EXAMINING PARENT DISTRESS AND YOUTH RESPONSE TO STRESS AS MEDIATORS IN THE ASSOCIATION BETWEEN ILLNESS INTRUSIVENESS AND CHILD DEPRESSIVE SYMPTOMS IN YOUTH WITH INFLAMMATORY BOWEL DISEASE

By

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Abstract: **Objective:** To examine parent depressive symptoms and child response to stress as potential serial mediators in the relation between parents’ illness intrusiveness and child depressive symptoms in youth with inflammatory bowel disease (IBD) and their caregivers. **Methods:** Caregivers of youth with IBD completed measures of illness intrusiveness and depressive symptoms. Youth completed measures of response to stress and depressive symptoms. Pediatric gastroenterologists provided estimates of disease activity. **Results:** Bias-corrected bootstrapped confidence intervals revealed a non-significant illness intrusiveness → parent depressive symptoms → response to stress → child depressive symptoms serial mediation path. However, results revealed a significant illness intrusiveness → response to stress → child depressive symptoms indirect path. **Conclusions:** Results provided partial support for the notion that heightened levels of illness intrusiveness have an impact on youths’ perceptions of parents’ stress, resulting in increased child depressive symptoms. However, the present findings suggest that illness intrusiveness does not operate through parent depressive symptoms. Although speculative, it may be that other parent adjustment variables (e.g., parenting stress) may play a role in the association between parent-perceived illness intrusiveness and child adjustment outcomes.
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CHAPTER I

INTRODUCTION

Inflammatory bowel disease (IBD) is a broad term that is used to describe a group of inflammatory diseases that are characterized by intermittent and chronic abdominal pain that is associated with inflammation of the digestive track (Szigethy, McLafferty, & Goyal, 2010). IBD represents three autoimmune disorders: ulcerative colitis, Crohn’s disease, and indeterminate colitis (Kappelman, Moore, Allen, & Cook, 2013; Loftus, 2004). The precise cause of IBD remains largely unknown, however, research suggests that environment and genetic factors contribute to its development (Kugathasan et al., 2003; Wei, Baldassano, & Hakonarson, 2013). The symptoms of IBD include abdominal pain, frequent diarrhea, weight loss, and fatigue (Szigethy et al., 2010). The goals of IBD management include reducing inflammation in the digestive track in order to minimize amounts of diarrhea, fatigue, and physical discomfort (Tamboli, 2007). Treatment regimens can vary depending on the type and severity of IBD, but typically include dietary restrictions, taking multiple medications (i.e., immunomodulatory and corticosteroids), and in severe cases, surgery (Szigethy et al., 2010). Approximately 62,000-100,000 youth in the United States are affected by IBD, and about 25% of new diagnoses each year are child or adolescent cases (Kappelman et al., 2013; Loftus, 2004).
Psychosocial Adjustment in Pediatric IBD: Depressive Symptoms

The unpredictable and chronic nature of IBD along with its burdensome and invasive treatment regimens pose difficult challenges for youth with IBD and place them at increased risk for experiencing psychosocial adjustment difficulties (Banez & Cunningham, 2003; Mackner, Crandall, & Szigethy, 2006; Mackner & Crandall, 2013; Schuman, Graef, Janicke, Gray, & Hommel, 2013; Szigethy et al., 2010). Much of the extant literature that has examined adjustment outcomes in youth with IBD suggests that this population is prone to experience elevated levels of depression and/or depressive symptoms (e.g., Mackner & Crandall, 2006; Shuman et al., 2013; Szigethy et al., 2004). Other research, however, has shown that youth with IBD exhibit levels of depressive symptoms that are comparable to their healthy peers and youth with other chronic illnesses (e.g., Herzog et al., 2012; Mackner & Crandall, 2005; Reed-Knight, Blount, & Gilleland, 2014). Although findings are mixed regarding the level of depressive symptoms that youth with IBD experience, numerous studies examining adjustment outcomes such as quality of life, medication adherence, and school functioning have found that depressive symptoms are related to those adjustment outcomes (Englemann et al., 2015; Herzer, Denson, Baldassano, & Hommel, 2011; Gray, Denson, Baldassano, & Hommel, 2012; Loreaux, Denson, & Hommel, 2015; Mackner, Bickmeier, & Crandall, 2012).

Because studies have found that depressive symptoms are often associated with adjustment outcomes in youth with IBD, research is needed to identify other variables that could play a key role in the development and variability of depressive symptoms in this population. As such, research in pediatric IBD has begun to identify potential variables that are determinates of depressive symptoms. Although parenting stress, socioeconomic status, and disease activity have been found to be predictive of depressive symptoms in youth with IBD (Clark et al., 2014; Guilfoyle, Gray, Herzer-Maddux, & Hommel, 2014), the literature has yet to fully explore other key variables that determine child depressive symptoms.
Parent adjustment and parent cognitive appraisal variables are two of the more robust predictors of youth emotional outcomes in the pediatric chronic illness literature (e.g., Chaney et al., 1997; Friedman, Holmbeck, Jandasek, Zukerman, & Abad, 2004; Ramsey et al., 2013; Ryan et al., 2010; Wagner et al., 2003). These findings embody the parent-child transactional stress and coping model (Thompson & Gustafson, 1996), which proposes that parent and child adjustment to a child’s chronic illness is dependent on the interaction of cognitive processes, illness parameters, and demographic variables. Interestingly, few studies have investigated how parent variables relate to child adjustment in youth with IBD. For example, parent depression has been shown to moderate the relationship between adolescent reported health related quality of life and depressive symptoms (Loreaux et al., 2015). Even fewer studies have examined the contribution of parent cognitive appraisals to youth emotional adjustment outcomes. Although parenting stress has been identified as a variable associated with youth internalizing and depressive symptoms in youth with IBD (Gray, Graef, Schuman, Janicke, & Hommel, 2013; Guilfoyle et al., 2014), it is the only parent cognitive appraisal variable that has been examined in this population. Further, the mechanisms by which parent variables may impact youth adjustment are unknown.

Given the findings across a number of childhood chronic illness populations documenting the role of parent appraisals in youth adjustment, more research is needed to fill this gap in the literature. Moreover, it would seem important to include illness-specific parent cognitive appraisals that may be relevant to the challenges inherent in having a child with IBD. The identification of parent appraisal variables related to child depressive symptoms could potentially inform clinical interventions aimed at reducing youth adjustment challenges.

**Illness Intrusiveness**

Research has shown that increased illness intrusiveness is significantly associated with decreased social emotional well-being (e.g., mental health, social role, sleep, physical functioning) in adults with irritable bowel syndrome (Dancey, Hutton-Young, Moye, & Devins, 2002). In the pediatric chronic illness literature, parent-reported illness intrusiveness has been
identified as a key variable that contributes to both parent distress and child depressive symptoms in other pediatric autoinflammatory diseases (e.g., juvenile rheumatic disease; Fedele et al., 2012; Gamwell et al., 2016). Successful management of pediatric IBD requires caregivers to assist with complicated medical regimens, attend numerous medical appointments, oversee nutritional modifications, and monitor disease symptoms (Greenley, Reed-Knight, Blount, & Wilson, 2013). The unpredictable course of IBD, arduous medical regimens, and intrusive nature of IBD may impede caregivers’ abilities to engage in routine social, family, or occupational activities.

Existing IBD literature has noted that “daily routines may also be disrupted [by IBD] due to unpredictable symptom exacerbations” (Gray et al., 2013). The invasive aspects of IBD and its treatment make illness intrusiveness particularly relevant when examining parent variables associated with child adjustment.

Illness intrusiveness refers to the extent to which an individual perceives an illness and its treatment as disrupting or interfering with involvement in valued interests and activities (Devins et al., 1983). Illness intrusiveness is conceptualized as a variable that connects subjective well-being and emotional distress to a disease and its treatment (Devins, Bezjak, Mah, Loblaw, & Cotowiec, 2006) and is theorized to stem from perceived “illness induced barriers” that prevent individuals from engaging in interests or usual activities in a variety of contexts (e.g., family, work, community involvement, religious expression; Devins et al., 1983; Mah, Bezjak, Loblaw, Gotowiec, & Devins, 2011). The main premise of the illness intrusiveness theory is that lifestyle disruptions impact psychosocial well-being in individuals with chronic illnesses 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, Seland, Klein, Edworthy, & Saary, 1993). Thus it may be that parents of youth with IBD experience significant disruptions or limitations in their daily routines as a result of the inherent, invasive nature of IBD and its treatment regimens (e.g.,
managing medications, caring for the child during a flare, monitoring diet). Furthermore, parents may respond to their child’s IBD management by limiting their involvement in pleasurable activities (e.g., occupational responsibilities, family outings), which could then have downstream effects on their psychosocial adjustment.

**Parent Distress and Youth Response to Stress**

Studies in the pediatric literature have consistently demonstrated that parental emotional adjustment is one of the most reliable predictors of child outcomes (e.g., Chaney et al., 1997; Ramsey et al., 2013), making it a variable of interest in examining of child adjustment outcomes. Findings in the extant pediatric IBD literature have produced mixed results regarding the emotional functioning in parents of youth with IBD. Some research suggests that parents of a child with IBD are likely to experience psychological distress and psychopathology (Szajnberg, Krall, Davis, Treem, & Hyams, 1993). Other findings indicate that parents of youth with IBD do not experience psychological distress that is significantly different from that of other adults (Greenley & Cunningham, 2009) or that psychological distress is only significantly different in mothers (Engstrom, 1991). Additionally, research suggests that mothers of youth with IBD are prone to have a history of depression or experience depressive symptoms (Burke, Kocoshis, Chandra, Whiteway, & Sauer, 1990; Burke et al., 1994). Regardless of which parent experiences depressive symptoms or the extent to which they experience depression, child depressive symptoms have been shown to be associated with parent depressive symptoms in youth with IBD (Loreaux et al., 2015). It is plausible, therefore, that it is the presence of parent depressive symptoms rather than the extent of symptoms that should be assessed in parents of youth with IBD.

Research in other pediatric chronic illness populations suggests that parent psychological functioning may be causally antecedent to child adjustment (Friedman et al., 2004; Ryan et al., 2010). It remains unclear, however, how parent psychological functioning leads to child adjustment, particularly child emotional functioning. Many studies hypothesize mechanisms
through which parent adjustment affects child adjustment (e.g., Chaney et al., 2016), but no studies to date have identified variables to explain how parent emotional adjustment affects child emotional adjustment. Exposure to stress in the family environment associated with parents’ depressive symptoms may be one way through which parental depressive symptoms increase the risk of youth depressive symptoms (Bettis et al., 2016). In parent-child interactions, the behavior of depressed parents is often characterized by intrusiveness and withdrawal, which contribute to an unpredictable family environment for youth (e.g., Jaser et al., 2005; Lovejoy, Graczyk, O’Hare, & Neuman, 2000). The unpredictable nature of interactions with depressed parents can cause youth to experience increased stress, which is associated with increased levels of internalizing problems in youth (Goodman & Gotlib, 1999). In youth of depressed parents, depressive symptoms in particular have been found to be associated with parental intrusiveness, withdrawal, and interparental conflict (e.g., Fear et al., 2009; Jaser et al., 2005). As such, it is suspected that youth with IBD who experience stress resulting from having a parent with depressive symptoms may be more likely to internalize that stress and exhibit depressive symptoms.

The Present Study

The present study examined parent depressive symptoms and youth response to stress as potential serial mediators in the relationship between parental illness intrusiveness and child depressive symptoms. Due to the invasive and restrictive aspects of IBD as well as its demanding treatment regimens, a model was proposed in which parent reported illness-intrusiveness acts as a primary antecedent that drives parental depressive symptoms, which youth perceive as stressful, and subsequently result in elevated youth depressive symptoms. It was hypothesized that results would reveal a significant parent illness intrusiveness → parent depressive symptoms → child response to stress → child depressive symptoms serial mediation path, in which parental depressive symptoms and response to stress would carry sequential indirect effects from parent illness intrusiveness to child depressive symptoms.
CHAPTER II

METHODOLOGY

Participants and Procedures

Parent-child dyads (N=105) were recruited from a pediatric gastroenterology clinic at a children’s hospital in the Southwest United States. Participants were youth between the ages of 10 and 18 who had a confirmed IBD diagnosis and their caregivers (see Table 1 for descriptive statistics). All procedures adhered to the American Psychological Association and Institutional Review Board Standards. Each parent-child dyad signed a consent and assent to participate in the study. Inclusion criteria for the study were as follows: (1) both caregiver and child were English proficient; (2) the child/adolescent had an IBD diagnosis that was confirmed by a pediatric gastroenterologist; (3) the child/adolescent was between 10-18 years old; and (4) the child nor caregiver had any existing, documented cognitive deficits. Pediatric gastroenterologists identified families who were eligible to participate in the study. Members of the research team informed families of their eligibility via mail and recruited them during routine clinic visits. During these visits, participants were administered self-report measures and physicians completed ratings of disease severity. After completing the measures, participants were compensated for their time and effort with $20.
Measures

**Background Information Questionnaire.** A 24-item demographic questionnaire was administered to caregivers to obtain information including child age, child gender, parent age, parent gender, family income, parent marital status, ethnicity information, and living arrangements.

**The Physicians Global Assessment (PGA).** The attending pediatric gastroenterologist completed the PGA \((M = .26; SD = .62)\), a measure used to assess disease severity and activity in pediatric IBD patients during their routine clinic visits. The PGA is a physician rating scale in which patient disease activity/severity is rated on a scale from one to four (i.e., inactive, mild, moderate, and severe) in which higher scores indicate greater disease severity. The PGA is a widely used measure of disease severity that is highly correlated with specific measures of CD and UC severity and activity (e.g., Pediatric Crohn’s Disease Activity Index [PCDAI], Pediatric Ulcerative Colitis Disease Activity Index [PUCDAI]; Hyams et al., 2005; Turner et al., 2009).

**Illness Intrusiveness Scale-Parent (IIS-P).** The IIS-P \((M = 20.2; SD = 9.8)\) is an adapted form of the Illness Intrusiveness Rating Scale (IIRS; Devins et al., 1983) and is a self-report questionnaire that measures the degree to which parents perceive their child’s illness as interfering across 13 life domains (e.g., family relationships, health, financial situation). Parents rated how intrusive they perceive their child’s IBD (e.g., My child’s illness interferes with work) on a seven-point Likert scale where one is “a little” and seven is “a lot.” Scores were summed in order to obtain a total intrusiveness score. In studies across other pediatric chronic illnesses, the IIS-P has demonstrated high internal consistency (e.g., Andrews et al., 2009; Fedele et al., 2012). In the current sample, the IIS-P also had high internal consistency \((\alpha = .90)\).

**Brief Symptom Inventory - Depression (BSI-DEP).** Parents/caregivers completed the BSI, a 53 item self-report measure that is designed to assess psychological distress (Derogatis & Melisaratos, 1983). Parents rated on a four-point scale \((1= not at all to 4= extremely)\) the extent to which they were distressed during the past week by symptoms across various domains (e.g.,
depression, anxiety, somatization). For this study, parents’ depression subscale scores on the BSI-DEP ($M = 1.9; SD = 2.9$) were obtained by summing each of the six depression subscale items. In previous studies examining adjustment to pediatric chronic illness, the BSI has demonstrated high internal consistency (e.g., Gamwell et al., 2016; Ramsey et al., 2013; Tackett et al., 2015). The current sample had high internal consistency ($\alpha = .97$).

**Response to Stress Questionnaire (RSQ).** The RSQ ($M = 17.2; SD = 4.7$) is adapted from the parental depression version of the RSQ (Connor-Smith et al., 2000) and includes 12 questions that assess child stress that results from three areas of parent-child interactions (i.e., parental withdrawal, marital conflict, and parental intrusiveness). Children rated how stressful they find various interactions with their parents on a scale from one to four in which lower scores represent lower levels of stress (e.g., “Sometimes I feel responsible for the way my parents feel”: 1 = not at all, 2 = a little, 3 = somewhat, 4 = very). The RSQ has shown adequate to excellent internal consistency when used with healthy youth (e.g., Bettis et al., 2015; Connor-Smith, Compas, Wadsworth, Thomsen, & Saltzman, 2000). The RSQ had good internal consistency in the current study ($\alpha = .80$).

**Children’s Depression Inventory- 2nd Edition (CDI-2).** The CDI-2 ($M = 8.8; SD = 6.8$) is a 28 item self-report measure used to assess child and adolescent 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). Items on the CDI-2 assess functioning across five areas: negative mood/physical symptoms, interpersonal problems, functional problems, ineffectiveness, and negative self-esteem (Kovacs, 2011). A total score was calculated by summing all 28 items. Higher total scores are indicative of more severe depressive symptoms. The original CDI has demonstrated good internal consistency in youth with IBD (Clark et al., 2014; Reed-Knight et al., 2014; Schuman et al., 2013). The CDI-2 has also demonstrated good internal consistency and reliability in previous studies on portions of the sample included in this study (Gamwell et al., 2017). The present sample also had high reliability ($\alpha = .87$).
CHAPTER III

RESULTS

Preliminary Analyses

Bivariate correlations revealed significant associations among the primary variables of interest, most notably between parent illness intrusiveness (IIS-P) and youth depressive symptoms (CDI-2). No significant correlations were found between child depressive symptoms (CDI-2) and child age, family income, or PGA (see Table 2). A significant relationship was observed between child depressive symptoms (CDI-2) and child gender. As a result, child gender was included as a covariate in the primary analyses.

Primary Analyses

Mplus version 7.31 structural equation modeling software was used to test mediation (Muthén & Muthén, 1998-2012). Direct and indirect effects were assessed by evaluating asymmetric 95% confidence intervals yielded from 5000 bias-corrected bootstrapped resampling draws with replacement (Hayes, 2013; MacKinnon, Lockwood, & Williams, 2004). For the primary hypothesis, mediation was specified for a serial mediation path with illness intrusiveness predicting child depressive symptoms through sequential indirect effects of both parent depressive symptoms and child response to stress (i.e., illness intrusiveness $\rightarrow$ parent depressive symptoms $\rightarrow$ response to stress $\rightarrow$ child depressive symptoms; see Figure 1). Direct effects were also examined along with alternative indirect paths among the variables (i.e., illness intrusiveness $\rightarrow$ parent depressive symptoms $\rightarrow$ child depressive symptoms and illness intrusiveness $\rightarrow$ response to stress $\rightarrow$ child depressive symptoms paths).
**Direct effects.** *Mplus* SEM model analyses (controlling for gender) revealed significant direct effects from illness intrusiveness to parent depressive symptoms (IIS-P→BSI-DEP; 95% CI .019, .369) and youth’s response to stress to child depressive symptoms (RSC→CD-2; 95% CI .139, .518). No significant direct associations were observed between parent illness intrusiveness and child depressive symptoms (IIS-P→CDI-2), parent illness intrusiveness and youth response to stress (IIS-P→RSC), or parent depressive symptoms and child depressive symptoms (BSI-DEP→CDI-2).

**Indirect effects.** Results revealed that the overall IIS-P → BSI-DEP → RSC → CDI-2 serial mediation path was not significant. The BSI-DEP → RSC → CDI-2 indirect path was also not significant. However, analyses revealed that the IIS-P → RSC → CDI-2 indirect path was significant (95% CI .002, .201), suggesting that youth response to stress mediated the relationship between illness intrusiveness and child depressive symptoms.
CHAPTER IV

DISCUSSION

To date, only a handful of variables (e.g., parenting stress, disease activity, and socioeconomic status) have been identified as possible determinants of depressive symptoms in youth with IBD (Clark et al., 2014; Guilfoyle et al., 2014). Studies have yet to fully explore other variables with demonstrated links to youth depressive symptoms in other pediatric chronic illness populations (e.g., Andrews et al., 2007; Wagner et al., 2003). The present study examined parent depressive symptoms and youth response to stress as potential mediators in the association between parent perceptions of illness intrusiveness and child depressive symptoms in a sample of youth with IBD and their caregivers.

Results did not support the hypothesized parent illness intrusiveness $\rightarrow$ parent depressive symptoms $\rightarrow$ youth response to stress $\rightarrow$ child depressive symptoms serial mediation path. However, findings did reveal a significant parent illness intrusiveness $\rightarrow$ youth response to stress $\rightarrow$ child depressive symptom indirect path. This finding suggests that the bivariate association between parent illness intrusiveness and child depressive symptoms could be accounted for by youths’ response to stress. Thus, results provide partial support for the notion that heightened levels of illness intrusiveness have an impact on youths’ perceptions of parents’ stress, resulting in increased child depressive symptoms. However, the present findings suggest that parent depressive symptoms is not the route through which illness intrusiveness operates. In other words, the indirect effect of parent illness intrusiveness on child depressive symptoms through youth response to stress suggests that youth indeed experience increased stress related to parental
reaction to illness. However, the present results did not allow us to identify specifically the nature and/or source of the perceived stress.

Contrary to previous studies (e.g., Chaney et al., 1997), no significant relation was observed between parent depressive symptoms and either youth response to stress or youth depressive symptoms, which may have accounted for the non-significant serial mediation results. It may be that the BSI-DEP measure was unrelated to both the RSQ and CDI-2 due to low levels of depressive symptoms reported by parents, along with limited variability (i.e., reduced variance) of the measure. However, reduced variance would not explain the observed significant association between IIS-P and BSI-DEP. Thus, because parents completed both the IIS-P and BSI-DEP, it is possible that these measures were significantly associated due to single-source measurement bias. Although shared method variance could explain these associations, this would not account for the significant associations between IIS-P and both RSQ and CDI-2, which were independently completed by youth.

Thus, results indicating that youth with IBD experience stress and ultimately depressive symptoms in response to parent reactions to their medical condition may suggest that parent adjustment variables other than parent depressive symptoms may play a role in the association between parent illness appraisals and child adjustment outcomes. Research by Gray and colleagues (2013) identified parenting stress as one variable associated with internalizing symptoms in youth with IBD. Although speculative, it could be that parents who perceive their child’s IBD as being more intrusive experience higher levels of parenting stress related to their child’s illness, which could be perceived and internalized by youth. Furthermore, illness intrusiveness could negatively impact youth adjustment through specific domains of parenting stress (e.g., family, relationship, child rearing) that have a more direct influence on parent-child interactions. It could be that parents who view their child’s IBD as being more intrusive engage in compensatory behaviors intended to aid in disease management. For example, parents who view their child’s illness as being intrusive may over parent in an attempt to manage their child’s
illness in an attempt to gain control over and/or minimize illness disruptions. This could potentially result in parents engaging in intrusive parenting, which could then have negative effects on youth’s self-esteem and emotional functioning. As such, future studies may benefit from examining parenting stress as a potential intermediary variable in the parent illness intrusiveness → youth response to stress → youth depressive symptom association.

**Limitations**

Findings of the current study should be interpreted in light of several limitations. First, the sample of this study was rather homogeneous. The majority of parent/child dyads who participated were Caucasian and from middle to upper socioeconomic classes. It is important to note that many of the demographic characteristics observed in our sample mirrored those of other studies (e.g., Gray et al., 2011; Hommel, Denson, & Baldassano, 2011). Given these demographic limitations, the results of the present study may not be generalizable to more diverse and economically disadvantaged populations.

Additionally, the current study was cross-sectional in nature, which precludes assertions regarding the causal sequence of the modeled variables. Maxwell and Cole (2007) demonstrated that cross-sectional studies are insufficient for examining longitudinal processes such as mediation and can result in biased estimates of direct and indirect effects among variables. As such, it could be argued that the initial variable in our hypothesized model (parent illness intrusiveness) might have been precipitated by other variables not included in the present study. Further, all variables in the present study were gathered via self-report measures. Thus, it is possible that results could be due to artificial inflation of associations due to common method variance and/or biases in reporting. Although this is a valid concern, it should be noted that our data regarding parent illness appraisals and youth depressive symptoms were gathered independently from one another in an attempt to mitigate this possibility (Podsakoff, MacKenzie, Lee, & Podsakoff, 2003).
**Future Directions**

Although research suggests that youth with IBD may be prone to experiencing depressive symptoms (e.g., Mackner & Crandall, 2006), few studies have sought to identify variables that influence the development of depressive symptoms in these youth. Even fewer studies have examined cognitive appraisal variables that influence parent and youth psychosocial adjustment in this population. Although parent illness intrusiveness had an indirect effect on youths’ depressive symptoms through its impact on youth perceptions of parents’ stress in the present study, parent depressive symptoms did not appear to be the mechanism by which illness intrusiveness operates. Future studies should examine a variety of variables (e.g., parenting stress) that may play a role in the association between parent and youth psychosocial adjustment. Further, other illness-related variables that have demonstrated links to parent and child adjustment (e.g., illness uncertainty, perceived stigma, functional disability) should be examined as potential precipitants in this process.
CHAPTER V

REVIEW OF THE LITERATURE

The current chapter will review the literature pertinent to the proposed study. The first section will provide an overview of pediatric inflammatory bowel disease including classification, etiology, incidence, symptomology, and treatment. The second section will discuss child psychosocial adjustment to inflammatory bowel disease. The third section will then provide a broad overview of illness uncertainty as it pertains to parents of youth with IBD. The fourth section will review how youth respond to stress resulting from parent psychological distress. The final section will provide a brief outline of how these variables relate.

Pediatric Inflammatory Bowel Disease

Inflammatory Bowel Disease (IBD) is a broad term used to describe several autoimmune diseases that are characterized by chronic, recurrent, and episodic inflammation of the digestive track (Szigethy, McLafferty, & Goyal, 2010). Ulcerative colitis (UC), Crohn’s disease (CD), and indeterminate colitis (IC) are the three most common subtypes of pediatric IBD (Loftus, 2004; Kappelman, Moore, Allen, & Cook, 2013; Kugathasan et al., 2003). The etiology of IBD remains largely unknown, however, some speculative data suggests that IBD develops as the result of environmental triggers (e.g., infectious, microbial, dietary) acting on individuals who are genetically susceptible (Kugathasan et al., 2003; Peloquin, Goel, Villablanca, & Xavier, 2016; Wei, Baldassano, & Hakonarson, 2013). The prevalence of IBD is currently rising fastest among children. It is estimated that 2 million Americans are affected by IBD and of those 2 million,
80,000-100,000 are children (Peloquin et al., 2016). Up to 25% of new diagnoses each year are child or adolescent cases (Loftus, 2004). The presentation of pediatric IBD is similar to adult IBD, however, youth with IBD are likely to experience pubertal delay, poor growth, and decreased adult height (Dubinsky, 2008; Sauer & Kugathasan, 2009). This template is best used for directly typing in your content. However, you can paste text into the document, but use caution as pasting can produce varying results.

**Ulcerative Colitis.** Ulcerative Colitis (UC) is one of the main subcategories of IBD. UC primarily affects the innermost lining of the colon and rectum, manifesting as continuous areas of ulceration and inflammation with an absence of normal tissue (Head & Jurenka, 2003). The Crohn’s and Colitis Foundation of America has defined the following types of UC: ulcerative proctitis, limited/distal colitis, and pancolitis (Crohn’s and Colitis Foundation of America [CCFA], 2017). Disease involving the entire colon is termed pancolitis. Ulcerative proctitis refers to UC affecting only the most distal portion of the colon. Disease occurring in the descending colon downward is referred to as distal colitis (CCFA, 2017; Head & Jurenka, 2003). Approximately 80-90% of pediatric UC patients have pancolitis, making it the most common subtype of UC in children (Sauer & Kugathasan, 2009).

UC can be diagnosed throughout the lifespan, but is typically diagnosed before age 30 (Head & Jurenka, 2003). UC is most prevalent among Caucasians, with Jewish people with European descent being 3-6 times more likely to develop the disease (Head & Jurenka, 2003; Mayo Clinic, 2017). Pediatric UC appears to affect both sexes equally (Mamula, Markowitz, & Baldassano, 2003). The cause of UC is unknown, but it appears to be related to genetic and environmental factors (Wei et al., 2013; Kugathasan et al., 2003; Head & Jurenka, 2003). Although there is no known cause of UC, there are several known risk factors associated with its onset. One risk factor is having a close relative with IBD. It is estimated 20% of individuals with UC have a close relative with IBD (CCFA, 2017). Other risk factors for developing UC include
race/ethnicity, being under the age of 30, and using the medication isotretinoin (Mayo Clinic, 2017).

The symptoms of UC can vary depending on the intensity and location of inflammation (Mayo Clinic, 2017). Common symptoms include diarrhea (often accompanied by pus or blood), rectal pain, abdominal pain/cramping, weight loss, fatigue, fever, and failure to grow in children (Head & Jurenka, 2003). Because many of the symptoms of UC overlap with other gastrointestinal disorders such as irritable bowel syndrome, Crohn’s disease, and diverticulitis, gathering a complete patient history is essential in order to eliminate other potential disorders that may be causing symptoms. Other diagnostic tests such as stool cultures, ova, and parasite analyses are typically performed early in the diagnostic process to rule out infectious causes. A diagnosis of UC is typically confirmed with a colonoscopy or a flexible sigmoidoscopy (Head & Jurenka, 2003).

Ideal treatment for UC involves quickly reducing and maintaining remission of symptoms while healing colonic mucosa (Hyams, 2013). Commonly used medications used to treat UC include aminosalicylates, corticosteroids, immunomodulators, and antibiotics (Head & Jurenka, 2003; Hyams, 2013). Many of the medications used to manage the symptoms of IBD can have adverse side effects. For example, the side effects of aminosalicylates include headaches, nausea, vomiting, and fever. Short-term use of corticosteroids can have side effects such as mood swings, fluid retention, and weight gain. Additionally, long-term use of corticosteroids can result in increased risk of cataract development, myopathy, osteoporosis, adrenal insufficiency, and immune suppression (Head & Jurenka, 2003).

**Crohn’s Disease.** Crohn’s Disease (CD) is the second main subcategory of IBD. Whereas UC affects the innermost lining of the colon and rectum, CD is the transmural, chronic inflammation of the digestive tract. CD can be found in any part of the digestive tract from the mouth to the anus, but primarily affects the terminal ileum and/or colon (Head & Jurenka, 2004). CD has several subtypes that are categorized based on the portion of the colon that is affected by
The disease. Ileocolitis, the most common form of CD, affects the ileum and colon. The term ileitis is used to describe CD that only affects the ilium. Gastroduodenal CD affects both the duodenum and the stomach. Jejunoileitis refers to CD that only affects the jejunum. The final subtype of CD is Crohn’s colitis, which describes CD that affects only the colon and anus (CCFA, 2017).

The asymmetrical inflammation and ulceration in CD occurs in patches and is interspersed with areas of healthy tissue. The inflammation and ulceration of CD results in the formation of lesions deeply within the intestinal wall. CD affects men and women equally across the lifespan, but the majority of cases are diagnosed between the ages of 15-35 years (Head & Jurenka, 2004). No etiology has been identified for CD, however, there is a known genetic component to the disease. Statistics indicate that approximately 25% of CD patients have a family member with IBD (CCFA, 2017). Risk factors for CD include smoking, use of oral contraceptives, nonsteroidal anti-inflammatory drugs, antibiotics, adult appendectomy, and left-handedness (Head & Jurenka, 2004).

Common symptoms of CD include diarrhea, blood in stools, decreased appetite, weight loss, fatigue, anemia, and moderate to severe abdominal tenderness in the lower right quadrant of the abdomen. CD can be difficult to diagnose because its symptoms overlap with several gastrointestinal disorders, particularly UC. As a result, many diagnostic tests are usually conducted prior to diagnosing CD. Complete blood counts, stool cultures, and diagnostic imaging tests such as barium enemas, small-bowel series, capsule endoscopies, and colonoscopies are some of the methods used determine a CD diagnosis (Head & Jurenka, 2004). The goals of CD treatment are to reduce and manage symptoms as well as suppress the inflammatory response in the digestive tract. Aminosalicylates, corticosteroids, immune-modulating agents, and antibiotics are some of the medications that are frequently used to treat CD. Unfortunately, these medications are often accompanied by unpleasant side effect such as nausea, weight gain, insomnia, acne, and night sweats (Head & Jurenka, 2004).
**Indeterminate Colitis.** The third main subcategory of IBD is indeterminate colitis (IC). The term “indeterminate colitis” has changed through the years. Some patients with IBD have endoscopic and histologic features of both UC and CD, which makes a diagnosis of either disease impossible (Romano et al., 2008). IC was first used to describe those patients who had overlapping features of both UC and CD. The term IC was later used to describe patients who have IBD, but lack sufficient evidence for physicians to make confident diagnoses of either UC or CD (Geobes, 2008). Due to the ambiguity of the term IC, a pediatric working party suggested only giving an IC diagnosis after a full diagnostic work up (Telakis & Tsironi, 2009).

It is estimated that 10-15% of IBD patients are diagnosed with IC (Geobes et al., 2008). IC is most prevalent in youth with IBD (Carvalho et al., 2006). In newly diagnosed pediatric IBD patients, approximately 4-23% have a diagnosis of IC. As symptoms progress, many IC patients are given a diagnosis of CD or UC. Of the pediatric IBD patients with a diagnosis of IC, roughly 60% will be reclassified as having UC or CD (Geobes et al., 2008).

**Youth Psychological Adjustment to Inflammatory Bowel Disease**

Given the unpredictable and chronic nature of IBD along with its invasive and complex treatment regimens, it is not surprising that youth with IBD are at risk for experiencing psychological difficulties, particularly depressive symptoms (Banez & Cunningham, 2003; Greenley et al., 2010; Mackner, Crandall, & Szigethy, 2006; Mackner et al., 2013; Szigethy et al., 2004). The majority of extant literature suggests that these pediatric patients are prone to experience elevated levels of depression and/or depressive symptoms (e.g., Burke et al., 1994; Mackner & Crandall, 2006; Shuman, Graef, Janicke, Gray, & Hommel, 2013; Szigethy et al., 2004). Research suggests that 20-25% of youth with IBD experience clinical levels of depression (Schuman et al., 2013; Szigethy et al., 2004).

Research by Mackner & Crandall (2006) found that youth with IBD have higher levels of depressive symptoms than healthy youth. Similar findings have emerged from studies comparing depressive symptoms in youth with IBD to youth with other chronic illnesses. A meta-analysis
conducted by Greenley and colleagues (2010) found that youth with IBD tend to have higher rates of depressive disorders, but not necessarily higher depressive symptomology than youth with other chronic illnesses. This finding is slightly inconsistent from other studies, which found higher levels of depressive symptoms in youth with IBD compared to youth with other chronic illnesses. Engstrom (1992) compared the psychological functioning of youth with IBD patients to youth with diabetes, headaches, and healthy children. Results showed that on average, youth with IBD reported higher levels of depressive symptoms than either of the other three groups (Engstrom, 1992). Burke and colleagues (1989) compared the lifetime and current prevalence of depression disorders in youth with CD, UC, and cystic fibrosis. These researchers found that although the lifetime prevalence of depression was relatively low in all three illness groups, depressive disorders were more common in youth with IBD than youth with cystic fibrosis (Burke et al., 1989).

In contrast, some research has indicated that youth with IBD exhibit relatively low levels of depressive symptoms that are comparable to youth with other chronic illnesses. Walter and colleagues (2016) examined the rates of internalizing symptomology in a large sample of youth with IBD. The researchers found that only 13% of their sample had clinically elevated symptoms of anxiety and depression and less than 4% exceeded the clinical cutoff score for depression (Walter et al., 2016). A study conducted by Gold, Issenman, Roberts, and Watt (2000) compared the mental health profiles of youth with IBD to youth with functional gastrointestinal complaints. They found that although both groups were psychologically healthy overall, youth with functional gastrointestinal complaints reported more depressive symptoms than youth with IBD (Gold et al., 2000). Maddux, Bass, Geraghty-Sirridge, Carpenter, and Christenson (2013) evaluated the psychological functioning in youth with newly diagnosed IBD. Results of this study showed that their sample actually reported higher levels of quality of life than healthy youth, with less than 4% being at risk for developing depression and less than 2% meeting the clinical cutoff score for depression (Maddux et al., 2013).
Some research also suggests that youth with IBD experience depressive symptoms that are lower than those of their healthy peers. Mackner and Crandall (2005) compared the behavioral and emotional functioning of youth with IBD to healthy youth and found that youth with IBD reported lower depressive symptoms than their healthy peers. Additionally, none of the youth with IBD reported levels of clinical depression whereas two of their healthy counterparts did (Mackner & Crandall, 2005). Similar findings emerged from a study conducted by Herzog and colleagues (2012), which found that there was a lower prevalence of clinical depression in youth with IBD than youth without chronic illnesses. Reed-Knight, Blount, and Gilleland (2014) compared depressive symptomology in youth with IBD to healthy youth and found that youth with IBD actually reported lower levels of depressive symptoms.

Although findings are mixed regarding the level of depressive symptoms that youth with IBD experience, research has linked depressive symptoms in these youth to a plethora of other adjustment outcomes. Engelmann et al. (2015) examined the influence of psychiatric comorbidity on health related quality of life in adolescents with IBD. Results showed that along with disease activity, psychiatric comorbidity contributed to reduced quality of life in adolescents with IBD (Engelmann et al., 2015). Gray, Denson, Baldassano, and Hommel (2012) examined the relationship between anxiety and depressive symptoms, barriers to adherence, and adherence in a sample of adolescents with IBD. These researchers found that anxiety and depressive symptoms strengthened the negative impact of barriers to adherence on adolescents’ abilities to adhere to their treatment regimens (Gray et al., 2012). A study examining school functioning in adolescent IBD patients and healthy youth (Mackner, Bickmeyer, & Crandall, 2012) found that depression predicted lower school attendance in adolescents with IBD. Results of all the aforementioned studies indicate that depressive symptoms impact child adjustment in this population.

Because studies have found that depressive symptoms often drive adjustment outcomes in youth with IBD, research has begun to identify other variables that could play a key role in the development and variability of depressive symptoms in this population. Clark and colleagues
(2014) investigated predictors of depressive symptoms in youth with Crohn’s disease. Results demonstrated that disease severity and socioeconomic status were the strongest predictors of depression in their sample (Clark et al., 2014). Another study conducted by Guilfoyle, Gray, Herzer-Maddux, & Hommel (2014) investigated the relationship between parenting stress and depressive symptoms in youth with CD and UC. Currently these are the only two studies that have examined variables that may predict depressive symptoms in pediatric IBD patients. It is clear that studies have yet to fully explore other key variables that determine child depressive symptoms.

Parent and Youth Adjustment to Inflammatory Bowel Disease

The emotional sequela that confront a child with IBD does not merely affect them on an individual level, but rather involves parents or caregivers as well. This parent-child adjustment paradigm embodies the parent-child transactional stress and coping model (Thompson & Gustafson, 1996), which proposes that parent and child adjustment to a child’s chronic illness is dependent on the interaction of cognitive processes, illness parameters, and demographic variables. The transactional parent-child adjustment relationship has been demonstrated in a variety of pediatric chronic illnesses including juvenile rheumatic diseases (Fedele et al., 2011), asthma (Lopez, Mullins, Wolfe-Christensen, & Bourdeau, 2008), cancer (Colletti et al., 2008), and diabetes (Chaney et al., 1997). Interestingly, few studies have investigated how parent variables relate to child adjustment in youth with IBD. In fact, only one parent appraisal variable, parenting stress, has been examined in relation to adjustment outcomes in youth with IBD.

A recent study conducted by Gray, Graef, Schuman, Janicke, and Hommel (2013) found that parenting stress was associated with internalizing symptomology in youth with IBD. Additionally, Guilfoyle and colleagues (2014) examined the temporal association between parenting stress and adolescent depressive symptoms. Findings from this study indicated that parenting stress had a temporal effect on adolescent reported depressive symptoms, such that parenting stress contributed to adolescent depressive symptoms (Guilfoyle et al., 2014). More
research is needed in order to fill this gap in the literature and identify other parent adjustment variables that are related to child depressive symptoms. Because parenting stress is the only parenting variable in the current pediatric IBD literature that has been studied in relation to child outcomes, the literature reviewed in this paper will primarily focus on other chronic illness populations.

**Illness Intrusiveness**

In order to ameliorate depressive symptoms in youth with IBD, driving factors of depressive symptoms must first be identified. Illness intrusiveness refers to the extent to which an individual perceives an illness and its treatment as disrupting or interfering with involvement in valued interests and activities (Devins et al., 1983). Illness intrusiveness is conceptualized as a variable that connects subjective well-being and emotional distress to a disease and its treatment (Devins, Bezjak, Mah, Loblaw, & Cotowiec, 2006). Illness intrusiveness is theorized to stem from a plethora of “illness induced barriers” that prevent patients from engaging in interests or activities in a variety of contexts such as family, work, community involvement, or religious expression (Devins et al., 1983; Devins et al., 1990). The main premise of the illness intrusiveness theory is that lifestyle disruptions impact psychosocial well-being in individuals with chronic illnesses by 1) decreasing the amount 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, Seland, Klein, Edworthy, & Saary, 1993).

Illness intrusiveness is considered to be an underlying determinant of the psychosocial impact of chronic disease due to the way that it connects objective aspects of a disease and its treatment with psychosocial impacts of the disease (Dancey, Hutton-Young, Moye, & Devins, 2002). In the pediatric chronic illness literature, caregiver perception of illness intrusiveness has been identified as a key variable that contributes to child depressive symptoms. Results from a
study conducted by Fedele and colleagues (2012) indicated that parent perceptions of illness intrusiveness were related to child depressive symptoms. Additionally, 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).

Although illness intrusiveness has yet to be examined in parents of youth with IBD, research from other chronic illness populations suggests that it could be a determining factor of depressive symptoms in pediatric patients. Successful management of pediatric IBD requires caregivers to assist with complicated medical regimens, attend numerous medical appointments, oversee nutritional modifications, and monitor disease symptoms (Greenley, Reed-Knight, Blount, & Wilson, 2013). The unpredictable course of IBD, arduous medical regimens, and intrusive nature of IBD may impede on caregivers’ abilities to engage in social, family, or occupational activities. Thus, the invasive aspects of IBD and its treatment make illness intrusiveness particularly relevant when examining parenting variables that could be predictive of child adjustment.

**Parent Distress and Youth Response to Stress**

Research in the pediatric chronic illness literature has consistently demonstrated that parental emotional adjustment is one of the most reliable predictors of child outcomes (e.g., Chaney et al., 1997; Ramsey et al., 2013), making it a variable of interest in examining predictors of child adjustment outcomes. Findings in the extant pediatric IBD literature have produced mixed results regarding the psychological functioning in parents of youth with IBD. Some research suggests that psychological disorders are relatively common in parents of youth with IBD. For example, Szajnberg, Krall, Davis, Treem, and Hyams (1993) found that in a group of 27 parents of youth with IBD, 21 had psychiatric diagnoses. In contrast, other research suggests that parents of youth with IBD experience psychological well-being that does not statistically differ
from that of other adults. Greenley and Cunningham (2009) examined quality of life in parents of youth with IBD. Results from this study indicated that parents of youth with IBD actually had higher emotional quality of life than adults in the normative population (Greenley & Cunningham, 2009).

More specifically, some research also suggests that mothers of youth with IBD are prone to have a history of depression or experience depressive symptoms. Engstrom (1991) compared psychological distress in parents of pediatric IBD patients to parents of healthy children. This study found that mothers of children with IBD reported higher levels of distress than mothers of healthy youth. The psychological distress of fathers, however, did not differ between the two groups (Engstrom, 1991). Burke, Kocoshis, Chandra, Whiteway, and Sauer (1990) found that in a sample of 13 mothers of youth with IBD, six mothers reported a history of depression. Burke et al. (1994) compared the lifetime psychiatric histories of mothers of youth with IBD to mothers of youth with cystic fibrosis. Although there was no significant difference in the rates of depressive histories between the groups, over half of the mothers in the IBD group reported having a history of depression and a high proportion had histories of prior suicide attempts (Burke et al., 1994). Regardless of which parent experiences depressive symptoms or the extent to which they experience depression, child depressive symptoms have been shown to be associated with parent depressive symptoms in youth with IBD (Loreaux, Gray, Denson, & Hommel, 2015). It is plausible, therefore, that it is the presence of parent depressive symptoms rather than the extent of symptoms that should be assessed in parents of youth with IBD.

Research in other pediatric chronic illness populations suggests that parent psychological functioning is causally antecedent to child adjustment. Results from a longitudinal study conducted by Friedman, Holmbeck, Zukerman, and Abad (2004) revealed that associations between parent functioning and child functioning tended to be in the direction of parent to child in a sample of youth with spina bifida and their healthy peers. Another study by Ryan et al. (2010) examined the longitudinal relationship between parent distress and child distress in
children with juvenile rheumatic diseases. The results from this study also demonstrated the temporal precedence of parent distress relative to child distress in the relationship between parent and child functioning (Ryan et al., 2010). Data from both studies suggest that there may be a downstream effect of parent distress on child adjustment in youth with chronic illnesses. It remains unclear, however, how parent psychological functioning leads to child adjustment, particularly child emotional functioning.

Many studies hypothesize mechanisms through which parent psychological adjustment affects child emotional adjustment (e.g., Chaney et al., 2016), but no studies to date have identified a variable that explains the mechanisms by which parent emotional adjustment affects child emotional adjustment. Research in the clinical child psychology literature suggests exposure to stress in the family environment associated with parents’ depressive symptoms may be one way through which parental depressive symptoms increase the risk of youth depressive symptoms (Bettis et al., 2016). Research suggests that exposure to stressful life events and chronic stressful environments are some of the most robust predictors of depression (Compas, Connor-Smith, & Jaser, 2004). Extant literature also suggests that children of depressed parents often experience heightened levels of stress in their environments due to the unpredictable nature of interactions they have with their depressed parent (Goodman & Gotlib, 1999), suggesting that children of depressed parents may experience stress related to their parents’ depression.

Results from a study by Lovejoy, Graczyk, O’Hare, & Neuman (2000) demonstrated that behavior of depressed parents is often characterized by negative coercive behaviors (i.e., intrusiveness) as well as disengagement behaviors (i.e., withdrawal) in parent-child interactions. Additionally, parents with depression also experience increased interparental conflict and marital discord (Goodman & Gotlib, 1999). Empirical studies have shown that interparental conflict, intrusiveness, and withdrawal are related to depressive symptoms in children of depressed parents (e.g., Fear et al., 2009; Jaser et al., 2005). Moreover, research examining the relationship between stress related to parental depression and symptoms of depression in children suggests that stress
related to parental depression may be a transdiagnostic correlate of depressive symptoms in children (Bettis et al., 2016). It could be possible, therefore, that youth with IBD experience stress related to parental depressive symptoms, which then eventuates into youth depressive symptoms.

**Summary**

Youth with IBD are at increased risk for developing depressive symptoms due to the intermittent, invasive, and chronic nature of the disease (e.g., Banez & Cunningham, 2003; Mackner, Crandall, & Szigethy, 2006). Empirical findings have indicated that depressive symptoms in pediatric IBD patients often influence other adjustment outcomes such that youth with higher levels of depressive symptoms experience lower levels of quality of life, medication adherence, and school functioning (Engleman et al., 2015; Herzer, Denson, Baldassano, & Hommel, 2011; Gray et al., 2012; Loreaux et al., 2015; Mackner, Bickmeier, & Crandall, 2012). Consequently, research is needed to identify variables that could influence the development of depressive symptoms in these youth. To date, only parenting stress, disease activity, and socioeconomic status have been identified as variables predictive of depressive symptoms in youth with IBD (Clark et al., 2014; Guilfoyle et al., 2014). Studies have yet to fully explore other variables that may influence depressive symptoms in this population.

Parent adjustment to pediatric chronic illnesses has been identified as one of the most robust predictors of child adjustment outcomes (i.e., Chaney et al., 1997; Ryan et al., 2010; Ramsey et al., 2013). Currently, parenting stress is the only parent appraisal variable that has been examined in parents of children with IBD (Guilfoyle et al., 2014). In other chronic illness populations, illness intrusiveness is a cognitive appraisal variable that has been found to be related to parent psychological distress (Andrews et al., 2009) as well as child depressive symptoms (Fedele et al., 2012; Wagner et al., 2003). Effective management of pediatric IBD requires caregivers to assist with medical regimens, monitor disease symptoms, and attend frequent medical appointments (Greenley et al., 2013). Given the unpredictable clinical course and complex treatment regimens associated with IBD, it is possible that parents of youth with
IBD may find the disease to be a very intrusive illness that impedes their abilities to enjoy daily activities, which could result in parents developing depressive symptoms.

Empirical evidence has indicated that parent depressive symptoms are related to youth depressive symptoms in this population (Loreaux et al., 2015). No studies, however, have identified variables that explain how parent depressive symptoms lead to child depressive symptoms. Research outside the pediatric chronic illness literature suggests that stress related to parental depression may be a transdiagnostic correlate of depressive symptoms in children (Bettis et al., 2016). Although these findings have not been replicated in the chronic illness literature, it may be that that youth with IBD experience stress related to parental depressive symptoms and it is stress that leads to youth depressive symptoms in this population.

The Present Study

The present study was designed to examine parent depressive symptoms and youth response to stress as potential serial mediators in the relationship between parental illness intrusiveness and child depressive symptoms in a sample of youth with IBD. Due to the invasive and restrictive aspects of IBD as well as its demanding treatment regimens, a model is proposed in which parent illness-intrusiveness acts as a primary antecedent that drives parental depressive symptoms, which youth notice, perceive as stressful, and subsequently result in elevated youth depressive symptoms. It is anticipated that results will reveal a significant illness intrusiveness $\rightarrow$ parental depressive symptoms $\rightarrow$ response to stress $\rightarrow$ child depressive symptoms serial mediation path, in which parental depressive symptoms and response to stress carry sequential indirect effects from parent illness intrusiveness to child depressive symptoms.
REFERENCES


APPENDICES

APPENDIX A: TABLES

Table 1. Descriptive Statistics

<table>
<thead>
<tr>
<th>Variable</th>
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<tr>
<td><strong>Annual Household Income</strong></td>
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<td>0-19,999</td>
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<tr>
<td>20,000-39,999</td>
<td>15 (14.3)</td>
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<td>40,000-59,999</td>
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<td>60,000-79,999</td>
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<tr>
<td>100,000 or greater</td>
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<td>Girl</td>
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<tr>
<td>Boy</td>
<td>51 (48.6)</td>
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<td>Father</td>
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<td>Grandmother</td>
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<td>Other</td>
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Table 2. Bivariate Correlations

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<td>3. Child Gender</td>
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<td>4. PGA</td>
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<td>-.13</td>
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<td>5. IISP Total</td>
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<td>-.05</td>
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<td></td>
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<td>-.02</td>
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<td>.20*</td>
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<td>.09</td>
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<td>-.28**</td>
<td>.08</td>
<td>.25**</td>
<td>.16</td>
<td>.35**</td>
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</tr>
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</table>

Note: *p<.05, **p<.01
APPENDIX B: FIGURE

Figure 1. Serial Mediation Model

Note.

- IIS-P → BSI-Dep → RSC → CDI-2 (indirect 2)
- IIS-P → BSI-Dep → CDI-2 (indirect 1)
- IIS-P → RSC → CDI-2 (indirect 3)*
- BSI-Dep → RSC → CDI-2 (indirect 4)

P < .05 = *

Indirect 2 = NS
CI = -0.005 to .042

Indirect 1 = NS
CI = -0.44 to .057

Indirect 3*
CI = .002 to .201

Indirect 4 = NS
CI = -.041 to .136

(c') = NS
CI = -0.079 to .230
APPENDIX C: IRB APPROVAL

Institutional Review Board for the Protection of Human Subjects

Continuing Review with Proposed Modification – Expedited Approval

Date: November 30, 2016  IRB#: 5856
To: Noel Jacobs, PhD  Approval Date: 11/29/2016
Study Title: Parent and Child Psychological Adjustment in Pediatric Inflammatory Bowel Disease  Expiration Date: 10/31/2017
Study Status: Active - Open - Expedited
Reference Number: 657252

On behalf of the Institutional Review Board (IRB), I have reviewed and approved the Application for Continuing Review for the above-referenced research study. Study documents (e.g. protocol, consent, survey, etc.) associated with this submission are listed on page 2 of this letter. To review or access the submission documents (e.g. application, review response form) as well as the study documents approved for this submission, open this study from the My Studies option, click to open this study, go to Protocol Items, click to open Application, Informed Consent, or Other Study Documents to viewprint the most current approved document.

The approved modification is: Add Dana Bakula as key study personnel. We made changes to the protocol.

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 @ 405-271-2045 or irb@ouhsc.edu.

Sincerely,

Karen Beckman, MD
Chairperson, Institutional Review Board
VITA

Marissa Nicole Baudino

Candidate for the Degree of

Master of Science

Thesis: EXAMINING PARENT DISTRESS AND YOUTH RESPONSE TO STRESS AS MEDIATORS IN THE ASSOCIATION BETWEEN PARENT-PERCEIVED ILLNESS INTRUSIVENESS AND CHILD DEPRESSIVE SYMPTOMS IN YOUTH WITH INFLAMMATORY BOWEL DISEASE

Major Field: Psychology

Biographical:

Education:

Completed the requirements for the Master of Science in Psychology at Oklahoma State University, Stillwater, Oklahoma in July, 2018.

Completed the requirements for the Master of Education in Child Studies at Vanderbilt University, Nashville, Tennessee in 2015.

Completed the requirements for the Bachelor of Arts in Elementary Education and Applied Psychology at Boston College, Chestnut Hill, Massachusetts in 2014.

Experience:

2016-Present: Pediatric Behavioral Health Research Lab, Stillwater OK Graduate Research Assistant, Oklahoma State University Adviser: John M. Chaney, Ph.D.

Professional Memberships:

2015-Present: American Psychological Association, Student Member
2016-Present: Society of Pediatric Psychology, Student Member
2016-Present: Psychology Graduate Student Association, Oklahoma State University; Treasurer: Fall 2018-Summer 2019