

**Child and Family Perspectives on Adjustment To and Coping With Pediatric
Inflammatory Bowel Disease**

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Abbreviations: IBD – Inflammatory Bowel Disease

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Contributors' Statement Page

Dr. Easterlin conceptualized and designed the study, collected data, carried out the analyses and interpretation of data, drafted the manuscript, and reviewed and revised the manuscript.

Dr. Berdahl carried out the analyses and interpretation of data, drafted the manuscript, and reviewed and revised the manuscript.

Drs. Rabizadeh and Spiegel conceptualized and designed the study, oversaw acquisition of data, and reviewed and revised the manuscript.

Lauren Agoratus and Clarissa Hoover were involved with analysis and interpretation of data and reviewed and revised the manuscript.

Dr. Dudovitz conceptualized and designed the study, oversaw the analyses and interpretation of data, and reviewed and revised the manuscript.

All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

Abstract

Objectives: Children with inflammatory bowel disease (IBD) are at increased risk for poor mental health. The etiology of this risk is not clear, though may be related to the disease, its treatment, and/or the experience of these. We sought to 1) describe the challenges that children with IBD and their families face in living with a chronic condition and undergoing repeated intravenous infusions; 2) identify coping mechanisms to understand how medical systems may support resilience.

Methods: Semi-structured qualitative interviews with 18 patient-guardian dyads at a tertiary outpatient infusion center, explored feelings related to IBD, the infusion process, and coping. Interviews were recorded, transcribed, and analyzed in ATLAS.ti. Two coders 1) identified themes; 2) developed a codebook and coded transcripts using the constant comparative method; and 3) described themes/patterns.

Results: Participants identified challenges related to IBD (unpredictable nature, disrupted normalcy, treatment decisions, managing relationships, life transitions) and a subset of challenges related to the infusion procedure (anxiety of unknown, managing pain/anxiety during IV placement, logistics). Participants coped through social support, cognitive strategies (positive attitude) and/or behavioral strategies for managing emotions (preparation for IV placement), and confidence in the medical care. By employing these coping strategies, participants came to accept IBD, adapt to the “new norm,” and learned life lessons and resilience.

Conclusions: To support coping clinical teams might provide anticipatory guidance to decrease anxiety of the unknown and identify cognitive-behavioral strategies for managing emotions. Delivery systems that build relationships, maintain normalcy, and consider needs of the family may further facilitate coping.

What is known:

- Approximately 25% of new diagnoses of inflammatory bowel disease (IBD) occur in childhood or adolescence
- Pediatric patients with IBD are at increased risk for poor mental health

What is new:

- Medical teams might support healthy coping through anticipatory guidance to decrease anxiety of the unknown and identifying cognitive and behavioral strategies for managing emotions and pain.
- Delivery systems that build relationships, maintain normalcy, and are family-oriented may further facilitate coping.

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INTRODUCTION

Inflammatory bowel disease (IBD) including crohn's disease and ulcerative colitis, is characterized by chronic, relapsing inflammation of the intestine.¹ Symptoms include abdominal pain, diarrhea, fatigue, and weight loss. Treatment is aimed at symptom control and prevention of disease progression and may involve oral and rectal medications, specific diets, and infusions of biologic agents.ⁱⁱ About 25% of new diagnoses of IBD occur in childhood or adolescence.²

Pediatric patients with IBD are at increased risk for depression and anxiety, poor health-related quality of life, difficulties with social and school functioning, and attempted suicide.^{2,iii,iv,v} Adult IBD patients are also at increased risk for depression and anxiety.^{vi,vii} The etiology of these increased risks may be related to disease symptomatology, disease experience, treatment experience and/or side effects, and interplay between the gut, chronic inflammation, and central nervous system.^{5,viii} Additionally, the effect of repeatedly experiencing painful or distressing procedures required for diagnosis and treatment is not well understood. Two studies, both in adult patients, have examined post-traumatic stress symptoms in IBD patients and prevalence ranged from 19-32%.^{8,ix}

To better understand how medical systems may support resilience against poor mental health outcomes for children with IBD, we sought to qualitatively examine the challenges children with IBD and their families face and how families cope. While a number of studies have examined IBD challenges, fewer studies have qualitatively examined coping,^{x,xi} especially with the intention of informing the delivery of clinical care, and none have specifically looked at how undergoing repeated minor medical procedures, such as regular intravenous infusions contributes to this experience.

METHODS (415 / up to 750-1000 words)

We conducted qualitative interviews with 18 pediatric IBD patients and their guardians (June-September 2018) to explore reactions related to the diagnosis of IBD, repeated medical procedures (intravenous infusions of medication typically every 6 weeks), and factors that enable coping. This study was approved by the IRBs of Cedars-Sinai Medical Center and University of California Los Angeles.

Participants

We recruited: 1) pediatric patients (age 8-18 years) with a diagnosis of IBD seen in a large tertiary outpatient infusion center, and 2) guardians accompanying these children to their appointment who spoke English, by intentional sampling to ensure the range of feelings and experiences was captured. Interviews were conducted until thematic saturation was achieved. Twenty patient-guardian dyads were approached for consent; eighteen agreed to participate (acceptance 90%).

Interview Protocol

Semi-structured interview guides were based on the literature, research objectives, and investigators' experience. Separate interview guides were developed for patients and guardians (Supplemental Digital Content <http://links.lww.com/MPG/B802>). We included both IBD patients and their guardians to better understand the interplay between child and parent health, as family functioning and parental affect play a role in the patient's mental health,^{2,xii} and parental mental health is in turn affected by their child's health. Interviews were conducted in English during an infusion appointment in a private room and lasted approximately 40 minutes (range 25-60). All interviews were conducted by the first author. Patients and guardians had the choice to be interviewed together or apart; all chose to be interviewed together. More than one guardian (mother and father) was allowed to participate if the family chose. Interviews were first performed with patients followed by guardians. Guardian permission and informed consent were obtained prior to all interviews, in addition to child assent for patients aged 13-17. Interviews were audio-recorded and transcribed for analysis.

Data Analysis

Two coders independently coded transcripts. All analyses were conducted using the qualitative analysis software ATLAS.ti (Scientific Software Development GmbH, Berlin, Germany). A three-step coding approach was used: First, the coders identified themes related to the two main study areas: 1) challenges families with IBD face; and, 2) coping mechanisms. Second, each coder independently developed a codebook and coded transcripts using the constant comparative method. Finally, the coders described themes, sub-themes, and patterns. The coders met to discuss themes and patterns and identify representative quotations.

Discrepancies were resolved by consensus between the two coders. Results were further reviewed with family stakeholders to assess accuracy, generalizability, and clinical applicability. Family stakeholders were experienced family caregivers and advocates, and are co-authors of this paper.^{xiii}

RESULTS (1497 / up to 750-1000 words)

The average age of patients was 13 years, about half were female, the majority were non-Hispanic white, and had private insurance (Table 1). Mothers were the most common guardian respondent. 61% of patients had crohn's disease and 39% had ulcerative colitis; the duration of their disease, time from diagnosis to initiation of infusions, duration of infusions, and disease severity score at both initiation of infusions and time of interview are shown in Table 1. All patients were in remission at time of interview. Further, disease characteristics including type, location, need for surgery, and extraintestinal manifestations are presented in the Supplemental Digital Content Table 1 <http://links.lww.com/MPG/B802>. Overall, participants described a process of accepting their diagnosis and adapting to the “new norm” of infusions (Figure 1). They identified challenges related to IBD (the unpredictable nature, disrupted normalcy of life, anxiety about treatment decisions, challenges managing social relationships, and anxiety about transitions from childhood to adulthood) and a subset of challenges related to the infusion procedure (anxiety related to the unknown, managing pain and anxiety during IV-placement, and logistical considerations of appointments). Participants described coping strategies that addressed these challenges. By employing these strategies, participants not only came to accept IBD diagnoses and adapt to the “new norm,” but also learned life lessons and built resilience.

1. ACCEPTING THE DIAGNOSIS AND ADAPTING TO THE “NEW NORM”

Patients described a process by which they came to accept their diagnosis (Supplemental Digital Content Table 2 <http://links.lww.com/MPG/B802>). Their initial reaction was surprise, as the diagnosis represented a disruption of their identity as “normal” healthy children. Following initial shock, some patients described denial and questioning while others described sadness and trepidation due to concerns about frequent medications, needles and pain, and changed dietary habits. Ultimately, most patients came to accept the diagnosis with symptom control as patients

felt they had achieved a “new normal.” One patient explained, *“I don't think of it much until I come here (the infusion center). I'm like, 'Oh, I have Crohn's again.'”*

Like patients, guardians described a process of adjusting to IBD diagnoses. They felt it was a “roller coaster”, especially until a treatment regimen stabilized the child’s disease. Most guardians had not adjusted to their child’s disease until approximately 2 years after the diagnosis: *“That first couple months to even couple years for some families can be really challenging until you get your kid in a good treatment plan. Even then, everybody is always like, 'How's he doing?' I'm like, 'You know, some days good, some days bad.' It's just the way it is. It's a new normal.”*

2. CHALLENGES WITH IBD AND INFUSIONS

Within the context of acceptance and adaptation to the new norm, families described challenges that persisted. Patients struggled with the unpredictable nature of the disease and disrupted normalcy of life, while parents worried about treatment decisions, managing social relationships, and transitions from childhood to adulthood.

Pediatric Patient Perspectives

Unpredictable Nature of Disease

Patients described the unpredictable nature of IBD as a major challenge (Table 2). They worried the disease could flare at any time and flares could be triggered by stress and lifestyle factors. Flares are not only painful but disrupt social and school-related activities. One patient described, *“...when I'm under a lot of stress... it takes a hard toll on my stomach, and I can potentially flare..... That makes it hard in school, if I'm missing school because I'm in a flare up, it's hard to catch up and get back on track.”*

Disrupted Normalcy

For most patients, one of the main challenges was not being “normal.” They expressed frustration with needing to prioritize their health, which sometimes meant missing social events. A few patients hid their diagnosis from friends because they feared being “viewed as a disease.” Most were more open, but acknowledged that, because symptoms involve bowel habits and manifestations are not outwardly obvious, it was difficult to initiate conversations about their disease. One patient summarized, *“I feel like the biggest challenge is ...trying to be a normal kid*

even though there's that one thing that stands out for me from everyone else.” Infusion appointments also disrupted normalcy due to time away from school and difficulty explaining absences.

Guardian Perspectives

Treatment Decisions

Guardians worried about obtaining quality medical care and making informed treatment decisions, particularly with regards to medication side effects. They also worried about the financial stress of medical care and insurance coverage.

Managing Social Relationships

Guardians recognized that chronic illnesses affected the whole family, including relationships with siblings and between spouses, as well as parenting decisions. They also worried their children would be treated differently by friends or teachers.

Life Transitions

Finally, guardians worried about life transitions, such as high school, college, and adulthood. They worried about preparing their child to manage their health and healthcare, and the implications of that responsibility on other life choices: *“I worry about the long term management for him....At some point in time, he's gotta take control of his own life, right?..What's he gonna do when he has a job and he's sick?”*

CHALLENGES WITH INFUSIONS

A subset of IBD-challenges related to the infusion procedure. Patients and guardians described similar infusion-related challenges and agreed that anxiety related to the unknown and managing pain and anxiety during IV-placement were the biggest challenges.

Anxiety Related to the Unknown

Similar to adapting to the diagnosis of IBD, families described a process of adapting to the infusion procedure. At first, they felt anxious because they did not know what to expect. - With experience, families came to learn the process and could anticipate what was going to happen. They developed comfort with the care team and realized the infusions helped control the disease.

Managing Pain and Anxiety with IV-Placement

Patients described anxiety leading up to IV-placement and pain with placement. For a few, the anticipatory anxiety started 1-2 days before the appointment and lasted until returning home. Similarly, parents described feeling helpless watching their child suffer through IV-placement. They struggled to support their child while managing their own anxiety. One parent explained her biggest challenge was *“The IV. And helping him through the anxiety of it. And me trying not to exacerbate that anxiety.”*

Managing Logistics

Parents also worried about managing day-to-day activities around appointments, including scheduling around school/work, the drive/traffic, and care for siblings.

3. COPING MECHANISMS, LIFE LESSONS, AND BUILDING RESILIENCE

Patients and parents described similar mechanisms for coping with IBD and infusions including: social support, cognitive strategies for managing emotions, behavioral strategies for managing pain and anxiety, and confidence in the medical care (Table 3).

Social Support

Families drew strength from relationships. Children relied on parents to navigate the diagnosis of IBD and repeated IV-placement. Parents relied on spouses and family members for support. Families also relied on information from others affected by IBD and educational supports such as tutors. Both children and parents highlighted the strength they drew from their relationships with the care team.

Cognitive Strategies for Managing Emotions

Families used a variety of cognitive strategies to manage emotions, including cognitive reframing, maintaining optimism, and focusing on treatment benefits. They dealt with negative emotions about the infusion process by focusing on the benefits of treatment and the opportunities the appointment afforded to interact with the healthcare team. Some parents hid their emotions from their child, trying to be positive and calm.

Behavioral Strategies for Managing Pain and Anxiety

Families described a variety of behavioral strategies for managing pain and anxiety during IV-placement. For most patient-parent dyads, these were well-practiced with clear role

assignments. Adherence to a routine helped both patients and parents cope with the procedure. For some families, routines involved preparation steps starting at home such as hydration, applying topical anesthetic, and discussing appointment-related anxiety. At the time of IV-placement, many patients used breathing exercises and distraction techniques, and parents assisted with this. Patients also found opportunities to exert control over the procedure such as choosing the IV location and counting down to IV-placement reduced their anxiety. A few families who had major challenges with IV-placement used meditation, psychotherapy, and anti-anxiety medications.

Confidence in Medical Care

Patients and families expressed that confidence in the medical care was essential to coping. Parents emphasized their reassurance from obtaining what they perceived to be high-quality care, often making sacrifices to receive that care. Parents also emphasized the importance of obtaining good information, but specified the source was of utmost importance. Therefore, they valued care teams that were knowledgeable and responsive to questions via phone or email. They were also highly supportive of care delivered in a multi-disciplinary team-based manner.

Life Lessons and Building Resilience

Unexpectedly, when asked about lasting impacts of the disease or infusion experience, patients were more likely to identify positive (life lessons and resilience) than negative impacts (Table 3). Similarly, parents relayed positive growth from the challenges they faced due to their child's IBD – they learned new things, formed new relationships, and assumed new responsibilities. They felt it had given them more empathy and led their children to develop resilience, inner strength, and a positive outlook on life.

DISCUSSION (799 / up to 1000 words)

This study sheds light on the challenges families with IBD face undergoing repeated medical procedures and the coping mechanisms they use to build resilience. The findings align with Pearlin's stress process model, which holds that the effects of stressors depend on the extent to which stressors proliferate as well as on individuals' social and personal resources, including social support and self-concept.^{xiv,xv,xvi} Extensions of the model suggest negotiating meaning over stressful life circumstances (focusing on life lessons, building resilience), can enhance coping and lead to better outcomes.^{xvii}

The findings are consistent with previous research on challenges of and coping with other chronic diseases, but expand this literature by specifically investigating IBD and a repeated minor medical procedure. Like in studies of other chronic diseases, we find that it takes time for families to accept or “resolve” the diagnosis of a chronic condition and adapt to the new norm^{xviii} and for parents to find the balance between “controlling” and “letting go” as children transition through life stages.^{xix} Also like previous studies, we find that coping mechanisms include social support and education about the illness.^{xx} We expand upon this literature by studying coping with the intention of informing clinical care and by specifically examining the effects of repeated minor medical procedures, which are common among those with chronic illness.

Positive coping styles are associated with less illness uncertainty and better outcomes.^{xxi,xxii} Our participants described cognitive strategies for managing emotions as particularly helpful when undergoing procedures and hence might be especially effective at decreasing mental health effects from medical trauma. Medical teams and care delivery systems may be able to use this information to promote coping. For instance, clinical teams might provide anticipatory guidance to decrease anxiety related to the unknown, both in living with a chronic illness and preparing for medical procedures. For IBD this might include introductory information about the condition, stories from other patients and parents, and detailed information about the infusion procedure. One parent suggested a video that would walk a family through the infusion process before their first appointment. Connecting families to others with IBD might provide further anticipatory information and social support.

Medical teams might also support coping by helping patients identify cognitive and behavioral strategies for managing emotions. Many families described facing serious stress and pain with IV-placement before learning behavioral techniques such as use of topical anesthetics, pre-hydration, breathing exercises, and distraction. Although families developed a variety of helpful behaviors over time, this process could be expedited if healthcare teams routinely incorporated these strategies into their practice. Child Life Specialists are an important source of education and coping skills and could assist. Additionally, clinics could offer a checklist or menu of options that would allow patients and families to identify interventions to control pain and anxiety to use during their procedures. The families in our study also described coping strategies that are cognitive behavioral therapy techniques (reframing, optimism, focusing on benefits).

Incorporating psychologists into the healthcare team could help disseminate and hone these techniques.

Finally, healthcare delivery systems that build social relationships, maintain normalcy, and consider the needs of the whole family may further facilitate coping. Both patients and guardians felt relationship-building, especially with the healthcare team, facilitated coping. Conversely, disruption to normalcy, logistical considerations, and effects on other family members were challenges. Healthcare delivery systems that are multidisciplinary, incorporate flexible hours (evenings, weekends), and are family-oriented (offer child care and integrated mental healthcare for family members) may facilitate relationship building, decrease logistical costs, and improve mental health and coping for the entire family.

Our study was conducted among patients with a single condition at a single institution serving largely Caucasian middle class families, which may limit the generalizability. Coping repertoires are likely influenced by social and economic circumstances.¹⁴ It is unclear if the generally positive narrative provided by families reflects the usual course, a selection bias in the sample, or a reluctance to share negative stories with researchers. Additionally, although participants were given the option to have their interviews conducted separately, all chose to be interviewed together. As a result, parental respondents heard the interview questions and their child's responses prior to giving their own responses, which may have affected their answers. However, many of the questions focused on parents' own thoughts and parents' answers were largely distinct from their child's.

Ultimately, patients and families were able to find optimism and positivity in a challenging situation. Without prompting, families offered that these challenges created new life experiences, life lessons, and resilience. The coping mechanisms identified, including social support, cognitive techniques for managing emotions, behavioral strategies for managing pain and anxiety, and confidence in the healthcare team might decrease negative mental health effects of chronic illness. We hope that medical providers and healthcare delivery systems may use this information to promote coping.

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Legends for Tables and Figures

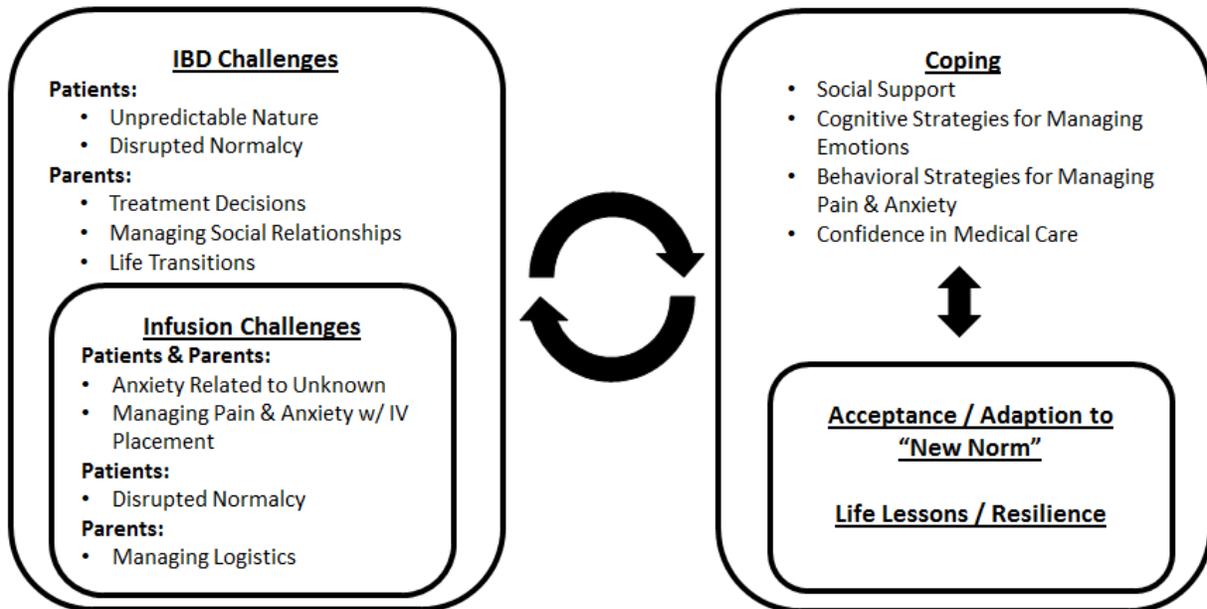


Figure 1. Schematic Depicting Process of Adaptation and Acceptance, with IBD Challenges, Infusion Challenges, and Coping Mechanisms

Participants identified challenges related to IBD and a subset of challenges related to the infusion procedure. They described coping strategies that addressed these challenges. By repeatedly facing challenges and coping, participants came to accept IBD diagnoses and adapt to the “new norm.” They also learned life lessons and built resilience.

Table 1. Descriptive Statistics for Patient Population (n=18 patients)

	Range or Frequency	Median (1st, 3rd Quartile) or Percent
Patient Age	8 – 17 years	13.5 (12, 14.75) years
Gender		
Female	10	56%
Male	8	44%
Race/Ethnicity		
White	16	89%
Hispanic	1	6%
Asian	1	6%
Insurance Type		
Private	17	94%
Public	1	6%
Duration of Disease	1 month – 8 years	3.5 (1, 5.75) years
Time from Diagnosis to Initiation of Infusions	0.5-96 months	3 (1.25, 6.75) months
Duration of Infusions	1 month – 6.5 years	2.25 (0.94, 3.86) years
Crohn's Disease	11	61%
PCDAI		
At Infusion Initiation*	0-40	20 (7.5, 30)
At Time of Interview	0-25	0 (0, 5)
Ulcerative Colitis	7	39%
PUCAI		
At Infusion Initiation*	0-60	35 (7.5, 42.5)
At Time of Interview	0-15	0 (0, 0)
Family Respondent		
Mother	9	53%
Both	5	29%
Father	2	12%

Other	1	6%
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Notes: N=18 for patients. N=17 for family respondent (there was one parental respondent for two sibling patients). PUCAI=Pediatric Ulcerative Colitis Activity Index; PCDAI=Pediatric Crohn's Disease Activity Index. Family Respondent denoted as "Other" was the patient's grandmother who had custody of the patient.

*Data for PCDAI/PUCAI at time of infusion initiation was not available for 2 patients with crohn's disease and for 2 patients with ulcerative colitis as infusions were started at an outside institution. In these cases, severity scores were given at the time of first visit to our center. Time to first visit at our center for these patients ranged from 0.5-23 months with median (1st, 3rd quartile)=11 (2.38, 20) months post Remicaide initiation. Severity scores given at time of first visit were included in the analysis resulting in lower severity scores as infusions had already been started. If severity scores for these individuals are excluded the data are as follows: PCDAI at infusion initiation range=5-40 and median (1st, 3rd quartile)= 25 (20, 30); PUCAI at infusion initiation range=0-60 and median (1st, 3rd quartile)=42.5 (20, 57.5).

Table 2. Selected Quotes Illustrating Challenges Related to IBD and Repeated Infusions

Theme	Representative Quotation	Theme	Representative Quotation
Child		Parent	
<p>IBD Challenges</p> <ul style="list-style-type: none"> • Unpredictable nature of disease 	<ul style="list-style-type: none"> • <i>“Well, with IBD I’ve actually had a really hard time because in the beginning, my symptoms were consistent and they were just stomach related, but then as the years went by, like every single year, I’d have a new kind of outbreak of IBD in a different area....It’s all related to IBD and I didn’t know that.”</i> • <i>“But, it (getting infusions) is much better than having to go potty like 20 times a day...Like I would miss my favorite classes at school.”</i> • <i>“I don’t really face that many</i> 	<p>IBD Challenges</p> <ul style="list-style-type: none"> • Treatment decisions - considering medication side effects / insurance coverage 	<ul style="list-style-type: none"> • <i>“I think the biggest challenge is probably deciding Remicade...because you also have to look at all sides...the possible side effects and risks and the possible upsides, and you just have to weigh it.”</i> • <i>“I also worry sometimes about whether the medicine will continue to work, whether she will develop antibodies, what the possible side effects are. What side effects does she deal with now? Does it make her tired? Does she get sun burned all the time? All that kind of stuff.”</i> • <i>“So for me, keeping my job to have that insurance, it’s a main</i>

	<p><i>challenges, but it's just the fact that it can, at any time, come back, so that's scary."</i></p>		<p><i>thing."</i></p> <ul style="list-style-type: none"> • <i>"The insurance, they're hard to deal with... They ask for so much, they ask for everything."</i>
<ul style="list-style-type: none"> • Disrupted Normalcy - not being "normal" / "like everyone else" 	<ul style="list-style-type: none"> • <i>"I think the biggest challenge for me is accepting it. I still, I guess you'd say was a little in denial that I have it, even though I've had it for like three years. Because it's hard for me to accept that I'm not like normal or whatever, compared to my other friends. Even though I feel normal, I have to do all this to stay healthy."</i> • <i>"A lot of time spent in the bathroom, a lot of urgency, pain. It's almost like a stigma sometimes around it, people not really understanding."</i> • <i>"It's all about poo and stuff that no one</i> 	<ul style="list-style-type: none"> • Managing social relationships - relationships between spouses, treatment of siblings, feelings of siblings, worry about differential treatment of child by teachers, friends 	<ul style="list-style-type: none"> • <i>"It's been challenging. I think when one person in your family has a chronic illness the entire family is affected, there's no way around that. There's still lasting effects."</i> • <i>"Maybe sometimes the challenges between spouses, because my wife gets really worried about every little last thing, and I don't. She visits Dr. Google a little too much, which for Crohn's disease can be very... I don't recommend that for any parent."</i> • <i>"So it changed our life. It was difficult, even between us (spouses), how to manage the whole family. From my perspective, it was hard, because all the attention</i>

	<p><i>really wants to talk about or know about. It's not very fun to talk about. It's not very cute.”</i></p> <ul style="list-style-type: none"> • <i>“Having IBD makes me consider my health and prioritize it a lot more whereas a lot of my friends can do things that may be just more time pressured and where they have to stay up later, and I do that too, but I shouldn't really, and so I've just had to think a lot more about my health at a much younger age, whereas most of my peers don't. That's challenging.”</i> 		<p><i>was on the girls. I have a little boy, and I had to be fair to make sure he doesn't feel left out.”</i></p> <ul style="list-style-type: none"> • <i>“But that's something else I worry about too, is as he gets older, are the teachers gonna judge him? Are they gonna hold things against him?”</i>
		<ul style="list-style-type: none"> • Concern about life transitions 	<ul style="list-style-type: none"> • <i>“For me, it's just thinking about her college experience. We have to figure out how this will all work where she is...Her situation might be a little different</i>

			<p><i>about where she might end up and how we make this all work for her there. I know that seems like far from now, but that certainly is a bigger thing. Just how that whole experience will work out for her.”</i></p> <ul style="list-style-type: none">• <i>“But then, knowing how we are gonna maintain it for the rest of their life, as they're gonna go to college, get married, have children, that type of stuff, it's kind of like something that's always in my mind to think about.”</i>• <i>“But as she's getting older, she's 17 and a half, I feel like my role is to pull back a little bit and have her step up and learn how to advocate for herself and ask the questions herself and she's started to do that. So, it's an important transition because she's going into</i>
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			<p><i>senior year of high school, and we wanna see that she's ready when it's time to go to college - like even one of the things that we're experimenting with this summer, and I think it's a great opportunity - she's gonna go for three weeks, live in a dorm and manage her schedule and herself for three weeks, and I think that's great."</i></p>
<p>Infusion Challenges</p> <ul style="list-style-type: none"> • Anxiety related to unknown 	<ul style="list-style-type: none"> • <i>"Well I used to be quite nervous about it. I know it would be coming and... like it's my impending doom, like oh my God, I'm going to have to get an infusion today. But that's changed...I don't have that much anxiety at all about it anymore."</i> • <i>"I think the first time I was here I was nervous just because</i> 	<p>Infusion Challenges</p> <ul style="list-style-type: none"> • Anxiety related to unknown 	<ul style="list-style-type: none"> • <i>"Certainly the infusions - didn't know what to expect, didn't know how he was gonna respond, didn't know how everything was gonna happen. I think that was anxiety for everybody."</i> • <i>"When we first found out we were going to do them (infusions) it was difficult for all of us, because we didn't know what to expect..."</i> • <i>"The first time we came</i>

	<p><i>it's like, I don't know, something that you don't really think of ever doing when you're 12, but after like the first couple times, it just becomes very normal."</i></p> <ul style="list-style-type: none"> • <i>"It's not as bad as I thought...At first, you're like, 'Oh no, needles.' And then you just get used to it. It's not that big of a deal."</i> 		<p><i>I was pretty anxious because of the not-knowing what's going on and how they do this."</i></p>
<ul style="list-style-type: none"> • Managing pain and anxiety with IV placement 	<ul style="list-style-type: none"> • <i>"Most challenging? It's probably like the IV going in, the pinch. I don't like needles going into me, but I've gotten a little better at that."</i> • <i>"When they put the IV in then I get a little... I dread it..."</i> • <i>"[In the beginning it was] scary...Because I'd have to come every two weeks to get an IV in... I've had to get poked so</i> 	<ul style="list-style-type: none"> • Managing pain and anxiety with IV placement - helping the child manage the procedure and also managing parental anxiety 	<ul style="list-style-type: none"> • <i>"In the beginning, it was challenging because I know it (IV placement) was hard for her, and I wanted to just make sure she was calm and comfortable, and I wanted to support her. And I know she had anxiety about it because it hurt and she was scared. I just tried to be supportive."</i> • <i>"The IV. And helping him through the anxiety of it. And me trying not</i>

	<p><i>many times, and when I was in the hospital too. After like two years it was like nothing.”</i></p> <ul style="list-style-type: none"> • <i>“When we first came in and they said we had to come in every month for infusions, I was very scared. {Because of} the needles [and] the pain.”</i> • <i>“I guess the worst part is just like getting poked.”</i> 		<p><i>to exacerbate that anxiety.”</i></p> <ul style="list-style-type: none"> • <i>“Oh my gosh it's frustrating because he's screaming. It's the last thing you want to hear is your child screaming.”</i>
<ul style="list-style-type: none"> • Challenges to normalcy - time away from school, not telling friends 	<ul style="list-style-type: none"> • <i>“Waiting, being here for a while, missing school, not telling your friends really why you're never at school for these types of times.”</i> • <i>“I have to miss school, and sometimes there's a lot going on in school, and then I just miss everything and don't know what's going on. So</i> 	<ul style="list-style-type: none"> • Managing logistics- transportation, time away from work/school, impact on other family members 	<ul style="list-style-type: none"> • <i>“Well from the sublime to the ridiculous, just the logistics -- of coordinating everybody's schedules, when the infusions are and carpooling and school and who to tell and who not to tell and calling the insurance and sometimes they approve things and sometimes they don't.”</i> • <i>“Just getting him ready, getting things ready,</i>

	<p><i>that's hard.”</i></p> <ul style="list-style-type: none"> • <i>“When I'm here (in the infusion center) is like the only time that I really feel like I have a disease. When I'm going through life with friends in school and sports, I don't really feel like I ever have it, if that makes sense. I feel mostly normal.”</i> 		<p><i>really. Making sure whatever time we have to come, whether I have to get him from school...I have to make sure that school is taken care of, so I can pull him out and bring him here. Just the process of making the day basically scheduling the day properly just to get there.”</i></p> <ul style="list-style-type: none"> • <i>“[What is most challenging about this experience for myself and family is] driving, and, he has a sister and finding things to do with her, so I can get him here.”</i>
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Table 3. Selected Quotes Illustrating Coping Mechanisms and Life Lessons and Resilience-Building

Theme	Representative Quotation	
	Patient	Parent
Selected Quotes Illustrating Coping Mechanisms		
<p><u>Social Support</u></p> <ul style="list-style-type: none"> Strength from relationships (parents, nurses, doctors, friends) 	<ul style="list-style-type: none"> <i>“The nurses all know me very well and I like them. It's just like, it's a very calming experience. No one gets you all freaked out or nervous.”</i> <i>“My family. They were always there for me.”</i> <i>“I'd say definitely try to get a team of people that can help you and support you so that you're not doing it, like you and your parents just on your own, like my mom has done so much research, which has been like really helpful, on like everything involved with IBD, but like if your parents aren't going to do that, then like try to get in contact with people who know about it, or who have gone through</i> 	<ul style="list-style-type: none"> <i>“They hand hold me just as much as they hand hold him, so I feel totally supported through it. I feel like they're here to take care of me too. And they do. They have a nice support system here. I can ask questions, they can give me a hug if I needed it.”</i> <i>“Now they laugh, and they joke, and they have a wonderful relationship and if (specific nurse) is not here he's like, ‘What do you mean? Someone else? Where is she?’ They've developed a really nice friendship. I think that also makes the experience different when you know who's going to be here and you know what to expect...familiar faces...The consistency of that has been really beneficial.”</i> <i>“I have family and friend support. In this case, when we come here. And during the diagnosis, we had a lot of support.”</i>

	<i>it, I guess.”</i>	
<p><u>Cognitive Strategies for Managing Emotions</u></p> <ul style="list-style-type: none"> • Cognitive reframing • Optimism and positivity • Focusing on treatment benefits 	<ul style="list-style-type: none"> • <i>“I try not to look at it in a bad way. I try to work my way around it, try to find something...To do the stuff that I like and to eat the stuff I like, but like work my way around it. To find a different way where it doesn't affect me in a bad way.”</i> • <i>“I just think of what's positive and not negative.”</i> • <i>“I feel better. I have more energy, less pain. That's the one thing I can think about, yeah.”</i> 	<ul style="list-style-type: none"> • <i>“I don't think about it. It just needs to be done, we just do it, and we don't really...I think both of us, we don't really think about it. Something needs to be done, and we just do it, and get it over with and move on, and make the best out of it.”</i> • <i>“Just trying to be very positive and know that a lot of people deal with a lot of challenges in life and this is just what it is, and we're gonna get through it, and you know, trying to just be optimistic.”</i> • <i>“Think about the positive part and having the support of each other, I guess that was how we made it so far.”</i> • <i>“A lot of self-training on how to cope with your psychological, emotional stuff that you are going through.”</i> • <i>“If you show scared, your child is going to be the same way, so just try to be strong for them too. Don't try to [show] your emotions in front of them. If you have to, leave afterwards and cry.”</i> • <i>“It is stressful, you know, knowing that</i>

		<p><i>my child is gonna go through a stress and I'm gonna go with her, maybe double of her experience, but maybe I don't show it, but it's just not fun to go through, and the only thing I tell myself again, 'Well, at least her disease is under control, so that's why we come over here.'</i>"</p>
<p><u>Behavioral Strategies for Managing Pain and Anxiety</u></p> <ul style="list-style-type: none"> Hydrating beforehand, Breathing, Directing IV placement, etc... Distraction techniques Reward after infusion appointment 	<ul style="list-style-type: none"> <i>"So definitely deep breathing, thinking about other things that are more enjoyable, or just whatever. Sometimes listening to conversation...squeezing something. I guess you could say watching a movie or something just to distract yourself. Or listening to music, yeah. Anything that distracts and also just like calms."</i> <i>"I've watched TV before while they're putting the IV in and that's kind of distracting me. But I think music was the most efficient because that's one of my favorite things, it just kind of calmed me down."</i> 	<ul style="list-style-type: none"> <i>"Well first she introduced the (anesthetic) cream which is awesome. Then helped us get a prescription. So we could actually bring it with us. And then marinate the hands for quite a bit, so that actually makes a huge difference. And then she will sometimes put a heat pad. And she told us about hydration beforehand. That the combination... And then once she's doing it (the nurse is placing the IV), and she's really quite slow, gentle, and talks with her. And so she (the patient) can kind of get that sense of connection and comfort. And to know assurance, and to know that she's listening. And then she'll make her count (the patient will make the nurse count). She'll ask the same question, would you please be gentle? And would you please count? Yeah, and then and squeeze me when I'm hugging her. That's the routine every time."</i>

	<ul style="list-style-type: none"> • <i>“I listen to music when I get the IV. It kind of takes my mind off it, helps me relax a little bit. I used to use numbing cream on my arm and that sometimes helped.”</i> • <i>“Getting food helps break it up...Bringing my phone and stuff to watch videos or whatever in between homework is helpful. Other than that, just passing the time basically.”</i> • <i>“I just do homework during the school year.”</i> • <i>“Have a reward at the end that you look forward to, have their parents help them do that.”</i> 	<ul style="list-style-type: none"> • <i>“We've done everything from him going to therapy to talk it through, to him doing meditation and breathing exercises. What else did we do? Oh the numbing cream, distraction, videos, music, tickling, reading, anything that we could possibly think of, bribery.”</i> • <i>“We spend the afternoons, it's actually kind of sweet because I never would have spent that much time with my teenage son.”</i> • <i>“It was kind of our little outing together. Our time.”</i>
<p><u>Confidence in Medical Care</u></p> <ul style="list-style-type: none"> • Knowledgeable staff / Team approach to care 	<ul style="list-style-type: none"> • <i>“Trust in your doctors because they probably know what's best for you and that it does get better.”</i> • <i>“Just that my parents are here and the doctors are nice here.”</i> • <i>“I like it here because everyone's really friendly,</i> 	<ul style="list-style-type: none"> • <i>“I think the quality of care can alleviate most of the things that are trouble for a parent.”</i> • <i>“Where you're treated is a big deal. That's my biggest advice.”</i> • <i>“Someone has suggested to me that we do home infusions and that gives me hives. There's no way. I want you all here to hold my hand...just being here with everyone who knows what they're</i>

	<p><i>and I know the nurses, and they know me. They're just like looking out for my best interest, I guess."</i></p>	<p><i>doing...I love the team approach. I like having all that support."</i></p>
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Selected Quotes Illustrating Life Lessons and Resilience-Building

<p>Life Lessons from living with chronic illness</p> <ul style="list-style-type: none"> • Resilience • Positive outlook • Empathy • Resource to others • Self-learning <p>Perspective, flexibility</p>	<ul style="list-style-type: none"> • <i>"I think I'm a lot better at handling difficult things just in other parts of my life because of this. It's challenging, but I'm able to go through it. It's not fun, but I think I have a good attitude about it, and so that teaches me that like, okay, I can have the same attitude going into other things that may also suck, but it's okay."</i> • <i>"I think it's made me stronger emotionally. I have more sympathy for other people but I also am way more calm. When I'm having problems like with asthma, I'm able to think smart and know what's going on. Because of Crohn's, when I'm having stomach issues, I'm way more understanding of my</i> 	<ul style="list-style-type: none"> • <i>"She's developed a very strong resilience, and she has a very positive outlook in life, and it's not always easy. I mean, there are times that it's a real struggle, and you know, you don't get to do what you wanna do sometimes, just because of health reasons. That's challenging, but I see that she's developed this inner strength, it's a weird way of looking at something that's a challenge, but it has helped her develop herself into a strong-"</i> • <i>"I think I've learned a lot about something I knew nothing about. I think I'm a lot more aware of people who live with a chronic illness and what they have to deal with. I think I can help. I've been a resource to other people whose kids have been diagnosed, or they've been diagnosed themselves."</i> • <i>"It just brought a new aspect to our lives. Thank God we're all okay still. I guess I have more empathy for parents</i>
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	<p><i>body and able to be smart about what's going on, even if it has nothing to do with Crohn's. It's just the same thought process.”</i></p> <ul style="list-style-type: none"> • <i>“It's given me more confidence and stuff. It definitely has given me an outside thought that like everyone's the same in some way...we're all humans and everyone has that one secret that they don't like to share.”</i> • <i>“I have developed a way of finding my way into any bathroom. I can talk my way now, I've just developed that skill. I think it gives me a lot of character and I've also built a lot of friendships around it, I go to camp and stuff like that with a lot of kids that have it. I think it's not as bad. I think it's been interesting because I wouldn't have met a lot people, I wouldn't have</i> 	<p><i>who have kids that aren't in treatable situations.”</i></p> <ul style="list-style-type: none"> • <i>“It pushes you as a parent maybe out of your comfort zone, I guess is the expression. That's not always a bad thing because you learn about yourself. I think it's done that with our whole family, sort of pushed us in ways that we wouldn't normally and it still pushes us to do things.”</i> • <i>“There's no daily reminder that our kids are sick, so we don't run the house like we've got sick kids and the world must-- we haven't shifted any of that.”</i> • <i>“I think that (the infusion experience) made her more resilient. Stronger...Like you're kind of more okay with things changing when you figure out just how to roll with stuff a little bit.”</i> • <i>“That's really what you come to realize that there is no one path and there's no one way. It could look completely different and still be really pretty amazing.”</i>
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	<p><i>experienced a lot of things I have experienced without it.”</i></p> <ul style="list-style-type: none">• <i>“Not in a bad way. In a whole new experience...Like having this done, and finding out I have this, and just looking at it from a different perspective. Seeing other kids, other people have this. Sports athletes have this, and you know, a whole new experience.”</i>• <i>“I think you kind of get an appreciation, certainly for doctors and I think for resources that you have, because I know that stuff like, diseases like Crohn's are a lot impacted by the medicine you get, the food you eat. So, just to be grateful for things you have.”</i>	
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