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ORIGINAL ARTICLE

A Smooth Transition: Assessing Transition Readiness in Adolescents with Inflammatory Bowel Disease

Shahzaib M. Khan[1] · **David Tuchman**[2] · **Alizeh Imran**[3] · **Fatima Mustafa Lakdawala**[3] · **Sana Mansoor**[2] · **Joseph Abraham**[4]

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Abstract

Background Inflammatory Bowel Disease (IBD) is an early onset condition that affects individuals of all ages. Approximately 15%–25% of patients present before the age of 20 years, with peak onset occurring during adolescence.

Aims To evaluate transition readiness among adolescents diagnosed with IBD and identify barriers to transition.

Methods We conducted a cross-sectional study of patients with IBD aged 12–21 years. Patients were stratified by age into three groups: A (12–14 years), B (14–17 years), and C (17 + years). Patients were asked to complete a questionnaire which assessed patient knowledge in three areas of transition: 'Taking Charge,' 'My Health,' and 'Using Health Care.' Fisher's Exact and Chi-Square tests were used to evaluate the associations between age and transition readiness.

Results A total of 127 participants (68 males and 59 females) with a mean age of 16.14 years were included. Transition readiness increased with age from 60.7% in Group A to 63.2% and 77.9% in Groups B and C, respectively ($p < 0.001$). Patient confidence and the importance of transition increased with age, with means of 5.51, 6.17, and 6.94 in Groups A, B, and C ($p = 0.02$). Patient-reported knowledge of their health condition was > 70%, with no statistical differences between the groups ($p = 0.65$). Patient knowledge regarding 'Using Health Care' increased from 52% in Group A to 79% in Group C ($p < 0.001$). The greatest barriers to transitioning were carrying health information for Group A (100%) and obtaining provider referrals for Groups B (75%) and C (51%).

Conclusion This study demonstrated that transition readiness increases with age in adolescents with IBD.

Keywords Inflammatory bowel disease · Transition · Adolescents · Ulcerative colitis · Crohn's disease · IBD

Introduction

Inflammatory bowel disease (IBD) comprises chronic disorders of the gastrointestinal tract, including ulcerative colitis (UC), Crohn's disease, and indeterminate colitis. These disorders are characterized by mucosal ulceration and inflammation along the length of the gastrointestinal tract. Although the etiology of IBD remains unknown, environmental stimulation that alters the microbiota of genetically

✉ Alizeh Imran
alizehimranhussainy@gmail.com; alizeh.15483@zu.edu.pk

Shahzaib M. Khan
shahzaibmkhan1@gmail.com

David Tuchman
DTuchman@lifebridgehealth.org

Fatima Mustafa Lakdawala
fatimamustafa2002@gmail.com

Sana Mansoor
smansoor@lifebridgehealth.org

Joseph Abraham
apexepi@gmail.com

[1] Department of Pediatrics, Aga Khan University, Karachi, Pakistan

[2] Division of Pediatric Gastroenterology, Hepatology and Nutrition, Department of Pediatrics, Sinai Hospital, Baltimore, USA

[3] Ziauddin Medical College, Karachi 75000, Pakistan

[4] Department of Pediatrics, Sinai Hospital of Baltimore, Baltimore, USA

susceptible hosts is an important factor in the development of these disorders [1, 2].

While IBD can affect all age groups, approximately 25–30% of patients with Crohn's disease and 15–20% of patients with ulcerative colitis present before 20 years of age [3, 4]. Although the incidence of IBD was previously uncommon in children, this age group is now experiencing the greatest increase in the incidence of the disease [5]. Furthermore, pediatric-onset IBD is often extensive with ileo-colonic and upper gastrointestinal tract involvement and different treatments than adult-onset disease [6, 7]. In 2016, one in 209 adults and one in 1299 children aged 2–17 were affected by IBD [8]. Adolescence remains the peak age of onset in the pediatric population, although approximately 4% of patients are diagnosed during early childhood before the age of five years [9]. The psychological impact associated with chronic illness causes adolescents with IBD to demonstrate heightened anxiety, lack of maturity, poor adherence to treatment, and insufficient knowledge of their disease. IBD presenting during adolescence reportedly interferes with growth, education, and psychosocial and sexual development [9, 10]. Therefore, the acquisition of self-management skills in this population is essential to facilitate a smooth transition to adult care providers. Hence, transition clinics play a vital role in ensuring seamless facilitation from pediatric to adult caregivers.

Transition of medical care in pediatric patients with a chronic illness is defined as "a purposeful, planned process that addresses the medical, psychosocial, and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centered to adult-oriented health care systems" [11].

This process aims to provide a harmonious and comprehensive transfer of care from pediatric to adult care providers. If not managed properly, this period may be associated with challenges for adolescents and adverse health outcomes [12]. Identifying an appropriate adult care provider, offering familial and institutional support, and addressing adolescents' emotional and psychological needs are all crucial elements in facilitating a smooth transition [13].

Transition readiness is a crucial aspect of the transfer process and is defined as making specific decisions and operationalizing a plan to build the capacity of the youth, parent and health care providers to participate in the process of transition and develop self-management skills [14, 15]. Self-management may be defined as the "interaction of health behaviors and related processes that patients and families engage in to care for a chronic disease" [16]. The lack of proven instruments and absence of an established criterion to gauge transition readiness has led pediatric gastroenterologists to overestimate their patients' readiness for transition to an adult care provider [17]. Multiple checklists have been created to serve this purpose, namely, the Transition Readiness Assessment Questionnaire (TRAQ) [18], the Social-ecological Model of AYA readiness for transition (SMART), and the University of North Carolina (UNC) transition scale [19]. The objectives of this study were to assess transition readiness, as self-reported by pediatric patients with IBD, and to identify barriers in the transition process.

Methods

Study Design

This study was a cross-sectional survey of patients with IBD who were being followed up by the Division of Pediatric Gastroenterology at Sinai Hospital. At this institution, there are no formal transitional clinics. Patients typically transition to an adult gastroenterologist by age 21 years and continue to be cared for by them. The division at the time of the study included four pediatric gastroenterologists, one pediatric nurse practitioner, one dietitian, and two pediatric nurses. The study period was July 2018 to May 2020.

The inclusion criteria were patients between the ages of 12 and 21 years who were diagnosed with IBD using standard means [20]. Patients without a diagnosis of IBD or those with IBD who were younger than 12 years or older than 21 years of age were excluded. Patients who were unable to complete the questionnaire due to developmental/cognitive impairment, non-English speaking, or other illnesses were excluded from the study. This study was exempt from the Sinai Institutional Review Board (IRB).

Data Collection

A Pediatric IBD Registry was established that captured data using a spreadsheet (Smartsheet™). The collected data consisted of patient information such as their name, date of birth, and details about their primary pediatric gastroenterologist. The spreadsheet also recorded the date when the patient and family received an introductory letter, which was a letter from their primary pediatric gastroenterologist explaining the transition process and its significance. Patients were then asked to complete a questionnaire called the Health Care Provider Transitioning Checklist (HCPTC), to assess their transition readiness. This checklist included key areas for self-management and transition, as identified by several national organizations involved in the health care of pediatric patients with IBD, including the North American Society for Pediatric Gastroenterology and Nutrition (NASPGHAN), Children's Digestive Health and Nutrition Foundation (CDHNF), and Digestive Health for Life. Development of the checklist was based on 'faculty expertise, review of existing publications and adaptations of the

Transition Planning Checklist by the Children's and Women's Health Center of British Columbia' [21–23]. These key areas were merged into a template known as the Transition Readiness Assessment supplied by Got Transition, a national organization involved in improving the transition from pediatric to adult health care.

Three unique HCPTC questionnaires were designed (Addendum A, B, and C), one for each of the three age groups: early adolescence (12–14 years) labeled as Group A, middle adolescence (14–17 years) labeled as Group B, and late adolescence (17 + years) labeled as Group C. Each of these templates had three sections, 'Taking Charge,' 'My Health,' and 'Using Health Care,' comprising separate questions. The section labeled 'Taking Charge' consisted of questions that assessed the patients' confidence in the transition process. 'My Health' included questions about the patient's disease process, and the section labeled 'Using Health Care' consisted of questions related to maneuvering the health care system, as suggested by the name. In the first section, ('Taking Charge'), responses to the questions were documented on a Likert scale of 0–10, where 0 meant the lowest confidence/importance given to transition and 10 meant the highest level of importance/confidence in the transition process. For the remaining two sections, there were three possible responses to each question: 1. "Yes, I know this," 2. "I need to learn," or 3. "Someone needs to do this." A question answered "Yes, I know this" was considered an affirmative answer regarding the individual's knowledge. Similarly, a question answered as "I need to learn" or "Someone needs to do this" indicated a potential challenge in the transition process for that individual patient. Although the second and third response differed based on degrees of help required, they were merged as one for the purpose of our analysis due to considerable overlap and the requirement of some degree of help in each. Each answered question was treated as an individual response and as a separate data point. The questionnaires were completed by patients who were present at the pediatric GI clinic. For patients who completed two questionnaires due to stepping into a higher age group during the process of data collection, the most recent questionnaire was utilized for the study. Incomplete questionnaires were excluded from the analysis.

The questions in the first section, 'Taking Charge,' remained the same in the HCPTC questionnaires for all three age groups. This section explored patients' confidence in becoming independent and in controlling their communication with the physician. For the remaining two sections of the HCPTC questionnaires, 'My Health,' and 'Using Health Care,' we included more age-appropriate transition-related questions, which meant that each of the three age groups had a separate set of questions, with some overlap, for these two remaining sections. For example, in the early adolescence age group, the 'My Health' and 'Using Health Care' sections primarily focused on patients' awareness of their condition and familiarity with processes within the health care system. In the mid- and late-adolescent age groups, however, the questions in the above-mentioned sections were expanded to encompass the patient's knowledge about insurance, sexuality, and the effects of drugs on their disease.

Data Analysis

The collected data were transcribed from hard copies of the surveys using a Microsoft Excel spreadsheet. Responses were assigned numerical values to score the data as follows: "Yes, I know this" = 1, "I need to learn" = 2, and "Someone needs to do this" = 3. The results were analyzed using the STATA and Fisher's Exact Tests and Chi-Square measures were used to determine statistical significance. Kruskal–Wallis tests were also run on median ranks for the first section, 'Taking Charge,' in which a Likert scale of 0–10 was utilized to collect data. Statistical significance was set at $p < 0.05$. All data were coded to keep personal identifiable information (PII) confidential.

Results

Study Sample

In total, 127 patients completed the HCPTC questionnaire. Of these, 26 were in Group A, 40 were in Group B, and 61 belonged to Group C, with a mean age of 16.14 ± 2.63 (Table 1). This study included 68 male and 59 female patients.

Transition Readiness

The combined data from all three sections of the HCPTC questionnaires displayed an increase in patient-reported transition readiness across all age groups, with 60.7% of patient responses from Group A being "Yes, I know this," compared to 63.2% for Group B and 77.9% for Group C ($p < 0.001$) (Fig. 1).

Table 1 Patient demographics

Demographics	Number of participants ($n = 127$)	Percentage of participants (%)
Males	68	53.5
Female	59	46.5
< 14 years of age	26	20.5
14–17 years of age	40	31.5
17 + years of age	61	48

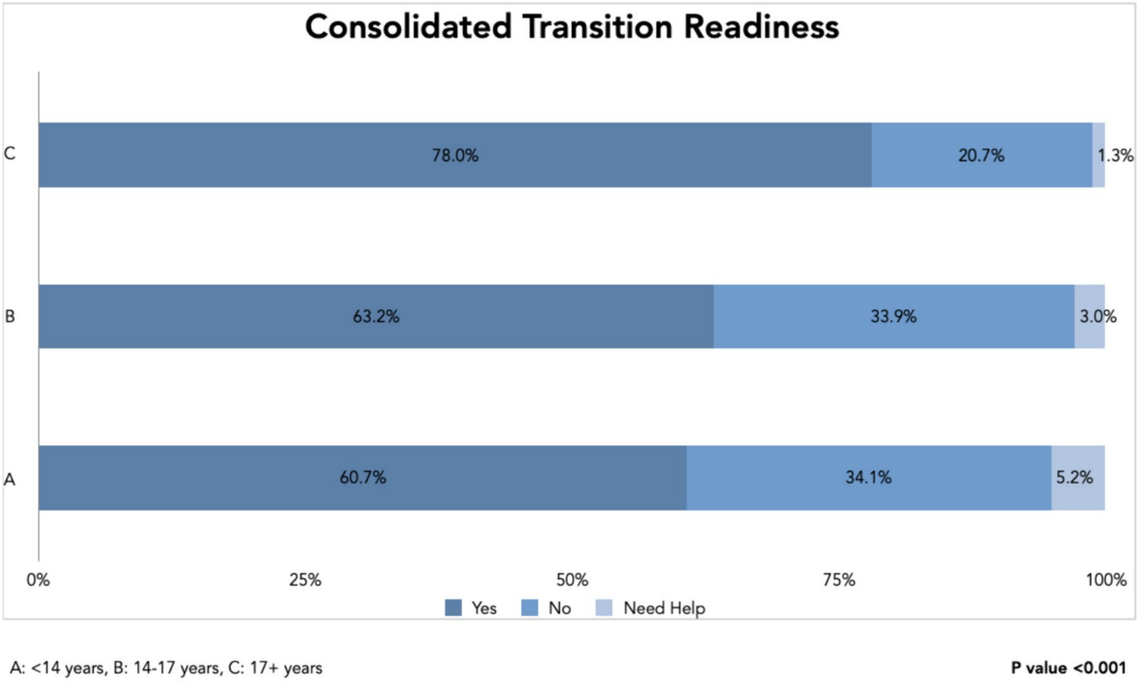

Fig. 1 Bar chart illustrating consolidated responses across age groups for three options: "Yes, I know this," "I need to learn," and "Someone needs to do this" for all questions in the HCPTC Questionnaire

The first section of the HCPTC questionnaire, 'Taking Charge,' consisted of two questions that examined patient-reported importance toward preparing for the transition to an adult care provider and confidence in undertaking this transition. In Groups A, B, and C, both increased with age, with mean values of 5.51, 6.17, and 6.94 in Groups A, B, and C, respectively ($p = 0.02$). The median scores for each age group also increased from 6 in Group A to 7 and 8 in Groups B and C, respectively ($p = 0.004$) (Fig. 2).

In the second section of the HCPTC questionnaire, 'My Health,' we assessed the knowledge and understanding related to the patient's health, including their ability to describe their disease and medication. We observed that 72% of questions were answered "Yes, I know this" from Group A, compared to 26% that answered, "I need to learn" and 2% answered as "Someone needs to do this." Groups B and C also yielded similar responses, with 73%, 25%, and 1.5% for Group B and 76%, 22%, and 2% for Group C, respectively ($p = 0.65$) (Fig. 3). There were no significant differences among the age groups in this category.

The third section, 'Using Health Care,' examined patients' independence and ability to maneuver basic tasks within the health care system, including making appointments, ordering medication refills, or conducting tests. In Group A, 52% of questions were answered as "Yes, I know this" compared to 41% which were answered as "I need to learn" and 7% which were answered as "Someone needs to do this." The responses for Group B resembled those of Group A, with percentages of 55%, 41%, and 4% for "Yes, I know this," "I need to learn," and "Someone needs to do this," respectively. The findings from Group C revealed a different trend, with 79% of questions answered as "Yes, I know this," only 20% of responses as "I need to learn," and 1% of responses as "Someone needs to do this" ($p < 0.001$) (Fig. 4).

We then identified those questions in the HCPTC questionnaire that were common to all age groups and compared the responses to these specific questions or areas of transition (Table 2). We observed a statistically significant increase in transition readiness across the three age groups. The table below shows the percentage of each question answered "Yes, I know this" for all three age groups. For instance, only 35% of patients from Group A answered "Yes, I know this" when asked if they knew or were able to find their doctor's phone number. This number increased to 58% in Group B for the same question and further increased to 90% in Group C.

Barriers to Transition

Finally, we identified areas of transition that posed challenges or barriers to our patients. These were determined by the "I need to learn" response option. Although each

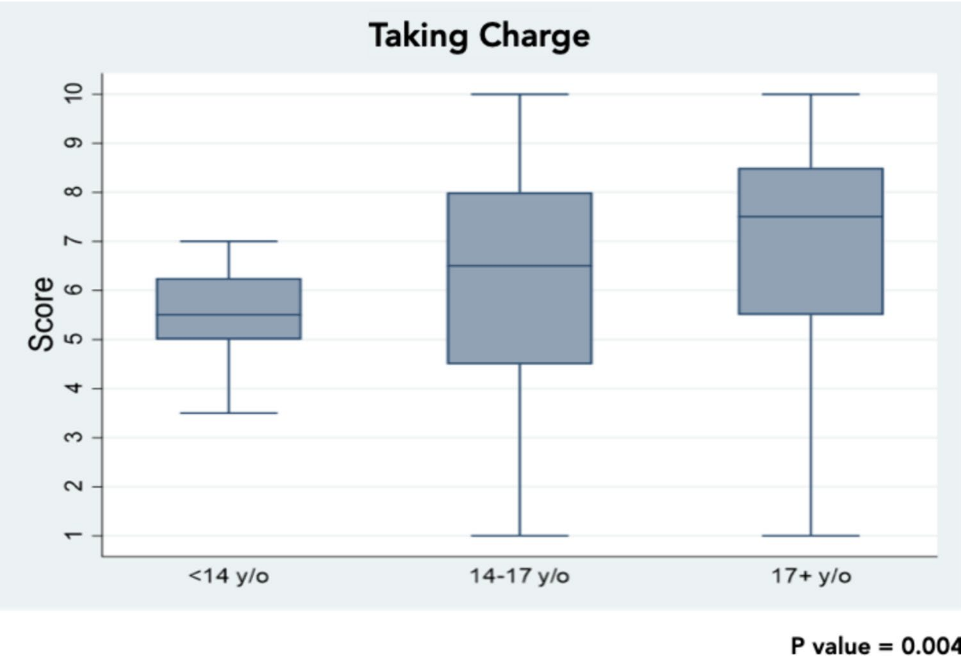

Fig. 2 Box plots representing overall scores for 'Taking Charge' questions within the three age groups. The *p* value represents the median rank score based on the Kruskal–Wallis one-way analysis of variance

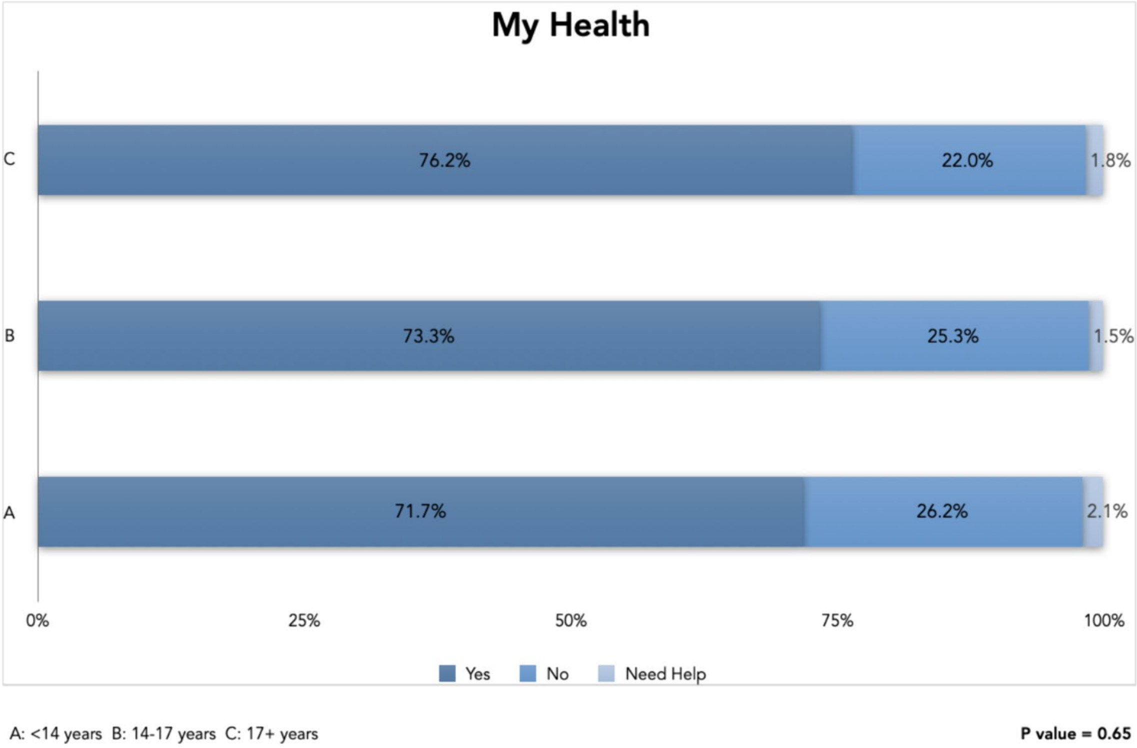

Fig. 3 Bar chart illustrating the overall distribution of responses across age groups for patient-reported transition readiness for the 'My Health' sub-category

patient had challenges in the transition process, the biggest barrier for Group A seemed to be carrying health information, which was answered as "I need to learn" by 100% of the patients in this age group (Fig. 5). This was followed by obtaining medical assistance when the doctor's office was closed (65%) and refilling their prescriptions (65%). For Groups B and C, the greatest challenge was obtaining provider referrals (75% and 51%, respectively).

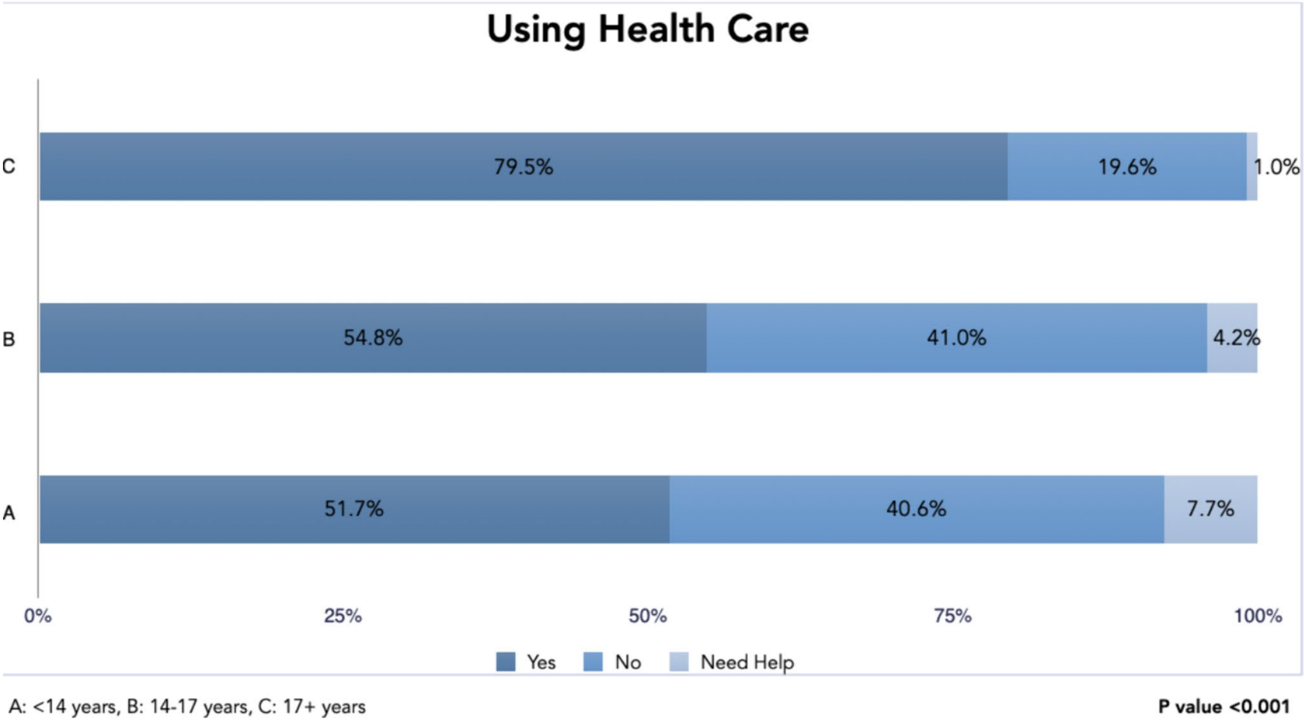

Fig. 4 Bar chart illustrating the overall distribution of responses across age groups for patient-reported transition readiness for the 'Using Health Care' sub-category

Table 2 Percentage of affirmative responses ("Yes, I know this"), for common questions across all three age groups

Questions	< 14 years	14–17 years	17 + years	*p*-value
I can carry important health information with me every day (e.g., insurance card, allergies, medications, emergency contact information, and medical summary)	0	38	61	0.01
I know or I can find my doctor's phone number	35	58	90	< 0.001
I know my doctors' and nurses' names and roles	58	83	85	0.02
I know to show up 15 min before the visit to check in	77	88	97	0.007
I know where to go to get medical care when the doctor's office is closed	19	45	87	< 0.001
I know where my pharmacy is and how to refill my medicines	27	60	85	< 0.001
I know where to get blood work or x-rays if my doctor orders them	46	50	92	< 0.001

Discussion

Our cross-sectional analysis of pediatric patients with IBD was designed to explore transition readiness using self-reported data from patients' age groups of 12–21, while simultaneously identifying potential barriers to the transition process. Our study showed an increase in transition readiness with age. A similar trend was seen when the results were categorized into sections, specifically for the first and third sections, namely 'Taking Charge' and 'Using Health Care.' However, there were no significant differences between the age groups in the second section, 'My Health.' Our results are consistent with the findings of a study conducted in 2015 by Whitefield et al., which reported that transition readiness is linked with age as opposed to disease duration [12].

More than half of the patients aged 14 years or older reported the ability to complete tasks independently, such as knowing what to do in case of a medical emergency. Only one-third of patients from Group A answered "Yes, I know this" when asked if they knew or were able to locate their health care provider's contact information. However, this percentage increased to more than half for Group B and more than two-thirds in Group C. Our findings align with the results of a study conducted by Huang et al., who discovered

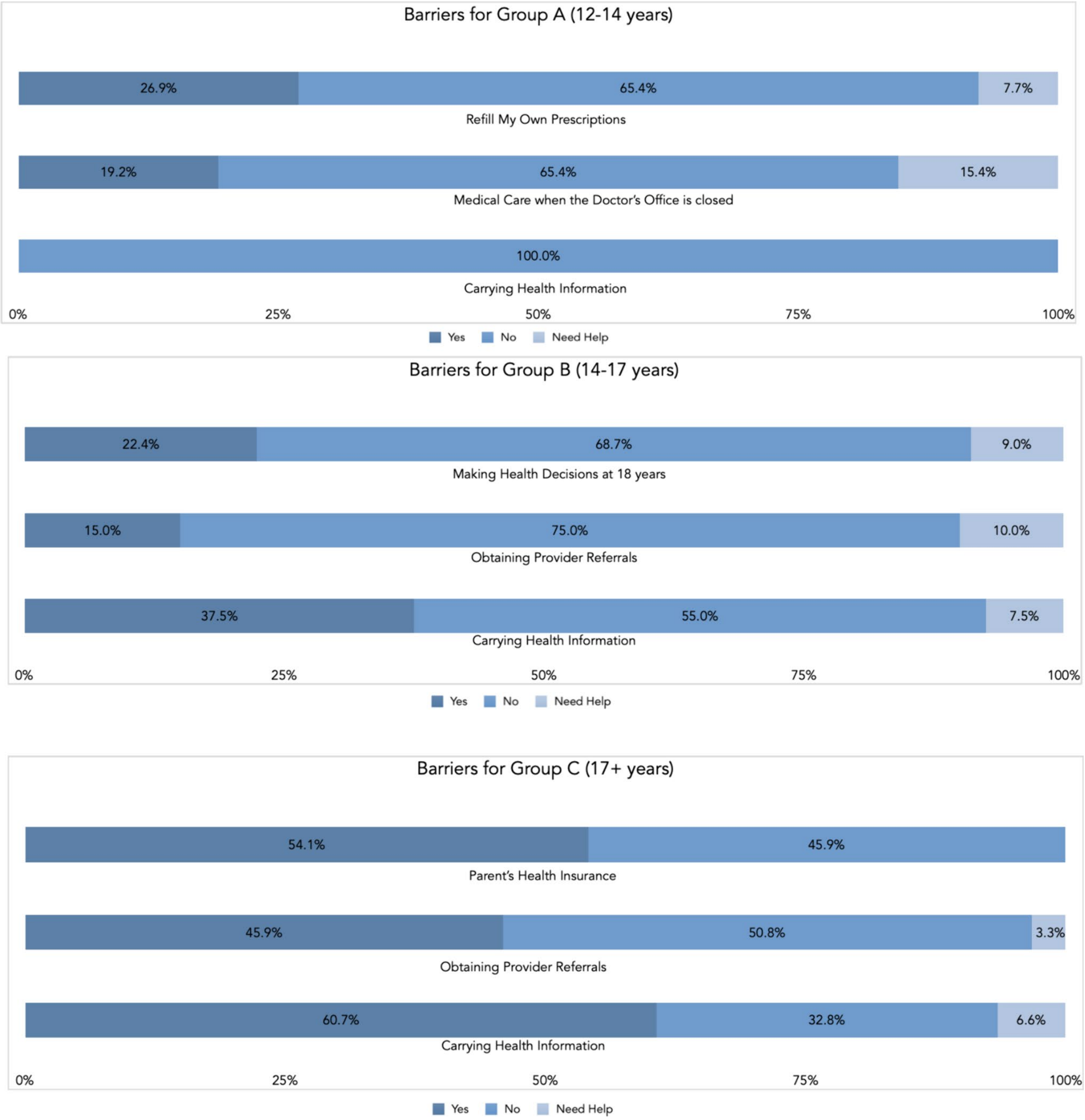

Fig. 5 Barriers to the transition process

that as patients with IBD grew older, self-efficacy related to health literacy improved [17].

Adolescence is a period of rapid growth characterized by the onset of puberty, along with significant emotional and cognitive development. The psychological impact of receiving a diagnosis of a chronic disease can manifest as elevated anxiety, poor adherence to treatment, and limited knowledge of the disease and its complications [10]. A cross-sectional study conducted by Alhadab et al. found scores for quality of life in pediatric IBD patients were lower when compared to healthy controls [24]. As a result, pediatric patients who transition to adult providers may be faced with medical decision-making they are not prepared for, such as drugs with which they are unfamiliar [13]. The absence of validated measures available specifically for IBD assessment poses a considerable obstacle when evaluating the maturity and readiness of children with IBD for transition to an adult gastroenterologist [25].

According to the most recent guidelines published by the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN), a transition package should be compiled through collaboration between the pediatric and adult team containing a medical summary, the final transition readiness assessment, an updated plan of care and an emergency care plan. An appointment with an adult provider should be confirmed and the teams should participate in a final review of care. The final stage in the transition is confirmation by the pediatric provider that care has been established with an adult provider and evaluation of the youth's experience with transition [26]. The difference in the clinical approach between pediatric and adult health care providers is a significant challenge for the transition process. Visits with pediatric providers tend to be family focused and longer in duration, with an approach that strikes a balance between the patient, family, and physician. In contrast, adult visits were shorter and more patient centered. A NASPHAGAN survey of adult gastroenterologists reported deficits in patient knowledge regarding both medical history (55%) and prescribed medication regimens (69%) [14]. Hence, young adults must learn how to actively participate and manage their health care, schedule timely appointments, and communicate effectively [13, 27].

A lack of confidence and maturity among adolescents is often a challenge in the transition process and may evoke concerns or manifest as anxiety across different age groups. This was evident in the first section of our study, 'Taking Charge,' where results suggested that although there was an increased importance given to preparing for transition as patients grew older, there remained a lack of confidence in their ability to carry out the process and adjust to the new responsibilities it entailed. These results support the findings of the study conducted by Whitefield et al. [12] and a systematic review and meta-analysis by Stapersma et al., which revealed that symptoms of anxiety and depression are prevalent in pediatric patients with IBD [28].

Our analysis further revealed that more than half of the patients in Group B required assistance in understanding the impact of their GI condition on their sexuality. It is important to note that sexuality, including sexual desire, has been reported to be lower in patients with IBD [29]. These findings may be difficult for adolescents to comprehend. These results are in line with those of other studies that suggest that not all patients psychologically adapt to IBD at the same pace. There is no fixed age limit for transition care; adolescents develop and mature on their timescale, and some may need to stay in transition care longer than others [10]. It is worth mentioning that these differences might also be attributed to special circumstances, such as the presence of developmental or neurological delays, which necessitate a distinct set of resources to provide comprehensive understanding and care. Additionally, some patients suffer from secondary issues to their condition, such as social interaction, negative self-image, and behavioral problems. Patients who have undergone an ostomy surgery often grapple with heightened problems of body image and feel conspicuously different from their adolescent peers [30]. An analysis by Kunz et al. revealed that these patients often experience social isolation and distress, are absent from school, and are impacted by restrictions in daily life, hobbies, and fear of bloody stools [31, 32].

It is also noteworthy that from the Group C subset of patients, 22% and 20% of responses were answered as "I need to learn" for the 'My Health' and 'Using Health Care' categories, respectively. This highlights that even as these patients were approaching the transition phase, a substantial percentage expressed a need for further education and support in navigating the health care system and appropriately managing their health. This reiterates the importance of ongoing transition support and education tailored to the individual needs of patients with inflammatory bowel disease as they transition to adult care.

It is also essential to recognize that several systemic barriers within the health care system can also hinder the transition process, such as improper coordination between pediatric and adult health care services or inadequate infrastructure. Financial constraints pose a very common obstacle, access to health insurance is often insufficient or nonexistent for pediatric and adolescent patients [33]. Additionally, primary caregivers of patients may be overwhelmed by workload, finances, or responsibilities related to caring for multiple children. As a result, they may lack the time or capacity to provide adequate support and guidance to their child during the transition process and may not fully grasp the significance of transition readiness in their child's overall well-being.

In light of the findings from our study, we highly recommend the development of tailored educational materials that target the most frequent barriers identified in our study. These resources can be in the form of accessible informative handouts provided to adolescents during regularly scheduled visits. Furthermore, a comprehensive list of adult providers should be provided so late adolescents can make informed decisions and select their desired adult care provider therefore facilitating the primary gastroenterologist in making the appropriate referrals may reduce feelings of abandonment and increase trust with new providers [33]. Joint clinics with the patient, pediatric, and adult providers as well as social workers should be established to help relieve anxiety associated with the transition process [34]. It is also crucial to continue assessing the readiness to transition for all adolescent patients on a frequent basis [35]. Adolescents also need to be taught about the possible side effects of recreational drugs, smoking, or alcohol on their condition. Additionally, it is very important to raise awareness among patients and families about the importance of a successful transition, which can ultimately lead to improved quality of care, reduced mental and emotional stress, and a smoother transition between health care providers.

Limitations

Our study was conducted at a single institution with a small hospital-derived sample size [36]. The use of one template with the same questions for each age group may have allowed for better comparison. Our study did not distinguish between patients with Crohn's disease, ulcerative colitis, or terminal colitis or include demographic data, such as ethnicity, race, education status, or menstrual maturity. We also did not integrate disease severity or identify co-morbid conditions and their association with patient independence. Consequently, we did not determine the association of transition readiness with disease severity. The data presented in our study were subjective and only on self-reported information from our patients. Further studies which assess transition readiness from the providers standpoint, both pediatric and adult, are warranted.

Conclusion

Our study demonstrates that transition readiness increases with age. Additionally, we identified several barriers to transition across all age groups. These findings suggest opportunities for the development of targeted educational materials and a support system for adolescents with IBD during this challenging phase.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s10620-024-08484-9.

Author's contributions Conceptualization and protocol design were primarily led by S.M.K and D.T. Data collection was conducted by D.T, S.M, and S.M.K. Analysis of the data was performed by J.A, S.M.K, and D.T. The initial draft of the manuscript was prepared by S.M.K, D.T, A.I, and F.M.L. Supervision throughout the research process was provided by D.T and S.M. The final version of the manuscript was prepared and edited by A.I and F.M.L. All authors critically reviewed and approved the final version of the manuscript for submission.

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Data availability The data used in this report was sourced directly from patient-answered questionnaires.

Declarations

Conflict of interest All authors declare that they have no conflicts of interest.

Informed consent We obtained verbal, informed consent from the patients.

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