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Focus Groups for Developing a Peer Mentoring Program to Improve Self-Management in Pediatric Inflammatory Bowel Disease

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Abstract

Objectives—Inflammatory bowel disease (IBD) presents challenges for self-management in many areas. A peer mentoring program may offer advantages over other forms of self-management interventions since youth may be more receptive to learning self-management skills from a peer than a parent or professional. The purpose of this study was to identify themes from focus groups to inform development of a peer mentoring program for improving self-management in pediatric IBD.

Methods—Focus groups were conducted for youth ages 12 – 17, stratified by age (3 groups; n=14), young adults ages 18 – 20 (1 group; n=5), and parents of the youth (3 groups; n=17). Broad questions covered program goals, general program characteristics, mentor/mentee characteristics and family involvement, and transcriptions were analyzed via directed content analysis, with the a priori codes specified as the broad questions above.

Results—Participants identified the primary goals of a program as support, role model, information/education and fun. They described a program that would include a year-long, one-on-one mentor relationship with a peer who has had IBD for at least a year, educational group activities, fun activities that are not focused on IBD, expectations for in-person contact 1 – 2 times per month, and mentor-to-mentor and parent support.

Conclusions—Many of the suggestions from the focus groups correspond with research findings associated with successful mentoring programs. Using participants' suggestions and empirically-based best practices for mentoring may result in an effective peer mentoring program for improving self-management in youth with IBD.

Keywords

Self-management; mentoring; inflammatory bowel disease

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Introduction

The term “self-management” is primarily used to refer to medical management, but inflammatory bowel disease (IBD) affects many domains of functioning, all of which can affect medical management. A broader conceptualization of self-management has been proposed and includes both managing one’s life to accommodate the chronic condition and managing the emotions associated with having the condition.(1) This broader view of self-management fits well with the current perspective on defining the concept of “health,” which includes self-management in physical, mental and social domains.(2)

IBD presents challenges for self-management in many areas. Unpredictable symptoms of abdominal pain, frequent diarrhea and fatigue can make it difficult to live well with this chronic disease. The symptoms can be embarrassing and can result in spending a great deal of time in the bathroom. Children with IBD can be reluctant to talk about their symptoms, and they may fear becoming the target of the “bathroom humor” popular among youth.(3) They may limit social and typical life activities, including school attendance, to those in which a bathroom is easily accessible.

In fact, up to 35% of youth with IBD experience clinically significant difficulty in non-medical areas of self-management, particularly in managing social functioning and the overall impact of the disease on typical life activities.(4, 5) Social difficulty may be even more common than other problems in pediatric IBD.(4) Youth with IBD also have been found to have school difficulty such as significant absences, even those with mild or remitted disease.(6) In this study, psychosocial factors were significant predictors of absences, but disease factors were not.(6) Self-management interventions typically focus on medical management,(7) but this study highlights the importance of psychosocial contributions and suggest that interventions focusing on medical management may be of limited utility in promoting management of typical life activities such as school attendance.

Interventions for medical management in pediatric IBD have shown promise. Interventions using formats such as individually-tailored treatment,(8) group-based treatment,(9) and telehealth(10) have shown potential for improving medication adherence, but little has been done to address broader areas of self-management. A mentoring intervention may be particularly well-suited for addressing multiple domains of functioning. Mentoring programs are common in the general population and are known to improve a plethora of outcomes for youth, including social, emotional and academic outcomes.(11) Peer mentoring programs in particular may offer advantages over other forms of intervention: A peer mentor is a role model who normalizes and de-stigmatizes the disease in a way that a professional cannot. Peer mentors are at least two years older than those they mentor,(12) but youth may be more receptive to learning new self-management skills when provided by a peer mentor rather than a parent or professional. Thus, engaging in self-management and typical life activities with a peer role model may result in improved self-management in these neglected areas of self-management.

This study was the first step in developing a mentoring program to improve multiple areas of self-management in pediatric IBD, defining self-management broadly as behaviors used to

manage IBD medically, to manage its effect on life, and to manage associated emotions. The purpose of this study was to identify themes from focus groups with youth with IBD, their parents, and young adults with IBD to inform development of this program.

Materials and Methods

Participants

Participants were recruited from (1) an ongoing, longitudinal study investigating social functioning in pediatric IBD (n=12) and (2) from the IBD Clinic (n=7) at a large pediatric medical center. For the longitudinal study, inclusion criteria included diagnosis of IBD, age 11 to 17 years, and exclusion criteria included participation in full-time special education. Participants in the longitudinal study were recruited at diagnosis via letter and phone call and followed for two years. Social functioning in multiple areas (e.g., peer acceptance, friendship quality, social activities) and related factors (e.g., depression symptoms, stress, coping) were assessed at four time points (baseline, 6-, 12-, 24-months). For the focus groups, participants were recruited via letter followed by a phone call, and eligibility criteria were the same except for age, which was 11 to 22 years. Participants recruited from the IBD Clinic were identified via clinic schedule review with the same eligibility criteria. They were recruited via letter followed by a phone call or a visit during an IBD Clinic appointment. All of these subjects participated in one focus group and were otherwise not followed for the current study. In general, one parent per adolescent participated in the study, but in each focus group, one additional parent participated. Both parent and adolescent needed to agree to participate in order for either one to participate.

As recommended, recruitment was stratified in order to represent the ages of potential mentors and mentees in a future program, and to create groups of 5 – 8 participants, with an age range within two years in youth groups.(8) This created a focus group of children in middle school (n=5, all recruited from longitudinal study), two focus groups of youth in high school (n=4 and 5, respectively, 6 recruited from IBD Clinic), three groups of the parents of these adolescents (n=6, 5, 6), and a focus group of young adults (n=5, 4 from longitudinal study). The project was approved by the Institutional Review Board. Written informed consent was obtained from all parents and young adults, and written assent was obtained from all adolescents.

Demographic and disease characteristics are presented in Table 1. Current disease severity was assessed by most participants' gastroenterologists at a clinic visit within a month of the focus group. Three participants did not have clinic visits within a month of their focus groups, but all were in remission during the clinic visits before and after the group, with no mention of a flare occurring in the post-group clinic note. Two participants had transitioned to adult care, so their clinical data was unavailable. Despite the high rates of remission at the time of the focus groups, 57% of adolescents and 66% of young adults experienced clinical activity such as a recurrent fissure, recurrent rectal bleeding or flares in the previous year.

Procedures

A standardized interview guide was developed and tested on a pilot focus group. The purpose of the focus group was described (developing a mentoring program for youth with IBD), and questions covered program goals, general program characteristics and mentor/mentee characteristics. Please see the Supplemental Online Table for specific questions asked in each group. Parent and child groups were conducted separately and were two hours long. For the first half hour, participants ate dinner and became acquainted with one another. The young adult and parent groups were each conducted by two of the authors (L.M. and J.R.), and the adolescent groups were conducted by an author (K.V.) and a research assistant. The lead moderators were clinical psychologists who are experienced in interview techniques, and they undertook additional training to adapt their interview styles for focus groups. The moderators used the interview guides and were careful to allow the focus group participants fully answer questions and develop ideas. All groups were digitally video- and audio-recorded.

Data analysis

Digital recordings were transcribed verbatim, and transcriptions were then verified against the recordings. As recommended, the analysis was conducted by the moderators who had been present in the room when the focus group was conducted.(13) Transcriptions were analyzed via directed content analysis.(14) Content analysis is a commonly-used method to analyze text data through a systematic classification process of coding and identifying themes. With directed content analysis, existing theory or prior research is used to identify a priori key concepts or variables as initial coding categories. Text is then categorized into these categories, and any text that cannot be categorized is given a new code. Subcategories may also be developed. Newly identified categories can further refine the phenomenon under study.(12)

In the current study, program goals, general program characteristics, mentor/mentee characteristics, and family involvement were used as a priori coding categories. Each author independently read transcripts and sorted thought units into clusters of similar content within these categories, developing new categories as needed. Parent transcripts were coded separately from those of the adolescents and young adults. As a group, the authors then analyzed the identified content areas and sorted them into subthemes by consensus.

Results

The subthemes identified for each of the a priori primary categories and representative quotes are described below.

Program goals

The primary goals of a program described by the participants were support, role model, information/education, and fun.

Support—Adolescents and their parents described a mentoring program that provided accessible support. In the middle school group, this goal was described as having “a person

that you could always contact no matter what. If anything were to come up, if you just needed someone to talk to.” Participants in the high school groups similarly stated that they would want “somebody to talk to about like what you’re going through. Like, I don’t know, troubles,” and that “I almost feel like, or at least for me, if I need to talk to them immediately or discuss something with them, I could just call them up.” Similarly, a parent expressed that “I guess it would be just, like, guidance and support from someone who’s already been there and done that.”

Role model—Participants also described a mentoring program that provided role models, with a participant in one of the high school groups noting that a mentor would be “someone to look up to, to talk to.” A young adult identified a mentor as “somebody who you can look up to and you don’t have a problem like going to them with anything. It’s kinda like a role model in that way.” A parent expressed that “I think that they could give the child hope to say ‘I got through middle school with this, I am playing sports,’ cause your child might think ‘will I be able to play sports again?’”

Information/education—Information and education also played a role. A participant in one of the high school groups saw a mentor as “someone your own age mentoring you and like teaching you stuff about things you don’t know.” As a young adult pointed out, “there’s always more to know.” A parent stated that “I think it would be helpful if a mentor could maybe be there to give some advice about lifestyle changes that could help manage the Crohn’s.” Specific areas of education that were recommended included coping with IBD symptoms, managing school and social situations, treatment options and nutrition.

Fun—Participants also felt that a program should be fun and not solely focused on IBD. A participant in the middle school group suggested “do stuff you like to do. Go bowling or something.” A young adult suggested that a program should be “... not always, like about like Crohn’s or IBD. You know, like you can just call them and be like, ‘Hey, let’s go to the movies.’” Similarly, a parent said, “I like your idea of bringing them together even maybe in a social activity like bowling or something so they don’t always feel like we are talking about the disease.”

Program characteristics

Program Format—In general, the adolescents and young adults described a program format of a one-on-one, mentee-mentor relationship with group activities, some of which would be educational and others simply fun. Some of the younger adolescents preferred a one-on-one relationship without group activities, such as one who said “it would probably be better alone in case you have any concerns and you don’t want a lot of people to know.” A participant in one of the high school groups thought that “it would be constructive to have the majority be one-on-one meetings with your mentor and then every once in a while have group ones.”

Parents’ ideas for program format were more varied. They suggested multiple formats, including a one-on-one, mentee-mentor relationship, groups that included youth and parents, small groups with one to two mentors, and an online program. A parent of a middle school

participant said “I guess I’m thinking about this all in terms of a mentoring group, as a group being mentored. As opposed to an individual having their own mentor.” A parent of a high school student thought that a mixed group of youth and parents would be most useful, saying “I’m not sure, in keeping the two groups [of youth and parents] separate, there would be a benefit.” Other parents suggested an online component:

Parent 1: “Maybe an online thing ... you know, like a facebook thing.”

Parent 2: “Or a combination of both. Online and get together every so often.”

Amount of contact—There was some variation in the amount of contact participants thought mentors and mentees should have. An adolescent from the middle school group suggested mentors and mentees should have contact “at least once a week, maybe twice a week.” Parents recommended less frequent contact:

Parent 1: “I do think once a month would be too much”

Parent 2: “I was thinking maybe once every three months.”

However, there was general consensus among participants about mentee-mentor contact in person 1 – 2 times per month with other contact throughout the month (e.g., texting, Facebook, phone).

Program length of one year was most commonly mentioned, although some participants thought it should be longer, including one high school participant who said “I mean it is a chronic disease, it’s not like we’re ever going to get over it, I mean it’s not like there’s a cure for it, it’s not going to go away.” A high school student in the other group suggested that the program last “maybe a year, and then if they want they can continue it themselves, continue to meet with that person.”

First introduction—Most adolescents and young adults felt it would be easiest to meet a mentor for the first time during a group activity “so it’s not as awkward,” according to a participant in one of the high school groups. Another high school student noted that “I think the group setting is probably more comfortable for some people, but it’s a preference. I mean, I wouldn’t mind one-on-one.”

Mentoring for everyone—The young adults wanted mentor-to-mentor support for assistance in working with their mentees in addition to programmatic support:

Young Adult 1: “I think it’s also important that the mentors form relationships with other mentors.”

Young Adult 2: “Yeah, ‘cause I think it’s bonding for us, too.”

They also wanted support for living with IBD as a young adult. As one participant pointed out, “I really think you always need a mentor. You never really get comfortable with everything.”

Parents recommended including a parent support component in a program. A parent of a high school participant even suggested that “I think it’s more important for parents to have mentors.” Another participant highlighted the need for support by discussing how difficult parenting a child with IBD can be:

“Some days you just want to cry and regroup and you know there’s no one to really talk to because you don’t really want to burden someone with all your crap. And I don’t even know if they would understand it.”

Mentor characteristics

Age—Participants suggested that mentors should be 2 – 3 years older than mentees. A middle school student said “... age needs to be closer or slightly older, not a huge age gap though because then it’s harder to relate to them.” A parent, saying, “I would think like two years older. A lot more feels like a different generation to a teenager.”

Experience with IBD—Participants recommended that mentors should have had IBD for at least one year. A young adult thought that “the hardest stage is like the first year.” A parent of a high school participant noted that “after that first year, they’re kind of more adapted to different things and adjusted to things better.” A participant in one of the high school groups suggested a mentor should be an “IBD veteran.”

Personality characteristics—Participants also recommended that mentors should be outgoing, invested, responsible, empathic and optimistic. “It has to be somebody experienced and willing, really willing to help someone,” according to a high school participant. A parent thought that “... empathy is probably the most important thing, being able to not put down the other person, what they’re going through.” Another parent suggested that “I think anybody’s mentor probably has to be somebody that is optimistic about the future.”

Mentee characteristics

Participants agreed that mentees would benefit most from a mentor during the first year after diagnosis, but they also wanted the option of joining a program other times, e.g., during a “critical incident” such as hospitalization or surgery. A participant in the middle school group suggested that “they can ask right when you are diagnosed.” A young adult agreed, noting that “their first year, so it’s really tough, at least with me.” A parent thought that “the best time to start something like this is or to get kids involved is when they have a critical incident. Like they get sick enough that they need to be hospitalized.”

Participants also recognized the importance of mentees participating voluntarily and being invested in a program, “someone that wants to be there, feels like it’s their choice. Willing to receive help and advice,” according to a high school student. Participants in the middle school group agreed:

Middle School Student 1: “They have to want to ‘cause if they don’t then it would be very awkward”

Middle School Student 2: “Like your parent can’t just sign you up for this.”

However, the parents of some high school participants suggested making attendance mandatory:

Parent 1: “Maybe like a forced appointment. I mean, some things you need, like a clinic. Just like you meet every eight weeks with your doctor.”

Parent 2: “Instead of a judge ordering you to go, the parents are ordering you to go.”

Parent 3: “For my child ... it’s gonna have to be their motivation. Us ordering them to go, well, they’re gonna go with an attitude. They’re going to go in with a bad attitude and they’re gonna shut down.”

Family involvement

Parents and adolescents had different ideas about the amount of family involvement in a program. The youth wanted very little family involvement, valuing privacy so that they could tell a mentor anything:

Middle School Student 1: “I say you wouldn’t want them that involved because they don’t know a ton of the things you are talking about and it’s like your special friend so you can have a little privacy.”

Middle School Student 2: “Yeah ‘cause you could talk about your parents, you wouldn’t want them to get angry like ‘You’re grounded ‘cause you said that about me!’”

Participants in one of the high school groups thought that family involvement could be limited to informing parents about the existence of the mentor:

“I think they need to know you have a mentor, but well, I think it should just be between two people. I guess you could choose how much to tell them. Or just let them know you have a mentor.”

Conversely, parents recommended a great deal of involvement, including talking with the mentor about the mentor-mentee relationship, leading icebreakers for the adolescents, helping with activities, and including siblings in activities. A parent of a high school student reasoned that:

“It would be good for us to be involved ‘cause we can see the other side of it, like how well we think the mentoring relationship is going. And maybe some things we see that need to be tweaked a bit.”

Another parent suggested “maybe you’ll have the parents lead the way [to get a program started],” and a parent of a middle school participant suggested “having the parents help arrange an activity.” A parent of a high school student said that “I think it impacts the whole family enough to involve everybody.”

Discussion

The primary goals identified for a peer mentoring program to improve self-management in pediatric IBD mirrored a broader conceptualization of self-management, one that includes managing one’s life and emotions associated with the disease, not simply managing treatment. The focus groups also resulted in a broader target population for a mentoring program, recognizing that parents, siblings, and even those with considerable experience with the disease would benefit from comprehensive self-management support. Current self-management interventions are not meeting these needs by focusing solely on medication management.⁽⁷⁾ The areas that participants recommended for education also suggest that families are interested in more than medical management. Parents and children agreed on themes such as program goals, mentor characteristics and many important mentee characteristics. However, the youth stressed the importance of participating in a program

voluntarily, whereas some parents thought attendance should be mandatory. Parents also suggested much more family involvement than their children recommended, who valued privacy in a one-on-one mentor-mentee relationship. The request for mentor-to-mentor support highlights the challenges of living with IBD during the transition as a young adult.

Clearly there are multiple challenges for adolescents with IBD. The developmentally normative changes in autonomy, daily routines, peer interactions and social support and family dynamics that occur during this time all have the potential to impair self-management. Perhaps not surprisingly, adolescents have often been found to have difficulty with self-management.(7) Developing healthy self-management patterns in a range of areas is important both during adolescence and for establishing effective management into adulthood.(15) Childhood social and academic problems are predictive of occupational, social and emotional problems in adulthood,(16) and in IBD, \$5.5 billion is lost each year due to work force nonparticipation,(17) further highlighting the importance of these other areas of self-management and the need for mentorship during this time.

We had anticipated that the program format would be a one-on-one mentee-mentor relationship with group self-management activities, and the focus groups assisted in determining details such as expectations for the amount of contact, the age range of the mentors, and areas for education/information. Specific new ideas that were generated included entry into a program via group activities and mentor and parent support components.

The new ideas generated by the focus groups point to the role of stakeholders in program development. Stakeholders such as potential mentees, potential mentors and parents can offer important insights. By engaging a range of stakeholders with different perspectives, more ideas are generated and a clearer picture of their needs is developed. Involving stakeholders can also increase support, credibility, and long-term sustainability, potentially resulting in a more effective program.

Many of the suggestions from the focus groups correspond with research findings on mentoring. Mentoring programs in the general population have been well-researched, and best practices to optimize success have been identified.(11) For example, including structured activities such as group activities in a mentoring program is associated with longer mentee-mentor relationships and better outcomes in areas such as social, behavioral/emotional and academic functioning.(11, 18) Mentoring relationships that last at least one year are also associated with better outcomes in these areas.(19) Mentor-to-mentor support results in longer mentor-mentee relationships and more frequent contact within those relationships.(20) Other best practices have been identified, including ongoing training for mentors, expectations for frequency of contact, mechanisms for support, and monitoring overall program implementation.(11)

Another best practice for mentoring programs is parent involvement. Including parents is associated with improved social, behavioral/emotional, academic and family functioning for mentees in mentoring programs.(11, 21) Similarly, in chronic illness-related interventions, research suggests that family involvement is associated with improved quality of life (QOL),

depression, and social outcomes for caregivers, too. In pediatric IBD specifically, parents with a child with IBD report feeling a lack of social support,(22) parent psychosocial functioning is strongly tied to child functioning, and parenting stress has been linked with child QOL.(23, 24)

Potential study limitations include using a convenience sample that consisted primarily of people who had participated in prior research with the authors. Additionally, gastroenterologists, patients and parents were not involved in the analysis. Including their perspectives could have identified other themes or further validated the themes that were found. Using directed content analysis may result in finding evidence that is supportive rather than nonsupportive of preexisting theories and could limit discovery of other important factors. Strengths of the study include the richness of the data, including the new ideas that the focus groups generated. A self-management program developed without focus group input could result a program that does not meet all of the needs of its participants, and needs were identified in the current study that we had not anticipated. Similarly, conducting focus groups increases stakeholder support, which is also important for a program's success.

Next steps include implementing the stakeholders' suggestions and the empirically-based best practices for mentoring to develop and pilot a multifaceted peer mentoring program for improving self-management in multiple areas. As suggested in previous research on mentoring and our focus group data, an effective program may include a year-long, one-on-one mentor relationship with a peer who has had IBD for at least a year, educational group activities, fun activities that are not focused on IBD, expectations for in-person contact 1 – 2 times per month, and mentor and family support. Such a program would address the broader self-management needs identified by the participants.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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References

1. Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms. *Ann Behav Med.* 2003; 26:1–7. [PubMed: 12867348]
2. Huber M, Knottnerus JA, Green L, et al. How should we define health? *BMJ.* 2011; 343:d4163. [PubMed: 21791490]
3. Casati J, Toner BB, de Rooy EC, Drossman DA, Maunder RG. Concerns of patients with inflammatory bowel disease: a review of emerging themes. *Dig Dis Sci.* 2000; 45:26–31. [PubMed: 10695609]
4. Mackner LM, Crandall WV. Brief report: Psychosocial adjustment in adolescents with inflammatory bowel disease. *J Pediatr Psychol.* 2006; 31:281–285. [PubMed: 15802606]
5. Greenley RN, Hommel KA, Nebel J, et al. A meta-analytic review of the psychosocial adjustment of youth with inflammatory bowel disease. *J Pediatr Psychol.* 2010; 35:857–869. [PubMed: 20123705]
6. Mackner L, Bickmeier R, Crandall W. School achievement, absence and quality of life in pediatric inflammatory bowel disease. *J Dev Behav Pediatr.* 2012; 33:106–111. [PubMed: 22267107]

7. Hommel KA, Greenley RN, Maddux MH, Gray WN, Mackner LM. Self-management in pediatric inflammatory bowel disease: A clinical report of the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition. *J Pediatr Gastroenterol Nutr.* 2013; 57:250–257. [PubMed: 23648790]
8. Hommel KA, Herzer M, Ingerski LM, Hente E, Denson LA. Individually-tailored treatment of medication nonadherence: A pilot study. *J Pediatr Gastroenterol Nutr.* 2011
9. Hommel KA, Hente EA, Odell S, et al. Evaluation of a group-based behavioral intervention to promote adherence in adolescents with inflammatory bowel disease. *Eur J Gastroenterol Hepatol.* 2012; 24:64–69. [PubMed: 21989119]
10. Hommel KA, Hente E, Herzer M, Ingerski LM, Denson LA. Telehealth behavioral treatment for medication nonadherence: a pilot and feasibility study. *Eur J Gastroenterol Hepatol.* 2013; 25:469–473. [PubMed: 23325274]
11. DuBois DL, Holloway BE, Valentine JC, Cooper H. Effectiveness of mentoring programs for youth: a meta-analytic review. *Am J Community Psychol.* 2002; 30:157–197. [PubMed: 12002242]
12. Karcher, MJ. Cross-age peer mentoring. In: DuBois, DL.; Karcher, MJ., editors. *Handbook of Youth Mentoring.* 2nd Ed. Sage; Los Angeles: 2013. p. 233-257.
13. Krueger, R.; Casey, M. *Focus Groups: A Practical Guide for Applied Research.* 4th Edition. Sage; Thousand Oaks, CA: 2009.
14. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res.* 2005; 15:1277–1288. [PubMed: 16204405]
15. Williams PG, Holmbeck GN, Greenley RN. Adolescent health psychology. *J Consult Clin Psychol.* 2002; 70:828–842. [PubMed: 12090386]
16. Gest SD, Sesma A Jr, Masten AS, Tellegen A. Childhood peer reputation as a predictor of competence and symptoms 10 years later. *J Abnorm Child Psychol.* 2006; 34:509–526. [PubMed: 16850285]
17. Park KT, Bass D. Inflammatory bowel disease-attributable costs and cost-effective strategies in the United States: a review. *Inflamm Bowel Dis.* 2011; 17:1603–1609. [PubMed: 21053357]
18. Herrera, C.; Kauh, T.; Cooney, S.; Grossman, J.; McMaken, J. *High School Students as Mentors.* 2008.
19. Rhodes J, DuBois D. Mentoring relationships and programs for youth. *Curr Dir Psychol Sci.* 2008; 17:254–258.
20. McClanahan, W. *Relationships in a career mentoring program: Lessons learned from the Hospital Youth Mentoring Program.* Philadelphia: 1998.
21. Hartmann M, Bänzner E, Wild B, Eisler I, Herzog W. Effects of interventions involving the family in the treatment of adult patients with chronic physical diseases: a meta-analysis. *Psychother Psychosom.* 2010; 79:136–148. [PubMed: 20185970]
22. Engström I. Parental distress and social interaction in families with children with inflammatory bowel disease. *J Am Acad Child Adolesc Psychiatry.* 1991; 30:904–912. [PubMed: 1757439]
23. Herzer M, Denson LA, Baldassano RN, Hommel KA. Patient and parent psychosocial factors associated with health-related quality of life in pediatric inflammatory bowel disease. *J Pediatr Gastroenterol Nutr.* 2011; 52:295–299. [PubMed: 21297508]
24. Tojek TM, Lumley MA, Corlis M, Ondersma S, Tolia V. Maternal correlates of health status in adolescents with inflammatory bowel disease. *J Psychosom Res.* 2002; 52:173–179. [PubMed: 11897236]

Table 1

Demographic and Clinical Characteristics

	Adolescents (n = 14)	Young Adults (n = 5)
Median age (years; range)	15.25 (12 – 17)	19.26 (18-20)
Gender (% female)	43%	60%
Median disease duration (years; range)	2.00 (.08 – 7)	2.57 (2 – 3)
Current disease severity (Physician Global Assessment)		
Remission	86%	100% ^a
Mild	7%	
Moderate/Severe	7%	
Clinical activity in previous year		
1 disease flare	29%	33% ^a
1 hospitalization	21%	0% ^a

^aNote: n = 3.