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Are expectations too high for transitioning adolescents with IBD? Examining adult medication knowledge and self-management skills

Laurie N. Fishman, MD⁺, Paul D. Mitchell, MS^{*}, Paul R. Lakin, MS^{*}, Lisa Masciarelli, PNP[§], and Sarah N. Flier, MD^{**}

⁺Division of Gastroenterology and Nutrition, Boston Children's Hospital, Harvard Medical School

^{*}Clinical Research Center, Boston Children's Hospital

[§]Bouve School of Health Sciences, Northeastern University

^{**}Division of Gastroenterology, Beth Israel Deaconess Medical Center, Harvard Medical School

Abstract

Objective—Transition readiness assessment has focused attention on adolescent knowledge and skills, but data-driven benchmarks have not been established.

Methods—Patients with IBD, aged 25–55 years, attending an outpatient gastroenterology clinic, were recruited to complete a voluntary, confidential survey asking patients to recall medications and potential side effects, and to rate their degree of independence performing health maintenance tasks.

Results—The 141 respondents (48% response rate) had mean age of 36 years with median disease duration of 11 years. They were 60% female, 54% had Crohn's disease, and 23% were diagnosed before age 18. Nearly all patients were fully independent answering doctor's questions during the visit (93%) and scheduling office visits (92%). Excluding pharmacy pick up, full independence seen in only 57%, while 16% significantly delegated tasks. No differences by gender, disease type, medication class, age at disease onset, or disease duration were found across levels of self-management. Almost all (97%) respondents could recall medication name, while fewer were able to recall dose (63%) or frequency (65%). Side effect knowledge was poor; among 81 patients on a biologic or immunomodulator, only 17 (21%) cited cancer and 22 (27%) cited infection.

Conclusions—Adolescent IBD transition programs now have empiric data from this study about adult benchmarks for independence in self-management skills. Further research can establish

Corresponding author: Laurie N. Fishman, M.D., Boston Children's Hospital – Division of Gastroenterology and Nutrition, 300 Longwood Avenue, Boston MA 02115, Phone: 617-355-1836, Fax 617-730-0495, Laurie.fishman@childrens.harvard.edu.

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Lisa Masciarelli participated in data acquisition and analysis, and revising the manuscript.

Sarah Flier helped design the study, acquire data and help with interpretation, and substantially revised the manuscript.

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which skills correlate with medication adherence and active collaboration with the medical team. This study also exposes important gaps in medication risk knowledge and may allow improved patient education for subgroups of adult IBD patients.

Keywords

transition; adult; medication knowledge; self-management; IBD

Introduction

Inflammatory bowel disease (IBD) is a chronic, relapsing condition of intestinal inflammation that is often diagnosed in childhood [1]. As pediatric patients mature, they must develop the skills and knowledge that will allow them to succeed in the adult health care setting. Although there has been tremendous focus on transition and transfer [2–5], empiric data is lacking to guide the ideal process to improve outcomes.

It has previously been shown that providers in adult practices perceive transitioning adolescents to have limited medication knowledge and consider this lack of knowledge to be a barrier to effective transfer [6]. Expecting all transitioning patients to know every medication name, dose and side effect is probably unrealistic. However, there is insufficient published data about the current knowledge levels of adult patients to establish appropriate bench mark targets. The majority of literature assessing knowledge of medications has focused on patients in an acute care setting, such as those in the emergency room or at the time of discharge from a hospitalization in which their medications may have changed [7]. Furthermore, much of this work has focused on the geriatric population.

The primary goal of this study was to describe the extent of medication knowledge and self-management skills among a population of adults with IBD to help design appropriate standards for transitioning patients. The secondary aim was to identify patient characteristics associated with differences in either medication knowledge or report of self-management skills.

Materials and Methods

Patients between the ages of 25 and 55 years with an established diagnosis of IBD were recruited from the Center for Inflammatory Bowel Disease at Beth Israel Deaconess Medical Center. Invitation to participate was by written introductory letter provided at check-in for an outpatient visit. Participation was explained to be both voluntary and confidential. Consenting participants were instructed to complete the paper survey anonymously and to secure it in a sealed envelope prior to seeing their provider. Patients who declined participation were asked to return the empty survey in a sealed envelope in order to avoid the provider knowing if the patient participated or refused.

The survey utilized in this study was adapted from an adolescent survey that was developed with the aid of a survey methodologist and pilot tested [8] in a cohort of 90 IBD patients between the ages of 16 and 18 years old. This adolescent survey has been administered to over 400 youth with IBD ages 10–22 to evaluate medication knowledge and self-

management skills in an outpatient setting [9,10]. The survey was minimally changed for adults in this study by substituting “my spouse, parent, significant other” for “my parent.”

The survey elicited demographic information such as age, gender and age at diagnosis of IBD. The participants were asked to select their condition from a list (Crohn’s, ulcerative colitis, indeterminate colitis, other) and to list all IBD medications and the prescribed doses that they were taking at the time of the visit. The survey also requested patients to recall potential side effects, even if they had not experienced that side effect. Participants were given the survey upon arrival at the clinic, prior to receiving their usual medication list for reconciliation, to avoid additional prompting. ID numbers, linked to patient names in a secure and confidential file, were affixed to the surveys to allow subsequent confirmation of diagnosis and medications by the medical record.

The survey asked participants to identify who “usually” performs a variety of tasks that included refilling prescriptions, scheduling visits and contacting the provider between visits if there is a problem. Response options were listed on a 5-point Likert scale as: “Only myself”, “Mostly myself”, “Me and my (spouse, significant other, parent) equally”, “Mostly my (spouse, significant other, parent),” or “Only my (spouse, significant other, parent).” Henceforth, “spouse, significant other, parent” will be referred to as “relative.” Two questions allowed a response of “no one.”

Data analysis

Outcomes of interest included the 5-point and 6-point Likert scales items for self-management, as well as dichotomies for correct medication recall, correct dose recall, and correct dose frequency recall. Additionally, the ability to recall potential side effects of infection and cancer was investigated. Nine self-management tasks were combined and coded for analysis as fully independent (“only me” response for every task), partially independent (“only me”, “mostly me” or “me and my relative” for every task), and delegating (“mostly my relative” or “only my relative” for any task). Responses of “no one” for two tasks were recoded as “only me.” Picking up medication from the pharmacy was not included in the definition of independence, because this may reflect convenience rather than independence. Degree of independence was not defined for three patients who did not respond to one or more task questions.

The association of several patient characteristics with outcomes was investigated, including respondent age (years), sex, disease classification (Crohn’s vs. all others), disease duration (years), pediatric disease onset (<18 versus ≥18 years), and drug classification (aminosalicylates, immunomodulators, and biologics). Complete data were obtained for these characteristics except for disease duration (n=13 unknown) and pediatric disease onset (n=2 unknown). The number unknown is shown in a footnote for each table, but may differ across tables based on availability of outcome data. Comparisons across outcome categories was made by Pearson Chi-square test for categorical variables, or Fisher’s exact test when one or more expected cell counts was <5. Disease duration was right-skewed, and is presented as median (interquartile range; IQR) and compared across outcome categories with an appropriate nonparametric test (Wilcoxon rank-sum for two categories, Kruskal-

Wallis for three). Since all but four respondents could recall the name of their medication, comparisons of patient characteristics by medication name recall were not made.

A stepwise logistic regression was used to investigate the effect of patient characteristics on correct recall of potential side effects. Variables were required to have $P < 0.10$ to enter the model and $P < 0.05$ to remain in the model. Data were analyzed with SAS® version 9.2 (Cary, NC). All tests of significance are two-sided, with $P < 0.05$ considered statistically significant.

Ethical Considerations

Institutional Review Board approval was obtained for the study at Boston Children's Hospital (where the survey was designed and the analysis was done) and reliance granted by the Beth Israel Deaconess Medical Center (where the patients were recruited and medical records were reviewed).

Results

Demographics

A total of 296 surveys were distributed and 141 returned for a response rate of 48%. Two partially completed surveys were included in the analysis whenever possible. Non-respondents did not differ from respondents by age or diagnosis. Respondents were 36 ± 7 years on average (range 24 – 55), 60% female and 54% were diagnosed with Crohn's disease. Time since IBD diagnosis ranged from as little as 1 year to as many as 32 years, with a median (IQR) duration of 10.5 (6.0, 16.0) years. Pediatric disease onset, defined as diagnosis prior to 18 years of age, occurred in 32 (23%) subjects at a median (IQR) age of 13 (11, 16) years, while adult onset occurred at 25 (22, 30) years.

Self-Management

Responses to questions targeting self-management tasks are shown in Table 1. Many patients performed individual tasks without assistance from others (i.e. "only me" response), particularly the tasks of answering doctor's questions during the visit (93%) and clinic visit scheduling (92%). Patients were least likely to independently pick up medication from the pharmacy (56%) or prepare a list of questions before visiting the doctor (52%).

When pharmacy pick up was excluded, full independence, indicating "only me" to every task (or that the task was not performed), was found for just 57%, followed by 27% who were partially independent and 16% who delegated. No differences by sex, disease type, medication class, age at disease onset, or disease duration were found across the three levels of self-management as seen in Table 2.

Medication

Nearly all subjects (97%) were able to recall at least one of their medications by name, while fewer were able to recall their medication dose (63%) and frequency (65%). Table 3 compares medication dose and frequency recall according to several key patient characteristics. No differences were found among patients in recall of details for

aminosalicylates or immunomodulators; however, dose recall for biologics was higher among men than women ($P=0.03$), and pediatric onset patients recalled the dosing interval for biologics better than those with adult onset ($P=0.03$).

Patients were asked to indicate potential side effects of the drugs they could recall, even if they had not experienced the side effect. Among 122 patients responding to this question, 55 (45%) were able to recall a potential side effect (Table 4). Patients able to recall at least one side effect were more likely female (67% vs. 52%; $P=0.09$), less likely to be on aminosalicylates only (20% vs. 45%; $P=0.004$), and more likely to be on immunomodulators (40% vs 24%; $P=0.06$). A stepwise multiple logistic regression model of gender, disease type, drug class, age of disease onset, and disease duration found that female respondents were more likely to recall a potential side effects than males (OR 2.24, $P=0.04$) as were patients on immunomodulators or biologics compared to those on aminosalicylates only (OR 3.67, $P=0.003$;). Most respondents did not mention serious side effects; of the 81 patients on either a biologic or immunomodulator, only 17 (21%) mentioned cancer and 22 (27%) mentioned infection.

Discussion

Self-management

There is a consensus that adolescents approaching the time of transfer to adult care need assessment and teaching of self-management skills in order to succeed in adult health care settings. [11][12] A wide variety of assessment tools have been proposed and studied [13] without emergence of a single best tool. The transition process also varies among settings, ranging from joint clinics, specialized transition clinics, alternating visits between adult and pediatric clinics, and a coordinator as bridge [2] [5][14]. The only aspect that is consistently cited as a crucial element is the structure. [15–17]

While data has shown that adult providers report problems with young patients with IBD transferring into their practice [6], there is little information about how adult patients with IBD compare. Several studies evaluate younger IBD patients' self-management skills. Gray and colleagues evaluated 195 patients with the TRAQ (transition readiness Assessment questionnaire) and found only 5.6% of patients demonstrated transition readiness. [18] Whitfield and colleagues assessed 67 patients aged 10–21 and found some tasks but not communication with health care providers showed improvement with age but not duration of illness. (19) van Groningen and colleagues studied over 400 patients over the age of 10 and noted age-related improvements but still showed a significant proportion relying on parents for these tasks above the age of 18. [10] The goals of self-management teaching are rarely articulated, leaving the implication that patients need to master all the skills completely. In one elegant study, the benchmarks are set by expert opinion involving both adult and pediatric providers at mastery of 90% of the skills. [18]

Our study found that only 57% of adult patients with IBD reported full independence with self-management tasks such as scheduling office visits, obtaining refills or contacting providers between visits if there is a problem. More than 10% of adult patients bring a relative with them into the exam room. It is not known whether these findings are typical.

However, if other researchers confirm these findings, it would have important consequences for the transition planning of adolescents with IBD and perhaps even other chronic conditions.

Medication

The patients in our study showed excellent recall for medication name at a higher rate than is reported in the literature. A study of 100 IBD patients in Ireland noted 86% of patients correctly identified their medication name, although did not discuss dose or frequency [20]. One report notes that, of 94 patients in a preoperative clinic, more than 90% had discrepancies between what patients listed for medications and what was recorded in the clinic medication list with an average discrepancy of 4 medications per patient [21]. In another study, only 31% of patients had all medications and doses match between patient interview and medical record [22]. In many ambulatory situations, patients are given a medication list and asked to reconcile their current use with the list. It has been assumed that this prompting improves accuracy. However, at least one study of 315 adult patients demonstrated that patients completing the medicine reconciliation from a list made 2.3 errors compared with 1.2 for those completing from memory and 1.8 for those completing from their pill bottles ($P < .001$)[23].

Our higher recall rate may stem from the fact that this is a specialty clinic and patients have been exposed to repeated provider contact and discussion of the same medications over time. This is in contrast to most of the literature, which has focused on primary care settings or patients at the onset of a problem such as in preoperative or emergency care. Another difference may be that our study was quite lenient, for example, we gave credit for dosing if the patient mentioned the number of tablets or gave the milligram dosage. It is difficult to establish whether other studies had a similar bias. Another difference is that our population, by design, did not include geriatric patients. It is known that even cognitively intact patients over the age of 65 have very poor recall of medications. In one study of 99 elderly patients only 22% could correctly recall the names of their medications[24].

As more patients are given immunosuppressant and immunomodulatory medications, the risk for infection increases and requires more vigilance on the part of patients as well as their providers to be alert for early symptoms[25]. The poor recall of side effects in this study is concerning but not surprising as other groups have shown similarly disappointing results. For example, Siegal et al. surveyed 165 adult patients with IBD and found that 37% did not think infliximab was associated with a risk of lymphoma[26].

Patients seem willing to have interval educational offerings. One Canadian study asked 271 IBD patients at 11 years post-diagnosis about their preferences, and noted that approximately 60% rated having information given now on medications and self-management would be helpful [27]. However, repeated education sessions are probably necessary as one study of IBD patients compared videotaped visits with a survey of these patients 3 weeks later and found patients remembered about half of what was discussed[28].

Limitations

This study is limited to the experience of a single academic center. We did not elicit highest educational level achieved nor test the functional health literacy of the patients, and it is known that recall of medications is far lower if health literacy is inadequate (29). Race and socioeconomic data were not collected. We did not distinguish who the “other” participant was in relation to the patient. It would be interesting to determine whether spouses, romantic partners, friends, siblings or children played a role in the patient’s health care and the reasons for the involvement.

While social desirability bias always needs to be considered, the results were returned to the front desk in a sealed envelope without a name, so that patients could return even a blank form without concern for offending their provider. Furthermore, the variability of the answers across question blocks would indicate that respondents considered each question separately.

Conclusions

Mastery of medication knowledge and self-management skills are generally deemed important for patients moving into the adult health care settings. However, this is the first study to examine skills previously assessed in a pediatric IBD practice in a population of adults with IBD in order to develop data-driven standards for transition programs. Benchmarks should ideally be within reach and represent actual practice. In our study, almost half of the adult patients with IBD reported delegating some tasks related to self-management despite being almost entirely independent in answering doctor’s questions and scheduling visits. Furthermore, despite correct recall of medication names and (to a lesser extent) dose and frequency, side effect knowledge was poor. This study therefore suggests that our current expectations for transitioning patients are too high if we are basing them on adult behavior. As such, our findings indicate the need for changes in IBD patient education as well as better benchmarks for transition. Perhaps collaboration with family members will be incorporated into self-management teaching for both adult and pediatric programs. Likewise interval questions and re-education about medication may be helpful for adults as well as pediatric patients. A larger and more diverse sampling of national IBD programs will help guide appropriate benchmarks for the emerging transition programs across the country.

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What is Known

Inadequate transition readiness has been shown to affect outcome in adult health in diabetes and transplant patients.

Adult GI providers report medication knowledge is problematic in over half of patients transferring from pediatric IBD care.

Increasing number of IBD programs are assessing transition readiness with checklists or questionnaires, however thresholds are either absent or based entirely on expert opinion.

What is new

Adults with IBD have poor knowledge of medication side effects, and one third cannot recall dose or frequency of IBD medication.

In adults aged 25 to 50, only 57% are fully independent in self-management tasks such as contacting provider between visits if a problem arises, calling in refills of medication or asking questions during an office visit.

Patients with pediatric onset of disease have same self-management skills and medication knowledge as those with adult onset of IBD

Table 1

Responsibility for Self-management tasks.

Question	Only me	Mostly me	Me and relative	Mostly relative	Only relative	No one
1. Who answers the doctor's questions during the visit?	131 (92.9%)	5 (3.6%)	4 (2.8%)	1 (0.7%)	0 (0.0%)	N/A
2. Who schedules your office visit?	129 (91.5%)	9 (6.4%)	1 (0.7%)	0 (0.0%)	2 (1.4%)	N/A
3. Who is present with you in the exam room?	124 (89.2%)	2 (1.4%)	13 (9.4%)	N/A	N/A	N/A
4. Who comes with you to the doctor's office?	122 (86.5%)	1 (0.7%)	18 (12.8%)	N/A	N/A	N/A
5. Who contacts the doctor or nurse between visits if there is a problem?	120 (85.1%)	15 (10.6%)	4 (2.8%)	1 (0.7%)	1 (0.7%)	N/A
6. Who reminds you to take your medication?	115 (82.1%)	17 (12.1%)	7 (5.0%)	0 (0.0%)	1 (0.7%)	N/A
7. Who calls in your medication refills?	115 (81.6%)	16 (11.4%)	4 (2.8%)	4 (2.8%)	2 (1.4%)	N/A
8. Who asks questions of the doctor during the visit?	112 (79.4%)	8 (5.7%)	7 (5.0%)	1 (0.7%)	0 (0.0%)	13 (9.2%)
9. Who picks up your medication from the pharmacy?	79 (56.0%)	35 (24.8%)	19 (13.5%)	3 (2.1%)	5 (3.6%)	N/A
10. Who prepares a list of questions before coming to the doctor?	73 (51.8%)	11 (7.8%)	6 (4.3%)	0 (0.0%)	2 (1.4%)	49 (34.7%)

N=141 for all questions except #3 (n=139) and #6 (n=140).

Relative = spouse, significant other, or parent.

N/A = not applicable. Only questions 8 and 10 provide the response option "no one."

Table 2

Comparison of patient characteristics with degree of self-management.

Characteristic	Total n=138	Fully independent n=79 (57%)	Partially independent n=37 (27%)	Delegator n=22 (16%)	P
Female	83 (60%)	49 (62%)	18 (49%)	16 (73%)	0.16
Crohn's disease	73 (53%)	39 (49%)	22 (59%)	12 (55%)	0.59
Aminosalicylates only	41 (30%)	26 (33%)	10 (27%)	5 (23%)	0.60
Any immunomodulator	38 (28%)	20 (25%)	9 (24%)	9 (41%)	0.31
Any biologic	46 (33%)	23 (29%)	13 (35%)	10 (45%)	0.34
Pediatric onset (diagnosis at < 18y old)	31 (23%)	18 (23%)	11 (30%)	2 (10%)	0.21
Disease duration (years since diagnosis)	10.5 (6.0, 16.0)	11.0 (7.0, 16.0)	10.5 (6.0, 17.0)	5.0 (4.0, 16.0)	0.14

Degree of self-management excludes picking up medication from the pharmacy, and is undefined for 3 patients who failed to respond to one or more task questions.

Crohn's patients were compared to colitis patients.

Patients on immunomodulators or biologics were compared to patients only on aminosalicylates or prescribed no drugs.

P-value from Pearson chi-square test or Kruskal-Wallis test. Age at diagnosis is unknown for 1 patient, and disease duration is unknown for 11 patients.

Table 3

Patient characteristics associated with recall of medication dose and frequency.

Characteristic	Recall dose	P	Recall frequency	P	Recall both(dose + frequency)	P
Aminosalicylates (n = 74 on drug)						
	n = 49		n = 52		n = 45	
Female	33 (67%)	0.53	35 (67%)	0.50	31 (69%)	0.37
Crohn's disease	18 (37%)	0.78	20 (38%)	0.86	17 (38%)	0.99
Pediatric onset (diagnosis at < 18y old)	6 (12%)	0.72	8 (15%)	0.71	5 (11%)	0.49
Disease duration (years since diagnosis)	9.0 (4.5, 14.5)	0.97	10.5 (4.5, 16.0)	0.36	9.0 (5.0, 15.0)	0.88
Immunomodulators (n = 41 on drug)						
	n = 31		n = 34		n = 30	
Female	16 (52%)	0.15	20 (59%)	1.00	16 (53%)	0.31
Crohn's disease	13 (42%)	0.72	13 (38%)	0.21	12 (40%)	0.49
Pediatric onset (diagnosis at < 18y old)	9 (29%)	1.00	8 (24%)	0.17	8 (27%)	0.70
Disease duration (years since diagnosis)	8.5 (6.0, 15.0)	0.79	8.0 (6.0, 15.0)	0.24	8.0 (6.0, 16.0)	0.69
Biologics (n = 48 on drug)						
	n = 33		n = 31		n = 26	
Female	15 (45%)	0.03	15 (48%)	0.14	12 (46%)	0.13
Crohn's disease	26 (79%)	0.29	23 (74%)	1.00	20 (77%)	0.50
Pediatric onset (diagnosis at < 18y old)	10 (32%)	0.28	11 (38%)	0.03	9 (38%)	0.07
Disease duration (years since diagnosis)	9.0 (6.0, 19.0)	0.10	9.0 (6.0, 17.0)	0.38	9.0 (7.0, 19.0)	0.25

P-value from Pearson chi-square test, Fisher exact test, or Wilcoxon rank-sum test. Age at diagnosis is unknown for 2 patients, and disease duration is unknown for 12 patients.

Table 4

Comparison of patient characteristics by potential side effect recall.

Characteristic	Recalled potential side effect		P
	No(n=67)	Yes(n=55)	
Female	35 (52%)	37 (67%)	0.09
Crohn's disease	34 (51%)	30 (55%)	0.68
Aminosalicylates only	30 (45%)	11 (20%)	0.004
Any immunomodulator	16 (24%)	22 (40%)	0.06
Any biologic	24 (36%)	24 (44%)	0.38
Pediatric onset (diagnosis at < 18y old)	14 (21%)	12 (23%)	0.82
Disease duration (years since diagnosis)	10.0 (6.0, 15.0)	9.0 (5.0, 16.0)	0.81

P-value from Pearson chi-square test or Wilcoxon rank-sum test. Age at diagnosis is unknown for 2 patients, and disease duration is unknown for 12 patients.