

Observational Study

Transition clinic attendance is associated with improved beliefs and attitudes toward medicine in patients with inflammatory bowel disease

Nancy Fu, Kevan Jacobson, Andrew Round, Kathi Evans, Hong Qian, Brian Bressler

Nancy Fu, Brian Bressler, Division of Gastroenterology, Department of Medicine, University of British Columbia, Vancouver, BC V5Z 1M9, Canada

Kevan Jacobson, Kathi Evans, Division of Gastroenterology, Hepatology and Nutrition, Department of Pediatrics, University of British Columbia, Vancouver, BC V6H 3V4, Canada

Andrew Round, Faculty of Medicine, University of British Columbia, Vancouver, BC V6T 1Z3, Canada

Hong Qian, Centre of Health Evaluation and Outcome Sciences, Vancouver, BC V6Z 1Y6, Canada

Author contributions: Fu N and Bressler B designed the study; Fu N, Round A and Evans K distributed the questionnaires; Fu N and Round A collected data; Qian H analyzed data; Fu N, Jacobson K, Evans K and Bressler B interpreted and evaluated the data; Fu N drafted initial manuscript; Fu N, Jacobson K, Evans K and Bressler B critically revised the manuscript.

Institutional review board statement: The study was reviewed and approved by Research Ethics Board of University of British Columbia.

Informed consent statement: All study participants, or their legal guardians, provided informed written consent prior to study enrolment.

Conflict-of-interest statement: All authors declare no conflicts of interest.

Data sharing statement: No additional data are available.

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Manuscript source: Unsolicited manuscript

Correspondence to: Nancy Fu, MD, Division of Gastroenterology, Department of Medicine, University of British Columbia, 250 - 6091 Gilbert Road, Richmond, BC V7C 5L9, Canada. nfu@interchange.ubc.ca
Telephone: +1-604-2734447
Fax: +1-604-2734254

Received: January 8, 2017

Peer-review started: January 11, 2017

First decision: February 9, 2017

Revised: March 7, 2017

Accepted: May 19, 2017

Article in press: May 19, 2017

Published online: August 7, 2017

Abstract**AIM**

To evaluate the differences in knowledge, adherence, attitudes, and beliefs about medicine in adolescents with inflammatory bowel disease (IBD) attending transition clinics.

METHODS

We prospectively enrolled patients from July 2012 to June 2013. All adolescents who attended a tertiary-centre-based dedicated IBD transition clinic were invited to participate. Adolescent controls were recruited from university-affiliated gastroenterology offices. Participants completed questionnaires about their disease and reported adherence to prescribed therapy. Beliefs in Medicine Questionnaire was used to evaluate patients' attitudes and beliefs. Beliefs of medication overuse, harm, necessity and concerns were rated on a Likert

scale. Based on necessity and concern ratings, attitudes were then characterized as accepting, ambivalent, skeptical and indifferent.

RESULTS

One hundred and twelve adolescents were included and 59 attended transition clinics. Self-reported adherence rates were poor, with only 67.4% and 56.8% of patients on any IBD medication were adherent in the transition and control groups, respectively. Adolescents in the transition cohort held significantly stronger beliefs that medications were necessary ($P = 0.0035$). Approximately 20% of adolescents in both cohorts had accepting attitudes toward their prescribed medicine. However, compared to the control group, adolescents in the transition cohort were less skeptical of (6.8% *vs* 20.8%) and more ambivalent (61% *vs* 34%) (OR = 0.15; 95%CI: 0.03-0.75; $P = 0.02$) to treatment.

CONCLUSION

Attendance at dedicated transition clinics was associated with differences in attitudes in adolescents with IBD.

Key words: Inflammatory bowel disease; Adolescents; Transition; Beliefs; Knowledge; Attitudes

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Core tip: Inflammatory bowel disease (IBD) transition clinics may improve care of adolescents. Comparing ones attended transition clinics to those didn't, this study assessed adolescents with IBD's self-reported adherence to prescribed therapy and evaluated their attitudes and beliefs using Beliefs in Medicine Questionnaire. Self-reported adherence rates were poor in both cohorts. Adolescents in the transition cohort held significantly stronger beliefs that medications were necessary. They were also less skeptical of and more ambivalent to prescribed treatments. Attendance at dedicated transition clinics was associated with differences in attitudes in adolescents with IBD.

Fu N, Jacobson K, Round A, Evans K, Qian H, Bressler B. Transition clinic attendance is associated with improved beliefs and attitudes toward medicine in patients with inflammatory bowel disease. *World J Gastroenterol* 2017; 23(29): 5405-5411 Available from: URL: <http://www.wjgnet.com/1007-9327/full/v23/i29/5405.htm> DOI: <http://dx.doi.org/10.3748/wjg.v23.i29.5405>

INTRODUCTION

Inflammatory bowel disease (IBD) is a chronic, idiopathic, immune-mediated illness that typically follows a relapsing and remitting course^[1]. Pediatric-onset IBD accounts for up to 25% of all IBD cases, and its natural history and health impacts can differ greatly

from adult-onset IBD^[2,3]. Adolescence is a critical period for physical, cognitive, emotional, and social development. Compared to their peers, adolescents with IBD often face additional challenges such as difficult decisions concerning therapeutic options, trouble with medication adherence, and potential anxiety surrounding health-related appointments and interventions^[4].

Two commonly identified issues surrounding the transition of adolescents with IBD are this patient population's limited disease-specific knowledge and poor adherence to medical therapy^[5,6]. These are important elements for the establishment of self-management skills and protection against future disease flares. Many adult gastroenterologists feel the deficiencies in understanding among adolescents relating to their condition and treatment are prevalent and consequently represent a substantial barrier to successful transition^[5,6]. Previous studies have demonstrated that adolescents with IBD could provide basic disease-related information such as their diagnosis and current medication; however, participants were unable to recall specifics pertaining to disease extent, medication side effects, previous surgery, and results of investigations^[7,8]. Nonadherence to medical therapy in adolescents with IBD is reported to be very high, ranging from 50% to 75%^[9-12]. Typical reasons for nonadherence to medication among adolescents with IBD include forgetfulness, feeling well, lack of time, interference with other activities, medication side effects, and complex medical regimens^[9-12]. Medication nonadherence can lead to undesirable consequences such as disease flares, health deterioration, and increased healthcare utilization^[13-16]. Important predictors of adherence to medical therapy are patients' beliefs and attitudes toward medicine^[17-22].

The aim of this study was to explore the attitudes toward, and beliefs about, medical therapy among adolescents with IBD. Additionally, this study compared the differences in disease-specific knowledge and adherence to medical therapy between adolescents who attended the IBD transition clinics and those who did not.

MATERIALS AND METHODS

Adolescent transition clinic

British Columbia (BC) is the third largest province in Canada with a population of 4.4 million^[23]. Ninety-five percent of all children diagnosed with IBD in BC are treated at the BC Children's Hospital (BCCH), a tertiary-care academic hospital. An IBD transition clinic was established at BCCH in 2010. Annually, approximately 80 adolescents with IBD graduate from BCCH, typically at around 17 to 18 years of age.

Adolescents selected to attend the transition clinics are usually those with a more complex disease course or those receiving anti-tumor necrosis factor (anti-

TNF) agents. Many of them have disease phenotypes such as extensive or pancolitis; upper tract, extended small bowel involvement, stricturing or penetrating Crohn's disease (CD); or have required surgical resections. Adolescents who have had adverse effects or intolerances to conventional IBD medications are also chosen. Approximately half of the adolescents graduating from BCCH attended the transition clinics.

Adolescents attending the IBD transition clinics were jointly assessed by adult and pediatric IBD specialists and nurses. Most adolescents, prior to transfer of care, attended the transition clinic up to twice in their last year at BCCH. The transition clinics served as the final summative clinical visits. During the transition clinic visits, medical/surgical histories, past/current medications, and future therapeutic plans of the patient were thoroughly reviewed. Both adult and pediatric IBD specialists discussed each patient in detail with each other and with the patient to establish a comprehensive plan. Adolescents were reminded of the importance of IBD medications, potential side effects of the medications, and the need for regular monitoring of blood work. Pediatric IBD nurse assisted in creating a one-page concise summary for the patients to take home after the clinic. Complete summaries were later prepared and provided to patients and the adult gastroenterologists who received the transfer of care.

Another form of care transfer was direct referrals to adult gastroenterologist. Selected documents depicting patients' diagnosis, therapies and progressions were sent to the receiving adult gastroenterologists along with a discharge/transfer summary from BCCH. The adolescents then attend regular adult gastroenterology clinics for consultation and meet their physicians at the appointment.

Unlike direct care transfer, the transition clinics provide an intermediate step for the adolescents to become acquainted with the differences in practice styles between pediatric and adult settings. The transition clinic visit is longer but not as frequent as the usual adult gastroenterology appointment. Both pediatric and adult IBD nurses are present to give additional support. Although adolescents graduating from BCCH are typically referred to adult gastroenterologists based on geographical locations and their residence in BC, many adolescents attended the transitions clinics are preferentially referred to university-affiliated IBD specialists as opposed to community-based gastroenterologists.

Study design

We prospectively enrolled IBD patients from July 1st, 2012 to June 30th, 2013. All adolescents within 1 year of their attendance at the BCCH IBD transition clinics were invited to participate as the study cohort. Aged-matched patients who did not attend the transition clinics but were being treated at a university affiliated gastroenterology office served as the control cohort.

Study invitation letters and web-linked questionnaires were delivered via secured personalized emails to potential participants (73 transition and 75 control). Follow-up telephone calls, to provide further details or to clarify any questions, were placed to all adolescents interested in participating in the study. All available clinical charts were reviewed and compared with responses provided by the participants. All participants provided signed informed consent. The study received full institutional ethics approval.

All participants completed an online questionnaire regarding their disease and their adherence to prescribed medical therapy (see Supplementary Table 1). Attitudes and beliefs about medical therapy were assessed using the Beliefs about Medicine Questionnaire (BMQ) (see Supplementary Table 2), a validated 17-question tool evaluating patient opinions on medical therapy^[24,25]. The BMQ assesses both specific and general beliefs about medicine; specific beliefs include those relating to either necessity or concerns, while general beliefs include those relating to overuse or harm. Respondents indicate their degree of agreement with each statement about medicine on a five-point Likert scale (1 = strongly disagree, 5 = strongly agree). The BMQ has been used in various chronic diseases and recently in IBD^[20,21,24], and has consistently demonstrated greater adherence to be associated with a stronger perception of necessity and fewer concerns relating to treatment^[26]. Additionally, the BMQ allows for further analysis of patient attitudes toward medicine by delineation of respondents into one of 4 attitudinal groups: "accepting" (high necessity, low concerns), "ambivalent" (high necessity, high concerns), "skeptical" (low necessity, high concerns), or "indifferent" (low necessity, low concerns)^[21,22].

Disease-specific knowledge among the adolescents was assessed by comparing responses provided on the questionnaire to information available in their clinical charts. If necessary, the patient's healthcare professionals were consulted for clarification. Level of basic knowledge such as the type of IBD (CD or ulcerative colitis, without specifying disease location) and previous gastrointestinal surgery (yes or no) was formally evaluated by comparing physician records and patient responses. Information on disease phenotypes and current IBD-specific medication (yes or no for mesalamines, immunomodulators, anti-TNF agents) was also collected. The general concern among healthcare professionals about the increased risks of loss to follow up in the adolescent population prompted us to collect the self-reported physician contact/follow up rate. Self-reported adherence to prescribed medical therapy was recorded and subsequently dichotomized by classifying those who were missing less than 30% of prescribed therapy as adherent. This cuff-off, as opposed to conventional 20%, was selected to account for previously observed high nonadherence rate in the adolescent population. Self-reporting of adherence was

Table 1 Demographics

	Transition <i>n</i> (%) or mean \pm SD	Control <i>n</i> (%) or mean \pm SD	<i>P</i> value
Gender			
Female	23 (40.4)	31 (56.4)	0.13
Diagnosis			
CD	47 (79.7)	34 (64.2)	0.07
UC/IBDU	12 (20.3)	19 (35.8)	
Age (yr)			
At diagnosis	13.0 \pm 2.9	13.0 \pm 3.8	0.87
Current	19.7 \pm 1.3	20.6 \pm 1.2	0.001 ²
Disease duration (yr)	6.9 \pm 3.2	7.6 \pm 3.9	0.30
Prior GI surgery	13 (22.0)	12 (21.8)	0.98
Medication ¹			
5-ASA	14 (25.0)	20 (37.0)	0.24
IM	17 (30.4)	12 (22.2)	0.33
Anti-TNF	6 (10.7)	6 (11.1)	1.00
Combination	13 (23.2)	5 (9.3)	0.07
Any	43 (76.8)	37 (68.5)	0.33
Regular blood work	45 (80.4)	30 (55.6)	0.01 ²

¹Subgroups in medication row denote patients receiving oral 5-ASA products, IM only, anti-TNF only, combination therapy (IM and anti-TNF) only, or any IBD medication; ²Statistically significant. 5-ASA: 5-aminosalicylic acid; anti-TNF: Anti-tumour necrosis factor agents including infliximab and adalimumab; CD: Crohn's disease; IBDU: Inflammatory bowel disease unspecified; IM: Immunomodulators including methotrexate, 6-mercaptopurine, and azathioprine; UC: Ulcerative colitis.

used for ease of data collection although it carries a known risk of overestimation^[22,27,28].

The BMQ responses were examined in several ways, as per published literature^[21,24,25]. The individual scores for each subclass (necessity, concerns, overuse, harm) were summed and analyzed as a continuous variable or a scaled score by dividing the summed value with the number of questions in each subclass. A higher score indicated stronger agreement with the scale constructs. A necessity-concerns differential was also calculated by subtracting the summed concerns score from the summed necessity score. A higher differential signified greater belief in the necessity of treatment. Finally, to explore attitudes toward medicine in a clinical meaningful way, we divided the patients into one of four attitudinal groups ("accepting", "ambivalent", "skeptical", or "indifferent") based on whether their scaled necessity and concerns scores were above or below midpoint (< 3 or \geq 3). Self-reported medication adherence of participants was then correlated to their attitudes and beliefs. Comparisons between adolescents who attended the transition clinics and those did not were also performed.

Statistical analysis

Statistical analyses were conducted using SAS Version 9.2 (Cary, NC, United States). The sample size calculation determined that 42 participants per cohort was required in order to detect a 30% difference while assuming 40% nonadherence rate in the study cohort and bearing an 80% power. All statistical tests were

two-sided with a 0.05 significance level.

Continuous variables were summarized as means and standard deviations. Categorical variables were reported as counts and percentages. Comparisons between groups were conducted using two-sample *t*-test for continuous data and χ^2 or Fisher's exact test when appropriate for categorical data.

Logistic regression modelling was performed to explore the association of transition clinic use with medication adherence. Attitudes toward medicine were analyzed with the use of a multinomial logistic regression model. Linear regression was conducted to assess the impact of the transition clinic on beliefs about medicine. All models were adjusted for pre-specified confounding variables including age, gender, diagnosis, disease duration, surgical history, and medication use.

RESULTS

A total of 112 adolescents participated in the study. Of those, 59 attended transition clinics. The response rates were 81% and 71% for transition and control group, respectively. Most adolescents continued to have physician contact (with family physicians or adult gastroenterologists) after leaving the pediatric setting (transition vs control: 85.1% vs 87.3%). The predominant reasons for care discontinuation were difficulty obtaining accepting physicians and a belief that physician assessments were not needed.

Demographic data were similar between cohorts (Table 1). However, the transition group had a higher proportion of patients with CD (79.7% vs 64.2%), and on both anti-TNF medication and immunomodulator therapy (23.2% vs 9.3%), compared to controls. Similar levels of disease-specific knowledge and self-reported adherence rates were found between cohorts (Table 2). Approximately 80% of the adolescents reported their basic knowledge (diagnosis and surgical history) in concordance with physician reports. Awareness of specific disease phenotype was similar in both transition and control groups (65.5% vs 60.4%; *P* = 0.69). Self-reported adherence to any medication was poor among adolescents with IBD in both transition and control groups (67.4% vs 56.8%). No significant difference was observed between the two groups on self-reported adherence (OR = 1.38; 95%CI: 0.49-3.86; *P* = 0.54).

The beliefs about and attitudes toward medicine among the adolescents were assessed using the BMQ. Adolescents in the transition cohort held significantly stronger beliefs that medications were necessary (3.4 vs 3.0, *P* = 0.0035), but had comparable concerns (3.2 vs 3.1, *P* = 0.29) toward those medications (Table 3). A higher necessity-concern differential was also noted in the transition cohort (0.2 vs -0.06, *P* = 0.11). The higher differential signifies a greater belief in the necessity of treatment. Both groups had comparable general beliefs (overuse or harm) about

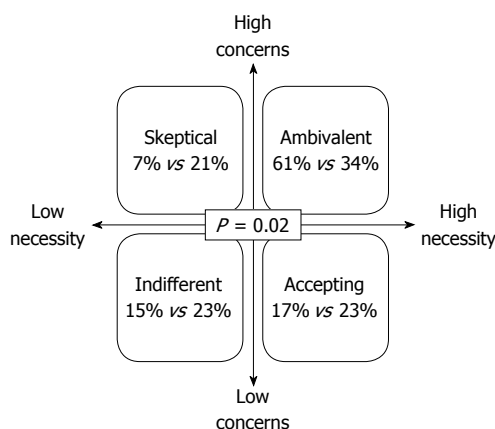


Figure 1 Attitudes toward medicine in adolescents with inflammatory bowel disease (percentages denote proportion of adolescents who attended transition clinics vs control). Adolescents who attended the transition clinics were more ambivalent and less skeptical toward medicine. Overall, significant different composite attitudes were noted between the two groups of adolescents.

Table 2 Disease-specific knowledge and self-reported adherence to prescribed medical therapy *n* (%)

	Transition	Control	<i>P</i> value
Knowledge ¹			
Diagnosis	44 (78.6)	44 (80.0)	1.00
Prior GI surgery	50 (84.7)	49 (89.1)	0.49
Adherence ²			
Medication ³			
5-ASA	8 (57.1)	13 (65.0)	0.73
IM	10 (58.8)	7 (58.3)	1.00
Anti-TNF	5 (83.3)	3 (50.0)	0.55
Combination	13 (76.9)	4 (80.0)	1.00
Any	29 (67.4)	21 (56.8)	0.33
Regular blood work	31 (68.9)	18 (60.0)	0.43

¹Knowledge is defined as concordant physician records and patient responses; ²Adherence is defined as missing less than 30% of prescribed therapy; ³Subgroups in medication row denote patients receiving oral 5-ASA products, IM only, anti-TNF only, combination therapy (IM and anti-TNF) only, or any IBD medication. 5-ASA: 5-aminosalicylic acid; anti-TNF: Anti-tumour necrosis factor agents including infliximab and adalimumab; IM: Immunomodulators including methotrexate, 6-mercaptopurine, and azathioprine.

medicine. Overall, approximately 20% of adolescents had an accepting attitude toward their prescribed medication. However, the transition cohort was less likely to be skeptical (6.8% vs 20.8%) and more likely to be ambivalent (61% vs 34%) to their treatment compared to controls (OR = 0.15, 95%CI: 0.03-0.75; *P* = 0.02) (Figure 1).

DISCUSSION

Appropriate transitioning of pediatric patients with IBD into an adult setting is an important and complex process. Common difficulties identified among adolescents with IBD include poor knowledge related to their disease and a lack of adherence to medical therapy^[5,6].

Table 3 Beliefs about and attitudes toward medicine

	Transition <i>n</i> (%) or mean ± SD	Control <i>n</i> (%) or mean ± SD	<i>P</i> value
Beliefs about medicine ¹			
Specific			
Necessity	17.2 ± 3.8	15.0 ± 4.0	0.0035 ³
Concern	3.4 ± 0.8	3.0 ± 0.8	0.29
Differential	16.1 ± 4.0	15.3 ± 3.5	
General	3.2 ± 0.8	3.1 ± 0.7	
Overuse	1.1 ± 4.7	-0.3 ± 4.7	0.11
Harm	0.2 ± 0.9	-0.06 ± 0.9	
General			
Overuse	9.7 ± 2.5	9.4 ± 2.9	0.63
Harm	3.2 ± 0.8	3.1 ± 1.0	
Composite	14.9 ± 2.7	14.7 ± 2.8	0.70
Attitudes toward medicine ²			
Accepting	10 (16.9)	12 (22.6)	0.45
Ambivalent	36 (61.0)	18 (34.0)	0.004 ³
Skeptical	4 (6.8)	11 (20.8)	0.03 ³
Indifferent	9 (15.3)	12 (22.6)	0.32
Composite			0.02 ³

¹Results presented in each subcategory were summative (top) and scaled (bottom). Differential was calculated by subtracting concerns score from necessity score; ²Four attitudinal groups were created after dichotomizing scaled necessity and concerns scores above or below midpoint (< 3 high or ≥ 3 low) giving: accepting (high necessity, low concerns), ambivalent (high necessity, high concerns), skeptical (low necessity, high concerns), and indifferent (low necessity, low concerns); ³Statistically significant.

Despite the potential for inflation of adherence rates due to self-reporting^[27], we still observed rates as low as 56.8% for medication and 60% for blood work. These data are comparable to previously reported adherence rates of 50%-75% for adolescents with IBD^[9-12]. Similarly, adherence rates among adolescents with other chronic diseases such as asthma and diabetes, as well as those who have undergone procedures where subsequent nonadherence to medication can greatly compromise treatment efficacy (*e.g.*, hematopoietic stem cell transplant), are also reported to be low (40%-80%)^[15,29,30].

Studies have investigated factors that may influence adherence rates in adolescents. Some modifiable aspects include lifestyle, medication regimen, social/healthcare support, knowledge, beliefs, and attitudes^[9,10,17,18,21,22,25,30-34]. A substantial proportion of adolescents in this study had general basic knowledge about their disease type. However, it was difficult to detect subtle and more refined differences in knowledge between the two groups. Similar to reports by Fishman *et al*^[7] and Benchimol *et al*^[8], we noted a limited number of adolescents who were aware of their disease location and/or phenotype. Compared to controls, slightly more adolescents in the transition cohort were better informed of their disease phenotype. This may be a result of more intense education and healthcare support provided^[30,32-34]. Indeed, increased knowledge and awareness of disease has been associated

with better adherence in adolescents with other chronic diseases typically diagnosed in childhood (*e.g.*, asthma)^[30,34].

Attitudes and beliefs regarding medication are strong predictors of adherence to medical therapy^[21,22,24-26]. Compared to controls, adolescents in the transition cohort showed significantly stronger beliefs about the necessity of medical therapy. They were also more ambivalent and less skeptical toward medication. Patients with IBD who have an “accepting” attitude have been found to be least likely to be nonadherent compared to those with one of the other three attitudes^[21,22]. Augmented education sessions such as review on the importance of IBD medications, their side effects and the need for regular monitoring blood works provided in the transition clinics may contribute to the observed difference in attitudes. It is likely that adolescents attending the transition clinics are more aware of the necessity of medical therapy, but remain concerned about the potential side effects, leading to their ambivalent attitudes. Nonetheless, that our study did not demonstrate a significant difference between cohorts in adherence to therapy, suggests that other factors, together with beliefs and attitudes, influence adherence^[9,10,17,18,21,22,25,30-34]. Therefore, clinicians not only should thoroughly review planned medical therapy with the adolescents but also explore other potential aspects such as finance, cultural practices, family and social stability that may impact adherence^[9,10,17,32].

One potential limitation of this study was that the control cohort included patients from a university-affiliated clinic, many of whom were treated by an IBD specialist and as such may have received education comparable to those in the transition group. Therefore, some of the observed differences may be diminished. Additionally, characteristics such as socioeconomic status, ethnicities and locations of residence (urban vs. rural) may affect the adolescents’ beliefs and were not collected in this study.

To our knowledge, this is the first study assessing the impact of transition clinics on the knowledge, attitudes, and beliefs of medical therapy in adolescent patients with IBD. This study also explored the differences in adherence rates. Future studies should focus on determining ways to improve knowledge and adherence among adolescents, as well as the impact of transition clinics on long-term outcomes. Moreover, healthcare professionals should work on determining factors that are essential to conducting successful transition clinics.

In conclusion, adolescents with IBD were found to have low overall adherence to medical therapy, despite exhibiting adequate general knowledge about their disease. Attendance at dedicated transition clinics was associated with adolescents who held a stronger belief that medical therapies were necessary and carried attitudes that were more ambivalent (high necessity, high concerns), but less skeptical (low necessity, high concerns) toward their prescribed therapies.

COMMENTS

Background

Commonly identified issues surrounding the transition of adolescents with inflammatory bowel disease (IBD) are this patient population’s limited disease-specific knowledge and poor adherence to medical therapy. Medication nonadherence can lead to undesirable consequences. Important predictors of adherence to medical therapy are patients’ beliefs and attitudes toward medicine.

Research frontiers

Adolescence is a vulnerable period. Determining key factors associated with successful transition of adolescents with IBD to adult service may minimize complications. Previous studies have demonstrated that adolescents with IBD could only provide basic disease-related information. Nonadherence to medical therapy in adolescents with IBD is reported to be very high, ranging from 50% to 75%.

Innovations and breakthroughs

This study was the first to show that dedicated transition clinics were associated with differences in beliefs and attitudes. Adolescents who attended held a stronger belief that medical therapies were necessary and carried attitudes that were more ambivalent (high necessity, high concerns), but less skeptical (low necessity, high concerns) toward their prescribed therapies.

Applications

This study showed association between attendance to transition clinic with differences in beliefs and attitudes towards medical therapy. Future studies should focus on determining the impact of transition clinics on long-term outcomes. Moreover, healthcare professionals should work on determining factors that are essential to conducting successful transition clinics.

Terminology

IBD, encompassing Crohn’s disease and ulcerative colitis, is a chronic, idiopathic, immune-mediated illness that typically follows a relapsing and remitting course. Transition is defined as the purposeful planned movement of adolescents and young adults from child-centered to adult-oriented healthcare system. Beliefs about Medicine Questionnaire (BMQ) is a validated 17-question tool that evaluates both specific and general beliefs about medicine. BMQ allows for further analysis of attitudes toward medicine.

Peer-review

The authors reported transition clinic attendance is associated with improved beliefs and attitudes toward medicine in patients with IBD. The article is informative and well-presented.

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P- Reviewer: Chiba T, Rosen DJ **S- Editor:** Gong ZM
L- Editor: A **E- Editor:** Zhang FF





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ISSN 1007-9327

