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Decision-making in ostomy surgery: The lifeworld experiences of women with inflammatory bowel disease and the views of healthcare professionals

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ABSTRACT

This study investigates the lifeworld experiences of women who underwent ostomy surgery to manage severe symptoms of inflammatory bowel disease (IBD). IBD includes ulcerative colitis and Crohn's disease and involves chronic inflammation of tissue in the gastrointestinal tract with recurrent symptoms of diarrhea, rectal bleeding, abdominal pain, fatigue, and weight loss. Data collection involved semi-structured interviews with nine women between the ages of 19 and 30 years living with an ostomy they received at a younger age. Seven healthcare professionals who care for IBD patients with an ostomy also participated in interviews. Prior to surgery, the women reported struggling with progressive, severe and unrelenting symptoms of IBD not alleviated by pharmacotherapy that became potentially life threatening. Consequently, the women underwent ostomy surgery to create a stoma opening of the bowel that allowed stool to pass into a bag attached to the opening. Using Habermas's theory of communicative action, this paper examines how IBD altered the women's lifeworld prior to surgery and their ability to socially engage with others in day-to-day life. The paper also discusses the absence of communicative action as an aspect of the women's interactions with medical practitioners, and the strategic subsumption of their lifeworld by the voice of medicine. Additionally, the paper reports on the perspective of healthcare professionals on the care and support they provide patients who receive ostomy surgery. In conclusion, an argument is made for the benefits of a lifeworld approach in IBD care.

1. Introduction

Inflammatory bowel disease (IBD) comprises of ulcerative colitis (UC) and Crohn's disease (CD), two chronic autoimmune conditions characterized by symptoms that include diarrhea, fever, and intestinal bleeding, resulting in weight loss, fatigue, and abdominal pain (Crohn's and Colitis Canada, 2019). Diagnosed before age 30, IBD typically has periods of remission and relapse although some individuals may experience aggressive IBD symptoms at the onset with a rapid progression of the disease (Di Sabatino et al., 2013). These symptoms significantly impact quality of life along with physical and emotional well-being and can lead to social stigmatization due to the taboo nature of bowel function (Taft & Keefer, 2016). Treatments such as corticosteroids, immunosuppressants, and/or biologic therapies can induce remission of IBD symptoms (Renna et al., 2014) although surgical bowel intervention may be needed when these treatments lack effectiveness or fail (Hwang & Varma, 2008).

This study explores the social processes surrounding ostomy surgery,

a procedure that diverts the intestine through the abdominal wall to allow bodily waste to pass through a surgically created stoma and into a prosthetic bag that is removed and emptied manually (Steinhart, 2006). There is minimal information about patient decision-making as it pertains to ostomy surgery particularly among younger women who live with IBD. In addressing this knowledge gap, this study focuses on the experiences of adult women who underwent ostomy surgery early in life as teenagers or young women and their interactions with medical practitioners regarding the procedure. The study also reports on the views and experiences of hospital and community-based healthcare professionals (HPs) concerning ostomy surgery.

2. Literature review

Diagnosed typically between the ages of 15 and 30, IBD impacts the health and mental well-being of affected individuals in multiple ways (Jelsness-Jorgensen et al., 2011). Engelmann et al. (2015) found that 55.3 % of adolescents living with IBD met DSM-IV (American Psychiatric

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Association, 1994) criteria for one or more psychiatric disorders such as anxiety and depression during periods of increased disease activity. Adolescents also have concerns with self-image and low self-esteem due to the stigmatization of bowel-related symptoms and changes in bodily appearance brought on by surgical intervention (McDermott et al., 2015). Young adults with IBD also experience social isolation as painful symptoms and unpredictable bowel movements make social outings problematic particularly when there is limited access to public washrooms (Nicholas et al., 2007). While many IBD patients respond to pharmacotherapy, severe symptoms such as stricture formation, bowel obstruction, fistula, stenosis, or perianal disease can lead to the need for ostomy surgery (Galandiuk et al., 2005). Approximately 10 % of individuals living with CD require a temporary or permanent ostomy over the course of their disease while estimates for UC are lower (Cosnes et al., 2011). Surgery required before adulthood ranges from 28 to 56 % for those living with CD; and 25 % of those living with UC will require complete removal of their large intestine within 5 years of diagnosis, thus requiring an ostomy (Gupta et al., 2006). In some cases, a temporary ostomy may be used to allow the bowel to rest and induce remission, while in other cases an ostomy is used as definitive treatment for CD when inducing remission by other means is unsuccessful (Amiot et al., 2011). While an ostomy brings symptom relief, complications are possible particularly when surgery is done emergently as a result of potentially life-threatening symptoms (Zelga et al., 2021). An ileostomy or colostomy can also be used to treat complications such as small bowel obstructions, fistulas, or severe perianal disease (Galandiuk et al., 2005). CD that involves active, chronic perianal disease will often require a permanent ostomy (Cosnes et al., 2011). In UC, complete removal of the large intestine is considered a cure; surgery involves a temporary ostomy followed by the creation of an internal pouch with the preserved small intestine that becomes attached to the anus (Mosli et al., 2014).

Young adults with IBD are fearful of ostomy surgery due to the way a stoma and stoma bag alter the body's appearance (Jelsness-Jorgensen et al., 2011). This fear can lead to surgery postponement although once symptoms are severe and potentially life-threatening, the intervention is performed most often emergently with an increased risk for complications, poorer outcomes, and longer recovery (Pittman, 2011). Under such circumstances, patients tend to have negative beliefs about their illness, and experience poorer quality of life and higher rates of depression when compared to patients who receive ostomy surgery electively (Knowles et al., 2013). Patients also find it difficult to adjust following surgery, report an altered sense of self, and have an intense fear that their stoma bag will become visible and produce gas and/or odour (Persson & Hellström, 2002). In contrast, patients who receive ostomy surgery electively are able to work with their surgeon to find the ideal location for their stoma on the abdomen to reduce the risk of leakage, increase comfort, and improve management of the stoma bag (Pittman, 2011).

There is research suggesting that women adjust psychosocially to ostomy surgery better than men, except for sexual attraction where women report more concern (Gautam & Poudel, 2016). Also, some women may experience significant anxiety prior to ostomy surgery which could impact their emotional well-being post-surgery. For example, Maroli et al. (2022) assessed patients for stress, anxiety, and depression prior to elective colectomy resection and found that anxiety prior to surgery was greater in the group with postoperative complications with women showing higher anxiety scores than men. The authors recommended developing preoperative educational intervention strategies to support patients with mild and moderate anxiety.

This literature review shows that current research offers broad information on patient adjustment to ostomy surgery and the concerns individuals have about living with a stoma and stoma bag, post-surgery. There is, however, very limited information on the decision-making process for ostomy surgery particularly for young women living with IBD. An older study reports that younger women contemplating ostomy surgery have concerns about its impact on bodily appearance and

physical attractiveness and worry about how it may affect conception, pregnancy, and delivery (Allison et al., 2013). There is, however, no information on how young women make the decision about ostomy surgery and how the process unfolds in the context of their interactions with medical practitioners.

3. Research objectives and questions

The study aims to understand women's lived experiences of IBD in the context of decision-making about ostomy surgery and as an aspect of their interactions with medical practitioners.

Several reasons justify the focus of this study on women. First, minimal understanding exists of the unique social and cultural circumstances that women with IBD encounter as part of the decision-making process. Further information is particularly needed on the degree to which prevalent norms of femininity shape the perception of the surgery and its impact on body image (Manderson, 2005). In what way do women contemplate the risks versus the benefits of ostomy surgery, i.e., giving up a sense of physical attractiveness to regain physical health and a relative sense of normalcy post-surgery (O'Brien, 1999)? There is also a need to know more about the relationship between decision-making and concerns about how ostomy surgery might impact intimacy and engagement in sexual activity post-surgery. We also need more information on how women navigate recovery post-surgery and re-engage in social activities. Preliminary research suggests that both male and female patients with IBD see their ostomy as having given them a new lease on life (Persson & Hellström, 2002; Savard & Woodgate, 2009). The study concomitantly considers the experiences of HPs who provide care for ostomy surgery and the way they understand patients' views and concerns with surgery. To our knowledge, this topic remains largely unexplored in the research literature.

Four questions guide the study: (1) How do young women living with IBD make the decision to undergo ostomy surgery?; (2) To what extent is social stigmatization involved in the decision-making process?; (3) How do HPs view ostomy surgery and understand their patients' views and experiences with this intervention?; and (4) How do understandings of ostomy surgery and living with a stoma compare between women living with IBD and HPs?

4. Theoretical framework

4.1. Habermas and the theory of communicative action

Habermas's (1987) theory of communicative action and his conceptualization of the lifeworld and the system guide this study. The lifeworld consists of the unreflective taken-for-granted dimension of experience that gives the world unquestioned meaning and value (Arnold, 2015). The lifeworld exists as the everyday social world of individuals where communicative action predominates—individuals rely on speech acts to interact and achieve a shared definition of the situation along with “consensual coordination of individually pursued plans of action” (Habermas, 1984, p. 289). Communicative action tends to result in agreed interpretations of the situation by participants, cooperative behaviour, and an agreement on meaningful joint goals reflecting shared values (Scambler & Britten, 2001). This is possible by virtue of individuals sharing “a background stock of cultural knowledge ... [that] makes mutual understanding possible” (Habermas, 1987, p. 154). For Habermas, communicative action occupies a fundamental place in society as it is “encompassed and structured by the actors' lifeworlds” (Wallace & Wolf, 1999, p. 175).

Separate and lying in opposition to the lifeworld, the system consists of large organizational formations in capitalist society such as “economic and bureaucratic spheres ... in which social relations are regulated only via money and power” (Habermas, 1987, p. 154). The system coordinates the actions and functions of the market and government that are too complex to be managed by communicative action (Finlayson

et al., 2023). In the system, communication is strategic and “instrumentalises speech acts for purposes that are contingently related to the meaning of what is said” (Habermas, 1984, p. 289). Individuals thus may resort to deception or distorted communication and use technical jargon to achieve a dominant position over others (Jütten, 2011). Habermas views the interrelation between the lifeworld and system as a fundamental concern. He points to the risk of the system colonizing the lifeworld to produce a “pathological de-formation of the communicative infrastructure of the lifeworld” (Habermas, 1987, p. 375) and a “loss of freedom, loss of meaning, crises in legitimation, anomie, and alienation” (142–3).

Researchers have used Habermas’ theory to gain a deeper understanding of the impact of healthcare practices on patients as they navigate hospitals and clinics where efficiency predominates and power is exerted through regulation and legislation (Assing Hvidt et al., 2021; Boye et al., 2021). Yet, such systems can intrude into the patients’ lifeworld when doctors fail to engage in communicative action and where there is no consensual coordination of action between them and patients (Boye et al., 2021). This research has documented how medicine, as a system, colonizes the lifeworld when doctors are unable or unwilling to acknowledge their patients’ subjective experiences in a meaningful way. This is more likely to occur when doctors rely on medical jargon as they interact with patients (Mishler, 1984) and prioritize “the efficient resolution of discrete, manageable ailments over the development of shared understanding between patients and clinicians” (Martin et al., 2021: 7). Under those circumstances, patients cannot interact at an equal level and negotiate a mutual understanding of their condition and course of treatment. Unsurprisingly, such encounters have been linked to lower quality of care and poorer health outcomes (Greenhalgh et al., 2006).

Habermas’ (1984) theory of communicative and strategic action and his lifeworld/system dichotomy is highly relevant for understanding communicative encounters between female patients living with an ostomy and HPs. This study aims to use this theory to examine how IBD symptoms disrupt the everyday life of women and the degree to which the process of lifeworld colonization occurs in context of ostomy surgery and care. The theory also offers guidance in examining the testimonies of HPs who deliver ostomy care and the way they perceive their patients’ experiences. The intent is to reveal ways in which the experiences of women become overlooked during their encounters with HPs and to give voice to their lifeworlds. Habermas’ theoretical perspective is also a useful tool when considering effecting change in healthcare practice so as to achieve a more equal and respectful pattern of communication between women and their IBD practitioners and ostomy specialists.

5. Methods

5.1. Ethics

The University of Victoria’s Human Research Ethics Board granted approval for the study (protocol number 18-1037). To address any discomfort participants might feel in discussing this sensitive topic, the interviewer (first author) disclosed that she lives with IBD and an ostomy at the start of the interview. All women were assigned a pseudonym to ensure anonymity.

5.2. Recruitment and sampling

Nine adult women living with IBD (UC or CD) and an ostomy were recruited through advertising the study on the Participate in Research webpage of the Crohn’s and Colitis Canada website (<https://crohnsandcolitis.ca/Research/Participate-in-Research>) and on social media. The participants met the following inclusion criteria: (1) identify as female, (2) between the ages of 19 and 30 years, (3) currently living with an ostomy to treat their IBD, and (4) fluent in English. Nineteen years of age is when patients transition from pediatric to adult care in British

Columbia (Philpott, 2011). The upper range of 30 years was selected to allow capturing women in the various stages of younger adult life. The advertising poster included a summary of the study and a request for individuals to email the first author if interested in participating. The first author emailed responding individuals a letter of invitation and consent form. She subsequently contacted them by phone to review the consent form, explain the study procedures, answer questions, and schedule an interview. At the beginning of the interview, participants provided verbal consent which the first author recorded in her notebook.

The nine women in the sample were between the ages of 19 and 30 years. Seven women were Canadian and two American; five had CD, three UC, and one indeterminate colitis; and seven had a permanent ostomy and two a temporary one with plans to reverse later. The women received their ostomy in their early years of adulthood, i.e., 18 years of age to early twenties, and one woman underwent surgery as a teenager in pediatric care and later transferred to adult care. The sample’s age range gives insight into living with IBD and ostomy in the various stages of teenage-hood and early adulthood (e.g., living at home, attending university, starting full-time work). As shown in Table A, about half of the women were in their early twenties, the remainder were in their late twenties, and one was 30 years of age. The women were either single, in a relationship, engaged or married. One woman had a pregnancy post-surgery.

HPs were recruited from a hospital-based ostomy clinic in British Columbia. The first author distributed a poster at the clinic while a gastroenterologist and IBD nurse shared information about the study with colleagues via word-of mouth and email. The poster requested those interested in participating to email the first author. Inclusion criteria included: (1) work directly with IBD patients, and (2) fluent in English. The sample of HPs included one male gastroenterologist, one female and two male colorectal surgeons, two female clinical IBD nurses, and one female nurse specialist in wound, ostomy and continence (NSWOC) care. IBD nurses worked at the clinic or in the community and provided advice to patients contemplating ostomy surgery, offered outpatient support, and managed IBD-related and ostomy services (Glatter et al., 2013). Gastroenterologists explained treatment possibilities to IBD patients and were responsible in making the decision to refer patients to a colorectal surgeon for ostomy surgery. Colorectal surgeons were not involved in the treatment of IBD symptoms but offered consultation to patients referred for ostomy surgery by gastroenterologists. They performed ostomy surgery and delivered postsurgical care along with ostomy nurses. The HPs provided informed consent through the same protocol used with the women. None of the HPs provided care to the women in the study. HPs are identified by clinical position in the findings section.

5.3. Data collection

The semi-structured interviews were conducted via video call (Zoom), by telephone, or in-person. At the start of the interview, the first author explained the consent process and study procedures and asked if the participants had any questions. She used open-ended questions and encouraged participants to elaborate on what they felt was important about their experiences. The interviews with the women lasted 1–1.5 h with questions focused on their condition (e.g., current disease status, time since ostomy surgery, and type of ostomy), their experiences with ostomy and their decision to receive ostomy surgery, and the type of care they received during and post surgery. The interviews with HPs were 20 min to 1 h long with questions on their role in ostomy care, interactions with patients regarding ostomy surgery, and their views on how patients experience surgery.

5.4. Data analysis

Interviews were audio-recorded, transcribed verbatim, and inputted

Table A
Demographic description of women in the sample.

Pseudonym	Age	Country	Diagnosis	Ostomy	Permanency	Level of Education	Relationship Status
Lindsay	23	Canada	Indeterminate Colitis	Ileostomy	Permanent	Diploma	Engaged
Heather	20	Canada	CD	Ileostomy	Permanent	Highschool	Single
Milla	25	Canada	CD	Ileostomy	Permanent	Bachelor's degree	Single
Chloe	22	United States	UC	Ileostomy	Permanent	Associate's degree	Married
Breanna	21	Canada	UC	Ileostomy	Temporary	Highschool	Single
Clara	26	Canada	CD	Ileostomy	Temporary	Bachelor's degree	Single
Kimberly	29	Canada	CD	Ileostomy	Permanent	Master's Degree	In a relationship
Lily	26	United States	UC	Ileostomy	Permanent	Master's Degree	Single
Alexa	30	Canada	CD	Ileostomy	Permanent	Bachelor's degree	In a relationship

into NVivo 11 (QSR International Pty Ltd, 2017). The first author inductively coded the data using the constant comparative method. This analytical approach involves continuous comparison of new and old data and codes in the process of forming and refining categories and themes (Boeije, 2002). The first author began the analysis by reading transcripts multiple times to familiarize herself with their content. She then assigned descriptive codes to text segments that reflected salient aspects of the participants' experiences and assembled these codes into categories according to similarity. She then compared the codes and categories to ascertain that no further information could be added to the existing categories and to identify interrelationships and patterns in the data. The analysis also included memo writing, reflecting on the data, codes, and emerging categories, and making comparisons between them to gain a full understanding of the data and interrelationships between categories (Braun & Clarke, 2006). Habermas' concept of communicative action and his distinction between the lifeworld and system informed the interpretation of the data and development of themes capturing the experiences of women with IBD and ostomy and those of HCPs.

The analysis of the women's interview data reached thematic saturation when repetitive codes and themes appeared, and no new information could be generated from further analysis (Guest et al., 2020). Reaching thematic saturation suggests that the sample of women, although small, was sufficient to capture a diversity of experiences with decision-making and living with an ostomy. The sample of HPs was too small and diverse for thematic saturation to occur. The credibility of the data analysis (Nowell et al., 2017) was enhanced by the first author's sensitivity to the phenomenon under study as a young woman living with IBD and an ostomy and extensive interactions with healthcare specialists in the course of her illness. She also acquired an intimate knowledge of the data from conducting all the interviews, transcribing them, and reading the transcripts multiple times before starting coding. The following strategies strengthened the trustworthiness of the findings: ensuring coherence between research questions, methodological approach and interpretations; attention to sample appropriateness; and maintaining a log of methodological and analytic decision making (Thorne, 2000).

6. Findings

6.1. Life with IBD prior to ostomy surgery

The women spoke of struggling with severe and recurrent IBD symptoms prior to surgery and how these symptoms interfered with daily life. Clara said, "I couldn't go to work without having accidents. I was going to the bathroom, I couldn't even hold my bowel, and everything was just so painful." Kimberly similarly noted, "I think by that point, I was so sick, and I couldn't eat anything. I remember throwing up after everything I was eating and not even swallowing half my meal and being in the bathroom." Participants recalled trying and failing multiple medications, including steroids, biologic therapies, and immunosuppressants, and having difficulty coping with side-effects such as vomiting and headaches. They also struggled with difficult-to-treat IBD

complications like anal fissures (tears in the lining of the anus) and fistulas (abnormal tunneling between the intestines and a nearby organ or skin). All women experienced severe weight loss. As Lily shared, "I was not in very good shape at all ... I was like 72 pounds at the time."

The women bemoaned the way symptoms impacted social life as illustrated by Breanna's comment, "I was ... missing out on so much of my life. I'm always sick, I'm not doing anything fun with my friends because I always feel crappy and I don't want to go out, so help me out here." Chloe voiced a similar complaint:

I had just become a teenager. I was supposed to be doing all of these sports, all this fun stuff and field trips, we had long field trips and stuff like that, and I missed out on all of that, so I guess it's a lot of just being bummed about it.

Several women mentioned being private about their diagnosis to maintain an image of normalcy with their peers. One participant, however, said not disclosing her condition felt like hiding part of her identity, "It's really hard for me to even tell new people that I meet and ... I kind of feel like I'm hiding a major part of my life ... so I think it's made me more hesitant to like put myself out there to make new friends and you know hang out with people (Lily).

The women talked of how severe IBD symptoms, along with the ineffectiveness of medications lead them to view ostomy surgery as the one solution that could alleviate suffering and allow them to regain a normal life. As Milla commented, "I was so sick and I was just, I wasn't going to school at this point ... and at that point I was just willing to try anything."

6.2. The decision to have ostomy surgery: fear, desperation, and encountering physician reluctance

The women spoke of their profound fear of ostomy surgery as indicated by Breanna's comment, "I was really scared of the surgery and I really didn't want it, I wanted to try anything else before getting surgery ..." Similarly, Alexa said, "It was also the medical fear of it ... at that time I also felt trapped kind of like, I don't have any other options, I feel like I'm in a corner and I have no choice and it's either that or death." Despite such fears, eight of the women said they made a request for ostomy surgery to be performed electively to alleviate their disabling symptoms. In all cases, the doctor or surgeon dismissed the requests for a variety of reasons. For example, Breanna mentioned that her surgeon felt she was too young for surgery:

I was like please just do the surgery, I've already decided that I want it and please just do it and he was like, "Oh I don't wanna give you a stoma if I don't have to, you're 20, you should be out living your life" and I was like I know, I'm not living my life so help me out and do the surgery ... He kept telling me that since it was so bad like eventually, I would need the surgery in a couple of years, I'm like well just do it now then.

Several women mentioned bringing up ostomy surgery to the attention of their treating doctor. Alexa said, "The first time ever I talked about it with my doctor, it was me who brought it up because I was kind

of seeing where it was going ... and I knew it was a possibility.”

All women in the study received ostomy surgery on an emergency basis after their symptoms had progressed to the extent that they became potentially life-threatening. Several women fell severely ill soon after diagnosis and required ostomy surgery immediately. In such cases, as indicated by Kimberly, women were given minimal information prior to surgery and had insufficient time to adequately grasp what the surgery entailed,

I was 16 and it was 2 days notice and it was all just kind of ... fast, so I think I wasn't thinking about like what life would be like after and more just like as a kid like in the immediate like I'm gonna miss a whole bunch of school, I was a competitive figure skater so I'm gonna miss practice and like how long am I gonna be in the hospital for and those were kind of the only things that were on my mind.

Several women experienced a sense of failure once told they needed ostomy surgery as illustrated by Alexa's comment,

I just honestly at that moment ... it's kind of stupid to say but I felt like I lost, like it was a game and I lost you know? Or if it was a battle and I lost or I don't know but it was just like the disease won and I was the one who lost ... for me that was ... not the end of my life but it was really a sign that I just lost my battle.

6.3. HPs' views on ostomy surgery: A last resort

The HPs in our sample presented ostomy surgery as an absolute last option treatment for IBD patients. As one IBD nurse described, “We get to a point where patients haven't been responding to medication and they continue to go downhill, and quality of life is just not very good and it's generally at that point that I think surgery comes into play.” (IBD Nurse 1). The gastroenterologist characterized ostomy as “a last resort ... so as we're well aware, that is a fear that many patients ... no I shouldn't say many, all patients have to have that.” He outlined the circumstances under which ostomy became necessary:

... the disease is no longer at a state where ... the medications we have would be presumably effective ... meaning that there's no longer significant inflammation, there has been damage from old inflammation that has led to a state that requires attention, which would not be suitable to be given medications to manage.

One colorectal surgeon underlined the importance of considering a patient's quality of life with severe IBD symptoms when deciding on surgery:

One part is, what surgery is needed to address the underlying disease process to say, control the fistula or relieve the obstruction, remove the sick colon or whatever part. The second aspect about stoma versus no stoma is that it comes to, can you reconstruct that person with a reasonable quality of life. (CS1)

She added, “what can you actually do, like what are you given to work with? And the other part of it is like what do the patients want? What do they value?”

The HPs also elaborated on the strategies they used to communicate with patients about the need to perform ostomy surgery. One colorectal surgeon brought up ostomy as an intervention that would not only relieve immediate symptoms but also prevent future complications:

If someone is so sick that they need to be in hospital because they have horrible colitis or a horrible obstruction or they have something that's like an emergency ... the safest thing is to take out the bad part but if the tissue quality is bad or they are so sick, putting them back together puts them at risk for more complications. Then the safe thing to do even though nobody comes asking for a bag ... no one's like give me that bag, I really want it or are excited about it. I try to frame it as you know this is the issue, medical therapy is not working

... this is the operation that we need to do and ... part of getting well again is to have that ostomy. (CS1)

Another colorectal surgeon emphasized the importance of positioning ostomy surgery as one of several treatments for IBD rather than as the last remaining option when other treatments fail to avoid the risk that patients construe this outcome as a personal failure:

It's not a battle that has anything to do with your character, it's not being tough to take the medications longer you know, that's not how you win this war, you do the best choice of treatment for you under the circumstances you're in. When you put that all together, people don't feel like they're failing, they feel like they're embarking on a new treatment and many of them will do better than they've done for months or years with this treatment. (CS 3)

For this reason, he emphasized the need for surgeons to introduce ostomy soon after diagnosis rather than until the patient was very ill:

It's kind of posed as this kind of big terrible thing that you have to go through if you don't have success, you know so to speak, so we diminish that by seeing them earlier so they're aware of surgery as a treatment possibility, not at the last minute when they're as sick as they can possibly be. (CS 3)

Contrastingly, one gastroenterologist said he presents ostomy as the last remaining treatment option for IBD so that patients never doubt they needed the surgery at a later stage,

The way I was taught as a medical student is when you have to deliver bad news, it's like ripping off a band-aid. It sounds like a harsh way to do it ... it's not what a patient wants to hear ... I'm so blessed to have a nurse who can back me up and provide more compassion because I imagine for some patients it would almost seem harsh. I'm not doing it to be mean but doing it so that there's clarity in what we're saying and we were told is that although it may initially be hard for them, it actually allows patients to deal with it better. (CS3)

Mindful of professional boundaries, the nurses saw providing advice about ostomy surgery as beyond their role, although one IBD nurse said she occasionally mentioned the intervention to patients who presented with very severe symptoms.

6.4. Gaps in communication pre and post ostomy surgery

Several women complained of the inadequacy of the information on ostomy they received prior to surgery. As Chloe stated, “I had never heard of one until I got one [laughter].” Likewise for Kimberly, “I was only like 16 so I was young, so it was never something that was like brought up.” The women talked of not fully grasping what an ostomy entailed prior to surgery and being overwhelmed by the information they received when admitted to hospital. As Milla recalled,

Right before I had the notice of my surgery, that entire day once they said okay, you'll go in tomorrow and have the surgery, we were being visited by people, you know anesthesiologists, pain management people and I was visited by the ET [enterostomal therapy] nurse and they did give me some things to read and they did show me a picture of what it would look like and so that was really my first idea of what it looked like.

The women found the information generic and not addressing concerns they had as young women. As Kimberly explains:

I was given so many samples of literature and I had to watch these little videos on a tablet in the hospital and everything ... but the topics that they were talking about in those were not the questions I had as a twenty-one-year-old female, you know just fresh out of college and trying to navigate life, because I was wondering about you know, can I wear my favourite jeans? Can I go swimming? Are

my friends going to accept me? Am I going to find a boyfriend? Things, you know, that you worry about when you're 21 years old.

All women reported receiving insufficient information on managing a stoma and post surgery complications. As Kimberly noted, such information needs to be provided to patients prior to hospitalization:

I think more emphasis on the pre-education as opposed to trying to give the education afterwards when the surgery has already happened and you're in pain in the hospital and trying to get out of the hospital and go home because once you leave the hospital ... it's very hard, if not impossible to get back into contact with anyone who you were dealing with in the hospital to get information. At that point so you are kind of on your own.

Breanna recalled being on her own post-surgery as she learned to adjust to living with a stoma:

I was told I was gonna get nursing care in home but the nursing care I would have received would have just been for wound care, it wouldn't have been a stoma nurse care. Once I left, it was kind of, figure things out on my own.

Kimberly recollected going to emergency because the skin around her stoma became unexpectedly sore and excoriated:

That is apparently another form of prolapse [bowel protruding through the stoma opening in the skin]. We were not told that this could happen, and when I went to the hospital like thinking I'm dying, they're like oh it just prolapsed and we were like what the heck does that mean? They were like oh they didn't tell you that this could happen? There's like a 60 % chance that this could happen within a year of surgery, and I was like no one told us any of this so just like you know terrifying things like that that could happen.

Several women deplored the absence of information about the visibility and noticeability of the stoma bag. Lindsay shared, "I was really worried about the smell and if other people would be able to notice. My questions weren't really medical related, it was more to do with my appearance and how it would change." Similarly, Breanna said, "I do have anxiety about going to someone's house and having it smell and cause we're here in my house it will smell, and it will linger ... like it's not like pooping in the toilet, it's a little different." Chloe spoke about this concern in relation to finding a partner, "I want my own family one day, so my thing was who's gonna wanna date me, I have a bag of poop taped to my side. I went through a very dark period of time for a few months."

Despite concerns, having an ostomy meant participants could engage in social life again and become involved in activities they missed out on before. Clara shared: "I wasn't doing anything, like I wasn't going out, I wasn't spending time with my friends and now like I'm back in [town] with all my roommates and we get to do stuff, and I can eat stuff that I couldn't eat before like specifically pizza." She added, "We went out on a 4k hike the other day and ... I was not worried about like if there was a bathroom around, I was just enjoying the moment."

6.5. HPs' varied views on patients' knowledge of ostomy surgery

The HPs expressed different views on how patients learned about ostomy surgery. One IBD nurse felt most patients became aware of ostomy around the time of their IBD diagnosis:

I've not met many people that are not aware of it, I think once you get the diagnosis of IBD, people start reading and do generally have an understanding of what that is but if they don't then I can go through it with them. I have photos or pictures that I can show to them but I don't know that I've done that a lot actually with patients because they generally do have a fairly good understanding of it.

One colorectal surgeon thought all patients knew about ostomy by

the time he saw them:

Well, I think most of the time they are aware of it before they get to me because I'm usually the last person they wanna see ... the surgeon, uh, so they are aware of it and they may have questions related to how does it work? You know, how do I look after it? Does it affect my activities? (CS2).

Another colorectal surgeon discussed being proactive in educating patients about ostomy irrespective of what they knew already, "If I know someone's gonna have an ostomy that's planned, I try to get them some teaching with the stoma nurse beforehand if possible" (CS1). The NSWOC nurse underlined the value of assessing a patient's knowledge upon their referral for surgery:

My first question to the patient is, you know I've received your referral from Dr. X and he has stated that he's offered you this type of surgery, can you tell me what your understanding is that you're having done? ... That's how I start, so that I can gauge how much they know. Some don't have a clue but again, like I say with the younger set, because that's what we're really talking about, they know exactly what they're having done because they go and google that.

All HPs pointed to the insufficiency of social and emotional support patients receive pre and post surgery. One surgeon singled out his lack of training in this regard,

I don't think I do a very good job of more of that social support. If someone has a specific, like my bag falls off, that's something that I can send someone to do something about. But living with an ostomy and normalizing it in terms of ... like did you know that there are Olympians with them? And like making it socially normalized, I don't think that medical people do a good job of that. (CS1)

Interestingly, the gastroenterologist found interacting with emotional patients over their surgery to be problematic: "There's always tears or almost always tears and obviously at that point it's not really appropriate to further have any sort of meaningful discussion because they're emotional." He believed an indication that patients had adjusted well to their ostomy was when they no longer wanted to talk about their surgery:

There are some patients who come back and ask questions, but they actually don't wanna talk ... it's not that they don't wanna talk, it's that ... they don't feel like there's any need to talk to us anymore, they've moved on ... it actually makes me feel satisfied cause it makes me feel like we delivered something in a way that they really understood.

One surgeon supported patients by telling stories of other patients who successfully adjusted to their ostomy:

I try to have them talk to other people who have been in that circumstance because I can't tell them what it's like to live with a stoma ... and I can share with them experiences others have told me, but you know it's often even more powerful when they can speak to someone who has been through the experience themselves, who have been through those tough times, who are doing well with the stoma. (CS 3)

The nurses saw providing anything beyond informal support as exceeding their job description, "I mean we're there to support patients, but I don't necessarily feel like as an IBD Nurse, we're specialized in that and maybe we could do a little bit more" (IBD Nurse1). The community-based NSWOC nurse pointed to the importance of monitoring one's reaction to a patient's ostomy: "They do rely on us and when ... the first time we see their ostomy, they look at us because they're seeing their ostomy through our eyes." She also noted the challenge of offering support to patients in the community who have questions about their surgery and hospitalization as health policies forbid the transfer of patient hospital records to the community.

7. Discussion

7.1. IBD and the lifeworld: adapting to disrupted day-to-day life

Habermas (1987: 154) conceptualizes the lifeworld as “a background stock of cultural knowledge that is ‘always already’ familiar to agents” that facilitates mutual understanding among family members, friends, co-workers, and acquaintances. Culturally grounded interactions shape day-to-day life in the lifeworld by reinforcing communal solidarity and thus contributing to a person’s overall sense of identity (Wallace & Wolf, 1999). The findings show how the unremitting symptoms of IBD such as diarrhea, abdominal cramping, and incontinence drastically alter a person’s ability to navigate the lifeworld. Being in a public space to socialize with others requires adaptation and acceptance of the potentiality of public humiliation if incontinence occurs. The women in this study identified several strategies they used to manage their social outings which have been well-described in other studies (e.g., Casati et al., 2000) such as mapping the location of toilets prior to going out or bringing a change of clothing in case of an accident.

Another lifeworld burden comes from interacting with others about IBD. As a socially invisible disease, there is minimal appreciation of the level of discomfort and suffering associated with IBD symptoms and any interactions about these symptoms inevitably involves mentioning the taboo topics of bowel function and intestinal symptoms (Lenti et al., 2020). Unsurprisingly, the women in the study feared being stigmatized and treated differently if they disclosed their illness—they instead preferred to hide their condition from others to avoid the risk of rejection and social isolation (Taft et al., 2009).

Receiving an ostomy gave women a semblance of control in the lifeworld albeit not without challenges. Several women internalized the ineffectiveness of drug treatment and the need for an ostomy as a personal failure. This is unsurprising given the privileging of pharmacotherapy by IBD clinicians and the “messages of medical failure” (Dibley et al., 2018, p. 240) conveyed by positioning ostomy as a last resort intervention. The women also struggled with developing “a sense of identity unrelated to the body, so that they are recognized for “themselves,” despite and apart from the barrier to this that their non-conforming body might present” (Manderson, 2005, p. 406). For example, the women in the study spoke of being themselves again, socializing and enjoying activities with others without the fear of incontinence, but also expressed profound concerns that attention might be drawn to their stoma bag. As Miller and Peck (2022) explain, people with an ostomy convey normalcy with their stoma bag hidden from view but always remain aware that their bowel function is now being managed by an apparatus that could reveal itself through noise or ballooning from gas or leaking feces. Yet, it is worth noting that despite societal pressures initially contributing to the fear of surgery and intimacy and body image concerns, these women adjusted remarkably well to their ostomy. Although there was an adjustment period, most women described feeling well almost instantly after surgery and most shared that they would not reverse their ostomy if they were given the choice.

7.2. Women’s encounters with health care providers: A case of colonizing the lifeworld

Habermas’ theory of communicative action helps us understand the role of strategic action in the clinical encounters described by the women in the study. Their accounts show how communication is distorted and oriented towards success. Crucial here is the distinction that Habermas makes between communicative action which is social and oriented towards mutual understanding and strategic communication which involves manipulating others to achieve one’s particular goals and desires. These encounters demonstrate how strategic action negates any engagement with the voice of the lifeworld. All but one woman spoke of pleading with their doctor for elective ostomy surgery to relieve

severe and painful symptoms and regain a sense of normalcy in day-to-day life. Yet, their requests were dismissed with doctors preferring to continue with pharmaceutical treatment. The women perceived this decision as rooted in the doctors’ inability to fully grasp the disruption IBD symptoms brought into their lives. An analysis of their accounts showed how doctors use strategic language in clinical encounters to frame ostomy as a catastrophic intervention, and position drugs or biologics as the superior treatment for IBD (Wong et al., 2019). Yet, the outcome for these women was the same: pharmaceutical treatments failed, and they received ostomy surgery on an emergency basis. The women’s accounts show how strategic rationality colonizes the lifeworld by undermining communicative action and eroding the legitimacy of their lived experience of IBD symptoms (Boye et al., 2021; Schreiber et al., 2013).

The nature of the support women received during their hospitalization also evidenced a reliance on strategic rationality. Several women were overwhelmed with the abundance of information they received upon admission and thought no one appreciated the challenge involved in sorting out this information as they struggled with incapacitating and painful symptoms. The women saw this information as generic and failing to address their concerns over the impact of ostomy on their social and intimate life. The information was also provided on computer tablets to free HPs from having to interact face-to-face with the women, a strategy designed to maximize efficiency in care delivery (Ruben, 2016).

Strategic communication was also evident in the way HPs speculated about what their patients knew about ostomy and ostomy surgery. IBD nurses said patients learned about ostomy when diagnosed with CD or UC while the colorectal surgeons believed patients would have received information from other HPs by the time they arrived for surgery. Only one surgeon talked of the importance of assessing ostomy knowledge by listening to patients instead of making assumption about what they knew. Communicative action was also evident in how IBD nurses offered personalized care in addressing patients’ individual needs and in the way the NSWOC nurse provided social, and emotional support to patients in the community. The nurses also showed insight into their patients’ lived experience with adjusting to their stoma and ostomy bag and the worries they had regarding their changed physical appearance.

Framing the study’s results in relation to Habermas’ (1984) theory provides insight into how deficits in communication impact the trust female ostomy patients have in healthcare services. HPs are more likely to undermine this trust if they rely on strategic communication instead of communicative action, thus undermining patient-centered care. This is unfortunate as there is considerable evidence of the benefits of a high level of trust on health outcomes, quality of life, and patient satisfaction (Birkhäuser et al., 2017). Of course, given the limited sample size of this study, we cannot imply that insufficient communicative action is characteristic of all ostomy surgery care, but at the very least there are circumstances where this can occur, such as in emergency surgery which these women underwent where fewer opportunities for communicative action exist.

7.3. Implications

The testimonies in this study reveal several issues associated with the absence of communicative action in IBD care. The women singled out their doctors’ lack of appreciation of the way severe IBD symptoms disrupted their ability to be in the world; this may have contributed to their unwillingness to consider ostomy surgery as an elective intervention. The women did receive surgery subsequently but on an emergency basis—an outcome that negatively impacts patients’ adjustment to life with a stoma. In comparison, patients who undergo elective ostomy surgery have a better quality of life, are more accepting of their stoma and stoma bag, and show greater competence in handling stoma appliances (Davis et al., 2022).

The findings also have an emancipatory aim by underlining the need

to shift communication in this field of care so as to empower women to gain active control in their own lives as they manage their IBD symptoms and navigate decision-making concerning ostomy surgery. As Boyle et al. (2021) note, HPs who engage in communicative action with their patients go “beyond assigned tasks and rules, listening to a patient’s request and arguments and helping by following the patient’s wishes and needs.” (398). In clinical encounters informed by the principles of communicative action, doctors make decisions that rest on deeper insight into the complex nature of symptoms as they are experienced in the lifeworld of patients (Hemingway, 2011). In hospital care, staff engaging in communicative action aim to personalize information so as to address the specific concerns of patients as they transition back to the community and provide tailored support in helping them adapt to living with a stoma (Thorpe et al., 2016). Also beneficial would be procedures and training to foster communicative action between hospital HPs and those in the community in assessing the concerns and desires of IBD patients with ostomy (Freeman et al., 2003). Additionally, there is a need for initiatives to facilitate the opportunity of women with recent ostomy and stoma to meet other women who already have a stoma (Summers, 2018).

8. Limitations

The study’s results come from the testimonies of a small sample size of adult women living with an ostomy who recollected about the surgery they received as young women. The extent to which their experiences with ostomy surgery correspond to those of other women is unknown. Capturing the full variety of situations for ostomy surgery and stoma formation would require a much larger sample and recruitment ideally taking place in a hospital or specialized clinic. The interviews with the women took place after ostomy surgery had occurred. Hence, they recollected their experiences of surgery that in some cases occurred several years ago. Such recollections can be subject to recall bias (Morse et al., 2002) meaning that participants may have remembered salient events and forgotten more specific aspects of their surgery and decision-making. Also, how we recruited women might have influenced sample composition. Most women responded to recruitment via social media and were involved in online IBD communities. It is possible that these women were more accepting of their ostomy and further along in the adjustment process than women who do not belong to an online community. This might have influenced how they recollected their previous experiences. In addition, women in this study underwent emergency ostomy surgery which may be a factor in accounting for the limited degree of communicative action that took place at the time of surgery. A study with a larger and more diversified sample of women would help address this limitation. Finally, the first author disclosed to the women that she lives with IBD and an ostomy. This might have influenced participant responses but in a positive way as such disclosure likely reduced any discomfort participants might have felt in discussing their experiences with surgery and ostomy. In that sense, we feel this disclosure generated richer interview data.

Likewise, the number of HPs in the study was small—a larger sample would offer further insight into how they relate to and interact with ostomy patients. In particular we had only one gastroenterologist in the sample. A larger sample of gastroenterologists would allow a more fulsome understanding of the role they play in assessing and referring patients to a surgeon and their impact on the decision-making process for young women with IBD. Nonetheless, the findings with HPs highlight how IBD care practices in the absence of communicative action hinder their ability to develop a therapeutic relationship with patients and involve them in shared decision-making about their care (Walseth & Schei, 2011).

9. Conclusion

This study examined ostomy surgery as a phenomenon in the

lifeworld of women with IBD and as clinical care in the absence of communicative action. Women recollected requesting ostomy surgery as an elective intervention for life-altering symptoms but were told by their doctor that pharmaceutical treatment was preferable, that is until a worsening of symptoms required ostomy surgery to be performed emergently. The women’s experiences illustrate the process by which medicine colonizes the lifeworld of patients in clinical encounters. Doctors used strategic rationality to justify treatment decisions while their inability to engage in communicative action prevented them from fully appreciating how IBD symptoms disrupted the women’s ability to live in the lifeworld. The findings also show how the absence of communicative action impacts the delivery of hospital care for ostomy surgery. Medical colonization took the form of information given to women on computer tablets instead of through interactions with HPs. This information was also generic and failed to address the women’s concerns regarding the impact of ostomy on one’s social and intimate life.

The testimonies from HPs in this study gave insight into the occurrence of communicative action pre and post surgery. Communicative action occurred in interactions with patients, but in a limited way when HPs assessed patient knowledge of ostomy surgery. A lifeworld-led approach in IBD and ostomy care would help address this issue by fostering the acquisition of communication skills needed to fully appreciate the complex and diverse lifeworlds of patients and develop mutual understanding in the decisions surrounding ostomy surgery. The outcome of this approach would be to make patients feel involved, listen to, and guided through decision-making about their care.

CRediT authorship contribution statement

Ashley Clark: Writing – original draft, Methodology, Investigation, Formal analysis. **André P. Smith:** Writing – review & editing, Supervision, Formal analysis, Conceptualization.

Declaration of the use of AI assisted technologies

The authors did not use any AI-assisted tools or services in the writing of the article.

Ethics statement

This is to confirm that this study involved human participants, and that the research adhered to the Declaration of Helsinki and that informed consent was obtained from all participants. It received approval from the University of Victoria Human Research Ethics Board (protocol # 18–1037).

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