

A Standardized Approach to Transition Improves Care of Young Adults with Inflammatory Bowel Disease

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Abstract

Introduction: Young adults with inflammatory bowel disease (IBD) are at the risk of poor outcomes when transferring to adult providers. We aimed to increase the percentage of patients with 14–17 years of age undergoing the transition of care and the percentage of patients 18–21 years of age initiating the transfer of care to 50% for 12 months. Our goal was also to improve patient satisfaction with the transfer process. Our balancing measure was not to increase the duration of IBD visits. **Methods:** We implemented 3 interventions through iterative plan-do-study-act cycles. To understand the impact of the interventions for 12 months, we used statistical process control charts. The duration of IBD visits was used as a balancing measure. We administered an anonymous satisfaction survey through the electronic health record. **Results:** Total transition discussions increased to a mean of 38% (n = 68). Transition discussions with patients 14–17 years of age increased from baseline, though not consistently. Patients 18–21 years of age initiating transfer of care increased to a mean of 5% (n = 1) following the first intervention and to a mean of 30% (n = 13) following our second and third interventions with special cause variation. There was no significant difference in the duration of IBD visits before and after the intervention period ($P = 0.54$). No patients were dissatisfied following our interventions. **Conclusions:** We saw improved transition discussions and transfer initiation rates by implementing the first steps of a new process to transition young adults with IBD. (*Pediatr Qual Saf* 2025;10:e786; doi: 10.1097/pq9.000000000000786; Published online January 7, 2025.)

INTRODUCTION

Young adults with inflammatory bowel disease (IBD) are a vulnerable population at the risk of experiencing poor outcomes and incurring high healthcare costs if inadequately prepared to transfer care to

adult gastroenterologists.^{1–3} The importance of a gradual transition before the transfer of care for patients with chronic medical conditions is well established.⁴

Known barriers to transitioning patients with IBD specifically include differences between adult- and pediatric-onset IBD, patients' lack of maturity and knowledge of their disease, adolescent anxiety and depression, poor adherence to therapy, differences between pediatric and adult IBD care, and parental and provider reluctance to transfer care.^{5,6} Due to the previous lack of published guidelines, practices regarding transition still vary greatly between centers, and many young adults do not feel prepared to transfer care.^{7,8}

Before this quality improvement initiative, our institution lacked a formal process to transition young adults with IBD. As a result, we suspect transition education was not occurring, and we were poorly coordinating our patients' care transfer. A few reasons for this included our institution's lack of transition resources, previously poor communication between pediatric and adult gastroenterologists, and our patients' variable health literacy and socioeconomic backgrounds. Despite these factors, our global aim was to improve the transfer of care of young adults with IBD at our institution to prevent adverse outcomes by implementing a new standardized approach to transition.

Our primary outcome was to increase overall transition discussions among patients 14–21 years of age who

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Supplemental digital content is available for this article. Clickable URL citations appear in the text.

Disclosure: The authors have no financial interest to declare in relation to the content of this article.

Presented at The Florida Pediatrician Journal, Summer 2023 Pediatric Resident Forum Abstracts section.

To cite: Katz D, Lee S, Sathananthan V, Bayes Santos L, Langshaw A. A Standardized Approach to Transition Improves Care of Young Adults with Inflammatory Bowel Disease. *Pediatr Qual Saf* 2025;10:e786.

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Received for publication May 25, 2024; Accepted December 4, 2024.

Published online January 7, 2025

DOI: 10.1097/pq9.000000000000786



were not newly diagnosed with IBD or recently referred to our center to a mean of 50%. Specifically, we aimed to increase our percentage of patients 14–17 years of age with IBD to 50% for 12 months by introducing them to the concept of transition of care, helping with knowledge building, and encouraging them to practice independence. We also aimed to increase our percentage of patients 18–21 years of age with IBD initiating the transfer of care to 50% for 12 months. Our goal was to improve patient satisfaction with the transfer process. The balancing measure was not to significantly increase the duration of IBD visits from a baseline median of 36 minutes.

METHODS

Context

We implemented this initiative within the University of Miami (UM) Health System, the only university-based medical system in South Florida. UM is a not-for-profit corporation primarily serving patients from Miami-Dade, Broward, Palm Beach, and Collier counties, including a large immigrant population. UM is affiliated with Jackson Memorial Hospital, the largest public hospital in the United States.

At the time of the interventions, 6 providers within the UM Leonard M. Miller School of Medicine Division of Pediatric Gastroenterology (GI), Hepatology, and Nutrition were seeing patients in 4 UM outpatient clinic sites that share 1 electronic health record (EHR: Epic HYPERSPACE, Epic Systems, Verona, Wis.). The clinics are located on the main UM Health System campus and in three satellite locations in South Florida. This quality

improvement initiative took place at all 4 clinic sites. There are 250 patients with IBD on average seen annually in these clinics.

Improvement Team

In January 2022, we formed a team that included a pediatric GI attending and a pediatric GI fellow, 3 adult GI attendings, 2 combined internal medicine and pediatrics residents, and a pediatric hospitalist/quality improvement expert. We met to identify potential barriers at our institution to implementing a transition program (Fig. 1).

Planning the Interventions

As this was a new process, we did not collect baseline data regarding the number of patients we discussed transition with before the intervention period. Alternatively, we obtained baseline data from March 2022 in the EHRs to determine the average duration of IBD visits. Anonymous patient satisfaction surveys were administered via the EHR in the patient messaging portal to a random sample of patients we transferred to adult gastroenterologists within the preceding year. (See **Supplemental Digital Content 1**, which displays patients satisfaction survey. <http://links.lww.com/PQ9/A617>.) We created this survey as no validated survey exists to address our questions.

We defined 3 specific measurable and time-bound aims. Our target population was young adults between the ages of 14 and 21 years with IBD in remission. Therefore, our goal was specifically set at 50% and not higher, as we felt that transition discussions are not suited for patients presenting to address acute concerns. Different outcomes were chosen for patients 14–17

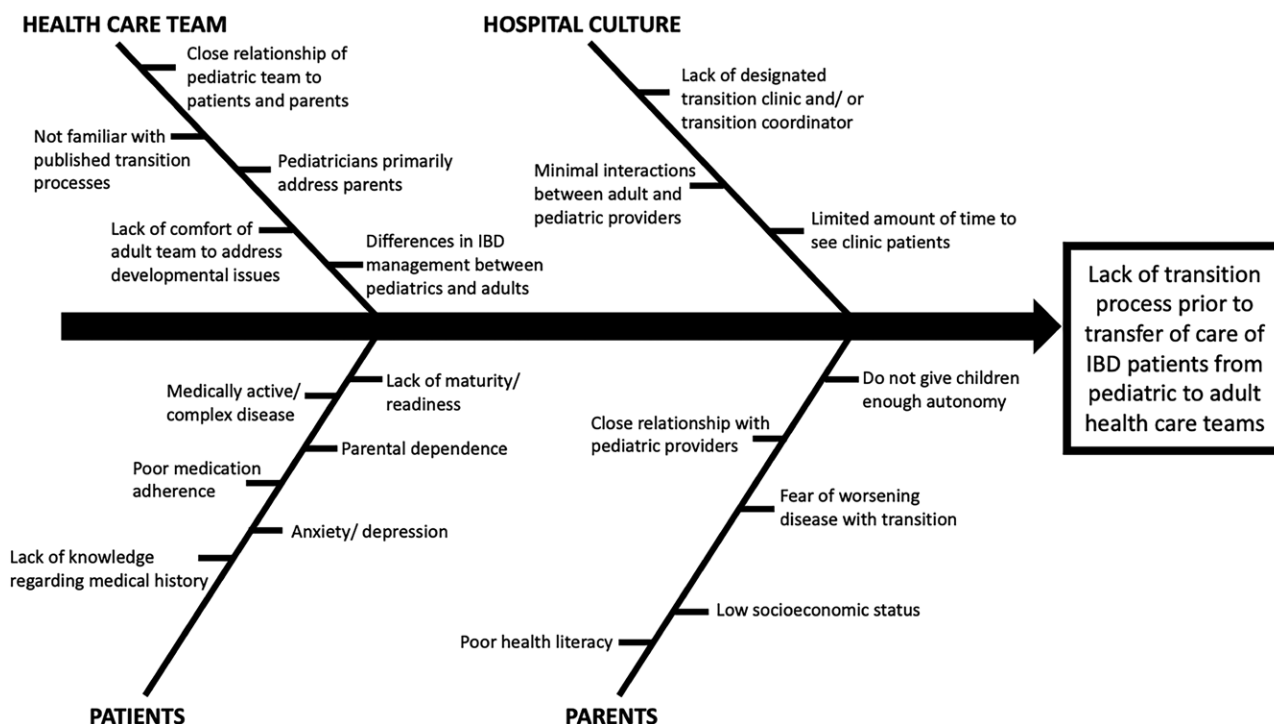


Fig. 1. Ishikawa diagram.

years versus 18–21 years based on the North American Society for Pediatric Gastroenterology, Hepatology & Nutrition’s (NASPGHAN) published transition checklist that differentiates topics for transition based on these age groups. We created a Key Driver Diagram (Fig. 2) to guide our improvement process. Using iterative plan-do-study-act cycles, we implemented patient-centered interventions theorized to impact these drivers significantly.

Interventions

From April 2022 to March 2023, we implemented 3 interventions primarily aimed at training pediatric GI providers on transition processes so that we could work together to improve the process for patients long-term. Furthermore, we hoped that by bringing attention to the transition issue, our hospital would allocate resources to build on our initiative.

The first intervention involved providing formal training to all pediatric GI providers on how to transition young adults with IBD effectively. To support this training, we created a concise one-page guide adapted from NASPGHAN’s published transition checklist, broken down into 2 checklists, one with topics of discussion for providers with patients 14 - 17 years of age and the other for patients 18–21 years of age. (See Supplemental Digital Content 2, which describes IBD transition guide—how to transition from a pediatric to adult healthcare team. <http://links.lww.com/PQ9/A618>.) The guide also included information on using a dot phrase with a 4-section drop-down menu we created in the EHR (Fig. 3) to standardize documentation of transition discussions and information on contacting the adult gastroenterologists specializing in IBD at UM for transition. We encouraged providers to

focus on and document 1 or 2 aspects of transition during each visit to build on prior discussions at each subsequent visit.

The second intervention consisted of automatic biweekly email reminders sent to pediatric GI providers, prompting them to discuss the transition with their patients. These reminders included brief instructions on using the transition dot phrase and links to additional published transition resources, such as the IBD toolkit published online by IMPROVECARENOW (Transfer Toolkit). The second intervention aimed to build on provider training by raising awareness and improving engagement in transition processes.

The third intervention involved conducting a follow-up training session for pediatric GI providers focused on appropriate billing for transition discussions using the International Classification of Diseases Code for Encounter for pediatric-to-adult transition counseling (ICD-10: Z71.87). At the training session, we also presented informative signs in the pediatric GI clinic exam rooms with information on transition adapted from Got Transition, a federally funded national resource center on healthcare transitions, the Crohn’s and Colitis Foundation, and NASPGHAN. We hoped the displayed signs would remind providers that we can be compensated for time devoted to transition, resulting in more pediatric GIs incorporating transition processes into practice.

Study of the Interventions

One study team member generated a UM Information Technology request each month to obtain a list of IBD patients seen in the pediatric GI clinics based on a search of the following ICD codes: K50–52, which pertain to noninfective enteritis and colitis. We reviewed the IBD

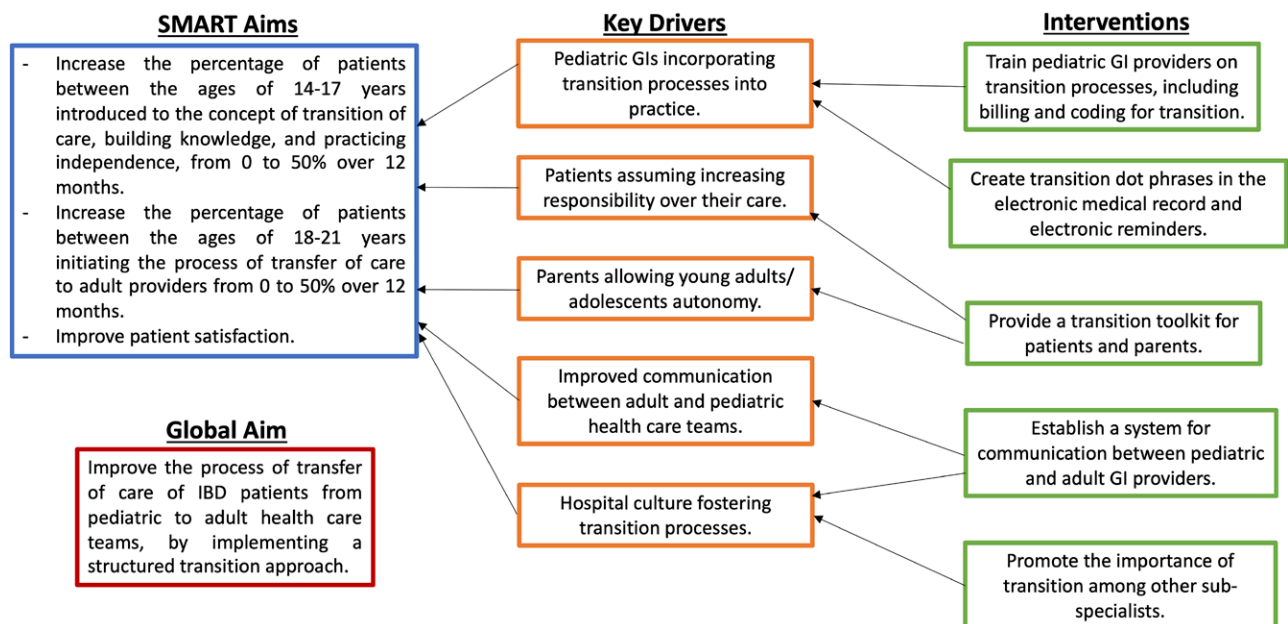


Fig. 2. Updated key driver diagram.

.IBDTransition

The process of transitioning from a pediatric to adult IBD provider was reviewed today, including:

Drop down menu (select all that apply):

- 1-introducing the concept of transition to the patient +/- their family.
- 2-helping the patient with knowledge building.
- 3-encouraging the patient to practice independence and self-management.
- 4-initiating the process of transfer of care.

Fig. 3. Transition dot phrase utilized in the EHR.

clinic visit notes from each study month to determine how often we utilized the transition dot phrase with eligible patients and whether we were making the appropriate selection from the drop-down menu based on each patient's age. Of note, we excluded visits with patients newly diagnosed with IBD referred to our center within the prior 6 months and patients younger than 14 years, as we considered these encounters to be suboptimal opportunities to introduce our transition process.

To assess patient satisfaction, we administered follow-up surveys 6 months after the first intervention and 12 months before the project concluded. We hoped that improved provider training throughout the study would increase patient satisfaction.

Measures and Analysis

We defined the outcome measure as the percentage of eligible IBD patients with whom we discussed any aspect of transition, as defined by using the transition dot phrase in the visit note. We calculated this measure every 2 weeks by dividing the number of patients with whom transition was discussed by the total number of patients with IBD eligible for transition discussion.

Our secondary outcomes included the percentage of patients 14–17 years of age with whom we introduced the concept of transition, helped with knowledge building and/or encouraged them to practice independence. We also tracked the percentage of patients 18–21 years of age with whom the transfer of care was initiated. We defined all of these measures by including the appropriate selection from the drop-down menu of the transition dot phrase.

Our balancing measure was the duration of IBD visits. We calculated this measure by subtracting the time the patient checked out from their scheduled appointment time. Patients without an available check-out time were excluded from the analysis of the duration of IBD visits as it was impossible to calculate the visit duration based on the equation we devised (ie, check-out time – scheduled appointment time = visit duration).

Statistical process control and run charts displayed the biweekly percentage of patients with whom we discussed

any aspect of transition, patients 14–17 years of age, and patients 18–21 years of age. These charts allowed us to monitor changes over time and understand the impact of our interventions on the transfer of care process. We established a mean, illustrated as the centerline on all control charts with upper and lower control limits. We used the Montgomery rules to determine if observed changes in measures were due to random variation (common cause variation) or caused by a specific assignable cause, in this case, the intervention (special cause variation). We also used the Mann–Whitney U test, a nonparametric test, to calculate *P* values to determine statistical significance between the baseline and intervention period regarding the duration of IBD visits. We used SAS version 9.4 (SAS Institute, Inc., Cary, N.C.).

Ethical Considerations

The present initiative fell within the UM institutional review board's guidance for quality improvement projects that did not constitute human subjects research. We did not obtain external funding.

RESULTS

We reviewed 176 patient encounters during the intervention period. The mean percentage of young adults with IBD with whom we discussed any aspect of transition utilizing the new process after 12 months was 38% (*n* = 68). Stratifying transition discussions by age, among patients 14–17 years of age, we introduced the concept of transition or assisted with knowledge building, and/or patients were increasingly encouraged to practice independence as a result of our interventions, though not yet at a consistent level (Fig. 4). For patients 18–21 years of age, we specifically initiated the care transfer process among 5% of patients following the first intervention (*n* = 1), which increased to 30% (*n* = 13) with special cause variation following the second and third interventions (Fig. 5).

Baseline data (*n* = 10 patient visits) regarding the duration of IBD visits revealed that the median duration was 36 minutes (10th percentile = 9 min, and 90th percentile = 79 min) for young adults seen in the pediatric

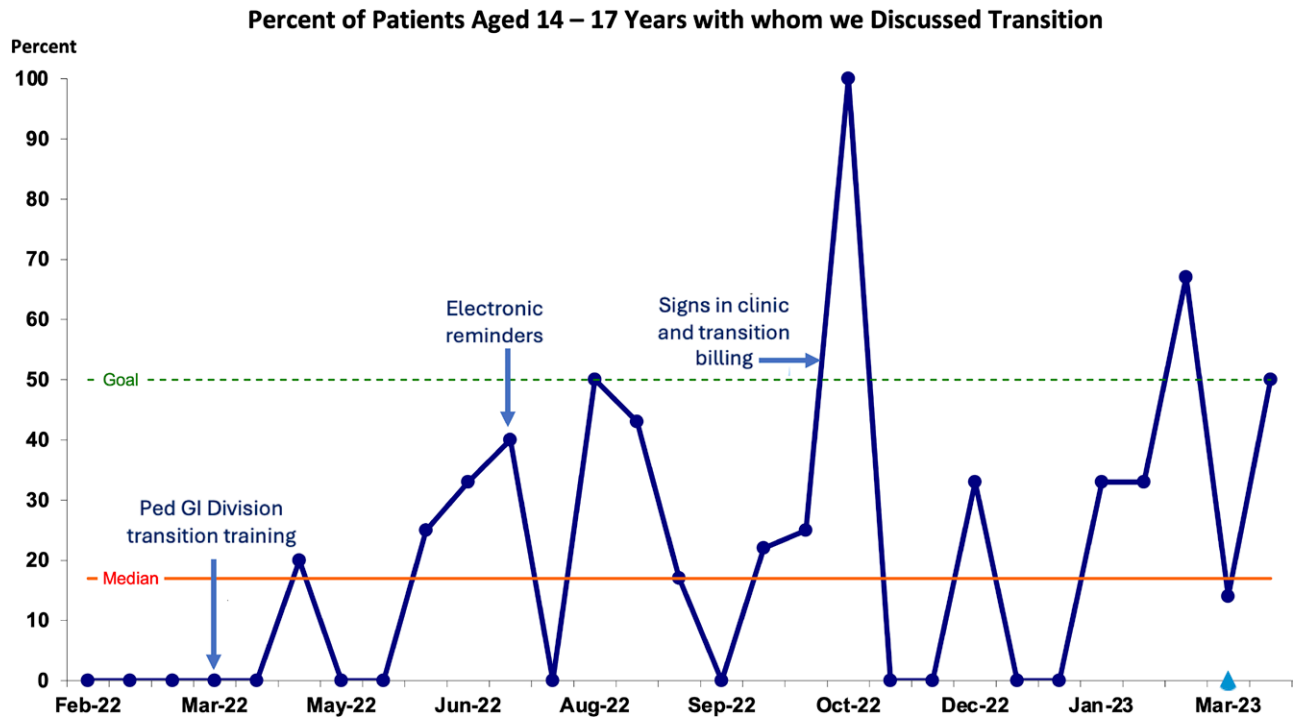


Fig. 4. Run chart displaying the biweekly percentage of patients 14–17 years of age with whom we discussed transition.

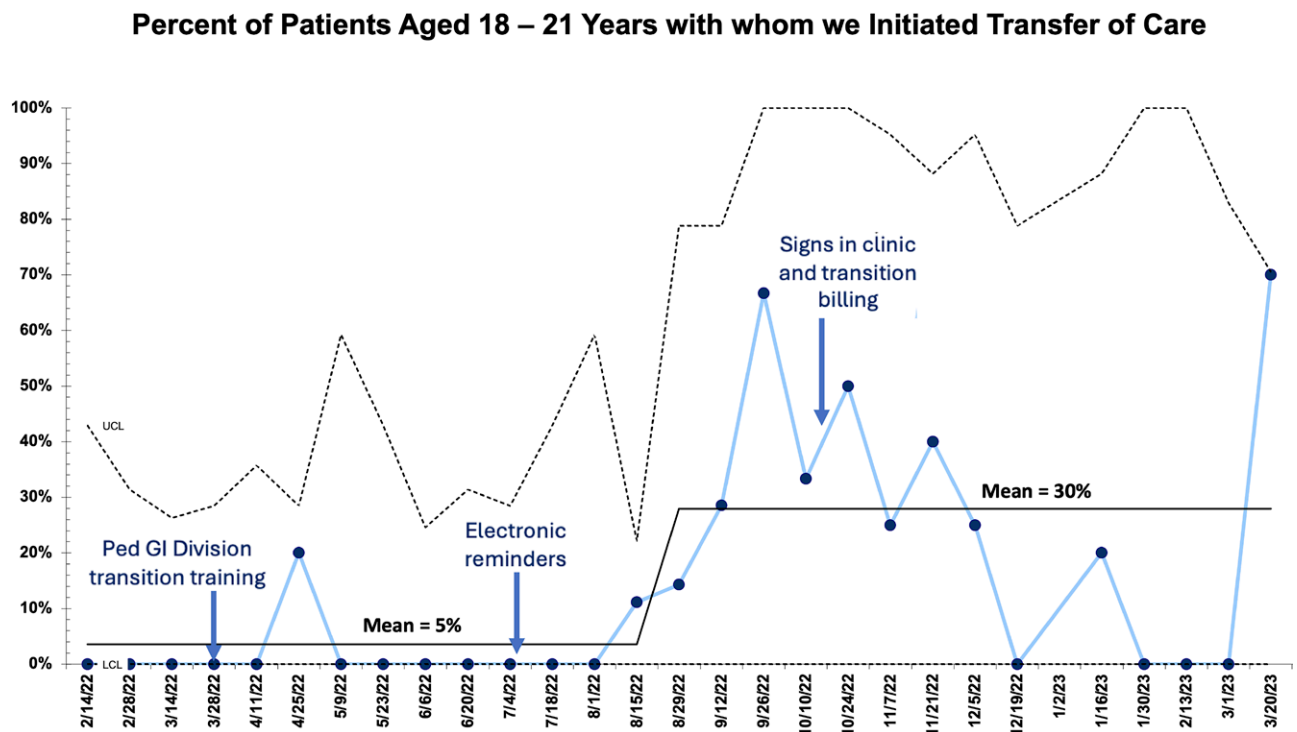


Fig. 5. Statistical process control displaying the biweekly percentage of patients 18–21 years of age with whom we initiated the transfer of care.

gastroenterology clinic in March 2022 with a mean of 41.75 minutes (± 25.94). The median duration of IBD visits during the intervention period ($n = 147$ patient visits) was 45 minutes (10th percentile = 10 min and 90th percentile = 120 min), with a mean of 60 minutes (± 57.4). The duration of the IBD visit during the intervention

period did not significantly differ from the baseline ($P = 0.54$). We could not calculate the visit duration for 29 encounters during the intervention period due to missing check-out times.

Baseline satisfaction survey results (response rate = 6/7 patients) showed that 20% of young adult patients with

IBD were very satisfied with their transfer of care, 60% were satisfied, and 20% were dissatisfied. In contrast, in follow-up surveys (response rate = 4/21 patients), 33% indicated they were very satisfied, 67% were satisfied, and no patients were dissatisfied following the interventions.

DISCUSSION

The global aim of this project was to improve the transfer of care of young adults with IBD to adult gastroenterologists at our institution. We implemented the first steps of a standardized process, after which we saw an initial increase in patients undergoing transition, which we hope will be consistently sustained. This initiative is particularly important given the risk to our young adult IBD patients of adverse outcomes when we previously had no transition process in place. Our interventions primarily aimed to enhance the knowledge and skills of pediatric GI providers regarding transition, promote consistent documentation of transition discussions, and provide ongoing resources to support the transition process moving forward. Our findings are useful for other centers looking to initiate a transition program that similarly lacks dedicated resources.

Primary and Secondary Outcomes

The most effective intervention appeared to be providing a visual informative reminder on the topic of transition in the examination rooms of the pediatric gastroenterology clinics and providing follow-up training to pediatric providers, including demonstrating how to bill for transition discussions. The signs in the clinic were likely effective because they reminded the entire healthcare team, including patients and parents, to discuss the transition. This intervention is in line with The Six Core Elements of Health Care Transition published by Got Transition and endorsed by the American Academy of Pediatrics/American Academy of Family Physicians/American College of Physicians Clinical Report on Health Care Transition, as well as previously published transition quality improvement initiatives in the primary care setting, that recommend displaying the transition policy in a shared practice space.^{2,9,10}

Of note, our initial significant increase in transition discussions during the third intervention period was not consistently sustained, perhaps due to a decline in momentum after the initial positive effect of the visual reminders. However, we believe the potential for reimbursement using the billable code for transition counseling (Z71.87), which became effective in October 2022, could help incentivize physicians long-term to dedicate time to transition discussions. Improving communication between pediatric and adult gastroenterologists is also an important component of published guides on IBD transition^{1,7,11,12} Although we initially planned to create a list serve for pediatric and adult gastroenterologists, this was not ultimately done, as

communication through the EHR proved to be efficient. (See **Supplemental Digital Content 3**, which displays key driver diagram, original version. <http://links.lww.com/PQ9/A619>.)

Though the interventions did not achieve our goal of discussing transition with 50% of patients 14–21 years of age, we observed a large increase from baseline (38%). A smaller and less consistent increase was seen among patients 14–17 years of age, possibly due to patients' lack of maturity, a barrier frequently cited in the context of transition programs.^{1,13,14} In retrospect, if our goal was to initiate transfer among 50% of eligible patients with IBD 18–21 years of age, we should have set a higher goal for introducing the transition process among patients 14–17 years of age. However, as patients in this age group have more time in pediatrics, transition topics can seem less relevant. We achieved special cause variation in patients 18–21 years of age about initiating the transfer of care. Overall, we successfully implemented a new process using minimal resources. In light of our project, other pediatric divisions at our institution, including transplant hepatology and nephrology, are developing standardized transition programs.

Balancing Measure

We did not significantly increase the duration of IBD visits with our interventions, a potential adverse outcome of implementing a transition program. This result is likely because we trained providers to initiate a focused transition discussion, with the goal of not overwhelming patients with the prospect of transfer of care. Our approach was aligned with other published transition experiences that recommend a gradual increase in young adults' responsibility with their IBD care.^{1,15}

Although not significant, IBD visits during the intervention were longer. However, there was great variability in the duration of the IBD visit. Additionally, we could not calculate the duration of the IBD visit in 29 encounters due to missing check-out time. We believe this may have been due to different check-out practices among clinic staff or patients occasionally leaving the clinic without formally checking out. We hope there will be less variability in the duration of the IBD visit as transition discussions become more routine.

Patient Satisfaction

Though our patient satisfaction data were limited, we learned from baseline survey responses that some patients had difficulty scheduling appointments with adult gastroenterologists. The higher satisfaction levels reported following our interventions likely stemmed from patients feeling more supported by pediatric gastroenterologists when transferring to adult care.

Limitations

Our project was limited because we did not have funding or additional services to support our initiative. This

limitation is unique from other published effective transition initiatives highlighting the utility of a transition coordinator,^{8,16,17} a dedicated transition clinic,¹⁸ and social workers and behavioral health specialists within a transition program.¹⁹ We work in a small division where limited provider availability during summer and winter holidays affected the strength of our initiative. Moreover, including all four clinic sites required additional effort to ensure our interventions were adaptable to each workflow. Finally, we had a very low response rate for patient satisfaction surveys, impacting our results.

Future Directions

Future directions will include continuing the current interventions and refining our efforts to achieve more transition discussions and improved patient satisfaction. Specifically, we plan to standardize the process by which we help patients 14–17 years of age build knowledge and practice independence (ie, by providing patients with a medical summary and asking parents to step out of the room for part of clinic visits). We also plan to administer a standardized form to evaluate patient transfer readiness among patients 18–21 years of age and study how different patient characteristics, such as varying socioeconomic factors impact transfer readiness. We hope that increased utilization of the billable transition code will generate increased revenue, enabling our institution to invest in a transition coordinator in the future.

Concluding Summary

By implementing the first steps of a new standardized approach to transition, we saw an initial improvement in transferring care of young adults with IBD at our institution without negatively impacting the length of IBD visits. Importantly, the institution's overall culture shifted toward developing transition programs across other chronic diseases.

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