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Living with an ostomy: A needs assessment in pediatric inflammatory bowel disease

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ABSTRACT

Background: Inflammatory bowel disease (IBD) is a chronic, immune-mediated inflammatory condition of the digestive tract associated with substantial psychosocial difficulties. Treatment often focuses on medications but may also include surgical approaches (e.g., intestinal ostomy). Unfortunately, literature regarding the psychosocial implications of ostomy surgeries is scarce, and even less is known about adolescent experiences, which may differ markedly from adults.
Objective: This study aimed to explore the perspectives of adolescents with IBD and their caregivers to understand their perceived needs when they have undergone, are anticipating, or have anticipated the possibility of experiencing a stoma surgery. Study findings hoped to inform clinical practice in IBD care and beyond.
Method: A purposive sample of patients and caregivers were recruited from a large pediatric hospital. Twelve patients and thirteen caregivers participated in the study. Participants completed a demographic background questionnaire and virtual semi-structured interview. Inductive content analysis was used to examine participant feedback.
Results: Qualitative results identified four overarching themes and thirteen subthemes: fear of the unknown, perceived barriers, being supported, and recommendations for creating a more positive experience. Specifically, participants described the transition process from pediatric to adult care as particularly intimidating and having a supportive and inclusive handover was a helpful piece that supported the shift to adult care.
Conclusion: This study reflects the importance of a holistic approach to care that attends to adolescent patients' physical well-being and emotional and social needs. Patient-driven recommendations for enhancing age-specific care of adolescents with ostomies are provided.

1. Introduction

Inflammatory bowel disease (IBD) is a chronic, incurable gastrointestinal (GI) disorder that results in recurrent acute and persistent inflammation of the GI tract.[1] Two main IBD subtypes include Crohn's disease (CD) and ulcerative colitis (UC), both associated with remission and relapse.[2] With the stigma attached to CD and UC symptoms, stress, anxiety, and depression are common.[3] IBD poses a significant public health burden, with an estimated 4.9 million cases reported worldwide in 2019.[4] By 2030, 1 % of Canadian children and youth will be diagnosed with IBD, double the number in Canada in 2019.[5] Onset of IBD is often in adolescence, a critical social and emotional development period when risks of disability and mental health concerns are high.[6] IBD is associated with unpredictability, including intermittent symptom flares. For some, inflammatory symptoms are managed with diet changes and/or medications. However, surgical interventions may be used when unresponsive to medical therapies to maintain and induce gut remission and avoid disease progression.[7]

During IBD treatment, some adolescents may undergo an intestinal ostomy surgery.[8] The procedure interrupts normal bowel movement,

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and waste is passed through the abdominal wall through an opening called a stoma into an ostomy bag. This approach can be temporary or permanent and ultimately aims to improve the patient's disease control, and pain and discomfort. In emergent situations, an ostomy may be necessary to save patients' lives. Research on the psychosocial implications of ostomy surgeries is scarce. Even less is known about adolescent experiences,[9] which may differ from adults.[10,11]

For adolescents who have undergone, are anticipating, or have anticipated undergoing ostomy surgeries, risks to their psychosocial health can worsen.[9,10,12,13] Social functioning difficulties in peer relationships are especially concerning during adolescence, as it is a significant transitional period for developing one's sense of self and gaining independence.[14] Anticipating, undergoing, and living with an ostomy includes psychosocial challenges like changes in physical and social selves,[13] sexuality and engaging in sex.[9,15,16] Concerns surrounding managing the stoma and stoma appliance (e.g., pouch leakage, odour, skin irritation, and sounds) can have psychosocial-related implications.[10] Moreover, adolescents can experience sadness around how their IBD impacts the time their caregivers spend managing their health and time away from their siblings.[9]

The challenges around 'normalness'[13,16,17] and stigmatization[10,17–19] amongst adolescents with stoma bags, can lead to resentment towards their 'damaged' or 'flawed' bodies.[9] Notably, adolescents who have undergone an ostomy surgery have reported greater adverse social outcomes compared to physical implications.[13] While undergoing an ostomy surgery can be challenging psychosocially, it also has the potential to be a positive experience for adolescents. Mohr and Hamilton[13] found that participants expressed relief when they felt their healthcare providers took their health concerns seriously. Moreover, adolescents who had experienced an ostomy surgery identified strengths from the adversity around being ill or managing an ostomy device and believed their stoma-related experiences brought them closer to family and friends.[9]

There are some recommendations in the literature for how the psychosocial health and wellbeing of individuals with ostomies can be supported. Healthcare professionals and families may support the psychosocial health of adolescents with IBD by working collaboratively and respecting their agency. Proactive approaches for adolescents who have undergone, or may undergo, an ostomy surgery,[10,13] where patients can exercise self-determination and agency, are recommended.[12] Further, peer support, particularly from fellow ostomy users can be beneficial.[9,13] Adolescents undergoing ostomy surgery find it supportive when their agency is recognized and valued as in having access to relevant literature,[10] patient supports such as toolkits,[12] opportunities to practice dressing, navigating the ostomy appliance, being informed regarding the surgery and what to expect, as well as being allowed to provide input.[10]

With limited research examining the lived experiences of adolescents with IBD and ostomy surgeries, the existing research may not represent the lived experiences of all individuals with IBD. Specifically, the current literature focuses on post-ostomy experiences, with limited research directly exploring the adolescent and caregiver perspective before and after surgery, particularly within the context of Canada's healthcare system.[9,13,15] Capturing both patients and caregiver perspectives can enhance the richness and depth of findings through providing a more comprehensive understanding of the experience faced by both child/-adolescents and the family. Capturing the caregiver perspective is essential as they play a significant role in disease management experience of their child. From the perspectives of adolescents with IBD and their respective caregivers, this study explored their psychosocial experience when they are anticipating, have anticipated the possibility of, or have undergone an ostomy surgery. Caregiver perceptions of patient needs and preferences were also captured. This study addresses a crucial gap in the literature by exploring adolescent patient and caregiver perspectives on adolescent IBD patients' experiences with stoma surgeries and their recommendations for improving care.

2. Method

The present study utilized a qualitative design using purposive sampling to capture the experiences of IBD adolescents and their caregivers. Ethical approval was provided by the authors institution (approval no. 1000067379). All participants provided written informed consent prior to enrollment in the study.

2.1. Participants

Eligible adolescents with IBD at risk of or who underwent ostomy surgery (and their caregivers) were recruited from a large pediatric hospital in Toronto, Canada, between May and September 2020. Patients and caregivers were eligible to participate if they met the following criteria: a) patient or caregiver of a child with an IBD diagnosis; b) patient identified as either having been a potential candidate for ostomy surgery or having undergone ostomy surgery; c) patient between ages 10 and 21 years, d) proficient in speaking and understanding English or willing to use an interpreter; and e) could assent/consent. Participants were excluded if any cognitive impairment would limit their ability to provide assent or participate in an interview.

2.2. Procedure

Existing patients and their caregivers within the IBD program at a large pediatric hospital were identified by healthcare practitioners and invited to participate in this study. The IBD clinic nurse first approached eligible participants and their caregivers and gave them an information letter summarizing the study and potential study involvement. If interested, the clinician asked for verbal consent to pass along their information to the Clinical Research Project Coordinator (CRPC), who then contacted them via phone or approached them in the clinic to discuss the study in more detail and obtain written consent. The CRPC engaged in a maximum of two follow-up approaches, after which the patient/caregiver was assumed to be uninterested in study participation and was marked as lost to follow-up. Following consent, the CRPC, a trained research team member unknown to the participant, conducted all semi-structured interviews lasting between 30–60 min. At study completion, participants received a $25 gift card and a thank you letter for their time and effort. Patient participants also received a letter acknowledging the study's two hours of volunteer time. The authors iteratively determined that the study had achieved sufficient 'information power' to address the study aims after interviewing 12 participants.[20] This assessment was based on several factors, including the study's narrow focus, specificity of ostomy experiences, the quality of dialogue, and the cross-case analysis conducted.[20] In a systematic review, Hennink and Kaiser[21] concurred that saturation could be achieved within a range of 9–17 interviews, particularly for studies that were homogenous or had narrowly defined objectives.

2.3. Measures

2.3.1. Demographics

Patients and caregivers were asked to complete a baseline demographic questionnaire to collect information regarding their self-reported sex, ethnicity, and languages spoken. Patients were also asked to indicate their age, school grade, disease activity, IBD diagnosis, disease activity, and self-reported mental health conditions (e.g., "do you have any mental health conditions?"). Adolescents were also asked to disclose whether they had experienced pain in the last month, to self-report average levels of pain intensity and pain unpleasantness on a scale from 0, "no pain", to 10, "worst pain imaginable". Pain intensity questions were assessed using questions seven to ten from the validated Wisconsin Brief Pain Questionnaire.[22] The pain unpleasantness questions were adapted from Stinson et al. [23] Caregivers were also asked to specify employment, marital status, total annual household income, and health insurance.

2.3.2. Semi-structured interview

Interviews followed a semi-structured cognitive-interviewing format to elicit participants' experience surrounding considering an ostomy surgery (e.g., informational preparedness for surgery, psychosocial support related to surgery experience), and if they underwent one, their experience following the surgery (e.g., impact on quality of life and relationships, suggestions to improve their experience). Questions asked adolescents to comment on their experience leading up to learning they may/would be receiving an ostomy (e.g., "how much choice did you feel you had in deciding to have the surgery or receiving an ostomy?"), experience discussing the potential surgery with their healthcare team, peers, and family (e.g., "did you talk to your peers and friends about the possibility of receiving an ostomy?"), and if they underwent the surgery, attitudes towards receiving an ostomy (e.g., "what surprised you most after getting a stoma?"), and experience receiving an ostomy surgery (e.g., "how does your stoma/use of an ostomy appliance affect other aspects of your life?"). Caregiver interviews asked caregivers for their perspective regarding their experience leading up to learning their child may/would need an ostomy (e.g., "tell me about your experience leading up to learning that your child may/would be receiving an ostomy appliance?"), conversations regarding undergoing an ostomy with family and the healthcare team (e.g., "who spoke to you, and your child and what types of conversations did you have about the impending surgery?"), and if their child underwent surgery, their perspective regarding how the surgery went (e.g., "tell us a little bit about your child's surgery and how their health has been since?"), impact on their child's quality of life (e.g., "tell me about how your child's stoma/use of an ostomy appliance affects the other aspects of their life? "), and solutions to improve the surgery experience (e.g., "please think about how your healthcare team has supported you and your child since his or her stoma. What are they doing that works? What else could they do to provide more support?). Interviews were conducted online using videoconference technology (Zoom) and were audio recorded, de-identified, and transcribed verbatim by a research team member.

2.4. Data analysis

Data analysis followed an inductive qualitative content analysis approach. The inductive qualitative content analysis allowed for a systematic data classification to identify categories based on patterns and provided a rich narrative description.[24,25] By not imposing a pre-existing coding schema, the inductive content analysis allowed for novel insights and understanding from participants' perspectives grounded in their experiences.[12] Three coders reviewed the transcripts independently to determine the common topics and immersed themselves in the data through reading and re-reading. All authors reviewed the themes' descriptions with exemplar quotes to provide feedback, ask questions, and ensure the themes were grounded in the data. To ensure trustworthiness of the data, which includes credibility, transferability, dependability, and confirmability, authors engaged in triangulation through capturing caregiver perspectives, reflexivity, and peer debriefing.[26]

3. Results

3.1. Participants

Fifty-eight families were screened for eligibility. Of the 58, 21 were ineligible to participate due to not meeting inclusion criteria. Ten families were lost to follow-up, and eight families declined to participate. Twelve patients ($M = 15.7$, $SD = 3.5$) and thirteen caregivers ($M = 47.5$, $SD = 2.5$) participated in the study. Caregivers were all biological parents of a child with IBD. Five patient participants were diagnosed with CD and seven with UC. Patient participants were, on average 10.2 ($SD = 3.3$) when they received their diagnosis. Ten adolescents (83 %) underwent an ostomy surgery with two adolescents (17 %) reporting on their experience anticipating the surgery. Nine caregivers of adolescents (69 %) who received an ostomy and four caregivers of adolescents (31 %) who only anticipated the ostomy surgery participated in the study. Six caregivers (46 %) found paying for their child's medication/ostomy supplies difficult. See Table 1 for additional participant demographic and health information.

3.2. Qualitative analysis

Four themes and thirteen subthemes related to the needs and preferences of patients and their caregivers when they had undergone or anticipated the possibility of undergoing an ostomy surgery were produced: *fear of the unknown, being supported, perceived barriers, and recommendations for creating a more positive experience* (see Fig. 1 for all themes and subthemes).

3.2.1. Fear of the unknown

Participants discussed fears associated with the ostomy surgery. Specifically, participants described a sense of fear/anxiety regarding the ostomy surgery, taking care of the ostomy post surgery, how their body would look with an ostomy, and not wanting to receive pity from friends and family. Some adolescents and caregivers also discussed fears around infertility associated with undergoing an ostomy.

3.2.1.1. Fear of surgery. Adolescents reflected on their feelings of fear about the ostomy both before and after surgery. For many, there was a "fear of the unknown" associated with a lack of knowledge regarding ostomy surgery and how the surgery "worked." A 21-year-old female diagnosed with CD noted:

> *I was terrified, I'm not gonna lie, because… they said a bit of your intestine is going to be on your skin. And I'm like how is that going to be? Just the whole thought of a whole bag on your skin that's going to hold your bowel movements and not being able to go to the washroom through your bum. It was just bunch of questions. I was confused. I was scared it was just a fear of the unknown, and it was just more worry.*

However, some caregivers and adolescents were surprised with quick post-surgery recovery and adolescents acknowledged how well they felt compared to pre-surgery. For many this quick recovery was indicative of surgery being the right decision. For example, a 17-year-old female diagnosed with UC explained how surprised she felt after surgery:

> *I think what surprised me is how much better I felt almost immediately. I don't remember too much else, but the fact that I could eat anything I wanted was well within limitations of what you can eat with an ostomy, but I could actually eat food, not just be on mostly liquids or like the restricted diet.*

While most adolescent patients were pleased with the outcome of the ostomy surgery, one unexpected outcome reported was rashes and infections at the surgical site. Moreover, participants explained that part of their ostomy story was how much or how little choice they felt they had regarding the surgery. Many adolescents and caregivers expressed feeling that they did not have much choice to undergo an ostomy surgery, given it was often the final option after trying many medications and diet changes. Caregivers described feeling "pushed into a corner" when it came time to decide about their child's ostomy surgery. A 20-year-old male with CD explained, "*It was the only option really. So, I didn't think too much of it. I just thought like, if it has to be done, it has to be done*". Caregivers noted their concern regarding if they tried a new medication before surgery, it might have taken too long to be effective while their child remained in pain or experienced other health implications.

3.2.1.2. Taking care of an ostomy. Adolescents spoke about the extent to

Table 1
Demographic and disease characteristics.

Characteristic	Adolescent ($n = 12$) n(%)	Caregiver[a] ($n = 13$) n(%)
Sex		
Male	3(25 %)	0(0 %)
Female	9(75 %)	13(100 %)
Self-identified ethnicity		
Caribbean	1(8 %)	1(8 %)
European	2(17 %)	4(31 %)
North American	3(25 %)	4(31 %)
South/Southeast Asian	2(17 %)	1(8 %)
West Asian/Middle Eastern	1(8 %)	1(8 %)
Other	3(25 %)	2(14 %)
Language spoken at home[b]		
Arabic	-	1(8 %)
English	-	5(38 %)
French	-	1(8 %)
Hebrew	-	1(8 %)
Punjabi	-	1(8 %)
Tamil	-	1(8 %)
Turkish	-	1(8 %)
Received Ostomy Surgery[c]	10(83 %)	9(69 %)
IBD Diagnosis		-
Crohn's	5(41 %)	-
Ulcerative colitis	7(58 %)	-
Mental Health Condition[d]	1(1 %)	-
Disease activity over past 6 months (based on patient report)		
Constantly active	1(8 %)	-
Sometimes active	2(17 %)	-
Occasionally active	4(33 %)	-
Rarely active	2(17 %)	-
Remission	3(25 %)	-
Abdominal pain in last month		
Yes	5(42 %)	-
Average pain intensity $M(SD)$[e]	4.6(2.7)	-
Average pain unpleasantness $M(SD)$[f]	4.2(2.7)	-
Adolescent current grade[g]		
Elementary	3(25 %)	-
High school	5(42 %)	-
University	3(25 %)	-
Parent highest educational background		
Some college	-	3(23 %)
Graduated college	-	9(69 %)
Graduate degree	-	1(8 %)
Parent paid employment status		
Yes	-	8(61 %)
No	-	5(39 %)
Marital status		
Married/common law	-	10(77 %)
Separated	-	2(15 %)
Divorced	-	1(8 %)
Type of health insurance[h]	-	
OHIP +	11(92 %)	–
Parent employer	8(67 %)	–
Trillium	1(8 %)	
Hard to pay for child's medications/ ostomy supplies		
Yes	-	6(46 %)
No	-	7(54 %)
Household income		
Less than $20,000	-	1(8 %)
$20,000 to $34,999	-	2(15 %)
$50,000 to $74,999	-	1(8 %)
$100,000 to $149,999	-	2(15 %)
$150,000 +	-	6(46 %)
Prefer not to answer	-	1(8 %)

Note. OHIP+ = Ontario Health Insurance Plan, Ontario's provincial health plan, Trillium = Trillium Drug Program is a provincial plan to address expensive prescription drug costs for individuals who qualify for OHIP and have chronic health conditions but are not covered by other provincial programs.

[a] All caregivers were biological parents.

[b] Language data was not able to be collected for two caregiver participants.

[c] Adolescents or caregivers with an adolescent who received an ostomy surgery versus those who just anticipated whether they should undergo the surgery.

[d] Adolescent participants were asked to self-disclose any mental health conditions. Only one participant stated they had a mental health condition but did not specify the type.

[e] Average pain intensity and average pain unpleasantness according to Stinson et al.[23] and Daut et al.[22] Adolescents were asked to self-report average levels of pain intensity and pain unpleasantness on a scale from 0, "no pain", to 10, "worst pain imaginable"

[f] Average pain intensity and average pain unpleasantness according to Stinson et al.[23] and Daut et al.[22] Adolescents were asked to self-report average levels of pain intensity and pain unpleasantness on a scale from 0, "no pain", to 10, "worst pain imaginable".

[g] Adolescent current grade was not able to be collected for one participant

[h] Participants were permitted to choose multiple insurance options.

which they cared for their ostomy independently and noted feeling nervous and even fearful about the ostomy site, "*I was really cautious because I felt like I didn't have any protection on it. I felt like if someone hit me it would really hurt, and I was really scared*" (15-year-old female diagnosed with UC).

3.2.1.3. *Change in body image.*

Participants noted concerns regarding body image post-surgery, with many frightened to look at the ostomy site:

> *It was funny because I didn't look at it for two days 'cause I was kind of scared to look at it…I didn't think I would be scared. I was really well prepared when I went in, so I don't know. Maybe it was just because I felt like it would look different then and it was just something that was supposed to be inside my body that's like out* (17-year-old female diagnosed with UC).

Adolescents also reported feeling insecure after surgery. Some reported hiding their ostomy with clothing, while others discussed not being able to wear what they wanted due to the visibility of the ostomy appliance. Adolescents described using clothing as a tool to hide the ostomy.

3.2.1.4. *Experiencing pity.*

In addition to the physical considerations of undergoing an ostomy procedure, adolescents explained the concern over not wanting to feel pity from friends and family post-surgery. The idea that others would feel sorry for them or feel bad about the ostomy was discussed by adolescents:

> *The one thing with me, I don't wanna make other people feel like pity. Like people that I…that I don't necessarily know, so I usually won't bring it up. My close friends and family are ok with it. They still… feel sorry for me sometimes and it does kinda… change the mood* (20-year-old male diagnosed with CD).

Moreover, participants discussed the difficulty of being pitied due to pathologizing versus normalizing the ostomy.

3.2.1.5. *Future planning.*

The concern about future family plans, particularly the relationship between the ostomy and fertility was discussed by some of the caregivers of female ostomy patients. The risk of compromising fertility was at the forefront of concerns and gave some patients pause when considering the ostomy. One mother noted about her daughter: "*because I mean she desperately wants to have children someday and the idea that it would be so much you know, that she might not be able to as a result of this, was awful*" (caregiver of a child diagnosed with UC). A second mother described her 9-year-old daughter asking her doctor about having a child in the future:

> *…she said, can I still have a baby with an ostomy? So, at nine, she was worried, and I didn't even know that was something she was thinking about, and he said yeah, he said actually that's something to think about because with a J pouch, your infertility risks increase significantly* (caregiver of a child with UC).

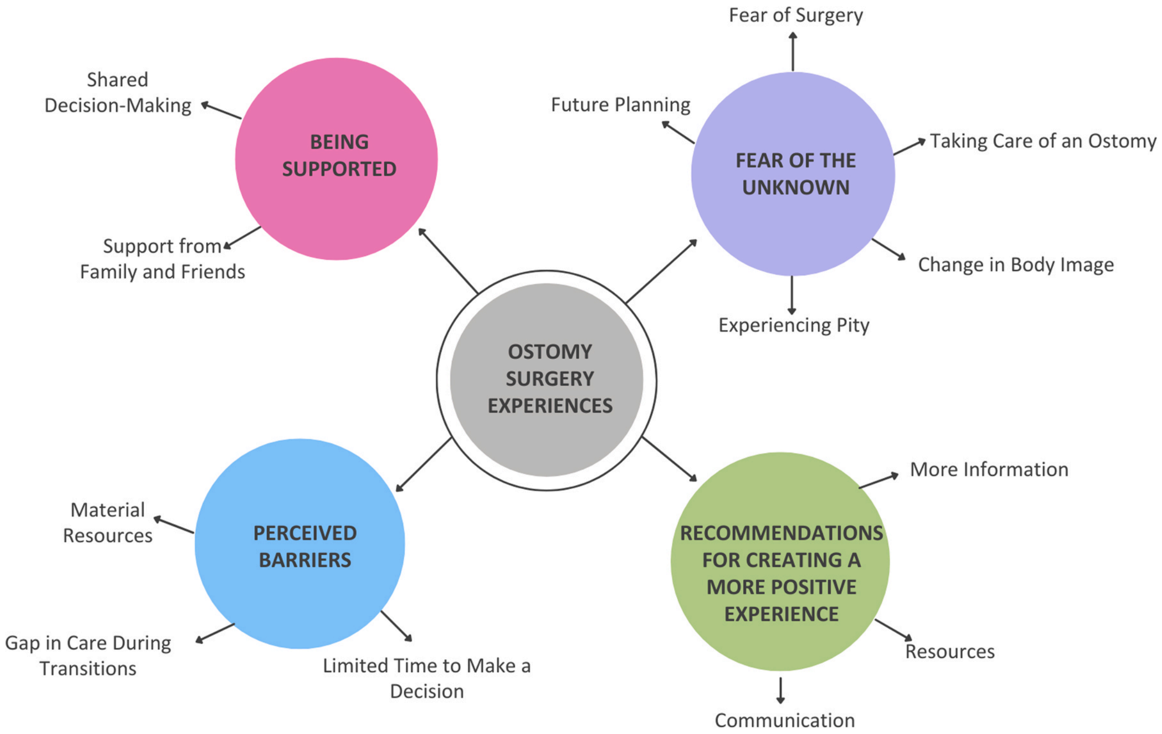

Fig. 1. Map of themes and subthemes.

3.2.2. *Perceived barriers*

When describing the lived experience of the ostomy, caregivers and adolescents acknowledged multiple barriers that impeded their experience, including access to material resources needed to support ostomy care, gaps in care during transitions from the hospital to home and from pediatric to adult care, and limited time to make the decision regarding undergoing an ostomy procedure.

3.2.2.1. Material resources. Both adolescents and caregivers reported challenges around the material resources necessary to care for an ostomy. Caregivers reported finding the costs of the ostomy supplies expensive and expressed concern for how their children might pay for the supplies in the future, particularly if they did not have a job with benefits/insurance. Caregivers also reported the challenges in navigating grants or support for medical subsidies. One caregiver of a child with UC noted the financial challenges associated with ostomy supplies for her family:

> *When public health would come to change his supply, like change the bag, they were bringing supplies with them, or the nurse would order them and then have them delivered to our house so we never had to pay for them. At that point, it was afterwards when he had to do the change himself, that we had to pay for the supplies, and I found they were extremely expensive*

3.2.2.2. Gap in care during transitions. Adolescents and caregivers described the gaps in care in the transition from hospital to home post-surgery and the transition from pediatric to adult care. Caregivers reported the steep learning curve in ostomy care after being discharged. One caregiver of a child with UC explained not anticipating how challenging homecare would be, noting that it would have been helpful to have videos or resources to be more prepared:

> *…I think if there had been videos or something like, you know, just to be more prepared for the challenges. It just ended up being harder than we thought it would be. And yeah, I just wasn't prepared for that. I didn't expect it to be so tough and it's just like breastfeeding, right? They don't tell you about that part that much. They tell you how glorious it is to have a baby, and then you struggle with breastfeeding. This was kind of the same, but different, you know?*

When transitioning from pediatric to adult care, caregivers noted the importance of setting expectations and highlighting the differences between the two models of care. Caregivers also noted that the transition from pediatric to adult care should not be abrupt but rather a process that involves handover from the pediatric team to the new adult GI team. A 20-year-old male reflected on his transition to an adult hospital, explaining that his pediatric team recommended him to colleagues and gave him confidence that his new team would be supportive. Noting that the transition process was intimidating and having a supportive and inclusive handover was a helpful piece that supported the shift to adult care.

3.2.2.3. Limited time to make a decision. Both caregivers and adolescents recalled needing time to come to terms with the surgery and many felt they did not have enough time as the surgical intervention was a life-or-death situation. One caregiver of a child with UC explained, "*I felt that we didn't have any choice actually because it was a matter of life and death, so we didn't even, you know, talk to anybody else or get anyone else's opinion. We had to make the decision right then and there*". An 18-year-old male diagnosed with CD highlighted the time-sensitive nature of his ostomy surgery, "*I didn't really learn about what it [the ostomy] was, but it was really just like we have to do it now, or you're going to die*".

3.2.3. *Being supported*

Caregivers and adolescents talked about the importance of support and shared decision making from the healthcare team, friends, and families, which were salient features of the ostomy surgery journey.

3.2.3.1. Shared decision-making. A 17-year-old female with UC explained that she was confident going into her ostomy surgery because of the conversations she had with both her surgeon and the stoma nurse. She learned about caring for the ostomy and was allowed to have her and her caregivers' questions answered. Importantly, she framed the surgery as an active decision. The collective conversations with the healthcare team supported this adolescent in making a choice that she felt positively towards.

Participants described early discussions about ostomy surgery as a possibility gave time for the family to process and accept the ostomy. Adolescents and caregivers addressed the importance of making the patient a part of the conversation or decision-making process regarding the surgery. Moreover, families appreciated having age appropriate and patient-centered discussions. A caregiver of a child with UC described how much she valued the healthcare team addressing her daughter directly and including her in the preparation for the ostomy:

> *They talked to the child, they made the child understand, try to make them understand what was happening. You know what they were doing for her in language that she understood, getting down on their knees so that they could talk to her face to face. To me, that was just so touching to see them trying to communicate and connect with her, you know. Treating her as she should be treated as a child and trying to get her to understand.*

3.2.3.2. Support from family and friends. Both youth and caregivers discussed a sense of support from family and friends post-surgery. Whereas immediate family members will by nature of proximity, know about the ostomy, with friends there was selective disclosure regarding whether to disclose the ostomy. Families noted close friends of the adolescent with IBD became closer post-surgery, and adolescents were more selective about who they told about their ostomy when it came to other peers (e.g., only disclosing the ostomy to a few peers at school). Conversely, some adolescent participants noted not telling any peers about the ostomy and only disclosing to the adults in their life (e.g., caregivers, extended family, and teachers). One caregiver of a child with CD explained that her daughter's friends had all been very supportive post-surgery and made an effort to check in on her daughter:

> *…friends are very, very, very nice. Like they'll call checking up on us, so we've been very lucky, but I think it's our openness that's why we're lucky because how can people be compassionate if they don't know, or you don't educate them? You know? I mean, like I have no problem showing somebody what a bag and appliance looks like.*

Moreover, adolescents and caregivers emphasized the strong sense of support from family and friends post-surgery and the option of being in control of whom to disclose their ostomy to.

3.2.4. Recommendations for creating a more positive experience

Participants described recommendations to improve their experience before and after undergoing an ostomy surgery. Recommendations included, receiving more information about the ostomy procedure and what to expect prior to undergoing the surgery, receiving additional resources (e.g., peer support, supplies, representation in the media), and ensuring ongoing and accessible communication with the healthcare team before and after surgery.

3.2.4.1. More information. Patient and caregiver participants discussed wanting more information about what to expect from the ostomy procedure (e.g., what the stoma looks like, what it is like to live with a stoma, maintaining a stoma). For example, one 18-year-old male diagnosed with CD explained wanting to know more information before the surgery:

> *Maybe just explaining it and showing me how it looked. 'Cause I was kind of completely in the dark until it happened… it would have been better to know kind of what I was getting into. When you see the organ hanging out, it freaks you out a bit.*

Moreover, participants expressed wanting to talk more about what could go wrong with the ostomy surgery. For example, one 15-year-old female diagnosed with CD stated, "*my ostomy had prolapsed, and I didn't even know that could happen and I was really scared…I guess they didn't tell me 'cause they didn't wanna scare me, but it was more scary not knowing what was happening*". Participants also noted wanting to know more about everyday life with an ostomy pre-surgery and what to expect regarding appliance care (e.g., how stomas could leak, might leak after certain foods, shower), diet, and clothing to wear with the appliance. Specifically, participants noted wanting to learn more about "*less important situations*" such as "*the basics of when [the stoma] would most leak or what should I do if it does leak, diets, and those types of questions*" (15-year-old female diagnosed with CD). Another patient recommended using medical mannequins to better illustrate the stoma as one solution for patients to become more familiar and knowledgeable about the procedure and its implications. Participants also recommended that the medical team share more details regarding different supply options and more direction about financial support. A 15-year-old diagnosed with CD noted: "*They only had the [brand] that's all they really showed me, so, it might have been helpful if they showed other brands at the beginning*".

3.2.4.2. Resources. Participants expressed wanting more resources, including representation in the media, peer support, and supplies. Specifically, adolescents discussed wanting to have more representation of others who live with ostomies in the media (e.g., athletes, influencers, bloggers) to normalize the ostomy journey. Unlike peers that adolescents could potentially connect with, representation was referenced as someone undertaking a role model position who demonstrates successfully living with an ostomy. For example, a 14-year-old female diagnosed with UC recalled a conversation with her doctor in which the doctor noted an athlete living with an ostomy, "*There was this football player, and my doctor was like if he can play football, then I'm sure you can do anything cause football is such an intense sport*". Participants also noted that watching YouTube videos of individuals who have an ostomy was helpful. Adolescents turned to various social media platforms to search for ostomy representations and noted a gap in representation of adolescents living with an ostomy.

> *It wasn't like me like learning about the stoma, but I was able to like see it. In a way, hers [YouTuber] obviously looked different cause she was an adult, but like I was able to see it and like learn about her feelings, which definitely helped* (14-year-old female diagnosed with UC).

Moreover, adolescents reported wanting more images and videos of adolescents with stomas provided by the hospital (e.g., changing appliance, and stories about living with an ostomy). For example, one 17-year-old female diagnosed with UC noted, "*the videos [the hospital] recommended were boring. Those videos were people who didn't have an ostomy bag!*".

In addition, adolescent and caregiver participants expressed the desire to connect with other peers who had experienced an ostomy surgery. Many adolescents reported not knowing anyone, particularly people their age, who had an ostomy appliance and explained that this would have been a helpful part of their ostomy journey. A 17-year-old female diagnosed with UC explained it would have been helpful to have had the advice of someone who had undergone an ostomy surgery:

> *One thing I would have loved was to sort of hear someone else's experience because I feel like one of the biggest things is that like you know it's different when someone else has been able to know what they go through like there's someone out there that shares the same pain as you, so it's always nice to hear their advice as well. I just feel like that would be a good thing. I would have loved that if that was possible.*

Caregivers also described the value of peer support for themselves. While there was mixed feedback about whether a caregiver would talk to another caregiver, this support was universally considered valuable. Caregivers wished they had been connected to another family to discuss the ostomy experience. Understanding what is typical of the ostomy process or what to expect would have been helpful and reassuring. Additionally, caregivers noted that receiving supplies post-surgery would have been beneficial.

3.2.4.3. Communication. Caregiver participants also expressed that the use of simple terms and explanations from the medical team would be beneficial for their comprehension. In addition, participants expressed wanting more sessions with the stoma nurse and check-ins around the transition from hospital to home to feel more comfortable with the ostomy. Specifically, participants expressed that having more healthcare team support in transitioning from the hospital to home settings would have made the process easier. One caregiver of a child with UC stated, "*I think there should have been more follow-up with even a dietitian or someone to follow his nutrition. More help in teaching him how to take care of his ostomy. There was really only one visit from an ostomy nurse once he was home*". Another caregiver expressed how care differs between in hospital and home settings. Participants expressed that it would be beneficial for the medical team to discuss the possibility of ostomy well ahead of time for all patient's diagnosed with IBD, ensuring the discussion was not left to the last minute. For example, one 21-year-old female diagnosed with CD explained:

> *The best thing that [the medical team] did is they gradually introduced me to the process… in the initial first couple years they were like 'oh, so there's these types of surgeries that we might need to do if this doesn't work'. So, I always had the ostomy surgery in the back of my head because they repeated it so many times. It was always like if this doesn't work the that's out next step. … I liked how they gradually introduced me to things.*

4. Discussion

The qualitative analysis captured the multi-faceted experiences and needs of patients and their caregivers undergoing or anticipating the possibility of undergoing an ostomy surgery. Our findings support and add to existing research on ostomy experiences of adolescents with IBD, indicating some important nuances. Four major themes represented the essence of the lived experience of participants and their caregivers: *fear of the unknown, being supported, perceived barriers,* and recommendations for *creating a more positive experience*. These findings highlight the critical gaps and opportunities to tailor care for adolescent IBD patients undergoing an ostomy procedure.

Our work builds on studies of patient experiences with an ostomy in identifying areas of improvement specific to the adolescent IBD population. In this study, participants described their ultimate fear regarding the procedure and living with the ostomy, change in body image, experiencing pity from others, and planning for a family in the future. Most of these findings were consistent with research reporting that adolescents anticipating or undergoing an ostomy surgery also experience psychosocial challenges related to sexuality and body image,[9,15,16] being a burden to others,[27] and female IBD patients' concerns regarding future family planning, showing that even young adolescents share these concerns.[28] Interestingly, findings emphasized fears specific to adolescents about undergoing an ostomy procedure and ultimately living with the device.

Participants' acknowledgement of the importance of having a support network ranging from healthcare providers to family and friends was also noteworthy. These results are consistent with existing literature on the role of support in undergoing or anticipating an ostomy procedure.[9,13] An ostomy procedure may strengthen the relationship between individuals with IBD and their supports.[9] Our results emphasize the importance of supportive social networks and a healthcare team supporting adolescents in decision-making.

Participants also described multiple barriers while anticipating or undergoing an ostomy procedure highlighting areas of improvement. Specifically, the limited knowledge of ostomy care, materials to use, and the gap in care specific to transition periods. Many participants (46 %) noted ostomy supplies' financial cost, supporting findings from other studies that have emphasized the substantial out-of-pocket IBD-associated costs for adolescent patients.[29] Importantly, psychological distress can be heightened during the transition in care,[30] emphasizing a need for further care and resources. Participant perspectives confirm the unmet psychological needs identified from patient experiences and reveal how adolescents undergoing an ostomy procedure face unique challenges related to their developmental stage.

Based on our interpretation, Canadian adolescent patients with IBD might benefit from resources that address the following (see Table 2). First, ensuring healthcare teams discuss the common and possible health and intervention trajectories at early stages of diagnosis and treatment (i.e., ostomy surgery). Including adolescents' in the decision process by asking for their opinions while tailoring conversations to their developmental level (e.g., using simple terms) may increase agency but must be monitored for opposite effects. Further, ensuring healthcare providers adopt patience and compassion while working with adolescents and their families and remembering that an ostomy surgery is life-altering for families is essential because of the "finality" of colon removal. Congruent with research, increasing patient agency has been identified as a supportive factor in IBD-related outcomes by ensuring the patient understands what to expect with the procedure, allowing patients to provide input[10] and offering toolkits and opportunities to practice dressing/navigating with an ostomy appliance.[12] Specific to caregivers, findings suggest a need for more tools and/or information to support caregivers' decisions regarding undergoing an ostomy surgery (e.g., information supporting or against surgery to enhance comfort with their decision, family information nights to hear other caregivers' tips and tricks). Moreover, incorporating additional check-ins around transition periods from hospital to home care and pediatric to adult care is recommended.

The need for peer support was emphasized throughout participant interviews. Individuals with IBD noted a need to interact with other individuals with IBD who have specifically undergone an ostomy procedure.[9,13] Peer support assists individuals in coping and managing disease and may serve as a modifiable factor to improve psychological symptoms (e.g., depression, anxiety) among adolescents with IBD.[31–33] Peer support programs can encompass a variety of formats including one-on-one peer mentoring, camps, groups, and online social communities that can serve different purposes (e.g., educational, emotional). As Dave et al.[34] noted, individuals living with IBD can have variable psychosocial needs, thus it is essential to provide various peer-support options that are known and available to adolescents living with IBD. Although peer support amongst individuals who share a similar chronic illness can be beneficial, most peer support studies focus on adults,[35,36] indicating a need to examine peer mentorship programs for adolescents

Table 2
Recommendations for creating a more positive experience.

Requested action items		
Information	Resources	Communication
• Showing patient what a stoma looks like • Using a medical mannequin • Discussing what could go right and wrong • Talking about everyday life with a stoma and appliance care (e.g., how stomas can leak, clothing to wear with appliance) • Sharing more information regarding different supply options • Providing more direction regarding financial support	• Creating images/ videos of adolescents with stomas o Changing appliance o Stories about living with an ostomy • Meeting other youth and caregivers of youth with ostomies • Providing post-surgery supplies	• Using simple terms • Providing more sessions with stoma nurse • Discussing ostomy as an option well ahead of time • Providing additional check-ins around transitions

with IBD undergoing or anticipating an ostomy.

Participants acknowledged that they would also benefit from the increased representation of adolescents with an ostomy in the media by creating images/videos of adolescents with stomas (e.g., changing the appliance and stories about living with an ostomy). This theme was echoed in other studies where adolescents emphasized expanding the presence of individuals with IBD on social media to educate patients and the public on IBD topics, aid in the connection of IBD adolescents, and advocate for improved IBD care.[37] Moreover, these findings shed new light on the needs of IBD adolescents and their caregivers undergoing or anticipating an ostomy procedure. Efforts to address these unmet needs can potentially improve the overall quality of life for adolescents with IBD.

4.1. Limitations and future directions

There are several important limitations and future directions. While a qualitative approach was a strength of the study, the situatedness of the participants' experiences must be acknowledged. There is a notable overlap in the participants' experiences with those described in other studies. However, there are likely subtleties of the participants' experiences that are unique to their context (e.g., culture, geographical location, available treatment, Canadian healthcare system, and enrollment at one Canadian healthcare center). Accordingly, our recommendations may be more appropriate in some cases than others. Moreover, participants were asked to recall their experiences surrounding anticipating or undergoing an ostomy surgery, which may have occurred over a long time frame, potentially reducing their recollection. Our sample also consisted predominantly of mothers and experiences captured may not generalize to other primary caregivers as well. Future research should address how different aspects of one's identity or markers of social location (e.g., gender, race, class) shape illness-related experiences. Future studies should investigate the experiences of caregivers and adolescents anticipating and undergoing ostomy surgery at multiple centers. These studies should consider the amount of time elapsed since the decision to undergo ostomy surgery to reduce recall bias and should make efforts to capture perspectives from all caregivers. Ultimately, future studies are needed to build upon our study's findings and continue improving our understanding of IBD patients and their caregivers' experiences undergoing an ostomy surgery.

4.2. Conclusion

This study shares perspectives of adolescents with IBD and their caregivers about ostomy surgeries to provide new insights and suggestions to inform clinical practice in pediatric IBD care. It is evident that adolescent experiences of undergoing or anticipating an ostomy surgery are characterized by physical, emotional, and social challenges unique to their developmental stage. Our themes of *being supported*, *fear of the unknown*, *perceived barriers*, and *creating a more positive environment* indicate an opportunity to enhance existing or develop new resources and programs to support adolescents living with IBD and their families while anticipating or undergoing an ostomy. Additional support is specifically needed during transitions from the hospital to home and from pediatric to adult care. Efforts to meet these needs should provide more age-friendly care that attends not only to their physical well-being but also their emotional and social needs.

CRediT authorship contribution statement

Sara Ahola Kohut: Writing – review & editing, Writing – original draft, Supervision, Resources, Project administration, Methodology, Formal analysis, Conceptualization. **Ashley Cruden:** Writing – review & editing, Conceptualization. **Amanda Ricciuto:** Writing – review & editing. **Dean A Tripp:** Writing – review & editing, Writing – original draft. **Peter C Church:** Writing – review & editing, Conceptualization. **Meghan K Ford:** Writing – review & editing, Writing – original draft, Visualization, Formal analysis, Conceptualization.

Ethical Statement

This study was granted ethical approval by the Hospital for Sick Children (approval no. 1000067379). All participants provided written informed consent prior to enrollment in the study.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

The data that has been used is confidential.

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