

ORIGINAL ARTICLE**Gastroenterology: Inflammatory Bowel Disease**

Is it “all in the bag?” Multidisciplinary perspectives on ostomy surgery in pediatric IBD across the ImproveCareNow network

Jennie G. David^{1,2}  | Jennifer Dotson^{1,2,3,4} | Laura Mackner^{1,2,5} |
ImproveCareNow Learning Health System

¹Department of Pediatrics, The Ohio State Wexner Medical Center, Columbus, Ohio, USA

²Nationwide Children's Hospital, Columbus, Ohio, USA

³Division of Pediatric Gastroenterology, Hepatology and Nutrition, Nationwide Children's Hospital, Columbus, Ohio, USA

⁴Center for Child Health Equity and Outcomes Research, Abigail Wexner Research Institute at Nationwide Children's Hospital, Columbus, Ohio, USA

⁵Center for Biobehavioral Health, Nationwide Children's Hospital, Columbus, Ohio, USA

Correspondence

Jennie G. David, Nationwide Children's Hospital, 700 Children's Dr, Columbus, OH 43205, USA.
Email: jennie.david@nationwidechildrens.org

Funding information

The Abigail Wexner Research Institute at Nationwide Children's Hospital

Abstract

Objectives: Pediatric inflammatory bowel disease (IBD) is a chronic illness with various treatments, including ostomy surgery. Ostomy-related medical decision-making (MDM) is complex for multidisciplinary healthcare professionals (HCPs). This study sought to understand national multidisciplinary HCPs' perceptions about pediatric IBD ostomy surgery in the United States.

Methods: This cross-sectional REDCap survey recruited HCPs in pediatric IBD HCP roles from the ImproveCareNow (ICN) Learning Health System. The survey gathered data on, (1) demographics, (2) participants' perspectives on patients/families' ostomy perceptions, (3) participants' own perspectives on ostomies, and (4) participants' perspectives on multidisciplinary collaboration in ostomy surgery.

Results: Participants ($n = 69$, across $n = 30$ American ICN sites) were 84% White, 62% female, and 54% gastroenterologists. In reflecting on patients/families' perceptions, participants endorsed most (86%) view ostomies as a “failure,” various psychosocial concerns (e.g., 97% endorsed body image concerns), and most (81%) have moderate to significant stigma about ostomies. In reflecting on their own perceptions, nearly half (44%) endorsed some to moderate stigma about ostomies and felt ostomy discussions were difficult when families had negative perceptions (88%). Over half (54%) endorsed currently having multidisciplinary care for pediatric IBD surgery. Most (70%) endorsed variability in the amount and/or quality of multidisciplinary collaboration.

Conclusion: MDM related to pediatric IBD ostomy surgery presents nuanced clinical complexities for HCPs. This work underscores interest in multidisciplinary care, notable ostomy-related psychosocial needs, and ostomy-related stigma. Future work should develop systematic approaches to multidisciplinary pediatric IBD ostomy care, bolster psychosocial support, and evaluate how systematic care may impact psychosocial, and healthcare utilization outcomes.

KEYWORDS

inflammatory bowel disease, multidisciplinary care, ostomy

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2024 The Authors. *JPGN Reports* published by Wiley Periodicals LLC on behalf of The European Society for Pediatric Gastroenterology, Hepatology, and Nutrition and the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition.

1 | INTRODUCTION

Pediatric inflammatory bowel disease (IBD) is a chronic, immune-mediated illness that has a growing armamentarium of treatment options, including ostomies.^{1–3} The extant literature on ostomies in pediatric IBD, while somewhat limited, continues to highlight the psychosocial considerations of this complex surgical decision, limited knowledge amongst patients with pediatric IBD about ostomies, variability in multidisciplinary care for these patients, and the persistent ostomy-related stigma that can impact patients, families, and healthcare professionals (HCPs) in nuanced ways.^{4–12} For example, ostomy-related stigma for a patient may engender worries that an adolescent may not be able to play competitive sports and contribute to a strong preference to not pursue surgery. Multidisciplinary care remains the gold standard in caring for pediatric patients living with IBD,^{13,14} with ongoing exploration of different models of multidisciplinary care in daily practice,¹⁴ if multidisciplinary care is equitable and accessible to this population,^{15–17} and how surgical decisions may impact the make-up, coordination, and collaboration amongst a multidisciplinary team.⁸

While previous research has sought to understand the lived experiences of patients with IBD who have ostomy surgery, there is a significant need to better understand the HCPs and systems that shape medical decision-making (MDM), education, and collaboration related to ostomy surgery. Ostomy surgery in pediatric IBD often requires patients and HCPs to repeatedly cross outpatient, inpatient, medical, and surgical settings, presenting many challenges to multidisciplinary care and collaboration.⁸ Additionally, HCPs have expressed difficulties in knowing when the right time to begin discussions about ostomies may be and which HCP may be ideal to lead these discussions⁸—does the gastroenterologist (GI) lead the discussion as the patient's primary HCP or defer to the surgeon? Ostomy-related stigma for HCPs remains pervasive,^{18–22} including perceptions by HCPs that people living with ostomies have lower quality of life,²³ though there is limited scientific understanding of how HCPs perceive ostomy-related stigma for themselves and their receptions of ostomy-related stigma for patients and families; understanding ostomy-related stigma from HCPs' perspectives would represent a critical opportunity to directly tackle and work to reduce stigma for this surgery and support neutral and calm conversations about complex care decisions.

This study sought to explore perspectives on ostomy surgery in pediatric IBD from multidisciplinary HCPs caring for this patient population to continue to increase the understanding of ostomy surgery in pediatric IBD to inform the future of multidisciplinary IBD care.

What is Known

- Ostomy surgery is a surgical treatment in pediatric inflammatory bowel disease (IBD).
- The consideration and discussions related to ostomy surgery in pediatric IBD often involves complex medical decision-making for families and healthcare professionals (HCPs).

What is New

- Multidisciplinary HCPs endorsed various perceptions of how patients and families think about ostomy surgery, including viewing ostomy surgery as a “failure” of care, various psychosocial needs specific to living with an ostomy, and stigma about ostomies.
- Multidisciplinary HCPs endorsed their own perceptions of ostomy surgery in this population, including nearly half endorsing ostomy-related stigma and worries about scaring families when talking about ostomies in outpatient care.
- This work also found that while some multidisciplinary care exists for pediatric IBD patients considering and undergoing ostomy surgery, not all institutions have access to such care and multidisciplinary care can be variable when it occurs.
- This work underscores the roles of multidisciplinary care, psychosocial care, and stigma in ostomy surgery, as well as the need to develop and evaluate systematic approaches for equitable access to multidisciplinary care.

2 | METHODS

This IRB-approved cross-sectional study recruited HCPs to complete a brief REDCap survey. Participants were recruited from the ImproveCareNow (ICN) Learning Health System focused on improving pediatric IBD care²⁴; ICN includes >100 pediatric IBD centers primarily in the United States with several international sites where multidisciplinary stakeholders collaboratively engage to improve pediatric IBD care and consenting patients are entered in a network-wide data registry.^{25,26} Inclusion criteria for this study included of being a HCP at an American ICN center caring for pediatric IBD patients, being a HCP in certain roles (GI, advanced nurse practitioner/nurse practitioner [APN/NP], surgeon, social worker, GI psychologist, child life specialist, and wound ostomy continence [WOC] nurse), and fluency in written English. Survey

participants were offered a \$5 gift card for study completion.

Potential participants were recruited via several modalities, including posts through ICN's internal site, biweekly emails from ICN to individuals who had signed up for these emails (e.g., HCPs), and personalized emails to key contacts at ICN centers to complete and share the survey with other eligible HCPs.

The survey content was informed by qualitative themes identified via qualitative analysis by trained research team members in the first phase of this study following focus groups using a semistructured script exploring multidisciplinary HCPs' perspectives on MDM and education in pediatric IBD and ostomy surgery.⁸ Following identification of qualitative themes that emerged from the first phase of this study, the research team iteratively developed questions under each qualitative theme to fully represent the theme (e.g., stigma with ostomies) until all authors agreed that the questions developed reflected the qualitative themes. The survey (included as Supporting Information S1: Appendix 1) gathered (1) demographic and practice data (e.g., length of time providing care to IBD patients), (2) participants' perspectives of how they think patients and families perceive ostomy surgery, (3) participants' own perspectives on ostomies and ostomy surgery, and (4) participants' perspectives on coordination and collaboration in multidisciplinary care related to ostomy surgery.

3 | RESULTS

A total of 74 participants completed the survey, with five participants removed who did not meet inclusion criteria (one participant removed who did not care for IBD patients, four participants removed as they worked at non-ICN sites). Descriptive and frequency analyses were conducted on the remaining cohort of $n = 69$, representing $n = 30$ American ICN sites (30.6% of American ICN sites at the time of study recruitment (total American ICN during time of study recruitment, $n = 98$).

Participants were 84% White ($n = 58$), 93% non-Hispanic ($n = 64$), 62% female ($n = 43$), 54% GI physicians ($n = 37$), 26% working in IBD for 5 to <10 years ($n = 18$), 81% providing inpatient care ($n = 56$), and 88% providing outpatient care ($n = 61$). Demographic, practice, and geographical location of ICN sites is summarized in Table 1. Participant breakdown by HCP role is depicted visually in Figure 1.

3.1 | Participant perspectives on patient and family's perceptions of ostomies

Participants endorsed perspectives that most patients view ostomies as a failure or last resort (86%) and as an

unexpected part of their IBD care (59%). Participants endorsed perspectives that virtually all patients worry about ostomy surgery impacting body image/clothing (97%), about doing activities (94%), about going to school (91%), and having an ostomy for an extended period (83%). Similarly, participants endorsed perspectives that most parents worry that their child will have an ostomy for an extended time (88%), about their child going to school with an ostomy (81%), about their child doing activities with an ostomy (78%), and about their child independently caring for an ostomy (73%). Participants also endorsed that ostomy surgery is generally overwhelming for parents (81%), overwhelming for patients (78%), increase patient anxiety (56%), and increase patient depression (52%).

Participants endorsed various factors they perceived happening when patients coped well, including being connected with WOC nursing postoperatively (84%), having experienced preoperative outpatient conversations about ostomy surgery (80%), and experienced preoperative inpatient conversations about ostomy surgery (80%), and were connected with WOC nursing preoperatively (78%). Participants endorsed perceptions that some patients think somewhat negatively or very negatively about ostomies (43%), and most patients perceive moderate to significant stigma about ostomies (81%); participants' perceptions of family's ostomy-related stigma is visually displayed in Figure 2. Most participants (58%) endorsed that some patients cope well with ostomies and perceiving that most patients cope much better over time with ostomies (59%).

3.2 | Participant perspectives on ostomies and ostomy-related conversations

When asked to reflect on their own perspectives about ostomies, nearly half of participants endorsed thinking somewhat positively about ostomies (44%) and endorsed some to moderate stigma about ostomies themselves (46%); participants' perception of ostomy-related stigma is shown in Figure 2. Virtually all participants endorsed that ostomy surgery can improve quality of life (94%) and reduce IBD symptoms (91%).

Participants endorsed perceiving ostomy-related conversations had gone well related to the following factors: when families share their questions (91%), when families have a good relationship with the HCP (84%), when the participant has resources to share with the family (83%), when participant/HCPs have more time for a conversation (80%), and when families have a positive perspective on ostomies (73%). Conversely, participants endorsed perceiving that ostomy-related conversations had been challenging when: families have a negative view of ostomies (88%), families have psychological needs without established psychosocial care (73%), families anticipate a permanent ostomy (67%), when

TABLE 1 Demographic and practice data.

	<i>n</i>	%
Participant race		
Caucasian	58	84.1
Asian	5	7.2
Multiracial	2	2.9
Other	2	2.9
Black/African American	1	1.4
Prefer not to say	1	1.4
Participant ethnicity		
Non-Hispanic	64	92.8
Hispanic	3	4.3
Prefer not to say	1	1.4
Missing	1	1.4
Participant gender		
Female	43	62.3
Male	25	36.2
Prefer not to say	1	1.4
Participant healthcare professional role		
GI physician	37	53.6
Surgeon	8	11.6
WOC nurse	7	10.1
APN/NP	5	7.2
Psychologist	3	4.3
CCLS	3	4.3
Nurse	3	4.3
Social worker	2	2.9
Other (GI fellow)	1	1.4
Length of clinical experience in IBD (including fellowship if relevant) (years)		
<3	9	13
3 to <5	9	13
5 to <10	18	26.1
10 to <15	9	13
15 to <20	10	14.5
≥20	14	20.3
Provides IBD care in outpatient settings		
Yes	61	88.4
Provides IBD care in inpatient settings		
Yes	56	81.2

TABLE 1 (Continued)

	<i>n</i>	%
ICN center geographical region (<i>n</i> = 30)		
East Midwest	22	31.9
Northeast	20	29
Atlantic Coast	13	18.8
Southeast	5	7.2
West Midwest	5	7.2
Pacific Northwest	3	4.3
South Central	1	1.4

Abbreviations: APN/NP, advanced practice nurse/nurse practitioner; CCLS, certified child life specialist; GI, gastrointestinal; IBD, inflammatory bowel disease; ICN, ImproveCareNow; WOC, wound care.

there is limited time to talk about surgery in clinical care (65%), and when families are concerned about functional changes after ostomy surgery (65%).

During outpatient conversations about ostomy surgery, most participants reported adjusting wording for the developmental level of the patient (83%), normalizing psychosocial reactions (e.g., worry) (74%), and talking about other deidentified patients with ostomies (68%). Notably most participants endorsed worries that they may scare a family by talking about ostomy surgery (65%) and some endorsed worries they do not know enough about ostomy surgery to discuss the surgery (22%). Inpatient conversations about ostomy surgery were found to have similar considerations, most participants reported adjusting wording for the developmental level of the patient (83%), talking about other deidentified patients with ostomies (70%), and inviting other colleagues to join the conversation (65%). In inpatient settings, some participants also endorsed worries that they may scare a family by talking about ostomy surgery (23%) and endorsed worries they do not know enough about ostomy surgery (18%).

Participants endorsed several opportunities in clinical care to talk about ostomies, including many reporting talking about ostomy surgery when symptoms impact quality of life (73%), with poor response to ≥1 treatment (64%), and when families bring the topic up (55%).

Most participants endorsed that it was helpful for trainees to be a part of these conversations for the trainee's learning (71%). Most participants also endorsed that their ICN site has a multidisciplinary team for IBD patients undergoing surgery (54%), with most reporting that they agreed or strongly agreed that their ICN site would like a multidisciplinary team for IBD patients undergoing surgery (71%).

Participants reported collaboration with other specialists preoperatively, including many collaborating with surgeons (83%), WOC nurses (70%), GI physicians (64%), and GI/IBD psychologists (64%). Postoperatively,

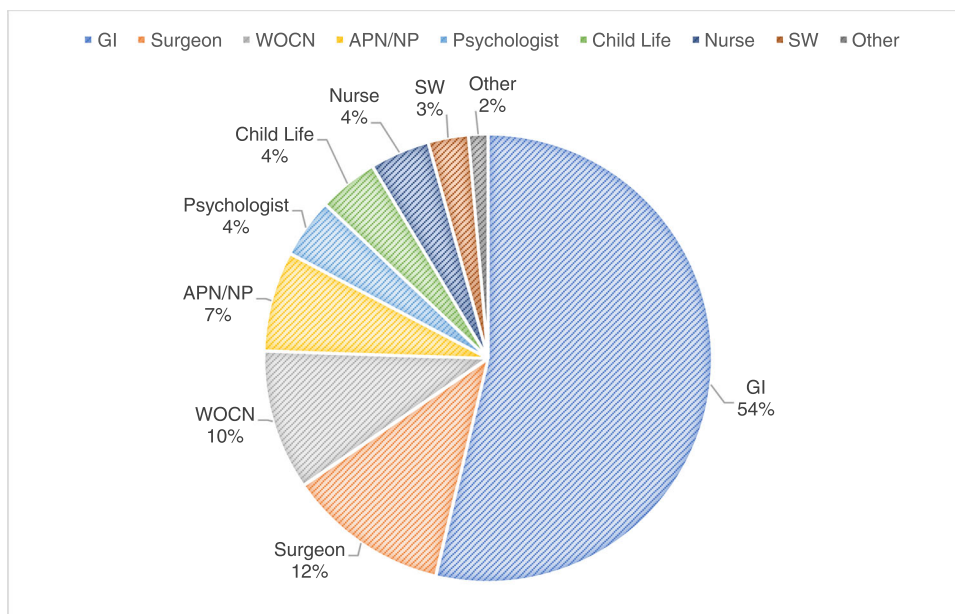


FIGURE 1 Healthcare professionals participant breakdown. APN/NP, advanced practice nurse/nurse practitioner; GI, gastroenterologist; SW, social work; WOCN, wound ostomy continence nurse.

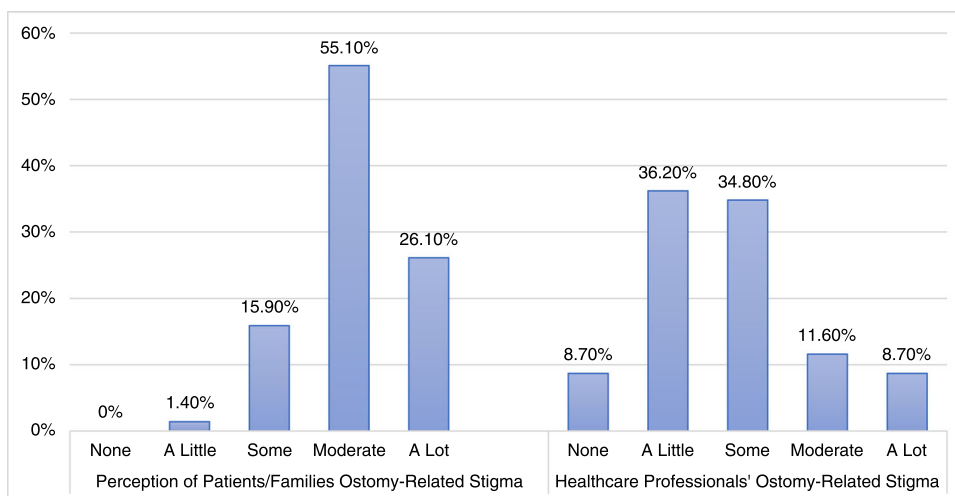


FIGURE 2 Participant perceptions of ostomy-related stigma.

many participants endorsed collaborating with WOC nurses (86%), surgeons (75%), registered dietitians (70%), and with GI/IBD psychologists (67%).

3.3 | Participant perspectives on coordination and collaboration in multidisciplinary IBD ostomy care

Participants were asked to rate the importance of specialists in ostomy surgery conversations (Figure 3). Almost all participants strongly endorsed that it was easier to collaborate in outpatient settings (93%) and endorsing that they disagreed or strongly disagreed that collaborating

can be confusing to the multidisciplinary team (86%). Most participants endorsed agreeing or strongly agreeing that the amount and/or quality of collaboration can vary across IBD patients undergoing ostomy surgery (70%).

4 | DISCUSSION

4.1 | Participant perspectives on patient and family's perceptions of ostomies

When asked to share their perceptions of what patients navigating ostomy surgery in pediatric IBD may

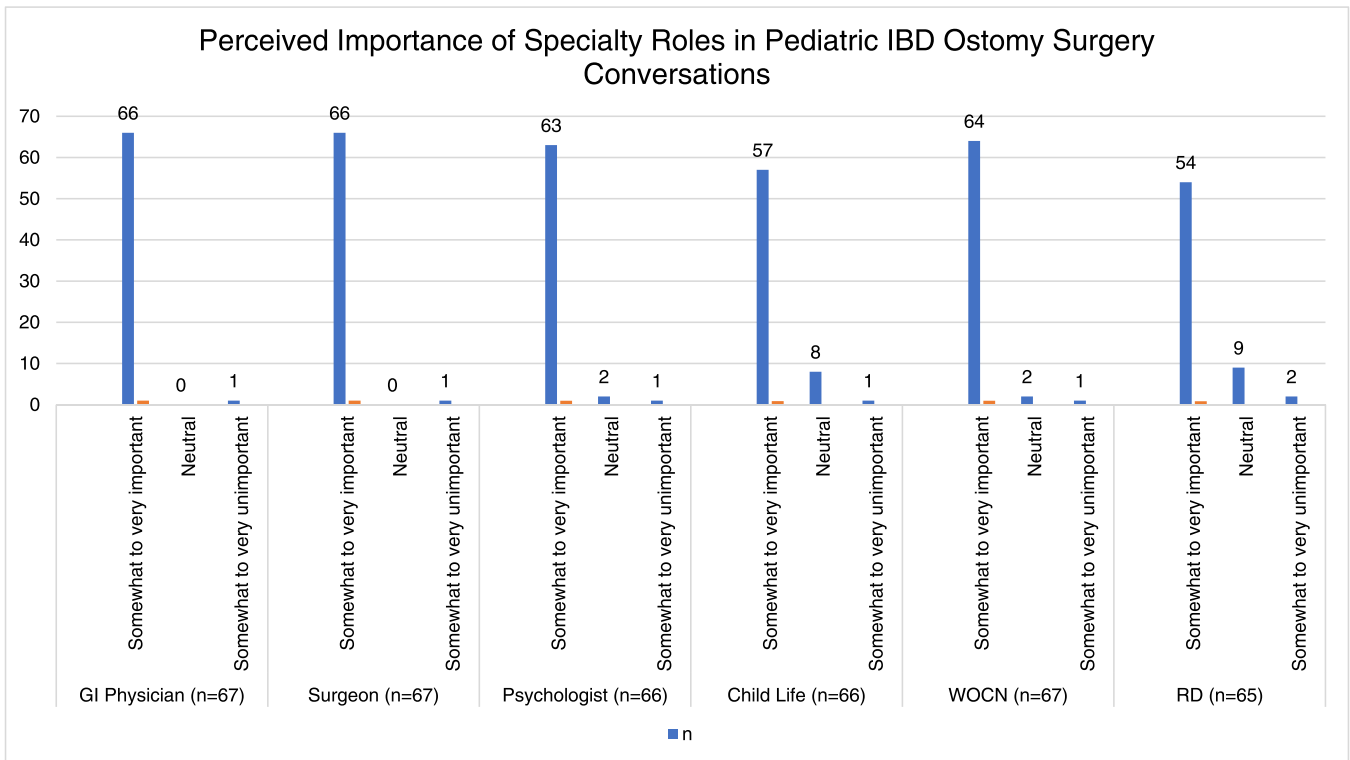


FIGURE 3 Participants' perceived importance of specialty roles in pediatric IBD ostomy surgery conversations. IBD, inflammatory bowel disease.

experience, most participants endorsed perceiving that patients view ostomy surgery as a “failure,” which may reflect how conversations about surgery and ostomies in IBD are often framed and how the term “failure” is often synonymous with lack of/poor response to treatment. This continues to emphasize the importance of how HCPs discuss care options and the language choices we make as in clinical care (e.g., “you failed medication X” may be heard as “it is your fault that you failed medication X”).⁷ This lens of “failure” may also reflect a HCP's own normative emotions about a patient not responding to a nonsurgical IBD treatment, such that a HCP may experience normative emotions of frustration and disappointment that a treatment was not effective. HCPs should be encouraged and supported in developing skills for their own coping with complex medical and surgical decisions, such as ostomy surgery in pediatric IBD.^{27,28}

Multidisciplinary HCPs in this study highlighted various psychosocial considerations related to ostomies in pediatric IBD, including worries related to body image, doing daily activities, going to school, worrying about the duration of time they would live with an ostomy, and the patient autonomously caring for an ostomy. These psychosocial considerations echo the extant literature and highlight the ongoing need to integrate psychosocial care across the perioperative spectrum, as well as ongoing development of

resources to address psychosocial needs.^{4,5,7} Some participants endorsed perceiving that patients can cope well with living with ostomies and that most patients with ostomies generally cope better over time; this insight is notable to shift patient and parents' focus to coping and adjustment over time.

Participants' insights about factors that positively impacted coping with ostomy surgery also aligns with the literature, including being connected with a WOC nurse pre- and postoperatively as well as having previously discussed ostomy surgery in outpatient or inpatient settings.^{8,29–31} Participants also endorsed perceiving that the vast majority of patients have moderate to significant stigma about ostomies,^{32,33} which is likely a barrier to HCPs in feeling comfortable to initiate conversations about ostomy surgery if they perceive most patients will experience strong stigma with the discussion.

4.2 | Participant perspectives on ostomies and ostomy-related conversations

Nearly half of participants endorsed moderate stigma about ostomies themselves as HCPs, which likely impacts assumptions that patients/families will negatively perceive ostomies.^{18,32} This may color and shape

ostomy-related stigma for patients and families when HCPs with stigma discuss ostomies, whereby ostomy-related stigma amongst HCPs may increase ostomy-related stigma among patients/families, which in turn may increase difficulty in discussing ostomy surgery. For example, a HCP may use stigmatizing language or reinforce stigma in care discussions (e.g., “I know patients think that ostomies are gross and weird to have poop in a bag outside of the body.”) and this may negatively impact a patient/family's stigma related to ostomies (e.g., a patient perceiving further stigma after a HCP used negative words in describing an ostomy and implied that ostomies are “bad”). Future work should investigate the potential relationship between ostomy-related stigma among HCPs and patients/families and how stigma may be inadvertently compounded. There are also important diversity, equity, and inclusion (DEI) considerations in recognizing the stigma and cultural understanding of ostomies depending on the cultural background of the family.³⁴

In sharing insights on when conversations about ostomies go well, participants endorsed having appropriate time, strong clinical rapport, and available resources to share were important factors. Notably, participants endorsed that having a positive perspective of ostomies is an important ingredient in conversations about ostomy surgery, and this underscores the importance of addressing and dismantling stigma of ostomies in patients and HCPs alike. These factors also highlight how talking about the role of surgery, including ostomy surgery, as a tool in pediatric IBD earlier in care may help to support these complex discussions; talking about surgery earlier in care creates more time to provide neutral and calm education, explore and address concerns, and provide relevant resources. Discussions about surgery earlier in a pediatric IBD patient's care may also help to reduce HCPs' anxiety about these discussions via graded exposures and practice.

Participants also highlighted how communication style—adjusting wording for a child's development, sharing deidentified stories of other patients who have thrived with ostomies, and normalizing psychosocial reactions—were important in having supportive conversations about ostomies in pediatric IBD care.⁷ Future quality improvement and/or research should seek to build communication tools for HCPs to support these complex discussions, such as providing examples of neutral ways to discuss ostomies and normalizing psychosocial experiences during these conversations. As noted above, supporting HCPs in their own comfort and emotional coping with these sensitive discussions may positively impact their engagement in these discussions earlier in care, as well as increase comfort and practice during these conversations.

While over half of participants endorsed feeling worried that they would scare a family by talking about

ostomy surgery in an outpatient setting, less than one quarter endorsed this worry in an inpatient setting. This discrepancy may be related to the acuity of the patient's health and that being inpatient may make the patient's IBD feel more salient and pressing to talk about surgical options. Participants endorsed various points in clinical care where they currently begin discussions about ostomy surgery including when quality of life is impacted, poor response to ≥ 1 treatment; future work should consider talking about the role and tool of surgery in IBD as one of several potential treatment options at IBD diagnosis and continue to calmly revisit throughout care. This would align with previous research that demonstrated that pediatric patients with IBD have limited knowledge about ostomies and this likely negatively impacts MDM and coping if ostomy surgery is a part of future care.⁵

Multidisciplinary care continued to be highlighted by participants as important for pediatric IBD patients deciding about and undergoing ostomy surgery. This aligns with the literature about the importance of multidisciplinary care in pediatric IBD.^{13,14} A multidisciplinary clinic with integrated medical, surgical, and psychological care would build on previous research demonstrating that multidisciplinary clinics (medical and surgical) reduced emergency room visits, readmissions for patients, and improved postoperative outcomes.^{35,36}

4.3 | Participant perspectives on coordination and collaboration in multidisciplinary IBD ostomy care

Participants endorsed strong interest in multidisciplinary pediatric IBD care for patients considering and undergoing ostomy surgery, and notably endorsed that all members of the multidisciplinary team as somewhat to very important (Figure 2). Participants endorsed that collaboration in outpatient settings can be easier, which likely reflects patients being more medically stable and less time acuity to coordinate and collaborate services. Notably, for many ICN sites there are integrated care models for psychosocial health, which may also increase ease and availability of collaborative care with psychologists in these clinical cases.^{37,38}

Participants endorsed that while collaboration is common, the amount and/or quality of collaboration can be variable in this cohort of patients. This resonates with empirical knowledge of how collaboration can vary depending on many factors including surgery being elective or emergent, patient/family openness to multidisciplinary care, and variability amongst HCPs of knowing who and how other specialties can contribute to care needs (e.g., a GI who is on service and does not specialize in IBD is on service may be less familiar with a WOC nurse's role

preoperatively). This highlights the importance of ongoing education across multidisciplinary services to be aware of how other specialty services can benefit the patient's whole-person care.⁷

4.4 | Limitations

Study findings should be considered thoughtfully within the limitations of this work, including data from a subset of American ICN sites (30.6% of American ICN sites), not all IBD centers in the United States being a part of ICN, and having modest recruitment of surgeons and psychologists as participants. Although many IBD centers are a part of ICN, ICN does not currently encompass all American pediatric IBD centers, and ICN sites may have additional exposure to and value of multidisciplinary care. This work may reflect trends within ICN regarding ostomy surgery in pediatric IBD but may be less reflective of these trends within non-ICN IBD centers. While HCPs across role types participated in the study, surgeons and psychologists represented 11.6% and 4.3% of participants, respectively. The low representation of surgeons and psychologists may be emblematic of GI physicians as the primary HCP for IBD patients and hence the primary participants.

4.5 | Future directions

The extant literature and study findings highlight the importance of multidisciplinary care for pediatric patients with IBD considering and undergoing ostomy surgery, with important future directions for this work. Future work should develop and implement systematic approaches to multidisciplinary pediatric IBD care for ostomy surgery, including recommendations for clinical care across outpatient and inpatient settings. Future guidelines should also work to incorporate DEI-specific considerations and recommendations to integrate psychosocial care/resources when a site does not have a dedicated GI/IBD psychologist. Having multidisciplinary guidelines established may also increase consistency of collaboration of care for these patients and increase equity in care delivery. The medical, psychosocial, and healthcare utilization outcomes that may be associated with multidisciplinary approaches will also be critical to evaluate in future work and may add to momentum to provide integrated care if future findings demonstrate improved outcomes with a multidisciplinary approach. While Short et al.³⁵ demonstrated positive outcomes associated with their multidisciplinary medical and surgical IBD clinic, it is unclear how integration of other multidisciplinary services (e.g., GI/IBD psychology) may impact outcomes and particularly contribute to psychosocial outcomes (e.g., ostomy-related stigma perception).

Lastly, improved understanding of ostomy-related stigma is likely critical to multidisciplinary care in pediatric IBD. Future work should study if ostomy-related stigma impacts how HCPs discuss ostomies, the resulting effects on patients and families, and how to best ameliorate these effects. Future work in this area has the potential to indeed make multidisciplinary care for pediatric IBD patients having ostomy surgery "all in the bag."

ACKNOWLEDGMENTS

This research was funded by The Abigail Wexner Research Institute at Nationwide Children's Hospital.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

ORCID

Jennie G. David  <https://orcid.org/0000-0002-6340-7663>

REFERENCES

1. Conrad MA, Rosh JR. Pediatric inflammatory bowel disease. *Pediatr Clin North Am.* 2017;64(3):577-591.
2. Bouhuys M, Lexmond WS, van Rhee PF. Pediatric inflammatory bowel disease. *Pediatrics.* 2023;151(1):e2022058037. doi:10.1542/peds.2022-058037
3. Phillips MR, Brenner E, Purcell LN, Gulati AS. Pediatric inflammatory bowel disease for general surgeons. *Surg Clin North Am.* 2022;102(5):913-927.
4. David JG, Jofriet A, Seid M, Margolis PA. "A guide to gutsy living": patient-driven development of a pediatric ostomy toolkit. *Pediatrics.* 2018;141(5):e20172789. doi:10.1542/peds.2017-2789
5. David JG, Moreno S, Daniel R, Pall H. The perceived ostomy educational needs of pediatric patients with inflammatory bowel disease and their caregivers. *J Pediatr Gastroenterol Nutr.* 2020;70(6):849-852.
6. David J, Dotson J, Mackner L. Multidisciplinary providers' perspectives on medical decision-making and education related to ostomy surgery in pediatric patients with IBD: qualitative themes from provider focus groups. In: *Society of Pediatric Psychology Annual Conference.* 2022.
7. David JG, Michel HK, Dotson JL, et al. Psychosocial considerations in ostomy surgery for pediatric IBD patients. *J Wound, Ostomy, Continence Nurs.* 2023;50(2):104-106.
8. David J, Dotson J, Mackner L. Medical decision-making and education related to ostomy surgery in pediatric patients with IBD: qualitative themes from multidisciplinary provider focus groups, in *Crohn's & Colitis Congress.* 2022: Virtual Conference.
9. Polidano K, Chew-Graham CA, Farmer AD, Saunders B. Access to psychological support for young people following stoma surgery: exploring patients' and clinicians' perspectives. *Qual Health Res.* 2021;31(3):535-549.
10. Farahani MA, Sargolzaei MS, Shariatpanahi S, Dehkordi AH, Dalvand P, Heidari-Beni F. The prevalence of anxiety and depression in patients with ostomy: a systematic review and meta-analysis. *Psycho-Oncology.* 2022;31:2020-2035.
11. Kittscha J, Fairbrother G, Bliokas V, Wilson V. Adjustment to an ostomy: an integrative literature review. *J Wound, Ostomy Continence Nurs.* 2022;49(5):439-448.

12. Chandrasekhar D, McGee M. Overcoming the “stoma stigma”: patients' perspective of life with a stoma. *Seminars in Colon and Rectal Surgery*. Elsevier; 2023.
13. Wren AA, Maddux MH. *Integrated Multidisciplinary Treatment for Pediatric Inflammatory Bowel Disease*. Multidisciplinary Digital Publishing Institute; 2021:169.
14. Michel HK, Boyle B, David J, et al. The pediatric inflammatory bowel disease medical home: a proposed model. *Inflamm Bowel Dis*. 2022;28(9):1420-1429.
15. Anyane-Yeboah A, Quezada S, Rubin DT, Balzora S. The impact of the social determinants of health on disparities in inflammatory bowel disease. *Clin Gastroenterol Hepatol*. 2022;20:2427-2434.
16. Daniel R, Jimenez J, Pall H. Health equity and social determinants of health in pediatric gastroenterology. *Pediatr Clin North Am*. 2021;68(6):1147-1155.
17. Britto SL, Qian J, Ihekweazu FD, Kellermayer R. Racial and ethnic variation in presentation, diagnosis, treatment, and outcome of pediatric crohn disease: a single center study. *J Pediatr Gastroenterol Nutrition*. 2022;75(3):313-319.
18. Miller LR, Peck BM. Marginalization in the medical encounter: ostomy patients experience of perceived stigmatizing sentiments from medical clinicians. *SAGE Open Nurs*. 2022;8:237796082210953.
19. Qin F, Zhen L, Ye X, et al. Stigma and its influence on patients with temporary ostomy: a cross-sectional survey. *J Wound, Ostomy, Continence Nurs*. 2020;47(3):244-248.
20. Miller LR, Peck BM. Patient-centered care: an examination of provider-patient communication over time. *Health Serv Res Manag Epidemiol*. 2019;6:233339281988287.
21. Taft TH, Keefer L, Leonhard C, Nealon-Woods M. Impact of perceived stigma on inflammatory bowel disease patient outcomes. *Inflamm Bowel Dis*. 2009;15(8):1224-1232.
22. Taft TH, Keefer L. A systematic review of disease-related stigmatization in patients living with inflammatory bowel disease. *Clin Exp Gastroenterol*. 2016;9:49.
23. Eid MA, Goldwag JL, Gray PP, Shaw RD, Ivatury SJ. Physicians perceive that ostomates have decreased quality of life but not overall health: an international survey of physicians. *Colorectal Disease*. 2022;24(12):1602-1612.
24. Crandall W, Kappelman MD, Colletti RB, et al. ImproveCareNow: the development of a pediatric inflammatory bowel disease improvement network. *Inflamm Bowel Dis*. 2011;17(1):450-457.
25. Hartley DM, Keck C, Havens M, Margolis PA, Seid M. Measuring engagement in a collaborative learning health system: the case of ImproveCareNow. *Learning Health Systems*. 2021;5(2):e10225.
26. Seid M, Hartley DM, Dellal G, Myers S, Margolis PA. Organizing for collaboration: an actor-oriented architecture in ImproveCareNow. *Learning Health Systems*. 2020;4(1):e10205.
27. Luff D, Martin EB, Mills K, Mazzola NM, Bell SK, Meyer EC. Clinicians' strategies for managing their emotions during difficult healthcare conversations. *Patient Educ Couns*. 2016;99(9):1461-1466.
28. Kerasidou A, Horn R. Making space for empathy: supporting doctors in the emotional labour of clinical care. *BMC Med Ethics*. 2016;17(1):8.
29. Vickers K. Does the use of a pre-operative mock stoma improve stoma care education? *J Stomal Therapy Australia*. 2022;42(4):10-16.
30. Danielsen AK, Burcharth J, Rosenberg J. Patient education has a positive effect in patients with a stoma: a systematic review. *Colorectal Dis*. 2013;15(6):e276-e283.
31. Zhou H, Ye Y, Qu H, Zhou H, Gu S, Wang T. Effect of ostomy care team intervention on patients with ileal conduit. *J Wound, Ostomy, Continence Nursing*. 2019;46(5):413-417.
32. Frohlich DO, Zmyslinski-Seelig AN. How uncover ostomy challenges ostomy stigma, and encourages others to do the same. *New Media Soc*. 2016;18(2):220-238.
33. Smith DM, Loewenstein G, Rozin P, Sherriff RL, Ubel PA. Sensitivity to disgust, stigma, and adjustment to life with a colostomy. *J Res Pers*. 2007;41(4):787-803.
34. Ore AS, Vigna C, Fabrizio A, Messaris E. Evaluation of racial/ethnic disparities in the surgical management of inflammatory bowel disease. *J Gastrointest Surg*. 2022;26(12):2559-2568.
35. Short SS, Rollins MD, Zobell S, Torres H, Guthery S. Decreased ER visits and readmissions after implementation of a standardized perioperative toolkit for children with IBD. *J Pediatr Surg*. 2022;57(4):604-609.
36. Boldovjakova D, Scrimgeour DSG, Parnaby CN, Ramsay G. Improved outcomes for patients undergoing colectomy for acute severe inflammatory colitis by adopting a multi-disciplinary care bundle. *J Gastrointest Surg*. 2022;26:218-220.
37. David JG, Sejkora E, Michel HK, Mackner L. Pediatric GI health care professionals' perceptions of and engagement with psychosocial providers in pediatric IBD care. *JPGN Rep*. 2023;4(2):e305. doi:10.1097/PJG9.0000000000000305
38. Winnick J, Jacobs N, David JG, Moua MK, Saeed S. Availability of psychosocial services within the ImproveCareNow Learning Health System, in *American Psychological Association Conference*. 2023.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: David JG, Dotson J, Mackner L. Is it “all in the bag?” Multidisciplinary perspectives on ostomy surgery in pediatric IBD across the ImproveCareNow network. *JPGN Rep*. 2024;5:101-109. doi:10.1002/jpr3.12044