THE COMBINED EFFECTS OF YOUTH AND PARENT ILLNESS INTRUSIVENESS ON DEPRESSIVE SYMPTOMS IN ADOLESCENTS WITH INFLAMMATORY BOWEL DISEASE

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THE COMBINED EFFECTS OF YOUTH AND PARENT ILLNESS INTRUSIVENESS ON DEPRESSIVE SYMPTOMS IN ADOLESCENTS WITH PEDIATRIC INFLAMMATORY BOWEL DISEASE

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Abstract: **Purpose/Background:** Inflammatory bowel disease (IBD) presents physical and emotional challenges for families, and imposes significant lifestyle intrusions on both youth and parents. The present study examined the effects of disease severity and youth illness intrusiveness on depressive symptoms in adolescents with IBD, and the moderating influence of parent illness intrusiveness on these associations. **Methods:** Adolescents and parents completed measures of illness intrusiveness; youth completed a measure of depressive symptoms. Physicians provided estimates of IBD severity. **Result**s: Mediation analysis revealed an *IBD severity → youth intrusiveness → youth depressive symptoms* indirect effect. Moderated mediation analyses revealed this indirect effect to be greater among youth whose parents endorsed more IBD-related lifestyle intrusions. **Conclusion:** Youth encountering greater activity disruptions related to IBD severity are vulnerable to depressive symptoms. When parents also experience IBD-induced intrusions, youth are at even greater risk for depressive symptoms. Clinical implications are discussed within the context of youths' and parents' experience of IBD.

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CHAPTER I

INTRODUCTION

Inflammatory bowel disease (IBD) describes a group of chronic autoinflammatory diseases of the gastrointestinal (GI) tract. IBD is one of the most common chronic conditions managed by gastroenterologists in the United States, with roughly 25% of cases diagnosed during childhood. Medical treatment primarily focuses on achieving/maintaining remission of inflammation and can include multiple medications, dietary restrictions, and surgical intervention in more severe cases. Although each IBD subtype affects different regions of the GI tract, as a group, they are characterized by an episodic disease course and invasive symptoms, such as frequent bowel movements, abdominal pain/swelling, bloody stool, diarrhea, and fecal incontinence (Mamula et al., 2017). Youth are also at an increased risk for depressive symptoms (Guilfoyle et al., 2014), with higher rates of depressive symptoms observed among youth with IBD compared to healthy cohorts and other chronically ill groups (e.g., Greenley et al., 2010; Keethy et al., 2014). In fact, clinically elevated depressive symptoms are found in 20 to 25% of pediatric IBD samples (Clark et al., 2014; Szigethy et al., 2004), and depressive symptoms can negatively impact IBD management (e.g., non-adherence; Mackner et al., 2020).

Although it is reasonable to assume that youth with more severe disease would be at greater risk for poorer emotional adjustment, the empirical findings are equivocal

(e.g., Herzer et al., 2011; Guilfoyle et al., 2014; Reed-Knight et al., 2016; Walter et al., 2016). These inconsistent findings point to the presence of intermediary variables that could explain the link between objective indices of IBD severity and youth adjustment difficulties. Previous studies have demonstrated that youths' subjective experience or appraisals of IBD have significant effects on youth depressive symptoms beyond the influence of IBD severity (Baudino et al., 2019; Gamwell et al., 2018; Roberts et al., 2020), suggesting the need for continued examination of potentially modifiable illness appraisals that could inform clinical interventions aimed at improving youth emotional adjustment outcomes.

One illness appraisal variable that has begun to receive attention in the pediatric IBD literature is *illness intrusiveness*, or the experience of illness-induced intrusions that hinder one's ability to engage in routine and valued activities (Devins et al., 2001). Illness intrusiveness is considered a central feature of IBD given the potential disruptions in youths' routine functioning that can limit their participation in a range of important activities (e.g., school, social), especially during times of increased IBD symptom activity (e.g., Gray et al., 2011; Guilfoyle et al., 2014). IBD lifestyle disruptions are suspected of exerting a negative influence on youths' emotional adjustment by interfering with their ability to maintain involvement in regular activities and by limiting their opportunities for positive social engagement. Several studies suggest that adolescents with IBD may be particularly at risk for experiencing difficulties with social functioning and depressive symptoms, due to the socially disruptive nature of IBD symptoms during this critical developmental period (Karwowski et al., 2009; Mackner et al., 2013).

These disruptions extend beyond youth experiences, as parents are integrally

involved in managing their child's IBD well into adolescence (Fishman et al., 2010). Consequently, parents are also subjected to ongoing IBD-induced lifestyle intrusions (e.g., scheduling/attending medical visits, disease flares; symptom management) that can disrupt their established routines and involvement in meaningful activities (e.g., work, family/leisure, social interaction; Gray et al., 2011; Guilfoyle et al., 2014). Indeed, recent studies indicate that disease severity is a source of heightened IBD-induced intrusiveness for youth and their parents, and that youth and parent IBD intrusiveness appraisals are associated with youth depressive symptoms (e.g., Baudino et al., 2021; Roberts et al., 2019).

Thus, consistent with findings in other pediatric chronic illness groups (e.g., diabetes, juvenile rheumatic disease; Chaney et al., 1997; Chaney et al., 2016; White et al., 2005; Wagner et al., 2003), these studies illustrate the impact of IBD on caregivers, and highlight the transactional nature of youth and parent influences on youth adjustment outcomes. However, studies have yet to examine the potential combined influence of youth and parent IBD intrusiveness on youth depression to explore the possibility that youth who face greater activity disruptions may be at increased risk for depressive symptoms if their parents likewise experience significant IBD-induced lifestyle intrusions. Such evidence could provide clinically relevant information regarding the contribution of parents' experience of IBD intrusiveness to youth adjustment, which could have implications for comprehensive management of youth and parent responses to IBD.

The purpose of the present study was to: 1) examine the indirect role IBD severity plays in youth depressive symptoms as a function of youths' experience of IBD

intrusiveness; and 2) examine the potential moderating effect of parent IBD intrusiveness on the association between IBD severity, youth intrusiveness, and depressive symptoms. Both mediation and moderated mediation analyses were performed to examine youth IBD intrusiveness as a mediator in the association between IBD severity and youth depressive symptoms (i.e., IBD severity → youth intrusiveness → youth depressive symptoms), and to examine the potential moderating influence of parent IBD intrusiveness in these associations.

CHAPTER II

METHOD

Participants and Procedures

Participants included 119 adolescent-parent dyads recruited from a pediatric gastroenterology clinic located within a large children's hospital in the southwestern US. Youth diagnosed with IBD were between the ages of 13 and 18 years, with an average duration of illness of 2.49 years (*SD* = 2.42). Parents ranged in age from 32-77 years (M_{age} = 44.24, *SD* = 7.24) and were primarily female (see Table 1 for complete sample description).

Eligible participants diagnosed with IBD were identified by a pediatric gastroenterologist and were included if: (a) youth were between 13 and 18 years; (b) neither youth or parents had documented cognitive deficits; and (c) both youth and parents were fluent in English. Of the 123 dyads approached to participate, 119 consented to take part in the study (97% participation rate), and complete data were gathered on all 119 participants (100% completion rate). The research protocol followed APA guidelines and was approved by the hospital Institutional Review Board. After obtaining written informed consent and assent, youth and their parents completed self-report measures separately. Physicians provided ratings of disease severity. After completing the questionnaire packets, participants were compensated with $20.

Measures

A 24-item *Background Information Questionnaire* was administered to caregivers to obtain demographic information (e.g., child age, marital status, family income, and race/ethnicity). Medical chart reviews also gathered disease information such as current medications and illness duration.

Physician's Global Assessment. The Physicians Global Assessment (PGA) was used to evaluate disease severity. The PGA was completed by the attending pediatric gastroenterologist on a scale from 0-3 (i.e., quiescent, mild, moderate, and severe), with higher scores indicating greater IBD severity. The Physicians Global Assessment has been utilized in numerous pediatric IBD studies (Carreon et al., 2018; Plevinsky et al., 2018), and has shown to be reliably associated with measures of CD and UC activity (e.g., Pediatric Crohn's Disease Activity Index, Pediatric Ulcerative Colitis Activity Index; Hyams et al., 2005; Turner et al., 2009).

Illness Intrusiveness Scale-Child (IIS-C; Wagner et al., 2003). Youth completed the IIS-C to measure the extent to which their illness disrupts their ability to engage in routine and rewarding activities, such as school, family, friends, and extracurricular activities. Youth rated each of twelve items (e.g., "Rate how much your illness or its treatment interferes with activities outside of school") on a Likert scale (0 = "does not apply to me" to 7 = "a lot"). Items were summed to create a total score, with higher scores indicating greater illness intrusiveness. The IIS-C has demonstrated good internal reliability in other pediatric chronic illness populations (Bonner et al., 2015; Ramsey et al., 2014) and in youth with pediatric IBD (Roberts et al., 2019). Internal consistency in the current study was .88.

Illness Intrusiveness Scale-Parent (IIS-P; Andrews et al., 2009). Parents completed the 13-item IIS-P to assess illness-induced intrusions associated with their child's illness across multiple lifestyle domains (e.g., work, family/leisure, social). Parents rated items (e.g., "Rate the extent to which your child's illness interferes with relationships with other persons") on a 1-7 scale, ranging from "a little" to "a "lot." Items were summed for a total score; higher scores indicated greater parent illness intrusiveness. The IIS-P has established reliability in a number of pediatric chronic illness populations, including IBD (e.g., Fedele et al., 2012; Gamwell et al., 2016; Roberts et al., 2019). In the current sample $\alpha = .90$.

Children's Depression Inventory-2nd Edition (CDI-2; Kovacs, 2011). The CDI-2 is a 28-item measure used to assess youth depressive symptoms for the preceding two weeks. The severity of each depression-related item was rated by youth on a three-point scale from 0 to 2 (e.g., 0 = I feel like crying once in a while, 1 = I feel like crying many days, 2 = I feel like crying all the time). Items were summed, with higher scores indicating more severe depressive symptomatology. The CDI-2 has demonstrated good internal consistency in adolescents with IBD (Baudino et al., 2019). In the present study, Cronbach's alpha was $\alpha = .87$.

Data analytic plan

Preliminary analyses examined the rate of clinically elevated CDI-2 youth depressive symptoms. A series of bivariate correlations were also conducted to determine potential demographic (e.g., age, income) and disease (i.e., duration) covariates. Mean comparison *t-tests* examined differences in CDI-2 depressive symptoms by sex,

race/ethnicity, IBD subtype, and current medications. Variables significantly related to CDI-2 were used as covariates in the primary analyses.

Primary analyses employed bootstrapped mediation regression analysis to examine the direct associations between the modeled variables (i.e., IBD severity, youth illness intrusiveness, parent illness intrusiveness) and youth depressive symptoms, as well as the IBD severity → youth illness intrusiveness → depressive symptoms indirect path. Moderated mediation analysis examined the conditional (i.e., moderating) effect of parent illness intrusiveness on both the youth illness intrusiveness → depressive symptoms association and the conditional effect of parent illness intrusiveness on the IBD severity → youth illness intrusiveness → depressive symptoms indirect path (see Figure 1). Bootstrapped regression analyses were conducted via Hayes' PROCESS 3.2.01 Model 14 in SPSS using 95% confidence intervals yielded from 5,000 bootstrapped resampling draws with replacement (Hayes, 2018).

CHAPTER III

RESULTS

Preliminary analyses

Using general scoring guidelines (i.e., CDI-2 raw scores ≥ 14; Kovacs, 2011), approximately 21% ($N = 25$) of youth endorsed clinically elevated levels of depressive symptoms. Low levels of disease severity were observed on the PGA, with the majority of youth rated as having quiescent disease (see Table 1). Youths' mean scores and bivariate correlations for the study variables are shown in Table 2. Correlations revealed no potential demographic (i.e., age and income) or disease (i.e., duration) covariates significantly associated with youth CDI-2 depressive symptoms. Mean comparison *t*-tests indicated that CDI-2 scores did not differ by race/ethnicity, IBD type (UC or CD), nor were any CDI-2 differences observed for medication type (all *p's* > .05). However, CDI-2 scores differed by youth sex, with females ($M = 10.06$, $SD = 6.94$) endorsing higher levels of depressive symptoms than males ($M = 6.49$, $SD = 5.63$), $t(117) = 3.07$, $p = .003$. Thus, youth sex was included as a covariate in the primary analyses.

Primary analyses

Bootstrapped mediation regression analyses (see Figure 1) revealed significant direct effects for PGA → IIS-C (path $a = 3.64$; 95% CI = .15 to 7.13) and IIS-C → CDI-2 (path $b_1 = .17$; 95% CI = .09 to .25), controlling for youth sex. Neither PGA (path $c = -1.11$; 95% CI = -2.80 to .58) or IIS-P (path $b_2 = .10$; 95% CI = -.01 to .22) were significantly

associated with CDI-2 scores. More importantly, mediation analysis revealed a significant PGA → IIS-C →CDI-2 indirect effect (path ab_1 = .68; 95% CI = 0.03 to 1.65). Thus, although IBD severity was not directly associated with youth depressive symptoms, it conveyed an indirect effect on depressive symptoms through its impact on youth IBD intrusiveness.

Moderated mediation analyses revealed a significant IIS-C x IIS-P focal interaction effect on CDI-2 (path b_3 = .01; 95% CI = .01 to .02), indicating that a significant portion of the observed association between youth illness intrusiveness and depressive symptoms was conditional on (i.e., moderated by) the presence of elevated parents' illness intrusiveness. Post hoc analysis indicated that IIS-C had a significant effect on CDI-2 under conditions of high IIS-P (coefficient = .23; 95% CI = .14 to .33) but not low IIS-P (coefficient = .08; 95% CI = -.03 to .18) (see Figure 2). Further, similar to the focal moderation results for IIS-P, moderated mediation results indicated that the PGA → IIS-C → CDI-2 indirect association was significant under conditions of high (coefficient = .85; 95% CI = .02 to 1.83), but not low IIS-P (coefficient = .28; 95% CI = -.14 to .97). Thus, the indirect effect of IBD severity on youth depressive symptoms was also amplified for youth whose parents reported higher levels of intrusiveness.

CHAPTER IV

DISCUSSION

Youth with IBD are at increased risk for experiencing depressive symptoms, and IBD severity accounts for only a portion of youths' emotional difficulties. Because the pediatric literature has begun to highlight the intrusive nature of IBD (e.g., Baudino et al., 2021), the present study examined the mediating role of youth illness intrusiveness in the association between IBD disease severity and youth depressive symptoms. Further, given the transactional nature of youth and parent influences on youth adjustment outcomes in IBD (e.g., Baudino et al., 2019; Guilfoyle et al., 2014; Roberts et al., 2019), we examined the moderating influence of parent illness intrusiveness on these associations. Collectively, mediation and moderated mediation results suggest that youth who experience more IBD-induced activity disruptions in response to increased disease severity may be at risk for depressive symptoms, and parents' concomitant experience of IBD intrusiveness amplifies this risk.

The present findings are consistent with behavioral conceptualizations of depression, which posit that depressive symptoms can arise when environmental changes result in decreased availability of potential reinforcers in the environment, avoidance of aversive stimuli, and subsequent social withdrawal (Carvalho & Hopko, 2011; Lewinsohn, 1974). We suspect that periods of increased IBD disease activity likely pose significant disruptions in youths' ability to engage in routine and positively valued

activities (e.g., Carreon et al., 2018; Gray et al., 2011; Guilfoyle et al., 2014). Further, given the stigmatizing nature of IBD symptoms, youth may actively avoid a variety of situations in an attempt to limit their exposure to aversive social experiences (e.g., Gamwell et al., 2018, 2020; Roberts et al., 2020). The net effect of these circumstances (together or in isolation) is the potential for IBD-induced intrusions to impede youths' participation in a host of activities, resulting in a narrowed range of environmental reinforcement, decreased access to positive social engagement, and ultimately depressive symptoms. It is important to note that such diminished opportunities for social reinforcement may be particularly detrimental to adolescents' emotional functioning, given the critical role of peer relationships in adolescents' social and emotional development (e.g., Carter et al., 2015).

Our results are also consistent with observations in the literature that IBD can impede parents' involvement in routine and enjoyable activities (e.g., Guilfoyle et al., 2014). Further, our findings indicate that parents' experience of lifestyle intrusions amplified the effect of youth intrusiveness on youth depressive symptoms. However, our data do not tell us how parents' intrusiveness operates to influence the youth intrusiveness → depressive symptoms association. Several authors have suggested that IBD restrictions on parents' discretionary family and leisure time, and their avoidance of potentially stigmatizing social situations may have the unintentional effect of further limiting their child's opportunities for positive social engagement and rewarding activities (e.g., Baudino et al., 2021; Roberts et al., 2019). Such additional limitations on/access to environmental and social reinforcement may compound youths' existing sense of IBD intrusiveness, thereby increasing their risk of experiencing depressive

symptoms.

Clinical implications

Our results have a number of clinical implications. First, the rate of clinically elevated depressive symptoms observed in our sample highlights the need for routine depression screening for youth with IBD, particularly adolescents (Mackner et al., 2020). Further, existing cognitive-behavioral therapy (CBT) programs for adolescents with IBD have produced positive treatment effects for depression (Szigethy et al., 2004; 2007), indicating that the cognitive and behavioral impacts of IBD on youth depressive symptoms are modifiable. Relevant to the present findings, these programs address maladaptive IBD perceptions and emphasize behavioral activation strategies that encourage youth to maintain engagement in routine and positively valued activities to reduce the risk of depressive symptoms (see Carvalho et al., 2011). Also, our findings suggest that parents' experiences of their child's IBD need to be taken into consideration to adequately address youth adjustment challenges. Indeed, family-based CBT interventions that address both youths' and parents' IBD-specific appraisals and coping skills have demonstrated positive effects on parents' responses to IBD symptoms and youths' health-related quality of life and depressive symptoms (e.g., Levy et al., 2016).

Limitations

Several limitations qualify the present results. First, our findings are based on a relatively homogeneous sample of adolescents comprised largely of White middle- to upper-class families, and may not apply to younger children or youth from more diverse ethnic and socioeconomic backgrounds. Further, youth and parent variables were collected via self-report measures, which increases common method variance concerns (e.g., Holmbeck et al., 2002). However, because we independently gathered multi-

informant data (e.g., physician, youth, and parent), it is unlikely that the observed results were exclusively an artifact of measurement method. We also did not assess additional aspects of IBD (e.g., functional disability, school absences; Mackner et al., 2012; Walter et al., 2016) or other psychosocial variables related to youth depressive symptoms (e.g., stigma, parent distress; Baudino et al., 2021; Loreaux et al., 2015). Thus, our findings do not constitute a complete picture of youths' depressive symptoms, but rather an illustration of the central role of IBD-induced intrusiveness in youths' adjustment outcomes. Finally, the cross-sectional nature of our study limits the temporal interpretation of our results (see Maxwell & Cole, 2007). For example, it could be argued that pre-existing youth depressive symptoms had an exacerbating effect on IBD activity (see Reed-Knight et al., 2017) and subsequent illness intrusiveness. Although the absence of a direct association between IBD severity and youth depressive symptoms in the present study makes this an unlikely interpretation of our data, future prospective studies could help disambiguate the temporal nature of these associations.

Summary and Future Directions

The present findings highlight the risk of depressive symptoms in youth with IBD and emphasize the contribution of IBD-induced intrusions to youth emotional adjustment challenges. Our results also serve as a reminder of the complex interplay between youths' and parents' experience of IBD in determining youth adjustment outcomes. In addition to prospective designs, future studies examining the impact of illness intrusiveness on youth adjustment would benefit from investigating other parent (e.g., parenting stress) and disease variables (e.g., functional disability). Studies of this nature could potentially identify youth whose experience of intrusiveness and subsequent emotional difficulties

are largely due to the physical limitations imposed by IBD, versus youth whose experience of IBD intrusions may be determined more by subjective youth and parent illness perceptions. A better understanding of the multiple influences on youth depressive symptoms could guide intervention strategies aimed at reducing the impact of IBD on youth emotional difficulties.

CHAPTER V

REVIEW OF THE LITERATURE

The current chapter consists of a review of the literature for the proposed study. The review includes a description of pediatric inflammatory bowel disease, otherwise referred to as IBD. The chapter covers the different types, incidence, treatment regimens, and common symptoms of IBD. The review then examines psychosocial adjustment in the pediatric IBD population. Illness appraisal variables are also described across the pediatric chronic illness literature, including pediatric IBD. The primary variables of interest include *disease severity, perceived illness intrusiveness, and youth depressive symptoms* in youth with IBD. Lastly, this chapter will close with a summary of the current study and its aims.

Pediatric Inflammatory Bowel Disease

Inflammatory bowel disease (IBD) is comprised of a group of chronic autoinflammatory diseases of the gastrointestinal tract, such as Crohn's disease, ulcerative colitis, and indeterminate colitis. In the United States, IBD is the most widespread chronic gastrointestinal condition in youth, with around 45,000 to 100,000 children and adolescents currently facing the disease, and approximately 10,000 new cases diagnosed each year (Saeed & Kugathasan, 2017). Crohn's disease, ulcerative colitis, and indeterminate colitis can occur at any age; however, the peak onset of IBD is typically during the adolescent years (Benchimol et al., 2011). Recent literature suggests

that nearly one third of all IBD diagnoses occur during childhood years, and over half of total cases are diagnosed between 10-14 years of age (Day et al., 2012; Mamula et al., 2017).

Ulcerative Colitis

Ulcerative colitis is characterized by continuous inflammation of the rectal and colonic mucosa, affecting the rectum and large intestine continuously (Da Silva et al., 2014). Ulcerative colitis is typically characterized by the location of ulceration (e.g., colon, rectum). Symptoms of ulcerative colitis typically include lower abdominal cramping, diarrhea, fatigue, and blood in stool depending on disease severity (Head & Jurenka, 2004). The wide range of observable characteristics of pediatric ulcerative colitis has made the prediction of the disease course difficult (Mamula et al., 2013). The clinical course of ulcerative colitis is characterized by phases of active disease and remission, which can occur suddenly or in response to treatment (Da Silva et al., 2014). Pediatric ulcerative colitis affects males and females at a similar rate, unlike Crohn's disease (Sauer & Kugathsasan, 2009). The prevalence of ulcerative colitis has continued to rise in recent years, primarily in developing nations (Da Silva et al., 2014). Ulcerative Colitis impacts approximately 2/100,000 individuals aged 1-17 years in the United States alone (Kugathasan et al., 2003).

Crohn's Disease

Crohn's disease is a chronic disease of the gastrointestinal tract that can affect anywhere from the mouth to anus, although typically causes inflammation of the small colon and small intestine (Loftus et al., 2004). Most people with Crohn's disease suffer from a disease subtype known as ileocolitis. This type of Crohn's disease is due to

inflammation of the lower part of the colon and small intestine, known as the ileum. There are four other types of Crohn's disease that are less common and exhibit different symptoms (i.e., ileitis, gastroduodenal Crohn's disease, jejunoileitis, granulomatous). No cure exists for Crohn's disease or any of its subtypes, nor have any etiological factors been discovered (Head & Jurenka, 2004). Literature has shown a considerable variation in the reported prevalence of Crohn's disease. In North America, it has been reported that between 400,000 and 600,000 patients suffer from Crohn's disease (Loftus et al., 2004). Crohn's disease impacts approximately 4.5/100,000 individuals aged 1-17 in the United States alone (Kugathasan et al., 2003). In previous research, it was believed that Crohn's disease was more common among Caucasians with European Jewish descent (Head & Jurenka, 2004; Smolen & Topp, 1998); however, there is also evidence to suggest that Crohn's disease is not constrained to that specific demographic populations (Ballinger et al., 2003, Baron, 2002; Ferry, 1999; Marx & Seidman, 1999).

Indeterminate Colitis

Indeterminate colitis is an "unknown" type of inflammatory bowel disease. This type of IBD is diagnosed when the colitis does not meet the criteria for ulcerative colitis or Crohn's disease, or when the physician cannot make a definite diagnosis (Geboes, 2008). A diagnosis for indeterminate colitis is typically given after a physician implements an all-inclusive assessment and the patient still does not meet diagnosis fully for either ulcerative colitis or Crohn's disease. Typically, 23% of youth recently diagnosed with IBD are given an indeterminate colitis diagnosis. However, after symptoms develop further, 60% of those youth are diagnosed with Crohn's disease or

ulcerative colitis. Subsequently, a diagnosis of indeterminate colitis is given to roughly 10-15% of IBD patients (Head & Jurenka, 2004).

There is currently no known cause or cure for IBD. However, existing research suggests that genetic influences (e.g., disruption of mucosal barriers, aberrant inflammatory signals, loss of tolerance) and environmental influences such as infections, diet, and adverse risk factors (Loftus et al., 2004; Peloquin et al., 2016; Wei et al., 2013) may be related to the origin of the disease. Treatment goals are geared toward managing the illness by reducing inflammation and symptoms in order to maintain remission. Remission in IBD is the absence of symptoms (e.g., bloody stool, diarrhea, abdominal pain). Treatment in IBD populations usually consists of medication regimens, diet restrictions, and surgical intervention (Bernick & Kane, 2011; Mamula et al., 2017). Surgical interventions typically include partial resection of the gastrointestinal tract where the disease has spread. Surgical treatments can improve remission rates by decreasing illness symptoms, depending on the type of IBD (Head & Jurenka, 2004). However, more recent literature suggests that the rate of surgery has continued to decrease as non-invasive treatments continue to improve (Jakobsen et al., 2011; Qualia, & Bousvaros, 2013).

Medication treatments in IBD often consist of non-steroidal anti-inflammatory, immunosuppressants, biologic agents, and corticosteroid treatments. Unfortunately, corticosteroid treatments have been linked to bone growth issues in youth, consequently leading to physical development difficulties (Mushtaq & Ahmed, 2002). There have also been adverse side effects found in the use of biologics in IBD patients, especially when used in combination with classical immunosuppressive agents (Stallmach et al., 2010).

Side effects include malignancies, acute infectious disease, heart failure, and miscellaneous complications due to injection or infusion reactions (Stallmach et al., 2010).

Primary symptoms of IBD include recurrent inflammation of the gastrointestinal tract which can lead to unpleasant symptoms such as bloody stools and diarrhea (Day et al., 2012). Secondary symptoms typically consist of unintended weight loss, fatigue, and severe abdominal pain (Mamula et al., 2008). Anemia, thrombocytosis, and leukocytosis are commonly found in up to half of IBD patients (Rabizadeh & Olivia-Hemker, 2008). Although ulcerative colitis and Crohn's disease share symptoms, there are some differences in clinical indicators. However, because of the variability in clinical course within the two disease subtypes, few features reliably distinguish ulcerative colitis and Crohn's disease (Varni et al., 2015).

Proposed Variables

Psychosocial Outcomes

In the pediatric literature, psychosocial outcomes typically refer to behaviors, relationships, social interactions, feelings, and social cognition (Abda et al., 2019).

As a result of the symptoms that accompany many chronic illnesses, psychosocial outcomes are often examined as outcomes and are often targets of interventions (Drotar, 2006). Due the invasive symptoms that IBD presents, youth are at an increased risk of experiencing problems with social and emotional functioning (Mackner et al., 2004; Mackner et al., 2012). Thus, it is important to broaden the literature regarding psychosocial outcomes in this population. Although some studies have examined other psychosocial variables such as embarrassment, school functioning, and social

relationships (e.g., Carter et al., 2015; Greenley et al., 2012; Mackner, et al., 2012), the current IBD literature primarily focuses on depressive symptoms as outcomes for these youth (Clark et al., 2014; Gamwell et al., 2018; Greenley et al., 2010; Keethy et al., 2014; Reed-Knight et al., 2018).

Depressive Symptoms. Previous IBD literature offers findings that indicate that youth with IBD do indeed experience heightened levels of depressive symptoms when compared to healthy youth. For example, Clark et al., (2014) examined 550 youth ages ranging from 9 to 17 years diagnosed with Crohn's disease exclusively and indicated 22% of these youth scores endorsed clinically significant depressive symptoms. Szigethy et al. (2004) examined a sample of 102 youth with ages ranging from 11 to 17 years diagnosed with IBD and found that twenty-five (24.5%) had clinically significant depressive symptoms. Further, Mackner & Crandall, (2006) examined a comparison group of 50 youth with IBD and 42 healthy youth and found that youth with IBD reported to have worse anxiety and depressive symptoms than that of their healthy cohort. More recently, Baudino et al. (2018) examined a sample of eighty-five youth ranging from 13 to 18 years old diagnosed with IBD. In this study, authors discovered that twenty-two (25.8%) youth had a CDI-2 score consistent with clinically significant depressive symptoms.

There is also literature that suggests youth with IBD face higher rates of depressive symptoms when compared to other pediatric chronic illness groups (Keethy et al., 2014). For example, Burke et al., (1989) examined a group of 41 children with Crohn's disease, 12 children with ulcerative colitis, and 52 children with cystic fibrosis and found that youth with Crohn's disease and ulcerative colitis were more likely to

develop depression and anxiety disorders than youth with cystic fibrosis. Further, Engstrom (1992) examined a group of 20 youth with IBD, 20 youth with diabetes, and 20 healthy youth in a comparison study. In this study, findings indicated that 60% of children and adolescents with IBD experience depressive symptoms compared with 15% of healthy controls and 20% of youth with diabetes. More recently, in a meta analytic review of 19 studies, Greenley et al., (2010) found that youth with IBD are at a higher risk for depressive disorders than youth in other chronic illness populations (i.e., cystic fibrosis, diabetes, GI disorder, chronic headache, cancer). Depressive symptoms in IBD have also been shown to have a detrimental impact on IBD management. For example, Patel et al., 2019 examined a pediatric inpatient database in the United States consisting of 4,179 hospitals across 44 states. In a sample of 8,222 adolescents, authors found that depression relates to increased length of stay in the hospital, increased risk of blood transfusion, increased abdominal imaging, and likelihood for surgical procedures. Recent studies have recognized the need to address depressive symptoms and management in youth with IBD. For example, Mackner et al., 2020 aimed to establish clinical guidelines for depression screening due to the found impact that depression has on the physical and mental health of these youth. Although depressive symptoms tend to be the primary focus in the IBD literature, further research is needed to better understand its precursors and other mechanisms involved in the development of depressive symptoms in the pediatric IBD population.

Disease Severity. In pediatric IBD, disease is characterized as being in an active or remissive state. Active disease occurs when patients have symptoms such as abdominal pain, internal swelling, bleeding, and diarrhea, whereas remission occurs when

patients do not experience symptoms (Reed-Knight et al., 2014). Disease severity often refers to the extent to which those symptoms appear. Because of the unpredictable and severe symptoms of IBD, disease severity has been commonly examined as a key factor in the literature (e.g., Clark et al., 2014; Mackner et al., 2012; Herzer et al., 2011; Schuman et al., 2013; Varni et al., 2017). Disease severity is often examined via disease activity specific measures (e.g., Pediatric Crohn's Disease Activity Index [PCDAI], Pediatric Ulcerative Colitis Activity Index [PUCAI]; Hyams et al., 2005; Turner et al., 2009) or through a physician's global assessment (PGA; Carreon et al., 2018; Plevinsky et al., 2018; Ryan et al., 2013) which is a combined measure of IBD severity that is not disease specific. The presence of IBD symptoms and its treatment impact youth beyond physical health challenges. For example, Gray et al. (2011) examined a group of 62 adolescents with IBD and found that greater disease severity, externalizing symptoms, and internalizing symptoms were all independently associated with lower health related quality of life. Higher disease severity has been linked to other numerous negative psychosocial outcomes for youth with IBD (e.g., unpredictability, uncertainty, family stress; Guilfoyle et al., 2014; Reed Knight et al., 2018; Varni et al., 2017).

Disease severity is more commonly examined as it relates to depressive symptoms in the IBD literature (Guilfoyle et al., 2014; Reed-Knight et al., 2018; Varni et al., 2017). There have been inconsistent findings reported in the literature linking disease severity and depressive symptoms in youth with IBD. For example, there is literature to suggest that youth with higher disease activity do not exhibit negative adjustment or clinically elevated depressive symptoms (Burke et al., 1990; Herzog et al., 2012; Szigethy et al., 2004; Van der Zaag-Loonen et al., 2004; Walter et al. 2016; Wood et al.,

1987). However, disease severity has been linked to numerous psychosocial outcomes including depressive symptoms in other pediatric IBD studies (Clark et al., 2014; Gamwell et al., 2018; Gray et al., 2013; Guilfoyle, 2014; Shuman et al., 2013, Szigethy et al., 2004). These inconsistent findings suggest that there are intervening factors at play in the relationship between disease severity and depressive symptoms in these youth that may better explain this relationship. Indeed, recent literature suggests that the link between IBD severity and adjustment difficulties include a variety of psychosocial factors.

Illness Appraisals

Illness appraisals encompass the impact of an illness on an individual's health through their own subjective meaning of their illness. Appraisals may include perceptions, experiences, and interpretation of the illness and its symptoms (Fife, 1994; Leventhal et al., 1984). Illness appraisals have been examined across numerous pediatric chronic illness populations (e.g., cancer, diabetes, sickle cell anemia, cystic fibrosis, epilepsy, congenital heart diseases; Davis et al., 1998; Mullins et al., 2016; Nguyen et al., 2015; Thompson et al., 1998; Wiebe et al., 2005). Many studies have demonstrated the importance of examining cognitive appraisals, which are the individuals understanding of a situation that ultimately affects the extent to which the situation is perceived (Lazarus, 1991). Cognitive appraisals are often valued as they relate to emotional adjustment. Multiple cognitive appraisals have been examined in youth with IBD (e.g., uncertainty, stigma, intrusiveness, Baudino et al., 2018; Gamwell et al., 2018; Gamwell et al., 2020; Roberts et al., 2019; Roberts et al., 2020). In the IBD literature specifically, studies have examined illness appraisals in relation to depressive symptoms. For

example, Gamwell et al. (2018) demonstrated the role of perceived stigma and thwarted belongingness as they relate to depressive symptoms in a sample youth with IBD and found that illness stigma does indeed negatively impact social belongingness and depressive symptoms of youth. Roberts et al., 2019 replicated and extended these findings, in a group of 75 youth diagnosed with IBD by demonstrating that health communication difficulties mediates the relationship of stigma and thwarted belongingness. Baudino et al., (2018) examined the role of illness uncertainty of youth as it pertains to youth depressive symptoms in a sample of 85 youth diagnosed with IBD. Findings suggested that youth illness uncertainty did play a role in elevated depressive symptoms in this sample. Although these studies have highlighted the importance of understanding the role of illness appraisals and their relation to depressive symptoms, further research on more illness symptom specific appraisals are needed to understand the disruptions that IBD may lead to.

Illness Intrusiveness. In other chronic illness populations, one illness appraisal that is commonly attributed to disruptions and negative outcomes is known as illness intrusiveness. Illness intrusiveness refers to the feelings of disruption in the daily function and activities due to illness (Gray et al., 2011; Guilfoyle et al., 2014). Devins et al., (2001) indicated that among other chronic illness populations, people experience personal demands other than health difficulties such as work, recreational activities, social relationships, and community involvement, that can interrupt time that could be spent in other routine or rewarding activities.

Although there are a number of studies in the pediatric literature examining illness intrusiveness across various disease types, the majority cover illness intrusiveness as it

relates to the caregiver adjustment (Andrews et al., 2007; Andrews et al., 2009; Fedele et al., 2012; Prikken et al., 2020, Welkom, 2012). However, there are some studies that examine illness intrusiveness is related to youth adjustment in the juvenile renal disease (JRD) literature. For example, Bonner et al. (2015) examined the impact of illness intrusiveness in a sample of 45 youth diagnosed with JRD. Their research indicated that elevated youth perceptions of illness intrusiveness ultimately increased youth depressive symptoms. Further, Ramsey et al. (2014) examined illness intrusiveness, barriers to care, and depressive symptoms in 66 youth diagnosed with JRD. Authors found that child perceived illness intrusiveness mediated the relationship of barriers to care and depressive symptoms. Findings supported the illness intrusiveness theoretical framework model in that the impact of disease differed across the different life domains and contextual factors. Thus, there is an overwhelming amount of literature suggesting that perceived illness intrusiveness plays an important role in the adjustment of those with chronic conditions. Although illness intrusiveness has been examined in a number of the populations mentioned above, only one known paper has examined illness intrusiveness in the pediatric IBD population.

Roberts et al. (2019) examined a group of 107 youth ages 10 to 18 years old with IBD and their caregivers. In this sample, 58 were diagnosed with Crohn's disease, and 49 were diagnosed with ulcerative colitis. The majority (73%) of the participants in this study were Caucasian. In this study, authors aimed to examine the influence of youth perceptions of illness uncertainty and illness intrusiveness on youth adjustment outcomes. Authors used Physicians Global Assessment (PGA) to measure youth's disease activity and severity. In this study, disease severity was not directly associated with depressive

symptoms. However, was indirectly associated through the cognitive appraisal variables. This study emphasized the transactional nature of illness appraisals and adjustment in the pediatric IBD literature; however, further research is needed to examine the relationship between disease severity and illness intrusiveness as that relates to adjustment in this population.

Illness intrusiveness may be an important intermediary variable that explains the link between disease severity and youth depressive symptoms in the IBD population. Devins et al. (1983) defines "illness intrusiveness" as a subjective view of "illness-induced barriers" across life domains such as family, work, and social connections. Perceived illness intrusiveness may become problematic in the pediatric IBD population when these intrusive feelings lead to decreased involvement in routine and rewarding activities. In the IBD literature specifically, it has been suggested that intrusions that youth experience influence their adjustment to their diagnosis of IBD (Mackner et al., 2013). Further, Fishman et al. (2010) examined a cohort of ninety-four youth diagnosed with IBD and found that IBD was associated with disruptions in school and social activities. There is a need to examine disease severity and how it relates to the adjustment of youth with IBD, specifically regarding perceived feelings of illness intrusiveness. Due to the numerous studies demonstrating the relationship of disease severity and adjustment in youth with IBD and between illness intrusiveness and adjustment across chronic conditions (Fishman et al., 2010; Gray et al., 2011; Guilfoyle et al., 2014; Mackner et al., 2013; Mullins et al., 2017; Mullins et al., 2001), findings highlight the need for the examination of disease severity and youths' perceptions of illness intrusiveness and how it is associated with negative psychosocial outcomes in this population.

Summary

Inflammatory bowel disease (IBD) consists of a group of autoinflammatory diseases that includes Crohn's disease, ulcerative colitis, and indeterminant colitis. IBD symptoms include diarrhea, bloody stools, and frequent bathroom use. In the IBD literature, there have been inconsistent findings linking disease severity and psychosocial outcomes, such as depressive symptoms. Although there have been multiple studies examining illness appraisals in pediatric chronic illness populations, studies examining illness intrusiveness are largely absent from the literature. It is likely that when youth experience greater disease severity, they perceive IBD as disruptive or intrusive to their daily functioning, which has been related to negative psychosocial outcomes. Illness intrusiveness may serve an intermediary link between disease severity and depressive symptoms in the pediatric IBD population.

The purpose of the current study is to examine the potential influence of illness intrusiveness in the relationship between disease severity and depressive symptoms in a sample of youth with IBD. It is hypothesized that youth who perceive their illness as intrusive due to higher disease activity experience heightened levels of depressive symptomology (i.e., *disease severity → illness intrusiveness → depressive symptoms).*

The Proposed Study

The aim of the present study is to add to relevant findings in the pediatric IBD literature by investigating a mediation model that examines the *disease severity → illness intrusiveness → depressive symptoms* relation. It is suspected that the intrusive nature of IBD and its symptoms negatively impacts youths' ability to engage in routine and rewarding activities, which in turn contributes to increased depressive symptoms.

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APPENDICES

APPENDIX A

Table 1. Descriptive sample statistics ($N = 119$)

Variable	*M*	*SD*	Frequency	Percent
Age	15.55	1.55		
Child Sex				
Female			62	52.1
Male			57	47.9
Child Ethnicity				
White			80	67.2
Native American			10	8.4
Black			8	6.7
Hispanic			5	4.2
Other			16	12.6
Disease Type				
Ulcerative Colitis			52	43.7
Crohn's Disease			67	56.3
Disease Severity				
Quiescent			89	74.8
Mild			17	14.3
Moderate			12	10.1
Severe			1	0.8
Prescribed Medication				
Aminosalicylates			44	37.0
Steroids			47	39.5
Immunosuppressant/Anti-metabolites and Biologic agents			71	59.7
Caregiver Type				
Mother			94	79.0
Father			20	16.8

Grandmother	2	1.7
Adoptive Mother	1	0.8
Adoptive Father	1	0.8
Other	1	0.8

Table 2. Correlations and means for study variables

Variables	1	2	3	4	5	6	7	*M*	(*SD*)
1. Child gender	—								
2. Child age	.14	—							
3. Income	.13	-.03	—						
4. Illness Duration	.04	.17	.23*	—					
5. PGA	-.22*	-.05	-.08	-.16	—			.37	.70
6. IIS-C	-.22*	.08	-.04	-.17	.23*	—		15.99	13.53
7. IIS-P	-.10	.14	-.16	-.09	.47**	.31**	—	19.71	9.95
8. CDI-2	-.27**	-.06	-.09	.08	-.05	.39**	.18*	8.35	6.56

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

APPENDIX B

Figure 1. Moderated mediation model.

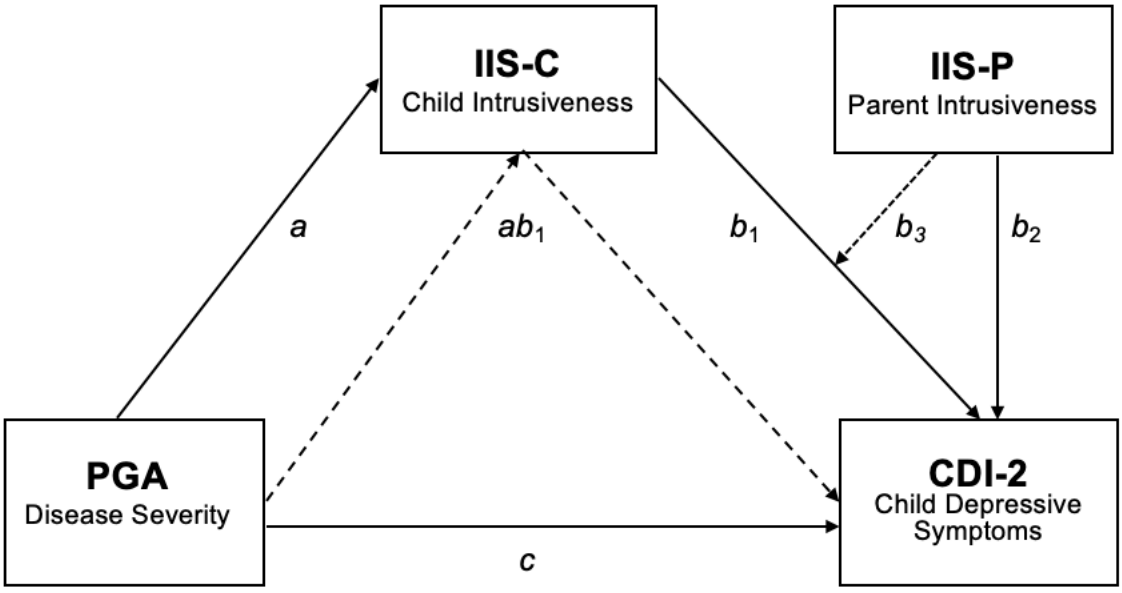
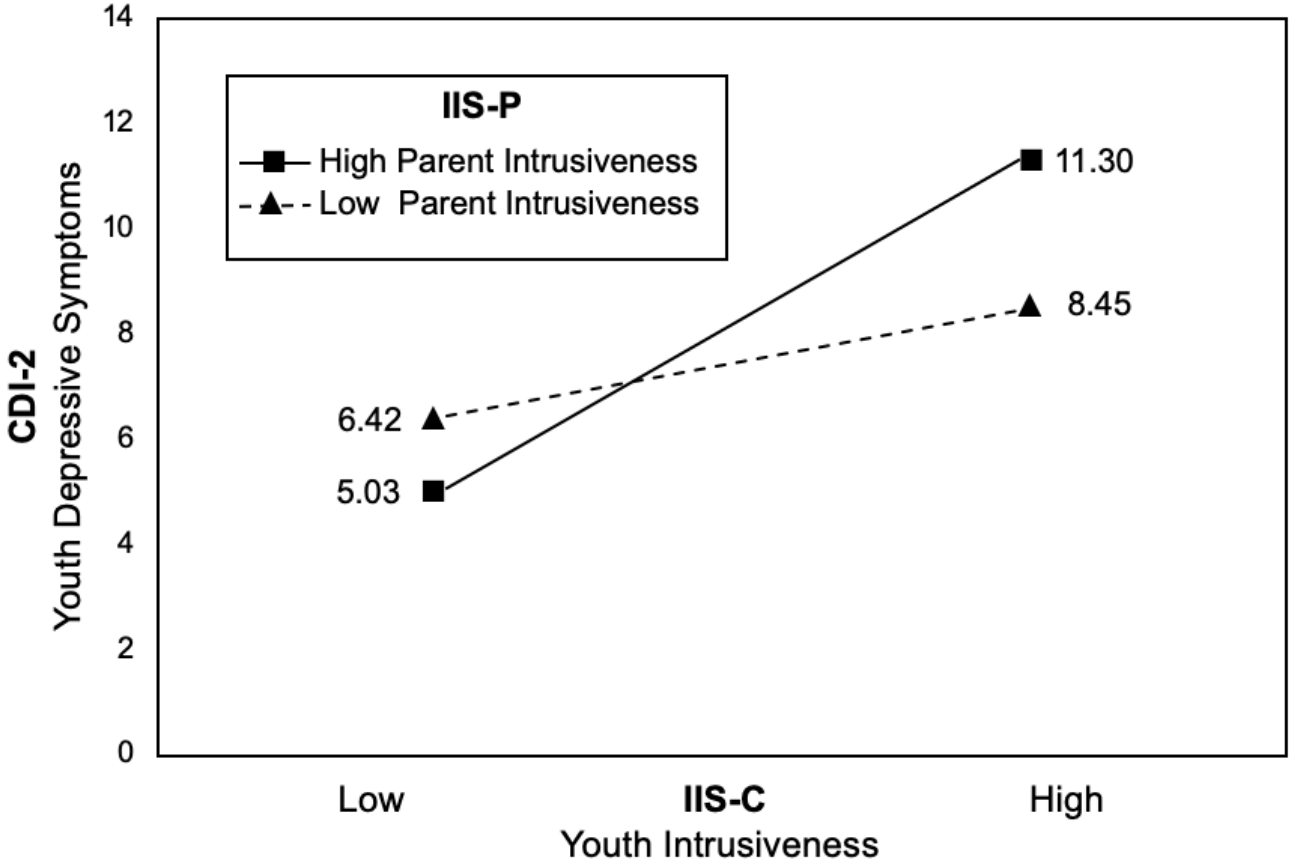


Figure 2. Focal interaction of youth intrusiveness x parent intrusiveness on youth depressive symptoms.



APPENDIX C

Institutional Review Board for the Protection of Human Subjects

Continuing Review – Expedited Approval

Date: September 27, 2019 **IRB#:** 5856
Approval Date: 09/27/2019

To: Noel Jacobs, Ph.D. **Expiration Date:** 08/31/2020

Study Title: Parent and Child Psychological Adjustment in Pediatric Inflammatory Bowel Disease **Study Status:** Pre RCR | Active - Open - Expedited
Reference Number: 694917

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. **As part of this approval, future continuing review is required and must be approved prior to the expiration date indicated above.**

The approved modification that was submitted with this Continuing Review is: Update application to new template

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 research study.

Study documents associated with this submission are listed on page 2 of this letter. To access the submission forms and study documents approved for this submission, log in to iRIS and go to *My Studies*, click to open this study, and look under 'Protocol Items' to click on the current *Application*, *Informed Consent* and *Other Study Documents*. 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, Vice Chair Institutional Review Board

1105 N. Stonewall Avenue, Oklahoma City, OK 73117 (FWA0007961)

The study documents associated with this submission:

Study Document
Title Version # Version Date Outcome Last signed Consent Version 1.1 09/16/2019 Noted

Information for Industry Sponsors: the columns titled Version Number and Version Date are specific to the electronic submission system (iRIS) and should not to be confused with information included in the Document and/or Consent title(s).

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

Clayton Edwards

Candidate for the Degree of

Master of Science

Thesis: THE COMBINED EFFECTS OF YOUTH AND PARENT ILLNESS INTRUSIVENESS ON DEPRESSIVE SYMPTOMS

Major Field: Psychology

Biographical:

Education:

Completed the requirements for the Master of Science in Psychology at Oklahoma State University, Stillwater, Oklahoma in July, 2021.

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

Experience: Graduate Research Assistant from August 2019 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.