# The Experience of Ostomy Surgery in Young Women with Inflammatory Bowel Disease

by

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# Abstract

**Background:** Inflammatory Bowel Disease (IBD) is a chronic, relapsing, autoimmune disease, affecting one in every 150 Canadians. Failure to induce remission of IBD with pharmacotherapy can necessitate surgical interventions, such as the creation of an ostomy. Ostomy surgery can help manage severe IBD and thus improve quality of life; however, individuals living with IBD report the possibility of ostomy surgery as a top concern, which can lead them to refuse or delay this decision until the disease becomes life threatening.

**Research Objective**: The aim of this study is to understand what factors influence the decision to have ostomy surgery in young women with IBD, how the perception of the surgery compares to the reality of living with an ostomy, and the role healthcare professionals play in this decision.

**Methods:** Nine participants who (1) identify as female, (2) are between the ages of 19 and 30, and (3) are currently living with an ostomy to treat IBD were recruited for this study. Additionally, seven healthcare professionals who work with IBD patients were recruited. Participants were invited for an individual, semi-structured interview.

**Findings:** Young adult women living with an ostomy to treat their IBD reflected on their initial fears and concerns about undergoing surgery. Due to the severity of their illness, the majority of participants had requested surgery after having some time to adjust to the idea. This request, however, was often met with resistance or obstacles in the healthcare system. Healthcare professionals share mixed perceptions of ostomy surgery, with some viewing it as a last resort and others perceiving it as a treatment option. Once surgery had been performed, young adult women describe some challenges adjusting to life with an ostomy; but the majority report experiencing an overall improvement in quality of life.

**Conclusion:** Understanding the perceptions that influence how young women perceive ostomies prior to versus after surgery will help identify the factors that influence the decision-making process for ostomy surgery, such as gender, age and stigma. Challenging current beliefs and assumptions may allow more supportive conversations between healthcare professionals and patients and provide insight on the actual lived experience of young women living with an ostomy.

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# Chapter One: Introduction

Inflammatory Bowel Disease (IBD) is a chronic, relapsing, autoimmune disease (Kappelman et al., 2011), affecting one in every 140 Canadians (Crohn's and Colitis Canada, 2021). The two main types of IBD are ulcerative colitis (UC) and Crohn's disease (CD), which share major symptoms of diarrhea, fever, intestinal bleeding, weight loss, fatigue, and abdominal pain; although the areas of inflammation in the colon differ (Mawdsley & Rampton, 2006). UC is marked by continuous inflammation, which starts in the rectum and continues along the innermost layer of the large intestine, whereas CD is marked by patchy inflammation that can occur anywhere along the digestive tract, affecting up to all three layers of the intestinal wall.

Treatment usually includes corticosteroids, immunosuppressant therapies, and/or biologic therapies (Renna et al., 2014). Failure to induce remission of IBD with pharmacotherapy can necessitate surgical interventions, such as bowel resection and/or the creation of an ostomy. A bowel resection involves removal of a portion of the small or large intestine or, in some cases, complete removal of the entire large intestine (Steinhart, 2006). An ostomy is a diversion of the intestine through the abdominal wall, creating a stoma, where stool is collected in a bag attached to the abdomen (Steinhart, 2006). There are two types of ostomies that can be created to treat IBD: an ileostomy or a colostomy (Wang & Shen, 2018). An ileostomy is created when the small intestine is pulled through the abdomen, whereas a colostomy involves the large intestine being pulled through the abdomen (Steinhart, 2006). The type of ostomy can impact location of stoma site as well as daily management of the ostomy. Whether someone with IBD gets an ileostomy or a colostomy depends on where the inflammation is in their digestive tract.

This study explores the experiences of young women with IBD (UC or CD) who have made the decision to undergo ostomy surgery to treat their disease. This surgery can potentially be beneficial for managing IBD symptoms and thus improve quality of life (Steinhart, 2006). However, individuals living with IBD report the possibility of undergoing ostomy surgery as a major concern, which can lead them to refuse or delay the decision to have surgery until the disease symptoms are very severe and life threatening (Daniel, 2001; Jelsness-Jorgensen, et al., 2011). There can be a disconnect between perceptions of living with an ostomy and the reality of living with one; ostomies are often feared and perceived negatively by those living with IBD, yet those who do undergo the surgery have reported that it saved their lives and improved their quality of life (Allison, et al., 2013). The aim of this study is to understand what factors influence decision-making in young women with IBD, how the perception of the surgery compares to the reality of living with an ostomy, and the role healthcare professionals play in the decision to have surgery and the subsequent experience of living with an ostomy.

# Chapter Two: Literature Review

## 2.1 Living with IBD

Diagnosis of IBD frequently occurs during adolescence and young adulthood, between the ages of 15 and 29 (Benchimol et al., 2014; Lomer, 2011). Those diagnosed during this time are at an increased risk of experiencing a more aggressive disease course compared to older populations (Saad et al., 2016). Additional challenges accompany being diagnosed at a young age, such as pubertal and growth delays due to malnourishment (Bishop, et al., 2014; Nicholas et al., 2007). As a result, adolescents with IBD must be closely monitored to determine whether nutritional interventions are needed to ensure that developmental milestones are met (Bishop et al., 2014). Beyond the physical aspects of disease, there are a variety of psychosocial challenges that young people with IBD experience.

Research suggests that IBD is associated with high rates of anxiety and depression (Abautret-Daly et al., 2017), particularly during phases of increased disease activity (Graff, et al., 2009). One study found that 55.3% of adolescents living with IBD met the Diagnostic and Statistical Manual of Mental Disorders criteria for a psychiatric disorder during phases of increased disease activity (Engelmann et al., 2015). Loftus et al. (2011) found that young people diagnosed with CD were at a significantly greater risk of developing persistent anxiety and depressive disorders, defined as lasting one year or more, and were more likely to be treated with psychotropic medications compared to those without CD. In addition to anxiety and depressive symptoms, young people living with IBD often experience a variety of social implications.

Body image and self-esteem are commonly reported as problematic for young persons living with IBD as a result of bowel-related symptoms, surgery, and/or medications that can alter appearance (Casati et al., 2000; Daniel, 2001; Junkin & Beitz, 2005). For example, medication side effects can include weight gain or loss, fluid retention, and/or acne (Daniel, 2001; Decker, 2000). Physical attractiveness is often emphasized during adolescence and young adulthood, which can make changes to the body caused by IBD challenging and upsetting for young people. One study found that young adults with IBD were more likely to recall being teased about their weight as a child and reported weight-teasing as being more upsetting compared to healthy controls (Quick, et al., 2014). When interviewing adolescents, another study found that participants negatively compared their physical appearance to their peers; participants viewed themselves as paler and skinnier, which they felt was socially unacceptable (Nicholas et al., 2007).

Reduced engagement in school-related activities and social isolation are also common for adolescents living with IBD (Hummel, 2013). Adolescents have reported a number of different reasons that contribute to decreased involvement with peers, including physical symptoms, embarrassment over their appearance, fear of being left out, and fear of having to use a public washroom (Nicholas et al., 2007). Fear surrounding the use of washrooms is common for those living with IBD. A need to be close to washrooms at all times contributes to social isolation, significantly restricts living space, and causes constant worrying and planning (Carlsson et al., 2001; Devlen et al., 2014; Dudley-Brown, 1996). The unpredictability of IBD and urgent need for a washroom can make individuals feel a lack of control and cause concern about being unable to predict their bodily functions in public spaces (Casati et al., 2000; Daniel, 2001). A loss of control over when and how often symptoms present can be extremely limiting for individuals with IBD and have a widespread impact on everyday life. As a result, those living with IBD express an intense desire to gain control over their disease (Beitz, 1999).

Key treatments for IBD include corticosteroids, immunosuppressive treatments, and/or biologic therapy. The primary goal of treatment for IBD is mucosal healing or the absence of lesions in the intestine; individuals who achieve mucosal healing have lower hospitalization rates, fewer surgeries, and decreased clinical disease activity (Darr & Khan, 2017). Oral corticosteroids, such as Prednisone, are used for the acute treatment of IBD while other medications such as immunosuppressant medications are commonly used as maintenance therapy (Engel & Neurath, 2010). Significant side effects such as bone loss and pancreatitis are common with these medications (Engel & Neurath, 2010). Despite its efficacy, Prednisone can also cause fluid retention, insomnia, increased urination, headaches, mood changes, and/or bruising (Lozada, et al., 1984). Due to the serious side effects associated with corticosteroids, a more recent goal of treatment for IBD includes the achievement of remission without the use of corticosteroids (Jeuring et al., 2018). Immunosuppressant medications are another common form of treatment for CD or UC. Since IBD is thought to be the result of an abnormal immune response in the body, medications that modulate the immune system can be effective in decreasing or eliminating inflammation in the digestive tract (Khan et al., 2011). However, immunosuppressant treatments such as azathioprine and 6-mercaptopurine have been found to significantly increase the risk of lymphoma in IBD patients after one year of exposure, and those under the age of 30 were at the highest risk (Kandiel, et al., 2005). More recently, however, biologic therapy has emerged.

Biologic therapy is the treatment of choice for individuals with IBD who respond poorly to other forms of therapy. Biologic therapy involves proteins delivered intravenously or subcutaneously; this type of therapy also modulates the immune system and is currently considered the most effective form of treatment for IBD (Sandborn & Targan, 2002). Biologic therapy has been found to significantly reduce hospitalization rates and the need for surgery in individuals living with CD or UC (Mao, et al., 2016). Despite many benefits associated with this form of treatment, significant side effects have also been found that must be considered. Specifically, biologic therapies have been found to increase the risk of infections, cancer, and metabolic disorders (Blomqvist, et al., 2001; Colombel et al., 2004). While complications associated with ostomy surgery are common, the risk of being on immunosuppressants or biologic therapy are also important for consideration in the decision-making process.

## 2.2 Ostomy Surgery

Despite medical advances in the treatment of IBD, ostomy surgery is often necessary for treatment-resistant disease, stricture formation, bowel obstruction, or perianal disease (Galandiuk, et al., 2005; Van Limbergen et al., 2008; Pikarsky, et al., 2002). Surgery required before adulthood ranges from 28-56% 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 and thus require an ostomy (Freeman, 2004; Gupta et al., 2006; Hyams et al., 1996). Approximately 10% of individuals living with CD will require a temporary or permanent ostomy at some point throughout their disease course, while estimates for UC are less well known but assumed to be lower (Brown & Randle, 2005; Cosnes, et al., 2011). 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 (Amiot et al., 2011).

An ileostomy or colostomy can also be used to treat complications such as small bowel obstructions, fistulas, or severe perianal disease (Hirsch et al, 2015). 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 ileoanal pouch anal anastomosis (IPAA) several months later (Mosli et al., 2014). IPAA involves the creation of an internal pouch with the preserved small intestine that becomes attached to the anus (Mosli et al., 2014). Individuals with UC who experience pouch failure or who are at risk of the pouch becoming inflamed may have to get a permanent ileostomy (Mosli et al., 2014); however, those with a successful IPAA operation report quality of life that is comparable to healthy peers (Heikens, de Vries, & van Laarhoven, 2012).

There are several risks and complications associated with ostomy surgery. Up to 71% of patients with an ileostomy and 43% with a colostomy experience complications (Persson, et al., 2005). There are three main categories of risk factors for ostomy complications: (1) patient-related (i.e., age and weight), (2) disease-related, and (3) surgery-related (i.e., emergency versus elective, ileostomy versus colostomy) (Wang & Shen, 2018). Specific factors that put individuals at risk of experiencing ostomy complications include higher body mass index, older age, emergency surgery, and IBD (Duchesne, et al., 2002; Park et al., 1999).

Common complications of ostomy include stoma stricture, stoma fistula, prolapsed stoma, retracted stoma, and/or parastomal hernia (Wang & Shen, 2018). Additionally, ostomies can become problematic in their management, causing skin irritation and pouching difficulties that can lead to problems such as leakage, which require ongoing medical care (Richbourg, et al., 2007). As a result of the potential for ongoing management issues and complications, it is recommended that all ostomy patients receive home health care after leaving the hospital (Pittman, 2011). Another issue is that, despite ostomy surgery, individuals with CD are still at risk of disease recurrence, as CD can cause inflammation anywhere along the digestive tract (from mouth to anus) and will often require pharmacological treatment after surgery (Lopez et al., 2014; Wang & Shen, 2018). In contrast, those with UC who undergo surgery are essentially cured from their disease, as UC only affects the rectum and large intestine, which are removed during surgery (Gucela & Steinhagen, 2009). There are thus significant differences between the circumstances for those with UC versus CD. Sensitivity must be drawn to these differences when considering factors that influence the decision-making process for those contemplating surgery.

Whether the surgery is elective or done on an emergency basis is also a factor in relation to the potential to ensure the success of the surgery. Emergency ostomy surgery is immediate and unplanned (Stothert, et al., 1982) and those who undergo emergency surgery typically have worse outcomes when compared to those who choose elective surgery (Borwell, 2009; Persson & Hellström, 2002). Knowles et al. (2013) found that CD patients who underwent emergency ostomy surgery had worse beliefs about their illness, a poorer quality of life in relation to their ostomy, and higher rates of depression compared to those who underwent elective surgery. In contrast, elective surgery can allow time for marking of where the stoma will be on the abdomen, which can lead to better outcomes and easier management (Pittman, 2011). An appropriate stoma site can reduce the risk of leakage and be more comfortable for individuals living with this operation. Better outcomes for those who undergo elective surgery calls for a better understanding of the decision-making process for ostomy surgery. Factors that help assist individuals with CD or UC in making surgical decisions before health deteriorates and symptoms become life threatening are needed so that proper planning and preparation can occur prior to surgery.

## 2.3 The Decision to have an Ostomy

Jelsness-Jorgensen et al. (2011) found that the majority of individuals living with IBD ranked having to get an ostomy as their top disease-related concern. Similarly, Daniel (2001) found that young adults living with IBD were greatly concerned about having an ostomy and expressed a strong desire to avoid surgery. In a study on adolescents living with a variety of different chronic illnesses, a 16-year old boy living with CD reported the fear of having to get a colostomy as a major worry for him (Woodgate, 1998), which suggests that this concern begins at a young age. Negative perceptions of living with an ostomy can create a fear of having to live with an ostomy and make the decision to undergo surgery challenging for people with IBD. As noted by Steinhart (2006), individuals who are reluctant to have surgery will often become sicker and sicker until surgery must be performed in an emergency setting with poorer outcomes due to worsened health and nutritional status at the time of surgery.

There are several possible factors that might explain the reluctance of individuals with IBD to undergo ostomy surgery. One factor is whether the ostomy will be temporary or permanent, as this plays a role in how it is perceived and experienced. Participants of a qualitative study who had lived with a temporary ostomy reported isolating themselves and restricting their lifestyles until their surgery was reversed (Allison, et al., 2013). A participant in this study also revealed that while he had initially decided not to undergo surgery, he ultimately decided to get a temporary ostomy to just “get it over with,” as he knew it would eventually be reversed. Additionally, interviews with adolescents who had lived with a temporary ostomy to treat UC revealed that knowing the ostomy was temporary helped them cope, as they knew their bodies would eventually return to normal (Savard & Woodgate, 2009). Deciding to undergo a temporary ostomy may be relatively easier, as these individuals are reassured that the surgery can be reversed or they have planned to get an IPAA. On the other hand, individuals who have to decide whether to get a permanent ostomy may experience more challenges during the decision-making process (Sinclair, 2009).

Another factor is disease recurrence. In the case of UC, which is a disease restricted to the large intestine, removal of the colon with the creation of an ostomy is advocated as a cure for disease, with the expectation that disease will not return regardless of whether the ostomy is temporary or permanent (Wang & Bo Shen, 2018). This reduces their risk of colorectal cancer and often improves their quality to life to a level comparable to the general population in all domains (Kuruvilla, et al., 2012). On the other hand, individuals living with CD have the additional burden of not knowing whether disease will return after ostomy surgery (Knowles et al., 2013). Those with CD may undergo ostomy surgery and bowel resection but are still at risk of disease returning, as CD can affect anywhere along the digestive tract (Wang & Shen, 2018).

Another factor is concern with body image and sexuality (Bosaeus & Nordgren, 2009; Junkin & Beitz, 2005; Manderson, 2005). Individuals who experience a dramatically altered body image after surgery have a more difficult time adjusting to their ostomy (Piwonka & Merino, 1999). Savard and Woodgate (2009) reported that young adults with UC and an ostomy experienced embarrassment and an altered sense of self due to the drastic change to their body. Participants expressed a desire to hide their ostomy from others because they were afraid of being judged. Persson and Hellström (2002) interviewed men and women two to three months after ostomy surgery and discovered that all participants felt less attractive as a result of their surgery. Additionally, they were afraid that their stoma would become visible or produce gas or odour. Participants also described having less self-respect, feeling less confident since surgery, and experiencing difficulty looking at their stoma (Persson & Hellstrom, 2002). Ostomy surgery thus alters perceptions of the self and feelings about level of attractiveness, which may generate fear about this operation for those living with IBD who are considering surgery.

A final factor is how the surgery is presented by doctors. Surgical treatment for IBD, especially the formation of an ostomy, has been defined as a “salvage therapy” and is often described as a last resort after pharmacotherapy has failed (Biondi et al., 2012). As medical advancements are made in treating IBD, such as with biologic therapies, individuals requiring an ostomy are seen as only the most severe and untreatable cases (Biondi et al., 2012). Therefore, having to suggest ostomy surgery may be distressing for healthcare professionals. Additionally, declines in surgery rates are often defined as a success in the medical field (Burisch et al., 2013), which may contribute to the notion that surgical interventions are a last resort and not ideal.

# Chapter Three: Research Questions

This literature review underlines the importance of understanding the concerns of individuals with regard to ostomy surgery and the manner in which these concerns contribute to the decision to undergo this treatment. A better understanding of the factors influencing individuals with CD or UC in making surgical decisions is needed so that surgery can be undertaken before health deteriorates and symptoms become life threatening. Individuals facing the decision to have ostomy surgery contemplate the risks versus the benefits of surgery, e.g., giving up a sense of physical attractiveness to regain physical health and a relative sense of normalcy (O'Brien, 1999). While ostomy surgery is often feared, some individuals with IBD who have undergone surgery have described their experiences as a 'rebirth,' giving them a new lease on life (Junkin & Beitz, 2005; Persson & Hellström, 2002; Savard & Woodgate, 2009). These unique circumstances call for more research on the process by which individuals with IBD make the decision to have an ostomy and how they view this decision following surgery.

## 3.1 Research Questions

This study seeks to understand the perceptions of ostomy surgery in young women living with IBD (UC or CD) and the factors that influence their decision to have this surgery. The circumstances that necessitate surgery and anticipated outcomes are substantially different compared to those with UC and CD (Wang & Shen, 2018). Individuals living with CD make the decision to undergo ostomy surgery with the risk of disease returning and having to continue pharmacological treatment in combination with this surgical intervention (Amiot et al., 2011). Their experiences, therefore, might be different from those with UC who undergo ostomy surgery as a curative procedure for their disease (Wang & Shen, 2018).

The following research questions will guide the study:

(1) What are the lived experiences of young women living with IBD and an ostomy?

(2) How is ostomy surgery perceived prior to surgery? How do these perceptions evolve after surgery?

(3) What factors influence the decision-making process in getting an ostomy to treat IBD?

Research is also needed on how healthcare professionals perceive ostomy surgery in treating IBD. From a medical standpoint, ostomy surgery may be seen as a last a resort intervention when pharmacotherapy fails to induce remission in IBD (Peyrin-Biroulet & Lémann, 2011). Yet, little is known on how healthcare professionals view ostomy surgery and how they discuss the potential risks, benefits and improvements in quality of life with patients who are contemplating the intervention. The following two additional questions will guide research on the perceptions of healthcare professionals concerning ostomy surgery:

(4) How do healthcare professionals view ostomy surgery in the treatment of IBD?

(5) How do healthcare professionals discuss ostomy surgery with their patient?

The overall findings of this study could help healthcare professionals better counsel their patients as they decide whether or not to have the surgery. This is critical for improving health outcomes, as healthcare professionals have an important role in forming the perceptions of ostomies for their patients.

## 3.2 Theoretical Framework

This study seeks to understand the experiences of young women living with IBD and an ostomy using the concept of stigmatization. This concept will help provide insight into the fear surrounding surgery and how young women arrive at the decision to get an ostomy to treat their IBD.

**3.2.1 Concept of Stigmatization.** Stigma has been defined as a discrediting attribute that can result in actual, anticipated, or perceived negative responses from others (Goffman, 1963). Those who experience stigma perceive themselves to be less than those without their stigmatizing attribute (Goffman, 1963) Specifically, those who experience stigma related to their illness might worry about others finding out about their condition, or that they will be perceived negatively as a result of their condition (Dibley, et al., 2017). Link and Phelan (2001) state that stigmatization occurs when people do not fit within the norm or are labeled as different and subsequently linked to a negative stereotype. Three types of stigma have been described: internalized, experienced, and anticipated. Internalized stigma has been defined as the extent to which a person embodies negative beliefs associated with their disease or condition (Link, 1987). Since this type of stigma is internalized, it is brought into different social contexts, including the healthcare system (Earnshaw & Quinn, 2011). Experienced stigma is the perception of experiencing stereotyping, prejudice, and discrimination from others (Scambler & Hopkins, 1986). This differs from internalized stigma because it occurs within interpersonal interactions rather than within one's self (Earnshaw & Quinn, 2011). Finally, anticipated stigma is the expectation that one will experience stereotyping, prejudice, or discrimination (Markowitz, 1998). This anticipation may stem from previous experiences of internalized or experienced stigma. Earnshaw and Quinn (2011) found that these different types of stigma are related to each other. For example, internalized stigma was related to higher levels of anticipated stigma. Internalized stigma was also associated with lower quality of life and decreased care access, i.e., the extent to which people choose to access care rather than the amount of care that is available to them (Earnshaw & Quinn, 2011). This suggests that stigma can have a significant impact on the lives of those living with chronic health conditions.

**3.2.2 Stigmatization of IBD.** As noted by Chelvanayagam (2014), bowel function is often stigmatized, especially when there are problems or issues. Those living with IBD have reported stigma associated with their condition due to bowel-related symptoms and the lack of understanding of IBD from their family, friends, and health professionals (Chelvanayagam, 2014). Struggling to disclose symptoms to family and friends have also been reported, while discussions with healthcare professionals who are familiar with the disease and its symptoms are often easier (Dibley, et al., 2018). In general, discussion of feces is stigmatized within society and considered disgusting (Tsagkamilis, 1999). For most people, this bodily function is hidden from others and not discussed in public settings.

People living with IBD report feeling stigmatized due to their bowel-related symptoms (Saunders, 2014; Thompson, 2013). As a result, these individuals might be hyper vigilant to conceal their symptoms from others. Some methods that have been reported are planning social activities around the location of bathrooms (sometimes called "bathroom mapping"), avoiding social activities altogether, and not disclosing their diagnosis to others (Dibley, et al., 2017). With planning and hyper vigilance, individuals can be successful in hiding their diagnosis from others, as IBD is an invisible illness that does not always show outward symptoms.

However, individuals who are faced with the decision to undergo ostomy surgery may feel a threat to their ability to conceal their diagnosis. An ostomy is a physical reminder of one's diagnosis and remains present even symptoms have subsided. In other words, an ostomy can make an invisible illness become visible. While an ostomy can be hidden beneath clothing, the internalized stigma associated with an ostomy may be more intense than that of simply having bowel-related symptoms. Additionally, an ostomy cannot always be concealed, such as in intimate relationships. As suggested by Dibley et al. (2017), most people attempt to hide their

IBD in order to fit the expected adult “norms”. However, an ostomy may limit one’s ability to do so, which might increase internalized stigma and threaten one’s ability to feel “normal.”

**3.2.3 Stigma and Ostomy.** An ostomy alters the appearance of the body and one’s control over bodily functions, which may explain why the procedure is feared by individuals living with IBD. Without an ostomy, the internal nature of IBD symptoms allows people to hide their disease and present themselves as “normal.” While the symptoms of IBD may be burdensome and, in some cases, debilitating, the invisibility of this disease helps individuals to feel ‘normal’ whereas, those with an ostomy might be constantly reminded of their disease and feel different than their peers. An ostomy also changes the mechanics of bowel functioning and thus acts as a constant reminder of one’s disease, regardless of whether symptoms are present.

The concern over an ostomy becoming exposed, particularly in intimate relationships, may be challenging. For example, young people living with an ostomy have reported that they try to conceal their ostomy through clothing choices (Savard & Woodgate, 2009). Gender may be an important factor to consider in this context (Kendrick, 2008). The societal expectations of beauty placed on women may be a barrier in the decision to have an ostomy along with the fear that the procedure will change their status from able-bodied to disabled.

Healthcare professionals can play a role in the stigmatization of an ostomy. An ostomy can alleviate the symptoms of IBD and allow individuals to live a relatively normal life compared to their preoperative state (Junkin & Beitz, 2005). However, Elcoat (1988) argues that any signs of distaste from healthcare professionals, specifically nurses, can perpetuate individuals’ fears surrounding ostomy surgery and reinforce that they are socially unacceptable. Healthcare professionals’ perception of an ostomy and how they treat ostomy patients likely influence how patients adjust to life after surgery. Deeny and McCrea (1991) also found that while physical needs are often met during hospitalization, psychological and social needs are left unsatisfied. It is important, therefore, to understand the influence of healthcare professionals in the process of adaptation and normalization of living with an ostomy.

# Chapter Four: Methodology

## 4.1 Sample

Purposive sampling was used to identify young women living with IBD (UC or CD) and an ostomy. Nine participants who met the following inclusion criteria were recruited for the study: (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 was chosen as the lower limit, as this is when patients transition from pediatric to adult care in British Columbia (Philpott, 2011). The upper age limit of 30 years was chosen in order to capture women at various stages within their young adult life (i.e., living at home, going to university, joining the workforce, starting relationships, experiencing long-term relationships, etc.).

Purposive sampling was also used to recruit seven healthcare professionals who treat and/or counsel patients living with IBD and who are involved in the decision-making process for ostomy surgery. Inclusion criteria include: (1) work directly with IBD patients, and (2) fluent in English. An effort was made to recruit at least one healthcare professional from each of the following areas of care: colorectal surgery, gastroenterology, and nursing (specializing in IBD and/or ostomy care). Nurses specializing in IBD typically work at a Gastroenterology office providing advice to patients over the phone, educating patients and colleagues, providing follow-up and in-patient support, and managing and developing IBD-related services (Glatter, et al., 2013). IBD nurses may consult and provide support to patients contemplating ostomy surgery. While colorectal surgeons are not primarily involved in the treatment of IBD-related symptoms, a consultation between the surgeon and the patient is necessary prior to ostomy surgery; their consultation with patients may influence the decision-making process. Finally, Gastroenterologists are typically responsible for explaining treatment possibilities to patients and therefore play a vital role in the decision to undergo ostomy surgery for the treatment of IBD.

## 4.2 Recruitment

Nine young adult women between the ages of 19 and 30 currently living with an ostomy were recruited for this study through various avenues, including the Crohn's and Colitis Canada website, social media, and word-of-mouth. Study information was shared on the Crohn's and Colitis Canada website, Participate in Research webpage (crohnsandcolitis.ca/Research). The study poster (see Appendix G) asked potential participants to contact the researcher directly if they wanted more information about the study or if they were interested in participating in the study. Prospective participants were then emailed a Letter of Invitation (see Appendix A) and asked to provide their preferred method of contact (i.e., phone, email, etc.). The researcher then contacted the participant directly to review the Participant Consent Form (see Appendix B) to explain study procedures further, answer any questions, and schedule an interview if the participant continued to express interest in the study.

Five participants were diagnosed with Crohn's disease, three with ulcerative colitis and one with Indeterminant colitis. Seven of the participants resided in Canada and two resided in the United States. All participants were living with an ileostomy (as opposed to a colostomy). Seven participants currently had a permanent ostomy and two were told their stoma was temporary and therefore had plans to get it reversed in the future. Participants were assigned fictitious names to protect anonymity (see Appendix F).

Healthcare professionals were recruited through a Health Centre in Canada. More than ten gastroenterologists work out of this office, as well as nurses specializing in IBD. In addition to the researcher distributing posters to this office, both a Gastroenterologist and IBD nurse distributed study information via word-of mouth and email to other nurses and gastroenterologists in the office. Study information was also shared via word-of-mouth among healthcare professionals outside of the Health Centre. Healthcare professionals who met the inclusion criteria and express interest in the study were emailed a Letter of Invitation (see Appendix C) and a Letter of Consent (see Appendix D).

## 4.3 Data Collection

Participants who agreed to participate in the study were invited for an individual interview. The interviews lasted anywhere from half an hour to an hour and a half. The researcher arranged a date and time that was convenient for each participant. All correspondence prior to the interview took place through email and all interviews took place over Zoom or telephone, with the exception of two participant interviews that took place in person in a private location of the participant's choice. Consent forms were signed and completed prior to the date of the interview. At the beginning of the interview, each participant was reminded of study procedures and given the chance to ask questions. The interviews had a semi-structured format, in which open-ended questions guided the interaction (DiCicco-Bloom & Crabtree, 2006). Participants were also given the opportunity to discuss issues that were most important to them more extensively. Semi-structured interviews have been used to understand the impact of chronic disease for a variety of different populations and age groups, such as heart conditions and chronic fatigue (Cappelli et al., 1989; Kuhnle, et al., 1995; Whitehead, et al., 2016). This approach is particularly useful for exploratory research, as it will allow new topics to emerge that are important to participants but might have been previously unknown to the researcher.

For young women with IBD and an ostomy, the interview began with basic disease information (i.e., current disease status, time since ostomy surgery, and type of ostomy) and then moved into general, open-ended questions related to experiences of living with an ostomy and how they arrived at their decision to undergo ostomy surgery before finishing with basic demographic questions. Interviews took approximately 1 to 1.5 hours, depending on how much detail and depth the interviewee decided to provide. For healthcare professionals, the interview began with basic demographic information and questions related to their roles and responsibilities surrounding ostomy surgery for individuals living with IBD. Subsequently, open-ended questions related to their perceptions of ostomy surgery in treating IBD and how they discuss this treatment option with patients were asked. These interviews took approximately 20 minutes to one hour.

## 4.4 Data Analysis

Interviews were audio-recorded, transcribed verbatim, and inputted into the qualitative software program NVivo 11 (QSR International Ltd, 2017). A thematic analysis was conducted in this software program, which involved a focus on what was being told rather than how it was being told (Riessman, 1993). The analysis began with a transcription of the interviews into text so that the data could be easily seen and interpreted (Castleberry & Nolen, 2018). Secondly, the data was grouped together into meaningful patterns through inductive coding, which involved the development of codes as the analysis occurred, rather than beginning the analysis with a predetermined set of codes (Casteberry & Nolen, 2018; Thomas, 2006). The development of themes and concepts was based on similarities among narratives. Themes were created through the grouping of codes into categories that were then contextualized (Castleberry & Nolen, 2018). Finally, conclusions about the data were drawn from the codes and themes that were revealed through the analysis (Castleberry & Nolen, 2018).

In order to inductively code the data, narratives were read multiple times to identify topics that were discussed and to create appropriate codes (Thomas, 2006). Based on codes that emerge, categories that represent certain groups of related topics were created. Throughout this process, topics/codes were constantly compared to interpret the broader meaning of the data and decisions were made about the importance of each category. The constant comparative process involves new data being continuously compared to existing data and codes (Bowen, 2008). Previously coded data was compared to new codes to develop and refine categories or themes (Bowen, 2008). On an ongoing basis, memos were also created to track important ideas about the meaning of the data and the codes that were being created (Friese, 2014). Memos were then referred to once the analysis was complete to assist in the general understanding of the data and how categories related to one another. The final categories that emerged contributed to the framework that summarizes key themes of the data. Finally, these key themes in combination with the memos created throughout the analysis were used to complete the results for the completion of this thesis, and later for the dissemination of results in the form of presentations and a journal article.

## 4.5 Ethics

Prior to conducting the proposed study, ethics approval was obtained from the Human Research Ethics Board (HREB) at the University of Victoria (see Appendix H). The HREB application included details on the research objectives, recruitment and selection of participants, data collection methods, risks and potential harms, incentives, consent, confidentiality, and use and disposal of data.

Sensitivity was given to the fact that discussing the experiences of living with ostomy may be embarrassing for young women living with IBD. In order to reduce potential discomfort, the researcher disclosed to participants that she also lives with IBD and an ostomy. It was planned that if participants reported any emotional distress , they would be provided with information of available services and resources to seek support, such as Crohn’s and Colitis

Canada, which offers monthly support groups to people living with IBD in communities throughout Canada (http://www.crohnsandcolitis.ca/). It was also planned that participants would be made aware of the Ostomy Canada Society, which is an organization that provides support to individuals living with an ostomy for any reason (https://www.ostomycanada.ca/). Beyond these free services available in the community, contact information for Susan McConnell, Kirsten Mueller, and Dimitri de Morea were readily available, as these are private counselors in the Victoria area who have experience with chronic illness. However, none of the participants reported emotional distress that required support or resources.

Strict confidentiality guidelines were followed to protect the anonymity of the participants and the confidentiality of the data. Only the Principal Investigator and supervisors had access to the data. Electronic data files were stored on password-protected and encrypted computers at the University of Victoria (UVic). Paper data was stored in locked facilities in the Department of Sociology, Cornett Building at the UVic campus.

Data was stripped of identifying variables. Each subject was assigned a code number by the researcher; data associated with each subject was identified only by this code number once it had been removed from the secure server. No additional identifying information was attached to these data at this point. Any paper documents simultaneously containing identifying information and participant code numbers were kept in a locked filing cabinet at the UVic campus.

The findings from this study will be disseminated in the form of journal articles in social sciences journals as well as in more clinical journals such as Inflammatory Bowel Diseases, Journal of Crohn’s and Colitis, or Gastrointestinal Nursing. The findings may also be presented at conferences such as United Ostomy Associations of America annual conference, Ostomy, and Continence Nursing Annual Conference, Lakeside Ostomy Day, Canadian Association for

Enterostomal Therapy National Conference Education Program, and the annual conference hosted by the Ostomy Canada Society.

According to the ethical principles that govern behavioural research, the data will be preserved for five years after the defence of the thesis. After this period, if a decision is made to destroy the data, it will be done in a way that ensures confidentiality (i.e., through shredding of paper documents and deletion and destruction of all electronic files).

# Chapter Five: Results: Lived Experience of Young Adult Women with Ostomies

This chapter explores the themes that emerged from analyzing the interviews with young adult women on their experience of having had and living with an ostomy. This section consists of the following sub-themes: life before ostomy, decision-making process, adjustment phase, living with an ostomy, stoma-specific concerns and fears, decision making, and adjustment phase.

## 5.1 Life Before Ostomy

During the interviews, participants were first asked to share about their diagnosis. All nine participants described experiencing a severe case of IBD with multiple failed medications and missing out on their lives due to the nature of their symptoms prior to getting an ostomy. For example, Clara stated "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 described her severe disease symptoms: "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 described having tried and failed multiple medications, such as various types of steroids, biologic therapies, and immunosuppressants. Through trying these medications, participants experienced side effects that were difficult to cope with, such as vomiting and headaches. They also described experiencing challenging complications of their IBD, such as fissures and fistulas. Fistulas occur when an ulcer extends through the intestinal wall, forming an abnormal connection between two body parts that is essentially an infection filled with pus, which are difficult to treat. Extreme weight loss was a common experience for these participants as they suffered through the severity of their illness. Participants lost significant amounts of weight (up to 70lbs) and one participant noted, “I was not in very good shape at all… I was like 72 pounds at the time” *(Lily)*.

The severity of the participants’ disease caused many of them to miss out on living their life. For example, Chloe shared,

> I missed out, I had just become a teenager, I was supposed to be doing all of these sports, all these 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.

Breanna stated, “I was like I’m 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 wanna go out.” Due to the severity of illness experienced by all participants, either their health care professionals or patients themselves eventually brought forward the possibility of ostomy surgery.

## 5.2 Decision-making Process

A large portion of the interviews were spent discussing the complex decision-making process for ostomy surgery and the many factors that influenced this process, such as education, ostomy-related fears and concerns, and the nature of surgery. However, before getting into these factors and the complex nature of this decision, many participants shared a wide range of negative emotions that they experienced during this contemplation phase, such as anger, fear, a sense of failure, and a general mental toll. For example, in relation to her diagnosis of Crohn’s disease and going through the process of requiring ostomy surgery, Milla stated “I felt really angry, I felt that I had this kind of embarrassing thing that set me apart and when you’re in middle school it really feels like the worst thing that could happen to anybody.” A lot of fear was expressed in relation to ostomy surgery and the unknown of what it would mean for the participant: “I was terrified, I had never been sick a day in my life… we were confused and just had so many questions and didn’t know where to go from there” (Lindsay). Breanna also conveyed her fear before surgery, stating “I was really scared of the surgery and I really didn’t want it, I wanted to try anything else before getting surgery…” She shared that a lot of this fear stemmed from the nature of the surgery itself and the fact that it was a major surgery to undergo:

> It’s a big surgery you know you go in for a good amount of time… and then I know mine is temporary so then just the option of doing another surgery in the future is just another thing to worry about… just going through it was just scary to think about like such a huge surgery. (Breanna)

Alexa shared a similar testament, that the medical aspect of surgery was scary for her:

> 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… I don’t really wanna make this choice.

However, other participants were less concerned about the medical aspect and had more concerns and questions about how having an ostomy would impact their life after surgery: “I was really worried about the smell and if other people would be able to notice but a lot of my questions weren’t really medical related, it was more to do with my appearance and how it would change” (Lindsay).

When reflecting on the moment that ostomy surgery was first presented to Alexa, she shared:

> I just honestly at that moment… it’s kind of stupid to say but I felt like I lost, like if 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.

Alexa also shared that “even though you didn’t do anything wrong, it feels like you kind of did, I don’t know, it feels like you’re the one who’s doing something that’s not right.” This sense of failure was described by other participants as well. Many participants were told by their health care professionals that as a result of all of the failed medications and the severity of their disease, ostomy surgery was their only option left.

**5.2.1 Education.** A huge aspect of the decision-making process was education. Many participants expressed that there was a lack of education, and they did not know anything about ostomies prior to getting one themselves. Chloe shared “I had never heard of one until I got one [laughter].” Additionally, Kimberly shared “I was only like 16 so I was young, so it was never something that was like brought up.” As a result of this lack of education pre-operatively, participants who did have a chance to learn about ostomies prior to their own surgery usually did not have much time to process what it entailed or what it meant for them and their body. For example, Milla stated that

> …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 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

This lack of education contributed to many patients feeling resistant to the idea of ostomy surgery at first. Interestingly, Heather shared

> When I was first diagnosed, they brought it up in 2008 and I was against the idea because I’d never been sick before and I was overwhelmed and terrified and then 2 years later I

> brought it up to them because I was just… they were like there's more medications, there's more we can do and I was like I'm over it.

This participant's experience of feeling afraid and resistant when ostomy surgery was first presented and then coming to terms with the idea, educating themselves and eventually asking for the surgery was not an uncommon trajectory. Eight out of nine of the participants did eventually ask for ostomy surgery at some point in their health care journey. Breanna noted,

> I was like I'm 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.

When asked about the first time having the discussion of ostomy surgery with her health care team, Alexa shared that she brought it up before her health care team. She had already gone through the stages of educating herself and realizing it might be a good option for her before her doctor discussed it with her:

> …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 so I kind of had the feeling, like nothing was working and I [could] kind of see it was maybe coming so the first time we talked about it it was me… and maybe it was like a year before it happened.

These experiences with health care professionals and their perceptions of ostomy surgery and how they influence the patient experience will continue to present themselves in future themes.

**5.2.2 Ending the Suffering.** Many participants also reflected on the decision for getting their ostomy as an attempt to end the suffering because of the severity of their illness, which motivated them to make the decision to get an ostomy despite the lack of education. Heather shared:

> I had never really known anyone with one before so I didn't really actually know much about it but I think at that point I was so ill that it didn't really matter to me in that moment what happened… like if it happened or not, I just really knew I did need to have surgery.

Milla similarly shared, "at that point, 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." This was a common experience for participants, where they were severely ill and desperate to become healthy to the point that they no longer cared what they had to do to get there. Kimberly described this notion as having to choose to between either getting an ostomy or remaining severely ill: "I think it was like the lesser of two evils is how I think of it like, am I happy with the decision? I don't know I think obviously no one wants to have surgery… but I think it's like, it was the lesser of two evils."

While reaching the decision on their own was not true for all participants, for the ones that did decide they wanted surgery and were willing to try anything to end their suffering, many ended up having to advocate for the ostomy surgery with a reluctant health care professional. For example, Breanna disclosed:

> 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.

Similar reluctance from healthcare professionals was mentioned on multiple different accounts, At this point in their healthcare journey where they had been suffering for some time and decided on their own that an ostomy could be a good option, many participants shared that they brought the idea forward to their healthcare professional who wanted to try other options first instead, despite the participant being severely ill.

Breanna revealed her health care professional's reluctance once she had made the decision that she wanted ostomy surgery, "he was just like I don't know if that's what you want like if I don't have to do the surgery, but then he kept telling me that since it was so bad like eventually I would need the surgery in a couple years, I'm like well just do it now then." This participant's experience also speaks to the notion that health care professionals tended to either avoid surgery or delay it for as long as possible, which often resulted in participants taking the initiative to do their own learning and reach the decision for ostomy surgery before their health care team.

There were also circumstances where participants got diagnosed and became severely ill very quickly, which necessitated ostomy surgery quite quickly but again with little to no education around what that meant and little notice for being able to learn on their own or process the decision prior to undergoing the surgery. Kimberly shared:

> 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.

Milla also shared the short timeline of finding out she required surgery and hearing about ostomies for the first time before actually having to undergo the surgery:

> …right before I had the notice of my surgery, that entire day once they said okay you're gonna 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 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, what it looked like.

Regardless of how much notice was given prior to ostomy surgery, participants expressed undergoing a huge learning curve. While participants shared that a larger timeframe for learning would have been helpful, the reluctance from patients and health care professionals contributed to the shorter window between deciding ostomy surgery was going to happen and actually undergoing the surgery.

**5.2.3 Fertility.** Other than the general reluctance of giving ostomy surgery to young patients that was expressed by health care professionals, there were also concerns around fertility issues, given the participants' demographic (young adult women). Five participants shared that either themselves or their health care professionals expressed concerns about fertility when contemplating ostomy surgery. For example, Milla explained that while fertility was not a concern for her when contemplating ostomy surgery, it had been for her Gastroenterologist:

> I really had to fight with my GI because they were worried… and why they didn't remove my rectum the first time was because of the infertility issue that happens when you operate on young women close to the pelvic area… and to me like having children… is not a thing I am interested in… even when I am in my twenties I know this but they try and kind of persuade you that oh you might change your mind, what if, what happens then… but for me it was… my quality of life is so low that I can't even, even if I wanted to I can't think about that right now… so that was kind of a thing I had to really advocate.

In relation to this experience Milla reflected and shared, “that was something that really bothered me where I felt that they were acting like they know me better than I do.” On the other hand, some participants shared that having kids was something they knew they wanted and therefore fertility and their ability to parent children were important factors in their decision-making process:

> When I brought it up, I was like I just want healthy kids and my surgeon kind of like she didn’t want to say it, she’s like well we don’t know if that’d be possible, we don’t know the damage that’s there until it’s done.

This participant was pregnant at the time of the interview and shared, “now that I’m pregnant it’s like… all been worth it, it’s like that’s everything that I’ve been through has been for that, so it’s all worth it now.”

For others, however, they had to make these heavy medical decisions when they were young and likely unable to fully comprehend what these decisions meant for them and their future. For example, Kimberly shared:

> I remember very distinctly when I was like 16 the surgeon coming through and talking about the risks and complications that occur after and as a 16 year old you’re like okay sure like this doesn’t mean anything to me and I do remember them saying there’s a 30% chance that we’ll nick your fallopian tubes and it can impact your fertility later and as a 16 year old like who cares and then at 21 they had the same conversation because they had to go in a second time, they said you know there’s a chance we could nick something because they’re so close together and again you’re like okay that sucks but like what am I gonna do about it and then now kind of as a 29-year old I’m kind of like in that world of thinking about family and stuff… I’m like well that’s crappy.

Participants who had to make these decisions as minors similarly expressed difficulty in being able to comprehend how these decisions would impact them in the long-term; rather, they were simply focused on trying to feel better in their immediate future and then later came to understand and have to deal with the aftermath of these decisions and the impact that their illness had had on their bodies.

**5.2.4 Emergency vs Elective.** When discussing decision-making and varying lengths of time given to participants for mentally and physically preparing for surgery, it was challenging to differentiate emergency versus elective surgery. As a result of the resistance both from health care professionals and participants, many of these young women underwent surgery under critical circumstances where they no longer had a choice; however, they did not consider their surgery to be emergent due to the resistance period that occurred beforehand. In other words, while ostomy surgery might have once been a treatment option and therefore considered an elective surgery, the resistance from health care professionals and/or participants that delayed surgery resulted in participants undergoing surgery in emergency circumstances. When asked if their surgery was elective or an emergency, many had a hard time categorizing it due to the complex nature of these circumstances. Additionally, many participants underwent multiple surgeries (i.e., bowel resection and temporary ostomy, total colectomy and permanent ostomy, proctectomy, etc.) and shared that some felt elective, while others were emergent. For example, Breanna shared: “they ended up scheduling it as like an emergency surgery because I was like so sick even though it technically wasn’t an emergency but they scheduled it like that so that I could get it done like soon.”

**5.2.5 Temporary vs Permanent.** Participants had different experiences in terms of whether they were told that their ostomy would be temporary or permanent when they were contemplating surgery for the first time. Some participants and their families felt that the decision to undergo surgery was easier if they thought the ostomy would be temporary and would have the option to reverse it in the future. Kimberly shared:

> …they really focused on the fact that it was gonna be temporary which obviously it wasn't but it was kind of like okay so just do it for a couple of years and then everything will go back to normal and that's really what was pushed and that's what my parents latched onto too was like it's temporary, just let it heal and we can go back.

However, when explicitly asked if they felt the nature of their ostomy being permanent or temporary influenced their decision and ability to accept the surgery, some participants shared that they did not feel it had a conscious impact on their decision-making and were just desperate to feel better at the time of their decision to go through with ostomy surgery,

Many participants were told their ostomy would be temporary when surgery was first presented to them but ultimately had to make it permanent at some point in the future. Making the ostomy permanent after participants had already been living and adjusting to life with an ostomy that was intended to be temporary, seemed to be a different nature of decision-making and acceptance than the initial surgery. Reflecting on making her ostomy permanent, Kimberly shared:

> …after like five years of adjusting to it and then… even thinking about potentially having to go back to like okay everywhere I go I need to identify where there was a washroom and do I wanna use the washroom in a public place and just that stress and thinking about the pain and the stomach cramps and not being able to eat what I wanna eat and cutting out foods that… I love because is it worth, like do I have to do this in my head like okay

> if I eat this one piece of cheese is it going to bother me for the next three weeks or you know, so it just it didn’t make sense to me to give up like the quality of life.

Kimberly’s account of her feelings towards making it permanent were similar to others in that it was a difficult decision to make but there were less factors to considered and less ‘downsides’ because they had already been living with and adjusting to life with an ostomy. There were also less unknowns to consider and participants were able to compare their life with an ostomy versus without to be able to make an informed decision.

Some participants also shared that even if their ostomy had been temporary, they would not have taken the opportunity to reverse it. Chloe shared:

> I just have a peace of mind at this point now with the ostomy and it’s, I don’t think I’d ever go back like if I had the option to have just like a rectum replacement or anything, I don’t think I would take it.

Another participant had the opportunity to get J Pouch surgery at the time of the interview and therefore could no longer live with an ostomy; although she did plan to try J Pouch surgery in the future, she shared that she was not in any rush to do so:

> …the surgeon did tell me at first, he was like I’m pretty sure it can be temporary but we’ll have to see during the surgery if it actually can be and knowing that I still… would rather have an ostomy than be living like this [laughter] I was like yeah like let’s do it and even now like I could have the second surgery in February because I was healthy enough… time had passed, whatever, but I’m just enjoying not feeling sick.

Another participant whose ostomy was permanent shared that she was grateful that it was originally presented to her that way because it forced her to accept it rather than keep her wondering when/if she would be able to reverse it: “if they told me like oh we are 99% sure it’s gonna be permanent but like there’s 1% possibility that maybe it could be temporary, I would have hung onto that 1% possibility that maybe it could be temporary” (Alexa).

**5.2.6 Accepting the Decision.** The trajectory of participants’ health care journey had similarities of their severe disease symptoms leading up to surgery. Typically, they experienced a period of resistance and reluctance to ostomy surgery either from themselves, their families, and/or their health care professionals and then their stories often lead to a memorable moment of acceptance when they knew they needed the surgery to become healthier. Many participants remembered and reflected on this significant moment in their health care journey. For example, Lily shared:

> I was willing to try everything… but… in a weird way when it finally came down to the point where it was basically a life-or-death situation for me… I just… I was upset but I kind of knew that the time was right, you know I could tell that this is the right thing for me and it’s going to be hard and it [laughter] you know it’s going to change my life forever but I almost felt like a sense of peace because I kind of… all the resistance and stuff that I had had before just kind of melted away because it was like the time was right… it’s hard to explain what the feeling was but I just kind of knew, like as much as I don’t wanna do this I think you know this is what needs to happen.

Many participants shared similar testaments, that although they might have been resistant to the idea in the beginning, their symptoms had progressed and they were desperate to get better. Once they reached the decision that they wanted ostomy surgery, many shared that they were certain in their decision and then were either able to get the surgery shortly thereafter or were up against advocating for themselves and convincing others, such as healthcare professionals and/or family members.

**5.2.7 Stoma-specific Concerns and Fears.** When reflecting on the decision-making process, many participants shared that their fears leading up to getting their ostomy were related to the unknowns. In relation to the lack of education previously described, many participants had not heard of ostomy surgery prior to it being presented to them and therefore had a lot of questions about what living with an ostomy and the surgery itself would mean for them. When asking about the moment ostomy surgery was discussed with participants, Lindsay shared "when I was first diagnosed they brought it up… and I was against the idea because I'd never been sick before and I was overwhelmed and terrified." In addition to having a lot of questions and feeling overwhelmed at the idea of getting a surgery that participants had never heard of before, there was also a lot of sharing about the fear of the surgery itself. For example, when asked about any specific concerns or fears she had, Clara shared: "I don't really remember specifics, mostly just the surgery in general, like it's a big surgery you know you go in for like a good amount of time…" This was similarly expressed by other participants who had fears immediately prior to their surgery, with strong memories of medical equipment in the operating room.

Other specific concerns were related to odour, body image and appearance. Specifically, some participants expressed concerns around whether the ostomy would elicit an unpleasant scent. Lindsay shared, "I remember having a list of questions and one of them was like, I was really worried about the smell and if other people would be able to notice but like a lot of my questions weren't really medical related, it was more to do with my appearance and how it would change." Another participant shared that she asked her mom to buy her baggy t-shirts prior to surgery in anticipation of needing to conceal it. Many participants shared similar fears about how they would be able to hide their ostomy after surgery and if they would have to change their clothing choices to accommodate for this. Alexa shared:

> …all the physical part for me was hard like, I’m not someone who’s particularly… looking after like how I look or anything, it’s not like, but still I was like uh I don’t know like what’s gonna change for my pants, what’s gonna change for what I wear, what is… like everybody’s gonna see it, everybody’s gonna know all the time or like it was like those fears.

Another participant expressed a great deal of concern in relation to body image and dating, stating

> I want my own family one day and so my whole thing was like who’s gonna wanna even like date me, like I have a bag of poop taped to my side and so I went through a very dark period of time for a few months. (Chloe)

Similarly, another participant expressed her fears around intimacy and shared that she confided in another young adult woman living with an ostomy to discuss this concern. During this conversation she was told that “they so don’t care, once you’re naked they don’t care”, which she shared helped her with this fear prior to her own surgery.

## 5.3 Adjustment Phase

Participants had lived with their ostomy for varying lengths of time, from four months to eight years, and all of them described a memorable time period of having to adjust and get used to life with an ostomy. Some participants described being in survival mode when they were sick leading up to surgery and that their decision to get an ostomy to end their suffering did not set in until after they got their ostomy and started feeling better, which made for a challenging adjustment phase. Lily shared, “that’s when I truly felt like I hit rock bottom you know, some people say that they hit rock bottom before the surgery and things like that but I think for me it was afterwards.” Two participants shared that they had to wear gloves when first dealing with their stoma because it grossed them out, “I cried a lot and I asked for gloves, I wasn’t gonna touch it… the first change” (Lindsay). Another participant talked about looking in the mirror for the first time after the surgery as a memorable moment for them,

> …it was alarming to look in the mirror the first time I like showered after cuz I had all that like medical tape on my stomach and like blood and scars and just… strange, like just different and it felt… yeah just a little weird, I wouldn’t say it was horrible and I wasn’t like scared cause I knew it was coming.’ Later she went on to say, ‘it was just different so like sometimes I still think about it that like my body just like looks different now than it like ever has… so sometimes it’s just like a little I don’t know not alarming but a little bit more conscious of it, I guess. (Breanna)

On the other hand, one participant described being fascinated with her stoma after surgery and thinking it was “awesome” when she looked at it for the first time. She also shared “I remember like immediately after surgery I was like in this high, which I’m pretty sure was the anesthesia but I was like oh my god my life is going to be so much better” (Clara). Regardless of how participants felt about it, looking at their stoma and doing their first bag change were memorable moments for most participants.

Some participants also described a time period of trying to find an appliance that worked for them:

> I think it took me a while to find a system like a bag and flange system that worked for me and worked for my lifestyle so I was using the open-ended ones that you empty out into the toilet and I’m pretty small so those big bag like they were… quite big.

She later shared,

> I switched to like a smaller bag… a closed system so that I just throw it out when it's full and that worked a lot better for me just in terms of being able to wear the clothes I wanted to wear and it not taking up my whole pelvic [area] and coming down my leg and all of that and just like, it fit my lifestyle better. (Kimberly)

Similarly, other participants shared this same need to find an appliance that worked for them and being able to adjust to their ostomy better once they had an appliance that fit their lifestyle. While ostomy nurses typically help with finding appropriate appliances, participants had varying access to such nurses and therefore finding an appliance that suited them was more difficult for certain participants and typically something that was done in a trial-and-error approach after leaving the hospital.

Participants talked about being less bothered by aspects of living with an ostomy over time. For example, Lily talked about leaks and how they bothered her less as she got more used to living with her ostomy:

> …if I get a leak in the middle of the night you know I'm a little perturbed… but you know, I just kind of take care of it and I move on… because in the beginning it kind of, every time I would get a leak in the middle of the night or something it would spiral into all of these thoughts of, why is this happening to me, I hate this so much, why can't I just go back to the way that I was [laughter]… but I definitely, I don't really feel that much anymore… which kind of tells me that I've adapted to… you know just kind of this new way of life and everything.

Clothing choices were noted by many participants when discussing the adjustment phase and many shared that it took them some time to feel comfortable wearing certain clothes after their surgery. Breanna shared,

> I think at first like the first maybe month or two after um I was scared to wear certain clothes like leggings specifically, I was like it's gonna get squished [laughter] it's not gonna be good.

In relation to this, Heather similarly shared that it took some adjusting for her to feel comfortable in certain clothing, but that adjustment was not linear and went up and down based on how she was feeling overall:

> I feel like I definitely got more confident sort of in my like clothing choices and I did sort of be a little more open about talking about it but I sort of feel like… my body image was sort of up and down, I feel like depending on how I was feeling too like I feel like if my disease was better you know then maybe I felt a little better about my ostomy I think, cause it wasn't filling up as fast either and then when I'm sicker and it's filling up really fast I feel like my body image isn't the best.

Body image and appearance was mentioned by many participants when discussing the adjustment phase, as it took some time for participants to get comfortable with the look and the feeling of the bag attached to their stomach. Breanna shared:

> …right after surgery it's like a lot more swollen too so I was always like, I don't know, aware of it and also just like now I don't really even notice like feeling it on my body but like right after I would always just like feel the adhesive and like feel the weight of it I guess and it was just kind of off putting maybe sometimes just to like always have something attached to my body.

Getting an ostomy was considered a significant change to the body and it took some time for participants to get used to the feeling of the adhesive on their skin, the bag attached to their abdomen and the clothing that they felt comfortable wearing. This was all part of the adjustment phase and such concerns tended to go away as participants got used to their new body.

## 5.4 Living with an Ostomy

Participants ranged on a variety of factors regarding how they felt about their day-to-day life now that they had an ostomy and now that they had time to adapt and work through those initial, raw emotions and adjustments. More specifically, participants varied in terms of whether they disclosed that they had an ostomy to others, in the challenges they experienced, their relationships, and their quality of life.

**5.4.1 Disclosure.** Many participants described disclosure of their ostomy as somewhat of a journey to reaching comfortability. Some participants had their ostomy for many years and described having originally been secretive about their ostomy, not disclosing it to anyone aside from a short list of close family and friends. Lindsay shared an important moment prior to surgery where she decided she would try to keep it hidden in the beginning:

> I was given a magazine prior to surgery from I don't know… where they had gotten it from but it was all about how to hide your ostomy and who to keep it a secret from and when to tell people and like don't tell people if you don't want to and it was just so heavily focused on isolating your ostomy and it made me, like, I was going into this experience I was like alright I'm gonna go under this big thing but I can never talk to anyone about it.

She later shared that she got a lot of support from family and friends, and she no longer cared about how people reacted to her ostomy, which allowed her to become more open about it in her personal life and on social media. After living with her ostomy for so long, she shared that she is now completely open about her ostomy and comfortable talking about it with others. Many participants shared a similar trajectory of wanting to keep it hidden initially after surgery but eventually letting those ideas go and opening up about it once they felt more comfortable. Participants also shared that sometimes they would assess the person that they were considering disclosing their ostomy to to try to get a sense of whether the person was a safe, non-judgmental person to share this information with and therefore their comfortability with disclosing changed based on the person and the situation:

> I feel like I can kind of tell the kind of person who would be able to understand and that's generally I think has to do with the people I surround myself with… as I get older I have friends who I know are good people, it's not like we're in high school anymore and you're embarrassed about stuff so I'm generally okay with disclosing it with people. (Chloe)

Another participant who had more recently undergone ostomy surgery shared that she was afraid of judgment and similarly expressed having to assess the person before deciding whether or not she felt comfortable telling them that she had an ostomy:

> I don't really care but at the same if I feel like someone's gonna be super judgmental, I don't really think I'm ready for them to say anything to me so I kind of refrain I guess for the most part. (Clara)

Participants shared that some of their hesitation in sharing stemmed from the idea that other people would not understand the circumstances that led them to their ostomy and would not understand that their life had gotten better because of it. Breanna spoke to this by saying: "yeah I accepted it and I was okay with it but I was just kinda like how do I explain this to other people, the people who don't get it that really it made my life that much better." In other words, participants were worried about telling people who did not know them when they were sick because they might not understand the severity of the illness and how much their ostomy had helped them because they had not lived through it.

Some participants who were open about their surgery said that they wanted people to know about their ostomy and ask questions, as they felt this was important for breaking down the existing stigma. Kimberly talked about being very open about her ostomy and stated, “I would rather people ask me questions and actually get an educated response than make assumptions and I think that’s how stigma is propagated.”

Still others were very private about their diagnosis and ostomy and wanted to maintain a sense of normalcy with their peers. However, the participant who shared this experience of disclosure also shared that it created an internal conflict within herself because she felt like she was hiding a huge piece of who she was:

> …it’s really hard for me to even tell new people that I meet to be friends with about it… and if I don’t, I kind of feel like I’m hiding it and I’m hiding a major part of my life… so I think it’s kind of made me… more hesitant to like put myself out there to make new friends and you know hang out with people and stuff like that. (Lily)

When explaining her reasoning for not wanting to disclose her ostomy to new people, Lily also shared:

> I’d like them to know but I don’t want them to treat me differently after they find out… I don’t want them to worry about me, thinking I won’t be able to keep up or go to the pool with them or anything like that… so that’s kind of why I choose with friends just to kind of keep it concealed and coworkers and things like that because I don’t want them to view me differently… even if it’s not negative.

As depicted above, there was a wide range of comfortability with disclosure for participants. Some were completely open about it, some assessed the situation before deciding whether they were comfortable, and others tended to keep it more hidden. For those who were comfortable with sharing at the point of these interviews, many of them had gone through a period of time after surgery where they did not feel as comfortable and had to go through an adjustment phase before they reached this point of openness and willingness to share.

**5.4.2 Relationships.** One area where disclosure became more complicated was in relation to intimate relationships. Intimate relationships were an important topic of discussion for all participants, with many single participants expressing fear around dating and intimacy with their ostomy or participants in a relationship talking about how their relationship had changed or stayed the same since surgery and how important the support of their partner had been throughout their healthcare journey. Participants ranged from never having an intimate relationship to being married and having been with their partner for a number of years, which meant that participants shared a variety of different experiences regarding the navigation of such relationships with an ostomy. Those who had not yet had an intimate relationship expressed fear around dating and having to disclose the fact that they have an ostomy to a potential partner:

> I guess it is a concern like when I start talking to someone new I'm like oh I don't know if I wanna tell them or if I just want it to kind of like happen like do I tell them before? Do I tell them after? Do I just not even mention it and like how are they gonna take it? Are they gonna be weird about it? (Clara)

Other participants who were single expressed similar concerns, that they were unsure of when to bring it up once they start dating someone and they were worried about how the person might react. Dating seemed to add an extra layer of fear and hesitation when it came to disclosure compared to other relationships, such as family and friendships. For example, Breanna shared:

> …it's not like I'm gonna purposely hide it or guard it, I don't think there would be any particular people I would guard it from other than like dating, that's not something I've dipped my toes into for a little while [laughter].

For those who had tried dating with their ostomy, many of those participants shared positive experiences, with their partner being more accepting than they had anticipated. Heather reflected on when she first started dating her husband and shared how accepting he had been of her ostomy:

> …he was very understanding about it and just like oh that's cool, just didn't care, he's always treated me just like a normal person… he always pushes me and for mental and physical limits, even though I don't want to but that's why he does that [laughter] he's always just treated me like any other person so that's great.

Clara similarly shared a positive experience of disclosure while navigating the dating world, she shared "…we hung out a bit and I told him about it and I showed him and then he was really… like good about it so I was like okay nice…" This was a common theme for participants who had to disclose their ostomy to someone they were dating, with most partners being supportive and kind and/or simply asking questions to get a better understanding of what an ostomy was because they too had never heard of one before. Two participants shared that their bag had leaked the first time they were intimate and that their partner had been supportive and understanding in this situation as well:

> When I lost my virginity my bag leaked… all over… so bad… and he was great, like helped me clean up… now [he's] my fiancé, he's incredible if my bag ever leaks… I'll

> have a shower and I come back and like the sheets are completely changed on the bed and he just doesn't see it as anything abnormal so it's never really been a huge barrier for intimacy.

Other participants were already in a relationship when they had to undergo ostomy surgery. These participants similarly received acceptance from their partners and additionally expressed that their partners provided them with a great deal of support throughout the decision-making process and throughout their surgery recovery. Alexa shared that when she was going through the decision-making process for ostomy surgery, her partner had been supportive and helped to alleviate some of her fears and concerns:

> I was also really afraid for my boyfriend at the time because I was like oh my god you're gonna think I'm so ugly you're not gonna like me anymore… I remember just breaking down… and crying and saying all of those things and he had the best answer in the world, like it sounds mean but it's not mean but he just looked at me and he was like… are you stupid? I was like what? Like don't attack me right now… and he was like but this makes no sense, why are you afraid of this? I don't care, why do you even think about that, I was like well… because those are my fears and he was like well yeah but they're all in your head like I'm not going anywhere it's okay.

Other participants who were in relationships during the decision-making process shared similar responses from their partners, where their partner had encouraged them to get the surgery in hopes that it would make them feel better.

When asked about intimacy specifically, participants shared that their ostomy was not a barrier. However, participants did mention that they likely navigated the dating and intimacy world differently than their friends because of their ostomy:

> I definitely think like where some of my friends in university would bring home people after the bar and things like that like I definitely didn’t do that cause I was like this is not something I wanna deal with [laughter] as like a one night type of thing. (Kimberly)

In relation to the challenges that the ostomy brought to actual acts of intimacy, one participant shared that it took away the spontaneity of being intimate but other than that it had no impact: “…of course it’s gonna kind of cut out the spontaneity… of intimacy because well… we’re on the sofa, we’re starting to cuddle and I’m like well I have to empty my bag first” (Alexa). Another participant shared that her lower sex drive and fatigue were the only factors that impacted intimacy with her partner. Aside from these challenges mentioned, participants shared that their ostomy itself did not have an impact, it had just become part of their relationship and was easy to ignore when being intimate. Overall, most of the impact on intimate relationships was around fear of disclosure and acceptance from their partner. Most participants who had tried dating or who were in relationships either before undergoing ostomy surgery or after, received understanding and support from their partners. In general, participants shared that their partners actually cared a lot less about their ostomy than they had anticipated or than they did themselves.

**5.4.3 Friendships.** While friendships were less of a concern than intimate relationships, participants did still struggle with when and who they could disclose to. Chloe shared that there were only certain friends that she felt comfortable disclosing her ostomy to:

> There were some friends that I could tell… because they had come to visit me in the hospital, I had been hospitalized for… really most of the school year… so they knew like kind of what was happening so I felt comfortable telling them… but everyone else, it really, I would not disclose it.

Another participant shared that her ostomy had prevented her from putting herself out there and meeting new people:

> …it's been tough navigating it and I think, I can definitely say that… it has affected my willingness to kind of put myself out there and maybe get to know people and not even, not even just on like a romantic relationship basis, I think it's affected my friendships as well. (Lily)

Similarly, for participants who got their ostomy at a younger age, they did note that their high school peers were more judgmental and non-supportive and labeled them as the 'sick girl' but that later they were able to find a lot of support in the friendships they made in university.

One participant did share that it was challenging to see the difference between herself and her friends in terms of their energy and the foods they were able to eat:

> …growing up I started seeing differences with my friends and the level of energy when I saw they could eat whatever they want, they could have coffee every morning and I was like really you can drink that thing? It just wrecks me for my day… it was like all of those things that I, like it took me maybe four years I would say to really grasp and understand that there were gonna be differences, that there were gonna be… challenges. (Alexa)

Similarly, other participants shared that their disease and their ostomy set them apart from their friends even when they felt supported by their friends. Some participants felt apprehensive about being the only young person they knew who had an ostomy and that it made them different. Overall, participants tended to have found friendship support but had limited their circle in terms of who they felt comfortable disclosing to and how willing they were to put themselves out there due to fears around disclosure and their energy level and physical ableness to do the same things as their friends.

**5.4.4 Family.** Family was an important factor for participants, with many of them sharing that usually one or more of their parental figures were highly involved in the decision-making process due to how old they were when they had ostomy surgery. Some participants were minors when they had their surgery and therefore had to have parental involvement in the decision-making, which caused them to feel frustrated about how little they felt they were included in the process:

> I was often excluded from decisions, they would often just turn to my parents and I think that's common in children's hospitals and with minors, it is the parents making the decisions but you know, I tried to put up a fuss about everything and wanted to be part of the decision making but for this I really didn't have a choice. (Kimberly)

Similar testaments were shared by participants who had been minors when they got ostomy surgery; however, even those who were treated in adult care and therefore able to make their own decisions at the time of surgery shared that their parents had been very involved in the process. Many participants shared that their mother was at every appointment and was someone they leaned on for support and guidance with the decision. Family support ranged from very supportive with more than one participant having a parental figure who also had an ostomy to participants with parents who told them not to get an ostomy.

Two different participants shared that they had a parent with an ostomy; while both mentioned that they still found it difficult to relate to their parent and understand what their life would be like with an ostomy because of the age difference between themselves and their parents. However, these participants did mention that their parents were very supportive of the surgery. Other participants as well shared that their parents had been a huge support system for them throughout the process:

> …it was great to have someone to talk to about it, like yeah you can get angry but it's your body and it's the one you have and like… you kind of just have to deal with it… she was really… really there for me, so when I needed the surgery, she was like… really… present for me and she really, she really helped on that. (Alexa)

Alexa went on to share that she leaned on her mom for a great deal of emotional support, while her dad provided more practical support in advising her that the surgery would make her feel better physically and would be the right decision in that sense. Similarly, other participants shared that their mom had a been a huge emotional support.

The need for ostomy surgery was also challenging for some parents to hear. For example, when reflecting on first being told she needed ostomy surgery, Lily shared: "I was feeling terrible but I remember my parents being you know kind of upset because I mean it's a hard topic." Although she shared that they were greatly supportive, she also shared that the process elicited some challenging emotions for her and her family. This was similarly expressed by another participant who shared that her mom got emotional in the doctor's office when she was first told that ostomy surgery was needed.

There was also a participant who shared that her mom was not supportive and did not want her to get an ostomy, which had a lot of implications for her moving forward:

> …my mom's like 'no no you don't wanna be on a bag' and like she's always had that mentality of that, she's like 'you don't want… you don't want that, like we'll try medications and stuff but after I had learned what it was and I was like you know that's not that bad considering I'm literally dying. (Heather)

Throughout this narrative, Heather also shared that this caused her to suppress a lot of the challenging emotions that she experienced throughout the decision-making process, which caused her to experience a delay in feeling them and expressing them years later. She later shared:

> …my mom… she's come to support it cause she knows it's for the best but I don't think it's something that she could handle if she were in my position… I don't know, she still worries about my bag more than I do like she's more self-conscious about it than I am even though it's on me.

For the most part, however, most participants shared that their parents were supportive of ostomy surgery and wanted them to get healthy. Many participants shared that their parents, more commonly the mothers, were a huge source of emotional support for participants.

Overall, participants had varying experiences with their families and their level of support and involvement depending on how old they were at the time of their ostomy surgery and based on their parents' perception of ostomy surgery.

**5.4.5 Challenges.** With the ostomy came challenges for participants in their social life and in terms of their practicalities of managing their ostomy. In terms of participants social life, fighting the stigma against ostomies was an ongoing challenge. For Kimberly, she shared that the stigma motivated her to be open about it so that she could educate others:

> …the only way to crush that is to be open about it and you have to have people that are willing to be open about it… I've been open about it because I think it's important and that's the only way that people will feel comfortable to ask you questions as opposed to make assumptions so it's worked for me so far like people are open and a lot of people

> send people my way where they're like oh this person is thinking about surgery, do you mind talking to them about your experience?

Kimberly also shared that she did presentations and was featured in a documentary where she shared her experience of ostomy surgery and that this helped to spread awareness. Breanna similarly shared that there was a lack of education, which resulted in a lot of the stigma that she had experienced from others. For example, she shared "… the fact that they didn't know, that was education too… it's not like it was my fault but… in the run of things it's somebody's fault just not to educate people." This lack of education was prevalent among peers and some family members. As a result, many participants took it upon themselves to educate others and bring an awareness and understanding to their need for surgery.

Participants also shared a couple of ostomy-related challenges, such as proximity to washrooms and smell. One participant shared that even now that she had her ostomy, she still felt the need to be close to a washroom at all times and therefore did not get the sense of freedom she had been hoping for,

> I still feel like it's hard because I still feel like I have to be close to a bathroom and things like that… so it hasn't taken the… yeah I still sometimes feel like I don't have a lot of freedom like I can't just go somewhere, like I gotta make sure I've got all my supplies packed up. (Milla)

The need to be prepared and always make sure supplies were packed was similarly expressed by another participant, however she shared that it did not bother her because she also had to ensure she always had an epi pen on her and including ostomy supplies in her already existent medical supplies bag was not a big deal for her.

Another ostomy-related challenge was related to smell. One participant shared that she was worried about the smell of the ostomy bag and having to empty it at someone else’s house. Breanna shared, “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.” On a similar note, participants shared experiences of their bags leaking that was especially challenging when they first got their ostomy. For example. Chloe shared that the first time her bag leaked it was terrible and then as she got used to it, she adjusted to the fact that leaks are bound to happen. Lily similarly shared that her bag leaking was especially challenging for her when she first got her ostomy and made her question why she had to get the surgery in the first place, whereas now she feels frustrated but is more likely to simply deal with it and move on with her evening.

When specifically asked if participants experienced challenges related to their ostomy, many participants shared that the ostomy itself was not their biggest challenge. Rather, the fatigue associated with their disease was more limiting. For example. Kimberly shared:

> I still struggle with energy level and fatigue and those unfortunate types of symptoms and those are like the only residual symptoms that I have so that plays into it just in the sense of just like being able to use energy conservation and planning and all that type of things that as a younger teenager I didn’t really think about more but now that I’m working and… not working actively, like I’m in a management position now but when [my job required me to be moving all day]… like really hands on physical work and then coming home and being wiped and being able to manage kind of life and work um I think have been more of the complications and challenges I’ve seen.

Alexa similarly shared that even since her surgery she has struggled with her energy levels and being unable to complete tasks as a result. She described the guilt associated with her fatigue and feeling like her body should be able to do more than it could. In addition, she shared that hearing about what her friends were able to accomplish in a day was surprising for her because she was not able to do as much due to her low energy:

> …sometimes it's really surprising… my friend tells me stuff they did and I'm like and that was your whole day? And [they're] like yeah, I did this this this and this and I'm like that would have been like my whole week.

This challenge with energy levels was described primarily in the context of relationships and work and participants felt that it was a frustrating symptom that tended to linger despite the others going away since their ostomy surgery.

Another challenge that came up was the relationship participants had with food, which tended to stem from life before ostomy surgery and continued. Participants shared that they had developed a fear around food, which they had to manage alongside the judgment of others. For example, Lindsay shared

> I still struggle with that because people don't understand that sometimes I can eat and sometimes I cannot eat and I tell them no I can't eat right now, like if you ask me three more times I'm still not gonna be able to eat… so ya, it's still a pretty… umm food is frustrating for me.

Lindsay went on to share that she often did not have an appetite and would sometimes crave something specific that might not be healthy but it was important to eat it anyways because her body needed the calories but that caused other people to judge her food choices. Specifically, she shared

> …sometimes when we haven't eaten for a long time we crave something incredibly specific and our moms will go out and get us that incredibly specific thing because if we can eat it's a miracle and we should eat what we can you know.

Another participant shared that she similarly struggled with fears around food and the food choices she could make due to the conflicting advice of foods that are easy to digest versus foods that a healthy and nourishing:

> I needed to gain weight but I also wanted to keep my body healthy… you know because I had doctors saying like… eat all the milkshakes, you know eat all the hamburgers and I was like I don't want to fuel my body with those things you know when I gain weight, I want it to be health. (Lily)

Lily also shared that there was little support in rebuilding her relationship with food after she had developed a strong fear of food due to the learned association of eating and pain leading up to her surgery:

> I think another really big aspect that the doctors kind of leave you like… out [laughter] kind of on your own is… you know when I came home, so underweight from surgery and you know being sick and to adjust to an ostomy, I had a lot of issues with food, because for months before that, I equated eating with pain so… you know even once I came home and I realized that, okay eating doesn't hurt anymore, I struggled severely with just getting myself to you know, adapt to new foods, adopt new foods into my diet and understand that like you know, this isn't going to cause pain, this isn't going to cause a blockage.

Although these challenges related to stigma, fatigue, and relationship with food were not experienced by all participants, they were significant and impacted participants well-being and daily life.

**5.4.6 Quality of Life.** When describing their lives now, the majority of participants described having a significantly improved quality of life compared to prior to their ostomy surgery. For example, Clara shared: “I’m really glad that I went through with it… just every part of my life is better now.” Similar testaments were shared by other participants, and many pointed out that they began feeling better quickly after their surgery. Chloe stated, “…I had ostomy surgery and honestly within just a couple days, all those issues that I had, like my blood work that was looking terrible before came back all clear because I had my colon removed.” Others shared that they had been underweight prior to surgery and were able to establish a healthy weight after they got their ostomy, which resulted in them feeling better and regaining energy.

One participant shared that when she woke up from surgery the pain was gone, which had been a debilitating symptom for her and when it was gone, she experienced a sense of relief:

> …well when I woke up my stomach was finally not in pain, well okay it was in pain cause of the incision [laughter], but it was a different kind of pain so I was just so relieved in that sense.

Participants also shared how they did not know how unwell they were until they started to feel better after surgery. For example, Chloe shared:

> …things are umm… I mean they are just so much better, especially I think after I had the second surgery as well… it took a while to really turnaround from that but once it did I realized that, I didn’t realize how bad I was feeling until I didn’t feel like that anymore.

Regaining their health meant participants were able to start engaging in their social lives again and be involved in things they might have missed out on before. For example, 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 went on to share, "I'm just feeling so much better, like we went out on a 4k hike the other day and I wasn't dying [laughter] and I was not worried about like if there was a bathroom around, I was just enjoying the moment." Other participants similarly shared that they were able to go out a lot more after they got their ostomy because they were less concerned about being close to washroom, which they had to be vigilant about prior to surgery. Kimberly shared: "I think I feel less anxious going out and doing things now than I did pre-ostomy because I would actually like, as soon as I entered a space, would immediately look for the bathrooms."

Overall, participants expressed that their life became less restricted after ostomy surgery. They were able to gain weight, their pain had lessened or completely went away, and the majority of them felt less anxious about being within close proximity to a washroom. All of these factors allowed them to begin living their lives again and doing things they felt they were missing out on prior to surgery.

# Chapter Six: Results: Medical Encounters

## 6.1 Patient Experiences with Healthcare Professionals

Participants had a variety of healthcare professionals involved in their care throughout the process of having severe IBD, needing ostomy surgery, having the surgery, and adjusting/living with the ostomy. Participants shared a lot about their health care professionals in both positive and negative ways. The support, or lack thereof, impacted patients in not only their decision to get surgery but also in their adjustment to living with an ostomy, especially due to the respect and trust that some participants had for their health care professionals. For example, Breanna shared:

> …because it was him, I think I was okay with it so yeah it kinda depends on who the doctor was but the surgeons I respected more than the GIs in the sense that they've had experience doing this more than once and they've seen it more than once.

**6.1.1 Reluctance.** Some participants shared that their health care professionals were not upfront about them needing ostomy surgery to avoid their emotional response. For example, when reflecting on surgery first being proposed to her, Chloe shared:

> I was pretty emotional at the time… if I got news I didn't like I'd be very upset and they knew this so he was really dancing around the idea that I would have to have surgery.

For others, however, they wanted the surgery but experienced reluctance from their health care professionals. For example, Lindsay shared "I wanted the surgery but the doctors and professionals had also made it out to be like this life ending decision that I was making." Similarly, other participants shared that their healthcare professionals sought out other medications before being willing to move forward with ostomy surgery and one participant shared that her physician tried treating her for a fungal infection before wanting to move forward with ostomy surgery, in hopes that it would alleviate her symptoms:

> the surgeon scheduled the surgery but then they found a fungus in my intestine so then he was like okay maybe if we treat that and you might feel better in a couple months and then we can try a different biologic and then maybe it will work better if the fungus is gone but the whole process was gonna take like 6 months and I was like I don’t have time for that, I’m in school right now, I feel like crap I don’t wanna wait, I can’t do it so he was like okay like let’s just wait a few days on this anti-fungal medication [to] see if you get better, I’m like okay whatever so waited a few days, did not get better and then 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. (Clara)

While multiple participants expressed this similar reluctance from their health care professionals and having to advocate for surgery at some point throughout their healthcare journey, one participant shared that she was grateful for her healthcare professionals’ reluctance because it reassured her that ostomy surgery was the only option left:

> Something I don’t wish was different was probably the attempt to not have surgery, like every single time I got sick, I was like ‘just take it out of me, just get rid of it’… I wasn’t really aware of what I was saying when I was saying that but I said like is there an organ transplant? Can I just get a new colon? And… that, I’m glad they didn’t just revert to surgery um… not that it’s bad but I do definitely appreciate that I now have the feeling that I’ve exhausted all other options first, since this was the last option it feels like the best option. (Breanna)

Ostomy surgery being a last option or last resort was not uncommon and reluctance among healthcare professionals at some point throughout the disease process leading up to surgery often delayed the process significantly.

**6.1.2 Support.** Despite the reluctance from healthcare professionals that many participants struggled with, there was also a lot of support. Specifically, participants commonly expressed feeling supported by their nurses and ostomy nurses for those who had one as part of their healthcare team. For example, one participant shared that her ostomy nurse played a supportive role in her care throughout the entire process leading up to surgery, getting surgery and during the follow up care:

> They did have an ostomy nurse, yes and she was incredible… once I finally got in touch with her and like… I remember when she came and marked my stoma and all of that and how like surreal it was looking at the little tegaderm on my stomach but yeah she was a great support and was a continued support throughout my J Pouch problems and revisions and all of that stuff. (Lindsay).

While ostomy nurses were not always available to participants, the ones who were cared for by an ostomy nurse similarly shared how helpful it was to have them mark their stoma and show them appliances prior to surgery so that they felt better prepared and supported. Nurses in general were also described as playing a more supportive role in patients' care, compared to gastroenterologist and surgeons:

> I was lucky enough that I had amazing nurses that I still like, there is like those two nurses working with my doctor, I always see them, they're always like sending me emails and just asking how everything is going so it was them who like… took care of me and were more supportive around the emotional part of this, it was those nurses and like it felt… like after everything it felt better. (Alexa)

Participants also talked about the important relationship they had with their Gastroenterologist and how much of a difference it made to have one that they trusted and respected. One participant who was underage at the time of her ostomy surgery, shared that she felt supported by her Gastroenterologist because she trusted him and because he made an effort to speak directly to her about medical decisions, rather than just her parents:

> I really trusted my GI at the time, he sadly passed away since so I had to switch GIs but he was like very well known in the field and he was the first physician that like my parents would come to the appointments and they would ask questions and he would look at them and just ignore them and continue talking to me… my parents were pissed and like why won't he answer my questions? But as soon as I asked the question, he would answer it so he really wanted like me to be in control and I really appreciated that as someone who had been like ignored by the doctors previously. (Kimberly)

Participants expressed how important the support of their healthcare professionals was at multiple points throughout their disease journey, such as leading up to surgery, during their hospital stay, and during the recovery and adjustment phase. However, support varied for participants depending on their relationship with their healthcare team and the type of support they had access to (specifically whether they had access to an ostomy nurse). Participants tended to seek out more educational support from their Gastroenterologist and surgeon and more emotional support from their nurses and ostomy nurses.

## 6.2 Patients Ideas for Improvement

When asked to share any ideas for improving the process of getting an ostomy, participants shared a variety of ideas including, improving education, providing the opportunity to meet others with an ostomy, increasing representation and online support, and improving communication between healthcare professionals and patients.

**6.2.1 Education.** Education was one of the most talked about areas of improvement for participants. Many of these women expressed that there was a lack of education prior to surgery and that they knew little about ostomies before getting one themselves. They shared that they would have benefited from having more education prior to surgery as opposed to all the education occurring in the short time that they were in the hospital postoperatively or on their own at home after they were discharged:

> "I think more emphasis on the pre-education as opposed to trying to give the education afterwards when the surgery's already happened and you're in pain in the hospital and trying to get out of the hospital and go home cause 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're kind of on your own." (Kimberly)

Kimberly went on to share specific ways that education could be provided to patients prior to surgery, she suggested: "whether it's classes or workshops or web… anything, like an online resource where… whether it's kids or adults, there's something that you can click through to just… understand what's gonna happen and the implications." Another participant similarly shared that more education was needed prior to surgery, but she also noted that education specific to being a young adult would have been helpful. She shared that the information she was provided with was not relatable to her as a young adult woman. Specifically, when asked how the process could be improved, she shared:

> "…maybe the preparation beforehand and then… the information that I was provided afterwards you know, I mean I was given so many samples and items of literature and everything to read through and I had to watch these little videos on a tablet in the hospital and everything… but… those, 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, um because I was wondering about you know, can I wear my favourite jeans? Can I go swimming? Can I… are my friends going to accept me? Am I going to find a boyfriend? [laughter] things like, you know, that you worry about when you're 21 years old."

In addition to wanting more education around ostomies themselves and resources that would have been helpful for younger populations, participants also talked about complications coming up and them not knowing how to deal with them, again as a result of the lack of education. For example, Kimberly shared that she experienced severe skin issues and had not known what to expect in this regard. She shared that her and her family had to take it upon themselves to educate themselves and problem solve because they were not initially given the proper resources or education:

> "That is apparently another form of prolapse… we were not told any of this, 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 [laughter] so just like you know… terrifying things like that that could happen [laughter] that no one tells you about."

These experiences were common with participants, where they experienced complications after surgery that they had not been educated on. The educational window described by participants was in the short time leading up to surgery or during the short time after surgery where they were still in the hospital. It was also common for participants to receive little to no care after they left the hospital, meaning that they had to figure out most things on their own:

> “I had an ostomy nurse in the hospital, she just didn’t mention some of those things and then 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 stoma nurse care, which I was told different information in the hospital once I left so it was kind of, figure things out on my own.” (Breanna)

As participants described a desire to be better educated about ostomies leading up to surgery and during the adjustment phase, an idea for improvement that some participants had was to meet somebody else with an ostomy.

**6.2.2 Meeting Others with an Ostomy.** Two participants shared that they had a parent with an ostomy, who they were able to learn from and one participant shared that her nurse connected her with another person living with an ostomy prior to getting her own. All three of these participants shared that this helped them immensely and that a similar opportunity should be provided to all patients contemplating ostomy surgery. For example, Clara shared:

> “I feel like other people, having someone like my mom who have lived through it would be extremely helpful [laughter] umm just getting someone to talk to people who are debating it maybe who have had the surgery, who have lived through it who have had ulcerative colitis or Crohn’s or whatever… to talk to would be super helpful, like I was lucky enough to have it with my mom, I know that’s not the case for a lot of people.”

Clara continued to share that this would be meaningful because it would help patients understand the actual lived experience of their bodies changing from *‘being sick to being healthy’* and that this would be extremely beneficial for people considering surgery. She shared:

> "They tell you the risks, they tell you the benefits but they don't really speak much on, about comparison of being sick to healthy to like pros and cons and I don't know if I would have went through with it if I didn't have that side to it from my mom so… that's my only idea [laughter] I think I was pretty well off making that decision."

Another participant who had a parent with an ostomy shared the benefits of having somebody so close to her who had a lot of information but she also shared that as a result of his situation being different from her own at the time of surgery, she would have benefited from being able to connect to another young person with an ostomy who she could relate to.

Finally, the participant whose nurse connected her with somebody else with an ostomy shared that it helped her in her decision to get an ostomy and normalized it:

> "If I had that talk earlier maybe the decision would have been faster cause it really helped me to meet her, like I met her in a small café, not so far from my house and coincidentally not so far from her house, it was a place we were both comfortable and like… it was normal clothes and like normal things, no gown no nothing, just like.. and she was I think maybe, 4 years older than me, like not really much older than me and she was a girl like everything was good."

This participant suggested that having a bank of people ready to talk to patients contemplating ostomy surgery would be beneficial and help them reach the decision sooner.

**6.2.3 Representation and Online Support.** A couple of participants talked about the importance of representation of others with ostomies that they could relate to. They shared that the existing representation was typically older populations but wanted others to know that this can happen to anyone and wanted to see images that they could relate to in the media and in ostomy resources:

> "…and finding other people like me… you know, because the images and stuff and all the booklets were older people and so it's like navigating dating with an ostomy but it's like these two elderly people and I'm like well [laughter] you know dating in the 21st century is quite different um… [laughter] so I just wish that there was more kind of catered towards… where the state that I was at in my life.. you know as far as navigating all of that." (Lily)

Many participants shared how much social media had helped them in this regard, as they were able to see others in their 20s who had gotten an ostomy and who were sharing their story online. However, many of them shared that this was something that they had to seek out on their own. For example, Clara shared:

> "I think that is a good thing as well is just using social media in that way to kind of find communities, I didn't do that until after the surgery but I feel like it would have helped and maybe I would have made the decision earlier than I did if I had looked into that type of thing a little bit sooner."

She continued to share that it was "…just nice to see other people doing what you wanna do when you're sick, like going, living their life and enjoying and like who cares about their ostomy." It was evident that being able to look at these other people that these participants could relate to, who were living a better life with an ostomy than they were able to while they were sick, was helpful in normalizing it and showing them that it could improve their quality of life.

#### 6.2.4 Improving Communication Between Healthcare Professionals and Patients.

Finally, an idea for improvement was around communication between healthcare professionals and patients, with one participant noting that they received mixed signals from their healthcare team regarding whether an ostomy was necessary for her care. Specifically, she shared that one of her surgeons told her an ostomy was necessary, while the other one told her that she would be fine without it. The mixed signals from her healthcare team made it more challenging to reach this decision because she did not know if it was necessary and did not know if she was receiving accurate information.

The same participant shared that the involvement of multiple healthcare professionals made it difficult for her to know who to reach out to for different problems that arose and that more clarity around who to go to for specific issues would have been helpful. Similarly, regarding communication, two participants shared the challenges associated with being a minor during the contemplation phase of ostomy surgery and how they were not included in the process. One of these participants suggested that not excluding minors from this conversation would have improved the process for her.

# Chapter Seven: Healthcare Professional Perspectives

This section summarizes the interviews with health care professionals (HCPs) who care for patients with IBD for part of or all of their disease trajectory leading up to ostomy surgery. Seven health care professionals were interviewed, including three colorectal surgeons, two clinical IBD nurses, one nurse specialist in Wound, Ostomy and Continence (NSWOC), and one Gastroenterologist. These HCPs were asked questions around how they care for IBD patients, how and why they would recommend ostomy surgery and how they support patients through this process. This section will consist of the following themes drawn from the interviews with these HCP participants: decision to recommend surgery, presenting surgery, providing support, HCP perception of ostomy surgery, patient adjustment and quality of life after surgery, and desire to improve.

## 7.1 Decision to Recommend Surgery

**7.1.1 Last Resort.** Two HCPs shared that ostomy surgery was considered a last resort and that it was recommended to patients who had failed all other treatment options and were very unwell:

> I think it’s generally recommended when we’ve tried all medical treatments and patients have failed those treatments and where it… where it’s getting to a point where patients are too unwell to, even if there is another maybe medical option… they’re too unwell to give that a chance… you know, so we get to a point where patients haven’t been responding to the medication and they continue to go downhill and quality of life is just not very good and um it’s generally at that point that I think surgery comes into play. (Clinical IBD Nurse 1)

The Gastroenterologist from the same health centre shared that ostomy surgery was a last resort option: "…it really would be as a last resort… so as we're well aware, that is a fear umm that many patients… no I shouldn't say many, all patients have um to have that." Regarding when he would recommend ostomy surgery, he went on to share:

> It's when I feel there is no other safe medical option to treat a patient but yet they need to have some attention to their disease or um 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.

However, a different approach was shared by a Colorectal Surgeon (1), regarding when surgery is required and how participants decided which surgery would be most appropriate. She shared that she identifies the worst problem the patient is presenting and aims to tackle that first:

> In the setting of Crohn's is really targeted towards, what can I do that's going to address the problem that is bothering someone the most? Um or what is like the most urgent problem, so if we're addressing fistula symptoms for example, you know we can work down the line of well, can we divert and then are there still symptoms? Okay then maybe we need the proctectomy and then… so you can work down a more minimalistic sort of line.

This approach was less about the ostomy being a last resort and more about tackling the worst problem that was presented to the surgeon and choosing whichever surgery would best alleviate that problem or symptom.

**7.1.2 Considering Quality of Life.** The majority of HCPs described quality of life as an important consideration when recommending ostomy surgery in addition to the biomedical aspect. For example, when asked about when ostomy surgery would be recommended, one of the Colorectal Surgeons shared:

> …one part is, what surgery is needed to address the underlying disease process to say, control the fistula or leave the obstruction, remove the sick colon or whatever part… the second aspect about stoma versus no stoma is that it comes down to, can you reconstruct that person with a reasonable quality of life." (Colorectal Surgeon 1)

She went on to say, "…what can you actually do like what are you given to work with? And the other part of it is like what is… what do the patients want? What do they value?" On a similar note, another colorectal surgeon participant shared that when he is deciding to recommend ostomy surgery, it is important to compare their current situation with what their lifestyle might look like with a stoma and how/if it might be improved. Another Colorectal Surgeon (3) similarly shared that based on the patient's lifestyle, their decision to get an ostomy might differ. He shared a couple of different scenarios of where a patient's lifestyle impacted whether they wanted an ostomy:

> You know the example with the teacher, he's a music teacher and he does not want to have six bowel movements a day, he feels like if he's teaching… musical students then he can't come and go like that and so his perception is that with a stoma, which is how he lives right now, it would be easy for him to continue so you know that's an easy decision… I have had a long haul truck driver who goes, you know I can manage the stoma in the cab but I can't go to the bathroom easily and the many circumstances that

> they've had, if they already have a partner in their life then they are more apt to make that choice or it makes that choice easier but not always.

This concept of quality of life and how it can look different for different patients, came up as a significant factor for these Colorectal Surgeon as well as the NSWOC when considering ostomy surgery for their patients.

**7.1.3 Difference Between Crohn's Disease and Ulcerative Colitis.** HCPs were asked if there was a difference in recommending ostomy surgery for patients diagnosed with CD versus those with UC. Many HCPs shared that there was a significant difference for these populations based on how the disease presents, what the ostomy would mean for the patient, and whether there is a possibility for them to get the ostomy reversed in the future (i.e., whether it is temporary or not):

> I think with Crohn's… overall, because in the back of their mind... we always know that surgery is usually not curative for Crohn's in the same way that we think about it for ulcerative colitis… so the surgery for… in the setting of Crohn's is really targeted towards, what can I do that's going to address the problem that is bothering someone the most. (Colorectal Surgeon 1)

This Colorectal Surgeon went on to share considerations for ostomy surgery in ulcerative colitis patients:

> I think with ulcerative colitis, part of it is if they come to the point where they need surgery, you're pretty much committed to doing the big operation by taking out the entire colon and rectum, and then we're talking about whether or not to reconstruct… there's still a risk with that because some people have overlap colitis… so yeah the surgical approach is a little bit different because if someone has Crohns-colitis but it doesn't affect

> the entire colon, we may be a bit more selective about what operation we do and then perhaps that means more reconstruction options or more… you know just kind of different… different piping is possible. (Colorectal Surgeon 1)

When asked this same question regarding the difference between CD and UC patients when recommending surgery, the Gastroenterologist shared a similar testament that there are many differences:

> Yes in many regards, because uh… though it is still a fear for patients who have ulcerative colitis, the expected results, if they needed surgery would be ultimately to have a J pelvic pouch… it wouldn't be a permanent ostomy… so the threshold to perhaps accept that particular new anatomy would be less than the threshold for someone who… would require a permanent ostomy.

Other HCPs similarly agreed that there were differences between these two populations because of what the surgery meant for patients (i.e., whether it was 'curative' or not) and whether it would be temporary or permanent differed, making the recommendations and decision-making process different between the two groups.

## 7.2 Presenting Surgery

HCPs differed in how they presented surgery to patients once they knew that it was necessary. Some HCPs framed surgery as a last resort after many failed medications (as previously touched on), while others presented it as a treatment option rather than a failure. Additionally, some HCPs framed surgery around what their goals were in treating the patient, others had discussions about quality of life, and still others were more direct in their approach. However, regardless of how they presented surgery, each participant had a reason for their approach, with good intention in caring for the patient.

**7.2.1 Framing Surgery.** One of the colorectal surgeons shared that she tried to be goal-focused when presenting ostomy surgery to her patients:

> I think what I try to do to frame it is if someone is so sick that they actually need to be in hospital because they have horrible colitis or they have a horrible obstruction or they have something that's like an emergency, I try to frame it as you know the goal of what we're going to do or what I'm going to do is to get them well… and part of getting them well is to you know… the safest thing is to take out the bad part and if it's… 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, um medical therapy is not working… this is the operation that we need to do and part of the operation and part of getting well again is potentially to have that ostomy and depending on the context, that may be temporary or end up being permanent. (Colorectal Surgeon 1)

She went on to share:

> I think that's mentally how I approach it is that I'm gonna do what is going to get you safely over this because if you don't do it there are bunch of other bad things that could happen, the least of which is having an ostomy, maybe temporarily.

Another solorectal surgeon shared that it is important for him to emphasize that the recommendation for ostomy surgery is not a failure on their part but an effective treatment option that could help them feel better:

> …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've embarking on a new treatment and many of them will do better than they've done for months or years with this treatment. (Colorectal Surgeon 3)

On a similar note, he went on to share that ostomy surgery is typically recommended in a negative way and that he does his best to approach it in a different way and break down these beliefs in his recommendations for surgery:

> …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… (Colorectal Surgeon 3)

On the other hand, the Gastroenterologist took a different approach by reassuring patients that they had exhausted and failed all other treatment options, which is why ostomy surgery was recommended. He shared that this was reassuring for patients and did not let them ask themselves 'what if' and allowed them to accept surgery better because it let them know that they did not have any other options left. Therefore, he never brought up ostomy surgery early in treatment, but thought it was best to wait until surgery was absolutely necessary. He also shared that it was important to be direct in sharing bad news so that patients had clarity:

> The way we're taught in medicine, or at least 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 that although it sounds like a harsh way to do it… and obviously in a much more unfortunately common way as a Gastroentrologist, we have to deliver the news that a patient has cancer but we… and I, not that I would by any means associate this with cancer but it's bad news, it's not what a

> patient wants to hear… so what we were taught is that patients can deal with certainty as opposed to waffle so the way I present it is… and is also why I'm so blessed to have a nurse who can then kinda back me up and provide a little bit more compassion cause I imagine for some patients it would almost seem harsh that I'm bringing it up and I'm not doing it to be mean but doing it so that there's clarity in what we're saying and what we were told is that although it may initially be hard for them, it actually allows patients to deal with it better." (Gastroenterologist)

He went on to share that he wants patients to know that the recommendation for ostomy surgery is without a doubt the best option for them and that being direct in his approach gives patients this clarity.

Finally, both types of nurses shared that it was not necessarily within their roles to present ostomy surgery to patients; rather, they acted in more of a supportive role to patients after surgery had already been presented. However, the NSWOC did share that she would sometimes ask patients if they had every considered ostomy surgery in some circumstances but that she needed to be careful to not overstep and to respect the surgeon's and Gastroenterologist's boundaries.

**7.2.2 Patients' Decision.** Ultimately, however, the recurring theme throughout the discussion of when and how to present ostomy surgery was that it was the patient's choice. HCPs shared that it was their role to present patients with the treatment option that they felt would be best, but ultimately it was up to the patient in terms of whether they went through with it. For example, a colorectal surgeon shared:

> You can probably tell, you know you're probably gonna keep having issues but you're not likely to end up on death's door… you're probably gonna limp along for a long time

> and at some point maybe someone will be like okay that's enough… and until that happens like I can't make that decision, they have to do it on their own. (Colorectal Surgeon 1)

One of the clinical IBD nurses similarly shared that there are some patients who should have ostomy surgery but they continue suffering without it; there is not much they can do as a healthcare professional in this situation, because again it is ultimately the patient's choice: "I can think of a couple of patients in our practice that truly should have had the surgery but they… they are… and understandably, they're terrified of it." (Clinical IBD Nurse 1)

Many participants noted that it was a personal decision of the patient's that was based on their individual lifestyle choices and what was most important to them. Therefore, each patient had to weigh their own pros and cons of surgery. However, HCPs noted that many patients who reached this stage of illness where they had been recommended to get surgery, eventually decided that having an ostomy would improve their quality of life:

> … they will have the pros and cons right… and generally the pros outweigh the cons… they might have a list of cons, the pros list might be shorter… but the pro list will win. (NSWOC)

HCPs agreed that this decision was a difficult and highly personal decision for patients and that each considered different factors based on their disease, symptoms, potential outcomes, and lifestyle factors.

**7.2.3 Time.** HCPs described the importance of time and how time was a luxury when it came to recommendations around ostomy surgery. Time spent with the disease, where patients might have the opportunity to learn about the possibility of ostomy surgery was one factor and time between the recommendation for ostomy surgery and when it might become required was another factor. For example, in relation to time spent living with the disease, one Colorectal Surgeon shared:

> I guess they have would have had a longer um I use the word time… with the disease and having thought about it more than someone who suddenly gets the diagnosis of cancer and you have to have it or trauma then you're stuck with it right. (Colorectal Surgeon 2)

The time between the recommendation for surgery and undergoing the surgery marks an opportunity for education and support that not all patients are able to receive. The NSWOC talked about the limitations of time as a nurse trying to teach patients about ostomies in the hospital. She shared that during her time in acute care, many patients did not have much time to make the decision to get ostomy surgery, despite it being a big medical decision:

> When you're in the hospital, it's… you've often been in the hospital, you've been treated likely with IV medications, you know your steroids and etc… and um you know you're… you often end up having surgery with only a couple of days notice or whatever and having to make that decision… I mean in many cases it's a lifelong decision right…

When patients did decide to undergo surgery, she also shared the experience of not having enough time to adequately teach and support those patients:

> I have 30 minutes to teach you, you know that's what I'm saying in my head right but I mean I try to get [support] in where I can, you know… and unfortunately today… um they're so pushed for beds and times in acute care that you know people are often pushed out… um without the amount of teaching that they would get say 10 years ago. (NSWOC)

This NSWOC now works in the community and shared that she is able to spend much more time with patients, teaching and supporting them through the learning process and adjustment phase of ostomy surgery: "…in private practice I actually see more clients and talk with them because I have more time… I make my time and I can sit with them for quite a length of time and they can… get a good sense of where they should go." However, it was noted by many HCPs that time is a luxury and often this process was rushed, giving little time for education and support.

## 7.3 Providing Support

Among this sample, it was common for nurses (clinical IBD nurses and NSWOC) to act in a more compassionate and supportive role for patients, while Gastroenterologists and Colorectal Surgeons provided more of the educational support. However, there were some exceptions where Colorectal Surgeons shared that they tried to provide more than just educational support to their patients or had the desire to learn more in this area.

Before sharing the educational support providing by HCP participants, it is important to note that many of them felt that their patients were already educated by a different health care professional before reaching their care. Specifically, in the Clinical IBD Nurses experience, many IBD patients learned about ostomies at the point of their diagnosis, knowing that it could be a possibility in their future:

> 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 and again I can… I have photos or pictures that I can show to them… um 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… and then they get more of the details I guess from the surgeon. (Clinical IBD Nurse)

From a Colorectal Surgeon's perspective, however, patients have already received the information and been educated about ostomies before reaching their care:

> Well I think most of the time they are aware of it before they get to me… cause I'm… 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? Etc. (Colorectal Surgeon 2)

A different approach shared by the NSWOC was to ask patients how much they knew and what they understood about ostomies before educating them so that she could teach them based on their individual knowledge base. She shared that patients were varied in how much they understood by the time they reached her care:

> Okay so my first question to the patient is, you know I've received your referral from ____ and um 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… right… but um again, like I say with the younger set, cause that's what we're really talking about, they know exactly what they're having done cause they go on and google that and they're telling me, 'no I think he's doing…'… but yes… so I work with that…

Therefore, these HCPs varied in terms of their assumptions about how much education patients had received before reaching their care, with many of them believing that the patient had been educated by a different health care professional.

**7.3.1 Educational Support.** Participants were asked how they support patients through the process of recommending ostomy surgery to patients and having them in their care as they went through with it. As previously mentioned, some participants believed that education had already been provided by a different healthcare professional, however others shared that they provided support to patients in the form of education. For example, when asked how a Colorectal

Surgeon would provide support to a patient going through this process, one responded: "Uh just information… talking to them, providing written information um there are support groups as well with other patients um and the stoma nurses are well versed in care of ostomies" (Colorectal Surgeon 2). Another Colorectal Surgeon shared, "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" (Colorectal Surgeon 1). Another Colorectal Surgeon shared that his entire team worked together to provide patients with an adequate level of education and support leading up to ostomy surgery:

> I'm fortunate to work in a really good team and in that sort of one I think that I do a fairly extensive counselling discussion and often over multiple appointments so it's not a one time discussion um I encourage people to have a little booklet when they get here so they can write down questions, sometimes in the middle of the night when they wake up, because it's easy to forget when you're in the room with us so um… but we also have an awesome ostomy nurse team who have really worked with hundreds and hundreds of people with stomas and are really sensitive to it and are engaged with ostomy magazines and online resources and so you know I can't be everything for the patients and so I'm grateful that I have these teammates who can help with that information. (Colorectal Surgeon 3)

In terms of educational support, the NSWOC shared her perspective of providing a more extensive level of education to patients:

> I really uh I go through, you know I have a thing that I go through, a booklet that we look at the body systems and this is the type of ostomy you'll have and this is where it will sit and… and then I go into the pouches and uh samples and then I put stoma markings on

> them you know um I sit people up, stand up, lay down, and it has to be in a place where they can see it and take of it themselves and foster independence… and something that's low profile… that's a big thing uh especially with women, I really work hard on low profile appliances… (NSWOC)

Overall, for many of the HCPs, they felt most comfortable providing educational support to patients and worked as a team to provide adequate information. However, in addition to education, the importance of social and emotional support was also discussed.

**7.3.2 Social and Emotional Support.** Many participants shared that they were not able to provide adequate social and emotional support to their patients. For example, one Colorectal Surgeon identified the need for social support but shared that she was not necessarily trained in this area:

> I think different people need different things but I don't think I do a very good job of more of that social support, like I think if someone has a specific, like my bag falls off, I can… that's something that I can… I can send someone to do something about um if they say I want to get rid of it, that's something that's like tangible but I think more of the, 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. (Colorectal Surgeon 1)

While not explicitly saying it, another Colorectal Surgeon similarly suggested a need for more social and emotional support, while sharing that this was typically where the stoma nurse stepped in:

> …dealing with a stoma is different, just an education thing and there's no question it takes adjusting, both from acceptance of the things you have to do everyday to look after

> it… it may be an acceptance of disfigurement… um you know, it's not natural… um yeah… and then there's the support that you get from the stoma nurses and I think they are [a] real value obviously to patients who have stomas. (Colorectal Surgeon 2)

In regard to emotional support, the Gastroenterologist shared this was not something in his area of expertise, rather this was more part of his nurse's role: "I'm so blessed to have a nurse who can then kinda back me up and provide a little bit more of that compassion cause I imagine for some patients it would almost seem harsh." He later shared that it was difficult for patients to have a conversation once they became emotional, which is why he would typically end the conversation at this point. Regarding patients' response to needing ostomy surgery, he shared: "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." This Gastroenterologist also shared that the clarity he provides during his discussions with patients regarding ostomy surgery, meant that few of them needed additional support and preferred to move on with the surgery:

> Like I said, what usually happens is although we always say we're there and there are some patients that come back and ask questions but… they're ready and they've internalized it and they actually don't wanna talk… it's not that they don't wanna talk, it's that… I shouldn't say they don't wanna, they don't feel like there's any need to talk to us anymore, they're moved on… it actually makes me feel satisfied cause it makes me feel like we delivered something in a way that they really understood.

Therefore, from this Gastroenterologist's perspective, after the decision was made and the patient received the clarity that they needed, few patients returned to seek emotional support.

Despite many of the Colorectal Surgeons and the Gastroenterologist sharing that they did not feel equipped to provide this emotional and social support, there was an exception where one Colorectal Surgeon shared that he did try to engage in these types of conversations with his patients in addition to directing them to other meaningful sources of support:

> Often I try to engage and 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, I haven't had to do that you know and I can share with them experiences that 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. (Colorectal Surgeon 3)

From the perspectives of the NSWOC and the Clinical IBD Nurses, who are leaned on for more of this social and emotional support, they agreed that while counselling was not officially part of their role, they did provide this type of support to patients. The NSWOC shared that she took this role seriously and was mindful of how she responded to patients' ostomies, knowing that it would impact their acceptance and their view of themselves:

> I mean, we're not counsellors right… the only counselling courses we've had is basically what we've done through the years I guess with communication skills and the degree program there's some and then our course itself… but um they do rely on us and when it's… it's almost like when they look at their spouse the first time… the first time we see their ostomy, they look at us because they're seeing their ostomy through our eyes.

The Clinical IBD Nurse also shared that she played a supportive role in the patient's journey but at the same time felt that she did not have the answers to more of the educational side of ostomies:

> I mean we're there to support patients but I do um… I don't necessarily feel like as an IBD Nurse, we're specialized in that… um and maybe we could do a little bit more. (Clinical IBD Nurse 1)

Overall, the more supportive role was typically taken on by the nurses, while many of the Colorectal Surgeons and Gastroenterologist felt more comfortable and equipped to provide educational support. Some acknowledged that this is a potential area for improvement, while others were grateful for the team effort that went into caring for patients. However, the NSWOC was one of the only health care professionals who provided both educational *and* social and emotional support to patients, specifically regarding ostomies. Unfortunately, however, this NSWOC shared that because she worked in the community, she did not have access to her patients' medical records, which was a limitation in her practice and her role as a NSWOC.

## 7.4 HCP Perception of Ostomy Surgery

Many of the HCP participants also shared how they believed patients' felt about ostomy surgery. Specifically, some of these participants shared that there were no patients who wanted an ostomy: "all patients want to avoid these types of surgeries so… and I think that um that's the reality of it" (Gastroenterologist). This participant later shared that the fear that patients had around ostomy surgery, influenced when he presented it:

> …it's my opinion and I uh but it's just my opinion and I could be wrong um that I feel that most patients would want to avoid it, where I do bring it up, I do bring it up but not… so that I think that uh they would actually would want to do it, I do it when I clearly see they're heading in the wrong direction, I need them to consider another form of therapy and they don't want to…

Another participant similarly shared that ostomy surgery was not something that patients wanted but he did acknowledge that some patients reached a point where they felt they would feel better with the surgery: “I don’t think anyone wants to have one right, it’s just that if they’ve been struggling you know then they would choose to say I could do better having the surgery” (Colorectal Surgeon 2). Similar testaments were made by other HCPs who shared that ostomy surgery was never something that patients wanted.

However, the NSWOC was one participant who shared her own positive view of ostomies, suggesting that an ostomy is for living and that patients should not and cannot live with severe illness:

> …it is for living… whether a person is dealt an illness that you know, um they’ll die without it or you’ll continue with the… you know the IBD and a life of pain and agony… and when you’re young… you got a whole life to live, and you can’t live it like that.

While she acknowledged that some patients struggled with the idea of ostomy surgery, she emphasized the positive aspects of surgery and the improvement in quality of life that patients would experience.

## 7.5 Patient Adjustment and Quality of Life After Surgery

When discussing the point at which patients had already had ostomy surgery, Colorectal Surgeons spoke about the adjustment phase and their experience of watching patients regain their health, which helped with acceptance:

> I think early on is always challenging because you’re adjusting to something new… and that’s universal… once they’re like a couple of months out from that surgery, I think that’s when they start to regain their energy, they start to see like… they start to see the benefit of having it um the potential downside… obviously ostomies aren’t without their

> own set of potential complications… so that really sucks, like if you have a permanent ostomy and then you have like leaks and what have you, so… um if that happens that that's very disheartening um… but usually once the decision is made, especially in people who are sick enough to need that for Inflammatory Bowel Disease… I think they are eventually like 'oh yes this is better' you know… like a common sentiment is people say, I didn't realize how sick I was until I had surgery and then I wasn't chronically ill anymore…

This Colorectal went on to speak about younger populations specifically and how regaining their health was a new normal for them:

> …especially young people because they have such great reserve and they always kind of look okay when we see them but they're walking around with grumbling colitis… they have literally a sick organ inside their body and a lot of them are like 'oh I didn't realize that it wasn't normal to like take a nap all the time'… you know, because they've never known anything else… and since they've been diagnosed, they've been compensating really well… um so I think yeah if it's working well for them and they kind of get their energy back then I think people generally are pretty happy. (Colorectal Surgeon 1)

Another Colorectal Surgeon similarly shared that it is a natural perspective to not want ostomy surgery but that once patients underwent the operation, they felt much better and were well for the first time in a while, making them grateful for the disease to be gone. It was also shared that patients went through a transition of being fearful of surgery to being knowledgeable about ostomies and being able to manage their disease on their own:

> I find it interesting because they go from someone who is fearful and again I'll use the word ignorant, again in the true term in the way that I would have been ignorant if I was

> 18 years and had the disease um to incredibly knowledgeable you know, and that happens in a very short period of time because when you're living with it and you have to manage it, all the different powders, all the different appliances, all of the different subtleties to changing them and managing them, all the things they can do to their diet to manipulate when they'll go and when they won't go um they really go from being fearful to being masterful [laughter] at managing and balancing their life with this, you know… so I would say that the confidence that comes with that is impressive. (Colorectal Surgeon 3)

In addition to the ostomy becoming more manageable and patients becoming knowledgeable, all different types of health care professionals touched on how much better patients felt overall after they had ostomy surgery. For example, one Clinical IBD Nurse reflected on patients' perceptions after surgery and shared:

> I mean I would say the majority of people wish they had had it sooner because they generally do feel so much better afterwards… you know it's not, obviously not perfect for everyone but I would say the majority of people are very grateful to have had it and um are so thankful that they feel better and like themselves again and that it wasn't… the actual dealing with the ostomy is not as bad as they had envisioned… (Clinical IBD Nurse 1).

Health care professionals expressed that this was a common experience for patients to feel significantly better after surgery and that these examples of people feeling well were used when presenting surgery to patients who had not undergone the procedure yet.

The NSWOC also noted that younger populations tended to adjust more quickly than other populations, which typically resulted in her having to reach out to them, rather than the other way around:

> I also find that the younger set are much more um… cause you know, you've lived with IBD for so long… that having this little inconvenience, you know uh that's making you life way more acceptable… that um they just get on with it, like I have to phone, I have to phone the younger set and say, you know could you… I'd like to see you, I'd like to see how you're doing and like… you know, I'd like to keep my job… you have to keep my in business [laughter].

**7.5.1 Fears and Concerns.** The NSWOC was the only health care professional to discuss fears and concerns that came up after surgery for patients, which could be because of the more supportive role she played in their care. She mentioned three significant fears and concerns that patients shared with her, related to body image, clothing, and hernias.

The NSWOC shared that body image was a huge concern for different types of patients, not just younger populations:

> …body image, it's huge… and not just for the younger set but for the older as well… it's really important but for the younger set, like teenagers upwards, it's body image… is a huge issue… or it CAN be, so you know right from the get go you have to come from the… space where you know, this is going to be your normal now, right… and um focus on that… and you know build confidence in yourself.

In addition to providing support around body image issues, the NSWOC also provided support and advice for concerns related to clothing:

> …the biggest thing is clothing, that's huge… we try to encourage people not to… not to change their wardrobe… you know, because by changing your wardrobe, that kind of indicates 'oh well this is not normal so I have to change my wardrobe' you know… men buy braces, their pants are falling off because you know… so we try to discourage that,

> and that's where the really low profile ostomy products come in now… so that women don't have to um… you know, get baggy dresses and shirts and the guys can still wear their dress pants and you know… we have concealment belts, there's all kinds of fancy things on the markets now and we have a seamstress that makes… you know and dignity belts, they're called dignity belts and… like for intimacy.

Finally, she shared that hernias were a fear and a big issue for patients that did experience them post-operatively. She shared that this is something that she has to watch for in her patients and being able to identify patients who might be at risk was important so that she could recommend support belts to prevent hernias. She also talked caring for patients who did present with a hernia, again providing them support with certain belts that would prevent the hernia from getting bigger of bulging.

## 7.6 Desire to Improve

Throughout these themes, there has been acknowledgment from some health care professionals to improve their ability to support patients undergoing ostomy surgery. For example, Clinical IBD Nurses acknowledged that they could improve their knowledge base of ostomies to provide more educational support, while Colorectal Surgeons acknowledged that they could improve their ability to provide emotional support. Beyond that, Clinical IBD Nurses and the Gastroenterologist (working from the same health center) acknowledged some tangible ways that they would like to improve.

For example, one of the Clinical IBD Nurses shared that they would like to get more involved with the surgical aspect of care for their patients. Specifically, they have plans to work more closely with the surgical team partnered with their own center:

> …the nurses are meant to getting involved a little bit more, which I think is gonna be great because we're gonna be able to be more involved on that side of the care and you know our learning, I would expect would increase so that we can support patients I think a little bit better regarding the surgeries that are involved for our patients, you know ostomy and all of that kind of stuff. (Clinical IBD Nurse 1)

The Gastroenterologist from this health center also identified some areas for improvement. He shared that while they have a psychologist working out of their center as well, she is not well-versed in this topic but this is something that could and should be done. He also shared that their health center had previously tried running an Ambassador Program, where patients already living with an ostomy were paired to patients contemplating ostomy surgery. While this Program had been discontinued, it was something that the Gastroenterologist expressed interest in starting again.

He also acknowledged that patients might feel confused about where to go for support with their ostomies, because of the amount of people involved in their care and the differing levels of knowledge:

> That's where our… I wanna say our system fails… but that's where we could do better is that, rightfully so, [patients] are very dependent on their Gastroenterologist because we've been with them, for some patients, many years, whereas for the surgeons, they've just met them once or twice… um but I don't, we don't know much about ostomies is one of the challenges.

In addition to wanting to learn more about ostomies himself, he also shared that his goal is to hire an ostomy nurse to join his team at the health center:

> …just like how before the patient has surgery, the point of contact in our office is our nurse and she triages, it should be an ostomy nurse that triages patients with ostomy questions cause they are probably more knowledgeable than anyone else in the care model so they can probably deal with most things on their own but when they can't they'll send them to the right person and the patient won't kind of get that feeling perhaps of not really knowing who their connection will be. (Gastroenterologist)

Overall, all the HCP participants had a desire to support patients, whether that be educationally, socially, emotionally, or in all three domains. However, where HCPs fell short was in their own personal lack of understanding or confidence in being able to provide certain types of care. The majority of them had a desire to improve for the sake of the patient and acknowledged gaps in their care.

# Chapter Eight: Discussion

This chapter summarizes the key findings of this research in relation to the research questions that guided this study for both young women living with an ostomy and healthcare professionals caring for patients throughout the decision-making process and during follow-up care. Secondarily, this chapter situates the overall findings in the broader context of existing literature to share their relevance and implications.

This research was driven by the lack of existing literature on the decision-making process for young women to get ostomy surgery as a treatment option for severe IBD, both from the patient perspective and the healthcare professional perspective. Therefore, it is exploratory in nature to discover factors that influence this decision-making process as well as to better understand the actual lived experience of young women with ostomies and to learn how these experiences compare to their perceptions and understandings of what life would be like living with an ostomy prior to undergoing surgery.

## 8.1 Summary of the Lived Experience of Young Adult Women with Ostomies

Overall, participants shared experiences of becoming severely ill prior to undergoing surgery. Their disease had progressed to a point where getting an ostomy was no longer a choice, rather it was a matter of life-or-death. However, the contemplation phase leading up to this point was marked by a variety of negative emotions such as anger, fear, and a sense of failure. Most participants did not know much about ostomies prior to getting one themselves, and they had many worries related to the physical aspect of surgery itself as well as concerns about the social aspect of living with an ostomy and the uncertainty that came with this adjustment. It was evident that education around ostomies was lacking prior to surgery as well as postoperatively.

From the perspective of young adult women as patients, there was reluctance from their healthcare professionals for them to get an ostomy. While many of them initially resisted the surgery, it was typical for them to become severely ill and then end up asking for an ostomy. At this point, participants shared that their healthcare professional would suggest other options and, in many cases, they expressed that they did not want to give the patient an ostomy until later. This then led to little time for preparation and education when it was finally agreed upon between healthcare professionals and the patients that ostomy surgery was necessary. These complicated trajectories of patients leading up to surgery made it difficult for them to identify and categorize whether their surgery was considered emergency or elective; in some aspects it was done as an emergency surgery and in other aspects it was considered elective.

Once these young adult women had their ostomy, they shared that the decision to make their ostomy permanent was easier than going from not have an ostomy to getting one. Additionally, many participants shared that if they had the opportunity to reverse their ostomy, they would not take it; while others who currently did have this opportunity chose not to or chose to delay their reversal and enjoy the quality of life their ostomy gave them first.

### 8.1.1 Perceptions Prior to Surgery versus Afterwards

Common fears that participants recollected having prior to surgery were related to the medical aspect of undergoing the surgery itself, potential odour, and body image/appearance concerns. Another fear brought up by many participants was related to fertility, which was a large part of their decision-making process for surgery. Many of these fears manifested in the adjustment phase of living with an ostomy; specifically, participants shared that it took some time to get comfortable with their appliance changes since the ostomy was difficult to touch and look at in the beginning. Additionally, it took participants some time to find clothes that they felt comfortable in or to just get used to the ostomy underneath their clothes.

Participants shared their experiences of the reality of living with an ostomy. Many of them described disclosure with others as a journey, where it took them time to get comfortable and there was a fear that others would judge them. The fear of disclosure was heightened for those seeking intimate relationships. However, for participants who disclosed that they had an ostomy in a relationship setting expressed that it went better than they had anticipated; for others, however, it prevented them from wanting to seek out such relationships. Participants who had been intimate since getting their ostomy shared that it was not a concern and did not impact intimacy. Therefore, the anticipation of disclosing in intimate relationships was more challenging than the reality of it. Friendships, on the other hand, were less concerning when it came to disclosure, however they were still a concern for some participants and disclosure regarding one's ostomy prevented some participants from creating new friendships.

Likely due to the age of these participants, parental involvement varied. Some participants had very involved parents and others went through this process largely on their own or with their partners. Additionally, parents ranged in their level of supportiveness for getting the ostomy; some of them shared that their parents were against the idea, while others shared that their parents wanted them to get it in hopes that it would make them healthy. Some challenges experienced by participants were related to the management of their ostomy, the smell, and the need to always be prepared. Carrying around medical supplies is something that needed to be considered and this took away a sense of spontaneity in participants' lives. Interestingly, some participants shared that the fatigue associated with their disease was more challenging than the ostomy itself. The lack of energy made it difficult for them to navigate their lives and relationships in the ways that they wanted to, whereas their ostomy was less of a barrier. Finally, participants' relationship with food was important, with many of them struggling to have an appetite and struggling with their fear of food from associating it with pain for such a long period of time.

Overall, however, many of these young adult women share that they felt better incredibly quickly after surgery and they were able to return to a healthy weight. Participants shared that their life had improved in many ways, as they were finally able to do the things they wanted to do prior to surgery but had not been able to because of their poor health. For example, spending time with their friends, eating good food, going to school, and engaging in physical activity.

## 8.2 Summary of Medical Encounters

**8.2.1 Patient Perspective of the Healthcare System.** Interaction with the healthcare system was an important topic throughout these young adult women's disease trajectories. While many of these participants noted that their healthcare professionals had been reluctant to give them an ostomy, many of them also shared that their healthcare team had been a huge source of support for them. Specifically, many participants noted that the support from their IBD nurses and ostomy nurses had been incredibly supportive. However, participants did share that they experienced a great deal of reluctance and a lack of emotional support from their healthcare professionals when they decided they would like to proceed with ostomy surgery.

Some ideas for improvement shared by participants included an increase in education, especially due to the short hospital stay where patients typically receive their education, which meant that not much time was given to them to learn about managing their ostomy before they were discharged and left to figure it out on their own. Therefore, more education both prior to surgery and after discharge was recommended by participants. Additionally, some participants were able to meet another person with an ostomy prior to getting their own and they found this incredibly helpful. Others had a family member who lived with an ostomy but thought it would be more beneficial to talk to someone their age who they could relate to help normalize it and to help understand the actual lived experience of having ostomy and answer age-specific concerns they had. The third idea for improvement included representation and online support. Participants shared the importance of being able to see others online with ostomies who they could relate to. Social media was expressed as an important tool for this. Finally, improving the communication between healthcare professionals and patients was another idea for improvement. Many participants shared that they had a complex healthcare team and experienced poor communication for their care within this team and/or that they were unclear of which healthcare professional to turn to for issues that came up.

## 8.3 Healthcare Professionals' Perspective

Some healthcare professionals perceived ostomy surgery as a last resort, once medications had failed and there were no alternative options left to explore, which influenced how ostomy surgery was presented to the patient. However, others saw it as a treatment option and presented it as such. Regardless of how surgery was presented, quality of life was always an important factor in healthcare professionals' decisions to recommend ostomy surgery. Furthermore, healthcare professionals acknowledged that this was a very personal decision that was ultimately the patient's decision.

### 8.3.1 How Ostomy Surgery is Discussed

When asked how their patients are supported, many of these healthcare professionals shared that a different member of the healthcare team typically provided information and support. For example, Gastroenterologists thought that the surgeon provided information and support, while surgeons thought that patients came to them at a point in their disease course where they had already received information and support.

The type of support that these healthcare professionals provided to their patients varied, with some explicitly mentioning that they did not feel equipped to provide emotional support; rather, when they gave support it was in the form of education. This was likely influenced by healthcare professionals' perception of how their patients would view ostomy surgery, with many of them sharing that no patients wanted an ostomy. However, all healthcare professionals shared that after surgery, they watched their patients regain their quality of life and saw their health improve significantly. Ultimately, there was a collective desire to improve healthcare services, with many of these healthcare professionals acknowledging gaps in their care for patients and a genuine desire to fill them.

## 8.4 Factors that Influence the Decision-Making Process

### 8.4.1 Stigma and Ostomy Surgery

Stigma has been defined as a discrediting attribute that can result in actual, anticipated, or perceived negative responses from others (Goffman, 1963). While it is known that individuals living with IBD experience stigma, which in turn leads to poorer quality of life and psychological functioning (Taft, et al., 2012; Taft & Keefer, 2016), less is known about the stigma associated with living with an ostomy. The ostomy, being a body-altering surgery, deviates from the norm and therefore puts these individuals into a stigmatized group. Stigma was both explicitly and implicitly mentioned by these young adult women living with an ostomy and the healthcare professionals involved in recommending surgery. Despite feeling unwell, many of these young women originally felt resistant to having an ostomy. With ostomy surgery being the top disease-related fear associated with living with IBD, this response is not uncommon (Jelsness-Jorgensen, et al., 2011).

To fight against existing stigma, there is an online health community of individuals spreading awareness and increasing the representation individuals living with ostomies (Rademacher, 2018). Photos of individuals showing their ostomy bag can normalize life with an ostomy and help to reduce the stigma that exists by cultivating a community of others that one can relate to and feel “normal” around. This community of empowerment was studied by Rademacher (2018) in response to a viral photo that was shared of a young woman wearing a bikini with her ostomy showing; however, through an analysis of this photo being shared online, it was noted that despite an overwhelmingly positive response, there were a select number of negative comments that seemed to carry more weight and reinforce ostomy stigma. This emphasizes the sensitive nature of ostomy stigma and how internalized it can be by those living with it, where despite the fact that there were more positive comments than negative, the negative ones still carry more weight. Not only does this reinforcement of stigma make it harder for patients to undergo surgery in the first place, stigma is also known to impact stoma acceptance as well as the ability to manage one’s stoma on their own (Jin, et al., 2019).

Internalized stigma occurs when one embodies negative beliefs about their disease or condition (Link, 1987) and since it is internalized, it can be brought into different social contexts (Earnshaw & Quinn, 2011). This was evident for these young adult women who carried around negative beliefs about their ostomies into various different relationships and social settings. It is likely that this internalized stigma comes from societal standards and norms as well the lack of representation, however it is also important to consider where it might come from within the healthcare system and in medical encounters. If healthcare professionals are reluctant to recommend surgery for their patients and frame it as a failure, this might convey a message to patients that surgery is something that is highly unwanted. It is therefore important for healthcare professionals to be mindful of the beliefs they might be instilling in patients through these medical encounters, which could follow patients through their decision for surgery as well as in their acceptance process and how they navigate the social world afterwards. As the NSWOC nurse shared in this study, she is mindful of how she looks at her patients' ostomies for the first time, as she believes they are seeing it through her eyes. This is a mindset that should be adopted by all healthcare professionals, as it has been found that any distaste from healthcare professionals can perpetuate fear and reinforce stigma (Elcoat, 1998).

### 8.4.2 Gender and the Decision for Ostomy Surgery

Specific beauty standards and ideals exist for women in today's culture. For example, Awad et al (2015) share that thin bodies, small facial features, light eyes, and long, straight hair are valued in North American culture. Patients who are sick with IBD have an invisible illness and therefore continue to fit within the norms and standards set forth by society. Therefore, choosing to stay within these strict guidelines of beauty is easier when one is severely ill than if they were to undergo ostomy surgery, which is a disfigurement of the body and an exposure of illness. Results from this study support this notion, as body image was a major concern and these young adult women shared an interest in ways to conceal their ostomy with their clothing choices. This was the result of a significant concern about how the ostomy would impact their body image, which is consistent with previous research (Bosaeus & Nordgren, 2009; Manderson, 2005; Junkin & Beitz, 2005). While gender differences in relation to ostomy surgery have not been studied widely, the immense societal pressures for women to fit certain guidelines of femininity to remain attractive might override the desire the become healthy, at least until the disease progresses to the point of becoming unlivable. In many of these young adult women's experiences, they became ill to the point that surgery was no longer a choice for them, but a matter of a life or death.

As discovered by Curtin et al. (2011), women who accept and internalize traditional femininity beliefs are more self-conscious and less comfortable with their bodies during sex. Therefore, the societal messages that women receive can have a significant impact on how they navigate their social worlds and feel in intimate relationships or with sexual partners. With ostomies being outside of the normative societal standards for women, this supports the findings that many women feared how their ostomy would impact their ability to find an intimate partner, which is consistent with existing literature where individuals fear sexual intimacy with an altered body after ostomy surgery (Ramirez et al., 2014). However, as was evident for those in a relationship at the point of surgery, the ostomy did not actually negatively impact their sexual health and relationships. Therefore, the societal standards and pressures of femininity might change the perception of living with an ostomy due to how it disfigures the body; yet the reality of living with one is more 'normal' than anticipated.

Also worth noting is that despite these societal pressures that might have contributed to the fear of surgery in the first place and manifested fears around intimacy with an ostomy and body image concerns, these women adjusted remarkably well to their ostomy. Although this required an adjustment period for most of these women, participants described feeling well almost instantly after surgery and shared that they would not reverse their ostomy if they were given the choice. This supports existing literature, which suggests that women adjust better psychosocially to ostomy surgery than men, aside from being concerned about sexual attraction where women report more concern than men (Gautam & Poudel, 2016). However, women report more psychological distress from severe illness than do men (Fife, et al., 1994). While we did not learn about the experiences of men in this study, this might explain why the women in this study had relatively good psychosocial adjustment after ostomy as they became less ill and regained their health and quality of life.

### 8.4.3 Medical Encounters

Young adult women in this study described reaching a point in their illness where they asked for ostomy surgery, at which point they were often met with a resistant healthcare provider and had to advocate for their surgery. One participant in particular was told by her healthcare provider that he did not want to recommend surgery for her, despite her requests, because he wanted her to be out living her life as a young woman. Ironically, not getting the surgery meant she was not healthy enough to be out living her life. Existing literature suggests that unless patients have a positive attitude, practitioners tend to rely on gender stereotypes when making treatment decisions, which is even more common under time pressure (Di Caccavo & Reid, 1998). Given the nature of ostomy surgery, where decisions need to be made quickly as the patients' health is typically deteriorating, it is fair to assume that gender stereotypes are likely to play into these healthcare providers' decisions to recommend ostomy surgery. This might mean that healthcare providers perceive their female patients as more emotional (Di Caccavo & Reid, 1998) and therefore might be less likely to recommend more advanced interventions (Biernat & Manis, 1994), or perhaps this subconsciously makes healthcare providers reluctant to recommend surgery because ostomy surgery requires a disfigurement of the body.

In other cases, some of these young adult women describe being told they need ostomy surgery without acknowledgement of the emotional challenges encompassed in this decision. This was similarly expressed by many healthcare providers, who shared that they did not feel equipped to provide emotional or psychological support to their patients. In support of these findings, much of the existing literature suggests that a large majority of patients are typically not asked by their physicians about their quality of life (Ghosh & Mitchell, 2007; Rubin et al., 2010) and typically the impact of IBD on their lives is underestimated (Schreiber et al., 2013). Therefore, research suggests that improved communication with a recognition of psychological distress is needed in the patient-physician relationship when managing IBD (Chew, Zhiqin, Ibrahim, & Ali, 2018).

Finally, many of the healthcare professionals’ perspectives in this study were aligned with previous research, which suggests that ostomy surgery is a last resort after pharmacotherapy has failed (Biondi et al, 2012; Peyrin-Biroulet & Lémann, 2011). While this might be true, reframing the presentation of surgery might change the way it is perceived by both patients and healthcare professionals. For example, one of the colorectal surgeons in the study shared that he presented surgery as a treatment option, rather than a failure. This reframing could (1) make the surgery easier to present for healthcare professionals, and (2) create a different narrative for the patient where they are encouraged to consider ostomy surgery in relation to their other options. Perhaps this simple reframing could take away the negative connotation of surgery and help patients reach the decision to undergo ostomy surgery sooner, before the patient becomes sicker and the possibility of negative health outcomes rises (Steinhart, 2006).

# Chapter Nine: Conclusion

This study explores the experiences of young women who decide to undergo ostomy surgery to treat their IBD and the perspectives of healthcare professionals who support patients throughout this process.

## 9.1 Contributions and Implications

Overall, healthcare professionals had great intentions for their patients, demonstrating a great deal of care and wanting the best outcomes for their patients. Many of these healthcare professionals were also aware of how big the decision to undergo ostomy surgery can be and the emotional toll it can take. At the same time, there are likely many unconscious biases at play in relation to the existing stigma around ostomies, gender roles, and expectations around age that influence when and how ostomy surgery is presented by healthcare professionals and how it is received and interpreted by patients.

Both from the perspective of healthcare professionals and of patients, there is significant room for improvement regarding medical encounters that occur during the decision-making process and available support and education surrounding ostomy surgery. More emphasis and attention is needed for the emotional and psychological aspect of undergoing ostomy surgery and more supports are necessary for healthcare professionals to become better equipped for having these conversations with their patients and for patients being able to access additional resources if they wish to do so.

In addition to the emotional and psychological component, a general need for education was evident. Many of these participants had not heard about ostomy surgery prior to getting one themselves, which impacted their ability to make the decision, their adjustment to surgery and the internalized, anticipated, and experienced stigma they felt. With greater education for patients and the general public, individuals living with ostomies might feel more comfortable disclosing to their friends, family, and in intimate relationships, which could significantly improve their quality of life. With education would come an increase in representation and normalization, which was shared throughout these narratives as something that can be life changing during these disease trajectories.

Regarding education, healthcare professionals should assume their patients do not know anything about ostomies when coming into their care. As was evident in this data, many of the healthcare professionals assumed that another professional had already educated the patient and therefore they did not have to. However, each of these healthcare professionals shared a similar testament, meaning that having multiple healthcare professionals involved in the process was actually a disadvantage for patients regarding their likelihood of being educated, as opposed to something that could be used as an advantage. On a similar note, patients testaments of those around them not knowing about ostomies, suggests that greater education not just for patients but in the general public would be highly beneficial.

It is hoped that through this research, an understanding of how young women perceive ostomies prior to surgery and after surgery will help others who are faced with this decision. The evolution of their perceptions might allow those contemplating surgery to gain insight into the perceived versus the actual lived experiences of having an ostomy. Providing patients with an understanding of life with IBD versus life with IBD and an ostomy will help alleviate some of the fears associated with the unknown of surgery. Knowing the experiences of young women living with an ostomy can be a supportive tool for those contemplating surgery, which aligns with requests from patients who want to connect with others living with an ostomy that they can relate to and have more representation and normalization within the community.

Additionally, this study examined factors that might help or hinder the decision-making process prior to surgery to encourage more constructive and effective conversations leading up to surgery that can help individuals in their decision and their adjustment to life with an ostomy. The experiences of young women living with an ostomy and their recollections of events leading up to their surgery will hopefully help contribute to the knowledge base of healthcare professionals who are involved in the decision-making process of ostomy surgery for young patients. Understanding factors that allowed young people to reach this decision may inform healthcare professionals on how to approach this topic with their patients with the sensitivity to allow them accept surgery before their health deteriorates and to support them in adjusting to their life with an ostomy post-surgery. Ultimately, this research may help individuals living with IBD in their decision-making process prior to ostomy surgery and allow healthcare professionals to gain a deeper understanding of the patient perspective and encourage them to act and communicate in a way that facilitates positive outcomes for patients contemplating surgery.

## 9.2 Limitations

It is important to consider the limitations of this study. First, this study consisted of a small sample size of both young adult women and healthcare professionals. Specifically for healthcare professionals, it would be beneficial to have a larger sample within each area of care (i.e., for Gastroenterologists, surgeons, IBD nurses, ostomy nurses, etc.). With each of these healthcare professionals acting in different roles throughout the decision-making process and in the type of support they provided, it would be beneficial to interview more professionals within each field to gain a more in-depth and fulsome understanding of each their perspectives.

Secondly, these interviews took place after ostomy surgery had occurred. For some, this meant they were recollecting their experiences from years ago of having to make this decision, including who was involved in the process and the initial concerns and fears they had. As was realized in the research, many participants became well-adjusted to life with their ostomy and therefore this new interpretation of their ostomy could influence how they recollect their previous experiences. It would be beneficial to interview participants who are going through this decision-making process, ideally at various points throughout this trajectory.

Finally, the way in which participants were recruited could have influenced the sampling. Specifically for young adult women living with an ostomy, recruitment was done via social media. Those who responded to the study poster and expressed an interest in the study might be those who are already involved in these health community and more well-adjusted than perhaps those who have not tapped into these online communities. As a result, these participants might be more accepting of their ostomy and/or further along in the adjustment process than those who are not part of the online communities.

## 9.3 Future Directions

Due to the exploratory nature of this research, further research is necessary to elaborate on these findings. Specifically, more research is needed on the gender differences in the decision to undergo ostomy surgery as well as how one navigates their social world as they live with an ostomy. While speculations were made about the unconscious gender biases that impacted recommendations for surgery and the decision-making process, more research is needed on men's experiences to compare and contrast the results of this research and the experiences of women.

Additionally, specific research on the stigma around ostomy surgery would be beneficial for understanding how this influences patients emotionally and psychologically throughout their disease trajectory and how it influences the reluctance of both healthcare professionals and patients. If the root of this stigma is understood better along with how and where it is perpetuated, it will be easier to unpack how to work on breaking down these barriers.

Finally, while it added value to interview these healthcare professionals separately and gain their individual perspectives and an accurate understanding of their practices and how they perceive ostomy surgery, it would also be beneficial to do a focus group of these healthcare professionals together. Interviewing them in one setting could help to better understanding where the lack of communication that was emphasized in this research stems from and how to come up with tangible ideas to improve this shortcoming. This could help generate more practical implications for healthcare and how to improve medical encounters during this highly sensitive decision-making process.

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# Appendix A

# Letter of Invitation

## The Experience of Ostomy Surgery in Young Women with Inflammatory Bowel Disease

Dear Participant,

I am conducting interviews as part of my thesis project to understand the perceptions of ostomy surgery in young women living with IBD and the factors that influence their decision to have surgery.

The interview takes approximately 1 to 2 hours and will involve a variety of open-ended questions related to your experience of living with an ostomy and your decision to undergo surgery. Your responses to the questions will be kept confidential and only reviewed by the researchers (Dr. André Smith, Dr. Debra Sheets, and Ashley Clark). After the interview, we will assign a code to your information to help ensure that personal identifiers are not revealed during the analysis and write up of the findings for the study.

Due to the sensitivity of these topics, it is important to me that you feel comfortable during our interview. I myself am a 27-year-old woman living with an ostomy to treat my Crohn's disease. I hope that my shared diagnosis and surgical decisions will help you feel more comfortable sharing your experiences with me.

There is no compensation for participating in this study. However, your participation will be important for helping other people living with IBD who are contemplating ostomy surgery. Your responses will also help to inform healthcare providers of the patient experience leading up to surgery and living with an ostomy. I hope that my research will bring sensitivity to healthcare professionals when discussing ostomy surgery with their patients; as well, it could potentially help to alleviate fears associated with the unknown of surgery so that young people will have a better idea of what living with ostomy would be like and potentially be more willing to undergo this procedure ostomy before their health deteriorates.

If you are willing to participate in this study, please respond to this email address (clarkash@uvic.ca) and provide your contact information (i.e., name, phone number, and email) and your preferred method of contact. I will contact you shortly to answer any of your questions and arrange a date, time, and location that are convenient and comfortable for you.

If you have any questions, please do not hesitate to ask.

Thank you!
Ashley Clark
MA Candidate, Social Dimensions of Health Program
University of Victoria

## Appendix B

***Participant Consent Form***

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# Experience of Ostomy Surgery in Young Women with Inflammatory Bowel Disease (IBD)

**Principal Investigator:**
André Smith, PhD
Department of Sociology and
Centre on Aging
University of Victoria
Victoria, British Columbia
Phone: (250) 721-7583
Email: apsmith@uvic.ca

Ashley Clark, MA Candidate
Social Dimensions of Health Program
University of Victoria
Victoria, British Columbia
Phone: (250) 812-8908
Email: clarkash@uvic.ca

**Co-Investigator:**
Debra Sheets, PhD, MSN, RN-BC, CN
School of Nursing
University of Victoria
Victoria, British Columbia
Phone: (250) 853-3947
Email: dsheets@uvic.ca

## Invitation to be involved

You are invited to take part in this research study because you are a young woman living with IBD and an ostomy. We would like to conduct a face-to-face interview to ask questions about your perception of living with an ostomy and your experiences leading up to surgery.

## Purpose and Objectives

The purpose of this research project is to understand the perceptions of ostomy surgery in young women living with IBD and the factors that influence their decision to have this surgery. The aim of this study is to gain insight into the lived experiences of young women living with IBD and an ostomy, how ostomy surgery is perceived prior to surgery, how these perceptions evolve after surgery, and what factors influence the decision-making process to get an ostomy.

## Importance of this Research

Understanding the experiences of individuals who have made the decision to undergo ostomy surgery and are currently living with this procedure is needed to help others who are contemplating surgery. This research will also help to inform healthcare professionals of their patients' experiences so that they can approach this topic with sensitivity and an understanding of the patient's perspective.

## Your participation is voluntary

Participation in this study is entirely voluntary and deciding not to participate has absolutely no consequences in relation to your involvement with Crohn's and Colitis Canada. This consent form tells you about the study, why this research is being done, what will happen during the study, and the possible benefits, risks, or discomforts from participation. Please read this consent form carefully and take your time to decide whether or not you would like to participate. Please keep in mind that you can withdraw from the study at any time, without providing a reason, and without any consequences.

## Who is conducting the research?

This study is led by Ashley Clark under the supervision of Dr. André Smith, who is an Associate Professor in the Department of Sociology and a Research Affiliate at the Centre on Aging at the University of Victoria. He has extensive experience in qualitative research and illness narrative. He can be reached by phone at (250) 721-7583 or by email at apsmith@uvic.ca.

Ashley Clark is a Master of Arts Candidate in the Social Dimensions of Health Program at the University of Victoria. She can be reached at (250) 812-8908 or by email at clarkash@uvic.ca.

Dr. Debra Sheets is a co-investigator for this study. She is an Associate Professor in the School of Nursing at the University of Victoria and can be reached via phone at (250) 853-3947 or email at dsheets@uvic.ca

You may verify the ethics approval of this study or raise any concerns you may have by contacting the Human Research Ethics Assistant, Office of Research Services at the University of Victoria (250) 472-4545.

## Participants Selection

You are being asked to participate in this study because you meet the following criteria:

(1) Female,
(2) Between the ages of 19 and 30,
(3) Currently living with an ostomy to treat IBD (for any length of time), and
(4) Fluent in English.

## What does participation in the research involve?

If you consent to voluntarily participate in this research, your participation will include a one-on-one interview with one of the researchers (Ashley Clark) and the completion of a questionnaire package. You and the researcher will arrange a time and place that is convenient and comfortable for you. The researcher will ask you questions related to your experience of deciding to undergo surgery to treat your IBD and your experiences of currently living with an ostomy. You will be given the opportunity to discuss issues that are most important to you more extensively. The interview will take approximately 1 to 2 hours.

With your permission, the interview will be audio-recorded and later transcribed. At this point, your interview will be de-identified. Written notes may also be taken throughout the interview and included in the analysis of the data.

Once the interview is complete, you will be given a questionnaire package and asked to email the completed version back to the researcher. The questions are related to living with IBD before your surgery and your experience of living with an ostomy today. These questions are expected to take 15 – 20 minutes to complete.

## What are the possible harms of participation?

There may be some discomfort for participants. Some of the questions that will be asked may be sensitive. If any of the questions upset you please inform the interviewer or any of the researchers so that appropriate resources can be provided.

## What are the benefits of participating in the research?

There is no direct benefit to you as a result of the study. However, the results of this study might help other young people as they decide whether to get an ostomy to treat their IBD. As well, the results might help healthcare professionals become more aware of patients' experiences leading up to surgery and their experience of living with an ostomy. It is hoped that this awareness and understanding will help with decision-making before health deteriorates and support young people who are contemplating surgery.

## What happens if I decide to withdraw my consent?

Your involvement in the study is voluntary. If you join the study, you can withdraw for any reason at any time and by whatever means you find easiest. When you leave, your records will be destroyed. If you want to withdraw from the study, we ask that you contact Ashley Clark, (250) 812-8908.

**Will my taking part in the study be kept confidential?**

Your confidentiality will be respected. We conform to the highest research standards. Each participant is assigned a unique study number and only this number is used on any research related materials. Only approved study staff have access to personal information and only after they have submitted a signed oath of confidentiality. Your personal information and study number are stored separately. All offices, computers, filing cabinets are locked and password protected as appropriate.

Please note that given the small sample, characteristics of participants in this study, and the recruitment method used (i.e., word-of-mouth) there may be some limits in confidentiality. However, any circumstances or events that could potentially identify anyone will be altered/disguised to protect anonymity.

The research team will provide you with guidance on how to protect your identity and increase the protection of your personal information when using Zoom or Skype. For example, you will be welcome to use a disguised nickname, turn off your camera, and/or turn off your microphone and use the chat box instead throughout the interview.

These findings will be de-identified and shared with professionals in the field, at conferences, in journal publications, and with students and other patients. No personal information will be included in any of these publications.

Our files will be stored for seven years as required by University policy. During this time, all audio recording will be preserved on password-protected, encrypted computers on the University campus and then deleted after this seven-year period. Computer storage devices will be erased and over-written with non-sense data. Paper documents will be shredded and burned.

**CONSENT**

☐ Please √ check this box if you consent to participate in the "Experience of Ostomy Surgery in Young Women with Inflammatory Bowel Disease (IBD)" study.

By checking this box, you are agreeing that:

- You have read and understood the study information.
- You had sufficient time to consider the information and seek advice as necessary.
- You have the opportunity to ask questions and have them answered to your satisfaction.
- You understand that the information we collect is confidential.
- You understand that the researchers will use aggregate results for scientific objectives such as research and publications.
- You understand that your participation is voluntary and you are free to refuse to participate, withdraw, or answer specific questions at any time.

- You understand that your participation or withdrawing from the study will not impact your employment.
- You understand that you are not waiving any of your legal rights as a result of signing this consent form.
- You have read this form and freely consent to participating in the study.

☐ Please √ check this box if you consent to contact the principal investigator or research coordinator to arrange another brief interview should you wish to share further information at a later time.

With your permission, we would like to record the interview so as to not to disrupt the interview process by taking notes while you are talking. However, recording is entirely optional and you can indicate your preference here.

**I do____/do not _____agree to have the interview audio recorded.**

## CONSENT SIGNATURE PAGE

Your signature below indicates that you have read and understood this consent form, that you have had the opportunity to have your questions answered by the researchers, and that you give your consent to participate in the "The Experience of Ostomy Surgery in Young Women with Inflammatory Bowel Disease (IBD)."

**First and Last Name (please print):** ____________________________________

**Participant Signature:** ____________________________________________

**Date Signed:** ____________________________________________________

***A copy of this consent will be left with you, and a copy will be taken by the researcher.***

# Appendix C
# Letter of Invitation
## The Experience of Ostomy Surgery in Young Women with Inflammatory Bowel Disease

Dear Healthcare Provider Participant,

I am conducting interviews as part of my thesis project to understand the perceptions of ostomy surgery in young women living with IBD and the factors that influence their decision to have surgery.

The interview takes approximately 15 to 30 minutes and will involve open-ended questions related to your experience of working with individuals living with an ostomy or contemplating surgery. Your responses to the questions will be kept confidential and only reviewed by the researchers (Dr. André Smith, Dr. Debra Sheets, and Ashley Clark). After the interview, we will assign a code to your information to help ensure that personal identifiers are not revealed during the analysis and write up of the findings for the study.

There is no compensation for participating in this study. However, your participation will be important for helping people living with IBD who are contemplating ostomy surgery. Your responses will also help to inform other healthcare providers of the patient experience leading up to surgery and living with an ostomy. I hope that my research will bring sensitivity to this topic and provide information that will help with the discussion of ostomy surgery with patients. This knowledge could potentially alleviate some of the fears associated with the unknown of surgery so that young people will have a better idea of what living with an ostomy would be like and potentially be more willing to undergo this procedure before their health deteriorates.

If you are willing to participate in this study, please respond to this email address (clarkash@uvic.ca) and provide your contact information (i.e., name, phone number, and email) and your preferred method of contact. I will contact you shortly to answer any of your questions and arrange a date, time, and location that are convenient and comfortable for you.

If you have any questions, please do not hesitate to ask.

Thank you!
Ashley Clark
MA Candidate, Social Dimensions of Health Program
University of Victoria

## Appendix D

## *Healthcare Provider Consent Form*

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# Experience of Ostomy Surgery in Young Women with Inflammatory Bowel Disease (IBD)

**Principal Investigator**:
André Smith, PhD
Department of Sociology and
Centre on Aging
University of Victoria
Victoria, British Columbia
Phone: (250) 721-7583
Email: apsmith@uvic.ca

Ashley Clark, MA Candidate
Social Dimensions of Health Program
University of Victoria
Victoria, British Columbia
Phone: (250) 812-8908
Email: clarkash@uvic.ca

**Co-Investigator**:
Debra Sheets, PhD, MSN, RN-BC, CN
School of Nursing
University of Victoria
Victoria, British Columbia
Phone: (250) 853-3947
Email: dsheets@uvic.ca

### Invitation to be involved

You are invited to take part in this research study because you are a healthcare professional who works directly with IBD patients living with ostomies or who are contemplating surgery. We would like to conduct a one-on-one interview to ask questions about your perception of ostomy surgery for the treatment of Inflammatory Bowel Disease.

### Purpose and Objectives

The purpose of this research project is to understand the lived experiences of young women living with an ostomy to treat their IBD and the factors that influenced their decision to have this surgery. The aim of this study is to gain insight how ostomy surgery is perceived prior to surgery, how these perceptions evolve after surgery, and what factors influence the decision-making process to get an ostomy.

## Importance of this Research

Understanding the experiences of young women who have made the decision to undergo ostomy surgery and are currently living with this procedure is needed to help others who are contemplating surgery. Healthcare professionals' role in the process is important and could potentially influence individuals in arriving at this decision before their health deteriorates. Thus, understanding both patients' and healthcare professionals' experiences will give valuable insight into this decision-making process leading up to surgery.

## Your participation is voluntary

Participation in this study is entirely voluntary and deciding not to participate has absolutely no consequences. This consent form tells you about the study, why this research is being done, what will happen during the study, and the possible benefits, risks, or discomforts from participation. Please read this consent form carefully and take your time to decide whether or not you would like to participate. Please keep in mind that you can withdraw from the study at any time, without providing a reason and without any consequences.

## Who is conducting the research?

This study is led by Ashley Clark under the supervision of Dr. André Smith, who is an Associate Professor in the Department of Sociology and a Research Affiliate at the Centre on Aging at the University of Victoria. He has extensive experience in qualitative research and illness narrative. He can be reached by phone at (250) 721-7583 or by email at apsmith@uvic.ca.

Ashley Clark is a Master of Arts Candidate in the Social Dimensions of Health Program at the University of Victoria. She can be reached at (250) 812-8908 or by email at clarkash@uvic.ca.

Dr. Debra Sheets is a co-supervisor for this study. She is an Associate Professor in the School of Nursing at the University of Victoria and can be reached via phone at (250) 853-3947 or email at dsheets@uvic.ca

You may verify the ethics approval of this study or raise any concerns you may have by contacting the Human Research Ethics Assistant, Office of Research Services at the University of Victoria (250) 472-4545.

## Participants Selection

You are being asked to participate in this study because you meet the following criteria:

(1) Work directly with IBD patients  
(2) Fluent in English

**What does participation in the research involve?**

If you consent to voluntarily participate in this research, your participation will include a one-on-one interview with one of the researchers (Ashley Clark). You and the researcher will arrange a time and place that is convenient and comfortable for you. The researcher will ask you questions related to your experience of working with Inflammatory Bowel Disease patients who might require ostomy surgery. You will be given the opportunity to discuss issues that are most important to you more extensively. The interview will take approximately 30 minutes.

With your permission, the interview will be audio-recorded and later transcribed. At this point, your interview will be de-identified. Written notes may also be taken throughout the interview and included in the analysis of the data.

**What are the possible harms of participation?**

There are no known harms or risks associated with participating in this study.

**What are the benefits of participating in the research?**

There is no direct benefit to you as a result of the study. However, the results of this study might help young people as they decide whether to get an ostomy to treat their IBD. As well, the results might help other healthcare professionals when discussing ostomy surgery with their patients. It is hoped that this awareness and understanding will help with decision-making before health deteriorates and support young people who are contemplating surgery.

**What happens if I decide to withdraw my consent?**

Your involvement in the study is voluntary. If you join the study, you can withdraw for any reason at any time and by whatever means you find easiest. When you leave, your records will be destroyed. If you want to withdraw from the study, we ask that you contact Ashley Clark, (250) 812-8908.

**Will my taking part in the study be kept confidential?**

Your confidentiality will be respected. We conform to the highest research standards. Specific information about you will not be collected by the study. Each participant is assigned a unique study number and only this number is used on any research related materials. Only approved study staff have access to personal information and only after they have submitted a signed oath of confidentiality. Your personal information and study number are stored separately. All offices, computers, filing cabinets are locked and password protected as appropriate.

Please note that given the small sample, characteristics of participants in this study, and the recruitment method used (i.e., word-of-mouth) there may be some limits in confidentiality. However, any circumstances or events that could potentially identify anyone will be altered/disguised to protect anonymity.

The research team will provide you with guidance on how to protect your identity and increase the protection of your personal information when using Zoom or Skype. For example, you will be welcome to use a disguised nickname, turn off your camera, and/or turn off your microphone and use the chat box instead throughout the interview.

These findings will be de-identified and shared with professionals in the field, at conferences, in journal publications, and with students and other patients. No personal information will be included in any of these publications.

Our files will be stored for seven years as required by University policy. During this time, all audio recording will be preserved on password-protected, encrypted computers on the University campus and then deleted after this seven-year period. Computer storage devices will be erased and over-written with non-sense data. Paper documents will be shredded and burned.

**<u>CONSENT</u>**

☐ Please √ check this box if you consent to participate in the "Experience of Ostomy Surgery in Young Women with Inflammatory Bowel Disease (IBD)" study.

By checking this box, you are agreeing that:

- You have read and understood the study information.
- You had sufficient time to consider the information and seek advice as necessary.
- You have the opportunity to ask questions and have them answered to your satisfaction.
- You understand that the information we collect is confidential.
- You understand that the researchers will use aggregate results for scientific objectives such as research and publications.
- You understand that your participation is voluntary and you are free to refuse to participate, withdraw, or answer specific questions at any time.
- You understand that your participation or withdrawing from the study will not impact your employment.
- You understand that you are not waiving any of your legal rights as a result of signing this consent form.
- You have read this form and freely consent to participating in the study.

☐ Please √ check this box if you consent to contact the principal investigator or research coordinator to arrange another brief interview should you wish to share further information at a later time.

With your permission, we would like to record the interview so as to not to disrupt the interview process by taking notes while you are talking. However, recording is entirely optional and you can indicate your preference here.

**I do____/do not _____agree to have the interview audio recorded.**

## <u>CONSENT SIGNATURE PAGE</u>

Your signature below indicates that you have read and understood this consent form, that you have had the opportunity to have your questions answered by the researchers, and that you give your consent to participate in the "The Experience of Ostomy Surgery in Young Women with Inflammatory Bowel Disease (IBD)."

**First and Last Name (please print):** ________________________________________

**Participant Signature:** ________________________________________________

**Date Signed:** ________________________________________________________

***A copy of this consent will be left with you, and a copy will be taken by the researcher.***

# Appendix E

## Interview Questions for Young Women with IBD and an Ostomy

Can you tell me your diagnosis?

When did you first experience the symptoms of _____?

When were you diagnosed with _____?

What was it like to be diagnosed?

What treatments did you try before having an ostomy?

How old were you when you had surgery?

What type of ostomy do you have (ileostomy or colostomy)?

Is your ostomy temporary or permanent?

Could you tell me the circumstances leading to your decision to have ostomy surgery?

Who was involved in this decision?

How was the surgery discussed with you?

What were your thoughts before making the decision to have an ostomy?

Did you have specific concerns?

How do you feel now about your decision?

What has it been like to live with an ostomy?
Are there any treatments you still take?

Have you talked about your ostomy with others? What has that been like?

Were you in an intimate relationship when you had your surgery or have you been involved in one since?

How has been like to live with an ostomy in this relationship? Have there been any challenges, a process of adaptation?
Demographic Questions:

How old are you?

What is your highest level of education?
What is your occupation?
What is your relationship status?

I want to thank you for sharing this personal information. I really appreciate it. I am wondering if there anything else you want to add to what you've shared so far?

## Sample Interview Questions for Healthcare Professionals

How are you involved in caring for people with Crohn's or colitis?

When is an ostomy recommended in the treatment of Crohn's? How does this compare to colitis?

How do you support patients who need to make a decision about having an ostomy?

How do you explain to them the surgery?

How do patients view the ostomy surgery? Do they express specific concerns or fears?

How do you address these fears and concerns?

How would you characterize the impact of an ostomy on a patient's life?

# Appendix F

Table A. Demographic Description of the Sample

| **Fictional Name** | **Age** | **Geographic Location** | **Diagnosis** | **Ostomy** | **Permanency** | **Highest 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 | Associates 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 |

# Appendix G

## LIVING WITH AN OSTOMY?

## RESEARCH PARTICIPANTS NEEDED!

**If you:**

(1) Identify as female

(2) Are between the ages of 19 and 30

(3) Currently live with an ostomy (for any length of time)

**You are eligible to participate in an important research study!**

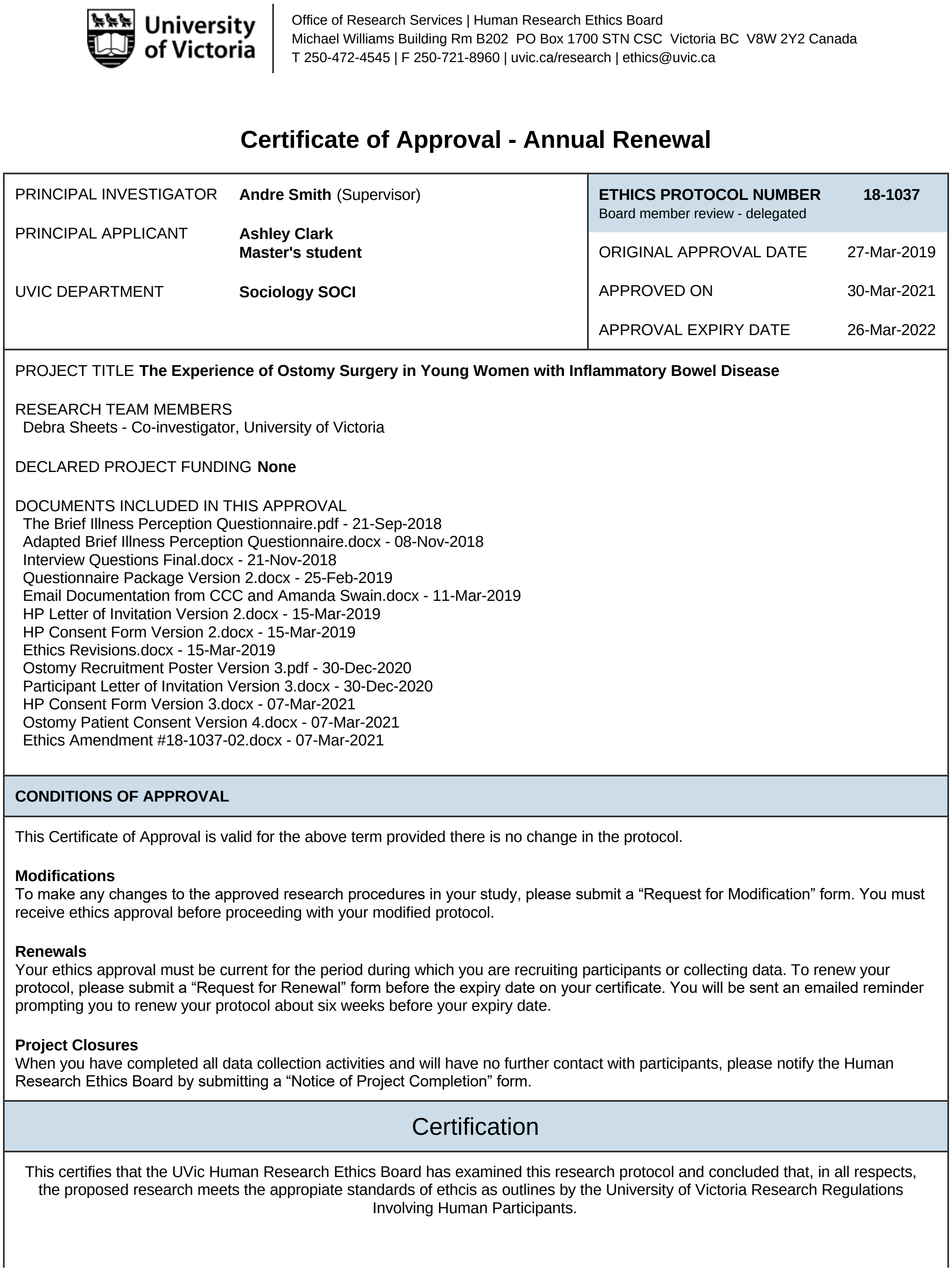
**What is this study about?** I am looking for young adult women to participate in my study that will look at the experiences of living with an ostomy as a result of Inflammatory Bowel Disease. Specifically, I will be looking at the decision-making process leading up to surgery and the actual lived experience of having an ostomy.

**What is required?** Short survey (~10 minutes) as well as a 1-2 hour interview via Skype, Zoom, or telephone (your preference). The interview will involve questions related to your experiences of living with an ostomy and events leading up to your surgery.

**About me:** My name is Ashley Clark and I am a Master of Arts student in the Social Dimensions of Health Program at the University of Victoria. I was diagnosed with Inflammatory Bowel Disease (IBD) eight years ago and have had my ostomy for the last three years. These experiences have shaped my career path and inspired me to improve the lives of those with IBD through research!

If interested please direct message me or contact me at **clarkash@uvic.ca** or at **1 (250) 812-8908**

# Appendix H



University of Victoria

Office of Research Services | Human Research Ethics Board
Michael Williams Building Rm B202 PO Box 1700 STN CSC Victoria BC V8W 2Y2 Canada
T 250-472-4545 | F 250-721-8960 | uvic.ca/research | ethics@uvic.ca

## Certificate of Approval - Annual Renewal

| | | | |
|---|---|---|---|
| PRINCIPAL INVESTIGATOR | **Andre Smith** (Supervisor) | **ETHICS PROTOCOL NUMBER**<br>Board member review - delegated | **18-1037** |
| PRINCIPAL APPLICANT | **Ashley Clark**<br>**Master's student** | ORIGINAL APPROVAL DATE | 27-Mar-2019 |
| UVIC DEPARTMENT | **Sociology SOCI** | APPROVED ON | 30-Mar-2021 |
| | | APPROVAL EXPIRY DATE | 26-Mar-2022 |

PROJECT TITLE **The Experience of Ostomy Surgery in Young Women with Inflammatory Bowel Disease**

RESEARCH TEAM MEMBERS
Debra Sheets - Co-investigator, University of Victoria

DECLARED PROJECT FUNDING **None**

DOCUMENTS INCLUDED IN THIS APPROVAL
The Brief Illness Perception Questionnaire.pdf - 21-Sep-2018
Adapted Brief Illness Perception Questionnaire.docx - 08-Nov-2018
Interview Questions Final.docx - 21-Nov-2018
Questionnaire Package Version 2.docx - 25-Feb-2019
Email Documentation from CCC and Amanda Swain.docx - 11-Mar-2019
HP Letter of Invitation Version 2.docx - 15-Mar-2019
HP Consent Form Version 2.docx - 15-Mar-2019
Ethics Revisions.docx - 15-Mar-2019
Ostomy Recruitment Poster Version 3.pdf - 30-Dec-2020
Participant Letter of Invitation Version 3.docx - 30-Dec-2020
HP Consent Form Version 3.docx - 07-Mar-2021
Ostomy Patient Consent Version 4.docx - 07-Mar-2021
Ethics Amendment #18-1037-02.docx - 07-Mar-2021

**CONDITIONS OF APPROVAL**

This Certificate of Approval is valid for the above term provided there is no change in the protocol.

**Modifications**
To make any changes to the approved research procedures in your study, please submit a “Request for Modification” form. You must receive ethics approval before proceeding with your modified protocol.

**Renewals**
Your ethics approval must be current for the period during which you are recruiting participants or collecting data. To renew your protocol, please submit a “Request for Renewal” form before the expiry date on your certificate. You will be sent an emailed reminder prompting you to renew your protocol about six weeks before your expiry date.

**Project Closures**
When you have completed all data collection activities and will have no further contact with participants, please notify the Human Research Ethics Board by submitting a “Notice of Project Completion” form.

## Certification

This certifies that the UVic Human Research Ethics Board has examined this research protocol and concluded that, in all respects, the proposed research meets the appropiate standards of ethcis as outlines by the University of Victoria Research Regulations Involving Human Participants.

# Appendix I

Acronyms and Abbreviations

| **Acronyms/Abbreviations** | **Definition** |
|---|---|
| CD | Crohn’s Disease |
| CCC | Crohn’s and Colitis Canada |
| HREB | Health Research Ethics Board |
| IBD | Inflammatory Bowel Disease |
| IP | Ileoanal Pouch Anal Anastomosis |
| UC | Ulcerative colitis |
| UVic | University of Victoria |