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Barriers and facilitators to successful transition from pediatric to adult inflammatory bowel disease care from the perspectives of providers

Christine Weirich Paine, MPH¹, Natalie B. Stollon, MSW^{1,2}, Matthew S. Lucas, PhD, RN^{3,4}, Lauren D. Brumley, BA^{5,6}, Erika S. Poole, PhD⁷, Tamara Peyton, MA⁷, Anne W. Grant, MSN, CRNP⁸, Sophia Jan, MD, MSHP^{1,9,10,11}, Symme Trachtenberg, MSW, LSW^{2,9}, Miriam Zander, BA¹, Petar Mamula, MD^{8,9}, Christopher P. Bonafide, MD, MSCE^{1,9,10,12}, and Lisa A. Schwartz, PhD^{5,9}

¹Division of General Pediatrics, The Children's Hospital of Philadelphia, Philadelphia, PA

²Division of Developmental and Behavioral Pediatrics, The Children's Hospital of Philadelphia, Philadelphia, PA

³Department of Emergency Medicine, The Children's Hospital of Philadelphia, Philadelphia, PA

⁴School of Nursing, University of Pennsylvania, Philadelphia, PA

⁵Division of Oncology, The Children's Hospital of Philadelphia, PA

⁶School of Arts and Sciences, University of Pennsylvania, Philadelphia, PA

⁷College of Information Sciences and Technology, The Pennsylvania State University, University Park, PA

⁸Division of Gastroenterology, Hepatology and Nutrition, The Children's Hospital of Philadelphia, PA

⁹Perelman School of Medicine at the University of Pennsylvania, Philadelphia, PA

¹⁰Leonard Davis Institute of Health Economics, University of Pennsylvania, Philadelphia, PA

¹¹CHOP PolicyLab, The Children's Hospital of Philadelphia, Philadelphia, PA

¹²Center for Pediatric Clinical Effectiveness, The Children's Hospital of Philadelphia, Philadelphia, PA

Abstract

Background—For adolescents and young adults (AYA) with inflammatory bowel disease (IBD), the transition from pediatric to adult care is often challenging and associated with gaps in care. Our study objectives were to (1) identify outcomes for evaluating transition success and (2) elicit the major barriers and facilitators of successful transition.

Corresponding author: Christine Weirich Paine, The Children's Hospital of Philadelphia, 34th St and Civic Center Blvd, Suite 12NW79, Philadelphia, PA 19104, painec@email.chop.edu, work 267-426-2902, fax 215-590-2180.

Conflicts of Interest: None.

Methods—We interviewed pediatric and adult IBD providers from across the United States with experience caring for AYAs with IBD until thematic saturation was reached after 12 interviews. We elicited the participants' backgrounds, examples of successful and unsuccessful transition of AYAs for whom they cared, and recommendations for improving transition using the Social-ecological Model of Adolescent and Young Adult Readiness to Transition framework. We coded interview transcripts using the constant comparative method and identified major themes.

Results—Participants reported evaluating transition success and failure using healthcare utilization outcomes (e.g. maintaining continuity with adult providers), health outcomes (e.g. stable symptoms), and quality of life outcomes (e.g. attending school). The patients' level of developmental maturity (i.e. ownership of care) was the most prominent determinant of transition outcomes. The style of parental involvement (i.e. helicopter parent vs. optimally-involved parent) also influenced outcomes as well as the degree of support by providers (e.g. care coordination).

Conclusion—IBD transition success is influenced by a complex interplay of patient developmental maturity, parenting style, and provider support. Multidisciplinary IBD care teams should aim to optimize these factors for each patient to increase the likelihood of a smooth transfer to adult care.

Keywords

Transition to Adult Care; Continuity of Patient Care; Inflammatory Bowel Diseases; Adolescent; Qualitative Research

Introduction

Transition, defined as “the purposeful, planned movement of adolescents and young adults (AYA) with chronic [health] conditions from [pediatric to adult care],”¹ is well-recognized as a critical time for adolescents and young adults (AYAs) with inflammatory bowel disease (IBD).^{2–10} While adolescents with IBD often have more medically complex disease than adults with IBD, they have lower clinic attendance and therapeutic adherence than their adult counterparts.^{11,12} Pediatric and adult gastroenterologists report deficiencies in the transition readiness (ability to plan, initiate, continue, and complete the transition process)¹³ of AYAs with IBD, with the highest reported deficiencies in knowledge of their medical history and treatments, self-advocacy, and care coordination.^{6,10} Moreover, many clinicians overestimate transition readiness in their IBD patients.¹⁴ The risk of adverse health outcomes after transfer (the end stage of transition) due to poor transition is firmly established.^{15–19} Yet, evidence-based recommendations for IBD transition are lacking.^{3,5,7,8} Research that provides an in-depth understanding of how each stakeholder contributes to and defines outcomes of transition for AYAs with IBD is a necessary step to establishing evidence-based recommendations.

Understanding barriers and facilitators of achieving optimal outcomes is critical. Schwartz and colleagues have developed and validated a theoretical model of transition readiness called the Social-ecological Model of Adolescent and Young Adult Readiness to Transition (SMART).^{20,21} This model acknowledges the important influences of the patient, parent, and provider in transition and identifies seven modifiable components of these groups:

knowledge, skills, beliefs/expectations, goals/motivation, relationships/communication, psychosocial functioning/emotions, and patient's developmental maturity. Less amenable factors include socio-demographics/culture, insurance/access, medical status/risk, and neurocognition/IQ. SMART can inform both barriers and facilitators of transition.²⁰

To address these gaps in knowledge of IBD transition related to outcomes, barriers, and facilitators, we solicited perspectives on transition from IBD providers across the United States. Specifically, we conducted semi-structured clinical interviews to (1) identify measurable endpoint outcomes for evaluating transition, and (2) elicit providers' perspectives on SMART-informed barriers and facilitators of successful transition from pediatric to adult care. In this paper, we present the results of the interviews which were later used in developing specifications for a user-centered mobile health (mHealth) intervention to improve transition outcomes for AYAs with IBD.

Materials and Methods

Setting

We conducted semi-structured interviews with pediatric and adult IBD providers from across the United States with experience caring for AYAs with IBD. Two trained research assistants who were not IBD providers interviewed participants over the phone or in-person between December 2012 and April 2013.

Participants

We recruited IBD providers who have cared for AYAs with IBD through snowball sampling and review of IBD transition literature. First local providers were identified by asking the Gastroenterology Division Chiefs at The Children's Hospital of Philadelphia and The University of Pennsylvania Health System for names of faculty specializing in the care of AYAs with IBD. Outside of these institutions, we identified nationally-recognized experts in IBD transition by reviewing the transition literature on IBD for the past 5 years and selecting first and senior authors based on article relevance to the objectives of this study. We then used snowball sampling to further identify IBD providers. Snowball sampling is a recruitment method in which the interviewer asks initial participants to recommend others well-suited for the study.²² This method ensures key informants, or experts, of the topic are identified who can provide rich feedback.²³ We purposively selected providers in pediatric and adult care and from multiple cities until thematic data saturation (i.e., no new themes presented) was reached in each group.²⁴

Data Collection

We developed our semi-structured interview guide based on SMART, a detailed review of the literature, and consultation with experts. The interview guide is available from the authors upon request. Prior to each interview, we emailed the participant a figure of SMART. During the interview, we investigated 3 major foci related to IBD transition: (1) measurable outcomes representing successful and unsuccessful transitions, (2) barriers to success, and (3) facilitators of success. The interviews specifically asked providers to recall exemplar patients to illustrate their points about outcomes post-transfer and related barriers

and facilitators. They were also asked to describe examples of how SMART components resonated with their experiences of barriers and facilitators. The findings described in this manuscript represent one component of a study that evaluated multiple, distinct aims. In addition to evaluating measurable outcomes with barriers and facilitators to transition success, the larger study aimed to elicit recommendations for improving transition and develop a user-centered mHealth intervention that incorporates these recommendations. Interviews took about 60 minutes. Each interview was recorded, professionally transcribed, and imported into NVivo 9.0 software for thematic analysis.

Data Analysis

Two team members independently coded each interview into themes based on the topics addressed in the interview guide and the SMART framework, including measurable outcomes of transition and contributing barriers and facilitators based on attributes of the patients, parents, and providers. The coders then reviewed their coding together and discussed any discrepancies with a third team member to reach a consensus.

In weekly meetings while the interviews were ongoing, we compared newly collected data with themes that had previously emerged in order to guide further thematic development and refinement (the constant comparative method).²⁵ Thus, the process of coding and interviewing was simultaneous and iterative, with one informing the other. After all of the interviews were completed and consensus had been reached for each individual interview, we discussed and finalized major recurring themes for successful and unsuccessful transition during ongoing team meetings.

Ethical Considerations

The Children's Hospital of Philadelphia Institutional Review Board granted this study an exemption.

Results

Participants

We interviewed 12 IBD providers: 8 physicians, 2 psychologists, 1 nurse practitioner, and 1 administrator. Of these, 8 engaged in pediatric care and 4 in adult care (Table 1). Participants practiced in 6 states— Illinois, Maryland, Massachusetts, Missouri, Ohio, and Pennsylvania—and all worked at academic medical centers in urban areas. The average number of years spent caring for AYAs with IBD was 16.3 years for pediatric providers and 14.1 years for adult providers.

Thematic Analysis

We first present the measurable outcomes that represent successful and unsuccessful transitions. Table 2 lists representative quotations of each outcome type. We then present major attributes of the patients, parents, and providers that serve as barriers and facilitators during the successful or unsuccessful transition and discuss their relation to SMART. The presence or absence of certain SMART components can determine whether the attributes serve as barriers or facilitators. Table 3 lists representative quotations of the SMART

components represented by the subthemes, and Table 4 lists the number of times each SMART component appears as either a facilitator or barrier.

Theme 1: Measurable Outcomes—Participants' discussion of measurable outcomes is organized into 3 subthemes: healthcare utilization, health, and quality of life.

Subtheme 1a: Healthcare Utilization Outcomes: Eleven participants shared healthcare utilization outcomes as measures for success or failure. Participants most commonly described maintaining continuity with adult providers without returning or “bouncing back” to pediatric care as a measurable outcome for IBD transition, with 10 participants emphasizing it. Other utilization outcomes included appropriate use of the emergency department for true emergencies only, maintaining stable health insurance, and receiving the standard of care for IBD in terms of clinic visits, laboratory tests, and endoscopies.

Subtheme 1b: Health Outcomes: When asked which outcomes determined whether the transition was successful or unsuccessful, 10 participants discussed health outcomes. They defined successful transitions as minimizing unanticipated hospitalizations and surgeries, avoiding the need for steroid treatment of flares, and maintaining stable symptoms and laboratory results. Failure to meet any of these criteria resulted in an unsuccessful transition. Symptoms that helped to indicate health status during and after transition include number of stools per 24 hours (especially if bloody) and pain level. Laboratory tests indicating good health include improvements in C-reactive protein (CRP), erythrocyte sedimentation rate (ESR), serum iron level, and appropriate drug or metabolite levels reflecting medication adherence. Three participants warned against relying on health outcomes too heavily, since health outcomes are not always reflective of care received or medical adherence due to the sometimes fluctuating natural course of the disease.

Subtheme 1c: Health-related Quality of Life Outcomes: Three participants described quality of life as an outcome for transition success that involves the patient's ability to meet the day-to-day demands of life, such as attending school or work and having a family. One participant stated, “If you cannot meet the day-to-day demands of your life, then chances are you are not going to be able to meet the demands of anything else, including a chronic medical condition.”

Theme 2: Barriers—Participants described perceived attributes of the patient, parent, and provider that threatened the likelihood of a successful transition for their patients. Subthemes include patients' developmental maturity, “helicopter parenting” (defined as over involvement of parents in their children's lives),²⁶ and insufficiently supportive providers.

Subtheme 2a: Patient's Developmental Maturity: All participants reported that the most pronounced determinant of transition success was the patients' developmental maturity. Developmental maturity, as is the case in the SMART model, encompassed many aspects of transition readiness factors including abstract reasoning skills, psychosocial functioning, motivation and goals related to disease self-management and the future, and communication and relationships. The providers described that, despite the best laid plans for transfer of care, the transfer would fail if the patient was not sufficiently mature enough.

2a-1: Insufficient Abstract Reasoning Ability: Participants described insufficient abstract reasoning ability as the norm for most AYAs, and described how it influenced transition outcomes. Abstract reasoning related to lack of problem-solving ability in balancing disease-related demands and developmental tasks typical of adolescence (being a “normal teenager”). It also related to lack of ability to consider consequences of various choices related to disease management. This can impact motivation for disease management. One example of insufficient abstract reasoning was the mismatch between medication adherence and medical outcomes. Patients lacking abstract reasoning sometimes stop taking their medications when feeling well, without realizing that their current lack of symptoms may not be representative of their disease activity, as exemplified by 1 participant: “Something that hurts us is when patients stop their meds and end up doing well for a while[...]. It usually takes a little while before they flare and [in the interim] they are like, ‘You know I am doing fine without them.’”

2a-2: Psychosocial Difficulties: In addition, participants described how some patients struggle with emotional difficulties that prevent successful transition. Some of these may have been family-wide issues related to family functioning or stressors, while some patients had their own depression or anxiety struggles. Patients with psychosocial difficulties often either failed to prioritize their IBD-related healthcare needs or chose to blame others instead of taking ownership of their disease management. One participant explained how emotions related to a failed transfer: “I don't think she really was resigned to the fact that she had this disease.[...]She was still very angry about having it even though she had had it for about six or seven years[...]she just wanted to pretend it wasn't there and kind of go on and ‘Why can't you just fix me?’[...]It is not like the knowledge wasn't there. I think she just emotionally was struggling with it.”

2a-3: Lack of Motivation and Goal-Setting for Disease Management and Transfer: Moreover, participants often cited the patient's lack of motivation and goals for disease management and transfer as a barrier to successful transition. One participant said, “A lot of young people don't want to deal with being sick. They want to be normal like their friends. They don't want to take meds, they don't want to have tests done, and they don't want to see a doctor.” Participants described how some patients refused to independently manage their disease or adhere to treatment while other patients simply refused to transfer to adult providers. This lack of motivation and goal-setting was often times attributed to underlying psychosocial difficulties or missed opportunities by the parents or providers to encourage independent ownership of disease management.

2a-4: Difficult Communication and Relationships with Providers: Lastly, participants described patients with whom maintaining positive relationships and effective communication was difficult, and as a result, had unsuccessful transitions. One patient was described as not comfortable communicating her needs to the provider. Another patient was described as needing constant reassurance and clarification from her providers, indicating an overly dependent relationship that did not result in improved disease self-management. Several patients were described as oppositional or even combative, as exemplified by one participant: “She was just fairly resistant and oppositional and somewhat combative, even

with our providers, meaning that if they made changes to her treatment plan that she didn't like, she got very angry and she wouldn't follow through.[...] I feared that she would potentially turn off her adult provider.”

Subtheme 2b: Helicopter Parenting: Eleven participants repeatedly cited the concept of “helicopter parenting” as a barrier to successful transition, defining it as overinvolved parents who want to maintain control of their children's care out of fear that their children might have adverse outcomes if they “let go.” One participant described the concept well: “There are some parents who, for lack of better terms, we call helicopter parents; they just really ride over their child. The majority of parents really do want their child to be more independent and mature, but I don't think they know what to do to prepare the child for that.” Patients with helicopter parents were successful with the transfer until they were allowed to navigate the healthcare system on their own. When patients were unable to practice disease self-management before the transfer, they were more likely to experience lapses in their management when on their own.

In general, there were 2 types of helicopter parents: 1) those who believed that they would always be able to manage their child's care, and 2) those who wanted to help their child be independent, but were not able to execute this. In the SMART model, these were all dyads with overly dependent patient/parent relationships; some were attributed to lack of parent skills in “letting go” and some were attributed to parents' beliefs and expectations that the best way to manage their child's disease was to remain in control.

Subtheme 2c: Deficits in Provider Skills to Prepare Patient and Parent for Transfer and/or Address Patient's Needs, and Insufficient Communication Between Providers

2c-1. Deficits in Provider Skills: Ten participants cited that inadequately supportive providers became a barrier to successful transition when they were unable to recognize and address the needs of the patients and parents or did not adequately coordinate the care of the patient. Both adult and pediatric participants cited the pediatric provider's inadequate preparation of the patient as a potential barrier to transition. The adult participants understood this as something lacking in the pediatric provider's care, and the pediatric participants often internally questioned how they might have provided more preparation, as reflected by 1 participant: “I did the best I could to make sure that everything was set up; I wrote everything out, I typed things out, but I still wonder what I could have done differently.”

In addition, adult providers who were not aware of and responsive to incoming AYA patients' needs and expectations contributed to unsuccessful transfer. One participant described how an adult provider refused to write a needed disability letter to the patient's college due to distrust in the patient: “I could see [how] the provider who didn't have a relationship with [the patient] thinking that, ‘Oh, she just doesn't want to do this in college.’”

2c-2. Insufficient Provider Communication: Participants identified poor communication or care coordination between providers as one critical barrier to successful transition, especially between the pediatric and adult providers. Examples included receiving a poor

medical summary of the patient, lack of access to medical records, and disagreement on the patient's treatment plan. One participant stated, "One of the obstacles[...]is also how to get those [medical] records, even though we are on the same electronic health record for both [pediatric and adult] centers, they don't talk to each other."

Theme 3: Facilitators—Participants viewed facilitators as attributes of the patients, parents, or providers that assisted in overcoming barriers to successful transition. Subthemes include exceptionally mature patients, parents optimally involved in the patient's care, and adequately supportive providers.

Subtheme 3a: Exceptionally Mature Patients with Ownership of Care: Patients who were exceptionally mature for their age and took ownership over their care were often featured in descriptions of successful transition by all participants. These patients were described as using advanced abstract reasoning and/or having developed resilience in the face of adversity. This led patients to improved coping with their medical condition, a willingness and ability to consider future consequences of their decisions, and engaged and open conversations with their providers. Their maturity was sometimes exemplified by their understanding of their disease and by asking the provider thoughtful questions.

In describing his successful patient, one participant stated, "Emotionally, she was very precocious in terms of her understanding of her disease and her assessment of kind of where she was in space and with her illness." He later described how this patient even researched her treatment options on her own before deciding on her care: "[The patient] had found a video blog that documented[...]getting a colectomy and J pouch[...]and she watched that after we talked to her about surgery." The participant then suggested that this advanced maturity may be due to resilience developed during a stressful family life, because "she was someone who might have been the mom figure in the house for her younger siblings."

Subtheme 3b: Parents Optimally Involved in the Patient's Care: Ten participants described how parents optimally involved in the patient's care facilitated the transition. Supportive parents fostered their children's ownership of care, and were resourceful, were trustful and respectful of their children and the provider, were educated on the disease, and were cooperative with the provider. This often meant working alongside the pediatric provider to determine how to encourage the patient to take responsibility and how and when to relinquish their parental control while continuing support, as seen in the following example:

Really the biggest thing was that the family trusted me enough to allow me time so that I didn't feel like I had to work around it, to allow me time to independently meet with their daughter [...]. The family also pushed their daughter to be independent, but at the same time, when they felt their daughter was making choices and initially that they didn't completely agree with, they would gently say you know why don't we ask Dr. ——— about X, Y, Z and see what her thoughts are.

Subtheme 3c: Adequate Provider Skills in Proactively Recognizing and Addressing the Needs of the Patients and Parents and Effective Care Coordination with Other

Providers: Eleven participants described how providers contributed to transition success through proactive preparation of their patients and parents and/or ongoing support of the patients. While there was great variation in the recommended age at which transition should begin, all agreed that the transition process should begin long before the transfer to adult care. Pediatric providers who facilitated transition addressed helicopter parenting by discussing transition at an early age with the parents and patient, talking directly with the patient instead of the parents at appointments, insisting on seeing the patient alone after a certain age, and teaching parents how to safely “let go” through encouraging the patient gradually take on an increasing amount of responsibility. It was also important that the adult provider allow the parents to attend the patient's first couple appointments with the adult provider to build up the parents' trust in the new provider. Both pediatric and adult providers addressed aspects of patient developmental maturity. Examples include explaining the importance of medication adherence during disease remission, providing emotional support of the patient, and developing a plan to handle the social pressures of drinking alcohol.

Nine participants cited effective care coordination between providers as important contributors toward transition success. Networking across institutions allowed providers to better coordinate care of the patient and match the patient with well-suited providers. The match between the personalities of the receiving adult provider and the patient is crucial to the success of the transition. It was important that the adult provider be able to recognize and address the unique needs of AYA patients. One participant stated that matching personalities between patients and adult providers is even more important than matching patients with adult providers who have a high level of expertise in IBD, explaining, “[The patients] are starting to make huge life decisions about pregnancy, about marriage, about family planning, so they need to feel really comfortable discussing some of these very intimate subjects.”

Discussion

The key findings of our study were that (1) providers determined transition success or failure for AYAs with IBD through outcomes of healthcare utilization, health, and quality of life, and (2) many SMART components, including the level of patient developmental maturity, the style of parental involvement, and the degree of provider support, influenced these transition outcomes. Our findings further validate SMART by highlighting the relevance of patient, parent, and provider components in transition readiness and demonstrating the interconnectedness of SMART components in the transition of AYAs with IBD. This is the first study to apply SMART to IBD and also the first study to examine adult provider perspectives of SMART components.

Our findings explain how providers commonly gauge the success of an IBD transition. While short-term transition outcomes, such as knowledge and skills, are widely discussed in the literature,^{27–29} medium- and long-term, disease-specific outcomes of transition for AYA patients with IBD have been analyzed in only 2 studies.^{11,12} Of all the health and healthcare utilization outcomes analyzed, only 2—clinic attendance and adherence—showed statistically significant differences before and after transfer. Our study found that

maintaining continuity of care with adult providers was the most commonly used indicator of transition success. Nonetheless, providers commonly use other indicators as well, such as the number of hospitalizations and use of steroids. Lastly, a few providers noted quality of life as an indicator of a successful transition. The Inflammatory Bowel Disease Questionnaire is a validated tool that measures the quality of life for patients with IBD and has not been used as an outcome measure of transition.³⁰ Future research should include developing a single tool or a suite of tools consisting of validated measures of transition success.

Our study also contributes to knowledge of barriers and facilitators of IBD transition. Past studies have surveyed pediatric and adult gastroenterologists on the transition needs of AYAs with IBD, with the highest deficiencies in knowledge of their medical history and treatments, self-advocacy, and care coordination.^{6,10} Huang and colleagues surveyed pediatric gastroenterologists on the perceived health literacy-related transition readiness of their patients and found that they greatly overestimated the actual readiness of their patients.¹⁴ Our findings expand on previous studies by highlighting specific components of transition readiness that hinder and facilitate successful outcomes, thus identifying important targets of intervention. Specifically, patients often may not be developmentally mature enough to understand the long-term consequences of their actions, to communicate their needs appropriately, or to be motivated to learn about their medical history and treatments or how to navigate the health system. Complicating this, the parents and providers may not be offering the patients opportunities to practice disease self-management prior to transfer. Our findings suggest that providers may help patients to overcome these barriers by acknowledging and addressing all of the needs of the patient beyond the merely the physiologic needs by providing emotional support, teaching skills necessary for independence in disease self-management, and pressing upon patients the reasons for disease self-management. Several studies suggest the use of strength-based motivational interviewing and problem-solving to improve health literacy, motivation, and resilience in adolescents with chronic health conditions.^{31,32} In addition, providers should work closely with parents to teach them skills in encouraging independent disease self-management in their children. Providers should also work closely with other providers to better coordinate care.

This study had several limitations. First, all of our participants worked in large, academic, urban hospitals. It is possible that the responses of providers in rural areas, small clinics, or private practices may differ. Secondly, the data are from providers who interact with the patients and families only in a very limited context (the clinic). As such, the themes presented here, while still valuable, reflect the providers' perceptions of the successful and unsuccessful transitions based on those limited interactions. Next, we did not interview patients or families. Investigation of their perspectives and comparison of their responses by disease severity will provide a more complete understanding of the barriers and facilitators of transition for patients with IBD. Finally, patients with active IBD may have more difficulties with transitioning than patients with IBD in remission.

In summary, IBD transition success is influenced by a complex interplay of patient, parent, and provider components including patient developmental maturity, parenting style, and

provider support. Multidisciplinary IBD care teams should aim to optimize these factors for each patient to increase the likelihood of a smooth transfer to adult care.

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References

1. Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions: a position paper of the Society for Adolescent Medicine. *J Adolesc Health*. 1993; 14(7):570–576. [PubMed: 8312295]
2. Baldassano R, Ferry G, Griffiths A, et al. Transition of the patient with inflammatory bowel disease from pediatric to adult care: recommendations of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition. *J Pediatr Gastroenterol Nutr*. 2002; 34(3):245–248. [PubMed: 11964946]
3. El-Matary W. Transition of children with inflammatory bowel disease: big task, little evidence. *World J Gastroenterol*. 2009; 15(30):3744. [PubMed: 19673014]
4. Escher JC. Transition from pediatric to adult health care in inflammatory bowel disease. *Dig Dis*. 2009; 27(3):382–386. [PubMed: 19786769]
5. Goodhand J, Hedin CR, Croft NM, et al. Adolescents with IBD: the importance of structured transition care. *J Crohns Colitis*. 2011; 5(6):509–519. [PubMed: 22115368]
6. Hait EJ, Barendse RM, Arnold JH, et al. Transition of adolescents with inflammatory bowel disease from pediatric to adult care: a survey of adult gastroenterologists. *J Pediatr Gastroenterol Nutr*. 2009; 48(1):61–65. [PubMed: 19172125]
7. Leung Y, Heyman MB, Mahadevan U. Transitioning the adolescent inflammatory bowel disease patient: guidelines for the adult and pediatric gastroenterologist. *Inflamm Bowel Dis*. 2011; 17(10):2169–2173. [PubMed: 21910179]
8. Philpott JR. Transitional care in inflammatory bowel disease. *Gastroenterol Hepatol*. 2011; 7(1):26.
9. Pinzon JL, Jacobson K, Reiss J. Say goodbye and say hello: the transition from pediatric to adult gastroenterology. *Can J Gastroenterol J Can Gastroenterol*. 2004; 18(12):735–742.
10. Sebastian S, Jenkins H, McCartney S, et al. The requirements and barriers to successful transition of adolescents with inflammatory bowel disease: differing perceptions from a survey of adult and paediatric gastroenterologists. *J Crohns Colitis*. 2012; 6(8):830–844. [PubMed: 22398082]
11. Bollegala N, Brill H, Marshall JK. Resource utilization during pediatric to adult transfer of care in IBD. *J Crohns Colitis*. 2013; 7(2):e55–e60. [PubMed: 22677118]
12. Goodhand J, Dawson R, Heffernon M, et al. Inflammatory bowel disease in young people: the case for transitional clinics. *Inflamm Bowel Dis*. 2010; 16(6):947–952. [PubMed: 19834978]
13. Telfair J, Alexander LR, Loosier PS, et al. Providers' perspectives and beliefs regarding transition to adult care for adolescents with sickle cell disease. *J Health Care Poor Underserved*. 2004; 15(3):443–461. [PubMed: 15453180]
14. Huang JS, Tobin A, Tompane T. Clinicians poorly assess health literacy-related readiness for transition to adult care in adolescents with inflammatory bowel disease. *Clin Gastroenterol Hepatol*. 2012; 10(6):626–632. [PubMed: 22387250]
15. Brousseau DC. Acute care utilization and rehospitalizations for sickle cell disease. *JAMA*. 2010; 303(13):1288. [PubMed: 20371788]
16. Gurvitz MZ, Inkelas M, Lee M, et al. Changes in hospitalization patterns among patients with congenital heart disease during the transition from adolescence to adulthood. *J Am Coll Cardiol*. 2007; 49(8):875–882. [PubMed: 17320746]
17. Dugueperoux I, Tamalet A, Sermet-Gaudelus I, et al. Clinical changes of patients with cystic fibrosis during transition from pediatric to adult care. *J Adolesc Health*. 2008; 43:459–465. [PubMed: 18848674]

18. Wysocki T, Hough BS, Ward KM, et al. Diabetes mellitus in the transition to adulthood: adjustment, self-care, and health status. *J Dev Behav Pediatr JDBP*. 1992; 13(3):194–201.
19. Nakhla M, Daneman D, To T, et al. Transition to adult care for youths with diabetes mellitus: findings from a universal health care system. *Pediatrics*. 2009; 124(6):e1134–e1141. [PubMed: 19933731]
20. Schwartz LA, Tuchman LK, Hobbie WL, et al. A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions: transition readiness. *Child Care Health Dev*. 2011; 37(6):883–895. [PubMed: 22007989]
21. Schwartz LA, Brumley LD, Tuchman LK, et al. Stakeholder validation of a model of readiness for transition to adult care. *JAMA Pediatr*. 2013; 167(10):939. [PubMed: 23959392]
22. Crosby, R.; Salazar, L.; DiClemente, R. *Research Methods in Health Promotion*. San Francisco, CA: Jossey-Bass; 2006. Principles of sampling; p. 289-316.
23. Patton, M. *Qualitative research and evaluation methods*. Thousand Oaks, CA: Sage; 2002. Purposeful sampling; p. 230-245.
24. Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. *Field Methods*. 2006; 18(1):59–82.
25. Glaser, B.; Strauss, A. *The Discovery of Ground Theory: Strategies for Qualitative Research*. New York, NY: Aldine De Gruyter; 1967.
26. LeMoyne T, Buchanan T. Does “hovering” matter? Helicopter parenting and its effect on well-being. *Sociol Spectr*. 2011; 31(4):399–418.
27. Sawicki GS, Lukens-Bull K, Yin X, et al. Measuring the transition readiness of youth with special healthcare needs: validation of the TRAQ--Transition Readiness Assessment Questionnaire. *J Pediatr Psychol*. 2009; 36(2):160–171. [PubMed: 20040605]
28. Benchimol EI, Walters TD, Kaufman M, et al. Assessment of knowledge in adolescents with inflammatory bowel disease using a novel transition tool. *Inflamm Bowel Dis*. 2011; 17(5):1131–1137. [PubMed: 21484961]
29. Zijlstra M, Breij L, van der Woude J, et al. P194-Assessment of self-efficacy during transition in adolescents with inflammatory bowel disease. *J Crohns Colitis*. 2009; 3(1):S87.
30. Irvine EJ, Feagan B, Rochon J, et al. Quality of life: a valid and reliable measure of therapeutic efficacy in the treatment of inflammatory bowel disease. Canadian Crohn's Relapse Prevention Trial Study Group. *Gastroenterology*. 1994; 106(2):287–296. [PubMed: 8299896]
31. Ginsburg KR, Carlson EC. Resilience in action: an evidence-informed, theoretically driven approach to building strengths in an office-based setting. *Adolesc Med State Art Rev*. 2011; 22(3): 458–481. [PubMed: 22423460]
32. Chung RJ, Burke PJ, Goodman E. Firm foundations: strength-based approaches to adolescent chronic disease. *Curr Opin Pediatr*. 2010; 22(4):389–397. [PubMed: 20489640]

Table 1
Characteristics of Participants

	Pediatrics	Adult
Role		
Physician	4	4
Psychologist	2	0
Nurse Practitioner	1	0
Administrator	1	0
Location		
Philadelphia	4	2
Other Cities	4	2
Gender		
Male	2	4
Female	6	0
# Years Caring for AYA		
0-5	1	0
5-10	1	1
11-15	2	2
16-20	1	1
21-25	2	0
26-30	1	0
% Time in Direct Patient Care		
0-25	2	1
26-50	1	0
51-75	4	2
76-100	1	1

Table 2

Quotations Representing Outcomes

Type of Outcome	Quotation
Healthcare Utilization	I said "I'm getting ready to leave so we need to make a decision. Did you ever follow up with the physician who I contacted for you?" and she said, "Oh, no, I forgot." So I said, "Let's sit here again, we are going to talk about this; we are going to go through everything you need to know. Do you feel comfortable with insurance?" And we actually spend an hour going through this again and I had my nurses go through things. Then she contacted me and left me a message when I had already left asking if I could help adjust her medications. It is one of those things that I still agonize over because that was not successful.
Healthcare Utilization	She was really hooked in and had embraced the connection with the new doctor and was really using that person as a provider.
Health	I think Crohn's is such a fluctuating disease. I think it is very hard to connect the disease severity with outcomes. It is very tough to measure because she could have had a beautiful transition and still ended up with multiple surgeries or she could have been completely noncompliant and gone through remission.
Health	I have some kids that just like some of my adults who have had underlying social situations and maybe they will get pregnant; they don't always take their meds; often don't follow up and then they just end up getting in trouble as far as their disease getting really bad. Every now and then it gets to the point that we can no longer control it and sometimes in the worse cases where there really aren't great surgical options there and you kind of wish they never got away from everyone. That sometimes happens more in the kids who haven't had their transition program; more with the transfers than maybe the transition kids.
Quality of Life	[The patient] is actually doing well and pregnant.
Quality of Life	He might not have needed to miss the amount of school that he missed. As a result, because the initial interaction with the adult GI team was so abrupt and abrasive, we don't follow him.

Table 3
Quotations Representing SMART Components of the Barriers and Facilitators

Stake-holder	SMART Component	Barriers	Quotation	Facilitators
Patient	Developmental Maturity, Skills (Abstract Reasoning)	We tried to act open with questions. I get a lot of yeses and nos, and a lot of smiles and thank you very much, but should I have asked more because was she still in that concrete reasoning phase and we just assumed because chronologically she was older, because she said the right things, because her disease was under control, because she was compliant, and because she was coming [to her visits] independently that she understood it and I wonder if some of that abstract thinking had not fully developed.		Again, just very independent and kind of advanced in her thought process and kind of individually researching something to kind of get around that, which I thought was pretty impressive. She was a very bright girl. She, throughout the course of my treatment with her, she was already taking primary responsibility for the bulk of her healthcare needs.
	Motivation/Goals + Knowledge in Facilitator quote	This was a kiddo who made frequent visits to the emergency room for symptoms of IBD[...][that were directly associated with the fact that she wasn't adherent to her treatments[...][She hated [her treatment].		Typically, the most successful patients are the ones that are very knowledgeable about their own disease and are highly motivated individuals in general who tend to be really good students or very focused on their jobs or careers or both and are also not just motivated in general as far as life goes, but also motivated in terms of wanting to break away and be on their own and do this stuff themselves.
	Psychosocial/Emotions	The patient was helping to raise many other siblings. There was a lot of life stress that, unfortunately, took a lot of priority and precedence over her health needs.		She reached the milestone of taking primary responsibility for her health. Part of the reason being that she had to grow up really fast, just because of the family structure and environment.
	Communication/Relationships	She didn't seem very comfortable reaching out to me when things weren't going well. That made me sad because I tried to be as open as I could; we had nice conversations throughout her care but she just didn't seem to think, 'Oh I should call _____ if I have a problem.'		He was more active than some young people are in terms of interactions with his pediatric provider. He would ask more questions, [...] emailing his doctor if he had a problem or question.
Parent	Skills, Relationship + Knowledge in Facilitator quote	I think the extent to which families are [not] supportive of having patients practice various aspects of their care, whether it is making calls to set up appointments, refill prescriptions, making contact with an adult care provider, learning how insurance works, how to read labels on food[...] Just basically not giving them the opportunity to demonstrate[...] skill acquisition is probably the biggest issues.		[The parents] were informed about the disease. They understood what needed to be done. They supported her, in terms of making that transition, pushed her to some extent, in terms of making sure that she was taking on the responsibility to make her appointments and things like that.
	Relationship + Knowledge, Expectations in Facilitator quote	Sometimes [with] the helicopter parents, the shit gets done... But in the long run that probably won't fly when the kid gets out on their own they are probably going to be not knowing what to do because the parent has done it. And it can also backfire in the short run where the kid is like, "Screw you mom. I'm not doing it because you tell me to do it." That kind of thing: "I'm tired of my parents[...]. Micromanaging every little facet of my life."		It helps to have parents that are invested and care about their kids and [...] care about their health. I guess ideally they have parents that are educated and [...] understand the importance of patients following up and doing the test that we recommend because it helps us monitor their disease more aggressively and ideally parents that want their kid to grow up and be able to do this stuff on their own with the realization that they won't always be living at home and have someone to remind them to take their stuff.
	Beliefs/Expectations	When [the parents'] expectations are that they can call every other day and that they are now controlling the child's health, to the point where it is overbearing, then I think that you are dealing with the potential of vulnerable child syndrome, where... you end up with a whole host of other problems that are unrelated to the disease activity.		I think [the parents] understood the need for her to take on more responsibility, especially in anticipation of moving out of the house and moving away to college. Parents were on board with the process, which isn't always the case.
Provider	Communication/Relationship	I could really see that [adult] provider feeling that way, like, all right, I am going to be taken here for a ride by this family, but I think that's where the		We also met with [adult] providers next door to identify who would be physicians who would accept, because one of the

Paige said that she had

Table 4
Number of Participants Who Mentioned Each SMART Component

SMART Component	Subtheme	Number of Participants (out of 12)
Developmental Maturity	Patient's Developmental Maturity	12
	Patient's Abstract Reasoning Ability	6
Skills	Parents Encouraging the Patient's Independence	7
	Provider's Preparation & Support	10
Psychosocial	Patient's Emotional Acceptance of Medical Condition	7
Motivation	Patient's Motivation for Therapeutic Compliance	12
Relationships/Communication	Patient's Communication Style	9
	Parent's Level of Support & Involvement	11
	Provider's Care Coordination & Support	12
Knowledge	Parent's Knowledge to Foster Disease Management	6
Beliefs	Parent's Beliefs about the Patient's Care/Trust in Provider	8