RETROSPECTIVE SCHOOLING REFLECTIONS AMONG YOUNG ADULTS WITH PEDIATRIC-ONSET INFLAMMATORY BOWEL DISEASE: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

by

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Abstract

Students with Inflammatory Bowel Disease (IBD) face physical, psychological, social, and educational challenges (e.g., inadequate support from teachers; interrupted attendance and engagement in instruction) that can negatively impact learning trajectories. However, researchers have reported that individuals with pediatric-onset IBD do not demonstrate negative long-term outcomes as many appear to be academically successful upon reaching adulthood. It is unclear why this trend has emerged in recent literature.

In this study, the lived-experience of seven young adults with pediatric-onset IBD were examined. Participants were asked to retrospectively reflect on how they navigated living with IBD while also attending school, learning academic concepts, and navigating relationships with teachers and peers. The Interpretative Phenomenological Analysis (IPA) methodological framework was used to guide this investigation. To enhance the credibility and trustworthiness of the findings, numerous strategies included: prolonged engagement, reflective journaling, member checks, and measuring the re-occurrence of experience across cases.

Six super-ordinate themes and corresponding subthemes emerged from the interviews. *IBD Related Experience* provided contextual information about participants’ diagnostic process, physical symptoms, mental health concerns, and key sources of stress. *Coping Strategies* outlined information about individualized medical and holistic treatments used to manage symptoms. *Educational Implications* revealed participants experienced educational successes in addition to educational challenges and greater levels of difficulty after transitioning to university level programs. *Educational Accommodations* included formal and informal accommodations and personally developed academic strategies used to overcome educational challenges. *Processes of Normalization* depicted participants’ journey from experiencing feelings of
embarrassment, finding connections with others, and working towards establishing a “new normal.” Social Interactions involved participants keeping their diagnosis private or disclosing to others. After disclosing, participants experienced positive and negative interactions from others. Overall, these participants were academically high achieving and experienced successful educational outcomes. This conclusion (a) likely offers a realistic description of what some students with IBD experience while in school (i.e., mixed experience of successes and challenges) and (b) supported recent researchers who have argued that students with IBD experience long-term educational success. Limitations, strengths, and implications associated with the study along with recommendations for future directions are discussed.
Lay Summary

The educational experience among students with Inflammatory Bowel Diseases (IBD) is not well understood. This study was designed to investigated schooling experience through the perspective of seven young adults with pediatric-onset IBD. Participants were impacted by physical pain, psychological difficulties, and stress. To overcome these difficulties, participants worked to identify individualized coping strategies. Participants experienced academic struggles and successes. High school programs were perceived as manageable and greater degrees of academic struggle occurred at the university level. Increased academic burden coupled with inflexible expectations were perceived as stressful and exacerbated medical symptoms. Participants experienced greater academic success when given formally assigned accommodations and effective medical treatments. Socially, participants were unwilling to disclose information about their condition due to embarrassment which was overcome after they established connections and accepted their new way of life. Disclosing the status of their condition was met with positive or undesirable reactions from others.
Preface

This thesis is original, unpublished, independent work by the author, C. M. Fuchs.
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Chapter 1: Introduction

Inflammatory Bowel Disease (IBD) involves chronic inflammation of the gastrointestinal track and requires ongoing symptom management. Primary symptoms include diarrhea, cramping, abdominal pain, vomiting, weight loss, and fatigue (Fabisiak, Murawska, Mokrowiecka, Malecka-Panas, & Fichna, 2016). Casati and colleagues (2000) identified eight categories of concern for adults with IBD including: loss of energy, feelings of loss of control, negative body image, isolation, fear, not reaching full potential, feeling dirty, and lack of information provided to them from the medical community.

Children and adolescents with IBD also face concerns pertaining to their educational experience in addition to the concerns identified by Casati and colleagues (2000) among adults. In general, students with chronic medical conditions are absent from school more frequently than their peers (Msall et al., 2003), and high levels of absenteeism have been linked to poorer academic progress (Carroll, 2015). Specifically, students with IBD are at risk of experiencing pain, fatigue, and/or symptoms of anxiety and depression (Deshmukh, Kulkarni, & Lackamp, 2010; Gastrointestinal Society, 2014; Msall et al., 2003; Nicholas et al., 2007). These undesirable physical and psychological symptoms may negatively impact students’ quality of engagement and attention during class time hours (Filce & LaVergne, 2011; Gordon, 2004). As such, students with medical conditions including IBD may require modified or adapted activities, schedules, and/or instructions (Shaw & McCabe, 2008; Wodrich et al., 2013). Unfortunately, teachers may be less willing to make accommodations for these students if they perceive the accommodations to be burdensome (West et al., 2013). Many teachers lack formal training and guidance on how to support students with medical conditions (Lucas et al., 2012; Robinson & Summers, 2012; West et al., 2013). Students with IBD have reported that when they have disclosed their medical
diagnosis, their teachers lacked empathy regarding their IBD symptoms (Akobeng et al. 1999; Kilroy, Nolan, & Sarma, 2011; Richardson et al., 2001).

Interestingly, despite the various medical, psychological, and educational obstacles students with IBD face, available evidence indicates that individuals with pediatric-onset IBD appear to be more financially and academically successful upon reaching adulthood than their non-diagnosed peers. In a cross-sectional study conducted by El-Matary, Dufault, Moroz, Schellenberg, and Bernstein (2016), individuals with IBD were significantly more likely to (a) earn a higher yearly wage and (b) attain a post-secondary degree or diploma when compared to the randomly selected healthy peers matched by age and sex. These findings are particularly novel as individuals with other pediatric medical conditions typically face poorer long-term educational and vocational outcomes compared to the average population (Maslow, Haydon, Ford, & Halpern, 2011; Maslow, Haydon, McRee, Ford, & Halpern, 2011). Given this counterintuitive evidence pertaining to the long-term outcomes of adults with pediatric-onset IBD conditions, an investigation identifying the lived-experience of former students with pediatric-onset IBD is warranted to help clarify factors that contribute to academic and financial success in adulthood while also identifying specific ways to support this population of students while attending primary and secondary school.

1.1 Definition of Key Terms

**Inflammatory Bowel Disease.** Inflammatory bowel disease (IBD) is an autoimmune disease and represents a group of intestinal disorders that cause prolonged inflammation of the digestive tract (Kim, 2015). The digestive tract is composed of the mouth, esophagus, stomach, small intestine, and large intestine. It is responsible for breaking down food, extracting the nutrients, and removing any unusable material and waste products. Inflammation anywhere
along the digestive tract disrupts this normal process. Inflammatory Bowel Disease can be very painful and disruptive, and in some cases, may even be life-threatening. Primary symptoms include diarrhea, bleeding ulcers, cramping, abdominal pain, vomiting, weight loss, and fatigue (Fabisiak et al., 2016; Kim, 2015). The most common IBD conditions include Crohn’s disease and ulcerative colitis. While Crohn’s disease involves patches of inflammation that can affect any part of the gastrointestinal tract, spanning from the mouth to the anus, ulcerative colitis specifically affects the inner layer of the colon. Additional, but less prevalent IBD conditions include: Microscopic colitis, Diversion colitis, Behçet’s disease, and Indeterminate colitis (Gastrointestinal Society, 2014).

**Pediatric-onset IBD.** Pediatric-onset IBD refers to when the individual was diagnosed with an IBD condition before reaching adulthood (Rodrigues & Devadason, 2010). Individuals with pediatric-onset IBD receive developmentally appropriate and interdisciplinary health care services and transition to the adult health care system upon turning 18 years of age (Goodhand & Croft, 2011; Pinzon, Jacobson, & Reiss, 2004).

**Health.** The concept of health is dynamic as it is considered to be a state of physical, mental, and social prosperity; it does not merely refer to the absence of disease (World Health Organization, 2013). Health is typically associated with well-being and improved quality of life.

**Schooling.** The concept of schooling encompasses various factors students are exposed to while attending school from Kindergarten to Grade 12. Schooling experience incorporate academic exposure (e.g., reading, writing, math), additional subjects (e.g., physical education, art), as well as social interactions with educators, peers, and friends.

**Educators.** For the purposes of this study, the term educator encompasses various adults and teaching staff that students may interact with while attending primary or secondary school
(e.g., classroom teachers, homeroom teachers, special education teachers, education assistants, school counselors, school psychologists, and principals).

**Post-secondary programs.** Post-secondary programming referred to academic study via college or university. This type of programming is pursued by students who have earned a high school level diploma and applied to attend a specific college/university institution or program. The purpose of pursuing a post-secondary education has typically been to expand attendees’ knowledge base and to receive training required for specialized jobs/careers.

**Professors.** Professors referred to educators at the post-secondary level and applied to professors ranked at sessional, assistant, associate, and tenure levels, as well as lecturers and lab instructors.

1.2 **Significance of the Study**

Understanding the lived-experience of young adults with IBD while attending school is important for several reasons. First, while research and literature regarding the experience of children with various types of medical conditions is available (e.g., pediatric cancer, diabetes, asthma; see Jonsson, Egmar, Hallner, Kull, & Röda, 2014; Lowes et al., 2015; Wiener, Kazak, Noll, Patenaude, & Kupst, 2014), empirical investigations regarding students with IBD conditions specifically is relatively sparse. Second, researchers who conduct research involving individuals with IBD commonly focus on individuals’ health related quality of life and experience during adulthood (e.g., Bannaga & Selinger, 2015; Casati et al., 2000; Haapamäki, Roine, Sintonen, & Kolho, 2011; Holdam, Bager, & Dahlerup, 2016; Norton, Thomas, Lomax, & Dudley-Brown, 2012; Nurmi et al., 2013; Savard & Woodgate, 2009; Skrastins & Fletcher, 2016)—significantly less research has focused on the experience related to the impact of IBD on schooling and education. Third, current research is counterintuitive regarding the long-term
outcomes associated with people with pediatric-onset IBD (El-Matary et al., 2016; Maslow et al., 2011).

1.3 Purpose of the Study

The purpose of this study is to explore the lived-experience of students with IBD through the perspective of young adults who were diagnosed with pediatric-onset IBD during their schooling years. The study intends to examine participants’ perceptions of how they balanced (a) living with an IBD condition and managing their symptoms while also (b) attending school, learning academic concepts, and navigating relationships with teachers, friends, and peers. Understanding the phenomenon managing IBD symptoms and attending school through a phenomenological lens will contribute to the current body of literature in the area of childhood illness and development.
Chapter 2: Literature Review

The purpose of this chapter is to summarize the existing research relevant to medical, psychological, social, and the educational experience of individuals with pediatric-onset IBD conditions. This includes a description of the IBD conditions, incident rates, psychological, social, and educational considerations, as well as the long-term implications of living with the disease. At the conclusion of this chapter, the need for understanding the retrospective perspectives from a qualitative viewpoint will be highlighted.

2.1 Inflammatory Bowel Disease

Inflammatory Bowel Disease (IBD) involves chronic inflammatory conditions of the gastrointestinal track (i.e., the organ system that takes in food, digests it to extract and absorb energy and nutrients, and expels the remaining waste as feces and urine; Kim, 2015). IBD conditions require ongoing symptom management as it is an incurable, chronic autoimmunity disease and can cause permanent damage in the bowel tissues. Primary symptoms include: (a) diarrhea—occurring when affected parts of the bowel cannot reabsorb water; (b) bleeding ulcers—which may cause blood to show up in the stool; (c) stomach pain, cramping, and bloating due to bowel obstruction; (d) vomiting; (e) fatigue; and (f) weight loss and anemia—potentially causing delayed growth or development in children (Fabisiak et al., 2016; Kim, 2015). IBD refers to various medical conditions, although the most common diagnoses include Crohn’s disease and ulcerative colitis. Ulcerative colitis affects the inner lining layer of the large intestine via inflammation and ulcers (Fabisiak et al., 2016; Gordon, 2016; Kim, 2016) while inflammation can appear anywhere along the digestive track (i.e., from the mouth to the anus) among those with Crohn’s disease. Furthermore, Crohn’s disease typically affects all layers of the large intestine (Fabisiak et al., 2016; Gordon, 2016; Kim, 2016). Notably, relapse of
remission is commonly experienced by people with IBD conditions. It can be difficult to find appropriate treatment plans and identify various agents that initiate relapses of symptoms as the medical profile of individuals with IBD generally varies from person to person (Crohn’s and Colitis Foundation of Canada, 2008; Kim, 2015). To date, the specific cause(s) of IBD remains unknown in the medical community (Gastrointestinal Society, 2014).

To diagnose an IBD condition, various diagnostic tests are performed and have been described as painful. Medical procedures include stool samples, blood tests, flexible sigmoidoscopies and colonoscopies (i.e., inserting flexible probes into a person’s esophagus and anus in order for a camera to capture the severity of internal damage), biopsies (i.e., removing small samples of the large intestine wall), capsule endoscopy (i.e., swallowing a small camera to capture damage within the small intestine as it passes through the digestive system), as well as X-radiation, Computer Tomography (CT) scans, and Magnetic Resonance Imaging (MRI; Kim, 2015). Not only can the diagnostic process be painful, it can also be time consuming since various testing is required to rule out alternative conditions, and for a physician to make the diagnosis of an IBD condition (Gastrointestinal Society, 2014).

Canadians are disproportionately impacted by IBD as approximately one in every 150 individuals in Canada lives with an IBD condition (Rocchi et al., 2012). People are typically diagnosed before the age of 35 years with approximately 45% of individuals among this population receiving a diagnosis before the age of 20 years (Abdullah et al., 2002). Indeed, researchers cite that pediatric-onset IBD has rapidly increased in recent years (Benchimol et al., 2009; Paerregaard et al., 2011; Qualia & Bousvaros, 2013). The average rate of increase indicates 4.1% per year in a study consisting of 5415 individuals diagnosed with IBD between 1987 and 2014 (Virta, Saarinen, & Kolho, 2017). Crohn’s disease has almost doubled since 1995
among Canadian children (Crohn’s and Colitis Canada, 2015). As incident rates rise among child and adolescent populations, it becomes critical to consider the unique psychological, social, and educational implications that accompany this invisible chronic condition.

2.2 Psychological Considerations

As outlined below, young people with IBD are at greater risk of experiencing negative self-concept, fear, anxiety, and depression. It appears that a combination of factors, such as medical side effects and negative peer interactions can contribute to this risk.

2.2.1 Self-Concept

Some students with IBD may experience undesirable side effects as a result of receiving medical treatment including facial swelling, acne, hair growth, and weight gain (Baumgart & Carding, 2007; Mackner, Sisson, & Crandall, 2004). Due to having a medical condition and possibly exhibiting treatment side effects, students with IBD tend to perceive themselves negatively and believe they are different from their peers. Nicholas and colleagues (2007) explored child and adolescent perspectives (ages 7 to 19 years; N = 80) regarding the challenges they faced as a result of having an IBD condition. In this study, male students with IBD reported concern if they were physically smaller than male peers. On the other hand, female students noted concern if they weighed more than their female peers (Nicholas et al., 2007). In a different study, 30 out of 108 students with IBD (aged 8 to 18 years) endorsed At-Risk self-esteem levels as identified via the Behavior Assessment System for Children, Second Edition (Herzer-Maddux, Bass, Geraghty-Sirridge, Carpenter, & Christenson, 2013).

Unfortunately, some students not only perceived themselves negatively but also were victims of bullying which likely further contributed to their negative self-evaluations (Nicholas et al., 2007). Participants aged 18 to 26 years were asked to retrospectively recall instances of
when they were teased by their peers regarding their weight and physical size. The sample consisted of 135 participants with bowel conditions and 540 control participants. The control group was matched by age and body mass index. Participants with a bowel condition were significantly more likely to have received weight-teasing comments when growing up and recalled feeling more upset after receiving the weight-teasing comments compared to control participants (Quick, McWilliams, & Byrd-Bredbenner, 2015).

2.2.2 Fear

Students reported fear of future episodic pain, symptom flare ups and experienced a sense of heightened vulnerability due to their lack of privacy (Nicholas et al., 2007; Richardson et al., 2001). As such, students with IBD have reported worries associated with typical childhood activities such as attending school and participating in recess or gym class (Gordon, 2004). For instance, pain related to IBD could interfere with full activity engagement and prematurely oblige them to seek rest to alleviate discomfort. Students noted underlying anxieties about their lifelong condition and felt unsure of whether medical advances would come available to help treat their conditions. Finally, students feared for their future and career prospects (Akobeng et al., 1999). Richardson and colleagues (2001) found that English and Canadian children ages 8 to 18 years ($N = 180$) worried that having IBD would make it difficult for them to get a job in the future and might overall diminish their chances of success in the workplace.

2.2.3 Anxiety and Depression

In addition to fear, students with IBD have also reported feelings of vulnerability and a lack of control (Nicholas et al., 2007). Such psychological distress is not surprising considering the various obstacles, concerns, and fears faced by students with IBD. Specifically, it has been documented that individuals with IBD are at an increased risk of experiencing anxiety and
depression compared to the general population (e.g., Deshmukh, Kulkarni, & Lackamp, 2010). Clinical levels of anxiety are estimated to occur among 14-22% of individuals with IBD while depressive symptoms have been observed in 30-32% of individuals with IBD (Deshmukh et al., 2010; Reigada et al., 2011). Depression symptoms are especially noteworthy given that researchers find a positive correlation between depressive symptomatology and the severity of children’s and adolescents’ IBD symptoms (Szigethy et al., 2004). Similarly, in a large self-reported study consisting of 15- to 30-year-old Canadians \( (n = 5947) \), Ferro (2016) found that lifetime prevalence of mental disorders was significantly higher among individuals with chronic medical conditions (e.g., respiratory, musculoskeletal/connective tissue, cardiovascular, neurological, and endocrine/digestive conditions) when compared to healthy controls. Levels of reported disability and pain mediated the association between chronic health conditions and mental disorders (Ferro, 2016). This is particularly concerning as worsening psychological problems are often followed by worsened IBD symptoms and vice versa (Filipovic & Filipovic, 2014). Similar to depression, adolescents with self-reported higher levels of anxiety were also more likely to experience active IBD symptoms (e.g., more abdominal pain and a greater number of loose stools) as well as a decreased sense of wellbeing (Reigada et al., 2015). Given that individuals with IBD are more likely to experience psychological difficulties, they could benefit from enhanced levels of social support. Unfortunately, as described in the following sections, social support appears to be inconsistently provided within the school system for a variety of reasons.

### 2.3 Social Considerations

IBD is considered an invisible medical condition as symptoms are largely internal without significant observable external symptoms (Gordon, 2016). Invisible illnesses are
sometimes sporadic in nature and are often inconspicuous (Defenbaugh, 2013). Living with an invisible medical condition poses challenges for the ‘believability’ that such an illness exists, especially when there appears to be few outward signs of its presence. Moore (2014) highlighted that individuals living with an invisible medical condition must often legitimize and sometimes defend their status as an ill individual. The lack of visible symptoms often threatens the credibility of illness claims (Barned, Stinzi, Mack, & O'Doherty, 2016). Further, people living with invisible medical conditions sometimes refuse to grant legitimacy to their own illness for fear of unwanted attention (Charmaz, 2000). People with invisible, or hidden, disabilities may be deemed as less credible according to bystanders compared to other people with more visible indicators (e.g., use of a wheelchair) who are viewed as experiencing a more legitimate limitation (Goffman, 1963).

Moreover, individuals with IBD may interpret their illness disclosure as a violation of personal privacy due to the unpleasant symptoms associated with their condition (e.g., diarrhea) or the awkwardness of discussing bowel movements. Students with IBD can be reluctant to disclose or talk about their condition as they may fear being the target of teasing that involves bathroom humor (Casati, Toner de Rooy, & Drossman, 2000). Given the sensitive nature of IBD symptoms, it is particularly common for young people with IBD to not to disclose their illness to others (Barned et al., 2016; Hommel, 2013).

In an academic setting, students may choose not to self-disclose with classmates to circumvent anticipated peer rejection. Indeed, various researchers have found that adolescents with chronic illnesses typically experience challenges achieving a level of social conformity (Jackson, 2013), sense of acceptance, and belonging (Ferguson & Walker, 2014). Others have noted that students may experience bullying when their peers perceived their differences were
due to their medical condition (Ferguson & Walker, 2014). As a result of experiencing negative social interactions, some students with IBD report being less inclined to leave home and engage in social activities outside of school (Nicholas et al., 2007). Conversely, Gordon (2013) found via qualitative interviews that other students with IBD ($n = 6$) experienced positive social connections with their friends and peers—they felt that they were not treated differently because of their IBD condition.

2.4 Educational Considerations

School is widely acknowledged as a stabilizing and normalizing influence for young people with chronic medical conditions (Dockett 2004; Lightfoot, Wright, & Sloper 1999; Taylor, Gibson, & Franck 2008). Engaging in typical behaviours is of high importance for students living with chronic medical conditions because it is important they see themselves as being like their healthy peers (Taylor, Gibson, & Franck, 2008).  

2.4.1 General Students’ Educational Perspectives and Experience

Before discussing the unique challenges students with medical conditions face, it is informative to outline what is considered a typical schooling experience. In 1992, Phelan, Davidson, and Cao collaborated with 54 high school level students who were diverse in terms of gender, achievement level, ethnicity, and schooling location. The researchers made classroom observations and conducted multiple interviews with participating students over a two-year span. Thematically, the participants reported that teachers played a primary role in their educational experience, and many noted their preference for being seen as individuals. Teachers were perceived to care and be compassionate when they provided specific and helpful feedback for students’ academic work, made direct personal interactions, and provided emotional support to reduce feelings of loneliness. Teacher contributions were so important to academic achievement
that students who were considered to be lower grade obtaining earned A and B grades in classes with caring teachers while simultaneously earning D and F grades in classes with teachers that appeared less caring. Dedicated teachers helped these students divert their attention away from personal problems and refocus attention on achieving long term goals (e.g., high school level graduation). Students who obtained higher marks demonstrated to have deep-rooted internalized goals and were able to overlook, ignore, or rationalize classroom circumstances that were not optimal and were able to earn high grades in from all types of teachers. Regardless, high achieving students also preferred to learn from caring teachers (Phelan, Davidson, & Cao, 1992). These conclusions have been endorsed by additional researchers (e.g., Johnson, 2009; O’Connell & Schmakel, 2008; Petersen, 2008; Rodríguez, 2008; Sands, Guzman, Stephens, & Boggs, 2007).

In terms of learning, students cited a preference of learning actively from teachers rather than memorizing facts and reading textbooks (Phelan, Davidson, & Cao, 1992). At the time of the Phelan study in 1992, textbook teaching and lecturing were common methods of instruction. Despite students’ noted preferences for interactive teaching styles, similar methods of academic delivery nevertheless continue to be the norm over 25 years later (Yusof, Oei, & Ang, 2018). In a survey consisting of 81,499 high school students enrolled in schools of various sizes and locations, 75% of students endorsed they were bored in class because they did not find the material to be interesting, and 39% endorsed that the information material was not relevant (Yazzie-Mintz, 2007). The teaching format and way information is presented may be a reason the majority of students report dissatisfaction with their learning. Johnson (2008) conducted a study that match-paired students whereby one group engaged in collaborative work and the other group engaged in lecture and independent work. Findings indicated that among the students
engaging in lecture and independent work, this group reported lower levels of interest and enjoyment. Consequently, high achieving students typically comply while lower achieving students more frequently withdraw, fail to meet academic demands, and increasingly believe that education is irrelevant to their lives (Phelan, Davidson, & Cao, 1992). Taken together, teachers play a significant role in contributing to students’ engagement and learning in terms of (a) the relationships they curate with their students and (b) how they facilitate learning opportunities.

2.4.2 Perspectives and Experience of Students with Medical Conditions

Petersen (2008) acknowledged that various conditions outside of the school environment affect students' academic performance and their engagement in learning. Some of the conditions Petersen (2008) identified include: family stress, rising rates of adolescents dying by suicide, increasing prevalence of drug use, increasing rates of aggression and violent acts, discrimination leading to bullying, dramatic and distracting romantic relationships, and increasing emphasis on test scores. For the purposes of this study, the outside school focus is medical illnesses, more specifically, IBD conditions. Unfortunately, remaining connected with school, both academically and socially, can be challenging for most students with chronic medical conditions (Ferguson & Walker, 2014). It is generally accepted that students with various types of chronic medical conditions experience excessive school absences, poor academic performance, fatigue, memory concerns, attention problems, and disruptions in their social lives (Ferguson & Walker, 2014; Msall et al., 2003). As the impact of IBD on students’ education experience is an emerging area of research, further information about educational concern are highlighted below by illustrating research findings pertaining to students with diverse medical conditions inclusive of students with IBD diagnoses.

2.4.3 Absenteeism
Students with chronic medical conditions, including students with IBD, miss school more frequently than their peers (Assa, Ish-Tov, Rinawi, & Shamir, 2015; Caldwell et al., 1997). Students with IBD between five and 17 years have been reported to be absent for upwards of three to four months during the school year (Akobeng et al., 1999). Some students with chronic medical conditions miss a portion of each day when they leave the classroom to use the washroom or for routine procedures. They may also be absent for medical appointments (e.g., routine checkups, diagnostic procedures, and surgeries; Caldwell et al., 1997). Mackner, Bickmeier, and Crandal (2012) identified that 50 adolescents with IBD (ages 11 to 17 years) were commonly absent due to physical symptoms as well as internalizing problems (i.e., anxiety, depression). High levels of absenteeism have been linked to poor academic progress among students (Carroll, 2010). Specifically, absenteeism has the potential to disrupt school functioning (Gordon, 2004; Gordon, 2013), resulting in the student having less time in which to receive instruction and reduced opportunity for learning to take place. Further, if a student with IBD is experiencing pain, fatigue, and/or symptoms of anxiety and depression while they are at school, their quality of engagement and attention may be negatively impacted. Combined, students with IBD are at risk of receiving infrequent and interrupted schooling thus potentially leading to inadequate levels of knowledge and a decreased understanding of critical course content (Needham, Crosnoe, & Muller, 2004).

2.4.4 Interactions with Teachers

Considering the various obstacles associated with managing IBD symptoms, teachers may be required to offer accommodations to students with IBD. Unfortunately, if teachers find accommodations for students with chronic medical conditions too burdensome, they are less likely to make necessary accommodations (West et al., 2013). In addition, many teachers lack
formal training and understanding on how to best support students with medical conditions (e.g., asthma, diabetes, epilepsy; Lucas et al., 2012; Robinson & Summers, 2012; West et al., 2013). This includes a lack of knowledge of how learning problems are associated with medical conditions (Wodrich et al., 2011).

Researchers have found that once teachers are provided with information about a student’s condition, they are better able to accommodate the students’ academic needs (Cunningham & Wodrich, 2006; Wodrich, 2005). However, as illustrated in a study of 247 elementary school teachers, less than half of teachers report that they felt confident in meeting the academic needs of students with medical conditions (Nabors et al., 2008). Additional barriers perceived by teachers include misconceptions about health conditions and perceptions of risk and accountability during a potential medical emergency (Hinton & Kirk, 2015). Lack of communication between school personnel, health care professionals, and families was also reported as a common obstacle that negatively affects students with medical conditions (Hinton & Kirk, 2015).

In turn, students with medical conditions report disappointment and frustration surrounding teachers’ lack of knowledge, classroom rules, and negative attitudes (Gordon, 2004; 2015; Kirk et al., 2012). Additionally, the embarrassing and stigmatizing nature of IBD can make it difficult for students to talk about their illness and needs at school with their teacher(s). As a result, school staff may not only lack knowledge about IBD, but may also be unaware that a student has IBD and is enduring difficult and painful disease related symptoms. Despite some students’ unwillingness to disclose their illness, others reveal their IBD diagnoses to teachers for practical reasons (e.g., to receive additional access to the bathroom; Micallef-Konewko, 2013). Unfortunately, among those who do disclose, students note that their teachers lacked sufficient
empathy surrounding students’ IBD symptoms post-disclosure (Akobeng et al. 1999; Gordon, 2004; Kilroy, Nolan, & Sarma, 2011; Richardson et al., 2001). In a qualitative study comprising of six participating students, findings concluded that the main accommodation students required in school was to be able to go to the bathroom whenever the need arose, yet not all teachers were willing to accommodate this request (Gordon, 2013). The students predominantly spoke of simply wanting their teachers to believe them when they described the physical symptoms they were suffering and to have a more informed understanding of the disease. The children explained that these features would make their school experience easier to manage. Gordon (2013) found that students with IBD were willing to take on an advocacy role to increase their teacher’s awareness of IBD as a result.

2.5 Educational Transitions and Post-Secondary Education Pursuits

This chapter has primarily focused on students’ elementary and high school level experience. However, as increasing numbers of students are choosing to pursue post-secondary level education (Statistics Canada, 2016), it is also important to review individuals’ experience as they transition to, and participate in, post-secondary level programs (e.g., university). Using interpretative phenomenological analysis, Denovan and Macaskill (2013) investigated the phenomenon of transitioning from high school to university by interviewing 10 first year undergraduate students. University level adjustments included: the novelty and responsibility associated with independent living, feelings of homesickness, a need for support networks, differences between high school and university level education programs (e.g., at the university level, participants reported increased levels of learning independence, unclear expectations and work standards, larger class sizes), the need for academic focus (i.e., self-discipline, motivation, learning from experience), and academic difficulties involving exams and oral presentations.
Once university students have adjusted to their new learning environment, persisting stressors include financial insecurities, lack of sleep, and family problems (Redhwan, Sami, Karim, Chan, & Zaleha, 2009). University-level students with active IBD conditions reportedly adjust less well to college life compared to healthy peers—physical and emotional factors likely contributed to their difficulties (Adler, Raju, Beveridge, Zhu, & Zimmermann, 2008). Students with IBD also appear to experience additional obstacles whereby some (a) university-level lectures were perceived to be indifferent to students’ illness, (b) the students are unable to complete examinations due to symptoms associated with their condition, and (c) students felt that their condition prevented them from obtaining the education they wished to pursue (Mayberry, Probert, Srivastava, Rhodes, & Mayberry, 1992). Unfortunately, information involving the educational experience of university level students with IBD is scarce and more recent literature was not available.

2.6 Long-term Implications of IBD

By definition, IBD is a chronic and lifelong condition. It is therefore necessary to consider the long-term consequences associated with pediatric-onset IBD and its subsequent impact on later success and/or achievement in adulthood. Outcomes relating to academics and finances have been investigated. Surprisingly, despite facing numerous challenges while enrolled in the education system, students with IBD do not appear to experience academic disadvantages. Singh and colleagues (2015) compared the academic performance of Grade 12 students with IBD ($n = 337$) to randomly selected peers ($n = 3093$) matched by age and sex. The researchers found no significant differences between the two groups regarding language arts and mathematic scores. Further, in a cross-sectional Canadian study conducted by El-Matary, Dufault, Moroz, Schellenberg, and Bernstein (2016), individuals with IBD ($n = 112$; age of IBD diagnosis ranged
from 4.3 to 17 years) were significantly more likely to (a) attain a post-secondary degree or diploma and (b) earn a higher yearly wage when compared to the randomly selected and healthy peers matched by age and sex ($n = 565$). In fact, among the participants studied, nearly two-thirds had achieved a university degree. These findings led El-Matary and colleagues to conclude that individuals with IBD were just as, if not more likely to become financially and academically successful once they reached adulthood as compared to typical peers.

These findings are particularly novel as it is well documented in the literature that individuals with other medical conditions are known to face poorer long-term educational and vocational outcomes compared to individuals without chronic health concerns (Maslow, Haydon, Ford, & Halpern, 2011; Maslow, Haydon, McRee, Ford, & Halpern, 2011). For instance, Champaloux and Young (2015) determined that adolescents with chronic health conditions (e.g., asthma, cancer, diabetes, epilepsy, and heart conditions; $n = 2002$) were less likely to complete high school than adolescents who did not report health concerns ($n = 6795$). Similarly, individuals with pediatric-onset lupus (i.e., systemic lupus erythematosus), which is also classified as an autoimmunity disease, were less likely to be employed compared to individuals who began experiencing lupus in adulthood (Lawson et al., 2014). While participants with pediatric-onset lupus ($n = 115$) were just as likely as those with adult-onset lupus ($n = 814$) to complete college education, having pediatric-onset lupus significantly increased the risk of not working in adulthood, even when controlling for disease and demographic factors (Lawson et al., 2014). Ultimately, the findings El-Matary and colleagues (2016) concluded appear contrary to outcomes found in similar studies.
2.7 **Summary and Need for the Proposed Study**

As a student, having IBD poses a variety of obstacles including symptom flare ups which generate pain and fatigue as well as experiencing a greater risk of developing a poor self-concept, depression, being bullied, receiving inadequate accommodations and support from teachers, and interrupted access to academic instruction. Despite these challenges, researchers have recently reported that students with IBD do not demonstrate negative long-term academic outcomes. On the contrary, findings highlight the fact that individuals with IBD appear to be both academically and financially successful in adulthood.

It is unclear why individuals with IBD attain higher financial and academic outcomes than people with other chronic health conditions. It is also unclear what factors contribute to the long-term success of individuals with pediatric-onset IBD. The following chapter of this thesis outlines how the researcher worked to develop a better understanding of the lived-experience of individuals with pediatric-onset IBD attending school. Investigating the lived-experience of individuals with pediatric-onset IBD who have completed school may help clarify what factors contribute to long-term outcomes described in the literature.
Chapter 3: Methodology

The aim of this study was to explore and better understand the phenomenon involving the experience of students with pediatric-onset IBD as they attended school. To achieve this aim, semi-structured interviews were used as the primary method of data collection via the Interpretative Phenomenological Analysis (IPA) methodological framework. In this chapter, the design of the study, including the purpose, research question, theoretical framework, participation criteria, recruitment strategies, as well as data collection and analysis procedures are described.

3.1 Purpose of Study

The purpose of this study was to examine the lived-experience (i.e., phenomenon) of students with IBD through the perspective of young adults who experienced pediatric-onset IBD symptoms during their schooling years. The researcher aimed to investigate participants’ perceptions of how they lived with and addressed their IBD symptoms while also attending school, learning academic concepts, and navigating relationships with educators, friends, and peers. The following research question was investigated: Through the perspective of adults with pediatric-onset IBD, what is the phenomenon of attending school as a student with IBD symptoms?

3.2 Interpretive Phenomenological Analysis

To answer the research question outlined above, the lived-experience of individuals with pediatric-onset IBD were analyzed in an exploratory, comprehensive, and flexible manner. IPA was used as the methodology for this study. It was selected because the IPA framework facilitated an exploration and understanding of how participants make sense of and gave meaning to their lived-experience in terms of their own perspectives and perceptions (Chapman
& Smith, 2002; Larkin, Watts, & Clifton, 2006; Smith & Osborn, 2003). Within IPA studies, each participating person is conceptualized as a dynamic, meaning-making individual, embodying a unique perspective. The goal of this study was to attend to the voices of people who shared a similar lived-experience as it related to attending school while also navigating their IBD conditions.

The researcher was tasked with conducting a structural synthesis wherein an exploration of all possible convergent and divergent meanings emerging from participant interviews were thematically interpreted and recorded. Pietkiewicz and Smith (2012) explained that IPA researchers must try to understand a phenomenon from individual participants’ perspectives while also trying to formulate critical questions referring to the information provided by all participants. As recommended by Smith and Osborn (2007), the researcher of this study considered the following during the data analysis process: “what is the person trying to communicate?”, “is there anything meaningful being said, which was not intended?”, and “do I have a sense of something going on here that the person himself or herself is perhaps less aware of?”. When people struggle to express what they are thinking and feeling, there may be underlying reasons for non-disclosure. Therefore, the researcher sought to interpret participants’ mental and emotional states from what they said to make the analysis richer and more comprehensive (Smith & Osborn, 2007).

3.3 Researcher’s Role

While engaging in this study, certain considerations were taken into account. First, researchers who use the IPA methodology are required to acknowledge biases and examine preconceived assumptions as much as possible upon entering the inquiry process (i.e., bracketing; Cross, Coleman, & Stewart, 2003). However, complete neutrality is considered
impossible when using an IPA framework (Mehra, 2002). Although the researcher worked to be open and receptive towards participants’ experience, the researcher’s perception of participants’ accounts was inevitably colored by her own experience, biases, and existing understanding of schools and experience of students with IBD. As such, the researcher drew partly upon her own conceptualizations and experience to understand the participants’ lived-experience. Notably, the researcher did not have any connection to IBD, either personally or within her immediate social networks. In addition, although the researcher met various people with different IBD conditions, their decision to disclose their medical condition focused very little on how it impacted their educational pursuits. Consequently, most of the researcher’s knowledge in this area was established via attending specialist (e.g., nurses, researchers) presentations and reading about the condition (e.g., peer-reviewed journal articles, websites dedicated to disseminating scientifically accurate information about IBD). Finally, the researcher was not able to achieve a first-person account or complete understanding of each participants’ lived-experience. Rather, the researcher and participants constructed lived-experience accounts together. Caution was used to ensure that every effort was made to accurately represent the voices of the participants.

3.4 Research and Ethics Approval

Ethics approval was successfully obtained through the University of British Columbia Behavioural Research Ethics Board (BREB). The research study was designed to follow ethical guidelines outlined by the BREB.

3.5 Recruitment

Initially, participants were recruited via contacts associated with the 2017 Invisible Conditions Conference. The Invisible Conditions Conference was developed to support youth, ages 12-18 years, who were experiencing an invisible condition. Youth attended a day-long
A partnership with this organization was established when the primary researcher served both as an executive member of the planning committee and volunteered as a Research Coordinator. The founder and Project Coordinator, Simon Lisaingo, granted the researcher permission to use the conference as a platform to access and recruit participants. At the time of recruitment for this study, the conference was in the piloting stage of implementation whereby individuals with IBD conditions were invited to attend the conference. As participants within this proposed study were required to have completed Grade 12, people with IBD who had volunteered to be part of the planning committee were invited to participate in the study via email. The message advised of the research project, purpose of the study, need for participants, and inclusion criteria. Snowball sampling was also employed as interested participants and people associated with the Invisible Conditions Conference were asked to share the primary researcher’s contact information with others who had a pediatric-onset IBD condition. Snowball sampling was the most effective method of recruitment. Interested individuals contacted the researcher to initiate participation in the study.

3.6 Participants

In IPA, psychological similarities and differences are usually analysed within a group that has been defined as similar according to important characteristics. Random or representative sampling is not appropriate for this type of methodology. For the study, participants included men and women between the ages of 21 and 35 years who had self-declared to be diagnosed with an IBD condition (e.g., Crohn’s disease, ulcerative colitis) by a medical doctor.
The age range of 21 to 35 years was selected for two reasons. First, it is important for the participants to have recently completed schooling to discuss primary or secondary schooling experience thereby working towards answering the research question developed for this study. It is intended that interviewing people who were 35 years or younger increased the likelihood that participants provided more rich and detailed descriptions of their schooling experience compared to individuals who have been away from school for longer spans of time. Second, as participants were asked to discuss and reflect on educational experience, participants younger than 21 years likely would not have had as many educational opportunities to discuss with the researcher. While not a required inclusion criterion, each participant had obtained, or was in the process of obtaining a post-secondary degree.

Participants were required to have experienced IBD symptoms while attending primary or secondary schooling. Specifically, participants were required to have first began experiencing symptoms for at least the last two years of high school because this retrospective study was designed to have participants reflect on multiple years of schooling experience and to explain how they perceived various experience such as: school structures, sources of support, and relationships with various educators and peers. This was developed in an effort to identify what experience were perceived to be beneficial and what was challenging.

While participants were required to have an IBD condition that was diagnosed by a medical professional (e.g., gastroenterologist, family physician, surgeon; Wong et al., 2012) to participate in the study, they were not required to have been formally diagnosed with their IBD while in primary or secondary school. This decision was made because it can be painful, difficult, and time consuming to officially conclude that a patient has IBD (Kim, 2015). Initial symptom onset likely influenced individuals’ schooling experience and the timing of receiving a
formal diagnosis should not limit participants’ ability to participate in the study. The opportunity to further our understanding of individuals’ schooling experience during the diagnostic process will help further our knowledge of students’ experience as they simultaneously navigate their IBD symptoms and schooling requirements. The distinction between not being required to have a formal diagnosis while in school but being required to have a diagnosis at the time of the interview was appropriate because the study was retrospective.

Additional criteria for inclusion included the ability to engage in conversations in the English language as the interviews were conducted in English. Participants were also required to have previously been enrolled in traditional classroom settings. For example, enrollment in public or private (e.g., Catholic) school was appropriate while solely receiving home schooling did not suit the requirements of the study as participants were required to explain their experience with various former teachers and peers in the school setting.

Recommendations suggest that six to eight participants represent an appropriate sample size for an IPA study (Smith, Flowers, Larkin, 2009; Turpin et al., 1997). This sample size range typically allows researchers to examine similarities and differences between individuals while also allowing for in-depth interviews and detailed case-by-case analysis for each participant (Pietkiewicz & Smith, 2012).

### 3.7 Relationship Building

Due to the sensitive and sometimes embarrassing nature of symptoms associated with IBD, it was important to ensure that each participant was comfortable with the researcher and wanted to talk openly during the interview sessions to achieve the most comprehensive understanding of participants’ lived-experience. Relationship and rapport building was a key way to ensure that the participants felt supported and open to sharing personal experience (Nair,
Dolovich, Brazil, & Raina, 2008) as solid rapport between interviewer and participant has been found to elicit superior quality data (Ryan & Dundon, 2008).

Ryan and Dundon (2008) recommend developing rapport in stages throughout the interview process. First, the primary researcher should begin the interview by explaining the research project, the interviewee’s role, and that the interviewee’s participation is important as research outcomes may benefit future generations of people with pediatric-onset IBD. Second, to develop a bond with the interviewee, the researcher was encouraged to demonstrate empathy. This stage generally elicits more natural, fluid, and relaxed explanations that result in more detailed and deep descriptions of interviewees’ lived-experience. Third, once rapport is established, overfamiliarity may take place. For instance, conversations that are unrelated to the research agenda may occur or interviewees may offer information that he or she assumes the researcher wants or prefers to hear. Overfamiliarity is something researchers should be aware of to keep interviews focused, succinct, and to limit the collection of inaccurate information. On the other hand, overfamiliarity can create an environment of safety to generate comprehensive narratives and detailed examples. Lastly, upon ending the interview, positive researcher-interviewee dyads may increase the likelihood that the interviewee will inform other potential participants about the opportunity to take part in these research-based interviews.

Discussing consent forms in an open and conversational fashion was done to help each participant better understand his or her role. Participants were informed that their participation was voluntary, that they could withdraw consent at any time without penalty, and that they were not required to answer any questions that may make them feel uncomfortable. Interviews began with the researcher asking informal questions to establish familiarity with the interviewing
procedure and become comfortable in discussing more sensitive topics, specifically regarding one’s lived-experience of having an IBD condition.

The researcher strived to be open, non-judgmental, and demonstrated unconditional positive regard with each participant to show respect and maintain ethical behavior throughout the overall research process. This was pursued by practicing active listening skills where the researcher demonstrated engaged body language (e.g., open posture, facing the participant, nodding and smiling when appropriate), and making empathetic and summary statements (e.g., paraphrase what the participant had explained; Ivey, & Zalaquette, 2013).

3.8 Data Sources

As outlined in the recruitment section of this chapter, interested individuals contacted the primary researcher to schedule an interview session. Upon initial contact, the researcher determined whether individuals represented a suitable candidate for the research (see Appendix A, Screening Questionnaire). When it was determined candidates met inclusion criteria, interview appointments were subsequently scheduled via email and participants completed an online survey in advance to provide demographic information (e.g., questions about years of schooling, occupation, IBD diagnosis, age of IBD onset, treatments used, and health status; See Appendix B, Demographic and Background Questions).

3.8.1 Semi-Structured Interview

Participants took part in confidential, one-on-one, semi-structured interviews which comprised the primary source of data for this project. Semi-structured interviews were selected as the method of data collection because this form of interviewing allows the researcher and participant to engage in a flexible dialogue such that initial questions could be modified in light of the participants’ responses. In addition, semi-structured interviewing allowed for the
introduction and exploration of new information that the researcher did not anticipate when initially compiling interview questions. Finally, the follow-up question format allowed the researcher to develop a clearer understanding of participants’ experience.

Interviews were conducted during a time that was mutually convenient for each participant and the researcher. The interviews were conducted in private locations via an online video teleconferencing platform (e.g., Skype, FaceTime, Zoom) which allowed the researcher to connect with participants despite being in different cities. This allowed for an easier pursuit of purposive sampling and financially affordable mode of data collection (Lo Iacono, Symonds, & Brown, 2016).

The interview questions were asked in a narrative progression (see Appendix C, Interview Schedule). Specifically, participants were asked to share their experience leading up to receiving the IBD diagnosis, the process of receiving the diagnosis and initial treatment, and symptom navigation strategies and medical treatment pursuits. Participants were also asked to explain their experience at school during these times and how these two factors (i.e., symptom navigation and schooling) impacted each other.

Each participant was invited to take part in a follow up interview aimed at gaining further clarifying participants’ lived-experience after having time to reflect on what was discussed during the initial interview to bring forth additional information he or she may have felt was important to share. No participants elected to participate in a second interview as they reported to perceive that they had no additional information to discuss following the initial interview. The participants appeared to live busy lifestyles and scheduling the initial interviews was difficult—this logistical barrier may have contributed to participants’ willingness to engage in a second interview. Notably, the researcher advertised the second interview as an optional meeting;
however, greater participant retention for the second interview may have occurred if the study
was advertised as a two-part interview whereby the second interview was scheduled at the end of
the first meeting. Further compensation for their time (e.g., incentives) and a preview of what
would specifically be asked in the second interview may have also enhanced participant
retention.

3.9 Data Analysis

The aim of data analysis was to identify and explore themes that emerged from the
interview data. This process was systematic, and statements were categorized into clusters to
represent the phenomenon. As IPA was the guiding methodology, the interviews were analyzed
in two parts. First, phenomenological segmentation required that the researcher identified,
described, and understood concerns and experiential claims reported by each participant. Second,
interpretative segmentation necessitated that the researcher interpreted what participants were
inferring. This dual approach allowed for an insiders’ perspective as it may exceed participants’
own understanding or conceptualization of their lived-experience.

A multiple phase method was used during the data analysis process (see Smith et al.,
2009; Smith, Jarman, & Osborn, 1999; Smith & Osborn, 2003). As the interviews were audio
recorded, the researcher began by transcribing the data. The researcher read each transcript
multiple times to become familiar with the data and took notes. The notes were (a) descriptive,
whereby key events were identified, (b) linguistic, as a participant’s phrasing and word choices
were highlighted (e.g., key quotes that best represented a certain theme was extracted and used to
illustrate participants’ lived-experience), and (c) conceptual, meaning the researcher identified
abstract ideas such as the participant’s overarching understanding. The conceptual form of
notetaking required the researcher to draw from experiential or professional knowledge. The
researcher examined the notes to identify emergent themes to condense the volume of information while maintaining the level of detail within the data provided by each participant. Connections across themes were identified to consolidate and conceptualize the data. Clusters of similar themes (i.e., subthemes) were then grouped to represent overarching super-ordinate themes. At this stage of the data analysis, the researcher repeated the aforementioned steps for each remaining interview transcript. Each interview was considered individually to allow for the development of unexpected or novel information. Lastly, the researcher looked for patterns across cases to capture and summarize the lived-experience among participants.

3.10 Enhancing Rigor and Trustworthiness

Several strategies were employed throughout the research process to enhance the level of rigor and trustworthiness associated with this research project. In preparation for the study, during data collection, and analysis, the following strategies were used: prolonged engagement, reflective journaling, member checks, and identify re-occurrence of themes. Descriptions of each of these strategies are outlined below.

3.10.1 Prolonged Engagement

Prolonged engagement was employed to learn about and understand the culture, social setting, and phenomenon under investigation. To better understand the medical aspects, the researcher worked to develop an understanding of IBD conditions and symptoms via viewing specialist (e.g., nurses, researchers) webinar presentations and reading about IBD conditions via peer-reviewed journal articles and websites dedicated to disseminating scientifically accurate information about IBD conditions (e.g., http://www.crohnsandcolitis.ca/). Additionally, the researcher participated in the Invisible Conditions Conference as a planning committee member thereby interacting with a community of young adults with IBD conditions. Additionally, the
researcher worked to develop an appropriate level of rapport with each participant at the start of their interview as previously described within this proposal (see Section 3.7). Lastly, the researcher received masters level training in School Psychology and completed literature reviews to gain clarity regarding the educational implications associated with having an IBD condition.

3.10.2 Reflective Journaling

Reflections via journaling took place in preparation of the study as well as throughout the data collection and analysis phases. Specifically, the researcher wrote full descriptions of her personal experience prior to interviewing to allow the researcher to acknowledge pre-conceptions and work to limit personal biases (i.e., engagement in bracketing; Cross et al. 2003). The researcher continued using the journal to facilitate reflections and to critically review and monitor the interview process. Emotions, thoughts, initial insights, and ways to improve her interviewing techniques were recorded in the journal during the data collection phase. The researcher lastly referenced the journal throughout the data analysis process to compare interpretations during this stage with impressions that occurred while collecting data to help inform her analysis and interpretation decisions.

3.10.3 Member Checks

Member checks with each of the participants were conducted throughout the study whereby the researcher asked questions to clarify her understanding during the interview sessions. Additionally, each participant was invited to review a summary of the findings after the data analysis was completed and themes were identified. This strategy has commonly been employed by researchers using the IPA approach (see Smith, Flowers, & Larkin, 2009) as it can support the interpretations made by the researcher and clarify whether the findings accurately reflect the phenomenon (Creswell, 1998).
Two participants (i.e., Greg and Gabby) elected to take part in this process, and the researcher sent the participants the summary (see Appendix E) in advance over email. Greg shared that it was obvious that “the combination of interviews [were] with many people, but from what I see and recognize, it all accurately portrays what I remember telling you.” He reported no need to discuss further as he was satisfied with the discovered themes and the corresponding descriptions. Gabby shared that she “absolutely love the key themes you were able to identify and I think they are integral to people with IBD and how they experience schooling and cope with commitments [and] responsibilities.” The researcher and Gabby discussed the themes further revealing that Gabby felt validated that she was not the only individual who faced specific challenges. Further, Gabby helped identify that a subtheme could be reworded to better represent the intended meaning. Specifically, the subtheme was originally titled as “self-acceptance.” However, the subtheme was intended to capture that participants accepted that they were experiencing a “new normal” state of living. The concept of self-acceptance was too generalized and Gabby reported that this phrasing incorrectly suggested that participants reached a sense of enlightenment. Some additional information she recalled sharing during the interview were not listed in the summary document but were represented in Chapter 4. Gabby’s comments were incorporated into the final analytic description (i.e., information outlined throughout Chapter 4).

3.10.4 Re-Occurrence of Experience

Measuring the re-occurrence of experience across cases was also examined to enhance the rigor and trustworthiness of the study. After analyzing the various super-ordinate themes and subthemes, the researcher identified which participants discussed information involving each specific theme. As informed by an a-priori decision, each theme was required to be experienced
by at least half of the participants to report the theme in the final draft of the research findings (i.e., at least 4 out of 7 participants). Various themes were removed or absorbed into larger themes throughout the data analysis and writing stages as the researcher found that some themes were redundant or did not apply to the purpose of the study. However, upon examining the re-occurrence of experience, all themes appeared to be appropriately represented by over half the participants and therefore no themes were removed during this final stage of analysis. As evident in Table 2, 57% to 100% of participants discussed information pertaining to each subtheme.

<table>
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<th>Theme</th>
<th>Jessica</th>
<th>Greg</th>
<th>Gabby</th>
<th>Megan</th>
<th>Clint</th>
<th>Zoey</th>
<th>Cruz</th>
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<td>×</td>
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3.11 Summary of Methodology

The study sought out to gain a comprehensive and in-depth understanding of the lived-experience of individuals with pediatric-onset IBD during their schooling years. The use of IPA as the methodology allowed participants the opportunity to tell their story and contextualize their experience within their larger life experience leading up to the development of their current selves. This investigation was retrospective in nature and employed IPA methodology using semi-structured interviews. Detailed exploration of participant experience through IPA may help bridge the gap between existing literature regarding (a) childhood and adolescent experience related to having an IBD condition via an educational perspective and (b) long-term outcomes.
This study also aimed to contribute to theories and practices pertaining to supporting students with pediatric-onset IBD in classrooms.
Chapter 4: Findings

The purpose of this study was to understand the meaning of the lived-experience of students with IBD conditions attending school using the methodology of Interpretive Phenomenological Analysis (IPA). This chapter includes a table outlining participant characteristics, a figure summarizing super-ordinate themes and subthemes that emerged from the data, and detailed descriptions of the themes that represent the lived-experience of students with IBD conditions while attending school. The generated themes represent information about the phenomenon of going to school while having IBD symptoms rather than offering generalizations about the participants within this study.

While the study was retrospective in nature, participants described previous, as well as current, IBD related experience. Acquiring this information allowed for a more complete and progressive understanding of the phenomenon in order to understand the types and severity of symptoms that were experienced while attending school. The phenomenon of attending school while experiencing IBD symptoms was described as a journey whereby participants recounted that they engaged in self-discovery as it pertained to their identity as a student and an individual with a chronic medical condition. Notably, the research project was initially proposed as an investigation of individuals’ schooling experience at the primary and secondary schooling levels. However, participants demonstrated a desire to discuss their entire educational journeys which included post-secondary programs. As such, the semi-structured interview script allowed for a discussion about participant’s university experience as well. The conversations revealed that the educational experience significantly differed from high school to university levels. This novel information will likely add a valuable contribution to the existing literature. Lastly, a purely educational focus involving the lived-experience of people with IBD conditions was not
possible, nor was it the intended scope of this project. Rather, a comprehensive description of the various elements that contribute to educational experience was investigated.

4.1 Participant Characteristics

Seven participants (3 male, 4 female) with IBD conditions participated in the study and each participant selected their own pseudonym to protect their confidentiality. The participants current ages ranged from 21 to 35 years. All self-declared to be diagnosed with Crohn’s Disease by a medical doctor and experienced symptoms beginning at age 10 to 17 years while living in various urban and rural locations across Canada (i.e., British Columbia, Saskatchewan, Manitoba, Ontario). For various reasons, initial symptom onset to receiving a formal diagnosis ranged from brief (i.e., less than 1 year after initial symptoms surfaced) to delayed time spans (i.e., 4, 7, and 21 year delays). Notably, the individual who experienced a 21-year diagnostic delay was predominantly due to unique personal circumstances (see Appendix D for Participant Descriptions).

At the time of the interviews, subjective severity was deemed: “not severe” by two participants who were classified as being in remission; “slightly severe” by one; “moderately severe” by three participants; and “very severe” for one individual. All participants had attended some university as two where in the midst of completing undergraduate degrees, one was enrolled in a graduate level program, three had completed an undergraduate degree, and one individual had completed two undergraduate programs. Programs of study included Business Administration, Natural and Applied Science, Education, Liberal Arts, and Fine Arts. All participants reported to easily learn in traditional school settings and self-identified as high achieving and academically inclined individuals. All seven participants discussed their high school and university level schooling experience as the majority of participants’ symptoms began
during their adolescents. One participant began experiencing symptoms in childhood and described her elementary school experience as well. See Table 1 for a summary of the participants’ characteristics; additional background information regarding each participant (i.e., Participant Descriptions) is provided in Appendix D.

**Table 2. Participant Characteristics**

<table>
<thead>
<tr>
<th>Participant Pseudonym</th>
<th>Age (years)</th>
<th>Age of Symptom Onset (years)</th>
<th>Diagnosis</th>
<th>Location of High School</th>
<th>Diagnosis Process</th>
<th>Current Symptom Severity (^2)</th>
<th>Education</th>
<th>Academically High Achieving (^2)</th>
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</thead>
<tbody>
<tr>
<td>Jessica</td>
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<td>10</td>
<td>Crohn’s Disease</td>
<td>Urban, British Columbia</td>
<td>Brief (^l)</td>
<td>In Remission</td>
<td>BBA</td>
<td>Yes</td>
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<td>Greg</td>
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<td>15</td>
<td>Crohn’s Disease; ulcerative colitis</td>
<td>Urban, British Columbia</td>
<td>Brief (^l)</td>
<td>In Remission</td>
<td>BSc; MSc degree in progress</td>
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<td>Gabby</td>
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<td>15</td>
<td>Crohn’s Disease</td>
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<td>Moderate Severity</td>
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<td>Megan</td>
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<td>16</td>
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<td>Rural, Sask.</td>
<td>Delayed, 4 years</td>
<td>Moderate Severity</td>
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<td>Clint</td>
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<td>15</td>
<td>Crohn’s Disease</td>
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<td>Very Severe</td>
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<td>Zoey</td>
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<td>Participant Pseudonym</td>
<td>Age (years)</td>
<td>Age of Symptom Onset (years)</td>
<td>Diagnosis</td>
<td>Location of High School</td>
<td>Diagnosis Process</td>
<td>Current Symptom Severity</td>
<td>Education</td>
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</tr>
<tr>
<td>------------------------</td>
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</tr>
<tr>
<td>Cruz</td>
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<td>Brief&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Slightly Severe</td>
<td>BA</td>
<td>Yes</td>
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</tbody>
</table>

<sup>1</sup> Diagnosed less than one year after initial IBD related symptoms emerged
<sup>2</sup> Self-declared

### 4.2 The Meaning of the Phenomenon of Attending School: Super-Ordinate Themes and Subthemes

Six super-ordinate themes and corresponding subthemes emerged from the data analysis that depicted the experience of students with IBD (see Figure 1). Overarching themes (i.e., super-ordinate themes) included: IBD Related Experience, Coping Strategies, Educational Implications, Educational Accommodations, Process of Normalization, and Social Interactions.

Descriptions of the super-ordinate themes as well as the subthemes are discussed in detail throughout this chapter with selected direct quotes are offered to further illustrate themes using participants’ own words. As recommended by Smith, Flowers, and Larkin (2009), the researcher typically chose one extract to represent the core of multiple participants’ shared lived-experience. Quotes were also chosen to illustrate emotion, elicit empathy, and/or capture the reader’s imagination. Atypical quotes were also outlined in this chapter to illustrate the complexity of participants’ experience as some themes contained convergent and divergent information. An effort was made to proportionately quote each participant so all voices could be heard in this account.

Certain formatting strategies were used to present participants’ quotes. Square brackets (i.e., [ ]) were used within quotes to include additional information not spoken by the
participant—the information was added to offer additional context and help clarify the message. Ellipsis points (i.e., ...) were used to indicate that additional information was shared within the quote but that text was omitted from the extracts as the information was deemed redundant or did not assist with illustrating the participant’s message. Next, double quotation marks (i.e., “ ”) were used to indicate what part of the text was a verbatim quote spoken by a participant while single quotation marks (i.e., ‘ ’) were used within a quote to indicate when the participant was describing what another person said to him or her while recounting experience.

**Figure 1: Super-Ordinate Themes and Subthemes of Students with IBD Conditions Attending School**

<table>
<thead>
<tr>
<th>IBD Related Experience</th>
<th>Coping Strategies</th>
<th>Educational Implications</th>
<th>Educational Accommodations</th>
<th>Process of Normalization</th>
<th>Social Interactions</th>
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</thead>
<tbody>
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<td>Diagnostic Process</td>
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<td>Feelings of Embarrassment</td>
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<td>Holistic Treatments</td>
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<td>Key Sources of Stress</td>
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</tbody>
</table>

### 4.3 Theme 1: IBD Related Experience

A super-ordinate theme that emerged throughout the interviews involved IBD related experience. Participants shared how their IBD related symptoms were perceived to produce unique hurdles that they would have not faced if they did not have this condition. Four subthemes emerged within this super-ordinate theme: (a) diagnostic process, (b) physical symptoms, (c) mental health concerns, and (d) key sources of stress. As this study was retrospective in nature, participants described their previous and current IBD related experience.
Acquiring this information allowed for a more complete and contextual understanding of the participants’ medical experience necessary to better understand the schooling phenomenon.

4.3.1  **Subtheme 1a: Diagnostic Process**

Participants’ diagnostic process were described during the interviews as this occurred for each participant while attending school. The diagnostic experience generally occurred in one of two ways and could be considered to be a separate phenomenon exceeding the scope of this research study. First, some participants (i.e., Jessica, Greg, Clint, Cruz) experienced a relatively quick assessment and diagnostic process shortly after they began experiencing IBD related symptoms. Jessica described her diagnostic journey as efficient:

> I went into the emergency. Uh, I want to say it was because of blood loss—so, bloody diarrhea. And that was a big situation for my parents so they brought me to the emergency. […] Doctors wanted to check my stool samples, […] they wanted to check to see if I had appendicitis and the doctor there said that, um had me get an appointment with the GI at the children’s hospital as soon as possible. So I think that because he knew someone that had it, he fast tracked me.

Second, some participants (i.e., Gabby, Megan, Zoey) faced ineffective or delayed medical assessments resulting in being diagnosed much later compared to when symptoms first emerged. Gabby was initially misdiagnosed; she shared: “when I really started to have stomach troubles and stuff, like my family doctor at the time told me ‘it’s just IBS [Irritable Bowel Syndrome…], you’ll be fine, bye’.” Her symptoms persisted and she shared that:

> They referred me for […] a colonoscopy, and I went for it and I remember when I woke up from the procedure the doctor was like ‘uh, we didn’t find anything, you’re clear, you’re good to go, it’s just IBS’. […] Six years later, I was in [larger city] and got another scope done and he was like ‘yeah, you’re full of scar tissue and it’s Crohn’s disease and likely the doctor in [smaller city] missed it’. […] So yeah, that was probably why it took so long, just a bad test and bad doctors.

Based on additional informational context, it was interpreted that streamlined diagnostic processes were largely due to the participants living in an urban setting and having access to
specialized medical professionals and technology. Conversely, those who experienced a delayed diagnosis generally lived in rural areas and worked with general health practitioners whom did not utilize specialized technology properly, or at all.

4.3.2 Subtheme 1b: Physical Symptoms

Throughout the interviews, each participant referred to experiencing a combination of various types of symptoms related to IBD which included feeling gassy, bloated, frequently needing to use the washroom, experiencing diarrhea, constipation, fatigue, difficulty swallowing, nausea, vomiting, and weight loss, as well as abdominal, joint, back, hips, and ankle pain. Clint referred to his symptoms as a “flare up” and described his symptoms as sometimes “being a nightmare, I was always trying to find bathrooms.” All participants shared that they frequently needed to use the “washroom” and Megan and Cruz shared that they also frequently needed to “throw up.”

Jessica shared that IBD symptoms were pervasively chronic and extended above and beyond symptoms related to digestion:

It affects everything. It’s not like it’s just affecting your bowel, […] you can’t control it by what you eat. It’s not like if you cut certain things out of your diet, you’re going to have more energy. It really does affect everything. Like if you have it, like your skin, […] eyes, […] and joints are going to have issues, […] there’s just so many things that affects a person.

Unfortunately, feelings of fatigue appeared pervasive for some as it negatively influenced academic engagement and resulted in participants feeling isolated and disconnected from their school-aged peers. Jessica also shared:

I think it was harder connecting to other peers. I had lower energy, there was obviously something wrong with me, I just didn’t have it in me. […] My friends all had a lot of energy and so it was hard to keep up with them.
Lastly, Gabby emphasized how symptoms of IBD can differ from person to person: “The thing about IBD is that no two people are the same and everybody is so unique and the challenges they deal with, how they grew up, how they were brought up, and the care that they received and everything.”

### 4.3.3 Subtheme 1c: Mental Health Concerns

The majority of participants shared that they developed mental health difficulties in conjunction with their physical symptoms. Psychological challenges were predominantly found to occur in the form of fear and worry that physical symptoms would unexpectedly return and persist. Gabby shared that she had experienced:

Lots of stomach pains and cramps. When, I remember in high school there would be quite a few times where like out of nowhere there would be these sharp shooting pains that just come in my lower abdomen where I would either have to sit down or keel over, they were sharp and sudden and last for like a minute or so and you’d just have to breathe through it and it would finally go away and I’d be like ‘ok, I’ll just keep going, hopefully it doesn’t come back again’ but it was always in the back of your mind, like ‘oh, when is this going to happen again’ kind of thing so I guess a lot of worrying and having to plan ahead and think ahead because, you know, you're always looking for where a washroom is in case you need it.

To capture the interplay of physical symptoms (e.g., pain) leading to increased feelings of stress—later leading to significant mental health difficulties (e.g., depression, suicidal ideation)—consider the following quotation provided by Zoey:

I was in so much pain and you literally are dying, you don’t know what’s happening to you, you don’t know what’s going on, the pain is so, you can’t eat, you can’t sleep, you can’t lay in the bathroom properly, it’s just like, the progression, and the pain is so traumatic to the body, so so traumatic, I remember going into a severe depression because of this severe pain and I remember, I’ve been diagnosed with depression with other flares because that’s when it started, I’ve gone to the doctor and said like, ‘I, my tummy hurts really bad, what can we do about it?’ and he gave me nortriptyline and all these things that weren’t really working and buscopan and antispasmodics and stuff, none of it was working and finally he said ‘I think you’re dealing with depression’ and I was just blown away, I didn’t even know what he was talking about and like, I was totally dealing with depression but it was also caused by the pain that I was in and I couldn’t do things so yeah, I recognized that the depression was happening, […] 2 summers ago, I was laying
in the bathtub crying and was literally like, ‘I don’t want to be alive, if I died right now, that would be ok’ and I was like, ‘shit, I know it’s happening again, depression is happening again’ so I went back to the doctor and got anti-depression or anti-anxieties but I think it’s the same, the one I’ve taken does both and so started taking a low dose, a really low dose, and it helped me for sure get through the stuff that I dealt with for the last couple of years but yeah, no, it’s a, the pain triggers more stress for sure.

Greg explained that these fears could last longer than the physical health challenges associated with IBD as is fearful that symptoms will re-emerge despite currently being in long-term remission:

Even though I haven’t had a flare up in seven or eight years, I’m still as afraid of having a flare up as I was back then as I’ve built myself up to where I am right now and if I have a flare up I’m afraid I’m going to lose everything so that’s shaped my lifestyle right now. I’m really careful with my diet, I’m vigilant about every other aspect that I can be on top of taking my medications. […] So, there’s that fear in the back of my mind saying, ‘uh if you’re not careful and even do everything that you can do, and stress you can’t deal with, you get to lose everything’.

Cruz’s low mood also “stayed for a little bit after, even when I started to feel better physically” as the lifelong implications of having a chronic disease was viewed as a “burden” (i.e., “I have it for life”). Similarly, Megan shared that she felt she had to “basically cope with this life sentence of ‘you have this disease, there is no cure for it, good luck.’” As such, perceived lack of control was interpreted to be an additional factor that negatively influenced the mental health of these participants.

4.3.4 Subtheme 1d: Key Sources of Stress

Participants endorsed that symptoms were triggered or exacerbated by stressors. Stressors were numerous and were related to their medical condition, educational sources of stress, and personal stressors (e.g., parental divorce, severe car accident). Some participants attributed these additional stressors as contributing to the onset or exacerbating their IBD symptoms. For example, Gabby reported that “different professions I have talked to, counsellors, or even like my doctors had said, like a naturopath had said there is a pretty clear link between when your
symptoms started and all that stress started in your life so it’s likely that that contributed to it as well.” Participants discussed key sources of stress which emerged which are outlined below.

All participants, male and female, referenced losing a significant amount of weight and associated the weight loss with being unhealthy and problematic. As a high school student, Gabby stated: “looking back at pictures of me, like grade 11, I was like a rail, like I didn’t look healthy.” Cruz shared that he continues to struggle with his weight: “I don’t know if I’m healthy, right? I haven’t really put on weight in a long time so when I try to, I can’t pass a certain barrier, when I try to eat more and work out, it’s just really hard.” To capture the significance of potential changes in weight, consider Megan’s changes in weight:

I remember I basically dropped 30 pounds in 2 months. […] High school is kind of a weird time where people look at you and automatically think ‘oh my gosh, you look so great, you’ve lost weight’ type thing as oppose to ‘you look sick’, I’m not a huge person but 30 pounds less of me is pretty drastic.

The combination of her health struggles, weight loss, and interactions with other people negatively influenced her body image and mental health. As a teenager, she recalled transitioning from feeling, “‘ok, finally accepted [my body]’ to ‘now I’m skin and bones’, my hair started falling out so I was definitely in an inner battle of ‘what the hell’s happening to me?’ and it definitely affected me psychologically, like I was depressed.” Lastly, Greg hypothesized that his health difficulties interfered with his growth and physical development trajectory: “my brothers are big, they’re over 6 feet tall and over 200 pounds, like they’re built big, and because IBD impacted me during puberty, we think that that, combined with inadequate nutrition, stunted my growth to some degree.”

The majority of participants also reported to struggle with their relationship with food as they knew food to be nutritious as well as a source of pain thus leading to their significant weight loss. As a student, Jessica shared:
I loved food, so I would dream about all these different types of food but I barely ate any lunch or snacks or anything so I was, I was obviously really struggling with my weight in a medical term that […] I would sit and look at my food and want to eat this food but I couldn’t. […] Most of the time nothing [I ate for breakfast] could settle. So going to school was always pretty tough because um I think it’s worse for me in the morning […] because my stomach didn’t handle food.

Both Greg and Zoey would not eat in front of other people while in high school. Following effective treatment and symptom management, Zoey shared that she needed to re-develop her relationship with food as she previously would not eat to avoid adverse physical symptoms (e.g., pain) and needing to quickly use a washroom after eating:

I’m constantly thinking about food […] because my body was starving, my brain is constantly thinking about food and eating because I got to the point where when I could eat, I would eat as much as I can because I didn’t know the next time was that I would be able to eat. [She reported that she needed to tell herself that] its ok, it’s there, and you're going to be able to eat and you don’t need to be sacred that you're going to be in pain.

Lastly, interrupted access to bathrooms and toilets were continuously endorsed as significantly stressful experience. Zoey shared that as a student, “if I had to go to the bathroom, I had to go, so actually I did have anxiety of having to ask the teacher if they would let me, like I had plans in my head of how I was going to deal with if the teacher didn’t let me go to the bathroom.”

4.3.5 Summary of IBD Related Experience

The theme of IBD Related Experience largely represented an additional phenomenon description of having an IBD condition; this theme also offered invaluable contextual information pertaining to participants’ unique experience while attending school. The process of receiving a diagnosis, experiencing physical symptoms, struggling with mental health concerns, and facing key IBD related stressors (i.e., body image, participants’ relationships with food, and bathroom access) were found to largely influence participants’ schooling experience. Further,
participant recollections helped articulate the significant interplay between IBD related physical symptoms and adverse psychological difficulties and stressors.

4.4 Theme 2: Coping Strategies

Much like the super-ordinate theme of IBD related experience, a second super-ordinate theme that emerged within the data that was IBD specific and involved coping strategies used to manage symptoms. An in-depth understanding of these strategies also helped to contextualize participants’ educational experience. Two subthemes emerged within this super-ordinate theme: (a) medical treatments and (b) holistic treatments.

4.4.1 Subtheme 2a: Medical Treatments

First and foremost, overall health, wellbeing, and academic success was interpreted to be influenced by successful medical treatments. Each participant explained that his or her symptoms changed over time, indicating that (a) some responded well to treatment and benefited from a reduction in symptoms while (b) others reported that symptom concerns have progressed and worsened as they aged. Cruz reported to experience IBD symptoms in high school and had found an effective treatment plan while completing high school. As such, upon beginning university, he remembered being “fine at that point and the transition would have been no different than anyone else’s, really.” He further explained:

I guess we found what worked and I was more aware of what was going on and why so I was just, treatment really. […] I responded well I guess because I was deemed moderate-severe, I took steroids, and I took those tablets that coat your stomach and now I’m taking Humira and now I’m good.

Greg also found an effective medical treatment that allowed him to go back to school after briefly withdrawing from university due to his difficulty simultaneously navigating his IBD symptoms and taking classes:
I started a new medication that worked really well so my symptoms were almost totally in control […] so I made my mind up to go back, re-enrolled, but I still had a couple more months to work so that whole time at the job I was thinking about what it was going to be like going back and mentally preparing and all that.

Despite the various positive features associated with effective medical treatment, participants have expressed concern that their medical interventions may produce adverse long-term effects. Megan expressed that:

The drugs themselves, they’re kind of terrible for you, they are really bad for your liver, they’re really bad for your kidneys, […] they’re kind of a double-edged sword […] it’s kind of like taking chemo, you’re essentially killing other parts of your body in the process.

4.4.2 Subtheme 2b: Holistic Treatments

Generally, coping strategies were described as a progression journey whereby participants were initially unaware of alternative, healthier, and more beneficial coping strategy options. Greg explained that finding individualized and effective coping strategies “took years to develop.” Generally, when participants were younger ineffective strategies were employed to manage IBD symptoms. Zoey shared that as a teenager, she “remember[ed] on a Friday night, I would just stop eating […] so I wouldn’t have to go to the bathroom […] I would remember my mom making supper on Friday night and I would never eat it if I was going out with friends.

Ineffective or immature coping strategies were interpreted to be due to participants being young and unfamiliar with their condition and personal needs. Participants explained that they discovered healthy, affective, and individualized coping strategies over time via learning from other people as well as through trial and error.

As stated above, people experience IBD in a variety of different ways. Similarly, treatment and coping strategies were found to be highly individualized. Participants shared numerous holistic methods to lessen the severity of their symptoms. Changing one’s diet was
found to be the primary holistic intervention strategy. Most participants avoided foods that “triggered” their symptoms. Gabby shared that she cut caffeine out of her diet and ate “clean” food; Cruz expressed that he viewed eating a vegan diet and consuming smaller meals more frequently as beneficial; and Clint reflected on the following:

I definitely found that when I cut down on fast food I was eating, I wasn’t having symptoms daily or having way more painful movements and I stopped eating corn, I know that one usually sets me off quite a bit […] I guess that’s just more like take-out food, Chinese, or something like that, Indian, so I try to avoid those, and whole wheat, stuff with a lot of fiber tends to just cause pain for me.

Various exercise routines such as weight lifting, yoga, and swimming have been described as beneficial for participants. As an example, Greg shared:

I felt like having that physical outlet of going to the gym, I’d lift weights, I wouldn’t do cardio or anything because I didn’t really feel the same sort of relief, […] anxiety was the central problem that I had that really aggravated my symptoms, lifting heavy weights would sequester that anxiety.

Two participants discussed how cannabis has helped treat some symptoms as they perceived less bodily pain after consuming medical marijuana. Lastly, rest and sleep were described as key strategies to help with reducing some negative effects of IBD. Zoey shared how she initially struggled with allowing herself enough rest:

The second biggest symptom in Crohn’s is fatigue, right and so that’s hard on kids, right, they want to have energy and they want to do stuff but they can’t so allowing that extra time for them. […] Your brain is ready, your brain wants to do stuff but your body is not able to do that and so it’s very difficult to stop yourself. […] If I push myself too much, then I start feeling sick so I had to learn not to do that but you learn from your teachers and your peers and people around you to push forward and get through it but we can’t do that, our bodies are sick so we can’t do that so you have to take care of your body in a different way.

4.4.3 Summary of Coping Strategies

The super-ordinate theme of coping strategies illustrated the dramatically different levels of efficacy medications had for individuals with IBD as this condition is not currently well
understood within the medical community and proves to be difficult to treat. Various other individual coping strategies have been tried by participants and were generally described as a journey of trial and error; participants took time to learn what options worked best for their unique needs. Strategies included diets, physical activity, medical marijuana, and rest.

4.5 Theme 3: Educational Implications

The third super-ordinate theme that was found within the interviews involved educational implications associated with having IBD symptoms while attending school. Specifically, participants shared that they experienced (a) educational successes, (b) educational challenges, and (c) transitional struggles from high school to university.

4.5.1 Subtheme 3a: Educational Successes

All participants of this study self-identified as being academically inclined and high achieving students. As an example, Gabby shared that “I always did really well in school and you know, good grades, and really involved and stuff, so school wasn’t stressing me out or anything.” Similarly, Zoey explained “I was a super smart kid and […] I guess I’m the kind of person that if you teach me, I learn.” Participants’ cognitive abilities and work ethics appeared to result in educational successes despite facing barriers associated with experiencing IBD symptoms while in school. Cruz perceived his schooling endeavors as successful and he shared that “I got good grades, […] I got into the school [i.e., university] I wanted to.” Greg reported:

In terms of how it impacted me at school, it wasn’t that bad. […] After missing school for a month, “when I came back to math class, uh I had stayed on top of it and I think got the highest mark I think on the unit test. […] I came back and the teacher made a point of saying ‘[Greg] was gone for an entire month and still got the highest mark.’

In fact, Greg sought out additional academic challenges as he enrolled in “a French honours class.” Similarly, Jessica sought out additional academically enriching opportunities throughout
her schooling career (e.g., joining the French immersion stream, advanced placement courses) after being diagnosed with IBD:

I was pretty bored in general—in normal classes. So there is always some really slow students—students that don’t necessarily understand as fast as I do so I would just sit there and draw anyways or just be bored because I’d already know the answer and you’d be asking the same question 10 times over. […] I’d get pretty bored in the classroom anyway um and it depends on the different classes. So, one thing I think you should know about me, I was in mostly academic classes so French Immersion from grade 6 to 12 and then high school, in high school, I was in the accelerated math and science, so I was in, like I did calculus in grade 12, physics 12, chem[istry] 12, like I was pretty good in those.

4.5.2 Subtheme 3b: Educational Challenges

While participants experienced schooling success—especially at the high school level—educational challenges were also prominently discussed. IBD related symptoms appeared to hinder academic functioning. Difficulties included fatigue, nausea, vomiting, abdominal pain, and bowel movements all of which impeded on concentration, engagement, work completion, and learning. Cruz stated that he “wasn’t reaching my full potential” when his symptoms interfered with his schooling. Clint shared that “it makes it harder to concentrate, there’s been lots of times where I had to sprint to the bathroom because I feel like I won’t make it.” Similarly, Greg reported:

I would feel the cramping and the pain and I would be—I’d lose attention to what was going on in class, huddle over my desk and I guess make, try to make the pain go away […] but sometimes that the cramps would be so bad that I’d have to excuse myself from class.

Megan emphasized how experiencing a combination of symptoms made schooling particularly challenging:

“When I got super sick, […] I almost had to drop out of university that year, […] just getting up and actually having the motivation and not be in pain to do anything, […] I was just in pain all the time because we hadn’t found a cocktail mixture of drugs that worked yet so I basically spent all my time in the bathroom or throwing up or thinking I needed to throw up, I had no energy so all I did was sleep so when you have no energy, I just to live on the top floor of my building so its 4 flights of stairs when your joints are
starting to corrode, it wasn’t really worth it so I just didn’t go to class, I just couldn’t find the motivation, I was in pain so I just didn’t and it got to the point where my grades were suffering, I’ve always been a relatively high achieving GPA type student and I was getting 50s and 60s and it kind of got to the point of ‘is this worth it?’ I mean, I pushed through because I’m stubborn like that but, it, my grades definitely took it hard.

Specific schooling events were prominent for some participants. Jessica found that:

> All kinds of smells would make me nauseous. I can just remember this one time, you know how you have to dissect a salmon or something, or a fish, in grade 6, I think? That was the worst day, for me. Just the smell that fish. It just made me feel nauseous and just made everything in my body just revolt. So, it was, that was tough, just trying to get through that day.

Greg also reflected on a particular event that demonstrated to be stressful, painful, and socially embarrassing in addition to being high stakes as this occurred during a university level final exam:

> In one of my final exams that semester uh when I was going through my worst flare up where I had to leave to use the washroom 12 or 13 times in a couple of hours and again, I had never experienced that before and I was having, or feeling, that the whole room was watching me leave and come back so many times and it was embarrassing and painful.

As a result of the various university level challenges, Greg shared:

> When I withdrew from [University Y], I felt like my career options were limited because I thought if I was going to be stressed during university then I thought I’d be stressed during a job that required a university education so I looked into other options.

Both Greg and Clint revealed that they have needed to “drop” or “withdraw” from certain university level courses and programs due to symptoms interfering with their academic performance. To further emphasize how IBD impacted these participants during high stake situations, interview conversations revealed that some individuals were not eligible for certain academic scholarships or were unable to apply to certain educational programs. While Jessica was transitioning back to school after surgery in Grade 11, she recalled that “I had missed a lot of school because I was out of school for about a month and it was the end of the term so my grades weren’t very good and those are important because those are the ones you need to bring
into university.” She also reported that she did not receive a “passport to education” scholarship and attributed this to her absences contributing to her lower grades that semester. Greg shared that medical school program application options were reduced as a result of him working to manage his IBD symptoms:

A lot of schools in Ontario require and Alberta require that you have taken a full course load for multiple semesters and done well. So throughout my undergrad, I feel like I hadn’t been able to take a full course load, like 5 courses, for multiple semesters and that was one of my coping mechanisms of dealing with the stress. […] So if I had taken those 5 courses then maybe I would have had another flare up and it would have been counterproductive.

4.5.3 Subtheme 3d: Transitional Struggles

As articulated in the previous two subthemes, participants experienced academic challenges as well as successes. Participants reported to experience more academic success while in high school. Participants also shared that they experienced different, and lesser, expectations and requirements while in high school compared to when they were in university. Megan shared that she “did miss some school but I mean its high school, it’s not life or death type thing, like they’re pretty accommodating, like ‘oh you missed a test, just write it this day’ type thing so that wasn’t super bad.” Clint also shared that navigating and managing his IBD symptoms while in high school were inconsequential as “it didn’t really interfere too much, […] I just kind of went on with my days and stuff.” However, since entering university, he reported that his academics have been negatively impacted:

If I end up having to go to the bathroom during class then I’m pretty much going to miss the whole thing especially if I’m not feeling well already, it can be 10, 20, 30 minutes and you're shit out of luck if it’s only a short class […] it can just happen out of nowhere, where all of a sudden not feeling well and like trying, having a hard time seeing my doctor already, by the time I get a note, I’m kind of screwed, classes and exams, if it’s bad I miss a week almost which is 2 labs, 3 labs, you can’t make those up so I’m kind of screwed especially if its during midterms or anything like that.
Expectations and responsibilities increased at the university level. Unfortunately for some, symptom severity also increased during participants’ transitions into university. Gabby shared:

In university, I’d say more of the symptoms started and like, I was more sleep deprived in university because I was also having to work to afford to go to school so I didn’t get a whole lot of sleep a lot of the times and then late-night papers and all that jazz.

Greg recalled a variety of struggles as well during this time in his life:

I’d say in university when things were worse for me, symptomatically […]. It wasn’t just university that started, it was a whole lifestyle change. Like in high school, like in math, everything [involving high school] was so comfortable, it was a 5-minute walk from home, it was like my second home, I knew everybody, felt super comfortable, especially towards the end in Grade 12. Life was easy and when I started university I also started my first job so the combination of those 2, I was the new person, surrounded by people I didn’t know and sort of had to interact with and it was further away so first time taking the [public transportation] so there was lots of elements of uncertainty and with that came a lot of anxiety and it was the anxiety that really aggravated the symptoms in me.

Some transitional struggles were typical and unrelated to difficulties associated with IBD. For example, Zoey identified that “I think my big stress started when going to university, what the heck am I going to be? What am I going to do?” Similarly, Clint stated: “honestly, I have no idea what to do with my life, kind of bouncing around a bunch, I haven’t really decided.” He continued to describe difficulties that take place for many students entering university: “I think that what kind of hurt me too when I went to university was that all of a sudden, I needed to study and I wasn’t really used to doing it.”

4.5.4 Summary of Educational Implications

The super-ordinate theme of Educational Implications illustrated that despite experiencing undesirable IBD related hurdles, the participants’ experienced academic successes and possessed personal strengths—such as strong cognitive abilities, work ethics, and high levels of motivation—that positively impacted their academic performances. Academic challenges were also a salient experience among most participants and were typically associated with IBD.
related symptoms. Lastly, participants experienced transitional struggles as high school level schooling experience were viewed as more flexible while expectations and responsibilities increased at the university level resulting in more challenges.

4.6 Theme 4: Educational Accommodations

Educational accommodations emerged as a super-ordinate theme. While this theme presents information similar to the second theme of educational implications, educational accommodation information was salient as four specific subthemes related to educational accommodations were found and included: (a) lack of accommodations, (b) informally offered accommodations, (c) formally assigned accommodations, and (d) personally generated strategies to succeed academically. Notably, accommodations drastically varied from participant to participant. Each type of accommodation experience is outlined in an effort to maintain individual participants’ voices and unique experience that likely represent what most students with IBD may encounter.

4.6.1 Subtheme 4a: Lack of Accommodations

Notably, the primary accommodation that participants reported to find most beneficial was unlimited access to a washroom. Jessica shared that this need was not always offered. She shared that:

[The urge to use the bathroom] would always happen when there was a quiz or a test, that I really needed to go to the bathroom and it was probably because of the stress or whatever. […] So I’d be like ‘I gotta go to the bathroom’ just in the middle of the quiz, and they’d be like ‘no, you can’t’ and I’d be like, ‘ok’ and it was really uncomfortable.

Jessica also shared that when she was in high school, she missed a few weeks of school due to undergoing surgery to help manage her IBD symptoms. As a result, she missed a number of assignments, quizzes, and exams. She stated that some teachers wouldn’t let her “make up all the
stuff [...] because I had already passed the course, but my grade just wasn’t reflective” of what grade she would have earned if she completed all the course material.

4.6.2 Subtheme 4b: Informally Offered Accommodations

Informally offered accommodations were typically offered at the high school level. Further, participants specified that the accommodations were offered to most students and it did not appear that having and IBD condition had any bearing on teachers’ decision to offer these accommodations to students. Jessica shared that “if I missed a test or a quiz, I would be able to make it up. I think that’s pretty normal anyways, I’d just do it after school or whatever. So, nothing special.”

4.6.3 Subtheme 4c: Formally Assigned Accommodations

While high school level teachers offered non-specific accommodations in an informal fashion, some participants pursued formally appointed accommodations at the university level of their schooling. Gabby reported that:

> When I went to the University of [X], I went and registered myself at the student center for accessibility just because I felt like the stakes were a little bit higher and I just wanted to cover my butt and I went got an accommodation letter and sent it out to all my profs every semester and stuff.”

Megan also described her accommodations as being a source of security and a beneficial resource. She also described what she had been offered as forms of support as she worked to complete assignments, midterms, and finals:

> I have accommodations to the university, basically it’s there in case I get sick to kind of cover my butt. [...] Basically the accommodations I have right now is that I don’t write finals in the gym, stuff like that because you can’t just get up and leave so when I’m writing, not necessarily for midterms, but for finals because they are 3 hours, they stick me in a room near a where I can get up and come and go so that’s one thing and then basically, if I’m sick and not making it to class, not making it to school, I’m allowed extensions on projects and stuff but otherwise that’s pretty much it [...] extensions are nice, they are definitely one of those things, I don’t always use them, obviously, I’ve only used it once because currently I’m in remission more or less, whenever my intestines
decide to hate me, um, so it’s really, really depends when it’s needed and when it’s not so I haven’t really had to use the extensions. Being able to write in a different room, it’s nice, its quieter, you have the ability to not freak out about time because I also have extended time for tests because if I have to go out and spend 20 minutes in the washroom while I have a 3 hour exam, that really cuts a lot of your time away. So stuff like that has been really beneficial.

Greg also endorsed that formally assigned accommodations were a beneficial resource as he shared “I grew to like taking exams after taking those accommodations at the disability office at [University Y], it became a lot more enjoyable.” His accommodations included “free access to the washroom” and additional time while writing exams. Notably, he stated that the extra time:

Made the biggest difference, like without that, I don’t know if I’d been able to get through my undergrad. […] That uncertainty and the anxiety that arises, ‘what do I do if I have to go to the washroom?’, and when you’re sitting in a room close to a washroom, the need to use it just goes away so a lot of the time I wouldn’t need to use the accommodations, but it was the security and certainty that ‘it’s going to be ok, everything’s ok’.

While university level accommodations were largely described as helpful, this support was difficult to obtain. Greg also shared that:

After I transferred to [University X…], I stopped using them, I didn’t want to go through the hassle of having to prove everything, having to talk to my doctor and getting those notes for everything, and my symptoms were pretty under control so I didn’t need to use them.

Further, Clint expressed that he has not obtained formally offered accommodations due to the level of persistence and follow up associated with the time and paperwork associated with the service:

I just, I knew probably if I would have worked at it, I could have gotten some sort of exception form or something for stuff I missed but I just never got around to doing it and it was always such a pain, every time I got sick I ended up missing something like a lab and having to get a doctor’s note […] every single time […] I need to get their [University] specific form and get the doctor to fill it out […] it would almost be like a week after or I’d just, I’d just never do it.
As such, perceived obstacles associated with obtaining formally assigned accommodations can lead to participants accessing a lack of accommodations—which was discussed within the same super-ordinate theme—thereby appearing to aggravate participants’ physical symptoms and hindering academic achievement.

4.6.4 Subtheme 4d: Personally Generated Academic Strategies

Much like physical and medical coping strategies, some strategies participants employed to succeed academically were found to be beneficial while others were somewhat harmful. Beneficial strategies included taking a reduced course load. Zoey explained that short term stressors were less likely to lead to difficulties while university level demands were continuous and likely exacerbated symptoms for some participants. In reference to midterms and final exams:

\[
\text{Those times were stressful but I’m pretty good at hunkering down and doing that, I think it’s the prolonged stress, the constant assignments, the constant, you never really have any down time and I now know that my body needs a lot of rest and it needs rest before I do an activity and I need rest after I do an activity so not knowing that in university, you’re just going all the time so stress on the body right?}
\]

Strategies to combat prolonged stress associated with university level demands were employed by most participants. Clint shared that he “took a reduced load, I only took 4. And I found that helped a bit, I was able to just keep it under control I guess […] well I did start with 5 and I ended up dropping my English class, I just didn’t have time for it.” Greg reported greater degrees of success when he took “2 or 3” courses a semester. Participants also emphasized the importance of regular attendance. As an example, Clint recommended that other students with IBD conditions “go to class, that’s the biggest thing, as soon as you start not going to one class, you think ‘oh I’ll just miss one’ and all of a sudden it just kind of steam rolls.”
Second, some ineffective strategies were employed to address educational obstacles. Basic physiological symptoms were ignored and participants’ general wellbeing and learning likely suffered. Greg explained:

In high school it was just the urgency of having to go to the bathroom and in class I handled that by stopping paying attention to what was going on in class and just shutting myself down and focusing on not going until the feelings subsided and that is how I handled that all throughout high school.

To combat an excessive number of school related responsibilities, Clint shared “I know I did manage to catch up one semester, I had to pull a couple of all-nighters to get my work done […] I just remember being so out of it, I was barely getting any sleep.” Other participants recommended against working excessively hard and sacrificing sleep. Gabby shared:

I think when you're used to feeling a certain way, that’s just kind of your normal and you just push through it, I’m not saying that a good thing, pushing through it all the time because obviously over time kind of ignoring things or pushing them down did me a disservice.

Similarly, Zoey shared that she would manage her health and schooling differently if she had the opportunity to re-experience that time in her life:

I would just be so sick all the time, I have no idea how I survived for 15 years like this, […] I’d just go to class and sit there, hood up and shit and just be there […] I would go to school and I guess I would take Tylenol sometimes, I just powered through it, I did, I did, I don’t know how I did it, I have no freaking clue and I’d never do it again.

4.6.5 Summary of Educational Accommodations

As informed by these interviews, accommodations varied substantially between participants as each person demonstrated varying degrees of willingness to disclose information to their educators. Some participants experienced a lack of accommodations. At the elementary and high school level, simply being allowed to use the washroom was sometimes not permitted and was found to be a source of stress. Some students were permitted to receive extended deadlines for high school level assignments, tests, and exams—this informal accommodation
was left to the discretion of individual teachers. Next, high school level accommodations were more flexible and more easily obtained while university level accommodations followed a strict protocol. Over time, participants generally developed individualized academic strategies which included taking a reduced course load, attending class, and rest.

4.7 **Theme 5: Process of Normalization**

The process of normalization emerged as a super-ordinate theme. Three progressive subthemes related to participants’ journeys of developing a sense of normalization were identified: (a) internalized feelings of embarrassment and a perceived need to keep this information secret, (b) finding connections among others experiencing similar conditions, and (c) acceptance of their “new normal” way of life.

4.7.1 **Subtheme 5a: Feelings of Embarrassment**

Participants recalled feeling embarrassed as a result of the bathroom related symptoms experienced while in class. As an example, Zoey shared:

> I was really cautious about going to the bathroom, I’d go right at the beginning of class, there’d be less people in the bathrooms, yeah, yeah I was really cautious, I didn’t tell anyone really, not even my mom, no one really knew I was going through this actually.

Similarly, Gabby shared that she was:

> Going to the bathroom a lot so like, having to leave class frequently and for long periods of time, like no one really said anything to me but in the back of my mind I was like ‘oh they’re going to know I was in the bathroom doing a number 2, like so embarrassing’ you know? Or like, after coming out of the bathroom and someone else goes in, it’s like ‘they’re going to know what happened’ so like that was an embarrassing part of it.

Clint shared that “it’s embarrassing for me sometimes, if I go to the bathroom and end up taking a long time or I have to go a couple times in a day especially if I’m not feeling well, maybe 5 times.” Jessica described that going back to school after being absent for a couple of weeks. She explained that she provided this response because “no kid wants to feel abnormal”:
Was embarrassing I think a little bit because I think then people realized there was something wrong with me and I didn’t want to believe there was something wrong with me, I think, so I kept trying to hide it but I kept on going to the washroom all the time anyways. So it was hard to hide it. […] people were like, ‘oh, is everything ok?’ [and I would respond with:] ‘Yup, everything’s fine.’

Greg explained why he chose to not share information about his condition with others:

I was diagnosed in the middle of high school, I [was] caught in between it being part of my identity and how others would see me, and I guess that was one of the reasons I didn’t tell people, I didn’t want them to see me as the person with the disease.

This information was interpreted to represent internalized feelings of embarrassment in addition to feeling abnormal, and ashamed.

4.7.2 Subtheme 5b: Finding Connections

Over time, participants reported feeling less alone and embarrassed as they encountered other people that had similar conditions. Megan shared, “I’m finding out that a lot more people have it than you think.” Jessica began feeling less isolated as a result of “just being around people with other different dietary issues and stuff.” Participants have also begun to engage in mentorship relationships with newly diagnosed people to help reduce incidents of others feeling isolated. Gabby expressed a desire to make “improvements for other people so they don’t have to go through all the things that I did too.” Similarly, Zoey reported:

If I could help anybody not have to go through all this pain, and like psychological pain, mental pain, emotional pain, physical pain, all of it, if I could help someone not go through all of that pain, that’s amazing, that’s why I was like ‘we got to help little people, I want to be part of this study, I will, I’ll do it, I’ll help them.’

4.7.3 Subtheme 5c: Acceptance of “New Normal”

While initially embarrassed, participants have grown to accept that their conditions are chronic and life-long, therefore accepting that what they experience are their “new normal” way of living. Gabby described her process of establishing acceptance:
I just got to the point, sorry for my language but, ‘fuck this, there is nothing I can do to change this so it’s like whatever’ so I started making light of it really, like if you ask any of my friends, I talk about poop a lot because it’s a human function, there’s no getting around it. I found taking that approach was way better than trying to hide it or feel bad about it because there’s nothing I can do about it.

Additionally, Jessica stated that her symptoms are “just something that happens” and part of her “day to day normal life.” Megan emphasized that “it’s not something to be ashamed about.”

4.7.4 Summary of the Process of Normalization

Participants’ interviews were interpreted to involve a developmental sequence of first feeling embarrassed about having an IBD condition and not sharing symptom and diagnostic related information with others. Next participants generally reflected on times they found connection with peers experiencing similar medical difficulties. Lastly, in the process of normalization theme, most participants had developed a sense of acceptance.

4.8 Theme 6: Social Interactions

The broad theme of Social Interactions emerged throughout all interviews. While the previous theme largely represented internalized feelings that incorporated some behaviors of secrecy, this sixth theme represents social interactions when participates discuss their condition and information about IBD related experience with other people. The following subthemes best illustrate their social interactions: (a) disclosures, (b) desirable interactions, and (c) undesirable interactions.

4.8.1 Subtheme 6a: Disclosures

Participants reported varying degrees of willingness to verbally disclose information about their symptoms and diagnosis to others; willingness to disclose appeared to develop over time. First, participants were generally hesitant to disclose. Jessica recalled that:

I’m sure sometimes they [teachers] were probably wondering but I just never really told them anyways—unless I really had to tell them what the issue was. […] When symptoms
got really bad, my friends would be asking, trying to figure out stuff but I still didn’t tell them anything.

Similarly, Greg shared that “I didn’t really tell people. I was hospitalized for a week and I ended up missing I think a whole month of school and even then, I didn’t tell anybody my diagnosis.” Cruz explained that he rarely disclosed information about his condition to others while in high school, and he generally continues to not share this information now that he has completed school and has joined the work force: “I didn’t [tell the majority of my teachers], to be honest, a lot of my friends don’t even know, I just don’t even know how to tell them which is a problem I have. I didn’t tell a lot of people.”

Some participants disclosed information about their condition due to feeling that they had no other options (i.e., feelings of necessity). Jessica shared that she would disclose to teachers “if I really really wasn’t feeling good that day or if I was missing a bunch of classes, or something like that, then I would but most of the time I just didn’t.” Greg identified that he disclosed to “maybe one or two close friends and that’s it because it was necessary, I had to explain to them that I have to use the washroom sometimes a lot more than normal.” It was interpreted that over time, and as participants began engaging in the process of normalization and experienced feelings of self-acceptance, they began to disclose information about their conditions more openly, freely, and willingly. Jessica shared that “later in life that I started becoming more comfortable with saying stuff.”

4.8.2 Subtheme 6b: Desirable Interactions

As a byproduct of disclosing information about their condition participants reported that people interacted in one of two ways. One reaction type, generally interpreted to be desirable and positive reactions from others is outlined here. As a result of disclosing, Greg reported, “I’ve never met anyone that’s actually been judgmental or thought lesser of me.” People who produced
desirable responses generally knew a person with an IBD condition and had a more comprehensive understanding of what is involved with having the condition. Megan stated, “I had a prof whose sister had Crohn’s disease and she totally understood, was very understanding, like ‘if you need anything, I understand’ and like ‘I will put you near a washroom, it's ok’.” Other people who produced desirable responses were close friends or family members of the participant.

“My family and most of my friends have been super supportive of it and they know that I, I’m kind of bad for pushing myself even when I shouldn’t, I do, so they’re more like keeping me in check, when I’m running, they’re like ‘take a minute, just, if you can’t do it, you can’t do it, it’s fine’ which has been really helpful because I’m probably my worst enemy if I want to do it, I want to do it […] I’ve learned who your real friends are and who is actually willing to support you during a big change in your life.

Participants have identified benefits associated with disclosing information about their symptom to others. Zoey shared:

“Don’t be afraid to talk about your poop, don’t be afraid to talk about your tummy aches and be open about that. […] Make a plan with your teacher, […] you can get support if you're open, if you're not open with your symptoms, you're not going to get support, […] if the teacher doesn’t know, they’re not going to let you leave the classroom or they’re not going to understand but as soon as a teacher understands what’s happening, they’re usually very open and willing to help out the kid.

Additional desirable interactions included the positive influences of key people which participants found to be beneficial and supportive. In particular, Greg talked about various people making a positive impact whereby he felt encouraged to re-enroll into university, pursue graduate level education, and seek out educational accommodations.

I talked to one of my professors because I had to use the washroom during the midterm and told her that, I was totally up front about it, I said ‘I have ulcerative colitis’ and she […] told me about [University Y]’s equivalent of Access and Diversity. And that’s when I found out about all the accommodations that [University Y] had and that’s when I started telling every professor and got it all handled appropriately.
Cruz shared that he valued the influence of a professor who took on a mentorship role and supported him reach career goals:

He cared about his students, like university is a tough time for students, […] I think personal relationships will take you to the next level, it will help you achieve what you want and help you feel better, profs do that, just do that, be mentors, be friends, very basic things are helpful […] be[ing] a mentor to someone goes a long way, that’s what I would say, be something more than a teacher, a prof.

4.8.3 Subtheme 6c: Undesirable Interactions

The second reaction type associated with disclosing and discussing information about one’s condition to other people is outlined next. Reactions discussed within this subtheme section were interpreted as undesirable and negative in nature. Undesirable interactions from others have largely occurred because other people lacked an understanding of IBD and reacted in what was perceived as naïve or ignorant. Gabby shared that she has told people about her condition and observed:

People who don’t understand or never known someone with an illness like this, they’ll be like ‘oh that’s too bad so, have you tried cutting out gluten?’ And it’s like ‘yes, I have thought of that, thank you for your input’ but you know it’s a very like naïve or, I don’t mean ignorant in a bad way, it’s just not knowing.

Peoples’ lack of understanding produced prolonged negative outcomes for Megan. People in her small community noticed that she was throwing up and losing weight and generally assumed she was either pregnant or had an eating disorder. Before receiving a diagnosis, Megan did not “understand what’s happening and other people don’t really understand what’s happening, they assume things so rumors happened.” Participants shared that part of the challenge with interacting with others was “tied in with the invisible aspect of the illness, just because someone looks or appears fine” does not necessarily mean they were experiencing feelings of health or wellness.
People have lacked empathy towards participants; Cruz recalled that both his father and a high school level teacher were unsupportive upon finding out he was struggling with processing his diagnosis:

I remember the day I got diagnosed in the morning, I still went to school even though I didn’t want to because my parents were kind of like ‘get over it’, they told me that, so I had to school even though I probably didn’t say a word to anybody […] my dad told me ‘well, you got to go to school, get over it.’ […] My teacher actually said the same things as my parents, ‘we all struggle, you got to get over it,’ she told me that too.

In further reference to interactions with teachers, some educators were unsupportive or interfered with educational pursuits. Gabby recalled negative interactions with a professor who refused to honor formally assigned accommodations and the conflict led to Gabby withdrawing from the course:

There was a day where [the professor] set me up to do a presentation on something and I believe I was booked for a colonoscopy or something related to my illness and she argued with me, […] she was like ‘you can’t miss this day, I’ve got the schedule set, you have to be here.’ […] She just didn’t want to deal with or accept that. […] I said, ‘I’m sorry but I am done with this, I don’t deserve this and it’s kind of too far gone to be reconciled.’

4.8.4 Summary of Social Interactions

In terms of social interactions whereby participants shared information about their IBD conditions, participants were interpreted to become increasingly comfortable disclosing this information over time as there is some overlap between this theme and the fifth theme involving the Process of Normalization. While in elementary and high school, participants recalled being reluctant to share information and typically disclosed out of necessity. At the time of the interviews, most participants openly disclosed information about their condition when interacting with other people. As a result of these disclosures, peers, teachers, and acquaintances have demonstrated varying degrees of support and understanding. Positive interactions were generally associated with the other person being familiar and knowledgeable about IBD conditions.
Further, close friends and family members have been described as invaluable assets for participants as these individuals have provided various forms of support. Participants generally perceived people who demonstrated undesirable reactions as being somewhat ignorant or lacking empathy. In terms of educational experience, some teachers have provided desirable interactions while other teachers have been the source of negative interactions.

### 4.9 Summary of Phenomenon of Attending School while Experiencing IBD Symptoms

Six super-ordinate themes and corresponding subthemes emerged from in-depth interviews with seven participants with pediatric-onset IBD conditions regarding the phenomenon of going to school while navigating IBD related symptoms. Information pertaining to high school as well as university level experience were discussed in addition to the experience related to having IBD. Physical symptoms were pervasive at times, affecting various parts of the body (e.g., back and joint pain) in addition to significant pain and atypical functioning in digestion regions. Other symptoms included fatigue, severe weight loss, and mental health difficulties that were exacerbated by stress and pain related to the IBD condition. Participants perceived their condition to be a life-long, chronic, burden. Key sources of stress included participants’ negative self-image, challenging relationships with food, and interrupted access to washrooms.

Most participants’ experience were interpreted as a journey of learning and self-discovery as symptoms and environments altered as the participants progressed through the education system. Medically, each participant explained that his or her symptoms changed over time, indicating that (a) some responded well to treatment and benefited from a reduction in symptoms while (b) others reported that symptom concerns progressed and worsened as they aged. Beyond
medical treatments, diet changes, exercise, medical marijuana, and stress management strategies helped alleviate or prevent symptom progression.

Academically, participants recalled experiencing academic success while navigating IBD related symptoms. Academic success was attributed to a variety of factors. First, participants demonstrated school related talents and strong work ethic. Second, high school level expectations and requirements were perceived as manageable. Greater degrees of academic struggle were reported at the university level as most participants struggled with their transition into post-secondary education programs. Regardless of level or program, some IBD related symptoms interfered with academic engagement and learning. In an effort to overcome academic challenges, formal and informal accommodations were assigned while participants also developed personal academic strategies. Accommodations were sometimes denied by educators (i.e., teachers, professors) or difficult for participants to obtain; these obstacles contributed to the participants’ academic challenges. Numerous participants withdrew from university level courses and/or programs as a result of IBD related difficulties and lack of academic accommodations.

As part of their journey of learning and self-discovery, participants demonstrated varying degrees of willingness to disclose information about their condition. Participants recalled initially feeling embarrassed due to their symptoms and as a result from being different from their peers. Over time, the participants interacted and established connections with other people experiencing similar conditions which helped facilitate reduced feelings of abnormality and isolation. As adults, the majority of participants accepted their condition and demonstrated a willingness to openly disclose information about their condition to other people. As a result of these disclosures, other people have either been supportive or yielded undesirable interactions. Desirable social interactions were generally attributed to the other person having previously
established knowledge about IBD conditions. Positive interactives were perceived as supportive and vital as participants worked to achieve short and long-term goals. Undesirable social interactions were thought to occur due to the other person lacking information about the condition, making assumptions, and discounting the effects associated with invisible diseases. Negative interactions included uncomfortable or stigmatizing conversations.
Chapter 5: Discussion

In this chapter, the findings and contributions of this study are discussed in relation to available literature. Limitations and strengths of the study, recommendations for future research, and implications for the practice of school psychologists are also discussed.

5.1 Significant Findings of the Research Study and Relation to Literature

The current study aimed to understand the meaning of the phenomenon of attending school while simultaneously experiencing IBD symptoms. Using IPA as the methodology, the researcher sought to complete an in-depth investigation of the phenomenon. Seven young adults diagnosed with pediatric-onset IBD completed semi-structured interviews with the researcher. During these conversations, participants shared information about their medical symptoms offering contextual information to help the researcher better understand how medical circumstances impacted the phenomenon. Notably, all seven participants pursued post-secondary education programs and the conversations extended to incorporate their experience at this level of schooling and therefore expanded the scope of the research study. Six super-ordinate themes and corresponding subthemes emerged from the data analysis. These findings, and how they relate to previous literature, are discussed below.

5.1.1 IBD Related Experience and Coping Strategies

Participants’ experience that specifically related to IBD included the diagnostic journey, physical symptoms, mental health concerns, and key sources of stress. Participants’ process of identifying effective medical and holistic coping strategies were also identified.

The process of being diagnosed with an IBD condition varied significantly. Some participants were quickly and accurately diagnosed upon first experiencing symptoms while others experienced symptoms for years before receiving a diagnosis. As per participants’
statements, those who quickly received a diagnosis were largely living in remission and managing their symptoms well at the time of the interviews. Conversely, those who waited years to receive an accurate diagnosis and appropriate treatment continued to experience adverse symptoms. Medical researchers have concluded that early onset treatment, facilitated by early identification, typically led to better long-term health benefits (Baldwin & Kaplan, 2017; Nasiri, Kuenzig, & Benchimol, 2017). Participants within this study offered valuable case study examples to support this medical conclusion. It appeared that the largest contributing factor for schooling success and wellbeing involved the status of participants’ medical symptoms. When symptoms were active, participants recalled much greater academic difficulties. Based on participants’ recollections, adverse effects were conceptualized as a hierarchy. Those who experienced active symptoms also generally began to develop mental health concerns; both areas then contributed to schooling difficulties. Logically, when symptoms were well managed, participants perceived their schooling experience to be typical.

Also in reference to physical symptoms associated with IBD, all participants discussed the negative impact of losing weight. It was deemed undesirable as they perceived themselves as being unhealthy. Further, female participants shared that they were a topic of gossip as people in their community questioned whether they had an eating disorder. This finding was novel as previous researchers had concluded that males with IBD were typically upset with being perceived as thin while female students noted concern if they weighed more than their female peers due to side effects associated with their medication (Nicholas et al., 2007). Evidently, being an atypical weight on either side of the spectrum (e.g., underweight or overweight) can be perceived as concerning among individuals with IBD.
A third facet regarding physical symptoms involving IBD included previous literature listing symptoms of diarrhea, bleeding ulcers, cramping, abdominal pain, vomiting, weight loss, and fatigue (Fabisiak et al., 2016; Kim, 2015). Participants in this study emphasized the pervasive impact of fatigue, bodily joint, and muscle pain. It is important to remember that IBD conditions are autoimmune diseases and do not simply involve difficulties with digestion. It is also important to consider how these symptoms can affect students’ engagement in school and overall wellbeing.

Participants within this current study self-reported to experience difficulties with anxiety and depression. Goodhand and colleagues (2012) also found that anxiety and depression were commonly experienced by people with IBD who experience heightened levels of stress and active IBD symptoms. Indeed, feelings of stress appeared to exacerbate IBD related symptoms for participants within this current study. Researchers have estimated that 30-32% of individuals with IBD experience depression (Reigada et al., 2011) at a given time while incidence rates of depression among the average student population is much lower (i.e., 2-13%; Avenevoli, Knight, Kessler, & Merikangas, 2008). It appears that people with IBD (14-22%; Deshmukh et al., 2010) experience comparable rates of anxiety compared to the average student population (16-19%; Kessler et al., 2012). Notably, while current participants did not appear to actively be experiencing anxiety or depression at the time of the interviews, they provided details about experiencing mental health difficulties in the past. It is unclear how many people with IBD experienced pervasive and harmful sub-clinical mental health difficulties at some point in their lives. Based on the information provided by the participants associated with this current study, individuals with IBD conditions would likely benefit from psychological monitoring and intervention regardless of whether they met full diagnostic criteria for a mental health diagnosis.
Additionally, mental health difficulties in academic papers are typically described using clinical and objective terms. Providing direct quotes from participants who lived with feelings of excessive fear, worry, sadness, and thoughts of suicide articulated the severity of the mental health symptoms that people with IBD can experience.

Participants in the present study described how they developed personalized coping strategies and self-advocacy skills to overcome challenges associated with their condition. Indeed, while it is desirable for healthcare professionals to develop generalized recommendations for people with medical conditions to follow, as this would undoubtedly make treatment processes easier, IBD symptoms significantly varied from person to person and therefore a generalized list of recommendations is not feasible. For example, while some participants found following a specific diet and avoiding certain foods helpful, others found they reacted to a specific food differently depending on the day. However, physical rest and practicing healthy lifestyles were largely found to be beneficial coping strategies for all participants. Given participants’ busy schedules, these lifestyle practices were difficult to achieve as the strategies required ongoing dedication and effective time management (e.g., preparing healthy meals ahead of time, scheduling time to exercise; Martin, Williams, Haskard, & DiMatteo, 2005). Lastly, medical cannabis was deemed to be helpful by two participants; however, cannabis currently appears to adversely affect child and adolescent neurological development (e.g., Lubman, Cheetham, & Yücel, 2015) and it is not appropriate to recommend cannabis as coping strategy for younger students with IBD symptoms.

5.1.2 Educational Implications and Educational Accommodations

As all participants in the current study had pursued post-secondary education, they demonstrated a desire to comprehensively discuss their educational experience. It was
informative to the research question to include all levels of education that participants
experienced to produce a conceptually complete description of their lived-experience associated
with schooling. Consequentially, educational successes and challenges were discussed—some of
which were uniquely experienced at the post-secondary level. Additionally, varying degrees of
support and accommodations were provided by school personnel at each level of schooling.

Students with various types of chronic medical conditions typically experienced
undesirable academic performances, fatigue, memory concerns, attention problems, and
disruptions in their social lives (Ferguson & Walker, 2014; Msall et al., 2003). It appeared that
participants in this current study also experienced some of these obstacles but did not experience
poor academic performance and memory concerns. Perhaps a protective factor of IBD is that this
condition does not negatively affect neurological and cognitive abilities.

In terms of educational successes, participants in this study appeared to manage well
despite exposure to various obstacles. While students with IBD had previously been reported to
be absent for upwards of three to four months during the school year (Akobeng et al., 1999),
participants in the current study were unable to recall how many days of school they missed.
Retrospectively, while current participants were absent due to medical appointments, physical
symptoms, and mental health difficulties, they simultaneously did not perceive their absences to
be a source of difficulty and typically benefited from informally assigned accommodations at the
elementary and high school levels.

Systematically, at the elementary and high school levels, formally assigned
accommodations would be offered by the student’s support team. The team would create a plan
to support at-risk students (e.g., an Individualized Instruction Plan in Saskatchewan; an
Individual Education Plan in British Columbia). However, while these support systems exist, all
the participants within this study were not offered formal accommodations until they personally requested support at the post-secondary level. Instead, informally offered accommodations were generally more prevalent at the high school level, for example, as teachers allowed their students to write exams after returning from an absence. Formally assigned accommodations were more common during participants’ post-secondary level experience and these accommodations were viewed by participants as a source of protection, security, and insurance. Further, when participants did not receive accommodations at the post-secondary level, they faced greater degrees of difficulty and typically withdrew from courses or programs as university level programs were considerably structured and rigid.

Notably, a large portion of participants’ success may have been attributed their personal characteristics and personally generated academic strategies. As these participants have all pursued university programs and had either earned degrees or were in the process of completing degrees, they likely possess average to above average cognitive and academic abilities relative to the general population in addition to higher levels of motivation and perseverance. Other studies that described considerably greater educational challenges at the elementary and high school levels (Akobeng et al., 1999; Gordon, 2004; Gordon, 2013; Kilroy, Nolan, & Sarma, 2011; Mackner, Bickmeier, & Crandal, 2012; Micallef-Konewko, 2013; Richardson et al., 2001) may have involved students who were disadvantaged due to somewhat lower academic achievement rankings as well as other unspecified limitations and/or lack of resources.

Nevertheless, despite current participants’ various desirable characteristics, participants in this study also experienced educational challenges. Previous researchers indicated that some students with IBD originally attended public school but later enrolled in homeschooling due to negative experience with educators (e.g., Gordon, 2004). While this did not occur for participants
at the elementary or high school level, one participant felt it necessary to withdraw from a university level course due to lack of support and accommodation of a professor. Further, several current participants withdrew from single courses and entire post-secondary programs as a result of IBD related symptom difficulties. Participants shared that simultaneously attending university while experiencing severe IBD symptoms was difficult to manage and was sometimes unmanageable. After clarifying personal educational and career goals, in addition to perceiving that their symptoms were better managed, these same participants returned to school. This trend represented the complexity of pursuing a post-secondary education. Current participants faced struggles that are typical for most university students (e.g., selecting appropriate areas of study to specialize in, demanding course loads, and financial burden; Denovan & Macaskill, 2013; Redhwan et al., 2009). As stress can trigger IBD symptoms (Filipovic & Filipovic, 2014), these typical university level obstacles appeared to produce an influx in physical symptoms, psychological difficulties, and negative interactions with other people who facilitated undesirable interactions and/or were unsupportive (Adler et al., 2008; Mayberry et al., 1992) among current participants.

Much like individuals from other studies (e.g., Schneider & Fletcher, 2008), participants from this current study shared that they typically experienced heightened levels of IBD symptoms when feeling anxious. The symptom onset triggered a cascade of negative outcomes including physical (e.g., pain, more frequent bowel movements) and emotional distress (e.g., embarrassment). Luckily, the mere presence of a nearby washroom as well as the comfort associated with participants’ knowing they could access the washroom at any time typically reduced the frequency to which participants needed to use the facilities and consequently allowed them to better attend to their academic tasks (e.g., exam). Such arrangements were not
always offered and appeared to be the greatest injustice that students with IBD encountered; it is unfortunate that such a pivotally basic necessity that fosters significant peace of mind for students with IBD was monitored and limited by educators. Ultimately, the main priority of the participants from the current study was to have unlimited access to washrooms. Gordon (2013) also reached this conclusion.

5.1.3 Process of Normalization and Social Interactions

In this present study, the interview data outlining social interactions involved other people engaging in positive or negative interactions after participants disclosed that they had IBD. Prior to disclosing information about their conditions, current participants initially felt embarrassed. After finding connections with experiential peers, participants established a sense of belonging and acceptance for their new way of life.

Other researchers who investigated outcomes associated with attending IBD focused summer camps offered direct insight into the value associated with interacting with other people who also have IBD conditions. Short-term benefits included improved social functioning, improved total quality of life, and better acceptance of IBD symptoms (Shepanski et al., 2005). Long-term benefits associated with interacting with peers that also had IBD conditions included significant improvements in emotional and day-to-day functioning as well as adherence to medical treatment (Lawton, 2016). While participants in this current study did not take part in IBD focused summer camps, they made connections with other people that shared similar conditions; it was interpreted that participants developed a sense of belonging over time thereby feeling less isolated and abnormal.

Participants in this study, as well as other studies, indicated they were reluctant to disclose information about their condition due to desires to maintain their personal privacy and
because it is not socially common to discuss many of the symptoms associated with IBD (Barned et al., 2016; Hommel, 2013). In this current study, participants were told by professors that they need not disclose information about their condition because it was private; however, not discussing their condition would have resulted in a lack of accommodations. Much like other studies (Micallef-Konewko, 2013), current participants typically disclosed out of necessity. Later in life, participants disclosed more openly upon reaching adulthood and after overcoming feelings of embarrassment.

The researcher chose to present the current data in terms of positive and negative interactions within Chapter 4 of this document because this organizational strategy best represented the participants’ social interactions. Current participants discussed interactions with people in general and did not offer information to suggest that teachers, for example, did anything particularly unique or novel compared to other people in their lives. Previous data did not present information in this format, and instead discussed specific interactions with teachers and/or peers. In terms of interactions with educators, participants in this present study described an appreciation for teachers and professors who were caring, compassionate, and saw them as individuals—this preference has been found among other students as well (e.g., Phelan, Davidson, & Cao, 1992). Previous researchers have found that students felt their teachers lacked empathy regarding their IBD symptoms following the students’ choice to disclose their medical diagnosis (Akobeng et al., 1999; Kilroy, Nolan, & Sarma, 2011; Richardson et al., 2001). As the majority of the participants in this current study did not disclose their condition to educators until later in life (e.g., while in university), it was not possible to conclude whether their teachers lacked empathy. Further, as current participants achieved strong academic outcomes, it was
interpreted that teachers were not aware that they may have benefited from additional support above and beyond what educators would typically offer to other individual students.

Similarly, while in high school, current participants rarely disclosed information to their friends. They were even less likely to disclose information about their symptoms to classmates with whom they did not share close and personal bonds. It was interpreted that participants largely demonstrated invisible symptoms and were not subject to direct adverse interactions with their peers. This was contrary to other research studies that described instances of bullying as a result of having an IBD condition (e.g., Nicholas et al., 2007; Quick et al., 2015). Rather, participants in this study feared for the possibility of being viewed as atypical from their peers and the possibility of being victim to ridicule and bullying as a result. While other researchers found that students chose to stay home and not engage in social activities outside of school as a result of being bullied (Ferguson & Walker, 2014; Nicholas et al., 2007), participants in this present study articulated that they stayed at home because they were exhausted or struggling with mental health difficulties. Overall, this present study, along with Gordon (2013), produced examples of students with IBD experiencing typical peer interactions.

Problematic social support was observed, however, in isolated instances. Participants were frustrated with other people’s (a) lack of knowledge and feeling as if they had to educate the other person, (b) negative attitudes, and (c) lack of empathy. Similar perceptions were recorded by other researchers (Akobeng et al. 1999; Gordon, 2004; Kilroy, Nolan, & Sarma, 2011; Richardson et al., 2001). For individuals within this present study, these frustrations not only occurred via interactions with select teachers (as identified by Gordon, 2004; 2015; Kirk et al., 2012) but also professors, acquaintances, friends, and miscellaneous people within their community.
5.2 Limitations and Strengths of the Study

As with any research project, there were limitations associated with this current study. First, it is unknown whether theoretical saturation was achieved. Typically, data collection (i.e., interviews) should continue until a researcher believes no new data that could enhance conceptual understandings for this study would come forward (Francis, Johnston, Robertson, Glidewell, Entwistle, Eccles, & Grimshaw, 2010). The researcher stopped collecting data after interviewing the seventh participant because of the limited number of people who met the narrow inclusion criteria. Further, in IPA structured studies, interviewing additional participants generally yields greater levels of difficulty retaining individual voices while also making claims for the larger group (Smith et al., 2009). As the seventh participant offered additional information that enhanced the researcher’s understanding of the targeted phenomenon, it was unclear whether additional interviews would have also yielded new data.

Second, the researcher was new to conducting research interviews and the IPA methodology. The researcher reflected on her interviewing techniques after each interview and some questions were not adequately open-ended or the researcher sometimes missed opportunities to query further to perhaps yielded additional information or insights. As participants did not volunteer to engage in secondary interviews (see Section 3.8.1 of this report), it remains unclear whether additional information was available to further enhance the breadth and depth of understanding as it pertains to the phenomenon under investigation. Similarly, two of the seven participants elected to participate in the final member check stage of the data analysis. This non-optimal number of participants confirmed that the themes accurately represented their individual experience and it was unclear whether the other participants also perceived the overall analysis of the data to be accurate.
Third, in terms of the interview script (see Appendix C), specific questions were asked in an open-ended fashion (e.g., “Please tell me about your experience of when you first began having IBD symptoms”); however, scripted follow-up questions were narrower and, therefore, likely contributed to the types of themes that emerged within the findings. For example, the theme involving Educational Accommodations may have not emerged or would have been less prominent if the researcher did not directly inquire with each participant about how educators offered schooling support. While the interview script was developed to inform the research question and was also based on gaps and inconsistencies within the literature, there may have been an inflated correspondence between targeted questions and identified themes.

Fourth, while the original intent of this study was to investigate elementary and high school level experience, participants predominantly began experiencing symptoms while in high school. An in-depth understanding of the phenomenon at the elementary school level was not possible nor was the opportunity to compare and contrast elementary and high school level phenomenon.

Fifth, the study was designed to consider how psychological, social, and academic factors influenced the schooling experience of students with IBD conditions to offer a comprehensive description of the schooling experience. In pursuit of gathering a more manageable amount of data to inform this research question, little focus was placed on participants’ family interactions while attending school. Students’ home lives and parenting practices can greatly influence schooling phenomenon (Elmelid, Stickley, Lindblad, Schwab-Stone, Henrich, & Ruchkin, 2015; Petersen, 2008; Steinberg, Lamborn, Dornbusch, & Darling, 1992) but these factors were not investigated and incorporated into the data analysis.
Despite the limitations of the current study, there were several clear strengths that contributed to the understanding of the phenomenon. First, as the study was qualitative and retrospective in nature, the researcher gathered contextual information involving the phenomenon of attending school over several years. This approach allowed the researcher to compare and contrast experiential differences between high school and university levels of education. Further, inquiring about experience during the stage of symptom onset, rather than age of diagnosis, offered novel insights into the diagnostic process of children and adolescents with IBD conditions and how onset of symptoms also impacted their schooling experience.

Similarly, as is the intent of qualitative research, novel and unexpected findings were acquired. The researcher gathered information about (a) the university level schooling experience of people with IBD, and (b) how this phenomenological stage differed from the high school level. These findings offer valuable contributions to the currently sparse amount of literature on the topic.

Next, individuals who participated in this study were largely homogeneous (i.e., all participants self-identified as academically high achieving and pursued post-secondary academic programs). Key similarities among participants allowed for a more harmonious analysis of young adults’ previous schooling experience and achieved a better description the specific phenomenon. While academically high achieving individuals were not specifically targeted during the recruitment stage of this study, this was indeed the outcome. It is likely that this population of individuals participated in this study because the initial group targeted for recruitment (i.e., the Invisible Conditions Conference; see the Methodology Section) was developed and organized by undergraduate and graduate level students. Similarly, the most effective recruitment strategy (i.e., snowball sampling) was also associated with Invisible
Conditions Conference; individuals who assisted with recruitment shared that they met their acquaintances with IBD while in university.

Lastly, scientific rigor was practiced to enhance the credibility and trustworthiness of the findings. Creswell (2007) recommended that at least two additional validation strategies are used in qualitative research to achieve integrity and credibility. This study employed the following strategies: (a) prolonged engagement, (b) reflective journaling, (c) member checks during primary data collection stage as well as after data analysis was complete, and (d) measuring the re-occurrence of experience across cases. See section 3.10 of this document for details regarding each strategy.

5.3 Recommendations for Future Research

Findings from this study illustrate the need for additional research involving the schooling experience among individuals with IBD. In particular, investigating the lived-experience among students who were less academically inclined is warranted to expand our understanding of the targeted phenomenon. As previously mentioned, all participants in this study endorsed that they earned high grades throughout elementary and high school. It is unclear whether additional or alternative themes would emerge if students who retrospectively struggled in academic areas were interviewed. Similarly, as outlined as a limitation associated with this study, minimal information involving elementary school experience was available due to participants’ symptom onset demographics. Conducting retrospective and IPA guided interviews with young adults who clearly began experiencing IBD symptoms as young children would also offer valuable insights into the targeted phenomenon.

Next, research involving post-secondary level experience among individuals with IBD is scarce. It would be valuable to gather additional insights into factors that contribute to students
seeking out formally assigned accommodations. Consequently, this information would be used to support students with IBD conditions become informed about their educational options and rights.

Lastly, an experimentally designed study is warranted to investigate outcomes associated with formally implementing mentorship relationships between individuals with IBD conditions. The Invisible Conditions Conference, as discussed within the Methodology Section of this document, offers a novel opportunity for adolescents with IBD conditions to socialize, share, and exchange information about their disease with experiential peers. Perhaps structured mentorship opportunities would accelerate the establishment of connections between people who have similar health conditions. As informed by findings that emerged in this study, it is hypothesized that enhanced feelings of belonging and self-acceptance would increase individuals’ willingness to disclose information about their condition to educators and therefore more likely to receive accommodations.

5.4 Implications for School Psychologists

The findings of this study have implications for the practice of psychologists. School psychologists are in the position to consult with teachers, parents, and students who experience IBD symptoms as well as collaborate with education teams to create Individualized Education Plans. As access to support appeared to produce a reduction in feelings of worry and physiological IBD symptoms, structured and formally assigned support would be beneficial for students at every education level. As each individual’s IBD symptoms and journey appear to be unique, individualized supports would be optimal. Some students may simply benefit from receiving extensions to complete assignments, tests, or exams. Other students may demonstrate gaps in their academic knowledge due to interrupted instruction as a result of frequent absences.
School psychologists have specialized training in academic assessment and intervention strategies to effectively and efficiently narrow these learning gaps. School psychologists are also well suited to support students with IBD in the areas of mental health counseling and self-advocacy skill development. Lastly, school psychologists would offer valuable assistance to students with IBD as they transition to post-secondary education programs whereby informing students about their access to formally assigned accommodations.

5.5 Conclusions

This study was designed to explore the lived-experience of students with IBD conditions. The phenomenon under investigation was attending school and this was examined via retrospective means as young adults who were diagnosed with pediatric-onset IBD were interviewed. While six separate themes were described within the findings, the phenomenon of students with IBD conditions were interconnected: (a) medically, IBD related experience and coping strategies were discussed; (b) educationally, positive and negative outcomes were experienced among participants and various forms of accommodations were provided by educators; and (c) socially, participants underwent a process of normalization and engaged in desirable as well as undesirable social interactions. None of these components occurred in a vacuum and themes were used to capture the categorical “essence” of participants’ lived-experience (Starks & Brown-Trinidad, 2007, p. 1373).

Findings from this study demonstrated that the schooling phenomenon may drastically vary depending on what level of education they pursue. Indeed, the educational phenomenon was described as typical and successful in certain areas—this conclusion (a) contradicted previous research findings that outline the various negative barriers associated with being a student with a chronic health condition (Champaloux & Young, 2015; Maslow, Haydon, Ford, & Halpern,
2011; Maslow, Haydon, McRee, Ford, & Halpern, 2011), and (b) supported recent researchers who argued that adults with pediatric-onset IBD obtain long-term educational success (El-Matary et al., 2016; Singh et al., 2015). This should not be interpreted as a reason to not provide additional support to students with IBD. Rather, findings generated from this study identified medical, educational, and social obstacles and also emphasized the strengths and skills students with IBD possess to cope with adversity.
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Appendix A: Screening Questions

1. Are you 18 years of age or older?

2. Have you completed grade 12?

3. Has a physician diagnosed you with an IBD condition?

4. What medical condition were you diagnosed with?

5. When did you receive this diagnosis?

6. Did you experience IBD symptoms while in elementary or high school? (Please specify when symptoms began).

7. Are you willing to meet for approximately 90 minutes to discuss your IBD condition and schooling experience?
Appendix B: Demographic and Background Questions

What is your age?

What is your highest completed level of education?
   a. Some high school
      Grade _____
   b. High school/GED
   c. Some college or university
      Number of years completed: _____
   d. College diploma
   e. University degree
   f. Graduate degree
   g. Other: _____________

What post-secondary subject(s) did you study? For example, what program were you enrolled in?

Are you currently in school? Please describe what level and program you are pursuing:

What is your employment status?
   a. Working full-time
   b. Working full-time
   c. Working part-time
   d. Full-time student
   e. Part-time student
   f. Not employed

Occupation:

What is your ethnicity?
   a. Aboriginal (e.g., First Nations, Metis, Inuit)
   b. Black
   c. Caucasian/white
   d. Chinese
   e. Filipino
   f. Japanese
   g. Korean
   h. Latin American
   i. South Asian (e.g., East Indian, Sri Lankan)
   j. Southeast Asian (e.g., Vietnamese, Cambodian)
   k. West Asian (e.g., Iranian, Afghan)
   l. Prefer not to answer
   m. Other, please specify ___________
What is your sex?
   a. Male
   b. Female
   c. Prefer not to disclose
   d. I identify as ___________

How old were you when you began experiencing Inflammatory Bowel Disease (IBD) symptoms? __________ years

How old were you when you received an IBD diagnosis? __________ years

What type of IBD condition were you diagnosed with?
   a. Crohn’s Disease
   b. Ulcerative Colitis
   c. Other: ___________

How often does your condition affect you?
   a. Daily
   b. Weekly
   c. Monthly
   d. Other: ________________

Please rate the current severity of your IBD condition and associated symptoms:
   a. Extremely Severe
   b. Very Severe
   c. Moderately Severe
   d. Slightly Severe
   e. Not Severe

What specialists have you previously seen for your condition, or its symptoms? (Please select all that apply):
   a. General Practitioner
   b. Gastroenterologist
   c. Immunologist
   d. Endocrinologist
   e. Neurologist
   f. Counsellor
   g. Psychiatrist
   h. Psychologist
   i. Pediatrician
   j. Surgeon
   k. Nutritionist
What specialists are you *currently* seeing for your condition, or its symptoms? (Please select all that apply):

a. General Practitioner
b. Gastroenterologist
c. Immunologist
d. Endocrinologist
e. Neurologist
f. Counsellor
g. Psychiatrist
h. Psychologist
i. Surgeon
j. Nutritionist
Appendix C: Interview Schedule

Introduction and Orientation
1. Introduction of researcher and research study
2. Review and sign consent form
3. Have participant complete the Demographic and Background Question form
4. Review plan to use interview questions as a guide. Participants will be encouraged to freely discuss perceived schooling and IBD related experience as they come to mind.

IBD Symptom Onset
1. Please tell me about your experience of when you first began having IBD symptoms.
   a. What was going on in your life around the time you first began to experience IBD symptoms?
   b. How did this time in your life effect your schooling? What was it like to go to school at this time?
   c. Who did you go about telling people at school (e.g., teachers, friends, classmates) that you were experiencing symptoms? Please describe how you felt sharing this information. How did people responded?

IBD Symptom Management
1. What was it like having IBD symptoms while you were in elementary school? High school? University? Regarding:
   a. Academic classes? Other classes (e.g., gym, art)? Recess? Extra-curricular activities?
   b. What was it like interacting with educators as you were going to school and managing your IBD symptoms?
      i. How did your teachers provide accommodations? Support?
      ii. How was it decided that additional accommodations or support were provided? What role did the teachers play? Your parents? You?
   c. What was it like interacting with classmates as you were going to school and managing your IBD symptoms? Friends?
2. Please tell me about your journey finding ways to manage your IBD symptoms.
   a. What did you do to manage your IBD symptoms (e.g., treatment, coping strategies)?
   b. What was helpful?
   c. What was not helpful?
3. What, if any, factors made it difficult for you to go to (i.e., attend) school? Pay attention to what you were learning?
4. Now that you are done high school, what do you wish current students with IBD would know? Their classmates? Educators who work with students with IBD?
Appendix D: Participant Descriptions

Jessica

Jessica was a 27-year-old women who had completed an undergraduate degree in Business Administration and was working full-time in her field of training. While in elementary school, and simultaneously working to manage her IBD symptoms, she reported to feel unchallenged and transferred to a French Immersion program. Her symptoms became easier to manage after receiving a surgery in Grade 11 and she reported to be in remission at the time of the interview. Also while in high school, she successfully completed accelerated courses. As a university student, she earned several scholarships and bursary awards. Primary IBD symptom difficulties included fatigue and nausea. School-based concerns included teachers not allowing her to use the washroom and not allowing her to complete all missed assignments, tests, or exams because she had already earned enough points to pass the course. At the time of the interview, Jessica was volunteering as a mentor to younger individuals who also had IBD conditions.

Greg

Greg, a 27-year-old male, was in the process of completing a Master of Science degree and had recently been accepted to medical school at the time of the interview. While in high school, he was diagnosed with Crohn’s disease. High school level difficulties were social in nature as he was uncomfortable using the school washroom and eating in front of other people. His symptoms significantly worsened upon entering university and his diagnosis was changed to ulcerative colitis. Greg attributed his influx in symptom severity to stem from the various stressors he was encountering while transitioning to university. As he was working to manage his symptoms, he elected to withdraw from university and began working in the trades. Academics
was always a passion for Greg and he chose to re-enroll in university. At that time, Greg sought out formally appointed accommodations which he attributed to being highly beneficial. He was in remission at the time of the interview, shared various personal coping strategies that worked well for him (e.g., stress management, weight lifting), and he was volunteering as a mentor to younger individuals who also had IBD conditions.

**Gabby**

While in high school, Gabby reported that she was highly involved in extra-curricular activities and was academically successful. She recalled feeling well supported by her high school teachers. However, she regularly experienced stomach pain and cramps in the classroom but the cause was unknown throughout her time as a student in high school and during most of her time at university. Her symptoms worsened while in university and she attributed this to lack of sleep and stress. After being diagnosed, Gabby sought out accommodations and experienced a highly negative encounter with a professor who refused to agree to her accommodation requirements. At the time of the interview, Gabby was 31 years old and was significantly affected by joint and back pain which has been attributed to being an IBD related symptom as well as a side effect associated with her medications designed to treat IBD symptoms. Personalized coping strategies that worked well for Gabby included eliminating certain foods from her diet, swimming, yoga, recommendations from a Naturopath, and medical cannabis.

**Megan**

At the time of the interview, Megan was in the process of finishing an undergraduate degree with a double major in Sociology and Psychology. While in high school, she frequently vomited and experienced significant weight loss due to her IBD condition. Her struggles were predominately social in nature as peers and adults in her community were unsupportive, gossiped
about her symptoms, and assumed she was either pregnant or had an eating disorder. Throughout her time as a university student, Megan was significantly affected by nausea, joint pain, and fatigue which she reported to cause her to miss numerous lectures and fall behind in her coursework. She attributed effective medications to be the primary reasons she was able to successfully complete her degrees. Other significant areas of difficulty while in university included problematic infrastructure including limited parking options, frequently inaccessible bathrooms, and professors acting in stigmatizing ways when she shared the status of her condition and accommodation requirements. While Megan had been in remission for the past 1.5 years, she was considered about the adverse long-term side effect associated with her treatment.

**Clint**

He experienced symptoms for the last 3 years of high school and symptoms had persisted throughout his time as a university student. At 25 years, Clint was currently enrolled in an Engineering program, and he had previously taken computer science and engineering courses at three different institutions. He withdrew from various courses and programs due to complications associated with his IBD symptoms. Clint did not view his condition as a disability and had not sought out accommodations from Student Support Centers. He had also transferred to different universities and programs in the search of finding an area of study that he was highly interested in as he was experiencing difficulty identifying what career path he wanted to pursue. His symptoms were not well managed at the time of the interview as he had not found an effective treatment intervention. He also reported to have a difficult time consistently practicing healthy lifestyle practices (e.g., eliminating certain foods, exercise) that he found to be helpful with managing his symptoms in the past. He struggled to find health care providers that he felt
were receptive to his concerns and met his medical needs. Conversely, he enjoyed positive social support via his friends and coped with symptoms by using humor.

**Zoey**

To become an art teacher, Zoey completed a Bachelor in Fine Arts degree as well as a Bachelor of Education degree. She was a certified teacher working part-time due to being on medical leave for IBD difficulties at the time of the interview. She potentially first began experiencing symptoms when she was six years old but Zoey clearly remembered beginning to experience IBD related symptoms when she was 14 years old. As a student, her schooling was impacted by ongoing physical pain as well as worry and embarrassment regarding asking to use the washroom. She suspected that she has met criteria for the predominantly inattentive presentation of Attention-Deficit/Hyperactivity Disorder but was not formally diagnosed at the time of the assessment—her inattention difficulties also negatively affected her schooling. She experienced a significant needle phobia throughout her life which interfered with her ability to receive proper medical testing and treatments for her symptoms. Approximately two years ago, Zoey had produced so much scar tissue within her intestines that she was unable to absorb nutrients, lost a significant amount of weight and nearly died due to starvation. She underwent surgery to combat this complication. To overcome her needle phobia, she shared that she employed a combination of anti-anxiety medications and psychological strategies. While not in remission, her symptoms were well managed but she was struggling with rapid weight gain that may be due to her increased caloric intake and/or side effects associated with her medication. Various personal coping strategies that worked well for Zoey included stress management, desirable social support, and physical rest.
Cruz

At the time of the interview, Cruz was 23 years old, had recently completed a Bachelor of Arts degree in Political Science, and was working full-time in his area of specialty. He experienced symptoms for the last 2 years of high school and was in remission once he started university. However, he reported that mental health difficulties have persisted as he had struggled with the burden of having a chronic condition and has unfortunately received minimal social support. His academics were minimally impacted and his symptoms are fairly well managed via medications despite eating a diet that he understands to typically cause symptom flare ups.
Appendix E: Summary of Themes Sent to Participants to Complete Member Checks

1. *IBD Related Experience* provided contextual information about what simultaneously happened for participants while going to school. This subtheme illustrated differing ways individuals can be diagnosed therefore leading to a streamlined or delayed timeframe in which participants were able to understand the source of their symptoms and pursue medical treatment options. This theme also provided insight into the various interactions between physical and psychological symptoms associated with IBD conditions. Mental health difficulties were exacerbated by stress and pain related to the IBD condition. Participants perceived their condition to be burdensome and stressful. Sources of non-academic stress were categorized and included negative body-image, challenging relationships with food, and interrupted access to washrooms.

2. *Coping Strategies* was also contextually informative as managing symptoms better allowed participants to be able to attend or return to school. This theme offered information about individualized medical treatments and holistic intervention strategies that participants tried. These treatments produced varying degrees of benefit. Beyond medical treatments, diet
changes, exercise, medical marijuana, and stress management strategies helped alleviate or prevent symptom progression.

3. *Educational Implications* directly informed the research questions developed for this study. It was revealed that participants with IBD conditions enjoyed educational successes in addition to facing educational challenges. Successes were numerous and were largely attributed to participants’ personal strengths (i.e., academic talent, hard work, perseverance). Participants experienced greater levels of academic difficulty at the university level as high school expectations and requirements were perceived as manageable while university level courses and programs were viewed as ridged and demanding; participants experienced greater levels of difficulty catering to their symptoms at the university level as a result (e.g., taking breaks when sick or attending medical appointments). IBD related symptoms also interfered with academic engagement and learning throughout the participants’ educational pursuits.

4. *Educational Accommodations* offered insight into the varying ways students with IBD symptoms were supported academically. In an effort to overcome academic challenges, formal and informal accommodations were assigned while participants also developed personal academic strategies. Accommodations were sometimes denied by educators (i.e., teachers, professors) or were difficult to obtain and these obstacles contributed to the participants’ academic challenges. Numerous participants withdrew from university level courses and/or programs as a result of IBD related difficulties and lack of academic accommodations.

5. *Process of Normalization* depicted that participants’ journey of self-discovery and acceptance. Participants recalled initially feeling embarrassed due to their symptoms and as a result from being different from their peers. Over time, the participants interacted and
established connections with other people experiencing similar conditions; these interactions helped facilitate participants’ reduced feelings of abnormality and isolation. As adults, the majority of participants have reached the stage of self-acceptance and have identified that navigating their IBD related symptoms is part of their “new normal” life.

6. **Social Interactions** was also progressive in nature as participants generally kept information about their condition a secret. Participants’ willingness to openly disclose information about their condition to other people occurred as a result of establishing a sense of self-acceptance. As a result of these disclosures, other people have either been supportive or yielded undesirable reactions. Desirable social interactions were generally attributed to the other person having previously established knowledgeable about IBD conditions. Positive interactives were perceived as supportive and vital as participants worked to achieve short and long-term goals. Undesirable social interactions were thought to occur due to the other person lacking information about the condition, making assumptions, or discounting the effects of invisible diseases. Negative interactions included uncomfortable or stigmatizing conversations and sometimes generated gossip and rumors about the participant within his or her community.