The Characterization and Assessment of Transition Success in Young Adults with Inflammatory Bowel Disease

by

Allison Katelin Joanne Bihari

A thesis submitted in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

Department of Medicine
University of Alberta

Abstract

Canada has one of the highest incidence rates of inflammatory bowel disease (IBD) worldwide, particularly among adolescents and young adults. As the incidence of pediatric-onset IBD is projected to increase in the upcoming years, more patients will need to transition from pediatric to adult care. The process of transition is a challenging period, overlapping with the life period of emerging adulthood, where patients gradually assume more responsibility, make independent decisions, and become financially independent. This period of transition has been associated with an increase in health care utilization, and nonadherence to medical appointments and medications. While the literature supports the importance of preparing patients for transition and the need for structured transition programs, there remains a gap in understanding transition outcomes from the perspectives of all partners involved in the transition process. This thesis aims to address this gap, with the overall goal of improving the transition process for young adults with IBD.

A qualitative descriptive approach was used, involving semi-structured interviews with transitioned patients, their parents, and health care providers to define transition success. Data analysis was done using latent content analysis to develop themes that partners used to characterize a successful transition from pediatric to adult care. Themes of these indicators of transition success provided the foundation for a cross-sectional study using a self-administered online questionnaire to assess whether young adults aged 18-25 with pediatric-onset IBD have achieved these indicators of transition success. The questionnaire was also administered to young adults aged 18-25 with adult-onset IBD to explore the role of age period of IBD onset in achievement of transition outcomes. The transition success indicators identified in the qualitative study were subsequently referred to as health care autonomy indicators to account for participants with adult-onset IBD not having undergone transition. Descriptive statistics, including proportions, means and medians, were calculated for each health care autonomy indicator within each IBD onset group (pediatric-onset and adult-onset).

Seventeen patients, 13 parents, and 15 providers from Alberta, Canada, participated in semi-structured interviews, with additional providers recruited from British Columbia. The theme of independence in one's care emerged across all partner groups. The theme of disease management emerged within parent and provider groups, while the theme of relationship with/ trust in adult care team was common to patients and parents. Additional themes of care team management, general knowledge, care stability, and health outcomes emerged within specific partner groups. In the cross-sectional study (n=56), 37 participants with pediatric-onset IBD and 19 with adult-onset IBD completed the questionnaire. Among participants with pediatric-onset IBD, 46.0% had scores suggestive of high independence in their IBD care, 51.4% reported a score categorized as high satisfaction with their relationship with the IBD care team, and 84.2% achieved a score that corresponded to high medication adherence. When compared to participants with pediatric-onset IBD, participants in the adult-onset group (n=19) scored higher on IBD knowledge (mean scores: 11.8 vs. 10.5), had slightly greater independence in their IBD care (mean scores: 52 vs. 46), a higher proportion of participants with high medication adherence (84.2% vs. 93.8%), and had a similar reported satisfaction with their IBD care team (mean scores: 37.4 vs. 37.5).

The findings suggest that while many young adults with pediatric-onset IBD achieve key health care autonomy indicators, there remains areas of improvement. Young adults with pediatric-onset IBD exhibit comparable or lower indicator achievement when compared to those with adult-onset IBD, underscoring the need for supportive interventions for all young adults with IBD.

Preface

This thesis is an original work by Allison Bihari. The work presented in this thesis received ethics approval from Research Ethics Boards at the University of Alberta and the University of Calgary, as project name “Defining and Predicting Transition Success for Young Adults with Inflammatory Bowel Disease” (UofA: Pro00099184; UofC: REB20-0979).

Chapter 2 of this thesis has been published as Bihari A, Olayinka L, Kroeker KI. Outcomes in Patients with Inflammatory Bowel Disease Transitioning from Pediatric to Adult Care: A Scoping Review. J Pediatr Gastroenterol Nutr. 2022;75(4):423-430. In this scoping review, I was responsible for the conception and development of the study, data collection and analysis, and manuscript composition. Lily Olayinka aided with data analysis as a second reviewer and contributed to manuscript edits. Karen Kroeker was the supervisory author and acted as a third reviewer when needed.

Chapter 3 of this thesis has been published as Bihari A, Hamidi N, Seow CH, Goodman KJ, Wine E, Kroeker KI. Defining Transition Success for Young Adults with Inflammatory Bowel Disease According to Patients, Parents and Health Care Providers. J Can Assoc Gastroenterol. 2022;5(4):192-198. In this journal article, I was responsible for the study design, data collection, data analysis, and manuscript composition. Nima Hamidi and Cynthia Seow aided with participant recruitment and manuscript review. Karen Goodman and Eytan Wine consulted on the study design and manuscript review. Karen Kroeker was the supervisory author.

Chapter 4 of this thesis has been published as an advanced article as Bihari A, Wine E, Seow CH, Goodman KJ, Kroeker KI. Perspectives of patients, parents, and health care providers on facilitators of and barriers to the transition from pediatric to adult care in inflammatory bowel disease: a qualitative descriptive study. J Can Assoc Gastroenterol. 2024:1-8. In this journal article, I was responsible for the study design, data collection, data analysis, and manuscript composition. Cynthia Seow aided with participant recruitment and manuscript review. Karen Goodman and Eytan Wine consulted on the study design and manuscript review. Karen Kroeker was the supervisory author.

Dedication

To my mother, who raised me to believe that I could achieve any dream of mine no matter how big or how small they were. Your ability to provide me with unwavering support and encouragement in every single dream that I have set out to achieve has had a profound impact on how I navigate life.

Acknowledgements

I would first like to express my gratitude for my principal supervisor, Dr. Karen Kroeker who throughout the past four years has provided me with endless support, encouragement, guidance, and kindness. She has wholeheartedly supported all my career goals and personal growth during my time as a student. I am ending my graduate degree not only a better researcher but a better human thanks to her exceptional mentorship. I can only aspire to become half as inspirational a supervisor as she is one day. With that, I would also like to thank Dr. Robert Bailey who first introduced me to Dr. Kroeker. Dr. Bailey is a remarkable coach who has continued to encourage me to pursue my dreams whether in ringette, graduate studies or anything else that I set out to achieve. His support and guidance throughout the years is greatly appreciated.

I would like to express my gratitude to my supervisory committee for supporting my decision to transfer into a doctoral degree program and for providing me with unwavering support over the past four years. Dr. Wine, thank you for agreeing to be my co-supervisor and for supporting me throughout this journey. I deeply appreciate the time he has dedicated to offering his valuable perspectives on the study design of my projects, as well as his support for my goals outside of my PhD. Thank you to Dr. Goodman who has provided me with valuable insight into the field of epidemiology. Her guidance, support, and willingness to spend time with me on the methodology and providing feedback on my writing is very much appreciated. I would also like to thank Dr. Puneeta Tandon for her expertise, kindness, and useful suggestions during my degree. I would also like to thank Dr. Cynthia Seow who was a key collaborator in this work. I am deeply

grateful for her kindness and willingness to help with all stages of the work outlined in this thesis.

I would like to thank my friends and family for their unwavering support throughout this journey. Thank you for always believing in me and cheering me on every step of the way, especially during times when I had to cancel plans and work on weekends to meet deadlines. I would specifically like to thank Kaitlyn Chappell, who has been on this graduate school journey with me for past few years. Thank you for always being there to discuss my studies –this thesis has greatly benefited from our conversations. Your willingness to listen, empathize, and encourage me has been truly invaluable.

Last but not least, I would also like to thank the patients without whom this thesis would not be possible. Their ability to navigate the complexities of entering adulthood while managing a chronic disease is inspiring. Further, their willingness to participate in research to improve the care of other young adults is equally inspiring.

Table of Contents

List of Tables

List of Figures

List of Abbreviations

CD-RISC: Connor-Davidson Resilience Scale

CISS: Chronic-Illness-Related Shame Scale

IBD: Inflammatory Bowel Disease

IBD-KID2: Inflammatory Bowel Disease Knowledge Inventory Device 2

IQR: Interquartile Range

MARS-5: Medication Adherence Report Scale

UofA: University of Alberta

UofC: University of Calgary

Chapter 1. Introduction

The following chapter provides an overview on topics included in this thesis including an overview on inflammatory bowel disease, impact of inflammatory bowel disease, the differences between pediatric and adult diagnoses, and the transition from pediatric to adult care. These topics will be explored in depth in the introduction of the chapters in this thesis.

1.1 Inflammatory Bowel Disease

Inflammatory bowel disease (IBD) is a term that describes incurable and chronic diseases of the gastrointestinal tract, including Crohn's disease and Ulcerative Colitis. The etiology of IBD is complex and multifaceted with an interplay of environmental, immunological, and genetic factors resulting in chronic inflammation of the gastrointestinal tract[1]. Common symptoms of IBD, such as diarrhea, abdominal pain, and fatigue occur in an unpredictable relapsing-remitting cycle resulting in periods of disease flares and disease remisson[2]. Treatment goals focus on the induction and maintenance of remission, prevention of complications, such as perianal disease, intestinal strictures, and fistulas, and achievement of mucosal healing[3]. Failure to respond to therapies may result in disease progression, therapy escalation, and the potential need for hospitalizations and surgical interventions.

1.2 Impact of Inflammatory Bowel Disease

IBD can have a profound impact on multiple facets of a person's life outside of their physical health. Patients with IBD often experience an impairment in health-related quality of life[4,5] and report a high prevalence of symptoms of anxiety and depression[6,7]. An IBD diagnosis can also have significant social implications through the disease's interference in social activities. Additionally, IBD patients frequently report missing work because of symptoms, having difficulties in their intimate relationships, and experiencing perceived and internalized shame because of their IBD[8-11]. These social impairments are further illustrated by one study that found 66% of IBD patients worried about the availability of toilets when going to an unfamiliar place[7] and in another qualitative study, patients mentioned the need to ensure availability and location of toilets in unfamiliar places.[11] In this qualitative study, patients also mentioned how IBD negatively impacts intimacy, autonomy, and their self-esteem[12].

While the impact on patients is significant, IBD also has a notable impact on society, demonstrated by the indirect costs of IBD, which in Canada were estimated to be at least $1.15 billion in 2023[13]. The biggest contributor to the indirect cost of IBD is unemployment, followed by absenteeism (e.g., lost wages likely because of IBD symptoms) and presenteeism (e.g., present at work, but a reduction in productivity largely because of fatigue)[12]. IBD can also have serious impacts on the families of patients with IBD. Interviews with family members of individuals with IBD note that due to their loved one's IBD, these family members face feelings of anxiety around the unpredictability of IBD flares, incur additional financial challenges, and experience interruptions to their own social lives (e.g., not inviting friends over, considering toilet access when travelling)[14].

1.3 Differences between Pediatric and Adult IBD Diagnoses

Currently, Canada has one of the highest occurrences of IBD worldwide, with particularly high incidence rates in adolescents and young adults[15,16]. Further, the incidence of pediatric-onset IBD in Canada is projected to increase from 15.6 per 100,000 in 2023 to 18.0 per 100,000 in 2035[16]. Pediatric-onset IBD differs substantially from adult-onset IBD, thereby warranting distinctive disease management. Patients with pediatric-onset IBD tend to have more extensive disease and face additional complications, such as being at risk for growth failure, pubertal delays, and adverse impacts on bone health[17-19].

1.4 Critical Milestone: Transition from Pediatric to Adult Care

A critical landmark in the IBD journey of patients with pediatric-onset IBD is the process of undergoing the transition from pediatric to adult care. Transition is gradual, planned, and purposeful and partly continues into adult care[20]. While transition refers to a progressive change in care as described above, transfer refers to the actual moment a patient’s care is moved to adult care. Transfer represents a specific event in a patient’s transition. Fundamental differences between pediatric and adult care pose challenges for patients’ navigating the transition from one to the other; the pediatric-care model takes a family-focused approach while the adult-care model necessitates patient independence[21].

Essential to appropriate transition care is ensuring patients are prepared to take responsibility for their disease management as is required in adult care. A recent multi-center cross-sectional

Western Canadian study in IBD found that based on their ability to meet or surpass the criteria of the transition readiness tool (ON TRAC), of 186 participants 26.6% of young adults at a pediatric center and 40.4% at an adult center were ready to transition to adult care [22]. In this same study, older age was associated with higher transition readiness scores. This relationship between older age and transition readiness is consistent with other IBD studies[23-25] and with studies of populations with other chronic diseases[26-30].

Schwartz et al, developed a social-ecological model of transition readiness that represents the perspectives of patients, parents, and providers. This model portrays pre-existing and modifiable factors that contribute to transition readiness. Pre-existing factors, such as disease history, access to care, and socio-demographic variables are described in the social-ecological model as being less amenable to interventions, where modifiable factors, such as knowledge, skills, beliefs, goals, etc., which can be used as targets for transition interventions[31]. The need for transition interventions that target the multi-factorial nature of transition readiness is highlighted by the 2022 Canadian consensus statements on best-practices for transitioning IBD patients[32]. The consensus statements emphasize a need for structured transition intervention programs in the IBD population[32]. In response to these transition consensus statements, a multi-center randomized controlled trial (RCT) is currently underway in Canada[33]. The intervention in this RCT consists of four core components: individualized assessment, transition navigator, skill-building, and an education program. Overall, this ongoing RCT further underscores the importance of proactively improving transition IBD care.

1.5 Thesis Overview

The overarching purpose of this thesis is to contribute to the existing IBD transition literature by addressing the limitations surrounding outcomes of a successful transition from pediatric to adult care. This thesis is organized into three parts.

Part I of this thesis is titled, '*Characterizing transition success in inflammatory bowel disease*." For this part, I led a scoping review to characterize how transition outcomes have been evaluated in the literature and if/how studies have characterized a successful transition from pediatric to adult care (Chapter 2). Based on this scoping review, I then designed a qualitative study using semi-structured interviews with patients, parents, and health care providers to obtain their input on characterizing indicators of successful transition (Chapter 3), along with their perceptions on the facilitators of and barriers to transition success (Chapter 4).

Part II of this thesis is titled, 'A*ssessing transition success in young adults with IBD*'. For this part, I designed a cross-sectional study to assess the achievement of transition success by young adults with both pediatric-onset IBD and adult-onset IBD, using the indicators identified in part I to define transition success.

Part III is titled, '*Bringing it all together: improving outcomes for IBD transition*'. For this part, I summarize and discuss the main findings of this thesis, and outline future directions. I also provided personal reflections on the challenges I faced while undertaking this thesis.

1.6 References

1. Kofla-Dłubacz A, Pytrus T, Akutko K, et al. Etiology of IBD—Is It Still a Mystery? *Int J Mol Sci.* 2022;23(20):12445.

2. Perler BK, Ungaro R, Baird G, et al. Presenting symptoms in inflammatory bowel disease: descriptive analysis of a community-based inception cohort. *BMC Gastroenterol*. 2019;19(1):47.

3. Cai Z, Wang S, & Li J. Treatment of inflammatory bowel disease: a comprehensive review. *Front Med*. 2021;8:765474.

4. Lix LM, Graff LA, Walker JR, et al. Longitudinal study of quality of life and psychological functioning for active, fluctuating, and inactive disease patterns in inflammatory bowel disease. *Inflamm Bowel Dis*. 2008;14(11):1575-1584.

5. Jones JL, Nguyen GC, Benchimol EI, et al. The impact of inflammatory bowel disease in Canada 2018: quality of life. *J Can Assoc Gastroenterol*. 2019;2(Supplement_1):S42-S48.

6. Mikocka-Walus A, Knowles SR, Keefer L, Graff L. Controversies revisited: a systematic review of the comorbidity of depression and anxiety with inflammatory bowel diseases. *Inflamm Bowel Dis*. 2016;22:752–62.

7. Barberio B, Zamani M, Black CJ, Savarino EV, Ford AC. Prevalence of symptoms of anxiety and depression in patients with inflammatory bowel disease: a systematic review and meta-analysis. *Lancet Gastroenterol Hepatol*. 2021;6(5):359-370.

8. Lönnfors S, Vermeire S & Avedano L. IBD and health-related quality of life—discovering the true impact. *J Crohns Colitis*. 2014;8(10):1281-1286.

9. Argyriou K, Kapsoritakis A, Oikonomou K, et al. Disability in patients with inflammatory bowel disease: correlations with quality of life and patient's characteristics. *Can J Gastroenterol Hepatol*. 2017;2017:6138105.

10. Becker HM, Grigat D, Ghosh S, et al. Living with inflammatory bowel disease: a Crohn's and Colitis Canada survey. *Can J Gastroenterol Hepatol.* 2015;29(2):77-84.

11. Taft TH & Keefer L. A systematic review of disease-related stigmatization in patients living with inflammatory bowel disease. *Clin Exp Gastroenterol*. 2016;9:49-58.

12. Wilburn J, Twiss J, Kemp K & McKenna SP. A qualitative study of the impact of Crohn's disease from a patient's perspective. *Frontline Gastroenterol.* 2017;8(1):68-73.

13. Kuenzig ME, Im JH, Coward S, et al. The 2023 Impact of Inflammatory Bowel Disease in Canada: Indirect (Individual and Societal) and Direct Out-of-Pocket Costs. *J Can Assoc Gastroenterol.* 2023;6(Supplement_2):S16-S22.

14. Thapwong P, Norton C, Rowland E & Czuber-Dochan W. Our Life Is a Rollercoaster! A Qualitative Phenomenological Study Exploring the Impact of IBD on Family Members. *Inflamm Bowel Dis*. 2024;izae028.

15. Kuenzig ME, Fung SG, Marderfeld L, et al. Twenty-first century trends in the global epidemiology of pediatric-onset inflammatory bowel disease: systematic review. *Gastroenterol.* 2022;162(4):1147-1159.

16. Coward S, Benchimol EI, Kuenzig ME, et al. The 2023 impact of inflammatory bowel disease in Canada: Epidemiology of IBD. *J Can Assoc Gastroenterol*. 2023;6(Supplement_2):S9-S15.

17. Rosen MJ, Dhawan A & Saeed SA. Inflammatory bowel disease in children and adolescents. *JAMA pediatr*. 2015;169(11):1053-1060.

18. Pigneur B, Seksik P, Viola S, et al. Natural history of Crohn's disease: comparison between childhood-and adult-onset disease. *Inflamm Bowel Dis*. 2010;16(6):953-961.

19. Chaparro M, Garre A, Ricart E, et al. Differences between childhood-and adulthood-onset inflammatory bowel disease: the CAROUSEL study from GETECCU. *Aliment Pharmacol Ther*. 2019;49(4):419-428.

20. Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. *J Adolesc Heal*. 1993;14(7):570-576.

21. El-Matary W, Carroll MW, Deslandres C, et al. The 2023 impact of inflammatory bowel disease in Canada: special populations—children and adolescents with IBD. *J Can Assoc Gastroenterol*. 2023;6(Supplement_2):S35-S44.

22. Foster A, Chan JM, Wine E, et al. Transition readiness in youth with inflammatory bowel disease. *J Pediatr*. 2023;258:113403.

23. Gray WN, Holbrook E, Morgan PJ, et al. Transition readiness skills acquisition in adolescents and young adults with inflammatory bowel disease: findings from integrating assessment into clinical practice. *Inflamm Bowel Dis.* 2015;21(5):1125-1131.

24. Rosen D, Annunziato R, Colombel JF, Dubinsky M & Benkov K. Transition of inflammatory bowel disease care: assessment of transition readiness factors and disease outcomes in a young adult population. *Inflamm Bowel Dis*. 2016;22(3):702-708.

25. Whitfield EP, Fredericks EM, Eder SJ, Shpeen BH & Adler J. Transition readiness in pediatric patients with inflammatory bowel disease: a patient survey of self-management skills. *J Pediatr Gastroenterol Nutr*. 2015;*60*(1):36-41

26. Mackie AS, Rempel GR., Islam, S, et al. Psychosocial maturity, autonomy, and transition readiness among young adults with congenital heart disease or a heart transplant. *Congenit Heart Dis*. 2016;11(2):136-143.

27. Zhong Y, Gilleskie DB, van Tilburg MA, et al. Longitudinal self-management and/or transition readiness per the TRxANSITION index among patients with chronic conditions in pediatric or adult care settings. *J Pediatr*. 2018;203:361-370.

28. Marchak Gilleland J, Reed-Knight B, Amaral S, Mee L & Blount RL. Providers' assessment of transition readiness among adolescent and young adult kidney transplant recipients. *Pediatr transplant.* 2015;19(8):849-857.

29. Lazaroff SM, Meara A, Tompkins MK, Peters E, & Ardoin SP. How do health literacy, numeric competencies, and patient activation relate to transition readiness in adolescents and young adults with rheumatic diseases? *Arthritis Care Res*. 2019;71(9):1264-1269.

30. Bingham CA, Scalzi L, Groh B, Boehmer S & Banks S. An assessment of variables affecting transition readiness in pediatric rheumatology patients. *Pediatr Rheumatol*. 2015;13(1):42.

31. Schwartz LA, Tuchman LK, Hobbie WL & Ginsberg JP. A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. *Child Care Health Dev.* 2011;37(6):883-895.

32. Fu N, Bollegala N, Jacobson K, et al. Canadian Consensus Statements on the Transition of Adolescents and Young Adults with Inflammatory Bowel Disease from Pediatric to Adult Care: A Collaborative Initiative Between the Canadian IBD Transition Network and Crohn's and Colitis Canada. *J Can Assoc Gastroenterol*. 2022;5(3):105-115.

33. Bollegala N, Barwick M, Fu N, et al. Multimodal intervention to improve the transition of patients with inflammatory bowel disease from pediatric to adult care: protocol for a randomized controlled trial. *BMC gastroenterol.* 2022;22(1):251.

Part I: Characterization of Transition Success in Young Adults with IBD

Part I (Chapters 2-4) of this thesis focuses on characterizing transition outcomes in patients with inflammatory bowel disease.

Chapter 2 is a scoping review focused on characterizing how transition outcomes in IBD have been evaluated in the literature or how a successful transition from pediatric to adult care has been defined. Chapter 3 and 4 outline the results of a qualitative study that used semi-structured interviews to explore the perspectives of patients, parents, and health care providers on outcomes associated with transition success (Chapter 3) and the facilitators of and barriers to successful transition (Chapter 4). In Chapters 2-4, patients, parents, and health care providers are collectively referred to as stakeholders. However, beyond these already published works, we chose to refer to these groups as partners, acknowledging the colonial context of the term stakeholder.

Chapter 2. Outcomes in Patients with Inflammatory Bowel Disease Transitioning from Pediatric to Adult Care: A Scoping Review.

This manuscript has been published as *Bihari A, Olayinka L, Kroeker KI. Outcomes in Patients with Inflammatory Bowel Disease Transitioning from Pediatric to Adult Care: A Scoping Review. J Pediatr Gastroenterol Nutr. 2022;75(4):423-430. doi: 10.1097/MPG.0000000000003581*

Authors: Allison Bihari, Lily Olayinka, Karen I. Kroeker.

2.1 Abstract

Purpose: Approximately 25% of IBD patients are diagnosed in childhood and the incidence is increasing. Thus, more patients will transition to adult care in the future. Within the literature, transition readiness has been deemed important to achieving a successful transition; however, it is unclear what outcomes define success. This scoping review aims to summarize the literature on outcomes surrounding transition from pediatric to adult care in patients with inflammatory bowel disease.

Methods: A scoping review was conducted with the following steps: 1) identifying the research question, 2) identifying relevant studies, 3) study selection, 4) charting the data, 5) collating, summarizing, and reporting results, and 6) consultation with an additional researcher. Studies were identified from five databases and were included in part if 1) inflammatory bowel disease was a disease of interest, 2) referred to transition as the movement and adjustment from pediatric to adult care, and 3) evaluated patient outcomes up to five years after first adult appointment and/or defined a successful or unsuccessful transition.

Results: Twenty-six peer-reviewed studies were included. Four studies defined transition success, while two studies defined an unsuccessful transition. Transition outcomes were categorized into these six themes: being comfortable in adult care (n=4); health care utilization (n=19); disease management (n=15); knowledge (n=5); quality of life (n=6); self-efficacy (n=7).

Conclusions: Most studies evaluated transition outcomes by themes of health care utilization (n=19) and disease management (n=15). Future research should focus on engaging patients along with providers in order to create a consensus on indicators of transition success.

2.2 Introduction

Inflammatory bowel diseases (IBD) are chronic and debilitating diseases of the gastrointestinal tract and include Crohn's disease (CD) and ulcerative colitis (UC)[1]. Symptoms such as abdominal pain, cramps, and diarrhea can negatively impact daily life, employment, and relationships[2]. Additionally, these individuals are at a higher risk for depression and anxiety than the general population[3,4].

In Canada, approximately 25% of patients are diagnosed with IBD in childhood[5–7]—a frequency that is increasing[8,9]. These children may face additional challenges compared to those diagnosed as adults such as delayed growth, greater extent of disease, and the need to transition to adult care[8]. Typically, pediatric patients are supported by their guardians who assist in disease management, but in adult care, these patients need to take on this responsibility and make medical appointments, know their disease history, and make medical decisions.

While transfer of care generally refers to the handover from pediatric to adult care, transition of care is the gradual shift and ongoing process of the patient taking responsibility for their care[10]. Transition typically starts in pediatric care and continues after transfer while the patient adapts to adult care. This period is challenging for young adults as it coincides with potential lifestyle changes, such as becoming financially independent, moving out, and starting post-secondary schooling or employment[11,12]. Transition readiness—the appropriate preparation of an individual to transition—has been thought necessary for a successful transition, but the indicators of success have not been fully described[12,13]. A common belief in the literature is that the skills associated with transition readiness are indicators of transition success, but readiness itself does not necessarily correlate with success.

The goal of this review is to summarize current research surrounding outcomes after a patient has transitioned from pediatric to adult care. This review will identify overall themes of transition outcomes and provide guidance for future research.

2.3 Methods

Guidelines used for this scoping review were first described by Arksey and O'Malley and then modified by Levac et al. Essential steps include (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, (5) collating, summarizing, and reporting results, and (6) consultation (optional) (LO)[14,15]. Although consultation is optional, we introduced an additional researcher to screen title and abstracts for inclusion and to review results.

Scoping reviews differ from systematic reviews as study quality is not assessed and can identify gaps in literature before pursuing a systematic review[14]. As this was not a systematic review and included diverse study populations, interventions, and outcome measures, a meta-analysis was not within the scope of this review.

The overarching research question used was: what is known in the literature about the outcomes of transition from pediatric to adult care in patients with IBD?

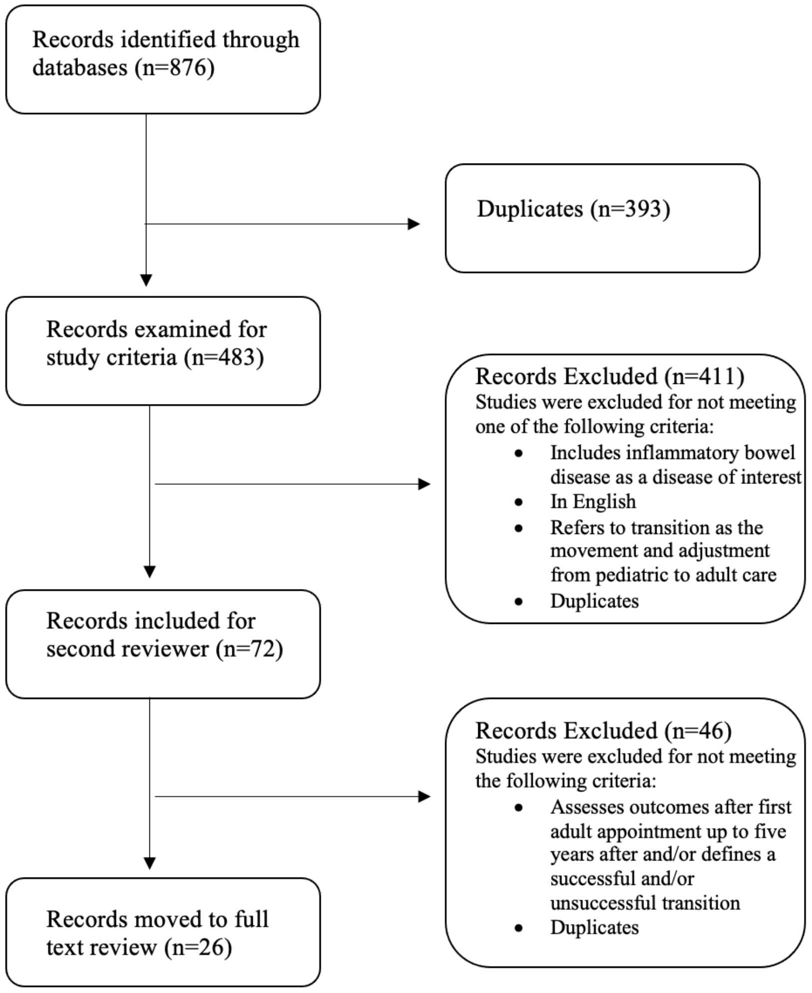
2.3.1 Identifying Relevant Studies

Databases searched were Medline (OVID), Scopus, CINAHL, Embase (OVID), and PsycINFO. Search terms were identified through consultation within the team and with a librarian. Keyword terms were searched through title and abstract for sources of research. Search strategies for each database are in **Appendix A**. Studies were included in this scoping review if they met the following criteria: 1) written in English, 2) published from database inception to January 10th, 2021, 3) inflammatory bowel disease as a disease of interest, 4) referred to transition of care as the ongoing movement and adjustment from pediatric to adult care, and 5) evaluated outcomes up to five years after first adult appointment and/or defined a successful or unsuccessful transition. All original published peer-reviewed literature, including abstracts, were included in this study.

2.3.2 Study Selection

Study references were entered into Covidence, a review management system (https://www.covidence.org). Title and abstracts were independently screened by 2 reviewers according to inclusion criteria (AB & LO). Disagreements were discussed and if consensus could not be reached, a third reviewer was introduced (KK). From this process, 26 studies underwent final review (**Figure 2.1**).

Figure 2.1 Study Selection



2.3.3 Charting the Data and Collating, Summarizing, and Reporting Results

Studies were divided into four categories based on the study focus (**Table 2.1**): studies that defined a successful and/or unsuccessful transition; studies with controlled implementation of a transition program; studies with implementation of a transition program with no control; and studies that measured transition outcomes.

A descriptive analysis of the studies was done for themes relating to transition outcomes[14,15]. Outcomes were grouped together based on similarity until an overall theme was created. Before finalizing themes, a second reviewer screened the results and provided further input. Themes were created with no precedent, by the authors, based on how outcomes related to one another.

Table 2.1 Study Characteristics and Summary of Outcomes Measured

Author (year)	Sample Size	Method	Themes and Measured Outcomes					
			Comfort in Adult Care	**Health Care Utilization**	**Disease Management**	**Knowledge**	**Quality of Life**	**Self - Efficacy**
Studies focused on defining a successful and/or unsuccessful transition:								
van den brink (2019)	Health care providers: 74 Patients: 61	Multinational Delphi study			Refill prescriptions; medication adherence	Medication dose and frequency	Health related	Appointment attendance; independence (decisions & communication)
Pearlstein (2020)	Patients: 104	Retrospective chart review		Return to pediatric care; ED visits	Therapy escalation			
Paine (2014)	Health care providers: 12	Semi structured interviews		ED visits; hospitalizations; surgery; laboratory testing; endoscopies;	Therapy escalation; disease activity (biomarkers); symptom stability; insurance		Meets demands of daily life	

				return to pediatric care				
			Comfort in Adult Care	**Health Care Utilization**	**Disease Management**	**Knowledge**	**Quality of Life**	**Self - Efficacy**
Controlled studies of a transition intervention								
Dijoseph (2020)	**Intervention:** Patients: 50 **Control:** Patients: 65	Retrospective chart review		Hospitalizations; appointment no-show rates	Therapy escalation			
Sarlos (2018)	**Intervention:** Patients: 24 **Control:** Patients: 21	Outcome evaluation of structured transition program		Diagnostic imaging	Disease activity (biomarkers)			
Mccartney (2016)	**Intervention:** Patients: 95 **Control:** Patients: 34	Retrospective case note review; cross-sectional patient survey of outcomes		Hospitalizations	Therapy escalation; disease exacerbations			

Cole (2015)	**Intervention:** Patients: 44 **Control:** Patients: 28	Review of patient records		Surgery; diagnostic imaging	Medication adherence			
Moulton (2013)	**Intervention:** Patients: 13 **Control:** Patients: 19	Randomised to progressive or standard transition		Hospitalizations	Therapy escalation	Medication; insurance information		
Eros (2020)	Patients: 160 randomized into intervention and control	Randomised controlled two-arm multicentre trial	CACHE (IBD specific questionnaire)	Hospitalizations; surgery; diagnostic imaging; endoscopies; ED visits	Perianal CDAI; disease activity (biomarkers); therapy escalation; not lost to follow up; medication adherence		IMPACT-III questionnaire	IBDSES-A
Shaikh (2017)	**Intervention:** Patients: 33 **Control:** Patients: 24	Evaluation of treatment requirement and service engagement		Surgery	Therapy escalation			

Sattoe (2020)	**Intervention:** Health care providers: 5 Patients: 80 **Control:** Health care providers: 3 Patients: 81	Controlled mixed-methods evaluation		ED visits	Disease exacerbations; medication adherence		Pediatric Quality of Life Inventory Young Adult	On Your Own Feet Self – Efficacy Scale; appointment attendance & independence
Schutz (2019)	**Intervention:** Patients: 24 **Control:** Patients: 11	Evaluation of patients with and without structured transition		Costs of medications, hospitalizations, and surgery; diagnostic imaging; endoscopies	Disease exacerbations		IBDQ-32	
			Comfort in Adult Care	**Health Care Utilization**	**Disease Management**	**Knowledge**	**Quality of Life**	**Self - Efficacy**
Studies that measured outcomes after implementation of a transition program								
Yadav (2017)	Patients: 19	Cross-sectional study	Questionnaire			Questionnaire		Questionnaire

Picardo (2019)	Patients: 59	Interviews & questionnaire			Disease activity – clinical disease		IBD-DI	
Avni-Biron (2016)	Patients: 50	Retrospective review of patient files		Hospitalizations; surgery	Therapy escalation	Diagnosis;disease location; medications		
Yerushalmy-Feler (2017)	Patients: 27	Evaluation of transition clinic				Questionnaire		IBD Yourself
Mollah (2018)	Patients : 71	Medical records; questionnaire	IBD-PSQ	ED Visits				
Williams (2017)	Patients: 28	Evaluation of IBD transition clinic						Appointment attendance
			Comfort in Adult Care	**Health Care Utilization**	**Disease Management**	**Knowledge**	**Quality of Life**	**Self - Efficacy**
Studies that measured outcomes following transition								
Zhao (2016)	Patients: 536	Population-based cohort		Hospitalizations; ED visits; laboratory use				

Szanto (2018)	Patients: 59	Retrospective evaluation of transfer		Surgery; endoscopies	Therapy escalation			
Edwards (2017)	Patients: 4 Parents: 10	Phone survey						
Testa (2019)	Patients: 106	Evaluation before and after transition		Hospitalizations; surgery; number of outpatient visits	Partial mayo; CDAI; disease exacerbations			
Bollegala (2013)	Patients: 95	Retrospective chart review		Hospitalizations; surgery; endoscopies; ED visits; outpatient clinic visits	Medication adherence			
Pamela (2014)	Patients: 9	Review of patient records			Disease exacerbations; medication adherence			Appointment attendance
Setya (2020)	Patients: 7381	Retrospective cohort		Hospitalizations; diagnostic				

				imaging; ED visits				
Bollegala (2017)	Patients: 2043	Population-based retrospective cohort		Hospitalizations; surgery; diagnostic imaging; endoscopies; ED visits				

2.4 Results

Of the twenty-six studies moved to full text review, 73% (19/26) were published between 2017 – 2020 with a range of 2013 – 2020. Most were conducted in the United States (n=8) with the remainder published in the Netherlands (n=4), Canada (n=4), Israel (n=2), United Kingdom (n=3), Hungary (n=3), Italy (n=1) and Germany (n=1). In addition to studies that provided a definition of a successful or unsuccessful transition, there were 6 themes surrounding transition outcomes. Themes were (1) comfort in adult care; (2) health care utilization; (3) disease management; (4) knowledge; (5) quality of life; and (6) self-efficacy (**Table 2.1**).

2.4.1 Themes of Transition Outcomes

Comfort in Adult Care

Four studies measured patient's comfort in adult care as an outcome of transition[16,17,18,19]. Eros et al., employed an IBD specific questionnaire (CACHE), which uses a 5-point Likert scale to explore patient's attitudes towards the medical team, accessibility, and facilities of the centre[17]. Mollah and Giles developed the IBD Patient Satisfaction Questionnaire[18]. This questionnaire had questions composed of categories relating to satisfaction with doctor-patient communication, clinic expectations, and clinic logistics. Other studies either explored patients' transition experiences using the On Your Own Feet Transition Experience Scale and a subscale of American Consumer Assessment of Health Plan surveys to explore the perceived patient-centeredness of care[16] or a questionnaire conducted virtually[19].

Health Care Utilization

Nineteen studies examined health care utilization as an outcome of transition[16-18,20,21,22-34.] The most common measures was whether the young adult required IBD-related hospitalization[16,17,20,22-29,34] and whether there was a need for surgical intervention[17,20, 22-24, 29.] Procedures such as diagnostic imaging and associated radiation exposure were measured[17,22,24,28,29,30]; as well as the need for endoscopies[17,22,23,29,32]. Another measurement of health care utilization was emergency department (ED) visits[16-18,23,30,34]. Paine et al., conducted semi structured interviews with pediatric and adult IBD providers to define transition success. Key outcomes that arose were appropriate ED use, maintaining standard of care in terms of lab tests and endoscopies, while minimizing hospitalizations and surgeries[21].

Disease Management

Fifteen studies measured outcomes categorized as disease management[7,16,17,20,21,23,24,26-29,30-33,35,36]. The most common outcome was disease activity. Within three studies, disease activity was measured by indices, such as Pediatric Crohn's Disease Activity Index, Pediatric Ulcerative Colitis Activity Index, Crohn's Disease Activity Index (CDAI), Mayo score, and Perianal CDAI[17,33]; and Partial Mayo score or Harvey Bradshaw index[36]. Disease activity was also measured by laboratory parameters, such as C-reactive protein, and stool calprotectin[17,28]. Shaikh et al., used therapy escalation, such as the requirement for steroid or anti-TNF initiation, as a marker for disease activity[31]. Without specifically referring to the measurement of disease activity, other studies examined therapy escalation leading to initiation of steroid treatment, anti-TNF and/or azathioprine or modification of the previously established treatment regimen[17,20,26,32]. Disease exacerbations such as moving into an active flare, and/or developing intestinal complications or extra intestinal manifestations were also measured[17,26,27,29,33,35]. Medication adherence was also measured[16,24,35]. Two studies, measured adherence through patient reports in either clinic notes or through a medication adherence rating scale[16,24]. In a three stage Delphi study, the ability to refill prescriptions on time and then adhere to medication was thought to be important for success[7]. Paine et al., found that avoiding steroid treatment initiation and having stable symptoms and laboratory results were indicative of successful transition[21].

Knowledge

Five studies examined knowledge outcomes[7,20,21,27,37]. Avni-Biron et al., conducted a telephone survey assessing patients' knowledge of their diagnosis, dose and side effects of medications, and disease location[20]. Moulton et al., measured knowledge of medication names, doses, side effects, monitoring requirements, and insurance information[27]. Other studies implemented a questionnaire to assess patient's IBD knowledge, their treatment, and diagnostic tests[21,37]. In a multinational Delphi study, included in the final list was the patient's ability to recall medication doses and frequency[7].

Quality of Life

Six studies measured patients' quality of life (QoL)[7,16,17,21,29,36]. To assess QoL, four studies implemented questionnaires, such as validated IMPACT-III Questionnaire[17]; Inflammatory Bowel Disease Disability Index[36]; IBD Questionnaire [29]; Pediatric Quality of Life Inventory

Young Adult[16]. The remaining two studies sought to define transition success. Van den brink et al., found that providers and patients included health related QoL one year after transfer as an important outcome[7]. Paine et al., found providers indicated that health related QoL was important and was defined as patients meeting the demands of daily life in terms of school, work and family[21].

Self-Efficacy

Seven studies measured self-efficacy[7,16,17,21,35,37,38]. Van den brink et al., identified that outcomes important for transition success include appointment attendance within 3-6 months after transfer, ability for patients to contact and communicate with their physicians/nurses independently, and ability to make their own medical decisions[7]. Attending or missing the initial appointment in adult care and regular clinic appointments were measured[16,35,38]. Sattoe et al., examined patients' independence during consultations using self-reported measures and Partners in Health Scale to assess self-management skills; to assess self-efficacy, the study used On Your Own Feet Self-Efficacy scale[16]. Four studies utilized questionnaires to measure self-efficacy. One questionnaire assessed independence with visits and within transition in general[19]. To measure general coping with IBD, self-efficacy in medication use, and patient's independence and behaviours at appointments, the questionnaire "IBD Yourself" was used[37]. Eros et al., used an IBD Self-Efficacy Scale for Adolescents and Young Adults, which assesses patient's confidence in their ability to manage the demands of IBD[17].

Above describes the six themes in the literature on IBD transition outcomes. The following paragraphs discuss study results based on their focus.

2.4.2 Studies with Controlled Implementation of a Transition Program

In the nine studies that compared the outcomes of patients who attended a transition program with those who did not, most involved joint consultations with adult and pediatric gastroenterologists prior to transitioning[16,17,27,29]. These studies mainly measured outcomes at one year[17,26-28,] or within two years[16,24,29] after transfer. These studies found that compared to patients who did not attend a transition clinic, those who did had lower hospital admissions (29% vs 61%; mean of 0.16 vs 0.51; 20% vs 50%), fewer appointment no-shows (29% vs 78%; mean of 0.36 vs 0.89), and were less likely to require surgical intervention (25% vs 46%; 13% vs 46%)[16,24,25,28,29]. Patients in non-clinic groups were also less likely to be steroid free (vs 41% vs 71%), more likely to require steroid initiation (mean dose of 0.88 vs 0.50), develop intestinal complications (21% vs 64%, use biologics (6.7% (year 1), 10% (year 2) vs 50% (year 1), 47.8% (year 2)) , and have less disease knowledge (e.g. medication names, doses, and side effects)[16,25-27,29]. Cole et al., found that 46% of patients who did not attend a transition clinic fully adhered to their medication, whereas this was 89% in patients who attended a clinic[24].

2.4.3 Studies with Implementation of a Transition Program

In the six studies that implemented a structured transition program, most administered a patient questionnaire to assess patient outcomes[18,19,36,37]. Studies that used self-efficacy questionnaires found that after the implementation of a transition program, patient's scores increased in the domains of coping with IBD and knowledge of disease, tests, and medications (average score of 1.85±0.3 before and 1.41±0.21 after)[19,37]. Picardo et al., measured IBD disability index at 12 months after program completion and found that scores of transitioned patients (20.69±13.19) did not differ significantly from adult patients (24.90±14.18)[36]. Additionally, 75% of patients had stable disease activity throughout the 12 months post transfer. Avni-Biron et al., implemented joint consultations and found that within the first year, 94% of patients had continuous care, 74% required medication modification, and 20% required hospitalization[20]. Williams et al., found an 80% retention rate in adult care and a 0% no-show rate, which was compared to 33% and 46% before the implementation of a transition clinic[38]. Mollah and Giles found IBD-related ED visits decreased by 24% over a one-year period after transition clinic attendance[18].

2.4.4 Studies Measuring Outcomes of Transition

Eight studies measured transition outcomes without an intervention. One study found no statistically significant differences in hospitalizations pre- and post-transfer demonstrated by a relative incidence (RI) of 0.70 (CI: 0.42-1.18) for CD patients and 2.41(CI: 0.62-9.40) for UC patients[34]. This study did find significant pre- and post- differences in ED utilization, as demonstrated by a RI of 2.12 (CI: 1.53-2.93) for CD and 2.34 (CI: 1.18-2.01) for UC[34] and found CD patients had a RI of 1.43 (1.26-1.63), UC patients with RI of 1.38 (CI: 1.13 – 1.68) as it related to laboratory utilization. Another two studies found significant differences in ED use (20% vs 12%) and hospitalizations (0.1±0.3 vs 0.28±0.44) compared to in pediatric care[30,33]. Setya et al., found females had a higher number of ED visits (18.7% vs 15.0%), opioid (63.5%

vs. 56.7%) and benzodiazepine prescriptions (41.0% vs 37.4%) compared to males [30]. Bollegala et al., found that although there were no differences in hospitalizations and ED visits when comparing academic versus community adult gastroenterologist, patients seeing a community gastroenterologist had less ED visits compared to in pediatric care (mean of 0.4) [22]. Two studies found that 67% and 88% of patients became established in adult care[35,39]. Pamela et al., reported 67% of patients in adult care regularly attended appointments, and adhered to medications, and lab tests[35]. Bollegala et al., documented 43% were non-adherent with medications compared to 29% in pediatric care[23]. Szanto et al., reported that within 9 months after transfer, 58% of patients required steroid initiation[32].

2.5 Discussion

This review is the first to summarize outcomes in the literature after a patient with IBD has transitioned from pediatric to adult care by characterizing outcomes into six themes. The two most common themes were health care utilization and disease management. Within these themes, health care utilization was commonly categorized by hospitalizations (63%), surgical intervention (53%), and ED visits (47%), whereas disease management was mainly in terms of therapy escalation (60%) and medication adherence (40%). Considering the wide use of these outcomes, we suggest these aspects of health care utilization and disease management be incorporated for future research on transition outcomes. Although these themes were commonly used to evaluate transition, we also believe that these factors may not fully represent transition outcomes, as they may be independent of transition and rather related to natural fluctuations of disease activity[42]. Given the interplay in these outcomes, reliance should not be placed solely on the outcomes of health care utilization and disease management when evaluating transition. Rather, these outcomes should be used in conjunction with others outlined in this study.

The findings highlight the range of outcomes assessed after a patient has transitioned. There remains a need to fully understand the outcomes that providers should be assessing before determining that a transition has been successful. Of the 26 studies included, 2 focused on defining transition success[7,39], whereas another 4 studies provided a definition of successful or unsuccessful transition[16,20,38,41]. Where a definition was provided, attending appointments and avoiding return to pediatric care was thought to be successful. By solely defining success as regular follow up, we may miss out on patients lacking other important outcomes, such as medication nonadherence or an inability to communicate with their physician. We suggest that, for a process as collaborative, individualistic, and complex as transition, a definition be created that is equally as robust and multifactorial.

Sixteen studies used medical charts or health administrative data to assess outcomes with 5 of these 16 employing a survey or questionnaire to patients. As transition highly relies on patients taking control of their own disease management, we believe that patients should be involved in defining transition success. If providers are aware of how patients view transition success, which may differ from providers' perspectives, they would be able to provide patient-centered support and intervene with patients not likely to achieve success.

Studies that measured comfort in adult care as an outcome were all conducted in European countries—specifically the Netherlands where 75% of studies mentioning this theme originated. The emphasis on comfort in adult care in this region may reflect cultural attitudes and differences in managing transitioning patients. The Netherlands may place more value on ensuring that the patient is established and confident when navigating adult care. Future studies could focus on analyzing transition outcomes trends by region, which will allow for an understanding of the optimal approach to transition as reflected by the outcomes.

Survivor bias is a potential limitation to the studies included in this article. Patients who may have moved and transferred clinics or became lost to follow up and never attended adult care were often overlooked. By not including these patients, the impact of transition interventions may be overestimated. Most studies measured outcomes at 1 year or 2 years after transfer. As there exists no guidelines on when to assess outcomes, these studies could be missing the optimal timeframe; however, we hoped to minimize this limitation by including studies that measured outcomes up to 5 years after first adult appointment.

The strength of this scoping review is that it identifies overall themes of IBD transition outcomes in the literature. We recommend that future research focus on defining transition success according to both patients and providers. This will enable a consensus on transition success indicators, which can then be used to systematically evaluate studies implementing a transition program. We also suggest that once systematic evaluation is available, the focus is on addressing questions of an optimal transition program, such as “what should be covered in consultations?” and “how many visits are needed?” By identifying and outlining the key steps of a successful transition program, we can provide the best opportunity for patients to achieve success. This will be especially valuable in centers where implementation of a transition program is not feasible.

2.6 References

1. Hanauer SB. Inflammatory Bowel Disease: Epidemiology, Pathogenesis, and Therapeutic Opportunities. *Inflamm Bowel Dis*. 2006;12:S3-S9.

2. Calkins BM, Mendeloff AI. Epidemiology of inflammatory bowel disease. *Epidemiol Rev*.1986;8:60-91.

3. Neuendorf R, Harding A, Stello N, et al. Depression and anxiety in patients with Inflammatory Bowel Disease: A systematic review. *J Psychosom Res*. 2016;87:70-80.

4. Lönnfors S, Vermeire S, Greco M, et al. IBD and health-related quality of life-Discovering the true impact. *J Crohns Colitis*. 2014;8:1281-1286.

5. Gray WN, Holbrook E, Morgan PJ, et al. Transition readiness skills acquisition in adolescents and young adults with inflammatory bowel disease: findings from integrating assessment into clinical practice. *Inflamm Bowel Dis*. 2015;21(5):1125-113.

6. Goodhand J, Hedin CR, Croft NM, et al. Adolescents with IBD: The importance of structured transition care. *J Crohns Colitis*. 2011;5(6):509-519.

7. Van den Brink G, van Gaalen MAC, Zijlstra M, et al. Self-efficacy did not predict the outcome of the transition to adult care in adolescents with inflammatory bowel disease. *Acta Paediatr*. 2019;108:333-338.

8. Carroll MW, Kuenzig ME, Mack DR, et al. The impact of inflammatory bowel disease in Canada 2018: children and adolescents with IBD. *Can J Assoc Gastroenterol*. 2019;2:S49-S67.

9. Benchimol EI, Manuel DG, Guttmann A, et al. Changing age demographics of inflammatory bowel disease in Ontario, Canada: a population-based cohort study of epidemiology trends. *Inflamm Bowel Dis*. 2014;20(10):1761-1769.

10. Philpott JR. Transitional care in inflammatory bowel disease. *Gastroenterol Hepatol*. 2011;7(1):26-32.

11. Bollegala N, Nguyen GC. Transitioning the Adolescent with IBD from Pediatric to Adult Care: A Review of the Literature. *Gastroenterol Res Pract*. 2015;2015:1-6.

12. Maddux MH, Ricks S, Bass J. Patient and Caregiver Perspectives on Transition and Transfer. *Clin Pediatr*. 2017;56(3):278-283.

13. Gray WN, Holbrook E, Morgan PJ, et al. Transition readiness skills acquisition in adolescents and young adults with inflammatory bowel disease: findings from integrating assessment into clinical practice. *Inflamm Bowel Dis*. 2015;21(5):1125-113.

14. Levac MR, Colquhoun H, Obrien KK. Scoping studies: Advancing the methodology. *Implement Sci*. 2010;5(1):1-9.

15. Arksey H, O'Malley L. Scoping studies: Towards a methodological framework. *Int J Soc Res Methodol*. 2005;8(1):19-32.

16. Sattoe JNT, Peeters MAC, Haitsma J, et al. Value of an outpatient transition clinic for young people with inflammatory bowel disease: a mixed-methods evaluation. *BMJ Open*. 2020;10(1):e033535.

17. Eros A, Dohos D, Veres G, et al. Effect of joint transition visits on quality of life in adolescents with inflammatory bowel diseases: a protocol for a prospective, randomized, multicentre, controlled trial (TRANS-IBD). *BMJ Open*. 2020;10(10):e038410.

18. Mollah T, Giles E. Impact of a newly established young adult inflammatory bowel disease clinic on clinical outcomes and patient satisfaction. *J Gastroenterol Hepatol*. 2018;33:146-147.

19. Yadav AM, O'Toole FA, Patchett S. Perspective, and self-efficacy of adolescents with inflammatory bowel disease post transition to adult care. *J Crohns Colitis*. 2017;11:S344.

20. Avni-Biron I, Fraser G, Rosenbach Y, et al. Early outcomes for adolescent inflammatory bowel disease patients treated in a transition clinic. *J Crohns Colitis*. 2016;10:S325-326.

21. Paine CW, Stollon NB, Lucas MS, et al. Barriers and Facilitators to Successful Transition from Pediatric to Adult Inflammatory Bowel Disease Care from the Perspectives of Providers. *Inflamm Bowel Dis*. 2014;20(11):2083-2091.

22. Bollegala N, Benchimol EI, Griffiths AM. Characterizing the posttransfer period among patients with pediatric onset IBD: the impact of academic versus community adult care on emergent health resource utilization. *Inflamm Bowel Dis*. 2017;23(9):1483-1491.

23. Bollegala N, Brill H, Marshall JK. Resource utilization during pediatric to adult transfer of care in IBD. *J Crohns Colitis*. 2013;7(2):e55-60.

24. Cole R, Ashok D, Razack A. Evaluation of outcomes in adolescent inflammatory bowel disease patients following transfer from pediatric to adult health care services: case for transition. *J Adolesc Health*. 2015;57(2):212-217.

25. Dijoseph KM, Roasio VS, Gorrepati V, et al. Pediatric to adult IBD patient care: A comparison of outcomes between transitional clinic care and traditional clinic care. *Am J Gastroenterol*. 2020;115:S419.

26. Mccartney SJO, Lindsay RK, Russell DR, et al. A structured paediatric to adult transition service in patients with inflammatory bowel disease reduces disease flares, requirement for steroids and emergency admissions: the transit study. *United European Gastroenterol J*. 2016;4(5):A457-A458.

27. Moulton DE, Rosen MJ, Beaulieu DB, et al. Prospective randomized trial of a progressive pediatric to adult transition of care program in adolescents with inflammatory bowel disease. *Gastroenterol*. 2013;144(5):S532.

28. Sarlos P, Caroline O, Feher D, et al. Planned transition of adolescent inflammatory bowel disease patients from pediatric to adult care results in higher remission rates. *United European Gastroenterol J*. 2018;6(8):A465.

29. Schutz L, Radke M, Menzel S, et al. Long-term implications of structured transition of adolescents with inflammatory bowel disease into adult health care: a retrospective study. *BMC Gastroenterol*. 2019;19(1):128.

30. Setya A, Molina M, Homsi M, et al. Age-specific healthcare utilization trends in a transitional IBD population. *Gastroenterol*. 2020;18(6):S-735.

31. Shaikh O, Harvey P, Cooney R, et al. Do self-selected "non-transitioned" referrals from peadiatric services have lower treatment requirements? *J Crohns Colitis*. 2017;11:S255.

32. Szanto K, Farkas K, Rutka M, et al. Transfer of care of adolescent IBD patients without longitudinal transition: Lesson from 10-year experiences. *J Crohns Colitis*. 2018;12:S427.

33. Testa A, Giannetti E, Rispo A, et al. Successful outcome of the transitional process of inflammatory bowel disease from pediatric to adult age: A five years experience. *Dig Liver Dis*. 2019;51(4):524-528.

34. Zhao X, Bjerre LM, Nguyen GC, et al. Health services utilization in adolescents with inflammatory bowel disease transitioning from pediatric to adult care: A population based, cohort study. *J Pediatr Gasteroenterol Nutr*. 2016;63:S354.

35. Pamela M, Erin H, Lynne G, et al. A retrospective look at an IBD transition initiative. *Inflamm Bowel Dis*. 2014;20:S88.

36. Picardo S, Panaccione R, Kaplan G, et al. Improvement in disease activity is associated

with less disability in a prospective study of pediatric transition patients with IBD. *Gastroenterol*. 2019;156(6):S-390.

37. Yerushalmy-Feler A, Ron Y, Barnea E, et al. Adolescent transition clinic in inflammatory bowel disease: Quantitative assessment of self-efficacy skills. *Euro J Gastroenterol Hepatol*. 2017; 29(7):831-937.

38. Williams E, Coates M, Tinsley A, et al. Formalized IBD transition clinic leads to high retention and low no show rates of young adults in a single tertiary center. *Am J Gastroenterol*. 2017;112:S388-S389.

39. Edwards P, Whitworth J, Arnold S. A single center evaluation of transition in inflammatory bowel disease. *J Pediatr Gastroenterol Nutr*. 2017;65:S275.

40. Thoreson R, Cullen JJ. Pathophysiology of Inflammatory Bowel Disease: An Overview. *Surg Clin North Am*. 2007;87:575-585.

41. Paine CW, Stollon NB, Lucas MS, et al. Barriers and Facilitators to Successful Transition from Pediatric to Adult Inflammatory Bowel Disease Care from the Perspectives of Providers. *Inflamm Bowel Dis*. 2014;20(11):2083-2091.

42. Pearlstein H, Afzali A, Bricker J, et al. Predicting sub-optimal transitions in adolescents with inflammatory bowel diseases. *Gastroenterol*. 2020;158(6):S-966.

Chapter 3. Defining Transition Success for Young Adults with Inflammatory Bowel Disease According to Patients, Parents, and Health Care Providers.

This manuscript has been published in the Journal of Canadian Association of Gastroenterology Lippincott Williams & Wilkins. Doi: 10.7/1MPG.0000000000003581

Authors: Allison Bihari, Nima Hamidi, Cynthia H. Seow, Karen J. Goodman, Eytan Wine, Karen I. Kroeker.

3.1 Abstract:

Background: The transition from pediatric to adult care is associated with changes centered around the patient taking responsibility for their health. As the incidence of childhood-onset inflammatory bowel disease (IBD) is increasing, it is important to address gaps in transition literature – specifically, the indicators signifying achievement of transition success. The study objective was to define transition success according to health care providers, patients, and parents involved in IBD transition.

Methods: This study used the method of qualitative description to conduct semi-structured interviews with health care providers, patients, and parents. During interviews, demographic information was collected, and interviews were recorded and transcribed. Data analysis was conducted independently of each group using latent content analysis. Participant recruitment continued until thematic saturation was reached within each group.

Results: Health care providers, patients, and parents all defined transition success with the theme of independence in one’s care. The theme of disease management emerged within parent and provider groups, while the theme of relationship with / trust in adult care team was common to patients and parents. Additional themes of care team management, general knowledge, care stability, and health outcomes emerged within specific groups.

Conclusions: This study demonstrated differences between how health care providers, patients, and parents view transition success. This finding reveals the value of using a multifaceted definition of transition success with input from all stakeholders. Further research prioritize the identification of factors common to patients who do not reach transition success as defined by patients, their parents, and providers.

3.2 Introduction

Patients with inflammatory bowel disease (IBD) diagnosed in childhood or adolescence need to adjust to the changes of moving from pediatric to adult care. This period of gradual change of care from the pediatric system where the emphasis is on parental involvement to the adult system where patient independence is essential is known as transition of care[1,2]. During transition, patients begin to take responsibility for their health rather than relying on parents or caregivers for disease management[3]. Transition often overlaps with life events such as starting postsecondary schooling or employment, moving out or away from family, and financial independence[1,4]. These additional stressors may diminish patients' ability to take responsibility for their own health by contributing to feelings of being overwhelmed.

IBD presents most commonly in the mid-20s and 30s[5]; however, approximately 25% of patients are diagnosed in childhood[6,7,8.] Further, the incidence of childhood-onset IBD is increasing in western countries[5,9,10]. When compared to those diagnosed as adults, patients diagnosed in childhood present more often with extensive disease, and more frequently having perianal disease and/or upper gastrointestinal involvement[2,11]. Additionally, these patients are more likely to be admitted to hospital and less adherent with clinic appointments[2,12]. Due to the risks and complexity of a pediatric IBD diagnosis, a smooth, uninterrupted transition to adult care should be a priority.

Within the literature, the importance of transition readiness has been widely recognized[6,13] and while most studies have highlighted the specific skills needed to be successful, they tend to not specifically define a successful transition[14,15,16]. Because transition is a collaborative process involving the coordination of multiple stakeholders[17], a robust and comprehensive definition of success could be developed by engaging key stakeholders. We conducted this research based on the belief that establishing effective recommendations for defining transition success requires consulting patients, their parents, and health care providers.

3.3 Methods

3.3.1 Study Design

This study used naturalistic inquiry to address the research question: "What is transition success according to health care providers, patients, and parents involved in IBD pediatric to adult care transition?". Naturalistic inquiry aims to study events in their natural state with no pre-selection or manipulation of variables[18,19]. In theoretical alignment with this approach, qualitative description is considered the best method for this study[18]. The goal of qualitative description is to stay close to the data by presenting facts in everyday language[18,20,21]. This study was conducted by a student researcher (AB) as part of a graduate thesis.

3.3.2 Study Population

This study recruited participants using purposive sampling from three different stakeholder groups – health care providers, patients, and parents[22]. Participants were recruited from IBD clinics in Edmonton and Calgary, Alberta, Canada. Additional providers were recruited from British Columbia, Canada. Patients were identified through clinical records if they had transitioned to adult care from 2018 – 2020 and if they were diagnosed with IBD at least a year prior to transitioning. Patients were excluded if they had comorbidities unrelated to IBD. Parents of these patients were excluded if they had another child with a chronic disease other than IBD as it may be difficult to separate their experience with their other child. Providers included were pediatric and adult gastroenterologists or nurses with at least one-year experience.

3.3.3 Data Collection

Patients were approached in clinic by their gastroenterologist. Those who consented to being contacted were called by AB to further inform them about the study and answer any questions. Patients were informed that parents were also being recruited and if parents were interested, they should contact AB. Providers with expertise in patients transitioning to adult care were recommended by the study's authors. Providers were then contacted via email about study participation. All participants who expressed interest were emailed a recruitment letter, study information sheet, and a consent form (**Appendix B**). After participants had time to read the material and ask any additional questions, a semi-structured interview was conducted either through Skype for Business™, Google Meet™, or telephone, according to the preference of the participant. During the scheduled interview time, verbal consent was obtained and demographic information was collected. All interviews were conducted by AB, tape-recorded, and transcribed verbatim for data analysis using Microsoft® Word 2010.

A separate interview guide was developed for each stakeholder group to achieve the aims: 1. to describe the stakeholders' perspectives on what a successful transition looks like, and 2. to describe stakeholders' beliefs on how successful transition impacts long-term health outcomes and daily life. The interview guides are in **Appendix C.**

3.3.4 Data Analysis

Data analysis was done concurrently with data collection using NVivo 1.2™ (QSR International Pty Ltd, Melbourne, Australia)[23]. This allowed for the identification of any areas that needed to be explored in subsequent interviews. Analysis of the transcribed interviews was done separately within each stakeholder group using latent content analysis, which is the process of identifying, coding, and categorizing patterns in the data[24,25]. During the coding, AB highlighted sections of the transcribed interviews while making comments in the margins about what was salient in the data. When new codes emerged from subsequent interviews, all previously coded interviews were re-coded to reflect these new codes. Once no more codes seemed to emerge from the data, the researcher moved to grouping the codes into categories. After checking that the codes fit within categories with a critical friend[24], themes were formed to reflect how the categories related to one another. The role of a critical friend is to engage in ongoing discussions during analysis to ensure that conclusions come from interview data rather than the researcher's assumptions. Additionally, all themes were then reviewed with AB's supervisor – a gastroenterologist with direct experience caring for transitioning patients (KK) – to ensure conclusions were plausible. Recruitment was terminated within each group when thematic saturation was reached[26]. Saturation is reached when there are no more themes emerging from the data[24,27]. The identification of indicators that signify achievement of a successful transition were based on analysis of participants' responses to questions about the key indicators they believe signify success, and/or the indicators that signify that their transition was successful.

3.3.5 Establishing Trustworthiness

In qualitative research, the concept of rigor is suggested to be replaced with trustworthiness[28]. Lincoln and Guba suggest four criteria for ensuring trustworthiness: credibility, transferability, dependability, and confirmability[28]. Credibility was ensured through use of a critical friend (peer debriefing) and verifying/checking interpretations with participants throughout the interview. Transferability was addressed through providing a detailed description of the participants and setting of interviews. Dependability and confirmability was achieved through an audit trail where AB documented decisions, choices, and insights as it related to the study. Further, this study was conducted by a graduate student (AB). AB practiced reflexivity throughout the study. As AB was in her mid-20s, time was spent reflecting on personal difficulties becoming an adult to ensure that any preconceived opinions did not influence the data. She also engaged in field notes after each interview to address any bias or opinions starting to form.

3.4 Results

3.4.1 Participant Demographics

Thematic saturation was achieved after seventeen interviews in the patient group, thirteen in parent group, and fifteen in the provider group. The median interview length for patient interviews was 29 minutes (IQR: 25 – 33); parent interviews was 35 minutes (IQR: 29 – 40);

provider interviews was 30 minutes (IQR: 27 – 40). Demographics for each group are outlined in **Table 3.1**.

Table 3.1. Demographics of Patients, Parents, and Health Care Providers who Participated in Semi-Structured Interviews

Demographics	Total N	n (%)
Patients	17	
Sex		
Female		10 (58.8)
Male		7 (41.2)
Diagnosis		
Crohn's		9 (52.9)
Ulcerative Colitis		8 (47.1)
Age at Diagnosis		
0 – 4		0 (0)
5 – 9		2 (11.8)
10 – 14		5 (29.4)
15 – 17		10 (58.8)
Location of Clinic		
Edmonton		8 (47.1)
Calgary		9 (52.9)
Occupation		
Post-secondary student		10 (58.8)
Continuing education student		2 (11.8)

Full-time employment		5 (29.4)
Parents	13	
Relationship to Patient		
Mother		13 (100)
Father		0 (0)
Child Living Situation		
Lives with parent		4 (26.7)
Does not live with parent		9 (69.2)
Highest Education Level Attained		
High school		5 (38.5)
Certificate		2 (15.4)
Diploma or undergraduate degree		5 (38.5)
Master’s degree		1 (7.7)
Providers	15	
Sex		
Female		11 (73.3)
Male		4 (26.7)
Location		
Calgary, Alberta		5 (33.3)
Edmonton, Alberta		6 (40.0)
British Columbia		4 (26.7)
Job Title		
Adult Gastroenterologist		5 (33.3)
Pediatric Gastroenterologist		2 (11.8)
Adult IBD nurse		6 (40.0)

Pediatric IBD nurse	1 (6.7)
Years of Experience	
0 – 5	2 (13.3)
6 – 10	6 (40.0)
11 – 15	4 (26.7)
16 – 20	1 (6.7)
21 – 25	1 (6.7)
26 – 30	1 (6.7)

3.4.2 Transition Characterization

Patients and parents were asked if they would characterize their/their child's transition as successful or unsuccessful. Of the seventeen patients interviewed, sixteen indicated that they viewed their transition as successful. Ten parents thought that their child's transition was successful, while two thought it was unsuccessful, and one was undecided.

3.4.3 Themes of Transition Success

Seven themes emerged from the interviews across the three groups: 1) independence in one's care, 2) disease management, 3) relationship with / trust in adult care team, 4) care team management, 5) general knowledge, 6) care stability, and 7) health outcomes. An additional theme of the impact of transition emerged within the interviews. Overlapping and themes exclusive to stakeholders are represented in a Venn diagram (**Figure 3.1**). Representative quotes from each theme have been outlined (**Table 3.2**).

Figure 3.1 Venn Diagram Showing Themes of Transition Success that Emerged within each Stakeholder Group

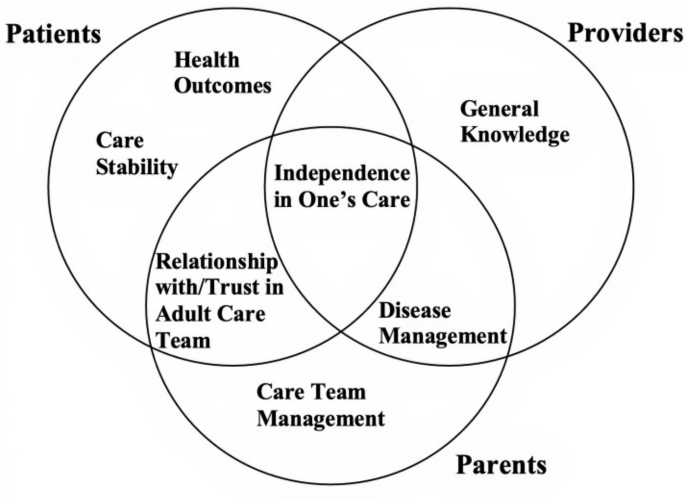


Table 3.2. Representative Quotes from each Theme According to Patients, Parents, and Health Care Providers.

Theme	Group	Quotations
Independence in One's Care	Patients	"It's nice having more responsibility with my appointments… when I get news and stuff, I get the phone calls and it's not to my mom anymore." "I would say ya defiantly be more a part of your care, not saying that as a pediatric patient you can't but be really constant in your own care and ask as many questions as you need to, whether it is about the care you'll be getting or if you have concerns about your health and just ask questions and be part of your own care as much as possible."

		"Someone who is defiantly more aware of their body and who is checking in with themselves, who can take that responsibility because… you're not a kid anymore you can check in with yourself being prepared and comfortable doing that"
	Parents	"… the amount of administrative work on part of patient to manage setting up all appointments and making sure blood tests are done and making sure that you know all stool samples are done and sent in and correctly done." "I think it is booking their appointments, going to the doctors on their own - maybe procedures on their own"
	Health Care Providers	"Taking on that care versus having mom and dad tell them to do everything." "Patient is booking their own appointments, attending all those appointments and not missing them." "Advocate for themselves is also important right and not relying on their parents to be their voice."
Disease Management	Parents	"That they will call and make an appointment when they are not feeling well." "She is finally on a medication that works."
	Health Care Providers	"They are taking their medications as they are prescribed, they know how to refill their medications and can keep track of that."

		"Basically, compliant with all the factors that they have to do with managing their disease - educated on it, being compliant with their infusions, labs and appointments and side effects, being aware of what triggers to look for, what side effects and when to call for help and therefore, avoiding flares, hospitalizations and more recent flares"
Relationship with / Trust in Adult Care Team	Patients	"I can be open to talk and not be judged because I know that she knows it's tough going through transition from like doctor to doctor and she wanted to make sure I felt comfortable."
		"I have found a doctor that doesn't have that judgement and understands that like I'm younger and trying to deal with it all."
		"She asks not just how I'm doing with my disease but my personal life, so I thought that was very reassuring."
		"I just really wanted a doctor that I was as close and comfortable with and someone who got to know me on a personal level"
		"The feeling of them taking the time to care. It's not just a job to them, they care for sure."
	Parents	"We've found a doctor who we liked, who jived with us. We didn't ever once feel like we were out of place with that doctor …"

		"Well, she has found a physician she is comfortable with. Flat out being the nurse that she speaks to and where she goes is exceptional and has taken her concerns seriously." "I would define it as gaining good rapport to all of the doctors."
Care Stability	Patients	"There being no drop off and your own health because of the change. I think that there should be same amount of contact with doctors" "The nurse checks up on me here and there and I haven't found that I have slipped through the cracks, which I heard can happen to kids." "Constant contact is still there and any issues I've had are addressed. I never felt like my health has gotten out of control because I didn't have access to anything." "They just never stopped being continuous with how I am feeling even if it is like they don't see me for six months they stay on top of that kind of stuff, which is great."
Health Outcomes	Patients	"I don't think my symptoms deteriorated in anyway…" "I never felt like my health has gotten out of control…" "I was hoping was that I could be in remission and just get it all under control."

Care Team Management	Parents	“There was really not one blip in his care. Not one missed Remicade because no communication.” “They made it easy – ‘oh he is going to school?’ ‘Yup’ ‘We can work this around his school schedule. We can work it around where he is living.’”
General Knowledge	Health Care Providers	“What is their overall understanding of medications if they are on medications in terms of the overall safety and effectiveness of those medications.” “He knew the importance of how these medications can maintain health and prevent any complications of his Crohn’s disease and we had a very successful transition.” “Having knowledge about what their disease is, and you know past medications and experiences that they’ve had related to disease and being able to talk openly about it,”

Independence in One’s Care

Independence in one’s care was a theme that emerged across all groups as an indicator of successful transition. Seven parents, twelve patients, and thirteen providers mentioned this theme. All groups mentioned the ability for patients to take responsibility and initiative for their care, including being able to self-advocate and ask questions. Additionally, patients making and attending appointments and having an awareness of what is happening in their care was deemed important. Nine of the providers interviewed emphasized the ability of patients to attend appointments on their own.

Disease Management

Eleven providers and seven parents described disease management as an indicator. This was characterized as patients adhering to prescribed medications and lab tests requested by providers, refilling prescriptions, and having the confidence to reach out when experiencing a disease flare up. Parents also highlighted the importance of being on medication that worked for the patient.

Relationship with / Trust in Adult Care Team

Twelve patients and nine parents described relationship with / trust in the adult care team as an indicator. Patients reported feeling comfortable with their new care team, that they cared, took the time to get to know them, and was supportive of them as an indicator. Similarly, nine parents communicated that trusting and feeling comfortable with the new care team were indicators.

Care Team Management

Five parents mentioned how the adult care team managed their child's IBD as a determinant of transition success. Specifically, parents indicated that success required a care team that understood that their child was coming from a different care system and might need additional guidance and support. One parent described their child's adult care team as being flexible about the demands of attending post-secondary education. Additionally, parents thought attentiveness and regular follow up from the team were important determinants of a successful transition.

General Knowledge

Seven providers mentioned general knowledge was key. The patient having knowledge and an understanding of their current and past medication and disease history was mentioned by five providers.

Care Stability from Provider

Seven patients highlighted having a doctor who is readily available and regularly checks in to provide consistent follow up. Six patients further described a continuity of care in terms of no loss to follow up from pediatric to adult care.

Health Outcomes

Thirteen patients mentioned their health remaining stable as an indicator. Patients also mentioned that finding and adhering to the appropriate medication for controlling their disease was important. Two of these patients who were not in remission at time of transition said they were hoping to reach remission by the end of transition and that would indicate successful transition.

3.4.4 Impact of Transition

Providers highlighted that achieving success in transition will serve as a foundation in the patient’s care. They mentioned that patients will know who to reach out to when they encounter health problems, have more confidence, feel more supported in their care, and adhere to medications. Providers and patients said they believed that unsuccessful transition could impact a patient’s mental health through increasing both general and social anxiety, and feelings of depression. All groups said they believed that if transition is unsuccessful, a patient would likely experience health deterioration such as more frequent disease flare ups, abdominal pain, and disease progression with the eventual need of therapy escalation. All groups expressed the belief that health deterioration lowers the quality of life through more frequent feelings of tiredness, stress, and low energy levels. All groups indicated that such feelings would negatively impact patients’ employment, schooling, and relationships. One patient speculated that if their transition had been unsuccessful, “I would probably be very much struggling in school. There is no way I would keep up with sports and I think that I would just sleep all day…”. Another patient said “I think it would be difficult every day. When I have a flare, I don’t have energy to do school, I don’t feel comfortable leaving the house...”.

3.5 Discussion

This qualitative description study is the first to engage multiple stakeholders involved in IBD care using semi-structured interviews. We identified seven themes to define successful transition; some of which have been identified in other studies. Van den brink et al., conducted a three stage Delphi study with patients and providers to identify indicators of successful transition in IBD[29].

Their study demonstrated a unified agreement on six items related to self-management skills and autonomy, and two items related to health-related quality of life and patient satisfaction about the transition process. Self-management skills and autonomy showed similarity to our theme of independence in one's care. In this Delphi study, patients and providers rated "independent attendance at outpatient clinic" low when compared to the other items. In our study, providers emphasized the ability of patients to attend appointments alone. This difference may reflect cultural differences as most participants for the Delphi study were recruited from Europe, whereas our study recruited participants from Western Canada.

Our provider interviews revealed themes of independence in one's care, disease management, and general knowledge, similar to other published studies in IBD and sickle cell disease[30,31]. These studies revealed themes of health care utilization, health outcomes, quality of life, and a stable disease trajectory. The theme of health care utilization had similar components to our theme of independence in one's care and disease management because it incorporated the importance of the patient making and attending appointments, having recommended lab tests, and adhering to medications. Health outcomes was a theme that emerged with patients and was similarly characterized as health remaining stable throughout transition. Although the theme of quality of life did not emerge in our study as an indicator of success, it was highlighted as being influenced by successful transition.

Compared to a United States (US) study that interviewed providers, patients, and parents about transition success in type 1 diabetes, our results demonstrated some parallels with similar categories of appointment attendance and disease knowledge[32]. Another theme that emerged, described as navigating a new health care system, was characterized in part by forming a relationship with the adult provider. Our analysis identified relationship and trust as a theme in and of itself, our participants may have more strongly emphasized its importance. The US study identified additional themes: balancing care with other adult roles, such as socializing and schoolwork; and taking ownership for their disease. Several differences between the US study of diabetic patients and our study of IBD patients should be highlighted. The age range of participants in the US study was 18-25 years, in contrast to our study with 18-20 years. In the US, pediatric patients can transition to adult care into their 20s, while in Canada, patients need to transition before their 18th birthday. As a result, patients from the US study may be more mature and may have developed greater independence prior to transitioning. Additionally, the US study combined interviews across stakeholder groups to determine when saturation was reached (themes potentially being driven by a dominant group), while we aimed to achieve saturation within each stakeholder group, potentially resulting in more consensus within each stakeholder group and more divergence across groups.

This research highlights the differences between how each stakeholder group characterizes successful transition. We believe that a key difference is the theme of relationship with / trust in the adult care team, which was common to patients and parents. When interviewed, many participants commented on the close relationship they had with their pediatric team and how they had hoped to develop a similar relationship with the adult team, which echoes the literature on transition in chronic diseases[33,34]. Adult care providers who strive to offer successful transition experiences could prioritize getting to know their transitioning patients and striving to make them feel understood. Transitioning patients who feel that they have developed a secure relationship with their new team may reach out earlier when they have a concern related to their disease.

The finding that different themes emerged from the stakeholder groups suggest that only focusing on the opinions of one group could result in a failure to recognize themes important to other stakeholders. Although health outcomes were a theme that emerged within the patient stakeholder group, most providers cautioned against using this as a sole measure of transition success. Specifically, providers pointed out the natural fluctuations of disease activity[35] and how a patient who has had a smooth transition may still experience a disease flare up. A comprehensive assessment of transition success, therefore, should use health outcomes in conjunction with the other themes of success, such as those identified in this study.

Selection bias is a potential limitation to this study. Individuals who viewed their transition as successful may have been more likely to agree to participate, whilst those who viewed their transition as unsuccessful may have declined to participate, perhaps wanting to avoid reflecting on this experience. All health care providers specialized in IBD and so these results may not reflect the opinions of general gastroenterologists. Further limitations include only mother’s perspectives within the parent stakeholder group, and absence of information about ethnicity/race or socioeconomic status.

The strength of this manuscript is that it explores the various stakeholders' perspectives on indicators of successful transition. We recommend that future research focuses on measuring the identified indicators – potentially through administering a questionnaire with quantifiable scales or indices. This definition of transition success should be used both clinically to ensure patients have achieved success and in research to systematically evaluate transition interventions to allow for the development of an optimal transition program. Future research should also attempt to identify factors that impede transition success and hopefully provide the opportunity to meaningfully intervene to facilitate a successful transition.

3.6 References

1. Afzali A, Wahbeh G. Transition of pediatric to adult care in inflammatory bowel disease: Is it as easy as 1, 2, 3? *World J Gastroenterol*. 2017;23:3624-3631.

2. Goodhand J, Dawson R, Hefferon M et al. Inflammatory bowel disease in young people: the case for transitional clinics. *Inflamm Bowel Dis*. 2010;16:947-952.

3. Philpott JR. Transitional care in inflammatory bowel disease. *Gastroenterol Hepatol*. 2011;7:26-32.

4. Soanes C, Timmons S. Improving transition: a qualitative study examining the attitudes of young people with chronic illness transferring to adult care. *J Child Health Care*. 2004;8:102-112.

5. Carroll MW, Kuenzig ME, Mack DR et al. The impact of inflammatory bowel disease in Canada 2018: children and adolescents with IBD. *J Can Assoc Gastroenterol*. 2019;2:S49- S67.

6. Gray WN, Holbrook E, Morgan PJ et al. Transition readiness skills acquisition in adolescents and young adults with inflammatory bowel disease: findings from integrating assessment into clinical practice. *Inflamm Bowel Dis.* 2015;21:1125-113.

7. Goodhand J, Hedin CR, Croft NM et al. Adolescents with IBD: The importance of structured transition care. *J Crohns Colitis*. 2011;5:509-519.

8. Van den Brink G, van Gaalen MAC, Zijlstra M et al. Self-efficacy did not predict the outcome of the transition to adult care in adolescents with inflammatory bowel disease. *Acta Paediatr*. 2019;108:333-338.

9. Benchimol EI, Manuel DG, Guttmann A et al. Changing age demographics of inflammatory bowel disease in Ontario, Canada: a population-based cohort study of epidemiology trends. *Inflamm Bowel Dis*. 2014;20:1761-1769.

10. Benchimol EI, Fortinsky KJ, Gozdyra P et al. Epidemiology of Pediatric Inflammatory Bowel Disease: A Systematic Review of International Trends. *Inflamm Bowel Dis*. 2011;17:423-439.

11. Guariso G, Gasparetto M, Visona Dalla Pozza L et al. Inflammatory Bowel Disease Developing in Paediatric and Adult Age. *J Pediatr Gastroenterol Nutr*. 2010;51:698-707.

12. Kappelman MD, Rifas-Shiman SL, Porter CQ. Direct Health Care Costs of Crohn’s Disease and Ulcerative Colitis in US Children and Adults. *Gastroenterol.* 2008;135:1907-1913.

13. Maddux MH, Ricks S, Bass J. Patient and Caregiver Perspectives on Transition and Transfer. *Clin Pediatr*. 2017;56:278-283.

14. Gray WN, Reed-Knight B, Morgan PJ et al. Multi-site comparison of patient, parent, and pediatric provider perspectives on transition to adult care in IBD. *J Pediatr Nurs*. 2018;39:49-54.

15. Sebastian S, Jenkins H, McCartney S et al. The requirements and barriers to successful transition of adolecents with inflammatory bowel disease: Differing perceptions from a survey of adult and paedriatric gastroenterologists. *J Crohns Colitis*. 2012;6:830-844.

16. Hait EJ, Barendse RM, Arnold JH. Transition of adolescents with inflammatory bowel disease from pediatric to adult care: a survey of adult gastroenterologists. *J Pediatr Gastroenterol Nutr*. 2009;48:61-65.

17. Schwartz LA, Tuchman LK, Hobbie WL et al. A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. *Child Care Health Dev*. 2011;37:883-895.

18. Sandelowski M. Whatever Happened to Qualitative Description? *Res Nurs Health*. 2000;23:334-340.

19. Lincoln YS, Guba EG. Naturalistic Inquiry. Sage Publications: Newbury Park, 1985.

20. Neergaard MA, Olesen F, Andersen RS et al. Qualitative description – the poor cousin of health research? *BMC Med Res Methodol*. 2009;9:1-5.

21. Sandelowski M. What's in a Name? Qualitative Description Revisited. *Res Nurs Health*. 2010;33:77-84.

22. Bernard HR. Research methods in anthropology: Qualitative and quantitative approaches, 3rd edn. Alta Mira Press: Walnut Creek, 2002.

23. NVivo qualitative data analysis software [computer program] Version 1.2. Melbourne, Australia: QSR International Pty Ltd, 2012.

24. Mayan MJ. Essentials in qualitative inquiry. Left Coast Press: Walnut Creek, 2009.

25. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*. 2004;24:105-112

26. Charmaz K. 'Grounded Theory: Objectivist and Constructivist Methods', in N.K. Denzin and Y.S. Lincoln (eds) Strategies for Qualitative Inquiry, 2nd edn. Sage Publications: Thousand Oaks, 2003.

27. Morse JM, Barrett M, Mayan M et al. Verification strategies for establishing reliability and validity in qualitative research. *Int J Qual Methods*. 2002;1:1-19.

28. Lincoln YS, Guba EG. But is it rigorous? Trustworthiness and Authenticity in Naturalistic Evaluation. *New Dir Eval*. 1986;1986:73-84.

29. van den Brink G, van Gaalen M, de Ridder L et al. Health care transition outcomes in inflammatory bowel disease: A multinational Delphi Study. *J Crohns Colitis*. 2019;13:1163-1172.

30. Paine CW, Stollon NB, Lucas MS et al. Barriers and Facilitators to Successful Transition from Pediatric to Adult Inflammatory Bowel Disease Care from the Perspectives of Providers. *Inflamm Bowel Dis*. 2014;20:2083-2091.

31. Stollon NB, Paine CW, Lucas MS et al. Transitioning adolescents and young adults with sickle cell disease from pediatric to adult healthcare: Provider perspectives. *J Pediatr Hematol Oncol*. 2015;37:577-583.

32. Pierce JS, Aroian K, Schifano E. Health Care Transition for Young Adults with Type 1 Diabetes: Stakeholder Engagement for Defining Optimal Outcomes. *J Pediatr Psychol*. 2017;42:970-982.

33. Karim S, Porter JA, McCombie A et al. Transition clinics: An observational study of themes important to young people with inflammatory bowel disease. *Transl Pediatr*. 2019;8:83-89.

34. Reiss JG, Gibson RW, Walker LR. Health Care Transition: Youth, Family, and Provider Perspectives. *Pediatr*. 2005;115:112-120.

35. Thoreson R, Cullen JJ. Pathophysiology of Inflammatory Bowel Disease: An Overview. Surg *Clin North Am*. 2007;87:575-585.

Chapter 4. Perspectives of Patients, Parents, and Health Care Providers on Barriers and Facilitators of the Transition from Pediatric to Adult Care in Inflammatory Bowel Disease: A Qualitative Descriptive Study

This manuscript has been published as an advanced article in the Journal of Canadian Association of Gastroenterology Lippincott Williams & Wilkins.

Authors: Allison Bihari, Eytan Wine, Cynthia H. Seow, Karen J. Goodman, Karen I. Kroeker.

4.1 Abstract:

Background: The typical transition from pediatric to adult care in patients with inflammatory bowel disease occurs with an increase in health care utilization and a decrease in adherence to scheduled appointments and medication. An effective transition could reduce negative impacts but requires identifying opportunities to improve this process. This study aims to describe barriers and facilitators of transition according to patients, parents, and health care providers.

Methods: This study used a qualitative description approach. The lead author conducted semi-structured interviews with 17 patients, 13 parents and 15 providers recruited from Western Canada. Latent content analysis identified themes in interview transcripts.

Results: The theme of preparedness emerged across all groups as a transition facilitator. Other facilitators that emerged included patient characteristics, supportive parents, home environment, and supportive adult care team. Themes of barriers that emerged included patient factors, ‘hovering parents’ and family factors, navigating a new health care system, and travel distance.

Conclusions: This study describes barriers and facilitators according to each stakeholder involved in the transition process. Future studies should focus on designing and evaluating interventions aimed at addressing identified barriers and promoting facilitators in patients preparing to transition from pediatric to adult care.

4.2 Introduction

Transition, defined as “the purposeful, planned movement” from pediatric to adult care, is a critical step in the journey of patients diagnosed with a chronic disease in childhood[1]. While transition is a gradual process of changing care, transfer refers to the actual movement from pediatric to adult care[2]. During transition, young adults with chronic diseases need to assume responsibility for disease management - a role typically held by their parents. Parents of young adults with chronic diseases simultaneously undergo a transition that requires them to support and facilitate the transfer of responsibility to their child[3,4]. This is a vulnerable time when they may experience emotional and psychological challenges as they adapt to a new health care team and care setting[5]. Specifically, in inflammatory bowel disease (IBD) transition typically occurs with an increase in health care utilization [emergency department (ED) visits] and a decrease in adherence to scheduled appointments and medication[6-10].

In Canada, ~10-15% of IBD patients are diagnosed before 18 years old[11]. Further, the number of IBD cases diagnosed during childhood is predicted to triple between 2008 and 2030[12]. Due to this projected increase in the prevalence of IBD, there is an emphasis on young adults with IBD undergoing appropriate transitioning from the pediatric to the adult healthcare system[13,14]. Therefore, improving the transition process is currently of great relevance to the field of IBD.

Studies of barriers to and facilitators of transition from pediatric to adult IBD care have typically explored one point of view: that of patients or health care providers. Because transition is a collaborative process involving patients, parents, and providers, comprehensive identification of transition barriers and facilitators requires considering perspectives of all stakeholders.

This study addresses existing limitations by describing reported transition barriers and facilitators according to patients, parents, and providers. This knowledge will be useful for clinicians providing care for transitioning patients and designing transition interventions that acknowledge and address barriers and facilitators from the perspectives of diverse stakeholders.

4.3 Methods

4.3.1 Study Design and Aims

The current analysis is part of a study for which the primary author (A.B.) conducted interviews with the primary aim of defining IBD transition success from the perspective of patients, parents, and providers[15]. This analysis used a qualitative descriptive approach to provide a rich account of the phenomenon of transition from pediatric to adult care[16,17]. This approach allowed the authors to address the additional research question: “What are the facilitators and barriers to achieving a successful transition according to patients, parents, and health care providers?”. The study was approved by all site research ethics boards (University of Alberta: Pro00099184; University of Calgary: REB20-0979; University of British Columbia: H20-01722). We used the standards for reporting qualitative research (SRQR) to guide the reporting of results[18].

4.3.2 Settings and Recruitment

We recruited IBD providers, patients, and their parents from IBD clinics in Edmonton and Calgary, Alberta, Canada using purposive and snowball sampling. Providers were additionally recruited from British Columbia. Details of participant recruitment are published[15]. We included patients if they transferred to adult care within the preceding two years and had been diagnosed with IBD for at least a year before transfer. Providers were included if they had at least one year of experience caring for IBD patients. Patients were excluded if they had comorbidities unrelated to IBD. No parents met the exclusion criterion of having another child with a chronic disease other than IBD.

4.3.3 Trustworthiness and Positionality Statement

Efforts to ensure trustworthiness were guided by criteria from Lincoln and Guba[19]. Lincoln and Guba suggest the criteria of credibility, transferability, dependability, and confirmability for promoting trustworthiness in qualitative research. **Table 4-1** outlines the steps taken to ensure each of the above criteria was met.

Table 4.1. Criteria of Credibility, Transferability, Dependability, and Confirmability

Criteria	**Steps taken**
Credibility	*Peer debriefing:* Regular discussions with the authors focused on ensuring plausibility of the themes and limit the influence of the coding author's biases on the formation of codes and themes. *Member checking:* During interviews, A.B verified interpretations with the participants to ensure accuracy in meaning.
Transferability	*Rich description:* A detailed description of participants and settings of the interview was provided in both this manuscript and in the original article.
Dependability	*Audit Trail:* Decisions, choices, and insights related to the study were documented, including materials, such as interview transcripts.
Confirmability	*Reflexivity:* A.B engaged in field notes directly after each interview and focused on documenting interview setting, overall impression, and any opinions and bias forming from the interview. Additional efforts to practice self-reflexivity included the documentation of A.B's positionality statement.

Positionality Statement

The first author (A.B) is a female, who was in her mid-20s at the time of conducting the interviews and had taken a course on qualitative research during her graduate degree. A.B approached this research from an outsider perspective, not having experience with a chronic disease, being a parent, nor a health care provider. A.B did however have experience with the transition to becoming a young adult and moving out to pursue post-secondary schooling; therefore, self-reflexivity efforts focused on acknowledging personal opinions on barriers and facilitators to young adulthood to prevent its influence on the data. Further, A.B had no prior relationship with any of the study participants. E.W, C.H.S, and K.I.K had prior relationships with the providers interviewed (colleagues) and patients in their role as clinicians. To prevent potential influence of these relationships on the data, none of these authors were involved in the data collection and participants were made aware of the confidentiality of their answers. Ongoing meetings with the study team ensured that personal opinions on barriers and facilitators as clinicians caring for transitioning patients served to confirm the plausibility of the themes, but not the creation of themes.

4.3.4 Data Collection and Analysis

Separate interview guides were developed for each stakeholder group with consultation from an expert in qualitative research. IBD clinicians (E.W, C.S, K.K) reviewed the guides for content. A.B conducted interviews virtually between June 2020 and March 2021. Interviews were recorded and transcribed verbatim. A.B used latent content analysis to analyze interviews with NVivo 1.2™[20]. Latent content analysis uses a process of identifying, coding, and categorizing patterns within discursive data from transcribed interviews until themes emerge[21]. A.B analyzed interviews concurrently with data collection and coded interviews independently within each stakeholder group. Interviews were analyzed at the same time for the primary aim of defining transition success and for the aims specific to this study. For this study, questions analyzed included asking each stakeholder to describe facilitators and barriers to either their/their child's/patient's transition (when applicable) and then to transition in general. Participant recruitment concluded when saturation was achieved for the study's primary aim.

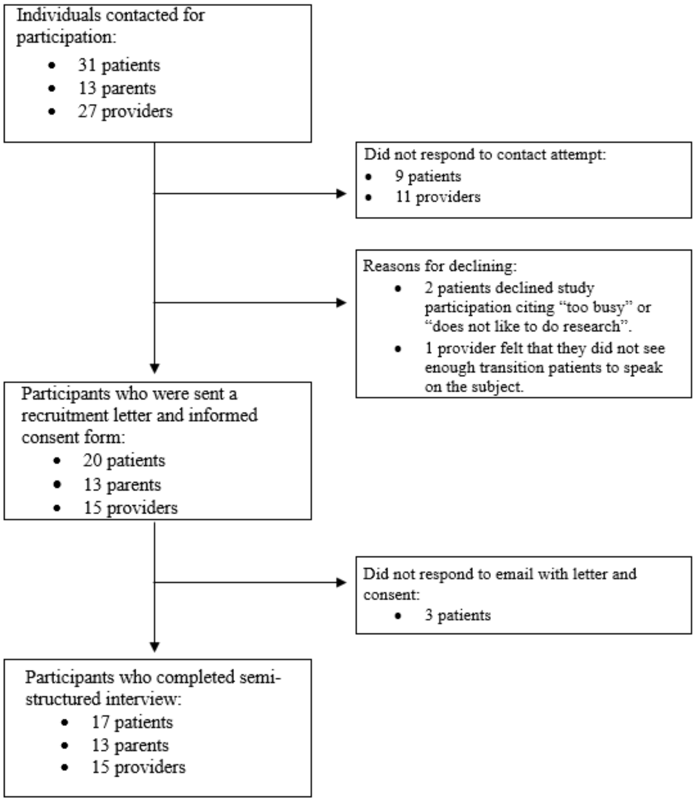
4.4 Results

4.4.1 Participants

31 patients, 13 parents, and 27 providers were initially contacted for study participation. Of these stakeholders, 9 patients and 11 providers could not be reached, while 5 patients and 1 provider declined study participation. 17 patients, 13 parents, and 15 providers participated in an interview. **Figure 4.1** provides a flowchart of participant recruitment including reasons for declining participation when available. Participant demographics have been outlined[15]. In brief, 58.8% of patients were female sex, 52.9% had Crohn's disease, and 58.8% were diagnosed between the ages of 15-17. At the time of interview, 29.4% of patients were on biologic medications; 17.6% on either 5-ASA or an immunosuppressant; 41.1% on a combination biologic; 5.9% not on medication. Although not directly asked, 3 patients mentioned having had a surgery for their IBD. All 13 parents were mothers of IBD patients, 10 parent-patient dyads

participated, and 61.5% of parents did not have their IBD child living with them at the time of interview. Five providers were adult gastroenterologists; 2 were pediatric gastroenterologists; 6 were adult IBD nurses; 1 was a pediatric IBD nurse.

Figure 4.1. Flowchart of Participant Recruitment



4.4.2 Facilitators

We asked stakeholders to describe facilitators of successful transition. Themes included preparedness, supportive adult care team, patient characteristics, and supportive parents and home environment. Facilitator themes are represented in **Figure 4.2** and quotations are in **Table 4.2**.

Preparedness

Patients (7/17), parents (7/13), and providers (6/15) mentioned preparedness for transition as a facilitator. Patients gave examples of preparedness such as patients speaking for themselves in pediatric care, asking questions about adult care, and knowing the differences between pediatric and adult care (e.g., frequency of appointments) and being able to report their disease management/history accurately.

Parents suggested that there be an overlap between pediatric and adult care and/or their child having a visit with the adult care team before transferring to adult care. They pointed out that an overlap would allow for transitioning patient to feel prepared for adult care. Parents also described being mentally prepared for changing care. One parent mentioned how their child's pediatric doctor talked positively about the adult doctor, which helped make them and their child feel more prepared to transition. Three parents suggested that there be a peer support program so patients could ask questions to patients who already transitioned. Parents suggested that counseling be available to help transitioning patients cope with changes in care.

Providers defined preparedness as patients knowing about their disease and how the pediatric and adult care systems differed (e.g., appointment frequency, endoscopy sedation, etc.). One provider mentioned that prepared patients would know the expectations of patients in adult care (e.g., attending appointments independently).

Supportive Adult Care Team

Ten patients and four parents mentioned the adult care team as a facilitator of successful transition. Patients gave examples such as feeling that their adult care team cared about them, made them feel welcome, and ensured that they understood their care plan. Patients described a supportive adult team as providing regular follow-up to the patient, maintaining open lines of communication, and being responsive to the patient's questions. Logistic facilitators included an adult team who offered the patient a first visit before their 18th birthday and an appointment routine that was like their pediatric appointment routine. Patients described the location of their adult care appointments as a facilitator. For example, appointments that were in the same hospital as their pediatric clinic or easy to get to with public transportation were described as facilitators.

Parents described a supportive adult care team as understanding that transitioning patients needed to adjust to the new care system and providing patients with information and resources on who to call and how to arrange health insurance. The adult clinic being in the same location as the patient's pediatric clinic was described as facilitating better communication between the two systems.

Patient Characteristics

Nine providers and four parents described patient characteristics as facilitators. Providers mentioned maturity, having organizational skills, demonstrating independence to make decisions, and prioritizing their health needs independently from their parents as facilitators. Parents described the ability reach out to the care team, make health decisions, identify symptoms, and having organizational skills and a positive attitude about transition.

Supportive Parents and Home Environment

Eight providers emphasized supportive parents and home environment as facilitators of successful transition. Providers described supportive parents and home environment as a family system that promoted the patient's self-confidence and encouraged the patient to advocate for themselves, and where the patient had an open relationship with their family to discuss mistakes, could make their own decisions with limited parental inference, and where parents promoted their child's independence in managing their health.

4.4.3 Barriers

We asked stakeholders to describe barriers to successful transition. Themes that emerged included patient factors, hovering parents and family factors, travel to clinic, and navigating a new health care system. Although all parents were asked about barriers, only 10/13 felt that they could provide input based on their experience. Barrier themes are represented in **Figure 4.2** and quotations are in **Table 4.2**.

Patient Factors

Patient factors emerged in eight provider and four parent interviews. Four providers mentioned mental health comorbidities, such as anxiety and depression, as barriers to transition. Providers described barrier characteristics as being unorganized, irresponsible, in denial of their disease extent, and uninformed about IBD progression, medications and the importance of disease management, as well as having fatigue related to their disease activity and engaging in substance use. One provider mentioned that patients with well-controlled disease may not recognize the importance of disease management.

Parents emphasized similar factors, such as being unable to self-advocate, not feeling comfortable asking questions or reaching out to their care team and lacking maturity.

Hovering Parents and Family Factors

Twelve providers indicated the transitioning patient's family could be a barrier to successful transition. Providers gave examples of parents who were "hovering and overbearing", reluctant to allow their child to become responsible for disease management, and who speak on their child's behalf during appointments. Other examples included families who experienced economic and personal challenges and unstable families. One provider mentioned the potential for cultural barriers and emphasized the need to understand family dynamics in different cultures and how these dynamics may impact the family's ability to transfer responsibility for disease management and promote independence in their child.

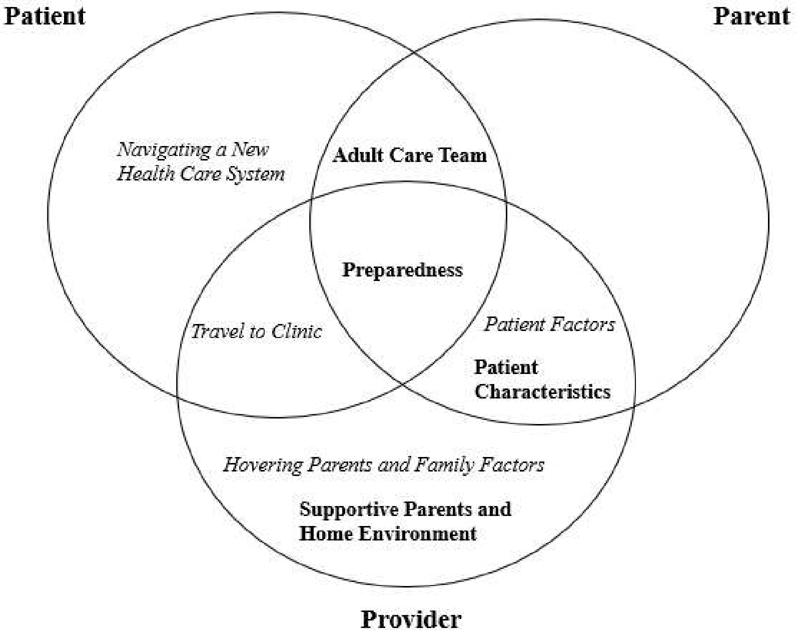
Navigating a New Health Care System

Eleven patients mentioned the need to navigate the new adult care system as a barrier. Two patients commented on differences in infusion clinics between pediatric and adult care, with one patient saying "…then I switched to an [adult] infusion clinic and you're nowhere near a doctor's office or if you have questions or concerns there is no one to talk to." Patients mentioned having to figure out transportation to the IBD clinic, organizing referrals and feeling intimidated by the adult care system.

Travel to Clinic

The need to travel to the IBD clinic emerged in five patient and four provider interviews. Patients gave examples of moving away for school, living far from the IBD clinic, or not driving and having to rely on local transportation or rides from others to get to their appointments.

Figure 4.2. Venn diagram of Themes of Facilitators of and *Barriers* to a Successful Transition According to Patients, Parents, and Providers.



Note: Themes in **bold** are facilitators and themes in *italics* are barriers.

Table 4.2. Quotations of Facilitators of and Barriers to a Successful Transition

Themes	**Stakeholder (n)**	**Quotations**
Facilitators		
Preparedness	**Patients (7)**	"I think the most important is just asking a lot of questions and if you know you're uncomfortable with the process making sure that there is someone that you can ask questions to and that someone can answer those questions…"
	Parents (7)	"I think that [transitioning patient] could use some counselling or something [that] could have helped especially in the transition when he was 18/19 trying to cope with this stuff on his own now." "I think that mentally prepared. Some kids are totally mentally prepared and making their own appointments and some kids just aren't."
	Providers (6)	"How well they have been set up on the other side. A lot of the kids come over from the pediatric GIs and some of the kids seem better set up by the person who set them over."
Adult Care Team	**Patients (10)**	"I think that the [adult] clinic somehow needs to put a little extra attention onto kids or young adults because you do get busy and forget things and you're stressed out going to school… so I think like a scheduled 3-month call would be nice for a lot of people to remind them like *'hey we are here if you're having issues. How are your symptoms? How have they been this last season?'*" "[The] new doctor being in the same hospital already made it easier."
	Parents (4)	"…even just someone at the clinic - maybe the GI clinic has a liaison person and that person's job is to check up on these kids that are coming out of [pediatric care team]."

		“… give [the transitioning young adult] a year to adjust because they are used to an entirely different approach.”
Patient Characteristics	**Parents (4)**	“…a positive attitude and being willing to understand more about the importance of acknowledging symptoms, following up with physician when you have symptoms and respecting the disease I guess is the best way to say it...”
	Providers (9)	“A little bit of less reliance on their parents and taking their own control of their own health, reporting their own symptoms, right?” “It depends on their maturity levels as well and whether they’re usually independent at that age and use to undertaking initiative to looking after their own affairs.”
Supportive Parents and Home Environment	**Providers (8)**	“Parents who are just there to listen and act as a fly on the wall are certainly much easier for the patient overall.” “I think if the patient has a stable home environment where they feel confident, where they feel supported, where they have the ability to make some decisions on their own…”
Barriers		
Patient Factors	**Parents (4)**	“They just aren’t good about advocating for themselves that they are lost in the system a bit, or they can potentially get lost.”
	Providers (8)	“I think [transitioning patients] are young and they think they’re invincible and they haven’t really- it’s just a lack of knowledge of their disease and what is involved in maintaining remission and avoiding the progression.” “When there are mental health issues, I think that that can make it quite challenging so anxiety, depression can really make it challenging.”
Hovering Parents and Family Factors	**Providers (11)**	“A lot of the families that we do see struggle often [because] they have so much other stresses and factors on their plate that it’s hard for them.”

		“The parents may be overprotective and not interested in supporting youth independence.”
Navigating a New Health Care System	**Patient (11)**	“There was a lot of follow up all the time, but then I switched to an infusion clinic and you’re nowhere near a doctor’s office or if you have questions or concerns there is no one to talk to…” “I think a big barrier was it was very intimating that was the biggest thing. I was just terrified. It didn’t feel super comfortable about the adult setting because it is very strange, I think.”
Travel to Clinic	**Patient (5)**	“…moving cities is really hard and then you’re also really young trying to do things on your own. My parents weren’t involved at all so I was the one transferring different cities and my health care and everything like that. You don’t really know how to do that – how to make those phone calls, how to find doctors, how to find referrals is all new.” “I mean the only issues are that I don’t drive so sometimes getting around is a little tough because I also don’t live at home anymore…”
	Provider (4)	“… [transitioning patients] are going into post-secondary education and often they’re moving away to different places and then you have to hand off care to someone else and that again [is] another point they can fall off in terms of follow up from that aspect.” “I certainly think if they live further away from a center where their practitioner is – that definitely makes it more difficult.”

4.5 Discussion

To the best of our knowledge, this is the first multi-center study in Canada to describe barriers to and facilitators of patients transitioning from pediatric to IBD adult care according to patients, parents, and health care providers. Engagement of all stakeholders in transition allows for the assessment of similarities and differences in barriers and facilitators identified by the stakeholder groups.

A systematic review conducted by Gray et al (2018) summarized barriers to and facilitators of transition in chronic diseases[22]. IBD studies in this review showed overlap with our themes of hovering parents and family factors and patient characteristics[24,25]. A study of transition barriers that interviewed IBD providers in the United States (US) identified themes of helicopter parenting and patients' developmental maturity[23]. Nearly all (11/12) providers in this US study gave the example of parents who wanted to maintain control of their child's care. The characterization of parents wanting to maintain control as a barrier was prominent in our study where 11/15 providers described "hovering parents" as a barrier. The theme of patients' developmental maturity that arose in the US study was like themes focused on the importance of patient maturity that emerged in our study. The US study found barriers to include patients being inadequately prepared by the pediatric team where in our study, patients' preparedness to transition emerged as a facilitator.

Gray et al (2015) conducted focus groups with patients, parents, and health care professionals about the transition to IBD adult care in the United States[25]. The theme of high parental involvement, like the theme of hovering parents and family factors in our study, emerged as a barrier in the focus groups. The theme of over-parental involvement emerged in all groups in the focus group study, whereas in our study, this theme only emerged in the provider group. One possible explanation for this difference is that the focus group study asked specifically about "concerns with transitioning", while our study asked about "barriers". Parents and patients may be hesitant to acknowledge parental over-involvement as a barrier, but they may be more likely to acknowledge parental involvement as a concern. In the focus group study, the theme of receiving poor quality of care emerged. The theme of poor quality of care overlaps facilitator themes that emerged in our study, including a supportive adult care team and the need to navigate a new system. Other themes from the focus group study that did not emerge in our study included finance and the loss of relationships with the pediatric team that transition entails. The first theme may be more related to the private healthcare system landscape in the United States compared to the publicly funded system in Canada. In the focus group study, the second theme of loss of relationships emerged within the pretransfer group only and not the already transferred group, whereas our study only included patients who already transferred.

Our study reveals similarities and differences between how different stakeholder groups characterize barriers to and facilitators of transition. The only theme to emerge across all groups as a facilitator was preparedness. Concordance on this facilitator supports the need to develop guidelines and resources to ensure patients are prepared to transition.

Our finding that different themes emerged across diverse stakeholders shows the need to engage patients, parents, and providers to achieve a comprehensive characterization of barriers to and facilitators of transition. For example, most providers viewed patients as potential barriers, but this theme was mentioned by four parents and no patients. Patients may be reluctant to recognize themselves as a detriment to their transition and more inclined to focus on the responsibility of the adult care system, as reflected by the themes of navigating a new health care system and having a supportive adult care team. Further, although a few patients and providers acknowledged the impact that a patient moving away may have on their transition, this theme did not emerge in the parent interviews. Parents of patients who move out may have been less involved in their child's care and thus, did not see this as a barrier.

Patients were the only group to mention having to navigate the adult care system as a barrier to transition. During transition, patients are the primary group taking responsibility and navigating the adult care system, which may explain why this theme only emerged in the patient group. Providers can help patients understand the differences between the pediatric and adult system with the goal of developing patients' self-confidence in navigating the new care system.

Providers were the only group to mention aspects of the patient's family as both a facilitator and barrier, shown by the themes of supportive parents and home environment and hovering parents and family factors. Future research could explore this discrepancy to find out the extent to which patients view their parents' involvement during their transition as detrimental or helpful.

Study limitations include the potential for selection bias; parents and patients who viewed transition favorably may have been more likely to participate than those who viewed their transition unfavorably. Additionally, this study only represents the viewpoints of mothers, given that fathers and other guardians did not participate in the study. The exclusive participation of mothers is consistent with the literature on parental involvement in their child's chronic disease[27-29]. As 70% of patients were either on a biologic or combination biologic, this study likely reflects the viewpoints of patients with moderate-severe IBD. Further, there were no trends of themes emerging within groups based on specific characteristics. For example, 6/7 patients on combination biologic mentioned the theme of supportive adult care team, but the theme also emerged in 3/3 patients on 5-ASA or immunosuppressants. Similar results were found when looking at age of diagnosis, and parent's education level. Because this study did not collect information on sociocultural data, we cannot assess how representative the study population was of IBD cases in Alberta. The parents and patients interviewed may have been from a higher socioeconomic class and, if so, it could be for this reason that they did not view finances as a barrier to transition. Further, it is not clear if the characteristics of participants prevented cultural differences from emerging as a barrier to or facilitator of.

The strength of this study is that it describes transition barriers and facilitators according to the stakeholders involved in the process of transition. Future research could focus on designing transition interventions that promote facilitators while addressing the barriers identified in this study.

4.6 References

1. Blum RW, Garell D, Hodgman CH, Jorissen TW, Okinow NA, Orr DP, Slap GB. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *J Adolesc Health*. 1993;14:570–576.

2. Philpott JR. Transitional care in inflammatory bowel disease. *Gastroenterol Hepatol*. 2011;7(1):26-32.

3. Reed-Knight B, Blount RL and Gilleland J. The transition of health care responsibility from parents to youth diagnosed with chronic illness: a developmental systems perspective. *Fam Syst Health*. 2014;32:219–234.

4. Heath G, Farre A, Shaw K. Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents’ experiences. *J Patient Educ Couns*. 2017;100(1):76-92.

5. McDonagh, J. E. Growing up and moving on: transition from pediatric to adult care. *Pediatric Transplant*. 2007;11(7), 766-769.

6. Pamela M, Erin H, Lynne G, et al. A retrospective look at an IBD transition initiative. *Inflamm Bowel Dis*. 2014;20:S88.

7. Bollegala N, Brill H, Marshall JK. Resource utilization during pediatric to adult transfer of care in IBD. *J Crohns Colitis*. 2013;7(2):e55-60.

8. Zhao X, Bjerre LM, Nguyen GC, et al. Health services utilization in adolescents with inflammatory bowel disease transitioning from pediatric to adult care: A population based, cohort study. *J Pediatr Gasteroenterol Nutr*. 2016;63:S354.

9. Setya A, Molina M, Homsi M, et al. Age-specific healthcare utilization trends in a transitional IBD population. *Gastroenterol*. 2020;18(6):S-735.

10. Testa A, Giannetti E, Rispo A, et al. Successful outcome of the transitional process of inflammatory bowel disease from pediatric to adult age: A five years experience. *Dig Liver Dis*. 2019;51(4):524-528.

11. Benchimol EI, Bernstein CN, Bitton A, et al. Trends in Epidemiology of Pediatric Inflammatory Bowel Disease in Canada: Distributed Network Analysis of Multiple Population-Based Provincial Health Administrative Databases. *Am J Gastroenterol*. 2017;112:1120-1134.

12. Caroll MW, Kuenzig ME, Mack DR, et al. The impact of inflammatory bowel disease in Canada 2018: children and adolescents with IBD. *Can. J. Assoc. Gastroenterol*. 2019;2:S49-S67.

13. American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatr*. 2002;110(6 Pt 2):1304–6.

14. El-Matary WE, Carroll MW, Deslandres D, et al. The 2023 impact of inflammatory bowel disease in Canada: special populations – children and adolescents with IBD. *J Can Assoc Gastroenterol*. 2023;6:S35-S44.

15. Bihari A, Hamidi N, Seow CH, et al. Defining transition success for young adults with inflammatory bowel disease according to patients, parents, and health care providers. *J Can Assoc Gastroenterol*. 2022; 5(4):192-198.

16. Sandelowski, M. What's in a name? Qualitative description revisited. *Res Nurs Health*. 2010;33(1):77-84.

17. Sandelowski, M. Whatever happened to qualitative description? *Res Nurs Health*. 2000;23(4):334-340.

18. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med*. 2014;89(9):1245-1251.

19. Lincoln YS, Guba EG. But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New Dir Eval*. 1986;1986(30):73– 84.

20. NVivo qualitative data analysis software [computer program] Version 1.2. Melbourne, Australia: QSR International Pty Ltd, 2012.

21. Mayan MJ. Essentials in qualitative inquiry. Walnut Creek: Left Coast Press. 2009.

22. Gray WN, Schaefer MR, Resmini-Rawlinson A, Wagoner ST. Barriers to Transition from Pediatric to Adult Care: A Systematic Review. *J Pediatr Psychol*. 2018;43(5). 488-502.

23. Paine CW, Stollen NB, Lucas MS, et al. Barriers and facilitators to successful transition from pediatric to adult inflammatory bowel disease care from the perspectives of providers. *Inflamm Bowel Dis*. 2014;20:2083-91.

24. Fishman LN, Barendse RM, Hait E, Burdick C & Arnold J. Self-management of older adolescents with inflammatory bowel disease: A pilot study of behavior and knowledge as prelude to transition. *Clin Pediatr*. 2010;49:1129–1133.

25. Gray WN, Resmini AR., Baker KD, et al. Concerns, barriers, and recommendations to improve transition from pediatric to adult IBD Care: Perspectives of patients, parents, and health professionals. *Inflamm Bowel Dis*. 2015;21:1641–1651.

26. Gray, W. N., & Maddux, M. H. Current transition practices in pediatric IBD: Findings from a national survey of pediatric providers. *Inflamm Bowel Dis*. 2016;22:372–379.

27. Plevinsky JM, Gumidyala AP, Poulopoulos N, et al. Illness-related parenting stress among parents of adolescents and young adults with inflammatory bowel diseases. *Child Health Care*. 2018;47(2):136-149.

28. Guilfoyle SM, Gray WN, Herzer-Maddux M, Hommel KA. Parenting stress predicts depressive symptoms in adolescents with inflammatory bowel disease. *Eur J Gastroenterol Hepatol*. 2014;26(9):964-971.

29. Ingerski LM, Baldassano RN, Denson LA, Hommel KA. Barriers to Oral Medication Adherence for Adolescents with Inflammatory Bowel Disease. *J Pediatr Psychol*. 2010;35(6):683-691.

Part II: Assessment of Transition Success in Young Adults with IBD

In Chapter 5, I present the methods, results, and discussion of a cross-sectional study designed to assess the achievement of the indicators of transition success by young adults with IBD. In the subsequent chapters, I refer to the transition success outcomes characterized in Chapter 3 as health care autonomy indicators to provide clarity that participants with adult-onset IBD have not transitioned from pediatric to adult care.

Chapter 5. A Survey of Health Care Autonomy Indicators in Young Adults with Inflammatory Bowel Disease.

5.1 Introduction

Industrialized societies have been described as having prolonged achievement of adulthood relative to pre-industrialized societies, manifested as increased participation in postsecondary education, pre-marital cohabitation among domestic partners, and a later average age at marriage and parenthood[1]. Arnett (2000) classifies this period as emerging adulthood, which encompasses individuals aged 18 to 25 years old[2]. This period is suggested to be the most heterogeneous period in an individual's life course because it is the least structured life period[2]. Further, this period is when markers of adult status are gradually attained (e.g., accepting responsibility for oneself, making own decisions, and becoming financially independent).

For individuals diagnosed with chronic disease in childhood or adolescence, this period of emerging adulthood coincides with the additional challenge of transitioning from pediatric to adult care. Studies have reported a decrease in appointment attendance and medication adherence, as well as an increase in disease activity and emergency department (ED) utilization after IBD patients have transferred to adult care[3-7]. The recent 2023 Impact of Inflammatory Bowel Disease in Canada report highlights the transition from pediatric to adult care as an important area of concern for patients with pediatric-onset IBD[8].

To characterize outcomes associated with a successful transition, I conducted a qualitative study using semi-structured interviews with patients, parents, and health care providers to address the research question of, "what is transition success according to patients, parents, and health care providers involved in the transition from pediatric to adult care for IBD?"[9] The results demonstrated that partners involved in IBD transition characterize successful transition in six themes: 1. Independence in one's care; 2. Disease management; 3. Relationship with/trust in adult care team; 4. General knowledge; 5. Care stability; 6. Health outcomes.

There remains a need to estimate the proportions of patients who are achieving these indicators of transition success. Further, young adults diagnosed with IBD between the ages of 18-25 are also in the life stage of emerging adulthood and doing so while having the additional challenges of being diagnosed with and learning to live with IBD. One qualitative study found that both young adults with adult-onset IBD and those with pediatric-onset IBD reported emotional distress associated with their IBD and mentioned they lacked information about their IBD[10], suggesting that both groups may benefit from similar types of support. However, there remains a need to further explore the similarities and differences between patients with pediatric-onset IBD and those with adult-onset IBD, particularly concerning the achievement of health care autonomy indicators. Addressing this limitation will help identify areas where additional support may be beneficial for both pediatric-onset IBD and adult-onset IBD patients, ultimately, enhancing the care provided to all young adults with IBD.

5.2 Methods

5.2.1 Study Objectives

The primary objective of this study was to assess the overall achievement of health care autonomy indicators — self-management, disease knowledge, medication and appointment adherence, and relationship with the IBD care team — in young adults with IBD patients who previously transferred from pediatric to adult care.

In this chapter, I refer to the transition success outcomes identified in Chapter 3 as health care autonomy indicators to provide clarity that participants with adult-onset IBD have not transitioned from pediatric to adult care.

The secondary objectives of this study were:

- To assess the similarities and differences in the achievement health care autonomy indicators between young adults with pediatric-onset IBD and those with adult-onset IBD.

- To assess similarities and differences in exploratory variables, such as the impact of IBD on life domains, resilience in young adults, and feelings of shame associated with IBD, between young adults with pediatric-onset IBD and those with adult-onset IBD.

5.2.2 Study Design

To achieve the study objectives, I designed a multi-site cross-sectional study. Participants completed a self-administered questionnaire collected and managed using REDcap (Research Electronic Data Capture) hosted at the University of Alberta[11,12]. Study participants included young adults aged 18-25 diagnosed with either Crohn's disease, ulcerative colitis or indeterminate colitis, who received IBD care in Alberta, Canada and could provide their Alberta personal healthcare number (PHN) for confirmation of their IBD diagnosis. Exclusion criteria included patients who were unable to provide informed consent, lacked a sufficient understanding of English, or had a major cognitive impairment.

I determined that a cross-sectional study was the most appropriate design to achieve my objectives. I required a method that involved minimal patient follow-up, was time efficient, and included patients at different ages of emerging adulthood. A prospective cohort study, an alternative study design that requires follow-up over time, could be subject to high rates of patient drop out and would be time intensive. A retrospective cohort study was also inappropriate due to the potential for incomplete or missing documentation of desired outcome variables in patient medical charts. Additionally, as this study aims to measure multiple outcomes, I was unable to use a case-control study design.

5.2.2.1 Study Variables

5.2.2.1.1 Participant Characteristics

Patients were asked to disclose their gender, race, age, IBD type, as well as, the name of their IBD health care provider and the location where they receive IBD care.

Patients were also asked questions about their current living situation, employment and student status, as well as their highest level of education attained at the time of questionnaire completion. Patients who were enrolled in or had completed post-secondary education were asked about the age at which they began their post-secondary studies and whether they relocated to attend school. These questions were asked as indicators of negative impact on post-secondary education (e.g., entrance at a later age, attending a school closer to their family). Patients were also asked whether they currently have a family doctor as having a primary care physician has been deemed important for continuity of care and essential for transition[13].

Patients were also asked information about their childhood and parent-specific information. To assess the patients' familiarity with the Canadian healthcare system and potential for cultural differences, information was collected on whether anyone the patient lived with growing up experienced a significant health issue and whether the patient and/or their parents were born in or outside of Canada. Patients were also asked who they primarily lived with from the ages of 14-18 (e.g., living with both parents or only one parent) to assess family dynamics and their parent's highest level of education.

I used the MacArthur Scale of Subjective Social Status – The Socioeconomic Status Ladder to obtain information on a patient's perception of their family's social status during their adolescent years (ages 14-18)[14]. This is a single item tool used to assess an individual's perceived rank relative to others in society. This tool has been previously utilized within the Canadian context[15,16]. I adapted this tool to have patients reflect on their family's social status when they were between the ages of 14-18, using a slide scale rather than a 10-rung ladder.

Patients were asked to reflect on when they were 14-18 years old as this encompasses a time period immediately preceding emerging adulthood. This age range of 14-18 offered insights into the patient's family dynamics before the patient entered emerging adulthood. Additionally, individuals are more likely to recall events if they are able to anchor them to a memory, event, or life stage, such as ages 14-18 years corresponding to when the patient is likely in high school[17].

5.2.2.1.2 Primary Outcomes

The following section explains the primary outcomes of the study, which were defined by the themes in Chapter 3 that they are meant to measure. **Appendix G** highlights other instruments considered and reasons for their exclusion.

Theme: General Knowledge

IBD knowledge was assessed using the 15-item questionnaire Inflammatory Bowel Disease Knowledge Inventory Device 2 (IBD-KID2), which has been validated in the adult IBD population[18]. IBD-KID2 provides a total score that ranges from 0-15, with a higher score corresponding to a higher level of IBD knowledge.

Theme: Independence in One's Care

The theme of independence in one's care was assessed by questions on self-management skills based on previously published questions that assessed self-management skills in adult IBD populations[19]. I obtained permission to use these questions from the first author of the original study. Self-management questions asked patients to identify the individual most responsible for ten different tasks of IBD disease management (e.g., who schedules your medical appointments?). To calculate a total score for all the self-management questions, I assigned a point value of 1-6 to each response option to reflect the degree of independence associated with the respective task (e.g., 6 points for 'only me' responses, 5 for 'mostly me', 4 for 'me and parent', 3 for 'me and partner', 2 for 'mostly partner', and 1 for 'mostly parent' answers). A total score for each participant was calculated by adding the points from each of the ten questions. I then classified total scores into high self-management, moderate self-management, and low-self management. High self-management (scores 50-60) included a combination of the responses 'only me' and 'mostly me.' Moderate self-management (scores 21- 49) included a combination of the responses 'mostly me', 'me and parent' and 'me and partner'. Low self-management (scores 10-20) included a combination of the responses 'me and parent', 'me and partner', 'mostly partner' and 'mostly parent'.

Theme: Relationship with/Trust in Adult Care Team, Care Stability & Care Team Management

The themes of relationship with/trust in adult care team, care stability & care team management all centered on patients' perceptions of their adult IBD care team; therefore, I decided that these themes could be combined into a set of statements related to different aspects of the patient's relationship with their adult IBD care team. I designed 12 statements that focused on assessing patients' perceptions of different aspects of their relationship with their adult IBD care team guided by the descriptions of the themes in Chapter 3. I developed these statements as existing tools in the literature primarily assessed patient satisfaction with their most recent medical appointment, rather than focusing on aspects of the patient's relationship with their IBD care team, as described in the themes outlined in Chapter 3.

Patients rated their agreement with statements, such as "I trust my health care team with managing my disease" and "My health care team provides me with the guidance and support that I need", using a 5-item Likert scale corresponding to responses: strongly agree (4 points), agree (3 points), neutral (2 points), disagree (1 point), and strongly disagree (0 points). I calculated a total score for each participant by adding points from each of the 12 questions. I then classified scores into ratings of high satisfaction, moderate satisfaction, and low satisfaction. The high satisfaction category (scores of 36-48), corresponds to mostly 'strongly agree' and 'agree' responses. The moderate satisfaction category (scores of 25-36), corresponds to mostly 'agree' and 'neutral' responses. The low satisfaction category (scores of 0-24) corresponds to a combination of 'neutral', 'disagree', and 'strongly disagree' responses.

Theme: Disease Management

Patients who reported that they were on medications where the route of administration is either intravenous/injection, pills, or enemas/suppositories were prompted to complete the medication adherence report scale (MARS-5)[20]. MARS-5 is a 5-item validated tool to measure patients' self-reported medication adherence. The scores on the MARS-5 range from 0-25 with a higher score signaling higher medication adherence.

MARS-5 (medical appointment) assessed nonadherence to medical appointments (e.g., appointments with their IBD provider, colonoscopy appointments, or biologic infusions appointments). The MARS-5 (medical appointments) is a tool to assess whether patients have missed any appointments in the past year and the reasons for those missed appointments. I felt that it was necessary to include infusions under the MARS-5 medical appointments as these are scheduled appointments where other types of medications that are injections or pills rely on more patient autonomy when taking these medications.

5.2.2.1.3 Exploratory Variables

The following outcomes did not emerge as themes of transition success in the interview study (Chapter 3). However, these variables offer additional insight into the experience of young adults with IBD.

Furthermore, these variables may be associated with the achievement of the health care autonomy indicators:

- Impact on life domains
- Resilience
- Shame

I used the Secondary 7 Lifestyle Effects Screening (S7-LES) to assess patient's perspectives on the impact that IBD has on different life domains[21]. The S7-LES is a self-administered checklist designed to assess maladaptive responses to medical illness with respect to seven life domains – developmental, intrapersonal (self), relationships, career/occupation, existential, avocational/leisure, and spiritual. S7-LES first asks patients if their medical diagnosis/illness has had an impact on one of the seven life domains and if the respondent answers yes, the next question asks whether they are experiencing emotional distress because of this impact. For this study, this tool used "my IBD diagnosis' instead of "my medical procedure/diagnosis".

To assess resilience, the Connor-Davidson Resilience Scale (CD-RISC) was included[22]. The CD-RISC is a 10-item validated scale that provides an indication of one's ability to bounce back and adapt in response to setbacks. This scale contains items corresponding to flexibility, self-efficacy, ability to regulate emotion, optimism, and cognitive focus/maintaining attention under stress. The CD-RISC was chosen because of its use in the IBD literature[23,24] and its short length. The Connor Davidson resilience scale has ten statements, each with five response options: 'Not true at all' (0 points), 'Rarely true' (1 point), 'Sometimes true' (2 points), 'Often true' (3 points), and 'True nearly all the time' (4 points). The total score ranges from 0 to 40. A higher score indicates greater resilience.

To measure the shame that respondents feel related to their inflammatory bowel disease, I included the chronic-illness-related shame scale (CISS)[25]. The CISS is a 7-item scale that measures feelings of internal and external shame associated with having an illness. The Chronic Illness-Related Shame Scale has seven statements, each with five response options: 'Never' (0 points), 'Seldomly' (1 point), 'Sometimes' (2 points), 'Frequently' (3 points), and 'Always' (4 points). The total score ranges from 0 to 28. A higher score indicates higher level of shame associated with illness.

5.2.3 Participant Recruitment and Setting

I recruited eligible study participants from throughout Alberta, Canada. My recruitment strategy took a multi-faceted approach, which relied primarily on gastroenterologists across the province of Alberta. Practicing gastroenterologists in the province were made aware of the study through email by the study's gastroenterologists and were asked if they would be willing to aid in patient recruitment. Providers who consented to helping with participant recruitment were sent a recruitment package by myself, which included a letter outlining the study (**Appendix E**), study posters and postcards with the QR code for patients to scan to be directed to the questionnaire. Additional recruitment efforts included in-person recruitment at IBD clinics, infusion and endoscopy appointments. The study was also advertised through the Crohn's and Colitis

Canada’s website, social media platforms, and University emails sent weekly to employees, undergraduate and graduate students.

I included patients from across Alberta to increase the number of potential participants, their potential diversity, and the heterogeneity of their experiences. For example, a patient who sees a gastroenterologist at an academic center might be more likely to be in school compared to a patient who sees a gastroenterologist at a community clinic due to the proximity of academic centers to universities. This sampling approach allowed to capture a wide range of patients’ experiences.

Patients who met the study criteria and expressed interest in learning more about the study were directed to the REDcap survey where they had the option to read study information and a consent page that detailed the study, outlined measures taken to ensure confidentiality, their rights as a study participant, and provided study contact information. The consent page asked patients to provide electronic consent to study participation, including linking their questionnaire responses with their health information by providing their Alberta healthcare number (PHN). I confirmed the IBD diagnosis of participants who completed the questionnaire through an electronic medical chart review.

5.2.4 Questionnaire Development

To assess the previously identified health care autonomy indicators, the questionnaire was made up of both created questions and validated tools. Permission to use previously published instruments was received from all authors. As most of the questions in the questionnaire had been previously used in the IBD patient population, I piloted the questionnaire to ensure its overall readability, comprehensibility, and average completion time. For questions that were designed specifically for this questionnaire (e.g., relationship with IBD care team), the individuals who piloted the survey were asked if they felt the working was understandable and if they understood what was being asked in this section. **Appendix F** contains the questionnaire delivered to participants.

In the initial steps of piloting, eight volunteers without IBD aged 22-27 completed the questionnaire. These individuals were asked to review the questionnaire for the timing and readability of questions. I selected eight young adults based on familiarity (e.g., friends, coworkers, siblings, etc.). These individuals who piloted the questionnaire exhibited diverse educational backgrounds (e.g., never attended university, current undergraduate or graduate student, graduate of university) and varied in their familiarity with the healthcare system (e.g., having received health care for a chronic disease or not). These individuals agreed that the timing of the questionnaire was appropriate and that it was coherent, but they identified a few instances of incorrect spelling in the instructions. After incorporating the suggested changes, the questionnaire was reviewed by three patients with IBD, aged 26-30, who were selected based on familiarity with me. The group consisted of two females and one male, all diagnosed with IBD in adulthood, and with diverse educational backgrounds — two had a university degree, while one had not attended university. They also had varied experiences with IBD, including being on or off IBD medications, and having or not having experienced an IBD-related hospitalization. These individuals were asked to assess the timing and readability of the questions, and to provide feedback on the IBD-specific questions, including questions about IBD medications and insurance. All individuals agreed that the questionnaire's timing, readability, and IBD-specific questions were appropriate and clear.

5.2.5 Data Analysis

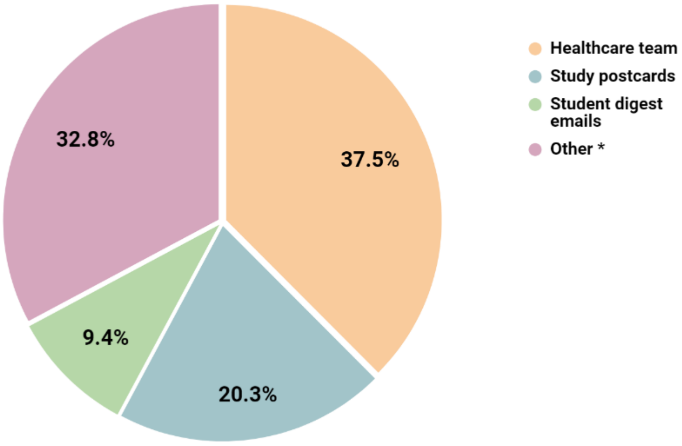
To assess the relationship between life period of IBD onset and health care autonomy indicators, I compared the average scores on each health care autonomy indicator between IBD patients with pediatric-onset IBD and those with adult-onset IBD. To evaluate the level of achievement for each indicator category within the IBD onset groups, I calculated proportions of patients in each category, along with exact 95% confidence intervals. I primarily reported means with exact confidence intervals to describe central tendency and variability. In cases of skewed data distributions, I reported medians and range to provide a more robust representation of central tendency as these measures are less affected by outliers. Additionally, I calculated proportions with 95% confidence intervals to assess the attainment of predefined cutoff values for each indicator within each IBD onset group. Precision was evaluated by examining the width of the 95% confidence intervals for each point estimate. I used STATA 17 for statistical analysis[26].

5.3 Results

5.3.1 Participant Recruitment

Fifty-six participants aged 18-25 years old completed the online questionnaire during December 12th – February 28th, 2024. Of the 56 participants, 37 participants had pediatric-onset IBD and 19 had adult-onset IBD. Nearly all participants (94.6%) received IBD care in Edmonton, Alberta. Participants in the study sample were patients of 15 gastroenterologists across Alberta; however, 66.1% of participants received IBD care from four gastroenterologists. The most common way participants became aware of the study was through their health care team (**Figure 5.1**).

Figure 5.1 Participant Referral Channels



* Other ways that participants were referred to the study included being contacted directly because they had previously consented to being contacted about research studies or during an infusion clinic visit.

5.3.2 Study Population

Participant Demographics

In the pediatric-onset group, the median age of participants was 22 years old (IQR: 19-23) and the median age at IBD diagnosis of participants was 14 years old (IQR: 12-15). In the adult-onset group, the median age of participants was 23 years old (IQR: 21-25) and the median age of IBD diagnosis of participants was 19 years old (IQR: 18- 21). **Table 5.1** provides an overview of demographic information from participants within the pediatric-onset and adult-onset group. **Table 5.2** provides an overview of the IBD history of participants.

Table 5.1. Demographic Information of Study Participants by IBD Onset Group.

	Pediatric-onset IBD patients		**Adult-onset IBD patients**	
Total	**N**	*%*	**N**	*%*
Current Age	**37**		**19**	
18	7	*19.0*	1	*5.30*
19	5	*14.0*	1	*5.30*
20	2	*5.40*	1	*5.30*
21	2	*5.40*	3	*15.8*
22	4	*10.8*	2	*10.5*
23	9	*24.3*	3	*15.8*
24	3	*8.10*	2	*10.5*
25	5	*14.0*	6	*31.6*
Gender				
Woman	22	*59.5*	11	*57.9*
Man	13	*35.0*	8	*42.1*

Transgender	1	*2.70*	-	-
Non-Binary	1	*2.70*	-	-
Two-Spirit	-	-	-	-
Another gender not listed above	-	-	-	-
Prefer not to answer	-	-	-	-
Ethnicity				
White	28	*75.7*	17	*89.5*
South Asian	4	*10.8*	2	*10.5*
Middle Eastern	2	*5.40*	-	-
Latin American	1	*2.70*	-	-
Southeast Asian	1	*2.70*	-	-
Black	-	-	-	-
East Asian	-	-	-	-
Indigenous	-	-	-	-
Another race category	1	*2.70*	-	-
Do not know	1	*2.70*	-	-
Prefer not to answer	-	-	-	-
Born in Canada				
Yes	34	*91.9*	18	*94.7*

Table 5.2 IBD Diagnosis, Medications, and IBD History of Study Participants by IBD Onset Group.

	Pediatric-onset IBD patients		**Adult-onset IBD patients**	
IBD Diagnosis	**N=37**	*%*	**N=19**	*%*
Crohn’s disease	26	*70.3*	15	*78.9*
Ulcerative colitis	11	*29.7*	4	*21.1*
Indeterminate Colitis	-	-	-	-

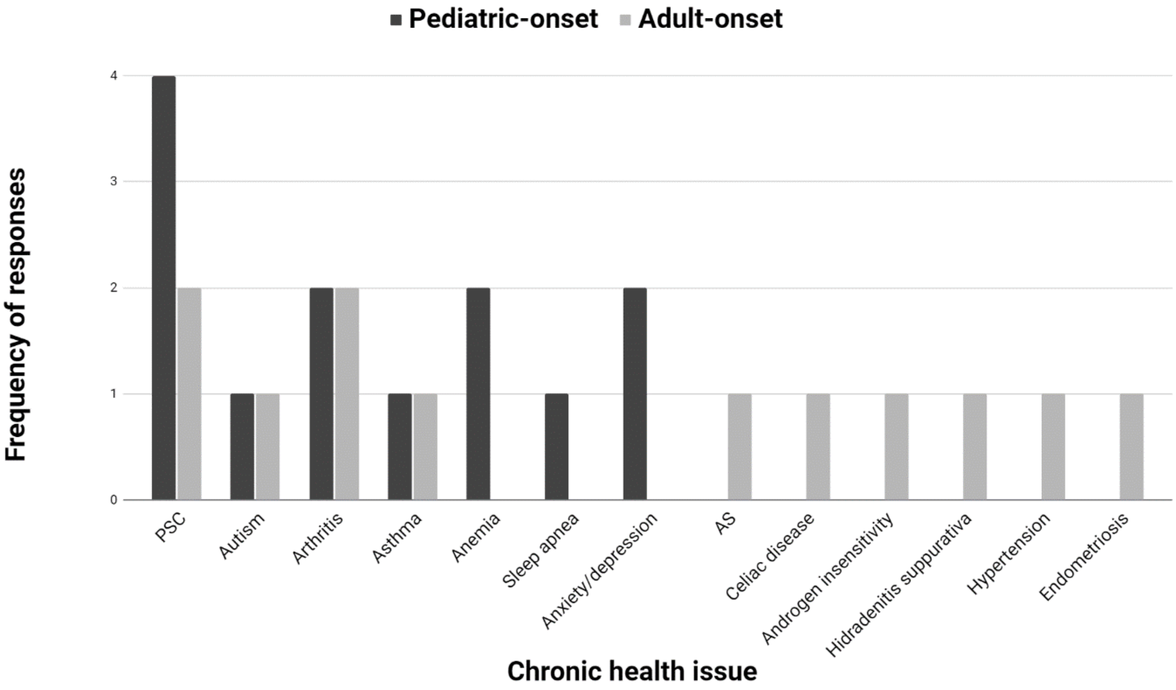
Unsure	-	-	-	-
Reported length between IBD diagnosis and start of symptoms				
0-1 years	16	*43.2*	9	*47.4*
1-2 years	8	*21.6*	6	*31.6*
2+ years	9	*24.3*	2	*10.5*
Unsure	4	*10.8*	2	*10.5*
Current IBD medication type	**N=34**		**N=19**	
Biologic	26	*76.5*	14	*73.7*
Combination (Biologics + 5-ASA/Immunosuppressant)	5	*14.7*	2	*10.5*
5-ASA/Immunosuppressant	3	*8.82*	3	*15.8*
History of IBD surgical intervention				
Yes	8	*21.6*	5	*26.3*
History of IBD hospitalization*				
Yes	22	*59.5*	10	*52.6*

***** Participants who indicated that they had a prior IBD surgical intervention were asked whether they had been hospitalized because of their IBD not including when they had surgery.

Chronic Health Issues Besides IBD

Eleven (29.7%) participants in the pediatric-onset group and 11 (57.9%) in the adult-onset group indicated that they had another chronic health issue besides IBD. **Figure 5.2** provides a breakdown of the chronic health issues mentioned by participants in the pediatric-onset group and by those in the adult-onset group respectively.

Figure 5.2 Chronic Health Issues Mentioned by Study Participants by IBD Onset Group.



PSC: Primary sclerosing cholangitis (PSC), AS: Ankylosing Spondylitis

Employment and Education

Over half of study participants in the pediatric-onset IBD group (62.2%) and of those in the adult-onset IBD group (57.9%) indicated they were enrolled in a post-secondary school either full-time or part-time. Further information on study participants' employment and education is available in **Table 5.3**.

Table 5.3 Employment and Education of Study Participants by IBD Onset Group.

	Pediatric-onset IBD patients		Adult-onset IBD patients	
Employment status	**N=37**	*%*	**N=19**	*%*
Full-time	10	*27.0*	7	*36.8*
Part-time	15	*40.5*	2	*10.5*
Causal	3	*8.1*	4	*21.1*
Not working	9	*24.3*	6	*31.6*
Highest level of education				
High School	24	*64.9*	8	*42.1*
Diploma/Certificate	6	*16.2*	4	*21.1*
Undergraduate Degree	6	*16.2*	5	*26.3*
Graduate Degree	-	-	2	*10.5*
Other	1	*2.7*	-	-
Currently in school				
Yes	23	*62.2*	11	*57.9*
Moved for post-secondary schooling	**N=30**		**N=18**	
Yes	11	*36.7*	8	*44.4*

Childhood Information

MacArthur Scale of Subjective Social Status

As outlined in Chapter 5.5.1, I used the MacArthur Scale of Subjective Social Status to assess participants' perceptions of their family's social status during their adolescence (ages 14-18) using a scale from 1-10. In the pediatric-onset IBD group, the mean ranking was 6.11 (95% CI: 5.46, 6.76) and in the adult-onset IBD group, the mean ranking was 6.47 (95% CI: 5.50, 7.44).

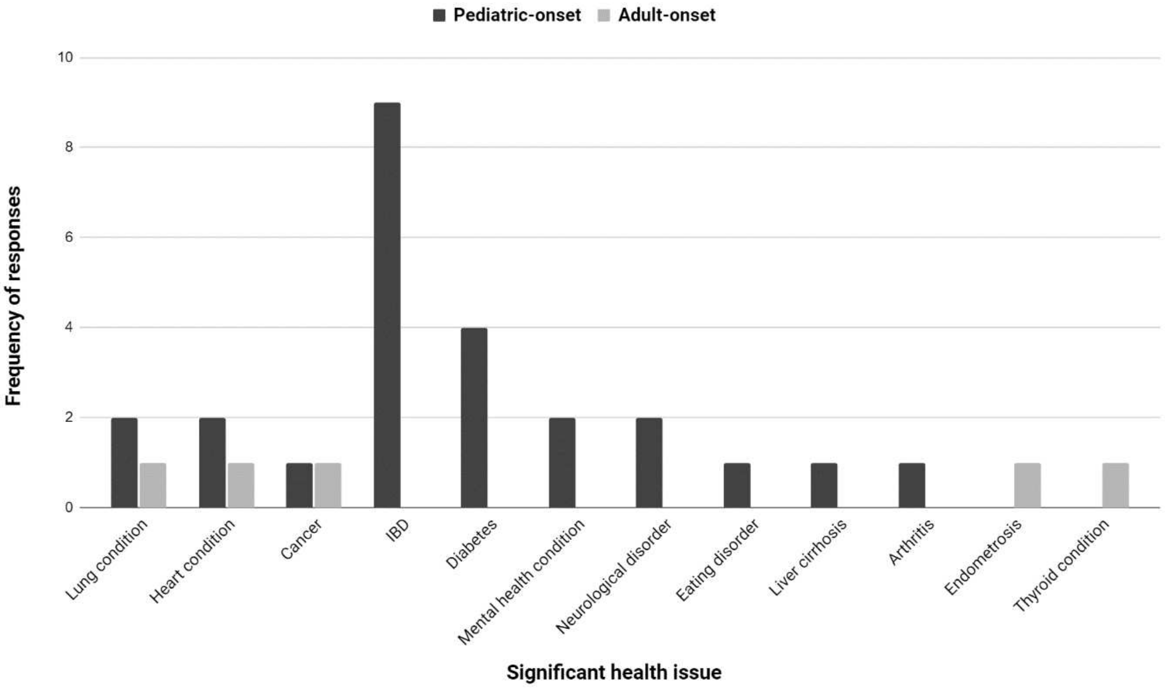
Household Member with a Significant Health Issue during Childhood

Overall, 54.0% of participants in the pediatric-onset group and 15.8% of those in the adult-onset group indicated they grew up with someone with a significant health issue (**Table 5.4**). The frequency of health issues mentioned by participants are in **Figure 5.3**.

Table 5.4 Growing up with a Household Member with a Significant Health Issue by IBD Onset Group.

	Pediatric-onset IBD patients		**Adult-onset IBD patients**	
Grew up with someone with a significant health issue	**N=37**	**%**	**N=19**	**%**
Yes, parent(s)	16	*43.2*	3	*15.8*
Yes, sibling	1	*2.70*	-	-
Yes, parent and sibling	1	*2.70*	-	-
Yes, relative(s)	2	*5.41*	-	-

Figure 5.3 Type of Significant Health Issue in Household Member by IBD Onset Group.



Challenges Accessing Healthcare

Nine (24.3%) participants in the pediatric-onset group and one (5.26%) participant in the adult-onset group answered, 'yes' to the question, '*Have you ever experienced any challenges accessing health care for your IBD?*' Challenges described by participants mainly focused on difficulties scheduling an appointment with their specialist (n=2), travelling for care (n=2), being on holidays and unable to access necessary care (n=2), and not feeling believed with regards to their symptoms (n=3).

Current Level of Comfort Interacting with the Healthcare System

I asked participants to answer on a scale of 1-10, '*how comfortable do you currently feel interacting with the healthcare system?*' with 1 being not comfortable and 10 being very comfortable. In the pediatric-onset group, the mean rating was 7.19 (95% CI: 6.51, 7.86), while in the adult-onset group, the mean rating was 8.11 (95% CI: 7.28, 8.94).

I also asked participants, *'how comfortable did you feel interacting with the healthcare system when you were first diagnosed?'* **Table 5.5** describes how participants' comfort interacting with the healthcare system changed before and after being diagnosed with IBD. A decrease in a participant's comfort indicates that a participant became less comfortable interacting with the healthcare system after diagnosis. This scenario could, for example, be illustrated by a participant rating their comfort a 7 before diagnosis and a 5 after diagnosis.

Table 5.5 Change in Level of Comfort Interacting with the Healthcare System since Diagnosis by IBD Onset Group.

	Pediatric-onset IBD patients		**Adult-onset IBD patients**	
	N=34	***%***	**N=18**	***%***
Improvement	21	*61.8*	13	*72.2*
Remain the Same	6	*17.6*	4	*22.2*
Decrease	7	*20.6*	1	*5.56*

5.3.3 Primary Outcomes

Theme: General Knowledge

Inflammatory Bowel Disease Knowledge Inventory Device 2 (IBD-KID2)

The pediatric-onset group had a mean IBD-KID2 score of 10.5 (95% CI: 9.66, 11.3), while the adult-onset group had a mean IBD-KID2 score of 11.8 (95% CI: 10.7, 12.9). The proportion of participants who responded incorrectly to each of the 15 questions in the IBD-KID2 is in **Table 5.6**.

Table 5.6 IBD-KID2 Questions Answered Incorrectly by IBD Onset Group

	Pediatric-onset IBD patients		**Adult-onset IBD patients**	
	N (%)	*95% CI*	N (%)	*95% CI*
1. From start to finish, the correct order of the digestive tract is:				
Incorrect Answer	8 (21.6%)	*9.80%, 38.2%*	5 (26.3%)	*9.20%, 51.2%*
2. Doctors and scientists know what causes IBD.				
Incorrect Answer	6 (16.2%)	*6.20%, 32.0%*	4 (21.1%)	*6.10%, 45.6%*
3. Emotional stress can trigger a flare-up of IBD.				
Incorrect Answer	1 (2.70%)	*0.100%, 14.2%*	3 (15.8%)	*3.40%, 29.6%*
4. The reason someone might have a colonoscopy of their large bowel is to:				
Incorrect Answer	2 (5.40%)	*0.700%, 18.2%*	2 (10.5%)	*1.30%, 33.1%*
5. IBD can affect organs other than the bowels.				

Incorrect Answer	**13 (35.1%)**	***20.2%, 53.5%***	**1 (5.30%)**	***0.100%, 26.0%***
6. Which one fact about Osteoporosis (weakening of your bones) is true?				
Incorrect Answer	10 (27.0%)	*13.8%, 44.1%*	3 (15.8%)	*3.40%, 39.6%*
7. IBD that is in remission can slow down a young person's growth.				
Incorrect Answer	**27 (73.0%)**	***55.9%, 86.2%***	**10 (52.6%)**	***28.9%, 75.6%***
8. How do biologic medicines work?				
Incorrect Answer	6 (16.2%)	*6.20%, 32.0%*	2 (10.5%)	*1.30%, 33.1%*
9. If a person with IBD has had no symptoms for a few months they should stop taking their drugs.				
Incorrect Answer	3 (8.10%)	*1.70%, 21.9%*	0 (0.00%)	*0.000%, 17.6%**
10. If both parents have IBD their children will definitely develop IBD.				
Incorrect Answer	11 (29.7%)	*15.9%, 47.0%*	4 (21.1%)	*6.10%, 45.6%*
11. Which one fact about complementary and alternative products is true? (example – herbal drugs)				
Incorrect Answer	11 (29.7%)	*15.9%, 47.0%*	4 (21.1%)	*6.10%, 45.6%*
12. If a person gets side effects from taking steroids they should stop taking them at once.				
Incorrect Answer	20 (54.1%)	*36.9%, 70.5%*	8 (42.1%)	*20.3%, 66.5%*

13. Not eating certain foods will stop you having IBD flares (example - milk).				
Incorrect Answer	**26 (70.3%)**	***53.0%, 84.1%***	**7 (36.8%)**	***16.3%, 61.6%***
14. Which one fact about IBD surgery is true?				
Incorrect Answer	2 (5.40%)	*0.70%, 18.2%*	0 (0.000%)	*0.000%, 17.6%**
15. People with IBD can get all the nutrients they need if they eat the right foods.				
Incorrect Answer	21 (56.8%)	*39.5%, 72.9%*	8 (42.1%)	*20.3%, 66.5%*

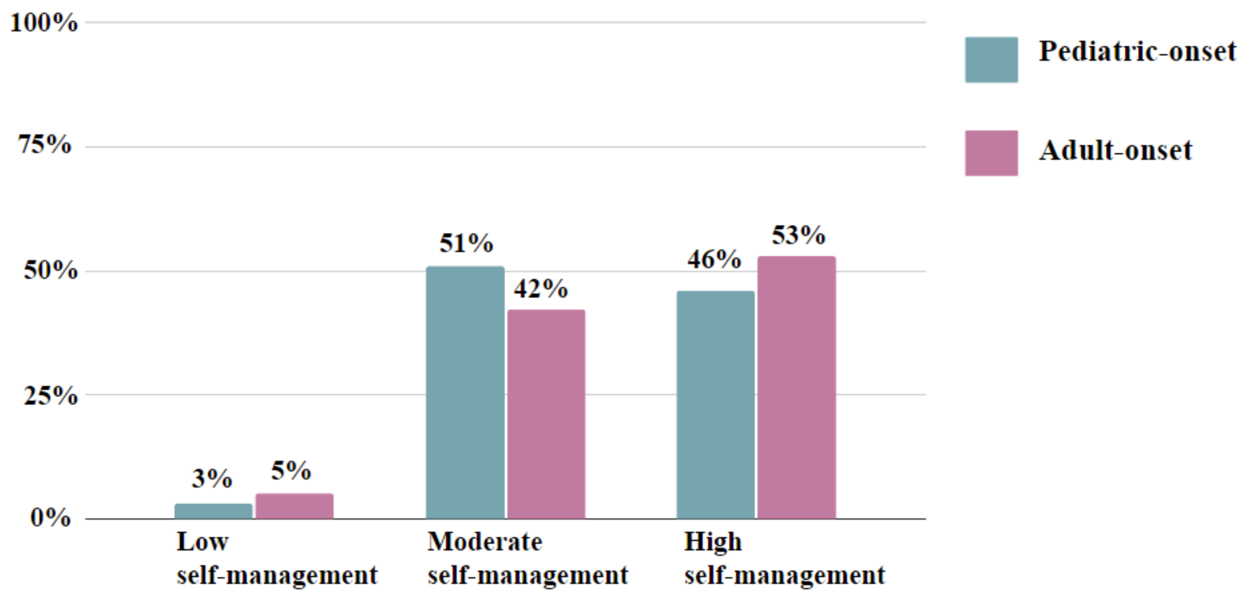
Theme: Independence in One's Care

Self-Management Questions

I measured self-management across ten questions. Total scores can range from 10-60 with a higher score representing more independence in disease management. The overall median score on the ten self-management questions was 46 (IQR: 36-56) in the pediatric-onset group and 52 (IQR: 42-56) in the adult-onset group. **Appendix H** contains the proportion of responses for each self-management question by onset group type.

I then classified total scores into high self-management (scores of 50-60), moderate self-management (scores 21-49), and low-self management (scores 10-20). **Figure 5.4.** shows the proportion of each self-management score category by IBD onset group type.

Figure 5.4. Self-Management in Study Participants by IBD Onset Group.



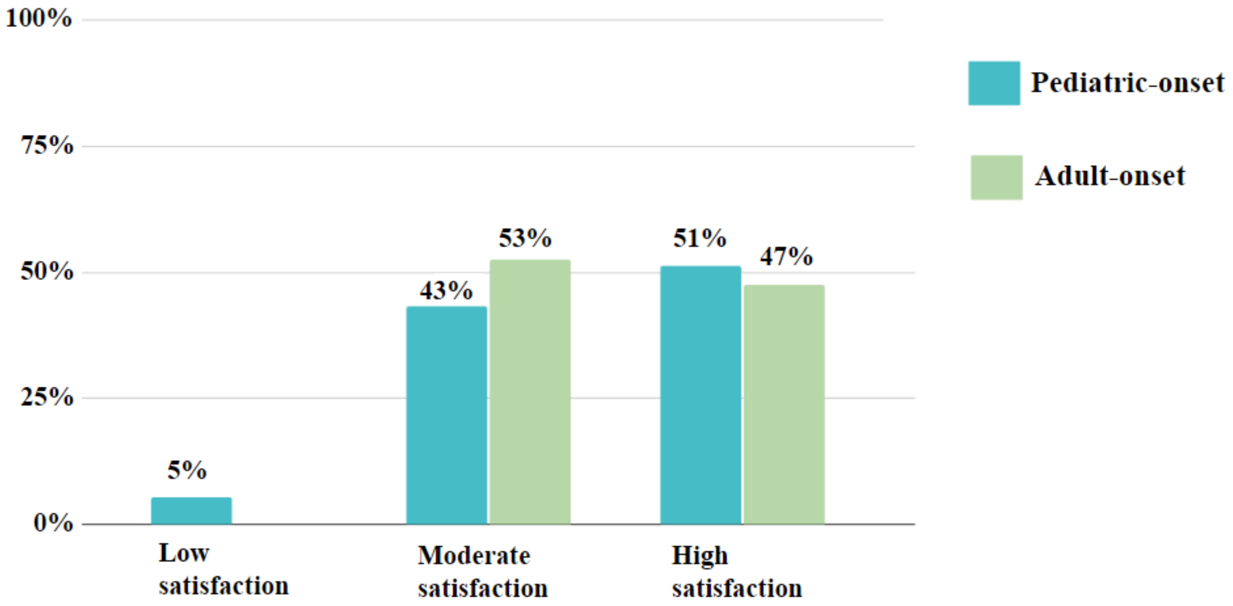
Themes: Relationship with/Trust in Adult Care Team, Care Stability, & Care Team Management

Relationship with IBD Care Team

I measured participants' reported relationship with their IBD care team across 12 different statements. Total scores can range from 0-48 with a higher score representing a greater satisfaction with the relationship with the IBD care team. The overall mean score in the pediatric-onset group was 37.4 (95% CI: 34.9, 39.9), while the overall mean score in the adult-onset group was 37.5 (95% CI: 33.9, 41.1). **Appendix I** contains the proportion of responses for each relationship with care team statement by IBD onset group type.

I then classified scores into high satisfaction (scores 36-48), moderate satisfaction (scores 25-36), and low satisfaction (scores 0-24). **Figure 5.5** includes the proportion of each relationship rating category by IBD onset group type.

Figure 5.5. Relationship with IBD Care Team in Study Participants by IBD Onset Groups.



Theme: Disease Management

The Medication Adherence Report Scale (MARS-5)

The Medication Adherence Report Scale 5 (MARS-5) was administered to participants who indicated that they were prescribed an IBD medication that relies on self-administration (injection, oral, enemas, suppositories); therefore, patients on biologic monotherapy did not complete the MARS-5. Nineteen participants in the pediatric-onset group and 16 in the adult-onset group completed the MARS-5 medication adherence questionnaire. Total scores on the MARS-5 range from 5-25 with a higher score corresponding to higher adherence. 84.2% (16/19) of participants in the pediatric-onset group and 93.8% (15/16) in the adult-onset group achieved scores equal to or greater than 20. **Table 5.7** includes the proportion of responses to each response option of the MARS-5 by IBD onset group.

Table 5.7 MARS-5 Response Options by IBD Onset Group.

Reasons for missing medications	**Pediatric-onset IBD patients (N=19)**		**Adult-onset IBD patients (N=16)**	
I forget to take them	N	*95% CI*	N	*95% CI*
Never or Rarely	13 (68.4%)	*43.4%, 87.4%*	13 (81.3%)	*54.4%, 96.0%*
Sometimes	4 (21.1%)	*6.05%, 45.6%*	2 (12.5%)	*1.60%, 38.3%*
Often or Always	2 (10.5%)	*1.30%, 33.1%*	1 (6.30%)	*0.200%, 30.2%*
I alter the dose				
Never or Rarely	19 (100.0%)	*82.4%-100.0%**	13 (81.3%)	*54.4%, 96.0%*
Sometimes	-	-	3 (18.8%)	*4.10%, 45.6%*
Often or Always	-	-	-	-
I stop taking them for a while				
Never or Rarely	17 (89.5%)	*66.9%, 98.7%*	15 (93.8%)	*69.8%, 99.8%*
Sometimes	1 (5.26%)	*0.100%, 26.0%*	1 (6.30%)	*.200%, 30.2%*
Often or Always	1 (5.26%)	*0.100%, 26.0%*	-	-
I decided to miss out a dose				
Never or Rarely	17 (89.5%)	*66.9%, 98.7%*	14 (87.5%)	*61.7%, 98.4%*
Sometimes	2 (10.5%)	*1.300%, 33.1%*	1 (6.30%)	*.200%, 30.2%*
Often or Always	-	-	1 (6.30%)	*.200%, 30.2%*
I take less than instructed				
Never or Rarely	19 (100.0%)	*82.4%-100.0%**	15 (93.8%)	*69.8%, 99.8%*

Sometimes	-	-	-	-
Often or Always	-	-	1 (6.30%)	*.200%, 30.2%*

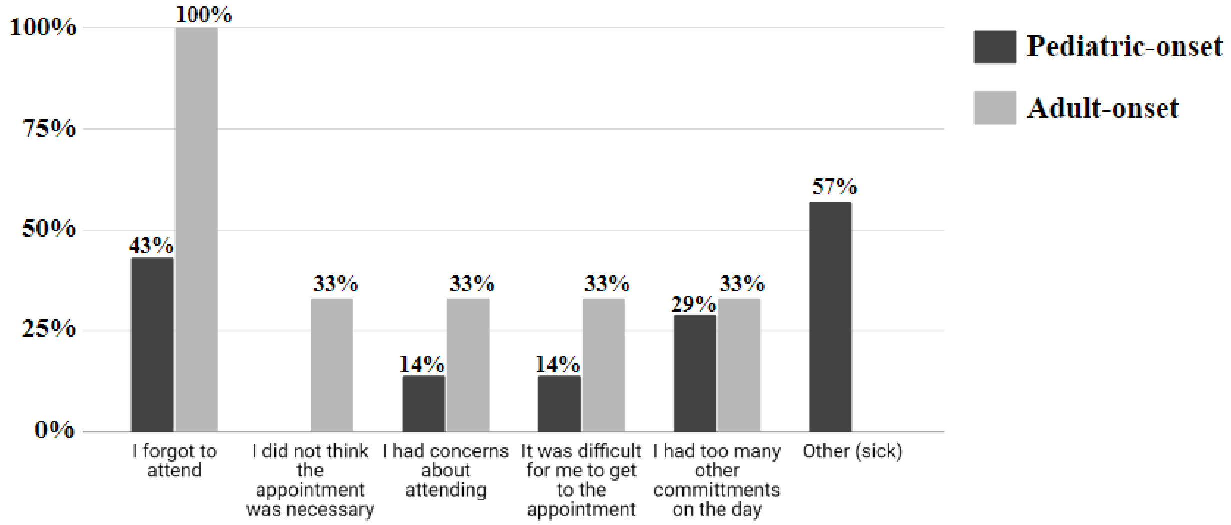
*One-sided 97.5% CI

The Medication Adherence Report Scale (MARS-5): Medical Appointments

Seven participants (18.9%) with pediatric-onset IBD and three (15.8%) with adult-onset IBD indicated they had missed at least one medical IBD appointment in the past year. Scheduled medical appointments included infusion, endoscopy, and clinical medical appointments. Of the ten participants who missed at least one appointment, seven (70.0%) indicated that they had only missed one IBD medical appointment in the past year, two indicated three (20.0%), and one (10.0%) estimated between 5-8. Participants' reasons for missing appointments are reported in **Figure 5.6**.

*Participants were able to select more than one response

Figure 5.6 Reasons for Missing Medical Appointments by IBD Onset Group



5.3.4. Exploratory Variables

5.3.5 IBD Impact on Life Domains

As previously outlined, the Secondary 7 Lifestyle Effects Screening (S7-LES) assesses the impact of a chronic illness (IBD) on seven different life domains. Thirty-two (86.5%) participants in the pediatric-onset group and 16 (84.2%) in the adult-onset group indicated IBD impacted at least one life domain. In the pediatric-onset group, the mean number of life domains that participants reported being impacted by their IBD was 2.73 (95% CI: 2.04, 3.42). In the adult-onset group, the mean number of impacted life domains was 2.84 (95% CI: 1.94, 3.74).

For each life domain that participants indicated was impacted by their IBD, they were asked whether they were experiencing emotional difficulties as a result of the impact of IBD on that life domain. Twenty-four (64.9%) participants in the pediatric-onset group and 16 (84.2%) in the adult-onset group indicated that they were experiencing emotional difficulties in at least one life domain. The mean number of life domains participants were experiencing emotional difficulties in was 2.53 (95% CI: 1.75, 3.31) in the pediatric-onset group and 2.69 (95% CI: 1.70, 3.67) in the adult-onset group. **Figures 5.7.1** and **5.7.2** presents the proportions of life domains impacted by IBD and the proportions of participants experiencing emotional difficulties within each life domain. **Appendix J** contains the distribution of responses for each life domain question.

Figure 5.7.1 Life Domains Impacted by IBD by IBD Onset Group

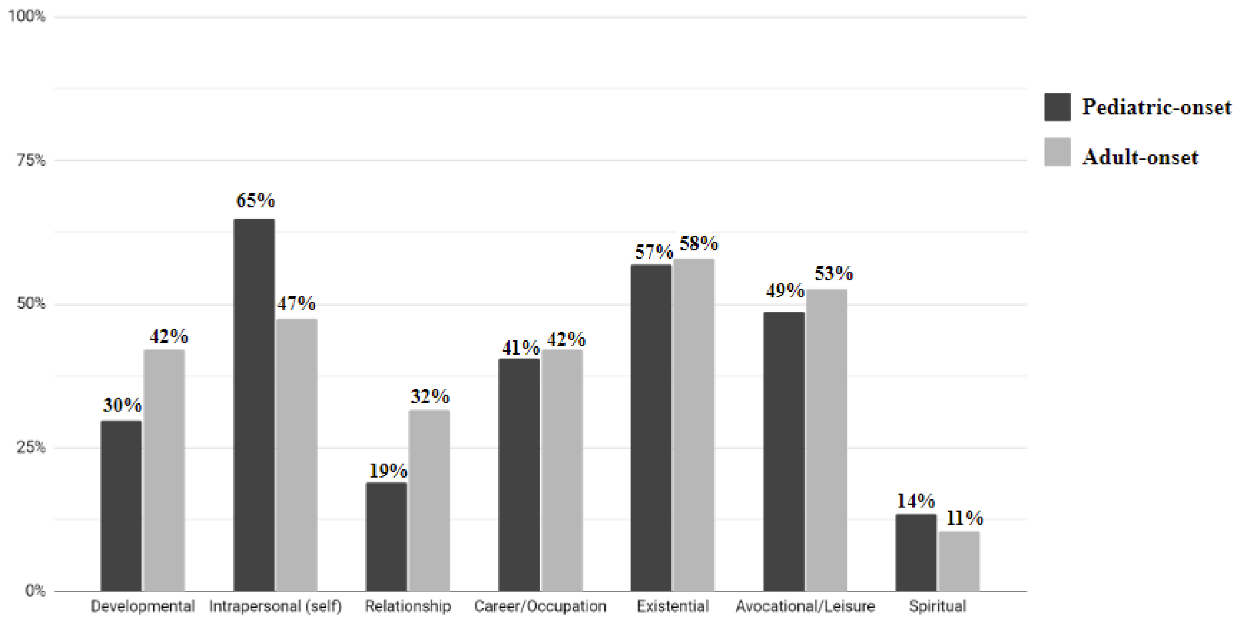
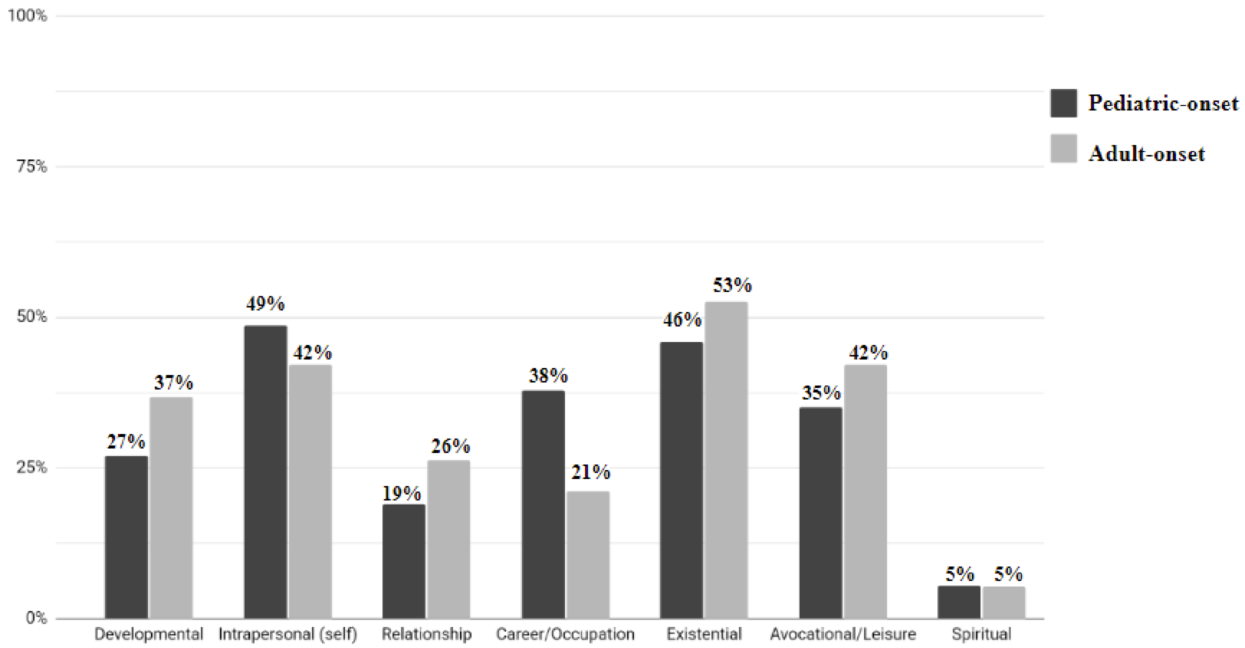


Figure 5.7.2 Life Domains Study Participants are Experiencing Emotional Difficulties in by IBD Onset Group.



5.3.6. Shame and Resilience

Chronic Illness-Related Shame Scale (CISS)

As previously outlined, total scores on the Chronic Illness-Related Shame Scale can range from 0-28 with scores on each question ranging from 0-4. A higher score indicates higher level of shame associated with illness. The mean score on the Chronic Illness-Related Shame Scale was 10.0 (95% CI: 7.61, 12.4) in the pediatric-onset group and 10.4 (95% CI: 6.80, 13.9) in the adult-onset group. Further, 27.0% of participants in the pediatric-onset group and 31.6% of participants in the adult-onset group obtained scores of 14-28, which corresponds to a combination of the response options ‘sometimes’, ‘frequently’ and ‘always true’. **Table 5.8** displays mean scores for each question of the chronic illness-related shame scale. **Appendix K** contains the distribution of response options to each statement on the CISS.

Table 5.8 Mean Scores on Each Question of the Chronic Illness Related Shame Scale by IBD Onset Group.

	Pediatric-onset IBD patients		**Adult-onset IBD patients**	
	Mean	*95% CI*	**Mean**	*95% CI*
I feel isolated/alone due to my illness.	**1.51**	*1.15, 1.88*	**1.58**	*1.06, 2.09*
I’m ashamed of talking with others about my illness or symptoms	**1.57**	*1.19, 1.95*	**1.68**	*1.02, 2.35*
I feel inferior and disregard myself because of my illness.	**1.08**	*0.740, 1.43*	**1.00**	*0.440, 1.56*
I feel that my illness is embarrassing.	**1.59**	*1.15, 2.04*	**1.84**	*1.17, 2.51*

I'm insecure due to my illness.	**1.57**	*1.16, 1.98*	**1.74**	*1.04, 2.43*
I feel that others may evaluate me negatively (or criticize me) due to my illness and symptoms.	**1.35**	*0.920, 1.78*	**1.42**	*0.770, 2.07*
I feel inadequate because of my illness and symptoms.	**1.32**	*0.920, 1.73*	**1.11**	*0.460, 1.75*

Connor-Davidson Resilience Scale (CD-RISC-10)

As outlined in Chapter 5.5.3, total scores on the Connor-Davidson resilience scale (CD-RISC-10) can range from 0-40. A higher score indicates greater resilience associated with illness. The mean score on the CD-RISC-10 scale was 26.7 (95% CI: 24.5, 28.9) in pediatric-onset group and 28.8 (95% CI: 25.0, 32.6) in the adult-onset group. 11.1% of participants in the pediatric-onset and 27.8% of participants in the adult-onset group met the score cut off for high resilience (high resilience score ≥ 35). **Table 5.9** displays mean scores for each question of the Connor-Davidson resilience scale. **Appendix L** contains the distribution of response options to each statement on the CD-RISC-10.

Table 5.9 Mean Scores on Each Question of the Connor-Davidson Resilience Scale by IBD Onset Group

	Pediatric-onset IBD patients		**Adult-onset IBD patients**	
	Mean	*95% CI*	**Mean**	*95% CI*
I am able to adapt when changes occur.	**2.86**	*2.60, 3.12*	**2.84**	*2.44, 3.24*
I can deal with whatever comes my way.	**2.70**	*2.44, 3.00*	**2.84**	*2.39, 3.31*

I try to see the humorous side of things when I am faced with problems.	**2.78**	*2.47, 3.09*	**3.16**	*2.76, 3.56*
Having to cope with stress can make me stronger.	**2.43**	*2.08, 2.78*	**2.58**	*2.02, 3.14*
I tend to bounce back after illness, injury, or other hardships.	**2.97**	*2.73, 3.21*	**2.95**	*2.51, 3.39*
I believe I can achieve my goals, even if there are obstacles.	**3.05**	*2.80, 3.30*	**3.11**	*2.65, 3.56*
Under pressure, I stay focused and think clearly.	**2.49**	*2.10, 2.88*	**2.79**	*2.35, 3.23*
I am not easily discouraged by failure.	**2.22**	*1.87, 2.56*	**2.56**	*2.10, 3.01*
I think of myself as a strong person when dealing with life's challenges and difficulties.	**2.78**	*2.44, 3.13*	**2.79**	*2.20, 3.38*
I am able to handle unpleasant or painful feelings like sadness, fear, and anger.	**2.53**	*2.20, 2.86*	**2.95**	*2.57, 3.32*

5.4 Discussion

In this discussion, I first discuss the objective of assessing the achievement of health care autonomy indicators in patients with pediatric-onset IBD who have transferred from pediatric to adult care. I then discuss the second objective of assessing similarities and differences between the participants with pediatric-onset and those with adult-onset IBD.

5.4.1 Achievement of Health Care Autonomy Indicators in Patients with Pediatric-onset IBD

For the first objective of assessing the overall achievement of health care autonomy indicators in participants with pediatric-onset IBD, the study findings suggest both support for the achievement of health care autonomy indicators and areas where more support is needed for participants. Participants with pediatric-onset IBD had adequate overall IBD knowledge, as indicated by a mean score of 10.5 on the IBD-KID2. This mean score is comparable with the mean score of 10.9 reported in a study that validated the use of IBD-KID2 in 75 adults with IBD[18]. While the overall IBD knowledge among participants was good, the results also suggest the need for further education on specific topics in this patient population. For example, a large proportion (73.0%) of participants with pediatric-onset IBD selected the incorrect answer to '*IBD that is in remission can slow down a young person's growth*' and '*Not eating certain foods will stop you having IBD flares*' which was answered incorrectly by 70.3% of participants with pediatric-onset IBD. Additionally, over half of these participants selected the incorrect answer on the questions about steroids (54.1%) and getting nutrients from food (56.8%).

A large proportion (46.0%) of participants with pediatric-onset IBD had a high level of independence in their IBD care based on the scores on the ten self-management questions, which suggests that most participants with pediatric-onset IBD have taken on most of the responsibility for their disease management. While there was a low proportion of these participants who had a score in the 'low self-management' category (2.70%), most participants (51.4%) had scores in the moderate-self management category. The moderate self-management category reflects aspects of IBD care where patients have not yet attained full independence as they continue to rely on other individuals (e.g., parents or partners), for either the complete IBD management or assistance in their IBD management. Patients with scores categorized into the moderate self-management group may benefit from additional support to attain full independence in managing their IBD care.

Although the majority (51.4%) of participants with pediatric-onset IBD reported a total score corresponding to high satisfaction with their relationship with their IBD care team, a large proportion (43.2%) reported a total score corresponding to moderate satisfaction. Statements with a higher proportion of 'neutral' or disagree' responses pertain to aspects of holistic care. For example, 37.6% of participants with pediatric-onset IBD answered 'neutral' or 'disagree' to the statement, '*I feel my health care team supports my goals beyond my disease.*' and 40.0% answered 'neutral' or 'disagree' to the statement, '*I feel my health care team takes the time to get to know me*.' These statements in particular represent an area where the health care team can improve on the care delivered to ultimately better support patients.

With respect to the theme of disease management, 84.2% of participants with pediatric-onset IBD reported scores corresponding to high medication adherence (≥35). Additionally, 10.5% of these participants selected 'often' or 'always' to the statement, '*I forget to take them*' as a reason for missing medications. Seven (18.9%) participants with pediatric-onset IBD reported missing at least one medical appointment in the past year. Of these seven participants, three reported missing their medical appointment because they were sick, while three reported missing their medical appointment because they forgot about it. These results suggest that although adherence to medication and medical appointments was high, there remains a proportion of patients who may benefit from supports to enhance their autonomy.

To conclude, while most participants with pediatric-onset IBD who have transferred from pediatric to adult care demonstrated achievement of some health care autonomy indicators, there still remain areas in need of improvement. For example, most scores on self-management and relationship with IBD care team fell into the moderate category, which suggests that these are areas where further support may be beneficial in helping patients achieve higher scores. Similarly, scores on specific IBD-KID2 questions demonstrate areas where most patients did not have adequate knowledge (e.g., impact of remission, relationship with food, and IBD flares). Additionally, since forgetfulness was identified in participants with pediatric-onset IBD as the most common reason for nonadherence to both medication and medical appointments, supports could prioritize providing patients with resources, such as appointment reminder apps, to help them keep track of appointments.

5.4.2 Similarities and Differences of Achievement of Health care Autonomy Indicators in Patients with Pediatric-Onset IBD and Patients with Adult-Onset IBD

Participants in the pediatric-onset group reported a somewhat lower average rating of their level of comfort interacting with the healthcare system (mean score: 7.19) compared to those in the adult-onset group (mean score: 8.11). Further, the pediatric-onset group had a substantially higher proportion of participants who reported a decrease in level of comfort interacting with the healthcare system from diagnosis to now when compared to the adult-onset group (20.6% vs. 5.56%). While the clinical significance of a one-point difference in the level of comfort between the groups is unknown, the results suggest that prior experience with pediatric care may have an impact on current level of comfort in adult care.

The results suggest similarities and differences in the achievement of health care autonomy indicators between participants with pediatric-onset and those with adult-onset IBD. With respect to IBD knowledge, participants in the pediatric-onset group scored slightly lower than participants in the adult-onset group with mean scores of 10.5 (pediatric-onset) and 11.8 (adult-onset). While the mean score for the adult-onset group surpassed that of the pediatric-onset group by 1.3 points, it important to consider whether this difference holds clinical significance in terms of differences in patient outcomes. Further, while As mentioned above, the mean score of 10.5 in the pediatric-onset group is consistent with the validation study in adults with IBD that reported a mean score of 10.9, but the mean score in the adult-onset group (11.8) is slightly higher than the validation study[18].

The self-management mean scores between the pediatric-onset (46) group and the adult-onset group (52) were similar with indications of slightly higher independence in the adult-onset group. Fishman et al (2016) administered the same questions used in my study to 141 IBD patients aged 25 to 50 (mean age of 36) and found a higher level of independence in completing tasks compared to my results[19]. For example, in the older adult study, 92.9% of patients indicated ‘only me’ to the answering doctor’s questions during the visit where in my study ‘only me’ was selected by 59.5% of participants in the pediatric-onset group and by 78.9% of participants in the adult-onset group. Similarly, in the older adult study, 91.5% of participants selected ‘only me’ when asked who scheduled their own office visit and 85.1% selected ‘only me’ when asked who contacted the doctor or nurse between visits if there was a problem. In my study, 56.8% of pediatric-onset patients and 89.5% of adult-onset patients scheduled their own office visits, while 62.2% of pediatric-onset patients and 89.5% of adult-onset patients were the ones who primarily contacted their health care team. Interestingly, in the older adult study, 56.0% of older adults independently picked up medication from the pharmacy. This finding is similar to my study that reported 59.5% of participants in the pediatric-onset group and 52.6% of those in the adult-onset group were fully independent in picking up their medications. A potential explanation for the lower independence observed in picking up medications, as suggested by the older adult study, may be that picking up medications is influenced more by convenience than independence. Furthermore, in the context of my study, convenience may be accentuated, given that the participants were at an age when individuals are less likely to have the means or ability to drive themselves to a pharmacy. The comparison between my study and the older age study on independence suggests that participants in the emerging adulthood period with pediatric-onset IBD lack full independence in their care, whereas those with adult-onset IBD exhibited greater independence. While a higher proportion of participants in the pediatric-onset group (51.4%) fell into the moderate self-management category compared to those in the adult-onset group (42.1%), it is worth noting the potential for differences within the moderate self-management category in the responses of each group. For instance, the pediatric-onset group may exhibit greater diversity in the responses ranging from ‘only me’, ‘mostly me’, to ‘me and parent’, whereas the adult-onset group may exhibit more polarization, with responses tending to be either ‘only me’ or ‘mostly parent’. These results suggest that participants with pediatric-onset IBD may require more time to achieve independence in managing their IBD compared to those with adult-onset IBD. Furthermore, the suggested delay in achieving full independence among participants with pediatric-onset IBD may also imply parental reluctance to fully handover responsibility for IBD management to their child.

The mean overall score of participants' reported relationship with their IBD care team was nearly identical between the pediatric-onset group (37.4) and the adult-onset group (37.5). The finding of nearly identical scores is interesting as pre-transfer patients with various chronic diseases have described difficulties and sadness about leaving behind the long-term relationship they had with their pediatric care team[27-30]. It might be anticipated that as a result of being reluctant to give up their long-term relationship with their pediatric team, patients with pediatric-onset chronic diseases may be more critical of or dissatisfied with their relationship with their adult team. My results suggest that the experience in pediatric care may not negatively impact participants' perceptions of their relationship with their adult care team, as evidenced by similar overall mean scores between participants with pediatric-onset IBD and those with adult-onset IBD who have not had an established relationship with a pediatric care team.

Participants in the pediatric-onset group and those in the adult-onset group had high adherence to medications (≥80%) according to the medication adherence report scale (MARS-5). Although my study had a small number of participants who completed the MARS-5, the results are consistent with other studies in IBD that showed adherence rates of ≥80%[31,32]. Crohn's disease has been identified as a predictor of medication adherence; therefore, the high medication adherence in my study could be attributed to the high proportion of participants with Crohn's disease (70.9% of pediatric-onset patients, 78.9% of adult-onset patients)[31]. Further, while our study used a cut off for medication adherence, an Australian study with 129 IBD patients (50 pediatric, 38 transitioned, and 41 young adults) found no significant differences in medication nonadherence between adults with pediatric-onset IBD who have transitioned to adult care and those with adult-onset IBD[32]. This finding from the Australian study complements our finding of similar proportions of patients with medication adherence between young adults with pediatric-onset IBD and those with adult-onset IBD, suggesting that medication adherence may not be influenced by age period of IBD onset.

As it relates to medical appointment adherence, there were similarities in the proportions of participants in the pediatric-onset group (15.8%) and those in the adult-onset group (18.9%) who missed at least one medical appointment in the past year. Although IBD studies have found that patients are more likely to miss medical appointments during transition[4,33,34], my results suggest that the number of young adults with pediatric-onset IBD who missed at least one medical appointment is similar to those diagnosed with adult-onset IBD. It is possible that in medical appointment adherence between the groups would emerge with a larger study size.

5.4.3 Exploratory Variables

As previously outlined, I included a few exploratory variables that were not identified as health care autonomy indicators, but could be used to inform future research.

Impact of IBD on Life Domains, Resilience, and Shame

The results of the secondary 7 lifestyle effects screening (S7-LES) suggest that participants in both the pediatric-onset and those in the adult-onset group report a similar mean number of life domains impacted by IBD (2.73 vs 2.84) and report experiencing emotional difficulties in a comparable number of life domains (2.53 vs. 2.69).

The mean score on the Chronic Illness-related Shame Scale (CISS) was similar in the pediatric-onset (10.0, [95% CI: 7.61, 12.4]) group and the adult-onset group (10.4, [95% CI: 6.80, 13.9]). In a 2020 Portuguese study with 161 IBD patients aged 19-76 years old (mean age: 36.7), the mean CISS score was 8.64[35]. In a study with college students who had a chronic health condition the mean CISS score was 6.58. Although this study had participants who were closer in age to the participants used in my study, the most common chronic health condition reported was asthma (22.6%) with only 9.6% having Crohn's disease; therefore, this study may not be relevant to mine as the type of chronic health condition may impact CISS scores[36]. Similarly, my study had higher mean scores than studies of shame in adults with breast cancer (mean: 6.75)[37] and knee osteoarthritis (mean: 4.25)[38]. The finding of higher shame scores in my study compared to other conditions may be attributed to specific challenges associated with IBD, such as the unpredictable nature of symptoms (e.g., potential bowel urgency and incontinence), which may negatively impact social relationships and self-perception. Collectively, these factors may contribute to a higher level of shame that may be less common in other chronic conditions, where such factors might be less prevalent.

Greater resilience is thought to reduce the effects of shame and ultimately contribute to greater quality of life in IBD patients[39,40]. In my study, the mean score on the Connor-Davidson resilience scale (CD-RISC 10) was 26.7 (95% CI: 24.5, 28.9) in the pediatric-onset group and 28.8 in the adult-onset group (95% CI: 25.0, 32.6).The resilience scores in the two groups were similar or slightly lower than other studies in adults with IBD (mean CD-RISC of 29)[24] and in adolescent/young adult IBD patients (mean CD-RISC of 30.5)[23]. Further, participants in both groups in my study exhibited lower or slightly lower resilience scores compared to nationwide studies involving over 2,500 young adults aged 18-35 without a chronic condition, conducted in Poland (CD-RISC mean score: 35.5) and Scotland (CD-RISC mean score: 29.6)[41,42].

5.4.4 Strengths and Limitations

A key strength of this study is that it takes a multidisciplinary approach in assessing multiple aspects of transition outcomes, rather than focusing on one or two outcomes. The online asynchronous delivery of the questionnaire provided participants with flexibility to complete it so that participants who did not have time in clinic to complete the questionnaire, could still participate in the study. Additionally, participants who may have declined participation in other research studies, such as semi-structured interviews or prospective studies requiring follow-up, may have been more likely to participate in the one-time survey study due to low demand. This explanation may be supported by my data in which 53.5% of participants indicated that they were not interested in participating in an interview study about challenges they faced in their IBD care. If I had chosen a different study design that required follow-up or was more time-intensive, there might have been lower participant participation, potentially limiting the generalizability of the findings.

This study has several limitations. Firstly, while I utilized tools validated for the IBD population, some health care autonomy indicators could not be measured by existing tools. In such cases, I created statements based on the indicator descriptions. However, this approach introduced some limitations, as these statements might not fully capture the intended indicators. This could lead to inconsistent results among participants and limit generalizability of the findings. An additional limitation is a small sample size, particularly in the adult-onset group there were only 19 patients. Due to the limited sample size, there were instances of low counts for certain outcomes (e.g., one pediatric-onset participant with low self-management). As a result, the small study size limited my ability to estimate associations with adequate precision.

Additional limitations relate to the participant characteristics and the generalizability of the study results. First, as most participants were seen by one of four gastroenterologists, there may be similarities in their care experiences. Similarities in care experience may influence responses to the relationship with IBD care team statements so that there is less variability in responses.

Self-selection bias may also be a limitation as participants who agreed to complete the questionnaire might have exhibited greater independence and responsibility in other areas of their life, as well as greater independence in their IBD care and greater IBD knowledge, compared to those who do not complete the questionnaire. If the study is impacted by a self-selection bias of this kind, I may have overestimated the achievement of favorable outcomes in the population. Unfortunately, because of the types of recruitment strategies used, I am unable to know how many patients were made aware of the study and declined participation.

This study may be subject to differential misclassification due to the influence of social desirability as participants may be reluctant to disclose negative experiences and to select extreme answers. For example, participants may be less inclined to select ‘disagree’ or ‘strongly disagree’ to a statement about their IBD care team and instead select ‘neutral’. If this is the case, the results may have appeared more favorable, suggesting that participants achieved better outcomes. To counter some of the influence of social desirability, I defined moderate self-management and moderate satisfaction of relationship with IBD care term to include a combination of the ‘strongly disagree’, ‘disagree’, and ‘neutral’ responses.

5.5 References

1. Arnett JJ. Emerging Adulthood: What Is It, and What Is It Good For? *Child Dev Perspect*. 2007;1:68-73.

2. Arnett JJ. Emerging adulthood: A theory of development from the late teens through the twenties. *Am Psychol*. 2000;55(5):469.

3. Pamela M, Erin H, Lynne G, et al. A retrospective look at an IBD transition initiative. *Inflamm Bowel Dis*. 2014;20:S88.

4. Bollegala N, Brill H, Marshall JK. Resource utilization during pediatric to adult transfer of care in IBD. *J Crohns Colitis.* 2013;7(2):e55-60.

5. Zhao X, Bjerre LM, Nguyen GC, et al. Health services utilization in adolescents with inflammatory bowel disease transitioning from pediatric to adult care: A population based, cohort study. *J Pediatr Gasteroenterol Nutr*. 2016;63:S354.

6. Setya A, Molina M, Homsi M, et al. Age-specific healthcare utilization trends in a transitional IBD population. *Gastroenterol*. 2020;18(6):S-735.

7. Testa A, Giannetti E, Rispo A, et al. Successful outcome of the transitional process of inflammatory bowel disease from pediatric to adult age: A five years experience. *Dig Liver Dis*. 2019;51(4):524-528.

8. El-Matary W, Carroll MW, Deslandres C, et al. The 2023 impact of inflammatory bowel disease in Canada: special populations—children and adolescents with IBD. *J Can Assoc Gastroenterol*. 2023;6(Supplement_2):S35-S44.

9. Bihari A, Hamidi N, Seow CH, Goodman KJ, Wine E, Kroeker KI. Defining transition success for young adults with inflammatory bowel disease according to patients, parents, and health care providers. *J Can Assoc Gastroenterol*. 2022;5:192-198.

10. Cho R, Wicket NM, Klassen AF, et al. Identifying Needs in Young Adults with Inflammatory Bowel Disease: A qualitative study. *Gastroenterol Nurs*. 2018;41(1):19-27.

11. Harris PA, Taylor R, Thielke R, et al. Research electronic data capture (REDCap) – A metadata-driven methodology and workflow process for providing translational research informatics support**.** *J Biomed Inform.* 2009;42(2):377-81.

12. Harris PA, Taylor R, Minor BL, et al. The REDCap consortium: Building an international community of software partners, *J Biomed Inform.* 2019;95:103208

13. Fu N, Bollegala N, Jacobson K, et al. Canadian consensus statements on the transition of adolescents and young adults with inflammatory bowel disease from pediatric to adult care: A collaborative initiative between the Canadian IBD transition Network and Crohn’s and Colitis Canada. *J Can Assoc Gastroenterol*. 2022;5(3):105-115.

14. Adler NE, Epel ES, Castellazzo G & Ickovics JR. Relationship of subjective and objective social status with psychological and physiological functioning: Preliminary data in healthy, White women. *Health Psychol*. 2000;9(6):586–592.

15. Sampasa-Kanyinga H & Hamilton HA. Does socioeconomic status moderate the relationships between school connectedness with psychological distress, suicidal ideation and attempts in adolescents? *Prev Med*. 2016;87:11-17.

16. Martin-Storey A, Marcellin S, Purtell KM, Tougas A, Lessard A. "*It's about having money, but also happiness*:" A qualitative investigation of how adolescents understand subjective status in themselves and others. *J Adolesc Health*. 2018;68(1): 198-206.

17. Bhandari A, Wagner T. Self-Reported utilization of health care services: improving measurement and accuracy. *Med Care Res Rev*. 2006;63(1):217-230.

18. Buerkle KS, Vernon-Roberts A, Ho C, Schultz M, Day AS. A Short Knowledge Assessment Tool is Valid and Acceptable for Adults with Inflammatory Bowel Disease. *Dig Dis Sci*. 2022;67: 2049-2058.

19. Fishman LN, Mitchell PD, Lakin PR, et al. Are Expectations Too High for Transitioning Adolescents With Inflammatory Bowel Disease? Examining Adult Medication Knowledge and Self-Management Skills. *J Pediatr Gasteroenterol Nutr*. 2016;63(5):494-499.

20. Horne R, Weinman H. Self-regulation and self-management in asthma: Exploring the role of illness perceptions and treatment beliefs in explaining non-adherence to preventer medication. *Psychol Heal*. 2002;17(1):17-32.

21. Hall SE & Hall MF. "Secondary 7 Lifestyle Effects Screening" *Managing the Psychological Impact of Medical Trauma: A Guide for Mental Health and Healthcare Professionals* (2017).

22. Campbell-Sills L, Stein MB. Psychometric analysis and refinement of the Connor–Davidson resilience scale (CD-RISC): validation of a 10-item measure of resilience. *J Trauma Stress*. 2007;20:1019–1028.

23. Carlsen K, Haddad N, Gordon J, et al. Self-efficacy and Resilience Are Useful Predictors of Transition Readiness Scores in Adolescents with Inflammatory Bowel Diseases. *Inflamm Bowel Dis*. 2017;23(3):341–346.

24. Philippou A, Sehgal P, Ungaro RC, et al. High Levels of Psychological Resilience Are Associated with Decreased Anxiety in Inflammatory Bowel Disease. *Inflamm Bowel Dis.* 2022;28(6):888–894.

25. Trindade IA, Ferreira C & Pinto-Gouveia J. Chronic Illness-Related Shame: Development of a New Scale and Novel Approach for IBD Patients' Depressive Symptomatology. *Clin Psychol Psychother*. 2017;24(1):255-263.

26. StataCorp. Stata Statistical Software Release 17. Published online 2021.

27. Ritholz MD, Wolpert H, Beste M, Atakov-Castillo A, Luff D, Garvey KC. Patient-Provider Relationships Across the Transition From Pediatric to Adult Diabetes Care: A Qualitative Study. *The Diabetes Educ*. 2014;40(1):40-47.

28. Gray WN, Schaefer MR, Resmini-Rawlinson A, Wagoner ST. Barriers to Transition from Pediatric to Adult Care: A Systematic Review. *J Pediatr Psychol*. 2018;43(5):488–502.

29. Sawin KJ, Rauen K, Bartelt T, et al. Transitioning Adolescents and Young Adults with Spina Bifida to Adult Healthcare: Initial Findings from a Model Program. *Rehabil Nurs J*. 2015;40(1):3-11.

30. Reiss JG, Gibson RW & Walker LR. Health Care Transition: Youth, Family, and Provider Perspectives. *Pediatr.* 2005;115(1):112–120.

31. Stone JK, Shafer LA, Graff LA, et al. Utility of the MARS-5 in Assessing Medication Adherence in IBD. *Inflamm Bowel Dis*. 2021;27(3):317-324.

32. Jeganathan J, Lee CH, Rahme A, et al. Pediatric-to-adult transition and medication adherence in patients with inflammatory bowel disease patients. *Inflamm Bowel Dis.* 2017;23(7):1065-1070.

33. Goodhand J, Dawson R, Hefferon MN, et al. Inflammatory bowel disease in young people: The case for transitional clinics. *Inflamm Bowel Dis*. 2010;16(6):947–952.

34. Cole R, Ashok D, Razack A, Azaz A & Sebastian S. Evaluation of outcomes in adolescent inflammatory bowel disease patients following transfer from pediatric to adult health care services: case for transition. *J Adolesc Health*. 2015;57(2):212-217.

35. Trindade IA, Ferreira C & Pinto-Gouveia J. Shame and emotion regulation in inflammatory bowel disease: Effects on psychosocial functioning. *J Health Psychol*. 2020;25(4):511-521.

36. Trindade IA, Duarte J, Ferreira C, Coutinho M & Pinto-Gouveia J. The impact of illness-related shame on psychological health and social relationships: Testing a mediational model in students with chronic illness. *Clin Psychol Psychother*. 2018;25(3):408-414.

37. Trindade IA, Marta-Simões J, Ferreira C & Pinto-Gouveia J. Chronic illness-related cognitive fusion explains the impact of body dissatisfaction and shame on depression symptoms in breast cancer patients. *Clin Psychol Psychother*. 2018;*25*(6):886-893.

38. Yeo JY, Lim CJ & Tan BY. Adaptation and validation of the chronic illness-related shame scale among patients with knee osteoarthritis in Singapore. *BMC Musculoskelet Disord*. 2023;24(1):633.

39. Luo D, Zhou M, Sun L, et al. Resilience as a Mediator of the Association Between Perceived Stigma and Quality of Life Among People with Inflammatory Bowel. *Front Psychiatry*. 2022;12:709295.

40. Ruddy J & Taft T. The pervasive impact of the stigmatization of gastrointestinal diseases—A patient's perspective. *Gastroenterol Clin*. 2022;*51*(4):681-695.

41. Metel D, Arciszewska A, Daren A, et al. Resilience and cognitive biases mediate the relationship between early exposure to traumatic life events and depressive symptoms in young adults. *J Affect Disord*. 2019; 254: 26-33.

42. Wetherall K, Cleare S, Eschle S, et al. From ideation to action: Differentiating between those who think about suicide and those who attempt suicide in a national study of young adults. *J Affect Disord*. 2018;241:475-483.

Part III: Bringing it all together: Improving Outcomes for IBD Transition

In the final chapter of this thesis, I bring together all the findings presented in this thesis through a discussion of the main findings and outline future directions. Importantly, I also provide personal reflections on the challenges I faced throughout this thesis.

Chapter 6. Conclusions

6.1 Summary of Findings

I characterized transition success by conducting semi-structured interviews with transitioned patients, their parents, and IBD health care providers. Through the interviews, I identified seven themes of outcomes signaling the achievement of transition success. The seven themes that emerged across the partner groups include, 1. Health Outcomes (Patients); 2. Care Stability (Patients); 3. Relationship with/Trust in Adult Care Team (Parents & Parents); 4. Care Team Management (Parents); 5. Disease Management (Parents & Providers); 6. General Knowledge (Providers); 7. Independence in One's Care (Patients, Parents & Providers). These themes characterize partners' perceptions of the indicators of successful transition, and also the difference between how each partner group characterizes successful transition.

The differences between each partner group are further demonstrated through the descriptions of transition facilitators and barriers from pediatric to adult care in Chapter 3. The findings suggest that partners view the following themes as facilitators of transition: 1. Preparedness (Patients, Parents & Providers); 2. Supportive Adult Care Team (Patients & Parents); 3. Patient Characteristics (Parents & Providers); 4. Supportive Parents and Home Environment (Providers). Partners view the following themes as barriers to transition: 1. Patient Factors (Providers & Parents); 2. Hovering Parents and Family Factors (Providers); 3. Navigating a New Health Care System (Patients); 4. Travel to Clinic (Patients & Providers). In the subsequent chapters, I refer to transition success outcomes as health care autonomy indicators.

Overall, the results of the cross-sectional study suggest that most patients with pediatric-onset IBD who transferred to adult care achieved adequate scores on health care autonomy indicators. An adequate achievement of health care autonomy is supported by IBD knowledge scores similar to those in the original studies, high or moderate self-management scores (98.3% of participants), high or moderate satisfaction of the relationship with IBD care team (94.6% of participants), and high medication and appointment adherence (84.2% & 81.1%). Scores on health care autonomy indicators measured in young adults with pediatric-onset IBD were similar compared to young adults with adult-onset IBD. These similarities existed in self-management (51.4% of participants), high satisfaction of the relationship with care team (47.4%) and high medication and appointment adherence (93.8% vs. 84.2%). IBD knowledge appeared to be slightly higher in the adult-onset group compared to the pediatric-onset group. Additionally, participants with adult-onset IBD demonstrated greater resilience, with a mean score of 28.8, compared to those with pediatric-onset IBD, who had a mean score of 26.7. I also found similarities with respect to the exploratory variables, such that both participants with pediatric-onset IBD and those with adult-onset IBD identified IBD as having an impact on more than one life domain, and had similar levels of shame related to their illness.

While the findings presented in this thesis offer valuable insights into the area of transition for IBD patients, it is important to acknowledge limitations regarding the generalizability and considerations of equity, diversity, and inclusion (EDI) within the study population. Firstly, nearly all participants in the qualitative study (Chapter 3) reported viewing their transition as successful, suggesting that the patient sample may primarily represent those who have had favorable transition experiences. Additionally, I conducted the semi-structured interviews virtually during the COVID-19 pandemic, which may have excluded patients without reliable communication means or those who had to work during the pandemic, potentially skewing the sample towards individuals of higher socioeconomic status. Furthermore, the participant characteristics in the cross-sectional study (Chapter 5) may limit the generalizability of the findings to the broader population of young adults with IBD. For example, over 70% of participants identified as white and over 90% were born in Canada. The perspectives of IBD patients from other racial backgrounds or those who have immigrated to Canada, and who may face different systemic and cultural challenges, are not represented in this study. Additionally, recruitment primarily from clinic settings may have limited the representativeness of the sample, as the perspectives of individuals who have difficulty accessing care or are in remission and do not frequently see their IBD provider may not be reflected in the findings. Overall, these limitations underscore the need to adopt more diverse and inclusive methodologies to ensure that the findings are applicable to the entire young adult with IBD population.

6.2 Challenges and Lessons Learned

The design of part I of this thesis began in March 2020. As a result, this study overlapped with the COVID-19 pandemic. Challenges related to starting a study during COVID-19 included a delay in obtaining necessary approvals due to the prioritization of COVID-19 studies and having to adapt to the COVID-19 restrictions in place leading to a change in the format of the semi-structured interviews from in-person interviews to virtual interviews. Once approvals were in place, the study had a high positive response rate, with 77% (17/22) of contacted patients agreeing to participate. Despite the challenges posed by the COVID-19 pandemic, it may have also benefited this study. Participants may have been at home with more time available to participate, and the virtual interview format was more widely accepted, potentially facilitating participation for participants who would have been unable to attend in-person interviews.

In part II of this thesis, the challenge was how best to measure the outcomes characterized in part I. Initially, I proceeded with conducting an electronic medical chart review of patients who had undergone the transition from pediatric to adult care within the past 5 years. I proceeded with extracting the identified outcome variables, but faced some challenges. The first challenge was that I was unable to extract all the outcome variables that were more patient-focused (e.g., disease knowledge, relationship with care team) and the outcome variables that I could extract were limited by the accuracy of provider notes (e.g., reporting of medication adherence, accurate disease history). The second challenge was that not all of the IBD clinics were on Connect Care at the time so I was restricted to using patients who transferred from the Edmonton Pediatric IBD Clinic to the University of Alberta IBD Clinic resulting in a sample size limitation (about 100-150 patients). Further, even with the use of administrative data, analysts were unable to distinguish IBD patients throughout Alberta who were diagnosed in pediatric care from those who were diagnosed in adult care without relying on hospitalizations or emergency department visits, which would exclude patients who met the criteria, but had not experienced one of these health care utilization events while in childhood/adolescence. For these reasons, I decided to proceed with the study outlined in this thesis.

Like the qualitative study, the cross-sectional study also experienced challenges. I experienced challenges mainly with time delays through needing to obtain permission from authors to use tools, and needing to obtain operational and administrative approvals to start patient recruitment from sites throughout Alberta.

Further, while most patients who were approached about the study expressed an interest in participating, individuals aged 18-25 represent a small proportion of IBD patients in Alberta, so recruitment took a long time. For example, the University of Alberta IBD clinic has approximately 6-10 patients a week meeting the study criteria so obtaining an adequate sample to participate in the study within timeframe of this thesis was difficult. Because of the low number of patients seen in clinic, efforts focused on expanding recruitment beyond clinics to include advertising the study in university emails, infusion clinics, on social media, and using lists of patients who had already consented to being contacted about research. While I attempted to anticipate and account for time delays before initiating this study, it proved challenging to predict the exact duration of delays, especially when delays affected subsequent steps of the study.

While both studies in this thesis experienced challenges, the qualitative study did not struggle with sample size; whereas, this was a challenge in the second study. Notably, the transition IBD population is relatively small, which could make recruitment a prolonged process. Given this constraint, qualitative studies may be more appropriate approach to provide rich data on aspects of the complex phenomenon of transition.

6.3 Future Directions

This thesis provides the foundation for future research. As outlined in the discussion of Chapter 3, the characterization of the indicators of successful transition provides guidance for the design of transition interventions that focuses on my study's definition of transition success. Additionally, efforts should focus on promoting facilitators and reducing barriers as characterized in Chapter 3.

The results suggest that there is a large proportion of patients with pediatric-onset IBD whose self-management score is in the moderate categories (e.g., 51.4% in self-management; 43.2% in relationship). Understanding the clinical significance of the scores is essential for setting targets for patient achievement. For example, exploring whether there are differences in clinical outcomes, such as disease activity, hospitalization, etc., between patients who fall into moderate or high categories on the scores would allow us to determine if there is benefit to delivering transition interventions to patients with moderate scores.

Further, since the study had a small sample size, I was unable to estimate associations between exposures and outcomes with adequate precision. For example, since most participants achieved high or moderate scores on self-management and only a few achieved low scores, the small number of participants with low self-management scores limited my ability to estimate associations with adequate precision. Future studies will focus on the recruitment of more participants. More participants will allow for the identification of predicators transition outcomes in participants with pediatric-onset IBD and those with adult-onset IBD. Overall, investigating predictors of poor outcomes will help identify patient populations that could benefit from interventions aimed at improving overall scores.

The exploratory variables in the cross-sectional study provided insight into the impact of IBD on various life domains, as well as insight into participant's IBD-related shame and resilience. Future studies should explore the relationship between these three variables and how these variables impact the achievement of health care autonomy indicators. Further, a large proportion of participants in both the pediatric-onset group and in the adult-onset group reported IBD impacting at least one life domain (86.5% & 84.2%) and reported experiencing emotional difficulties in at least one life domain (64.9% & 84.2%). These findings of the impact of IBD on life domains warrants future research focused on investigating the underlying reasons for why IBD is impacting their life domains. Additionally, future research should collaborate with patients to investigate optimal strategies for supporting patients with the aim of mitigating the impact of IBD. Studies could also investigate the impact of other chronic diseases on life domains to determine whether my findings are specific to IBD or similar to those with other chronic diseases.

Knowledge translation of the work presented in this thesis will be a central focus, ensuring a widespread awareness and impact of this scholarly work. Efforts will include disseminating research findings to health care providers through manuscript publication, conference presentations, and informal engagements to foster dialogue about the important contributions made in this thesis. A significant aspect of knowledge translation efforts will be engaging and collaborating with partners such as patients and parents. It is crucial that patients are informed about the outcomes and efforts to improve care for young adults with IBD. Future knowledge translation initiatives might involve establishing a patient advisory committee to collaborate with patients in interpreting the results and implementing findings. This collaboration could also extend to designing interventions to enhance the care provided to young adults with IBD.

6.4 Conclusion

To conclude, the work presented in this thesis contributes to improving the care delivered to young adults with IBD. By characterizing the outcomes of transition success, I was able to implement these findings by designing a cross-sectional study aimed at measuring these outcomes. This cross-sectional study reported that while most of the patients with pediatric-onset IBD achieved the indicators of transition success, there are areas, such as specific knowledge gaps and self-management tasks, where the health care team can better support patients. Overall, health care providers can develop a targeted approach to support patients in the achievement of the indicators of transition success; ultimately, promoting personalized IBD care.

Bibliography

Adler NE, Epel ES, Castellazzo G & Ickovics JR. Relationship of subjective and objective social status with psychological and physiological functioning: Preliminary data in healthy, White women. *Health Psychol*. 2000;9(6):586–592.

Afzali A, Wahbeh G. Transition of pediatric to adult care in inflammatory bowel disease: Is it as easy as 1, 2, 3? *World J Gastroenterol*. 2017;23:3624-3631.

American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatr*. 2002;110(6 Pt 2):1304–6.

Argyriou K, Kapsoritakis A, Oikonomou K, et al. Disability in patients with inflammatory bowel disease: correlations with quality of life and patient's characteristics. *Can J Gastroenterol Hepatol*. 2017;2017:6138105.

Arksey H, O'Malley L. Scoping studies: Towards a methodological framework. *Int J Soc Res Methodol*. 2005;8(1):19-32.

Arnett JJ. Emerging adulthood: A theory of development from the late teens through the twenties. *Am Psychol*. 2000;55(5):469.

Arnett JJ. Emerging Adulthood: What Is It, and What Is It Good For? *Child Dev Perspect*. 2007;1:68-73.

Avni-Biron I, Fraser G, Rosenbach Y, et al. Early outcomes for adolescent inflammatory bowel disease patients treated in a transition clinic. *J Crohns Colitis*. 2016;10:S325-326.

Barberio B, Zamani M, Black CJ, Savarino EV, Ford AC. Prevalence of symptoms of anxiety and depression in patients with inflammatory bowel disease: a systematic review and meta-analysis. *Lancet Gastroenterol Hepatol*. 2021;6(5):359-370.

Becker HM, Grigat D, Ghosh S, et al. Living with inflammatory bowel disease: a Crohn's and Colitis Canada survey. *Can J Gastroenterol Hepatol.* 2015;29(2):77-84.

Benchimol EI, Bernstein CN, Bitton A, et al. Trends in Epidemiology of Pediatric Inflammatory Bowel Disease in Canada: Distributed Network Analysis of Multiple Population-Based Provincial Health Administrative Databases. *Am J Gastroenterol*. 2017;112:1120-1134.

Benchimol EI, Fortinsky KJ, Gozdyra P et al. Epidemiology of Pediatric Inflammatory Bowel Disease: A Systematic Review of International Trends. *Inflamm Bowel Dis*. 2011;17:423-439.

Benchimol EI, Manuel DG, Guttmann A, et al. Changing age demographics of inflammatory bowel disease in Ontario, Canada: a population-based cohort study of epidemiology trends. *Inflamm Bowel Dis*. 2014;20(10):1761-1769.

Bernard HR. Research methods in anthropology: Qualitative and quantitative approaches, 3rd edn. Alta Mira Press: Walnut Creek, 2002.

Bhandari A, Wagner T. Self-Reported utilization of health care services: improving measurement and accuracy. *Med Care Res Rev*. 2006;63(1):217-230.

Bihari A, Hamidi N, Seow CH, et al. Defining transition success for young adults with inflammatory bowel disease according to patients, parents, and health care providers. *J Can Assoc Gastroenterol*. 2022; 5(4):192-198.

Bingham CA, Scalzi L, Groh B, Boehmer S & Banks S. An assessment of variables affecting transition readiness in pediatric rheumatology patients. *Pediatr Rheumatol*. 2015;13(1):42.

Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. *J Adolesc Heal*. 1993;14(7):570-576.

Bollegala N, Barwick M, Fu N, et al. Multimodal intervention to improve the transition of patients with inflammatory bowel disease from pediatric to adult care: protocol for a randomized controlled trial. *BMC gastroenterol*. 2022;22(1):251.

Bollegala N, Benchimol EI, Griffiths AM. Characterizing the posttransfer period among patients with pediatric onset IBD: the impact of academic versus community adult care on emergent health resource utilization. *Inflamm Bowel Dis*. 2017;23(9):1483-1491.

Bollegala N, Brill H, Marshall JK. Resource utilization during pediatric to adult transfer of care in IBD. *J Crohns Colitis*. 2013;7(2):e55-60.

Bollegala N, Nguyen GC. Transitioning the Adolescent with IBD from Pediatric to Adult Care: A Review of the Literature. *Gastroenterol Res Pract*. 2015;2015:1-6.

Buerkle KS, Vernon-Roberts A, Ho C, Schultz M, Day AS. A Short Knowledge Assessment Tool is Valid and Acceptable for Adults with Inflammatory Bowel Disease. *Dig Dis Sci*. 2022;67: 2049-2058.

Cai Z, Wang S, & Li J. Treatment of inflammatory bowel disease: a comprehensive review. *Front Med*. 2021;8:765474.

Carlsen K, Haddad N, Gordon J, et al. Self-efficacy and Resilience Are Useful Predictors of Transition Readiness Scores in Adolescents with Inflammatory Bowel Diseases. *Inflamm Bowel Dis*. 2017; 23(3): 341–346.

Campbell-Sills L, Stein MB. Psychometric analysis and refinement of the Connor–Davidson Resilience Scale (CD-RISC): validation of a 10-item measure of resilience. *J Trauma Stress*. 2007;20:1019–1028.

Carroll MW, Kuenzig ME, Mack DR, et al. The impact of inflammatory bowel disease in Canada 2018: children and adolescents with IBD. *Can J Assoc Gastroenterol*. 2019;2:S49-S67.

Calkins BM & Mendeloff AI. Epidemiology of inflammatory bowel disease. *Epidemiol Rev*.1986;8:60-91.

Chaparro M, Garre A, Ricart E, et al. Differences between childhood-and adulthood-onset inflammatory bowel disease: the CAROUSEL study from GETECCU. *Aliment Pharmacol Ther*. 2019;49(4):419-428.

Charmaz K. ‘Grounded Theory: Objectivist and Constructivist Methods’, in N.K. Denzin and Y.S. Lincoln (eds) Strategies for Qualitative Inquiry, 2nd edn. Sage Publications: Thousand Oaks, 2003.

Cho R, Wicket NM, Klassen AF, et al. Identifying Needs in Young Adults with Inflammatory Bowel Disease: A qualitative study. *Gastroenterol Nurs*. 2018;41(1):19-27.

Cole R, Ashok D, Razack A. Evaluation of outcomes in adolescent inflammatory bowel disease patients following transfer from pediatric to adult health care services: case for transition. *J Adolesc Health*. 2015;57(2):212-217.

Coward S, Benchimol EI, Kuenzig ME, et al. The 2023 impact of inflammatory bowel disease in Canada: Epidemiology of IBD. *J Can Assoc Gastroenterol*. 2023;6(Supplement_2):S9-S15.

Dijoseph KM, Roasio VS, Gorrepati V, et al. Pediatric to adult IBD patient care: A comparison of outcomes between transitional clinic care and traditional clinic care. *Am J Gastroenterol*. 2020;115:S419.

Edwards P, Whitworth J, Arnold S. A single center evaluation of transition in inflammatory bowel disease. *J Pediatr Gastroenterol Nutr*. 2017;65:S275.

El-Matary W, Carroll MW, Deslandres C, et al. The 2023 impact of inflammatory bowel disease in Canada: special populations—children and adolescents with IBD. *J Can Assoc Gastroenterol*. 2023;6(Supplement_2):S35-S44.

Eros A, Dohos D, Veres G, et al. Effect of joint transition visits on quality of life in adolescents with inflammatory bowel diseases: a protocol for a prospective, randomized, multicentre, controlled trial (TRANS-IBD). *BMJ Open*. 2020;10(10):e038410.

Fishman LN, Barendse RM, Hait E, Burdick C & Arnold J. Self-management of older adolescents with inflammatory bowel disease: A pilot study of behavior and knowledge as prelude to transition. *Clin Pediatr*. 2010;49:1129–1133.

Fishman LN, Mitchell PD, Lakin PR, et al. Are Expectations Too High for Transitioning Adolescents with Inflammatory Bowel Disease? Examining Adult Medication Knowledge and Self-Management Skills. *J Pediatr Gasteroenterol Nutr*. 2016;63(5):494-499.

Foster A, Chan JM, Wine E, et al. Transition readiness in youth with inflammatory bowel disease. *J Pediatr*. 2023;258:113403.

Fu N, Bollegala N, Jacobson K, et al. Canadian Consensus Statements on the Transition of Adolescents and Young Adults with Inflammatory Bowel Disease from Pediatric to

Adult Care: A Collaborative Initiative Between the Canadian IBD Transition Network and Crohn's and Colitis Canada. *J Can Assoc Gastroenterol*. 2022;5(3):105-115.

Goodhand J, Dawson R, Hefferon M et al. Inflammatory bowel disease in young people: the case for transitional clinics. *Inflamm Bowel Dis*. 2010;16:947-952.

Goodhand J, Hedin CR, Croft NM, et al. Adolescents with IBD: The importance of structured transition care. *J Crohns Colitis*. 2011;5(6):509-519.

Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*. 2004;24:105-112.

Gray WN, Holbrook E, Morgan PJ, et al. Transition readiness skills acquisition in adolescents and young adults with inflammatory bowel disease: findings from integrating assessment into clinical practice. *Inflamm Bowel Dis*. 2015;21(5):1125-113.

Gray WN & Maddux MH. Current transition practices in pediatric IBD: Findings from a national survey of pediatric providers. *Inflamm Bowel Dis*. 2016;22:372–379.

Gray WN, Reed-Knight B, Morgan PJ et al. Multi-site comparison of patient, parent, and pediatric provider perspectives on transition to adult care in IBD. *J Pediatr Nurs*. 2018;39:49-54.

Gray WN, Resmini AR., Baker KD, et al. Concerns, barriers, and recommendations to improve transition from pediatric to adult IBD Care: Perspectives of patients, parents, and health professionals. *Inflamm Bowel Dis*. 2015;21:1641–1651.

Gray WN, Schaefer MR, Resmini-Rawlinson A, Wagoner ST. Barriers to Transition from Pediatric to Adult Care: A Systematic Review. *J Pediatr Psychol*. 2018;43(5):488-502.

Guariso G, Gasparetto M, Visona Dalla Pozza L et al. Inflammatory Bowel Disease Developing in Paediatric and Adult Age. *J Pediatr Gastroenterol Nutr*. 2010;51:698-707.

Guilfoyle SM, Gray WN, Herzer-Maddux M, Hommel KA. Parenting stress predicts depressive symptoms in adolescents with inflammatory bowel disease. *Eur J Gastroenterol Hepatol*. 2014;26(9):964-971.

Heath G, Farre A, Shaw K. Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences. *J Patient Educ Couns*. 2017;100(1):76-92.

Hait EJ, Barendse RM, Arnold JH. Transition of adolescents with inflammatory bowel disease from pediatric to adult care: a survey of adult gastroenterologists. *J Pediatr Gastroenterol Nutr*. 2009;48:61-65.

Hall SE & Hall MF. "Secondary 7 Lifestyle Effects Screening" Managing the Psychological Impact of Medical Trauma: A Guide for Mental Health and Healthcare Professionals (2017)

Hanauer SB. Inflammatory Bowel Disease: Epidemiology, Pathogenesis, and Therapeutic Opportunities. *Inflamm Bowel Dis*. 2006;12:S3-S9.

Harris PA, Taylor R, Minor BL, et al. The REDCap consortium: Building an international community of software partners, *J Biomed Inform.* 2019;95:103208

Harris PA, Taylor R, Thielke J, et al. Research electronic data capture (REDCap) – A metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform*. 2009;42(2):377-81.

Horne R, Weinman H. Self-regulation and self-management in asthma: Exploring the role of illness perceptions and treatment beliefs in explaining non-adherence to preventer medication. *Psychol Heal*. 2002;17(1):17-32.

Ingerski LM, Baldassano RN, Denson LA, Hommel KA. Barriers to Oral Medication Adherence for Adolescents with Inflammatory Bowel Disease. *J Pediatr Psychol*. 2010;35(6):683-691.

Jeganathan J, Lee CH, Rahme A, et al. Medication adherence in transitional inflammatory bowel disease patients: a multicenter pilot study. *J Gastroenterol Hepatol*. 2014;29:111.

Jones JL, Nguyen GC, Benchimol EI, et al. The impact of inflammatory bowel disease in Canada 2018: quality of life. *J Can Assoc Gastroenterol*. 2019;2(Supplement_1):S42-S48.

Kappelman MD, Rifas-Shiman SL, Porter CQ. Direct Health Care Costs of Crohn's Disease and Ulcerative Colitis in US Children and Adults. *Gastroenterol*. 2008;135:1907-1913.

Karim S, Porter JA, McCombie A et al. Transition clinics: An observational study of themes important to young people with inflammatory bowel disease. *Transl Pediatr*. 2019;8:83-89.

Kofla-Dłubacz A, Pytrus T, Akutko K, et al. Etiology of IBD—Is It Still a Mystery*? Int J Mol Sci*. 2022;23(20):12445.

Kuenzig ME, Fung SG, Marderfeld L, et al. Twenty-first century trends in the global epidemiology of pediatric-onset inflammatory bowel disease: systematic review. *Gastroenterol.* 2022;162(4):1147-1159.

Kuenzig ME, Im JH, Coward S, et al. The 2023 Impact of Inflammatory Bowel Disease in Canada: Indirect (Individual and Societal) and Direct Out-of-Pocket Costs. *J Can Assoc Gastroenterol.* 2023;6(Supplement_2):S16-S22.

Lazaroff SM, Meara A, Tompkins MK, Peters E, & Ardoin SP. How do health literacy, numeric competencies, and patient activation relate to transition readiness in adolescents and young adults with rheumatic diseases? *Arthritis Care Res*. 2019;71(9):1264-1269.

Levac MR, Colquhoun H, Obrien KK. Scoping studies: Advancing the methodology. *Implement Sci*. 2010;5(1):1-9.

Lincoln YS, Guba EG. But is it rigorous? Trustworthiness and Authenticity in Naturalistic Evaluation. *New Dir Eval*. 1986;1986:73-84.

Lincoln YS, Guba EG. Naturalistic Inquiry. Sage Publications: Newbury Park, 1985.

Lix LM, Graff LA, Walker JR, et al. Longitudinal study of quality of life and psychological functioning for active, fluctuating, and inactive disease patterns in inflammatory bowel disease. *Inflamm Bowel Dis*. 2008;14(11):1575-1584.

Lönnfors S, Vermeire S, Greco M, et al. IBD and health-related quality of life-Discovering the true impact. *J Crohns Colitis*. 2014;8:1281-1286.

Luo D, Zhou M, Sun L, et al. Resilience as a Mediator of the Association Between Perceived Stigma and Quality of Life Among People with Inflammatory Bowel. *Front Psychiatry*. 2022;12:709295.

Mackie AS, Rempel GR., Islam, S, et al. Psychosocial maturity, autonomy, and transition readiness among young adults with congenital heart disease or a heart transplant. *Congenit Heart Dis*. 2016;11(2):136-143.

Maddux MH, Ricks S, Bass J. Patient and Caregiver Perspectives on Transition and Transfer. *Clin Pediatr*. 2017;56(3):278-283.

Marchak Gilleland J, Reed-Knight B, Amaral S, Mee L & Blount RL. Providers' assessment of transition readiness among adolescent and young adult kidney transplant recipients. *Pediatr transplant*. 2015;19(8):849-857.

Mayan MJ. Essentials in qualitative inquiry. Left Coast Press: Walnut Creek, 2009.

Mccartney SJO, Lindsay RK, Russell DR, et al. A structured paediatric to adult transition service in patients with inflammatory bowel disease reduces disease flares, requirement for steroids and emergency admissions: the transit study. *United European Gastroenterol J*. 2016;4(5):A457-A458.

McDonagh, J. E. Growing up and moving on: transition from pediatric to adult care. *Pediatr Transplant*. 2007;11(7):766-769.

Metel D, Arciszewska A, Daren A, et al. Resilience and cognitive biases mediate the relationship between early exposure to traumatic life events and depressive symptoms in young adults. *J Affect Disord*. 2019; 254: 26-33.

Mikocka-Walus A, Knowles SR, Keefer L, Graff L. Controversies revisited: a systematic review of the comorbidity of depression and anxiety with inflammatory bowel diseases. *Inflamm Bowel Dis*. 2016;22:752–62.

Mollah T & Giles E. Impact of a newly established young adult inflammatory bowel disease clinic on clinical outcomes and patient satisfaction. *J Gastroenterol Hepatol*. 2018;33:146-147.

Morse JM, Barrett M, Mayan M et al. Verification strategies for establishing reliability and validity in qualitative research. *Int J Qual Methods*. 2002;1:1-19.

Moulton DE, Rosen MJ, Beaulieu DB, et al. Prospective randomized trial of a progressive pediatric to adult transition of care program in adolescents with inflammatory bowel disease. *Gastroenterol*. 2013;144(5):S532.

Neergaard MA, Olesen F, Andersen RS et al. Qualitative description – the poor cousin of health research? *BMC Med Res Methodol*. 2009;9:1-5.

Neuendorf R, Harding A, Stello N, et al. Depression and anxiety in patients with Inflammatory Bowel Disease: A systematic review. *J Psychosom Res*. 2016;87:70-80.

NVivo qualitative data analysis software [computer program] Version 1.2. Melbourne, Australia: QSR International Pty Ltd, 2012.

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med*. 2014;89(9):1245-1251.

Paine CW, Stollon NB, Lucas MS, et al. Barriers and Facilitators to Successful Transition from Pediatric to Adult Inflammatory Bowel Disease Care from the Perspectives of Providers. *Inflamm Bowel Dis*. 2014;20(11):2083-2091.

Pamela M, Erin H, Lynne G, et al. A retrospective look at an IBD transition initiative. *Inflamm Bowel Dis*. 2014;20:S88.

Pearlstein H, Afzali A, Bricker J, et al. Predicting sub-optimal transitions in adolescents with inflammatory bowel diseases. *Gastroenterol*. 2020;158(6):S-966.

Perler BK, Ungaro R, Baird G, et al. Presenting symptoms in inflammatory bowel disease: descriptive analysis of a community-based inception cohort. *BMC Gastroenterol*. 2019;19(1):47.

Philippou A, Sehgal P, Ungaro RC, et al. High Levels of Psychological Resilience Are Associated with Decreased Anxiety in Inflammatory Bowel Disease. *Inflamm Bowel Dis*. 2022;28(6):888–894.

Philpott JR. Transitional care in inflammatory bowel disease. *Gastroenterol Hepatol.* 2011;7(1):26-32.

Picardo S, Panaccione R, Kaplan G, et al. Improvement in disease activity is associated with less disability in a prospective study of pediatric transition patients with IBD. *Gastroenterol*. 2019;156(6):S-390.

Pigneur B, Seksik P, Viola S, et al. Natural history of Crohn's disease: comparison between childhood-and adult-onset disease. *Inflamm Bowel Dis*. 2010;16(6):953-961.

Pierce JS, Aroian K, Schifano E. Health Care Transition for Young Adults with Type 1 Diabetes: Stakeholder Engagement for Defining Optimal Outcomes. *J Pediatr Psychol*. 2017;42:970-982.

Plevinsky JM, Gumidyala AP, Poulopoulos N, et al. Illness-related parenting stress among parents of adolescents and young adults with inflammatory bowel diseases. *Child Health Care*. 2018;47(2):136-149.

Reed-Knight B, Blount RL & Gilleland J. The transition of health care responsibility from parents to youth diagnosed with chronic illness: a developmental systems perspective. *Fam Syst Health.* 2014;32:219–234.

Reiss JG, Gibson RW, Walker LR. Health Care Transition: Youth, Family, and Provider Perspectives. *Pediatr*. 2005;115:112-120.

Ritholz MD, Wolpert H, Beste M, Atakov-Castillo A, Luff D, Garvey KC. Patient-Provider Relationships Across the Transition From Pediatric to Adult Diabetes Care: A Qualitative Study. *The Diabetes Educ*. 2014;40(1):40-47.

Ruddy J & Taft T. The pervasive impact of the stigmatization of gastrointestinal diseases—A patient's perspective. *Gastroenterol Clin*. 2022;51(4):681-695.

Rosen D, Annunziato R, Colombel JF, Dubinsky M & Benkov K. Transition of inflammatory bowel disease care: assessment of transition readiness factors and disease outcomes in a young adult population. *Inflamm Bowel Dis*. 2016;22(3):702-708.

Rosen MJ, Dhawan A & Saeed SA. Inflammatory bowel disease in children and adolescents. *JAMA pediatr*. 2015;169(11):1053-1060.

Sandelowski M. Whatever Happened to Qualitative Description? *Res Nurs Health*. 2000;23:334-340.

Sandelowski M. What's in a Name? Qualitative Description Revisited. *Res Nurs Health*. 2010;33:77-84.

Sattoe JNT, Peeters MAC, Haitsma J, et al. Value of an outpatient transition clinic for young people with inflammatory bowel disease: a mixed-methods evaluation. *BMJ Open*. 2020;10(1):e033535.

Sarlos P, Caroline O, Feher D, et al. Planned transition of adolescent inflammatory bowel disease patients from pediatric to adult care results in higher remission rates. *United European Gastroenterol J*. 2018;6(8):A465.

Sawin KJ, Rauen K, Bartelt T, et al. Transitioning Adolescents and Young Adults with Spina Bifida to Adult Healthcare: Initial Findings from a Model Program. *Rehabil Nurs J*. 2015;40(1):3-11.

Schutz L, Radke M, Menzel S, et al. Long-term implications of structured transition of adolescents with inflammatory bowel disease into adult health care: a retrospective study. *BMC Gastroenterol*. 2019;19(1):128.

Schwartz LA, Tuchman LK, Hobbie WL et al. A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. *Child Care Health Dev*. 2011;37:883-895.

Sebastian S, Jenkins H, McCartney S et al. The requirements and barriers to successful transition of adolescents with inflammatory bowel disease: Differing perceptions from a survey of adult and paediatric gastroenterologists. *J Crohns Colitis*. 2012;6:830-844.

Setya A, Molina M, Homsi M, et al. Age-specific healthcare utilization trends in a transitional IBD population. *Gastroenterol*. 2020;18(6):S-735.

Shaikh O, Harvey P, Cooney R, et al. Do self-selected “non-transitioned” referrals from pediatric services have lower treatment requirements? *J Crohns Colitis*. 2017;11:S255.

Soanes C & Timmons S. Improving transition: a qualitative study examining the attitudes of young people with chronic illness transferring to adult care. *J Child Health Care*. 2004;8:102-112.

StataCorp. Stata Statistical Software Release 17. Published online 2021.

Stollon NB, Paine CW, Lucas MS et al. Transitioning adolescents and young adults with sickle cell disease from pediatric to adult healthcare: Provider perspectives. *J Pediatr Hematol Oncol*. 2015;37:577-583.

Stone JK, Shafer LA, Graff LA, et al. Utility of the MARS-5 in Assessing Medication Adherence in IBD. *Inflamm Bowel Dis*. 2021;27(3):317-324.

Szanto K, Farkas K, Rutka M, et al. Transfer of care of adolescent IBD patients without longitudinal transition: Lesson from 10-year experiences. *J Crohns Colitis*. 2018;12:S427.

Taft TH & Keefer L. A systematic review of disease-related stigmatization in patients living with inflammatory bowel disease. *Clin Exp Gastroenterol*. 2016;9:49-58.

Testa A, Giannetti E, Rispo A, et al. Successful outcome of the transitional process of inflammatory bowel disease from pediatric to adult age: A five years experience. *Dig Liver Dis*. 2019;51(4):524-528.

Thapwong P, Norton C, Rowland E & Czuber-Dochan W. Our Life Is a Rollercoaster! A Qualitative Phenomenological Study Exploring the Impact of IBD on Family Members. *Inflamm Bowel Dis*. 2024;izae028.

Thoreson R, Cullen JJ. Pathophysiology of Inflammatory Bowel Disease: An Overview.

Surg Clin North Am. 2007;87:575-585.

Trindade IA, Duarte J, Ferreira C, Coutinho M & Pinto-Gouveia J. The impact of illness-related shame on psychological health and social relationships: Testing a mediational model in students with chronic illness. *Clin Psychol Psychother*. 2018;25(3):408-414.

Trindade IA, Ferreira C & Pinto-Gouveia J. Chronic Illness-Related Shame: Development of a New Scale and Novel Approach for IBD Patients' Depressive Symptomatology. *Clin Psychol Psychother*. 2017;24(1):255-263.

Trindade IA, Ferreira C & Pinto-Gouveia J. Shame and emotion regulation in inflammatory bowel disease: Effects on psychosocial functioning. *J Health Psychol*. 2020;25(4):511-521.

Van den Brink G, van Gaalen M, de Ridder L et al. Health care transition outcomes in inflammatory bowel disease: A multinational Delphi Study. *J Crohns Colitis*. 2019;13:1163-1172.

Van den Brink G, van Gaalen MAC, Zijlstra M, et al. Self-efficacy did not predict the outcome of the transition to adult care in adolescents with inflammatory bowel disease. *Acta Paediatr*. 2019;108:333-338.

Wetherall K, Cleare S, Eschle S, et al. From ideation to action: Differentiating between those who think about suicide and those who attempt suicide in a national study of young adults. *J Affect Disord*. 2018;241:475-483.

Wilburn J, Twiss J, Kemp K & McKenna SP. A qualitative study of the impact of Crohn's disease from a patient's perspective. *Frontline Gastroenterol.* 2017;8(1):68-73.

Williams E, Coates M, Tinsley A, et al. Formalized IBD transition clinic leads to high retention and low no show rates of young adults in a single tertiary center. *Am J Gastroenterol*. 2017;112:S388-S389.

Whitfield EP, Fredericks EM, Eder SJ, Shpeen BH & Adler J. Transition readiness in pediatric patients with inflammatory bowel disease: a patient survey of self-management skills. *J Pediatr Gastroenterol Nutr*. 2015;*60*(1):36-41.

Yadav AM, O'Toole FA & Patchett S. Perspective, and self-efficacy of adolescents with inflammatory bowel disease post transition to adult care. *J Crohns Colitis*. 2017;11:S344.

Yeo JY, Lim CJ & Tan BY. Adaptation and validation of the chronic illness-related shame scale among patients with knee osteoarthritis in Singapore. *BMC Musculoskelet Disord*. 2023;24(1):633.

Yerushalmy-Feler A, Ron Y, Barnea E, et al. Adolescent transition clinic in inflammatory bowel disease: Quantitative assessment of self-efficacy skills. *Euro J Gastroenterol Hepatol*. 2017; 29(7):831-937.

Zhao X, Bjerre LM, Nguyen GC, et al. Health services utilization in adolescents with inflammatory bowel disease transitioning from pediatric to adult care: A population based, cohort study. *J Pediatr Gasteroenterol Nutr*. 2016;63:S354.

Zhong Y, Gilleskie DB, van Tilburg MA, et al. Longitudinal self-management and/or transition readiness per the TRxANSITION index among patients with chronic conditions in pediatric or adult care settings. *J Pediatr*. 2018;203:361-370.

Appendices

Appendix A

A-1. Search String for Each Database Used in the Scoping Review

PsycINFO

#	Searches	Results
1	Continuity of patient care.mp.	2512
2	Transition to adult care.mp.	284
3	Transitional care.mp.	396
4	(transition*adj4 care).mp.	2759
5	Change of care.mp.	167
6	P?ediatric to adult care.mp.	118
7	1 or 2 or 3 or 4 or 5 or 6	5345
8	Inflammatory bowel diseases.mp.	414
9	(IBD or inflammatory bowel disease* or crohn’s or colitis).mp.	2111
10	8 or 9	2111
11	7 and 10	16

Embase (OVID)

#	Searches	Results
1	Exp transition to adult care/	2051
2	Exp transitional care/	3350
3	Continuity of patient care.mp.	893
4	(transition*adj4 care).mp.	16678
5	Change of care.mp.	806
6	P?ediatric to adult care.mp.	1132
7	1 or 2 or 3 or 4 or 5 or 6	18697
8	Exp inflammatory bowel disease/	156711

9	(IBD or inflammatory bowel disease* or crohn’s or colitis).mp.	224197
10	8 or 9	235482
11	7 and 10	374

Medline (OVID)

#	Searches	Results
1	“continuity of patient care”/ or transition to adult care/ or transitional care/	21,557
2	(transition*adj4 care).ti,ab,kw.	8,079
3	Change of care.ti,ab.	559
4	P?ediatric to adult care.ti,ab.	561
5	1 or 2 or 3 or 4	27,967
6	Exp Inflammatory Bowel Disease/	82,273
7	(IBD or inflammatory bowel disease* or crohn’s or colitis).ti,ab,kw.	122,155
8	6 or 7	135,425
9	5 and 8	166

CINAHL

#	Searches	Results
S1	(MH “Continuity of Patient Care”) OR (MH “Transitional Care”)	16,676
S2	(transition* N4 (care or program*))	12,385
S3	“change of care”	376
S4	“p?ediatric to adult care”	71
S5	S1 OR S2 OR S3 OR S4	26,213

S6	(MH “Inflammatory Bowel Diseases”) OR (MH “Colitis, Ulcerative”) OR (MH “Crohn Disease”)	15,621
S7	(IBD or “inflammatory bowel disease”or crohn’s or colitis)	25,625
S8	S6 OR S7	25,625
S9	S5 AND S8	98

Scopus

(TITLE-ABS-KEY ((transition* W/4 (care OR program*)) OR "continuity of care" OR "change of care" OR "p?ediatric to adult care") AND TITLE-ABS-KEY ((ibd OR "inflammatory bowel disease*" OR crohn* OR colitis)))

Appendix B

B-1. Information Sheet and Consent Form: Patient Edition

Defining and Predicting Transition Success in Young Adults with Inflammatory Bowel Disease

Information Sheet & Consent: Semi-Structured Interview

Principal Investigator

Dr. Karen Kroeker

Zeidler Gastrointestinal Health Centre

University of Alberta

8540 112 St

Edmonton, AB T6G 2X8

780-492-4873

Graduate Student/Study Coordinator

Allison Bihari

Zeidler Gastrointestinal Health Centre

University of Alberta

780-248-1040

What is transition?

Transition refers to the period of time around the transfer from pediatric into adult care. This period of transition can be stressful for young adults as they are expected to take responsibility for their own health, while having to balance the regular challenges associated with becoming a young adult, such as becoming more financially independent, moving out, and starting postsecondary schooling.

Why do we want to do this study?

During this transition period, some patients may be more likely to miss appointments, not take their medications regularly and therefore, have more flares, ER visits, or need surgery. We want to understand more about the outcomes associated with transition in inflammatory bowel disease. As transition is a process that involves parents, patients, and health care providers we believe that understanding its success should also reflect the perspectives of these key groups. Therefore, the information that you provide during the interview will contribute to our understanding of what transition success is. This definition of transition success will contribute to the development of a model that could be used to predict patients who are unlikely to achieve transition success, and thus, who will need more support during transition.

What would be your role as a study participant?

As a study participant, you will have the option to choose between a telephone or an online video (Google Hangouts or Skype) interview with our research coordinator. Additionally, if the current social distancing requirements due to the covid-19 pandemic have been lifted, you will also have the option to choose to participate in an in-person interview. During the interview, you will be asked about your experience transitioning, your opinions on what defines a successful and an unsuccessful transition and any factors that you believe influences experiencing a successful transition. All interviews will be audio recorded and then transcribed to be analyzed. The information that you provide during the interview will be confidential. During the interview, you may ask that the recorder be turned off at any time and you do not have to answer every question. Additionally, the total time to complete the interview is estimated to be between 45-60 minutes.

Who will have access to your information?

Only the individuals directly involved in this study will have access to the information you disclose during the interview. Your identity will remain anonymous in any published report and the information you provide will be confidential unless its release is required by law. The Health Research Ethics Board may also have access to your records to monitor the research and verify accuracy of the data.

Why consider helping us?

By being a participant in this study, you will be contributing to advancements in IBD transition research. The information you provide will allow us to better understand transition outcomes. This study will also be used to fulfill the requirements for a graduate degree for the graduate student involved in this project. Additionally, you will be compensated with a $15 gift card if a telephone or online video interview is conducted and a $20 gift card for an in-person interview once the current social distancing requirements have been lifted.

What if you change your mind after participating in the study?

Your participation in this study is completely voluntary and you are free to withdraw from the study at any time up until the completion of data analysis. If you wish to withdraw from the study, you must express your desire to the project coordinator. As a participant, you will be entitled to the gift card even if you choose to withdraw from the study early.

Who should you contact if you have concerns or questions?

If you have concerns about your rights as a study participant, you may contact the University of Alberta Health Research Ethics Board at 780-492-9724. This office is independent of the study investigators.

If you have questions or concerns about this study, please contact any of the individuals below.

Allison Bihari, University of Alberta, Project Coordinator: 780-248-1040 or bihari@ualberta.ca

Dr. Karen Kroeker, University of Alberta, Principal Investigator: 780-492-4873

Title of Study: Defining and Predicting Transition Success for Young Adults with Inflammatory Bowel Disease

Principal Investigator: Karen Kroeker, MD Phone Number(s): 780-492-4873

Study Coordinator: Allison Bihari Phone Number(s): 780-248-1040

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Do you understand that you are free to withdraw from the study at any time without having to give a reason and without affecting your future medical care?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand that the interview will be audio recorded and transcribed?	☐	☐
Do you understand who will have access to your study records, including personally identifiable health information?	☐	☐

Who explained this study to you? ____

I agree to take part in this study: YES ☐ NO ☐

Signature of Research Participant: ____

(Printed Name) ____ Date: _______________

Signature of Investigator or Designee: _________________________Date: _____________

Alternatively, telephone and online video interviews will need to obtain verbal consent as follows:

Name of Participant giving Verbal Consent:
____

Name of Investigator or Designee Obtaining Verbal Consent:
____

Date of Obtaining Verbal Consent: ___________________________ Time: ______________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A SIGNED COPY GIVEN TO THE RESEARCH PARTICIPANT

B-2. Information Sheet and Consent Form: Parent Edition

Defining and Predicting Transition Success in Young Adults with Inflammatory Bowel Disease

Information Sheet & Consent: Semi-Structured Interview

Principal Investigator

Dr. Karen Kroeker

Zeidler Gastrointestinal Health Centre

University of Alberta

8540 112 St

Edmonton, AB T6G 2X8

780-492-4873

Graduate Student/Study Coordinator

Allison Bihari

Zeidler Gastrointestinal Health Centre

University of Alberta

780-248-1040

What is transition?

Transition refers to the period of time around the transfer from pediatric into adult care. This period of transition can be stressful for young adults as they are expected to take responsibility for their own health, while having to balance the regular challenges associated with becoming a young adult, such as becoming more financially independent, moving out, and starting postsecondary schooling.

Why do we want to do this study?

During this transition period, some patients may be more likely to miss appointments, not take their medications regularly and therefore, have more flares, ER visits, or need surgery. We want to understand more about the outcomes associated with transition in inflammatory bowel disease. As transition is a process that involves parents, patients, and health care providers we believe that understanding its success should also reflect the perspectives of these key groups. Therefore, the information that you provide during the interview will contribute to our understanding of what transition success is. This definition of transition success will contribute to the development of a model that could be used to predict patients who are unlikely to achieve transition success, and thus, who will need more support during transition.

What would be your role as a study participant?

As a study participant, you will have the option to choose between a telephone or an online video (Google Hangouts or Skype) interview with our research coordinator. Additionally, if the current social distancing requirements due to the covid-19 pandemic have been lifted, you will also have the option to choose to participate in an in-person interview. During the interview, you will be asked about your child’s experience transitioning, your opinions on what defines a successful and an unsuccessful transition and any factors that you believe influences experiencing a successful transition. All interviews will be audio recorded and then transcribed to be analyzed. The information that you provide during the interview will be confidential. During the interview, you may ask that the recorder be turned off at any time and you do not have to answer every question. Additionally, the total time to complete the interview is estimated to be between 45-60 minutes.

Who will have access to your information?

Only the individuals directly involved in this study will have access to the information you disclose during the interview. Your identity will remain anonymous in any published report and the information you provide will be confidential unless its release is required by law. The Health Research Ethics Board may also have access to your records to monitor the research and verify accuracy of the data.

Why consider helping us?

By being a participant in this study, you will be contributing to advancements in IBD transition research. The information you provide will allow us to better understand transition outcomes.

This study will also be used to fulfill the requirements for a graduate degree for the graduate student involved in this project. Additionally, you will be compensated with a $15 gift card if a telephone or online video interview is conducted and a $20 gift card for an in-person interview once the current social distancing requirements have been lifted.

What if you change your mind after participating in the study?

Your participation in this study is completely voluntary and you are free to withdraw from the study at any time up until the completion of data analysis. If you wish to withdraw from the study, you must express your desire to the project coordinator. As a participant, you will be entitled to the gift card even if you choose to withdraw from the study early.

Who should you contact if you have concerns or questions?

If you have concerns about your rights as a study participant, you may contact the University of Alberta Health Research Ethics Board at 780-492-9724. This office is independent of the study investigators.

If you have questions or concerns about this study, please contact any of the individuals below.

Allison Bihari, University of Alberta, Project Coordinator: 780-248-1040 or bihari@ualberta.ca

Dr. Karen Kroeker, University of Alberta, Principal Investigator: 780-492-4873

Title of Study: Defining and Predicting Transition Success for Young Adults with Inflammatory Bowel Disease

Principal Investigator: Karen Kroeker, MD Phone Number(s): 780-492-4873

Study Coordinator: Allison Bihari Phone Number(s): 780-248-1040

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Do you understand that you are free to withdraw from the study at any time without having to give a reason and without affecting your child’s future medical care?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand that the interview will be audio recorded and transcribed?	☐	☐
Do you understand who will have access to your study records?	☐	☐

Who explained this study to you? ____

I agree to take part in this study: YES ☐ NO ☐

Signature of Research Participant: ______________________________________

(Printed Name) ________________________________ Date: ____________

Signature of Investigator or Designee: ____________________ Date: ___________

Alternatively, telephone and online video interviews will need to obtain verbal consent as follows:

Name of Participant giving Verbal Consent:
____

Name of Investigator or Designee Obtaining Verbal Consent:
____

Date of Obtaining Verbal Consent: ______________________ Time: ____________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A SIGNED COPY GIVEN TO THE RESEARCH PARTICIPANT

B-3. Information Sheet and Consent Form: Provider Edition

Defining and Predicting Transition Success in Young Adults with Inflammatory Bowel Disease

Information Sheet & Consent: Semi-Structured Interview

Principal Investigator

Dr. Karen Kroeker

Zeidler Gastrointestinal Health Centre

University of Alberta

8540 112 St

Edmonton, AB T6G 2X8

780-492-4873

Graduate Student/Study Coordinator

Allison Bihari

Zeidler Gastrointestinal Health Centre

University of Alberta

780-248-1040

What is transition?

Transition refers to the period of time around the transfer from pediatric into adult care. This period of transition can be stressful for young adults as they are expected to take responsibility for their own health, while having to balance the regular challenges associated with becoming a young adult, such as becoming more financially independent, moving out, and starting postsecondary schooling.

Why do we want to do this study?

During this transition period, some patients may be more likely to miss appointments, not take their medications regularly and therefore, have more flares, ER visits, or need surgery. We want to understand more about the outcomes associated with transition in inflammatory bowel disease. As transition is a process that involves parents, patients, and health care providers we believe that understanding its success should also reflect the perspectives of these key groups. Therefore, the information that you provide during the interview will contribute to our understanding of what transition success is. This definition of transition success will contribute to the development of a model that could be used to predict patients who are unlikely to achieve transition success, and thus, who will need more support during transition.

What would be your role as a study participant?

As a study participant, you will have the option to choose between a telephone or an online video (Google Hangouts or Skype) interview with our research coordinator. Additionally, if the current social distancing requirements due to the covid-19 pandemic have been lifted, you will also have the option to choose to participate in an in-person interview. During the interview, you will be asked about your opinions on what defines a successful and an unsuccessful transition and any factors that you believe influences experiencing a successful transition. All interviews will be audio recorded and then transcribed to be analyzed. The information that you provide during the interview will be confidential. During the interview, you may ask that the recorder be turned off at any time and you do not have to answer every question. Additionally, the total time to complete the interview is estimated to be between 45-60 minutes.

Who will have access to your information?

Only the individuals directly involved in this study will have access to the information you disclose during the interview. Your identity will remain anonymous in any published report and the information you provide will be confidential unless its release is required by law. The Health Research Ethics Board may also have access to your records to monitor the research and verify accuracy of the data.

Why consider helping us?

By being a participant in this study, you will be contributing to advancements in IBD transition research. The information you provide will allow us to better understand transition outcomes.

This study will also be used to fulfill the requirements for a graduate degree for the graduate student involved in this project.

What if you change your mind after participating in the study?

Your participation in this study is completely voluntary and you are free to withdraw from the study at any time up until the completion of data analysis. If you wish to withdraw from the study, you must express your desire to the project coordinator. As a participant, you will be entitled to the gift card even if you choose to withdraw from the study early.

Who should you contact if you have concerns or questions?

If you have concerns about your rights as a study participant, you may contact the University of Alberta Health Research Ethics Board at 780-492-9724. This office is independent of the study investigators.

If you have questions or concerns about this study, please contact any of the individuals below.

Allison Bihari, University of Alberta, Project Coordinator: 780-248-1040 or bihari@ualberta.ca

Dr. Karen Kroeker, University of Alberta, Principal Investigator: 780-492-4873

Title of Study: Defining and Predicting Transition Success for Young Adults with Inflammatory Bowel Disease

Principal Investigator: Karen Kroeker, MD Phone Number(s): 780-492-4873

Study Coordinator: Allison Bihari Phone Number(s): 780-248-1040

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Do you understand that you are free to withdraw from the study at any time without having to give a reason and without affecting your future employment?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand that the interview will be audio recorded and transcribed?	☐	☐
Do you understand who will have access to your study records?	☐	☐

Who explained this study to you? ____

I agree to take part in this study: YES ☐ NO ☐

Signature of Research Participant: ____

(Printed Name) ____ Date: ________________

Signature of Investigator or Designee: _________________________Date: ______________

Alternatively, telephone and online video interviews will need to obtain verbal consent as follows:

Name of Participant giving Verbal Consent: ____

Name of Investigator or Designee Obtaining Verbal Consent: __________________________________

Date of Obtaining Verbal Consent: ____________________________ Time: _______________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A SIGNED COPY GIVEN TO THE RESEARCH PARTICIPANT

Appendix C

C-1. Demographic Form: Patient Edition

Participant Demographic Information - Patient Version

Participant ID: ___ ___ - ___ ___

Participant Name: ____________________________________

Date of Interview (dd/mm/yyyy): __ __ / __ __ / __ __ __ __

Location of Participant: ________________________________

Sex: ☐ Male ☐ Female

Date of Birth (dd/mm/yyyy): __ __/ __ __/ __ __ __ __

Phone number: (__ __ __) __ __ __ - __ __ __ __

Email address: ____

Address: ____

Interview Type: ☐ In Person ☐ Telephone ☐ Online Video

Background Information

1. What is your current occupation? If unemployed, what was your last occupation?

____

2. Are you currently in school?

☐ Yes

a) what grade, level or program:

____

☐ No

b) What is the highest level of education you have completed?

____

3. What is your IBD diagnosis?

____

4. What age were you when you got diagnosed with IBD?

____

5. What medications are you currently taking for your IBD?

____

C-2. Demographic Form: Parent Edition

Participant Demographic Information– Parent Version

Participant ID: ___ ___- ___ ___

Participant Name: ____

Date of Interview (dd/mm/yyyy): __ __ / __ __ / __ __ __ __

Location of Participant: ____

Sex: ☐ Male ☐ Female

Phone Number: (__ __ __) __ __ __ - __ __ __ __

Email address: ____

Interview Type: ☐ In Person ☐ Telephone ☐ Online Video

Background Information:

1. What is your current occupation? If unemployed, what was your last occupation?

____

2. What is your highest level of education completed? ______________________________

3. Do you have IBD or another type of chronic disease?

☐ Yes

a) Name of chronic disease? ___________________________________

b) How long have you been diagnosed with this disease? __________________

☐ No

4. What is your child's IBD diagnosis? ____

a. How old was your child when they were first diagnosed with IBD? _________________

5. Does this child currently live with you?

☐ Yes

a) How long have they lived with you? ___________________

☐ No

a) How far from you do they live? _______________________

b) Do they live with anyone else? ________________________

6. Do you have any other children (not including child with IBD)?

☐ Yes

a) How old are they? ____

☐ No

C-3. Demographic Form: Provider Edition

Participant Demographic Information - Provider Version

Participant ID: ___ ___- ___ ___

Participant Name: ______________________________________

Date of Interview (dd/mm/yyyy): __ __ / __ __ / __ __ __ __

Participant Location: ___________________________________

Sex: ☐ Male ☐ Female

Phone Number: (__ __ __) __ __ __ - __ __ __ __

Email address: ____

Interview Type: ☐ In Person ☐ Telephone ☐ Online Video

Type of provider: ☐ Pediatric Gastroenterologist

☐ Adult Gastroenterologist

☐ Pediatric IBD Nurse

☐ Adult IBD Nurse

Background Information:

1. What is your current job title?

____

2. How many years have you been caring for IBD patients? This may include years in training.

____

3. What percentage of your time is devoted to patient care?

____

Appendix D

D-1. Interview Guide: Patient Edition

Semi-structured Interview Guide: Patient Edition

Aims for Interviews:

1) To understand patient's perspectives on what a successful and an unsuccessful transition is.
2) Whether patients feel that they have achieved a successful or an unsuccessful transition.
3) Explore patient's perspectives on any barriers that may prevent one from achieving a successful transition.
4) Explore patient's perspectives on any factors that may contribute to achieving a successful transition.

Preamble:

[after consent is given]

Thank you for taking the time to speak with me today. As you know, the point of this interview is to learn more about the outcomes associated with the transition and transfer from pediatric to adult care for young adults with IBD. We want to know about your experience transitioning to adult care and your opinion on what a successful and an unsuccessful transition looks like. Throughout this interview, I will be referring to transition and transfer. By transition, I mean the process of preparing young adults to change their care from pediatric to adult care. I will refer to transfer in this interview as the actual exit from pediatric into adult care.

The answers that you provide in this interview will not be linked with your name in any presentation or publication. Only I will have access to your information name, but it will be kept confidential.

In this interview, we will first talk about your transition, then about the outcomes you experienced and the factors you believed played a role, then finally we will talk about how transition has influenced you…

I will need to ask you some personal questions for this project. Please answer as honestly as possible. You do not need to answer every question, and you are free to ask that the recorder be turned off at any point during this interview. As well, there are no right or wrong answers to any of the questions.

Do you have any questions for me before we begin?

We are going to start by filling out a participant demographic form to collect some background information. (attached).

Ok, now we're ready to start the interview. I am now going to turn on the recorder. I will now start with some questions about your transition experience…

1. Transition Experience

a) Overall, on a scale of 1-5, with 1 being "not well, there were issues" to 5 being "excellent with no issues", how do you feel your transition and transfer from pediatric care went?

i) Why did you assign this number?

b) Can you tell me a little more about your experience transitioning and transferring to adult care?

i) How were you prepared?

ii) How did you feel?

iii) At what time point did your parents stop being involved in your health? What did this look like? (in terms of when they stopped telling you to take your medications and stopped making your own appointments/ reminding you to)

iv) How comfortable did you feel managing your own health?

v) How much of your health are you currently managing yourself?

c) Was there anything unexpected about your transition and transfer to adult care?

d) While in pediatric care, did you have any hopes or expectations about the outcomes you wanted to achieve at the end of transition and transfer?

If yes, “What were some of the expectations and hopes did you have?”

If no, “Why do you think you did not have any hopes or expectations?”

Awesome. These next few questions that I will be asking will focus more on your opinion on how you view your transition…

e) Would you define your transition and transfer as being successful or unsuccessful?

i) Why do you think your transition was [successful or unsuccessful]?

ii) What are the key outcomes that you believe indicate that your transition was [successful or unsuccessful]?

f) In your opinion, are there any outcomes that you didn't achieve that would have made your transition more successful?

If so, "What are they?"

g) How would you characterize a [either unsuccessful or successful (use the opposite to how they defined their transition)] transition for a patient?

i) What are the key outcomes that you believe would indicate that a transition was [successful or unsuccessful]?

h) In general, can you think of any factors that would make it easier for a patient to achieve a successful transition?

i) If have indicated that they had a successful transition, ask "Were there any specific factors that made it easier for you to achieve a successful transition?"

i) Alternatively, can you think of any factors that make it more difficult for a patient to achieve a successful transition?

i) Were there any specific factors that made it more difficult for you to achieve a successful transition?

j) Do you think now that you have gone through transition and have transferred to adult care, that your views on what you would have liked to achieve has changed?

If yes, “In what ways have your views changed?”, “Why have they changed?”

k) If you were talking to someone just starting to transition, how would you define a [either successful or unsuccessful] transition to them?

Use successful if they have previously said their transition is successful and unsuccessful if they have indicated it is unsuccessful.

i) What outcomes would you tell them to aim for?

Now for the final question…

l) Do you think that your transition experience has impacted your health? What about your day-day life?

i) If participants indicated that they experienced a successful transition, ask “If you had experienced an unsuccessful transition, how do you think this would have impacted your health? What about your day - day life?”

ii) If participants indicated that they experienced an unsuccessful transition, ask “If you had experienced a successful transition, how do you think this would have impacted your health? What about your day – day life?”

Ok. Great. This brings us to the end of the interview. Thank you for taking the time to be interviewed today.

Are you willing to be contacted if we need to clarify anything or have further questions?

Is there anything that I have not asked you during this interview that you feel is important I know regarding transition outcomes?

Do you have any questions for me?

If you think of anything else that you forgot to mention, feel free to contact me using the email address we used to schedule this interview. You will also receive an electronic gift card within the week for participating in this study. Is the email you provided the best email to send it?

Thank you again for your time. We appreciate your contribution to this study. Have a great day.

D-2. Interview Guide: Parent Edition

Semi-structured Interview Guide: Parent Edition

Aims for Interviews:

1. To understand parent's perspectives on what a successful and an unsuccessful transition is.
2. Whether parents feel that their child has achieved a successful or an unsuccessful transition.
3. Explore parent's perspectives on any barriers that may prevent one from achieving a successful transition.
4. Explore parent's perspectives on any factors that may contribute to achieving a successful transition.

Preamble:

[after consent is given]

Thank you for taking the time to speak with me today. As you know, the point of this interview is to learn more about the outcomes associated with the transition and transfer from pediatric to adult care for young adults with IBD. We want to know about your experience as a parent with a child who has transitioned to adult care and your opinions on transition outcomes.

Throughout this interview, I will be referring to transition and transfer. By transition, I mean the ongoing process of preparing young adults to change their care from pediatric to adult care. I will refer to transfer in this interview as the actual exit from pediatric into adult care.
The answers that you provide in this interview will not be linked with your name in any presentation or publication. Only I will have access to your information, but it will be kept confidential.

In this interview, we will first talk about your child's transition, then about the outcomes your child experienced and the factors that you believed played a role, and then how you think transition has influenced your child …

I will need to ask you some personal questions for this project. Please answer as honestly as possible. You do not need to answer every question, and you are free to ask that the recorder be turned off at any point during this interview. As well, there are no right or wrong answers to any of the questions.

Do you have any questions for me before we begin?

We are going to start by filling out a participant demographic form to collect background information. (attached).

Ok, now we're ready to start the interview. I am now going to turn on the recorder. I will now start with some questions about your child's transition experience…

1. Transition Experience

a) Overall, on a scale of 1-5, with 1 being “not well, there were issues” to 5 being “excellent with no issues”, how do you feel your child’s transition and transfer from pediatric care went?

i. Why did you assign this number?

b) Can you tell me a little more about your child’s experience transitioning and transferring to adult care?

i. Did you feel that they were prepared for it?

ii. How did you feel about it overall?

c) On a scale of 1-5, with 1 being “not involved at all” to 5 being “very involved”, how involved do you feel you were in your child’s transition and transfer?

i. Why did you assign this number?

ii. At what time point did you stop being as involved in your child’s care? What did this look like?

d) Was there anything unexpected about your child’s transition and transfer to adult care?

e) While your child was in pediatric care, did you have any hopes or expectations about the outcomes you wanted them to achieve at the end of transition and transfer?

If yes, “What were some of the expectations you had?”

If no, “Why do you think you did not have any hopes or expectations?”

Awesome. These next few questions that I will be asking will focus more on your opinion about whether you view your child's transition as being successful or unsuccessful …

f) Would you define your child's transition and transfer as being successful or unsuccessful?

i. Why do you think your child's transition was [successful or unsuccessful]?

ii. What are the key outcomes that you believe indicate that your child's transition was [successful or unsuccessful]?

g) In your opinion, are there any outcomes that your child didn't achieve that would have made your child's transition more successful?

If so, "What are they?"

h) How would you characterize an [either unsuccessful or successful (use the opposite to how they defined their child's transition)] transition for a patient?

i. What are the key outcomes that you believe would indicate that a transition was [successful or unsuccessful]?

i) In general, can you think of any factors that would make it easier for a patient to achieve a successful transition?

i. If have indicated that their child had a successful transition, ask "Were there any specific factors that made it easier for your child to achieve a successful transition?"

j) Alternatively, can you think of any factors that make it more difficult for a patient to achieve a successful transition?

i. Were there any specific factors that made it more difficult for your child to achieve a successful transition?

k) Do you think now that your child has gone through transition and has transferred to adult care, that your views on what you would have liked your child to achieve has changed?

If yes, “In what ways have your views changed?”, “Why have they changed?”

l) If you were talking to a parent of a child just starting to transition, how would you define a [either successful or unsuccessful] transition to them?

Use successful if they have previously said their transition is successful and unsuccessful if they have indicated it is unsuccessful.

i. What outcomes would you tell them their child should aim for?

Now for the final question …

m) Do you think that your child’s transition experience has impacted their health? What about their day-day life?

i. If participants indicated that their child experienced a successful transition, ask “If your child had experienced an unsuccessful transition, how do you think this would have impacted their health? What about their day - day life?”

ii. If participants indicated that their child experienced an unsuccessful transition, ask "If your child had experienced a successful transition, how do you think this would have impacted their health? What about their day – day life?"

Ok, Great. This brings us to the end of the interview. Thank you for taking the time to be interviewed today.

Are you willing to be contacted if we need to clarify anything or have further questions?

Is there anything that I have not asked you during this interview that you feel is important I know regarding transition outcomes?

Do you have any questions for me?

If you think of anything else that you forgot to mention, feel free to contact me using the email address we used to schedule this interview. You will also receive an electronic gift card within the week for participating in this study. Is the email you provided the best email to send it?

Thank you again for your time. We appreciate your contribution to this study. Have a great day.

D-3. Interview Guide: Provider Edition

Semi-structured Interview Guide: Provider Edition

Aims for Interviews:

1. To understand provider's perspectives on what a successful and an unsuccessful transition looks like.
2. Explore provider's perspectives on any factors that may contribute to patients achieving a successful transition.
3. Explore provider's perspectives on any barriers that may prevent patients from achieving a successful transition

Preamble:

[after consent is given]

Thank you for taking the time to speak with me today. As you know, the point of this interview is to learn more about the outcomes associated with the transition and transfer from pediatric to adult care for young adults with IBD. We want to know about your opinion on what a successful and unsuccessful transition looks like.

Throughout this interview, I will be referring to transition and transfer. By transition, I mean the process of preparing young adults to change their care from pediatric to adult . I will refer to transfer in this interview as the actual exit from pediatric into adult care.

The answers that you provide in this interview will not be linked with your name in any presentation or publication. Only I will have access to your information, but it will be kept confidential.

Do you have any questions for me before we begin?

We are going to start by filling out the participant demographic form to collect background information. (attached).

Ok, now we're ready to start the interview. I am now going to turn on the recorder. Ok I will start with some questions about the transition process at your practice …

1. Transition

a) Is there anything specific you do in your practice to help with the process of transitioning and transfer of care?

If yes, "what do you do to help with transition?"

Awesome. Now, I will move on to questions that involve your opinions on transition outcomes. We will first talk about what it means to have a successful transition…

2. Successful Transition

a) In your opinion, at what point in time would you assess whether a patient's transition has been successful or unsuccessful?

b) If possible, could you tell me about a patient with IBD that in your opinion had a successful transition and transferred smoothly? Please refrain from using the patient's name.
If not, then ask "what outcomes would you define a successful transition and a smooth transfer of care with? and then skip next question.

c) What were the outcomes that made it clear that the transition was successful?

d) In your opinion, are there any factors that may make it easier for a patient to achieve a successful transition?

  a. In the case of the patient previously mentioned, were there any specific factors that contributed to them achieving a successful transition?

e) As a general definition, would you define transition success as meeting the outcomes you have described for this patient or would you use a definition that is broader or narrower?
If no, ask "how else would you define transition success?"

f) Do you think that having a successful transition plays a role in a patient's long-term health? What about their day – day life?

Awesome. Now that we have talked about transition success, the next section will ask questions about an unsuccessful transition.

3. Unsuccessful Transition

a) If possible, could you tell me about a patient with IBD that in your opinion had an unsuccessful transition and transferred poorly? Please refrain from using the patient's name. If not, then ask "what outcomes would you define an unsuccessful transition and a smooth transfer of care with? and then skip next question.

b) What were the outcomes that made it clear to you that the transition was unsuccessful?

c) In your opinion, are there any factors that may make it more difficult for a patient to achieve a successful transition?

a. In the case of the patient previously mentioned, were there any specific factors that made it more difficult for them to achieve a successful transition?

d) When do you think you can first suspect that the transition is going to be unsuccessful?

a. Do you think there are any specific signs to look for?

b. In the patient you have mentioned, were there any indications that the transition was going to be unsuccessful?

e) As a general definition, would you define an unsuccessful transition as meeting the outcomes you have described for this patient? Or would you use a definition that is broader or narrower?

f) Do you think that having an unsuccessful transition plays a role in a patient's long-term health outcomes? What about their day – day life?

Ok. Great. That brings us to the end of the interview. Thank you for taking the time to be interviewed today.

Are you willing to be contacted if we need to clarify anything or have further questions?

Is there anything that I have not asked you during this interview that you feel is important I know regarding transition outcomes?

Do you have any questions for me?

If you think of anything else that you forgot to mention, feel free to contact me using the email address we used to schedule this interview. As well, if you can think of any other individuals treating IBD that would provide valuable insight please feel free to let us know.

Thank you again for your time. Have a great day.

Appendix E. Email Sent to Providers to Aid in Recruitment

Dear ___,

My name is Allison Bihari and this study is part of my thesis research for my PhD with Dr. Kroeker. We are hopeful that you will be able to help with recruitment for our study: **Young Adults – Inflammatory Bowel Disease Care Experience (YA-ICE).** We hope that this study will provide insights into the outcomes and skills, such as self-management and disease knowledge, achieved by young adults with IBD. This study will also further an understanding of the impact that IBD may have on young adults.

Attached are both study posters and postcards with a QR code that directs the patient to the questionnaire. In addition to putting the posters up around your clinic, if you could please distribute the study postcards to patients who meet the study criteria, that would be greatly appreciated.

Patients who are eligible:

- Aged 18-25 years old
- Diagnosed with IBD

As a reminder, the questionnaire is about 20-minutes long and patients will be compensated with a $10 electronic gift card.

For virtual appointments, you can direct your patients to complete the survey using the link: https://redcap.link/YAICE.

Please let us know if you have any questions about the study or recruitment. You can contact either Dr. Kroeker (karen.kroeker@ualberta.ca) or myself, Allison Bihari (bihari@ualberta.ca). I will follow up with you each month to inquire if you need additional study recruitment materials, but feel free to reach out if you need more materials before then.

Again, we are very grateful for all your help.

Sincerely,

Karen I. Kroeker, MD, MSc, FRCPC	Allison Bihari
Associate Professor	PhD Candidate

Appendix F. Questionnaire Administered to Participants

Young Adults - Inflammatory Bowel Disease Care Experience (YA-ICE)

Principal Investigators:

University of Alberta:

Dr. Karen Kroeker
780-492-4873

University of Calgary:

Dr. Cynthia Seow
403-592-5015

Study Coordinator:

Allison Bihari
bihari@ualberta.ca
780-248-1037

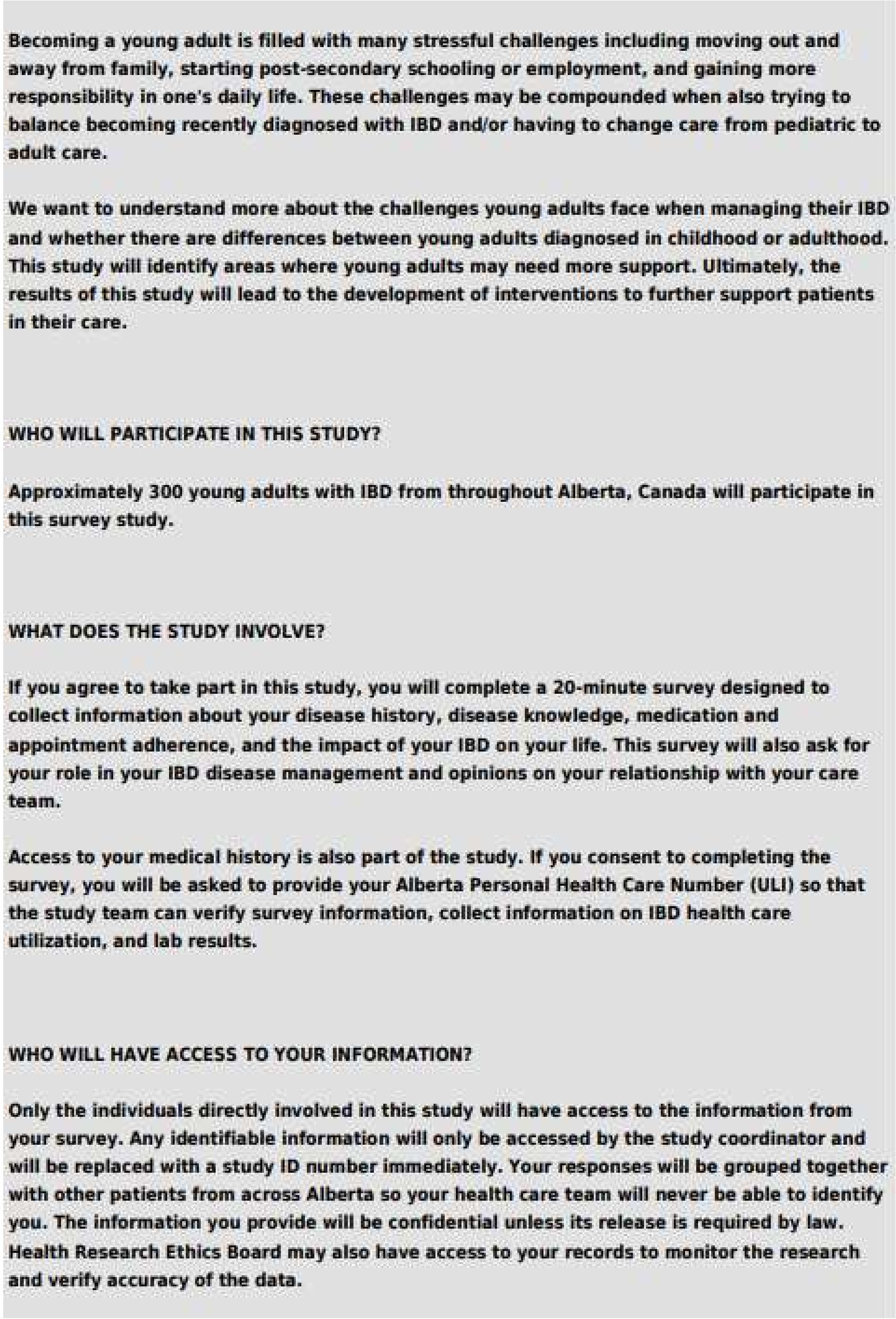
INTRODUCTION

You have the option to take part in a research study. The goals of this form are to give you information about what will happen in the study if you choose to take part and to help you decide if you want to be in the study.

You are being invited to participate in this research study because you have inflammatory bowel disease (IBD) and are a young adult (aged 18-25 years-old). This form provides a summary of the study information.

Before agreeing to participate, it is important for you to understand all the information related to this optional research study. You are encouraged to contact either the principal investigator or study coordinator with questions if you feel anything needs to be made clearer.

WHY ARE WE DOING THIS STUDY?



Becoming a young adult is filled with many stressful challenges including moving out and away from family, starting post-secondary schooling or employment, and gaining more responsibility in one's daily life. These challenges may be compounded when also trying to balance becoming recently diagnosed with IBD and/or having to change care from pediatric to adult care.

We want to understand more about the challenges young adults face when managing their IBD and whether there are differences between young adults diagnosed in childhood or adulthood. This study will identify areas where young adults may need more support. Ultimately, the results of this study will lead to the development of interventions to further support patients in their care.

WHO WILL PARTICIPATE IN THIS STUDY?

Approximately 300 young adults with IBD from throughout Alberta, Canada will participate in this survey study.

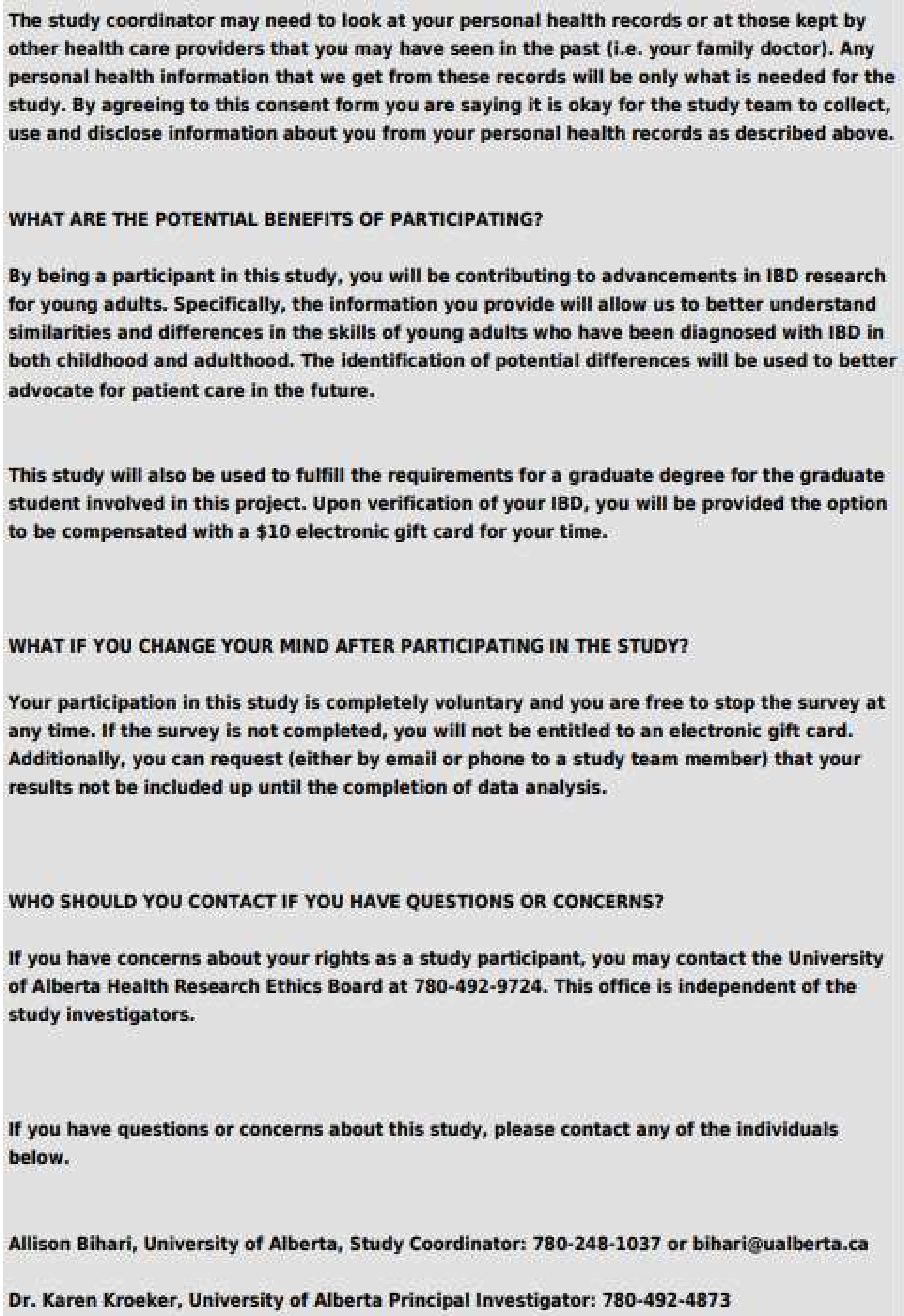
WHAT DOES THE STUDY INVOLVE?

If you agree to take part in this study, you will complete a 20-minute survey designed to collect information about your disease history, disease knowledge, medication and appointment adherence, and the impact of your IBD on your life. This survey will also ask for your role in your IBD disease management and opinions on your relationship with your care team.

Access to your medical history is also part of the study. If you consent to completing the survey, you will be asked to provide your Alberta Personal Health Care Number (ULI) so that the study team can verify survey information, collect information on IBD health care utilization, and lab results.

WHO WILL HAVE ACCESS TO YOUR INFORMATION?

Only the individuals directly involved in this study will have access to the information from your survey. Any identifiable information will only be accessed by the study coordinator and will be replaced with a study ID number immediately. Your responses will be grouped together with other patients from across Alberta so your health care team will never be able to identify you. The information you provide will be confidential unless its release is required by law. Health Research Ethics Board may also have access to your records to monitor the research and verify accuracy of the data.



The study coordinator may need to look at your personal health records or at those kept by other health care providers that you may have seen in the past (i.e. your family doctor). Any personal health information that we get from these records will be only what is needed for the study. By agreeing to this consent form you are saying it is okay for the study team to collect, use and disclose information about you from your personal health records as described above.

WHAT ARE THE POTENTIAL BENEFITS OF PARTICIPATING?

By being a participant in this study, you will be contributing to advancements in IBD research for young adults. Specifically, the information you provide will allow us to better understand similarities and differences in the skills of young adults who have been diagnosed with IBD in both childhood and adulthood. The identification of potential differences will be used to better advocate for patient care in the future.

This study will also be used to fulfill the requirements for a graduate degree for the graduate student involved in this project. Upon verification of your IBD, you will be provided the option to be compensated with a $10 electronic gift card for your time.

WHAT IF YOU CHANGE YOUR MIND AFTER PARTICIPATING IN THE STUDY?

Your participation in this study is completely voluntary and you are free to stop the survey at any time. If the survey is not completed, you will not be entitled to an electronic gift card. Additionally, you can request (either by email or phone to a study team member) that your results not be included up until the completion of data analysis.

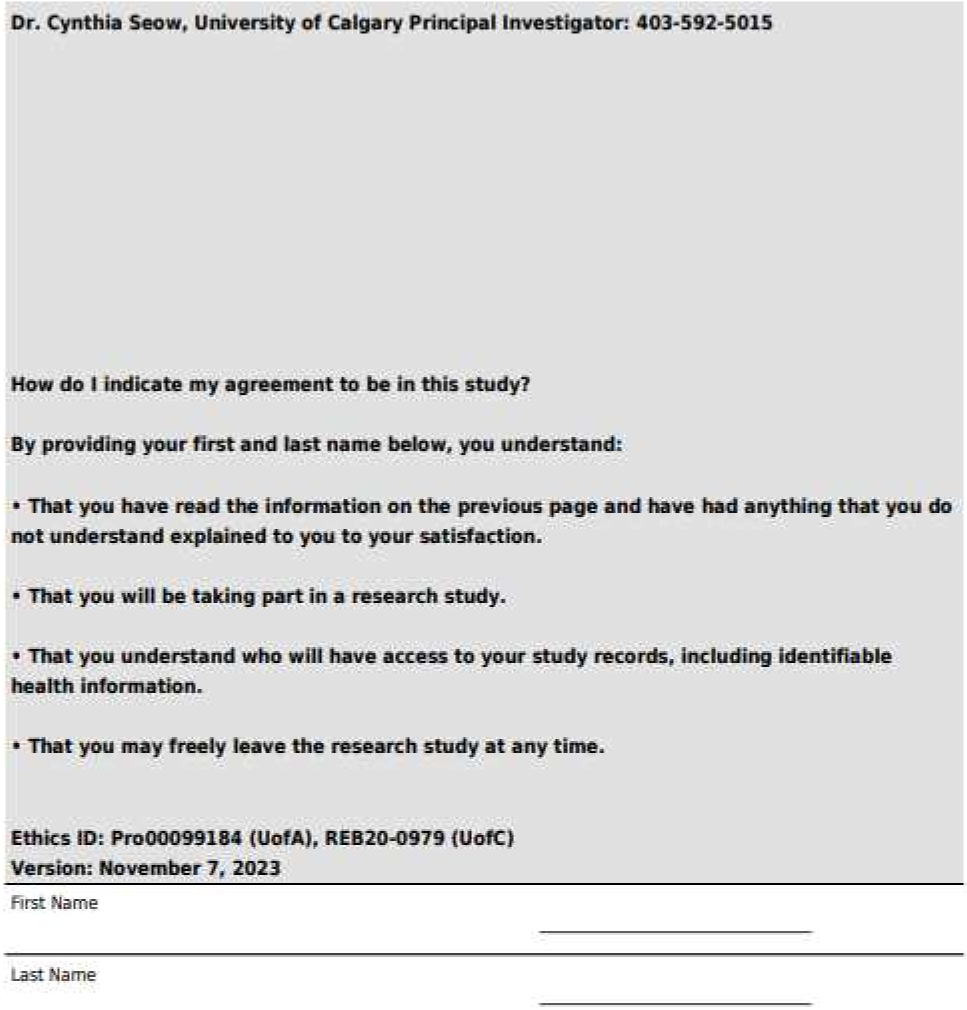
WHO SHOULD YOU CONTACT IF YOU HAVE QUESTIONS OR CONCERNS?

If you have concerns about your rights as a study participant, you may contact the University of Alberta Health Research Ethics Board at 780-492-9724. This office is independent of the study investigators.

If you have questions or concerns about this study, please contact any of the individuals below.

Allison Bihari, University of Alberta, Study Coordinator: 780-248-1037 or bihari@ualberta.ca

Dr. Karen Kroeker, University of Alberta Principal Investigator: 780-492-4873



Dr. Cynthia Seow, University of Calgary Principal Investigator: 403-592-5015

How do I indicate my agreement to be in this study?

By providing your first and last name below, you understand:

• That you have read the information on the previous page and have had anything that you do not understand explained to you to your satisfaction.

• That you will be taking part in a research study.

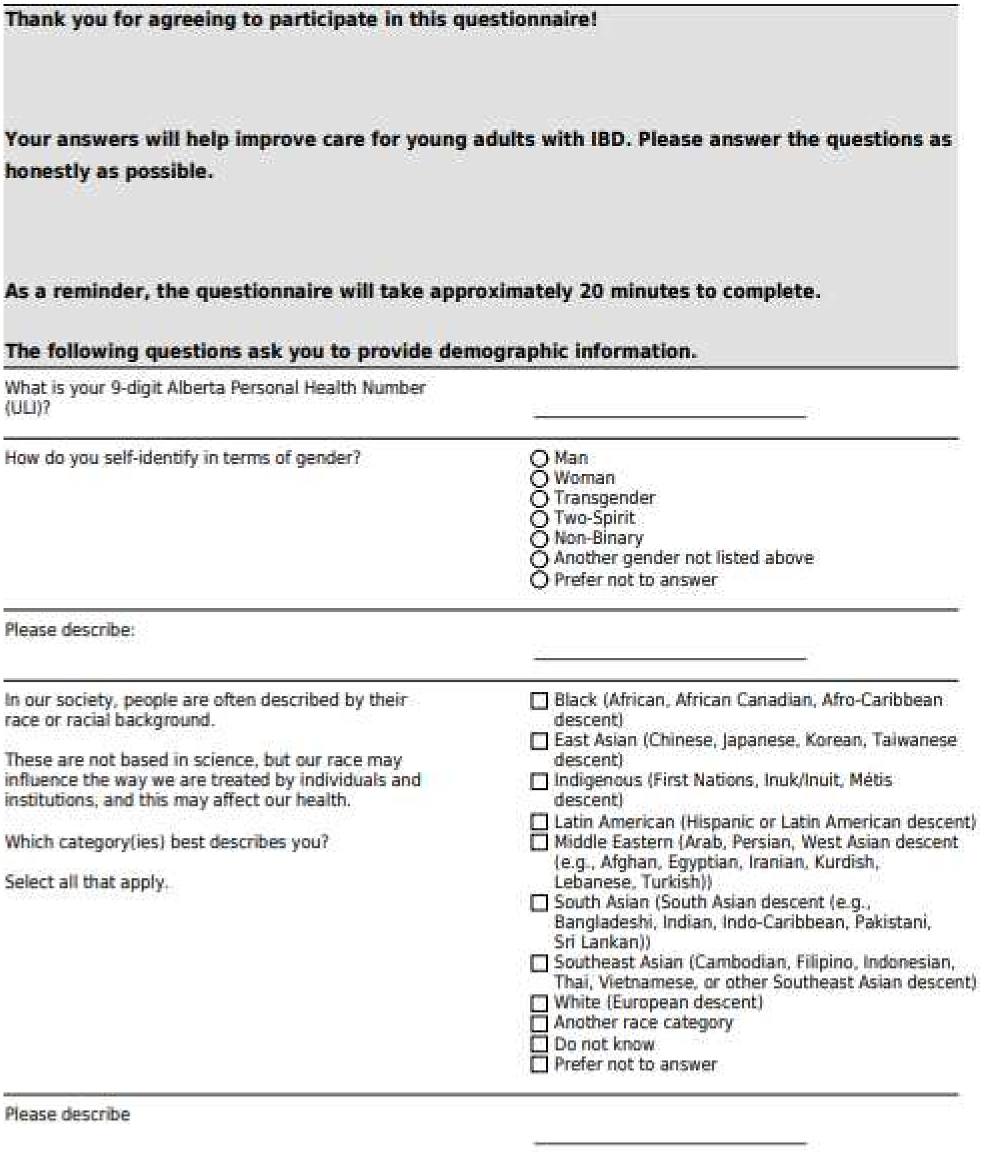
• That you understand who will have access to your study records, including identifiable health information.

• That you may freely leave the research study at any time.

Ethics ID: Pro00099184 (UofA), REB20-0979 (UofC)
Version: November 7, 2023

First Name ______________________

Last Name ______________________



Thank you for agreeing to participate in this questionnaire!

Your answers will help improve care for young adults with IBD. Please answer the questions as honestly as possible.

As a reminder, the questionnaire will take approximately 20 minutes to complete.

The following questions ask you to provide demographic information.

What is your 9-digit Alberta Personal Health Number (ULI)?	________________________
How do you self-identify in terms of gender?	○ Man ○ Woman ○ Transgender ○ Two-Spirit ○ Non-Binary ○ Another gender not listed above ○ Prefer not to answer
Please describe:	________________________
In our society, people are often described by their race or racial background. These are not based in science, but our race may influence the way we are treated by individuals and institutions, and this may affect our health. Which category(ies) best describes you? Select all that apply.	☐ Black (African, African Canadian, Afro-Caribbean descent) ☐ East Asian (Chinese, Japanese, Korean, Taiwanese descent) ☐ Indigenous (First Nations, Inuk/Inuit, Métis descent) ☐ Latin American (Hispanic or Latin American descent) ☐ Middle Eastern (Arab, Persian, West Asian descent (e.g., Afghan, Egyptian, Iranian, Kurdish, Lebanese, Turkish)) ☐ South Asian (South Asian descent (e.g., Bangladeshi, Indian, Indo-Caribbean, Pakistani, Sri Lankan)) ☐ Southeast Asian (Cambodian, Filipino, Indonesian, Thai, Vietnamese, or other Southeast Asian descent) ☐ White (European descent) ☐ Another race category ☐ Do not know ☐ Prefer not to answer
Please describe	________________________

What is your current age?	○ 18 ○ 19 ○ 20 ○ 21 ○ 22 ○ 23 ○ 24 ○ 25
What type of IBD have you been diagnosed with?	○ Crohn's Disease ○ Ulcerative Colitis ○ Indeterminate Colitis ○ Unsure
How did you hear about this study?	☐ Health care team ☐ Poster/Postcard ☐ Mail ☐ Social media ☐ Student digest ☐ Crohn's and Colitis Canada ☐ Other
Please describe:	________________________
Where do you primarily receive IBD care?	○ Edmonton ○ Calgary ○ Fort McMurray ○ Grand Prairie ○ Medicine Hat ○ Red Deer ○ Lethbridge ○ Other
Please enter the location where you primarily receive IBD care	________________________
What is the name of the health care provider you primarily see for your IBD? As a reminder, responses are anonymous.	________________________

The following questions ask about your current lifestyle.

Who do you currently live with? Select all that apply.	☐ Spouse ☐ Kids ☐ Parents ☐ Roommates ☐ Other relative(s) (eg., grandparents, aunts/uncles, cousins) ☐ Alone
Are you currently working?	○ Yes, Full-time ○ Yes, Part-time ○ Yes, Causal ○ No
Do you currently have a family doctor?	○ Yes ○ No ○ Unsure
Are you currently attending a post-secondary school (e.g., college, university)?	○ Yes, Full-time ○ Yes, Part-time ○ No
What is your highest level of education completed?	○ High School ○ Diploma/Certificate ○ Undergraduate Degree ○ Graduate Degree ○ Other
Please describe:	________________________
What age did you start attending your first post-secondary school (e.g., college, university)?	________________________
Did you attend your first post-secondary school in a different city than where you attended high school?	○ Yes ○ No

The following questions ask about your childhood.

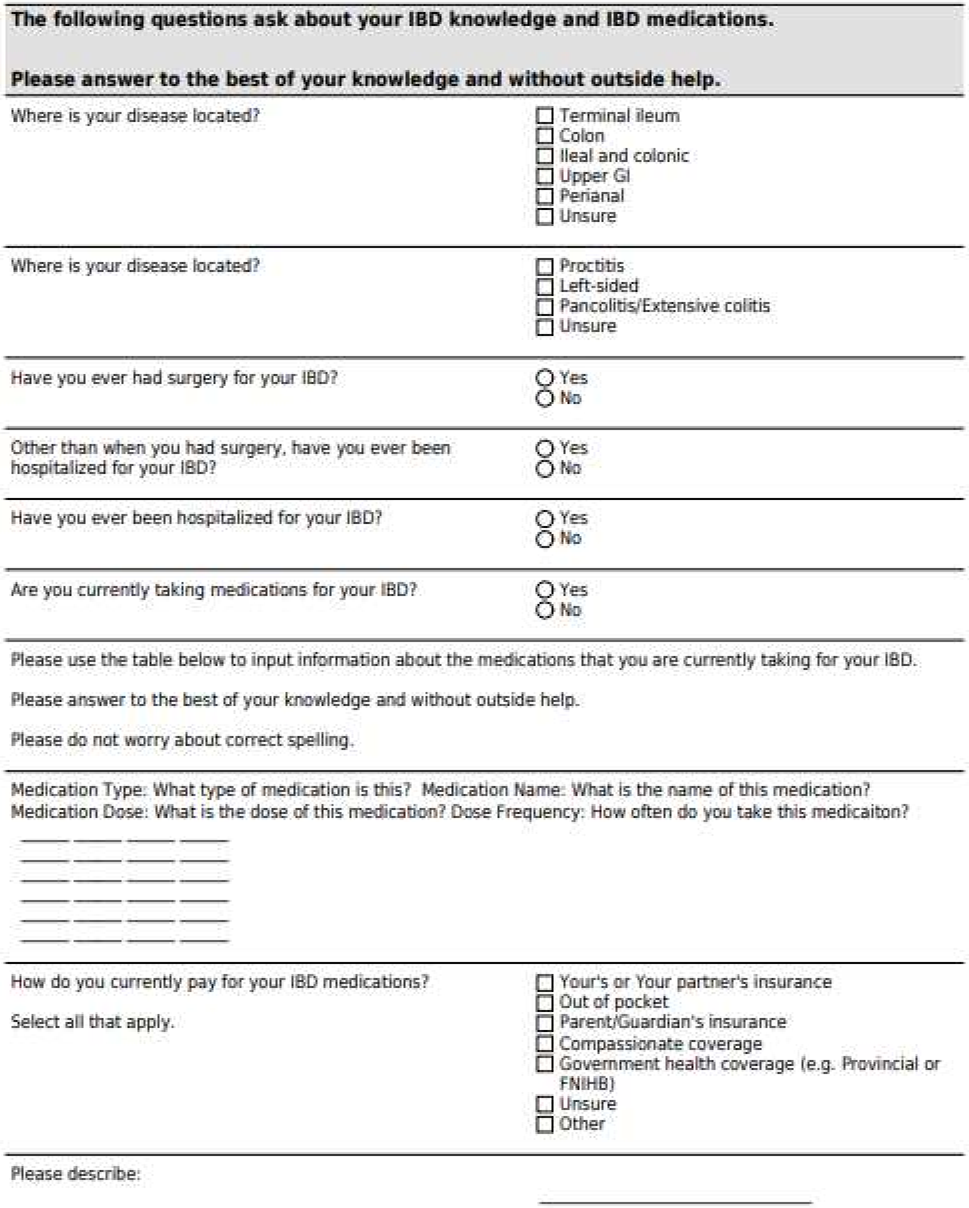
Were you born in Canada?	○ Yes ○ No
What age did you move to Canada?	__________________________
Were your parents born in Canada?	○ Yes, both ○ Yes, only one ○ Neither
Please read the following description and then move the slider to the position that best represents where you think your family stood on the ladder when you were between the ages 14-18. At the top of the ladder are the people who are the best off, those who have the most money, most education, and best jobs. At the bottom are the people who are the worst off, those who have the least money, least education, worst jobs, or no job.	Least Money, Education, Worst/No jobs (0) (5) Most Money, Education, Best jobs (10) *(Place a mark on the scale above)*
Between the ages of 14-18, who did you primarily live with? Select all that apply.	☐ Parent/Guardian 1 ☐ Parent/Guardian 2 ☐ Sibling(s) ☐ Other relative(s) (eg., grandparents, aunts/uncles, cousins) ☐ Other
Please describe:	__________________________
What is the highest level of education achieved by Parent/Guardian 1?	○ Some high school ○ High school ○ Diploma/Certificate ○ Undergraduate Degree ○ Graduate Degree
What is the highest level of education achieved by Parent/Guardian 2?	○ Some high school ○ High school ○ Diploma/Certificate ○ Undergraduate Degree ○ Graduate Degree
Growing up, did anyone you live with have a significant health issue?	○ Yes ○ No
Who? Select all that apply.	☐ Parent/Guardian 1 ☐ Parent/Guardian 2 ☐ Sibling(s) ☐ Other Relative(s) ☐ Other
Other:	__________________________

What health issue did Parent/Guardian 1 have?	________________ (List all major health issues.)
What health issue did Parent/Guardian 2 have?	________________ (List all major health issues.)
What health issue did your sibling(s) have?	________________ (List all major health issues.)
What health issue did your other relative(s) have?	________________ (List all major health issues.)
What health issue did they have?	________________ (List all major health issues.)
Growing up, did anyone you live with regularly smoke cigarettes?	○ Yes ○ No

20%

Completion

The following questions ask about your Inflammatory Bowel Disease (IBD).	
What age were you diagnosed with IBD?	________________
How long before your diagnosis did your IBD symptoms start?	○ 0-1 years ○ 1-2 years ○ 2+ years ○ Unsure
Do you have any chronic health issue(s) besides your IBD?	○ Yes ○ No
What health issue(s)?	________________
Have you ever experienced any challenges accessing health care for your IBD?	○ Yes ○ No
Please describe these challenges	________________
When you were first diagnosed with IBD, how comfortable did you feel interacting with the healthcare system?	0 (Not Comfortable 5 (Comfortable) 10 (Very Comfortable) *(Place a mark on the scale above)*
How comfortable do you currently feel interacting with the healthcare system?	0 (Not Comfortable) 5 (Comfortable) 10 (Very Comfortable) *(Place a mark on the scale above)*



The following questions ask about your IBD knowledge and IBD medications.

Please answer to the best of your knowledge and without outside help.

Where is your disease located?	☐ Terminal ileum ☐ Colon ☐ Ileal and colonic ☐ Upper GI ☐ Perianal ☐ Unsure
Where is your disease located?	☐ Proctitis ☐ Left-sided ☐ Pancolitis/Extensive colitis ☐ Unsure
Have you ever had surgery for your IBD?	○ Yes ○ No
Other than when you had surgery, have you ever been hospitalized for your IBD?	○ Yes ○ No
Have you ever been hospitalized for your IBD?	○ Yes ○ No
Are you currently taking medications for your IBD?	○ Yes ○ No

Please use the table below to input information about the medications that you are currently taking for your IBD.

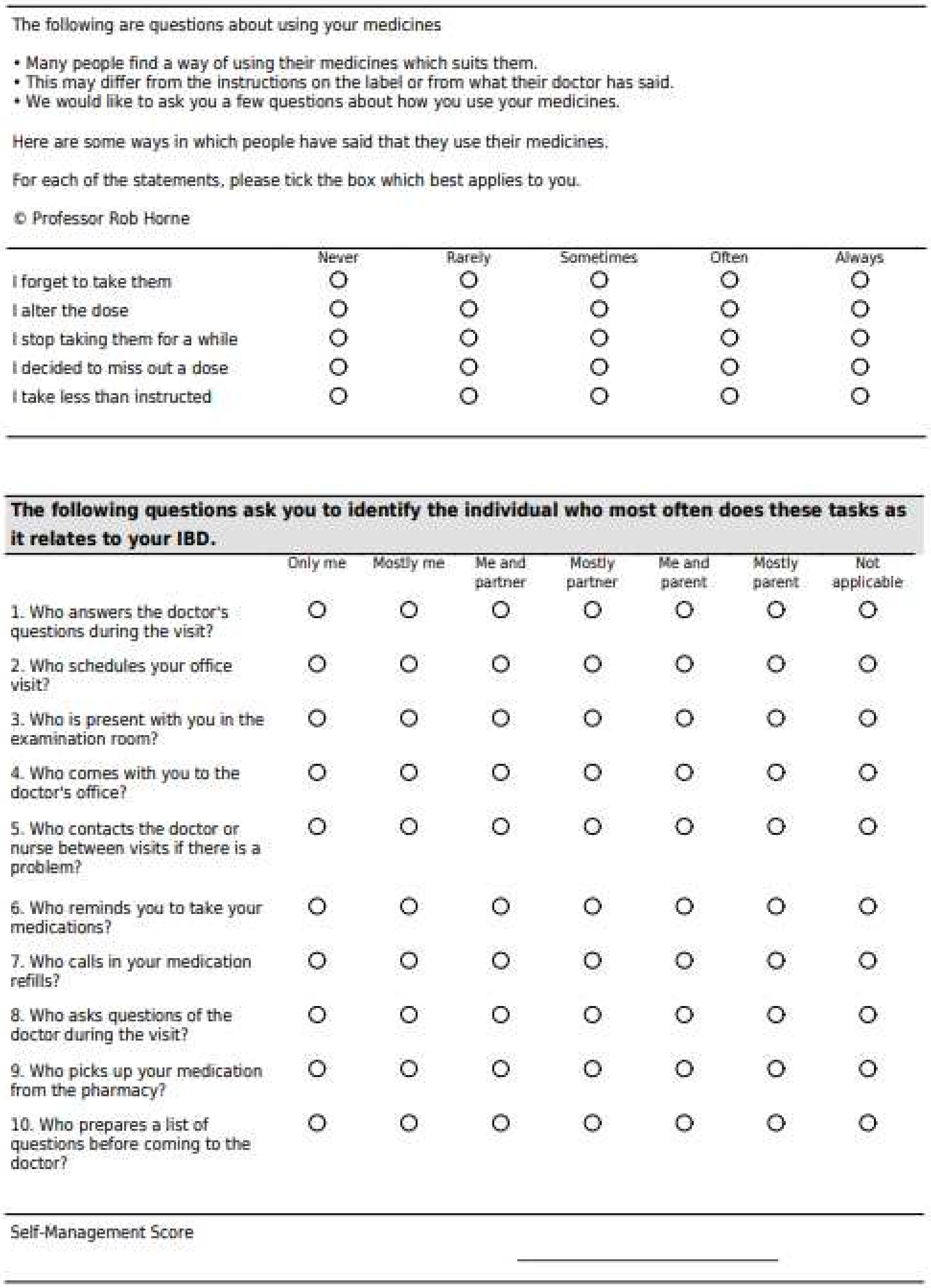
Please answer to the best of your knowledge and without outside help.

Please do not worry about correct spelling.

Medication Type: What type of medication is this? Medication Name: What is the name of this medication? Medication Dose: What is the dose of this medication? Dose Frequency: How often do you take this medicaiton?

_____ _____ _____ _____
_____ _____ _____ _____
_____ _____ _____ _____
_____ _____ _____ _____
_____ _____ _____ _____
_____ _____ _____ _____

How do you currently pay for your IBD medications? Select all that apply.	☐ Your's or Your partner's insurance ☐ Out of pocket ☐ Parent/Guardian's insurance ☐ Compassionate coverage ☐ Government health coverage (e.g. Provincial or FNIHB) ☐ Unsure ☐ Other
Please describe:	__________________________



The following are questions about using your medicines

- Many people find a way of using their medicines which suits them.
- This may differ from the instructions on the label or from what their doctor has said.
- We would like to ask you a few questions about how you use your medicines.

Here are some ways in which people have said that they use their medicines.

For each of the statements, please tick the box which best applies to you.

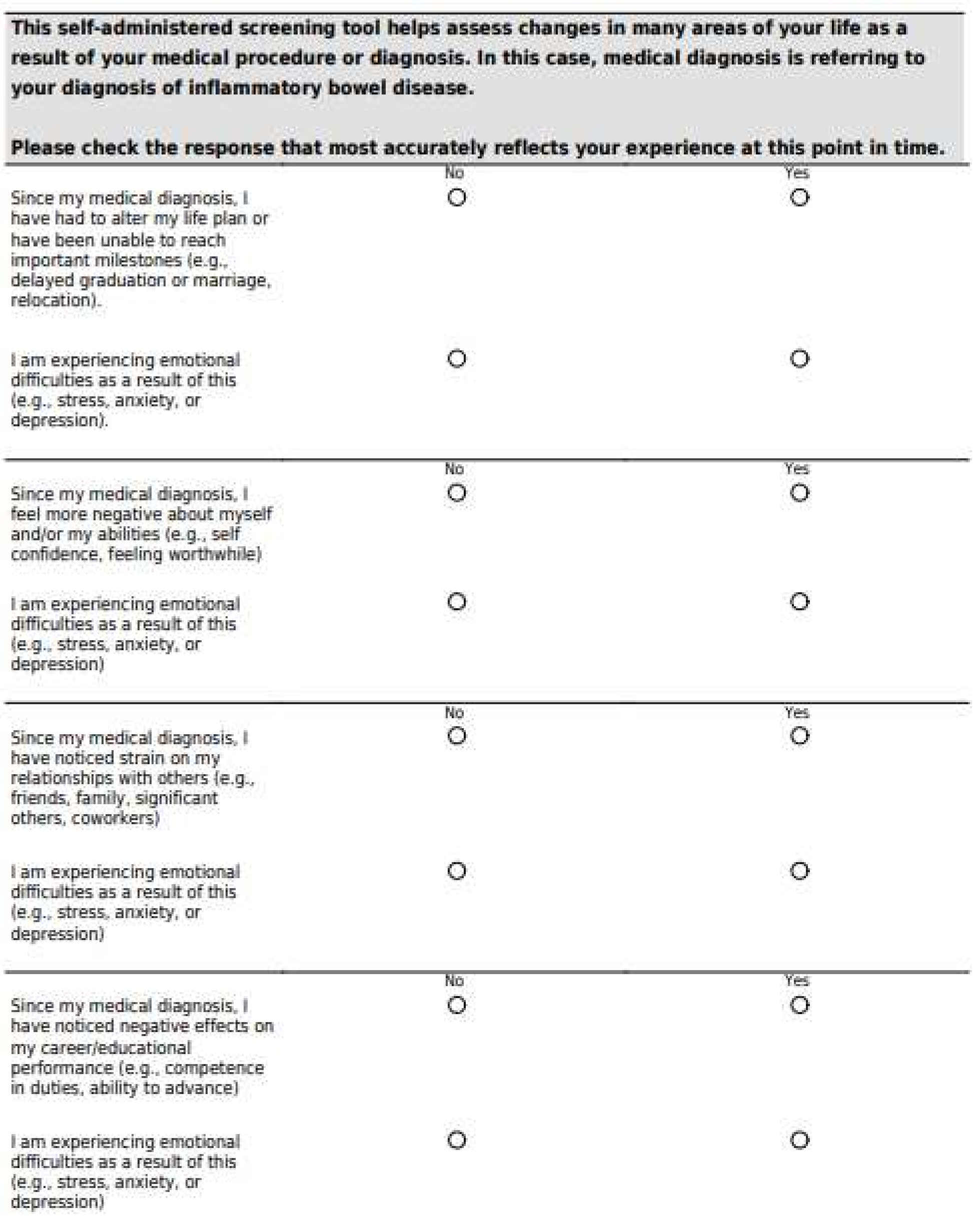
© Professor Rob Horne

	Never	Rarely	Sometimes	Often	Always
I forget to take them	○	○	○	○	○
I alter the dose	○	○	○	○	○
I stop taking them for a while	○	○	○	○	○
I decided to miss out a dose	○	○	○	○	○
I take less than instructed	○	○	○	○	○

The following questions ask you to identify the individual who most often does these tasks as it relates to your IBD.

	Only me	Mostly me	Me and partner	Mostly partner	Me and parent	Mostly parent	Not applicable
1. Who answers the doctor's questions during the visit?	○	○	○	○	○	○	○
2. Who schedules your office visit?	○	○	○	○	○	○	○
3. Who is present with you in the examination room?	○	○	○	○	○	○	○
4. Who comes with you to the doctor's office?	○	○	○	○	○	○	○
5. Who contacts the doctor or nurse between visits if there is a problem?	○	○	○	○	○	○	○
6. Who reminds you to take your medications?	○	○	○	○	○	○	○
7. Who calls in your medication refills?	○	○	○	○	○	○	○
8. Who asks questions of the doctor during the visit?	○	○	○	○	○	○	○
9. Who picks up your medication from the pharmacy?	○	○	○	○	○	○	○
10. Who prepares a list of questions before coming to the doctor?	○	○	○	○	○	○	○

Self-Management Score ____________________



This self-administered screening tool helps assess changes in many areas of your life as a result of your medical procedure or diagnosis. In this case, medical diagnosis is referring to your diagnosis of inflammatory bowel disease.

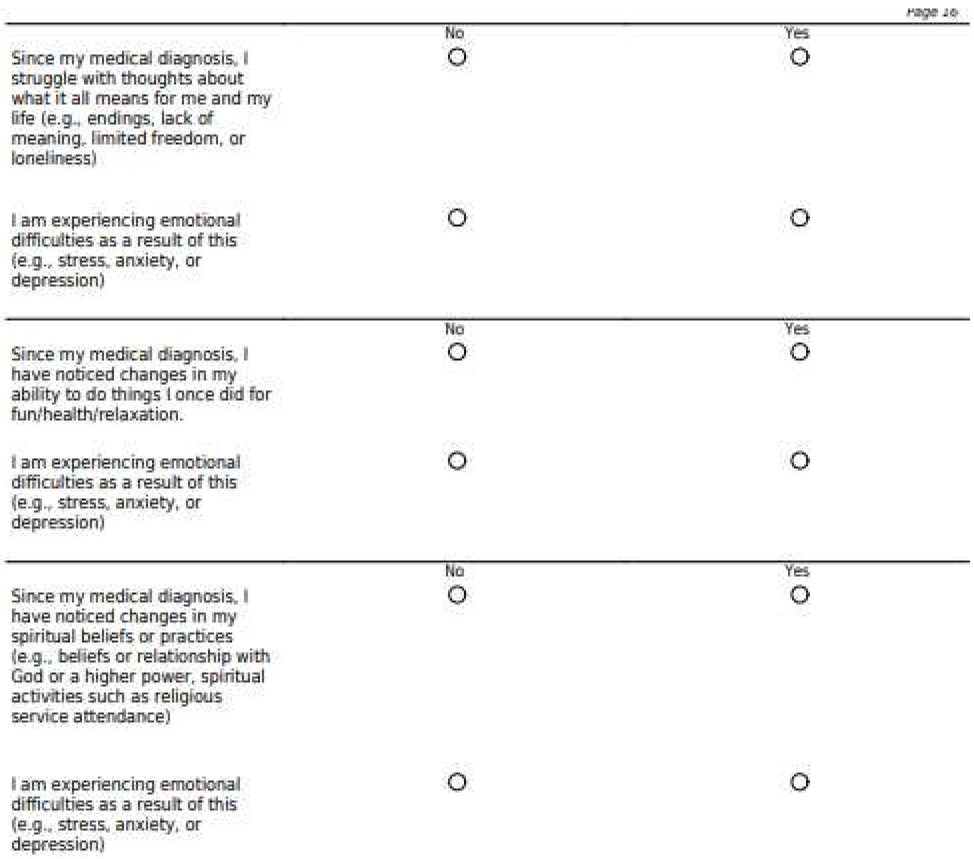
Please check the response that most accurately reflects your experience at this point in time.

	No	Yes
Since my medical diagnosis, I have had to alter my life plan or have been unable to reach important milestones (e.g., delayed graduation or marriage, relocation).	○	○
I am experiencing emotional difficulties as a result of this (e.g., stress, anxiety, or depression).	○	○

	No	Yes
Since my medical diagnosis, I feel more negative about myself and/or my abilities (e.g., self confidence, feeling worthwhile)	○	○
I am experiencing emotional difficulties as a result of this (e.g., stress, anxiety, or depression)	○	○

	No	Yes
Since my medical diagnosis, I have noticed strain on my relationships with others (e.g., friends, family, significant others, coworkers)	○	○
I am experiencing emotional difficulties as a result of this (e.g., stress, anxiety, or depression)	○	○

	No	Yes
Since my medical diagnosis, I have noticed negative effects on my career/educational performance (e.g., competence in duties, ability to advance)	○	○
I am experiencing emotional difficulties as a result of this (e.g., stress, anxiety, or depression)	○	○

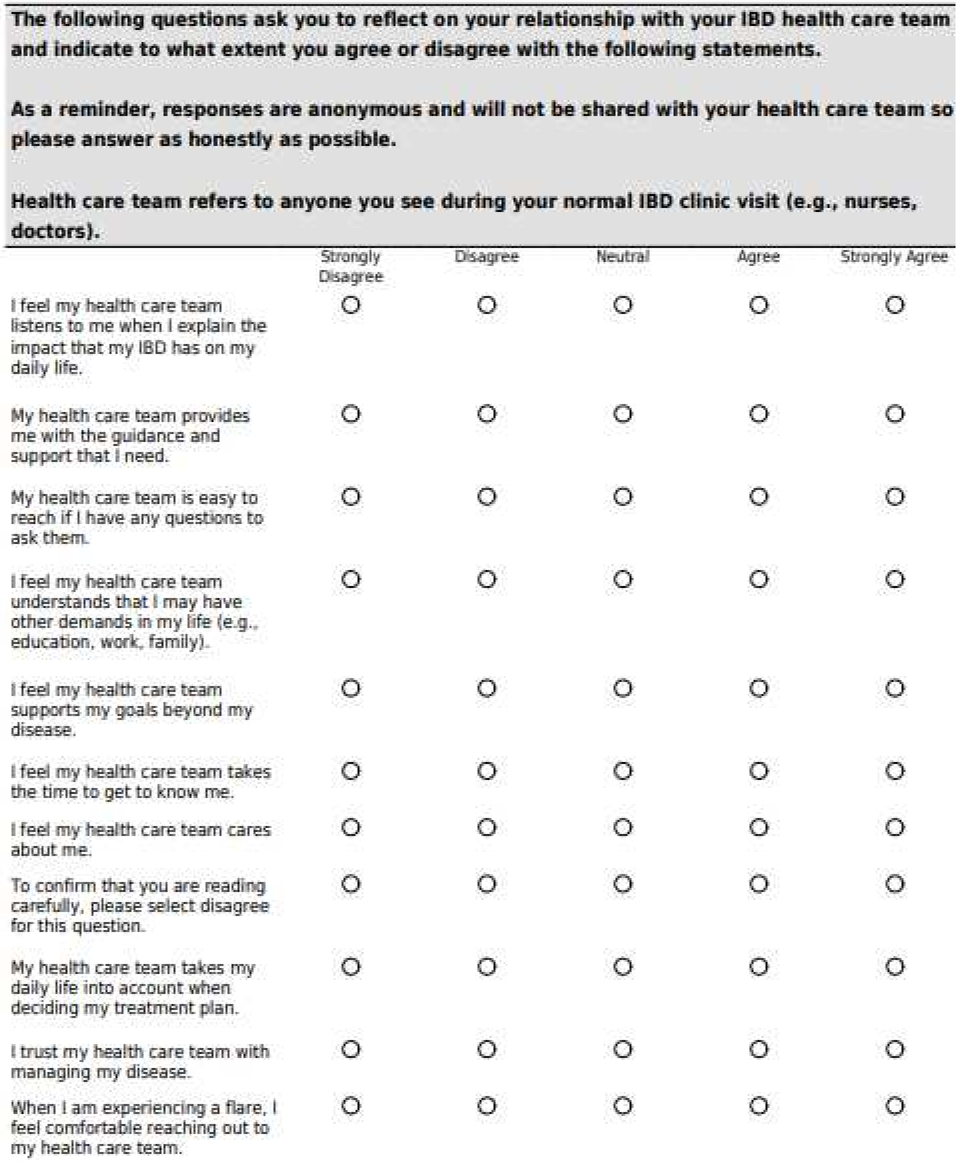


Page 16

	No	Yes
Since my medical diagnosis, I struggle with thoughts about what it all means for me and my life (e.g., endings, lack of meaning, limited freedom, or loneliness)	○	○
I am experiencing emotional difficulties as a result of this (e.g., stress, anxiety, or depression)	○	○

	No	Yes
Since my medical diagnosis, I have noticed changes in my ability to do things I once did for fun/health/relaxation.	○	○
I am experiencing emotional difficulties as a result of this (e.g., stress, anxiety, or depression)	○	○

	No	Yes
Since my medical diagnosis, I have noticed changes in my spiritual beliefs or practices (e.g., beliefs or relationship with God or a higher power, spiritual activities such as religious service attendance)	○	○
I am experiencing emotional difficulties as a result of this (e.g., stress, anxiety, or depression)	○	○



The following questions ask you to reflect on your relationship with your IBD health care team and indicate to what extent you agree or disagree with the following statements.

As a reminder, responses are anonymous and will not be shared with your health care team so please answer as honestly as possible.

Health care team refers to anyone you see during your normal IBD clinic visit (e.g., nurses, doctors).

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I feel my health care team listens to me when I explain the impact that my IBD has on my daily life.	○	○	○	○	○
My health care team provides me with the guidance and support that I need.	○	○	○	○	○
My health care team is easy to reach if I have any questions to ask them.	○	○	○	○	○
I feel my health care team understands that I may have other demands in my life (e.g., education, work, family).	○	○	○	○	○
I feel my health care team supports my goals beyond my disease.	○	○	○	○	○
I feel my health care team takes the time to get to know me.	○	○	○	○	○
I feel my health care team cares about me.	○	○	○	○	○
To confirm that you are reading carefully, please select disagree for this question.	○	○	○	○	○
My health care team takes my daily life into account when deciding my treatment plan.	○	○	○	○	○
I trust my health care team with managing my disease.	○	○	○	○	○
When I am experiencing a flare, I feel comfortable reaching out to my health care team.	○	○	○	○	○

Please indicate how much you agree with the following statements as they apply to you over the last month.

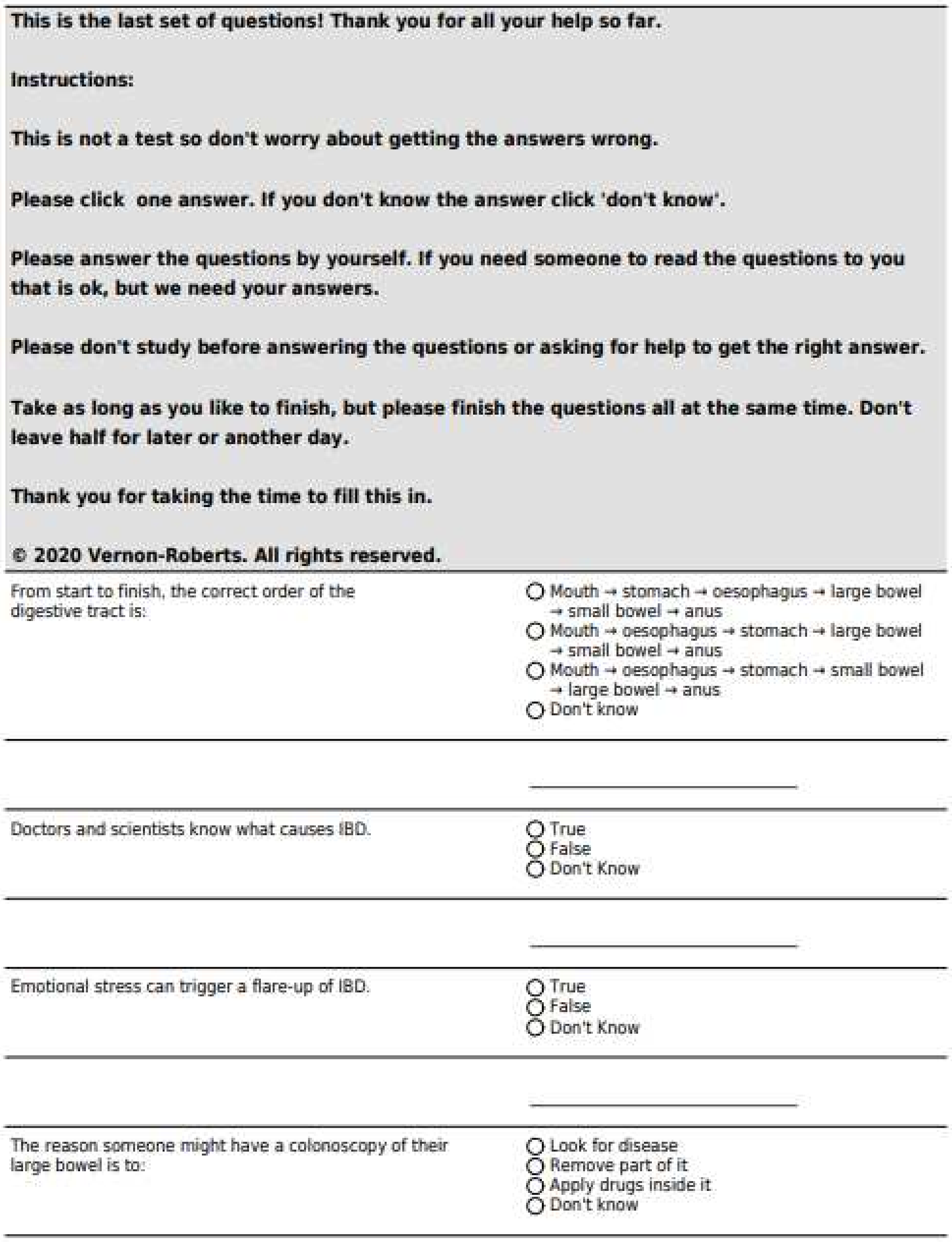
If a particular situation has not occurred recently, answer according to how you think you would have felt.

	Not True At All	Rarely True	Sometimes True	Often True	True Nearly All The Time
I am able to adapt when changes occur.	○	○	○	○	○
I can deal with whatever comes my way.	○	○	○	○	○
I try to see the humorous side of things when I am faced with problems.	○	○	○	○	○
Having to cope with stress can make me stronger.	○	○	○	○	○
I tend to bounce back after illness, injury, or other hardships.	○	○	○	○	○
I believe I can achieve my goals, even if there are obstacles.	○	○	○	○	○
Under pressure, I stay focused and think clearly.	○	○	○	○	○
I am not easily discouraged by failure.	○	○	○	○	○
I think of myself as a strong person when dealing with life's challenges and difficulties.	○	○	○	○	○
I am able to handle unpleasant or painful feelings like sadness, fear, and anger.	○	○	○	○	○

Resilience Score ______________________

Please answer the following items taking into consideration your personal experience with your illness. In this case, illness refers to your IBD.

	Never	Seldomly	Sometimes	Frequently	Always True
I feel isolated/alone due to my illness.	○	○	○	○	○
I'm ashamed of talking with others about my illness or symptoms.	○	○	○	○	○
I feel inferior and disregard myself because of my illness.	○	○	○	○	○
I feel that my illness is embarrassing.	○	○	○	○	○
I'm insecure due to my illness.	○	○	○	○	○
I feel that others may evaluate me negatively (or criticize me) due to my illness and symptoms.	○	○	○	○	○
I feel inadequate because of my illness and symptoms.	○	○	○	○	○



This is the last set of questions! Thank you for all your help so far.

Instructions:

This is not a test so don't worry about getting the answers wrong.

Please click one answer. If you don't know the answer click 'don't know'.

Please answer the questions by yourself. If you need someone to read the questions to you that is ok, but we need your answers.

Please don't study before answering the questions or asking for help to get the right answer.

Take as long as you like to finish, but please finish the questions all at the same time. Don't leave half for later or another day.

Thank you for taking the time to fill this in.

From start to finish, the correct order of the digestive tract is:	○ Mouth → stomach → oesophagus → large bowel → small bowel → anus ○ Mouth → oesophagus → stomach → large bowel → small bowel → anus ○ Mouth → oesophagus → stomach → small bowel → large bowel → anus ○ Don't know
	______________________________
Doctors and scientists know what causes IBD.	○ True ○ False ○ Don't Know
	______________________________
Emotional stress can trigger a flare-up of IBD.	○ True ○ False ○ Don't Know
	______________________________
The reason someone might have a colonoscopy of their large bowel is to:	○ Look for disease ○ Remove part of it ○ Apply drugs inside it ○ Don't know

IBD can affect organs other than the bowels.	○ True ○ False ○ Don't Know
Which one fact about Osteoporosis (weakening of your bones) is true?	○ It doesn't affect males or young women ○ If I drink plenty of milk I won't get it ○ It can be caused by IBD ○ Don't know
IBD that is in remission can slow down a young person's growth.	○ True ○ False ○ Don't Know
How do biologic drugs work?	○ They reduce the chance of infections ○ They block the chemicals or cells in the body that cause inflammation ○ They help the body absorb enough nutrients ○ Don't know
If a person with IBD has had no symptoms for a few months they should stop taking their drugs.	○ True ○ False ○ Don't Know
If both parents have IBD their children will definitely develop IBD.	○ True ○ False ○ Don't Know
Which one fact about complementary and alternative products is true? (example - herbal drugs).	○ They may interact with prescribed drugs. ○ Herbal products are natural so do not have side effects. ○ They are all safe to use with prescribed drugs. ○ Don't know
If a person gets side effects from taking steroids you should stop taking them at once.	○ True ○ False ○ Don't Know

	__________________________
Not eating certain foods will stop you having IBD flares (example - milk).	○ True ○ False ○ Don't Know
	__________________________
Which one fact about IBD surgery is true?	○ All people with IBD will need surgery at some point ○ Surgery is not helpful for people with IBD ○ Some people with IBD may need surgery to help with their symptoms ○ Don't know
	__________________________
People with IBD can absorb all the nutrients they need if they eat the right foods.	○ True ○ False ○ Don't Know

Thank you for participating in our study! :)

We are extremely grateful for your contribution.

Please provide the following information so that we can send you an electronic gift card as a token of our appreciation.

Would you like to provide an email so that you can receive a gift card as a thank you for your participation?	○ Yes ○ No
Please enter your email.	__________________________ (This is the email we will send the gift card to.)
Where would you like a gift card to?	○ Starbucks ○ Amazon
We are also interested in understanding the challenges faced by young adults with IBD and how we can better support patients in their care. Would you be interested in being contacted about participating in an interview on your care experience?	○ Yes ○ No
What is the best phone number to reach you at?	__________________________

Please proceed to the next page to review and submit the survey to complete your participation.

Appendix G. Instruments Considered to Assess Indicators of Transition Success

Theme	**Instrument Considered**	**Reason for excluding**
Independence in One's Care	Transition Readiness Assessment Questionnaire (TRAQ)	• Did not capture who helps patient with various tasks. • Some questions did not relate to the themes from part one and seemed relevant to a younger patient population.
	Inflammatory Bowel Disease Self-Efficacy Scale (IBD-SES)	• Did not capture who helps patient with various tasks • Some questions overlapped with other outcomes in our survey
Disease Knowledge	CCKNOW	• Length (CCKNOW has 24 items compared to 15 items in the IBD-KID2). • An acceptability survey showed that adults with IBD preferred the IBD-KID2 to the CCKNOW.
	Short Knowledge Questionnaire	• Focuses on knowledge about what increases risk of developing disease and what may impact severity
Disease Management	Morisky medication adherence scale-8 (MMAS-8)	• Does not explore reasons why patients may be non-adherent to medications.
	Brief Medication Questionnaire	• Does not explore reasons why patients may be non-adherent to medications.

Appendix H. Responses to Each Self-Management Question by IBD Onset Group

	Pediatric-onset IBD patients (N=37)		**Adult-onset IBD patients (N=19)**	
	N	*%*	**N**	*%*
Who answers doctor's questions during the visit?				
Only me	22	*59.6*	15	*79.0*
Mostly me	10	*27.0*	2	*10.5*
Me and partner	-	-	-	-
Mostly partner	-	-	-	-
Me and parent	5	*13.5*	2	*10.5*
Mostly parent	-	-	-	-
Not applicable	-	-	-	-
Who is present with you in the examination room?				
Only me	17	*46.0*	9	*47.4*
Mostly me	7	*18.9*	5	*26.3*
Me and partner	3	*8.11*	1	*5.30*
Mostly partner	-	-	-	-
Me and parent	9	*24.3*	4	*21.1*
Mostly parent	1	*2.70*	-	-
Not applicable	-	-	-	-
Who comes with you to the doctor's office?				
Only me	11	*29.7*	7	*36.8*
Mostly me	7	*18.9*	3	*15.8*
Me and partner	5	*13.5*	2	*10.5*
Mostly partner	-	-	-	-
Me and parent	13	*35.1*	7	*36.8*
Mostly parent	1	*2.70*	-	-
Not applicable	-	-	-	-
Who contacts the doctor or nurse between visits if there is a problem?				
Only me	23	*62.2*	17	*89.5*
Mostly me	6	*16.2*	-	-
Me and partner	2	*5.41*	-	-
Mostly partner	-		-	-
Me and parent	3	*8.11*	-	-
Mostly parent	3	*8.11*	2	*10.5*
Not applicable	-	-	-	-
Who reminds you to take your medications?				

Only me	20	*54.1*	10	*52.6*
Mostly me	6	*16.2*	5	*26.3*
Me and partner	-	-	1	*5.26*
Mostly partner	-	-	1	*5.26*
Me and parent	4	*10.8*	1	*5.26*
Mostly parent	4	*10.8*	-	-
Not applicable	3	*8.11*	1	*5.26*
Who calls in your medication refills?				
Only me	25	*67.6*	12	*32.4*
Mostly me	2	*5.41*	2	*10.5*
Me and partner	-	-	-	-
Mostly partner	-	-	-	-
Me and parent	1	*2.70*	2	*10.5*
Mostly parent	5	*13.5*	1	*5.26*
Not applicable	4	*10.8*	2	*10.5*
Who asks questions of the doctor during the visit?				
Only me	22	59.5	10	*52.6*
Mostly me	6	*16.2*	5	*26.3*
Me and partner	1	*2.70*	-	-
Mostly partner	-	-	-	-
Me and parent	7	*18.9*	3	*15.8*
Mostly parent	1	*2.70*	-	-
Not applicable	-	-	1	*5.26*
Who picks up your medication from the pharmacy?				
Only me	14	*37.8*	8	*42.1*
Mostly me	11	*29.7*	5	*26.3*
Me and partner	-	-	-	-
Mostly partner	-	-	1	*5.63*
Me and parent	5	*13.5*	2	*10.5*
Mostly parent	4	*10.8*	1	*5.26*
Not applicable	3	*8.11*	2	*10.5*
Who prepares a list of questions before coming to the doctor?				
Only me	18	*48.7*	8	*42.1*
Mostly me	5	*13.5*	5	*26.3*
Me and partner	-	-	-	-
Mostly partner	-	-	-	-
Me and parent	3	*8.11*	3	*15.8*
Mostly parent	5	*13.5*	1	*5.26*
Not applicable	6	*16.2*	2	*10.5*

Appendix I. Responses to Each Statement on Relationship with IBD Care Team by IBD Onset Group

	Pediatric-onset IBD patients (N=37)		**Adult-onset IBD patients (N=19)**	
	N	**%**	**N**	**%**
I feel my health care team listens to me when I explain the impact that my IBD has on my daily life.				
Strongly disagree	-	-	-	-
Disagree	-	-	1	*5.26*
Neutral	10	*27.0*	2	*10.5*
Agree	11	*29.7*	7	*36.8*
Strongly agree	16	*43.2*	9	*47.4*
My health care team provides me with the guidance and support that I need.				
Strongly disagree	-	-	-	-
Disagree	-	-	2	*10.5*
Neutral	6	*16.2*	1	*5.26*
Agree	15	*40.5*	9	*47.4*
Strongly agree	16	*43.2*	7	*36.8*
My health care team is easy to reach if I have any questions to ask them.				
Strongly disagree	1	*2.70*	-	-
Disagree	2	*5.41*	1	*5.26*
Neutral	6	*16.2*	4	*21.1*
Agree	21	*56.8*	7	*36.8*
Strongly agree	7	*18.9*	7	*36.8*
I feel my health care team understands that I may have other demands in my life (e.g., education, work, family).				
Strongly disagree	-	-	-	-
Disagree	-	-	-	-
Neutral	6	*16.2*	4	*21.1*
Agree	22	*59.5*	8	*42.1*
Strongly agree	9	*24.3*	7	*36.8*
I feel my health care team supports my goals beyond my disease.				
Strongly disagree	1	*2.70*	-	-
Disagree	2	*5.41*	1	*5.26*
Neutral	9	*24.3*	8	*42.1*
Agree	12	*32.4*	4	*21.1*
Strongly agree	13	*35.1*	6	*31.6*
I feel my health care team takes the time to get to know me.				

Strongly disagree	-	-	-	-
Disagree	4	*10.8*	2	*10.5*
Neutral	11	*29.7*	5	*26.3*
Agree	11	*29.7*	5	*26.3*
Strongly agree	10	*27.0*	7	*36.8*
I feel my health care team cares about me.				
Strongly disagree	-	-	-	-
Disagree	2	*5.41*	-	-
Neutral	7	*18.9*	2	*10.5*
Agree	17	*46.0*	9	*47.4*
Strongly agree	11	*29.7*	8	*15.8*
My health care team takes my daily life into account when deciding my treatment plan.				
Strongly disagree	-	-	-	-
Disagree	-	-	1	*5.26*
Neutral	7	*18.9*	4	*21.1*
Agree	21	*56.8*	9	*47.4*
Strongly agree	9	*24.3*	5	*26.3*
I trust my health care team with managing my disease.				
Strongly disagree	-	-	-	-
Disagree	-	-	-	-
Neutral	1	*2.70*	2	*10.5*
Agree	17	*46.0*	9	*47.4*
Strongly agree	19	*51.3*	8	*42.1*
When I am experiencing a flare, I feel comfortable reaching out to my health care team.				
Strongly disagree	-	-	-	-
Disagree	-	-	-	-
Neutral	6	*16.2*	5	*26.3*
Agree	16	*43.2*	8	*42.1*
Strongly agree	15	*40.5*	6	*31.6*
I feel comfortable asking questions to my health care team.				
Strongly disagree	-	-	-	-
Disagree	-	-	-	-
Neutral	4	*10.8*	3	*16.0*
Agree	14	*37.8*	7	*36.8*
Strongly agree	19	*51.3*	9	*47.4*
Overall, I am happy with my relationship with my health care team.				
Strongly disagree	-	-	-	-

Disagree	2	*5.41*	-	-
Neutral	2	*5.41*	2	*10.5*
Agree	17	*46.0*	9	*47.4*
Strongly agree	16	*43.2*	8	*42.1*

Appendix J

Responses to Each Life Domain on the Secondary 7 Lifestyle Effects Screening (S7-LES) by IBD Onset Group

Domain	**Pediatric-onset IBD patients (N=37)**		**Adult-onset IBD patients (N=19)**	
	N (%)	*95% CI*	N (%)	*95% CI*
Developmental	11 (29.7%)	*15.9%, 47.0%*	8 (42.1%)	*20.3%, 66.5%*
Intrapersonal (self)	24 (64.9%)	*47.5%, 79.8%*	9 (47.4%)	*24.4%, 71.1%*
Relationship	7 (18.9%)	*8.0%, 35.2%*	6 (31.6%)	*12.6%, 56.6%*
Career/Occupation	15 (40.5%)	*24.8%, 58.0%*	8 (42.1%)	*20.3%, 66.5%*
Existential	21 (56.8%)	*39.5%, 72.9%*	11 (57.9%)	*33.5%, 79.7%*
Avocational/Leisure	18 (48.7%)	*31.9%, 65.6%*	10 (52.6%)	*28.9%, 75.6%*
Spiritual	5 (13.5%)	*4.5%, 28.8%*	2 (10.5%)	*1.3%, 33.1%*

Experiencing Emotional Difficulties in Life Domains on the Secondary 7 Lifestyle Effects Screening (S7-LES) by IBD Onset Group

Domain	**Pediatric-onset IBD patients (N=37)**		**Adult-onset IBD patients (N=19)**	
	N (%)	*95% CI*	N (%)	*95% CI*
Developmental	10 (27.0%)	*13.8%, 44.1%*	7 (36.8%)	*16.3%, 61.6%*
Intrapersonal (self)	18 (48.6%)	*31.9%, 65.6%*	8 (42.1%)	*20.3%, 66.5%*
Relationship	7 (18.9%)	*7.96%, 35.2%*	5 (26.3%)	*9.2%, 51.2%*
Career/Occupation	14 (37.8%)	*22.5%, 55.2%*	4 (21.1%)	*6.1%, 45.6%*
Existential	17 (45.9%)	*29.5%, 63.1%*	10 (52.6%)	*28.9%, 75.6%*
Avocational/Leisure	13 (35.1%)	*20.2%, 52.5%*	8 (42.1%)	*20.3%, 66.5%*
Spiritual	2 (5.4%)	*0.661%, 18.2%*	1 (5.3%)	*0.13%, 2.6%*

Appendix K. Responses to Each Statement on the Chronic Illness-Related Shame Scale by IBD Onset Group

	Pediatric-onset IBD patients (N=37)		**Adult-onset IBD patients (N=19)**	
	N	**%**	**N**	**%**
I feel isolated/alone due to my illness.				
Never (0 points)	8	*21.6*	4	*21.1*
Seldomly (1 point)	10	*27.0*	3	*15.8*
Sometimes (2 points)	12	*32.4*	10	*52.6*
Frequently (3 points)	6	*16.2*	1	*5.26*
Always true (4 points)	1	*2.70*	1	*5.26*
I'm ashamed of talking with others about my illness or symptoms				
Never (0 points)	7	*18.9*	4	*21.1*
Seldomly (1 point)	13	*35.1*	7	*36.8*
Sometimes (2 points)	7	*18.9*	1	*5.26*
Frequently (3 points)	9	*24.3*	5	*26.3*
Always true (4 points)	1	*2.70*	2	*10.5*
I feel inferior and disregard myself because of my illness.				
Never (0 points)	13	*35.1*	9	*47.4*
Seldomly (1 point)	12	*32.4*	4	*21.1*
Sometimes (2 points)	9	*24.3*	3	*15.8*
Frequently (3 points)	2	*5.41*	3	*15.8*
Always true (4 points)	1	*2.70*	-	-
I feel that my illness is embarrassing.				
Never (0 points)	11	*29.7*	5	*26.3*
Seldomly (1 point)	6	*16.2*	1	*5.26*
Sometimes (2 points)	11	*29.7*	8	*42.1*
Frequently (3 points)	5	*13.5*	2	*10.5*
Always true (4 points)	4	*10.8*	3	*15.8*
I'm insecure due to my illness.				
Never (0 points)	11	*29.7*	6	*31.6*
Seldomly (1 point)	5	*13.5*	2	*10.5*
Sometimes (2 points)	11	*29.7*	4	*21.1*
Frequently (3 points)	9	*24.3*	4	*21.1*
Always true (4 points)	1	*2.70*	2	*10.5*
I feel that others may evaluate me negatively (or criticize me) due to my illness and symptoms.				
Never (0 points)	12	*32.4*	5	*26.3*
Seldomly (1 point)	11	*29.7*	8	*42.1*

Sometimes (2 points)	6	*16.2*	1	*5.26*
Frequently (3 points)	5	*13.5*	3	*15.8*
Always true (4 points)	3	*8.11*	2	*10.5*
I feel inadequate because of my illness and symptoms.				
Never (0 points)	12	*32.4*	9	*47.4*
Seldomly (1 point)	10	*27.0*	4	*21.1*
Sometimes (2 points)	8	*21.6*	2	*10.5*
Frequently (3 points)	5	*13.5*	3	*15.8*
Always true (4 points)	2	*5.41*	1	*5.26*

Appendix L. Responses to Each Statement on the Connor-Davidson Resilience Scale by IBD Onset Group

	Pediatric-onset IBD patients (N=37)		**Adult-onset IBD patients (N=19)**	
	N	*%*	**N**	*%*
I am able to adapt when changes occur.				
Not true at all (0 points)	-	-	-	-
Rarely true (1 point)	1	*2.70*	1	*5.26*
Sometimes true (2 points)	11	*29.7*	5	*26.3*
Often true (3 points)	17	*45.9*	9	*47.4*
True nearly all the time (4 points)	8	*21.6*	4	*21.1*
I can deal with whatever comes my way.				
Not true at all (0 points)	-	-	-	-
Rarely true (1 point)	2	*5.41*	1	*5.26*
Sometimes true (2 points)	12	*32.4*	7	*36.8*
Often true (3 points)	18	*48.6*	5	*26.3*
True nearly all the time (4 points)	5	*13.5*	6	*31.6*
I try to see the humorous side of things when I am faced with problems.				
Not true at all (0 points)	-	-	-	-
Rarely true (1 point)	3	*8.11*	1	*5.26*
Sometimes true (2 points)	11	*29.7*	2	*10.5*
Often true (3 points)	14	*37.8*	9	*47.4*
True nearly all the time (4 points)	9	*24.3*	7	*36.8*
Having to cope with stress can make me stronger.				
Not true at all (0 points)	-	-	1	*5.26*
Rarely true (1 point)	8	*21.6*	2	*10.5*
Sometimes true (2 points)	12	*32.4*	6	*31.6*
Often true (3 points)	10	*27.0*	5	*26.3*
True nearly all the time (4 points)	7	*18.9*	5	*26.3*
I tend to bounce back after illness, injury, or other hardships.				
Not true at all (0 points)	-	-	-	-
Rarely true (1 point)	-	-		
Sometimes true (2 points)	10	*27.0*	5	*26.3*
Often true (3 points)	18	*48.6*	7	*36.8*
True nearly all the time (4 points)	9	*24.3*	6	*31.6*
I believe I can achieve my goals, even if there are obstacles.				

Not true at all (0 points)	-	-	-	-
Rarely true (1 point)	-	-	1	*5.26*
Sometimes true (2 points)	9	*24.3*	4	*21.1*
Often true (3 points)	17	*45.9*	6	*31.6*
True nearly all the time (4 points)	11	*29.7*	8	*42.1*
Under pressure, I stay focused and think clearly.				
Not true at all (0 points)	2	*5.41*	-	-
Rarely true (1 point)	4	*10.8*	1	*5.26*
Sometimes true (2 points)	15	*40.5*	7	*36.8*
Often true (3 points)	6	*16.2*	6	*31.6*
True nearly all the time (4 points)	10	*27.0*	5	*26.3*
I am not easily discouraged by failure.				
Not true at all (0 points)	2	*5.41*	-	-
Rarely true (1 point)	7	*18.9*	2	*10.5*
Sometimes true (2 points)	12	*32.4*	7	*36.8*
Often true (3 points)	13	*35.1*	6	*31.6*
True nearly all the time (4 points)	3	*8.11*	3	*15.8*
I think of myself as a strong person when dealing with life's challenges and difficulties.				
Not true at all (0 points)	1	*2.70*	1	*5.26*
Rarely true (1 point)	2	*5.41*	2	*10.5*
Sometimes true (2 points)	12	*32.4*	4	*21.1*
Often true (3 points)	11	*29.7*	5	*26.3*
True nearly all the time (4 points)	11	*29.7*	7	*36.8*
I am able to handle unpleasant or painful feelings like sadness, fear, and anger.				
Not true at all (0 points)	-	-	-	-
Rarely true (1 point)	5	*13.5*	-	-
Sometimes true (2 points)	14	*37.8*	6	*31.6*
Often true (3 points)	10	*27.0*	8	*42.1*
True nearly all the time (4 points)	7	*18.9*	5	*26.3*