STIGMA BY ASSOCIATION: THE INFLUENCE OF PARENTS' EXPERIENCE OF STIGMA ON PARENT/YOUTH ILLNESS INTRUSIVENESS AND YOUTH DEPRESSIVE SYMPTOMS IN PEDIATRIC INFLAMMATORY BOWEL DISEASE

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Abstract: **Objective:** Examine the indirect association between parents' experience of stigma (i.e., associative stigma) and youth depressive symptoms through the serial effects of associative stigma on parent and youth illness intrusiveness in pediatric inflammatory bowel disease (IBD). **Methods:** During routine clinic visits, 150 youth with well-controlled IBD (ages 10-18 yrs.) completed measures of perceived *illness intrusiveness* and *depressive symptoms*. Parents completed measures of *associative stigma* and *illness intrusiveness*. Pediatric gastroenterologists provided ratings of IBD disease severity. **Results:** Structural equation modeling revealed significant direct associations for *associative stigma → parent illness intrusiveness*, *parent illness intrusiveness → youth illness intrusiveness*, and *youth illness intrusiveness → youth depressive symptoms*. Results also revealed a significant *associative stigma → parent illness intrusiveness → youth illness intrusiveness→ youth depressive symptoms* serial mediation path, indicating that parents' experience of associative stigma indirectly influenced youth depressive symptoms through its sequential effects on parent and youth perceived illness intrusiveness. **Conclusions:** Parents who face stigma related to their child's IBD (i.e., associative stigma) are more likely to experience IBD-induced lifestyle intrusions (i.e., illness intrusiveness), which in turn is associated with youths' illness intrusiveness and ultimately youth depressive symptoms. These findings provide further evidence for the important role of illness-related stigma in pediatric IBD, particularly the transactional relation between parents' associative stigma and youths' illness appraisals and emotional functioning. The clinical implications of our results for addressing adjustment difficulties in youth with IBD are also discussed.

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CHAPTER I

INTRODUCTION

Inflammatory Bowel Disease (IBD) is a broad term used to describe a group of conditions (e.g., ulcerative colitis, Crohn's disease, indeterminate colitis) characterized by chronic, episodic inflammation of the gastrointestinal tract. During active phases of IBD, youth often experience symptoms such as intestinal cramping/pain, diarrhea, rectal bleeding, and weight loss. The primary goal of IBD treatment is to minimize inflammation in the digestive tract to reduce symptoms and maintain remission. Medical management often involves multiple medications (e.g., steroids, biologics), dietary modifications/restrictions, and even surgical intervention (Tamboli, 2007).

There is growing consensus that the impact of IBD on youth adjustment goes beyond the physical difficulties posed by IBD and involves social and emotional difficulties as well (Gray et al., 2011; Reed-Knight et al., 2018), particularly depression and depressive symptomology (e.g., Mackner & Crandall, 2006; Szigethy et al., 2004). Research in pediatric IBD populations consistently suggests that up to 25% of youth with IBD experience clinical levels of depression (e.g., Baudino et al., 2019; Gamwell et al., 2018; Hommel, 2013; Schuman et al., 2013; Szigethy et al., 2004).

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Although disease severity appears to be related to depressive symptoms in youth with IBD (e.g., Clark et al., 2014; Guilfoyle et al., 2014; Schuman et al., 2013), research indicates that other variables such as parenting stress (Gray et al., 2013) and socioeconomic status (Clark et al., 2014) are also associated with youth depressive symptoms. There is growing consensus that the impact of IBD on youth adjustment goes beyond the physical difficulties posed by IBD and involves social and emotional difficulties as well (Gray et al., 2011; Reed-Knight et al., 2018), particularly depression and depressive symptomology (e.g., Mackner & Crandall, 2006; Szigethy et al., 2004). Research in pediatric IBD populations consistently suggests that up to 25% of youth with IBD experience clinical levels of depression (e.g., Baudino et al., 2019; Gamwell et al., 2018; Hommel, 2013; Schuman et al., 2013; Szigethy et al., 2004). Although disease severity appears to be related to depressive symptoms in youth with IBD (e.g., Clark et al., 2014; Guilfoyle et al., 2014; Schuman et al., 2013), research indicates that other variables such as parenting stress (Gray et al., 2013) and socioeconomic status (Clark et al., 2014) are also associated with youth depressive symptoms.

Unlike other areas of the chronic illness literature (e.g., juvenile rheumatic diseases; Chaney et al., 2016, diabetes; Carpentier et al., 2007), relatively few studies in youth with IBD have examined illness appraisal variables that are known to be associated with youth depression. In fact, only two studies to date have examined the impact of youth illness appraisals (e.g., stigma, uncertainty, intrusiveness) on depressive symptoms in youth with IBD (Gamwell et al., 2018; Roberts et al., 2019). Interestingly, although the literature suggests that parent cognitive appraisals are some of the most reliable predictors of youth adjustment outcomes (e.g., Chaney et al., 1997; Friedman et al., 2004; Ramsey et al., 2013; Ryan et al., 2010) only one known study has examined how parent illness appraisals may influence youth adjustment in this population (see Baudino et al., 2019).

Clinical and anecdotal observations in the IBD literature suggest that the embarrassing and stigmatizing aspects of IBD symptoms (e.g., fecal incontinence, frequent bowel movements, flatulence) may play a role in youth adjustment outcomes (Mackner et al., 2012; Karwowski et al., 2009). Recent empirical work indicates that youth who perceive their IBD as more stigmatizing are

also more likely to experience poorer adjustment outcomes, particularly depressive symptoms (Gamwell et al., 2018). Although studies in the IBD literature have demonstrated that a range of parent variables are associated with youth depressive symptoms (e.g., uncertainty, parenting stress, parent distress; Baudino et al., 2019; Guilfoyle et al., 2014; Herzer et al., 2011), studies examining parents' experience of stigma are absent from the literature. Findings from the adult IBD literature suggest that IBD related stigma is associated with psychological distress (Taft & Keefer, 2016) and depression (Taft, Keefer et al., 2009; Taft et al., 2011). Other research in adults with irritable bowel syndrome (IBS) suggests that illness related stigma can negatively impact quality of life (Dancey et al., 2002). Research in adolescents and young adults with chronic illnesses (including IBD) has yielded similar findings, suggesting illness stigma is related to poor emotional outcomes (e.g., depression; Bakula et al., 2019). Taken together, these findings indicate that illness related stigma is associated with an array of negative adjustment outcomes for adult IBD patients.

Although some studies in various pediatric chronic illness conditions (e.g., epilepsy) have examined parent perceptions of illness related stigma, the overwhelming majority tend to focus on parents' observations of their child's experience of stigma associated with a chronic illness or condition (e.g., Benson et al., 2016; Carlton-Ford et al., 1997; Kanemura et al., 2016). However, there are indications that parents of children with other chronic medical and/or disabling conditions such as attention-deficit/hyperactivity disorder (ADHD; e.g., DosReis et al., 2010; Norvilitis et al., 2002; Mikami et al., 2015) and autism spectrum disorder (ASD; Kinnear et al., 2016; Werner & Shulman, 2013; Mak & Cheung, 2008) experience stigma due to their child's condition. This *associative stigma* refers to stigma that a person may experience by virtue of his or her close association with someone who is socially stigmatized (Goffman, 1963).

Research indicates that parents who experience associative stigma incur a plethora of negative psychosocial adjustment outcomes. For example, research in parents of youth with ADHD has demonstrated that experiencing negative comments about their child's behavior during interpersonal interactions is associated with parental depression (e.g., Norvilitis et al., 2002). In

parents of youth with autism, intellectual disabilities, and mental illness, associative stigma is associated with higher levels of parenting stress (e.g., Mak & Cheung, 2008). A study by Kinnear and colleagues (2016) also found that associative stigma was associated with social exclusion in parents of youth with autism. Although speculative, parents of youth with IBD may experience similar outcomes resulting from associative stigma. For example, during interpersonal interactions parents may notice if others become uncomfortable when talking about their child's IBD and/or symptoms. Alternatively, parents may fear experiencing embarrassing situations in public related to their child's IBD (e.g., fecal incontinence). As such, parents of youth with IBD may experience feelings of associative stigma due to the socially aversive aspects of their child's disease.

Research in parents of youth with ADHD (e.g., Koro-Ljungberg & Bussing, 2009; Mikami et al., 2015) and autism (e.g., Kinnear et al., 2016) also indicates that parents who experience associative stigma report using coping strategies such as social isolation and withdrawal in an attempt to minimize exposure to potentially embarrassing and/or uncomfortable situations. Studies involving parents of youth with autism have demonstrated that the use of these coping strategies frequently results in parents limiting their involvement in routine and rewarding pursuits such as social interactions and family/leisure activities (e.g., Kinnear et al., 2016; Werner & Schulman, 2013).

Given the restrictions that are already imposed on parents by their child's IBD (e.g., managing complex medication regimens, attending medical appointments, managing diet), associative stigma may contribute to heightened appraisals of IBD-induced disruptions in parents' abilities to engage in valued interests and activities. For example, the variable and unpredictable nature of IBD may cause parents to have difficulties planning activities, due in part to unanticipated symptoms and/or disease flares that result in their child's participation being cancelled. The ongoing challenge for parents to provide repeated explanations for why their child can no longer participate, in addition to the embarrassment they experience as a function of their child's IBD, may lead to parents to avoid planning and/or restricting the number of activities in which their child participates.

Alternatively, parents may simply experience frustration related to scheduling and cancelling plans, which may also contribute to the perceived intrusiveness of their child's IBD.

Although this process is speculative, it embodies the main premise of the illness intrusiveness theory, which is that is that lifestyle disruptions impact psychosocial well-being in individuals with chronic conditions by 1) decreasing the number of rewarding or positive experiences through decreased involvement in valued interests and activities and 2) by reducing the amount of personal control an individual feels he or she has in important life domains, which then compromises the ability to obtain positively valued outcomes and/or to avoid negative ones (Devins et al., 1993). Caregiver perception of illness intrusiveness has been identified as a key variable related to both parent and youth adjustment outcomes in other pediatric chronic illness populations (i.e., juvenile rheumatic disease; Fedele et al., 2012; Gamwell et al., 2016). However, these associations have not been examined in parents of youth with IBD, and the precise mechanisms by which parent illness intrusiveness influences youth adjustment outcomes remain unclear.

Empirical findings across pediatric chronic illnesses (i.e., juvenile rheumatic diseases, diabetes, asthma, cystic fibrosis) suggest that parents' perceptions of their child's disease are conveyed to youth, often resulting in negative adjustment outcomes (e.g., Page et al., 2012; Ramsey et al., 2013). Further, recent research in the pediatric IBD literature indicates that negative parent illness appraisals can have untoward influences on youth illness appraisals, which then impact youth adjustment outcomes (Baudino et al., 2019; Roberts et al., 2019). In other childhood illness populations (i.e., juvenile rheumatic diseases), parent illness intrusiveness has been identified as a key variable contributing to both youth illness intrusiveness and youth depressive symptoms (Fedele et al., 2012; Ramsey et al., 2014). It is suspected that a similar transactional process may unfold for pediatric IBD populations. Although similar findings have not yet been replicated in the IBD literature, it may be that that parents of youth with IBD directly or indirectly communicate feelings of illness intrusiveness to their children resulting from associative stigma, which contributes to youths' increased feelings of illness intrusiveness and ultimately depressive symptoms.

The Present Study

The present study was designed to examine illness intrusiveness appraisals as potential mediators in the association between parent perceived illness stigma (associative stigma) and child depressive symptoms in youth with IBD. A model will be tested in which associative stigma acts as a primary antecedent that drives parent and youth illness intrusiveness, which subsequently results in elevated youth depressive symptoms. In addition to testing the proposed *parent associative stigma → parent illness intrusiveness → youth illness intrusiveness→ child depressive symptoms* serial mediation path, the direct and indirect paths of the modeled variables will also be examined.

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CHAPTER II

REVIEW OF THE LITERATURE

The current chapter will review the literature relevant to the proposed study. In the first section, an overview of pediatric inflammatory bowel disease will be provided including classification information, etiology, prevalence, symptomology, and treatment/management. The second section will discuss child psychosocial adjustment to inflammatory bowel disease. The third section will then provide a broad overview of illness stigma as it pertains to parents and youth with IBD. The fourth section will provide an overview of illness intrusiveness in parents and youth with IBD. The final section will provide a brief outline of how these variables may relate.

Pediatric Inflammatory Bowel Disease

Inflammatory Bowel Disease (IBD) is a broad term used to describe a group of conditions which are characterized by chronic, episodic inflammation of the gastrointestinal tract (Sauer & Kugathasan, 2010). IBD encompasses three diseases: Crohn's disease (CD), ulcerative colitis (UC), and indeterminate colitis (IC). The two most common subtypes of IBD are UC and CD (Loftus, 2004; Kappelman et al., 2013; Kugathasan et al., 2003; Yu & Rodriguez, 2017). Although the precise etiology of IBD is unknown, there is some evidence which suggests that IBD develops in genetically susceptible individuals due to environmental (e.g., infectious, microbial, dietary) triggers (Benchimol et al., 2010; Peloquin et al., 2016; Wei et al., 2013).

Two million Americans are affected by IBD, with over 80,000 being children (Peloquin et al., 2016). IBD develops during childhood or adolescence in up to 25% of patients and it is estimated that the incidence of pediatric-onset IBD is increasing (Benchimol et al., 2010). Pediatric-onset IBD has a presentation similar to that of adult-onset IBD. However, youth with IBD are prone to experience symptoms unique to childhood and/or adolescence such as poor growth, pubertal delay, and decreased adult height (Peloquin et al., 2016; Sauer & Kugathasan, 2009). Additionally, pediatric IBD is frequently more severe and extensive than adult-onset IBD and is accompanied with atypical presentation. Common symptoms of IBD include diarrhea, fever, fatigue, and abdominal pain. Because these symptoms overlap with numerous other diseases and illnesses (e.g., gastroenteritis, irritable bowel syndrome, allergy associated gastroenteritis), diagnosing IBD during childhood can be difficult (Yu & Rodriguez, 2017). IBD is a systemic disease and can affect multiple organs, patients with can also present with extraintestinal manifestations of IBD (Levine & Burakoff, 2011). Rates of extraintestinal manifestations of IBD range from 25-40% and tend to be higher in pediatric patients than in adults. In patients who do experience extraintestinal symptoms of IBD, up to 25% will experience more than one extraintestinal manifestation. Extraintestinal manifestations commonly involve organ systems such as the skin, biliary tract, eyes, and joints (Yu & Rodriguez, 2017), however, they can involve nearly any organ system. Symptoms that are extraintestinal frequently parallel disease severity/activity and improve with IBD treatment (Levine & Burakoff, 2011). Pediatric IBD patients may also experience failure to thrive as well as symptoms unique to childhood such as growth impairment and pubertal delay (Laas et al., 2014).

Crohn's Disease. Crohn's disease (CD) is a chronic, lifelong, relapsing type of inflammatory bowel disease (Laas et al., 2014). Between 59-73% of pediatric IBD patients are diagnosed with CD, making it the most common subtype of pediatric IBD (Yu & Rodriguez, 2017). Patients with CD experience transmural, chronic inflammation of the gastrointestinal tract. Although CD can affect any portion of the digestive tract from the mouth to the anus, it

typically affects the colon and/or terminal ileum (Head & Jurenka, 2004). Patients with Crohn's disease often experience symptoms such as fever, abdominal pain, diarrhea, and weight loss. Up to 50% of patients with CD also experience manifestations of IBD which involve other organ systems. Some of the most common extraintestinal symptoms of IBD are peripheral arthritis, ankylosing spondylitis, erythema nodosum, and uveitis.

Because the symptoms of CD often overlap with other disorders, particularly ulcerative colitis, diagnosing CD can be challenging. No single test can diagnose CD; instead, physicians will often conduct physical exams, and order laboratory tests such as stool samples. Physicians may also order x-rays of the gastrointestinal tract and perform colonoscopies and/or endoscopies to aid in diagnosis (CCFA, 2019). Although there is no etiology has been identified for CD, research indicates that up to 25% of CD patients have a relative with IBD, suggesting that there is a genetic component to CD (CCFA, 2019). Known risk factors for CD include the use of oral contraceptives, smoking, nonsteroidal anti-inflammatory medications, antibiotic use, having an appendectomy during adulthood (Head & Jurenka, 2004).

There are five subtypes of CD which are classified based on the part of the digestive tract which is affected by the disease. The most common subtype of CD is ileocolitis, which affects both the colon and the end of the small intestine (the ilium). In ileocolitis, patients often experience symptoms such as diarrhea and pain in the middle or right lower portion of the abdomen. Significant weight loss frequently accompanies this IBD subtype. Ileitis refers to CD which only affects the ilium. The symptoms of ileitis mirror the symptoms of ileocolitis, however, in severe cases of ileitis, patients may have fistulas or inflammatory abscesses in the right lower quadrant of the abdomen. Gastroduodenal CD affects the stomach and the beginning of the small intestine (the duodenum). Symptoms of gastroduodenal CD are poor appetite, weight loss, nausea, and vomiting. Jejunoileitis is a subtype of CD which is characterized by patchy sections of inflammation in the upper portion of the small intestine (the jejunum). The symptoms of jejunoileitis can include intense abdominal pain, cramping after meals, and diarrhea. Severe

cases may also result in the formation of fistulas. Crohn's (granulomatous) colitis is the final subtype of CD and affects only the colon. It symptoms include rectal bleeding, diarrhea, and abscesses, fistulas, and ulcers around the anus. Patients with Crohn's colitis are more prone to experience skin and joint extraintestinal manifestations of IBD (i.e., skin leisons and joint pain) than patients with other subtypes of CD (CCFA, 2019).

The goals of CD treatment are symptom management and reduction. Treatment options for CD include taking medications to suppress the immune system's inflammatory response. Common medications prescribed to manage CD include aminosalicylates, corticosteroids, immune-modulating agents, and antibiotics. Although these medications can aid in symptom reduction, they often cause unpleasant side effect such as nausea, weight gain, insomnia, acne, and night sweats (Head & Jurenka, 2004). Although no research suggests that certain foods trigger CD symptoms, patients are encouraged to monitor their diet and nutrition in order to maintain a healthy weight and promote growth. Approximately 70% of people with CD will eventually require some type of surgical procedure to remove parts of the colon which are diseased. Surgery becomes necessary when medications are ineffective at controlling symptoms or when patients develop fistulas, fissures, or intestinal obstructions (CCFA, 2019).

Ulcerative Colitis. Ulcerative colitis (UC) is the other main subtype of IBD. Approximately 24-32% of pediatric IBD patients are affected by UC. Although CD is the most prevalent type of IBD seen in pediatric patients, UC is the predominant type of IBD seen in children younger than six years of age (Yu & Rodriguez, 2017). Symptoms of ulcerative colitis include abdominal pain, mucosal inflammation, diarrhea, and rectal bleeding. Whereas CD can affect any area of the gastrointestinal tract, UC primarily affects the colon and rectum (Conrad et al., 2014). Small ulcers form in the colons of UC patients which produce mucous and pus, often resulting in abdominal pain as well as the frequent need to empty the colon (CCFA, 2019).

As with CD, UC can be difficult to diagnose due to symptoms which overlap with other diseases and/or illnesses such as irritable bowel syndrome, Crohn's disease, gastroenteritis, and

diverticulitis. During the diagnostic process, physicians must rule out infectious causes of cramping and diarrhea by obtaining stool cultures. Complete blood counts and fecal occult blood counts may also be used to check for anemia and intestinal blood loss. A diagnosis of UC is usually confirmed with a colonoscopy or flexible sigmoidoscopy (Head & Jurenka, 2003). As with CD, the etiology of UC is not well understood. However, research indicates that its development could be the result of an interaction between a virus or bacterial infection in the colon and the body's immune response. A normal immune response to an infection would result in temporary inflammation which is helpful in eliminating infection. Once the infection is eliminated, the inflammation would then go away. It is hypothesized that in ulcerative colitis patients, inflammation continues after an infection is eliminated and white blood cells are sent to the lining of the intestines, which produces chronic inflammation (CCFA, 2019).

There are three main subtypes of UC: ulcerative proctitis, left-sided colitis, and extensive colitis; as with CD, the subtypes of UC classified based on the area of the colon which is affected by the disease. In ulcerative proctitis, inflammation typically affects less than six inches of the rectum. Symptoms of ulcerative proctitis often include rectal pain, rectal bleeding, and the urgency to have bowel movements. In left-sided colitis, inflammation begins at the rectum and extends into the colon. The symptoms of left-sided colitis may include poor appetite, weight loss, bloody diarrhea, and pain on the left portion of the abdomen. Extensive colitis is the final subtype of UC. In extensive colitis, the entire colon is affected by inflammation. Common symptoms of extensive colitis include loss of appetite, bloody diarrhea, weight loss, and abdominal pain (CCFA, 2019).

Although there is no known cure for UC, many different treatment options can be used to reduce inflammation and regulate the immune response in UC patients. Treatment options for UC are often multifaceted and involve using medications to suppress inflammation in the colon and promote tissue healing. Common medications used in UC patients include aminosalicylates, corticosteroids, immunomodulators, and antibiotics (CCFA, 2019). Usage of these medications is

often accompanied by unpleasant side effects such as nausea, vomiting, weight gain, rashes, and diarrhea (Head & Jurenka, 2003). Some patients may notice that their UC symptoms are triggered by certain foods. As such, it may be beneficial for patients to monitor their diet to avoid trigger foods and replace nutritents which are lost due to UC symptoms (e.g., diarrhea). Medical therapy is not effective for up to one-third of UC patients. For these patients, surgical removal of the colon may be necessary (CCFA, 2019).

Indeterminate Colitis. In 2005, the Montreal working group coined another subtype of IBD called indeterminate colitis (IC). IC refers to "patients with colonic disease who cannot be classified into one of the two major subtypes of IBD [UC or CD]" (Yu & Rodriguez, 2017). Individuals with indeterminate colitis have symptoms that overlap with both CD and UC. IC tends to be diagnosed most frequently in children under two years of age and the incidence of IC decreases with age (Geobes et al., 2018; Yu & Rodriguez, 2017). Because there is often uncertainty with pediatric IBD classification due to overlapping symptoms, an estimated 5-33% of youth are diagnosed with IC. As IBD symptoms progress, the majority (approximately 60%) of patients with indeterminate colitis are reclassified as having either CD or UC (Geobes et al., 2008). Although it is often difficult to differentiate whether pediatric patients have CD or UC, it is recommended to avoid diagnosing IC when possible to aid in treatment decisions (Carvalho et al., 2006; Yu & Rodriguez, 2017).

Psychological Adjustment in Youth with IBD

Youth with IBD face unique challenges due to the unpredictable, chronic nature of the disease as well as its potentially embarrassing symptoms. As such, it is not surprising that youth with IBD are at risk for experiencing psychological difficulties, particularly depressive symptoms (Greenley et al., 2010; Mackner et al., 2006; Mackner et al., 2013). Further, research in pediatric IBD populations consistently suggests that up to 25% of youth with IBD experience clinical levels of depression (Baudino et al., 2019; Gamwell et al., 2018; Schuman et al., 2013; Szigethy et al., 2004). Research by Mackner & Crandall (2006) compared rates of depressive symptoms in

youth with IBD to healthy youth. The results indicated that although the youth with IBD had higher levels of anxious/depressive symptoms than healthy youth, the symptoms in the two groups did not significantly differ. However, it should be noted that youth with IBD in the sample were 4.6 times more likely to experience clinically significant symptoms of anxiety/depression than the healthy youth (Mackner & Crandall, 2006). A meta-analysis conducted by Greenley and colleagues (2010) compared depressive symptoms in youth with IBD to youth with other chronic health conditions (e.g., chronic headaches, cystic fibrosis, functional gastrointestinal disorders, diabetes) and healthy youth. Interestingly, findings from this study indicated that youth with IBD tend to have higher rates of depressive disorders, but not necessarily higher depressive symptomology than youth with other chronic illnesses and healthy youth (Greenley et al., 2010).

The results found by Greenley et al. (2010) differ from other studies which have found higher levels of depressive symptoms in youth with IBD compared to youth with other chronic illnesses. For example, Burke and colleagues (1989) compared the prevalence of current and lifetime depressive disorders in youth with IBD to youth with cystic fibrosis. Findings indicated that the lifetime prevalence of depression was 29% in youth with Crohn's disease, 21% in youth with ulcerative colitis, and 11.5% in youth with cystic fibrosis. Further, youth with Crohn's disease were significantly more likely to have a lifetime history of depression compared to youth with cystic fibrosis. When comparing lifetime and current prevalence of depression in youth with cystic fibrosis, Crohn's disease, and ulcerative colitis, the researchers found that the rates of persistent depressive disorder (dysthymia) were significantly higher in youth with ulcerative colitis than in youth with either Crohn's disease or cystic fibrosis. Lifetime prevalence rates of atypical depression were significantly greater in youth with Crohn's disease and ulcerative colitis than in youth with cystic fibrosis. However, there was no difference between any of the groups in prevalence rates of current prevalence of depression, atypical depression, or lifetime and current prevalence of anxiety disorders (Burke et al., 1989).

A study conducted by Engstrom (1992) compared psychological functioning in youth

with IBD to youth with diabetes, headaches, and healthy youth. Both mother and youth in the four groups completed measures of psychological adjustment. Mothers of youth with IBD reported significantly ore behavior problems than mothers of healthy youth and youth with diabetes. However, mothers of youth with tension headaches reported similar levels of behavior problems compared to mothers of youth with IBD. Researchers also examined levels of internalizing problems in the groups and significant differences were found between the groups. Mothers of youth with tension headaches and IBD reported more internalizing problems than mothers of healthy children. On self-report measures, youth with IBD and headaches reported significantly more depressive symptoms than healthy youth and youth with diabetes. Although overall anxiety symptoms were similar among the groups, youth with headaches reported significantly more anxiety than healthy youth; anxiety in youth with IBD was not significantly different from any of the groups (Engstrom, 1992).

Some research suggests that youth with IBD may have relatively low levels of depressive symptoms. A recent study conducted by Walter and colleagues (2016) assessed rates of internalizing symptomology in youth with IBD. Their findings indicated that only 13% of the sample had clinically elevated symptoms of anxiety and depression. Further, less than 4% of the sample exceeded the clinical cutoff score for depression (Walter et al., 2016). Gold, Issenman, Roberts, and Watt (2000) compared the mental health profiles of youth with IBD to youth with functional gastrointestinal complaints. Findings suggested that youth with functional gastrointestinal complaints reported more depressive symptoms than youth with IBD, however, both groups were psychologically healthy overall (Gold et al., 2000). Maddux, Bass, Geraghty-Sirridge, Carpenter, and Christenson (2013) compared psychological functioning in youth with newly diagnosed IBD to normative data gathered in healthy youth. The results of this study indicated that less than 4% of the IBD sample was at risk for depression and less than 2% met the clinical cutoff score for depression. Additionally, youth with IBD actually reported higher levels of quality of life than healthy youth (Maddux et al., 2013).

Other research suggests that youth with IBD experience behavioral and emotional functioning that is comparable to healthy youth. For example, Mackner and Crandall (2005) assessed the behavioral and emotional functioning of youth with IBD and healthy youth. Their sample of youth with IBD actually reported fewer depressive symptoms than healthy youth. Further, no youth with IBD reported levels of clinical depression whereas two of their healthy peers did (Mackner & Crandall, 2005). Herzog and colleagues (2012) examined rates of clinical depression in youth with IBD to youth without chronic illnesses. Youth with IBD in their sample had lower prevalence rates of clinical depression than their healthy peers (Herzog et al., 2012). Reed-Knight and colleagues (2014) also compared depressive symptomology in youth with IBD to healthy youth. Similarly, Reed-Knight et al. (2014) found that youth with IBD reported lower levels of depressive symptoms than their healthy counterparts.

Findings are inconsistent regarding the level of depressive symptoms that youth with IBD experience, however, research indicates that depressive symptoms are linked to several other adjustment outcomes. For example, Mackner, Bickmeyer, and Crandall (2012) compared school functioning (achievement, grade retention, school-related quality of life, special education, and absences) of youth with IBD to their healthy peers. Results showed that youth with IBD had poorer school functioning in all areas, however, the only significant difference between the two groups was the number of school absences; the IBD group had significantly more absences than healthy youth. Interestingly, internalizing problems predicted the number of school absences in youth with IBD (Mackner et al., 2012).

Gray, Denson, Baldassano, and Hommel (2012) examined the relationship between behavioral dysfunction, disease activity, and quality of life in adolescents with IBD. Results of this study demonstrated that both internalizing and externalizing symptoms were associated with lower quality of life. Further, internalizing symptoms appeared to be a mechanism through which disease severity affected quality of life (Gray et al., 2012b). Engelmann et al. (2015) also examined the influence of psychiatric comorbidity (adjustment disorders, depression, anxiety,

learning disorders, and attention deficit/hyperactivity disorder) on health related quality of life in adolescents with IBD. Results indicated that psychiatric comorbidity and disease activity contributed to lower quality of life (Englemann et al., 2015). In another study by Gray and colleagues (2012a), the researchers examined the impact of barriers to adherence and anxiety/depressive symptoms on adherence in youth with IBD (Gray et al., 2012a). The results of this study showed that anxiety and depressive symptoms moderated the relationship between barriers to adherence and adherence with adherence being lower in youth with higher anxiety/depressive symptoms (Gray et al., 2012a). Taken together, these findings indicate that depressive symptoms (regardless of severity) appear to be determinants of youth adjustment outcomes.

Parent/Youth Adjustment to Pediatric Inflammatory Bowel Disease

Given that existing pediatric IBD literature indicates that youth with IBD may be at risk for experiencing depressive symptoms and consequential adjustment difficulties, studies have begun to examine variables which may play key roles in the development of depressive symptoms. A study by Clark et al. (2014) investigated whether or not demographic (e.g., age, sex, and socioeconomic status) and medical variables (e.g., disease severity, yearly steroid use, daily steroid use, and erythrocyte sedimentation rate) were predictive of depressive symptoms in youth with Crohn's disease. Analyses from this study suggested that the strongest predictors of depression in the sample were socioeconomic status and disease severity (Clark et al., 2014). Disease severity was also found to be associated with depressive symptoms in youth with IBD in studies by Guilfoyle, Gray, Herzer-Maddux, and Hommel (2014) and Schuman, Graef, Janicke, Gray, and Hommel (2013).

Although disease severity appears to be related to depressive symptoms in youth with IBD, research indicates that other parent variables are also associated with youth depressive symptoms. For example, a study conducted by Gray, Graef, Schuman, Janicke, and Hommel, (2013) examined the relationship between parenting stress and depressive symptoms in youth

with IBD. The authors found that parenting stress was significantly associated with youth depressive symptoms. Additionally, the aforementioned study by Schuman et al. (2013) found that in a sample of adolescents with IBD, family problem-solving significantly predicted parent reported adolescent depressive symptoms.

Unlike other areas of the chronic illness literature (e.g., juvenile rheumatic diseases; Chaney et al., 2016, diabetes; Carpentier et al., 2007), relatively few studies in youth with IBD have examined illness appraisal variables that are known to be associated with youth depression. In fact, only two studies to date have examined the impact of youth illness appraisals on depressive symptoms in youth with IBD. A recent study by Gamwell et al. (2018) investigated the association between perceived illness stigma, thwarted belongingness, and depressive symptoms in youth with IBD. Results suggested that perceived illness stigma negatively impacted both thwarted belongingness and depressive symptoms in youth with IBD (Gamwell et al., 2018). Another study by Roberts et al. (2019) investigated the roles of parent and youth appraisals in relation to both parent and youth adjustment outcomes. In this study, the authors found that youth perceptions of illness intrusiveness and illness uncertainty were associated with youth depressive symptoms. Collectively, these studies suggest that youth perceptions of IBD are related to psychosocial adjustment.

Interestingly, although the literature suggests that parent cognitive appraisals are some of the most reliable predictors of youth adjustment outcomes (e.g., Chaney et al., 1997; Friedman et al., 2004; Ramsey et al., 2013; Ryan et al., 2010) only one known study has examined how parent illness appraisals may influence youth adjustment in this population. A study by Baudino and colleagues (2019) examined parent and youth appraisals of uncertainty as potential serial mediators in the relationship between disease activity and depressive symptoms in youth with IBD. Results indicated that increased disease activity heightened parental perceptions of uncertainty, which in turn, heightened youth perceptions of uncertainty and ultimately youth depressive symptoms (Baudino et al., 2019). This research indicates that parent illness appraisals

can have untoward influences on youth illness appraisals, which then impact youth adjustment outcomes. In the aforementioned study conducted by Roberts et al. (2019), the authors also investigated the roles of parent appraisals in relation to youth adjustment outcomes. Findings revealed that parent appraisals (uncertainty, intrusiveness) were related to youth depressive symptoms.

Research across various chronic illness groups including juvenile rheumatic diseases (Chaney et al., 2016; Fedele et al., 2011), diabetes (Chaney et al., 1997), cancer (Colletti et al., 2008), and asthma (Lopez et al., 2008) has demonstrated that youth adjustment to chronic illness does not occur in isolation, but rather involves parents and caregivers as well. This parent-child adjustment exemplifies the parent-child transactional stress and coping model (Thompson & Gustafson, 1996), which suggests that parent and youth adjustment to a child's chronic illness is determined by the interaction of cognitive processes, demographic variables, and illness factors. Although speculative, results from Baudino et al. (2019) and Roberts and colleagues (2019) provide further support for the idea that there may be a transactional relationship between parent and youth adjustment in IBD.

Illness and Associative Stigma

In addition to the invasive nature of IBD symptoms and treatment, the embarrassing and stigmatizing aspects of IBD symptoms (e.g., fecal incontinence, frequent bowel movements, flatulence) have long been suspected of playing a role in youth adjustment outcomes (e.g., Greenley et al., 2010; Guilfoyle et al., 2014; Herzer et al., 2011; Mackner et al., 2012; Schuman et al., 2013). Goffman (1963) defined stigma as an attribute that is "deeply discrediting" and changes a person "from a whole and usual person to a tainted and discounted one." Recent empirical research indicates that youth who perceive their IBD as more stigmatizing are also more likely to experience poorer adjustment outcomes, particularly depressive symptoms (see Gamwell et al., 2018). Interestingly, although studies in the IBD literature have demonstrated that a range of parent variables are associated with youth depressive symptoms (e.g., uncertainty,

parenting stress, parent distress; Baudino et al., 2019; Guilfoyle et al., 2014; Herzer et al., 2011), studies have yet to examine parents' experience of stigma and its potential influence on youth adjustment outcomes.

Findings from the adult IBD literature suggest that IBD related stigma is associated with a variety of maladaptive psychosocial outcomes. For example, a study by Taft and Keefer (2009) examined the impact of perceived illness stigma on a variety of psychosocial outcomes including psychological distress, quality of life, medication adherence, self-esteem, and self-efficacy. Results from the study indicated that illness stigma predicted lower quality of life, psychological distress, and decreased self-esteem as well as self-efficacy (Taft & Keefer, 2009). These findings were replicated by Taft, Keefer, Artz, Bratten, and Jones (2011) in a sample of IBD and irritable bowel syndrome patients. Other research in adults with irritable bowel syndrome (IBS) suggests that illness related stigma can negatively impact quality of life (Dancey et al., 2002). Research in adolescents and young adults with chronic illnesses (including IBD) has yielded similar findings. Bakula and colleagues (2019) investigated the role of stigma in relation to adjustment outcomes in adolescents and young adults with chronic illnesses (including IBD). Results from this study showed that illness stigma was related to poor emotional outcomes (e.g., depression; Bakula et al., 2019). Taken together, these findings indicate that illness related stigma is associated with a plethora of negative adjustment outcomes for adult IBD patients.

Although some studies in various pediatric chronic illness conditions (e.g., epilepsy) have examined parent perceptions of illness related stigma, the overwhelming majority tend to focus on parents' observations of their child's experience of stigma associated with a chronic illness or condition (e.g., Austin et al., 2004). For example, Benson and colleagues (2016) assessed parent perceptions of stigma with a scale designed to assess the amount of stigma which parents believed their child experienced as a function of having epilepsy (e.g., "People who know that [my child] has a seizure condition treat him or her differently"). A study conducted by Carlton-Ford, Miller, Nealeigh, and Sanchez (1997) also examined parent perceptions of child stigma in

youth with epilepsy by asking questions such as “People treat [my child] fairly” and “[my child] always feels [he/she] has to prove [himself/herself].”

It is important to note that parents of children with other chronic medical and/or disabling conditions such as attention-deficit/hyperactivity disorder (ADHD; e.g., dosReis et al., 2010; Norvilitis et al., 2002; Mikami et al., 2015) and autism spectrum disorder (ASD; Kinnear et al., 2016; Werner & Shulman, 2013) experience stigma due to their child’s condition. This “associative stigma” refers to stigma that a person may experience by virtue of his or her association to someone who is stigmatized (Goffman, 1963).

Research indicates that parents who experience associative stigma incur a plethora of negative psychosocial adjustment outcomes. For example, Norvilitis and colleagues (2002) assessed attitudes regarding ADHD in mothers of youth with and without ADHD. In this study, mothers of youth with ADHD endorsed more associative stigma than mothers of youth without ADHD. Additionally, experiencing associative stigma was related with parental depression (Norvilitis et al., 2002). In parents of youth with autism, associative stigma has also been found to be associated with poor psychosocial outcomes. A study by Mak and Cheung (2008) found that associative stigma was associated with higher levels of parenting stress in parents of youth with autism, intellectual disabilities, and mental illness. A study by Kinnear and colleagues (2016) also found that associative stigma was associated with social exclusion in parents of youth with autism. Although speculative, parents of youth with IBD may experience similar outcomes resulting from associative stigma. For example, during interpersonal interactions, parents may notice if others become uncomfortable when talking about their child’s IBD and/or symptoms. Alternatively, parents may fear experiencing embarrassing situations in public related to their child’s IBD (e.g., fecal incontinence). As such, parents of youth with IBD may experience feelings of associative stigma due to the socially aversive aspects of their child’s disease.

Research in parents of youth with ADHD and autism suggests parents who experience associative stigma attempt to cope with being stigmatized by limiting social interactions. For

instance, in a study by Koro-Ljungberg & Bussing (2009), the authors sought to examine how parents manage associative stigma. Results indicated that many parents attempted to cope with associative stigma by avoiding social exposure when their social network members were unfamiliar with their child's diagnosis (Koro-Ljungberg & Bussing, 2009). A study by dosReis et al. (2012) also found that parents of youth with ADHD reported socially isolating themselves from colleagues, friends, and family members as a result of affiliate stigma. Similarly, Kinnear and colleagues (2016) found that parents of youth with autism frequently report isolating themselves from friends and family frequently due to their child's behavior and the potential stigma that they may face. Studies involving parents of youth with autism have demonstrated that when parents attempt to cope with associative stigma in these ways, parents often limit their involvement in routine and rewarding pursuits such as social interactions and family/leisure activities (e.g., Kinnear et al., 2016; Werner & Schulman, 2013).

Given the restrictions that are already imposed on parents by their child's IBD (e.g., managing complex medication regimens, attending medical appointments, managing diet), associative stigma may contribute to heightened appraisals of IBD-induced disruptions in parents' abilities to engage in valued interests and activities. For example, the variable and unpredictable nature of IBD may cause parents to have difficulties planning activities. The child's symptoms and/or disease flares may often result in their child's participation being cancelled. Parents having to explain why their child can no longer participate in addition to the embarrassment they experience as a function of their child's IBD may lead to parents avoiding planning activities altogether. Alternatively, parents may experience frustration related to scheduling and cancelling plans, which may also contribute to the perceived intrusiveness of their child's IBD.

Illness Intrusiveness

Although this process is speculative, it embodies the main premise of the illness intrusiveness theory, which is that is that lifestyle disruptions impact psychosocial well-being in

individuals with chronic conditions by 1) decreasing the number of rewarding or positive experiences through decreased involvement in valued interests and activities and 2) by reducing the amount of personal control an individual feels he or she has in important life domains, which then compromises the ability to obtain positively valued outcomes and/or to avoid negative ones (Devins et al., 1993). Caregiver perception of illness intrusiveness has been identified as a key variable related to both parent and youth adjustment outcomes in other pediatric chronic illness populations. For example, in a study by Fedele and colleagues (2012), the authors found that symptoms of depression in children with juvenile rheumatic diseases were associated with parent perceptions of illness intrusiveness. Ramsey et al. (2014) examined the impact of parent appraisals on the adjustment of children with juvenile rheumatic diseases. Findings from this study indicated that parents' perceptions of illness intrusiveness were associated with youth perceptions of illness intrusiveness, which were subsequently associated with youth depressive symptoms (Ramsey et al., 2014). Interestingly, theses associations have not been examined in parents of youth with IBD and the precise mechanisms by which parent illness intrusiveness influences youth adjustment outcomes remain unclear.

Empirical findings across pediatric chronic illnesses (i.e., juvenile rheumatic diseases, diabetes, asthma, cystic fibrosis) suggest that parents' perceptions of their child's disease are conveyed to youth, often resulting in negative adjustment outcomes (e.g., Page et al., 2012; Ramsey et al., 2013). Further, recent research in the pediatric IBD literature suggests that negative parent illness appraisals can have untoward influences on youth illness appraisals, which then impact youth adjustment outcomes (Baudino et al., 2019; Roberts et al., 2019). In other childhood illness populations (i.e., juvenile rheumatic diseases), parent illness intrusiveness has been identified as a key variable contributing to both youth illness intrusiveness and youth depressive symptoms (see Fedele et al., 2012; Ramsey et al., 2014). It is suspected that a similar transactional process may unfold for pediatric IBD populations. Although similar findings have not yet been replicated in the IBD literature, it may be that that parents of youth with IBD directly

or indirectly communicate feelings of illness intrusiveness resulting from associative stigma to their children, which ultimately results in increased feelings of illness intrusiveness and ultimately depressive symptoms in youth with IBD.

The Present Study

The present study was designed to examine illness intrusiveness appraisals as potential mediators in the association between parent perceived illness stigma and child depressive symptoms in youth with IBD. A model will be tested in which associative stigma acts as a primary antecedent that drives parent and youth illness intrusiveness, which subsequently result in elevated youth depressive symptoms. In addition to testing the proposed *parent perceived illness stigma → parent illness intrusiveness → youth illness intrusiveness→ child depressive symptoms* serial mediation path, the direct and indirect paths of the modeled variables will also be examined.

CHAPTER III

METHODOLOGY

Participants and Procedures

Participants included 150 parent-youth dyads recruited from a pediatric gastroenterology clinic at a large children's hospital in the southwest US. Portions of the present sample were included previously in Roberts et al.'s 2020 study examining youth stigma and depressive symptoms. Youth (55% female) diagnosed with IBD (Crohn's disease 54%, ulcerative colitis 46%) were between the ages of 10 -18 years (M_{age} = 14.7, *SD* = 2.3 yrs.). Eighty-three percent of caregivers were mothers, 16% were fathers, and 1% were grandparents. Seventy-percent of youth were White (Native American = 7%; African American = 6%; Hispanic = 3%; Asian = 2%; Other = 12%) and from families with a range of annual household incomes (45% = $10K - 70K; 22% = $70K - 100K; 33% = $100K+). Medications included anti-inflammatory (*n* = 57; 38%), steroid (*n* = 31; 21%), and immunosuppressant/biologic regimens (*n* = 96; 64%).

Eligible participants were identified by their pediatric gastroenterologist if youth were between the ages 10-18 years and had received a confirmed IBD diagnosis, and both youth and caregiver participants were proficient in English and had no documented cognitive deficits (e.g., developmental disabilities, neurodevelopmental conditions). Parents were notified of their eligibility for the study via mail, and were consented in person during a routine clinic visit. Self-report measures were independently completed by parents and youth on site.

Physicians provided disease information, such as disease severity, date of diagnosis, and current medication regimen. Of the 154 eligible parent-child dyads identified, 150 (97.4%) agreed to participate in the study. Reasons for declining participation were primarily due to scheduling difficulties or lack of time. All consented parents and youth completed the questionnaires (100% completion rate). Participants were compensated with $20 for their participation. Institutional Review Board approval was obtained prior to initiation of the study and all procedures adhered to American Psychological Association standards.

Measures

Background Information Questionnaire. Parents completed a 24-item demographic questionnaire to obtain information including, but not limited to: child age, child gender, parent age, parent gender, household income, and race/ethnicity.

Physicians Global Assessment (PGA). At the time of recruitment, the attending pediatric gastroenterologist completed the PGA to assess disease severity (quiescent, mild, moderate, severe) coded on a 4-point scale (0 – 3). Higher PGA scores indicated greater disease severity. The PGA is a commonly used measure of disease severity and correlates with Crohn's Disease and Ulcerative Colitis disease activity (e.g., Pediatric Crohn's Disease Activity Index [PCDAI], Pediatric Ulcerative Colitis Activity Index [PUCAI]; Hyams et al., 2005; Turner et al., 2009).

Stigma Scale-Parent (SS-P). The SS-P is an 8-item self-report measure adapted with permission from the Child Stigma Scale (CSS; Austin et al., 2004), which was developed for youth with epilepsy. The format of the SS-P in the present study is identical to the CSS, except "epilepsy" is replaced with "IBD" and the wording is modified to reflect parents' personal experience of stigma related to their child's IBD (e.g., "*How often do you feel different from other parents because your child has IBD?*", *"How often do you try to avoid talking to other people about your child's IBD?"*). Parents rated their experience of IBD-related stigma on a five point

Likert scale (1 = *Never* to 5 = *Very Often*). A total score was calculated by summing the items, with higher scores indicating increased perceptions of IBD-related stigma. Although no psychometric data currently exist for the SS-P used in the present study, the parent version of the CSS examining parents' estimates of their child's experience of stigma has shown good internal consistency in studies in pediatric epilepsy populations (i.e., Austin et al., 2004). Cronbach's alpha in the present study was .75.

Illness Intrusiveness Scale-Parent (IIS-P). The IIS-P is a 13-item self-report measure adapted from the Illness Intrusiveness Rating Scale (Devins et al., 1993). The IIS-P assesses the degree to which parents experience illness-induced lifestyle disruptions across numerous domains (e.g., work, social and family relationships, leisure). Parents rated the intrusiveness of their child's IBD (e.g., "*Rate the extent to which your child's illness interferes with work"*, "*Rate the extent to which your child's illness interferes with relationships with other people"*) on a 7-point scale (1= *a little to* 7= *a lot*). Higher sum scores indicated greater parent intrusiveness. In studies of pediatric chronic groups (including IBD), the IIS-P has demonstrated excellent internal consistency (e.g., Andrews et al., 2009; Fedele et al., 2012; Roberts et al., 2019). In the current sample, the IIS-P also had high internal consistency (α = .90).

Illness Intrusiveness Scale-Child (IIS-C). The IIS-C (Wagner et al., 2003) is a 12-item, self-report measure adapted from the Illness Intrusiveness Rating Scale (Devins et al., 1993). Similar to the IIS-P, the IIS-C measures the degree to which children experience their illness and/or treatment as impeding their ability to engage in a variety of activities (e.g., school, family, social). Youth rated each item (e.g., "*How much does your illness and its treatment interfere with activities outside of school?*", "*How much does your illness and its treatment interfere with relationships with your friends?"*) on 7-point scale (i.e., 1= *does not apply to me* to 7 = *a lot*). Items were summed to obtain total scores, with higher scores indicating increased youth illness intrusiveness. The IIS-C has shown good internal consistency in youth with IBD and in other

pediatric chronic illness groups (e.g., Fedele et al., 2012; Roberts et al., 2019; Wagner et al., 2003). The IIS-C had high internal consistency in the current study (α = .89).

Children's Depression Inventory-2nd Edition (CDI-2). The CDI-2 (Kovacs, 2011) is a 28 item self-report measure used to assess youth depressive symptoms during the past two week period (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 was calculated by summing all 28 items with higher total scores indicating more severe depressive symptoms. The CDI-2 has demonstrated good internal consistency in youth with IBD (Baudino et al., 2019; Gamwell et al., 2018). In the present sample, α = .87.

CHAPTER IV

FINDINGS

Preliminary Analyses

Preliminary analyses were conducted to provide descriptive information for the study variables, including levels of PGA disease severity and rates of clinically elevated depressive symptoms on the CDI-2. To test for potential covariates in the primary analyses, bivariate correlations and mean comparison *t*-tests were also conducted to examine the relations between CDI-2 scores and both demographic and disease variables. Primary analyses were conducted using Mplus version 7.31 (Muthén & Muthén, 1998-2012) structural equation modeling software to test the *parent associative stigma → parent illness intrusiveness → youth illness intrusiveness → youth depressive symptoms* serial mediation model. All direct and indirect effects were evaluated by assessing asymmetric 95% confidence intervals yielded from 5000 bootstrapped resampling draws with replacement (see Table 2 for specific paths). Because our model was saturated, our model fit was artificially perfect and model fit was not interpreted.

Although relatively low scores were observed on the SS-P, IIS-P, and IIS-C measures, 70% of parents endorsed experiencing stigma at least *some of the time* (i.e., ≥ 9 on the SS-P).

Mean scores on the IIS-P (M = 20.64) were comparable to those seen in youth with JRD (M = 20.39, SD = 14.38; Ramsey et al., 2014), with 73% percent of parents endorsed experiencing intrusiveness at least *sometime* (i.e., ≥ 14 on the IIS-P;). Observed IIS-C mean scores (M = 15.28) were slightly lower than scores reported for comparably aged youth with JRD (M = 17.59, SD = 14.40; Ramsey et al., 2014), with 91% of youth reporting at least *some* illness intrusiveness (i.e., ≥ 13 on the IIS-C). Low levels of disease severity were also observed on the PGA, with 75% of participants rated as having quiescent IBD activity (mild = 15%; moderate = 9%; severe = 1%). Despite the absence of elevated mean levels of depressive symptoms on the CDI-2, clinical scoring guidelines (raw scores ≥ 14; Kovacs, 2011) indicated that 22% (n = 33) of youth reported clinical levels of depressive symptoms. Only IIS-P fell outside acceptable skewness range (+2.39), but was within acceptable kurtosis range (+5.74). All other variables were within acceptable skewness (-2.0 to +2.0) and kurtosis (-7.0 to +7.0) parameters (Hair et al., 2010).

Correlations revealed no significant associations between CDI-2 scores and demographic (i.e., youth age, family income) or disease variables (i.e., PGA, duration; see Table 1). Mean comparison t-tests revealed that CDI-2 scores did not differ by child race, IBD type, or medication type (all p*'s* > .05). Depressive symptom severity on the CDI-2 also did not differ between youth with a documented mental health diagnosis (n = 12; 8%) compared to never-diagnosed youth. A significant youth gender difference on the CDI-2 indicated higher depressive symptom scores for girls (t [148] = 2.82, p = .01). Although PGA was not significantly related to CDI-2 scores, it was correlated with the IIS-P and IIS-C measures. Based on the preliminary analyses, child gender and PGA were included as covariates in the primary analyses.

Primary Analyses

Results of the primary analyses (see Table 2) revealed significant direct effects for SS-P → IIS-P (path a_1), IIS-P → IIS-C (path d_{21}), and IIS-C → CDI-2 (path b_2), indicating reliable

associations between associative stigma and parent intrusiveness, parent intrusiveness and youth intrusiveness, and between youth intrusiveness and youth depressive symptoms. No significant direct associations were observed between parents' associative stigma and youth intrusiveness (SS-P → IIS-C; path a_2) or between parent intrusiveness and youth depressive symptoms (IIS-P → CDI-2; path b_1). Similarly, parents' associative stigma was not directly related to youth depressive symptoms (SS-P → CDI-2; path c'), independent of youth gender, disease severity, parent intrusiveness, and youth intrusiveness. All variables in the model accounted for significant variance in youth depressive symptoms ($R^2 = .25$, $p < .01$).

Mediation analyses (see Figure 1) revealed significant simple indirect paths for SS-P → IIS-P → IIS-C (a_1d_{21}) and IIS-P → IIS-C → CDI-2 ($d_{21}b_2$), suggesting greater parent associative stigma had an indirect effect on youth intrusiveness via increased parent intrusiveness, and heightened parent intrusiveness indirectly influenced youth depressive symptoms through elevated youth intrusiveness. Importantly, examination of the serial mediation model revealed a significant SS-P → IIS-P → IIS-C → CDI-2 indirect path ($a_1d_{21}b_2$), indicating that parent intrusiveness and youth intrusiveness carried sequential indirect effects from parent associative stigma to youth depressive symptoms.

CHAPTER V

CONCLUSION

The present study examined the link between parents' experience of IBD stigma (associative stigma) and lifestyle intrusions (illness intrusiveness) posed by their child's IBD, and the potential associations with both youths' illness intrusiveness and depressive symptoms. In addition to observing clinically elevated depressive symptoms in a substantial number of youths, our results revealed a significant serial mediation path for *parent associative stigma → parent illness intrusiveness → youth illness intrusiveness → youth depressive symptoms*. Findings suggest that parents who face associative stigma are more likely to experience their child's illness as disrupting/intruding on their ability to engage in routine and rewarding activities (e.g., work, family, social pursuits). Further, our results suggest that parents' heightened illness intrusiveness is associated with greater youth illness intrusiveness, which is ultimately related to increased youth depressive symptoms.

In general, our results support previous studies in other pediatric populations indicating that parents' associative stigma has a negative impact on youths' adjustment outcomes (e.g., Mitter et al., 2019).

Although we did not directly assess activity (dis)engagement, our results could suggest that parents who experience associative stigma may find it challenging to participate in situations they deem stigmatizing, which could disrupt parents' perceived enjoyment of and/or ability to engage in routine and rewarding pursuits (e.g., dosReis et al., 2010; Kinnear et al., 2016), resulting in an increased sense of illness intrusiveness.

Unfortunately, our data do not tell us the mechanism(s) by which parent intrusiveness influences youth intrusiveness. However, it may be that parents' avoidance of certain situations in response to stigma has an unintended collateral effect of limiting their child's participation in rewarding activities, thus reducing youths' opportunities for social reinforcement and increasing the likelihood for depressive symptoms (e.g., Roberts et al., 2019). Alternatively, our data could point to findings indicating that heightened parent stress in response to stigma may negatively impact caregiver-child relationships. For example, parents' attempts to minimize exposure to stigmatizing situations and overcorrect for IBD-induced disruptions could potentially translate into well-intentioned, but excessive parenting (i.e., over parenting; Herzer et al., 2011) that youth experience as intrusive and may serve to reinforce their perceptions of illness-induced restrictions on their activities (e.g., O'Toole et al., 2015). Conversely, the additional burden of stigma associated with IBD may heighten parents' experience of IBD-induced restrictions on their ability to engage effectively in parenting, potentially leaving youth feeling as though they are unsupported in dealing with the intrusive symptoms and daily management of their IBD (e.g., Schuman et al., 2013). Any of these scenarios, together or in isolation, may heighten youths' illness intrusiveness and increase their risk for depressive symptoms.

Clinical implications

The percentage of youth in our sample reporting clinically elevated symptoms of depression is consistent with previous studies (e.g., Clark et al., 2014; Szigethy et al., 2004) and underscores the need for routine screening for depressive symptoms (see Mackner et al., 2020). Our results are also consistent with longitudinal studies in pediatric chronic illness groups,

including IBD, that highlight the influence of parent functioning on youth adjustment (e.g., Guilfoyle et al., 2014; Ryan et al., 2010). It is important to note that both elevated levels of youth depressive symptoms and our primary findings were observed in a sample of youth with well-controlled IBD. Thus, clinicians should be mindful that parents and youth may face ongoing challenges requiring psychological intervention even during periods of quiescent IBD disease activity.

Research in other pediatric populations (e.g., cancer, diabetes) suggests that altering parent illness appraisals has positive effects on youth adjustment, even when youth are not involved in treatment (Mullins et al., 2012). Because parents are "key agents of change" (Herzer et al., 2011; p. 299), modifying parents' experiences of stigma and intrusiveness through clinical intervention (e.g., cognitive restructuring) may benefit both parents and youth. Further, youth-based cognitive-behavioral protocols (e.g., Szigethy et al., 2007) have produced positive treatment effects for depressive symptoms in youth with IBD. Behavioral activation strategies may also be utilized to encourage both parents and youth to remain engaged in valued lifestyle activities. In light of findings indicating parents of youth with IBD experience high levels of psychological distress and low social support (Engstrom, 1991), parents may also benefit from enhanced psychoeducation and access to informal support resources (e.g., Mackner et al., 2020).

Limitations

The findings of the present study should be interpreted in light of several limitations. Due to the cross-sectional nature of our study, the temporal sequence of our modeled variables cannot be assumed (Maxwell & Cole, 2007). For example, given the transactional nature of parent-child functioning in pediatric illness (e.g., Chaney et al., 1997), it could be argued that youths' experience of illness intrusiveness serves to heighten parents' intrusiveness and subsequent elevations in parent associative stigma. Further, although our sample characteristics mirror those in the pediatric IBD literature (e.g., mild disease activity, Caucasian, middle to upper socioeconomic status; Hommel et al., 2011; Herzer et al., 2011), the homogeneous nature of our

sample limits generalizability of our findings to ethnically diverse or socioeconomically disadvantaged populations. Additionally, the present model did not include other potential variables related to parents' associative stigma and youth adjustment (e.g., youth illness stigma, parenting stress/depression; Gamwell et al., 2018; Guilfoyle et al., 2014; Loreaux et al., 2015). Though we did assess for the impact of youth mental health diagnoses (e.g., clinical depression) on depressive symptoms, we did not assess for parent diagnoses. Thus, parents with existing mental health diagnoses may have more negative perceptions of their child's IBD, which could adversely impact parents' coping strategies and youth adjustment outcomes. Further, although parent and youth data were gathered separately, all variables were gathered via self-report measures, and it is possible that the observed associations were artificially inflated due to common method variance. Finally, and perhaps most important, we did not assess actual levels of parent and youth behavioral (dis)engagement, only their self-reports of IBD-induced activity disruptions across a range of lifestyle domains. Although we suspect that increased associative stigma likely serves to discourage parents' involvement in routine and rewarding activities (similar to adults with IBD; Polak, 2020; Taft & Keeler, 2016), our interpretation is speculative and largely informed by findings regarding the impact of associative stigma on social functioning in parents of youth with other chronic conditions (e.g., ADHD; ASD).

Summary and Future Directions

These considerations notwithstanding, our results represent the only known empirical examination of parents' associative stigma and youth emotional adjustment in IBD, and indicate illness intrusiveness is one mechanism by which parents' associative stigma influences youth depressive symptoms. Clearly longitudinal studies are needed, as well as studies assessing both functional disability and voluntary behavioral (dis)engagement to differentiate between activity limitations due exclusively to IBD versus activity restrictions merely attributed to IBD. Future studies would also benefit from identifying specific sources of parent stigma susceptibility, concordance in parent-child activity disruptions, and parent resilience variables that mitigate the

impact of parent associative stigma on youth adjustment. Future research examining these and other variables potentially related to associative stigma may contribute to the development and refinement of interventions to address IBD-related stigma and improve both parent and youth functioning.

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APPENDICES

APPENDIX A: TABLES

Table 1. Correlations and Descriptive Statistics

Variables	1	2	3	4	5	6	7	8	M	SD	Range
1. Child gender	—								—	—	—
2. Child age (yrs.)	.15	—							14.70	2.33	10.0 – 18.0
3. PGA	-.13	-.03	—						.40	.70	0.0 – 3.0
4. Duration (yrs.)	-.02	.15	-.19*	—					2.44	2.33	0.0 – 14.0
5. SS-P	-.07	-.20*	.10	.05	—				10.98	3.38	8.0 – 24.0
6. IIS-P	-.09	-.70	.37**	-.07	.35**	—			20.64	10.40	13.0 – 70.0
7. IIS-C	-.16*	.07	.29**	-.14	-.01	.25**	—		15.28	14.41	0.0 – 59.0
8. CDI-2	-.23**	-.03	.10	.09	.07	.20*	.45**	—	8.98	7.00	0.0 – 33.0

Note: **$p < .01$, *$p < .05$.

PGA = Physicians Global Assessment; SS-P = Stigma Scale-Parent; IIS-P = Illness Intrusiveness Scale- Parent; IIS-C = Illness Intrusiveness Scale-Child; CDI-2 = Children's Depression Inventory-2nd Edition. Age and Duration of the Illness are measured in years.

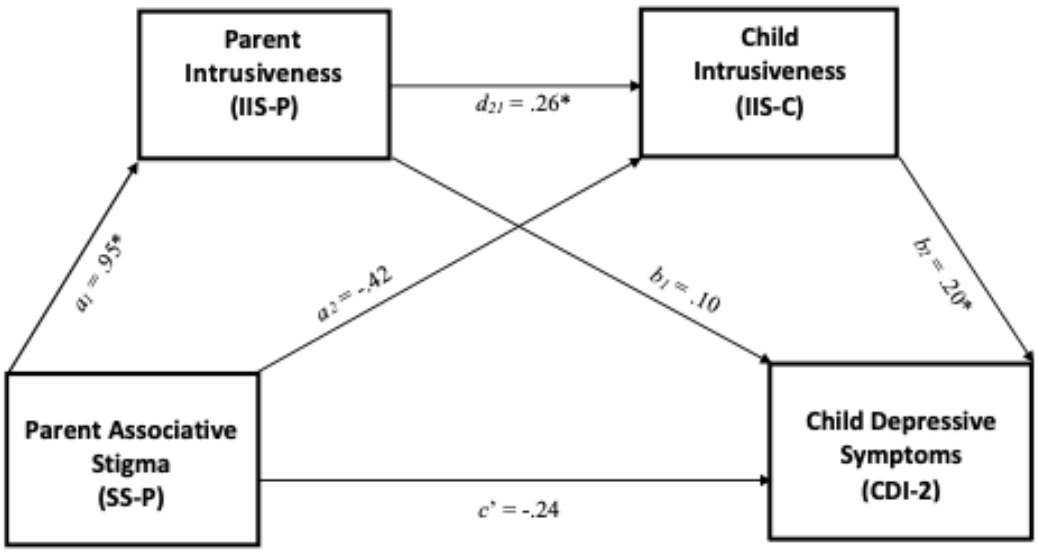
Table 2. Direct and Indirect Path Estimates for Serial Mediation Analysis

	Estimates	95% CI	*p*-value
Direct Paths			
SS-P → IIS-P	a_1 = .95	.33 to 1.50	<.01
SS-P → IIS-C	a_2 = -.42	-1.11 to .25	.23
IIS-P → IIS-C	d_{21} = .26	.05 to .60	.05
IIS-P → CDI-2	b_1 = .10	-.02 to .24	.13
IIS-C → CDI-2	b_2 = .20	.11 to .30	<.001
SS-P → CDI-2	c' = -.24	-.53 to .06	.11
Indirect Paths			
SS-P → IIS-P → CDI-2	a_1b_1 = .10	-.01 to .26	*ns*
SS-P → IIS-C → CDI-2	a_2b_2 = -.08	-.25 to .04	*ns*
SS-P → IIS-P → IIS-C	a_1d_{21} = .25	.04 to .70	<.05
IIS-P → IIS-C → CDI-2	$d_{21}b_2$ = .05	.01 to .13	<.05
SS-P → IIS-P → IIS-C → CDI-2	$a_1d_{21}b_2$ = .05	.01 to .20	<.05

Note. SS-P = Stigma Scale-Parent; IIS-P = Illness Intrusiveness Scale-Parent; IIS-C = Illness Intrusiveness Scale- Child; CDI-2 = Children's Depression Inventory - 2nd Edition.

APPENDIX B: FIGURE

Figure 1. Serial Mediation Model



Note. Indirect paths *SSP* → *IIS-P* → *IIS-C* (a_1d_{21}), *IIS-P* → *IIS-C* → *CDI-2* ($d_{21}b_2$), and *SSP* → *IIS-P* → *IIS-C* → *CDI-2* ($a_1d_{21}b_2$) were statistically significant (*p*'s < .05).
*p < .05

APPENDIX C: IRB APPROVAL

The UNIVERSITY of OKLAHOMA

Institutional Review Board for the Protection of Human Subjects

Continuing Review – Expedited Approval

Date: October 04, 2018

To: Noel Jacobs, PhD

IRB#: 5856
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.

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

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.

Sincerely,
Oklahoma State University IRB

VITA

Marissa Nicole Baudino

Candidate for the Degree of

Doctor of Philosophy

Dissertation: STIGMA BY ASSOCIATION: THE INFLUENCE OF PARENTS' EXPERIENCE OF STIGMA ON PARENT/YOUTH ILLNESS INTRUSIVENESS AND YOUTH DEPRESSIVE SYMPTOMS IN PEDIATRIC INFLAMMATORY BOWEL DISEASE

Major Field: Psychology

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Education:

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

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Experience:

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