

# Experiences of Adolescents Who Are Living with Inflammatory Bowel Disease

E. Ann Holmes<sup>1</sup>, Cathy Banwell<sup>1</sup>, Robyn M Lucas<sup>1</sup>, Joanna Hawkes<sup>2</sup>, David Moore<sup>2</sup> & Rachael Rodney Harris<sup>1</sup>

<sup>1</sup>National Centre for Epidemiology and Population Health, Research School of Population Health, The Australian National University, Australia

<sup>2</sup>Gastroenterology Department, Women's and Children's Hospital, Adelaide, Australia

Correspondence: E. Ann Holmes, National Centre for Epidemiology and Population Health, Research School of Population Health, Australian National University, Canberra 2600, Australia.

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## Abstract

**Background:** Inflammatory bowel disease (IBD) is an incurable, chronic, gastrointestinal condition characterised by recurrent bouts of debilitating abdominal pain and diarrhoea. There is little information on how adolescents with paediatric IBD (PIBD) face the challenges of living with the disease and their perceptions of their journeys towards adulthood. This paper reports the findings of a qualitative study on these issues in adolescents living with PIBD in South Australia.

**Methods:** Potential study participants, aged between 12 and 17 years were selected by a treating clinician from the PIBD clinic of a major referral hospital, to achieve gender balance and some diversity in the PIBD stage and severity. In-depth face-to-face interviews focused on participants' perceptions about living with IBD during adolescence and for the future. Interviews were recorded, transcribed and analyzed thematically.

**Results:** Nine adolescents aged 15-17 years consented to participate in the study. Using an overarching theme of 'the journey', three major temporal themes were apparent, namely, 'Reactions at time of diagnosis', 'Learning to cope with IBD' and 'Acceptance and the future with IBD'.

This study demonstrates that, even with optimum support, the pathways towards adulthood were often turbulent and challenging for these young people due to the unpredictability of painful and/or embarrassing physical symptoms. They nevertheless developed strategies which enabled them to accept and cope with a new 'normality' with positivity and determination. More research is warranted to investigate the skills required to navigate this path successfully.

**Keywords:** adolescent, coping, Crohn's disease, inflammatory bowel disease, journey, ulcerative colitis

## 1. Introduction

### 1.1 Inflammatory Bowel Disease

Inflammatory bowel disease (IBD) is a group of debilitating gastrointestinal disorders, including Crohn's disease (CD), ulcerative colitis (UC) and indeterminate (i.e. not able to be classified as either CD or UC) IBD (IBDU). Paediatric IBD (PIBD) affects an increasing number of children and adolescents around the globe (Chouraki et al. 2011; Abraham, Mehta, & El-Serag, 2012; Hong et al., 2018; Lopez, Appleton, Geary, & Day, 2018; Sykora et al., 2018) with research suggesting that the overall incidence of PIBD (before age 18) is 10-20% of the total incidence. The highest annual incidence rates reported are (per 100,000 person years) 23 in Europe, 15.2 in North America, and 11.4 in Asia/the Middle East and Oceania (Sykora et al., 2018).

### 1.2 Living with Inflammatory Bowel Disease

PIBD is often more active and affects a greater part of the bowel than is typical of IBD at older ages (Pigneur et al., 2010; Ruel, Ruane, Mehndru, Gower-Rousseau, & Colombel, 2014). As well as experiencing the common gastrointestinal symptoms of abdominal pain, diarrhoea, passing blood and weight loss (Yu & Rodriguez, 2017),

children with PIBD may also present with the unique manifestations of significant growth retardation (Ley et al., 2016) and delayed puberty (Kao, Denker, Zacharin, & Wong, 2019).

This combination of symptoms and signs seems to be a potential recipe for negative impacts on various facets of life and this view is supported by a number of research studies which found that adolescents with chronic diseases, including PIBD, are at a high risk for clinically relevant emotional or behavioural problems often resulting in significantly lower quality of life than that of healthy individuals (Greenley et al., 2010; Rosen, Dhawan, & Saeed 2015; Varni et al. 2015; Diederer, Haverman, Grootenhuys, Benninga, & Kindermann, 2018; Knowles et al., 2018), and that this is closely positively related to disease activity and fatigue (Marcus et al. 2009; Chow, Otis, & Simons, 2016). Despite this evidence, other research questions the generalisation that all adolescents with PIBD have poorer health-related quality of life than their healthy peers (Rogler et al., 2014, Chouliaras et al., 2017; Mahlmann et al., 2017; Nasiri, Kuenzig, & Benchimol, 2017). The variability across past research findings may be a result of issues related to study methodology, for example, small sample sizes for quantitative data collection, and/or lack of consideration of disease stage and activity, or a focus on specific environments (home, school, social and healthcare) in which children and adolescents live with PIBD.

There has been considerable research on transitioning youth with PIBD through adolescence into adulthood, to managing their disease independently (NASPGHAN, 2015). This self-efficacy is essential for a successful transition. Understanding the acquisition of the skills and knowledge required for this self-efficacy can be partly achieved by examining the journeys, experiences, skills and attitudes of adolescents with PIBD as they approach adulthood.

Much valuable research has been devoted to examining the experiences of adolescents who have PIBD and other chronic diseases (Haas, 2012, Bamed, Stinzi, Mack, & O'Doherty, 2016; Chen, 2016; Sezgin, Weiler, Weiler, Lin, & Hart, 2020), often by using a standard Health Related Quality of Life Questionnaire (Greenley et al., 2010). Few studies have conducted in-depth face-to-face interviews with children with PIBD (Lynch, Bamed et al., 2016, Kluthe et al., 2018; Vejzovic, Bramhagen, Idvall, & Wennick, 2018) and the single one focussing on adolescents (Haas, 2012) was only about CD. To date no face-to-face research has specifically addressed the question of the journey traversed by adolescents as they learn to live with and adjust to these chronic, debilitating, unpredictable and life-long inflammatory bowel diseases as they approach adulthood. In a recent review of qualitative research studies on living with IBD (Fourie, Jackson, & Aveyard, 2018) it was noted that "Further research should be done on adolescents/young adults living with the condition as a significant gap was found in the literature". This study seeks to address this specific gap by using face-to-face interviews to explore the PIBD-related journey of Australian adolescents as they grow towards acceptance, adulthood and independence. It specifically seeks to better understand the experiences and challenges of young adults with IBD and how they navigate the social world at the intersections of chronic illness and young adulthood

## **2. Method**

### *2.1 Participants and Sampling*

Participants were recruited from the Outpatients Department at the Paediatric Gastroenterology Unit at the Women's and Children's Hospital in Adelaide, South Australia between October 2019 and March 2020. The hospital draws patients from the Adelaide metropolitan area and surrounds.

A purposive sampling strategy (Palinkas et al., 2015) was used to recruit male and female participants of various adolescent ages to obtain a range of experiences with PIBD. Participants were recruited by the senior gastroenterologist and senior nurse during visits to the clinic. Inclusion and exclusion criteria were assessed by the senior gastroenterologist at the hospital.

Inclusion criteria included: aged between 12 and 17 years; diagnosed with PIBD; able to understand and respond to questions in English. Adolescents with PIBD were excluded from this study if they had active acute disease, recent surgery or any other condition which was deemed to make them unsuitable for interviewing or if in the opinion of the senior gastroenterologist and senior nurse (as experts in the care of these patients), participation in the study would provoke excessive anxiety or other mental stress on the part of the adolescent. For a small qualitative study, 8-12 participants is recognized as being sufficient (Clarke & Braun, 2013).

### *2.2 Information and Consent to Participate*

Written information sheets about the study were provided to all potential participants and to the parents of those under 16. If potential participants agreed to be contacted about the study, the primary investigator (EAH) phoned them and provided any further study information required. This emphasised that participation was entirely voluntary, that the decision to take part or not would not affect their care in any way and that anonymity would be

protected in any presentation or publication of data collected. They then received consent forms per email. Following this, interviews were scheduled in February 2020 and conducted individually at the Women's and Children's Hospital in Adelaide, South Australia. Following any further explanations and answers to any questions, all patients and all parents of children under 16 years of age provided written consent prior to interviews commencing.

### 2.3 Semi-Structured Interviews

Children aged under 16 years were interviewed with one or both parents present. Those 16 years or over could choose to have a parent present if they wished. Face-to-face interviews were conducted and recorded at the hospital in a designated interview space (Interview protocol was set by the Women's and Children's Health Network Human Research Ethics Committee). All interviews began with an informal chat before the recording started so that the interviewer could establish rapport. After starting the recording, the interviewer invited the adolescent participant to talk about their life before and after diagnosis of PIBD, particularly in relation to sporting activities, schooling, friends, social activities and family, and "life with IBD" now and in the future. The interview guide was used flexibly with follow-up prompts to clarify the adolescent's narrative and check the interviewer's own understanding of the narrative.

### 2.4 Analysis

The recorded data were transcribed by a professional transcriber. The interview transcripts were analyzed thematically by EAH in consultation with CB, following Braun and Clarke's approach (Braun & Clarke, 2006) of familiarization with the transcripts, and developing an inductive and deductive coding framework to identify novel concepts while also addressing the major focus of the study. Ultimately we aimed to identify emergent themes, and the inter-relationships between them. In order to maintain confidentiality, participants have been given pseudonyms in this paper.

### 2.5 Ethics Approval

This study was approved by the Women's and Children's Health Network Human Research Ethics Committee and the Australian National University ARIES Human Ethics Committee; Governance approval was also gained from the Women's and Children's Hospital in Adelaide where the interviews were carried out.

## 3. Results

### 3.1 The Participants

All nine participants were high school students (Table 1) with a clinical diagnosis of PIBD who had not had surgery to treat their condition. All five 16 and 17 year olds opted to be interviewed without a parent present. All but one participant had been living with a diagnosis of PIBD for two years or more at the time of interview (see Table 1).

Table 1. Characteristics of participants

Code name	Gender	Age (years)	Age at diagnosis	disease	Time since diagnosis	Active disease or remission
Ann	female	17	17	UC	4 months	active
Laura	female	17	14	UC	3 years	active
Frank	male	17	11	CD	6 years	active
Bill	male	16	11	CD	7 years	active
Kate	female	16	11	UC	5 years	active
Carl	male	15	10	CD	5 years	remission
David	male	15	13	CD	2 years	active
Grace	female	15	10	CD	4 Years	remission
Jane	female	15	11	CD	3 years	active

UC = ulcerative colitis; CD = Crohn's disease.

### 3.2 Findings

Within an overarching meta-theme of the journey, participants described traversing physical and emotional

instabilities which led towards acceptance of their life-long disease. Their experiences of learning to live with IBD are described below under three temporally organized major themes, namely, “Reactions at the time of diagnosis”, “Learning to cope with PIBD” and “Acceptance and the future with IBD”. There are intertwining and continuing issues and underlying factors shared between the three major themes.

### 3.2.1 Reactions at the Time of Diagnosis: “*what’s happening?*” (Laura)

The journey started with participants generally questioning why they were experiencing pain, fatigue, diarrhoea, vomiting, weight loss and other discomforts that they did not understand and which left them confused. At least two participants were diagnosed reasonably quickly after the onset of symptoms; one, who had three members of her family with IBD, could not remember pre-diagnostic problems so it seems that her diagnosis may have come quickly. Another young man, Frank, also recalled “*So, we went to the doctor. Then he ....told us to go to a hospital for a specialist and check what’s going on. And he discovered the Crohn’s there*”.

But several others had experienced delays in diagnosis which meant that they lived with these debilitating symptoms for varying lengths of time, from a few weeks up to a year. Two thought that general practitioners (GPs) may not have recognized the symptoms of IBD and so treated them for other ailments before referral to a gastroenterologist.

One young woman spoke about how her GP thought she had bulimia or anorexia which led to her parents also having that view: “*They thought the same. They were like, “Well, if the doctor says that, it must be true.” And it was .....I was really upset. It was frustrating*” (Ann).

During this time some participants recounted: giving up sport because of lack of energy, interruptions to school; self-restrictions on social activities for fear of embarrassment; and negative effects on mental health leading several to ask ‘*what’s happening to me, and what am I doing?*’ All but one participant spoke about their search for different foods, thinking that diet may be the cause of their problems. Two participants remembered with great distaste having endoscopies and colonoscopies during the final stages of diagnosis. Jane described this period of the journey as: “*the most difficult time*”.

This time is exemplified in this excerpt:

“*So I got quite depressed from it because.... – my weight was fluctuating constantly, .... bad skin and everything.... self-conscious because I would try everything. Nothing would work. ...why is this happening to me.... I got anxiety because I didn’t want to go out anywhere because of how I felt and how I looked. I was always scared I was going to have to go to the toilet constantly... So I always never wanted to go out or do anything.... never was happy because, yeah, it just affects everything. And especially my mental health....*” (Ann).

The experiences of living with PIBD before and during diagnosis left most of the participants anxious lest they should return to this state of health.

The second stage of their journey began with a clinical diagnosis of IBD which was received with positive but mixed feelings by the participants. They were all pleased that they would now receive treatment, with some expressing relief: “*So finally they found it what it was, so we know the answers to everything*” (Ann). However, Carl identified the significant downside: “*I was relieved...– a bit upset, bit shocked. I was, like – because there’s no cure for it*”. After acceptance of the diagnosis the next step in this journey involved a thorough assessment of the disease and then medication and treatment to control the symptoms. It was clear from most participants that continual medical surveillance and ongoing treatment and medication involved a number of changes in their lives over time with the need to go to the hospital for check-ups, infusions, medication adjustments and other procedures at least every three months. The number of hospital visits changed over time, “*So, I went from eight weeks, every eight weeks to every six weeks, to four weeks then back again. And just chopped and changed*” (Laura). None of the participants expressed any problem with changing regimes.

Medication sometimes changed over time with the need to identify an effective treatment. One concern voiced about medication was about steroid treatment, where Bill said that it made him ‘*emotional*’ and ‘*snappy*’ and Kate said steroids “*plump you up...and make you feel insecure*”. Also Kate, who took a lot of tablet medication each day, thought that this may affect her immune system, as she got sick easily, and that it caused her muscle and joint pain. Laura, who also took a lot of medication, was concerned about how her body ‘*digests it*’.

Nevertheless, all participants seemed to be adjusting to the treatment demands and did not find them too burdensome, with all voicing positive effects on their moods such as: ‘*reasonably calmed down*’, ‘*mostly fine*’, ‘*good*’, ‘*I’m OK*’, ‘*going well*’, ‘*the best at the moment*’, ‘*best I’ve ever been*’. Treatment and medication rendered life for some participants almost similar to that prior to onset of the disease and improved the lives of all of them by

helping to control their symptoms.

Nevertheless, ongoing symptoms may well continue throughout life for many of these adolescents: *“It hasn’t been too bad. But I know if you have a really big flare-up... flare-ups make it very difficult for you to do things ...,”* (Bill). Consequently, a very important, necessary, but often difficult, part of this journey was the need to make adjustments in order to maintain control of their disease and lives.

3.2.2 Learning to Cope with PIBD: *“But, you know, there’d be the hard times sometimes.”* (Frank)

The daily lives of Ann, Carl, Grace and David were not affected a great deal as long as they were careful about their diets and took their medication. But they did not know if and when they may get a ‘flare-up’ with the accompanying pain, diarrhoea and other symptoms. As Carl said: *“So it’s kind of just watch out for any negative signs that something bad is happening or anything”*.

Other participants related various symptoms which they had had to learn to cope with whilst trying to live a ‘normal’ life and the strategies which have helped them to do this. Even when they felt quite well, the unpredictability of the arrival of symptoms made them feel insecure: *“but it’s just been concerning for me and I get nervous”* (Kate). Pain, incontinence, fatigue and nausea, or ‘not feeling well’ were the main ongoing symptoms which all participants had to deal with from time to time with the unpredictability of faecal incontinence being one of the most difficult problems for several of the participants. When the urge occurred they needed to locate a toilet very quickly: *‘So it’s not very lovely’,* (Bill) and *“There’s been a few times where I haven’t made it to the toilet before and it’s gone like through my undies and my pants and stuff where it’s gone onto the floor. Yeah, that was a bit hard”* (Laura at school). Anxiety about incontinence limited some of these adolescents from immersing themselves completely in their social lives as they dared not go anywhere where they did not know where the toilets can be found; some don’t stay with friends anymore or only at the homes of close friends. Travel and eating out were other activities impacted by the threat of faecal incontinence. Surprisingly this hardship did not stop most of them from travelling. One had been to Vietnam and another to the USA. Several just didn’t eat out, missed school camps or social outings to avoid embarrassment and one agreed that she travelled ‘from toilet to toilet’.

The participants constantly struggled with this problem when trying to live ‘normal’ lives. They had a constant fear of embarrassment and some feared being bullied with two participants having to deal with this; one changed schools and one ‘developed a ‘wall’ against it. For some, the presence of symptoms also impacted their whole active life; as Jane put it: *“Yeah, well, it just sucks because like sometimes I just like can’t even move because it’s like that painful. And I just like have to, I just stay in bed”*.

School absenteeism was common amongst the five with most active disease as Frank observed: *“There’s been some tough times. Like getting to school”*. Teachers had been told of the difficulties when it was deemed necessary, allowing extensions to assignment deadlines and, in one case, making ‘special provisions’. With this assistance they all managed to cope with and to stay positive about their educations, noting the importance of education and satisfaction with their progress. All but one aimed to go on to further education after school

Participants knew a lot more about food than before they developed IBD and had taken responsibility to eat foods which did not upset them, carefully watching their diets to discover what was OK for them to eat and two becoming lactose-free. They played a surprising amount of sport and vigorous activity, choosing sports which suited them, with only one not participating in any sport after having been very keen, but eager to return to it. Despite the limited control some participants had over the unpredictable behaviour of their IBD only one had severely limited his social life. This was Frank, who *‘doesn’t go out a lot’* because of insecurity.

Paramount in the process of making adjustments and maintaining control over their lives was the support, understanding and sympathetic awareness they received from parents. This was eloquently stated by Carl: *“Whenever I’m sick or anything, they listen and take care of me, and then if it gets bad enough, they’ll take me to where I need to go to get it helped”*. Friendship support was also important. Five participants had told friends about their illness and all were supportive and understanding. Four participants had told only a few of their friends with two explaining why they had been reluctant to tell more: *“Not all of them know about it. It’s just it’s kind of hard to explain to them, so they don’t ever actually understand, so there’s no point in telling them really”* (Kate); and *“it’s a bit gross what I went through, but I did tell a couple of people because I was away from school quite a lot for it”* (Ann).

Several participants mentioned the importance of ‘understanding’ when talking about parents and/or friends and inferred that this helped them to deal more effectively with the periodically embarrassing and personal nature of their symptoms: *“People that aren’t strong and don’t have the support that I would have, it would be a lot harder to deal with”* (Bill). Another benefit of this understanding was that it helped them feel less isolated and helpless. Yet

Kate felt that true understanding was hard to find: *“no one who doesn't have it like understand”*.

Participants expressed a certain amount of understandable frustration and anxiety in living with PIBD, with perhaps the most forthcoming participant being Kate who said:

*“Oh, sometimes I get a lot, I get breakdowns from that. Like — I cry. I don't know. I think it's just because I just, sometimes it just hits you and you're like why does this have to happen to me. But – Yeah, I don't know. It's just it's a bit like confronting that it had to happen at such a young age. Because some people only get it in their twenties”*.

And Jane who was more succinct: *‘I just don't like it’* and *‘Yeah, well, it just sucks’*. And Bill summed it up for everyone with: *“Some days are just a struggle”*. Possibly the most socially affected of the group of nine was Frank who appeared to only leave his home to go to school. He conducted his social life over the internet with friends:

*“Well, because I'm at home a lot, it makes you lose confidence a bit. Makes you a bit anxious ‘about going out and, you know, going out with friends and stuff like that. And making friends. It can be a bit tough doing that. Yes, it makes that anxious, so you lose your confidence a bit.”*

Three other interesting sources of anxiety were revealed. Bill was concerned that he was a burden to his busy family; Frank feared that he might pass on the disease to children if he had them; and David was concerned that he may not be able to drink alcohol when he is older.

Despite setbacks and continuing symptoms for some, every participant fortified their feelings of self-efficacy using positivity and they talked about inner ‘strength’, comparing their lives favourably with others who were worse off, by *“helping themselves”*, *“trying to be strong”*, or as Grace put it *“Just not worry about it. Sort of get along in life, I guess”*.

As they approached the transition to adulthood older participants were aware that they needed to take more personal control of their lives. Bill reflected: *“I know I can take care of myself. And also I'm getting older, so I'm going to need to do that more”*.

### 3.2.3 Acceptance of a Future with IBD

With time and support participants had learned to deal with the unpredictability of their symptoms and the anxieties which accompanied them. This helped them face and accept the recurring nature of their life-long illness. This group of nine young people showed resilience, a desire for normality, and a positivity that was heart-warming.

Bill, who has had PIBD the longest, can hardly remember life without IBD so it is just ‘normal’ for him. Two others had family members with IBD which helped them accept their condition. As Laura said: *“But I think it'll be - it won't be a normal life but it'll be what I know is normal”* and Kate: *“there's nothing you can do about it, so you might as well just live your life really”*. All were adjusting to a new ‘normality’.

Many of these participants found positive aspects of their condition. They reflected on how having PIBD had made them more mature and more understanding of themselves and others. Carl learned to be more thoughtful of others: *“...someone could have something that you don't know about, but you shouldn't, like, push and try to get them to tell you and stuff”*, while another said: *“I'm stronger than I thought I was honestly”*.

All but one of these participants had plans to further their education, while Frank wanted to start working straight away. Most had high but realistic hopes about their futures. Some were cautiously optimistic saying it would probably be *‘fine but perhaps hard’*, or *‘if it stays like it is now’* and Laura: *“Well, I think the way I'm going now it'd be hard having to still go to hospital and have infusions and be on medication daily and all that jazz. But I think it'll be, it won't be a normal life but it'll be what I know is normal”*. Others had no qualms at all: *‘It doesn't worry me at all’* said Kate, and Jane hadn't given the future any thought at all so far.

## 4. Discussion

This small qualitative study builds upon others that have explored the factors and themes related to young people living with IBD to provide a rich understanding of their health journeys through adolescence. It has produced findings that are mainly consistent with other studies but also provides some new insights. It has demonstrated that, even with optimum support, adolescents will undergo difficulties as their sometimes severe and unpredictable physical symptoms cause them anxiety and embarrassment and disrupt their everyday social lives. Findings overwhelmingly indicated that the frequently turbulent journey for the Australian adolescents in this study was undertaken with surprising positivity as they learned to accept a new normality, while managing the complexities of their lives with pragmatism, determination and resilience. Within the themes identified above, it is clear that the participants were transitioning well through the stages in their journey towards acceptance and adulthood.

First was the acknowledgement and acceptance of the diagnosis of IBD. This was often delayed due to difficulties

in reaching a diagnosis especially for CD (Schoepfer et al., 2017). Subtle signs and symptoms such as unexplained fevers, iron deficiency, anaemia, and non-specific abdominal pain early in the disease course (Purc- Stephenson, Bowlby, & Qaqish, 2015; Carroll et al., 2019) may delay referral to a specialist gastroenterologist (El Mouzan et al. 2019). The relief and often shock at diagnosis is well documented (Haas, 2012; Germeni, Vallini, Bianchetti, & Schulz, 2018; Kluthe et al., 2018). The memory of the difficulties before diagnosis understandably lingered on and caused some mild anxiety; this has also been reported in adults diagnosed with CD (Norton, Thomas, Lomax, & Dudley-Brown, 2012).

Second came the formation of a positive attitude towards a changing and life-long routine of medication and treatment. Despite some unpleasant side effects, participants welcomed the relief brought by medication. As PIBD is incurable, the medication taken by the participants is intended to induce and maintain the patient in remission and ameliorate the disease's secondary effects. Medication is prescribed according to the current needs of a patient and may change many times (Lahad & Weiss, 2015). For young women in particular, steroids can cause sudden unpleasant bodily changes which can influence adolescents' assessment of their body image (McCabe & Ricciardelli, 2004). Nevertheless, all participants appeared to have integrated their medical regimes – both medicines and specialist treatments – into their lives, and adherence to medication did not seem problematic, although no specific question was asked about this. Indeed, adolescent attitudes towards medicine do not appear to have been well researched, although KyngAs et al. (2000) reported a similar finding that medication was not problematic.

Next was the necessity for these participants to learn how to manage ongoing and unpredictable symptoms of their disease. The most common gastrointestinal symptoms of PIBD are fatigue and abdominal pain in CD and rectal bleeding and diarrhea in UC (Perler et al., 2019). Other symptoms include frequency and urgency, loss of appetite and weight loss (Chuong, Haw, Stintzi, Mack, & O'Doherty, 2019). Those participants with less severe disease, or for whom treatment was very successful, were barely affected by ongoing symptoms, but some had to constantly watch for signs of imminent 'flare-ups'. Several were careful about their diets and followed typical dietary strategies to manage PIBD (Norton et al., 2012; Devlen et al., 2014; Chuong et al., 2019).

The two most debilitating symptoms reported by the participants were pain and faecal incontinence. Pain has been shown to negatively impact the ability to attend school regularly, to concentrate in school, and to achieve academic success (Lynch, Calsbeek, Rijken, Bekkers, Dekker, & van Berge Henegouwen, 2006; Assa, Ish-Tov, Rinawi, & Shamir, 2015). It can be relieved somewhat by medication but Norton et al. (2017) (Norton, Czuber- Dochan, Artom, Sweeney, & Hart, 2017) in a review of IBD pain intervention studies concluded that there was a scarcity of evidence for effective treatment, and room for further research in abdominal pain management. It is possible that 'elimination of all abdominal pain among youth with IBD may be an unrealistic treatment goal' (Wojtowicz, Greenley, Gumidyal, Rosen, & Williams, 2014).

Despite medical treatment and advice, several participants noted the devastating social impact and fear of faecal incontinence. Some did not mention it by name yet it was clear from their self-reported behavior that this was a paramount consideration in social activities and adds a significant burden to their lives. Faecal incontinence is a humiliating loss of self-control at any age and possibly more so for young people who fear stigmatization and isolation from their peer group as a result. It is inextricably linked to self-confidence and daily activities and relationships (Khera, Chase, Salzberg, Thompson, & Kamm, 2019). Yet, despite this there does not seem to be a good solution for this problem (Saldana, Ruiz, & Kaiser 2017) with management of faecal incontinence and investigations into therapeutic interventions receiving little attention (Khera et al., 2019).

There is evidence that active PIBD can affect school attendance, participation, and performance (Assa et al. 2015, Carreon, Bugno, Wojtowicz and Greenley 2018, Carroll et al. 2019). Diarrhoea, abdominal pain, and rectal bleeding have been singled out as the most common causes of school absenteeism amongst children with PIBD (Eloi et al. 2019) with medical appointments and hospitalization also contributing (Assa et al. 2015).

There are conflicting reports concerning the effect of chronic illness on educational outcomes for adolescents with chronic pain. In a large longitudinal study in USA, adolescent chronic pain was associated with reduced educational attainment (Murray, Groenewald et al., 2020). However, the school success of our participants, including those who reported frequent pain, is in agreement with the bulk of the literature which finds that most children with PIBD achieve similar school participation (Santos-Antunes, Nunes, Lopes, & Macedo 2016) and success (Mackner, Bickmeier, & Crandall, 2012; Assa et al., 2015; Singh et al., 2015; Malmberg et al., 2019) as those without PIBD. Requesting and receiving extra support from school and staff possibly resulted in our participants coping well. This extra support is a positive step towards optimizing the chances for academic success for these adolescents (Carreon et al., 2018; Freckmann et al., 2018; Carroll et al., 2019; Malmberg et al., 2019).

Another important stage in the journey from adolescence to adulthood is learning to manage their social lives; establishing control over their lives and ‘normalizing’ their experiences helped these adolescents to defeat negative thoughts and facilitate resilience, although this is hard to accomplish alone. Participants in this study relied heavily on family, friends and medical support as has been previously reported in the literature (Nicholas et al., 2007; Bishop, Lemberg, & Day, 2014; Carroll et al., 2019).

Participants indicated that they were mostly very aware of the difficulties connected to their disease; they described them and the impacts they produced and told how they were adapting their behaviour to new circumstances. The importance of acceptance is well documented in the literature (Ambrosio et al., 2015; Zheng, Bruzzese, & Smaldone, 2019; Richard et al., 2020). These participants developed coping skills by learning what to eat, where they could go, and what activities they could participate in, with support, so that they felt socially safe. This was not always easy for those with continuing pain and incontinence, and some level of anxiety correlating with disease severity was to be expected (McCombie, Mulder, & Gearry, 2013; Mahlmann et al., 2017). These results are similar to those reported as experienced by children with chronic disease generally (Cartwright, Fraser, Edmunds, Wilkinson, & Jacobs, 2015; Oppenheimer, Krispin, Levy, Ozeri, & Apter, 2018).

Finally, there was developing a new ‘normal’ with positive hopes for the future; the acceptance of having a life-long debilitating disease was paramount for these adolescents in coming to terms with their futures (Richard et al., 2020). This they seem to have accomplished, or were well on the way to doing so, and without exception they displayed optimism for a positive future and a new ‘normality’. Many were pleased with how they were negotiating this journey and the insights they had gained as a consequence; this unexpected result has been documented previously (Nicholas et al., 2007). The difficulty in continuing to live as normally as possible will always be hindered by the uncertainty of their disease. And this is acknowledged by the participants, illustrating that they are forearmed for the challenges of the future as they approach adulthood.

#### *4.1 Limitations and Strengths.*

This in-depth study collected rich and detailed accounts to build an understanding of the intricate and frequently difficult journeys of adolescents living with PIBD and the skills they acquired to successfully negotiate this journey. However, there are several limitations in our study. Participants were recruited from one paediatric hospital clinic, had similar demographic and socio-economic backgrounds and strong family and medical support which, whilst acknowledging that no two journeys would be the same, contributed towards a similitude in results. Adolescents with less privileged backgrounds may be at a higher risk for poorer clinical disease outcomes.

This study is based on a small (n=9) sample although this is considered sufficient for some qualitative research (Clarke & Braun, 2013; Vasileiou, Barnett, Thorpe, & Young, 2018). Given that IBD is a difficult subject for young people to discuss with strangers, we recruited mainly older adolescent volunteers. Consequently, the findings in this study cannot be generalized to all adolescents with PIBD or to adolescents with other chronic diseases.

Despite these limitations, the participants provided stories that captured some of the complexity of their experiences. Our findings point to the relatively unrecognized strengths and positivity of adolescents living with PIBD, the skills they develop to deal with their conditions, the importance of support from all involved in their lives and the clear implication that more research is needed into answers to the debilitating problem of faecal incontinence in IBD.

This study is the first conceptualization of how some Australian adolescents manage their illness journeys from pre-diagnosis as they move towards greater independence to adulthood and adds to our existing knowledge on adolescents’ own understanding of their illnesses and their road towards self-management of IBD. Such knowledge may contribute towards assisting all adolescents with their transitions to independence.

Though participants in this study reported having developed a good capacity to take charge of their health care regimes with a degree of certainty, much remains unknown about how they develop the skills to achieve this (Szulczewski, Mullins, Bidwell, Eddington, & Pai, 2017). Additional research which focusses on adolescent acquisition of such skills could inform less fortunate adolescents via educational programs.

## **5. Conclusion**

In summation, this study has demonstrated that, even with optimum support, adolescents will undergo difficulties as their severe and unpredictable physical symptoms cause them anxiety and embarrassment and disrupt their everyday social lives. It throws light on the challenges that Australian adolescents living with IBD face as they move towards independence and the critical importance of understanding and support from friends, family and medical staff to develop resilience and optimism for the future.

## Competing Interests Statement

The authors declare that there are no competing or potential conflicts of interest.

## References

- Abraham, B. P., Mehta, S., & El-Serag, H. B. (2012). Natural history of Pediatric-onset Inflammatory bowel Disease: a Systematic Review. *J Clin Gastroenterol*, 46(7), 581-589. <https://doi.org/10.1097/MCG.0b013e318247c32f>
- Ambrosio, L., Senosiain García, J. M., Riverol Fernández, M., Anaut Bravo, S., Díaz De Cerio Ayesa, S., Ursúa Sesma, M., ... Portillo, M. C. (2015). Living with Chronic illness in Adults: a Concept Analysis. *J Clin Nurs* 24(17-18), 2357-2367. <https://doi.org/10.1111/jocn.12827>
- Assa, A., Ish-Tov, A., Rinawi, F., & Shamir, R. (2015). School Attendance in Children With Functional Abdominal Pain and Inflammatory Bowel Diseases. *J Pediatr Gastroenterol Nutr*, 61(5), 553-557. <https://doi.org/10.1097/MPG.0000000000000850>
- Barned, C., Stinzi, A., Mack, D., & O'Doherty, K. C. (2016). To tell or not to tell: A Qualitative Interview Study on Disclosure Decisions among Children with Inflammatory Bowel Disease. *Soc Sci Med*, 162, 115-123. <https://doi.org/10.1016/j.socscimed.2016.06.023>
- Bishop, J., Lemberg, D. A., & Day, A. (2014). Managing Inflammatory Bowel Disease in Adolescent Patients. *Adolesc Health Med Ther*, 5, 1-13. <https://doi.org/10.2147/AHMT.S37956>
- Braun, V., & Clarke, V. (2006). Using Thematic Analysis in Psychology. *Qual Res Psychol*, 3(2), 77-101. <https://doi.org/10.1191/1478088706qp063oa>
- Calsbeek, H., Rijken, M., Bekkers, M. J. T. M., Dekker, J., & van Berge Henegouwen, G. P. (2006). School and Leisure Activities in Adolescents and Young Adults with Chronic Digestive Disorders: Impact of Burden of Disease. *Int J Behav Med*, 13(2), 21-130. [https://doi.org/10.1207/s15327558ijbm1302\\_3](https://doi.org/10.1207/s15327558ijbm1302_3)
- Carreon, S. A., Bugno, L. T., Wojtowicz, A. A., & Greenley, R. N. (2018). School Functioning in Adolescents With Inflammatory Bowel Diseases: An Examination of Disease and Demographic Correlates. *Inflamm Bowel Dis* 24(8), 1624-1631. <https://doi.org/10.1093/ibd/izy026>
- Carroll, M. W., Kuenzig, M. E., Mack, D. R., Otley, A. R., Griffiths, A. M., Kaplan, ... Benchimol, E. I. (2019). The Impact of Inflammatory Bowel Disease in Canada 2018: Children and Adolescents with IBD. *J Can Assoc Gastroenterol*, 2(Suppl 1), S49-S67. <https://doi.org/10.1093/jcag/gwy056>
- Cartwright, T., Fraser, E., Edmunds, S., Wilkinson, N., & Jacobs, K. (2015). Journeys of Adjustment: the Experiences of Adolescents Living with Juvenile Idiopathic Arthritis. *Child Care Health Dev*, 41(5), 734-743. <https://doi.org/10.1111/cch.12206>
- Chen, A. T. (2016). The Relationship Between Health Management and Information Behavior Over Time: A Study of the Illness Journeys of People Living With Fibromyalgia. *J Med Internet Res*, 18(10), e269. <https://doi.org/10.2196/jmir.5309>
- Chouliaras, G., Margoni, D., Dimakou, K., Fessatou, S., Panayiotou, I., & Roma-Giannikou, E. (2017). Disease Impact on the Quality of Life of Children with Inflammatory Bowel Disease. *World J Gastroenterol*, 23(6), 1067-1075. <https://doi.org/10.3748/wjg.v23.i6.1067>
- Chouraki, V., Savoye, G., Dauchet, L., Vernier-Massouille, G., Dupas, J. L., Merle, V., ... Colombel, J. F. (2011). "The Changing Pattern of Crohn's Disease Incidence in Northern France: a Continuing Increase in the 10- to 19- year-old age bracket (1988-2007). *Aliment Pharmacol Ther*, 33(10), 1133-1142. <https://doi.org/10.1111/j.1365-2036.2011.04628.x>
- Chow, E. T., Otis, J. D., & Simons, L. E. (2016). The Longitudinal Impact of Parent Distress and Behavior on Functional Outcomes Among Youth With Chronic Pain. *J Pain*, 17(6), 729-738. <https://doi.org/10.1016/j.jpain.2016.02.014>
- Chuong, K. H., Haw, J., Stintzi, A., Mack, D. R., & O'Doherty, K. C. (2019). "Dietary Strategies and Food Practices of Pediatric Patients, and their Parents, Living with Inflammatory Bowel Disease: a Qualitative Interview Study. *Int J Qual Stud Health Well-being*, 14(1), 1648945. <https://doi.org/10.1080/17482631.2019.1648945>
- Clarke, V., & Braun, V. (2013). Teaching Thematic Analysis: Overcoming Challenges and Developing Strategies for Effective Learning. *The Psychologist*, 26(2), 120-123.

- Devlen, J., Beusterien, K., Yen, L., Ahmed, A., Cheifetz, A. S., & Moss, A. C. (2014). The Burden of Inflammatory Bowel Disease: a Patient-reported Qualitative Analysis and Development of a Conceptual Model. *Inflamm Bowel Dis*, 20(3), 545-552. <https://doi.org/10.1097/01.MIB.0000440983.86659.81>
- Diederer, K., Haverman, L., Grootenhuis, M. A., Benninga, M. A., & Kindermann, A. (2018). Parental Distress and Quality of Life in Pediatric Inflammatory Bowel Disease: Implications for the Outpatient Clinic. *J Pediatr Gastroenterol Nutr*, 66(4), 630-636. <https://doi.org/10.1097/MPG.0000000000001756>
- El Mouzan, M. I., AlSaleem, B. I., Hasosah, M. Y., Al-Hussaini, A. A., Al Anazi, A. H., Saadah, O. I.,... Assiri, A. A. (2019). Diagnostic Delay of Pediatric Inflammatory Bowel Disease in Saudi Arabia. *Saudi J Gastroenterol*, 25(4), 257-261. [https://doi.org/10.4103/sjg.SJG\\_457\\_18](https://doi.org/10.4103/sjg.SJG_457_18)
- Eloi, C., Foulon, G., Bridoux-Henno, L., Breton, E., Pelatan, C., Chaillou, E., ... Dabadie, A. (2019). "Inflammatory Bowel Diseases and School Absenteeism. *J Pediatr Gastroenterol Nutr*, 68(4), 541-546. <https://doi.org/10.1097/MPG.0000000000002207>
- Fourie, S., Jackson, D., & Aveyard, H. (2018). Living with Inflammatory Bowel Disease: A Review of Qualitative Research Studies. *Int J Nurs Stud*, 87, 149-156. <https://doi.org/10.1016/j.ijnurstu.2018.07.017>
- Freckmann, M., Seipp, A., Laass, M. W., Koletzko, S., Classen, M., Ballauff, A., ... Timmer, A. (2018). "School-related Experience and Performance with Inflammatory Bowel Disease: Results from a Cross-sectional Survey in 675 Children and their Parents. *BMJ Open Gastroenterol*, 5(1), e000236. <https://doi.org/10.1136/bmjgast-2018-000236>
- Germeni, E., Vallini, I., Bianchetti, M. G., & Schulz, P. J. (2018). Reconstructing Normality Following the Diagnosis of a Childhood Chronic Disease: Does "rare" Make a Difference? *Eur J Pediatr*, 177(4), 489-495. <https://doi.org/10.1007/s00431-017-3085-7>
- Greenley, R. N., Hommel, K. A., Nebel, J., Raboin, T., Li, S. H., Simpson, P., & Mackner, L. (2010). A Meta-analytic Review of the Psychosocial Adjustment of Youth with Inflammatory Bowel Disease. *J Pediatr Psychol*, 35(8), 857-869. <https://doi.org/10.1093/jpepsy/jsp120>
- Haas, E. (2012). *Adolescent Perceptions of Living with Crohn's Disease*. Master of Nursing Dalhousie University Faculty of Graduate Studies Online Theses 2012-08-14. URI <http://hdl.handle.net/10222/15235>. Retrieved August 3rd, 2020, from <https://dalspace.library.dal.ca/handle/10222/15235>
- Hong, S. J., Cho, S. M., Choe, B. H., Jang, H. J., Choi, K. H., Kang, ... Hwang, J. H. (2018). Characteristics and Incidence Trends for Pediatric Inflammatory Bowel Disease in Daegu-Kyungpook Province in Korea: a Multi-Center Study. *J Korean Med Sci*, 33(18), e132. <https://doi.org/10.3346/jkms.2018.33.e132>
- Kao, K. T., Denker, M., Zacharin, M., & Wong, S. C. (2019). Pubertal Abnormalities in Adolescents with Chronic Disease. *Best Pract Res Clin Endocrinol Metab*, 33(3), 101275. <https://doi.org/10.1016/j.beem.2019.04.009>
- Khera, A. J., Chase, J. W., Salzberg, M., Thompson, A. J. V., & Kamm, M. A. (2019). Systematic Review: Pelvic Floor Muscle Training for Functional Bowel Symptoms in Inflammatory Bowel Disease. *JGH Open*, 3(6), 494- 507. <https://doi.org/10.1002/jgh3.12207>
- Kluthe, C., Isaac, D. M., Hiller, K., Carroll, M., Wine, E., van Manen, M., & Huynh, H. Q. (2018). Qualitative Analysis of Pediatric Patient and Caregiver Perspectives After Recent Diagnosis With Inflammatory Bowel Disease. *J Pediatr Nurs*, 38, 106-113. <https://doi.org/10.1016/j.pedn.2017.11.011>
- Knowles, S. R., Graff, L. A., Wilding, H., Hewitt, C., Keefer, L., & Mikocka-Walus, A. (2018). Quality of Life in Inflammatory Bowel Disease: A Systematic Review and Meta-analyses-Part I. *Inflamm Bowel Dis*, 24(4), 742- 751. <https://doi.org/10.1093/ibd/izx100>
- KyngAs, H. A., Kroll, T., & Duffy, M. E. (2000). Compliance in Adolescents with Chronic Diseases: a Review. *J Adolesc Health*, 26(6), 379-388. <https://doi.org/10.1046/j.1365-2702.2000.00368.x>
- Lahad, A., & Weiss, B. (2015). Current Therapy of Pediatric Crohn's Disease. *World J Gastrointest Pathophysiol*, 6(2), 33-42. <https://doi.org/10.4291/wjgp.v6.i2.33>
- Ley, D., Duhamel, A., Behal, H., Vasseur, F., Sarter, H., Michaud, L., ... Turck, D. (2016). Growth Pattern in Paediatric Crohn Disease Is Related to Inflammatory Status. *J Pediatr Gastroenterol Nutr*, 63(6), 637-643. <https://doi.org/10.1097/MPG.0000000000001177>
- Lopez, R. N., Appleton, L., Gearry, R. B. & Day, A. S. (2018). Rising Incidence of Paediatric Inflammatory Bowel Disease in Canterbury, New Zealand, 1996-2015. *J Pediatr Gastroenterol Nutr*, 66(2), e45-e50.

<https://doi.org/10.1097/MPG.0000000000001688>

- Lynch, T., & Spence, D. (2016). A Qualitative Study of Youth Living With Crohn disease. *Gastroenterol Nurs*, 31(3), 224-230. <https://doi.org/10.1097/01.SGA.0000324114.01651.65>
- Mackner, L., Bickmeier, R., & Crandall, W. (2012). Academic Achievement, Attendance, and School-Related Quality of Life in Pediatric Inflammatory Bowel Disease. *J Dev Behav Pediatr*, 33(2), 106-111. <https://doi.org/10.1097/DBP.0b013e318240cf68>
- Mahlmann, L., Gerber, M., Furlano, R. I., Legeret, C., Kalak, N., Holsboer-Trachsler, E., & Brand, S. (2017). "Psychological Wellbeing and Physical Activity in Children and Adolescents with Inflammatory Bowel Disease Compared to Healthy Controls. *BMC Gastroenterol*, 17(1), 160. <https://doi.org/10.1186/s12876-017-0721-7>
- Malmborg, P., Mouratidou, N., Sachs, M. C., Hammar, U., Khalili, H., Neovius, ... Olen, O. (2019). Effects of Childhood-onset Inflammatory Bowel Disease on School Performance: A Nationwide Population-based Cohort Study Using Swedish Health and Educational Registers. *Inflamm Bowel Dis*, 25(10), 1663-1673. <https://doi.org/10.1093/ibd/izz040>
- Marcus, S. B., Stropole, J. A., Neighbors, K., Weissberg-Benchell, J., Nelson, S. P., Limbers, C., ... Alonso, E. M. (2009). Fatigue and Health-related Quality of Life in Pediatric Inflammatory Bowel Disease. *Clin Gastroenterol Hepatol*, 7(5), 554-561. <https://doi.org/10.1016/j.cgh.2009.01.022>
- McCabe, M. P., & Ricciardelli, L. A. (2004). A Longitudinal Study of Pubertal Timing and Extreme Body Change Behaviors among Adolescent Boys and Girls. *Adolescence*, 39(153), 145-166. PMID: 15230071.
- McCombie, A. M., Mulder, R. T., & Gearry, R. B. (2013). How IBD Patients Cope with IBD: a Systematic Review. *J Crohns Colitis*, 7(2), 89-106. <https://doi.org/10.1016/j.crohns.2012.05.021>
- Nasiri, S., Kuenzig, M. E., & Benchimol, E. I. (2017). Long-term Outcomes of Pediatric Inflammatory Bowel Disease. *Semin Pediatr Surg*, 26(6), 398-404. <https://doi.org/10.1053/j.sempedsurg.2017.10.010>
- NASPGHAN. (2015). Inflammatory Bowel Disease Monographs: Healthcare Provider Checklist for Transitioning a Patient from Pediatric to Adult Care, North American Society for Pediatric Gastroenterology, Hepatology and Nutrition. Retrieved August 10<sup>th</sup>, 2020, from [https://www.naspghan.org/files/documents/pdfs/medicalresources/ibd/Checklist\\_PatientandHealthcareProvider\\_TransitionfromPedtoAdult.pdf](https://www.naspghan.org/files/documents/pdfs/medicalresources/ibd/Checklist_PatientandHealthcareProvider_TransitionfromPedtoAdult.pdf)
- Nicholas, D. B., Otley, A., Smith, C., Avolio, J., Munk, M., & Griffiths, A. M. (2007). Challenges and Strategies of Children and Adolescents with Inflammatory Bowel Disease: a Qualitative Examination. *Health Qual Life Outcomes*, 5, 28. <https://doi.org/10.1186/1477-7525-5-28>
- Norton, B. A., Thomas, R., Lomax, K. G., & Dudley-Brown, S. (2012). Patient Perspectives on the Impact of Crohn's Disease: Results from Group Interviews. *Patient Prefer Adherence*, 6, 509-520. <https://doi.org/10.2147/PPA.S32690>
- Norton, C., Czuber-Dochan, W., Artom, M., Sweeney, L., & Hart, A. (2017). Systematic Review: Interventions for Abdominal Pain Management in Inflammatory Bowel Disease. *Aliment Pharmacol Ther*, 46(2), 115-125. <https://doi.org/10.1111/apt.14108>
- Oppenheimer, S., Krispin, O., Levy, S., Ozeri, M., & Apter, A. (2018). The Impact of Coping Patterns and Chronic Health Conditions on Health-related Quality of Life among Children and Adolescents. *Eur J Pediatr*, 177(6), 935-943. <https://doi.org/10.1007/s00431-018-3146-6>
- Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Adm Policy Ment Health*, 42(5), 533-544. <https://doi.org/10.1007/s10488-013-0528-y>
- Perler, B., Ungaro, R., Baird, G., Mallette, M., Bright, R., Shah, S., ... Sands, B. E. (2019). Presenting Symptoms in Inflammatory Bowel Disease: Descriptive Analysis of a Community-based Inception Cohort. *BMC Gastroenterol*, 19(1), 47. <https://doi.org/10.1186/s12876-019-0963-7>
- Pigneur, B., Seksik, P., Viola, S., Viala, J., Beaugerie, L., Girardet, J. P., ... Cosnes, J. (2010). Natural History of Crohn's Disease: Comparison Between Childhood- and Adult-onset Disease. *Inflamm Bowel Dis*, 16(6), 953-961. <https://doi.org/10.1002/ibd.21152>
- Purc-Stephenson, R., Bowlby, D., & Qaqish, S. (2015). "A Gift Wrapped in Barbed Wire" Positive and Negative

- Life Changes after being Diagnosed with Inflammatory Bowel Disease. *Qual Life Res*, 24(5), 1197-1205. <https://doi.org/10.1007/s11136-014-0843-0>
- Richard, L., Noller, G., Derrett, S., Sullivan, T., Doolan-Noble, F., McCombie, ... Stokes, T. (2020). Patients' Accounts of Living with and Managing Inflammatory Bowel Disease in Rural Southern New Zealand: a Qualitative Study. *BMJ Open*, 10(11), e041789. <https://doi.org/10.1136/bmjopen-2020-041789>
- Rogler, D., Fournier, N., Pittet, V., Buhr, P., Heyland, K., Friedt, ... Swiss, I. B. D. C. S. G. (2014). Coping is Excellent in Swiss Children with Inflammatory Bowel Disease: Results from the Swiss IBD Cohort Study. *J Crohns Colitis*, 8(5), 409-420. <https://doi.org/10.1016/j.crohns.2013.10.004>
- Rosen, M. J., Dhawan, A., & Saeed, S. A. (2015). Inflammatory Bowel Disease in Children and Adolescents. *JAMA Pediatrics*, 169(11), 1053-1060. <https://doi.org/10.1001/jamapediatrics.2015.1982>
- Ruel, J., Ruane, D., Mehandru, S., Gower-Rousseau, C., & Colombel, J. F. (2014). IBD Across the Age Spectrum: is it the Same Disease? *Nat Rev Gastroenterol Hepatol*, 11(2), 88-98. <https://doi.org/10.1038/nrgastro.2013.240>
- Saldana Ruiz, N., & Kaiser, A. M. (2017). Fecal Incontinence - Challenges and Solutions. *World J Gastroenterol*, 23(1), 11-24. <https://doi.org/10.3748/wjg.v23.i1.11>
- Santos-Antunes, J., Nunes, A. C., Lopes, S., & Macedo, G. (2016). The Relevance of Vitamin D and Antinuclear Antibodies in Patients with Inflammatory Bowel Disease Under Anti-TNF Treatment: A Prospective Study. *Inflamm Bowel Dis*, 22(5), 1101-1106. <https://doi.org/10.1097/MIB.0000000000000697>
- Schoepfer, A. M., Vavricka, S., Safroneeva, E., Fournier, N., Manser, C., Frei, P., ... Braegger, C. (2017). "Systematic Evaluation of Diagnostic Delay in Pediatric Inflammatory Bowel Disease. *J Pediatr Gastroenterol Nutr*, 64(2), 245-247. <https://doi.org/10.1097/MPG.0000000000001238>
- Sezgin, E., Weiler, M., Weiler, A., Lin, S., & Hart, L. (2020). It Is a Life Journey: A Roadmap of Teens With Chronic Diseases in Transitioning to Independence. *J Pediatr Health Care*, 34(4), 346-355. <https://doi.org/10.1016/j.pedhc.2020.02.001>
- Singh, H., Nugent, Z., Brownell, M., Targownik, L. E., Roos, L. L., & Bernstein, C. N. (2015). Academic Performance among Children with Inflammatory Bowel Disease: A Population-Based Study. *J Pediatr*, 166(5), 1128-1133. <https://doi.org/10.1016/j.jpeds.2014.12.010>
- Sykora, J., Pomahacova, R., Kreslova, M., Cvalinova, D., Stych, P., & Schwarz, J. (2018). Current Global Trends in the Incidence of Pediatric-onset Inflammatory Bowel Disease. *World J Gastroenterol*, 24(25), 2741-2763. <https://doi.org/10.3748/wjg.v24.i25.2741>
- Szulcowski, L., Mullins, L. L., Bidwell, S. L., Eddington, A. R., & Pai, A. L. H. (2017). Meta-Analysis: Caregiver and Youth Uncertainty in Pediatric Chronic Illness. *J Pediatr Psychol*, 42(4), 395-421. <https://doi.org/10.1093/jpepsy/jsw097>
- Varni, J. W., Bendo, C. B., Nurko, S., Shulman, R. J., Self, M. M., Franciosi, ... Pediatric Quality of Life Inventory Gastrointestinal Symptoms Module Testing Study, C. (2015). Health-related Quality of Life in Pediatric Patients with Functional and Organic Gastrointestinal Diseases. *J Pediatr*, 166(1), 85-90. <https://doi.org/10.1016/j.jpeds.2014.08.022>
- Vasileiou, K., Barnett, J., Thorpe, S., & Young, T. (2018). Characterising and Justifying Sample Size Sufficiency in Interview-based Studies: Systematic Analysis of Qualitative Health Research over a 15-year Period. *BMC Med Res Methodol*, 18(1), 148. <https://doi.org/10.1186/s12874-018-0594-7>
- Vejsovic, V., Bramhagen, A. C., Idvall, E., & Wennick, A. (2018). Swedish Children's Lived Experience of Ulcerative Colitis. *Gastroenterol Nurs*, 41(4), 333-340. <https://doi.org/10.1097/SGA.0000000000000295>
- Wojtowicz, A. A., Greenley, R. N., Gumidyal, A. P., Rosen, A., & Williams, S. E. (2014). Pain Severity and Pain Catastrophizing Predict Functional Disability in Youth with Inflammatory Bowel Disease. *J Crohn's Colitis*, 8(9), 1118-1124. <https://doi.org/10.1016/j.crohns.2014.02.011>
- Yu, Y. R., & Rodriguez, J. R. (2017). Clinical Presentation of Crohn's, Ulcerative Colitis, and Indeterminate Colitis: Symptoms, Extraintestinal Manifestations, and Disease Phenotypes. *Semin Pediatr Surg*, 26(6), 349-355. <https://doi.org/10.1053/j.sempedsurg.2017.10.003>
- Zheng, K., Bruzzese, J. M., & Smaldone, A. (2019). Illness Acceptance in Adolescents: A Concept Analysis. *Nurs Forum*, 54(4), 545-552. <https://doi.org/10.1111/nuf.12368>

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