



Published in final edited form as:

Health Soc Care Community. 2011 January ; 19(1): 80–88. doi:10.1111/j.1365-2524.2010.00951.x.

Treatment Adherence in Paediatric Inflammatory Bowel Disease: Perceptions from Adolescent Patients and Their Families

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Abstract

The objective of this study was to examine patient- and parent-perceived factors that impact adherence to inflammatory bowel disease treatment using a qualitative descriptive individual interview approach. Sixteen adolescents and their parents were recruited from May through August 2007 and interviewed about medication adherence using an open-ended semi-structured interview format. Interviews were audio recorded, transcribed, and coded into themes. Parent-child dyads identified forgetting, interfering activities, parent-child conflict and oppositional behaviour, and inadequate planning for treatment as challenges to adherence. Participants reported that family support and good parent-child relationships, routines, monitoring and reminding, and organizational tools such as pill boxes facilitated treatment adherence. Other issues that emerged included immediacy of treatment effects and parent-adolescent responsibility for treatment. Patients and parents experience a number of challenges related to adherence within behavioural, educational, organizational, and health belief domains. Behavioural interventions should focus on these issues, reduction of perceived barriers, and effective transition of responsibility for treatment adherence. Future research considerations are discussed.

Keywords

Adolescent Health; Bowel Disease; Compliance; Chronic Disease Management

Crohn's Disease and ulcerative colitis, collectively inflammatory bowel disease (IBD), affects approximately 71 in 100,000 individuals (Kappelman et al 2007) with approximately one fourth of patients diagnosed as children or adolescents. Inflammatory bowel disease is characterized by intermittent, yet chronic and unpredictable inflammation of the gastrointestinal tract, with symptoms including recurrent diarrhoea, fatigue, abdominal pain, growth delay, and perianal disease (Drossman 2003, Mackner et al 2006). Treatment can involve multiple medications with varying regimens, dietary modifications, infusions, and

potentially surgery. Undesirable side effects of medication (i.e., weight gain, cushingoid appearance) combined with complex medication regimens and intermittent symptoms present significant challenges to effective disease management in this population.

Treatment regimen adherence is a significant behavioural health issue in paediatric chronic illness that impacts upon clinical decision making, morbidity and treatment outcome, (Sly 1988, Lemanek 1990, Berg et al 1993, Rapoff 1999), and treatment outcome. Only 50% of children adequately adhere to their prescribed treatments, and only 25% to 35% of adolescents demonstrate adequate adherence rates (Rapoff and Barnard 1991, Logan et al 2003). This is particularly troublesome given that during adolescence, autonomy and decision making skills are supposed to increase (Miller and Byrnes 2001, Miller and Drotar 2007), and adolescents with a chronic condition assume greater responsibility for treatment adherence. Studies in adolescents with IBD have reported nonadherence prevalence rates ranging from 50% to 88% (Riekert and Drotar 2002, Mackner and Crandall 2005b, Oliva-Hemker et al 2007, Hommel et al 2009) using patient self-report, parent report, pharmacy refill data, and pill count measurement methods. Nonadherence frequency rates (i.e., percentage of doses not taken) of 38% for 6-mercaptopurine (6-MP)/azathioprine and 49% for 5-aminosalicylic acid (5-ASA) (Hommel et al 2009) have been observed using pill count data. Taken together, these studies suggest that approximately 50% to 90% of adolescent IBD patients are nonadherent to medication regimens, and that, depending on the medication, as much as 50% of doses are not taken by these patients. Thus, nonadherence is a considerable health issue in paediatric IBD; yet, there is a lack of evidence regarding the specific factors that facilitate or present barriers to treatment adherence in this population.

Examination of factors related to adherence has been researched in a few paediatric populations. Studies in cystic fibrosis and asthma have identified forgetting, medication palatability, oppositional behaviour, medication side effects, and time constraints as key barriers to treatment regimen adherence (Modi and Quittner 2006). Forgetting, time constraints, and failure to refill medications on time have been reported as barriers to sickle cell disease treatment (Witherspoon and Drotar 2006). Importantly, the relationship between reported barriers to adherence and actual adherence behaviour has also been examined. Studies in asthma, HIV, and IBD have reported that increased number of barriers to adherence was correlated with poorer adherence based on self- and provider-reported adherence ratings (Riekert and Drotar 2002, Logan et al 2003). It is important to understand the unique issues that might decrease or facilitate adherence in other paediatric populations, such as IBD, in order to assist patients and families in illness management.

While it is plausible that patients with IBD and their families experience similar obstacles to treatment adherence that have been reported in other populations, this has yet to be examined empirically. Further, research examining issues related to adherence has generally utilized forced-choice questionnaires or interviews and excluded examination of factors that facilitate adherence. Although these questionnaires are valid and evidence-based, they are essentially limited in the type and quality of data obtained, and cannot account for the range of patient and family perceptions of issues that might affect adherence. Thus, a qualitative approach to identification of factors that impact treatment adherence is ideal as an inquiry into the difficulties surrounding disease management in this paediatric population. Adequate understanding of these issues is important to the development of assessment tools and treatment interventions aimed at improving regimen adherence in paediatric IBD.

In order to address the aforementioned limitations in the extant research, the present study was designed to examine adolescent patient and parent perceptions of factors that impact adherence to IBD treatment regimens using a qualitative descriptive approach. The specific aim of this study was to generate themes of patient- and parent-reported factors that impact

treatment adherence to enhance understanding of disease self-management in paediatric IBD and identify targets for intervention to improve adherence in this population.

Method

Participants and Procedure

Adolescent patients were recruited from a gastroenterology clinic in a large tertiary care children's hospital in the northeastern United States from May through August 2007. Inclusion criteria were: 1) diagnosis of Crohn's disease or ulcerative colitis, 2) 13–17 years of age, 3) current prescription of 6-mercaptopurine (6-MP)/azathioprine and 5-aminosalicylic acid (5-ASA) as these are the two most commonly prescribed medications in this population, and 4) English fluency. Exclusion criteria were: 1) diagnosis of pervasive developmental disorder and 2) comorbid chronic illness. Twenty patients met eligibility criteria; two were never reached for recruitment and two declined participation. Of the two who declined, one was not interested and one had limited time available after his/her clinic appointment and was not interested in rescheduling. Thus, a final sample of 16 adolescents and their parents served as participants in this study.

Patients meeting eligibility criteria were identified via medical chart review and both patients and parents were approached simultaneously during a regularly scheduled clinic appointment or infliximab infusion by a nurse unaffiliated with the study to inquire whether the patient and parent were interested in hearing about an opportunity to participate in a study. A thorough description of the study was then provided to parents and patients. They were given opportunity to ask questions, discuss the option privately, decline participation, or either participate that day or consider participation further at home and schedule a time during their next appointment for participation. Details regarding study procedures outlined in the consent and assent forms were carefully and thoroughly reviewed with both patients and parents. Patients were specifically told their care would not be affected by their decision to participate or decline participation. Upon agreeing to participate, parents and patients independently provided written informed consent/assent. A semi-structured interview was then administered during the clinic appointment. Both patients and parents were asked to respond to each question so as to include both patient and caregiver perceptions of treatment adherence. Chart reviews were conducted to obtain disease severity data from the clinic appointment corresponding to the study visit. Study personnel completed disease severity assessments using patient chart note data and laboratory values obtained during the clinic appointment corresponding to the study visit. Participants were compensated with a \$50 gift card for their participation. This study was approved by the Institutional Review Board.

Measures

Treatment Adherence Interview—A semi-structured patient/parent interview was used to examine factors affecting treatment adherence. Individual interviews were chosen as the preferred method over focus groups in order to avoid consensus effects on data integrity. Parents and patients were interviewed together in order to encourage identification and discussion of different perspectives with the interviewer. While this is a substantial advantage, an important disadvantage of this approach is the potential to have adolescent patients defer answers/opinions to their parents. When this occurred, patients were asked to voice their thoughts about the issue being discussed. Interview questions were developed with input from a psychologist, gastroenterologist, and anthropologist, representing expertise in paediatric behavioural medicine and treatment adherence, paediatric gastroenterology, and qualitative inquiry. Consensus on item inclusion was reached among these individuals prior to proceeding with interviews. The interview utilized open-ended questions designed to elicit discussion by adolescent patients and their parents regarding

specific educational (e.g., knowledge of regimen, use of medication, etc.), organizational (e.g., placement of medication in house, who refills pill organizer, etc.), and behavioural (e.g., refusal to take medication, depressive symptoms, etc.) factors related to medication adherence. Follow up probes were used for clarification and extension of responses by patients and parents. Differing perspectives between parents and adolescents were sought and discussed when revealed. The interview guide presents the order in which questions were asked.

Paediatric Crohn's Disease Activity Index (PCDAI) (Hyams et al 1991): The PCDAI is a well-validated (Hyams et al 2005) disease activity assessment for paediatric patients with Crohn's disease. Scores range from 0–100, with higher scores representing more severe disease, and includes subjective criteria (e.g., pain), objective criteria (e.g., physical exam), laboratory findings, and growth parameters. Scores < 10 = inactive disease; 11–29 = mild disease, and ≤ 30 = moderate to severe disease activity (Hyams et al 2005). Adequate reliability estimates of the PCDAI have been reported in prior research with internal consistency of .83 (Hommel et al 2008).

Lichtiger Colitis Activity Index (LCAI) (Lichtiger et al 1994): The LCAI is a validated disease severity index for ulcerative colitis. It is scored 0–21, with higher scores representing more severe disease, and assesses eight ulcerative colitis related variables including number of daily stools, nocturnal diarrhoea, visible blood in stool, faecal incontinence, abdominal pain or cramping, general well-being, abdominal tenderness, and need for anti-diarrheal medication. The LCAI has demonstrated adequate construct validity when compared with clinical outcomes (Lichtiger et al 1994, Fanjiang et al 2007) and reliability, with internal consistency of .87 (Hommel et al 2008).

Data Management and Analyses

Interviews were conducted by a doctoral level licensed clinical psychologist (KH) and lasted 20–45 minutes. Interview data were collected via audio recordings, subsequently transcribed by a professional transcriptionist, and checked for accuracy by the interviewer. NVivo software was used for data coding and analyses. Coding of transcripts was conducted by two trained master's level psychology graduate students under the supervision of the study principal investigator. Training of coders involved use of the software, review of initial coded transcripts to ensure agreement across coders, and weekly supervision. Inter-rater reliability analyses were conducted to determine percent agreement between coders, which was 90%. A directed content analysis (Hsieh and Shannon 2005) of the transcripts was conducted to sort data into codes.

Results

Adolescents were 11 males and five females with a mean age of 15.75 years ($SD = 1.08$ years) and parents were 12 mothers with a mean age of 46.44 years ($SD = 5.32$) and four fathers with a mean age of 48.81 years ($SD = 7.49$). The sample consisted of 94% Caucasians, and 6% African Americans. The modal annual household income category was \$75,001–\$100,000. Table 1 summarizes additional family demographic data. Mean disease severity was in the mild to inactive range for the PCDAI (10.67) and LCAI (7.00). During interviews, both patients and parents spoke candidly about their experience with IBD and their perceptions of issues that impact treatment adherence. Participants did not decline to answer any of the questions and openly discussed positive and negative issues. Multiple factors emerged that impede or facilitate treatment adherence.

Factors that Impede Treatment Adherence

Several issues across behavioural, educational, organizational, and health belief domains were perceived as significant challenges to adherence by patients and their parents. Participants reported that forgetting to take medications was a behavioural/cognitive factor that presented significant challenges to disease management. This theme was evident in both patient and parent accounts of their adherence to IBD treatments. Moreover, forgetting appears to occur in multiple contexts, including home, school, and activities such as sleepovers, and the issues that might lead to forgetting are complex.

PARENT (Mother of 16 y/o male): There are times when... every other weekend he visits his father for the weekend. And normally I'll make sure he packs his pills. You know, I remind him. And I wasn't there to do that (one time), and he forgot them. So he had missed a day of pills... I think that's the difficult part. He's at an age now where he has an active social life. And... it's just a constant – there it is and you have to take it no matter what. It's part of his life and at the same time, he's trying to balance that with being sixteen.

ADOLESCENT (14 y/o male): Um, forgetfulness and maybe just sleepovers and... hanging out with friends. Sometimes you just kinda forget or you just don't have a chance to because you don't have your medication with you and you just have a change of plans.

Given that the majority of paediatric IBD patients are in the developmental stage of adolescence, it is notable that activities were also a theme related to difficulties with adherence. Adolescents are often involved in a number of extracurricular activities, and adherence to multi-dose regimens might be difficult if priority by the teen is given to other activities.

PARENT (Mother of 14 y/o boy): I would just say that you have the schedules of three children plus two adults and family activities and school activities and sport activities, you're just always on the run. And running in and out. Just multi-tasking... and at this point, I'm hoping that he will step up and realize that he's gotta start taking medication.

ADOLESCENT (16 y/o female): Definitely... during the summer, I don't take them as much as I should. I guess I don't have... a set schedule and I travel a lot, so when I have to... pack them with me on vacation, I usually wind up missing... a day or something.

ADOLESCENT (16 y/o male): I don't think it's important enough to stop what I'm doing and go take the pills, especially if I'm going to work or going to school or something. I don't want to be late because of the pills.

Parents and adolescents occasionally experience conflict over adherence. Participants reported that this conflict occurred commonly between mothers and their children, which is understandable as mothers often take primary responsibility for monitoring their children's treatment. In addition, adolescent oppositional behaviour appears to impact patient adherence.

PARENT (Mother of 17 y/o female): But... it's not something to be taken lightly, I don't think. You're on them for a reason. And that's how I feel... he wouldn't have you on all this stuff just for fun and games, and (the pharmacy) is getting rich from us buying medicine all the time.

PARENT (Mother of 17 y/o female): She's already up in bed, and I say, "Did you take your medicine?", and she's like "sigh...No", like it's annoying that she now has to get out of bed, go downstairs... and I'm not bringing them, but sometimes

when she's sick, I'll bring her morning's up to her, cause she'll stay in bed until... noon. I don't want her to miss them.

An additional theme was adolescents' social comparisons with peers and consequent embarrassment about taking medications resulting in nonadherence.

PARENT (Mother of 14 y/o male): Or sometimes I just think it's one of those things where his friends aren't on medication. And I'll have to bring it to a sleep-over, and it's embarrassing sometimes.

Another recurrent theme in the data was concerns about regimen complexity. Patients and parents reported that the number of medications, number of pills per dose, and/or timing of doses presented difficulties in adhering to treatment regimens. Of considerable concern is that the complexity of regimens appeared to result in arbitrary changes in regimens by parents and patients that were not suggested by the health care team.

PARENT (Mother of 14 y/o male): ...like the calcium is just a supplement that we're giving him and... he can have it three times a day to get the maximum amount and not too long ago, I just took away the morning one... that was just... kinda stressing him out in the morning...that's a pretty big pill and so I said to him, let's just back off on that one and took it to the important ones...and at one point, I was giving him the multivitamin and the zinc in the morning, and I just moved those to a later time. So it's just not so overwhelming in the morning.

ADOLESCENT (16 y/o female): ... at first it was difficult 'cause I had to take... over twenty pills a day, and I just didn't want to. So, I skipped it a lot. And, at first, I couldn't swallow pills.

Patients and parents demonstrated general knowledge about IBD and treatment approaches. Further, although patients and parents demonstrated specific knowledge of their treatment regimen, there was a very limited understanding of the function of specific medications (i.e., how the medication works and what symptoms it treats). Moreover, patients' descriptions of the function of medications were notably less explicit than their parents' descriptions, with responses such as "I don't know (how the medication works)".

PARENT (Mother of 16 y/o male): Um, I just know the 6-MP lowers your immune system, so it also makes it easier for him to catch colds.... But, I know that without it, it seems that he has more flare-ups. I don't know if his intestines actually work against themselves, or how it works exactly.

Organizational issues did not appear to play a significant role in treatment adherence. One exception to this is that patient-parent dyads reported that missed doses of medication in the past were often due to a lack of planning ahead for treatments when other activities might interfere with taking medications. Perceived barriers to adherence, in the health belief domain, were a common issue that impacted adherence. Patients and parents identified 17 barriers to adherence, including financial barriers, work/school barriers, and several other barriers such as difficulty swallowing pills were viewed by patients and parents as negatively impacting adherence. Pill swallowing difficulties were surprising given that these patients were all adolescents and would likely have had experience swallowing pills, thus desensitizing them to any fears that might present difficulties with treatment adherence.

Factors that Facilitate Treatment Adherence

Patients and parents reported several behavioural factors as facilitators of treatment adherence. Of these, family support and good parent-child relationships were highly valued.

ADOLESCENT (17 y/o female): I know I can go to them about anything and they're always there for me. And... they're really understanding about the whole IBD thing. And... they're really nurturing....

PARENT (Mother of 17 y/o male): Well, I think... he just knows he has our support and we all... the whole family is invested...in keeping him feeling well. You know, we all went through a tough time when he was first diagnosed. And it was very scary, and I think we all as a family want to avoid that at all... cost.

Several other behavioural factors facilitated adherence. Participants indicated that establishing a routine was integral to remembering to take medications. Parental monitoring of their child's adherence also facilitated adherence. Importantly, there was variability with respect to how monitoring occurred (e.g., checking in at the end of the day, watching the child take medications), and at what age parental monitoring should increase or decrease. Generally, parents felt it was important to monitor their child's adherence, but expressed uncertainty about the best approach. Similarly, adolescents reported that reminders by parents, siblings, or self facilitated adherence. Despite the positive influence this was perceived to have by families, it also was often interpreted by adolescents as their parents nagging them to take their medicine.

As previously noted, participants indicated that conflicts about nonadherence between parents and adolescents occasionally occurred. They indicated that conflict that was resolved by discussion as opposed to fighting enhanced adherence.

PARENT (Mother of 15 y/o male): Yes, we would talk about it. Ask why he just doesn't want to take it... find out if it's making him sick or it's... causing him pain. ... and then we'll talk to the doctor about it, but ... at one point he was saying that one of his medications was making him nauseous, but he wasn't telling me that he was nauseous so he just stopped taking the medication. And we had a long discussion about that.

ADOLESCENT (14 y/o male): I'll get the "You need to do this cause it's gonna keep you healthy". I'm not going to get into trouble for it because it doesn't happen that often. But I'd probably get into trouble if I was constantly... hiding that I wasn't taking my medication.

Participants were fairly knowledgeable about the aetiology of IBD and general treatment approaches. Organizational attributes that served as facilitators of treatment adherence included keeping medications accessible to adolescents and having a specific place within the home that medications were kept at all times. Additionally, patients and parents reported use of a pill box as an organizational tool either currently or in the past, and that it was helpful for them to have multiple medications organized by dose and by day. They also reported that planning for medication doses around other activities was helpful.

Patients and parents discussed their beliefs and experience regarding how well medication works to treat their symptoms and the issues related to delayed relief of symptoms with some medications. Generally, participants' views of medication management for their symptoms were positive and patients' and parents' perceived benefit of taking medications emerged as a significant health belief theme related to adherence.

ADOLESCENT (15 y/o male): Well, it's easy because I know that it's going to be beneficial when I do take it. So, why (would someone) not take it and feel pain? If you take it, you'll be relieved. It's not really difficult.

PARENT (Mother of 17 y/o male): His... school attendance has been outstanding. Pretty much the only days he misses school are when he has to come here. Maybe,

a day here or there, but nothing like it was... in those months leading up to the diagnosis.

ADOLESCENT (14 y/o male): It's important to stay healthy...for me, cause I play a lot of sports. You don't wanna miss practices... especially 'cause I'm going into high school, I don't want to fall behind in schoolwork. So it's important to make sure that you're... not missing school cause of stomach problems or something like that.

Related to this was a theme concerning physiological ramifications of not taking medications. Adolescents reported concern that if they missed doses, they would experience an increase in IBD symptoms.

ADOLESCENT (17 y/o male): ...you feel miserable if you don't have it. So that's pretty much my motivation to take it.

Additional Factors Related to Adherence

Two additional factors emerged from the data that did not appear to act exclusively as an impediment or facilitator of adherence. The first theme concerned the immediacy of medication effects or the association made between taking medication and how quickly symptom relief was achieved. This is a temporal distinction from the aforementioned theme regarding perceived benefit of taking medication in that while patients and parents believed that taking medication over time improved their health and functioning, they did not necessarily see an immediate positive effect from taking medication. A particularly interesting aspect of this theme was that adolescents' rationale for taking medication was bidirectional. That is, the perceived effect medication had on patients resulted in decisions to adhere or not adhere to the treatment regimen.

ADOLESCENT (17 y/o female): ... it's hard I think with this stuff 'cause, if I don't take it, I don't see an immediate... effect from not taking it.... Like, it doesn't feel like it's a problem missing it.

ADOLESCENT (16 y/o female): ... usually I feel fine. ... I guess I think I don't need to take my medicine because... I've felt fine for over a year. So, if I miss a few days, it won't hurt me at all, but I guess in the long run it could cause a flare-up. So, I should probably stick to them.

PARENT (Mother of 16 y/o male): I think when he's not feeling well, it's a lot easier for him to remember to take it. But when he's feeling well, then I think it sometimes slips his mind.

The other additional theme was allocation of responsibility for treatment adherence. Both parents and adolescents made comments regarding assumption of responsibility for taking medication, and parents often expressed confusion or uncertainty about whether they were handling the transition of responsibility from parent to adolescent appropriately.

PARENT (Mother of 16 y/o male): We really are working on trying to make him responsible for himself 'cause we know he's going off to college. And... I want him to already have been responsible for it. ... but of course now that I realize how severe it is, I think we're probably going to try to make a little bit ...adjustment in our schedule, but...I'm not going to punish him. I'm not gonna make him feel bad about it. That just doesn't seem like that would be productive.

PARENT (Mother of 17 y/o female): I mean... we're looking at colleges and... I'm not going to sign up if she's not going to be compliant. I can't be checking her pill box every day to make sure she's taking her meds, so... she's gonna have to show

me...It's something that she needs to get more responsibility for.. So, either she stays home and goes to school and proves to me that she's gonna be compliant...

Discussion

This study examined factors related to treatment regimen adherence in adolescents with IBD and their parents via qualitative assessment. Participants reported a number of issues that presented challenges to adhering to their treatments including forgetting, activities, parent-child conflict, adolescent oppositional behaviour, poor understanding of the purpose of a prescribed medication, regimen complexity, embarrassment about taking medications around peers, failure to plan appropriately for treatments, and there were several barriers identified such as financial and work/school barriers. This is consistent with prior research indicating that organizational difficulties, forgetting, being away from home, interference with other activities, and medication side effects have emerged as barriers to adherence in paediatric transplant recipients (Simons and Blount 2007). Factors that participants perceived to facilitate treatment adherence included family support and good parent-child relationships, establishing a routine of taking medications, parental monitoring and reminders, concern about physical consequences of nonadherence, calm discussion of nonadherence when it occurs, keeping medications accessible and in the same location, using a pill box, planning for treatments, and perceived benefit of taking medications. Other salient factors that were not necessarily impediments or facilitators of adherence included perceived relationships between taking medication and symptom relief resulting in both adherent and nonadherent behaviours and responsibility for treatment adherence. Treatment responsibility might be an important issue since, without proper guidance by health care providers, diffusion of responsibility between parent and adolescent can occur, potentially leading to significant disease mismanagement.

This is the first study to document patients' and parents' perspectives of factors related to treatment adherence in paediatric IBD using a qualitative approach. Data were thoroughly coded and analyzed using procedures to protect against misinterpretation of data (e.g., review of transcript accuracy, dual coding, inter-rater reliability). Nevertheless, the findings should be interpreted within the context of a few methodological limitations. First, despite the richness and diversity of qualitative data obtained, the sample size was fairly modest. However, research has demonstrated that data saturation can occur within the first twelve interviews (Guest et al 2006). Indeed, we found that no new themes were emerging by the twelfth interview. Consistency across participants' reports also suggests sufficient sampling. Second, parents and adolescents were interviewed together, which may have inhibited some responses by participants. This study was conducted during regularly scheduled clinic appointments, in which space is quite limited, making separating families for prolonged interviews unfeasible. Nevertheless, additional information might be gleaned from individual interviews in future studies. Third, follow-up interviews were not conducted to discuss the veracity of themes identified by participant interviews. Fourth, although IBD is primarily diagnosed in Caucasians, there was a slightly lower percentage of minority patients in this study compared to IBD population in general. Finally, annual household income reported by participants was fairly high, though similar to data reported in prior studies with adolescent IBD patients (Mackner and Crandall 2005a, Hommel et al 2008). Additionally, parent education level was fairly high, which may have influenced responses as well. Further research needs to be done in order to generalize these findings to economically disadvantaged IBD patients and families.

Implications

Several targets for behavioural intervention were identified in this study. Perhaps the most salient targets include management of conflict, improving family support and parent-child relationships, management of oppositional behaviour, anticipating and reducing barriers to treatment adherence, and monitoring and reminding. Thus, a number of behavioural targets that are appropriate for behavioural intervention were revealed in this study. Providers' efforts to promote treatment adherence should focus on these targets as patients and parents perceive them to impact adherence.

Given that this study is an initial attempt to understand issues related to treatment adherence in adolescents with IBD, there are several areas of research that warrant continued development. For example, further qualitative inquiry with greater diversity in sample characteristics may yield additional barriers and facilitators of treatment adherence in this population. Additionally, the next logical step in this area of research will include development and testing of behavioural treatment protocols aimed at improving adherence in paediatric IBD. Also, transfer of responsibility for treatment adherence from parent to adolescent is an important area of research that warrants development. Moreover, the possibility of integrating interventions that simultaneously target behaviours to promote adherence and facilitate the transition of treatment adherence responsibility to adolescents/young adults should be examined as a complementary approach to long-term management of IBD.

Box 1

1. Tell me what you know about IBD in terms of how someone gets it, how it is treated, and how long someone has it.
2. Tell me about your medication regimen and how each medication is supposed to work.
3. How is your medication organized and who is in charge of making sure medication is taken?
4. What gets in the way or prevents you from taking your medication? What makes it easier to take medication?
5. Why do you think it is easy/difficult for you to take medication?
6. When you miss a dose, whom do you tell? What happens when you tell them?
7. What type of relationship do you and your parents have, related to your IBD and in general? How do you reconcile differences?
8. What do you think would make things less/more difficult on you and your family with respect to taking medications?

Acknowledgments

Funding for this study was provided by NIDDK K23 DK079037 and PHS Grant P30 DK 078392.

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Table 1

Demographic characteristics for sample.

	<u>Mean</u>	<u>SD</u>	<u>N (%)</u>
IBD Diagnosis			
Crohn's disease			15 (94%)
Ulcerative colitis			1 (6%)
Child Grade	10.13	1.50	
Mother's Marital Status			
Married			13 (81.3%)
Divorced			3 (18.7%)
Single			
Separated			
Widowed			
Father's Marital Status			
Married			12 (75%)
Divorced			3 (18.7%)
Single			1 (6.3%)
Separated			
Widowed			
Mother's Highest Level of Education			
8 th grade or less			
Partial high school			
High school graduate			4 (25%)
Vocational degree			2 (12.5%)
Partial college			
Associate's degree			
Bachelor's degree			7 (43.8%)
Graduate degree			3 (18.7%)
Father's Highest Level of Education			
8 th grade or less			1 (6.3%)
Partial high school			
High school graduate			3 (18.7%)
Vocational degree			
Partial college			3 (18.7%)
Associate's degree			
Bachelor's degree			4 (25%)
Graduate degree			5 (31.3%)