

The Gray Zone: Adolescent and Young Adult Decision Support Needs for Ulcerative Colitis

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Abstract

Purpose. To understand the medical decision support needs specific to adolescents and young adults (AYAs) with ulcerative colitis (UC) and inform development of a decision support tool addressing AYAs' preferences. **Methods.** We conducted focus groups with AYAs with UC and mentors from a pediatric inflammatory bowel disease clinic's peer mentoring program. Focus groups were led by a single trained facilitator using a semistructured guide aimed at eliciting AYAs' roles in medical decision making and perceived decision support needs. All focus groups were audio recorded, transcribed, and coded by the research team. Data were analyzed using content analysis and the immersion crystallization method. **Results.** The facilitator led six focus groups: one group with peer mentors aged 18 to 24 years, three groups with patients aged 14 to 17 years, and two groups with patients aged 18 to 24 years. Decision timing and those involved in decision making were identified as interacting components of treatment decision making. Treatment decisions by AYAs were further based on timing, location (inpatient v. outpatient), and family preference for making decisions during or outside of clinic. AYAs involved parents and health care providers in medical decisions, with older participants describing themselves as "final decision makers." Knowledge and experience were facilitators identified to participating in medical decision making. **Conclusions.** AYAs with UC experience changes to their roles in medical decisions over time. The support needs identified will inform the development of strategies, such as decision support tools, to help AYAs with chronic conditions develop and use skills needed for participating in medical decision making.

Keywords

adolescents, inflammatory bowel disease, medical decision making, shared decision making

Date received: March 3, 2020; accepted: June 8, 2020

Pediatric inflammatory bowel disease (IBD), including Crohn's disease and ulcerative colitis (UC), affects more than 3 million people in the United States, and of those >200,000 are adolescent and young adults (AYA).^{1,2} Given that the median age of pediatric IBD onset is 12 years, and 26% to 40% of pediatric IBD patients are diagnosed with UC,^{1–3} AYA patients with UC are often forced to grapple with a new diagnosis at the same time as they seek increasing autonomy and self-efficacy in all aspects of their life, including managing their IBD.⁴ In collaboration with their health care team, AYA patients and their families often face many medical decisions related to their

chronic condition. These clinical decisions coincide with developmental changes that occur during adolescence, creating additional challenges for decision-making.

As adolescents age, there is an increase in global decision-making autonomy in several domains such as personal appearance, schoolwork, and social life.⁵ AYAs

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with chronic conditions, such as UC, experience a unique intersection of health care needs and a developmentally-appropriate need for increased independence.⁶ In turn, developmental changes in adolescence also lead to an evolution of the patients' roles in medical decision making. This leads to AYAs, some of whom have only recently been diagnosed, needing to learn to manage their own medical care, including decision-making skills, in preparation for transition to adult health care providers.⁶ Prior research, by our team, looking at a specific treatment decision, indicated that adolescents with chronic medical conditions report needing more information about their disease and treatment.⁷ These self-identified deficits in knowledge as well as a potential lack of skills needed for integrating the information into health care decisions may negatively affect AYAs' ability to engage in shared decision making with their health care team.

Previous research indicates many AYA patients participate in decision making during medical appointments, yet the role AYA patients have in decisions is not always the role they want.^{7,8} In contrast, parents typically see themselves as the leader in medical decisions.⁸ Adolescent patients have differing decision influences from their parents, as shown in our work examining the most influential decision factor for initiating tumor necrosis factor- α inhibitors in which adolescents were more often focused on immediate quality of life factors and parents on long-term impact of the decision.⁹ AYA patients with Crohn's disease and juvenile idiopathic arthritis also value the involvement of others, such as parents in their treatment decisions.⁷ Patient decision support tools designed for AYA patients may be used to facilitate shared decision making by providing information about treatment options and facilitating discussions about treatment goals and plans. Such tools have been shown to benefit adult patients and parents making decisions

for their children through improved patient knowledge and better information about both benefits and harms of treatment options.¹⁰⁻¹² They have been shown to increase decision quality and lower decisional conflict in chronic conditions.¹⁰

Given the potentially complex interactions between the adolescents' developmental stage and their chronic condition, decision support tools designed specifically for this population are needed. The purpose of this study was to conduct a decision support needs assessment using semi-structured focus groups with AYA patients to understand where and when their decision making happens, their preferences for receiving and sharing treatment-related information, how they work with others to make treatment decisions, and what tools they feel are needed to support AYA decision making.

Methods

Participants

Patients with UC, aged 14 to 25, who had an appointment at the Cincinnati Children's Hospital Gastroenterology (GI) clinic within the past 12 months, were recruited to participate in a 1-hour focus group. Additionally, we recruited peer mentors aged 18 to 25 from the clinic's IBD peer mentoring program. This study focuses on patients with UC due to the broader array of both medical and surgical treatment options available to them. However, we included peer mentors with either UC or Crohn's disease due to a more limited pool of potential participants and because their mentoring experiences may have included individuals with either diagnosis. Patients were sent a letter or email informing them about the study, and then recruited via phone and email. A waiver of documentation of informed consent and parental permission were obtained for participation in the focus group. Participants were provided a study information sheet prior to the start of the focus group and the choice to remain in the focus group indicated consent. The study was approved by the Cincinnati Children's Hospital Medical Center Institutional Review Board.

Focus Groups

The research team, which included a pediatric gastroenterologist, developed a semistructured focus group guide based on our prior work^{7-9,13,14} and literature review. The focus group guide was reviewed by a patient consultant using cognitive interviewing techniques and revised based on feedback. The semistructured interview guide included four sections: an introduction that included,

Division of Adolescent and Transition Medicine (AM), James M. Anderson Center for Health Systems Excellence (NMD, EAL), Research in Patient Services (NMD), and Division of Pediatric Gastroenterology, Hepatology and Nutrition, Schubert-Martin Inflammatory Bowel Disease Center (PM, MS), Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio; Department of Pediatrics, University of Cincinnati College of Medicine, Cincinnati, Ohio (NMD, PM, EAL). The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article. The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by an "Independent Grant for Learning and Change" from Pfizer, Inc. The sponsor had no role in the study design; collection, analysis and interpretation of data; writing of the report; or decision to submit the manuscript for publication.

Table 1 Participants

Characteristic	Peer Mentors (n = 5)	Patients Aged 14–17 (n = 11)	Patients Aged 18–25 (n = 6)	Total (n = 22)
Gender, n (%)				
Male	2 (40%)	4 (36.36%)	4 (66.66%)	10 (45.45%)
Female	3 (60%)	7 (64.63%)	2 (33.33%)	12 (54.54%)
Age (years), median	22	16	19.5	17.5
Duration of disease (years), median	8	3	7	4.5
Race, n (%)				
African American	0 (0%)	3 (27.27%)	1 (16.67%)	4 (18.18%)
Asian	0 (0%)	0 (0%)	1 (16.67%)	1 (4.55%)
Caucasian	5 (100%)	7 (63.64%)	4 (66.67%)	16 (72.73%)
More than one race	0 (0%)	1 (9.09%)	0 (0%)	1 (4.55%)
Ethnicity, n(%)				
Non-Hispanic	5 (100%)	11 (100%)	6 (100%)	22 (100%)

ground rules for the discussion, a warmup activity to allow group members to connect, discussion about decision making experience and decision tools, and summary of the group discussion. The core of the guide was the decision-making discussion focused on AYAs' involvement in decision making, how they would like others to support their decision making, and where decision making occurred outside of clinical encounters. All focus groups were led by a single, experienced facilitator at the hospital in a private conference room. Based on the guide, the facilitator prompted the group with general open-ended questions about individuals' health care experience and interactions with others regarding their diagnosis. Each group concluded with brainstorming ideas for a decision support tool for AYA patients. Focus groups were age-based (14–17 years old and 18–25 years old) with peer mentors (18–25 years old) participating in a separate group. Focus groups were continued until we reached thematic saturation, in which no new major themes were introduced in two consecutive groups. All focus groups were audio recorded, professionally transcribed, and verified by a research team member who attended the focus group. Nonverbal interactions were also added to the final transcript. Participants also completed a demographic questionnaire.

Data Analyses

One focus group transcript was read by the entire research team and open-coded to identify themes and develop a coding structure. Next, two members of the research team independently coded the transcripts from each focus group utilizing the coding structure from the larger research team and adding additional themes when

appropriate (NVivo 11, QSR International, Victoria, Australia). Coding was compared and discrepancies resolved through discussion. Content analysis was used to analyze data from the focus group while also incorporating the immersion-crystallization method in which transcripts are read multiple times with reflection time between readings to assist identifying themes and patterns in the data.^{15–17}

Results

In total, there were six focus groups: one group with peer mentors who had UC or Crohn's disease, three groups with patients with UC aged 14 to 17 years, and two groups with patients with UC aged 18 to 25 years. The median age was 17.5 years old and patients had been diagnosed with IBD for a median of 4.5 years (Table 1). Results from all focus groups are combined with differences by age indicated where appropriate. Findings from the peer mentor group were not different from those of similarly aged peers, with the exception of peer mentors being more likely to discuss connections to other people with IBD. Results of our thematic findings, organized by theme, follow with illustrative quotations in the accompanying tables.

Determinants of Decision Making

The process of treatment decision making is determined based on two interacting components: decision timing and who is involved in decision making (Box 1). Decision timing relates to both health care setting (inpatient v. outpatient) and patient or family preference for making a decision during the health care visit versus discussing it

Box 1 Determinants of Decision Making

Decision timing

“We . . . kind of get our thoughts like together before we go in. Then when we talk to the doctor, we kind of have decided together, we’re kind of ready to tell them.” (Male, 17 years)

“If there’s something we are quite sure on and then we’ll talk, my parents and I will talk about it afterwards, after the visit, like on the way home.” (Male, 21 years)

Evolving role

“As you live with it longer, you know, you start to . . . get more confident in handling your disease and I feel like you get much more, you know, involved in your own decision making.” (Male, 22 years)

“I just recently became an adult. So I’m starting to make my own decisions and that’s somewhat scary.” (Female, 18 years)

“My mom knows I’m getting ready to go off to college next year. She wants me to be more in control of what goes on with me medically because she’s not going to be there next year to help me with that.” (Female, 17 years)

People involved in decision making

“When we make a decision, it’s usually my doctor, me and my parents.” (Male, 14 years)

“I’ll go to the doctor and I’ll come home and tell my parents what I’m switching to or keeping on it’s just like I’ll change it or keep it.” (Female, 20 years)

“So I think at this point—for me, I wouldn’t go to anybody . . . my parents would be involved but I don’t think—I’m at a point in my . . . level of expertise . . . that the only two people involved in my care would be my doctor and me.” (Male, 22 years)

Box 2 Barriers and Facilitators to Participation

Knowledge

“Lack of knowledge. . . . I had no idea what I was getting into, . . . I had no idea what the medicines were either. . . . So basically, lack of medical knowledge of both the medicines and the diseases.” (Male, 14 years)

“Being involved in [the decision] and knowing . . . your options and knowing what you can do on your own to help other than medicine, like diet, drinking a lot of water, going regularly . . .” (Female, 16 years)

Experience

“. . . experience with it, having had UC for so long and like I know my body and I know what I’m feeling and I think sometimes you just know what’s best for you because you know everything you’re thinking, everything you’re feeling mentally and like physically.” (Female, 14 years)

“I wish I was as independent as all of you but my mom. . . . Because I want to make my own decisions just so I could feel more like an adult and that if I make the wrong decision, I’ll learn from that and if I make the right decision, I’ll keep going on that path.” (Male, 17 years)

“I’ve had to figure it out on my own what works for me.” (Female, 17 years)

“If anyone is going to know my body, it’s going to be me.” (Female, 17 years)

further outside the visit. Younger participants and those more recently diagnosed felt they had a limited role in the decision making, and expressed either wanting a greater role or anticipating an increased role in coming years. While older participants considered themselves to be the “final decision maker,” most felt this had taken many years to achieve and many still involved their parents in the decision process. Participants did not involve anyone other than their parents or health care providers in decision making. However, a few did report seeking advice from friends with UC or other chronic conditions but did not consider the friend a participant in decision making.

Barriers and Facilitators

AYAs clearly identified both barriers and facilitators to participation in medical decisions (Box 2). AYAs reported that lack of knowledge about their disease, personal health history and the treatment options, as well as a lack of medical experience due to recent diagnosis, limited their ability to participate in medical decision making. Negative emotions such as hopelessness and frustration, related to UC and the treatment options, were additional barriers. In addition to experience and knowledge, having personal connections to others, including friends with UC, was a facilitator of decision participation. Participants identified parents and physicians as individuals who could

Box 3 Decision Support Tool

Gray zone

“... we’re in that gray zone, where there’s like nothing because there’s stuff for like the little kids and the middle school kids and the people out of college. There’s nothing for the people in high school and transitioning to college . . .” (Female, 19 years)

Decision support needs

“... we want to know our options and we don’t want to go into things blind . . . we feel more ready to make a decision, more confident . . .” (Male, 21 years)

“I would love some type of pro versus con thing, with different people’s experiences.” (Female, 18 years)

“It would be nice to like have someone who would be able to listen to you and like know what you’re going through every now and then . . .” (Female, 17 years)

“Help me process, . . . help me to help [my friends] understand what’s going on and like ask me questions of like, ‘Do you really think this is the right idea,’ ‘How will this help you? What are the side effects? Are you willing to go through those side effects?’” (Female, 19 years)

Tool format and content

“I think for people like in our age group like an app kind of what the things we’ve been talking about on it would be pretty helpful.” (Male, 17 years)

“I think the app [would be] helpful, . . . doctor insight on like the medication that you take.” (Female, 15 years)

“... an app with just the medications that would be possible to take, the side effects, things like that. Other things like exercise, eating, factors like would’ve been on there. Maybe like a medicine tracker . . .” (Female, 20 years)

“... An app, just a few different components that would let you holistically track like all the different factors related to day to day like wellbeing. Something like that, I would definitely like download and use in the future.” (Male, 18 years)

facilitate or prevent the AYA from participating in decision making through their attitude toward the patient, skill at engaging the patient and recognition of the role the AYA could play.

Decision Support Tool

Following the discussion about barriers and facilitators to engaging in medical decision making, we asked participants to brainstorm about tools that could be used outside of a clinic visit to facilitate participation in medical decision making (Box 3). Participants noted that such tools, aimed at AYAs were needed because while they knew of resources for young children and adults, they felt they were in a “gray zone” between childhood and adulthood, with minimal interventions designed specifically for them. They described wanting a digital, “one stop shop” that would be an information source, a health tracking device, a connection to their health care team and others with UC. In their vision, the information aspect would contain both scientific and anecdotal information about the pros and cons of various treatment options, so they could be well prepared for treatment discussions with their doctor, as well as basic information about UC to help them discuss their condition with others. The second feature participants desired was health tracking in which they could track symptoms, moods, and reactions to specific foods. They felt this feature would aid in decision participation by helping them

discuss their symptoms with their health care team. The final feature requested was connection to others—both health care providers and other AYAs with UC. They wanted a means of messaging their health care team in real time, as well as their physician being able to view their health tracking and contact them if there were concerning changes. They desired a social media platform in which they could connect to other patients for opinions about treatment options. One participant suggested a feature that would allow users to “vote on the best medication.” In general, participants felt that such a tool would facilitate decision making by improving their knowledge and making it easier to discuss their symptoms, while offering general support for living with UC.

Discussion

This study explored the unique needs and preferences of AYA patients with UC as they navigate medical decisions. Decisions for AYA patients with UC are dependent on both timing and the people involved in the decision making. Decision timing includes whether it occurs during an inpatient or outpatient encounter, as well as personal preferences related to making decisions in clinic versus deciding at home and reporting back to the health care provider. The support and involvement of others in the decision were dependent on the patient’s age, length of time since diagnosis, and experience navigating UC-related medical decisions. Younger patients,

with less experience in managing their UC relied more heavily on parents when making decisions, whereas older adolescents felt they were the primary decision maker. This aligns with previous research indicating that younger adolescents have not developed the same decision-making skills as older adolescents.¹⁸ Parents were identified as both a potential barrier and potential facilitator to decision making, consistent with prior research on decision making.¹⁹ Although adolescence is typically a time in which peers may influence decisions,²⁰ this was not reflected in our study as participants reported not including friends, unless they had UC or another chronic condition, in their decision-making process.

We found that roles in medical decision making evolve with the transition of the AYA patient from pediatric to an adult care setting—aligning with previous research.^{19,21} Decision-making competence varies depending on the developmental stage of the adolescent, in part due to changes in neurologic processing related to rewards and risks, self-regulation and peer role in decisions that occur during adolescent years.²⁰ In order to feel successful during this transitional period, reliable resources and tools are imperative for decisional skill development.^{20,22}

AYAs in our study identified barriers to engaging in decision making including lacking knowledge about UC or their personal health history. This is consistent with prior research showing knowledge deficits related to both IBD disease management and IBD complications, among AYAs with IBD,²² and with adults with UC who reported wanting information about their disease and being concerned about long-term disease complications.²³ Other knowledge deficits in AYA patients with IBD include knowledge of how to navigate disease-related health care resources, such as medical insurance, and lack of awareness about personal health history, such as surgeries and disease localization.^{21,22,24} In addition to knowledge deficits, we found limited experience with UC to be a barrier to decision making.

Data from this study will be utilized to develop a decision support tool for AYA patients with UC focused on the aspects of treatment decision making that occur outside of the clinic visit. The decision aid will address decision support needs identified in this study. During the brainstorming portion of the focus groups, the overwhelming consensus was that a decision support tool in the form of a mobile application was the desired delivery mode. The need for such a tool is further confirmed by a recent systematic review of computerized decision aids for serious or chronic illnesses, which identified six such

aids, none of which targeted AYA patients or IBD decisions.²⁵

Themes generated in this study confirm the importance of providing developmentally appropriate guidance to AYAs to successfully promote the development of shared decision making skills. AYA participants identified wanting a decision support tool developed specifically for their age group. Furthermore, they identified that such a tool should be structured to allow them to use it at their own pace, both during and outside of clinic visits. Future work will allow us to use these data to design a decision support tool specifically for AYA users with UC, catering to their unique decisional support needs. Use of such a tool may help AYA patients to move toward autonomy in medical decision making related to UC.


This qualitative study was designed to assess the breadth and depth of AYAs' decision-making experiences and preferences rather than be generalizable. We used a focus group methodology to allow participants to build off one another in their discussion and therefore generate a more robust discussion of future directions. However, this approach does have some limitations. We sought to minimize social desirability bias²⁶ by carefully building rapport and emphasizing confidentiality; however, some bias may still be present. Additionally, some participants may not have felt comfortable sharing all their insights in a group setting. To address this, we invited participants to write private comments for later review by the research team, but none did. We attempted to accommodate patients by offering parking, and focus groups at varying times and days throughout the week. Nevertheless, holding the focus groups at the main hospital campus which may have limited participation from patients living farther away.

Despite not seeking generalizability, given the largely nonspecific findings including the role of setting and people in decision making, as well as barriers related to knowledge, experience, and emotions, our findings may well be relevant for AYA patients with other chronic conditions. Participants suggested disease-specific support content; however, the design elements recommended such as symptom tracking and medication information may have utility for other conditions. Although there are only limited studies looking at decision support tools for AYA patients,^{27–29} integration of a decision support tool, whose design is informed and tested by AYA patients, into the health care system will address AYA-specific barriers to participation in medical decision. In turn, this may lead to improved physical, behavioral, and emotional outcomes, and readiness for successful transition

to the adult care setting.²¹ Shared decision making facilitated by a decision support tool may also enhance clinical outcomes; however, data are limited.¹²

In summary, our results indicate that AYA patients with UC may benefit from a decision support tool that focuses on their specific needs, which may be distinct from those of younger pediatric patients or adults. The development of such a tool will require ongoing engagement from AYA patients with UC to ensure it meets their decision support needs and is both acceptable and feasible for use in their daily lives. Given the general nature of most needs identified in this study, once developed, such a tool could be adapted for other chronic conditions. Integrating decision support tools into routine care for adolescents and young adults with chronic conditions will promote their engagement in shared decision making, increase their disease-specific knowledge, and help facilitate their growth and transition to the adult care setting.

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