisfaction, thwarted belongingness) to the primary dependent variable (i.e., youth depressive symptoms).

Hypothesis 1: An examination of the *illness stigma* → *thwarted belongingness* → *depressive symptom* simple mediation path will be performed to test for successful replication of findings in Gamwell et al. (2018).

Hypothesis 2: Mediation analyses will be conducted to test for the *illness stigma* → *body dissatisfaction* → *thwarted belongingness* → *depressive symptom* serial mediation path. In addition to the overall serial mediation path, analyses will also examine the direct effects of modeled variables on youth depressive symptoms.

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APPENDICES

APPENDIX A

Table 1. Descriptive Statistics and Demographics ( $N = 75$ )

Variable	<i>M</i>	<i>SD</i>	Frequency	Percent
Child Age	14.63	2.14		
Child Sex				
Female			42	56.0
Male			33	44.0
Child Race/Ethnicity				
White			47	62.7
Black			7	9.3
Native American			7	9.3
Hispanic			3	4.0
Other			11	14.7
Child BMI Classification				
Underweight			5	6.7
Normal Weight			49	65.3
Overweight			14	18.7
Obese			7	9.3
Disease Type				
Ulcerative Colitis			32	42.7
Crohn's Disease			43	57.3
Disease Severity				
Quiescent			38	50.7
Mild			23	30.7
Moderate			11	14.7
Severe			3	4.0
Prescribed Medication				

Aminosalicylates	26	34.7
Steroids	17	22.7
Immunosuppressant/Anti-metabolites and Biologic Agents	53	70.7

Note. Total number and percentage of medication is greater than 75 (100%) due to multiple prescriptions per participant.

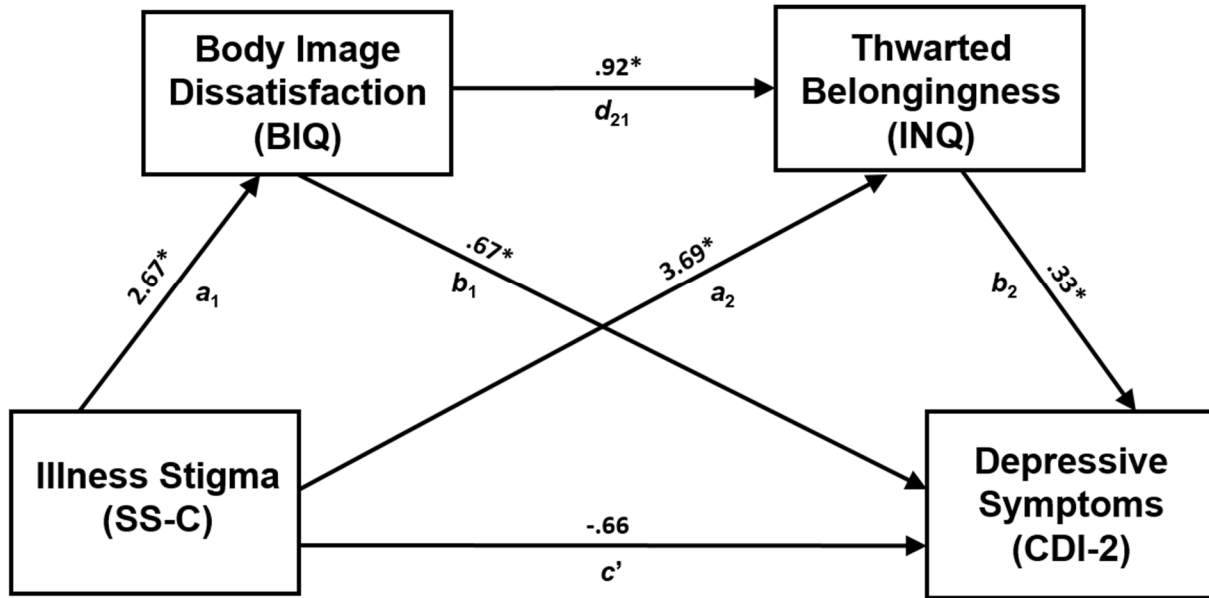
Table 2. Correlations and Descriptive Statistics (N = 75)

Variables	1	2	3	4	5	6	7	8	M	SD
1. Gender	—								—	—
2. Age	-.01	—							14.63	2.14
3. BMI	-.00	.33**	—						21.87	4.90
4. Illness Duration	.04	.09	-.05	—					1.84	2.12
5. PGA	-.12	.29*	.01	-.12	—				.72	.86
6. SSC	-.35**	-.15	-.05	.05	.07	—			15.29	6.42
7. BIQ	-.36**	.05	.03	.19	.03	.54**	—		12.20	4.52
8. INQ	-.21	.05	.24*	.02	.12	.46**	.54**	—	20.77	10.56
9. CDI-2	-.23*	.00	.17	.09	.14	.39**	.66**	.71**	8.56	6.93

Note: \*\* $p < .01$ , \* $p < .05$ . Age and illness duration are measured in years. PGA = Physicians Global Assessment; SS-C = Stigma Scale-Child; BIQ = Body Image Scale; INQ = Thwarted Belonginess Scale; CDI-2 = Children's Depression Inventory-2<sup>nd</sup> Edition.

APPENDIX B

Figure 1. Serial mediation model



## APPENDIX C



### Institutional Review Board for the Protection of Human Subjects

#### Continuing Review – Expedited Approval

**Date:** October 04, 2018

**IRB#:** 5856

**To:** Noel Jacobs, PhD

**Approval Date:** 10/04/2018

**Expiration Date:** 09/30/2019

**Study Title:** Parent and Child Psychological Adjustment in Pediatric Inflammatory Bowel Disease

**Study Status:** Active - Open - Expedited

**Reference Number:** 683852

On behalf of the Institutional Review Board (IRB), I have reviewed and granted expedited approval of the Application for Continuing Review for the above-referenced research study. Study documents associated with this submission are listed on page 2 of this letter. To review and/or access the submission forms and study documents, open this study from the *My Studies* option, go to *Protocol Items*, click to open the *Application*, *Informed Consent*, or *Other Study Documents* to view/print the most currently approved document.

As principal investigator of this research study, it is your responsibility to:

Conduct the research study in a manner consistent with the requirements of the IRB and federal regulations at 45 CFR 46 and/or 21 CFR 50 and 56.

Obtain informed consent and research privacy authorization using the currently approved, stamped forms and retain all original, signed forms, if applicable.

Request approval from the IRB prior to implementing any/all modifications.

Promptly report to the IRB any harm experienced by a participant that is both unanticipated and related per IRB Policy.

Maintain accurate and complete study records for evaluation by the HRPP quality improvement program and if applicable, inspection by regulatory agencies and/or the study sponsor.

Promptly submit continuing review documents to the IRB upon notification approximately 60 days prior to the expiration date indicated above.

Submit a final closure report at the completion of the project.

If you have questions about this notification or using iRIS, contact the IRB at 405-271-2045 or [irb@ouhsc.edu](mailto:irb@ouhsc.edu).

Sincerely,

Candaca M. Marshall, MD  
Institutional Review Board



Oklahoma State University Institutional Review Board

Date: 08/12/2019  
Application Number: AS-19-92  
Proposal Title: Parent and Child Psychological Adjustment in Pediatric Inflammatory Bowel Disease

Principal Investigator: Caroline Roberts  
Co-Investigator(s):  
Faculty Adviser: JOHN CHANEY  
Project Coordinator:  
Research Assistant(s):

Processed as: Not Human Subjects Research

Status Recommended by Reviewer(s): Closed

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Based on the information provided in this application, the OSU-Stillwater IRB has determined that your project does not qualify as human subject research as defined in 45 CFR 46.102 (d) and (f) and is not subject to oversight by the OSU IRB. Should you have any questions or concerns, please do not hesitate to contact the IRB office at 405-744-3377 or [irb@okstate.edu](mailto:irb@okstate.edu).

Sincerely,  
Oklahoma State University IRB

## VITA

Caroline M. Roberts

Candidate for the Degree of

Doctor of Philosophy

Dissertation: ILLNESS STIGMA, BODY IMAGE DISSATISFACTION, THWARTED  
BELONGINGNESS, AND DEPRESSIVE SYMPTOMS IN YOUTH WITH  
INFLAMMATORY BOWEL DISEASE

Major Field: Psychology

Biographical:

Education:

Completed the requirements for the Doctor of Philosophy in Psychology at Oklahoma State University, Stillwater, Oklahoma in July, 2022.

Completed the requirements for the Master of Science in Psychology at Oklahoma State University, Stillwater, Oklahoma in July, 2019.

Completed the requirements for the Master of Arts in Clinical Psychology at University of Houston- Clear Lake, Houston, Texas in 2017.

Completed the requirements for the Bachelor of Arts in Psychology at Trinity University, San Antonio, Texas in 2015

Experience: Graduate Research Assistant from August 2017 to the present in the Pediatric Psychology Behavioral Health Lab working on the project titled Adjustment and Cognitive Appraisals in Pediatric Inflammatory Bowel Disease supervised by John M. Chaney, Ph.D.