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Parenting stress and child psychosocial functioning over the first year of inflammatory bowel disease diagnosis

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By

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M.S., The University of Georgia, 2010
Ph.D., The University of Georgia, 2013

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An abstract of
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Abstract

Parenting stress and child psychosocial functioning over the first year of inflammatory bowel disease diagnosis

By Eva Bonney Reed

A diagnosis of inflammatory bowel disease (IBD) in children can disrupt the family system, including altered routines and increased medical responsibilities. This may increase parenting stress; however, little is known about how parenting stress changes over the first year following an IBD diagnosis, as well as what demographic, disease, or psychosocial factors may be associated with parenting stress over time. Fifty-three parents of children newly diagnosed with IBD (*M*age=14.17 years; *M*days since diagnosis=26.15) completed questionnaires assessing parenting stress frequency and difficulty (Pediatric Inventory for Parents), child anxiety (Screen for Child Anxiety Related Disorders), and child health-related quality of life (HRQOL; IMPACT) within 1-month of diagnosis and at six-month and one-year follow-up. Multilevel longitudinal models assessed change and predictors of parenting stress. Parenting stress at diagnosis was associated with greater child anxiety and lower HRQOL, while caregivers of color and caregivers of female youth reported higher parenting stress (*p*s<.05). Significant variability and declines in parenting stress over one year were observed. In final models, caregiver race/ethnicity and child HRQOL were significantly related to parenting stress frequency and difficulty over the first year of diagnosis. Parenting stress decreases for caregivers across one year of diagnosis. However, caregivers of color and those who rate their child's HRQOL as lower may be at risk for greater parenting stress. More research is needed to understand why caregivers of color reported greater parenting stress compared to White caregivers. Results highlight the importance of providing whole-family care when a child is diagnosed with IBD.

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INTRODUCTION

Inflammatory bowel diseases (IBD) are a group of gastrointestinal diseases that include Crohn's disease (CD) and ulcerative colitis (UC). Individuals with IBD experience inflammation of the gastrointestinal tract, which can cause abdominal pain, fever, fatigue, diarrhea, hematochezia, weight loss, and growth delays in youth (Diefenbach & Breuer, 2006; Mackner et al., 2004). An estimated 20-30% of individuals with IBD have an onset of symptoms before the age of 18 (Malaty et al., 2010; Sawczenko et al., 2001). A diagnosis of pediatric IBD may affect the child most directly, but impacts are felt across the entire family system. Caring for a child with IBD places caregivers at risk for increased parenting stress as they manage the demands of a complex treatment regimen, their child's relapsing and remitting symptoms, risk for long-term consequences, and the emotional impacts of an unpredictable chronic illness on all family members (Gray et al., 2013). These potential stressors are on top of the expected parenting demands. Recognition of the additive stressors experienced by parents of children with chronic illnesses led to the development of the Pediatric Inventory for Parents (PIP), an assessment tool validated to measure both the *frequency* and *difficulty* of parenting stress associated with caring for a child with a chronic condition (Streisand, 2001).

Parenting stress has been examined in relation to both child and parent demographic variables in pediatric IBD samples. Older caregiver age and completion of a four-year college degree have been associated with lower frequency of parenting stress (Guilfoyle et al., 2012). Parent report of parenting stress has not consistently differed based on parent marital status, family socioeconomic status, child age or gender (Guilfoyle et al., 2012; Plevinsky et al., 2018). Across several studies examining disease variables related to parenting stress, studies have yielded mixed results, such that parenting stress is related to greater disease severity or activity in

some samples, while others show no relation between parenting stress and disease variables (G. Cushman et al., 2020; Gray et al., 2015; Guilfoyle et al., 2014; Plevinsky et al., 2018). Differences in parenting stress have also been investigated based on child psychosocial functioning including internalizing symptoms (e.g., anxiety, depression, somatization), externalizing symptoms (e.g., aggression), and global psychological functioning. In cross-sectional studies of youth diagnosed with IBD, higher parenting stress has been associated with greater adolescent-reported internalizing, but not externalizing problems (Gray et al., 2013), as well as with poorer overall psychological functioning (Plevinsky et al., 2018). When parents of youth with IBD rated their children's symptoms of psychopathology, parenting stress was significantly greater among those reporting borderline and clinically-elevated internalizing symptoms in their children (Gray et al., 2013).

Using a cross-lagged panel model, Guilfoyle and colleagues (2014) demonstrated that baseline parenting stress frequency contributed to elevated adolescent-reported depressive symptoms 6 months later (Guilfoyle et al., 2014). Beyond this study, multi-time point assessments of parenting stress and child psychosocial outcomes in youth with IBD have not been published, limiting conclusions on how these constructs change and are related to one another over time. Further, the majority of current literature in pediatric IBD relies on internalizing symptoms grouped together, limiting conclusions on how parenting stress may be differentially related to distinct aspects of child functioning, which may inadvertently limit clinical application of findings. The current study aims to examine parenting stress as it relates to child anxiety symptoms, one facet of the broader internalizing symptom scales found to be associated with parenting stress in past research. Anxiety symptoms may be particularly relevant for youth newly diagnosed with IBD, given the uncertainty associated with diagnostic testing,

starting treatment, and adjusting to a new illness. Past research outside of pediatric IBD also suggests that symptoms of anxiety may be particularly relevant to parenting stress and healthcare utilization. In a primary care sample, children whose parents reported more parenting stress had worse health-related quality of life (HRQOL) and visited the physician more for health-related complaints. Interestingly, this relationship was moderated by child anxiety, such that highly anxious children whose parents reported higher parenting stress had worse HRQOL than children with low symptoms of anxiety (Kidwell et al., 2015). Finally, the initial validation of the PIP relied on caregiver anxiety scores to support construct validity of the measure, such that parental anxiety was significantly associated with both parenting stress frequency and difficulty (Streisand, 2001). The current study expands upon this work by describing parenting stress in a pediatric IBD sample as it relates to *child* anxiety symptoms.

Higher parenting stress measured using the PIP has previously been associated with lower child HRQOL in a sample of adolescents diagnosed with IBD for varying amounts of time (Herzer et al., 2011). Child HRQOL is a particularly meaningful outcome given cross-sectional associations between poorer HRQOL and clinically elevated difficulties in problem solving, communication, and general family functioning in youth with IBD (Herzer et al., 2011). However, these findings are yet to be examined longitudinally or with regards to changes in parenting stress over time. This is particularly warranted given prior literature demonstrating significant improvements in HRQOL over the first year of diagnosis among youth recently diagnosed with IBD (Otley et al., 2006). It is not yet clear in the existing pediatric IBD literature how parenting stress and child HRQOL may relate over time.

The present study was designed to fill gaps in the literature on parenting stress by using three waves of data collected from youth newly diagnosed with IBD and their families. The

extent to which parenting stress frequency and difficulty changed over three time points across the first year of a child's diagnosis with IBD was examined using multilevel growth modeling. We hypothesized that both parenting stress frequency and difficulty would decrease over the first year of diagnosis as families adjusted to disease symptoms and treatment. We next sought to test change in parenting stress as a function of demographic and disease factors as well as changes in child anxiety, a component of internalizing symptoms, and HRQOL.

METHODS

Participants

Participants included 53 children and adolescents recently diagnosed with IBD and their caregivers. All study procedures were approved by the Institutional Review Board. This study is part of a larger longitudinal investigation into psychosocial functioning and physiological reactivity. Inclusion criteria were (1) diagnosis with biopsy-confirmed IBD within the last 45 days, (2) child ages 8–17 years, (3) English language proficiency, and (4) accompanied by at least one caregiver to appointment. Exclusion criteria included a documented history or caregiver report of a developmental disorder or non-verbal presentation that would impede completion of questionnaires. Families were approached at their gastroenterology clinic appointment by research staff and invited to complete questionnaires and physiological reactivity tasks. Only the research questionnaires are utilized in the present study. Families were invited to participate within 45 days of the child's diagnosis with IBD (Time 1). Subsequent longitudinal follow-up at 6-month (Time 2) and one-year (Time 3) since diagnosis was undertaken. Families were invited to complete questionnaires at Time 2 and Time 3 follow-up at in-person clinic visits if a previously scheduled appointment aligned with research timeline or via email or phone-call communication. All questionnaires were completed through RedCap, a HIPAA compliant data collection software (Harris et al., 2009, 2019). Participants were compensated with $25 gift cards for completion of study measures at each time point.

Measures

Demographics. Demographic information for youth and caregivers was collected using a standard demographic questionnaire.

Pediatric Inventory for Parenting (PIP). Stress associated with caring for a child with a chronic illness was measured using the Pediatric Inventory for Parenting (PIP; (Streisand, 2001). The measure consists of 42 medically related tasks and cognitions. Caregivers used a 5-point Likert scale to rate how often the task or thought occurs (PIP-Frequency) and how difficult/stressful they found the task or thought (PIP-Difficulty). PIP-Frequency and PIP-Difficulty domains achieved excellent internal consistency at each time point (αs 0.94 to 0.96)

Screen for Child Anxiety Related Disorders (SCARED). Anxiety was examined using the caregiver-report Screen for Child Anxiety Related Emotional Disorders (SCARED; (Birmaher et al., 1999). This 41-item measure consists of 5 domains: Panic/Somatic, Generalized Anxiety, Separation Anxiety, Social Anxiety, and School Anxiety. Items across domains are summed together to yield a total symptom severity score, with higher scores indicating greater anxiety. SCARED achieved excellent internal consistency at each time point (αs 0.93 to 0.95).

IMPACT. Caregiver-report of their child's HRQOL was assessed using the 35-item IMPACT-III-P (G. K. Cushman et al., 2020). The IMPACT-III-P is comprised of 6 subscales: Bowel Symptoms (7 items), Systemic Symptoms (3 items), Emotional Functioning (7 items), Social Functioning (12 items), Body Image (3 items), and Treatment/Interventions (3 items). Each item uses a 5-point Likert scale with values ranging from 1 to 5, with higher scores representing better HRQOL. A total score was calculated by summing the responses from all 35 questions, achieving good to excellent internal consistency at each time point (αs 0.87 to 0.92).

Clinical Disease Activity. Clinical disease activity was examined via the Physicians Global Assessment (PGA). The PGA is a global measure of patients' disease severity routinely completed by the treating pediatric gastroenterologist at each medical appointment as part of the site's participation in ImproveCareNow (Crandall et al., 2011). Participants were assigned a

rating of quiescent (i.e., inactive), mild, moderate, or severe disease activity based on clinical symptoms, examination, and labs. Child-reported symptoms were examined with the Self-Report Disease Activity (SRDA) measure, which assesses symptoms of IBD (G. K. Cushman et al., 2020). Patients rated abdominal pain frequency and intensity in the past week, number of bowel movements (i.e., solid, mushy, diarrhea), presence of nocturnal diarrhea, blood in stool, and impairment in daily activities. Higher scores indicate more clinical symptoms.

Analytic Plan

Data were analyzed using SAS 9.4 (Cary, NC). The MIXED procedure was used for multilevel longitudinal modeling. Multilevel longitudinal modeling, also referred to as longitudinal growth curve modeling, has several advantages to traditional longitudinal models (e.g., ANOVA), including the ability to model individual change (as compared to aggregate change in ANOVA models) and retain participants with missing data at some point during longitudinal data collection (as compared to listwise deletion). Further details about the advantages and applications of growth curve modeling within pediatric psychology research are available from DeLucia and Pitts (DeLucia & Pitts, 2006).

Two separate multilevel modeling procedures were conducted to assess predictors of change in parenting stress frequency and difficulty domains via PIP subscales. For each domain, the unconditional means model was first modeled to determine whether there was variation in the outcome and the proportion of variance occurring between persons, calculated as the Intraclass Correlation Coefficient (ICC). Next, fixed linear growth models determined whether there was change over time on average across participants. After assessing for average change over time, unconditional linear growth models were examined to determine whether there was significant variability in the change of parenting stress frequency and difficulty over time across individuals.

Results from the saturated means, unstructured variance models revealed adequacy of a constant residual variance in the model for parenting stress frequency and the need for random intercept variance, given comparisons to nested models without these parameters. This is consistent with prior research demonstrating variability in parenting stress levels among caregivers of youth with IBD as assessed via the PIP (Gray et al., 2015; Guilfoyle et al., 2012). Alternative variance-covariance structures (e.g., Compound Symmetry, Autoregressive, Toeplitz) were assessed for adequacy of fit for both models. Alternative structures were evaluated compared to unstructured covariance structure through likelihood ratio tests conducted with the Hoffman FitTest macro (Hoffman, 2015). In the current models, alternative structures did not provide a significantly improved fit from unstructured. As such, unstructured models were retained for both models. Further, a comparison of model fit indices using -2LogLikelihood of nested fixed linear time and random linear time models revealed that modeling random linear time was not significantly better than fixed linear time, as such, fixed linear time was used for final models. The final longitudinal multilevel models included fixed linear time, random intercept, and unstructured covariance structures. Interaction terms of time with time-varying predictors were also assessed in the models to determine whether predictors' impact on the outcome differed by time. Interaction terms did not significantly improve model fit and were therefore excluded in final models.

Selection of predictor variables for inclusion in longitudinal multilevel models was based on those factors found to be significantly associated with outcomes of interest at $p < .05$ using tests of correlation and mean differences in addition to a priori hypotheses regarding constructs of interest. Time invariant predictors (e.g., caregiver race/ethnicity) and time varying predictors (e.g., caregiver-reported child HRQOL and anxiety) were entered into the multilevel model.

Time-varying predictors were entered into the model as both within-person variability (e.g., how values differ from a person's individual average over time) and between-person variability (e.g., how individuals differ from the grand mean average over time) to account for between and within-person variability in predictors over time (Hoffman, 2015). For each time-varying predictor, a random time slope was examined to determine whether the predictor showed individually varying change over time. These were non-significant for the two time-varying predictors (i.e., anxiety, HRQOL), indicating that a random time slope was not indicated for these predictors. To calculate within-person mean-centered values, a person's individual average over one year was subtracted from their provided values at each completed wave. This determines how different a person is from their individual average at each timepoint. To calculate between-person variability values, the grand mean of the sample over one year was subtracted from each person's average to determine how different a person's average is from the sample's average over one year. Both within and between-person variability were included in separate interaction terms with time to assess whether predictor impact on parenting stress differed over time. Residual maximum likelihood (REML) was used in estimating and reporting all model parameters. Denominator degrees of freedom were estimated using the Satterthwaite method. For all tests, a *p* value of less than .05 was considered significant.

RESULTS

Participant Demographic Information

Participants include 53 children and adolescents (*M* age in years = 14.17, *SD* = 2.31) recently diagnosis with IBD (*M* days since diagnosis = 26.15, *SD* = 11.68) and their caregivers (*M* age in years = 45.21, *SD* = 5.56). Fifty-seven percent of children were female, and the majority were diagnosed with Crohn's disease (79%). Most caregivers were biological mothers (77%) and White (74%). Full descriptives are presented in Table 1. Fifty-three caregivers participated at Time 1, 39 at Time 2, and 32 at Time 3, resulting in a follow-up participation rate of 74% and 60%, respectively. Common reasons for attrition included inability to make contact with families for follow-up or no longer interested in participating in study.

Relationships Among Study Variables

There was no relationship between parenting stress frequency or difficulty and child or caregiver age at the time of diagnosis, child diagnosis (i.e., Crohn's versus UC), PGA, or child self-reported disease activity. At Time 1, caregivers of girls reported significantly higher parenting stress frequency (*M* = 108.17, *SD* = 24.11) and difficulty (*M* = 93.00, *SD* = 30.28) compared to boys (*M*frequency = 89.26, *SD* = 20.58, *t* (51) = 3.01, *p* = .004, *d* = .83; *M*difficulty = 74.96, *SD* = 19.88, *t* (51) = 2.48, *p* = .02, *d* = .69). Caregivers who identified as White reported significantly lower levels of parenting stress frequency (*M* = 95.51, *SD* = 21.25) at Time 1 compared to caregivers who identified as Black/African American, Hispanic, Asian American, or multiracial identity (*M*frequency = 112.36, *SD* = 28.76; *t* (51) = -2.31, *p* = .03, *d* = .72). Figure 2 displays mean levels of parenting stress frequency and difficulty for caregivers who identified as White compared to caregivers who identified as Black/African American, Hispanic, Asian American, or multiracial identity. No differences in parenting stress frequency or difficulty

emerged related to caregiver-reported family income based on median split at $100,000 or caregiver education level based on median split at bachelor's degree or higher. Comparisons of parenting stress frequency and difficulty based on demographic factors are presented in Table 4. Caregiver-reported child anxiety was significantly related to parenting stress difficulty at diagnosis (Time 1: $r = .35$, $p = .01$) and one year later (Time 3: $r = .36$, $p = .046$). Caregiver-reported child HRQOL was related to parenting stress difficulty and frequency at all three timepoints across one-year of diagnosis (rs -.47 to -.55, ps < .01). Correlations among study variables within the 3 time points are presented in Table 5. Differences between participants who completed measures at all time points versus those who were missing a data collection point were examined with tests presented in Table 6. No significant differences between the groups were found, suggesting that drop out was likely not due to one of the variables examined.

Changes in Parenting Stress Frequency and Difficulty Over Time

Figure 1 shows raw data trajectories of parenting stress frequency and difficulty across the first year of the child's IBD diagnosis. These graphs reveal two key points, 1) there appears to be variability in caregivers' self-reported initial parenting stress frequency and difficulty at diagnosis, but also 2) variability in how caregivers' self-reported parenting stress frequency and difficulty change over time across the first year of diagnosis. These points of variability are further modeled using longitudinal multilevel modeling. In the unconditional means model, ICCs of .28 and .46 for parenting stress frequency and difficulty respectively, revealed that 28% and 46% of the variability in each domain was occurring at the between person level.

For parenting stress frequency, estimated random intercept variance was 209.40 ($p < .01$) and residual variance was 444.95 ($p < .001$), suggesting substantial between and within-person variance. A fixed linear time, random intercept multi-level model of parenting stress frequency

with a main effect of time is summarized in the top half of Table 2. There was a significant main effect of time (β = -8.52, $p < .001$), such that parenting stress frequency decreased on average by approximately 8.52 every 6 months in the first year of IBD diagnosis.

For parenting stress difficulty, estimated random intercept variance was 357.12 ($p < .001$) and residual variance was 382.39 ($p < .001$), suggesting substantial between and within-person variance. A fixed linear time, random intercept multi-level model of parenting stress difficulty with a main effect of time is summarized in the top half of Table 2. There was a significant main effect of time (β = -5.23, $p = .03$), such that parenting stress difficulty decreased on average by approximately 5.23 every 6 months in the first year of IBD diagnosis.

Factors Associated with Parenting Stress Frequency and Difficulty

Multi-level models with predictors were constructed to examine factors associated with change in parenting stress frequency and difficulty in the first year of diagnosis with IBD. Given significant differences in parenting stress based on child gender and caregiver race/ethnicity, these variables were included as predictors in addition to caregiver-reported child HRQOL and anxiety symptoms. The model examining parenting stress frequency is detailed in the bottom half of Table 2. Caregiver race/ethnicity (β = -3.99, $p < .001$), child HRQOL variation within-person (β = -0.67, $p = .004$), and child HRQOL variation between-person (β = -0.78, $p < .001$) were significantly related to parenting stress frequency, such that caregivers who identified as Black/African American, Hispanic, Asian American, or multiracial identity reported significantly greater parenting stress frequency, as well as caregivers who reported their child's HRQOL as being poorer than the sample average and poorer than their child's average HRQOL over time. Time and child gender were not significantly related to parenting stress frequency in the full model.

The model examining parenting stress difficulty is detailed in the bottom half of Table 2. Caregiver race/ethnicity ($\beta = -19.63$, $p < .001$), caregiver-reported child HRQOL variation within-person ($\beta = -0.76$, $p < .01$), and child HRQOL variation between-person ($\beta = -0.67$, $p < .001$) were significantly related to parenting stress difficulty, such that caregivers who identified as Black/African American, Hispanic, Asian American, or multiracial identity reported significantly greater parenting stress difficulty, as well as caregivers who reported their child's HRQOL as being poorer than the sample average and poorer than their child's average HRQOL over time. Time, child gender, and caregiver-reported child anxiety were not significantly related to parenting stress difficulty in the full model.

DISCUSSION

Caring for a child diagnosed with IBD, a chronic, intermittent disease, introduces sources of parenting stress that are unique and typically novel for caregivers at the time of their child's diagnosis. Results from the current study, which utilized multilevel growth modeling to examine changes in parenting stress across the first year of a child's diagnosis with IBD, demonstrated that parenting stress frequency and difficulty both decreased across the first year of diagnosis. Furthermore, caregivers who identified as Black/African American, Hispanic, Asian American, or multiracial identity reported significantly greater parenting stress frequency and difficulty than White caregivers, as well as caregivers who reported their child's HRQOL as being poorer than the sample average and poorer than their child's average HRQOL over time. Although child anxiety was associated with parenting stress difficulty at diagnosis and 1 year after diagnosis, it was not significant in the final model after including demographic factors and HRQOL.

In the present study, overall parenting stress frequency and difficulty declined significantly over the first year of IBD diagnosis. Such declines may relate to increased understanding of their child's new IBD diagnosis over time, as well as efficacy of medical treatments stabilizing IBD symptoms and thus reduced child disease burden. This is consistent with findings from other pediatric medical conditions, including decreased parenting stress and distress over time following initial cancer diagnosis (Fedele et al., 2011; Phipps et al., 2005). Yet, there was significant variation in caregivers' parenting stress trajectories over one year, highlighting that not all caregivers experienced decreases in stress over time. The phenomenon of stable or even increasing parenting stress following medical diagnoses has been observed in other pediatric samples, including epilepsy (Bakula et al., 2021) and diabetes (Nieuwesteeg et al., 2017).

Several demographic factors were related to baseline levels of parenting stress shortly after their child's initial diagnosis. Caregivers who identified as Black/African American, Hispanic, Asian American, or multiracial identity in the present sample reported significantly higher levels of parenting stress frequency and difficulty shortly after their child's diagnosis when compared to White caregivers. Furthermore, the effect of caregiver race/ethnicity remained significant in the final multilevel model after accounting for other demographic and psychosocial variables. Previous examinations of parenting stress across development and among children with and without chronic medical conditions have shown racial-ethnic disparities in parenting stress, possibly due to systemic disadvantages resulting in fewer caregiver and family resources (Nomaguchi & House, 2013). For example, caregivers of color caring for children diagnosed with Type 1 diabetes also reported significantly higher levels of parenting stress, using the same measure in the present study (i.e., PIP; (Streisand et al., 2005). As such, in addition to having a child with a new IBD diagnosis, Black/African American, Hispanic, and Asian American caregivers in the present study may have also experienced other parenting stressors which interplay with managing their child's new medical condition, although a more nuanced investigation was outside the scope of the present study. Further, in the current investigation, child gender was significantly related to parenting stress at diagnosis, such that caregivers of female youth with IBD reported significantly higher parenting stress than caregivers of male youth. However, the effect of gender was not significant when included in the final multilevel model with other demographic and psychosocial variables. This is largely consistent with a previous study within a pediatric IBD sample which found no parenting stress differences across child gender (Guilfoyle et al., 2012), suggesting other factors may play a more clinically meaningful role in parenting stress over time.

At each time point during the first year following diagnosis, caregiver-reported child anxiety and child HRQOL were independently associated with parenting stress, such that higher levels of child anxiety and lower HRQOL were related to higher parenting stress. This is consistent with previous studies in which poorer child psychosocial functioning (e.g., greater anxiety symptoms) and lower HRQOL was associated with higher parenting stress and poorer family functioning (G. Cushman et al., 2020). Though most frequently examined in cross-sectional analyses, some preliminary longitudinal examinations have demonstrated this relationship as well (G. Cushman et al., 2020). However, it is notable in the present study that when accounting for demographic variables, child anxiety symptoms, and child HRQOL in the final models, only caregiver race/ethnicity and caregiver-reported HRQOL remained significant in predicting parenting stress over time. HRQOL in the context of new IBD diagnosis is likely intrinsically linked with parenting stress; health-related functioning impacts not only the child but also the caregivers largely responsible for supporting youth wellbeing and medical care (Gray et al., 2015). Further, HRQOL likely captures a more comprehensive understanding of a child's functioning within the context of an IBD diagnosis as compared to anxiety symptoms specifically, which may be relevant to parenting stress at specific times or in particular settings (e.g., during medical treatment).

Findings from the present study suggest several clinical implications. While parenting stress decreased over the first year of diagnosis, significant variability was observed, highlighting the importance of continued assessment and screening for parenting stress at the individual-level and longitudinally. Higher baseline levels of parenting stress were observed among Black/African American, Hispanic, Asian American, and multiracial caregivers, suggesting the need for increased awareness of and attention to the potential unique stressors affecting families

of color. Additional research will be essential to understanding the unique experiences of these caregivers and to guide clinical care for providing optimal support during the new diagnosis period. Further, significant variability and change in parenting stress over the first year of diagnosis across the overall sample suggests that time alone may not be sufficient in relieving the parenting stress experienced by all caregivers. Caregiver-specific assessment and interventions to address parenting stress and coping following new diagnosis may enhance caregivers' ability to adjust during this transitional period. Although interventions for caregivers of pediatric patients with IBD are limited, findings from an intervention conducted by McCormick and colleagues demonstrated significant declines in parents' pain catastrophizing and more adaptive behavioral reactions to their children's physical symptoms following a one-day intervention and 6-week skills review (McCormick et al., 2010). Pediatric psychologists within medical clinics may consider adapting similar interventions to decrease parenting stress and improve child HRQOL during the year following diagnosis.

As with all research, the current study is not without limitations, which inform several future research directions. The reliance on caregiver report of child anxiety and HRQOL in addition to parenting stress may have introduced source bias, which may be problematic if a caregiver's generally negative outlook inflated scores on all measures. Future studies should examine parenting stress in relation to children's reports of their own anxiety symptoms and HRQOL in addition to depression symptoms, as internalizing symptoms as a composite have shown associations with parenting stress. In the current sample, caregivers of color reported significantly greater parenting stress and difficulty compared to their White counterparts although the percentage of the sample who identified as a person of color was small, presenting a need to explore more nuanced analyses to understand the differential stress experienced by

caregivers of color caring for youth newly diagnosed with IBD. While common among pediatric IBD samples (Hommel et al., 2008), the present sample was predominately of high socioeconomic status (SES) and as such, future research is needed to determine whether these results remain consistent among families of lower SES. Although parenting stress decreased over time for the sample as a whole, inspection of individual trajectories suggests that future research with larger samples may seek to identify whether there are distinct group-based trajectories of parenting stress. It would be especially exciting to examine whether factors associated with lower than expected levels of parenting stress can be identified and whether these factors could be potentially modifiable for parents of children with IBD experiencing greater stress.

A child's diagnosis with a chronic disease such as IBD is likely to be a significant stressor for the vast majority of caregivers, but these results demonstrate that for most caregivers, this stress decreases across the first year of diagnosis. Results suggest, however, that caregivers of color and those who perceive their child's HRQOL to be negatively impacted may be at risk for greater parenting stress. Findings are relevant not only for caregivers themselves but also for youth with IBD since parenting stress has been shown to be associated with their internalizing symptoms and subsequent depressive symptoms (Guilfoyle et al., 2014). Professionals treating youth with IBD should consider how caregivers' experience of their child's disease impacts and is impacted by the child's health and that, regardless of objective disease criteria, perceptions of health are influential for caregivers' overall wellbeing.

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Table 1. Demographics Table

	Mean (*SD*) / n (%)	Range
Days since diagnosis at Time 1	26.15 (11.68)	11 – 46
Caregiver age (years)	45.21 (5.56)	30 – 57
Child age (years)	14.17 (2.31)	8.91 – 17.88
Child gender		
Female	30 (57%)	
Male	23 (43%)	
Relationship to child		
Mother	41 (77%)	
Father	11 (21%)	
Grandparent	1 (2%)	
Caregiver Race/Ethnicity		
White	39 (74%)	
Black/African American	10 (19%)	
Hispanic	1 (2%)	
Asian American	1 (2%)	
More than one race	2 (4%)	
Diagnosis		
Crohn's	42 (79%)	
Ulcerative colitis	10 (19%)	
Indeterminate colitis	1 (2%)	
Physician's Global Assessment		
Quiescent	20 (38%)	
Mild	23 (44%)	
Moderate	9 (17%)	
Child-reported disease activity at Time 1	10.28 (9.27)	0 – 40
Family income at Time 1		
$10,000 to $24,999	4 (8%)	
$25,000 to $49,999	3 (6%)	
$50,000 to $74,999	12 (23%)	
$75,000 to $99,999	7 (14%)	
$100,000 to $124,999	9 (17%)	
$125,000 to $149,999	6 (12%)	
Above $150,000	11 (21%)	
Caregiver education		
Less than bachelor's degree	16 (31%)	
Bachelor's degree or higher	36 (69%)	

Note. Physician's Global Assessment available for $n = 52$ participants.

Table 2. Linear mixed model with time as main effect of parenting stress frequency and difficulty.

Parameter	Estimate	SE	Test (*df*)	*p*
Parenting Stress Frequency				
Intercept	**99.21**	**3.36**	***t* = 29.50 (99.4)**	**< .0001**
Time	**-8.52**	**2.43**	***t* = -3.50 (85.2)**	**.0007**
Parenting Stress Difficulty				
Intercept	**85.14**	**3.60**	***t* = 23.62 (88.1)**	**< .0001**
Time	**-5.23**	**2.29**	***t* = -2.28 (82.6)**	**.0250**

Note. df = degrees of freedom.

Table 3. Linear mixed models with time as main effect and predictors of parenting stress frequency and difficulty.

Outcome: Parenting Stress Frequency				
Parameter	Estimate	SE	Test (*df*)	*p*
Intercept	**109.10**	**4.54**	***t* = 24.01 (78.8)**	**< .0001**
Time	-4.40	2.57	*t* = -1.71 (96.0)	.0906
Child gender (ref = female)	-2.36	4.01	*t* = -0.59 (52.7)	.5576
Caregiver race (ref = caregivers of color)	**-16.35**	**4.10**	***t* = -3.99 (48.3)**	**.0002**
Within person mean-centered IMPACT	**-0.67**	**0.22**	***t* = -2.98 (79.9)**	**.0038**
Between person, grand mean-centered IMPACT	**-0.78**	**0.13**	***t* = -5.97 (60.8)**	**< .0001**
Outcome: Parenting Stress Difficulty				
Parameter	Estimate	SE	Test (*df*)	*p*
Intercept	**96.40**	**5.33**	***t* = 18.07 (71.2)**	**< .0001**
Time	-0.18	2.42	*t* = -0.08 (88.7)	.9401
Child gender (ref = female)	-1.93	5.02	*t* = -0.38 (54.3)	.7022
Caregiver race (ref = caregivers of color)	**-19.63**	**5.32**	***t* = -3.69 (53.0)**	**.0005**
Within person mean-centered IMPACT	**-0.76**	**0.22**	***t* = -3.39 (75.8)**	**.0011**
Between person, grand mean-centered IMPACT	**-0.67**	**0.18**	***t* = -3.73 (59.2)**	**.0004**
Within person mean-centered SCARED	0.17	0.39	*t* = 0.44 (72.7)	.6601
Between person, grand mean-centered SCARED	0.36	0.25	*t* = 1.44 (57.4)	.1561

Note. df = degrees of freedom; HRQOL = health-related quality of life; IMPACT = caregiver-reported child HRQOL measure; SCARED = caregiver-reported child anxiety measure.

Table 4. Demographics by Parenting Stress Frequency and Difficulty at Diagnosis

	Parenting Stress Frequency			Parenting Stress Difficulty		
	Test statistic	*p* value	Effect Size	Test statistic	*p* value	Effect Size
Caregiver age	$r = .06$	.69		$r = .04$	.80	
Caregiver race/ethnicity *(Identifying as White, Identifying with communities of color)*	$t = 2.31$	.03*	$d = .72$	$t = 2.02$	.05	$d = .63$
Child age	$r = -.18$	.21		$r = -.17$	.24	
Child gender *(Male, female)*	$t = 3.01$	< .01**	$d = .83$	$t = 2.48$	.02*	$d = .69$
Child diagnosis *(Crohn's, Ulcerative colitis)*	$t = .88$	.38	$d = .31$	$t = 1.04$	.30	$d = .37$
Physician's Global Assessment *(Quiescent, mild, moderate)*	$F = .08$	.92	$\eta^2 < .01$	$F = .15$	.86	$\eta^2 < .01$
Family income *(Median split, +/- $99,999)*	$t = 1.27$	.21	$d = .35$	$t = 1.14$	.26	$d = .32$

Note. *$p < .05$, and **$p < .01$. Caregiver race/ethnicity dichotomized as those identifying as White and those identifying with communities of color (Black/African American, Hispanic, Asian American, or multiracial identity) due to limited sample size. Cohen's *d* interpretation: .10 ≤ small effect, .30 ≤ medium effect, .50 ≤ large effect. η^2 interpretation: $\eta^2 = .01$ indicates a small effect; $\eta^2 = .06$ indicates a medium effect; $\eta^2 = .14$ indicates a large effect.

Table 5. Correlations Between Study Variables Within Study Timepoint

Time 1 (*N*=53)	1A	2A	3A	4A	5A	M (SD)	Range
1A. PIP-Frequency T1	1.00	.89**	.27*	-.53**	.10	99.96 (24.35)	61 - 159
2A. PIP-Difficulty T1		1.00	.35*	-.53**	.00	85.17 (27.57)	46 - 160
3A. SCARED T1			1.00	-.52**	.18	16.58 (12.41)	1 - 53
4A. IMPACT T1				1.00	-.34*	126.34 (18.48)	81 - 164
5A. SRDA T1					1.00	10.28 (9.27)	0 - 40
Time 2 (*N*=39)	1B	2B	3B	4B	5B	M (SD)	Range
1B. PIP-Frequency T2	1.00	.85**	.18	-.47**	.20	90.00 (23.52)	52 - 147
2B. PIP-Difficulty T2		1.00	.13	-.48**	.19	81.00 (24.33)	43 - 129
3B. SCARED T2			1.00	-.28	-.06	11.87 (10.74)	0 - 44
4B. IMPACT T2				1.00	-.13	134.63 (13.86)	108 - 162
5B. SRDA T2					1.00	9.13 (10.40)	0 - 35
Time 3 (*N*=32)	1C	2C	3C	4C	5C	M (SD)	Range
1C. PIP-Frequency T3	1.00	.94**	.30	-.55**	.19	83.03 (29.19)	8 - 142
2C. PIP-Difficulty T3		1.00	.36*	-.54**	.19	74.47 (30.78)	7 - 129
3C. SCARED T3			1.00	-.57**	.67**	14.10 (13.94)	0 - 55
4C. IMPACT T3				1.00	-.52**	139.55 (17.81)	92 - 159
5C. SRDA T3					1.00	7.79 (8.98)	0 - 40

Note. *$p < .05$ and **$p < .01$. PIP: Pediatric Inventory for Parents. SCARED: Screen for Child Anxiety Related Disorders; IMPACT = caregiver-reported child HRQOL measure; SRDA: Self-reported disease activity. Time 1 = within 45 days of diagnosis, Time 2 = 6-month follow-up, Time 3 = 1 year follow-up.

Table 6. Comparisons Between Full Completers Versus Those Missing a Data Collection Point

	Completed 3 Time Points (N=27)	Did Not Complete 3 Time Points (N=30)	*p*-value
Caregiver Race			0.76
White	19 (70.37)	20 (74.07)	
Non-White	8 (29.63)	7 (25.93)	
Missing	0	3	
SCARED	16.07 (10.96)	17.33 (13.74)	0.71
IMPACT	126.1 (17.79)	126.5 (19.14)	0.94
Physician's Global Assessment			0.10
0	14 (51.85)	7 (25.00)	
1	10 (37.04)	14 (50.00)	
2	3 (11.11)	7 (25.00)	
Missing	0	2	
Parenting Stress Frequency	98.63 (27.55)	101.30 (20.98)	0.69
Parenting Stress Difficulty	85.82 (32.20)	84.50 (22.39)	0.86

Note. Categorical variables are shown as frequency (percentage) while continuous variables are shown as mean (standard deviation). Caregiver race/ethnicity dichotomized as those identifying as White and those identifying with communities of color (Black/African American, Hispanic, Asian American, or multiracial identity) due to limited sample size. SCARED: Screen for Child Anxiety Related Disorders; IMPACT = caregiver-reported child HRQOL measure.

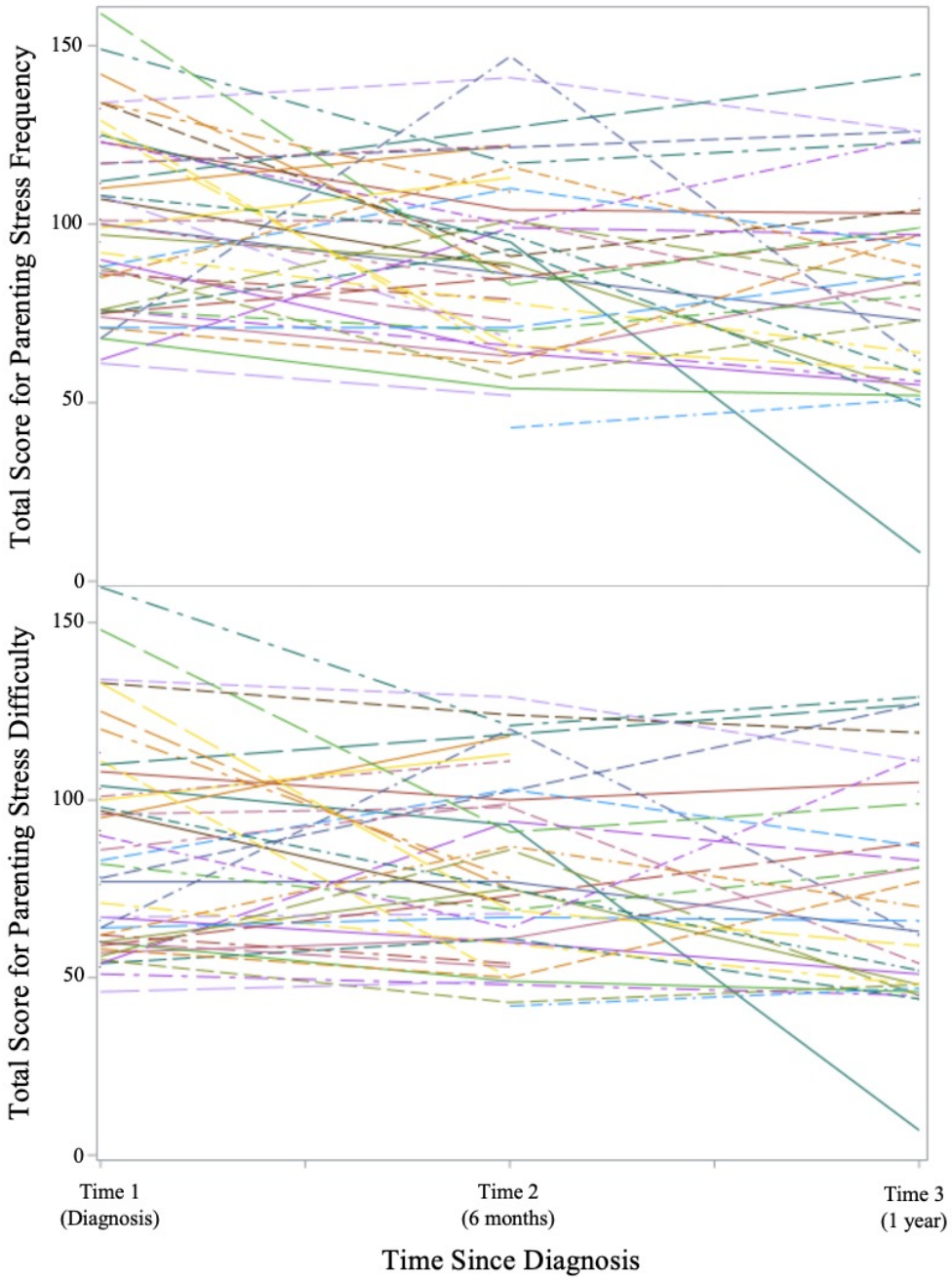
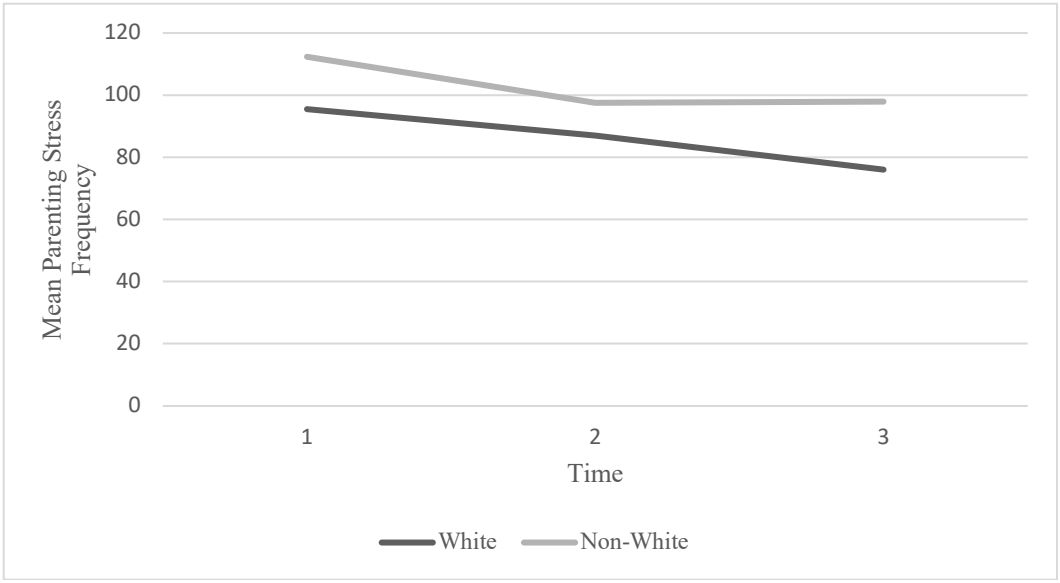


Figure 1. Data trajectories for parenting stress frequency and difficulty over one year of IBD diagnosis.



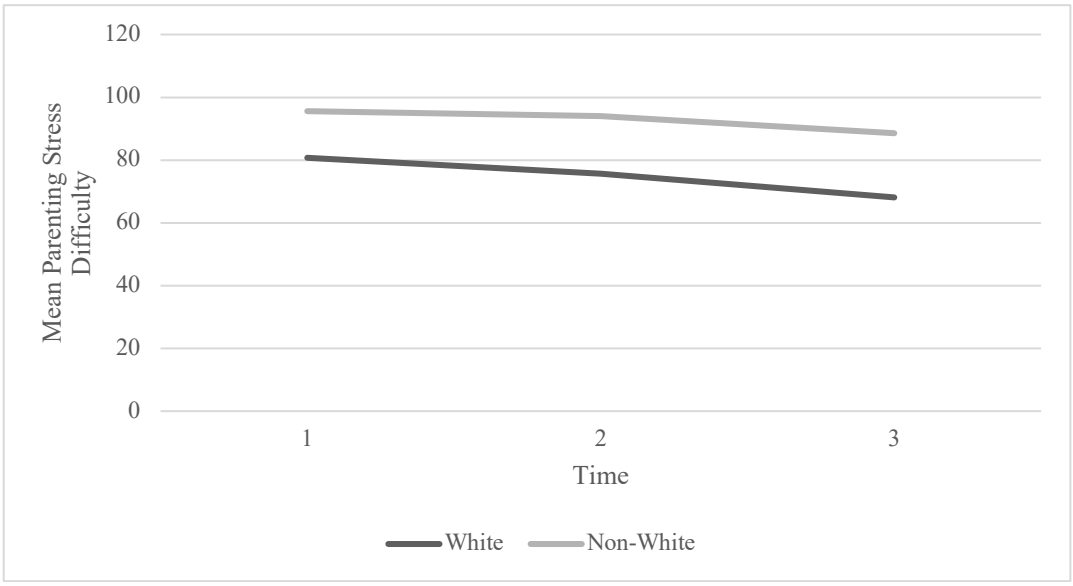


Figure 2. Mean levels of parenting stress frequency and difficulty for caregivers who identifed as White compared to caregivers who identified as Non-White over one year of IBD diagnosis.