

Caregiver and Adolescent Patient Perspectives on Comprehensive Care for Inflammatory Bowel Diseases: Building a Family-Centered Care Delivery Model

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Background: Children with inflammatory bowel diseases (IBDs) require primary and gastrointestinal (GI) care, but little is known about patient and family preferences for care receipt. We aimed to understand caregiver perceptions of current healthcare quality, describe barriers to receiving healthcare, and elicit caregiver and adolescent preferences for how comprehensive care ideally would be delivered.

Methods: This was an anonymous survey of caregivers of 2- to 17-year olds with IBD and adolescents with IBD aged 13–17 years at a large, free-standing children's hospital. Surveys assessed patient medical history, family demographics, perceptions of health care quality and delivery, barriers to primary and GI care, and preferences for optimal care delivery.

Results: Two hundred and seventeen caregivers and 140 adolescents were recruited, 214 caregivers and 133 adolescents consented/assented, and 160 caregivers and 84 adolescents completed the survey (75% and 60% response rate, respectively). Mean patient age was 14 years (SD = 3); 51% male; 79% Crohn's disease, 16% ulcerative colitis, and 4% indeterminate colitis. Caregivers were primarily female (86%), Caucasian (94%), and living in a 2-caregiver household (79%). Most caregivers reported that their child's primary care physician (PCP) and GI doctor oversaw their primary care (71%) and their IBD care (94%), respectively. Caregivers were satisfied with communication with their PCP and GI providers (>90%) but did not know how well they communicated with one another (54%). Barriers to primary and GI care varied, and few caregivers (6%) reported unmet healthcare needs. Caregivers and adolescents saw PCPs and GI doctors having important roles in comprehensive care, though specific preferences for care delivery differed.

Conclusion: Caregivers and adolescent perspectives are essential to developing family-centered care models for children with IBD.

Lay Summary

This study presents caregiver perceptions of care quality and delivery for pediatric patients with inflammatory bowel diseases, assesses care gaps and barriers to care, and elicits preferences for ideal comprehensive care delivery from caregivers and adolescents.

Key Words: care delivery model, patient-centered medical home, specialty medical home, primary care, specialty care

INTRODUCTION

Inflammatory bowel diseases (IBDs), including Crohn's disease (CD), ulcerative colitis (UC), and indeterminate colitis (IC), are chronic inflammatory conditions of the gastrointestinal (GI) tract. Prevalence estimates for IBD in Western

countries are around 0.3%, with approximately 20% of patients diagnosed younger than 20 years of age.^{1,2}

Patients with IBD require life-long gastrointestinal (GI) care, as well as routine primary health care services. Guidelines summarizing these healthcare services have been published both for pediatric and adult patients with IBD and allude to

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a co-management model of care, with both primary care and specialty care input.³⁻¹⁰ However, they often fail to indicate which provider is responsible for what services. Although multiple patient-centered care delivery models have been described for those with chronic medical conditions such as IBD, no one model is accepted for comprehensive care over the lifetime. As pediatric and adolescent patients progress through different developmental stages, their needs evolve as well, adding another layer of complexity.

The Chronic Care Model was developed in the 1990s; the goal of this model was to improve clinical outcomes for people with chronic disease through systems-based changes in the domains of self-management support, delivery system design, decision support, and clinical information systems.¹¹ Although used more in adult chronic disease care, it has been applied successfully in pediatrics including in the development of the ImproveCareNow pediatric IBD quality improvement collaborative.^{12, 13} The Patient-Centered Medical Home (PCMH) is a widely recognized model that emphasizes accessible, continuous, comprehensive, family-centered, coordinated, and compassionate care.^{14, 15} PCMH concepts have been applied in adult IBD care and proven successful in improving patient quality of life and decreasing unnecessary healthcare utilization and overall costs.^{16, 17} Incorporation of patient and caregiver perspectives into clinical program development is applied in both of these models and is increasingly recognized as essential to the delivery of patient and family-centered care.¹⁸

In this study, we aimed to understand perceptions of current healthcare quality and delivery for children with IBD from the viewpoint of caregivers of pediatric patients with IBD and adolescent patients, describe perceived barriers to receiving comprehensive healthcare, and elicit caregiver and patient preferences for how comprehensive care ideally would be delivered. Using this information, we hope to reshape pediatric care delivery models so that they optimally meet the needs of children and adolescents with IBD and their families.

MATERIALS AND METHODS

Study Design

This was an anonymous, cross-sectional, single-site survey study conducted at a large free-standing children's hospital. Participants were caregivers of pediatric patients with IBD and adolescent patients with IBD. Inclusion criteria for caregivers included being a parent or legal guardian of a patient 2–17 years old diagnosed with IBD (CD, UC, or IC) at least 12 months before recruitment. Inclusion criteria for adolescents included being 13–17 years old, having IBD for at least 12 months, and having a caregiver who agreed to participate in the study. Exclusion criteria for both groups included the inability or unwillingness to consent/assent and complete the

survey in English. If a caregiver had more than one child with IBD, they were asked to complete the survey about the child who was diagnosed first.

Recruitment

We used an institutional pediatric gastroenterology research registry to identify study participants. At the time of the study, our center was seeing approximately 500 patients with IBD in the age range of 2–17 years. They were 56% male; 76% had CD, 20% had UC, and 4% had IC. Caregivers and adolescents who met inclusion criteria were recruited over the phone, in person, or via a letter mailed to their home. Caregivers of adolescents were not excluded if their child did not provide assent, but any adolescent who assented needed a caregiver to consent as well, as demographic and patient medical information was reported on the caregiver survey. There was no incentive for participation.

Survey Procedures

Participants received a link to the survey via email and completed it electronically. A small number of participants completed a paper version of the survey and their responses were transcribed by study staff. Study data were collected, managed, and stored anonymously using REDCap (Research Electronic Data Capture) tools hosted at the University of Pittsburgh.^{19, 20}

Survey Data

Surveys consisted of a maximum of 55 (caregiver survey) and 3 (adolescent survey) mixed-format questions including Likert-type scales, multiple-choice, matrix style, and free text. Caregiver surveys assessed patient medical history (current age, sex, disease type and duration, therapies, and presence of other chronic medical conditions) and family demographics [caregiver age, sex, ethnicity, living setting (rural/urban/suburban), insurance type (private/public/none/more than one), the highest level of education, and current occupation]. Occupational prestige scores were calculated as described by Entwisle and Astone.²¹ The scores are a proxy for socioeconomic status, ranging from 15 for unemployed to 97 for physicians, with a higher value indicating higher socioeconomic status. In 2-parent households, the higher value is presented. Perceptions of current health care quality and delivery were assessed by eliciting opinions regarding physician responsibility for various types of care, confidence in physician knowledge, satisfaction with communication within the healthcare team, and unmet healthcare needs. Finally, we assessed the degree to which the following items existed as barriers to care: travel, finances, communication, scheduling, and continuity of providers.

Both caregiver and adolescent surveys assessed preferences for how care ideally would be delivered with the question

“which provider(s) should address the following topics” with response options being “PCP, GI doctor, both, no preference on which doctor, or no need for a doctor to address this issue.” Topics asked only of caregivers included the following: annual checkups, routine vaccinations, care for minor illness, care for other chronic problems, monitoring of IBD activity, checkup for GI symptoms, changing IBD treatment, and referral to other providers. Topics specifically relevant to adolescent and young adult patients, or ones that may only be addressed in a confidential adolescent social history, were asked of both caregivers and adolescents: transition to an adult provider, drug and alcohol use, sexual and reproductive health, body image, puberty, mood, extracurriculars, school, peer relationships, and family relationships. Survey readability was assessed at a fourth-grade level by the Flesch–Kincaid readability test.²²

Data Analysis

Descriptive statistics were used for patient and caregiver characteristics, perceptions of care delivery and quality, barriers to care, preferences for care receipt, and to compare caregiver and patient preferences for care receipt. Fisher's exact and Pearson chi-squared tests were used to compare differences between categorical variables as appropriate. Data from one caregiver were not usable, as they completed information about their child's disease, but then abandoned the survey.

Ethical Considerations

University of Pittsburgh Institutional Review Board approval and a waiver of written informed consent were obtained before study initiation (PRO17100303).

RESULTS

Survey Response Rates

Two hundred and seventeen caregivers and 140 adolescents were recruited, 214 caregivers and 133 adolescents consented/assented, and 160 caregivers and 84 adolescents responded to the survey (75% and 60% response rate, respectively).

Patient and Caregiver Demographics and IBD Characteristics

Participant demographics and patient IBD characteristics are reported in [Tables 1](#) and [2](#).

Caregiver Perceptions of Physician Responsibility

Most caregivers reported their child's primary care physician (PCP) was responsible for their primary care (71%) versus their GI doctor (5%) versus both PCP and GI (23%). Most caregivers reported their child's GI doctor was responsible for their IBD care (94%) versus their GI and PCP (6%), N = 158.

TABLE 1. Caregiver-Reported Patient Demographics and IBD Characteristics (N = 160)

Current age, years; mean (SD)	14 (3)
Duration of disease, years; mean (SD)	4 (3)
Male; N (%)	81 (51)
Disease type; N (%)	
Crohn's disease	127 (79)
Ulcerative colitis	25 (16)
Indeterminate colitis	7 (4)
Do not know	1 (1)
Current medication use; N (%)	
Aminosalicylates (5-aminosalicylate, sulfasalazine)	30 (19)
Immunomodulators (thiopurine, methotrexate)	61 (38)
Biologics	124 (78)
IBD-nutritional therapy (exclusive or partial enteral nutrition)	9 (6)
Steroids (budesonide or prednisone)	10 (6)
Antibiotics	1 (1)
None	0 (0)
Patients with >1 other chronic condition; N (%)*	48 (30)

*N = 159; total N varied for different questions as responses to survey questions were not required.

Caregiver Confidence in Physician Knowledge

Of caregivers whose children had seen a PCP in the last 12 months (N = 139), confidence in their PCP's knowledge about IBD ranged from very (28%), to somewhat (53%), to not at all (14%); 6% did not know. Caregivers (N = 158) were very (72%), somewhat (23%), and not at all (3%) confident in their GI doctor's primary care knowledge; 3% did not know.

Caregiver Perception of Communication Quality With Providers

Regarding communication between the caregiver and PCP, 47% thought their PCP did very well, 43% pretty well, and 8% not very well; 2% did not know (N = 138). Regarding communication between the caregiver and the GI doctor, 85% thought their GI doctor communicated very well, 15% pretty well, and 1% not very well (N = 156). Seventy-three percent of caregivers did not know how well their child's PCP and GI doctor communicated with one another: 13%, 28%, and 7% of caregivers thought they communicated very well, pretty well, and not very well, respectively (N = 138).

Unmet Care Needs and Barriers to Primary and GI Care

Ninety-six percent (N = 158) of caregivers reported their child's physical and behavioral healthcare needs were being met. Very few caregivers (6%) reported difficulty receiving physical or behavioral healthcare services for their children. Caregivers

TABLE 2. Caregiver-Reported Demographics (N = 153*)

	n (%)
Female caregiver completing survey	132 (86)
Racial/ethnic background	
Hispanic/Latino	2 (1)
African American/Black	2 (1)
Asian/Pacific Islander	3 (2)
White/Caucasian	144 (94)
Mixed/multiple race/ethnicity	2 (1)
Living setting	
Rural	48 (31)
Urban	17 (11)
Suburban	87 (57)
Health insurance type	
Private only	65 (43)
Public only	32 (21)
Private primary with public secondary [†]	52 (34)
Prefer not to say	4 (3)
Two-parent household	121 (79)
Highest household education level—either parent	
High school degree or equivalent	11 (7)
Some college, no degree	15 (10)
Associate degree	22 (14)
Bachelor's degree	49 (32)
Graduate/professional degree	56 (36)
Family occupational prestige score; mean (SD)	62.5 (21) [‡]

*Total N varied for different questions as responses to survey questions were not required.

[†]In Pennsylvania, children with chronic illnesses like IBD are eligible for secondary public insurance.

[‡]Comparable to occupations of teachers, clergy, chemical and electrical technicians, and inspection and compliance officers.²⁰

who reported unmet healthcare needs had the option of elaborating further in free-text responses; topics included the need for improved communication and coordination between PCPs and specialists (GI and other); access to GI and specialist care at more convenient locations and times (including after hours and weekends); and access to behavioral health and emotional support for both parents and patients in the form of support groups and counseling.

The frequency with which caregivers reported specific barriers to receiving care from PCP and GI doctor is reported in Table 3. The most commonly reported barriers to PCP care were related to scheduling (23%) and continuity of care (21%). The most commonly reported barriers to GI care were related to scheduling (38%) and travel (30%). Having public versus private/multiple types of insurance had little impact on report of barriers to care in our survey. The only statistically significant differences between groups were scheduling GI appointments, which was reported to be difficult by 22% of those with public

insurance and 42% of those with private insurance ($P = 0.038$), and continuity of GI providers, which was difficult for 6% of those with public insurance versus 0% with private/multiple ($P = 0.045$).

Caregiver and Patient Preferences for Care Receipt

Caregiver and adolescent preferences regarding which provider should address specific health care topics are shown in Figures 1 and 2. A majority of caregivers thought annual checkups, routine vaccinations, care for minor illnesses, and non-IBD chronic problems should be addressed by the PCP (82%, 83%, 88%, and 54%, respectively). On the other hand, most caregivers thought checkups for GI symptoms, monitoring of IBD activity, and changing IBD treatment should be addressed by the GI doctor (84%, 80%, and 93%, respectively). Opinions regarding which provider should address topics such as family and peer relationships, school and extracurricular activities, mood, puberty, body image, sexual/reproductive health, alcohol/drug use, referrals to other providers, and transition to an adult provider were much more variable, with most caregivers indicating both the PCP and GI doctor.

Nearly half of surveyed adolescents thought both the PCP and GI doctor should address puberty (55%), a transition to an adult provider (51%), mood (49%), and drug and alcohol use (48%). About a third thought both providers should discuss family relationships (31%), school (35%), extracurricular activities (39%), and sexual/reproductive health (36%). Adolescents most commonly responded that there was “no need for a doctor to address” body image (33%) or peer relationships (34%).

Comparing Caregiver and Adolescent Preferences for Care Receipt

As discussed in the Methods section, preferences regarding which provider (if any) should address a subset of healthcare topics were assessed in both caregivers and adolescents. Of caregiver-adolescent pairs who responded, complete agreement occurred with the following frequencies: family relationships 41% (N = 78); peer relationships 40%, school/grades 36%, extracurricular activities 42%, mood 44%, and puberty 43% (N = 77); body image 44%, sexuality and reproductive health 41%, alcohol and drug use 46%, and transitioning to an adult provider 46% (N = 71).

DISCUSSION

This is the first study to comprehensively explore caregiver perceptions of primary and specialty care quality and delivery and elicit preferences for ideal care delivery from both caregivers and adolescent patients with IBD. This differs from our

TABLE 3. Frequency With Which Caregivers Reported Specific Barriers* to Receiving Care From PCP and GI Doctor by Insurance Type (N = 149)

		Frequency of Barrier to Care, n (%)			P
		Overall	Public Insurance	Private/Multiple Insurance	
From PCP	Travel	10 (7)	4 (13)	6 (5)	0.223
	Financial	18 (12)	7 (22)	11 (9)	0.068
	Communication	20 (13)	4 (13)	16 (14)	†
	Scheduling	35 (23)	7 (22)	28 (24)	†
	Continuity	32 (21)	3 (9)	29 (25)	0.060
From GI	Travel	45 (30)	11 (34)	34 (29)	0.562
	Financial	29 (19)	10 (31)	19 (16)	0.057
	Communication	17 (11)	4 (13)	13 (11)	†
	Scheduling	56 (38)	7 (22)	49 (42)	0.038
	Continuity	2 (1)	2 (6)	0 (0)	0.045

*Items were considered a barrier if caregivers reported they made receiving care “very” or “somewhat” difficult.
 †Statistical tests not run as differences unlikely to be clinically significant.

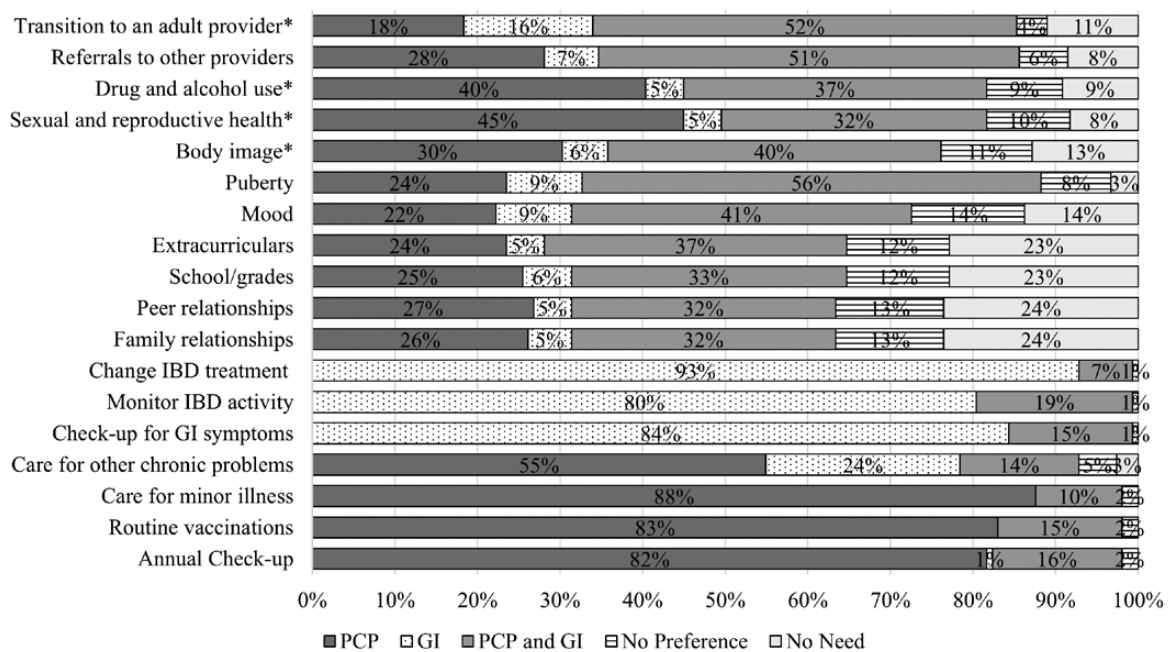


FIGURE 1. Parent preferences for which provider should address assorted topics (N=153); *109—total N varied for different questions as responses to survey questions were not required.

prior publications, where caregiver and patient reports of actual care receipt were presented, including which providers delivered care (*Journal of Pediatrics*, accepted April 2020) and in what settings (office vs emergency department vs urgent care).²³ In this study, we found that caregivers believed PCPs were primarily responsible for primary care and GI doctors for IBD care. They were generally satisfied with the quality of communication with their providers, though unsure about communication between providers. They had high levels of confidence in provider

knowledge, though were more confident in their IBD provider’s primary care knowledge than their PCP’s IBD knowledge. Barriers to care varied between PCP and GI care receipt, and though few caregivers reported that their child had unmet needs, those who did cited poor access to behavioral healthcare and patient/family emotional support. Overall, caregivers and adolescents indicated that ideal comprehensive care would involve a partnership between primary care and GI providers, though their specific preferences varied.

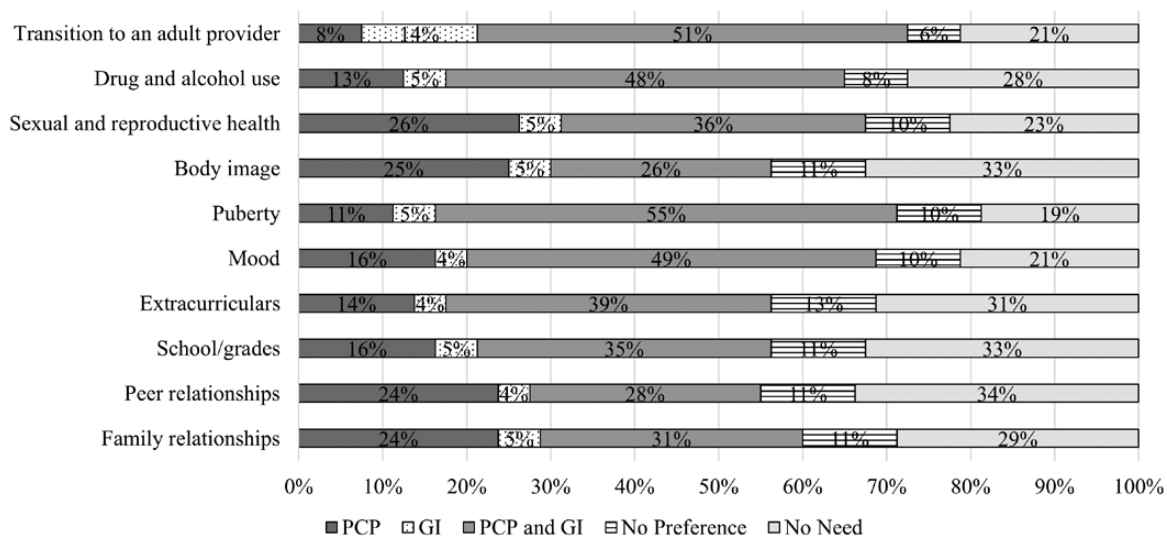


FIGURE 2. Adolescent preferences for which provider should address assorted topics (N = 80).

In our study, we asked caregivers which provider they thought was responsible for their child’s primary care and IBD care, respectively, and found that the majority of caregivers saw 2 distinct roles: 71% believed their child’s PCP was responsible for primary care and 94% believed the GI doctor was responsible for IBD care. This is similar to findings from studies of caregivers of children with congenital heart disease, who preferred their PCP address general health concerns, and cardiologist address cardiovascular ones.^{24, 25} However, it challenges a primary pillar of the PCMH model, where a “personal physician” serves as the coordinator of a patient’s medical care.^{26, 27} In the traditional description of the PCMH, the personal physician is a PCP, with the subspecialist serving as part of the surrounding medical “neighborhood.”²⁸ However, there is nothing barring specialty providers from serving as the personal physician as long as they (and their practice) are willing and able to take on the coordinator role and meet the PCMH criteria. The best-known example of the subspecialty medical home in IBD was built and described by Regueiro et al^{16, 17} in their IBD Total Care model. Our data seem to indicate that both primary and specialty physicians have important roles to play in the eyes of caregivers, though future work should explore whether caregivers see one physician as their child’s “personal physician.”

No matter who a patients’ personal physician is, co-managed care requires efficient, effective communication between primary and specialty providers to prevent omissions and/or duplications of care.²⁹ Although caregivers were quite satisfied with the communication between themselves and their child’s PCP and GI providers, they were largely unaware of whether their child’s doctors were communicating with each other. Although not directly assessed in this study, the existing literature suggests that communication problems between primary and specialty care are prevalent.^{30, 31} Examples include issues communicating care delivered by individual providers,

instructions for follow-through, and discussions of how care from each provider should be integrated. Often, caregivers themselves serve as communication intermediaries between primary care and specialists, a role with which both caregivers and physicians have variable comfort.³² As we seek to build a care delivery system that truly addresses the needs of patients and their families, plans for clear communication between providers are essential.

Next, we sought to understand the unmet needs of children with IBD and explore barriers to both primary and IBD care. Although only 6% of caregivers reported unmet physical or behavioral healthcare needs, those who did described difficulty accessing behavioral healthcare for their child and emotional support for children and families, especially at the time of diagnosis. These findings are not surprising, as the potential effects of IBD on the psychosocial health of both patients and families are known,³³⁻³⁵ as are the gaps in behavioral health care worldwide.³⁶

When asking about specific barriers to care receipt, we found that caregiver’s responses varied between primary and GI care. For example, travel problems (distance to the doctor’s office, the ability to get transportation) made accessing GI care difficult for nearly a third of participants. This was not the case for primary care receipt, likely because 89% of families in our study reported living within 15 miles of their child’s PCP.²³ Scheduling problems, on the other hand (reaching a scheduler on the phone, scheduling an appointment in an ideal timeframe), made receiving primary and GI care difficult for 23% and 38% of caregivers, respectively. It is unclear if these findings, especially with access to the GI provider, reflect issues with support staffing, scheduling systems, or the number of providers available to see patients. Prior work has demonstrated variable access to pediatric subspecialty care across the United States³⁷ and highlighted increased access challenges for

children with public insurance.³⁸ In our study, the type of insurance (public vs private/multiple) had very little effect on the report of barriers.

Less than a fifth of caregivers reported financial issues as barriers to receiving primary or GI care. This may be attributable to the fact that all study participants were insured, and their caregivers tended to be highly educated with high occupational prestige scores. Communication issues were also infrequently described as barriers to either primary or GI care, which is consistent with the high levels of satisfaction caregivers reported with communication presented earlier. Finally, continuity with providers was reported as a barrier to primary care by 25% of caregivers compared to only 1% of caregivers regarding IBD care. Continuity is a tenet of quality care and depends on having an established provider following a patient longitudinally who understands the patient and his/her multiple needs.³⁹ Continuity of care has been associated with a variety of benefits including improved health outcomes and patient satisfaction.^{40, 41} The effect of this barrier on comprehensive care receipt in children with IBD is unknown but may highlight an area where the GI doctor serves as the patient's "personal physician" and care coordinator with the PCP as an invaluable consultant.

When discussing unmet healthcare needs and barriers to care, it is essential to note that our caregiver population was largely white, suburban, and well-educated. This limits the generalizability of our results. Prior studies from more diverse groups have identified disparities in IBD treatment and outcomes, including different rates of testing and treatment,⁴² lower rates of parenteral nutrition provision in patients with protein-calorie malnutrition,⁴³ higher rates of healthcare utilization and increased patient costs,^{42, 44, 45} higher rates of postoperative complications,⁴⁶ and longer hospital stays.^{46, 47} It would not be surprising, then, that unmet needs and barriers to care differ for other socioeconomic, racial, and geographic groups. In order to build health care delivery systems that serve all patients and families, future work must focus on understanding the needs of patients and families affected by IBD needs to include a more diverse sample. Potential means of accomplishing this include conducting surveys at multiple centers, focusing on those with more diverse patient populations, and incorporating patient and parent stakeholders into research planning to ensure inclusive research recruitment and retention.

Survey questions assessing how caregivers and adolescents envisioned optimal care delivery revealed that both groups seemed to support a co-managed care model. Although most caregivers believed that some tasks were specific to the PCP (annual checkups, vaccines, and care for minor illnesses) and others were specific to the GI doctor (evaluating GI symptoms, monitoring IBD activity, and adjusting IBD treatments), they thought the remainder of topics should be addressed by both providers. Many adolescents thought that the majority of topics should be addressed by both the PCP and GI doctor as

well, with approximately 50% indicating discussions of mood, puberty, substance use, and transition to an adult provider as a joint task. However, there were significant discrepancies between caregiver-adolescent pairs in regard to who (if anyone) should address specific healthcare topics, with only 36%–46% agreement depending on the topic.

The incorporation of adolescent perspectives is a strength of our study. Most pediatric patients with IBD are diagnosed during adolescence, such that they are navigating their disease and its management during a crucial developmental period.^{48, 49} Prior work has revealed that most adolescents want to be involved in their healthcare to varying degrees and often in ways different than what is currently occurring.^{50, 51} Perceptions about chronic disease and preferences for management and medical decision making are known to vary between adolescent patients and their parents.^{52, 53} Thus, seeking their input and addressing their specific needs are essential to building a care delivery model that is truly patient- and family-centered.

An interesting population identified in our study is those caregivers and adolescents who thought certain topics need not be addressed by any doctor; for example, 20% of caregivers thought family and peer relationships, school/grades, and extracurricular activities need not be addressed. Adolescents were even more likely than their caregivers to indicate "no need" for certain topics to be addressed, including 29% in regard to family relationships, 34% regarding peer relationships, 33% regarding school, 31% regarding extracurriculars, 21% regarding mood, 19% regarding puberty, 32% regarding body image, 23% regarding sex, 28% regarding drug and alcohol use, and 21% regarding the transition to an adult provider. In clinical practice, supported by published studies, many of these topics are essential to patient-centered, whole-person pediatric care.^{35, 54} Even the small percentage of caregivers in our study who cited gaps in care reported them in the psychosocial realm. Our data suggest that some caregivers and patients may not consider these topics as part of medical care and may benefit from education regarding the potential psychosocial impacts of IBD. Our findings could also be related to how the response options were worded: "no need for a *doctor* to address this." Participant responses may have differed if response options had included other members of the medical team such as a nurse, social worker, or psychologist. Finally, participants' responses may be shaped by their prior experiences with healthcare, likely limited to one care delivery model. Thus, they may be unaware that other models exist that may serve them better.

Limitations

As with all survey studies, these results are susceptible to response bias. Additionally, our sample, although reflective of our overall population in terms of age, sex, and disease type, only represented about 40% of our eligible patient population, potentially contributing to sampling bias. We attempted to

mitigate recall bias by restricting questions about care receipt to the last 12 months. Generalizability is limited by the fact that our sample was largely white, well-educated, and insured as discussed above.

CONCLUSIONS

Although caregivers of pediatric patients with IBD are generally satisfied with their healthcare, barriers to care remain and vary between the primary and specialty care settings. Though specific preferences for care delivery exist between caregivers and adolescent patients, most seem to desire a comprehensive care model where PCPs and GI providers share responsibilities. However, we should consider that they might prefer other models of care, but simply have not been exposed to them. Developing and improving upon health care systems will require ongoing, stake-holder informed processes, including the voices of adolescent patients.

DATA AVAILABILITY

Data are available in the supplementary material.

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