OPEN

Provider Awareness Alone Does Not Improve Transition Readiness Skills in Adolescent Patients With Inflammatory Bowel Disease

*Laurie N. Fishman, †Sonja I. Ziniel, ‡Max E. Adrichem, §Susan M. Fernandes, and *Janis Arnold

ABSTRACT

Objective: Adolescent patients with chronic health conditions must gradually assume responsibility for their health. Self-management skills are needed for a successful transfer from adolescent to adult health care, but the development of these skills could be resource intensive. Pediatric providers are already instrumental in teaching patients about their health and may improve these skills. The aim of the study was to evaluate whether informal education of pediatric providers regarding transition improves inflammatory bowel disease (IBD) patient self-management skills.

Methods: Consecutive patients with IBD older than 10 years who presented to the outpatient setting were administered a survey regarding self-management behaviors in 2008 and 2011. During this time, several conferences on transition were presented to the providers.

Results: In 2008, 294 patients completed the survey (82%) compared with 121 patients (89%) in 2011. The patient groups were comparable with respect to sex (boys 50% vs 42%), mean age (16.7 vs 16.2 years), and type of IBD (Crohn 68% vs 66%). The 13- to 15-year-olds reported calling in refills (11%, 8%, respectively), scheduling clinic appointment (0, 1%), preparing questions (13%, 5%), and taking the main role in talking during clinic visits (15%, 24%). The 16- to 18-year-olds reported calling in refills (13%, 27%), scheduling clinic appointments (9%, 6%), preparing questions (9%, 16%), and taking the main role in talking in clinic visits (36%, 45%). Responsibility for behaviors gradually increases with age, but did not differ significantly between 2008 and 2011.

Conclusions: Increasing awareness around transition readiness for pediatric providers had an insignificant effect on the self-management skills of patients with IBD. A more formal or structured approach is likely required to improve transition skills in adolescent patients.

Key Words: inflammatory bowel disease, self-management, transition

(*JPGN* 2014;59: 221–224)

Inflammatory bowel disease (IBD) is often diagnosed in the pediatric age group, and these patients will eventually transfer from pediatric to adult health care. The prevailing culture of pediatric- and adult-centered care, however, differs tremendously (1,2). Although pediatric care values nurturance and often includes family members, the adult-centered care model values autonomy and respect for a patient's privacy, often with subsequent exclusion of family members. Adult-centered care requires a more active level of participation and self-management by the patient. Thus, the development of self-management skills is essential for a successful transition. Decision making, self-advocacy, communicative skills, and medication knowledge are all important aspects of self-management and need to be developed to facilitate a smooth transition to adult health care (3–5). Medication knowledge can be imparted as early as 10 to 12 years (6) and recommendations have been made for the gradual assumption of other self-management skills as patients mature. These skills include understanding the disease and the ability to schedule appointments and contact the provider.

Transition planning is increasingly recognized as an essential aspect of clinical care, yet <50% of children with special health care needs nationally are receiving these services (7). Although the need for transition planning is clear, the way to accomplish this is less certain. The majority of transition literature consists of expert opinion and recommendations rather than evidence-based conclusions (1,8–11). It is not yet known what constitutes the best way to accomplish efficient and effective transition planning (12). Some programs have transition coordinators who track all patients in the age range of interest or who attend visits with the patient in the adult setting (13). In some conditions, joint pediatric and adult clinics allow the providers to see patients together. Creating a formal comprehensive assessment and education program would be time and resource intensive. Transition clinics, whether for a single-disease entity or for all graduating patients, can add an institutional political element to the discussion. Without a clear reimbursement strategy, the approach to a formal structured transition seems expensive.

Providers, however, impart tremendous amounts of information to patients in their typical interactions and patients view providers as the single best source of information. Providers presently report providing transition assessment and information on an informal basis (14). It seems plausible that increasing the awareness and knowledge of providers could have a large impact on their patients' behavior. Before allocating extensive resources, we sought to examine the role of provider education and awareness in the

---

Received November 19, 2013; accepted April 11, 2014.

From the *Center for Inflammatory Bowel Disease and Division of Gastroenterology and Nutrition, Boston Children's Hospital, the †Department of Pediatrics, Harvard Medical School, Boston, MA, the ‡University of Amsterdam, Amsterdam, The Netherlands, and the §Division of Pediatric Cardiology, Lucile Packard Children's Hospital at Stanford, Palo Alto, CA.

Address correspondence and reprint requests to Laurie N. Fishman, MD, 300 Longwood Ave, Boston MA 02115 (e-mail: Laurie.fishman@childrens.harvard.edu).

This article has been developed as a Journal CME Activity by NASPGHAN. Visit *http://www.naspghan.org/wmspage.cfm?parm1=742* to view instructions, documentation, and the complete necessary steps to receive CME credit for reading this article.

The authors report no conflicts of interest.

DOI: 10.1097/MPG.0000000000000405

patients' self-management skill acquisition in an evidence-based manner.

METHODS

Consecutive patients with IBD older than 10 years who presented to the outpatient setting were identified and administered a survey before seeing their provider. Patients given the diagnoses of Crohn disease, ulcerative colitis, or indeterminate colitis by histologic and endoscopic criteria were included. Patients were excluded if they had only recently been diagnosed as having IBD (<2 months) or if they were unable to fill out the survey (non–English-speaking patients or patients with severe developmental delays). The surveys were distributed consecutively at outpatient IBD clinic appointments during 2008 and 2011. A total of 358 patients were approached in 2008 and 156 patients in 2011. The survey was introduced by a letter given with the survey with parallel questionnaires for patients and parents. Participation was confidential, voluntary, and identified only by coded numbers. The survey was deidentified by putting it in a nameless sealed envelope, coded with serial numbers, and then collected by a member of the research staff before the appointment with the doctor to ensure confidentiality and anonymity. The providers were unaware of the patients' answers or even whether they had completed the survey. Details of the survey can be found in previously published work (15).

Educational sessions on the topic of transition were held in 2009 and 2010 for all clinicians in the gastroenterology division, including attendings, fellows, nurses, dietitians, and social workers. All faculty attended at least 2 sessions and some attended all sessions. Two 60-minute sessions were factual, evidence-based lectures on transition. Two 60-minute sessions were case-based discussions designed to challenge and shift provider attitude. One of these cases is published and can be used publicly (16). The sessions raised awareness of the topic but did not prescribe or mandate any specific behavior. Informal discussions and hallway conversations among various providers on this topic once it was raised were noted and advice was sought from the educational session presenters for specific patient recommendations.

Data Analysis

The committee on clinical investigation deemed this study to be a quality improvement initiative not requiring formal review. Patient demographics and Likert scores were described by frequency and described as proportions. Analyses included descriptive statistics, cross-tabulations for categorical variables, and analyses of variance for continuous variables and logistic regressions. Significance was determined using the Fisher exact test for cross-tabulations and Wald test statistics for the coefficients of the logistic regressions. All analyses were performed using SPSS version 19 (IBM SPSS Statistics, Armonk, NY).

RESULTS

In 2008, 294 of 313 (94%) participants completed surveys. In 2011, 142 of 154 (92%) participants completed surveys. There were 40 patients who participated in both the 2008 and the 2011 cohorts. Demographics of both cohorts were similar (Table 1). The mean age in years was 16.7 (standard deviation 3.5) in 2008 and 16.5 (standard deviation 3.5) in 2011. There were no significant differences in the 2 groups, and previous exposure to the survey did not demonstrate reports of increased self-management skills.

Independent self-management behaviors regarding medication-related tasks did not differ between the 2 groups (Table 2). There was a steady rise in reported participation in both groups. Patients showed the least independence in behaviors that occur

TABLE 1. Demographics of respondents

Demographics	2008	2011	*P*
N	294	142	
Age, y (%)			
10–12	50 (17)	19 (13)	ns
13–15	82 (28)	36 (25)	ns
16–18	77 (26)	50 (35)	ns
19–21	51 (17)	25 (18)	ns
>21	34 (12)	12 (9)	ns
Sex (%)			
Male	148 (50)	62 (44)	ns
Female	146 (50)	80 (56)	ns
Diagnosis (%)			
CD	201 (68)	96 (68)	ns
UC	82 (28)	44 (31)	ns
IC	11 (3)	2 (1)	ns
Duration of disease, y (%)			
3 or less	159 (54)	63 (44)	ns
>3	54 (46)	79 (56)	ns
Medication (%)			
On calcineurin inhibitors	6 (2)	3 (2)	ns
On biologics	84 (29)	55 (39)	ns
On immunomodulators	133 (45)	25 (18)	ns
On aminosalicylates	122 (41)	52 (37)	ns

For each cohort the number of respondents is listed with corresponding percentages. Patients could be taking >1 medication so the percentages do not add up to 100. There are no significant differences in the cohorts in terms of age, sex, diagnosis, or duration of disease, or in medication. CD = Crohn disease; IC = indeterminate colitis; ns = not significant; UC = ulcerative colitis.

TABLE 2. Independent behavior regarding medication among respondents

Behavior by age, y	2008	2011	*P*
Calls in refills (%)			
10–12	0	0	ns
13–15	11	8	ns
16–18	13	27	ns
19–21	45	65	ns
>21	76	70	ns
Picks up medication at pharmacy (%)			
10–12	0	0	ns
13–15	0	0	ns
16–18	10	15	ns
19–21	47	52	ns
>21	73	60	ns
Remembers to take medication (%)			
10–12	26	11	ns
13–15	41	36	ns
16–18	59	57	ns
19–21	84	87	ns
>21	94	100	ns

Independent behavior is considered 4 (''mostly me'') or 5 (''I do it totally myself'') and represents the responsibility for doing the task rather than whether the task was always completed. Percentage is proportion of those who answered 4 or 5 over the total number in that age group that year. There were no significant differences seen in any group. ns = not significant.

TABLE 3. Independent between-visit behaviors among respondents

Behavior by age, y	2008	2011	*P*
Contact MD if problem (%)			
10–12	0	0	ns
13–15	1	0	ns
16–18	12	12	ns
19–21	31	56	ns
>21	65	67	ns
Schedules appointments (%)			
10–12	2	0	ns
13–15	1	0	ns
16–18	9	6	ns
19–21	34	56	ns
>21	67	75	ns
Remembers appointments (%)			
10–12	2	0	ns
13–15	3	0	ns
16–18	14	12	ns
19–21	41	52	ns
>21	73	83	ns

Independent behavior is considered 4 (''mostly me'') or 5 (''I do it totally myself'') and represents the responsibility for doing the task rather than whether the task was always completed. Percentage is proportion of those responding 4 or 5 compared with the total in that age group that year. There is no statistically significant difference between groups. ns = not significant.

outside the visit, such as scheduling appointments or contacting the provider if there was a problem that arose (Table 3). There was a trend toward independence over time, with 31% of 19- to 21-year-olds contacting the provider between visits in 2008, increasing to 56% in 2011, although this did not reach statistical significance. Patients showed the most independence with behaviors during the provider visits (Table 4). Preparing questions was the only category that reached statistical significance and only with those >21 years, increasing from 30% in 2008 to 67% in 2011.

DISCUSSION

We found that exposing providers to the concept and issues of transition did not result in significant changes in the reported self-management of patients in this evidence-based study. There remain extremely large gaps in the self-management skill sets of patients by age 18, an age at which many patients live apart from parents at college or are required to switch to adult-centered care.

In previous studies, we have shown that self-management skills often develop late, past the age at which many patients transfer to adult-centered care. This is in line with other studies that report psychosocial developmental milestones may be delayed in this population. Patients with IBD are reported to have fewer jobs in secondary school, vacation without adults less often, and fall in love later (17). Young adults with other pediatric-onset conditions tend to have similar delayed development (18).

The need for increased self-management skills in patients is clear because the health outcomes after transition often worsen, as has been documented in patients with diabetes mellitus, sickle cell disease, congenital heart disease, and liver transplantation (19–23). The added costs of teaching patients, coordination of care, and extra communication with accepting providers can, however, be problematic in this resource-conscious time. The American Academy of Pediatrics surveyed pediatricians and found that a low percentage followed transition guidelines because of limited staff training, lack of an identified staff member responsible for transition, and financial barriers (24). In Rhode Island, 1 multidisciplinary pilot transition clinic found that clinical billing did not cover the cost of care (25).

TABLE 4. Independent visit–related behaviors among respondents

Behavior by age, y	2008	2011	*P*
Prepared questions (%)			
10–12	12	11	ns
13–15	13	5	ns
16–18	9	16	ns
19–21	22	24	ns
>21	30	66	0.041
Main role in talking (%)			
10–12	8	17	ns
13–15	15	24	ns
16–18	36	45	ns
19–21	61	76	ns
>21	85	92	ns
Asks questions (%)			
10–12	4	6	ns
13–15	10	11	ns
16–18	14	20	ns
19–21	54	52	ns
>21	68	83	ns
Answers questions (%)			
10–12	16	22	ns
13–15	36	32	ns
16–18	56	64	ns
19–21	86	92	ns
>21	100	100	ns

Independent behavior is considered 4 (''mostly me'') or 5 (''I do it totally myself'') and represents the responsibility for doing the task rather than whether the task was always completed. Percentage is proportion of those responding 4 or 5 compared with the total in that age group that year.

Many of the suggested transition interventions involve the expenditure of extra time or hiring of extra staff. A pilot study of liver transplant patient outcomes was improved by the addition of a transition coordinator (13). Some specialty clinics have joint clinics, with staff from both adult and pediatric providers (26), but insurance coverage may be problematic. Another recommendation is to have scheduled observations by each set of providers; however, that author notes ''reimbursement for such activities may be challenging in systems of care dominated by insurance companies'' (27).

This was a single-center study. The survey documents reported behavior rather than observed behavior; thus, there may be a social desirability bias that causes overestimation of independence. We also did not collect disease severity, which has been shown to affect shared management (28), and transitional care is limited during a flare of the disease (29). This study may have been underpowered, because many categories showed a trend toward improved self-management skills but failed to reach statistical significance.

CONCLUSIONS

Patients look to their providers for information about their condition and management. Although informal education of providers does seem to effect small shifts in patient behavior, it seems clear that a structured transition program would be needed to effectively move patients to more consistent self-management. Future studies are needed to assess the most cost-effective way to educate patients and providers, as well as to judge the outcomes of various transition strategies.

REFERENCES

1. Leung Y, Heyman MB, Mahadevan U. Transitioning the adolescent inflammatory bowel disease patient: guidelines for the adult and pediatric gastroenterologist. *Inflamm Bowel Dis* 2011;10:2169–73.
2. Goodhand J, Hedin CR, Croft NM, et al. Adolescents with IBD: the importance of structured transition care. *J Crohns Colitis* 2011;5:509–19.
3. Rosen DS. Transition of young people with respiratory diseases to adult health care. *Paediatr Respir Rev* 2004;5:124–31.
4. Giarelli E, Bernhardt BA, Mack R, et al. Adolescents' transition to self-management of a chronic genetic disorder. *Qual Health Res* 2008;18: 441–57.
5. Hess JS, Straub DM. Preliminary findings from a pilot health care transition education intervention for adolescents and young adults with special health care needs [brief report]. *J Pediatr Psychol* 2011;36:172–8.
6. Hait E, Arnold JH, Fishman LN. Educate, communicate, anticipate-practical recommendations for transitioning adolescents with IBD to adult health care. *Inflamm Bowel Dis* 2006;12:70–3.
7. McManus MA, Pollack LR, Cooley WC, et al. Current status of transition preparation among youth with special needs in the United States. *Pediatrics* 2013;6:1090–7.
8. Baldassano R, Ferry G, Griffiths A, et al. Transition of the patient with inflammatory bowel disease from pediatric to adult: recommendations of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition. *J Pediatr Gastroenterol Nutr* 2002;3:245–8.
9. American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics* 2002;110:1304–6.
10. Escher JC. Transition from pediatric to adult health care in inflammatory bowel disease. *Dig Dis* 2009;27:382–6.
11. El-Matary W. Transition of children with inflammatory bowel disease: big task, little evidence. *World J Gastroenterol* 2009;15:3744–7.
12. Stinson J, Kohut SA, Spiegel L, et al. A systematic review of transition readiness and transfer satisfaction measures for adolescents with chronic illness. *Int J Adolesc Med Health* 2014;26:159–74.
13. Annunziato RA, Baisley MC, Arrato N, et al. Strangers headed to a strange land? A pilot study of using a transition coordinator to improve transfer from pediatric to adult services. *J Pediatr* 2013;163:1628–33.
14. Fernandes S, Fishman LN, O'Sullivan-Oliveira J, et al. Current practices for the transition and transfer of patients with a wide spectrum of pediatric-onset chronic diseases: results of a clinician survey at a free-standing pediatric hospital. *Int J Child Adolesc Health* 2010;3:507–17.
15. van Groningen J, Ziniel S, Arnold J, et al. When independent health care behaviors develop in adolescents with inflammatory bowel disease. *Inflamm Bowel Dis* 2012;18:2310–4.
16. Fishman L. But Tommy likes it here: moving to adult medicine. *www.mededportal.org/publication/9190*. Accessed June 26, 2014.
17. Hummel TZ, Tak E, Maurice-Stam H, et al. Psychosocial developmental trajectory of adolescents with inflammatory bowel disease. *J Pediatr Gastroenterol Nutr* 2013;2:219–24.
18. Stam H, Hartman EE, Deurloo JA, et al. Young adult patients with a history of pediatric disease: impact on course of life and transition into adulthood. *J Adolesc Health* 2006;1:4–13.
19. Pacaud D, Yale JF, Stephure D, et al. Problems in transition from pediatric care to adult care for individuals with diabetes. *Can J Diabetes* 2005;29:13–8.
20. Cadario F, Prodam F, Bellone S, et al. Transition process of patients with type 1 diabetes (T1DM) from paediatric to the adult health care service: a hospital-based approach. *Clin Endocrinol* 2009;71:346–50.
21. Gurvitz M, Valente AM, Broberg C, et al. Prevalence and predictors of gaps in care among adult congenital heart disease patients: HEART-ACHD (The Health, Education, and Access Research Trial). *J Am Coll Cardiol* 2013;61:2180.
22. Brousseau DC, Owens PL, Mosso AL, et al. Acute care utilization and rehospitalizations for sickle cell disease. *JAMA* 2010;303:1288–94.
23. Annunziato RA, Emre S, Shneider B, et al. Adherence and medical outcomes in pediatric liver transplant recipients who transition to adult services. *Pediatr Transplant* 2007;6:608–14.
24. Cooley WC, Sagerman PJ. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics* 2011;128: 182–200.
25. McLaughlin S, Bowering N, Crosby B, et al. Health care transition for adolescents with special health care needs: a report on the development and use of a clinical transition service. *RI Med J* 2013;4:25–7.
26. Dabadie A, Troadec F, Heresbach D, et al. Transition of patients with inflammatory bowel disease from pediatric to adult care. *Gastroenterol Clin Biol* 2008;32 (5 pt 1):451–9.
27. Camfield P, Camfield C, Pohlmann-Eden B. Transition from pediatric to adult epilspsy care: a difficult process marked by medical and social crisis. *Epilepsy Curr* 2012;12 (suppl 3):13–21.
28. Kieckhefer GM, Trahms CM, Churchill SS, et al. Measuring parent-child shared management of chronic illness. *Pediatr Nurs* 2009;35: 101–8.
29. McDonagh JE, Kelly DA. Transitioning care of the pediatric recipient to adult caregivers. *Pediatr Clin North Am* 2003;50:1561–83.