An Individualized and Multi-faceted Transition Intervention is Needed for Pediatric Patients with Inflammatory Bowel Disease

by

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Abstract

The transition of chronically ill patients from pediatric to adult care can be challenging for patients and families and there is no gold standard for how to facilitate this process. An unsuccessful transition has been associated with more negative health outcomes. It is generally agreed upon by researchers in the field that a successful transition should foster knowledge of the patient’s disease, as well as skills such as self-advocacy and self-management in relation to health and medication knowledge. Current research is aimed at elucidating the best transition process or intervention to avoid negative health outcomes that have been observed with unstructured transition, or to improve patient scores on assessments that measure skills believed to contribute to prevention of these outcomes.

Inflammatory bowel disease (IBD) is one illness for which young adults must transition to an adult gastroenterologist before turning 18. While checklists, guidelines and recommendations have been synthesized using expert opinion, limited research addresses the opinions and transition experiences of young adults with IBD. Development of an effective transition intervention requires: assessing the current transition experience (seeking ideas for what could be improved upon), determining preferred intervention content and format, and assessment of young adult IBD patients with respect to skills required for successful transition. This first phase of a larger transition improvement project was designed to collect and analyze this essential information, in order to inform the design of an intervention.

A mixed-methods design was used for this study, which employed semi-structured interviews and validated quantitative assessments of self-management/self-advocacy, medication adherence and IBD knowledge. The participant group was composed of 20 young adults (ages 17-20 years) with IBD, who had transitioned from pediatric care at the Edmonton Pediatric IBD Clinic (EPIC) to adult care at the Zeidler Gastrointestinal Health Centre, both University of Alberta clinics. Interviews were analyzed thematically, using the qualitative method of interpretive description. Scores on assessments were compared to published reference data by estimating proportion or mean differences and 95% confidence intervals.

Even though transition was discussed using fairly positive commentary by this group of participants, the concept of a transition intervention was well-received by study participants. Preferred content centered on medications, disease and what to expect during transition. Preferred ways to learn were one-on-one instruction, handouts and websites. Themes identified from the interviews, which were key for guiding intervention development, were: “individualized and multi-faceted,” “teach about transition” and “support the shift in responsibility.” Quantitative assessments showed that among participants, 5.0% achieved 90% mastery of transition skills (0.64% lower [95% CI: -10.7%, 9.4%] than the reference estimate), 35% had poor medication adherence (17% [95% confidence interval (CI): -39%, 6%] lower than the reference estimate) and the mean knowledge score was 15.15 (3.86 [95% CI: 2.27, 5.45] points higher than the reference estimate).

This study identified preferred intervention formats and content as well as skill areas to target for improvement. It was novel in its consideration of the current transition experience from the patient perspective, as well as their recommendations for an intervention. The results of this study led the researchers to design an interactive website, which delivers a customized experience and can be implemented at clinics across Canada.

Preface

This thesis is an original work by Natalie Klostermann. The research project, of which this thesis is a part, received ethics approval from the University of Alberta Health Research Ethics Board, “Improving Healthcare Transition for Young Adults with Inflammatory Bowel Disease,” No. Pro00054381, February 2015.

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1 Introduction

1.1 Healthcare Transition

Transition is the process by which young adults with chronic illness are prepared to transfer from a pediatric to an adult provider;[1–3] transfer of care is one step in the process.[1,4] Transition is known to be a crucial and complex phase in the care of people with chronic illness.[5] In Canada, patients transfer to adult care providers prior to their 18th birthday, as they cannot be treated in a pediatric hospital once they have reached this age.[3,6] Successful preparation for transfer to adult care requires effective communication between the patient, the family and the provider.[4] The provider must be attuned to patient needs as transition progresses and provide “developmentally appropriate care” to help build the skills necessary to succeed on the adult side.[4] Transition is necessary for adolescents to prepare for the future, develop important life skills[6–8] and receive appropriate care during adulthood.[2,9] Transition has the capacity to support health, but proceeding without a plan can be detrimental.[4]

Transition researchers have defined a successful transition as one that encourages the patient to develop self-sufficiency in managing his/her disease.[5,6,8,10–13] Skills such as self-efficacy (belief in one’s own ability to do something),[3,10,14,15] self-advocacy [3,4,6,10,16] and knowledge of disease and medications[3,5,10,16,17] are widely recognized as beneficial to the transitioning patient.

1.1.1 The Impact of Unsuccessful Transition

Transition can be difficult for some young adults due to the expectation that they will take responsibility for their health,[10,18] resistance to leaving a familiar pediatric provider,[6,18,19] parents' desire to stay involved with care[18,20,21] and the differing expectations[5,10,20] and practices[12] of pediatric and adult health care providers. Becoming a young adult, in and of itself, can be a tumultuous time involving many changes.[4,22] Adverse health outcomes have been associated with this stage of life and may result from inadequate support. Transitioning patients with chronic diseases who are ill-prepared for the adult care environment may feel discouraged to return and drop out of follow-up care.[23] One study found that 40% of young adults with diabetes registered at a clinic for 16-25 year olds were not attending the clinic.[24] Cadario *et al.* showed in a study of diabetic patients, after 3 years in adult care, among those experiencing an unstructured transition, 57% had regular attendance, while 80% had regular attendance among those who had a structured transition, even though the two groups had similar attendance rates in their last year of pediatric care.[25]

Unsupported transfer to adult care was associated with poorer glycemic management in multiple studies of diabetic transition patients.[25,26] Transition-aged chronic illness patients also have increased hospitalization[27] and emergency department visits,[28] which may be due to differences in adult care, or lack of continuity of care. Transition can be a time of vulnerability for chronically ill young adults. Evidence from research in pediatric transition care for chronic illness justifies the need for additional transition strategies.

1.1.2 Improving Transition

In order to support patients through transition, physicians and researchers have recognized the need to develop strategies, interventions or tools. One such transition tool that has been used with young adults requiring transplant is the ON TRAC model, developed by Paone at the Children's & Women's Health Centre of British Columbia.[4,29] It is a checklist encompassing areas of competency in self-advocacy, knowledge and accessing supports that healthcare providers must help address before the patient transfers.[4,29] The "Good 2 Go Transition Clinic" at The Hospital for Sick Children in Toronto works to help young adults with chronic illness and complex needs to transition smoothly.[30] As part of their program, they also provide an online tool to create a printable medical history summary called MyHealth Passport.[31] Large academic centres in Washington, DC have noted the lack of formal transition policies and have undertaken a quality improvement initiative.[32] This program is focused on creating and implementing a more comprehensive transition protocol by training providers and measuring their success at following 6 criteria aimed at improving transition services: having a transition policy, a registry of transitioning patients, transition preparation (using a readiness assessment), transition planning (including an action plan and medical history), transfer to adult care, and documentation of completed transition.[32]

While it is widely accepted that the transition experience needs to be improved, it is important to assess the outcomes of the implementation of these new strategies, tools or interventions to be able to evaluate their usefulness and further refine them in future research. Several nonrandomized transition studies have shown that using an educational or supportive intervention to improve knowledge or skills is followed by improved health outcomes, for example, better metabolic control for type 1 diabetics[25,33] and increased scores in health-related quality of life measures for young adults with juvenile idiopathic arthritis.[34] In a recent investigation of an educational intervention offered by a nurse to pediatric transition patients with congenital heart disease, the intervention was followed by improvement in self-management skills and knowledge among patients.[35] Overall, research in transition care for chronic illness confirms the usefulness of supportive, structured transition strategies and tools.

Interventions have led to improved patient outcomes outside of transition-age as well. Kennedy *et al.* demonstrated in a randomized controlled trial that an intervention comprised of an information package, consultation and self-management plan offered to adults with inflammatory bowel disease (IBD) was followed by reduced trips to the hospital and increased feelings of being able to cope.[36] Similarly, in a randomized, controlled trial involving patients with chronic illness, Lorig *et al.* found that practices to improve self-management behaviors were followed by increases in patient-perceived self-efficacy,[37] improved health status,[37,38] decreased hospitalization[38] and decreased health care utilization.[37]

In the interest of healthcare economy, media technology is increasingly being incorporated into the design of transition interventions. In a randomized clinical trial using an internet intervention along with text messages and healthcare team contact, participants in the intervention group demonstrated improved disease management, self-efficacy and communication.[39] Using media technology could be a cost-effective way to provide support while using less healthcare resources.[39] Patients with chronic illness in a focus group study have shown a preference for interactive websites to help with transition preparation.[40] While it is clear that a variety of interventions have been associated with improvements in skills and outcomes, there is still a call for further research into the best intervention(s) for a successful transition.[1,3,41,42]

Benchimol *et al.* report that an educational transition intervention should be designed to specifically target transition-aged patients and their particular needs for knowledge.[11] Current transition patients are part of Generation Z, born between 1995 and the present.[43] This generation has been called “Digital Natives,” being the first generation to grow up with digital technology.[44] A report from the Media Technology Monitor in Ottawa shows that they are highly active on their cell phones and have an affinity for online video consumption, watching an average of 10.5 hours per week.[45] The need to update teaching methods and content to suit students of the digital era has been acknowledged in education.[44] The current education curriculum in Alberta is designed so that graduating students can use, access, and communicate via a variety of technologies.[46] Thus, transition-aged patients may be seeking information in new ways, different from older Canadians.

There are numerous, innovative ways to communicate with people. Patient education strategies set forth by University Health Network in Toronto include lectures, discussion, written documents/handouts, audiovisual components, demonstration, role playing, computer technology and simulated games.[47] Traditionally, medical information has been delivered in print, both as pamphlets and more recently information has been developed on websites. It is clear that Generation Z is very adept at working with media technology; indeed they are the first generation to “grow up online” with access to infinite information.

While a number of recent qualitative[41,48–50] and mixed-method[51–54] studies are beginning to illuminate the firsthand transition experiences of chronically ill, young adults through interviews,[41,49–51,53,54] focus groups[48] or surveys[52,55] (with some studies including the experiences of parents[48,51,54] or healthcare providers[49]), there is still a lack of investigation of patients’ perspectives on how to teach the necessary information and skills. One study by Applebaum *et al.* used qualitative focus groups to ask young adults with various chronic diseases how they preferred to learn health information, with an emphasis on media technology.[40] Rather than continuing to use traditional educational methods, or make assumptions about young adults’ learning styles or preferences, researchers are starting to recognize that it is important to ask how they want to receive educational information about their health. Transition interventions need to be informed by the patients that will use them.

1.2 Inflammatory Bowel Disease

IBD is one chronic illness for which people diagnosed in childhood must make the transition to the adult care environment. The two main forms are Crohn’s disease and ulcerative colitis. IBD is increasing in incidence and prevalence;[56–58] Canada has some of the highest rates of IBD in the world,[59,60] with approximately 0.5% of the Canadian population having IBD.[59,60] Evidence from the province of Ontario suggests that incidence rates are rising most in the pediatric population, especially in children under the age of 10.[60]

IBD is a burdensome disease for the individual, as well as the healthcare system.[56] Approximately 25% of patients are diagnosed in childhood,[61–64] which means they will have IBD for most of their lives. Quality of life for people with IBD can be impaired[1,56,57,65–67] as having the disease can affect mental wellbeing,[65,68–70] academic attendance,[71–73] employment[67,73] and relationships.[71–73] Adequate care of this patient population should be a concern of the Canadian healthcare system. Ensuring that individuals are knowledgeable and able to be responsible and proactive in the management of their disease could help with quality of life[65] and consequently lessen the healthcare burden.[1] Thus, the transition of young adults with IBD is a pivotal time for which more research into useful interventions is needed.

1.2.1 IBD and Transition

Pediatric IBD care is more family-centered[3,12] and multidisciplinary,[12,67] compared to adult care, which focuses on the individual.[3,12] The goals of care in childhood versus adulthood can be quite different, with growth and development being main health concerns at a young age, while reproduction and cancer surveillance come to the forefront in adulthood.[42] The adult gastroenterologist is likely to expect an independently functioning patient.[5,12,42] Young adults need to be prepared for the differences in care that they will experience when making the switch from pediatric to adult care.

In a retrospective study comparing IBD patients at a transition clinic to disease-duration matched adult IBD patients, the young adults were found to have more extensive inflammation on average, were treated more often with immunosuppressants and biologics, had more missed appointments on average and a larger proportion had required hospital admission.[74] Considering that the disease and medications can be quite complex and difficult to manage at this crucial time-point, support through transition is necessary.[74] Many issues in transition of the IBD patient are similar to those of other chronic illnesses.[5,12,22]

1.2.1.1 Characterizing Skill and Knowledge Gaps of Young Adults with IBD

Using the Transition Readiness Assessment Questionnaire, which has sub-sections focusing on medications, appointments, health issues, communication in healthcare and tasks of day-to-day life, Gray *et al.* found that only 5.6% of transitioning young adults were meeting an institution-wide benchmark, meaning that nearly all have not attained important skills deemed beneficial for transition.[75] In another transition readiness study, health literacy (evaluated using a combination of assessments of knowledge of disease, medical history and ability to perform certain health management tasks) was used as a benchmark for transition readiness.[76] While the assessments qualified 11% of patients as ready to transition, gastroenterologists identified 47% as ready to transition, over-estimating the proportion of these patients with adequate health literacy for adult care.[76] A University of Michigan investigation to assess self-management skills in IBD patients 10-21 years of age used the

ImproveCareNow Transition Checklist, which includes items in IBD knowledge and health-related behaviours or communication skills.[77,78] Self-reported self-management improved with age but not time since diagnosis; however, many patients 18 or older were unable to independently arrange for refills, appointments, or communicate while at their appointments, and some required help identifying a flare of their IBD.[77] Checklists can be useful to monitor these skills and identify potential areas of weakness for interventions to address.[77] Using an IBD version of the MyHealth Passport, many adolescent patients with IBD have been shown to lack knowledge about their health history and disease location.[11]

Medication knowledge is a valuable aspect of establishing self-management in adult care.[79] In a survey of 16-18 year olds with IBD, participants were able to name their medications and dosages but unable to list side effects of their current medications.[16] This study also highlighted that more than 75% of the 40 participants still relied on parents to help with booking appointments, transportation to appointments and the pharmacy, as well as medication refills.[16] Nearly all participants were good at remembering to take medications, with only 4/40 still relying on parents for this.[16] An investigation of adherence to oral IBD medication in adolescents 13-17 years old found that average adherence by pill count, measured as a percentage of prescribed doses taken, was between 62% and 64%, depending on the medication, and family-report of adherence was higher than pill counts indicated.[80] The most frequently identified obstacle to adherence was “forgetting.”[80] Less than half of adolescent participants surveyed said that they were the main person ensuring they took their medication and only 27% manage refills themselves, with the others letting the medication responsibilities fall mainly on their mothers.[80] In another study of barriers to medication adherence for adolescents with IBD, some participants cited side effects, feeling better and lack of confidence in medication efficacy as reasons for poor adherence.[81] Perceived barriers should be addressed to encourage improved medication management before transition to adult care.

These skill and knowledge gaps in young adults with IBD have been acknowledged by gastroenterologists, in a few studies. From a survey of 363 gastroenterologists in the United States, it was reported that transitioned patients were found to be lacking knowledge about health history, medications and the disease.[5] A survey of gastroenterologists in Australia and New Zealand identified patients' lack of responsibility for their own care as one of the strongest barriers to a successful transition.[10] A lack of self-advocacy skills as well as knowledge of the disease and treatment options were identified as patient-related barriers to successful IBD transition in a questionnaire study of gastroenterologists in the United Kingdom.[17] Improved education of IBD patients is clearly needed.[5,10,11]

1.2.1.2 The Current IBD Transition Process: Checklists, Recommendations and Assessments

Checklists and guidelines have been developed, based on expert opinion, to help patients and providers work toward attaining the skills and knowledge required for progression to adult care, but have not been validated.[77] In 2002, the North American

Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) presented their care recommendations for IBD transition, encouraging: the development of patient independence and self-advocacy in pediatrics by having teenaged patients attend clinic on their own, discussion of the benefits of transition, selection of an adult gastroenterologist with a special interest in young adults with IBD, and the transfer of complete medical records along with a summary letter from the pediatric gastroenterologist.[6] In partnership with Digestive Health for Life and Children's Digestive Health & Nutrition Foundation, NASPGHAN developed transition checklists for both providers and patients.[82,83] Both the patient and provider versions cover skills and knowledge that the patient should be achieving by early, mid and late adolescence, including developing self-management and self-advocacy behaviours and attaining knowledge of their disease, medications, as well as health effects of lifestyle choices.[82,83]

Hait *et al.* propose a timeline of developmentally-appropriate steps that encourage gradual attainment of self-advocacy and health management across age categories from 11 to 23 years, which can be followed according to the abilities of the patient.[12] This program also outlines checkbox tasks for the healthcare team to help encourage this development.[12] Some of the goals for the patient include: "able to articulate his or her GI condition", "knows his or her medical history", and "demonstrates consistent ability to book own appointments, fill prescriptions, contact medical team."[12] Examples of things the healthcare providers can do are: "directs all questions and explanations to patient" and "initiates discussion about eventual transfer of care."[12]

Another example, with similar goals, is the patient-focused ImproveCareNow Transition Checklist, which was developed by pediatric IBD specialists in Ohio as part of the booklet, "Living Well with Inflammatory Bowel Disease: A Self-Management Handbook for Patients and Families with IBD."[78] This checklist was adapted for a previously mentioned study by Whitfield *et al.* to help assess transition readiness based on the self-management skills contained within it.[77]

Leung *et al.* provide a set of recommendations for both pediatric and adult gastroenterologists, as well as a list of knowledge and skill criteria for patients to master before adult care, including: disease, medical history and insurance knowledge and the ability to self-manage healthcare activities, such as appointment making and prescription refills.[84] The pediatric provider guidelines suggest increased communication to ensure the patient and family know what to expect for transition and adult care, along with making sure the patient is knowledgeable about his/her disease.[84] Adult care guidelines involve collaborating with the pediatric provider, offering patient education, anticipating questions, and allowing the shift of responsibility from the parent to happen gradually.[84]

Other validated tools and measures to assess disease knowledge and/or self-efficacy behaviours specific to IBD have been developed to evaluate the level of transition readiness or deficits experienced by young adults. As previously mentioned, Benchimol *et al.* were able to use the MyHealth Passport tool during transition to evaluate patient knowledge and identify issues in areas of medical history and disease knowledge.[11] After the participant's entries were reviewed, a corrected version of the

MyHealth Passport was created with the patient. The IBD-Yourself questionnaire was created and piloted to evaluate the self-efficacy of young adults with IBD, anticipating future use for improving transition.[42] The IBD- Knowledge Inventory Device (IBD-KID) was created to evaluate knowledge of disease in pediatric patients, but can be used with young adults to improve areas of knowledge weakness.[85]

Along with the aforementioned recommendations and tools, suggestions of potentially beneficial transition practices include: joint clinics or meetings of the pediatric and adult gastroenterologist[3] (with or without the patient, parent and nurse),[10] alternating visits with pediatric and adult providers for a period of time,[3,10] tours of the adult office, the aid of transition coordinators, transition clinics, evaluation of the patient's readiness to transfer[3] and educational interventions to increase patient knowledge.[3] It is generally agreed that transition should start during pediatric care to prepare the patient and parent/guardian for the expected changes,[3,20,42] and advance in a step-wise fashion.[3]

The authors of a recent survey study of 99 pediatric IBD practices across the United States (141 healthcare professional respondents), report that currently, the most commonly used transition supports are: informing the patient about transition and transfer, promoting patient participation in their own healthcare, assessing knowledge of the patient in regards to disease and treatment and providing contact information for adult gastroenterologists.[19] Only 20.6% reported using joint pediatric and adult care visits.[19] Although only 40% of participants said their transition process was based upon American Academy of Pediatrics' guidelines, 75% said they were using measures of transition readiness, with the NASPGHAN checklist and TRAQ being the top two reported.[19] Although there is no shortage of recommendations for how to support young adults through transition, there is no current standard for the process for IBD patients[10,42,84] and current evidence shows that practices can be quite different.[19]

1.2.1.3 Evidence Supporting IBD Transition Interventions

While many interventions have been suggested and created, there is a lack of research examining the success of IBD transition interventions by examining post-transition outcomes.[86] In a United Kingdom study of young adults with IBD, investigators reviewed the impact of a comprehensive transition clinic, which involved appointments with both pediatric and adult gastroenterologists, the IBD nurse and, potentially, a dietitian and a clinical psychologist, along with individualized disease-specific information and a transition plan.[1] Those who had not attended a transition clinic experienced more surgery, hospital admission, nonattendance to clinic, smoking, opiate use, and radiation exposure in the two years after transferring to adult care.[1] They were also less likely to be in university, be employed or achieve their expected height than those who attended a transition clinic.[1] While these results provide compelling evidence for supportive transition practices, it was a retrospective comparison with the control group selected from an earlier time period and, thus, it should be noted that the findings may be confounded by potential changes in IBD care protocols over the time period in which the intervention was instated. Prospective or randomized clinical trials are needed in this field of research, as they have the potential to result in more robust findings in terms of the effects of transition interventions.

In a survey follow-up of young adults who had transitioned through a joint appointment with pediatric and adult gastroenterologists, the majority of patients and parents agreed that it was helpful to meet the new gastroenterologists.[87] They felt it was useful to build trust, for the gastroenterologist to get to know the patient's medical history and that it improved follow-up care.[87]

Gray *et al.* reported that healthcare providers needed more resources and time to create and carry out transition interventions,[19] which could support the need to develop a more feasible solution than joint clinics that could give the same benefits to the transitioning IBD population.

1.2.1.4 The Experience of the IBD Patient in Transition

Recent research has begun to examine the transition experience from the perspective of the IBD patient. This feedback is important to evaluate transition processes and provides firsthand insight into how to improve them to suit the patients that they serve.[86] An online survey was used to assess transition experiences and the relationship with the adult gastroenterologist of participants who had previously transitioned from Boston's Children Hospital.[52] In terms of transition preparation, 9 of 29 participants said transition was not discussed and 4 said they did have a discussion with the provider before their second last appointment in pediatric care.[52] Positive themes identified in reference to the provider relationship were "trust", “communication”, “comfort”, “autonomy and parent presence,” whereas the negative issues identified were to do with logistics and being uncomfortable in initial adult appointments.[52] Participants appreciated aspects of transition including greater independence and involvement in health decisions, and only one person had no positive things to say.[52]

Another retrospective survey carried out in France reviewed the experiences of 34 IBD transition patients, 20 of whom had experienced a joint appointment-style transition.[87] All of the patients reported that discussion of transition with their pediatric gastroenterologist took place far enough in advance and that there was successful transfer of their medical file.[87] The majority of participants felt they were ready to transition and only 7 reported feeling “apprehensive” about moving to adult care.[87] For the patients who went through the joint appointment, this aspect of transition was evaluated as very helpful.[87]

In a recent publication, researchers surveyed participants about their thoughts on transition and compared transitioned patients’ health and social status post-transition to an IBD control group that was matched for age, disease type and duration, but in which the patients had always been treated in adult care.[86] Positive aspects of transition identified were to do with communication and provision of information, while negative aspects were having to see a new gastroenterologist, and issues with communication and disease knowledge.[86] Almost ¼ of transitioned patients did not feel prepared and only 43% felt strongly prepared to transition.[86] Although transition patients reported these issues, there were no major differences in current medication use, social status (relationship status, education, employment) or disease between those who had been through a transition and those who had not.[86] Regardless of the ostensible lack of effect of transition on current health and social measures, researchers concluded that the transition experience needs to be improved and patient perspectives are invaluable for this purpose.[86] Further investigation of patient transition experiences is warranted in order to create a transition process that addresses their needs and is acceptable to them.

1.2.1.5 IBD Transition from the Edmonton Pediatric IBD Clinic (EPIC) to Zeidler Gastrointestinal Health Centre

In Edmonton, the IBD transition process largely follows the recommendations set out by NASPGHAN.[6] Patients and families are usually made aware of the transition well in advance, it is discussed with patients in an age-appropriate manner and patients may be encouraged to begin communicating for themselves a few appointments before leaving. Information may be given in handout form. Patients are transferred to the adult provider by way of a referral letter that includes all of their relevant medical history. Complicated cases are discussed in a meeting between the pediatric and adult gastroenterologists. In addition, the pediatric and adult gastroenterologists and IBD nurse specialists hold an annual “Transition Education Session” to help inform the patients and families about the changes and challenges they can expect, although not all patients/families are able to attend this session.

1.3 Study Purpose

The subject of this thesis is a study that is the first phase of a larger, 3-phase project to be conducted at the EPIC and Zeidler Centre. The overarching goal of the project is to improve the transition of young adults with IBD from pediatric to adult care. The phases are 1. “Assess”, 2.“Develop” and 3.“Implement.” The phases were so named as the first aim was to assess the current transition process and intervention preferences, the second was to develop an intervention to help improve the process, and the last was to implement the new intervention with a group of currently transitioning patients.

The purpose of this study (the “Assess” phase) was to examine the transition experience from the perspectives of the young adults who have experienced it, including what could be improved, their views on a transition intervention (including preferred format and content) and to assess their skills and knowledge relevant to transition, for the purpose of informing the design of an intervention.

1.3.1 Primary Objectives

The primary objectives were to:

1) Assess the transition experience of young adults with IBD (what was positive or negative about it and ideas for improvement).
2) Describe participant views on a transition intervention as well as their preferred intervention format and content.

3) Assess participants with respect to key transition skills and knowledge (medication adherence, self-management/self-advocacy, and knowledge of IBD).

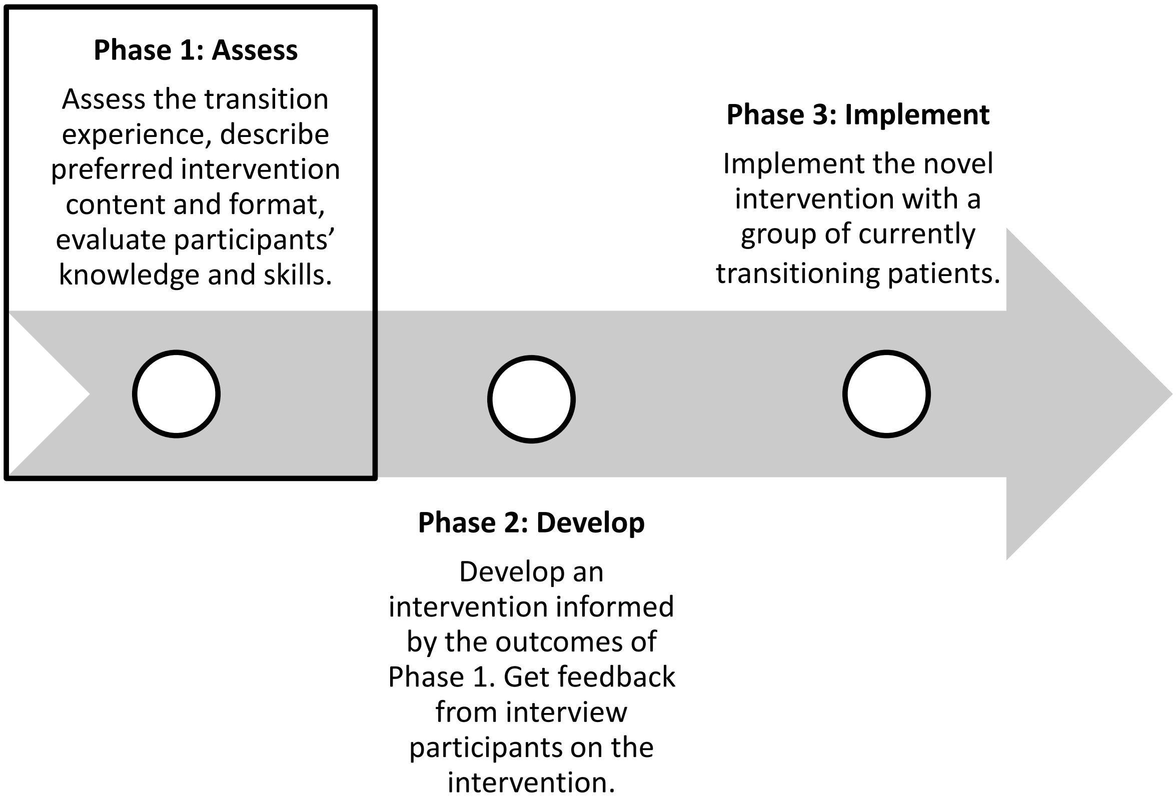
1.4 Significance of the Study

This study builds upon the current body of literature, and is novel in its focus on both describing the transition experiences of young adults with IBD and exploring their preferred method of intervention content and format. The result of this study is an intervention informed by patients, which may, in the future, improve IBD transition practices and outcomes in Canada.

2 Methods

2.1 Study Design

Phase 1 of the larger intervention project was designed to assess participant transition experiences, describe views on a transition intervention, including preferred format and content, and to evaluate participants' skills and knowledge relevant to successful transition. This study was essential to the overall project, by creating a needs assessment to inform the design of an intervention to address identified needs.



Phase 1: Assess

Assess the transition experience, describe preferred intervention content and format, evaluate participants' knowledge and skills.

Phase 3: Implement

Implement the novel intervention with a group of currently transitioning patients.

Phase 2: Develop

Develop an intervention informed by the outcomes of Phase 1. Get feedback from interview participants on the intervention.

Figure 2-1 Project design, with focus on current study – Phase 1: Assess.

To achieve these objectives, a mixed-method design, which combined qualitative and quantitative data-generating strategies, was chosen.[88] A mixed-methods study was selected as the best approach, as the goals of the research required data in the form of firsthand participant perspectives as well as scores from validated instruments to create a more complete picture of the current transition. The core component in a mixed methods study is the main focus, whereas the supplemental component adds to the description.[88] The core component of this study was a semi-structured, qualitative interview and validated quantitative assessments supplemented the description of the transition experience. The aims of the semi-structured interview were to seek the opinions, experiences and feelings of recently transitioned patients surrounding the transition process, their thoughts on an intervention, including preferred content and format, and any other suggested improvements to the process.

Previously validated, quantitative assessments of skills and knowledge were carried out to assess the skill and knowledge levels of participants who transitioned without structured programs or resources in place. The scores were also used as indicators of areas for improvement in the transition process and targets for the intervention, as well as to assess how representative participant skills/knowledge were of the general IBD transition population.

2.1.1 Study Outcomes

The outcomes of the study that will be examined in this thesis are:

1) The themes and ideas generated from the qualitative thematic analysis of the semi-structured interviews. These address the aims of assessing the transition experience, including ideas for intervention and improvement.
2) The scores of participants on the three validated assessments of skills/knowledge. These fulfill the objective of evaluating participant knowledge and skills relevant to transition, determining areas for intervention focus or transition improvements and comparing participant skills to published references.

2.2 Participant Recruitment and Setting

Study participants were recruited from a list of patients who had transitioned at the University of Alberta Hospital from EPIC at the Stollery Children's Hospital to adult IBD care at Zeidler Gastrointestinal Health Centre in Edmonton, Canada during 2013-2015. Inclusion criteria were a known diagnosis of IBD, transitioned from pediatric to adult care within the last two years and living in the greater Edmonton area (to be accessible for an in-person interview). The two-year time limit was used to help ensure that participants would be able to recall their transition. Participants were excluded if they were unable to communicate in English or had a developmental or cognitive disability.

A total of 84 patients transitioned between January 2013 and April 2015. Nine patients were excluded for living farther than a one-hour drive from the centre, leaving a pool of 75 potential participants, all of whom were mailed a letter or approached at a clinic visit. Five participants responded to the mailed letter, 13 participants were successfully recruited from a total of 19 approached in clinic and the last 2 participants were recruited by phone out of a total of 5 called. Recruitment of consecutive consenting participants continued throughout the study period, until thematic saturation was reached at 20 participants. Thematic saturation is achieved when no new information is arising in the interviews.[89,90]

In qualitative research, the aim of sampling is to select people who allow for an in-depth understanding of the topic of interest,[90] which is why individuals who had experienced the transition from pediatric to adult care firsthand were chosen. The study was limited to patients who transitioned through the Edmonton Centres in order to obtain a thorough interpretation of the particular transition experience at this care institution. The supervisor and committee members have the most experience at this site and, therefore, are well placed to use the study results to effect change.

The interviews and assessments were conducted in a private room on the University of Alberta campus. Participants were first asked to complete the three short assessments, a participant registration form (**Appendix A**) with information about education, living situation and medications and lastly the interview was carried out.

2.3 Qualitative Interviews

Having knowledge of the topic of interest from reviewing the literature and clinical experience, but lacking the firsthand perspective and ability to answer specific questions about the experience, semi-structured interviews were determined to be the best way to generate the data of interest.[91] In this interview style, participants answer open-ended questions, which are usually asked in the same order each time, unless already addressed.[91] The format permits flexibility in modifying the course of the interview, depending on information provided by participants; the interviewer can ask probing questions to elucidate further information and clarify participants' ideas, enabling important information to come to the forefront.[91–93]

2.3.1 The Interview and Guide Development

Authoritative qualitative methodology references were consulted to confirm that semi-structured interviews were the appropriate data generation strategy to address the study aims and for guidance on best practices for interview structure and interviewing techniques.[91–93] Studies using interviews with young adults were reviewed to consider how the wording of questions and interview methods might impact the resulting outcomes.[40,49,53,54]

To ensure the interview guide would be able to fulfill the aims of the interview and that questions were understandable, it was piloted[93] with three test participants (who did not have IBD) of similar age to the group of interest and reviewed by two young adults with IBD. The first four interviews with recruited participants were also considered a pilot of the interview guide; however, since they were no different than study interviews the data was included in analysis. The guide remained flexible to improvement throughout the interview process, although, only minor wording changes were required. A summary of the interview guide can be found in **Table 2-1** (complete interview guide in **Appendix B**).

The four main categories of discussion were Background/Diagnosis, Ongoing Management of Disease, Transition, and Learning Style/Information Retrieval Methods/Knowledge Delivery. The guide also included ranking or rating a few items that focused on preferred learning methods and how the transition went. Interviews were conducted by the author of this thesis, who was not involved in patient care. The interviews were recorded and transcribed verbatim by the thesis author. The transcription process allowed for re-familiarization and immersion in the data, which is essential for analysis.[94] Informal field notes and/or journaling were completed immediately following each interview to document any thoughts on prevalent ideas or reflect on the interview.[95]

Table 2-1 Summary interview guide

1. Background/Diagnosis

a. At what age were you first diagnosed with IBD?

b. At what age was your first appointment with an adult gastroenterologist?

c. Have you had any other gastroenterologists or IBD specialists?

2. Ongoing management of IBD

a. How do you usually book appointments with your gastroenterologist?

b. Are you supposed to have regular blood work done?

c. Tell me what you do when you need to refill your prescriptions.

d. Do you have insurance coverage that pays for your medications?

e. How would you define a “flare”?

f. On this diagram, please indicate how responsible you feel for your own medical care.

g. At the time of your first adult appointment with the GI specialist, where do you think you fell on the spectrum then?

h. What have you done to take more responsibility for your care since you stopped seeing a pediatric GI specialist?

i. What are some things preventing you from taking more responsibility for your care?

j. What aspects of managing your IBD do you still find difficult to deal with?

3. Transition

a. What are the most noticeable differences between pediatric and adult care?

b. What do you like or not like about adult care?

c. What did you like or not like about pediatric care?

d. How do you feel your transition from pediatric care went? (Likert)

e. Tell me about your transition.

f. What was difficult about it?

g. What was easy about it?

h. Do you feel the timing of transition was right for you?

i. Do you feel like you were prepared to transfer to an adult provider? (Likert)

j. How did your pediatric specialist address transition?

k. What was your impression of your first appointment in adult care?

l. Do you have any recommendations to make the transition process smoother?

m. Would you have liked to have access to more information on IBD or IBD management?

n. What about an educational tool or educational program designed specifically for transitioning patients?

<u>4. Learning style/information retrieval methods/knowledge delivery</u>

a. When you were going through transition, was there anything about IBD you didn’t understand that well?

b. Did you ever seek out more information on IBD during transition?

c. How do you find you best learn information (for example, in school)? (Ranking)

d. Thinking about your learning style/preferred methods of learning from the previous question, how would you have liked to learn about IBD when you were going through transition?

e. What about ways to improve ongoing management of your disease – how would you have liked to learn about that?

f. What do you think would be the best way to convey information to transition patients to help them learn about IBD? (Ranking)

g. What do you think would be the best way to convey information to transition patients to help them manage their IBD medical care? (Ranking)

h. How much time should be devoted to learning about IBD or IBD care management in or outside of clinic? OR How often do you think patients going through transition would want to be contacted with IBD or IBD care information?

i. Given what we have just covered about how you like to learn and what you think would be the best way to teach transition patients, could you describe for me what kind of tool/program/intervention you would design to help transitioning patients?

j. Is there anything I have not asked you, that you feel is important to know about transition?

2.3.2 Interpretive Description

The method of interpretive description was followed for the qualitative interview component, as described by Thorne.[95–97] Research following this method derives questions from what is known through experience and literature, with the goal of describing and interpreting the findings to apply them for use in clinical situations.[95] Other qualitative methods require that the investigators put aside *a priori* knowledge and approach questions as though nothing is known, but interpretive description allowed the study to be informed by and build upon what has already been established.[97] Transition from pediatric to adult gastroenterology has been shown to be a critical time in the care of a person with chronic illness; thus, the interview was approached from an existing framework of knowledge or “informed questioning,” using clinical experience with this patient group and knowledge of current literature, with the aim of creating a description of the current transition experience and needs, to be interpreted for improving transition practices.[96] This was the best-suited qualitative method for this study, as “products of interpretive description ideally ought to have application potential, in the sense that a clinician would find the sense in them and they would therefore provide a backdrop for assessment, planning and interventional strategies.”[96] This fit well with the goal to use phase 1 study findings to create an intervention relevant to the clinical practice of patient transition in inflammatory bowel disease care.

2.3.3 Thematic Analysis

The goal of thematic analysis is to generate themes through the process of coding, categorizing and connecting data from interview transcripts.[94,98] During the coding process, one becomes “immersed in the data” to make sense of it, in order to be able to present it in an organized way, while staying true to the interview content.[98]

The analysis was facilitated by the use of computer software, NVivo 10,[99] to keep coded and categorized text organized electronically. To stay open to new ideas as the interviews progressed, the thesis author coded interviews continuously throughout the interview and analysis process. As new codes surfaced in interviews, previous transcripts were re-read and any information fitting the new coding was incorporated as such.[90,95] All transcripts were coded for information relevant to the aims of the interview. Categories were developed based on grouping the codes into common topics. Themes became clear through writing/summarizing each category and code, and breaking out predominant codes and categories on a visual chart to elucidate common elements relevant to transition and the aims of the interview.

The thesis author discussed coding and analysis of the interviews with a "critical friend"[90,91] experienced in interview analysis, to ensure that conclusions were coming from the interview data and not *a priori* assumptions of the researchers; it is important to keep an open mind to avoid allowing the framework of prior knowledge to overshadow new thoughts or directions that surface in the interviews.[95,96] Coding was also reviewed via the "thoughtful clinician test,"[96] in which the gastroenterologists involved in transition confirmed whether conclusions drawn from the interview transcripts are plausible and fitting of the transition patient group.

2.3.4 Rigour in Qualitative Methods

In order for qualitative research to be deemed rigourous and to allow for judgment of the quality of the study, researchers must demonstrate how they supported a certain set of criteria in their study.[89] The goal of one prominent set of criteria is to achieve "trustworthiness;"[90,100] according to Lincoln and Guba, who introduced this term, the criteria one must aim to fulfill are credibility, transferability, dependability and confirmability.[90,100] While these may be thought of as analogues to internal validity, external validity, reliability and objectivity, respectively, qualitative researchers defined this set of trustworthiness criteria to avoid confusion of the meanings of the aforementioned words with their traditional use in quantitative research.[90] There are a number of methods that can be employed to establish these criteria in a study.

In terms of credibility, steps were taken to ensure that this study would be able to generate accurate results or findings.[90,100] To check that the interview questions were comprehensible and that the guide would elicit the types of responses that would answer the questions and meet study objectives, it was designed with the participants' gastroenterologist, piloted with people of a similar age and read through by two transitioned young adults with IBD for feedback.[93] The guide was also designed to promote the attainment of thematic saturation.[90] Saturation is important because it demonstrates completeness of a study. When the responses begin to replicate within the data and no new information is forthcoming, it suggests that all pertinent experiences have been considered.[89,91]

During interviews and thematic analysis, responsiveness and reflexivity were demonstrated through the analytic approach and openness to changes of the interview guide if new information surfaced.[89–91,96] Lincoln and Guba also recommend the continuous refinement of ideas throughout coding and interviewing.[100] Staying open to new information and being critical of background knowledge prevented previous assumptions from obscuring new thoughts.[89,96] Iterative and concurrent analysis allowed for the identification of new ideas and systematic checking of whether codes/categories/themes fit with the data.[89,91,96] As new codes surfaced in interviews, previous transcripts were re-read and any information fitting the new coding was incorporated as such. These approaches support that what has been described in the findings is truly present in the data, and the data was not forced into frameworks of prior knowledge.[96]

To further confirm the results, member checking of the data was employed with gastroenterologists involved in transition care, to confirm the plausibility or accuracy of findings and emerging themes or ideas.[90,100] Thorne, Reimer Kirkham and O'Flynn-Magee refer to the "thoughtful clinician test, in which those who have expert knowledge of the phenomenon in a particular way find that the claims are plausible and confirmatory of 'critical hunches' at the same time as they illuminate new relationships and understandings";[96] the "thoughtful clinician[s]" in this case were the gastroenterologists involved in the care of the participants. Throughout the coding process, meetings were held with a "critical friend":[90,91] a colleague with a Master of Science in Global Health and expertise in interview analysis. Also referred to as "peer debriefing,"[100] these meetings allowed for a fresh perspective and helped with the formulation of new ideas or clarifying emerging ones to ensure that what was coded and categorized was, in fact, found in the data.

Readers must be able to discern transferability of a qualitative study – whether the results can be superimposed onto a similar population in order to make use of them. This is dependent upon the population to which one is comparing the study; the investigators must do their best to describe the details of the study group so that readers are well informed in making any generalizations to another group.[100] This is done by providing a "rich description" of the participants.[91] This was achieved by reporting the analyzed responses of people with an in-depth experience of the topic[89,90] of transition and by providing sufficient depth and detail about the characteristics of our sample.[90]

The author reinforced dependability and confirmability by keeping an audit trail, to allow for insight into research process decisions, including changes to the interview guide and coding.[90,91,100] The interviews were recorded and transcribed verbatim by the author, who completed field notes and/or reflexive journaling following interviews.[90,91,100] Interview coding, memo'd and original transcripts, rough field notes, post-interview journaling and the initial summaries of thoughts or categories were also kept as part of the audit trail.[100] The interview guide and coding audit trail can be found in **Appendix C**. Further evidence of the research process, which can be made available for audit purposes, are past interview guide versions, test coding prior to NVivo, NVivo coding summary reports, sticky notes, chart matrices, meeting notes and emails.

In research, there is no way to prove beyond a doubt that results are completely accurate. The setting in which qualitative inquiry is conducted has been referred to as an "open-system"[100] and the ideas of randomization, statistical analyses and controlling for confounders are not suited to this form of investigation (although even employing such methods do not make the results of a study incontrovertible). Establishing and upholding criteria for rigour or trustworthiness can only aim to convince the reader of the quality of the study,[100] and has been called for by leaders in the field to maintain the value and acceptability of the work.[89,100]

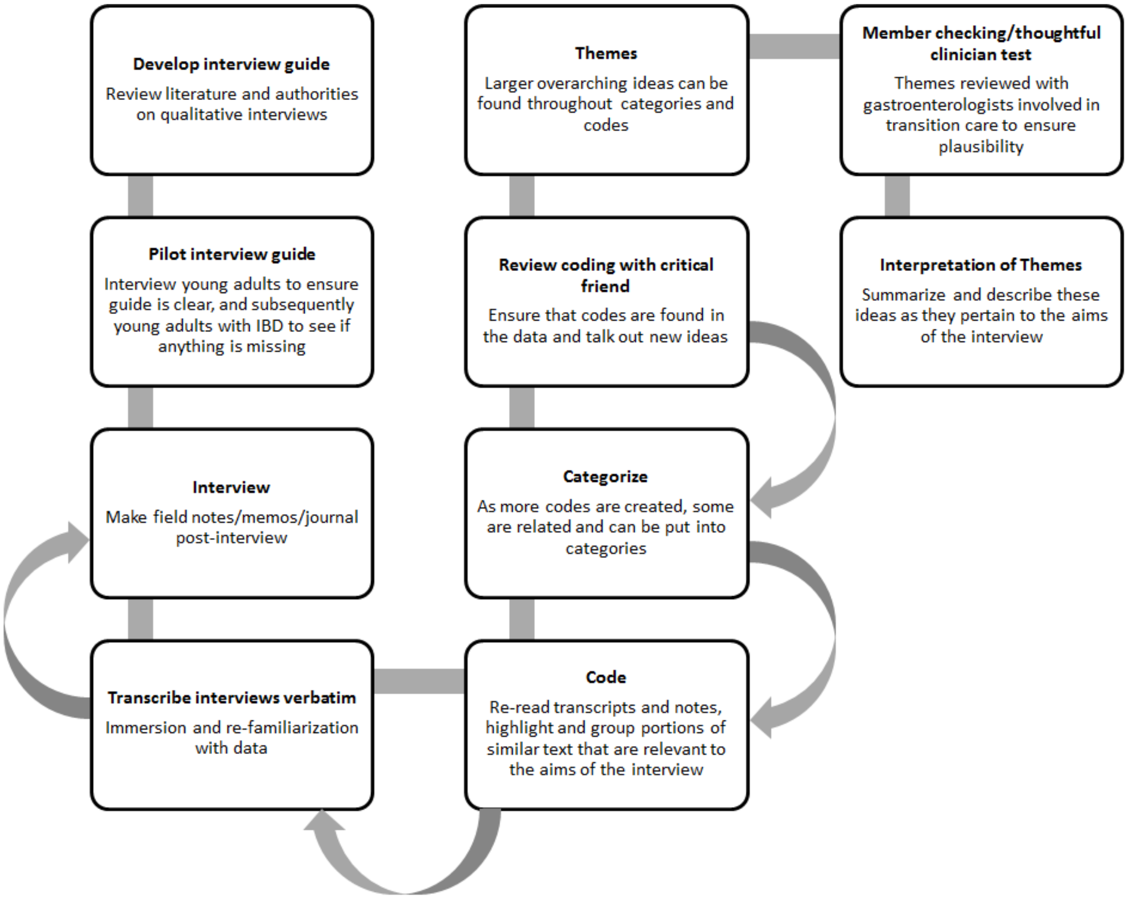


Figure 2-2 Summary of the qualitative analysis process, illustrating constant and repetitive review of data as coding and interviewing progresses.

2.4 Quantitative Assessments

Three validated assessments were used to assess the participant group in terms of transition readiness skills (self-management/self-advocacy), medication adherence and knowledge of the disease. As previously mentioned, this was done to investigate how the participants fared without a transition intervention and if they were experiencing deficits in some knowledge or skill areas which could be targeted by a future intervention. To determine how representative participants were of the IBD transition population, in terms of skills and knowledge in these areas, scores were compared to published estimates.

Literature was reviewed to consider assessments that had been validated with IBD patients (specifically young adults if possible) and which evaluated the skills and knowledge of interest based upon their relevance to successful transition. The assessment also had to have been used in existing published studies with which to compare the participants' scores.

In selecting an assessment of transition readiness to evaluate skills of self-advocacy and self-management, the IBD-Yourself,[42] UNC TR$_x$ANSITION Scale,[101] IBD-Self-Efficacy Scale (IBD-SES),[102] and Transition Readiness Assessment Questionnaire (TRAQ)[13,103] were considered. TRAQ was found to be the most appropriate measure due to its use in studies of young adults with IBD[75,104] and questions that were specific to transition skills. The other assessments were not validated with the group of interest,[42,101,102] did not have literature benchmark scores with which to compare scores from this study, were too lengthy (74 questions)[42] or had subdomains containing irrelevant questions.[102]

The Transition Readiness Assessment Questionnaire (TRAQ, see **Appendix D**) is a transition readiness measurement tool that was developed by Sawicki *et al.* and validated with young adults with chronic illness.[13,103] The tool was designed for assessment of patient readiness for transition and improvement of interventions to aid in the transition process.[13] The original version had two subdomains assessing self-management and self-advocacy.[13] After further development, the questionnaire was reduced from twenty-nine to twenty items, to remove less relevant or unclear questions, and broken into five sub-scales: “Managing Medications”, “Appointment Keeping”, “Tracking Health Issues”, “Talking with Providers” and “Managing Daily Activities.”[103] Each of the 20 questions has response options in the form of a 5-point Likert scale: (1) “No, I do not know how”; (2) “No, but I want to learn”; (3) “No, but I am learning to do this”; (4) “Yes, I have started doing this”; and (5) “Yes, I always do this when I need to”.[103] The overall score is an average of the scores on the individual questions.[103]

A benchmark for mastery of skills for IBD transition patients was defined by the Transition Task Force at the Cincinnati Children’s Hospital and University of Cincinnati Health as obtaining a full score on 90% of the scale items.[75] A participant would have to get 5/5 on at least 18 of the 20 TRAQ questions to meet this benchmark. In the Cincinnati study, 5.6% of participants 16 to 25 years old had achieved a score of at least 18/20.[75] This was used as the comparison value for the TRAQ scores of the participant group in the present study. This comparison was chosen over one other study reporting TRAQ scores for IBD transition aged patients,[104] because it had a larger sample size, the age range was slightly more appropriate for the transition population and it presented a firm benchmark established by their Transition Task Force.[75]

To choose a measure of medication adherence, the Medication Adherence Report Scale (MARS),[105,106] Brief Medication Questionnaire[107] and Morisky Medication Adherence Scale – 8 (MMAS-8) were reviewed.[108–110] Although Ediger *et al.* used the MARS with a group of IBD patients, the study validating MARS use with IBD patients had not been published and was not accessible.[105] This questionnaire did not encompass some of the questions that were found to be useful on the MMAS-8,[108–110] such as whether patients stop medications when they feel well or because of side effects (important issues to identify in transitioning patients).[81] The Brief Medication Questionnaire was ruled out because it had not been validated with IBD patients and had open-ended questions which would be more challenging to score.[107]

The Morisky Medication Adherence Scale – 8 (MMAS – 8, the details of which may not be published as per contract agreement - available from dmorisky@ucla.edu) was initially designed and validated with a population of hypertensive people to assess medication adherence and has since been used in numerous chronic illness studies and validated with IBD patients.[108–112] MMAS-8 is an 8 item questionnaire, with 7 yes/no questions followed by a Likert Scale.[108–110] Each question is scored 0 or 1 with the last question receiving a score from 0 up to 1.[108–110] Full details on the scoring of this assessment can be obtained from Dr. Donald Morisky (dmorisky@ucla.edu). Scores below 6 are considered poor adherence, 6 and 7 are medium adherence and 8 is high adherence.[108–110] These cut-offs were established during the initial adherence scale design, based on their relationship with blood pressure control.[109]

In a study examining thiopurine adherence in IBD patients, 52% of the study population of 145 adults with IBD had MMAS-8 scores of less than 6 (poor adherence).[112] This was used as the comparison value for the proportion of the participants who had low adherence.[112] This study was chosen as the comparison value over one other,[111] because it included 16 and 17 year olds and had a larger sample size.[112]

Disease knowledge assessments considered include the Crohn's and Colitis Knowledge Score (CCKNOW),[113] A Patient Knowledge Questionnaire,[114] Keegan *et al.*'s short questionnaire to assess disease-related knowledge[115] and the Inflammatory Bowel Knowledge Inventory Device (IBD-KID).[85] Although the CCKNOW is a well-known assessment, it was validated with adults[113] and some researchers believe questions are designed for an older audience.[116] The Patient Knowledge Questionnaire was published in 1993 and was not used in studies with young adults with IBD.[114] Keegan *et al.*'s short questionnaire was not found to be comprehensive enough compared to the other assessments, with only 9 questions.[115] The IBD-KID was the most user-friendly in terms of language, having been written at a grade 6 reading-level.[85] It also encompassed many areas of disease knowledge: cause, genetics, life expectancy, effect of stress, gastrointestinal anatomy, extraintestinal manifestations, cancer risk, diet, medications and surgery.[85] In a second validation study of the IBD-KID, when compared to the CCKNOW, both parents and children found the IBD-KID easier to understand.[117]

The Inflammatory Bowel Disease-Knowledge Inventory Device (IBD-KID, see **Appendix E**) is an IBD knowledge assessment designed specifically for children and young adults.[85] It is a self-administered true/false questionnaire with 23 questions.[85] In the validation study for the IBD-KID, the average score of 99 participants (mean age 14) was 11.29 (standard deviation = 0.37) out of 23.[85] Although the age of the participant group is younger than in this study group, the IBD-KID score was observed to be uncorrelated with age in the validation study and was thus used as the benchmark for the IBD-KID scores.[85]

2.4.1 Statistical Analysis

Score comparisons from the validated assessments were incorporated into the interpretation after analysis of the interviews, to help with the description of patients' needs at this particular junction in healthcare.[88] To assess the extent to which benchmarks for transition/self-efficacy skills, IBD knowledge and medication adherence were being met, scores on assessments were compared to published reference estimates and 95% confidence intervals were calculated. Differences were calculated between the proportion of participants scoring within a certain range in the study and the published reference data, for the MMAS-8 (low adherence, <6) and TRAQ (≥90% mastery of skills). The difference between mean scores was calculated between study and reference data for the IBD-KID.

2.5 Ethical Considerations

This study was approved by the Health Research Ethics Board at the University of Alberta, Edmonton. The following ethical issues were carefully considered in the design of the project:

All participants were given a recruitment letter (**Appendix F**) and information sheet (**Appendix G**), had the opportunity to ask questions and signed a consent form (**Appendix G**) to acknowledge that they understood: the study, who had access to their charts, that the interviews were recorded & transcribed, that they could withdraw at any point in time, and that they had the opportunity to ask questions.

A $20 Chapters/Indigo gift card was given as remuneration for participating. This was not of high enough value to be considered coercive and was a token of appreciation for time spent.

All data, including audio files from interviews were stored in encrypted files on a secure electronic database on the University of Alberta server drive. Original audio files were deleted from the recording device after each interview was completed. Any hard copies of data collection sheets were stored in a locked cabinet. Anyone directly involved in collecting study information and accessing medical records had completed the Health Information Act and Freedom of Information and Protection of Privacy Act training module.

During the interviews, sensitive topics about the participants' health and healthcare experiences were discussed. To mitigate any risk of participants feeling embarrassed or worried during the interview, they were well-informed of the anonymity of the interview data and reassured that it was a safe, non-judgmental environment. The author (interviewer) worked to build rapport to help participants feel at ease. If any participants were identified as emotionally/psychologically distressed during the interview, the supervisor (gastroenterologist) was prepared to arrange for the appropriate care.

3 Results

3.1 Participant Characteristics

A total of 20 participants aged 17-20 (median 19) years old were recruited for the study. The group was 50% male and 50% female, with the majority of participants (65%) being diagnosed with Crohn's Disease. All of them lived with parents and/or family members, and almost half (9) were in university at the time of the interview. The complete list of participant characteristics can be found in **Table 3-1**.

Table 3-1 Characteristics of participants at the time of interview

	n	**% of total**
Total	20	100
Age (years)		
17	4	20
18	4	20
19	9	45
20	3	15
Gender		
Male	10	50
Female	10	50

Age at diagnosis (years)		
7-9	6	30
10-12	4	20
13-15	7	35
16-18	3	15
IBD sub-type		
Crohn’s Disease	13	65
Ulcerative Colitis	7	35
Medications		
5-ASA	2	10
Prednisone	2	10
Immunosuppressants	5	25
Anti-TNF	4	20
Anti-TNF + immunosuppressant	8	40
Highest level of education		
In grade 12	6	30
Completed high school (but not currently studying)	4	20
In university	9	45

Post-secondary diploma/certificate	1	5
Employed		
Part-time/summer job	8	40
Full-time job	4	20
Not working	8	40
Living situation		
With parents or other family member	20	100

3.2 Qualitative Results: Coding & Themes Generated

Interviews lasted from 0.5 to 1.25 hours. Transcription of all 20 interviews took 86 hours. Transcription of the interviews by the author allowed for re-immersion in the data and was followed by multiple re-readings of each transcript, in whole and in part, during coding. Transcripts ranged from 13 to 31 pages each. Eight categories, 38 codes, 37 sub-codes and 17 sub-sub codes were generated from the data during the qualitative analysis; these are summarized in **Table 3-2** below. “Sources” refer to the number of interview transcripts in which the code or category exists and “quotes” refer to the number of transcript excerpts coded under each code or category.

Table 3-2 Coding summary

Category		
CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
Views on intervention	**20**	**66**
Whether participants felt that an intervention was necessary; any other thoughts they had about the design/approach of the intervention that did not fit into what the content should include or what medium should be used. This category helped to answer the question of whether previously transitioned patients believed an intervention during transition was a good idea.		
NO NEED FOR CHANGE Participants felt like they knew what they needed to and did not see any room for improvement that could be addressed by a knowledge/educational intervention.	**5**	**5**
CUSTOMIZE Participants referred to the differing needs of the transition population, when it comes to a transition intervention.	**14**	**34**

Category		
CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
SUPPORTIVE OF INTERVENTION Participants were supportive of the need for improvement in the intervention process.	**18**	**27**
Feelings, experiences and opinions of transition	**20**	**417**
This category addressed the aim to determine the participants' feelings, opinions and experience of transition. It encompasses their overall thoughts of the transition, whether they felt prepared, what resources might have been available to them, what could be improved, any complications that occurred during that time and how they felt about any differences between the pediatric and adult environment.		
POSITIVE Participants had positive things to say about the experience of transition.	**19**	**55**
NEGATIVE Participants had negative things to say about the experience of transition.	**13**	**32**

Category		
CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
NEUTRAL The things participants said about the experience of transition are not explicitly positive or negative.	**16**	**37**
PREPAREDNESS Participants discussed their feelings of being ready or not ready to transition.	**15**	**39**
Prepared Participants said that they felt prepared.	*14*	*31*
Not prepared Participants explicitly said that they did not feel prepared.	*2*	*8*
TRANSITION RESOURCES Participants cited things that helped them during the transition process.	**20**	**116**
Active transition preparation by pediatrics Participants listed engaging activities or multiple steps that the pediatric provider/team took to prepare them for the transition to adult care.	*12*	*24*

Category		
CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
Existing helpful tools or supports Participants discussed supportive resources that were useful during transition.	*15*	*59*
Improving current processes and existing helpful tools or supports Participants discussed aspects of transition resources or general IBD care processes that could be improved upon to be more supportive.	*17*	*33*
HEALTH & OTHER COMPLICATIONS AROUND TRANSITION TIME Participants mentioned a negative health event or disruption in care at the time of transition.	**10**	**25**
DIFFERENCES AND SIMILARITIES BETWEEN PEDIATRIC AND ADULT Participants talked about the differences between pediatric and adult care environments and also how their roles changed between the two systems.	**20**	**113**

Category		
CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
Positive differences Participants discussed aspects of adult care that participants preferred compared to pediatric care.	*13*	*32*
Negative differences Participants discussed aspects of adult care that were not as good as pediatric or that they did not like.	*10*	*30*
Neutral differences Participants mentioned differences they noticed, but that are neither negative nor positive.	*17*	*29*
Similarities or no difference between pediatrics and adult Participants said that there is no difference between the two care environments or that they are similar.	*8*	*22*

Category		
CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
Knowledge	**20**	**600**
This category covers discussion of knowledge that participants have about IBD, what topic areas they would like to learn more about or would have liked to learn about during transition. It also captures how they seek information, how they would ideally like to learn information and how they would have liked to learn during transition. This is a large category that addresses the aim of what format transition patients would like to receive new health information in and what the content of that information might be.		
SUFFICIENT INFORMATION Participants had adequate information about the disease/disease management or felt that they did not need more.	**15**	**23**
EXISTING KNOWLEDGE OF IBD Participants mentioned having prior knowledge about disease/medical care or that they feel comfortable with their level of knowledge in this area.	**14**	**28**

Category		
CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
WANT TO LEARN ABOUT This code encapsulates what patients indicated wanting to know more about or what they needed more coverage of in terms of IBD or IBD management and related skills or information.	**20**	**98**
Learning about insurance Participants mentioned wanting to know more about insurance and how to set it up/how coverage works.	*6*	*8*
Learning about the disease Participants were interested to know more about IBD; why certain symptoms occur, how the disease "works", progression/prognosis.	*11*	*18*
Learning about medical history Participants expressed wanting a consistent record of their own medical history which they could keep.	*1*	*5*

Category		
CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
Learning about self-advocacy or self-management Participants said they believe it is important to learn about how to perform self-management tasks like booking appointments, taking care of medications and also advocating for oneself in appointments.	*4*	*11*
Learning about research Participants were interested to know about current research on cause or treatment of IBD.	*2*	*3*
Learning about procedures Participants wanted to know how procedures (mainly colonoscopy) differ in adult vs. pediatrics.	*2*	*4*
Learning about what to expect for transition and the process Participants felt it would be helpful to know the "plan" or steps for transition, to be able to anticipate how the process should occur.	*8*	*18*

Category		
CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
Learning about medications Participants wanted to know how medications work, what medications are available and what the process is for Remicade in adult care.	*17*	*26*
Learning about diet Participants wanted to learn about what foods to eat or avoid and why certain foods work for them or do not.	*3*	*5*
INFORMATION SEEKING PRACTICES This code covers the discussion of the ways in which participants were currently finding information (at the time of interview) to answer their health or IBD-related questions, and how they have done so in the past.	**20**	**136**
No information seeking Participants were not actively looking for information on IBD.	*10*	*14*

Category		
CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
Information sessions Participants attended information sessions on IBD put on by foundations, hospitals.	*4*	*5*
Information seeking from nurse or other healthcare professionals Participants asked questions of physicians, nurses, or other healthcare professionals.	*4*	*10*
Information seeking from parents or other family members Participants asked questions of family members, some of whom are nurses.	*6*	*11*
Information seeking online Participants sought answers to their questions on the internet.	*17*	*43*
Google or search Participants either referenced “Googling” or searching for things online.	14	25

Category		
CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
Specific websites Participants visited particular websites for information.	6	8
Social or blog Participants read blogs or visited sites with a “social” format that involved comments left by others with IBD.	5	10
Information seeking in text Participants mentioned learning information from text-based sources (such as a binder they were given in pediatric care, or pamphlets for example).	*8*	*9*
Information seeking from other people with IBD Participants mentioned engaging with other people who have IBD to hear about their experiences/opinions.	*7*	*22*
Information seeking from doctor Participants asked questions of their physicians.	*13*	*22*

Category		
CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
HOW TO LEARN	**20**	**309**
This codes the ways in which participants would like to learn information to do with their IBD healthcare.		
Learning through experience	*6*	*9*
Participants described how experiences or executing a healthcare behaviour can be beneficial to learning skills necessary to take responsibility.		
Ideas to improve skills for transition	*5*	*10*
Participants gave ideas for how to encourage the development of self-management and self-advocacy skills.		
In-person education	*20*	*119*
Participants preferred to learn in-person.		
Role play	5	6
Participants wanted to act out disease management scenarios with others or a health provider.		

Category CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
Videos in clinic Participants wanted to watch videos during clinic time.	7	15
Group Participants wanted to learn information in a group setting.	6	11
One-on-one Participants wanted to learn information through a one-on-one meeting with a healthcare professional.	20	78
Transition night or info session Participants attended transition night and thought this was a good way to learn, or wanted a variation of that.	6	9
Interactive technological ideas Participants liked the idea of a technological intervention.	*19*	*95*
Website Participants thought a website would be a good way to learn new information.	16	46

Category		
CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
Online videos Participants wanted to watch online videos to learn.	9	17
App Participants thought an app on their phones would be a good way to learn.	2	7
Email Participants wanted to receive emails to learn new information, communicate or receive reminders.	8	20
Text Message Participants wanted to receive text messages for learning or reminders.	4	5
Other people with IBD to talk to Participants thought having other people with IBD to talk to would be a good way to learn information.	*6*	*8*
Text based learning Participants wanted to learn through reading.	*17*	*68*

Category		
CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
List or questionnaire Participants liked lists or questions to help prepare for the transition process.	4	5
Handouts, pamphlets, booklets or info packets Participants wanted a hard copy of information to read from.	16	56
Diagrams Participants wanted pictures to help them learn.	2	3
Other These are other ideas that participants had for ways to learn that did not fit into one of the pre-existing media/codes.	1	4
MISSING INFORMATION Participants were missing crucial information necessary for success in the adult clinic.	**3**	**6**

Category		
CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
Healthcare responsibility	**20**	**432**
This category codes the discussion of who is responsible for managing the healthcare (appointments, seeking help, medication refills) of the participant, advocating on behalf of them, as well as whether the participant engages in behaviours relevant to their health.		
SHIFT IN RESPONSIBILITY Participants referred to healthcare behaviours that they have taken over from their parents, or a shift in mentality/realization about what they need to begin taking responsibility for.	**18**	**67**
NEGATIVE HEALTH BEHAVIOURS Participants referenced behaviours that they willingly undertook, which have negative impacts on their health.	**1**	**3**
UNSURE ABOUT INSURANCE Participants were unsure about their insurance coverage and/or until what age they are covered.	**9**	**13**

Category		
CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
PARENT SUPPORT Participants described areas of healthcare management/advocacy in which parents are still involved.	**19**	**95**
PROACTIVE HEALTH RESPONSIVE BEHAVIOUR Participants mentioned engaging in preventative or proactive behaviour that likely benefits their health.	**14**	**37**
UNCERTAIN ABOUT MEDICAL CARE COORDINATION OR FOLLOW-UP Participants mentioned confusion about whether to follow-up, when appointments need to be scheduled, or what the processes are for the adult clinic.	**8**	**13**
SELF-RELIANT Participants cited engaging in behaviours that show they are responsible for their care, instead of their parents managing it for them.	**20**	**185**

Category		
CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
Medications Participants said they were responsible for some aspect of managing their medication regimen (ordering, picking up, paying for refills or taking medication independently).	*15*	*33*
Appointments Participants booked their own medical appointments, arranged bloodwork appointments and/or attended appointments on their own.	*19*	*61*
Advocacy Participants managed their own information/communication at appointments, spoke up about medical concerns, and in general looked out for their own medical needs.	*12*	*38*
Transportation Participants indicated getting to the appointment on their own.	*4*	*5*

Category		
CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
Knowing when or how to seek help When discussing flares or other health complications, participants mentioned contacting healthcare providers/seeking medical attention.	*18*	*25*
Independently motivated Participants mentioned deciding to take (or enjoying taking) responsibility because they were self-motivated to do so.	*15*	*23*
ROUTINE Participants discuss health behaviours or activities that they make a habit of, or are scheduled in a specific way so that they are part of a routine.	**14**	**19**
Living with IBD	**20**	**79**
This category captures the things participants struggle to deal with, and what becomes easier through time and experience.		

Category		
CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
DIFFICULTIES Participants discussed aspects of having IBD that negatively affect their day-to-day lives.	**15**	**35**
HOSPITALIZATION Participants spoke about the experience of being hospitalized for IBD-related illness.	**5**	**15**
GETTING EASIER Participants talked about aspects of having IBD that have gotten easier to cope with/manage.	**18**	**29**
Healthcare providers	**15**	**84**
Participants referred to nurses, physicians or other health providers and how they influence their care. NURSE ROLE Participants discussed interactions with a nurse or family members that are nurses and how this impacts their experience, care and/or knowledge.	**9**	**35**

Category		
CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
NEGATIVE EXPERIENCES WITH HEALTHCARE PROFESSIONALS Participants shared negative experiences about interactions with healthcare professionals.	**12**	**29**
POSITIVE EXPERIENCES WITH HEALTHCARE PROFESSIONALS Participants shared positive experiences about interactions with healthcare professionals.	**8**	**20**
Attitudes and thoughts about IBD	**12**	**43**
Participants discussed how they feel about the disease or management/treatment of it, and what they think when they think about it.		
FUTURE (THINKING AHEAD) Participants talked about what will happen in the future, planning for it and questioning what will happen in terms of disease and treatment and/or the effect it will have on their lives.	**9**	**15**

Category		
CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
APATHY Participants expressed indifference or not caring about learning about the disease and/or its treatment or management.	**4**	**15**
COMFORTABLE Participants identified a need to feel comfortable; be it with their level of knowledge/understanding, in clinic appointments or in communicating with care providers.	**6**	**10**
MATURITY Participants mentioned maturity as a factor in performing self-management behaviours.	**2**	**3**
Mental health	**8**	**26**
This category encompasses any reference to mental health as it relates to or interacts with IBD and participants lives. This unexpected category emerged during the interviews and was considered potentially important to address in the intervention.		

Category		
CODE *Sub-code* Sub-sub-code	# of sources	# of quotes
STRESS Participants mentioned stress as a factor in IBD or as a comorbidity.	**6**	**8**
OTHER Participants mentioned any other mention of mental health in relation to IBD management but did not specify whether the mental health concern was stress, anxiety or depression.	**2**	**6**
ANXIETY Participants mentioned anxiety as a factor in IBD or as a comorbidity.	**4**	**9**
DEPRESSION Participants mentioned depression as a factor in IBD or as a comorbidity.	**3**	**3**

While all information that seemed relevant to the aims of the study was coded and categorized, the thematic analysis focused largely on the main categories that, after several readings, held the most relevant content (“views on intervention”, “feelings, experiences and opinions of transition”, “knowledge” and “healthcare responsibility”).

The discussions encoded in the “living with IBD”, “healthcare providers”, “attitudes and thoughts about IBD” and “mental health” categories did not centre around the time of transition and thus were not as informative in helping understand transition and participant needs, however, they did provide valuable insight into the lives of this group of young adults and “mental health” in particular was taken into consideration in the design of the intervention.

Through thematic analysis, three themes were found to be pervasive throughout the data. Themes constructed were “individualized and multi-faceted”, “teach about transition” and “support the shift in responsibility.” Given that specific questions were asked about transition experience, knowledge of IBD and preferred learning styles, much of the discussion centered on these topics and therefore the coding reflects this. **Table 3-3** illustrates the connection found between categories, themes and the study aims addressed.

Table 3-3 Categories and themes addressing aims

Categories	Themes	Aims addressed
Views on intervention	- Individualized and multi-faceted	- Perspectives on transition intervention - How to learn (format)
Healthcare responsibility	- Support the shift in responsibility	- How to improve the process - What they need to learn about (content)

Knowledge	- Teach about transition - Individualized and multi-faceted	- What they want to learn about (content) - How to learn (format)
Feelings, experiences and opinions of transition	- Teach about transition - Individualized and multi-faceted - Support the shift in responsibility	- Transition Experience - How to improve the process

3.2.1 Transition Experience & How to Improve the Process

Overall, many participants described the experience of transition positively. When characterizing the conversation about the transition experience in terms of the proportion of statements coded as negative, neutral or positive, almost all of the participants (19/20) had something positive to say; however, 13 of them also had negative experiences with 3 of them having over 50% of their transition comments coded as negative. One person only had positive things to say and one person only neutral comments.

Some of the positive aspects of current transition that were cited include: adequate preparation involving patients coming to appointments on their own or answering their physician’s questions by themselves in clinic appointments and existing helpful supports, such as an information binder, a friend with IBD to talk to, or the

"Transition Education Session" organized by the adult and pediatric gastroenterologists. Participants appreciated when their physicians were able to answer their questions and acknowledged some positive aspects of being seen on their own, without a parent (one-on-one), in adult care (**Table 3-4**, quotes 1-3). Participants spoke about being encouraged to take responsibility for their own appointments by calling to schedule and attending by themselves, and seeing the benefit of advocating for themselves in clinic appointments.

In one interview question, we asked participants to rank on a 5-point Likert Scale, from 1 "Not well, there were issues" to 5 "Excellent, there were no issues," how the process went. Twelve participants scored their transition experience as 4 or higher, while 8 scored it 2 or below, see **Figure 3-1.**

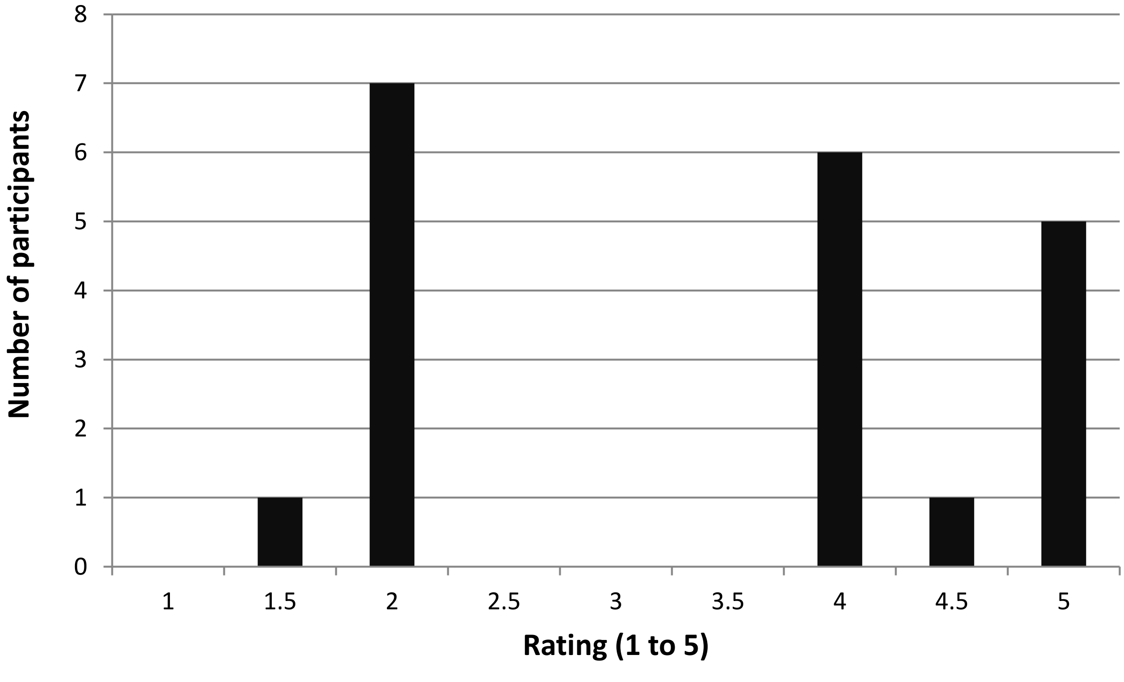


Figure 3-1 Participants were asked to circle how they felt about their transition on a 5 point Likert Scale, from 1 "Not well, there were issues" to 5 "Excellent, there were no issues."

When asked to rate their transition preparedness, from 1 “I was not prepared at all (0-20%)” to 5 “I was completely prepared (80-100%),” 17 participants chose option 4 or 5, which is at least 60% prepared. This corresponds with what was discussed during interviews, as many participants mentioned being told about transition early on in pediatrics (usually around age 16). Some of them said the pediatric gastroenterologist began to communicate solely with them at the last few appointments to help prepare them for the self-advocacy required in adult care, or provided information about transition.

As they begin to be seen in adult care, participants are very aware of the shift in responsibility and some even feel motivated to become more of a self-advocate. They reported many behaviors which were coded under “self-reliant,” such as starting to attend medication infusion, bloodwork and other medical appointments on their own; making their own appointments; knowing how and when to seek help during a flare; managing medications and communicating with the physician. Some participants mentioned deciding to get a handle on their own information and management while in remission because it is easier to slowly take things on from their parents while in good health. There was evidence of being interested in what is going on with their health through their current and past information-seeking habits, and a few mentioned wanting to be involved in medication decisions. Many participants’ parents still provided support when needed by calling the physician’s office, picking up or refilling medications, attending appointments, providing transportation, paying for medications and managing insurance, but it is evident that most participants are beginning to function as self-managing patients in adult care.

While the majority of discussion reflected positive evaluations of the current transition process, participants had some struggles with the switch to adult care. There was confusion and questions went unanswered; for example, not knowing what was going to happen in adult care or what to expect and how to navigate the adult biologic infusion appointments. The timing of transition was inconvenient in some cases, coinciding with flares or hospital stays (**Table 3-4**, quote 4). Some young adults felt that they weren't adequately informed of what to expect (**Table 3-4**, quote 5). The changes from what participants were used to in pediatric care, compared to adult care, were sometimes felt to be negative; for example, difficulties were encountered in making phone contact to have a question answered (**Table 3-4**, quote 6). On some occasions young adults had been told their parents should not be at the adult appointment. This was difficult for those who weren't yet comfortable with the new one-on-one appointment dynamic, which can differ from attending with a parent(s) in pediatric care (**Table 3-4**, quote 7).

Suggestions to improve transition included shifting the responsibility more gradually from the parent(s) to the patient, allowing the patient to decide whether or not to have parents present in adult care appointments, having more than one "Transition Education Session" per year and making sure patients are healthy at the time of transition.

Table 3-4 Participant quotes

Quote Number	**Quote**
Transition Experience & How to Improve the Process	
1	*"Um, a couple appointments before the transition, he (*pediatric gastroenterologist) *had me start, um, coming to the appointments alone, or at least um being the – ha – having my mom not respond to questions or anything. Um, s – so he did um prepare me, gave me a taste of the shift in responsibility."*
2	*"Um well it's just easier to – to make appointments on my own 'cause before I had to work around my mom's schedule but now it's like I said, I can go drop in and get my blood work done or on the way back from school I can schedule an appointment at 2pm if my class ends at 1 and I can – I can just do it on my own way, so that's a lot easier than before."*
3	*"As much as it's hard going like – being focused on myself, it's – I think I like that more, because then I get to know I – I can personally deal with it. If I have any questions, I can ask without y'know 'my parents are there, I dunno if I wanna ask this or not.' I – they might not understand what's going on internally. So sometimes I used to have them uh y'know retort back like 'No, I don't see this happening,' but this way it's just kind of focused on me."*

4	*"Ya, um, actually I was transitioning – it was real – I was really – it was really stupid because I was in pediatric and then literally like a day or two after my first surgery, they transitioned – they moved me into the adults thing, so, ya. Wasn't too – really too happy about that 'cause like it was like a MONTH after my seven – it was like a month or two after my 17th birthday."*
5	*"He talked to me about – he – well he mentioned that I would be switching to the adult doctors and um he kinda just like told me what the process was gonna be like, but the process was nothing like it – what he said. So, I – I just – I didn't feel like I knew what was gonna happen, I felt like I was just being switched. I felt like a football. That's – that's the metaphor that keeps coming back in my head – I felt like a football. Like I was just being thrown from one place to the other, and ya."*
6	*"Um.. Pediatric, if we had like any question um the IBD nurses would get back to us immediately. They would like either phone us back or email us back that same day. Um, in adult though it seems like it's a little harder to get a hold of the nurses and especially Dr. X. So I think that's the biggest change - is like actu- like knowing that you can get ahold of them if you – if something's serious but just for like a simple question, find your own answer kind of."*

7	*"Umm, well like I was sorta used to – 'cause I would share everything with my mom like at – in pediatric, like if I had a problem I would tell her and then she's like kind of the talkative type so as soon as we get in the room she wants to answer all of the questions, so I'm sort of quiet and she's sayin' 'This was – this was happenin' and this and this and this.' She has a bit of a better memory than me so if – like if something happened like a couple months back before our appointment, then she would say 'Oh ya that happened on this Friday of this month and this was happening,' and then I'd be like 'Yep, that sounds about right.' But now coming back like all the questions are sorta more directed at me so I sort of struggled a little bit answering like right away on like sort of like the times of everything happening and what – what went on."*
Perspectives on Transition Intervention	
8	*"Um, I think at the beginning it really just depends on how much the patient wants to know. I dunno, I guess you could just ask them. Like, um, how much they wanna know and then they could have different – I dunno, like different segments or something that they – if they wanna go through everything or just something specific, so."*
9	*"Ya, I do like the verbal communication but I think since everyone learns differently, then they should have the option as well."*

10	*"Depending on how much information you can fit in or how much they don't know. 'Cause like say you have someone who just got IBD at 17 and started in the adult, they're gonna need a lot more information than someone who started when they were 8 and went through all pediatrics."*
11	*"Ya and like it's gonna depend, like if somebody started taking responsibility while they were still in peds, they're not gonna need the same amount of time as like me."*
Intervention Format: How Participants Want to Receive New Information	
12	*"Um. Probably just havin' like the doctor or nurse or somethin' like that explaining things and either y'know having me like write things down as we go or have like a sheet that she can give me afterwards with like a summary of what she had talked about, is probably the best way."*
13	*"I feel like it would take like almost like a – sorta like the full transition, if they showed them like 'K, this is how you use the tool. If you ever have any questions, this is what you can go to and then once they've learned – like they've been taught by the doctor how the tool works, then they can use it to their own advantage, I guess."*
14	*"I guess one-on-one may be good, just for the patient to – can ask whatever they want in – in private, if they're having – have concerns about what's going on and transitioning to adult care, so. Ya, I guess that's an option you could have – having it separate from the appointment."*

15	*"Ya, instead of uh holding seminars or something because those can get a little… boring. So you could just put it online and let people look at their own leisure, and then they can discuss it with you if they want to at their next appointment and that sort of stuff."*
16	*"Um, I think when you learn about managing it they should be sort of checking up periodically throughout the transition um so if like a 6 month period, uh where the transition – where you're going from peds to adult. So say 3 months you're still in peds and 3 months you're adult um sorta check in on you and make sure you know information about managing your disease, and what you should be doing with insurance and what you should be doing with appointments and all that sort of stuff um like once a month would be beneficial, just to keep following- up and then if you have any other questions after the 6 months, just provide someone that they could talk to."*
17	*"Umm, I'd rather learn about IBD in a reading sort of format because like it – it's a lot of information. Um, and there's also a lot of complicated words and a lot of complicated sort of phrases and sentences and so it's nice when you're reading it because you can go refer back to what it originally meant if you sort of get lost along the way, whereas - when as someone's speaking you have to try to keep up, which can be hard when it's something as technical as diseases."*

18	*“Like I know when I first uh was diagnosed they had all these – these like booklets that would talk about like y’know having IBD in school and all that so if they had somethin’ like that for transitioning, I think would be a good thing.”*
19	*“Um, just sort of a general uh quite involved information package would’ve been nice, uh ‘cause there’s a lot of things and that would just be nice from a reference point of view and sort of a lot of – because there was a lot of information about it, so being able to absorb some of that, and then um, uh, I’m not sure if like a lecture style would be right but I – maybe a conversation with somebody about it, um probably after having looked through that information, with any questions,...”*
20	*“I think if it was – like I said online, um especially ‘cause kids our age and younger kids are more internet centric. Um, if they had sort of a resource tool online like um an IBD page or website, sponsored by AHS, like it would be really cool to figure out what steps go into transition and be able to refer back to that, uh, every once-in-a-while and what changes are made and um what you can do to become more independent, but also what your parents can do to still be involved. That sorta stuff, but just have it in one place online.”*

21	*"If there was just a resource like – like you said online, um where they could put like new links to studies or new different information and - and all that sorta stuff. It would be really cool just to have access to that, but from your own providers of care instead of someone from just like a news article or – or some other hospital, ya."*
22	*"Um but as for IBD – like learning about it themselves, I think at the beginning they should provide the information but it's up to the patient after that to sort of go from there. Um, just because there are so many channels of research you can go down that it might be more of a hindrance for the – someone to be checking in on them every s – once in a while than to just sort of give them the resources and tell them 'Ok this is what – if you wanna learn you can take this at the – at the beginning and sort of find out everything you want to from there' and uh 'Here are some links to websites and here are some links to videos that have more information' and that sort of stuff, ya."*
23	*"So you could just put it online and let people look at their own leisure, and then they can discuss it with you if they want to at their next appointment and that sort of stuff."*
24	*"So that way if you do have questions and you don't have time to ask, you can always just go on to the website..."*

25	*“Maybe like, since it’s 17-year olds transitioning, something like online where you could post about like what you’re experience was, so other people can read it, like I did a lot of that when I was first on Remicade, I would like talk to other kids about it, and like so they would have like a person not just a brochure. Like a place to go where you can be like ‘Oh I had my transition today, and it was fine.’ Just so you have that like support of people going through the same thing as you.”*
Intervention Content: What Participants Want to Learn About	
26	*“I searched up methotrexate and was kind of – the part I didn’t know was – I didn’t know it was harmful for my liver. Ya, and then I was like read it and it was like ‘Oh, don’t drink alcohol when you’re on this medication, it’s really bad and I was like ‘Oh, ok! Not gonna do that!’ ‘Cause on the bottle it just says um ‘May cause drowsiness’ and whatever, but I didn’t know it was bad for my liver if I drank alcohol with it, so I was like ‘Ok, not gonna drink anymore.’”*
27	*“Well it would be more helpful if I knew more about like the medication, if I could like – I – I’m still not sure like if I have to take it for the rest of my life or everything, so like a little bit more about the medications and how long I have to take them and stuff. Ya.”*

28	*"Ya, I wasn't like uh – like throughout pediatric care, like when my friends would ask and be like 'Oh what is this medication for?' and this and that, like if I took it or if it was at home, like I didn't – I didn't really have an answer, I'd be like 'Oh like I think that's just like a problem with my colon' and stuff like that. So I never really bothered to look into it but um afterwards, ya, I became more interested 'cause I was like 'y'know what I'm going into adult care'..."*
29	*"…a lot of how the medication reacts, like what it's actually doing, I don't really know that part, like honestly don't know what Remicade is actually doing inside but I – that – ya, I think a lot of more information about how medication is reacting with you, not the side effects but what it's actually doing I think is important. 'Cause you pretty much don't know a lot of the time."*
30	*"Maybe more info on IBD, like the actual just straight up facts about what it is and what's going on 'cause sometimes I'm still like ' I don't know.' And people have asked, 'n I don't know what it's about. I just know I have it and this is how I deal with it."*
31	"*Well I guess – like I guess there's still things that I wanna learn more about, like, um the like disease progression and like um - 'cause like I did get diagnosed fairly early in my life, so like what is gonna happen like when I'm like 50 or like 60 and I've had this disease for like 40 years, or like um if it's ok to be on the drugs for that amount of time."*

32	*"Ya and I really didn't know what like – well you hear a lot of things about adult care and how drastically different it is, and I didn't really know what to expect in terms of the reality. So I think that, that was a bit intimidating."*
33	*"Um and then the – the s- colonoscopies were weird because in pediatrics they put you completely under, um but in adult they didn't, so they - there was a big difference in going through the adult surgical day ward instead of the pediatric surgical day ward, ya."*
34	*"Um, but I think even just, um, something that provides more information about the transition and says y'know 'These are the steps that you're gonna need to go through, have you thought about y'know your medical history, have you thought about how you're gonna get in contact with your pharmacist, have you thought about,' – I mean in my case, 'how your insurance changes when you turn 18' 'cause that was a significant one, especially for people on a lot of expensive medications, like Remicade."*

35	*"Ya, like there was – when I was in – first in peds, like first in the IBD clinic, there was lots of like 'What is Crohn's?', 'What is Colitis', like 'What are your options?' – those kind of things and I think like a management one would be good to have in the adult one, and then maybe a transition one to have in the peds one, like so that you could take it and read about it and like at your appointment you should prepare to like be taking over your responsibilities from your parents and like give you like some things to like prepare, like learning how to fill out a prescription or like learning more about your disease, and like learning about your medication."*

3.2.2 Perspectives on Transition Intervention

When asked about their thoughts on a transition intervention, 15 out of 20 participants were completely supportive of the idea. Three participants thought there wasn't much need for it, but later in the interview they indicated it could be a beneficial thing to have. Two others did not think there needed to be further improvement to the process. The two participants who were not supportive of an intervention were coded as describing their transition process using entirely neutral or entirely positive statements. Of the 18 who ultimately supported a transition intervention, 13 had some negative things to say, but all of them also had positive things to say about the process. The other 5 of the 18 in support of intervention had a mix of positive and neutral experiences to report.

Participants who were supportive of creating a transition intervention were adamant that the intervention be customized to each individual, tying into the theme of "individualized and multi-faceted." Many suggested the intervention design should provide the flexibility to address individuals' varying information requirements and preferred methods for obtaining the information (**Table 3-4**, quotes 8-11). Participants acknowledged that although they had preferred learning styles, they knew others would have different approaches to learning that would need to be addressed in the design of a transition intervention.

3.2.3 Intervention Format: How Participants Want to Receive New Information

During the interview, there were two questions in which participants were asked to rank how they want to learn: one about IBD and the other about IBD management. **Table 3-5** includes the overall ranking and options participants selected from. The top 3 choices did not differ for learning about IBD or IBD management. Participants were allowed to "tie" choices in their rankings of 1 to 9. While participants were interested in different ways of learning, many had ideas for a multi-faceted approach involving a combination of the teaching strategies. The top ranked strategies were one-on-one with a physician or nurse, handouts and websites. These were also the three most frequently discussed by participants during the interviews, see **Figure 3-2**.

Table 3-5 Participant rankings of learning methods, when asked how they prefer to learn about IBD or IBD management

Intervention Medium	Overall Rank	# of rankings in top 3 for learning about IBD management	# of rankings in top 3 for learning about IBD
Verbally communicate info in clinic (one-on-one)	1	18	17
Provide patients handouts to read at home	2	13	15
Provide link to website for info to read	3	12	10
Show patients videos in clinic	4	8	7
Provide link to website for videos to watch	5	5	8
Email the patients	6	4	4
Text the patients	7	3	1
Engage in role play of disease management scenarios	8	1	2
Other	9	1	1

Note: Participants were able to "tie" options

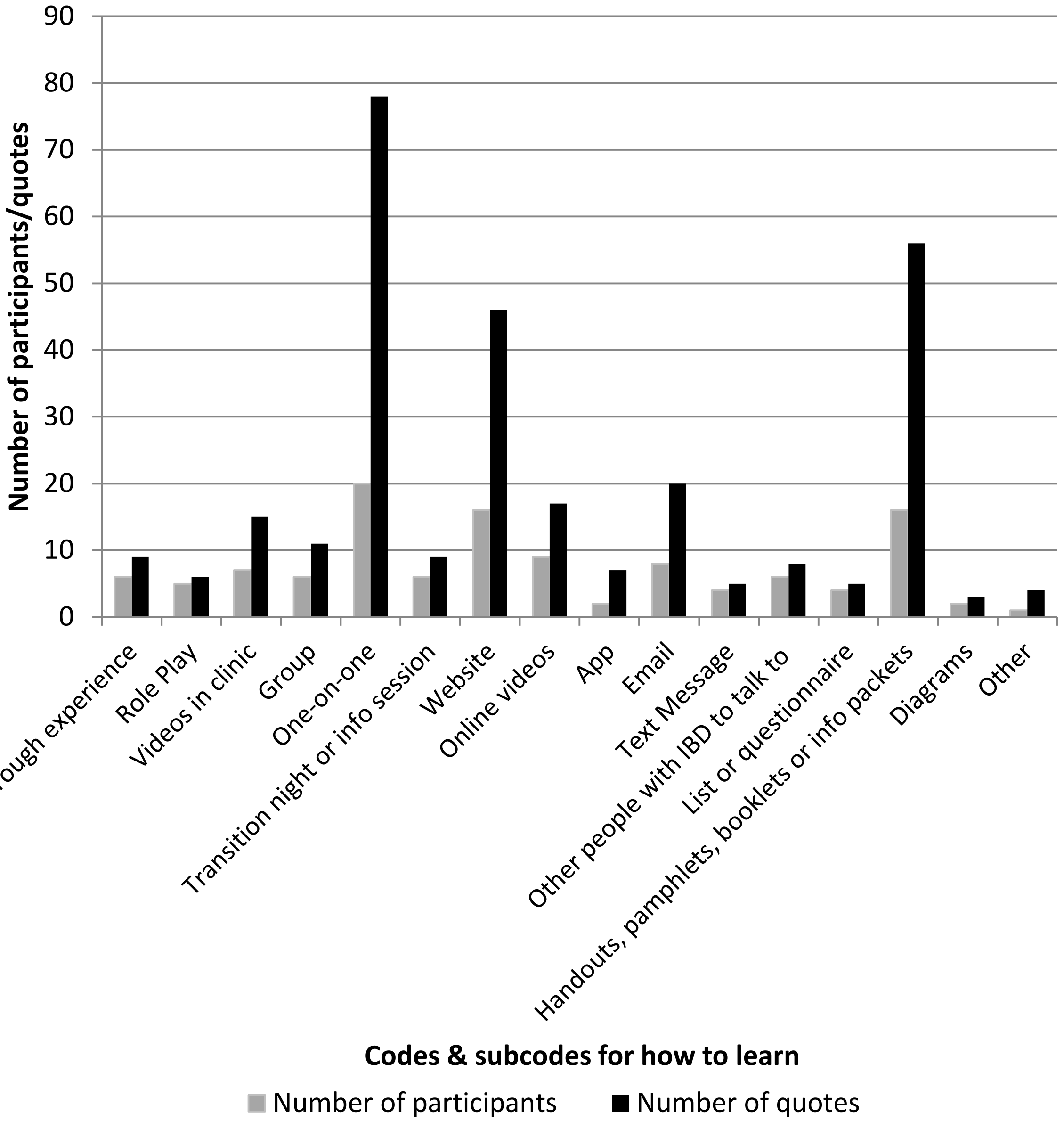


Figure 3-2 The number of participants and number of quotes referring to various ways of learning coded.

ONE-ON-ONE

Some discussions surrounding the use of a one-on-one clinic appointment during transition included having the physician or nurse deliver the information/intervention orally (**Table 3-4**, quotes 12-13), having a physician or nurse available to answer individual questions (**Table 3-4**, quotes 14-15), or physician “check-ins” during appointments throughout the process to see how things are going (**Table 3-4**, quote 16).

HANDOUTS

Handouts were deemed advantageous by some young adults as something that expands on what the physician talks about, to refer to later (**Table 3-4**, quotes 17-18). Similarly, being able to read it on their own time and ask questions, if necessary, was viewed as an advantage (**Table 3-4**, quote 19).

WEBSITE

Websites from a trusted source were seen as convenient and customizable one-stop-shops (**Table 3-4**, quote 20-23). Websites can serve as an effective extension of what is learned in clinic that transitioning patients can visit if they want further information (**Table 3-4**, quote 24). Participants reflected positively on being able to interact with other individuals with IBD and learn from their experience. A website intervention could incorporate this social element in the form of testimonials or “Frequently Asked Questions” (**Table 3-4**, quote 25).

3.2.4 Intervention Content: What Participants Want to Learn About

Participants were interested in more information regarding medications, disease and the transition process itself. Medications should be reviewed during the transition along with any new questions they may have, such as: how medications work, what to do if their medication stops working, what the new medication options are in adult care, how long their medication needs to be taken for, and logistical details about anti-TNF treatment in adult care (**Table 3-4**, quotes 26-29).

Whereas most participants seemed fairly confident in their knowledge about what their disease was, the questions they asked were about getting a more in-depth understanding of what exactly is going on in their bodies, so that they could explain it to a friend. Some questions that should be addressed in a customized intervention might be: “What is going on in my body?”; “Where is the disease?”; “How do I explain the disease?” (**Table 3-4**, quote 30); “What is the prognosis? What are other potential symptoms or risks?” (**Table 3-4**, quote 31).

Another important topic to include is what to expect during the transition process: “How does adult care differ?”; “How do procedures differ?”; “A transition plan or checklist would be helpful” (**Table 3-4**, quotes 32-35). Although there is an annual IBD “Transition Education Session” where parents, patients, adult and pediatric gastroenterologists, and nurse specialists meet to discuss the process and what transition means, not everyone is able to make it to the session and some are not comfortable asking questions in a large group.

3.3 Quantitative Assessment Scores: How Participants Measure up and What They Need to Learn About

TRAQ

Only one out of 20 participants demonstrated the literature benchmark of 90% mastery of transition readiness skills (scored 5/5 on 18/20 questions).[75] Compared to the published reference value of 5.6%,[75] a nearly equally small proportion of 5.0% achieved 90% mastery of transition skills (proportion difference: -0.64% [95% CI: -10.7%, 9.4%]). The median score was 4.18 (interquartile-range (IQR): 0.7).

The TRAQ questions with the lowest average scores had to do with health insurance, managing expenses, and preparing questions for the appointment. Participants scored best on skills involving using community services/stores, following a medication regimen independently, communicating in the appointment and arranging for transportation to the appointment (**Table 3-6**).

Table 3-6 Average score for each TRAQ question

TRAQ Question	Average Score
<u>Managing Medications</u>	
Do you fill a prescription if you need to?	4.0
Do you know what to do if you are having a bad reaction to your medications?	4.3
Do you take medications correctly and on your own?	4.7
Do you reorder medications before they run out?	4.1
<u>Appointment Keeping</u>	
Do you call the doctor's office to make an appointment?	3.9
Do you follow-up on any referral for tests or check-ups or labs?	4.0
Do you arrange for your ride to medical appointments?	4.9
Do you call the doctor about unusual changes in your health (For	4.2

example: Allergic reactions)?	
Do you apply for health insurance if you lose your current coverage?	2.1
Do you know what your health insurance covers?	2.9
Do you manage your money & budget household expenses (For example: use checking/debit card)?	3.6
Tracking Health Issues	
Do you fill out the medical history form, including a list of your allergies?	4.5
Do you keep a calendar or list of medical and other appointments?	4.0
Do you make a list of questions before the doctor's visit?	3.2
Do you get financial help with school or work?	3.1
Talking with Providers	
Do you tell the doctor or nurse what you are feeling?	4.9
Do you answer questions that are asked by the doctor, nurse or clinic staff?	4.8
Managing Daily Activities	
Do you help plan or prepare meals/food?	4.4
Do you keep home/room clean or clean-up after meals?	4.6
Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?	4.7

MMAS-8

The published reference estimate of 52% with low adherence[112] (scores <6/8) is higher than the 35% of participants in this study with scores <6, (proportion difference: -17% [95% CI: -39%, 6%]); however, the wide confidence interval around this estimate reflects substantial uncertainty about the precise degree to which our participants are more adherent relative to the reference group. The median score was 6.13 (IQR: 2.8).

The question with the most answers of score “0” was “Do you sometimes forget to take your IBD medication(s)?”; 10 of the 20 participants reported that they sometimes forget. The question with the most answers of score “1” was “Have you ever cut back or stopped taking your medication(s) without telling your doctor, because you felt worse when you took it?” to which 19 participants responded “No.”

Half of the participants with low adherence indicated they sometimes forget to bring medications with them when they travel, sometimes stop taking their medications when their disease feels under control, and feel hassled about sticking to the treatment plan. All of the participants with low adherence indicated they sometimes forget to take their medications and missed them at one point over the last two weeks. None of them reported ever cutting back or stopping medications due to feeling worse without telling their doctor.

IBD-KID

Only 2 participants scored below the published reference average score of 11.29. With a difference in mean scores of 3.86 [95% CI: 2.27, 5.45], participants scored better on average (mean 15.15) than the mean reported in the literature. The median score was 15.5 (IQR: 5).

50% or less of the participants correctly answered questions from this assessment involving knowledge about colon cancer risk, side effects of corticosteroids, use of herbal remedies, IBD surgery and diet. The questions to which 80% or greater of the participants responded correctly involved knowledge of IBD etiology and the genetic component, the effects of stress, life expectancy, reasons for colonoscopies and not to stop taking medications when symptom free.

Participant scores for each assessment are shown in **Table 3-7**.

Table 3-7 Assessment scores by participant

Participant	TRAQ Score (out of 5)	MMAS-8 Score (out of 8)	IBD-KID Score (out of 23)
1	4.25	5.75	14
2	4.35	6.00	13
3	4.75	6.75	16
4	3.05	6.25	9
5	4.05	5.75	9
6	4.25	6.00	18
7	3.80	8.00	11
8	4.20	8.00	18
9	4.45	3.50	13

10	4.15	8.00	18
11	4.20	8.00	21
12	4.10	8.00	18
13	3.60	7.00	17
14	3.35	8.00	17
15	4.40	4.75	15
16	4.30	3.50	16
17	3.60	1.50	11
18	4.50	6.00	20
19	3.55	8.00	15
20	3.65	4.00	14

4 Discussion

4.1 Improvement in the Transition Process

In discussing transition experiences, the majority of participants spoke about it and rated it fairly positively; however, there were a number of comments about adverse or confusing events and how the process could be improved. The transition experience described by participants highlights the need for individualized intervention, as transition is different for everyone; while some may be prepared and ready to take on adult care, others are struggling with health complications and feel abandoned when healthcare providers change suddenly in the middle of it. In a somewhat similar study using mixed methods to retrospectively investigate the transition experience in IBD, only one out of 29 participants surveyed did not have anything positive to say about transition, yet these researchers identified gaps in preparation and issues with process logistics.[52] Thus, while patients who have experienced transition may have felt positively about it overall, there were issues that came out upon further investigation.

The key theme of supporting the shift in responsibility was evident in participant comments about learning to communicate in appointments, being encouraged to take over responsibilities, but in some cases, not being quite ready to attend adult appointments without a parent present. While it seems that most participants are well on their way to becoming self-managing patients, they still rely on their parents for help. Some participants appreciated attending appointments with their new physicians on their own, while others struggled with it. A few explicitly suggested that the shift to being responsible for their own care should be more gradual. Some voiced appreciation for their pediatric providers having prepared them for communicating during appointments in the years before the transition. Others were concerned when they were told their parents shouldn't go with them to their first adult appointment. Overall, participants indicated that a more gradual and informed transition of healthcare responsibilities was necessary. "Achieving responsibility" was found to be a major theme in a metasynthesis of 18 qualitative studies of transition in chronic illness, where, similar to this participant group, some participants across studies seemed to struggle with the new responsibilities and others saw it as an opportunity to thrive and become more independent.[118] In Tuchman, Slap and Britto's interviews with adolescents (aged 15-21) with chronic illness, they discovered the theme of the "parent's changing role," in which participants found parent support to be valuable during transition.[50] While some apprehension about being seen alone in appointments was reported, again participants cited that attending appointments alone turned out to be beneficial.[50]

The experience of participants illustrates that it was not always clear what to expect from the process, or the experience of transition was not how the pediatric physician described it. This suggests the need to teach about the actual transition process, and what to expect so that young adults are able to prepare. In the same metasynthesis referred to previously, "being prepared for transfer" was a common theme of the 18 qualitative studies; participants of these studies also had similar negative experiences of illness during transition, or felt that transfer happened very quickly and that readiness needed to be assessed rather than decided by an arbitrary age.[118] A transition intervention would support providers in communicating detailed and consistent information about the transition process.

Outside of an intervention, some feasible improvements were suggested by participants that providers could begin to incorporate: ensuring patients have the option for parents to attend adult appointments, hosting additional “Transition Education Sessions” and trying to avoid transition around the time of a flare or surgery. Based on issues participants cited, where they experienced some confusion, transitioning patients need to be educated on how biologic therapy appointments work in adult care and the differences they can expect to encounter between the adult clinic and pediatric clinic. Providers should continue to encourage self-advocacy during appointments by having the patient try attending on their own, as the participants saw this as beneficial to transition preparation.

4.2 Views on Intervention

The idea of an intervention was viewed favourably by IBD patients who have experienced the current transition process from the EPIC to the Zeidler Clinic. While a couple of participants who described their transition experiences as entirely neutral or positive were not in favour of an intervention, nearly all of participants interviewed thought an intervention would be helpful regardless of how they described their own transition. This confirms that although most of the discussion around the transition experience was positive, participants still saw a need for improvement.

Participants had diverse needs in terms of intervention format and content. While some felt they had sufficient knowledge, others still had many questions. Many participants expressed a strong sentiment that whatever intervention is created, it must be customized to the individual's needs. This preference for individualized education was echoed by 90% of patients in an Italian study of 100 adults with IBD.[119]

It would be best to provide learning materials via multiple channels and/or formats so young adults can access information in the manner that best suits their learning style. As Friedman *et al.* point out in their systematic review of teaching strategies and methods of patient education, the needs of each patient can be very different.[47] Multi-faceted teaching strategies may be advantageous and the material should be patient-specific, culturally appropriate, and delivered in a structured and planned way, rather than at random.[47]

4.2.1 Intervention Format

The preferred intervention formats that participants were interested in were one-on-one with a doctor or nurse, handouts or a website. While participants still seem interested in the traditional modes of medical communication involving interaction with the healthcare provider and reading hard copy handout information, websites featured prominently in the discussion of both how they currently find information about their health, as well as how they would have liked to receive information in the form of a transition intervention. Studies suggest that interventions with components using media technology may be a good way to educate or build skills with transitioning patients.[35,39]

The study by Applebaum *et al.* using focus groups of transition-aged chronically ill participants to examine preferences for technology in transition intervention, found that participants were in favour of websites that were verified by their providers.[40] Similar to the participants in this study, the focus groups also expressed interest in handouts; however, they demonstrated a stronger desire for online tools.[40]

Some participants in the present study suggested a multi-faceted approach, which could involve introducing an interactive, web-based intervention in clinic and being able to use it on their own, but also being able to ask the provider questions in future appointments. While each medium has its specific advantages, it will be imperative to choose a strategy that allows for customization in terms of learning styles by incorporating various elements of communication, including text, audio, video and interactivity. Many participants shared the view that one solution will not work for every young adult, and the intervention must allow for multiple learning strategies as well as a choice of content that caters to each patient's needs. In Applebaum's study, participants wanted the online intervention to be easy and fun to use, with elements of interactivity, as well as the ability to be customized to the user.[40] These desires will be important to consider in the development of an intervention; especially the element of providing individualized content, which appears to be common among transitioning young adults.

It is important to continually re-assess patient-preferred education methods or formats, as these needs are likely to vary over age groups and can change over time as technologies advance; for example, in 1992, investigators from Italy who surveyed 100 adult IBD patients (aged 16-78) reported that preferred learning formats were books, video cassettes and leaflets.[119] The participants also expressed that a discussion with a healthcare provider would not be sufficient to improve their knowledge.[119] These findings are drastically different from the present findings, not only due to the fact that adults may prefer different information platforms, but also because of the change in available technologies.

4.2.2 Intervention Content

The three areas participants wanted to learn more about were medications, disease and what to expect for transition. It should not be assumed that young patients making the transition are always equipped with information on how their medications work and what the side effects are. It is important to acknowledge that, in many cases, medications may have started years earlier, before the patient was involved in treatment discussions. Participants need to be knowledgeable about their medications to prevent perceived barriers, such as understanding side effects, how the medications work and the need to continue them even when feeling well.[81] Interviews with adolescents with IBD and their parents, recruited from the Cincinnati Children’s Hospital gastroenterology clinic, revealed that there was a need for more in-depth information about the function of medications.[120] It is speculated that informed patients, who know about their medications and why they are taking them, will have better medication adherence and consequently better health outcomes.[121] Additionally, they should be informed about the logistical changes to infusion appointments that may come with the transfer to adult care for those on biologic therapies, as lack of information could lead to missed doses.

Patients who want to be more involved in their medical decisions must have sufficient understanding of the disease.[121] The young adults in this study were interested in learning more in-depth information about their condition. Again, some of these participants were very young when diagnosed and may not be able to communicate exactly what the disease does or what it might mean for their future. In fact, while physicians might assume that those patients diagnosed at a younger age have better knowledge of their health or be more involved, Plevinsky, Gumidyala and Fishman found that those diagnosed at a younger age may actually play less of a role in their health decisions.[52] Even adult patients (32/50 of those with ulcerative colitis and 39/50 of those with Crohn's) in the study by Martin *et al.*, reported not knowing enough about their disease.[119]

Disease information would ideally be individualized depending on the patient's disease and medications. Participant interest in learning about disease also illustrates that young adults want to take on more responsibility for understanding and communicating about their disease. Disease knowledge has been recognized in the literature as one of the key aspects of transition readiness that is lacking in young adults with IBD,[5,11,17] so it is of note that participants are recognizing this need in themselves.

Simply teaching about medications, disease and other aspects of management may not be sufficient to support young adults through the transition. During the interviews, participants were asked mostly about whether they wanted to learn about the disease or the management of it, but it became clear that many of them were more concerned about insufficient education about the transition process. In order to prepare these young adults for the transition to adult care, they need to know what to expect.

Even though many participants discussed steps taken during pediatric care to prepare them for the adult clinic, specifics of the process or what to expect for adult care were not always felt to be clear. In one study at the Boston Children's Hospital, 9/29 of young adults said they had not discussed transition with their pediatric gastroenterologist and just 4/29 said they had advance preparation.[52] Although it seems participants at the clinics of the present study are faring better in this regard, as most were made aware and given some preparation for the upcoming transition, the transition process could be outlined more clearly in advance of the transfer of care and certainly before the first adult appointment.

The theme of teaching about transition has been reported in previous literature on chronic illness. In Al-Yateem's study about understanding the transition experience of young adults with cystic fibrosis, one of their themes, "Preparing for the Transition", encompasses the concern of not yet knowing what is going to happen during transition and echoes the worries of our participant group about not knowing what their future in adult care will entail.[41] Al-Yateem also calls for a structured transition that should address the needs of the young adults.[41] DiFazio *et al.* conducted focus groups with adults and parents of adults with cerebral palsy about their experiences of transition, and recognized through their "Road Map to Care" theme, the importance of a clear plan for what happens in the transition to adult care.[48] Participants in the DiFazio study further noted the need to be aware of the differences they will encounter in the adult environment,[48] which was also a concern of the group interviewed in the present study.

The fact that similar themes arise across studies of transition in different chronic illnesses suggests that research outcomes may be applicable, to some extent, outside of the current disease of study.[52] However, not all needs will be shared across these populations and it is important to continue investigating young adults' perspectives to determine how interventions can be similar, or must vary, to suit individuals and their illnesses.

4.3 Relevant Skills and Knowledge of Transitioning Patients

It is accepted that assessments of skills and knowledge of transitioning patients can be used as measures to indicate the success or need for improvement of a transition process.[67] While assessments in this study indicate some clear gaps in skills and medication adherence, participants should be given credit for the many healthcare management tasks they are starting to take on. Many of the participants discussed important self-management or self-advocacy tasks, which checklists and guidelines have recognized are important for successful transition.[4,12,29,77,82–84] The majority of participants have achieved important milestones and goals outlined, such as knowing what to do in times of flare, knowing diagnosis, naming medications, dosage and schedule, booking appointments, filling prescriptions and knowing how to seek information when needed.[4,12,29,77,82–84]

While there is an apparent trend toward increased health responsibility among participants in this study, only one of the 20 participants scored 90% mastery of skills outlined on the TRAQ. Results indicate that some key skills related to “tracking health issues” and dealing with insurance are still lacking. Although, on average, participants scored poorly when asked if they make a list of questions before the appointment, participants scored higher on average when asked whether they communicate how they feel and whether they answer questions asked in appointments. Preparing a list of questions could be redundant if patients are able to communicate their needs during the appointment. Similar to the participant group in this study, adolescents with chronic illness were found to have issues with health insurance (knowing about their current coverage or what to do in future) when asked about health-management behaviours.[40] Interventions should inform young adults about the insurance options available to them, so they are prepared to seek coverage if necessary.

TRAQ identified taking medications correctly as one of the questions with a high average score, but over 1/3 of the participants had low adherence according to the MMAS-8. Perhaps the meaning of “taking medications correctly” in the TRAQ was misinterpreted, because it asks two questions at once: “Do you take medications correctly and on your own?” It could be that the participant takes their medications correctly, *when they do take them* and/or that they take them on their own.

Forgetting medicine was the question on the MMAS-8 that half of the participants in this study scored poorly on. As previously mentioned, one of the most common obstacles to adherence identified in a study of 74 adolescents with IBD (and their parents) was forgetting.[80] This theme of forgetting was also uncovered via interviews of adolescents with IBD and their parents in a study by Hommel *et al.*[120] Therefore, teaching patients easy ways to remember to take or order medications could be a target for transition intervention.

A study of adherence barriers in adolescents with IBD indicates that young adults may be non-adherent due to medication side effects.[81] Contrary to this finding, 19 out of 20 participants in the present study said they never cut back on medications due to feeling worse without consulting their physician, which may demonstrate that participants appreciate the importance of continuing a medical regimen and/or that they may be aware of potential side effects and would seek advice before abruptly stopping.

Hommel, Davis and Baldassano reported that 64% of 42 adolescent patients with IBD on 6-mercaptopurine (6-MP)/azathioprine (AZA) and 88% on 5-aminosalicylic acid (5-ASA) were non-adherent by pill-count, although only 10% reported it for 6-MP/AZA and 2% for 5-ASA,[122] indicating that adolescents are under-reporting their non-adherence. Furthermore, these patients with low adherence were missing between 40% and 50% of doses.[122] Ingerski *et al.* similarly found that participants were reporting better adherence than found by pill-count.[80] In this study, participant adherence was measured with the MMAS-8 and compared to literature values that utilized the same assessment. It is possible that this assessment underestimated the level of non-adherence, as discrepancies between patient self-report and pill count have been found in the literature. Perhaps, in a more in-depth study of medication adherence, it would be beneficial to use multiple or more objective ways of measuring adherence. In a 2013 report from NASPGHAN, Hommel *et al.* recommended using adherence measurements, such as the MMAS-8, to avoid providers asking leading questions that could result in inaccurate adherence measurement.[123] Currently, there is no recognized standard for measuring medication adherence in IBD.[80,122]

While knowledge of IBD among the participants in this study seems better, on average, than reflected in the literature, at least half of the participants incorrectly answered questions about colon cancer risk, side effects of corticosteroids, issues with herbal remedies, IBD surgeries and diet. Issues with knowledge about colon cancer risk, herbal remedies, surgery and diet were also discovered in the validation study of the IBD-KID: only 37/99 answered the question about colon cancer risk correctly, 24/99 knew that herbal remedies could interfere with medications, 16/99 correctly answered the question about surgery, and just 36/99 knew that cutting out foods would not stop flares.[85] The risk of colon cancer was also reported not to be well understood by a group of adult patients with IBD, in an Italian study.[119]

Participants in the present study were well aware of the unknown etiology of IBD, the role of genetics, effects of stress, life expectancy, the purpose of a colonoscopy and importance of continuing medications in the absence of symptoms. Over 70% of patient participants in the IBD-KID validation study correctly answered questions to do with etiology, genetics, life expectancy and stress.[85] There is some overlap in the general knowledge gaps and strengths identified in study populations, indicating areas for intervention targets to improve knowledge.

While participants in this study may be faring better in terms of disease knowledge than the average IBD transition patient, perhaps better in terms of medication adherence and comparable to the literature estimate (but not meeting benchmarks) for transition readiness, it cannot be said with certainty that this subset of transitioning patients represents the skills and knowledge level of all patients transitioning from the EPIC to the Zeidler Clinic. Nonetheless, these assessments do indicate that there is a need for improvement in the transition process, in terms of encouraging medication adherence, promoting the development of self-management and self-advocacy skills and addressing identified knowledge gaps.

4.4 Strengths and Limitations

This study was conducted with individuals in the greater Edmonton area at specific healthcare facilities, and therefore the results may not be generalizable to other patient populations. The small sample sizes deemed optimal for qualitative research allow in-depth information to be reported, thus permitting healthcare providers to assess how similar their patient population is to the study group. A diverse range of individuals was interviewed for this study and the variation in their views is represented in this report. It cannot be concluded that the learning preferences of this patient group are representative of the entire generation of IBD patients currently transitioning to adult care, but rather that one method of patient communication or education seems insufficient, and supportive interventions that aim to fill an identified need are warranted.

Although there are limitations to using the assessment score estimates found in the literature as comparisons/benchmarks, because it is not clear how accurate or generalizable they are, they are the best available reference values and provide a basis for knowing how typical the transition patients who participated in this study are and how they are faring compared to patients in other settings. It is also important to acknowledge that while the quantitative results supplement the qualitative data, they cannot stand alone as estimates that characterize IBD transition patients, due to being imprecise because of the small sample size. While comparisons to the reference estimates suggest that this study may have selected participants who had higher-than-average levels of knowledge and adherence, and average levels of transition readiness, the study limitations make unclear to what degree the knowledge and skill scores of this group are comparable to those in the target population of young adults with IBD. To address this limitation, the intervention designed will emphasize topics of interest identified by this group, while offering a wide breadth of information in these areas and utilizing assessments so that the information delivered will be customizable according to individual needs.

A strength of the study is that it represents the viewpoints of the patient group for whom this intervention is being created. As such, this study has and will continue to guide and inform the design of an intervention.

4.5 Conclusions

Patient-centered care is a concept that is being widely incorporated into medical practice, and the importance of considering patient experiences in the design of any intervention has been recognized.[41,48] Researchers agree that it is necessary to understand the patient needs for transition in order to create a better process.[52]

The interviews and assessments demonstrate how this group of participants was managing after transition from pediatric to adult care and help to identify the gaps and needs for supportive interventions. It was found that the intervention should center on the following themes: “individualized and multi-faceted”, “support the shift in responsibility” and “teach about transition.” The participants wanted to learn more about disease, medication and what to expect for transition, through various media but foremost: one-on-one with a healthcare provider, handouts and websites.

As prior studies have suggested, an intervention with transitioning patients is warranted. This study recognizes the importance of acknowledging the needs and preferences of transitioning patients, and will utilize their valuable input rather than assume that providers know best what patients require and how to deliver it. It is important that the educational intervention not only contains credible, accurate, and relevant content, but also, that the communication and teaching strategies are acceptable and effective for IBD patients in this age group. By creating an educational intervention that includes acceptable and effective communication and teaching strategies for this patient population that addresses the needs identified in this study, the overall project will aim to improve the transition process for young adults with IBD.

It is believed that a good transition will lead to better health outcomes.[52] An improved transition process that educates young adults can increase the quality of life for these patients and decrease the burden on the healthcare system. Furthermore, as study outcomes indicate, patients are in favour of an intervention, which could involve one-on-one discussion, handouts and websites, all of which could be incorporated into a feasible and scalable intervention and implemented in any clinic across Canada and, potentially, internationally.

5 Future Directions

5.1 Phase 2 “Develop”

Although the present thesis reports on the results of phase 1 “Assess,” the “Develop” phase of the study has commenced, with the aim of designing a novel intervention and seeking the feedback of interview participants on the intervention created. The project is expected to progress to the 3rd phase “Implement,” in the coming weeks when the intervention will be piloted with current transition patients.

Phase 2 of the study involves developing an intervention that responds to the themes and needs identified in phase 1. A multimedia and interactive website has been created that assesses the user’s knowledge and skill level to provide a customized online experience based on that assessment. Ideally, the website will be introduced to patients in the pediatric clinic through a “one-on-one” discussion with a nurse or gastroenterologist and patients will be welcome to ask questions in follow-up with their healthcare providers about material they learn on the site. Patients and physicians will be able to readily print handouts from the site for those who prefer to read and/or store a hard copy. Patients will also be able to access all parts of the website to search and read at their leisure, if they are interested in topics that were not part of their customized experience. This website will be easy to implement at any IBD clinic. The Edmonton group will still continue with their annual “Transition Education Session,” where the website will also be introduced.

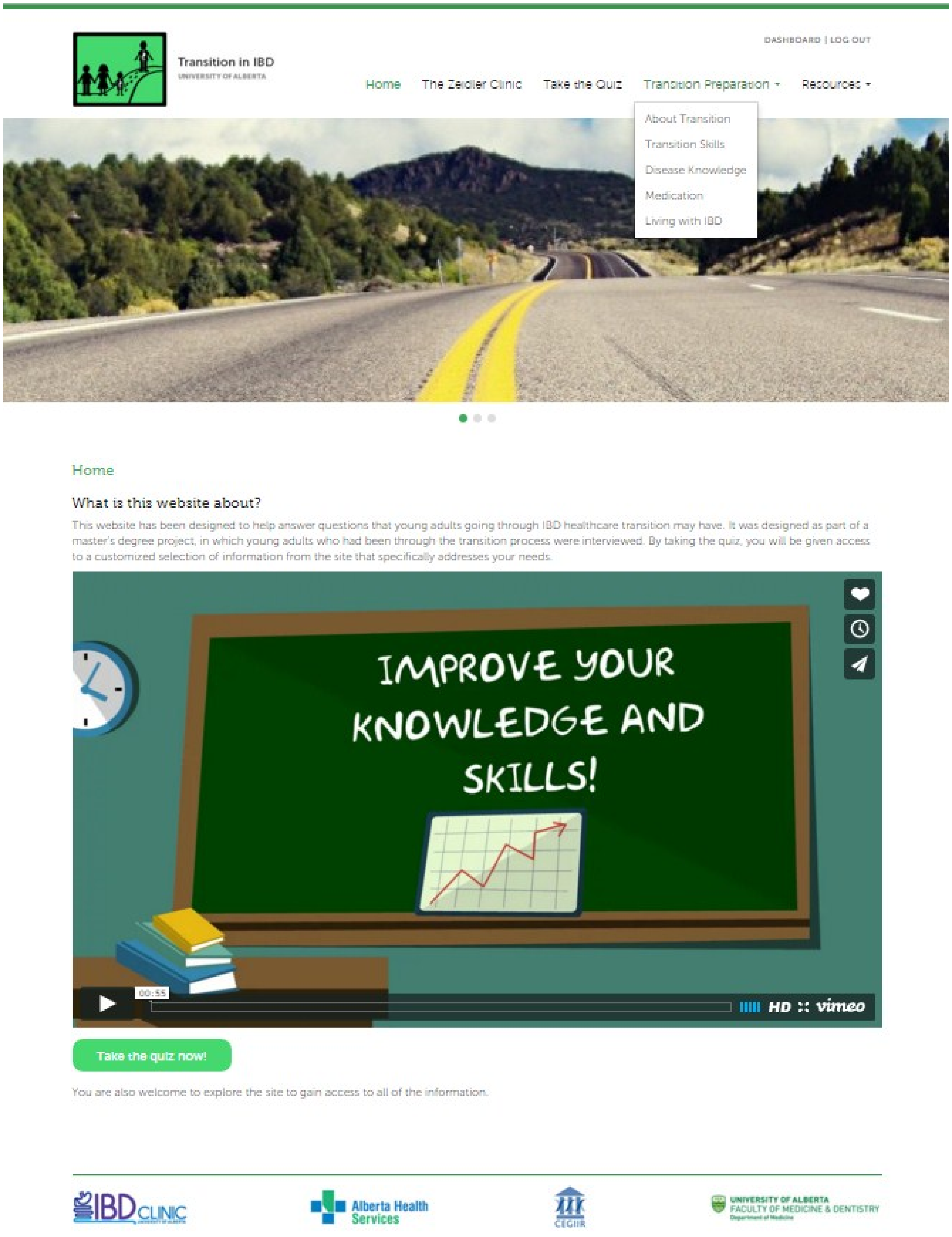
5.1.1 Website Design

The website was conceptualized and designed by the thesis author and supervisor, in partnership with a local digital development agency. Over the course of 4 months, the development quickly progressed from the content outline and wireframes, via many updated progress statuses, to a fully-functional website. All 6 cartoon videos on the site were created by the author, using Powtoon.com. All content was written by the author and supervisor, with input from an IBD nurse specialist and pediatric IBD gastroenterologist. Website content was planned to answer questions study participants had, as well as address the topic areas covered in the assessments. As dictated by the results of phase 1, content was mostly organized into the 3 main topic areas of “Transition Skills,” “Medication,” and “Disease Knowledge.” Upon arrival at the site homepage, users are able to watch a video or read about the purpose of the site. It is made evident that there is a quiz available, but also that users are free to peruse the site as they wish.

To make the website interactive and deliver a more customized learning experience, assessments were built into the quiz, the result of which determines what content is subsequently served to users. The online quiz delivers the TRAQ, IBD-KID and a medication adherence survey, which was designed by the author and supervisor. They decided not to continue using the MMAS-8 due to a prohibitive cost per use rate. The IBD Medication Adherence Survey can be found in **Appendix H**. Taken together, the three assessments making up the online quiz are scored on the back-end (not visible to the user) of the website to determine the user’s score category in each of the 3 topic areas of “Transition Skills,” “Medication,” and “Disease Knowledge.” These score categories dictate what participants see on a score report that follows, as well as what content they will be served. Score cut-offs for each category were decided based on a combination of literature benchmarks as well as expert opinion.

Upon completing the online assessment, participants see a report of their individual scores on each of the TRAQ, IBD-KID and Medication Adherence Survey; furthermore, they see the 3 topic areas sorted into the score categories of “Strengths,” “On the Right Track” and “Things to Work On.” Depending on the user’s score categories, they can then navigate to customized landing pages. The following pages with varying levels of information were created: one of each of “On the Right Track” and “Things to Work On” for “Transition Skills” and “Disease Knowledge,” as well as “On the Right Track” and “Things to Work On” for oral/rectal medications and infusion/injection medications. It was decided to break the “Medication” customized content into oral/rectal and infusion/injection so that the information provided to the user would be more relevant, based on how they answered the Medication Adherence Survey. If someone was on both oral/rectal and infusion/injection medications, they would be served both customized pages in whatever score category they achieved.

Informative videos as well as images were incorporated into the website to make it interactive and reach users who would prefer video or images, where possible. The general outline of the website can be seen in **Figure 5-1** or found at transition.ibdclinic.ca. An example of the score report page is seen in **Figure 5-2**.



Home

What is this website about?

This website has been designed to help answer questions that young adults going through IBD healthcare transition may have. It was designed as part of a master's degree project, in which young adults who had been through the transition process were interviewed. By taking the quiz, you will be given access to a customized selection of information from the site that specifically addresses your needs.

You are also welcome to explore the site to gain access to all of the information.

Figure 5-1 The transition website homepage.

ON THE RIGHT TRACK

- Transition Skills → click here for more information

THINGS TO WORK ON

- Medications (oral/rectal) → click here for more information
- Disease knowledge → click here for more information

YOUR TRANSITION SKILLS SCORE: ON THE RIGHT TRACK

🟥 Needs Work (11-33)
🟧 On the Right Track (34-44)
🟩 Excellent (45-55)

YOUR DISEASE KNOWLEDGE SCORE: NEEDS WORK

🟥 Needs Work (0-10)
🟧 On the Right Track (11-12)
🟩 Excellent (13-16)

YOUR MEDICATION SCORE: NEEDS WORK

🟥 Needs Work (4 to <21)
🟧 On the Right Track (21 to <27)
🟩 Excellent (27-33)

YOUR 1ST ASSESSMENT SCORES

TRANSITION READINESS ASSESSMENT QUESTIONNAIRE (TRAQ)

Overall Score: 3.6 / 5

Managing Medications: 2.75 / 5

Appointment Keeping: 4.14 / 5

Tracking Health Issues: 3.25 / 5

Talking with Providers: 4 / 5

Managing Daily Activities: 3.67 / 5

THE IBD KNOWLEDGE INVENTORY DEVICE (IBD-KID)

9 / 23

IBD MEDICATION ADHERENCE SURVEY

3.75 / 6 - Low adherence

Figure 5-2 An example score report.

5.1.2 Participant Feedback

Once the website was complete, participants from phase 1 interviews were re-contacted to test the site. Thus far, 16 participants have been reached and were sent a website feedback form (**Appendix I**) to complete upon taking the quiz and exploring the website. User feedback will inform future edits to further refine the site and increase usefulness and engagement among transitioning patients.

5.2 Phase 3 “Implement”

Once final edits are made to the website, patients who are currently transitioning will be recruited for Phase 3 “Implement.” Participants will take the quiz online and have a month to work through information linked to the customized score report. They will be prompted after one month to re-take the quiz. Initial scores will be compared to the scores at one month to assess the impact of the intervention on relevant skill and knowledge areas. The website will be shared with the Canadian Digestive Health Foundation (CDHF) to promote implementation at gastroenterology clinics across Canada.

5.3 Future Studies

Improving patient health outcomes is a burgeoning area of research and this type of intervention lends itself well to investigation of its longer-term impact on health outcomes in transitioning IBD patients. It is important to evaluate the effectiveness of interventions to assess whether they are needed and learn more about the factors to which successful transition may be attributable. Although it was not a goal of this study, perhaps with a larger group of participants taking the assessments and a more simply structured questionnaire focusing solely on transition readiness, preparedness and experience, researchers could consider whether there is any correlation between those that had a self-reported positive experience, were prepared and ready to transition, and their scores on assessments, disease outcomes or their ability to succeed in the adult clinic, however that may be defined.

While the bulk of current research calls for transition interventions, it is important to assess and refine them to ensure utility and cost-effectiveness; although, it should be noted that the intervention designed in this project is of relatively low cost and could be applied at a wide range of IBD transition clinics. The author hopes that it provides a substantial benefit to the transition patients who use it in future.

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APPENDICES

APPENDIX A. Participant Registration Form

PARTICIPANT REGISTRATION AND BASELINE DEMOGRAPHICS FORM

Participant ID: __ __ __ - __ __

Participant Name: ______________________________________

Sex: ○ Male ○ Female

Date of Birth (D/M/Y): __ __ /__ __ / __ __ __ __

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

Address:

____

____

- Is phone the best way to contact the participant? ○ Yes
  ○ No; Specify in notes below

Notes: (e.g., e-mail address, relation to other participants, preferable time to contact):

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

2. Are you currently in school?
   ☐ Yes, please specify grade, level or program: __________________________________
   ☐ No

3. What level of schooling have you completed?
   ☐ High School
      a) *If you completed high school*: Have you completed any education or training beyond high school?
         ☐ Yes *List:*__________________________
         ☐ No
   ☐ High School not completed - What is the highest grade you completed?*:*_______________
      b) Have you completed any education or training outside of high school?
         ☐ Yes *List:*__________________________
         ☐ No

4. With whom do you currently live, and for how long have you lived this way?____

5. What is your IBD diagnosis?

____

6. What medications (and amounts) are you currently taking for your IBD?____

____

Date of project enrolment (when informed consent completed) (D/M/Y)

__ __/ __ __/__ __ __ __

Signed project consent form: ○ No ○ Yes

Please check the project activities the respondent participated in:

- ☐ Semi-structured interview completed (D/M/Y)
  __ __/ __ __/ __ __ __ __
- ☐ 3 assessments completed (D/M/Y)
  __ __/ __ __/ __ __ __ __
- ☐ Pilot study period commenced/initial assessments completed
  (D/M/Y) __ __/ __ __/ __ __ __ __
- ☐ 3 assessments completed 1 month post-intervention (D/M/Y)
  __ __/ __ __/ __ __ __ __
- ☐ 3 assessments completed 6 months post-intervention (D/M/Y)
  __ __/ __ __/ __ __ __ __

APPENDIX B. Interview Guide

Detailed Semi-structured Interview Guide

Aims of interview:

1) Whether previously transitioned patients think an educational intervention for transition is a good idea
2) How they would like to receive new health information and whether they seek out information about IBD
3) Suggestions for improvement of pediatric transition
4) In general, their experiences and feelings about the transition process (what worked and what were the challenges)
5) Whether they are functioning as self-managing patients

Preamble

The point of this interview is to learn about the process of pediatric transition for young adults with inflammatory bowel disease (IBD for short). We want to know if some aspects of transition were difficult for you and how we could improve the process for future transition patients. We also want to know if access to more information on IBD or managing your IBD care would have helped you during the process.

We did the three short assessments of your skills and knowledge as they relate to IBD. This will help us see how well patients who have already transitioned are doing. Your input will help us make the transition process better for future patients. Our hope is that we can use the information gathered from these interviews and assessments to improve the process, if necessary. If we do get to this phase of the project, we may ask you to return and give feedback on what we have created.

The answers you provide in the interview and assessments will not be linked with your name in any presentation or publication. I will have access to your name, sex and birth date so that I can compare your answers with your assessments for analysis purposes, but this information will be kept confidential.

There are four sections to this interview and I will let you know as we move on to each one so that you know how we are progressing. The first one is just general background information, then we will talk about how you manage IBD, your transition, and lastly learning style.

For the purpose of this project I need to ask you some personal questions. Please answer as honestly as possible. You do not have to answer every question, and you may ask that the recorder be turned off at any point.

Do you have any questions for me before we begin?

We are going to start by filling out the participant registration form to collect your contact information, level of education, and IBD history (attached).
Ok, now we're ready to start the interview. I'm going to start with some more questions about yourself and your health background…

1. Background/Diagnosis

- a. At what age were you first diagnosed with IBD?
  - i. Were you still in high school at this time? If no, what were you doing?
  - ii. What was your living situation at this time?
- b. At what age was your first appointment with an adult gastroenterologist?
- c. Have you had any other gastroenterologists or IBD specialists?

Now I'm going to move on to some questions about how you typically manage your IBD…

2. Ongoing management of IBD

- a. How do you usually book appointments with your gastroenterologist?

- b. Are you supposed to have regular blood work done?
  - i. Do you have to book an appointment for blood work or can you just walk-in?
  - ii. How do you keep track of when blood work should be done?

- c. Tell me what you do when you need to refill your prescriptions.

Let's talk about who pays for your prescriptions.

- d. Do you have insurance coverage that pays for your medications?
  - i. Is this your own insurance plan or your parents'?
  - ii. What type of coverage do you have? (Parents (employer); Non-group Blue Cross (your plan or family plan); Student plan)
  - iii. Do you have out of pocket costs? If so, who pays for them?
  - iv. If you are covered by a parent's plan - what age are you covered until?
  - v. What will happen after that?

Now let's move on to some questions about your IBD (Crohn's/Colitis).

- e. How would you define a "flare"?
  - i. What do you do when you are having a flare?

f. On this diagram, please indicate how responsible you feel for your own medical care. (*diagram/spectrum attached for patient to indicate level of responsibility – "Where do you think you are on this spectrum?"*)

g. At the time of your first adult appointment with the GI specialist, where do you think you fell on the spectrum then? (*Mark on the diagram again*)

(Depending on answer to above two questions)…

h. What have you done to take more responsibility for your care since you stopped seeing a pediatric GI specialist?
    i. Who or what helped you take on more responsibility for your care (for example: your own motivation, support from your family, support from the nurse or your doctor)?

i. What are some things preventing you from taking more responsibility for your care?
    i. What would help you take more responsibility for your medical care?
    ii. Is there anything your doctor or any of the IBD team could do to make it easier?

j. What aspects of managing your IBD do you still find difficult to deal with?
    i. What aspects have become easier?

I am now going to move on to some questions about the transition process from pediatric care to adult care, so please recall what you can from that time…

3. Transition

a. What are the most noticeable differences between pediatric and adult care?

b. What do you like or not like about adult care?

c. What did you like or not like about pediatric care?

d. How do you feel your transition from pediatric care went? (*Likert – attached)*

e. Tell me about your transition.

f. What was difficult about it?

g. What was easy about it?

h. Do you feel the timing of transition was right for you?
    i. If not, what age would have been a more appropriate age to transition?

i. Do you feel like you were prepared to transfer to an adult provider? (*Likert – attached)*

j. How did your pediatric specialist address transition?

k. What was your impression of your first appointment in adult care?
l. Do you have any recommendations to make the transition process smoother?
    i. Is there anything physicians, nurses or staff could do or provide to help future transitioning patients?

m. Would you have liked to have access to more information on IBD or IBD management?

n. What about an educational tool or educational program designed specifically for transitioning patients?
    i. Would you prefer something that can be used on your own or in clinic with the doctor or nurse, or both?

This is the last section, which deals with your learning style and how you like to receive new information. Try to think about these questions in the context of transition and what would have been helpful for you at that time…

4. Learning style/information retrieval methods/knowledge delivery

a. When you were going through transition, was there anything about IBD you didn't understand that well?
    i. What about IBD did you want to learn more about?
    ii. What do you know now that you didn't know when you were going through transition?
    iii. Is there anything you still want to learn more about (aside from what you've learned since then)?

b. Did you ever seek out more information on IBD during transition?

i. If yes, where did you get your information on IBD (doctor/nurse, pharmacist, parent, search online, books, pamphlets, etc)?
ii. Do you currently seek out information?

c. How do you find you best learn information (for example, in school)? Do you prefer:
Lectures given by the teacher
Reading information (online, in a handout or textbook)
Group discussion/collaboration
Watching videos
Role playing/Presenting skits
Other: ______________
(Rank 1 to 6– attached)

d. Thinking about your learning style/preferred methods of learning from the previous question, how would you have liked to learn about IBD when you were going through transition?

e. What about ways to improve ongoing management of your disease – how would you have liked to learn about that?

f. What do you think would be the best way to convey information to transition patients to help them learn about IBD? Should we:
Verbally communicate this information in clinic, potentially using illustrations and handouts
Text the patients
Email the patients
Provide a link to a website that provides information to read
Provide a link to a website for videos to watch
Show patients videos in clinic
Engage in role play to help patients learn about IBD
Provide patients handouts to read at home
Other: ________________
(Rank 1 to 9– attached)

g. What do you think would be the best way to convey information to transition patients to help them manage their IBD medical care? Should we:
Verbally communicate this information in clinic, potentially using illustrations and handouts

Text the patients
Email the patients
Provide a link to a website that provides information to read
Provide a link to a website for videos to watch
Show patients videos in clinic
Engage in role play of disease management scenarios with the patients
Provide patients handouts to read at home
Other: ________________
(Rank 1 to 9– attached)

h. How much time should be devoted to learning about IBD or IBD care management in or outside of clinic? OR How often do you think patients going through transition would want to be contacted with IBD or IBD care information?

i. Given what we have just covered about how you like to learn and what you think would be the best way to teach transition patients, could you describe for me what kind of tool/program/intervention you would design to help transitioning patients?

    i. Would the tool or strategy you design be different for learning about IBD vs. helping with managing IBD medical care (appointment reminders, medication refills, etc)?

j. Is there anything I have not asked you, that you feel is important to know about transition?

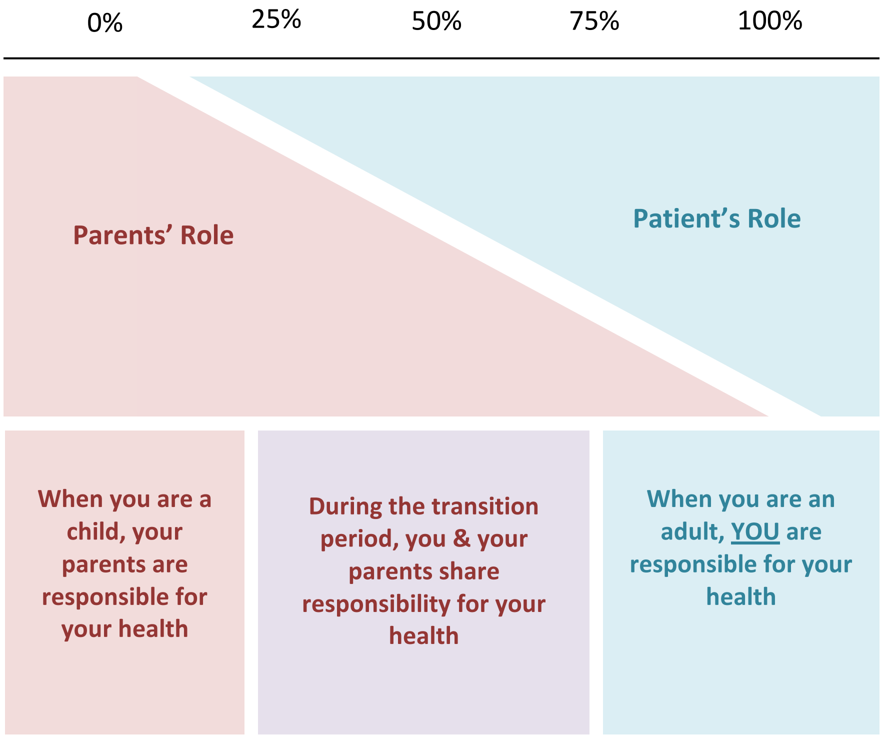
After interview questions:

Do you have any questions for me?

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

Would you be willing to come back to test out whatever tool or intervention we design?

CURRENT LEVEL OF RESPONSIBILITY

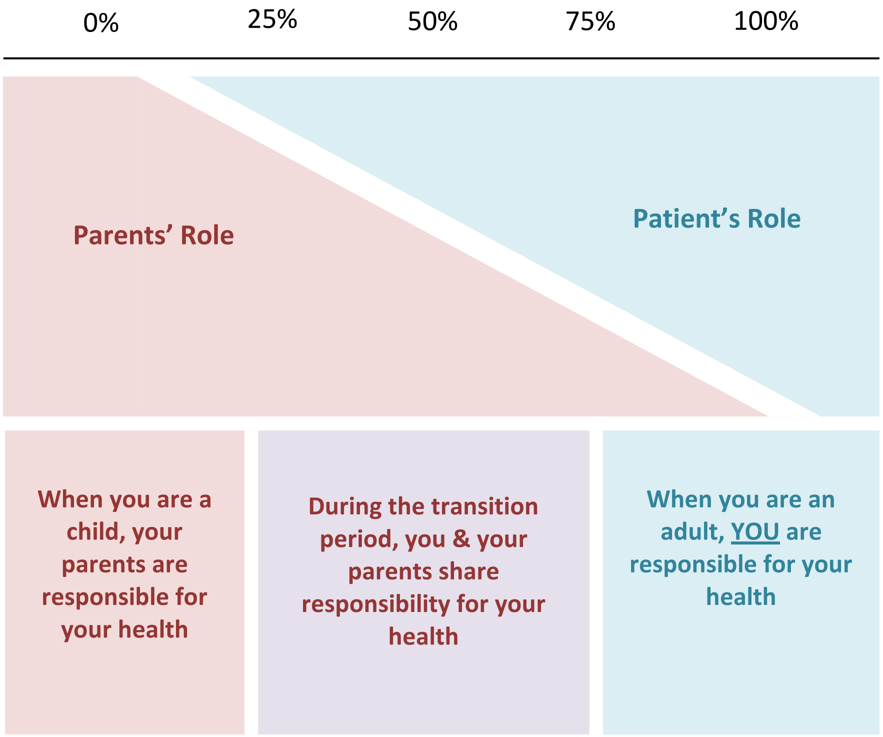


When you are a child, your parents are responsible for your health

During the transition period, you & your parents share responsibility for your health

When you are an adult, YOU are responsible for your health

LEVEL OF RESPONSIBILITY AT FIRST ADULT APPOINTMENT



When you are a child, your parents are responsible for your health

During the transition period, you & your parents share responsibility for your health

When you are an adult, YOU are responsible for your health

LIKERT SCALES

How do you feel your transition from pediatric care went?

1	2	3	4	5
Not well, there were issues	Somewhat well, there might have been minor issues	Neutral or can't recall	Well, there were no issues that I know of/remember	Excellent, there were no issues

Do you feel like you were prepared to transfer to an adult provider?

1	2	3	4	5
I was not prepared at all (0-20%)	I was somewhat ready (20-40%)	Neutral or can't recall (40-60%)	I felt fairly prepared (60-80%)	I was completely prepared (80-100%)

RANKINGS

How do you find you best learn information (for example, in school)? Do you prefer:

	Lectures given by the teacher
	Reading information (online, in a handout or textbook)
	Group discussion/collaboration
	Watching videos
	Role playing/presenting skits
	Other: ___________________________________

Note: Rank 1 to 6 but you do not have to rank every item

What do you think would be the best way to convey information to patients to help them learn about IBD? Should we:

	Verbally communicate this information in clinic, potentially using illustrations and handouts
	Text the patients
	Email the patients
	Provide a link to a website that provides information to read
	Provide a link to a website for videos to watch
	Show patients videos in clinic
	Engage in role play of disease management scenarios with the patients
	Provide patients handouts to read at home
	Other:__________________________________

Note: Rank 1 to 9 but you do not have to rank every item

What do you think would be the best way to convey information to patients to help them manage their IBD medical care? Should we:

	Verbally communicate this information in clinic, potentially using illustrations and handouts
	Text the patients
	Email the patients
	Provide a link to a website that provides information to read
	Provide a link to a website for videos to watch
	Show patients videos in clinic
	Engage in role play of disease management scenarios with the patients
	Provide patients handouts to read at home
	Other:__________________________________

Note: Rank 1 to 9 but you do not have to rank every item

APPENDIX C. Audit Trail for Interview Guide and Coding

Interview Guide Changes

Changing from Feb 19 to Mar 6 version of interview guide, after discussing with Kate Storey (Qualitative Methods Professor):

- Added question about living situation at time of transition and education completed.
- Decided to focus the last section of the interview more on transition because we have already focused the interview toward that in the section beforehand. We want to know how they would have wanted to learn/what they would have wanted to know then ("think back to transition"). I will re-iterate the point of the interview to find out what they would have liked to know and have access to.
- Took "scores" out of preamble because this term can cause tension with participants.

From Mar 6 to Mar 17 version:

- Changed 4 e to be 4 d i:

  d. Thinking about your learning style/preferred methods of learning from the previous question, how would you have liked to learn about IBD when you were going through transition?

    i. What about ways to improve ongoing management of your disease – how would you have liked to learn about that?

Post- pilot interview edits from Mar17 to April 7 version:

- Changed Mar 17 edit back to how it was:

  d. Thinking about your learning style/preferred methods of learning from the previous question, how would you have liked to learn about IBD when you were going through transition?

  e. What about ways to improve ongoing management of your disease – how would you have liked to learn about that?

- In preamble, decided to say we “did” the three short assessments because I start the interview meeting with them and then read the preamble before we start recording.
- Removed question 1 c “How long were you with your previous gastroenterologist?” as it is redundant (or can be figured out from previous questions).
- Changed “Now let’s move on to some questions about your disease” to “about your IBD (Crohn’s/Colitis) because it sounds less negative.
- Removed 2 d vi “Optional: If <18 years – do you know what’s going to happen for medication coverage after your parent’s coverage stops?” because it is redundant.
- Removed 2 e i “How do you know you are having a flare?” because it was answered by previous question when piloting (“How would you define a ‘flare’?”).
- Modified 2 f from “How responsible do you feel for your own medical care?” to “On this diagram please indicate how responsible you feel for your own medical care.”
- Removed “give an example” from 2 h because redundant.
- Changed 3 e & f from “Did you have positive experiences or feelings about the transition process?” and “Did you have negative experiences or feelings about the transition process” to “Tell me about your transition.” to be more open-ended and less directing them toward categorizing into positive or negative.
- Changed 2 l from “What recommendations do you have to make the transition process smoother?” To “Do you have any recommendations to make the transition process smoother?” so as not to coerce them into thinking up recommendations if they don’t have any.
- Changed 2 n into a probe to ask if necessary. Instead of “What could we (physicians, nurses, staff) do or provide that would help future transitioning patients?” I reworded to “Is there anything physicians, nurses or staff could do or provide to help future transitioning patients?”
- Removed 4 e & f because they were redundant with the following ranking communication strategy questions (“How would you have preferred to receive information to help you learn more about IBD?” and “How would you have preferred to receive information to help you with IBD care management?”)
- Changed 4 i & j because they were awkwardly worded/confusing (“How often do you think patients going through transition would want to be contacted (emailed, texted, etc.) or how many clinic appointments/how much time in clinic should be devoted..” and “How much time would you want to spend, how

long/how many pages should it be?") → Reworded to "How much time should be devoted to learning about IBD or IBD care management in or outside of clinic?" OR "How often do you think patients going through transition would want to be contacted with IBD or IBD care information?" → Will ask one or other depending on participant's selection.

- Reworded 4 k because two of the pilot interviews needed the question repeated (likely too long and too many ideas in it). Changed "Given what we have discussed about how often patients should be contacted, what information delivery strategy might be best and how you best learn, could you describe for me what kind of intervention you would design to help transitioning patients?" to "Given what we have just covered about how you like to learn and what you think would be the best way to teach transition patients, could you describe for me what kind of tool/program/intervention you would design to help transitioning patients?"
- Added: "Is there anything I have not asked you, that you feel is important to know about transition?" to ensure that we are covering all of the information they think is important about this experience.
- Added the following as "after interview" questions (not truly part of the interview or analysis):
- "Do you have any questions for me?" to give participants the opportunity to voice any concerns or get clarification on anything discussed.
- "Are you willing to be contacted if we need to clarify anything or have further questions?" – In case we need to do any of those things, it is good to know they are open to further communication.
- "Would you be willing to come back to test out whatever tool or intervention we design?" – To check whether they want to be part of the patient group that gives feedback.

Coding Audit Trail

4/6/2015

Changed "parent reliant" to "parent support" and "parent independent" to "self reliant"

Changed "text-based ideas" to "text-based learning"

5/6/2015
Changed "Improving existing helpful tools or supports" to "Improving current processes and existing helpful tools or supports"

Organized nodes into categories and added new nodes to go through and separate things into more specific nodes→ See exported node organization for June 5

Changed "Feelings and experience of transition" to "Feelings, experiences, and opinions of transition"

Remodeled node hierarchy again→ See exported node organization for June 5 v2

<u>New codes added between 4/6/2015 and 9/6/2015</u>

Interview 50108:

Improving existing helpful tools or supports

Sufficient info

No info seeking

Interview 50710:

Prepared

Not prepared

Active transition prep by peds

Learning through experience

Interview 50811:

Stress→ under Mental Health

Knowing when to call→ under self-reliant (healthcare responsibility)

Learning about medical history

Ideas to improve skills for transition

Learning about self-advocacy or self-management

Missing information

Positive differences

Negative differences

Email

Interview 52016:

Learning about research

Role play

Videos in clinic

Interview 52618:

Text message

Interview 52919:

Info sessions

Interview 60420:

Learning about what to expect for transition and the process

11/6/2015

Decided that having a parent node called "differences and similarities between peds and adult was unnecessary→ coded everything from that node into either Differences (pos, neg, neutral) or similarities/no difference (which were two codes I collapsed together, since they are similar ideas)

15/6/2015

Changed "Google" to "Google or search" in case it was not specifically referenced where they searched it online

Added "one-on-one" to "in-person"

Created sub-nodes under "Text based learning" to break it out into "list or questionnaire," "handouts, pamphlets, booklets or info packets," "diagrams," and "other"

16/6/2015

Added "Transition night or info session" under "in-person education"

17/6/2015

Changed "Other people to talk to" to "Other people with IBD to talk to"

Changed "Info seeking from other people" and broke into specific groups "Info seeking from other people with IBD," "Info seeking from parents or other family members," and "Info seeking from nurse or other healthcare professionals"

22/6/2015

Changed "knowing when to call" to "knowing when to seek help"

24/6/2015

Added a node under healthcare responsibility called "unsure about insurance" to code the instances where participants were unsure about their current insurance plan or what would come after

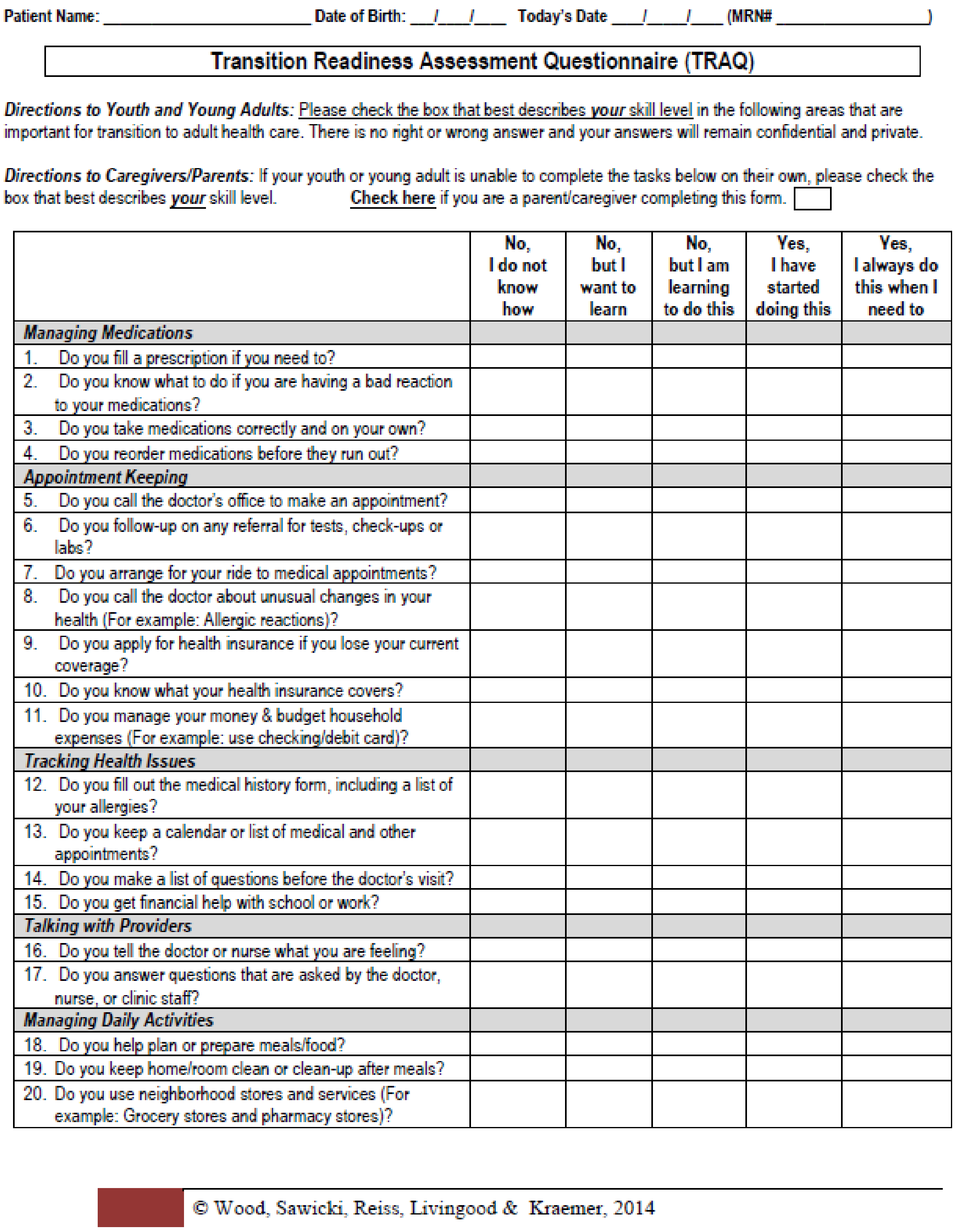
Created a new node under "self reliant" called "independently motivated" for those cases where the participant took on the new behaviours or responsibilities because they wanted to and are working toward being independent

3/7/2015

Added "other" node under mental health to cover other mention of mental health issues that weren't classified into stress, anxiety, depression

Changed "knowing when to seek help" to "knowing when or how to seek help"

APPENDIX D. Transition Readiness Assessment Questionnaire (TRAQ)



Patient Name: ________________________ **Date of Birth:** ___/___/___ **Today's Date** ____/____/____ **(MRN#** __________________**)**

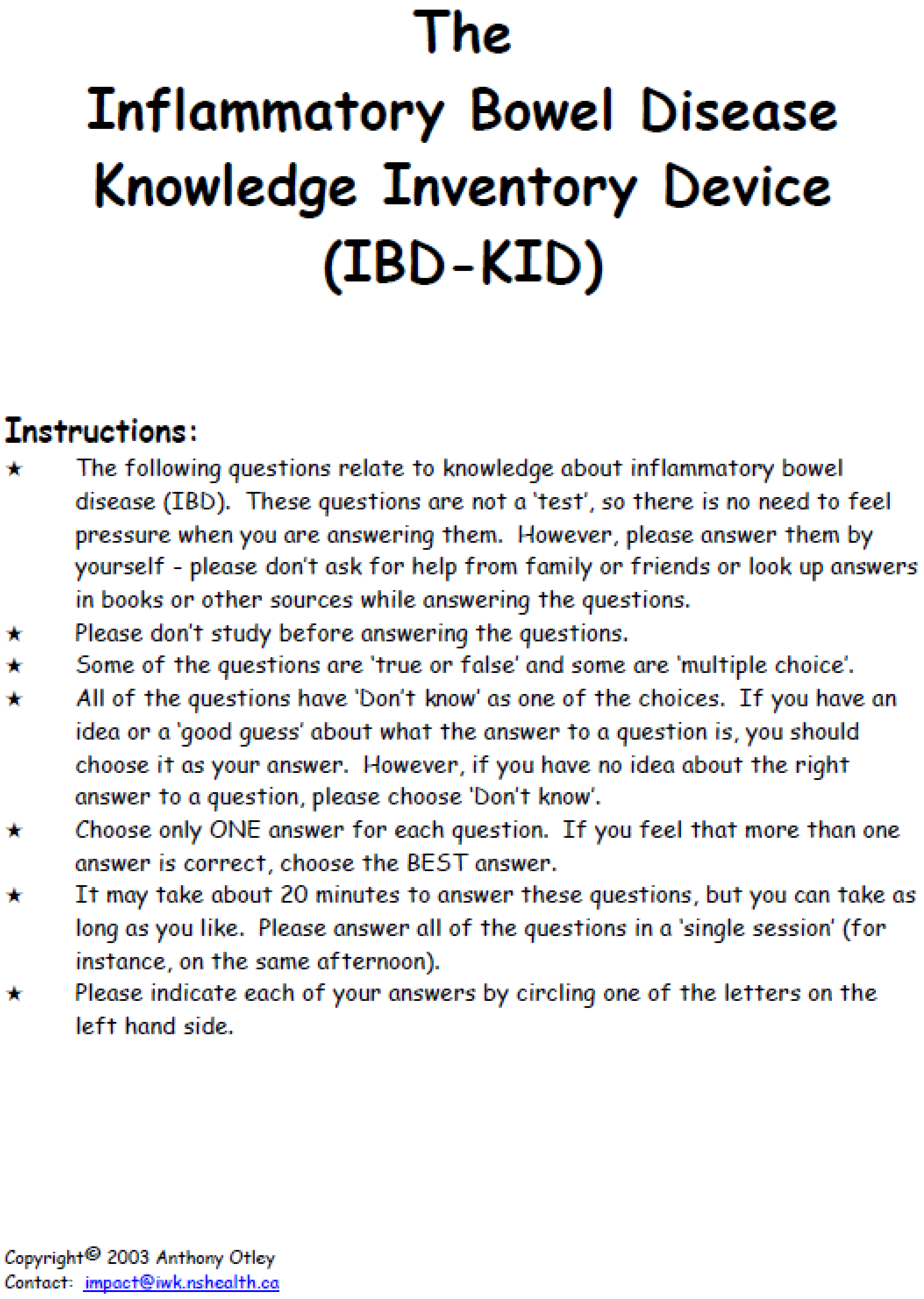
Transition Readiness Assessment Questionnaire (TRAQ)

Directions to Youth and Young Adults: Please check the box that best describes ***your*** skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

Directions to Caregivers/Parents: If your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes ***your*** skill level. **Check here** if you are a parent/caregiver completing this form. ☐

	No, I do not know how	**No, but I want to learn**	**No, but I am learning to do this**	**Yes, I have started doing this**	**Yes, I always do this when I need to**
Managing Medications					
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you take medications correctly and on your own?					
4. Do you reorder medications before they run out?					
Appointment Keeping					
5. Do you call the doctor's office to make an appointment?					
6. Do you follow-up on any referral for tests, check-ups or labs?					
7. Do you arrange for your ride to medical appointments?					
8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?					
9. Do you apply for health insurance if you lose your current coverage?					
10. Do you know what your health insurance covers?					
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?					
Tracking Health Issues					
12. Do you fill out the medical history form, including a list of your allergies?					
13. Do you keep a calendar or list of medical and other appointments?					
14. Do you make a list of questions before the doctor's visit?					
15. Do you get financial help with school or work?					
Talking with Providers					
16. Do you tell the doctor or nurse what you are feeling?					
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
Managing Daily Activities					
18. Do you help plan or prepare meals/food?					
19. Do you keep home/room clean or clean-up after meals?					
20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?					

APPENDIX E. IBD-Knowledge Inventory Device (IBD-KID)



The
Inflammatory Bowel Disease Knowledge Inventory Device
(IBD-KID)

Instructions:

- ★ The following questions relate to knowledge about inflammatory bowel disease (IBD). These questions are not a 'test', so there is no need to feel pressure when you are answering them. However, please answer them by yourself - please don't ask for help from family or friends or look up answers in books or other sources while answering the questions.
- ★ Please don't study before answering the questions.
- ★ Some of the questions are 'true or false' and some are 'multiple choice'.
- ★ All of the questions have 'Don't know' as one of the choices. If you have an idea or a 'good guess' about what the answer to a question is, you should choose it as your answer. However, if you have no idea about the right answer to a question, please choose 'Don't know'.
- ★ Choose only ONE answer for each question. If you feel that more than one answer is correct, choose the BEST answer.
- ★ It may take about 20 minutes to answer these questions, but you can take as long as you like. Please answer all of the questions in a 'single session' (for instance, on the same afternoon).
- ★ Please indicate each of your answers by circling one of the letters on the left hand side.

Contact: impact@iwk.nshealth.ca

1. The large bowel is longer than the small bowel.
    a. True
    b. False
    c. Don't know

2. From start to finish, the correct order of the digestive tract is:
    a. mouth → stomach → esophagus → large bowel → small bowel → anus
    b. mouth → esophagus → stomach → large bowel → small bowel → anus
    c. mouth → small bowel → esophagus → stomach → large bowel → anus
    d. mouth → esophagus → stomach → small bowel → large bowel → anus
    e. Don't know

3. A person can get IBD if they:
    a. share food with someone who has IBD
    b. use a toilet that someone with IBD has used
    c. both of the above
    d. none of the above
    e. Don't know

4. Doctors and scientists know what causes IBD.
    a. True
    b. False
    c. Don't know

5. Emotional stress can trigger a flare-up of IBD.
    a. True
    b. False
    c. Don't know

6. IBD can affect organs other than the bowels.
    a. True
    b. False
    c. Don't know

7. Osteoporosis (weakening of bones) can be caused by:
   a. IBD
   b. Corticosteroids
      (a class of drugs also called 'steroids'; prednisone is an example)
   c. poor nutrition
   d. all of the above
   e. Don't know

8. IBD that is in remission can slow down a young person's growth.
   a. True
   b. False
   c. Don't know

9. People with IBD that has involved the colon for more than ten years will probably develop colon cancer.
   a. True
   b. False
   c. Don't know

10. People with IBD don't usually live as long as other people.
   a. True
   b. False
   c. Don't know

11. The reason(s) a doctor might perform a colonoscopy is/are to:
   a. look for disease in a person's large bowel
   b. remove a large section of a person's large bowel
   c. apply medication to a person's large bowel
   d. all of the above
   e. Don't know

12. For an IBD patient who is free from symptoms, which of the following medications can help keep symptoms from coming back.
    a. salicylates (such as sulfasalazine and 5-ASA)
    b. Imuran (also called azathioprine)
    c. both salicylates and Imuran
    d. neither salicylates nor Imuran
    e. Don't know

13. If a person with IBD has been free from symptoms for several months, she/he should stop taking her/his medications.
    a. True
    b. False
    c. Don't know

14. Corticosteroids can cause which of the following side effects in children?
    a. hair loss
    b. decreased weight gain
    c. decreased height growth
    d. all of the above
    e. Don't know

15. If a patient who is taking corticosteroids experiences side effects, she/he should stop taking the drug immediately.
    a. True
    b. False
    c. Don't know

16. Which of the following statements about herbal remedies is/are true?
    a. Herbal remedies are safer than drugs because herbal remedies don't cause side effects
    b. Herbal remedies can interfere with drugs
    c. both a) and b) are true
    d. neither a) nor b) are true
    e. Don't know

17. Which of the following statements about surgery for IBD is/are true?
    a. If a person with Crohn's disease has part of his/her small bowel removed, Crohn's disease will never affect another part of the bowels.
    b. If a person with ulcerative colitis has his/her large bowel removed, ulcerative colitis will never affect another part of the bowels.
    c. both a) and b) are true
    d. neither a) nor b) are true
    e. Don't know

18. IBD tends to run in families.
    a. True
    b. False
    c. Don't know

19. A child whose parents both have IBD will eventually develop IBD.
    a. True
    b. False
    c. Don't know

20. Removing certain foods from the diet (for instance milk) will prevent flare-ups of IBD
    a. True
    b. False
    c. Don't know

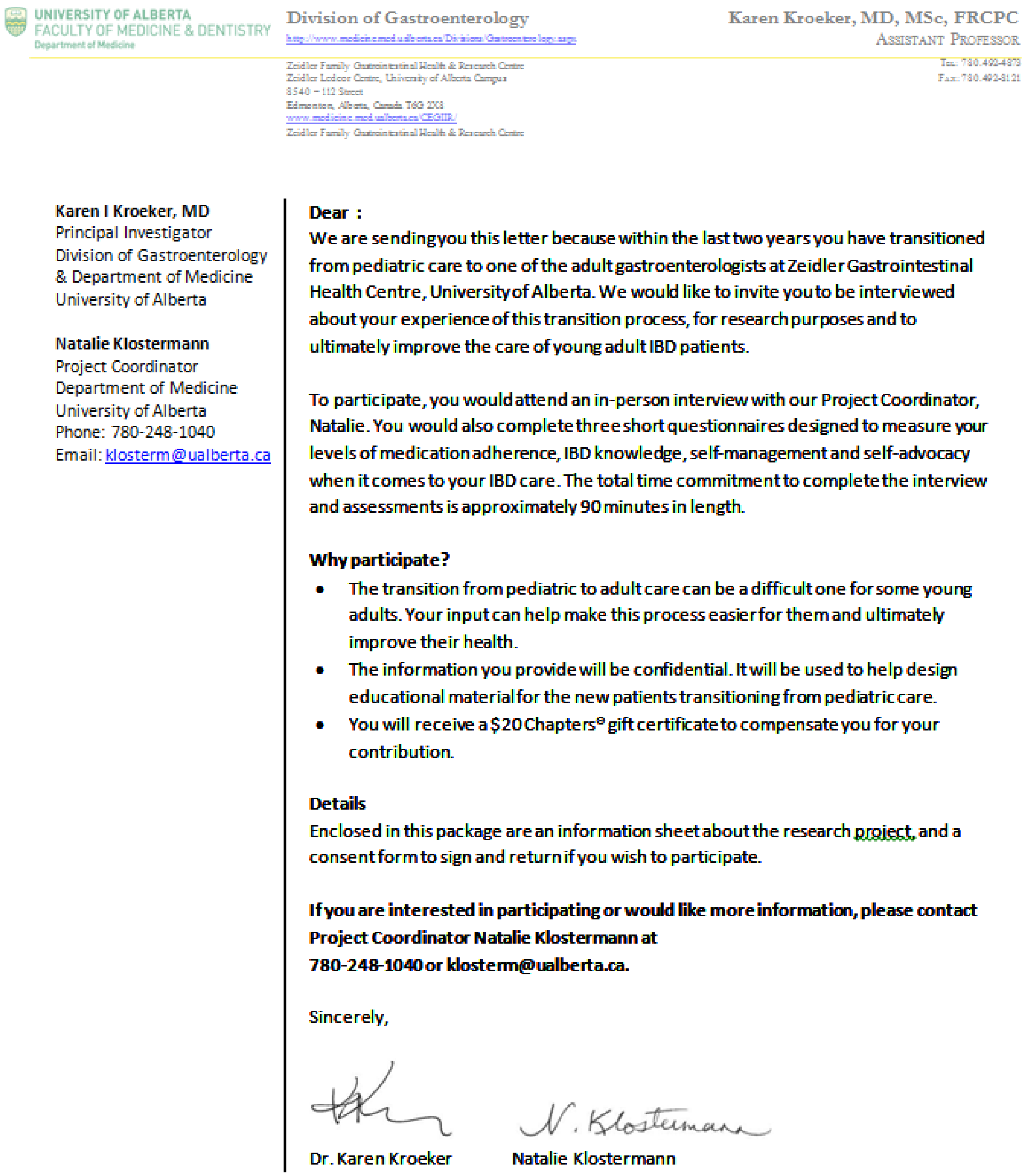
21. IBD patients can always get the nutrients they need if they eat the right foods.
    a. True
    b. False
    c. Don't know

22. Enteral nutrition (liquid diets that patients usually take by nasogastric or gastric tube feeds):
    a. can be used to control active disease or prevent disease flare-ups in some Crohn's disease patients
    b. can be used to help some patients grow and gain weight
    c. have not been proven to prevent flare-ups in ulcerative colitis patients
    d. all of the above
    e. Don't know

23. When doctors are testing a new drug for IBD in a study, some study patients might receive a 'placebo'. If a person receives a placebo, it means that:
    a. his or her IBD will stay active for a long time
    b. he or she will not be taking the new drug
    c. he or she will have unpleasant side effects
    d. none of the above
    e. Don't know

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE!

APPENDIX F. Recruitment Letter



UNIVERSITY OF ALBERTA
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Department of Medicine

Division of Gastroenterology
http://www.medicine.med.ualberta.ca/Divisions/Gastroenterology.aspx

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Email: klosterm@ualberta.ca

Dear :

We are sending you this letter because within the last two years you have transitioned from pediatric care to one of the adult gastroenterologists at Zeidler Gastrointestinal Health Centre, University of Alberta. We would like to invite you to be interviewed about your experience of this transition process, for research purposes and to ultimately improve the care of young adult IBD patients.

To participate, you would attend an in-person interview with our Project Coordinator, Natalie. You would also complete three short questionnaires designed to measure your levels of medication adherence, IBD knowledge, self-management and self-advocacy when it comes to your IBD care. The total time commitment to complete the interview and assessments is approximately 90 minutes in length.

Why participate?

- The transition from pediatric to adult care can be a difficult one for some young adults. Your input can help make this process easier for them and ultimately improve their health.
- The information you provide will be confidential. It will be used to help design educational material for the new patients transitioning from pediatric care.
- You will receive a $20 Chapters® gift certificate to compensate you for your contribution.

Details

Enclosed in this package are an information sheet about the research project, and a consent form to sign and return if you wish to participate.

If you are interested in participating or would like more information, please contact Project Coordinator Natalie Klostermann at 780-248-1040 or klosterm@ualberta.ca.

Sincerely,

N. Klostermann

Dr. Karen Kroeker   Natalie Klostermann

APPENDIX G. Information Sheet and Consent

Improving Healthcare Transition for Young Adults with Inflammatory Bowel Disease

Information Sheet & Consent: Semi-Structured Interview & Assessment

Principal Investigator

Dr. Karen Kroeker
Zeidler Gastrointestinal Health Centre
University of Alberta
8540 112 St
Edmonton, AB T6G 2X8
780-492-4873

What is healthcare transition?

Healthcare transition is the transfer of care from one doctor to another. In this case, we are interested in the transfer from a pediatric gastroenterologist to an adult gastroenterologist. This pediatric transition can be a difficult one for some inflammatory bowel disease patients, who sometimes end up stopping their medications and missing appointments, which can result in poor health. The difficulty stems from the expectation that young adults are ready to take full responsibility for the management of their healthcare. The adult healthcare clinic can be very different from the family-oriented pediatric clinic that patients are transitioning from.

Why do we want to do this study?

We want to make sure that the pediatric transition process in Alberta, and hopefully across Canada, is the best it can be. We understand that some things may not be working or could be improved upon and we would like to hear firsthand from people like you, who have experienced the process. We want your opinions on what would have made your transition a great one, so that we can improve it for the many patients that will follow in your footsteps. The information you provide will contribute to the development of an educational intervention.

What would be your role as a study participant?

As a study participant, we will ask you to come in for an interview with our research coordinator. She will ask you to answer questions about your health, clinic experiences, opinions on the transition process and ideas for improvement. The interview will be audio recorded and transcribed to be analyzed along with the interviews of other IBD patients who have gone through transition. The information you provide will be confidential. You may ask that the recorder be turned off at any time, and you do not have to answer every question.

We will also ask you to fill out three questionnaires. These questionnaires are designed to measure your levels of medication adherence, IBD knowledge, self-management and self-advocacy when it comes to your IBD care.

We will require you to be as honest as possible during the interview and assessments. Remember, this information will never be linked with your name in publication.

The total estimated time to complete the interview and assessments is 90 minutes.

Who will have access to your information?

Only project staff will have access to the information you give us for this study. We would also like access to your medical records to ensure completeness of medications and medical history provided in the interview. We will not disclose your name outside the research project office. We will not identify you by name in any published report. We will use the information we collect only for the purpose of this research study. We will keep your information confidential unless release is required by law. In addition to the investigators, the Health Research Ethics Board may have access to your records; they may access your records to monitor the research and verify the accuracy of study data.

Why consider helping us?

By being a part of this research study, you will be contributing to scientific research and it will hopefully help improve the lives of the IBD patients who will transition after you. The information you provide will help us design an educational intervention. We will compensate you with a $20 Chapters® gift card.

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

Your participation is strictly your choice. As a participant, you are free to withdraw at any time during the study up until the completion of data analysis. If you wish to stop participating in the study after having done the interview or assessments, any data you have provided to that point will be included as part of the study data, with your identity kept confidential, unless you request otherwise. If you would like your data removed from the study, you must request this when you notify us that you wish to stop participating. You are entitled to the gift card even if you withdraw 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.

- Natalie Klostermann, University of Alberta Project Coordinator, 780-248-1040
- Dr. Karen Kroeker, University of Alberta Principal Investigator, 780-492-4873

Title of Study: Improving Healthcare Transition for Young Adults with Inflammatory Bowel Disease
Principal Investigator: Karen Kroeker, MD Phone Number: 780-492-4873
Project Coordinator: Natalie Klostermann Phone Number: 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 you can ask more questions later on if you like?	☐	☐
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 the information you provide, including your medical 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 Witness ______________________________

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee ______________________________ Date ____________

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

APPENDIX H. IBD Medication Adherence Survey

IBD MEDICATION ADHERENCE SURVEY

SCORING IN BOLD (NOT TO BE SHOWN ON ACTUAL QUIZ)

1. I take medications (check all that apply):
    - By mouth (pills)
    - Rectally (suppositories/enema)
    - Injections or infusions (e.g. Humira/adalimumab or Remicade/infliximab)

No score for this question → determines whether shown oral/rectal customized page at end and/or infusion/injection.

2. On average, in one month, I miss taking my medication (by mouth or rectally):
    - <10% of the time **2**
    - 10-25% of the time **1.5**
    - 25-50% of the time **1**
    - >50% of the time **0.5**
    - I have stopped taking any medication **0**

2. On average, in one year, I get my injection or infusion late:
    - Never (I always receive it within 3 days of the scheduled date **2**
    - 10-25% of the time **1.5**
    - 25-50% of the time **1**
    - >50% of the time **0.5**
    - I have stopped my injection or infusions **0**

If a participant is on both oral/rectal and injection/infusion, they will have to answer both of question 2 and the score will be averaged between them

3. I do not take my medication(s) as prescribed because (check all that apply):
    - Not applicable (I do take my medication as prescribed) **1.5 – if this is selected, the items below should go grey (not selectable) and if they select any of the below, then "Not applicable" should go grey**
    - I forget to take it/I forget to get a refill/I forget to go to the appointment

- ○ I only take it when I want to feel better
- ○ I stop taking it when I am feeling well
- ○ It is not always convenient to take it
- ○ I worry about the side effects or risks
- ○ I think I can get by without it
- ○ I cannot afford it

If the participant selects one choice from the list above (excluding "Not applicable") the score would be 0.75, and if they choose 2 items (excluding "Not applicable") the score would be 0.5, if they choose greater than 2 items (excluding "Not applicable") the score is 0.

4. I understand why I have been prescribed medication:
   Yes **1** /No **0** /Somewhat (or unsure) **0.5**

5. I understand how my medication works:
   Yes **1** /No **0** /Somewhat (or unsure) **0.5**

6. I use the following to help me remember to take my medication(s) (Check all that apply):
   - ○ Calendar
   - ○ Electronic device (smart phone, iPad, calendar)
   - ○ Pill box
   - ○ Partner
   - ○ Parent or caregiver
   - ○ Other
   - ○ Nothing **0**

0.5 point awarded (total) if any of above are checked off (excluding "Nothing"). If "Nothing" is selected, the other options should not be selectable and if any of the options are selected then "Nothing" should not be selectable.

MAX SCORE: 6; MIN SCORE: 0

STRENGTH: 5-6; MEDIUM: 4 to <5; THINGS TO WORK ON: <4

APPENDIX I. Website Feedback Form

WEBSITE FEEDBACK FORM

Please review all sections of the website, take the assessment and review your scores and customized content. Provide your feedback below, giving your honest opinion of what you like or do not like about the website.

Design elements:

Font:

Layout:

Video Style:

Quiz functionality (ease of use):

Customized content elements:

Was the scoring report informative?

Do you think it accurately represents your knowledge/skill level in this area?

Did the content teach you something new?

Was the content interesting?

Was the content relevant to you?

Overall experience:

Did you find the website enjoyable to use?

Was the website easy to use?

Would you use the website again?

Would you recommend it to a friend going through transition?

Other:

When do you think transitioning patients should start using this website (for example: while in pediatric care, after their last pediatric appointment, once they have been seen in adult care)?

Will it be helpful for transitioning patients?

Comments for further improvements:

Would you want to write a short description about your transition experience (we may post some of them as cartoon videos or “testimonials” on our website)?